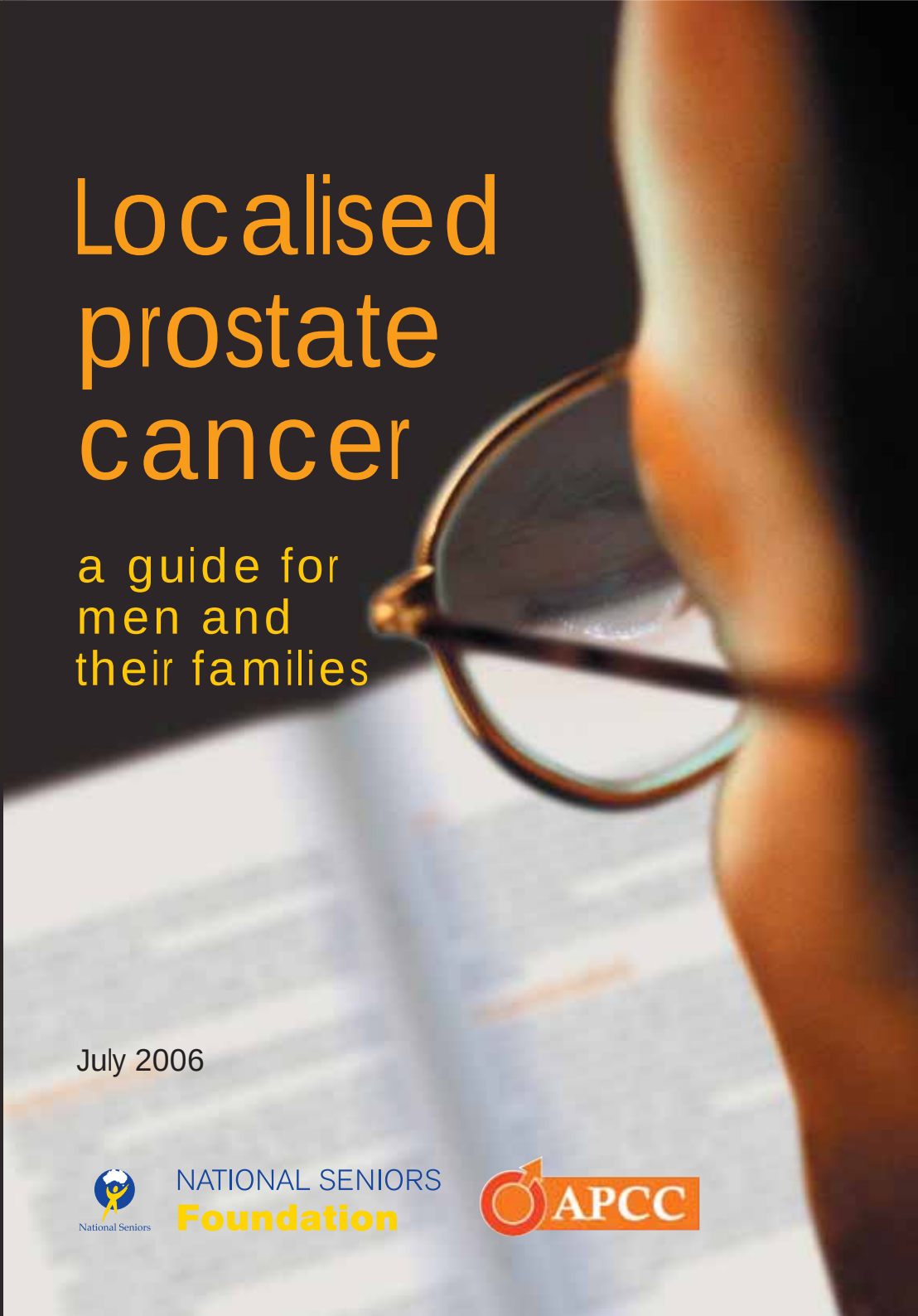

Localised prostate cancer

a guide for men and their families

July 2006

National Seniors

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Foundation

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About this book

The contents of this book are based on the NHMRC's Clinical Practice Guidelines: *Evidence-based information and recommendations for the management of localised prostate cancer*, accredited and published by the National Health and Medical Research Council (NHMRC) and produced by the Management of Early Prostate Cancer Working Party of the Australian Cancer Network (ACN) in March 2003. A multi-disciplinary steering committee was convened by the ACN with the Australian Prostate Cancer Collaboration, to produce a consumer version of the Guidelines, with comment and suggestions by the Urological Society of Australasia and the Prostate Cancer Foundation of Australia. The Guide was reprinted with minor revisions in 2003, and more substantial revisions in 2006. Future updates will be in parallel with the Evidence-based Recommendations.

Copies can be obtained from the Cancer Council in your state: phone 13 11 20

Acknowledgement

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Disclaimer: The information in this guide is not intended to take the place of medical advice. Information on prostate disease is constantly being updated. A patient's general practitioner or specialist may provide them with new or different information which is more appropriate to their needs.

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Foreword

Since the first edition in 2001, the consumer guide has been requested at an average rate of 10,000 copies per year and listed as a 'decision aid' with the Cochrane Inventory of Identified Decision Aids. This third edition has been updated by a multi-disciplinary working group listed on page 96. Updates are consensus based and literature sources quoted in the text. It is our hope that the Guide will continue to help men make the best possible decisions regarding treatment for localised prostate cancer.

Who is this book for?

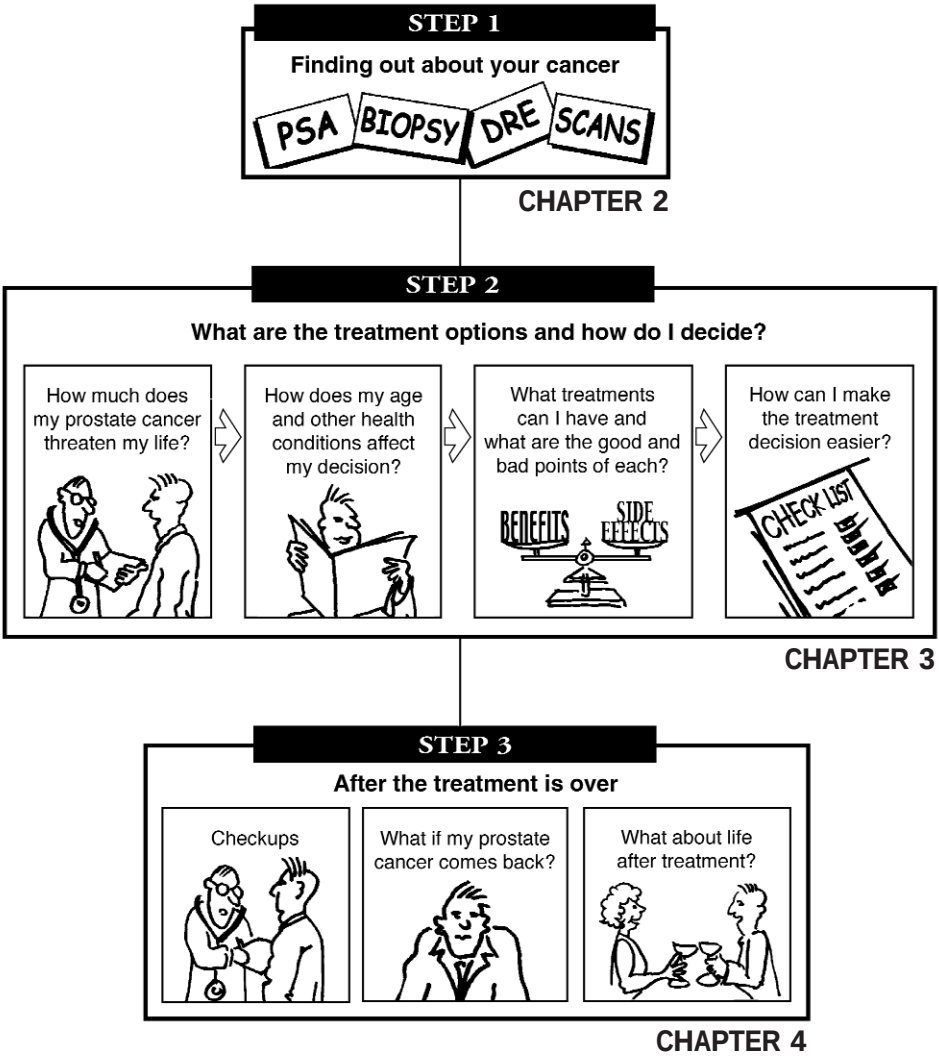
This book may be helpful to any man affected by prostate cancer and his family. However, it is particularly designed for men who have localised prostate cancer (cancer which has not spread beyond the prostate gland) and who need to make a treatment decision. It gives information on what localised prostate cancer is, how it is tested and the treatment options.

This book will probably not be helpful if you are looking for information about testing for prostate cancer, screening using prostate specific antigen (PSA) or treatment for advanced prostate cancer. For more information on these areas, contact the Cancer Council Helpline on 13 11 20.

Receiving a diagnosis of any cancer is not easy, however we have come a long way in our ability to cure and control it. Prostate cancer has more uncertainties than many cancers, but it is also one that many men live with for many happy and productive years. We hope this book will help you work through the issues and achieve that goal. The purpose of this book is to help men make decisions about treatment for localised prostate cancer. Words in **bold** are explained in the glossary.

Contents

Figure 1: Making a decision about the treatment for localised prostate cancer: the steps



Introduction to prostate cancer

When you are first told you have prostate cancer, you may or may not understand much else. Hearing the word 'cancer' may come as a great shock. Some people may find it hard to think of anything else for quite some time. Don't expect too much at first—you need time to take in the information, think about what you have been told, and discuss it with your family and friends.

Prostate cancer is an unusual cancer for a number of reasons:

- it usually grows slowly and for many men it may not be a problem
- there are often no symptoms in the early stages
- treatment can have unwanted effects—especially on your sexual function
- the choice of treatment is not clear-cut: we can't always be sure which are the best treatments.

'You don't ask what the side effects are. You're too taken aback, too upset to find out and ask your doctor.'

You may want only a little information at first and then, step by step, to find out more before reaching a treatment decision. To help you progress, we suggest you follow the steps outlined in Figure 1. We have arranged Chapters 1 to 4 to give you more detailed information on each of these steps. Chapter 5 has questions which may be close to the ones you have in mind and tells you where you can find information on them in this book.

Your doctor will probably go through your test information with you. It may be useful to record information he or she gives you about your test results in the back of this book.

As you read through the book, remember that doctors are always finding out new information about prostate cancer. It is important that you often ask your family doctor or specialist if they are aware of any new developments.

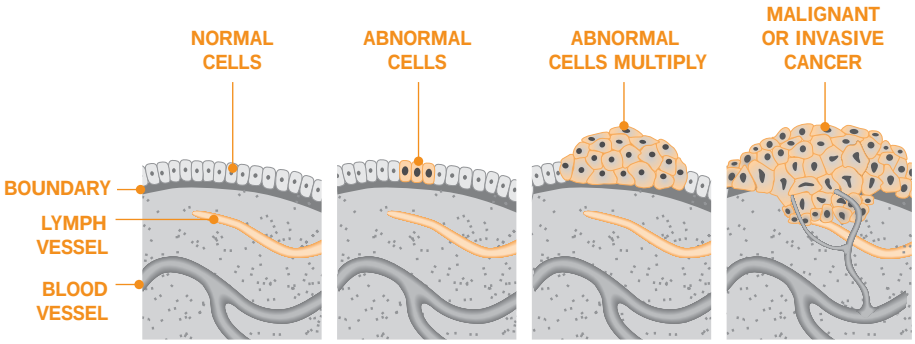
What is cancer?

Cancer is a disease of the body's **cells**. Our bodies are always making new cells: so we can grow, to replace worn-out cells, or to heal damaged cells after an injury. This process is controlled by certain **genes**. All cancers are caused by changes to these genes. Changes usually happen during our lifetime, although a small number of people inherit such a change from a parent. Changed genes can cause cells to behave abnormally. They may grow into a lump, which is called a **tumour**.

Tumours can be **benign** (not cancerous) or **malignant** (cancerous). Benign tumours do not spread to other parts of the body. A malignant tumour is made up of cancer cells.

When it first develops, this malignant tumour may be **confined to** its original site. If these cells are not treated they may spread into surrounding **tissues** and to other parts of the body.

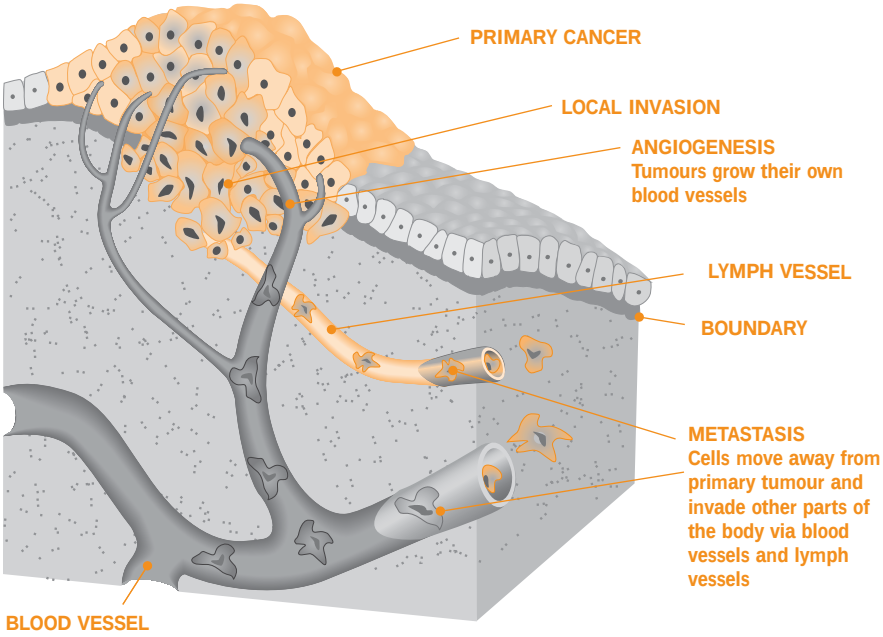
Figure 2: The beginnings of cancer



When these cells reach a new site they may continue to grow and form another tumour at that site. This is called a secondary cancer or **metastasis**.

For a cancer to grow bigger than the head of a pin, it must grow its own blood vessels. This is called **angiogenesis**.

Figure 3: How cancer spreads

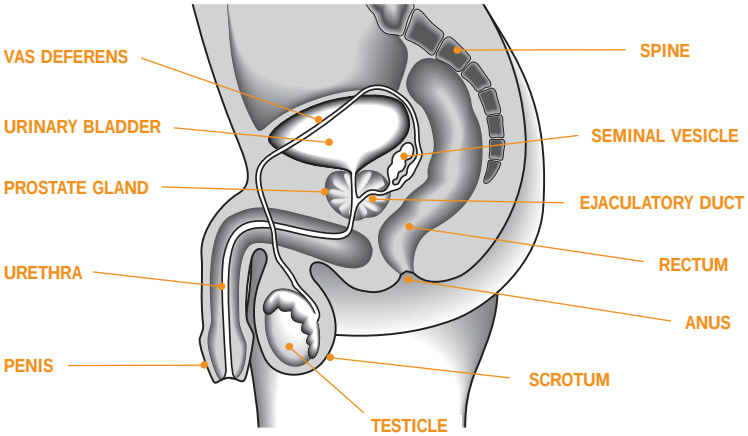


What is prostate cancer?

