

Understanding

Locally advanced and advanced prostate cancer

Caring for people with cancer

Understanding

Locally advanced and advanced prostate cancer

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:	

Tel:

If you like, you can also add:

Your name

Pharmacist

Address

This booklet has been produced by 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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The following sources were used in the publication of this booklet:

- A Strategy for Cancer Control in Ireland, National Cancer Forum, 2006.
- Recent Trends in Prostate Cancer, National Cancer Registry Ireland, May 2010.
- Guidelines on Prostate Cancer, European Association of Urology, 2011.
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- 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.

Published in Ireland by the Irish Cancer Society.

© Irish Cancer Society, 2013, 2015

Next revision: 2017

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ISBN 0953236901

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Introduction

This booklet has been written to help you understand more about locally advanced and advanced prostate cancer.

- About prostate cancer gives an introduction to prostate cancer, including symptoms and diagnosis.
- Treatment and side-effects discusses the different treatments used for prostate cancer and possible side-effects.
- Coping and emotions discusses how you can cope with your feelings and the emotional effects of having prostate cancer.
- Support resources gives information on further sources of help and support. This includes helpful organisations, books, support groups and websites. You will also find an easy-to-read explanation of words and terms used throughout this booklet.

We hope the booklet answers some of your questions and encourages you to discuss them with your doctors and nurses. Talk to your doctor about your treatment and care, as the best choice for you will depend on your particular cancer and your individual circumstances.

>>>

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 our Cancer Nurseline on Freephone 1800 200 700 or email us at cancernurseline@irishcancer.ie. The Nurseline is open Monday to Thursday 9am–6pm and Friday 9am–5pm. You can also visit a Daffodil Centre. See page 69 for more about Daffodil Centres.



Cancer Nurseline Freephone 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*. For a free copy call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or order it online at www.cancer.ie.



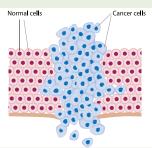
About prostate cancer

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What is cancer?

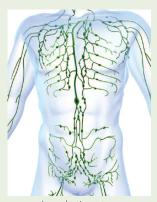
Cancer is a word used to describe a group of diseases, not just one. There are more than 200 different types of cancer. Each is named after the organ or type of cell in which the cancer first grows. For example, prostate cancer, breast cancer or leukaemia. All cancers are a disease of the body's cells, 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, the abnormal cells grow without control. Groups of abnormal cells can 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 form a tumour in another part of your body. This is called a metastasis or secondary tumour.



What is the lymphatic system?

The lymphatic system is made up of groups of lymph nodes throughout the body. Lymph nodes are found mainly in the neck, armpit, groin and tummy. Lymph nodes are connected by a network of lymph vessels. These lymph vessels are tiny tubes, which usually lie just under the skin. The lymph vessels transport lymph fluid, which carries extra fluid and waste from body tissues. Sometimes cancer cells spread into lymph nodes or start in the lymph nodes themselves. If this happens the lymph nodes become swollen.



Lymphatic system



To sum up

Cancer is a disease of the cells of your body.

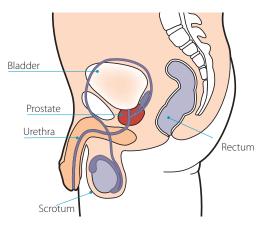
Understanding locally advanced and advanced prostate cancer

- 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 to form a tumour 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.



The 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 prostate cancer that has spread just outside your prostate gland but not to other parts of your body.

Advanced prostate cancer is prostate cancer that has spread beyond your prostate gland to other parts of your body. It is also called metastatic or secondary 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 3300 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 before the age of 55 or if you have more than one relative with the disease. You may have a higher risk of getting prostate cancer if your mother or sister was diagnosed with breast cancer at a young age and they had faults in the genes BRCA1 or BRCA2.
- Race: If you are a black African or black Caribbean man, you are more at risk than other ethnic groups.
- Diet: 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.

- Weight: Staying a healthy weight may help to reduce the risk of prostate cancer. Being over weight or obese may increase the risk of getting prostate cancer that is more likely to spread.
- **Exercise:** 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

Some men may have no symptoms.

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.

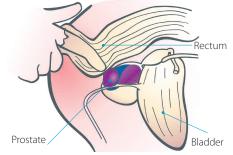
How is prostate cancer diagnosed?

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)
- Prostate biopsy

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

Prostate biopsy: A sample of your

prostate tissue can be taken and examined under a microscope. This is called a biopsy. The sample is taken using a needle, which is passed into your prostate through your back passage (transrectal biopsy). An ultrasound probe helps to guide the needle to the right place. This test is called a transrectal ultrasound guided biopsy or TRUS biopsy. A biopsy can also be taken through the area between your scrotum and your back passage (transperineal biopsy).

Occasionally some men with advanced prostate cancer may have a very high PSA or their scan may show that their cancer has spread. If this happens they might start treatment without having a biopsy.

Email: cancernurseline@irishcancer.ie

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

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MRI scan

CT 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 vou about this.

CT scan: This is a special type of X-ray that builds up a detailed picture of the tissues inside your body. The scan is painless and takes 10-30 minutes. For some CT scans, you may be asked not to eat (fast) for a few hours beforehand. For others, you may be given a special drink or injection which helps to show up parts of your body on the scan. Before you take the drink or injection, let the radiographer know if you are allergic to iodine or have asthma. The injection may make you feel hot all over for a few minutes.

Preparation for a CT scan can vary but the doctor or nurse in your hospital will tell you what to do. This test is usually done as an outpatient, so you should not need to stay in hospital.

>>> 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 (covering) 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 vou. 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 or secondary prostate cancer. With advanced prostate cancer, it has spread to other parts of your body through your bloodstream or lymph vessels. Prostate cancer commonly spreads to bones. It is not yet possible to cure advanced 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.

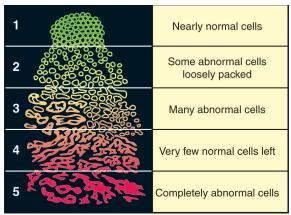
- **T** refers to the size and depth of the tumour. For example: T3 is when the prostate cancer can be felt breaking through the capsule (covering) of the prostate gland. T4 is when the cancer has spread to nearby organs.
- N refers to cancer present in your lymph nodes or not. This is recorded as N0 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 grade helps your doctor to predict how the cancer may grow and behave.



Gleason score

Lower grades are slower growing, while the higher grades are fast growing or look very abnormal. 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 grades of prostate cancer in each sample and adds them together to give an overall score. This is called the Gleason score. The Gleason score 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and speak to one of our cancer nurses.

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.

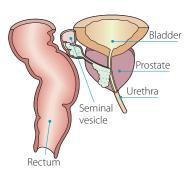


To sum up

- The following tests are used to diagnose prostate cancer: PSA blood test, rectal exam, prostate biopsy.
- 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 or CT 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 Gleason score is worked out by adding together the 2 most common grades of prostate cancer in each sample.

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.



