How to Use This Guide

To connect to Internet links

When you see blue underlined type it is a link you can click to go directly to a website, as long as the link has not changed since publication. (See page 2 for more information about links and how to get a free e-book of the next edition of this guide when it is updated.) You will need to be connected to the Internet to go to the website. When you click on the link it will either open your Internet browser software or, if it is already open, it will open the page within the browser. If you have your browser open and minimized at the bottom of your screen, click on it to view the webpage. Book covers and pictures of DVDs are linked to webpages where you can find more information and purchase the product.

To move around

You can move through the guide in any of the following ways:

• You can simply start reading, and move around by using the scroll bar on the right side of your screen. As you drag the scroll button, you can see the page number indicated. (By the way, the Table of Contents starts on page 4.)

• Another option is to use the arrow buttons. You can find them at the top of the screen or at the bottom of the screen beside the white box indicating the page number. To go to a specific page, type it into the white box and press enter.

• If you want to start with a particular topic, you can click on the topic that interests you in the Table of Contents which begins on the next page. You will then be taken to that topic. (The screen may be small when you get there, so adjust the size using the instructions given below.)

• If you want to find a particular word or phrase, go to the Edit menu at the top of your screen. From the drop-down menu choose “Find” or “Search”, then type in the word or phrase you want to search for.

To read with ease and comfort

To read this guide most easily and comfortably, we recommend you adjust the viewing size. You can easily change the viewing size to the one that's best for you by changing the percentage size. Click on the arrow to the right or left of the percentage and you can adjust the size. A size of 125% will be comfortable for many readers. If that looks too big or small on your screen, adjust the size up or down to find the best size for you.
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About the Authors

George Goulet and Terry Goulet have written this book from a couple’s perspective. In the fall of 2000, the authors were confronted with a formidable dilemma, when George was diagnosed with prostate cancer. Their successful search for a treatment is the cornerstone of this book, which is intended to show that there can be hope and healing in combating this disease, as well as inspiration for those facing this challenge.

A retired lawyer, George presently devotes his time to researching, writing and public speaking. He is the author of Public Share Offerings and Stock Exchange Listings in Canada and The Trial of Louis Riel, Justice and Mercy Denied.

Prior to her retirement, Terry was an editor and freelance indexer of corporate and securities law reporters for an international publishing firm. She was the chief researcher, publisher, and editor for George’s book on Louis Riel.

Since the publication of their Riel book, George and Terry have jointly given many talks on Louis Riel at public libraries, universities, schools, historical societies, and similar groups.

Acknowledgements

We wish to express our appreciation to various people who in one way or another assisted us in this project.

Information was derived from many friends, relatives and other sources too numerous to mention. We would particularly like to thank our friends who gave us invaluable advice concerning prostate cancer when we most needed it. Our family doctor gave us his support during a very trying time. Members of our extended family and our friends who had experienced cancer willingly shared their knowledge and advice with us. We would also like to thank those who kindly read our manuscript and provided us with their comments. Any errors contained herein remain the sole responsibility of the authors. Special appreciation is given to the members of the Brotherhood of the Balloon.

Our five children and our beloved grandchildren have provided us with unconditional love and support throughout our journey with prostate cancer and in the writing of this book.
1. The Challenge of Prostate Cancer

“There is in the worst of fortunes the best of chances for a happy change.”
— Euripides

A diagnosis of prostate cancer is a devastating and emotional experience for anyone who has had to face this potentially mortal disease. A person is faced with a multifaceted challenge to determine the extent of the cancer, what treatment to follow, and how this condition and its treatment will affect one’s future.

George described his feelings after he learned that he had prostate cancer:

“I was initially stunned. I had not expected this. I could not understand how this could have happened to me. I then felt as if I had been smashed square in the face by a sneak roundhouse punch and knocked flat on my back.”

Shortly after receiving his diagnosis, we had a serendipitous visit with friends. While exchanging pleasantries, George mentioned that he had been diagnosed with prostate cancer. His friend said that he had prostate cancer four years earlier and he had been treated with proton beam therapy. He heartily added “Look at me, I’ve been cured”. He and his wife told us that after extensive research it was their view that proton beam therapy stood out above all the others. They advised us to review the various types of prostate cancer treatments, including proton beam, before making a final decision as to the appropriate treatment for George.

At this point of time we knew very little about prostate cancer. This advice from our friends was a crucial element in our determination to find out as much as we could about prostate cancer and its various treatments before deciding on our course of action.

We quickly realized that this silent scourge affected not only the individual, but also his spouse and family members. After the visit with our friends in Victoria, the two of us spent a great deal of time discussing prostate cancer. We both had many questions, such as:

• How serious was it?
• How should it be treated?
• Can it be cured?
• What side effects could result from various treatments?
• What additional therapy would be available if the initial treatments failed?

...and so on.

George’s oldest brother Al had recently been diagnosed with a recurrence of prostate cancer after having a radical prostatectomy some 12 years earlier. As a result we decided that we had to take into consideration the possibility of the cancer returning and what avenues of treatment would be available if this occurred.

Another matter that concerned us was the need of receiving timely and effective treatment. Gideon, George’s best pal in grade school, had died from prostate cancer a few months prior to George’s diagnosis. Gideon’s choice had been watchful waiting as his doctor had told him that he would probably die of something else before the prostate cancer could take its toll. Unfortunately Gideon had a very fast growing cancer; it quickly spread, and he was dead within two years of his diagnosis.

When we met with our family doctor and subsequently with George’s urologist we received some very confusing information. Our family doctor cautioned against George having a radical prostatectomy unless it was performed by a highly experienced surgeon. He further warned against conventional radiation because of its potentially damaging side effects. He suggested that we speak to the urologist about “freezing the thick tissue”, which we later learned was cryosurgery, a treatment about which we knew nothing.

When we met with the urologist he informed us of the results of George’s prostate biopsy. He then discussed with us several types of treatment, namely radical prostatectomy, conventional radiation, cryosurgery, and watchful waiting. He also briefly discussed with us brachytherapy, but told us that this treatment was not currently available locally. He informed us that he would advise against George having a radical prostatectomy because of abdominal scarring from surgery that George had when he was a child.

We had earlier discussed cryosurgery at a meeting arranged by the urologist’s office with a nurse at the local cancer clinic. Both the nurse and the urologist told us that George was only eligible for this treatment if he participated in a clinical trial (in which the urologist was a co-principal investigator) comparing cryosurgery and conventional radiation and was randomly selected by a computer for cryosurgery rather than radiation.
Earlier we had both agreed that we did not want George to be used as a guinea pig in some experimental study. When we found out that cryosurgery was an experimental treatment with serious side effects, we concluded that we would have to take matters into our own hands and do extensive research in order to come to an educated and informed decision as to what the most beneficial treatment for George would be for his cancer.

We did not realize the mammoth challenge we were facing. While neither of us are medical professionals, we knew that we had specific skills and work experiences that would be of assistance to us in this undertaking.

We experienced many conflicting emotions in our journey with prostate cancer. We have written about the personal and emotional aspects of our experiences in another book entitled *Prostate Cancer: A Couple’s Journey of Hope and Healing on Eagles’ Wings* (forthcoming).

On the other hand, this book deals with the nitty-gritty aspects that we have learned about prostate cancer. During our self-education process and afterwards, we analyzed and sorted various data into two large binders and a number of files. We have drawn on this information in order to write this book in layman’s terms, which we hope will assist the readers in learning about prostate cancer. In this respect we have also prepared a glossary of prostate related terms, which is set forth as Appendix A to this book.

Each person should follow their own road in educating themselves about prostate cancer and finding and making the right decision as to the treatment that is best for them and for their own personal situation. In doing so, a patient should discuss treatment options with informed and unbiased medical professionals.

Our aim in writing this book was to provide a source of hope and encouragement to those confronting this condition. Being diagnosed with prostate cancer need not be the “worst of fortunes”. When faced as a challenge, it can provide an opportunity to experience growth and the “best of chances for a happy change”.
2. Conducting Prostate Cancer Research

"Raise new questions, explore new possibilities."
— Albert Einstein

Our meetings with the doctors and with the local cancer clinic had raised new questions for which we needed to do intensive research. We quickly learned this would take a great deal of time and effort. We were fortunate that our daughter Catherine offered to assist us in this task, and we were able to divvy up the various areas of research among the three of us.

Since we were both retired, we were able to devote most of our time and energy to educating ourselves about prostate cancer, its various treatments, and their side effects. We were determined to gain an in-depth knowledge of this disease in order that we ourselves could make an informed decision about George’s treatment. Our extensive research led us down many enlightening paths.

Our principal research sources on prostate cancer were the following.

A. Friends, Relatives and Others

We spoke to a number of friends and relatives from sea to sea (Massachusetts to Vancouver Island) who had encountered cancer, particularly those who had experienced prostate cancer. Without exception they were forthcoming and informative. All described at length and in detail their respective treatments and the side effects they experienced. Many of them referred us to reference sources they had consulted, including the Internet and books on prostate cancer, etc.

B. Books

There are numerous books devoted specifically to prostate cancer. Librarians are more than willing to assist in locating resource material. We obtained copies of various books on prostate cancer from the public library and other sources. These books included:

Prostate Cancer – a Family Guide to Diagnosis, Treatment and Survival, by Dr. Sheldon Marks
http://www.amazon.com/exec/obidos/tg/detail/-/0738208396/
We have subsequently read many other books on cancer and prostate cancer.

We noted that there are sometimes contrary opinions on different aspects relating to prostate cancer between one author and another. This may be due to personal bias by the author in favor of his preferred form of treatment. In some instances there was no mention whatsoever of an accepted mainstream treatment — conformal proton beam radiation. At the time that we were referred to the Osterling book, we were not aware of a 1997 controversy surrounding him at the University of Michigan which subsequently led to his resignation as chief urologist.

A limited sampling of books on prostate cancer and related matters appears in the Bibliography section of this book. Many books also provide extensive bibliographies. Books are helpful in providing information concerning cancer and prostate cancer, but for the most current data on methods of treatment and diagnosis one should also review other sources which may provide more up-to-date information.

Shortly after George’s prostate cancer diagnosis, our daughter Tag gave us an outstanding book on cancer by Dr. Bernie S. Siegel entitled *Love, Medicine & Miracles*. Bernie Siegel is a New Haven, Connecticut surgeon who taught at Yale University. The message conveyed to us in this book is Dr. Siegel’s belief, if not conviction, that the body can be healed and life made worthwhile by the mind and the spirit.

*Love, Medicine & Miracles*, by Dr. Bernie S. Siegel
http://www.amazon.com/exec/obidos/ASIN/0060919833

A subsequent book by Dr. Siegel, *Peace, Love & Healing* is inspirational in its theme that a serious illness can point the way to meaningful new directions in one’s life. He also notes (and we firmly agree) that one should not let the doctors be the only experts on one’s case; rather the patient should actively participate in the treatment and become an expert in the disease. The patient should take responsibility in making the decisions as to the treatment(s) to be received. Both of Dr. Siegel’s books contain extensive reading lists.
Another book that we found exceptional in dealing with a serious disease is *Anatomy of an Illness*, by Dr. Norman Cousins. While his disease was not prostate cancer, Cousins’ message is heart-warming for anyone with a serious malady. He determined to fight his supposedly progressive and incurable disease with hope, faith, laughter, a fighting spirit and other means. He would not be a passive observer. He was concerned about quality of life and emphasized the role of the mind in the patient’s battle with one’s illness.

*Anatomy of an Illness*, by Dr. Norman Cousins
http://www.amazon.com/exec/obidos/ASIN/0393326845

It is important to read books specifically dealing with one’s particular medical condition, but it is also insightful to go beyond a simple mechanistic knowledge and approach to disease. Books that provide inspiration and hope should form a large part of one’s research.

### C. The Internet

There is a vast, seemingly unlimited, collection of material relating to prostate cancer and cancer generally to be found on the Internet, which is accessible via the World Wide Web. The task is to separate the wheat from the chaff. Because of the extensive information available it is necessary to make sure that information is reliable, accurate and pertinent and is fair and unbiased in its approach to the subject matter.

Among their vast storehouses of information, Internet web sites include information particulars on:

- what cancer and prostate cancer are
- what to do if cancer strikes
- cancer and the immune system
- descriptions of various types of cancer treatments
- deciding on a treatment plan
- resource directories listing where to call for help and information
- groups offering cancer information
• moral support, coping techniques and patient advocacy
• support groups
• PSA test, free PSA test and Gleason score
• diet and nutrition
• sources of health information
• glossaries of prostate cancer-related terms
• meanings of relevant acronyms
• views on prostate cancer provided by a number of medical doctors
• clinical staging of prostate cancer
• prostate enlargement (benign prostatic hyperplasia)
• symptoms and diagnosis of prostate cancer
• numerous other data relevant to prostate cancer

To access the Internet, a computer, a modem, and an account with an Internet Service Provider are required. However many public libraries provide Internet facilities on their premises, often free or for a minimal charge to library cardholders.

There are numerous web sites containing pertinent data relating to prostate cancer. Note that many web addresses change from time to time and it may occasionally be necessary to surf the web in order to find a current site.

Here are some helpful web sites.

**The Cancer Research Institute**
This site provides data on many of the items listed above.
http://www.cancerresearch.org

**Prostate Cancer Information Center**
This site provides links to sites that provide information on treatment options and on prostate cancer.
http://websites.afar.org/site/PageServer?pagename=IA_d_prost_home
The American Cancer Society
Type in “prostate cancer” in the search box to find prostate cancer patient education and support, a glossary, general information and links to other sites.
http://www.cancer.org/docroot/lrn/lrn_0.asp

National Cancer Institute
This Institute is the United States Government Agency which supports cancer research and provides information about cancer. The Physician Data Query (PDQ) is available at this website, as are published research and abstracts. The PDQ contains current information on standard treatments and ongoing clinical trials.

The University of Pennsylvania Cancer Center
Click on “Types of Cancer” in the left frame menu, then look for the “Prostate” link in the alphabetical listings
http://www.oncolink.com

The Mayo Clinic
This website deals with PSA, screening, treatments, and other matters.
http://www.mayoclinic.com/health/prostate-cancer/DS00043

Proton Therapy Links
Links connecting to a number of sites containing information about proton treatment and research are listed, including links to other proton sites, including Particles, the newsletter of the Proton Therapy Cooperative Group.
http://www.proton-therapy.org/links.htm

Loma Linda University Medical Center (LLUMC)
This site gives an overview of the Proton Treatment Center at LLUMC including a description and explanation of conformal proton beam radiation treatment and related matters.
http://www.llu.edu/proton/patient/overview/index.html

MedBroadcast.com
Click the link below and do a search for "prostate cancer."
http://www.medbroadcast.com/condition_info_details.asp
The Prostate Cancer Web Directory
This site provides a number of links related to prostate cancer, and also provides resource links to many countries.
http://www.cancerindex.org/clinks3b.htm

The International Association of Cancer Registries
This site provides a link between various cancer registries in different parts of the world.

Various universities, medical journals, cancer institutes, and the like have web sites dealing with prostate cancer which may be found by the Internet user surfing the web. Some of these, as well as some of those listed previously, may prohibit access to non-registrants or non-members.

D. Articles and Pamphlets

There are many articles and pamphlets that deal with cancer and prostate cancer and various aspects related thereto. Generally the pamphlets provide an overview of their subject matter but do not provide in-depth information. Here is a small sampling.

What You Need to Know About Prostate Cancer is issued by the National Institutes of Health and the National Cancer Institute. This pamphlet discusses what cancer is; symptoms of prostate cancer and diagnosis; questions to ask the doctor; some methods of treatment and their side effects; nutrition; support; and provides a glossary as well as other information. It is available from the National Cancer Institute in Bethesda, Maryland at telephone number 1-800-4CANCER (1-800-422-6237). The pamphlet is also available at the National Cancer Institute’s website:

http://www.cancer.gov/cancerinfo/wyntk/prostate

After Diagnosis: Common Questions and Expectations of Cancer Patients provides common questions and answers about cancer, treating cancer, and how to cope with cancer. It sets forth what to expect from your doctor, your hospital, your family and health care services, as well as questions to ask your doctor. After Diagnosis: Prostate Cancer, Understanding Your Treatment Options gives general information about prostate cancer, different treatments, usual side effects, and some other sources. The PSA Blood Test and Prostate Cancer discusses the PSA test as a tool to aid in detecting prostate cancer. These three pamphlets are available from the American Cancer Society in Atlanta, Georgia at telephone number 1-800-ACS-2345 (1-800-227-2345).
The Journal of Urology is a fertile source of articles on various aspects of prostate cancer. For example, a four page article entitled “Prostate Cancer: a Patient's Perspective” by Richard J. Howe appears in volume 152, November 1994, pages 1700 to 1703.

The Info on Prostate Cancer, Information Sheets are issued by the Canadian Cancer Society. These sheets, twelve in all, give an overview of prostate cancer, its diagnosis, staging, understanding risks, where to find more information on prostate cancer, a discussion of some treatments, and more. Canadian readers can consult their phone book to find a local number for the Canadian Cancer Society. The society's Toronto, Ontario headquarters can be reached at telephone number 1-416-961-7223 or by visiting the following website:

Canadian Cancer Society  
http://www.cancer.ca

Natural History & Diagnosis of Prostate Cancer is an article published on the website of the American Urological Association. It sheds light on the prostate and prostate diseases, asks and answers a number of important questions and provides a helpful glossary of terms related to prostate cancer and its treatment. You can reach the AUA by telephone at toll free (U.S. only) 1-866-RING AUA (1-866-746-4282) or at (410) 689-3700.

Causes, Natural History & Diagnosis of Prostate Cancer  

A booklet entitled Proton Treatment Center is issued by Loma Linda Medical Center in Loma Linda, California at telephone number 1-800-PROTONS (1-800-776-8667) or (909) 558-4288. It describes the facilities at the Proton Treatment Center and gives a medical overview of proton therapy. A discussion of the Proton Treatment Center appears in later chapters.

The Immune System — How It Works is a booklet available from the National Cancer Institute (NCI) in Bethesda, Maryland at telephone number 1-800-4CANCER (1-800-422-6237). It describes the immune system, its structure and how it normally responds to attacks on the body. It also deals with the immune system’s failure, which may result in diseases. Immunity and cancer are briefly discussed. This booklet is available online at:

The Immune System — How It Works  
Another pamphlet issued by the NCI is *Understanding Gene Testing*. This pamphlet gives basic information about genes, gene testing and key genetic concepts. The relationship between genes and cancer is explored but not extensively. Although research into the relationship and potential use of immunology and genetics is in the early stages, they give promise of providing tools for improving cancer diagnosis and treatment in the future. This pamphlet is available online through AccessExcellence.org:

*Understanding Gene Testing*
http://www.accessexcellence.org/AE/AEPC/NIH/

In addition to the *Journal of Urology* there are many other medical journals which have articles on prostate cancer. Many of these journals are available for viewing in medical libraries of the universities that have medical faculties as well as in some hospital libraries. A number of these journals are also available on the Internet but may require a password to access them.

**E. Videos and Tapes**

We viewed several videotapes on prostate cancer, its diagnosis and treatment.

*Prostate Cancer – Conquering the Fear* is a tape sponsored by the Ontario Cancer Institute and Princess Margaret Hospital in Toronto, Ontario, Canada. The tape refers to symptoms of prostate cancer and to biopsy procedures. Radiation therapy, brachytherapy, radical prostatectomy, hormone therapy and chemotherapy treatments for prostate cancer are discussed as well as the hospital’s project to study conformal prostatic irradiation.

*Treatment of Localized Prostate Cancer: a Study Group* explains the randomized trial study (that George was invited to participate in) comparing the efficacy of cryosurgery and conventional external radiation therapy in the treatment of localized prostate cancer.

*Breakthrough: Proton Therapy, Beam of Hope (ABC-20/20); Proton Treatment Center Development;* and *Invisible Blessings* are three videos available from Loma Linda University Medical Center, whose telephone number is 1-800-PROTONS (1-800-776-8667). These videos provide information and history on conformal proton beam therapy as a treatment for prostate cancer and other cancers.

Cancer clinics and prostate cancer institutes usually have a selection of videos and tapes on prostate cancer, its diagnosis and treatment. One should contact their local cancer facility to determine what is available in their own community.
F. Medical and Other Health Care Professionals

After George’s prostate cancer diagnosis, we consulted not only our family doctor but also the urologist and a nurse at the cancer clinic to whom we had been referred. We also spoke to Terry’s nephew (who is a medical doctor at an internationally renowned medical clinic in the United States) and also exchanged e-mail letters with him. He in turn spoke to one of his colleagues involved in the treatment of prostate cancer. The information he gave us on treatment was primarily directed to brachytherapy since he advised us that their clinic had particular expertise in this treatment.

We spoke to our pharmacist to obtain his advice with respect to a number of matters, including hormone therapy. At the time we had thought that George would have to take hormone therapy (anti-androgen drugs) in conjunction with his prostate cancer treatment. This arose from a mistake on our part. We assumed that because the trial study comparing conventional radiation with cryosurgery (referred to earlier) required the participants in the trial to take these anti-androgen drugs that this was a standard requirement before commencing actual prostate cancer treatment.

We subsequently found out that in George’s particular circumstances, if he was not then taking anti-androgen drugs, there was no necessity for him to do so. This was an eye-opener for us, as we had been dismayed at the hideous side effects that George would suffer if he had been prescribed these anti-androgen drugs. We wanted nothing to do with them if they were not necessary for George’s treatment and George was not prescribed these hormone therapy drugs nor did he take them.

Our pharmacist was also helpful in providing information to us on the effects of the medication Proscar on George’s PSA readings. George had been taking Terazosin and Proscar for an enlarged prostate gland for several years before being referred to a urologist by our family physician in March 2000. At that time the urologist told George that there appeared to be no problem with his prostate. He also said that although George should continue to take Terazosin, he could discontinue taking Proscar. He advised him to return for a further examination in six months with an up-to-date PSA test.

However a number of weeks before the follow-up appointment with the urologist, George resumed taking Proscar on the advice of his family doctor. This PSA test showed a level of 6.3. A subsequent PSA test some four months later after he had resumed taking Proscar showed a PSA level of 3.3, a substantial decrease from the earlier test.
We found out from our pharmacist that the current edition of the Canadian Pharmacist Association Compendium of Pharmaceuticals and Specialties stated the following with respect to Proscar (also known as finasteride):

“When PSA laboratory determinations are evaluated, consideration should be given to the fact that PSA levels are decreased in patients treated with finasteride. …Therefore, in typical patients treated with finasteride for six months or more, PSA values should be doubled for comparison to normal ranges in untreated men.” [emphasis added].

The printed information sheet that the drug manufacturer enclosed with George’s medication stated that Proscar “can alter PSA values” but did not give the specific information quoted above that the PSA values “should be doubled”. It is our view that the enclosure sheet should have contained the more specific information found in the Pharmaceutical Compendium.

G. Research Discretion and Judgment

When doing research, caution should be exercised no matter what the source may be. A determination and assessment should be made as to the source and the reliability of the information, any sponsors that may be involved, what agenda and bias they may have, their credentials, their relevant personal experiences, whether a treatment is proven or experimental, and so forth.

This advice is particularly pertinent with respect to research done on the Internet as it is largely unregulated and anyone can provide information on it. It is often necessary to determine whether the source of the information is owned or funded by a pharmaceutical company or associated corporate entity or institution. Accordingly it is prudent to find other unrelated opinions or facts in order to compare and evaluate research information.

We have met many couples who have done extensive research on prostate cancer. On the whole their research enabled them to better understand this condition, to make an informed decision as to treatment, and to handle the ramifications of prostate cancer.
3. Support Groups, Resource Services and Agencies

"... enjoy to the full the resources that are within thy reach".
— Pindar, Pythian Odes

In addition to the sources referred to in the previous chapter, information on prostate cancer and help in coping with this silent scourge are available from support groups as well as certain resource services and agencies.

A. Support Groups

There are prostate cancer support groups far and wide, likely in every major and mid-sized city in North America with a hospital and undoubtedly in many cities in other parts of the world where prostate cancer is treated.

These support group meetings should remove any sense of isolation and “why me?” questions a patient might have. The atmosphere at the meetings should leave no room for self-pity or misery — only for sharing experiences (and jokes), educating oneself, socializing, and inspiring hope.

In most groups guest speakers, especially those specializing in prostate cancer, frequently attend meetings and discuss matters of relevance to the gathering.

We firmly believe that a support group should afford a positive environment and experience. In such a group a sense of camaraderie can develop and new friendships may be formed.

Unfortunately, not all support group meetings may provide up-lifting benefits. There should be no feeling of being a “victim” of cancer. There should be a convivial atmosphere precluding that kind of thought entering anyone’s mind.

A support group should empower; for without power one is powerless. If participants at a support group are generally down-in-the-mouth, pessimistic, cheerless, despairing and the like, and there is little prospect of a change in this depressing climate, a patient should run, not walk, to the nearest exit. Without hope, such a support group is hopeless.

There may be participants in a support group that inaccurately describe their condition or treatment. For example, a Winnipeg pharmacist who has had prostate cancer told
us that he attended a talk where the speaker inaccurately stated the TURP (transurethral resection of the prostate), that had been performed on him, was a treatment for prostate cancer. Since TURP is a medical procedure for a blocked urethra or BPH (benign prostatic hyperplasia), it should not be perceived as a treatment for prostate cancer.

During George’s treatments, we were blessed to be members of an exceptional support group. To this day we continue to be members and to share with this support group through e-mails containing minutes of this group’s current weekly meetings. These minutes are replete with on-going information on prostate cancer interspersed with humor.

There are local and national support groups open to anyone concerned about prostate cancer. Besides those who are undergoing treatment or have been treated, a recently diagnosed patient and his spouse should consider attending support group meetings to learn about prostate cancer, and witness how others have dealt with it. Information on a local support group may be obtained from the nearest cancer center to a patient’s hometown or from the social service office or similar department of a local hospital.

There is a Prostate Cancer Support Network (PCSN) in the United States. The address for PCSN is Suite 402, 300 W. Pratt St., Baltimore, Maryland, 21201. The toll free number in the United States is 1-800-828-7866. Other national support groups in the United States include US TOO International Inc., and Man to Man.

The non-profit organization US TOO was formed in 1990, and is governed by men who have had prostate cancer. It was developed to make information available to prostate cancer patients and their loved ones. It has numerous chapters in dozens of states and in Canada. Meetings are open not only to those with prostate cancer but also to their family and friends and professionals interested in prostate cancer. The name US TOO is the male alternative to Y ME, the name of the breast cancer support group. Its United State’s toll free prostate cancer hot line is 1-800-80-USTOO (1-800-808-7866). Its web sites are:

US TOO
http://www.ustoo.org

Man to Man was formed about ten years ago and performs functions similar to US TOO. In 1993 the American Cancer Society (AMC) approved this Man to Man support group as a national program. Information on Man to Man in the United States can be obtained from the AMC toll free number at 1-800-ACS-2345 (1-800-227-2345).

There is also a website for the national association of prostate cancer support groups in Canada. Its website is:
Canadian Prostate Cancer Network
http://www.cpcn.org

B. Resource Services and Agencies

There are local and national cancer societies, institutes, centers and agencies that provide a range of services for cancer patients. The mandate for these institutions and agencies varies from organization to organization. Many provide counseling and emotional support, some provide diagnostic services and others provide treatment facilities or research funding. On the whole these services and agencies rely on donations from the public, although many receive government grants and some are provided with financial patronage from drug companies.

Pamphlets and information booklets on prostate cancer are normally available free of charge from most of these resource agencies. Our local cancer institute shares the same suite of offices as the radiology firm where George received his biopsy. We visited this institute several times and received a number of pamphlets from them and the loan of a video on prostate cancer. As mentioned earlier, we also had a consultation at the local cancer clinic.

A list of the national offices of a number of cancer agencies and institutions in various countries is found in Appendix B herein.

As mentioned earlier, other areas of support one should rely on are family and friends. They are generally sympathetic and, in our own experience, will offer assistance and unqualified emotional and spiritual support. Our children were and continue to be a font of love for us.
4. The Prostate Gland and Prostate Cancer

"The only thing we have to fear is fear itself."
— Franklin D. Roosevelt, Inaugural Address, 1933

This chapter is written from a layman’s point of view and briefly outlines some of our research findings with respect to the prostate and prostate cancer. In the process of searching out a treatment for George, we learned about the prostate gland and discovered data and insight into prostate cancer, diagnostic information, various treatments, and other relevant data. Treatments for prostate cancer are discussed in a following chapter.

Much of this information would have been helpful to us at the time of George's biopsy, but unfortunately we did not do our research until after he was diagnosed with prostate cancer. In our research, we learned that we had to be continuously open to new ideas and knowledge. This approach was helpful to us in confronting prostate cancer and taking charge of our decision as to his treatment. We continue our active interest in information and further enlightenment on prostate cancer, as there is always a chance of recurrence of this dreaded disease.

A. Prostate Gland

The major sex glands in men are the prostate, the seminal vesicles and the testicles. The prostate is an internal gland whose principal role is to produce fluid that together with fluids from the seminal vesicles and the testicles produce semen, which conveys the sperm ejaculated through the urethra during sexual intercourse.

The prostate gland is about the shape and size of a walnut and is found deep within the body cavity. It weighs only about one ounce and sits below the bladder and surrounds the upper part of the urethra, the tube that carries urine from the bladder and semen through the penis. Prostate is from a Greek word meaning "one standing before", and is believed by some scientists to protect the male reproductive organs from infection in the urethra.

Commencing about the age of 40, a man’s prostate gland is affected by changes in the metabolism of his testosterone. At this time production of a specific enzyme that converts testosterone into the male hormone dihydrotestosterone (DHT) increases. It is believed that DHT plays a significant role in causing:
• loss of hair

• enlargement of the prostate

• abnormal growth of benign cells in the prostate, which may be instrumental in converting these benign cells into cancer cells

All men experience these changes to some degree, but they are more evident in men who follow Western dietary customs.

B. Prostate Cancer

There are billions of cells in the human body. Cells that become abnormal by excessively dividing in a disorderly and uncontrolled manner cause the formation of too much tissue. An abnormal growth of cells may be benign or malignant. A benign growth or tumor is not cancerous and these cells do not travel to other areas of the body. A benign tumor in the prostate is called benign prostatic hyperplasia (BPH). The prostate is enlarged by BPH and this enlargement causes the prostate to press against the urethra and the bladder, leading to symptoms such as urination difficulties.

A malignant growth from an abnormal and uncontrolled division of body cells is cancer, a disease of the body. This abnormal and uncontrolled growth of cells or tissue results in a tumor. Cancer cells may break loose from the tumor, enter the body fluids (i.e. the blood and lymphatic systems), and travel to other parts of the body and grow there. This process is called metastasis, and these secondary sites are sometimes known as secondary cancers. It is this seemingly sideways or crab-like activity from which cancer derives its name. The Greek word for "crab" is "karkinos" from which the word cancer is derived, while the word carcinoma results from the Greek word "karkinoma". Most prostate cancers are adenocarcinomas, which are malignant tumors that develop in the inner surface or lining of a glandular organ.

Prostate cancer is the growth of cancer cells in the prostate gland. In its early stages, prostate cancer is microscopic and can only be detected by a biopsy of a tissue sample. As the cancer grows, a tumor is formed and can sometimes be felt by a digital rectal examination (DRE), or may be observable by means of electronic imaging.

The term "surgical margin" is used to denote the outer edge of the tissue removed during a radical prostatectomy. If there is no sign of cancer in this area, this is known as "negative margins". The term "positive margins" indicates that there may be cancer cells beyond the outside edges of the tissue removed by the surgeon.
As with other cancers, the cancer cells in the prostate may progress from the prostate gland to other parts of the body. When they metastasize, they may crop up in the lymph nodes adjacent to the prostate, or the bones, liver, bladder or other organs. A cancer that has spread to other parts of the body is designated with the same name as the primary cancer; for example, metastatic prostate cancer instead of bone cancer, liver cancer, etc.

Statistics show that prostate cancer can and does kill if not treated or diagnosed early enough. In the United States and Canada alone, over 35,000 men die each year from this inglorious affliction. Metastasized prostate cancer can result in a very painful death.

The estimate of men diagnosed with prostate cancer in the United States and Canada in the year 2003 was over 200,000. The challenge is to discover this condition early on. When diagnosed and treated in a timely fashion in its early stage, prostate cancer can be healed. Most prostate cancer treatments may have side effects that result in indignities that cut to the core of male self-esteem and sexuality, and go to the very heart of male masculinity. In our view it is judicious to determine not only the success rate but also the potential side effects of a particular treatment consistent with the stage of the cancer.

C. Likely Causes of Prostate Cancer

Environmental factors (such as diet, smoking, pesticides, chemically hazardous occupations, toxic substances, and lifestyle) are believed to be a major cause of cancers. In the case of prostate cancer, there is an abundance of evidence that heredity of prostate cancer in the family is a significant element that increases the tendency and risk of developing this cancer.

Genes are any of the units occurring in chromosomes by which hereditary characteristics of an individual are determined and transmitted. They consist primarily of DNA (deoxyribonucleic acid) or RNA (ribonucleic acid). A person’s family history should include that of the mother’s male siblings as well as the father, as there is a belief that the hereditary factor can be inherited through the maternal as well as through the paternal side of one’s family.

Another question that needs to be taken into consideration is the failure of the immune system to react to the invasion of the body by cancer cells. The failure to trigger a response of the immune system, or the failure of the immune system itself to produce adequate or accurate immunity, are other aspects that need to be considered. It would appear that instead of most cancers being caused by one single factor, they are likely the result of a variety of factors.
Since the causes of prostate cancer are not definitively known, there is continuing scientific and medical research attempting to ascertain what they are. There have been a number of recent studies on genetics as a cause of prostate cancer, and one study found one culprit gene that shows a propensity towards a particular type of inherited prostate cancer. There are various types of prostate cancer; for instance, most grow at a very slow rate, while others may be very aggressive. At the present time there appears to be no definitive way of determining the particular type of prostate cancer. Further research is being done to determine the genetic DNA of other types of potentially inherited prostate cancer.

Another factor that has yet to be determined is what triggers the start of the cancer. It may be a lack of immunity, or some external influence such as environment, diet, some other agent, or a combination of these factors.

In our opinion, if it can be determined what triggers cancer cells to start growing, and why an individual’s body does not stop the reproduction and spread of these cells, the cause or causes of prostate cancer will be known. Once the cause of prostate cancer is found it will be much easier to develop methods of prevention. This emphasizes the importance of investing more research facilities and funds to find the cause of prostate cancer and discover preventative measures. In the meantime, measures that should assist in the prevention of prostate cancer include good dietary practices, a healthy lifestyle and the avoidance of adverse environmental factors.

The chance of developing prostate cancer increases with age. It is diagnosed primarily in men over age 55 and approximately one-third of men over the age of 50 have prostate cancer. Prostate cancer plays no favorites and crosses all economic, social and racial boundaries. Some of the well-known American men who have experienced prostate cancer are the senators John Kerry and Robert Dole, the actor Telly Savalas, the mayor Rudy Giuliani, the general Norman Schwarzkopf, the financier Michael Milken, the golfers Ken Venturi and Arnold Palmer, and the singer Robert Goulet (a distant relative of George).

Some prominent Canadians who have had prostate cancer are Alan Rock (when he was the Federal Minister of Health), Preston Manning (when he was Leader of the Federal Opposition Party), and Pierre Elliott Trudeau (the former Prime Minister of Canada). Ex-Prime Minister Trudeau died from prostate cancer in the fall of 2000, a few weeks before George received his own diagnosis.

The National Cancer Institute has stated that the disease is more common in African-American men. The Institute also states that prostate cancer is not contagious. Research indicates that a man whose father or brother has had prostate cancer is at
greater risk and that risk increases with each additional close relative that has been diagnosed with prostate cancer. This certainly proved true in George’s case as his older brother Al died from a recurrence of prostate cancer, and another brother Will was diagnosed with prostate cancer in 2003.

The following table gives a sample comparison of age statistics of some of the men (in an organization to which George belongs) who received treatment for prostate cancer:

<table>
<thead>
<tr>
<th>Age</th>
<th>Number</th>
<th>Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td>80 and over</td>
<td>15</td>
<td>2.2%</td>
</tr>
<tr>
<td>70-79</td>
<td>250</td>
<td>36.5%</td>
</tr>
<tr>
<td>60-69</td>
<td>291</td>
<td>42.5%</td>
</tr>
<tr>
<td>Under 60</td>
<td>129</td>
<td>18.8%</td>
</tr>
<tr>
<td>Totals</td>
<td>685</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

At the time of treatment, the average age for this sample group of 685 men was 66.3 years. In comparison, the National Cancer Institute has stated that the average age at the time of diagnosis is 72 years, while there are indications that this may since have been reduced to 69 years of age.

There is considerable scientific evidence suggesting that a diet high in fat will increase the risk factor for developing prostate cancer. One basis for this view is the fact that the incidence of prostate cancer in Asia (where the intake of dietary fat is low) is significantly less than it is in North America (where a high fat diet is more common). When Asian men move to North America, the rate of prostate cancer becomes similar to that of North American men after approximately a generation.

D. Symptoms of Prostate Cancer

Prostate cancer does not announce its presence with any fanfare. It usually sneaks up on a man without warning. It has been called the silent scourge. A small cancer confined to the prostate may not exhibit symptoms and may not be detectable by a DRE during a routine medical checkup.

With the growth of the cancer, however, symptoms are likely to occur. These could include one or more of the following:

- blood in the semen or urine
- necessity to frequently urinate (particularly in the middle of the night)
• pain or difficulty in urination
• painful ejaculation
• erection problems
• reoccurring pain in the lower back or hips

However these symptoms may not be those of prostate cancer, but may be a result of some other disorder of the prostate gland such as BPH (benign prostatic hyperplasia) or prostatitis, a treatable infection or inflammation of the gland. Our personal view is that every male starting at age 40 should have an annual PSA test followed by a DRE, and should maintain his own record of the test results. Further information on PSA tests and DREs is given in the following chapter.
5. Prostate Tests and Diagnostic Procedures

"A wise man should consider that health is the greatest of human blessings, and learn how by his own thought to derive benefit from his illnesses."

— Hippocrates, Regimen in Health

This chapter provides, from a layman’s point of view, some of the information from our research findings with respect to various medical tests and procedures relating to the prostate gland and prostate conditions.

A. PSA Test and DRE

Prostate specific antigen (PSA) is a protein secreted by cells of the prostate gland and is measured in ng/ml (nanograms per milliliter). As part of an annual medical checkup many doctors will order a PSA test, a very simple blood test that became widespread in the late 1980s. The PSA test should always be followed by, not preceded by, a digital rectal examination (DRE). A DRE is the insertion into the rectum by a physician of a lubricated-gloved finger in order to palpate the prostate gland through the wall of the rectum. This is a medical examination to test for palpable tumors, abnormalities, or irregularities in the prostate and the rectum. However, there is no assurance that a DRE will detect cancer in the prostate, particularly if the tumor is microscopic or too small to be felt. Also the tumor may be inaccessible to the touch if it is on the far side of the prostate gland.

A PSA test should be part of a man’s annual physical examination preferably if he is over 40, and definitely after the age of 40 if his father or brother had prostate cancer. Although rare, it is not unheard of for a man in his thirties to be diagnosed with prostate cancer.

If the PSA level in the blood is high, this could be indicative of an abnormal condition of the prostate gland, either malignant or benign. Anything that excites or irritates the prostate gland can influence a PSA test and result in a higher than normal reading. Examples that may result in higher readings include ejaculation, bicycling, a DRE, urinary retention, inflammation of the prostate, etc. Any of the activities listed above that may influence the reading should not be performed for three to seven days prior to a PSA test.
There can also be an artificial reduction of PSA levels, such as those caused by medications prescribed for benign prostatic hyperplasia, or the hormone drugs often prescribed for enlarged cancerous prostates. When PSA laboratory findings are assessed, consideration should be given to the fact that PSA levels may be significantly decreased in those patients treated with these drugs. The dramatic reduction in George’s PSA level from 6.3 to 3.3 when he recommenced taking Proscar is discussed in an earlier chapter. The herbal remedy saw palmetto can also artificially reduce PSA levels by up to 50%, but most likely by a lesser amount.

Although a PSA test cannot in itself diagnose cancer, it can and should be used as an indicator of the possibility of prostate cancer. The result of an individual’s latest PSA test should be compared to his prior tests to determine any trends. The rate or speed of change in PSA values from year to year is known as PSA velocity. Three successive gradual increases in PSA levels or one significant increase in a patient’s PSA level should be a red flag to alert the physician and the individual that further testing is required to determine the cause of this increase and whether or not prostate cancer is present. It is prudent for a man to keep records of his PSA levels in order to track his own PSA velocity.

Annual medical checkups for a number of occupations such as airplane pilots, policemen, firemen, etc., frequently include PSA tests. As a result, early diagnosis of prostate cancer has increased in many men in these occupations who receive PSA tests in their annual checkups. It is well known that the earlier prostate cancer is diagnosed the greater the chance of cure. This points out the importance of PSA tests as a means of alerting one to the possibility of prostate cancer.

Some doctors are opposed to the use of a PSA test, arguing, among other matters, that there is no proof that it extends a man’s life and yet it can lead to invasive medical procedures and treatments. This attitude fails to recognize the fact that the longer a prostate cancer remains undetected the less chance there is for a cure and the greater possibility of the development of advanced prostate cancer with its horrendous side effects.

This negative and, in our view, ill-advised approach also fails to recognize the advances that have been made in the diagnosis and treatment of prostate cancer in the last number of years resulting in earlier diagnosis and more beneficial treatments. After the introduction of a free program of PSA screening for prostate cancer in the Tyrol region of Austria, there was a dramatic decrease of 42 percent in deaths there due to prostate cancer in the period between 1993 and 1998.

In Canada, patients cannot see a specialist without first being referred to one by a general practitioner. Also, most patients go to their general practitioner for their annual medical checkups. Since general practitioners are in the front line in the recognition of
medical problems, it is important that they be trained and knowledgeable about prostate cancer, PSA tests, DREs and other related matters. Proper PSA testing and tracking of PSA levels can lead to the early detection of prostate cancer and decrease both morbidity (side effects) and mortality from this potentially fatal disease.

It has generally been considered that a PSA level of 4 and below is normal. However, some physicians use age-adjusted criteria to determine which men should undergo biopsies. They consider PSA to be above the normal level if the ng/ml exceeds 2.5 for men in their 40s; 3.5 for men in their 50s; 4.5 for men in their 60s; and 6.5 for men in their 70s.

It should also be noted that the Journal of Urology (2001; 165:757-760) stated that 24.5% of those referred to in the article, who were diagnosed with prostate cancer by a biopsy, had a PSA reading between 2.5 and 4.0, with 67.6% being clinically significant cancers. Consequently, many men in the so-called "diagnostic gray zone" (those having regular PSA levels between 4 and 10 and a DRE which does not disclose an abnormality) should opt to also have a free PSA test as well as a regular PSA test. The free PSA test is discussed in the next section of this chapter.

Anything unusual in a DRE, regardless of the PSA level, is sufficient in itself to require further testing to determine the reason. Although as previously mentioned a high PSA level may indicate a risk of cancer, prostate cancer cannot be diagnosed by the results of a PSA test alone. There are a number of incidents of men with quite low PSA levels who nevertheless have been diagnosed with prostate cancer. The rate of change in PSA levels (PSA velocity) is the important factor as is any initial high reading. One elevated reading may or may not be significant, but conspicuous consecutive rises in PSA levels require further attention. One source indicates that a cause for concern is a rise of more than 0.75 ng/ml over one year.

PSA tests, together with DREs, also have an important role in monitoring a patient after he has completed treatment for prostate cancer. Regular tests can determine the effectiveness of the particular treatment on the cancer and can provide indications if there is a recurrence of the cancer. For the first two years these monitoring tests should be on a semi-annual basis, and thereafter on an annual basis. With certain treatments (such as radical prostatectomy) there is an immediate radical reduction in PSA levels, whereas other treatments (such as conformal proton beam therapy) may take approximately two years of gradual reduction until a nadir is reached.

Records of these post-treatment monitoring tests should be kept in order that any undue variations may be observed and dealt with appropriately. This type of record keeping parallels our recommendation that records should be kept of all PSA tests and PSA velocity whether or not a person has been diagnosed with prostate cancer.
B. Free PSA Test (fPSA Test)

If a doctor is concerned about the high level of PSA in the blood or if the latest PSA reading is within the level considered normal but has markedly increased from prior readings, the doctor should recommend, or the patient should request, a free PSA test (also known as fPSA test) prior to a biopsy. This further test should also be recommended if there is any irregularity in the DRE. However, some urologists do not inform the patient of this free PSA test. For example, George’s urologist never mentioned this test even though George was in the diagnostic gray zone, and George only found out about this test subsequently when we were in California for George’s treatment. Many urologists skip advising of the free PSA test and recommend a biopsy only on the strength of a high PSA reading.

This free PSA test is a relatively new test that measures the percentage of free PSA to total PSA in the blood. It does not mean that the test is performed for no charge. There are two forms in which PSA circulates in the blood; "free" or bound to a protein molecule. There is more free PSA in benign prostate conditions; therefore the percentage of free PSA in the blood is higher. The amount of free PSA declines in the presence of prostate cancer; consequently the percentage of free PSA is lower. Significantly lower levels of free PSA are present in men with prostate cancer than those whose conditions are non-cancerous.

This test is helpful in assessing whether a biopsy should be performed, since the percentage of free PSA below a certain level may indicate cancer, while the percentage of free PSA above a certain level may indicate a benign condition. Indications are that if the ratio of free PSA to total PSA is above 25% the patient likely does not have prostate cancer and his doctor may advise that it is unnecessary to perform a biopsy. If the free PSA of a man in the diagnostic gray zone is at or below 25%, it is recommended that he should undergo a biopsy. If the free PSA percentage is noticeably below 25% the individual should definitely undergo a biopsy, since the evidence is that the lower this percentage is the higher the risk of prostate cancer.

The following statistics are found in the Journal of the American Medical Association (v. 279; 1543, 1998). This table provides an interpretation of the probability of prostate cancer based on PSA levels and free PSA percentages.

<table>
<thead>
<tr>
<th>PSA Level</th>
<th>Probability of Cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-2 ng/ml</td>
<td>1%</td>
</tr>
<tr>
<td>2-4 ng/ml</td>
<td>15%*</td>
</tr>
<tr>
<td>4-10 ng/ml</td>
<td>25%</td>
</tr>
<tr>
<td>over 10 ng/ml</td>
<td>50% plus</td>
</tr>
<tr>
<td>FPSA %</td>
<td>Probability of Cancer</td>
</tr>
<tr>
<td>---------</td>
<td>-----------------------</td>
</tr>
<tr>
<td>0-10%</td>
<td>56%</td>
</tr>
<tr>
<td>10-15%</td>
<td>28%</td>
</tr>
<tr>
<td>15-20%</td>
<td>20%</td>
</tr>
<tr>
<td>20-25%</td>
<td>16%</td>
</tr>
<tr>
<td>over 25%</td>
<td>8%</td>
</tr>
</tbody>
</table>

Note that the article referred to earlier in this chapter from the *Journal of Urology* (2001; 165:757-760) shows a higher percentage of 24.5% for men in that study with PSA levels between 2.5 and 4.0 ng/ml.

C. Conventional and Transrectal Ultrasound (TRUS)

Ultrasound is a noninvasive type of imaging of internal body organs using high frequency sound waves. For diagnostic purposes, a patient may have a conventional ultrasound examination of the kidneys and bladder, as well as a transrectal ultrasound to image the prostate.

A transrectal ultrasound of the prostate (called a TRUS/P) is performed by placing a small probe in the rectum, aiming it at the prostate and recording ultrasound images. Abnormal conditions such as nodules, enlargement of the prostate, or presence of any tumor outside the glandular capsule, may be visually seen by a TRUS/P examination. Ultrasound itself does not have the capacity to distinguish or to determine whether an abnormal tissue growth is benign or malignant. It is also unable to detect any abnormality of cells that can only be identified microscopically. A TRUS/P is also used to guide transrectal needle biopsies of the prostate gland.

D. Biopsy

A biopsy is the surgical removal of body tissue or other matter for examination under a microscope for diagnostic purposes. There are two methods of performing prostate biopsies, either through the perineum or by ultrasound-guidance through the rectum.

If a urologist is concerned about the high level of PSA and the low percentage of free PSA in the blood, he will likely recommend a biopsy. In our opinion, notwithstanding a PSA reading, any abnormality felt in a DRE unequivocally indicates the need for a biopsy. A biopsy usually involves the removal of a small amount of prostate tissue (in George’s case ten samples) by means of a prostate biopsy gun (or probe) with a needle that penetrates the prostate to retrieve the tissue samples.
The transrectal biopsy is the most commonly used procedure for a biopsy of the prostate. In this procedure, an ultrasound instrument is inserted in the rectum to guide the needle during the biopsy. Subsequently, a pathologist microscopically examines the tissue in order to make a diagnosis.

After this procedure there may be blood in the rectum, the semen, or the urine. There can be some pain during a biopsy, but medication and the skill of the physician can minimize the discomfort and some biopsies are now done under anesthesia. In George’s case, he incurred only a mild feeling of discomfort during the biopsy and had no subsequent side effects from it. We know of many men who found this procedure to be very painful. There are potential complications from a transrectal biopsy, the major one being infection for which antibiotics are normally prescribed to be taken prior to and after the procedure.

A potentially more serious problem is the use of unsterilized or improperly sterilized medical instruments during medical treatments. A news item in the National Post of November 18, 2003 informed readers that an internal audit at Sunnybrook Hospital in Toronto, Ontario discovered that infection control measures were not being followed. Consequently some 860 men who had undergone prostate biopsies between December 1999 and August 2003 were sent warnings that they had undergone this procedure with unsterilized probes. The hospital further offered them blood testing as the biopsy procedure had potentially exposed them to HIV and hepatitis B and C.

Because it is possible that a biopsy may have taken only samples of tissue that evidence no cancer on microscopic examination (notwithstanding that prostate cancer is actually present), a false negative report may be issued. Sources indicate that there is a 25% chance that a negative cancer report is false and, contrary to that report, there is actually undetected prostate cancer. Consequently we are of the view that if there are any prostate concerns, re-testing of both regular and free PSA and a DRE should be performed more frequently — i.e. at least every six months rather than only at an annual medical checkup.

**E. Staging**

If a biopsy indicates that the tissue is malignant, the pathologist examining the samples assigns a stage to the cancerous tissue. The stage of a cancer is based on its size and physical extent. The stage will affect treatment options. Staging is the process of assigning a stage to the cancer based on relevant information.

The following are two “staging systems” used to describe the size and extent of a cancer:

- the Whitmore-Jewett System of 1956
- the more recent (1992) and detailed TNM (tumor, nodes, metastases) System
The TNM System is currently most frequently used. The following is a brief description of the two systems.

The Whitmore-Jewett System uses stages A, B, C, and D, while the TNM System uses stages T, N, and M. Stage A in Whitmore-Jewett is similar to T1 in the TNM System, Stage B to T2, and Stage C to T3. In Stage D metastasis has occurred. In the TNM System, Stage T deals with the primary tumor, stage N with the lymph nodes nearby the prostate, and stage M with metastasis at a distance from the prostate.

There are four T stages — T1, T2, T3, and T4. Each of these stages is further divided. Stage T1 is a small primary tumor which cannot be felt on a DRE; it is not palpable. Stage T1a is found incidentally and not more than 5% of the tissue removed is found to be cancerous on microscopic examination. Stage T1b is similar to T1a but more than 5% of the tissue removed is found to be cancerous. Stage T1c is a tumor found by a needle biopsy, usually as a result of a high PSA level without other clinical indicators of prostate cancer. Stage T1c (which was George’s stage) is determined rather frequently due to the number of men having biopsies pursuant to elevated PSA levels.

In Stage T2, the tumor is confined within the prostate. Stage T2a is a tumor felt by a DRE in one-half or less of one lobe of the prostate; Stage T2b involves more than half of one lobe or is palpable in both lobes.

The radiologist’s report with respect to George’s biopsy on October 25, 2000 stated that George’s clinical stage was T2c. We were subsequently advised that George’s stage was actually T1c, not T2c. We were taken aback by this significant error in George’s biopsy report, especially since the physicians involved had not felt any palpable tumor in George’s prostate. We later learned that the use of T2c as a stage had been abolished internationally some time before and many months prior to it being used incorrectly as a stage for George’s cancer in his biopsy report.

Stage T3 is an extension of the prostate cancer cells out of the prostate capsule into surrounding tissue. In Stage T4 the tumor has moved beyond the prostate and seminal vesicles. Each of Stages T3 and T4 has subdivisions.

Prostate cancer with Stages N or M involves regional lymph nodes and prostate-distant metastasis respectively. There are subdivisions for each of these stages.

The foregoing is very brief and is only indicative of various stages. It is always possible that in some instances the designated staging may not be accurate. Various books on prostate cancer give much more detail, and they should be consulted together with one’s urologist, for precise information on staging and the staging systems.
F. Grade of Prostate Cancer — Gleason Score

After a biopsy the tissue samples are examined under a microscope for appearance and are graded. The grade is a method of measuring the potential aggressiveness or rate of growth of the prostate cancer. The Gleason score is commonly used to grade prostate cancer.

A pathologist examines the tissue samples for the pattern of the cancer cells to assess the degree or grade of aggressiveness. Cancer cells that appear more like normal cells are less malignant and vice versa. “Differentiation” is the term used to describe the capability of a tumor to imitate the structure of a normal gland. A well differentiated, or near normal form of tumor, likely acts in a biological manner not far from normal, in other words, not too aggressively malignant.

Based on cellular differentiation two numbers, each from one to five, are assigned to the two most predominant patterns. The two are added together and the result is called the Gleason score. The lower the score, the better the differentiation and the less aggressive the cancer while the higher the score, the poorer the differentiation and the more aggressive the cancer. Scores of 2 to 4 are considered low grade (less aggressive); scores of 5 to 7 are considered middle grade (moderately aggressive); scores of 8 to 10 are considered high grade (most aggressive). George’s grade was 3+3 for a Gleason score of 6.

Anyone diagnosed with prostate cancer should insist on knowing not only his PSA level but also his Gleason score. We should emphasize the fact that we know of men who have had very low PSA readings but had middle of the range Gleason scores indicating moderately aggressive prostate cancer.

G. PSA Density

Some specialists believe that PSA density (or PSAD) can be helpful in treating a patient by determining whether his condition is due to prostate cancer or to benign prostatic hyperplasia (BPH). PSA density is calculated by dividing the volume of the prostate into the PSA level in order to measure the concentration of PSA in a man’s prostate. The volume of the prostate is ascertained by transrectal ultrasound. The belief is that if the PSA level is between 10% and 15% of the prostate’s weight, the condition is likely BPH, whereas a higher percentage may be indicative of prostate cancer. However PSAD is not a definitive means of determining the presence of prostate cancer.
H. Partin Tables

The Partin Tables, developed at Johns Hopkins Medical Institutions, are available on the Internet and from other sources. These Tables are intended to estimate the pathological stage of prostate cancer based on Gleason score, PSA level and clinical stage. These Tables are not unqualified indicators of the extent of the prostate cancer, but as the introduction to the Tables on the Internet states, they "show the probability that the prostate cancer has spread into the lymph nodes". The 2001 update of these Tables is based on 5,079 men treated only with radical prostatectomy at Johns Hopkins Hospital having an average age of 58 years.

I. PIN

There are some physicians that view a condition called prostatic intraepithelial neoplasia (usually called PIN, but sometimes called dysplasia) as a possible harbinger of prostate cancer at a future date. However, there is no incontestable evidence confirming that the presence of PIN means the presence of prostate cancer. PIN is located by means of a biopsy as it is microscopic.

Low-grade PIN is usually regarded as insignificant. However, it is thought that the existence of high-grade PIN may signal a risk of prostate cancer, particularly localized cancer. If a biopsy shows that PIN is present, the urologist may recommend a further PSA test and biopsy in order to ascertain if there is prostate cancer. If there is not, the urologist may recommend further PSA tests and biopsies at six month intervals, and later annually for a few years.

J. CAT Scan, MRI and PET Scan

CAT scans (Computerized Axial Tomography), MRIs (Magnetic Resonance Imaging) and PET scans (Positron Emission Tomography) are non-invasive diagnostic procedures to look inside the body and produce images. The CAT scan and MRI technologies were developed in the 1970s, before which tumors in the body could not be precisely located using conventional x-rays.

The CAT scan uses a computer to control and produce three-dimensional or cross-sectional pictures of internal organs by combining multiple x-ray images. These images can be used to identify abnormalities. In the case of the prostate gland, a CAT scan can provide the size of an enlarged prostate, but it is not able to evaluate the precise stage of any cancer that may be present. This scan can be helpful in instances of locally advanced prostate cancer and in cases with high grade and/or high PSA, where the chance of lymph node involvement is higher. A CAT scan is significantly more capable of assessing the spread of the prostate cancer to the lymph nodes or other soft tissue sites.
Using a magnetic field of super-cooled magnets, MRIs can produce detailed x-ray type images that more distinctly differentiate between diseased and healthy tissue. In the case of prostate cancer, it can indicate if the lymph nodes are enlarged, or if the tumor has spread outside the prostate capsule (also referred to as extracapsular penetration).

A PET scan is a form of tomography that uses positron-emitting isotopes placed inside the body as a source of radiation, instead of external radiation. Because a PET scan reveals molecular activity and function, rather than structure, it can often distinguish between normal and abnormal tissue. A PET scan can produce a three-dimensional image. It is usually used as an adjunct to, rather than as a substitute for, information obtained from a CAT scan or MRI. It is our understanding that these three imaging procedures do not presently have the capability of detecting microscopic cancer cells, in other words cells that can only be seen under a microscope.

At the present time the only sure method for diagnosing very early stage prostate cancer is by means of a biopsy. Since a biopsy has the potential to seed the cancer, it is hoped that in the future the technology of various imaging techniques or some other breakthrough will eliminate the need for invasive biopsies. A promising study to determine if a blood test may avoid unnecessary biopsies is presently underway at the University of North Carolina. Another study, presented at the American Association for Cancer Research Annual Meeting in July 2003, measured proPSA in relation to PSA with a view to detecting early aggressive prostate cancer.

In the meantime CAT scans, MRIs and PET scans are extremely helpful in three-dimensional reconstruction of the tumor or gland for diagnostic purposes and for treatment planning. The information received from these imaging methods can provide invaluable assistance and information to the physician in planning an appropriate treatment for the prostate cancer patient and in carrying out an individualized program of treatment.

**K. Bone Scan**

A bone scan is a body-imaging technique using a radioactive substance injected into the bloodstream in order to view bones. Although it does not identify microscopic cancer cells, it is a means of detecting abnormalities in the bones that may indicate prostate cancer. These abnormalities (or hot spots) may be found at an earlier stage than they would be by using regular x-rays. Since the prostate contains no bones, a bone scan is not helpful in finding localized prostate cancer but may be of some assistance in ascertaining if metastasized cancer has spread from the prostate gland into the bones. A person with localized prostate cancer would not normally undergo a bone scan.
6. Clinical Trials and Research

“For extreme diseases extreme strictness of treatment is most efficacious.”

— Hippocrates, *Aphorisms*

Before discussing the various types of treatments available for prostate cancer, we want to discuss the role of clinical trials and research.

A clinical trial is an experimental study that has been carefully planned by qualified professionals or researchers to assess the effectiveness, safety, and side effects of new or unproven treatments or drugs on the persons receiving them. In some cases, a clinical trial may be used to compare the efficacy of an unproven method or product to currently accepted treatments or drugs. If they prove efficacious or superior to existing techniques, they may become new or additional methods to treat a particular disease. Also, favorable results may be commercially exploited.

