Irish Cancer Society

Understanding

Metastatic prostate cancer

Caring for people with cancer

Understanding

Metastatic prostate cancer

This booklet has information on:

- Treatment for metastatic (advanced) prostate cancer
- Side-effects and how to manage them
- Coping with the emotional side of cancer
- Financial and practical matters

Useful numbers

Medical oncologist

Radiation oncologist

Urologist

Urology specialist nurse/Oncology nurse

Medical social worker

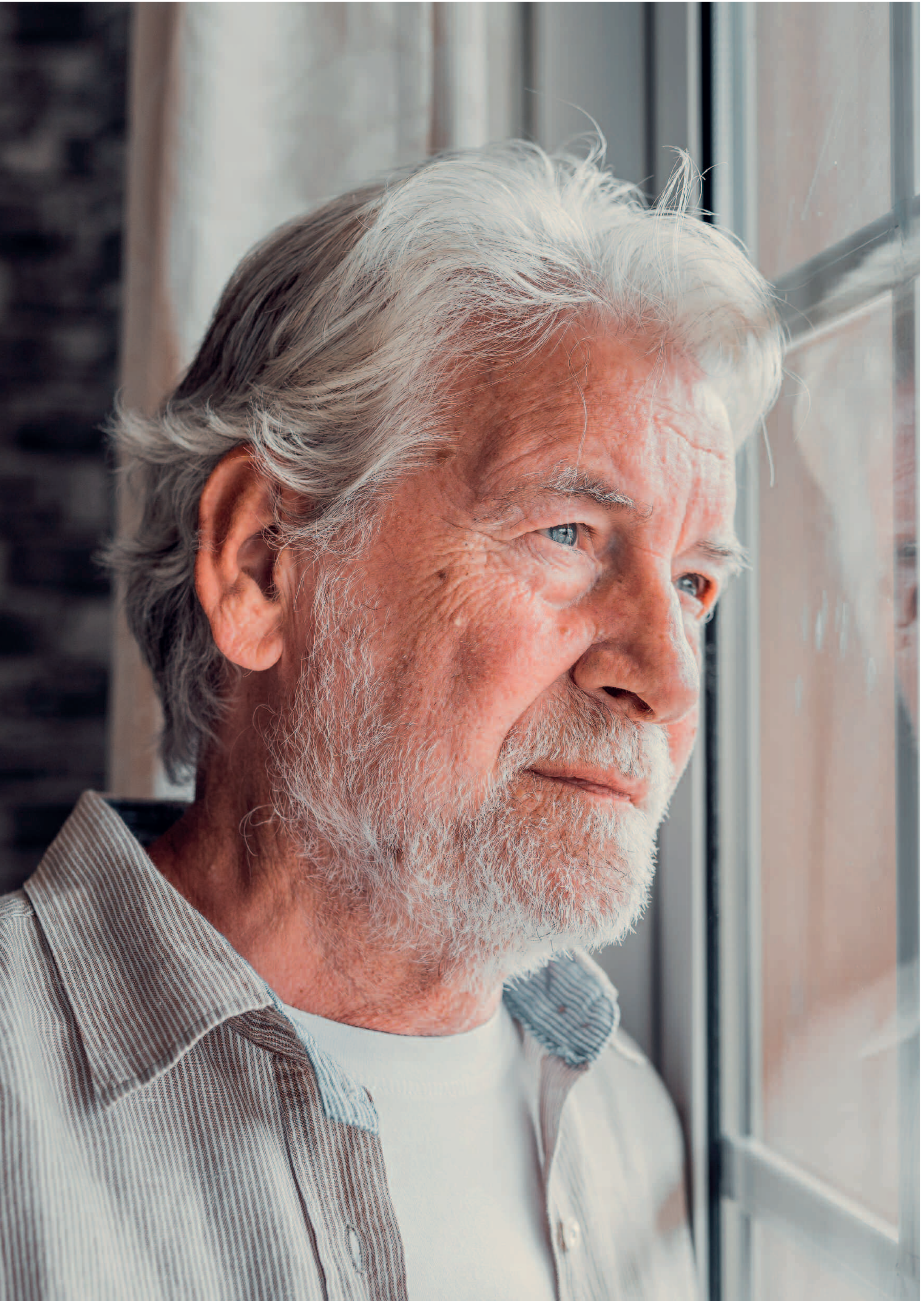
Pharmacist

Main hospital number

Emergency department

Family doctor (GP)

Hospital records number (MRN)



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Fast facts

Can my cancer be treated? Page 35

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 33

Many people live a long time with metastatic prostate cancer. What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things. The best thing to do is to ask your consultant about your own situation.

What treatment might I have? Page 45

Hormone therapy: Injections or tablets to control the cancer.

Chemotherapy: Drugs that kill cancer cells 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 might my cancer and treatment affect me? Page 77

Metastatic prostate cancer can often cause symptoms, but it doesn't always. 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 73

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. Ask your consultant if there are any trials suitable for you.

We're here for you Page 123

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 Support Line on 1800 200 700
- Drop into a Daffodil Centre.
  Email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.
- Email us: supportline@irishcancer.ie

Reading this booklet

This booklet is to help you throughout your cancer treatment and afterwards. You will probably find different sections useful at different times, so keep it for reference.

If you need more information or don’t understand something, ask your doctor or nurse. You can also ask one of our cancer nurses:

- Call our Support Line on Freephone 1800 200 700
- Visit a Daffodil Centre
- Email the nurses at supportline@irishcancer.ie

About our information

While we make every effort to ensure the information in this booklet is correct and up to date, treatments and procedures in hospitals can vary.

You should always talk to your own medical team about your treatment and care. They know your medical history and your individual circumstances. We cannot give advice about the best treatment for you.

We use gender-inclusive language. We sometimes use man/woman and male/female when they are needed to explain a person’s treatment and care – for example, talking about hormones or body parts – and when needed to describe research or statistics.

Helplines Partnership Member

Keeping track of information

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

Date of diagnosis

PSA level at diagnosis

Clinical stage at diagnosis

Gleason score

Treatment

If you are receiving hormone therapy, you may like to record your treatments using the tables on pages 133-136.

About metastatic prostate cancer

What is the prostate gland?

The prostate is about the size of a walnut. It lies below your bladder just in front of your rectum (back passage).

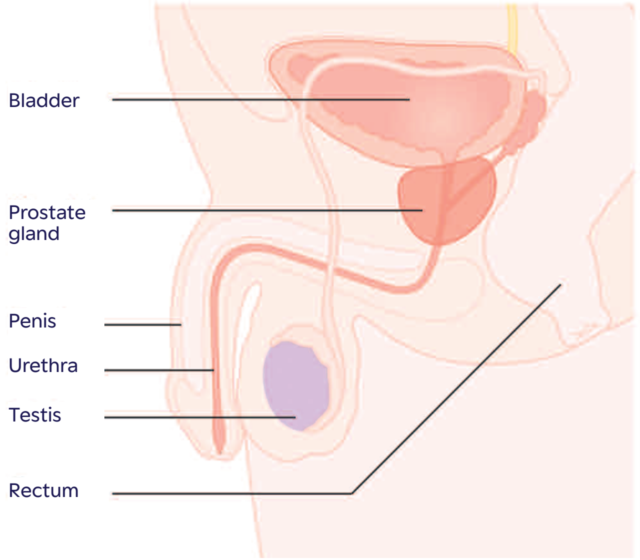


Image courtesy of Cancer Research UK – Wikimedia Commons

Running through your prostate is a tube that carries urine through your penis. This tube is known as your urethra or water pipe. An enlarged prostate gland can cause trouble passing urine because the gland can put pressure on or squeeze the urethra.

