

Understanding

Cancer of the Kidney

Caring for people with cancer

Understanding

Cancer of the Kidney

This booklet has been written to help you understand more about kidney cancer. It has been prepared and checked by surgeons, cancer doctors, nurses and patients. The information in this booklet is an agreed view on this cancer, its diagnosis and treatment and how it may affect you.

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



Specialist nurse

Tel:



Family doctor (GP)

Tel:

Medical social worker

Tel:

Surgeon or urologist

Tel:

Medical oncologist

Tel:

Emergency number

Tel:

Treatments

Review dates

If you like, you can also add:

Your name

Address

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

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- *Guidelines on Renal Cell Carcinoma*, European Association of Urology, 2007.
- *Clinical Practice Guidelines in Oncology: Kidney Cancer*. National Comprehensive Cancer Network, 2011.
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Introduction

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

- **About kidney cancer** gives an introduction to cancer of the kidney, including symptoms and diagnosis.
- **Treatment and side-effects** looks at the different treatments used and possible side-effects.
- **Coping and emotions** discusses your feelings and the emotional effects of having cancer of the kidney.
- **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 kidney 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 freefone National Cancer Helpline on 1800 200 700. It is open Monday to Thursday 9am–7pm and Friday 9am–5pm. You can also visit a Daffodil Centre. See page 52 for more about Daffodil Centres.



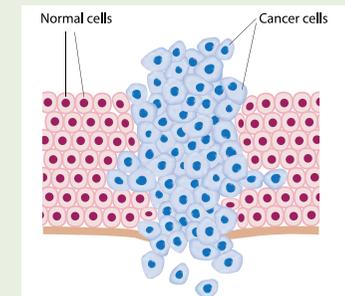
National Cancer Helpline Freefone 1800 200 700

About kidney cancer

>>> What is cancer?

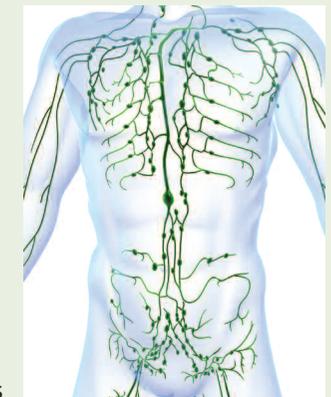
Cancer is a word used to describe a group of diseases, not just one. There are more than 200 different types of cancer. Each is named after the organ or type of cell in which the cancer first grows. For example, prostate cancer, breast cancer or leukaemia. All cancers are a disease of the body's cells, 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.



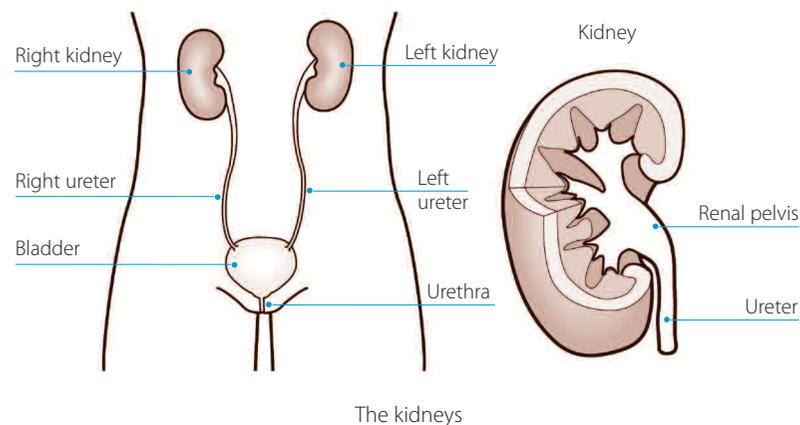


To sum up

- 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 help to spread cancer cells.

What are the kidneys?

The kidneys are small bean-shaped organs about the size of your fist. There are normally two in your body, but you can survive with just one. They are found on either side of your spine, just below your ribcage and around the middle of your back. The right kidney is slightly lower than the left. On top of each kidney sits a much smaller gland called the adrenal gland. The two glands are covered in fatty tissue with an outer layer of fibrous tissue called Gerota's fascia.



The kidneys are full of blood vessels and remove waste products from your blood. This waste is then changed into urine. The urine flows

into a hollow space in the middle of each kidney called the renal pelvis. It then passes down into your bladder through a tube called the ureter. From the bladder the urine leaves your body through another tube called the urethra. This opens just in front of the vagina in women and at the tip of the penis in men.

Your kidneys also make three important hormones. These are erythropoietin, renin and calcitriol.

- **Erythropoietin** tells your bone marrow to make more red blood cells.
- **Renin** controls your blood pressure.
- **Calcitriol** is a form of vitamin D that helps your bowel to absorb calcium from your food. This keeps your bones healthy.

The adrenal glands make hormones that are vital for living. These hormones are cortisol, aldosterone and adrenaline.

- **Cortisol** is a natural steroid involved in your response to stress and inflammation.
- **Aldosterone** controls your body's water balance.
- **Adrenaline** and **noradrenaline** are needed to prepare your body for emergency situations. For example, by increasing your heart rate and raising your blood pressure.

What is kidney cancer?

Kidney cancer starts when the cells change and grow in an abnormal way. They form a single mass or tumour within your kidney and sometimes more than one tumour can develop. Usually only one kidney is affected and it is rare for cancer to occur in the other kidney. As the cancer grows it can affect how your kidney works normally and can cause problems. In most cases, the cancer is found before it has spread to other organs.

The most common type of kidney cancer is renal cell cancer (RCC). See page 12 for more about the types of kidney cancer.

»»» The most common type of kidney cancer is renal cell cancer.

How common is kidney cancer?

In Ireland about 480 people are diagnosed with kidney cancer each year. It is more common in men than women and becomes more common as you get older. It is rare for people under 40 to get kidney cancer but a rare type can affect very young children.

