

Understanding

Kidney cancer

Caring for people with cancer

Understanding

Kidney cancer

This booklet has information on:

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

Useful numbers

Urology nurse specialist

Surgeon or urologist

Medical oncologist

Medical social worker

Family doctor (GP)

Emergency number

Hospital records number (MRN)



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Fast facts



What kind of treatment might I have? Page 31

Surgery: An operation to remove your kidney or part of your kidney.

Thermal ablation: Using a needle-type instrument to deliver heat to the tumour to destroy it.

Targeted therapies: Drugs that target cancer cells in different ways to stop or slow down their growth.

Radiotherapy: Uses high-energy rays to kill cancer cells.

Arterial embolisation: Injecting a substance into the main blood vessel to your kidney, to block the blood supply to the tumour and slow its growth.

Will I be OK? Page 28

What is likely to happen to you (your prognosis) is hard to predict. Your doctor will advise you on what is likely to happen in your situation.

Will I get side-effects? Page 45

Some treatments can cause side-effects, but these usually get better after treatment has ended. You can read about the different treatments to learn more about any possible side-effects.

There are treatments to help with most side-effects, so tell your doctor if you have any. Don't suffer in silence!

Clinical trials Page 61

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. Ask your consultant if there are any trials suitable for you. You can also see a list of current cancer trials at www.cancertrials.ie

We're here for you Page 96

If you or your family have any questions or worries, want to know where to get support, or if you just need to talk, you can talk to one of our cancer nurses.

Ways to get in touch

- Call our Support Line on 1800 200 700
 - Drop into a Daffodil Centre.
Email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.
 - Email us: supportline@irishcancer.ie
- See page 96 for more about our services.

Support Line Freephone 1800 200 700

Reading this booklet



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

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

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

About our information

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

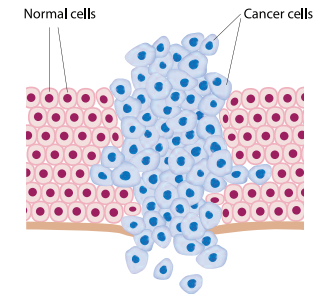
You should always talk to your own team about your treatment and care. They know your medical history and your individual circumstances. We cannot give advice about the best treatment for you.

About kidney cancer

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What is cancer?

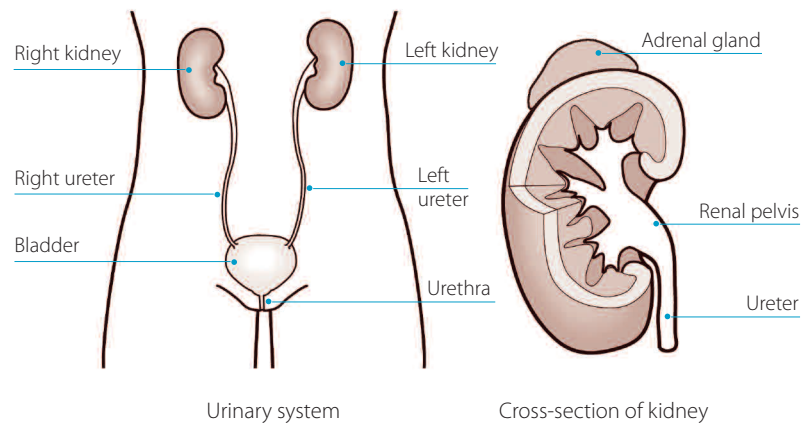
- **Cancer is a disease of the body's cells.**
Cancer cells are abnormal cells that grow without control. They can form a lump (tumour).
- **Cancers are named after the organ or cell where the cancer starts.**
Kidney cancer starts in cells in the kidney.
- **Cancers sometimes spread.**
If a tumour is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



What are the kidneys?

The kidneys are small bean-shaped organs about the size of your fist. You normally have two, 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. A gland called the adrenal gland sits on top of each kidney.

The kidneys remove waste products from your blood. This waste is then changed into urine (pee). 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.

