

Understanding

Advanced (metastatic) prostate cancer

Caring for people with cancer

Understanding

Advanced (metastatic) prostate cancer

This booklet has been written to help you understand more about prostate cancer that has spread to other parts of your body. 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 metastatic 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. You can also make a note below of the contact names and information you may need.

>>>	Name	Telephone
	Urology specialist nurse	
	Oncology nurse	
	Family doctor (GP)	
	Surgeon/Urologist	
	Medical oncologist	
	Radiation oncologist	
	Radiation therapist	
	Medical social worker	
	Palliative care nurse	
	Palliative care consultant	
	Pharmacist	
	Emergency	

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. We especially thank the people who generously shared their personal experiences of cancer throughout this booklet. We also acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave up their time and expertise to contribute to previous editions of this booklet.

PROSTATE CANCER ADVISERS

Mr David Galvin, Consultant Urologist

Professor Ray McDermott, Consultant Medical Oncologist

Professor Frank Sullivan, Consultant Radiation Oncologist

Rachael Dalton, Clinical Nurse Specialist, Prostate Cancer Survivorship Programme

Christine Leonard, Oncology Liaison Clinical Nurse Specialist

Fiona Roulston, Dietitian Manager

CONTRIBUTOR

Anne-Marie McGrath, Cancer Nurseline Nurse

EDITOR

Sarah Lane

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- *Fast Facts: Prostate Cancer*, R Kirby & M Patel. Health Press, 2009.
- *DeVita, Hellman, and Rosenberg's Cancer: Principles and Practice of Oncology*. R Govindan (ed), 9th edn. Lippincott Williams & Wilkins, 2011.

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Quick facts

Can my cancer be treated?

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Metastatic prostate cancer can be treated. The treatments are to keep the cancer under control and to improve your quality of life, rather than to cure it. Sometimes the cancer can be kept under control for a long time.

How long will I live?

Page 17 >>

What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things, and every man's prognosis is different. The best thing to do it to ask your consultant about your own situation. See page 17.

What kind of treatment will I have?

Page 20 >>

- **Hormone therapy:** Injections or tablets to control the cancer.
- **Chemotherapy:** Drugs to slow down and control the growth of the cancer.
- **Radiotherapy:** X-ray treatments or injections to control the disease and relieve symptoms
- **Bone-strengthening drugs:** Tablets to prevent and treat bone problems

Your doctor will discuss which treatment or combination of treatments will be of most benefit for you.

How will my cancer and treatment affect me?

Page 42 >>

Metastatic prostate cancer can often cause symptoms, although not for all men. Urinary problems or bone pain are common symptoms when metastatic prostate cancer is diagnosed, but starting treatment often improves these symptoms. Your doctor and the team caring for you will talk to you about possible side-effects of treatment.

There are treatments to help with most side effects, so tell your doctor. Don't suffer in silence!

Clinical trials

Page 38 >>

Clinical trials are when cancer patients get a new type of treatment to see if it works better than existing treatments. Ask your consultant if there are any trials suitable for you.

We're here for you

Page 72 >>

If you or your family have any questions or worries, want to know where to get support, or if you just need to talk, you can talk to one of our cancer nurses.

Ways to get in touch

- Call our Cancer Nurseline on 1800 200 700
- Drop into a Daffodil Centre
- Email us: cancernurseline@irishcancer.ie

See page 72 for more about our services.

Introduction

This booklet has been written to help you understand more about metastatic prostate cancer. This is when prostate cancer has spread to other parts of your body, outside the area around the prostate.

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. 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 that you are interested in. Then read another section when you want to know more.



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 the nurses at cancernurseline@irishcancer.ie

You can also visit a Daffodil Centre. See page 72 for more about Daffodil Centres. You can email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.



Cancer Nurseline Freephone 1800 200 700

My cancer story

“Your blood tests were fine on the whole, just one of them was a bit high and I think we should have a consultant look at you” said my GP. With these fateful words in April 2002 I made my first acquaintance with my prostate and what turned out to be prostate cancer. My PSA tests and later biopsy and various scans indicated that I had locally advanced cancer and that I was what was termed ‘Intermediate Risk’.

Unfortunately, after 4 years my PSA started to rise slowly and eventually, in late 2006, I accepted that the cancer was back, and I commenced long-term intermittent androgen deprivation therapy, which I continue to this day.

But I learned that there is life after cancer. In many ways ... it has given me a whole new lease of life. I have become not just somebody living with their cancer but – through Men Against Cancer – a patient advocate and activist, first in Ireland and more recently at a European level.

Whatever the future brings, I have had the great love and support of my family, the friendship of many of my prostate cancer comrades and desire to see that all men are accorded the best possible diagnosis and such treatment as may be appropriate and that they are offered the support of those who have already experienced much of the prostate journey. ☺

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

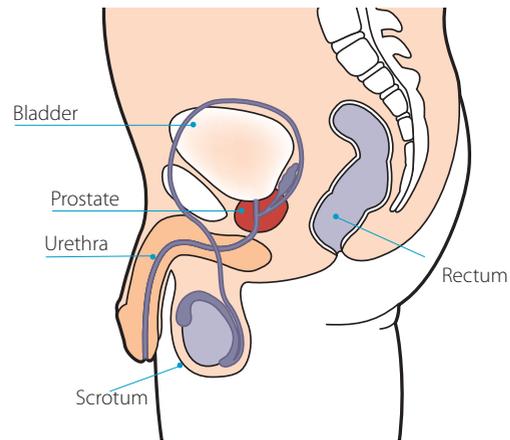
Email: cancernurseline@irishcancer.ie

About metastatic (advanced) prostate cancer

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What is prostate cancer?	10
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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. This is 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 cancer cells mainly depend on the male sex hormone, testosterone, to grow. Testosterone is made mainly in your testicles.

What is prostate cancer?

Prostate cancer occurs when the cells of your prostate gland grow in an abnormal way to form a lump (tumour).

- **Early (localised) prostate cancer:** This is prostate cancer found only within the prostate gland.
- **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.

See the booklet, *Understanding Prostate Cancer* for more about early and locally advanced prostate cancer.

- **Metastatic prostate cancer:** This is when prostate cancer cells have spread and are affecting other parts of your body, away from the prostate gland. It is also known as advanced or secondary prostate cancer. Your cancer may be advanced when it is first diagnosed, or your cancer may have come back or spread some time after your first diagnosis.

What causes metastatic prostate cancer?

Metastatic prostate cancer happens when prostate cancer cells spread via the lymphatic or blood system from your prostate gland to other parts of the body. These cancer cells may have been inactive for many years since your first diagnosis and be undetectable on any scans. Some men's prostate cancer has already spread when they are first diagnosed.

What parts of the body can be affected by metastatic prostate cancer?

Metastatic prostate cancer can affect one part of your body or more than one. The most common place for prostate cancer to spread to is your bones. Prostate cancer may also spread to other parts of the body, such as your lymph nodes, or your lungs, liver or brain.

The cancer is still prostate cancer, even if it is found in other parts of your body. It will be treated with prostate cancer treatments.

What are the symptoms of metastatic prostate cancer?

Metastatic prostate cancer can often cause symptoms, although not all men have symptoms. Urinary problems or bone pain are common symptoms when advanced prostate cancer is diagnosed, but starting treatment often improves these symptoms.

Your symptoms will depend on how your cancer has affected you.

If your prostate gland is enlarged you may have symptoms such as:

- Difficulty passing urine
- Passing urine more often day and night
- Feeling that your bladder isn't empty after going to the toilet.

If the cancer is affecting your bones symptoms can include:

- A nagging ache in a particular bone
- More severe bone pain
- Weakened bones that break easily
- Too much calcium in your blood, which can cause tiredness, constipation, nausea, thirst and confusion.