The structure, protocol and procedures of clinical trials will vary from one to another. In some trials, for example, the new or unproven treatment may be received by one set of participants while the other set receives an accepted treatment or a placebo. In other studies, all participants may receive the same treatment.

There are a number of clinical trials for prostate cancer in progress. An example of a trial study with respect to prostate cancer that George was told he was eligible to participate in, but which he declined, was the trial study comparing cryosurgery to conventional external radiation therapy referred to previously.

Clinical trials may benefit some people by providing them with top-rate cancer care, and the participants may be first in line to profit from successful new methods. As well, some people may participate in trials for altruistic reasons, hoping their involvement will provide an advancement in the treatment of a particular disease. However, new approaches may prove ineffective or of lesser benefit than existing treatments and unforeseen side effects may cause serious problems.

It is essential that a participant be given all relevant data in an open and clear manner, and that if he is to be a guinea pig, he should be told so. The information should include the type of trial, the potential dangers and benefits, possible side effects, its experimental nature, lack of long-term information concerning the treatment, what other treatments can be given if the clinical treatment is ineffective, and any conflicts or financial interests involved. A patient should only become a participant in a clinical study after he has given a fully informed consent to the procedure.
Although a treatment may be a mainstream treatment, it can be incorporated into a clinical trial. This can occur when a mainstream treatment is combined with a new medication, or a different use of a medication is being tested in conjunction with that treatment. A recent clinical trial in Calgary is in point. In this study, the results of hormone treatment prior to radiation therapy were being compared for three months in some patients versus seven months in others.

A clinical study may also test the impact of a drug on a particular disease. An example is a study funded by the National Cancer Institute to test the effects of finasteride (sold under the brand name Proscar) on prostate cancer prevention. The study was abruptly ended in June 2003 because of the significance of the results. While researchers found that men who took Proscar daily for seven years had 25% fewer cases of prostate cancer than those that took a placebo, the men who developed prostate cancer were likely to have more aggressive tumors.

As in the case with complementary and alternative therapies, we recommend that qualified, trusted and objective professional advice be sought and considered in arriving at a decision concerning a clinical trial. However, a patient should himself assess the risks of a clinical trial, especially when a new drug or unproven treatment is involved. In the case of new or unproven drugs, he should be circumspect in assessing at face value the information provided to him. This is particularly so if the research on which the information is based has been sponsored or funded by members of the pharmaceutical industry.

It appears to us that the pharmaceutical industry perceives its primary duty is to sell medication. Its financial bottom line is better served by long-term use of medications, rather than by the cure of a disease that would no longer require the use of medication. In the April 14, 2001 issue of the medical journal The Lancet (Vol. 357, No. 9263, p.1141), there is an article titled “The tightening grip of big pharma”. This article indicates that the efforts of drug companies to influence findings that did not suit their commercial purposes extended back as far as 40 years ago to a tragedy involving thalidomide, a sedative which caused fetal malformations. It further states that “the insidious tactics of big pharma have changed little”, notwithstanding that government regulation of the industry is now prevalent.

In The Lancet vol. 358, September 15, 2001, editors of a number of leading medical journals (including The Lancet, the New England Journal of Medicine, and the Canadian Medical Association Journal) issued a joint commentary expressing concern over the manner in which some clinical research is conceived and reported. They agreed not to review or publish articles where the sole control of the data or the right to withhold publication was in the hands of the sponsor. The journal editors added that researchers should have a substantial input into trial design, access to the raw data, responsibility for the analysis and interpretation of data, and the right of publication.
However there are many medical and scientific journals that did not participate in this joint commentary. Since pharmaceutical companies are a principal source of advertising in most of these journals, we have a concern regarding a potential conflict of interest.

There is also a potential problem with respect to news releases on medical and scientific discoveries sent to daily newspapers, periodicals and other news media. This information is sometimes reported to the public by the media as equivalent to an exceptional breakthrough or magic bullet. Many of these releases tout new drugs and treatments that have not undergone sufficient study and scrutiny to determine their effectiveness, potential side effects, or other relevant matters. For someone suffering from a terminal or debilitating disease, such a news release may provide false hope and inaccurate information about a so-called magic cure that does not materialize. As a result, we feel that one should be extremely circumspect concerning news releases, and should be cautious as to the source on which they are based.

The public should be aware that the pharmaceutical industry is providing huge sums of money to hospitals and universities for medical and scientific research. It is entering into what have been called “partnerships” with hospital research centers, university medical schools, and other research institutions.

The public relies on these centers and medical schools to test new drugs in an independent manner to determine if they are beneficial and not harmful to the user. However, this drug-company funding, on which many researchers and institutions rely, may lead to conflicts of interest and institutional pressures in support of a report approving the advantages of the new drug while downplaying its less than salutary effects. As well, a researcher may have a personal financial interest, direct or indirect, in the outcome of a clinical trial or research, thereby creating the potential for a conflict of interest.

Many researchers, aware of their funding source, may have a natural predilection (some might say a bias) favoring the new drug, thereby giving rise to the concerns expressed in The Lancet and other medical journals. The same concerns may apply to clinical trials of new or experimental treatments. Other researchers may find that the institutional pressures to placate the drug companies (including in some cases suppression of an unfavorable report) can result in the loss of their academic freedom.

It should be the role of the academic or other institution to intercede on behalf of the researcher and his or her right to academic freedom, provided the researcher is acting out of scientific and not personal financial interests. However, many institutions do not wish to cut off the financial backing of these commercial enterprises and, in some instances, may wish to commercialize for themselves the research discoveries.
Because of the potential for publication bias in industry-sponsored research and the impact of any financial conflicts of interest, it has been recommended that a comprehensive publicly accessible central registry should be established for all clinical trials. The registry should disclose funding sources, financial interests of sponsors and investigators and research results, good or bad. A number of articles in medical journals have recommended a form of registry for clinical trials. These include “Scope and Impact of Financial Conflicts of Interest in Biomedical Research” by Bekelman et al (Journal of the American Medical Association (JAMA) January 22/29, 2003 – V. 289, No. 4 p. 454); “Association of Funding and Conclusions in Randomized Drug Trials” by Als-Nielsen et al (JAMA August 20, 2003 – V. 290, No. 7 p. 921); and “Pharmaceutical industry sponsorship and research outcome and quality: systematic review” by Lexchin et al (British Medical Journal V. 326 31 May, 2003 p. 1.)

The National Cancer Institute has published an informative booklet entitled What are Clinical Trials all About? The Institute also has a comprehensive database PDQ from which, among other matters, information can be acquired about clinical trials currently under way in many places. Incidentally, PDQ is an acronym for “physicians data query” and not for “pretty damn quick”, although hopefully an inquirer will receive the information PDQ. The Institute’s Cancer Information Service can be reached toll-free in the United States at 1-800-4-Cancer (1-800-422-6237).

Reference is also made to a website which provides current data about clinical trials.

National Institutes of Health
http://www.clinicaltrials.gov
7. Prostate Cancer Treatments

“As to diseases make a habit of two things — to help, or at least, to do no harm.”

— Hippocrates, Epidemics

At the present time even the professionals do not have all the answers as to the cause of cancer, nor do they have a surefire cure for every cancer. There is continuous research into the cause and the cure of various cancers. As more knowledge is acquired, new ideas and potential methods of treatment are being developed for prostate cancer.

In our research we found a number of treatment options available for prostate cancer. We have come to the firm conclusion that the decision as to which treatment will be taken should be that of the patient, not the doctor. The patient, of course, will consult with his family doctor and the medical specialists and he will need to give serious consideration to their views in arriving at a treatment modality appropriate to him.

However, human nature being what it is, it would not be unusual for a medical specialist to have a bias towards his own specialty and, perhaps subconsciously, the treatment that he is most familiar with or with respect to which he is conducting medical research. It is most likely that a surgeon favors radical prostatectomy, a radiation oncologist favors radiation, an urologist who mainly performs cryosurgery favors this procedure, etc. After the urologist had advised against a prostatectomy for George because of potential problems from abdominal surgery he had as a child, we were subsequently advised by other medical practitioners that the scar tissue from that surgery would not be a problem if he elected to have a radical prostatectomy.

In our opinion it is imperative for someone (who intends to not be a passive observer, and who intends not to let his fate be determined solely by others) to do intensive research on the various treatments and their side effects. Every person should weigh the advice he is receiving, how extensive and impartial it is, and take ample but reasonable time in order to review all treatment options in an objective manner without feeling pressured, influenced or intimidated into making a snap decision.

One should not accept at face value the claim that a particular treatment is the so-called “gold standard” which other treatments try to emulate. Such a statement may only show the bias of that particular physician and, as well, the touted treatment may not be the right one for that particular patient. One should seek out other opinions and advice from qualified medical practitioners, other patients, medical journals, books, the Internet, and other sources to arrive at that treatment decision which he considers most appropriate for himself.
As a result of one’s consultations and research, he will then be able to make an in-formed rational decision, not have one thrust upon him due to his lack of knowledge or the bias which a medical adviser may have for a particular treatment.

During the course of our research we found some treatments for prostate cancer were considered mainstream, while others were viewed as experimental, complementary or non-conventional. It should be borne in mind that the available choice of treatment is significantly affected if the cancer has spread beyond the prostate gland.

The following discusses a number of these treatments. In doing so we wish to re-emphasize that a person should do his own research, make his own inquiries, consider his favored options and make his own decision, while giving due and rational weight to the opinions of medically qualified cancer specialists and cancer patients who have undergone treatment.

A. Radical Prostatectomy (Radical Surgery)

Radical prostatectomy (or radical surgery) is major invasive surgery that removes the entire prostate gland, and is one of the mainstream treatments for prostate cancer. The most frequent method is by means of an incision in the abdomen (retropubic prostatectomy) to remove the prostate and seminal vesicles. The incision runs from the navel to the pubic area. Alternatively the prostate and seminal vesicles may be taken out by way of an incision between the scrotum and the anus (perineal prostatectomy).

Indications are that radical prostatectomy is performed more often than other treatments for prostate cancer. However, it is likely that a doctor will recommend against surgery if he deems the man is either too old or too ill to survive longer than ten years. One of George’s former partners (who was then 75 years old) was told by his doctor that because of his age the doctor would not operate on him and he would have to take some other form of treatment. A further discussion on the question of age and prostate cancer treatment is given later in this chapter in the section titled “Watchful Waiting”.

The principal and most severe side effects of radical prostatectomy include impotence (also known as erectile dysfunction) and incontinence. Side effects of this procedure may be temporary or, in some cases, permanent. Different institutions have asserted vastly different statistics with respect to side effects from radical prostatectomy. We have read of claims ranging from 2% to 50% incontinence, and varying degrees of impotence from 14% to 80% after radical prostatectomy.

The skill of the surgeon will often have a major bearing on the extent of the side effects. Occasionally, instead of incontinence, the opposite occurs with the urethra becoming blocked requiring dilation by means of a TURP (discussed hereafter).
The original procedure for radical prostatectomy was to cut through the nerves as it was believed that the nerves ran through the prostate. In 1981 the Dutch urologist Pieter Donker and Dr. Patrick Walsh (of Johns Hopkins University) did anatomical research that established that the penile nerves did not run through the prostate but were outside it. As a result, Dr. Walsh developed a nerve-sparing technique for removal of the prostate gland, and one might say that he was on the cutting-edge of nerve-sparing surgery. This surgical technique, or variations of it, is now extensively used for radical prostatectomy.

However, the nerve-sparing technique is not always completely successful. One example of a distressing experience with a radical prostatectomy is given by Michael Korda in the 1996 book titled *Man to Man, Surviving Prostate Cancer*. In our view, he paints a horrendous picture of the side effects he suffered as a result of his own surgery at Johns Hopkins University Hospital. In his book, Korda describes the post-operative pain he suffered. He also points out that after surgery he was fitted with a drain for five days to catch seeping blood, his blood pressure dropped, and he had a catheter (which frequently leaked urine) for several weeks after the surgery. When he returned home from the hospital he was faced with “no wine, no sex, no coffee”, and a cupboard full of Depends (adult diapers).

Korda experienced severe complete incontinence for some period of time after surgery, but he indicated that at the time of writing his book (nine months after surgery) this incontinence had decreased to a level he could live with. He wrote that although his impotence had decreased, he was still unable to obtain an erection “to speak of”. Korda wrote that the medical notes of his operation indicated that only one of the two bundles of nerves had been completely spared.

*Man to Man, Surviving Prostate Cancer, by Michael Korda*

http://www.amazon.com/exec/obidos/tg/detail/-/0679781234/

In general, the major concern of a physician is the total removal of all cancerous cells. Out of caution, some surgeons prefer to save only the nerves on the opposite side of the prostate to the location where the cancer was diagnosed, in order to assure themselves that all cancer has been removed.

The reason for this nerve-sparing surgery is to preserve the bundles of nerves that are an indispensable element for penile erections. After 12 to 18 months, some men are able to have an erection after a radical prostatectomy if these nerves are not removed.

In January 2000 the Fred Hutchinson Cancer Research Center of Seattle issued an outcomes study (funded by the National Cancer Institute) of 1,291 men who underwent radical prostatectomy for localized prostate cancer. This study showed that the rate of
impotence differed according to whether “nerve-sparing” or “non nerve-sparing” surgery was performed. It indicated that the percentage of men who were potent before surgery and who reported impotence 18 months or more after surgery was as follows:

- 56.0% of those who had bilateral (two-sided) nerve-sparing surgery
- 58.6% of those who had unilateral surgery
- 65.6% of those who had non nerve-sparing surgery

While radical prostatectomy may be a beneficial treatment or cure for a localized condition, it is of little advantage for those with advanced disease. A major benefit of a radical prostatectomy is that the prostate and surrounding tissue, when removed, can be examined under a microscope to determine the extent of the prostate cancer and whether it has spread outside the prostate capsule.

Tissue from the lymph nodes in some instances is removed and dissected before the removal of the prostate. If the cancer is found to have spread outside of the capsule, many physicians will opt to abort the surgery without removing the prostate. Some physicians faced with extra-capsular cancer may decide to remove the prostate and send the patient for further treatment. A more recent procedure is for some surgeons to automatically remove both the prostate and the lymph nodes for pathological examination subsequent to the surgery.

If the cancer has spread outside the prostate, the patient is then treated with hormone therapy to retard the growth of the cancer, or he may receive further treatments such as radiation consisting of conventional, or proton, or a proton/photon combination.

In March 2004, an article entitled “Salvage Radiotherapy for Recurrent Prostate Cancer After Radical Prostatectomy” was published in the Journal of the American Medical Association (JAMA 2004:291:1325-1332). This article pointed out that after a radical prostatectomy, prostate cancer will recur in the United States in approximately 30,000 men each year. However, it indicated that at the present time the majority of patients with recurrent prostate cancer will receive only ADT (androgen deprivation therapy), a treatment that offers no hope for cure. Another term for ADT is hormonal therapy. This article pointed out that salvage radiotherapy was currently underused for recurrent prostate cancer after a radical prostatectomy. The comment stated: “For patients with recurrent prostate cancer after radical prostatectomy, salvage radiotherapy remains the only potentially curative therapy.”

Some of the major factors that a patient opting for radical prostatectomy should take into consideration are the training, skill, experience and track record of the surgeon that is to perform the operation. In addition the patient should be given detailed information
concerning the prostatectomy. This information should include whether it will be nerve-sparing surgery, whether it will be retropubic or perineal, together with information as to the possible short and long term side effects.

B. Conventional External Beam Radiation Therapy

According to the United States Cancer Research Institute, external beam radiation is the sending by a machine of x-rays or gamma rays into a tumor. The high-energy x-rays (photons) or gamma rays are sent into the body to harm the cancer cells and to inhibit their growth and subdivision. This type of radiation therapy originates and is delivered into the patient’s body by a machine outside the patient's body. This contrasts with radioactive material implants (see Brachytherapy below) which are temporarily or permanently placed inside one’s body.

Conventional external beam radiation may be used if the cancer is not advanced and also for those patients for whom surgery is inadvisable due to other illnesses or their age. Each treatment lasts about four or five minutes. The treatments are usually given five times a week on weekdays for a period of seven to eight weeks. This type of radiation may also be used after surgery to damage any remaining cancer cells in the area. Types of equipment for conventional external beam radiation treatment have included cobalt machines, betatron machines, and linear accelerators.

Because photons (standard x-rays) lack charge and mass, their power declines as they progress through the body. The maximum radiation dose is lodged in the first tissues encountered, namely the healthy tissues near the surface of the body, and not at the depth in the body where the prostate is located. In addition, significant energy carries on beyond the prostate delivering radiation where it is not wanted or desirable, such as the rectum in the case of prostate cancer patients.

Some early side effects during conventional external beam radiation may include tiredness and lethargy, bladder irritation and spasms, frequency of nighttime urination with slowing of the urine flow, rectal irritation with burning, and aggravation of hemorrhoids and occasional blood in the stool. These early side effects may settle down and go away once the radiation is complete.

Long term and possible permanent side effects can occur months to years after the radiation is completed and may not disappear. These side effects include impotence (in about 50% of patients), bladder irritation, bladder shrinkage, stress incontinence (urinary leakage), complete incontinence, rectal irritation with bleeding, and bowel
damage. Our family physician was particularly concerned with the potential bowel and rectal damage that George could suffer as a result of conventional external beam radiation, and recommended against George receiving it.

There is also “conformal” prostatic conventional external beam radiation, which focuses the radiation beam more precisely in order to give a stronger dose of radiation to the cancer site. This technique uses three-dimensional imaging. Higher doses may be given and the proponents of this technique are hoping that the long-term side effects will be no worse than non-conformal conventional external beam radiation.

Another type of three-dimensional conformal radiation is intensity-modulated radiotherapy (IMRT). This technique, which uses a linear accelerator-based technology, conforms the x-ray treatment to fit the shape of the tumor. It is able to modulate the intensity of the radiation, thereby permitting a higher dose to be given to the tumor rather than to the healthy tissue. It appears that the side effects, although similar to those caused by conventional external beam radiation therapy, may be less severe and less frequent.

However with both of these types of radiation therapy, the conformability of the x-rays and photons, which each uses, is limited by their very nature. X-rays and photons lack charge and mass, and thus unlike protons are unable to achieve a Bragg Peak, which is the point at which the highest radiation dose is deposited directly into the targeted area. Proton beam radiation therapy is discussed in the following section.

Another type of radiation therapy that has been studied is the use of neutrons. Although it may be very effective in killing cancer cells, the nature of neutrons does not permit neutron radiation from preventing serious side effects. This is because neutrons, like photons or x-rays, do not have a charge. As a result neutrons cannot be controlled electronically and must be controlled mechanically. On the other hand, protons have a charge allowing the physician to control the procedure electronically, resulting in a more precise treatment with less damage to healthy tissue.

C. Conformal Proton Beam Radiation Therapy

Proton beam radiation therapy is a mainstream, noninvasive, painless type of external beam radiation treatment given on an outpatient basis. Besides being an aggressive treatment for prostate cancer, proton beam radiation has characteristics that minimize detrimental effects on a person’s quality of life. Because of its conformal aspects, proton beam radiation therapy is also called “conformal proton radiation therapy”.
A proton is a subatomic particle with a positive charge and a heavy mass. It is a heavy charged particle, unlike neutrons and photons that do not have a charge. Protons can be conformed to the shape of the cancerous tumor or target volume. The protons are formed into proton beams and the proton beams are conformed to the targeted area in three dimensions (height, width, and depth).

Unlike photon or x-ray beams used in conventional external beam radiation therapy, proton beams retain most of their energy on entering the body. A proton beam can be programmed to travel a certain distance into the body, controlled to release its largest burst of energy at a designated site (called the Bragg Peak), and programmed not to go beyond the outer side of the targeted area. The Bragg Peak is the point at which the deposition of energy is at its highest. These unique qualities of a proton beam minimize radiation of healthy tissue and usually result in minimal side effects.

Because of their qualities, proton beams can be controlled with much greater precision than conventional external beam x-ray or photon radiation. This permits a more intensified radiation dose to provide more effective cancer-killing powers. At the same time, this enhanced control (assisted by computers) permits placement of the Bragg Peak precisely as planned, resulting in normal cells adjacent to the target volume receiving substantially less radiation and less morbidity (undesirable side effects). A more detailed discussion of proton beam therapy is provided later in this book.

Currently, proton beam radiation therapy is confined to certain types of cancers due to scanning limitations with respect to large volumes, but enhancements to facilities are presently underway to extend the scope of cancers that can be treated with proton beam radiation. Fortunately, localized prostate cancer is one of a number of cancers that have been successfully treated by proton beam therapy for a number of years. Initial tests for early localized breast cancer are scheduled to begin in 2004.

The prostate gland, although fairly small, is located deep within the body cavity. The capability of conformal proton beam radiation for improved precision in radiation delivery to the targeted volume, while avoiding undesigned healthy tissue, is particularly important with respect to prostate cancer. Because of the heavy mass of the protons, there is minimum side-scatter and the lowest degree of inaccuracy, thereby significantly reducing unwanted side effects and maximizing treatment effectiveness.

There is no danger of radiation exposure to others (as in the case of brachytherapy) as the radiation does not remain in the body, and the patient does not become radioactive. Patients are encouraged to continue with a normal sex life during the course of treatment.

The successful history of proton beam treatment of cancer, and the minimal side effects associated with this treatment, were significant factors that we took into consideration in our research. The unique qualities of conformal proton beam radiation helped us in our deliberations on a choice of treatment for George.
Conformal proton radiation treatment is one of the options that can be used for “salvage radiation therapy” after a radical prostatectomy when there is a concern that not all of the cancer has been removed or where the cancer has recurred. In these instances, the proton treatments are directed to the “prostate bed” and adjacent region. The prostate bed is the area where the prostate gland had been situated prior to its removal by surgery.

D. Combined Proton and Photon Treatments

With certain patients, conformal proton beam therapy is combined with conventional external beam x-ray therapy in order to provide irradiation of a larger volume of tissue. Because the conformal proton beam equipment presently has scanning limitations, it is currently unable to treat larger target volumes. In the case of prostate cancer, conformal proton radiation is not currently able to treat lymph nodes. Since these nodes may be outside the target volume obtainable by the proton beam, they would not be reached by only conformal proton beam treatment.

When there is a significant risk that the lymph nodes may be involved, there is a need to use conventional radiation to “boost” the site of the disease to a larger volume in order to sterilize microscopic cancer in this enlarged site.

In such instances, x-ray therapy (photon) replaces some of the conformal proton beam treatments. The attending physician will prescribe proton therapy for the primary target and photon therapy for the larger area that may be involved, perhaps 15 proton and 25 photon treatments. This is done because photon therapy has an advantage in being able to target a broader field. This combination of proton and photon treatments permits treatment of lymph nodes that may possibly be involved while greatly reducing the x-ray radiation dose, with its enhanced morbidity, if only x-ray radiation was given.

This combination of proton and photon radiation treatment is one of the options that can be used for “salvage radiation therapy” after a radical prostatectomy. This is used when there is a concern that not all of the cancer has been removed or where there is a recurrence of prostate cancer after a prostatectomy or other treatment. In this protocol, the proton treatments are used to radiate the prostate bed, and the photon treatments are used to radiate the larger area adjacent to the prostate bed.

E. Brachytherapy

Brachytherapy is a form of internal radiation therapy for early stage prostate cancer. It is best suited for a small volume tumor. Prostate cancer brachytherapy is performed by implanting tiny radioactive material (generally called “seeds”) directly into or close by
the cancerous tumor by means of a fine needle placed through the perineum (the skin between the rectum and the scrotum). It is a form of invasive surgery. Initially an assessment of the prostate gland will be made by a detailed transrectal ultrasound. This will enable a radiation oncologist (and a physicist) to plan on the number and placement of the radioactive seeds.

The seed implant is performed under either a spinal or general anesthetic. The patient lies on his back with his knees raised and his feet in stirrups. Seed placement takes about one hour, usually on an outpatient basis. During the implant, the prostate is imaged by means of an ultrasound probe inserted in the rectum. The seeds, which number in the dozens, remain inside the patient and, in effect, he takes his treatment home with him, usually the same day.

Radioactive seeds may be Iodine-125 or Palladium-103. They deliver the intended radiation dose over a number of months. For example, iodine seeds have a half-life of two months (i.e. 50% of the radiated dose is delivered in the first two months, another 25% in the next two months and 12.5% in the two months after that). Consequently, it takes about six months to deliver seven-eighths of the dose. Palladium seeds lose their radioactivity over a period of about three months.

The literature indicates that achieving good results with brachytherapy requires substantial technical skill. Technical and clinical results may vary substantially from one practitioner to another.

Brachytherapy avoids some of the side effects caused by conventional external radiation beams penetrating the body since the seeds are placed directly into the prostate. This permits safer delivery of higher radiation doses.

However, brachytherapy does result in various side effects. Needle punctures from the procedure will likely result in swelling and bruising and take a week or more to heal. Some men may require a catheter for a time. The major side effect is urinary retention. Inflammation of the urethra occurs where it passes through the prostate, which may cause a burning sensation, frequent nocturnal urination, and more urgent and frequent daytime urination. Symptoms may continue in some cases for one to two years. Impotence may occur in a minority of men, and a small percentage of men may experience bowel problems.

Occasionally the seeds float from the prostate to other organs or tissue in the body or may be passed during urination. Patients are warned that if a seed is excreted in the urine not to physically handle the seed, as it is radioactive. If the seed is still highly charged and migrates to another part of the body, it can cause radiation damage to healthy tissue, in that part of the body to which it has traveled, for example the lung or the rectum.
After radioactive seed implants, a patient should avoid physical contact with pregnant women and with young children for a period of six to twelve months after the implant as small amounts of radiation are emitted from the patient. Such contact would include holding them or having them sit on one’s lap. One source found on the Internet entitled the “Wellness Web Prostate Cancer Center” even contained a recommendation that for the two months immediately succeeding the seed implantation, children and expectant mothers-to-be should not come closer than six feet to the brachytherapy patient.

At the time of George’s diagnosis, four of his grandchildren were under eight years of age and our three daughters were all of childbearing age. There was no way that George, who dotes on his grandbabies, could stand the thought of telling them to get away from him due to the fact that he was radioactive.

At the time we were looking for a treatment for George’s cancer, an Internet site indicated that the Prostate Cancer Initiative (a partnership project of the American Cancer Society and the Cancer Research Institute) referred to brachytherapy as “experimental”.

The advantage of brachytherapy in relation to a radical prostatectomy is that it is less invasive. In relation to conventional external beam radiation therapy, the side effects of brachytherapy may be less severe and the procedure itself is much faster, not requiring daily treatment visits over seven weeks.

There is another procedure called high dose radiation (HDR), involving temporary implants, that is not as frequently used. Radioactive seeds are placed into the patient’s prostate gland through catheters (hollow tubes) inserted between the patient’s legs and then removed. This procedure is repeated over several days during which the patient is hospitalized. During each of the treatment sessions, the patient is required to stay comparatively motionless to prevent movement of the catheters, in order to retain the seeds in their location. After completion of the HDR brachytherapy, a course of external beam radiation usually follows.

Andy Grove, chief executive officer of Intel, described the HDR temporary seed implant procedure that he received in an article entitled “Taking on Prostate Cancer” in the May 13, 1996 issue of Fortune Magazine on page 55. This procedure was performed under local anesthesia on four different occasions over 48 hours. Grove then followed up with 28 conventional external radiation treatments on a one-a-day basis.

After reviewing the pros and cons of brachytherapy, we probably would have opted for this procedure if we had felt there was no better treatment to choose from.
F. Cryosurgery

Cryosurgery (also called cryoablation and cryotherapy) is the use of liquid nitrogen probes to freeze a particular organ to extremely low temperatures in order to kill the tissue, including any cancerous tissue. Cryosurgery as a treatment for prostate cancer is a form of invasive surgery that freezes the prostate gland to extremely low temperatures. At the patient’s option, the surgery is done under a spinal or general anaesthetic, and takes about two and one-half to three hours.

An ultrasound probe is inserted up the rectum in order to guide the needles (likely five of them). The fine needles are inserted from behind the scrotum into the prostate gland, after which the cryoprobes are inserted through the tracks made by the needles. The freezing process then takes place with the cooled liquid nitrogen flowing through the probes to their tips, and they adhere to the tissue in a manner similar to a tongue on cold metal. After the initial freezing (with the patient lying on his back with his legs in stirrups), the prostate is allowed to warm up and thaw out, and the procedure is repeated for a second time.

A more advanced procedure for cryosurgery uses argon gas (in place of liquid nitrogen) and six to eight needle probes (rather than five).

The prostate, as well as the tissue adjoining it, is frozen by cryosurgery. This results in killing not only the cancer cells but also all the cells in the prostate. As the prostate atrophies, it is replaced by scar tissue. Semen is no longer produced, as the prostate is no longer functional.

To prevent freezing of the urinary passage during cryosurgery, an urethral warming catheter is inserted through the penis up to the bladder. Warm water is circulated through this catheter in order to keep the tissue surrounding it at body temperature. This raises the possibility that prostate tissue closest to the heated area may not be frozen, thereby failing to reach the objective of the total freezing of the entire prostate.

A consent form that we received from our local cancer center listed a number of potential side effects of prostate cryosurgery. The form indicated that the risk of impotence was at least 67% in the first six months following the surgery. It also stated that recent experience indicated that the impotence rate is as high as 100%, and that while nerve regeneration may result in some men regaining their potency, the impotency is expected to be permanent in most men.

According to the form, some of the other potential side effects of cryosurgery are partial or complete incontinence; failure to control the cancer; a numb penis for up to six months; an unstable bladder for up to five months; bleeding; etc. Sloughing of tissue may occur and might require a transurethral resection, a surgical removal sometimes called the Roto-Rooter Procedure.
It has been said that cryosurgery may be used as a secondary treatment if conventional radiation fails as a primary treatment for prostate cancer.

G. Watchful Waiting

Watchful waiting is active observation and regular monitoring of a patient who has been diagnosed with localized prostate cancer without the patient receiving any actual treatment. Observation and monitoring are by means of regular PSA tests and DREs by a physician. It is intended that active treatment will commence when the prostate cancer progresses or causes symptoms.

Watchful waiting is not a treatment at all. It amounts to doing nothing to actively eradicate the disease. The ostensible rationale for this do-nothing approach is that many men that die of causes other than prostate cancer are also found to have prostates containing cancer cells. It is sometimes said that the benefits from active treatment may be less than the resultant side effects that (as noted in the case of a number of treatments) can be awful. It has also been suggested that a slow growing, small tumor in older men may not cause any troubles before the men die of other causes. The saying goes that most men die “with” prostate cancer, not “because” of it.

The danger of these arguments is that there are different types of cancer and presently it is difficult to distinguish between aggressive and slow-growing prostate cancers. There is a risk that untreated prostate cancer may metastasize and spread to other areas of the body such as the lymph nodes, bones, liver, bladder, etc. Early diagnosis and proper treatment of localized prostate cancer will most likely result in a cure, but metastasized cancer is rarely curable although it may sometimes be controlled. By watchful waiting, a man with prostate cancer may sacrifice his only chance for a cure.

Another factor that should be taken into consideration is that advanced metastasized prostate cancer can cause extreme pain. We have heard of a number of men with advanced metastasized prostate cancer who have suffered greatly due to their condition.

In our personal view, the watchful waiting approach is somewhat akin to playing Russian roulette. Prostate cancer in North America afflicts over 200,000 men annually and tens of thousands of men die from it each year. A friend of ours in his early sixties opted for watchful waiting and he was dead within two years. We have been told anecdotes of men who received medical advice to follow watchful waiting, and only a short time later their prostate cancer had progressed significantly.

It seems to us that if watchful waiting was recommended for women with breast cancer as frequently as it has been recommended for men with prostate cancer, there would
be a public hue and cry. In our opinion, the same reaction to watchful waiting for men with prostate cancer is appropriate, since it is an equally deadly disease even though some prostate cancers may grow slower than breast cancer.

Many older men are given advice to follow watchful waiting due to their age and their diminished life expectancy. In Sweden and some northern European countries, many men over 70 years of age are regularly placed on watchful waiting. Watchful waiting is the most cost-effective solution to prostate cancer in many countries that have socialized medicine. This is comparable to a death sentence for some men whose medical condition could have been cured by early treatment. This approach also does not take into consideration various changes in lifestyle, medical advances, and other factors that have accounted for the extension of life expectancy in men.

We have met or heard of men in their 80s with prostate cancer (one aged 87) who undertook active treatment. An article entitled “Watchful Waiting in Prostate Cancer” is found by following the links from the website at:

“Watchful Waiting in Prostate Cancer”
http://www.johnshopkinshealthalerts.com/alerts/prostate_disorders/JohnsHopkinsHealthAlertsProstate_526-1.html

We are of the opinion that watchful waiting is a choice that should be rejected by the vast majority of men. The waiting itself may cause apprehension and mental distress when a man knows that a time bomb with an unknown fuse length is ticking inside his body. It seems to us that in the face of a confirmed, potentially fatal disease, a man should take the bull by the horns and with a positive attitude determine to select the best treatment available to crush the invading monster within. An added benefit in taking decisive action to destroy the unwelcome invader is a sense of being more in control of one’s destiny, rather than being a passive recipient of the unknown fickleness of diseased cells.

A man diagnosed with prostate cancer should personally make the decision on watchful waiting and not abandon this responsibility to a third party. After all, it is the one with prostate cancer whose life is at stake, not that of a doctor or third party.

H. Interstitial Microwave Therapy

Interstitial microwave therapy is perhaps the opposite side of the coin from cryosurgery. Also known as thermotherapy, interstitial microwave therapy is an experimental treatment for prostate cancer that has recurred in men who have previously had conventional external beam radiation therapy. The procedure involves inserting a number of probes (about four to six) to deliver heat at high temperatures to the prostate gland.
The probes, which are long fine needles, are inserted through the skin guided by transrectal ultrasound. The objective is to maintain the temperature in the prostate to not more than 70 degrees Celsius for about 20 minutes.

Much further study and clinical trials are required to determine if microwave thermotherapy may become a viable option for recurrent and primary prostate cancer. *The Journal of Urology* issue of November 2001 (166:1707-1714) contains an article that discusses method of treatment and results of a phase I/II trial.

### I. Hormonal Therapy

The scientific community believes that male hormones called androgens, particularly testosterone, assist the growth of prostate cancer cells. The aim of hormonal therapy (also called hormone therapy) is to block the body’s production of testosterone by the use of drugs or certain surgical procedures. This therapy may shrink the size of the cancerous tumor, inhibit its growth, and reduce the size of an enlarged prostate gland. A prostate tumor that has a small volume should help to make radiotherapy and surgery more effective.

Hormonal therapy is used as a treatment for advanced prostate cancer where the disease has metastasized. Its objective is to minimize the effects of the cancer. However, hormonal therapy by itself does not cure the disease. The reason for this is that some prostate cancer cells are hormone-independent (also called androgen-independent or hormone-insensitive) and these independent cells will not discontinue their growth due to the hormone therapy. On the other hand, hormone therapy will have an effect on hormone-dependent cells and may in some cases retard prostate cancer.

Although the PSA levels may be reduced and the tumor shrunk, the prostate cancer will not be eradicated. Because the PSA level is artificially reduced (usually significantly) by hormonal therapy, there is no longer any method to check on what the real and precise PSA level is. In addition, hormone-independent cells supplant hormone-dependent cells as those latter cells recede.

Combined hormonal therapy is the concurrent use of a castration method with anti-androgen drugs. There is evidence that eventually this combination, as in the case of other hormonal therapies, will cease to be effective.

Many times in early stage prostate cancer hormonal therapy is given in conjunction with radiation or a radical prostatectomy. Some believe that in localized cancer it should only be considered where the prostate gland is extremely large or there will be an undue delay in receiving active treatment for the prostate cancer. Accordingly, it is sometimes used to reduce the volume of very enlarged prostates. Others may also elect to use it
immediately after diagnosis in order to buy time to make a decision on treatment. If this is their only purpose and this treatment is not medically necessary, they should seriously consider the adverse side effects associated with hormone therapy that they will most likely experience.

We are personally aware of one instance in which a person with localized prostate cancer had hormonal therapy “thrust on” him by the urologist, and he believed that it was standard procedure for those just diagnosed with prostate cancer. We are of the view that, except where medically necessary or appropriate, hormonal therapy should not be used on patients with early stage prostate cancer. In most cases it should only be employed for advanced prostate cancer that has metastasized.

Hormonal therapy is also called “medical castration”. The testicles produce over 90% of the testosterone in the body and the adrenal glands produce the balance. The hormone responsible for stimulating the production of testosterone in the body is Luteinizing hormone-releasing hormone (LHRH). In hormonal therapy injection by needle or orally of LHRH agonists (such as Lupron or Zoladex) and oral ingestion of antiandrogen drugs (such as Flutamide or Nilutamide) are usually used. The LHRH agonists are drugs that inhibit the action of LHRH and shut down the production of the LH hormone by the pituitary gland. Luteinizing hormone (LH) is a chemical transmitted by the pituitary to signal the production of testosterone by the testes.

The term “neoadjuvant therapy” is applied to hormonal therapy taken before or during another primary treatment, while “adjuvant therapy” is the term used when hormonal therapy is given after the primary treatment.

Side effects of hormonal therapy are not very nice. They can include hot flashes, fatigue, and enlarged breasts. Other results of this treatment may include impotence, nausea, depression, and loss of sexual drive. Osteoporosis (loss of bone density that can lead to fractures) is considered by some researchers to be one of the most significant side effects of some hormonal suppression therapies used as a treatment for prostate cancer.

Once breast enlargement occurs, it is relatively permanent notwithstanding discontinuance of the hormone therapy. In Canada some patients are given low dosage radiation to the breasts prior to receiving hormonal treatment, in order to prevent enlargement of the breasts.

An important factor is that after a period of time the cancer cells may become hormone-refractory (the patient becomes androgen-independent), and the prostate cancer will then resume its growth. “Refractory” is a term that designates a condition in which a disease is no longer responding to the current type of treatment. When a patient becomes resistant to treatment based on the use of hormones, he has hormone-refractory prostate cancer. This amounts to progression of the cancer.
When George's brother Al had a recurrence of prostate cancer he was initially treated with only hormonal treatment. Although his PSA decreased, the cancerous tumor unknowingly continued to grow and he died a short time later of metastasized prostate cancer.

There are presently clinical trials to determine the effectiveness of hormonal therapy in the treatment of prostate cancer.

As noted earlier, if George had been selected for the trial study involving cryosurgery and elected to proceed with it, he would have been required to take hormonal therapy. This was so, even though he was subsequently advised that there was no necessity whatsoever that he receive hormonal therapy in conjunction with the treatment that he eventually opted for. We feel fortunate that George did not have to undergo hormonal therapy.

J. Orchiectomy

Orchiectomy is a form of non-reversible hormonal therapy which amounts to “surgical castration”. Orchiectomy is the surgical removal of the testicles that produce over 90% of the body’s testosterone. This surgery does not require the removal of the scrotum, the sac containing the testicles.

After this surgery there are no longer testicles to produce testosterone, but small amounts of male hormones continue to be produced by the adrenal glands. It is likely that only a man with advanced prostate cancer would opt for this form of castration. The one-time procedure is supposed to be relatively straightforward, given under local or general anesthetic, and it usually requires no hospital stay. While it is possible that this procedure may hinder the cancer, eventually most prostate cancers are able to grow with little or no male hormones, and further alternative treatment may still be required.

Many men find this surgery emotionally unacceptable. Since the adrenal glands still produce small amounts of testosterone after an orchiectomy, the cancerous tumor retains the potential to continue to grow.

An Internet summary of an article that appeared in The Journal of the National Cancer Institute of November 1, 2000 sets forth findings of University of Toronto researchers led by Dr. Ahmed Bayoumi. The researchers determined that based on its effectiveness and one-time cost for the surgery, as compared to other treatments in which drugs were a part, orchiectomy was a cost-effective approach to hormonal treatment of advanced prostate cancer patients.
The researchers stated that for men who accept orchiectomy it is the most “cost-effective androgen suppression strategy”. The study concluded that orchiectomy offers better value because it is cheaper than drugs. On the other hand if drugs are prescribed, the cost of these drugs could continue until the death of the patient. It appears that the study neglected to sufficiently assess the quality-of-life decisions of patients, at least according to Dr. Bruce Hillner. Dr. Hillner wrote a simultaneous editorial to this effect in the same medical journal. In our opinion, it would not be appropriate to influence men to be surgically castrated because of the lower cost.

K. Chemotherapy

Chemotherapy is the use of powerful drugs to attack and kill cancer cells. However because it cannot differentiate between healthy cells and cancer cells, it can also destroy normal healthy cells such as those in the hair, blood, bone, and in other areas. Chemotherapy is primarily used when the cancer is in an advanced stage. Many men with prostate cancer find that chemotherapy does not work well. The American Cancer Society has stated that chemotherapy is ineffective against early, localized prostate cancer.

If the cancer is metastasized, or if the cancer cells recommence their growth (because hormone therapy is not working, i.e. the cancer has become hormone resistant) chemotherapy may be helpful in relieving symptoms. However, the cancer will likely return since chemotherapy does not kill all of the cancer cells. The drugs may be given orally or by injection.

Side effects invariably occur as a result of taking chemotherapy drugs. This is due to the drugs attacking not only the cancerous cells but also healthy cells. Side effects may include loss of hair, diarrhea, nausea, fatigue, greater infection risk, and others. Most side effects disappear when chemotherapy ceases due to replacement of the injured cells by the body. For example, hair will re-grow. Chemotherapy should only be considered when the prostate cancer is not localized.

L. Complementary Medicine

There are adherents of complementary and alternative therapies in the treatment of disease, including prostate cancer. The health care practices of complementary or alternative therapies are invariably not considered part of mainstream medical care.

Complementary therapies are frequently used with mainstream treatments, while alternative therapies may be used in lieu of generally recognized treatments and, in some cases, they may not have been the subject of clinical trials to evaluate their effectiveness. Some complementary and alternative practices have long histories while others smack of quackery.
Many people look to integrate their approach to health by bringing complementary therapy into their mainstream medical care. Others, fearful of modern scientific medicine (also called allopathic medicine), may rely on alternative methods. Many allopathic medical practitioners are likely opposed to non-mainstream therapies.

However there are medical doctors, such as Dr. Andrew Weil, who emphasize complementary healing while not discounting what they consider appropriate medical treatment. Dr. Weil is the Director of the Program in Integrative Medicine at the University of Arizona in Tucson where he practices natural and preventive medicine. Although we do not agree with all of Dr. Weil's medical views, we have found much of his writing quite helpful, particularly with respect to diet and health.

In his 1995 *New York Times* bestseller book *Spontaneous Healing*, he refers to himself as a “dedicated follower of Hygeia”, the goddess of health in Greek myth. He does not use the same expression for the follower of Hygeia’s father Asklepios, the god of medicine. To paraphrase his view, the Eastern approach to medicine (Hygeian) of enhancing internal resistance to disease may be of greater usefulness in the long run than the Western focus (Asklepian) of finding the causes of disease and fighting them with medical technology.

*Spontaneous Healing, by Dr. Andrew Weil*

http://www.amazon.com/exec/obidos/tg/detail/-/0679436073/

Some approaches, complementary to and not in substitution for conventional treatments, may include among others visualization, relaxation, nutrition and exercise. An example of the approaches of an organization that espoused the incorporation of safe and efficacious complementary and alternative practices into mainstream health care was the Tzu Chi Institute. This not-for-profit institute was located in Vancouver, British Columbia, Canada. It had a number of partners, several of which included the Vancouver Hospital and Health Sciences Center, the British Columbia Cancer Agency, and the Canadian Cancer Society (British Columbia and Yukon Division).

One of the Tzu Chi Institute’s undertakings was an integrated program for prostate health. This program for men with prostate cancer, or those wishing to reduce their chances of getting it, provided clinical services that aimed to complement mainstream medical care, not to displace it. Its Information Resource Center provided relevant data and materials. The Institute’s leaflet on prostate health indicated that its approaches included a mind-body program (one example, meditation), herbs and other natural health products (one example, Chinese herbal medicine), nutrition and supplements (one example, selenium), and exercise (one example, Qi Gong). Due to funding cutbacks, it has had to suspend operations. Hopefully this or a similar institution will be able to obtain the necessary funding to provide this type of integrated program.
There are treatments or practices which some individuals with cancer may decide to follow in place of mainstream treatment, in which event they may be considered alternative measures. These include (but are not limited to) acupuncture, traditional Chinese medicine, homeopathy, guided imagery and visualization, meditation, naturopathy, herbal treatments, holistic medicine, and ayurvedic medicine.

Some alternative practices may be problematic. For example, a participant in a clinical study at the University of California at Irvine who had been on saw palmetto was diagnosed with prostate cancer, although he had a relatively low PSA. The doctors at that University did research and found that saw palmetto has been shown to decrease PSA levels by approximately 50%, and this had masked that participant’s true PSA reading.

Since the content of saw palmetto may vary from one product to another, the effect on PSA levels may also vary. One oncologist suggested that saw palmetto reduced PSA levels but less than the approximate 50% reduction associated with the prescription drug Proscar. We suggest it would be prudent to be aware of possible consequences of using herbal remedies.

Another supplement that some people may use for prostate cancer is Essiac, a tea brewed from herbs based on a formula originally provided by an Ojibwa medicine man. In the course of our research, we read an article in a Canadian news magazine that gave remarkable anecdotal evidence of this tea’s benefits. After talking to a man in New York City referred to in the article, George commenced taking this herbal tea while we were in the decision-making process as to his active treatment.

In our view, a person with prostate cancer should not rely solely on alternative treatments. Before participating in them that person should discuss their use, in conjunction with his recommended conventional therapy, with his trusted qualified medical practitioners and advisers. In addition, he should consider obtaining a qualified second opinion before embarking on alternative methods to the exclusion of conventional treatment. Not all complementary therapies or alternative therapies are helpful with respect to prostate cancer. As well, one should ascertain what, if any, risks are involved in these therapies.

M. Research in Virus and Immunotherapy Treatments

There are a number of studies underway in the United States, Canada, and Europe to test the use of viruses to kill cancer cells. To give one example, Dr. Patrick Lee and others of the Cancer Biology Research Group at the University of Calgary (consisting of 30 full-time members) have finished the first phase of a trial to test the safety of a
reovirus. A reovirus is a benign human virus that can bring on a runny nose and minor upset stomach, particularly in small children. The tumors of 18 people with a number of cancers were injected with the reovirus, and no serious side effects occurred. At the time of writing this book, a Phase II trial is underway to test 45 men who have prostate cancer.

Indications are that results of virus injections to fight cancer cells are encouraging, but the procedure is still experimental. The Mayo Clinic and the Universities of Stanford, Harvard and Duke are a few of the other institutions conducting laboratory research or trials with other types of viruses.

The theory of stimulating macrophages (a large white cell usually found at points of infection) and NK cells to more effectively kill targeted cancer cells is called immunotherapy. One therapy that has been used is Bacillus Calmette-Guerin (the organism in TB vaccine). It has been used after surgical removal of a malignant tumor in order to stimulate the macrophages to prevent metastasis by killing any cells that had escaped from the malignant melanoma. Subsequent studies have shown this organism to be useful in treating superficial bladder cancers and basal cell carcinomas. Immunotherapy is an interesting area of cancer research, but it is still an experimental treatment for cancer.

N. High Intensity Focused Ultrasound

Several institutions in the United States are proceeding with clinical studies of High Intensity Focused Ultrasound (HIFU), in the treatment of patients with localized prostate cancer or whose cancer has recurred. Information on the Internet indicates that the treatment is minimally invasive and uses an ultrasound scanner or device to obtain an ultrasound image of the prostate gland, and to outline the treatment area. The ultrasound device uses HIFU to heat the targeted area from 70 degrees to 90 degrees Centigrade, or to therapeutic temperatures.

Indiana University School of Medicine in Indianapolis, Case Western University in Cleveland, and Georgetown University Medical Center in Washington, D.C. are among the institutions involved in clinical trials.

Relevant Internet web sites are:

Focus Surgery Inc.
http://www.focus-surgery.com

EDAP
O. Laparoscopic Radical Prostatectomy

New techniques for prostate cancer surgery are presently under review and study. One method is removal of the prostate using a minimal invasive technique called laparoscopic radical prostatectomy. This type of prostatectomy has been performed at a number of medical centers in the United States including Seattle's Harborview Medical Center, the Cleveland Clinic, the UMass Memorial Medical Center, and Detroit's Henry Ford Hospital (where this pioneering procedure is now standard).

This type of prostate surgery uses robotic fingers to wield surgical instruments, and laparoscopic techniques to see inside the body. The result is smaller incisions, less loss of blood, shorter hospital stays, and faster healing. The main disadvantage of this technique is that it provides no opportunity for the surgeon to have tactile sensation of the surgical area.

Although in the future this technique may perhaps become the surgical treatment of choice for localized prostate cancer, it does require further research and follow-up studies. Any surgeon using this radical prostatectomy technique should be highly trained and skilled.

P. Transurethral Resection of the Prostate (TURP)

Transurethral resection of the prostate (TURP) is a surgical procedure used to remove blockages of the urethra. This is a surgical procedure to bore through the prostate or remove portions of the prostate gland through the penis. This technique is most often used to treat patients with BPH who suffer from urine flow obstructions. This is not a treatment for prostate cancer; it is a surgical treatment for urination problems and is often referred to as the Roto-Rooter Procedure.

With respect to prostate cancer, TURP may also be used to treat men who can’t have a radical prostatectomy, and where it is necessary to remove part of the tumor when it is causing severe urinary canal obstruction. It is also used when there is an obstruction in the urethra caused by the accumulation of scar tissue after some other treatment for prostate cancer, such as radical prostatectomy or cryosurgery. These treatments can occasionally result in the urethra becoming blocked with scar tissue, resulting in a total inability to urinate and requiring dilation of the urethra by means of a TURP.

A patient with a high-grade prostate cancer, whether known or unknown, has a very definite increased risk of having the cancer seeded by the TURP. This could result in
the development of bone cancer or other secondary cancers. For this reason, many urologists will not perform a TURP on a patient with diagnosed prostate cancer until the patient has first been treated with radiation or hormonal therapy to reduce the danger of spreading the cancer.

The foregoing is a brief summary of our research relating to treatments for prostate cancer. It should be noted that our research focused on treatments for localized prostate cancer and that specific details of these treatments should be discussed with qualified medical consultants.

At the present time there appears to be no cure for advanced prostate cancer that has metastasized and spread to other parts of the body. However some of the treatments discussed herein may help to control the effects of the advanced cancer and in some instances may extend the life expectancy of the patient. The information contained in this book is not a replacement for medical evaluation, advice, diagnosis or treatment by a qualified and unbiased health care professional.

We were fortunate that in George’s case his prostate cancer was localized and found at an early stage. After ruling out experimental clinical trials, we subsequently eliminated treatments where we had serious concerns about the availability of follow-up therapy if the prostate cancer recurred at a later date.

When we had singled out a number of comparable effective treatments, we then compared the potential morbidity of each procedure. Morbidity is the medical term for unhealthy or horrendous side effects from a particular type of treatment. Without consciously intending to do so, we were actually following the words of Hippocrates with respect to the treatment of disease: “... to help, or at least to do no harm”.

We decided to go with a mainstream treatment that was approximately equal to other mainstream treatments; one which was most likely to result in the least side effects; and one which would allow for various treatment options if the prostate cancer was to reoccur subsequent to the initial treatment. Our treatment decision was to go with conformal proton beam radiation therapy, which we discuss in more detail hereafter.
8. Overview of External Radiation Therapy

“... when a God-given brightness comes, a radiant light rests on men.”

— Pindar, Pythian Odes

This chapter provides information on external radiation therapy for prostate cancer.

A. Description of Proton Beam Therapy

Conformal proton beam radiation therapy (generally referred to herein as proton beam therapy) is a mainstream external beam radiation therapy effective for a number of cancers, particularly for localized prostate cancer. It is a treatment that concentrates the radiation on the target area, while normally sparing the patient's adjoining organs from serious side effects. In most cases, this treatment preserves quality of life to a greater extent in comparison to other treatments. In the case of prostate cancer the radiation dose is concentrated in the gland, while the adjacent organs (the rectum and the bladder) receive minimal radiation.

Proton beams are positively charged sub-atomic particles. They are highly conformable, enabling the beam to be directed with precision to designated volumes in the body. Because it is conformal, the beam can be shaped very closely to conform to the target area in a three-dimensional pattern (i.e. three-dimensional conformed irradiation techniques are used). The “conformal” aspect means that computers can be utilized to control the shape and angle of the proton radiation beams to conform them in three dimensions (width, height and depth) to the target area. This conformal characteristic permits the delivery of higher doses of radiation to the cancerous target area and less to nearby healthy tissue. As a result, there is significantly less injury to healthy tissue and significantly less severe side effects.

In the majority of cases the side effects are inconsequential. Treatment is given on an outpatient basis. A prostate cancer patient will have approximately 40 treatments over a seven to eight week period, with one treatment a day from Monday to Friday of each week. The total time involved in the actual treatment is about two minutes, although it takes about one hour from the time of arrival at the hospital for the treatment to the time of departure. Almost invariably the patient is able to continue with his usual affairs before and after treatment each day including working, golfing, hiking, touring, and other activities.
In some instances, x-ray therapy (photon) may replace some of the proton beam treatments. If, for example, there is a possibility that the lymph nodes may be affected by the cancer, proton treatment may not reach the cancerous nodes because the beam has been conformed to the size and shape of the prostate. In this situation, the attending physician will prescribe proton therapy for the primary tumor and photon therapy for the larger targeted area. This is done because photon therapy has an advantage in being able to target a broader field. Unlike the proton beam, the photon beam’s inherent nature is to diverge.

B. Features of Proton Beam and X-Ray (Photon) Radiation

In conventional external beam radiation therapy, high-energy photons traveling through a patient’s body deliver energy with its radiation consequences to whatever the beam passes through, whether cancerous or healthy. Because photons lack charge and mass, their power declines as they progress through the body. Consequently, the maximum radiation dose is lodged in the first tissues they encounter, i.e. the healthy tissues near the surface of the body and not, as in the case of prostate cancer, at the depth in the body where the cancerous tumor is located. In addition, significant energy carries on beyond the tumor and entirely through the body and healthy tissue, delivering radiation where it is not wanted or desirable, such as the rectum in the case of prostate cancer patients.

Because of the inner depth of the prostate gland, a stronger x-ray beam is required to penetrate that far. However, the larger the dose of photon radiation, the larger the dose received by healthy tissue and the greater the risk of increased unwelcome side effects caused by radiating the healthy tissue. This presents a dilemma — the higher the photon radiation dose the greater the damage to the cancerous tumor, but the higher the radiation dose the greater the risk of more severe undesirable side effects. As a result, to minimize damage to healthy tissue less than an optimum dose (that would be desirable if there were no side effects) is given, thereby reducing the chances of killing all of the malignant cells.

Protons are well understood by knowledgeable radiologists, physicists and engineers since their radiobiologic characteristics resemble those of photons. However in contrast to a photon, a proton (a positively charged sub-atomic particle) has a charge and heavy mass. Its mass is about 1,800 times that of an electron. This gives a proton more advantageous qualities than those possessed by a photon. Charge and mass have unique qualities for controlling the patterns of energy deposition. By virtue of these features and qualities, a proton beam dose can be intensified over and above standard x-ray radiation and be energized to precise speeds.
In addition to the conformal aspects of a proton beam, which can be shaped to the cancerous targeted area, an appropriate energized proton beam has the following attributes:

- It can be programmed to travel a circumscribed distance within the body.
- It deposits a lower dose on entering the body than does a photon beam.
- It slackens its velocity as it reaches the targeted area containing the cancer, delivering a greater amount of energy as it slows down.
- It stops at the designated area and releases its largest burst of energy at a site called the Bragg Peak.
- It does not exit the body but stops at the outer edge of the targeted area, thereby sparing the healthy tissue beyond.

The placement of the Bragg Peak will have been predetermined with precision by the professional treatment planning team to ensure that it is within the cancerous targeted area, that the cancerous tissue receives the greatest energy, and that the adjacent normal cells receive substantially less radiation.

A computer regulates the positioning of the Bragg Peak. A number of Bragg Peaks are directed to the targeted site during treatment. The effect is to impart the greatest radiation intensity to the tumor to destroy the cancerous cells.

Because of the heavy mass of the proton, very little divergence and very little dispersion occur, major determinants in enhancing the effectiveness of the treatment and in mitigating side effects. The physics of these proton particles enable proton therapy procedures to be managed in a manner not available to x-rays.

In the ideal world of radiation therapy, only morbid tissue would receive ionizing radiation. In the case of protons, ionization occurs when positively charged protons in the nucleus of the atom pull nearby negatively charged orbiting electrons out of their orbits, thereby altering the make-up of the atom and the molecule in which it is housed. Ionizing radiation impairs the molecules inside the cells and especially the DNA.

The acronym DNA stands for deoxyribonucleic acid, the self-replicating material in almost all living organisms and the carrier of genetic information. Damaging the DNA impairs certain cell functions, which may inhibit or prevent their division or multiplication. All cells endeavor to revivify themselves and reproduce. However, the capacity of cancer cells for regeneration is generally subordinate to that of healthy cells. Consequently, the damage to the cancer cells is longer lasting and more of them are killed while the healthy cells will regenerate.
Both conventional external beam x-ray radiation and proton beam radiation employ this process of ionization and selective cell destruction. However because of the above mentioned attributes of the proton (which the photon does not have), proton beam therapy is more precise and controllable, permitting the treatment to be better managed and more effective. The main advantage of proton beam therapy over x-ray therapy is that the side effects are minimized in proton beam therapy, thus providing a better quality of life for the prostate cancer patient.

While improved machines in some locations have the ability to conform x-ray beams, their conformability is less exact than proton beams. The x-ray beams penetrate not only into the targeted area but also into and out of healthy tissues on entering the body and on its far side, leading to undesired side effects as the x-rays exit the body. On the other hand, proton beams can be programmed to deposit their energy at and go no farther than the outer boundary of the targeted site.

In brief, contrary to the x-ray beam of conventional radiation therapy, the proton beam’s energy is primarily deposited and distributed inside the cancerous tumor site, significantly sparing normal tissues and minimizing side effects.

The amount of radiation dose received during proton beam therapy can be calculated to provide what the equivalent radiation dose would be if conventional radiation had been used. In George’s case, the Radiation Medicine Treatment Summary he was given after treatment shows that his total dose was 78 cobalt Gy equivalent. The Gy is the unit of the absorbed dose of ionizing radiation based on the international system of units.

C. Comparison of Proton Therapy with Other Treatments

The most noteworthy advantages of proton beam therapy over other prostate cancer treatments discussed herein are that the results for early stage localized prostate cancer compare favorably with other treatments, and it has significantly less short and long term serious side effects.

In the summer of 1999, researchers at Loma Linda University Medical Center (LLUMC) released the results of a five-year outcome study with respect to disease-free survival rates for the 319 patients in the study who received proton beam therapy. The results demonstrated that, for early stage prostate cancer, this treatment compares favorably with radical prostatectomy.
For that five-year period, 97% of the patients in the study who had been treated with protons showed an overall clinical disease-free survival rate, and 88% were bio-chemically disease-free. As well, material side effects that generally accompany a radical prostatectomy were frequently absent for those who received proton beam therapy. Since the prostate gland is deep within the body cavity, it is not a simple operation to remove it and requires intensely invasive major surgery.

