



**Irish  
Cancer  
Society**

Action  
Prostate  
Cancer

*Understanding*

# Prostate Cancer beyond the Prostate Gland

*Caring for people with cancer*



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## Understanding prostate cancer beyond the prostate gland

This booklet has been written to help you understand more about prostate cancer that has spread beyond the prostate gland. It has been prepared by cancer nurses and checked by urologists, cancer doctors and nurses. The information in this booklet is an agreed view on prostate cancer, its diagnosis and treatment and 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. For example, they can tick the relevant parts on the contents page. You can also make a note below of the contact names and information you may need.



Urology specialist nurse Tel:

Oncology nurse Tel:

Family doctor (GP) Tel:

Surgeon/Urologist Tel:

Medical oncologist Tel:

Radiation oncologist Tel:

Radiation therapist Tel:

Medical social worker Tel:

Emergency number Tel:

Pharmacist Tel:

If you like, you can also add:

Your name

Address

This booklet has been produced by Nursing Services 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.

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- *Fast Facts: Prostate Cancer*, R Kirby & M Patel. Health Press, 2009.
- *DeVita, Hellman, and Rosenberg's Cancer: Principles and Practice of Oncology*. R Govindan (ed), 9th edn. Lippincott Williams & Wilkins, 2011.
- *Cancer Nursing: Principles and Practice*, CH Yarbro, MH Frogge, M Goodman & SL Groenwald. Jones and Bartlett, 2000.

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## Introduction

This booklet has been written to help you understand more about prostate cancer that has spread beyond the prostate gland. It is aimed at men diagnosed with prostate cancer at a later stage or for older men diagnosed with prostate cancer. By reading it, you can learn what prostate cancer means and about its diagnosis and treatment and ways of coping with it. If your prostate cancer is diagnosed at an early stage, call the National Cancer Helpline on 1800 200 700 for a copy of the booklet, *Understanding Early Prostate Cancer*.

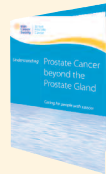
We hope this booklet answers some of your questions and encourages you to discuss them with your doctors and nurses too. In it, we talk about ways to treat this cancer and side-effects that may happen after treatment is given.

The booklet also discusses some of the feelings you and those close to you may have when a diagnosis of cancer is made. At the end of the booklet, you will find a list of useful books to read. There is also a list of websites and special groups to help and support you at this time.



### Reading this booklet

Remember you do not need to know everything about prostate cancer straight away. Read a section about a particular item as it happens to you. Then 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 National Cancer Helpline on Freefone 1800 200 700. It is open Monday to Thursday 9am–7pm and Friday 9am–5pm. Or if you wish, you can also visit a Daffodil Centre if one is located in your hospital. See page 74 for more about Daffodil Centres.

National Cancer Helpline Freefone 1800 200 700

## Keeping track of information

You may like to fill in these tables with information about your cancer and treatment. Or if you prefer, ask your doctor or nurse to fill them in for you. Ask them to explain the information again if you are unsure.

### Grading your prostate cancer

Date of diagnosis	
PSA level at diagnosis	
Clinical stage at diagnosis	
Gleason score	
Treatment	

### Hormone therapy

Date	Drug	Dose	Duration	Next due

➤➤➤ If you need more space to record your hormone therapy, there is a useful pocket diary available called the *Prostate Passport*. It has been produced by Men Against Cancer (MAC) and the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 for a free copy.

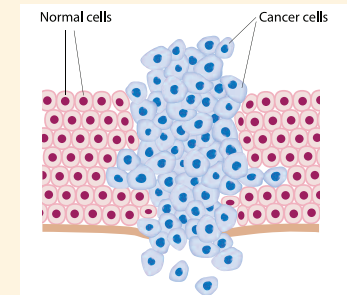


## About prostate cancer

### >>> What is cancer?

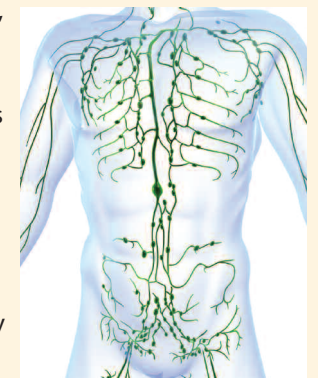
Cancer is a word used to describe a group of diseases, not just one. There are more than 100 different types of cancer. Each is named after the organ or type of cell in which the cancer starts. For example, prostate cancer, breast cancer and leukaemia. All cancers are a disease of the body's cells, which are the building blocks of your body. Normally, cells grow and divide in a controlled way and replace old cells to keep the body healthy. But with cancer, abnormal cells grow without control. Groups of abnormal cells can then form a growth or tumour.

Tumours can be either benign or malignant. Benign tumours do not spread to other parts of your body but malignant tumours do. This happens when a cell or group of cells breaks away and is carried by your bloodstream or lymph vessels to other tissues and organs in your body. This is called a metastasis or secondary tumour.



### What are lymph vessels?

Lymph vessels are part of your lymphatic system, which helps your body defend itself against infection. Like your bloodstream, it carries waste material around your body from your tissues. It is made up a network of tiny tubes that pass through most of the tissues in your body. These tubes carry lymph, a clear watery fluid that is leaked into your tissues and returned to your body. Along the network are hundreds of small glands and nodes which remove the lymph. They are mainly found in your neck, armpit and groin. Lymph nodes can trap cancer and as a result grow bigger and hard.



Lymphatic system



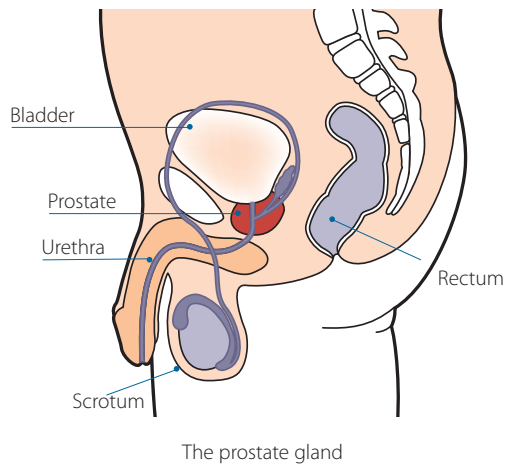
## To sum up

- Cancer is a disease of the cells of your body.
- With cancer, the cells do not behave as normal. They keep on growing even when there is no need.
- If a tumour is malignant, cells can break away and be carried by your bloodstream or lymph somewhere else. This is called a metastasis or secondary tumour.
- Lymph nodes can spread cancer cells.

## What is the prostate gland?

The prostate is a gland found only in men. About the size of a walnut, it lies below your bladder just in front of your rectum (back passage). Running through your prostate is a tube that carries urine through your penis. This tube is known as your urethra or water pipe. It is the reason why some men have trouble passing urine when they have an enlarged prostate gland.

The prostate makes a thick white fluid that mixes with sperm. This fluid is known as semen. It also makes a protein called prostate specific antigen (PSA), which turns the semen into liquid. Prostate cells depend on the male sex hormone, testosterone, to grow. This hormone is made in your testicles. Small groups of lymph nodes are also found near your prostate gland.



## What is prostate cancer?

Prostate cancer occurs when the cells of your prostate gland grow in an abnormal way. In some men prostate cancer grows slowly, while in others it grows more quickly and spreads to other parts of your body. For example, your bones.

**Locally advanced prostate cancer** is cancer that has spread just outside your prostate gland but not to other parts of your body.

**Advanced prostate cancer** is cancer that has spread beyond your prostate gland to other parts of your body. It is also called metastatic prostate cancer.

### How common is prostate cancer?

In general, prostate cancer affects men over 50 and is quite common in men in their 70s and 80s. About 2800 men are diagnosed with prostate cancer in Ireland each year.

## What causes prostate cancer?

The exact cause of prostate cancer is unknown. Research continues to study possible causes and risk factors. A risk factor is anything that can increase your chance of getting the disease. These include:

- **Age:** Your risk of prostate cancer increases with age. It is rare in men under the age of 50.
- **Family history:** If you have a brother or father with the disease, your risk is higher. The risk is also higher if your relative developed prostate cancer at a younger age or if you have more than one relative with the disease.
- **Race:** If you are an African-American or Afro-Caribbean man, you are more at risk than other ethnic groups.
- **Diet and exercise:** If you eat a lot of red meat, processed food and high-fat dairy products but not enough fruit and vegetables, you might have a higher risk of prostate cancer than those who eat a healthy diet. If you exercise regularly, you might be less at risk than those who do little or no exercise.

Remember prostate cancer is not infectious and cannot be passed on to other people.

## What are the symptoms of prostate cancer?

If you have prostate cancer, you may have some or all of the following symptoms:

- Trouble starting or stopping the flow of urine
- Passing urine more often
- Feeling you have not fully emptied your bladder after passing urine
- Pain or difficulty when passing urine
- Blood in your urine
- Bone pain

In some men prostate cancer grows slowly, while in others it grows more quickly and can spread to other parts of your body.



### To sum up

- Prostate cancer is common, especially in older men.
- The cause of prostate cancer is unknown in most cases.
- The symptoms of prostate cancer can include trouble starting or stopping the flow of urine, passing urine more often, feeling you have not emptied your bladder after passing urine, pain or difficulty when passing urine, blood in urine, and bone pain.

National Cancer Helpline Freefone 1800 200 700

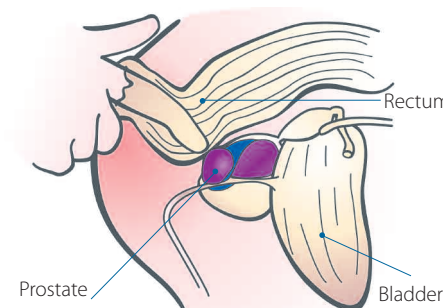
## How is prostate cancer diagnosed?

Your family doctor (GP) will refer you to a hospital specialist if he is concerned about your symptoms. Your hospital specialist will then arrange tests to diagnose prostate cancer. The following tests may be carried out:

- PSA blood test
- Digital rectal exam (DRE)
- Transrectal ultrasound (TRUS) and biopsy of prostate

**PSA blood test:** Prostate specific antigen (PSA) is a protein that can rise due to disease in your prostate gland. A sample is taken from your blood and measured.

**Digital rectal exam:** In a digital rectal exam (DRE), your doctor feels your prostate gland through your back passage (rectum) using a gloved finger. He or she can check if your prostate has enlarged or has abnormal tissue, such as hard or lumpy areas.



Digital rectal exam

### Transrectal ultrasound (TRUS)

**and biopsy:** A sample of your prostate tissue can be taken and examined under a microscope. This is called a biopsy. It is done at the hospital using an ultrasound probe placed in your back passage. This is known as a transrectal ultrasound and biopsy.

## What are the stages of prostate cancer?

Staging means finding out the size of the tumour and if it has spread to other parts of your body. Some tests are used to stage the cancer. Staging allows your doctor to decide the best treatment for you. Remember that staging may not be complete until all the tests are done. Your doctor will advise you more about this matter. You may have some or all of the following staging tests:

- Bone scans
- X-ray tests
- MRI scan

**Bone scans:** Prostate cancer can sometimes spread to your bones. In this case, bone scans can find cancer spots before they show up on an ordinary X-ray. For this test, a tiny amount of a radioactive liquid is put into one of your veins, usually in your arm. After the injection, you must wait for up to 3 hours. A scan is then taken of all the bones in your body. Abnormal bone takes up more radioactive liquid than normal bone. These areas will show up on the scan and are known as 'hot spots'. It can also show bone changes like arthritis.



Bone scan

**X-ray tests:** You may need further X-rays if the bone scan shows up hot spots. These X-rays will help to confirm if the cancer has spread or not. A chest X-ray may be done to check your general health.

**MRI scan:** This special scan uses magnetic energy to build up a picture of the tissues inside your body. It does not hurt but can be quite noisy, so you may be given earplugs to wear during it. Beforehand you might have an injection to show up certain areas of your body. During the scan you cannot wear metal jewellery. If you have certain medical devices implanted in your body, like pacemakers, you might not be suitable for the test. Your hospital doctor will advise you about this.

>>> Staging allows your doctor to decide the best treatment for you.

### Describing the stages of prostate cancer

- **Localised prostate cancer:** This is prostate cancer found only within the prostate gland. It is often called early prostate cancer. See the booklet, *Understanding Early Prostate Cancer* for more details.

- **Locally advanced prostate cancer:** If the cancer has broken through the capsule of the prostate or has spread outside the gland to nearby tissues, it is called locally advanced cancer. Some treatments for locally advanced prostate cancer hope to cure it, while others aim to control the disease or stop it from growing. Your doctor will decide which type of treatment is most suitable for you. It will depend on how much cancer is outside your prostate gland, your PSA test, Gleason score, general health and your age.
- **Advanced prostate cancer:** This is also called metastatic prostate cancer. With advanced prostate cancer, it has spread to other parts of your body through your bloodstream or lymph vessels. See page 7 for more details on lymph vessels. Prostate cancer commonly spreads to bones. It is not yet possible to cure advanced or metastatic prostate cancer but there are treatments available to help keep it under control.

### TNM

There are ways to describe the different stages of cancer. The staging system normally used in prostate cancer is called TNM. This stands for tumour, node, metastasis. Numbers follow the letters, depending on the extent of the cancer. In general the higher the number the more advanced the cancer is.






- **T** refers to the size and depth of the tumour. For example: T3 is when the prostate cancer can be felt breaking through the capsule. T4 is when the cancer has spread to nearby organs.
- **N** refers to cancer present in your lymph nodes or not. This is recorded as N0 or N1. For example, if your MRI scan has shown that your cancer has spread to the lymph nodes (N1) or not (N0).
- **M** refers to cancer that has spread (metastasised) or not. This is recorded as M0 or M1. For example, if your bone scan results show that your cancer has spread to the bones (M1) or not (M0).

The TNM system can be hard to understand, so do ask your doctor and nurse for more information if you wish.



## What are the grades of prostate cancer?

After the biopsy a doctor called a pathologist will look at the samples under a microscope. Grading refers to how the cancer cells look under the microscope. It describes how normal or abnormal the cells are. The patterns of abnormal cancer cells that are seen are given a grade by the pathologist. This is known as the Gleason score or grade. The grade helps your doctor to predict how quickly the cancer may grow and behave.

1		Nearly normal cells
2		Some abnormal cells loosely packed
3		Many abnormal cells
4		Very few normal cells left
5		Completely abnormal cells

Gleason score

Lower grades are slower growing, while the higher grades are fast growing or the least-normal looking. Because prostate cancer cells can vary a lot in how they look, your doctor cannot rely on just one sample. Your doctor takes the two most common scores of prostate cancer in each sample and adds them together to give an overall score. This means the Gleason scale is usually from 6 to 10.

