Irish Cancer Society

Understanding

Testicular cancer

Caring for people with cancer

Understanding

Testicular cancer

This booklet has information on:

- Treatment for testicular cancer
- Side-effects and how to manage them
- Coping with the emotional side of cancer
- Financial and practical matters

Useful numbers

Specialist nurse

Urologist

Medical oncologist

Radiation oncologist

Radiation therapist

Emergency

Family doctor (GP)

Medical social worker

Hospital records number (MRN)

Contents

Fast facts

Can my cancer be treated? Page 29

Yes. Testicular cancer can be treated and, in most cases, cured.

What kind of treatment will I have? Page 43

In most cases, the testicle is removed with the cancer. Often you will have surgery straight away – maybe only a day or 2 after first going to hospital. Most people won't need any other treatment. For certain types of testicular cancer or if the cancer has spread, you may also have chemotherapy, further surgery or radiotherapy.

Will I get side-effects? Page 43

If you have surgery, your scrotum will feel different, as the testicle inside will no longer be there. You can have a false testicle put in so that it looks and feels more normal. Other treatments like chemotherapy and radiotherapy can cause side-effects, but they usually go away soon after treatment has ended. You can read about the different treatments to find out about the possible side-effects.

Will treatment affect my sex life or fertility? Page 73

Most treatments for testicular cancer shouldn't affect your sex life too much. You should still be able to have a child after surgery if you have one healthy testicle. Some other treatments may have an effect on your fertility. Speak to your consultant or nurse specialist if you have any concerns about your future fertility.

Clinical trials Page 69

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 115

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**

See page 115 for more about our services.

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.

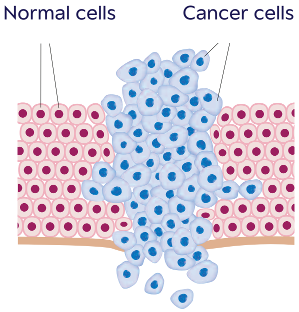
You should always talk to your own medical team about your care. They know your medical history and your individual circumstances. We cannot give advice about the best treatment for you.

We use gender-inclusive language in our booklets. 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

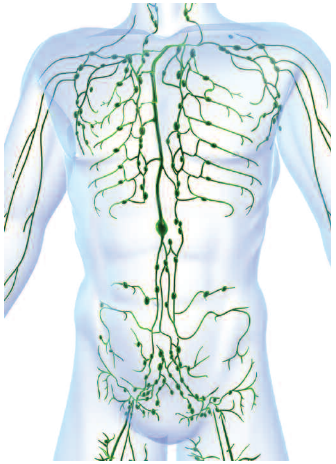
About testicular cancer

What is cancer?



- **Cancer is a disease of the body's cells**
  Cancer cells are abnormal cells that grow without control. They can form a lump (tumour).
- **Cancers are named after the organ or cell where the cancer starts**
  Testicular cancer starts in cells in the testicles (testes).
- **Cancers sometimes spread**
  If a tumour is cancerous (malignant), a cell or group of cells can be carried by your blood or lymph fluid to another part of your body, where it can form a new (secondary) tumour. This is called metastasis.

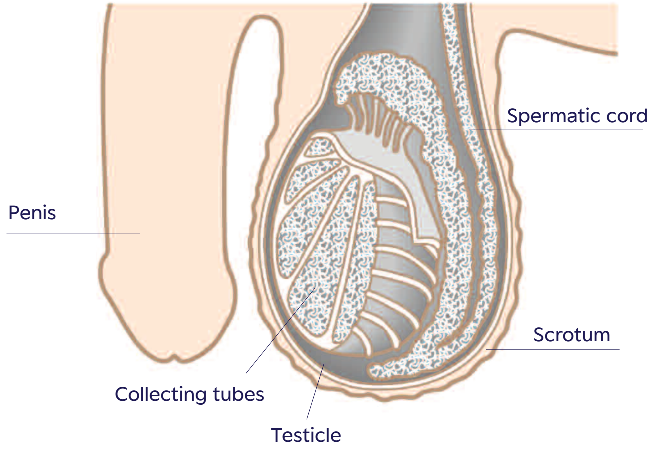
What is the lymphatic system?



- The lymphatic system is part of our immune system, which protects us from infection and disease and removes extra fluid and waste from the body's tissues.
- It is made up of lymph nodes connected by tiny tubes called lymph vessels.
- Lymph nodes are found mainly in the neck, armpit, groin, chest and tummy.
- If cancer cells spread into lymph nodes or cancer starts in the lymph nodes, they can become swollen.

What are the testicles?

The testicles (also known as the testes) are two small, egg-shaped organs found below your penis in a pouch of skin called the scrotum. They are part of the male reproductive system. Once you reach the age of puberty the testicles make sperm. The testicles lie outside your body because they need to be at a lower temperature than the body to make sperm. Sperm is needed to fertilise a female egg after sex, which may grow into a baby. The testes also make the hormone testosterone. This hormone is responsible for qualities such as a deep voice, facial hair and strong muscles. It also plays a role in your sex drive and your ability to have an erection.



What is testicular cancer?

Testicular cancer is when normal cells in the testicles change and grow into cancer. They often begin in the germ cells of the testicles, which are the cells that make sperm. The cancer can affect how the testicles work normally. Sometimes testicular cancer cells spread to lymph nodes at the back of the abdomen, the chest or neck.

What are the types of testicular cancer?

There are different types of testicular cancer. Your doctor will be able to tell you which type you have from how your cells look under a microscope. Knowing which type of testicular cancer you have will help your doctor to decide which type of treatment and aftercare you need.

Germ cell tumours

Most testicular cancers are germ cell tumours. Germ cells are cells that make sperm. There are two types of germ cell tumours: seminomas and non-seminomas.

- **Seminomas:** These usually develop between the ages of 30 and 50. They tend to grow slowly and respond very well to treatment. People with seminoma are at lower risk of cancer having spread at the time of diagnosis.
- **Non-seminomas:** These tend to develop earlier in life than seminomas. They are most common in people aged 20-35. Non-seminomas can include cells called teratoma, embryonal, yolk sac and choriocarcinoma.

  People with non-seminoma tumours are more likely to need additional treatment after surgery (see page 45 for information on surgery). They are still highly curable in most cases, even if they have spread.

A tumour can include both seminoma and non-seminoma cells. They are called mixed germ-cell tumours. They tend to grow and spread faster.

How common is testicular cancer?

Testicular cancer is quite a rare cancer. It usually affects young or middle-aged men. It is the most common cancer in young men aged between 15 and 34 years. Each year, about 170 men are diagnosed in Ireland. Testicular cancer is very treatable and is nearly always curable.

What caused my cancer?

We don't know exactly what causes many cancers, but there are things that can increase your risk of getting cancer. If you want to know more about why cancer happens or to learn about risk factors for testicular cancer, see our website **www.cancer.ie** or talk to a cancer nurse – call our Support Line or visit a Daffodil Centre.

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 – remember, 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 medications. 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 any 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, if you are not fasting
- Your phone and your phone number
- 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
- Ensure you are 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

What is testicular cancer?

What type of testicular cancer do I have?

What stage is my cancer at?

What treatment do I need?

Are there other treatment options? Why is this one best for me?

How successful is this treatment for my cancer?

How long will my treatment take?

Would I be suitable for a clinical trial?

Is there anything I can do to help myself during treatment?

What side-effects or after-effects will I have?

What can be done about side-effects?

How soon after treatment can I have sex?

Will I be able to have children?

Do I need to use contraception during my treatment?

How often will I need check-ups?

Why do I need to attend for regular blood tests?

What if the cancer comes back?

Diagnosis and tests

What happens after diagnosis?

- Usually you will have your testicle removed if testicular cancer is suspected or diagnosed.
- The testicle will be tested for cancer in the laboratory once it is removed.
- A CT scan can help to show if the cancer has spread.

Removing the testicle (orchidectomy)

If testicular cancer is suspected, your testicle will usually be removed. When the lump has been removed it is examined under a microscope to confirm the diagnosis. It is not usually possible to diagnose testicular cancer by taking a tissue sample (biopsy) without removing the testicle. It's safest just to remove the whole testicle. The operation to remove the testicle is called an orchidectomy. See page 31 for more details.

CT scan

This is a special type of X-ray that gives a detailed picture of the tissues inside your body. A CT scan of your chest, abdomen and pelvis will be done to check if there are any enlarged lymph nodes which may be a sign that your cancer has spread. This may be done before or just after an operation to remove the affected testicle.

