

Caring for people with cancer



Understanding

prostate cancer

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This booklet has been written to help you understand prostate cancer. It has been prepared and checked by cancer doctors, other relevant specialists, nurses and patients. The information in this booklet is an agreed view on this cancer, its diagnosis and treatment, and the key aspects of living with it.

If you are a patient, your doctor or nurse may wish to go through the booklet with you and mark sections that are important for you. You can also make a note below of the contact names and information that you may need quickly.

Specialist nurse/contact names	Family doctor
_____	_____
_____	_____
_____	_____
Hospital	Surgery address
_____	_____
Tel	_____
Emergency Tel	Tel
_____	_____
Treatments	Review dates
_____	_____
_____	_____
_____	_____



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The Irish Cancer Society thanks CancerBACUP – the British Association for Cancer United Patients – for permission to adapt the text of their booklet, *Understanding Prostate Cancer*.



If you like, you can also add:

Your name _____



Address _____



Irish Cancer Society, 43/45 Northumberland Road, Dublin 4
 Tel: 01 231 0500 Fax: 01 231 0555
 Email: info@irishcancer.ie
 Website: www.cancer.ie

The Irish Cancer Society is the national charity for cancer care, dedicated to eliminating cancer as a major health problem and to improving the lives of those living with cancer.

This booklet has been produced by the Nursing Services Unit of the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible.

EDITOR

Antoinette Walker

HEALTHCARE ADVISERS

Prof John Armstrong, Consultant Radiation Oncologist
 Dr John McCaffrey, Consultant Medical Oncologist
 Mr Michael Butler, Consultant Urologist
 Prof John Fitzpatrick, Consultant Urologist
 Angela Kissane, Clinical Nurse Specialist in Urology

SERIES EDITOR

Joan Kelly, Nursing Services Manager

ILLUSTRATOR

Michael H. Phillips

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■ Introduction

This booklet has been written to help you understand more about prostate cancer. We hope it answers some questions you may have about its symptoms and diagnosis, how it is treated, and how to cope with any side-effects that may occur. The treatment for prostate cancer can vary a little between doctors and hospitals. As a result, you may have questions and concerns about your own treatment which this booklet does not answer. We cannot advise you about which treatment to choose. It is best to discuss details of your own treatment with your doctor. At the back of the booklet you will also find lists of useful organisations, books and websites.

Reading this booklet

Read the sections of this booklet that are of interest to you only. You may find that there is a lot of information to take in and that it can be hard to concentrate, especially if you are feeling anxious or worried. Remember that you do not need to know everything about prostate cancer straight away. Read a section and when you feel relaxed and want to know more, read another section. If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the Prostate Cancer Information Service 1800 380 380.

If you found the booklet helpful, you could pass it on to your family and friends too. The more they know about your illness, the more they can help.

■ What does that word mean?

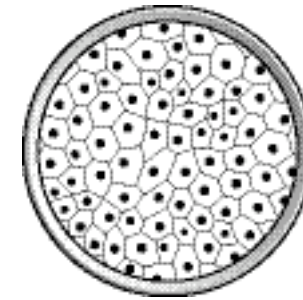
Benign	Not cancer.
Biopsy	The removal of a small amount of tissue from your body to find out if cancer cells are present.
Cells	These are the building blocks that make up your body. They are very small and can only be seen under a microscope.
Chemotherapy	Treatment with anti-cancer drugs.
Erectile dysfunction	The inability to have an erection.
Malignant	Cancer.
Medical oncologist	A doctor who specialises in treating cancer patients using chemotherapy and other medications.
Metastasis	The spread of cancer from one part of the body to other tissues and organs. Also called secondaries.
Oncology	The study of cancer.
Orchidectomy	The surgical removal of one or both testicles.
Prostatectomy	The surgical removal of the prostate gland.
Radiation oncologist	A doctor who specialises in treating cancer patients using radiotherapy.
Radiotherapy	The treatment of cancer using high energy X-rays.

Rectum	Lower part of the bowel (back passage).
Staging	A series of tests that measure the size and extent of cancer.
Urinary incontinence	The inability to control the flow of urine.
Urologist	A surgeon who specialises in treating urinary complaints.

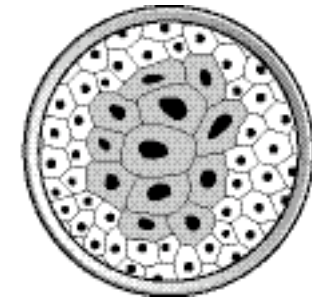
Before diagnosis

What is cancer?

Cancer is a word used to describe a group of diseases. Each one has its own name. For example: skin cancer, lung cancer, and breast cancer. Each has its own type of treatment and chance of being cured.



Normal cells



Cells forming a tumour

The organs and tissues of the body are made up of tiny building blocks called cells. All cancers are a disease of the body's cells. In healthy tissue these cells replace or repair themselves when they get worn out or injured. Where there is cancer, the cells do not behave as normal and keep on growing even when there is no need. These abnormal cells can form a tumour.

Tumours can either be **benign** or **malignant**. Benign tumours do not spread to other parts of the body, so are not called cancer. Malignant tumours are made up of cancer cells that can spread from where they started and go on to damage other tissues and organs. This may happen when a cell or group of cells breaks away

and enters the bloodstream or lymphatic system to form a new tumour somewhere else in the body. This is called a **metastasis** or **secondary tumour**.

Lymphatic system

The lymphatic system defends the body against infection. It has a network of tiny tubes like blood vessels that pass through most of the tissues in the body. These vessels carry a clear watery fluid called **lymph**.

There are hundreds of small bean-shaped glands called **lymph nodes** along this network. Their job is to filter the lymph for foreign particles as it passes through. They also allow blood cells called lymphocytes to protect the body against infection.

Lymph nodes can be found in groups throughout the body such as in the neck, armpits and groin. Sometimes you may become aware of these glands if they become swollen or enlarged. More of these lymph nodes are found grouped together in the chest and abdomen. Other parts of the lymphatic system include the liver, spleen, thymus, tonsils and bone marrow.

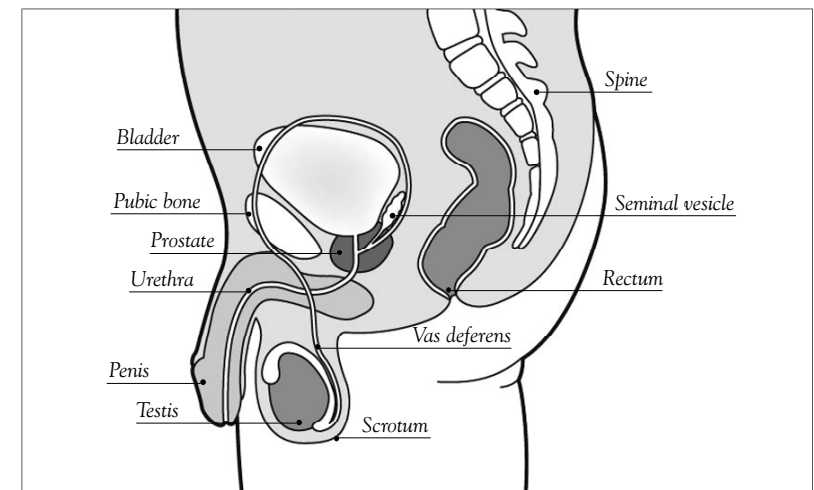
To sum up

- Cancer is a disease of the cells of the body.
- In cancer the cells do not behave as normal and keep on growing even when there is no need.
- These abnormal cells can form a tumour.
- If a tumour is malignant, cells can break away and enter the bloodstream or lymphatic vessels to form a new tumour somewhere else. This is called a **metastasis** or **secondary tumour**.

■ *The prostate*

The prostate is a small gland found only in men. It surrounds the first part of the tube (urethra) that carries urine from the bladder to the penis. The prostate produces a thick white fluid that mixes with sperm and is known as semen. It also produces a protein called prostate specific antigen (PSA), which turns the semen into liquid.

The way the prostate gland works and the growth of prostate cells depend on the male sex hormone, testosterone. This is produced in the testicles. The rectum (back passage) is close to the rear of the prostate gland. Near the prostate are clusters of lymph nodes.



The prostate gland

Prostate cancer

In general, prostate cancer affects men over the age of 50. It differs from most other cancers in the body because small areas of

cancer in the prostate are very common. They can remain unchanged for some time before they begin to grow.

These cancers may grow very slowly, especially in elderly men, and so never cause any problems. In other cases, the cancer can grow more quickly and may spread to other parts of the body, such as the bones.

■ *What causes prostate cancer?*

The cause of prostate cancer is unknown, but research is going on all the time. However, you may be more at risk if there is a history of prostate cancer in your family. African-American and African-Caribbean men seem to be more at risk than other ethnic groups. Prostate cancer is not infectious and cannot be passed on to other people.

■ *What are the symptoms of prostate cancer?*

As men get older the prostate gland may increase in size. This is usually due to **benign enlargement of the prostate**. It can also be called benign prostatic hypertrophy (BPH). The symptoms of this benign condition and malignant tumours are similar. They may include any of the following.

- Pain or difficulty when passing urine
- Trouble starting or stopping the flow of urine
- Passing urine more often, especially at night

- The feeling of not having emptied your bladder
- Painful ejaculation
- Blood in the urine or sperm (very rare).

If you have any of the above symptoms you must have them checked out by your doctor. But remember that most enlargements of the prostate gland are not cancer and can be easily treated. Prostate cancer is often a slow growing cancer, particularly in older men, and symptoms may not occur for many years. In some cases, the symptoms are caused by the spread of the cancer to other parts of the body. These symptoms may include pain in the back, hips or pelvis caused by the cancer spreading to the bones.

Screening

In recent years, screening for cancer has become an important part of cancer care. In Ireland, no screening programme is available on a regular basis for prostate cancer. This is because there is still debate on whether early detection and screening increases the chances of cure. Many prostate cancers grow very slowly. The side-effects from treatment may be worse than the effects of early prostate cancer.

At present there is no single test that can diagnose prostate cancer. A number of tests must be done to get a firm diagnosis. Research is continuing to see if screening is of benefit. If there is a history of prostate cancer in your family, you should talk to your family doctor. He or she will advise you what to do. You may have to be screened for prostate cancer. The tests will include a rectal examination and a blood test to check your PSA levels.

Prostate specific antigen (PSA)

PSA is a protein produced by the prostate. The level of this protein in the body is increased by prostate cancer as well as benign enlargement of the prostate. PSA levels can be measured in the blood. Men with prostate cancer tend to have higher levels of PSA than those who have benign enlargement of the prostate.

If blood tests show that you have a raised PSA level, you may need further tests. In men with prostate cancer, the PSA levels may show if the cancer has spread or not and help to measure the effects of treatment. It is important to remember there is no one test that can diagnose prostate cancer. A raised PSA test does not always mean you have prostate cancer. And a PSA may be normal, even when cancer is present.

For more information about the PSA test, call the Prostate Cancer Information Service 1800 380 380 and also for a free copy of the booklet, *Understanding the PSA Test*.

■ *How does the doctor make the diagnosis?*

Most men begin by visiting their family doctor (GP). If your doctor has concerns about you, he or she will ask you some questions about your health and examine you as well.

It may involve the following:

A digital rectal examination: To do this the doctor will place a gloved finger into your back passage to feel the prostate and to check for any lumps or swelling. This quick test is not painful but may be slightly uncomfortable.

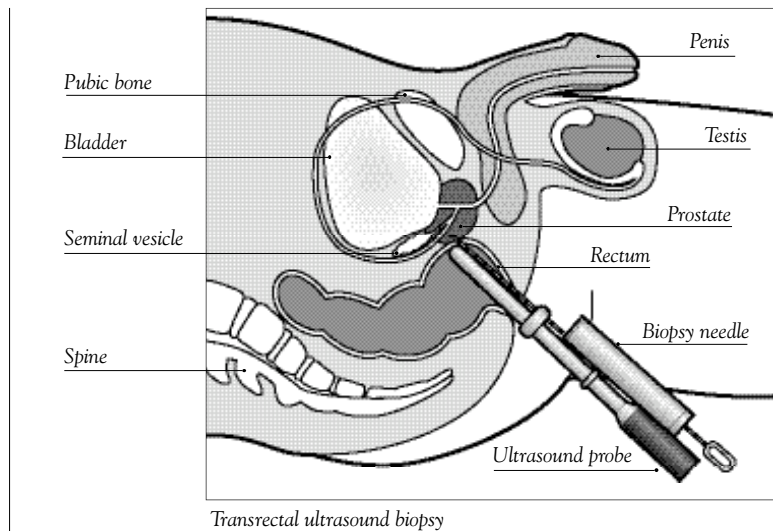
Blood tests: Samples of blood are taken to check the levels of PSA in the blood. A high level of PSA can be a sign of cancer, although the level can also be raised in benign prostate conditions. The higher the level of PSA the more likely it is to be cancer. If your doctor is concerned, he or she will refer you to hospital for further tests.