The prostate is a small gland about the size of a walnut found only in men. It sits just below the **bladder** and surrounds the **urethra** (the tube which takes urine from the bladder through the penis). The prostate produces part of the fluid that makes up **semen**. The growth and development of the prostate depends on **testosterone** (the male sex hormone), which is made by the **testicles**.

The prostate normally gets bigger with age. After middle age, changing hormone levels can cause the prostate to increase five times or more in size. This growth does not spread to other parts of the body and is not cancer. This is known as **benign prostate enlargement**. Benign prostate enlargement can block the flow of urine, causing urinary problems and other symptoms similar to **advanced prostate cancer**.

Figure 4: The male reproductive system



Prostate cancer is a **malignant** growth in the **prostate gland** (referred to throughout this book as 'the prostate'). **Localised prostate cancers** are those which have not grown beyond the prostate (although this can be hard to tell). These early cancers often do not produce symptoms and may progress only slowly. This book only refers to localised prostate cancer.

Some prostate cancers do not stay in the prostate but spread to other parts of the body such as the bones and **lymph nodes**. This is called **metastatic** prostate cancer. For more information on metastatic prostate cancer, contact the Cancer Council Helpline on 13 11 20.

How common is prostate cancer?

Prostate cancer is the most common cancer in Australian men (except for skin cancer). More than 11,000 men are diagnosed with it and 2700 die of it in Australia each year. It is very age-dependent. More than half of all new prostate cancers and over 80% of prostate cancer deaths occur in men over the age of 70[1]. For each age decade, the chance of developing prostate cancer increases (see Table 1). Amongst 1000 Australian men, about 137 could be expected to be diagnosed with it before age 80 years, but far fewer—about 27—would die of it[2]. Men with prostate cancer can have long, productive lives despite their disease.

Although rarer at young ages, the threat from prostate cancer is greater if it is diagnosed at an early age (say 50 years). There are two reasons for this: in younger men the cancer has time to progress, and in older men, the risk of death from other causes is greater[2]. Prostate cancer contributes to only 4% of deaths in Australian men. As a cause of death, it ranks sixth

after heart disease, stroke, lung cancer, chronic obstructive pulmonary (lung) disease and colorectal cancer[1].

Table 1: Risk of a prostate cancer diagnosis related to age

(For 1000 men in each age group, the number diagnosed with prostate cancer)

Age (years)	Risk
40–49	1 in 1000
50–59	12 in 1000
60–69	45 in 1000
70–79	79 in 1000
80–89	105 in 1000

Data from Baade 2005[2]

Can I inherit prostate cancer?

Prostate cancer develops when cells in the prostate grow in an abnormal way as described on page 6. For most men, the cause of this is not known.

However, for men who have a father or brother with prostate cancer, their risk is known to be higher. Your risk is higher again if more than one member of your family has prostate cancer. It is also higher if that person is diagnosed at an earlier age. For example, if you had a father diagnosed with prostate cancer at the age of 50 years, your risk of prostate cancer is doubled. If you had two relatives diagnosed with prostate cancer at 50 years, then your risk of prostate cancer is up to seven times higher[3].

What are the risk factors for prostate cancer?

We are learning more about the risk factors for prostate cancer. But there is still a lot we are not sure about, such as what you

can do to reduce your risk of getting prostate cancer.

We know that the percentage of men with prostate cancer differs around the world. For example, African-American men have a much higher rate of prostate cancer than Japanese men do. Some studies suggest that eating a lot of fat, in particular animal fat, may increase your chances of prostate cancer.

On the other side, nutrients in the diet such as selenium (low in some Australian soils) and lycopene (found in tomatoes) have been shown to reduce the risk of prostate cancer. These need testing in well-controlled trials before we know for sure. Eating a low animal fat, high fruit, vegetable and legume (beans) diet may offer some protection against prostate cancer. For now, there are *no definite recommendations* about what you should and shouldn't eat. However, having a high intake of plant foods, including legumes, high dietary fibre and low fat and animal fat makes a lot of sense. There are many health benefits from this kind of diet[1].

Does localised prostate cancer spread?

Localised prostate cancer may spread outside the prostate gland, but remain in the prostate region (**locally advanced prostate cancer**). It may then invade nearby organs (**advanced prostate cancer**). It may ultimately spread to different parts of the body, such as bones (**metastatic** prostate cancer). However, it can be **confined to** the prostate for many years before moving to other parts of the body. This gives your doctors a chance to cure the cancer by surgery or **radiotherapy**, if it is detected early enough. It can be hard to know, for sure, whether the cancer has spread outside the prostate. Prostate cancer that spreads beyond the prostate can be controlled for a time but not cured.

What are the symptoms of localised prostate cancer?

In the early stages, prostate cancer usually causes no symptoms at all.

Many men over 50 years have urinary symptoms such as:

- a need to pass urine (urinate) more often, especially at night
- difficulty starting to urinate
- difficulty holding back the flow of urine
- not being able to urinate when you feel the need to
- poor urine flow or a flow that stops and starts.

However these symptoms (called **lower urinary tract symptoms** or LUTS) are more often caused by **benign prostate enlargement** rather than by cancer. Benign enlargement (sometimes called benign prostatic hyperplasia or BPH) is a non-cancerous condition of the prostate. It usually occurs in a different part of the prostate and does not 'turn into' prostate cancer. Benign enlargement is non-life-threatening and can be effectively treated. Both benign enlargement and prostate cancer can be present at the same time in the same prostate gland.

Later stage prostate cancer may cause symptoms, including the symptoms caused by obstructed urine flow (such as those listed above). In addition, it may cause:

- pain or burning when urinating
- pain during ejaculation
- blood in urine or **semen**
- continuing pain or stiffness in the lower back, hips or upper thighs.

It is important to note that having these symptoms does not necessarily mean you have prostate cancer. However, you should have these symptoms investigated by a doctor.

See your doctor if you have:

- pain when you urinate or ejaculate
- blood in your urine
- continuing pain or stiffness in your lower back, hips or upper thighs.

Finding out about your cancer

Who is on your care team?

As a first step, your general practitioner has probably referred you to a specialist, a urologist, to find out if you have prostate cancer or to treat it. Several different kinds of specialists are involved in the treatment of prostate cancer:

- **Urologists**, surgeons who specialise in treating diseases of the urinogenital tract (which in men includes the kidneys, bladder, prostate and sexual organs).
- **Radiation oncologists**, specialist doctors who use **radiotherapy** to treat cancer.
- **Medical oncologists**, who specialise in chemotherapy treatments for cancer. New chemotherapy agents have recently become available for prostate cancer, although normally reserved for later stage disease.
- **Pathologists**. You may not see or talk to a pathologist, but they play an important role in assessing the stage and aggressiveness of your cancer. They examine tissue from your biopsy and, if you have surgery, the tissue removed at operation. As with other specialists, there can be uncertainty with these assessments and occasionally a second pathology opinion may be sought.
- **Urology nurses**, who can give assistance through your prostate cancer journey. Some specialise in the care of men with prostate cancer, and manage aspects such as incontinence and sexual dysfunction.
- **Other professionals**, including psychologists, physiotherapists and social workers.

Not all of these professionals are available in every treatment centre.

'I think probably initially it was blind panic but after weighing and talking we were able to make rational decisions and maybe it wasn't necessarily a death sentence.'

Deciding on a doctor

Choosing a doctor you feel comfortable with is important. You need to feel that the specialist is acting in your best interest, and can give you the help and answers you need. There is also good evidence that seeing a doctor with a special interest and extensive experience in prostate cancer will result in improved outcomes. Consumer organisations recommend that you ask what experience a specialist has in the recommended treatment. (We give examples of these types of questions in Chapter 5.)

Other things may also affect your choice. Some people are able and happy to travel a long way for specialist care. Others either cannot travel or prefer to remain at home, close to family and friends. Some people like specialists who deal with them as equals, discussing all options with them and assisting them to make the final decision. Others like their doctors to take the lead and make decisions for them.

Studies have shown that specialists are more likely to recommend treatments that they understand and practice. It is possible that you will get different recommendations from different specialists. This is because for **localised prostate cancer** we do not know as yet which treatment options are better. Speaking to both urologists and radiation oncologists can be helpful.

Communication between doctors occurs at different levels. You should ask your specialist doctors to talk with your general practitioner. This will make sure he or she is kept up to date with your treatments and results.

Your general practitioner can also help if you would like a second opinion. Getting an opinion from another doctor about your cancer and treatment can help you feel that you are doing the right thing.

There are two ways to get a second opinion. One is to tell your specialist you want to see someone else. The other is to ask your general practitioner to refer you to another specialist. If someone you know has seen a specialist whom they recommend, ask your general practitioner for a referral. It is helpful to take with you to the second doctor a summary from the treating doctor, including PSA level, biopsy result and any scans. ***Seeking a second opinion is the right of every cancer patient. If you feel awkward about it, remember that most doctors are used to it.***

Some city hospitals offer multi-disciplinary care. This means that specialists from different disciplines work as a team to decide which treatment is best for you. This team usually includes urologists, radiation oncologists, medical oncologists, pathologists and urology nurses.

How is it diagnosed? What are the tests?

At the present time the main means of diagnosing prostate cancer is to perform a biopsy. Occasionally men are diagnosed with cancer after having an operation on the prostate called a **transurethral resection of the prostate** or TURP. Before proceeding to a biopsy, most men will have had the following tests.

Blood test (PSA)

The initial test that is carried out to attempt to diagnose prostate cancer is the prostate specific antigen (**PSA**) test.

This test is done to measure the level of a protein in your blood called PSA. PSA is made by normal prostate cells as well as prostate cancer cells. More recently, the rate of rise of PSA, as well as the absolute level, is thought to be an important guide as to the need for a **biopsy**.

PSA can be found in the bloodstream on its own (free PSA—commonly produced by benign prostate tissue) or bound to other proteins (complexed PSA—more often produced by cancers). Each of these PSA forms can be measured in a single blood test. The **free PSA to total PSA** (free + complexed PSA) ratio is then calculated. If it is greater than 25%, there is a low risk of cancer and a biopsy may not be recommended. If this ratio is less than 25%, it would require further investigation. If the ratio is very low (less than 10%) a biopsy may be recommended even if the total PSA level is 'normal'.

A high PSA reading (over 4ng/ml) does not always mean you have cancer. It can mean you have benign prostate enlargement, inflammation or an infection in the prostate. Some cancers, particularly aggressive ones, don't produce much PSA, and so can grow quite large while your PSA levels stay low (less than 4 ng/ml). For these reasons, the meaning of a PSA level may be difficult to interpret at times. However, once the diagnosis is made, it is a very useful test to monitor the outcome of treatment.

Digital rectal examination (DRE)

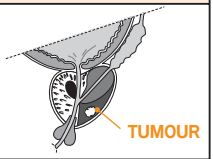
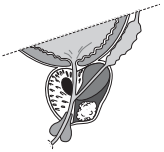
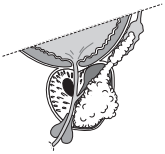
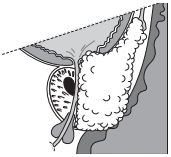
DRE is used to check your prostate through your **rectum** (or back passage).

The prostate is located just in front of the rectum, so your doctor can insert a gloved finger into your rectum and feel the size of your prostate through the rectal wall. This test may feel uncomfortable, but should not be painful. DRE can give an idea of how big the prostate cancer is and if there is any obvious growth into surrounding **tissues**. The DRE findings assist in determining the clinical **stage** or the local extent of the cancer. However, it is not always possible to tell how big the cancer is by DRE. Tumour size estimates from the DRE do not relate well

with the actual tumour size when the gland is removed by surgery. Some prostate cancers cannot be felt on DRE (clinical stage T1) and can only be detected using the PSA test.

There are staging systems, or numbers to describe the stage of your cancer. The most common (**TNM system**) is summarised in Table 2. See also Appendix 1.

Table 2: Prostate cancer stages

Stage	How far the cancer has spread	
T1	The tumour cannot be felt by the doctor or detected on ultrasound	
T2	The doctor can feel the cancer but it does not appear to have spread beyond the prostate	
T3	The cancer feels as though it has spread outside the prostate into surrounding tissues	
T4	The cancer has grown into surrounding organs such as the bladder or the rectum	

Prostate biopsy

A **biopsy** is the usual means of diagnosing prostate cancer. It is performed under **ultrasound** guidance.

An ultrasound probe, a little larger than a middle finger, is placed into your **rectum**. Ultrasound shows the shape and the nature of your prostate on a screen. Local anaesthetic is injected around the prostate before the biopsy and this makes the procedure more comfortable (some urologists use sedation or general anaesthetic). A small needle is inserted through the rectal wall into your prostate. Eight to twelve or more samples of **tissue** are taken from different parts of the prostate.

The ultrasound does not identify areas of cancer, but ensures that samples are taken reliably from different parts of the gland. The cancer may not be detected by the first set of biopsies, particularly if only a small amount is present. A negative biopsy doesn't mean for certain that cancer is not present. If the PSA continues to rise after the first set of biopsies, the biopsies may need to be repeated.

Because there is a small risk of infection, you will have antibiotics before and after the biopsy to reduce this risk. Very occasionally, hospitalisation and intravenous antibiotics may be needed if an infection develops. A small amount of bleeding from the back passage, some blood in the urine or blood staining of the ejaculate can occur after biopsy. Blood in the ejaculate may continue for several weeks. If there is a large amount of bleeding or you are concerned, it is important to contact your doctor.

The tissue removed will be examined by a pathologist to find if cancer is present. The pathologist will then assign a **grade** to the tumour. Grade is a measure of how quickly your cancer is likely to grow, and how much of a threat to you it may be. The most common way of describing grade is by the

Gleason score. This is explained further in Appendix 2. The lower your Gleason score, the less aggressive your cancer is likely to be. Your threat from prostate cancer according to its grade or Gleason score is shown in Table 3.

Table 3: Prostate cancer grades

Grade (Gleason score)	Your risk from prostate cancer
2–6	Low
7	Intermediate
8–10	High

Prostate cancer is sometimes found after a **transurethral resection of the prostate** (TURP). This is an operation on the prostate for men, not usually for cancer, but for **benign prostate enlargement**. As discussed in Chapter 1, benign enlargement causes urinary symptoms such as slow urine stream, a need to go frequently during the day or to get up often at night, needing to go urgently, and not quite making it! Many men believe these symptoms are due to prostate cancer, however prostate cancer in its early stages rarely causes any symptoms. It is only when it is locally advanced or has spread to other parts of the body that you will experience symptoms. By this time it may no longer be curable. So, if you are considering a PSA test, do not wait for symptoms to appear before discussing it with your doctor. There is no connection between prostate cancer and benign prostate enlargement; however, they often occur together in the same prostate gland.

Bone scan

You may have a bone scan to see if your prostate cancer has spread to your bones. A small amount of a radioactive material (called technetium) is injected into a vein in your arm and a scan is done one to two hours later. The radioactive material is slowly absorbed into your bones in areas of new bone growth or healing activity. If the prostate cancer has spread to your bones, there will often be many sites of increased activity seen on the bone scan.

There are a few important things to note:

i. Many other conditions can cause healing bone to be seen on a bone scan—for example, arthritis, Paget's disease and infection. Hot spots seen near joints are usually not due to cancer but due to wear and tear on the joints.
ii. A bone scan will only find fairly large numbers of cancer cells in the bones (that is, when numbers are high enough to cause bone damage). It will not find small numbers of prostate cancer cells that have spread into the bones and do not yet cause bone damage.
iii. A bone scan is rarely positive when the PSA level is less than 20 and many doctors do not recommend it for men with low PSA levels.
iv. If your bone scan does show that your prostate cancer has spread into your bones, you will need treatments that aim at the whole body and not just at the prostate. This generally involves **androgen deprivation therapy**, which is described in Chapter 3.