What causes kidney cancer?

The exact cause of kidney cancer is unknown. But there are certain things called risk factors that can affect your chances of getting the disease. Different cancers have different risk factors. Some things that can increase your risk of kidney cancer are:

- **Age:** As you get older, your risk increases. Most kidney cancers occur in men and women over the age of 40.
- **Smoking:** If you smoke, it can double your risk of developing kidney cancer. The longer you smoke and the more cigarettes you smoke, the higher your risk.
- **Obesity:** Your chance of getting kidney cancer is much higher if you are very overweight or obese. This is because obesity may cause changes in certain hormones that affect your metabolism.
- **Inherited conditions:** Kidney cancer can be caused by some inherited conditions due to a faulty gene passed on in your family. These conditions are rare, for example, von Hippel-Lindau disease.
- **Exposure to chemicals:** If you are exposed to certain chemicals in your workplace over a long period, it may increase your risk of kidney cancer. These chemicals include asbestos, cadmium, some herbicides, benzene, and organic solvents like trichloroethylene.
- **Family history:** If you have family members like a brother or sister who have kidney cancer, you have a much higher chance of getting the disease.
- **Advanced kidney disease:** If you have advanced kidney disease, especially needing dialysis, you have a higher risk of developing kidney cancer.
- **High blood pressure:** The risk of kidney cancer is also higher if you have high blood pressure. It is not certain if the blood pressure or the drugs used to treat it or both may be the cause of kidney cancer.

Can I be screened for kidney cancer?

Testing for kidney cancer when you have no symptoms is called screening. If one of the inherited conditions that increase the risk of kidney cancer runs in your family, you may be offered screening. This means having an ultrasound, CT or MRI scan of your kidneys every year. There is also a genetic blood test available for von Hippel-Lindau disease. Further genetic tests may become available in the future.

If you are concerned about kidney cancer, do talk to your family doctor (GP).

What are the symptoms of kidney cancer?

Symptoms of kidney cancer can be vague at first. Most kidney cancers are too small to feel or notice. The cancer may be discovered by chance during an ultrasound scan done for another reason. Once the cancer begins to grow, the symptoms can become more obvious. The most common symptom is blood in your urine, known as haematuria.

Symptoms of kidney cancer include:

- | | |
|---|-----------------------------------|
| ▪ Blood in your urine | ▪ Tiredness |
| ▪ A lump or mass in your kidney area | ▪ Loss of appetite |
| ▪ A dull ache or pain in your side that won't go away | ▪ Feeling unwell |
| ▪ Weight loss | ▪ High blood pressure |
| ▪ High temperature and heavy sweating | ▪ Fewer red blood cells (anaemia) |

These symptoms can also be caused by conditions other than cancer. For example, blood in your urine can be caused by an infection, enlargement of your prostate (in men) or kidney stones.

Do visit your GP to get your symptoms checked out. Remember kidney cancer is not infectious and cannot be passed on to other people.



To sum up

- Your kidneys change waste products into urine and also make important hormones.
- About 480 people are diagnosed with kidney cancer in Ireland each year.
- The cause of kidney cancer is unknown. Your risk increases with age, smoking, obesity, inherited conditions, exposure to chemicals, a family history of kidney cancer, advanced kidney disease, and high blood pressure.
- The symptoms of kidney cancer include blood in your urine, a lump in your kidney area, a dull ache or pain in your side, weight loss, high temperature and sweating, tiredness, loss of appetite, feeling unwell, high blood pressure and anaemia.

How is kidney cancer diagnosed?

Usually a symptom like blood in your urine, a lump in your side or a dull ache brings you to your family doctor (GP). He or she will examine you and check your urine and blood. If your GP has concerns about you, he or she can do more tests or refer you to a specialist.

At the hospital, you will be seen by a urologist. He or she will do a physical exam and ask you about your symptoms as well as your family medical history. Blood tests will be taken to check your general health.

There is a range of tests to check for kidney cancer. You may need some of the tests listed below:

- Blood tests
- Urine tests
- Ultrasound scan
- CT scan

Blood tests: Blood tests to check your liver and kidney will be done. A full blood count will also be done to see if you have enough or too many red blood cells.

Urine tests: Your urine may be tested for blood and cancer cells.

Ultrasound scan: An ultrasound scan uses sound waves to take pictures of your kidneys and bladder and nearby organs. A gel is first put onto your tummy and a device like a microphone passed over it. The sound waves are changed to pictures and any abnormal changes can be seen on a computer screen. The scan only lasts a few minutes.

CT scan of chest, abdomen and pelvis: This is a special type of X-ray that gives a detailed picture of the tissues inside your body. The scan itself is painless. For a CT scan, you might need to fast for a few hours before the test. You may also be given a special drink to help show up parts of your body on the scan. Preparation for a CT scan can vary but your doctor or nurse will tell you what to do. 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 you are anxious about this, contact the radiographer the day before. They may be able to give you medication to relax you on the day.



>>> Ultrasound and CT scans can help to diagnose kidney cancer.

Further tests

Depending on the results of the above tests, you may need more tests. These include:

- Cystoscopy
- Image-guided biopsy

Cystoscopy: This test might be done if you have blood in your urine. It checks for any signs of bleeding in the lining of your bladder rather than from your kidneys. A small, flexible tube with a light at one end (cystoscope) is passed into the entrance that leads to your bladder. This lets your doctor see the entire lining of your bladder and urethra. The test takes about 5 minutes and is usually done while you are awake. An anaesthetic gel or spray can help to numb the area. You may be a little sore afterwards when you pass urine for the first time.