At the hospital

You may need all or some of the following tests. Your doctor will discuss the tests with you in detail beforehand and explain what they are used for. The tests may include:

Transrectal ultrasound (TRUS) and biopsy

This test is carried out in the urology department of the hospital. With an ultrasound, a picture is built up of the inside of your body using sound waves. A nurse will ask you to lie on your side and a small, lubricated metal tube called a probe is placed in your back passage. A device like a microphone is used to take the scan which is converted into a picture by a computer.



You may have a small sample of cells (biopsy) taken at the same time for examination under a microscope. This test usually reveals if you have prostate cancer, but also how quickly it may develop. This procedure may be uncomfortable but only takes a few minutes to do.

There is a slight risk of infection after a biopsy. To help prevent infection your doctor may prescribe a short course of antibiotics a few days before the biopsy. After the test you may notice a small amount of blood in your urine, some bleeding from the rectum or some blood in your semen. These are very common side-effects and should go away after a few days. But let your doctor know if these symptoms persist or if you develop any pain in your back passage. He or she will advise you what to do.

Further tests

If the tests show that you have prostate cancer you may need other tests. This is known as **staging**. These extra tests are very important

because they will show if the disease has spread to other parts of the body. The results of the tests will help to decide on the best treatment for you.

The tests may include all or some of the following:

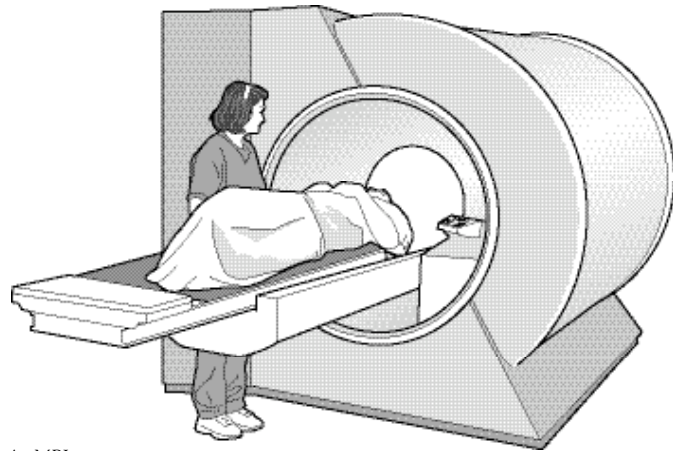
Bone scan: Bone scans are very sensitive and can detect cancer cells before they show up on an X-ray. For this test a very small amount of mildly radioactive substance is injected into a vein, usually in your arm. A scan is then taken of all the bones in your body. Because abnormal bone absorbs more of the radioactive substance than normal bone, it can show up on the scan. It can also show bone changes like arthritis.

After the injection you must wait for up to 3 hours before the scan can be taken. You may want to take a book or magazine with you, or a friend to keep you company. The level of radioactivity used in these scans is very low and safe. It disappears from the body within a few hours.

X-rays: You may need bone X-rays if the bone scan shows doubtful areas in certain bones. These X-rays will help to confirm whether you have benign or malignant bone disease.

CT scan (CAT scan): This is a special type of X-ray that builds up a detailed picture of the inside of your body. It does not hurt. Before the scan you may have to fast for 4 hours. You may be given a special drink or injection which helps show up parts of the body on the scan. It is important to let the radiographer know if you are allergic to iodine or have asthma before you take the drink or injection. The injection may make you feel hot all over for a few minutes. Preparation for a CT scan can vary. The doctor or nurse will tell you what to do. This test is usually done as an outpatient.

MRI scan: This special type of scan uses magnetic energy to build a picture of tissues inside your body. It does not hurt but it can be noisy. You will be given earplugs to wear during the scan. You may have an injection before the scan to show up certain areas of the body. You cannot wear metal jewellery during the scan. People who have certain medical devices implanted, e.g. a pacemaker, are not suitable for the test. The doctor in the hospital will advise you. Most people can go home after the scan.



An MRI scan

To sum up

Some tests need to be done to diagnose prostate cancer. They may include:

- PSA blood test
- Rectal examination
- Transrectal ultrasound and a biopsy of the prostate.

If you have prostate cancer, further tests might include:

- Bone scan
- CT scan
- Bone X-rays
- MRI scan.

■ Grading and staging of prostate cancer

Grading of prostate cancer

Grading refers to the appearance of the cancer cells under the microscope. The grade gives an idea of how quickly the cancer may develop. The Gleason grading system is most commonly used in prostate cancer. This system looks at how the cancer cells are arranged within the prostate and grades them as a result. The two most frequent patterns of prostate cancer are assessed and the grades added together to give an overall score from 2 to 10. The lower the score, the lower the grade of cancer.

Low-grade tumours are grade 2–4. They are usually slow growing and less likely to spread. A score of 5–7 is a moderate grade. High-grade tumours are grade 8–10. They tend to grow more quickly and are more likely to spread.

Stage of prostate cancer

The stage of a cancer is a term used to describe its size and whether it has spread to other parts of the body. By knowing the stage and the grade of the cancer, it helps the doctors to decide the best treatment for you. There are a few different staging systems for prostate cancer, but the following one is used most often.

Prostate cancer is generally divided into four stages depending on the tumour size. If the tumour is within the prostate, this is known as T1 and T2 and called **early prostate cancer**. Tumours that have spread beyond the prostate are known as T3 and T4.

If the cancer has spread to other parts of the body, this is known as secondary or metastatic prostate cancer.

- T1 The tumour is within the prostate gland but is too small to be found during a rectal examination. It may be found by tests such as the PSA test, a biopsy or by surgery such as transurethral resection of the prostate. Usually there are no symptoms.
- T2 The tumour is still within the prostate gland but is large enough to be felt during a rectal examination or show up on ultrasound. Often there are no symptoms.
- T3 to T4 The tumour has spread beyond the prostate gland into the surrounding tissues. This is known as **locally advanced prostate cancer**.

To sum up

- T1 and T2 tumours are known as early prostate cancer.
- T3 and T4 are known as locally advanced prostate cancer.
- If the cancer has spread to other parts of the body, this is called secondary or metastatic disease.

Treatment and side-effects

■ *Types of treatment*

Surgery, radiotherapy and hormone therapy are all used for the treatment of prostate cancer. Chemotherapy is used more often for more advanced disease. It can also be used to reduce the size of the tumour and relieve symptoms. These treatments are used on their own or in combination.

The type of treatment your doctor decides to give you will depend on a number of factors. These include:

- the size and grade of your tumour
- your age
- if it has spread locally or to other parts of your body
- your general state of health
- your own wishes and preferences.

Early prostate cancer

If the cancer is fully contained within the prostate gland, it is known as early prostate cancer. The treatment options for early prostate cancer include:

- active monitoring without treatment
- radical prostatectomy (removal of the prostate gland)
- radiotherapy
- hormonal therapy.

A combination of treatments may be used to give the best results. Prostate cancer often grows very slowly with few symptoms. If the cancer is found at an early stage it is possible that treatment may not be given immediately. Your doctor may decide on a period of monitoring with regular blood tests and check-ups to find out how

the tumour is doing. Some men find this watch and wait approach hard to accept. But it is usually done because a small cancer may not cause many problems. The side-effects of treatment may be worse than the effects of the cancer.

Your doctor may suggest **surgery** if the tumour is small and within the prostate gland. The aim of surgery is to remove the entire tumour and cure the cancer. Some men have no further problems after surgery for prostate cancer. For others, some of the cancer cells may remain after surgery or the cancer may return.

Radiotherapy is also used to treat cancer that is still within the prostate gland. The aim of treatment in early prostate cancer is to destroy the tumour completely and to cure the cancer. Surgery and radiotherapy are equally effective at treating the cancer, but each treatment has different benefits and side-effects. Surgery is discussed on page 23 and radiotherapy is discussed on page 29. Hormonal therapy may be given before or after radiotherapy. It is also used in combination with other treatments or on its own. Hormonal therapy is discussed on page 41.

Newer treatments

Some newer treatments for early prostate cancer may become available in Ireland in the future. For those who might want to avoid surgery, **cryotherapy** may be an option. Cryotherapy is a way of killing cancer cells by freezing them using special gases. It is also known as cryosurgery. It can also be used for men whose disease has come back after radiotherapy. Another new treatment is called **high-intensity focused ultrasound** (HIFU). This acts in the opposite way to cryotherapy. With HIFU the prostate cancer cells are killed by heat using ultrasound waves.

It is possible to control most locally advanced prostate cancers.

Locally advanced prostate cancer

It is possible to control most locally advanced prostate cancers. This can be done by using hormonal therapy, radiotherapy to the prostate and the surrounding area, or a combination of both. Some locally advanced prostate cancers are cured following treatment.

In some elderly men who have no symptoms of prostate cancer, or who have other medical problems, it may be best to give no treatment at all. Your doctor may continue regular monitoring instead and control any symptoms that occur. This is because the rate of growth of the cancer may be so slow that it is not worth risking the side-effects that may occur with treatment.

Secondary prostate cancer

If the cancer has spread to other parts of the body, **hormonal therapy** can be very effective for many months or years. It can often shrink tumours and reduce symptoms such as tiredness, problems in passing urine, discomfort or pain. There is a range of hormonal therapies available nowadays.

While **chemotherapy** was less frequently used in the past, it may be given if hormonal therapy is no longer effective. It may reduce the size of the tumour and relieve symptoms. More and more men are suitable for chemotherapy for prostate cancer to improve their quality of life. In general chemotherapy is well tolerated, with few side-effects. In recent times, there is evidence that some chemotherapy drugs lengthen the life span of such patients.

Your doctor may advise a course of **radiotherapy** to relieve pain if the cancer has spread to other parts of the body such as the bones. The treatment is given to the affected bone or area only.

Treating symptoms of cancer

Drugs such as Aredia or Zometa can be given by infusion into a vein (drip) to treat pain or strengthen the bones. If the bones in the spine are affected, this can sometimes lead to weakness, tingling or numbness in the legs or arms (due to pressure on the spinal nerves). If you develop any feelings of weakness, numbness or pins and needles in the legs or arms, contact your cancer specialist immediately. By receiving treatment quickly it may prevent the nerves from being permanently damaged.

The best treatment for you

You may notice that other men at the hospital are having different treatments to you. Their cancer may not be at the same stage as yours and their treatment needs may be different. At this time you may be anxious about what is going to happen next. Do not be afraid to ask your doctor or nurse any questions you may have.

Before any treatment your doctor and nurse should discuss all the possible side-effects of treatment with you. This includes temporary and permanent ones. You may want to use the fill-in page at the back of this booklet to write down your questions and the answers you receive.

Your doctor will tell you about your treatment choices too. He or she may suggest that there is more than one treatment option open to you. In this situation, it is very important that you are aware of the side-effects of each treatment before you decide on which treatment to choose. Some treatments may be equally effective but the possible side-effects may vary and can be more severe, depending on the treatment you receive.

If you have concerns about the different treatments available,

If you have concerns about the different treatments available, discuss them with your doctor.

discuss them with your doctor. He or she will be happy to answer any questions you may have and will advise you on the treatment most suitable for you.

Second opinion

Some people find it helpful to have another medical opinion to help them decide about their treatment. Doctors can refer you to another specialist if you think that would be helpful.

■ *Surgery*

Surgery for prostate cancer is usually a **total prostatectomy**. This is where the prostate is fully removed from your body.

Before consenting to this treatment, make sure you understand why you should have it done and its chances of success. You will also need to know about the side-effects of surgery and how long they will last.