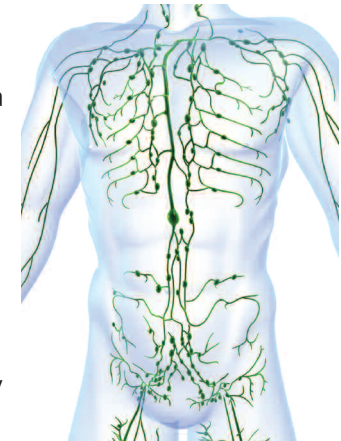


What is kidney cancer?

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

What is the lymphatic system?

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



What caused my cancer?

We don't know exactly what causes many cancers, but there are things that can increase your risk of getting cancer. Sometimes kidney cancer can be genetic, but this is very uncommon. If you want to learn more about the risk factors for kidney cancer, see our website www.cancer.ie or talk to a cancer nurse on our Support Line or visit a Daffodil Centre.

What are the types of kidney cancer?

Renal cell cancer (RCC)

Renal cell cancer is the most common type of kidney cancer in adults – it accounts for about 9 out of 10 kidney cancers. It's also known as renal cell adenocarcinoma or clear cell renal cell cancer.

This booklet deals mainly with the treatment of renal cell cancer.

Urothelial kidney cancer

Urothelial kidney cancer (also known as transitional cell cancer – TCC) is a rare type of kidney cancer that affects the renal pelvis. This 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 cancers and usually needs different treatment. Ask your medical team for more information about this type of cancer, or speak to a cancer nurse on our Support Line 1800 200 700.

Wilms' tumour

This is the most common type of childhood kidney cancer. It is very rare. It is not like adult kidney cancer and the tests and treatment for it are different.

How common is kidney cancer?

About 700 people are diagnosed with kidney cancer each year in Ireland. 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.

Preparing for your hospital appointments

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Preparing for your hospital appointments

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



Before your appointment

- **Write down a list of questions** and things you would like to discuss.
- **Know where you are going and plan your journey** (build in extra time for unexpected delays).
- **Dress in warm comfortable clothes and shoes** – sometimes you can be waiting around for a while. Layers are best, as the temperatures in hospitals can vary a lot. Loose-fitting clothing will be easier to manage if you are having your blood pressure taken, blood tests or a physical examination.
- **Try to drink clear fluids** (water or juice without pulp) if you are having a blood test as it makes it easier for the nurse or doctor to find a vein. If you are told to fast, you may only drink water.
- **Check with the hospital if it is okay to bring someone with you.** Ask a friend or family member to go along for extra support.

What to take to your appointment

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

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

Before leaving the appointment

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

After the appointment

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

Note

If you have to cancel your appointment...

If you are unable to attend your appointment, contact the hospital in advance and they will try to arrange a new appointment for you. If you don't go to your appointment or contact the hospital, you may have to return to your GP and go back on the waiting list for a new appointment.



Diagnosis and further tests

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Being diagnosed with kidney cancer

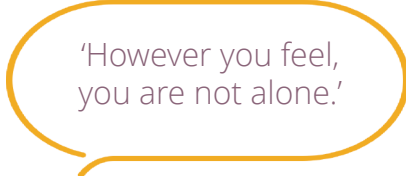
Hearing that you have kidney cancer can be a huge shock. You may be feeling:

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

However you feel, you are not alone.

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

- **Ask to speak to the cancer (oncology) liaison nurse or the medical social worker at the hospital.** They can help you and your family to cope with your feelings and advise you about practical matters.
- **Talk to one of our cancer nurses in confidence** – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- **Speak to an Irish Cancer Society Survivor Support volunteer** who has had a cancer diagnosis and really knows what you are going through. Our cancer nurses can put you in touch with a volunteer.
- **Talk to other people affected by cancer.** Join our online community at www.cancer.ie/community
- **Go to your local cancer support centre.** For more information, see page 102.



'However you feel,
you are not alone.'

Telling people about your diagnosis



Telling people about your diagnosis can help you to get support from friends and family. But you may feel you don't want to tell people straight away. You may be unsure how to break the news. You may also worry about how other people will react. For example, they may fuss over you or be upset. If you would like to talk things over with a cancer nurse, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

You can also ask for a copy of our booklet *Understanding the emotional effects of cancer*. It can help you find ways to talk about your cancer and to ask for the help and support you need.



