

Understanding

Testicular Cancer

Caring for people with cancer

Understanding testicular cancer

This booklet has been written to help you understand more about testicular cancer. It has been prepared and checked by surgeons, cancer doctors, nurses, radiation therapists and patients. The information in this booklet is an agreed view on this cancer, its diagnosis and treatment and key aspects of living with it.

If you are a patient, your doctor or nurse may go through the booklet with you and mark sections that are important for you. You can also make a note below of the contact names and information you may need quickly.



Specialist nurse

Tel:

Family doctor (GP)

Tel:

Surgeon/urologist

Tel:

Medical oncologist

Tel:

Radiation oncologist

Tel:

Radiation therapist

Tel:

Emergency number

Tel:

Treatments

Review dates



Irish Cancer Society, 43/45 Northumberland Road, Dublin 4
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Email: info@irishcancer.ie
Website: www.cancer.ie

If you like, you can also add:

Your name

Address

This booklet has been produced by Nursing Services of the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible.

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- *Cancer Nursing: Principles and Practice*, CH Yarbrow, MH Frogge, M Goodman & SL Groenwald, Jones and Bartlett, 2000.
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Contents

- 4 Introduction
- 5 What does that word mean?

About testicular cancer

- 7 What is cancer?
- 9 What are the testicles?
- 9 What is testicular cancer?
- 10 What causes testicular cancer?
- 11 What are the symptoms of testicular cancer?
- 12 How is testicular cancer diagnosed?
- 15 What are the types of testicular cancer?
- 15 What are the stages of testicular cancer?

Treatment and side-effects

- 17 How is testicular cancer treated?
- 21 Surgery
- 23 Radiotherapy
- 26 Chemotherapy
- 33 High-dose chemotherapy with stem cell support
- 35 What follow-up do I need?
- 36 Will treatment affect my sex life?
- 37 Will treatment affect my fertility?
- 39 How can I cope with fatigue?
- 41 Research – what is a clinical trial?
- 42 Cancer and complementary therapies

Coping and emotions

- 45 How can I cope with my feelings?
- 51 How can my family and friends help?
- 52 How can I talk to my children?
- 53 What else can I do?

Support resources

- 57 Who else can help?
- 58 Health cover
- 66 Irish Cancer Society services
- 69 Useful organisations/Helpful books
- 75 Questions to ask your doctor
- 76 Your own questions

Introduction

This booklet has been written to help you understand more about testicular cancer. By reading it, you can learn about its diagnosis, treatment and side-effects. We hope that it answers some of the questions you may have.

We cannot advise you about which treatment to choose. You can only make this decision along with your doctors, when all your test results are ready. But we can tell you about some ways to treat this cancer and their possible side-effects.

This booklet also discusses some of the feelings you and those close to you may have when a diagnosis of cancer is made. At the end of the booklet, you will find a list of books that are useful to read. There is also a list of websites and special groups to help and support you at this time. You can also call the freefone National Cancer Helpline 1800 200 700 to discuss any queries or concerns you have.



Reading this booklet

Remember you do not need to know everything about testicular cancer straight away. Read a section about a particular item as it happens to you. Then when you feel relaxed and want to know more, read another section.



If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the National Cancer Helpline 1800 200 700.

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.
Adjuvant treatment	Treatment for cancer given soon after surgery.
Alopecia	Loss of hair or no hair where you normally have hair.
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.
Fatigue	Severe tiredness.
Malignant	Cancer.
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 or wanting to be sick.
Neo-adjuvant treatment	Treatment such as chemotherapy or radiotherapy that is given before surgery to shrink a tumour.
Non-seminoma	A type of testicular cancer that begins in the germ cells that give rise to sperm.

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.
Staging	Tests that measure the size and extent of cancer.
Seminoma	A type of testicular cancer.

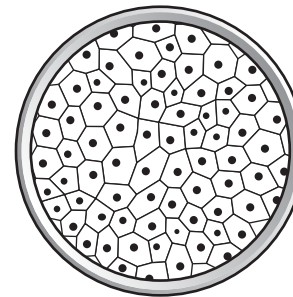
About testicular cancer

What is cancer?

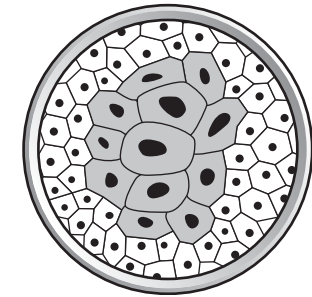
Cancer is a word used to describe a group of diseases. Each one has its own name. For example: skin cancer, lung cancer and breast cancer. Each has an individual type of treatment and chance of being cured.

In the body, the organs and tissues are made up of tiny building blocks called cells. All cancers are a disease of the body's cells. In healthy tissue these cells replace or repair themselves when they get worn out or injured. With cancer, the cells do not behave as normal and keep on growing, even when there is no need.

These groups of abnormal cells can form a lump or tumour. Tumours can be either **benign** or **malignant**. Benign tumours are less likely to spread to other parts of the body and so are not called cancer. Malignant tumours are cancer cells that can spread from where they first grew. This happens when a cell or group of cells breaks away and is carried by the bloodstream or lymph glands to form a new tumour elsewhere in the body. This is called a **metastasis** or secondary tumour.



Normal cells

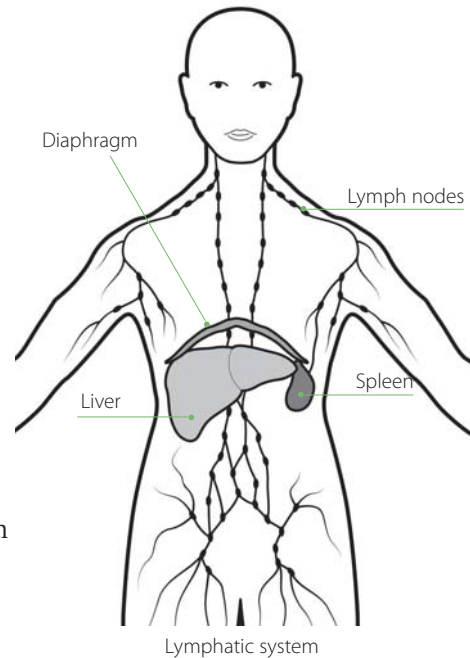


Cancer cells growing

What is the lymphatic system?

Every day the body defends itself against infection in many ways. The lymphatic system is one way. Like the bloodstream it carries material around the body. It is made up a network of tiny tubes that pass through most of the tissues in your body. These tubes carry a clear watery fluid called **lymph**.

Along the network are hundreds of small glands shaped like beans. These are called **lymph nodes** and remove unwanted material from the lymph like a sieve. They also help white blood cells called lymphocytes to protect your body against infection.



Lymph nodes are found in groups throughout your body, such as in your neck, armpits and groin. Sometimes you may notice these glands if they become swollen. More of these lymph nodes are found in larger groups in your chest and abdomen. Other parts of the lymphatic system include your spleen, thymus, tonsils and bone marrow. Lymph nodes can also spread cancer cells.

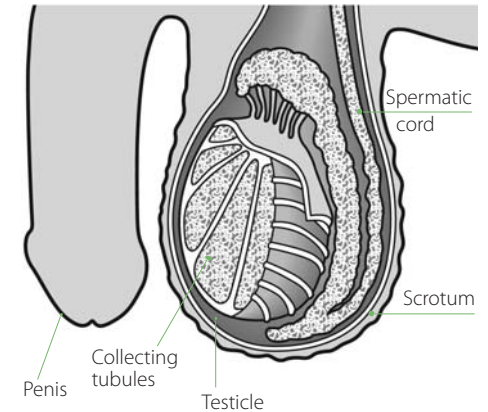


To sum up

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

What are the testicles?

The testicles are part of the male reproductive system. They are also known as the testes. They are two small egg-shaped organs found below your penis in a pouch of skin called the scrotum. Once you reach the age of puberty they 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 the female egg after sex, which will grow into a baby. The testes also make the hormone testosterone. This hormone is responsible for male qualities such as a deep voice, facial hair and strong muscles. It also gives you a sex drive and the 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 used to make sperm. The cancer can affect how the testicles work normally. Sometimes testicular cancer cells spread to lymph glands at the back of the abdomen, the chest or neck. See page 15 for more about the types of testicular cancer.

How common is testicular cancer?

Testicular cancer is quite a rare cancer. But it is the most common cancer in young men aged between 15 and 34 years. Each year about 164 cases are diagnosed in Ireland. The number of men developing the cancer has been increasing for the past few years. Even so, testicular cancer is very treatable and is nearly always curable.

What causes testicular cancer?

The exact cause of testicular cancer is unknown. Research continues to look into possible causes. There are certain things called risk factors that can increase your chance of getting cancer. Different cancers have different risk factors. Some of the risk factors for testicular cancer are:

- **Undescended testicle:** Testicular cancer is more common in men with a testicle that did not descend or which descended some time after birth.
- **Previous history of testicular cancer:** You are slightly more at risk if you have had testicular cancer in the past.
- **Family history of testicular cancer:** You are more at risk if your father or brother had the disease. Research shows that in some men a particular gene causes the cancer.
- **Fertility problems:** If you have fertility problems, you have a small risk of testicular cancer. But a vasectomy does not increase your risk of developing it.
- **Mumps:** If you had a rare complication of mumps called mumps orchitis, you might develop testicular cancer.
- **Ethnic and social group:** If you are white skinned, you have a higher chance of getting testicular cancer than African-Caribbean or Asian men. Testicular cancer occurs more often in wealthier social groups.
- **Klinefelter's syndrome:** This is a sex chromosome disorder with low levels of male hormones, sterility, breast enlargement and small testes. It raises your risk of testicular cancer.

There is no evidence that injury to your testicle will cause cancer but it may make it easier to notice. It is not certain if exposure to chemicals can cause testicular cancer. Research is also checking to see if tall men have a higher risk or not. Remember testicular cancer is not infectious and cannot be passed on to other people.

>>> A painless lump or swelling in a testicle is a common symptom of testicular cancer.

What are the symptoms of testicular cancer?

The most common symptoms of testicular cancer are:

- A painless lump or swelling in a testicle
- Pain or discomfort in a testicle or in the scrotum
- An enlarged testicle or change in the way it feels
- A heavy feeling in your scrotum

If the cancer has spread, you may get:

- A dull ache in your back
- Breast tenderness
- Stomach ache
- Shortness of breath
- A painless lump in the side of your neck

Even though these symptoms can be caused by conditions other than cancer, do get them checked out by your doctor. Most testicular lumps are not cancer.

Most testicular cancers are curable. If they are found early, they can be very easily treated.

Can I be screened for testicular cancer?

Checking for testicular cancer when you have no symptoms is called **screening**. Because testicular cancer is not common, screening is not done for the general public at present.