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 the 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). There are 4 stages of growth:

Early prostate cancer

Stage 1 (I) The cancer is small and is only found inside the prostate.

Stage 2 (II) The cancer is larger and may be in both lobes of the prostate but it is still contained within the prostate gland.

Locally advanced prostate cancer

Stage 3 (III) The cancer has broken through the capsule (covering) of the prostate and has started to spread outside the gland to nearby tissues or lymph glands.

Some treatments for locally advanced prostate cancer hope to cure it, while others aim to control the disease or stop it from growing.

Our booklet ***Understanding prostate cancer*** has more about early and locally advanced prostate cancer.

Metastatic prostate cancer

Stage 4 (IV) This is when prostate cancer cells have spread outside the prostate to other parts of your body. It is also known as advanced or secondary prostate cancer.

Why did the cancer spread?

Prostate cancer spreads for the following reasons:

- Treatment for early-stage prostate cancer sometimes does not remove all the cancer cells. These cells may be tiny and cannot be picked up on scans. With time these cancer cells can grow and spread.
- The cancer did not give you any problems or symptoms and so it wasn't diagnosed until it had grown enough to spread outside of the prostate.

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

When prostate cancer has spread outside of the prostate gland it is said to be metastatic. Metastatic prostate cancer can affect one or more parts of your body. The most common places for prostate cancer to spread to are your bones and lymph nodes. Prostate cancer may also spread to other parts of the body such as your lungs, liver or brain.

The metastatic cancer is made up of prostate cancer cells, 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 everyone has symptoms. Urinary problems or bone pain are the most common symptoms, but starting treatment often improves these.

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. Tell your doctor if you have any new symptoms.

Spinal cord compression

Spinal cord compression happens if the cancer presses on the nerves in your spine. Although this is a less common symptom, it's very important to treat spinal cord compression urgently.

Go to your doctor immediately if you have symptoms such as pain, weakness or tingling in your leg, reduced mobility, 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.

Preparing for your hospital appointments

Preparing for your hospital appointments

Preparation is key to getting the most out of your hospital appointments. Being prepared also helps the doctors and nurses get the information they need to plan your care.

Before your appointment

- Write down a list of questions and things you would like to discuss.
- Know where you are going and plan your journey (build in extra time for unexpected delays, such as parking).
- Dress in warm comfortable clothes and shoes – sometimes you can be waiting around for a while. Layers are best, as the temperatures in hospitals can vary a lot. Loose-fitting clothing will be easier to manage if you are having your blood pressure taken, blood tests or a physical examination.
- Try to drink clear fluids (water or juice without pulp) if you are having a blood test and are not fasting. This can make it easier for the nurse or doctor to find a vein.
- Check with the hospital if it is okay to bring someone with you. Ask a friend or family member to go along for extra support.

What to take to your appointment

Put together a list of things you might need to bring for your visit, including:

- Your medical card, if you have one
- Your private health insurance details, if you have insurance
- The appointment letter from the hospital, if you got one
- A referral letter or GP letter, if you got one
- Your GP's name and contact details
- Your medical history – your doctor will likely ask you lots of questions so it's a good idea to have everything written down beforehand
- Your list of questions
- A notebook and pen to take notes. (Some healthcare professionals/nurses may be happy for you to record the meeting, but make sure you ask for their permission before doing so)
- A list of your medications or the medication itself – ask your pharmacist to print off a list of your medication. Hand-written lists can be hard to read or inaccurate
- Be aware of when your prescription is due, so you can ask for a prescription before you leave, if needed
- Medications and medical supplies you may need that day, in case you are delayed
- A light snack and drink if you are likely to have to wait for some time. Make sure you're not meant to be fasting – check with the hospital before if you're not sure
- Your phone
- Details of your own phone number and the contact details of your person to call in an emergency.
- Your glasses and hearing aid, if you use them
- A book or something to listen to (including headphones) to pass the time while you wait.

Before leaving the appointment

- Make sure you feel satisfied that your questions were answered and that you have written down what you need to know
- Make sure you know what will happen next
- Ask for the name or number of someone you can contact in case you have further questions
- Make sure you're booked in for your follow-up appointment before you leave, if required

After the appointment

- Arrange any tests in advance of your next appointment as soon as you can, for example, a blood test – if your healthcare professional has asked for it

It's important to go to your appointments

If you can't go to your appointment, contact the hospital as soon as possible and ask them for a new appointment. Contact your GP if you have any trouble getting an appointment.

Questions to ask your doctor

Here is a list of questions that you may wish to ask. There is also some space at the back of the booklet for you to write down your own questions.

What tests do I need?

Where has the cancer spread?

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?

Will treatment affect my sex life and fertility? Will I develop erectile dysfunction?

Diagnosis and tests

Being diagnosed with metastatic prostate cancer

If your cancer has come back, or you have metastatic cancer as your first diagnosis, it can be hard to deal with your emotions. You may feel:

- Upset and overwhelmed by your emotions
- Confused by all the information being given to you
- Worried about what will happen next
- Angry that this is happening to you

However you feel, you are not alone.

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

- Ask to speak to the cancer (oncology) liaison nurse or the medical social worker 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 – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- Speak to an Irish Cancer Society Peer Support volunteer who has had a similar cancer experience and is fully trained to provide emotional and practical cancer support in a safe, responsible and kind way. Our cancer nurses can put you in touch with a volunteer.
- Go to your local cancer support centre. For more information, see page 130.

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 Support Line 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 ***Understanding the emotional effects of cancer***. This booklet can help you find ways to talk about your cancer and to ask for the help and support you need.

What tests will I have?

- After a diagnosis of metastatic prostate cancer, you may have a PSA test, biopsy, bone scan, X-rays, MRI, CT scan, PET scan or PSMA CT/PET scan.
- The tests will tell your medical team more about your cancer and help them to decide on the best treatment for you.

With metastatic cancer you may have tests to see 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 be detected in your blood. It 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 your cancer is responding to treatment.

Biopsy

A biopsy is where a sample of your prostate tissue is taken and examined under a microscope. In some cases you may not need 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.

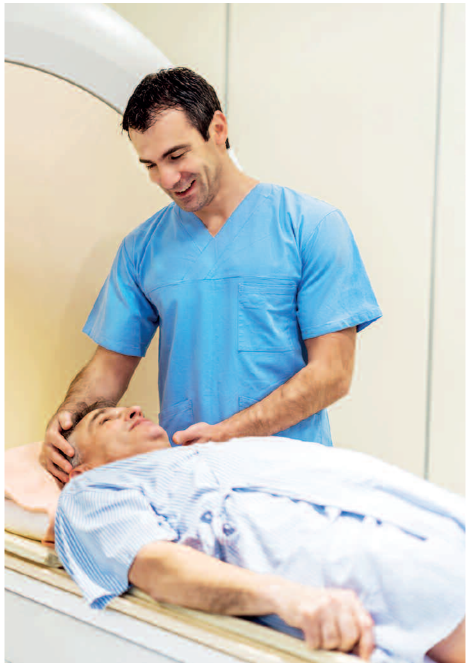
After the injection, you must wait for up to 3 hours. It's nice to have someone with you to keep you company if you're having this test, as it takes a while and involves a bit of waiting around. After the waiting period, a scan is taken of all the bones in your body. Abnormal bone takes up more radioactive 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. After a bone scan you may have an X-ray, MRI or PSMA PET scan to give your doctors more information.