What tests will I have after diagnosis?

- Tests you may have include scans, cystoscopy and image-guided biopsy.
- The tests will tell your medical team more about your cancer and help them to decide on the best treatment for you.

The following tests give doctors more information about your cancer. Some tests may also be used to see how well you are responding to treatment.

Scans

Ultrasound scan

This is a scan that uses sound waves to look at your kidneys. The scan is painless and only takes a few minutes. Some gel is first put on your abdomen (tummy area) and then a small hand-held device is passed over the gel.

CT scan

This is a special type of X-ray that gives a detailed 3D picture of the tissues inside your body. You might be asked to fast (not eat) for a few hours before the test. You may also be given an injection or a special drink to help show up parts of your body on the scan. The injection may make you feel hot all over for a few minutes. During the scan you will lie on a table which passes through a large doughnut-shaped machine. The scan is painless and takes between 10 and 30 minutes. You'll probably be able to go home as soon as the scan is over.

MRI scan

This is a scan that uses magnetic energy to create a picture of the tissues inside your body. During the test you will lie inside a tunnel-like machine. Some people are afraid they will feel claustrophobic inside the tunnel. Tell the radiation therapist if you're feeling anxious.

An MRI can also be noisy, but you will be given earplugs / headphones to help block out the sound. You might get an injection before the scan to show up certain parts of your body.

During the scan you cannot wear metal jewellery. If you have any medical device in your body, like a pacemaker or pin, you may not be suitable for the test.

Usually you can go home soon after the scan.

For most scans you will be alone in the treatment room, but the medical team can still see you, hear you and speak to you. Just speak or raise your hand if you need anything.

Cystoscopy

This test might be done if there is 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

Biopsy means taking a sample of cells from your kidney. This test is done if your doctor wants more information to help them plan the best treatment for you.

Your doctors will use an ultrasound or CT scan to guide them to the 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 to have any other tests.


Waiting for test results



It usually takes up to 2 weeks 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 our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse. Once all the tests have been completed, the multidisciplinary team will meet to decide on how to manage your illness.



How is kidney cancer staged and graded?

- 
- Staging cancer means finding out its size and location.
 - Grading means looking at the cancer cells to see how they might grow.
 - Your prognosis is what your doctor expects to happen with your cancer.

The tests you have after diagnosis help the doctor to give your cancer a stage and a grade.

Knowing the stage and grade helps your medical team to decide the best treatment for you.

What are the stages of kidney cancer?

A cancer stage is a way to describe the extent of the cancer at the time you are first diagnosed. The staging system normally used in kidney cancer is called TNM. This stands for:

- **Tumour (T):** What is the size and extent of the main tumour?
- **Nodes (N):** Is there cancer in the lymph nodes?
- **Metastasis (M):** Has the cancer spread to other parts of the body?

Staging can be hard to understand, so ask your doctor and nurse for more information if you need it. Sometimes you may need surgery to find out the exact stage. This means that your treatment plan may only be decided or may change after you have had surgery.

Number stage

Your doctor often uses the TNM information to give your cancer a number stage – from 0 to 4. In general, the lower the number, the less the cancer has spread. Some stages are further divided into stage A and B.

Stage 1

The cancer is less than 7cm in size and found only in the kidney (also described as T1a–T1b).

Stage 2

The cancer is more than 7cm and found only in the kidney or only in a renal vein (also described as T2).

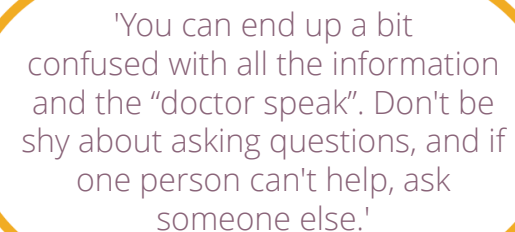
Stage 3

The cancer has spread into the 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 usually spreads to your bones, lungs, liver or brain. When this happens, it is called secondary or metastatic kidney cancer. Not all kidney cancers spread, especially if diagnosed early.

