A STRANGE PLACE

AN INFORMATION GUIDE TO PROSTATE CANCER

Acknowledgement is made, and thanks given, to Donna Pogliano; members of the Prostate Support Action (PSA) Group and the YANA – You Are Not Alone Now website and members of my family who assisted in the final editing of this booklet. And to members of the YANA site for their generous donations that made this edition possible.

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INTRODUCTION

A diagnosis of prostate cancer is shocking. Life will never be the same. Everything changes. You feel lost; you don't know what to do.

The late Robert Young, who was diagnosed in the latter part of 1999 with a PSA of over 1,000 ng/ml, compared it to being dropped, without your consent, into a new country where the language, customs, terrain, roads and rules are all foreign. You are in a **Strange Place**, and it's frightening.

This book is intended, like a good travel guide, to help men (and their partners and those who are close to them) to find their way around this **Strange Place**. From it they can learn some of the basic language, customs and options, including the Golden Rule:

THE GOLDEN RULE OF PROSTATE CANCER IS - THERE ARE NO RULES

The process of diagnosis is subjective, with significant variances in the interpretation of test results: the choice of the most appropriate treatment is difficult because of a lack of good comparative information; the outcome of any treatment is variable.

Despite the lack of rules, this book should enable them to find a path through the **Forest of Fear** to **Diagnosis.** They will be able to cross the **Doubtful Desert** to get to **Treatment** and to decide which option may suit them best. It will take them through the highs and the lows of the **Plains of Recovery** and may help them deal with the side effects of treatment. It will give them a significantly better chance of reaching the final goal of **Remission**.

What follows is not intended to take the place of the more personal and detailed information and advice, which can only come from a trained medical advisor. Its goal is to provide a better understanding of some of the basic aspects about the diagnosis and treatment of prostate cancer.

Ideally, all men who have prostate problems, an elevated PSA (Prostate Specific Antigen) or even those men having their annual DRE (Digital Rectal Examination) and PSA check-up will read this book. This would help them deal more easily with the issues they may face in the event of warning signs being discovered or if they have a positive diagnosis for prostate cancer.

Before exploring this new country and all its features, it should be said that the normal reaction to a diagnosis of prostate cancer is one of shock, dismay, fear and confusion. But uppermost in the minds of most men who have just been diagnosed with this disease are two questions:

How long have I got? What is it like to die from prostate cancer?

HOW LONG HAVE I GOT? HOW SOON WILL I DIE?

The terrifying thing about the word "cancer" is its association with an inevitable and often painful death. Many men on hearing that they have prostate cancer assume that it is a matter of days or weeks until they die. <u>They are wrong!</u>

<u>Less than 5% of men diagnosed with prostate cancer will die from it within ten years of their diagnosis</u>. The life expectancy of most men will not be changed by the diagnosis. They will live until they die of something else – most notably a heart attack. A recent study, using US statistics, indicated that in a 20 year period more than 87% of men diagnosed with prostate cancer would not die from the disease.

Prostate cancer can, and does, kill thousands of men each year throughout the world. It should not be underestimated or treated lightly. But many more men survive the disease than succumb to it. It is important to know that.

Although the immediate focus, on hearing the word 'cancer' applied to us concerns the prospect of dying from the disease, the subject is something of an Elephant In The Room. It rarely comes up for discussion on Internet Lists or Forums and if it does is greeted with a hushed silence. There is very little published material - yet it is the main driver behind all decisions to do with the disease – ***"How long have I got?"***

Many doctors avoid these issues, if they can, because they are difficult enquiries to answer. If they do respond, the question and answer that is remembered by the patient may not 'match' what the doctor said. Patients often qualify the question by asking *"How long have I got? What is the worst case, doctor?"* The doctor's answer may be along the lines that although some men with advanced

prostate cancer may only live three to five years, most men, even men with aggressive disease, will live for many years; that the actual outcome depends on many factors; and so on. But what the questioner remembers is ***"Three to five years."*** And that is almost certainly the wrong message.

There are no definitive answers to these questions. There are too many variables: prostate cancer is not a simple 'one size fits all' disease. These variances result in significantly different diagnoses and outcomes. Some say that there are two varieties of the disease – the very aggressive 'tigers' and the not so worrisome kitty cats. But in fact there is a very large feline community in this Strange World, including kitty cats, feral cats, wild cats, lynx, bobcats, servals, caracals, cougars, jaguars, mountain lions, pumas, cheetahs, leopards, lions and tigers. They all represent different variants of the basic disease. The way in which the disease prowls, attacks and spreads can vary from man to man, depending on a wide number of factors, such as genetic background, diet, body mass, or exercise.

These are some of the issues that have a bearing on life expectancy after diagnosis:

The diagnosis. Although the terms used will probably not be understood at this stage all are covered later in this booklet and are recorded here only for completeness.

A **"bad"** diagnosis – the tiger of the family - carries a high, but not a 100%, chance of early rather than late death. It will generally be associated with a number of pointers. They are a combination of high Gleason Score of 8, 9 or 10; a history of continuously sharply rising PSA numbers; a low free PSA percentage (under 15%); a high PSA level, well over 20 ng/ml and probably in the hundreds; a staging of T3 or T4. Such a "bad" diagnosis carries a high, but not certain chance of early death.

At the other end of the range is the **"good"** diagnosis – the kitty cat – carrying a very low risk of death, but not a zero risk. typified by a Gleason Score of 6 – the lowest score for a diagnosis; a history of small or no continuous increments in PSA levels; a high free PSA percentage (over 25%); a PSA level below 10 ng/ml; a staging of T1. Such a diagnosis carries a very low risk of disease specific death, but not a zero risk.

These diagnostics are variable – for example there is a very dangerous form of the disease – you might liken it to a leopard - with a low PSA level that is often only diagnosed late in the day through DRE (Digital Rectal Examination) or the development of symptoms because the PSA levels generated never hit any of the levels that are defined as "abnormal" – this will be covered later in the book.

Age at diagnosis.

The latest available statistics show the median age at death for cancer of the prostate was 80 years of age. That is to say, *half the men who died from prostate cancer were more than 80 years of age*. The figures also show that over 90% of the men who died were over the age of 65. The same statistics show the median age at diagnosis for prostate cancer was 68 years of age with about 62% being men over the age of 65. Or to put it another way, although almost 40% of the men who were diagnosed were under the age of 65, only 10% of the men who died of the disease were under this age.

There is a view that any form of the disease diagnosed in a young man – usually regarded as a man in his late 40s to mid 50s - is more likely to be a 'tiger' and aggressive, but this is not supported by available data. What has been established from the limited data available is that a young man with a "good" diagnosis will have an even better survival rate than an older man, while if he has a "bad" diagnosis this is likely to progress more quickly than a similar diagnosis in an older man.

Risk of other causes of death:

Overall, despite the statements in publicity material, prostate cancer is not a major killer of men. In most Western countries, such deaths account for only about 3% of male deaths (which means that 97% of men die from some other cause) and, generally speaking, even men who have been diagnosed with prostate cancer still have a higher risk of dying from some cause other than this disease.

Two recent studies illustrate this point. The first, published in 2008 was a study of 19,271 men aged 66 years or older diagnosed with clinical stage T1-T2 prostate cancer (down towards the "good" or kitty cat end of the range). During the follow-up period - a little under 7 years - almost two thirds of the men died, but relatively few died from prostate cancer. Causes other than prostate cancer accounted for 11,045 (88%) of all deaths and far fewer - 1,560 (8% of the men in the study) were from prostate cancer.

The second study is an ongoing one on Active Surveillance (the term for decision not to have immediate treatment) and interim results were published in 2009. The median follow-up in this study of 453 men, was 7.2 years. In that time 77 (17%) of the men in the study died but only 5 (1%) died from prostate cancer. The ratio of non-prostate

cancer to prostate cancer mortality was therefore 16:1. The men in this study had diagnoses similar to the "good" diagnosis set out above.

It is important to understand that much of the available information will refer to 'average' or 'median' life expectancy. Many people do not understand these terms which are used interchangeably, but which are in fact different. Stephan Jay Gould wrote an excellent piece titled "The Median Isn't The Message" - after he was diagnosed with a form of cancer (not prostate cancer) with a median life expectancy of only eight months, yet he lived for 20 years after his diagnosis. He explains:

> *Consider the standard example of stretching the truth with numbers - a case quite relevant to my story. Statistics recognizes different measures of an "average," "mean" or central tendency. This mean is our usual concept of an overall average - add up the items and divide them by the number of sharers (100 candy bars collected for five kids next Halloween will yield 20 for each in a just world). The median, a different measure of central tendency, is the half-way point. If I line up five kids by height, the median child is shorter than two and taller than the other two (who might have trouble getting their mean share of the candy). A politician in power might say with pride, "The mean income of our citizens is $15,000 per year." The leader of the opposition might retort, "But half our citizens make less than $10,000 per year." Both are right, but neither cites a statistic with impassive objectivity. The first invokes a mean, the second a median. (Means are higher than medians in such cases because one millionaire may outweigh hundreds of poor people in setting a mean; but he can balance only one mendicant in calculating a median).*

So, while none of the three factors discussed above can, in themselves, produce a firm answer to the question "How long have I got?", taken together they can help to give an indication of the range of potential survival time for an individual. He can assess where his diagnosis fits into the range; how old he is; what his general state of health is and what his work and leisure activities are. Hopefully in completing this exercise he will come to the conclusion that he has many years ahead of him; that he will realise that there is indeed life after Prostate Cancer and that he will understand that this is still primarily a disease of old men, at least as far as death is concerned. As Willet Whitmore, a prostate cancer specialist, said many years ago: *"Growing old is invariably fatal while prostate cancer is only sometimes so".*

HOW WILL I DIE?

Many people shy away from the second question – ***"How does death come?"*** because the word "cancer" is emotionally laden. It is usually associated with a drawn out, painful death and this is particularly so as far as prostate cancer is concerned, when metastasis (spread) to the bone can create significant pain, so let's deal with that first.

There is no doubt that bone metastasis can, and does happen to a minority of men and it is an awful fate for them and their loved ones. In the few discussions that have occurred on the Internet, experts in the field of prostate cancer have said that modern pain management techniques can deal with most of the issues and that, in any event, the dreaded painful bony metastasis is less common than imagined, at least in their experience.

A piece written by Dr Michael Glode (Professor of Medical Oncology M.D., Washington University), on his blog in October 2007 says in part:

> *"Prostate cancer tends to spread to lymph nodes or bones. There are some studies that begin to show us why this is different in different patients ……. but have yet to lead to more practical management decisions.*
>
> *We treat all metastases first with androgen deprivation. In those patients with nodes, we …….keep the urethras open as they may be compressed by the enlarging nodes. Without these interventions, the kidneys can stop working and lead to death from accumulation of toxins normally excreted in the urine.*
>
> *For those patients in whom bone metastases dominate, the main issue is often pain management. Radiation to bones that have tumor deposits can be extremely helpful along with appropriate pain medications. It is highly unusual to have a patient in whom pain cannot be well controlled with radiation, opiates, NSAIDs and attentive care."*

A response to a discussion of this subject on the Internet said in part:

> *"I am a hospice social worker who was diagnosed with prostate cancer in 2005. So I have two perspectives on the disease, as a survivor and as individual who has provided counseling, emotional support, education and advocacy to patients dying from prostate cancer. The focus of hospice is to maximize a patient's quality of life while assisting him/her with the transition from this life. Prostate*

cancer patients generally enter a hospice program when they have six months or less to survive. ***The majority of PC patients who have died under my agency's care went peacefully with a minimal amount of physical pain and emotional stress****."*

There is a somewhat irrational fear that use of opiates to deal with pain will lead to addiction. Dame Cicely Saunders, regarded as the founder of the modern hospice movement, had a clear view of that. As a nurse, she knew that, as she said, "dying is hard work" and she transformed the way we look at death and dying, ridiculing some of the medical profession for not giving large doses of pain-killing drugs on the grounds that they might become addictive. If the patient were dying anyway, what did it matter? Nor did she believe that drug doses big enough to remove pain entirely would necessarily cause the patient to develop such a tolerance to the drug that it would become ineffective. Regrettably many medical institutions and doctors still hold outmoded views and too many people suffer unnecessarily if they are not aware of these issues and are led to believe that there can be no relief from their pain.

Dr Michael Glode's blog also refers to hospice care when he continues:

"The thing that leads to death in most patients, however, is not direct involvement of an organ like the liver, lungs or brain. Instead, most patients seem to have a "wasting syndrome" not unlike AIDS. Loss of appetite, loss of energy and general debilitation lead to weight loss and patients don't feel like getting out of bed. Hospice care can be extremely helpful for this stage of illness and is usually available either at home or in an inpatient facility."

The 'wasting syndrome' to which he refers can come from emotional issues like depression but is usually from Cachexia or Anorexia (not to be confused with the anorexia nervosa of young women). If caught early on, anorexia may be treated and weight loss reversed with nutritional supplements or increased consumption of food. In prostate cancer patients some molecular causes of cachexia are now known and work is being done to try to address these, but cachexia does not respond to nutritional supplementation or increased consumption of food.

One final point. People who reach this 'end of life' stage will often have fought against the disease for some time and they, and their doctors, may misjudge how long they have to live. One study showed that Doctors who referred terminally ill patients to hospice care were consistently incorrect. In only 20 percent of cases were their predictions accurate.

Two Very Important Things To Remember About Prostate Cancer

Because of the high survival rates and the relatively slow progress of the disease in most men:

One: No one should give up hope as far as this disease is concerned. The journey to recovery or remission through diagnosis and treatment can be a long and hard one. It is made easier by the knowledge that there is a good chance of successfully completing it.

Two: There is time for men and their families to educate themselves about the disease and then to work with their medical team to make the best choices they can.