Self-exam of testicles

It can help to examine your testicles yourself every month. The best way to do this is after a warm bath or shower when the skin of your scrotum is relaxed.

- Hold your scrotum in the palms of your hands.
- Use your fingers and thumb on both hands to examine your testicles.
- Gently feel each testicle one at a time for any change in size or weight.

- It is common for one testicle to be slightly larger or hang lower than the other.
- The testicle itself should be smooth with no lumps or swellings.
- It is normal to feel a soft tube at the top and back of the testicle.

If you notice any swelling or lump or different sensation than normal, get it checked by your doctor as soon as possible. Call the National Cancer Helpline 1800 200 700 if you would like more information.



To sum up

- Testicular cancer is not a common cancer.
- The cause of testicular cancer is unknown. An undescended testicle and a history of testicular cancer are some risk factors.
- The symptoms of testicular cancer include a painless swelling or lump in one of your testicles or a heavy feeling in your scrotum.
- Examine your testicles once a month.

How is testicular cancer diagnosed?

Usually you visit your family doctor (GP) first if you have a symptom or concern. He or she will examine you and refer you to a hospital specialist for more tests if needed. This hospital specialist is called a urologist. At the hospital, the urologist will ask you some questions about your health before examining you.

The following tests may be done:

- Ultrasound of the scrotum and testes
- Blood tests
- Chest X-ray

Ultrasound of the scrotum and testes: This is a scan that uses sound waves to look at the tissues inside your scrotum. It can show if there is a mass in your testes but cannot tell if it is cancer or not. The scan only takes a few minutes and does not hurt. When lying on your back, the nurse will spread a gel over the area to be scanned. A small device is used to take the scan, which is converted into a picture by a computer. The test is done in the X-ray department of the hospital.

Blood tests: Bloods tests may be done to check your general health. Other blood tests may check if you have tumour markers. See below for more details.

Chest X-ray: This is done to check your general health and see if cancer has spread to the lymph nodes in the chest.

Removing the testicle (orchidectomy)

The only way your doctor can know if the lump or swelling is cancer is by removing the lump. The cells can then be examined under a microscope.

It is not possible to remove some tissue (a biopsy) without taking the whole testicle. There is a danger that if only a sample is taken it may cause the disease to spread or recur. The operation to remove the testicle is called an orchidectomy. See page 21 for more details.

Further tests

If you have testicular cancer, your doctor will want to do more tests. These extra tests are important as they will show if the disease has spread to other parts of your body. The results of the tests will also help to decide on the best treatment for you.

Blood tests: Some testicular cancers make chemicals that can be found in your bloodstream. These are called blood tumour markers or biomarkers. They include alpha-fetoprotein (AFP), beta human chorionic gonadotrophin (bHCG) and lactate dehydrogenase (LDH). During your treatment and follow-up, samples of blood will be taken regularly to check the levels of these markers.

CT scan: This is a special type of X-ray that gives a detailed picture of the tissues inside your body. It can examine your chest and abdomen (belly) to see if any cancer cells are found there.

The scan itself is painless.

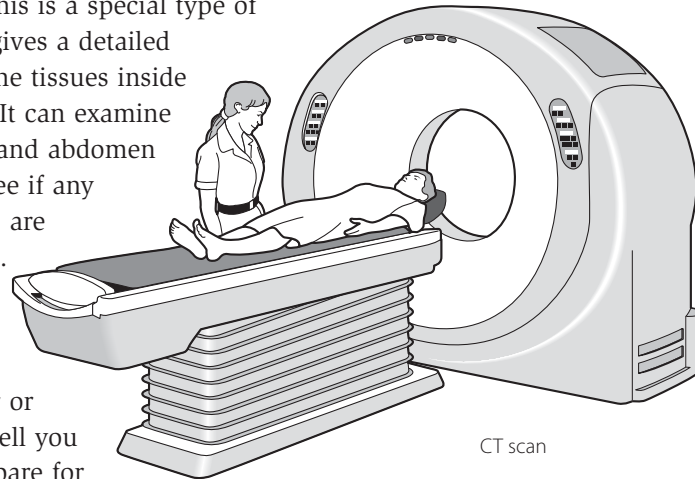
Your doctor or nurse will tell you how to prepare for

the scan. You may be asked to fast beforehand. You may also be given a special drink to help show up parts of your body on the scan. This can make you feel hot all over for a few minutes. The test is usually done as an outpatient. Some people feel anxious about this test and are afraid they may feel claustrophobic during it. If this worries you, contact the radiographer the day before. They may be able to give you medication to relax you on the day.

Your doctor may order some extra tests such as an MRI scan or a PET scan if he or she feels it would give more information on the stage of the cancer.

Waiting for results

It may take some time for all the test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You may also wish to call the National Cancer Helpline 1800 200 700 to speak to one of our specially trained nurses.



CT scan

What are the types of testicular cancer?

Most testicular cancers are germ cell tumours. Germ cells refer to cells that give rise to sperm in men. There are two types of germ cell tumours: seminomas and non-seminomas.

Seminomas: These usually develop between the ages of 30 and 50. One in every three testicular cancers is a seminoma. They tend to grow slowly but respond very well to treatment.

Non-seminomas: These develop earlier in life from the age of 15 to early 40s. They tend to grow and spread faster than seminomas. They include teratomas, embryonal cancers and mixed germ-cell tumours.

The type of tumour can be identified under a microscope. Both types are treated slightly differently.

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

What are the stages of testicular cancer?

Your doctor will arrange some tests to stage the cancer. Staging means finding out the size of the tumour and seeing if it has spread to other parts of your body. Staging is very important as it allows your doctor to decide the best treatment for you.

Staging looks at the size of the tumour, if lymph nodes are involved, if the cancer has spread to other parts of the body, and if tumour markers are present.

Stage 1: This means the tumour is found only in the testicle. It has not spread and no lymph nodes are involved. Tumour markers are absent or only slightly raised.

Stage 2: Here the cancer has spread outside the testes to the lymph nodes in the abdomen (belly). The size of the nodes can vary from less than 2 cm, between 2 cm and 5 cm, or larger than 5 cm. The tumour markers are also raised.

Cancer Helpline 1800 200 700

Stage 3: Here the cancer has spread to the lungs, followed by the liver, bone and brain. The tumour markers are raised.

Recurrent: This means that the cancer has come back after it has been treated. It may recur in the other testicle or in another part of your body. If the cancer does appear in the other testicle, it usually happens within 2 years but it can also happen many years later.

Most testicular cancers are diagnosed at an early stage. Even if they have spread beyond the testicle, they can still be cured.



To sum up

- Most testicular cancers are germ cell tumours.
- Germ cells tumours can be either seminoma or non-seminoma.
- There are three stages of testicular cancer. Treatment can vary depending on the stage.
- Recurrent cancer is when the cancer has come back after it has been treated.



Treatment and side-effects

How is testicular cancer treated?

Most testicular cancers can be cured. Often it is one of the easiest cancers to treat. The treatment of testicular cancer can vary but the first treatment is usually surgery. In general, the type of treatment you receive will depend on:

- The size and stage of the cancer
- The type of testicular cancer: seminoma or non-seminoma
- If the cancer has spread or not
- Your general state of health

>>> Your doctor will discuss your treatment options with you.

Treatment for seminoma

Surgery, radiotherapy and chemotherapy work well in the treatment of seminoma. Nearly all seminomas can be cured. Some testicular cancers have a high risk of recurrence after surgery. For this reason, your doctor will watch your condition closely.

Surgery: Here the affected testicle is removed in an operation called an orchidectomy. See page 21 for more details.

Radiotherapy: Radiotherapy can be given after surgery even if the cancer is only in the testicle. It can also be given to the lymph glands at the back of your abdomen. See page 23 for more details on radiotherapy.

Chemotherapy: Chemotherapy can be given after surgery depending on the stage of the disease. If the cancer is at stage 1, it might involve just one or two doses of the drug carboplatin. If the tumour has spread to other parts of your body, you will need a course of chemotherapy. See page 26 for more details.

High-dose treatment with stem cell support: High doses of

chemotherapy can be given if the first treatment did not work or if the cancer has returned. See page 33 for more details.

Surveillance: If you have early stage seminoma and no radiotherapy or chemotherapy after surgery, your doctor may decide to watch you closely. Blood tests, X-rays and scans will be done regularly.

Treatment for non-seminoma

Surgery and chemotherapy are mostly used to treat non-seminomas. Both work very well and will cure most of these cancers.

Surgery: The affected testicle will be removed during surgery. If the tumour is found at an early stage and the tumour markers return to normal after surgery, you may not need any more treatment. In some cases, surgery to remove the lymph nodes at the back of your abdomen may also be done. See page 21 for more details on surgery.

Chemotherapy: If the tumour has spread to other parts of your body, like the lymph nodes in your abdomen or lungs, or you are at a high risk of recurrence, you will need chemotherapy. See page 26 for more details.

High-dose treatment with stem cell support: High doses of chemotherapy can be given if the first treatment did not work or if the cancer has returned. See page 33 for more details.

Surveillance: If you have early stage non-seminoma and no radiotherapy or chemotherapy after surgery, your doctor may decide to watch you closely. Blood tests, X-rays and scans will be done regularly.

Cancer treatment

In Ireland testicular cancer is treated in specialist cancer centres. The staff at these centres have expertise and experience in managing patients with testicular cancer. As a result, you may be transferred to another hospital from the one where you received your diagnosis.

>>> In Ireland testicular cancer is treated in specialist cancer centres.

Deciding on treatment

At this time you may be anxious about your treatment. You may still be in shock from the diagnosis and forget what you have been told. Do not be afraid to ask your doctor or nurse for more information. They will discuss your treatment options with you. You might like to use the fill-in page at the back of this booklet to write down your questions and the answers you receive.

Some patients like to get a second opinion from another cancer specialist. If you feel this would help, do discuss it with your doctor. He or she or your GP may be able to recommend another specialist.

>>> No medical treatment will be given without your consent.

You may be asked to sign a consent form saying you give permission for treatment to be given. In some cases you may give verbal permission. No treatment can be given without your consent. Also, you should be told the likely benefits and risks of the treatment.

You are also free to choose not to have the treatment. But you will need to discuss it in detail with your doctor or specialist nurse. They can let you know what might happen if you chose not to have treatment. The helpline nurses on the National Cancer Helpline 1800 200 700 can also discuss it with you.

>>> Who will be involved in my care?

Some of the following health professionals may be involved in your care at the hospital. Usually, a team of cancer care doctors will decide your treatment.



Urologist

A doctor who specialises in diseases of the male reproductive system and urinary system. He or she can remove a tumour from this area of the body.

