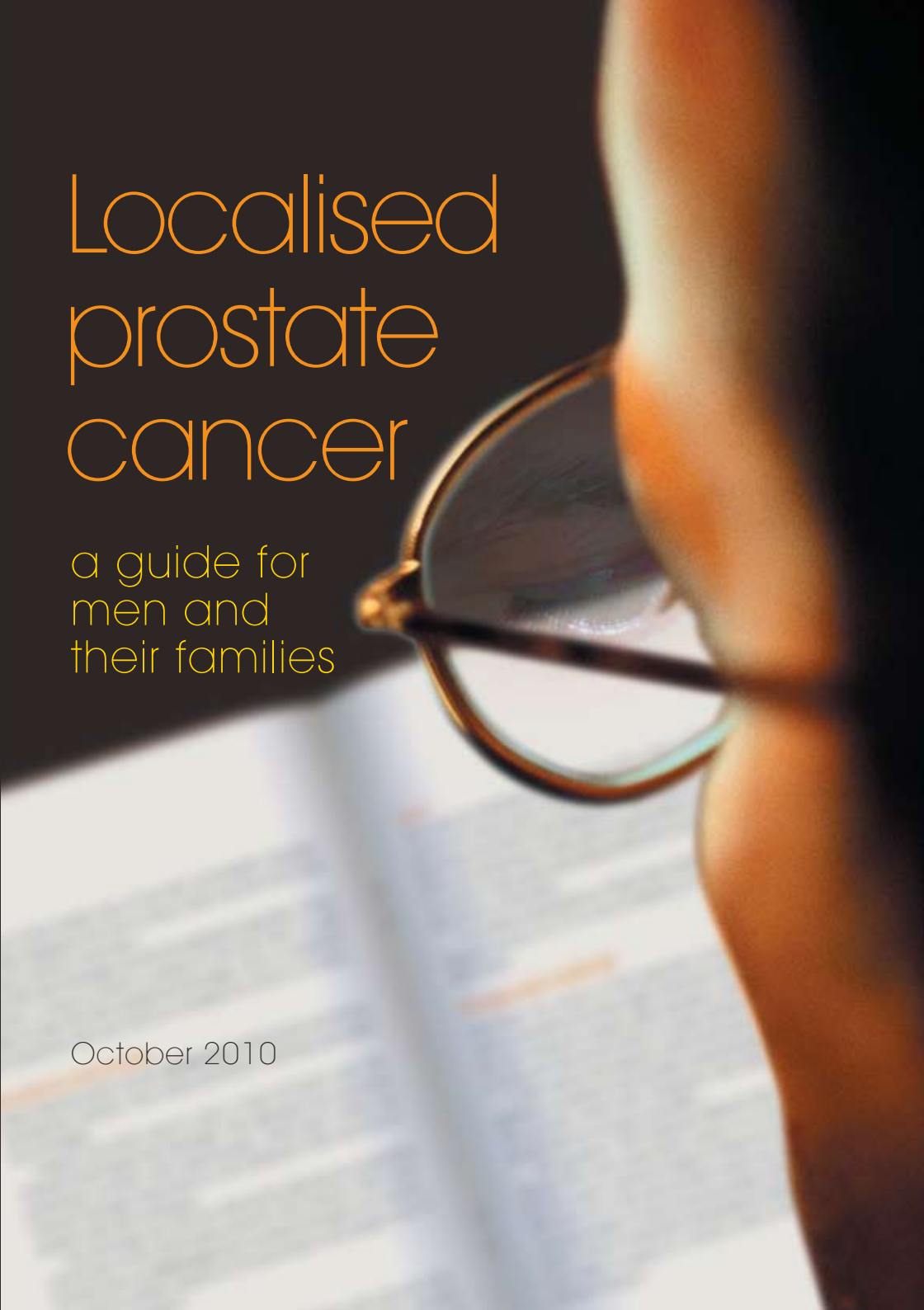
Localised prostate cancer

a guide for men and their families



October 2010

First published in December 2001 by the Australian Prostate Cancer Collaboration
Fourth edition October 2010

ISBN 0-9579938-1-1

About this guide

This is the fourth edition of this guide. Originally produced in 2001, the guide underwent minor revision in 2003, more substantial revision in 2006 and has been updated again, in 2010. It is based on the *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) originally produced by the Australian Cancer Network (ACN) in March 2003. The original 2001 consumer version was produced by a multidisciplinary committee convened by the ACN and the Australian Prostate Cancer Collaboration. This 2010 update has been produced by the ACN with input from the Urological Society of Australasia and the Prostate Cancer Foundation of Australia. It draws on international evidence-based clinical practice guidelines listed on page 102 (see Appendix 4: Resources). It has been disseminated through these organisations, the cancer councils in each state and territory, the national Cancer Council Helpline, the Repatriation General Hospital in South Australia and Andrology Australia. We are grateful to all of these organisations for their support of this widely-used resource.

Copies can be obtained from the cancer council in your state or territory (phone 13 11 20), or from Andrology Australia (1300 303 878).

Acknowledgment

The production of the fourth edition of this guide has been generously funded by the National Seniors Foundation Trust and the CM and JA Whitehouse Foundation. The National Seniors Foundation Trust promotes medical research, education and charitable work for the benefit of senior Australians. We are grateful to the members of the working group, as well as men with prostate cancer and their families, who have so generously contributed their time to this edition.

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 GP or specialist may provide them with new or different information that is more appropriate to their needs.

Cover and book design by Con Stamatis, courtesy of Cancer Council Victoria.
Editing and layout by Cancer Council Victoria. Step diagram by BTS International.

Foreword to the fourth edition

This is the fourth edition of this consumer guide, which was first produced in 2001. About 10,000 copies are distributed each year to urologists, the state and territory cancer councils, the Prostate Cancer Foundation of Australia and Andrology Australia. This edition has been updated by the multidisciplinary working group listed on page 123. Updates are consensus based and referenced to evidence-based clinical practice guidelines. It is our hope that the guide will continue to help men understand the complex issues raised by prostate cancer treatment, and make the best treatment decision possible, supported by their family and medical team.

This guide may be helpful to any man affected by prostate cancer and his family. It is particularly designed for men who have localised prostate cancer (cancer which has not spread beyond the prostate gland). It explains what localised prostate cancer is, the treatment options and their pros and cons. Its purpose is to help men make decisions about these treatments.

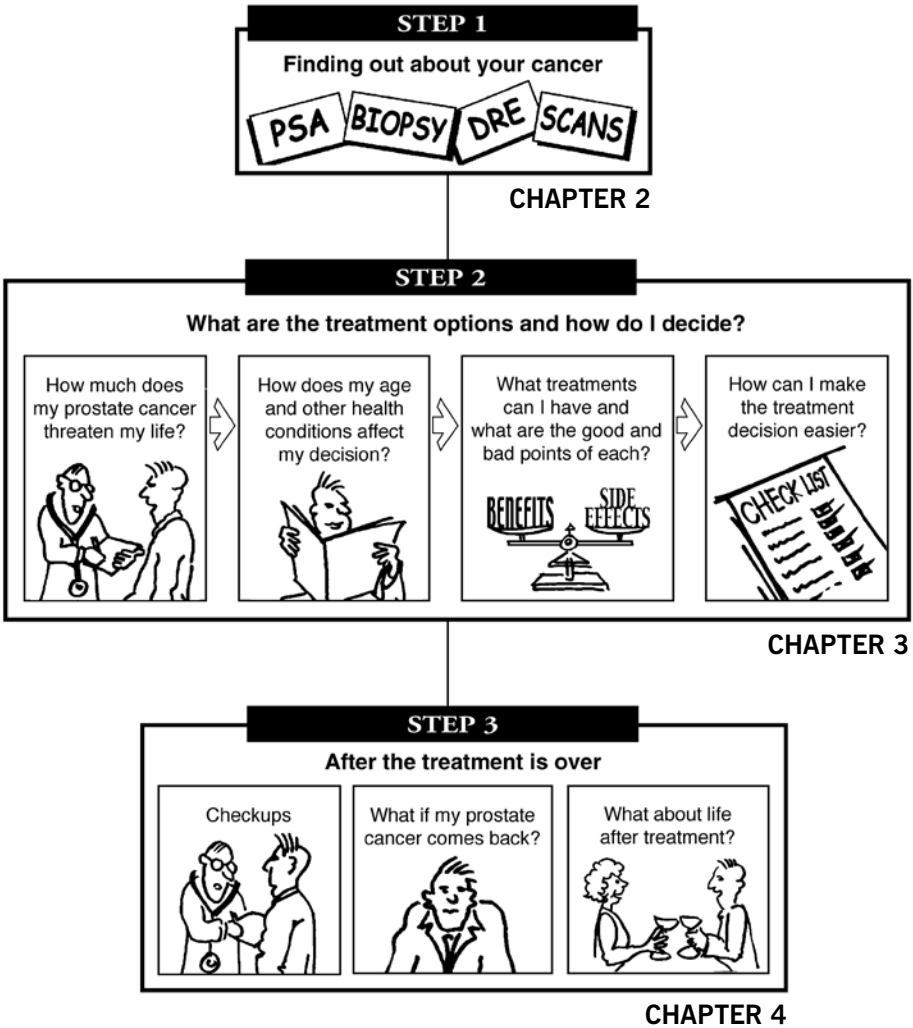
This guide does not discuss screening for prostate cancer using the prostate-specific antigen (PSA) test or treatment for advanced prostate cancer. For more information on advanced prostate cancer refer to the companion volume: Advanced Prostate Cancer: A Guide for Men and Their Families. For other topics, 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 control it and in some cases offer cure. Prostate cancer entails uncertainties, but it is also a cancer that many men live with for many happy and productive years. We hope this guide will help you work through the issues and achieve that goal.

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

Key points

- *The prostate is a small gland that forms secretions for semen.*
- *Prostate cancer is uncontrolled growth that starts in the ducts of this gland.*
- *It is the second most common cancer in Australian men: over 17,000 are diagnosed annually.*
- *Men with a father or brother diagnosed with prostate cancer are at increased risk of the disease.*
- *Prostate cancer can spread but is curable if still confined to the prostate.*
- *Difficulty with urination is normally due to benign prostate disease. Early prostate cancer does not usually have symptoms.*

Cancer is now an extremely common diagnosis: about one in three Australians are affected by it. However, cancer is not the risk it once was. We have made enormous gains in our ability to cure and control it, and many improvements have been made in the treatment of prostate cancer.

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

- there are rarely symptoms in the early stages
- it usually grows slowly and for some men it may not become a problem and need treatment
- treatment can have unwanted effects, especially on sexual function

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

- the choice of treatment is not clear-cut: we can't always be sure which treatments are best
- early treatment offers the best chance of cure but it is still difficult to establish when early detected cancers have spread beyond the prostate and are controllable but not curable.

After you receive a diagnosis, you may want to start with a little information and then, step by step, find out more before you reach 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 explains where you find the answers in this guide.

Your doctor will probably go through your test information with you. It may be useful to record this information in the back of this guide.

As you read through the guide, 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.

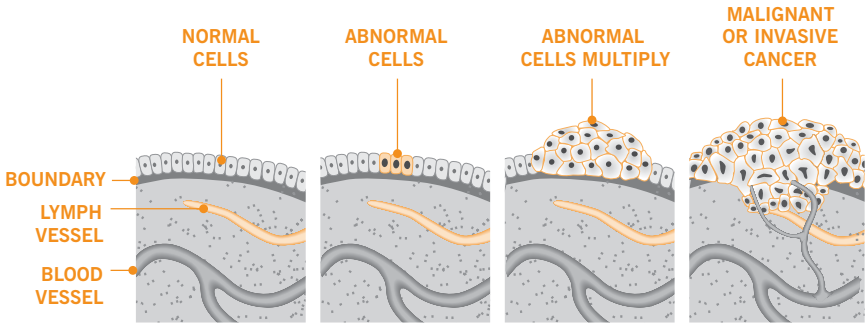
What is cancer?

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, a 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.

