

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:

Medical social worker

Tel:

Surgeon/urologist

Tel:

Medical oncologist

Tel:

Radiation oncologist

Tel:

Radiation therapist

Tel:

Emergency number

Tel:

Treatments

Review dates

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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- *A Strategy for Cancer Control in Ireland*, National Cancer Forum, 2006.
- *Cancer in Ireland: A Summary, 1994–2005*, National Cancer Registry Ireland, 2005.
- *Guidelines on Testicular Cancer*, European Association of Urology, 2009.
- *Improving Outcomes in Urological Cancers: The Manual*, NICE Guidelines (UK), 2002.
- *Testicular Cancer Treatment*, National Cancer Institute (USA), 2009.
- *Cancer Nursing: Principles and Practice*, CH Yarbro, MH Frogge, M Goodman & SL Groenwald, Jones and Bartlett, 2000.
- *The Chemotherapy Source Book*, M Perry, Lippincott Williams and Wilkins, 1997.
http://www.ncri.ie/sites/ncri/files/factsheets/FACTSHEET_testis.pdf www.nccn.org
<http://www.nice.org.uk/guidance/IPG158>

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Contents

4 Introduction

About testicular cancer

- 5 What is cancer?
- 6 What are the testicles?
- 7 What is testicular cancer?
- 7 What causes testicular cancer?
- 8 Success of treatment for testicular cancer
- 9 What are the symptoms of testicular cancer?
- 10 How is testicular cancer diagnosed?
- 12 What are the types of testicular cancer?
- 12 What are the stages of testicular cancer?

Treatment and side-effects

- 15 How is testicular cancer treated?
- 16 Surgery
- 22 Chemotherapy
- 33 Radiotherapy
- 36 Will treatment affect my sex life?
- 38 Will treatment affect my fertility?
- 40 How can I cope with fatigue?
- 42 What follow-up do I need?
- 43 What if my cancer comes back?
- 45 Research – what is a clinical trial?
- 46 Cancer and complementary therapies

Coping and emotions

- 49 How can I cope with my feelings?
- 51 Family and friends
- 52 You and your partner
- 53 How to talk to someone with cancer
- 53 How can I talk to my children?
- 55 How can I help myself?

Support resources

- 57 Who else can help?
- 58 Health cover
- 62 Irish Cancer Society services
- 66 Useful organisations/Helpful books
- 73 What does that word mean?
- 75 Questions to ask your doctor

Introduction

This booklet has been written to help you understand more about testicular cancer. It is divided into four parts:

- **Part 1 About testicular cancer** gives an introduction to testicular cancer, including symptoms and diagnosis.
- **Part 2 Treatment and side-effects** discusses the different treatments used for testicular cancer and possible side-effects.
- **Part 3 Coping and emotions** discusses how you can cope with your feelings and the emotional effects of having testicular cancer.
- **Part 4 Support resources** gives information on further sources of help and support. This includes helpful organisations, books, support groups and websites. You will also find an easy-to-read explanation of words and terms used throughout this booklet.

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

>>> Reading this booklet

Remember you do not need to know everything about 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 on 1800 200 700. It is open Monday to Thursday 9am-7pm and Friday 9am to 5pm. Or you can also visit a Daffodil Centre. See page 63 for more about Daffodil Centres.



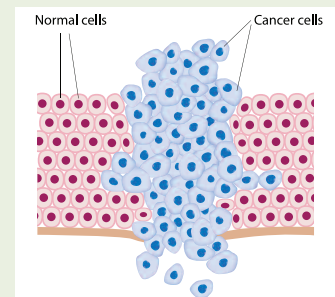
National Cancer Helpline Freefone 1800 200 700

About testicular cancer

>>> What is cancer?

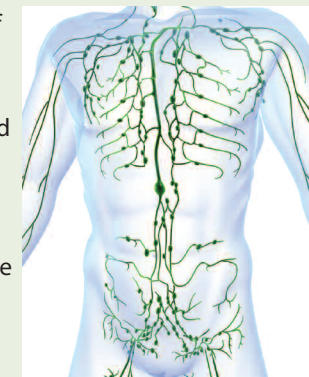
Cancer is a word used to describe a group of diseases, not just one. There are more than 100 different types of cancer. Each is named after the organ or type of cell in which the cancer first grows. For example, prostate cancer, breast cancer or leukaemia. All cancers are a disease of the body's cells, which are the building blocks of your body. Normally, cells grow and divide in a controlled way and replace old cells to keep the body healthy. But with cancer, the abnormal cells grow without control. Groups of abnormal cells can form a growth or tumour.

Tumours can be either benign or malignant. Benign tumours do not spread to other parts of your body but malignant tumours do. This happens when a cell or group of cells breaks away and is carried by your bloodstream or lymph vessels to other tissues and organs in your body. This is called a metastasis or secondary tumour.



What is the lymphatic system?

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



Lymphatic system



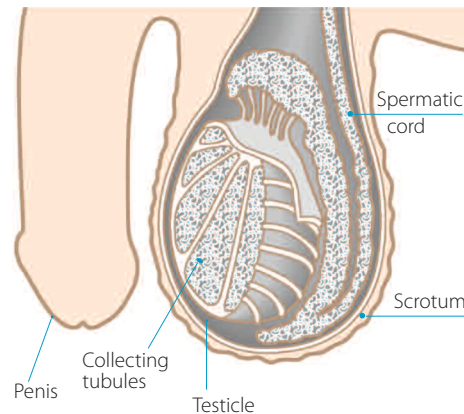
To sum up

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

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.



National Cancer Helpline Freefone 1800 200 700

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 12 for more about the types of testicular cancer.

How common is testicular cancer?

Testicular cancer is quite a rare cancer. It usually affects young or middle-aged men. It is the most common cancer in young men aged between 15 and 34 years. Each year about 175 men are diagnosed in Ireland. The number of men developing testicular 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 who were born with a testicle that did not come down into the scrotum before they were born. Having an operation to fix the testicle down in the scrotum at a young age can help to reduce the risk again.
- **Previous history of testicular cancer:** You are slightly more at risk of getting testicular cancer in your other testicle if you have had testicular cancer.
- **Family history of testicular cancer:** You are more at risk if your father or brother had the disease. Only about 1-2% of testicular cancers are thought to be related to family history.

- **Fertility problems:** If you have fertility problems, you have a slightly increased risk of testicular cancer. A vasectomy does not increase your risk of developing testicular cancer.
- **Ethnic group:** If you are white skinned you have a higher chance of getting testicular cancer than African-Caribbean or Asian men.

There is no evidence that injury to your testicle causes cancer. Sometimes if you get a knock to your testicle when you examine yourself you may notice a change in your testicle which you wouldn't have otherwise checked for. So it may be that the knock helps people notice testicular cancer because they become more aware of their testicle because of the pain.

Remember testicular cancer is not infectious and cannot be passed on to other people.



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, groin or abdomen (tummy)
- An enlarged testicle or change in the way your testicle feels
- A heavy feeling in your scrotum

If you feel any testicular lump it is important to go to your doctor. Most swellings in the scrotum are not cancer. Your doctor will examine you and decide if you need any further investigation or treatment.

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

About 10% of men with testicular cancer will have disease that has spread outside the testicle when they are diagnosed. This means that the first symptoms may be noticed in other parts of the body, such as

- A dull ache in your back
- Pain in your tummy (abdomen)
- Shortness of breath
- Swollen lymph glands in the abdomen, groin or chest



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 will be done:

- Ultrasound of the scrotum and testes
- Blood tests

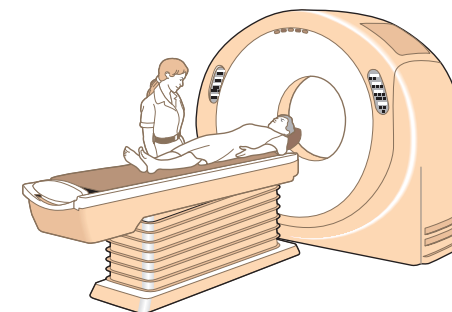
Ultrasound of the testicle: This is a scan that uses sound waves to look at the tissues inside your scrotum. It will show the lump in your testicle and can show if the lump is likely to be cancer or not. The scan only takes a few minutes and does not hurt. When lying on your back, the doctor will spread a gel over the area to be scanned. A small device is used to take the scan, which is changed into a picture by a computer. The test is done in the X-ray department of the hospital. It is normal for both your testicles to be scanned.

Blood tests: Often testicular cancers make chemicals that can be found in your bloodstream. These are called tumour markers. Blood tests will be taken to see if you have high levels of tumour markers. Tumour markers include Alpha-fetoprotein (AFP), Beta human chorionic gonadotrophin (bHCG) and Lactate dehydrogenase (LDH).

Removing the testicle (orchidectomy): If testicular cancer is suspected your testicle will usually be removed. When the lump has been removed it can be examined under a microscope. It is not usually possible to remove some tissue (a biopsy) without removing the 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 16 for more details.

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

The scan itself is painless. Your doctor or nurse will tell you how to prepare for the scan. You may be asked not to eat or drink for a few hours 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.