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.
Clinical nurse specialist	A specially trained nurse who cares for patients who have testicular cancer.
Liaison oncology nurse/ clinical nurse specialist	A specially trained nurse who works in a special cancer care unit. She or he gives information and reassurance to patients and their families from diagnosis and throughout treatment.
Radiation therapist	A radiotherapist who specialises in giving radiotherapy and advice to cancer patients.
Medical social worker	A person specially trained to help you and your family with social issues and practical needs. They are skilled in giving counselling and emotional support to children and families at times of loss and change. They can give advice on benefits, entitlements and services available to you when you go home.
Psychologist	A specialist who can talk to you and your family about emotional and personal matters and can help you make decisions.
Counsellor	A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness. The Irish Cancer Society provides a counselling service. For details call the National Cancer Helpline at 1800 200 700.



To sum up

- The main treatment of testicular cancer is surgery.
- Other treatments include chemotherapy and radiotherapy.
- A team of specialists will decide which treatment is best for you.

Surgery

The aim of surgery is to remove the testicular cancer and the area close to it. The operation to remove a testicle is called an **orchidectomy**. As mentioned before, this operation is the only way to get a sample (biopsy) of the tissue and diagnose the cancer. If the cancer is only found in the testicle, you may not need any more treatment. Your doctor will discuss your options with you.

»»» The main treatment for testicular cancer is surgery.

During the operation: The surgery is done under general anaesthetic. First a small cut is made in your scrotum and then the affected testicle is removed. Your scrotum will be smaller than before. If you are worried that this will affect your body image, there are ways to help. A false testicle (prosthesis) can be placed in your scrotum later to give a normal appearance. Do talk to your doctor about this before surgery.

After the operation: You may get some pain for a day or two afterwards. Sometimes there may be some swelling or bruising of the scrotum as well. If you need painkillers, your doctor can prescribe them. Most likely you can go home 2/3 days after the operation. On the day you go home, you will be given a date to come back for a check-up, usually about 3 weeks later.

Fertility

You will still be able to have an erection and orgasm with just one testicle. If you have surgery to remove the lymph nodes near the testicle, it might damage nerves that control the release of sperm from the penis (ejaculation). As a result, you might be less fertile, but there is still a high chance you could father a child. If you have both testicles removed, you will be infertile.

Before your operation, your doctor will discuss these possible side-effects with you. He or she may be able to do an operation that spares the nerves near the lymph nodes. You will also be given the chance to save your sperm beforehand and freeze it for later use. See page 37 for more details on infertility.

More surgery

Further surgery is sometimes needed after radiotherapy or chemotherapy.

Lymph nodes: Sometimes lymph nodes may be removed during your first surgery or later. This can happen if the cancer has spread to the lymph nodes at the back of your abdomen or to other parts of your body.

Sometimes these secondary tumours can be quite large when testicular cancer is first diagnosed. Chemotherapy or radiotherapy may cause them to shrink or disappear completely. Once they are smaller, they can be easier to remove during surgery. As mentioned before, your surgeon might be able to spare the nerves near the lymph nodes. This can help to reduce the risk of ejaculation problems and infertility. When removing lymph nodes, it may be done by keyhole surgery.

Enlarged/scar tissue: Many men who have chemotherapy for stage 3 testicular cancers may get enlarged tissues or scar tissue after treatment. A special type of X-ray called a PET scan can show if scar tissue or any remaining cancer cells are present. Your surgeon may need to operate again to remove these tissues.



To sum up

- Surgery is the main treatment for testicular cancer.
- You may get some pain, swelling or bruising after surgery.
- Your scrotum will be smaller but you can get a false testicle to give a better appearance.
- You will still be able to have an erection and orgasm after surgery.
- You may be less fertile but there is a high chance you can father a child.

Radiotherapy

Radiotherapy uses high-energy X-rays to cure or control cancer. It is often used to treat seminomas but normally not non-seminomas. Seminomas are very sensitive to radiation and only a short course is needed. Most men will be cured by it. Radiotherapy can prevent the cancer coming back after surgery. It can also be given if the cancer has spread to the glands at the back of the abdomen.

The X-rays come from a machine called a linear accelerator and are aimed at the testicle or lymph nodes. This is known as external radiotherapy.

Planning your treatment

The doctor who specialises in radiotherapy is called a radiation oncologist. He or she plans how best to deliver your treatment with a team of doctors. They will decide how much radiotherapy is needed to treat the cancer while doing the least possible damage to normal cells. On your first visit to the radiotherapy department you may be asked to lie under a machine called a simulator that takes X-rays of the area to be treated. You are usually given an injection of a dye, which will show up on X-ray. The dye will clearly show areas to be avoided by the radiation beam.



External radiotherapy

Treatment planning is a very important part of radiotherapy. It may take a few visits before your treatment can go ahead. You will be marked on the skin where you are to get treatment so that the X-rays can be aimed

at the same area each day. Usually a single tattoo is used to avoid repeated marking of your skin. Before starting radiotherapy, your nurse or radiation therapist will tell you how to look after your skin during and after treatment.

»»» Seminomas are very sensitive to radiation and only a short course is needed.

Getting your radiotherapy

Having radiotherapy is quite straightforward. You will come for treatment every day during the week with a rest at weekends. Your treatment may last for 3–4 weeks. Each treatment session only takes a few minutes. You will not feel any pain during treatment but you will have to lie still. How much treatment you receive will depend on the stage of the cancer. Your doctor will discuss your treatment with you.

On each visit you will go into a radiotherapy room. The radiation therapist will ask you to lie in a certain position under the machine. When you are ready, he or she will leave the room. The machine will be turned on and your treatment given. Even though you are on your own in the room, your radiation therapist can see you all the time through a closed circuit camera. You can talk to the radiotherapy staff through an intercom if you need to speak.

External radiotherapy does not make you radioactive. It is safe for you to mix freely with family and friends.

Will I get any side-effects?

The side-effects of radiotherapy depend on the part of the body being treated. How severe these side-effects are vary between patients and depend on the amount of radiotherapy received. Before treatment begins, your doctor or nurse will explain how these effects can be managed. The side-effects may include:

Feeling sick or getting sick: Your nurse can give you medication to help prevent feeling sick. Take it one hour before treatment. It can also help to eat small amounts often.

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 recommends. Avoid perfumed creams or powders. If you need to wash the area, use warm water and pat it dry with a soft towel. Do not rub the skin while washing and drying. Check with your radiation therapist or nurse before putting anything on your skin.

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. Rest as much as you can during this time. It can help to cut down on activities while you are on treatment too. See page 39 for more about fatigue.

Hair loss: You may have some hair loss in and around the pubic area or abdomen. If this happens, the hair will fall out quickly. But try not to worry, as the hair should start to grow again once treatment is over. You may find that the new hair is thinner or finer than before.

Other side-effects

These or any other side-effects you develop are watched very carefully during your treatment. Most side-effects go away once treatment is over, but do let your doctor know if they continue. If you would like more information on radiotherapy, call the National Cancer Helpline 1800 200 700 for a copy of the free booklet *Understanding Radiotherapy* or a DVD called *Radiation Therapy: A Patient Pathway*.



To sum up

- Radiotherapy is a treatment using high-energy X-rays.
- The X-rays are aimed at the cancer to cure or shrink it.
- Radiotherapy is painless and only takes a few minutes.
- Treatment may last for 3–4 weeks.
- Side-effects of radiotherapy depend on the area being treated and the amount given.

Chemotherapy

Chemotherapy is a treatment that uses drugs to cure or control cancer. These drugs travel through your bloodstream to almost every part of your body. As a result, it can treat cancers that have spread. If you have a large seminoma, you will usually have chemotherapy. It can also be given if you have non-seminoma. This can either prevent the cancer from coming back after surgery or treat any cancer that has spread.

How is chemotherapy given?

Chemotherapy is usually given into a vein or as a tablet. If given into a vein, it can be as an injection or through an infusion or drip. If you need regular treatment by injection or infusion, your doctor may decide to put in a central line. A central line is a long narrow plastic tube put into a main vein in your chest. It can be left in place throughout your treatment. It will then be easier for you to get treatment as there will be no more repeated needle jabs.

Before the line is put in, you will be given a local anaesthetic. Putting the line in normally only takes a few minutes. When you no longer need it, the line can be simply removed again.

There are other ways to have easy access to veins for taking blood and for treatment. Sometimes a tube is attached to a small round metal or plastic disc placed under your skin. This tube (port) can be used for as long as needed.

Talk to your doctor or nurse about the different ways of getting chemotherapy into a vein. For a free copy of a DVD on caring for central lines, contact the National Cancer Helpline 1800 200 700.

Where do I get chemotherapy and for how long?

Usually you receive the treatment as a day patient at the hospital. Depending on the drugs used, you might have to stay in hospital overnight for treatment.

If you have early stage testicular cancer, you may receive one or two injections of carboplatin. Otherwise, treatment is given in cycles. A course of chemotherapy followed by a rest period is called a **cycle**. The rest period will allow your body time to recover from the drugs.

The number of cycles you have will depend on the stage of your cancer and how well it is responding to treatment. For early testicular cancer, you may have only 1 or 2 cycles. But if your cancer has spread, you may need 3 or 4 cycles or even more. You may have to visit the hospital for 3–6 months for treatment.

What drugs are used?

Sometimes the drugs are used on their own or in various combinations. Most patients will get a combination of two or three drugs. The most common drugs used are cisplatin, etoposide and bleomycin. This treatment is sometimes called BEP. Your doctor may decide to leave out bleomycin if the cancer has only a small chance of coming back. Other drugs are used to treat testicular cancer as well. One or two injections of carboplatin may be given after surgery if you have early stage testicular cancer.

Other drugs include ifosfamide, vinblastine and paclitaxel. These may be used if the cancer did not respond to the other drugs or if it has spread or recurred.

»»» The most common drugs used are cisplatin, etoposide and bleomycin.

If you would like more information on drugs used for testicular cancer, see the Irish Cancer Society website:

www.cancer.ie/cancerInfo/chemotherapydrugs_list.php

Some research studies called clinical trials can find out if the drugs can improve the treatment results. Your doctor may ask you to take part in a trial. These studies are quite safe. See page 41 for more details.

Cancer that has spread or recurred

Most men have no further problems after their first treatment for testicular cancer. But for a few men the cancer may come back. It may even have spread to other organs by the time your diagnosis is made. Even so, it can still be treated and even cured. In many cases, chemotherapy alone or surgery after chemotherapy will cure the disease.

Before a decision is made on the best treatment for you, your doctor will consider your general health and where the cancer is found. He or she will also take into account the kind of treatment you have had in the past.

Side-effects of chemotherapy

The side-effects of chemotherapy vary between patients and depend on the drugs used. These unwanted side-effects happen because chemotherapy can affect both cancer cells and normal cells too. The side-effects can be short term or long term. In most cases the side-effects go away once the treatment ends or soon after. Your doctor or nurse can give you medication to stop most side-effects or make them easier to cope with. Possible side-effects include:

- Infection
- Bruising
- Anaemia
- Feeling sick or getting sick
- Numbness/pins and needles in hands and feet
- Shortness of breath
- Diarrhoea
- Sore mouth
- Feeling tired (fatigue)
- Not wanting to eat
- Hair loss
- Hearing changes
- Infertility

»»» Your doctor or nurse can give you medication to stop most side-effects or make them easier to cope with.