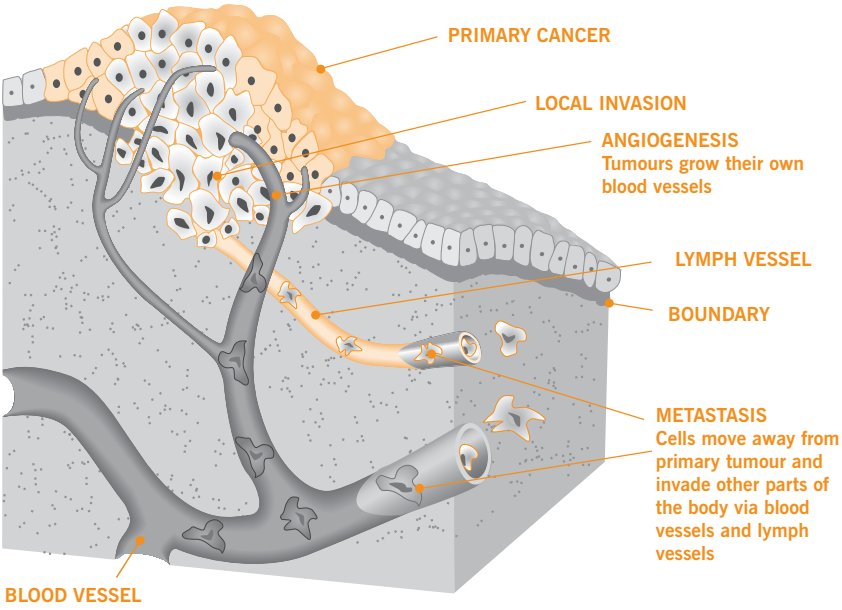
Figure 2: The beginnings of cancer



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

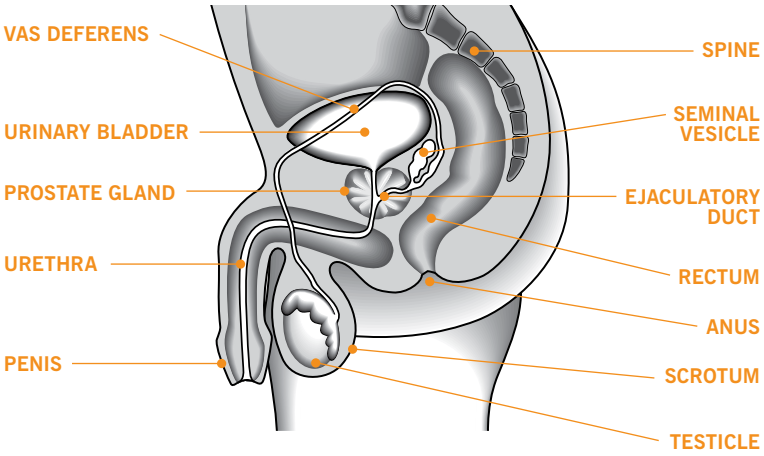


What is prostate cancer?

The prostate is a small gland about the size of a walnut and is 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 guide 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 not become **advanced prostate cancer**. This guide 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 advanced or metastatic prostate cancer, see the companion book: *Advanced Prostate Cancer: A Guide for Men and Their Families* (in Appendix 4: Resources).

How common is prostate cancer?

Prostate cancer is the most common cancer in Australian men (except for skin cancer). More than 17,000 men were diagnosed with it in 2006 and an estimated 20,000 will be diagnosed in 2010. These increases are mainly due to increases in testing. Approximately 3000 men die of the cancer in Australia each year and this number is not increasing.

Prostate cancer is very age-dependent. More than two-thirds of all new prostate cancers are diagnosed in men aged 60 to 79 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). Among 1000 Australian men, about 193 could be expected to be diagnosed with it before age 80 years, but far fewer (about 23 men) would die of it[1]. 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 fifth after heart disease, lung cancer, stroke and lower respiratory tract diseases[1]. Recent increases in the number of men tested for prostate cancer mean that the number diagnosed with it has also increased. Men diagnosed at a very early stage do not necessarily need active treatment; we discuss the treatment option of **active surveillance** in Chapter 3.

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

For 1000 men in this age group, the number diagnosed with prostate cancer is:

Age (years)	Risk
40–49	2
50–59	24
60–69	73
70–79	94
80–89	93

Note: data from AIHW 2009[1] based on incidence rates in 2006

Can I inherit prostate cancer?

Prostate cancer develops when cells in the prostate grow in an abnormal way as described on page 9. 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. The 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].

You can't inherit prostate cancer, but you can inherit faulty cancer protection genes. Several inherited **genes** that seem to raise prostate cancer risk have been identified. These probably account for less than 10% of all prostate cancer cases diagnosed in Australia. Studies have shown an aggregation of breast and prostate cancer in some families. Certain inherited genes raise the risk for more than one type of cancer. For example, inherited mutations of the BRCA1 or BRCA2 genes raise the risks of breast and ovarian cancers in some families. Mutations in these genes, particularly in BRCA2, may also increase prostate cancer risk in some men, but they appear to account for a very small percentage of prostate cancer cases[4].

What are the risk factors for prostate cancer?

While we are learning more about the risk factors for prostate cancer, there is still a lot we are not sure about, for example how to reduce your risk of getting prostate cancer.

As we say above, an important risk factor, apart from age, is your family history.

We do 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. 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 cooked tomatoes) have been shown to reduce the risk of prostate cancer in some studies. Vitamin D has been shown to protect against the growth of prostate cells in the laboratory, however population studies, mainly in America and Scandinavia, have shown mixed results on the association between vitamin D and prostate cancer in humans. A Mediterranean style diet, with its high content of cooked tomatoes, is thought to be protective.

Eating a diet low in animal fat and high in fruit, vegetables and legumes (beans) 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 low animal fat makes a lot of sense. There are many health benefits from this kind of diet.

'I've eaten tomatoes for 55 years of my life and it certainly didn't prevent me from getting prostate cancer'.

Does localised prostate cancer spread?

Localised prostate cancer may spread outside the prostate, but still remain in the prostate region (**locally advanced prostate cancer**). It may 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 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 prostate 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.

Later stage prostate cancer may cause the symptoms listed above plus:

- 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

Key points

- *A diagnosis can come as a shock; however, prostate cancer is not the risk it once was.*
- *Talking to others with prostate cancer can be reassuring.*
- *Support groups can put you in touch with men who have experienced a wide variety of treatments and disease stages and will be willing to discuss their experiences with you.*
- *The prostate-specific antigen blood test and digital rectal examination indicate the likelihood you may have prostate cancer.*
- *A biopsy is needed to be sure.*
- *Scans tell you whether the cancer has spread to other parts of the body.*
- *Results of these tests give the grade (how abnormal the cells are) and stage (how far it has spread).*
- *Combining these will tell the doctor just how much of a threat this cancer is.*
- *Urologists and radiation oncologists treat prostate cancer Other professionals are on the care team too.*

After the diagnosis

When you are first told you have cancer it can be a shock. You may find it difficult to hear what the doctor is saying and may not take much in. It is important to realise that cancer is not the risk it once was. We have made enormous gains in our ability to cure and control it and this particularly applies to prostate cancer. You need time to take in the information, think about it and discuss it with your family. You do not need to make a decision about treatment that day; some men take

several weeks to make a decision. It is important to remember that, after the decision and subsequent treatment, most men eventually return to feeling normal.

'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.'

After a diagnosis it can be helpful to talk to another man who has also walked this path. This can help you form a personal idea of what lies ahead, find useful resources and see that while life may change after cancer, it can still be full and rewarding. There are prostate cancer support groups all over Australia; most can connect you one-to-one with a man who has had a similar experience with prostate cancer. If you want to join a support group, you can find one in your area: see the Prostate Cancer Foundation of Australia website: www.pcfa.org.au or call the Cancer Council Helpline on 13 11 20. The Cancer Council can also tell you about Cancer Connect, where you can be put in touch with someone who has been through a similar cancer experience. Ensuring you have enough information, and using strategies such as meditation and relaxation, can also help.

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. Taking your partner or someone close to you to a medical appointment can help you remember items as well as being helpful to your partner. Partners may also find support groups helpful because they can talk to other partners. 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) may be valuable (see Appendix 4: Resources).

How is it diagnosed? What are the tests?

At present, the main way of diagnosing prostate cancer is with a **biopsy**. This involves removing a sample of prostate tissue so it can be assessed by a pathologist. Occasionally men are also diagnosed with cancer after having an operation on the prostate called a **transurethral resection of the prostate** or TURP, where cancer is found unexpectedly in the tissue removed.

Before proceeding to a biopsy, most men will have had the following tests.

Blood test: prostate-specific antigen (PSA)

The initial test that is carried out to attempt to diagnose prostate cancer is the 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. In general, the higher the level of PSA, the greater the chance that a cancer will be found on **biopsy**. This risk is continuous: the lower the level, the lower the risk, but there is no level without a small risk of prostate cancer.

A high PSA reading does not always mean you have cancer. It can mean you have other prostate conditions such as **benign prostate enlargement** (a non-cancerous condition), inflammation or an infection in the prostate.

Refinements of the PSA test can help distinguish these other causes of PSA increases. Age-based normal ranges are sometimes used to take into account increases in PSA levels due to ageing and **benign** conditions. A measure called **free to total PSA** is also helpful for this purpose. PSA can be found in the bloodstream on its own (known as 'free PSA' and 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 ratio (free PSA/total PSA) is then calculated. It is usually expressed as a percentage. This ratio can be used to predict the risk of cancer and is particularly useful in men with enlarged prostates that feel benign. Low ratios (less than 15% free to total PSA) indicate a higher risk of a cancer while higher ratios (greater than 20% free to total PSA) can be reassuring.

A low PSA reading does not necessarily mean cancer is not present. In an important study called the Prostate Cancer Preventions Trial, participants were biopsied regardless of their PSA level. Prostate cancer was found in 15% of men with a PSA below 4 ng/ml (usually taken as 'normal')[5]. Some cancers don't produce much PSA, and so can grow quite large while the PSA levels stay low. For this reason a **digital rectal examination** is usually done as well as a PSA test, to increase the chance that these low-PSA tumours will be picked up.

For these reasons, the meaning of a PSA level prior to biopsy may be difficult to interpret at times.

The absolute level of PSA at which a biopsy may be recommended varies for each patient and depends on age, prostate size, family history, change in PSA over time and, crucially, the findings on the digital rectal examination (see below). Two online risk calculators are available which bring these factors together into a single risk estimate (see Appendix 5: About nomograms). However, these tools need to be used with caution and in discussion with your doctor.

Once the diagnosis is made, PSA is a very useful test to monitor the outcome of treatment. The test can also provide

your doctor with an indication of the extent of the disease. Table 4 (see page 26) gives the probability of cancer being **confined to** the prostate at different PSA levels.

Digital rectal examination (DRE)

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

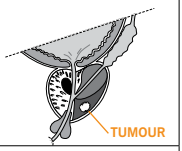
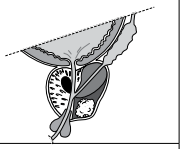
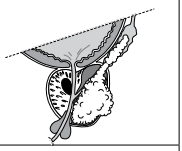
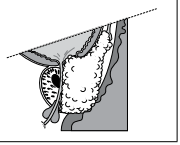
The prostate is located just in front of the rectum, so your doctor can insert a gloved finger into your rectum and feel the size of your prostate through the rectal wall. This test may feel uncomfortable, but should not be painful. DRE can give an idea of how big the prostate cancer is and if there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

Some prostate cancers cannot be felt on DRE (clinical stage T1) and can only be detected using the **PSA** test. Conversely, it is important to realise that some cancers may only be detectable by a DRE, so if a DRE is not performed, the cancer may be missed.

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 help your doctors work out 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 correlate well with the actual tumour size when the gland is removed by surgery.

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: Staging and the TNM system.)

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 may feel the cancer but it does not appear to have spread beyond the prostate 
T3	The cancer 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 an index finger, is placed into your **rectum**. Ultrasound shows the shape and the nature of your prostate on a screen. The ultrasound does not identify areas of cancer, but ensures that samples are taken reliably from different parts of the gland.

Local **anaesthetic** is injected around the prostate prior to the biopsy and this makes the procedure more comfortable. Some urologists use sedation or general anaesthetic. As more biopsies are taken from the prostate now than in the past, the need for some form of anaesthetic is important. Ask your doctor what kind of anaesthetic he or she will use before the procedure.

At biopsy, a small needle is inserted through the rectal wall into your prostate. At the initial biopsy, usually 12 samples of tissue are taken from different parts of the prostate. Some urologists may recommend that the biopsies are taken through the **perineum** (the area between the **scrotum** and the **anus**). This method is better able to sample from the front part of the prostate, and so may find some cancers which would be missed by the trans-rectal route. The perineal technique is more likely to require sedation or anaesthesia.

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 a serious infection develops. A small amount of bleeding from the back passage, some blood in the urine or blood staining of the **ejaculate** usually occurs 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 see if cancer is present. If it is, the pathologist will 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. (See Appendix 2: The Gleason grading system.) The lower your **Gleason score**, the less aggressive your cancer is likely to be. The 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
6 or less	Low
7	Medium
8–10	High

Prostate cancer is sometimes found after a **transurethral resection of the prostate** (TURP). This operation is 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.

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 known 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 **computerised tomography** (CT or CAT) **scan** is a fairly simple scan. It takes about an hour. A dye is injected into a vein in your arm and you drink a fluid which provides images of all your pelvic organs including your prostate. It has the potential to detect spread to **lymph nodes**. Unfortunately, it does not detect small amounts of cancer, making it a relatively insensitive test. However, it is very important for planning **external beam radiotherapy**.

MRI scan

Magnetic resonance imaging (MRI) is increasingly used to identify local spread of the cancer outside the prostate gland before **surgery**. It uses a powerful magnetic field to produce pictures of the internal organs, bone and soft **tissues**. Sometimes an MRI coil is placed within the **rectum**. You then go into the 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.