CT scan

Getting your test results

It may take a little time for all the test results to come back and you may feel very anxious while you are waiting. If you are diagnosed with testicular cancer you may feel a range of emotions, such as shock, fear or anger. You may also be worried about if and when to tell other people, and how to do it. There's no one right time or way to tell people about your cancer, but remember that every friend and family member will have their own emotional reaction to finding out that you have cancer. It may help to talk things over with a specialist nurse or with a relative or close friend. You can also speak in confidence to a specially trained nurse by calling the National Cancer Helpline on 1800 200 700. They can also put you in touch with another man who has had a testicular cancer diagnosis. For more information on dealing with feelings and emotions see page 49.

What are the types of testicular cancer?

There are different types of testicular cancer. Once the cancer cells are looked at under the microscope your doctor will be able to tell you which type you have. This will help your doctor to decide which type of treatment and after care you need.

Germ cell tumours: Most testicular cancers are germ cell tumours. Germ cells are cells that make sperm in men. There are two types of germ cell tumours, known as seminomas or 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 and respond very well to treatment. Men with a seminoma are at lower risk of cancer having spread at the time of diagnosis.

Non-seminomas: These tend to develop earlier in life than seminomas. They peak in men age 20-35. They include teratomas, embryonal cancers and mixed germ-cell tumours. They tend to grow and spread faster. Men with non-seminoma tumours are more likely to need additional treatment after surgery (see page 18 for information on treatment after surgery).

What are the stages of testicular cancer?

The results of your scan and other tests can help your doctor to stage the cancer.

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

See page 5 for more information on lymph nodes.

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

There are different ways to describe testicular cancer stages. The main way to stage testicular cancer is the Stage 1, 2 or 3 system. Some doctors may use other systems, such as the TNM system.

The stage 1, 2 or 3 system

Stage 1: This means the tumour is found only in the testicle. It has not spread and no lymph nodes are involved. Tumour markers (blood tests) are normal or only slightly raised. Stage 1s means markers are raised after surgery.

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

Stage 2a nodes are less than 2cm

Stage 2b nodes are 2-5cm

Stage 2c nodes are larger than 5cm.

Stage 3: Here the cancer has spread to other organs such as lungs, liver, bone and brain. This is known as metastasis.

Stage 3a means the cancer has spread to distant lymph nodes or to your lungs. Your blood marker level may be normal (S0) or slightly raised (S1).

Stage 3b means the cancer has spread to nearby lymph nodes or lungs and you have a moderately high marker level (S2).

Stage 3c can mean that you have a very high tumour markers (S3), or that your cancer has spread to another organ, such as the liver or brain.



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 will vary depending on the stage and type of the cancer.



Treatment and side-effects

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

How is testicular cancer treated?

Almost all men with testicular cancer have surgery to remove the affected testicle. This operation is known as an orchidectomy.

Very often everything moves very quickly if testicular cancer is suspected or diagnosed – you may have surgery to remove your testicle only a day or two after first going to hospital, sometimes before the results of your tests are available. It can be hard to take in what is happening and you may need some time afterwards to recover from the shock. If you need to talk to someone call the National Cancer Helpline to talk to a nurse or to be put in contact with a man who has had testicular cancer.

>>> Almost all men with testicular cancer have surgery to remove the affected testicle.

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

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

If you are confused about the treatment, let your doctor or nurse know straight away. They can explain it to you again. Some cancer treatments are complex, so it is not unusual for people to need repeated explanations. It is important that you know how the treatment is likely to affect you.

After orchidectomy your doctor will decide if you need any further treatment. Chemotherapy, further surgery, and radiotherapy can all be used to treat testicular cancer after orchidectomy. Rarely chemotherapy may be given before surgery. You may also be offered surveillance, which means closely monitoring you for any changes to your health.

In general, the type of treatment you receive after orchidectomy will depend on:

- The stage of your cancer (see page 12)
- 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 testicular cancer

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 ask some of the questions on page 75 or 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.

Surgery

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

remove the testicle. Usually the operation is done as quickly as possible after you have seen a urologist, often within a week or two. A few men will need to see another cancer doctor called an oncologist before they have surgery.

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

False testicle (prosthesis)

If you are worried about how you will feel about your body, it is possible to put in a false testicle (prosthesis). The prosthesis can be placed in your scrotum to give a more normal appearance. Most young men prefer to have one inserted. Prostheses are safe in the long term. They are filled with silicone or saline (salt water). They can feel firmer than your normal testicle. A small number of men find they can 'ride up' in warmer weather and may sit higher than before. Do talk to your surgeon to find out more about this before surgery.

After the operation

Once you have recovered from your anaesthetic you can move around and eat and drink normally. Usually you will have a dressing over the wound which can be removed after a day or so. You may get some pain for up to a week or so afterwards. Your doctor will prescribe painkillers for you. There is often some swelling or bruising of the scrotum for a while. It is best to avoid heavy lifting and vigorous exercise or sport for a few weeks after the operation.

Usually you can go home 1-2 days after the operation. You will be given instructions about removal of your stitches or clips if necessary. On the day you go home, you will usually be given a date to come back for a check-up.

Most men will be able to go back to work after a couple of weeks. Talk to your doctor first if your work involves heavy lifting.

It is normal to have your tumour markers (blood tests) checked again after your surgery. This may be done before you leave the hospital or you may have them checked at a later date.

Sex after orchidectomy

After an operation to remove one testicle you will still be able to have an erection and orgasm and continue your normal sex life. This surgery usually does not affect your ability to father a child (fertility). For more information on sexuality and fertility after other treatments for testicular cancer see pages 36–40.

Men with a single testicle

If you have only one testicle because of previous cancer, an undescended testicle or injury it may be possible to remove only the affected part of your testicle. Your doctor will talk to you in more detail if this applies to you. Your doctor will talk to you about testosterone replacement therapy if you must have an orchidectomy and your other testicle does not produce enough testosterone. Your doctor will also talk to you about sperm banking. For more information on sperm banking see page 39.



To sum up

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

Further treatment after orchidectomy

Why might I need more treatment after my testicle has been removed?

In testicular cancer you may have chemotherapy or radiotherapy:

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

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

Deciding on further treatment

Your doctor may ask you to make a decision about whether you want to have surveillance (monitoring your condition) or further treatment.

Sometimes people find it hard to make a decision like this. Make sure that you have enough information about the different options, what is involved and the possible side-effects, so that you can decide on the best choice for you.

Remember to ask questions about any aspects that you don't understand or feel worried about. It may help to discuss the benefits and disadvantages of each option with your doctor, nurse specialist or with our National Cancer Helpline or Daffodil Centre nurses.

It often helps to make a list of questions and to take a relative or close friend with you.

Treatment for seminoma after orchidectomy

Surveillance, chemotherapy and radiotherapy can be used in the treatment of seminomas after orchidectomy.

It is quite common to feel stressed and anxious about surveillance and about scans and appointments as they come near. Talk to your family and friends if you can or call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre and talk to our specialist nurses.



Surveillance: If you have early stage seminoma your doctor may decide to watch you closely. Blood tests, X-rays and scans will be done regularly. This means that you may avoid the need for chemotherapy and radiotherapy. If there are any changes in your condition you may be given chemotherapy or radiotherapy at a later date.

Chemotherapy: Chemotherapy can be given after surgery depending on the stage of the disease. In stage 1 cancer you will usually have a short course of chemotherapy. If you have stage 2 or 3 cancer that has spread to other parts of your body, you will need a long course of chemotherapy. See page 22 for more details on chemotherapy.

Radiotherapy: Radiotherapy can be given after surgery but this is rare. See page 33 for more details on radiotherapy.

Treatment for non-seminoma after orchidectomy

Surveillance, further surgery or chemotherapy can be used to treat non-seminomas after orchidectomy.

Surveillance: If you have early stage non-seminoma your doctor may decide to watch you closely. Blood tests, X-rays and scans will be done regularly. This means that you may avoid the need for chemotherapy or further surgery. If there are any changes in your condition you may need treatment at a later date.

Surgery: Surgery to remove the lymph nodes at the back of your abdomen (tummy) may be needed. This is known as retro peritoneal lymph node dissection or RPLND. See page 30 for more details on RPLND.

Chemotherapy: If your cancer has spread to other parts of your body or you are thought to have a high risk of the cancer coming back (recurrence) your doctor may recommend you have chemotherapy. If you have stage 1 non seminoma but have risk factors for recurrence you may have just 1 or 2 cycles of chemotherapy. If your cancer has spread outside of the testicle you may need to have more cycles of treatment. Your doctor will explain to you how much treatment you need. See page 22 for more details on chemotherapy.



To sum up

- The main treatment for testicular cancer is surgery.
- You may have further treatment after surgery or you may be suitable for surveillance, where your condition is monitored closely.
- A team of specialists (MDT) will decide which treatment is best for 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, called a multi-disciplinary team (MDT), will decide your treatment.



Urologist	A surgeon who specialises in diseases of the male reproductive system and urinary system.
Medical oncologist	A doctor who specialises in treating cancer patients using chemotherapy and other drugs.
Radiation oncologist	A doctor who specialises in treating cancer patients using radiotherapy.
Liaison oncology nurse/ clinical nurse specialist	A specially trained nurse. 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.