Talk to your doctor or nurse. Ask them to go over the procedure with you in detail. Write down your questions if necessary. No operation or course of action can take place without your consent.

Total prostatectomy

This means the surgical removal of the prostate through the abdomen. It is also known as a radical prostatectomy. This operation is only done when the cancer is confined to the prostate. This is because the entire tumour can be removed and cure the cancer.

Getting ready for surgery

To make sure you are fit for surgery, you will also have some extra tests. These may include a heart test (ECG) and some more blood tests. An anaesthetist may examine you to make sure you are fit for surgery.

If you are having a total prostatectomy, there are simple exercises that you can do before the operation. These will help to strengthen the muscles that control your bladder. As a result, it may reduce the risk of urinary incontinence after your operation. A physiotherapist or nurse will show you how to do these exercises. He or she will also show you how to do deep breathing and leg exercises. These will help prevent you getting a chest infection or blood clot after your operation.

On the day before surgery you will be given an enema to clear out your bowels. You will not be allowed to eat anything from the night before your operation. You may receive an injection of heparin to prevent a clot developing in your legs afterwards. Before you go to theatre, your nurse may give you a tablet that will make you feel more relaxed and sleepy.

After your operation

When you wake up you will notice a number of tubes attached to your body. They may look alarming but they are normal after an operation like this.

- There will be a plastic tube inserted near your wound site to drain away fluid.
- A 'central line' (drip) will be put into a vein in your neck. You will be given fluids through this until you can drink again.

- You may be wearing an oxygen mask or nose prongs. These will give you extra oxygen to help you breathe.
- A small tube called a catheter will be placed in your bladder so that your urine can be drained off into a bag. This will save you having to get out of bed to go to the toilet.
- There may be a small pump attached to the drip. This may contain medication to provide you with pain relief if required.

Pain

You may have some pain after surgery for prostate cancer. Your nurse can give you pain-killing injections or tablets if you need them. Always ask for help before the pain gets too bad. If the medication does not work, let your nurse know as it can be changed. If you have a patient controlled analgesia pump (PCA), a nurse will show you how to use it. There is a button on the pump that you can press to release the medication when you need it. Mild discomfort can last for several weeks. Your doctor will give you a prescription for painkillers to take home with you if needed.

Eating and drinking

The effect of the anaesthetic during your operation will slow down your bowels. As a result, it will take a day or two before you can start eating and drinking. But you will quickly be able to take sips of water again. The amount of fluids you can take will then be increased. Most men can manage a light meal within 1 or 2 days of surgery. As soon as you begin to drink again, the central line will be removed. All other tubes and drains will be taken out as you get better.

Most men can manage a light meal within 1 or 2 days of surgery.

Exercise

A physiotherapist will help you with your breathing exercises. He or she will also show you how to cough and turn in the bed. By

doing these exercises you will help to prevent a chest infection. Even when you are in bed, you should move your legs and do your deep breathing exercises at least once an hour. On the day after surgery the nurses will help you get out of bed and take you for a short walk. These walks will become more frequent and longer as you get better. Soon you will be able to go for walks on your own.

Passing urine

The urinary catheter will remain in place for about 3 weeks after the operation. Any urine you produce will pass through the catheter into a drainage bag. While the catheter is in place, you must drink plenty of clear fluids. It is best to drink about 3 litres a day. By doing this, you will keep the urine flowing and reduce the risk of getting an infection.

Before you go home, a nurse will show you how to use a drainage bag. You may experience bladder spasm while you have a catheter in place, but this is normal. This may occur when your bowels move. Your doctor can prescribe medication if this becomes a problem.

You may be admitted to hospital to have the urinary catheter removed. The procedure only takes a moment or two but you will have to stay in hospital for a day or two afterwards. You can go home as soon as you are passing urine normally. You should continue to do the bladder exercises as often as possible.

going home

Most men are ready to go home 7 to 10 days after surgery. If you live alone or have problems getting around the house, talk to your nurse or medical social worker on your ward as soon as you are

While the catheter is in place you must drink about 3 litres a day.

admitted to the hospital. He or she can prepare in advance the community services you may need once you leave hospital. On the day you go home you will be given a date to come back. Usually it is about 2 weeks' later so that the catheter can be removed. If you have a worry or symptom before this date, contact your doctor, cancer nurse specialist or hospital ward for advice.

Possible long-term side-effects

Urinary incontinence

Long-term problems with controlling the bladder due to surgery are less common than short-term problems. It can be hard to tell who will have problems and for how long. Most men are incontinent when the catheter is first removed. Usually this improves with time but it can be frustrating.

Talk to your urologist or nurse about the possible risk of urinary incontinence before you consent to surgery. In general, less than 4% of men will have long-term problems with leakage of urine. Around 2% of men will experience the occasional dampness or drop of urine. Less than 1% of men will have to wear a permanent catheter.

There is help available if you develop urinary incontinence.

There is help available if you develop urinary incontinence. But remember it usually improves with time. Talk to your doctor, nurse or local public health nurse. All the HSE areas (former health boards) have continence advisers who will show you ways to cope. Contact your local HSE office for more information. See page 75 for more details.

Erectile dysfunction

Surgery to the prostate gland can lead to problems in having an

erection. This is called erectile dysfunction or sexual impotence. It is caused by a reduced blood flow to the penis due to damage to the arteries or nerves near the prostate. Often the need to remove all the cancer cells makes it impossible to avoid nerve damage. Even a small amount of damage can lead to the failure of erections, especially in older men.

The risk of erectile dysfunction after total prostatectomy is about 60–70%. It can take at least a year after the operation to find out if the impotence is permanent or not. Your urologist will try to spare the nerves located near the prostate. It is a special type of operation called a nerve-sparing prostatectomy. If this can be achieved, the risk of erectile dysfunction is much less.

After a prostatectomy, an orgasm during sexual activity will not result in the ejaculation of semen. The semen passes into the bladder instead and does not come out the penis.

It may be possible to achieve an erection by using medication. This can be discussed with your doctor when you go for check-ups. See page 51 for more details.

Infertility

Surgery for prostate cancer will cause infertility. This means you will no longer be able to father a child. You may find this effect of surgery very distressing. Your doctor will discuss this with you before your operation. If you have a partner, you may find it helpful to see the doctor together so that you can both talk about your concerns. If your sperm count is satisfactory it may be possible to store sperm before surgery, for use at a later date. In Ireland this is done at the HARI Unit at the Rotunda Hospital in Dublin. For more information on sperm banking see page 53.

Other surgery you may need

Orchidectomy (removal of the testes)

The aim of removing the testes is to reduce the level of testosterone (male hormone) in the body. Although this procedure involves an operation, it is discussed in the section on hormonal therapies (see page 41).

To sum up

- The aim of surgery is to remove the entire tumour.
- This operation is only done when the cancer is confined to the prostate.
- Most men are ready to go home 7 to 10 days after surgery.
- Surgery for prostate cancer may cause short or long-term side-effects.

■ *Radiotherapy*

This is a treatment where high-energy X-rays are aimed at a cancer to cure or control the cancer. The X-rays are usually delivered through a machine called a linear accelerator. This is known as **external radiotherapy**. However, for some men with early prostate cancer, radiotherapy can be given by inserting small radioactive seeds into the tumour. This is known as **brachytherapy**.

In early prostate cancer, the radiotherapy is aimed at the tumour in the prostate gland. The aim is to destroy the cancer cells, while doing as little harm as possible to normal cells. This is known as radical radiotherapy.

Radiotherapy may be given if the cancer has spread to other parts of the body, such as the bones. In this situation, the treatment cannot get rid of all the cancer cells and cure the cancer. However, it can reduce symptoms such as pain and make you more comfortable. This is known as **palliative radiotherapy**. It is usually not used for general pain because painkillers are better in this case. Radiation can help single areas of pain best.

A booklet called *Understanding Radiotherapy* is available from the Irish Cancer Society. It gives more details about the types of radiotherapy and possible side-effects. Call the Prostate Cancer Information Service 1800 380 380 for a copy.

External radiotherapy

Planning your treatment

Before radiotherapy, your radiation oncologist will plan how best to give your treatment. He or she will decide how much radiotherapy is needed to treat the cancer while doing the least possible damage to normal cells. On your first visit to the radiotherapy department you will have a CT scan that will show the area to be treated. Treatment planning is a very important part of radiotherapy. It will take a few visits before your treatment can go ahead.

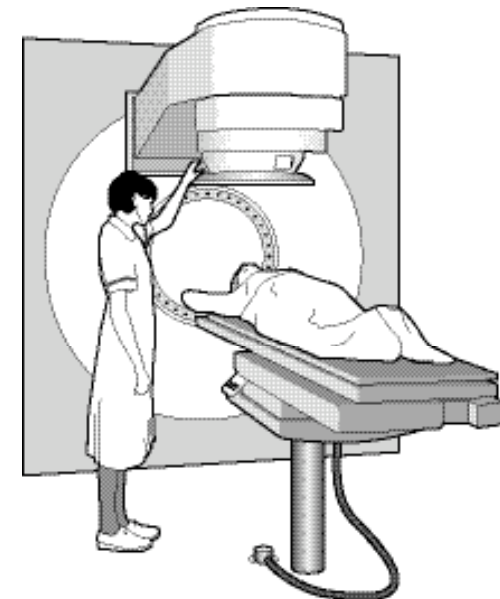
The radiation therapist will mark the area on your skin where you are to receive treatment. This is so that the X-rays can be aimed at the same area each day. Before starting radiotherapy your nurse will tell you how to look after your skin during and after treatment.

Getting your radiotherapy

Having radiotherapy is quite straightforward. You will have to attend for treatment every day during the week with a rest at

weekends. A course of radical radiotherapy may continue for 7 weeks or more. Each treatment session only takes a few minutes. You will not feel any pain during treatment but you will have to lie still. How much treatment you receive will depend on the extent of the cancer. Your doctor will discuss your treatment with you.

Each time you go for treatment you will go into a radiotherapy room. The radiation therapist will ask you to lie in a certain position under a radiotherapy machine. When you are ready he or she will leave the room. The machine will be turned on and your treatment given. Even though you are on your own in the room, your radiation therapist can see you all the time through a closed-circuit camera. You can talk to the radiotherapy staff through an intercom if you need to.



External radiotherapy

External radiotherapy does not make you radioactive.

External radiotherapy does not make you radioactive. It is perfectly safe for you to mix freely with family and friends.

Will I have any side-effects?

Radiotherapy is given directly to the site of the cancer. This means that any side-effects that occur are related to the part of the body being treated. The severity of these side-effects will vary from person to person and depend on the amount of radiotherapy received. Some side-effects will go away after treatment has ended or soon after. Other side-effects may persist and develop into long-term problems. Before you start your treatment your doctor or nurse will explain how these effects can be managed.

The side-effects may include:

Passing urine more often

During radiotherapy for prostate cancer your bladder may become irritated. This can result in passing urine more often and cause a burning feeling when you do pass urine. You may have a trace of blood in your urine too. If you have problems passing urine or notice blood in your urine, discuss it with your doctor. He or she will give you medication to reduce these effects. In rare cases a catheter may need to be inserted for the rest of treatment.

These side-effects usually go away gradually a few weeks after treatment has ended.

Diarrhoea

You may develop diarrhoea towards the end of treatment. This is because the prostate gland is located very close to the rectum. Passing watery bowel motions more than twice a day is known as

If you have problems passing urine or notice blood in your urine, discuss it with your doctor.

diarrhoea. You may also have cramping and/or abdominal pain. If this occurs it is important to drink lots of clear fluids to replace the fluids you are losing. Let your doctor know if the diarrhoea lasts for over 24 hours. There is medication that can stop this side-effect of treatment.

Rectal discomfort

Radiotherapy to the prostate area may irritate the back passage (rectum) and cause discomfort. It can also cause soreness around the anus. You may notice some blood on toilet tissue after passing a bowel motion. Indeed you may feel as if you have piles. If this happens tell your doctor or nurse. Your doctor can prescribe medication that will help this problem.

Skin changes

During radiotherapy the skin in the treated area may become red and sore. It may look like sunburn. You can use a special cream to treat this problem. Only use creams recommended to you by the nurses or radiation therapists. If you need to wash the area use warm water and pat it dry with a soft towel. Do not rub the skin while washing and drying. Avoid perfumed creams or powders. Check with your radiation therapist or nurse before applying anything to your skin.