X-ray tests

You may have bone X-rays if the bone scan shows up 'hot spots'. X-rays can check the health of your bones and if you are at risk of bone fractures. A chest X-ray may be done to check your general health.

MRI scan

This 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/headphones to wear. 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.

For most scans you will be alone in the treatment room, but the medical staff can still see you and hear you. If you need anything, just speak or raise your hand.

PET scan

A low dose of radiotracer (radioactive sugar) is injected into your arm. An hour or so later you will have a scan. The PET scan uses the radiotracer to highlight cancer cells in the body.

Before the scan, you may have to fast (not eat) and drink only plain unflavoured water for a few hours. You may also be asked to avoid strenuous exercise the day before and the morning of the scan.

During the scan, you will lie on a table that moves through a scanning ring. The scan usually lasts between 20 and 60 minutes.

You will be slightly radioactive after the PET scan, so you should not have close contact with pregnant women, babies or young children for a few hours after the scan.

PSMA scan

This test uses a radioactive dye to show up certain areas of the body. PSMA-PET or CT scans look for areas of the body where the PSMA protein is found. The PSMA protein is found on prostate cancer cells and can show the presence of prostate cancer cells with greater accuracy than CT and bone scans. Not every patient with prostate cancer will need a PSMA scan, but they may be used in certain situations. For example, they are often used when there is biochemical recurrence. This is when your PSA level starts to rise again after treatment.

Waiting for test results

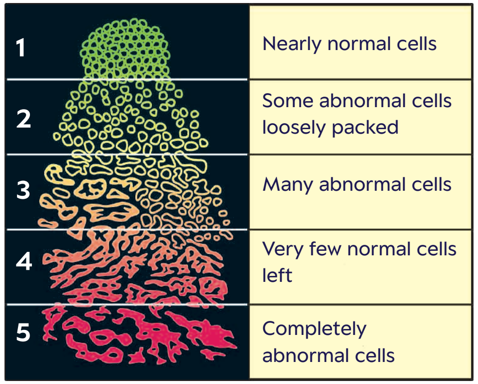
It usually takes a number of weeks for all your test results to come back. This can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre and speak to one of our cancer nurses. You can also email the nurses at supportline@irishcancer.ie

Grading metastatic prostate cancer

If you had a biopsy (tissue samples) taken as part of your diagnosis, the biopsy samples would have been sent to the laboratory where the histopathologist would look at them. They are graded based on the amount of abnormal cells that are seen using a number from 3 to 5.

What is the Gleason score?

The Gleason score is described using a number from 6 to 10. The two most common grades are added together to make the Gleason score. So if the most common grade in the sample is 3, and the second most common grade in the sample is 4, then your Gleason score will be 7 (3+4). However, if only one grade is found, then this grade is added to itself. So if only grade 4 is found, the Gleason score will be 8 (4+4).



Gleason score	Prognostic grade group
6 or less	1
7 (3 + 4)	2
7 (4 + 3)	3
8	4
9-10	5

Sometimes a prognostic grade group number from 1 to 5 is used with the Gleason score to describe the cancer. In metastatic prostate cancer the Gleason score is usually high and the prognostic grade group is 5.

Asking about your prognosis

Your prognosis includes information about how your cancer is likely to progress, including average survival times or life expectancy.

It's not always easy for doctors to answer a question about life expectancy. Everyone is different so what happens to you might be quite different from what the doctor expects.

Should I ask about my 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 by 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.

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. They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- Ask a friend or family member to go with you if you would like some support.
- Be careful with online information. It may be hard to understand or it may be incorrect. Also, it might not really apply to your situation or to your particular cancer type. Ask your doctor or specialist nurse for advice and recommended websites.
- 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 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 Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that may help you.

Treating metastatic prostate cancer

Treatment for metastatic prostate cancer

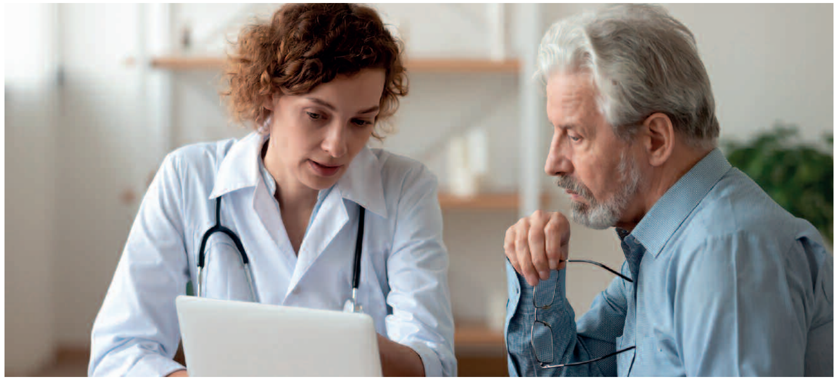
- Treatment for metastatic prostate cancer aims to slow its growth and relieve any symptoms.
- Hormone therapy is the main treatment for metastatic prostate cancer.
- Other treatments include chemotherapy, steroids, bone-strengthening drugs, radiotherapy and radioactive injections.

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 people, 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.



What treatments are available?

The main treatment for metastatic prostate cancer is hormone therapy (see page 47).

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

- Other hormone treatments
- Chemotherapy (page 58)
- Steroids (page 63)
- Bone-strengthening drugs (page 64)
- Targeted therapy drugs (page 65)
- Radiotherapy and radioactive injections (page 66)

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 will be planned based on your individual case.

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

- Where the cancer is in your body
- The results of your tests
- Your age
- Your previous cancer treatments and response to those
- 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 urologist, pathologist, specialists in hormone therapy or chemotherapy treatments (medical oncologists), radiotherapy (radiation oncologists, radiologists), 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

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 Support Line on 1800 200 700 or visit a Daffodil Centre and talk to one of our cancer nurses.

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

Your treatment plan

- **The treatment or treatments your doctors recommend for you are based on the latest research and international guidelines about the best ways to treat metastatic prostate cancer.**
- **You may notice that other people are not getting the same treatment as you. Their cancer may not be the same type or at the same stage as yours, so your treatment plan may be different.**
- **Talk to your doctor or nurse if you have any questions about your treatment plan.**

Other opinions

You might find it reassuring to have another medical opinion to help you decide about your treatment. Your treating doctor or GP will refer you to another specialist for a second 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.

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.

Urologist: A surgeon who specialises in diseases of the male reproductive system and urinary system.

Advanced nurse practitioner (ANP): ANPs give expert information and support and are specially trained to carry out tests and help to review your treatment.

Oncology liaison nurse/clinical nurse specialist: A specially trained nurse who works in a cancer care unit. They give 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 your social issues and emotional and practical needs. They can also give advice on benefits and financial matters and on supports and services available to you.

GP (family doctor): While your medical team will be your main point of contact, your GP is still very much a part of your care and can be a great support to you.

Pharmacists: Pharmacists in hospital and in your local pharmacy dispense chemotherapy and other cancer drugs. They can give advice on cancer drugs, such as how to take them, side-effects, and possible interactions between your cancer drugs and other medicines, food and drink, and supplements such as herbs and vitamins.

Palliative care team: This team is experienced in managing pain and other physical symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the symptom management team. A specialist palliative care service is available in most hospitals. Palliative care teams also work in the community.