Infection: Chemotherapy can make you more likely to get infections. This happens because most of the drugs affect the bone marrow that makes the white blood cells that fight infection. If you do not have

enough white cells, even a minor infection like a cold or a sore throat could make you ill. During each treatment cycle, you will have blood tests to make sure that you have enough white blood cells.

Your doctor will ask you to watch out for signs of infection at all times, especially if your white cell count is low. These signs could include feeling shivery and unwell or running a high temperature of 38°C or higher. If this happens, even at night-time, tell your hospital doctor straight away. He or she will tell you what to do. Some hospitals prefer you to ring them directly. You can check with your nurse or doctor before you start treatment. If you have a high temperature or feel unwell, you will need to have a blood test to check if your white cells are low. You may need medication to treat the infection.

You will be more at risk of picking up infections too. Try to avoid close contact (such as hugging or kissing) with people who have colds or flu and other infections such as chickenpox, shingles or measles. Let your doctor know if you are in contact with these or any other infections. Wash your hands often during the day, especially before you eat and after going to the toilet.

Bruising: The drugs may also reduce the number of blood cells called platelets. If there are not enough platelets in your blood, you may bleed or bruise more easily, even from a minor injury. Let your doctor or nurse know straight away if you are bruising easily or notice tiny red spots under your skin like a rash. You may need a platelet transfusion if the number of cells is very low.

Anaemia: Chemotherapy can also lower the number of red blood cells (haemoglobin) in your blood. This is known as anaemia. If you have anaemia, you may feel very tired and breathless. It can be treated with blood transfusions if needed.

Feeling sick or getting sick: Not everyone feels sick or gets sick with chemotherapy. It all depends on the drugs being given. But if you do, it can happen before, during or after treatment and may last for several hours. Your doctor or nurse will give you medication to stop you feeling sick. This may be as an injection or tablet. While on treatment, take the medication as advised by your doctor or nurse.

Numbness/pins and needles in hands and feet: Some of the drugs may cause a tingling or burning sensation in your hands and feet. You may have trouble picking up small objects or buttoning up a shirt or jacket. This side-effect usually goes away after treatment stops. But it may take several months for the numbness to fully go away. Tell your doctor or nurse if you get this side-effect, as some changes may need to be made to your treatment.

Shortness of breath: In rare cases, the drug bleomycin may cause inflammation of the lungs. This can lead to shortness of breath. Your doctors will check your lungs before, during and after treatment. If you notice a change in your breathing, tell your doctor as soon as possible. He or she may stop or reduce the amount of drug you receive.

Diarrhoea: Some of the drugs can cause diarrhoea. Passing watery bowel motions more than twice a day is known as diarrhoea. You may also have cramping and/or abdominal pain. If this happens, drink lots of clear fluids to replace the fluid you are losing. Do tell your doctor or nurse if you have diarrhoea for more than 24 hours. There is medication that can stop this side-effect.

Sore mouth: Some drugs may cause a sore mouth. They can also cause little ulcers to appear on your tongue, gums and inside your cheeks. To help prevent mouth infection, keep your teeth, gums and mouth very clean. Clean your teeth after each meal using a soft toothbrush. If you have dentures, remove them if your gums are sore. There are also special mouthwashes available. Your nurse will give you advice and show you how to use them properly.

If your mouth or throat becomes very painful, let your doctor or nurse know as soon as possible. Your doctor can prescribe painkillers or other medication to treat the infection if needed.

Feeling very tired: It is normal to feel very tired during treatment. This tiredness can last for some weeks after treatment has ended. If this happens, take things easier. Do less than you would normally do. Rest more if you can. Ask your family or friends to help you at work

or at home. Do tell your doctor about the way you are feeling during your treatment as most side-effects can be eased with medication. See page 39 for more about fatigue.

Not wanting to eat: It is often hard to eat well due to chemotherapy. But try to eat as well as you can to keep your strength up and speed up your recovery. It can help to eat smaller amounts often. If you do not feel like eating during treatment, ask to see a dietitian who can give you special advice about what to eat. This can include special food supplements. You can also call the National Cancer Helpline 1800 200 700 for a copy of the booklet, *Diet and Cancer*.

Hair loss (alopecia): This is a common side-effect of drugs used to treat testicular cancer. If you do lose your hair, it usually happens about 2–3 weeks after starting chemotherapy. Try not to worry, as your hair will start to grow again once treatment ends.

You might feel upset at the thought of losing your hair. Talk to your nurse or medical social worker about ways to cope with hair loss. You can get a wig or hairpiece when it happens or you may prefer to wear a hat or bandana.

If you would like a wig/hairpiece, do organise it before your hair falls out. You will then get a better match to your own hair colour. Your medical social worker or nurse may be able to advise you about getting a wig. If your hospital does not have a social worker, ask if they have the name of a wig fitter that you could go to see. Your local hairdresser may be able to help as well. In some cases you might be able to get financial assistance towards the cost of a wig or hairpiece. Ask your medical social worker or nurse for more information. You can also call the National Cancer Helpline 1800 200 700 for a copy of the factsheet, *Hair Loss and Cancer*.

Hearing changes: In some cases, the drug cisplatin can cause ringing in your ears (tinnitus). You may not be able to hear some high-pitched sounds as well. This side-effect usually improves when treatment ends. Let your doctor know if you have any problems with your hearing. You may need to have a hearing test done.

Cancer Helpline 1800 200 700

Infertility: Some of the drugs used to treat testicular cancer may cause infertility. It may be temporary or permanent. See page 37 for more information.

Other side-effects: If you have a side-effect or symptom not listed above, tell your doctor or nurse straight away. He or she will tell you what to do. For more information on chemotherapy, contact the National Cancer Helpline 1800 200 700 for a copy of the free booklet *Understanding Chemotherapy*.

Teenagers and chemotherapy

There are some things to keep in mind if your son is having chemotherapy. Most teenagers can go to school in between courses of chemotherapy. But do let the teachers know about your son's illness. Ask them to tell you when there are any infections in your son's class. This can include chickenpox, shingles or measles.



Try not to let your child get overtired. For this reason, it may help to avoid games and PE during treatment. It might be hard for your child to go back to school as he might be embarrassed about hair loss. Try to let him express his feelings and gently encourage him. Do let your child keep in touch with his friends and keep life as normal as possible. If there is a problem, talk to the doctor and teachers about it. Gentle reassurance and a little counselling can help resolve any issues.

If your son would like to talk to other teenagers who have had treatment for cancer, you can contact CanTeen. This is a support group for teenagers in Ireland. Please contact the National Cancer Helpline 1800 200 700 for more details.



To sum up

- Chemotherapy is a treatment using drugs to cure or control testicular cancer.
- Chemotherapy can be given in tablet form, 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.

High-dose chemotherapy with stem cell support

For some men there is a high chance of the cancer coming back even after treatment. Other men might need more treatment, if the cancer did not fully respond to the first treatment. Very high doses of chemotherapy can sometimes be given in these cases. A side-effect of high-dose treatment is that it destroys the bone marrow that makes the blood cells in your body. For this reason, the bone marrow is removed before treatment and replaced afterwards.

Even though the word 'transplant' is used, your own bone marrow or stem cells are actually involved. Stem cells are the basic cells in the bone marrow from which all other blood cells grow.

There are two ways to do the transplant: a peripheral blood stem cell transplant (PBSCT) and an autologous bone marrow transplant (ABMT). You are more likely to be offered a peripheral blood stem cell transplant.

Peripheral blood stem cell transplant

When the stem cells are taken from the bloodstream, it is called a peripheral blood stem cell transplant (PBSCT).

Collecting the stem cells: Before the stem cells are collected from the bloodstream, they are first moved out of the bone marrow. This is done by stimulating the bone marrow to make a lot of stem cells. As a result, the bone marrow gets overcrowded and the extra stem cells spill over into the bloodstream. Chemotherapy and/or a special drug called a growth factor are used to stimulate the bone marrow.

The chemotherapy is usually given over a couple of days. The growth factor is given daily for 10–14 days as a small injection under your skin. After about 10 days when your blood is ready, the stem cells are collected. This takes about 3–4 hours each day for 2 to 3 days. Sometimes all the stem cells that are needed are collected in one day.

The stem cells are collected using a central line or a drip put into a large vein in your arm. Blood is taken out through the central line or drip into a machine that separates the stem cells from the rest of your blood. The stem cells are collected into a bag and the rest of the blood is returned to you. The stem cells are frozen until you have had the high-dose chemotherapy.

Giving the high-dose treatment: After a rest period, you are given the high-dose chemotherapy. It is normally given over a few days. Some of the drugs used include carboplatin, etoposide or cyclophosphamide. Your doctor will let you know which drugs are being used and for how long.

Returning the stem cells: After the high-dose chemotherapy, the stem cells are thawed out. They are then returned to you through a drip or central line. These stem cells will help your bone marrow to recover from the effects of treatment. This normally takes about 2 weeks. But it may take 6–12 months before you are fully recovered from the effects of the treatment. You may need to stay in hospital for several weeks due to infection or other effects of treatment.

Autologous bone marrow transplant

If the cells are taken directly from your own bone marrow, this is called an autologous bone marrow transplant (ABMT).

Taking bone marrow: The bone marrow is usually taken from your hip bones. It can be uncomfortable so a general anaesthetic is given beforehand. You cannot eat or drink for several hours before the anaesthetic. But your doctor may give you a sedative before going to theatre to relax you.

Once you are asleep, a thin needle is passed through your skin into the hip bone. The bone marrow is drawn up through the needle into a syringe and stored until needed. Bone marrow is usually taken from both hips. It takes about 30–40 minutes from start to finish. You cannot eat or drink anything for at least 4 hours afterwards. Your hips may feel tender and sore for a few days afterwards. Do ask your nurse for painkillers if you need them.

Giving high-dose treatment: The high-dose chemotherapy is normally given over a few days. Some drugs used include carboplatin, etoposide or cyclophosphamide. Your doctor will let you know which drugs are being used and for how long.

Returning bone marrow: After chemotherapy, the bone marrow is returned to you in a drip through a central line. It will take your bone marrow some weeks to recover and be able to fight infection again. But it may take 6–12 months before you are fully recovered from the effects of the treatment. You may need to stay in hospital for several weeks due to infection or other effects of treatment.

Discussing your options

Do ask your doctor questions about the high-dose treatment if you are unsure about it. There is a lot involved so it can be a little hard to explain. But it is important that you know why it is needed and for how long. Do ask about any side-effects that you can expect. It can help to write down your questions before you talk to your doctor.

What follow-up do I need?