CT scan

A CT (computerised tomography, also CAT) scan is a fairly simple scan that takes about one hour. A dye is injected into a vein in your arm and then you drink a fluid which can give

images of all your pelvic organs including your prostate. Unfortunately, it does not detect small amounts of cancer, making it a relatively insensitive test. However, it can be useful for planning **radiotherapy** (including **brachytherapy**).

MRI scan

Magnetic resonance imaging (MRI) is a new technology currently being researched, which has considerable potential. It is used to identify local spread of the cancer outside the prostate gland and before surgery to determine the extent of the tumour. An MRI coil is placed in the rectum and you are then placed in MRI machine for the scan. The procedure takes about 45 minutes to complete. It may also be combined with spectroscopy, which may help determine which parts of the prostate are cancerous. MRI scans are not yet a part of standard care.

Combining stage, grade and PSA level

Taken together, stage, grade and PSA level can give doctors a better idea of whether your cancer is confined within your prostate, and also the chance of you being free of cancer after treatment. Some Australian doctors use the guide in Table 4 for working out the risk posed by a particular prostate cancer.

Table 4: The risk from prostate cancer indicated by grade and PSA level

Risk	Grade and PSA level	Likelihood prostate cancer is confined to the prostate and can be cured
Low	Gleason 2–6 and PSA <10	Good
Intermediate	Gleason 7 or PSA 10–20	Moderate
High	Gleason 8–10 or PSA >20	Poor

Note: by cure, we mean that you are free of cancer after 15 years.

Doctors can also estimate these chances using tables called 'nomograms'. A nomogram is based on the experience of many thousands of patients, usually drawn from US hospitals. Some nomograms predict cancer behaviour, based on the **PSA** level, **Gleason score, clinical stage** and other features of the **tumour**. The most widely used nomograms estimate the chance of cancer recurring after surgery or radiotherapy based on PSA level and Gleason score and clinical stage.

These nomograms are continuing to be developed and can be useful in helping men to decide on the most appropriate treatment for them. Some are web-based: by entering the PSA, Gleason score and T stage it is possible to get a prediction of the likelihood that a particular cancer is localised to the prostate. See Appendix 5 for more information.

Social and emotional issues

For most people, the experience of being diagnosed with cancer is a stressful event. Recent guidelines explain just how common these reactions are and what doctors can do to help patients[4]. Some men may experience very high levels of distress. It is important to remember, however, that most people in time return to feeling normal. Strategies to minimise stress may include taking your partner to consultations so you can discuss it together afterwards and talking to other men who have survived prostate cancer (see Appendix 4: Resource list). Ensuring you have enough information, and using strategies such as meditation and relaxation, can also help.

'I felt like I'd been thrown up against a brick wall.'

Prostate cancer affects others in the family, too, and some studies have found that family members, such as a spouse or partner, can experience as much or even more distress than men themselves. This can add to the burden of a man dealing with his illness. Spouses and other family members may find it useful to talk with a prostate nurse adviser or urology nurse in the hospital or clinic. In addition, talking with the Cancer Council Helpline (13 11 20) and partners of other men with prostate cancer in support groups may be valuable (see Appendix 4: Resource list).

What are the treatments and how do I decide?

Before you see the doctor

You will probably find that there is a lot to understand when you discuss treatment options with the doctor and it can be hard to remember everything. It may help to prepare beforehand. Here are some suggestions:

- ask your partner or a friend to go with you
- ask your doctor whether you can tape record your visit so that afterwards you can go through what was said
- write down questions such as those listed in Chapter 5, to ask your doctor at your next visit.

If you do not speak English very well, you may like to use a qualified interpreter, rather than a family or staff member. Interpreters are available free of charge, although you will have to book first through the hospital.

It is important to remember to make a longer appointment with your doctor if you have a lot to ask. This means you will have time to get the information and your doctor will not have to rush.

'He said there was a good chance that by having treatment, there would be a reasonable chance of a complete cure.'

Treat the information you can get on the Internet with care. We have suggested some sites; however, not all the information you read may apply to you. Always check this information with your doctor.

Your doctor may talk to you about the chance of, for example, your treatment curing your cancer. Understanding your risk can help you decide what treatment to have. Risk can be explained in different ways. For example, a 1 in 5 or 20% risk that something will happen may look better if you turn the figure around and remind yourself that this also means that you have a 4 in 5 or 80% chance that it won't. If you do not understand your doctor when he or she talks about your risk of a certain thing happening, ask them to explain it another way.

Working through the options with your doctor

If you have **localised prostate cancer**, you generally have three main choices of treatment. These are: to do nothing for now and just have check-ups, to have surgery, or to have a form of **radiotherapy**.

It is not known which type of treatment is the best for localised prostate cancer. Therefore, when you decide which treatment to have, it is important to think about the quality of your life after you have had treatment. Your preferences are important.

Your doctor will work with you towards a decision. He or she will probably discuss the following four points:

A. How much your prostate cancer threatens your life.
B. How old you are and whether you have any other conditions that may affect your health.
C. What treatments you can have and the good and bad points of each.
D. How your own preferences affect your decision.

In this guide we discuss these points in detail so that you can see how they contribute to your decision.

A. How much does my prostate cancer threaten my life?

Your doctors can work out how much of a threat your prostate cancer is to you by finding out how far it has spread (**stage**) and how fast it is likely to grow (**grade**). Also, finding out your PSA level before you have treatment is important. In Chapter 2 we discussed how grade, stage and **PSA** level can indicate how much of a risk your cancer presents (Table 4). If you have a high

risk cancer, your doctor may suggest a more aggressive approach, such as a combination of treatments.

B. How do my age and other health conditions affect my decision?

Your life expectancy, or the number of years you would expect to live if you did not have prostate cancer, can also affect your choice of treatment. How long you can expect to live depends on both your age and your state of health. An Australian man aged 50 years has an average life expectancy of nearly 30 years (see Table 5), whereas a man aged 80 has an average life expectancy of 7.5 years. A man with a serious health condition such as heart disease or diabetes will have a shorter life expectancy than the average. Of course these are just statistics—no one can actually predict how long they are going to live!

Table 5: Average life expectancy of Australian men

Age	Life expectancy (years)
At birth	78.1
At 50 years	30.6
At 60 years	21.8
At 70 years	14.1
At 80 years	8.0

Note: from Australian Bureau of Statistics 2004[5]

If you are relatively young (have a longer life expectancy), you are more likely to get a benefit from having treatment. This

is because in many cases prostate cancer is slow growing. A person who is expected to live less than 10 years may decide that the threat from their other health conditions is greater than the threat from the prostate cancer. It is also important to think about your quality of life after the treatments. For an early stage, slow-growing cancer, you may find your quality of life is better if you choose active surveillance.

C. What treatments can I have and what are the good and bad points of each?

As discussed above, treatment approaches need to be tailored to your age and health, the risk posed by the cancer (its stage and aggressiveness) and your preferences. The main treatment approaches to be considered are:

1 to do nothing for now except have regular check-ups
2 to have surgery
3 to have a form of **radiotherapy**.
4 to have **androgen deprivation therapy**.

In the following sections we explain what these treatments are and how the choice is made—the circumstances in which a particular treatment approach may be most helpful.

For many men, we do not know as yet which of these treatment options is likely to be the best. This is one of the reasons why it is difficult for your doctor and you to make a decision.

Do nothing for now except have regular check-ups

This option is sometimes called 'active surveillance' or **watchful waiting**. We know that many men who are diagnosed with prostate cancer will not die from prostate cancer or get symptoms which they find bothersome. This is

especially the case for men diagnosed with low risk disease. Elderly men, particularly those older than 75 years, are less likely than younger men to be affected by symptoms during their lives. Young men, on the other hand, may be concerned about the effects of active treatment on, for example, their **fertility** or other aspects of lifestyle. In these circumstances, there is an option not to have treatment immediately, but to monitor the progress of the cancer or watch and wait. If the cancer shows signs of faster growth or aggressiveness, active treatment can begin. Signs of an aggressive cancer include

'It certainly pays you to read and learn a lot about it but I think you can overdo it.'

- A rapidly rising PSA level (often indicated by a PSA doubling time of less than two years)
- A repeat biopsy (often at 12 months) showing more extensive cancer or a higher grade cancer (Gleason 7 to 10).

However, there is a risk that your cancer, if left untreated, can progress so that it extends beyond the prostate area. If this happens, treatments such as surgery and **radiotherapy** will be much less effective. In the worst case, patients may develop **metastases**, requiring **androgen deprivation therapy** (or 'hormone' therapy). This also has significant side effects which will affect your quality of life (see Chapter 3) and it cannot 'cure' the cancer.

A 2005 study comparing surgery with **watchful waiting** suggests that in the long term (after eight years or more), men undergoing watchful waiting may have more distant spread, and die more often from prostate cancer, than men who have had surgery for it, although the difference was relatively small[6].

Table 6 gives a summary of the good and bad points of no initial treatment.

Table 6: Good and bad points of having no initial treatment

Good points	Bad points	Patient most likely to benefit
No side effects from treatment	Your cancer could spread outside your prostate when treatments are less effective or cure is no longer possible	Low risk cancer: Small tumour (can't be felt at rectal examination) Low to moderate grade tumour (Gleason 4 to 6) Low PSA (less than 10 ng/ml)
Can still check on your cancer with PSA	You may worry because you are not doing anything' You may need regular rectal examinations and repeat biopsies	Life expectancy (apart from cancer) less than 10 years Prefer to have no treatment

Surgery

The aim of surgery is to remove all of your cancer. This is relatively major surgery. It takes on average three to six days in hospital for open surgery (less if a **robotic prostatectomy** or 'keyhole' approach is used), and you will need time to recover.

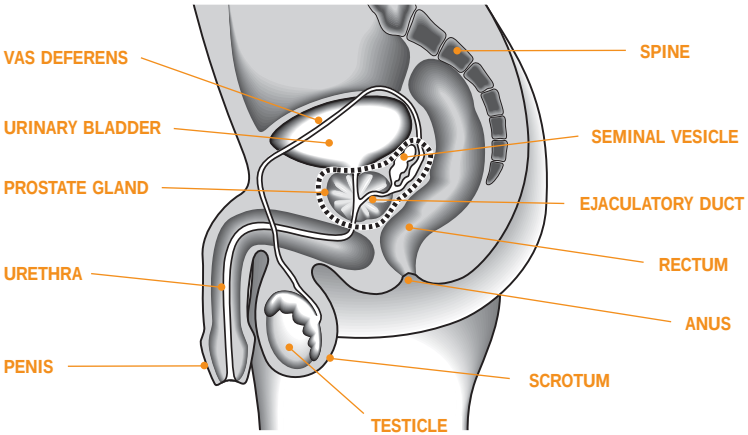
Surgery is a good option if you have **localised prostate cancer**, are fit for surgery, expect to live longer than 10 years and have not yet had any **radiotherapy**.

Will it cure me?

The answer is 'yes' provided that the cancer is **localised** or **confined** to the prostate at the time of treatment. The problem at the present time is that it is not possible to be sure of this. However we can estimate the chance that it is still contained within the prostate, and the chance of cure, using new tools called 'nomograms'. One commonly used nomogram[7] estimates the risk that the cancer will recur after surgery. The estimate is based on clinical stage, Gleason score, and PSA value. See Appendix 5.

The results of surgery are very good and many men live free of disease for 10 years or more (see Outcome, below). A recent study suggests that after 10 years, men who have surgery are less likely to die from prostate cancer and live longer than those who have **watchful waiting**[6].

Figure 5: Radical prostatectomy



The dotted line shows which organs are removed.

What type of surgery might I have?

Surgery to remove the entire prostate and the **tissue** around it is called a **radical prostatectomy**. The aim of this surgery is to remove all of the cancer with as little impact as possible on your normal lifestyle.

'I regret now (six years after diagnosis), that I didn't seriously consider naming my third son, born just 12 months ago, for the urologist who recommended watchful waiting.'

What happens when I have surgery?

If you have a radical prostatectomy, your surgeon will remove the prostate, part of your **urethra** (the tube through which your urine passes and which runs through the prostate), the **seminal vesicles** next to the prostate, and a small part of the **vas deferens** which passes through the prostate. This can be seen by the dotted line in Figure 5. Sometimes, before proceeding with the surgery, your surgeon may take out some **lymph nodes** near your prostate to find out if the cancer has spread. If the nodes contain cancer, then he or she may not continue with the operation because the cancer is no longer **localised**.

Your urethra will then be joined to your **bladder**. This way your bladder can still do its normal job. While this join heals, you will need to have a **catheter**. This is a thin tube that runs from inside your bladder (where it is held in place by a balloon), along the penis to the outside of your body where it connects to a bag. This bag is used to collect your urine instead of you passing it in the normal way. The bag can then be emptied into a toilet. You normally need a catheter for about one week after you leave hospital and occasionally up to three weeks. After the catheter is removed, it is normal to have urinary **incontinence** (loss of urine control) for a short time. You should receive help from hospital staff to prepare for this.

When you do get home from hospital, you should try not to do anything strenuous, such as lifting, for six weeks. You can generally drive a car two to three weeks after surgery.

Surgery for prostate cancer can affect your ability to have an **erection**. The chance of this will depend on how big your cancer is when you have surgery. The nerves that affect erections lie on either side of the prostate. If these can be left in place because there is no cancer near them (called a **nerve-sparing operation**) your chance of returning to your pre-operation **potency** is greater. Age is also a factor affecting the return of erections, with older men less likely to achieve their pre-treatment erection strength.

For most prostate cancer surgery, the surgeon makes the initial cut through the abdomen (it could also be made close to the **anus**, but this type of approach is rarely used in Australia).

More recently, urologists have been able to offer laparoscopic or **robotic (robot-assisted laparoscopic) prostatectomy**. Generally, the telescopic instruments are inserted through six small cuts in the abdomen. The surgeon controls the movement of the instruments remotely, assisted by a 'robot', which also provides a magnified view of the operation field. Like all new procedures, the surgeon will have a 'learning curve' for this operation, achieving the best results after about 100 operations. The advantage of this 'keyhole' approach is that men recover more quickly from the surgery and return to normal activity more rapidly. At this time, it is too early to know whether this type of surgery will result in better or worse outcomes with regard to erectile function, continence and cure. It will be a number of years before we know its long term effectiveness.

There may be a need for extra blood during this operation. Your surgeon may talk to you about donating your own (**autologous**) blood, two to three weeks before surgery.

Treatment with androgen deprivation therapy before you have surgery (called **neo-adjuvant therapy**) has been offered in the past, but it has not yet been shown to be useful.

What is the outcome of surgery?

The results of cancer treatment can be measured in three ways: by the percentage of men who remain cancer free, by the percentage of men who survive the cancer (do not die from it), and by the percentage of men who survive death from any cause.

The figures from studies reporting on men who remain free of cancer after surgery are good: after five years between 75 and 85% of men were free of cancer; after 10 years between 70 and 80% were still free of it and after 15 years, 60% of men were still cancer free[8] (these figures have been rounded to nearest 5%).

The figures from studies reporting on men who survive the cancer (they may have it but do not die from it) after surgery are also good: after five years, between 96 and 98% of men have survived (not died from) the disease; after 10 years this figure is 90 to 96%; and after 15 years between 81 and 82%[8].