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

> “Remember staff are friendly and will inform you and support you.”

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.

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.

Types of treatment

Hormone therapy

- Prostate cancer cells use your body's own hormone testosterone to grow. Hormone therapy reduces the amount of the hormone testosterone in your body to help slow the growth of the cancer.
- Hormone therapy is the main treatment for metastatic prostate cancer.
- It may cause short-term or long-term side-effects, including changes in sexual function, hot flushes, weight gain, fatigue, mood changes, breast swelling and tenderness, osteoporosis and effects on the heart or heart vessels.

Hormone therapy is the main treatment for metastatic prostate cancer. Most people with metastatic prostate cancer will stay on hormone therapy. Hormone therapy can be used alone or with other treatments.

Hormone therapy aims to control the cancer and improve any symptoms such as poor urine flow or bone pain. Hormone therapy can work well for many years as a treatment for metastatic cancer.

How does hormone therapy work?

Hormone therapy is a treatment designed to stop the cancer cells getting the testosterone they need to grow.

Testosterone is a hormone. Hormones control how normal cells grow and work. Testosterone is produced mainly in the testes. Small amounts are also produced in the adrenal gland.

Hormone therapy can slow the growth of metastatic prostate cancer 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

All hormone therapies aim to prevent male hormones from helping the cancer to grow, but the different drugs work in different ways. There are 2 main types:

- Injections or tablets to help stop your body making testosterone, named androgen deprivation therapy (ADT).
- Hormonal tablets called androgen receptor pathway inhibitors. These stop testosterone being produced or block the effect of testosterone so it doesn't help the prostate cancer cells to grow.

Your doctor will decide which is best for you at different times in your treatment. This decision will be based on bone, CT and PSMA PET scans, any previous treatment you've had and any other medical problems you have.

Androgen deprivation therapy

Some drugs work by stopping male hormones being made in your testicles. These drugs are injected under your skin or into a muscle or given as an oral tablet. Examples include the injections goserelin (Zoladex®), leuprorelin (Prostap®), triptorelin (Decapeptyl®), leuprorelin acetate (Eligard®) and degarelix (Firmagon®) and the tablet relugolix (Orgovyx ®)

Starting hormone therapy injections: When you start this therapy, you may be asked to take anti-androgen tablets for a week or 2 before your first injection. This is because with some 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 may prescribe these tablets for some time before and after starting injection treatment to help prevent this problem.

How often will I have hormone therapy? 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. This might save you from having to make more trips to your GP to have injections. If you are on tablets, they are usually taken daily.

Androgen receptor pathway inhibitors

You may also be given newer drugs that also stop testosterone causing cell growth. These drugs are called androgen receptor pathway inhibitors and are given as tablets that you take at home. These drugs can block testosterone from entering prostate cancer cells. This prevents testosterone from helping the cancer cells to grow. For example, enzalutamide (Xtandi®), darolutamide (Nubeqa®) and apalutamide (Erleada®).

Other tablets help to stop the production of testosterone in your body. For example, abiraterone (Zytiga®). You may have to take a steroid tablet with some treatments. Your doctor will advise you on this.

Combinations of different hormone therapy drugs or hormone therapy with chemotherapy often control metastatic prostate cancer for many months or years.

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:

- Changes in sexual function
- Hot flushes
- Weight gain
- Fatigue
- Mood changes
- Breast swelling and tenderness
- Osteoporosis or bone thinning
- Increased risk of cardiovascular problems, such as heart disease or stroke

You might find that your testicles become smaller in size once you have been on hormone therapy injections for a while.

Changes in sexual function

Hormone therapy can affect your interest in sex, known as your libido and 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 93 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 Support Line on 1800 200 700 or visiting a Daffodil Centre. You can email the nurses at supportline@irishcancer.ie. Ask the nurses for a copy of our booklet, ***Understanding sex, sexuality and cancer*** or download it from **www.cancer.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 as there may be medication that can help to improve them.

Hints and tips: Hot flushes

- **Wear cotton or special wicking-fabric clothing.** Cotton absorbs moisture and wicking fabrics take moisture away from the body to keep you dry and comfortable.
- **Have layers of clothing and bedding so that you can remove or add layers** as your body temperature changes.
- **It may help to avoid certain foods and drinks** such as spicy foods, caffeine, alcohol and hot drinks – try and keep a note of any food or drink that makes your flushes worse so that you can avoid them.
- **Have cool drinks, avoid warm areas, use an electric fan.**
- **Use sprays or moist wipes,** to help lower your skin temperature.
- **Avoid hot baths or showers**, as they may trigger a hot flush.

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. If you are troubled by fatigue, talk to your doctor so that they can rule out other causes of fatigue and adjust your medication, if necessary.

There is evidence that taking regular exercise improves tiredness in men on hormone therapy for prostate cancer. 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 89.

Psychological effects

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. Exercise may also be beneficial. You can also discuss your concerns with your doctor or nurse. They can refer you to a professional counsellor or doctor if indicated. See page 104 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 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. Your doctor may advise bone strengthening medications. See page 87 for more bone health tips or get in touch with the Irish Osteoporosis Society **www.irishosteoporosis.ie**.

Increased risk of cardiovascular problems

Research suggests that longer term use of hormone therapy may increase the risk of heart problems. Managing other risk factors for your heart health are important while on treatment for prostate cancer. This includes looking after your general health such as having your blood pressure and cholesterol checked. Being physically active and trying to keep a healthy weight may help to protect your heart health. Ask your doctor about this and about any checks you should have.

More information

For more information about hormone therapy and how to manage side-effects, talk to our cancer nurses. Call our Support Line on 1800 200 700 or visit a Daffodil Centre. The nurses can also put you in touch with a trained Peer Support volunteer, who has had a prostate cancer diagnosis and understands what you're going through. There's also information and videos about hormone therapy for prostate cancer 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, alongside how you are feeling physically. 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. This is called becoming castrate resistant or hormone refractory. If this happens, your doctor will discuss which treatment options are open to you. For example, they may give you extra treatments or try a new type of treatment.

Chemotherapy

- Chemotherapy is a treatment using drugs to kill cancer cells.
- Some common side-effects are fatigue, nausea and vomiting, sore mouth and nerve changes.
- Most side-effects can be well controlled with medication.

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 a week or once every 2 or 3 weeks, usually 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). You may have a central venous access device fitted. This is a long thin tube (line) which goes directly into a vein and stays in place until your treatment is over. This saves you having repeated injections. There are different types of central venous access devices, such as ports, central lines and PICC lines. Your doctor will decide on what is best for you. Usually your chemotherapy will be given in the chemotherapy day unit.

You may get also chemotherapy as part of a clinical trial. See page 73.

Understanding your drug treatment

It's important that you understand the drugs you have been given. Ask your doctor or specialist nurse for more information about your drug treatment and any possible side-effects. They should give you a printed sheet to take home with you.

If you know the name of your drug, you can visit the Health Products Regulatory Authority's website at **www.hpra.ie** for information about the drug and possible side-effects.

If you have any questions or need any more information, you can speak to our cancer nurses by calling our Support Line on 1800 200 700.

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. You may also be given growth factors to help your white blood cells recover after your chemotherapy.

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.

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, as they can reduce the number of white blood cells you have. White blood cells play an important role in fighting infection. 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. If you have a temperature, it is important not to take any medicine to lower your temperature, such as paracetamol, without getting permission from your hospital or doctor.