PREPARING FOR THE JOURNEY

To help you orientate yourself in this **Strange Place**, you might want to know the answer to these two questions:

Where is my prostate gland? and **What does it do?**

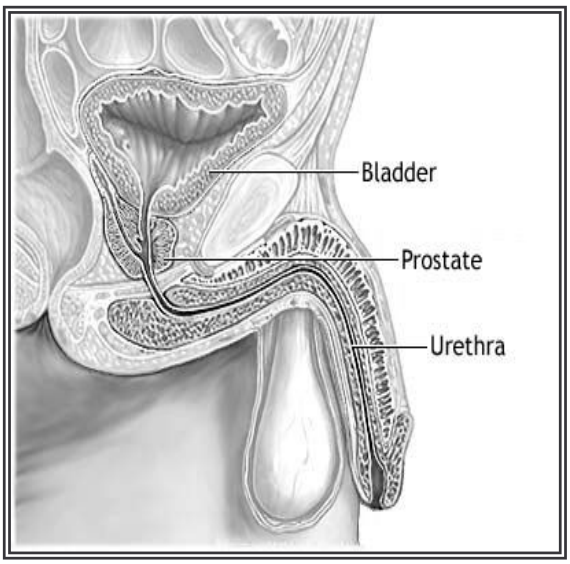
That's not as silly as it sounds. Most men don't know where the prostate gland is, even though only men have them. This is not really surprising. It is one of the best-protected glands in the human body; it rarely causes any trouble until after the age of fifty and it is not very big – about the size of a walnut. So why would you know where it is?

The prostate gland will usually have a volume of about 25 cc which is the same as a weight of 25 gm. It is contained within the bony structure of the pelvis and is very close to the bladder and rectum. In fact the duct that empties the bladder (urethra) passes through the prostate. This means that both prostate disease and treatment of the prostate gland after a diagnosis of prostate disease can cause problems with urination.

The main function of the prostate is to provide the fluid that carries the sperm on ejaculation. The nerves that control erections are along the sides and at the base of the gland. Damage to the nerves during treatment can, and often does, cause erectile dysfunction or impotence. This means that attaining an erection can be difficult or impossible after treatment. New techniques have reduced the incidence of erectile dysfunction, but most men will

have some erectile problems after treatment. The degree of erectile dysfunction can vary significantly and may be temporary or permanent depending on the individual, the treatment option chosen and the skill of the person carrying out the treatment.

The relative positions of bladder, prostate and urethra



HOW DO I GET TO THE STRANGE PLACE?

So, how do you get to the **Strange Place**? What's the procedure? Let's start with some background information to answer frequently asked questions:

How will I know if I have prostate cancer - what are the symptoms?

Most prostate cancer diagnosed today is termed asymptomatic - there are no symptoms. In most cases, diagnosis occurs after a routine examination, including a PSA blood test. If the PSA level is elevated, the normal process of diagnosis follows as described below.

Where there are symptoms, they are likely to include urinary problems (like frequent or painful urination, difficulty in starting urination, blood in the urine), problems with erections and ejaculation (such as pain or discoloured ejaculate) and pain in the bones.

But before worrying too much about these symptoms, it is important to know that many other diseases less dangerous than prostate cancer, such as infection of the bladder or prostate (prostatitis), can be responsible for many of them. Nevertheless, anyone with these symptoms should seek medical advice – and sooner rather than later.

Older men tend to have some urination problems – often frequency and urgency issues. The most common cause is BPH (Benign Prostatic Hyperplasia) or enlargement of the prostate. As the prostate grows it restricts the channel that passes through it carrying urine from the bladder. BPH is not a malignant disease and often starts showing up when men reach their 50s. It can be dealt with by means of procedures such as a TURP (Transurethral Resection of the Prostate), TUNA (Transurethral Needle Ablation) TUMT (Transurethral Microwave Thermotherapy) or with drugs. A herbal treatment known as Saw Palmetto has been reported as being helpful in relieving some of the symptoms of BPH, as have pumpkin seeds.

The only way prostate cancer can be diagnosed with any certainty is by a biopsy of the gland. Before that happens there are usually some preliminary steps. These are described below. In reading them you will start to learn some of the language and customs that might be new to you.

What causes prostate cancer?

No one can answer this question, but one school of thought links inflammation of the gland to a potential for tumour to form and grow. Even if this is not correct, there is general agreement that a healthy life style – good eating habits, correct weight, exercise, stress reduction - will lead to a lower probability of prostate cancer and may well inhibit the growth of any tumours. A healthy life style would also help in the recovery process after any treatment.

Can prostate cancer be spread to my partner from our sexual activity?

There is no evidence that cancers can be spread in this way.

Basic Language Hints

Before moving onto the diagnostic procedures, there are some basic language issues to be learned. Firstly and most importantly, many words have acquired specific meanings in this Strange Place – meanings that differ from those you may have attached to the words in the past.

The best example, perhaps, is the use of the words "positive" and "negative." In your usual "pre-cancer" place, broadly speaking, positive = good and negative = bad or not good. These positions are somewhat reversed in **Strange Place** talk.

You soon learn that a positive result to a test is not one you want to have. A positive result means that there are definite signs of the disease. On the other hand, as you are frequently told, a negative result does not mean you are disease free. There are merely no positive signs. So in this **Strange Place**, positive = bad and negative = not positive.

Another very important word to understand is "cure". This word has many meanings in the **Strange Place**. There is rarely agreement amongst medical practitioners who often use differing definitions of "cure" for the same therapies. A study published in 2008 found over 200 definitions of "failure" so that means there are as many definitions of "cure". The achievement of a "cure" follows observation for signs of any recurrence of the disease once it has been treated. This is true of all treatments, including surgery and can stretch over a period of many years, making the journey a long one. For many people the main goal is "remission" – a freedom of any signs of the disease – rather than "cure".

Even the word "cancer" can be misleading. To quote Dr Christopher Logothetis, a leading specialist in advanced prostate cancer: *"One of the problems with prostate cancer is definition. They* [the pathologists] *label it as a cancer, and they force us all to behave in a way that introduces us to a cascade of events that sends us to very morbid therapy."* This view is shared by well known and respected pathologist Dr Jon Oppenheimer who believes that there should be a clear distinction between what we call the aggressive forms of the disease and what we call those that are less likely to prove fatal.

There are other words and phrases you will need to understand. Many are three-letter acronyms, such as PSA, DRE and HDR: some are two- and four- letter acronyms such as RP, SI and EBRT. All of these will seem tremendously confusing at first, but will hopefully become clearer as you learn the language. **For easy reference you will find a short glossary of common terms and expressions at the back of this book.**

GETTING STARTED – THE FOREST OF FEAR

Going through the process of diagnosis is a frightening experience for most. Tests are ordered, often without any apparent reason or explanation; results are given in language that is difficult to interpret or understand; and all the time the fear grows. Hopefully, this section will take some of that fear away from the process. There is also often a feeling that time is limited, that a decision regarding treatment must be made very soon after diagnosis. For the vast majority of men the window of opportunity for successful treatment is a wide one and decision-making may safely take some months.

The first important fact about all medical tests

No test is always 100% accurate. Diagnosis is not an exact science.

The degree of error can vary considerably, depending on the complexity of the test – and some tests are very complex indeed. Sophisticated machinery is used for some – the maintenance of the machinery can alter the result. Chemicals are used in other tests – the use-by date of these chemical agents can alter results. Technicians run the tests – their training can alter results. The outcome of all tests needs to be interpreted by a specialist – their expertise can vary.

All this adds up to a degree of uncertainty and explains why it is very important to have all results checked by the most knowledgeable person available – and why second opinions should be sought automatically.

The second important fact about many medical tests

The value of many medical tests lies in measuring the change in the results, not in the results themselves.

Thus for PSA tests, it is important to measure the size and speed of any change from prior results, since this gives an indication of the aggressiveness of the disease. To get this measurement it is necessary to have a series of tests at regular intervals. This may mean delaying the start of treatment but the information is invaluable.

And the third important fact – mistakes can be made

The medical world is no different to any other place. Human beings run it and they can make mistakes. Get copies of all test results - ensure they are yours. If an unusual result does not relate to other results, have a re-test in case a mistake has been made.

Collect and keep the paperwork

Studies show that people who take an interest in the diagnosis and details of their disease and who involve themselves in the process of selecting the most suitable treatment have the best chance of recovery.

Appointments with medical advisors are often confusing, and sometimes rather rushed, affairs. Many people feel they do not want to waste their doctor's time and sometimes doctors give the impression their patients are indeed doing just that. But whether the time with the medical people is long or short, the information will often be bewildering or overwhelming. It is a good idea therefore to:

- Make notes before the appointment of all the issues you want to discuss or ask about;
- Attend all appointments with a companion – two heads being better than one for the interpretation of the information;
- Take a portable tape recorder to the appointment and record what is said, if the doctor is agreeable – you will then have time to gain a greater understanding of what was said when you play back the tape;
- Not be reticent in expressing reservations, asking for the rationale for a suggested course of action or determining the likely side effects. Ensure that you receive all the information you will need to make your decision.

It is very important to obtain, study and keep copies of all medical reports. Try to understand what they say and what they mean. If anything isn't clear, ask for more information and keep asking until you understand. It may be difficult for a medical person to reduce the complexities of a diagnosis to simple, non-technical terms, but you are entitled to this, so keep at it.

It is also a good idea to check reports for factual errors. Even typing errors can be a cause for concern and lead to misunderstandings. It may not be of great importance if the report records your age incorrectly. Whether a man is circumcised or uncircumcised does not affect the diagnosis or choice of treatment. But if this type of detail is wrong, there may be other errors, on the technical side, that are not so obvious.

Travelling Companions

The diagnosis and treatment of prostate cancer affects not only the man with the disease, but also his wife or partner and family. It is particularly hard on the womenfolk. A woman is not only concerned about her man, but also about her own future without him – and often feels guilty about this. It is much more difficult to deal with these issues alone than it is with the support of other people. Family and friends should be told and be involved in the process of sifting information and coming to a decision. A word of warning here – the help offered by well-meaning people can be somewhat overwhelming at times, so it may be best to keep the circle of helpers small initially.

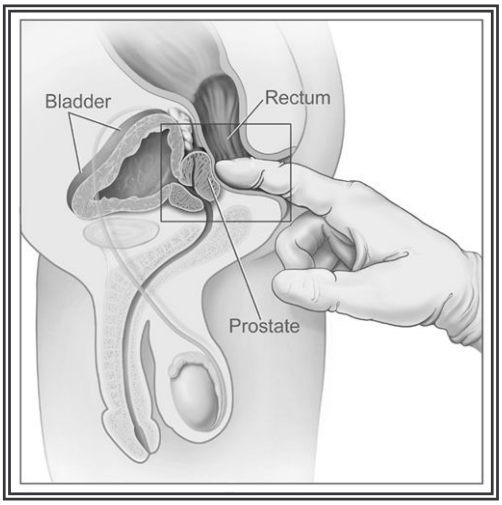
Support groups – terrestrial or in the cyberworld - can provide invaluable encourage-ment and advice. Most men and their companions who join support groups speak highly of the comfort in knowing they are not alone, and being able to speak to people who are on the same journey they are. Even talking to strangers can help – many men have traveled this way before and most will be only too pleased to pass on what they have learned. By taking these steps some of the feeling of "aloneness" is dissipated. It is worth asking your doctor or making enquiries at your local hospital to find the nearest support group.

Diagnosis with a potentially life-threatening disease can cause tremendous emotional upset – there is sorrow, anger, fear for the future and a whole host of aspects that must be worked through. The combination of these can often lead to the development of clinical depression which is very difficult to deal with alone. Men are notoriously reluctant to seek professional help for mental conditions like this but should get to a counselor. It will assist in regaining their balance.

If you have access to the Internet, join one of the discussion lists or forums and ask questions. The collective knowledge of the men and women on these lists is substantial and very few questions cannot be answered. Above all, never be concerned about appearing 'stupid' in asking a question. The only 'stupid' questions are those not asked.

GETTING STARTED – THE PROCESS

DRE – Digital Rectal Examination



The first step in the process of getting to the **Strange Place** is usually what is referred to as a DRE. This stands for Digital Rectal Examination and is dreaded by most men. Many refuse to even consider it. Most women cannot understand what the fuss is about. It is a simple procedure and there is no discomfort when it is done well – and if the man is relaxed. The examination does not take very long – usually less than 30 seconds.

If you have an understanding of where the prostate is located, it is pretty obvious that the only way it can be reached practically is via the rectum. The doctor inserts a finger to feel the prostate. In doing so, the doctor is trying to establish whether there is anything unusual about the gland: a firmness perhaps, or nodules, or roughness on the surface. A biopsy may well be ordered if the DRE reveals any abnormal features.

In days gone by the DRE was one of the few ways in which prostate cancer was diagnosed – men with symptoms were often diagnosed after a TURP. The DRE is not a very accurate method of diagnosis because of the limits imposed by the examination. For one thing the doctor can only feel one side of the gland; for another, the examining finger is clad in a glove.

There are considerable differences of opinion in the recommendations of various authorities around the world, but broadly speaking, the DRE should be a standard item on an inclusive health checklist for men over 50 years old, or for men over 40 years of age if they are 'at risk' – for example if breast or prostate cancer has been diagnosed in parents, aunts, uncles or siblings. In the US Afro-American men are seen to be at risk because of the high incidence of prostate cancer amongst these men.

PSA – Prostate Specific Antigen

This is the most widely used test for detecting prostate cancer today. It is simple to do. A small sample of blood is taken, usually from a vein in the arm, and is tested for the presence of PSA (Prostate Specific Antigen). This is an enzyme initially thought to be formed only by the prostate gland – hence "prostate specific". It is now known that very small quantities of the enzyme are produced by other glands – and even by women.

The laboratory testing the blood will report a number, which reflects the level of PSA in the blood, usually in nanograms per milliliter (ng/ml). A nanogram is one billionth of a gram; a milliliter is one thousandth of a litre. The method used to measure these very small amounts differs between the manufacturers of the testing equipment and the results produced vary considerably. Although manufacturers agreed to calibrate their equipment to produce comparable results, this is often not done in practice. It is best if you can have all tests run by the same laboratory using the same equipment. Most laboratories will only guarantee accuracy to within 80%.