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 for five to 10 years or cured. 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, PSA level and stage

Risk	Grade, PSA level and stage*	Chance prostate cancer is confined to the prostate
Low	Gleason 2–6 and PSA less than 10 T1c T1 T2a	High
Medium	Gleason 7 or PSA 10–20 T2b –T2c	Moderate
High	Gleason 8–10 or PSA >20 T3a	Low

**For an explanation of T stages, see Appendix 1: Staging and the TNM system*

Doctors can also estimate these chances using devices called **nomograms**. These are mathematical prediction tools based on the experience of many hundreds of patients. We explain nomograms and their uses in Appendix 5.

Who is on the care team?

As a first step, your GP will probably refer you to a specialist called 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**, doctors who specialise in treating diseases of the urogenital tract using **surgery** (in men the urogenital tract 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 they are 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. Urology nurses may also be your care coordinator, if multidisciplinary care is available in your hospital (see below).
- Other professionals, including psychologists, physiotherapists and social workers.
- Multidisciplinary care. Some city hospitals offer multidisciplinary 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. It can increase your access to services and ensure your care is well coordinated. Your care coordinator (often a nurse) will explain the process to you. This type of care is not available in all states.

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

Deciding on a doctor

Choosing a doctor you feel comfortable with and can talk to 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 prefer specialists who deal with them as equals, discussing all options with them and assisting them to make the final decision, while 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 practise. 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 best. Speaking to both **urologists** and **radiation oncologists** can be helpful.

You can talk to other men who have had various treatments at your local prostate cancer support group.

Communication between doctors occurs at different levels. Ask your specialist doctors to talk with your GP. This will make sure he or she is kept up to date with your treatments and results.

Your GP 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 GP to refer you to another specialist. If someone you know has seen a specialist whom they recommend, ask your GP for a referral. When you see the second doctor, take a summary from your 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.*

What are the treatments and how do I decide?

Key points

- *There is a lot to understand at your first consultation. It helps to prepare: take someone with you, write down questions and make a longer appointment. We give other suggestions, too.*
- *To choose a treatment, you and your doctor need to consider how much of a threat the cancer is, your state of health, the different treatment options and their side effects.*
- *Your preference is important and it is usually okay to take time with the decision.*
- *The main approaches are active surveillance (deferring treatment until the cancer progresses), surgery and radiotherapy. There are different types of surgery and radiotherapy.*
- *Each treatment will have side effects and these could affect your bladder, erectile function and sometimes bowel function.*
- *Your doctor will explain which treatments are suitable for your particular cancer and explain the pros and cons of each.*
- *You may want to get more background information or see more than one type of doctor before you decide.*

Before you see the doctor

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, so you can ask your doctor at your next visit.

If you have not yet had a **biopsy**, ask the specialist if you can have some detailed information about the treatment options if the biopsy is positive. This means you will have had the chance to consider the options before you receive a cancer diagnosis. Men often find it difficult to focus on treatment details once they are informed they have cancer. Being a little prepared may help you to understand more fully what is said at the next appointment.

If you do not speak English very well, you may like to use a qualified interpreter, rather than a family or staff member. Ask your GP how you can access a qualified interpreter for your appointment with the specialist.

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.

Be careful about information you can get on the Internet. We have suggested some sites; however, not everything 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 which 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 what your doctor says about your risk of a certain thing happening, ask for it to be explained it another way.

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

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 see doctors who are specialists in the different types of treatment. Some centres offer multidisciplinary care (described on page 27). It is also important to think about the quality of your life after you have had treatment and to let your doctor know what is important to you. Your preferences are an important part of the decision.

Your doctor will work with you towards a decision. They 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 (see 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 31.5 years (see Table 5), whereas a man aged 80 has an average life expectancy of 8.3 years. A man with a serious health condition such as heart disease or diabetes will have a shorter life expectancy than the average. However a man with no significant medical problems will often live longer than 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	79.2
At 50 years	31.5
At 60 years	22.7
At 70 years	14.8
At 80 years	8.3

Note: from Australian Bureau of Statistics 2009[6]

If you are relatively young (and thus 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 five to 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. A number of treatment options can be considered:

1. No treatment and only return if symptoms develop
2. Active surveillance
3. Surgery
4. Radiotherapy (including external beam radiotherapy and brachytherapy)
5. Other treatments including androgen deprivation (hormone) therapy

In the next 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.

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

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.

1. No treatment (watchful waiting)

Some men, particularly elderly men with low-risk cancers and other major health problems, may decide against aggressive treatment and seek help only if they develop symptoms of more advanced disease such as bone pain. Some doctors call this approach **watchful waiting**. The type of treatment which can be used should symptoms develop is 'androgen deprivation' or 'hormone' therapy. We discuss this on page 59.

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[7].

2. Active surveillance

We know that many men who are diagnosed with prostate cancer will not die from prostate cancer or get symptoms that bother them. This is especially the case for men diagnosed with low-risk disease. Elderly men, particularly those older than 75 years, are less likely to die from prostate cancer. A recent study compared men with low and medium risk cancer on **active surveillance** with similar men who had active treatment. It found that the prostate cancer death rate was higher in the active surveillance group: 3.6% over 10 years in those undergoing surveillance compared with 2.7% in the active treatment group[8].

Younger men are often 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. If the cancer shows signs of faster growth or aggressiveness, active treatment can begin.

For this approach to be appropriate, given our current knowledge of the natural history of prostate cancer, men need to take part in a carefully designed follow-up program with frequent PSA tests and periodic repeat prostate biopsies. The details of such a program will be discussed with you by your specialist.

Should you choose active surveillance, the signs that you may need to reconsider this approach include:

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

The drawback of this approach is the risk that your cancer, if left untreated, can progress so that it extends beyond the prostate area and is less easily cured: hence the need for very careful follow-up. In some studies, about 30% of patients on active surveillance were reported to need active treatment[9]. Of these patients, 50% had a cancer **recurrence** after active treatment. If this happens, 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.

The PRIAS study (Prostate Cancer Research International: Active Surveillance) is an international study collecting data on patients offered active surveillance with strict entry criteria and **monitoring** protocols. It may soon be available in Australia.

Table 6 gives symptoms of patients three years after starting active surveillance in an Australian study[10]. In some of these

patients the cancer progressed and they consequently had active treatments, including hormone therapy (see page 59). The high rates of **impotence** in this group reflect the outcome of patients who went on to have active treatment, as well as those who had no active treatment but were impotent due to other causes.

Table 6: Symptoms from a study of NSW patients three years after beginning active surveillance

Urinary incontinence*	3%
Moderate or severe bowel problems†	6%
Impotence‡	54%

** Needing to wear one or more pads per day to control urinary leakage*

† Response to the question 'Overall, how big a problem have your bowel habits been?'

‡ Being unable to obtain an erection sufficient for sexual intercourse

Table 7: Good and bad points of having no initial treatment (active surveillance)

Good points	Bad points	Patient most likely to benefit
Fewer side effects than treatment	Your cancer could spread outside your prostate when treatments are less effective or cure is no longer possible	Low risk: small size tumour 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	Prefer to have no treatment

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

3. Surgery

The aim of **surgery** is to remove all your cancer. Although this is relatively major surgery, it usually only requires between one and three days in hospital. The shortest hospital stay is for a type of keyhole surgery performed with a robot (see page 41).

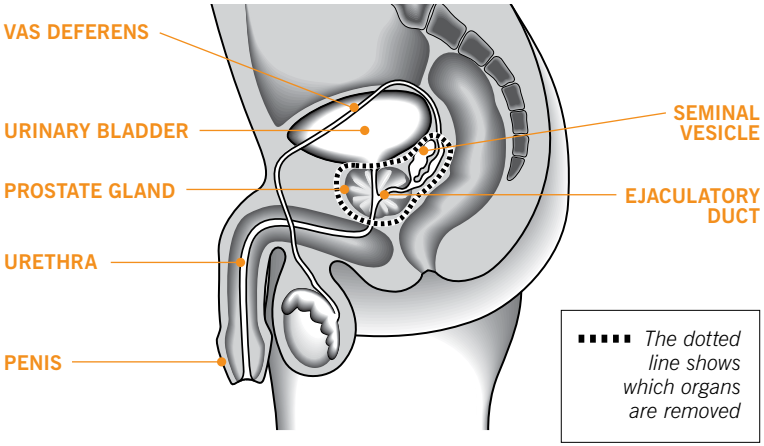
Surgery is a good option if you have **localised prostate cancer**, are fit for surgery, expect to live longer than 10 years and have not yet had **radiotherapy**.

Will it cure me?

Surgery may cure prostate cancer if the cancer is localised or **confined to** the prostate at the time of treatment. The problem at present is that it is not possible to be sure of this. We can, however, estimate the chance that it is still contained within the prostate and the chance of a cure. To do this, we use new tools called 'nomograms'. One commonly used nomogram[11] 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: About nomograms.)

The results of surgery are very good, with 47% to 75% of men living cancer-free for 10 years or more[12]. The chance is better (75%) for patients with low-risk cancer. Cancer **recurrence** after surgery may mean that the cancer was no longer confined to the prostate at the time of surgery, rather than that the surgery was unsuccessful. As mentioned above, a trial of surgery versus active surveillance for men with **localised prostate cancer** suggested that after 10 years, men who had surgery were less likely to die from prostate cancer and would live longer than those who did not[7].

Figure 5: Radical prostatectomy



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.

What happens when I have surgery?

If you have a **radical prostatectomy**, your surgeon will remove the prostate. With it will come the part of your **urethra** that runs through the prostate and a small part of the vas deferens, which also passes through the prostate. The surgeon will also remove the **seminal vesicles** next to the prostate. The dotted line in Figure 5 shows exactly what will be removed.

Sometimes your surgeon may take out some **lymph nodes** near your prostate to see if the cancer has spread. If the nodes contain cancer, then the surgeon may recommend further treatment because the cancer is no longer localised. There is still some uncertainty whether an extensive removal of lymph nodes that possibly contain cancer will provide better cure rates.

After removal of the prostate, your urethra will 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 be emptied into a toilet. Men normally need a catheter for a week after **surgery**. Occasionally they need it for up to three weeks.

After the catheter is removed, it is normal to have some **urinary incontinence** (loss of urine control). This usually lasts for a short time but can be ongoing. You should receive help from hospital staff to prepare for this.

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

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. Sometimes these can be left in place because there is no cancer near them (this is called a **nerve-sparing operation**). If so, your chance of returning to your pre-operation **potency** is greater. Age is also

a factor affecting the return of erections. Older men are less likely to achieve their pre-treatment erection strength.

Following a radical prostatectomy, men may notice that their **penis** is a little shorter. While the reason for this has not been firmly established, it is likely that damage to nerves running close to the prostate or interruption to blood supply is the cause.

For most prostate cancer surgery, the surgeon makes the initial cut through the lower abdomen. It could also be made close to the **anus**, called a **perineal** approach; this type of approach is rarely used in Australia.

More recently, urologists have been able to offer **laparoscopic** (keyhole) surgery. It may involve using a robot (**robot-assisted laparoscopic prostatectomy**). With this type of operation, telescopic instruments are inserted through six small **incisions** in the abdomen. The surgeon controls the movement of the instruments remotely, assisted by a 'robot'. The robot also provides a magnified view of the operation field. You are positioned in a steep 'head down' position for a robot-assisted laparoscopic prostatectomy and this can occasionally cause **anaesthetic** complications.

Like all new procedures, the surgeon will have a 'learning curve' for this operation, achieving the best results after about 200 operations[13]. The advantage of this 'keyhole' approach is shorter time in hospital and less blood loss[14].

At this time, however, it is too early to know whether this type of surgery will have better or worse results with regard to erectile function, continence and cure. The early results suggest that the short-term outcomes are very similar for both robot-assisted and open prostatectomy. It will be a number of years before we know whether there are any significant

differences in long-term outcomes. Choosing an experienced surgeon in whom you have confidence and trust may be the best approach if you decide on surgery.

What is the outcome of surgery?

The results of treatment can be measured in three ways, by the percentage of men who over a given period:

- remain cancer-free
- do not die from prostate cancer
- do not die 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% were still free of cancer, after 10 years between 70% and 80% were still free of cancer, and after 15 years 60% of men were still cancer-free[15] (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 survived (did not die from) the disease, after 10 years this figure was 90% to 96%; and after 15 years the figure was between 81% and 82%[15] (figures rounded to nearest 5%).

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, low **Gleason score** and low **PSA**; see Table 4). Surgery will not cure cancer which has spread outside the prostate and is not removed during the operation. A recent trial compared surgery and watchful waiting. Its results suggested that the number of deaths from

any cause was greater in the watchful waiting group[7]. It also found that after 10 years, 14.9% of men in the **watchful waiting** group had distant metastases compared with only 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[16]. Other aspects of quality of life were similar.

One important factor to consider is that currently, because of frequent PSA testing, men tend to be diagnosed at an earlier stage with smaller cancers. Thus data from studies that are even 10 years old may not be entirely relevant as a guide to what may occur in men diagnosed today. This means you need to have detailed discussions with your specialist about the possible risks of complications, taking into account your age, the stage of your disease and the nature of the treatment.

What are the side effects of surgery?

The most common side effects (complications) of prostate surgery are listed in Table 8. They 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 (less than 0.5%) that you could die as a result of the surgery.