Other signs of infection include having a cough or pain passing urine. Again, it is important to let your doctor know if you have any of these symptoms.

Fatigue

Fatigue is very common. It can make you feel tired and weak. For more information see page 89.

Nausea and vomiting

Chemotherapy can cause nausea (feeling sick) and vomiting (getting 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 or sore mouth. There are many mouthwashes and medications to help, which your doctor can prescribe for you.

Constipation and diarrhoea

Chemotherapy can cause constipation. This is when you don’t have a bowel movement (poo) often enough. It can also cause diarrhoea. This is when you have frequent loose or watery bowel movements. Your doctor can give you medication to help, if needed.

Hair loss (alopecia)

Some chemotherapy drugs can cause hair loss from all over your body. This can be very distressing. It can affect your confidence and make you feel self-conscious about your cancer. 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 or liver function

Some drugs can irritate or damage kidney and liver cells. Decreased urination, swelling of the hands or feet (oedema) or headaches are some of the signs of kidney damage. Yellowing of the skin or eyes (jaundice) can be a sign of liver problems. Tell your doctor if you have these or any other changes in your body. Blood tests will check your kidney and liver function regularly.

Peripheral neuropathy

Some drugs can affect your nerve endings. Tell your doctor if you have numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy.

Blood clots

Chemotherapy and having cancer can both increase your risk of developing blood clots. A blood clot can cause pain, redness and swelling in your leg, or breathlessness and chest pain. Contact your hospital immediately if you have any of these symptoms, as blood clots can be serious. Usually they are treated with medication to thin your blood.

For more information on the side-effects of chemotherapy or a copy of the booklet ***Understanding chemotherapy and other cancer drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also attend one of our chemotherapy education sessions, online or in person, before you start your treatment. These can help you to understand more about chemotherapy and how it's given and to learn about managing side-effects. See page 125 for more about patient education.

> “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 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 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 91).

> 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.

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. You should 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 87 or visit our website, **www.cancer.ie**. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Targeted therapy drugs

A combination of hormone therapy and chemotherapy usually controls metastatic cancer. However, if your cancer has started to regrow your doctor may recommend a targeted therapy.

Targeted therapy refers to drugs that are designed to specifically attack cancer cells without harming normal cells. They aim to affect the way that cancer cells grow, divide, repair themselves or interact with other cells.

Medicines used include olaparib and niraparib, which are PARP inhibitors. Their aim is to block the pathway that prostate cancer cells use, which often leads to the death of these cells.

Some of the side effects of PARP inhibitors include:

- Nausea and vomiting
- Fatigue
- Shortness of breath
- Skin rash
- A low number of red blood cells (anaemia)
- Weakened immune system (neutropenia)

For more information on the side-effects of targeted therapy or a copy of our booklet ***Understanding chemotherapy and other cancer drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also view our targeted therapies patient education videos before you start your treatment to help you understand more about what the treatment is, how it's given, and receive advice on managing side-effects. Visit **www.cancer.ie** to find out more about patient education.

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 and radioactive injections

- Radiotherapy uses high-energy rays to kill cancer cells.
- Side-effects depend on the area being treated. They include urinary problems, bowel problems, discomfort at back passage, skin changes and fatigue.
- Radioactive injections can help to relieve bone pain.

Radiotherapy for metastatic prostate cancer aims to control the cancer and relieve symptoms, such as pain. It may also be used to treat your prostate cancer if you have low volume disease. You can discuss with your doctor whether this would be appropriate for you. You can have external radiotherapy, where high-energy X-rays are aimed at the cancer, or you may benefit from radioactive injections (see page 71).

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.

The radiation oncologist 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 to be 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?

The amount of radiotherapy delivered depends on the site being treated and the reason for treatment. Usually you will only need a short course of radiotherapy. You may have a single dose or a dose divided into a few sessions. Radiotherapy to the prostate gland involves a longer course of treatment.

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.

Cut down on food and drinks with caffeine, like cola, tea, green tea, coffee and dark chocolate, as they may irritate your bladder.

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 they may continue in the long term for some people. 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: You may find your bowel movements change and your 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).

You may develop diarrhoea, which means passing watery bowel motions more than 3 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 people 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 from travelling if you have to travel long distances for treatment. Rest as much as you need to and continue to do the things you like. But you may have less energy than before treatment. Regular gentle exercise such as walking can help to improve tiredness. You may continue to work during treatment or you may take some time off. You may feel tired for some weeks or even months. Usually tiredness improves within a couple of months of finishing treatment. For more about fatigue see page 89.

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 Support Line 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**. We also have patient education videos detailing what radiotherapy is, how it is given and advice on possible side-effects. Visit **www.cancer.ie** to view the videos.

> 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. Flush the toilet a couple of times after passing urine as well. Be careful of any spills of urine or blood, but it is 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.

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects.

Patients with cancer are sometimes asked to take part in a clinical trial. This means that instead of the standard treatment you may get a new trial drug. Or you may be given existing treatments used in different ways. For example, you may be given a different dose of a drug or you may be given 2 treatments together.

Because the drugs are still in trial, you'll be very closely monitored and may have extra tests and appointments. Trials often investigate very specific features of a particular cancer or treatment. You may not be suitable for a trial, even if it is researching your particular cancer. Your doctor can advise you about this.

> "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."

More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial.

For 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 Support Line on 1800 200 700 or by dropping into a Daffodil Centre.

You can see a list of current cancer trials at **www.cancertrials.ie**

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.

Palliative care includes physical, psychosocial and spiritual care. 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 team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, chaplains and counsellor. Palliative care also offers emotional support and comfort to patients and their families.

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.

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. Palliative care teams work both in hospitals and in the community and sometimes visit patients at home.

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 palliative care web pages at **www.cancer.ie** or visit The Palliative Hub at **www.adultpalliativehub.com**

Managing side-effects and symptoms

If you have any side-effects or symptoms, tell your medical team so they can help and advise you.

Urinary problems

Possible urinary problems 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

Leaking urine

You might notice that you don't get much warning before you have the urge to pass urine and you may leak some urine before you get to the bathroom. This may be due to the cancer growing near the muscles which control the opening and closing of the bladder, causing them to weaken. 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.

A slow flow of urine/difficulty emptying your bladder fully

A slow flow of urine may be caused by a narrowing of your urethra (water pipe). If you have a slow flow of urine let your urologist know, so they can find the cause and see if you need treatment. Your doctor may give you tablets called alpha blockers to help. These can help to relax the muscle in the prostate and to reduce the narrowing of the water tube that runs through the centre of the prostate. Or you may need a short procedure to widen the tube to help you to pee more easily again.

Hints and tips: Managing urinary problems

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

- **Cut down on food and drinks with caffeine**, like cola, tea, green tea, coffee and dark chocolate, as they may irritate your bladder.
- **Drink 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.
- **If you find your need to pee is usually urgent, make sure you can reach the toilet easily and that your clothing can be easily undone.** For example, trousers with an elasticated waist.
- **Eat plenty of fibre to avoid constipation.** Constipation can put pressure on your bladder and make urinary problems worse.

- **Get some exercise, if you feel able to.** Your doctor can advise you about suitable exercises for you.
- **Go to the toilet at regular intervals.**
- **Have 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.
- **Keep the area clean and dry** to avoid skin irritation and to stay fresh. Use a mild soap and gently pat the area dry.
- **Plan ahead** – keep a bag with wipes and pads with you and make sure you know where the public toilets are if you're going out.
- **Bed protectors are available** if you're worried about leaking during the night.
- **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 Irish Cancer Society has a card that you can show at shops and other public places to ask for urgent access to a toilet. Get a toilet card from a Daffodil Centre or by calling our Support Line on 1800 200 700.