Some symptoms may be vague, such as feeling unwell, unusually tired or weak.

Spinal cord compression

Spinal cord compression happens if the cancer presses on your nerves. Although this is a less common symptom, it's very important to treat spinal cord compression quickly. Go to your doctor immediately if you have symptoms such as pain, weakness or tingling in your leg or loss of bladder and bowel control. If you can't see a doctor, go to a hospital emergency department and explain that you have metastatic prostate cancer.



>>> Tell your doctor if you have any new symptoms.



To sum up

- Prostate cancer is when abnormal cells in your prostate gland have grown to form a tumour.
- Metastatic (advanced) prostate is when the cancer cells have spread to parts of your body, away from the prostate gland.
- Urinary problems or bone pain are common symptoms when advanced prostate cancer is diagnosed, but starting treatment often improves these symptoms.

Diagnosis and tests

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Being diagnosed with metastatic prostate cancer

Hearing that you have metastatic cancer can be a huge shock. You may be feeling:

- **Upset** and overwhelmed by your emotions
- **Confused** by all the information being given to you
- **Worried** about what will happen next
- **Scared** about the future

Everyone reacts differently to a cancer diagnosis. However you feel, you are not alone. There are many people who can help and support you at this time.

If you need to talk to someone, or if you want more information or advice:

- Ask to speak to the medical social worker or cancer liaison nurse at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters
- Talk to one of our cancer nurses in confidence – call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre
- Email our cancer nurses at cancernurseline@irishcancer.ie
- Talk to other people going through the same thing. Our cancer nurses can help to put you in contact with another man living with metastatic prostate cancer, or to find a local support group. You could also join our online community at www.cancer.ie/community

We hope this booklet will help you too. It has information on what to expect from treatment. It also has tips on how to cope – practically, emotionally and financially. More helpful information is available on our website www.cancer.ie

Telling people about your diagnosis

It can be hard to tell other people the news that you have been diagnosed with metastatic cancer.

You may want to talk about your diagnosis, or you may prefer not to tell people straight away. Talking can help you to get support from friends and family. On the other hand, you may find it hard to cope with other

people's reactions when they hear the news. For example, they may fuss over you or be upset.

Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre if you would like to talk things over with a cancer nurse. You can also ask for a copy of our booklet *Who Can Ever Understand?* This booklet can help to you find ways to talk about your cancer and to ask for the help and support you need.

What tests will I have?

With metastatic cancer you may have tests to see to how far the cancer has spread. If you are generally not very well it may not be necessary to do extra tests. Your doctor will still be able to recommend treatment.

You may have some or all of the following tests:

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. A PSA test can also show how well your cancer is responding to treatment,

Biopsy: A biopsy is where a sample of your prostate tissue is taken and examined under a microscope. It isn't common to have a biopsy with metastatic prostate cancer, but if this is your first prostate cancer diagnosis it may be necessary. Treatment can still start without a biopsy.

Bone scans: Metastatic prostate cancer often spreads to the 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'. The scan can also show bone changes like arthritis.



Bone scan

It's nice to have someone with you to keep you company if you're having this test, as it takes a while and involves a bit of waiting around.

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

MRI scan: This special scan uses magnetic energy to build up a picture of the tissues inside your body. It does not hurt but can be quite noisy, so you may be given earplugs to wear during it.

Beforehand you might have an injection to show up certain areas of your body. During the scan you cannot wear metal jewellery. If you have certain medical devices implanted in your body, like pacemakers, you might not be suitable for the test. Your hospital doctor will advise you about this.

CT scan: This is a special type of X-ray that builds up a detailed picture of the tissues around your chest, abdomen and pelvis. 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.

PET scan: This scan uses a low dose of radioactive sugar to measure the activity of your cells. This sugar is first injected into your arm and travels to all the cells in your body. Because cancer cells absorb more sugar, there will be more radioactivity where the cancer cells are found. An hour after the injection, the scan is taken and can show if the cancer has spread to other tissues and organs. During the scan, you will lie on a table which moves through a scanning ring. Before the scan, you may have to fast (not eat) for a few hours.

>>> These tests can help your doctor to decide the best treatment for you.

Grading metastatic prostate cancer

When your cancer was diagnosed, you probably had a biopsy – a sample of cells taken from your prostate. Your prostate cancer cells will be graded from the biopsy taken. The grade of the cells helps your doctor to predict how the cancer will behave and how quickly it might grow. The 'grading' system used is usually the Gleason score or sometimes just grade (or 'group') 1-5 is used. In metastatic prostate the Gleason score is high and the grade is 5.

Waiting for results

It usually takes a number of weeks for all your test results to come back. There might also be a multidisciplinary team (MDT) meeting to decide the best treatment for you (see page 21). 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. You can also email the nurses at cancernurseline@irishcancer.ie



To sum up

- Tests you may have include blood tests, bone scans, a CT scan or an MRI scan
- The tests help your medical team to decide on the best treatment for you

Asking about your prognosis

Your prognosis is information about how your disease is likely to progress, including average survival times for your type of cancer (life expectancy). Many people with cancer have questions about their prognosis.

If your prognosis is better than expected, you may feel more hopeful about your illness and your future. You may feel more in control having as much information as possible. Or you may not want to

know about your prognosis. You may prefer not to think about the future too much or you may worry how you will cope if you get bad news.

It is not always easy for doctors to answer a question about life expectancy, as the answer is based on a 'typical' experience. Experiences can vary a lot from person to person. What happens to you might be quite different from what the doctor expects.

If you decide you want information on your prognosis:

- **Think carefully about how you will cope with the information** before asking for your prognosis.
- **Get information on prognosis from your doctor.** He or she knows about your cancer and your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Avoid looking online.** It can be hard to understand the information you find online without an expert like a doctor to help. The information may not really apply to your situation or to your particular cancer type.
- **Accept that you will need some time to think about what you have been told.** You may forget some things or there may be things you didn't understand. You may need to talk to your doctor again after you have thought about everything. Get the name and contact details for the prostate nurse specialist, too. Specialist nurses are a great source of information and support.
- **Get emotional support if you need it.** If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

Email: cancernurseline@irishcancer.ie

Treatment and side-effects

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Can metastatic prostate cancer be treated?

Yes, metastatic prostate cancer can be treated. The aim of treatment is to:

- Slow down the growth and spread of the cancer
- Relieve your symptoms
- Improve your quality of life

Although it isn't possible to cure metastatic prostate cancer with current treatments, there are many treatments that can keep the cancer and its symptoms under control, sometimes for many years.

For some men, living with metastatic prostate cancer is like living with a chronic (long-term) illness. Your specialist will tell you about the likely progress of your cancer and what you might expect.

How can my prostate cancer be treated?

The main treatment for metastatic prostate cancer is hormone therapy (see page 24).

Your doctor may also recommend other treatments, in combination with your hormone therapy or as an alternative. For example:

- Other hormone treatments
- Chemotherapy (p30)
- Steroids (p33)
- Bone-strengthening drugs (p33)
- Radiotherapy and radioactive injections (p34)

If one treatment doesn't work, or if the side-effects are difficult to manage, your doctor will look at other treatment options. The exact order or combination of treatments is not the same for all men.

Your medical team will advise you on the best treatments for you. This will depend on:

- Where the cancer is in your body
- Your age
- Your previous cancer treatments and response to those treatments

- How the cancer affects your everyday living and quality of life
- Possible side effects from treatment
- Any other conditions or medical problems you may already have ('co-morbidities')
- Your personal preference

“ There are huge advances in treatment and metastatic patients are living much longer with improved quality of life. A new drug or a clinical trial may totally change things for you. I am alive because of one such drug. ”

Deciding on treatment

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

Making a decision: If you have to decide about a particular treatment option, 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. 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.