Chemotherapy

Chemotherapy is a treatment that uses drugs to destroy cancer cells. These drugs travel through your bloodstream to almost every part of your body. As a result, it can treat cancer cells wherever they are in your body.

If your cancer has spread to other parts of your body or if there is a high risk of your cancer coming back, your doctor may recommend chemotherapy for you.

Where do I get chemotherapy and for how long?

Chemotherapy 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. Your doctor or nurse will explain to you how often you need to have your treatment and how many cycles of treatment you need to have.

It can take a bit of time to get used to the fact that chemotherapy, which is designed to make you better, can make you feel worse when you are taking it. Call the National Cancer Helpline on 1800 200 700 if you need support or information on dealing with chemotherapy treatment.

Remember...

When you are having treatment you may need to plan ahead. Try and involve your friends and family. Let them know what is happening so that they can help with any arrangements that need to be made while you are having treatment school, work, childcare etc.

How is chemotherapy given?

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

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.

What chemotherapy drugs will I have?

If you have early stage seminoma, you may receive one cycle of carboplatin. Otherwise the drugs most commonly used in testicular cancer are bleomycin, etoposide and cisplatin, used together. This is often known as BEP chemotherapy. Other combinations of drugs may be used, for example your doctor may decide not to give you bleomycin if you have a lung condition. BEP is used for both seminoma and non-seminoma testicular cancer. Sometimes ifosfamide, etoposide and cisplatin (known as VIP) may be used instead of BEP.

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

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 chemotherapy side-effects:

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

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

Infection: Chemotherapy can affect your bone marrow, which is responsible for making blood cells. White blood cells fight infection and when these are low in your body (neutropenia) you are more prone to picking up infections. While on chemotherapy it is important to avoid children and adults who have colds or other infections, such as chickenpox, shingles or measles. You should contact your doctor if you have a sore throat, cough, pain passing urine, redness or swelling or have a temperature of 38°C (100.4°F) or higher. You should take extra care with your personal hygiene, making sure you wash your hands well after using the bathroom. Eat a well-balanced diet, wash foods thoroughly and avoid fast food or takeaway food. You will have regular blood tests to measure your number of white blood cells. Sometimes your doctor will prescribe a white blood cell growth factor called GCSF, which is given as an injection under your skin.

»»» If you are feeling shivery and unwell or running a high temperature of 38°C (100.4°F) or higher, tell your doctor straight away.

Bruising: Platelets are other blood cells that are made in your bone marrow. They help to stop bleeding by clotting the blood. If your platelet count is low (thrombocytopenia), you will be more prone to bruising and bleeding. Let your doctor know if you have unusual or prolonged bleeding or if you notice a pinpoint-like rash on your body. Your platelet count will be measured regularly and you may need a platelet transfusion.

Anaemia: Anaemia occurs when the red blood cells that carry oxygen around your body are reduced. You may feel very tired, breathless, dizzy and light-headed. You will have regular blood tests to measure your red blood cell count (haemoglobin). You may need a blood transfusion or your doctor may prescribe an injection called erythropoietin to make more red blood cells.

Feeling sick or getting sick: Some chemotherapy drugs make you feel sick (nausea) or get sick (vomit), but many people experience no sickness at all. When it occurs will depend on the drugs given. It can vary from soon after to several hours or even several days after chemotherapy injections.

If you are receiving a drug that can cause sickness, your doctor will prescribe medications to prevent it. These are called anti-emetics. You may receive them immediately before your treatment and in tablet form for when you go home. The aim of the anti-emetics is to prevent nausea and vomiting, so if you do experience any nausea or vomiting it is important to tell your doctor. Some anti-emetics work well for some people and not for others, and your doctor will be able to prescribe another one for you. You may need a combination of anti-emetics to help prevent any nausea and vomiting. If you are unsure how to manage nausea, contact the oncology nurse for advice. He or she will give you telephone numbers to call if you have problems due to chemotherapy, day or night.

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.

Lung changes and 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. Not smoking will help to reduce the risk of this happening to you. If you are a scuba diver then you should talk to your doctor about any possible risks of this associated with bleomycin treatment. If you need an anaesthetic for an operation after bleomycin you should also make sure you inform your anaesthetist that you have had this treatment

Constipation and diarrhoea: Chemotherapy can also cause a change in your bowel habits. Some drugs may cause diarrhoea. Passing watery bowel motions more than twice a day is known as diarrhoea. If you have diarrhoea you should drink plenty of fluids, avoid a high-fibre diet and contact your doctor if it persists. There are medications that can be taken to relieve this symptom. Chemotherapy may also slow down the movement of your bowel, making it difficult to pass a bowel motion. This is called constipation. If you get constipated, drink plenty of fluids and eat a high-fibre diet. Tell your doctor if it persists as you may need medication to help relieve it. For example, laxatives.

Sore mouth: The cells lining your mouth can be affected by chemotherapy, causing a sore mouth. It is important to take special care of your mouth. Your doctor will prescribe mouthwashes, which should be used regularly. You should use a soft toothbrush, remove and clean dentures regularly and drink plenty of fluids to keep your mouth moist. Keep your lips moist by applying Vaseline and avoid very hot or acidic drinks. If you develop an ulcer, let your doctor know, as these can become infected. Chemotherapy can also cause your sense of taste to change. This will improve after your treatment has finished.

Feeling very tired (fatigue): 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. Short walks each day are a good idea. 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 40 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, particularly BEP. Carboplatin does not usually cause hair loss. If you do lose your hair, it usually happens about 2–3 weeks after starting chemotherapy. Your hair will start to grow again once treatment ends. You might feel upset at the thought of losing your hair. Some people choose to cut it short or shave it off before treatment starts. Some men choose to cover up with a cap, beanie or bandana. Hair loss can affect how you see yourself and your confidence to go out with your friends. One way to help cope is to try not to compare how you look with how you looked before your treatment. Talk to your nurse or medical social worker about ways to cope with hair loss. When hair grows back after chemotherapy it may be a different colour or texture than it was before. It may be curlier, thicker or softer than it was.

Some men choose to get a wig. Medical card holders are entitled to a free or subsidised wig. For information on wig suppliers contact us for our factsheet: *Hair Loss and Cancer Treatment* by calling the National Cancer Helpline 1800 200 700 or dropping in to a Daffodil Centre. You can also download it from www.cancer.ie

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.

Changes in kidney function: Some drugs like Cisplatin can have an effect on your kidney function. You will have regular blood tests during your treatment to monitor for this.

Infertility: Some of the drugs used to treat testicular cancer may cause infertility. It may be temporary or permanent. See page 38 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, contact the National Cancer Helpline 1800 200 700 or visit a Daffodil Centre for a copy of the free booklet *Understanding Chemotherapy*. You can also download it from www.cancer.ie

Later side-effects: There is an increased risk of developing high cholesterol, diabetes and heart problems after having chemotherapy as a young adult. For this reason it is a good idea to follow a healthy lifestyle with good diet and exercise. Many years after chemotherapy there is a very slightly increased risk of developing a second cancer. For more information on your risks talk to your doctor.

After chemotherapy

You may continue to feel tired or have other side-effects for a few months or more after your chemotherapy treatment has ended, depending on the regime and number of cycles you have. Take this into account when you are considering going back to school or work or starting to do your normal activities again. You may not be able to go straight back to everything immediately after treatment. Ask for help with practical issues from friends and family. You should also let your doctor know if you continue to have side-effects for a long time after your treatment has ended. Your local cancer support centre can also help you during this time.

For parents: 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 if he has had chemotherapy. 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. Counselling is available free of charge through cancer support centres for those with cancer and their families. Brothers and sisters of cancer patients can be affected too.

If your son would like to talk to other teenagers who have had treatment for cancer, call the National Cancer Helpline 1800 200 700 or visit a Daffodil Centre for details of support groups, online forums and websites for young people with cancer. Some are also listed at the back of this book.



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.

Lymph node surgery – RPLND

For around one third of men who have cancer that has spread to lymph nodes these nodes may not shrink back to normal size after chemotherapy. It is very difficult to tell on a scan why they are enlarged. It may be due to a collection of dead cells in the glands, known as necrotic tissue. It may be because the nodes contain cells that may turn cancerous in the future or it may be due to cancer cells that remain. For this reason your doctor may advise you that you need to have an operation to remove these lymph nodes. This operation is called a retro peritoneal lymph node dissection or RPLND. RPLND removes the lymph nodes at the back of the tummy (abdomen). Sometimes RPLND surgery may be performed without chemotherapy.

You may have a special type of X-ray called a PET scan before an RPLND. This might be able to show if scar tissue or any remaining cancer cells are present, or your surgeon may need to operate again to remove these tissues to know for sure why they are still enlarged. The only way to know for sure why the glands have not shrunk back down is to take them out and send them to be looked at under a microscope.

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

All operations have a risk of complications such as bleeding and infection. In RPLND there is a risk of needing to have your kidney removed or you may need a graft to the blood vessels to or from your heart. Before your operation, your doctor will discuss these possible complications with you.

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

How do I prepare for an RPLND operation?

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

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

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

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

Morning of surgery: You will continue to fast at this time. Before you go to theatre, you may get a tablet to make you feel sleepy and more relaxed.