Your doctor or nurse will tell you how to prepare for the scan. You may be asked not to eat (fast) or drink for a time before your CT scan. You may also be given a special drink and an injection to help show up parts of your body on the scan. This can make you feel hot all over for a few minutes. During the scan you will lie on a table which passes through a large doughnut-shaped machine. The scan is painless. You'll probably be able to go home as soon as the scan is over.

Waiting for test results

It usually takes around 2 weeks for the test results to come back. Some tests can take longer. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

Being diagnosed with testicular cancer

Even though testicular cancer can usually be cured, hearing that you have cancer can still be a huge shock. You may be feeling:

- **Upset** and overwhelmed by your emotions
- **Confused** by all the information being given to you
- **Worried** about what will happen next
- **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 liaison (oncology) nurse or 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.
- Talk to other people affected by cancer. You could join an online community.
- Go to your local cancer support centre. For more information, see page 122.

Telling people about your diagnosis

Telling people about your diagnosis can help you to get support from friends and family. But you may feel you don't want to tell people straight away. You may be unsure how to break the news. You may also worry about how other people will react. For example, they may fuss over you or be upset.

If you would like to talk things over with a cancer nurse, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a copy of our booklet ***Understanding the emotional effects of cancer***. It can help you find ways to talk about your cancer and to ask for the help and support you need. This booklet is available on our website **www.cancer.ie**

What are the stages of testicular cancer?

- Staging means finding out if the cancer has spread to other parts of your body.
- There are 3 stages of testicular cancer.
- Treatment will vary depending on the stage and type of cancer.

Staging means finding out if the cancer has spread to other parts of your body, such as your lymph nodes or lungs. Staging is very important as it allows your doctor to decide the best treatment for you.

There are different ways to describe testicular cancer stages. The main way to stage testicular cancer is the stage 1, 2 or 3 system. There is no stage 4 with testicular cancer. Some doctors may use other systems, such as the TNM system.

The stage 1, 2 or 3 system

Stage 1 (I): This means the tumour is found only in the testicle. It has not spread and no lymph nodes are involved. Tumour markers are normal or only slightly raised. (Tumour markers are chemicals or proteins found in the blood. While not everyone with testicular cancer will have raised tumour markers, they can help to diagnose testicular cancer and will be monitored during and after treatment.)

Stage 1S means markers are raised after surgery.

Stage 2 (II): Here the cancer has spread outside the testes to the lymph nodes in the abdomen (tummy). The size of the nodes can vary:

- Stage 2a nodes are less than 2cm.
- Stage 2b nodes are 2-5cm.
- Stage 2c nodes are larger than 5cm.

Stage 3 (III): Here the cancer has spread to other organs such as the lungs, liver, bones or brain. This is known as metastasis.

- Stage 3a means the cancer has spread to distant lymph nodes or to your lungs. Your blood marker level may be normal (S0) or slightly raised (S1).
- Stage 3b means the cancer has spread to nearby lymph nodes or lungs and you have a moderately high marker level (S2).
- Stage 3c can mean that you have very high tumour markers (S3), or that your cancer has spread to another organ, such as the liver or brain.

TNM staging system

The TNM staging system looks at the size of the tumour (T), if the cancer has spread to your lymph nodes (N), and if the cancer has spread to other parts of your body (M for metastasis).

Your doctor often uses this information to give your cancer a number stage – from 0 to 3.

A higher number, such as stage 3, means a more serious cancer. Some stages are further divided into stage A and B.

Staging can be hard to understand, so ask your doctor and nurse for more information if you need it.

Asking about your prognosis

Your prognosis is information about how your disease is likely to progress, including average survival times (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 incorrect. Also, the information may 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 can help you.

Treating testicular cancer

How is testicular cancer treated?

The cure rate for testicular cancer is very high. Actual figures depend on the stage and type of your cancer. Your doctor can talk to you in more detail about this if you want to know more. Even when testicular cancer has spread to other parts of the body (metastasised), it can still be cured.

Surgery

Almost all people with testicular cancer have surgery to remove the affected testicle. This operation is known as an orchidectomy. See page 45 for more on testicular cancer surgery.

Treatment may happen very quickly

Very often everything moves quickly if testicular cancer is suspected or diagnosed. You may have surgery to remove your testicle soon after first going to hospital, sometimes before you get the results of your tests. It can be hard to take in what is happening and you may need some time afterwards to recover from the shock.

If you need to talk to someone, call our Support Line or go to a Daffodil Centre to talk to one of our cancer nurses. The nurses can also put you in contact with a Peer Support volunteer who has had testicular cancer.

> “Always talk. If you are ever worried about anything, just ask. Everyone is there to help you.”

Treatment after orchidectomy

Your doctor will decide if you need any further treatment after your orchidectomy. In general, the type of treatment you receive after orchidectomy will depend on:

- The stage of your cancer (see page 25)
- The type of testicular cancer: seminoma or non-seminoma (see page 11)
- If the cancer has spread or not
- Your general health

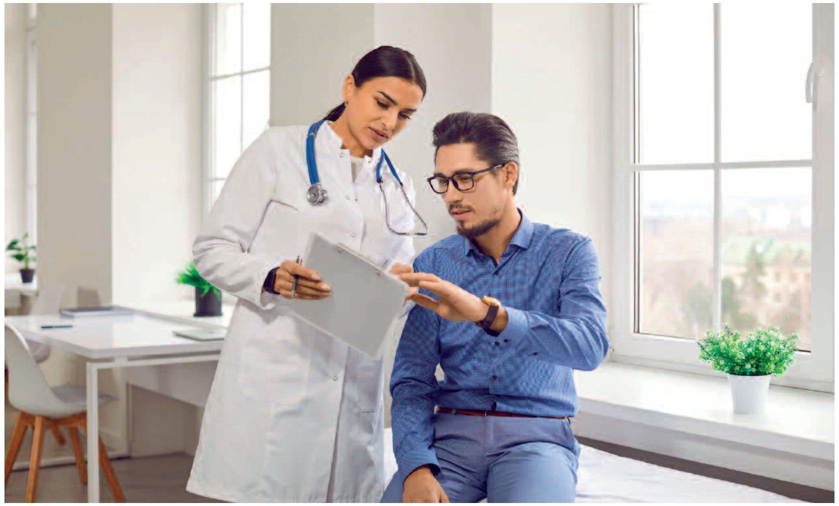
Treatment for seminoma after orchidectomy

Chemotherapy and rarely radiotherapy can be used to treat seminomas after orchidectomy.

Treatment for non-seminoma after orchidectomy

Chemotherapy or further surgery can be used to treat non-seminomas after orchidectomy.

See page 51 for more about treatment after orchidectomy.



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 (surgeon), specialist nurse, radiologist (doctor who examines scans and X-rays), pathologist (doctor who examines cells to diagnose cancer) and oncologist (cancer doctor). The team will meet to discuss your test results and your suggested treatment plan.

Understanding your treatment

Your doctor and nurse will explain your treatment options. Ask as many questions as you like. You could write down any questions you have in advance so you don't forget anything. If you do forget something or need more explanations, ask your specialist nurse or talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Second opinion

You might find it reassuring to have another medical opinion to help you decide about your treatment. Your treating doctor or GP can refer you to another specialist for a second opinion if you feel this would be helpful.

But be assured, your medical team will use the latest scientific information and best practice to develop your treatment plan.

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 want to refuse a particular 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, 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
- Possible side-effects from 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.

Specialist cancer centres

You may be transferred to a specialist cancer centre in a different hospital from the one where you received your diagnosis, depending on your treatment plan.

> “Have some questions ready about the treatment and how it may affect you physically, emotionally, socially.”

Who will be involved in my care?

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

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

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 person who delivers radiotherapy and gives advice to cancer patients about their radiation treatment.

Oncology liaison nurse/clinical nurse specialist (CNS) 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.

Advanced nurse practitioner (ANP) ANPs give expert information and support and are specially trained to carry out tests and help to review your treatment. In some hospitals, ANPs run acute oncology clinics for people who need help with side-effects or other problems during their treatment. Ask your doctor or nurse if there is an acute oncology clinic in your hospital.

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 social welfare benefits, financial matters and practical supports and services available to you.

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

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.

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

Pharmacists Pharmacists – in hospital and 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.