Table 4 of an April 2002 article written by Dr. James Metz gives a comparison of the side effects associated with protons, conventional radiotherapy (photons) and prostatectomy. This article is:

“Reduced Normal Tissue Toxicity With Proton Therapy”
http://www.oncolink.com/treatment/article.cfm?c=9&s=70&id=211

The LLUMC Report indicates that if a patient shows no symptoms or no indication on a physical examination or radioactive nuclide scan, he is regarded as clinically disease-free; likewise he is deemed bio-chemically disease-free if his PSA results subsequent to treatment are stable. Research particulars were published in July of 1999.

It is our understanding that a stable PSA is one that is not likely to change or be affected adversely, and that is steady and non-rising. LLUMC considers three consecutive post-treatment rises in PSA after its nadir has been reached (subsequent to treatment) to be biochemical failure. This is the same definition used by the American Society for Therapeutic Radiation and Oncology (ASTRO). The nadir is determined as the lowest point reached in a series of PSA tests. One post-treatment increase in PSA may be considered not significant (and only a bump) if it is not substantial.

Unlike brachytherapy, radiation from proton beam treatment does not stay in the body. Since he is not radioactive, the proton beam patient poses no danger of radiation exposure to anyone else. Side effects caused by brachytherapy and cryosurgery have been discussed earlier.

There is an aspect of proton beam therapy (also shared by conventional external beam x-ray therapy) which may be bothersome or inconvenient for some patients, such as those who continue to work during the course of their treatments. This is the length of time the treatments take compared to radical prostatectomy, brachytherapy and cryosurgery. The latter treatments last only a few days at the most, while proton beam therapy and external beam x-ray treatments occur over a seven to eight week period.

However, the recovery time after treatment should also be taken into consideration. There is almost always no recovery time required after proton radiation therapy. In contrast, there can be a lengthy recovery time after radical surgery, or several weeks of recovery time after cryosurgery, or many months of radioactivity as a result of brachytherapy. Many men who take these treatments continue to have side effects after their recovery time.
A disadvantage of proton beam therapy, depending on one’s point of view, is that the locations where treatment is available are limited and, in many cases, a patient will have to leave his home for seven or eight weeks and stay in the city where the treatment is given. However, if one is retired or simply wants to get out of the business rat race for awhile, the lengthy treatment period may seem more like an extended holiday only briefly interrupted each weekday by actual treatment.

Another disadvantage of proton beam therapy for some is the financial cost of the treatment if it is not covered by the patient’s medical insurance. However we found most patients living in the United States are covered in this respect.

D. Historical Background of Radiation Treatment

Three centuries ago Isaac Newton said that if he saw further than others “it is because I was standing on the shoulders of giants”. It was the contributions of giants in varied scientific disciplines that led to the eventual discovery of proton beam therapy. A proton is part of an atom. Consequently, an essential antecedent to the rise of this therapy was the development of atomic theory.

In the 5th century B.C., Leucippus posited the existence of an individual particle (in Greek an “atomon”). His pupil, the Greek philosopher Democritus of Abdera (c. 460-370 B.C.), subsequently developed an atomic theory. He advanced a proposition that the universe is composed of atoms moving in the Void, i.e. space. However, the foundation for modern atomic theory was laid by an English chemist, John Dalton, in his 1808 book A New System of Chemical Philosophy.

The pathway to proton beam therapy received a major impetus in the late 19th century with the discovery of radiation. From that breakthrough to the latter part of the 20th century, prominent luminaries in the fields of science, physics and medicine have contributed to unearthing the mysteries of matter. Although some did not specifically have medical objectives in mind, their pioneering efforts led to advances in nuclear science and in high-energy physics that were brought into the field of medicine and therapy for the benefit of the human race.

The following is a very brief condensation of some of the highlights of this journey and the names of some, but by no means all, of the renowned personalities that were involved.

It was in 1895 that a German physicist, Wilhelm Konrad Roentgen, discovered the x-ray. Roentgen so named it because of the then unknown nature of x-rays, the algebraic
symbol for an unknown quantity being an “x”. In brief, x-rays are a form of electromagnetic radiation (or rays of short wavelength) able to penetrate solid or opaque substances. The energy of x-rays is carried by photons. A photon is a quantum of electromagnetic energy with both particle and wave behavior having momentum. This find by Roentgen (for which in 1901 he won the first Nobel Prize issued for physics) was to form part of the groundwork for nuclear science and modern medicine.

A short time later radioactivity in uranium, polonium and radium, which emitted radiant energy, was discovered. Antoine-Henri Becquerel (a French physicist) discovered natural radioactivity in uranium, and Marie and Pierre Curie (physicists in France) discovered the latter two elements. All three shared the 1903 Nobel Prize for physics.

Two other German-born physicists who also won Nobel Prizes for physics, Max Planck and Albert Einstein, advanced the science. Planck was the founder of the quantum theory, one of the foundations of 20th century physics. In brief, his theory was that energy is not radiated as a continuous flow but discontinuously in waves or particles, in discrete units or quanta of energy.

In 1888 Heinrich Hertz, a father of quantum physics, discovered radio waves and the photoelectric effect. Subsequently Einstein won the Nobel Prize in 1921 for his services to theoretical physics “especially for his discovery of the law of photoelectric effect” in 1905 based on Planck’s quantum theory and light quantum (later called “photon”) — the particle associated with electromagnetic radiation.

Yet another Nobel Prize recipient, Sir Ernest Rutherford, a British physicist born in New Zealand in 1871, is regarded as the father of nuclear physics. He delved into the hidden world of the atom and discovered the atomic nucleus. He posited that, analogous to the planetary system in which planets orbit the Sun, negatively charged electrons orbit around a central nucleus, which has a positive charge and constitutes virtually all of the atom’s mass. He used the term “proton” to refer to a part of the dense nucleus of the atom. He developed a method by which protons could be forced out of the nucleus by inducing a collision between an atom and an alpha particle. In 1920 he inferred the conceivable presence of a neutron, which was in fact subsequently discovered by James Chadwick. Rutherford and Frederick Soddy (a 1921 Nobel laureate who coined the term ‘isotope’) proposed the laws of radioactive decay.

In 1913 a Danish physicist, Niels Bohr, combined the concepts of the quantum theories of Planck and Einstein with Rutherford’s model of the atom. Bohr postulated that an atom had a central nucleus and electrons with a quantum, or fixed amount, of energy orbiting it. When an electron’s orbit is altered to another orbit, a photon (radiant energy without charge or mass) results. He was awarded a Nobel Prize in 1922 for his work on atoms and their radiation emission.
A French physicist, Prince Louis-Victor de Broglie, was the first to propose that sub-atomic particles can also have the properties of waves, and he was awarded the Nobel Prize for Physics in 1929.

The United States physicist Arthur Compton (who won the Nobel Prize in 1927) proposed the Compton effect theory, which provides evidence of the dual wave-particle nature of radiation.

Werner Heisenberg developed the uncertainty principle in quantum mechanics for which he received a Nobel Prize for Physics in 1934. Quantum mechanics is the mathematical form that deals with the interaction and motion of subatomic particles and includes the concept that these particles can also be regarded as waves. The axiom that the momentum and position of a particle cannot both be precisely determined at the same time is the uncertainty principle.

At the Curie Institute in Paris in the 1930s, Marie and Pierre Curie’s daughter Irene and son-in-law Jean-Frederic Joliot-Curie jointly participated in the discovery of artificial radioactivity and received the Nobel Prize for Chemistry in 1935. Their work led to the application of radioisotopes for diagnosis and treatment. The Curie Institute was in the vanguard in the treatment of cancer by use of x-ray beam radiation. These x-ray beams consist of photons.

Following the work of Irene and Jean-Frederic, an Italian, Enrico Fermi, received a Nobel Prize in 1938 for his work in the identification of new radioactive elements and for his discovery of nuclear reaction effected by slow neutrons. After relocating to the United States in the late 1930s, he became a member in 1942 of the Manhattan Project for the production of the first atomic bomb. He also participated in the construction of the synchrocyclotron, a large particle accelerator, at the University of Chicago.

Ernest Lawrence, an American physicist, further advanced radiation therapy. While at the University of California at Berkeley, Lawrence and other scientists developed the first circular accelerator. This accelerator (later called a cyclotron) was capable of enormously intensifying the acceleration of the heavy particles, boosting ions to previously unheard of velocities. With the cyclotron, nuclear transformations could occur making possible the formation of new elements. The outcome was far-reaching.

Ernest Lawrence and his brother John initiated a research plan to enlist the possibilities of physics in the healing of human disease. An indication of their profound belief in what they were doing is the fact that they treated their own mother for cancer. Ernest Lawrence was awarded the Nobel Prize for physics in 1939.

In the 1940s experimental nuclear reactors were built in the United States and Canada. Canada’s nuclear research program under the National Research Council built a heavy water reactor in Ontario. Heavy water contains deuterium atoms, instead of hydrogen.
Both of these elements have simple nuclei, although deuterium’s consists of a proton and a neutron, while hydrogen’s consists of a proton. When Canada’s reactor went into service in 1947, physicists attempted to create artificial isotopes — other forms of the same element having different atomic weights. This led to the discovery of Cobalt-60, a promising source of radiation for cancer therapy.

The peaceful benefits of this atomic research resulted in the prototypes of two cobalt facilities being built at two hospitals in Canada in 1951. A Canadian physicist at the University of Saskatchewan, Dr. Harold E. Johns (who devoted his career to the application of physics to medicine and biology) was responsible for developing the first Cobalt-60 therapy unit to go into service. According to the Canadian Encyclopedia this development “revolutionized the radiation treatment of cancer worldwide”. Subsequently, the M.D. Anderson Hospital in Houston opened the first United States cobalt facility in 1953.

In the United States shortly after World War II, the recently created Atomic Energy Commission made radioisotopes and atomic research open to investigation and study for medical purposes. The concept of employing proton beams for medical use came about in the 1940s. Robert Wilson (a physicist who had obtained his Ph.D. at Berkeley where Ernest Lawrence was located) had been at Los Alamos, New Mexico during the war. Los Alamos was the center of nuclear research during the war and the first atomic and hydrogen bombs were developed there.

At Los Alamos, Wilson had become familiar with cyclotrons. After the war, Harvard University recruited Wilson to work in its Research Laboratory of Physics to develop a new cyclotron capable of generating much higher energy. It was there that he came up with the trailblazing idea of using the proton, not the photon, for radiation therapy. He published a paper in July 1946 in the Journal of Urology. His treatise was the first time anyone had advocated using protons for medical purposes.

Dr. Wilson was prescient in indicating that the capabilities of a proton beam were such that it could be managed to provide radiation in high doses to a confined site while concurrently avoiding non-targeted tissue. A cyclotron with its Bragg Peak capability would be ideal to achieve this result. However because of the ensuing Cold War with the Soviet Union, Wilson’s idea remained relatively dormant for a number of years. Development of a linear accelerator did progress and resulted in improved x-ray therapy.

Harvard University did do research in proton therapy and carried on a program under which over 8,500 patients were treated for several types of cancer, but not prostate cancer. These cancer treatments were given in a laboratory, not in a hospital based proton center. On June 5, 1999, a symposium celebrating 50 years of proton beams at the Harvard Cyclotron Laboratory was held at the Harvard University Science Center in Cambridge, Massachusetts.
In the 1980s and earlier, Dr. James Slater of Loma Linda University had a vision to bring proton therapy out of the physics laboratory and into a hospital setting. It had become apparent that, with the development of CAT scans and sophisticated computers, radiation medicine could be better planned and controlled in both diagnostic and treatment aspects. Starting in 1974 scientists at LLUMC, under the leadership of Dr. Slater, had developed computer-based planning systems for radiation therapy using color video screens and ultrasound imaging devices.

Scientists at LLUMC were also unhappy with the restrictions of available radiation equipment (betatron and cobalt machines, and linear accelerators) for cancer and believed that there had to be a better method for delivering treatment. Dr. Slater knew of the advantages of proton radiation treatment and was determined to bring it into reality at LLUMC.

Dr. Slater collaborated with the U.S. Department of Energy’s Fermi National Accelerator Laboratory (Fermilab) of Chicago to help fulfill his dream. Fermilab is operated by Universities Research Association, a consortium of 57 universities from around the world. It is a producer of rapid accelerators. Representatives of Fermilab, together with a group of some 95 scientists from a number of countries, met in 1985 to formulate ideas to implement this type of proton treatment envisioned by Dr. Slater.

LLUMC and Fermilab cooperated in a project to have a synchrotron (a circular accelerator) created and manufactured for proton beam therapy at LLUMC. It was a marriage of nuclear science to treatment in a clinical medical setting. Fermilab built the proton accelerator for LLUMC. Leon M. Lederman, the former Fermilab director and Nobel Prize winner, is quoted as follows in a LLUMC brochure:

“The Fermilab proton synchrotron, designed and fabricated for Loma Linda University Medical Center, is a quintessential example of technology spin-off from abstract basic research to humanitarian use.”

The LLUMC Proton Treatment Center was completed in time to permit the first patients to be treated in 1990. Since then, numerous patients from around the world have received proton beam therapy at LLUMC for various types of cancer, many thousands of them for prostate cancer starting in 1991.

The Massachusetts General Hospital in Boston opened the Northeast Proton Therapy Center and its facilities for proton beam cancer treatment in the fall of 2001. It did not immediately commence treating prostate cancer, although it now does. The Massachusetts General Hospital was established in 1811 and is the original and largest teaching hospital of Harvard Medical School.
There are a number of other countries (such as Japan, Russia, Sweden, France, Italy, Canada, Germany and Switzerland) which use proton beam therapy for some cancer treatments, but invariably not in a medical setting. Over 20 proton beam facilities are presently being built or are in the planning stages at institutions in various cities throughout the United States and in a number of other countries, such as China, Austria, Italy, Korea, South Africa, Taiwan, etc.

Projects in the United States include the Midwest Proton Radiotherapy Institute at Indiana University in Bloomington, Indiana; the M. D. Anderson Cancer Clinic in Houston, Texas (which broke ground in July 2003); and the Shands Hospital in Jacksonville, Florida (where groundbreaking ceremonies occurred in January 2003).

E. Proton Therapy as a Mainstream Treatment

Proton beam therapy and conventional external radiation are both mainstream treatments for prostate cancer. However, proton beam therapy is not well known. There are several reasons for this. In comparison with other forms of treatment there are only a small number of locations that provide proton beam therapy. Until LLUMC opened its Proton Treatment Center in 1990, there was no proton beam therapy available in a hospital-based facility. Because of the many tens of millions of dollars it takes to build such a facility, most medical centers are unable or unwilling to fund this type of center.

As a consequence, the vast majority of men struck with prostate cancer do not have a proton beam facility in their community. As well, this disease has not had the same priority in research and treatment as high profile cancers, such as breast cancer. Coupled with this, in our opinion, is the likelihood that a cancer specialist who is consulted in one’s own community will have a natural inclination to feel that his specialty or interest is the best treatment option — a surgeon will tend to favor surgery, a radiologist to favor radiology, etc. It would not be surprising to us if it was determined that in many cases the specialist has no detailed or, in some cases, any knowledge of proton beam therapy.

While we were exploring treatment options after George’s diagnosis we spoke to Terry’s nephew, who is a medical doctor in a large clinic in the United States, to get his views on treatment options for prostate cancer, including proton beam. Because his specialty is not cancer, he was not familiar with proton therapy. After speaking to one of his medical colleagues involved in prostate cancer treatment, he called us back and stated that his colleague did not think much of proton beam therapy. He advised us that brachytherapy was one of the treatments that their clinic was using for prostate cancer,
and that his colleague thought that we should go to their clinic for a consultation. Needless to say, the particular clinic does not provide proton beam therapy for cancer. We used the information received from him to compare brachytherapy with other forms of treatment for prostate cancer to assist us in arriving at our treatment of choice.

We have personally heard of a number of proton beam therapy patients at support group meetings say that their urologist, in recommending a treatment for prostate cancer, never mentioned proton beam therapy to them. In some cases when the patient raised the matter of proton beam treatment, the urologist said it was experimental and recommended against it, often vociferously. In one instance when Gerald, a patient from Northern California, raised the matter of proton beam therapy, his urologist “just stood up and walked out of the door”, and Gerald has not seen or talked to him since.

Other patients have stated that their urologists have never heard of proton beam radiation. If the urologist you entrust to be an expert has never heard of this treatment or has not provided it as an option to consider, it raises the question in our minds of whether one should take any further advice at all from that urologist. It appears to us that either the urologist is not fully informed or is unwilling to consider or recommend a proven mainstream treatment because of his bias for his own specialty. In George’s personal case, the urologist to whom he was referred made no mention of proton beam therapy.

Proton beam therapy is not experimental. Patients have been treated with it for over half a century. Tens of thousands of patients have obtained the benefits of this unique treatment, but up until 1990 it was not being provided in a hospital-based setting. In February 1988, LLUMC was advised by the United States Department of Health and Human Services that it had examined the proton therapy system, had decided that LLUMC could put into effect its program to treat cancer, and could provide information relating to its technology and services to others.

In the early 1990s, the United States National Cancer Institute and the United States Medicare program examined relevant information and designated proton beam therapy as an accepted therapy for a number of localized tumors as well as intra-cranial aneurysms.

A significant number of health insurers in the United States have recognized proton beam therapy as an accepted coverage. This includes about 180 health insurance companies and HMOs (Health Maintenance Organizations). For example, Blue Cross of California issued a Medical Policy numbered 4.01.04 showing an Initial Review date of February 27, 1997 stating in part: “Proton-beam radiation therapy is NON-INVESTIGATIONAL.” This Blue Cross policy added that proton beam therapy may be medically necessary for the treatment, among others, of “prostate malignancies.”
The United States Medicare program issued Bulletin 406 on March 31, 1997 retroactive to June 27, 1996. This bulletin stated in part:

“Proton-beam radiation therapy is non-investigational in the treatment of malignancies... Benefits will be provided when services are considered medically reasonable and necessary to treat the Prostate Cancer”.

It goes without saying that someone contemplating proton beam therapy should check with his own health insurance provider or HMO to find out if coverage will be provided. From the prostate cancer support group we belong to, we know of a number of proton beam patients whose health insurance provider or HMO refused to accept liability for payment, claiming proton beam therapy was investigational and therefore not covered. In some cases, the health care provider reversed its negative decision after being apprised of the facts and ascertaining that proton beam therapy was not an investigational treatment. In other cases, where the patient was determined to receive proton beam therapy and coverage was denied, those patients sued the health insurance provider. One may only speculate on the number of potential patients who, after refusal of coverage, simply sought other types of treatment rather than becoming embroiled in litigation.

There are also a number of patients who, having been denied coverage by their initial insurer, took matters into their own hands and changed to a health insurance provider or HMO that provided coverage for proton beam treatment of their prostate cancer. We were not so fortunate with respect to coverage for George’s treatment, as our mandatory government-run health care system in Canada covered only a small percentage of the costs.
9. The First Proton Beam Treatment Center in a Medical Setting

“And we are put on earth a little space, That we may learn to bear the beams of love.”
— William Blake, *The Little Black Boy*

As indicated earlier, the first proton beam treatment facility established in a medical center was in Loma Linda, California.

A. Proton Treatment Center

Loma Linda University Medical Center (LLUMC) is a non-profit private teaching hospital with an operating budget in excess of $400,000,000 and more than 5,500 employees, including over 1,000 physicians. Many of the physicians are on the faculty of the School of Medicine at Loma Linda University, which is nearby the center. Currently LLUMC attends to tens of thousands of inpatients and hundred of thousands of outpatients each year. It is the principal trauma institution in the area, and provides medical care and research in a broad range of clinical specialties.

Among a number of other facilities at LLUMC are the Proton Treatment Center, a Children’s Hospital (world-renowned for infant heart transplants), and a research wing with laboratories. The hospital is in a picturesque setting in Loma Linda, a city of some 20,000 people located in Southern California. Los Angeles is about a one-hour drive to the west and Palm Springs is 45 miles to the east. In the July 19, 1999 issue of *US News & World Report*, LLUMC was named one of “America’s Best Hospitals for Cancer Treatment”.

The patients being treated at LLUMC come from many walks of life, represent a diversity of religious beliefs, and come from all 50 states of the United States and from many parts of the world. An International Circle of Care has been established at LLUMC for its international patients.

The Drayson Center is a part of the University of Loma Linda. There is a gymnasium, health club, exercise facility, spa, swimming pool and running track located at this center. Patients of LLUMC and their spouses are given a free membership to the Drayson Center during the term of treatment. This center provides excellent facilities for performing physical activity to enhance the benefits of a patient's treatment.
The LLUMC facilities (collectively called the Proton Treatment Center) to treat various cancers by conformal proton beam therapy opened in 1990. Planning and construction of the center took about four years and cost many tens of millions of dollars. The center was the world leader in providing proton beam therapy in a hospital setting. While it is only one area of LLUMC, the center itself is as big as a number of hospitals. The center currently treats approximately 160 cancer patients each day. It operates about 16 hours per day for the treatment of patients, and is used for research during the late-night hours when patients are not being treated.

The Proton Treatment Center is found on Levels A and B of the Children’s Hospital wing of LLUMC. Level A includes a reception area, offices, consultation rooms, and administration facilities. Level B contains a reception area, change rooms, offices, x-ray facilities, and the various constituent elements of the proton beam treatment system, etc.

The spacious reception area on Level B is where patients and their companions wait in comfortable chairs pending the patient’s treatment or pre-treatment preparations. Because of the commonality among them, there is camaraderie and a sense of community that pervades the area and develops continuing friendships. The atmosphere in the reception area is convivial and leaves no room for moping. It is unlike any other medical or hospital reception area we have ever been in.

**B. Proton Beam Treatment Delivery System**

The Proton Treatment Center contains the necessary and highly technical machinery and equipment required for producing and delivering conformal proton beam therapy to cancer patients.

There are many facets to the proton treatment delivery procedures and mechanisms at the Proton Treatment Center at LLUMC. They collectively amount to an integrated system of highly trained and technical personnel together with sophisticated equipment that work in unison to provide conformal proton beam radiation therapy in order to kill cancerous tumors in human beings, while minimizing side effects. This is all done in a highly professional yet hospitable manner.

The principal components of the proton beam treatment facilities for prostate cancer are an injector, a synchrotron, a proton beam transport system, and a proton beam delivery system including gantries. The following provides some information on the modality of the proton treatment delivery procedures and mechanism at the time that George received his treatment in 2001.
(1) Procedures

The proton beam equipment is put into action for an individual patient after several procedures have first occurred, namely:

- Manufacture of a tailor-made immobilization pod to ensure that the patient’s treatment alignment position is consistent from one day to the next.

- Taking of a computerized axial tomography (a CAT scan) with the patient in the same position in his pod as he will be in when he receives his treatments. The CAT scan creates a three-dimensional image of the cancerous tumor and adjacent structures.

- Subsequent to the CAT scan, the preparation of a computerized outline of the target area by the attending physician.

- Customized manufacture of boluses (fashioned out of jeweler’s wax) and cold metal apertures as tissue-compensating filters to take into account density of tissue, and the shape and volume of the patient’s prostate gland.

- Preparation of a computerized treatment plan specifically designed for the particular patient by dosimetrists and physicists. A dosimeter is a device used to measure an absorbed dose of ionizing radiation. A calculation of the radiation dose to be given to the target area is worked up based on different angles at which a number of proton beams are introduced.

- The treatment plan is examined by the attending physician and, on his acceptance, the bolus and aperture referred to previously are tailor-made and the modulator wheel is selected for that particular patient. Prior to the initial treatment of the patient, these items are then calibrated by the appropriate personnel to ensure accuracy and are bar-coded to ensure proper identification for the specific patient.

- The patient, in his gown, enters the assigned gantry room, gets into his pod, and has a balloon (filled with four ounces of warm water) inserted in his rectum. Guided by laser beams and low-power x-rays, the patient’s treatment alignment is set by a radiation therapist and approved by the on-duty physician. The patient’s bolus and other devices are then scanned and placed into the equipment.
(2) Mechanism

The intricate equipment that produces and transmits the proton beam radiation is housed in a rectangular area with steel-reinforced concrete walls up to 15 feet thick. A brief description of the equipment and the mechanical process of creating and delivering conformal proton beams into the patient follows.

(a) Injector

The injector is the first step in creating a proton beam. Within an electric field, in the blink of an eye, the protons are stripped out of the nucleus of hydrogen atoms. Separation of the hydrogen atoms into positively charged protons and negatively charged electrons occurs in this electric field. Initially, the energy of the protons is raised to two million electron volts (MeV) by transmitting them through a vacuum tube within a pre-accelerator. From there they are injected into the synchrotron.

(b) Synchrotron

The synchrotron is a particle accelerator with the capability of exponentially accelerating the speed of protons and significantly increasing their energy. A medically dedicated accelerator, the synchrotron consists of a ring of large and powerful magnets with a diameter of approximately 20 feet.

A cyclotron (which is not what LLUMC has) is also a particle accelerator, usually beloved by atomic particle engineers, and capable of producing a proton beam. However, a cyclotron is not as efficient in controlling the proton beam. It creates a beam by using a great deal of hydrogen and spins it in various directions dissipating much of it, and utilizing the little that is left in the desired direction.

On the other hand the synchrotron, with its complex control of the potent magnets, can force the protons to form into a single beam, more precisely directing the beam to where it can achieve the intended result. Within one-quarter of a second, the synchrotron at LLUMC can boost the energy of the protons to 70 MeV, and within one-half of a second to a maximum of 250 MeV. The latter voltage is strong enough that the proton beam has the capability of penetrating to any extent inside the patient.

Accuracy and consistency in the provision of conformal proton beam therapy in accordance with the patient’s treatment plan requires a number of features. These include a system monitored and regulated by computers, resulting in a proton beam which can be highly controlled in its energy and intensity, in its size and shape, in its flexibility, and in the extent of its placement within the target area.
In the synchrotron, the protons circulate in a tube in a near perfect vacuum. In only one second, the protons speed along within the synchrotron at approximately ten million times per circuit. With each circuit the protons are administered an accelerating radio frequency voltage which substantially heightens their energy from 70 MeV up to 250 MeV, enabling the proton beam to be precisely placed at any desired depth in the patient's body.

(c) Transport System

The magnetic field of the synchrotron’s ring is held steady when the field attains the value equivalent to the pre-designated proton beam energy. At this juncture, the protons are gradually removed from the ring and sent into the proton beam transport system. The transport system conveys the proton beam from the synchrotron to the patient’s treatment room through a vacuum tube. The system is made up of a number of computer-controlled and monitored electromagnets by which the proton beam is curved around corners and focused and steered through the vacuum tube to the appropriate treatment room.

Computers regulate the proton beam’s magnitude, location and energy to ensure that they coincide with those prescribed for the particular patient. Any deviation is automatically rectified, failing which the system is programmed to turn off.

(d) Delivery System and Gantries

After the proton beam transport system has carried the beam to the treatment room, a proton beam delivery system comes into play. This system directs the proton beam to the exact spot where it is to enter the patient’s body in the treatment room. This system is also computer-regulated to ensure that the patient’s prescribed treatment plan is followed in the administration of the beam.

There are four treatment rooms, one of which is for treating tumors of the eye, the central nervous system, certain other types of cancer, as well as macular degeneration of the eye. This room has a fixed beam.

The other three rooms each have a gantry used to treat prostate cancer, and certain other cancers. A gantry is a humongous piece of complex equipment. It is 35 feet wide, three stories high and weighs in the neighborhood of 90 tons. Hidden behind thick walls except for an aperture into the treatment room, a gantry rotates around the patient and guides the proton beam to the patient.
What a prostate patient sees while lying in his pod immediately prior to the actual treatment is the oval ceiling (in the alcove where his pod is located) rotating around him. The rotation continues until the side of the patient’s body (through which the beam is to enter that day) is placed next to a nozzle protruding from the aperture mentioned above. It is this nozzle that is the final piece of the equipment through which the proton beams travel before entering the patient’s body. The three-dimensional pattern of the proton beam is shaped and conformed by the nozzle.

Lying in his pod, the patient has a view of the beam’s eye and hears the whirring and beeping of the equipment over a period of about two minutes. That is when he realizes that the magic beam is entering his body and doing its fabulous job.

C. Ongoing Research

Training and high-energy physics research in connection with the center is continuous. Over 20 physicists and dosimetrists work for LLUMC, three of whom are on an all-night shift.

A few years ago, the United States National Aeronautics and Space Administration (NASA) entered into a partnership with the center to use the proton facilities of LLUMC for space radiation research. Another area of LLUMC study is to expand the scope of proton beam therapy to other cancers affecting larger areas. After much research, proton radiation clinical trials for early localized breast cancer are scheduled for 2004.

There is also a continued search for improvements in current technology of cancer treatments. For example it is anticipated that the use of boluses, apertures, and energy modulators will cease in the near future due to engineering and technical developments and plans for robotics in the gantries. This, together with digital imaging and precision cameras, will utilize computer-controlled positioning of the beam, thus shortening the set-up time for patients. These advancements will enable the Proton Treatment Center to almost double the number of patients treated to approximately 300 per day.

The researchers at LLUMC are also inquiring into the “gated beam delivery” system used in Japan. The purpose of this system is to program the proton beam for delivery according to the respiratory cycle of the patient, to allow for any minimal movement of the prostate within the body during breathing.

D. Proton Patient Support Group

The support group at LLUMC meets every Wednesday evening in the hospital. Immediately prior to the meeting, the patients and spouses in attendance (who frequently number up to 150) gather around chatting with each other while eating sandwiches and cookies and drinking fruit juices contributed by LLUMC.
The meeting room is set up with long tables and chairs on each side so that those in attendance sit face to face across from each other. This physical setup contributes to group dynamism and fellowship. We found these elements absent in a support group meeting we later attended at home in Calgary, which had theater-style seating with a person’s back (rather than their face) in front of one — an arrangement not conducive to conversation and congeniality.

Gerry Troy, the affable staff social worker with a great sense of humor, usually chairs the support group meetings. Before starting the meeting, Gerry always points out where the washroom facilities are down the hall from the meeting room. He puts everyone at ease by stating that it is normal for some of the prostate patients to use the facilities during the meeting and encourages them to feel free to leave and return to the meeting at any time.

Gerry always starts the meeting by telling several jokes, resulting in peals of laughter ringing throughout the room. One example that had everyone laughing uproariously was the following:

“Diapers and politicians have one thing in common. They should be changed regularly and for the same reason”.

On occasion, Gerry then asks for the occupations of the patients who are present. Proportionately speaking, there are usually more professional engineers and physicists than other professions, perhaps because their training gives them a better understanding of the physics involved in the delivery of proton beam therapy.

There are usually a fair number of patients who are in the health-care field, including medical doctors. During the time we attended the meetings we met a medical doctor from Germany who had come specifically to Loma Linda for proton beam treatment of his prostate cancer. He came from a medical family; both his wife (in Germany) and his daughter (in the United States) are medical doctors.

The informal format for a meeting includes a few words from past alumni (usually two or three) who are visiting; those who are completing treatment that week and are called “graduates”; and those who have just commenced treatment or are at their first meeting and are called “newbies”. From time to time there are one or two persons at the meeting who are checking out LLUMC before making a treatment decision.

The alumni usually report on their post-treatment situation (such as PSA history and side effects), and they often tell a joke or two. The graduates, without exception in our experience, praise the caring and friendly attitude of LLUMC doctors, nurses, social workers, and other personnel, as well as their own spouses or partners. Some with tears in their eyes thank God that they found LLUMC. A few graduates sing their farewells and some recite poetry, which in some cases has been specifically written by them for their graduation.
The newbies relate how their cancer was discovered, their PSA levels and Gleason score, and how they happened to choose LLUMC for their treatment. A number state that when they received their cancer diagnosis, they felt that their urologist had a scalpel in his hand while recommending surgery and advised them they were fortunate because the urologist would be able to schedule them for a radical prostatectomy later that week or the following week.

The highlights of many meetings are the guest speakers. Some examples include:

- Dr. James Slater, a graduate in both physics and medicine, the LLUMC visionary who spearheaded proton therapy treatment in a hospital setting. He discussed the background to the planning and designing of the Proton Treatment Center, pointing out that it had input from over 90 scientists from around the world. He answered questions on what the Bragg Peak is; why the proton beam is aimed through the hips; what the wax block (bolus) does; what happens to the protons after the treatment; whether a biopsy may cause the cancer to spread; and other questions.

- Dr. Carl Rossi, Assistant Professor in the Department of Radiation Medicine of LLUMC, who also happened to be George’s attending physician. He provided a slide show presentation on proton beam treatment for prostate cancer. Among other things, this talk provided considerable statistical and other current information, including a comparison of radical prostatectomy with proton beam radiation therapy. His talk was followed by a question and answer period.

- Dr. Dan Miller, Ph.D. and Chief Physicist at the LLUMC Proton Treatment Center. Dr. Miller oversees a staff of over 20 physicists and dosimetrists at the center. Using an overhead projector for visual effect, Dr. Miller spelled out how proton beam radiation works; what the conforming devices (bolus, aperture and modulator wheel) do; the planning of the tumor target area; and other details; and then he answered questions.

Support group meetings last about two and one-half hours with some patients coming in from treatments part way through, and with others leaving the meeting early to go for their treatments. The group disperses in a happy mood, in a buzz of conversation, and filled with hope and inspiration.

E. The Brotherhood of the Balloon

One of the steps that precedes the actual delivery of the proton beam into the patient’s prostate gland during each treatment is the insertion of a tubular balloon up the patient’s rectum. The balloon is filled with four ounces of warm water. The purpose of this
The procedure is to stabilize and lock the prostate gland in place by pushing much of the bladder and the rectum out of the way of the proton beam, in order to minimize radiation-caused side effects.

Chitchat in the reception area among prostate cancer patients at some point invariably gets around to the famous balloon, usually in a rather humorous way. This is frequently accompanied by an exchange of information on how treatments are going, urination problems, fatigue, and so forth.

It was just such encounters at the Proton Treatment Center at LLUMC in December 2000, which led to the formation of the Brotherhood of the Balloon, better known by its acronym “the BOB”. A proton patient (with a most apt first name), Bob Marckini from Massachusetts, was on the verge of graduating, that is completing his treatments.

He and some other proton patients and their spouses that he had met at LLUMC had become friends (as frequently happens there) and thought it would be desirable and helpful if, after they returned to their respective homes, they continued to stay connected. In this way, they could pass along to each other any pertinent facts or concerns that they had, side effects they experienced, and other relevant data. They also wanted to provide information on proton beam therapy to other men diagnosed with prostate cancer.

An inaugural meeting was held that month at which it was decided to invite other proton beam patients at LLUMC to become members. The social worker, Gerry Troy, stated he would invite patients at each Wednesday support group meeting to become BOB members. Under the title BOB Tales, minutes of the support group meetings at LLUMC are transcribed and sent to members of the BOB.

Essentially the BOB is a prostate cancer support group, with each member having a common bond in their proton beam therapy at LLUMC. Communication is primarily by e-mail. The BOB was initiated and sponsored by proton patients, and it is not an official organization of LLUMC.

The BOB and its mission are a work in progress. Its membership is continually growing. In early 2004, the BOB had over 1,500 members and was reaching out to the thousands of LLUMC proton patients (who received treatment prior to the BOB’s formation) to invite them to join the BOB.

The BOB currently has a number of objectives. Some, but not all, of them include:

- Assisting and supporting BOB members and prospective patients in dealing with a broad range of questions, concerns or issues they may have such as treatment information, side effects, insurance coverage or denial, nutrition, etc.
• Keeping the BOB members advised of goings-on at the Wednesday night support group meetings by e-mailing them BOB Tales.

• Spreading the good news about proton beam therapy.

• Maintaining a BOB membership list with various data, such as name, address, e-mail address, telephone number, date of graduation from treatment, age when treated, PSA reading when treated and currently, Gleason score, insurance carrier, etc.

• Distribution of videos and other material relating to LLUMC and proton beam therapy to members and inquirers.

• Receiving and charting the ongoing PSA levels of members who provide them.

• Maintenance of a website that came online in July 2002. It provides information to the public on proton beam therapy and matters relating to prostate cancer, including testimonials from former patients. It also has dedicated areas for BOB members only. It is at:

BOB Support Group Website
http://www.protonbob.com

Undoubtedly, the scope of the BOB’s activities will continue to expand. We have received and we continue to receive information on prostate cancer from the BOB that we find helpful and encouraging. We believe that the mission of the BOB will continue to inspire not only its members, but provide invaluable knowledge and assistance to all those seeking information on proton beam treatment for cancer, particularly prostate cancer.

F. Other Activities

Regional reunions of patients who have been treated with proton beam therapy are an ongoing activity of LLUMC. A principal person involved in these reunions is Dr. Lynn Martell, Vice President of Advancement at LLUMC.

We attended the first reunion for the Northwestern United States and Western Canada that was held in Seattle on May 5, 2002 at Seattle Pacific University. About 80 graduates and their spouses attended to hear talks by Dr. James Slater (Professor of Radiation Medicine at LLUMC) and Dr. Jerry Slater (Chairman of the Department of Radiation Medicine at LLUMC). Other speakers were Dr. Lyn Martell, Gerry Troy, Jerry Klein (from
the Seattle area and one of the founders of the BOB) who announced the formation of a Cancer Research Chair at LLUMC in the name of Dr. James Slater, and Bob Marckini who spoke on the BOB.

Each year for more than a decade, Ken Venturi (a professional golfer who won the United States Open in 1964) has hosted the Proton Invitational Celebrity Golf Tournament in the Palm Springs area of California. This tournament is a charitable event that benefits the Proton Treatment Center at LLUMC. Venturi was diagnosed with prostate cancer in August 2000, and was treated at LLUMC with conformal proton beam therapy.

The Proton Treatment Center established an International Proton Advisory Council in the early 1990s. It now consists of over 20 members. The council’s basic function is to assist, advise and support the center in its mission of helping cancer patients by means of the clinical application of proton beam radiation. Members act as advisers in the promotion and support of a number of relevant matters, such as the benefits of proton beam therapy and the development of ideas and plans to enhance quality of life.
10. A Proton Treatment Experience

“Nothing ever becomes real till it is experienced.”
— John Keats

Each person experiences cancer and its treatment in his or her own manner. Another book we have written titled *Prostate Cancer: A Couple’s Journey of Hope and Healing on Eagles’ Wings* gives the personal and emotional aspects of our journey, whereas the following will provide some insight into the process we took in making a decision as to which therapy to choose, and what a patient may experience if he undergoes proton beam therapy for prostate cancer.

**A. Making a Treatment Decision**

With the help of our daughter Catherine, we did extensive research and homework. We also consulted with friends, relatives, nurses and doctors. We did so to become educated and knowledgeable about prostate cancer together with its various treatments, side effects, and other relevant matters in order that we could make an informed decision on the most appropriate treatment for George.

The prime focus of our research was on the effectiveness of the treatment; the side effects; the subsequent quality of life; and options for later treatment if the prostate cancer recurred. In addition, we did not want George to be used as a human guinea pig (i.e. to be involved in an investigational or experimental study).

Terry’s initial reaction at the time of George’s diagnosis with cancer was that he should have his prostate gland cut out. At the time, she believed in the theory that cancerous tumors were fed through the blood supply, and that the best way to destroy the cancer was to excise the tumor, thereby eliminating the supply of blood to it. This process by which new blood vessels are formed is known as angiogenesis, and a tumor uses this process to grow.

After the Calgary urologist informed us that George was not a good candidate for radical prostatectomy, and our family doctor was unable to refer us to an appropriate surgeon, Terry had to rethink her previous opinion as to what treatment she thought was best for George. As we worked through our research together, we determined there were other treatments that might possibly provide the type of healing that we wished to achieve for George’s prostate cancer.
The one treatment that really changed Terry’s initial viewpoint about excising the prostate gland was conformal proton beam therapy. It was a proven mainstream treatment that had been used for many years with little or no side effects. She was particularly impressed with its success rate with eye cancers. Removal of the eye is the treatment used by some ophthalmologists for ocular melanoma. However Loma Linda University Medical Center (LLUMC) indicated that with conformal proton beam treatment the eye is saved in more than 95% of the patients, with most retaining useful eyesight. Considering how sensitive an organ the eye is, such a success rate indicated to us the remarkable ability for precise and accurate treatment using conformal proton beam therapy.

Our research filled two thick three-ringed loose-leaf binders, as well as many files and two scribblers. George used one scribbler as a daily journal to record our prostate cancer experiences and our journey of hope and healing.

As we became more informed, the idea of going to LLUMC for conformal proton beam therapy began to animate us with its inspirational hope. We decided to have a telephone conversation with our friends in Victoria who had first told us about this treatment. In our lengthy telephone conversation with them, we discussed numerous matters relating to prostate cancer, LLUMC, proton beam therapy, details of treatment, side effects and on and on. We came away from this telephone call with our spirits buoyed by the prospects of a treatment that appeared to meet our priorities.

Meanwhile, Catherine (our daughter who had done research with respect to LLUMC and conformal proton beam therapy) requested an information packet from LLUMC. She also inquired what medical records would be needed, and as to other information including the cost of treatment.

After reviewing the data on proton beam therapy, we faxed the relevant medical reports and records to LLUMC for a medical assessment as to whether George would be a suitable candidate for proton beam therapy. However, before making our final decision, we still had a number of questions we wanted answers to.

Consequently, we had a conference call with Lian Funada, the Intake Coordinator at the International Circle of Care at LLUMC. In this conversation Lian told us that Dr. Carl Rossi, Assistant Professor in LLUMC’s Department of Radiation Medicine, had checked George’s medical records. She advised us that Dr. Rossi stated that George was a very good candidate for proton beam therapy and that he would accept him for this treatment.

She described to us various matters related to the treatments including the likely number, days, and the length of time of the treatments; possible side effects; and other pertinent data. She answered our many questions in a professional and open manner. With respect to some of our specific questions, she said she would speak to the attending physician and get back to us shortly.
Lian subsequently advised us on the questions of whether George’s treatment would entail his taking the hormone drug Lupron. This was because earlier the urologist in Calgary and the video tape from the local prostate cancer clinic indicated that George would need to take hormone therapy treatment if he participated in the radiation/cryosurgery trial study referred to earlier. Not having been told to the contrary, we mistakenly thought that hormone therapy treatment was automatic for all prostate cancer treatments. Also at that time, George’s brother Al was receiving Lupron as the only treatment for his recurrence of prostate cancer.

Dr. Rossi’s advice, conveyed through Lian, was a welcome surprise. His recommendation was that if George was presently taking Lupron he should continue on with this treatment, otherwise it was not necessary for him to start on hormone treatment.

We were told that George could continue to take Proscar and Terazosin (the medications for an enlarged prostate gland that he had been taking for several years). We were also advised that Dr. Rossi did not see any problem with the triangular scar on George’s abdomen (from surgery when he was a child).

Lian also advised us that if George opted for LLUMC, a consultation with Dr. Rossi could be arranged for some time in January.

Pursuant to our request to Lian we subsequently received, for our review, a letter of agreement for the proton beam treatments from the Financial Coordinator of LLUMC’s International Circle of Care. The contract provided us with a package price for an outlier treatment plan. Since we were not American citizens covered by a United States medical plan, LLUMC’s International Patient Financial Policy applied to George.

Later on when we were in Loma Linda, we found out that we would have been far better off financially if George had been eligible for United States health care coverage. Our mandatory government Health Care Plan in Canada only covered about 6% of the costs of George’s treatments outside of Canada. We understand that Medicare in the United States covers about 80% of the cost of proton beam treatment for Americans over the age of 65. For those patients who also have a secondary health care plan, that plan will often pick up the remaining 20% of the cost of this medical procedure, resulting in many patients over the age of 65 receiving 100% coverage for proton beam treatment. Numerous HMOs and insurance plans cover proton beam treatment for patients under the age of 65.

We would advise any patients contemplating proton beam therapy to first check with their medical and insurance providers to determine whether they will be covered for this treatment. If they find any resistance in getting coverage, they should contact the alumni patient group of LLUMC (the Brotherhood of the Balloon) in order to get ideas and suggestions as to how they can handle any medical coverage problems.
The Brotherhood of the Balloon website is:

**Brotherhood of the Balloon**
http://www.protonbob.com

It was only after thoughtful consideration that we made the decision that, in George’s particular circumstances, proton beam therapy would be our treatment of choice. We then commenced the appropriate steps to implement our decision. Once our final decision was made, we felt like an onerous burden had been lifted from our shoulders.

**B. Consultation and Treatment Preliminaries**

A few weeks after making our treatment decision we traveled to Southern California for our consultation appointment at LLUMC’s Proton Treatment Center.

The first person we met with was Sharon Hoyle, a registered nurse and Dr. Rossi’s Case Manager in the Department of Radiation Medicine. She greeted us and chitchatted before taking us into the consult room. She gave George a folder with a number of documents, which she asked us to review and, in some instances, to sign. She also gave each of us visitors’ badges to wear when we came for George’s treatments so that we would not have to register at the visitors’ desk each time we entered the hospital.

The documents in the folder included an instruction sheet for patients receiving proton beam treatment, a restricted consent for release of medical information, a radiation therapy consent, a list of possible early and late side effects, and a contact information sheet. We signed the appropriate documents and returned them to Sharon.

Sharon explained to us that each doctor in the Proton Treatment Center had a clinic day. If we wished to see Dr. Rossi, his clinic day was every Wednesday and no appointment was needed. At other times during the workweek, we could call her and she would get in touch with Dr. Rossi if we had any problems or questions. If we wanted information or needed attention in the evening or on weekends, she advised us to telephone or go to the Emergency Department at the hospital, and ask for the Radiation Medicine Physician on call.

Sharon fit the mold of the other LLUMC personnel we had earlier met at the International Circle of Care — warm, friendly and caring. As we got to know her better during the course of treatments, Sharon displayed an additional trait – a flair for humor – and we had a lot of laughs with her.
Sharon weighed George, took his blood pressure, and took his temperature. We gave Sharon a copy of the Proton History Sheet that we had previously been asked to complete. Sharon then thoroughly reviewed our nutritional habits with us and determined that it was not necessary for us to see a dietician at LLUMC. We were amazed at how thoroughly and knowledgeably she reviewed our eating habits, particularly after the disinterest in nutrition of the nurse at our local cancer clinic.

After these preliminaries we then saw Dr. James Baer, a senior resident who asked us a number of questions and discussed proton therapy with us. As we were discussing medical matters with him (including other types of treatments and their side effects), a burst of energy entered the room in the person of Dr. Carl Rossi. An Assistant Professor in the Department of Radiation Medicine at LLUMC, Dr. Rossi was to be George’s consulting physician.

While Dr. Rossi discussed medical matters with us and answered our questions, Dr. Baer checked George’s upper front and back with a stethoscope. Both of them examined the triangular scar on George’s abdomen. Dr. Rossi stated that in his opinion this scar would not be an obstacle to George having a radical prostatectomy, if that was his treatment of choice.

Dr. Rossi advised that if he felt a tumor during a digital rectal examination (DRE), he would prescribe external photon radiation in addition to proton therapy. He then performed a DRE on George. He told us that he could not feel a tumor, and accordingly all of George’s treatments would be proton beam. He advised us that proton beam therapy covered the prostate gland and seminal vesicles. A somewhat larger area than the prostate is radiated because a CAT scan can outline the prostate, but it does not outline a tumor unless it is large.

We were advised that the curative effect on prostate cancer of proton beam radiation was comparable to that of radical prostatectomy. The main area of difference was in the side effects, which were generally relatively minimal with proton beam therapy in comparison with other types of treatments for prostate cancer. Drs. Rossi and Baer explained to us that the proton beam radiation would kill the cells in the prostate. Because cancer cells were unable to replicate themselves after proton radiation, the cancer cells would be destroyed. On the other hand, the nature of normal prostate cells allowed for new healthy cells to be produced in the prostate, thereby resulting in a healthy revitalized prostate gland after proton radiation.

Dr. Rossi also told us that it was not necessary to discontinue having sexual relations during the treatments, since proton radiation did not result in the patient being radioactive during the course of treatment. In fact, he encouraged patients to continue with normal conjugal relations.
Dr. Rossi said that he wanted both of us to know as much as possible about the treat-
ment and its related procedures. He said that a principal objective he had for his pa-
tients was their quality of life. We were both awestruck at this open, inclusive man-
er of practicing medicine, and Dr. Rossi’s concern not only for the effectiveness of the
treatment in relation to George’s cancer, but also its effect on his life.

At no time during this eye-opening conference did Dr. Rossi give the impression that he
was hurried or harried, and neither did Dr. Baer nor Sharon Hoyle. On the contrary, they
were all easygoing and friendly while retaining a professional aura and giving the im-
pression that we could spend as much time with them as we required. Although before
we left Calgary we had made the decision that conformal proton beam radiation therapy
was the best treatment for George’s prostate cancer, this consultation with Dr. Rossi
and Dr. Baer convinced us that indeed we had made the right decision.

After our consultation, we took the daily orientation and educational tour of the Proton
Treatment Center. Gerry Troy (the staff clinical social worker with a Master of Social
Work degree) conducted the tour. He gave a short talk on LLUMC and its facilities,
urged everyone to have a good time during treatment, briefly described treatment
procedures, and said the patients should exercise, eat right, and be cheerful.

Gerry told the group that the social workers at LLUMC had designed a temporary
community to keep the patients and spouses connected with each other and to keep
their spirits up. Each week a bulletin of activities is published and provided to the
cancer patients and their spouses, all of whom are invited to participate on a voluntary
basis. The activities listed include lunch each Tuesday at a different restaurant in the
area; the Wednesday evening support group meeting; Thursday night dinner at a
previously untried restaurant in one of the nearby communities; and a Monday meeting
for spouses to discuss their specific concerns.

Gerry Troy supplied the tour group with lists of places to see and things to do within
driving distance from Loma Linda, and a free membership to “Just for Seniors, 55+
Club” with certain benefits for people over the age of 55. Free memberships to
LLUMC’s Drayson Center, a health and fitness club, were also provided to all patients
and their spouses for use during the treatment period.

After Gerry Troy’s introductory words, he took us on a two-hour behind-the-scenes tour
of the Proton Treatment Center and its facilities. Along the way, he introduced us to
various staff members involved in different functions. The staff members gave explana-
tions and sometimes demonstrations of their work, supplemented by comments from
Gerry.

We were shown the room where each patient’s immobilization device is custom-made.
In the case of prostate cancer patients, the immobilization pod is an open-topped, body-
hugging foam liner enveloped by a firm plastic frame. The purpose of the pod is to
assist in ensuring that the patient is properly positioned for treatment each day.
We moved on to another room where special devices are custom-made, one for each hip. The apertures are constructed out of cold metal and the “boluses” are fashioned out of jeweler’s wax. These act as tissue-compensating filters to take into account differences in density of tissue and shape and volume of the prostate gland from one patient to another. These devices, together with a modulator wheel, are placed in the proton beam equipment before treatment commences in order to conform and distribute the radiation to treat the patient effectively according to his specific computer plan of proton beam treatment.

A staff member, Alfonso, demonstrated the computerized technique used to manufacture the bolus, based on a medical physicist’s design done in a dosimetry laboratory. He also showed us how the liquid cold metal is handled in preparing the aperture.

Gerry Troy also took us to other facilities involved in proton therapy, and explained their functions. This included a behind-the-scenes view of one of the gantries. The gigantic gantry rotates around the patient and provides the ability to direct the proton beam. He explained to the group the treatment delivery process, consisting of a number of major components that are described in the preceding chapter.

We were then taken into a treatment room to indicate what a patient would be walking into each day. For privacy reasons, there was no patient in the room at the time. We next toured the adjacent monitoring and control room where we were introduced to the staff working there. An explanation was given of the treatment monitoring process, and we were able to see the computers and television views of the treatment room. The tour covered a number of other areas including the fixed beam room (also known as the stationary beam room) used for treating eye, central nervous, brain and other tumors.

That afternoon, after this highly informative and fascinating familiarization with the inner workings of these facilities, we returned to the Proton Treatment Center for George’s CAT Scan and for the fitting of his own custom-made immobilization pod.

C. The Proton Treatments

After the consultation and treatment preliminaries, a period of several weeks usually elapses before the date of the first treatment to allow for the implementation of required procedures. These include the preparation of the computerized outline of the target area by the attending physician; the customized manufacture of boluses and cold metal apertures; the preparation of a computerized treatment plan specifically designed for the particular patient; and the approval of the treatment plan by the attending physician.

Thirty minutes prior to every treatment the patient is required to drink two eight ounce glasses of water. The purpose of this is to ensure that the bladder is full during the
treatment procedure. Upon entering the gantry room for the first time, a radiation therapist fully explains the treatment procedures. The patient then climbs into his pod that is clearly marked with his name.

Once the patient is in his pod, the circular roof about seven or eight feet above rotates until the beam nozzle is directly next to his side. One of the radiation therapists then inserts a lubricated tube containing a balloon into patient’s rectum and fills the balloon with four ounces of warm water. This balloon plays a significant role in minimizing side effects. It pushes most of the bladder and a large part of the rectum out of the way of the proton beam, thereby resulting in less damage to healthy tissue.

The patient is then positioned more precisely in the pod by a radiation therapist, and told not to move from that position until the treatment is completed. This position, determined by laser beams, is in accordance with the specific plan designed for that particular patient’s treatment. To ensure optimal accuracy in targeting the cancer, prior to each treatment low power x-rays (lasting only a few minutes) are taken of the target area of the patient while he is lying in his pod.

The custom-made devices made for the patient and his designated modulator wheel are placed in the equipment. Since corresponding parts of a person’s body are not symmetrical, custom-made devices for each hip are specifically made for the purpose of shaping the proton beam to have it conform, on a three-dimensional basis, to the precise shape of the prostate of each individual patient. These devices consist of bar-coded tissue-compensating filters and apertures. A computer program effectively prohibits commencement of treatment until the computer is satisfied that a laser-scan of the bar codes has correctly identified the items as those made and prescribed for that specific person, and not for another patient.

The on-duty medical physician checks over the x-rays, positioning and measurements prior to giving authorization to commence treatment. Since other treatment rooms share the proton beam, the treatment does not start until the equipment is available. The actual treatment takes only a couple of minutes each day. It is accompanied by a quiet whirring sound, interspersed with beeps, about one beep every five seconds. A patient feels and sees nothing. After approximately 25 beeps the whirring sound ends, signaling that the proton beam is no longer being administered, and the treatment is over.

Subsequent treatments alternate on a daily basis from one hip to the other in order to balance the radiation dose through each hip into the prostate gland. The entire treatment process takes less than one hour each day.

Although the foregoing describes the procedures that were in place at the time of George’s treatment, the process is evolving. When implemented, technological enhancements currently under development will streamline and further refine the delivery of proton beam radiation.
A number of days before the end of scheduled treatments, the Case Management Nurse provides the patient with a folder containing a follow-up schedule and information sheet. The Proton Therapy Follow-Up Schedule provides dates for follow-up examinations, PSA tests and DREs, commencing four months after completion of treatment, at six-month intervals for the following five years, and annually thereafter. It is not necessary to return to LLUMC for these follow-ups; they can be performed in the patient’s hometown by his own family physician. Since the Proton Treatment Center wishes to follow its proton patients on a lifetime basis, it asks that the results of the follow-up procedures be forwarded to them.

Patients usually visit their attending physician on his clinic day a few days before their last treatment at Loma Linda. Our final visit to George’s attending physician ended up as a jovial photo-op for us with Dr. Rossi, Sharon Hoyle and Ed Schultz (the scheduling co-ordinator). We were told that Dr. Rossi’s final treatment report would be mailed to us shortly after we returned home.

When we received this final report titled “Radiation Medicine Treatment Summary”, it gave a summary of George’s proton beam treatment. Some of the pertinent headings were the following:

- Lab Data or X-Ray Findings
- Plan of Treatment
- Dose
- Status of Tumor
- Tolerance
- Acute Morbidity Score
- Disposition

This summary indicated that the dose (calculated at isocenter) was 2.0 cobalt Gy equivalent fractions daily with a proton beam energy of 225 MeV over a period of 39 treatment days, thus delivering 78 cobalt Gy equivalent.

Besides drinking the two glasses of water prior to each treatment, George received advice at Loma Linda that he should drink a total of eight glasses of water a day. As a result of the proton therapy and the water intake, George’s urinary frequency increased during the time of his treatments, particularly during the night. He often arose from bed
four or five times a night to urinate, which interrupted his sleep and resulted in in-
creased fatigue during daylight hours. During this time he napped twice a day, rather 
than his usual one nap a day, and this compensated for the sleep he had lost at night.

Once we returned home, George's fatigue and urination frequency during the night 
abated and he returned to his regular routine of one nap a day. During the treatments 
he experienced skin erythema (redness of the skin) on the area of his hips where the 
proton beam was directed. This redness disappeared shortly after returning to Calgary.

After completion of his treatments George had only minor side effects. A late side effect 
was blood in his stool. This occurred infrequently during the eighth to tenth months 
after George finished his treatments. As a precaution, George had a barium x-ray that 
indicated there was only minor irritation to his bowel (obviously due to his treatments). His initial Consultation Report from Dr. Rossi had stated:

“The late effect most commonly experienced by patients has been 
mild rectal bleeding occurring anywhere from six months to two 
years following treatment. This resolves spontaneously in most 
patients.”

Within a few weeks of its onset, this mild side effect did resolve spontaneously and it 
has not recurred. He also initially had some nighttime urination hesitancy, which has 
since significantly lessened. He remains sexually potent, although he produces less 
ejaculate and is not as virile as when he was younger.

D. Follow-Up

Pursuant to the Proton Therapy Follow-Up Schedule that he received, George had his 
first PSA test and digital rectal examination (DRE) four months after completion of his 
treatment. As mentioned earlier, a DRE may affect PSA readings and should be per-
formed only after blood is drawn for the PSA test. However as some tumors can be 
felt, a DRE should always be done shortly after the PSA test. A PSA reading by itself, 
whether high or low, is not a conclusive indicator of whether or not one has cancer.

At the time of his first follow-up, George’s PSA level had fallen from 6.3 to 0.5 and the 
DRE following this test indicated that his prostate gland was soft. Sixteen months after 
completion of his treatment George’s PSA level reached its nadir of 0.1, and in early 
2004 (34 months after completion of his treatments) it has remained at that level.

Within a short time after the completion of his treatments, George discontinued taking 
Proscar and Terazosin, the medications that our family doctor had prescribed for his 
enlarged prostate gland.
George urinates more frequently than he did prior to his treatments. He attributes this to the fact that he previously drank only two or three glasses of water per day, and now drinks eight or more glasses daily. He is physically, mentally and emotionally healthy and leads a full active life.

Besides receiving a remarkable treatment, we experienced the warmth, kindness, and professionalism of the medical staff who provided healing medicine while we were at LLUMC.
11. Nutrition and Diet

“Hearken diligently to me and eat that which is good.“
— Holy Bible, Isaiah c.55, v.2

Although some observers are of the view that there is no conclusive connection between diet and cancer, from our readings we personally have no doubt that diet has a prominent impact on whether or not one is afflicted with cancer, and on the healing process.

Statistically, the prevalence of prostate cancer in North American men, including Canadians, is substantially higher than in Japan and China. Many attribute this difference to the disparate eating habits between the two areas. A principal suspect for causing the extremely high North American percentages of prostate cancer compared to the percentages in Asia is the elevated amount and type of dietary fat consumed in North America. Processed foods, fast food items and many baked items may contain fats that are not healthful. In Japan much less fat is eaten and soy, seaweed and fish are dietary staples. Another aspect of their diet is that Asians drink a lot of green tea, which some believe to be a potent cancer preventative.

The following are capsulized observations on our readings with respect to the cancer hazards of ingesting the wrong fats, and what they are. We also point out which other foods should be avoided and those that should be consumed. However, anyone who wishes to be more fully and precisely informed on these matters should read books on the subject (many are available at public lending libraries), and consult with a medical dietician.