Image-guided biopsy: A sample of the kidney tissue can be taken. This is called a biopsy. This test is occasionally done and only if the CT scan shows up an unusual area and your doctor wants more information before deciding on the best treatment for you. Your doctors will use an ultrasound or CT scan to guide them to the kidney area where the biopsy will be taken. A long thin needle will be put into your kidney and the cells removed. These are then checked for cancer cells under a microscope in the laboratory. Taking a biopsy is not without risk. There is a small chance of infection and bleeding.

Your doctor will let you know if you need any other tests.

Waiting for results

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



To sum up

- Kidney cancer is usually diagnosed by blood and urine tests, ultrasound scan and CT scan. Sometimes kidney cancer is found when a patient is having a scan for another reason.
- Further tests include cystoscopy and image-guided biopsy.

What are the types of kidney cancer?

The most common type of kidney cancer is called renal cell cancer (RCC). This is also known as renal cell carcinoma or clear cell carcinoma. About 9 out of 10 kidney cancers are of this type.

A rare type of kidney cancer is transitional cell cancer. This affects the renal pelvis, which is the part of your kidney that collects urine before it drains into your bladder. This cancer behaves in a different way to renal cell carcinomas and usually needs different treatment.

Wilms' tumour is the most common type of childhood kidney cancer. It is also known as nephroblastoma and is very rare. It is not like adult kidney cancer and the tests and treatment for it are different.

Other rarer types of kidney cancer can be identified by looking at their cells under a microscope. Your doctor can explain these to you if needed. If you would like more information on any type of kidney cancer, contact the National Cancer Helpline 1800 200 700 or call into a Daffodil Centre.

What are the stages of kidney cancer?

Staging means finding out the size of the tumour and if it has spread anywhere else in your body. Your doctor may arrange some tests to stage the cancer. Staging will help your doctor to plan the best treatment for you.

The staging system normally used in kidney cancer is called TNM. This stands for tumour, node, metastasis. It refers to how deeply the tumour has grown into your kidney (T), if there is cancer in your lymph nodes (N), and if the cancer has spread to other parts of your body (M for metastasis).

Depending on the size of the tumour, T can be subdivided into T1a, T1b, T2, T3abc and T4. N0 refers to no lymph nodes affected, one lymph node is N1 or more than one affected is N2. M1 refers to if the cancer has spread and M0 if not.

There are usually four stages of kidney cancer.

- **Stage 1:** The cancer is not more than 7cm in size and found only in the kidney. (Also described as T1a–T1b.)
- **Stage 2:** The cancer is more than 7cm but found only in the kidney. (Also described as T2.)
- **Stage 3:** The cancer has spread into your adrenal gland or the fat around the kidney or nearby large blood vessels but not beyond the fibrous tissue of the kidney. It may also have spread to a nearby lymph node. (Also described as T1a–T3b, N1 or T3a–T3c.)
- **Stage 4:** The cancer has spread outside the fibrous tissue surrounding the kidney or to distant parts of your body. Near and distant lymph nodes are affected. (Also described as T4, N0–N1, M0 or any T, N2, M0 or any T, any N, M1.)

If kidney cancer spreads, it is more likely to go to your bones, lungs, liver or brain. When this happens, it is called secondary or metastatic kidney cancer. Remember that not all kidney cancers spread, especially if diagnosed early.

What are the grades of kidney cancer?

The grade of a cancer is known by looking at its cells under a microscope. These cells are usually acquired during surgery to remove the cancer. The grade describes the cell structure of the tumour and gives your doctors an idea of how the cancer will behave. For example, how quickly it might grow and spread. It also helps your doctors to decide if you need more treatment and what the outlook (prognosis) is.

The most common system used to grade kidney cancer is the Fuhrman Grade. It describes the size and shape of the nucleus in the cancer cells and how much they differ from normal kidney tissue. The nucleus is the part of the cell that stores DNA, which is its genetic make-up.

The cancer cells are graded 1 to 4. Grade 1 means the cancer cells look very like normal kidney cells. They grow slowly and are less likely to spread. As you go up the scale the cancer cells start to look more and more abnormal and are more likely to spread quickly. For more about grades, talk to your doctor. You can also call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre to talk to a specialist nurse.



To sum up

- The most common type of kidney cancer is renal cell cancer (RCC).
- Staging finds out the size of the cancer and if it has spread.
- Staging helps your doctor to plan the best treatment for you.
- There are four stages of kidney cancer (1 to 4).
- Grading refers to the structure of the cancer cells under the microscope.
- There are four grades of kidney cancer (1 to 4).

Treatment and side-effects

How is kidney cancer treated?

The way kidney cancer is treated depends on the stage of the disease. In general the main treatment is surgery. The type of treatment you receive will depend on:

- The size and stage of your cancer
- The type of cancer
- If it has spread or not
- Your age and general state of health

Types of treatment

Treatments for kidney cancer can include:

- Surgery
- Surveillance
- Thermal ablation
- Embolisation
- Biological (targeted) therapies

Surgery: Surgery is the main treatment for kidney cancer. Early stage kidney cancer is often cured by surgery alone. The aim of the surgery is to remove the tumour and the nearby tissues. This is called a nephrectomy. It is often possible for you to have keyhole surgery instead of open surgery. See page 19 for more about surgery.

Surveillance: Some small abnormal areas in the kidney may be monitored by seeing if they change on CT scan. This usually applies to very small masses (lumps) or if you have other medical conditions that mean it is better for you to avoid surgery. Often these small masses (called small renal masses by doctors) need no treatment and cause you no symptoms or harm. Your doctor will talk to you about surveillance if they think it is the best option for you.

Thermal ablation: This treatment uses heat to destroy the cancer cells. It can be used if you have small kidney tumours and cannot have surgery. It is sometimes used to help symptoms from advanced kidney cancers too.

Embolisation: This treatment can be used to block the flow of blood to kidney cancer. Rarely it can be used if you are not suitable for surgery. It may also be used to help control bleeding in more advanced cancer. Sometimes it is used before surgery.