Locally advanced prostate cancer (cancer cells in light green)

>>> If your prostate cancer is diagnosed at an early stage, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a copy of the booklet, *Understanding Early Prostate Cancer*. You can also download it from our website www.cancer.ie

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. If this is not possible, the treatment aims to control it and stop it from growing. Your doctor will decide which treatment is suitable for you once all your test results are ready. He or she will consider factors such as:

- The results of your staging tests (see page 12), 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

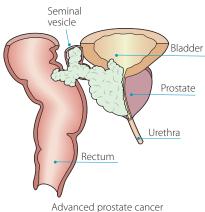
There are a range of treatment options for locally advanced prostate cancer. These include:

- 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 23 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 23 for more on hormone therapy.
- Surgery (radical prostatectomy) and/or external beam radiotherapy: Surgery for prostate cancer is 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. You 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, metastatic or secondary prostate cancer when it has spread to other parts of your body. Your cancer may be advanced when it is first diagnosed, or your cancer may have come back or spread. 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 available that can control your prostate cancer for months or years.



Advanced prostate cancer (cancer cells in light green)

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 38 for more about treating symptoms.

What treatment can I have for advanced prostate cancer?

Hormone therapy is usually 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.

Some men with advanced prostate cancer may be given chemotherapy in combination with their first hormone therapy. For more information on chemotherapy see page 46.

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.

For more information on hormone therapy and its side-effects, see page 23. You can also read the factsheet *Hormone Therapy and Prostate Cancer*. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy. You can also download it from the website: **www.cancer.ie**. You can also watch a podcast on hormone therapy and prostate cancer online.

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 42.
- Radiotherapy to relieve pain. See page 39.
- Medication to relieve pain. See page 39.

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.

Other treatments

New treatments for cancer are being developed all the time. Your doctor will advise you about any other treatments that may help you. You may be offered a new treatment as part of a clinical trial. See page 37 for more about clinical trials.

Coping with a diagnosis of locally advanced or advanced prostate cancer

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 63 for more information on where help is available. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk to a specialist cancer nurse in confidence. You can also email the nurses: cancernurseline@irishcancer.ie.



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 23.
- Watchful waiting see page 28.
- Radiotherapy see page 30.

For information on surgery for prostate cancer, see our booklet Understanding Early Prostate Cancer. You may be offered a different treatment as part of a clinical trial. For example, chemotherapy. See page 37 for more about clinical trials.

For information on other, later treatments for advanced prostate cancer, see page 45.

Deciding on treatment

Multidisciplinary team meeting: A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. For example, a surgeon (urologist), specialists in radiotherapy (radiation oncologists), hormonal therapy or chemotherapy treatments (medical oncologists), specialist nurses and other healthcare professionals. They will meet to discuss your test results and your suggested treatment plan.

Making a decision: 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. If you forget to ask a question or would like more explanations, call our

Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and talk to one of our specialist cancer nurses.

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It can help to talk to another man who has had a prostate cancer diagnosis. Call our Cancer Nurseline on Freephone 1800 200 700 and we can put you in contact with a trained Survivor Support volunteer who has been in a similar situation.

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, 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.

Giving consent for treatment

Before you start any treatment, your doctor will explain the aims of the treatment to you. You should be asked to sign a consent form saying that you understand what the treatment is for and that you give permission for treatment to be given. Before treatment, you should have been given full information about:

- What the treatment is for
- The type and amount of treatment you will have
- The benefits and risks of the treatment
- Any other treatments that may be available

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again. Some treatments can be hard to understand and may need to be explained more than once. You can still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.

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, to see how well the treatment is working. 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. The hormone testosterone controls the growth and development of male sexual organs and also your sex drive (libido). Most testosterone is made in your testicles. A small amount of testosterone is also made by your adrenal glands near your kidneys. Testosterone can help prostate cancer cells to grow. 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.

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

Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free factsheet called Hormone Therapy and Prostate Cancer. You can also download it from our website www.cancer.ie or listen to a podcast about prostate cancer.

Injections

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®) and degarelix (Firmagon®). These drugs are injected under your skin or into a muscle. Injections can be given



Hormone injections

once a month or every 3 or 6 months. The amount of hormone therapy you get is the same whether you have the injection every 1, 3 or 6 months. 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 antiandrogen 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'. The tablets block the effect of the testosterone and stop this from 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 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 maximum androgen blockade

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 the small amount of testosterone that is 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 prevent the release of testosterone immediately. 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 decide to have this treatment.

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. See page 35 for more about sex and prostate cancer. Try to talk to your partner, and get advice from your doctor, nurse or a professional psychosexual counsellor if you need more help or support.

Medications, injections and vacuum devices to help with sexual problems are all available. Your doctor will advise you about which treatment is best for you. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a copy of the factsheet, Sex, Erectile Dysfunction and Prostate Cancer. You can also download it from our website www.cancer.ie

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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.

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. You can speak to a cancer nurse by calling our Cancer Nurseline on 1800 200 700 or by visiting a Daffodil Centre.

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 gives you more energy and helps you to cope. For more information and a booklet called Coping with Fatigue, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Mood changes: Testosterone can affect how your mind works. Less testosterone in your body might cause mood changes, poor concentration or memory problems, anxiety and sometimes depression. Some therapies, like relaxation therapy, meditation or yoga, might help you to cope with these frustrating symptoms. You can also discuss your concerns with your doctor or nurse. They can refer you to a professional counsellor. See page 55 for more about counselling.

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 formed and can lead to osteoporosis. This means that bones can become brittle, making them more likely to break (fracture). Taking exercise, such as walking, and eating foods rich in vitamin D and calcium can help to prevent osteoporosis. Avoiding smoking and excessive alcohol can also help. 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 71 for contact details.

More information

For more information about hormone therapy and how to manage sideeffects, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. Ask for a free factsheet called Hormone Therapy and Prostate Cancer or download it from www.cancer.ie.

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 know if the treatment is working or not.

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 45.



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-term 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 few or no symptoms when you are diagnosed. In this case, your doctor may decide to watch (monitor) you for a period of time before starting treatment. 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 choose watchful waiting, you will not begin treatment straight away. Usually you will 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 if you need to start hormone therapy or not.

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

You may start treatment once your PSA level reaches a certain point or if you get symptoms. For example, problems passing urine or new aches and pains in your back or bones. During watchful waiting, look out for these symptoms or any other new symptoms. 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.

You may be worried about delaying treatment. But your doctor may recommend watchful waiting if your cancer is not causing you any problems because 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.

If you would like more advice about watchful waiting, call our Cancer Nurseline on 1800 200 700. Or if you prefer, you can also visit a Daffodil Centre.

Cancer Nurseline Freephone 1800 200 700

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 23.

Understanding locally advanced and advanced prostate cancer

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 may take a few planning 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 7–9 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 the 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. Some side-effects may last for a long time or be permanent.

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 sideeffects. But there is no way of knowing in advance which of them you will get. 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, cola or alcohol can make these problems worse. If this happens, cut down on 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.