After the operation

You may stay in an Intensive Care or High Dependency Unit, sometimes called PACU (Post Anaesthesia Care Unit) where the staff will keep you under close observation for a day or two.

After surgery you will have a wound as well as drips attached to your body. These are normal in an operation like this.

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

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

Painkillers: You may have a thin tube in your back to relieve pain. This is called an epidural. You may have a pump which you can use

to give yourself painkillers. Your doctors and nurses will explain which type of pain killer you will have and will help to ease any pain or discomfort you have.

Bowel motions: The surgery will slow down your bowels for a short time. It can take from 3-10 days after an RPLND for your bowel to start moving again. Your doctors will check this with you after the operation. As a result, it may take a day or two before you can return to normal eating and drinking. At first, you will be able to take sips of water. Gradually the amount of fluids will be increased and you can begin to take light meals.

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

Recovery from RPLND

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

Sex and fertility after RPLND

RPLND surgery does not affect erections or the sensation of orgasm. But removing nerves during surgery may mean that you have 'dry orgasm' (anejaculation). This means that when you climax no liquid comes out of your penis. Your surgeon may be able to do an operation that spares the nerves near the lymph nodes to reduce the risk of this happening. You will also be given the chance to save your sperm beforehand and freeze it for later use. If you have dry orgasms you will be less fertile. See page 38 for more details on fertility.

Radiotherapy

Radiotherapy uses high-energy X-rays to kill cancer cells. The X-rays come from a machine called a linear accelerator. The aim of radiotherapy is to destroy cancer cells with as little damage as possible to normal cells. Radiotherapy only affects the area of your body being treated, unlike chemotherapy which can affect the cells in your entire body.

Radiotherapy is sometimes used in seminomas as they are very sensitive to radiation. Non-seminoma testicular cancer usually responds better to other types of treatment. Radiotherapy may be given to lymph nodes in the abdomen (tummy) known as retro-peritoneal nodes to help prevent testicular cancer spread or to treat cancer that has already spread.

Planning your radiotherapy 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.



CT simulator

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 with a tiny tattoo or pen so that the X-rays can be aimed at the same area each day.

Before starting radiotherapy, your nurse or radiation therapist will tell you how to look after your skin during and after treatment.

>>> Radiotherapy treatment for seminoma may last 2-3 weeks.

Getting your radiotherapy

Having radiotherapy is quite straightforward. You will need to go to hospital for treatment every day during the week, with a rest at weekends. Each treatment session only takes a few minutes. You will not feel any pain during treatment (just like when you have a scan, you do not feel the X-rays) 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 varies between patients and depends on the amount of radiotherapy received. Before treatment begins, your doctor or nurse will explain how these effects can be managed. Side-effects may include:

Feeling sick or getting sick: Radiation to the tummy (abdomen) may make you feel a bit sick. Your doctor can give you some medicine which can help. You may need to take these medicines regularly through your treatment. If you are troubled by nausea or sickness, talk to your nurse or radiation therapist. Try to eat little and often if you are troubled by sickness.

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 soap and creams. When you wash the area, use warm water and pat it dry with a soft towel. Do not rub the skin while washing and drying. 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 if you need to during this time, although gentle exercise can help to improve tiredness. It can help to cut down on activities while you are feeling tired. It is common for tiredness to continue for some time after treatment finishes so don't worry if this happens to you. See page 40 for more about fatigue.

Diarrhoea: You might get some diarrhoea during treatment. Usually this can be controlled with medicines that your doctor can give you. Let your nurse or radiation therapist know if you have diarrhoea and they can talk to you about the best way to deal with diarrhoea caused by radiation. They might advise you to alter what you eat for a while if you have diarrhoea. Eating a diet that is not too high in fibre can help ease diarrhoea.

Sex and fertility: Radiation to your lymph nodes does not normally affect sexual function or fertility.

>>> For information on your sex life and fertility see page 36.

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 or visit a Daffodil Centre 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.
- 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.

Will treatment affect my sex life?

It is natural for you to be concerned about your sex life – men often ask if treatment will affect their sex life. Treatment can affect you physically and mentally when it comes to sex. The important thing to remember is that the removal of one testicle will not affect your sexual performance or your ability to father children.

Physical effects

Surgery to remove the testicle (orchidectomy)

The remaining testicle will make more testosterone to make up for the missing testicle and will continue to make sperm.

Surgery to the lymph nodes (RPLND)

RPLND sometimes damages nearby nerves. Some men get a dry orgasm if this happens. This means that when you climax no liquid comes out of your penis (anejaculation).

Chemotherapy or radiotherapy

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

Sexuality and emotions

During your diagnosis and treatment, you may experience a range of emotions that can leave you confused and tired. As a result, it can be hard to relax and you may lose your sex drive. This is not uncommon – many men feel this way during and after treatment for testicular cancer. It may take a while to adjust to your diagnosis and the loss of your testicle. Having a false (prosthetic) testicle can help. See page 17 for more information. It can take time to get used to the look and feel of your false testicle but it will gradually happen.

There is no set time for you to be ready to have sex again. It varies from person to person. 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. It may help to reassure your partner too. 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.

If you are single you may find it daunting starting a new relationship. You may feel self-conscious if you have a scar or if your body has changed. You may worry about telling your partner about having had testicular cancer. There are no rules about this. Every couple is different, but it is a good idea to think ahead about what you might want to say. It might be that you need a sense of trust and friendship with your partner before you tell them. Talk to someone you trust about these issues if they affect you.

Contraception

Do not assume that you are infertile during or after treatment. You should use a barrier method of contraception while you are having chemotherapy and for some months afterwards. It is not known if chemotherapy drugs can pass into sperm so it is not safe to try for a

baby during treatment or for some months afterwards. You should talk to your doctor about how long you need to use condoms after chemotherapy.

If you need more information and support see sections 3 and 4 of this booklet, call the National Cancer Helpline or visit a Daffodil Centre. You can also visit our online message board at www.cancer.ie where you can discuss your concerns and experiences with other site users anonymously.

Will treatment affect my fertility?

Some treatments can affect your ability to father a child (your fertility). This is a subject you should discuss with your doctor before treatment starts. It may be that you are not ready to start thinking about becoming a dad at the moment but once your treatment is over and some years have passed you may feel differently. It is worth taking the time to consider your options before you have treatment.

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

Surgery to remove the testicle (orchidectomy)

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

Fertility after RPLND

RPLND can reduce fertility for some men. Your doctor will talk to you about the need to store sperm before this operation because of the risk of 'dry' ejaculation. This means the semen you produce does not come out of your penis when you climax. If you have a dry ejaculation you are less likely to be able to father a child naturally. Your doctor will explain this to you in more detail. If you want to start a family and have not stored sperm before surgery your doctor will talk to you about ways that your sperm can be collected.

Chemotherapy and fertility

Chemotherapy is known to affect sperm production and so can affect your fertility. This can happen in the short term or be permanent. 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. Many men go on to father healthy babies after treatment. 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.

You should use a barrier method of contraception while you are having chemotherapy and for some months afterwards. It is not known if chemotherapy drugs can pass into sperm so it is not safe to try for a baby during treatment or for some months afterwards. You should talk to your doctor about how long you need to use condoms after chemotherapy.

Radiotherapy and fertility

Radiotherapy for testicular cancer is usually given to lymph nodes. If you have radiotherapy to the nodes in your groin your remaining testicle will be shielded from the radiation to reduce the risk of infertility from treatment. Radiation to the lymph nodes in your tummy (abdomen) will not affect your being able to have sex and doesn't usually affect your fertility.

You should use an effective method of contraception during radiotherapy treatment and for a time afterwards. Talk to your doctor about how long you should wait before fathering a child after having radiotherapy treatment.

Sperm banking

Because testicular cancer is curable, do give yourself time to think about the future. Sperm tests will be done before treatment to see if you are infertile or if your sperm count is low. 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 and in some other fertility clinics. 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.

Dealing with infertility

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

How can I cope with fatigue?

Fatigue 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.

A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 or visit a Daffodil Centre for a free copy. You can also download it from our website.



Tips & Hints – fatigue



Fatigue can make it hard to keep up with your normal activities and your social life:

- If you are too tired to attend school, college or work at times, talk to your teachers or boss about how they can help you to create a routine that you can manage.
- Go out with your friends and carry on with sports and other activities if you feel like it – there's no reason why you can't. Just be careful to avoid crowded places when you're at more risk of getting an infection if you have had chemotherapy. You can talk to your nurse about this.
- Let your friends know that you might have to cancel plans at short notice if you're not up to it.
- Ask your friends to keep in touch through text, email or social networking sites so you don't feel you're losing touch.
- Try to make time to rest if you need it. If you are going somewhere special, have a rest before you go out.
- Keep your bedroom quiet and at a comfortable temperature to help you sleep well.
- Avoid stimulants before bedtime, such as alcohol, coffee, tea, cola or chocolate.
- Go to bed each night at the same time. Each morning get up at same time and do not lie in.
- Remember to eat well. Eat little and often, especially if your appetite is poor or you feel sick.

What follow-up do I need?

No matter what type of treatment you get, you will still need to return to hospital for regular check-ups. This is known as follow-up. At first these visits to the specialist will be quite frequent, sometimes every 3 or 4 months for the first 2 years. If testicular cancer comes back it is more common for it to do so within the first two years. After 2 years you will be seen less frequently, dropping back to once a year in time.