Incontinence

Minor **urinary incontinence** (a small loss of urine caused by exertion, for example, laughing) can occur in up to 40% of men after **surgery**. Severe, persistent urinary incontinence is much less common (about 5%). When the **catheter** is removed, it is normal to have temporary incontinence which requires the use of pads. If incontinence continues in the long term there are a number of ways of improving it (see Chapter 4). Strengthening the muscles of the **pelvic floor** with exercises both before and after surgery can help prevent minor incontinence. A trained physiotherapist or urology nurse can help you with this.

Problems with erections

Men are less likely to have problems with erections after **surgery** if they had good sexual function before the operation, if they are younger, if their cancer is still small and if they underwent a **nerve-sparing operation**. A nerve-sparing operation is only possible if the cancer has not spread along the nerves, however. Most studies report **erectile dysfunction** (impotence) rates of 40% to 80% following surgery. It takes time for the nerves to recover and most men do not have any activity for the first six to nine months. After that, erections may improve for up to three years post-operatively. This process can be speeded up with programs such as 'penile rehabilitation', where aids such as medications and injections are used to create erections during the recovery period (see Chapter 4 for ways of improving erectile problems after surgery). The side effects of surgery tend to improve with time after your operation.

The results of surgery have continued to improve as surgeons become more experienced. Studies show that the more radical prostatectomies a surgeon does, the better the results (fewer complications and the greater chance all of the cancer is removed)[17, 18, 19]. 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[17].

Table 8 shows the percentage of patients who experienced symptoms after surgery in a NSW study[10]. It should be remembered that patients may have had these symptoms before surgery: about 20% have **impotence** for example.

Table 8: Symptoms after surgery from a study of NSW patients three years after radical prostatectomy

	Nerve-sparing surgery (%)	Non-nerve-sparing surgery (%)
Urinary incontinence*	9	15
Moderate or severe bowel problems†	4	3
Impotence‡	68	87

* *Needing to wear one or more pads per day to control urinary leakage*

† *Response to the question 'Overall, how big a problem have your bowel habits been?'*

‡ *Being unable to obtain an erection sufficient for sexual intercourse*

Table 9: Good and bad points of surgery

Good points	Bad points	Patients most likely to benefit
You may be able to remove all the cancer Immediate, rapid fall in PSA Lower rates of bowel problems compared to radiotherapy	Greater risk of long-term problems with erections (impotence) No ejaculation at orgasm Infertility	Cancer confined to the prostate Low-risk cancer: early stage, small cancer Low PSA
Side effects usually get better with time and there are treatments for side effects	Higher rates of incontinence immediately after surgery Moderate long-term rates of incontinence	Life expectancy (apart from cancer) more than 10 years
Treatment completed in one day	Not suitable if you have other serious illnesses such as heart disease	Prefer to have surgery

4. Radiotherapy

The aim of **radiotherapy** is to kill all your prostate cancer cells using **x-rays**.

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

Will it cure me?

Radiotherapy may cure prostate cancer if the cancer is **confined to** the prostate or nearby at the time of treatment. The problem at the present time is that it is not possible to be sure of this. As for **surgery, nomograms** can be used to estimate the chance of this. Radiotherapy may be more effective than surgery at curing cancer which has spread outside the prostate but is still contained within the prostate region (stage T3). Having radiotherapy immediately after surgery (called adjuvant radiotherapy) in these situations has been shown to improve the average length of life by two years[20].

The results of radiotherapy are very good and most men live free of disease for 10 years or more (see 'What is the outcome of EBRT?' below). 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** for prostate cancer. In **external beam radiotherapy**, the **radiation** comes from a source outside the body; in **brachytherapy** (also called interstitial radiotherapy) the radioactive source is placed in the prostate. Generally, cure rates for both are similar.

External beam radiotherapy (EBRT)

This is a common form of treatment for prostate cancer. Recent comparisons of **surgery** and **radiotherapy** based on a patient's cancer **stage**, **grade** and **PSA** level suggest that the long-term outcomes of surgery and radiotherapy are similar.

EBRT focuses **radiation** from a machine (a 'linear accelerator' or 'linac') onto the prostate. It is carefully aimed, to minimise the effect on healthy body **tissues**.

It is important to note that you are not 'radioactive' during or after EBRT, and can still cuddle your partner and your grandchildren. Men only spend an hour or so a day in the radiotherapy department. At other times they can go about their normal activities including driving.

There are several steps before EBRT begins.

The first step is to determine the position of the prostate. A modern way of doing this is by using **image-guided radiotherapy** (IGRT). Sometimes this is done by inserting **fiducial markers** into the prostate. These markers, known as **gold seeds**, are not radioactive and are placed into the prostate by the urologist or radiologist. It is similar to a biopsy and is usually performed with a local anaesthetic. The seeds may incur a cost: ask your doctor about this.

The position of the prostate is determined by referring to the position of the gold seeds. The prostate position can change daily depending on the amount of gas in the rectum and the amount of urine in the **bladder**. In some centres, rather than using seeds, the marking is done with x-rays.

The next step involves scanning the prostate (**simulation**). This can be done with a **CT scan** or **MRI**. It helps to determine the exact position of the prostate and other normal tissues so

that the radiation can be aimed accurately and avoid normal tissue. To make sure that the same area is treated each time, the radiation therapist will make some marks on your skin. These marks will be made up of lines, crosses and dots drawn with special inks.

EBRT is an outpatient procedure, which means you do not need to be admitted to hospital. Usually, you will have radiotherapy five days a week for seven to eight weeks. It takes about 15 minutes but you may be in the department for up to an hour. The amount of radiation given will depend on the size and type of your cancer and your general health.

Most centres offer three-dimensional (3-D) conformal radiation therapy. With this technique the radiation beams are shaped to match the **tumour**. Newer types of therapy called **intensity modulated radiotherapy** (IMRT) and **volumetric arc therapy** (VMAT or IMAT) are available in many centres in Australia. These new techniques decrease the radiotherapy dose received by normal cells, and can increase the dose to the cancer. This may result in fewer side effects and higher chances of cure compared to older types of EBRT. Ask your radiation oncologist if you will be receiving image-guided radiotherapy and intensity modulated radiotherapy.

If you have a medium or 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 begin three to eight months before radiotherapy and may continue for two to three years. By starting hormone therapy before radiotherapy, the hormones can kill cancer cells,

making the job of radiotherapy easier. This type of '**combined modality therapy**' has been shown to improve cure rates and **survival** in patients with medium and high-risk prostate cancer[21]. However it will have side effects (see page 59).

What is the outcome of EBRT?

The long-term cure rates after EBRT are believed to be the same as the cure rates after **surgery**. However, it is not possible to make good direct comparisons between **radiotherapy** and surgery because of **selection bias**. This bias occurs because patients selected to have surgery usually have more favourable features: the cancers are often smaller and patients are often fitter.

One very large study (a pooled analysis of nine US centres with almost 5000 patients[22]) 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. However these figures are from patients treated 15 years ago, and the type of radiotherapy and doses delivered are no longer in use today. Also none of the patients had hormone therapy. Modern radiotherapy with **intensity modulated radiotherapy, image-guided radiotherapy** and hormone therapy has been shown to give similar five-year cure rates to surgery[23]. Using doses of radiotherapy currently given, 10-year cure rates have been reported to be about 85%[24].

The figures from studies of modern radiotherapy doses show that the chance of dying from prostate cancer is less than 5% at five years[25]. One study showed that less than 2% of patients died of prostate cancer at 10 years[24].

Nomograms that are used for patients having surgery and older types of radiotherapy (see Appendix 5: About nomograms) may not be helpful for patients having modern radiotherapy. These nomograms are not based on techniques and doses used in current practice. They also may not include high-risk patients who have hormone therapy after radiotherapy.

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). Modern radiotherapy using **intensity modulated radiotherapy**, **volumetric arc therapy** and **image-guided radiotherapy** is much better focused on the prostate compared to the older types of radiotherapy given a few years ago. These newer techniques are better at avoiding the **bowel** and **bladder**, which means that the risks of side effects are much lower.

You are not 'radioactive' either during or after receiving EBRT. Nausea and vomiting rarely occur.

Even modern radiotherapy still has a small risk of side effects. There are short-term side effects that might 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 and they usually resolve within a few weeks of completing radiotherapy.

Long-term effects: Many men may find they slowly develop problems with erections (**erectile dysfunction**) after they have radiotherapy. This is due to a combination of radiotherapy

side effects and the men getting older. This can be helped in a number of ways. These are described in more detail in Chapter 4.

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

There is a small risk of second cancers in the long term after radiotherapy [26].

Table 10 gives the percentage of patients who experienced symptoms after radiotherapy in a NSW study[10]. It should be remembered that patients may have these symptoms before treatment; for example, about 20% have **impotence**. Long-term side effects often improve by themselves.

Table 10: Symptoms after radiotherapy in a study of NSW patients three years after treatment

	External beam radiotherapy (%)	Low dose rate brachytherapy (%)
Urinary incontinence*	3	5
Moderate or severe bowel problems†	15	0
Impotence‡	68	36

** Needing to wear one or more pads per day to control urinary leakage*

† Response to the question 'Overall, how big a problem have your bowel habits been?'

‡ Being unable to obtain an erection sufficient for sexual intercourse

One new way of treating some of the side effects of radiotherapy is **hyperbaric oxygen** (or HBO). This involves a number of daily treatments in a high pressure chamber. It has been shown to heal radiotherapy side effects affecting the **rectum** and bowel, including bleeding[27]. Hyperbaric oxygen is available in most Australian capital cities.

Table 11: Good points and bad points of external beam radiotherapy

Good points	Bad points	Patients most likely to benefit
Lower chance of long-term problems with erections (impotence) compared to surgery when the nerves are not able to be spared	Treatment involves daily visits on weekdays over a period of six to nine weeks	Cancer confined to prostate or nearby Low to medium and high-risk cancer (EBRT with or without hormone therapy)
Some effects get better with time and there are treatments for side effects	Some side effects may get worse with time	Life expectancy (apart from cancer) more than 10 years
Less immediate trauma to your body than when you have surgery	Greater risk of having bowel problems compared to surgery	Prefer to have radiotherapy
Less chance of urinary incontinence compared to surgery	You may be infertile	
There is a chance that it will kill any cancer that has spread just outside your prostate (i.e. EBRT can cure both early and locally advanced cancers)		

Availability of external beam radiotherapy

Public hospital **radiotherapy** is available in all major Australian cities and increasingly available in rural areas. Treatment in public centres is usually bulk-billed (i.e. there is no cost involved to patients having radiotherapy in a public hospital). As with **surgery**, it is known that the quality of radiotherapy treatment can vary. There is now good evidence that giving higher doses will improve cure rates. Australian public hospitals usually give a dose of 78 Gy. To be given safely, treatment needs to be accurately targeted with accurate localisation of the prostate, such as by using **image-guided radiotherapy**. Conformal radiotherapy is designed so that the **radiation** follows the shape of the prostate; the most conformal treatment is delivered using **intensity-modulated radiotherapy** or **volumetric arc therapy**. 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. The quality of care in public and private facilities is usually the same.

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

Many country centres have radiotherapy outreach clinics. Because of the extended period of treatment, some state governments and non-government organisations 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 is placed in the area being treated. This allows high doses of radiation to be given to the prostate and attempts to give lower doses to **tissues** close by, such as the **rectum**. Because the **urethra** is surrounded by the prostate in one section, it can receive high doses during brachytherapy, leading to side effects such as urine blockages.

There are two types of brachytherapy: 'low dose rate', in which radioactive seeds are permanently implanted in the prostate, and 'high dose rate', in which hollow needles containing radioactive materials are temporarily placed in the prostate.

Low dose rate, or interstitial brachytherapy, involves a minor operation during which doctors insert a small number of radioactive 'seeds', each about the size of a grain of rice, directly into your prostate. The seeds (up to 120) 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 radiation, which kills the cancer around them. 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 at least an overnight stay in hospital. 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 your urine 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. One of the disadvantages is that many men cannot be treated with brachytherapy because of the type of cancer, the size of their prostate, or because they have had prior **surgery** (such as **transurethral resection of the prostate** or **TURP**).

Babies and small children should not be held on the lap for two months after low dose rate brachytherapy because of the risk of radiation exposure.

Table 12: 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

Note: from NHMRC 2003. 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.

It is still too early for doctors to compare the **survival** rates of 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. Studies to date appear to show the results of brachytherapy are similar to the results of surgery and EBRT.

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 aims to deliver a high dose of radiation accurately to the prostate while minimising the dose to the normal surrounding tissues. A common approach is to give to give high dose brachytherapy first. This takes one to three days. Ten days later, EBRT begins and continues for five weeks. This is used for medium or high risk tumours. The doses delivered with high dose rate brachytherapy are similar to that used with **intensity-modulated radiotherapy** and **image-guided radiotherapy**. Studies appear to show the results of brachytherapy are similar to the results of surgery and EBRT.

What are the side effects of brachytherapy?

The procedure to insert the radioactive materials into the prostate can cause some discomfort. 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 relatively common but is usually a temporary side effect following **brachytherapy**. In the long term, blockages of the **urethra** can occur and may require surgical procedures to relieve the blockage. 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. If you are resuming sexual intercourse, use condoms for the first two weeks after the seeds have been implanted. This is in case a seed accidentally moves and is ejected in the **semen**.