Some men 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. 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. 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 only use creams recommended by your nurse or radiation therapist. Also, avoid perfumed creams or powders. 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy the booklet, Coping with Fatigue. You can also download it from our website www.cancer.ie

How long will the side-effects last? Any side-effects you have may continue to get worse for a short time after your treatment has finished. 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. Even if you are not thinking about sex at this time, 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the factsheet Sex, Erectile Dysfunction and Prostate Cancer or you can download it from www.cancer.ie You can also email a cancer nurse at cancernurseline@irishcancer.ie

Understanding locally advanced and advanced prostate cancer



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: For some men bowel problems may persist, while for others problems 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 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and ask for a copy of the free booklet Understanding Radiotherapy. You can also download the booklet on our website www.cancer.ie

Will treatment affect my sex life and fertility?

Sexual side effects: Treatment can affect your sex life. Many men worry about sexual side effects like finding it hard to get an erection or losing interest in sex. Talk to your doctor if you have any sexual side effects. There are medications and other treatments that can help. For example, tablets, injections, vacuum pumps or implants to help you get an erection. For more information read our factsheet: Sex, erectile dysfunction and prostate cancer. (See next page for details.)

Feelings and emotions: As well as the effect on your body, cancer can affect how you feel about sex and your relationships. Coming to terms with the fact that you have cancer can take quite a while. It can be hard to relax 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 normal reaction at this time.

You may find that talking about your feelings may ease any worries you have. 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 relationships counselling or sex therapy. This can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

Our Cancer Nurseline 1800 200 700 and our Daffodil Centres have a list of psychosexual counsellors who are experts in sex and relationships. Some relationship and marriage support organisations also offer relationships counselling and sex therapy services. See page 71 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 guite safe for you to have sex with your partner, both before and after treatment.

Asking for advice: If you have any queries about how treatment may affect your sex life, you can ask your doctor or nurse. Don't be put off by thinking the question is small or trivial or that you will be embarrassed. Many men having treatment for prostate cancer want information on sex and relationships. Your doctor and nurse are well used to talking about these matters and will give you advice.

You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at cancernurseline@irishcancer.ie

Infertility: Most treatments for prostate cancer are likely to cause infertility. This means you will be unable to father a child in the future. If it is important to you, talk to your doctor about this sideeffect before your treatment.

More information

Our factsheet Sex, erectile dysfunction and prostate cancer has lots of information on the sexual problems that can happen after prostate cancer treatment and the treatments available to help. It also has advice and support to help you with your relationships and sex life.

Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy. You can also download it on our website www.cancer.ie



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, visit a Daffodil Centre or call our Cancer Nurseline on 1800 200 700. You can also or visit our website 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. Others may be due to treatment. You may experience some of the following symptoms:

- Urinary problems
- Bone pain
- Weakened bones
- Constipation
- Fatigue

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.

Urinary problems

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
- Blood in the 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 our Cancer Nurseline on 1800 200 700. Ask for a copy of the factsheet, Urinary Symptoms, Catheters and Prostate



Cancer Treatment. You can also pick up a copy from a Daffodil Centre or download it from www.cancer.ie

Bone pain

Bone pain, for example a nagging ache in your bone, can be a sign that cancer has spread to the bone. This can make it hard to sleep and can be 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: Not all men with advanced prostate cancer have pain. 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for advice.

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 42 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 radiotherapy does not cure the cancer but can help you feel 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.

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? Is it always there or does it come 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. This helps your doctor 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 any extra pain not controlled by your usual medication.
- 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.

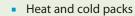
Radioactive injections: Sometimes a radioactive injection can help with symptoms of prostate cancer that has spread to the bones. Your doctor will tell you if this treatment is suitable for you or not. Examples of radioactive injections are strontium, samarium, and radium-223 (Xofigo®). This treatment can help to ease bone pain due to cancer. It may take up to 3 weeks for the pain to reduce but the pain relief can last for several months.

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 (see page 50). Talk to your local cancer support centre to see what services are available. For example, some centres provide yoga, Reiki and meditation classes. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for advice or for a copy of the booklet, Understanding Cancer and Complementary Therapies.

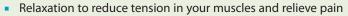


Tips & Hints – other ways to relieve pain









- 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, which are more likely to break (fracture). Even so, this symptom can still be treated.

Drug therapy: Your doctor may prescribe bone-strengthening drugs for you. The aim of all bone-strengthening drugs is to slow down or prevent bone damage, help increase bone strength and thickness, and reduce bone pain. The types of drugs commonly used for patients with cancer are bisphosphonates (for example, zoledronic acid) and monoclonal antibodies (for example, denosumab).

Drug therapy can help to prevent further bone loss and strengthen the bone to reduce the risk of bone damage, like fractures. The drugs 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 these drugs 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. Ask for a factsheet called *Bone Health and Cancer* or download it from www.cancer.ie

Surgery: Sometimes prostate cancer can weaken your bones so much that they are at risk of breaking. If this happens you may have an operation to strengthen a particular bone. A surgeon will use metal pins, screws and plates to hold the bone firmly so it won't break.

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 vour 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
- Having no control over emptying your bowels or bladder

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 you have constipation, 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. Talk to your doctor or nurse for advice on what exercises you can do.

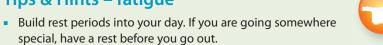
Fatique

Fatigue is a common symptom of cancer and is 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.

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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy. You can also download it from our website www.cancer.ie



Tips & Hints – fatique





- Try to have a stock of food prepared in advance or use nutritious readymade meals or snacks so you don't have to cook when you are tired.
- Wear clothes that are easy to put on and take off.
- Sit down when getting dressed or doing household jobs such as ironing.

- 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 the same time and do not lie in.
- Avoid stimulants before bedtime, such as alcohol, coffee, tea, cola or chocolate.
- Use relaxation techniques to get to sleep. For example, gentle exercise or relaxation tapes. 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 go back to see your doctor 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, or if you are finding it hard to cope. 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. This may be called hormone resistant prostate cancer.

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 may respond to other, newer types of hormone therapy or to other treatments. The exact order in which treatments are given is not the same for all men. Usually a medical oncologist will advise you on the best treatments for you. A medical oncologist is a doctor who specialises in using chemotherapy and other drugs to treat cancer. 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 some of the following treatments:

- Withdrawal of hormone therapy
- Steroid therapy

- Chemotherapy
- Other hormone therapies
- Radioactive injections

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

Understanding locally advanced and advanced prostate cancer

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 antiandrogen 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. You may be given chemotherapy as a treatment after hormone therapy if your cancer has spread beyond the prostate and is no longer controlled by your hormone therapy treatment. In certain cases chemotherapy may be used at the start of your treatment for advanced prostate cancer, in combination with hormone therapy. 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

Some examples of chemotherapy used for prostate cancer are docetaxel (Taxotere®) and cabazitaxel (Jevtana®). You may be given a steroid with your chemotherapy to reduce the side-effects of treatment.

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. Side-effects can usually 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy.