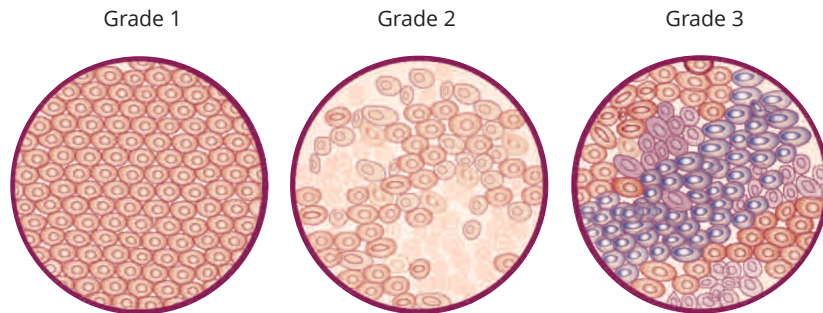


'You can end up a bit confused with all the information and the "doctor speak". Don't be shy about asking questions, and if one person can't help, ask someone else.'

What are the grades of kidney cancer?

Cancer can be low grade or high grade. It depends on how abnormal the cells look.

Lower grades are slower growing. Higher grades tend to grow more quickly. Different grades may need different treatments.



The most common system used to grade kidney cancer is the Fuhrman Grade. It describes the size and shape of the cancer cells and how much they differ from normal kidney cells. 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.

Asking about your prognosis

Your prognosis includes information about how your cancer is likely to progress, including average survival times or life expectancy. It's not always easy for doctors to answer a question about life expectancy. Everyone is different, so what happens to you might be quite different from what the doctor expects.

Should I ask about my prognosis?



If your prognosis is better than expected, you may feel more hopeful about your illness and your future. You may feel more in control by having as much information as possible. Or you may not want to know about your prognosis. You may prefer not to think about the future too much or you may worry how you will cope if you get bad news.

If you decide you want information on your prognosis:


- **Get the information from your doctor.** They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Ask a friend or family member to go with you,** if you would like some support.
- **Be careful with online information.** It may be hard to understand or even incorrect. Also, the information may not really apply to your situation or to your particular cancer type. Ask your doctor or nurse specialist for recommended websites.
- **Accept that you will need some time to think about what you have been told.** You may forget some things or there may be things you didn't understand. You may need to talk to your doctor again after you have thought about everything.
- **Get emotional support if you need it.** If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.



Treatment overview

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How is kidney cancer treated?

- 
- Surgery is the main treatment for kidney cancer.
 - If surgery is not an option for you, you may have surveillance or other treatments like thermal ablation, radiotherapy or drug treatments.
 - A team of healthcare professionals (multidisciplinary team) will be looking after you.

The type of treatment you receive will depend on:

- The size of the tumour
- Where the cancer is in your body
- The type of cancer
- If it has spread or is in your lymph nodes
- Your age and general health

Your doctor will discuss your treatment options with you.

Types of treatment

Surgery

Surgery is the main treatment for kidney cancer. The aim of the surgery is to remove the tumour. Early-stage kidney cancer is often cured by surgery alone. You will have part or all of your kidney removed. This type of surgery is called a nephrectomy. The surgery may be done through small cuts (keyhole surgery) or through one larger opening (open surgery). See page 47 for more about surgery.

Surveillance

Some small abnormal areas in the kidney may be monitored by watching if they change on CT scan. Often these areas (called small renal masses) need no treatment and cause you no symptoms or harm. Your doctors 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 for certain types of small kidney tumours, or sometimes if the person is not fit enough for surgery. See page 53 for more.

Arterial 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. See page 54.

Radiotherapy

Using high-energy rays to kill cancer cells. See page 54.

Targeted therapies and other drugs

These are drugs that can destroy cancer cells or stop them from growing. The main targeted therapy drugs for kidney cancer work by stopping the cancer from making new blood vessels. See page 56.

How is metastatic (advanced) kidney cancer treated



Metastatic cancer is when the cancer has spread to other parts of your body. The cancer may have spread when it is first diagnosed. Or it may have come back sometime after you were first treated. Targeted therapy drugs are often used to keep metastatic kidney cancer under control. See page 55 for more about treating metastatic kidney cancer.