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 low dose rate brachytherapy (seeds)

Advantages	Disadvantages	Patient most likely to benefit
Lower chance of problems with erections than other treatments	Not known yet whether long-term survival is as good as other treatments	Cancer confined to the prostate Low-risk cancer: small cancer, low-Gleason score, low PSA (<10)
For low dose rate brachytherapy, treatment involves only one visit, with short recovery time	Some evidence that survival is not as good for patients with medium to high risk of recurrence You may get some side effects months or years after treatment	Good urinary function No previous prostate surgery (e.g. TURP) Small prostate gland (<40 cc)
	You may be infertile Greater risk of having bladder problems compared to EBRT	Life expectancy (apart from cancer) more than 10 years
	High cost may be borne by patient (under review)	Preference for brachytherapy

Preserving erectile function

For younger men, preserving erectile function can be an important factor in their treatment decision. The ability to preserve erectile function is influenced greatly by the local stage of the cancer. The smaller the cancer volume and the lower the **Gleason score**, the more likely that all treatments can be focused with a greater chance of avoiding damage to the nerves and hence the preservation of erectile function.

Low dose rate **brachytherapy** appears to have the least impact on erectile function of any treatment, and if this is a key issue for a man, then he needs to ensure that he explores this option before making a final choice.

As we discuss in Chapter 4, during the recovery time, many specialists encourage the use of erectile aids such as medications and injections. There is evidence that the early introduction of these aids may improve long-term potency by assisting fresh, oxygen-carrying blood to get into the erectile cylinders of the **penis**. This keeps them healthier as the nerves recover. Treatments encouraging early recovery of erections in this way are called 'penile rehabilitation' programs.

5. Other types of treatment

Hormone therapy (androgen deprivation therapy)

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 chemically or surgically. The chemical method uses 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**

(male hormones) such as testosterone. The surgical method involves removing the testicles, the main site of testosterone production. Combinations of drugs may also be used.

As male hormones have many functions in the body, removing them can cause side effects. These 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[29]. 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 for men on hormone therapy.

Hormone therapy causes changes in the body's metabolism. It decreases the muscle mass and increases fat mass. Changes in the body's fat and sugar metabolism cause higher cholesterol and 'bad fat' levels increasing the risk of cardiovascular disease. Changes in sugar metabolism increase the risk of diabetes. Exercise and careful **monitoring** of risk factors can minimise some of these changes.

All types of hormone therapy have side effects, but they may differ. Ask the doctor who is prescribing the drug about side effects. Read the patient information you receive with the drug: it will describe the side effects in detail.

Hormone therapy on its own will usually stop prostate cancer growing. This **remission** can last for several years. However hormone therapy is not usually offered on its own for **localised prostate cancer**. It is more often added to curative treatments; for example it may be used with **radiotherapy**, if a cancer appears to be medium risk or high risk. In this situation, it is used for a fixed time period only.

Experimental treatments

Cryotherapy

Cryotherapy kills cancer cells by freezing them. It involves inserting an ultrasound probe into the rectum, and then passing needles containing a freezing gas through the perineum into the prostate area. Catheters inserted into the urethra contain a warming solution which protects this tissue. We know little about the effectiveness of cryotherapy as a primary treatment, although one study reported that 61% to 68% of patients remained **recurrence**-free at seven years[28]. **Erectile dysfunction** occurs in about 80% patients[12].

Cryotherapy could be chosen by patients who are eligible for surgery (i.e. cancer contained within the prostate). However we need to know more about the complications (erectile dysfunction and **incontinence**) and long-term likelihood of cure, before we can say if it is an effective alternative to **surgery**. Cryotherapy has also been used as a **salvage treatment** after **radiotherapy** (see below).

High frequency ultrasound (HIFU)

HIFU has been used as a primary treatment or when **radiotherapy** has not cured the prostate cancer and only local cancer spread has occurred. An ultrasound probe is placed in the **rectum** and a high energy beam is 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. Freedom from cancer **recurrence** has been reported as 63% at five years[12].

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% incidence).

HIFU is minimally invasive, but the same uncertainties exist as for **cryotherapy**. We don't yet have long-term data showing whether it is effective, 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 if HIFU does not work, we don't know for certain whether patients may be 'salvaged' using radiotherapy or surgery.

Focal therapy

This is a new approach. It attempts to remove small, individual areas of cancer from within the prostate with the aim of reducing side effects compared with radical **surgery**. It depends on all areas of cancer being detected in the **biopsy** so they can be treated. At this stage it is still experimental.

Adjuvant and neoadjuvant therapy

It is becoming common for hormone therapy to be given before **radiotherapy** to shrink the **tumour** before treatment. This is known as neoadjuvant therapy, which may be continued for as long as six months. Neoadjuvant therapy does not offer benefits before **surgery**.

Combined radiotherapy and hormone treatment may be particularly helpful for men with medium or high-risk or **locally advanced prostate cancer**. The benefits need to be weighed against the side effects. Hormone therapy may also be given for a period of time after radiotherapy. This is known as adjuvant therapy. We know that adjuvant hormone therapy used with radiotherapy can decrease the chance of cancer

recurrence and improve **survival**[30]. Both neoadjuvant and adjuvant hormone therapy may kill cancer cells, delay cancer recurrence and improve survival. Once the hormone therapy ends, **testosterone** levels usually return to normal.

Radiotherapy may also be given as an adjuvant treatment after surgery, usually within four months of surgery. This can be particularly useful if some prostate cancer cells remain after the prostate is removed (known as 'positive **surgical margins**'). It may also be recommended if the cancer is locally advanced (the cancer extends outside the prostate) or is a high-risk one, as described above. We cover treatment of locally advanced prostate cancer in more detail in the book *Advanced Prostate Cancer: A Guide for Men and their Families* (see Appendix 4: Resources). Locally advanced cancer is potentially curable with treatments such as radiotherapy with or without hormone therapy.

Salvage treatments

Salvage treatments are 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 radiotherapy after surgery is ideally given before PSA reaches 0.2 ng/ml.) Salvage surgery is not usually done after radiotherapy because of higher rates of erectile problems and **incontinence**. Other options for salvage after radiotherapy include hormone therapy, **chemotherapy** and experimental treatments such as **cryotherapy** and high frequency ultrasound (HIFU).

Salvage treatments are covered in the book Advanced Prostate Cancer: A Guide for Men and their Families (see Appendix 4: Resources).

Dietary approaches and weight

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) contribute to a higher risk of prostate cancer. Conversely, diets high in fruit and vegetables, which include anti-oxidants, such as lycopene (from tomato-based products), isoflavones (from soy) and green tea may be protective. Studies have suggested cruciferous vegetables such as cabbage and broccoli may be helpful.

While there is some evidence of association, no single nutrient has yet been shown to prevent prostate cancer or improve survival from it. Some dietary approaches promoted as therapeutic can actually do harm (an example is large doses of vitamin D, which can be toxic).

Recently, we have also learned that once men have prostate cancer, being overweight can affect how well they do. Very overweight men are more likely to have more advanced cancer and the disease is more likely to progress after treatment[31].

The period after treatment for **localised prostate cancer** presents a good opportunity to make changes to your lifestyle that may help your body fight the cancer. We discuss these in more detail in the book *Advanced Prostate Cancer: A Guide for Men and their Families* (see Appendix 4: Resources).

Complementary and alternative therapies

Men with prostate cancer often seek therapies apart from those recommended by their doctor. These are usually unproven and can include complementary and alternative therapies.

Complementary therapies are used *in addition to* standard therapy. Some complementary approaches have been tested in trials and have been accepted into standard care. These include acupuncture and meditation. Complementary therapies may help relieve symptoms of cancer, relieve side effects of cancer therapy, or improve your sense of well-being.

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; others are claimed to promote better quality of life. To date no alternative treatment has been shown to cure cancer.

Some alternative therapies, particularly those containing herbs, can cause problems. If you use herbs, ensure they are of good quality and that there has been no contamination during manufacture. You should be able to identify the substance clearly. It should be appropriately advertised: be alert to excessive claims. These substances are not regulated, so you need to take care if you choose to use them. Discuss any product you plan to take with your doctor before doing so. It is best to discuss any change in your treatment with your doctor.

See Appendix 4: Resources for contact numbers. The national Medicines Line 1300 633 424 provides consumers with independent information about prescription medicines, over-the-counter medicines, herbal and natural therapies.

Making a treatment decision and including your preferences

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 may take all your time. Understanding prostate cancer may involve understanding a whole new language. Overall there is no 'best' treatment and at present it is up to you to determine which treatment best serves your needs.

Before making a decision, you should be aware of all your options (including no treatment). Different specialists are better able to explain their own treatment to you. Ask your GP if you need a referral to a urologist or **radiation oncologist**.

Ask whether your case will be discussed in a multidisciplinary meeting. This type of meeting is a round-table discussion between specialist urologists, radiation oncologists, pathologists and other staff who will be involved in your care. These meetings can improve the outcomes of prostate cancer.

Your preferences, including 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 age and general health. Sometimes, however, the best treatment is not clear. You may need to choose between **surgery**, **radiotherapy**, or doing nothing for the time being. Your own preferences regarding the treatment, its side effects and how you feel these may affect your life and relationships are a very important part of your 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 others take 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 happier with their decision.

There is usually no rush to make a decision. Most men have time to consider options and talk to others. Ask your doctor if there is any urgency in your case.

How can I discuss the best treatment with my doctor?

Here is an example of how you and your doctor could work through the treatment options.

- Your doctor will tell you what level of risk your disease presents, and, based on your age and medical history, which types of treatments might be helpful.
- You can then discuss the potential advantages and side effects of each, and what your preference might be.

Table 14 is an example of how a doctor might present possible treatments and their pros and cons. He or she can point out what points are relevant to you. It may be helpful to talk to both a **urologist** and **radiation oncologist** to fully understand these options.

Table 14: Discussing treatment with your doctor

	Active surveillance	Surgery (open or robot)	Radiotherapy: low dose rate brachytherapy	Radiotherapy: external beam
May suit patients with	Very low-risk cancer Good access to doctor	Low or medium-risk cancer Young (70 or less) Otherwise healthy	Very low to low-risk cancer Young No urinary symptoms	Low, medium or high-risk cancer
May not suit these patients	Medium or high-risk cancer Rural or remote area Young patients (e.g. <60 years)	High-risk cancer Cancer has spread outside prostate Heart disease or other conditions	Medium or high-risk cancer Large prostate Previous prostate surgery*	Patients with some types of gastro-intestinal problems†
Potential advantages	No initial treatment side effects Low chance of progression if very low-risk cancer	Single procedure Can spare erection nerves in low-risk patients Can remove all cancer if still confined to prostate or nearby	Single procedure Lower risk of erectile problems Less invasive with a short hospital stay	Non-invasive Lower risk of incontinence, erectile problems Can kill cancer even if just outside of prostate
Potential disadvantages	Cancer may grow or spread while watching Ongoing tests, biopsies needed May be worrying	Higher risk of erection problems Higher risk of short and long-term incontinence More invasive and longer recovery	Higher risk of urinary symptoms such as low flow, urgent urination and blockages (strictures) Small risk of radiation exposure to others for two months	Treatment takes six to nine weeks Higher rates of bowel symptoms compared to surgery Some side effects may increase with time

* *Transurethral resection of the prostate*

† *Crohn's disease or ulcerative colitis*

Note: this table is for patients with localised prostate cancer. Advanced prostate cancer is covered in the book Advanced Prostate Cancer: A Guide for Men and Their Families.

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 guide).

- You need to know whether your cancer is actually a threat to you. Will it affect your health and well-being 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 GP. You are always free to seek a second opinion (see page 29).
- The cost and availability of treatment may be important to your choice. Some treatments, such as **brachytherapy**, may involve considerable cost and are not available in all cities. Ask about cost and availability before making a treatment decision.
- It may be helpful to:
  i. List each of the options that 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**, find accommodation and take 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 managed. Talk to people close to you, such as your partner, a close friend or the members of your local support group. You can also call Cancer Connect, a service of the Cancer Council that links you with men who have been through prostate cancer treatment.

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 shows you agree to have the treatment. This is called providing written consent. Giving consent means you understand the risks involved in the treatment, what may happen if you don't have the treatment and 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 for more information. 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 radiation therapist	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: Resources. 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.

Chapter 4

After the treatment is over

Key points

- *After treatment your progress is monitored with regular PSA tests and rectal examinations.*
- *Your PSA will drop rapidly after surgery but more slowly after radiotherapy as the prostate cells take time to die.*
- *A PSA above 0.2 ng/ml after surgery or 2 ng/ml above the lowest point after radiotherapy may indicate cancer is still present (there are some exceptions).*
- *If prostate cancer returns it can be treated with 'salvage' treatment: the type varies depending on the first treatment.*
- *You may find a number of things affect your social and emotional life after treatment. These can include symptoms such as incontinence and erectile problems.*
- *There are treatments that can help with the symptoms.*
- *Talking with others, including those who have experienced similar things, can help you adjust to these changes.*

Check-ups

Once your initial treatment is complete, your doctor will usually follow your progress with regular six-monthly to 12-monthly check-ups. These will probably involve measuring your **PSA** and an annual **digital rectal examination**. PSA tests to monitor progress after treatment are covered by Medicare. Your GP may perform these annual checks. Because there can be some variation between laboratories, it is important for your doctor to use the same pathology laboratories for the PSA tests.