Biological (targeted) therapies: There are many different types of biological therapies. In kidney cancer these are drugs that work by stopping the cancer from making new blood vessels. See page 24 for more details.

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

Deciding on treatment

Multidisciplinary team meeting: A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. They will meet to discuss your test results and decide your treatment plan.

Treatment options: Your doctor and nurse will explain your treatment options to you. Sometimes, depending on the stage of your cancer, you may have fewer choices.

Do ask as many questions as you like, no matter how small or trivial you think they are. All questions are important.

Time to think: When faced with a serious illness, it can be hard to decide what the right treatment is for you. It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You can always ask for more time to decide about your treatment, if you are unsure when it is first explained to you.

Second opinion: You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your doctor will refer you to another specialist for a second opinion if you feel this would be helpful.

Accepting treatment: You have the right to find out what a treatment option means for you, and the right to accept or refuse it. If you want to refuse treatment, let your doctor or nurse know your concerns first. It may help to talk to your GP as well. The important thing is that you are fully aware of the benefits and risks.

Giving consent: 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 information given to you, let your doctor or nurse know straight away. Some treatments can be hard to understand and may need to be explained more than once. You can always ask for more time to decide about the treatment, if you are unsure when it is first explained to you.

You can still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.

Individual treatment



You may notice that other people with kidney cancer are not getting the same treatment as you. Their cancer may not be the same type or at the same stage as yours. Everyone's treatment needs will be different. Do not be afraid to ask your doctor about your own treatment.



To sum up

- The main treatment for kidney cancer is surgery.
- Depending on the stage of your cancer, you may need other forms of treatment. For example, targeted therapies.
- A team of specialists 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. Usually, a team of cancer care doctors (multi-disciplinary team) will decide your treatment.



Surgeon	A doctor who specialises in surgery and who can remove a tumour from your body.
Clinical nurse specialist	A specially trained nurse who gives support and information to cancer patients.
Palliative care team	This team is specially trained in managing pain and other symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the 'homecare team' or the 'hospice homecare team'. A specialist palliative care service is available in most general hospitals.
Physiotherapist	A therapist who treats injury or illness with exercises and other physical treatments related to the illness.
Dietitian	An expert on food and nutrition. They are trained to give advice on diet during illness and use diet to help symptoms.
Medical social worker	A person specially trained to help you and your family with all your 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. For example, if you need Meals on Wheels.
Psychologist	A specialist who can talk to you and your family about emotional and personal matters and can help you to make decisions.
Counsellor	A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.

Surgery

Surgery is the main treatment for kidney cancer. The aim is to remove the cancer and the tissue close to it. Removing a kidney is called a nephrectomy. Removing part of a kidney is called a partial nephrectomy. Your surgeon will decide whether you need to have all or part of the kidney removed. He or she will look at:

- the size of the cancer
- which part of the kidney the cancer is in
- any other health problems you may have.

Partial nephrectomy: Here the part of the kidney containing the cancer is removed along with some tissue around it. This kind of surgery is done if the cancer is small and has not spread. The position of the cancer in the kidney is important in deciding if you are suitable for a partial nephrectomy or not. This operation can be done through keyhole surgery or open surgery. Ask your surgeon for more information.

Radical nephrectomy: Here the whole kidney and surrounding fatty tissue are removed. Sometimes the surgeon may remove the adrenal gland and nearby lymph glands as well.

The surgery usually involves a cut (incision) made between your lower ribs on the side where the cancer is found.

You can live a completely normal life with just one kidney. You will not need to make changes to your diet or lifestyle.

Keyhole surgery: For many patients it is possible to do kidney surgery through a special tube instead of having open surgery. This is known as a laparoscopic surgery. Part or all of your kidney and other tissues can be removed in keyhole surgery.



Keyhole surgery

For the surgery, your surgeon uses a laparoscope, which is a thin tube with a camera at the tip. All you need are small cuts in your skin rather than the large cut you have with open surgery. Your surgeon can use special long, thin instruments to remove all or part of the kidney. The benefits of this include a shorter stay in hospital, faster recovery, and less pain afterwards.

Keyhole surgery is specialised, so you may be referred to a different surgeon for this treatment. You can also ask to be referred to a suitable keyhole surgeon.

Before the surgery

You will need some extra tests to make sure you are strong enough for surgery. These tests may include a heart test (ECG) and more blood tests. An anaesthetist may examine you to make sure you are fit for surgery.

- **Exercises:** A physiotherapist or nurse will show you how to do special exercises. They will involve deep breathing and leg exercises. These will help to prevent you getting a chest infection or blood clot after your operation.
- **Marking your skin:** Your doctor will mark your skin to make sure the correct kidney will be removed.
- **Fasting:** You will not be able to eat anything for a number of hours before your operation. Your doctor or nurse will advise you about this.
- **Preventing clots:** Depending on your surgeon or the hospital, you may get an injection of an anti-clotting drug before surgery. For example, heparin. You may also get a course of it afterwards. This is to prevent a clot forming in your legs after surgery as you will be less mobile for a few days.
- **Arterial embolisation:** Occasionally your surgeon will want you to have a procedure before surgery to reduce the blood supply to the kidney. This is known as arterial embolisation. This procedure is done in the X ray department. You will be given some medicine to make you sleepy. A small cut is first made in your groin and a narrow tube put into the main blood vessel that flows to your kidney. Small pieces of a special gelatin sponge are then injected through the tube into the blood vessel. The sponges block the blood flow to your kidney or to the part of the kidney that contains the cancer.

After the surgery

When you wake up, you may notice a number of tubes attached to your body. They may look alarming but are quite normal after an operation like this.