Specialist cancer centres

Kidney cancer is treated in specialist centres in Ireland. The staff at these centres have a lot of experience in managing patients with kidney cancer. As a result, you may be transferred to another hospital from the one where you received your diagnosis, depending on your diagnosis and treatment plan.

Deciding on treatment

Multidisciplinary team



A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. For example, a urologist, medical oncologist, radiation oncologist, pathologist, radiologist and urology nurse specialist. The team will meet to discuss your test results and treatment plan.

Understanding your treatment

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

Time to think

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 the treatment, if you are unsure when it's 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 treating doctor or your GP can 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 a particular treatment, let your doctor or nurse know your concerns first. It may help to talk to your GP as well. The important thing is that you are fully aware of the benefits and risks.

Email: supportline@irishcancer.ie

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 (multidisciplinary team) will decide your treatment.

Consultant An expert doctor. They are in charge of your treatment. They have a team of doctors working with them.

Surgeon/urologist A doctor who specialises in surgery and who can remove a tumour from your body.

Advanced nurse practitioner A nurse who gives expert information and support and is specially trained to carry out tests and help to review your treatment.

Clinical nurse specialist A specially trained nurse who works in a cancer care unit. They give information and reassurance to you and your family from diagnosis and throughout your treatment.

Medical oncologist A doctor who specialises in treating cancer patients using chemotherapy and other drugs.

Radiologist A doctor who analyses scans, such as CT, MRI and ultrasound scans.

Pathologist A doctor who analyses the cancer under a microscope.

Medical social worker A person trained to help you and your family with all your social issues and practical needs. They can give counselling and emotional support. They can also give advice on social welfare benefits, financial matters and practical supports and services available to you from the time of your diagnosis, right through to returning to work.

GP (family doctor) Your GP is still very much a part of your care and can be a great support to you. You can talk to your GP about your medication and any side-effects you have. You can also contact your GP about any worries you have or if you are finding it hard to cope.

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

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

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

Occupational therapist (OT) A therapist who helps people adapt their living and working environment so they can manage their daily activities after treatment.

Psycho-oncology team These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses. A psychologist is 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.

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

Palliative care team This team is specially trained in managing pain and other symptoms. They can also help you and your family cope with any emotional distress. They are sometimes known as the 'symptom management team'. A specialist palliative care service is available in most general hospitals.

Giving consent for treatment

Before you start any treatment, you should be asked to sign a consent form saying that you understand what the treatment is for and that you give permission for treatment to be given. Before treatment, you should have been given full information about:

- What the treatment is for
- The type and amount of treatment you will have
- The benefits and risks of the treatment
- Possible side-effects from treatment
- Any other treatments that may be available

If you are confused about the information given to you, let your doctor or nurse know straight away. Some treatments can be hard to understand and may need to be explained more than once. You can still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.

Your treatment plan



The treatment or treatments your doctors recommend for you are based on the latest research and international guidelines about the best ways to treat kidney cancer.

Every person and every diagnosis is different, so your treatment plan may not be the same as someone else's. Talk to your doctor or nurse if you have any questions about your treatment plan.

Waiting for treatment to start

Planning cancer treatment takes time. Most people want to start treatment right away. You may worry that the cancer will spread during this time.

Cancer treatment should start soon after diagnosis. But for most cancers, waiting for scans or treatment for a few weeks does not usually affect how well the treatment works.

If you are worried, talk to your doctor. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

You might like to focus on your health and wellbeing while you're waiting for treatment to start. For example, eating well and staying active.

Pre-treatment education workshops



Ask your specialist nurse or visit a Daffodil Centre for information about our pre-treatment education workshops. The workshops give information on certain treatments, including what to expect and how to manage side-effects.

Email: supportline@irishcancer.ie

How can I help myself?

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

Eat well

Eating well can help you feel better. It can also help you to:

- Feel stronger and maintain a healthy weight
- Cope better with the side-effects of treatment
- Recover



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

Stay active and exercise regularly

Keeping active has many benefits. It can help to:

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



Talk to your doctor or nurse before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you. (See page 76 for more about exercise.)