Erectile dysfunction

Radiotherapy to the prostate can make it more difficult to achieve an erection (impotence). After radiation, some men find that an orgasm produces less semen than normally. For some men impotence may become a long-term problem following radiotherapy. There are various treatments that can help. See page 51 for more information.

Infertility

Radiotherapy for prostate cancer is likely to cause infertility. This means you will no longer be able to father a child. You may find this effect of treatment very distressing. Your doctor will talk to you about this before your treatment. If you have a partner, you may find it helpful to see the doctor together so that you can both talk about your concerns. If your sperm count is satisfactory it may be possible to store sperm before radiotherapy, for use at a later date. For more information on sperm banking see page 53.

Weight loss

If you have problems eating you may begin to lose weight. It is best to try to eat as well as you can while on treatment. Eating small meals more often can help. Ask to see a dietician if you are losing weight. He or she will give you advice on the best foods to eat. A booklet called *Diet and the Cancer Patient* is available from the Irish Cancer Society. Call the Prostate Cancer Information Service 1800 380 380 for a free copy. You may find this booklet helpful.

Tiredness

Tiredness can build up over the course of your treatment. You may feel tired because of the treatment itself or perhaps you have to travel long distances to come for treatment. Rest as much as you can and continue to do the things you enjoy. But remember that you may have less energy than you had before treatment.

Hair loss

You may have some hair loss in and around the pubic area. If this happens it will fall out quickly. But try not to worry, as the hair will start to grow again when treatment is over. You may find that

**Rest as much
as you can.**

the hair is thinner or finer than it was before. These or any other effects you develop are watched very carefully during your course of radiotherapy.

Information on how to prevent side-effects and medication will be prescribed if needed. Most of these side-effects should go away when treatment is over, but do let your doctor know about them if they continue.

Possible long-term side-effects

Radiotherapy to the prostate area can sometimes lead to long-term side-effects. But improved planning and methods of giving treatment have made these long-term side-effects less likely now. If you have radiotherapy to the prostate, it may not be possible to have surgery to remove the cancer if it recurs. This is because there is a high risk of complications developing.

Erectile dysfunction

Radiotherapy for prostate cancer can cause an inability to have an erection in about one-third of men who have this treatment. It may take up to 1 year after treatment has ended for sexual potency to return. It may develop into a long-term problem and may be permanent.

You may find this side-effect of treatment very difficult to deal with. It can affect your relationship with your partner and your sex life. But you should not feel embarrassed to talk to your doctor or nurse about this problem. They can give you advice on the practical ways to help overcome erectile dysfunction. See page 51 for more information.

Bladder symptoms and urinary incontinence

In a small number of cases the bladder may be permanently

affected by radiotherapy. The blood vessels in the bladder can become more fragile after radiotherapy and this can cause blood to appear in the urine. This can take many months or years to occur. If you notice any bleeding it is important to tell your doctor so that tests can be carried out and proper treatment given.

Sometimes radiotherapy can cause leakage of urine due to damage to the nerves that control the bladder muscles. But this is unlikely unless you have had a prostatectomy as well. If this occurs, it is important to discuss it with your doctor or nurse.

Diarrhoea or bowel problems

In rare cases, diarrhoea or bowel problems may persist. Occasionally, bowel movements may become more urgent and frequent after radiotherapy and rarely, you may have some difficulty in controlling your bowels. The blood vessels in the bowel can become more fragile after radiotherapy and this can cause blood to appear in your bowel motion.

Tell your doctor or nurse if you develop any of these symptoms so that suitable treatment can be given. These side-effects usually disappear about a month after treatment has ended. If you have persistent problems with diarrhoea or rectal bleeding, make sure to contact your doctor without delay.

Lymphoedema

If radiotherapy is given to the lymph glands in the pelvic area as well as the prostate, it can cause some swelling of the legs. This is known as lymphoedema. More information is available in a booklet, *Understanding Lymphoedema*, from the Irish Cancer Society. Call the Prostate Cancer Information Service 1800 380 380 for a free copy.

Brachytherapy (internal radiotherapy)

Sometimes radiotherapy for cancer of the prostate is given internally. This is called **brachytherapy**. Small radioactive seeds or beads are inserted into the tumour under general anaesthetic. This is so that radiation can be released slowly over a period of time. The beads are not removed but the radiation gradually wears out and there is no risk of it affecting other people. Depending on the size of the tumour, brachytherapy may be given with external radiotherapy.

About 3 weeks before the seeds are put into the prostate, a study of the prostate is done. This is called a **volume study** and finds out the exact size and position of the prostate. It is done in the operating theatre and you will need a short anaesthetic for the test. A transrectal ultrasound is used to take pictures of the prostate. The pictures will show the number of seeds needed for treatment and where they should be placed.

For 24 hours before the study you will have to follow a special diet to make sure that your bowel is empty. You will also be given an enema to empty the bowel, so that the ultrasound picture is as clear as possible.

Implanting the seeds

The day before the seeds are implanted you will have to follow a special diet and have an enema to clear the bowel. Implanting the seeds takes 1 to 2 hours. An ultrasound probe is placed in your back passage to show the prostate. Around 80 to 100 radioactive seeds are then put in through the skin between the prostate and the anus and guided into the prostate gland. As the procedure can cause some swelling of the prostate, a catheter is placed in the bladder to drain urine. This may be removed after a couple of hours or left in place overnight.

Most men go home the day after the implant.

Antibiotics are given after the implant to prevent infection. Most men go home the day after the implant. But some leave hospital as soon as they have recovered from the anaesthetic and are able to pass urine normally. After the implant, it is best to avoid heavy lifting or strenuous physical activity for 2 or 3 days.

The radioactivity from the seeds is absorbed within the prostate. It is considered completely safe for you to travel or be with other people. However, women who are pregnant (or who could be) and children should not stay close to you for long periods of time. You should not let children sit on your lap. But you can hold or cuddle them for a few minutes each day. It is safe for them to be in the same room as you at any time.

The seeds remain permanently fixed in the prostate gland. There is a tiny chance of a single seed being passed in the semen during sexual activity. So it is advisable to use a condom for the first few weeks after the implant. During this time the semen may be coloured black or brown. This is normal and due to bleeding that may have occurred during the procedure. Condoms should be double wrapped after use and disposed of in the dustbin.

Will I have any side-effects?

Brachytherapy may cause the same side-effects as external beam radiotherapy. But some of the side-effects are less likely. It is common to feel mild soreness and some bruising and discoloration between the legs for a few days after the procedure. Your doctor can prescribe mild painkillers to relieve this. If you have brachytherapy to the prostate, it may not be possible to have surgery to remove a cancer that recurs. This is because the surgery has a high risk of complication.

Urinary problems

You may notice some blood in your urine. This is quite normal but if it becomes severe or there are large clots present, you should let your doctor know at once. It is important to drink plenty of water to help prevent blood clots and flush out the bladder. Up to 1 in 7 men have problems passing urine after the procedure and may need to have a catheter inserted for a time. Some men find that they have pain or discomfort on passing water, need to pass urine more often or have a weaker urine stream. This is usually due to the radiation seeds in the prostate and improves over 6 to 12 months as the seeds lose some of their radioactivity. Drink plenty of fluids and avoid caffeine as it may help to reduce these effects.

Erectile dysfunction

Brachytherapy can cause an inability to have an erection (impotence) in about one-third of men who have this treatment for prostate cancer. It may take up to a year after treatment has ended for sexual potency to return. However, it may develop into a long-term problem and may be permanent. You may find this side-effect of treatment very difficult to deal with and it can affect your relationship with your partner and your sex life. You should not feel embarrassed to talk to your doctor or nurse about this problem. There are practical ways to help overcome erectile dysfunction. See page 51 for more information.

Palliative radiation

If the cancer has spread to the bones, radiotherapy can be given to relieve pain. It may be given as a single treatment or may be divided into a series of smaller treatments. Many men notice some pain relief within a couple of days. Others may have to wait 3 or 4 weeks. You can still take painkillers if you need them. The

radiotherapy staff will explain your treatment and the possible side-effects to you beforehand.

Strontium 89/Samarium

This treatment for bone secondaries uses a radioactive material (isotope) called strontium 89 or samarium, which is taken up by the affected bones. It is useful if several areas of bone are affected and are causing pain. You can have this treatment as an outpatient. The radiation (isotope) is given as an injection into a vein in your arm. After the injection a small amount of radioactivity remains in the urine, so men are advised to use flush toilets instead of urinals. This will reduce the risk of anyone else being exposed to the radiation.

Your doctor or nurse will discuss any special precautions with you before you go home. The amount of radiotherapy is very small, and it is safe for you to be with other people, including children. Most men feel some effect of the treatment within a few weeks, although occasionally the pain may get slightly worse before it gets better.

To sum up

- Radiotherapy is the treatment of cancer using high-energy X-rays.
- It can be given in different ways and for all stages of prostate cancer.
- The amount of treatment you receive will depend on the extent of the cancer.
- Radiotherapy for prostate cancer may cause short or long-term side-effects.

■ Hormonal therapy

Hormones are substances that occur naturally in the body. They control the activity and growth of normal cells. Cancer of the prostate depends on the male hormone testosterone for its growth. In the body the testes produce testosterone. By reducing the amount of testosterone in the body it is possible to slow down or stop the growth of the cancer cells. It can shrink the tumour and symptoms will often disappear fully.

The levels of testosterone in the body can also be lowered by removing the testes that produce testosterone or by using drugs. The drugs can be given as tablets or injections.

Recent studies have shown that for some men with early prostate cancer, a short course of hormonal therapy before and during radiotherapy improves the results of radiotherapy treatment. The drugs may be continued for 2 to 3 years after radiotherapy, if the cancer is advanced and there is a high risk that it has spread to other parts of the body. This is known as **adjuvant therapy**.

Hormone treatment can be effective for many years.

In cancers which have broken through the outer layer of the prostate gland, a 3-year course of treatment with hormonal therapy may be advised to reduce the risk of the cancer spreading. This treatment may last for an indefinite period.

Hormonal therapy is the standard treatment for prostate cancer that has spread or developed secondaries or metastases. Often the cancer shrinks well and symptoms disappear such as poor urinary flow, bone pain or tiredness. Hormone treatment can be effective for many years. Your doctor will watch your response to treatment by assessing any symptoms and examining you. He or she will also

measure your PSA level. This test is usually a good guide to the success of the treatment.

Different types of hormone treatment

Pituitary-down-regulators

Some drugs 'switch off' the production of male hormones from the testes. They are called pituitary-down-regulators. The drugs commonly used include goserelin (Zoladex), leuprorelin (Prostap) and triptorelin (Decapeptyl). These drugs are usually given as a pellet injected under the skin of the abdomen. Or they can be given as a liquid injected under the skin or into a muscle. Injections are given monthly or every 3 months.

Anti-androgens

Other hormonal therapy drugs work by attaching themselves to proteins on the surface of cancer cells. This blocks the testosterone from entering the cancer cells. They are called anti-androgens and are often given as tablets. Commonly used anti-androgens are flutamide (Drogenil), bicalutamide (Casodex) and cyproterone acetate (Androcur).

Anti-androgens are given for 2 weeks before the first injection of the pituitary-down-regulator and for 2 weeks afterwards. This prevents 'tumour flare', which is an increase in symptoms connected with the first dose of treatment.

Orchidectomy (removal of the testes)

Orchidectomy is an operation to remove the testicles (testes) which produce testosterone. The operation is done under general anaesthetic. A small cut is made in the scrotum (the sac which holds the testicles) and the testicles are removed. The scrotum will be smaller than before. You may have some pain for a day or

two after the operation. Your doctor will give you painkillers if required. You may need to stay in hospital for 2 or 3 days after the operation.

Many men find the idea of this operation very distressing. They may feel it makes them less of a man. Some men do not find this a problem but for those who do, drugs are an alternative to surgery. Removal of the testes can control the cancer and reduce symptoms in up to 80% of men. At first you may experience some pain and often swelling and bruising of the scrotum, but it heals quickly. Later the side-effects of hot flushes and sexual impotence are similar to those of drug treatment.

By removing the testes, it avoids the use of drugs and possible side-effects such as breast swelling and tenderness. It is often the option chosen by elderly men who have no desire for an active sex life.