It should be remembered that the results of surgery are strongly influenced by cancer risk. Cancer control is best in patients with low risk cancers (low stage, Gleason score and PSA—see Table 4).

A recent trial compared surgery and **watchful waiting**. Its results suggest that the number of deaths from any cause is greater in the watchful waiting group[6]. It also found that after 10 years, 14.9% of men in the watchful waiting group had distant metastases compared with 9.6% in the surgical group.

Fewer men in the surgical group died from their prostate cancer. Men undergoing watchful waiting had more urine flow problems (44%) than men undergoing surgery (28%), but were less likely to be incontinent and have problems with erections[9]. Other aspects of quality of life were similar.

What are the side effects of surgery?

Table 7: Side effects (complications) of prostate surgery

Complication	% of men
Erectile dysfunction (impotence)	30–90
Incontinence (urinary)	5–35
Death	Less than 1

NHMRC 2003[8]. Figures rounded to nearest 5%. Lower ends of ranges are for earlier stage cancer

The most common side effects (complications) of prostate surgery are listed in Table 7 and include urinary **incontinence** (loss of bladder control), **erectile dysfunction** (erections are not firm enough for penetration, also called impotence) and **infertility** (not able to conceive children in the normal way). A short-term side effect, which passes after the catheter is removed, is bladder spasm (painful muscle action of the bladder). As this is a fairly major operation, there is a very small risk that you could die during the operation (less than 0.5%).

Minor urinary **incontinence** (a small loss of urine caused by exertion, for example, laughing) can occur in up to 40% of men. Severe, persistent urinary incontinence is much less common (about 5%). It is normal to have temporary incontinence, requiring the use of pads, when the catheter is

removed. There are ways of managing incontinence (see Chapter 4).

Table 8: Good and bad points of surgery

Good points	Bad points	Patients most likely to benefit
You may be able to remove all of your cancer Side effects usually get better with time	High rates of problems with erections Infertility Moderate rates of incontinence, particularly in the early post-operative phase	Cancer confined to the prostate Low risk cancer: Early stage, small cancer Low PSA Life expectancy (apart from cancer) more than 10 years Prefer to have surgery

Men are less likely to have problems with erections after surgery if they have good sexual function before the operation, are younger, their cancer is still small and a **nerve-sparing operation** has been used. A nerve-sparing operation is only possible if the cancer has not spread along the nerves. Most studies report **erectile dysfunction** (impotence) rates of 40 to 80%. It takes time for the nerves to recover after surgery and few men see any activity for six to nine months after the operation. After that, for many patients, erections improve for up to three years after the operation. The use of aids such as medications and injections can speed up this process. There are ways of improving erectile problems after surgery (see Chapter 4). The side effects of surgery, such as incontinence and erectile dysfunction, tend to improve over time.

Results of surgery have continued to improve as surgeons become more experienced with the surgery. Studies show that the more **radical prostatectomies** a surgeon does, the better the results: meaning fewer complications and the greater chance all of the cancer is removed[10-12]. One US study showed the best results were achieved by surgeons who did more than 40 operations per year and hospitals which did more than 60 operations per year[10].

Radiotherapy

The aim of **radiotherapy** is to kill all your prostate cancer cells using **x-rays**. When treated with external beam radiation alone, it will generally mean that you will require treatment five days a week for between seven and eight weeks.

Radiotherapy is a good option if you have **localised prostate cancer** and expect to live longer than 10 years.

Will it cure me?

A cure is possible if radiotherapy kills all the cancer cells in the prostate and immediate area, and the cancer has not spread beyond this area. It is not always possible to be sure of this, however. We can estimate the chance that the cancer is contained within the prostate region using **nomograms** (see Appendix 5). As with surgery, many men enjoy long periods of life free from cancer after they have radiotherapy.

What type of radiotherapy might I have?

There are two main types of radiotherapy that you could have. These are called **external beam radiotherapy** (the radiation comes from a source outside the body) and **brachytherapy** (also called interstitial radiotherapy, where the radioactive source is placed in the prostate itself). In most circumstances, cure rates for both are similar.

External beam radiotherapy (EBRT)

This is a common form of treatment for prostate cancer. In the past, it has often been chosen for older men with more **advanced prostate cancer**, who cannot have surgery and whose rate of cancer recurrence is higher than surgery patients. For this reason, it is hard to compare the results from surgery with those from **radiotherapy** to decide which is better. However, more recent comparisons based on a patient's **stage**, **grade** and **PSA** level suggest that the outcomes between surgery and radiotherapy are very similar.

EBRT aims the **radiation** from outside your body to the cancer in your prostate. It is carefully aimed, to try not to harm your healthy body **tissues**.

A special **CT scan** is done before treatment to determine the exact position of your prostate so that the radiation beams can be aimed at the right place. In order to make sure that the same area is being treated each time, the radiation therapist will make a number of marks on your skin. These marks will be made up of lines, crosses and dots drawn with special inks. You will usually have this treatment every day, five days a week for about seven weeks. It takes only about 15 minutes, but you may be in hospital for up to an hour. The exact dose of radiation given will depend on the size and type of your cancer and your general health.

If you have a high-risk cancer, your EBRT might be combined with **androgen deprivation therapy** (or 'hormone therapy'). This involves treatment with drugs designed to remove or minimise the effect of **testosterone** on the body (described later in this chapter). Hormone therapy may be commenced three to six months before treatment and continued for two to three years. This type of combined therapy has been shown to improve survival in patients with

high risk prostate cancer[13]. However it does have side effects (see below).

What is the outcome of external beam radiotherapy?

One very large study, a pooled analysis of nine US centres with almost 5000 patients[14], found that after eight years, 70 to 80% of low risk patients, 60 to 70% of medium risk patients and 30 to 40% of high risk patients were free from cancer. (It should be remembered that there are other factors that can affect the results, such as radiotherapy dose and technique.)

It follows that the risk posed by your disease makes a big difference to the results of treatment. In Table 4, we explained how your cancer's **grade** and **PSA** level combined give an estimate of risk. However, increasingly doctors are using mathematical tools called **nomograms** to combine other features of the cancer with grade and PSA level to give a better estimate risk. Probably the best information about the results of radiotherapy comes from the Memorial Sloan Kettering Cancer Center in the US. They have produced prostate nomograms which are used widely by health professionals and patients across the world. By entering key information about the stage of your prostate cancer and the treatment given, the tables can give estimates of the chances of being free from cancer (having a normal PSA) five years after treatment. See Appendix 5.

What are the side effects of EBRT?

Radiotherapy, unlike chemotherapy, can only cause side effects where the beams are being directed (i.e. in the pelvic area). There are short-term side effects that appear during or soon after your treatment and long-term side effects that can appear months or years after your treatment.

Short-term effects These include diarrhoea, skin discomfort, burning when urinating and tiredness. Many of these symptoms can be helped with medications.

Long-term effects Many men may find they slowly develop problems with erections (**erectile dysfunction**) after they have radiotherapy. There are now a number of ways this can be helped. These are described in more detail in Chapter 4.

Less commonly, some men may find they have problems in their lower bowel or rectum months or years later. This can cause bleeding when passing a bowel motion and, more rarely, difficulty holding onto motions (faecal **incontinence**). The bleeding can often stop on its own or with treatment. It is important if you have any bleeding after radiotherapy to see a specialist to find out why. As with surgery, men are usually infertile after radiotherapy.

Table 9: Complications following external beam radiotherapy (EBRT)

Complication	% of patients
Problems with the rectum	0–10
Erectile dysfunction (impotence)	40–80
Incontinence (urinary)	5

NHMRC 2003[8]. Figures rounded to nearest 5%. Lower ends of ranges are for earlier stage cancers

Table 10: Good points and bad points of EBRT

Good points	Bad points	Men most likely to benefit
There is less immediate trauma to your body than when you have surgery There is less chance you will be impotent compared to a radical prostatectomy when the nerves are not able to be spared There is less chance you will be incontinent There is a chance that it will kill any cancer that has spread just outside your prostate	It takes longer to see a result You may get some side effects months or even years after treatment Surgery is not available as a salvage treatment, if radiotherapy fails There is a greater risk of you having bowel problems You may be infertile	Cancer confined to prostate Low to intermediate risk cancer (EBRT) High risk cancer (EBRT and hormone therapy) Life expectancy (apart from cancer) more than 10 years Preference for radiotherapy

Availability of external beam radiotherapy

Radiotherapy is available in all major Australian cities and increasingly available in rural areas. However, as with surgery, it is known that the quality of treatment can vary. There is now good evidence that giving higher doses will improve cure rates. Australian hospitals usually give a dose of 74 **Gy**. To be given safely, treatment needs to be accurately targeted, with accurate localisation of the prostate. Conformal radiotherapy is designed so that the radiation follows the shape of the prostate. Adequate dose and accurate targeting can make a difference to the success of the treatment and the side effects you may experience. It is important to ask your **radiation oncologist** how the facilities available at your local radiation oncology centre compare to other centres.

'Ask any questions you might have—make sure you know what's involved. You have to have confidence in the treatment you've chosen.'

There are radiotherapy outreach clinics in many country centres. With extended periods of treatment, some state governments and some non-government organisations (NGOs) provide assistance with travel and accommodation for country patients who need radiotherapy away from their homes. This may be important in your decision about treatment.

Brachytherapy

Brachytherapy is a form of radiotherapy where the **radiation** source itself is placed in the area being treated. This allows high doses of radiation to be given to the prostate without affecting **tissues** close by, such as the **rectum**. There are two types of brachytherapy: low dose rate (permanent radioactive 'seeds' are implanted) and high dose rate (radioactive materials within hollow needles are temporarily placed in the prostate).

Low dose rate, or interstitial brachytherapy, involves a minor operation where doctors insert a number of radioactive

'seeds', about the size of a grain of rice, directly into your prostate. The seeds (120 or more) are inserted through the skin between the **scrotum** and the **anus** using 20 or more needles. Their exact placement is guided by ultrasound. These seeds release **x-rays**, which kill the nearby cancer. The seeds gradually lose their radioactivity over time.

Before the operation you need to be 'measured' so that the dosage and distribution of the seeds can be planned. The procedure to implant the seeds takes three or four hours, is done under general **anaesthetic** and usually needs a stay in hospital at least overnight. After implantation, you screen your urine for about two weeks to catch any seeds which may have migrated into your **urethra**. Medication may be prescribed to improve urine stream flow.

One advantage of having low dose rate brachytherapy compared to external beam radiotherapy is that it only requires a short visit to a hospital instead of many visits to a radiotherapy clinic.

Table 11: Chance of remaining cancer free after low dose rate brachytherapy (indicated by increase in PSA levels)

Period (years)	% PSA recurrence-free survival
2	95
3	70–90
5	80

NHMRC 2003[8]. Figures rounded to nearest 5%. These figures are drawn from different studies than those shown for surgery and external beam radiotherapy, and so are not directly comparable. The lower end in these ranges are for patients with later stage disease, but still confined to the prostate.

It is still too early for doctors to compare the survival rates for men having brachytherapy with the survival rates of men having **external beam radiotherapy**. There are some studies reporting the first sign of cancer **recurrence**, namely patients experiencing a rise in **PSA** levels after treatment. However it takes some time for symptoms to appear after PSA levels start to rise.

The other type of brachytherapy (high dose rate brachytherapy) is not a stand-alone treatment, but is used together with external beam radiotherapy (see previous pages). This ensures a high dose of radiation is delivered accurately to the prostate while minimising the dose to the normal surrounding tissues. A common approach is to give EBRT for five weeks 10 days after receiving the high dose rate brachytherapy, which takes one to three days. It is used for 'intermediate' or high-risk tumours.

What are the side effects of brachytherapy? There can be some discomfort from the procedure to insert the radioactive seeds into your prostate. Other common side effects include painful urination, poor urine flow and bladder irritation (this can cause urinary symptoms such as needing to go frequently and urgently). These can begin a month after treatment and last for up to six months. Urinary retention (inability to urinate) is a relatively common but temporary side effect following brachytherapy.

Problems with **erections** and rectal problems are also common with this type of **radiotherapy**. While the seeds will gradually lose their radioactivity, there is a very small risk of **radiation** exposure to other people. Babies and small children should not be held on the lap for two months after treatment. If you are resuming sexual intercourse, condoms should be used for the first two weeks after the seeds have been

implanted. This is in case a seed is accidentally moved and ejaculated in the **semen**.

Table 12: Side effects (complications) of brachytherapy

Complication	% patients
Urinary incontinence	0–20
Obstructive/irritative urinary symptoms	5–30
Problems with the rectum	1–10
Erectile problems	50–55
Acute urinary retention	1–14
Perineal pain	20
Blood in the urine	5

NHMRC 2003[8]. Figures rounded to nearest 5%. Patients followed up to five years. Acute urinary retention figures from Wilt (2002[15]) and Crook (2001[16])

Availability of brachytherapy Brachytherapy is available in the private health care sector in every state, but its availability to public patients may vary. It is important to check with your doctor about costs before deciding on this form of treatment.

Table 13: Advantages and disadvantages of brachytherapy

Advantages	Disadvantages	Patient most likely to benefit
Fewer immediate side effects than surgery or EBRT Treatment involves only one visit (interstitial brachytherapy), with short recovery time Lower chance of problems with erections than surgery	Not known yet whether long-term survival is as good as other treatments Some evidence that survival not as good for patients with medium to high risk cancer Infertility High cost borne by patient (under review)	Cancer confined to the prostate Low risk cancer: Small cancer Low-Gleason score Low PSA Good urinary function Life expectancy (apart from cancer) more than 10 years Preference for brachytherapy

Other types of treatment

Hormone therapy (androgen suppression)

Because prostate cancer cells depend on the male hormone **testosterone** for growth, one method of treatment is to remove the supply or block the action of testosterone. This can be done in a number of ways—by using drugs which act through the brain (called luteinising hormone releasing hormone or LHRH analogues) to prevent the release of a hormone that causes the **testicles** to produce **androgens**, or by removing the testicles, the main site of testosterone production. Combinations of drugs may also be used.

Removing the action of male hormones has side effects because the male hormone has many functions in the body. Side effects include hot flushes, breast enlargement, loss of libido and erectile function, lack of energy, mood changes and weight gain. Recently, effects on mental function such as attention and memory have been reported[17]. Over the long term, osteoporosis (weakening of the bones) may be a concern. Many doctors now recommend a bone density scan every one to two years and supplementary vitamin D and calcium. If anti-androgens (drugs which block the action of testosterone) are used on their own, the side effects are not as severe and some sexual function may be maintained. All methods have slightly different side effects and it is important to ask the doctor prescribing the drug to inform you of these. All of these agents, when prescribed, will contain information describing the side effects in detail and it is important to read this information.

Combined hormone therapy

It is becoming common for hormone therapy to be given before radiotherapy to shrink the tumour before treatment. This is known as **neo-adjuvant therapy** and may last as long as six months. This kind of combined treatment may be particularly helpful for men with high risk or locally advanced prostate cancer. The benefits however need to be weighed against the side effects. Hormone therapy may also be given for a period of time after surgery or **radiotherapy**. This is known as **adjuvant therapy**. Both neo-adjuvant and adjuvant hormone therapy may delay return of the cancer and improve survival. Once the hormone therapy is discontinued, **testosterone** levels return to normal. Clinical trials are in progress to determine the benefits of this type of combined treatment.

Hormone therapy on its own

Hormone therapy on its own will usually stop prostate cancer growing. This remission can last for several years. It is not usually offered for localised prostate cancer because it is not a potential cure. However it may be considered for older men with high-risk localised prostate cancer.