A. Fats and Oils

There are four kinds of dietary fats. These are saturated fats, polyunsaturated fats (which include omega fatty acids), monounsaturated fatty acids, and trans-fatty acids. Not all fats are bad. The main culprits with the potential of weakening one’s healing system and contributing to the onset of prostate cancer (as well as heart and vascular problems) are saturated fats, some polyunsaturated fats, and trans-fatty acids. On the other hand monounsaturated fats and some polyunsaturated fats have beneficial effects.

(1) Saturated Fats

Saturated fats are primarily derived from animals and their by-products. They are also found in some vegetable-fats (palm kernel oil and coconut oil), and vegetable shortening.
Animal sources of saturated fats include meats of cloven-hoofed animals – i.e. red meats – namely ham, pork, lamb, veal, beef (which may be the biggest health menace of the lot), and the by-products of these red meats. Notwithstanding that the pork industry has promoted pork as a white meat, it and its by-products (ham, bacon, sausages, etc.) contain saturated fats.

Other sources of saturated fats include duck, unskinned chicken, whole milk, butter, cheese, cream, the vegetable fats referred to above, and animal fat products such as lard and suet.

(2) Polyunsaturated Fats

Some polyunsaturated fats are not beneficial in one’s diet, while others are. These fats are either omega-6 or omega-3 fats.

Omega-6 fatty acids are polyunsaturated fats found in vegetable products such as sunflower, corn, cottonseed, and safflower oils. A number of writers indicate that these polyunsaturated oils constitute an enhanced cancer threat.

Omega-3 fatty acids, which are also polyunsaturated fats and which are sometimes called essential fatty acids, may protect against cancer and promote healing. They are contained in certain fish and plants. Cold-water fish such as wild salmon, sardines, herring, mackerel, cod, and the like are good sources of omega-3 fatty acids. Hemp oil, flax oil, and flax seed are other sources of omega-3 fatty acids.

(3) Monounsaturated Fatty Acids

Monounsaturated fatty acids do not have the same cancer concern that is presented by saturated and some polyunsaturated fats. On the contrary, they may assist in preventing cancer. They are present in vegetable oils, of which olive oil is the most advantageous, and is a safe and sound edible fat. The best quality of olive oil is extra-virgin, in which the initial oil is removed in the manufacturing process.

Vegetable oils (those which are not polyunsaturated omega-6 fatty acids) are good, but vegetable shortenings (which contains saturated fats) are not. Although high in fat content, avocados are a good source of monounsaturated fat.

(4) Trans-fatty Acids

Trans-fatty acids are not natural. They are found in margarine and some cooking oils as a result of hydrogenation during processing. They are not beneficial to one’s health and may be a cancer risk.
Food labels that list “partially hydrogenated oil” indicate that the products contain trans-fatty acids, and those food items should be avoided like the plague. One should check the ingredients’ labels on prepackaged foods for the types of fats and whether the ingredients include the dreaded partially hydrogenated oils or any other unhealthy fat.

It is impossible to completely remove all fats from a person’s diet, nor would attempting to do so be advisable. Good fats are essential to good health and are needed for the absorption of vitamins and minerals, particularly fat-soluble vitamins.

Although some vitamins such as vitamin C are water-soluble, a number of vitamins such as vitamins A, D, E, and K are fat-soluble. The important factors are the selection of good fats to promote good health, and the elimination of saturated and other unhealthy fats from the diet.

**B. Antioxidants and Free Radicals**

When one eats, energy is created by oxidation as a result of metabolism. By the same process, free radicals (abnormal and unstable oxygen molecules having an unpaired electron) are also produced. There are sources that indicate that free radicals undermine the immune system, weakening its ability to identify and annihilate mutated cells.

In a nanosecond, free radicals hunt down other atoms or molecules in an endeavor to seize electrons from them. If they succeed (the process known as oxidation) they damage not only these other particles but also the cells and DNA in one’s body. This can lead to cancer, including prostate cancer, and other diseases. It is thought that the DNA in every cell may be attacked up to 10,000 times a day by free radicals, and that the greater the onslaught of free radicals on human cells, the greater the potential for cancer and other illnesses.

However, there are antioxidants that will fight and suppress or conquer the free radicals and block their activity. Antioxidants are substances that remove potentially damaging oxidation agents, and are found mainly in certain nutrients. Nutrients are nourishing substances necessary for life and growth.

Fresh fruits and vegetables are nutrients which contain the capability of warding off the cell damage that free radicals can cause. There are also a number of supplements available in health food stores that can assist in this respect, apparently to a lesser extent. These include selenium, carotenoids (particularly lycopene), and vitamins C and D.

Over the years, some studies have indicated the importance of dietary and supplemental vitamin C with respect to cancer. In 1971 Linus Pauling, Ph.D., advanced the use of vitamin C supplementation in large doses for the prevention and treatment of cancer.
Although there is some indication that vitamin C may be beneficial in the prevention of cancer, there appears to be no definitive proof that it has any curative powers for cancer.

Some sources express the view that massive doses of vitamin C may actually hinder the beneficial effects of certain cancer treatments. When Dr. Rossi of Loma Linda University Medical Center (LLUMC) was asked at a support group meeting about the use of supplemental vitamins, he recommended against high doses of vitamins (such as vitamin C) during proton radiation treatment. He added that theoretically antioxidants may reduce the effectiveness of radiation because the treatment relies on the formation of free radicals to do the cancer killing.

When turning to diet, writers on medicine invariably laud the prodigious benefits of fresh fruits and vegetables both in making the body less vulnerable to cancer and other diseases, and in enhancing the body’s healing processes and immune system. Research has indicated that phytochemicals (also called phytonutrients) have protective characteristics, as do flavonoids. Phytochemicals and flavonoids are found in fruits and vegetables. There are many fruits and vegetables that assist in the war against cancer and free radicals.

(1) Fruits

Sources indicate that beneficial fruits include raspberries, cranberries, black raspberries, blackberries, loganberries, boysenberries, red grapes, strawberries, kiwi, peaches, pears, oranges, melons, papayas, bananas, apples, mangoes, and others.

(2) Vegetables

There are a wide variety of recommended vegetables. Unfortunately for George Bush Sr., who is reputed to have said upon becoming President of the United States “Now I don’t have to eat broccoli”, that vegetable is highly rated as a cancer-preventive food.

Other beneficial vegetables include those that are deep yellow or dark leafy green in color, and those of the cabbage and onion families. Brussels sprouts, spinach, sweet potatoes, carrots, squash, cauliflower, tomatoes (a great source of lycopene, especially when cooked), turnips, onions, garlic, shallots, leeks, lettuce, cabbage and other vegetables are recommended.

In addition to the health advantages of fruits and vegetables, an added blessing is that the vast majority of them also taste delicious. Many sources state that the recommended daily intake of fruits and vegetables in a person’s diet should be eight to ten servings. Fruits and vegetables are the natural source of vitamins and minerals that are essential for health and wellness.
C. Grains and Legumes

As well as fruits and vegetables, various beans and foods made from whole grains are called “really good foods” by the American Cancer Society. These include lentils, garbanzos, pinto, kidney, lima, split peas and soy bean products such as tofu, as well as foods made mostly with wheat, rye, oats, barley and brown rice.

Sources of dietary fiber include fruits, vegetables, and cereal and bread made from whole grains. Fiber aids in removing cholesterol, in digestion, and in maintaining regular bowel movements.

D. Proteins

Proteins are essential to the human diet to generate fresh tissue, to aid development, and to heal tissue. Proteins are organic compounds made up of a complex union of amino acids.

Proteins are found in all animal and vegetable matter. Meat, fish, domestic fowls, milk and milk by-products are animal sources. Grains, beans, and several types of nuts, as well as soy products, are vegetable sources of protein. Wild fish is considered one of the most salutary protein sources, particularly salmon, herring, mackerel, cod, sardines, and others. It is now believed that large amounts of protein are not required in the human diet. In particular, animal protein should be consumed in moderation.

E. Soybean, Soymilk and Tofu

Soybean is a legume plant that is grown for the oil and flour harvested from it. Because it is high in protein, it can be used as a substitute for animal protein in various foods. For instance soybean milk, also known as soymilk, is a substitute for cow’s milk. Soybean milk is the ingredient used to make tofu, a varied textured curd. As a source of protein, tofu is used as a substitute for meat in vegetarian recipes and Asian cooking.

Research has shown that the isoflavons in soy, particularly genistein, protect against cancer. It has further been shown that the genistein found in soy may be able to reduce the growth of prostate cancer cells.

F. Carbohydrates

Carbohydrates contain carbon, hydrogen and oxygen and are the primary food sources for providing energy to the body. Sugars and starches are examples of carbohydrates.
that are frequently processed and refined. Breads, pastas, baked goods, refined sugars, and white rice are some examples of carbohydrates that are high in calories, but have little nutritional value compared to other foods. Fresh fruits and vegetables, which are unprocessed and unrefined, are an excellent source of carbohydrates and in addition they are a source of vitamins and minerals as well as fiber.

Diabetes is the metabolic disorder in which sugars and starches fail to be absorbed from the blood. There appears to be a hereditary link to diabetes, and since there is a history of diabetes in our family, we limit our consumption of processed and refined carbohydrates. With respect to sugars and sweeteners, honey and demerara brown sugar may be used instead of refined white sugar. As for pastas, it is more beneficial to use whole grain products cooked al dente (still firm when bitten). There are a number of healthy substitutes for white rice, such as brown rice or wild rice.

G. Water

Fluids are an essential part of a healthy diet, particularly water. Water helps to clean out a person’s system. Immune function can be compromised by dehydration, a lack of water. Since the body is being depleted of fluids on a continuous basis by urination and perspiration, it is essential to replenish the body with new supplies of water. Most sources indicate that a minimum of eight glasses of water should be consumed each day. The importance of consuming water during treatment for prostate cancer is discussed elsewhere in this book.

H. Other Fluids

A section of the Mayo Clinic website entitled “Prostate Cancer and Green Tea” indicates that a potent killer of prostate cancer cells is a plant substance in green tea. Others have referred to green tea as a powerful agent of cancer prevention.

One or two glasses of red wine a day is also considered to be effective as an antioxidant. However, anyone with a history of alcoholism in their family can achieve the same beneficial results by consuming red grapes and the juice made from them. It should also be noted that as one ages, the ability to tolerate alcohol significantly decreases.

I. Diet and Health

A healthy diet should include the consumption of omega-3 fatty acids and monounsaturated fatty acids; and it should restrict saturated fats, omega-6 fatty acids, and trans-fatty acids. In our opinion, a person diagnosed with prostate cancer should consider
discontinuing the consumption of all red meats, such as beef, ham, pork, lamb and veal. These meats can be replaced with skinless turkey and chicken, wild salmon and other fish, legumes, and soy products. Significant amounts of fresh fruits and vegetables should also be consumed daily.

Various factors may affect the wholesome quality of substances in our food chain. Some major concerns include pesticides, growth hormones, antibiotics, animal feed, and contaminated water. Wild salmon and trout should be consumed rather than the farmed varieties. Many people restrict their meat intake to free-range, antibiotic-free poultry and beef. Fruits and vegetables should be washed and, where appropriate, peeled prior to consumption.

Within the last year, several sources have indicated that plastic containers and wraps should not be used in microwave ovens. It is believed that the high temperatures in these ovens can cause the breakdown of the molecules in the plastic, causing unwelcome elements to enter the food. It is believed that fat, high heat and plastic in combination release dioxins (which are carcinogenic and highly toxic) into the food and subsequently into the cells of our body. Since we do not know the content of paper products, they too may be suspect and should be avoided when using a microwave oven. Ceramic or glass containers can be used to replace plastic wraps and paper products in microwave cooking.

Cooking foods for any length of time in a microwave can affect their chemistry and structure, particularly those foods that contain proteins. Accordingly, these appliances should not be used for recipes that require longer cooking times.

Some may think that dietary changes made after a prostate cancer diagnosis may be like closing the barn door after the horses have escaped. However, these dietary changes may be preventative measures reducing the risk of cancer recurrence. In addition, this type of diet is considered beneficial for people with a risk of heart disease.

Our readings indicate to us that the recommended nutrition for cancer prevention is relatively the same as that for heart and vascular medical problems. It is our view that good nutritional habits contribute to the overall maintenance and improvement of health.
12. Lifestyle Considerations

“...reach the body through the soul and use the latter as the physician of the former.“
— Immanuel Kant, *Critique of Pure Reason*

There is no doubt that a person’s lifestyle has a significant influence on that individual’s health. After George was diagnosed with prostate cancer, we made a number of lifestyle changes — in body, mind and spirit.

The use of tobacco and the immoderate consumption of alcohol are prime targets of behavioral reform. A heavy smoker of tobacco is much more likely to develop lung cancer and other ailments than one who does not smoke. An abuser of alcohol sustains a greater risk of cirrhosis of the liver and other health and social problems than does a person who abstains.

Alcohol and tobacco are recreational drugs. They are poisonous or toxic, the more so with increased usage. When moderately imbibed, alcohol may have some health benefits. It can be an icebreaker in social settings, putting one at ease and in a good mood and some believe that it may reduce cholesterol levels.

Readers, of course, are aware of the serious health risks caused by repetitive overindulgence of alcohol. Use of alcohol should only be considered if there is no history of drinking abuse by the individual. One should also take into consideration one’s family history in relation to alcohol abuse. With age, one’s ability to tolerate alcohol is lowered, and serious consideration should be given to the reduction of alcohol consumption in relation to one’s age level. Aside from its deleterious repercussions on the body, alcohol is a frequent contributor to automobile accidents and homicides.

Tobacco causes nicotine addiction and can be a very difficult and unhealthy habit to kick. That is why some people with cancer continue to smoke even though they know that, in their circumstances, it is irrational to do so. Tobacco contains carcinogens, substances that produce cancer. It can be and often is deadly. Tobacco smoke is a significant contributor to cancer, particularly lung cancer. It is said that second-hand smoke can have the same effect. We have never heard of a health-care professional who advocates smoking as a component of a healthy lifestyle.

Over and above the morbid consequences of indulgent smoking, tobacco smoke also has an unpleasant odor. It causes bad breath and impairs the olfactory sense. It infiltrates and smells up the clothing not only of the puffer but also of his or her spouse and family. Unlike temperate use of alcohol, smoking provides no value to a person’s health.
In addition to changes to diet in the manner described in the previous chapter, one should consider the value of exercise of a kind suitable to one’s age. A human needs to use his or her body to keep it in shape, to promote health, and to stimulate the immune system. Neither man nor woman is meant to be a sedentary creature, nor were they created to be indolent. Humans come into this world with two legs and the capability of walking on them, and with good reason. If a person does not use their legs and other parts of their body on a steady basis, atrophy will set in. This is quite noticeable in the legs of people who have become paraplegics and are unable to exercise them.

An added advantage of exercise is that as a purposeful activity it enhances a person’s feeling of being in charge of one’s self and contributes to self-esteem. These are factors that leave no room for helplessness or feelings of inadequacy, and since a person’s state of mind can play a prominent role in that person’s progress, they should aid in fighting off or in recovering from disease.

For a person of the older generation, as most prostate cancer patients are, walking is likely the best form of exercise. To be of the greatest benefit, a walk should be at a brisk pace and last about 25 to 30 minutes, either every day or every other day. Many people find group classes to be a good means of achieving proper exercise. Others enjoy hiking, biking, or similar activities. Needless to say, older people should not exercise in an over-strenuous manner or in a way which may cause injury. We believe that proper exercise and appropriate rest are beneficial both physically and mentally.

A number of medical professionals have a one-dimensional-approach to medical care. They deal with the body and give little credence to the power of the mind. This climate seems to be gradually changing, and the influence of the mind in contributing to the health and healing of the body is gaining the recognition of more and more health-care consultants.

Dr. Andrew Weil’s book *Spontaneous Healing* has an entire chapter entitled “The Role of the Mind in Healing”. Dr. Norman Cousins, Ph. D, in his classic book titled *Anatomy of an Illness*, repeatedly states that the mental attitudes of patients have a great deal to do with the course of their disease. Dr. Bernie S. Siegel in his book titled *Love, Medicine & Miracles* deals with, among other matters, the relationship between mind and body and affirms that the brain controls the immune system. His book talks about exceptional patients who are survivors.

*Spontaneous Healing, by Dr. Andrew Weil*
http://www.amazon.com/exec/obidos/tg/detail/-/0679436073/

*Anatomy of an Illness, by Dr. Norman Cousins*
http://www.amazon.com/exec/obidos/tg/detail/-/0553343653/
Love, Medicine & Miracles, by Dr. Bernie S. Siegel
http://www.amazon.com/exec/obidos/tg/detail/-/0060919833/

Dr. Carl Simonton and the other authors of the book titled Getting Well Again (which is a guide to overcoming cancer) are of the view that the mind and the body are an integrated system and that the "whole person" must be engaged towards health to make recovery more probable. They have set forth two "mind/body models", one to demonstrate how the mind and body can interact in the commencement of cancer and the other to show how they cooperate health-wise.

Getting Well Again, by Dr. Carl Simonton et al
http://www.amazon.com/exec/obidos/tg/detail/-/0553280333/

A placebo is a non-medicated pill or preparation given to and taken by a patient who erroneously believes it to be a medicine. In a startling number of instances, a beneficial result is produced by faith in the efficacy of the dose and not by any intrinsic value of the placebo itself. This placebo effect confirms the mind/body connection and their inter-workings. Although the immune system and the immune response are innate in living creatures, in some manner faith and hope help to kick-start the immune system and the immune response in many circumstances.

The immune system is the biological system within people that helps to maintain health by resisting the effects of infections, viruses, cancer cells, toxins, carcinogens, and other threats. It also aids in recovery from sickness and disease. An immune system that is seriously impaired is unable to fend off attackers of the body’s health. An example is AIDS (acquired immune deficiency syndrome). This disorder is characterized by a pronounced inability of the immune system to repel infection and is usually eventually fatal.

The National Institutes of Health in the United States have issued a booklet with a self-explanatory title The Immune System — How It Works.

The Immune System — How It Works

Some years ago Norman Cousins’ doctor told him that he had a "progressive and incurable" illness. He proved them wrong by taking control of his own destiny and following a lifestyle which included a strong will to live, confidence, laughter and ascorbic acid. In his book he stated that "laughter is good medicine".

There are scientific studies that demonstrate the association of positive emotional states generated by mirthful laughter with the enhancement of the immune system.
One such study is discussed in a 1996 audio tape, supplemented by a booklet, entitled *Laughter and the Immune System, A Serious Approach*, presented by Drs. Lee Berk and Stanley Tan and issued by Touch Star Productions of Meadville, Pennsylvania. Among other things, the study established that persons who viewed a comedy presentation had their natural killer cell activity significantly increased. Natural killer cells seek out and destroy abnormal cells.

*Laughter and the Immune System, A Serious Approach*,
by Drs. L. Berk and S. Tan

http://www.amazon.com/exec/obidos/tg/detail/-/0965024032/

There are a number of mental attitudes that we feel confident assist the immune system. These include faith in one’s treatment and medical consultants; hope for and confidence in the future; love for and by family and friends; forgiveness of those who may have hurt us; establishing meaningful achievable goals; and a spiritual outlook on life.

Many people consider that visualization (mental imagery) and meditation contribute to the healing process. Visualizing a tumor being attacked and eaten by barracudas is one example, and another is transcendental meditation. Some may find that constantly repeating a mantra and trying to clear one’s mind is not very fulfilling. However meditating about the destruction of the cancer, and about the body becoming healthy, may be much more satisfying. Some people find that other types of meditation, such as religious contemplation, prayer, and positive reinforcement are effective ways to supplement the healing process.

In a January 13, 2004 appearance on the Larry King Show televised on CNN, Dr. Andrew Weil made the following cogent statement with respect to mind/body health:

“...bring the healing power of the mind to bear on the immune system”.

While prayer, faith and spirituality may be insufficient in themselves to cure cancer (although faith healing does have its adherents), there are studies indicating that they could be beneficial to one’s health. Faith in a Supreme Being and belief in its omnipotence and power to heal may well stimulate an immune response to an illness. In conjunction with appropriate treatment, it certainly cannot hurt and may inspire hope (a boon to the immune system) or serenity when the future would otherwise appear bleak. As Alfred, Lord Tennyson sublimely put it: "More things are wrought by prayer than this world dreams of”.

Emotions are the very essence of one’s being. Emotions are the strong feelings a person gets from various complex reactions that have both physical and mental manifestations such as sorrow, fear, anger, love, happiness and hate. There is often a
tendency to suppress or hide one’s feelings. This is particularly true of feelings of fear, inadequacy and loss of control of one’s life. It is important to express emotions and give vent to one’s feelings in a positive way. If problems and troubles are not handled they end up as excess depressing baggage that is carried along with an individual for the rest of his or her life. If these emotions are buried deep, they end up eating away at the person and can result in illness to the mind or body.

If fears and concerns are faced head on and expressed in an appropriate fashion, the individual can minimize their deleterious effects and find positive and optimistic emotions to replace them. George’s diagnosis of prostate cancer has given us the opportunity to smell the roses and look at life through the eyes of our grandchildren.
13. Control Your Own Destiny

“...be something more than a passive observer.” — Norman Cousins, *Anatomy of an Illness as Perceived by the Patient*

There are various steps and stages that an individual experiences upon being diagnosed with cancer. The following provides a suggested framework from which one may start the process of treatment and healing. The most important step is for an individual to take responsibility for and control of his own situation.

A major step in controlling one’s own destiny is to set priorities in order to attain one’s goals. Reaching an informed decision as to the best treatment requires learning as much as one can about his or her condition and its various treatments.

The following helpful suggestions, based on our experiences, may be of assistance during this process. None of these concepts or ideas are set in stone; they should only be considered as starting points towards achieving the objectives that each person should set for himself.

**A. Taking Responsibility and Control**

A person diagnosed with prostate cancer is immediately confronted by a dramatic emotional reaction. The spectrum of feelings is wide and varies from person to person. Some of these emotions are shock, sorrow, rage, anger, fear, anxiety, depression, denial, guilt, despair, and frustration.

The important thing is to recognize that these reactions to such a traumatic diagnosis are normal. After regaining his composure, a man should take the time and energy to express these feelings in a way that will help him to overcome negative emotions in a reasonable way that will not injure or hurt those closest to him. For instance if a person feels the need to vent his anger or frustration, he should consider going out in the woods in order to release his built-up emotions to the wind. If a person needs to cry, he should do so.

When overwrought with deep emotions real men do cry when expressing their feelings. In the same way, other emotions may need to be similarly expressed or purged in order to regain one’s equilibrium. One of the most important factors in confronting cancer is to stay in control and not to give one’s power away to this disease. It is only after one has reacted to the diagnosis of cancer that one can then proceed to a level of acceptance, and from there progress to a realistic approach to assuming responsibility for
and control of one’s destiny. To do this, it is beneficial to discuss and debate the ques-
tions and problems as they arise, no matter how difficult this may be initially. We found
that the more open our discussions were, the easier it was to talk about concerns as
they arose.

For anyone who finds it extremely difficult to verbalize his emotions and reactions,
writing down one’s thoughts and feelings may be a helpful method for problem solving
and decision-making. Many people find that maintaining a daily journal is an effective
way of expressing emotions and, at the same time, keeping a record of events. For
years, George has kept a family journal of anecdotes relating to our children and grand-
children. Consequently, it was second nature to him to keep a journal with respect to
our prostate cancer journey.

The best way to turn a situation around is to look at it from a different perspective. After
all, prostate cancer is merely one of the challenges that life deals out, and it is up to the
individual to confront this challenge as he has confronted other serious challenges or
setbacks in his life.

Each individual is unique and each individual’s cancer is unique. A patient should
determine the correct treatment for himself, taking into account his own specific condi-
tion. Unless a person is mentally incapable of handling his own affairs, no one but that
individual should assume the responsibility for decisions concerning his treatment and
care.

The patient should choose his method of treatment only after consultation and study to
determine what in his view will be best for him. In speaking to inquirers, our advice is
"We can provide you with information, but it is up to you to determine and make the final
decision as to the most appropriate treatment for you in your particular circumstances."

In order to make an informed decision about treatment, one must take the time and
effort to learn as much as he can about prostate cancer, available treatments, and the
best treatment for him in his personal situation. In essence, this amounts to taking over
the control of the course that he is to take in dealing with his cancer. It may seem
easier and less stressful to have others (such as a doctor, spouse or companion) make
all the decisions concerning one’s condition and treatment. However in doing so one is
sticking his head in the sand, failing to be directly responsible for his own well-being,
and opening himself up to the possibility of receiving the treatment choice of a third
party.

On the other hand, facing reality and assuming responsibility infuses in a person both
confidence and self-esteem. These inspiring qualities boost one’s spirit and contribute
to the healing process. Once a person has taken on this mandate, he has faced a great
hurdle and everything that follows will become less difficult because he knows that he is
controlling his own destiny.
From being overwhelmed by the diagnosis of cancer, the individual has evolved into an empowered person capable of facing the battle of cancer. At this juncture, the patient, in cooperation with his partner, can confidently proceed with the research and consultations required in order that they may come to an informed and enlightened decision as to which treatment is best for him.

**B. Prioritizing Goals**

As one goes through the process of determining an appropriate treatment for prostate cancer, it is important to set certain priorities as to the type of treatment and the results that one wishes to achieve. We found that we both had priorities, and we needed to frequently discuss these with each other as we progressed through the learning period and into jointly finalizing our decision as to George’s treatment.

The priorities that we set when looking for the right treatment included effectiveness of the treatment, potential side effects, availability of subsequent treatments if there was a recurrence, and avoidance of highly experimental treatments.

Priorities may and should evolve and change as one progresses through the steps of educating oneself in order to make an informed decision on treatment. If objectives and goals are not set forth, one is likely to end up floundering around because of the overload of available information and, depending on the source, will be faced with significant differences of opinion on treatments and their side effects.

In our view, one should first set forth some goals, and then be flexible and open to new ideas and concepts as one progresses with research until one’s final objectives are solidified. Some initial objectives may last throughout the process, but others will unfold as one progresses through and into the decision phase.

**C. Helpful Suggestions**

The following are some suggestions that may be helpful in dealing with prostate cancer.

- Remember that medical records and test results belong to the patient and that he is entitled to receive copies of them on request.

- Prepare for a medical appointment by making a list of relevant questions and make notes of all the answers.

- A spouse, a significant other, or close friend should be present with the individual at all medical appointments and tests.
• Bring paper and pens to take notes of all information and advice received.

• Do not be intimidated by medical terminology; ask for and receive explanations that can be thoroughly understood.

• Determine the experience of the doctor and ascertain what biases he may have concerning various treatments.

• Do not base a decision solely on the consulting physician’s specialty or what motivates him.

• Do not be forced into making a decision as a result of time elements, either short or long, which may be imposed by a physician or a third party.

• Do not let the doctor impose a guilt-trip on you — i.e. consider what will benefit you and don’t feel obligated to go into a clinical trial on the basis of some hypothetical benefit to future prostate cancer patients.

• Ask for a second opinion.

• Seriously question the necessity of hormonal therapy if the diagnosis is of localized prostate cancer.

• Take sufficient time to learn as much as possible about prostate cancer and the various treatments in order that a knowledgeable treatment decision can be made.

• Find out all the potential and probable side effects of any contemplated treatment.

• Consider and evaluate the advantages and disadvantages of all mainstream treatments within the medical parameters of your particular diagnosis.

• Talk to friends and relatives about their experiences with cancer, particularly prostate cancer.

• Discuss specific types of treatments, and their side effects, with individuals who have actually undergone those particular treatments for prostate cancer.

• Make sure that your treatment takes into consideration your future quality of life.

• Seek out the best treatment for you as an individual.
• Make sure that there is a post-treatment follow-up program that includes regular PSA tests followed by digital rectal examinations.

• Make healthful changes in diet and lifestyle in order to practice preventative medicine.

• Seek out, follow and maintain a lifestyle that will provide health for one’s body, soul and mind.

• Keep up your self-esteem, confidence and spirit, and use humor as a daily dose of medicine.

• Nourish your spiritual beliefs in order to achieve inner peace and comfort.

• Surround yourself with optimistic, loving people.

Hopefully these suggestions will help in dealing with prostate cancer, but we have no doubt that readers will come up with additional or other ideas as they experience their own journey with prostate cancer.

If found early, prostate cancer is a disease that can be treated and healed. As one goes through the experience, one finds that life is put in perspective by cancer. While the diagnosis of prostate cancer can be traumatic, many will find that it is really a blessing in disguise that can provide an opportunity for personal growth and renewal, and a greater appreciation of family, of relationships, and of life.
Appendix A
Glossary of Prostate Related Terms

The focus of this glossary is prostate cancer, although some of the terms apply to other situations. This glossary is not all-inclusive, is provided in layman's terms, and in some instances contains personal comments.

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adenocarcinoma</td>
<td>A malignant tumor that develops in the inner surface or lining of a glandular organ. The vast majority of prostate cancers are adenocarcinomas, as was George's cancer.</td>
</tr>
<tr>
<td>Adjuvant therapy</td>
<td>In relation to hormonal therapy, it is the use of hormone drugs as an additional treatment after a primary treatment.</td>
</tr>
<tr>
<td>Advanced prostate cancer</td>
<td>See metastasized prostate cancer.</td>
</tr>
<tr>
<td>Androgens</td>
<td>Male hormones including testosterone.</td>
</tr>
<tr>
<td>Angiogenesis</td>
<td>The process by which new blood vessels are formed; a tumor uses this process to grow.</td>
</tr>
<tr>
<td>Antioxidants</td>
<td>Substances that remove potentially damaging oxidation agents including free radicals, and are found mainly in certain nutrients.</td>
</tr>
<tr>
<td>Anus</td>
<td>The opening for excretion situated at the lower end of the alimentary canal (the path through which food passes during digestion).</td>
</tr>
<tr>
<td>Benign</td>
<td>Non-malignant condition; relatively harmless.</td>
</tr>
<tr>
<td>Benign cells</td>
<td>Non-cancerous cells that look and act like normal cells.</td>
</tr>
<tr>
<td>Benign prostatic hyperplasia (or BPH)</td>
<td>A benign non-cancerous condition of the prostate in which the prostate is enlarged causing it to press against the urethra and the bladder, thereby impeding urination.</td>
</tr>
<tr>
<td>Biochemical failure</td>
<td>Three consecutive post-treatment rises in PSA after its nadir has been reached subsequent to treatment.</td>
</tr>
<tr>
<td>Term</td>
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</tr>
<tr>
<td><strong>Biopsy</strong> (or prostatic biopsy, or transrectal biopsy)</td>
<td>Extraction by a physician, and microscopic scrutiny by a pathologist, of tissue samples from the body to determine whether or not there are abnormalities, such as cancer, is the medical procedure called a biopsy. A prostatic biopsy is usually a transrectal biopsy in which a prostate biopsy gun is guided by an ultrasound probe, both of which are inserted into the rectum, and uses needles that are injected into the prostate to remove six or more tissue samples.</td>
</tr>
<tr>
<td><strong>Bladder</strong></td>
<td>A hollow organ in the pelvic cavity consisting of a membranous sac into which urine flows from the kidneys and is held there pending urination.</td>
</tr>
<tr>
<td><strong>Bone scan</strong></td>
<td>A body-imaging technique using a radioactive substance injected into the bloodstream in order to view bones.</td>
</tr>
<tr>
<td><strong>BPH</strong></td>
<td>See benign prostatic hyperplasia.</td>
</tr>
<tr>
<td><strong>Brachytherapy</strong></td>
<td>In the case of prostate cancer, an invasive form of internal radiation therapy (also known as interstitial radiation therapy) performed by implanting tiny radioactive material, called seeds or pellets, directly into the prostate.</td>
</tr>
<tr>
<td><strong>Bragg Peak</strong></td>
<td>The predetermined place in the body at which the deposition of energy is highest for delivering proton beams to the target area. This peak can be expanded along the axis of the beam to conform to the thickness of the volume of the designated area.</td>
</tr>
<tr>
<td><strong>Cancer</strong></td>
<td>A disease caused by a malignant abnormal growth of cells and division of cells in a disorderly and uncontrolled manner. The abnormal growth of cancer cells results in a tumor. The malignant cells may spread locally and also may migrate to other parts of the body by means of the blood or lymphatic systems.</td>
</tr>
<tr>
<td><strong>Cancer cells</strong></td>
<td>Cells characterized by poor differentiation and unregulated growth; these cells are cancerous and non-benign.</td>
</tr>
<tr>
<td><strong>Capsule</strong></td>
<td>The layer of fibrous tissue encircling the prostate.</td>
</tr>
<tr>
<td><strong>Castration</strong></td>
<td>See medical castration and surgical castration.</td>
</tr>
</tbody>
</table>
CAT scan (or computerized axial tomography) The diagnostic procedure that looks inside the body in a noninvasive manner. It does so with a sophisticated x-ray apparatus in conjunction with a computer to produce a series of detailed cross-sectional pictures of internal organs.

Cell All plants and animals are made up of cells, which are microscopic units of protoplasm consisting of cytoplasm and a nucleus enclosed in a membrane.

Chemotherapy The treatment of cancer by means of injection or ingestion of pharmaceuticals or other chemicals to kill cancer cells. Chemotherapy frequently kills healthy cells as well, such as blood cells, and itself has the potential to affect the immune system if powerfully given over a lengthy period. It rarely cures prostate cancer.

Clinical trial An experimental study, involving people, which has been carefully planned by qualified professionals or researchers to assess the effectiveness, safety and side effects of new or unproven treatments or drugs and, in some cases, to compare their efficacy to currently accepted treatments or drugs. A clinical trial may have several phases, with each subsequent phase having quite a few more patients than the previous phase.

Computerized axial tomography See CAT scan.

Conformal radiation Therapy in which radiation beams, by means of computer control, may be shaped and angled to conform to the tumor or target in three dimensions (depth, height and width). Proton beam therapy is conformal radiation, as is some conventional x-ray therapy.

Conventional external beam radiation therapy Also called conventional x-ray therapy, or photon radiation therapy. External beam radiation therapy that use gamma rays or x-rays (high-energy photons). Healthy cells as well as cancer cells are usually affected, frequently resulting in unwelcome side effects.

Conventional x-ray therapy See conventional external beam radiation therapy.

Cryoablation See cryosurgery.

Cryosurgery A treatment for prostate cancer also known as cryoablation, or cryotherapy. This invasive surgery uses liquid nitrogen or argon.
inserted by probes through the perineum to freeze the entire prostate to extremely low temperatures for the purpose of killing any cancerous tissue in the prostate. This also results in the prostate itself being killed in the process.

Cryotherapy
See cryosurgery.

Cure
Restoration to health or soundness.

Deoxyribonucleic acid (or DNA)
An essential part of all living organisms and a basic constituent of the chromosomes of the cell nucleus. It is the unit carrying the genetic code and conveys hereditary characteristics.

DHT
See dihydrotestosterone.

Digital rectal examination (or DRE)
The insertion of a physician’s lubricated gloved finger into the patient’s rectum in order to check the prostate and adjacent area for palpable tumors or other abnormalities.

Dihydrotestosterone (or DHT)
A male hormone that is made from the conversion in the prostate of healthy testosterone by a specific enzyme.

DNA
See Deoxyribonucleic acid.

Dosimetrist
A person who, together with a physicist, works up a treatment plan and calculates the radiation dose to be given to a cancerous target area (or tumor) and to adjacent normal tissue.

DRE
See digital rectal examination.

EBRT
See external beam radiation therapy.

Erectile dysfunction (or ED)
See impotence.

External beam radiation therapy (or EBRT)
Radiation therapy consisting of high energy rays or beams delivered in a noninvasive painless manner into the body by a machine outside the body to harm or destroy cancer cells and to inhibit their growth and subdivision. EBRT may be conventional external beam radiation therapy (defined above) which quite frequently damages some healthy tissue causing unwelcome side effects; or proton beam radiation therapy (defined below) which normally causes only insignificant damage to surrounding tissue and only minor side effects.
<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
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</table>
| **Free PSA**  
(or fPSA)               | Prostate specific antigen that is free in the blood stream is called free PSA. Other PSA is bound to proteins whereas free PSA is not bound to other proteins in the blood. |
| **Free PSA test**  
(or fPSA test)    | A relatively new test, called the free PSA test, measures the percentage of free PSA to total PSA. The lower the percentage of free PSA, the greater the risk of prostate cancer. The higher the percentage of free PSA, the lower the risk of prostate cancer. See also prostate specific antigen. |
| **Free radicals**             | Abnormal and unstable oxygen molecules that have an unpaired electron. They pursue and combine with other molecules, oxidizing them, and damaging the DNA in the cells of the body. |
| **Gantry**                   | A gigantic piece of equipment, forming part of the proton treatment delivery system, that rotates around the patient and directs the proton beam to a precisely predetermined point. |
| **Gleason score**            | An assessment or grading of the aggressiveness of cancerous tumor cells based on the cellular differentiation of cancerous tissues as they appear under microscopic examination. A well differentiated, or near normal, form of tumor is considered less aggressive. With lesser differentiation in the cancer cells, there is greater potential for aggressive growth of the cancer cells. Based on cellular differentiation, numbers from 1 to 5 are assigned to the two most predominant patterns. These numbers added together constitute the Gleason score. See also grade. |
| **Grade**                    | A method of measuring the potential aggressiveness or rate of growth of prostate cancer based on cell differentiation pursuant to microscopic examination. The more a tumor resembles normal tissue the lower the grade and vice versa. Low-grade tumors are inclined to grow and spread more slowly than high-grade tumors. See also Gleason score. |
| **Gy**                       | The unit of the absorbed dose of ionizing radiation based on the international system of units. |
| **Heal**                     | To make whole, healthy and sound. |
| **High dose radiation**  
(or HDR)             | Brachytherapy treatment using temporary implants of radioactive seeds. |
Hormonal therapy Also called hormone therapy or hormone treatment. In prostate cancer, the use of hormone drugs or certain surgical procedures to block the body's production of testosterone, the male sex hormone, with a view to retarding the growth of the prostate cancer or shrinking the cancerous tumor. Testosterone (which is produced in the testicles) is a contributor to the growth of prostate cancer cells. The drugs used cause significant unpleasant side effects; and the cancer cells may become hormone refractory if the drugs are taken for an extended period.

Hormone A substance produced in some organ of the body and transported by a body fluid such as blood in order to activate another organ or tissue. Hormones can be produced synthetically.

Hormone-refractory A condition in which the cancer is no longer responding to hormonal therapy.

Hormone therapy See hormonal therapy.

Hormone treatment See hormonal therapy.

Immune system The biological system innate in humans (as well as animals) which helps to maintain one's health by fighting the effects of infections, viruses, toxins, cancer cells, and other health threats. The immune system also assists in recovery from sickness.

Impotence The incapacity to have and sustain a penile erection suitable for sexual intercourse. Temporary or permanent impotence is a frequent side effect of most prostate cancer treatments, but normally much less so in the case of proton beam radiation therapy. Impotence is also known as erectile dysfunction and ED.

IMRT See intensity-modulated radiotherapy.

Incontinence The inability to control urination. There are three types of incontinence — lack of urinary control due to stress incontinence; inability to completely empty the bladder; or total failure in the ability to hold urine in the bladder.

Intensity-modulated radiotherapy (or IMRT) Brachytherapy treatment using temporary implants of radioactive material conforms the x-ray treatment to fit the shape of the tumor using a linear accelerator-based technology.
**Interstitial microwave therapy (or thermotherapy)**
The insertion of a number of probes to deliver high heat to the prostate gland as an experimental treatment for prostate cancer that has recurred.

**Invasive**
In a medical procedure an incision, or the insertion of an instrument, into the body.

**Localized cancer**
A malignant tumor that has not spread to other parts of the body and remains in its original site.

**Localized prostate cancer**
A malignant tumor confined to the prostate gland. The tumor has not metastasized.

**Luteinizing hormone (or LH)**
A chemical transmitted by the pituitary gland to signal the production of testosterone by the testes.

**Luteinizing hormone-releasing hormone (or LHRH)**
A hormone responsible for stimulating the production of testosterone in the body.

**Luteinizing hormone-releasing hormone agonists (or LHRH agonists)**
Drugs that inhibit the action of LHRH and that shut down the production of the LH hormone by the pituitary gland.

**Lymph nodes**
Small compact glands lying along the vessels of the lymphatic system. The lymphatic system in the body carries lymph, a colorless fluid containing white blood cells that filter out and help fight toxins, bacteria, and cancer cells.

**Magnetic resonance imaging**
See MRI.

**Malignant**
A non-benign condition; cancerous.

**Malignant tumor**
A cancerous tumor that has a tendency to invade normal tissue and metastasize.

**Margins**
See negative margins, positive margins, and surgical margins.

**Medical castration**
Hormonal therapy to suppress the production of testosterone.
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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</thead>
<tbody>
<tr>
<td>Metastasis</td>
<td>Spread of the cancer by means of the blood stream or the lymphatic system to other sites in the body where the cancer cells grow.</td>
</tr>
<tr>
<td>Metastasized prostate cancer</td>
<td>Cancer that has penetrated the prostate wall and spread outside the prostate gland to another site such as the lymph nodes, bones, liver, etc. It still bears the name of the primary cancer - prostate cancer and not bone cancer, liver cancer, etc. This is advanced prostate cancer.</td>
</tr>
<tr>
<td>Modality</td>
<td>The prescribed technique or method of treatment or procedure.</td>
</tr>
<tr>
<td>Morbidity</td>
<td>The medical term for an undesirable side effect or for an unhealthy result or complication arising from a treatment protocol, such as impotence, incontinence, etc. See side effects.</td>
</tr>
<tr>
<td>MRI (or magnetic resonance imaging)</td>
<td>A diagnostic procedure that produces images of internal organs of the body by non-invasive means.</td>
</tr>
<tr>
<td>Nadir</td>
<td>The lowest point reached in a series of PSA tests.</td>
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<tr>
<td>Nanograms per milliliter</td>
<td>See ng/ml.</td>
</tr>
<tr>
<td>Negative margins</td>
<td>Denotes that there is no sign of cancer in the outer edges of the tissue removed in a radical prostatectomy.</td>
</tr>
<tr>
<td>Neoadjuvant therapy</td>
<td>In hormonal therapy, it is the use of hormone drugs as an additional treatment before or during a primary treatment.</td>
</tr>
<tr>
<td>Ng/ml (or nanograms per milliliter)</td>
<td>A measurement used for PSA levels in the blood.</td>
</tr>
<tr>
<td>Nutrients</td>
<td>Nourishing substances necessary for life and growth.</td>
</tr>
<tr>
<td>Oncologist</td>
<td>A medical doctor who specializes in the diagnosis and treatment of various cancers.</td>
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<tr>
<td>Orchietectomy</td>
<td>Castration by surgical removal of the testicles, after which there is no longer production of testosterone from the testicles and the patient is sterile.</td>
</tr>
<tr>
<td><strong>Osteoporosis</strong></td>
<td>Loss of bone density especially due to hormonal changes resulting in brittle bones that can easily fracture.</td>
</tr>
<tr>
<td><strong>Oxidation</strong></td>
<td>The metabolic process that results in the production of energy from food that is consumed and, also, in the production of free radicals as a by-product.</td>
</tr>
<tr>
<td><strong>Penis</strong></td>
<td>The male genital organ, consisting in large part of erectile tissue, used for sexual intercourse and for voiding urine.</td>
</tr>
<tr>
<td><strong>Perineum</strong></td>
<td>The region of the body between the anus and the scrotum in men and between the anus and the vulva in women.</td>
</tr>
<tr>
<td><strong>PET scan (or positron emission tomography)</strong></td>
<td>A diagnostic non-invasive procedure that looks inside the body and produces images.</td>
</tr>
<tr>
<td><strong>Photon</strong></td>
<td>A quantum of light or other electromagnetic radiation having momentum. Electromagnetic radiation includes visible light, radio waves, gamma waves, x-rays, etc. Conventional external beam radiation therapy for the treatment of prostate cancer usually uses photons, which lack the mass, charge and controllability of protons. Due to their nature, photons release most of their power near the surface of the body (where the healthy tissues are), continue through and past the target area, and cause unwelcome side effects.</td>
</tr>
<tr>
<td><strong>Photon radiation therapy</strong></td>
<td>See conventional external beam radiation therapy.</td>
</tr>
<tr>
<td><strong>Positron emission tomography</strong></td>
<td>See PET scan.</td>
</tr>
<tr>
<td><strong>Positive margins</strong></td>
<td>Indicate that there may be cancer cells beyond the outside edges of the tissue removed during a radical prostatectomy.</td>
</tr>
<tr>
<td><strong>Prostate (or prostate gland)</strong></td>
<td>A male sex gland, about the size of a walnut, that surrounds the upper part of the urethra at the base of the bladder. Its principal function is to secrete fluid that is discharged with semen during ejaculation.</td>
</tr>
<tr>
<td>Term</td>
<td>Description</td>
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<tr>
<td>Prostate cancer</td>
<td>The growth of cancer cells in the prostate gland. Abnormal growth of cancer cells results in a malignant tumor. Cancer cells may break loose from the tumor and spread by means of the blood and lymphatic systems to other sites in the body, such as the bone or the liver, and grow there. A prostate cancer that migrates to another part of the body carries the same name as the primary cancer; it is metastasized prostate cancer.</td>
</tr>
<tr>
<td>Prostate gland</td>
<td>See prostate.</td>
</tr>
<tr>
<td>Prostate specific antigen (or PSA)</td>
<td>A protein secreted by cells of the prostate gland, including cancer cells.</td>
</tr>
<tr>
<td>Prostatic biopsy</td>
<td>See biopsy.</td>
</tr>
<tr>
<td>Prostatitis</td>
<td>A treatable infection or inflammation of the prostate gland.</td>
</tr>
<tr>
<td>Proteins</td>
<td>Organic compounds made up of a complex union of amino acids and found in all living organisms. Proteins are essential to the human diet to generate fresh tissue, aid development, and heal tissue.</td>
</tr>
<tr>
<td>Protocol</td>
<td>The term used in medical research to describe the precise procedures and methods to be followed. In the case of a patient, protocol is the term that describes the program of treatments for that patient.</td>
</tr>
<tr>
<td>Proton</td>
<td>A subatomic particle with a positive charge and a heavy mass. Protons can be conformed (or shaped) to the tumor or target volume, and retain most of their energy on entering the body. They can be programmed to travel a specific distance into the body, controlled to release their largest burst of energy at a designated site (called the Bragg Peak), and not to go beyond the far side of the target volume, thereby sparing radiation of healthy tissue and minimizing side effects.</td>
</tr>
<tr>
<td>Proton beam radiation therapy</td>
<td>A mainstream noninvasive painless type of external beam radiation treatment given on an outpatient basis. Protons are formed into proton beams that are conformed in three dimensions (height, width and depth) to the cancerous tumor or target volume. Due to their qualities, proton beams can be controlled with much greater precision. Enhanced control over proton beams, with the aid of computers, permits the Bragg Peak to be placed</td>
</tr>
</tbody>
</table>
precisely as planned at the target volume. This permits a higher radiation dose with more effective cancer-killing powers and lesser side effects.

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>PSA</strong></td>
<td>See <a href="#">prostate specific antigen</a>.</td>
</tr>
<tr>
<td><strong>PSAD</strong></td>
<td>See <a href="#">PSA density</a>.</td>
</tr>
<tr>
<td><strong>PSA density</strong> (or <strong>PSAD</strong>)</td>
<td>Calculated by dividing the volume of the prostate into the PSA level to measure the concentration of PSA in a man's prostate.</td>
</tr>
<tr>
<td><strong>PSA test</strong></td>
<td>Measures the level of PSA in the blood. An elevated level could be an indication of an abnormal condition, either malignant or benign, in the prostate. Screening based on PSA levels is used in an attempt to distinguish men with tumors from those who are tumor-free. PSA tests are also used at regular intervals to monitor a patient's post-treatment progress. All PSA tests should be accompanied by a DRE performed after the blood is taken for the PSA test.</td>
</tr>
<tr>
<td><strong>PSA velocity</strong></td>
<td>Rate or speed of change in PSA levels from year to year.</td>
</tr>
<tr>
<td><strong>Radiation therapist</strong></td>
<td>A person who has undergone specialized schooling to enable him or her to administer radiation therapy.</td>
</tr>
<tr>
<td><strong>Radiation therapy</strong></td>
<td>The application of high-energy rays or beams to destroy cancer cells. Proton beam radiation therapy and conventional external beam radiation therapy are both delivered to the malignant targeted area within the body by a machine outside the body. On the other hand, brachytherapy surgically implants radioactive seeds or pellets directly into the prostate gland.</td>
</tr>
<tr>
<td><strong>Radical prostatectomy</strong></td>
<td>A treatment for prostate cancer by means of major invasive surgery to remove the entire prostate gland and seminal vesicles. A retropubic prostatectomy is done by way of an incision in the abdomen from the navel to the pubic area. A perineal prostatectomy excises the prostate by an incision between the scrotum and the anus. Severe side effects, which may be temporary or permanent, normally ensue from this operation.</td>
</tr>
<tr>
<td><strong>Radiologist</strong></td>
<td>A medical doctor who specializes in the diagnosis and treatment of disease using high-energy radiation such as protons and x-rays.</td>
</tr>
</tbody>
</table>
Rectum  The section of the large intestine, which in humans stretches from the terminal portion of the descending colon to the anus. Part of the rectum is immediately against the back of the prostate gland.

Recurrence (or reoccurrence)  The return of a disease.

Refractory  A condition in which a disease is no longer responding to a current type of treatment.

Scrotum  The pouch of skin containing the testicles of a man.

Seminal vesicles  Small sacs in the body containing semen, the reproductive fluid of the male which is ejaculated during sexual intercourse.

Side effects  Usually used to denote undesirable consequences or reactions resulting from treatment or medication. The medical term for an undesirable side effect is morbidity. Side effects may be temporary or permanent and may vary in kind and severity. Depending on the treatment for prostate cancer, some side effects that may occur are impotence, incontinence, rectal bleeding, blood in the semen or urine, fatigue, infection, spasms, failure to control the cancer, bladder and rectal irritation, etc.

Stage (or staging)  The stage of a cancer is its size and physical extent, and affects treatment options. Staging is the process of assigning a stage to the cancer based on an assessment of relevant information. There are two systems of staging: the Whitmore-Jewett System of 1956, and the more recent and currently recommended TNM System of 1992.

Staging  See stage.

Surgical castration  See orchiectomy.

Surgical margins  The outer edges of the tissue removed during a radical prostatectomy. See also "negative margins" and "positive margins".

Synchrotron  A system that accelerates the speed of atomic or subatomic charged particles, such as protons. This significantly increases the energy of these particles.
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<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Target area</td>
<td>See target volume.</td>
</tr>
<tr>
<td>Target volume (or target area)</td>
<td>The area in the body to which the treatment is directed and which includes the confirmed malignant tumor, and may also include an adjacent area where the tumor may have spread.</td>
</tr>
<tr>
<td>Testosterone</td>
<td>The male sex hormone that is largely produced by the testicles and, to a much lesser extent, by the adrenal glands. Testosterone stimulates the development of male sexual characteristics and is essential for male fertility.</td>
</tr>
<tr>
<td>Therapy</td>
<td>The non-surgical treatment of disease or of physical or mental disorders.</td>
</tr>
<tr>
<td>Thermotherapy</td>
<td>See interstitial microwave therapy.</td>
</tr>
<tr>
<td>Tissue</td>
<td>The substance of which an organic body or organ is made, consisting of an accumulation of certain cells having a specific function, such as prostate cells, muscle cells, etc.</td>
</tr>
<tr>
<td>Transrectal biopsy</td>
<td>See biopsy.</td>
</tr>
<tr>
<td>Transrectal ultrasound (or TRUS)</td>
<td>The use of ultrasound waves to visually image an organ or gland in order to inspect for abnormal conditions using a device inserted in the rectum. It is also used to visualize prostate biopsies and for guiding needles and probes in certain procedures, such as cryosurgery.</td>
</tr>
<tr>
<td>Transurethral resection of the prostate (or TURP)</td>
<td>A surgical procedure used to remove blockages of the urethra.</td>
</tr>
<tr>
<td>Treatment</td>
<td>Application of medical remedies, care or attention to a patient, particularly in a systematic manner.</td>
</tr>
<tr>
<td>TRUS</td>
<td>See transrectal ultrasound.</td>
</tr>
<tr>
<td>Tumor</td>
<td>An abnormal swelling or growth in a part of the body due to an excessive uncontrolled increase or division of cells in tissue. A tumor may be either malignant or benign.</td>
</tr>
</tbody>
</table>
TURP  See transurethral resection of the prostate.

Ultrasound  A noninvasive, painless method of imaging tissue and glands by means of high frequency sound waves. It can be performed externally through the abdomen, or internally through the rectum.

Urethra  The membranous tube or canal through which urine is conveyed out of the body from the bladder. In men, part of the urethra is surrounded by the prostate gland and semen is also discharged through the urethra.

Urologist  A medical doctor specially trained in surgery and the branch of medicine dealing with disorders of the urinary tract and kidneys, and the sex organs of men.

Watchful waiting  The careful observation and vigilant monitoring of a patient diagnosed with cancer, without that patient receiving any actual treatment. Observation and monitoring are usually by means of regular PSA tests and digital rectal examinations.
Appendix B

Cancer Associations

The following lists the principal offices of a number of cancer associations in various parts of the world. It should be noted that these addresses and telephone numbers may be changed from time to time, and may require reference to current sources for up-to-date information.

American Cancer Society
http://www.cancer.org
Address: American Cancer Society
1599 Clifton Rd. NE
Atlanta, Georgia, 30329
USA
Telephone: (800) 227-2345

National Cancer Institute (“NCI”)  
http://www.nci.nih.gov/cancerinfo
Address: National Cancer Institute
Office of Cancer Communications
Building 31, Room 10A24
Bethesda, Maryland, 20892
USA
Telephone: (800) 422-6237

The Prostate Health Council
http://www.prostatehealth.com
Address: Prostate Health Council
c/o American Foundation for Urologic Disease
300 West Pratt Street, Suite #401
Baltimore, Maryland 21201
USA
Telephone: (800) 242-2383

Canadian Cancer Society
http://www.cancer.ca
Address: Canadian Cancer Society
10 Alcorn Avenue, Suite #200
Toronto, Ontario, M4V 3B1
Canada
Telephone: (416) 961-7223
Cancer Council Australia
http://www.cancer.org.au
Address: Cancer Council Australia
GPO Box 4708, Sydney NSW 2001
Australia
Telephone: (02) 9036 3100

British Association for Cancer United Patients
http://www.cancerbacup.org.uk
Address: British Association for Cancer United Patients
3 Bath Place, Rivington St.
London, EC2A 3JR
England
Telephone: 0808 800 1234

Irish Cancer Society
http://www.irishcancer.ie
Address: 5 Northumberland Rd.
Dublin 4
Ireland
Telephone: (800) 200 700

Cancer Society of New Zealand
http://www.cancernz.org.nz
Address: Cancer Society of New Zealand
PO Box 10847
Wellington, New Zealand
Telephone: 64 4 494 7270

Federation Nationale des Centres de Lutte Contre le Cancer
http://www.fnclcc.fr
Address: Federation Nationale des Centres de Lutte Contre le Cancer
101 rue de Tolbiac 75654
Paris Cedex 13
France
Telephone: 01 44 23 04 04

National Cancer Center Japan
http://www.ncc.go.jp
Address: 5-1-1 Tsukiji, Chuo-ku
Tokyo, 104-0045
Japan
Phone: (03) 3542-2511
Instituto Nacional de Cancerologia
http://www.incan.edu.mx

Address: Instituto Nacional de Cancerologia
Av. San Fernando 22-40 Piso
Col. Tlalpan
Mexico D.F. 14000
Mexico

Telephone: +52 5 573 5651

Cancer Association of South Africa
http://www.cansa.org.za

Address: Cancer Association of South Africa
PO Box 2121
Bedfordview 2008
South Africa

Telephone: 0800 226622

Cancer associations in other countries of the world may be accessed at the CancerIndex website:

CancerIndex
http://www.cancerindex.org
Appendix C

Bibliography

There are seemingly unlimited sources and references available on cancer generally and on prostate cancer in particular. In this book, chapter 2 (titled "Conducting Prostate Cancer Research") cites a number of the sources we consulted.

A number of books on cancer and prostate cancer contain no bibliography (or for that matter no index as well) while others contain such an extensive list that the vast majority of readers would certainly not read them all. One book on cancer that we consulted had a bibliography exceeding 250 items, while another book on illness had almost 200 items.

There are sometimes contrary opinions on different aspects relating to prostate cancer between one author and another, probably due to personal bias by the author in favor of his preferred form of treatment. There may also be unfamiliarity with a particular treatment, such as conformal proton beam radiation.

Rather than listing in this bibliography every source we consulted, the following are some of the books we considered either helpful in making our treatment decision or subsequent thereto in researching and writing this book. We have also included the websites of Loma Linda University Medical Center and our Support Group. We have not listed here every book, article, item or source referred to in the main text or that we consulted.

Cancer: 50 Essential Things to Do, by Greg Anderson
http://www.amazon.com/exec/obidos/ASIN/0452280745/

Brotherhood of the Balloon
http://www.protonbob.com

Anatomy of an Illness as Perceived by the Patient, by Norman Cousins
http://www.amazon.com/exec/obidos/ASIN/0393326845

The Healing Heart: Antidotes to Panic and Helplessness, by Norman Cousins
http://www.amazon.com/exec/obidos/ASIN/0393018164/

Dr. Gaynor’s Cancer Prevention Program, by Mitchell Gaynor and Jerry Hickey
http://www.amazon.com/exec/obidos/ASIN/1575665263/
Man to Man: Surviving Prostate Cancer, by Michael Korda
http://www.amazon.com/exec/obidos/ASIN/0679781234/

Cancer As A Turning Point, by Lawrence LeShan
http://www.amazon.com/exec/obidos/ASIN/0452271371/

Loma Linda University Medical Center Proton Treatment Center
http://www.llu.edu/proton

Prostate and Cancer: A Family Guide to Diagnosis, Treatment and Survival, by Sheldon Marks
http://www.amazon.com/exec/obidos/ASIN/0738208396/

Legacy — Daring to Care, by Richard Schaefer
http://www.llu.edu/info/legacy

Love, Medicine & Miracles, by Bernie Siegel
http://www.amazon.com/exec/obidos/ASIN/0060919833/

Peace, Love & Healing, by Bernie Siegel
http://www.amazon.com/exec/obidos/ASIN/0060917059/

Getting Well Again, by O. Carl Simonton, Stephanie Matthews Simonton, and James Creighton
http://www.amazon.com/exec/obidos/ASIN/0553280333/

Prostate Cancer: A Non-Surgical Perspective, by Kent Wallner
http://www.amazon.com/exec/obidos/ASIN/0964899132

Dr. Patrick Walsh’s Guide to Surviving Prostate Cancer, by Patrick Walsh and Janet Farrar Worthington
http://www.amazon.com/exec/obidos/ASIN/0446679143/

Spontaneous Healing, by Andrew Weil
http://www.amazon.com/exec/obidos/ASIN/0804117942/
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We wish you all the best for your recovery from prostate cancer.

Bonus Prostate Cancer E-Book

Scroll down to begin reading the bonus e-book On Eagles’ Wings: A Couple’s Personal Journey with Prostate Cancer, by George and Terry Goulet.
On Eagles’ Wings
A Couple’s Personal Journey with Prostate Cancer
by George Goulet and Terry Goulet
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About the Authors

George Goulet and Terry Goulet have written this book from a couple’s perspective. In the fall of 2000, the authors were confronted with a formidable dilemma, when George was diagnosed with prostate cancer. Their successful search for a treatment is the cornerstone of this book, which is intended to show that there can be hope and healing in combating this disease, as well as inspiration for those facing this challenge.