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

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

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

How can I help myself?

It can be very difficult to cope with a cancer diagnosis and all the changes that this can bring. Your healthcare team can offer you different types of support, but there are also things you can do yourself to prepare for treatment and feel better.

Eat well

Eating as well as possible can help you during your treatment. It can help you to:

- Keep up your energy and strength
- Keep your weight stable and avoid muscle loss
- Tolerate your treatment better, so you can finish your course of treatment
- Cope better with side-effects of treatment
- Reduce your risk of infection and other complications
- Recover faster

Ask to talk to the dietitian at the hospital for advice on the best diet for you. You can also read our booklet ***Understanding diet and cancer***. To get a copy, call our Support Line on 1800 200 700, visit a Daffodil Centre or download it on our website **www.cancer.ie**

Keep active

If you are able, it can really help to stay active before, during and after your treatment. Keeping up or increasing your activity levels can help to:

- Reduce tiredness and some treatment side-effects
- Reduce anxiety and depression
- Improve your mood and quality of life
- Strengthen your muscles, joints and bones
- Reduce the risk of other health issues

Talk to your doctor or nurse before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you. Be careful not to overdo it at the beginning – build up gradually.

Quit smoking

If you are coping with a cancer diagnosis, you may find it stressful to quit smoking. However, research tells us that:

- Non-smokers are likely to have fewer or less severe side-effects during cancer treatment, such as chest infections
- Smoking can reduce how well radiotherapy and some other anti-cancer treatments work
- Not smoking can help you to heal better after surgery
- Not smoking reduces your chance of further illness

If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203, visit **www.QUIT.ie** or Freetext QUIT to 50100. Ask your nurse or medical social worker about quitting – some hospitals have a stop-smoking service, with advisors who can help and support you.

> You will have a better quality of life if you give up smoking.

Other ways to help yourself

Get information about your cancer and treatment

Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people. If it makes you anxious, you could ask a friend to do the research for you and tell you anything important. Make sure you get your information from trustworthy sources like your medical team, the Irish Cancer Society and the HSE.

Involve your family and close friends

Don’t keep any worries or physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed. Your friends and family will be affected by your diagnosis too, so try to talk openly and find ways to support each other.

Use your support network

Don’t be shy about asking for help. Family and friends may not know the best way to help you, so tell them what you need. For example, lifts to the hospital, practical help at home, child-minding or just some company or support. Telling people what you need and how they can help means you will get the right amount of support to suit you.

Try relaxation and stress management techniques

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

Accept change in your life

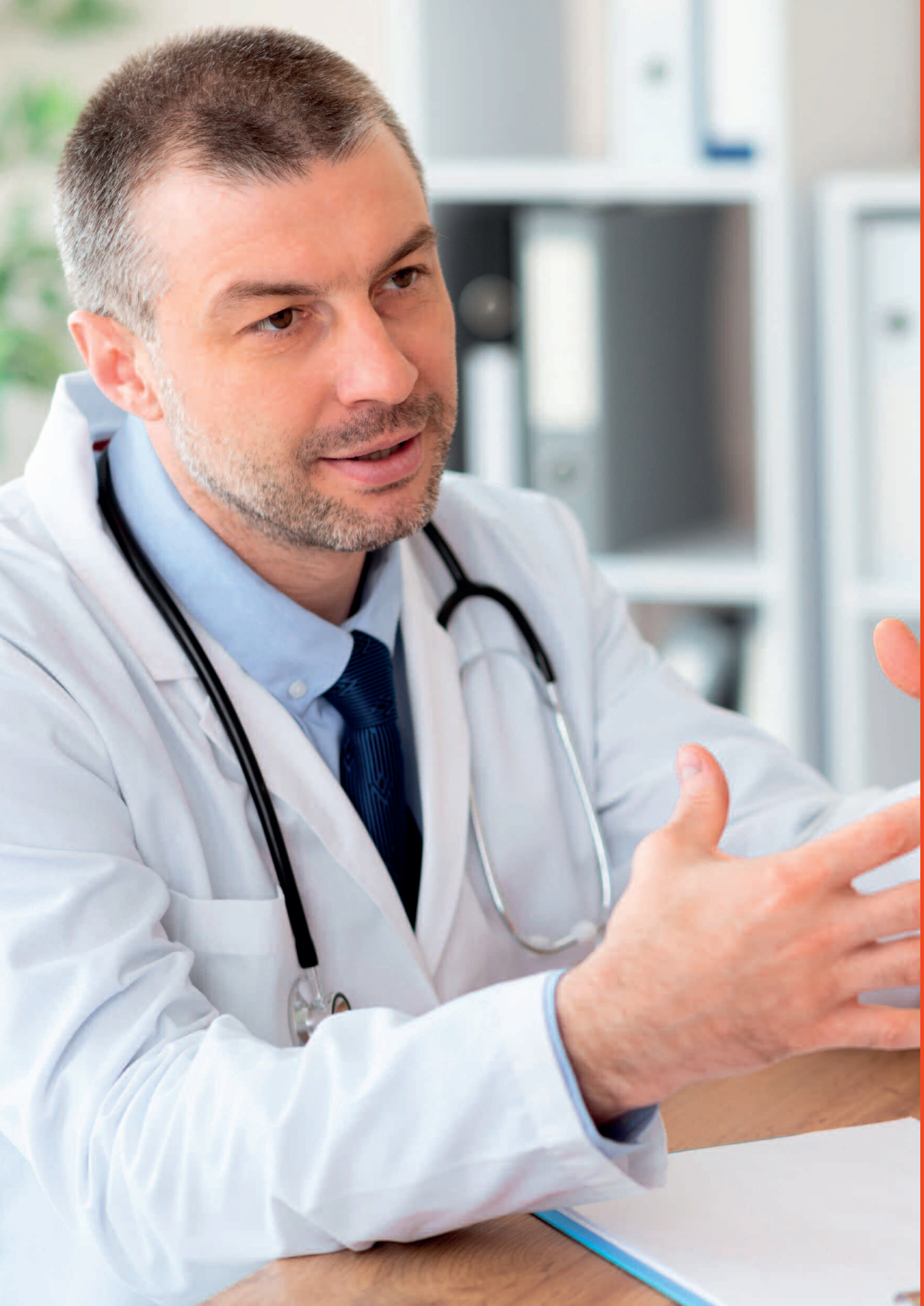
Accept that you may not be able to carry on exactly as before. Give yourself time to adjust to your new routine.

Be aware that there will be ups and downs

Sometimes people feel they have to be brave or positive all the time, but it’s normal to have bad days. Get help if you are finding it hard to cope.

Try to cope day by day

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



Types of treatment

Surgery

- Surgery is the main treatment for testicular cancer.
- You may get some pain, swelling or bruising after surgery.
- You should still be able to carry on your normal sex life after surgery to remove one testicle.

Surgery to remove the testicle is called an orchidectomy. It is normal to have your testicle removed to confirm that you have testicular cancer and to identify what type of cancer it is. It is not normally recommended to check a lump that is suspected of being cancerous by removing cells (a biopsy) because of the risk of spreading testicular cancer cells.

Almost everybody with testicular cancer needs to have an operation to remove the testicle. Usually the operation is done as quickly as possible after you have seen a urologist, often within a week.

The operation is usually done under a general anaesthetic. The surgeon makes a cut in your groin and removes the whole testicle and its cord from the scrotum, through the groin. Afterwards your scrotum will feel smaller and empty on one side.

Very occasionally, chemotherapy is given before surgery. If this applies to you, your doctor will explain everything to you.

False testicle (prosthesis)

You can have a false testicle (prosthesis) put into your scrotum. Prostheses are silicone implants that come in various sizes. They look natural and can help you to feel more confident about your appearance.

Your surgeon will talk to you about having an implant before the operation to remove your own testicle. You can have the prosthesis put in during this operation, or you can have the procedure at a later date if you're not ready to make a decision straight away.

After the implant is put in place, the neck of the scrotum is closed with stitches to stop the implant from moving out of position. A false testicle can feel firmer than your normal testicle. It also doesn't react to temperature like a normal one and will stay the same size.

Prostheses are safe, but they can sometimes cause minor problems in the longer term. For example:

- The implant moving out of its original position.
- Scar tissue forming around the implant. This can cause a thick fibrous growth of tissue, which can sometimes cause discomfort or make you worry that cancer has returned.
- The implant bursting due to vigorous activities such as contact sport, cycling or physical contact, including sexual intercourse. This is rare.