### Waiting for results

It usually takes some time for all your test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend.

You can also call the National Cancer Helpline on 1800 200 700 and speak to one of our specially trained nurses. Or if you wish, you can visit a Daffodil Centre if one is located in your hospital. There is also the option of talking to someone from Men Against Cancer (MAC), the support group for men with prostate cancer.

It is a good idea to take a family member or friend along with you to your doctor's appointments, if possible. Having someone else to listen to the information which the doctors and nurses give you can help you to remember afterwards.



### To sum up

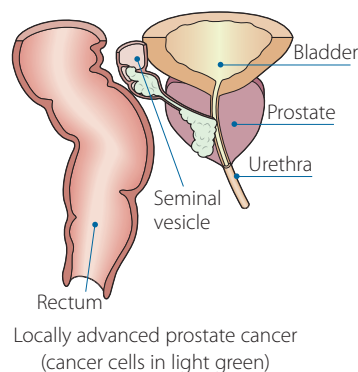
- The following tests are used to diagnose prostate cancer: PSA blood test, rectal exam, transrectal ultrasound and biopsy of prostate.
- Staging means finding out the size of the tumour and if it has spread to other parts of your body.
- The following tests can stage prostate cancer: bone scans, X-ray tests, MRI scan.
- Localised or early prostate cancer is cancer found within the prostate gland only.
- Locally advanced prostate cancer is cancer that has spread beyond the prostate gland to nearby tissues.
- Advanced prostate cancer is cancer that has spread from the prostate to other parts of your body, such as your bones.
- Grading refers to how the cancer cells look under the microscope.
- The patterns of abnormal cancer cells are given a grade or score known as the Gleason score.

National Cancer Helpline Freefone 1800 200 700

## Prostate cancer beyond the prostate gland

### Locally advanced prostate cancer

Once prostate cancer has spread outside the prostate gland, it can spread to nearby tissues and organs. If your cancer has spread outside your prostate gland to nearby tissues, it is called locally advanced cancer. This may include tissues such as your seminal vesicles, lymph nodes, neck of your bladder or your back passage (rectum). The seminal vesicles are two glands that sit just behind your prostate gland and make some of the fluid in semen.



➤➤➤ If your prostate cancer is diagnosed at an early stage, call the National Cancer Helpline on 1800 200 700 for a copy of the booklet, *Understanding Early Prostate Cancer*.

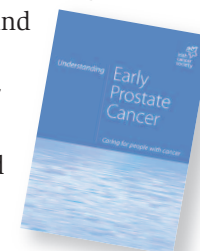
### What treatment can I have for locally advanced prostate cancer?

Locally advanced prostate cancer can be treated in a number of ways. Sometimes the treatment aims to get rid of the prostate cancer completely. But if this is not possible, the treatment aims to control it and stop it from growing. Your doctor will decide which one is suitable for you once all your test results are ready. He or she will consider factors such as:

- The stage of your cancer – whether it has spread just outside the prostate gland, how far outside, or whether it may have spread to other parts of your body
- The grade of your cancer – Gleason score
- Your PSA level
- If you have urinary symptoms or not
- Your general health

There are a range of treatment options for locally advanced prostate cancer. These include:

- **Hormone therapy:** Prostate cancer depends on the male hormone testosterone to grow. By reducing the amount of testosterone in your body the growth of cancer cells can be slowed down or stopped. See page 22 for more details on hormone therapy.
- **Watchful waiting:** Prostate cancer can grow slowly and some men have few or no symptoms. This is even if their prostate cancer has spread just outside the prostate gland. For some men it may be best to delay starting hormone therapy for a while, to avoid the side-effects of treatment, but without putting you at risk from your prostate cancer. See page 28 for more details on watchful waiting.
- **External beam radiotherapy with hormone therapy:** Radiotherapy is a treatment that uses X-rays to kill cancer cells. You may be suitable for radiotherapy but this will depend on how far your prostate cancer has spread. If a course of radiotherapy is needed, it usually lasts 7–9 weeks. In locally advanced prostate cancer, hormone therapy is given before, during and after radiotherapy. See page 30 for more on radiotherapy and page 22 for more on hormone therapy.
- **Surgery (radical prostatectomy) and/or external beam radiotherapy:** Surgery for prostate cancer is very occasionally used for men with locally advanced prostate cancer. Sometimes it is difficult to be completely certain if the cancer has broken through the prostate gland or not, or if only a very small amount is outside the prostate. This uncertainty may be there even after having an MRI scan. In this case you may be offered surgery. If prostate cancer is found outside your prostate gland during the operation, you may need to have radiotherapy after the surgery as well. Your doctor and specialist nurse will explain this to you in more detail. For more information on surgery and its side-effects, see the booklet *Understanding Early Prostate Cancer*.



## Advanced prostate cancer

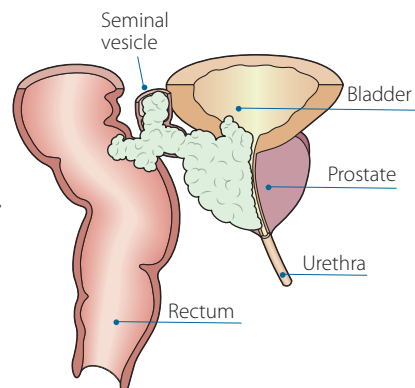
Prostate cancer is known as advanced or metastatic prostate cancer when it has spread to other parts of your body. Cancer cells can spread through your bloodstream or lymphatic system. The most common places for prostate cancer to spread to are your bones and lymph nodes or glands.

It is not possible to cure advanced prostate cancer but there are treatments which can control your prostate cancer for months or years. These treatments will be offered to you.

Advanced prostate cancer can often cause symptoms. Sometimes this is the first sign that there may be something wrong, although not all men have symptoms. Some symptoms of advanced prostate cancer can be caused by the cancer itself, while others may develop due to treatment. Your symptoms will depend on how your cancer has affected you. Urinary problems or bone pain are common symptoms when advanced prostate cancer is diagnosed, but starting treatment often improves these symptoms. See page 39 for more about treating symptoms.

### What treatment can I have for advanced prostate cancer?

Hormone therapy is the first treatment used to control advanced prostate cancer. Prostate cancer depends on the male hormone testosterone to grow. By reducing the amount of testosterone in your body, the growth of cancer cells can be slowed down or stopped. Hormone therapy treats prostate cancer cells wherever they are in the body, such as in your bone. Hormone therapy still works on prostate cancer cells in the bone to shrink them and help to keep them under control. So you will find it also helps with urinary symptoms or bone pain.

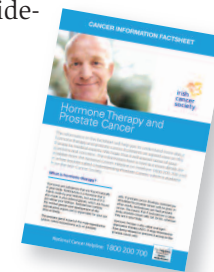


Advanced prostate cancer  
(cancer cells in light green)

Most men with advanced prostate cancer will stay on hormone therapy for the rest of their lives. But for some men it is possible to take hormone therapy now and then. This is called intermittent hormone therapy. You might need to take two types of hormone therapy as well. This is known as maximal androgen blockade.

For more information on hormone therapy and its side-effects, see page 25. You can also read the factsheet *Hormone Therapy and Prostate Cancer*. Call the National Cancer Helpline on 1800 200 700 for a free copy or download it from the website:

**www.cancer.ie**. You can also watch a podcast on hormone therapy and prostate cancer online.



When you start hormone therapy you will usually be asked to take tablets for a while before your first injection (unless you have Firmagon®). See page 24 for more information on starting hormone therapy. Along with hormone therapy your doctors and nurses will look at ways to help any symptoms you may have. These treatments can include:

- Medication to strengthen your bones. See page 43.
- Radiotherapy to relieve pain. See page 40.
- Medication to relieve pain. See page 40.

Other medications may also be given to help control any symptoms from your prostate cancer. Your doctor and nurse will discuss your treatment options with you in more detail.

### Coping with a diagnosis of prostate cancer outside the prostate gland

It can be a difficult time for you and your family when you hear that your prostate cancer has spread outside the prostate gland. It is normal to experience sadness along with other emotions at this time. It can be helpful to look for sources of support to cope with these difficult feelings. See page 65 for more information on where help is available or call the National Cancer Helpline on 1800 200 700 to talk to a specialist cancer nurse.



## Treatment and side-effects

### How can my prostate cancer be treated?

In this section, the different treatment options available for locally advanced or advanced prostate cancer are discussed.

- Hormone therapy – see page 22.
- Radiotherapy – see page 30.
- Watchful waiting – see page 28.

For information on surgery for prostate cancer, see our booklet *Understanding Early Prostate Cancer*. Or you can visit our website [www.cancer.ie](http://www.cancer.ie) to download it.

#### Deciding on treatment

Sometimes men with prostate cancer are asked to decide between various treatment choices. If this happens to you, before you decide make sure you know:

- What the treatment involves
- Possible side-effects
- Its advantages and disadvantages
- How your treatment will be monitored

**Asking questions:** At this time you may be anxious about what is going to happen next. Do ask your doctor and nurse as many questions as you like no matter how small or trivial you think they are. All questions are important. If you forget to ask a question or would like more explanations, call the National Cancer Helpline on 1800 200 700 and talk to one of our specialist nurses. It can also help to talk to someone who has been in a similar situation. Contact the support group Men Against Cancer (MAC) if you prefer. See page 74 for more details.

**Other opinions:** You might find it reassuring to have another medical opinion to help you decide about your treatment. Do not worry that you are offending your doctor by doing this. He or she will gladly refer you to another specialist for their opinion if you feel this would be helpful. If you are suitable for radiotherapy in particular, it may help to talk to a radiation oncologist before making a decision.

**Accepting treatment:** You have the right to find out what a treatment option means for you and the right to accept or refuse it. If you wish to refuse treatment, let your doctor or nurse know your concerns first. It may help to talk to your GP as well. The important thing is that you are fully aware of the benefits and risks of having treatment or not.

## Hormone therapy

Hormone therapy is the main treatment for prostate cancer that has spread outside your prostate gland. Hormone therapy aims to shrink the cancer and improve symptoms like poor urine flow or bone pain. Hormone therapy can work well for many years. During this time, you will have regular check-ups and your doctor will watch your response to treatment. He or she will check any symptoms and examine you as well. Your PSA level will be measured too. This test is used as a guide to the success of the treatment. Hormone therapy is frequently used alongside radiotherapy for early and locally advanced prostate cancer also.

### How does hormone therapy work?

Hormones are made naturally in your body and control how normal cells grow and work. Testosterone is a male hormone, which is also called an androgen. It controls the growth and development of male sexual organs and also your sex drive (libido). Most testosterone is made in your testicles and a small amount by your adrenal glands near your kidneys. The growth of prostate cancer cells can be driven by testosterone. But by reducing the amount of testosterone in your body, or by blocking it from getting to the prostate cancer cells, prostate cancer can be slowed down or stopped.

Hormone therapy can shrink prostate cancer cells both in your prostate gland and anywhere else in your body. Another name for hormone therapy is androgen deprivation therapy. Androgens are male hormones, so androgen deprivation means stopping or blocking the action of male hormones in your body.

➤➤➤ Hormone therapy is the main treatment for prostate cancer that has spread outside the prostate gland.

## Types of hormone therapy

There are three main types of hormone therapy that can either stop your body making testosterone or block the effects of it on prostate cancer cells:

- Injections or implants to stop your body making testosterone
- Tablets known as anti-androgens to stop the effect of testosterone
- Surgery to remove your testicles

Call the National Cancer Helpline on 1800 200 700 for a free factsheet called *Hormone Therapy and Prostate Cancer*. You can also download it from our website [www.cancer.ie](http://www.cancer.ie) or listen to a podcast about prostate cancer.

### Injections or implants

Some drugs ‘turn off’ the making of male hormones in your testicles. The drugs commonly used include goserelin (Zoladex®), leuprorelin (Prostap®), triptorelin (Decapeptyl®), leuprorelin acetate (Eligard®), degarelix (Firmagon®) and histrelin (Vantas®). These drugs are



Hormone injections

injected as a pellet or liquid under your skin or into a muscle. Injections can be given once a month or every 3 or 6 months, or every year in the case of the implant histrelin. The amount of hormone therapy you get is the same whether you have the injection every 1, 3 or 6 months or the implant every year. This is because some of the injections are ‘slow release’ and give you the medication slowly over a longer period of time. This might save you from having to make more trips to your GP to have the injection. Do discuss this with your doctor or nurse if you wish. You might find that your testicles become smaller in size once you have been on hormone therapy injections for a while.

### Starting injection hormone therapy

When you start taking hormone therapy, you will be asked to take anti-androgen tablets for a week or two before your first injection. This is because your body's first response to the injection is to try to make more testosterone. This could make your cancer grow more quickly and is known as 'tumour flare'. These tablets block the effect of the testosterone and stop this happening. Your doctor will prescribe these tablets for some time before and after starting injection treatment to help prevent this problem.

### Anti-androgen tablets

Other hormone drugs can block testosterone from entering your prostate cancer cells. This prevents the cancer cells from growing. These drugs are called anti-androgens. Common ones are flutamide (Drogenil®), bicalutamide (Casodex®) and cyproterone acetate (Androcur®).

**Combination therapy or maximal androgen blockade:** Hormone injections or tablets can be given on their own. Sometimes a combination of the injections and tablets may be used. This is known as combination therapy or complete androgen blockade (CAB) or maximum androgen blockade (MAB). Combination therapy prevents testosterone being made in your testicles and also blocks small amounts made by your adrenal glands from working on prostate cancer cells.

### Surgical hormone therapy

Most testosterone is made in your testicles, so removing these organs will block the release of testosterone straight away. Surgery to remove your testicles is known as an orchidectomy. It is done through a small cut in your scrotum. The scrotum is the sac that holds your testicles in your body. Very occasionally men choose this option, but it is no longer used that often as many men find the idea of this surgery very distressing. Your doctor and nurse will give you more advice, if you opt for this treatment.

National Cancer Helpline Freefone 1800 200 700

### What are the side-effects of hormone therapy?

The common side-effects of hormone therapy include:

- Change in sexual function
- Hot flushes
- Weight gain
- Fatigue
- Mood changes
- Breast swelling and tenderness
- Osteoporosis or bone thinning

**Change in sexual function:** Hormone therapy can affect your interest in sex, known as your libido, and also your ability to get an erection. Do discuss your concerns with your partner and get advice from your doctor, nurse or a professional psychosexual counsellor. Medications, injections and vacuum devices that may help with impotence are all available. Your doctor will advise you about which treatment is best for you. Call the National Cancer Helpline on 1800 200 700 for a copy of the factsheet, *Sex, Erectile Dysfunction and Prostate Cancer*.