Other hormone therapies

If your cancer is no longer responding well to the hormone therapy that you are taking, your doctor may suggest you try a different hormone therapy. The aim is still to prevent male hormones from helping the cancer to grow, but the drugs work in different ways. The aims of treatment include to shrink the prostate cancer or slow its growth, help with symptoms and lower your PSA level. Your doctor will discuss when is the right time for you to receive these types of drugs. Examples of other hormone therapies include abiraterone (Zytiga®) and enzalutamide (Xtandi®). These drugs may be given before or after chemotherapy.

Different hormone therapy drugs have different side-effects, and reactions to drugs vary from person to person. Ask your doctor about any sideeffects you may get from the drug you have been prescribed. Side-effects may include tiredness, low potassium, aching muscles and joints, high blood pressure, hot flushes, headaches and loss of fertility, depending on the drug used.

Targeted radioactive injections

Radioactive injections can help the symptoms of prostate cancer that has spread to the bones. The radioactive substance can treat the bone cancer cells directly and may help to relieve pain. Because the radiation is targeted at the cancer cells, side-effects are mild and may include

diarrhoea and sickness and sometimes low levels of blood cells called platelets after a few weeks. An example of a radioactive injection used in this way is radium-223 (Xofigo®).

After treatment, very small amounts of radiation may be present in your urine for a few hours or in your bowel motions for up to week. You can speak with your doctor or nurse about any precautions you need to take.



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, chemotherapy, other, newer hormone therapies and radioactive injections.

Other drug treatments

New drugs for cancer are being developed all the time. Your doctor will advise you about any other treatments that may help you.

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. See page 37 for more details on clinical trials.

Later symptoms of advanced prostate cancer

There is the possibility that over time the cancer could spread to other places and it may cause other symptoms. These symptoms may occur alongside some of symptoms described on pages 38-43. However, this doesn't always happen. Some of the later symptoms of advanced prostate cancer may include:

- Blood in the urine
- Kidneys not working properly. This can cause an increase in tiredness (fatigue) and sleepiness, poor appetite, swollen ankles or feeling sick.

- Hypercalcaemia. This means you have a high level of calcium in your blood. Hypercalcaemia can cause fatigue and lack of energy, loss of appetite, confusion, constipation, thirst, passing urine frequently and feeling sick or vomiting.
- Anaemia. This means that you have a lower than normal number of red blood cells in your blood. If you have anaemia you may feel tired (fatigued) and lacking in energy. You might become breathless while doing simple tasks and you may look pale.
- Lymphoedema. Lymphoedema is a swelling caused by damage to your lymph vessels. Lymphoedema from prostate cancer treatment usually causes swelling in one or both legs, in the tummy or around the genital area.

You may not experience any of these symptoms or some could be due to other reasons. Talk to your doctor if you have any symptoms that are troubling you. There are treatments available to help with most symptoms of advanced prostate cancer. For more information on these symptoms and treatments to help, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also email us at cancernurseline@irishcancer.ie

Palliative care

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.

The palliative care team in your area might see you when you have just a few symptoms. Your own medical team will also help deal with any cancer-related symptoms.

The palliative care team are experts in managing the symptoms of advanced cancer. The palliative care team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, chaplains and counsellors.

Palliative care can be arranged by your family doctor (GP), public health nurse or by the hospital. Palliative care is a free service for all patients with advanced cancer. You do not need medical insurance.

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 and you can spend a day or two there receiving treatment. In the late stages of cancer palliative care includes end-of-life care. Do talk to your doctor and nurse for more advice. Or if you do not feel well enough, your family can do so.

For more information, see our web pages on advanced cancer at www.cancer.ie. See page 61 for more about caring for someone with advanced prostate cancer.

Cancer and complementary therapies

Complementary treatments for cancer are treatments that can be given alongside standard medical treatment. For example, yoga or massage. Some people find them very helpful during their illness. The way cancer is treated often depends on the culture of the country in which you live. In Ireland conventional 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
- Aromatherapy

Shiatsu

- Relaxation
- Reflexology

Yoga

- Visualisation
- Music, art and dance therapyAcupuncture

- Gentle massage
- Nutrition therapy
- 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.

Alternative therapies

Alternative therapies are generally treatments that are used instead of conventional treatments. These therapies include diet therapy, megavitamin therapy and herbalism. Alternative therapies have not been scientifically proven. Some alternative therapies may even harm your health. Always talk to your doctor if you are considering an alternative to conventional treatment.



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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download it from our website www.cancer.ie



Coping and emotions

Reactions to a cancer diagnosis

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. There is no right or wrong way to feel about having cancer. 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.

You may experience a range of feelings at times like shock, fear, sadness, loss, anger and depression. You may also feel a loss of control or have feelings of uncertainty. Remember that these are normal emotions and that you are not alone. Many men who have prostate cancer have experienced similar feelings and emotions too.

Common reactions include:

- Shock and disbelief
- Sorrow and sadness
- Blame and guilt

- Fear and uncertainty
- Denial Anger

 Withdrawal and isolation

- Loss of control
- Resentment

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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy. Your medical social worker in the hospital is also available to support you.

How can I cope with my feelings?

Often men manage their reactions to living with locally advanced or advanced prostate cancer in different ways. Some men may feel empowered or in control by becoming more knowledgeable about their prostate cancer - they research it, ask lots of questions and talk openly. Other men may prefer to have less information and may choose to cope with their cancer in a more private way.

Living with the changes after a diagnosis of locally advanced or advanced prostate cancer may affect how you feel within yourself as well as how you might relate to others around you. The disease itself and the effect of the treatment on your life may make you feel low at times. Often this is because of the changes to your usual routine or the side effects of treatment. Other times, you might feel nothing or just numb.

You may worry about the future or the possibility that the prostate cancer is not responding well enough to the current treatment you may be receiving. It is not unusual for it to be more on your mind before your hospital follow-up visits or before PSA blood tests. You might find that you are afraid because you do not know enough about your illness or what to expect. Most people find that information can help to overcome their fears. You can ask your doctor or nurse for as much information as you need.

There is no one right way to cope, but it is important that you have whatever level of support that feels right for you. Remember it is not a sign of failure if you feel unable to cope on your own or to ask for help. Once other people understand how you are feeling they can give you more support. Who Can Ever Understand? Talking About Your Cancer is a useful booklet written for people with cancer. Call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre for a free copy of the booklet or to talk in confidence to a cancer nurse. You can also download the booklet from www.cancer.ie.

Anxiety and depression

If you feel that your low moods are getting the better of you or you are finding it hard to cope, try to talk about your feelings with someone you know who is a good listener.

Medical social workers can offer support, as well as practical advice to you and your family, both in hospital and at home. If you are finding it difficult to get over a period of depression, your doctor may suggest a treatment. Often a short course of antidepressants can be helpful. These can lift your spirits and have few side-effects in the short term.

Deep emotional difficulties can sometimes be hard to talk about. Talking to a counsellor or psychotherapist who is not personally involved in your situation can be a great help. See below for more information on counselling. Call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre for more advice about where to get help. You can also ask them for a free copy of the booklet, *Understanding the Emotional Effects of Cancer*.

Counselling

Sometimes it is difficult for people who are undergoing a stressful and emotional time to talk to the people closest to them, who may also be very upset. Some people find it easier to talk to someone who is outside their immediate circle. A trained counsellor can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support and help you to make decisions and cope better.