Salvage treatments

Salvage treatments are used for men who, despite having treatment to remove or kill their prostate cancer, find soon afterwards that their cancer has returned. For men who have had surgery, salvage radiotherapy is a treatment option. Salvage surgery is not usually undertaken after radiotherapy because of higher rates of erectile problems and **incontinence**.

Cryotherapy

Cryotherapy uses freezing to kill cancer cells. This technique involves inserting a probe into the **rectum**, through the bowel wall and into the prostate, where the freezing temperatures are then applied directly to the prostate area. We know little about the effectiveness of cryotherapy as a primary treatment, although one study[18] reported that 56% of patients remained **recurrence-free** at five years.

Cryotherapy could be chosen by patients who are eligible for surgery i.e. cancer contained within the prostate gland. However we need to know more about the complications (**erectile dysfunction** and **incontinence**) and long term likelihood of cure, before we can say it is an alternative to surgery.

High frequency ultrasound (HIFU)

HIFU has also been used as a treatment for prostate cancer: either as a primary treatment or when radiotherapy has failed and only local cancer spread has occurred. You will have an ultrasound probe placed in the rectum and a high energy beam focused at the prostate. This creates a burn, destroying the cancer. It is done under general or regional anaesthetic and involves a short stay in hospital. The main side effects are urinary symptoms, including urinary retention (inability to urinate), pelvic pain, urethral stricture, infections of the urinary tract, incontinence (rare), erectile dysfunction (about 30 to 50 %) and, rarely, an opening between the urethra and rectum (less than 1%).

It has the benefit of being minimally invasive, but the same uncertainties exist as for **cryotherapy**. We don't yet have long term data showing whether it is effective and so the treatment is still considered experimental. It may prove to be preferable to cryotherapy for men who are seeking a minimally invasive treatment. However we don't know for certain whether we can safely salvage failed HIFU with radiotherapy or surgery.

'I didn't realise at the time that there was no great rush—that I could have had a second opinion.'

Complementary and alternative therapies

Men with prostate cancer, like other people with cancer, frequently seek other therapies apart from those recommended by their doctor. The therapies are often unproven and can include complementary and alternative therapies.

Complementary therapies are used in addition to standard therapy. Some complementary approaches have undergone significant trials and have been accepted, when appropriate, into standard care. These include acupuncture and meditation.

Complementary therapies may include a sound diet, vitamin and trace minerals supplements and herbal preparations. They may help relieve symptoms of cancer, relieve side effects of cancer therapy, or improve your sense of well-being.

We suspect that diet is important for prostate cancer because of studies showing much lower rates of the disease in Asian and Mediterranean countries. When Japanese men migrate to America and adopt a Western diet, their prostate cancer rates increase. This type of epidemiological evidence suggests that certain nutrients, such as fat—particularly animal fat in the diet—contribute to a higher risk of prostate cancer. Conversely, diets high in fruit and vegetables, which include anti-oxidants such as vitamin E, selenium, lycopene (from tomato-based products), isoflavones (from soy) and green tea may be protective. However, while there is some evidence of association, to date no single nutrient has been shown to prevent prostate cancer or improve survival from it. Recently, we have also learned that once men have prostate cancer, being overweight can affect how well they do. They are more likely to have more advanced cancer and the disease is more likely to progress after treatment in very overweight men[19].

While we do not know for sure that they can help, complementary therapies can normally be used side by side with standard treatments. Some treatments, however, can work against your therapy and it is very important that you discuss any new treatment you plan with your doctor.

Some preparations, particularly certain herbs, may cause additional problems. If you use herbs, it is important to ensure they are of good quality and that there has been no contamination during manufacture. The identification of the substance should be clear and appropriately advertised. Be alert to excessive claims. There is no regulation requiring rigorous manufacturing of these substances, so take care in making your

choice. Discuss any product you plan to take with your doctor before doing so.

Alternative therapy refers to an unproven therapy that is used *instead of* standard or proven therapy. Some alternative treatments are claimed to be cancer cures and others to promote better quality of life. To date no alternative treatment has been shown to cure cancer.

It is best to discuss any alteration in your care program with you doctor.

See Appendix 4: Resources, for contact numbers. The National Medicines Line 1300 888 763 provides consumers with independent information about prescription medicines, over-the-counter medicines, herbal and natural therapies.

D. How can I make the treatment decision easier?

Making a decision with your doctor about treatment can be a difficult task. Initially you may not even want to think about treatment at all—coming to terms with the diagnosis is taking all your time. Understanding prostate cancer may involve understanding a whole new language.

Your preferences—how you feel about the cancer and the likely outcomes, including side effects of treatment—are crucial in making this decision. Your doctor will explain that in many cases the 'best', treatment depends on the 'risk' posed by your disease—how extensive it is (**stage**, **PSA**, **tumour** volume), how fast it is likely to grow (**Gleason score**, PSA rate of change) and your own age and general health. However, sometimes the best treatment is not clear. You may need to choose between surgery, **radiotherapy**, or doing nothing for the time being. Your preferences regarding the treatment, its side effects and how they may impact on your normal life and relationships are very important in this decision.

How other men make the decision

Individual men make this decision in different ways and there is no right or wrong way to decide. Some men like the doctor to make the decision for them. Others find they make a decision very quickly once they hear the possible choices, while still others take some time to consider their options and get more information. Many men say that taking time to find out all they could, and talking to a range of people (see Additional contacts, later in this chapter) made them more comfortable with their decision.

With prostate cancer, there is usually no rush to make a decision. This means you have time to consider your options and talk to others about what is best for you. Ask your doctor if there is any urgency in your case.

The decision steps

Here, we summarise again the points you need to consider with your doctor when making a treatment decision (see also Figure 1 at the beginning of this book).

- You need to know whether your cancer is actually a threat to you. Will it affect your health and wellbeing in the future?
- Your doctor will explain which treatment options are possible for you and their likely side effects. If you feel you don't understand, or need more information, talk it over with your specialist or general practitioner. You are always free to seek a second opinion (see page 15).
- The cost and availability of treatment may be important to your choice. Some treatments, such as **brachytherapy**, may involve considerable cost and are only available in some cities. Ask about cost and availability before making a treatment decision.

It may be helpful to:

i. ***List each of the options*** which are available to you.
ii. ***Write down what you like and don't like*** about each option.
iii. ***How important to you*** is each of these points? How important are these points to your family?
iv. ***Check with your doctor*** or another source whether there are ways around the problems. For example, someone from the country may be concerned about having to stay in the city for six weeks for radiotherapy, needing accommodation and time off work. For information about travel allowances and accommodation, contact the Cancer Council Helpline on 13 11 20.
v. ***Talk to other men*** who have received these treatments and find out how they went. Talk to people close to you, such as your partner or a close friend.

One reason that this decision can be difficult is because different men will place different values on the possible outcomes of treatment. It is important that you feel you have made the choice that is right for you.

Informed consent

Your doctor will ask you to sign a form that describes your treatment and its possible complications, and asks whether you agree to the treatment. This is called providing written consent. It means you understand the risks of the treatment, what may happen if you don't have the treatment, the likely outcome and anything else you want to know.

Your doctor may give you some material to read or suggest where you can find it. If it is not clear and you do not understand the information, ask your doctor. It is important to be fully informed before giving consent.

Additional contacts

Urologist or radiation oncologist	Can advise on treatment options. A repeat consultation may be useful. A second opinion may help build confidence in your choice.
General practitioner	Can discuss general medical issues, your own situation, rural travel allowances. Ask for a longer appointment.
Urology or prostate nurse adviser, or radiotherapist	Located in the hospital you are considering for treatment. Can give you practical details about the treatment, for example, how long it takes and managing afterwards. Call the hospital and ask to speak to one.
Cancer Council Helpline 13 11 20	Can explain cancer treatment, including its effects on families. Can refer you to useful community services, including local support groups.
Prostate cancer support groups	Can provide support and information. See Appendix 4: Resource list. The group convenor may provide useful information, or you may like to attend a meeting.
Continence Foundation of Australia 1800 33 0066	Can advise on managing continence after treatment and provide information about resources in your local area.

After the treatment is over

Check-ups

After your initial treatment is completed, your doctor will usually follow your progress with regular check-ups. These will probably involve measuring your **PSA**. PSA tests to monitor progress after treatment are covered by Medicare.

After surgery, your PSA should quickly drop to an undetectable level, as there should be no prostate cells left to make it. If it does not drop this far, or becomes detectable, this suggests that there are still prostate cancer cells somewhere in your body. Most specialists regard a PSA rising above 0.2ng/ml as indicating that cancer is present.

After radiotherapy, your PSA behaves a little differently. This is because the prostate cancer cells die more slowly and some normal cells still remain. Therefore, your PSA levels will drop slowly and reach their lowest level one to two years after your treatment. Should the PSA start to rise again, the lowest level reached before it rises is called the '**nadir**'. Current evidence suggests that if the nadir is less than 1.2ng/ml, there is a high probability of cure[20].

What if my prostate cancer comes back?

If your **PSA** levels begin to rise soon after your initial treatment (that is, within three years), but there is no sign of active cancer spread, this suggests you could still have cancer cells in your prostate region. It is possible to eradicate them with further treatment called **salvage treatment**. **Radiotherapy** is the most common salvage treatment after surgery. Surgery is usually not done after radiotherapy (see page 48). It is important to realise that even after the PSA starts to rise, many people live long lives free of symptoms of cancer.

Commonly, the next stage of treatment, if your cancer comes back, is **hormone therapy (androgen deprivation therapy,** covered in Chapter 3). Hormone therapy is the main treatment offered to men whose prostate cancer has spread beyond the prostate region (stage T4). In this situation, hormone therapy is taken indefinitely (although not always continuously). Before starting hormone therapy, you should discuss the effect it may have on your life with your doctor and your partner (if you have one). We do not talk about hormone therapy as a stand-alone (or single) treatment in this book. For more information on hormone therapy, ask your doctor or call the Cancer Council Helpline on 13 11 20.

What about life after prostate cancer treatment?

Most men find that, in time, they can return to their normal activities. The outcome of treatment for **localised prostate cancer** is good and many men lead productive, active lives for many years after treatment for prostate cancer. However, men can experience a number of common problems after treatment and we discuss them below.

Relationships, sexuality and prostate cancer

As you get older, it normally becomes harder to have and maintain an **erection**. For some men, additional **erectile dysfunction** or **impotence** (not being able to have an erection), caused through prostate cancer treatment, might not be a big concern. For others, it may be very important. Damage done to the nerves around the prostate during the operation can cause erectile dysfunction. Many **urologists** try to avoid damage by using a **nerve-sparing operation**. The extent to which this is possible will depend, among other things, on the

stage of your cancer—smaller cancers are easier to remove without damaging the nerves.

It is important to be aware of and address the impact that treatment may have on your sexual function before embarking on treatment. While it may be possible to retain or restore erectile function, ejaculation will not take place after a radical prostatectomy. This, of course, will affect **fertility** (the ability to conceive children in the normal way). Other treatments will also affect the ability to have an **erection** and **ejaculation**.

'I don't remember anyone saying I'd have this problem.'

Some solutions are discussed in this chapter. The Cancer Council Helpline (13 11 20) can also put you in touch with support groups, specialists and other resources in your community.

Some people will be in a stable relationship when they have treatment. Talk things over with your partner. Good, open communication goes a long way to sorting out any problems. It will also reassure both of you of your affection and need for each other. Some men will not be in a relationship, or may be in a relationship that is failing or has not dealt well with problems in the past. This will present its own challenges: you might need to seek support from a counsellor or doctor (for contact details see Resources section). However, it must be stressed that it is important to address and understand the implications of these effects before treatment is undertaken.

How can erectile dysfunction be treated?

If you find you have problems with erections after having treatment, there are now many things that can be done to help.

It takes time for the nerves to recover following radical prostatectomy: few men see any erectile activity for six to nine months, and it can continue to improve for two to three years.

During this time, many surgeons encourage the use of erectile aids such as medications and injections. There is evidence that these may improve long term potency by assisting fresh oxygen-carrying blood to get into the erectile cylinders of the penis, keeping them healthier as the nerves recover.

There is a class of drugs that relax the smooth muscle of the penis, allowing increased blood flow and erection. An example is sildenafil (Viagra). Some men (unfortunately not all) respond well to these tablets. The most common side effects are headaches and hot flushes. However, if you have had heart problems, chest pain, are taking or have taken drugs for angina (chest pain on activity), then you should not take these tablets. If you have any doubts, you should discuss this with your family doctor before starting treatment.

Another, less common form of treatment is penile injection therapy. This involves learning how to inject a substance into your penis that causes the blood vessels to dilate, resulting in an erection. This method is well tolerated and successful in most men. An automatic injection device is available. The dose needs to be carefully worked out so that the erection does not last too long. Your doctor will need to work with you to find the dose that is right for you. If used too frequently in the same place, scar tissue can develop in the penis. Some men find the injection causes a dull pain for a while following the injection. This treatment is no longer covered by Medicare.

Other methods for managing erectile dysfunction include the use of vacuum devices and penile implants. Both of these can be helpful for men who have found other methods unsatisfactory. For more information on managing erectile dysfunction, talk to your urologist or contact the Cancer Council Helpline on 13 11 20.

Some men cannot ejaculate after they have their treatment, which means they cannot conceive children in the usual way. This may or may not matter much to you, but should be considered when you are making a treatment decision. If this is important to you, sperm banking (storing your sperm) before your treatment may be an option. Discuss this with your doctor.

Urinary incontinence

Urinary incontinence refers to being unable to control the loss of your urine. It is a common side effect of radical prostatectomy, particularly immediately after the operation

Some men may have a persistent loss of a small amount of urine, called 'stress incontinence'. Stress incontinence is the accidental passing of urine that can happen when you go jogging, cough or sneeze. You will find that wearing incontinence pads will help.

Exercising the muscles which form the pelvic floor (the region between your anus and scrotum) is a good way of stopping or lessening leakage. With training, your muscles can be taught to contract inward and upward to counteract the increased abdominal pressure. These exercises can help with other types of incontinence also. Specially trained physiotherapists or nurses can show you this technique. Such exercises can be helpful both before and after the operation.

A small number of men get more severe incontinence, which persists and interferes with their lifestyle. Severe incontinence would require changing incontinence pads several times a day. Aids such as sheaths or condoms for the penis which drain to a bag can be used if larger volumes of urine are lost. If the problem persists, options include injecting bulking agents such as collagen around the neck of the bladder (where the bladder joins the urethra or urine tube) to assist it to

'I try to find others with similar experiences and discuss it with them.'

close, surgically constructing a sling to support the urethra, and lastly an artificial urinary sphincter prosthesis. This is an implanted device that keeps the urethra closed until you are ready to urinate. For most men, however, the problem is not severe and fixes itself within the first year after their treatment.

If you would like more information about managing incontinence, talk to a urology nurse at your treating hospital or contact the Cancer Council Helpline or the Continence Foundation of Australia (see Appendix 4: Resource list).

Social and emotional issues

Early on, as you get back to normal activities, concern about the cancer returning is natural. Some men say they worry unnecessarily about aches and pains that are part of normal life. If you are feeling this way, ask your doctor what to expect, should the cancer return. This may reassure you.

You may find also that this is a time of re-evaluation, of re-setting some of your immediate and longer-term goals. It is all part of a healthy approach to living with the cancer.

If you find, however, that your day-to-day life is becoming difficult—for example, you are having trouble sleeping or finding it hard to get going in the morning—talk to your general practitioner. There are plenty of resources available to help you. No person has to struggle with this on their own. Strategies for dealing with stress are given in the helpful booklet: *Coping with a diagnosis of prostate cancer* (see Appendix 4: Resource list).