IMPORTANT INFORMATION ON PSA LEVELS

PSA is <u>not</u> a prostate cancer specific marker. PSA levels can be elevated by a number of causes, from infection to physical activities. So it is very important to investigate the cause of any elevated PSA reported and not to assume that it is prostate cancer. In one reported case, a man with a PSA of 362 ng/ml was found to have an infection that responded to treatment – it was NOT prostate cancer. Although a PSA of 4.0 ng/ml is regarded as "normal", only a minority of men – between 25% and 35% - with a reading higher than that will be diagnosed as having prostate cancer. Men with a PSA level lower than the "normal" were biopsied in one study - many had positive results.

The scale of measurement is unlimited and PSA readings of over 1,000 ng/ml are not unheard of. One man in the United States had a PSA reading of 3,552 ng/ml in 1991, which climbed to 12,600 ng/ml in 1992. In 1999 his PSA was down to 109 ng/ml after treatment and he was still working as a commercial pilot on a large American cargo airline, subsequently rising to Chief Pilot before retiring in 2009. It is unusual for a man to survive so long with such high levels of PSA - this level is usually associated with a very aggressive tumor. Just another example of the Golden Rule.

When the PSA test was introduced as a diagnostic tool in 1990, a level of 10 ng/ml was considered "normal" and anything higher required further investigation. This figure was subsequently reduced to 4.0 ng/ml, which is regarded as "normal" in most countries. In the US there is a move to lower the measure to 2.6 ng/ml and there is even some pressure to go to 1.25 ng/ml as a "standard". Prostate cancer will **not** be found in roughly 65% of men with a PSA higher than 2.6 ng/ml. In many cases where prostate cancer is discovered after an "abnormal" PSA test, the tumor will be regarded as "insignificant" or "very low risk" and may not need immediate treatment.

There is another PSA test – the fPSA, PSA II or Free PSA test. This test refers to the amount of what is referred to as "unbound" or "free" PSA in a sample of blood and is discussed below.

The most common causes of an elevated PSA are prostatitis (an infection of the prostate), a bladder infection, or BPH (Benign Prostate Hyperplasia). This last condition affects most men over 50 years of age and is not deadly. There is little which can be done to reduce the effect of BPH on the PSA level in the short term, but any infection should be treated before a second PSA test is carried out. Acute prostatitis can cause the PSA levels to rise to five to seven times the normal level for up to six weeks. Infections of the bladder and prostate are often very difficult to deal with.

It is recommended that blood for PSA testing should be drawn as early in the day as is convenient and preferably before eating. Physical activities can affect the PSA level, and these should be avoided before drawing the blood. Examples of physical activities to avoid include:

- DRE (Digital Rectal Examination). Although doctors often carry out the DRE before drawing blood, they should reverse these procedures.

- Sexual activity: Ejaculation can elevate PSA levels for up to 48 hours after it has taken place.

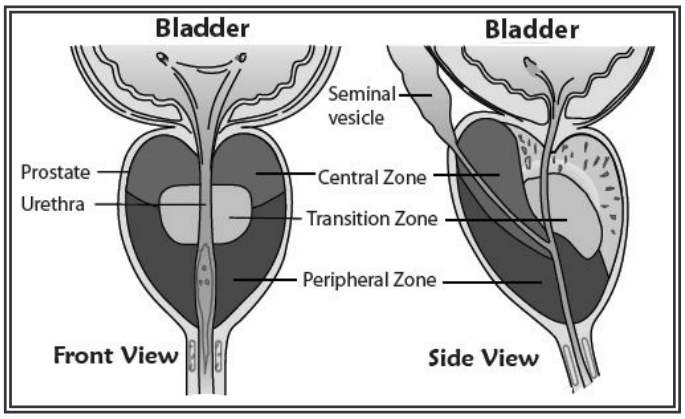
- Cycling or motor cycling: This can increase levels up to three times for up to a week, depending on how strenuous the cycling is. This includes use of an exercise bicycle.

- Alcohol and coffee: Both can irritate the prostate and should be avoided for 48 hours prior to blood being drawn.

If any PSA result is between 4 and 10 ng/ml, a second test should be run – the so-called fPSA, PSA II or Free PSA test. Some laboratories will do this automatically, while others require a specific request since the cost of the fPSA test is higher than the PSA test alone. The result of this test will usually be shown as a percentage of the total PSA measured and is a valuable part of the diagnostic process. The risk of cancer being present varies in inverse proportion to the percentage shown. So the higher the percentage, the less chance of the PSA being caused by prostate cancer. An fPSA of over 25% would mean that the most likely cause of the elevated PSA is not prostate cancer; an fPSA level of under 15% will point to prostate cancer as being potentially the main cause of the elevated PSA. If the fPSA level is high, alternative causes of the elevated total PSA level should be investigated before a biopsy is undertaken, since there are some risks associated with biopsy.

PSA levels can also vary significantly for no obvious reason. It is therefore usually important to have a series of PSA tests done to establish the average level before moving on to the next important test, which is the biopsy. Many men monitor their PSA levels for some years, watching for any upward trend in the numbers. There are two commonly used measures PSADT (PSA Doubling Time) and PSA Velocity (PSAV). The first looks at the time the PSA takes to double or it projects an estimated doubling time. The more rapid the PSADT, the more likely it is that prostate cancer is the cause of the high PSA result. So, a PSADT measured in months certainly requires investigation; a PSADT measured in years may be watched closely for some time further without any further direct intervention. The second measure is PSAV (PSA Velocity) which looks sequential increases in values of the PSA levels – if the increases are greater than a target figure (usually 0.75 ng/ml per year) further investigation may be warranted. It is important to note that if PSA values fluctuate up and down, it is far more likely that the cause will be infection or BPH - PSA values associated with prostate cancer tend to increase consistently.

Finally there is a school of thought that PSA density should be considered. This is measured by taking the PSA level and dividing it by the volume of the gland. The result is expressed in ng/ml/gm and the lower the figure the better. As an example, if a man has a PSA of 5.6 ng/ml and has a large gland estimated at 65 gm, his PSA density would be 0.086 ng/ml/gm, indicating that much of the PSA is generated by the normal cells in the large gland. A PSA density of over 0.15 ng/ml/gm may require further investigation.



The zones of a prostate gland – most tumours are found in the peripheral zone

Biopsy

If the DRE (Digital Rectal Examination) and/or the PSA tests indicate the possibility of cancer cells being in the prostate, the next step is to biopsy the gland - taking samples to examine under a microscope. A spring loaded biopsy "gun" is inserted into the rectum and very fine needles are 'shot' into the gland to collect samples. In the past six needles were used, but twelve needles, or more, are more common now. Occasionally a higher number of needles are used and up to 100 needles may be used in what is termed a 'saturation' or 'mapping' procedure intended to establish the precise site of any tumor. This is an unusual procedure and would rarely be undertaken in an initial biopsy, but rather when a focused treatment such as Cryotherapy or HIFU is being planned.

The biopsy procedure is uncomfortable - the procedure has been described rather like being kicked hard in the backside. However some men have reported considerable pain, especially from procedures using 12 or more needle, and recommend asking for an anesthetic spray or other pain deadening methods – for some reason many doctors do not offer this, and some are even reluctant to do so when asked. An ultrasound device is often used to establish whether there are any specific areas to be investigated. If any are identified, the biopsy "gun" is guided to these areas. If there is no specific target, the samples are taken in a standard pattern. Before the biopsy is done, confirmation should be sought that the samples will be clearly identified by site when the biopsy report is completed. This is not always done.

One of the developments in biopsy procedures is the use of Color Doppler Ultrasound. Some manufacturers of this equipment claim it can identify tumors without the necessity of biopsy procedures, but the more general view is that the procedure can be used to identify potential tumour sites more clearly and to guide the biopsy needles to those sites. Regrettably very few establishments use this procedure, which produces more definitive results.

CAN BIOPSY PROCEDURES SPREAD THE CANCER?

Concerns are often expressed about side effects from the biopsy procedure. The most worrisome of these is the speculation that the entry of the needles might cause any cancer to spread. There is no firm evidence of this happening, although there is a view that it is a possibility. It is clear that there can be an increase of cancer cells in circulation in the bloodstream after a biopsy. The unresolved argument concerns the possibility of these cells lodging in other parts of the body and establishing a metastasised disease.

Given the number of biopsy procedures carried out, especially in the United States, since the widespread use of PSA testing began there would be the expectation, if this concern was justified, that the incidence of prostate cancer would rise sharply. It has not but has in fact reduced.

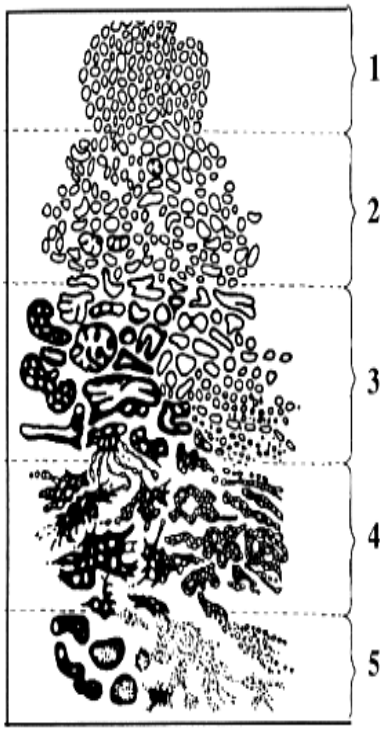
There are usually some short-term side effects. The prostate bleeds after the procedure, so both urine and ejaculate will usually be bloody for some time. Initially the urine will often be the color of Cabernet Sauvignon, but will fade to Rosé. The long-term side effects can include erectile dysfunction, but, as said previously, are very rarely reported. One study puts their incidence at less than 3%.

Because the biopsy needles pass through the lower bowel on their way to the prostate, there is a chance of infection so it is important to take the antibiotics, which will be prescribed before the procedure is carried out. Most samples taken by needle biopsy come from what is termed the peripheral zone of the gland

Samples are also submitted for analysis when men have the procedure known as a TURP (Transurethral Resection of the Prostate), the common way of dealing with BPH (Benign Prostatic Hyperplasia). This material is examined for cancer cells and if found these are graded in the same way as the samples from the biopsy procedure described above. If there is a positive diagnosis following a TURP, the material will have come from the transition zone of the gland. The majority of tumors in this area are very low risk and will probably not progress to become life threatening. This may make the man a candidate for what is termed Active Surveillance or watchful waiting.

Gleason Grades

The biopsy samples are examined in a pathology laboratory. The pathologist or technician will be looking for groups of abnormal cells – cells that have lost their natural shape and have created unusual glandular patterns. The first (prime) focus is on the abnormal patterns making up more than 50% of the sample. The second (secondary) and third (tertiary) foci are on abnormal glandular patterns that make up less than 50% of the sample. Not all abnormalities are identified as cancer – there are at least four conditions that can be confused with adenocarcinoma, the most common form of prostate cancer. Reference is also sometimes made to 'atypical' cells. This merely means that they are not normal, but does not necessarily mean they are cancerous.



Any cells with patterns appearing to be cancerous are evaluated using a scale known as the Gleason Grade (GG) which was established in the 1960s and which had five grades. Patterns that were well differentiated, but abnormal, were graded as 1; at the other end of the scale, poorly differentiated patterns were graded as 5. Healthy glandular tissue is well differentiated, so a Gleason Grade of 5 is bad news: a Grade of 1 is good news.

Illustration of GG 1 to 5

Originally, after each focus is graded, the primary and secondary Gleason Grades were added together to establish a Gleason Score (GS). The Gleason Score therefore was a scale that ran from 2 from (1+1=2=good) to 10 (5+5=10=(bad). Typical examples of Gleason Scores (and the most common) would be shown as GS 3+2=5 or GS 3+3=6. A score of 6 was the mid-point in the aggressiveness rating.

Note the difference between a Gleason **Grade** and a Gleason **Score** (which is the sum of the two grades.)

In January 2010, announcements were made in the United States that significant changes had been agreed by the **International Society of Urological Pathology** in the way in which prostate cancer tumours were graded internationally.

The key points of these changes were:

- Gleason grades 1 and 2 will "rarely if ever" be classified from a needle biopsy - they might be from "chips" resulting from a TURP (transurethral resection of the prostate)
- Some prostate cancers that would originally have been classified as a Gleason grade 2 cancers should now be graded 3 cancer
- Some prostate cancers that would originally have been classified as a Gleason grade 3 cancers should now be graded 4 cancer
- More attention should be paid to any tertiary Gleason grade 4 and 5 cancers in all specimens

It is not clear how the tertiary grades will be used since the value of this information in making clinical decisions is still controversial. The recommendation is that when biopsy cores show differing grades of prostate cancer, the pathologist should report the Gleason grades for each core individually, and the highest individual Gleason grade should be used in making decisions about treatment — regardless of the percentage of the involvement of that grade overall. (In other words if the patient has one core with Gleason 3 + 3 = 6 disease in 60 percent of the core; a second core showing Gleason 3 + 3 = 6 disease in 48 percent of the core; and a third positive core showing Gleason 3 + 4 = 7 disease in just 5 percent of the core, he should still be managed as though he has Gleason 3 + 4 = 7 disease.)

These announcements codified the changes that had been occurring since 2002 – the so called "Gleason Migration" – which saw very few diagnoses with Gleason Scores lower than 3+3=6. The immediate effects of the changes are:

- The range of Gleason Scores, previously a scale of 2 – 10 is now a scale of 6 – 10
- A diagnosis of Gleason Score 6 is therefore the lowest grade of prostate cancer
- There will be an increase in Gleason Score 7 diagnoses

- There will be more focus on the differences between what have been termed Gleason Score **7a** -3+4=7 and Gleason Score **7b** – 4+3=7

- There will be further subdivisions of 'risk' taking into account PSA levels and the size and number of positive biopsy specimens – termed **Very Low Risk: Low Risk: Intermediate Risk: High Risk** for the present

- Care must be taken in interpreting data from nomograms (such as the Partin's Tables – discussed below) which are used to estimate various probabilities of outcomes based on the specifics of diagnosis. Initially these nomograms will use old data.