No matter what type of treatment you get, you will still need to come back for regular check-ups. This is known as **follow-up**. At first these visits to the specialist will be quite often, sometimes every 3 or 4 months for the first 2 years. After 2 years, the visits may be just once or twice a year, depending on the treatment you received. Your doctor will let you know how often he or she 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 can check for signs of testicular cancer. Some testicular cancers have a high rate of recurrence after surgery. 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 worrying you, let your doctor know.

>>> You will have to see your doctor for regular check-ups.

Will treatment affect my sex life?

It is natural for you to be concerned about your sex life. Men often ask if it will be affected after treatment.

Physical effects: If your other testicle is healthy, then it will probably not affect your sex life or ability to have children. The remaining testicle will make more testosterone and sperm instead. There is no medical reason why you cannot have sex while on chemotherapy or radiotherapy, although you may feel too tired for it. Do not assume that you are infertile during or after treatment. If you are having sex, you must use a condom during treatment and for some time afterwards.

Sometimes the nerves near the lymph nodes get damaged during surgery. As a result, some men may get a dry orgasm. There are ways to help this problem, so do talk to your doctor if it happens.

Psychological effects: The impact of cancer may affect your sex life. It may take a while to adjust to your diagnosis and the loss of your testicle. Having a false (prosthetic) testicle can help. It will take time to get used to your false testicle but it will gradually happen.

During your diagnosis and treatment, you may experience a range of emotions that can leave you confused. As a result, it can be hard to relax and you may lose your sex drive.

There is no set time for you to be ready to have sex again. It varies from person to person. Once you return to your usual routine after treatment, your interest in sex should return. If you have a supportive partner, you may find that talking about your feelings may help ease your anxiety. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. He or she may refer you for specialist counselling if you feel that would be helpful.

Some people fear that cancer can be passed on to a partner during sex. This does not happen. It is quite safe for you to have sex again with your partner.

Will treatment affect my fertility?

Many men go on to father healthy babies after treatment for cancer. Even so, some treatments for testicular cancer can cause infertility. Sperm tests will be done before treatment to see if you are infertile or if your sperm count is low. This infertility may only last a short while or may be permanent. Before treatment begins, your doctor will talk to you about this in more detail. If you have a partner, it can help if you both see the doctor together to talk about your fears and worries.

»»» Many men go on to father healthy children after they have had treatment for cancer.

Sperm banking

Because testicular cancer is curable, do give yourself time to think about the future. If your sperm count is within normal limits, it may be possible to store your sperm before treatment begins. It can then be used at a later date. To do this, you will be asked to give several sperm samples. There will be a break for a couple of days between each sample to make sure good samples are received. The sperm is then frozen and stored until needed. Sperm banking can be done at the HARI Unit at the Rotunda Hospital in Dublin. Do not worry that collecting the sperm will delay the start of treatment. It is usually done while other tests are being carried out and you are waiting for results. For more information, talk to your doctor or nurse or call the National Cancer Helpline 1800 200 700.

Chemotherapy

Chemotherapy is known to cause infertility. This can happen in the short term or be permanent. Sometimes it can be hard for doctors to predict which drugs will cause lasting infertility. For this reason, it is best to store sperm before treatment starts. It can also be hard to tell how quickly your sperm count will recover. But it generally returns to normal within 2 to 3 years.

It is not known for certain what effect chemotherapy has on sperm. As a result, do use a condom during sex to protect your partner. Use it throughout treatment and for about a month afterwards. If there is a chance your partner could become pregnant, continue to use condoms or other reliable methods of contraception for some time afterwards. This is to reduce the risk of miscarriage or birth defects in babies conceived during or just after treatment.

Many doctors believe it is better for you and your partner to wait at least 2 years after treatment ends before getting pregnant. This gives you a chance to recover from the treatment and there is a low risk of the disease coming back by then.

Surgery

Testicle: If you have just one testicle left after surgery, you are unlikely to be infertile. If the second testicle is removed due to cancer, you will be infertile. You may need to take testosterone supplements for life.

Lymph nodes: Some men need an operation to remove the lymph nodes in the pelvis or at the back of the abdomen. This can happen if they are still enlarged after radiotherapy or chemotherapy. This type of surgery can affect the nerves that go to the sexual organs. If this happens, you may have problems with the release of sperm (ejaculation). This only happens in a few men and may clear up over time. Sometimes the damage is permanent. But this is less of a problem now that new ways of doing the surgery are being developed.

Radiotherapy

Most radiotherapy treatments for testicular cancer do not affect your fertility. You will still be able to father a child. But during treatment a small dose of radiation can reach the remaining testicle. If you are having sex and your partner is fertile, you must use a reliable method of contraception. This should last throughout your treatment and for some time afterwards. This will reduce the risk of miscarriage or birth defects in children conceived during or just after treatment.

Many doctors believe it is better for you and your partner to wait at least 2 years after treatment ends before getting pregnant. This gives you a good chance to recover from the treatment.

Dealing with infertility

Dealing with infertility may not be easy, especially if you are a young man. It may not have been something you thought about before. It can bring feelings of sadness, anger and loss of identity. You may also feel embarrassed over 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 is a common symptom with cancer and its treatment. It is often described as an overwhelming tiredness. You may also find it hard to concentrate or make decisions. The reason for this fatigue can be hard to identify at first. It can be caused by worry when a diagnosis of cancer is made or the added stress caused by treatment.

If you are feeling very worried, you may find it hard to sleep at night. Do tell your doctor or nurse, who may be able to help. Also, try talking to your family or close friends about your concerns. If you find this difficult, ask to see a counsellor. He or she will help you to find ways to cope.

If you are able for physical exercise, get some regularly. For example, a 30-minute walk 3 days a week might be a goal to boost your morale when you achieve it. Do get others to help you around the house, with travelling to hospital, at work, with the children or with shopping. You can use the extra free time to do something that you especially enjoy.

A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.

Cancer Helpline 1800 200 700



Tips & Hints – fatigue

- Stop before you get overtired.
- Build rest periods into your day. If you are going somewhere special, have a rest before you go out.
- Save your energy for doing the things you most enjoy.
- Ask for help at work or at home, especially with cooking, gardening, housework or childcare.
- Keep your energy for eating. Eat little and often and use ready-made meals or snacks.
- Wear clothes that are easy to put on and take off.
- Sit down when getting dressed or doing household jobs.
- If you find it hard to sleep, make sure your bedroom is quiet and not too hot or cold.
- Do some gentle exercise each day. Ask your doctor or nurse for advice.
- Go to bed each night at the same time. Each morning get up at same time and do not lie in.
- Use relaxation techniques to get to sleep, such as gentle exercise, relaxation tapes, etc.
- Avoid stimulants before bedtime, such as alcohol, coffee, tea, coke or chocolate.



Research – what is a clinical trial?

Research into new ways of treating testicular cancer goes on all the time. By using new drugs or new combinations of drugs and treatments already in use, doctors can find new and better ways of treating cancer. Many patients with cancer take part in research studies today. Even though the word 'research' or 'new drug' sometimes scares people, there is no need for fear. Before a drug or treatment is used on patients, it goes through many stages to make sure it is safe to use.



Phases of research

There are many stages or **phases** when research is being done. If a drug or treatment looks as if might be useful in treating cancer, it is given to patients in research studies called **clinical trials**. These aim to find a safe dose, see what side-effects may occur and see which cancers can be treated.

If early studies suggest that a new drug may be both safe and effective, further trials are carried out. These aim to:

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

Taking part in clinical trials

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

You cannot be included in a clinical trial without your permission. You can only give this consent if the trial has been fully explained to you, so that you understand what it is about. This is called **informed consent**. You will also need time to think about it and discuss it with your family or friends. If you decide not to take part, you will still be given the best proven treatment available. Even after agreeing to take part in a trial, you can still withdraw at any time if you change your mind. As part of research into the causes of cancer, your doctors may ask your permission to store some samples of your cancer cells or blood.

For more information call the National Cancer Helpline 1800 200 700.

Cancer and complementary therapies

There is great interest today in complementary treatments for cancer. Some people find them helpful and beneficial during their illness. The way cancer is treated often depends on the culture of the country you live in. In Ireland cancer treatments are based on scientific research, which allows the response to treatment, side-effects and the general effect of treatment to be predicted. You may hear about the following types of treatments or therapies.

Conventional therapies

Conventional therapies are treatments that doctors most often use to treat people with cancer. These include surgery, radiotherapy, chemotherapy and biological therapies. They are tried and trusted methods where there is a long history of use. Many of the treatments have been tested in clinical trials.

Complementary therapies

Complementary therapies are treatments that are sometimes given **together with** conventional treatment. They include therapies such as:

- Meditation
- Relaxation
- Visualisation
- Gentle massage
- Aromatherapy
- Reflexology
- Music, art and dance therapy
- Nutrition therapy
- Shiatsu
- Yoga
- Acupuncture
- Hypnotherapy

Many people find complementary therapies are very helpful in a number of ways. You may feel more positive about yourself and your illness. You may be better able to cope with the physical side-effects of cancer and the distressing emotions that it can often bring. Some complementary therapies also focus on the spiritual dimension of a person to aid healing.

Alternative therapies

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

Most doctors do not believe that such treatments can cure or control cancer.



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



Before you decide to change your treatment or add any methods of your own, be sure to talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects. For that reason, it is important to talk openly with your GP or cancer specialist if you are thinking of having treatment with either a complementary or alternative practitioner. Don't be afraid that your doctor will be offended by your wish for other treatments. In fact, he or she may be able to recommend therapies that could be safe and useful for you.

Be cautious in selecting a practitioner. Don't be misled by promises of cures. At present in Ireland, this area is not fully regulated. Ensure that the practitioners you plan to visit are properly qualified and have a good reputation. Check to see if they belong to a professional body or not. If you are unsure but would like to know what other patients have found helpful, contact your doctor or a patient support group. Also, it is important to make sure that the practitioner is charging a fair price for your treatment.

More information is available in a free booklet from the Irish Cancer Society called *Understanding Cancer and Complementary Therapies. A Guide for Cancer Patients*. If you would like a copy or more advice, call the National Cancer Helpline 1800 200 700.

Coping and emotions

How can I cope with my feelings?

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

Common reactions include:

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



Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. A helpful booklet which discusses them in detail is called *Understanding the Emotional Effects of Cancer* and is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.

Shock and disbelief

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

Shock is often the first reaction to a cancer diagnosis. In fact, you may feel numb and the situation may seem unreal. Many people think cancer will never happen to them and are totally shocked when it does. Even if your doctor and nurse discuss the cancer with you, the news may not sink in for a while. You may find yourself confused, asking the same questions over and over again.

Or else you may accept the news calmly and say nothing because you cannot believe what is happening to you.

Fear and uncertainty

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

There is no doubt that cancer is a scary word. Not surprisingly, you may have many fears when first told of your diagnosis. Often the first thing people think about is dying. They think the worst. But nowadays many cancers, especially testicular cancer, can be cured or controlled with modern treatments. Another great fear about cancer is pain. The fear of pain can sometimes overwhelm everything else. However, some cancers cause no physical pain at all or else can be controlled with good painkillers.