**Hot flushes:** Hot flushes and sweating happen because the lack of testosterone affects the part of your brain that regulates heat. Do speak to your doctor if these symptoms are troubling you, as medication may be prescribed.



### Tips & Hints – coping with hot flushes



- Wear cotton clothing as it absorbs moisture better.
- Wear layers of clothes or bedclothes to allow you to remove clothing as needed.
- Note when the hot flushes occur. There may be a pattern to them or certain things such as spicy food might trigger them off.
- Use moist wipes, sprays or an electric fan to help cool your skin temperature.
- Avoid smoking and cut down on spicy or sugary foods, alcohol and caffeine.
- Drink plenty of cool fluids.
- Keep a healthy weight for your height.
- Some medications can help – ask your doctor for advice.

**Weight gain:** Hormone therapy may affect your weight, particularly around your waist. You might also lose some of your muscle tone and strength. Taking regular exercise will help you stay a healthy weight, help prevent loss of muscle and bone strength, and is also good for your heart. A healthy diet can also help you to stay a healthy weight. Do get advice from your doctor or call the National Cancer Helpline on 1800 200 700.

**Fatigue:** Hormone therapy can cause fatigue or ongoing tiredness in some men. As with other side-effects, some men may not feel any tiredness at all, while others might feel very tired every day. If you are troubled by tiredness, talk to your doctor so that he or she can rule out other causes of fatigue. You might find that taking regular exercise helps you to manage your tiredness, gives you more energy and helps you to cope. For more information and a booklet called *Coping with Fatigue*, call the National Cancer Helpline on 1800 200 700.

**Mood changes:** Testosterone can also affect how your mind works. Less testosterone in your body might cause mood changes, poor concentration or memory problems, anxiety and sometimes depression. In this case, it often helps to talk to someone from a support group, such as Men Against Cancer, who has gone through a similar experience. Some therapies, like relaxation therapy, meditation or yoga, might help you to cope with these frustrating symptoms. Discuss your concerns with your doctor or nurse who might refer you to a professional counsellor.

**Breast swelling and tenderness:** Tenderness or swelling in your breast can occur if you are given hormone therapy. This swelling is also known as gynaecomastia. It occurs more commonly with anti-androgen therapy. It can vary from mild tenderness, with or without mild swelling, to a more obvious amount of tissue growth around the breast area. Medications like tamoxifen can help. If this side-effect concerns you, do mention it to your doctor or nurse.

**Osteoporosis or bone thinning:** Hormone therapy affects how your bones are normally formed and can lead to osteoporosis. This means that bones can be less dense and become brittle, making them more prone to fractures. Taking exercise, such as walking, and eating foods rich in vitamin D and calcium can help to prevent osteoporosis, while

avoiding smoking and excessive alcohol. You can get calcium and vitamin D from dairy products such as cheese, milk and yoghurt and also from tinned fish such as sardines and salmon. Calcium is also found in broccoli and leafy green vegetables. Your body needs vitamin D to work with the calcium, so do include this too.

Do talk to your doctor or nurse for advice or get in touch with the Irish Osteoporosis Society. See page 77 for contact details.

### More information

For more information about hormone therapy and how to manage side-effects, call the National Cancer Helpline on 1800 200 700. Ask for a free factsheet called *Hormone Therapy and Prostate Cancer* or download it from [www.cancer.ie](http://www.cancer.ie). Or if you prefer, you can also visit a Daffodil Centre if one is located in your hospital.

### How will I know my hormone therapy is working?

Your doctor will monitor your PSA level once you are on hormone therapy. Because hormone therapy stops the growth of prostate cancer cells, your PSA usually falls when you start hormone therapy. This is how your doctor will measure your response to the treatment.

Hormone therapy usually controls prostate cancer growth for many months or years. It is hard for doctors to predict how long it will work because it depends on a number of factors. For example, how much cancer is present and the grade of your cancer. If your PSA level goes up on a few occasions, it may be a sign that your hormone therapy is not keeping the cancer under control as well as it had been. For more information on treatments that are available after hormone therapy, see page 46.



### To sum up

- Hormone therapy is a treatment that uses drugs or surgery to control cancer.
- It can be used on its own or with other treatments.
- Hormone therapy may cause short or long-term side-effects. These include change in sexual function, hot flushes, weight gain, fatigue, mood changes, breast swelling and tenderness, and osteoporosis.
- Your doctor will monitor your PSA level while on hormone therapy.

## Watchful waiting

Prostate cancer can grow slowly and you may have little or no symptoms when you are diagnosed. In this case, your doctor may decide to watch (monitor) you before starting treatment for a period of time. During this time you will have regular PSA tests and check-ups to make sure your cancer is not growing too quickly. The idea of watchful waiting is to delay starting treatment because of the side-effects of treatment. Also, the treatment can work just as well if started at a later date. You may be suitable for watchful waiting if your prostate cancer is not causing you any symptoms or problems at present. You may also not be fit enough for treatment, especially if you have other medical conditions.

### What does watchful waiting involve?

If you opt for watchful waiting, you will not begin treatment straight away. Usually you will be asked to have your PSA checked every 4-12 months, depending on your own situation. From time to time you will have digital rectal exams as well as blood tests. Usually there is no need to have repeat prostate biopsies while on watchful waiting. If any changes are picked up on the above tests, your doctor will discuss the need to start hormone therapy or not.

You may start treatment once your PSA level reaches a certain point or if you get symptoms. For example, problems passing urine or bone pain. Hormone therapy can be given once your doctor and you decide you need to start treatment. During watchful waiting, look out for any new symptoms such as difficulty passing urine or new aches and pains in your back or bones

**>>> During watchful waiting, look out for any new symptoms such as difficulty passing urine or new aches and pains in your back or bones.**

It can often be hard to accept this watch and wait approach. Even so, it is usually done because your cancer is not causing you any problems and the side-effects of treatment can sometimes be difficult.

Your doctor and nurse will talk to you about how you feel about not having treatment. You can always choose to start treatment at any time.

### Advantage of watchful waiting

- You will avoid the physical side-effects of treatment and should be able to enjoy your normal life and activities.



### Disadvantages of watchful waiting

- You might become anxious or worry about your cancer changing and the chance of developing symptoms.
- Your partner and family might also worry about you and find it hard to understand why you are not having treatment.
- The cancer might grow and change more quickly than expected. If this happens you can start treatment, such as hormone therapy, to control the cancer.



Let your GP or hospital doctor or nurse know if you have any symptoms. You may need to have some further tests to see if your cancer has spread and you may be offered treatment. The most common treatment to help improve these symptoms is hormone therapy. If you would like more advice about watchful waiting, call the National Cancer Helpline on 1800 200 700. Or if you prefer, you can also visit a Daffodil Centre if one is located in your hospital.



## Radiotherapy

Radiotherapy is a treatment where high-energy X-rays are aimed at a cancer to cure or control it. Radiotherapy and hormone therapy are usually used together to treat locally advanced prostate cancer. This helps to make the radiotherapy work better at controlling your prostate cancer. Hormone therapy can be given for different lengths of time. For more information on hormone therapy, see page 22.

### Planning your treatment

Before radiotherapy is given, your doctor will plan how best to give your treatment. This doctor is known as a radiation oncologist. He or she will decide how much radiotherapy is needed to treat your cancer while limiting any damage to normal cells. On your first visit to the radiotherapy unit, you will have an MRI or CT scan to show the area being treated. 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 done so that the X-rays can be aimed at the same area each day. Before starting radiotherapy, your radiation therapist and nurse will tell you how to look after your skin during and after treatment.



External beam radiotherapy

### Getting your radiotherapy

Having radiotherapy is quite straightforward. You will visit the unit every day during the week with a rest at weekends. A course of radiotherapy may continue for 7–8 weeks. Each treatment session only takes a few minutes. You will not feel any pain during treatment but you will have to lie very still. How much treatment you receive will depend on the extent of your cancer. Your doctor will discuss your treatment with you, so do ask questions if you are concerned.

## Side-effects of radiotherapy to prostate gland

Side-effects occur when normal healthy cells near the area being treated are exposed to the beam of radiation. Some side-effects appear during the treatment, while others can develop after the treatment, and indeed some can become long-term side-effects.

### Short-term side-effects

The most common side-effects are those that develop during treatment or shortly afterwards. Remember not all men will get all of the side-effects. But there is no way of knowing in advance which of them you will get or how much trouble they will cause you. Your radiation therapists and other staff will be available to discuss your side-effects and help you manage them. Side-effects include:

- Urinary problems
- Bowel problems
- Discomfort at back passage
- Skin changes
- Fatigue

**Urinary problems:** During radiotherapy your bladder may become irritated. This can make you pass urine more often, during the day and at night. It can also cause a burning feeling when you pass urine. Sometimes drinking too much tea, coffee, coke or alcohol can make these problems worse. If this happens, do reduce your intake of these drinks for a time and change to water, juices or soft drinks.

You may notice a trace of blood in your urine too. If you have problems passing urine or do pass blood, discuss it with your doctor, nurse or radiation therapist. These symptoms usually start to settle down some weeks after your treatment has finished. But for a number of men they continue in the long term. On your way home from each treatment, you may have to stop to pass urine, especially if you are asked to drink water before each treatment.

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**Bowel problems:** Some men develop diarrhoea during treatment. This is because the prostate gland is very close to your back passage (rectum). Passing watery bowel motions more than three times a day is known as diarrhoea. You may also have cramping tummy pain and pass more wind and mucus. If this happens, drink lots of fluids to replace those you are losing. Do let your doctor or radiation therapist know if you have diarrhoea. There is medication that can stop this side-effect as well. You might also notice that you need to get to the toilet more quickly.

On the other hand, some men might have more difficulty opening their bowels and become constipated. The hospital team will help you find ways to manage your bowel symptoms during your treatment. Again these symptoms usually start to settle down a short time after your treatment has stopped.

**Discomfort at back passage:** Radiotherapy to the prostate area may irritate your back passage (rectum) and cause discomfort. It can also cause soreness around your anus. You may notice some blood on toilet tissue after passing a bowel motion. Indeed it 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 on your bottom or between your legs may become a bit darker and sore. It may even look like sunburn. It is best to avoid hot baths and to wear loose cotton clothes at this time. When you wash the area, use warm water and pat it dry with a soft towel. Do not rub the skin while washing and drying. You can use a special cream to treat this problem but make sure to only use creams recommended by your nurse or radiation therapist. Also, avoid perfumed creams or powders. Remember to check with your radiation therapist or nurse before applying anything to your skin.

**Fatigue:** Fatigue or 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 for treatment. Rest as much as you need to and continue to do the things you like. But remember you may have less energy than before treatment. Regular gentle

exercise such as walking can help to improve tiredness. Some men continue to work during their treatment while others take some time off. You may feel tired for some weeks or even months. Most men usually recover from their tiredness within a couple of months of finishing their treatment.

If you are having trouble with tiredness and fatigue, call the National Cancer Helpline on 1800 200 700 for a free copy the booklet, *Coping with Fatigue*.

**Duration of side-effects:** These side-effects may continue to get worse for a short time after your treatment has finished. Remember most side-effects settle down over the following weeks and months. Some side-effects can become long term, while others can appear some time after your treatment has finished.

»»» The side-effects may continue to get worse for a short time after your treatment has finished. Most settle down over the following weeks and months.

#### **Longer-term side-effects**

Longer-term side-effects can include:

- Erectile dysfunction
- Urinary problems
- Bowel problems
- Infertility

**Erectile dysfunction:** This is also known as impotence. Radiotherapy can cause damage to the nerves and blood vessels that control erections. This can make it difficult for you to get and keep an erection, especially if you are taking hormone therapy as well.

Using medication or vacuum therapy soon after radiotherapy might reduce your risk of erectile dysfunction. Granted, you may not be thinking about sex at this time but taking the tablets or using a vacuum pump at an early stage may improve your chances of getting erections when you are ready to think about sex again. Do discuss this with your doctor, specialist nurse or your GP. There are several

treatments available for erectile dysfunction which you might want to try. For more information and advice, call the National Cancer Helpline on 1800 200 700. Ask for a copy of the factsheet *Sex, Erectile Dysfunction and Prostate Cancer* or you can download it from **www.cancer.ie**

After radiotherapy some men find that an orgasm has less semen than usual. Indeed they may have a 'dry' orgasm where no semen is ejaculated.

**Urinary problems:** In a small number of men, the bladder may be permanently affected by radiotherapy. As well as the short-term symptoms described on page 31 some men can develop a narrowing of the urethra (water pipe). This can make it difficult to pass urine and may need to be treated with surgery. Occasionally, the blood vessels in your bladder can become more fragile after radiotherapy. This can cause some blood to appear in your urine many months or years later. If you notice any bleeding, tell your doctor so that tests can be done and proper treatment given.

Rarely, radiotherapy can cause leakage of urine due to damage to the nerves that control your bladder muscles. If this does happen, discuss it with your doctor or nurse.

**Bowel problems:** In some cases bowel problems may persist, while for others they develop years after treatment. Some men will find that their bowel habits change permanently after radiotherapy. For example, your bowel motions might become more urgent and frequent. This may mean opening your bowels a little more often than you did before your treatment. Or it may mean a bigger change which affects your everyday life. Tell your doctor about any bowel problems you have, as there are treatments that can help.

The blood vessels in your bowel can become more fragile after radiotherapy. This in turn can cause blood to appear in your bowel motions. As other bowel problems are common in older men, it is possible that symptoms are due to something else, so you may need tests to find out the cause of your symptoms. If you have ongoing problems with diarrhoea or bleeding from your back passage, do tell your doctor or nurse.



**Infertility:** Radiotherapy for prostate cancer can cause infertility. This means you will no longer be able to father a child. If this is important to you, talk to your doctor about this effect before your treatment begins.

### More information

For more information, call the National Cancer Helpline on 1800 200 700 and ask for a copy of the free booklet *Understanding Radiotherapy* or a DVD called *Radiation Therapy: A Patient Pathway*. You can also visit a Daffodil Centre if one is located in your hospital.

## Will treatment affect my sex life and fertility?

**Sex and relationships:** Treatment can certainly affect your sex life. The changes can sometimes be difficult for you and your partner to talk about. Needing treatment to get an erection can also change your relationship with your partner or how you see that relationship. Relationship counselling or sex therapy can help you and your partner get over this problem. There are several organisations that may be able to help, such as Relationships Ireland. See page 77 for contact details.

Coming to terms with the fact that you have cancer can also take quite a while. Your emotions will naturally be turned upside down. It can be hard to relax as well when you have a lot of worries on your mind. You may also be feeling tired from the effects of treatment and lose interest in sex as a result. This is a quite normal reaction at this time.