The National Comprehensive Cancer Network (NCCN) has also announced updates to the NCCN Clinical Practice Guidelines for Oncology™ for Prostate Cancer which incorporate these revisions to the Gleason Grading and Scoring system.

IMPORTANT INFORMATION ON BIOPSY AND GLEASON GRADES

The process of grading abnormal cells is a subjective one, so accuracy of the result will depend on a number of things, including the experience of the person doing the grading. Since the grading of any tumor has a significant influence on the chosen method of treatment, it is very important that any Gleason Score be verified by at least one independent laboratory. In other words, get at least one second opinion on any biopsy report, preferably from the laboratory with the most expertise.

Unfortunately there are no standard procedures for reporting on biopsy results. It is important for the samples collected in the biopsy procedure to be clearly labelled so the area where any cancerous cells are found can be identified. This makes focused treatment easier. Some laboratories do not do this automatically, so it is worth insisting upon it when arranging for the biopsy. A good report will show details such as:

- The part of the prostate where the material being reported on was collected;

- The amount of abnormal material in the total sample;

- The percentages of material which relates to the Gleason Grades reported;

- Any evidence of neural invasion or spread to tissue beyond the prostate capsule;

- The presence or absence of PIN (prostatic intraepithelial neoplasia).

The reference above to PIN is important. PIN can occur in a prostate and because it is similar in structure to adenocarcinoma (prostate cancer) it is sometimes mistaken for that condition. PIN is not malignant. There is a view in some parts of the medical profession that PIN may be a forerunner to prostate cancer but this has not yet been demonstrated conclusively. At least three other conditions exist where abnormal cells can be mistaken for adenocarcinoma – hence the importance of second expert opinions.

Additional Tests: Blood Tests and Scans

Treatment options can vary depending on whether the disease is contained within the gland or has moved on. So, if the results from the biopsy are positive – meaning that prostate cancer has been reported – then it is customary to have further tests to try to establish if the disease has gone beyond the capsule of the prostate gland. Some tests are not really diagnostic but are useful to establish a base line for tracking future developments. In addition to the tests, nomograms such as the Partin Tables (discussed further on) can be used to estimate probabilities of the disease having spread.

At this stage it might be worth having a quick overview of how prostate cancer spreads.

Diversion – Metastasis, or prostate cancer spread

The normal progression of prostate cancer is to move out of the prostate as the cancer grows. The first step is often to penetrate the capsule of soft tissue surrounding the prostate gland. This may be accomplished by the cancer tracking the nerves, in much the same way as the roots of a tree will follow pipes. Having penetrated the capsule, the spread will often be into adjacent tissue, specifically the seminal vesicles (glands on each side of the bladder) and the lymph nodes (an integral part of the immune system). From these sites the disease can migrate to other organs, although the normal target is the bone, specifically the pelvic girdle and spine. The process of this spreading of the disease beyond the capsule is called metastasis. Commonly a metastasized tumor is simply referred to as "mets" as in "mets to the bone" or "liver mets".

Back to the additional tests.

Blood Tests

PAP (Prostatic Acid Phosphatase)

This test should not be confused with the better-known Pap Smear women have for the detection of cervical cancer. It is a test measuring an enzyme in the blood.

Few specialists now recommend a PAP (Prostatic Acid Phosphatase) test after diagnosis, although it was once a standard test. It is not very accurate but it can give an indication of the possibility of the tumor having spread beyond the capsule – the soft tissue that surrounds the gland. The test, like the PSA test, is affected by sexual activity. It should not be done within 48 hours of ejaculation and not until at least six weeks after biopsy.

There is no universally accepted standard regarding the calibration of results, so if PAP results are used for tracking any developments, the blood should always be sent to the same laboratory. Although there is a high number of false negatives – about 25% of men with metastases do not have elevated PAP numbers – anyone with an elevated PAP score should be aware that this may make surgery a poor choice. Studies indicate men with high PAP scores can have up to four times the risk of a relapse after surgery.

Other markers

The presence of higher than normal levels of **CGA** (Chromagranin A) in the blood can be an indicator of a more aggressive form of prostate cancer. This is especially true if it is found in conjunction with elevated scores in other markers such as **NSE** (Neuron Specific Enolase) or **CEA** (Carcinoembryonic antigen). These markers can be used to track the effectiveness of treatment and it is important to view them as a series and not to take one isolated elevated score as a poor indicator.

Scans – X-rays, bone scans, CAT scans and MRI

Scans are done in order to try to see what, if any, spread there is beyond the capsule. The value of some of these scans is doubtful in many cases. Some leading practitioners consider the automatic ordering of CAT and bone scans, which occurs frequently, as a waste of money. Their necessity should be established before the scans are undertaken.

The Partin Tables (described further on) can help in making this decision. The chances of there being metastases to the bone are remote with a small volume, low-grade (Gleason Grade 6) tumor. However, there is a high correlation between high Gleason Grades (8 and above), a large tumor and the extent the disease has moved beyond the gland. According to one leading authority there is virtually no possibility of metastasis occurring until the tumor reaches a critical mass of about 12 ccs. The average prostate gland is about 25 ccs, so in this view about half the gland would be occupied by cancer cells before metastasis occurred. There would therefore usually be a positive DRE (Digital Rectal Examination) and a palpable mass. A leading expert has also expressed the view that metastasis will not occur if the PSA is less than 50 ng/ml, unless the Gleason Score is very high – greater than 8.

X-ray

X-rays are usually undertaken as a matter of course. However, the chances of any signs of spread being shown, using X-rays alone, are slim. If any of the other scans are being run, there is probably little point in having an X-ray. Many people strongly believe in avoiding any unnecessary exposure to X-ray to minimize the chance of cell damage.

Bone Scans

Bone scans fall under the general term of nuclear medicine. The way in which the bone scan works is the reverse of a CAT scan or an X-ray. In conventional X-ray or CAT scan examinations, the radiation comes out of a machine and then passes through the patient's body. Nuclear medicine examinations, however, use the opposite approach. A radioactive material is introduced into the patient's body (usually by injection), and is then detected by a machine called a gamma camera. The procedure for a bone scan involves nuclear material injected into a vein (usually in the arm). There is a wait of two to three hours for the material to circulate in the system. The person being examined then lies on a special table and the gamma cameras (one above and one below) slowly track down the length of the body. The entire procedure takes between 30 and 60 minutes.

Bone metastases are usually associated with advanced prostate cancer, so bone scans are not considered essential for early stage disease. For men with a PSA of less than 10 and a Gleason Grade of 6 or less, the chances of the disease having metastasized to the bone has been estimated at less than 1% - which is equivalent to zero in normal terms.

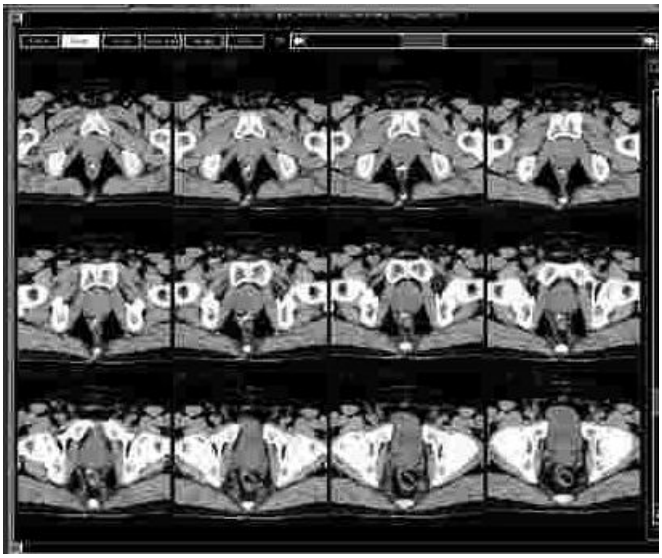
Some people are concerned about the introduction of nuclear material into the body, but it is said that the

radiation from this procedure is similar to that from a normal X-ray. The material is quickly cleared from the body. There is nothing painful about the procedure – apart from the injection, but the table upon which the person lies is made of metal and can be very cold, especially in winter, creating a degree of discomfort.

IMPORTANT POINT REGARDING BONE SCANS

The procedure is not cancer specific. It highlights local changes in bone metabolism, not cancer as such. So it will also highlight old fracture sites and even arthritis. Author Michael Korda, in his book *Man To Man*, describes the fear a positive bone scan raised. This showed what seemed to be clear signs of metastasis to his collarbone. It was only some time later that he remembered he had fractured his collarbone years before.

CAT (Computer Axial Tomography)
MRI (Magnetic Resonance Imaging)



Series from a pelvic scan

Although these two scans use differing technology, they are similar in their output. Both create a series of images, in effect showing views of the organ being examined in "slices". The CAT scan uses X-rays to create the images. The MRI scan uses a very strong magnetic field for this purpose. The MRI images can be enhanced by the use of an endorectal coil. This is a small device inserted into the rectum, which generates secondary fields.

Both examinations can be a little intimidating for those having them for the first time. The person being scanned lies on a small trolley, which enables them to be moved into a large cylindrical structure containing the scanning machinery. There is very little room in the older cylinders, especially for larger men, and a feeling of claustrophobia can result. Newer machinery has more room. The MRI process is noisy and operators should provide earplugs or headphones. There is nothing painful about either procedures – just a degree of discomfort from remaining immobilized during the scan, and the noise.

Some experts feel that CAT scans are only of value in the diagnostic process of advanced prostate cancer, which is usually associated with PSA readings of 50 ng/ml or higher and Gleason Scores greater than 8. CAT scans are highly insensitive in detecting disease in the lymph nodes, and valueless in most patients in detecting penetration of the capsule, which is usually the first stage of progression of the disease.

MRI scans with the endorectal coil can be much more useful but even then will only be associated with an accuracy rate of between 75% and 90%. Both types of scan have high false positive and false negative results. In other words they will identify tumors which don't exist or miss ones which do exist.

Staging And Diagnosis

The final step in this part of the journey through the **Forest of Fear** is to stage the disease. This summarizes the results of all the tests and results in the **Diagnosis.** It is very important to achieve as accurate a staging as possible because, as will be seen, some forms of treatment are more suitable for some stages than for others.

Until the late 1980s there were many systems of staging. The best known was probably the Whitmore-Jewett system, which showed four stages defined as A, B, C, D. The current system, used almost universally, is referred to as the **TNM** (**T**umor: **N**ode: **M**etastasis) system which has four **T** stages, which are then subdivided into a number of sub-sets. These are followed by the **N** and **M** stages, which are also subdivided.

The main divisions are as shown below, although there may be some variations in some definitions:

T 1: The tumor is discovered "incidentally". This is usually in connection with a TURP (Transurethral Resection of the Prostate) done to relieve the symptoms of BPH (Benign Prostate Hyperplasia). The material produced by the TURP is subjected to pathology analysis and if cancer is detected, the disease is staged as T1a or T1b depending on the amount of material exhibiting malignancy and the Gleason Score. If the tumor is discovered in the course of a biopsy following an elevated PSA test and if there are no other symptoms, then the stage is T1c.

T 2: For this stage, the tumor must be palpable. This means that the doctor carrying out the DRE (Digital Rectal Examination) must be able to feel the tumor. If the tumor occupies less than half of one lobe of the gland the disease is staged as T2a. If the tumor occupies more than half of one lobe, the disease is staged as T2b. When the disease can be felt in both lobes it is staged T2c.

T 3: A diagnosis of stage T3 disease requires penetration of the capsule – the soft tissue surrounding the prostate. Stage T3a disease has no evidence of involvement of other tissue and has penetration on one side of the capsule only. Stage T3b is similar to T3a except there is penetration on both sides of the capsule. Stage T3c indicates penetration from one or both sides, but with the involvement of the seminal vesicles - located on either side of the bladder

T 4: In this stage, the tumor has escaped from the capsule and the seminal vesicles, although it is still contained in the immediate area of the prostate gland. A stage T4a disease will have invaded the bladder neck or sphincter or the rectum. A stage T4b disease will have invaded the levator muscles or may be fixed to the pelvic wall.

N+: Disease staged as N+ will have evidence of spread to the pelvic lymph nodes. If there is no sign of this spread the stage will be shown as N0. If the presence of the cancer in the lymph nodes cannot be assessed the staging will be NX. Sometimes three stages of N (N1, N2, N3) are used to denote the extent of the spread into the lymph nodes.

M+: Disease staged as M+ will have evidence of spread beyond the pelvic lymph nodes; in other words, the disease has metastasized. If there is no sign of this spread the stage will be shown as M0. If the presence of distant metastases cannot be assessed the staging will be MX. Sometimes three stages of M (M1, M2, M3) are used to denote the extent of the metastases.

Illustration of Stage T2

And that's how to get to **DIAGNOSIS**. Anyone who has got here will be able to relate better to the denizens of this **Strange Place** because all will have the "numbers" that define their diagnosis. The normal sequence of these "numbers" is PSA, GS (Gleason Score) and Stage. A typical "number" might be PSA 7.2: GS 3+3=6: Stage T2bNXM0. This would relate to a man who has a slightly elevated PSA of 7.2 ng/ml, a Gleason Score of 6 that indicates a very low risk tumor occupying more than half of one lobe of his prostate. It is not clear whether the tumor has spread to the lymph nodes but there is no sign of metastasis beyond the pelvic area.

So now you know how to read some of the basic the language in the **Strange Place** !!

BEYOND DIAGNOSIS – THE DESERT OF DOUBT

Having assembled all the data available about the diagnosis, the next step is to decide what treatment to choose – if indeed treatment is required. It may sound like madness not to treat a disease diagnosed as cancer immediately. But not all cancers are equal and in many cases – probably the majority, prostate cancer is a slow growing or indolent disease which should be managed successfully as a chronic illness. Of course no one should ever ignore a potentially dangerous disease, but immediate action may not be essential. All treatments for prostate cancer have a risk of side effects (termed morbidity) which can, in many cases, significantly reduce the quality of life. It is important to ensure as far as possible that treatment is justified and that the most appropriate treatment is chosen. So -

WHICH TREATMENT IS THE ONE FOR ME?