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

It is natural for you to be afraid or concerned about the future too. You may wonder if you will be cured or if your cancer will recur. Living with this uncertainty can make you feel anxious and fearful. You may not wish to make any plans or decisions. Discuss your concerns with your doctor, nurse or medical social worker, who will give you advice and help. If living with uncertainty overwhelms you, it may help to talk to someone in a support group.

Loss of control

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

After a cancer diagnosis, it is common for people to feel their life is beyond their control. All your plans may be put on hold. You may even lose some independence and freedom. Because you don't know enough about your illness at first, you may rely totally on the advice of your doctors and

nurses. You may not feel confident to make any decisions about your treatment. When you experience a loss of control, it can lead to feelings of helplessness. You may also feel that you will be unable to cope with your treatment or that you will 'fall to pieces' or 'go crazy'. You may even lose hope.

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

>>> Learning more about your illness and treatment can help you feel more in control.

Sorrow and sadness

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

It is natural to feel sad when told you have cancer. You may feel sad for a variety of reasons: for the loss of your good health, for the plans that are put on hold, for the people you feel you've let down, and for any changes to your body due to treatment. Depending on your type of cancer, your fertility or body image may be affected by treatment. In this case, the sadness or sorrow can come from feeling as if a part of you has died. These feelings may not be there all the time and may come and go, but will gradually fade.

Denial

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

Sometimes after being told their diagnosis, people deny they have cancer. While this may seem unusual, it is a valid way of coping. As a result, you may not wish to mention or discuss your illness. Or else you may talk as if your illness is nothing serious. Denial may last for a short or long time, depending on how long it takes for you to adjust to your illness. Tell your family and

close friends that you would prefer not to talk about your illness, at least for the time being. Your doctors and nurses will also understand if you don't want to hear any information about your cancer until you're ready.

Anger

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

It is normal too to be very upset when told you have cancer. Many aspects of your illness can result in anger and distress. Anger can often hide other feelings such as fear, sadness or frustration. You may feel angry towards the doctors and nurses who are caring for you. Or if you have a religious belief, you may feel angry with God for allowing cancer to occur. You may vent your anger on those closest to you. Indeed being unable to protect the ones you love may frustrate you a lot.

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

Resentment

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

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

On the other hand, sometimes relatives, especially adolescents, can resent the changes that your illness makes to their lives. It is best to

admit that these feelings of resentment exist and to express them. Bottling up resentment helps no one. Instead everyone ends up feeling angry and guilty.

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

Blame and guilt

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

When diagnosed with a serious illness such as cancer, it is natural to want to know what caused it. Sometimes people blame themselves or others for their illness. As cancer experts rarely know exactly what has caused cancer, there is no good in blaming yourself. Other times, people feel guilty because they delayed going to the doctor with their symptoms, fearing the worst. No matter what the reason, don't torture yourself at this time.

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

Withdrawal and isolation

'I just need to be on my own.'

There is no doubt that a cancer diagnosis is stressful. It can leave you feeling confused and overwhelmed with so much information to take in. At times during your illness you may want to be left alone and withdraw from people. It is normal for you to need time to sort out your thoughts and feelings. You will want to take stock of things and work out how best you can cope. However, it is not a good idea to spend long hours on your own every day. Sometimes depression can make you avoid family and friends and stop you wanting to talk. If you isolate yourself, it can be hard for

your family and friends, as they will want to share this difficult time with you. They may worry about you needlessly. Let your family and friends know that you will talk to them once you are ready.

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

Learning to cope

After any treatment for cancer it can take some time to come to terms with your emotions. Coping with the physical effects of treatment can also add to the burden of dealing with cancer.

While it is true that some treatments can have some unpleasant side-effects, many people are able to live a normal life during treatment. You will need to take some time off for your treatment as well as time afterwards to recover. Just do as much as you feel like and take plenty of rest. It is not a sign of failure to ask for help or to feel unable to cope on your own. Once other people understand how you are feeling, they can give you more support.

Positive emotions

A cancer experience can also bring positive emotions. However, it may be some time before you are ready to accept these emotions as positive. You may experience great love, affection and closeness by those around you, not only family and friends but also neighbours and even the healthcare team. With that can come a sense of gratitude too.

The experience of cancer can also bring personal growth and knowledge – it can make you realise where your strength lies and what is important in life for you. You may also get the chance to do and enjoy different things that you would never have done otherwise.



How can my family and friends help?

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

How to talk to someone with cancer

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



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

Be patient

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

Lost for Words: How to Talk to Someone with Cancer is a useful booklet written for relatives and friends of people with cancer. Call the National Cancer Helpline 1800 200 700 for a free copy.

How can I talk to my children?

A cancer diagnosis can affect an entire family. It can bring changes that may be either great or small. Even so, it is best to keep family life as normal as possible. Continue with school and other activities, with birthdays and celebrations or work commitments. It may take a while but families can learn to adjust to big changes in their lives.

Every family deals with cancer in its own way. You may feel that you do not want your illness to upset family life, or feel guilty that you cannot do activities with your children or that you're letting the children down. These are all natural feelings to have at this time.

Be honest

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

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

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

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

Coping with children's emotions

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

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

What else can I do?

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

- **Communicate with your family and close friends:** Do not keep your worries or symptoms secret from the people closest to you. This includes physical or emotional problems. Ask the person closest to you to come with you when visiting the doctor and when treatments will be discussed.
- **Live one day at a time:** Don't think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.
- **Live well:** Try to eat as well as you can. Eat little and often, using lots of different types of foods with plenty of fresh fruit and vegetables. Do some regular exercise that you enjoy. Take it easy at first, building up the amount you do as you feel stronger.

- **Expect change in your life:** Even though you may want to stick to your old routines, sometimes this may not be possible. It may take a while for you to adjust to your new routine. Remember that change may bring new opportunities and blessings.
- **Keep an open mind:** Don't feel you have to be positive all the time. Expect ups and downs during your cancer journey. There will be times when you feel low but don't feel guilty about it, as it will pass.
- **Seek information:** Be sure to ask your doctor as many questions as you can and get involved in decisions about your treatment. Always ask for information that is personal to you. Ask what side-effects you can expect so you can prepare for them. Build up as much information about your cancer and treatment as possible. Follow your doctor's instructions carefully. Take your medication. If you forget and are not sure what to do, ask your doctor or nurse. Keep a notebook of all your dates for blood tests, X-rays, scans, treatments, symptoms, side-effects, medications, and your general health. Keep a record of any emotions you are feeling too, especially strong ones.
- **Find what works for you:** It can help to use whatever way of coping that has helped you solve problems in the past. Some people are comfortable taking about their illness, others are not. You may prefer relaxation, meditation, walking, listening to music, or other approaches helpful. Do whatever suits you. But if it's not working, be open to finding a new way to cope.
- **Build a support network:** Be realistic about what you can manage by yourself. No man is an island, so seek help from those who want to support you. Talk to your family, friends, nurses or doctors. Meet with other patients in support groups and self-help groups as they can understand what you are going through. If the group does not suit you and is not helping, leave it.
- **Seek professional help:** If you have any low moods or strong emotions, talk to your close friends and family – or someone who is a good listener. If your emotions are still getting the better of you, discuss them with your nurse and doctor. They may advise you to talk to a trained counsellor or other specialist.

- **Spiritual care:** When faced with a cancer diagnosis and treatment, you may start thinking about the meaning of life and the afterlife. For some people spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation can help you to focus on what has value and meaning in your life. Even if you do not consider yourself a religious or spiritual person, it is still possible to get support from prayer or meditation. Some complementary therapies that have a spiritual dimension may also help you to focus on being positive and hopeful.
- **Express yourself:** Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of your cancer journey and can bring great healing and relief. Other forms of creative expression, such as music and art, may help too.

A useful booklet called *Understanding the Emotional Effects of Cancer* has been written for people with cancer and is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.



Support resources

Who else can help?

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

- Medical social worker
- Oncology liaison nurses
- Cancer nurse co-ordinators
- Psycho-oncology services
- Community welfare officer and community health services
- Support groups and cancer support centres
- Irish Cancer Society helpline nurses



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

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

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

Community health services: When you go home, there are various community health services available from your local health centre.

These centres have family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. If you live far from the hospital where you have been treated, your community welfare officer can also help with practical issues such as transport costs, financial worries, etc. All these people in community health services can provide advice and support. More information on the services is available either from the social worker in the hospital before you go home or at your local health centre.

Support groups: Joining a support group can put you in touch with people who have been in a similar situation. They can give you practical advice about living with cancer. There are a range of support groups that will support you and your family at time of diagnosis, throughout treatment and afterwards. A list of support groups is given at the back of this booklet. Cancer support centres are found in every county in Ireland and can offer a wide range of services. Some of these are listed at the back of this booklet.

Irish Cancer Society: The staff of the Cancer Information Service will be happy to discuss any concerns you or your family may have, at any stage of your illness. Call 1800 200 700 for information about any of the services outlined above or for support services in your area.

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

Health cover

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

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



At the end of this section there are also some useful telephone numbers and addresses for further help.

Hospital cover

At present, everyone is entitled to hospital inpatient services in a public ward in all public hospitals. There is a €75 a night charge up to a limit of €750 in 1 year. These charges do not apply to medical card holders. Higher rates apply for semi-private or private care.

Outpatient cover

If you go to the outpatients or A&E unit of a public hospital, without being referred there by a GP, you may be charged €100. There is no charge if you have a medical card or are admitted to hospital because of attending the A&E unit first.

Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services as well as outpatient services and medical appliances.

To qualify for a medical card depends on a means test. If you are over 70 and your weekly income is €700 or less, you can apply for a card. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office. If your means are above but close to the guidelines, you should apply for a card anyway as a card may be granted in some situations. For example, if you have a large amount of medical expenses. Also, you may qualify for a medical card because you have a cancer diagnosis. In this case, your spouse and children will not be covered if your means are over the limit.

GP visit card

If you do not qualify for a full medical card, you may be eligible for a GP visit card. This card covers visits to your doctor only and you will

have to pay for drugs, outpatient/inpatient charges and medical appliances yourself. It is means tested but will take into account your after-tax income and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker at the hospital or your HSE office to see if you are eligible.

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families including spouses and dependent children pay a limit of €100 each month to cover the cost of prescribed drugs, medicines and appliances. You can apply for cover under the scheme by contacting your local HSE office. You can also register for this scheme by filling in a registration form at your local pharmacy.