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

The PSA will sometimes rise again after it has reached a low level. Usually this rise is not due to cancer, but due to normal prostate recovery. This small rise is called a 'bounce', and may occur any time in the first few years after radiotherapy. There may even be two bounces. After the bounce, the PSA will plateau, and often fall back down to very low levels.

The lowest level a PSA falls to is called the **PSA nadir**. Current evidence suggests that if the nadir is less than 1.2 ng/ml, there is a high probability of cure[32]. If the PSA rises to a level higher than the nadir + 2, this may indicate that prostate cancer is still present. Thus, if the nadir was 1.1 ng/ml, and the PSA rose to 3.1 (nadir + 2), this might indicate the cancer has returned.

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 **salvage treatment**.

Radiotherapy is the most common salvage treatment after **surgery** and may still cure the cancer if the PSA level is low (and especially if the PSA after surgery is less than 0.2 to 0.4 ng/ml).

Surgery is usually not done after **radiotherapy**. The risk of complications is high. This is because tissue damage after radiotherapy makes problems such as **erectile dysfunction**, blood loss, **incontinence** and damage to the **rectum** much more likely after surgery. If salvage surgery after radiotherapy is considered, you must discuss the risks and benefits with your **urologist** before proceeding.

Other experimental options that can be used after radiotherapy include **cryotherapy** and **high intensity focused ultrasound** (HIFU). HIFU may be suitable for some men.

More commonly, the next stage of treatment, if your cancer comes back, is **hormone therapy** (**androgen deprivation therapy**, see 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 or the person closest to you. We do not talk about hormone therapy as a stand-alone (or single) treatment in this guide. For more information on hormone therapy, see *Advanced Prostate Cancer: A Guide for Men and Their Families*, 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 most men will continue to lead productive, active lives. However, there are common problems after treatment, discussed below.

Relationships, sexuality and prostate cancer

As you get older, it becomes harder to have and maintain an **erection**. For some men, additional **erectile dysfunction** or impotence (not being able to have an erection), caused by prostate cancer treatment, is not be a big concern. For others, it may be a significant problem. Damage to nerves near the prostate during the operation to remove the cancer can cause erectile dysfunction. Many urologists try to avoid damage by using a **nerve-sparing operation**. The extent to which this is possible depends, among other things, on the stage of your cancer. Smaller cancers are easier to remove without damaging the nerves.

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

It is important to be aware of the impact that treatment may have on your sexual function before you have the 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. Ejaculation is still possible after **radiotherapy**.

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.

If you are in a stable relationship when you 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. If you are not in a relationship, or are in one that 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. You may also wish to contact the Cancer Council Helpline on 13 11 20.

How can erectile dysfunction be treated?

Younger men whose **erection** nerves were spared during **surgery** have the best chance of recovering erections after surgery. If you have problems with erections after treatment, however, many things can now 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. Improvement can continue for two to three years. Men who have **radiotherapy** without hormone therapy usually do not see any decline in their erections until several years later. Men who have hormone therapy before radiotherapy may regain their erections six to 12 months after radiotherapy.

During the recovery time, many surgeons and radiation oncologists 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. Encouraging this use of aids and medications is called 'penile rehabilitation'.

Tablets

Some drugs can 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. However, they will not usually work if the nerves controlling erections have been removed. The most common side effects are headaches and hot flushes. If you have had heart problems, chest pain or are taking or have taken drugs for angina (chest pain on activity), then you should not take these tablets. If you have any doubts, discuss this with your family doctor or specialist before starting treatment.

Injections

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 after the injection.

Other methods

Other methods for managing **erectile dysfunction** include the use of vacuum devices and penile implants. These can be useful even if it has not been possible to spare the erectile nerves. Both approaches can be helpful for men who have found other methods unsatisfactory. For more on managing erectile dysfunction, talk to your **urologist** or contact the Cancer Council Helpline on 13 11 20.

As indicated earlier, ejaculation no longer occurs after **surgery**. This means men cannot conceive children in the normal manner. This can be important for some men who are making a treatment decision. If it is important to you, sperm banking (storing your sperm) before your treatment may be an option. This is quite a complex process and you need to discuss it with your GP and specialist.

Urinary incontinence

Urinary **incontinence** means being unable to control urine loss. It is a common side effect of **radical prostatectomy**, particularly straight after the operation, but usually resolves after a few months. It is a less common problem after **radiotherapy**.

Some men may have a persistent loss of a small amount of urine after radical prostatectomy; this is called 'stress incontinence'. Stress incontinence is the accidental passing of urine: it can happen when you go jogging, cough or sneeze. Discuss it with your surgeon, as it may have other causes such as infection. Exercising the **pelvic floor muscles** (see Glossary) is a good way of stopping or lessening leakage and is an excellent way to hasten recovery of continence. 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 lifestyles. Severe incontinence requires 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, other options include:

- injecting bulking agents such as collagen around the **urethra** just below the **bladder** (where the bladder joins the urethra or urine tube) to assist it to close
- surgically constructing a sling to support the urethra
- a 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. Discuss this with your specialist before the surgery so that you are aware of the best strategies to manage the problem, particularly when you are first discharged from hospital.

For more 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: Resources).

Bowel symptoms after radiotherapy

After **radiotherapy**, some men have **bowel** symptoms. The risk of this is much lower with modern techniques such as **intensity modulated radiotherapy** and **image-guided radiotherapy**. Bowel problems are less likely after **surgery**, **brachytherapy** and image-guided radiotherapy compared to EBRT using older techniques. It is very important that any bowel problems are discussed with your doctor.

Bowel changes can occur during radiotherapy and almost always get better within a few weeks of completing treatment. In some patients bowel symptoms begin a few months to a few years after treatment, and then improve. Most patients do not

require treatment and the changes usually do not interfere with lifestyle.

It is usually recommended that *any patient* with a change in bowel habits after treatment should have a colonoscopy (a procedure to look at the bowel) to ensure that the change is due to treatment and not due to other causes.

The types of symptoms that can occur after radiotherapy include urgency (needing to rush to the toilet when having the urge pass a bowel motion), bleeding from the **rectum** and, rarely, **incontinence** (not being able to control bowel motions).

Urgency (if it occurs) is usually mild, and does not normally affect men's lives. You may find that it only occurs in the morning after breakfast, and avoiding cereals and fruit in the morning prevents it. Urgency may improve after a year or two, and usually does not require any treatment.

Bleeding from the **rectum** (if it occurs) is usually mild, like **haemorrhoids** (or 'piles'), and is not particularly troubling. Patients might notice a bit of blood on the toilet paper on occasions, after hard motions. Patients often can manage this by avoiding constipation, and taking stool bulking agents such as Metamucil or Benefiber. Rectal bleeding may resolve on its own after a year or two. Sometimes rectal steroid suppositories stop the bleeding. If the bleeding is a particular problem, it is often stopped by a single laser treatment (**argon plasma coagulation** or APC), or formalin application. In the rare cases where it continues to be a problem, **hyperbaric oxygen** often heals it completely (see Chapter 3, page 53).

Thankfully, the inability to control bowel motions (**incontinence**) is rare after modern types of radiotherapy. It may be improved by the use of pelvic floor exercises, or

'biofeedback', or it may resolve by itself. Your **radiation oncologist** can refer you to a continence advisor or bowel specialist to treat this.

The national EviQ website (www.eviq.org.au) has very helpful patient handouts that explain the treatment of these and other uncommon side effects of radiotherapy.

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

Social and emotional issues

Early on, as you get back to normal activities, it is natural to be concerned about the cancer returning. 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 also find that this is a time of re-evaluation, of re-setting some of your immediate and longer-term goals. This 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 GP. There are many resources available to help you. No person has to struggle with this on their own. Strategies are given in the helpful booklet *Coping with a Diagnosis of Prostate Cancer* (see Appendix 4: Resources).

When things seem particularly tough: depression

For some men, a diagnosis of prostate cancer can seem like an insurmountable problem. For others who are going through an already difficult period, it can seem like the final straw. Some men deal well with the immediate issues, but over time, feel a lack of motivation, an inability to enjoy life, and don't

have the energy for their normal tasks. These feelings can be intense. They may also persist for a long time and could be depression.

Depression is more than just a low mood. Men with depression can find it hard to carry out their normal daily activities and this may extend into all areas of their life. Being aware of the signs of depression is important because it can be managed with effective treatments.

More information on depression and anxiety is available from www.beyondblue.org.au. If you think you may be experiencing depression or anxiety, it is important that you see a health professional: your GP, a psychologist, psychiatrist, social worker or occupational therapist in mental health can help. There are Medicare rebates for these services when referred from a GP. See the *beyondblue* website and info line (1300 22 4636) and your cancer council for mental health professionals in your area, particularly those who have experience working with people with cancer. To find out more, call the Cancer Council Helpline on 13 11 20.

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 counsellors who specialise in people with cancer
- your doctor, who could refer you to a prostate nurse adviser, urology nurse or other person with skills in prostate cancer
- the Cancer Council Helpline.

Many other forms of support are available. These include:

- peer support: talking to other men who have had 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 has some difficulties. With good information and support, you will find it easier to deal with them.

Prostate cancer support groups

Prostate cancer support groups offer support and information to men with cancer and, often, to their family and carers.

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. You may also wish to contact Cancer Connect through 13 11 20.

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

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

There is a network of over 100 prostate cancer support groups in Australia, and you will usually be able to find one in your local area. These can be located at www.pcfa.org.au or call the Prostate Cancer Foundation of Australia (telephone 1800 220 099 or 02 9438 7000). Most meet monthly but you can also speak to the facilitators between meetings.

Max Shub of the Prostate Cancer Foundation of Australia says, *'Support groups are not for everyone but by at least attending one you will get a feel for what they have to offer. You may just be happy to be part of the 9000 people that receive regular newsletters and information about the latest when it comes to prostate cancer treatments and how to deal with the side effects after treatment. Some prostate cancer support groups also participate in community awareness events which can provide you with a feeling of wellbeing and a sense of giving something back by trying to prevent others from going through what you have.'*

Moderated mailing lists, where different aspects of prostate cancer are discussed by posts on the Internet, are becoming increasingly common. See Appendix 4: Resources.

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 any type of treatment. Contact the Cancer Council Helpline on 13 11 20 for more information. Other states may have similar services.

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.

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 services in your area. It is run by the cancer councils in each state and territory affiliated with Cancer Council Australia. Telephone 13 11 20.

Although there may be some changes, many men return to their normal activities and their full enjoyment of life after treatment. In the words of one prostate cancer survivor, *'There can be life, good life after prostate cancer. That's the story all men need to know. There are some good years left yet!'* (see resources by Barry Oakley in Appendix 4: Resources).

What questions could I ask?

Here is a list of questions you might like to ask your doctor. These reflect the points for discussion covered in Chapter 3. Under each one, we give you the page reference in this guide. There is space at the end of this chapter for you to write down other questions.

General questions

How do I know I have prostate cancer? You may not have any symptoms (Chapter 1, page 14). You may have a high **PSA** level (Chapter 2, page 18), but the only way a doctor can definitely tell is through a **biopsy** (Chapter 2, page 21). Sometimes, men find out after having an operation for **benign prostate enlargement** (Chapter 1, page 9).

What is localised prostate cancer? Prostate cancer is cancer occurring in the **prostate**, situated just under the **bladder**. Localised prostate cancer is still considered to be **confined to** the prostate (stage T1 or T2) and has not extended to other structures such as the **seminal vesicles** (Chapter 1, Figure 4, 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, page 16).

Can I be cured? Cancer which is still **confined to** the prostate or just outside it 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 can 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 29).

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: Resources) or the Cancer Council Helpline, or look up www.pcfa.org.au to contact a support group or talk to someone with prostate cancer.

Will it affect my sex life and my fertility? Because the prostate 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 4, page 75).

Is my family a 'prostate cancer family'? We know that family history is a risk factor for prostate cancer (Chapter 1, page 12). There is a higher risk for men with a father or brother who has been diagnosed (Chapter 1, page 11). 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 diet and lifestyle can prevent prostate cancer. Medications which lower PSA do so usually by lowering male hormone activity.

Can a biopsy spread cancer? For some cancers such as breast or bladder, cancers may be seeded along the track of the biopsy needle, however this has not been found for prostate cancer.

Questions about treatment

What are the options for treatment? There are three main options for treatment of localised prostate cancer: no initial treatment (also **watchful waiting** and active surveillance) (page 35), **surgery** (page 38) and **radiotherapy** (page 47). New therapies are emerging, too (page 61).

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 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 35).

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 35). 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 nearby organs is called a **radical prostatectomy** (Chapter 3, page 39).

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 43).

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 prostatectomy (Chapter 3, page 41).

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 39). Lymph nodes with cancer cells may also be removed.