Counselling is available free of charge at some local cancer support centres. To find out more about counselling or for details of your local support centre call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. They can give you details of where free counselling is available and also provide confidential advice, support and information on any aspect of cancer. You can also contact the nurses by email: cancernurseline@irishcancer.ie



Here are some ways to get support:

Find out about cancer support services in your area. There are lots of local cancer support services that provide a range of helpful services such as counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support.

Join a support or educational group. Many people find it very reassuring to talk to other people who are in a similar situation and facing the same challenges. Some cancer support centres run specific men's cancer support groups or prostate cancer educational support groups where you can meet other men to learn more and share experiences about treating and living with prostate cancer.

For information on support in your area, see the list of support services in the back of this book, call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre.

Get one-to-one support. The Irish Cancer Society can put you in touch with a trained Survivor Support volunteer who has been through a prostate cancer diagnosis and who can give you emotional and practical support. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for more information on Survivor Support.

Get online support. There are special websites called online communities where people with cancer can write questions, share stories, and give and receive advice and support. Visit www.cancer.ie/community to join the Irish Cancer Society online community.

Talk things through. It can be a great weight off your mind to share your feelings and concerns. You could talk to a friend or family member if you feel comfortable doing so. You could also speak to a specialist cancer nurse in confidence by dropping in to a Daffodil Centre or calling our Cancer Nurseline on 1800 200 700.

Seek spiritual support. Sometimes people with cancer cope better when they have spiritual support. When dealing with a serious illness, it is normal to think about the meaning and purpose of life. For some people spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation may 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.

How can my family and friends help?

Your family and friends can support you 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 may prefer to help you in a practical way with travelling to and from the hospital, with childcare if relevant, cooking, shopping or housework.



How to talk to someone with cancer

When someone close to you has cancer it can be hard to know what to do. 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. But 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 – let them know that you are always ready to listen and give help. You may think you are not doing much by just listening, but 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.

Support for family and friends

Our Cancer Nurseline 1800 200 700 and Daffodil Centres can give support, advice and information to family and friends too. Ask for a copy of *Lost for Words: How to Talk to Someone with Cancer*, a booklet written for relatives and friends of people with cancer. You can also download it from our website **www.cancer.ie**

You and your partner

A serious illness like cancer can change the roles you and your partner play within your relationship. For example, your partner may have to take a more active role in the running of the house or managing the finances.

Some partners may become very protective. Some may research as much information on the disease as possible, while others withdraw. Everyone is different in how they cope with a situation. Remember there is no right or wrong way. The most important thing is for both of you to express your concerns openly and honestly. At times your partner may feel isolated and unable to express his or her feelings and concerns. Support is available for your partner from local support groups or from counselling services. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for more information. You can also email the nurses at cancernurseline@irishcancer.ie

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. It is best to try 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download it from our website www.cancer.ie

Email: cancernurseline@irishcancer.ie

How can I help myself?

Many people live with cancer for a long time. Here are some things that can help if you are living with cancer.

Use your support network. Don't be afraid to ask for help from those who want to support you or to use the support services available. Doing things for yourself can help to make you feel more in control, but be realistic about what you can manage by yourself. Telling people what you need and how they can help means you will get the right amount of support to suit you.

Gather information about your cancer and treatment. Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy of the Journey Journal or Prostate Passport, to help you keep track of your cancer treatment.

Get some exercise. Exercising is a great way to boost your mood and sense of well-being and it can improve your energy levels if you are feeling very tired. The type and amount of exercise you can do will depend on your ability. Talk to your doctor or nurse about which activity will suit you best.

Try relaxation and stress management techniques. Many cancer support centres offer therapies like relaxation therapy, meditation or yoga. These can help you to cope with stress. You may need some instruction with these methods at first, and they may not suit everyone. Some cancer support centres provide groups to help you learn these techniques. Call our Cancer Nurseline or visit a Daffodil Centre for details of your nearest cancer support centre.

Try complementary therapies. Complementary therapies are treatments like acupuncture, yoga and aromatherapy that are given in addition to your standard treatment. They may help to relieve the symptoms of cancer or the side-effects of treatment. They can also help when dealing with fear, anxiety, hopelessness or stress. See page 50 for more information. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a copy of the booklet *Understanding Cancer and Complementary Therapies*.

Accept 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.

Know that there will be ups and downs. There will be times when you feel low. Sometimes people feel they have to be brave or positive all the time, but most people find it difficult to cope with cancer at times. Accept that it is normal to have bad days, but always look for help if you are finding it hard to cope. You can call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk in confidence to a cancer nurse.

Keep busy. Try to keep busy and make plans for the things you would like to do. This can mean taking trips, visiting loved ones or doing certain activities.

Think ahead. It's very understandable that you might feel anxious or reluctant to talk to your family or friends about how you might like to be looked after if your cancer progresses, for fear of upsetting yourself or them. However, it might be helpful for you, as it gives you the chance to be able to plan and deal with any practical concerns or worries you may have in your personal life. If your cancer is advanced, you can look at our advanced cancer web pages on our website www.cancer.ie. for more help with planning ahead. You can also call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for advice, information and support.

Caring for someone with advanced prostate cancer

Being a carer of someone with cancer can be both a challenging and a rewarding experience. Carers provide all sorts of emotional and physical support. 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. Ask of a copy of the free booklet, *A Time to Care: Caring for Someone Seriously Ill at Home.* You can also download it from our website **www.cancer.ie**

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Tips & Hints – for carers

- Information: Find out as much information as possible about advanced prostate cancer, especially its symptoms, treatment and side-effects. The Irish Cancer Society has lots of cancer information in its publications and on its website www.cancer.ie. 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 moving around, bathing and dressing, giving meals and medication. Ask the nurses for advice about 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: Stay in touch with your own friends and share any worries you have with someone else. Get out when you can even if you don't feel like it. Take a break each day: a walk to the shops, a trip to the library or cinema, or an evening out with friends. Make time to relax at home. Read a favourite magazine, sit down for a cup of tea or coffee, or 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.

- Cancer nurse specialists
- Medical social worker
- Psycho-oncology services
- Family doctor (GP)
- Community health services
- Support groups
- Irish Cancer Society nurses

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. The nurses work along with other members of your medical team to meet your needs.

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 support and services available when you go home.

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.

GP (family doctor): 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: 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 your 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 cancer. Cancer support groups and 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. You can also download the Irish Cancer Society's Directory of Cancer Support Services from www.cancer.ie.

Irish Cancer Society nurses: Our cancer nurses will be happy to talk about any concerns you or your family may have, at any stage of your illness. This can range from treatment information to practical advice about financial matters. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse in confidence. They can also give you information about any of the services outlined above or support services in your area. You can also email the nurses at cancernurseline@irishcancer.ie



>>> 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 a public hospital. 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 accident and emergency department of a public hospital without being referred there by a GP, you will be charged €100. There is no charge if you have a medical card or are admitted to hospital because of attending the accident and emergency department first.