Side-effects of hormonal therapy

Unfortunately, most hormonal therapies usually cause erectile dysfunction and loss of sexual desire. With an orchidectomy this is permanent. With drugs or tablets it normally continues for as long as the treatment is given. If the treatment is stopped the problem may disappear. However, you should not stop any treatment unless advised by your doctor. Some types of anti-androgens are less likely to cause erectile dysfunction than others.

In about half of the men who have drug hormonal therapies, the side-effects that cause the most problems are hot flushes and sweating. Flushes do end if the treatment is stopped. But in the meantime there are some medications that can help.

Hormonal treatment can also cause you to put on weight. You may also feel constantly tired, both physically and mentally. The

tiredness gets better if the treatment is stopped. For some hormone therapies it may be possible to receive treatment at intervals of 3 to 4 months. This allows the testosterone to return to normal levels and the side-effects of treatment to disappear. Some drugs may also cause breast swelling and tenderness.

Receiving hormone therapy for a long time can cause osteoporosis. Discuss this with your doctor. If your doctor feels that hormonal treatment is an option for you, he or she will discuss the benefits and unwanted effects of both drug treatment and surgery before you start treatment. Being warned about possible side-effects can make them easier to cope with at the time.

To sum up

- Hormonal therapy is a treatment that uses drugs or surgery to control cancer.
- It can be used on its own or with other treatments.
- Hormonal therapy may cause short or long-term side-effects.

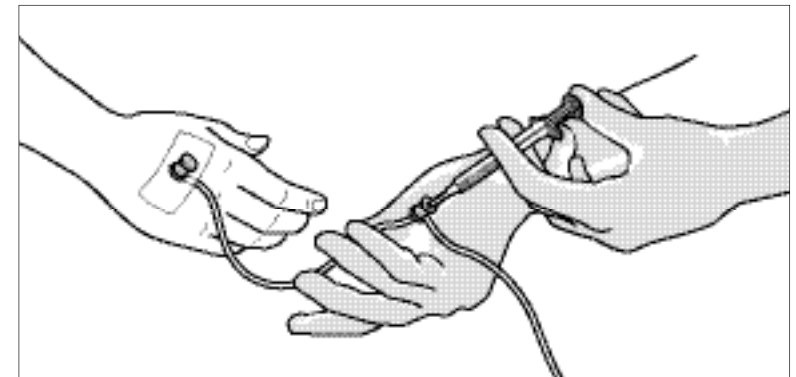
■ Chemotherapy

Chemotherapy is a treatment using drugs that cure or control cancer. Even though it is often used to treat some types of cancer, it has only recently been used to treat prostate cancer. Its aim is to prolong life rather than improve quality of life.

Chemotherapy may be used for men whose cancer has spread beyond the prostate, and is no longer controlled by hormone therapy. In some cases, chemotherapy will improve quality of life with better control of symptoms.

The drugs used in chemotherapy travel through the bloodstream to almost every part of the body. They are often given in cycles such as once every 3 weeks or once weekly with a rest period between treatments. The rest period allows your body to recover from the effects of the drugs. The number of cycles you receive will depend on how well the cancer is responding to treatment.

Chemotherapy may be given directly into a vein as an injection or by infusion (drip). It may also be given in tablet form. Depending on the type of chemotherapy you need, you may have to stay in hospital overnight for treatment. However, some treatments are given in day care.



Giving chemotherapy into a vein

Nowadays, docetaxel (Taxotere), mitoxantrone, vinblastine and doxorubicin are the drugs most often used. So far only Taxotere has been shown to improve survival rates.

Side-effects of treatment

The side-effects of chemotherapy vary from person to person and depend on the drugs used. It is possible to have this treatment and

have side-effects that are well controlled with medication. These unwanted effects happen because chemotherapy affects both cancer cells and normal cells too.

Before you start your treatment ask your doctor about any side-effects that may occur. Do tell your doctor about the way you are feeling during your treatment as most side-effects can be eased with medication. Hair and nail changes, diarrhoea and mouth soreness, fatigue and blood count changes are common side-effects. But often no side-effects are seen.

In most cases, the side-effects go away when the treatment ends or soon after. Your doctor or nurse can give you something to stop most of them or make them easier to cope with. If you would like more details about chemotherapy, a booklet called *Understanding Chemotherapy* is available from the Irish Cancer Society. Call the Prostate Cancer Information Service 1800 380 380 for a free copy.

To sum up

- Chemotherapy is a treatment using drugs to cure or control cancer.
- The drugs can be given in tablet form, directly into a vein as an injection or through an intravenous infusion (drip).
- The side-effects can vary and depend on the drugs used. Most side-effects are well controlled with medication.

■ Relief of symptoms

If you have symptoms that are troubling you, let your doctor or nurse know.

Sometimes when you have cancer it can be hard to know if the symptoms you are having are part of your illness or a side-effect of treatment. The symptoms can vary from time to time and be either mild or severe. If you have symptoms that are troubling you it is important to let your doctor or nurse know. He or she can give you treatment that will help. The most common symptoms of secondary prostate cancer are pain and fatigue.

Pain

For some men with prostate cancer, pain is one of the main symptoms that make them to go to their doctor in the first place. The pain may be constant or only present now and then. If you do have aches and pain in your bones, contact your doctor.

Your doctor will try to find out what is causing the pain. Surgery, radiotherapy, hormone therapy and chemotherapy can all help to ease pain. There is also a lot of good painkilling (analgesic) medication available today. Your doctor will decide on which painkiller is best suited to the type of pain that you have. If the medication does not kill the pain tell your doctor or nurse. You may need to try out different painkillers before you find what suits you best. There are other ways to treat pain such as nerve blocks and epidural injections.

What you can do

- If you are in pain tell your doctor or nurse about it straight away. Be honest about the level of pain that you are in. There is no need to suffer in silence or play down the amount of pain that you have.

- Try to describe the pain as clearly as you can. Is it a dull pain? A sharp sudden pain? A pain that is always there? One that comes over you in waves? Is it mild or severe? Do you wake up in pain during the night? It may be helpful to write down the times when you get the pain and what makes it better or worse. You could show this record to your doctor or nurse as it may help to explain your problem.
- If you only have pain from time to time, take the painkillers when you need them. However, if the pain is there most of the time or all of the time, take your painkillers regularly. This is most important to keep your pain under control.
- Even though your pain may be well controlled most of the time, you may notice that the pain is worse at night and wakes you up. Discuss this with your doctor or nurse. You can get extra medication to help with 'breakthrough pain'.
- Some painkillers have side-effects, especially the strong ones. These side-effects may include constipation (unable to pass a bowel motion), feeling sick (nausea) and drowsiness. If you have constipation it's a good idea to take a laxative every day. A laxative and drinking plenty of clear fluids such as water and fruit juice will help keep your bowel habit regular. Your doctor or nurse will give you something stronger if your bowels have not opened for 2 or 3 days.
- If you are feeling sick your doctor may give you anti-sickness tablets. These should be taken 30 minutes before your painkillers. This nausea often improves as you get used to your medication.
- Drowsiness may occur when you take a stronger painkiller. It usually wears off after a few days. Do not drive or work machinery if you feel drowsy.

Fatigue

Fatigue is something that lots of people complain of from time to time, even if they are not ill. For most people it is nature's way of telling them to slow down and take some rest. Fatigue is a common symptom of cancer and is often described as an overwhelming tiredness. You may find it difficult to concentrate or make decisions. The reason for the fatigue can be hard to identify. Fatigue may be caused by anxiety when a diagnosis of cancer is made and the added stress caused by treatment. Remember that even though you may find it hard to identify the reasons for your tiredness, there are things you can do to help.

What you can do

Treatment: For many men, treatment may help by easing symptoms such as pain and urinary problems. It can then allow you to get back to your normal routine. Ask your doctor before you start treatment what side-effects you can expect.

Sleep: If you are feeling worried and find it hard to sleep at night tell your doctor or nurse. He or she may be able to help.

Sharing worries: Try talking to your close family or friends about your concerns. If you find this difficult ask to see a counsellor. He or she will help you to find ways to relax.

Exercise: If your illness allows you to take part in physical exercise, do some on a regular basis. For example, a 10-minute walk 3 days a week might be a realistic goal and will boost your morale when you achieve it.

Eating and drinking: You may notice that you have lost weight. This may be due to the cancer or the treatment you are getting. Sometimes when you are feeling weak and tired you may lose

interest in your food. Ask for help in preparing your meals. Eat your favourite foods. Drink lots of clear fluids such as water and fruit juice.

Involve others: Get others to help you around the house, with travelling to hospital, at work, with the children or with shopping. Use the extra free time to do something that you especially enjoy.

A booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call the Prostate Cancer Information Service 1800 380 380 for a copy.

■ *General side-effects of treatment*

Unfortunately, treatment for cancer of the prostate can cause unpleasant and distressing side-effects. This can be in both the short and long term. Before you have any treatment it is important that you are fully aware of any side-effects.

It is not possible for doctors to predict accurately who is going to be affected by the side-effects of each treatment. That is why it is best to be fully informed about the risks beforehand and have plenty of opportunity to discuss them.

Urinary incontinence

Urinary incontinence may be caused by the cancer itself or following surgery. In rare cases it can be caused by radiotherapy. In recent years, a lot of progress has been made in dealing with incontinence. There are now several ways of coping with the problem and help is available. First talk to your doctor or nurse. Your local public health

nurse may also be able to help you. All the HSE offices (local health boards) have continence advisers who will show you ways to cope. See page 75 for more details on HSE offices.

It is important to say that these problems do not affect all men. You can ask your doctor as many questions as you like about your treatment and the possible side-effects, so that you are better prepared to cope if problems do arise.

Sexual problems/erectile dysfunction

Any type of treatment may make you too tired to be interested in sex. This is known as loss of libido and it is common to many illnesses, not just cancer.

You may find it difficult to talk about such private matters as erectile dysfunction, particularly with your doctor or other medical staff. Try not to be embarrassed as the doctor and staff looking after you will be happy to discuss any concerns you may have. Impotence may not be permanent and can sometimes be brought on by anxiety rather than the treatment. Depending on the treatment you receive, it can take up to year before you find out if the erectile dysfunction is permanent or not.

You may find it difficult to talk to your partner, for fear of rejection — but these fears are often unfounded. Sexual relationships are built on many things, like love, trust and common experiences. It can help to talk to your partner about your fears and worries.

If you find the loss of your sex life upsetting, discuss it with your doctor or nurse.

If you find the loss of your sex life upsetting, you could discuss this with your doctor or nurse. There are practical ways to overcome erectile dysfunction and your doctor can give you further information about these.

Medication

Tablets such as tadalafil (Cialis), sildenafil (Viagra) and vardenafil (Levitra) are available to help produce an erection. They work by increasing and retaining the blood supply to the penis. They are normally taken about 1 hour before lovemaking, and then, following direct stimulation an erection will occur. However, men who take nitrate-based medicines for heart problems cannot use Viagra.

A small pellet known as MUSE that contains alprostadil can be put into the tip of the urine tube (urethra) using a special applicator. The pellet melts into the area and after a few minutes produces an erection.

Drugs such as alprostadil (Caverjet) can be injected into the penis, using a small needle, to cause an erection. The drug restricts blood flow and traps blood in the penis, causing an instant erection. These work for many men, although injection can be sore and alprostadil can sometimes cause a prolonged painful erection.

Vacuum pumps

Vacuum pumps can also be used to produce an erection. The pump is a simple device with a hollow tube, which you put your penis into. The pump has a handle and sucks blood into the penis by creating a vacuum. The blood then gets caught in the penis by a rubber ring placed around the base. This ring then allows you to have sex without losing the erection.

The majority of men who become impotent after prostatectomy or radiotherapy will probably gain some benefits from the treatments described above. However, everyone is different and specialist advice and counselling can be useful for many men. If you need more help, talk to your doctor. He or she will refer you for special counselling if you think this might be helpful.

If you need more help, talk to your doctor.

Infertility

Most treatments for cancer of the prostate are likely to cause infertility. This means you will no longer be able to father a child. This may or may not worry you. For some men the prospect of infertility can be a difficult issue to come to terms with. It may help to talk to a member of your family or a close friend. Ask your doctor or nurse for advice on what you should do before you start treatment.