If you have a supportive partner, you may find that talking about your feelings may ease your anxiety. Even if you do not feel like having sex, or cannot get an erection, you can still enjoy a close and loving relationship with your partner. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. He or she may refer you for specialist counselling if you feel that would be helpful. The National Cancer Helpline 1800 200 700 has a

list of psychosexual counsellors who can help you and your partner find a way of being close again. Some organisations offer a sex therapy service to help couples who are experiencing a change in their sexual relationship. See page 77 for contact details.

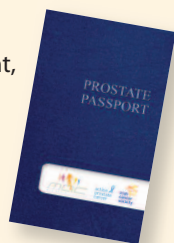
Some people fear that cancer can be passed on to a partner during sex. There is no truth to this. It is quite safe for you to have sex with your partner, both before and after treatment. For more information, call the National Cancer Helpline on 1800 200 700 and ask for a factsheet called *Sex, Erectile Dysfunction and Prostate Cancer*. Or you can download it from the website: [www.cancer.ie](http://www.cancer.ie)

**Asking for advice:** If you have any queries about how treatment may affect your sex life, do ask your doctor. Don't be put off by thinking the question is small or trivial or that you will be embarrassed. Your doctor is well used to taking about these matters and will give you advice.

**Infertility:** Most treatments for cancer prostate are likely to cause infertility. This means you will be unable to father a child in the future. This issue may or may not concern you. If it is important to you, talk to your doctor about this side-effect before your treatment.

### Prostate Passport

If you would like to keep track of all your dates of treatment, PSA results, 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 National Cancer Helpline on 1800 200 700 for a free copy.



National Cancer Helpline Freefone 1800 200 700



### Research – what is a clinical trial?



Research into new ways of treating prostate cancer that has spread goes on all the time. Many patients take part in research studies today. Even though the word 'research' or 'new drug' sometimes scares people, there is no need for fear. Before a drug or treatment is used on patients, it goes through many stages to make sure it is safe to use.

Your doctor will let you know if you and your type of cancer are suitable for a clinical trial.

#### Phases of research

There are many stages or phases when research is done. If a drug or treatment looks as if might be useful in treating cancer, it is given to patients in research studies called clinical trials. If early studies suggest that a new drug may be both safe and effective, further trials are carried out. These aim to:

- Find out if the treatment is better than ones already in use.
- Find out if there are more benefits when the new treatment is given together with current ones.
- Compare the new treatment with current best standard treatments.

#### Taking part in clinical trials

Your doctor may ask you to try a new treatment. There are many benefits to this. You will be helping to improve knowledge about cancer and new treatments. There is no need for worry as you will be carefully monitored during and after the study.

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 proven treatment available. Even after agreeing to take part in a trial, you can still withdraw 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 cancer cells or blood.

For a copy of our factsheet on clinical trials, call the National Cancer Helpline on 1800 200 700 or visit our website [www.cancer.ie/cancer-information/treatments/clinical-trials](http://www.cancer.ie/cancer-information/treatments/clinical-trials)



## How can my side-effects or symptoms be treated?

Some symptoms of prostate cancer can be linked to the cancer itself or due to treatment. Your symptoms will often depend on how your cancer has affected you. You may experience symptoms such as:

- Difficulty passing urine
- Bone pain
- Weakened bones
- Constipation
- Fatigue

It is unlikely that you will have all of these symptoms or even most of them. If you have any symptoms that are troubling you, let your doctor or nurse know. There are treatments that can help to make your life easier and more comfortable.

### Difficulty passing urine

Some men with prostate cancer have trouble passing urine. Some of the symptoms you might experience include:

- A slow flow of urine
- Difficulty emptying your bladder
- Sudden need to pass urine with little warning
- Dribbling after passing urine
- Getting up at night to pass urine

Occasionally, some men find they cannot pass urine at all. If this happens, you need to go to the hospital accident and emergency unit where they will fit you with a small, thin tube (catheter) to drain your bladder. If you would like more information on how to manage any urinary symptoms, call the National Cancer Helpline on 1800 200 700. Ask for a copy of the factsheet, *Urinary Problems after Prostate Cancer Treatment*. Or you can also download it from [www.cancer.ie](http://www.cancer.ie)



## Bone pain

Not all men with advanced prostate cancer have pain. But one of the first signs that cancer has spread to the bone can be an ongoing nagging ache in your bone. This can make it hard to sleep and sore when you move around. Remember pain in your bones can be caused by other things such as arthritis, simple sprains and everyday aches and pains as you get older. If you have a new ache that lasts more than a few weeks, talk to your doctor. He or she can organise tests to find the cause of the pain.

**Painkillers:** If you do get pain, it can be helped by painkillers or cancer treatments. Your doctor will decide which painkiller is best suited to the type of pain you have. If the medication does not kill the pain, tell your doctor or nurse. Mild pain is often helped with drugs such as paracetamol or anti-inflammatory drugs like ibuprofen. Moderate and severe pain needs stronger painkillers such as codeine or morphine. Your GP can advise you about which pain medication to take or you might see a specialist who manages pain and other symptoms. They can arrange for you to try out different painkillers to see which one suits you best. Beside painkillers, a number of other drugs can be helpful in reducing pain.

If you are troubled by pain, call the National Cancer Helpline on 1800 200 700 for advice. Ask for a copy of the factsheet called *Cancer Pain* or download it from the website: [www.cancer.ie](http://www.cancer.ie)

**Bisphosphonates:** Drugs known as bisphosphonates can also help to relieve bone pain. They work by helping to strengthen bone and so prevent bone damage such as fractures. See page 43 for more about bisphosphonates.

**Radiotherapy:** Radiotherapy is very good for treating bone pain so you might have radiotherapy if your cancer has spread to your bones. In this situation, the treatment cannot cure the cancer. But it can reduce symptoms like pain and make you more comfortable and feel better. This is known as palliative radiotherapy. It can be given as a single dose or divided over a few days. It usually takes 2–3 weeks to work.

Radiotherapy can also help with any pressure or bleeding. In this case again, radiotherapy does not cure the cancer but can help you feel



## Tips & Hints – pain



- If you are in pain, tell your doctor or nurse about it straight away. Be honest about the level of pain you are in.
- Describe the pain as clearly as you can. Is it a dull or sharp sudden pain, or always there or comes over you in waves? Is it mild or severe? Do you wake up in pain during the night? It may help to write down the times you get pain and what makes it better or worse. Giving this information to your doctor may help them to work out what is causing your pain and to decide which painkillers are best for you.
- If you only have pain from time to time, take the painkillers when you need them. But if the pain is there most or all of the time, take your painkillers regularly.
- Discuss with your doctor or nurse if the pain is worse at night and wakes you up. You can get extra medication to help with 'breakthrough pain'.
- If you are constipated from the painkillers, take a laxative every day. Drink plenty of fluids such as water and fruit juice to 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. Take them 30 minutes before your painkillers. The nausea often improves as you get used to your medication. Do not drive or work machinery if you feel drowsy.

better. Your doctor and radiation therapist will explain what is involved and any likely side-effects. You might get relief from the pain within a few days or a few weeks, depending on your situation. Many men can reduce their dose of painkillers afterwards, but you can still take them if needed.

**Radioactive injections:** Sometimes a radioactive injection can help with symptoms of prostate cancer that has spread to the bones. Your doctor will tell you if this treatment is suitable for you or not. Strontium and samarium are chemicals that tend to collect in bones like calcium. Their radioactive forms are used to shrink the bone cancer and slow its growth. This treatment can also help to ease bone pain due to cancer. It may take up to 3 weeks for the pain to reduce but it can last for several months.

You can have this treatment as an outpatient. The radiation is first injected into a vein usually in your arm. Then it travels to your bones, where it affects the cancer cells. After the injection, a small amount of radiation remains in your urine and blood. It is best to use flush toilets instead of urinals afterwards. This will reduce the risk of others being exposed to the radiation. Do flush the toilet a couple of times after passing urine as well. Be careful of any spills of urine or blood, but it is quite safe to be around people and pets. The radiation usually lasts about 7 days. Your doctor or nurse will discuss any special precautions with you before you go home.

**Complementary therapies:** There are other ways to control pain too. For example, some complementary therapies that involve relaxation can help to ease aches and pains and make you feel more comfortable. Talk to your local cancer support centre to see what services are available. For example, some centres provide yoga, Reiki and meditation classes. Call the National Cancer Helpline on 1800 200 700 for advice or for a copy of the booklet, *Understanding Cancer and Complementary Therapies*.



### Tips & Hints – other ways to relieve pain

- Heat and cold packs
- Massage
- Acupuncture
- Relaxation to reduce tension in your muscles and relieve pain
- Meditation
- Yoga or Reiki
- Imagery – you think of a pleasant scene to take your mind off your pain
- Distraction – you focus on other things such as reading or music rather than your pain
- Transcutaneous electric nerve stimulation (TENS) – a mild electric current is applied to the skin where the pain is



### Weakened bones

Cancer in your bone can cause bone pain. It also causes weaker bones, making you more prone to fractures. Even so, this symptom can still be treated.

**Drug therapy:** Drugs such as denosumab (Xgeva®) or zoledronic acid (Zometa®) can be given to help strengthen your bones. Zoledronic acid belongs to a family of drugs called bisphosphonates, which help to strengthen bone.

#### Bisphosphonates and denosumab

Bisphosphonates and denosumab can strengthen bones affected by prostate cancer or weakened by cancer treatment. They can help to prevent further bone loss and strengthen the bone to reduce the risk of bone damage, like fractures. They can also help to reduce pain from cancer that has spread to the bone and may slow the growth of bone secondaries. Bisphosphonates can also reduce high levels of calcium in your blood.

Bisphosphonates can cause flu-like side-effects. They can also affect your kidneys so your doctor will need to monitor this for you. Denosumab can cause nausea and diarrhoea. A rare side-effect of both bisphosphonates and denosumab is osteonecrosis of the jaw. This is when healthy bone tissue in your jaw dies. Do have a dental check-up before you start this treatment. Your doctor or nurse will discuss this with you in more detail.

For more information, call the National Cancer Helpline on 1800 200 700. Ask for a factsheet called *Bisphosphonates* or download it from [www.cancer.ie](http://www.cancer.ie)

**Spinal cord compression:** Prostate cancer can sometimes spread to your spine. In rare cases, this can lead to a complication called spinal cord compression. This is where the cancer presses on the nerves in your spine. Signs of spinal cord compression include:

- Weakness, tingling or numbness in your arms or legs
- A narrow band of pain in your arms, legs or body
- Difficulty using your arms and legs

**If you develop weakness, numbness or pins and needles in your arms or legs, contact your doctor straight away.** Receiving treatment quickly may prevent the nerves from being permanently damaged.

## Constipation

Constipation can be a common problem if you have advanced prostate cancer, especially when taking painkillers. If this happens, do talk to your doctor as soon as possible. He or she will want to examine you and find the cause before advising you on the best treatment. Constipation might also be linked to a low-fibre diet, not drinking enough fluids, not eating enough, or being less active. Do talk to your hospital dietitian to help you plan a diet high in fibre with plenty of fluids. Gentle exercises can help to keep your bowel movements regular too. Again, talk to your doctor or nurse for advice on what exercises you can do. Whatever the reason, bowel problems can be distressing especially when they affect your daily life.

## Fatigue

Fatigue is a common symptom of cancer and described as an overwhelming tiredness. Often it is not relieved by rest. You may also find it hard to concentrate or make decisions. The reason for the fatigue can sometimes be hard to identify. It can be caused by treatments or by the cancer itself. Whatever the reason, there are things you can do that can help. Do listen to your body and take a rest if you need to, even in the middle of the day. It helps to learn how to pace yourself as well. Try to give yourself time for something you enjoy when you are feeling least tired.

If your illness allows you to do physical exercise, do some regularly. For example, a regular, gentle walk might be a realistic goal and will boost your morale when you achieve it. Get others to help you with chores or with travelling to hospital. A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 for a free copy.



### Tips & Hints – fatigue

- Build rest periods into your day. If you are going somewhere special, have a rest before you go out.
- Keep your energy for eating. Eat little and often and use ready-made meals or snacks.



- Wear clothes that are easy to put on and take off.
- Sit down when getting dressed or doing household jobs such as ironing, etc.
- Do some gentle exercise each day. Ask your doctor or nurse for advice.
- Ask for help at work or around the house, especially with cooking or housework.
- Make sure your bedroom is quiet and not too hot or cold.
- Go to bed each night at the same time. Each morning get up at same time and do not lie in.
- Avoid stimulants before bedtime, such as alcohol, coffee, tea, coke or chocolate.
- Use relaxation techniques to get to sleep. For example, gentle exercise, relaxation tapes, etc. Advice on these techniques is available from your local cancer support centre. A list of national support centres is found at the back of this booklet.

## What follow-up do I need?

No matter what treatment you receive, you will still need to come back for regular check-ups. This is called follow-up. At each outpatient visit, your doctor or nurse will check your blood test results and ask you how you are. At some appointments a rectal exam will be done too. Other tests, like X-rays and scans, can be arranged if needed. The visits will allow your doctor to monitor your progress and follow up on any ongoing side-effects you may have. He or she can also 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.

Do tell your doctor or nurse how you have been since your last appointment. Remember to tell them about any new symptoms, aches or pains you have. Sometimes it helps to write down what you want to say before you see the doctor. That way you won't forget what you wanted to say. Do bring along your *Prostate Passport*, if you are using it to keep a record of your prostate cancer treatment.

If you are between check-ups and have a symptom or problem that is worrying you, let your doctor or nurse know. Make an appointment to see him or her as soon as possible.



## Treatment after hormone therapy

Over time prostate cancer cells can change and begin to grow even without testosterone. Despite your hormone therapy continuing to stop your body making testosterone, the cancer cells can start to grow and your PSA level can start to go up. A steady rise in your PSA level may be the only sign that your cancer is not responding to the hormone therapy as well as before.

If your PSA level rises slowly and you have no symptoms, your doctor may choose to monitor your PSA level for a while. This is because it is not yet clear when it is best to start other treatments. If your PSA level rises more quickly, or if you have symptoms such as pain, your doctor will discuss which treatment options are open to you.

### Other treatments

Your prostate cancer can respond to other types of hormone therapy or to other treatments. The exact order in which treatments are given is not the same for all men. The aim is to control your prostate cancer and to improve any symptoms you may have. When deciding which treatments are best for you, your doctor and you will balance the side-effects of treatment against the benefits of treatment.

You may be offered the following treatments:

- Withdrawal of hormone therapy
- Steroid therapy
- Chemotherapy
- Abiraterone
- Oestrogen therapy
- Ketoconazole therapy

### Coping with prostate cancer no longer controlled by hormone therapy

It is common for men to experience a variety of difficult emotions at this time. See page 53 for more advice on coping with your feelings and emotions.