The €100 charge applies to the first visit in relation to an illness or accident. If you have to return for further visits to an outpatient clinic in relation to the same illness or accident, you should not have to pay the charge again.

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 will have to pay a prescription charge of €2.50 per item up to a limit of €25 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 €500 or less (€900 for couples), 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. This is known as a discretionary medical card.

If you wish to apply for a medical card, you can download an application form and apply online (www.medicalcard.ie) or at your local health centre. LoCall 1890 252 919.

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) or at your local health centre, LoCall 1890 252 919.

Understanding locally advanced and advanced prostate cancer

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 or your local pharmacy.

Private healthcare cover

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

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

Benefits and allowances

You or a family member may qualify for a number of benefits and allowances. For example: Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

More information on these is available in a booklet called Managing the Financial Impact of Cancer: A Guide for Patients and Their Families. For a free copy, contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download it from www.cancer.ie



Application forms for the benefits are available from social welfare offices 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 or www.citizensinformation.ie

Appliances

If you have a medical card most appliances such as wigs and prostheses are free of charge or subsidised. The subsidy will depend on the HSE area. For further information, contact your local HSE office.

Travel to hospital

You may 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, usually for patients with medical cards.

See page 69 for information on the Travel2Care fund and the Volunteer Driving Service provided 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 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 – Information Service

Oisín House Tel: 1850 662 244 Website:

212-213 Pearse Street Leaflet line: 1890 202 325 www.welfare.ie

Dublin 2 Email: info@welfare.ie

For queries about local health and social services, contact the HSE. **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 Tel: 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 69 for more details. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre 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 71 for contact details. A useful book for preparing low-budget nutritious meals is 101+ Square Meals. See page 77 for more information.

Irish Cancer Society services

Our **Cancer Support Department** provides a range of cancer support services for people with cancer, at home and in hospital, including:

- Cancer Nurseline
- Daffodil Centres
- Survivor Support
- Support in your area
- Patient travel and financial support
- Night nursing
- Publications and website information
- Our Cancer Nurseline Freephone 1800 200 700. Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. The Cancer Nurseline is open Monday to Thursday 9am–6pm and Friday 9am–5pm. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at www.cancer.ie
- Our Daffodil Centres. Visit our Daffodil Centres, located in thirteen
 hospitals nationwide. The centres are staffed by cancer nurses and
 trained volunteers who provide confidential advice, support and
 information to anyone concerned about or affected by cancer.
- Our Survivor Support. Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.
- Support in your area. We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling.
- Patient travel and financial support. We provide practical and financial support for patients in need, undergoing cancer treatments. There are three services available through the Society:
 - Travel2Care is a fund, made available by the NCCP, for patients
 who are having difficulty getting to and from their treatments
 while attending one of the national centres of excellence.



- Through our **Financial Support** programme, limited, once off financial support is available to patients identified as being in need, who are undergoing cancer treatments nationally.
- Irish Cancer Society Volunteer Driving Service is mainly for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments.

To access any of these services please contact your hospital healthcare professional.

- Irish Cancer Society Night Nursing. We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.
- Our publications and website information. We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer and financial concerns. Visit our website www.cancer.ie or call the Cancer Nurseline on 1800 200 700 a free copy of our publications.



If you would like more information on any of the above services, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Useful organisations

ACCORD

Catholic marriage care service Tel: 01 505 3112 Email: admin@accord.ie Website: www.accord.ie

All Ireland Co-operative Oncology Research Group

Clinical trials information Website: www.icorg.ie

Assistireland.ie

Information website on daily living aids Tel: 0761 07 9200

Website: www.assistireland.ie

The Carers Association

Support services and information for carers in the home

Freefone: 1800 240 724 Email: info@carersireland.com Website: www.carersireland.com

Citizens Information

Free information and advice on public services and entitlements in Ireland

Tel: 0761 07 4000

Website: www.citizensinformation.ie

Get Ireland Active

Tips on being more active Website: www.getirelandactive.ie

HSE Continence Promotion

Local continence advice services

Callsave: 1850 24 1850 Email: info@hse.ie Website: www.hse.ie

Irish Association for Counselling and **Psychotherapy**

Accrediting body with an online directory of accredited therapists

Website: www.irish-counselling.ie

Irish Association for Humanistic and Integrative Psychotherapy

Professional body with an online directory of accredited therapists

Tel: 01 284 1665 Website: www.iahip.org

Irish Nutrition and Dietetic Institute

Nutrition information and help finding a dietitian

Tel: 01 280 4839 Website: www.indi.ie

Irish Oncology and Haematology Social Workers Group

Information on help available from medical social workers and how to contact a medical social worker Website: www.socialworkandcancer.com

Irish Osteoporosis Society

Information on bone health

Locall: 1890 252 751

Website: www.irishosteoporosis.ie

Irish Society of Chartered Physiotherapists (ISCP)

Information on physiotherapy and help finding a therapist Tel: 01 402 2148

Website: www.iscp.ie

Money Advice and Budgeting Service (MABS)

Help with managing money and debt

Helpline: 0761 07 2000 Email: helpline@mabs.ie Website: www.mabs.ie

Relationships Ireland

[Relationship counselling charity] 38 Upper Fitzwilliam Street

Dublin 2

LoCall: 1890 380 380

Email: info@relationshipsireland.com

Website:

www.relationshipsireland.com

Health insurers

AVIVA Health

PO Box 764 Togher Cork

Tel: 1850 717 717

Email: info@avivahealth.ie Website: www.avivahealth.ie

GloHealth

PO Box 12218, Dublin 18

Tel: 1890 781 781

Email: findoutmore@glohealth.ie Website: www.glohealth.ie

Laya Healthcare

Eastgate Road

Eastgate Business Park

Little Island Co Cork

Tel: 021 202 2000

LoCall: 1890 700 890

Email: info@layahealthcare.ie Website: www.layahealthcare.ie

Voluntary Health Insurance (VHI)

IDA Business Park Purcellsinch **Dublin Road** Kilkenny

CallSave: 1850 44 44 44 Email: info@vhi.ie Website: www.vhi.ie

National support services

Survivor Support

Irish Cancer Society

43/45 Northumberland Road

Dublin 4

Cancer Nurseline: 1800 200 700 Email: support@irishcancer.ie Website: www.cancer.ie

ARC Cancer Support Centres Dublin

[See page 73]

Brain Tumour Support Group

Medical Social Work Department

St Luke's Hospital Highfield Road Rathgar

Dublin 6

Tel: 01 406 5295

Canteen Ireland

[Teenage cancer support] Carmichael Centre North Brunswick Street

Dublin 7 Tel: 01 872 2012 Email: info@canteen.ie Website: www.canteen.ie

Cancer Support Sanctuary LARCC

[See page 73]

Connaught support services

Athenry Cancer Care

Social Service Centre

New Line Athenry Co Galway

Tel: 091 845 228 / 087 412 8080 Email: athenrycancercare@gmail.com Website: www.athenrycancercare.com