- **Wound:** A thin tube from your wound will drain any excessive fluid like blood and so help your wound to heal.
- **Catheter:** You will have a small tube (catheter) draining urine from your bladder into a bag.
- **Fluids:** You will have a drip going into your vein to give you fluids. It is removed once you can eat and drink normally.



A drip giving fluids

Pain: You may have some pain afterwards, especially when you cough or move. Your nurse can give you painkillers and medication to prevent you feeling or getting sick, if you need it. There are various ways to give painkillers. There may be a thin epidural tube in your back to help relieve any pain. Or you may be given a patient controlled analgesic (PCA) pump. This sends pain medication into your blood when you press a button. Your nurse will show you how to use it. Always ask for help if you have any pain or feel sick.

Getting up and about: How quickly you get up and about after the operation will depend on whether you have keyhole or open surgery. You will be asked to move your legs in bed and do deep breathing exercises regularly. On the day after surgery, your nurses will help you out of bed and take you for a short walk. As you get better, these walks will become longer and you can go on your own.

Risks of surgery

Surgery always involves some risks. Not everyone develops problems after surgery for kidney cancer but some do. Some of the possible risks include:

- Bleeding during or after surgery
- Unwanted air in your chest cavity (pneumothorax)
- Wound/chest infection

If any of these complications develop, they can be treated by your surgeon. For example, you may need a blood transfusion for any heavy bleeding. Antibiotics can be given for a wound/chest infection. Any unwanted air in your chest cavity can be relieved by having a chest drain (a thin tube) inserted into your chest for a short time.

Going home

If you live alone or have problems getting around the house, talk to the medical social worker or nurse on your ward once you are admitted. That way, they can organise the community services you may need after you leave hospital. On the day you go home, you will be given a date to come back for a check-up, usually in about 6 weeks' time.

If you have a worry or symptom that is causing you concern before your check-up date, contact your doctor, cancer nurse specialist or hospital ward for advice.

See page 28 for more about follow-up.



To sum up

- Surgery is the main treatment for kidney cancer.
- Removing a kidney is called a nephrectomy.
- There are different types of surgery. For example, a partial or radical nephrectomy.
- Keyhole surgery is possible in many cases.

➤➤➤ Removing a kidney is a big operation and may not be suitable for everyone.

Alternatives to surgery

If your cancer is small or you are not suitable for surgery your doctor may recommend one of the treatments below.

Thermal ablation: This treatment uses heat to destroy the cancer cells. It can be used if you have small kidney tumours or if you cannot have surgery. This procedure is often done in the X-ray department. A needle-type instrument is placed in the kidney tumour through your skin. A CT scan guides your doctor to put the needle in place. Once the needle is in place a machine generates heat, which kills the cancer cells. You may have some discomfort for a few days afterwards. You will be given painkillers for this. You may also feel tired.

Arterial embolisation: A treatment called arterial embolisation may be used to block the blood supply to the part of the kidney with cancer if you cannot have surgery. This is not a cure for kidney cancer, but it can stop it growing bigger. See page 20 for details on how arterial embolisation is done.

How is advanced kidney cancer treated?



Advanced cancer is when the cancer has spread to other parts of your body. Your cancer may be advanced even when it is first diagnosed. Or it may have come back sometime after you were first treated.

If this happens, it can still be treated. Your doctor will discuss the best treatment option for you.

Your doctor might also refer you to specialist palliative care doctors and nurses. Palliative care is treatment and care given if you are ill due to advanced cancer. The aim of the care is not to cure the disease but to relieve your symptoms and make sure you have the best quality of life possible.

Biological (targeted) therapies

There are many different types of biological therapies. Targeted therapies are a type of biological therapy commonly used in kidney cancer. Unlike chemotherapy, targeted therapies are aimed at cancer cells directly and are less harmful to normal cells.

Your doctors may decide to give you a targeted therapy if the cancer has already spread or is not suitable for surgery. They can also be used if the kidney cancer returns after surgery.

What drugs are used?

Targeted therapies work in different ways. Some work by blocking the growth of new blood vessels in cancer cells or by blocking enzymes needed for the cells to grow and divide.

Often the first type of drugs that are used to treat kidney cancer are cancer growth inhibitors known as tyrosine kinase inhibitors. Examples of these are: Sunitinib (Sutent®), axitinib (Inlyta®), pazopanib (Votrient®) and sorafenib (Nexavar®). These are taken as tablets.

Side-effects

As with any medicine there may be some side-effects. Side-effects include:

- Tiredness or fatigue – For more information see page 26
- Diarrhoea
- Hoarseness of your voice
- Taste changes
- Skin changes such as dryness, redness or a rash
- Hair colour changes
- Hand-foot syndrome – this causes soreness or swelling of the hands and feet. Some people develop blisters.
- Raised blood pressure – you may need to take tablets to control your blood pressure while on this medication
- Low levels of thyroid hormone

If you are troubled by side-effects be sure to tell your doctor or nurse. They will discuss with you ways to help manage them.



Hints & Tips – Hand-foot syndrome



- Take good care of your skin
- Use mild or unperfumed soaps and shampoo
- Use a moisturiser to stop your skin drying out
- Avoid extremes of heat such as hot baths or showers
- Wear comfortable shoes. Avoid shoes that put pressure on points of your feet. You may want to put insoles in your shoes to avoid pressure on the soles of your feet.



Hints & Tips – Diarrhoea

- Try low-fibre, starchy foods such as white rice, pasta, toast or potatoes
- Avoid high-fibre foods such as wholemeal or wholegrain bread and cereals, peas, beans and lentils
- Eat small amounts and eat more often

For more information on individual drugs see www.cancer.ie/cancer-information/treatments/biological-therapies. You can also call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for advice from a specialist nurse.

If the growth inhibitor treatment you are on stops working, other drugs such as bevacizumab (Avastin®), everolimus (Afinitor®) or temsirolimus (Torisel®) may be used. They work in different ways to the growth inhibitors.