### Withdrawal of hormone therapy

If you have been taking both hormone injections and tablets for your advanced prostate cancer, your doctor may suggest stopping the tablets

if your PSA level starts to rise again. In some men, stopping these anti-androgens tablets once the PSA level starts to rise can help to make it fall again. This is known as anti-androgen withdrawal. Some men find that this helps to lower their PSA level for a few months or sometimes longer.

### Steroid therapy

You might be given steroids either to take along with another treatment or on their own. Steroids can help to reduce the amount of testosterone made in your adrenal glands. Side-effects from steroids include an increased appetite and an improved mood. They can also cause bone thinning, a higher risk of diabetes, fluid retention, and other body changes. Your doctor will check for these side-effects regularly.

### Chemotherapy

Chemotherapy is a treatment using drugs to help kill cancer cells that have travelled to other parts of your body. It is used to control prostate cancer but cannot yet cure it. It may be used if your cancer has spread beyond the prostate and is no longer controlled by hormone therapy. It may reduce the size of the tumour and ease your symptoms. In some cases, chemotherapy will improve your quality of life with better control of your symptoms. Chemotherapy is given to help:

- Shrink your prostate cancer
- Slow down the growth of your cancer
- Control symptoms such as pain
- Improve your quality of life

Docetaxel (Taxotere®) is commonly used, usually with a steroid such as prednisolone. In this case, steroids can help to reduce the side-effects of treatment. A new drug called cabazitaxel (Jevtana®) has also recently become available to treat advanced prostate cancer.

The chemotherapy drugs travel through your bloodstream to almost every part of your body. They are often given in cycles such as once every 2 or 3 weeks 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.

The side-effects of chemotherapy vary from person to person. These unwanted effects happen because chemotherapy affects both cancer cells and normal cells too. Being more prone to infection, a sore mouth, and nausea and vomiting are common side-effects.

Nowadays, side-effects can be well controlled with medication.

Before you start your treatment, ask your doctor about any side-effects that may happen. Do tell him or her how you are feeling during your treatment, as most side-effects can be eased with medication. If you would like more details about chemotherapy, a booklet called *Understanding Chemotherapy* is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 for a free copy or visit a Daffodil Centre if one is located in your hospital.

### Abiraterone

Abiraterone (Zytiga®) is a new drug for men with advanced prostate cancer and might be given after chemotherapy. It is another type of hormone therapy but works in a different way. It blocks a certain enzyme so that testosterone cannot be made. The drug helps to shrink prostate cancer, helps with symptoms and lowers the PSA level.

Abiraterone comes in tablet form and should be taken with steroids. It is important to take it either 1 hour before food or 2 hours afterwards. The side-effects include tiredness, low potassium levels in your blood, aching muscles and joints, high blood pressure, and some changes to liver function. Your doctor will monitor these for you while taking the drug.

### Other drug treatments

There are other drugs that may become available for men with advanced prostate cancer in the next few years. For example, enzalutamide and Alpharadin®. These are currently going through the process of being approved and licensed.

National Cancer Helpline Freefone 1800 200 700

### Oestrogen therapy

Diethylstilbestrol (Stilboestrol®) is a drug like the hormone oestrogen. Oestrogen is made in small amounts by men and diethylstilbestrol can help stop your body making testosterone. It has been found that diethylstilbestrol can be useful in treating advanced prostate cancer that is no longer responding to hormone therapy. For some men diethylstilbestrol can help to lower their PSA level.

Side-effects of diethylstilbestrol include an increased risk of blood clots. Because of this, you will also need to take medication to help reduce this risk. Breast swelling and breast tenderness occur in some men too. You might also experience tiredness, nausea and vomiting. Do mention these side-effects to your doctors so they can help you to manage them.

### Ketoconazole therapy

Ketoconazole is a drug treatment that is sometimes used to block the making of testosterone. It is an anti-fungal treatment and can lower testosterone as a side-effect. This side-effect can be used to manage prostate cancer in some men. Ketoconazole can help reduce the PSA level and is used if your PSA has started to rise after hormone therapy.

Side-effects include nausea, vomiting, tiredness and liver problems. Your doctors will need to check your liver with blood tests if you take ketoconazole. The drug can also interact with other medications. Make sure to tell your GP or any doctor you attend that you are taking ketoconazole for prostate cancer. For more information, talk to your doctor or nurse. You can also call the National Cancer Helpline on 1800 200 700 for more advice.

### Clinical trials

Your doctor may ask you to take part in a clinical trial, especially if there is a promising new drug for advanced prostate cancer. It may be of benefit to you and can find out if there are any possible side-effects. See page 37 for more details on clinical trials.



## To sum up

- Different treatments are available if your hormone therapy no longer works well.
- Your doctor will talk to you about the options suitable for you.
- Some treatments include withdrawal of hormone therapy, steroid therapy, oestrogen therapy, ketoconazole therapy, abiraterone or chemotherapy.

## Palliative care

Many cancer doctors have a team approach to managing both the cancer itself and the symptoms due to the cancer or its treatment. The palliative care team in your area might see you when you have just a few symptoms but your own medical team will also help deal with any cancer-related symptoms. This palliative care team is expert in managing pain and also a variety of other symptoms.

Palliative care is care that focuses on your physical, psychological and spiritual needs rather than trying to cure or control the cancer. It helps you get the best quality of life available to you by relieving suffering and controlling pain and symptoms, as well as any emotional distress.

A team of doctors, nurses and other health professionals will be responsible for your care. Your GP, public health nurse or hospital can refer you to the specialist palliative care service close to where you live. Palliative care can be given in a hospice or community hospital or in your own home. You can attend a hospice for managing your symptoms as well. Nowadays hospices are places that specialise in symptom control and you can spend a day or two there receiving treatment. In later stages, palliative care can also help people to prepare for death. Do talk to your doctor and nurse for more advice. Or if you do not feel well enough, your family can do so.

See page 62 for more about caring for someone with advanced prostate cancer.

## Cancer and complementary therapies

Complementary treatments for cancer are very popular today. Many people find them very helpful during their illness. The way cancer is treated often depends on the culture of the country you live in. In Ireland, cancer treatments are based on scientific research, which 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 that doctors use most often to treat people with cancer. These include surgery, radiotherapy, chemotherapy, hormone therapy and biological therapy. They are tried and trusted methods where there is a long history of use. Many of the treatments have been tested in clinical trials.

### Complementary therapies

Complementary therapies are treatments that are sometimes given **together with** conventional treatments. 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 it can often bring. Some complementary therapies also focus on the spiritual dimension of a person to aid healing.

### Alternative therapies

Alternative therapies are generally treatments that are used **instead of** conventional treatments. These therapies include diet therapy, megavitamin therapy and herbalism. The diet therapy can often be

restrictive. This means it does not allow you to eat foods that could be nutritious for you. Some restrictive diets can harm your health and may even cause malnutrition. Most doctors do not believe that such treatments can cure or control cancer.



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



Before you decide to change your treatment or add any methods of your own, do 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, do talk openly with your GP or cancer specialist 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. At present in Ireland, this area is not fully regulated. Ensure that the practitioners you plan to visit are properly 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 *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients*. If you would like a copy or more advice, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre if one is located in your hospital.

National Cancer Helpline Freefone 1800 200 700

## Coping and emotions

### How can I cope with my feelings?

There are many reactions when told you have prostate cancer, especially if it is locally advanced or advanced. Reactions can often differ from person to person too. In fact, there is no right or wrong way to feel. There is also no set time to have one particular emotion or not. Some reactions may occur at the time of diagnosis, while others might appear or reappear later during your treatment. Or indeed it may not be until the later stages of your illness that your emotions hit hard.

#### Common reactions include:

- Shock and disbelief
- Fear and uncertainty
- Loss of control
- Sorrow and sadness
- Denial
- Anger
- Resentment
- Blame and guilt
- Withdrawal and isolation

Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. A helpful booklet that discusses them in detail is called *Understanding the Emotional Effects of Cancer* and is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 for a free copy or visit a Daffodil Centre if one is located in your hospital. Your medical social worker in the hospital is also available to support you.

#### Shock and disbelief

*'It can't be me.' 'Has there been a mistake?' 'Cancer happens to other people, not me.'*

Shock is often the first reaction to a cancer diagnosis. In fact, you may feel numb and the situation may seem unreal. Many people think cancer will never happen to them and are totally shocked when it does. Even if your

doctor and nurse discuss the cancer with you, the news may not sink in for a while. You may find yourself confused, asking the same questions over and over again. Or else you may accept the news calmly and say nothing because you cannot really believe what is happening to you.

### Fear and uncertainty

*'I'm going to die.'  
'Will it be painful?'  
'Will I become a  
different person?'*

There is no doubt that cancer is a scary word. Not surprisingly, you may have many fears when first told of your diagnosis. Often the first thing people think about is dying. No one knows how long anybody will live, but having locally advanced or advanced prostate cancer is likely to shorten your life. It can be very difficult to face an uncertain future and feel you are no longer in control. One way to reduce the stress of uncertainty is to make your plans day by day. Letting go of the past and not worrying about the future allows you to live fully in the present. Another great fear about cancer is pain. The fear of pain can sometimes overwhelm everything else. However, some cancers cause no physical pain at all or else can be controlled with good painkillers.

You may also have fears that your experience of cancer will change who you are or that people will reject or avoid you. For example, after some cancer treatments your body image may be different, and it will take some time for you and for others to adjust to your new look. You may also have practical worries and fears about the effect of your illness on your family, your finances, your job, and your lifestyle.

Do discuss your concerns with your doctor, nurse or medical social worker, as they can advise and help you. If living with uncertainty overwhelms you, it may help to talk to someone in a support group.

### Loss of control

*'I can't cope with  
this.' 'I'll never get  
through it.'*

After a cancer diagnosis, it is common for people to feel their life is beyond their control. All your plans may be put on hold. You may even lose some independence and freedom.

Because you don't know enough about your illness at first, you may rely totally on the advice of your doctors and nurses. You may not feel confident making any decisions about your treatment. When you experience a loss of control, it can lead to feelings of helplessness. You may also feel that you will be unable to cope with your treatment or that you will 'fall to pieces' or 'go crazy'. You may even lose hope.

It takes a while to know what is within your control and what is beyond it. Finding out as much as possible about your illness can help you regain some control. Taking an active part in making decisions about your treatment can also help you feel more in control of your illness.

### Sorrow and sadness

*'I used to be so  
healthy.' 'I had so  
many plans.' 'I've let  
my family down.'*

It is natural to feel sad when told you have cancer. You may feel sad for a variety of reasons: for the loss of your good health, for the plans that are put on hold, for the people you feel you've let down, and for any changes to your body due to treatment.

Depending on your type of cancer, your life may be affected by treatment. In this case, the sadness or sorrow can come from feeling as if a part of you has died. These feelings may not be there all the time and may come and go, but will gradually fade.

### Denial

*'I'm fine, really.'  
'I don't have cancer.'*

Sometimes after being told their diagnosis, people deny they have cancer. While this may seem unusual, it is a valid way of coping. As a result, you may not wish to mention or discuss your illness. Or else you may talk as if your illness is nothing serious. Denial may last for a short or long time, depending on how long it takes for you to adjust to your illness. Tell your family and close friends that you would prefer not to talk about your illness, at least for the time being. Your doctors and nurses will also understand if you don't want to hear any information about your cancer until you're ready.

## Anger

*'Why me? I always took care of my health.' 'Why did this happen now?'*

It is normal too to be very upset when told you have cancer. Many aspects of your illness can result in anger and distress. Anger can often hide other feelings such as fear, sadness or frustration. You may feel angry towards the doctors and nurses who are caring for you.

Or if you have a religious belief, you may feel angry with God for allowing cancer to occur. You may vent your anger on those closest to you. Indeed being unable to protect the ones you love may frustrate you a lot.

Your family and friends may not always be aware that your anger is really at your illness and not at them. It may be helpful to talk to them when you are calm, rather than feeling guilty or trying to bottle up your angry thoughts. Anger can sometimes affect your ability to think clearly. So if it persists and you are finding it hard to talk to your family, tell your nurse or doctor.

## Resentment

*'How can you talk, you don't have to deal with cancer.' 'How come I'm not getting better?'*

It is natural that you might be resentful and unhappy – even jealous – because you have cancer while other people are well. During the course of your illness similar feelings of resentment may occur for many reasons. You may resent that another patient receiving the same treatment as you has responded quicker

than you have. You may resent your healthy relatives or having to change your lifestyle in some way.

On the other hand, sometimes relatives, especially adolescents, can resent the changes that your illness makes to their lives. It is best to admit that these feelings of resentment exist and to express them.

Bottling up resentment helps no one. Instead everyone ends up feeling angry and guilty.

**>>> Don't bottle up your feelings – express them.**

## Blame and guilt

*'I should've been more careful.' 'If only I had a more positive attitude, I wouldn't have got sick.'*

When diagnosed with a serious illness such as cancer, it is natural to want to know what caused it. Sometimes people blame themselves or others for their illness. As cancer experts rarely know exactly what has caused cancer, there is no good in blaming yourself. Other times, people feel guilty because they delayed going to the doctor with their symptoms,

fearing the worst. No matter what the reason, don't torture yourself at this time.

Don't feel guilty if you can't keep a positive attitude, especially when you feel unwell. Low periods are to be expected. There is no evidence at all that your attitude will affect your health or cancer. Regret and guilt serve no useful purpose. Instead focus on what you can change or do to make you feel more in control of your illness.

## Withdrawal and isolation

*'I just need to be on my own.'*

It is true that a cancer diagnosis is stressful. It can leave you feeling confused and overwhelmed with so much information to take in. At times during your illness you may

want to be left alone and withdraw from people. It is normal to want to sort out your thoughts and feelings. You will want to take stock of things and work out how best you can cope. However, it is not a good idea to spend long hours on your own every day. Sometimes depression can make you avoid family and friends and stop you wanting to talk. If you isolate yourself, it can be hard for them, as they will want to share this difficult time with you. They may worry about you needlessly. Do let your family and friends know that you will talk to them once you are ready.

If you would like more information on how to talk about your cancer, there is a useful booklet available called *Who Can Ever Understand? Talking about Your Cancer*. If you would like a copy, call the National Cancer Helpline on 1800 200 700.

## How can my family and friends help?

Your family and friends can support you through your cancer journey in different ways. Some family members and friends can offer a listening ear and give you advice if needed. Others may gather up-to-date information on prostate cancer to know what you can expect and what you are going through. Others again may prefer to help you in a practical way with travelling to and from the hospital, with childcare if relevant, cooking, shopping or housework. It may take time to know which way suits you and your family or friends best.



### How to talk to someone with cancer

When someone close to you has cancer it can be hard to know what to do. Their welfare may be a priority for you, but you might still be unsure when to visit or what to talk about. You may be afraid of upsetting them or saying the wrong thing. So it may seem best to pretend that everything is okay and carry on as normal. Sadly, by not talking to your friend or loved one, it can make them feel even more lonely and isolated. Try not to withdraw because you're afraid of their illness or what might happen in the future.