If tests show that your sperm count is satisfactory it may be possible to store sperm before treatment begins. They can then be used at a later date. In Ireland sperm banking takes place in the HARI Unit at the Rotunda Hospital in Dublin. You will be asked to give several sperm samples. Between each sample there will be a couple of days break to make sure good samples are obtained.

The sperm will then be frozen and stored until required.

If you want to find out more about sperm banking, talk to your doctor or nurse. He or she will give you more information. Call the Prostate Cancer Information Service 1800 380 380 for advice in confidence or for details about the HARI Unit.

If you want to find out more about sperm banking, talk to your doctor or nurse.

■ *Research – what is a clinical trial?*

Research into new ways of treating prostate cancer goes on all the time. If a treatment looks like it might be of benefit, it is given to patients in research studies called **clinical trials**. These aim to find a safe dose, see what side-effects may occur and which cancers can be treated.

If early studies suggest that a treatment may be both safe and effective, further trials are carried out. These aim to:

- Find out if the treatment is better than existing ones.
- Find out if extra benefits result when the new treatment is given along with existing ones.
- Compare the new treatment with current best standard treatments.

Many patients with prostate cancer take part in research studies. Your doctor may ask you to try a new treatment. There are many benefits in doing this. You will be helping to improve knowledge about prostate cancer. You will also be carefully monitored during and after the study, so you will be quite safe.

You cannot be included in a clinical trial without your permission. You can only give this consent if the trial has been fully explained to you, so that you understand what it is about. This is called **informed consent**. You will also need time to think about it and discuss it with your family or friends. If you decide not to take part, you will still be given the best treatment available. You are also free to withdraw from a trial at any time if you change your mind.

As part of research into the causes of cancer, your doctors may ask your permission to store some samples of your blood. If you would like more information, a booklet called *Understanding Cancer Research Trials (Clinical Trials)* is available. Call the Prostate Cancer Information Service 1800 380 380 for a copy.

■ *Complementary and alternative therapies*

There is great interest today in complementary and alternative treatments for cancer. Lots of people find them helpful and beneficial during their illness. The way cancer is treated often depends on the culture and environment of the country in which you live. In Ireland cancer treatments are based on scientific research. This allows the response to treatment, side-effects and the general effect of treatment to be predicted.

You may hear about the following types of treatments or therapies.

Conventional therapies

Conventional therapies are treatments which doctors use most often to treat people with cancer. These standard treatments include surgery, radiotherapy, chemotherapy and biological treatments. They use tried and trusted methods where the experience with patients is over a long period of time. Many of these treatments have been tested in clinical trials.

Complementary therapies

Complementary therapies are treatments that are sometimes given **together with** conventional treatment. They include therapies such as:

- Meditation
- Relaxation
- Visualisation
- Gentle massage
- Aromatherapy
- Reflexology
- Music, art and dance therapy
- Nutrition therapy
- Shiatsu
- Yoga
- Acupuncture
- Hypnotherapy.

Many people find that complementary therapies are very helpful in a number of ways. You may feel more positive about yourself and your illness. You may be better able to cope with the physical side-effects of cancer and the distressing emotions that cancer can often bring. Some complementary therapies also focus on the spiritual dimension of a person. This can aid healing and promote a sense of well-being. Nowadays complementary therapies are often provided in hospitals, cancer treatment centres and support centres and can be given safely.

Alternative therapies

Alternative therapies are not conventional cancer treatments used by doctors. Generally they are treatments used **instead of** conventional treatments. Alternative therapies include:

- Diet therapy
- Megavitamin therapy
- Herbalism.

Because these therapies are not based on scientific evidence it is very hard to prove if they are generally effective or not. Many doctors do not believe that such treatments can cure or control cancer. They believe they should not be taken instead of conventional treatments.

Alternative treatments can interfere with standard treatment and may not be managed properly. At present in Ireland this is an unregulated area with no register of certified practitioners. For this reason, you should ensure that the alternative practitioners you plan to visit are qualified and have a good reputation. It is best to discuss your plans with your doctor too.

If you decide to have complementary or alternative treatments. . .

Before you decide to change your treatment or add any methods of your own, be sure to talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects. For that reason, it is important to talk openly with your GP or oncologist if you are thinking of having treatment with either a complementary or alternative practitioner. Don't be afraid that your doctor will be offended by your wish for other treatments. In fact, he or she may be able to recommend therapies that could be safe and useful for you.

Be cautious in selecting a practitioner. Don't be misled by promises of cures. Ensure that the practitioners you plan to visit are qualified and have a good reputation. Check to see if they belong to a professional body or not. If you are unsure but would like to know what other patients have found helpful, contact your doctor or a patient support group. Also, it is important to make sure that the practitioner is charging a fair price for your treatment.

More information is available in a free booklet from the Irish Cancer Society called *Cancer and Complementary Therapies*. If you would like a copy or more advice, call the Prostate Cancer Information Service 1800 380 380.

Follow-up

Once your treatment is over, you will have to come back for regular check-ups. This will happen no matter what type of treatment you have. These check-ups may include seeing your doctor and having some tests such as blood tests, X-rays and scans. These visits are very important as they will allow your doctor to check for signs of prostate cancer and to follow up on any ongoing side-effects that you may have. He or she will also be able to check for new side-effects that may develop. It is better to be aware of these as early as possible so that further treatment can be given.

If you are between check-ups or you have a symptom or problem that worries you, let your doctor know without delay. Make an appointment to see him or her as soon as possible.

If you would like to keep track of all your PSA results, dates of treatment, any side-effects, etc., there is a useful pocket diary available called the *Prostate Passport*. It is produced by Men Against Cancer (MAC) and the Irish Cancer Society. Call the Prostate Cancer Information Service 1800 380 380 for a free copy.

Coping and emotions

How to cope with your feelings

You might feel numb and shocked when you are told that you have cancer. You can feel swamped with many different emotions ranging from disbelief to anger. At first the news may be very hard to take in. It may all seem 'unreal'. All these feelings are normal and to be expected. It does not mean that you are not coping. Rather they are part of the process you must go through in coming to terms with your illness. Your family and friends may also be feeling the same way and need time to get used to it.

Reactions differ from one person to another. There is no right or wrong way to feel.

Reactions differ from one person to another. There is no right or wrong way to feel.

Shock and disbelief

'I can't believe it.' 'It can't be true.'

Shock is often the first reaction when a diagnosis of cancer is made. Most people think, 'It will never happen to me.' It will take a while for the news to sink in. At this stage you may be getting a lot of information about your illness. You may ask the same questions over and over again or seem to accept the news calmly. These are common reactions to a diagnosis of cancer. Because you don't quite believe what is happening, you may not want to talk about your illness, especially to your close family and friends.

Fear and uncertainty

'Am I going to die?' 'Will I be in pain?'

For most people when they are told they have cancer the first question is 'Am I going to die?' Cancer is a very scary word. It brings to mind many stories – most of them untrue. In fact, nowadays many cancers can be cured. When cure is not possible the cancer can be controlled for a number of years using modern treatments. There are new treatments being developed all the time.

Another common fear is that cancer is always painful. This is not true. Some cancers cause no physical pain at all. If you have pain there are many drugs that can control it. Other methods of pain relief include radiotherapy and nerve blocks.

Being concerned about your future is a normal way to feel. It can be hard for your doctor to predict the outcome of your treatment. Not knowing can make you feel anxious. The more you find out about your illness and its treatment, the less anxious you will be.

The real facts about cancer and its treatment are not as frightening as you might imagine. Talk to your doctor about your concerns, he or she should be able to help you. Discuss what you have found out with your family and friends, as they are probably worried too.

Denial

'There is nothing really wrong with me.' 'I haven't got cancer.'

Many people cope with their illness by not wanting to talk about it. If that is the way you feel, then just say quite firmly to the people around you that you would prefer not to talk about your illness, at least for the time being.

Sometimes, however, it's the other way round. You may find it is your family and friends who are denying your illness. They appear to ignore the fact that you have cancer. They may play down your worries and symptoms and keep changing the subject. If this upsets or hurts you because you want them to support you, try telling them. Start perhaps by saying that you do know what is happening and it will help you if you can talk to them about your illness.

Anger

'Why me of all people?' 'And why right now?'

Anger can hide other feelings such as fear or sadness. You may find that you vent your anger on those closest to you. You might also feel angry towards the doctors and nurses who are caring for you. If you have a religious belief you may feel angry with your God.

There is no need to feel guilty about your angry thoughts or irritable mood. Don't bottle up your feelings – express them.

It is easy to see why you may be deeply upset by many aspects of your illness. There is no need to feel guilty about your angry thoughts or irritable mood. Relatives and friends may not always be aware that your anger is really aimed at your illness and not against them. If you can, it might be helpful to tell them this at a time when you are not feeling so angry. Or if you would find that difficult, perhaps you could show them this section of the booklet.

If you are finding it difficult to talk to your family, tell your nurse or doctor. He or she may be able to help you.

Blame and guilt

'If I hadn't ...this would never have happened.'

Sometimes people blame themselves or others for their illness. Or else they wonder why it should have happened to them at all. This may be because we often feel better if we know why something has happened. As doctors rarely know exactly what has caused cancer, there is no reason for you to blame yourself. Don't bottle up your feelings – express them.

Resentment

'It's all right for you, you haven't got to put up with this.'

It is not unusual to feel resentful and miserable because you have cancer while other people are well. You may notice that similar feelings crop up from time to time during the course of your illness for a variety of reasons. Relatives too can sometimes resent the changes that your illness can make to their lives.

It is usually helpful to bring these feelings out into the open so that they can be aired and discussed. Bottling up resentment can make everyone feel angry or guilty.

Withdrawal and isolation

'Please leave me alone.'

There may be times during your illness when you want to be left alone to sort out your thoughts and feelings. This can be hard for your family and friends who want to share this difficult time with you. Let your family know that while you do not feel like talking about your illness at the moment, you will talk to them about it when you are ready.

Sometimes depression can stop you wanting to talk. It might be an idea to discuss this with your GP or hospital doctor who may prescribe a course of antidepressant drugs. He or she may decide

to refer you to a doctor who specialises in managing the emotional problems of cancer patients. It is common for patients with cancer to feel depressed, so there is no need to feel you are not coping if you ask for help.

Call the Prostate Cancer Information Service 1800 380 380 if you would like a free copy of *The Emotional Effects of Cancer*. Another useful booklet is *Who Can Ever Understand? Talking about Your Cancer*.

Learning to cope

After any treatment for cancer it can take a long time to come to terms with your emotions. Not only do you have to cope with the knowledge that you have cancer, but also the physical effects of treatment.

Even though the treatment for cancer can have some unpleasant side-effects, many people manage to live a relatively normal life during treatment. You will need to take some time off for your treatment as well as time afterwards to recover. Just do as much as you feel like and take plenty of rest. It is not a sign of failure to ask for help or to feel unable to cope on your own. Once other people understand how you are feeling they can give more support.

■ *What if you are a relative or friend?*

It can be hard to know what to say when someone close to you is diagnosed with cancer. It may seem best to pretend that everything is fine and carry on as normal. You may not want to add to the person's worry by seeming afraid or by saying the wrong thing. Sadly, denying strong feelings like this can make it even harder to talk openly together and can lead to the person feeling very lonely.

Partners, relatives and friends can help by listening carefully to what the person with cancer wants to say about his or her illness. Don't say too much. Just let them do most of the talking. Above all, let them know that you are there when they want to talk or need help.

A useful booklet called *Lost for Words – How to Talk to Someone with Cancer* is available from the Irish Cancer Society for relatives and friends of people with cancer. Call the Prostate Cancer Information Service 1800 380 380 if you would like a free copy.

■ *Talking to children*

How much you tell children will depend on how old they are. Very young children don't understand illness and need a very simple account as to why their parent or friend has had to go to hospital. Slightly older children will need to be told more. A simple story talking about good cells and bad cells may help. Every child needs

to know what will happen while you are in hospital. Who will look after them, prepare their meals and take them to school? They also need to be reassured that your illness is not their fault. Whether they show it or not, children feel they may somehow be to blame and may feel guilty. Most children over 10 years of age can grasp fairly detailed explanations of what is wrong.

An open honest approach is usually the best way for all children.