A retired lawyer, George presently devotes his time to researching, writing and public speaking. He is the author of Public Share Offerings and Stock Exchange Listings in Canada and The Trial of Louis Riel, Justice and Mercy Denied.

Prior to her retirement, Terry was an editor and freelance indexer of corporate and securities law reporters for an international publishing firm. She was the chief researcher, publisher, and editor for George’s book on Louis Riel.

Since the publication of their Riel book, George and Terry have jointly given many talks on Louis Riel at public libraries, universities, schools, historical societies, and similar groups.

Acknowledgements

We wish to express our appreciation to various people who in one way or another assisted us in this project.

Information was derived from many friends, relatives and other sources too numerous to mention. We would particularly like to thank our friends who gave us invaluable advice concerning prostate cancer when we most needed it. Our family doctor gave us his support during a very trying time. Members of our extended family and our friends who had experienced cancer willingly shared their knowledge and advice with us. We would also like to thank those who kindly read our manuscript and provided us with their comments. Any errors contained herein remain the sole responsibility of the authors. Special appreciation is given to the members of the Brotherhood of the Balloon.

Our five children and our beloved grandchildren have provided us with unconditional love and support throughout our journey with prostate cancer and in the writing of this book.
1. Prelude to an Epiphany

“The mind is its own place, and in itself
Can make a Heav’n of Hell, a Hell of Heav’n”
-- John Milton, *Paradise Lost*

The prelude to our inspirational journey with George’s prostate cancer was traumatic. On a wet and dreary Friday evening in November 2000, Terry answered the telephone at our son John’s home in Vancouver where we were staying while he and his partner were vacationing in Maui. Uncharacteristically, Terry was not engaging in conversation with the caller, but was listening to the information she was receiving. The calling party was our daughter Tag in Calgary.

After Terry hung up the telephone, she came to see George in another room where he was reading. She was somber in her demeanor. She said that Tag, who was periodically checking our Calgary home while we were away, had retrieved messages that evening from our telephone answering machine. One of the calls several days earlier was from the office of the Calgary urologist, to whom we had previously been referred by our family doctor. That office had left word that an appointment had been made for George to see the urologist the following Wednesday. Another message was from the office of our family physician stating that he had the results of George’s prostate biopsy and wished to see him “at your earliest convenience”.

At the end of October George had undergone a prostate biopsy in Calgary. After the biopsy the radiologist told us that the results would not be available for ten days to two weeks. We told him that we had a speaking tour lined up for the West Coast on a book that George had written and Terry had edited and published on Louis Riel, a United States citizen who was a Canadian hero in the 19th century. The book was titled *The Trial of Louis Riel, Justice and Mercy Denied*.

We explained to him that the various public libraries and other hosts of the speeches had already disseminated the advance publicity for the tour. We asked if there was any reason to postpone the trip. The radiologist told us that since he felt nothing of concern in the digital rectal examination and saw nothing untoward in the ultrasound, he saw no reason why we should not follow through with our planned West Coast speaking tour.

A couple of days later we started out by automobile for the West Coast feeling confident, happy and carefree because of what the radiologist had told us. Since at that time no diagnosis had been made, we had little knowledge of prostate cancer and its effects. This was the background scenario when a couple of weeks later our daughter Tag’s telephone call was received on that Friday evening. When George was told the messages left by the offices of both the urologist and our family doctor, in George’s words:
“I knew immediately that these calls meant my biopsy results indicated cancer. I was initially stunned. I had not expected this. I could not understand how this could have happened to me. I then felt as if I had been smashed square in the face by a sneak round-house punch and knocked flat on my back. I was filled with great consternation and fear - fear that I might soon die and leave Terry all alone - fear that I might soon die and leave my grandchildren and little grandbabies without their PaPere. I was emotionally overcome and broke down and wept while my Dolly (this is my affectionate name for my wife Terry) held me in her arms and tried to comfort me and assure me that we would triumph over this challenge.”

After awhile George calmed down and started to recover his composure. He said that we should consider returning home to Calgary right away, that he would now have no enthusiasm in giving the public talks, and that we had to find out all about prostate cancer and treatment options. In addition he felt that if we remained in Vancouver until we could telephone the doctors on Monday morning, we might find that the diagnosis required us to go home immediately. If that were to be the case, it would be prudent to pack up and head for home without delay.

After much heartfelt discussion we decided to remain in Vancouver for the weekend. If on Monday our doctors did not think it essential to return forthwith, we would soldier on with the talks, since the various libraries and institutions at which we were to speak had reserved rooms, put out publicity, and made other preparations.

In the meantime we made up our minds to banish all negative thoughts, take one day as at a time and endeavor to be positive and upbeat over the weekend until we could speak to the doctors on the following Monday.

Little did we know that the diagnosis of prostate cancer would be an epiphany for us. Little did we know that it would be a shining path lighting the way on our journey to a greater humanity, spirituality and awareness. Little did we know that it would provide us with a fresh look at life, accompanied by many happy experiences and many new “exceptional” friends. Little did we know that it would be, for us, a blessing in disguise.
2. On Eagles Wings

“I have raised you up on eagle’s wings, and have taken you to myself”

-- Holy Bible, Exodus c.19, v. 4

The day after our daughter Tag called to give us the ominous telephone messages, we were invited to dinner at the home of Terry’s cousin Mary and her husband Earl in North Vancouver. Their lovely home, on the side of Grouse Mountain, has a fabulous view overlooking Burrard Inlet and downtown Vancouver. The candlelight dinner with fresh salmon was delicious.

Mary gave us an update on her medical condition. She had undergone a radical hysterectomy two years previously when she was diagnosed with cancer of the uterus. She told us that she was still suffering from burns caused by the conventional radiation she had received for her cancer after her hysterectomy.

We then told her that George had recently had a prostate biopsy and that we had received telephone messages the night before which made us certain that the biopsy indicated prostate cancer, although we had not yet spoken to the doctors. However, when we started talking about prostate cancer with Earl and Mary, George found himself internally shivering. Earl mentioned that there was a prostate cancer treatment in which seeds were implanted in the prostate gland, but he didn’t know much about it. We later learned it is called “brachytherapy”, a Greek word for implant radiation.

The following day on Sunday, we decided to enjoy ourselves pending the news we knew we would receive from our family doctor the next day. We drove from our son’s home in the Kitsilano area of Vancouver across Burrard Inlet to Honey Doughnuts & Goodies, a favorite coffee shop of ours on the North Shore. It is on the main street of the village in Deep Cove, in a majestic setting with the water on one side and forested mountains on the other. The café is noted not only for its ambience but for its roly-poly donuts, which we had with steaming cups of tasty aromatic coffee.

After we left the café we headed west along the Upper Levels Highway through North and West Vancouver while watching the freighters, barges, yachts and sailboats plying their way to-and-fro in the waters far below. After passing Horseshoe Bay, we followed the winding road along Howe Sound; the views of the ocean, the islands and the snow-capped mountains were breathtaking. This is truly one of the most scenic drives we have ever experienced. We drove through the lumber town of Squamish and on to the village of Brackendale, our destination, about one hour from where we had started in Deep Cove.
Our purpose in going to Brackendale was to see the bald eagles that nest in the nearby tall trees in the winter. Due to the time of year we observed only a few eagles, and because they were in the trees on the other side of the river, several hundred yards away, we were only able to view them from afar. At this time a light rain was falling.

While returning to the car, George said to Terry he wished that we had been able to see some eagles up close. Seemingly out of nowhere there suddenly appeared directly over our heads, only 40 or 50 feet above, two soaring graceful bald eagles. As we looked at them they dipped their wings as if bowing to us, then circled and flew high up and across the river to a treetop on the far shore. This experience was awesome. We took it as an omen of hope for the future we were about to face.
3. A Serendipitous Visit

“A faithful friend is the medicine of life.”

-- Holy Bible, Ecclesiasticus c. 6, v. 16.

On Monday morning November 13th we telephoned the urologist’s office in reply to the phone message we had received from his receptionist concerning an appointment. An answering machine advised us that the urologist was away until Wednesday, and his receptionist would not be in the office until Tuesday. We left a message for the receptionist to call us in Vancouver.

We next called our family doctor in Calgary to discuss the biopsy results with him. When we spoke to him he told us that he really wanted to review the matter with us in person. We explained that we were presently in Vancouver on a speaking tour, not in Calgary, and would like to discuss the results with him over the telephone.

Our family doctor told us that three of George’s ten tissue samples disclosed cancer. He immediately advised against X-ray radiation as he had experienced too many patients with serious rectal burns as a result of this treatment for prostate cancer. He recommended a treatment that would “freeze the thick tissue”, something we had never heard of. We later found out that this treatment is known as cryosurgery or cryotherapy. Our family doctor told us that the advantage of this freezing technique was that if the treatment was not successful or if the prostate cancer came back in six, eight or ten years the patient could then have radiation therapy. He said that some treatments of prostate cancer limited future treatment options if the cancer recurred.

After discussing matters with him, we told him that we would return to Calgary immediately if necessary. He said that it was not necessary to rush home to keep the appointment with the urologist on Wednesday, and that we should reschedule it with the urologist’s receptionist for the following week. He also suggested we should ask that receptionist to start the preliminary steps involved in scheduling the “freezing treatment”, so that time would not be wasted pending our return to Calgary.

Our family doctor asked us to see him in his office as soon as we returned to Calgary to discuss further details and other treatment options with him.

The following morning we again telephoned to the urologist’s office and spoke to his receptionist and told her that we were on the West Coast giving talks and that we would be back in Calgary the end of the following week. She rescheduled our appointment date to the earliest date she could give us, November 29th (the Wednesday after our return to Calgary).
We then explained to her that although we had not made a decision on the type of treatment for George’s prostate cancer, our family doctor had advised us that we should start the ball rolling with respect to treatment options. He had suggested that we should look into “freezing the thick tissue” treatment that was being given to the urologist’s patients. She told us that this treatment’s correct name was cryosurgery and she didn’t know if George would be an eligible candidate for it. She said that the decision would have to be made by our local Cancer Clinic, that she would send George’s records to that clinic and have them call us after the records were reviewed to discuss this and other matters.

On Thursday a nurse from the Cancer Clinic called us in Vancouver. She advised us that she had received George’s records from the urologist’s office. She said that George’s Gleason score was six. Neither of us had ever heard the term “Gleason score” before. She said that it rates the aggressiveness of cancer and that George’s score was middle of the road. She said that three of the six tissue samples showed cancer. It was only later that it hit us that she had talked about six rather than ten tissue samples, the actual number of samples taken.

The nurse told us that it was up to the urologist to decide whether George was eligible for cryosurgery, but it was necessary to have a preliminary meeting with her. We made arrangements to meet with her at the Cancer Clinic on Monday, November 27th.

During the ensuing days, in the tradition that the ‘show must go on’, we gave four public talks on Louis Riel in the Greater Vancouver area. These talks took place at the main public libraries in Vancouver and Port Moody, at the First Nations House of Learning at the University of British Columbia, and to a group of high school teachers who taught history in the Langley School Division.

We also picked up some information at the Tzu Chi Institute for Complementary and Alternative Medicine, a not-for-profit society connected with the Vancouver General Hospital. The Institute then had an integrated program for prostate health.

We initially thought of going to visit Terry’s cousin, a lawyer in Powell River on the Sunshine Coast, that weekend prior to heading to Vancouver Island where we were scheduled to give a talk in Victoria the following Tuesday. However he was not available as he was preparing for an appeal court case to be heard that Monday. As a result we decided to go directly to Victoria for the weekend.

Before heading there we telephoned an old friend of ours in Victoria who had retired there, in order to invite him to the talk we were giving the following Tuesday at the Greater Victoria Public Library. He and his wife invited us to come to their home for dinner the next evening.
On Saturday we took the early afternoon ferry from Tswassen to Schwartz Bay on the outskirts of Victoria, a scenic boat ride through the Gulf Islands to Vancouver Island. That evening we went for dinner to Ray and Donna’s home situated in Cordova Bay overlooking the Ocean. The dinner consisted of savory barbecued beef tenderloin and delicious vegetables followed by fresh fruit and an assortment of cheeses.

The telephone call to Ray and Donna and their dinner invitation were serendipitous. When we arrived at their home and while exchanging pleasantries, George mentioned that while we were in Vancouver he received word that he had been diagnosed with prostate cancer. Ray then said that he had had prostate cancer four years earlier and he heartily added “Look at me, I’ve been cured”. We then recalled a letter from him several years earlier in which he told us that he had prostate cancer but we had no idea of the details, and within minutes the four of us were discussing Ray’s experience with prostate cancer.

At the time he was diagnosed, his cancer was Stage B (this classification is generally no longer used) and his prostate specific antigen (also known as “PSA”) was 9.3. Staging of prostate cancer and PSA are discussed later in this book.

At the time of his diagnosis Ray was a widower and engaged to Donna. He told her that under the circumstances she should break off the engagement. Instead she immersed herself in prostate cancer research. She discussed it with a number of people and then got on the Internet and found descriptions of various treatments. These included radical prostatectomy, conventional external beam radiation and others (referred to hereafter), all of which carried significant risks of horrendous side effects.

Donna provided Ray with her detailed research results and the two of them pored over the data. Initially they found it very confusing because of information overload on various types of treatments. They told us that in their view proton beam therapy was for them the one treatment that stood out above all the others.

Ray reviewed this proton treatment with his urologist who told him that, while it was the “Mercedes-Benz” treatment for prostate cancer, it was not available in Canada. At that time only Loma Linda University Medical Center (“LLUMC”) in Loma Linda, California provided this prostate cancer treatment in a medical setting in the United States.

Ray elected to apply to LLUMC for treatment of his cancer and after being accepted as a patient Ray told us that he and Donna traveled to Loma Linda, a small city east of Los Angeles for consultations and treatment at LLUMC on an out-patient basis. He told us that each treatment period lasted about 45 minutes, and he was able to carry on other activities after each treatment.
Ray is a golfer and belonged to a golf club in the resort area of Palm Springs, some 40 miles east of Loma Linda. Consequently he and Donna stayed in Palm Springs and commuted to and from LLUMC. Ray occasionally played golf over the two-month treatment period. Instead of breaking up their relationship, prostate cancer had brought Ray and Donna closer together and they were married.

They strongly recommended that we check out LLUMC when doing our research. We had never heard of proton beam therapy until that moment, although we knew some years earlier of LLUMC’s renowned worldwide reputation for infant heart transplants.

They told us that the costs of Ray’s treatments had not been covered by his medical plan. Being a Canadian resident, he was under a mandatory government medical plan that has significant limitations of coverage. He advised us to check out our coverage if we chose this type of treatment.

Ray also told us that prior to going to LLUMC his urologist had placed him on hormone therapy. These drugs had caused him terrible side effects including hot flashes, fatigue, and enlarged breasts. Ray jokingly said that due to this hormone therapy at one point he thought of buying a brassiere for himself.

Ray and Donna described LLUMC, the procedures, the treatments and related matters (including the famous balloon discussed hereafter). Ray stated that he had been “cured” and that he had no serious side effects such as incontinence or erectile dysfunction.

During our conversation, George initially shivered internally from fear of discussing his prostate cancer, but calmed down as the evening progressed and Ray related his positive experiences in handling his condition and its successful outcome.

We were quite impressed with the enthusiasm of Ray and Donna for LLUMC and decided that it and proton beam therapy would form part of the extensive prostate cancer research that we were determined to undertake when we returned home a few days later. This serendipitous visit with Ray and Donna uplifted our spirits with its awesome message of hope and healing.
4. A Thoughtful Trip Home

“God grant me the serenity to accept the things I cannot change. The courage to change the things I can. And the wisdom to know the difference.”

-- St. Francis of Assisi, *Prayer of St. Francis*

The last talk of our speaking tour was at the Greater Victoria Public Library on Vancouver Island. It was a successful evening and afterwards we went out for an evening snack with a number of old-time friends who had attended our presentation.

The next morning we took the ferry to the mainland and started the drive back home. The long drive gave us an opportunity to express to each other some of the fears and apprehensions that both of us were experiencing and to review the circumstances leading to the diagnosis of George’s prostate cancer.

George’s biopsy had taken place on October 25, 2000. The urologist had made the appointment at the Prostate Radiology Clinic. This Clinic is situated in the same suite of offices as the Prostate Cancer Institute and is located on the ground floor of the same building where a number of urologists have their offices. In anticipation of the biopsy procedure, the urologist had given George a prescription for antibiotics, which he took prior to and after the biopsy.

The radiologist and his technician, a young lady, carried out the procedures for the biopsy. After the technician performed a conventional ultrasound examination of George’s kidneys and bladder, she advised him that he could go to the nearby bathroom to eliminate the four glasses of water that he had been instructed to drink an hour before his appointment. George asked her if she would be present while the radiologist inserted the needles in his prostate through the rectum. She coyly said that she would be present but would be monitoring the computer screen. Presumably she added that statement thinking that a patient might be embarrassed at the prospect of a member of the opposite sex being present while the radiologist was poking around the patient’s bare bottom.

The radiologist gave George a digital rectal examination (commonly called a “DRE”) after which he inserted an ultra-sound probe in George’s rectum to obtain images of the prostate gland. Next, a prostate biopsy was performed. This involved a biopsy needle device being advanced into the prostate a specified distance to remove tissue samples. Ten samples were taken. George found the procedure painless but accompanied by some discomfort. The sensation of the needle penetrating the prostate gland was like a fingernail being snapped against one’s arm or leg on ten separate occasions.
The radiologist was quite friendly throughout and he, Terry and George chitchatted while he was performing the procedure. During this rather relaxed conversation, George’s knees were almost touching his chin. George asked him what caused prostate cancer. He said it was uncertain, but there definitely appeared to be both heredity and dietary factors. He mentioned that men in Asia had a significantly lower incidence of prostate cancer, but after residing in North America for two generations or less their offspring generally had the same levels of prostate cancer as North American residents. He added that it was unclear whether it was the type of food in or absent from their diet that affected the occurrence of prostate cancer. Since Asians eat very little red meat, he noted that prostate cancer could be related to the consumption of red meat, particularly barbecued meat. He also said that lower levels of prostate cancer in Asia might be due to tofu and green tea in their diet. He also discussed the Mediterranean diet and the significance of lycopene found particularly in cooked tomatoes.

It was then that we were told that the biopsy results would not be available for ten days to two weeks. When we told him about our West Coast speaking tour, he advised us that the DRE and the ultrasound did not indicate any problems. He said he saw and felt nothing of concern, and we should carry on with our trip as planned. He also told us the urologist was on a three-week vacation and wouldn’t be in Calgary when the biopsy report came back from the laboratory.

Shortly after George’s biopsy we left Calgary for our West Coast trip. At the time of our departure we had not received the results of George’s biopsy. Consequently our journey was full of joy and excitement in anticipation of our talks. Our return trip was much different. We had received the diagnosis of George’s prostate cancer while we were in Vancouver and our journey home, which combined feelings of concern and hope, gave us an opportunity to discuss the tasks that lay before us.

On the drive home after our speaking tour we discussed the radiologist’s remarks concerning diet as well as the information pamphlets that we had received in Vancouver from the Tzu Chi Institute (which had an Integrated Care Program for Prostate Health). The Institute was located on the grounds of the Vancouver General Hospital but has since closed due to lack of funding.

Our discussions en route led us to make certain decisions concerning our diet. We decided to discontinue eating red meat; to increase our consumption of cooked tomatoes and green tea; to reduce fat intake; and to make certain lifestyle changes. Diet and lifestyle are discussed hereafter.

We also discussed questions such as what kind of treatments were available; will the treatment chosen be a cure; what side effects would result; what was the likelihood of recurrence of the cancer; what subsequent treatments were available; and like matters.
At the time George’s oldest brother Al had recently been diagnosed with a recurrence of prostate cancer. After his initial diagnosis of prostate cancer, Al had had a radical prostatectomy and had gone cancer-free for the ensuing 12 years. As a result of a rise in his PSA, he had been again diagnosed with prostate cancer. Since this disease is blood-linked, his new diagnosis was prostate cancer notwithstanding that Al no longer had a prostate gland. As a result we knew that prostate cancer can, and it does, reoccur. We decided that our research into prostate cancer would take into consideration the possibility of recurrence and what avenues of treatment would be available if there was a subsequent recurrence of the disease.

We also both agreed that we did not want George to be used as a guinea pig in some experimental study. Consequently we concluded that we would have to do extensive research in order to come to an educated and informed decision as to what treatment George should elect to receive for his prostate cancer.
5. Some Disconcerting Information

“I only ask for information.”

-- Charles Dickens, David Copperfield

On the way home we stopped for a couple of days at our son’s vacation home in Canmore, a town in the Rocky Mountains near Banff, Alberta. Our trip home had given us time to reflect on and discuss George’s diagnosis of prostate cancer.

The following Monday morning, November 27th, we kept our appointment with the nurse at the Cancer Center. She went over George’s pathology report with us, and repeated the advice that she had previously given on the telephone that the report disclosed that three of the six tissue samples were cancerous. We told her that ten tissue samples had been taken, but she said that the biopsy report showed only six samples.

She went over several treatment options with us. These were radical prostatectomy, radiation therapy and cryosurgery (which she called cryotherapy). This was the procedure our family doctor had earlier referred to as “freezing the thick tissue”. She provided detailed information on the cryosurgery procedure.

She also told us of the various side effects that usually result from these treatments. She was an amply endowed, not unattractive woman in her early 40s, and was wearing a form-fitting pink sweater, not a nurse’s uniform. She said that after treatment there was the likelihood that George would have trouble having an erection. She also stated he could have incontinence problems and that side effects might or might not continue for years.

All this time there was a copy of Maclean’s Magazine (Canada’s weekly news-magazine), on her desk with a prominent cover photograph of Pierre Elliott Trudeau, a former Prime Minister of Canada. Trudeau was featured on this cover because he had recently died – of prostate cancer. George was more astonished than distressed.

The nurse mentioned that the urologist George was to see in two days was involved in a trial study related to cryosurgery. If George opted for this treatment, rather than external radiation, it was up to the urologist to make the decision whether George was eligible to participate in this study.

If the urologist found that George was eligible, George’s name would be entered into a computer and the computer would make a random selection of those who were to
receive cryosurgery and those who were to receive external radiation. Neither the doctor nor George would have any say in the selection of the treatment. The selection was solely that of the computer, which would give George a 50/50 chance of receiving cryosurgery or radiation. George asked her if this randomization process meant he was being treated like a guinea pig. She said "no".

She mentioned that the urologist had been part of a prior trial related to cryosurgery in which there were over 70 patients. The purpose of the current study was to compare the outcomes of cryosurgery with those of radiation therapy with respect to localized prostate cancer, i.e. cancer confined to the prostate gland.

She told us that prior to receiving either cryosurgery or radiation, everyone participating in the trial program would be required to undergo a three-to-four month course of hormone therapy. She said that prior to going on the three-to-four month course of hormone therapy, all the patients selected for the study were required to have an appointment with a radiation oncologist. She advised us that due to scheduling constraints if George were to be selected for this study, it would take seven to eight weeks before he would be able to see the oncologist. Adding the time frame for an appointment with the oncologist to the time frame of three to four months of anti-androgen drugs after the appointment with the oncologist, struck us as an inordinate length of time to wait before actually commencing cryosurgery or radiation treatment for the prostate cancer.

Consequently we asked her how long it would take before George would start receiving the actual medical treatment for his prostate cancer. If we made an immediate decision to enter into the cryosurgery study, she said that it would be the end of May or the beginning of June (over six months later) before George would commence actual treatment for his prostate cancer.

We asked her for a copy of George’s biopsy report that she had on her file, the results of which she had discussed with us. She said that she could not give us a copy of his biopsy report and that if we wanted a copy we would have to speak to the urologist about this matter.

She told us that only people accepted into the cryosurgery study could receive this cryosurgery treatment. The reason for this was that the Alberta Government Health Plan did not cover a patient’s costs for cryosurgery. She told us that even so we would not have to pay for the cryosurgery treatment. She said that funding of the study was coming from the National Cancer Institute, as well as the Calgary Regional Health Authority and from others whom she did not name.
With respect to the trial study we received from the nurse a video entitled “Treatment of Localized Prostate Cancer: A Study Group” which she told us to view and then return to the urologist’s office when we had our appointment with him two days later. She also provided us with an eight-page Consent Form, which she told us George would have to sign prior to being accepted into the study.

At the conclusion of the meeting, we asked the nurse about diet and prostate cancer. She told us that diet had nothing to do with the study. We were quite surprised by her reply considering the lengthy discussion about diet that we previously had with the radiologist when George, during his biopsy, asked him what caused prostate cancer.

After we left the Cancer Clinic we reviewed what she had discussed with us. We were appalled at the thought that if George mentally conditioned himself for cryosurgery there was a haphazard chance that a thoughtless machine, a computer, would reject his preference. To us the trial study was a game of chance as to what treatment a participant would actually receive.

It struck us that, in George’s case, a randomization trial could result in his being hit with a double whammy. The first hit was the prostate cancer diagnosis, and the second was the possibility that, if George opted for cryosurgery, the randomization could result in his not receiving the treatment he would have preferred. He would no longer be in control of his own fate and it could result in his receiving radiation, a treatment that his family doctor had recommended against. We were also dismayed at the prospect of waiting half a year or more before George could actually commence a treatment to kill his prostate cancer if he chose to enter into this study.

We were confounded as to why the biopsy report, as she told us, referred to only six tissue samples when ten were actually taken and why she had refused to give us a copy of George’s report. We were stunned at learning of the horrific side effects of all of the treatments she told us about. We were confused and unhappy as a result of this meeting at the Cancer Clinic.
6. Eye-Opening Consultation

“What hell it is to waste long nights in pensive discontent.”
-- Edmund Spenser, *Complaints: Mother Hubbard’s Tale*

The evening after we saw the nurse at the Cancer Clinic we telephoned one of George’s former law partners. Earlier that day a mutual acquaintance had told George that this former partner had been treated for prostate cancer two years before. When we called the ex-partner, he was very helpful in explaining his experience with the disease. At the time he was told that at his age (75 years) he was too old for a radical prostatectomy and therefore he opted for conventional external radiation.

However he soon discovered that he would not receive expeditious treatment in Calgary, even though he had been told that his cancer was aggressive. As a result he went for conventional radiation treatment to the Scripps Clinic in La Jolla, California where he had previously received other medical services. He also gave us the benefit of the research he had done and recommended a couple of books, especially *Prostate and Cancer – a Family Guide to Diagnosis, Treatment and Survival* by Dr. Sheldon Marks. He told us that he was awaiting the results of an appeal of the rejection by the Alberta Government Health Plan of his claim for reimbursement of the costs of his prostate cancer treatments at the Scripps Clinic.

*Prostate Cancer – a Family Guide to Diagnosis, Treatment and Survival,* Dr. Sheldon Marks
http://www.amazon.com/exec/obidos/tg/detail/-/0738208396

The next day we went to see our family doctor, a personable and friendly physician. He always chitchats with us about non-medical matters and we have had a lot of laughs with him, while he dispenses his medical advice with humor and feeling. On a prior visit with him some time before, he greeted us with a bruised face and black eyes. He told us that a few days earlier his car had hit an elk one evening while he was motoring through the Rocky Mountains. His windshield was smashed in and his face was badly cut and bruised. Since it was nighttime and he had a lot of photographic equipment with him, he kept driving with the cold wind blowing through the broken windshield. He became so enthusiastic in telling us about the incident that he briefly disappeared, then returned with photographs of his smashed car and of himself, bloody and battered.

On this current visit he was more solemn and serious, as he reviewed with us the diagnosis of George’s prostate cancer and the available treatments for it. George told him that he was shocked at the cancer diagnosis. He said that George should not have been surprised. Some nine or ten months earlier, when George had seen him for a
routine digital rectal examination ("DRE"), he said he felt a rounding in the prostate gland and had referred George to a urologist to have it checked out.

A short time before he saw the urologist for this referral in March 2000 George’s PSA level was 2.8. After performing a DRE on George, the urologist’s opinion was that the rounding was no problem, and had thereby allayed our concerns as to the condition of George’s prostate.

George told the urologist that he was presently taking Proscar and Terazosin for benign prostatic hyperplasia (an enlarged prostate) with which he had been diagnosed some months earlier. He told George he could go off the Proscar but should continue to take the Terazosin. He also asked George to return in about six months with an up-to-date PSA test for a further check-up after which “I will send you back to your family physician”. George immediately stopped taking Proscar.

In August 2000, we went to see our family physician to obtain a renewal of George’s prescription for Terazosin. Our family physician asked about a renewal of his Proscar prescription as well. We told him that in March 2000, the urologist had stated it was all right for George to discontinue the Proscar. Our family physician disagreed and recommended that George immediately resume taking Proscar. We were confused by this conflicting advice and went to see our pharmacist to get his point of view. He agreed with our family doctor and George resumed taking Proscar in August.

In anticipation of seeing the urologist for his six-month follow-up appointment, George had a PSA test done in September 2000. The urologist saw George in early October, and performed a DRE. He stated that George’s PSA level was now 6.3 and while that was not out of line for his age he was concerned about the significant increase from 2.8 some six or seven months earlier to the current 6.3 reading. It was only some two months later (in December 2000) that we found out that Proscar masks PSA levels to such an extent that for a more accurate reading one should double the PSA values for persons taking Proscar for comparison to normal ranges in untreated men. Using this information, George’s earlier PSA reading of 2.8 when he was on Proscar should have been equated to a reading of approximately 5.6.

In any event the urologist advised George to have a prostatic biopsy and stated that he had already arranged an appointment for him for October 25, 2000 at the clinic in the same building where a number of urologists have their offices.

When we saw our family doctor in late November, he discussed with us various treatments for prostate cancer and their side effects. First of all he advised against watchful waiting due to George’s age and overall good physical condition. Watchful waiting is active observation and regular monitoring of a patient without actual treatment. We told our family physician that we agreed with this advice because of what had happened to
George’s friend Gideon who had been diagnosed with prostate cancer three years earlier. Gideon had decided to opt for watchful waiting and died within two years.

Our family physician then discussed radical prostatectomy and its likely side effects of incontinence and impotence. Incontinence is the loss of urinary control, the inability to retain urine in the bladder or to control urination. We subsequently learned that there are three types of incontinence. Lack of urinary control may be due to one of the following causes:

- Stress incontinence caused by straining, sneezing, coughing, etc. resulting in the unintentional leakage of urine;
- The bladder not being fully emptied after urination, resulting in involuntary dribbling of urine; or
- Complete incontinence caused by a total failure in the ability to control the muscles associated with the bladder and the urethra, resulting in the inability to hold urine in the bladder.

Impotence (also called erectile dysfunction or ED) is the inability to have or maintain a penile erection suitable for sexual intercourse. There are nerves located adjacent to and just beneath the prostate gland that are involved in a penile erection. Impotence will result if these penile nerves are damaged.

Our family physician said that George should not be too concerned about impotence, as there were medical techniques for handling this side effect of prostate cancer treatments. These methods include drugs such as Viagra, and the surgical implantation of penile prostheses, in order to overcome erectile dysfunction. In the case of one type of prosthesis a small “pump” is surgically implanted which may be squeezed in order to make the penis erect.

He said that if we decided to go the route of a radical prostatectomy, the best results occurred when the surgeon restructured the urethra in conjunction with the surgical removal of the prostate gland. He told us that, in his opinion, the best surgeon, and the one in which he had the most confidence, had moved his medical practice from Calgary to Florida. He said that many of the best urologists had left Calgary. Not long before there had been over 40, but currently there were less than 10 urologists in the city.

Our family physician also advised George against conventional external beam radiation treatment. His reason was that a number of his patients returned to him after their treatments suffering severe rectal problems from radiation burns. Rectal burns from
radiation treatment are an additional side effect, over and above incontinence and impotence, that may occur with this treatment for prostate cancer.

He recommended that George consider cryosurgery, which our family physician said would freeze the “thick tissue”. He said that George should not worry about impotence resulting from cryosurgery. He said that if George’s treatment resulted in impotence one or other of the techniques (mentioned previously) could be used to counteract this side effect of the cancer treatment.

We told him what the nurse at the Cancer Clinic had told us about randomization and computer selection relating to the cryosurgery trials, and that George would have only a 50% chance of being selected for cryosurgery. Our family physician said he had never had a patient who wanted cryosurgery that did not receive it, and George should not worry because if he chose cryosurgery he should be able to have that treatment.

On our way home from this meeting, we discussed the various information we had received from our family physician. Our meeting with him had opened our eyes with startling clarity to this inglorious disease. The realization struck home to us that we were neophytes; we had a lot of homework to do before we would have a comprehensive knowledge of all relevant aspects of prostate cancer in order to make an informed decision as to the appropriate treatment for George.

Later that day our daughter Catherine came to visit us with “Logi Bear”, her two-month old, chubby-cheeked son Logan. While George cuddled and rocked his infant grandson, we told Catherine we were in the process of doing extensive research on the various treatments for prostate cancer.

Catherine immediately asked whether she could be of assistance to us in doing the research. We told her, among other matters, about our conversation with our friends in Victoria concerning a treatment at Loma Linda University Medical Center (“LLUMC”). We decided to split up the research work. Catherine agreed to check out LLUMC and its treatment for prostate cancer, while we researched other treatments.
7. Unhappy Campers

“Like one, that on a lonesome road doth walk in fear and dread.”
-- Samuel Taylor Coleridge, *The Ancient Mariner*

We spent the next morning reviewing the Consent Form and the video titled “Treatment of Localized Prostate Cancer: A Study Group” with respect to a trial study to compare cryosurgery with external radiation. We had received these items from the nurse at the Cancer Clinic and she had told us to review them prior to seeing the urologist, and to return the video to his office when we went for our appointment. She also said that if the urologist found George eligible to participate in this investigative study, George would have to sign this Consent Form.

In playing the video we found that George’s urologist was extensively involved in this trial as a co-principal investigator. In the video his urologist discussed cryosurgery, while a radiologist discussed radiation therapy, and an oncologist discussed various aspects including the randomization process.

The oncologist stated that cryosurgery was “a relatively new technology which is currently being explored”. He added that before initiation there would be a number of prostatic biopsies to ascertain if the cancer is confined to the prostate gland, since only patients whose disease was so confined were eligible to participate in the study.

The oncologist also said that all participants in the trial would be required to take hormone therapy (i.e. anti-androgen drugs) for three or four months prior to treatment, whether it was cryosurgery or radiation. He also emphasized that only a participant in the study would be allowed to receive cryotherapy (if of course the computer selected him for that treatment).

The Consent Form stated that prior to receiving either cryosurgery or radiation, everyone participating in the trial program would be required to undergo a course of hormone therapy for a maximum of four months. This meant receiving anti-androgen drug medications such as Lupron or Zoladex, with a view to shrinking the tumor and the prostate gland. In addition to those drugs, after the initial injection there would be a four-week treatment of a further anti-androgen drug (either Flutamide or Nilutamide). It pointed out some of the side effects caused by these various anti-androgen drugs.

This Consent Form indicated that some early side effects during radiation could include tiredness and lethargy; bladder irritation and spasms; frequency of nighttime urination with slowing of the urine flow; rectal irritation with burning and aggravation of hemorrhoids and occasional blood in the stool, etc. It stated that these early side effects would settle down and go away once the radiation was complete.
The Consent Form disclosed that a patient could suffer long term and possible permanent side effects that could occur months to years after the radiation was complete and may not disappear. The Form indicated that impotence averaged about 50%. It listed other long term and possible permanent side effects in varying degrees including bladder shrinkage, stress incontinence (urinary leakage); complete incontinence; rectal irritation with bleeding; rare bowel damage causing perforation or obstruction for which surgery may be required, and others.

With respect to cryosurgery the Consent Form listed a number of potential side effects and transient complications. Some were more serious than others, and some occurred more frequently than others. The Form indicated that the risk of impotence was at least 67% in the first six months following the surgery. It also stated that recent experience indicated that the impotence rate was as high as 100%; and that while nerve regeneration may result in some men regaining their potency, the impotency is expected to be permanent in most men.

A prominently featured article appeared in the *Calgary Herald* daily newspaper in December 2000 relating to this randomized trial at the local Cancer Center. The oncologist head of the Cancer Care Program said “This has put us on the map”. The article stated that the down side is that after cryosurgery the incidence of impotence was around 100%. “That’s part of the deal”, the newspaper quoted the oncologist as stating.

The Consent Form indicated that some of the other potential side effects of cryosurgery included partial or complete incontinence; failure to control the cancer; a numb penis; an unstable bladder; bleeding; serious infection; sloughing of tissue into the water passage of the penis. This sloughing of tissue may require drainage of the bladder by a catheter and, occasionally, a transurethral resection. Other sources call a transurethral resection, which is a surgical procedure, the Roto-Rooter Procedure.

That afternoon we went for our appointment with the urologist. When we arrived at his office his waiting room was full. His receptionist, who had scheduled our appointment, told us that she had no record of our appointment in her book and asked us who had arranged it. We explained to her that she had made it when we telephoned her from Vancouver. She told us to sit down and gruffly said that she would check the doctor’s schedule.

We sat down not knowing whether we would get to see the urologist that day. As a result, we took out and reviewed the notes we had made during our telephone conversation with her when we were in Vancouver. We went back to the reception desk to show her our notes confirming the appointment she had made for us. She said she didn’t want to see them and curtly instructed us to sit down and she would get us in to see the urologist. Her manner was abrupt and snippy.
When we sat down we saw a printed notice in the reception area titled “ATTENTION ALL PATIENTS”. It stated in part:

“We make every effort to deal with you promptly and courteously… Failure to treat our staff with courtesy and respect will result in you being asked to find another urologist.”

Both urologists who shared this office space had each personally signed the notice. Based on our experience, this notice apparently gave the staff a license to be on the surly side with patients, particularly when the staff had made an egregious error.

While we were sitting in the reception area, one of the other patients asked the receptionist if she had the doctors’ appointment schedules computerized. She said that she previously did so, but since her computer system had broken down twice and had lost all the appointments, she had stopped using her computer for recording his schedule.

When we saw the urologist, he advised us that three out of ten of George’s tissue samples were cancerous. We told him that the nurse at the Cancer Clinic had told us that the biopsy report showed only six tissue samples. Contrary to the nurse’s advice to us that there were only six samples, he confirmed that the biopsy report did indeed show ten tissue samples were taken and showed the results of all ten samples. He then went over the report with us in detail and he advised us that George’s Gleason score was six. He stated that this indicated that the cancer was in the middle range.

He immediately advised against George opting for “watchful waiting”. He then went through various treatment options with us, namely radical prostatectomy, external radiation, cryosurgery, and their side effects.

Radical prostatectomy is major invasive surgery that removes the entire prostate gland and may include removal of seminal vesicles. In reviewing radical prostatectomy with us, he advised us of some of the side effects.

These include a high risk of subsequently being unable to have a penile erection as well as possible urinary leakage. If dripping urine occurred, it might be dealt with by surgery. Stress incontinence (caused by coughing, sneezing or passing gas) could result in a few drops of urine for which perhaps one might wear one diaper pad a day.

This surgery would require hospitalization for five days. We were told it was not very painful afterwards and 50% of patients did not require painkillers. A catheter would be placed in the bladder for about 10 days after surgery. He told us that the advantage of this surgery was it cut out the cancer, although recurrence was possible.
We explained to him that we were aware of the possibility of recurrence as George’s oldest brother Al had undergone a radical prostatectomy some 12 years previously. Recent rising PSA levels had indicated a problem and a few months earlier Al had been re-diagnosed with prostate cancer, notwithstanding the fact that his prostate gland had been removed 12 years before. The urologist said that the cancer may have been lying dormant for years and something had triggered the reactivation of the prostate cancer.

With respect to possible radical surgery, George showed the urologist the large (somewhat triangular) scar on his abdomen situated between his navel and his penis. This scar was the result of an operation when George was a five-year old child in Winnipeg.

As an aside, George told him that he remembered being in the Winnipeg Children’s Hospital for the operation when King George VI and his wife Queen Elizabeth (the Queen Mom of Queen Elizabeth II of England) visited him and the other children on their cross-Canada tour in 1939. All of the hospitalized children were given balloons with pictures of the King and Queen on them, and each balloon had cardboard feet enabling it to stand upright.

The urologist inspected George’s abdominal scar and immediately said he would advise against radical surgery. He then added that if he was pressed into performing a radical prostatectomy on George he could operate, but if he encountered a problem with scar tissue he would abort the operation and sew George up.

He then discussed external radiation treatment with us. We were advised that radiation treatments would take place at the local Cancer Clinic on a daily basis, five days a week from Monday to Friday for seven weeks. The actual daily treatment itself would last only a few minutes. The total time involved each day would be 30 to 45 minutes. As for side effects we were told there should be nothing noticeable in the first three or four weeks. Thereafter there would be irritation of the bladder and the rectum, more frequent urination and perhaps an urgent need to urinate. He added that the “back passage” would also be affected. These problems, he said, should clear up within three to four weeks after treatment.

Longer-term side effects, we were told, may include impotence in about one third of patients and this was less than would occur with surgery. As well some patients continue with incontinence problems.

After discussing external radiation treatment with us, he very briefly reviewed brachytherapy, which he said was not available in Calgary but was available in Edmonton.

He then dealt with cryosurgery. In Calgary, cryosurgery is the use of liquid nitrogen probes to freeze a particular organ to extremely low temperatures to kill the tissue, including any cancerous tissue.
He said that cryosurgery was an “easy treatment”. He also told us that the only way at this time for George to receive cryosurgery in Calgary was to participate in a randomized trial comparing cryosurgery with external radiation. He said that the cryosurgery-radiation trial was the “only kind of its study in the world”.

He advised us that cryosurgery is given under spinal or general anaesthetic, and the patient is usually sent home one day after the freezing. He told us that a catheter is placed in the bladder through the skin of the lower abdomen to drain the bladder. The Consent Form stated that a suprapubic catheter is required until the patient is able to void normally (usually in 10 to 14 days). The video stated that this catheter is required because after freezing the prostate swells and the patient is unable to pass urine through the penis.

He stated that side effects of cryosurgery include frequent urination, urinary leakage in one-to-two percent of cases, total impotence in up to 50% of patients with some recovering in two to three years. He added results of cryosurgery are encouraging and that the procedure could be repeated. He also said that if radiation failed, cryosurgery could be used thereafter.

He confirmed that it would be necessary for each participant, whether he received radiation or cryosurgery, to take anti-androgen drugs. He told us that the Alberta Government Health Plan did not cover the procedure (presumably, we believed, because it was experimental). According to our understanding, this study was being funded by the Canadian Cancer Society, the Calgary Prostate Cancer Institute and others (although we were never told who these others were).

He told us that George would not have to pay for the cryosurgery treatment if he was chosen by the computer. With respect to cryosurgery, he confirmed that George would be eligible for this treatment if the computer selected him. He added that the protocol for this study required that there be a randomization process to determine on a 50/50 basis those who would receive cryosurgery and those who would receive radiation therapy. A computer, not the patient or the doctor, would determine which treatment George would receive.

We told him that our family doctor had told us that all of his patients who had opted for cryosurgery had received it, and that George should have no trouble getting this treatment if he wanted it. The urologist said that that was not correct and our family doctor was wrong since the computer had the final word on who received which treatment.

Although undoubtedly a different computer is used, an amusing aside is that only a short time earlier we had overheard his receptionist (who had lost our appointment time) state that she no longer scheduled appointments in her computer because it had crashed two times and she had lost all the appointment information.
The urologist then told us that it was important that patients like George participate in this investigational study in order that future prostate cancer patients would benefit from the information obtained from this study. He also said the trial could result in the Provincial Government Health Plan paying the costs of cryosurgery treatment for others in the future.

We asked a number of questions of him, including the stage of George’s cancer. He said that it was T1c. Clinical staging of prostate cancer is referred to later in this book. We asked him the size of George’s prostate gland. He said, off the top of his head, that the volume of George’s prostate was 39.

We asked him when George would commence the actual treatment for his prostate cancer if he chose to participate in this randomized trial. He said that because of the time elements involved in obtaining an appointment with the radiation oncologist, and the months of required hormone treatments, the earliest that George would undergo cryosurgery or start radiation treatment would be April or May. We told him that the nurse at the Cancer Clinic had advised us that the date would most likely be the end of May to sometime in June. He said that her date was probably more accurate.

This would mean that George would not receive the actual treatment for his prostate cancer for some six to seven months after this consultation. This in effect meant that in order to be treated by May or June, he would have to make an immediate decision. Any delays in making a decision would of necessity delay the start of the actual treatment of George’s prostate cancer.

We told the urologist that since we had just returned from the West Coast the previous weekend our research into prostate cancer and its treatments was still in progress. Accordingly we would like to come back and see him in about 10 to 14 days as we would undoubtedly have a number of additional questions to ask him before we could make an informed decision as to George’s treatment.

He said that it was not possible to see him that soon, and the earliest that he could see us again was the latter part of February (some three months later). We said that in that case we would like to ask him questions on the telephone in ten days or two weeks. He said that this could not be done because he did not take phone calls. We then said that we would email him the questions resulting from our research, to which he replied that he did not use email.

He told us that he was overworked, that he still had one more patient to see (it was now 6:00 p.m.), after which he had two hours of paper work to do, and he did not see much of his wife. He told us that several years ago there were 40 urologists in Calgary and now there was only nine.
He then told us that we could speak to the nurse at the Cancer Center or to his receptionist with respect to any questions we had. We found neither of these suggestions acceptable, since we had no confidence in receiving informed and knowledgeable replies to any questions that we might direct to them. The nurse had misread George’s biopsy report, and when we asked for a copy of it she had refused to provide one. A medical report is the property of the patient, and furthermore we had wanted to review George’s report prior to seeing the urologist but due to the nurse’s refusal we had been unable to do so. As for his receptionist, she had lost our appointment time and we had found her to be unfriendly and abrupt.

At the end of this meeting we asked him for copies of George’s biopsy report and his PSA report. Since his receptionist had left for the day, he made the copies for us. In an endeavor to chitchat with him during this activity, we told him of our trip to the West Coast and about our talks there. Our small talk with him was mostly one-sided, and we left immediately after receiving the copies of the reports.

During our consultation with the urologist, he never once mentioned to us proton beam therapy as a treatment for prostate cancer, and neither had our family physician or the nurse at the Cancer Clinic. We did not raise the matter with them as we were still in the very early phase of our research into various treatments for prostate cancer, and we knew that we still had a lot of work to do to familiarize ourselves with prostate cancer and its treatments.

When we arrived home from this meeting, we reviewed George’s biopsy report and we found that it showed a clinical stage of T2c (rather than the T1c stage given to us by the urologist); and further that the gland volume was shown as 37 (not 39 as stated by him). These discrepancies raised immediate questions in our minds. We did not know the significance of these inconsistencies and the urologist was not available to discuss these questions with us for some three months.

With respect to stage T2c our subsequent research indicated this to be detection by touch (by a DRE) of a palpable tumor in both lobes of the prostate (the left side and the right side). On the other hand stage T1c is a non-palpable tumor. We were subsequently told at Loma Linda University Medical Center that the use of T2c as an international medical term for a stage of prostate cancer had been discontinued many months before George’s biopsy.

At the time George had the DRE, ultrasound and biopsy on October 25th, the radiologist had told him that he felt and saw no problem. He made no mention of a palpable tumor and said that there was no reason we could not leave on our West Coast tour, and consequently we left without any concern about the matter.
When we left the urologist’s office on November 29th we were again disconcerted to find that if George did indeed wish to have cryosurgery an inanimate machine (a computer) would have the power to determine his fate. We also felt uncomfortable that the urologist (whom we had not selected but to whom we had been referred) was so intimately involved in the trial study fearful (perhaps unjustifiably) that his involvement might subconsciously or otherwise have an influence on our treatment decision. We were apprehensive concerning the requirement to take hormone therapy drugs, with their accompanying abysmal side effects, for up to four months prior to commencement of either treatment in this trial.

We were taken aback at the length of time that it would take before George actually received treatment for his prostate cancer under this study. We were astounded that, notwithstanding our rudimentary knowledge of a potentially fatal disease, we would be unable to see or talk to this urologist for upwards of three months.

That evening we were unhappy campers.
When we returned home after seeing the urologist we received a telephone call from our daughter Catherine telling us that she had received a brief email from Loma Linda University Medical Center (“LLUMC”). The email stated that a patient’s medical records pertaining to the diagnosis would have to be reviewed to determine if he was a possible candidate for proton beam treatment of prostate cancer. It added that if a mailing address was given, a packet of information would be sent for review by the patient.

When we returned home after seeing the urologist we received a telephone call from our daughter Catherine telling us that she had received a brief email from Loma Linda University Medical Center (“LLUMC”). The email stated that a patient’s medical records pertaining to the diagnosis would have to be reviewed to determine if he was a possible candidate for proton beam treatment of prostate cancer. It added that if a mailing address was given, a packet of information would be sent for review by the patient.

After our distressful experience earlier that day, we suggested that Catherine ask them to send the information packet. We also told her that we now had copies of George’s biopsy and PSA reports that we would give to her so that she could fax them to LLUMC to see if he would qualify for this treatment.

We now devoted all our time and attention to educating ourselves on prostate cancer, its various treatments, and their side effects. We wanted to find out as much as we could about this condition to help us determine what we ourselves considered the most appropriate treatment for George. We conducted in-depth research that gave us a broad understanding of various aspects to consider in arriving at our decision. During this process we encountered many terms relating to prostate cancer that were unfamiliar to us or required clarification. In this respect, we have prepared a Glossary in layman’s terms of a number of words that we encountered in our research or that are relevant to prostate cancer. This Glossary is set forth in Appendix A found at the back of this book.

This Chapter gives a brief outline of some research sources, resource services and support groups that we found. We have written more detailed information on this and other items in another book that we have co-authored entitled

_Prostate Cancer - Treatment and Healing_, George and Terry Goulet
http://www.fabjob.com/prostatecancer.asp

Research Sources

Our principal research on prostate cancer included a number of sources.
Friends and Relatives

We contacted a number of friends and relatives from coast to coast, especially those who had undergone treatment for prostate cancer, in order to learn from their experiences. They all provided us with their unique insight into this dreaded disease.

Books on Cancer

Public libraries have books that specifically deal with cancer, including prostate cancer. As well as those set forth in Appendix B, some examples of books are:

- *Prostate Cancer – a Family Guide to Diagnosis, Treatment and Survival*, Dr. Sheldon Marks  

- *Prostate Cancer*, Dr. S. Larry Goldenberg and Dr. Ian M. Thompson  

- *Prostate Cancer – a Non-Surgical Perspective*, Dr. Kent Wallner  

Books on Hope and Healing

We found that it was helpful to also read books with a positive message about hope and healing. Some books that deal with serious illness and healing that we found valuable include:

- *Love, Medicine & Miracles*, Dr. Bernie S. Siegel  

- *Peace, Love & Healing*, Dr. Bernie S. Siegel  

- *Anatomy of an Illness*, Dr. Norman Cousins  

On-line Materials

We found an abundance of material on prostate cancer available on the Internet, which is accessible via the World Wide Web. The task is to determine which sites provide reliable, unprejudiced, and current information. It is particularly important to determine the source of a Web site since many sites are owned, sponsored or financed by drug
companies and their primary concern may be to promote the sale of their products. Some of the Web sites that we found in doing our research include those set forth in Appendix C of this book.

**Articles and Pamphlets**

Many articles and pamphlets deal with cancer and prostate cancer. However, in general they do not provide detailed or extensive information; rather they provide a synopsis of the subject matter. A list of a few of the available articles and pamphlets is set forth in Appendix D of this book. In addition many universities and hospitals have medical libraries containing various medical journals, which have articles on prostate cancer. Some of these journals are available on the Internet but may require a password to access them.

**Video Materials**

Prostate cancer institutes and cancer clinics frequently have videotapes available on prostate cancer and various related aspects. Some of the tapes we viewed are set forth in Appendix D of this book.

**Information From Experts**

In addition to discussing George’s prostate cancer diagnosis with our family doctor, the urologist, and the nurse at the Cancer Clinic, we received helpful information from other medical and health care professionals. One of those whom we met with was our pharmacist to get his views, particularly with respect to hormone therapy.

Prior to seeing him, we had naively and mistakenly presumed from our meetings at the Cancer Clinic and with the urologist that hormone therapy (the use of anti-androgen drugs) was invariably a part of all prostate cancer treatments. We told him that we were contemplating going away for treatment, and asked him if he could fill a prescription from a United States physician. He said he could not as he could only accept prescriptions from local doctors.

Consequently we contacted the Intake Coordinator at Loma Linda University Medical Center (where we were thinking of going for George’s treatment) to find out what anti-androgen drugs we would need a prescription for if we decided to go there for his treatment. She in turn discussed the matter with a staff doctor in the Department of Radiation Medicine. She told us that if George elected to receive proton beam therapy at Loma Linda, in his circumstances it was not necessary for him to take anti-androgen drugs if he was not already taking them. We were delighted to here this as we were appalled at the horrendous side effects caused by these drugs. As it turned out, George never was prescribed and never did take these hormone therapy drugs.
Our pharmacist was also helpful in providing information to us on the effects of the medication Proscar on George's PSA readings. In December, prior to commencing his actual treatment for prostate cancer, George was asked to provide a current PSA report. When the PSA report came back it showed that his PSA had dropped from 6.3 in September to 3.3 in December. We were amazed at this significant reduction and our pharmacist provided us with information that clarified this change.

The background to this development was that George had been taking Terazosin and Proscar for an enlarged prostate for several years before being referred to the urologist in March 2000. George's PSA level was 2.8 when he saw the urologist who performed a digital examination and told him he could feel nothing. During this visit he told George to continue taking Terazosin and that he could discontinue taking the Proscar. The urologist then told George that he wanted him to have a PSA test in six months, after which he would re-examine George before sending him back to his family doctor.

However about two or three weeks before the ensuing PSA test in September 2000, George had resumed taking Proscar on the advice of his family physician. The September test showed a PSA level of 6.3. Since George resumed taking Proscar around the end of August, he had been taking Proscar for about 4 months prior to the subsequent December 2000 PSA test in advance of commencing his treatment for prostate cancer. This December test showed a PSA level of 3.3, a substantial decrease from the September 6.3 level only three months earlier.

We found out from our pharmacist that the current edition of the *Canadian Pharmacists Association Compendium of Pharmaceuticals and Specialties* stated the following with respect to Proscar (also known as finasteride):

> “When PSA laboratory determinations are evaluated, consideration should be given to the fact that PSA levels are decreased in patients treated with finasteride. … Therefore, in typical patients treated with finasteride for 6 months or more, PSA values should be doubled for comparison to normal ranges in untreated men.”

The printed information that the drug manufacturer enclosed with this medication stated that Proscar “can alter PSA values” but did not give the specific information quoted above that the PSA values “should be doubled”. We are of the opinion that the printed information should have been more specific in its wording and stated the same wording as was in the Compendium.

As we progressed through our research, we learned that discretion and prudence are required. One should be wary as to the origin, accuracy, and impartiality of the material that is reviewed. It is advisable to consider carefully and make a judgment as to the source and the reliability of the information, any sponsors that may be involved, what
agenda and bias they may have, their credentials, their relevant personal experiences, whether a treatment is proven or experimental, and similar matters.

The Internet is in large part ungoverned and there are few restrictions on who may input data and on that data itself. One should be particularly vigilant in assessing information obtained on the Internet. Since many sites are owned or funded by special interest groups with their own agendas, it is advisable to find other unrelated sources in order to verify material.

We generally have found that couples who did comprehensive research on prostate cancer had a better understanding of this condition and were more confident in dealing with it.

**Resource Services and Agencies**

There are various societies, institutes, centers and agencies that provide services for prostate cancer patients. These services may include diagnosis, treatment, emotional counseling, and the like. Many of them also provide videos and brochures on prostate cancer. A list of the national offices of number of cancer agencies and institutions in various countries is found in Appendix E herein.

**Sources of Support**

**Support Groups**

Support groups can be another source of information and assistance before, during and after treatment for prostate cancer. A local cancer clinic, hospital or prostate cancer institute can assist in locating the nearest group. Groups are found in nearly every major and mid-sized city in North America and in many cities in other parts of the world. A support group should not only provide camaraderie and knowledge, but also hope and encouragement. Unfortunately members of some support groups may dwell on negative aspects and do not contribute to a positive environment; if this is the general prevailing attitude one should look elsewhere for constructive support.

There are national support groups in the United States for prostate cancer, some with chapters in Canada.

**US TOO, International Inc.**

[http://www.ustoo.org](http://www.ustoo.org)

Men who have prostate cancer

**Telephone:** (800) 80-USTOO (808-7866)
**Man to Man**
A support group that was approved as a national program by the American Cancer Society (“AMC”) in 1993.

**Telephone:** (800) ACS-2345 (227-2345)

**Prostate Cancer Support Network**

**Address:** Suite 402, 300 W. Pratt St.
Baltimore, Maryland, 21201

**Telephone:** (800) 828-7866

There is a national association of prostate cancer support groups in Canada.

**Canadian Prostate Cancer Network**

[http://www.cpcn.org](http://www.cpcn.org)

**Address:** P.O. Box 1253
Lakefield, ON
K0L 2H0

**Telephone:** (705) 652-9200 or 866-810-CPCN (2726)

**Fax:** (705) 652-0663

There is also the Brotherhood of the Balloon that is discussed later in this book.

**Family and Friends**

Other areas of comfort and encouragement one should rely on are family and friends. They are generally sympathetic and, in our own experience, will offer assistance and unqualified emotional and spiritual support. Our children were and continue to be a font of love for us. After George’s diagnosis they even offered to help us financially with the cost of his treatment, which fortunately was not required by us.

During the course of George’s treatments (which took place some 1,500 miles from our home) three of our children and two of our small grandchildren came to visit us in California. We also took a weekend off between treatments to fly home to Calgary for another daughter’s wedding. This provided us with an opportunity to have a festive reunion with our five children and our grandchildren.

We also had visits in California with George’s sister and brother-in-law from Manitoba and with a number of friends from California, Canada and England. These reunions as well as frequent long-distance telephone calls with our loved ones and friends provided us with family support and lifted our spirits during the course of George’s treatments.
9. Overview of Prostate Cancer, Related Tests and Procedures

“But how I caught it, found it, or came by it, what stuff ‘tis made of, whereof it is born, I am to learn.”

-- William Shakespeare, *The Merchant of Venice*

Prostate cancer is a disease of the prostate gland. This chapter gives a summary of this organ and its function as well as a summary of prostate cancer, its likely causes and symptoms. Prostate tests and diagnostic procedures for prostate cancer are also briefly outlined.

We only learned about much of this information after George had been diagnosed with prostate cancer. We now know that it would have been beneficial to us if we had been more knowledgeable of this subject matter prior to his biopsy.

The Prostate Gland and Prostate Cancer

Prostate Gland

The prostate, the seminal vesicles and the testicles are the primary male sex organs. The prostate gland is the size and shape of a walnut, weighing about one ounce. It surrounds the upper part of the urethra that carries urine from the adjacent bladder and semen through the penis. The prostate gland is situated deep within the body cavity and is, together with the seminal vesicles, the primary source of semen that carries the sperm that is ejaculated through the urethra during sexual intercourse.