What is nerve grafting? In men where nerves responsible for erections have been removed, attempts have been made to restore function using a nerve from the leg. This is not routinely done. Men would need to discuss this in detail with their **urologist**.

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 28).

How long before I could get back to my normal life? It could take six weeks or so to completely recover your normal physical activity (Chapter 3, page 40).

Radiotherapy

Radiotherapy is discussed in Chapter 3, pages 47–48.

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. Treatment is given five days a week over many weeks, which gives time for 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 side effects to a minimum.

How long does it take? This will vary according to each centre, but generally takes six to nine 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 rarely occur. 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 to receive treatment? 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. Nausea and vomiting rarely occur after radiotherapy.

Will I be radioactive? You are not radioactive during or after external beam radiotherapy. After low dose **brachytherapy**, however, you are advised not to hold infants or small children in your lap for two months.

How is brachytherapy different from external beam radiotherapy? Brachytherapy means 'radiotherapy from within'. This means radioactive sources are placed into the prostate. 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 57. The other type is called high dose rate 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 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 57.

For surgery or radiotherapy

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 29).

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.

New treatments

Are there any new treatments which might be suitable for me? New surgical approaches, ways of delivering **radiotherapy**, drugs and other treatments are constantly being developed. You can ask whether there are any available that are suitable for your stage of disease. You may need to see a different specialist to discuss a different treatment. If you are not sure, or need a referral, discuss it with your GP.

What is cyberknife radiotherapy? It is a method of delivering **radiotherapy**, with the intention of targeting treatment more accurately than standard radiotherapy. The two main elements are (1) the radiation produced from a small linear particle accelerator and (2) a robotic arm which allows the energy to be directed at any part of the body from any direction. It is not widely available outside the US.

What is proton beam radiotherapy? This is a type of conformal **external beam radiotherapy** which uses a beam of protons (instead of x-rays) to irradiate tissue, in the treatment of cancer. Proton therapy may result in less **radiation** dose to normal tissues, and all parts of the cancer receiving the same dose of radiation.

How do I join a clinical trial? Most new treatments are tested in a **clinical trial** before becoming broadly available. Joining a clinical trial is the best way of accessing new treatments. They usually have strict entry requirements, so ask your doctor whether there are any available which are suitable for you. Clinical trials are discussed in Appendix 3: Clinical trials.

Your questions:

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. 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 a microscopic 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 by imaging
- **T2** Tumour which can be felt, but is still **confined** to the 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
- **N0** Tumour not found in pelvic **lymph nodes**
- **N1** Tumour is found in pelvic lymph nodes
- **M0** No distant metastases
- **M1** Tumour has distant metastases

This is a simplified description. Within each stage are subgroupings 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. Increasingly, pathologists provide a 'tertiary' score. This is where there is a small component of a third (generally more aggressive) pattern. An example could be a Gleason 3 + 4 with a tertiary component of pattern 5. This would be considered to be more aggressive than a prostate cancer that was Gleason 3 + 4 with no tertiary pattern 5.

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
Medium 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 European Association of Urology Guidelines on Prostate Cancer 2009 and the National Cancer Control Network Practice Guidelines in Oncology: Prostate Cancer Version 1.2010. 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 to 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?
- How much, if anything, will it cost me?
- 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.

Clinical trials need to be registered in a publicly accessible database. Australian trials can be viewed at the Australian and New Zealand Clinical Trials Registry at www.anzctr.org.au/default.aspx.

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

Andrology Australia www.andrologyaustralia.org A professional body, which undertakes research and programs that 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.

Cancer Council Helpline 13 11 20 A confidential telephone information and support service run by cancer councils in each state and territory, for the cost of a local call. Specially trained staff answer questions about cancer prevention, early detection and treatment. They can also assist with practical and emotional support.

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

EviQ Cancer Treatments Online www.eviq.org. au Includes evidence-based cancer treatment protocols, chemotherapy treatment protocols and patient information including assessment and management of toxicities.

Healthdirect Australia 24-hour Health Advice Line 1800 022 222 A free service staffed by registered nurses to provide expert health advice. It is available to residents of the ACT, NSW, Northern Territory, Tasmania, South Australia and Western Australia and is scheduled to be a national service by 2011.

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

National Comprehensive Cancer Network
www.nccn.org A network of 20 leading US cancer centres. The website has clinical practice guidelines for most cancers, updated annually. These are intended for use by cancer doctors.

Prostate Cancer Foundation of Australia
www.prostate.org.au 1800 22 00 99 A peak body raising funds, raising awareness and supporting men with prostate cancer. It has a network of support groups across Australia. You can access these by locating where you are on a map at www.pcfa.org.au.

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

Advanced prostate cancer

Advanced Prostate Cancer: A Guide for Men and Their Families By the Australian Cancer Network and Australian Prostate Cancer Collaboration 2009. Available from cancer councils 13 11 20, Andrology Australia 1300 303 878 or Prostate Cancer Foundation of Australia 1800 22 00 99.

Accessing peer support

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

- visit the PCFA website www.pcfa.org.au
- call the Prostate Cancer Foundation 1800 22 00 99
- call the Cancer Council Helpline 13 11 20.

Information on depression

www.beyondblue.org.au Search for the fact sheet on *Prostate Cancer and Depression and Anxiety*.

Taking Care of Yourself and Your Family: A Resource Book for Good Mental Health John Ashfield. This very helpful Australian book covers a range of mental health problems with explanations and practical help.

Relationships counselling

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

Clinical trials in Australia

The Australian Clinical Trials Registry www.actr.org.au/ The registry website has information about clinical trials available nationally as well as their inclusion criteria (the type of patients they are seeking) for those currently open on prostate cancer.

Cancer Council Victoria www.cancervic.org.au/trials/ Has a listing of cancer clinical trials on its website. Search for 'prostate cancer'.

Alternative and complementary therapies

Medicines Line 1300 633 424 This Australian service provides consumers with access to independent, accurate information including prescription medicines, over-the-counter medicines, herbal and natural therapies. Talk directly to a pharmacist.

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

Clinical practice guidelines referred to in this guide

National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology: Prostate Cancer Version 1.2010 Available from www.nccn.org

Guidelines on Prostate Cancer Heidenreich A et al. European Association of Urology. Update March 2009. Available from: http://www.urotoday.com/images/pdf_files/eau/eau_cap_guidelines_2009.pdf.

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 www.mskcc.org/mskcc/html/10088.cfm 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 and which ones to use.

Prostate Cancer Research Institute This non-profit organisation, founded in 1996 by medical oncologists with support from the Daniel Freeman Hospital Foundation 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

Advanced Prostate Cancer: A Guide for Men and Their Families Australian Cancer Network, Australian Prostate Cancer Collaboration 2009. Available from cancer councils 13 11 20, Andrology Australia 1300 303 878 or Prostate Cancer Foundation of Australia 1800 22 00 99.

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 medical oncologist, this book is for those seeking to understand the more technical aspects of their care.

Coping with Prostate Cancer This useful booklet from Cancer Council Queensland gives issues you may face after a diagnosis and strategies for dealing with them. It is available online from the Cancer Council Queensland website, or call 13 11 20 from Queensland.

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 website at www.communitywebs.org/SAProstateCancer/pages/psaadelaide/documents/lifes-in-the-pink.pdf

Promoting Wellness for Prostate Cancer Patients
Dr Mark Moyad, Ann Arbor Media Group, 2008. Dr Moyad is an expert in complementary medicine and prostate cancer. This book gives diet and lifestyle tips to maximise health for men with prostate cancer.

Sex after Treatment: Prostate Cancer This useful booklet from Cancer Council Queensland 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 Andrology Australia website at http://www.andrologyaustralia.org/docs/booklet_sex%20after%20treatment.pdf or call 13 11 20 from Queensland.

The Prostate Book: The Complete Guide to Overcoming Prostate Cancer, Prostatitis and BPH
Dr Peter Scardino and Judith Kelman, Penguin Group, New York, 2006. This 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. Download online from www.prostatehealth.org.au in Educational Resources section.

Your Guide to Prostate Cancer: The Disease, Treatment Options and Outcomes Dr Prem Rashid, Uronorth Group, Port Macquarie, 2010. This Australian book, written by a urologist, covers prostate cancer comprehensively and other prostate problems. Can be purchased online at http://www.prostatebook.com.au/default.aspx

What Women (and Their Men) Need to Know about Prostate Cancer Irene Madjar and Gail Tingle. Available from the Prostate Cancer Foundation of Australia.
Tel: 1800 220 099. Email: enquiries@prostate.org.au

About nomograms

When are they useful and when not?

Prostate cancers come in many different forms: some are 'lazy', meaning 'low risk' or slow-growing cancers. Others are faster growing. It is important to be able to predict a tumour's growth pattern: slow-growing, 'low-risk' cancers may not need treatment at all, while more aggressive, high-risk cancers may need more than one treatment to treat them effectively.

Clinical stage, Gleason score, PSA level and even the speed at which PSA increases—each tells 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 (see page 26). In Table 14: Discussing treatment with your doctor (see page 68), you can see that treatment choice can depend on the risk grouping of the cancer.

Factors such as PSA, grade and stage can also be combined in a mathematical expression in order to predict outcomes such as return of the cancer. These are called 'nomograms'. The expressions are drawn up based on the past experience of many thousands of patients, usually drawn from US hospitals, and here lies their limitation. If the treatment has changed and become more effective over the years, the results of past treatment may not predict accurately that for patients treated today. Similarly if a nomogram is developed in one country, it may not predict well in a country where the treatment is delivered more or less effectively.

The effectiveness of radiotherapy has increased with the introduction of 3D-conformal radiotherapy and then **intensity modulated radiotherapy** (IMRT) over the last decade. The results of the old forms of radiotherapy are not as good as the most recent forms. Moreover not all countries and

towns can offer patients IMRT, and so a nomogram predicting outcome of radiotherapy would not be accurate for these patients. It is very important, if you are using a nomogram, to discuss with your doctor whether it is appropriate for you.

Where are they found?

The best way to access a nomogram is with the help of your doctor, who can explain it to you.

Predictive tools can also be found on websites of some urological organisations. The Memorial Sloan-Kettering Cancer Center's website is at www.mskcc.org. The nomogram shown here is designed for use prior to treatment. Figure 6 shows results for a hypothetical patient, aged 60 with PSA 7, Gleason 7 and clinical stage T1c cancer, and 2 of 6 cores positive for cancer in the prostate biopsy. To achieve this result, we also needed to enter the primary and secondary Gleason scores (see Appendix 2: The Gleason grading system), 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).

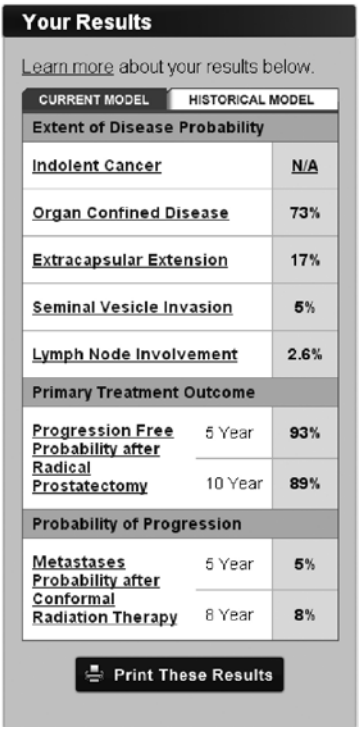
The results show that after radical prostatectomy, the chance of organ confined disease was 73%, and the chance of remaining free of progression at five years was 93%.

One famous risk assessment tool was developed from the Prostate Cancer Prevention Trial (PCPT). It predicts the risk of prostate cancer in a man who has had a PSA test and rectal examination. It includes age, ethnic background, family history and the results of any previous biopsy. It is available at http://deb.uthscsa.edu/URORiskCalc/Pages/uroriskcalc.jsp.

A second calculator which predicts risk of prostate cancer on biopsy comes from a European study on screening, completed recently. This calculator is available online at www.prostatecancer-riskcalculator.com/via.html.

If you would like to use a risk calculator or nomogram, we recommend you work through the exercise with your doctor, to ensure the nomogram is appropriate for you and to assist with understanding the meaning of the results.

Figure 6: Your results



Printed with permission from the Memorial Sloan-Kettering Cancer Center

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 digital rectal examination.

DRE: digital rectal examination. The doctor feels the prostate by placing a finger in the rectum. See Chapter 2, page 20.

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 23 and Appendix 2.

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 18 and Chapter 3, page 33.

Abbreviations

IMRT	Intensity modulated radiotherapy
IGRT	Image-guided radiotherapy
MRI	Magnetic resonance imaging
CT	Computerised tomography
VMAT	Volumetric arc therapy
IMAT	Intensity modulated arc therapy
HBO	Hyperbaric oxygen
EBRT	External beam radiation
TURP	Transurethral resection of the prostate

Glossary

Most of the words listed here are used in this guide; 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.

argon plasma coagulation A technique to control bleeding endoscopically using heat generated from ionised argon gas.

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 its path is traced through 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 rate brachytherapy involves the insertion of radioactive seeds directly into the prostate, which are retained. High dose rate 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).