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 will check for signs of testicular cancer that may have come back. Your doctor can also keep track of any ongoing side-effects that you may have. If you are between check-ups and have a symptom or problem worrying you, let your doctor know.

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

You might worry about the cancer coming back. This can be worse at times leading up to scans and follow up appointments and can put a strain on day-to-day activity. It can help to share your concerns so people know how you are feeling. Partners can also get anxious about these issues and it can help to talk them over. If you or your partner feel you might need help coping call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

It can be a good idea to keep a record of your treatment. This can come in useful if you need to see a new doctor later in life when they might not have full access to your medical records.

For details of helpful services and support groups, see pages 66–71, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

Getting back to normal after treatment

You can return to normal activity as soon you feel able after your cancer treatment. Finishing treatment can be both stressful and exciting at the same time. It can take some time for the tiredness to wear off after cancer treatment. This is quite common so do not worry if you do not get over your treatment as quickly as you thought you might. You might feel a bit alone once treatment has ended or when follow up is less frequent. You might miss the regular contact with the hospital staff. It can help to talk this through or to make contact with a cancer support centre at this time.

What if my cancer comes back?

When cancer has come back after it has been treated it is known as a recurrence or relapse. The risk of testicular cancer coming back depends on the type and stage of your testicular cancer. If a relapse is going to happen it is most likely to occur in the first two years after treatment. Unlike many cancers, even when testicular cancer does come back, it can still be cured.

Where in the body can testicular cancer recur?

Men who have had testicular cancer are at a slightly higher risk of getting cancer in the other testicle. For this reason it is a good idea to get into the habit of checking your remaining testicle on a regular basis. See www.cancer.ie for information on how to do this if you are not sure.

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

What treatment is there for me if the cancer comes back?

Chemotherapy and further surgery can be used to treat you, depending on where in your body the cancer is found.

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

High-dose chemotherapy and stem cell support: This may be used for men whose cancer did not respond to first line chemotherapy. It allows you to have much higher doses of chemotherapy than usual to try to destroy any remaining testicular cancer cells.

Stem cells are found in the bone marrow. They make all the blood cells in your body. When very high doses of chemotherapy are given your bone marrow is affected by treatment. For this reason, some stem cells are removed before high-dose chemotherapy treatment and replaced afterwards.

Your doctors will talk to you in detail if you need this treatment. For copies of our booklets *Understanding Stem Cell Collection* and *Understanding Autologous Stem Cell Transplants* call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

Surgery for recurrent testicular cancer: If the lymph nodes in your abdomen are affected by recurrent cancer, surgery to remove the lymph nodes may be performed. This operation is known as RPLND. See page 30 for more information on this operation.

Help and support for recurrent testicular cancer

Finding out that cancer has come back after treatment can be a very difficult time. Shock, disbelief, anxiety, fear, anger, grief, and a sense of loss of control are common emotions. All these feelings are normal responses to this difficult experience. Some people find this diagnosis more upsetting than the first one. It's a good idea to seek professional help to deal with these feelings. Counselling is available through a national network of cancer support centres. See a list of cancer support centres on page 67 or visit www.cancer.ie

It is important to remember that cure can still be reached even in this situation. For help and support at this time call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre, and talk to one of our specialist nurses.



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 might also receive a treatment that later proves better than the current best standard treatment. 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 on 1800 200 700.

Cancer and complementary therapies

Complementary treatments for cancer are treatments that can be given alongside standard medical treatment. For example, yoga or massage. Some people find them very helpful during their illness. The way cancer is treated often depends on the culture of the country in which you live. In Ireland cancer treatments are based on scientific research, which allows the response to treatment, side-effects and the general effect of treatment to be predicted.

You may hear about the following types of treatments or therapies:

Conventional therapies

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

Complementary therapies

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

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

Many people find that complementary therapies are very helpful in a number of ways. You may feel more positive about yourself and your illness. You may be better able to cope with the physical side-effects of cancer and the distressing emotions that cancer 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.

Alternative therapies have not been scientifically proven. Some alternative therapies may even harm your health. Always talk to your doctor if you are considering an alternative to conventional treatment.



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



Before you decide to change your treatment or add any methods of your own, 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, do talk openly with your GP or cancer specialist if you are thinking of having treatment with either a complementary or alternative practitioner. Don't be afraid that your doctor will be offended by your wish for other treatments. In fact, he or she may be able to recommend therapies that could be safe and useful for you. Be cautious in selecting a practitioner. Don't be misled by promises of cures. At present, this area is not fully regulated in Ireland. Make sure 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 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 on 1800 200 700 or visit a Daffodil Centre. You can also download it from www.cancer.ie



Coping and emotions

How can I cope with my feelings?

There are many reactions when told you have 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.

Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. Your medical social worker in the hospital can support you. There is also a helpful booklet called *Understanding the Emotional Effects of Cancer*. Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for a copy. You can also download it from our website, www.cancer.ie

Common reactions include:

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

Feelings and emotions

You may find that you are afraid because you do not know enough about your illness. Most people find that information can help them overcome their fears. Do ask your doctors and nurses for as much information as you need – and keep asking them. The disease itself and the effect of treatment on your life may make you feel low. Often this is because of the change to your usual routine, the side-effects of treatment, or perhaps the risk of infertility. Other times, you may feel nothing or just numb.

It is important to know that you are not alone. Many people who have had testicular cancer have experienced similar feelings and emotions.

For some people, the hardest time is when treatment has finished and things are getting back to normal. It can be daunting going back to work or school or re-starting your usual activities. The end to your hospital visits may make you feel alone and neglected. You may feel you need the most support at this time.

Remember it is not a sign of failure if you feel unable to cope on your own or to ask for help. Once other people understand how you are feeling, they can give more support. *Who Can Ever Understand? Talking about Your Cancer* is a useful booklet written for people with cancer. Call the National Cancer Helpline on 1800 200 700 for a copy or visit a Daffodil Centre. You can also download it from www.cancer.ie

Anxiety and depression

If you feel that your low moods are getting the better of you, talk about your feelings with someone close to you who is a good listener. Or you may find it helpful to discuss your feelings with a trained counsellor, a leader or a member of your religious faith or a medical social worker.

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

Also, deep emotional difficulties are not always easy to talk about. Often they can be hard to share with loved ones. In this case, talking to a counsellor or psychotherapist who is not personally involved in your situation can be a great help. They can help to make sense of your thoughts, feelings and ideas. Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for more advice. Ask for a copy of the booklet *Understanding the Emotional Effects of Cancer*.

Counselling

Sometimes it is difficult for people who are undergoing a stressful and emotional time to talk to the people closest to them, who may also be very upset. They may find it easier to talk to someone who is outside their immediate circle. It may be easier to untangle some of their deepest feelings and fears with someone who has been trained specifically in counselling skills. A trained counsellor can provide emotional support by allowing you to express your feelings and fears, helping to make decisions and offering insight. To find out more call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

Survivors Supporting Survivors

Survivors Supporting Survivors is the Irish Cancer Society's one-to-one support programme. You can be put in contact with a Survivors Supporting Survivors volunteer who has dealt with a testicular cancer diagnosis. Volunteers are carefully selected and trained to give support, practical information and reassurance. Some men may also find it helpful to talk to a counsellor. Call 1800 200 700 for more information or visit a Daffodil Centre.



Family and friends

Cancer not only affects you, the person diagnosed with it, but also those around you. Like you, your family friends and partner, if you have one, will have to adjust to learning you have cancer. For example, your parents may find it hard to cope with the fact that their child has a serious disease. How well those closest to you cope can also affect how you adjust and cope both during and after treatment.

Generally, family and friends can be a good source of support, both emotionally and physically. For example, helping to share the workload at home, maybe allowing time for you and your partner to get out to talk, or just being there to help out if necessary.

It can be good if you can talk about how you can support one another during this time. If you are feeling overwhelmed by calls from family asking how you are then you may want to ask them to call one nominated family member for news for example. Or if your mum rings you every day you may want to find a way to say that you're doing ok and that you'll ring her when you can. There is no right or wrong way, but do remember that every family member will have their own way of dealing with your cancer diagnosis.

Although people mean well sometimes, they can begin to define you by your cancer. As a result, the real you may feel lost. Some people may withdraw out of fear and lack of experience. Others may not understand that you feel too unwell to go out. Tell them how you feel or, if you cannot, ask another family member or friend to tell them. You may find our booklets useful, such as *Who Can Ever Understand? Talking about Your Cancer* or *Lost for Words: How to Talk to Someone with Cancer*. Contact the National Cancer Helpline on 1800 200 700 for copies. Or if you prefer, you can visit a Daffodil Centre or download it from our website, www.cancer.ie

You and your partner

Many couples do not think they will have to deal with a serious illness like testicular cancer, especially if this happens at a young age.

A serious illness can change the roles each of you play within your relationship. For example, your partner may have to take a more active role in the running of the house or managing the children. Some partners may become very protective. Some may research as much information on the disease as possible, while others withdraw.