When faced with the question, the traveler through this Strange Place will discover the greatest conundrum of the disease.

THERE IS NO AGREEMENT IN THE MEDICAL PROFESSION AS TO WHICH TREATMENT, OR COMBINATION OF TREATMENTS, IS BEST.

Relevant scientific data from randomized studies comparing the outcomes of various treatment options does not exist.

How can this be? This excerpt from a 1997 article in *The New England Journal of Medicine*, the prestigious American medical journal, sums up the position pretty clearly:

…. we have no firm guidelines for advising our patients about which therapeutic option is best. This means that education is more important than ever, but the art of multidisciplinary counseling is hampered by rivalries that seem more common among prostate cancer specialists than in other cancer specialties. This must change…. Close collaboration between surgeons, radiotherapists, and medical oncologists is mandatory for substantially improved control of prostate cancer.'

There is no sign of any great change since that was written more than ten years ago. In contrast to virtually every other cancer, where oncologists are directly involved in the choice of appropriate treatment, prostate cancer is still mainly treated by urologists, most of whom are surgeons. They will usually recommend surgery. If a second opinion is sought from a radiologist, radiation therapy may well be recommended for the same diagnosis. Both can quote statistics to support their position - how can both be right? Until this is resolved, the newcomer to this **Strange Place** must make up his own mind what is best for him and choose a course of treatment balancing risks versus reward as defined by his values - these generally include both survival and quality of life considerations.. Hopefully what follows will help him find his way through the uncertainty of this **Desert of Doubt.**

MORE LANGUAGE HINTS:

Before moving onto the treatment choices it is important to understand that there are no standard definitions for words like 'cured' or 'continent' or 'impotent' – all very important issues in the decision making process. Much published information avoids stating definitions and outcomes directly and as a result, men misunderstand the odds when choosing treatment. To make the decision that he will not regret, a man should understand his risk of morbidity (side effects) as well as his likelihood of a "cure" and how these terms are defined and measured.

When asked, a doctor may present percentage figures or other data regarding the likelihood of being 'cured', 'continent', and 'potent' following the course of treatment being recommended. It is essential to make sure that the terms used are understood. Most men expect 'cured' to mean that the tumor has been removed and that they will have no sign of the disease again: they do not expect to have regular PSA checks for the rest of their lives to ensure that the treatment has not failed. They expect 'continent' to mean that they will not leak and will be able to urinate without problems: they do not expect to have to use pads to remain dry or a penile clamp to stop leaking. And they expect 'potent' to mean that they will be able to achieve erections at will, whenever required: not to have to rely on medications such as Viagra or injections or mechanical devices. Yet studies have definitions of 'cured', 'continent', and 'potent' that differ markedly from these expectations and actual outcomes of treatment may be worse than they are said to be because of this. It is also important to understand that published information will usually show the results achieved by very skilled and experienced practitioners. Their results will almost certainly be better than someone who does not share these traits.

IMPORTANT INFORMATION REGARDING TREATMENT CHOICE

1. **Be certain that immediate treatment is required.** Published studies in Europe and USA demonstrate that majority of treatment procedures carried out for prostate cancer in are probably unnecessary – estimates vary widely between 25% and 80%.

2. **The choice of treatment may be less important than the choice of who does the procedure.** Published studies have shown that the experience of the person or team carrying out the chosen procedure is of utmost importance. The more experience, the lower the morbidity, the greater chance of remission. This may seem obvious, but many men only find out the hard way. It may be embarrassing to ask a surgeon or radiologist to provide evidence of their skill, but bearing in mind the consequences, this question should never be avoided. Those with a good record are happy to share it.

3. **It is important to be as certain as possible that the disease is contained within the prostate capsule before making any final treatment decision.** This is where the Partin Tables and other similar nomograms are very useful. The information obtained by using the Partin Tables is no guarantee of the actual situation for any individual. It does however provide some indication of what treatment options might achieve the best result, and which might be ruled out because of the possible extent of disease.

Men should be free to decide that they would rather live with the cancer than with the side effects of being treated for it. Men choosing treatment should not expect to be free of its side effects; men choosing Active Surveillance should expect eventual disease progression. These factors must be weighed against a man's expected longevity and pre-treatment situation – for example many men develop erectile problems as they age, so loss of this function might not be a big issue for them; a man with severe urinary problems from BPH (Benign Prostate Hyperplasia) might welcome the relief urinating freely again after surgery, and accept the possibility of bit of leakage. A young man diagnosed with aggressive disease is in a much different situation from that of an older man with low to moderate risk disease. If the probability of the tumour having spread beyond the gland is high, the odds of a 'cure' may be so low as to be a deciding factor not to have aggressive treatment. Family history should also be considered: sharing genes with someone gravely affected by prostate cancer may mean a genetic increase the risks of not being treated.

As long as the overall death rate from prostate cancer stays at about one in eight for those who have been diagnosed (regardless of stage and grade), the decision not to have immediate treatment in suitable cases should not be viewed as an illogical course.

TREATMENT OPTIONS

Treatment options vary from country to country. The greatest variety available is in the United States of America where, it is said, there are at least fifteen, none of which are demonstrably better than each other. The main options and sub-sets are:

- **Surgery** – This is the most common procedure, technically referred to as **RP** (Radical Prostatectomy). The main sub-sets are "open" and "keyhole" or laparoscopic procedures. Open surgery may be retropubic or perineal: keyhole surgery may be manual or robotic. Men with advanced prostate cancer may have their testicles removed surgically. This is called an Orchiectomy or an Orchidectomy, and although a surgical procedure it is really a form of hormone treatment.

- **Radiation Therapy** - The most common form is **EBRT** (External Beam Radiation Therapy) with a number of sub-sets that refer to the method of delivering the radiation dose. Another form of radiation therapy - **Brachytherapy** - has radioactive 'seeds' introduced into the prostate gland on a permanent or temporary basis

- **Androgen Deprivation Therapy** – This is referred to as **ADT**, but more commonly known as **Hormone Treatment**. There are many variations on this type of treatment, but essentially all involve using medication to suppress the hormonal mechanisms that help tumours to grow. Orchiectomy, surgical removal of the testicles, is an irreversible form of hormone treatment.

- **Active Surveillance** – **AS** is often referred to as "Watchful Waiting". No conventional treatment is undertaken unless regular monitoring indicates disease progression. Men choosing AS often make changes to diet and lifestyle with the intention of boosting the immune system.

- **Cryotherapy** – The prostate gland is frozen in this therapy usually referred to as **Cryo**. The treatment is evolving and now includes focal cryotherapy aimed at

targeting a tumor (like a lumpectomy in breast cancer) and thus reducing the probability of side effects. It is still regarded as somewhat experimental.

- **High Intensity Focused Ultrasound**– This procedure **HIFU** uses the heat generated by the ultrasound to focus on and destroy the tumor. Developed in China and used for some years in some European countries, Mexico and Canada, it is still regarded as experimental in the United States of America.

- **Chemotherapy** – This treatment has not been used very much in dealing with prostate cancer except as a last resort if all else fails. New chemicals and protocols mainly developed in the USA seem to be proving more effective than those in the past.

There is need now for a short diversion to the Partin Tables before getting back to the treatment choices.

Diversion to consider the Partin Tables:

Alan W. Partin, M.D., Ph.D., and Patrick C. Walsh, M.D. at the James Brady Urological Institute in Boston, USA developed these tables which are based on the analysis of many biopsies. Their aim was to try to establish if there was any relationship between the various aspects of diagnosis and the likelihood of the disease having moved beyond the capsule. The tables are too complex to reproduce in this document, but essentially they look at the three main aspects of diagnosis – PSA (Prostate Specific Antigen), Gleason Score and Clinical Staging - and show, as a percentage, the statistical likelihood of the disease having escaped the capsule or being contained.

To take the example referred to above, where the man was diagnosed as PSA 7.2: GS 3+3=6: Stage T2bNXM0, and referring to the relevant section of the Partin Tables we would find that the following chances of:

Organ-Confined Disease - 55%/68% (median 62%)
Capsular Penetration - 26%/38% (median 32%)
Seminal Vesicle Involvement -3%/8% (median 5%)
Lymph Node Involvement - 0%/2%(median 1%)

To give some idea of how one item might change these percentages, and how important the Gleason Score is, if the diagnosis was PSA 7.2: **GS 4+4=8:** Stage T2bNXM0, then the chances above would change to these:

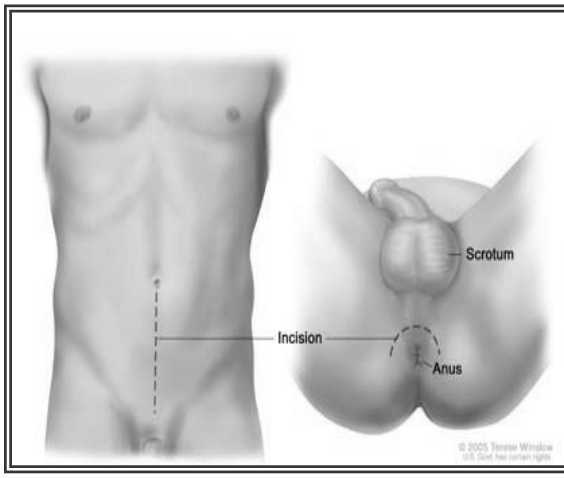
Organ-Confined Disease - 17%/33% (median 24%)
Capsular Penetration - 29%/48% (median 38%)
Seminal Vesicle Involvement - 16%/39% (median 27%)
Lymph Node Involvement - 3% /20%(median 10%)

There is a lower probability of benefit from surgery or other local treatments, if there is a high probability of the disease having escaped from the organ.

Now, back to treatment choices:

SURGERY: This treatment is technically called RP (Radical Prostatectomy), and is often referred to as the "gold standard" treatment, implying it is the very best. It is the treatment most commonly prescribed for younger men or early stage prostate cancer. The traditional surgery was an "open" procedure but there is enormous and rapid growth in laparoscopic– 'keyhole' – surgery, especially the Da Vinci robotic procedure.

In open surgery, the prostate gland is reached either from the lower part of the front of the body – this is a retropubic procedure – or through the area between the anus and the scrotum – this is a perineal procedure. There are no studies that show either of these procedures to be superior to the other. In the past the operation involved a substantial loss of blood. There have been significant improvements in surgical techniques and it is now unusual for a transfusion to be required. Some surgeons recommend the drawing and storing of the patient's own blood ahead of the operation as a precautionary measure.

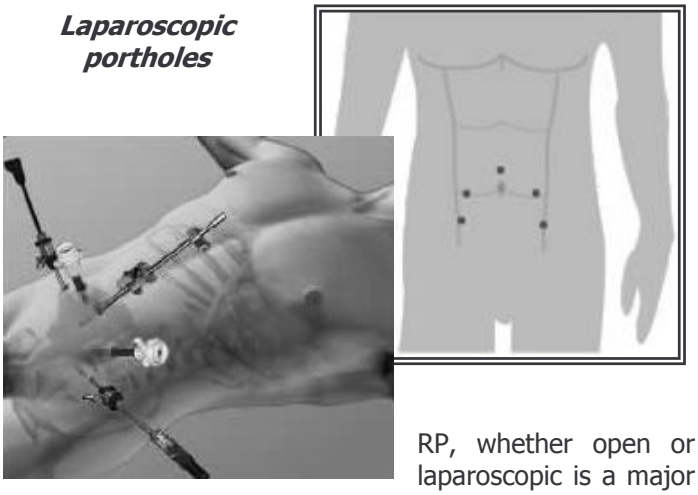


Retropubic ***Perineal***

Laparoscopic surgery on the other hand requires five small (five to 10 millimeters) incisions (or portholes), one just above or below the belly button and two each on both sides of the lower abdomen. Four arms are inserted into the portholes, three hold instruments, the fourth holds the camera – this is the laparoscope which enables the surgeon to get pictures of the prostate on a video monitor. Carbon dioxide is passed into the abdominal cavity through a small tube placed into the incision below the belly button. This gas lifts the abdominal wall to give the surgeon a better view of the abdominal cavity once

the laparoscope is in place. The arms are used by the surgeon to remove the gland, through one of the portholes and are manipulated manually, except where the procedure is robotic assisted – a procedure usually referred to as the Da Vinci procedure. The surgeon sits at the console and looks through two eye holes at a 3-D image of the procedure, meanwhile maneuvering the arms with two foot pedals and two hand controllers. The Da Vinci System translates the surgeon's hand movements into more precise micro-movements of the instruments

Laparoscopic portholes



RP, whether open or laparoscopic is a major surgical procedure and will usually take 3 – 4 hours. Discharge from hospital was normally be within 3 to 5 days for the 'open' procedures but is now likely to be 3 or less. Laparoscopic surgery, on the other hand, is far less traumatic and men are usually discharged from hospital in 24 hours. There is still a good deal of disagreement about the merits of the two procedures. Surgeons favoring open surgery say that they can feel the prostate and get a better idea of where the tumor might be and thus have more assurance of negative margins: doctors favoring laparoscopic surgery say that the better view obtained through the magnifying lens enables them to cut and stitch more accurately. As yet there are no long term studies to support either view. The incidence of initial morbidity are similar as are early failure rates. One thing has become clear – the learning curve for the laparoscopic procedure is a long one. One published study implies that it takes at least 250 procedures before the surgeon can be regarded as proficient.

In either case, a catheter will be in place, sometimes for some weeks. It normally takes about three months to regain control of the bladder function, although some men a achieve this sooner. Recovery of erectile function will almost certainly take a good deal longer, many months and sometimes a year or more. Recovery of erectile function is dependent to a large extent on the ability of the surgeon to spare the erectile nerves, although this is not the only factor.