Private healthcare cover

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

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

Benefits and allowances

Information on the following is given in this section:

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



Illness Benefit

This is a benefit for insured people. Your eligibility will depend on your PRSI contributions. You must be under 66 and unable to work due to illness. Each week you must send a social welfare medical certificate signed by your doctor to the Dept of Social and Family Affairs, PO Box 1650, Dublin 1. Tel (01) 679 7777. These certificates are available from your GP and from the hospital you attend during inpatient care. You should send your claim to the Department within 7 days of becoming ill and unable to attend work. A delay might result in loss of payment. The benefit lasts for 2 years.

Disability Allowance

You might qualify for disability allowance if you are not eligible for illness benefit and not able to work for at least 1 year. Disability allowance is a weekly allowance paid to people with an injury, disease or a disability who are aged between 16 and 65. For this allowance you must satisfy a means test, normally live in Ireland and be medically suitable. To be medically suitable you should have an illness that has continued or may continue for at least 1 year.

You are allowed a free travel companion pass and a household benefits package – including an electricity or gas allowance, telephone allowance and free television licence – and a fuel allowance. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme.

Application forms are available from post offices, social welfare offices or the Disability Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Invalidity Pension

This is a pension paid instead of an illness benefit or disability allowance, if you are unable to work permanently. There are three cases where you can be eligible. (1) If you have been incapable of work for at least 12 months and likely to be incapable for at least another 12 months. (2) If you are permanently incapable of work. (3) If you are over the age of 60 and have a serious illness or incapacity.

Your eligibility will also depend on your PRSI contributions and you must normally live in Ireland. You are allowed a free travel pass and a household benefits package – including an electricity or gas allowance, telephone allowance and free television licence – and a fuel allowance. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from the Invalidity Pension Claims Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Carer's Allowance

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

Application forms are available from your social welfare office or from the Carer's Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Carer's Benefit

Under carer's leave legislation, you may be entitled to unpaid temporary leave from your employment. Or if you are employed but wish to care for a sick relative full time, you may qualify for a carer's benefit. This is a payment made to insured persons who leave the workforce to care for someone in need of full-time care and attention. You must be employed for 8 weeks in the 26-week period immediately before applying for the benefit. You must be aged 16 or over, normally live in Ireland, not be self-employed or employed while caring for the person, and not live in a hospital or nursing home. More information is available from the Carer's Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Appliances

For patients who have medical cards most appliances are free of charge. For example, you are entitled to a new hairpiece or wig every 6 months.

Travel to hospital

Patients can be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services to hospitals for outpatient appointments and day centres. Sometimes the HSE may assist with transport costs for a person who has to travel a long distance to a hospital.

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

Further information

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements that may be relevant to you. Always have your PPS number (old RSI number) to hand when you are enquiring about entitlements and benefits. The most direct way to check your eligibility is to contact:

- Your community welfare officer in your local health centre
- The medical social worker in the hospital you are attending.

For social welfare queries contact:

Information Service
Dept of Social and Family Affairs
Oisín House
212–213 Pearse Street
Dublin 2
Tel: 1850 662 244

Leaflet line: 1890 202 325
Email: info@welfare.ie
Website: www.welfare.ie

If you have queries about health and social services, contact the HSE office in your area. The Health Service Executive is based in four regions: HSE Dublin North East, HSE Dublin Mid-Leinster, HSE South, and HSE West. For more information contact:

HSE infoline: 1850 241 850; **Email:** info@hse.ie; **Website:** www.hse.ie.

HSE East Coast Area

[Co Wicklow, South East Dublin]
Southern Cross House
Southern Cross Business Park
Boghall Road
Bray
Co Wicklow
Tel: 01 2014 200

HSE Northern Area

[North Dublin]
Swords Business Campus
Balheary Road
Swords
Co Dublin
Tel: 01 8131 800

HSE South Western Area

[Co Kildare, West Wicklow, South Dublin]
Oak House
Millennium Park
Naas
Co Kildare
Tel: 045 880 400

HSE Midland Area

[Counties Laois, Offaly, Longford, Westmeath]
Head Office
Arden Road
Tullamore
Co Offaly
Tel: 057 9321 868

HSE Mid-Western Area

[Counties Clare, Limerick, Tipperary North]
Head Office
31/33 Catherine Street
Limerick
Tel: 061 483 286

HSE North Eastern Area

[Counties Cavan, Monaghan, Louth and Meath]
Head Office
Navan Road
Kells
Co Meath
Tel: 046 9280 500

HSE North Western Area

[Counties Donegal, Sligo, Leitrim and West Cavan]
Head Office
Manorhamilton
Co Leitrim
Tel: 071 9820 400 / 1850 636 313

HSE South Eastern Area

[Counties Carlow, Kilkenny, Wexford, Waterford, South Tipperary]
Head Office
Lacken
Dublin Road
Kilkenny
Tel: 056 7784 100

HSE Southern Area

[Counties Cork and Kerry]
Head Office
Wilton Road
Cork
Tel: 021 4545 011

HSE Western Area

[Counties Galway, Mayo and Roscommon]
Head Office
Merlin Park Regional Hospital
Galway
Tel: 091 751 131

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

Citizens Information Board (formerly Comhairle)

7th Floor, Hume House, Ballsbridge, Dublin 4
Tel: 01 605 9000

Citizen Information Service: 1890 777 121

Email: information@ciboard.ie

Website: www.citizensinformationboard.ie

There are also some booklets available that may help you. These include:

- *Information Guide to Health Services* (published by the Dept of Health and Children). Copies are available from your local HSE area office. Tel: 01 671 4711 for local HSE numbers.
- *Guide to Social Welfare Services* (published by the Dept of Social and Family Affairs). Copies available from the Dept of Social and Family Affairs. Tel: 01 874 8444. Email: info@welfare.ie. Website: www.welfare.ie
- *Entitlements for People with Disabilities* (published by Comhairle). Available from Citizens Information Board. Tel: 01 605 9000 / 1890 777 121. Email: information@ciboard.ie

If you have financial worries...

A diagnosis of cancer can also bring the added burden of financial worries. You may find that you have a lot more expenses as well as your normal outgoings, such as medication, travel, food, heating, laundry, clothing and childcare costs. If you are not able to work or unemployed, this may cause even more stress. It may be hard for you to recover from cancer if you are worried about providing for your family and keeping a roof over your head.

There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses arising due to your illness. See page 68 for more details. You can also call the National Cancer Helpline 1800 200 700 for ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 1890 283 438. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. See page 69 for contact details.

Irish Cancer Society services

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

- Cancer Information Service (CIS)
- Breast Cancer Information Service
- Prostate Cancer Information Service
- Counselling
- Night nursing
- Oncology liaison nurses
- Homecare nurses
- Cancer support groups
- Cancer information booklets
- Financial aid



Cancer Information Service (CIS)

The Society provides a Cancer Information Service with a wide range of services: the **National Cancer Helpline** is a freefone service that gives confidential information, support and guidance to people concerned about cancer. It is staffed by specialist cancer nurses who have access to the most up-to-date facts on cancer-related issues. These include prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other support services. The helpline can also put you in contact with the various support groups that are available. The helpline 1800 200 700 operates Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- All queries or concerns about cancer can be emailed to the CIS at helpline@irishcancer.ie.

- The **walk-in caller service** allows anyone with concerns about cancer to freely visit the Society to discuss them in private.
- **Message Board** is a bulletin board on our website (www.irishcancer.ie) that gives you the chance to post your comments.
- The **CancerChat** service is a live chatroom with a link to a Cancer Information Service nurse.

Breast Cancer Information Service

The Breast Cancer Information Service (formerly ABC) provides breast cancer information and support. It also funds breast cancer research. Its services are free and confidential. They include a national helpline, publications, one-to-one support, breast awareness talks and advocacy. The Breast Cancer Information Service freefone helpline 1800 30 90 40 runs Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

Prostate Cancer Information Service

The Prostate Cancer Information Service provides prostate cancer information and support. A Prostate Cancer Information Service freefone 1800 380 380 runs Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm. All queries or concerns about prostate cancer can be emailed to prostate@irishcancer.ie

Counselling

Coping with a diagnosis of cancer can be very stressful. Patients and their families sometimes find it difficult to come to terms with the illness. Many people feel that they cannot talk to a close friend or relative. Counselling can provide emotional support in a safe and confidential environment. Call the helpline to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Night nursing

The Irish Cancer Society can provide a night nurse, free of charge, for up to 70 hours (mainly at night) to families who are caring for a

seriously ill person at home. If you need help, you can find out more about this service from a member of the homecare team, your GP or local public health nurse.

Oncology liaison nurses

The Irish Cancer Society funds oncology liaison nurses who provide information as well as emotional and practical support to the patient and his or her family. Oncology liaison nurses work as part of the hospital team in specialist cancer centres.

Homecare nurses

Homecare nurses are specialist palliative care nurses who offer advice on pain control and other symptoms. These nurses work with GPs and public health nurses to form homecare teams bringing care and support, free of charge, to patients in their own homes. Based in local hospitals, health centres and hospices, they can be contacted through your GP or public health nurse. The Irish Cancer Society contributes financially to this service.

Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards.

Cancer information booklets

These booklets provide information on all aspects of cancer and its treatment. They also offer practical advice on learning how to cope with your illness. The booklets are available free of charge from the Irish Cancer Society.



Financial aid

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

schemes such as Travel2Care or Financial Aid. If you would like to request this kind of help, contact your oncology or medical social worker at the hospital where you have been treated. He/she should fill in an application form and return it to the Irish Cancer Society. If there is no social worker, another health professional involved in your care may apply on your behalf.



If you would like more information on any of the above services, call the National Cancer Helpline 1800 200 700.