Everyone is different in how they cope with a situation. Remember there is no right or wrong way. The most important thing is for both of you to express your concerns openly and honestly. At times your partner may feel isolated and unable to express his or her feelings and concerns. Support is available for your partner from local support groups or from counselling services. Call 1800 200 700 or visit a Daffodil Centre for more information.



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 a few people do die from testicular cancer, most do not. Be honest with your own 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 on 1800 200 700 for a free copy. You can also pick one up at a Daffodil Centre or download it from www.cancer.ie

How can I talk to my children?

A cancer diagnosis can affect an entire family. It can bring changes that may be either great or small. 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. 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 on 1800 200 700.

How can I help myself?

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. There are things you can do at this time to feel more in control and better able to cope.

- 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.
- Make sure you have a contact number for the hospital in case you have any questions or problems.
- Let your doctor know if you have any problems or worrying side-effects. He or she can decide what to do to help you.
- Accept that a cancer diagnosis can be hard on you mentally and emotionally. Give yourself time and space to deal with your feelings.
- Do not keep your worries or symptoms secret from the people closest to you. This includes physical or emotional problems.
- Online forums and local cancer groups can give you support, but remember that everyone's experience is different. The National Cancer Helpline and Daffodil Centre nurses can put you in contact with a Survivors Supporting Survivors volunteer or give you details of other support services.
- Let someone know if you are finding it hard to cope with your feelings – help is available. Some people find it helpful to talk to a counsellor.
- 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.
- Keep an open mind: Don't feel you have to be positive all the time.
- As you begin to feel better, you can set yourself some simple goals and slowly build yourself up again. Take one step at a time.
- Try to eat as well as you can. Eat little and often. Eat lots of different types of foods and plenty of fresh fruit and vegetables.

- Get some regular exercise. Take it easy at first, building up the amount you do as you feel stronger. Some people find pleasure in keeping to their normal routine as much as possible. Others prefer to take a holiday or spend more time on a hobby. Some people find walking, listening to music or keeping busy can help them to cope. Find what works for you.



If you have financial worries...



A diagnosis of cancer can sometimes bring the added burden of financial worries. This can be difficult if you cannot work, can only work part-time or are unemployed. You may find you have a lot more expenses as well as your normal outgoings. This includes medication, travel, food and heating. There is help available if you find it hard to cope with all these expenses. Do ask the medical social worker in your hospital, your local social welfare office or Citizens Information Centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. These schemes are called Travel2Care and Financial Aid. See page 64 for more details. You can also call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for ways to help you manage.

If you are finding it hard to repay your mortgage or rent, talk to your bank or property owner to see if you can come to some arrangement with them. Having cancer may also affect your chance of getting a mortgage, a loan or insurance in the future. Talk to the medical social worker in the hospital or a financial adviser about any money issues you may have. A useful booklet available from the Irish Cancer Society is *Managing the Financial Impact of Cancer: A Guide for Patients and Their Families*. Call 1800 200 700 for a copy or visit a Daffodil Centre. You can also download it from www.cancer.ie.

Getting into debt

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 0761 07 2000. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. See page 66 for contact details.

Support resources

Who else can help?

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

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

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

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

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

Family doctor (GP): You may feel comfortable talking to your family doctor (GP) about your cancer too. He or she can discuss any of your queries and offer advice and support.

Community health services: There are various community health services available from your local health centre. These centres have public health nurses (who can visit you at home), welfare officers and home-help organisers. If you live far from your hospital, your community welfare officer can also help with practical issues such as

financial problems or exceptional needs. More information on the services is available either from the medical social worker in your hospital before you go home or at your local health centre.

Support groups: Joining a support group can put you in touch with people who have been in a similar situation. They can give you practical advice about living with cancer. Cancer support groups and centres are found in most counties in Ireland and can offer a wide range of services. Some are listed at the back of this booklet. You can search for a support group on www.cancer.ie.

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. This can range from treatment information to practical advice about financial matters. Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre 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
- GP visit card
- Private healthcare cover
- Outpatient cover
- Drug Payments Scheme (DPS)
- Benefits and allowances
- Medical card

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

Hospital cover

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

Outpatient cover

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

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

Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services as well as outpatient services and medical appliances. You will have to pay a prescription charge of €2.50 per item up to a limit of €25 per family per month.

To qualify for a medical card depends on a means test regardless of age. If you are over 70 and your weekly income is €500 or less (€900 for couples), you can still apply for a card. Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office. If your means are above but close to the guidelines, you should apply for a card anyway as a card may be granted in some situations. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

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

GP visit card

If you do not qualify for a full medical card, you may be eligible for a GP visit card. This card covers visits to your doctor only and you will have to pay for drugs, outpatient/inpatient charges and medical appliances yourself. It is means tested but will take into account your after-tax income and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker at the

hospital or your HSE office to see if you are eligible. If you wish to apply for a GP visit card, you can download an application form and apply online (www.medicalcard.ie) or at your local health centre. LoCall 1890 252 919.

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €144 each month to cover the cost of prescribed drugs, medicines and appliances. You can apply for cover under the scheme by contacting your local HSE office or your local pharmacy.

Private healthcare cover

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

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

Benefits and allowances

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

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



Application forms for the benefits are available from social welfare offices or the Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or LoCall 1890 927 770. You can also download the forms from websites such as www.welfare.ie or www.citizensinformation.ie

Appliances

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

Travel to hospital

You may be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your medical social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services to hospitals for outpatient appointments and day centres, usually for patients with medical cards.

See page 64 for information on the Travel2Care and Care to Drive schemes run by the Irish Cancer Society. Some local communities may also provide volunteer transport services.

Further information

Depending on your circumstances at the time of your illness, there are many other benefits and entitlements that may be relevant to you. Always have your PPS number (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:

Dept of Social Protection – Information Service

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

For queries about local health and social services, contact the HSE.
HSE infoline: 1850 24 1850 **Email:** info@hse.ie **Website:** www.hse.ie

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

Citizens Information

Tel: 0761 07 4000 **Email:** information@citizensinformation.ie
Website: www.citizensinformation.ie

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)
- Daffodil Centres
- Cancer support services
- Survivors Supporting Survivors
- Counselling
- Night nursing
- Cancer information booklets and factsheets
- Financial support
- Care to Drive transport project

Cancer Information Service (CIS)

The Society provides a Cancer Information Service with a wide range of services. The **National Cancer Helpline 1800 200 700** 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 is open Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- The website **www.cancer.ie** provides information on all aspects of cancer.
- All queries or concerns about cancer can be emailed to the CIS at **helpline@irishcancer.ie**

- **Message Board** is a discussion space on our website (**www.cancer.ie**) to share your stories, ideas and advice with others.
- The **walk-in caller service** allows anyone with concerns about cancer to freely visit the Society to discuss them in private.
- Find us on **Facebook** and follow us on **Twitter** (@IrishCancerSoc).

Daffodil Centres

Daffodil Centres are located in a number of Irish hospitals. These have been set up by the Irish Cancer Society in partnership with each hospital and are an extension of the Cancer Information Service. They are generally found near the main entrance of the hospital and are open during the day. Staffed by a specialist nurse and trained volunteers, they provide a range of information, advice, help and support on all aspects of cancer, free of charge.

Daffodil Centres give you a chance to talk in confidence and be listened to and heard. If you are concerned about cancer, diagnosed with cancer or caring for someone with cancer, you are welcome to visit the centre. Do check to see if there is a Daffodil Centre in your hospital.

Cancer support services

The Irish Cancer Society funds a range of services set up to support you and your family at time of diagnosis, throughout treatment and afterwards. See page 67 for more details.

Survivors Supporting Survivors

Being diagnosed with cancer can be one of the hardest situations to face in your lifetime. Survivors Supporting Survivors is a one-to-one support programme run by the Irish Cancer Society. It provides peer support to people who have been diagnosed with cancer. All of the volunteers have had a cancer diagnosis and have been carefully selected and trained to give you support, practical information and reassurance when you need it most. You can speak to someone who really knows what you are going through. If you would like to make contact with a volunteer, please call the National Cancer Helpline on 1800 200 700.

Counselling

Coping with a diagnosis of cancer can be very stressful at times. Sometimes it can be hard for you and your family to come to terms with your illness. You might also find it difficult to talk to a close friend or relative. In this case, counselling can give you emotional support in a safe and confidential environment. Call the Helpline on 1800 200 700 to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Night nursing

The Society can provide a night nurse, free of charge, for up to 10 nights if you need end-of-life care at home. The night nurse can also give practical support and reassurance to your family. You can find out more about this service from your GP, local public health nurse, a member of the homecare team or the palliative care services at the hospital. Homecare nurses can offer advice on pain control and managing other symptoms.

Cancer information booklets and factsheets

Our booklets provide information on all aspects of cancer and its treatment, while our factsheets deal with very specific topics. The booklets also offer practical advice on learning how to cope with your illness. The booklets and factsheets are available free of charge from the Irish Cancer Society by calling 1800 200 700. They can also be downloaded from www.cancer.ie or picked up at a Daffodil Centre.



Financial support

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances the Irish Cancer Society may be able to provide limited financial help to patients in need through schemes such as Travel2Care and Financial Aid.