Cell Growth

The human body contains countless cells (microscopic complex units of protoplasm). Cells are basic structural and functional units and consist of cytoplasm and a nucleus enclosed in a membrane. If cells divide in a disorderly and uncontrolled manner, too much tissue is formed and a tumor develops. A tumor may be benign (non-cancerous) or malignant (cancerous). Urination difficulties may result from an enlarged prostate, caused by a tumor, pressing against the urethra and the bladder. In the prostate, a benign tumor is called benign prostatic hyperplasia or BPH.
Prostate Cancer

Prostate cancer, a strictly male disease, is a malignant growth in the prostate gland as a result of an abnormal and uncontrolled division of body cells. These cancer cells can enter the body fluids (the blood and lymphatic system) and transfer to and start growing in other body sites. This transfer process is called metastasis and the new site is called a secondary cancer site. At the present time, only a biopsy of prostate tissue samples can discover early stage prostate cancer which is microscopic. Although a tumor may be felt by a digital rectal examination ("DRE") it is still necessary to have a biopsy to determine if it is benign or malignant. Prostate cancer is not contagious and if treated early it can be cured. However if not diagnosed or treated early, prostate cancer can be fatal.

Symptoms of Prostate Cancer

It is possible for a man to have prostate cancer without his knowledge and without any apparent indications. However, as the cancer grows symptoms will likely manifest themselves. Examples of symptoms that may be experienced are frequent urination (especially at night), pain or difficulty in urination, painful ejaculation, blood in the urine or semen, erectile dysfunction, recurring pain in the lower back or hips. Other non-cancerous disorders, such as BPH or prostatitis (an infection of the prostate gland), may exhibit similar symptoms. Consequently men having these symptoms should undergo a PSA test followed by a DRE.

Probable Causes of Prostate Cancer

The causes of prostate cancer are not definitively known. There are different types of prostate cancer; most grow at a very slow rate, while others may be more or very aggressive.

The probability of a man developing prostate cancer increases as he grows older. About one in every three men over the age of 50 has prostate cancer. The average age for a sample of 685 men forming part of a prostate cancer support group that George belongs to was 66.3 years at the time they received treatment. However 18.8% of these men were under the age of 60.

There is strong evidence of a hereditary factor that increases the chances of developing this disease. George’s oldest brother died from prostate cancer and another brother has recently been diagnosed with it. It is thought that this hereditary factor can be passed down through the female as well as the male side of the family. Accordingly if one’s father, brothers, or uncles have had prostate cancer it significantly increases a person’s risk for contracting this disease. According to the National Cancer Institute prostate cancer is more common in African-American men.
Environmental factors which many consider significant contributors to the development of cancer are smoking, pesticides, chemically hazardous occupations, toxic substances and lifestyle. Many believe that a diet high in fat increases the danger of developing prostate cancer. Another contributing factor to cancer is the failure of the immune system to adequately respond to risk factors, whether external or internal. It is possible that there may be several causes that are the underlying basis for many cancers.

**Prostate Tests and Diagnostic Procedures**

There are a number of medical tests and procedures with respect to the prostate. The following provides a brief outline in layman’s terms of pertinent items.

**PSA Test and DRE**

A PSA test is a test that measures in ng/ml the amount of prostate specific antigen (a protein secreted by cells of the prostate gland) in the blood. A high PSA level may be an indicator of an irregularity in the prostate gland, either benign or malignant. Conversely there is no certainty that a low reading indicates the absence of cancer. It should be noted that there are factors that can result in either an elevated or artificially reduced PSA reading. Furthermore on its own a PSA test cannot diagnose cancer, but a high reading may be a sign of potential problems.

A digital rectal examination ("DRE") is performed by a physician inserting a lubricated-gloved finger into the rectum of a patient in order to palpate the prostate gland through the wall of the rectum. This examination is to find out if there are abnormalities or tumors that can be felt in the prostate and the rectum. Because a PSA reading may be affected by a DRE, the blood for the PSA test should always be taken before, not after, the DRE. If a DRE indicates anything out of the ordinary, regardless of the PSA test results, further prostate testing should be made to determine the cause.

After completion of treatments for prostate cancer, patients should continue to have PSA tests followed by DREs in order to watch for possible reoccurrence of the cancer.

**Free PSA Test**

“A free PSA test may assist in determining whether or not it is advisable for a man to undergo a biopsy. This recently developed test measures the percentage of free PSA to total PSA in the blood. There are two forms in which PSA circulates in the blood; free or bound to a protein molecule. The lower the free PSA is in comparison to the other PSA (that is bound to a protein molecule) the greater the risk that cancer is present in the prostate, and vice-versa.
Ultrasound Imaging

The noninvasive imaging of internal organs using high frequency sound waves is called an ultrasound. A small probe is inserted into the rectum in order to perform a transrectal ultrasound (also called a TRUS) of the prostate for visualization of any abnormalities. This imaging is unable to determine whether an irregularity is benign or cancerous.

Biopsy

A biopsy is an invasive procedure to remove tissue samples for microscopic examination by a pathologist. A TRUS/P is used to guide transrectal needle biopsies of the prostate gland to remove a number of samples of prostate tissue. This procedure may cause complications such as infection, pain or blood in the rectum, urine or semen. In George’s case he incurred only a mild feeling of discomfort during the biopsy and had no after effects from it. There is always the chance (some sources say up to 25%) that the samples taken may miss the cancerous tissue resulting in a false negative report being issued.

Staging

The stage of a cancer is its size and physical extent and is assigned by the examining pathologist. Since the stage affects treatment options, the patient should ensure that he knows what his own is and that he understands staging generally. The most popular staging system, known as the TNM System, uses stages T, N, and M. Stage T deals with primary tumors; stage N with the lymph nodes; and stage M with metastasis. George’s stage was T1c (a tumor found by a needle biopsy) and is determined rather frequently due to the number of men having biopsies pursuant to elevated PSA levels.

The Calgary radiologist's report with respect to George’s biopsy indicated his clinical stage was T2c. We were subsequently advised by the Calgary urologist and both of the doctors we consulted at Loma Linda University Medical Center (“LLUMC”) that George’s stage was actually T1c, not T2c. We were surprised by this mistake in George’s biopsy report, particularly when we learned later that T2c as a stage had been abolished some time prior to his biopsy.

Gleason Score

A person diagnosed with prostate cancer should insure that he finds out what his Gleason score is. This score, also known as the grade, is the method for measuring the potential rate of growth or aggressiveness of prostate cancer. Microscopic examination of tissue samples to determine the pattern of cancer cells is done by a
pathologist. Two numbers, each from one to five, are assigned to the two most predominant patterns based on cellular differentiation. The sum of these two numbers is the grade or Gleason score. Scores of 2 to 4 are considered low grade (less aggressive) - scores of 5 to 7 are considered middle grade (moderately aggressive) - scores of 8 to 10 are considered high grade (most aggressive). George’s Gleason score was a middle grade 6 (3+3).

**PSA Density**

While not a sure method for ascertaining its existence, some consider that PSA density may determine whether one has prostate cancer or BPH. The volume of the prostate (as determined by an ultrasound) is divided into the PSA level to calculate the concentration of PSA in the gland. The result of this calculation is referred to as the PSA density, with a lower percentage indicating the likelihood of BPH and, and a higher percentage pointing to the possibility of prostate cancer.

**PIN**

It is believed by some doctors that the presence of high-grade prostatic intraepithelial neoplasia (better known as PIN), found by the microscopic examination of tissue samples taken in a biopsy, may signal the future possibility of prostate cancer. Further PSA tests and biopsies at regular intervals may be recommended by a urologist if high-grade PIN is present.

**Diagnostic Imaging Techniques**

There are imaging techniques that assist in diagnosis and treatment planning for prostate cancer. The most commonly used methods are CAT scans (Computerized Axial Tomography), MRIs (Magnetic Resonance Imaging) and PET scans (Positron Emission Tomography). These methods look inside the body and produce internal images that assist in planning and implementing a treatment program for a particular patient.

**Bone Scan**

Bones are viewed by this body-imaging technique which uses a radioactive substance injected into the bloodstream. This method is known as a bone scan, and while it may identify abnormalities in the bones (which may indicate metastasis) it is of no assistance with respect to identifying localized prostate cancer, since the prostate gland has no bones.
10. Types of Treatments for Prostate Cancer

“The most important medicine is tender love and care.”
-- Mother Teresa

When George was diagnosed with prostate cancer, we felt totally inadequate because we knew so little about this disease. This Chapter provides a brief summary in layman’s terms of various treatments we found in doing our research on prostate cancer. We have dealt in more detail with our research in our companion book referred to in a previous chapter.

In doing our research we found a number of treatment options available for prostate cancer, some considered mainstream, some experimental, and others complementary or non-conventional. It is our view that the patient, not a doctor, should make the final judicious decision on his form of treatment, after extensive research and consultation with qualified medical professionals. One should keep in mind that a medical specialist may have a bias towards his own specialty - a radiation oncologist may favor radiation; a surgeon may favor radical prostatectomy; and an urologist who mainly performs cryosurgery may favor this procedure; and so on. To find the most appropriate treatment for him, a patient should obtain and rationally assess information from other prostate cancer patients, medical professionals, medical journals, the Internet, and other resource material.

Short descriptions of the treatments that we reviewed follow. However it should be noted that if the cancer is not localized and has spread, the choice of treatments is more limited.

**Radical Prostatectomy (Radical Surgery)**

Radical prostatectomy is the removal of the prostate gland and seminal vesicles by means of an incision in the abdomen (retropubic prostatectomy) or by way of an incision between the scrotum and the anus (perineal prostatectomy).

This major invasive surgery is one of the most frequently used treatments for prostate cancer, but many doctors will not perform it on older men. Impotence and incontinence are the most common side effects and sometimes the urethra can become blocked requiring dilation by means of a TURP. Nerve-sparing techniques and the skill of the surgeon are factors which can determine the severity of the side effects. Reports of side effects from this operation vary widely from one source to another.
This surgery is mainly beneficial only for those patients whose cancer is localized; it is of little benefit for patients with advanced cancer. A main advantage of this procedure is that after removal, the gland and surrounding tissue can be microscopically examined by a pathologist to determine the extent and spread of the prostate cancer and whether it has escaped the prostate capsule.

**Conventional External Beam Radiation**

This radiation therapy uses an external machine to deliver x-rays or gamma rays into the prostate gland to destroy malignant cells and tissue. If the cancer is localized or if surgery is inadvisable or is undesired, this treatment can be used. It is also used as a follow-up treatment after radical prostatectomy if there is any concern that some of the cancer cells may have spread to the region adjacent to the gland.

This standard radiation treatment uses photons that lack charge and mass. By virtue of the characteristics of photons, a higher radiation dose is deposited in the healthy tissues near the surface of the body. Less radiation actually reaches the prostate gland located deep within the body and the radiation can carry through and cause damage to healthy tissue beyond the gland.

Some of the early side effects of this treatment may include tiredness and lethargy; bladder irritation and spasms; frequency of nighttime urination with slowing of the urine flow; and rectal irritation. Possible permanent or long term side effects include impotence (in about 50% of patients), bladder irritation, bladder shrinkage, stress incontinence (urinary leakage); complete incontinence; rectal irritation with bleeding; and bowel damage. Our family physician recommended against George receiving conventional external beam radiation because of his concern of potential bowel and rectal damage.

There are types of external three-dimensional conformal radiation that are designed to provide higher dosage to the cancer site. Examples are “conformal” prostatic conventional external beam radiation and intensity-modulated radiotherapy (“IMRT”). However these techniques are limited by the nature of the photons which they use.

**Conformal Proton Beam Radiation Therapy**

This aggressive form of external beam radiation treatment uses protons rather than photons to deliver the radiation to the target area. A proton is a sub-atomic particle with a positive charge and a heavy mass. The protons are formed into a beam, and because of their qualities the protons can be conformed on a three-dimensional basis to the shape and size of a target area.
On entering the body protons, unlike photons, retain most of their energy and are programmed to deposit their greatest energy at a designated site (called the Bragg Peak) and are programmed to stop there and not continue past this target area.

Because proton beams can be controlled more precisely than the photons of conventional external beam radiation, less radiation is delivered to healthy tissue resulting in less morbidity (side effects). Proton beam radiation therapy is presently limited to certain types of cancers, such as localized prostate cancer.

Because the radiation does not stay in the body (as in the case of brachytherapy) the patient is not radioactive and is not a danger to others. Patients are encouraged to continue with a normal sex life during the course of treatment.

In our research and in our choice of treatment for George, we took into consideration the successful history of proton beam treatment of cancer and the minimal side effects associated with this treatment.

**Combined Proton and Photon Treatments**

Conventional photon radiation will normally be combined with proton radiation if there is a risk that the cancer has spread outside the prostate gland to the lymph nodes. There are presently scanning limitations that restrict the size of the target area that can be treated with proton therapy alone, whereas conventional photon radiation has the ability to target a larger field.

Combined proton and photon therapy permits coverage of a broader area while significantly diminishing the x-ray dose with its greater morbidity. If there is concern that not all the cancer has been removed after radical prostatectomy, or if the cancer recurs, this two-step treatment can be used for “salvage radiation therapy”.

**Brachytherapy**

A form of internal radiation therapy for early stage small volume prostate cancer is called brachytherapy. In this invasive surgery, performed under an anaesthetic, tiny radioactive material (called “seeds”) is implanted directly into or close by the cancerous tumor by means of a fine needle placed through the perineum (the skin between the rectum and the scrotum). The seeds remain inside the patient and deliver their radiation over a period of months.

Urinary retention as well as other urinary problems are the major side effects from this procedure, and these symptoms may continue for up to two years. There are incidents of impotence as well as bowel problems. There is a possibility that a radioactive seed may migrate to another area of the body or may be excreted during urination.
For a period of 12 months after brachytherapy, a patient should avoid physical contact with pregnant women and with young children because the implanted seeds are radioactive. At the time of George’s diagnosis, four of his grandchildren were under eight years of age. “Logi Bear” (Logan) was a one-month old baby, the “Hindu God” (Devon) was one and one-half years old; “Lambie Pie” (Terez) was three going on four; and “Mitchums” (Mitchell) was seven years old. Our other grandchildren were a little older “Kitty” (Caitlin) was 15; “Mantha” or “Sam” (Samantha) was 11; and “Amor” (Amoreena) was 10. Our three daughters were all of childbearing age. There was no way that George, who dotes on his grandbabies, and loves them higher than the sky and deeper than the ocean, could stand the thought of telling them to get away from him due to the fact that he was radioactive.

High dose radiation (“HDR”) is another procedure which involves temporary seed implants. After completion of HDR, daily external beam radiation is usually given for a period of several weeks.

**Cryosurgery**

A form of invasive surgery using liquid nitrogen (or argon gas) probes to freeze a particular organ (such as the prostate gland) to extremely low temperatures to kill the tissue, including any cancerous tissue, is called cryosurgery. Cryoprobes are placed into the prostate through tracks made by needles inserted from behind the scrotum. The cooled liquid gas flowing through the probes is used to freeze the prostate, killing not only the cancer cells but all other cells of the prostate. The prostate is no longer functional and semen is not produced.

The Consent Form that we received with respect to this treatment listed a number of potential or probable side effects. It indicated that risk of impotence was at least 67% but added that it could be as high as 100% and it would be permanent in most men. Other potential temporary or long term side effects may include partial or complete incontinence; failure to control the cancer; a numb penis; an unstable bladder; bleeding.

**Watchful Waiting**

Watchful waiting is periodic monitoring and observation (by means of regular PSA tests and DREs) by a physician of a patient who has been diagnosed with localized prostate cancer. During this time no actual treatment is given; the intent is that if and when the cancer advances active treatment will commence.

The major drawback to this approach is that some cancers are more aggressive than others and it is difficult to ascertain which is which. If prostate cancer is caught early and treated promptly, there is a strong likelihood that it can be cured. However without
any active treatment there is a chance that the cancer will spread to other parts of the body. Although advanced prostate cancer may be controlled, it is usually incurable. By watchful waiting a man with prostate cancer may sacrifice his only chance for a cure.

George’s grade school chum Gideon opted for watchful waiting after he received his prostate cancer diagnosis and he was dead within two years. As a result this was not an option that we were willing to follow.

Older men are frequently advised to follow watchful waiting on the basis that they will most likely die with prostate cancer rather than because of it. Although this approach may save medical costs, it can also result in some men dying whose lives may otherwise have been prolonged by early diagnosis and active treatment. We know a number of men who opted for treatment when they were in their 80s rather than play Russian roulette with their health.

**Interstitial Microwave Therapy**

Interstitial Microwave Therapy is an unproven experimental treatment that uses high temperatures to heat the prostate gland by means of probes (long fine needles) directed by transrectal ultrasound.

**Hormonal Therapy**

Hormonal therapy is a pharmaceutical treatment, but not a cure, for advanced prostate cancer. It may assist in controlling the cancer and in some cases may slow its growth. It may be used in localized prostate cancer to shrink the size of the tumor and reduce the size of an enlarged prostate gland. Hormonal therapy blocks the body’s production of male hormones called androgens, particularly testosterone.

However, some prostate cancer cells are hormone-independent and will not discontinue their growth due to the hormone therapy. Since PSA levels are artificially decreased by hormonal therapy, there is no longer a way to ascertain actual PSA levels. An artificially reduced PSA level is not indicative that the cancer is abating.

In our view, if hormonal treatment is not necessary to reduce the size of the prostate gland a patient with localized prostate cancer should seriously question receiving these drugs, considering the serious adverse side effects associated with them. These side effects can include hot flashes, fatigue, and enlarged breasts, impotence, nausea, depression, osteoporosis, and loss of sexual drive.

If George had opted for the trial study involving cryosurgery, he would have been required to take hormonal therapy drugs. This was so, even though he was subsequently
advised by two other physicians that there was no necessity whatsoever that he receive hormonal therapy for the treatment that he eventually opted for. We feel fortunate that George did not have to undergo hormonal therapy.

In time the cancer cells may become hormone-refractory (the patient becomes androgen-independent), a condition in which a disease is no longer responding to the current type of treatment. This amounts to progression of the cancer.

George’s older brother Al was treated with only hormonal therapy after he had a recurrence of prostate cancer. Notwithstanding that his PSA decreased, his cancer continued growing and he died not long after.

**Orchiectomy**

Orchiectomy, also known as surgical castration, is the removal of the testicles and is non-reversible. Once removed the testicles no longer produce testosterone, which is thought to contribute to the growth of prostate cancer cells. However, minor amounts of male hormones continue to be produced by the adrenal glands and, since some prostate cancers are capable of growing with small amounts of hormones, an orchiectomy is not a certain cure.

**Chemotherapy**

When cancer is in an advanced stage, chemotherapy (powerful drugs) may be used to attack the cancer cells in the hope of killing them. Since chemotherapy cannot distinguish cancer cells, it can also destroy normal healthy cells resulting in loss of hair, fatigue and other side effects. The American Cancer Society has stated that chemotherapy is ineffective against early, localized prostate cancer.

**Complementary Medicine**

Complementary therapies are normally combined with mainstream treatments, while alternative therapies are generally used in place of mainstream medical practices. Although some alternative treatments have been around for a long time such as acupuncture and traditional Chinese medicine, others may hint of snake oil. Prostate patients, in our view, should not rely only on alternative methods.

Some complementary methods that may be combined with and enhance mainstream treatments include visualization, relaxation, nutrition and exercise.
Virus Research and Immunotherapy Treatments

Some unproven treatments for prostate cancer are presently being tested using viruses and immunotherapy methods to kill cancer cells. These procedures are experimental.

High Intensity Focused Ultrasound

Some United States institutions have studies using High Intensity Focused Ultrasound ("HIFU") being performed on patients with localized prostate cancer or whose cancer has recurred. This is an experimental technique that uses HIFU to heat the targeted area from 70 degrees to 90 degrees Centigrade, or high temperatures, with a view to kill the cancer cells.

Laparoscopic Radical Prostatectomy

In this type of prostate surgery, laparoscopic techniques to look inside the body and robotic fingers to wield surgical instruments are used to remove the prostate gland in cases of localized prostate cancer. It is a less invasive procedure with quicker healing, but technically more difficult due to the location of the prostate gland deep within the body cavity. This technique requires a high degree of surgical skill and training. Because this is a relatively new technique, further research and follow-up may be needed to determine its effectiveness.

Transurethral Resection of the Prostate

The surgical procedure to remove a blockage of the urethra by boring through the prostate or removing portions of the prostate gland through the penis is called a Transurethral resection of the prostate ("TURP"). This is NOT a treatment for prostate cancer, but may be used for urination problems resulting from a prostate cancer treatment or from benign prostatic hyperplasia. In the presence of prostate cancer the urologist may require the patient to take radiation or hormonal therapy before undergoing a TURP, due to the increased risk of spreading the cancer.

The forgoing provides our capsulized comments on various treatments for localized prostate cancer. Localized prostate cancer is curable by early diagnosis and treatment. While there appears to be no present cure for advanced prostate cancer, some of these treatments may help to control the effects of advanced prostate cancer and in some instances may extend the life expectancy of the patient. The information given in this book is not a substitute for medical advice, diagnosis, assessment, or treatment by qualified medical and health care professionals.
11. Clinical Trials

“In the full tide of successful experiment.”
-- Thomas Jefferson, First Inaugural Address

After some serious thought in assessing treatment options, including the randomized clinical trial involving cryosurgery, we concluded that we did not want George to be used as a human guinea pig and as a result he would not participate in an investigative or experimental trial. Since George’s brother’s prostate cancer had reoccurred 12 years after Al had undergone a radical prostatectomy, we also had to consider what treatment would allow for follow-up therapy if the prostate cancer returned at a later date. A further area of concern was the side effects of the various types of treatments, and in particular how they might limit or affect a secondary treatment should there be a recurrence.

Clinical trials are investigative or experimental studies to assess the effectiveness, safety, and side effects of new or unproven treatments or drugs to determine whether or not they will be beneficial to patients. Normally clinical trials compare the effectiveness of an untried procedure or pharmaceutical product to currently accepted treatments or drugs or to a placebo. If the outcome of the clinical trial is successful or is superior to current modalities, it may become a new or preferred method of treatment for a particular disease.

There are many clinical trials for prostate cancer in progress in the United States and elsewhere. As noted previously, George was told he was eligible to participate in a randomized trial study comparing cryosurgery and conventional external radiation therapy, but he elected not to do so.

Clinical trials can lead to new and better methods of diagnosis, treatment, prevention, and health promotion. The advantage of a clinical trial is that if there is a major breakthrough in an approach to a disease, the patients in the study are the first to gain the beneficial results from this new method. However, new procedures and treatments are not always better than or as good as standard care and they may prove ineffective and in some cases may cause unexpected and severe side effects.

Before entering into a clinical trial a patient should be fully informed that the advantages to him are unknown and that there are potential dangers to the treatment. Other matters that should be reviewed are any conflicts or financial interests on the part of the physician, the experimental aspects, lack of information as to long term aspects, possible side effects, as well as what other treatments are available if the clinical treatment is not successful. Only after reviewing all pertinent aspects to the clinical trial can a patient give a fully informed consent to the procedure.
Some conventional treatments may form part of a clinical trial when used for comparison purposes with a new or untested procedure or drug. A patient needs to assess for himself the risks of a clinical trial, especially when a new drug or unproven treatment is involved.

News releases announcing so called magic bullets or spectacular scientific innovations should be viewed with circumspection since news media frequently highlight the supposed benefits while downplaying the unproven aspects of the breakthrough or drug. Many of these releases do not highlight that extensive testing over many years may be required to determine the effectiveness, the potential side effects, and other factors. Such news releases may provide false hope to someone suffering from a terminal or debilitating disease about a so-called magic cure that in fact will not benefit them.

The pharmaceutical industry enters into “partnerships” with and funds much of the medical and scientific research with hospitals, universities and other research institutions. This may lead to conflicts of interest and institutional pressures in support of a report approving the advantages of the new drug while downplaying its less than salutary effects. Because of a desire for continued funding or in some cases because of a direct financial interest, a researcher or institution may have a bias towards a favorable report on a new drug or procedure.

An informative booklet is

**What are Clinical Trials all About?**

**Address:** National Cancer Institute  
Office of Cancer Communications  
Building 31, Room 10A24  
Bethesda, Maryland, 20892  
USA

**Telephone:** (800) 4-Cancer (422-6237)

Another source with current data on clinical trials is

**National Institutes of Health**  
[http://www.clinicaltrials.gov](http://www.clinicaltrials.gov)
12. Learning About Proton Beam Radiation Treatment

“.... a truly amazing new technique...believers have dubbed the beam of hope.”

-- Barbara Walters, ABC 20/20, Dec. 15/95

Through our research we learned that Proton Beam Therapy is a cancer treatment that is a mainstream noninvasive painless type of external beam radiation therapy. With respect to prostate cancer, it is a treatment that normally spares the patient's organs, such as the rectum and the bladder, thus preserving a patient's quality of life.

The most noteworthy advantages of proton beam therapy over other prostate cancer treatments discussed herein are that the results for early stage localized prostate cancer compare favorably with other treatments, and it has significantly less short and long term serious side effects.

Proton beams are positively charged sub-atomic particles that can be conformed to a targeted area in a three-dimensional pattern (depth, width and height). The characteristics of this treatment permit greater radiation doses to be administered to the cancerous area while causing less injury to healthy tissue and reduced side effects.

In the case of prostate cancer 38 or more treatments (one per day except on weekends) are given on an out-patient basis. The actual treatment takes only a couple of minutes, but the entire process each day takes about one hour.

If there is a possibility that the cancer is not confined to the prostate gland, the patient will receive a combination of proton and photon (x-ray) radiation. This is done because photon radiation can treat a larger field.

A principal advantage of proton radiation over photon radiation is that the proton beam has charge and mass that enables it to reach a Bragg Peak. The Bragg Peak is the targeted site at which the greatest charge of the proton beam can be deposited. The proton beam has characteristics that maintain most of its energy as it enters and travels through the body to the targeted area. After reaching the Bragg Peak and depositing its energy at the target area, its energy is dissipated so that the dose is essentially zero as it passes out of the body. Consequently there is less damage to healthy tissue and both long and short term side effects may be significantly reduced in comparison to x-ray therapy.
Proton beam treatment is comparable to other mainstream treatments for localized prostate cancer in its effectiveness, with the added benefit in most cases of minimum side effects. A comparison by Dr. James Metz of the side effects of proton, photon and radical prostatectomy treatments is found in the following April 2002 article:

“Reduced Normal Tissue Toxicity with Proton Therapy”
http://www.oncolink.com/treatment/article.cfm?c=9&s=70&id=211

Other than during the actual time of the treatments, a proton therapy patient is able to carry on with his usual activities. Many of those patients who live nearby the treatment facilities will schedule treatments in the early morning or in the evening in order to continue with their regular working hours. Others may play golf, while others may go bicycling, hiking or sightseeing. At the completion of proton radiation therapy there is little to no recovery time.

In the summer of 1999 researchers at Loma Linda University Medical Center (“LLUMC”) released the results of a five-year outcome study with respect to disease-free survival rates for the 319 patients in the study who received proton beam therapy. The results demonstrated that, for early stage prostate cancer, this treatment compares favorably with radical prostatectomy. As well, material side effects generally accompanying a radical prostatectomy were frequently absent.

The LLUMC Report indicates that if a patient shows no symptoms or no indication on a physical examination or radioactive nuclide scan, he is regarded as clinically disease-free; likewise he is deemed bio-chemically disease-free if his PSA results subsequent to treatment are stable. Research particulars were published in July of 1999.

An article in the International Journal of Radiation Oncology in Vol. 59, pp. 348-352, June 2004 titled “Proton Therapy for Prostate Cancer: the Initial Loma Linda University Experience” reported on the analyses of 1255 patients treated between October 1991 and December 1997. The conclusion stated:

“Conformal proton radiation therapy at the reported dose levels yielded disease-free survival rates comparable with other forms of local therapy, and with minimal morbidity.”

It is our understanding that a stable PSA is one that is not likely to change or be affected adversely, that is steady and non-rising. LLUMC considers three consecutive post-treatment rises in PSA after its nadir has been reached (subsequent to treatment) to be biochemical failure. This is the same definition used by the American Society for
Therapeutic Radiation and Oncology (ASTRO). The nadir is determined as the lowest point reached in a series of PSA tests. One post-treatment increase in PSA may be considered not significant (and only a bump) if it is not substantial.

Proton therapy was first used to treat patients with cancer in the 1950s at the University of California, Berkeley. Shortly thereafter cancer patients were treated with proton beam radiation at the University of Upsala in Sweden and at the Cyclotron Laboratory of Harvard University in Cambridge, Massachusetts. The use of protons was confined to laboratory facilities until Loma Linda University Medical Center (LLUMC), under the guidance of Dr. James Slater, developed a program to bring proton therapy into a hospital-based facility. The first patient was treated at the Proton Treatment Center at LLUMC shortly after its completion in 1990. Since then numerous patients from around the world have received proton beam therapy at LLUMC for various types of cancer. Since 1991 many thousands of patients have been treated there for prostate cancer.

The Massachusetts General Hospital in Boston opened the Northeast Proton Therapy Center and facilities for proton beam cancer treatment in the fall of 2001. This Hospital was established in 1811 and is the original and largest teaching hospital of Harvard Medical School. The Midwest Proton Radiotherapy Institute at Indiana University in Bloomington, Indiana recently opened. There are a number of other facilities in various parts of the world (such as Japan, Canada, Germany and Switzerland), which use proton beam therapy for some cancer treatments, but not in a medical setting.

Other proton beam facilities are presently being built or are in the planning stages at several other medical institutions in various cities throughout the United States as well as in a number of other countries. These projects include the M. D. Anderson Cancer Clinic in Houston, Texas; and the Shands Hospital in Jacksonville, Florida where groundbreaking ceremonies occurred in January 2003. Proton beam therapy is a mainstream treatment. It is not experimental and tens of thousands of patients have been treated with it for decades. The United States Department of Health and Human Services advised LLUMC in 1988 that it had examined the proton therapy system and had decided that LLUMC could put into effect its program to treat cancer and could provide information relating to its technology and services to others.

Many health insurers in the United States have recognized proton beam therapy as an accepted coverage. This includes about 180 health insurance companies and HMOs (Health Maintenance Organizations). For example, Blue Cross of California issued a Medical Policy numbered 4.01.04 showing an Initial Review date of February 27, 1997 stating in part: “Proton-beam radiation therapy is NON-INVESTIGATIONAL.” This Blue Cross Policy added that proton beam therapy may be medically necessary for the treatment, among others, of “Prostate malignancies.”
The United States Medicare program issued Bulletin 406 on March 31, 1997 retroactive to June 27, 1996 that stated in part:

“Proton-beam radiation therapy is non-investigational in the treatment of malignancies…. Benefits will be provided when services are considered medically reasonable and necessary to treat the Prostate Cancer.”

Someone contemplating proton beam therapy should check with his own health insurance provider or HMO to find out if coverage will be provided, since some insurers and HMOs are under the misapprehension that this treatment is experimental and may invalidly deny coverage.
13. Our Prostate Cancer Treatment Decision

“Once to every man and nation comes the moment to decide.”
-- James Russell Lowell, The Present Crisis

With the help of our daughter Catherine, we did extensive research and homework and consulted friends, relatives, nurses and doctors. We did so to become educated and knowledgeable about prostate cancer together with its various treatments, side effects and other relevant matters in order that we could make an informed decision on the most appropriate treatment for George.

The prime focus of our research was on three aspects of the various treatments:

• The effectiveness of the treatment;

• The side effects - the subsequent quality of life; and

• Options for later treatment if the prostate cancer reoccurred.

In addition we did not want George to be a guinea pig i.e. to be involved in an investiga-tional or experimental study.

Terry's initial reaction at the time of George’s diagnosis with cancer was that he should have his prostate gland cut out. At the time she believed in the theory that cancerous tumors were fed through the blood supply, and that the best way to destroy the cancer was to excise the tumor, thereby eliminating the supply of blood to it. This process by which new blood vessels are formed is known as angiogenesis, and a tumor uses this process in order to grow.

After the Calgary urologist informed us that George was not a good candidate for radical prostatectomy, and our family doctor was unable to refer us to an appropriate surgeon, Terry had to rethink her previous opinions as to what treatment was best for George. As they worked through their research together, she determined there were other treatments that might possibly provide the type of healing that they wished to achieve for George’s prostate cancer.

The one treatment that really changed her viewpoint was conformal proton beam therapy. It was a proven mainstream treatment that had been used for many years with little or no side effects. She was particularly impressed with its success rate with eye
cancers. Removal of the eye is the treatment used by some ophthalmologists for ocular melanoma. However Loma Linda University Medical Center ("LLUMC") indicated that with conformal proton beam treatment the eye is saved in more than 95% of the patients, with most retaining useful eyesight. Considering how sensitive an organ the eye is, such a success rate indicated to us the remarkable ability for precise and accurate treatment using conformal proton beam therapy.

Our research filled two thick three ringed binders, as well as notes and data that filled many files and two scribblers. George used one scribbler as a daily journal to record our prostate cancer experience and our inspirational journey of hope and healing.

As we became more informed, the idea of going to LLUMC for conformal proton beam therapy began to animate us with its inspirational hope. However before making our final decision, we spoke to and received answers to our questions, and advice, from staff at LLUMC. We also decided to have a telephone conversation with the couple who had invited us to dinner in Victoria, British Columbia the previous month, just after we had received the news that George had been diagnosed with prostate cancer. As noted previously, they related to us their experiences at LLUMC with respect to his prostate cancer and the results over the four years since his treatment.

In our lengthy telephone conversation with them, we discussed numerous matters relating to prostate cancer, LLUMC, proton beam therapy, details of treatment, side effects and on and on. We came away from this telephone call with our spirits buoyed about LLUMC.

Catherine, our daughter who had done research with respect to LLUMC and conformal proton beam therapy, made the initial contacts with LLUMC. She requested the information packet and inquired as to what medical information was required from us in order that they could assess whether George would be a suitable candidate for proton beam therapy, as well as the costs involved.

Together with Catherine we subsequently had a conference call with Lian Funada, the Intake Coordinator at the International Circle of Care of LLUMC. We obtained from Lian further information and answers to a number of questions. She was a warm, charming and knowledgeable nurse practitioner with a most engaging and friendly personality. We felt comfortable and confident talking to her. She described to us various matters relating to the treatments including the likely number, days, and the length of time of the treatments; possible side effects; and other pertinent data. She answered all our questions in a professional and open manner.

Lian told us that Dr. Carl Rossi, Assistant Professor in LLUMC’s Department of Radiation Medicine, had checked George’s medical records that Catherine had sent to
LLUMC. She advised us that George was a very good candidate for proton beam therapy and that Dr. Rossi had accepted him for this treatment.

One of the questions that had been previously raised with Lian was whether George’s treatment would entail his taking the hormone drug Lupron. This was because earlier the urologist in Calgary and the video tape that George had received from the local prostate cancer clinic indicated that he would need to take hormone therapy treatment if he participated in the radiation/cryosurgery trial study referred to earlier herein. Not having been told to the contrary, we mistakenly thought that hormone therapy treatment was automatic for all prostate cancer treatments. Also at that time George’s brother Al was receiving Lupron as the only treatment for his recurrence of prostate cancer.

Lian stated that she had spoken to Nurse Sharon Hoyle, Dr. Rossi’s case manager, who had in turn reviewed this matter with Dr. Rossi. Dr. Rossi’s advice, conveyed through Lian, warmed our hearts. His recommendation was that if George was presently taking Lupron he should continue on with this treatment, otherwise it was not necessary for him to start on hormone treatment.

We mentioned to Lian that George was presently taking Proscar and Terazosin, medications for an enlarged prostate gland. We also told her that George had a triangular scar on his abdomen as a result of surgery when he was a child and that the Calgary urologist was concerned that internal scarring could affect George’s treatment. We inquired whether these matters would have an effect on proton beam therapy. Lian told us that she would check these points out with Dr. Rossi and get back to us.

Lian also advised that if George opted for LLUMC a consultation with Dr. Rossi could be arranged for some time in January. The day following the consultation George would be given a CAT scan, followed by fitting of a tailor-made body mold called a “pod”. The pod is used to ensure that the patient does not move around during treatment. Lian told us that it could perhaps take two to three weeks for other necessary components to be custom-made for George’s treatments. After the manufacture of these devices, George’s actual treatments could commence.

Lian stated that if we wished she would have Kathy Gooch, the Financial Coordinator of LLUMC’s International Circle of Care, send us a letter of agreement for conformal proton beam radiation treatment. We requested that she have the letter of agreement sent to us. It arrived by fax from Kathy Gooch that very day.

Our friends in Victoria had previously given us an indication of the cost of the treatments (in particular what he paid). Consequently we should not have been surprised. However George’s reaction to the cost was the exact opposite of Terry’s reaction. When the fax came in George was having an afternoon nap. Terry rushed into the bedroom and roused George with the agreement in her hand and an exhilarated smile on her face.
She said “George, here’s the agreement. The cost is only $44,300 American dollars. Aren’t you happy?” Contrary to Terry’s upbeat manner George was staggered by the amount, which with the devalued Canadian dollar he calculated at over $67,000 Canadian dollars.

It may have been the after-effect of his nap, but he immediately said to Terry that it was too expensive and that we should give consideration to alternative treatments in Alberta, such as conventional external beam radiation, the costs of which would be covered under the Alberta Government Health Plan. Terry passionately disagreed and emphatically said to George: “Your quality of life is more important than a lousy bank account.”

When George continued to show reluctance Terry poignantly sobbed:

“I know if it was me who had to have cancer treatments at Loma Linda, you wouldn’t hesitate a second to take me there”, and then she burst into tears.”

George was so moved by the caring, compassionate thoughtfulness of his cherished wife of over 40 years (who was a young teenager when they first met) that he was momentarily overcome and tears welled up in his eyes. Fondly embracing Terry, and to relieve the tension of this deep intimate moment, George jokingly said:

‘Well MaMere [an alternative for Grandma, which our young grandchildren call her] you have to make a choice here. Either I get a new prostate gland at Loma Linda or you get a shiny new BMW sports convertible.”

Without dropping a beat Terry enthusiastically answered: “We’re going to Loma Linda for a new prostate gland”, and that was how we finalized our prostate cancer treatment decision.
14. Implementing Our Decision

“I was .... sick and you visited me.”

-- Holy Bible, Matthew c.25, v. 35-36

Our decision-making process seemed arduous and scary at times, what with learning how abominable cancer and its side effects can be. However, any apprehension we had about the often contradictory messages and material we received and reviewed during our research melted away after we made our decision to go to Loma Linda for proton beam therapy.

The very act of deciding on a course of action imbued in us a feeling of wellbeing and confidence. We had no doubt that for us the right choice had been made. Our first step in implementing our decision was to telephone to Lian Funada at Loma Linda University Medical Center (LLUMC) to let her know we had selected proton beam therapy at LLUMC as our treatment of choice for George’s prostate cancer. She was genuinely delighted when we told her. She stated that her office (the International Circle of Care) would help us find accommodation in Loma Linda, and added that we should feel free to telephone or email her at any time if we had any questions or concerns.

Lian also informed us that Dr. Rossi had advised that George’s abdominal scar would not cause a treatment problem, and also that it was fine for him to continue to take Proscar and Terazosin. Lian indicated that our consultation with Dr. Rossi would be at the end of January with treatments to probably commence in February about two or three weeks later. She also recommended that George obtain an up-to-date PSA test in Alberta to save costs and to send the results to LLUMC. We were impressed with the promptness and efficiency with which Lian handled matters. We were even more impressed with her warm and friendly, truly caring personality. We were overwhelmed by her beautiful attitude, particularly when contrasted with the frosty receptionist in the Calgary urologist’s office, and the all-business manner of the nurse at the Calgary Cancer Center.

We are convinced that the mind and the spirit play an integral role in the healing process and that the likelihood of curing an illness is markedly enhanced by an optimistic outlook and a desire to succeed, as well as affable supportive family members, friends, and medical and other care-givers. On the other hand, it would not be surprising to us if a sick person who mentally gives up, or accepts medical advice that a disease is terminal and to go home and die, does indeed face an increased prospect of failing to get well, and of an earlier demise.
The fact that we were leaving for Loma Linda “for a new prostate gland” did not literally mean, of course, that George would have a prostate transplant. His new prostate gland, please God, would be one in which the protons would have destroyed the malevolent cancer cells (in the prostate gland which God had given him), leaving only healthy cells rising up like a phoenix to form a healthy prostate.

Having made our treatment decision, we were now anxious to start on our journey of hope and healing as soon as possible. We telephoned back to Lian to tell her we were champing at the bit to begin treatment and asked if it was possible to start treatments any earlier than previously discussed. Lian told us that she would do her best. Late that very same day Lian sent us an email (with a copy to our daughter Catherine) which opened with “It’s always a pleasure speaking on the phone with you, as it was today”. She told us that she had spoken to Sharon Hoyle, Dr. Rossi’s case manager nurse, who was able to schedule George’s appointment with Dr. Rossi on January 16th (some two weeks earlier than previously thought). She also advised that his “immobilization” (i.e. CAT scan and fabrication of a custom-made body mold) had been scheduled for the day after his consultation. Lian also advised that several housing options would be lined up for us to review upon our arrival in Loma Linda, adding “We will work on further plans to ensure a pleasant stay for both of you. Thanks again! Happy Holidays! Best Regards.” Wow!

We made arrangements to transmit the funds to pay for the treatments by bank wire transfer, since LLUMC requires payment in advance. We obtained the money by significantly dipping into our Registered Retirement Savings Plan. Before doing this we talked with each of our five adult children about the arrangements we were making to go to Loma Linda. Without exception each of our children offered to help us in one way or another. Some even suggested that they would obtain personal loans to help us pay for the treatments. Fortunately we were in a position to decline these considerate offers of financial assistance.

We advised Lian that the Alberta doctors were then in a contract dispute with the Alberta Provincial Government and had curtailed their services. As a result we were not certain when we could obtain an up-to-date PSA report but would send it as soon as it was available.

During this period, commencing December 14th and continuing until Christmas our doorbell would ring each day but on each occasion when we answered it no one was there, only a Christmas package. The first package contained a picture of the Partridge family from the TV series and a basket of pears - “the first day of Christmas” - a partridge in a pear tree. On December 17th, to give another example, inside the parcel was a wreath with four ornamental birds on it. - “the fourth day of Christmas” - four calling birds.
This mystery continued every day until Christmas day when two of our beautiful granddaughters, Caitlin and Samantha, and their father came to see us at our daughter Catherine’s home where we were having Christmas dinner with her, her husband Mike and our small grandchildren Devon and Logi Bear. Caitlin and Samantha brought with them the last gift, twelve ice cream drum sticks for - “the twelfth day of Christmas” - twelve drummers drumming and joyously sang the Christmas song *The Twelve Days of Christmas*. It made us appreciate how much we were loved in the face of the cancer battle we were confronting.
15. Challenges

“Great experiences and crises show us how much greater our vital resources are than we had supposed.”
-- William James, The Letters of William James

In life whenever a person takes matters into their own hands there are inevitably some obstacles or restrictions in reaching his or her end goal. We try to look at potential problems as challenges. They then seem easier to confront and contend with. We were truly fortunate that we only had to face concerns that we could deal with and resolve. These matters included the significant financial costs of treatment, leaving our home and loved ones for an extended period of time, meeting family commitments at home during the time of George’s treatment many miles away, and determining why there was a very substantial unexpected reduction in his latest December PSA level.

A few days before Christmas we received a telephone call from Sharon Fox, one of the nurse coordinators at the International Circle of Care. She introduced herself and said that she would assist us on our arrival in Loma Linda. She told us she would familiarize us with Loma Linda University Medical Center (“LLUMC”), help us find nearby accommodations, grocery stores, and other facilities.

We told Sharon that our daughter Laura had very recently told us (not to our surprise) that she was going to be remarried during the time we would be in Loma Linda for George’s treatments. Sharon advised us that LLUMC could work George’s treatments around any travel plans that we would make to return to Calgary for the wedding.

We were able to obtain an up-to-date PSA result before the end of December. It showed a significant reduction of George’s 6.3 PSA level from the September test (three months earlier) to a current level of 3.3. When we picked up the December PSA Report our family doctor told us that Proscar, a medication for an enlarged prostate, can reduce PSA levels, but we had no idea how significantly.

Our pharmacist was helpful in providing us with a copy of information contained in the Canadian Pharmacists Association Compendium of Pharmaceuticals and Specialties concerning finasteride, a synthetic compound whose trade name is Proscar. As discussed in an earlier chapter, this helped us to understand the significant decrease in George’s PSA level from September to December and to realize that it was an artificial reduction caused by the Proscar.

This experience was our first understanding of how medication will significantly mask the true PSA levels. We feel there is a significant difference between the words “PSA
levels are decreased... and should be doubled” in the Compendium and the words that Proscar “can alter PSA values” in the information sheet provided by the pharmaceutical company with the medication. In our opinion the information sheet accompanying the prescription would have been more precise if it had stated in bold print “Proscar will reduce PSA values by approximately one-half” rather than “can alter PSA values”. Furthermore when the urologist was told that George was on Proscar and he advised George to go off this medication, the urologist did not inform us that the PSA levels could be doubled by going off of Proscar.

More recently we have learned that there may be other concerns with respect to the use of Proscar. For example, the urologist Dr. Sheldon Marks in his book Prostate & Cancer indicates that a small prostate cancer as it grows may be masked or hidden by Proscar. He further states it “may alter the tissue to make microscopic examination more confusing”. In our opinion, a pathologist should take into consideration whether or not Proscar has been used when examining biopsy tissue samples for prostate cancer.

Back in December 2000 when we sent George’s PSA report to LLUMC, we referred to the extract from the Pharmaceutical Compendium and the facts relating to George’s discontinuance and subsequent resumption of Proscar showing the effects on George’s PSA levels.

One decision we had had to make prior to going away was whether or not we should first apply to the mandatory Alberta Government Health Insurance Plan to see if it would approve and pay for conformal proton beam treatment for George at Loma Linda. Since this Government Plan did not require a prior application for approval for a case such as George’s, we determined to go forward without it because of the time that would be involved in processing such an application, thereby unnecessarily delaying commencement of active treatment for his cancer.

We were acutely conscious of the fact that there is no absolute in determining whether or not a cancer is aggressive, particularly as George’s school chum had died of prostate cancer during watchful waiting. Applying for authorization and subsequently making an appeal of any unfavorable decision would take months, as we later found out when we made application for reimbursement after completion of George’s proton treatments.

We found out that our judgment in going forward without delay was the correct one. In George’s case the Alberta Government Department of Health and Wellness, under which he was insured, reimbursed us approximately 6% of the costs of his proton beam treatment at LLUMC and refused coverage for the full amount. We also carried supplementary health care coverage with Alberta Blue Cross, for which we paid premiums, but which refused any reimbursement to us whatsoever.
In Canada there is a mandatory government health care system. Each province in Canada has constitutional jurisdiction over its own residents with respect to provision of health care. The Alberta Government levies health care premiums on its residents and in turn undertakes to provide health care coverage to them. Alberta, British Columbia and Ontario are the only provinces in Canada that charge their citizens a premium for health care coverage. None of the other provinces and territories in Canada charge premiums and instead fund their medical plans from general revenue. Although the Canadian Government advances the view that Canada has a comprehensive health care plan, in actual fact this is not the case.

Besides the three provinces that impose a premium on its residents many medical procedures, prescription medications, etc. are not covered under the various provincial plans. In addition the coverage varies from province to province. As a consequence many Canadians purchase travel medical insurance when travelling to other areas in or outside of Canada. This travel insurance covers only medical emergencies and provides no coverage for certain pre-existing medical conditions.

Currently due to budget restraints some provinces are considering cutting back on a number of medical services that they presently insure. In addition, because of government fiscal restraints, there has been job action among doctors (such as closing offices and clinics and withdrawal of medical services) and strikes among medical personnel. These factors have led or are leading to a reduction of medical services and a decrease in the quality of medical care in Canada.

As mentioned in an earlier chapter, the urologist to whom George was referred recommended against radical prostatectomy because of potential abdominal scar tissue due to surgery George received as a child. George’s family doctor recommended against conventional external x-ray radiation due to burns to the rectum that he had encountered with a number of his patients. Our enlightened family doctor provided a letter to the Alberta Government of Health and Wellness stating that in George’s

“… particular circumstances, the most appropriate treatment for him was proton beam therapy, a precise form of advanced radiation treatment for prostate cancer.”

Proton beam therapy is not available in Canada for prostate cancer.

The first letter of rejection of George’s Application for Reimbursement stated that:

“The evidence provided, by the specialists involved in your care, indicates that several treatment options were available to you locally.”
Notwithstanding the Department’s reference in the plural to “specialists” involved in George’s care, George had a consultation with only one specialist in Calgary, the urologist to whom he had been referred and who was involved in the trial study comparing conventional x-ray radiation and cryosurgery. This specialist had not mentioned proton beam therapy to George when he gave George advice about treatments. The Alberta Government Department did not consult any specialist at LLUMC.

Subsequently after George’s initial rejection, he appealed to the Alberta Government Out-of-Country Health Services Committee for reimbursement of the funds paid to LLUMC. We both appeared before the Committee. That Committee, whose members are appointed by the Alberta Government, was headed by a rheumatologist and also had a philosopher among its members. The Committee denied George’s Appeal in a letter issued the very same day as the Appeal Hearing. The letter stated in part:

“In Canada, external beam radiation therapy (EBRT) is the usual treatment for prostate cancer in your circumstances and the Committee found no evidence from a specialist that this was contraindicated in your case.”

The letter ended “With Best Wishes”. We wish! The letter of support from our family doctor, whose advice we give great weight to, was obviously not accepted. The Committee did not mention that by taking proton beam therapy at LLUMC instead of conventional external x-ray radiation in Alberta, the Alberta Government Health Care system undoubtedly saved the cost of paying for the consequences of side effects that could have resulted from George undergoing conventional x-ray radiation.

Also no mention was made of the fact that in order to reduce the side effects of conventional x-ray radiation it is necessary to reduce the x-ray radiation dosage, thus reducing the damage to the cancerous cells. This is the basic dilemma that exists with conventional x-ray radiation, whereas with the unique qualities of proton beam therapy a much higher radiation dosage is given to the cancerous cells with very little effect on the surrounding healthy tissue.

In rejecting George’s appeal on the basis that external beam radiation therapy is the usual treatment for prostate cancer in George’s circumstances, it is obvious that the Committee members failed to understand or appreciate that proton beam therapy is “external beam radiation therapy”. We question whether they took into consideration the qualities that make proton beam therapy a more beneficial treatment for prostate cancer than conventional x-ray radiation.

Since the only reason given in the Committee’s rejection letter was totally inapplicable in George’s circumstances, it appears to us that the real reason for George’s rejection
was that his external beam radiation treatment was received outside of Canada. This
decision did not deal with the benefits George received by having proton beam treat-
ment for his prostate cancer. We also feel that we would have been better served if
there had been on the Committee a physicist or an engineer who was informed and
understood the science and technology related to conformal proton beam therapy.

When we were in Loma Linda we found out that we would have been far better off
financially if George had been eligible for United States health care coverage. It is our
understanding that Medicare in the United States covers about 80% of the cost of proton
beam treatment for Americans over the age of 65. For those patients who also have a
secondary health care plan, that plan will often pick up the remaining 20% of the cost of
this medical procedure, resulting in many patients over the age of 65 receiving 100%
coverage for proton beam treatment.

Numerous HMOs and insurance plans cover proton beam treatment for patients under
the age of 65. We would advise any patients contemplating proton beam therapy to first
check with their insurance provider to determine whether they will be covered for this
treatment. If they find any resistance in getting coverage they should contact the alumni
patient group of LLUMC (the Brotherhood of the Balloon, whose acronym is the “BOB”),
in order to get ideas and suggestions as to how they can handle these insurance
problems. Further information on the BOB can be found in a later chapter of this book.

Since we are Canadians and not United States citizens, it was necessary for us to dig
into our retirement funds in order to pay for the financial costs of George’s treatment.
Although we incurred a personal substantial financial outlay for this treatment, in retro-
spect we would not hesitate one nanosecond in making the same decision if we had to
relive our LLUMC experience. Besides receiving a remarkable treatment, we experi-
enced the warmth, kindness, and professionalism of the medical staff who provided
healing medicine while we were at LLUMC.

We received a fax from Lian after Christmas confirming that she had arranged a hotel
room for us near LLUMC for our arrival. The fax also set forth our schedule for January
16th and 17th. The first item on it stated that Sharon Fox, the nurse coordinator we
spoke to the previous week, would meet us at 8:30 a.m. at Level A of the Proton
Therapy Center of LLUMC prior to our appointment with Dr. Rossi at 9:00 a.m. At 11:15
a.m. we were to be taken on a tour of the Proton Treatment Center. After lunch, Sharon
would take us to view several apartments. Our appointment on January 17th was for
3:00 p.m. for a CAT scan followed by the custom fitting of George’s immobilization pod.
16. Our Inspiring Journey of Hope and Healing

“Follow your spirit.”

-- William Shakespeare, King Henry V

We decided to leave Calgary early for Loma Linda in order that we could visit along the way with relatives and friends. We let our children know we were setting out on January 4th. On January 2nd our 11 year-old granddaughter Samantha (who is a beautiful, affectionate, and considerate young lady) called and asked if we could meet her at Café Salsa in Calgary to work on crossword puzzles with her. This was a hobby we share with her from time to time. We agreed and when we arrived at the Café, her mother (our daughter Laura), and Samantha’s 15 year-old sister Caitlin, and the girls’ soon-to-be stepbrother Terence were already there.

While the grown-up’s sipped café-latte and the children had hot chocolate, we started solving crossword puzzles in a book that Mantha had brought. Mantha even knew that “Ian” was the first name of Fleming, the creator of James Bond, Agent 007.

On breaking up, we kissed and hugged everyone and said we would see all of them when we returned from Loma Linda to Calgary for the weekend of Laura’s wedding.

The next day we went to see our son George, his wife Holly and our grandchildren Mitchell (age 7) and Terez (age 3). We had a great visit with them. On January 4th we packed the car in preparation for the start of our adventure to California later that morning. We were taking our car because we would be away for almost three months, and we had also spoken to relatives and friends in Vancouver, Oregon and California who had invited us to stay with them while en-route.

On that day Lian of the International Circle of Care of Loma Linda University Medical Centre (“LLUMC”) called and subsequently faxed us a Proton History questionnaire for George to complete prior to our arrival at LLUMC. Since we were just on the verge of leaving on our journey when the fax arrived, we did not have time to review and complete the questionnaire prior to our departure.

Just before we left our home, our eldest daughter Tag came to see us and wish us bon voyage from her and her husband Clay. We then headed to the home of our daughter Catherine and her husband Mike near Bragg Creek (some 45 minutes west of Calgary) to say goodbye to Catherine and our grandchildren, Amoreena (age 10), Devon (age 1), and Logan (then 3 months old).
While there we also said goodbye to the children’s Filipino nanny Maryann and the children’s stepsister Kimberley who had come from her home in London, England for the Christmas Season. All of the children were really pleased to see us. We told Catherine, with our hearts swelling, that it was our “grandbabies” that made our lives worthwhile. With tears in Terry’s eyes and with lots of ‘huggles’ (our term for a mix of hugs and cuddles) and kisses, they wished us farewell.

From Bragg Creek we drove west to Canmore (site of many of the 1988 Calgary Winter Olympic events) and stayed overnight at our son George’s retreat in the Rocky Mountains. After breakfast the next morning we hit the road motoring past Banff, Lake Louise, Field, and on to Revelstoke, British Columbia where we stopped for lunch. It was wintertime but the highway was generally clear, although we ran into some snow and occasional slippery patches in the high mountains.

Some distance east of Revelstoke we encountered a long line of motionless traffic. A flag girl told us that avalanche control was in progress and our wait would be up to two hours. Only a few weeks earlier we had heard a guest interviewed on the national Canadian Broadcasting Corporation radio station; he recounted his invitation to witness avalanche control near Revelstoke. He said everything was set up and precisely calibrated, after which a cannon fired at the snow near the crest of the mountain with the intent to have the snow tumble down before it became an avalanche hazard. After the shot was fired there was no sign on the mountain of the blast from the cannon shell nor did any snow slide down the mountainside. The missile had gone over the top of the mountain. The shot had missed the mountain - a spectacular feat. This gave us a bit of a chuckle - as we had been stopped for the same purpose.

Since we were told our wait would be a couple of hours, we decided to play a game of scrabble in the car. To our surprise the delay was much shorter, and we did not have time to finish our game before we were off again and on our way. About 7:00 p.m. we arrived at Greg and our son John’s home in Vancouver where we were to stay.

During our stay in Vancouver we went over the questionnaire that we had received from Lian of LLUMC immediately prior to our departure from home. In doing so we realized that we should be bringing with us to LLUMC George’s biopsy slides. We telephoned to our daughter Catherine and she agreed to get these slides and send them by courier directly to Lian.

We spent three enjoyable days in Vancouver. On Monday January 8th we said our good-byes and drove to Pike’s Place Market in Seattle for lunch and picked up a fresh cup of coffee from the original Starbucks Café located in a grand high-ceilinged heritage building across the street from the Market.

Later that afternoon we arrived at the Lake Oswego home of Terry’s sister Isabelle. Lake Oswego is a suburb of Portland, Oregon. Isabelle had prepared a delicious Pacific Coast salmon dinner for us.
The next morning after bidding her farewell, we drove south on the I-5 Highway stopping for our mid-morning café latte in Eugene. We carried on at a good pace. Shortly after crossing the border into California, we encountered blowing snow and slushy roads for about a 30-mile stretch before and after Mount Shasta. Darkness descended and the driving was slow, particularly when semi-trailer trucks raced by us, splashing our windshield and obliterating our vision in the process. When we stopped in Redding to spend the night, we were told that the highway was now closed and we were one of the last cars to get through this high mountain pass.

On Wednesday January 10th we drove to San Francisco where we spent the afternoon window shopping on Union Street, and eating a crab and shrimp cocktail at Fisherman’s Wharf. Leaving San Francisco we ran into a rainstorm and it got very dark, so we decided to stay the night in Salinas, where the novelist John Steinbeck was born.

On Thursday morning we drove to Monterey and Carmel-by-the Sea, quaint cities on the Pacific Ocean, where we browsed around. From there we motored on to Paso Robles to spend a few days at the home of our friends Andy and Marilyn. Andy had been a law school classmate of George’s in Winnipeg over 40 years earlier, but had left for Los Angeles as soon as he obtained his law degree. We had remained in touch and visited each other over the years.

When we arrived at their home, they told us that Lian Funada of LLUMC had telephoned us there to find out how we were making out on our travels. We called Lian to let her know we had arrived safely and were on schedule for our arrival in Loma Linda. She told us that she had received our biopsy slides from Catherine.

We had a really relaxing time during the four days we stayed with Andy and Marilyn. We even went to a Saturday night concert “An Evening of Music” at which performers included the Silver Belles (of which Marilyn was a member) singing golden oldies.

We all went for Sunday brunch at a Pismo Beach restaurant overlooking the Pacific Ocean, and then down the road to witness thousands of monarch butterflies flitting about and roosting in giant trees in a wooded grove where they had migrated for the winter.

After parting company with Marilyn and Andy, we drove through Santa Maria, Ojai, Santa Barbara, and other places, stopping at several points along the way until we arrived in Loma Linda in the late afternoon. In nearby San Bernardino we located the hotel where the International Circle of Care had reserved a room for us. San Bernardino is the community where the first McDonald’s Restaurant was launched.

We had arrived at our destination.
17. Consultation and Treatment Preliminaries

“…. hope divine informs my spirit.”


On Monday, we drove to the Medical Center (“LLUMC”), about 10 minutes from our hotel, to locate it and check it out before our appointment the next day. We then went to LLUMC’s International Circle of Care, which is in a bungalow-style office building a few blocks from the main buildings. We introduced ourselves to Lian Funada, an attractive and affable petite woman in her thirties and to Sharon Fox a genial, very warm and pleasant lady. They introduced us to Kathy Gooch (the Financial Coordinator), Ceci (the good-natured receptionist), and other staff members.