If you have any worries about your implant, let your medical team know.

After the operation

- Once you have recovered from your anaesthetic, you can move around and eat and drink normally.
- Usually you will have a dressing over the wound, which can be removed after a day or so. You may get some pain for up to a week or so afterwards. Your doctor will prescribe painkillers for you.

- There is often some swelling or bruising of the scrotum for a while.
- It is best to avoid heavy lifting and vigorous exercise or sport for a few weeks after the operation.
- You may be able to go home on the same day as your operation or you may be kept in hospital overnight. On the day you go home, you will usually be given a date to come back for a check-up.

- Usually the stiches used to close your wound are dissolvable, so they don't need to be removed. If you have stitches or clips that need to be removed, you will need an appointment to have these removed. This can be arranged with your GP, public health nurse or hospital.

- Most people will be able to go back to work after a couple of weeks. Talk to your doctor first if your work involves heavy lifting.
- It is normal to have blood tests to check your tumour markers again after your surgery. Your doctor will advise you when they would like these performed.

Sex after orchidectomy

Having only one testicle shouldn't affect your sex life unless your remaining testicle does not produce enough testosterone. See pages 73-79 for more on sex and fertility.

If you have a single testicle

If you have only one testicle because of a previous cancer, an undescended testicle or injury, it may be possible to remove only the affected part of your testicle. Your doctor will talk to you in more detail if this applies to you.

Surveillance after surgery

After orchidectomy, you will go to hospital for tests such as physical examinations, bloods tests, CT scans and X-rays for a number of years.

You can start treatment with chemotherapy, radiotherapy or more surgery if you need it, but you may not need treatment for many years, if at all.

Surveillance means you can avoid or delay having treatment like chemotherapy or radiotherapy. This way you can avoid treatment side-effects that can affect your quality of life.

Remember your surveillance appointments

- **It is very important to go to all your appointments** so that any changes are spotted early.
- **Note the date and time of your appointments on a calendar** or set a reminder on your phone.
- **If you cannot make your appointment, call the urology or medical oncology clinic to reschedule.**

Tell your consultant or ANP if you are planning to travel or live abroad. They will be happy to put your clinical information and surveillance plan together, so that you can continue your follow-up elsewhere.

Questions to ask about active surveillance

- What tests will I have?
- How often will I need to have tests?
- What happens if my surveillance tests are abnormal?

If you feel anxious

You may feel anxious or worry about your cancer changing. This can be worse at times leading up to scans and follow-up appointments. If surveillance makes you feel very anxious, you may need extra support to help you manage your feelings. Support groups, counselling and complementary therapies like mindfulness or aromatherapy may help. Read more about getting emotional support on page 99.

Further treatment after orchidectomy

- You may have further treatment after surgery.
- A team of specialists (MDT) will advise you about which treatment is best for you.

Some testicular cancers have a higher risk of coming back (recurrence) than others. Your doctor and healthcare team (MDT) will decide if you need further treatment.

You may have chemotherapy or radiotherapy:

- To prevent the cancer from coming back after surgery
- To treat any cancer that has spread outside the testicle
- To treat testicular cancer that comes back at a later date

Deciding on further treatment

Make sure that you have enough information about the different options, what's involved and the possible side-effects, so that you can decide on the best choice for you.

Remember to ask questions about anything you don't understand or feel worried about. It may help to discuss the benefits and disadvantages of each option with your doctor or nurse specialist.

You can also talk to our cancer nurses on our Support Line or at our Daffodil Centres. It often helps to make a list of questions and to take a relative or close friend with you.

Treatment for seminoma after orchidectomy

Chemotherapy can be used in the treatment of seminomas after orchidectomy. Radiotherapy may also be given after surgery, but this is rare.

A very small select group of patients may be offered surgery to remove lymph nodes from their abdomen (tummy) instead of chemotherapy. This is known as retro-peritoneal lymph node dissection (RPLND). See page 61 for more on RPLND.

Treatment for non-seminoma after orchidectomy

Chemotherapy or further surgery can be used to treat non-seminoma after orchidectomy.

Most patients with stage 1 non-seminona will only require surveillance — regular blood tests, X-rays and scans to monitor your condition. This means that you may avoid the need for chemotherapy or further surgery. If there are any changes in your condition, you can have treatment.

Chemotherapy: If your cancer has spread to other parts of your body or you are thought to have a high risk of the cancer coming back (recurrence), your doctor may recommend chemotherapy.

If you have stage 1 non-seminoma but have risk factors for recurrence, you may have just 1 or 2 cycles of chemotherapy. If your cancer has spread outside of the testicle you may need to have more cycles of treatment. Your doctor will explain to you how much treatment you need. See below for more details on chemotherapy.

Surgery: You may need surgery to remove lymph nodes from your abdomen (tummy). This is known as retro-peritoneal lymph node dissection (RPLND). See page 61 for more details on RPLND.

Chemotherapy

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

Chemotherapy is a treatment that uses drugs to kill cancer cells. If your cancer has spread to other parts of your body or if there is a high risk of your cancer coming back, your doctor may recommend chemotherapy for you.

How often will I have chemotherapy?

Chemotherapy is often given in cycles with a rest period between treatments. This rest period allows your body time to recover from the side-effects of treatment. The number of cycles can vary, depending on your cancer type and how well it is responding to treatment.

For early testicular cancer, you may have only 1 or 2 cycles. If your cancer has spread, you may need 3 or 4 cycles or even more. You may have to visit the hospital over a period of 3–6 months for treatment.

How is chemotherapy given?

Chemotherapy may be given directly into a vein as an injection and/or through an intravenous infusion (drip). Usually you will have to stay in the hospital for a few days during your treatment.

What kinds of drugs are used?

There are several chemotherapy drugs used to treat testicular cancer. They can be used on their own or in combination with each other.

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 more information about the drug and its possible side-effects.

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

Remember

When you're having treatment, it can help to plan ahead. Try and involve your friends and family. Let them know what is happening so that they can help with arrangements for things like school, work and childcare while you are having treatment.

What are the side-effects of chemotherapy?

The side-effects of chemotherapy vary from person to person. Some people have few side-effects. It mainly depends on the drugs used and the amount of chemotherapy given. Side-effects happen because chemotherapy can affect both healthy cells and cancer cells. Ask your doctor or nurse if you're worried about side-effects or have any questions.

Most side-effects can be helped by medication. Usually the side-effects go away when the treatment ends or soon after. Side-effects may include:

Fatigue: Fatigue is very common. It can make you feel tired and weak. For more information see page 79.

Nausea and vomiting: Chemotherapy can cause nausea (feeling sick) and vomiting (getting sick). You will be prescribed anti-sickness medication to take after each treatment. Thinking or talking about the treatment can also make you feel sick. This is called anticipatory nausea. Tell your doctor or nurse if you have these side-effects.

Infection: Chemotherapy drugs affect your immune system, making you more likely to get infections. You will be asked to watch out for signs of infection at all times. These signs include feeling shivery and unwell, having a high or low temperature, having a cough or pain passing urine.

Anaemia: Chemotherapy can cause the bone marrow to make fewer red blood cells. Having fewer red blood cells is called anaemia. Anaemia can make you feel tired and breathless. Regular blood tests to measure your red cell count will be done during treatment. You may need a blood transfusion to treat your anaemia.

Bleeding and bruising: Chemotherapy can stop your bone marrow from making enough platelets. With fewer platelets you may bleed or bruise very easily. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums.

Mouth and throat problems: Chemotherapy can cause mouth and throat problems including a dry mouth, ulcers and gum infections. There are many mouthwashes and medications to help, which your medical team can prescribe for you.

Hair loss (alopecia): Some chemotherapy drugs can cause hair loss from all over your body, including your eyebrows, armpits and pubic hair. How much hair falls out depends on the drug given, the dose and your own reaction to it. Hair will grow back after you stop chemotherapy. If you would like information on getting a wig, call our Support Line or call into a Daffodil Centre for more information.

Constipation and diarrhoea: Chemotherapy can cause constipation (not having a bowel movement/poo often enough) and diarrhoea (frequent loose or watery bowel movements). Ask your doctor or nurse about medicines to help with constipation and diarrhoea.

Skin and nail changes: Skin may become dry, flaky and itchy. A non-perfumed moisturiser can be used - ask your nurse for advice on products you can use. Nails may become dark, yellow or brittle.