Some people may be given biological therapies that stimulate the immune system such as Interleukin or Interferon also. For more information on these see www.cancer.ie, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

Research studies called clinical trials are being carried out on biological therapies all the time. They look to see if the drugs or new combinations of the drugs can improve the treatment results. Your doctor might ask you to take part in a trial. Do not worry as these studies are quite safe. See page 30 for more details.



To sum up

- Targeted therapies are drugs that block the growth and spread of cancer by interfering with specific molecules involved in tumour growth.
- They can also reduce the side-effects of other treatments.
- The side-effects of targeted therapies can vary. Talk to your doctor or nurse if you are troubled by any side-effects..

How can I cope with fatigue?

Fatigue is a common symptom of cancer. Fatigue is often described as an overwhelming tiredness. Often it is not relieved by rest. You may find it hard to concentrate or make decisions. The reason for the fatigue can sometimes be hard to identify. It may be caused by anxiety over a cancer diagnosis or the added stress caused by treatment. Whatever the reason, there are things you can do that may help.

For many patients, treatment may help by relieving symptoms such as pain and nausea, allowing you to get back to your normal routine. Ask your doctor before you start treatment what side-effects you can expect.

If you are feeling very worried, you may find it hard to sleep at night. Do tell your doctor or nurse, who can advise you. 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.

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 www.cancer.ie



Tips & Hints – fatigue



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

Will treatment affect my sex life and fertility?

Sex and sexuality

Coming to terms with the fact that you have cancer can take quite a while. Your emotions may be turned upside down. It can be hard to relax as well when you have a lot of worries on your mind. You may also be feeling tired from the effects of tests and treatment. As a result, you may lose interest in sex. This is quite normal when you are concerned about your health.

If you have a supportive partner, you may find that talking about your feelings may ease your anxiety. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. If you find it hard to express your feelings to your partner or

a close friend, talk to your doctor or nurse. He or she may refer you for specialist counselling if you feel that would be helpful.

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 your interest in sex should return too. But you may find it will be some weeks before you will feel well enough to have sex again after surgery. Some people fear that cancer can be passed on to a partner during sex. There is no truth to this. It is quite safe for you to have sex again with your partner.

Asking for advice

If you have any queries about how treatment may affect your sex life, do ask your doctor. Don't be put off by thinking the question is small or trivial or that you'll be embarrassed. Your doctor is well used to dealing with these matters and will give you advice.

Contraception

It is best to use a reliable method of contraception if you are having treatment with biological therapies, as it is not yet fully known how these treatments might affect a developing baby. You can talk to your doctor or nurse for advice about contraception or if you have any questions about your particular treatment. You can also talk to a specialist nurse in confidence by visiting a Daffodil Centre or calling the National Cancer Helpline on 1800 200 700.

What follow-up do I need?

No matter what type of cancer treatment you get, you will still need to come back for regular check-ups once it is over. This is called follow-up. At first these visits to your specialist will be quite often, sometimes every 3 to 6 months, especially for the first 2 years. The visits are likely to continue for up to 5 years. The follow-up may involve having a physical exam, blood and urine tests, chest X-rays, and ultrasound and chest CT scans.

If you are between check-ups and have a symptom or problem that is worrying you, let your doctor know. Make an appointment to see him or her as soon as possible.

Should I quit smoking?



It is never too late to quit smoking. If you quit, it reduces your chances of developing other cancers and illnesses. These include emphysema, heart disease, stroke and osteoporosis.

How can I quit?

Like many others, you may find giving up smoking hard. If you would like advice or support on quitting, freetext QUIT to 50100. You can also call the HSE Quit Team on CallSave 1850 201 203 Monday to Friday from 10am to 7pm, and Saturday 10am to 1pm.

Some hospitals also have stop smoking clinics. Ask your doctor or nurse if there is one in your hospital.





Research – what is a clinical trial?



Research into new ways of treating kidney cancer goes on all the time. By using new drugs or new combinations of drugs and treatments that are 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 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 to be 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 1800 200 700, drop into a Daffodil Centre or visit our website: www.cancer.ie

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
- Aromatherapy
- Acupuncture
- Reflexology
- Hypnotherapy

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 from the Irish Cancer Society called *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients*. If you would like a copy or more advice, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

National Cancer Helpline Freefone 1800 200 700

Coping and emotions

How can I cope with my feelings?

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

Common reactions include:

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

Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. A helpful booklet which discusses them in detail is called *Understanding the Emotional Effects of Cancer*. Call the National Cancer Helpline 1800 200 700 for a free copy. You can also pick up a booklet from a Daffodil Centre or download it from www.cancer.ie

Shock and disbelief

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

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

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

Fear and uncertainty

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

There is no doubt that cancer is a scary word. Not surprisingly, you may have many fears when first told of your diagnosis. Often the first thing people think about is dying. They think the worst. But many cancers can be cured or controlled with modern treatments. Another

great fear about cancer is pain. The fear of pain can sometimes overwhelm everything else. However, some cancers cause no physical pain at all or else can be controlled with good painkillers.

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

It is natural for you to be afraid or concerned about the future too. You may wonder if you will be cured or if your cancer will recur. Living with this uncertainty can make you feel anxious and fearful. You may not wish to make any plans or decisions. Do discuss your concerns with your doctor, nurse or medical social worker, as they can advise and help you. If living with uncertainty overwhelms you, it may help to talk to someone in a support group, such as a Survivors Supporting Survivors volunteer. See page 52 for more information.

Loss of control

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

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

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

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

Sorrow and sadness

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

It is natural to feel sad when told you have cancer. You may feel sad for a variety of reasons: for the loss of your good health, for the plans that are put on hold, for the people you feel

you've let down, and for any changes to your body due to treatment. Depending on your type of cancer, your fertility or body image may be affected by treatment. In this case, the sadness or sorrow can come from feeling as if a part of you has died. These feelings may not be there all the time and may come and go, but will gradually fade.