At 8:30 a.m. the next day we showed up at LLUMC’s Proton Treatment Center for our consultation appointment. Sharon Hoyle, a registered nurse and Dr. Rossi’s Case Manager in the Department of Radiation Medicine, greeted us and chatted before taking us into the consult room. She gave George a folder with a number of documents, which she asked us to review and in some instances to sign. She also gave each of us visitors’ badges to wear when we came for George’s treatments so that we would not have to register at the visitors’ desk each time we entered the hospital.

The documents in the folder included an instruction sheet for patients receiving proton beam treatment, a restricted consent for release of medical information, a radiation therapy consent, a list of possible early and late side effects, and a contact information sheet. We signed the appropriate documents and returned these to Sharon.

Sharon explained to us that each doctor had a clinic day. If we wished to see Dr. Rossi his clinic day was every Wednesday and no appointment was needed. At other times during the workweek, we should call her and she would get in touch with Dr. Rossi for us if we had any problems or questions. If we wanted information or needed attention in the evening or on weekends, she advised us to telephone or go to Emergency at LLUMC and ask for the Radiation Medicine Physician on call.

Sharon fit the mold of the other LLUMC personnel we had met - warm, friendly and caring, with an additional trait - as we got to know her better during the course of treatments, Sharon displayed a flair for humor, and we had a lot of laughs with her.
In the consult room Sharon weighed George (fully clothed) at 168 pounds, took his blood pressure (which she said was quite acceptable at 138/74), and took his temperature (which read 97.1, not 98.6).

We gave Sharon a copy of the Proton History Sheet that we had received by fax from Lian Funada of the International Circle of Care on the day we left home, and that we had completed on our way to Loma Linda. Sharon then thoroughly reviewed our nutritional habits with us and determined that it was not necessary for us to see a dietician at LLUMC. We were amazed at how thoroughly and knowledgeably she reviewed our eating habits, particularly after the disinterest of the nurse at the Calgary Cancer Center when we had broached the question of diet with her. A later chapter in this book deals with nutrition and diet.

After these preliminaries, Dr. James Baer arrived. He was a senior resident and a bear-sized man who exuded an aura of quiet confidence. He and Sharon asked us what we did for a living. George told them he was a retired lawyer and also an author. He mentioned that he had recently written a book on the trial of Louis Riel (today an acknowledged Canadian Metis hero) who had been unjustly executed for high treason in 1885. Terry said that she was retired and told them about her various past activities as an office manager, accountant, paralegal, legal editor, indexer, wife, mother, etc. She told them that she had been a researcher, editor and publisher of George’s book on Louis Riel and together we gave talks on Louis Riel and the Metis (descendants of the conjugal union in earlier centuries of Europeans and North American Indians) at universities, schools, public libraries and historical societies.

Sharon left the consult room for a short time and the conversation with Dr. Baer carried on. As we were discussing medical matters with Dr. Baer (including other types of treatments and their side effects) a bubbly burst of energy entered the room in the person of Dr. Carl Rossi. An Assistant Professor in the Department of Radiation Medicine at LLUMC, Dr. Rossi was to be George’s consulting physician. He was short and slim with radiant eyes and a winning smile. Although we had never seen or directly talked to him previously, he started the conversation by saying that before getting down to medical business he wanted us to tell him all about Louis Riel and our book, and also about Terry’s eclectic career. It turned out that Dr. Rossi, besides being a distance runner and coach, was a history buff. It was apparent that Sharon Hoyle had briefed him about us when she left the consult room for a short time.

While Dr. Rossi discussed medical matters with us and answered our questions, Dr. Baer checked George's upper front and back with a stethoscope. Both of them examined the triangular scar on George’s abdomen. Dr. Rossi stated that in his opinion the scar would not be an obstacle to George having a radical prostatectomy if that was his treatment of choice.
Dr. Rossi advised that if he felt a tumor during a digital rectal examination (DRE) he would prescribe external photon radiation in addition to proton therapy. He asked George to drop his trousers and shorts and performed a DRE on him. Dr. Rossi could not feel a tumor and said that all treatments for George would be proton beam. He advised that proton beam therapy covered the prostate gland and seminal vesicles. This is done because a CAT scan outlines the prostate but it does not outline a tumor unless it is large.

We were advised that the curative effect on prostate cancer of proton beam radiation was comparable to that of radical prostatectomy. The main area of difference was in the side effects, which were relatively minimal with proton beam therapy in comparison with other types of treatments for prostate cancer. Drs. Rossi and Baer explained to us that the proton beam radiation would kill all of the cells in the prostate. Because cancer cells were unable to replicate themselves after proton radiation, the cancer cells would be destroyed. On the other hand the nature of normal prostate cells allowed for new healthy cells to be produced in the prostate, thereby resulting in a healthy revitalized prostate gland after proton radiation.

Dr. Rossi also told us that it was not necessary to discontinue having sexual relations during the treatments, since proton radiation did not result in the patient being radioactive during the course of treatment. In fact, he encouraged patients to continue with normal conjugal relations.

Dr. Rossi said that he wanted both of us to know as much as possible about the treatment and its related procedures. He said that a principal objective he had for his patients was their quality of life. We were both awestruck at this open, inclusive manner of practicing medicine, and Dr. Rossi’s concern not only for the effectiveness of the treatment in relation to George’s cancer, but also its effect on his life.

At no time during this eye-opening conference did Dr. Rossi give the impression that he was hurried or harried, and neither did Dr. Baer nor Sharon Hoyle. On the contrary, they were all easy going and friendly while retaining a professional aura and giving the impression that we could spend as much time with them as we required. Although before we left Calgary we had made the decision that conformal proton beam radiation therapy was the best treatment for George’s prostate cancer, this consultation with Dr. Rossi and Dr. Baer convinced us that indeed we had made the right decision.

This heart-warming consultation made us happy campers. Afterwards we waited for a short time in the reception area for the commencement of the daily orientation and educational tour of the Proton Treatment Center that was scheduled for 11:00 a.m. At the appointed hour, about 20 patients and spouses had assembled for the tour. Gerald Troy, a staff clinical social worker with a Master of Social Work degree, conducted the tour. Gerry, who is in his fifties, is very knowledgeable with an affable manner. He
started by introducing himself and giving a talk on LLUMC and its facilities. He urged everyone to have a good time during treatment and not to mope. He briefly described treatment procedures. He said the patients should exercise, eat right, and be cheerful.

Gerry told the group that the social workers at LLUMC had designed a temporary community to keep the patients and spouses connected with each other and their spirits up. Each week a bulletin is published setting forth the activities for that week, and all the cancer patients and their spouses are invited to participate.

Every Tuesday the “lunch bunch” gathers at a different restaurant in the area and the members get to know each other. Every Wednesday evening, a Support Group Meeting is held at which refreshments are served. The Meeting consists of an abundance of jokes, personal stories from new patients, farewells from graduating patients, comments from visiting alumni, questions and answers and often a guest speaker. Thursday is dinner night at a previously untried restaurant in one of the nearby communities. Spouses are invited to a meeting each Monday to discuss their specific concerns.

Gerry Troy supplied the tour group with lists of places to see and things to do within driving distance from Loma Linda, such as dinner at the Queen Mary ocean liner in Long Beach, Disneyland in Anaheim, a weekend cruise to Mexico, etc.

He handed out free memberships to LLUMC’s Drayson Center to all patients and their spouses for use during the treatment period. The Drayson Center is the gymnasium, health club, exercise facility, running track, swimming pool and spa of the University of Loma Linda. We were also given a free membership to “Just for Seniors, 55+ Club”, a community health and wellness service of LLUMC for seniors. Membership benefits include discounts in the Hospital cafeterias, gift shop, and pharmacy prescriptions (for those with an American social security number). Other benefits are VIP hospital parking, escorted and narrated day coach trips, etc.

After Gerry Troy’s introductory words of 15 or 20 minutes, he took us on a two-hour behind-the-scenes tour of the Proton Treatment Center and its facilities. Along the way he introduced us to various staff members involved in different functions. The staff members gave explanations and sometimes demonstrations of their work supplemented by comments from Gerry.

We were shown the room where each patient’s immobilization device is custom-made. In the case of prostate cancer patients, the immobilization pod is an open-topped, body-hugging foam liner enveloped by a firm plastic frame. The purpose of the pod is to assist in ensuring that the patient is properly positioned for treatment each day.

We moved on to another room where special devices are custom-made, one for each hip. The apertures are constructed out of cold metal and the “boluses” are fashioned out of jeweler’s wax. These act as tissue-compensating filters to take into account
differences in density of tissue and shape and volume of the prostate gland from one patient to another. These devices, together with a modulator wheel, are placed in the proton beam equipment before treatment commences in order to conform and distribute the radiation to treat the patient effectively according to his specific computer plan of proton beam treatment.

A staff member, Alfonso, demonstrated the computerized technique used to manufacture the bolus, based on a medical physicist’s design done in a dosimetry laboratory. He also showed us how the liquid cold metal is handled in preparing the aperture.

Gerry Troy also took us to and explained the functions of other facilities involved in the proton treatments. This included a behind-the-scenes view of one of the gantries, of which there are three at LLUMC. There is also a fixed-beam treatment room. Each of the giant gantry machines is 35 feet wide, three stories in height and weighs 90 tons. The gantry rotates around the patient and provides the ability to direct the proton beam. Gerry Troy explained to us the treatment delivery process, which consists of a number of major components.

Gerry took us into a treatment room to let the patients know what they would be walking into each day. For privacy reasons there was no patient in the room at the time. He then took us to the adjacent monitoring and control room where he introduced us to staff members working there. An explanation was given of the treatment monitoring process, and we were able to see the computers and television view of the treatment room. We wandered through hallways visiting other areas. These included the stationary beam room for treating eye, central nervous, brain and other tumors.

After this highly informative and fascinating familiarization with the inner workings of these marvelous facilities, we had a quick lunch and then went to the International Circle of Care to meet up with Sharon Fox. Sharon took us to see several apartments as possible rental accommodations, and gave us the addresses of others to drive by that evening in case we wanted to look at them with her the next day.

The following morning our daughter Catherine (who had done the early research on LLUMC for us) telephoned from Calgary to ask how we were making out. She told us heart-warming anecdotes about our grandchildren. She then told us that she and our daughter Tag’s e-commerce Web site at http://www.fabjob.com was growing exponentially. They had started this site only six months earlier to sell career guides on the Internet. Next she said that she and her husband were coming to Los Angeles during the first week in March as were two of their friends from England whom we knew quite well, and they were all looking forward to getting together with us.

That afternoon we viewed a couple of apartments, after which we went to LLUMC for George’s afternoon appointment. George drank two large cups of water in preparation for a CAT scan. He then went to a room where two staff members (Aaron and Oscar)
had him lie down and they custom-made a body-mold for him - his pod - while Terry watched. Following this they wheeled George into the CAT scan room on a stretcher. Aaron then inserted a tubular balloon in George’s rectum and told him the balloon would be filled with warm water. The purpose of the water balloon was to push most of the bladder and rectum out of the way in preparation for the CAT scan.

Aaron and Oscar carried on a light and jocular conversation with us as they explained and went through the process of the various procedures. When George asked Aaron if he had filled the balloon with the water, Aaron said that he was just now going to fill it with six gallons, then hastily added that he had already finished filling it with the requisite four ounces of water. When George said to Oscar that he understood he had to remain still during the CAT scan, Oscar replied jokingly “That’s right, and you also have to hold your breath for 10 minutes.” The insertion of the balloon in George’s rectum did not hurt - it was only mildly uncomfortable.

The CAT scan lasted about 15 or 20 minutes, during which time George kept his eyes closed and arms crossed while lying in his own body mold.

After the CAT scan we met with Sharon Hoyle, the Case Manager for Dr. Rossi’s patients, and discussed a number of matters with her including the commencement of treatments. She told us to call her any time we had any questions. Since we were not going home to Calgary prior to the beginning of George’s actual treatments, Sharon suggested we speak to Ed Schultz who was in charge of scheduling, to find out the specific date of George’s first treatment.

The next morning we went to Ed Schultz’s office at LLUMC. Ed turned out to be a jolly soul who told us that his wife’s father had been born in Saskatchewan, the province next to our home province of Alberta. On noting George’s last name, he asked if George was related to Robert Goulet and said that Robert Goulet (who had starred in Camelot many years earlier with Richard Burton and Julie Andrews) was his wife’s favorite singer. George said that he is distantly related to Robert Goulet (who was brought up in Edmonton, Alberta) and that Robert is a prostate cancer survivor. George added that he confined most of his singing to the shower.

Since Ed had a meeting to attend, he advised us that he would check the treatment schedule that afternoon and let Sharon Hoyle know the date of George’s first treatment. He suggested we contact her the next morning and she could then provide us with the details.

We then drove to an apartment we had viewed the day before (Loma Linda Springs Apartments about a three-minute drive from LLUMC) where we made rental arrangements for the period when George would be having his treatments. The manager stated the apartment would be available to us on January 28th and confirmed that we would only have to pay for the time we actually had to stay in Loma Linda.
We then went back to LLUMC and up-dated Sharon Hoyle on developments. We let her know that we were going to travel to the San Diego and Palm Springs areas until George was scheduled to start his treatments. Since she would be speaking to Ed sometime late that afternoon, she asked us to telephone her in the morning and she would apprise us of the treatment timetable.

We then headed south and stopped at the ocean-side city of San Clemente. Richard Nixon made his home here for some years, and it was the White House West during his presidency. We spent the night in a hotel suite overlooking the beautiful blue Pacific Ocean and witnessed a majestic orange sun as it set into the Ocean. We played our usual game of Scrabble, watched Jeopardy hosted by Alex Trebek and a couple of other television shows (a rarity so far on our odyssey) and went out for dinner.

In the morning Sharon Hoyle advised us by telephone that George’s first treatment would be the following Thursday. We were ecstatic that it was to take place that soon, as we understand subsequent waiting periods after a patient’s consultation are now a number of weeks.

We realized that if we had opted at the end of November, 2000 to stay in Calgary and participate in the trial that our Calgary urologist had discussed with us, George’s actual treatments would not have commenced until the end of May or sometime in June, 2001. By deciding in mid-December to go to LLUMC for treatment, George was able to have his first treatment scheduled for about six weeks after we had made our decision.

To celebrate that we now had a fixed early date for the actual start of George’s treatments, we went to a neat coffee shop in San Clemente for a café-au-lait. En route to the coffee shop we got a laugh out of a restaurant we drove by named “Taste of China”. Below its name, the sign read “Hot Dog Heaven”.

We stayed another night in San Clemente before travelling on to San Diego, sightseeing along the way in Carlsbad, Del Mar, and La Jolla all highly attractive ocean-side communities.

After checking into our hotel in San Diego, we drove to Coronado and visited the grand Hotel del Coronado, a magnificent structure right on the ocean, very chic and posh. The next day, January 21st, we headed for Palm Springs where we stayed for the next number of days.

Since our apartment in Loma Linda was not available until the Sunday after George’s first treatment, Palm Springs was close enough that we could easily commute. On Thursday January 25th we drove from Palm Springs to LLUMC for George’s first proton beam therapy appointment at 1:00 p.m filled with anticipation and hope.
18. George’s First Treatment

“Your healing shall spring up quickly.”

-- Holy Bible, Isaiah, c. 58, v. 8

On arriving at Loma Linda University Medical Center (“LLUMC”) we parked in the hospital’s parking lot. We made our way to the B Level of the Proton Treatment Center (two floors below ground level) and checked in with Durleen, the receptionist, about 12:35 p.m. for the 1:00 p.m. appointment.

While waiting, George drank two glasses of water rather quickly. He had previously been instructed to do so to ensure that his bladder was full for the low power x-rays used for proper positioning of the patient in the pod, as well as for the treatment. Because the bladder is full, it is easier for the rectal water balloon to push the bladder out of the way of the proton radiation beam during treatment.

While sitting in the reception area waiting to be called, George was politely asked by Durleen if he had taken his two glasses of water. A short time later a staff member introduced herself and asked George if he had taken his two glasses of water. He said he had. She then took his photograph with a Polaroid camera. This photograph was to be placed on his file for identification purposes during his course of treatments. About 1:10 p.m. she returned and showed both of us to the change room and to the Gantry 3 room where George’s treatments were to take place each day.

In the change room she said that George could leave on his shirt and socks for warmth, but otherwise he should strip and put on the hospital’s “designer gown” (as she termed it) with the opening at the back. Terry was also in the change room and, until the treatment actually started, she was also in the treatment room. Spouses of patients are permitted to be present in the change and treatment rooms for the first, but not subsequent, treatments.

On entering the Gantry 3 treatment room at about 1:20 p.m., George was a little nervous and had a slight headache, probably due to the tension of undergoing his first treatment. In Gantry 3 the radiation therapists, wearing white lab coats, said “Hello Mr. and Mrs. Goulet” and introduced themselves. Their names were Marvin Berto and Troy Davis. They fully explained the treatment procedures to us. George then climbed into his pod without requiring any assistance. The pod was clearly marked with George’s name, and had a white sheet inside of it.

Once in the pod the circular roof, about seven or eight feet above George, rotated until the beam nozzle was directly next to George’s right side. With George lying on his
back, Marvin asked him to lift his right leg and lay it over the left side of the pod. Telling George what he was doing, Marvin then inserted a lubricated tube containing a balloon into George’s rectum and filled the balloon with four ounces of warm water. This balloon plays a significant role in minimizing side effects by pushing most of the bladder and a large part of the rectum out of the way of the proton beam, thereby resulting in less damage to healthy tissue.

The insertion of the balloon was more noticeable than when George had had the CAT scan previously, but it wasn’t too uncomfortable. In virtually all of George’s treatments, insertion of the balloon was smooth and painless, as was its removal. After the balloon was inserted, George replaced his right leg into the pod and the white sheet was folded around George’s body. Marvin then positioned George more precisely in the pod and told him not to move from that position until the treatment was completed. This position, determined by laser beams, is in accordance with the specific plan for George’s treatment.

The appropriate radiation dose to be given to a patient is calculated after dosimetrists and physicists have first worked up a plan of treatment by a computerized diagram representing a series of proton beams being administered from various angles. The attending radiation physician then approves the personalized plan. To ensure optimal accuracy in targeting the cancer, prior to each treatment low power x-rays, lasting only a few seconds, are also taken of the target area of the patient while he is lying in his pod in the treatment room. During George’s x-rays the therapists and Terry removed themselves from the treatment room.

The next step was to scan and insert George’s custom-made devices and his designated modulator wheel for his right hip into the equipment. Since corresponding parts of a person’s body are not symmetrical, custom-made devices for each hip had been specifically made for George for the purpose of shaping the proton beam to have it conform, on a three-dimensional basis, to the precise shape of his prostate. These devices consisted of bar-coded tissue-compensating filters and apertures. A computer program effectively prohibited commencement of treatment until the computer was satisfied that a laser-scan of the bar codes correctly identified the items as those made and prescribed for George, and not for another patient.

With a cheery “Hello”, the on-duty medical physician then came into Gantry 3. She checked over George’s x-rays, positioning and measurements, gave her authorization to commence treatment, and left.

Since other treatment rooms share the proton beam, the radiation therapists told us that the proton beam treatment would start as soon as the equipment was free. They then left the room with Terry. One minute later, Marvin popped in, told George the
equipment was now available and the treatment would begin immediately. He said it would take only a couple of minutes and George would hear the equipment when it started. He then left and returned to the control room.

After a minute or so George heard a quiet whirring sound, interspersed with beeps, about one beep every five seconds. He felt and saw nothing. After approximately 25 beeps covering about two minutes of time, the whirring sound ended. The radiation therapists and Terry came back into the room and he was told the treatment was over. George was asked to again lift his right leg on to the left side of the pod and the water balloon was removed. A little water from the balloon spilled out and wet part of George’s rectum and the left side of his buttocks. This turned out to be a regular occurrence.

George was told that the next day the treatment would be done through his left hip and that they would use his other bolus and aperture at that time. Subsequent treatments would alternate on a daily basis from one hip to the other in order to balance the radiation dose through each hip into the prostate gland.

We returned to the change room. George removed his designer gown and in the adjacent private washroom cleansed, dried and relieved himself. He then retrieved his clothing and shoes from the locker in the change room where he had stored them prior to going to Gantry 3 for his treatment.

We then headed for the elevators. While doing so Terry said that she had been in the monitor and control room while George was alone in Gantry 3. She told him she could see him on a television screen and viewed his treatment from there. George told her that during the actual time the proton beam was attacking his cancer he was praying.

It had taken about one hour from the time we had entered the hospital for George’s first treatment until we left it.
19. Loma Linda University Medical Center

“To make man whole.”

-- Loma Linda University Medical Center - Motto

Loma Linda University Medical Center (“LLUMC”) is a large non-profit private teaching hospital and trauma center in Loma Linda, California, a small city an hour east of Los Angeles. It provides a broad range of clinical and medical services to tens of thousands of inpatients and hundred of thousands of outpatients each year.

The LLUMC facilities consist of modern buildings with floor space comprising over 23 acres, including 800 hospital rooms. Among a number of other facilities at LLUMC are the Proton Treatment Center, a Children’s Hospital (world-renowned for infant heart transplants), and a research wing with laboratories. The main building has 11 floors.

The motto of LLUMC is “To Make Man Whole”. During our time in Loma Linda, we personally experienced and witnessed the practical application of this devotion by the staff collectively to the mind, body, and spirit of the patients. There is truly an institutional culture of compassion, dedication, and caring. In the July 19, 1999 issue of US News & World Report, LLUMC was named one of “America’s Best Hospitals for Cancer Treatment”.

This medical center is a Seventh-day Adventist institution. It is the principal educational center of the Seventh-day Adventist health-care system, a worldwide organization with nearly 600 medical facilities in over 70 countries. The roots of LLUMC go back to the founding of the Loma Linda Sanitarium in 1905 by the Seventh-day Adventists. Members of the Seventh-day Adventists are Protestant Christians who accept the Bible as their creed, and whose fundamental beliefs are based on their Church’s understanding and expression of the teaching of the Scriptures. They believe that the Second Coming of Jesus Christ is imminent.

Among other matters, adherents observe the Sabbath on Saturday and abstain from alcoholic beverages, tobacco, and irresponsible use of drugs and narcotics.

Seventh-day Adventist
http://www.adventist.org/beliefs/index.html

We ourselves are not Seventh-day Adventists and we have to say that there was absolutely no attempt whatsoever, directly or indirectly, to proselytize on the part of anyone before, during or after our sojourn in Loma Linda. No one talked to us in person
or at any meeting we attended in a manner that endeavored to persuade us or anyone present to convert to the religion or beliefs of the Seventh-day Adventists.

The patients being treated came from many walks of life and represented a diversity of religious beliefs. We have nothing but the highest admiration for the commitment of the LLUMC staff (some of whom are not Seventh-day Adventists) “To Make Man Whole”, and to their exemplary conduct and generally cheerful manner which we continuously beheld.

An International Circle of Care (“ICC”) has been established at LLUMC for its international patients. Since we are from Canada, the ICC took us under its wing. We have mentioned earlier the caring aid and assistance given to us by Lian Funada (the Intake Coordinator) and by a registered nurse Sharon Fox of the ICC. When we arrived at the ICC, they gave George his Patient Passport and asked him to keep it with him during his time at LLUMC as it provided his Medical Record Number and other information.

The mission of the ICC is to add to LLUMC’s ministrations by providing personalized attention and attentive support to the international patient that surpasses what he or she (or any physician who recommended LLUMC) anticipated or hoped for.

The ICC has qualified nurses and staff in its own suite of offices. The reception area at ICC is a welcoming one. Their professionals will provide assistance and help with respect to the various wants and necessities of the international patients during their time at Loma Linda. The services provided by the ICC include:

- A description and list of available housing in the area and assisting in finding accommodation, including personally driving the patient to view a number of sites;
- Accompanying the patient and spouse, if desired, to their initial consultation and support group meeting;
- Coordination of care;
- Culturally sensitive services;
- Advising of social and other activities; and
- Supplying information on local shopping, restaurants and services, means of transportation, airports, car rentals, the Metrolink train to and from Los Angeles, various attractions and sight-seeing venues (such as the Queen Mary Ocean Liner docked at Long Beach, the Getty Museum at Malibu, Disneyland, the San Diego Zoo, etc.)
The ICC also arranges for financial accounting and clearance and generally provides a great deal of emotional support through its welcoming open-door policy. It even permitted us the use of one of its computers.

**International Circle of Care**

[http://www.llu.edu/llumc/circle](http://www.llu.edu/llumc/circle)

In the same office complex is a Cancer Resource Center for all patients. This Center has a small lending library, videotapes and other material relating to cancer. It also has computers and a laser printer. Patients at LLUMC and their spouses are welcome to use this Center’s resource facilities, data, computers and printer.

One day after one of our visits to the ICC offices, we walked over to the Cancer Resource Center where a staff member showed us around. We used the Internet hook-up on a computer to print some articles on prostate cancer. We also picked up a number of relevant pamphlets on prostate cancer.

Since we believe that humor can enhance the immune system and can be helpful in the treatment of cancer, we were delighted to find an assortment of humorous cassettes and videotapes at the Resource Center. Before leaving, we borrowed from the Center a boxed series of four cassette tapes containing classic radio comedy shows from the 1930s, 1940s and 1950s. These shows included Jack Benny, Fred Allen, the Great Gildersleeve, Eddie Cantor, Burns and Allen, Our Miss Brooks, Fibber McGee and Molly, and others. We played these cassettes on our car radio whenever we were driving anywhere, and undoubtedly we discombobulated drivers in other cars caught in traffic jams on the freeway as we laughed hilariously.

Whenever we visited the Cancer Resource Center, there were usually one or more LLUMC patients on a computer retrieving emails from their home computer. Some of the other patients used the computers in the Loma Linda University Library for this same purpose.

The University of Loma Linda gymnasium, health club, exercise facility, spa, swimming pool and running track are located at the Drayson Center, a modern and comprehensive facility. As mentioned, patients of LLUMC and their spouses are given a free membership to the Drayson Center during the term of their treatment. This Center provides excellent facilities for performing physical activity to enhance the benefits of a patient’s treatment.

Our experiences at LLUMC substantiate that their motto “To Make Man Whole” is most appropriate. The words “whole” and “heal” have similar etymological roots. To heal a man is to make that man whole. One of the definitions of the word “whole” is “in all aspects of one’s being including the physical, mental, social, etc.”
20. The Proton Treatment Center

“All are but parts of one stupendous whole, whose body nature is, and God the soul.”

-- Alexander Pope, An Essay on Man

The facilities at Loma Linda University Medical Center (“LLUMC”), designed to treat various cancers by conformal proton beam therapy, opened in 1990. These facilities are collectively called the Proton Treatment Center and up to 160 cancer patients each day receive therapy. The Center was the world leader in providing proton beam treatments in a hospital setting. It cares for patients from early in the morning until late in the evening. The facilities are used for research during the late-night hours when patients are not being treated.

The Proton Treatment Center is in the Children’s Hospital wing of LLUMC and consists of two levels. The upper level has a reception area, offices, consultation rooms, administration and other facilities. The lower level (where the actual treatments take place) has a reception area, change rooms, offices, x-ray facilities, and the various constituent elements of the proton beam treatment system.

The spacious reception area on the lower level is where patients and their companions wait in comfortable chairs pending the patient’s treatment or pre-treatment preparations. There are always a number of patients either awaiting treatment or just completing it. Because of the commonality among them, there is camaraderie and a sense of community that pervades the area and develops continuing friendships. The brightly lit and wood-paneled reception area contains a television set, bookshelves, water cooler, card tables, washroom facilities, a play area for children, together with a supply of tea, hot chocolate, juice, and the like. While some people quietly read a newspaper or a book, most chitchat with each other while gathered around the water cooler, or while watching television, or working on a giant jigsaw puzzle or doing needlework or crossword puzzles. In the children’s playroom it is not unusual to see children or grandchildren playing, as did our grandchildren when they came with their parents to visit us.

The atmosphere in the reception area is convivial and leaves no room for moping. It is unlike any other medical or hospital reception area we have ever been in. The two of us actually looked forward to arriving at the reception area, being warmly greeted by the receptionist, and hobnobbing with the patients, spouses and companions that we had come to know and befriend. We in turn greeted those who arrived after us for later treatments. Chitchat and jokes often reverberated throughout the room.
Since George’s regularly scheduled time for treatment was soon set for 4:15 p.m., we straddled a change of shift for the receptionists. On our arrival Durleen was there, and was replaced at 4:00 p.m. by Jenny, an equally affable lady. The group receiving treatment around our time period came from places such as Indiana, Montana, Utah, California, and we met many people from numerous other States and from Europe.

One day Jenny told us that after our group left the reception area for the day she missed us and the laughter and socializing that occurred when our group was in the reception area. She said that later groups were not always as exuberant as ours.

Terry, whom George states is a highly engaging conversationalist who genuinely treats everyone as equally significant and worthwhile, was usually concurrently talking and crocheting baby blankets in the reception area, while she waited for George to have his treatment.

During our time in Loma Linda, Terry crocheted a total of six baby blankets. She gave one to the Level A receptionist’s new grandchild and the others we took at different times to the LLUMC Children’s Hospital Intensive Care Unit, and to Ronald McDonald House. This House is one of many such facilities in various cities where families may stay for a nominal charge while their critically sick or injured children are receiving medical treatment. Terry asked the nurses to give these blankets to sick babies who needed love, and the staff always expressed gratitude for these gifts. We received a note from the manager of the Ronald McDonald House that stated:

“Thank you for the beautiful baby afghan that you so lovingly made and donated to the Ronald McDonald House. We are so grateful to have such wonderful friends like you to help us better serve the families who stay with us.”

The Proton Treatment Center also contains the necessary and highly sophisticated machinery and equipment required for producing and delivering conformal proton beam therapy to cancer patients. Training and high-energy physics research in connection with the Center is continuous. Over 20 physicists and dosimetrists work for LLUMC, three of whom are on an all-night shift.

About a decade ago, the United States National Aeronautics and Space Administration (NASA) entered into a partnership with the Center to use the proton facilities of LLUMC for space radiation research. This facility is particularly suitable for NASA research since protons are the most common element of cosmic radiation. Another area of LLUMC study is to expand the scope of proton beam therapy to other cancers affecting larger areas. For example it is anticipated that proton therapy will be used for breast cancer at LLUMC in the near future.
There is a continuous search for improvements in current technology for cancer treatments. In the foreseeable future the necessity for the use of boluses, apertures, and energy modulators will cease due to engineering developments and plans for robotics in the gantries. Work is presently in progress to develop an active beam proton treatment system commonly known as the scanning beam. This system would use a pencil beam for three-dimensional scanning in the preparation of the precision patient alignment system and the delivery of the proton beam without the need for boluses and apertures.

Researchers at LLUMC are also inquiring into the “gated beam delivery” system in Japan. The purpose of this system is to program the proton beam for delivery according to the respiratory cycle of the patient to allow for any minimal movement of organs within the body during breathing.

Each year for more than a decade Ken Venturi has hosted the Proton Invitational Celebrity Golf Tournament in the Palm Springs area of California. This Tournament is a charitable event that benefits the Proton Treatment Center at LLUMC. Ken Venturi, a professional golfer who won the United States Open in 1964, was diagnosed with prostate cancer in August 2000, and was treated at LLUMC with conformal proton beam therapy.

The Proton Treatment Center established an International Proton Advisory Council about 10 years ago. It now consists of over 20 members. The Council’s basic function is to assist, advise and support the Center in its mission of helping cancer patients by means of the clinical application of proton beam radiation. Members act as advisers in the promotion and support of a number of relevant matters, such as the benefits of proton beam therapy and the development of ideas and plans to enhance the quality of life of human beings.
21. Our Southern California Experience

“A lasting inspiration, sanctified by reason, blest by faith:”
-- William Wordsworth, ... Tintern Abbey

After commuting from Palm Springs one hour to the east of Loma Linda for George’s first two treatments, we were able to move into an attractive apartment about a five minute drive from Loma Linda University Medical Center (“LLUMC”). The apartment was in a resort-like, gated community. It had swimming pools, large and small club-houses with various amenities, winding pathways bordered by palm trees, and regular activities for residents. Many cancer patients and their families from LLUMC stay there.

Although George’s treatments were the focal point of our weekdays, there were sundry activities and events that filled out our days in Southern California. These activities included:

• Tuesday lunches and Thursday dinners at area restaurants, organized by the LLUMC radiation social workers;

• Wednesday night support group meetings;

• Intermittent medical consultations with Doctors Rossi and Baer and Case Manager Sharon Hoyle;

• Many visits with family and friends both at Loma Linda and other locations such as La Jolla, Coronado, and Palm Springs;

• Shopping at the Nordstrom’s Rack at Chino, a half-hour drive away;

• Tuesday morning Mass at the smaller clubhouse of our apartment complex where additional acquaintances were made (Mary, a new friend from this group, gave George a beautiful crucifix on a chain to replace the one he had previously lost);

• A number of sight-seeing trips on weekends especially to various seaside communities along the Pacific Ocean;

• Daily walks for exercise and other activities.
When each of George’s Friday afternoon treatments was over, we felt like a couple of school children given the weekend off to enjoy ourselves as we saw fit, and we did.

Some prostate cancer patients at LLUMC told Wednesday night support group meetings that, except for the daily interruption of their treatments, they felt like they were on an extended holiday. They mentioned activities similar to those listed above and also that they went golfing, hiking, swimming, and biking. A nearby private golf club extended membership privileges to LLUMC cancer patients during their treatments.

As for the patients who lived in communities close to Loma Linda and who were not retired, it was not an extended holiday but work as usual since they were able to arrange their proton treatments around their work schedules. Some patients requested an early morning time for treatment in order to be behind their desk at the beginning of the workday and not miss a minute of work. Others made arrangements for late afternoon or evening treatment times in order to put in a full day’s work prior to their treatment.

From time to time the equipment in the Proton Treatment Center would temporarily break down and treatments would cease until the problem was remedied. On one occasion when we arrived for George’s daily treatment, the equipment had not been functioning for a couple of hours, and the repairmen were still at work fixing it. We saw Ed Schultz in the reception area talking to people. He spoke to us explaining that because of the complex mechanism, it sometimes takes several hours to trace the source of the problem. He then took a group of us on a behind-the-scenes look at a gantry. It was immense and looked very complicated. Ed told us that it was still uncertain whether or not the glitch in the equipment could be solved quickly.

After viewing the gantry, Ed invited the two of us back to his office for a chat pending repairs by the trouble-shooters. While in Ed’s office he told us that he had a girlfriend and that his wife was jealous. Consequently, he said, he kept his girlfriend in a trailer. We were taken aback at this revelation, but not quite because we knew the puckish sense of humor of this most jolly fellow. He then showed us a photograph of his wife and girlfriend together. His girlfriend was a beautiful Labrador dog.

During the course of treatments, our daughter Lolly’s (Laura) marriage was scheduled for March 10th, a Saturday. We arranged for a 5:45 a.m. treatment on March 9th in order that we could leave for the Los Angeles International Airport early that morning to catch a flight home to Calgary.

A stunningly beautiful and vibrant 40 year-old business executive with two children from a prior marriage, Lolly was married to Mike that weekend. We returned to Los Angeles and Loma Linda Sunday evening to ensure that George did not miss his regularly scheduled treatment on Monday. The whirlwind weekend at home had been filled with
much joy and merriment, huggles and kisses especially from our grandbabies. When our seven-year old grandson Mitchell saw George, his first words were “How are you feeling PaPere?”

During our time in Loma Linda we were visited on different occasions by our son George with his wife Holly and their children Mitchell and Terez; our daughter Catherine and her husband Mike and mutual friends from England, Carl and Karen; our son John from Vancouver; George’s sister Peggy and her husband Don from Manitoba; and our friends Andy and Marilyn from Paso Robles, California.

We in turn traveled to Palm Springs and Indian Wells for lunch or dinner with friends. We also spent a three-day weekend with our friends Mike and Mary in their La Jolla home and their oceanfront villa in Coronado Cay.

We continuously received and placed telephone calls from and to our children, siblings and friends. We were rather shocked at the size of our first month’s long distance telephone charges. However, our conversations always filled us with good cheer.

Humorously speaking, at times it seemed to us that George’s medical treatments were only a brief interlude in our extended winter vacation in beautiful, warm and sunny Southern California.
22. Wednesday-Night Magic

“…. what charms, what conjurations, and what mighty magic.”

-- William Shakespeare, Othello

The Cancer Support Group at Loma Linda University Medical Center (“LLUMC”) meets every Wednesday evening in the Hospital. Prior to commencement of the meeting, the patients and spouses in attendance (who frequently number up to 150) gather around chatting with each other while eating sandwiches and cookies, and drinking fruit juices provided by LLUMC.

On bringing the Meeting to order, Gerry Troy (the affable staff social worker with a great sense of humor) or a member of his staff puts everyone at ease by sharing a few jokes. One example that had the Group laughing uproariously was the following:

“Diapers and politicians have one thing in common. They should be changed regularly and for the same reason.”

The agenda for the Meeting includes brief comments from proton beam alumni who are visiting; patients imminently graduating from treatment; and those who have just commenced treatment or are at their first meeting, “newbies”. Occasionally there are one or two persons at the meeting who are checking out LLUMC before making a treatment decision.

The alumni usually report on their post-treatment situation (such as PSA history and side effects) and they often tell a joke or two. The graduates, without exception in our experience, praise the caring and friendly attitude of LLUMC doctors, nurses, social workers, and other personnel, as well as their own spouses or partners. Some with tears in their eyes thank God that they had found LLUMC. A few graduates sing their farewells and some recite poetry, which in some cases has been specifically written by them for their graduation.

The newbies relate how their cancer was discovered, their PSA levels and Gleason score, and how they happened to choose LLUMC for their treatment. A number state that when they received their cancer diagnosis, they felt that their urologist had a scalpel in his hand while recommending surgery and advised them they were fortunate because the urologist would be able to schedule them for a radical prostatectomy later that week or the following week.

When we attended the Support Group Meetings, patients then undergoing treatment often told of experiences or incidents that happened to them and asked the group for
advice or comments. For example, one patient said that during treatment he felt a metallic taste in his mouth, and asked if anyone else experienced this and what caused it. George, who was sitting not too far from Lisa (another of the social workers) who was chairing the meeting that evening, mischievously whispered to those around him “Maybe the rectal balloon was pushed up too high?”

Our little area erupted in raucous laughter. The gentleman who had asked the question had not heard George’s quip. Consequently he asked Lisa to repeat it, but with a broad grin on her face she demurred and said that she would tell him after the meeting.

The Support Group Meeting, at which 80 year old Warren from Florida graduated, witnessed Warren producing a life-size cardboard cutout of John Wayne dressed like a cowboy and pointing a pistol at everyone in the room. A message emanated from John Wayne’s mouth, which said “No More Balloons”. Warren had been a singer in musicals in his younger days and still visited Seniors Homes in Florida to sing to and entertain the residents, whom this octogenarian called “the old folks”.

As one Support Group Meeting was breaking up, Warren reminded everyone that St. Patrick’s Day was coming up in a few days. Terry, who is one-half Irish, said “Well, let’s sing some Irish songs”. She and Warren melodiously sang Danny Boy and When Irish Eyes Are Smiling, with many others joining in. This was a rousing finale to another upbeat Support Group Meeting.

One morning, when we were in the reception area on Level B to see Dr. Rossi, we bumped into Warren. George asked Warren if he had heard of the Proton Treatment Center’s new fire instructions. Warren said that he had not. George said: “In case of fire, grab your hat and get your coat, leave your worries on the doorstep. Just direct your feet to the sunny side of the street.”

After a burst of laughter, Warren said “I know those instructions, and I can sing them for you.” He burst into song with a spontaneous rendition of On the Sunny Side of the Street. We, as well as many of the patients and spouses in the reception area, heartily joined in. This positive milieu is radically different from the atmosphere we have found in reception areas of other cancer treatment facilities that we have been in. After we returned home to Calgary, Warren sent us a cassette tape of a number of songs that he sang and recorded especially for us along with a lovely personal message.

One of the highlights of many meetings is a guest speaker. Some of the guest speakers included:

• Dr. James Slater, a graduate in both physics and medicine and the LLUMC visionary who spearheaded proton therapy treatment in a hospital setting.
• Dr. Carl Rossi, Assistant Professor in the Department of Radiation Medicine of LLUMC, who also happened to be George’s attending physician.

• Dr. Dan Miller, Ph.D. and Chief Physicist at the LLUMC Proton Treatment Center. Dr. Miller oversees a staff of over 20 physicists and dosimetrists at the Center.

After their presentation, all of the speakers answer any questions that may be asked. For example the night Dr. Rossi spoke, George asked him if it was possible that a biopsy could spread the cancer.

Support Group Meetings last about two and one-half hours with some patients coming in from treatments part way through, and with others leaving the meeting early to go for their treatments. The group always disperses in a happy mood and a buzz of conversation.

What mighty magic has been performed.
23. The Majestic and Prestigious Brotherhood of the Balloon ("BOB")

“And crown thy good with brotherhood from sea to shining sea.”
-- Katherine Lee Bates, America the Beautiful

Inevitably the reception area at the Proton Treatment Center at LLUMC becomes a meeting place for prostate cancer patients and their spouses as they await the daily treatment. Various topics of discussion arise during the waiting period an eventually the conversation gets around to the famous balloon, usually in a rather humorous way. This is due to the fact that one of the procedures prior to the transmission of the proton beam into the patient's prostate is the insertion of a tubular balloon in his rectum that is then filled with four ounces of warm water. The balloon has the effect of keeping the prostate gland in place by pushing much of the bladder and the rectum out of the way of the proton beam, thus minimizing radiation-caused side effects.

In December 2000, Bob Marckini from Massachusetts was on the verge of finishing his treatments at Loma Linda. Over the coarse of his therapy, he and his wife had formed friendships with a number of men and their spouses that they had met in the reception area (a common occurrence). Bob suggested that they should remain in contact with each other after they returned to their various homes. By this means they could exchange information on their progress, any pertinent facts or concerns that they had, side effects they experienced, and other data. This proposal became the foundation stone for the Majestic and Prestigious Brotherhood of the Balloon, better known by its acronym “the BOB”.

To pursue this objective, they held a meeting and decided to invite other prostate cancer patients at LLUMC to become members of their group, which they subsequently named the BOB. Gerry Troy, the Chairman of the LLUMC Wednesday Night Support Group Meetings, agreed to extend an invitation to all patients in attendance at these meetings.

A graduate proton patient from a nearby community, Cal Jones, offered to attend the weekly Support Group Meetings at LLUMC, transcribe minutes of each meeting and transmit them by email to all members of the BOB. Sometime later the BOB members were asked to send in their nominations for the designation of the transcribed minutes. Out of many entries “BOB Tales” emerged as the winner. The job of taking minutes was subsequently taken over by volunteers attending meetings, and they are transmitted to the membership by the BOB organization.
The BOB prostate cancer support group communicates mainly by email, but there is a core of volunteers who fax or mail information to those without Internet facilities. While LLUMC is supportive of its objectives, the BOB is not an official organization of the Proton Therapy Center.

The BOB is a volunteer, non-profit group dedicated, among other matters, to assisting BOB members and spreading the good word of proton beam in the treatment of prostate cancer. There are no membership fees, and the only qualification is to have received proton beam therapy at LLUMC for prostate cancer. The membership is continually growing, and as of November 2004 the BOB had over 1,600 members. It has invited past LLUMC proton beam patients (who finished their therapy before the BOB was formed) to join the BOB.

The BOB activities include, among other matters:

- Assisting and supporting BOB members and prospective patients in dealing with a broad range of questions, concerns or issues they may have such as treatment information, side effects, insurance coverage or denial, nutrition, and similar matters.

- Keeping the BOB members advised of goings-on at the Wednesday night Support Group Meetings by emailing them the BOB Tales (a copy of the minutes of the meeting) or mailing them to members without email access.

- Spreading the good news about proton beam therapy.

- Maintaining a BOB membership list with various data, such as name, address, email address, telephone number, date of graduation from treatment, age when treated, PSA reading when treated and currently, Gleason score, insurance carrier, and other information.

- Distribution of videos and other material relating to LLUMC and proton beam therapy to members and inquirers.

- Receiving and charting the ongoing PSA levels of members who provide them, a task carried out by BOB member Roy Butler of Vermont.

- Maintenance of a Web site that provides information to the public on proton beam therapy and matters relating to prostate cancer, as well as dedicated areas for BOB members.

**Proton Bob**

[http://www.protonbob.com](http://www.protonbob.com)

- In conjunction with LLUMC, regional reunions of patients who have been treated with proton beam therapy. These meetings are held in various areas
of the United States and in Canada. A principal person involved in these reunions is Dr. Lynn Martell, Vice President of Advancement at LLUMC.

We attended the first reunion for the Northwestern United States and Western Canada that was held in Seattle on May 5, 2002 at Seattle Pacific University. About 80 graduates and their spouses attended to hear talks by Dr. James Slater (Professor of Radiation Medicine at LLUMC) and Dr. Jerry Slater (Chairman of the Department of Radiation Medicine at LLUMC). Other speakers were Dr. Lyn Martell, Gerry Troy, Jerry Klein (a proton beam alumnus from the Seattle area), and Bob Marckini who spoke on the BOB. After the meeting we attended a dinner with a number of people, including members of the BOB and LLUMC personnel.

We subsequently attended a BOB reunion in Calgary in August 2003.

From time to time BOB members are asked to provide information to inquirers with prostate cancer who are researching their treatment options, including proton beam therapy. For example a Californian who had been recently diagnosed with the disease emailed BOB members and stated that he would appreciate it if he could get some feedback on our experiences. Although we do not know how many replies he received, we responded as follows.

Dear Bill:

Further to your email of March 23/02, we found the Loma Linda experience exceptional. The staff were outstandingly caring and compassionate. At the time of diagnosis, George’s PSA was 6.3 and his Gleason score was 3+3=6. Since the end of his treatment in March 2001, George has had two post-PSA tests – one at 0.5 and the latest at 0.3.

George is feeling great and has had no major side effects. His minor effects are that his nighttime urination is hesitant; he remains potent but not as strong as previously; and he infrequently has small amounts of blood in his stool. In his Consultation Report, Dr. Rossi had pointed out mild rectal bleeding as a common late effect.

We live in Calgary, Alberta, Canada, and because of the mandatory government medical coverage in Canada the Alberta Government Medical Plan only reimbursed us for 6% of the cost of the Proton Beam Treatment that George received at Loma Linda. Notwithstanding this, if we had to make the choice over again we would still choose to go to Loma Linda for Proton Beam Therapy at our own expense, even though other treatments provided and received in Canada would
have been paid in full by the government medical plan. After George’s treatment we were contacted by two people from Calgary who have subsequently taken and recently completed Proton Beam Therapy at Loma Linda.

We researched many different types of treatment for prostate cancer and spoke to cancer patients and medical personnel before we made the decision to go for Proton Beam Therapy. In our research, we were particularly concerned with three aspects of the various treatments namely

- The effectiveness of the treatment;
- The side effects - the subsequent quality of life; and
- The options for later treatment if the prostate cancer reoccurs (George’s older brother had a radical prostatectomy for prostate cancer and the prostate cancer reoccurred 12 years later and he has since died).

Of course, only you can make the final decision, but we are of the opinion that you are right on track by researching and taking control of the decisions that must be made concerning your treatment for prostate cancer. We wish you success on the road to your decision and in the outcome of your treatment.

If you have any questions, please feel free to contact us again.

Do give Dr. Rossi and his Case Manager Sharon Hoyle our best wishes when you go for your consultation.

Best Regards & Dominus Vobiscum (“God be with you”).

The BOB’s activities continue to expand. We continue to receive information on prostate cancer from the BOB that we find helpful and inspiring. We believe that the mission of the BOB will continue to inspire not only its members, but provide invaluable knowledge and assistance to all those seeking information on proton beam treatment for cancer, particularly prostate cancer. The future looks bright for the Majestic and Prestigious Brotherhood of the Balloon.

The good which proton beam therapy rendered to George was indeed crowned with brotherhood - the Majestic and Prestigious Brotherhood of the Balloon - not only from sea to shining sea but also from many regions of the world.
24. Final Treatment

“And we find at the end of a perfect day the soul of a friend we’ve made.”

-- Carrie Jacob Bond, A Perfect Day

A number of days before the end of George’s scheduled treatments, Sharon Hoyle tracked us down on Level B of the Proton Treatment Center to give George another folder containing a follow-up schedule and information sheet. The Proton Therapy Follow-up Schedule provided dates for follow-up examinations, PSA tests and DREs, commencing four months after completion of treatment and at six-month intervals for the following five years and annually thereafter.

She explained that these follow-ups could be done in Calgary by our own doctor, but requested that all progress and testing reports be sent to LLUMC’s Oncology Clinical Research Office. She told us that LLUMC follows its proton patients on a lifetime basis.

During George’s last week of treatment, we went to see Dr. Rossi on his clinic day in order to personally bid him farewell prior to our departure for home. It ended up as a jovial photo-op for us with Dr. Rossi, Sharon Hoyle and Ed Schultz. Sharon told us that she would send to our Calgary home a copy of Dr. Rossi’s final treatment report. Information from this report is given hereafter.

That evening at the regular Wednesday support group meeting, Dr. Rossi was the guest speaker. He gave a highly informative talk to a standing-room only group of over 150 patients and spouses. Since the pointer for the overhead projector system was missing, Gerry Troy found a fishing rod as a replacement, causing a great deal of amusement to all present.

One of the other patients, Jim from Texas, videotaped Dr. Rossi’s presentation and sent us a copy of it after we returned home.

On each of the last two treatment days, the radiation therapists presented each patient with their own custom-made bolus (one for the left side and one for the right side). When a patient enters the reception room from the treatment area carrying a bolus, everyone is happy for that patient on the completion of his treatments.

The day before George’s final treatment we delivered small gifts to various staff members at LLUMC and the International Circle of Care. With hugs, we thanked them for their wonderful caring treatment and attention.
Lisa, a Radiation Medicine social worker, presented George with a Certificate of Completion of the prescribed treatments and gave a Distaff Diploma to Terry. Photographs were taken of these presentations. George’s Certificate stated that he: “… has successfully completed the prescribed treatments…. relating to his prostate cancer” and that he was “a graduate of the Water Balloon Brigade”

Terry’s diploma stated the she had received it for: “…. having cooperated with the Proton Radiation Department at LLUMC, by making no uxorial demands; withstanding the onslaught of demanding schedules in delivering her husband on time for his water balloon thrill, knowing the locations of all nearby relief stops; and in general being a major influence in the satisfactory completion by her husband of the ‘Water Balloon Brigade’ course offered at LLUMC.”

That evening we went for our final Thursday night dinner with the Cancer Support Group at Jean’s French Restaurant in nearby Colton. We said our good-byes to many of the new friends we had made at LLUMC. During the prior few days, some of our group of friends had finished their program of treatment and we had exchanged small gifts with a number of them and their spouses.

As each patient of our group entered the reception area after his final treatment or next to final treatment, he was greeted with cheers, blowing of horns and noisy merriment from everyone in the reception area, especially from our group.

Due to a stoppage of the equipment on the final Thursday, George’s last treatment was rearranged to the morning after our Thursday night dinner at Jean’s French Restaurant. Our regular group of friends and spouses, who were treated in the afternoon, were therefore not present.

Among the patients in the reception area that morning were a number of people we had met at the Wednesday Night Support Group Meetings or other activities. This group took up the slack and provided rousing cheers and congratulations as George entered the reception area after his final treatment. Photographs were taken of George and some other patients who had also finished their proton treatments.

After having lunch, we hit the road north for Paso Robles, California to visit our friends Andy and Marilyn for a few days on our way home. Another law school classmate of George and Andy was also visiting from Winnipeg, Manitoba. On Saturday morning we all attended the Paderewski Festival Breakfast in the historic Paso Robles Inn. Jan Paderewski, renowned pianist and one-time Prime Minister of Poland, had resided off and on for a number of years in the Paso Robles Inn.

We left early Sunday morning and leisurely drove home to Calgary, arriving four days later. It was the end of our remarkable, exhilarating journey of hope, inspiration and healing.
25. Final Medical Report

“Here is my journey’s end ....”
-- William Shakespeare, Othello

A short time after we returned to Calgary from our journey of treatment and healing for George’s prostate cancer, we received a copy of George’s Radiation Medicine Treatment Summary from Dr. Rossi. This Summary stated in part:

**PLAN OF TREATMENT**

Definitive radiation therapy consisting of conformal proton beam radiation therapy.

**DOSE**

The patient received a total dose of 78 cobalt Gy equivalent to the prostate and seminal vesicles.

The patient underwent a CT scan in a custom, whole body immobilization device for three-dimensional treatment planning. A beam’s eye view treatment plan was generated which encompassed the prostate, seminal vesicles and 1.2-cm margin, from which custom apertures and computer-milled bolus were fabricated. The appropriate aperture, bolus, and modulator wheel were utilized daily, which was confirmed by individual bar code scanning.

The patient was treated with parallel opposed lateral fields alternating between the right and left sides using 2.0 cobalt Gy equivalent fractions daily with a proton beam energy of 225 MeV. Dose was calculated at isocenter. A total of 39 fractions were given over 58 calendar days, thus delivering 78 cobalt Gy equivalent.

A water filled rectal balloon was placed daily prior to treatment, which had also been placed at the time of the CT planning scan, in order to displace the posterior rectal wall from the proton beam. The patient was also asked to drink 1 to 2 glasses of water, approximately 30 to 60 minutes prior to treatment and not empty the bladder, so as to displace as much of the bladder wall as possible outside of the proton field. Orthogonal films of diagnostic quality were taken by the radiation therapist and checked each day in order to verify the patient’s position prior to treatment.
STATUS OF TUMOR

No evidence of disease progression or recurrence.

TOLERANCE

Mr. Goulet tolerated treatment reasonably well. His weight remained generally stable throughout his course of treatment. He did experience some mild to moderate urinary hesitancy, which did not require treatment with symptomatic medications during therapy. He experienced the expected skin erythema by the completion of radiation treatment. There was no moist or dry desquamation noted.

DISPOSITION

Mr. Goulet will be returning to his home in Canada following completion of therapy. He will follow up with his physicians there as per our recommended protocol.

The amount of radiation dose received during proton beam therapy can be calculated to provide what the equivalent radiation dose would have been, had conventional radiation been used. In George’s case, the Radiation Medicine Treatment Summary he was given after treatment shows that his total dose was 78 cobalt Gy equivalent. The Gy is the unit of the absorbed dose of ionizing radiation based on the international system of units.

Besides drinking the two glasses of water prior to each treatment, George received advice at Loma Linda that he should drink a total of eight glasses of water a day. As a result of the treatment and the water intake George’s urinary frequency increased, particularly during the night. He often arose from bed four or five times a night to urinate, which interrupted his sleep and resulted in increased fatigue during daylight hours. During treatments he napped twice a day, rather than his usual one nap a day, and this compensated for the sleep he had lost at night.

Once we returned home, George’s fatigue and urination frequency during the night abated and he returned to his regular routine of one nap a day. As for the skin erythema (redness of the skin), this occurred on the area of his hips where the proton beam was directed. This redness disappeared shortly after returning to Calgary.
After treatment he has had only minor side effects. He did have some nighttime urination hesitancy, which has since significantly lessened. He remains sexually potent although he produces less ejaculate and is not as robust as he was when he was a young buck.

A late side effect was blood in his stool. This occurred infrequently during the eighth to tenth months after George finished his treatments. When this initially occurred, between Christmas and New Years, it frightened us. As our family doctor was away for the holidays, we telephoned the hospital at Loma Linda and asked for the urologist on call. We were immediately transferred to Dr. David Smith, who spent more than 15 minutes with us allaying our fears and advising us that this was not an unusual late side effect of treatment. He suggested that once our family doctor returned we should, as a precaution, make arrangements with him for George to have a colonoscopy (an examination of the colon to check for polyps, etc.) and a blood test (to check for anemia from loss of blood).

When our family doctor returned he told us that it would take nine months for George to obtain a colonoscopy in Calgary due to the backlog in our diagnostic facilities. He recommended a barium x-ray since this could be done in a matter of weeks, and we followed this advice. Due to a cancellation, George was able to get this barium x-ray in less than a week. This x-ray indicated that there was only minor irritation to George’s bowel, obviously due to his treatments. As for the blood test, it was fine. The intermittent blood in the stool disappeared after a couple of weeks and has not returned. In our anxiety when George first had blood in his stool, we had forgotten that George’s initial Consultation Report from Dr. Rossi in January 2001 had stated:

“The late effect most commonly experienced by patients has been mild rectal bleeding occurring anywhere from 6 months to 2 years following treatment. This resolves spontaneously in most patients.”

All in all George has felt great and has had no major side effects. Since his treatment he has had regular semi-annual follow-up exams with DREs and PSA tests. These follow-up tests have shown a sharp reduction in his PSA level that has filled our hearts with joy.
26. Nutrition and Diet

“... it lives by that which nourisheth it.”

-- William Shakespeare, Antony and Cleopatra

From the various material that we read, we came to the conclusion that what a person eats and drinks has a significant effect on one’s health and that what we eat could have an impact on whether or not we develop cancer, and subsequently on the healing process.

The incidence of prostate cancer is markedly lower in Asian countries, particularly Japan and China, than it is in North America. Many believe that the substantial variation is attributable to the different diets in Asia. The elevated amount and type of dietary fat consumed in North America is believed by many to be the cause of the higher percentage of prostate cancer in North America over that in Asia. Items in the North American diet that contain harmful fats include processed foods, fast food and many baked products. On the other hand in Asian diets soy, seaweed and fish are staples, and less fats are eaten. Green tea, which some believe to be a potent cancer preventative, is also consumed.

The following provides a brief description of information that we have noted from our research and in some instances suggestions as to what foods should be avoided and those that should be consumed. For more detailed information on these matters one should read books on the subject or consult with a qualified nutritionist.

Fats and Oils

The four types of dietary fats are saturated fats, polyunsaturated fats (which include omega fatty acids), monounsaturated fatty acids, and trans-fatty acids. Not all fats are bad. The main culprits with the potential of weakening one’s healing system and contributing to the onset of prostate cancer (as well as heart and vascular problems) are saturated fats, some polyunsaturated fats, and trans-fatty acids. Monounsaturated fats and some polyunsaturated fats have beneficial effects, while saturated fats, trans-fatty acids and some polyunsaturated fats (particularly the Omega-6 fatty acids referred to below) are considered unhealthy and may be a cancer threat.

Saturated Fats

Saturated fats are primarily derived from animals and their by-products (such as red meats, whole milk, butter, cheese cream, duck, unskinned chicken, lard and suet, ham, bacon, and sausages), and in some vegetable fats (such as palm kernel oil and coconut oil) and from vegetable shortening.
Polyunsaturated Fats

Some polyunsaturated fats are beneficial in one’s diet; others are not. These fats are either:

- Omega-6 fatty acids, considered unhealthy, which are found in vegetable products such as sunflower, corn, cottonseed (that likely has no nutritional value) and safflower oils.

- Omega-3 fatty acids (also known as essential fatty acids) which may protect against cancer and promote healing; they are contained in cold-water fish such as salmon, sardines, herring, mackerel, cod and the like, as well as in hemp oil, flax oil, and flax seed.

Monounsaturated Fatty Acids

Monounsaturated fatty acids may assist in preventing cancer. They are present in vegetable oils, of which olive oil is the most advantageous. The best quality of olive oil is extra-virgin, which is the initial oil removed in the manufacturing process. Vegetable oils (those which are not polyunsaturated Omega-6 fatty acids) are good, but vegetable shortening (which contains saturated fats) is not. Avocados are a good source of monounsaturated fat.