Useful organisations

Irish Cancer Society

43/45 Northumberland Road
Dublin 4
Tel: 01 231 0500
National Cancer Helpline: 1800 200 700
Breast Cancer Information Service:
1800 30 90 40
Prostate Cancer Information Service:
1800 380 380
Email: helpline@irishcancer.ie
Website: www.cancer.ie

Citizens Information Board (formerly

Comhairle)
7th Floor, Hume House
Ballsbridge
Dublin 4
Citizen Information Service:
1890 777 121
Tel: 01 605 9000
Email: information@ciboard.ie
Website: www.citizensinformationboard.ie

Dept of Social and Family Affairs –

Information Service
Oisín House
212–213 Pearse Street
Dublin 2
Tel: 1850 662 244
Email: info@welfare.ie
Website: www.welfare.ie

HARI Unit (Human Assisted

Reproduction Ireland)
Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732
Website: www.rotunda.ie

Health Promotion HSE

Website: www.healthpromotion.ie

Money Advice and Budgeting Service (MABS)

Commercial House
Westend Commercial Village
Blanchardstown
Dublin 15
Tel: 812 9350
Freefone 1890 283 438
Email: ndl@mabs.ie
Website: www.mabs.ie

Health insurers

Hibernian AVIVA Health

(formerly VIVAS Health)
One Park Place
Hatch Street
Dublin 2
Tel: 1850 717 717
Email: info@hibernianavivahealth.ie
Website: www.hibernianavivahealth.ie

Quinn Healthcare (formerly BUPA)
Mill Island
Fermoy
Co Cork
Locall: 1890 700 890
Fax: 025 42122
Email: info@quinn-healthcare.com
Website: www.quinn-healthcare.com

Voluntary Health Insurance (VHI)
VHI House
Lower Abbey Street
Dublin 1
Tel: 01 872 4499
CallSave 1850 44 44 44
Email: info@vhi.ie
Website: www.vhi.ie

National support groups

Bowel Cancer Support Group
Irish Cancer Society
43/45 Northumberland Road
Dublin 4
Freefone 1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

CanTeen Ireland
Young Peoples' Cancer Support Group
Carmichael Centre
North Brunswick Street
Dublin 7
Tel: 01 872 2012
Email: canteen@oceanfree.net
Website: www.canteen.ie

Lymphoma Support Ireland
Irish Cancer Society
43/45 Northumberland Road
Dublin 4
Freefone 1800 200 700
Email: info@lymphoma.ie
Website: www.lymphoma.ie

Men Against Cancer (MAC)
c/o Irish Cancer Society
43/45 Northumberland Road

Dublin 4
Freefone 1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

Reach to Recovery
Irish Cancer Society
43/45 Northumberland Road
Dublin 4
Freefone 1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

Support groups & support centres

ARC Cancer Support Centre
ARC House
65 Eccles Street
Dublin 7
Tel: 01 830 7333
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

ARC Cancer Support Centre
ARC House
559 South Circular Road
Dublin 8
Tel: 01 707 8880
Email: info@arccancersupport.ie
Website: www.arccancersupport.ie

Beacon Cancer Support Centre
Suite 15
Beacon Court
Sandyford
Dublin 18
Tel: 01 213 5654

Bray Cancer Support & Information Centre
36B Main Street
Bray
Co Wicklow
Tel: 286 6966
Email: bcsc@iol.ie
Website: www.braycancersupport.ie

Cancer Information & Support Centre
Mid-Western Regional Hospital
Dooradoyle
Co Limerick
Tel: 061 485163
Website: www.midwesterncancercentre.ie

Cancer Support Centre
St Vincent's University Hospital
Elm Park
Dublin 4
Tel: 01 221 4000
Email: cancersupport@svuh.ie
Website: www.stvincents.ie

CARE – South Tipperary Cancer Support Centre
14 Wellington Street
Clonmel
Co Tipperary
Tel: 052 82667
Email: caresupport@eircom.net
Website: www.cancercare.ie

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

The Cuisle Centre
Cancer Support Group
Block Road
Portlaoise
Co Laois
Tel: 057 868 1492
Email: cuislecentre@eircom.net

Dóchas – Offaly Cancer Support
Teach Dóchas
Offaly Street
Tullamore
Co Offaly
Tel: 057 932 8268
Email: dochasoffaly@hotmail.com
Website: www.dochasoffaly.ie

Dundalk Cancer Support Group
Community Office
Dundalk Partnership Court
Park Street
Dundalk
Co Louth
Tel: 042 933 0288
Website: www.dconroy@actioncancer.org

Éist – Carlow Cancer Support Group
Tel: 087 767 3240 /
086 316 3838 / 085 144 0510

Éist – East Inishowen Cancer Support Group
Moville
Co Donegal
Tel: 074 938 2874

The Gary Kelly Support Centre
Georges Street
Drogheda
Co Louth
Tel: 041 980 5100
Email: services@gkcancersupport.com
Website: www.gkcancersupport.com

Greystones Cancer Support
La Touche Place
Greystones
Co Wicklow
Tel: 01 287 1601
Email: greystonescancersupport@eircom.net

HOPE
Enniscorthy Cancer Support & Information Centre
22 Upper Weafer Street
Enniscorthy
Co Wexford
Tel: 053 923 8555
Email: mary@hopesupportcentre.ie

Inis Aoihinn – Cancer Care West
Costello Road
University College Hospital Galway
Tel: 091 545 000
Email: info@cancercarewest.ie
Website: www.cancercarewest.ie

Kerry Cancer Support Group

Kerry-Lee
Oakpark Road
Tralee
Co Kerry
Tel: 087 230 8734
Email: kerrycancersupport@live.ie

LARCC Retreat Centre

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

Listowel Cancer Support Group

Bedford
Listowel
Co Kerry
Tel: 068 21741 / 087 237 0766

Little Way Cancer Support Centre

4 Woods Way
College Road
Clane
Co Kildare
Tel: 045 902 996
Email: littlewayclane@eircom.net
Website:
www.littlewaycancersupport.com

Little Way Cancer Support Centre

8 Stanhope Street
Athy
Co Kildare
Tel: 059 864 1701

Living Beyond Cancer

c/o Oncology Department
Letterkenny General Hospital
Letterkenny
Co Donegal
Tel: 074 912 5888 (Bleep 674)

Mayo Cancer Support Association

Rock Rose House
32 St Patrick's Avenue
Castlebar
Co Mayo
Tel: 094 903 8407

Roscommon Cancer Support Group

Vita House Family Centre
Abbey Street
Roscommon
Tel: 090 662 5898
Email: vitahouse@eircom.net

Sligo Cancer Support Centre

2A Wine Street
Sligo
Tel: 071 9670 399
Email: scsc@eircom.net
Website: www.slilocancersupport.ie

'Solais' – Donegal Cancer Support Centre

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

South East Cancer Foundation

7 Sealy Close
Earlscourt
Waterford
Tel: 051 876 629
Fax: 051 876 718
Email: infosecf@eircom.net

Suimhneas Cancer Support

Pastoral Centre
Church Road
Nenagh
Co Tipperary
Tel: 067 37403

Tallaght Cancer Support Group

Tel: 087 217 6486

The Tuam Cancer Care Centre

30 Temple Jarlath Court
High Street
Tuam
Co Galway
Tel: 093 28522
Email: tccg@eircom.net
Website: www.tuamcancer.org

West Clare Cancer Support Group

Tel: 086 357 9055

Wicklow Cancer Support

1 Morton's Lane
Wicklow
Tel: 087 691 4657 / 0404 32696

Useful contacts outside Republic of Ireland

Action Cancer

Action Cancer House
1 Marlborough Park
Belfast BT9 6XS
Tel: 028 9080 3344
Fax: 028 9080 3356
Email: info@actioncancer.org
Website: www.actioncancer.org

American Cancer Society

1599 Clifton Road NE
Atlanta, GA 30329-4251
Website: www.cancer.org

Cancerbackup/Macmillan Support (UK)

89 Albert Embankment
London SE1 7UQ
Tel: 0044 207 840 7840
Website: www.cancerbackup.org.uk

Cancer Research UK

Website: www.cancerhelp.org.uk

Lance Armstrong Foundation

Website: www.livestrong.org

Macmillan Support & Information Centre

Belfast City Hospital Trust
79–83 Lisburn Road

Belfast BT9 7AB
Tel: 028 9069 9202
Fax: 028 9069 9203
Email: cancer.info@bch.n-i.nhs.uk
Website: www.actioncancer.org

Mayo Clinic (US)

Website: www.mayoclinic.com

Memorial Sloan-Kettering Cancer Center (US)

Website: www.mskcc.org

National Cancer Institute (US)

Website: www.nci.nih.gov

Royal Marsden Hospital Foundation NHS Trust

Fulham Road
London SW3 6JJ
Tel: +44 20 7808 2811
Fax: +44 20 7808 2336
Website: www.royalmarsden.org

Sexual Dysfunction Association

Suite 301, Emblem House
London Bridge Hospital
27 Tooley Street
London SE1 2PR
Tel: 0044 0207 486 7262
Email: info@sda.uk.net
Website: www.sda.uk.net

Testicular Cancer Resource Network

Website: www.tc-cancer.com

The Ulster Cancer Foundation

40/42 Eglantine Avenue
Belfast BT9 6DX
Tel: 048 906 63281
Website: www.ulstercancer.co.uk

University of Pennsylvania Cancer Center

Website: www.oncolink.com

Wessex Cancer Trust (UK)

Website: www.wessexcancer.org

Helpful books

Free booklets from the Irish Cancer Society:

- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Radiation Therapy: A Patient Pathway (DVD)*
- *Understanding Cancer and Complementary Therapies*
- *Coping with Fatigue*
- *Understanding the Emotional Effects of Cancer*
- *Lost for Words: How to Talk to Someone with Cancer*
- *Who Can Ever Understand? Taking About Your Cancer*
- *Talking to Children about Cancer: A Guide for Parents*



Bald Head

Ferdia MacAnna
Raven Arts Press, 1991
ISBN 1-85186-047-9

It's Not about the Bike: My Journey Back to Life

Lance Armstrong
Yellow Jersey Press, 2001
ISBN 0-42517-961-3

Taking Control of Cancer

Beverly van der Molen
Class Publishing, 2003
ISBN 1-85959-091-8

The Chemotherapy and Radiation Therapy Survival Guide: Information, Suggestions, and Support to Help You Get through Treatment

Judith McKay, Nancee Hirano & Myles E Lampenfeld
New Harbinger, 1998
ISBN 1-57224-070-9

The Key Model: A New Strategy for Cancer Recovery

Dr Sean Collins & Rhoda Draper
Ardagh Clinic, 2004
ISBN 0-95214-445-X

The Which? Guide to Men's Health

Stephen Carroll
Consumers' Association, 1999
ISBN 0-85202-758-3

What You Really Need to Know about Cancer

Dr Robert Buckman
Pan, 1997
ISBN 0-330336-28-2

Explaining cancer to children

Why Mum? A Small Child with a Big Problem

Catherine Thornton
Veritas, 2005
ISBN 1-85390-891-6

The Secret C: Straight Talking About Cancer

Julie A Stokes
Winston's Wish, 2000
ISBN 0-95391-230-2

Helpful DVD

Understanding Radiation Therapy: A Patient Pathway

Call 1800 200 800 for a copy.
Website: www.cancer.ie

Questions to ask your doctor

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

- What is testicular cancer?
- How long will it take to get the test results?
- 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?
- Will surgery cure my cancer?
- How successful is this treatment for my cancer?
- Would I be suitable for a clinical trial?
- How long will my treatment take?
- Do I have to stay in hospital for my treatment?
- What side-effects or after-effects will I have?
- What can be done about side-effects?
- Is there anything I can do to help myself during treatment?
- How soon can I have sex after treatment?
- Will I be able to have children?
- Do I need to use contraception during my treatment? What will happen if my partner becomes pregnant while I am on treatment?
- How often will I need check-ups?
- Why do I need to attend for regular blood tests?
- What if the cancer comes back?

Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

Answer

6

Answer

7

Answer

8

Answer

9

Answer

10

Answer



Notes



Notes



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Susan Rowan, Patient Education Editor

Would you like more information?

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

Would you like to be a patient reviewer?

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

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

Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, education and research. If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact us.

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

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

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