Peripheral neuropathy: Some drugs can affect your nerve endings. Tell your doctor or nurse if you have numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy. Peripheral neuropathy normally gets better after you have finished your chemotherapy, but if ignored, it could become a permanent side-effect.

Changes in kidney or liver function: Some drugs can irritate or damage kidney and liver cells. Signs of kidney damage can include peeing less than usual, swelling of the hands and feet (oedema) or headaches. Yellowing of the skin or eyes (jaundice) can be a sign of liver damage. Blood tests will check your kidney and liver function regularly. If you are experiencing any of these side-effects, talk to your doctor.

Lung changes and shortness of breath: In rare cases, inflammation of the lungs can happen if you are given a chemotherapy drug called bleomycin. Your doctors will check your lungs before, during and after treatment. If you're short of breath or notice a change in your breathing, tell your doctor as soon as possible. If you are a scuba diver, talk to your doctor about risks associated with bleomycin treatment. If you need an anaesthetic after bleomycin, tell the anaesthetist that you have had this treatment.

Allergy: On rare occasions, people can have a reaction to certain chemotherapy drugs. Reactions can include rash, itching, low blood pressure and shortness of breath.

Blood clots: Chemotherapy and having cancer can both increase your risk of developing blood clots. A blood clot may 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.

Fertility: For more information on fertility and chemotherapy, see page 77.

Contraception: You should use a barrier method of contraception while you're having chemotherapy and for some time afterwards, as the drugs may affect an unborn baby. Talk to your doctor about how long you will need to use condoms for.

Hearing changes: The drug cisplatin can cause ringing in your ears (tinnitus). You may not be able to hear some high-pitched sounds as well as before. You will have a hearing test before and during treatment to check your hearing. Let your doctor know if you have any problems with your hearing.

Later side-effects: There is an increased risk of developing high cholesterol, diabetes and heart problems after having chemotherapy as a young adult. It's a good idea to follow a healthy lifestyle. See page 89 for more details. Many years after chemotherapy there is a very slightly increased risk of developing a second cancer. For more information, talk to your doctor.

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.

If you have any symptoms that are troubling you or you feel unwell, tell your doctor or nurse straight away. There are treatments to help with most side-effects.

After chemotherapy

Side-effects: You may continue to feel tired or have other side-effects for a few months or more after your chemotherapy treatment has ended. This depends on the amount and type of chemotherapy you have had. Let your doctor know if you continue to have side-effects for a long time after your treatment has ended.

Going back to work or education: You may not be able to go back to work or education immediately after treatment. Stay in regular touch with your GP, medical oncologist and your employer, college or school to help you decide about when it's best for you to go back. Some people go back on a phased basis, starting off on reduced hours and increasing to full time when they feel ready. If you are in third-level education, the disability or welfare officer in your college may be able to support you during this time.

Get support: Ask for help with practical issues from friends and family. Your local cancer support centre can also help you during this time (see page 122).

For parents: teenagers and chemotherapy

There are some things to keep in mind if your teenager is having chemotherapy.

- Most teenagers can go to school in between courses of chemotherapy. Let the principal and teachers know about your teen's chemotherapy treatment. Ask them to alert you when there are any infections in your teen's class. This can include chickenpox, shingles or measles. Being exposed to these viruses can make your child very ill while on treatment.
- Try not to let your teen get overtired. It may help to avoid games and PE during treatment.
- It might be hard for your teen to go back to school as they might be embarrassed if chemotherapy has caused hair loss. Encourage them to express their feelings.
- Let your child keep in touch with their friends and keep life as normal as possible.
- If there is a problem, talk to the doctor and teachers about it.
- Reassurance and/or counselling can help with many issues. The Irish Cancer Society provides free counselling to patients and their families, including brothers and sisters.

For information on counselling and other services for teenagers with cancer, call our Support Line on 1800 200 700, email supportline@irishcancer.ie or visit a Daffodil Centre.

Our booklet, ***Your guide to dealing with cancer (for young people aged 16-24)***, has lots of information on topics such as treatment, side-effects, what to expect in hospital, dealing with changes to your body and managing relationships. 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.

Lymph node surgery – RPLND

Your doctor may advise you that you need to have an operation to remove lymph nodes at the back of the abdomen (tummy). This operation is called a retro-peritoneal lymph node dissection or RPLND.

Why might I have RPLND?

Occasionally, if you have cancer that has spread to your lymph nodes, these nodes may not shrink back to normal size after chemotherapy. It is often difficult to tell on a CT scan why they are enlarged:

- It may be due to a collection of dead cells in the glands, known as necrotic tissue
- It may be because the nodes contain cells that may turn cancerous in the future
- It may be due to cancer cells that remain

The only way to know for sure why the glands have not shrunk back down is to take them out and send them to be looked at under a microscope.

About RPLND

An RPLND operation may need to be carried out by a different surgeon to the one who performed your orchidectomy. This is because it is specialised major surgery and is only performed by a small number of surgeons in Ireland.

All operations have a risk of complications such as bleeding and infection. In RPLND there is a risk of needing to have your kidney removed or you may need a graft to the main blood vessels in your abdomen (tummy area). Before your operation, your surgeon will discuss these possible complications with you.

You will need to have a general anaesthetic for this operation. It is a long operation, usually lasting a number of hours. It involves a cut from the top of your abdomen down to below your belly button to allow the surgeon to remove the lymph nodes that are behind your organs. These nodes lie alongside your kidneys and the main blood vessels in your abdomen.

How do I prepare for an RPLND operation?

Tests: You will have some extra tests to make sure you are fit for surgery. These could include a chest X-ray, heart test (ECG), lung function tests, blood pressure and more blood tests.

Deep breathing exercises: A physiotherapist will show you how to do deep breathing exercises. These will help to prevent you getting a chest infection or blood clots after surgery. Your nurse will arrange for you to have a pair of elastic stockings. These are to prevent you getting blood clots in your legs after surgery.

Bowel preparation: You will be given advice on how to clear out your bowels fully. You may have to drink a special solution or take clear fluids only. This is so that your surgeon can move your bowel out of the way during the operation to make it easier to get to the lymph nodes.

Night before surgery: You will not be allowed to eat anything from 12 midnight. You will get an injection to prevent blood clots forming in your legs.

Morning of surgery: You will continue to fast (not eat). Before you go to theatre, you may get a tablet to make you feel sleepy and more relaxed.

After the operation

You may stay in an intensive care or high dependency unit (HDU), sometimes called PACU (post-anaesthesia care unit), where the staff will keep you under close observation for a day or 2. After surgery, you will have a wound and drips will be attached to your body. These are normal in an operation like this.

Wound: The wound will be along your tummy. The line of stitches will go from below your breastbone to your pubic bone. Stitches or staples are usually removed 7 to 10 days after your surgery.

Drip: A drip will be put into a vein in your neck or your arm to give fluids into your bloodstream. This will be removed once you can drink again.

Painkillers: You may have a thin tube in your back to relieve pain. This is called an epidural. You may have a pump, which you can use to give yourself painkillers. Your doctors and nurses will explain which type of painkiller you will have to help ease any pain or discomfort you have.

Bowel motions: The surgery will slow down your bowels for a short time. It can take from 3-10 days after an RPLND for your bowel to start moving normally again. It may take a day or 2 before you can eat and drink more normally. At first, you will be able to take sips of water. Gradually the amount of fluids will be increased and you can begin to take light meals.

Exercising: You must move your legs while in bed and do deep-breathing exercises regularly.

Recovery from RPLND

After the operation it may be 7–10 days before you and your doctor feel you are ready to go home. How long you need to stay in hospital will depend on how quickly you recover. For example, if your bowels are slow to move afterwards you may need to stay a little longer. It can take a couple of months before you are fully recovered and ready to return to normal activity after this operation.

Sex and fertility after RPLND

RPLND surgery does not affect erections or the sensation of orgasm. But removing nerves during surgery may mean that you have a 'dry orgasm' (anejaculation). This means that when you climax, no semen comes out of your penis. Instead, when you ejaculate, your semen goes into your bladder and passes out with your urine. As semen contains sperm, this will affect your fertility.

Your surgeon may be able to do an operation that spares the nerves near the lymph nodes to reduce the risk of this happening. If you develop sexual dysfunction after RPLND, let your oncology team know. They can refer you to a specialist team for assessment and treatment.