Incontinence pads

You may need to wear pads to absorb leaks for some weeks or months. You can get pads from your local pharmacy or online. If you have a medical card, your public health nurse may be able to get the pads for you.

Try a few different sizes and absorbencies until you get the right pad to suit you. Using a pad that absorbs more than you need can make your skin sore, so pick smaller sizes as your leakage reduces. Wear supportive underpants or special net pants to help keep pads in place.

Acute urinary retention

Occasionally, patients experience acute urinary retention. This means you cannot pass urine at all and cannot empty your bladder. 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 will need to go to the hospital emergency unit where they will fit you with a small, thin tube (catheter) to drain your bladder. The urine 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 thigh and 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 1½ 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 spasms 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.

Sometimes an operation is needed 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.

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. 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. They can organise tests to find the cause of the pain.

How is bone pain managed?

Painkillers

Not everyone has 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 relieve 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 need stronger painkillers such as codeine or morphine.

Your GP or oncology team 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 64 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. 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 66 for more about radiotherapy.

Your doctor and radiation therapist will explain what is involved and any likely side-effects. Often people can reduce their dose of painkillers afterwards, but you can still take them if needed.

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 71 for more about this treatment.

Complementary therapies

Some complementary therapies that involve relaxation may help to ease aches and pains and make you feel more comfortable (see page 99). You should always discuss any complementary therapies you're considering with your doctor to check they are safe for you.

Talk to your local cancer support centre to see what services are available. Call our Support Line on 1800 200 700 or visit a Daffodil Centre for advice or for a copy of our booklet, ***Understanding cancer and complementary therapies.***

Hints and tips: 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.
- **Take your painkillers as advised,** even if you don't have pain at a particular time. They will help to keep your pain under control.
- **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 pain not controlled by your usual medication.
- **If you are constipated from the painkillers, take a laxative every day, following your doctor's advice.** 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.

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 64.

Hints and tips: Looking after your 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. It is important to check with your doctor before starting an exercise programme to make sure it is safe and suitable for you, especially if you have cancer in your bones.
- **Eat well and get enough calcium and vitamin D:** A balanced diet with plenty of calcium and vitamin D is vital for healthy bones. Cheese, foods with added vitamins and minerals like fortified cereal and milk, and oily fish such as sardines, pilchards and salmon are good sources. Green vegetables like spinach and kale and dairy products like yoghurt are also good sources of calcium. Don't take 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 cola. Don't 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. They can refer you to an occupational therapist (OT) who can assess your needs and organise equipment like walking aids and grab bars 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 are tips on how to prevent falls in the bone health section of our website, **www.cancer.ie**

Constipation

Constipation is when you pass bowel motions (poo) less often or find it painful or hard to pass a bowel motion. 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.

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.

Fatigue

Fatigue means feeling extremely tired most or all of the time. You may also find it hard to concentrate or make decisions.

Fatigue when you have cancer is very common and 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.

Hints and tips: Fatigue

- **Ask your doctor about exercising.** Being active can help with fatigue.
- **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. Counselling may help too (see page 104).
- **If you are not sleeping well, try relaxation techniques** and avoid stimulants like caffeine and alcohol before bedtime.
- **Try complementary therapies** like meditation or acupuncture, if your doctor says they're safe for you.

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. The prostate may obstruct your bladder or stop your kidneys from draining properly, or the cancer may spread to lymph nodes near your kidneys. If your kidneys aren't working properly, it can 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 urgently 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 your local emergency department straight away.

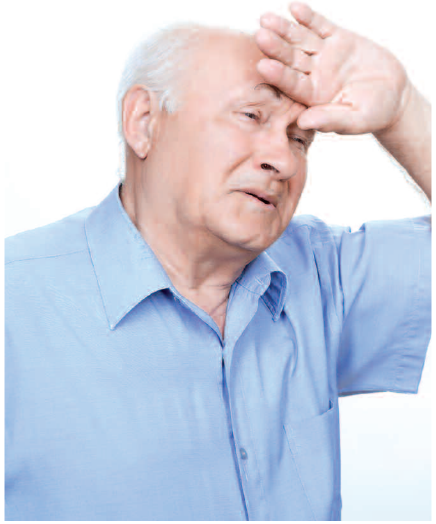
Hypercalcaemia (too much calcium in your blood)

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 64).

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. Your doctor will advise you on how to manage anaemia, if blood tests show your red cell count is low.



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. Tell your doctor if you notice any swelling or tightness in your leg. It's easier to manage lymphoedema when it's treated early.

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 Support Line on 1800 200 700 or visit a Daffodil Centre. You can also email us at supportline@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. 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 101 for more about prostate cancer and your emotions.

It's normal to 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 or specialist nurse 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. It's quite common for tablets not to work on their own. You may need another treatment or a combination of treatments.
- **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. The ring should be removed after 30 minutes to allow blood circulation back into the penis. It can take some practice to get the technique right, but you can use the pump as often as you like.
- **Urethral pellets and creams:** 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.
- **Penile implants:** This is an operation where tubes, a reservoir (container) and a pump are put inside your body. The implant means you can press on the pump to make your penis fill with fluid and get hard.

Most people and their partners are very satisfied with these devices. Possible side-effects include infection and pain.

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 or your specialist nurse 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 your diagnosis 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 people are troubled by feeling 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. Try to tell your partner how you feel and find out how your partner feels too. This can help to make sure neither of you feels rejected by any change in your physical relationship. 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. Our Support Line 1800 200 700 and our Daffodil Centres can help you to find supportive information and accredited therapists if you would like to talk to someone. Therapy can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. Try not to be embarrassed. Many people 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 Support Line 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 supportline@irishcancer.ie You can also ask for a copy of our booklet, ***Understanding sex, sexuality and cancer***, or download it from **www.cancer.ie**

Will treatment affect my fertility?

Most treatments are likely to cause infertility. Talk to your doctor or nurse specialist about this. If you wish to look at fertility options, it is important to highlight this before treatment starts.

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

Taking care of your health

Many people want to follow a healthy lifestyle 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:

- Being active
- Eating healthy foods
- Staying at a healthy weight
- Not smoking
- Protecting yourself from the sun
- Looking after your bone health
- Having any vaccinations recommended for you

Activity

Being as active as you can has many benefits. It can:

- Give you more energy
- Improve fatigue
- Boost your mood
- Reduce stress
- Keep you fit
- Improve bone health
- Improve the side-effects of hormone therapy

Ask your doctor or nurse about the type and amount of exercise that would be best for you and safe for you. Some cancer support centres have exercise classes or groups. See page 130 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 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 types 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 you to adapt your meals to the changes.

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 Support Line on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of our booklet ***Understanding diet and cancer***, or download it at **www.cancer.ie**

Cancer and complementary therapies

Complementary therapies are treatments and activities that you can have along with your standard medical treatment to try and feel better. For example, massage, yoga and aromatherapy.

Complementary therapies can't treat or cure cancer, but some people say that complementary therapies help them to feel more relaxed and better able to cope with their cancer and the side-effects of treatment.

It's very important to talk to your doctor if you're thinking of using complementary therapies. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your cancer diagnosis.