Ballinasloe Cancer Support Centre

Main Street Ballinasloe Co Galway Tel: 090 964 3431

Email: ballinasloecancer@yahoo.co.uk

Cara Iorrais Cancer Support Centre

2 Church Street Belmullet Co Mavo

Tel: 097 20590 / 087 391 8573 Email: caraiorrais@gmail.com

Gort Cancer Support Group

Garrabeg Gort Co Galway

Tel: 091 648 606 / 086 172 4500 Email: info@gortcancersupport.ie Website: www.gortcancersupport.ie

Hand in Hand

[Children's Cancer Support Centre]

Main Street Oranmore Co Galway Tel: 091 799 759

Email: info@handinhand.ie Website: www.handinhand.ie

Mayo Cancer Support Association

Rock Rose House 32 St Patrick's Avenue Castlebar

Co Mayo Tel: 094 903 8407 Email: info@mayocancer.ie Website: www.mayocancer.ie

Roscommon Cancer Support Centre

Vita House Family Centre

Abbey Street Roscommon Tel: 090 662 5898

Email: info@vitahouse.org

Sligo Cancer Support Centre

44 Wine Street Sligo

Tel: 071 917 0399 Email: scsc@eircom.net

Website: www.sligocancersupportcentre.ie

Tuam Cancer Care Centre

Cricket Court **Dunmore Road**

Tuam Co Galway Tel: 093 285 22

Email: support@tuamcancercare.ie Website: www.tuamcancercare.ie

Leinster support services

ARC Cancer Support Centre

ARC House 65 Eccles Street Dublin 7 Tel: 01 830 7333

Email: info@arccancersupport.ie Website: www.arccancersupport.ie

ARC Cancer Support Centre

ARC House

559 South Circular Road

Dublin 8

Tel: 01 707 8880

Email: info@arccancersupport.ie Website: www.arccancersupport.ie

Arklow Cancer Support Group

25 Kings Hill Arklow Co Wicklow

Tel: 0402 23590 / 085 110 0066 Email: info@arklowcancersupport.com Website: www.arklowcancersupport.com

Balbriggan Cancer Support Group

Unit 23, Balbriggan Business Park

Harry Reynold's Road

Balbriggan Co Dublin

Tel: 087 353 2872 / 086 164 2234

Cancer Support Sanctuary LARCC

Coole Road Multyfarnham Mullingar Co Westmeath Tel: 044 937 1971 CallSave: 1850 719 719 Email: info@cancersupport.ie Website: www.cancersupport.ie

Cara Cancer Support Centre

7 Williamson's Place

Dundalk Co Louth

Tel: 042 937 4905 Mobile: 087 395 5335 Email: info@ccscdundalk.ie Website: ccscdundalk.ie

Cois Nore Cancer Support Centre

8 Walkin Street Kilkenny

Tel: 056 775 2222

Email: coisnorekilkenny@gmail.com Website: www.kilkennycancersupport.ie

Cuisle Cancer Support Centre

Block Road Portlaoise Co Laois Tel: 057 868 1492

Email: cuislecentre@eircom.net Website: www.cuislecentre.com

Dóchas: Offaly Cancer Support Group

Teach Dóchas Offalv Street Tullamore Co Offaly Tel: 057 932 8268

Email: info@dochasoffalv.ie Website: www.dochasoffaly.ie **Dublin West Cancer Support Group**

Generic Social Work Department

Oak Unit

Cherry Orchard Hospital

Ballvfermot Dublin 10 Tel: 01 620 6273

Email: martina.mcgovern2@hse.ie/

noreen.obrien4@hse.ie

Éist Carlow Cancer Support Centre

The Waterfront Mill Lane Carlow Tel: 059 913 9684

Mobile: 085 144 0510

Email: info@eistcarlowcancersupport.ie Website: www.eistcarlowcancersupport.ie

Gary Kelly Cancer Support Centre

George's Street Drogheda Co Louth

Tel: 041 980 5100 Email: info@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

Hope Cancer Support Centre

22 Weafer Street Enniscorthy Co Wexford Tel: 053 923 8555

Email: info@hopesupportcentre.ie Website: www.hopesupportcentre.ie

Midlands Myeloma Support Group

Teach Dóchas Offalv Street Tullamore Co Offaly

Tel: 057 932 8268

Email: info@dochasoffaly.ie

Purple House - Cancer Support

Aubrev Court Parnell Road

Bray

Co Wicklow Tel: 01 286 6966

Email: info@purplehouse.ie Website: www.purplehouse.ie

Tallaght Cancer Support Group

Trustus House 1-2 Main Street Tallaght Dublin 24 Tel: 086 400 2736

Email: ctallaght@yahoo.ie

Website: tallaghtcancersupport.com

Wicklow Cancer Support Centre

Rear of Butler's Medical Hall

Abbev Street Wicklow Tel: 0404 326 96

Email: wicklowcancersupport@gmail.com

Munster support services

Cancer Information & Support Centre

University Hospital Limerick

Dooradovle 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: caresupport@eircom.net Website: www.cancercare.ie

Cork ARC Cancer Support House

Cliffdale

5 O'Donovan Rossa Road

Cork

Tel: 021 427 6688

Email: info@corkcancersupport.ie Website: www.corkcancersupport.ie **Kerry Cancer Support Group**

Acorn Centre

124 Tralee Townhouse Apartments

Maine Street Tralee Co Kerry

Tel: 066 719 5560 / 087 230 8734

Fmail:

kerrycancersupportgroup@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.com

Solas Centre

South Eastern Cancer Foundation

Williamstown Waterford

Tel: 051 304 604

Email: info@solascentre.ie Website: www.solascentre.ie

Suaimhneas Cancer Support Centre

2 Clonaslee Gortland Roe Nenagh Co Tipperary Tel: 067 37403 Fmail:

suaimhneascancersupport@eircom.net

Suir Haven Cancer Support Centre

Clongour Road Thurles Co Tipperary Tel: 0504 21197

Email: suirhaven@gmail.com

Ulster support services

Coiste Scaoil Saor Ó Ailse C/O Ionad Naomh Padraig

Upper Dore Bunbeg Letterkenny Co Donegal Tel: 074 953 2949

Email: ionadnp@eircom.net Website: www.scaoilsaor.ie

Crocus: Monaghan Cancer Support Centre

The Wellness Centre 19 The Grange Plantation Walk Monaghan

Tel: 087 368 0965 / 047 62565 Email: crocus.2011@yahoo.com

Cuan Cancer Social Support and Wellness Group

2nd Floor, Cootehill Credit Union 22-24 Market Street

Cootehill Co Cavan

Tel: 086 455 6632

Other support services

Aoibheann's Pink Tie

[Supporting children with cancer]

Unit 22

Docklands Innovation Centre

128- 130 East Wall Road

Dublin 3

Tel: 01 240 1300

Email: aoibheannspinktie2@gmail.com Website: www.aoibheannspinktie.ie

The Bella Rose Foundation

Merry Maid House West Park Campus Garter's Lane Citywest Dublin 24 Tel: 087 320 3201