Travel2Care: Travel2Care can help with your travel costs if you have genuine financial hardship due to travelling over 50 kilometres to a rapid access diagnostic clinic for tests or to a designated cancer centre

or approved satellite centre for cancer treatment. The scheme is funded by the National Cancer Control Programme (NCCP) and managed by the Irish Cancer Society. Travel2Care can help with some of the costs of public transport, such as trains or buses, private transport costs, or petrol expenses.

If this applies to you, contact the medical social work department in your hospital or speak to your cancer care nurse. You can also contact the Irish Cancer Society on (01) 231 6643 / 231 6619 or email:

travel2care@irishcancer.ie

Financial Aid: A special fund has been created to help families experiencing financial difficulty as a result of cancer. If this applies to you, contact the medical social work department in your hospital. You can also speak to your cancer care nurse or contact the Irish Cancer Society at (01) 231 6619.

Care to Drive transport project

Care to Drive is a scheme operated by the Irish Cancer Society. It provides free transport for patients to and from their treatments using volunteer drivers. All of the volunteers are carefully selected, vetted and trained. You are collected from your home, driven to your appointment and brought back home again. Call (01) 231 0522 to find out if Care to Drive is available in your hospital.



If you would like more information on any of the above services, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also visit the website www.cancer.ie

Useful organisations

Irish Cancer Society

43/45 Northumberland Road
Dublin 4
Tel: 01 231 0500
National Cancer Helpline:
1800 200 700
Email: helpline@irishcancer.ie
Website: www.cancer.ie

The Carers Association

Market Square
Tullamore
Co Offaly
Freefone: 1800 240 724
Email: info@carersireland.com

Citizens Information

Tel: 0761 07 4000
Email: information@citizensinformation.ie
Website: www.citizensinformation.ie

Get Ireland Active: Promoting Physical Activity in Ireland

Website: www.getirelandactive.ie

HARI: The National Fertility Centre

Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732
Email: info@hari.ie
Website: www.hari.ie

Health Promotion HSE

Website: www.healthpromotion.ie

All Ireland Co-operative Oncology Research Group

Website: www.icorg.ie

Irish Nutrition & Dietetic Institute

Ashgrove House
Kill Avenue
Dún Laoghaire
Co Dublin
Tel: 01 280 4839
Email: info@indi.ie
Website: www.indi.ie

Irish Oncology and Haematology Social Workers Group

Website: <http://socialworkandcancer.com>

Money Advice and Budgeting Service (MABS)

Commercial House
Westend Commercial Village
Blanchardstown
Dublin 15
Tel: 01 812 9350
Helpline 0761 07 2000
Email: helpline@mabs.ie
Website: www.mabs.ie

Health insurers

AVIVA Health

PO Box 764
Togher
Cork
Tel: 1850 717 717
Email: info@avivahealth.ie
Website: www.avivahealth.ie

GloHealth

PO Box 12218
Dublin 18
Tel: 1890 781 781
Email: findoutmore@glohealth.ie
Website: www.glohealth.ie

Laya Healthcare

Eastgate Road
Eastgate Business Park
Little Island
Co Cork
Tel: 021 202 2000
LoCall: 1890 700 890
Email: info@layahealthcare.ie
Website: www.layahealthcare.ie

Voluntary Health Insurance (VHI)

IDA Business Park
Purcellsinch
Dublin Road
Kilkenny
CallSave: 1850 44 44 44
Email: info@vhi.ie
Website: www.vhi.ie

National support services

Survivors Supporting Survivors

Irish Cancer Society
43/45 Northumberland Road
Dublin 4
National Cancer Helpline:
1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

ARC Cancer Support Centres Dublin

[See page 68]

Canteen Ireland

[Teenage cancer support]
Carmichael Centre
North Brunswick Street
Dublin 7
Tel: 01 872 2012
Email: info@canteen.ie
Website: www.canteen.ie

Cancer Support Sanctuary LARCC

[See page 69]

Connaught support services

Athenry Cancer Care

Social Service Centre
New Line
Athenry
Co Galway
Tel: 091 844 319 / 087 412 8080
Email: athenrycancercare@gmail.com
Website: www.athenrycancercare.com

Ballinasloe Cancer Support Centre

Main Street
Ballinasloe
Co Galway
Tel: 090 964 5574
Email: ballinasloecancer@yahoo.co.uk

Cara Iorrais Cancer Support Centre

2 Church Street
Belmullet
Co Mayo
Tel: 097 20590 / 087 391 8573
Email: caraiorrais@gmail.com

East Galway & Midlands Cancer Support

Cluain Mhuire
Brackernagh
Ballinasloe
Co Galway
Tel: 090 964 2088 / 087 984 0304
Email: info@egmcancersupport.com
Website: www.eastgalwaycancersupport.com

Gort Cancer Support Group

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

Hand in Hand

[Children's Cancer Support Centre]
Main Street
Oranmore
Co Galway
Tel: 091 799 759
Email: info@handinhand.ie
Website: www.handinhand.ie

Mayo Cancer Support Association

Rock Rose House
32 St Patrick's Avenue
Castlebar
Co Mayo
Tel: 094 903 8407
Email: info@mayocancer.ie
Website: www.mayocancer.ie

Roscommon Cancer Support Group

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

Sligo Cancer Support Centre

44 Wine Street
Sligo
Tel: 071 917 0399
Email: scsc@eircom.net
Website: www.sligocancersupportcentre.ie

Tuam Cancer Care Centre

Cricket Court
Dunmore Road
Tuam
Co Galway
Tel: 093 28522
Email: support@tuamcancercare.ie
Website: www.tuamcancercare.ie

Leinster support services**Aoibheann's Pink Tie**

[Supporting children with cancer]
Unit 22
Docklands Innovation Centre
128- 130 East Wall Road
Dublin 3
Tel: 01 240 1300
Email:
lindaconnell@aoibheannspinktie.ie
Website: www.aoibheannspinktie.ie

ARC Cancer Support Centre

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

ARC Cancer Support Centre

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

Arklow Cancer Support Group

25 Kings Hill
Arklow
Co Wicklow
Tel: 0402 23590 / 085 110 0066
Email: info@arklowcancersupport.com
Website: www.arklowcancersupport.com

Balbriggan Cancer Support Group

Unit 23, Balbriggan Business Park
Harry Reynold's Road
Balbriggan
Co Dublin
Tel: 087 353 2872 / 086 164 2234

Cara Cancer Support Centre

7 Williamson's Place
Dundalk
Co Louth
Tel: 042 937 4905
Mobile: 087 395 5335
Email: info@ccscdundalk.ie
Website: ccscdundalk.ie

Cois Nore Cancer Support Centre

8 Walkin Street
Kilkenny
Tel: 056 775 2222
Email: coisnorekilkenny@gmail.com
Website: www.kilkennycancersupport.ie

Cuisle Cancer Support Centre

Block Road
Portlaoise
Co Laois
Tel: 057 868 1492
Email: cuislecentre@eircom.net
Website: www.cuislecentre.com

Dóchas: Offaly Cancer Support Group

Teach Dóchas
Offaly Street
Tullamore
Co Offaly
Tel: 057 932 8268
Email: info@dochasoffaly.ie
Website: www.dochasoffaly.ie

Dublin West Cancer Support Group

Generic Social Work Department
Oak Unit
Cherry Orchard Hospital
Ballyfermot
Dublin 10
Tel: 01 620 6273
Email: martina.mcgovern2@hse.ie/
noreen.obrien4@hse.ie

Éist Carlow Cancer Support Centre

The Waterfront
Mill Lane
Carlow
Tel: 059 913 9684
Mobile: 085 144 0510
Email: info@eistcarlowcancersupport.ie
Website: www.eistcarlowcancersupport.ie

Gary Kelly Cancer Support Centre

George's Street
Drogheda
Co Louth
Tel: 041 980 5100
Email: info@gkcancersupport.com
Website: www.gkcancersupport.com

Greystones Cancer Support

La Touche Place
Greystones
Co Wicklow
Tel: 01 287 1601
Email:
info@greystonescancersupport.com
Website:
www.greystonescancersupport.com

Hope Cancer Support Centre

22 Weafer Street
Enniscorthy
Co Wexford
Tel: 053 923 8555
Email: info@hopesupportcentre.ie
Website: www.hopesupportcentre.ie

Cancer Support Sanctuary LARCC

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

Rathdrum Cancer Support Group

St Anne's
Lower Street
Rathdrum
Co Wicklow
Tel: 087 292 8660
Email: rathcan@gmail.com

Tallaght Cancer Support Group

Trustus House
1-2 Main Street
Tallaght
Dublin 24
Tel: 086 400 2736
Email: ctallaght@yahoo.ie
Website: tallaghtcancersupport.com

Wicklow Cancer Support Centre

Rear of Butler's Medical Hall
Abbey Street
Wicklow
Tel: 0404 32696
Email: wicklowcancersupport@gmail.com

Munster support services**Cancer Information & Support Centre**

University Hospital Limerick
Dooradoyle
Co Limerick
Tel: 061 485 163
Website: www.midwesterncancercentre.ie

CARE Cancer Support Centre

14 Wellington Street
Clonmel
Co Tipperary
Tel: 052 618 2667
Email: caresupport@eircom.net
Website: www.cancercare.ie

Cork ARC Cancer Support House

Cliffdale
5 O'Donovan Rossa Road
Cork
Tel: 021 427 6688
Email: info@corkcancersupport.ie
Website: www.corkcancersupport.ie