Often those with cancer do not wish to burden their family and friends with their worries and concerns. Gentle encouragement can sometimes help. But don't rush into talking about their illness – knowing that you are always ready to listen and give help may reassure them. You may think you are not doing much by just listening. In fact, it is one of the best ways to help.

#### Be patient

Sometimes your friend or relative may get cross or irritable for what may seem to be no good reason. These feelings are completely normal. Be as patient and understanding as you can. Give them the space and time to adjust to the changes in their life. Above all, let them know that you are there, if they want to talk or need help. In time, life will begin to be normal again.

*Lost for Words: How to Talk to Someone with Cancer* is a useful booklet written for relatives and friends of people with cancer. Call the National Cancer Helpline on 1800 200 700 for a free copy or visit a Daffodil Centre if one is located in your hospital.

## How can I talk to my children?

A cancer diagnosis can affect an entire family. It can bring changes that may be either great or small. Even so, it is best to keep family life as normal as possible. If you have young children, continue with school and other activities, with birthdays and celebrations or work commitments. It may take a while but families can learn to adjust to big changes in their lives. Every family deals with cancer in its own way. You may feel that you do not want your illness to upset family life, or feel guilty that you cannot do activities with your children or grandchildren or that you're letting them down. These are all natural feelings to have at this time.

### Be honest

The main thing to remember is that being honest with your family really helps. Keeping your illness a secret may not be the best thing for your children. It can put added pressures on your family and lead to confusion. Young children are very sensitive to stress and tension and if you try to protect them by saying nothing, they may feel isolated. In fact, they may have greater fears if told nothing.

It is best that you or your partner tell your children about your cancer diagnosis. If this is not possible, then someone else close to your children should break the news.

How much you tell children will depend on their age and level of maturity. Very young children do not understand illness and need a simple reason why their parent or friend is sick and has to go to hospital regularly. A story about good cells and bad cells usually works well. Most children over 10 years of age can take in fairly full explanations of why you are sick. Adolescents can understand far more.

It is best to prepare children for the side-effects of treatment before they happen and to answer their questions simply and honestly. For example, if you get hair loss due to treatment. It is also important not to force your children to talk about your illness. If they rebel or turn quiet, it may be their way of showing their feelings.

## Coping with children's emotions

During your illness, your children may experience a range of emotions from fear, guilt and anger to neglect, loneliness, isolation and embarrassment. They need to be reassured that your illness is not their fault. Whether they show it or not, young children may feel that they somehow are to blame. But by having an open honest approach, it may bring you a sense of relief too. Your family may also find new depths of love and inner strength that will boost your life together.

If you need some extra help in dealing with children, talk to your nurse or medical social worker. A useful booklet called *Talking to Children about Cancer: A Guide for Parents* gives practical advice for talking to children about cancer. If you would like a free copy, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre if one is located in your hospital.

## Living with cancer

Everyone experiences cancer in a different way. And how each person copes with cancer varies too. There is no right or wrong way to cope, only your way. During your illness there are many things that you can learn, not only about cancer itself but also about you as a person. Here is a list of things to help make you feel more involved and more in control of your illness. They can help to boost your self-esteem and well-being, making it easier to deal with cancer.

**Communicate with your family and close friends:** Do not keep your worries or symptoms secret from the people closest to you. This includes physical or emotional problems. Ask the person closest to you to come along when visiting the doctor and when treatments will be discussed.

**Live one day at a time:** Don't think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.

**Live well:** 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. Do some regular exercise that you enjoy. Take it easy at first, building up the amount you do as you feel stronger.

**Expect change in your life:** Even though you may want to stick to your old routines, sometimes this may not be possible. It may take a while for you to adjust to your new routine. Remember that change may bring new opportunities and blessings.

**Keep an open mind:** Don't feel you have to be positive all the time. Expect ups and downs during your cancer journey. There will be times when you feel low but don't feel guilty about it, as it will pass.

**Seek information:** Be sure to ask your doctor as many questions as you can and get involved in decisions about your treatment. Always ask for information that is personal to you. Ask what side-effects you can expect so you can prepare for them. Build up as much information about your cancer and treatment as possible. Follow your doctor's instructions carefully. Take your medication. If you forget and are not sure what to do, ask your doctor or nurse. Keep a notebook of all your dates for blood tests, X-rays, scans, treatments, symptoms, side-effects, medications, and your general health. Keep a record of any emotions you are feeling too, especially strong ones. Call 1800 200 700 for a free copy of *Journey Journal* or *Prostate Passport* to help you keep track of your cancer treatment.

**Find what works for you:** It can help to use whatever way of coping that has helped you solve problems in the past. Some people are comfortable taking about their illness, others are not. You may prefer relaxation, meditation, walking, listening to music, or other approaches helpful. Do whatever suits you. But if it's not working, be open to finding a new way to cope.

**Build a support network:** Be realistic about what you can manage by yourself. No man is an island, so seek help from those who want to support you. Talk to your family, friends, nurses or doctors. Meet with other patients in support groups and self-help groups as they can understand what you are going through. If the group does not suit you and is not helping, leave it.

**Seek professional help:** If you have any low moods or strong emotions, talk to your close friends and family – or someone who is a good listener. If your emotions are still getting the better of you, discuss them with your nurse and doctor. They may advise you to talk to a trained counsellor or other specialist.



**Spiritual care:** When faced with a cancer diagnosis and treatment, you may start thinking about the meaning of life and the afterlife. For some people spiritual and religious beliefs can bring comfort and hope. Prayer or meditation can help you to focus on what has value and meaning in your life. Even if you do not consider yourself a religious or spiritual person, it is still possible to take comfort and support from these practices. Some complementary therapies that have a spiritual dimension may also help you to focus on being positive and hopeful.

**Express yourself:** Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of your cancer journey and can bring great healing and relief. Other forms of creative expression, such as music and art, may help too.

**Putting your affairs in order:** If your illness is not getting any better, it may be time to think about putting your affairs in order. Do talk to your family and friends about this. You may wish to make a will or have religious or spiritual needs that need addressing or want to say goodbye to friends. A helpful booklet is *Time to Care: Caring for Someone Seriously Ill at Home*. Call 1800 200 700 for a free copy or advice.

A useful booklet called *Understanding the Emotional Effects of Cancer* has been written for people with cancer and is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 if you would like a free copy or visit a Daffodil Centre if one is located in your hospital.

## Caring for someone with advanced prostate cancer

Being a carer of someone with cancer can be both a challenging and a rewarding experience. In practice carers provide all sorts of emotional and physical support. It is true that caring for a loved one can bring great personal satisfaction. But there can be times when it is tiring, frustrating, distressing and isolating.

You may become a carer overnight and feel that you are not experienced enough to handle the care of your relative or friend. You may also be worried or anxious about the future and have fears about the effects of treatment. To keep your strength and spirits up, it is important to take good care of yourself. And remember to ask for and accept help when you need it. If you would like more advice, call the National Cancer Helpline on 1800 200 700. Ask of a copy of the free booklet, *A Time to Care: Caring for Someone Seriously Ill at Home*.



### Tips & Hints – for carers

- **Information:** Find out as much information as possible about advanced prostate cancer, especially its symptoms, treatment and side-effects. Talk to the doctor, nurses, National Cancer Helpline, and so on. Get information too about financial supports and community services from the medical social worker or see the back of this booklet for details.
- **Emergencies:** Find out who to call if you are particularly worried or in an emergency.
- **Physical care:** Being a carer may involve helping your relative or friend with mobility, bathing and dressing, giving meals and medication. Ask the nurses for advice with any of these tasks.
- **Eating and drinking:** Gently encourage your relative or friend to eat but do not push them. Pre-prepare snacks for the times when they feel like eating.
- **Help:** Take up all offers of help, especially with finances, cooking, housework, shopping. Do not get weighed down by all your friend or relative's needs. Expect ups and downs with treatment. If you find it hard to cope, get help. There are many healthcare professionals to advise you. Find out about self-help groups too, especially those for carers of people with cancer.
- **Caring for yourself:** Look after your own health too. Take regular meals and exercise. See your doctor sooner rather than later if you have any health concerns of your own. Talk to your doctor about any worries you have about caring for your relative or friend.
- **Time for yourself:** Make sure you share your worries with someone else. Stay in touch with your own friends. Get out when you can – even if you don't feel like it. Make time for a break each day: a walk to the shops, a trip to the library or cinema, or an evening out with friends. Give yourself little treats at home. Read a favourite magazine, sit down for a leisurely cup of tea or coffee, or have a relaxing soak in the bath.



## Support resources

### Who else can help?

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

- Medical social worker
- Cancer nurse specialists
- Psycho-oncology services
- Family doctor (GP)
- Community welfare officer and community health services
- Support groups and cancer support centres
- Irish Cancer Society helpline nurses

**Medical social worker:** The medical social worker in your hospital can help in many ways. He or she can give support and counselling to you and your family and give advice on practical and financial supports and services available when you go home.

**Cancer nurse specialists:** Some of the major cancer treatment hospitals have oncology liaison nurses and/or cancer nurse coordinators. These specially trained nurses can support you and your family from the time of diagnosis and throughout treatment. These nurses along with other members of your medical team work together to meet your needs.

**Psycho-oncology services:** In some larger hospitals there are special units that provide psycho-oncology services. This means that you can receive psychological care and support during your diagnosis, treatment and recovery by a team of experts. Usually the team consists of psychiatrists, clinical psychologists and nurses working closely together.

**Family doctor (GP):** You may feel comfortable talking to your family doctor (GP) about your cancer too. He or she can discuss any of your queries and offer advice and support.

**Community health services:** When you go home, there are various community health services available from your local health centre. These centres have public health nurses (who can visit you at home),

welfare officers and home-help organisers. If you live far from your hospital, your community welfare officer can also help with practical issues such as financial problems or exceptional needs. More information on the services is available either from the medical social worker in the hospital before you go home or at your local health centre.

**Support groups:** Joining a support group can put you in touch with people who have been in a similar situation. They can give you practical advice about living with prostate cancer. Men Against Cancer is a support group for prostate cancer. See page 74 for more information. Cancer support centres are found in most counties in Ireland and can offer a wide range of services. Some are listed at the back of this booklet.

**Irish Cancer Society:** The staff of the National Cancer Helpline will be happy to discuss any concerns you or your family may have, at any stage of your illness. This can range from treatment information to practical advice about your financial matters. For example, getting life insurance. Call 1800 200 700 for information about any of the services outlined above or for support services in your area. You can also visit a Daffodil Centre if one is located in your hospital.

»» Remember that there are many people ready to help you.

## Health cover

Health cover falls into two categories – cover for medical card holders and cover for all other categories. Details of the following are given here:

- Hospital cover
- Outpatient cover
- Medical card
- GP visit card
- Drug Payments Scheme (DPS)
- Private healthcare cover
- Benefits and allowances



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 €75 a night charge up to a limit of €750 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 €100. There is no charge if you have a medical card or are admitted to hospital because 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 as well as outpatient services and medical appliances. You may have to pay a prescription charge of €1.50 per item up to a limit of €19.50 per family per month.

To qualify for a medical card depends on a means test regardless of age. If you are over 70 and your weekly income is €600 or less, you can still apply for a card. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office. If your means are above but close to the guidelines, you should apply for a card anyway as a card may be granted in some situations. For example, if you have a large amount of medical expenses. Also, you might qualify for a medical card because you have a cancer diagnosis. But it will depend on your financial circumstances and how long your treatment is expected to last. In this case, your spouse and children will not be covered if your means are over the limit. If you wish to apply for a medical card, you can download an application form and apply online ([www.medicalcard.ie](http://www.medicalcard.ie)) or at your local health centre.

## GP visit card

If you do not qualify for a full medical card, you may be eligible for a GP visit card. This card 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 and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker at the hospital or your HSE office to see if you are eligible. If you wish to apply for a GP visit card, you can download an application form and apply online ([www.medicalcard.ie](http://www.medicalcard.ie)) or at your local health centre.

### Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €144 each month to cover the cost of prescribed drugs, medicines and appliances. 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 local pharmacy.

### Private healthcare cover

Private health insurance pays for private care in hospital or from various specialists in hospitals or in their practices. In Ireland, this is available through the VHI, Laya Healthcare, AVIVA Health, GloHealth and other schemes. They provide cover for day care/inpatient treatment and hospital outpatient treatment. Before attending hospital, do check the level of cover provided by your insurer, both for inpatient and outpatient services.

If you have private insurance, your tests might not get done as quickly as you would like. Your health insurer has to approve some tests in advance. For example, MRI and PET scans. Sometimes it might take 24–48 hours to get approval from your health insurer.

### Benefits and allowances

Information on the following is given in this section:

- Illness Benefit
- Disability Allowance
- Invalidity Pension
- Carer's Allowance
- Carer's Benefit
- Carer's Leave
- Appliances
- Travel to hospital



For a free copy of *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*, contact the National Cancer Helpline on 1800 200 700.

Application forms for the benefits below are available from your local social welfare office or the Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770. You can also download the forms from websites such as [www.welfare.ie](http://www.welfare.ie) or [www.citizensinformation.ie](http://www.citizensinformation.ie)

### Illness Benefit

This is a benefit for insured people. Your eligibility will depend on your PRSI contributions. You must be under 66 and unable to work due to illness. Each week you must send a social welfare medical certificate signed by your doctor to the Dept of Social Protection, 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. The benefit lasts for 2 years.

### Disability Allowance

You might qualify for disability allowance if you are not eligible for illness benefit and not able to work for at least 1 year. Disability allowance is a weekly allowance paid to people with an injury, disease or a disability who are aged between 16 and 66. For this allowance, you must satisfy a means test, live in Ireland and be medically suitable. To be medically suitable, you should have an illness that has continued or may continue for at least 1 year.

You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme.

### Invalidity Pension

This is a pension paid instead of an illness benefit or disability allowance, if you are unable to work permanently. 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 the age of 60 and have a serious illness or incapacity.

Your eligibility will also depend on your PRSI contributions. You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme.

### **Carer's Allowance**

This is an allowance for carers on low incomes who look after someone who needs full-time care and attention. You must be aged 18 or over, live in Ireland, satisfy a means test, not be self-employed or work more than 15 hours a week outside the home, and not live in a hospital or nursing home. You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a respite care payment every year. For more advice, talk to your medical social worker and/or the Department of Social Protection.

### **Carer's Benefit**

If you are employed but wish to care for a sick relative full time, you might 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. You must be employed for 8 weeks in the 26-week period immediately before applying for the benefit. You must be aged 16 or over, live in Ireland, not be self-employed or employed while caring for the person, and not live in a hospital or nursing home.