Email: thebellarosefoundation@gmail.com

Website: www.bellarose.ie

Cancer Care West

72 Seamus Ouirke Road

Galway

Tel: 091 545 000

Email: info@cancercarewest.ie Website: www.cancercarewest.ie

Cúnamh: Bons Secours Cancer Support Group

Bon Secours Hospital College Road

Cork

Tel: 021 480 1676

Website: www.cunamh.ie

Dundalk Cancer Support Group

Philipstown Hackballscross Dundalk Co Louth

Tel: 086 107 4257

East Galway & Midlands Cancer Support

Cluain Mhuire Brackernagh Ballinasloe Co Galway

Tel: 090 964 2088 / 087 984 0304 Email: info@egmcancersupport.com

Website:

www.eastgalwaycancersupport.com

The Forge Cancer Support Service

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

Email: theforgefrc@eircom.net Killybegs Cancer Support Group

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

Newbridge Cancer Support Group

Tel: 083 360 9898

Email:

newbridgecancerhealinghelp@gmail.com

Rathdrum Cancer Support Group

St Anne's Lower Street Rathdrum Co Wicklow Tel: 087 925 3915 Email: rathcan@gmail.com

Sláinte an Chláir: Clare Cancer Support

Tír Mhuire Kilnamona **Ennis** Co Clare

Tel: 1850 211 630

Email: admin@clarecancersupport.com Website: www.clarecancersupport.com

Solace: Donegal Cancer Support Centre

St Joseph's Avenue Donegal Town Tel: 074 974 0837

Email: solacedonegal@eircom.net

For other support services in your area, call 1800 200 700.

Useful contacts outside Republic of Ireland

Cancer Research UK

Website: www.cancerhelp.org.uk

Macmillan Cancer Support (UK)

Cancer information

Website: www.macmillan.org.uk

Movember Foundation

Men's health information and support Website: www.movember.com

Prostate Cancer UK

Prostate cancer information, advice, support and research Website: www.prostatecanceruk.org

Sexual Advice Association (UK)

Information about sexual therapy Website: www.sda.uk.net

Helpful books

Free booklets from the Irish Cancer Society:

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

• A Time to Care: Caring for Someone Seriously III at Home

To see a full list of our publications go to www.cancer.ie/publications

The Prostate Cancer Book

Jonathan Waxman Vermilion, 2002 ISBN: 0091857120

Kindle ed, Ebury Digital, 2010, ASIN:

B004E10RE0

Guide to Surviving Prostate Cancer

Patrick Walsh, Janet Farrar Worthington Grand Central Publishing, 2012

ISBN: 1455504181

Prostate and Cancer: A family quide to diagnosis, treatment and survival

Sheldon Marks, MD Da Capo Press, 2009 ISBN:0738213470

Intimacy with Impotence

Ralph and Barbara Alterowitz (May 2004; Kindle ed: 2011) ISBN: 0738207896

Saving your sex life: A guide for men with prostate cancer

John Mulhall

Kindle ed, CIACT, Inc 2011, ASIN: B005AO8UIU

101+ Sauare 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?

Understanding locally advanced and advanced prostate cancer

Androgen A male hormone.

Benign Not cancer. A tumour that does not spread.

Removing a small amount of tissue from **Biopsy**

your body to find out if cancer cells are

present.

A long, thin flexible tube that is passed into Catheter

your bladder. It drains urine into a bag.

The building blocks that make up your **Cells**

body. They are tiny and can only be seen

under a microscope.

Chemotherapy A treatment using drugs to cure or control

cancer cells.

Erectile dysfunction When you cannot get or keep an erection.

Can also be known as impotence.

Fatigue Ongoing tiredness often not helped by rest.

How normal or abnormal prostate cells look **Grading**

under a microscope.

When you cannot control the leakage of Incontinence (urinary)

urine from your body.

Malignant Cancer. A tumour that spreads.

Medical oncologist A doctor who specialises in treating cancer

patients using chemotherapy and other

drugs.

The spread of cancer from one part of your Metastasis

body to another.

Oncology The study of cancer.

Orchidectomy The surgical removal of one or both

testicles.

Palliative care Care that is given to relieve symptoms and

improve your quality of life, especially when

cancer cannot be cured and is advanced.

Prognosis The expected outcome of a disease.

PSA Prostate specific antigen. This is a protein

made by your prostate gland. It can be

measured in your bloodstream.

Radiation oncologist A doctor who specialises in treating cancer

patients using radiotherapy.

Radiotherapy The treatment of cancer using high-energy

X-rays.

The lower part of your bowel (back Rectum

passage).

Tests that measure the size and extent of Staging

cancer.

Urologist A surgeon who specialises in treating

prostate, kidney and bladder disease.



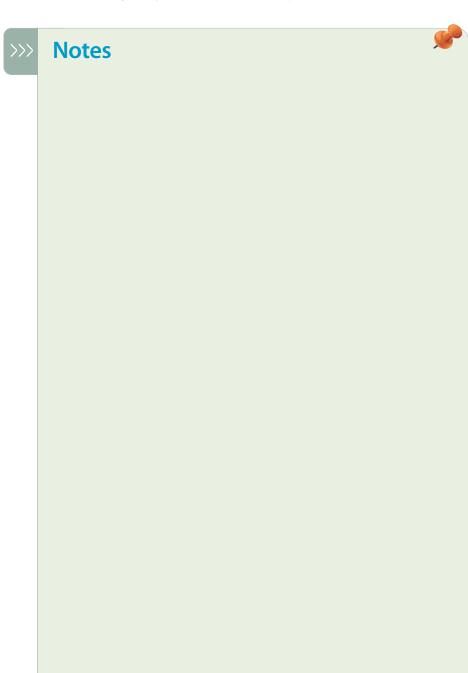
Questions to ask your doctor

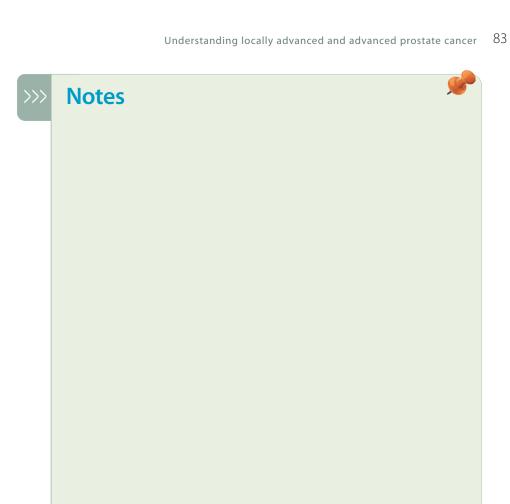
Here is a list of questions that you may wish to ask. There is also some space for you to write down your own questions if you would like. Never be shy about asking questions. It is always better to ask than to worry.

- 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

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Acknowledgements

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

Mr Ronald Grainger, Consultant Urologist

Helen Forristal, Clinical Nurse Specialist in Urology

Antoinette Walker, Patient Education Editor

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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

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.

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

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Cancer Nurseline Freephone 1800 200 700 Open Monday to Thursday 9am to 6pm Friday 9am to 5pm

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