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.

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.

Email: cancernurseline@irishcancer.ie

Remember staff are friendly and will inform you and support you through. 🙋

Who will be involved in my care?

Usually a team of healthcare professionals will be involved in your treatment and care.

Medical oncologist A doctor who specialises in treating cancer patients using chemotherapy and other drugs.

Radiation oncologist A doctor who specialises in treating cancer patients using radiotherapy.

Radiation therapist A specially trained person who delivers the radiotherapy and gives advice to cancer patients about their radiation treatment.

Oncology liaison nurse / clinical nurse specialist A specially trained nurse who works in a cancer care unit. She or he gives information and reassurance to you and your family from diagnosis and throughout treatment.

Medical social worker A person trained to help you and your family with all your social issues and practical needs. They can give counselling and emotional support. They can also give advice on benefits and financial matters and on practical supports and services available to you when you go home.

GP (family doctor) You can talk to your GP about your medication and any side-effects you have. You can also contact your GP about any worries you have or if you are finding it hard to cope.

Palliative care team This team are the experts in managing pain and other symptoms. They are sometimes called the 'symptom control team'. Though the word 'palliative' can make you think of end of life care, palliative care is very helpful at any stage for managing symptoms and helping you to feel better. This team can also help you and your family cope with any emotional distress. A specialist palliative care service is available in most general hospitals.

Physiotherapist A therapist who treats injury or illness with exercises and other physical treatments related to the illness.

Dietitian An expert on food and nutrition. They are trained to give advice on diet during your illness and use diet to help symptoms.

Psycho-oncology team These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.

Psychologist A specialist who can talk to you and your family about emotional and personal matters and can help you to make decisions.

Counsellor A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.

Community health services These include family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.

Hormone therapy

Hormone therapy aims to control the cancer and improve symptoms like poor urine flow or bone pain. Hormone therapy can work well for many years.

Hormone therapy is the main treatment for metastatic prostate cancer. Most men with metastatic prostate cancer will stay on hormone therapy.

Hormone therapy can be used alone or with other treatments.

How does hormone therapy work?

Hormones are made naturally in your body and control how normal cells grow and work.

The hormone testosterone can help prostate cancer cells to grow and spread. Hormone therapy can slow down the growth of prostate cancer by reducing the amount of testosterone in your body. It can do this by:

- Interfering with the production of testosterone
- or
- Stopping the testosterone from getting to the prostate cancer cells

Another name for hormone therapy is androgen deprivation therapy (ADT). Androgens are male hormones, so androgen deprivation means depriving the cancer cells of the male hormones that help them to grow.

Types of hormone therapy

There are 2 main types of hormone therapy:

- Injections to stop your body making testosterone
- Tablets to stop testosterone being produced or to block the effect of testosterone so it doesn't help the prostate cancer cells to grow

All hormone therapies aim to prevent male hormones from helping the cancer to grow, but the different drugs work in different ways. Your doctor will decide which is best for you at different times in your treatment.

Injections

Some drugs work by stopping male hormones being made in your testicles. Examples 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 once a month or every 3, 6 or 12 months. The amount of hormone therapy you get is the same, however often you have the injections. 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.



Hormone injection

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 probably be asked to take anti-androgen tablets for a week or two before your first injection. This is because with most hormone therapy drugs, 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.

Hormone therapy tablets

Some drugs can block testosterone from entering prostate cancer cells. This prevents testosterone from helping the cancer cells to grow. These drugs are called anti-androgens. For example, enzalutamide (Xtandi®) and bicalutamide (Casodex®).

Other tablets help to stop the production of testosterone in your body. For example, abiraterone (Zytiga®).

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.

What are the side-effects of hormone therapy?

Different hormone therapy drugs have different side-effects, and reactions to drugs vary from person to person. Ask your doctor or nurse about any side-effects you may get from the drug you have been prescribed. You may be given steroids to help with side-effects from some hormone therapy drugs.

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 and keep an erection. There are medications, injections and vacuum devices to help with sexual problems. Your doctor will advise you about which treatment is best for you. See page 51 for more about sex and prostate cancer or visit our website www.cancer.ie. 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.

You can also get support and information from one of our cancer nurses by calling our Cancer Nurseline on 1800 200 700 or visiting a Daffodil Centre. You can email the nurses at cancernurseline@irishcancer.ie

Hot flushes: Hot flushes and sweating happen because the lack of testosterone affects the part of your brain that regulates heat. Tell your doctor or nurse if these symptoms are troubling you. For tips on managing hot flushes call our cancer nurses on 1800 200 700 or see the hormone therapy section of our website, www.cancer.ie

Weight gain: Hormone therapy may affect your weight, particularly around your waist. You might also lose some of your muscle tone and strength. Taking some exercise and eating well may help you to avoid putting on too much weight. Your doctor can advise you on suitable exercise and diet, and can refer you to a dietitian, if necessary.

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 fatigue, talk to your doctor so that he or she can rule out other causes of fatigue and adjust your medication, if necessary. You might find that taking regular exercise gives you more energy and helps you to cope. For more about fatigue and ways to manage, see page 48.

Mood changes: 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 61 for more about counselling.

Breast swelling and tenderness: You may get tenderness or swelling in your breast if you are having 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, tell 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 regular exercise, such as walking, and eating foods rich in vitamin D and calcium will help to keep your bones strong. Avoiding smoking and excessive alcohol can also help. See page 47 for more bone health tips or get in touch with the Irish Osteoporosis Society www.irishosteoporosis.ie.

More information

For more information about hormone therapy and how to manage side-effects, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. There's also information on our website www.cancer.ie.

How will I know my hormone therapy is working?

While you are on hormone therapy you will have regular check-ups, including regular PSA tests. Because hormone therapy stops the growth of prostate cancer cells, your PSA level usually falls when you start hormone therapy. This is one of the ways your doctor will know if the treatment is working or not. Your doctor may also test the level of testosterone in your body, to check the hormone therapy is adequately blocking its production.

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. If this happens, your doctor will discuss which treatment options are open to you. For example, he or she may give you extra treatments or try a new type of treatment. Even if your doctor does stop your hormone therapy, the drugs should continue to work for a number of months afterwards.



To sum up

- Hormone therapy is a treatment that reduces the amount of testosterone in your body, to help slow the growth of the cancer.
- It can be used on its own or with other treatments such as chemotherapy or radiation.
- 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 you are on hormone therapy.

Chemotherapy

Chemotherapy is a treatment using drugs to help kill cancer cells that have travelled to other parts of your body.

Chemotherapy may be used at the start of your treatment in combination with hormone therapy, if your doctor feels you are well enough.

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

How often will I have chemotherapy?

The chemotherapy drugs 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.

How is chemotherapy given?

Chemotherapy may be given directly into a vein as an injection or through an intravenous infusion (drip). Usually your chemotherapy will be given in the chemotherapy day care unit.

You may get chemotherapy as part of a clinical trial. See page 38 for more details.

What kinds of drugs are used?

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.

Cancer Nurseline Freephone 1800 200 700



Tips & Hints – Understanding your drug treatment

It's important that you understand the medicine you have been given. Don't be afraid to ask your doctor or specialist nurse for more information about any drugs you are taking, what they are for and any possible side-effects. They may be able to give you a printed sheet to take home with you.

If you have any questions or need any more information, you can speak to our cancer nurses by calling our Cancer Nurseline on 1800 200 700 or call in to a Daffodil Centre.

What are the side-effects of chemotherapy?

The side-effects of chemotherapy vary from person to person and depend on the drugs used and the amount of chemotherapy given. Side-effects happen because chemotherapy affects both cancer cells and normal cells too.