Integrative care

Integrative care means combining (integrating) your standard cancer treatment with complementary therapies to try to feel as well as possible and to cope better with your cancer.

What's the difference between complementary and alternative therapies?

Complementary therapies are used **together with** standard medical treatment.

Alternative therapies are used **instead of** standard medical care.

Modern medical treatments are very effective at treating cancer and keeping it under control. An unproven alternative could harm your health, or you might miss out on a treatment that could really help you.

Coping and emotions

How can I cope with my feelings?

There are many different reactions to getting a cancer diagnosis. There is no right or wrong way to feel and there is no set time to have any particular emotion.

You may find it hard to come to terms with your diagnosis, you may blame yourself, resent other people who are healthy or feel very anxious or depressed.

Feelings like sadness, fear, grief, hopelessness, anxiety and anger can happen at different times, sometimes months or years after treatment.

A cancer diagnosis can be hard on you – mentally and emotionally. Give yourself time and space to deal with your emotions and get help if you need it.

A helpful booklet that discusses in detail how you may be feeling is called ***Understanding the emotional effects of cancer***. Call our Support Line on 1800 200 700 or visit a Daffodil Centre for a free copy.

Anxiety and depression

If you feel that anxiety or low moods are getting the better of you, or you're finding it hard to cope, it's important to get help. Try to talk with someone you know who is a good listener, join a support group or tell your GP. Medical social workers can also offer support to you and your family.

Your doctor may also suggest medication to help with anxiety or depression. Often a short course of medication 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

If you're feeling very distressed or finding it hard to cope, 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.

The Irish Cancer Society funds professional one-to-one counselling remotely or in person at many local cancer support centres. To find out more about counselling, call our Support Line on Freephone 1800 200 700, email the nurses at supportline@irishcancer.ie or visit a Daffodil Centre.

> "Talking about cancer made it feel less awful and helped ease my fears. I learned to cope and understand myself better."

Ways to get emotional support

Find out about cancer support services in your area: Most 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 130 for more about cancer support services.

Join a support or educational group: You might find it reassuring to talk to other people who are in a similar situation and facing similar challenges. Many cancer support centres have activities and groups where you can meet other people affected by cancer.

Ask about psycho-oncology services at the hospital: Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your healthcare team can refer you to psycho-oncology support services if they're available at your hospital.

Talk things through: It can be a great weight off your mind to share your feelings and worries. 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 Support Line on 1800 200 700 or drop into a Daffodil Centre.

Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. Peer support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way. To be referred to a Peer Support volunteer, call Freephone 1800 200 700 or visit a Daffodil Centre.

> “I am very happy and content…even though I have to live with this.”

Positive feelings

In time, some people say they can find positive things in their cancer experience. They say that cancer brought them closer to the people around them or made them appreciate what's important in life. Or it opened up new experiences and relationships. Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.

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 ***Understanding the emotional effects of cancer*** can help you to find ways to talk about your cancer and to ask for the help and support you need.

Changing relationships

You may feel that people are treating you differently. Some people may withdraw and not contact you as much because they are afraid of doing or saying the wrong thing. Others may not understand that you feel too unwell to do certain things or go out. Try to talk openly to your friends and family if there are any misunderstandings or problems. Tell them how you feel. If you find it hard, ask another family member or friend to talk to them.

Further information and support

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. The booklet is available free of charge from Daffodil Centres or by calling our Support Line on 1800 200 700. It's also available on our website **www.cancer.ie**

Planning ahead

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.
- Sorting financial affairs.

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**

Supporting someone with cancer

How you can help

Finding out someone you love has cancer and trying to care for them can be difficult. You might be unsure about how best to support them, practically or emotionally. You might also be struggling with your own feelings and responsibilities.

Here are some things that can help to make life a little easier:

Learn about cancer

Try to go to hospital visits and also read any information from the hospital so you can understand your loved one’s illness and treatment, how it might affect them, physically and emotionally, and how you can best support them. Visit our website **www.cancer.ie** or call our Support Line for free copies of our cancer information booklets.

Share worries

If you are feeling anxious or overwhelmed, share your worries with someone else. Call our Support Line on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence.

Be kind to yourself

Your health and happiness matter too. Make some time for yourself, stay in touch with your friends and don't be afraid to let other people help with the caring.

Try counselling

You might find it helpful to talk to a counsellor. The Irish Cancer Society funds professional one-to-one counselling for friends and family members remotely and through many local cancer support centres. Talk to your GP or see page 104.

Find out about support for carers

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

> "The emotional support I got made a huge difference to me."

Support for you

Our cancer nurses are there to support you. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information.

Our booklet, ***Caring for someone with cancer***, has lots of information on:

- **Getting organised**
- **Managing and giving medications**
- **Giving personal care**
- **Practical and money matters**
- **Relationships with other people**
- **Looking after yourself**
- **Life after caring**

Free copies are available from our Daffodil Centres and our Support Line or download it from our website **www.cancer.ie**

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.

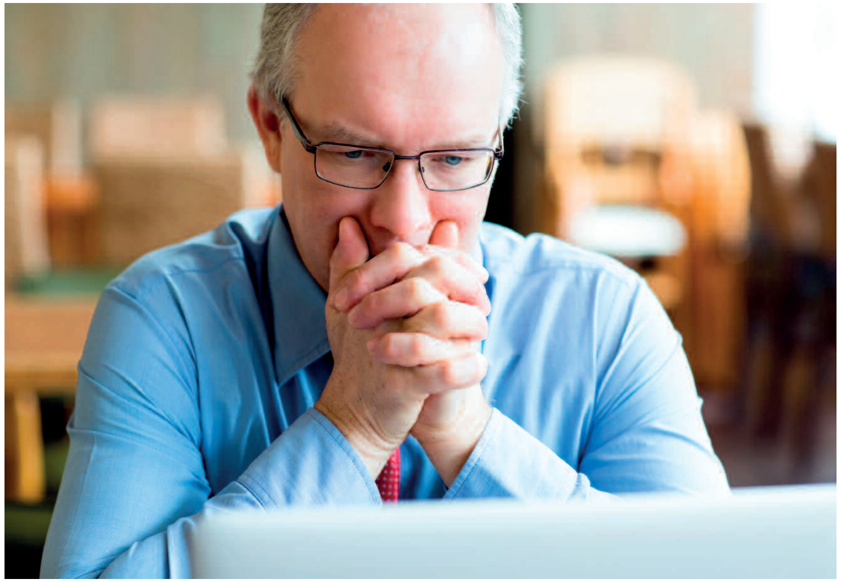
If you want advice on how to support a loved one with cancer, call our Support Line on 1800 200 700. Ask for a copy of our booklet, ***Caring for someone with cancer.*** The booklet gives advice on talking to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative. You can pick up a copy at your local Daffodil Centre or download it from our website.

Support resources

Money matters

- If you have cancer you may not be able to work for a time. You may also have extra expenses.
- You may have to pay for some of your cancer treatment.
- You might be entitled to certain social welfare payments.
- There are services to help you if you're finding it hard to manage.

A diagnosis of cancer often means that you will have extra expenses, such as 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 your illness if you are worried about money.



Irish Cancer Society Welfare and Supports Team

We provide appropriate supports and advice for people living with cancer. This includes:

- **Understanding your welfare entitlements**
- **Advice on accessing extra childcare**
- **Telling your boss about your diagnosis/returning to work**
- **Housing and homelessness issues**

We can tell you about the public services, community supports and legal entitlements that might help you and your family. We can also act as advocates for patients and their families who may need extra support after a diagnosis. This might include having an Irish Cancer Society Welfare Officer present when discussing your diagnosis with your employer or at meetings with your financial provider to help them understand your diagnosis.