Denial

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

Sometimes after being told their diagnosis, people deny they have cancer. While this may seem unusual, it is a valid way of coping. As a result, you may not wish to mention or discuss your illness. Or else you may talk as if your illness is nothing serious. Denial may last for a short or long time, depending on how long it takes for you to adjust to your illness. Tell your family and close friends that you would prefer not to talk about your illness, at least for the time being. Your doctors and nurses will also understand if you don't want to hear any information about your cancer until you're ready.

Anger

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

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

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

Resentment

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

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

On the other hand, sometimes relatives, especially adolescents, can resent the changes that your illness makes to their lives. It is best to admit that these feelings of resentment exist and to express them. Bottling up resentment helps no one. Instead everyone ends up feeling angry and guilty.

Blame and guilt

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

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

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

Withdrawal and isolation

I just need to be on my own.

It is true that a cancer diagnosis is stressful. It can leave you feeling confused and overwhelmed with so much information to take in. At times during your illness you may want to be left alone and withdraw from people. It is normal for you to want to be alone to sort out your thoughts and feelings. You will want to take stock of things and work out how best you can cope. However, it is not a good idea to spend long hours on your own every day. Sometimes depression can make you avoid family and friends and stop you wanting to talk. If you isolate yourself, it can be hard for your family and friends, as they will want to share this difficult time with you. They may worry about you needlessly. Let your family and friends know that you will talk to them once you are ready.

If you would like more information on how to talk about your cancer, there is a useful booklet available called *Who Can Ever Understand? Talking about Your Cancer*. If you would like a copy, call the National Cancer Helpline 1800 200 700 or visit a Daffodil Centre. You can also download it at www.cancer.ie

Learning to cope

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

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

Positive emotions

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

How can my family and friends help?

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



How can I talk to someone with cancer?



When someone close to you has cancer it can be hard to know what to do. Their welfare may be a priority for you, but you might still be unsure when to visit or what to talk about. You may be afraid of upsetting them or saying the wrong thing. So it may seem best to pretend that everything is okay and carry on as normal. Sadly, by not talking to your friend or loved one, it can make them feel even more lonely and isolated. Try not to withdraw because you're afraid of their illness or what might happen in the future. Although some people do die from cancer, many 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 think you are not 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 or visit a Daffodil Centre. You can also download it at 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 them down. These are all natural feelings to have at this time.

Be honest

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

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

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

It is best to prepare children for the side-effects of treatment before they happen and to answer their questions simply and honestly. For example, if you get hair loss due to treatment. 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 and 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 or visit a Daffodil Centre. You can also download it at www.cancer.ie



What else can I do?

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

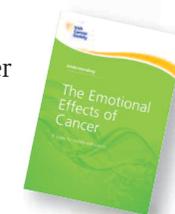
- **Communicate with your family and close friends:** Do not keep your worries or symptoms secret from the people closest to you. This includes physical or emotional problems. Ask the person closest to you to come with you when visiting the doctor and when treatments will be discussed.
- **Live one day at a time:** Don't think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.
- **Live well:** Try to eat as well as you can. Eat little and often, including lots of different types of foods with plenty of fresh fruit and vegetables. Do some regular exercise that you enjoy. Take it easy at first, building up the amount you do as you feel stronger.
- **Expect change in your life:** Even though you may want to stick to your old routines, sometimes this may not be possible. It may take a while for you to adjust to your new routine. Remember that change may bring new opportunities and blessings.

- **Keep an open mind:** Don't feel you have to be positive all the time. Expect ups and downs during your cancer journey. There will be times when you feel low but don't feel guilty about it, as it will pass.
- **Seek information:** Be sure to ask your doctor as many questions as you can and get involved in decisions about your treatment. Always ask for information that is personal to you. Ask what side-effects you can expect so you can prepare for them. Build up as much information about your cancer and treatment as possible. Follow your doctor's instructions carefully. Take your medication. If you forget and are not sure what to do, ask your doctor or nurse. Keep a notebook of all your dates for blood tests, X-rays, scans, treatments, symptoms, side-effects, medications, and your general health. Keep a record of any emotions you are feeling too, especially strong ones. Call 1800 200 700 700 or visit a Daffodil Centre for a free copy of *Journey Journal*, a special diary to help you keep track of your cancer treatment.
- **Find what works for you:** Some people are comfortable taking about their illness, others are not. You may prefer relaxation, meditation, walking, listening to music, or other approaches helpful. Do whatever suits you. But if it's not working, be open to finding a new way to cope.
- **Build a support network:** Be realistic about what you can manage by yourself. Ask for help from those who want to support you. Talk to your family, friends, nurses or doctors. Meet with other patients in support groups and self-help groups as they can understand what you are going through. If the group does not suit you and is not helping, leave it.
- **Seek professional help:** If you have any low moods or strong emotions, talk to your close friends and family – or someone who is a good listener. If they are still getting the better of you, discuss them with your nurse and doctor. They may recommend you talk to a trained counsellor or other specialist.
- **Spiritual care:** When faced with a cancer diagnosis and treatment, you may start thinking about the meaning of life and the afterlife. For some people spiritual and religious beliefs can bring comfort and hope. Prayer or meditation can help you to focus on what has value

and meaning in your life. Even if you do not consider yourself a religious or spiritual person, it is still possible to take comfort and support from these practices. Some complementary therapies that have a spiritual dimension may also help you to focus on being positive and hopeful.

- **Express yourself:** Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of your cancer journey. Other forms of creative expression, such as music and art, may help too.

A useful booklet called *Understanding the Emotional Effects of Cancer* has been written for people with cancer and is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 if you would like a free copy or pick one up at a Daffodil Centre. You can also download it at www.cancer.ie





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.