There are treatments to help with most side effects, so tell your specialist nurse or doctor if you have any.

- **Infection:** Chemotherapy drugs make you more likely to get infections. You will be asked to watch out for signs of infection at all times. These signs include feeling shivery and unwell and having a high or low temperature. Your hospital will let you know at what point you should contact them if you have a temperature. Other signs of infection include having a cough or pain passing urine.
- **Fatigue:** Fatigue is where you feel tired and weak and rest does not seem to help. For more information see page 48.
- **Nausea and vomiting:** Chemotherapy can cause nausea (feeling sick) and vomiting (being sick). There are very effective treatments to help prevent this. For example, your doctor can prescribe anti-sickness (anti-emetic) drugs for you.
- **Mouth and throat problems:** Chemotherapy can cause mouth and throat problems including a dry mouth or a sore mouth.

There are many mouthwashes and medications to help, which your doctor can prescribe for you.

- **Constipation and diarrhoea:** Chemotherapy can cause constipation (not having a bowel movement often enough) and diarrhoea (frequent loose or watery bowel movements).
- **Hair loss (alopecia):** Some chemotherapy drugs can cause hair loss from all over your body. How much hair falls out depends on the drug given, the dose and your own reaction to it. Before treatment your doctor and nurse will tell you if you are likely to have any hair loss.
- **Changes in kidney function:** Some drugs can irritate or damage kidney cells. Talk to your doctor if you have decreased urination or swelling of the hands or feet (oedema), as these can be a sign of kidney damage. It's important to drink plenty of fluids, about 1½ to 2 litres per day.
- **Peripheral neuropathy:** Some drugs can affect your nerve endings. This may cause numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy.

For more information on the side-effects of chemotherapy or a copy of the booklet *Understanding Chemotherapy*, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.



To sum up

- Chemotherapy is a treatment using drugs to kill cancer cells.
- Chemotherapy is usually given directly into a vein as an injection or through a drip (infusion).
- The side-effects vary from person to person and depend on the drugs used.
- Some common side-effects are fatigue, nausea and vomiting, sore mouth and nerve changes.
- Most side-effects can be well controlled with medication.

- 6 **Have some questions ready about the treatment and how it might affect you physically, emotionally, socially. If they cannot answer your questions they can refer you to someone who will.**

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 or they may help to reduce the side-effects of certain drug treatments.

Side-effects from steroids include an increased appetite and mood changes. 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.

Bone-strengthening drugs

Bone-strengthening drugs can help to reduce pain from cancer that has spread to the bone and may slow the growth of cancer in the bone. They can also help to prevent further bone loss and strengthen the bone to reduce the risk of bone damage, like fractures.

You may be given these drugs even if you don't have any symptoms, to protect your bones. The types of drugs commonly used for patients with cancer are bisphosphonates (for example, zoledronic acid (Zometa®) and monoclonal antibodies (for example, denosumab (Xgeva®)). Bisphosphonates can also reduce high levels of calcium in your blood (see page 50).

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 treatment. Your doctor or nurse will discuss this

with you in more detail and give you tips on looking after your mouth and teeth during treatment.

Tell your doctor or dentist immediately if you develop any problems with your teeth or gums, or swelling, pain, heaviness or numbness in your jaw.

For more information on bone health and cancer see page 47 or visit our website, www.cancer.ie. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

>>> It's extremely important to take bone-strengthening medications exactly as prescribed to get the best benefit and to avoid any interactions with other drugs.

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.

Radiotherapy

Radiotherapy for metastatic prostate cancer aims to control the cancer and relieve symptoms, such as pain. You can have external radiotherapy, where high-energy X-rays are aimed at the cancer, or you may benefit from radioactive injections (see page 37).

External radiotherapy

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.

An important part of the planning process is simulation. This involves using a CT scanner to pinpoint the area being treated. The treatment field or area will be marked on your skin, usually using tiny tattoo dots.

Getting your radiotherapy

During treatment you will lie on a treatment table. The machine will move around you so that you receive the precise treatment at different angles. Each treatment session only takes a few minutes. Radiotherapy itself is not painful, but you will have to lie very still, which can be a bit uncomfortable. Most people get radiotherapy as outpatients, travelling to the radiotherapy unit each day.

How much radiotherapy will I need?

Usually you will only need a short course of radiotherapy. You may have a single dose or a dose divided into a few sessions.

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. With a short course of radiotherapy any side-effects are usually mild and reversible. Longer term (chronic) side effects are much less common.

Short-term 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 need to 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 treatment.

Bowel problems: Some men find their bowel movements change and their stools (poos) are looser, and less firm during treatment. You might also notice that you need to get to the toilet more quickly. This is because the prostate gland is very close to your back passage (rectum). Some men develop diarrhoea, which means passing watery bowel motions more than three times a day. You may also have cramping abdominal (tummy) pain and pass more wind and mucus. If this happens, drink lots of fluids to replace those you are losing. High fibre foods like raw fruit and vegetables may make these bowel problems worse, so you may be advised to eat less fibre or avoid fibre-rich foods altogether for a time. Do let your doctor or radiation therapist know if you have diarrhoea. There is medication that can stop this side-effect as well.

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. 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. For more about fatigue see page 48.

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.

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

»»» With a short course of radiotherapy, side-effects are usually quite mild.

Radioactive injections

Radioactive injections can help with symptoms of prostate cancer that has spread to the bones. They can shrink any areas of cancer in the bone by killing the cancer cells, which can relieve pain and improve your overall prognosis. Radioactive injections will not lower your PSA.

Examples of radioactive injections are strontium 89 and radium-223 (Alpharadin® / Xofigo® (“zo-fee-go”). Your doctor will tell you if this treatment is suitable for you or not.

You will normally have the injection every month in the radiotherapy department as an outpatient, so you shouldn't need to stay in hospital overnight.

Because the radiation is targeted at cancer cells, side-effects are mild and may include diarrhoea and sickness, and sometimes reduced levels of blood cells. Bone pain may get a little worse before it gets better.

After the injection, a small amount of radiation remains in your urine, poo (stools) 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.



To sum up

- Radiotherapy uses high-energy rays to kill cancer cells
- Radiotherapy is painless and each session only takes a few minutes
- Side-effects depend on the area being treated. They include urinary problems, bowel problems, discomfort at back passage, skin changes, fatigue
- Radioactive injections can help to relieve bone pain
- Side-effects from the injections are usually mild and include diarrhoea and sickness

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating or diagnosing cancer.

Patients with cancer are sometimes asked to take part in a clinical trial. This means that instead of the standard treatment you get a new trial drug. Or you may be given existing treatments used in different ways. For example, giving a different dose of a drug or using two treatments together.

Drugs that are used in a clinical trial have been carefully tested to make sure they are safe to use in a clinical trial.

More information

If you are interested in taking part in a clinical trial or want more information, you can read our factsheet *Cancer and Clinical Trials*. It's available to read or download on our website, www.cancer.ie. You can also get a free copy by calling our Cancer Nurseline on 1800 200 700 or by dropping into a Daffodil Centre.

🗨️ Ask about drug trials, new combinations of drugs and research coming down the line. There is so much more hope for effective treatments now than when I was first diagnosed. 🗨️

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. 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 anything.

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.

If you don't feel well enough to travel to the hospital, tell the hospital and your GP. They may be able to arrange for the symptom control team to visit you at home. For more about the symptom control team (palliative care) see page 54.



Managing side-effects and symptoms

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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. For example, urinary problems, bone weakness or pain, or sexual side-effects.