To be referred, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre. Our nurses will chat with you and confirm if a discussion with one of our Welfare Officers or other supports might be of help.

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
- Medical aids and equipment (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. If you are over 70, you can get a free GP visit card.

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 don't have a medical card you will have to pay some of the cost of your care and medication.

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 to check you're covered.

Benefits and allowances

There are benefits 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: 0818 074 000
- Department of Employment Affairs and Social Protection – Tel: 0818 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 money problems

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 0818 072 000 for information.

If you are finding it hard to cope financially, contact the 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 127 for more details of our Transport Service and the Travel2Care fund.

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

Money and finances

Go to **www.cancer.ie** and see our **Welfare and support** page for information on:

- 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

Our website has lots of information on government supports for people who are unwell and their carers. Our Welfare and Supports Team may also be able to help (see page 120).

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:

- Support Line
- Daffodil Centres
- Telephone Interpreting Service
- Peer Support
- Patient Education
- Counselling
- Support in your area
- Transport Service
- Night Nursing
- Publications and website information
- Welfare and Supports Team (see page 120)

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information for anyone affected by cancer. Our Support Line is open Monday to Friday, 9am-5pm.

The Support Line service also offers video calls for those who want a face-to-face chat with one of our cancer nurses. From the comfort of your own home, you can meet a cancer nurse online and receive confidential advice, support and information on any aspect of cancer.

Our cancer nurses are available Monday to Friday to take video calls on the Microsoft Teams platform. To avail of this service, please go to **https://www.cancer.ie/Support-Line-Video-Form**

You can also email us at any time on supportline@irishcancer.ie

Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide face-to-face advice, support and information to anyone affected by cancer. The service is free and confidential.

This is a walk-in service; you do not need an appointment. For opening hours and contact details of your nearest Daffodil Centre, go to **www.cancer.ie** and search 'Daffodil Centres'.

Who can use the Daffodil Centres?

Daffodil Centres are open to everyone. Just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- Chemotherapy group education sessions
- Emotional support
- Practical entitlements and services
- Living with and beyond cancer
- End-of-life services
- Lifestyle and cancer prevention
- Local cancer support groups and centres

Telephone Interpreting Service

We make every effort to ensure that you can speak to our Support Line and Daffodil Centre nurses in your own language through our Telephone Interpreting Service.

If you would like to speak to us using the Telephone Interpreting Service, call our Support Line on Freephone 1800 200 700, Monday to Friday 9am-5pm, or contact your nearest Daffodil Centre.

Tell us in English the language you would like. You will be put on hold while we connect with an interpreter. You may be on hold for a few minutes. Don't worry, we will come back to you.

We will connect you to an interpreter. The interpreter will help you to speak to us in your own language.

Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way.

To be referred to a Peer Support volunteer, call Freephone 1800 200 700 or contact your nearest Daffodil Centre.

For more information on Peer Support, search 'peer support' at **www.cancer.ie**

Patient Education

At our free patient education workshops, our cancer nurses provide tailored information before and after cancer treatment.

The workshops take place in person, in one of our 13 Daffodil Centres nationwide, or online. To register for a place at one of our patient education workshops, call our Support Line on 1800 200 700, contact your nearest Daffodil Centre or email patienteducation@irishcancer.ie You can also learn about different treatments by watching our patient education videos at **www.cancer.ie**

Counselling

The Society funds professional one-to-one counselling for those who have been affected by a cancer diagnosis. Counselling is available for the person who has been diagnosed, family members and close friends. The services we provide are:

- Remote counselling nationwide, by telephone or video call.
- In-person counselling sessions in cancer support centres around the country.

For more information, call Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Support in your area

We work with local cancer support centres and the National Cancer Control Programme to ensure patients and their families have access to high-quality confidential support in a location that's convenient to them.

For more information about what's available near you, visit **www.cancer.ie/local-support**, contact your nearest Daffodil Centre or call our Support Line on 1800 200 700.

Transport Service

We provide patient travel and financial grants for patients in need who are in cancer treatment.

- Transport is available to patients having chemotherapy treatments in our partner hospitals, who are having difficulty getting to and from their local appointments.
- We have recently opened a pilot service for radiotherapy patients attending University Hospital Cork and the Bons Secours Hospital, Cork for treatment.
- Travel2Care is a fund for patients who are having difficulty getting to and from their diagnostic test appointments or cancer treatments. Patients can apply for the fund if they are travelling over 50km one way to a national designated cancer centre or approved satellite centre. Travel2Care is made available by the National Cancer Control Programme.

To access any of these services please contact your hospital healthcare professional, call Freephone 1800 200 700 or contact your nearest Daffodil Centre.

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 a unique service in Ireland, providing night-time palliative nursing care to patients, mostly between 11pm and 7am.

For more information, please contact the healthcare professional who is looking after your loved one.

> “We were really lost when we brought Mammy home from the hospital and the night nurse’s support was invaluable. She provided such practical and emotional support.”

> “Our night nurse was so caring and yet totally professional. We are so grateful to her for being there for Dad and for us.”

Publications and website information

We provide information on a range of topics including cancer types, treatments, side-effects and coping with cancer. Visit our website **www.cancer.ie** to see our full range of information and download copies. You can call our Support Line or visit your nearest Daffodil Centre for a free copy of any of our publications.

To find out more about the Irish Cancer Society’s services and programmes:

- **Visit us at www.cancer.ie**
- **Call our Support Line on Freephone 1800 200 700**
- **Email our Support Line at supportline@irishcancer.ie**
- **Contact your nearest Daffodil Centre**
- **Follow us on:**
  Facebook
  X
  Instagram
  LinkedIn

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, their partners, families and carers, during and after treatment, many of which are free. For example:

- Professional counselling (the Irish Cancer Society funds free one-to-one counselling through many local support services)
- Support groups, often led by professionals like social workers, counsellors, psychologists or cancer nurses
- Special exercise programmes
- 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 lymphoedema services, such as education, exercise, self-management 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 Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or go to **www.cancer.ie/local-support**

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 (pee) 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.

Hormone therapy

Date	Drug	Dose	Duration	Next due

Hormone therapy

Date	Drug	Dose	Duration	Next due

Hormone therapy

Date	Drug	Dose	Duration	Next due

Hormone therapy

Date	Drug	Dose	Duration	Next due

Notes/Questions

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Acknowledgments

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 would particularly like to 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.

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The following sources were used in the publication of this booklet:

- *National Cancer Strategy 2017-2026*, National Cancer Control Programme
- *Cancer in Ireland 1994-2020: Annual statistical report of the National Cancer Registry Ireland* (2022)
- *DeVita, Hellman, and Rosenberg's Cancer: Principles and Practice of Oncology.* R Govindan (ed), 12th edn. Lippincott Williams & Wilkins, 2023
- Prostate Cancer – CLASSIFICATION AND STAGING SYSTEMS – Uroweb Prostate Cancer

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Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team! Visit **www.cancer.ie** if you want to get involved.

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 Peer 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

Did you like this booklet?

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

Our cancer nurses are here for you:

- Support Line Freephone **1800 200 700**
- Email **supportline@irishcancer.ie**
- Contact your nearest Daffodil Centre

Irish Cancer Society

www.cancer.ie