Counselling and support

Most men cope with their illness better if they have good information and good support from their partner, family,

medical team and others. Accepting support is not always easy. Many men prefer to give support rather than receive it. However there is evidence that people with cancer who receive support are likely to do better.

Counselling can help, too. While some men are uncomfortable about the idea of counselling, it can make a real difference. It can help you to prioritise and fix problems and make the situation easier to live with. You can find out about counselling from:

- your hospital, which may have staff specialised in counselling people with cancer
- your doctor, who could refer you to someone, such as a prostate nurse adviser or urology nurse or other person with skills in prostate cancer
- the Cancer Council Helpline.

Many forms of support are available. These include:

- peer support: talking to other men who have experienced prostate cancer
- home help with, for example, looking after children, elderly parents or an elderly spouse
- help with transport
- hostel or other accommodation during treatment
- financial assistance in some cases.

Every man dealing with prostate cancer experiences some difficulties. If you have good information and good support, you will find it easier to deal with them. Talking to other men who have had prostate cancer can also help.

Prostate cancer support groups

Prostate cancer support groups offer support and information to men with cancer and, often, to their family and carers (people who care for someone with prostate cancer).

You may find it useful to talk with others who have gone through the treatment that you are thinking about. A support group can offer you the chance to share experiences, practical suggestions and ways of dealing with non-medical problems. These discussions can remind you of questions you may want to ask your doctor.

Family members can also benefit from talking to other family members in a support group (most include wives and partners).

Your hospital may run professionally led support groups. See Appendix 4: Resource list, or check with your doctor, nurse, social worker or the Cancer Council Helpline on 13 11 20.

There is a network of prostate cancer support groups in Australia, and you will usually be able to find one in your local area. You can contact them by calling the Prostate Cancer Foundation of Australia on 1800 22 00 99 or 02 9418 7942.

You can also find a prostate cancer support group in your area by checking the Lions Australian Prostate Cancer Website: www.prostatehealth.org.au. This site has extra information about prostate cancer, and the facility to ask a question and receive a response by email.

Moderated mailing lists, where different aspects of prostate cancer are discussed by emails posted on the Internet, are becoming increasingly common. We include examples in Appendix 4: Resource list.

Concerns of younger men

Because prostate cancer is less common in men under 55 years, some men in this age group feel isolated and frustrated: many of the issues they face differ from older groups and it seems hard to find someone with similar concerns. Prostate cancer and its treatment can interfere with family, children, career,

sport and future relationships. The disruption to the household can be very difficult. It can also be hard to find the opportunity to talk about what's on your mind and what the future holds.

The Cancer Council NSW telephone support service program conducts a confidential telephone support group for men aged 40 to 55 years with prostate cancer at any stage and receiving any type of treatment. Contact the Cancer Council Helpline on 13 11 20 for more information.

Other support services

Other support services can also help you while you are at home. These include home help, meals on wheels and visiting nurses. These services are provided by local councils and the Royal District Nursing Service (or equivalent in your state). Several other groups can also give you information and support. The Cancer Council Helpline can tell you about other services (see below).

Cancer Council Helpline

The Cancer Council Helpline is a telephone information and support service for people affected by cancer. It is a confidential service where you can talk about your concerns and needs with trained staff. The staff can send you written information and can put you in touch with appropriate services in your own area. The service is run by the cancer organisations in each state affiliated with The Cancer Council Australia. Telephone 13 11 20.

What questions could I ask?

Here is a list of questions you might like to ask your doctor/s. These reflect the points for discussion covered in Chapter 3. Under each one, we give you the page reference in this book.

General questions

How do I know I have prostate cancer? You may not have any symptoms (Chapter 1, page 12). You may have a high **PSA** level (Chapter 2, page 16), but the only way a doctor can definitely tell is through a **biopsy** (Chapter 2, page 19). Sometimes, men find out after having an operation for benign prostate enlargement (Chapter 2, page 20).

What is localised prostate cancer? Prostate cancer is cancer occurring in the **prostate gland**, situated just under the **bladder**. Localised prostate cancer is still **confined** to the prostate gland (stage T1 or T2) and has not extended to other structures such as the **seminal vesicles** (Chapter 1, page 9).

How do doctors know it has spread? Doctors get an indication of whether the cancer has spread beyond the prostate from the results of the **digital rectal examination**, **PSA** level, **PSA velocity**, **biopsy** and other tests (Chapter 2).

Can I be cured? Cancer which is still **confined to** the prostate can be cured. Most men live for many years after treatment for **localised prostate cancer** without the disease returning or progressing (Chapter 3).

Should I get a second opinion? If you are uncertain about treatment, a second opinion may be helpful. This may be with the same or a different type of specialist. With a second opinion, you may feel more confident in your choice (Chapter 2, page 16).

Is there anyone else with prostate cancer I could speak to? Yes. You can ask your urologist or contact the Prostate Cancer Foundation of Australia (see Appendix 4: Resource list) or the Cancer Council Helpline, or look up www.prostatehealth.org.au to contact a support group to talk to someone with prostate cancer.

Will it affect my sex life and my fertility? Because the prostate gland is part of your reproductive system and close to nerves controlling erections, treatment for cancer can affect your ability to have erections and your fertility (Chapter 3, pages 35, 40; Chapter 4, page 56).

Is my family a 'prostate cancer family'? We know that family history is a risk factor for prostate cancer (Chapter 1, page 10). There is a higher risk for men with a father or brother who have been diagnosed. However, we believe that most cancers are not due to inherited factors. Lifestyle factors may play a significant role.

Is there anything I can do to lower my PSA? Recent research indicates the levels of **PSA** may be influenced to some degree by lifestyle factors such as diet and exercise; however we don't know if this can prevent prostate cancer. Medications which lower PSA do so usually by lowering male hormone activity.

Questions about treatment

What are the options for treatment? There are four main options for treatment of localised prostate cancer: no initial treatment (also **watchful waiting** and active surveillance) (page 28), surgery (page 30) and **radiotherapy** (page 37). They may be combined with Hormone therapy (page 46).

Can you tell me about your experience with this treatment? Treatment results can vary among different groups of doctors and patients. Every man has a right to ask questions about the doctor's experience and expectations for a particular treatment. Some doctors can tell you what outcomes he or she has had with a particular treatment.

Watchful waiting / active surveillance

What happens if I do nothing? Will I get sick quickly? If your cancer is very small, low grade and has a low PSA velocity, it is unlikely that it will advance rapidly to become potentially invasive. Deferred treatment is an option if the cancer is not likely to be a threat or if you want to avoid the risk of erectile problems and other side effects. Your cancer grade gives an idea of how fast it is likely to grow (Chapter 2, page 23).

If I do nothing now, could I have active treatment later? You can change your mind and have surgery or radiotherapy as long as the cancer is still localised (Chapter 3, page 29).

If I do nothing now, and have treatment later, will it affect my chances of cure? It can affect your chances of cure depending on how fast the cancer is growing (Chapter 3, page 29). As part of your plan, it may be helpful to have a point at which you decide on further intervention.

Surgery

What operation would I have? Surgery to remove the prostate and close organs is called a **radical prostatectomy** (Chapter 3, page 32).

How often have you done this operation before? Doctors who do operations frequently may be more experienced in that procedure. This can be an important factor in choosing your doctor (page 15).

What are the risks? There is always a very small risk of death from surgery of any kind. However, there is a high risk of problems with erections, and a smaller risk of incontinence, after surgery for prostate cancer (Chapter 3, page 35).

For how long would I be in hospital? It could vary from three to six days for an open prostatectomy and as little as one day for a robotic-assisted laparoscopic operation (Chapter 3, page 30).

What would you take out? The prostate and organs called the seminal vesicles, vas deferens and part of the urethra which is surrounded by the prostate (see Figure 5, Chapter 3, page 31). Lymph nodes with cancer cells may also be removed.

Doctor, how many of this type of operation do you normally perform? Doctors who do operations frequently (say 20 or more a year) are more comfortable with undertaking an operation. This can be an important factor in choosing your doctor (page 15).

How long before I could get back to my normal life? It would take six weeks or so to completely recover your normal physical activity (Chapter 3, page 32).

Radiotherapy

Radiotherapy is discussed in Chapter 3, pages 37–66

How does external beam radiotherapy work? The radiation is given using a machine called a linear accelerator. The machine produces radiation which enters the body from outside and is directed at the prostate and a small amount of surrounding tissue. The radiation kills cancer cells inside the prostate when they try to grow. The treatment is given five days a week over many weeks, which gives time for the normal cells to repair themselves. Cancer cells lose the ability to recover well from the radiation.

What does it do? Radiotherapy is aimed at killing every cancer cell in the prostate while keeping to a minimum any side effects.

How long does it take? This will vary according to each centre, but generally takes six to seven weeks with treatment every day apart from weekends and public holidays.

Do I have to be in hospital? No, you have the treatment as an outpatient.

What are the risks? Towards the end of radiotherapy, many people experience some discomfort with their bowels and urination. Tiredness is also common. These side effects generally get better a few weeks after treatment finishes. You are not radioactive after treatment and will not lose head hair. Nausea and vomiting are also not common. A small number of men develop late side effects, which can start many months or even years after treatment has finished. The most common late side effects are **erectile dysfunction** (impotence) and rectal damage. Rectal damage is often in the form of bleeding that can be treated, for example with laser therapy if it occurs.

Can I get help if I need to travel? Yes: schemes providing assisted accommodation and transport for rural patients are available. Ask at your treating hospital.

Is it painful, and are there side effects? The radiation treatment itself is completely painless—just like having an x-ray. As mentioned before, radiotherapy can only cause side effects in places where the radiation beams are directed and won't affect other parts of the body. Hence, towards the end of radiotherapy, many people experience some discomfort with their bowels, skin around the anus and urination, but this settles fairly soon after treatment is completed. Tiredness is also common.

How is brachytherapy different from external beam radiotherapy? Brachytherapy means 'radiotherapy from within'. This means radioactive sources are placed into the **prostate gland**. There are two main types of brachytherapy used for prostate cancer. The first is low dose rate brachytherapy where small radioactive seeds are placed permanently into the prostate, and kill the cancer cells slowly over time. You only need one trip to the hospital and an overnight stay. It has some side effects—see page 44. The other type is called high dose brachytherapy and is generally used as a 'boost' either before or following four to six weeks of external beam radiotherapy. Plastic catheters are temporarily placed within the prostate (under a general anaesthetic) and you are connected to a machine which inserts a

highly radioactive ball bearing down the catheters for short periods. This process takes 15 to 30 minutes. The treatment may be repeated over a period of 24 to 36 hours. During this time you will be hospitalised and may have restricted movement. Side effects and complications can occur as outlined on page 44.

For surgery or radiotherapy

Can you tell me about your experience with this treatment? Treatment results can vary among different groups of doctors and patients. Every man has a right to ask questions about the doctor's experience and expectations for a particular treatment. Some doctors can tell you what outcomes he or she has had with a particular treatment.

Should I get a second opinion? If you are uncertain about treatment, a second opinion may be helpful. This may be with the same or a different type of specialist. With a second opinion you may feel more confident in your choice (see page 44).

What can I do to prepare myself for treatment? Ask your doctor what pre-treatment and post-treatment supports they offer. It makes sense to have enough sleep and a good diet to build up your strength. Before surgery, many hospitals explain how to strengthen the pelvic floor muscles, which are important for continence. Make arrangements for assistance with meals if you are living alone. Ask at your pre-treatment visit about what you will need immediately after treatment, for example, incontinence pads.

What can I do to speed my recovery? Make sure you have good information about what to expect. This helps reduce anxiety. After surgery, make sure you have adequate fluids. Restrict activities for first two to three weeks then gradually increase to normal lifestyle by four to six weeks, when you can for example, return to sports including tennis and bowls. Avoid constipation: dietary fibre is important.

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Staging and the TNM system

'Staging' refers to finding out how far the cancer has spread.

This is investigated in a number of different ways. Initially, at the **digital rectal examination**, the surgeon notes whether he or she can feel the tumour as a nodule or irregularity on the prostate, and if so, whether it extends beyond the prostate itself. This is referred to as **clinical staging**. However, the exact stage is not easy to determine from a clinical examination. Sometimes the number of **biopsy** cores with cancer in them is reported by the pathologist, and gives an indication of the extent of the cancer. If surgery is completed and the prostate removed, staging can be determined more precisely by pathological (using a microscope) examination of the prostate tissue and surrounding organs which have been removed. This is called pathological staging.

TNM system

This is a system for recording how far the cancer has spread. 'T' refers to tumour, 'N' to node and 'M' to metastasis. The system is used around the world to stage cancers which develop as tumours and **metastasise**. In the TNM system for prostate cancer, the staging is as follows:

T1 Tumour so small that it cannot be detected by feeling the prostate or on ultrasound.
T2 Tumour which can be felt, but is still confined within prostate.
T3 Tumour extends through the prostatic capsule and may have spread into seminal vesicles.
T4 Tumour invades adjacent structures other than seminal vesicles, such as bladder, rectum, pelvic wall.
N1 Tumour is found in lymph nodes.
M1 Tumour has distant metastases.

This is a simplified description. Within each stage are sub-groupings a–d, which indicate the extent of spread within that group.

The Gleason grading system

Grading systems score how abnormal the **tissue** looks. This is also related to how fast the cancer is likely to grow. Sometimes a pathology report refers to tissue as 'poorly differentiated'. This is another way of saying that the tissue does not look like the normal tissue (fully differentiated).

The main system for grading tissue taken at **biopsy** is the Gleason grading system. The pathologist identifies the two most common tissue patterns and gives them a score from 1 (most normal or differentiated) to 5 (most abnormal or poorly differentiated). The **Gleason score** is given as two numbers added together to give a score out of 10 (for example, 3 + 4 = 7). The first number is the most common pattern seen under the microscope and the second number is the next most common. The higher the Gleason score, the more aggressive the cancer, and the faster it is likely to grow. Gleason scores therefore reflect the 'risk' posed by the cancer.

Low risk: Low grade, well differentiated tumour, Gleason score 2–6

Intermediate risk: Intermediate grade, moderately differentiated, Gleason score 7

High risk: High grade, poorly differentiated, Gleason score 8–10

These risk categories are those adopted in the recently announced American Urological Association 2006 *Clinical Practice Guidelines for Localised Prostate Cancer* and the National Cancer Control Network Practice Guidelines in Oncology vs 2.2005 Prostate Cancer.

See www.nccn.org/professionals/physician_gls/PDF/prostate.pdf

Clinical trials

Your doctor may suggest that you consider taking part in a clinical trial.

Clinical trials are a necessary part of the search to find better treatments for cancer and involve patient and doctor cooperation. Doctors conduct clinical trials to test new or modified treatments and see if they are better than existing treatments. Clinical trials are conducted under strict ethical supervision, and your doctor will only suggest that you consider taking part if all the possible treatments in the trial are suitable for you. It is important to remember, however, that the decision to take part in a clinical trial is always yours.

If your doctor asks you to take part in a clinical trial, make sure that you fully understand the reasons for the trial and what it means for you. Before deciding whether or not to join the trial, you may wish to ask your doctor:

- Which treatments are being tested and why?
- What are the possible benefits to me or others?
- What extra tests apart from my normal treatment will I be involved in?
- What are the possible risks or side effects?
- How long will the trial last?
- Will I need to go into hospital for treatment?
- What will I do if any problems occur while I am in the trial?
- Can the trial affect my options for future treatment?
- Can I withdraw from the trial if I change my mind?