Adolescents can understand much more. They may have special needs in learning to cope with the situation. They may be torn between concern for you and trying to become more independent. An open honest approach is usually the best way for all children. You may find that your children rebel or turn quiet. This may be their way of showing their feelings. Even very young children can sense when something is wrong, so don't keep them in the dark. They may think that things are much worse than they are.

There is a booklet available called *What Do I Tell the Children? A Guide for the Parent with Cancer*. Call the Prostate Cancer Information Service 1800 380 380 if you would like a free copy.

■ *What you can do*

Many people feel helpless when they are first told they have cancer. They think there is nothing they can do other than hand themselves over to the doctors and hospital. This is not true. There are many things that you can do at this time.

If you and your family understand your illness and its treatment you will be better able to cope.

- Always ask for information that is personal from your own doctors.
- Follow your doctor's instructions carefully. Take your medication. If you forget and are not sure what to do, ask your doctor. Write down the answers if you want.
- Let your doctor know if you have any problems or worrying side-effects. He or she can decide what to do to help you. If you say nothing a small problem can become more serious.
- At times you may not be able to do the things you used to take for granted. As you begin to feel better you can set yourself some simple goals and slowly build your confidence again. Take one step at a time. Many people talk about 'fighting their cancer'. This can help some people feel more in control of what is happening to them. You can do this by becoming involved in your illness.
- Try to eat as well as you can. Eat little and often, using lots of different types of foods with plenty of fresh fruit and vegetables.
- Think about joining a support group. These groups allow you to talk through your feelings with others who have been diagnosed and treated for cancer. Men Against Cancer (MAC) is the support group for men with prostate and testicular cancer. It provides patients and relatives with information, advice and

emotional support at time of diagnosis, throughout treatment and afterwards. See page 79 for more information.

- Join a relaxation class or listen to relaxation tapes.
- Take some regular exercise. Take it easy at first. Gradually build up the amount you do, as you feel stronger.
- Some people find it helpful to talk to a counsellor or a specialist in psychological medicine.

If the idea of changing your diet or taking exercise does not appeal to you, don't do it. Just do whatever suits you. Some people find pleasure in keeping to their normal routine as much as possible. Others prefer to take a holiday or spend more time on a hobby.

■ *Who else can help?*

There are many people ready to help you and your family throughout treatment and afterwards.

- Medical social worker
- Oncology liaison nurses
- Cancer nurse co-ordinators
- Psycho-oncology services
- Community welfare officer and community health services
- Prostate Cancer Information Service.

Remember that there are many people ready to help you.

The **medical social worker** in your hospital can help in many ways. He or she provides support and counselling to the patients and their families and can provide advice on benefits, entitlements and services available when you go home.

Some of the major cancer treatment hospitals have **oncology liaison nurses** and/or **cancer nurse co-ordinators**. These specially trained nurses provide support to patients and their families from the time of diagnosis and throughout treatment. These people along with other members of your medical team work together to meet your needs.

In some larger hospitals there are special units that provide **psycho-oncology services**. This means that psychological care and support is given to patients with cancer during diagnosis, treatment and recovery by a team of experts. Usually the team consists of psychiatrists, clinical psychologists, nurses and medical and surgical doctors working closely together.

When you go home there are various **community health services** available from your local health centre. These centres have family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. If you live in an area which is remote or far from the hospital where you have been treated, your **community welfare officer** can also help with practical issues such as financial worries, etc. All the above people in the community health services can provide advice and support. You can get more information on the services available either from the social worker in the hospital before you go home or at your local health centre.

The staff of the **Prostate Cancer Information Service** at the Irish Cancer Society will be happy to discuss any concerns you or your family may have, at any stage of your illness. Call 1800 380 380 for information about any of the services outlined above or for support services in your area.

Support resources

■ *Health cover*

Health cover falls into two categories. Cover for medical card holders and cover for all other categories. Details of what these involve are given in the following pages. At the end of this section there are also some useful telephone numbers and addresses for further help.

Hospital cover

At present everyone is entitled to hospital inpatient services in a public ward in all public hospitals. There is a €60 a night charge up to a limit of €600 in 1 year. These charges do not apply to medical card holders. Higher rates apply for semi-private or private care.

Outpatient cover

If you go to the outpatients or A&E unit of a public hospital, without being referred there by a GP, you may be charged €60. There is no charge if you are referred by a GP. This charge does not apply if you have a medical card or are admitted to hospital as a result of attending the A&E unit first.

Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services, and outpatient services and medical appliances. Every person aged 70 or over has a right to a medical card and no means test is required. It covers the applicant only and not their dependents.

For most people, to qualify for a medical card depends on a means test. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office, i.e. the former health board. If your means are above but close to the guidelines, you should apply for a card anyway as a card is granted in some situations. For example, if you have a large amount of medical expenses. Also, you may qualify for a medical card because you have a cancer diagnosis. In this case your spouse and children will not be covered if your means are over the limit.

GP visit card

If you do not qualify for a full medical card, you may be eligible for a new type of medical card. This is the 'GP visit card' and was introduced in 2006. It covers visits to your doctor only and you will have to pay for drugs, outpatient/inpatient charges and medical appliances yourself. It is means tested but will take into account your-after tax income, your childcare, rent/mortgage and travel to work expenses. Check with the medical social worker or your HSE office to see if you are eligible.

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families including spouses and dependant children pay a limit of €85 each month to cover the cost of prescribed drugs, medicines and appliances. If you have not already received a DPS card for yourself and your family, you can apply for cover under the scheme by contacting your local HSE office. You can also register for this scheme by filling in a registration form at your pharmacy. If you opt for egg freezing, the cost of the drugs used in the procedure can be reclaimed through the DPS.

Private healthcare cover

Private health insurance is used to pay for private care in hospital or from various specialists in hospitals or in their practices. In Ireland this is available through the VHI, BUPA, VIVAS Health and other schemes. They provide cover for day care/inpatient treatment and hospital outpatient treatment. Before attending hospital, it is best to check the level of cover provided by your insurance company, both for inpatient and outpatient services.

Benefits and Allowances

Disability Benefit

This is a benefit for insured people. Eligibility will depend on your PRSI contributions. You must be under 66 and unfit to work due to illness. Each week you must send a social welfare medical certificate signed by your doctor to the Dept of Social and Family Affairs, PO Box 1650, Dublin 1. Tel (01) 679 7777. These certificates are available from your GP and from the hospital you attend during inpatient care. You should send your claim to the Department within 7 days of becoming ill and unable to attend work. A delay might result in loss of payment.

Disability Allowance

You may qualify for Disability Allowance if you are not eligible for Disability Benefit and not able to work for at least a year. Disability Allowance is a weekly allowance paid to people with a disability who are aged between 16 and 66. You must have a means test and be medically suitable for this allowance. To be medically suitable you should have an illness that has continued or may continue for at least 1 year. This means that you are unlikely to be able to work for at least a year due to your illness. Application forms are available

from post offices, social welfare offices or the Disability Allowance Section, Social Welfare Services Office, Ballinalee Road, Longford. Tel: (043) 45211 or (01) 874 8444.

Invalidity pension

This is a pension paid instead of a Disability Benefit or Allowance, if you are unable to work in the long term. There are three cases where you can be eligible. (1) If you have been incapable of work for at least 12 months and likely to be incapable for at least another 12 months. (2) If you are permanently incapable of work. (3) If you are over age 60 and have a serious illness or incapacity.

Your eligibility for this pension will also depend on your PRSI contributions. You are allowed a free travel pass and certain extra benefits, such as bottled gas, telephone rental, fuel allowance and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from the Invalidity Pension Claims Section, Social Welfare Services Office, Ballinalee Road, Longford. Tel: (043) 45211 or (01) 874 8444.

Carer's Allowance

This is an allowance for carers on low incomes who look after someone who needs full-time care and attention. There are a number of benefits with this scheme such as a free travel pass for the carer, free television licence, and home energy allowance. A telephone allowance has been extended to carers giving full-time care. There is also a contribution towards respite care. This is a means-tested allowance. For more advice, talk to your social worker and/or the Dept of Social and Family Affairs. Application forms are available from your social welfare office or from the Carer's Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 45211, Ext. 8940 or Dublin (01) 704 3000, Ext. 8940.

Carer's Benefit

If you are employed but wish to care for a sick relative, you may qualify for a Carer's Benefit. This is a payment made to insured persons who leave the workforce to care for someone in need of full-time care and attention. Under Carer's Leave legislation, you may be entitled to unpaid temporary leave from your employment. You should apply for Carer's Benefit 8 weeks before you intend to leave employment so that your eligibility can be assessed prior to leaving your employment.

More information is available from the Carer's Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 45211, Ext. 8787 / Dublin (01) 704 3000, Ext. 8787.

Appliances

For patients who have medical cards most appliances are free of charge. For example, you are entitled to a new hairpiece or wig every 6 months.

Travel to hospital

Patients can be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services to hospitals for outpatient appointments and day centres. Sometimes the HSE may assist with transport costs for a person who has to travel a long distance to a hospital.

In general, people who do not have medical cards may be charged for the service. However, the practice varies between HSE areas and is often dependent on personal circumstances. Charges may be waived in certain cases, e.g. hardship, etc.

Further information

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements which may be relevant to you. Always have your PPS number (old RSI number) to hand when you are enquiring about entitlements and benefits. The most direct way to check your eligibility is to contact:

- Your community welfare officer in your local health centre
- The medical social worker in the hospital you are attending.

For social welfare queries contact:

Information Service
 Dept of Social and Family Affairs
 Áras Mhic Dhiarmada
 Store Street
 Dublin 1
 Tel: 01 874 8444
 Leaflet line: 1890 202 325
 Email: info@welfare.ie
 Website: www.welfare.ie

If you have queries about health and social services, contact the HSE office in your area. In 2005 the functions of the local health boards were transferred to the Health Service Executive (HSE). Email www.hse.ie for more details.

HSE Eastern Region

[formerly Eastern Regional Health Authority]
 Customer Services Department
 Dr Steeven's Hospital
 Dublin 8
 Tel: 01 635 2400
 or Freefone 1800 520 520
 Email: customerservices@erha.ie
 Website: www.erha.ie

HSE Midland Area

[formerly Midland Health Board]
 Head Office
 Arden Road
 Tullamore
 Co Offaly
 Tel: 0506 218 68
 Fax: 0506 517 60
 Website: www.mhb.ie

HSE Mid-Western Area

[formerly Mid-Western Health Board]
 Head Office
 31–33 Catherine Street
 Limerick
 Tel: 061 316 665
 Fax: 061 483 250
 Website: www.mwhb.ie

HSE North Eastern Area

[formerly North Eastern Health Board]
 Head Office
 Navan Road, Kells
 Co Meath
 Tel: 046 9280 500
 Fax: 046 9241 459
 Website: www.nehb.ie

HSE North Western Area

[formerly North Western Health Board]
 Head Office
 Manorhamilton
 Co Leitrim
 Tel: 071 9820 400 / 1850 636 313
 Fax: 071 9820 431
 Website: www.nwhb.ie

HSE South Eastern Area

[formerly South Eastern Health Board]
 Head Office
 Lacken
 Dublin Road
 Kilkenny
 Tel: 056 7784 100
 Fax: 056 7784 388
 Website: www.sehb.ie

HSE Southern Area

[formerly Southern Health Board]
 Head Office
 Wilton Road
 Cork
 Tel: 021 4545 011
 Website: www.shb.ie

HSE Western Area

[formerly Western Health Board]
 Head Office
 Merlin Park Regional Hospital
 Galway
 Tel: 091 751 131
 Fax: 091 752 644
 Website: www.whb.ie

Information is also available from your local Citizens Advice Centre. A list of these centres is available from:

Comhairle (formerly the National Social Services Board)
7th Floor, Hume House, Ballsbridge, Dublin 4.

Tel: 01 605 9000. Citizen Information: 1890 777 121.

Email: comhairle@comhairle.ie Website: www.comhairle.ie

There are also some booklets available that may help you. These include:

- *Information Guide to Health Services* (published by the Dept of Health and Children). Copies are available from your local HSE area office. Tel: 01 671 4711 for local HSE numbers.
- *Guide to Social Welfare Services* (published by the Dept of Social and Family Affairs). Copies available from the Dept of Social and Family Affairs. Tel: 01 874 8444. Email: info@welfare.ie. Website: www.welfare.ie
- *Entitlements for People with Disabilities* (published by Comhairle). Available from Comhairle. Tel: 01 605 9000. Email: comhairle@comhairle.ie

■ *Irish Cancer Society services*

The Irish Cancer Society funds a range of cancer support services that provide care and support for people with cancer at home and in hospital.