The main benefit of surgery is that it introduces an element of certainty. The prostate gland can be examined closely to establish the extent of the tumor, to verify the Gleason Score and to clarify the likelihood of the tumor being contained within the gland. If there has been no spread beyond the gland, then the removal of the prostate should, by definition, remove the tumour. For many men that is of utmost importance.

However, surgery may not a good choice if the disease has metastasized – that is if the disease has spread to distant sites beyond the prostate. There is a view that, in such cases, the removal of the gland and the main tumor may accelerate the growth of the secondary, metastasized, tumors and make control of the disease much more difficult. Like many other aspects of prostate cancer, there is no consensus on this issue, which is the subject of some debate among physicians and researchers. Because it is so difficult to establish beyond doubt whether the disease has spread beyond the gland, there may be an element of risk in opting for surgery.

Success or "cure" is measured by taking PSA tests at intervals after the surgery. Ideally there should be no PSA measurement detectable with the normal PSA test. Ultra-sensitive PSA tests may show very low levels – well below 0.10 ng/ml. No formal studies have demonstrated the superiority of surgery over other forms of therapy, including Active Surveillance, in early stage cancer. There is a failure rate of about 30% - 35% over a period of 10 – 15 years for men undergoing surgery. Some failures have been reported at 20 years. In the event of recurrence or failure of the treatment, it is possible to use EBRT (External Beam Radiation Therapy) to treat recurrence thought to be confined to the prostate bed, or to use ADT (Androgen Deprivation Therapy) as a secondary treatment for recurrence where the disease has spread into other areas of the body.

The main side effects of surgery are erectile dysfunction (the difficulty or inability to have an erection) and bladder incontinence (the inability to control the bladder). The man also becomes infertile, since there is no ejaculate following the removal of the gland. Men intending to father children should bank sperm before surgery.

The first of these problems – erectile dysfunction (ED) – comes about because the nerves controlling erections are embedded near the surface of the prostate gland; one on each side of it. There has been a reduction in the reported rates of erectile dysfunction following the development of what is referred to as the "nerve-sparing" technique and the use of pharmaceutical drugs such as Cialis, Levitra or Viagra or one of the injectable materials – MUSE,Tri-Mix

and the like. However, the position of the tumor may affect the ability of even the best surgeon to spare one or both of the nerves while removing all the cancer. The ED rate is still high – probably over 50%, especially for men over the age of 50. Studies quoted with better rates should be examined very carefully, especially for definitions of potency or erectile function. These studies usually involve excellent surgeons and may not reflect the general outcome of surgeries carried out by surgeons with less experience.

Total bladder incontinence is reported in a small number of men – about 5% - but many men experience some leakage, particularly during sexual arousal or when lifting, coughing, sneezing or laughing. Again it is important to look at definitions when considering studies showing levels of continence after treatment. It is not uncommon for the use of 'only' one or two pads a day to be regarded as fully continent in such studies. The outcomes of surgery carried out by urologists who do not have the experience of surgeons in a centre of excellence are usually worse.

Another issue to be aware of is stricture from scar tissue, which can also cause urinary problems. If the man has a history of poor scarring (some reports suggest that if any scar on his body is more than 10 mm (about 3/8") wide) then there is about an eightfold increase in urinary problems following RP (Radical Prostatectomy).

Penile shrinkage is also reported in a significant number of men, thought to be the result of maintaining the penis in the flaccid state during what can be many months of recovery of erectile function. It is thought this can be counteracted by stimulating erections with drugs or manual devices as soon as post-surgical healing has taken place.

A final issue, rarely discussed, is that of Peyronie's Disease or Peyronie's Syndrome. This condition is one where the erect penis acquires a 'bend' or deflection. The vast majority of Peyronie's cases are very mild but others can cause severe problems. It seems unlikely that the condition is directly caused by a disease, or that it has any direct link with prostate cancer. A common cause is thought to arise from accidents during sexual activities, especially if the penis is not fully erect.

RADIATION THERAPY – the most common form of Radiation Therapy is known as EBRT (External Beam Radiation Therapy). There are many other acronyms, such as RT (Radiation Therapy), IMRT (Intensity Modulated Radiation Therapy) and 3DRT. All refer to the procedure where photon radiation is directed at the site of the prostate gland from an external source. The variations usually refer to the different aiming techniques. A form of EBRT known as CyberKnife® delivers what are termed hypofractionated doses – fewer doses, very much larger than normal EBRT but, it is claimed, delivered more accurately and thus reducing the potential for collateral damage. A significantly different form of EBRT is PBT (Proton Beam Therapy). It is claimed that the proton beams can be directed more accurately than photon beams, again with less likelihood of collateral damage. PBT for prostate cancer is only done at a few sites, mostly in the US.

Another form of radiotherapy, is Brachytherapy or SI (Seed Implants). Radioactive "seeds" are implanted directly into the prostate gland, where they remain. There is a variation of SI known as HDR (High Dose Rate Brachytherapy) where seeds are inserted repeatedly for a short time delivering hypofractionated doses and then removed.

Radiation therapy is intended to destroy the cancer cells while leaving healthy tissue intact and is often the recommendation for older men for whom surgery presents a health risk. EBRT is also used where it is felt that the tumour has spread just beyond the prostate gland itself and as a "salvage" treatment for failed surgery. EBRT used in conjunction with other treatments such as surgery or brachytherapy is known as adjuvant treatment. Radiation treatment is not recommended for men who have urinary problems prior to treatment since the procedure will often exacerbate these problems.

EBRT takes place over a number of weeks – usually six or seven – with daily sessions of therapy, the exception being CyberKnife® which takes about five days. The effect of radiation is cumulative, so low doses given on a regular basis build up into high doses, lethal to the tumor cells. Most men tolerate the procedure very well, although as time goes by, they may feel fatigued and it may be desirable to rest during the day. The feeling of fatigue will usually disappear some time after completion of the treatment.

Brachytherapy is usually considered as an alternative to surgery for men with a suitable diagnosis. SI is a relatively short procedure, taking two or three hours, after which the man can go home and carry on with his normal activities: HDR might need an overnight stay in hospital. There is sometimes a feeling of fatigue, as is the case with EBRT, but this usually recedes with time, as the dosage from the seeds reduces (they are only fully active for about six months). Brachytherapy is not a good option for a man who has previously had a TURP (Transurethral Resection of the Prostate).

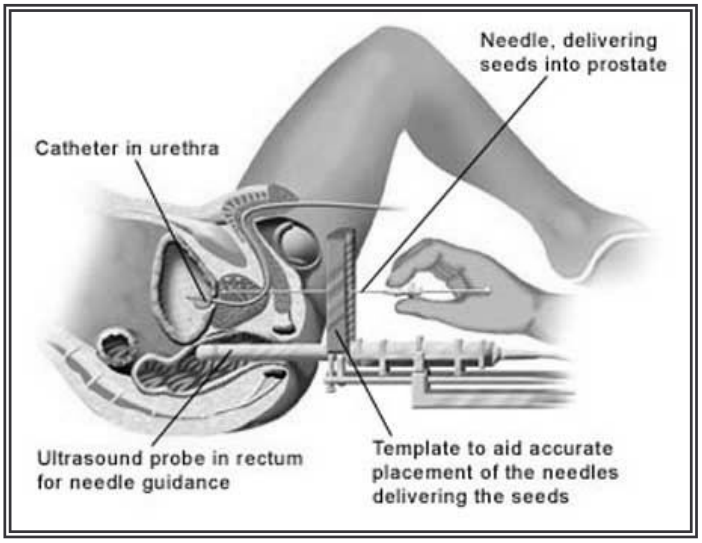


Illustration of placement of seeds into prostate in brachytherapy procedure

Two aspects of SI are often raised as concerns. Firstly, the man is carrying radioactive seeds in his prostate and the question asked is whether those seeds can injure anyone close to the man – for example, a grandchild sitting on his lap. Studies have demonstrated this is not a risk. The second concern is seeds migrating from the prostate to other parts of the body, notably the lungs. This happens when seeds work their way out of the prostate before the glandular tissue heals and locks them in place, or where they have not been securely placed. It is said this does not present any significant problem for the patient.

Success or "cure" for radiation treatments is measured by a gradual reduction in PSA level in the months after treatment is completed. The aim is to achieve a nadir, or low point, of 0.200 ng/ml and to maintain that level. Some authorities feel a nadir of under 1.00 ng/ml is an acceptable level. Some men experience what is referred to as a "bump" about 18 months after radiation when the PSA rises and then falls again. No formal studies have demonstrated the superiority of radiation therapy over other forms of therapy, including Active Surveillance. There is a failure rate of about 30% - 35% over a period of 10 – 15 years for men undergoing radiation therapy. A leading US institution claims better long-term freedom from disease using combined SI/EBRT therapy at than EBRT alone. They term this treatment procedure as ProstRcision®.

In the event of recurrence or failure of radiation treatment, surgery is not a good option and is rarely successful because of the damage done to the tissue by the procedure. The usual option for further management is ADT (Androgen Deprivation Therapy) although Cryotherapy can also be used as a salvage treatment.

The side effects of radiation therapy are similar to surgery with the added complication of urinary urgency/frequency, difficulty in starting a urine stream and incontinence. Radiation can sometimes result in bowel incontinence as well as rectal bleeding. ("Incontinence" is the inability to control bladder or bowel). The reported incidence of incontinence is fairly low for EBRT and even lower for SI and PBT. There is a reported improvement in radiation treatment side effects with modern techniques. Erectile dysfunction is reported to occur in a substantial number of cases, more so for EBRT than SI, but at about the same level as surgery. In contrast to surgery, where an immediate loss of function can be followed by a gradual recovery, erectile dysfunction associated with radiation therapy of any kind tends to occur well after treatment and to gradually grow worse over time.

ADT (ANDROGEN DEPRIVATION THERAPY) generally known as **Hormone Treatment.** There are many variations of this treatment, all with different acronyms. The theory behind this treatment is that growth of prostate cancer cells is fuelled by dihydrotesterone (DHT) a derivative of testosterone, the male hormone steroid, which is an androgen. A reduction in the production of androgen will therefore theoretically deprive these cells of nutrition and they will die. There are four methods by which the cells are deprived of androgen.

- *Ablation.* The testes produce approximately 90% of the male body's testosterone with the balance being produced by the adrenal glands. Thus a simple way to reduce testosterone production is the surgical removal of the testes by way of an orchiectomy or orchidectomy (castration).

- *Additive.* Testosterone production is attacked by dosing the man with estrogen.

- *Inhibitive.* This involves the use of chemicals to block signals from the brain to the production centers so that no testosterone is produced.

- *Competitive.* The final method of treatment involves what are known as antiandrogens. These do not prevent the production of testosterone, but block the receptors on the prostate gland, preventing the androgen from being absorbed.

The last three treatments are sometimes used in unison, in which case the treatment is usually referred to as CHT (Combined Hormone Therapy) or ADT3. Treatment is administered in a variety of forms, from pills to monthly or quarterly injections.

ADT was at one time only used to manage late stage prostate cancer, where the tumor had spread beyond the capsule and therefore could not be treated by surgery or radiation and/or as a "salvage" therapy for failed surgery or radiation treatment. There is however a growing use of this therapy as a precursor to other treatments. This is known as neo-adjuvant therapy. Many practitioners are opposed to this practice because studies do not show any significant advantage for the inevitable side effects and there are several disadvantages. Some leading practitioners of both surgery and brachytherapy in the US will not treat men who have had this neo-adjuvant therapy.

The aim of ADT is to manage and control the disease, since it is extremely unlikely that this therapy will result in a permanent "cure". The degree of success achieved is measured by the reduction of the PSA to as low a level as possible and keeping it there. In many cases the PSA level can be undetectable and there are reports of men treated with this therapy achieving mortality rates very similar to those of men without the disease. Failure of this treatment occurs when the tumour becomes androgen independent (AI). This condition is often referred to as Androgen-Independent Prostate Cancer (AIPC), or Hormone Refractory Prostate Cancer (HRPC). This means the tumor has found a way of growing without the androgen associated with testosterone. Management of the disease at such a stage is very difficult although some success has been reported with new chemotherapy drugs.

There are numerous, very variable, side effects associated with this form of treatment whether the treatment is being used as an adjuvant treatment for early stage tumors or as a palliative measure for advanced cancers. Many of the side effects are those that occur naturally as men age. **Some men have severe side effects, others have none: some appear early, some only after a long period of treatment.** The ones reported most frequently by men undergoing any of the ADT methods are erectile dysfunction, loss of libido (no interest in sexual activity), hot flushes, osteoporosis (loss of bone), loss of muscle tone, weight gain and mood swings, with depression being widely reported.

Individual methods have other side effects such as the development of breasts (gyneacomastia), increased risk of thrombosis, and an initial rise in tumor activity, known as a "flare". This last effect is usually of a temporary nature. Flare can be prevented by administering an anti-androgen one week prior to the first injection of the drug being used to inhibit testosterone production.

A list of potential side effects associated with ADT include:

Alcohol intolerance (with Casodex and Eulexin); Anemia; Anxiety or depression; Arthritic symptoms; Appetite loss; Blood in urine; Breast swelling and tenderness (gyneacomastia); Cholesterol and triglyceride increase; Constipation; Diarrhea (Eulexin); Disturbed sleep; Drowsiness; Dry mouth; Emotional instability (especially crying); Feet or lower legs, swelling of (peripheral edema); Flatulence; Flu syndrome; Hair: decrease in pubic and body hair; facial hair grows more slowly; Headache; High blood pressure (hypertension); Hot flushes; Hyperglycemia (high blood sugar); Impotence (during the period of treatment and some months after); Indigestion; Itching; Insomnia; Liver problems; Memory loss; Methemoglobinemia (a crystallization in the blood); Nausea; Nocturia (need to urinate frequently at night); Nervous and twitchy legs; Osteoporosis; Pain - abdominal, back, chest, in right side; Pressure - feeling of extreme pressure in head; Prickling sensation on the skin; Shortness of breath; Testicular atrophy (shrinking) and soreness; Sweating; Weight gain (weight gain may continue for a while after treatment); Weight loss.