If you decide to join a clinical trial, you will be given either the current standard of treatment or a potential new treatment. You will be assigned at random (like a 'toss of a coin') to receive one treatment or the other. The trial may be double blind, meaning that neither you nor your doctor will know which treatment you are on. You need to make sure you understand

the treatments and their effects well enough to give informed consent.

If you do join a clinical trial, you have the right to withdraw at any time. Doing so will not prejudice or compromise your treatment for cancer.

It is always your decision to take part in a clinical trial. If you do not want to take part, your doctor will discuss the best current treatment choices with you.

At the time of writing, there is no comprehensive list of prostate cancer trials available in Australia.

Resources

If you need more information about prostate cancer, you have a number of options. These include cancer organisations with informative websites, helplines (telephone or online), peer support groups and books. The following is a selection.

General information on prostate cancer

Lions Australian Prostate Cancer Website: This website, established by the Australian Prostate Cancer Collaboration, gives stage-by-stage information on prostate cancer, lists of support groups, news, how to access treatment and listings of other websites. You are also able to ask a question about prostate cancer online: www.prostatehealth.org.au

The Cancer Council Helpline: The Cancer Council Australia's Helpline is a free (cost of a local call), confidential telephone information and support service run by cancer councils in each state and territory. Specially trained staff answer questions about cancer prevention, early detection, and treatment. They can also assist with practical and emotional support. Telephone 13 11 20.

Prostate Cancer Foundation of Australia: The PCFA is a peak body raising funds, raising awareness and supporting men with prostate cancer. It also has a network of support groups across Australia. It has a toll-free number and informative website. Telephone 1800 22 00 99. www.prostate.org.au

The Urological Society of Australasia: This peak body representing urologists has an informative website which includes how to find a urologist in your area (Australia and New Zealand): www.urosoc.org.au

Andrology Australia: This professional body undertakes research and programs which improve the understanding of male reproductive health disorders, including prostate cancer.

The informative website has information on prostate disease, male infertility, testicular cancer and many other topics: www.andrologyaustralia.org

National Comprehensive Cancer Network: The NCCN is a network of 20 leading US cancer centres. Their website has clinical practice guidelines for most cancers, including versions for patients: *Prostate Cancer Treatment Guidelines* for Patients, updated in 2005: www.nccn.org

Continence Foundation of Australia Helpline: This peak professional body on continence problems provides a free national helpline on managing bowel or bladder problems. Telephone 1800 33 00 66.

Accessing peer support

You can find a peer support group in your area in a number of ways:

- visit the **Lions Australian prostate cancer website** and search by your state: www.prostatehealth.org.au
- **visit the PCFA website which has a listing**: www.prostate.org.au
- **call** the Prostate Cancer Foundation Infoline on 1800 22 0099
- **call** the **Cancer Council Helpline** on 13 11 20.

Relationships counselling

Mensline Australia: Mensline Australia is a national seven-day a week service that supports men who are dealing with family and relationship difficulties. Telephone 1300 78 99 78, or visit www.menslineaus.org.au

Clinical trials in Australia

The Australian Clinical Trials Registry: The registry website has information about clinical trials available nationally as well as their inclusion criteria (the type of patients they are seeking) www.actr.org.au

The Cancer Council Victoria: The Cancer Council Victoria has a listing of Victorian clinical trials on their website. At the time of going to press this was under construction, but check to see if it is available: www.cancervic.org.au/trials/

Alternative and complementary therapies

National Prescribing Service Medicines Line: This Australian service provides consumers with telephone access to independent, accurate information on prescription medicines, over-the-counter medicines, herbal and natural therapies. Telephone: 1300 888 763.

National Center for Alternative and Complementary Medicine: You can search for trials of complementary treatments on PubMed from this website of the US National Institutes of Health: nccam.nih.gov

American Cancer Society: The website of this peak US cancer body gives information on different types of complementary medicine as well as evidence supporting effectiveness: www.cancer.org/docroot/ETO/ETO_5.asp

Nomograms: software for estimating risk

This is sophisticated software for calculating the probability of different outcomes, given clinical information such as your stage, grade and PSA. It is based on published patient series and is free. However, it is not easy to understand without some medical knowledge.

Memorial Sloan Kettering Cancer Center: This leading US cancer centre provides access to a number of nomograms for calculating prostate cancer risk, together with an explanation of how to use them. www.mskcc.org/mskcc/html/10088.cfm

Prostate Cancer Research Institute: This non-profit organisation, founded in 1996 by medical oncologists in Southern California, provides a range of tools including nomograms and tools to calculate PSA doubling time: www.prostate-cancer.org/tools/software/pctools2.html or www.prostate-cancer.org/tools/software/software.html

Listing of websites

A list of annotated links to Australian and international prostate cancer websites is given on the Lions Australian Prostate Cancer Website: www.prostatehealth.org.au/links

Books and booklets

A primer on prostate cancer: the empowered patient's guide: Dr Stephen Strum and Donna Pogliano. The Life Extension Foundation, Florida 2005. Written by a US urologist, this book is for those seeking to understand the more technical aspects of their care.

Coping with prostate cancer: This useful booklet from the Queensland Cancer Fund gives issues you may face after a diagnosis and strategies for dealing with them. It is available online from the QCF website, or call 13 11 20 from Queensland. www.qldcancer.com.au/Cancer_Info_and_Services/PCS/CancerResources.html

Intimacy with impotence: the couple's guide to better sex after prostate disease. Ralph Alterowitz and Barbara Alterowitz. Da Capo Press, 2004. This book provides

information on relationships, commercial therapies and advice on love-making after prostate disease.

Life's in the pink. How to maintain a quality of life, by a prostate cancer survivor. Barry L. Oakley. A sequel to Barry's popular first booklet. Available from PSA Prostate Cancer Support Group, 39 Greenfield Rd, Seaview Downs, SA 5049, Phone Reg at (08) 8298 8040.

Prostate cancer and sex. This useful booklet from the Queensland Cancer Fund explains sexual function and how it is affected by prostate cancer treatment. It gives a range of strategies for dealing with these issues. It is available online from the QCF website, or call 13 11 20 from Queensland. www.qldcancer.com.au/Cancer_Info_and_Services/PCS/CancerResources.html

The prostate book: the complete guide to overcoming prostate cancer, prostatitis and BPH. Dr Peter Scardino and Judith Kelman. Penguin Group, New York, 2005. A book by one of the best-known US urologist covers every aspect of prostate cancer, including prevention, treatments, managing side effects and other prostate problems.

There's some good years left yet: the experience of a prostate cancer survivor. Barry Oakley talks about his experiences and tips for coping with prostate cancer. Available from Prostate Health Improvement Program, Repatriation General Hospital, Daw Park, South Australia. Telephone: 08 8275 1169.

Your guide to prostate cancer: the disease, treatment options and outcomes. Dr Prem Rashid. Uronorth Group, Port Macquarie, 2006. This Australian book, written by a urologist, covers prostate cancer comprehensively and other prostate problems.

About nomograms

Why do we need them?

Prostate cancers come in many different forms: some are 'lazy'—low 'risk' or slow growing cancers. Others are faster growing. It is important to be able to predict a tumour's growth pattern, because we can treat high risk cancers more aggressively and more effectively.

Clinical stage, Gleason score, PSA level and even the speed at which PSA increases, separately, tell a little about how aggressive a tumour is. But combined, they give us an even better idea. They can be combined in risk groupings such as those in Table 4, or combined in a graphical device which predicts a particular result such as return of the cancer. These devices (nomograms) are drawn up based on the experience of many thousands of patients, usually drawn from US hospitals.

What do they look like?

Figure 6 shows what a nomogram looks like for prostate cancer. It shows that the person's pre-treatment PSA, clinical stage, Gleason score, radiation dose and use of hormones are all important in determining the treatment result. The figure seems complicated at first but we give an example to take you through it step by step.

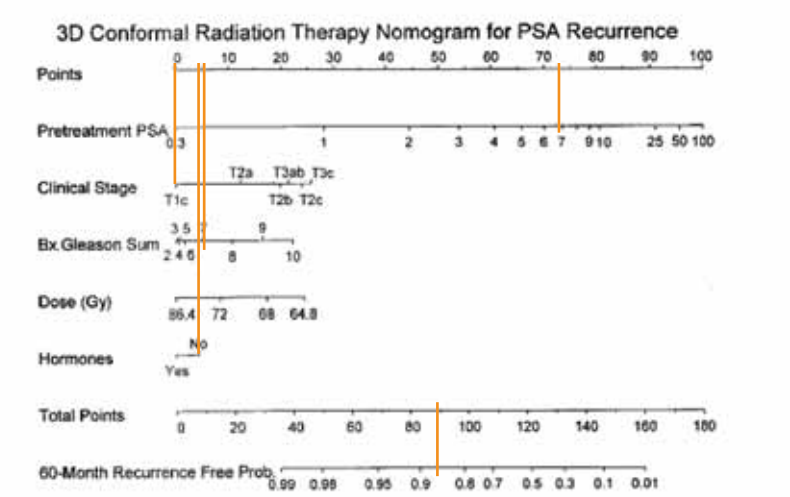
In this example, a man has:

- stage T1c prostate cancer (doctor can't feel it at rectal examination)
- a pre-treatment PSA of 7
- Gleason score of 7
- He is treated with radiation alone and no hormone therapy (androgen ablation).

Dose of radiation is also an important factor: the higher the dose, the more successful the treatment. Doses of 74Gy are commonly used in Australia.

Use a ruler placed vertically on the diagram to link the PSA line to the top line (points). This is shown in orange in Figure 1. Repeat this for his stage, Gleason, dose and treatment. Used this way, the figure says he will get 73 points for a PSA of 7, 0 points for having a T1c cancer, 6 points for a Gleason score of 7, 5 points for 74Gy and 5 points for having no hormones. This gives a total point score of 89. The total point score (second bottom row) is plotted against the bottom row. This estimates his probability of being free of cancer at five years as 0.86, which is the same as an 86% chance.

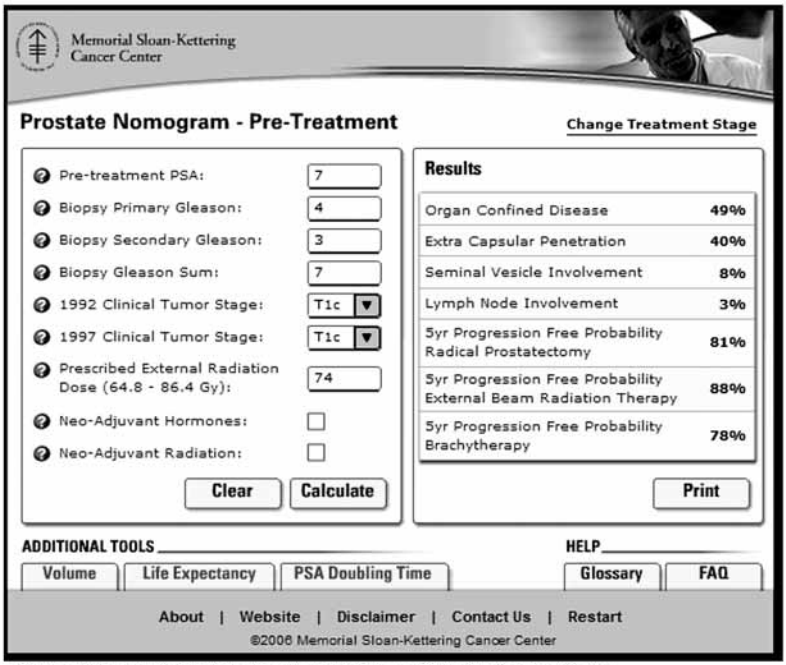
Figure 6: Nomogram calculation: orange lines show how the nomogram is used for the hypothetical example given in the text



Reprinted with permission from the American Society of Clinical Oncology. Kattan, M.W., et al., Pretreatment nomogram for predicting the outcome of three-dimensional conformal radiotherapy in prostate cancer. Journal of Clinical Oncology., 2000. **18**(19): p. 3352-9.

Another way of using a nomogram is available at the Memorial Sloan Kettering Cancer Centre's website at www.mskcc.org/mskcc/html/10088.cfm. This nomogram is designed for use prior to treatment. Figure 7 shows results for the same hypothetical patient with PSA 7, Gleason 7 and clinical stage T1c cancer. However we also needed to enter the primary and secondary Gleason scores (see Appendix 2), which clinical staging system was used, and whether a treatment such as hormone therapy or radiation had already been used (neo-adjuvant means used prior to the main treatment).

Figure 7: Nomogram calculation: screen showing results of an internet-based nomogram calculation for the hypothetical example given in the text



Printed with permission from the Memorial Sloan-Kettering Cancer Center

This time the results show the chance of organ confined disease, involvement of other organs, and the chance of remaining free of progression at five years, if you have either radical prostatectomy, surgery or brachytherapy. The estimate of 88% freedom from cancer progression at five years is similar to the 86% estimate from the top nomogram.

Nomograms can be used to give an indication of the risk posed by a particular cancer and therefore can be a useful guide to the best treatment approach. However it should be emphasised that most are based on the experience of patients treated in very large US hospitals and the results in Australian hospitals may not be the same. Also, some of the information needed may not be available to you. For this reason and to assist with interpreting nomograms we recommend you work through the calculation with your doctor and discuss the meaning of the results with them.

A record of your prostate cancer

You may find it useful to record the clinical details of your cancer at diagnosis to refer back to in the future. Ask your doctor to help you complete this.

Date of diagnosis...../...../.....

PSA level at diagnosis.....

Clinical cancer stage (from the DRE) .....

Cancer grade (Gleason score, from the biopsy)

..... +..... = ... (Gleason Total Score)

Explanation

Cancer stage indicates how far the cancer has spread. Clinical stage is found by rectal examination

DRE: digital rectal examination
The doctor feels the prostate by placing a finger in the rectum. See Chapter 2, page 17

Gleason score: a cancer grading system
It indicates how abnormal the cancer tissue looks. This is related to how rapidly the cancer is likely to grow: see Chapter 2, page 20 and page 23

PSA level: prostate specific antigen
The PSA level (amount in the blood) can give an indication of the amount of cancer present. See Chapter 2, page 16 and Chapter 3, page 23

Glossary: what does that word mean?

Most of the words listed here are used in this book; others are words you are likely to hear used by doctors and other health workers.

adjuvant therapy A treatment given in conjunction with or shortly after another treatment to enhance its effectiveness.

advanced prostate cancer Prostate cancer that has spread to neighbouring tissues or has spread to other parts of the body such as the skeleton.

anaesthetic A drug given to stop a person feeling pain. A 'local' anaesthetic numbs part of the body; a 'general' anaesthetic causes temporary loss of consciousness.

androgens Male sex hormones. The most active male hormone, testosterone, is produced by the testicles. Other male hormones are produced by the adrenal glands.

androgen deprivation therapy In prostate cancer, treatment with drugs that minimise the effect of testosterone in the body. This type of therapy can slow or stop the growth of prostate cancer. Also called androgen ablation.

angiogenesis The formation of new blood vessels to support tissue. Angiogenesis enables tumours to develop their own blood supply, which helps them to survive and grow.

anti-androgens Drugs which slow the growth of prostate cancer by blocking the action of the male hormone, testosterone, in the prostate.

anus The opening at the end of the rectum through which faeces pass to the outside.

autologous (blood) Where the donor and recipient are the same. You can donate your own blood before prostate surgery so that it is available if you need a transfusion.

benign Not cancerous.

benign prostate enlargement Non-cancerous enlargement of the prostate. An overgrowth of normal prostate tissue. It is caused by a condition known as benign prostate hyperplasia.

biopsy Removal of small pieces of tissue for examination. When prostate cancer is suspected, tissue samples are taken from different areas of the prostate, then examined under the microscope to see if they are cancerous.

bladder The hollow organ that stores urine.

bone scan A test in which a radioactive chemical is injected, then x-rays trace its path throughout the body. The chemical is concentrated in areas where there is increased bone activity, such as areas of cancer, infection or arthritis. Bone scans can be unreliable because they are not particularly specific, and so are often used to give guidance, rather than answers, to a problem.

brachytherapy Radiotherapy given from within the prostate. Low dose brachytherapy involves the insertion of radioactive seeds directly into the prostate, which are retained. High dose brachytherapy involves the temporary insertion of radioactive substances into the prostate.

cancer A class of diseases characterised by uncontrolled cell division and the ability of these cells to invade other tissues, either by direct growth into adjacent tissue (invasion) or by migration of cells to distant sites (metastasis).