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

Occasionally, some men find they cannot pass urine at all and cannot empty their bladder. This is called acute urinary retention. This may be due to the cancer pressing on the tube which drains the bladder (the urethra), making it more narrow than normal. This can become very uncomfortable and distressing. Not being able to pass urine also increases the risk of developing a bladder infection if it is not treated quickly.

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, or your homecare team may do this for you. The urine you make will pass through the tube into a drainage bag. Before you go home, your nurse will show you how to look after the catheter. The catheter drainage bag will be worn inside your trousers and will be secured around your lower leg.

It is important that the urine can drain easily from your bladder and into the drainage bag. Try to drink plenty of fluids every day (between 1.5 and 2 litres is usually best) to reduce the risk of getting an infection.

Wash your hands before and after handling the catheter. When washing the catheter entry tip, wash it in a one-way direction away from your body. Speak with your nurse if you notice any leaking around the outside of the catheter or if you notice that the catheter is not draining correctly.

You might experience bladder spasm while the tube is in place. This often feels like a strong urge to pass urine, despite the tube being there. It may happen when your bowels move. This is normal, but talk to your doctor or nurse if this happens to you a lot. Your doctor can prescribe medication if this becomes a problem for you.

Some men may need an operation to relieve the pressure on the narrowed urethra (water pipe). This is called a transurethral resection of the prostate (TURP). This will allow the urine to flow better.

Don't suffer in silence

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.

Leaking urine: Some men may notice that they don't get much warning before they have the urge to pass urine and may leak some urine before making it to the bathroom. This may be as a result of the cancer growing near the muscles which control the opening and closing of the bladder, causing them to weaken.

If this is the case you might need to wear an absorbent pad inside your underwear for protection. You can get these from a pharmacy. If you have a medical card your public health nurse may be able to get the pads for you.

Carry the card

The Irish Cancer Society have a card that you can show at shops and other public places to get urgent access to a toilet. Get one from a Daffodil Centre or by calling our Cancer Nurseline on 1800 200 700.





Tips & Hints – Managing urinary problems

Your doctor can help you to manage urinary problems, so always tell him or her if you have any symptoms. You could also try the following:

- Try cutting down on food and drinks with caffeine, like cola, tea, green tea, coffee and dark chocolate, as they may irritate your bladder.
- Try drinking less alcohol. Alcohol can increase the amount of urine you produce, making it more likely you'll have to get up during the night.
- Drink plenty of fluids every day – about 2 litres a day (average 6-8 cups). Not drinking enough will make your urine more acidic and this may irritate more.
- Try to eat plenty of fibre to avoid constipation. Constipation can put pressure on your bladder and make urinary problems worse.
- Try to take get exercise, if you feel able to. Your doctor can advise you about suitable exercises for you.
- Go to the toilet at regular intervals.
- Try having a rest in the afternoon. It may help the muscles around your bladder to tighten up and work better for you.
- If you need to use pads, make sure you pick the right size and absorbency to suit you. Wear supportive underpants to help keep them in place and keep a supply with you.
- Wear trousers with an elasticated waist, or use braces rather than a belt. This makes it easier when you want to go to the toilet quickly.
- Try pelvic floor exercises. They may help to improve your bladder control. Get advice from your hospital team or a local HSE continence adviser. There are instructions on how to do the exercises in the urinary symptoms section of our website, www.cancer.ie

The 'Knack'

'The knack' is a technique to help to reduce leakage. 'The knack' involves squeezing your pelvic floor muscles before you cough, sneeze or laugh or before or during other activities that can make leakage worse. Go to www.cancer.ie for more information.



Bone pain

Bone pain, for example a nagging ache in your bone, 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.

How is bone pain managed?

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 drugs and types of painkillers to see which one suits you best.

Bone strengthening drugs: Bone-strengthening drugs, such as denosumab (Xgeva®) or zoledronic acid (Zometa®) may also help to relieve bone pain. See page 33 for more about these drugs.

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 pain and make you feel better and more comfortable. This is known as palliative radiotherapy. It can be given as a single dose or a dose divided over a few days. The pain should reduce a few days after treatment. You may have a flare-up of pain just after treatment, so you may need to take painkillers for a few days. It may be a number of weeks before you feel the full benefit of the radiotherapy.

Radiotherapy can also help with any pressure or bleeding. See page 34 for more about radiotherapy.

Your doctor and radiation therapist will explain what is involved and any likely side-effects. 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: Radioactive injections can be effective at relieving bone pain. It may take up to 3 weeks for the pain to reduce but the pain relief can last for several months. See page 37 for more about this treatment.

Complementary therapies: There are other ways to ease 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 57). Talk to your local cancer support centre to see what services are available. Call our Cancer Nurseline

on 1800 200 700 or visit a Daffodil Centre for advice or for a copy of our booklet, *Understanding Cancer and Complementary Therapies*.



Weakened bones

Cancer in your bone can cause weaker bones, which are more likely to break (fracture). Some cancer treatments, such as hormone therapy, can also weaken bones. You will probably be prescribed bone-strengthening drugs to protect your bones or treat weakened bones. There's more about bone-strengthening drugs on page 33

What can I do to look after my bones?



Get physically active: Physical activity is good for bone health, particularly weight bearing exercise. Your doctor can refer you to a physiotherapist who can advise you on the best exercise for you. If you have cancer in your bones, it is important to check with your doctor before starting an exercise programme.

Eat well and get enough calcium and vitamin D: A balanced diet with plenty of calcium and vitamin D is vital for healthy bones. Calcium and vitamin D are found in cheese, foods with added vitamins and minerals like fortified cereal and milk, and oily fish such as sardines, pilchards and salmon. Green vegetables like spinach and kale and other dairy products like yoghurt are also good sources of calcium. Don't take any vitamin or mineral supplements unless your doctor advises you to.

Cut down on caffeine: Caffeine may cause you to pass more calcium in your urine. Limit your intake of energy drinks, dark chocolate and colas and do not drink more than 4 cups of tea or coffee per day.

Stop smoking: Smoking damages blood vessels, kills the bone-making cells and upsets the balance of hormones that bones need to stay strong.

Limit alcohol: Too much alcohol can increase your risk of osteoporosis. Limit your risk by drinking no more than 17 standard drinks, spread out over the week.

Prevent falls: If you feel unsteady on your feet talk to your GP. He or she can refer you to an occupational therapist (OT). The OT can assess your needs and organise equipment like walking aids and grab bars. This equipment can help to keep you and your home safe. Some medications can also increase the risk of falls (for example, enzalutamide), so take extra care if this applies to you.

There's more bone health information on our website www.cancer.ie, including tips on avoiding falls and making your home safer.

Constipation

Constipation can be a common problem if you have advanced prostate cancer. Taking painkillers, high calcium in the blood, eating less than normal or a lack of exercise can all cause constipation. If you have constipation, talk to your doctor or nurse as soon as possible, so that they can advise you and give you medications to help, if you need them. Your dietitian can also give you advice on dealing with constipation. Eating more high-fibre foods, drinking plenty of fluids and taking some gentle exercise may improve things. Your doctor or nurse can advise you about suitable exercises. Using a footrest so that your knees are above your hips when you go to the toilet may help too.

Fatigue

Fatigue means feeling extremely tired most or all of the time. You may also find it hard to concentrate or make decisions. Fatigue is a very common symptom of cancer.

Fatigue when you have cancer can be caused by many things, including the cancer itself, tests and treatments for cancer, not eating well, low levels of red blood cells (due to the cancer or its treatment), not sleeping well or dealing with difficult emotions and feeling anxious or depressed.

Tell your doctor or nurse if fatigue is affecting you, so that they can help you.

Finding out what is causing your fatigue makes it easier to treat. For example, if you have a low red blood cell count a transfusion can make you feel better. If you are not eating well a dietitian may be able to give you some advice to help you.