You may also be given the chance to save your sperm beforehand and freeze it for later use. See page 78 for more details on sperm-banking.

Radiotherapy

- Radiotherapy is a treatment using high-energy rays.
- Radiotherapy is painless and only takes a few minutes.
- Side-effects of radiotherapy depend on the area being treated and the amount given.

Radiotherapy uses high-energy rays to kill cancer cells. The rays come from a machine called a linear accelerator.

The aim of radiotherapy is to destroy cancer cells with as little damage as possible to normal cells.

Radiotherapy is sometimes used in seminomas as they are very sensitive to radiation. Non-seminoma testicular cancer usually responds better to other types of treatment.

Radiotherapy may be given to lymph nodes in the abdomen (tummy) known as retroperitoneal nodes, to help prevent testicular cancer spread or to treat cancer that has already spread.

Planning your radiotherapy treatment

Radiotherapy must be carefully planned so that the highest dose is given to the tumour area and as little as possible to the nearby cells.

You will go to hospital for a planning CT scan before your treatment (also called simulation). This is to pinpoint the area to be treated and decide on the position you will be in when you have your treatment. Usually you'll have an injection of a dye before the scan to show up areas to be avoided by the radiation beam.

After the scan, your skin will be marked with tiny tattoo dots, so that the machine can be lined up with these guide marks when you have your treatment.

Talk to the radiation therapists if you have any worries or concerns during treatment planning.

Having radiotherapy treatment

During treatment you will first be positioned carefully on a treatment table. Then the machine will move around you so that you receive the precise treatment at different angles.

The treatment normally takes only a few minutes and is painless.

How much radiotherapy do I need?

How much radiotherapy you have will depend on the type and stage of your cancer. Radiotherapy treatment for seminoma usually lasts 2-3 weeks. You will need to go to hospital for treatment every day during the week, with a rest at weekends.

Will I get any side-effects?

Radiotherapy side-effects tend to affect the area of the body being treated. With testicular cancer treatment, the most common side-effects are:

Feeling sick or getting sick: Radiation to the abdomen (tummy) may make you feel a bit sick. If you are troubled by nausea or sickness, talk to your nurse or radiation therapist.

Skin changes: The skin in the treated area may become red and sore during treatment. It may start to look like sunburn. A special cream can be used to treat this problem. Only use creams that your nurse or radiation therapist recommend.

Tiredness: Tiredness or fatigue can build up over the course of your treatment. You may feel tired because of the treatment itself or if you have to travel long distances for treatment.

It is common for tiredness to continue for some time after treatment finishes, so try not to worry if this happens to you. See page 79 for more about fatigue.

Diarrhoea: You might get some diarrhoea during treatment. Usually this can be controlled with medicines. Changing your diet may help too. Let your nurse or radiation therapist know if you have diarrhoea.

Sex and fertility: Radiation to your lymph nodes does not normally affect sexual function but it may affect your fertility. For information on your sex life and fertility see pages 73-79.

How severe these side-effects are will vary from person to person. It will depend on the amount of treatment you have. Most side-effects develop during or shortly after your treatment and get better within a few weeks. Late side-effects may develop some time after treatment. Some side-effects are long-term or may even be permanent.

If you feel unwell or have any other side-effects or symptoms — during or at any time after treatment — tell your doctor, nurse or radiation therapist.

If you would like more information on radiotherapy and its side-effects, call our Support Line on 1800 200 700 or visit a Daffodil Centre for a copy of our free booklet ***Understanding radiotherapy***.

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 consider taking part in a clinical trial. This means that instead of, or as well as, 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.

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**

Managing side-effects and symptoms

Will treatment affect my sex life?

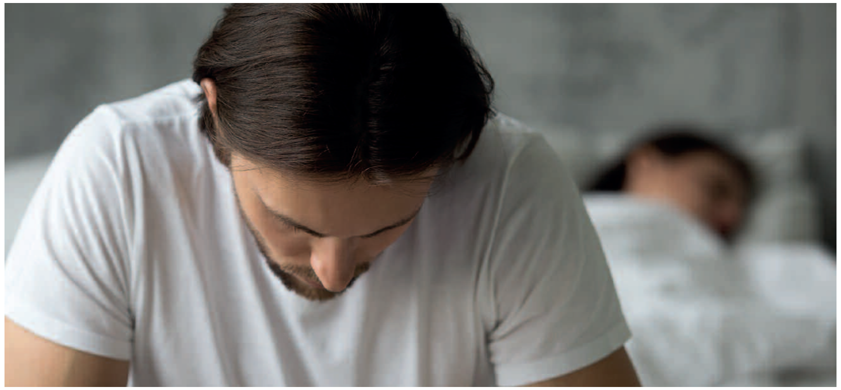
It is natural for you to be worried about your sex life.

Sex after surgery to remove the testicle (orchidectomy)

After an operation to remove one testicle, most people will still be able to have an erection and orgasm and continue their normal sex life. You should tell your urologist if you have any problems.

Low testosterone and your sex life

If you have had both testicles removed or your remaining testicle doesn’t produce enough of the male hormone testosterone, it may affect your ability to get an erection and reduce your sex drive. It can also cause tiredness, low mood and problems such as thinning of the bones (osteoporosis).



Let your doctor know if you’re having these or other symptoms. You can have a blood test to check your testosterone level. If your testosterone level is low, your doctor can prescribe testosterone replacement therapy. This will help with problems such as a low sex drive and feeling constantly tired. It can be given as a gel, an injection into a muscle, an implant or a patch that is stuck on the skin. Your doctor can give you more information about testosterone replacement therapy.

Sex after surgery to the lymph nodes (RPLND)

RPLND surgery sometimes damages nearby nerves. You may get a dry orgasm if this happens. This means that when you climax, no semen comes out of your penis (anejaculation). This will also affect your fertility (see page 77).

Sex after chemotherapy or radiotherapy

Chemotherapy or radiotherapy to your lymph nodes will not affect your ability to have sex, although you may feel too tired for it. It is not known if chemotherapy drugs pass into semen, so to protect your partner you should use a condom during chemotherapy and for some time afterwards. Talk to your doctor about how long you need to use condoms for after chemotherapy.

Sexuality and emotions

During your diagnosis and treatment, you may experience a range of emotions that can leave you confused and tired. As a result, it can be hard to relax and you may lose your sex drive. It's common to feel this way during and after treatment for testicular cancer.

It may take a while to adjust to your diagnosis and the loss of your testicle. Having a false (prosthetic) testicle can help. See page 46 for more information. It can take time to get used to the look and feel of your false testicle but it will gradually happen.

There is no set time for you to be ready to have sex again. It varies from person to person. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. You may find that talking about your feelings may ease any worries you have. 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 Daffodil Centre nurses can help you to find accredited therapists and supportive information if you would like to talk to someone. This can help you and your partner deal with a change in your sexual relationship and find ways of being close again. You can also ask for a copy of our booklet, ***Understanding sex, sexuality and cancer***, or download it from **www.cancer.ie**

Some people worry that cancer can be passed on to a partner during sex. This is not true.

If you're single

If you're single, you may worry that you will not be able to find a partner in the future, especially if your sexual functioning or fertility has been impacted. You may also wonder when is the right time to start dating and when should you tell a person you are seeing about your cancer. This is very much a personal choice. More information on how to deal with these issues can be found in our booklet, ***Understanding sex, sexuality and cancer***.

Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. Your doctor and nurse are well used to talking about these matters, so try not to feel embarrassed. 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 at **www.cancer.ie**

Will treatment affect my fertility?

Some treatments can affect your ability to have a child (your fertility). Ask your doctor about this before treatment starts.

Even if you're not thinking about having children at the moment, it's a good idea to keep your options open for the future. For example, you may be able to store your sperm before treatment starts. Many people go on to have healthy children after they have had treatment for cancer.