CT (also CAT) scan Computerised axial tomography: a series of x-ray pictures are taken in a circle around the body and are processed by a computer.

catheter A hollow, flexible tube through which fluids can be passed into the body or drained from it.

cells The 'building blocks' of the body. A human is made of millions of cells, which are adapted for different functions. Cells are able to reproduce themselves exactly, unless they are abnormal or damaged, as are cancer cells.

chemotherapy The killing of cancer cells with cytotoxic chemicals (cytotoxic means toxic to cells).

clinical staging Staging of prostate cancer by digital rectal examination.

clinical trial A trial of a new treatment, conducted by medical researchers on patients who have agreed to take part. Clinical trials must be conducted ethically and in keeping with internationally accepted principles.

confined to In the example of prostate cancer, when we say that the cancer is 'confined to' or 'confined within' the prostate, we mean that cancer cells have not spread from the prostate gland into other tissues or organs.

cryotherapy A method of killing cancerous cells by freezing the tissue.

cytoscopy A procedure in which an instrument is introduced along the urethra under local or general anaesthetic, to view the bladder and prostate.

cytotoxic Any substance which affects cells in a negative way. This term is commonly used to describe medications used to kill cancerous cells in the body.

DEXA scan Dual-energy x-ray absorptiometry: used to measure bone mineral density, for example in men considering hormone treatment.

digital rectal examination (DRE) An examination of the prostate through the wall of the rectum. The doctor inserts a finger into the rectum and feels the shape of the prostate. Irregularities may be caused by cancer.

doubling time The time taken for the PSA level to double, for example from 4ng/ml to 8ng/ml. It is a measure of how fast the cancer is growing.

dry ejaculation After a radical prostatectomy, a man may achieve orgasm, but produce no ejaculate (fluid). This is because the glands which produce much of the fluid in the ejaculate are removed. See also reverse ejaculation.

dysuria Difficult or painful urination.

ejaculate Fluid produced at ejaculation, which contains sperm and secretions from the prostate, seminal vesicles and testicles.

epididymis A long tube which lies atop each testicle, functions as a reservoir of sperm produced by the testes and carries the sperm into the vas deferens.

erectile dysfunction Inability to achieve an erection firm enough for penetration.

erection When the penis becomes enlarged and rigid.

external beam radiotherapy (EBRT) Radiotherapy given from a source outside the body.

fertility The ability to conceive children naturally.

free to total PSA ratio In both healthy men and those with prostate cancer, the prostate specific antigen (PSA) in the bloodstream can 'latch' onto protein. This is called 'bound' PSA. In men with benign prostate enlargement, there tends to be more 'free' or 'unbound' PSA. This test compares the ratio of unbound PSA to total PSA in the bloodstream.

five-year survival rate A scientific measure used to determine the success of a treatment, because it is hard to know if someone is cured or not. It measures the number of people who are alive five years after a particular treatment. It does not necessarily mean you will only live for five years after having treatment.

gene The tiny factors that govern the way the body's cells grow and behave. Each person has a set of many thousands of genes inherited from both parents. Genes are found in every cell of the body.

Gleason score A way of grading cancer cells. Low grade cancers (Gleason score 2, 3, 4) are slower growing than high grade (Gleason scores 8, 9, 10) cancers. The pathologist identifies the two most common tissue patterns and grades them from 1 (least aggressive) to 5 (most aggressive). The Gleason score is given as two numbers added together to give a score out of 10 (for example, 3 + 4 = 7). The first number is the most common pattern seen under the microscope and the second number is the next most common.

grade/grading A score which describes how abnormal the cancer cells look, and consequently how aggressive or fast-growing the cancer is likely to be. The most commonly used grading system is the Gleason score (see above).

gray (Gy) An international unit of radiation dose expressed in terms of absorbed energy per unit mass of tissue.

HIFU High intensity focused ultrasound. A method for killing cancer cells. The high intensity ultrasound is focused in the prostate, causing heat, which kills the tissue.

hormone resistance Prostate cancer cells are dependent on testosterone or male hormone for growth. Withdrawal of male hormone by surgery or by means of drugs is therefore a means of controlling its growth. However cancer cells may develop which do not need testosterone for growth. The cancer is then said to be `hormone resistant'.

hormones Natural chemical substances that are produced by one body organ, and travel through the bloodstream to other organs where they exert their effects. A well-known example is insulin, which regulates the blood sugar level.

hot flush A sudden rush of heat to the face, neck, sometimes chest and back. It can be associated with hormone therapy for prostate cancer.

impotence See erectile dysfunction.

incontinence Involuntary passing of urine (urinary incontinence) or faeces (faecal incontinence).

indolent Means 'lazy', usually referring to the type of cancer cells which grow only slowly.

infertility Inability to conceive naturally.

intermittent hormone therapy Hormone therapy which is started and stopped in cycles. Typically, it is continued for several months until PSA has reached a low level, and then discontinued. Once the PSA level in blood rises to a particular level again (and this can take many months), hormone therapy is re-started. The main expected benefit in this approach is reduction in side effects.

luteinising hormone releasing hormone (LHRH) agonist A substance that resembles LHRH, which controls the production of sex hormones. The LHRH agonists keep the testicles from producing testosterone.

libido Sex drive.

localised prostate cancer Prostate cancer which is at an early stage, and has not spread beyond the prostate gland.

locally advanced prostate cancer Cancer which has spread beyond the prostate capsule and may include the seminal vesicles, but is confined to the prostate region. Stage T3, or C.

locally recurrent Cancer that has recurred (come back) after treatment, but which is confined to the prostate or nearby tissues only.

lower urinary tract symptoms (LUTS) Symptoms related to the flow or passing of urine, such as poor stream, frequent urination, needing to get up at night two or more times to urinate, incontinence and incomplete emptying of the bladder. Often caused by benign enlargement of the prostate, but can also be caused by advanced prostate cancer.

lymph nodes Also known as lymph glands. Small, generally pea-sized pieces of tissue found all over the body but easier to feel in the neck, armpits and groin. They act as filters for foreign substances and commonly become inflamed if there is an infection nearby. They can also harbour cancer cells that have spread from elsewhere.

magnetic resonance imaging (MRI) A way of imaging the inside of the body using magnetic forces and without using x-rays.

malignant Cancerous.

medical oncologist A specialist in the treatment of cancer using chemotherapy.

metastasis/metastasise The spread of cancer away from the place where it began.

monitoring The process in which patients are followed up after initial diagnosis and treatment. It may include clinical examination and/or the regular performance of tests.

nadir The lowest PSA reading after treatment for prostate cancer, before the PSA starts to rise again. This can occur some months after radiotherapy to cure prostate cancer.

neo-adjuvant therapy Treatment given before another treatment to enhance its effectiveness.

nerve-sparing operation Surgery for prostate cancer which aims to preserve the nerves which are needed for erections. These nerves are on either side of the prostate gland. The technique is not always possible because cancer can affect the areas around the nerves.

oncologist A specialist in the treatment of cancer (see medical oncologist and radiation oncologist).

orchidectomy (also orchiectomy) An operation that removes the testicles, but leaves the scrotal sac or scrotum.

osteoporosis A condition that affects bones, making them thinner and weaker than normal and liable to fracture and break.

palliative care Care of people whose disease does not respond to curative treatment. The goal of palliative care is to achieve the best possible quality of life for the person and their family.

pathologist A doctor who specialises in the examination of cells and tissue removed from the body.

pelvic The area of the body located below the waist and surrounded by the hip and pubic bones.

penis Male reproductive organ: the body or shaft starts deep inside the body and extends externally to the end of the penis at the glans.

perineal (perineum) The area of body between the anus and the scrotum.

pituitary Part of the brain that produces hormones which stimulate the testicles to produce testosterone (male hormone).

potency The ability to have and maintain erections firm enough for penetration.

priapism A painful, prolonged erection lasting three or more hours.

primary cancer The original cancer. At some stage, cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form.

prognosis The course and likely outcome of a disease, as estimated by a person's doctor or treatment team.

prostatectomy An operation to remove all or part of the prostate.

prostate cancer: localised—confined within the prostate gland; locally advanced—contained within the prostate region but extending beyond the prostate gland and may include seminal vesicles; advanced—cancer has spread to adjacent organs such as bladder, rectum, pelvic wall; metastatic—cancer has spread to distant parts of the body such as bone.

prostate gland The gland that sits just below the bladder and opens into the urethra. It produces a fluid that forms part of semen.

prostate specific antigen (PSA) A protein produced by the cells in the prostate, which is usually found in the blood in larger than normal amounts when prostate cancer is present. It can be used as a test for prostate cancer or to monitor its recurrence.

PSA bounce Temporary rise in PSA reading during the first 18 months after brachytherapy to cure prostate cancer. The cause is not well understood.

PSA velocity How quickly the PSA rises. Measured in nanograms per millileter per year.

prostatitis Inflammation of the prostate. It can be caused by bacteria.

psycho-social Referring to the emotional, psychological, social and spiritual aspects of life.

quality of life Your overall appraisal of your situation and your wellbeing.

radiation Energy in the form of waves or particles, including x-rays. This energy can injure or destroy cells by damaging their genetic material. This ability is 'harnessed for good' when it is used in radiotherapy.

radiation oncologist A specialist in the treatment of cancer using radiation techniques.

radical prostatectomy An operation which removes the prostate, part of the urethra, a small part of the vas deferens and the seminal vesicles. This is usually done through a cut in the lower abdomen.

radiotherapy The use of radiation, for example, x-rays, to kill cancer cells.

rectum The last part of the bowel, leading to the anus, through which faeces pass.

recurrence The re-occurrence of cancer some time after it was first treated.

remission (Also known as complete response) The term used when, after treatment, there is no sign of any cancer. It is not necessarily the same as 'cure', as some cancer cells may be hidden. In partial remission, signs of the disease process have partly resolved but have not disappeared completely.

response A change in the size or extent of the disease due to treatment.

reverse ejaculation Also called retrograde ejaculation. This may occur after surgery for benign conditions of the prostate. The ejaculate travels back into the bladder instead of exiting through the penis. This means a man is usually infertile (cannot produce offspring in the conventional way), but he can still achieve orgasm.

robotic prostatectomy Minimally invasive surgery to remove the prostate. Small cuts are made in the abdomen. Surgery is conducted using telescopic instruments inserted through these cuts and controlled remotely by the surgeon with the aid of a computerised 'robot'.

salvage treatment Treatment, in prostate cancer usually radiotherapy, to try to destroy cancer cells that escaped the initial treatment.

screening Testing an at-risk population for an illness, to find people who have the illness, although they don't yet have obvious symptoms.

scrotum A pouch of skin which contains the testicles and some other parts of the male reproductive system. It hangs outside the body and behind the penis.

secondary cancer See metastasis.

semen The fluid ejaculated from the penis at sexual climax.

seminal vesicles Glands that lie very close to the prostate and produce secretions which form part of the ejaculate.

stage/staging The process of determining the extent of the disease. A system for describing how far the cancer has spread. The most common is the TNM system described in Appendix 1.

stress incontinence Uncontrolled loss of a small amount of urine as a result of any strenuous activity, laughing, coughing, sneezing or lifting heavy objects.

stricture Scar tissue which obstructs fluid flow; in the case of a urethral stricture, urine flow is obstructed.

surgical margins After a radical prostatectomy, the edges of the tissue which has been removed are examined to see if cancer cells are present. If they are not (negative surgical margins) the chance is higher that all of the cancer has been removed.

survival—disease free The proportion of people surviving without evidence of disease to a given time, such as five years.

survival—prostate cancer specific The proportion of people who do not die of prostate cancer in a given period, such as five years.

survival—biochemical The proportion of people surviving without an increase in PSA levels (this can be defined in different ways) in a given time, such as five years

testicles Organs which produce sperm and the male hormone, testosterone. They are found in the scrotum.

testosterone The major male hormone. It is produced by the testicles.

tissue A collection of cells.

TNM system A system for staging cancer, depending on the size and invasiveness of the tumour, whether lymph nodes are affected, and whether there is metastasis.

transrectal ultrasound (TRUS) A means of imaging the prostate. It is used to guide a biopsy needle that samples the prostate in order to investigate prostate cancer. The ultrasound probe is placed in the rectum.

transurethral resection of the prostate (TURP) A common operation for benign enlargement of the prostate, but only occasionally used to treat prostate cancer. An instrument is inserted, under anaesthetic, along the urethra (urine tube) and removes prostate tissue which may be blocking the flow of urine.

tumour Any abnormal growth of tissue. In the context of cancer, the word usually refers to malignant (cancerous) lumps of tissue.

urethra The tube which carries urine and ejaculate along the length of the penis and to the outside of the body.

urologist Surgeons who specialise in treating urogenital tract diseases.

vas deferens Ducts that take sperm to the urethra on ejaculation.

watchful waiting Not treating a disease, but monitoring it to see whether or how fast it is worsening.

x-ray A form of electromagnetic radiation.

Steering committee members

Below is an alphabetical list of members of the Steering Committee, convened by the Australian Prostate Cancer Collaboration (APCC), which produced this edition.

Don Baumber, Convenor, Gold Coast Prostate Cancer Support Group

Kate Dunlop, Project Manager, Centre for Genetics Education, University of Sydney

Mark Frydenberg, Clinical Associate Professor, Department of Surgery, and Chairman, Department of Urology, Monash Medical Centre, Melbourne; also Chair, Urological Oncology Committee, Urological Society of Australasia

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A final word

A final word from a prostate cancer survivor who talks about the road ahead.

'There can be life, good life after prostate cancer. That's the story that all men need to know. In summary, I think there are three things that are most important:

- Put yourself into a position of advantage: look after your diet, exercise, laugh a lot and learn to relax.
- Have a strong positive attitude and plan for the future, some long and short term goals. You have got some good life left yet.
- Surround yourself with the love and support of others and pass it on. You will live longer, happier and more fulfilled.

'I believe I have beaten my cancer. That's my story and I'm sticking to it. If perchance it does reappear down the road somewhere, well, I can handle that too, in the same way I might have to deal with a heart attack or arthritis or just old age. In the meantime, life goes on and I am going to live it to the full ...

'Who knows what medical science will come up with in the future. They have new significant breakthroughs all the time. Yes, there are some good years left yet!'

– Barry Oakley, *There's Some Good Years Left Yet. The Experience of a Prostate Cancer Survivor*. Published by the Prostate Health Improvement Program, Repatriation General Hospital, Daw Park, 1999.

Copies of this guide can be obtained from:

- the Cancer Council Helpline run by each state cancer council: telephone 13 11 20 from anywhere in Australia
- online at www.prostatehealth.org.au

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