Cuan House Cancer Support Centre

24 Gort Aoibhinn
Cork Hill
Youghal
Co Cork
Tel: 024 92353

Kerry Cancer Support Group

Acorn Centre
124 Tralee Townhouse Apartments
Maine Street
Tralee
Co Kerry
Tel: 066 719 5560 / 087 230 8734
Email: kerrycancersupportgroup@eircom.net
Website: www.kerrycancersupport.com

Recovery Haven

5 Haig's Terrace
 Tralee
 Co Kerry
 Tel: 066 719 2122
 Email: recoveryhaven@gmail.com
 Website: www.recoveryhavenkerry.com

Solas Centre

South Eastern Cancer Foundation
 Williamstown
 Waterford
 Tel: 051 304 604
 Email: info@solascentre.ie
 Website: www.solascentre.ie

Suaimhneas Cancer Support Centre

2 Clonaslee
 Gortland Roe
 Nenagh
 Co Tipperary
 Tel: 067 37403
 Email:
 suaimhneascancersupport@eircom.net

Suir Haven Cancer Support Centre

Clongour Road
 Thurles
 Co Tipperary
 Tel: 0504 21197
 Email: suirhaven@gmail.com

Ulster support services**Coiste Scaoil Saor Ó Ailse**

C/O Ionad Níomh Padraig
 Upper Dore
 Bunbeg
 Letterkenny
 Co Donegal
 Tel: 074 953 2949
 Email: ionadnp@eircom.net
 Website: www.scaoilsaor.ie

Crocus: Monaghan Cancer Support Centre

The Wellness Centre
 19 The Grange
 Plantation Walk
 Monaghan
 Tel: 087 368 0965 / 047 62565
 Email: crocus.2011@yahoo.com

Cuan Cancer Social Support and Wellness Group

2nd Floor, Cootehill Credit Union
 22–24 Market Street
 Cootehill
 Co Cavan
 Tel: 086 455 6632

Living Beyond Cancer

Oncology Day Services
 Letterkenny General Hospital
 Letterkenny
 Co Donegal
 Tel: 074 912 5888 (Bleep 674/734) / 074 910 4477
 Email: noreen.rodgers@hse.ie

Other support services**The Bella Rose Foundation**

Merry Maid House
 West Park Campus
 Garter's Lane
 Citywest
 Dublin 24
 Tel: 087 320 3201
 Email: thebellarosefoundation@gmail.com
 Website: www.bellarose.ie

Cancer Care West

72 Seamus Quirke Road
 Galway
 Tel: 091 545 000
 Email: info@cancercarewest.ie
 Website: www.cancercarewest.ie

Cúnamh: Bons Secours Cancer Support Group

Bon Secours Hospital
 College Road
 Cork
 Tel: 021 480 1676
 Website: www.cunamh.ie

Dundalk Cancer Support Group

Philipstown
 Hackballscross
 Dundalk
 Co Louth
 Tel: 086 107 4257

The Forge Cancer Support Service

The Forge Family Resource Centre
 Pettigo
 Co Donegal
 Tel: 071 986 1924
 Email: theforgefrcc@eircom.net

Killybegs Cancer Support Group

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

Newbridge Cancer Support Group

Tel: 083 360 9898
 Email:
 newbridgecancerhealinghelp@gmail.com

Purple House – Cancer Support

Aubrey Court
 Parnell Road
 Bray
 Co Wicklow
 Tel: 01 286 6966
 Email: info@purplehouse.ie
 Website: www.braycancersupport.ie

Sláinte an Chláir: Clare Cancer Support

Tír Mhuire
 Kilnamona
 Ennis
 Co Clare
 Tel: 1850 211 630
 Email: admin@clarecancersupport.com
 Website: www.clarecancersupport.com

Solace: Donegal Cancer Support Centre

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

Useful contacts outside Republic of Ireland**Action Cancer**

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

American Cancer Society

Website: www.cancer.org

Cancer Focus Northern Ireland

40–44 Eglantine Avenue
 Belfast BT9 6DX
 Tel: 048 9066 3281
 Email: hello@cancerfocusni.org
 Website: www.cancerfocusni.org

Cancer Network Buddies

Website: www.cancerbuddiesnetwork.org

Cancer Research UK

Tel: 0044 20 7242 0200
 Website: www.cancerhelp.org.uk

Healthtalkonline

Website: www.healthtalk.org

Macmillan Cancer Support (UK)

Tel: 0044 20 7840 7840
 Email: cancerline@macmillan.org.uk
 Website: www.macmillan.org.uk

Macmillan Support & Information Centre

Belfast City Hospital Trust
 77–81 Lisburn Road
 Belfast BT9 7AB
 Tel: 028 9069 9202
 Email: cancerinfo@belfasttrust.hscni.net
 Website: www.cancerinfo.net

National Cancer Institute (US)

Website: www.nci.nih.gov

Orchid

[Information on testicular and other male cancers, includes factsheets, films and post-treatment information.]
 Website: www.orchid-cancer.org.uk

Teenage Cancer Trust

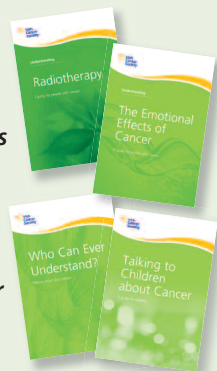
[Support and information for teenagers and young adults with cancer.]
 Website: www.teenagecancertrust.org

For other support groups or centres in your area, call 1800 200 700.

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*



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

Lance Armstrong
Yellow Jersey Press, 2001
ISBN 0425179613

Taking Control of Cancer

Beverly van der Molen
Class Publishing, 2003
ISBN 1859590918

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 095214445X

Explaining cancer to children

The Secret C: Straight Talking About Cancer

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

My Daddy's Cancer: An Interactive Book for Children

Michael J Gordon (Illustrator), John T Heiney, Cindy K Cohen
Promise Publishing Company (July 1999)
ISBN-13: 9780965649810

Can I Still Kiss You?: Answering Children's Questions about Cancer

Neil Russell
HarperCollins Publishers (Australia) Pty Ltd (1 July 2002)
ISBN-13: 9781558749283

For more details on helpful and up-to-date books, call the National Cancer Helpline on 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.
Anti-emetic	A tablet, injection or suppository to stop you feeling sick or vomiting.
Benign	Not cancer.
Biopsy	When a small amount of tissue is taken from your body to find out if cancer cells are present.
Cells	The building blocks that make up your body. They are tiny and can only be seen under a microscope.
Chemotherapy	Treatment using drugs that cure or control cancer.
Dry orgasm	No (or very little) fluid (semen) comes out of the penis when orgasm happens.
Fatigue	Severe tiredness.
Germ cells	Cells that produce sperm in men (and eggs in women). They are nothing to do with germs that cause infections.
Lymph nodes	Small glands scattered along vessels of your lymphatic system. They may become enlarged due to infection or cancer cells.
Malignant	Cancer. A tumour that spreads.
Medical oncologist	A doctor who specialises in treating cancer patients using chemotherapy and other drugs.
Metastasis	The spread of cancer from one part of your body to other tissues and organs.

Nausea	Feeling sick or wanting to be sick.
Necrotic tissue	A collection of dead cells.
Non seminoma	A type of testicular cancer which has more than one type of cell in it. It may have some seminoma cells and some teratoma cells for example.
Oncology	The study of cancer.
Orchidectomy	Removing a testicle by surgery.
Prognosis	The expected outcome of a disease.
Radiation oncologist	A doctor who specialises in treating cancer patients using radiotherapy.
Radiotherapy	The treatment of cancer using high-energy X-rays.
Retrograde ejaculation	Semen goes into the bladder rather than out through the penis during orgasm.
Retro-peritoneal	A space in the abdomen, towards the back where some lymph glands are present.
Seminoma	A type of testicular cancer identified by the way it looks under the microscope, also known as pure seminoma.
Staging	Tests that measure the size and extent of cancer.
Testosterone	A hormone produced by the testicles which is responsible for male characteristics.
Tumour marker	A chemical in your blood that may be a sign that cancer is present.
Urologist	A surgeon who specialises in diseases of the male reproductive system and urinary system. He or she can remove a tumour from this area of the body.

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?
- How successful is this treatment for my cancer?
- Would I be suitable for a clinical trial?
- How long will my treatment take?
- 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?
- How often will I need check-ups?
- Why do I need to attend for regular blood tests?
- What if the cancer comes back?

Acknowledgements

We would like to extend a special word of thanks to the following for their invaluable contributions to this booklet and/or previous editions:

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Sheila Kiely, Urology Clinical Nurse Manager

Denis Carroll, Men Against Cancer

Sinead Farrell, Cancer Nurse Co-ordinator

Amanda Stavros, Medical Social Worker

Dr David Galvin, Senior Registrar, Urology

Antoinette Walker & Susan Rowan, Patient Education Editors

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 on 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

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

National Cancer Helpline Freefone 1800 200 700

Open Monday to Thursday 9am to 7pm

Friday 9am to 5pm

Find us on Facebook

Follow us on Twitter: @IrishCancerSoc