### **Carer's Leave**

By law you may be entitled to unpaid temporary leave from your employment. Carer's leave allows you to leave your employment for up to 104 weeks to care for someone in need of full-time care and attention. The leave will be unpaid, but you will have your job kept open for you while you are on leave. You do not need to be eligible for carer's allowance or carer's benefit to apply for carer's leave. You must have worked for your employer for a continuous period of 12 months to be eligible to apply for carer's leave. The person you are

caring for can be a partner or family member, friend or colleague. The family doctor (GP) of the person you are caring for will also need to fill in part of your application form.

You can work while you are on carer's leave for up to 15 hours a week. But you must make sure your income from employment or self-employment is less than a weekly income limit set by the Department of Social Protection.

### **Appliances**

For patients who have medical cards most appliances are free of charge or subsidised.

### **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 medical 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, those who do not have a medical card may be charged for the service. However, the practice varies between HSE areas and often depends on personal circumstances. Charges may be waived in certain cases, like hardship.

See page 75 for information on the Care to Drive and Travel2Care schemes run by the Irish Cancer Society. Some local communities may also provide volunteer transport services.

### **Further information**

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements that 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:**

Dept of Social Protection – Tel: 1850 662 244  
 Information Service Leaflet line: 1890 202 325  
 Oisín House Email: info@welfare.ie  
 212–213 Pearse Street Website: www.welfare.ie  
 Dublin 2

If you have queries about health and social services, contact the HSE office in your area.

**HSE infoline:** 1850 24 1850 **Email:** info@hse.ie **Website:** www.hse.ie

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

**Citizens Information Phone Service:** 0761 07 4000

Email: information@citizensinformation.ie

Website: www.citizensinformation.ie

**If you have financial worries...**

A diagnosis of cancer can sometimes bring the added burden of financial worries. You may find that you have a lot more expenses, like medication, travel, food, heating, laundry, clothing and childcare costs. If you are unable to work or unemployed, this may cause even more stress. It may be hard for you to deal with cancer if you are worried about providing for your family and keeping a roof over your head.

There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. See page 75 for more details. You can also call the National Cancer Helpline on 1800 200 700 and the nurse will suggest ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 0761 07 2000. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. See page 77 for contact details. A useful book for preparing low-budget nutritious meals is *101+ Square Meals*. See page 83 for more information.

## Irish Cancer Society services

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

- Cancer Information Service (CIS)
- Daffodil Centres
- Cancer support groups
- Survivors Supporting Survivors
- Counselling
- Night nursing
- Oncology liaison nurses
- Cancer information booklets
- Financial support
- Care to Drive transport project



### Cancer Information Service (CIS)

The Society provides a Cancer Information Service with a wide range of services. The **National Cancer Helpline 1800 200 700** is a freefone service that gives confidential information, support and guidance to people concerned about 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. The helpline can also put you in contact with the various support groups that are available. The helpline is open Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- All queries or concerns about cancer can be emailed to the CIS at **helpline@irishcancer.ie**
- **Message Board** is a discussion space on our website (**www.cancer.ie**) to share your stories, ideas and advice with others.
- The **CancerChat** service is a live chatroom with a link to a Cancer Information Service nurse.
- Find us on Facebook and follow us on Twitter (**@IrishCancerSoc**).

## Daffodil Centres

Daffodil Centres are located in a number of Irish hospitals. They have been set up by the Irish Cancer Society in partnership with each hospital and are an extension of the Cancer Information Service. They are generally found near the main entrance of the hospital and are open during the day. Staffed by a specialist nurse and trained volunteers, they provide a range of information, advice, help and support on all aspects of cancer, free of charge.

Daffodil Centres give you a chance to talk in confidence and be listened to and heard. If you are concerned about cancer, diagnosed with cancer or caring for someone with cancer, you are welcome to visit the centre. Do check to see if there is a Daffodil Centre in your hospital.

## 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. See page 78 for more details.

## Survivors Supporting Survivors

Being diagnosed with cancer can be one of the hardest situations to face in your lifetime. Survivors Supporting Survivors is a one-to-one support programme run by the Irish Cancer Society. It provides emotional and practical support to newly diagnosed patients. For example, Men Against Cancer is a support group for men with prostate cancer. It can provide you and your relatives with information, advice and emotional support from time of diagnosis and for as long as is needed. All the volunteers have had a personal experience of prostate cancer and understand the emotional and physical impacts of the disease. They are carefully selected after recovery and are trained to provide information and reassurance. The service is provided on a one-to-one basis and is confidential. If you would like to make contact with a volunteer, call the National Cancer Helpline on 1800 200 700.

## Counselling

Coping with a diagnosis of cancer can be very stressful at times. Sometimes it can be hard for you and your family to come to terms with your illness. You might also find it difficult to talk to a close friend or relative. In this case, counselling can give you emotional support in a safe and confidential environment. Call the helpline 1800 200 700 to find out about counselling services provided by the Irish Cancer Society and services available in your area.

## Night nursing

The Society can provide a night nurse, free of charge, for up to 10 nights if you need end-of-life care at home. The night nurse can also give practical support and reassurance to your family. You can find out more about this service from your GP, local public health nurse, a member of the homecare team or the palliative care services at the hospital. Homecare nurses can offer advice on pain control and managing other symptoms.

## Oncology liaison nurses

The Society funds some oncology liaison nurses who can give you and your family information as well as emotional and practical support. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

## 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. They can also be picked up at a Daffodil Centre or downloaded from [www.cancer.ie](http://www.cancer.ie)



## Financial support

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society can provide limited financial help to patients in need. You may be suitable for schemes such as Travel2Care or Financial Aid.

Travel2Care is funded by the National Cancer Control Programme (NCCP) and managed by the Irish Cancer Society. The scheme can help with your travel costs if you have genuine financial hardship due to travelling to a designated cancer centre or approved satellite centre. It will help with the costs of public transport, such as trains or buses, private transport costs, or petrol and parking. If you are travelling to a Rapid Access Diagnostic Clinic, you may qualify for the Travel2Care scheme.

**Travel2Care:** If you would like to request this kind of help, contact your oncology nurse or the Irish Cancer Society at (01) 231 6643 / 231 6619 or email [travel2care@irishcancer.ie](mailto:travel2care@irishcancer.ie)

**Financial Aid:** A special fund has been created to help families in financial hardship when faced with a cancer diagnosis. If this applies to you, contact the medical social work department in your hospital. You can also speak to your oncology nurse or contact the Irish Cancer Society at (01) 231 6619.

See our website for more information: [www.cancer.ie](http://www.cancer.ie)

### Care to Drive transport project

Care to Drive is a scheme operated by the Irish Cancer Society. It provides free transport for patients to and from their treatments using volunteer drivers. All of the volunteers are carefully selected, vetted and trained. You are collected from your home, driven to your appointment and brought back home again. Call (01) 231 0522 for more information.



If you would like more information on any of the above services, call the National Cancer Helpline 1800 200 700. You can also visit the website: [www.cancer.ie](http://www.cancer.ie)

National Cancer Helpline Freefone 1800 200 700

## Useful organisations

### Irish Cancer Society

43/45 Northumberland Road  
Dublin 4  
Tel: 01 231 0500  
National Cancer Helpline: 1800 200 700  
Email: [helpline@irishcancer.ie](mailto:helpline@irishcancer.ie)  
Website: [www.cancer.ie](http://www.cancer.ie)

### Men Against Cancer

Irish Cancer Society  
43/45 Northumberland Road  
Dublin 4  
Freefone 1800 200 700  
Email: [support@irishcancer.ie](mailto:support@irishcancer.ie)  
Website: [www.cancer.ie](http://www.cancer.ie)

### The Carers Association

Market Square  
Tullamore  
Co Offaly  
Tel: 057 932 2920  
Freefone: 1800 240 724  
Email: [info@carersireland.com](mailto:info@carersireland.com)

### Citizens Information

Citizen Information Phone Service: 0761 07 4000  
Email: [information@citizensinformation.ie](mailto:information@citizensinformation.ie)  
Website: [www.citizensinformation.ie](http://www.citizensinformation.ie)

### Irish Oncology and Haematology Social Workers Group

Website: <http://socialworkandcancer.com>

### Irish Nutrition & Dietetic Institute

Ashgrove House  
Kill Avenue  
Dún Laoghaire  
Co Dublin  
Tel: 01 280 4839  
Email: [info@indi.ie](mailto:info@indi.ie)  
Website: [www.indi.ie](http://www.indi.ie)

### Irish Osteoporosis Society

12 Burlington Road  
Garden Level  
Ballsbridge  
Dublin 4  
Tel: 01 637 5050  
LoCall: 1890 252 751  
Email: [info@irishosteoporosis.ie](mailto:info@irishosteoporosis.ie)  
Website: [www.osteoporosis.ie](http://www.osteoporosis.ie)

### Money Advice and Budgeting Service (MABS)

Commercial House  
Westend Commercial Village  
Blanchardstown  
Dublin 15  
Tel: 01 812 9350  
Helpline: 0761 07 2000  
Email: [helpline@mabs.ie](mailto:helpline@mabs.ie)  
Website: [www.mabs.ie](http://www.mabs.ie)

### Relationships Ireland

[Relationship counselling charity]  
38 Upper Fitzwilliam Street  
Dublin 2  
LoCall: 1890 380 380  
Email: [info@relationshipsireland.com](mailto:info@relationshipsireland.com)  
Website: [www.relationshipsireland.com](http://www.relationshipsireland.com)

### ACCORD (Catholic Marriage Care Service)

ACCORD Central Office  
Columba Centre  
Maynooth  
Co Kildare  
Tel: 01 505 3112  
Email: [admin@accord.ie](mailto:admin@accord.ie)  
Website: [www.accord.ie](http://www.accord.ie)

### Health insurers

#### AVIVA Health

(formerly VIVAS Health)  
PO Box 764  
Togher  
Cork  
Tel: 1850 717 717  
Email: [info@avivahealth.ie](mailto:info@avivahealth.ie)  
Website: [www.avivahealth.ie](http://www.avivahealth.ie)

#### GloHealth

PO Box 12218  
Dublin 18  
Tel: 1890 781 781  
Email: [findoutmore@glohealth.ie](mailto:findoutmore@glohealth.ie)  
Website: [www.glohealth.ie](http://www.glohealth.ie)



**Laya Healthcare** (formerly Quinn)  
Eastgate Road  
Eastgate Business Park  
Little Island  
Co Cork  
Tel: 021 202 2000  
Local: 1890 700 890  
Email: [info@layahealthcare.ie](mailto:info@layahealthcare.ie)  
Website: [www.layahealthcare.ie](http://www.layahealthcare.ie)

**Voluntary Health Insurance (VHI)**  
IDA Business Park  
Purcellsinch  
Dublin Road  
Kilkenny  
CallSave: 1850 44 44 44  
Email: [info@vhi.ie](mailto:info@vhi.ie)  
Website: [www.vhi.ie](http://www.vhi.ie)

## National support groups

**ARC Cancer Support Centres**  
Dublin and Cork (see pages 79 and 80).

### I've Got What?!

[Support for young adults affected by cancer]

c/o Cross Cause Charity Shop  
Blackrock  
Co Louth  
Tel: 086 339 5690

**Lakelands Area Retreat & Cancer Centre**  
Multyfarnham  
Mullingar  
Co Westmeath  
Tel: 044 937 1971  
Callsave 1850 719 719  
Email: [info@larcc.ie](mailto:info@larcc.ie)  
Website: [www.larcc.ie](http://www.larcc.ie)

**Men Against Cancer**  
Irish Cancer Society  
43/45 Northumberland Road  
Dublin 4  
Freefone: 1800 200 700  
Email: [support@irishcancer.ie](mailto:support@irishcancer.ie)  
Website: [www.cancer.ie](http://www.cancer.ie)

## Connaught support groups & centres

**Athenry Cancer Care**  
Social Service Centre  
New Line  
Athenry  
Co Galway  
Tel: 091 844 319 / 087 412 8080

**Ballinasloe Cancer Support Centre**  
Society Street  
Ballinasloe  
Co Galway  
Tel: 090 964 5574 / 087 945 2300  
Email: [ballinasloecancer@yahoo.co.uk](mailto:ballinasloecancer@yahoo.co.uk)

**Cancer Care West**  
Inis Aoibhinn  
University Hospital Galway  
Costello Road  
Galway  
Tel: 091 545 000  
Email: [info@cancercareswest.ie](mailto:info@cancercareswest.ie)  
Website: [www.cancercareswest.ie](http://www.cancercareswest.ie)

**Cara Iorrais Cancer Support Centre**  
2 Church Street  
Belmullet  
Co Mayo  
Tel: 097 20590  
Email: [caraiorrais@gmail.com](mailto:caraiorrais@gmail.com)

**East Galway Cancer Support Centre**  
The Family Centre  
John Dunne Avenue  
Ballinasloe  
Co Galway  
Tel: 087 984 5574 / 087 945 2300  
Website: [www.eastgalwaycancersupport.com](http://www.eastgalwaycancersupport.com)

**Gort Cancer Support Group**  
The Hawthorn  
Ennis Road  
Gort  
Co Galway  
Tel: 086 312 4220  
Email: [gcsupport@eircom.net](mailto:gcsupport@eircom.net)  
Website: [www.gortcs.ie](http://www.gortcs.ie)

**Mayo Cancer Support Association**  
Rock Rose House  
32 St Patrick's Avenue  
Castlebar  
Co Mayo  
Tel: 094 903 8407  
Email: [info@mayocancer.ie](mailto:info@mayocancer.ie)  
Website: [www.mayocancer.ie](http://www.mayocancer.ie)

**Roscommon Cancer Support Group**  
Vita House Family Centre  
Abbey Street  
Roscommon  
Tel: 090 662 5898  
Email: [vitahouse@eircom.net](mailto:vitahouse@eircom.net)

**Sligo Cancer Support Centre**  
44 Wine Street  
Sligo  
Tel: 071 917 0399  
Email: [scsc@eircom.net](mailto:scsc@eircom.net)  
Website: [www.sligocancersupportcentre.ie](http://www.sligocancersupportcentre.ie)

**Tuam Cancer Care Centre**  
Cricket Court  
Dunmore Road  
Tuam  
Co Galway  
Tel: 093 28522  
Email: [support@tuamcancer.ie](mailto:support@tuamcancer.ie)  
Website: [www.tuamcancer.ie](http://www.tuamcancer.ie)

## Leinster support groups & centres

**ARC Cancer Support Centre**  
ARC House  
65 Eccles Street  
Dublin 7  
Tel: 01 830 7333  
Email: [info@arccancersupport.ie](mailto:info@arccancersupport.ie)  
Website: [www.arccancersupport.ie](http://www.arccancersupport.ie)