Tips & Hints – fatigue



- Try to do some exercise – ask your doctor for advice about the best exercise for you.
- Build rest periods into your day and save your energy for doing the things that are most important to you.
- Ask for help at work or at home, especially with cooking, housework or childcare.
- Eat little and often if your appetite is poor.
- Try to avoid stress. Talk to friends and family about any worries you have and take time to enjoy yourself.
- If you are not sleeping well, try relaxation techniques and avoid stimulants like caffeine and alcohol before bedtime.
- Try complementary therapies like meditation, acupuncture or massage.

Other side-effects

Blood in the urine

You may notice blood in your urine (haematuria). This may be coming from your prostate gland. It can usually be controlled with surgery or radiotherapy. Let your doctor or nurse know if you have this symptom, so they can see if you need treatment.

Kidneys not working properly

Sometimes kidneys can be affected by prostate cancer. This might happen if the cancer stops your bladder or kidneys from draining properly or spreads to lymph nodes near your kidneys. If your kidneys aren't working properly it can cause make you feel very tired (fatigue) or sleepy. Other symptoms include poor appetite, swollen ankles or feeling sick. These symptoms could be caused

by other things, but it's important to tell your doctor or nurse if you have any of these symptoms.

Treatment can help the urine to flow better from your kidney. This can be done by placing a small tube (stent) into the tube that drains the urine from the kidney into the bladder (ureter). Or you may have a tube called a nephrostomy (nef-frost-o-me) tube put into your kidney, which drains urine straight into a bag that sits outside your body. Radiotherapy may also help to relieve the blockage.

Spinal cord compression

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

- Weakness, tingling (pins/needles) in your arms, legs or body
- A narrow band of pain in your arms, legs or body
- Unsteadiness on your feet or your foot going from under you
- Difficulty using your arms or legs
- Having no control over your bowels or bladder
- Pain that moves down your legs or arms

It's important to get treatment quickly if this happens, to avoid the nerves being damaged permanently. If you notice any of these symptoms, try to contact your doctor or go to A&E straight away.

Hypercalcaemia (too much calcium in your blood)

Hypercalcaemia (hi-per-cal-see-mee-a) can happen if the cancer causes calcium to be released into the bloodstream from the bone, where it's normally stored. Signs of hypercalcaemia include fatigue and lack of energy, loss of appetite, confusion, constipation, thirst, passing urine frequently and feeling sick or vomiting. Tell your doctor if you're having these symptoms. They could be caused by other things, but your doctor can check your calcium level with a blood test. If your calcium is too high you may need to be connected to a drip to get fluids into your blood. This can help to flush out the excess calcium. You may also get medicines called bisphosphonates, which can help to lower the amount of calcium in your blood (see page 33).

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. 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



Sexual side-effects

Treatment can affect your sex life in different ways:

Hormone therapy: Erection problems and lower sex drive, due to having less of the male hormone testosterone.

Radiotherapy: Erection problems, producing less or no semen at orgasm. Uncomfortable ejaculation.

All treatments: Having prostate cancer can affect your desire for sex and your performance in other ways too. You may be stressed, depressed, very tired or less confident because of your cancer diagnosis. You may also have other side-effects from treatment or physical changes to your body that make you feel differently about sex. See page 53 for more about prostate cancer and your emotions.

Many men worry about sexual side effects like finding it hard to get an erection or losing interest in sex. If you are worried about any sexual side effects, talk to your doctor. There are medications and other treatments that can help.



What treatments can help with erection problems (erectile dysfunction)?

Your doctor will advise you on the best treatment for you, depending on your medical history. The treatment options for erectile dysfunction include:

- **Tablets:** These help you to get an erection. They only work if you are interested in having sex and you need to get sexually aroused for them to work.
- **Urethral pellets:** These contain drugs to help you get an erection. They are put into the opening or ‘eye’ of your penis.
- **Penile injections:** You inject a drug into the base of your penis to cause an erection, using a very fine needle.
- **Vacuum pump:** A tube is placed over your penis and a pump creates a vacuum, which causes an erection. A rubber ring is placed at the base of your penis to keep it hard while you have sex. The tube is removed.
- **Penile implants:** This is where tubes, a reservoir (container) and a pump are put inside your body during an operation. The implant means you can press on the pump to make your penis fill with fluid and get hard.

Getting the best from treatment

Don't expect too much the first few times you try a treatment. It can take time to get used to everything, so don't put too much pressure on yourself.

Don't give up. You might need to try a few different things or use 2 treatments together to find what works for you. Go back to the doctor if you feel a treatment isn't helping.

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. Some men feel less masculine or lose their confidence because of the cancer or the side-effects of treatment. These are all normal reactions, but things usually improve in 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 people fear that cancer can be passed on to a partner during sex. This isn't true. It's quite 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. You don't need to 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, so don't be afraid to ask.

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

Will treatment affect my fertility?

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 side-effect before your treatment. If you are having sex and you are fertile, you should use a reliable method of contraception during and for some time after treatment.

Our website www.cancer.ie 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.



Palliative care

Your doctor may refer you to specialist palliative care doctors and nurses, who are experts in managing the symptoms of advanced cancer, such as breathlessness, pain and nausea. They are also called the symptom control team.

You may be worried if your doctor suggests palliative care for you. You may think this means you are at the end of your life. Palliative care does include end-of-life care, but it can also be given at other times to help to manage your symptoms and improve your quality of life, including while you are having other active treatments like chemotherapy. The palliative care team can complement your oncology (cancer care) team to help you to feel as well as possible during your treatment.

Having palliative care doesn't mean that you're at the end of your life. The expertise of the palliative care team means that existing symptoms can be better managed and new problems can be spotted and treated early, to help you to feel as well as possible.

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 also offers emotional support and comfort to patients and their families.

Palliative care can be given in a hospital or at home. It can help you to feel supported at home if the palliative care team are involved with your care. You may also get palliative care in a hospice. You can go to a hospice for respite or to get treatment for your symptoms or you may stay at the hospice in the later stages of your illness.

For more information on palliative care including a booklet called *Palliative care – Asking the questions that matter to me*, visit The Palliative Hub at www.adultpalliativehub.com

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. You may also like to read about planning ahead (page 68).

Taking care of your health

Many people want to make positive changes to their lives to stay as well as possible. Having a healthy lifestyle can help you to:

- Feel better
- Cope better with the side-effects of treatment
- Keep up your energy and strength

A healthy lifestyle includes

- Exercising
- Eating healthy foods
- Staying at a healthy weight
- Not smoking

- Protecting yourself from the sun
- Looking after your bone health

Exercise

Exercise is very helpful in lots of ways. It can:

- Give you more energy
- Improve fatigue
- Boost your mood
- Reduce stress
- Keep you fit
- Keep your bones healthy

Ask your doctor or nurse about the type and amount of exercise that would be best for you. Some cancer support centres have exercise classes or groups. See page 74 for more about cancer support centres.

Eating well

Eating well generally means eating a diet rich in wholegrains, vegetables, fruit and pulses, with lean meat, fish and low fat dairy, and limiting foods that are high in added sugar and saturated fat.

Many people with advanced cancer find that their appetite becomes smaller. This can be because of the side-effects of treatment or the cancer itself.

You may find that the amount of food you eat or the type of food that you like changes. So it's important to eat the foods that you most enjoy and aim to have small meals when you feel able to eat. Talk to your doctor, nurse or dietitian about any changes in your appetite or weight. A dietitian can help to improve your comfort at mealtimes.

If you are feeling too tired to cook, stock up on tinned food or healthy ready-meals, or ask family and friends to help with shopping and cooking.