Homecare nurses

Homecare nurses are specialist palliative care nurses who offer advice on pain control and other symptoms. These nurses work with GPs and public health nurses to form homecare teams bringing care and support, free of charge, to patients in their own homes. Based in local hospitals, health centres and hospices, they can be contacted through your GP or public health nurse.

Night nursing

The Irish Cancer Society can provide a night nurse, free of charge, for up to seven nights to families who are caring for a seriously ill person at home. If you need help, you can find out more about this service from a member of the homecare team, your GP or local public health nurse.

Oncology liaison nurses

The Irish Cancer Society funds oncology liaison nurses who provide information as well as emotional and practical support to the patient and his or her family. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

Cancer Information Service (CIS)

The Society provides a Cancer Information Service (CIS) with a wide range of services. The **Prostate Cancer Information Service**

1800 380 380 gives confidential information, support and guidance to people concerned about prostate cancer. It is staffed by specialist cancer nurses who have access to the most up-to-date facts on cancer-related issues. These include prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services. People can also be put in contact with the various support groups that are available. The service operates weekdays from 9 am to 5 pm, and every Tuesday from 9 am to 9 pm. The **National Cancer Helpline** 1800 200 700 also operates at the same hours.

All queries or concerns about prostate cancer can be emailed to prostate@irishcancer.ie. The **walk-in caller service** allows anyone with concerns about cancer to freely visit the Society to discuss them in private. **CancerForum** is a bulletin board on our website (www.irishcancer.ie) that gives people a chance to post their comments. The **CancerChat** service is a live chatroom with a link to a CIS nurse.

Counselling

Coping with a cancer diagnosis can be very stressful. Patients and their families sometimes find it difficult to come to terms with the illness. Many people feel that they cannot talk to a close friend or relative. Counselling can provide emotional support in a safe and confidential environment. Call the Prostate Cancer Information Service to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Cancer information booklets

These booklets provide information on all aspects of cancer and its treatment. They also offer practical advice on learning how to

cope with your illness. The booklets are available free of charge from the Irish Cancer Society.

Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards.

Men Against Cancer (MAC) is the support group for men with prostate cancer. MAC provides men and their relatives and friends with information, advice and emotional support from time of diagnosis and for as long as it is needed. This support group consists of volunteers who have had treatment for prostate and prostate cancer. These men are carefully selected following recovery and are trained to provide information and reassurance at a time when you are most in need. This service is provided on a one to one basis and is confidential.

Patient grants

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society can provide immediate cash assistance to patients in need. If you would like to request this kind of help contact your oncology or medical social worker at the hospital where you have been treated. He/she should then make the request in writing to the Irish Cancer Society.

If you would like more information on any of the above services, call the Prostate Cancer Information Service 1800 380 380.

■ Useful organisations

Action Prostate Cancer

Prostate Cancer Information Service
43/45 Northumberland Road
Dublin 4
Prostate Cancer Information Service 1800 380 380
Email: prostate@irishcancer.ie
Website: www.cancer.ie

Irish Cancer Society

43/45 Northumberland Road
Dublin 4
Tel: 01 231 0500
Fax: 01 231 0555
Email: helpline@irishcancer.ie
Website: www.cancer.ie

Men Against Cancer (MAC)

c/o Irish Cancer Society
43/45 Northumberland Road
Dublin 4
Freefone 1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

Comhairle (formerly National Social Services Board)

7th Floor
Hume House
Ballsbridge
Dublin 4
Tel: 01 605 9000
Email: comhairle@comhairle.ie

Continence Promotion Unit

Dr Steeven's Hospital
Dublin 8
Tel: 01 635 2775
Email: customerservices@erha.ie

Dept of Social and Family Affairs – Information Service

Áras Mhic Dhiarmada
Store Street
Dublin 1
Tel: 01 874 8444
Email: info@welfare.ie
Website: www.welfare.ie

Everyman Clinic

4 Lower Mount Street
Dublin 2
Tel: 01 678 8010

HARI Unit (Human Assisted Reproduction Ireland)

Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732

Health Promotion Unit

Dept of Health and Children
Hawkins House
Hawkins Street
Dublin 2
Tel: 01 635 4000
Website: www.healthpromotion.ie

Wellman Clinic

10 Patrick Street
Dún Laoghaire
Tel: 01 280 3206

Health insurers

BUPA Ireland

Mill Island
Fermoy
Co Cork
Locall: 1890 70 08 90
Fax: 025 42122
Email: choices@bupa.ie
Website: www.bupa.ie

VIVAS Health

Paramount Court
Corrig Road
Sandyford
Dublin 18
Tel: 1850 717 717
Email: support@vivashealth.ie
Website: www.vivashealth.ie

Voluntary Health Insurance (VHI)

VHI House
Lower Abbey Street
Dublin 1
Tel: 01 872 4499
Email: info@vhi.ie
Website: www.vhi.ie

Support groups & support centres

ARC Cancer Support Centre

ARC House
65 Eccles Street
Dublin 7
Tel: 01 830 7333
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

Bray Cancer Support & Information Centre

36B Main Street
Bray
Co Wicklow
Tel: 01 286 6966
Email: bcsc@iol.ie
Website: www.braycancersupport.ie

Cancer Information & Support Centre

Mid-Western Regional Hospital
Dooradoyle
Co Limerick
Tel: 061 482615
Website: www.mwhb.ie/cancercentre

Cork ARC Cancer Support House

Cliffdale
5 O'Donovan Rossa Road
Cork
Tel: 021 434 6688

The Cuisle Centre
Cancer Support Group
2 Park Villas
Harper's Lane
Mountmellick Road
Portlaoise
Co Laois
Tel: 0502 81492
Email: cuislecentre@eircom.net

Donegal Cancer Support Group
Clar
Co Donegal
Tel: 074 974 0837

The Gary Kelly Support Centre
Georges Street
Drogheda
Co Louth
Tel: 041 980 5100
Fax: 041 980 5101
Email: info@garykellycentre.org
Website: www.garykellycentre.org

Greystones Cancer Support
La Touche Place
Greystones
Co Wicklow
Tel: 01 287 1601
Email: kk@kathleenkelleher.com

HOPE
Enniscorthy Cancer Support &
Information Centre
6 Church Street
Enniscorthy
Co Wexford
Tel: 054 34145

The LARCC Retreat Centre
Ballinalack
Mullingar
Co Westmeath
Tel: 044 71971
Callsave 1850 719719
Email: info@larcc.ie
Website: www.larcc.ie

Lios Aoibhinn Cancer Support Centre
St Vincent's University Hospital
Herbert House, St Anthony's
Herbert Avenue
Dublin 4
Tel: 01 277 3545

Mayo Cancer Support Association
Rock Rose House
32 St Patrick's Avenue
Castlebar
Co Mayo
Tel: 094 903 8407

Slánú Cancer Help Centre
Birchall
Oughterard
Co Galway
Tel: 091 550050
Email: info@slanu.ie
Website: www.slanu.ie

Sligo Cancer Support Centre
2A Wine Street
Sligo
Tel: 071 70399
Email: scsg@tinet.ie

South East Cancer Foundation
7 Sealy Close
Earlscourt
Waterford
Tel: 051 876629
Fax: 051 876718
Email: infosecf@eircom.net

The Tuam Cancer Care Centre
30 Temple Jarlath Court
High Street
Tuam
Co Galway
Tel: 093 28522
Email: info@tuamcancercare.ie
Website: www.tuamcancercare.ie

Turning Point – Positive Health Centre
23 Crofton Road
Dún Laoghaire
Co Dublin
Tel: 01 280 7888
Email: turningpoint@eircom.net
Website: www.turningpoint.ie

Useful contacts outside Ireland

American Cancer Society
1599 Clifton Road NE
Atlanta, GA 30329-4251
Website: www.cancer.org

CancerBACUP
3 Bath Place, Rivington Street
London EC2A 3JR
Tel: +44 207 696 9003
Helpline: +44 207 7392280
Website: www.cancerbacup.org.uk

The Continence Foundation
307 Hatton Square
16 Baldwins Gardens
London EC1N 7RJ
Email: continence.foundation@dial.pipex.com
Website: www.continence-foundation.org.uk

Macmillan CancerLine
Website: www.macmillan.org.uk

Memorial Sloan-Kettering Cancer Center (US)
Website: www.mskcc.org

National Cancer Institute (US)
Website: www.nci.nih.gov

Royal Marsden Hospital Foundation NHS Trust
Website: www.royalmarsden.org

Sexual Dysfunction Association
Windmill Place Business Centre
2-4 Windmill Lane
Southall, Middlesex UB2 4NJ
Tel: +44 0870 7743571
Email: info@sda.uk.net
Website: www.sda.uk.net

The Ulster Cancer Foundation
 40–42 Eglantine Avenue
 Belfast BT9 6DX
 Tel: 048 906 63281
 Website: www.ulstercancer.co.uk

■ *Helpful books*

Guide to Surviving Prostate Cancer
 Patrick Walsh & Janet Farrar
 Worthington
 Time Warner Books, 2001
 ISBN 0-44667-914-3

Living with Prostate Cancer
 David Wynn
 Blueberry Books, 2003
 [Available by mail order from 257
 Oxford Road, Macclesfield,
 Cheshire, SK11 8JY. Price £5.95
 plus postage and packing. Tel:
 +44 1625 431182 or +44 7976
 693 641]

*Prostate and Cancer: A Family
 Guide to Diagnosis, Treatment and
 Survival*
 R Persad, J Smith, K. Jefferson &
 B. Patel
 Fisher Books, 2000
 ISBN 1-55561-262-8

**University of Pennsylvania
 Cancer Center**
 Website: www.oncolink.com

*The Prostate Book: An Owner's
 Manual*
 Dr Peter Scardino
 Michael Joseph Ltd, 2005
 ISBN 0-71814-694-8

*Prostate Cancer: A Definitive Guide
 for Patients*
 Robert H. Phillips
 TFM Publishing Ltd, 2002
 ISBN 1-9033-7810-9

*The Prostate Cancer Book: The
 Definitive Guide to the Causes,
 Symptoms and Treatments*
 Prof Jonathan Waxman
 Vermilion, 2002
 ISBN 0-09185-712-0

*The Key Model – A New Strategy
 for Cancer Recovery*
 Dr Sean Collins & Rhoda Draper
 Ardagh Clinic, 2004
 ISBN 0-95214-445-X

■ *Frequently asked questions*

Here is a list of questions people often want to ask. There is also some space for you to write down your own questions if you would like. Never be shy about asking questions. It is always better to ask than to worry.

- What is prostate cancer? Where exactly is it?
- What are the signs and symptoms I should look out for?
- Do I need treatment straight away? If not, how will you know when I should have treatment?
- If I need treatment, what are my treatment choices?
- How successful is this treatment for my cancer?
- If my treatment is not successful, can I still have other treatment?
- Can I have surgery following radiotherapy?
- Do some treatments have more side-effects than others?
- Are the side-effects of treatment short or long term?
- Will I have problems with urinary incontinence after my treatment?
- Will treatment affect my fertility? Will I develop erectile dysfunction?
- Why is follow-up so important? Why do I need regular blood tests?

Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

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Answer

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Answer

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Answer

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Answer

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Answer

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Answer

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Answer

12

Answer

Acknowledgements

We would like to extend a special word of thanks to the following people for their invaluable contributions to this booklet:

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We hope that this booklet has been of help to you. If you have any suggestions as to how it could be improved, we would be delighted to hear from you. Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers.

If after reading this booklet or at any time in the future, you feel you would like more information or someone to talk to, please call the Prostate Cancer Information Service 1800 380 380.

Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, education and research.

If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact us.

Irish Cancer Society, 43/45 Northumberland Road, Dublin 4.

Tel: 01 231 0500 Email: info@irishcancer.ie

The Irish Cancer Society
is the national charity for cancer care,
dedicated to eliminating cancer as a
major health problem and to improving
the lives of those living with cancer.