Trans-Fatty Acids

Trans-fatty acids are not beneficial to one’s health and may be a cancer risk. Any food that contains “partially hydrogenated oil” is a product with trans-fatty acids and that food item should be avoided. This fat is found in margarine, some cooking oils and in the fat ingredients in most processed foods. Trans-fatty acids are a result of the hydrogenation process.

One cannot remove all fats from one’s diet, nor is it advisable to do so. Good fats are essential to good health and are needed for the absorption of vitamins and minerals, particularly fat-soluble vitamins. Although some vitamins such as vitamin C are water-soluble, a number of vitamins such as vitamins A, D, E, and K are fat-soluble. What is important is the selection of good fats to promote good health and the avoidance of saturated and other unhealthy fats in one’s diet.

Antioxidants and Free Radicals

Free radicals in the body undermine the immune system. When one eats, energy is created by oxidation as a result of metabolism and this process also creates free radicals. Antioxidants undermine and attack free radicals and block their potential to
cause cancer. These antioxidants are primarily found in certain nutrients, such as fresh fruits and vegetables. Supplements, such as vitamins C and D, carotenoids (particularly lycopene) and selenium are considered beneficial. Phytochemicals and flavonoids are found in fruits and vegetables. Many sources state that the appropriate intake of fresh fruits and vegetables in a person’s diet should be eight to ten servings per day. Some examples of nutrients that help in battling cancer and free radicals are:

- Fruits such as raspberries, cranberries, black raspberries, blackberries, loganberries, boysenberries, red grapes, strawberries, kiwi, peaches, pears, oranges, melons, papayas, bananas, apples, mangoes, and others.

- Vegetables that are deep yellow or dark leafy green in color and of the onion and cabbage families- examples include broccoli, brussels sprouts, spinach, sweet potatoes, carrots, squash, cauliflower, tomatoes (a great source of lycopene especially when cooked), turnips, onions, garlic, shallots, leeks, lettuce, cabbage.

Fruits and vegetables are the natural source of vitamins and minerals that are essential for health and wellness.

**Grains and Legumes**

The American Cancer Society states that besides fruits and vegetables, “really good foods” are various beans and foods made from whole grains. Examples are lentils, garbanzos, pinto, kidney, lima, split peas and soy bean products such as tofu, and foods made mostly with wheat, rye, oats, barley and brown rice. Fruits, vegetables, and cereal and bread made from whole grains, are sources of dietary fiber.

**Proteins**

Proteins are organic compounds made from chains of amino acids and are necessary in the diet for healing and the development of tissue. Both vegetable and animal matter contain protein. Animal sources include meat, fish (particularly salmon, herring, mackerel, cod, sardines, etc.), domestic fowls, milk; vegetable sources are grains, beans, several types of nuts, and also soy products. It is now believed that humans do not need large amounts of protein in their diet, and that animal protein should be consumed in moderation.

**Soybean, Soymilk and Tofu**

Since it is high in protein, the legume plant soybean is used as a substitute for animal protein. Soybean milk (which may also be used in place of dairy milk) is used to make
tofu (a curd of varying consistency) that is used in vegetarian recipes and Asian cooking in place of meat or fish.

**Carbohydrates**

The primary sources of energy for the body are carbohydrates. Non-processed and non-refined carbohydrates such as fresh fruits and vegetables are the best sources of carbohydrates. They have the added benefit of containing vitamins, minerals and fiber. Some examples of carbohydrates that are frequently processed and refined are white rice, breads, pastas, baked goods, white and light-colored sugars, and starches. They are high in calories but have little nutritional value compared to other foods. There are a number of healthy substitutes for some of these foods such as brown or wild rice instead of white rice, and demerara brown sugar or honey in place of white sugar.

**Water**

Fluids, particularly water, are not only a necessity in a healthy diet, they are essential to maintain life. The recommended daily intake of water is eight glasses, particularly since body fluids are continually being depleted by perspiration and urination. A lack of water can compromise the immune system.

**Other Fluids**

A number of sources indicates that green tea helps to prevent cancer and is a potent killer of prostate cancer cells. See for instance the section of the Mayo Clinic Web site entitled *Prostate Cancer and Green Tea*. One or two daily glasses of red wine may also be a source of antioxidants, although the same result may be obtained from red grapes and the juice made from them.

Based on our review of dietary factors after George’s diagnosis of prostate cancer, we came to the conclusion that we should totally discontinue eating all red meats, that is all beef, ham, pork, lamb and veal - and we have done so. We do eat skinless turkey and chicken, salmon and other fish, and legumes. We consume on a daily basis significant amounts of fresh fruits and vegetables. At a later date we all but discontinued the use of milk and replaced it with soymilk fortified with calcium.

After George’s diagnosis of prostate cancer, we continued having our usual daily breakfast. This consists of a big bowl of a variety of fresh fruit, an eight-ounce glass of non-concentrated juice, homemade granola with dried fruit and roasted nuts and seeds (also in George’s case a bowl of freshly cooked cereal) and a cup of black coffee. The granola and oatmeal cereal are fortified with a 12 grain cereal to which extra flaxseed has been added. This meal provides us with protein and fiber together with fresh and dried fruit.
We now usually drink a cup of clear green tea daily. Until we started using soymilk recently, we used only one-percent partly skimmed milk, and no cream. We purchase whole grain bread and use extra-virgin olive oil for cooking and salad dressing, and we eat eggs, butter and cheese in moderation. We discontinued using margarine, and avoid processed foods (with partially hydrogenated fats) and fast foods.

After he discontinued eating red meat, George’s unclothed weight dropped from 168 pounds to 160 pounds in a few weeks without any dieting. With the dietary changes we have made, our food tastes as good or better than previously and we do not experience the weightiness or distention to our stomachs that we experienced when eating red meat.

Besides eating tomatoes (which are rich in lycopene especially when cooked) George also takes a daily supplement of 10 milligrams of lycopene. Lycopene is a front-line fighter of free radicals, and is believed to significantly reduce the risk of prostate cancer.

Prior to commencing treatment for his prostate cancer at Loma Linda University Medical Center (“LLUMC”), George was required to complete a Personal History form. For the digestive system section of the form, George was asked to indicate average food selections for each meal. This section was completed as follows:

**Breakfast:** Juice, Fresh Fruit, Oatmeal and Granola with Milk, and Coffee.

**Lunch:** Soup and/or Sandwich, Fresh Fruit, Water.

**Dinner:** Fish or Fowl, 3 or 4 Vegetables, Dessert and Water.

When we gave the completed Personal History form to Sharon Hoyle she reviewed it, and in relation to our diet she asked us very specific questions as to types and quantities of foods. Her grasp and knowledge concerning good nutrition reflected the healthy lifestyle eating habits practiced at LLUMC.

There are at least eight to ten fresh fruits in our breakfast salad, the selection of which is made according to seasonal availability. In addition we sprinkle four or five types of dried fruit on our granola. To the granola we also add roasted seeds and nuts. Besides having fruit at lunch, our desserts with dinner are usually fruit-based.

Now and then we deviate from our dietary regimen, particularly when dining out. We may then share a tasty dessert, a sticky bun or a roly-poly donut, but we never have red meat.
We found that the easiest method of reducing the saturated and unhealthy fats from our diet was to discontinue their use in our home, except for moderate amounts of butter. We now use only extra-virgin olive oil and butter in the preparation of meals. Terry tried to eliminate butter entirely, but found that in some cases the food was quite unappetizing and bland. The solution was the moderate use of butter in appropriate recipes. As mentioned previously, we use very little milk and have replaced it with calcium-fortified soymilk.

Within the last year we received information from several sources that plastic containers and wraps should not be used in microwaves. It is believed that the high temperatures in microwave ovens can cause the breakdown of the molecules in the plastic causing unwelcome elements to enter the food. It is believed that fat, high heat and plastic in combination release dioxins (which are carcinogenic and highly toxic) into the food and subsequently into the cells of our body. Since we do not know the content of paper products, they too may be suspect and should be avoided when using a microwave oven. Since reviewing this information we have used only ceramic or glass containers, and eliminated the use of plastic wraps and paper products, in microwave cooking.

We have also noted a concern that cooking foods for any length of time in a microwave can affect their chemistry and structure, particularly those foods that contain proteins. Therefore these appliances should not be used for recipes that require longer cooking times.

Some people considered our dietary changes to be too late in the day, since some of them were made after George’s prostate cancer diagnosis. It was as if we were closing the barn door after the horses had escaped. Our feeling is that our dietary changes contribute to preventative measures that may reduce the risk of cancer recurrence in the future as well as the risk of heart disease. Our readings indicate to us that the nutrition for cancer prevention is relatively the same as that for heart and vascular medical problems. It is our view that good nutritional habits contribute to the maintenance and improvement of health.

Since we each have high blood pressure, this type of diet is also beneficial to our cardiovascular well-being. Following the same dietary regimen makes shopping for food and preparation of meals much more convenient. In addition, we both generally feel healthier as a result of these dietary changes.
27. Lifestyle Considerations

“By nature honest, by experience wise, healthy by temperance, and by exercise.”

-- Alexander Pope, Epistles and Satires

Lifestyle has a significant influence on a person’s health. For example, excessive use of alcohol and tobacco can cause serious medical or sociological problems. Lung cancer and emphysema are often a result of smoking, and cirrhosis of the liver can result from immoderate use of alcohol. Although both are considered recreational drugs, inordinate usage can deleteriously affect one’s health since both are toxic and poisonous.

As well, many homicides and fatal accidents are a direct consequences of the intemperate use of alcohol. We personally gave up alcohol in the 1980s because, as we drolly say, we figure God gave us a lifetime quota of how much we could drink and we used it up too fast.

If an individual or members of one’s immediate family have experienced problems with alcohol in the past, extra caution should be used in its consumption. Serious consideration should also be given to the amount of alcohol consumed in relation to a person’s age as one’s capacity to tolerate its effects is reduced with age.

Tobacco is a highly addictive narcotic and a very difficult habit to kick. George has never smoked, while Terry (then a two-pack a day smoker) gave up smoking cold-turkey in the late 1980s. Tobacco contains carcinogens, substances that produce cancer. Since the inhalation of tobacco smoke is a significant contributor to cancer, second-hand smoke can also cause lung cancer.

After George was diagnosed with prostate cancer we made a number of lifestyle changes - in body, mind and spirit.

In addition to changes to our diet as described in the previous Chapter, we exercise in a manner appropriate for our age. Exercise keeps the body in shape, promotes health, and stimulates the immune system. It heightens a person’s self-esteem and contributes to a feeling of well-being, leaving no room for feelings of helplessness or inadequacy. A positive state of mind can play a prominent role in a person’s health, and may assist in preventing disease and aid in recovering from illness.

Walking may be the most beneficial form of exercise for older persons. To receive the greatest benefit one should walk briskly for around 25 to 30 minutes, either daily or three
or four times a week. Other healthy types of exercise are hiking, biking, group classes, or similar activities. However, older people should not exercise in an over-strenuous manner or in a way which may cause injury.

We do light warm-up exercises every morning, including lifting five pound and eight pound weights. In addition to exercise, the human body requires adequate rest. We usually get over nine hours of sleep each night. In addition George has a nap for 20 to 30 minutes most afternoons, as was the case before his cancer treatments. We believe that proper exercise and appropriate rest are beneficial both physically and mentally.

Many medical professionals may have a one-dimensional-approach to medical care, dealing with the body but giving little attention to the power of the mind in the healing process. However, there appears to be a movement among a number of health care providers to give more credence to the significance that the mind plays in the well-being and in the healing process of patients.

In the book *Spontaneous Healing* by Dr. Andrew Weil there is an entire chapter that deals with “The Role of the Mind in Healing”. In his book *Anatomy of an Illness*, Dr. Norman Cousins, Ph. D, expresses the philosophy that the mental attitudes of patients have a great deal to do with the course of their disease. Besides other matters, the book *Love, Medicine & Miracles* by Dr. Bernie Segal deals with the relationship between mind and body and affirms that the brain controls the immune system. He also talks in this book about exceptional patients who are survivors.

*Spontaneous Healing, Dr. Andrew Weil*  

*Anatomy of an Illness, Dr. Norman Cousins*  

*Love, Medicine & Miracles, Dr. Bernie Segal*  

In the book titled *Getting Well Again*, Dr. Carl Simonton and his co-authors provide a guide to overcoming cancer. Their hypothesis is that the mind and the body are an integrated system and that the “whole person” must be engaged towards health to make recovery more probable. This book sets forth two “mind/body models”, one to demonstrate how the mind and body can interact in the commencement of cancer and the other to show how they cooperate health-wise.

*Getting Well Again, Dr. Carl Simonton*  
The startling beneficial results sometimes obtained from taking a placebo (a pill or medicine having no physiological effect) confirms the connection and inter-workings of the mind and the body. The immune system (innate to all living creatures and whose purpose is to fight off disease) cannot fend off attacks to the body’s health if it is impaired. In some manner a placebo may re-energize the immune system by providing faith and hope.

The National Institutes of Health in the United States have issued a booklet with a self-explanatory title *The Immune System - How It Works*.

*The Immune System - How It Works*
http://www.niaid.nih.gov/publications/immune/the IMMUNE SYSTEM.pdf

In his book Dr. Norman Cousins stated that “laughter is good medicine” and there are studies that support this view. An example is a 1996 audio tape supplemented by a booklet entitled *Laughter and the Immune System, a serious approach* by Drs. L. Berk and S. Tan. This study established that persons had their natural killer cell activity significantly increased by viewing a comedy presentation. Natural killer cells are cells that seek out and destroy abnormal cells.

*Laughter and the Immune System, a Serious Approach,*
Drs. L. Berk and S. Tan
http://www.amazon.com/exec/obidos/tg/detail/-/0965024032

We mentioned in an earlier Chapter that during George’s treatments we listened to tapes of old-time radio shows of classic comedians, and we would often laugh uproariously when driving around California. We regularly watch funny television shows particularly English comedies such as *Fawlty Towers, The Vicar of Dibley, Yes Prime Minister, Are You Being Served, As Time Goes By* and others. We call these our daily dose of humor. We also regularly receive emails with humorous stories and jokes from two of the couples that we met at Loma Linda, one from Florida and one from California.

It is our belief that mental attitudes can assist and vitalize the immune system. Some examples are faith in one’s treatment and medical consultants; love for and by family and friends; establishing meaningful achievable goals; forgiveness of those who may have hurt us; hope for and confidence in the future; and a spiritual outlook on life.

Our goals include continuing to collaborate in writing and producing a number of books, and continuing to give public talks. We have been mentally planning several other books, which will in total likely take eight to ten years to research and write after this book has been put to bed. We were well into the research stage of one of these books when our project was temporarily sidelined due to George’s prostate cancer diagnosis and our zeal to share our experiences in this book.
Visualization (mental imagery) and meditation are believed by some individuals to assist in the healing process. Contemplating a tumor being attacked and eaten by barracudas is one example of visualization. George’s brother Lionel in Toronto is a devotee of transcendental meditation and sent George tapes and literature on it. However, George found that constantly repeating a mantra and trying to clear his mind was not very fulfilling. Instead meditating about the destruction of his prostate cancer, and about his body becoming healthy, were much more satisfying to him. Some people find that other types of meditation, such as religious contemplation, prayer, and positive reinforcement are effective ways to supplement the healing process.

Some studies suggest that prayer, faith and spirituality may be beneficial to one’s health. Although they may be insufficient in themselves to cure cancer, they may activate a stronger immune response to disease. Together with appropriate treatment, they may inspire hope and peacefulness when one’s future appears dismal.

As a small boy, George was brought up during the Great Depression of the 1930s in a home where food was in short supply from time to time. He recalls his mother, in these distressing circumstances, reciting Psalm 23 “The Lord is my Shepherd, I shall not want”. Seemingly miraculously, food for the family would somehow materialize. As Alfred, Lord Tennyson sublimely put it:

“More things are wrought by prayer than this world dreams of.”

We believe in the powerful influence of prayer on the healing process, prayers not only by the person who needs them but also prayers by others. In our Christmas letters to friends and relatives we told them of George’s diagnosis with cancer, and asked them to join with our family in praying for the success of George’s treatments. This request for prayers also accompanied our annual Christmas charitable and religious donations. Our daughter Laura also requested prayers for George from her Internet prayer group.

We are practicing Roman Catholics and were so when George was diagnosed with prostate cancer. Nevertheless, after the diagnosis we became much more focused about prayer and spiritual matters. We wanted to have a feeling of spiritual well-being before George embarked on his cancer treatments. A short time before Christmas we went to see our Parish Priest, Father Robert Kazun, to let him know that George had cancer and that we were leaving shortly for treatment at Loma Linda. He gave both of us a blessing and made arrangements for the parishioners to pray for us during all Masses, and to have the Parish prayer group include George in their prayer intentions.

Millennium Year 2000 was a Jubilee year in the Catholic Church in which a Jubilee plenary indulgence could be obtained by fulfilling certain conditions, including acts of charity and penance, and confession of one’s sins. We went to confession for the first time in a number of years.
On Christmas Eve we went to the inner city looking for poor people to help. In one case, seeing someone at a distance near a large garbage-dumpster, we parked the car and went to talk to him. Arriving at the spot where we had initially seen him, he was nowhere to be found. We were mystified by his disappearance. Suddenly, a head popped out of the garbage-dumpster. He had been completely inside it, scavenging. We assisted him in a small way. He was so thankful that it made our hearts swell with joy. In retrospect, we are sure that we obtained greater gifts from these experiences than the recipients received from us.

That evening when we attended Midnight Mass our Church was overflowing with people. When the congregation was asked to pray for the sick, George’s name was included. As we left the Church, Terry humorously pointed out to George that he was really lucky that his diagnosis had been made shortly before Christmas, rather than at another time of the year, because he had a standing room only crowd praying for him. She explained that this extra-large congregation was due to the presence of many C and E Catholics (those that only attend Mass at Christmas and Easter), and they all ended up praying for George.

We commenced saying grace together before every meal. We had ceased this practice some years earlier except for family dinners. Although it often varies, a typical grace that we may say is: “Thank you dear God for all the blessings you have given to us, our children and grandchildren, our children’s spouses, the members of our family, and our friends and their families. Amen. For health and strength and daily bread we give our thanks, O Lord!” We also usually include in our prayers the names of particular persons with serious illnesses that may have recently come to our attention.

On our return home from Loma Linda we found that the Parishioners at our church were still praying for George at all the Masses. They had religiously been including him in their prayers for almost three months. Since on his return home George looked really healthy, he advised his Parish Priest that he was taking the optimistic view that he had been “cured”. Consequently George felt that it was no longer necessary to mention his name from the pulpit at each Mass when the congregation prayed for members of the Parish who were sick.

Emotions (the essence of our being) are the strong feelings from various complex reactions that have both physical and mental manifestations such as sorrow, fear, anger, love and hate. There is often a tendency to suppress or hide our feelings, particularly those feelings of fear, inadequacy and loss of control of our lives. It is important to express emotions and give vent to one’s feelings in a positive way. If we do not cope with troubles and handle our problems, we can end up going through life with depressing baggage that we may keep deep inside us. These feelings can eventually eat away at us and may result in illness to the mind or body. It is therefore important to express our emotions and feelings in a positive way.
When we face our fears and concerns head on and express them in an appropriate fashion, we can minimize their deleterious effect on us and find positive and optimistic emotions, such as confidence and self-esteem, to replace them. George’s diagnosis of prostate cancer has given us the opportunity to smell the roses and look at life through the eyes of our grandchildren.

When we visited Brackendale in British Columbia two days after becoming aware of George’s prostate cancer, two soaring bald eagles had flown over our heads and dipped their wings to us. We took this awesome event as a calming message and a hopeful omen as to what was to come.

Several months after completion of George’s treatments, we discussed this bald eagle experience with Linda, a native North American shaman, whom we knew through our friend Moira in Toronto. Linda explained to us that eagles were considered messengers of the Almighty and that we truly had received a message from them. What she found very significant was the presence of two eagles, when there is usually only one messenger. Linda explained that in her Salish culture it is a custom that one offers a ceremonial blessing or offering for having received such a message.

At the time we received this information from Linda we were staying at our son’s retreat at Canmore in the Rocky Mountains of Alberta. Not far from Canmore is Kananaskis Country, where thousands of golden and bald eagles pass through on their migration path each spring and fall. As a result we decided that Kananaskis would be an ideal place for us to ritually acknowledge the message we had received from on high from the two bald eagles in Brackendale.

In October 2001, we drove to a secluded area at the Mount Lorette Ponds in Kananaskis Country. We found two pine branches and walked onto a small bridge about six feet over the ponds. We used the pine branches to sprinkle water from the fresh mountain stream while we prayed to the East, to the West, to the North, and to the South. We thanked God for sending us his inspiring harbingers at such a crucial juncture in our lives.
28. Follow-Up Results

“.. A joyful heart is good medicine and works an excellent cure.”

-- Holy Bible, Proverbs: c. 17, v. 22

As mentioned previously shortly before our departure for home from Loma Linda, Sharon Hoyle gave George a Proton Therapy Follow-up Schedule. Pursuant to that Schedule, George had his first follow-up PSA test in July 2001, four months after completion of his treatment. We visited our family physician in Calgary to obtain the results of the test and also for George to have a digital rectal examination (“DRE”).

When performing a DRE, the doctor wears a surgical glove. He feels for abnormalities, lumps or irregularities in the prostate gland by inserting his gloved finger into the rectum and pushing it against the rectal wall a number of times. A DRE may affect PSA readings and should be performed only after blood is drawn for the PSA test. However as some tumors can be felt, a DRE should always be done shortly after the PSA test. A PSA reading by itself, whether high or low, is not a conclusive indicator of whether or not one has cancer.

Our family physician told us that George’s prostate gland was now soft. George’s PSA at the time he was diagnosed with prostate cancer was 6.3. At the time of his first follow-up after completing his treatment, his PSA level had dramatically fallen to 0.5. We left the doctor’s office walking on air - we were both highly elated and heartened by the result.

George’s second PSA test occurred in January 2002 followed by a DRE. The PSA reading was 0.3, another comforting result. Subsequent PSA tests every six months, each followed by DREs, resulted in PSA readings of 0.1.

Since completion of his treatments in March 2001 to date, George has had no serious side effects. The minor side effects that did occur have been mentioned earlier in this book and did not have a materially detrimental effect on George’s quality of life.

George urinates more frequently than he did prior to his treatments. He attributes this to the fact that he previously drank only two or three glasses of water per day, and now drinks eight or more glasses daily. Although less virile he remains potent, although from time to time he is slower in reaching his full potential.

He is physically, mentally and emotionally healthy and leads a full active life. We sometimes say we seem busier since we retired several years ago than when we were working but, of course, we do not have the same stress in our lives.
To keep our minds active, as well as for enjoyment, we play two games of scrabble every day, and together we solve several challenging crossword puzzles each weekend. We also write books and give public talks to historical societies, high school and university students, public libraries and other groups.

Immediately upon realizing that he had cancer, George was filled with intense dread and despair. His initial thought was that he might die shortly, that his beloved wife Terry would be left alone, and that he wouldn’t see his small grandbabies grow up.

As George now proclaims to one and all, Terry was a pillar of strength in his depths of anguish, and brought him out of his dark “Slough of Despond”, and into the sunshine of hope and inspiration. She took her marriage vows of “for better or for worse, in sickness or in health” and embraced them with all her heart. She was ever the optimist, never allowing a negative thought or emotion to sway her in her determination to keep up George’s spirit and see that he received the best treatment available. She was truly awesome and as George says “I love her more now than when we exchanged wedding vows over 45 years ago.”
29. Parting Thoughts on an Inspirational Journey

“When you were born, you cried while the whole world rejoiced. Live your life in such a way that when you die, the world cries while you rejoice.”

-- Ancient Sanskrit Saying

While no one can doubt the mental torment it brings, in a mysterious way cancer has brought us many blessings. It has provided us with opportunities for personal growth and renewal. We learned from our experience that one should take control of one’s own destiny. We realized that it is necessary to prioritize one’s goals while remaining flexible to new ideas and situations. At the same time, a person should not abandon the responsibility for making their own decisions affecting their personal health and well-being. In our book titled Prostate Cancer Treatment and Healing, we have listed a number of helpful suggestions in dealing with prostate cancer.

**Prostate Cancer Treatment and Healing**

Cancer has intensified our appreciation of life, of family and of relationships. It has made us more spiritual and dedicated to cherishing our loved ones. It has made us more resolute in endeavoring to contribute to the welfare of others. It has made us more determined to leave the world a little better place than we found it. It has made us thank God for the friendly, dedicated health-care personnel who have devoted their lives, their creativity and their talents to helping their fellow humans.

It has made us prize each day with its promises and challenges, its tears and its joys. As an ancient Sanskrit poem so eloquently exhorted:

“Look to this day for it is life, the very life of life, In its brief course lie all the realities and truths of existence, the joy of growth, the splendor of action, the glory of power. For yesterday is but a memory, and tomorrow is only a vision, but today well lived makes every yesterday a memory of happiness, and every tomorrow a vision of hope. Look well, therefore, to this day!”

A vision of hope! As the English poet Alexander Pope wrote: “Hope springs eternal in the human breast.” As the Holy Bible states in Romans c.15 v. 13 “May the God of hope fill you with all joy and peace.”
Hope makes one optimistic. It builds up self-esteem and gives purpose and direction to life. It is a tremendous ally in the battle against cancer. There should be a rule of life that everyone must be an optimist. Helen Keller, the American writer, academic, and social reformer, was deaf and blind from infancy until her death in 1968. Nevertheless, she acquired the ability to speak, read and type – she was an optimist. Her enormous physical challenges did not prevent her from making the profound statement:

“No pessimist ever discovered the secrets of the stars, or sailed to an uncharted land, or opened a new heaven to the human spirit.”

Life is put in perspective by cancer. The rat race, conspicuous consumption and the pursuit of materialistic comfort and prestige take on a lesser role in one’s life – they pale into relative insignificance when one has had a sword of Damocles suspended above one’s head.

The spiritual awareness and growth which George’s prostate cancer brought us has, in some ways, re-formed and altered our outlook on life. It has made us less cynical and more accepting of ourselves and of others.

Our cancer journey has made us more optimistic. True, it brought home with startling clarity the realization that death is an inherent characteristic of human nature, and death is inevitable. Reflecting on the eventual going down of the final curtain (one knows not when) has provided us with the insight and the desire to more fully appreciate the meaningful relationships that really count in life - children, grandchildren, family, and love for each other.

To these meaningful relationships we have embraced other significant considerations including unconditional love and kindness, forgiveness, enjoyment in the beauty of the world and people in it, friendships, our duty to society, and other spiritual values.

DOMINUS VOBISCUM.
Appendix A

Glossary of Prostate Related Terms

The focus of this glossary is prostate cancer, although some of the terms apply to other situations. This glossary is not all-inclusive, is provided in layman’s terms, and in some instances contains personal comments.

Adenocarcinoma
A malignant tumor that develops in the inner surface or lining of a glandular organ. The vast majority of prostate cancers are adenocarcinomas, as was the case with George’s cancer.

Adjuvant therapy
In relation to hormonal therapy, it is the use of hormone drugs as an additional treatment after a primary treatment.

Advanced prostate cancer
See metastasized prostate cancer.

Androgens
Male hormones including testosterone.

Angiogenesis
The process by which new blood vessels are formed; a tumor uses this process to grow.

Antioxidants
Substances that remove potentially damaging oxidation agents including free radicals, and are found mainly in certain nutrients.

Anus
The opening for excretion situated at the lower end of the alimentary canal (the path through which food passes during digestion).

Benign
Non-malignant condition; relatively harmless.

Benign cells
Non-cancerous cells that look and act like normal cells.

Benign prostatic hyperplasia, or BPH
A benign non-cancerous condition of the prostate in which the prostate is enlarged causing it to press against the urethra and the bladder, thereby impeding urination.

Biochemical failure
Three consecutive post-treatment rises in PSA after its nadir has been reached subsequent to treatment.
**Biopsy, or prostatic biopsy, or transrectal biopsy**  
Extraction by a physician, and microscopic scrutiny by a pathologist, of tissue samples from the body to determine whether or not there are abnormalities such as cancer is the medical procedure called a biopsy. A prostatic biopsy is usually a transrectal biopsy in which a prostate biopsy gun is guided by an ultrasound probe, both of which are inserted into the rectum, and uses needles that are injected into the prostate to remove six or more tissue samples.

**Bladder**  
A hollow organ in the pelvic cavity consisting of a membranous sac into which urine flows from the kidneys and is held there pending urination.

**Bone scan**  
A body-imaging technique using a radioactive substance injected into the bloodstream in order to view bones.

**BPH**  
See **benign prostatic hyperplasia**.

**Brachytherapy**  
In the case of prostate cancer, an invasive form of internal radiation therapy (also known as **interstitial radiation therapy**) performed by implanting tiny radioactive material called seeds or pellets directly into the prostate.

**Bragg Peak**  
The predetermined placement in the body at which the deposition of energy is highest for delivering proton beams to the target area. This peak can be expanded along the axis of the beam to conform to the thickness of the volume of the designated area.

**Cancer**  
A disease caused by a malignant abnormal growth of cells and division of cells in a disorderly and uncontrolled manner. The abnormal growth of cancer cells results in a tumor. The malignant cells may spread locally and also may migrate to other parts of the body by means of the blood or lymphatic systems.

**Cancer cells**  
Cells characterized by poor differentiation and unregulated growth; cancerous and non-benign.

**Capsule**  
The layer of fibrous tissue encircling the prostate.

**Castration**  
See **medical castration** and **surgical castration**.
| **CAT scan, or computerized axial tomography** | The diagnostic procedure that looks inside the body in a noninvasive manner. It does so with a sophisticated x-ray apparatus in conjunction with a computer to produce a series of detailed cross-sectional pictures of internal organs. |
| **Cells** | All plants and animals are made up of cells, which are microscopic units of protoplasm consisting of cytoplasm and a nucleus enclosed in a membrane. |
| **Chemotherapy** | The treatment of cancer by means of injection or ingestion of pharmaceuticals or other chemicals to kill cancer cells. Chemotherapy frequently kills healthy cells as well, such as blood cells, and itself has the potential to affect the immune system if powerfully given over a lengthy period. It rarely cures prostate cancer. |
| **Clinical trial** | An experimental study, involving people, which has been carefully planned by qualified professionals or researchers to assess the effectiveness, safety and side effects of new or unproven treatments or drugs and, in some cases, to compare their efficacy to currently accepted treatments or drugs. A clinical trial may have several phases, with each subsequent phase having quite a few more patients than the previous phase. |
| **Computerized axial tomography** | See CAT scan. |
| **Conformal radiation** | Therapy in which radiation beams, by means of computer-control, may be shaped and angled to conform to the tumor or target in three dimensions (depth, height and width). Proton beam therapy is conformal radiation as is some conventional x-ray therapy. |
| **Conventional external beam radiation therapy, or conventional x-ray therapy, or photon radiation therapy** | External beam radiation therapy using gamma rays or x-rays (high-energy photons). Healthy cells as well as cancer cells are usually affected, frequently resulting in unwelcome side effects. |
| **Conventional x-ray therapy** | See Conventional external beam radiation therapy. |
| **Cryoablation** | See cryosurgery. |
Cryosurgery or cryoablation, or cryotherapy
This invasive surgery uses liquid nitrogen or argon inserted by probes through the perineum to freeze the entire prostate to extremely low temperatures for the purpose of killing any cancerous tissue in the prostate, also resulting in the prostate itself being killed in the process.

Cryotherapy
See cryosurgery.

Cure
Restoration to health or soundness.

Deoxyribonucleic acid, or DNA
An essential part of all living organisms and a basic constituent of the chromosomes of the cell nucleus. It is the unit carrying the genetic code and conveys hereditary characteristics.

DHT
See dihydrotestosterone.

Digital rectal examination, or DRE
The insertion of a physician’s lubricated gloved finger into the patient’s rectum in order to check the prostate and adjacent area for palpable tumors or other abnormalities.

Dihydrotestosterone, or DHT
A male hormone that is made from the conversion in the prostate of healthy testosterone by a specific enzyme.

DNA
See Deoxyribonucleic acid.

Dosimetrist
A person who, together with a physicist, works up a treatment plan and calculates the radiation dose to be given to a cancerous target area (or tumor) and to adjacent normal tissue.

DRE
See digital rectal examination.

EBRT
See external beam radiation therapy.

Erectile dysfunction or ED
See Impotence.

External beam radiation therapy, or EBRT
Radiation therapy consisting of high energy rays or beams delivered in a noninvasive painless manner into the body by a machine outside the body to harm or destroy cancer cells and to inhibit their growth and subdivision. EBRT may be conventional external beam radiation therapy (defined above) which quite frequently damages healthy tissue causing unwelcome side effects: or proton beam radiation therapy (defined below) which normally causes only insignificant damage to surrounding tissue and only minor side effects.
<table>
<thead>
<tr>
<th><strong>Free PSA or fPSA</strong></th>
<th>Prostate specific antigen that is free in the blood stream is called free PSA. Other PSA is bound to proteins whereas free PSA is not bound to other proteins in the blood.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Free PSA test, or fPSA test</strong></td>
<td>A relatively new test, called the free PSA test, measures the percentage of free PSA to total PSA. The lower the percentage of free PSA, the greater the risk of prostate cancer. The higher the percentage of free PSA, the lower the risk of prostate cancer. See also prostate specific antigen.</td>
</tr>
<tr>
<td><strong>Free radicals</strong></td>
<td>Abnormal and unstable oxygen molecules having an unpaired electron. They pursue and combine with other molecules (oxidizing them), damaging the DNA in the cells of the body.</td>
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<tr>
<td><strong>Gantry</strong></td>
<td>A gigantic piece of equipment, forming part of the proton treatment delivery system, that rotates around the patient and directs the proton beam to a precisely predetermined point.</td>
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<tr>
<td><strong>Gleason score</strong></td>
<td>An assessment or grading of aggressiveness of cancerous tumor cells based on the cellular differentiation of cancerous tissues as they appear under microscopic examination. A well differentiated, or near normal, form of tumor is considered less aggressive. With lesser differentiation in the cancer cells, there is greater potential for aggressive growth of the cancer cells. Based on cellular differentiation, numbers from 1 to 5 are assigned to the two most predominant patterns. These numbers added together constitute the Gleason score. See also grade.</td>
</tr>
<tr>
<td><strong>Grade</strong></td>
<td>A method of measuring the potential aggressiveness or rate of growth of prostate cancer based on cell differentiation pursuant to microscopic examination. The more a tumor resembles normal tissue the lower the grade and vice versa. Low-grade tumors are inclined to grow and spread more slowly than high-grade tumors. See also Gleason score.</td>
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<tr>
<td><strong>Gy</strong></td>
<td>The unit of the absorbed dose of ionizing radiation based on the international system of units.</td>
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<tr>
<td><strong>Heal</strong></td>
<td>To make whole, healthy and sound.</td>
</tr>
<tr>
<td><strong>High dose radiation, or HDR</strong></td>
<td>Brachytherapy treatment using temporary implants of radioactive seeds.</td>
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</tbody>
</table>
Hormonal therapy, hormone therapy, or hormone treatment

In prostate cancer, the use of hormone drugs or certain surgical procedures to block the body’s production of testosterone, the male sex hormone, with a view to retarding the growth of prostate cancer or shrinking the cancerous tumor. Testosterone (which is produced in the testicles) is believed to be a contributor to the growth of prostate cancer cells. The drugs used cause significant unpleasant side effects; and the cancer cells may become hormone refractory if the drugs are taken for an extended period.

Hormone

A substance produced in some organ of the body and transported by a body fluid such as blood in order to activate another organ or tissue. Hormones can be produced synthetically.

Hormone-refractory

A condition in which the cancer is no longer responding to hormonal therapy.

Hormone therapy

See hormonal therapy.

Hormone treatment

See hormonal therapy.

Immune system

The biological system innate in humans (as well as animals) which helps to maintain one’s health by fighting the effects of infections, viruses, toxins, cancer cells, and other health threats. The immune system also assists in recovery from sickness.

Impotence or Erectile Dysfunction (ED)

The incapacity to have and sustain a penile erection suitable for sexual intercourse. Temporary or permanent impotence is a frequent side effect of most prostate cancer treatments, but less so in the case of proton beam radiation therapy.

IMRT

See intensity-modulated radiotherapy.

Incontinence

The inability to control urination. There are three types of incontinence - lack of urinary control may be due to stress incontinence; inability to completely empty the bladder; or total failure in the ability to hold urine in the bladder.

Intensity-modulated radiotherapy (IMRT)

Conforms the x-ray treatment to fit the shape of the tumor using a linear accelerator-based technology.

Interstitial micro-wave therapy or thermotherapy

The insertion of a number of probes to deliver high heat to the prostate gland as an experimental treatment for prostate cancer that has recurred.
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Invasive</td>
<td>In a medical procedure an incision, or the insertion of an instrument, into the body.</td>
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<tr>
<td>Localized cancer</td>
<td>The medical term for a malignant tumor that has not spread to other parts of the body and remains in its original site.</td>
</tr>
<tr>
<td>Localized prostate cancer</td>
<td>A malignant tumor confined to the prostate gland. The tumor has not metastasized.</td>
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<tr>
<td>Luteinizing hormone, or LH</td>
<td>A chemical transmitted by the pituitary to signal the production of testosterone by the testes.</td>
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<tr>
<td>Luteinizing hormone-releasing hormone, or LHRH</td>
<td>A hormone responsible for stimulating the production of testosterone in the body.</td>
</tr>
<tr>
<td>Luteinizing hormone-releasing hormone agonists, or LHRH agonists</td>
<td>Drugs that inhibit the action of LHRH and that shut down the production of the LH hormone by the pituitary gland.</td>
</tr>
<tr>
<td>Lymph nodes</td>
<td>Small compact glands lying along the vessels of the lymphatic system. The lymphatic system in the body carries lymph, a colorless fluid containing white blood cells that filter out and help fight toxins, bacteria, and cancer cells.</td>
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<tr>
<td>Magnetic resonance imaging</td>
<td>See MRI.</td>
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<tr>
<td>Malignant</td>
<td>A tumor with a tendency to invade normal tissue and metastasize; cancerous.</td>
</tr>
<tr>
<td>Malignant tumor</td>
<td>A cancerous tumor.</td>
</tr>
<tr>
<td>Margins</td>
<td>See <strong>negative margins, positive margins, and surgical margins.</strong></td>
</tr>
<tr>
<td>Medical castration</td>
<td>Hormonal therapy to suppress the production of testosterone.</td>
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<tr>
<td>Metastasis</td>
<td>Spread of the cancer by means of the blood stream or the lymphatic system to other sites in the body where the cancer cells grow.</td>
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<tr>
<td>Term</td>
<td>Definition</td>
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<tr>
<td>Metastasized prostate cancer</td>
<td>Cancer that has penetrated the prostate wall and spread outside the prostate gland to another site such as the lymph nodes, bones, liver, etc. It still bears the name of the primary cancer - prostate cancer and not bone cancer, liver cancer, etc. This is advanced prostate cancer.</td>
</tr>
<tr>
<td>Modality</td>
<td>The prescribed technique or method of treatment or procedure.</td>
</tr>
<tr>
<td>Morbidity</td>
<td>The medical term for an undesirable side effect or for an unhealthy result or complication arising from a treatment protocol, such as impotence, incontinence, etc. See side effects.</td>
</tr>
<tr>
<td>MRI, or magnetic resonance imaging</td>
<td>A diagnostic procedure that produces images of internal organs of the body by noninvasive means.</td>
</tr>
<tr>
<td>Nadir</td>
<td>The lowest point reached in a series of PSA tests.</td>
</tr>
<tr>
<td>Nanograms per milliliter</td>
<td>See ng/ml.</td>
</tr>
<tr>
<td>Negative margins</td>
<td>Denote there is no sign of cancer in the outer edges of the tissue removed in a radical prostatectomy.</td>
</tr>
<tr>
<td>Neoadjuvant therapy</td>
<td>In hormonal therapy, it is the use of hormone drugs as an additional treatment before or during a primary treatment.</td>
</tr>
<tr>
<td>Ng/ml, or nanograms per milliliter</td>
<td>Used as a measurement of PSA levels in the blood.</td>
</tr>
<tr>
<td>Nutrients</td>
<td>Nourishing substances necessary for life and growth.</td>
</tr>
<tr>
<td>Oncologist</td>
<td>A medical doctor who specializes in the diagnosis and treatment of various cancers.</td>
</tr>
<tr>
<td>Orchiectomy</td>
<td>Castration by surgical removal of the testicles, after which there is no longer production of testosterone from the testicles and the patient is sterile.</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>Loss of bone density especially due to hormonal changes resulting in brittle bones that can easily fracture.</td>
</tr>
<tr>
<td>Oxidation</td>
<td>The metabolic process that results in the production of energy from food that is consumed and, also, in the production of free radicals as a by-product.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Penis</td>
<td>The male genital organ, consisting in large part of erectile tissue, used for sexual intercourse and for voiding urine.</td>
</tr>
<tr>
<td>Perineum</td>
<td>The region of the body between the anus and the scrotum in men and between the anus and the vulva in women.</td>
</tr>
<tr>
<td>PET scan, or positron emission tomography</td>
<td>A diagnostic procedure that is noninvasive and looks inside the body and produces images.</td>
</tr>
<tr>
<td>Photon</td>
<td>A quantum of light or other electromagnetic radiation having momentum. Electromagnetic radiation includes visible light, radio waves, gamma waves, x-rays, etc. Conventional external beam radiation therapy for the treatment of prostate cancer usually uses photons, which lack the mass, charge and controllability of protons. Due to their nature, photons release most of their power near the surface of the body (where the healthy tissues are), continue through and past the target area, and cause unwelcome side effects.</td>
</tr>
<tr>
<td>Photon radiation therapy</td>
<td>See conventional external beam radiation therapy.</td>
</tr>
<tr>
<td>Positron emission Tomography</td>
<td>See PET Scan.</td>
</tr>
<tr>
<td>Positive margins</td>
<td>Indicate that there may be cancer cells beyond the outside edges of the tissue removed during a radical prostatectomy.</td>
</tr>
<tr>
<td>Prostate, or prostate gland</td>
<td>A male sex gland, about the size of a walnut, that surrounds the upper part of the urethra at the base of the bladder. Its principal function is to secrete fluid that is discharged with semen during ejaculation.</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>The growth of cancer cells in the prostate gland. Abnormal growth of cancer cells results in a malignant tumor. Cancer cells may break loose from the tumor and spread by means of the blood and lymphatic systems to other sites in the body, such as the bone or the liver, and grow there. A prostate cancer that migrates to another part of the body carries the same name as the primary cancer - it is metastasized prostate cancer.</td>
</tr>
<tr>
<td>Prostate gland</td>
<td>See prostate.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Prostate specific antigen, or PSA</td>
<td>A protein secreted by cells of the prostate gland, including cancer cells.</td>
</tr>
<tr>
<td>Prostatic biopsy</td>
<td>See biopsy.</td>
</tr>
<tr>
<td>Prostatitis</td>
<td>A treatable infection or inflammation of the prostate gland.</td>
</tr>
<tr>
<td>Proteins</td>
<td>Organic compounds made up of a complex union of amino acids and found in all living organisms, and essential in the human diet to generate fresh tissue, aid development and heal tissue.</td>
</tr>
<tr>
<td>Protocol</td>
<td>The medical term used in medical research to describe the precise procedures and methods to be followed. In the case of a patient, protocol is the term that describes the program of treatments for that patient.</td>
</tr>
<tr>
<td>Proton</td>
<td>A subatomic particle with a positive charge and a heavy mass. Protons can be conformed (or shaped) to the tumor or target volume, and retain most of their energy on entering the body. They can be programmed to travel a specific distance into the body, controlled to release their largest burst of energy at a designated site (called the Bragg Peak), and not to go beyond the far side of the target volume, thereby sparing radiation of healthy tissue and minimizing side effects.</td>
</tr>
<tr>
<td>Proton beam radiation therapy</td>
<td>A mainstream noninvasive painless type of external beam radiation treatment given on an outpatient basis. Protons are formed into proton beams that are conformed in three dimensions (height, width and depth) to the cancerous tumor or target volume. Due to their qualities, proton beams can be controlled with much greater precision. Enhanced control over proton beams, with the aid of computers, permits the Bragg Peak to be placed precisely as planned at the target volume. This permits a higher radiation dose with more effective cancer-killing powers with minimal side effects.</td>
</tr>
<tr>
<td>PSA</td>
<td>See prostate specific antigen.</td>
</tr>
<tr>
<td>PSAD</td>
<td>See PSA density.</td>
</tr>
<tr>
<td>PSA density, or PSAD</td>
<td>Calculated by dividing the volume of the prostate into the PSA level to measure the concentration of PSA in a man’s prostate.</td>
</tr>
</tbody>
</table>
PSA test
Measures the level of PSA in the blood. An elevated level could be an indication of an abnormal condition, either malignant or benign, in the prostate. Screening based on PSA levels is used in an attempt to distinguish men with tumors from those who are tumor-free. PSA tests are also used at regular intervals to monitor a patient's post-treatment progress. All PSA tests should be accompanied by a DRE performed after the blood is taken for the PSA test.

PSA velocity
Rate or speed of change in PSA levels from year to year.

Radiation therapist
A person who has undergone specialized schooling to enable him or her to administer radiation therapy.

Radiation therapy
The application of high-energy rays or beams to destroy cancer cells. Proton beam radiation therapy and conventional external beam radiation therapy are both delivered to the malignant targeted area within the body by a machine outside the body. On the other hand, brachytherapy surgically implants radioactive seeds or pellets directly into the prostate gland.

Radical prostatectomy
A treatment for prostate cancer by means of major invasive surgery to remove the entire prostate gland and seminal vesicles. A retropubic prostatectomy is done by way of an incision in the abdomen from the navel to the pubic area. A perineal prostatectomy excises the prostate by an incision between the scrotum and the anus. Severe side effects, which may be temporary or permanent, normally ensue from this operation.

Radiologist
A medical doctor who specializes in the diagnosis and treatment of disease using high-energy radiation such as protons and x-rays.

Rectum
The section of the large intestine, which in humans stretches from the terminal portion of the descending colon to the anus. Part of the rectum is immediately against the back of the prostate gland.

Recurrence, or reoccurrence
The return of a disease.

Refractory
A condition in which a disease is no longer responding to a current type of treatment.
Scrotum  The pouch of skin containing the testicles of a man.

Seminal vesicles Small sacs in the body containing semen, the reproductive fluid of the male which is ejaculated during sexual intercourse.

Side effects Usually used to denote undesirable consequences or reactions resulting from treatment or medication. The medical term for an undesirable side effect is morbidity. Side effects may be temporary or permanent and may vary in kind and severity. Depending on the treatment of prostate cancer, some side effects that may occur are impotence, incontinence, rectal bleeding, blood in the semen or urine, fatigue, infection, spasms, failure to control the cancer, bladder and rectal irritation, etc.

Stage, or staging The stage of a cancer is its size and physical extent, and affects treatment options. Staging is the process of assigning a stage to the cancer based on an assessment of relevant information. There are two systems of staging - the Whitmore-Jewett System of 1956, and the more recent and currently recommended TNM System of 1992.

Staging See stage.

Surgical castration See orchiectomy.

Surgical margins The outer edges of the tissue removed during a radical prostatectomy. See also negative margins and positive margins.

Synchrotron A system that accelerates the speed of atomic or subatomic charged particles, such as protons. This significantly increases the energy of these particles.

Target area See target volume.

Target volume, or target area The area in the body to which the treatment is directed and which includes the confirmed malignant tumor, and may also include an adjacent area where the tumor may have spread.

Testosterone The male sex hormone that is largely produced by the testicles and, to a much lesser extent, by the adrenal glands. Testosterone stimulates the development of male sexual characteristics and is essential for male fertility.

Therapy The non-surgical treatment of disease or of physical or mental disorders.
<table>
<thead>
<tr>
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<th>Definition</th>
</tr>
</thead>
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<td>Thermotherapy</td>
<td>See <em>interstitial microwave therapy</em>.</td>
</tr>
<tr>
<td>Tissue</td>
<td>The substance of which an organic body or organ is made, consisting of an accumulation of certain cells having a specific function, such as prostate cells, muscle cells, etc.</td>
</tr>
<tr>
<td>Transrectal biopsy</td>
<td>See <em>biopsy</em>.</td>
</tr>
<tr>
<td>Transrectal ultrasound, or TRUS</td>
<td>The use of ultrasound waves to visually image an organ or gland in order to inspect for abnormal conditions using a device inserted in the rectum. It is also used to visualize prostate biopsies and for guiding needles and probes in certain procedures such as cryosurgery.</td>
</tr>
<tr>
<td>Transurethral resection of the prostate, or TURP</td>
<td>A surgical procedure used to remove blockages of the urethra.</td>
</tr>
<tr>
<td>Treatment</td>
<td>Application of medical remedies, care or attention to a patient, particularly in a systematic manner.</td>
</tr>
<tr>
<td>TRUS</td>
<td>See <em>transrectal ultrasound</em>.</td>
</tr>
<tr>
<td>Tumor</td>
<td>An abnormal swelling or growth in a part of the body due to an excessive uncontrolled increase or division of cells in tissue. A tumor may be either malignant or benign.</td>
</tr>
<tr>
<td>TURP</td>
<td>See <em>transurethral resection of the prostate</em>.</td>
</tr>
<tr>
<td>Ultrasound</td>
<td>A noninvasive, painless method of imaging tissue and glands by means of high frequency sound waves. It can be performed externally through the abdomen, or internally through the rectum.</td>
</tr>
<tr>
<td>Urethra</td>
<td>The membranous tube or canal through which urine is conveyed out of the body from the bladder. In men, part of the urethra is surrounded by the prostate gland and semen is also discharged through the urethra.</td>
</tr>
<tr>
<td>Urologist</td>
<td>A medical doctor specially trained in surgery and the branch of medicine dealing with disorders of the urinary tract and kidneys, and the sex organs of men.</td>
</tr>
<tr>
<td>Watchful waiting</td>
<td>The careful observation and vigilant monitoring of a patient diagnosed with cancer, without that patient receiving any actual treatment. Observation and monitoring are usually by means of regular PSA tests and digital rectal examinations.</td>
</tr>
</tbody>
</table>
Appendix B

Bibliography

There are many sources and references available on cancer generally and on prostate cancer in particular. Some books on cancer and prostate cancer contain no bibliography (or for that matter no index as well) while others contain extensive lists. One book on cancer that we consulted had a bibliography exceeding 250 items, another book on illness had almost 200 items.

We are not listing herein all the sources we consulted. The following are some of the books we considered either helpful in making our treatment decision or subsequently in researching and writing this book.

*Cancer: 50 Essential Things to Do*, Greg Anderson
http://www.amazon.com/exec/obidos/ASIN/0452280745

*Anatomy of an Illness as Perceived by the Patient*, Norman Cousins
http://www.amazon.com/exec/obidos/ASIN/0553343653

*The Healing Heart: Antidotes to Panic and Helplessness*, Norman Cousins
http://www.amazon.com/exec/obidos/ASIN/0393018164

*Dr. Gaynor’s Cancer Prevention Program*, Mitchell Gaynor and Jerry Hickey
http://www.amazon.com/exec/obidos/ASIN/1575665263

*Man to Man: Surviving Prostate Cancer*, Michael Korda
http://www.amazon.com/exec/obidos/ASIN/0679781234

*Cancer As A Turning Point*, by Lawrence LeShan
http://www.amazon.com/exec/obidos/ASIN/0452271371

*Prostate and Cancer: A Family Guide to Diagnosis, Treatment and Survival*, Sheldon Marks
http://www.amazon.com/exec/obidos/ASIN/0738208396

*Legacy — Daring to Care*, Richard Schaefer
http://www.llu.edu/info/legacy
Love, Medicine & Miracles, Bernie Siegel
http://www.amazon.com/exec/obidos/ASIN/0060919833

Peace, Love & Healing, by Bernie Siegel
http://www.amazon.com/exec/obidos/ASIN/0060917059

Getting Well Again, by O. Carl Simonton, Stephanie Matthews Simonton, and James Creighton
http://www.amazon.com/exec/obidos/ASIN/0553280333

Prostate Cancer: A Non-Surgical Perspective, by Kent Wallner
http://www.amazon.com/exec/obidos/ASIN/0964899108

Dr. Patrick Walsh’s Guide to Surviving Prostate Cancer, by Patrick Walsh and Janet Farrar Worthington
http://www.amazon.com/exec/obidos/ASIN/0446679143

Spontaneous Healing, by Andrew Weil
http://www.amazon.com/exec/obidos/ASIN/0804117942
Appendix C

Web Sites

When using the Internet, one should exercise judgment and discretion in assessing the information since the Internet is largely unregulated and anyone can place information on it. It is particularly important to determine whether the site has a hidden agenda and whether the authors are providing unbiased and impartial material or opinions.

The following are some helpful Web sites. In many cases one must follow the links provided on these Web sites in order to access relevant material.

- The Cancer Research Institute  
  http://www.cancerresearch.org
- Brotherhood of the Balloon  
  http://www.protonbob.com
- The Prostate Cancer InfoLink  
  http://www.phoenix5.org
- Prostate Cancer Information Center  
  http://www.infoaging.org
- American Cancer Society  
  http://www.cancer.org
- National Cancer Institute ("NCI")  
  http://www.nci.nih.gov/cancerinfo
- The University of Pennsylvania Cancer Center  
  http://www.oncolink.com
- The Mayo Clinic  
  http://www.mayoclinic.com/index.cfm
- Proton Therapy Links  
  http://www.proton-therapy.org/links.htm
- Loma Linda University Medical Center (LLUMC)  
  http://www.llu.edu/proton/patient/overview/index.html
Medbroadcast Corp. and CanWest Global Communications
http://www.medbroadcast.com

The Prostate Cancer Web Directory
http://www.cancerindex.org

The International Association of Cancer Registries

Many universities, medical journals, cancer institutes, etc. also have Web sites dealing with prostate cancer. These sites can be accessed by surfing the Internet. It should be noted that some sites do not permit access to non-registrants or non-members. It should also be noted that a Web site address may be changed, in which case the new address can usually be found by surfing the Internet on a search engine.
Appendix D
Articles, Pamphlets and Videos

The following is a list of pamphlets and videos that can provide helpful information concerning prostate cancer.

What You Need to Know About Prostate Cancer is issued by the National Institutes of Health, National Cancer Institute. It is available from the National Cancer Institute in Bethesda, Maryland at telephone number 1-800-4CANCER (1-800-422-6237).

After Diagnosis – Common Questions and Expectations of Cancer Patients; and After Diagnosis: Prostate Cancer, Understanding Your Treatment Options; and The PSA Blood Test and Prostate Cancer are available from the American Cancer Society in Atlanta, Georgia at telephone number 1-800-ACS-2345 (1-800-227-2345).

The Journal of Urology is an excellent source of articles on prostate cancer such as the four page article entitled Prostate Cancer: a Patient’s Perspective by Richard J. Howe that appears in volume 152, November 1994 pages 1700 to 1703.

The Info on Prostate Cancer, Information Sheets (12 in all) are issued by the Canadian Cancer Society, at telephone number (416) 961-7223.

Prostate Disease: Vital Information for Men Over 40 is issued by the Prostate Health Council in Baltimore, Maryland at telephone number 1-800-242-2383.

Proton Treatment Center is issued by Loma Linda Medical Center in Loma Linda, California at telephone number 1-800-PROTONS (1-800-776-8667) or (909)558-4288.

The Immune System – How It Works and Understanding Gene Testing are booklets available from the National Cancer Institute (“NCI”) in Bethesda, Maryland at telephone number 1-800-4CANCER (1-800-422-6237).

Prostate Cancer – Conquering the Fear is a tape sponsored by the Ontario Cancer Institute and Princess Margaret Hospital in Toronto, Ontario, Canada.

Treatment of Localized Prostate Cancer: a Study Group is the tape discussing randomized trial study in Calgary comparing the efficacy of cryosurgery and conventional external radiation therapy in the treatment of localized prostate cancer.

Breakthrough: Proton Therapy, Beam of Hope (ABC-20/20); Proton Treatment Center Development; and Invisible Blessings provide information on conformal proton beam therapy and are available from Loma Linda University Medical Center at 1-800-PROTONS (1-800-776-8667) or (909) 558-4288.
Appendix E
Cancer Resource Services and Agencies

The following lists the principal offices of a number of cancer associations in various parts of the world. It should be noted that these addresses and telephone numbers may be changed from time to time, and may require reference to current sources for up-to-date information.

**American Cancer Society**
http://www.cancer.org
Address: American Cancer Society
1599 Clifton Rd. NE
Atlanta, Georgia, 30329
USA
Telephone: (800) 227-2345

**National Cancer Institute ("NCI")**
http://www.nci.nih.gov/cancerinfo
Address: National Cancer Institute
Office of Cancer Communications
Building 31, Room 10A24
Bethesda, Maryland, 20892
USA
Telephone: (800) 422-6237

**The Prostate Health Council**
http://www.prostatehealth.com
Address: Prostate Health Council
c/o American Foundation for Urologic Disease
1000 Corporate Blvd.
Linthicum, Maryland 21090
USA
Telephone: (800) 242-2383

**Canadian Cancer Society**
http://www.cancer.ca
Address: Canadian Cancer Society
10 Alcorn Avenue, Suite #200
Toronto, Ontario, M4V 3B1
Canada
Telephone: (416) 961-7223
Cancer Council Australia
http://www.cancer.org.au
Address: Cancer Council Australia
Level 5 Medical Foundation Building
2-94 Parramatta Rd
Camperdown NSW 2050
Australia
Telephone: (02) 9036 3100

British Association for Cancer United Patients
http://www.cancerbacup.org.uk
Address: British Association for Cancer United Patients
3 Bath Place, Rivington St.
London, EC2A 3JR
England
Telephone: 0808 800 1234 (info hotline)
44 (0) 20 7696 9003 (direct line)

CancerLink
Address: 17 Britannia St.,
London, WC1X 9JN, England
Telephone: 0171 833 2451

Irish Cancer Society
http://www.irishcancer.ie
Address: 5 Northumberland Rd.
Dublin 4
Ireland
Telephone: (800) 200 700 (info hotline)
353 1 2310 500 (direct line)

Cancer Society of New Zealand
http://www.cancernz.org.nz
Address: Cancer Society of New Zealand
PO Box 10847
Wellington, New Zealand
Telephone: 64 4 494 7270
Federation Nationale des Centres de Lutte Contre le Cancer
http://www.fnclcc.fr
Address: Federation Nationale des Centres de Lutte Contre le Cancer
101 rue de Tolbiac
Paris Cedex 13 75654
France
Telephone: 33 1 4423 0404

National Cancer Center Japan
http://www.ncc.go.jp
Address: 5-1-1 Tsukiji, Chuo-ku
Tokyo, 104-0045
Japan
Telephone: (03) 3542-2511

Instituto Nacional de Cancerologia
Address: Instituto Nacional de Cancerologia
Av. San Fernando 22-40 Piso
Col. Tlalpan
Mexico D.F. 14000
Mexico
Telephone: +52 5 573 5651

Instituto Nacional de Cancerologia
http://www.incancerologia.gov.co
Address: calle 1 No 9-85
Bogota, DC
Telephone: 334411

Cancer Association of South Africa
http://www.cansa.org.za
Address: Cancer Association of South Africa
26 Concorde Rd W.
Bedfordview 2008
South Africa
Telephone: 0800 226622 (info hotline)
(011) 616-7662 (direct line)

Cancer associations in other countries of the world may be accessed at the CancerIndex web site:

CancerIndex
http://www.cancerindex.org
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