If you want more information or advice, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of our booklet *Diet and Cancer*, or download it at www.cancer.ie



Cancer and complementary therapies

Some people with cancer find it helpful to try complementary therapies as well as their standard treatment.

Complementary therapies: Complementary therapies are treatments that can be given in addition to standard medical treatment. Examples of complementary therapies are yoga, meditation, acupuncture, aromatherapy and massage.

Standard treatment: Standard or conventional cancer treatments include chemotherapy, hormone therapy, radiotherapy and surgery. The effects and the side-effects of standard treatments have been scientifically tested.

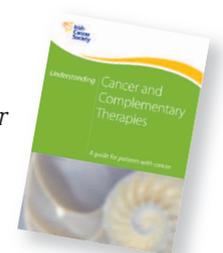
Alternative therapies: Alternative therapies are generally treatments that are used instead of standard treatments. For example, diet therapy, megavitamin therapy and herbalism. Alternative therapies have not been scientifically proven. Some alternative therapies may even harm your health.

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

Before you decide to change your treatment or add any methods of your own, 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.

More information

To find out more about the different complementary and alternative therapies, read our booklet *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients*. To get a copy call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also read or download the booklet on our website www.cancer.ie



Cancer Nurseline Freephone 1800 200 700

6 Life takes on new dimensions with this uncertainty, not all entirely negative. It makes many previously troublesome issues seem unimportant. Focus on living life in the present moment, just do those things you've always wanted to do! 9



Coping and emotions

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How can I cope with my feelings?

There are many reactions when you hear you have metastatic cancer. Reactions differ from person to person. There's no right or wrong way to feel and there's no set time to have one particular emotion or not.

Common reactions include:

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

You may also worry about the future or the possibility that the cancer is not responding well enough to your current treatment. It is not unusual for it to be more on your mind if you're having tests or before your hospital follow-up visits.

A helpful booklet that discusses in detail how you may be feeling is called *Understanding the Emotional Effects of Cancer*. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy.



Anxiety and depression

Sometimes a cancer diagnosis can cause anxiety and depression. If you feel that your low moods are getting the better of you or you are finding it hard to cope, it's important to get help. It's not a sign of failure to ask for help or to feel unable to cope on your own. Try to talk with someone you know who is a good listener or tell your GP. It's also a good idea to tell your doctor and nurse at the hospital. They will want to know how you're feeling and suggest ways to help. Medical social workers can also offer support to you and your family.

If you're finding it difficult to get over a period of depression, your doctor may suggest a treatment. Often a short course of antidepressants can work well. Professional counselling can also be very helpful.

>>> It's not a sign of failure to ask for help or to feel unable to cope on your own.

Counselling

Sometimes it can be hard to talk to the people closest to you if you are feeling very distressed or finding it hard to cope. You may worry about upsetting or worrying your friends or family. A trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support, help you to make decisions and learn ways to cope better.

Counselling is available free of charge at some local cancer support centres. To find out more about counselling call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at cancernurseline@irishcancer.ie

A list of counsellors funded by the Irish Cancer Society is available at www.cancer.ie

Ways to get emotional 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 like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 74 for more about cancer support services.

Ask about psycho-oncology services at the hospital: Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your doctor, specialist nurse or medical social worker can refer you to psycho-oncology support services.

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. Many cancer support centres have activities and groups where you can meet other people affected by cancer.

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 cancer diagnosis and who can give you emotional and practical 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 the medical social worker at the hospital or to one of our cancer nurses.

Seek spiritual support: 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.

If you need more information or help with finding support, call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre.

🗨️ **Talk to a counsellor as they can be invaluable. Ask for help. I found that hard, but talking and getting help can be of huge benefit.** 🗨️

Learning to cope

Everyone experiences cancer in a different way. And how each person copes with cancer varies too. There is no right or wrong way to cope with cancer, only your way.

It can take some time to come to terms with your emotions after a cancer diagnosis. Coping with the physical effects of treatment can also add to the burden of dealing with cancer, but most people are able to adjust.

How can I help myself?



Here is a list of things to help make you feel more involved and more in control of your illness. They can help to boost your self-esteem and well-being, making it easier to deal with cancer.

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

Involve your family and close friends: Don't keep your worries or any physical problems secret from the people closest to you. Ask someone close to you to come with you when you're visiting the doctor and when treatments will be discussed. If you're feeling alone, you can also talk in confidence to one of our cancer nurses by calling our Cancer Nurseline or visiting a Daffodil Centre.

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.

Look after your health: See page 55 for some tips.

Try relaxation and stress management techniques: Therapies like meditation or yoga can help you to cope with stress. Some cancer support centres provide groups to help you learn these techniques.

Try complementary therapies: Complementary therapies may help to relieve the side-effects of cancer and its treatment. They can also help you to feel better emotionally. See page 57 for more information on complementary therapies.

Accept change in your life: Accept that you may not be able to carry on exactly as before. Give yourself time to adjust to your new routine.

Know that there will be ups and downs: Sometimes people feel they have to be brave or positive all the time, but it's normal to have bad days. Get help if you are finding it hard to cope.

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.

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

Express yourself: Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of what you are going through. Other forms of creative expression, such as music and art, may help too.

Practical planning: 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 can give you the chance to plan and deal with any practical concerns or worries you may have in your personal life. See page 68 for more information on planning ahead, or look at our advanced cancer web pages on our website www.cancer.ie

You can also call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for advice, information and support from a cancer nurse.

Positive emotions

A cancer experience can also bring positive emotions. However, it may be some time before you are ready to accept these emotions as positive. You may experience great love, affection and closeness by those around you, not only family and friends but also neighbours and even the healthcare team. With that can come a sense of gratitude too. The experience of cancer can also bring personal growth and knowledge – it can make you realise where your strength lies and what's important in life for you. You may also get the chance to do and enjoy different things that you would never have done otherwise.

You and your family

Every family deals with cancer in its own way. You may feel that you don't want your illness to upset family life, feel guilty that you can't join in as much as before, or that you're letting down your partner or children. You may also worry about the emotional impact your illness will have on your loved ones. Our booklet *Who Can Ever Understand?* can help to you find ways to talk about your cancer and to ask for the help and support you need.



If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our cancer nurses. Call us on 1800 200 700 or visit a Daffodil Centre. The nurses can also support you if you have children and aren't sure what to say to them. You could also read our booklet *Talking to Children about Cancer*, which has practical advice about how to talk to children of different ages.



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. Some may gather up-to-date information on 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, cooking, shopping or housework. It may take time to know which way suits you and your family or friend best.

- Try to stay positive, but allow for down time. Keep as active as is comfortable. Counselling can help you and your family.

Advice for carers

Caring for someone with prostate cancer can be difficult at times. Some patients manage well and need little practical support from family and friends. Others may need more support and care.

Coping with both the practical and emotional issues of a cancer diagnosis can be hard. Here are some things that can help to make life a little easier:

Learn about cancer: Learn more about prostate cancer, any possible side-effects and the emotional effects it can cause. This will help you to understand how you can support your partner, relative or friend. Visit our website www.cancer.ie or call our Cancer Nurseline for a free copy of our publications.

Plan as much as you can ahead of the discharge date: Ask to speak to a medical social worker about the community services that are available. Tell your GP and local public health nurse that your loved one will be coming home. If medical supplies are needed, make sure you have some at home before the discharge date. Ask for a contact name and phone number /email address at the hospital that you can use if you have a problem.

Encourage your relative or friend: The more involved they are in their own care, the quicker they will adapt to a new way of life.

How to talk to someone with cancer

When someone close to you has cancer it can be hard to know what to say. You may find it difficult to talk about their cancer. Or you may be afraid of saying the wrong thing. Often what people with cancer want most is someone to listen to them.