The following symptoms may reflect serious problems and if they occur, medical attention should be sought immediately:

Bluish lips, fingernails, or palms of hands; Dizziness (extreme) or fainting; Fatigue, weakness; Pain: bone, joints, pelvic; Numbness, coldness, or tingling of hands or feet; Infections; Rash; Urinary incontinence; Urinary tract infection; Vomiting; Weak and fast heartbeat; Yellow eyes or skin.

A recent development has been towards "pulse" therapy known as IHT (Intermittent Hormone Treatment) or IHB (Intermittent Hormone Blockade). Some studies indicate that stopping the ADT once the PSA count has been reduced and reintroducing the therapy if the PSA count rises again might produce some benefit. The duration of the side effects of ADT are reduced and it appears the possibility of the disease becoming androgen-independent may also be lessened. In some very rare cases, the PSA does not rise again after the ADT is stopped and the man can be considered to be in remission. Men on ADT welcome the treatment "holidays" as many of the side effects disappear or diminish as the effect of the drugs wears off. In some cases some of the side effects are permanent.

CRYOTHERAPY: This procedure uses probes to freeze the gland. The targeted prostate tissue is then destroyed by the very rapid thawing process which ruptures the cell membranes. The probes are placed through the perineal skin - between the scrotum and anus, like the tubes for brachytherapy. They are guided using transrectal ultrasound which is also used to monitor the freezing process in real time. It is unusual for fewer than three probes to be placed; additional probes may be placed to allow for adequate freezing of more extensive disease. Incontinence levels are kept low by warm liquid being circulated in the urethra during the procedure.

When this procedure was first used, the entire gland was destroyed, which led to a very high incidence of erectile dysfunction – almost 100% of men were impotent according to some studies. Later developments have seen the development of focused cryotherapy, which destroys only identified tumors and the healthy cells in the immediate vicinity of the tumor, leaving some or all of the erectile nerves untouched and resulting in levels of ED that are comparable with those resulting from other treatments. It can be difficult to pinpoint the position of small tumors. This usually involved a mapping biopsy using a large number of needles – as a rule of thumb the volume of the gland + 20 up to a potential maximum of 100 needles. This type of biopsy is usually undertaken under a general anesthetic.

One advantage this form of treatment has is that it can be repeated and it can be used in suitable cases as a salvage procedure for other failed treatments, notably radiation.

HIGH INTENSITY FOCUSED ULTRASOUND (HIFU): This procedure was developed in China and used for liver and pancreatic cancers, but was not used initially for prostate cancer. Subsequently several European countries, notably France, Germany and Belgium started to treat men with prostate cancer. Basically the targeted prostate and tumour cells are cooked to death. The focused sound energy raises the temperature to around 140 degrees Fahrenheit (60 degrees Celsius), killing the cells in about one second. The ultrasound beam must travel through continuous tissue or fluid to the tumor site because the energy cannot be focused through gas or bone. By targeting tumor cells precisely, theoretically the tumor can be destroyed with minimum collateral damage. Like cryotherapy one of the immediate pre-treatment issues is how to identify the precise location of the cancerous cells.

HIFU is still regarded as experimental in a number of countries and has not been approved for prostate cancer by the FDA in the USA. Trials are being carried out there. There have been alarming reports of bladder damage creating severe urinary problems.

It is clear that experience with the equipment used for this therapy is even more important than in other therapies. An unskilled practitioner can do a deal of damage very quickly.

ACTIVE SURVEILLANCE: This option is still often referred to as WW (Watchful Waiting) although the terms have different meanings. In the past Watchful Waiting meant no action was undertaken unless the disease is seen to progress. Men choosing the Active Surveillance are monitored closely and will often use a variety of non-conventional or alternative treatments to manage the progression of the disease.

Dr Jon Oppenheimer, a leading pathologist in the USA is on record as saying:

"For the vast majority of men with a recent diagnosis of prostate cancer the most important question is not what treatment is needed, but whether any treatment at all is required. Active surveillance is the logical choice for most men (and the families that love them) to make."

The rationale for this statement is that prostate cancer is what is termed an "indolent" disease in most cases, because it progresses so slowly it may never be a threat to life. Many men choosing Active Surveillance believe by taking a proactive stance he can harness his immune system to either halt the progress of the disease or possibly even cause it to regress.

Prime candidates for this option are those who have been diagnosed with an insignificant tumor or very low risk disease. There are various definitions of these terms, but broadly speaking they are similar to the one established by Johns Hopkins University School of Medicine in the US, where the definition of an insignificant tumor was established some years as one with the following characteristics:

- *Non palpable* – the examining doctor would not feel anything when carrying out the DRE (Digital Rectal Examination)
- *Stage T1c* - the tumor is discovered in the course of a biopsy following an elevated PSA test where there are no other symptoms
- *Free PSA* - the percentage of free PSA should be 15% or greater

- *Gleason Score* - less than 3+4=7 – or, as some practitioners have it, 7 or less

- *Size* - less than three needle cores positive with none greater than 50% tumor. (In this definition it is assumed that a 12 needle biopsy is used)

The latest guidelines issued by National Comprehensive Cancer Network (NCCN®) following the codified changes to the Gleason grading system in January 2009 has this definition of very low risk disease:

- *Clinical Stage* T1-T2a – the examining doctor felt nothing on DRE or felt something on one side of the gland only

- *Gleason Score* 6 – the lowest score on the current range

- *PSA* less than 10 ng/ml

- *Size* - 3 positive needles or less with 50% or less positive material in each core

- *PSA density* - less than 0.15 ng/ml/gm

Old studies have shown the majority of men with a diagnosis similar to these will not have a life-threatening progression of the disease for many years. Current studies demonstrate that there is a negligible additional risk for suitable men in undertaking Active Surveillance.

The problem for any man considering this option is the uncertainty of the diagnostic process, which is more art than science. It is not possible to identify, with absolute certainty, which tumors are indolent (the kitty cats) and which are aggressive (the tigers) or just where they fit in the range of diseases. There are good indicators: The ones listed above indicate disease that is most likely indolent; on the other hand PSA doubling times measure in months or weeks, high Gleason Scores – over 20 ng/ml, late stage disease – stages T3 and T4 all indicate a disease that requires early attention. Indolent disease can often be treated like a chronic illness.

For many men choosing this course, the essence of Active Surveillance is a belief in the mind/body continuum. The aim is to maintain the immune system in good condition to deal with the tumor. Since there are very few studies to guide men in this endeavor, and the medical professionals are often ill-informed on nutritional matters and similar issues, there is a tendency for each man to develop his own unique program. Most of the programs for which there is anecdotal support include the following elements:

- **Stress reduction:** Stress is commonly regarded as one of the most universal causes of damage to the immune system. Stress reduction can be accomplished using activities such as meditation, visualization or yoga.

- **Exercise:** Moderate amounts of exercise are essential. Usually, subject to the fitness of the man, he is recommended to exercise at least three days a week at a level where the pulse rate is raised and sweat is formed.

- **Changes in diet:** This subject is covered in a little more depth in the section titled **Plains of Recovery**, but essentially, the aim is to attain a vegetarian diet or better still a vegan diet. Red meat and dairy products are regarded as bad: fresh vegetables and fruit are regarded as good. Smoking should, of course, be stopped, as should consumption of alcohol, although small quantities of wine, especially red wine, are thought to be beneficial. Consumption of coffee, animal fats, fried foods and sugar should be kept to a minimum.

- **Weight loss:** There is a clear connection between illness and obesity. Although following the steps above should lead to weight loss, this should also be incorporated as one of the aims of any successful program.

Successful Active Surveillance management should see a stabilizing or even a reduction in PSA levels, and this is the primary measure of success. Because of the vagaries of PSA counts, this should not however be the only measure. There should also be an annual DRE (Digital Rectal Examination) and, some recommend, an annual or biennial biopsy. In considering this latter test, some thought should always be given to the potential for side effects from biopsy. A continuous rise in PSA or a positive DRE would be the trigger to contemplate further, conventional treatment. Many men – more than 20% in one study - who have chosen Active Surveillance have negative biopsy results on repeat biopsy. This does not necessarily mean that there are no longer cancer cells in the gland, because the biopsy process is literally 'hit and miss' but it does imply that there has been little or no significant growth in the tumor.

The side effects of a successful Active Surveillance program are all positive since the enhanced immune system will generally result in better health all round.

It is often difficult to deal with the uncertainty associated with Active Surveillance. This is often seen to be greater than the uncertainty of those who have had conventional treatment. However in three studies it has been found that essentially, if men are 'worriers' they have similar levels of concern whatever the path they choose. Those who are more phlegmatic accept the uncertainty more easily.

Anyone embarking on Active Surveillance will need determination to continue. The medical profession along with well-meaning friends and relatives, often create a good deal of pressure to 'do something'. This leads many men to abandon Active Surveillance and opt for conventional treatment even if there is no significant change in the diagnostic pointers.

BEYOND TREATMENT – THE PLAINS OF RECOVERY

For many men, particularly those who have not had enough input from their medical advisors, the promise of a 'cure' is misleading. They think the surgery or radiation will have dealt with the disease, they will be cured and they will be able to get on with their life as it was before the start of this journey to a Strange Place. But this simply isn't so. As all travelers know, life is never quite the same when you have been exposed to experiences beyond your previous knowledge. Prostate cancer is no different and, in addition, there is usually a good deal to be done in the aftermath of a treatment choice.

One thing common to all treatment choices is the need for continual monitoring of PSA levels to ensure there is no progression of the disease. Men who have had surgery are often somewhat shocked to find this is a requirement, despite having been assured the removal of the gland will cure the disease. But all treatments have recurrence rates, some of which are quite high, so lifelong monitoring is therefore essential. PSA tests will usually start three months after treatment is completed and will follow at similar intervals for the first twelve months. Thereafter they will usually go to half yearly and finally annual tests. Significant rises in PSA levels will trigger further investigations and, in some cases, additional secondary treatment.

Although much of the focus at this stage of the journey is on morbidity or side effects, which vary depending on treatment chosen, perhaps it is a good idea to contemplate those factors all men should be taking into account, irrespective of their treatment choice. The journey from **Treatment** to **Remission** is a long one and it is as well to ensure that there are sufficient mental and physical resources to keep travelling this road. So the first step on the long trek across the **Plains of Recovery** is to optimise wellness and the immune system, which is going to have a good deal of work, particularly in the early stages. For those choosing conventional treatment, scar tissue has to be formed, infections fought off, toxic substances removed, damaged tissue replaced. For those choosing Active Surveillance, the tumour itself has to be dealt with.

Changes in Lifestyle

Most people will have to consider substantial modifications to their lifestyles to achieve this optimal state of wellness and to avoid further illness. These are some of the suggested steps:

- **Avoid Exposure to Damaging Substances:** Smoking has been demonstrated to cause immense damage to the immune system and has been linked to virtually every fatal illness. No one should continue smoking, least of all those diagnosed with a potentially terminal illness. Alcohol is also a poisonous substance and creates a great deal of additional work for the immune system. Some studies show a moderate amount of wine, particularly red wine, may have some beneficial effects. No studies demonstrate any value in drinking spirits. Coffee is another drink with a large question mark over it. Although evidence of damage is not as clear as for alcohol, coffee drinking should be kept to a minimum.

- **Reducing Stress:** Many studies show the linkage between stress and illness. Despite this, there has been a general denial that reducing stress can reverse the progress of an illness. This is beginning to change. More and more of the major medical institutions in the US are beginning to take this issue more seriously and are starting to study the effect of stress reduction on recovery rates following diagnoses of life-threatening illness. There are many ways this important facet of recovery can be initiated. These methods may be as drastic as considering a change in workload by changing jobs to being as simple as learning breathing and relaxation techniques. Whatever the choice, the benefits of stress reduction will become obvious.

- **Positive Attitudes:** Studies show those who have a determination to reach and achieve remission are more likely to attain their goal than those who have a negative view of their prospects. Although many consider only the negative aspect of the term "self-fulfilling

prophecies", these are just as likely to occur with positive beliefs. Joining support groups, either in real time or in cyberspace on the Internet, can help in developing this positive attitude because there are so many affirmative role models; so many who are further down the path; so many who have achieved **Remission**. Visualization and affirmation are two useful tools to gain and use in the process of making positive attitudes work.

- **Diet and Supplements:** This is an area where confusion reigns supreme, with views and counter-views being expressed vociferously. Claims of snake oil salesmen compete with those supported by well-designed studies. If it is possible a qualified nutritionist/dietician who specializes in oncology issues should be consulted. Everyone ultimately has to make their own decision, as with many other aspects of prostate cancer, but there is a degree of consensus on some of the issues such as:

    - *Meat, dairy products, fat, sugar, fried foods:* All should be avoided or reduced to a bare minimum. Red meat in particular is considered as a negative food. Most fish are a good substitute for meat products, although some farmed fish may have been given unhealthy feed and pharmaceutical products to get them to market quicker – as indeed is often the case with chicken. Because we eat so much sugar in the Western world it is often difficult to give up sugar and the temptation is to substitute sugar with artificial sweeteners, some of which reportedly have health issues attached to them and they should also be avoided.

    - *Refined products*: The more foodstuffs are processed before reaching the table, the more natural values are damaged or destroyed. The closer food is to its natural state, the better. Many 'fast foods', many of which are fried, have very little value.

    - *Fresh fruit and vegetables*: Regular and substantial helpings of fruit and vegetables are essential for good health. Canned fruit often has sugar or additives; stored fruit loses some of its value, so fresh fruit in season is a better bet. Fruit juices often have added sugar, but in any event are too concentrated and even if unsweetened will deliver a massive dose of natural sugar. Vegetables in salad form are ideal, but otherwise, to extract the most value, they should be lightly steamed and not overcooked. Cruciferous vegetables such as broccoli, cabbage and Brussels sprouts are particularly valuable in the fight against prostate cancer (so your parents were quite right to tell you to eat them all up!!).