GP (family doctor): 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 also download the Irish Cancer Society's Directory of Cancer Support Services from 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 pages 53/54 for information on the Care to Drive and Travel2Care 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 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



If you have financial worries...



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

There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. See page 53 for more details. You can also visit a Daffodil Centre or call the National Cancer Helpline 1800 200 700 and the nurse will suggest ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 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 68 for contact details. A useful book for preparing low-budget nutritious meals is 101+ Square Meals. See page 61 for more information.

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 56 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 service

Care to Drive is a programme operated by the Irish Cancer Society. It provides free transport for patients to and from their treatments delivered by volunteer drivers. The service is usually limited to patients receiving chemotherapy treatment. 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.



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

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

Rotunda IVF

Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732
Email: info@rotundaivf.ie
Website: www.rotundaivf.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 57]

Brain Tumour Support Group

Medical Social Work Department
St Luke's Hospital
Highfield Road
Rathgar
Dublin 6
Tel: 01 406 5295

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 57]

Connaught support services

Athenry Cancer Care

Social Service Centre
New Line
Athenry
Co Galway
Tel: 091 845 228 / 091 844 319
Email: athenrycancercare@gmail.com
Website: www.athenrycancercare.com

Ballinasloe Cancer Support Centre

Main Street
Ballinasloe
Co Galway
Tel: 090 964 3431
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 7590
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: aoibheannspinktie2@gmail.com
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

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

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

Midlands Myeloma Support Group

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

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

Other support services**The Bella Rose Foundation**

Merry Maid House
West Park Campus
Garther'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.purplehouse.ie

Rathdrum Cancer Support Group

St Anne's
Lower Street
Rathdrum
Co Wicklow
Tel: 087 925 3915
Email: rathcan@gmail.com

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 (US)

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 Buddies Network

Website: www.cancerbuddiesnetwork.org

Cancer Research UK

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

Healthtalkonline (UK)

Website: www.healthtalk.org

Kidney Cancer UK

Website: www.kcuk.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.cancerni.net

National Cancer Institute (US)

Website: www.nci.nih.gov

Helpful books**Free booklets from the Irish Cancer Society**

- *Understanding Cancer and Complementary Therapies*
- *Diet and Cancer*
- *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*
- *A Time to Care: Caring for Someone Seriously Ill at Home*
- *Managing the Financial Impact of Cancer: A Guide for Patients and their Families*
- *Journey Journal: Keeping Track of Your Cancer Treatment*

**Cancer at Your Fingertips**

Val Speechley & Maxine Rosenfeld
Class Publishing, 2001
ISBN 1859590365

Challenging Cancer: Fighting Back, Taking Control, Finding Options

Maurice Slevin & Nira Kfir
Class Publishing, 2002
ISBN 1859590683

Taking Control of Cancer

Beverley van der Molen
Class Publishing, 2003
ISBN 1859590918

101+ Square Meals

[Budget and nutrition]
Norah Bourke et al
MABS/HSE West/Paul
Partnership/Limerick
VEC/Safefood, 1998
ISBN 187407514X
[For more details, see
www.mabs.ie]

**Explaining cancer to children****The Secret C: Straight Talking About Cancer**

Julie A Stokes
Winston's Wish, 2000
ISBN 0953912302

Why Mum? A Small Child with a Big Problem

Catherine Thornton
Veritas, 2005
ISBN 1853908916

What does that word mean?

Adjuvant treatment	Treatment for cancer given soon after surgery.
Alopecia	Loss of hair or baldness. No hair where you normally have hair.
Anti-emetic	A tablet, injection or suppository to stop you feeling sick or vomiting.
Benign	Not cancer. A tumour that does not spread.
Biopsy	Removing a small amount of tissue from your body to find out if cancer cells are present.
Cells	The building blocks that make up your body. They are tiny and can only be seen under a microscope.
Chemotherapy	Treatment using drugs that cure or control cancer.
Fatigue	Ongoing tiredness often not helped by rest.
Grading	Tests that look at the structure of cancer cells under the microscope.
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.
Neo-adjuvant treatment	Treatment such as chemotherapy or radiotherapy that is given before surgery to shrink a tumour.
Oncology	The study of cancer.
Palliative care team	A team of doctors and nurses who are trained in managing pain and other symptoms caused by cancer. They can also help you cope with any emotional distress.
Prognosis	The expected outcome of a disease.
Radiation oncologist	A doctor who specialises in treating cancer patients using radiotherapy.
Radiotherapy	The treatment of cancer using high-energy X-rays.
Staging	Tests that measure the size and extent of cancer.
Targeted therapies	Drugs or other substances that block the growth and spread of cancer by interfering with specific molecules involved in tumour growth.

Questions to ask your doctor

Here is a list of questions that you might like to ask. Never be shy about asking questions. It is always better to ask than to worry.

- How long will it take to get the test results?
- What type of kidney cancer do I have?
- What stage is the cancer at?
- What treatment will I need?
- Will surgery cure the cancer?
- Are there other treatment options? Why is this one best for me?
- Would I be suitable for a clinical trial?
- How long will my treatment take?
- Do I have to stay in hospital for my treatment?
- What side-effects will I get?
- Is there anything I can do to help myself during treatment?
- Will treatment affect my fertility?
- How often will I need check-ups?
- What if the cancer comes back?

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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 call the National Cancer Helpline 1800 200 700.

Would you like to be a patient reviewer?

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



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

If you would prefer to phone or write to us, see contact details below.

Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, education and research. This includes patient education booklets. 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 at CallSave 1850 60 60 60 or email **fundraising@irishcancer.ie**

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National Cancer Helpline Freefone 1800 200 700

Open Monday to Thursday 9am to 7pm

Friday 9am to 5pm

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