If you want advice on how to support a friend or loved one with cancer, call our Cancer Nurseline on 1800 200 700. Ask for a copy of our booklet *Lost for Words – How to talk to someone with cancer*. The booklet gives advice on talking to someone with cancer. You can also pick up a copy of the booklet at any Daffodil Centre, or download it at www.cancer.ie



Looking after yourself as a carer

Share worries: You may feel tired with all the worry and extra work. It can also be difficult to adapt to a new way of life. Try to share your worries with someone else. Call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence. Stay in touch with your own friends and get out when you can, even if you don't always feel like it.

Take regular breaks: Try to take a break each day, even if it's just a walk to the shops. Ideally, try to organise longer breaks as well, such as an evening out with friends or a trip to the cinema. If you have young children, organise for your family or a babysitter to mind them for an hour or two, if possible.

Have little treats: If you don't want to take a break, then at least give yourself little treats to keep yourself going. Order your favourite magazine each week and give yourself an hour to sit down with a cup of tea or coffee to read it. Or make sure that you can watch your favourite TV programme, have a long soak in the bath after a difficult day, or an early night with a good book.

If you find it difficult to cope, get help: Talk through your feelings and frustrations with a friend or your GP. Your GP can suggest other services and sources of help.

Look after your own health: See your GP sooner rather than later if you have any health concerns of your own.

Find carers support organisations or local cancer support centres: Find out about groups and organisations for carers of people with cancer. Many local cancer support centres have services for carers too.

Support for you

Our cancer nurses are there to support you as a carer. Call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@irishcancer.ie for confidential support, advice and information. You could also ask for a copy of our booklet, *Caring for Someone with Cancer*, or download it from our website www.cancer.ie



Planning ahead

You can live for many years with metastatic prostate cancer and most people hope that this will be the case for them. But it can be hard to think about what might happen in the future when you have a diagnosis of metastatic prostate cancer. It might make you feel worried, scared or upset to think about the end of your life.

Many people find it puts their mind at rest to have medical plans in place and sort out legal and practical matters, even though they still hope to live for a long time. Planning ahead is useful for everyone, whether they have an illness or not.

Planning ahead might include:

- **Thinking about how you feel about different types of medical treatment**, including if you want to stop treatment at any stage or carry on for as long as possible.
- **Writing an advance care directive**. This is where you can write down your wishes about your medical care. Doctors can use this if you are not well enough to say what you want.
- **Picking someone to make medical decisions for you** if you are not well enough.
- **Making a will**.
- **Talking about what you want** to your family, friends, carers and healthcare providers.

Who can help me plan?

Think Ahead is a planning booklet with easy-to-read forms to fill in to record your personal, medical, financial and legal information and preferences. It's available from the Irish Hospice Foundation at www.hospicefoundation.ie



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Coping with the financial impact of cancer

A diagnosis of cancer often means that you will have extra expenses, like car parking during hospital visits, medication, travel, heating and childcare costs. If you can't work or you are unemployed, this may cause even more stress. It may be harder for you to deal with cancer if you are worried about money.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Appliances, like wigs

How much you pay towards your medical expenses depends on whether or not you qualify for a medical card and what type of health insurance you have, if any.

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication.

Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

An emergency medical card may be issued if you are terminally ill and in palliative care, irrespective of your income.

If you do not have a medical card you will have to pay some of the cost of your care and medication. If you are over 70 years old, you can get a free GP visit card.

If you have health insurance the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It's important to contact your insurance company before starting treatment.

Benefits and allowances

There are benefits available from the Department of Social Protection that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

If you want more information on benefits and allowances, contact:

- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0761 074 000
- Department of Social Protection (DSP) – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are asking about entitlements and benefits. It's also a good idea to photocopy completed forms before posting them.

If you have financial difficulties

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0761 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 73 for more details of our Volunteer Driving Service and the Travel2Care fund.

You can also call our Cancer Nurseline 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

Cancer Nurseline Freephone 1800 200 700

More information

For more information go to www.cancer.ie/publications and check out our booklet, *Managing the Financial Impact of Cancer – A Guide for Patients and their Families*.

This explains:

- Medical costs and help available
- Benefits and allowances that you or your family may qualify for
- Travel services
- Ways to cope with the cost of cancer

The booklet also has lots of other information to help you manage the cost of cancer. For example, disability and mobility supports, help for people in financial difficulty, help for carers and living at home and nursing home supports.



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 | ▪ Patient travel and financial support services |
| ▪ Daffodil Centres | ▪ Night nursing |
| ▪ Survivor Support | ▪ Publications and website information |
| ▪ Support in your area | |

- **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. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at www.cancer.ie

For the deaf community, our Cancer Nurseline is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: remote@slis.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. See page 74 for more information.
- **Patient travel and financial support services.** We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:
 - **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
 - **Irish Cancer Society Volunteer Driving Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

To access either 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 our Cancer Nurseline for a free copy of our publications.

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

Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients and their families, during and after treatment, many of which are free. For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free, one-to-one counselling in many affiliated support services)
- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**, like the Irish Cancer Society's *Strides for Life* walking group programme
- **Stress management and relaxation techniques**, such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what's available.

You can call our Cancer Nurseline on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at <http://www.cancer.ie/support/support-in-your-area/directory>

Helpful books

The Irish Cancer Society has a wide range of information on reducing your risk of cancer, different types of cancer, treatments, and coping. For free copies call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download or order the booklets on our website: www.cancer.ie.

You may find the following helpful:

Treatment and side-effects

Understanding Chemotherapy

Understanding Radiotherapy

Understanding Cancer and Complementary Therapies

Diet and Cancer

Coping with Fatigue



Coping and emotions

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

A Time to Care: Caring for Someone Seriously Ill at Home



What does that word mean?

Androgen	A male hormone.
Androgen deprivation therapy (ADT)	Hormone therapy to reduce levels of male hormones, called androgens, in the body, to stop them from helping prostate cancer cells to grow.
Benign	Not cancer. A tumour that does not spread.
Biopsy	Removing a small amount of tissue from your body to find out if cancer cells are present.
Catheter	A long, thin flexible tube that is passed into your bladder. It drains urine into a bag.
Cells	The building blocks that make up your 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.
Grading	How normal or abnormal prostate cells look under a microscope.
Incontinence (urinary)	When you cannot control the leakage of 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.

Metastasis	The spread of cancer from one part of your 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.
Rectum	The lower part of your bowel (back passage).
Staging	Tests that measure the size and extent of 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?
- What type of prostate cancer do I have?
- What are my treatment choices?
- How successful is this treatment for my cancer?
- If my treatment is not successful, can I still have other treatments?
- Can my symptoms be controlled?
- Do some treatments have more side-effects than others?
- Are the side-effects of treatment short or long term?
- Will I have problems with urinary incontinence after my treatment?
- Will treatment affect my sex life and fertility? Will I develop erectile dysfunction?

Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

Answer

6

Answer

7

Answer

8

Answer

Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team!

Support people affected by cancer

Reaching out directly to people with cancer is one of the most rewarding ways to help:

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Survivor Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

Share your experiences

Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:

- Share your cancer story
- Tell people about our services
- Describe what it's like to organise or take part in a fundraising event

Raise money

All our services are funded by the public's generosity:

- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Contact our Cancer Nurseline on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

We would love to hear your comments or suggestions.
Please email reviewers@irishcancer.ie

More information and support

If you would like more information or someone to talk to, now or at any time in the future, please call our Cancer Nurseline on 1800 200 700.

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Cancer Nurseline Freephone 1800 200 700

Email: cancernurseline@irishcancer.ie

Find us on Facebook

Follow us on Twitter: @IrishCancerSoc