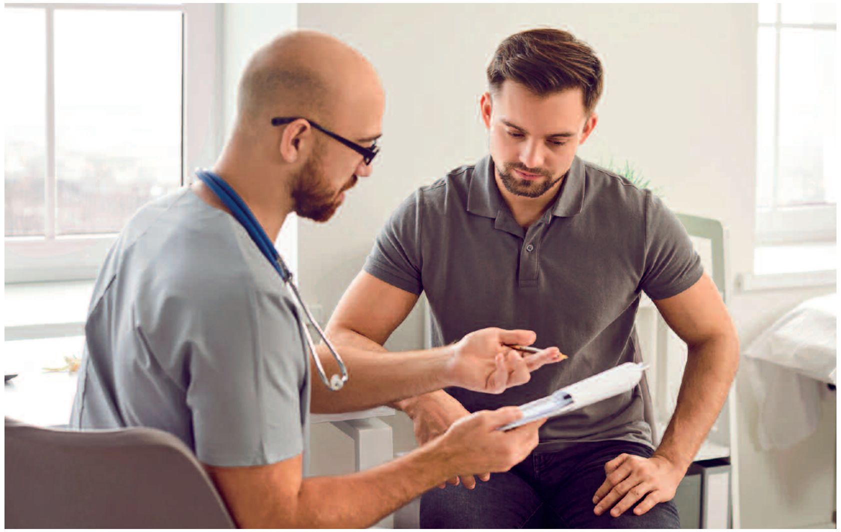
Fertility after surgery to remove the testicle (orchidectomy)

An orchidectomy should have no effect on your ability to have a child (fertility) if you have a normal testicle on the other side. Your doctor will discuss fertility with you if your other testicle is small or your sperm count is low. If you have had one testicle removed and you need to have the second one removed, you will be infertile and your doctor will discuss testosterone replacement with you.

Fertility after RPLND surgery

RPLND surgery can reduce fertility for some men. Your doctor will talk to you about the need to store sperm before this operation because of the risk of 'dry' ejaculation. This means the semen you produce does not come out of your penis when you climax.

If you have a dry ejaculation, you won't be able to have a child naturally. If you want to start a family and have not stored sperm before surgery, it may be possible to collect sperm from your urine or directly from your testicle. Your doctor will explain this and talk to you about your options.



Chemotherapy and fertility

Chemotherapy is known to affect sperm production and so can affect your fertility. This can happen in the short term or be permanent. For this reason, it is best to store sperm before treatment starts (see page 78). Sperm counts generally return to normal within 2 to 3 years. Many people go on to have healthy babies after treatment.

Before treatment begins, your doctor will talk to you about this in more detail. It is not known if chemotherapy drugs can pass into sperm so it is not safe to try for a baby during treatment or for some time afterwards. You should talk to your doctor about how long you need to use condoms for after chemotherapy.

Radiotherapy and fertility

Radiotherapy for testicular cancer is usually given to lymph nodes. Radiotherapy to the nodes in your groin significantly reduces fertility. Talk to your doctor about your fertility concerns before treatment starts if this is important to you.

You shouldn't assume you are infertile after radiotherapy, so you should still use an effective method of contraception during radiotherapy treatment and for a time afterwards. Ask your doctor about this.

Sperm banking

Sperm tests will be done before treatment. If your sperm count is within normal limits, it may be possible to collect and freeze sperm before treatment begins. This can then be used at a later date for artificial insemination or other assisted reproduction techniques such as IVF. Your doctor can explain these techniques to you.

How is sperm banking done?

You may be asked to give a single semen sample, or occasionally several samples, to try to ensure a good number of quality sperm are frozen for future use. Sometimes there is a break for a couple of days between samples to ensure a good number of sperm are retrieved. The sperm is then frozen. Using stored sperm is not always successful, as the freezing and thawing process can affect its quality.

Not everyone is suitable for sperm banking. In this case, it may be possible to extract sperm from testicular tissue using a technique called testicular sperm extraction (TESE). Your consultant can give you more information about this.

If sperm banking may be an option for you and you are over 18, your consultant can refer you to SIMS IVF Clinic. This service is funded for cancer patients by the clinic and the HSE. You can also use other fertility clinics for sperm banking, but there will be a fee. For more information, visit **www.sims.ie/oncology-patients**

Dealing with infertility

Dealing with infertility may not be easy. You might not have thought about it before. It can bring feelings of sadness, anger and loss of identity. You may also feel embarrassed talking about such a personal matter. It can help to talk through your concerns with someone who is a good listener. Do ask your doctor or nurse for advice on ways to cope. Your doctor can refer you to a specialist for counselling if you feel it would help.

How can I cope with fatigue?

Fatigue means feeling extremely tired. Fatigue is very common. Usually fatigue starts to improve once treatment is over, but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you, so that they can help you.

Fatigue when you have cancer can be caused by many things, including:

- The cancer itself
- Tests and treatments for cancer
- Not eating well
- Low levels of red blood cells (due to the cancer or its treatment)
- Dealing with difficult emotions and feeling anxious or depressed
- Not sleeping well
- Low testosterone levels
- Symptoms like pain, breathlessness or fluid retention

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.

Hints and tips: Fatigue

- **Being active can help with fatigue.** Ask your oncology team about exercising. They may also be able to recommend an exercise programme for you.
- **Try to eat a well-balanced diet.** Eat little and often if your appetite is poor. Our booklet ***Understanding diet and cancer*** has tips to help.
- **Try to make time to rest if you need it.** If you are going somewhere special, have a rest before you go out.
- **Let your friends know that you might have to cancel plans at short notice** if you're not up to it.
- **If you are too tired to go to school, college or work at times, talk to your teachers or boss about how they can help you** to create a routine that you can manage.

- **Go out with your friends and carry on with sports and other activities if you feel like it** – there's no reason why you can't. Just be careful to avoid crowded places when you're at more risk of getting an infection if you have had chemotherapy. You can talk to your nurse about this.
- **Ask your friends to keep in touch** through text, email or social media so you don't feel you're losing touch.
- **Get to know when your energy levels tend to be better.** You may have to decide which tasks are important to finish and do them over the course of the day or when you have most energy.
- **Try to avoid stress.** Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling (see page 98) may help too.
- **If you are not sleeping well, try to get a good bedtime routine and try relaxation techniques.** Avoid stimulants like caffeine and alcohol in the evening and try not to use electronic devices for an hour before bedtime.
- **Short naps (less than an hour) and rest periods can be helpful,** as long as they don't stop you from sleeping at night. If naps help, try to have them earlier in the day. Our booklet, ***Coping with fatigue***, has tips to help.
- **Try complementary therapies** like meditation, acupuncture or yoga, if your doctor says they're safe for you.

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, acupuncture, meditation 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. Tell them also if you're using or considering using over-the-counter or herbal medications. 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 curing cancer and keeping it under control. An unproven alternative treatment could harm your health, or you might miss out on a treatment that could really help you.

More information

To find out more about complementary therapies, you can talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a free copy of our booklet ***Understanding cancer and complementary therapies***, or download it from our website **www.cancer.ie**

After treatment

What follow-up do I need?

No matter what type of treatment you get, you will still need to have regular check-ups. This is known as follow-up or active surveillance. At first, these appointments will be quite frequent, sometimes every 3 or 4 months for the first 2 years. This is because the risk of testicular cancer coming back is highest in the first 2 years after your initial diagnosis. After 2 years, you will be seen less frequently, dropping back to once a year in time. Your doctor or specialist nurse will let you know how often they would like to see you.

The check-up may involve having a physical exam, blood tests, X-rays and CT scans. At these visits, your doctor will check for signs of testicular cancer that may have come back. Your doctor can also keep track of any ongoing side-effects that you may have.

If you are between check-ups and have a symptom or problem that is worrying you, call your specialist nurse for advice or to arrange an earlier outpatient appointment if necessary.

If you become suddenly unwell and can’t contact your specialist nurse or hospital team, go to your GP or the emergency department at the hospital.

You might worry about the cancer coming back. This can be worse at times leading up to scans and follow-up appointments. It can help to share your concerns so people know how you are feeling. Loved ones can also get anxious, so it can help to talk to them about it. If you or your loved ones feel you might need help coping, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

It can be a good idea to keep a record of your treatment. This can come in useful if you need to see a new doctor later in life when they might not have full access to your medical records. For more information or support, contact our Support Line on 1800 200 700 or visit a Daffodil Centre.

Life after treatment

You can return to normal activity as soon you feel able after your cancer treatment. Finishing treatment can be both stressful and exciting at the same time. It can take some time for the tiredness to wear off after cancer treatment. This is quite common so do not worry if you do not get over your treatment as quickly as you thought you might.

Staying healthy after treatment

Many people want to live a healthy lifestyle after their treatment has ended. Having a healthy lifestyle is important as it can help you to:

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

A healthy lifestyle includes:

- Exercising
- Eating healthy foods
- Staying at a healthy weight
- Not smoking
- Protecting yourself from the sun

If you want more information or advice, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also go to our website **www.cancer.ie** for tips and publications on healthy living.