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.

combined modality therapy Use of more than one therapy at once, often used for high-risk cancers. Therapies may include surgery, radiotherapy, hormone therapy and chemotherapy.

computerised tomography (CT) scan A series of x-ray pictures taken in a circle around the body and processed by a computer.

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 into other tissues or organs.

conformal radiotherapy A type of external beam radiotherapy (EBRT) where the radiotherapy dose is delivered by a number of beams shaped so that the region where they overlap is similar to the shape of the prostate. This minimises the dose to adjacent healthy tissue.

cyberknife radiotherapy Another method of delivering conformal radiotherapy. The two main elements are (1) the radiation produced from a small linear accelerator and (2) a robotic arm which allows the energy to be directed at any part of the body from any direction. Cyberknife may result in less radiation dose to normal tissues, with all parts of the cancer receiving the same dose of radiation.

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.

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 4 ng/ml to 8 ng/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 radiation (EBRT) Radiotherapy given from a source outside the body.

faecal incontinence Involuntary loss of faeces.

faecal urgency An urgent need to go to the toilet to pass faeces.

fertility The ability to conceive children naturally.

fiducial marker A marker (often gold seeds) inserted in the prostate to help accurately locate it. It is part of the radiotherapy planning process and helps the accuracy of image-guided radiotherapy (IGRT). The seeds are not radioactive.

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 mean someone will only live for five years after having treatment.

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.

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, which ranges from 2 to 10 (see above).

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

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.

hormone resistance Prostate cancer cells are dependent on testosterone ('male' hormone) for growth. Withdrawal of testosterone 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'.

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.

hyperbaric oxygen Oxygen delivered at high pressures. Can be helpful relieving some long-term side effects of radiation therapy.

image-guided radiotherapy Radiotherapy guided by specialised imaging tests, such as CT scans, ultrasound or x-rays. These tests are done in the treatment room just before the patient is to receive his or her daily radiation treatment.

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.

intensity modulated radiotherapy (IMRT) A type of conformal external beam radiotherapy where the radiotherapy dose is delivered by dozens of mini-beams of radiation. IMRT may result in less radiation dose to normal tissues, with all parts of the cancer receiving the same dose of radiation.

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 restarted. The main expected benefit in this approach is reduction in side effects.

laparoscopic surgery An approach to surgery where the operation is performed using small incisions through thin telescopic instruments; often a video-camera is inserted. It is also called minimally invasive or 'keyhole' surgery.

libido Sex drive.

localise To locate the exact position in the body: important in planning radiotherapy treatments.

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

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. They are often caused by benign enlargement of the prostate, but can also be caused by advanced prostate cancer.

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 hormone (testosterone).

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.

margin positive When cancer cells are present at the cut edge (margin) of the removed prostate, after surgery to remove prostate cancer.

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. The technique is not always possible because cancer can affect the areas around the nerves.

nomogram Factors such as PSA, grade and stage combined in a mathematical expression in order to predict outcomes such as return of the cancer.

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 persons whose disease is not responsive to curative treatment. The goal of palliative care is achievement of the best possible quality of life for the person and their family.

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

pelvic floor muscles These span the opening of the pelvis and support the bladder and rectum. They can help with stress incontinence by supporting the bladder when sneezing or coughing.

penis The male reproductive organ consisting of a body or shaft which 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 The 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; locally advanced: contained within the prostate region but extending beyond the prostate 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. Referred to in this guide as the 'prostate'.

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.

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

proton beam radiotherapy A type of conformal external beam radiotherapy which uses a beam of protons (instead of x-rays) to irradiate tissue, in the treatment of cancer. Proton therapy may result in less radiation dose to normal tissues, and all parts of the cancer receiving the same dose of radiation.

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

PSA velocity The speed of PSA change over time: how quickly the PSA level rises.

quality of life Your overall appraisal of your situation and your well-being.

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, 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.

robot-assisted laparoscopic 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 behind the penis.

secondary cancer *See* metastasis.

selection bias Refers to differences in the selection of patients into groups. For example patients who are selected for surgery are often younger and fitter than those selected for radiotherapy. Because of differences between the two groups prior to treatment, the outcome of treatment cannot be directly compared.

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: Staging and the TNM system.

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.

surgery An operation; a medical procedure involving an incision or cut in order to investigate or treat a medical condition.

surgical margins After a radical prostatectomy, the edges of the tissue that 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. Prostate cancer specific: the proportion of people who do not die of prostate cancer in a given period, such as five years. 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.

volumetric arc therapy (VMAT) and intensity-modulated arc therapy (IMAT) Newer types of intensity-modulated radiotherapy (IMRT) treatment technique that enable highly conformal cancer treatments, and may increase the sparing of the healthy tissue around the target.

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 Cancer Network which produced this guide.

Professor Suzanne Chambers, General Manager of Research at Cancer Council Queensland

Dr Bruce Kynaston, Radiation Oncologist (ret'd), member, Prostate Cancer Foundation of Australia Support Groups

Jill Margo AM, Medical Journalist, Australian Financial Review

Professor Villis Marshall AC, Urologist, Chair, Australian Cancer Network Localised Prostate Cancer Working Group, Surgical Specialty Services, Royal Adelaide Hospital, Adelaide

Dr Carole Pinnock AM, Chair, Education Committee, Australian Prostate Cancer Collaboration and Principal Research Scientist, Urology Unit, Repatriation General Hospital Division of Surgery. Steering Committee Chair

Professor Tom Reeve AC CBE, Senior Medical Adviser, Australian Cancer Network

Dr Andrew Richards, Urologist, Member, Urological Society of Australia and New Zealand Uro-Oncology Advisory Group

Assoc Prof Tom Shakespeare, Senior Radiation Oncologist and Director, North Coast Cancer Institute, Coffs Harbour, Port Macquarie and Lismore, NSW

Mr Max Shub member, Prostate Cancer Foundation of Australia Support Groups

Dr David Smith, Epidemiologist, Research Coordinator, Cancer Epidemiology Research Unit, NSW Cancer Council

We are grateful to **Professor Mark Frydenberg**, **Dr Alan Stapleton**, members of the Support and Advocacy Committee and peer support groups of the Prostate Cancer Foundation of Australia, for review and suggestions on the drafts of the updated guide. We thank *beyondblue* for its review of the section on depression.

Index

References

1. Australian Institute of Health and Welfare, Incidence and Prevalence of Chronic Disease, 2009 [sighted 23.4.09]. Available from: http://www.aihw.gov.au/cdarf/data_pages/incidence_prevalence/index.cfm#Diabetes.
2. Baade, P.D., et al., Communicating prostate cancer risk: what should we be telling our patients? Medical Journal of Australia, 2005, 182(9): 472–5.
3. Johns, L.E. and R.S. Houlston, A systematic review and meta-analysis of familial prostate cancer risk. BJU International, 2003, 91(9): 789–94.
4. Ostrander, E.A. and Udler, M.S. The role of the BRCA2 gene in susceptibility to prostate cancer revisited. Cancer Epidemiol Biomarkers Prevention. 2008 Aug;17: 1843-8.
5. Thompson, I.M., et al., Prevalence of prostate cancer among men with a prostate-specific antigen level < or =4.0 ng per milliliter. New England Journal of Medicine, 2004, 350(22): 2239–46.
6. Australian Bureau of Statistics, Life Tables, Australia 2006–2008. 2009.
7. Bill-Axelson, A., et al., Radical prostatectomy versus watchful waiting in early prostate cancer. New England Journal of Medicine, 2005, 352(19): 1977–84.
8. Stattin, P., et al., Outcomes in localized prostate cancer: National Prostate Cancer Register of Sweden follow-up study. Journal of the National Cancer Institute, 2010, 102(13): 950–958.
9. Klotz, L., et al., Clinical results of long-term follow-up of a large, active surveillance cohort with localized prostate cancer. Journal of Clinical Oncology, 2010, 28(1): 126–131.
10. Smith, D.P., et al., Quality of life three years after diagnosis of localised prostate cancer: population based cohort study. British Medical Journal, 2009, 339: 817.
11. Stephenson, A.J., et al., Preoperative nomogram predicting the 10-year probability of prostate cancer recurrence after radical prostatectomy. Journal of the National Cancer Institute, 2006, 98(10): 715–7.
12. Heidenreich, A., et al. Guidelines on Prostate Cancer. European Association of Urology March 2009 [viewed 16 September 2010]; Available from: http://www.urotoday.com/images/pdf_files/eau/eau_cap_guidelines_2009.pdf.

13. Jaffe, J., et al., Robot-assisted laparoscopic prostatectomy: a single-institutions learning curve. Urology, 2009, 73(1): 127–33.

14. Ficarra, V., et al., Retropubic, laparoscopic, and robot-assisted radical prostatectomy: a systematic review and cumulative analysis of comparative studies. European Urology, 2009, 55(5): 1037–63.

15. National Health and Medical Research Council and Australian Cancer Network, Clinical Practice Guidelines: Evidence-Based Information and Recommendations for the Management of Localised Prostate Cancer. A report of the Australian Cancer Network Working Party on Management of Localised Prostate Cancer. 2003, Canberra: NHMRC.

16. Holmberg, L., et al., A randomized trial comparing radical prostatectomy with watchful waiting in early prostate cancer. New England Journal of Medicine, 2002, 347(11): 781–9.

17. Hu, J.C., et al., Role of surgeon volume in radical prostatectomy outcomes. Journal of Clinical Oncology, 2003, 21(3): 401–5.

18. Eastham, J., et al., Variations among individual surgeons in the rate of positive surgical margins in radical prostatectomy specimens. Journal of Urology, 2003, 170(6 Pt 1): 2292–5.

19. Joudi, F.N. and B.R. Konety, The impact of provider volume on outcomes from urological cancer therapy. Journal of Urology, 2005, 174(2): 432–8.

20. Thompson, I.M., et al., Adjuvant radiotherapy for pathological T3N0M0 prostate cancer significantly reduces risk of metastases and improves survival: long-term followup of a randomized clinical trial. Journal of Urology, 2009, 181(3): 956–62.

21. Bolla, M., et al., Improved survival in patients with locally advanced prostate cancer treated with radiotherapy and goserelin.[see comment]. New England Journal of Medicine, 1997, 337(5): 295–300.

22. Kuban, D.A., et al., Long-term multi-institutional analysis of stage T1-T2 prostate cancer treated with radiotherapy in the PSA era. International Journal of Radiation Oncology, Biology, Physics, 2003, 5 7(4): 915–28.

23. Aizer AA, Y. JB, and C.J. et al., Radical prostatectomy vs. intensity-modulated radiation therapy in the management of localized prostate adenocarcinoma. Radiotherapy Oncology, 2009, 93(2): 185–91.

24. Zietman, A., K. Bae, and J. Slater, et al., Randomized trial comparing conventional-dose with high-dose conformal radiation therapy in early-stage adenocarcinoma of the prostate: long-term results from proton radiation oncology group/American College of Radiology 95-09. Journal of Clinical Oncology, 2010, 28(7): 1106–11.

25. Viani, G., E. Stefano, and S. Afonso, Higher-than-conventional radiation doses in localized prostate cancer treatment: a meta-analysis of randomized, controlled trials. International Journal of Radiation Oncology, Biology, Physics, 2009. 74(5): 1405–18.

26. Bhojani, N., et al., The rate of secondary malignancies after radical prostatectomy versus external beam radiation therapy for localized prostate cancer: a population-based study on 17,845 patients. International Journal of Radiation Oncology, Biology, Physics, 2010, 76(2): 342–348.

27. Bennett, M., et al., Hyperbaric oxygen therapy for delayed onset muscle soreness and closed soft tissue injury. Cochrane Database Syst Rev., 2005, (4): CD004713.

28. Bahn, D., et al., Targeted cryoablation of the prostate: 7-year outcomes in the primary treatment of prostate cancer. Urology, 2002, 60 (2 Suppl 1).

29. Mottet, N., et al., Optimizing outcomes and quality of life in the hormonal treatment of prostate cancer. BJU International, 2006, 98(1): 20–7.

30. Bolla, M., et al., Long-term results with immediate androgen suppression and external irradiation in patients with locally advanced prostate cancer (an EORTC study): a phase III randomised trial. Lancet, 2002, 360(9327): 103–6.

31. Freedland, S.J., et al., Obesity and risk of biochemical progression following radical prostatectomy at a tertiary care referral center. Journal of Urology, 2005, 174(3): 919–22.

32. DeWitt, K.D., et al., What does postradiotherapy PSA nadir tell us about freedom from PSA failure and progression-free survival in patients with low and intermediate-risk localized prostate cancer? Urology, 2003, 62(3): 492–6.

A final word

This is 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. www.prostatehealth.org.au

Copies of this guide can be obtained:

- from the Cancer Council Helpline run by each state and territory cancer council: phone 13 11 20 from anywhere in Australia
- from Andrology Australia www.andrologyaustralia.org or phone 1300 303 878
- online at www.prostatehealth.org.au

Level 1, 120 Chalmers Street
Surry Hills NSW 2010
GPO Box 4708 Sydney NSW 2001
T: +61 2 8063 4100
F: +61 2 8063 4101
info@cancer.org.au

www.cancer.org.au