**ARC Cancer Support Centre**  
ARC House  
559 South Circular Road  
Dublin 8  
Tel: 01 707 8880  
Email: [info@arccancersupport.ie](mailto:info@arccancersupport.ie)  
Website: [www.arccancersupport.ie](http://www.arccancersupport.ie)

**Arklow Cancer Support Group**  
25 Kingshill  
Arklow  
Co Wicklow  
Tel: 085 110 0066  
Email: [arklowcancersupport@gmail.com](mailto:arklowcancersupport@gmail.com)

**Balbriggan Cancer Support Group**  
Unit 23, Balbriggan Business Park  
Balbriggan  
Co Dublin  
Tel: 087 353 2872

**Bray Cancer Support & Information Centre**  
36B Main Street  
Bray  
Co Wicklow  
Tel: 01 286 6966  
Email: [info@braycancersupport.ie](mailto:info@braycancersupport.ie)  
Website: [www.braycancersupport.ie](http://www.braycancersupport.ie)

**Cuisle Centre Cancer Support Group**  
Block Road  
Portlaoise  
Co Laois  
Tel: 057 868 1492  
Email: [info@cuislecentre.com](mailto:info@cuislecentre.com)  
Website: [www.cuislecentre.com](http://www.cuislecentre.com)

**Dóchas: Offaly Cancer Support**  
Teach Dóchas  
Offaly Street  
Tullamore  
Co Offaly  
Tel: 057 932 8268  
Email: [info@dochasoffaly.ie](mailto:info@dochasoffaly.ie)  
Website: [www.dochasoffaly.ie](http://www.dochasoffaly.ie)

**Dundalk Cancer Support Group**  
Philipstown  
Hackballs Cross  
Dundalk  
Co Louth  
Tel: 086 107 4257

**Éist Cancer Support Centre Carlow**  
The Waterfront  
Mill Lane  
Carlow  
Tel: 059 913 9684  
Mobile: 085 144 0510  
Email: [info@eistcarlowcancersupport.ie](mailto:info@eistcarlowcancersupport.ie)  
Website: [www.eistcarlowcancersupport.ie](http://www.eistcarlowcancersupport.ie)

**Gary Kelly Support Centre**

George's Street  
Drogheda  
Co Louth  
Tel: 041 980 5100 / 086 817 2473  
Email: services@gkcancersupport.com  
Website: www.gkcancersupport.com

**Greystones Cancer Support**

La Touche Place  
Greystones  
Co Wicklow  
Tel: 01 287 1601  
Email: info@greystonescancersupport.com  
Website: www.greystonescancersupport.com

**Haven Cancer Support and Therapy Group**

Haven House  
68 Hazelwood  
Gorey  
Co Wexford  
Tel: 053 942 0707 / 086 250 1452  
Email: info@thehavengroup.ie  
Website: www.thehavengroup.ie

**HOPE Cancer Support Centre**

22 Upper Weafer Street  
Enniscorthy  
Co Wexford  
Tel: 053 923 8555  
Email: mary@hopesupportcentre.ie  
Website: www.hopesupportcentre.ie

**Kilkenny Cancer Support Services**

Walkin Street  
Kilkenny City  
Tel: 085 721 9280  
Email: info@kilkennycancersupport.com  
Website: www.kilkennycancersupport.com

**Lakelands Area Retreat & Cancer Centre**

Ballinalack  
Mullingar  
Co Westmeath  
Tel: 044 937 1971  
Callsave 1850 719 719  
Email: info@larcc.ie  
Website: www.larcc.ie

**Rathdrum Cancer Support Centre**

34 Main Street  
Rathdrum  
Co Wicklow  
Tel: 087 292 8660  
Email: rathcan@gmail.com

**Stillorgan Cancer Support**

c/o Marsham Court  
Stillorgan  
Co Dublin  
Tel: 01 288 5725

**Tallaght Cancer Support Group**

Millbrook Lawns  
Tallaght  
Dublin 24  
Tel: 087 217 6486  
Email: ctallaght@yahoo.ie

**Wicklow Cancer Support Centre**

1 Morton's Lane  
Wicklow  
Tel: 0404 32696  
Email: wicklowcancersupport@gmail.com

**Munster support groups & centres****Cancer Information & Support Centre**

Mid-Western Regional Hospital  
Dooradoyle  
Co Limerick  
Tel: 061 485 163  
Website: www.midwesterncancercentre.ie

**CARE Cancer Support Centre**

14 Wellington Street  
Clonmel  
Co Tipperary  
Tel: 052 618 2667  
Email: cancersupport@eircom.net  
Website: www.cancercare.ie

**Cork ARC Cancer Support House**

Cliffdale  
5 O'Donovan Rossa Road  
Cork  
Tel: 021 427 6688  
Email: karen@corkcancersupport.ie  
Website: www.corkcancersupport.ie

**Cúnamh: Bons Secours Cancer Support Group**

Bon Secours Hospital  
College Road  
Cork  
Tel: 021 480 1676  
Website: www.cunamh.ie

**Kerry Cancer Support Group**

124 Tralee Town House Apartments  
Maine Street  
Tralee  
Co Kerry  
Tel: 066 719 5560 / 087 230 8734  
Email: kerrycancersupport@eircom.net  
Website: www.kerrycancersupport.com

**Recovery Haven**

5 Haig's Terrace  
Tralee  
Co Kerry  
Tel: 066 719 2122  
Email: recoveryhaven@gmail.com  
Website: www.recoveryhavenkerry.org

**Sláinte an Chláir: Clare Cancer Support**

Tír Mhuire  
Kilnamona  
Ennis  
Co Clare  
Tel: 1850 211 630 / 087 691 2396  
Email: admin@clarecancersupport.com  
Website: www.clarecancersupport.com

**South Eastern Cancer Foundation**

Solas Centre  
7 Sealy Close  
Earlscourt  
Waterford  
Tel: 051 876 629  
Email: infosecf@eircom.net  
Website: www.secf.ie

**Suimhneas Cancer Support Centre**

2 Clonaslee  
Gortland Roe  
Nenagh  
Co Tipperary  
Tel: 067 37403  
Email: suaimhneascancersupport@eircom.net

**Suir Haven Cancer Support Centre**

Clongour Road  
Thurles  
Co Tipperary  
Tel: 0504 21197  
Email: suirhaven@gmail.com

**Youghal Cancer Support Group**

161 North Main Street  
Youghal  
Co Cork  
Tel: 024 92353 / 087 273 1121

**West Cork Cancer Support**

Community Work Department  
HSE Skibbereen  
Co Cork  
Tel: 027 53485 / 086 862 5417

**Ulster support groups & centres****Cancer Support and Social Club**

Tiernaleague  
Carndonagh  
Co Donegal  
Tel: 086 602 8993 / 087 763 4596

**Crocus: Monaghan Cancer Support Centre**

The Wellness Centre  
19 The Grange  
Plantation Walk  
Monaghan  
Tel: 087 368 0965

**The Forge Cancer Support Group**

The Forge Family Resource Centre  
Pettigo  
Co Donegal  
Tel: 071 986 1924

**Good and New Cancer Drop In Centre**

Unit 1, Portlink Business Park  
Port Road  
Letterkenny  
Co Donegal  
Tel: 074 911 3437

**Killybegs Cancer Support Group**

Kille  
Kilcar  
Co Donegal  
Tel: 074 973 1292  
Email: riverbankdunne@eircom.net

**Living Beyond Cancer**

Oncology Day Services  
 Letterkenny General Hospital  
 Letterkenny  
 Co Donegal  
 Tel: 074 912 5888 (Bleep 674/734) / 074 910 4477

**Solace: Donegal Cancer Support Centre**

St Joseph's Avenue  
 Donegal Town  
 Tel: 074 974 0837  
 Email: solacedonegal@eircom.net

For other support groups or centres in your area, call 1800 200 700.

**Useful contacts outside Republic of Ireland****Action Cancer**

Action Cancer House  
 1 Marlborough Park  
 Belfast BT9 6XS  
 Tel: 028 9080 3344  
 Email: info@actioncancer.org  
 Website: www.actioncancer.org

**American Cancer Society**

Website: www.cancer.org

**Cancer Focus Northern Ireland**

40-44 Eglantine Avenue  
 Belfast BT9 6DX  
 Tel: 048 9066 3281  
 Website: www.cancerfocusni.org

**Cancer Network Buddies**

Website:  
 www.cancerbuddiesnetwork.org

**Cancer Research UK**

Tel: 0044 20 7242 0200  
 Website: www.cancerhelp.org.uk

**The Continence Foundation (UK)**

Tel: 0044 020 7831 9831  
 Email:  
 continence.foundation@dial.pipex.com  
 Website: www.continence-  
 foundation.org.uk

**Yana Cancer Support Centre**

Belturbet  
 Co Cavan  
 Tel: 087 994 7360

**Healthtalkonline**

Website: www.healthtalkonline.org

**Macmillan Cancer Support (UK)**

Tel: 0044 207 840 7840  
 Email: cancerline@macmillan.org.uk  
 Website: www.macmillan.org.uk

**Macmillan Support & Information Centre**

Belfast City Hospital Trust  
 77-81 Lisburn Road  
 Belfast BT9 7AB  
 Tel: 028 9069 9202  
 Email: cancerinfo@belfasttrust.hscni.net

**National Cancer Institute (US)**

Website: www.nci.nih.gov

**Prostate Cancer UK**

Website: www.prostatecanceruk.org

**Royal Marsden Hospital Foundation NHS Trust**

Website: www.royalmarsden.nhs.uk

**Sexual Advice Association (UK)**

Tel: 0044 020 7486 7262  
 Email:  
 info@sexualadviceassociation.co.uk  
 Website: www.sda.uk.net

**Helpful books****Free booklets from the Irish Cancer Society:**

- *Understanding Early Prostate Cancer*
- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Understanding Radiation Therapy: A Patient Pathway (DVD)*
- *Understanding Cancer and Complementary Therapies*
- *Diet and Cancer*
- *Coping with Fatigue*
- *Understanding the Emotional Effects of Cancer*
- *Lost for Words: How to Talk to Someone with Cancer*
- *Who Can Ever Understand? Taking About Your Cancer*
- *Talking to Children about Cancer: A Guide for Parents*
- *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*
- *Journey Journal: Keeping Track of Your Cancer Treatment*
- *A Time to Care: Caring for Someone Seriously Ill at Home*

**Prostate and Cancer: A Family Guide to Diagnosis, Treatment and Survival**

Sheldon Marks  
 Da Capo Press, 2003  
 ISBN 978-0738208398

**Prostate Cancer: A Comprehensive Guide for Patients**

Kieran Jefferson  
 TFM Publishing, 2004  
 ISBN 1903378109

**The Prostate: An Owner's Manual**

Dr Peter Scardino  
 Michael Joseph, 2005  
 ISBN 0718146948

**The Prostate Cancer Book: The Definitive Guide to the Causes, Symptoms and Treatments**

Jonathan Waxman  
 Vermilion, 2002  
 ISBN 0091857120

**101+ Square Meals**

[Budget and nutrition]  
 Norah Bourke et al  
 MABS/HSE West/Paul  
 Partnership/Limerick VEC/Safefood, 1998  
 ISBN 187407514X  
 [For more details, see www.mabs.ie]

## What does that word mean?

<b>Androgen</b>	A male hormone.
<b>Benign</b>	Not cancer. A tumour that does not spread.
<b>Biopsy</b>	Removing a small amount of tissue from your body to find out if cancer cells are present.
<b>Catheter</b>	A long, thin flexible tube that is passed into your bladder. It drains urine into a bag.
<b>Cells</b>	The building blocks that make up your body. They are tiny and can only be seen under a microscope.
<b>Chemotherapy</b>	A treatment using drugs to cure or control cancer cells.
<b>Erectile dysfunction</b>	When you cannot get or keep an erection. Can also be known as impotence.
<b>Fatigue</b>	Ongoing tiredness often not helped by rest.
<b>Grading</b>	How normal or abnormal prostate cells look under a microscope.
<b>Incontinence (urinary)</b>	When you cannot control the leakage of urine from your body.
<b>Malignant</b>	Cancer. A tumour that spreads.
<b>Medical oncologist</b>	A doctor who specialises in treating cancer patients using chemotherapy and other drugs.
<b>Metastasis</b>	The spread of cancer from one part of your body to another.
<b>Oncology</b>	The study of cancer.
<b>Orchidectomy</b>	The surgical removal of one or both testicles.

<b>Palliative care</b>	Care that is given to relieve symptoms and improve your quality of life, especially when cancer cannot be cured and is advanced.
<b>Prognosis</b>	The expected outcome of a disease.
<b>PSA</b>	Prostate specific antigen. This is a protein made by your prostate gland. It can be measured in your bloodstream.
<b>Radiation oncologist</b>	A doctor who specialises in treating cancer patients using radiotherapy.
<b>Radiotherapy</b>	The treatment of cancer using high-energy X-rays.
<b>Rectum</b>	The lower part of your bowel (back passage).
<b>Staging</b>	Tests that measure the size and extent of cancer.
<b>Urologist</b>	A surgeon who specialises in treating prostate, kidney and bladder disease.



## Questions to ask your doctor

Here is a list of questions that you may wish 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 tests do I need?
  
- How is prostate cancer confirmed?
  
- What type of prostate cancer do I have?
  
- 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 treatments?
  
- Can my symptoms be controlled?
  
- 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 sex life and fertility? Will I develop erectile dysfunction?

## Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

Answer

6

Answer

7

Answer

8

Answer

## Acknowledgements

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

Men Against Cancer

## Would you like more information?

We hope this booklet has been of help to you. If you feel you would like more information or someone to talk to, please call the National Cancer Helpline on 1800 200 700.

## Would you like to be a patient reviewer?



If you have any suggestions as to how this booklet could be improved, we would be delighted to hear from you. The views of patients, relatives, carers and friends are all welcome. Your comments would help us greatly in the preparation of future information booklets for people with cancer and their carers. Please fill in the postcard in the pocket inside the back cover, and post it back to us for free.

If you wish to email your comments, have an idea for a new booklet, or would like to review any of our booklets, please contact us at **reviewers@irishcancer.ie**

If you prefer to phone or write to us, see contact details below.

## 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. This includes patient education booklets. 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 at CallSave 1850 60 60 60 or email **fundraising@irishcancer.ie**

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

**Tel:** 01 231 0500 **Email:** info@irishcancer.ie **Website:** www.cancer.ie

The mission of the Irish Cancer Society is to play a vital role in achieving world-class cancer services in Ireland, to ensure fewer people get cancer and those that do have better outcomes. Our goals are focused around prevention, survival and quality of life with three programme areas to achieve them: advocacy, cancer services and research.



Action  
Prostate  
Cancer