Our booklet, ***Life after cancer: A guide to living well***, is for people who have finished their cancer treatment. It covers topics such as follow-up care, how to manage side-effects, financial matters and living a healthy lifestyle. You can read it or download from **www.cancer.ie**. You can also get a free copy by calling our Support Line on 1800 200 700 or calling into a Daffodil Centre.

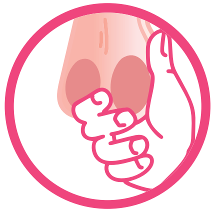
Checking your testicles

It's important to continue to check your remaining testicle for any changes after your treatment.

How to check yourself

1 Cup your testicle using both hands – best done during or after a warm bath or shower

2 Examine by rolling the testicle between thumb and fingers – use slight pressure



3 Get to know the spermatic cord and epididymis – tube-like structures that connect on the back side of the testicle

4 Feel for lumps, swelling, change in size or weight or any other changes

If you notice any changes, let your GP or consultant know.

Feelings after treatment

It can take some time to adjust to life after cancer treatment. It isn't unusual to feel quite low and lost after your treatment has ended, especially during the first few months.

Feelings you may have include:

- Fear of cancer coming back and worrying about every small symptom
- Loneliness without the company and support of your medical team and fellow patients
- Stress at having to deal with things that may have been on hold during your treatment, such as your finances, going back to work and family issues
- Isolation or guilt if your family and friends expect you to get back to normal before you are ready
- Anxiety and self-doubt about sexual and romantic relationships
- Anger at what has happened and the effect on you and your loved ones
- Depression or sadness

There is more about how to cope with these feelings and adjusting to life after cancer on our website **www.cancer.ie**

After-treatment workshops

You might like to join our **Life and Cancer – Enhancing Survivorship (LACES)** programme when you have completed treatment or are on maintenance therapy and are living well with advanced cancer. This workshop covers topics such as diet, exercise, wellbeing, finance and self-management and gives information on support and services to help you. Call our Support Line or visit a Daffodil Centre for details.

What if the cancer comes back?

If your cancer has come back after it has been treated, it is known as recurrence. The risk of testicular cancer coming back depends on the type and stage of your testicular cancer. If recurrence is going to happen, it is most likely to occur in the first 2 years after treatment. It is also possible that the cancer could recur in later years, however this risk is small.

Even if testicular cancer does come back, it can still be cured.

Where in the body can testicular cancer come back?

Men who have had testicular cancer are at a slightly higher risk of getting cancer in the other testicle. For this reason, it is a good idea to get into the habit of checking your remaining testicle on a regular basis. See page 90.

Testicular cancer can also come back in other parts of the body such as lymph nodes or your lungs. This is why the CT scan is an important part of your follow-up.

What treatment can I have if the cancer comes back?

Chemotherapy: If you have already had chemotherapy, your doctor may choose different drugs to give to you. Rarely, you may need high-dose chemotherapy with a stem cell transplant.

High-dose chemotherapy and stem cell support: This is rare, but may be used for those whose cancer did not respond to first-line chemotherapy. It allows you to have much higher doses of chemotherapy than usual to try to destroy any remaining testicular cancer cells. Stem cells are found in the bone marrow. They make all the blood cells in your body. When very high doses of chemotherapy are given, your bone marrow is affected by treatment. For this reason, some stem cells are removed before high-dose chemotherapy treatment and replaced afterwards.

Your doctors will talk to you in detail if you need this treatment. For copies of our booklet, ***Understanding autologous stem cell transplants***, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Surgery for recurrent testicular cancer: If the lymph nodes in your abdomen are affected by recurrent cancer, you may have surgery to remove the lymph nodes. This operation is known as RPLND. See page 61 for more information on this operation.

Help and support for recurrent testicular cancer

Finding out that cancer has come back after treatment can be a very difficult time. Shock, disbelief, anxiety, fear, anger, grief and a sense of loss of control are common emotions. All these feelings are normal responses to this difficult experience. Some people find this diagnosis more upsetting than the first one. However, it is important to remember that a cure can still be reached even in this situation. For help and support at this time, call our Support Line on 1800 200 700 or visit a Daffodil Centre and talk to one of our cancer nurses.

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.

Emotions 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 to someone you know is a good listener, tell your GP, join a support group, contact your local cancer support centre or call into your nearest Daffodil Centre. Medical social workers can also offer support to you and your family.

All cancer centres in Ireland have a psycho-oncology multi-disciplinary team who can offer specialist support. Your medical team, cancer support centre or Daffodil Centre nurse can refer you to this team if needed.

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 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 free 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, visit a Daffodil Centre or email the nurses at supportline@irishcancer.ie

> "Counselling has helped me with every part of my life. I feel I have a future now."

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 122 for more about cancer support services.

Join a support or educational group: You might find it reassuring to talk to other people with cancer who are 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 doctor, specialist nurse or medical social worker can refer you to psycho-oncology support services if they're available at your hospital.

Get online support: Special websites called online communities let you write questions, share stories, and give and receive advice and support.

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 contact your nearest Daffodil Centre.

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.

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.

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 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.

Talking to children and teenagers

Saying nothing

If you have children, you may feel it's best not to tell them anything. You may be worried about what to say or how they will react. But children and teenagers can often sense that there is a problem. If no one explains to them why things have changed, they may imagine something worse or blame themselves. By talking openly you can answer their questions and help them to cope with their emotions.

How to tell your children

It's best that you or your partner tell your children about your cancer diagnosis. How you discuss your cancer and treatment with them will depend on their age and character. A useful booklet called ***Talking to children about cancer*. *A guide for parents*** gives practical advice for talking to children about cancer, with specific advice for different age groups. It also has information on supporting children and teenagers and helping them to deal with their emotions.

Our cancer nurses can also support you if you have children and aren't sure what to say to them.

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 the person with cancer, 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 out with the caring.

Try counselling

You might find it helpful to talk to a counsellor. Free one-to-one counselling is available to friends and family members at some local cancer support centres. Talk to your GP or see page 98.

Find out about support for carers

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

How to talk to someone with cancer

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

If you want advice on how to support a friend or loved one with cancer, call our Support Line on 1800 200 700. Ask for a copy of our booklet ***Caring for someone with cancer***. The booklet has a section 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 also pick up a copy of the booklet at any Daffodil Centre or download it at **www.cancer.ie**

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**

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 119 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 supports** 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 112).

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 112)

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

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 also Freephone our Support Line or call into 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**

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.

What does that word mean?

Abdomen The part of your body that lies between your chest and hips. Sometimes known as the belly or tummy.

Anti-emetic A tablet, injection or suppository to stop you feeling sick or vomiting.

Benign Not cancer.

Biopsy When a small amount of tissue is taken from your body to find out if cancer cells are present.

Cells The building blocks that make up your body. They are tiny and can only be seen under a microscope.

Chemotherapy Treatment using drugs that cure or control cancer.

Dry orgasm No (or very little) fluid (semen) comes out of the penis when an orgasm happens.

Fatigue Severe tiredness.

Germ cells Cells that produce sperm in men (and eggs in women). They are nothing to do with germs that cause infections.

Lymph nodes Small glands scattered along vessels of your lymphatic system. They may become enlarged due to infection or cancer cells.

Malignant Cancer. A tumour that can spread to other parts of the body.

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 other tissues and organs.

Nausea Feeling sick.

Necrotic tissue A collection of dead cells.

Non-seminoma A type of testicular cancer that tends to develop earlier in life. It is most common in people aged 20-35.

Oncology The study of cancer.

Orchidectomy Removing a testicle by surgery.

Prognosis The expected outcome of a disease.

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

Radiotherapy The treatment of cancer using high-energy X-rays.

Retrograde ejaculation Semen goes into the bladder rather than out through the penis during orgasm.

Retro-peritoneal A space in the abdomen, towards the back, where some lymph glands are present.

Seminoma A type of testicular cancer that tends to grow slowly and responds well to treatment.

Staging Tests that aim to find out how big your cancer is and if it has spread to other parts of your body.

Testosterone A hormone produced by the testicles that is responsible for male characteristics, such as a deep voice and facial hair. It also affects your sex drive and ability to maintain an erection.

Tumour marker A chemical in your blood that may be a sign that cancer is present.

Urologist A surgeon who specialises in diseases of the male reproductive system and urinary system. They can remove a tumour from this area of the body.

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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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