    - *Vitamins and other supplements*: Those opposed to taking supplements make the good point that people eating a well-balanced diet should not need anything more. The problem with this argument is two-fold. Firstly, with modern methods of growing, storing and distributing food, much of the natural value of food is lost. Secondly, the area or conditions in which the food grows may be poor. Food grown where the soil is rich and where natural methods are used for fertilization – such as manure and compost may have very different characteristics from that grown hydroponically, for example. For most men eating a healthy diet, a general, good quality multi-vitamin will be the main supplement, with the use of garlic, Vitamins D, C and E in support. This should prove a sound basis to proceed from. Excess quantities of Vitamin C are excreted, but it is possible to overdose with Vitamins D and E, so recommended doses should not be exceeded.

- **Exercise:** Appropriate amounts of suitable exercise are essential for wellness. Exercise induces a feeling of well-being through the release of endorphins, improves circulation of essential elements throughout the body and assists in the removal of waste through the lymph system. Just how much exercise is acceptable depends on the individual and any other health issues, but as a general rule it is considered raising the pulse rate and a sweat three times a week is a good minimum to aim for. Walking in the fresh air at a brisk pace is a good way to start an exercise program.

- **Body Mass Index:** Obesity is linked to many illnesses and every effort should be made to achieve the lean body mass considered correct for age and height. Following a good diet and exercise program should result in a gradual and healthy reduction of body fat and mass.

As has been said, these are general guidelines for the journey through the **Plains of Recovery**. One area here – **The Swamp of Depression** - traps a substantial number of men and their partners to a greater or lesser degree, following diagnosis. A leading medical oncologist in the US has said that depression is the single biggest hurdle faced by most of the men he sees. Yet it is something rarely discussed, seemingly because of a complete misunderstanding of the nature of depression and mental health.

Most men seem to regard an inability to cope with mental stress as a shameful weakness. They feel that they should be able to 'snap out of it' – advice which is often given by those who should be providing support. People suffering from depression would like nothing more than to be able to do just this, but they can no more 'snap out of it' than a drowning person can save themselves by heeding the advice to 'start swimming' if they don't know how to swim. Anyone suffering from depression should seek professional help. This debilitating condition can be overcome – sometimes in a remarkably short time – with help.

All treatment choices have side effects

All of the conventional treatments will have side effects. The range and type of morbidity associated with these treatments is wide as is the individual experience of each man. Some have comparatively minor problems they can 'live with' others have severe and often painful conditions that are difficult to treat. Some side effects are of short duration; others are not.

Unfortunately it is not possible to establish the degree of morbidity any individual will experience with any degree of accuracy. There is little doubt that the experience of the medical people carrying out the procedure is the greatest predictive factor in the degree of side effects experienced after treatment. Quite simply stated, men have less severe side effects when treated by an experienced practitioner or medical team. This may seem obvious, but the embarrassment of seeking evidence of expertise has led to severe consequences for many men. This awkwardness must be overcome for the best outcome.

There is a summary of the potential side effects of ADT (Androgen Deprivation Therapy) in the relevant section of this booklet. As is the case with side effects from other treatments, the number of men who experience these side effects and the severity of the morbidity is widely variable. Many men have reported having no significant problems with ADT, while for others it is barely tolerable.

Erectile Dysfunction: This is the morbidity or side effect upon which the majority of men focus and it occurs in the majority of men who have treatment for prostate cancer. Although some studies show a high rate of recovery of erectile function for men who have had surgery, it is important to establish the definition of recovery, which may not even refer to the ability to achieve regular sexual penetration.

The ability to achieve or maintain an erection is, for most men, an important part of their life and their view of manhood. Loss of this ability can be devastating and, for some men, literally make life not worth living. It is probably the greatest source of the depression already discussed. In many cases it also creates an enormous amount of stress for the partners of men in this position, with both parties mourning the loss of the physical aspect of their relationship.

There is no doubt this is a serious issue, but it is also important not to make it the sole focus of life after treatment, or to link it specifically to the treatment itself. The majority of men will suffer some form of erectile dysfunction as they age, a fact often overlooked by men with problems after treatment. Erectile problems should therefore be considered in this broader view.

Although most men will have some erectile issues to deal with after treatment, a leading institution in the USA recently published the preliminary findings of a study which suggested that early treatment, starting even before the surgery, might protect erectile tissue and might facilitate the chances of erectile function recovery. It is suggested that the following course of action may minimize atrophy and optimize recovery – this protocol should only be followed after consultation with qualified medical advisors:

- Take Viagra 25mg (a quarter of a pill) before bedtime, nightly. Start this treatment 2 weeks prior to the surgery. You should not expect any erection to occur at such a low dose.

- Discontinue Viagra 25mg the night before surgery and during your hospital stay.

- Resume Viagra 25mg nightly, after you are discharged home even with the catheter in place.

- After catheter removal (usually at 7-14 days after surgery), consult your surgeon whether it is safe to attempt to get an erection.

- After this time (usually 2-3 weeks after surgery), switch to Viagra 25mg 6 nights per week and Viagra 100mg once per week. The Viagra 100mg dose should be taken in an effort to get an erection. Take the pill on an empty stomach (it is suggested 2 hours before your evening meal). The pill lasts at least 8 hours so you will have plenty of time to attempt stimulation.

- It is suggested that you should make 3-4 attempts at Viagra 100mg after surgery before you see your doctor again - usually about 6 weeks after surgery to discuss how you responded to the Viagra 100mgs dose.

Many will recover some or all their erectile function without the program outlined above with the help of the numerous mechanical and chemical aids that are available, the most common of which are mentioned below.:

- *Viagra, Cialis, Levitra:* These pills have without a doubt been hailed as the greatest aid for men with erectile problems. Some failures are reported and some men cannot tolerate the side effects from the drug, but by and large most reports are positive.

- *Injections:* Most men shy away from the thought of injecting themselves with a drug in this sensitive area, but many men report an excellent result from penile injections said to be a comparatively simple skill to acquire. Proprietary preparations are available, with variable results reported.

- *VED (Vacuum Erectile Device):* There is a variety of these devices on the market. All work on the same principle: they create a flow of blood to the penis, creating an erection and then mechanically maintain the erection, which many reports say are adequate for intercourse.

- *Penile Implant:* Reports on the success of this procedure are very mixed. For most men, this is a last resort.

Although the focus is generally on the utmost importance of gaining an erection, this in itself can be self-defeating because of the anxiety created. Many men are seemingly unaware of the satisfaction that can be gained without penetration. Techniques taught by sex therapists can result in the sexual fulfillment of both parties and some men have said they have found the experiences of these techniques as being even better than their previous sexual encounters. So there is life after treatment in spite of everything.

Incontinence: There are two types of incontinence associated with treatment for prostate cancer.

Bowel or fecal incontinence is the more serious of the two and is associated with radiation treatment rather than surgery, where it is rarely reported. It occurs in radiation treatment because of the close proximity of the prostate gland to the bowel and bladder. The occurrence, according to most studies, is not high and appears to be falling with the introduction of more modern equipment capable of focusing the radiation beams with a greater degree of accuracy. It is very rarely reported in conjunction with brachytherapy or proton beam therapy carried out by an expert operator. Severe bowel incontinence is difficult to remedy - the damage done by radiation makes surgery almost impossible. In some cases colostomy is an option, to provide a better quality of life.

Bladder or urinary incontinence occurs with both surgery and radiation treatments. The degree of incontinence can vary from what is termed stress incontinence – the most commonly reported variety – to complete lack of control. Stress incontinence occurs when a small amount of urine escapes in conjunction with actions such as coughing, sneezing, laughing or lifting and can often be controlled by building up the muscle in the area. This is done by practicing what are known as Kegel Exercises, which consist of tightly clenching the relevant muscles, holding the tension, relaxing and repeating. To get a feel for which muscles are involved, men should start urinating as usual and then stop the stream. That is the action required in doing Kegels. The exercise should be done in short sets repeated at intervals many times throughout the day.

If the leakage problem does not respond to these exercises, the usual recommendation is for the man to wear incontinence pads, especially if a comparatively small amount escapes. Mechanical devices such as a penile clamp can be used to stem the flow, medications may provide some relief, and condom catheters with collection bags are available. Various degrees of success have been reported with these means.

For incontinence that cannot be dealt with by any of these methods, an indwelling catheter can be fitted to drain the bladder into a suitable receptacle. It may even be possible to surgically install a male sling or an artificial sphincter to regain control of the bladder. The reported success rate for these operations is not high, particularly in cases of high-volume incontinence.

Another aspect of bladder incontinence, not often mentioned, occurs during arousal for sexual intercourse, which can cause leakage of urine. This happens frequently and can be particularly disconcerting to some men and their partners.

On the opposite end of the urinary scale from incontinence is stricture, where it becomes very difficult to urinate, usually because of the build-up of scar tissue. Although surgery will often alleviate this condition, it is often not helpful for men with keloid scars. In those cases, a urethral stent may be helpful.

It is important to bear in mind that the definition of incontinence can vary tremendously. Some studies do not regard a man who uses two pads a day as incontinent. This may not be the man's view.

REMISSION

Most men diagnosed with prostate cancer finally arrive at **Remission** defined as *"the state of absence of disease activity in patients with a chronic illness, with the possibility of return of disease activity".* The journey is a long one and fraught with difficulties, as we have seen. It requires many years before anyone can say with any certainty they have made it free and clear. The risk of recurrence for most local treatments after five years is small and diminishes as time goes by until, at ten years, the risk of recurrence is very small indeed. Unfortunately it is always there.

Most of the people who make it here to **Remission** – men and their partners – say that the experience has been beneficial. They appreciate life and their loved ones more. They enjoy each day because they have had an intimation of mortality. It seems ironic that we have to be diagnosed with a life-threatening disease before we truly appreciate how wonderful our lives are.

NEVER FORGET: THERE IS LIFE AFTER A PROSTATE CANCER DIAGNOSIS.

SUMMARY OF SOME COMMON TERMS

ADT	Androgen Deprivation Therapy – the more correct term for Hormone Therapy. The prostate cancer is deprived of the testosterone androgen that fuels growth.
AI	Androgen Independent – see AIPC
AIPC	Androgen-Independent Prostate Cancer – late stage prostate cancer which no longer responds to ADT (Androgen Deprivation Treatment)
Brachy	Brachytherapy - a form of radiation therapy in which radioactive seeds are inserted into the prostate gland. Also known as SI (Seed Implants) or HDR (High Dose Rate).
CAB	Combined Androgen Blockade – see CHT
CAT scan, Also CT scan	Computer Axial Tomography scans. An advanced form of X-ray scan that creates detailed images of the prostate
CHB	Combined Hormone Blockade – see CHT
CHT	Combined Hormone Therapy – where more than one method of ADT (Androgen Deprivation Therapy) treatment is used
AS	Active Surveillance – the term used to signify men who have elected not to have immediate conventional treatment
Cryotherapy Cryo	This is a treatment where the prostate gland is frozen following the insertion of thermal probes, the aim being to destroy the cancer cells .
DRE	Digital Rectal Examination – the standard basic examination of the prostate where a finger is inserted into the rectum

EBRT External Beam Radiation Therapy – the normal radiation therapy which uses a beam from a machine, focused on the prostate gland

HT Hormone Therapy – more correctly ADT (Androgen Deprivation Treatment)

HDR High Dose Rate Brachytherapy – radiation therapy where radioactive seeds are inserted into the prostate gland and then withdrawn.

HRPC Hormone Refractory Prostate Cancer – see AIPC above

IADT Intermittent Androgen Deprivation Therapy – see IHT

IHT Intermittent Hormone Therapy, also known as Pulse Therapy, where ADT (Androgen Deprivation Treatment) is given for a short time and then stopped. The theory is that this reduces the chance of AIPC (Androgen Independent Prostate Cancer) developing

LUTS Lower Urinary Tract Symptoms – the generic term covering urinary problems such as nocturia, urgency and incontinence

Nocturia The term used to describe the frequency of urination at night

Metastasis Mets The spread of the cancer from its original site. The secondary cancers are referred to as metastases and the disease is said to have metastasized

MRI Magnetic Resonance Imaging – this type of scan uses a very strong magnetic field, rather than X-rays to create pictures of internal organs

Orchiectomy, Orchidectomy The surgical removal of the testicles. This is a form of hormone therapy to remove the primary source of testosterone

Partin Tables A set of tables which uses collected data to demonstrate the potential for the disease having spread beyond the prostate organ

PSA Prostate Specific Antigen – the standard blood test used as a marker to indicate the possibility of a diseased prostate. It is not cancer specific, so an elevated PSA does not always mean that the man has cancer

FPSA, Free PSA, PSA II Free PSA is "unbound" PSA and differs chemically from normal PSA. The amount of fPSA is usually shown as a percentage of the total PSA. The higher the percentage, the less the chance of prostate cancer being present. A fPSA of 25% or greater is usually regarded as indicative of a low probability that malignancy is present

SI Seed Implants – a form of radiation therapy in which radioactive seeds are inserted permanently into the prostate gland. Also known as brachytherapy

TRUS Transrectal Ultrasound – the imaging technique used to guide a biopsy

RP Radical Prostatectomy – the surgical removal of the prostate gland

WW Watchful Waiting, a previous term for Active Surveillance, where no conventional treatment is undertaken unless the disease progresses

Terry Herbert, the author of this booklet, has no medical training. He was diagnosed as having prostate cancer in August 1996 and has learned something about the subject since then. In 1998, with colleagues Gregg and Kerry Morrison he established a website – YANA - You Are Not Alone Now at www.yananow.net. The stated aim of the site, which is still active, is:

"To provide comfort to any man diagnosed with prostate cancer, to offer thoughtful support to him and his family and to help them to decide how best to deal with the diagnosis by providing them with and guiding them to suitable information, being mindful at all times that it is the individual's ultimate choice; that the path he decides to follow is his own and that of his family, based on his particular circumstances."

This booklet is primarily for those who do not have access to the website. Its aims are the same as the website.