Email: supportline@irishcancer.ie

Quit smoking

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

- Non-smokers are likely to have fewer or less severe side-effects during cancer treatment.
- Smoking can reduce how well chemotherapy or radiotherapy work.
- Smoking increases risk of complications following surgery, such as delayed wound healing and chest infections.



If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203, visit www.quit.ie or Freetext QUIT to 50100. Some hospitals have smoking cessation officers who can help and support you – you can ask your doctor or nurse for a referral to this service.

Other ways to help yourself

Get information about your cancer and treatment

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

Involve your family and close friends

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

Use your support network

Don't be shy about asking for help. Family and friends may not know the best way to help you, so tell them what you need. For example,

lifts to the hospital, practical help at home, child-minding or just some company or support. Telling people what you need and how they can help means you will get the right amount of support to suit you.

Try relaxation and stress management techniques

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

Accept change in your life

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



Be aware that there will be ups and downs

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

Try to cope day by day

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

Types of treatment

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Surgery



- Surgery can often cure early-stage kidney cancer.
- You may have all or part of your kidney removed.
- Keyhole surgery is possible in many cases.

Surgery is the most common treatment for kidney cancer. The aim is to remove the cancer and the tissue close to it. Your surgeon will decide whether you need to have all or part of the kidney removed. They will look at:

- The size of the cancer
- Which part of the kidney the cancer is in
- Any other health problems you may have

Types of surgery

Partial nephrectomy

The part of the kidney containing the cancer is removed along with some tissue around it, leaving as much normal kidney tissue as possible. This kind of surgery is performed if the cancer is small and is contained within the kidney. It is also known as kidney-sparing surgery.

The position of the cancer in the kidney is important in deciding if you are suitable for a partial nephrectomy. This operation can be done through keyhole surgery (see page 49) or open surgery. Ask your surgeon for more information on both types of surgery.

Radical nephrectomy

The whole kidney and surrounding fatty tissue are removed. Sometimes the surgeon may remove the adrenal gland and nearby lymph nodes as well. They will discuss this with you before surgery.

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.

Cytoreductive nephrectomy (if the cancer has spread)

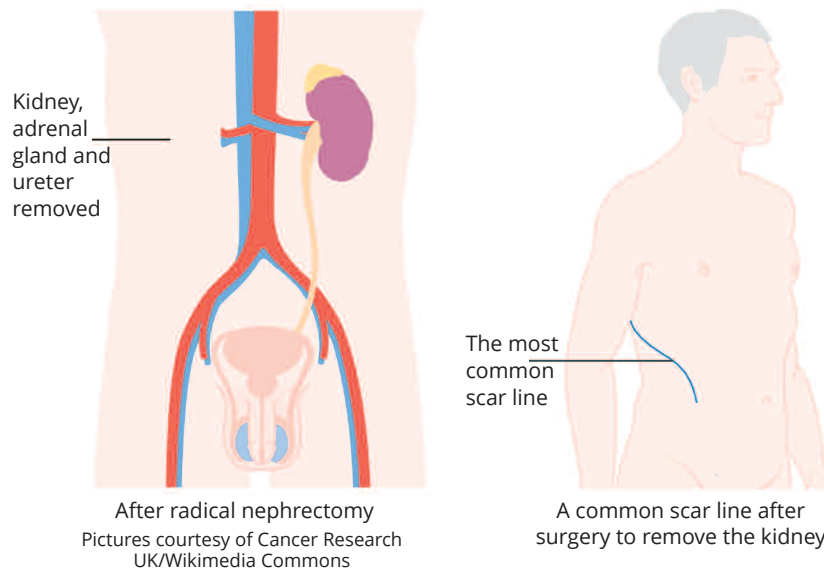
A cytoreductive nephrectomy is an operation to remove the kidney when the cancer has spread to other areas. See page 60 for more on this procedure.

How is surgery done?

There are two main ways of doing surgery for kidney cancer: open surgery and keyhole surgery.

Open surgery

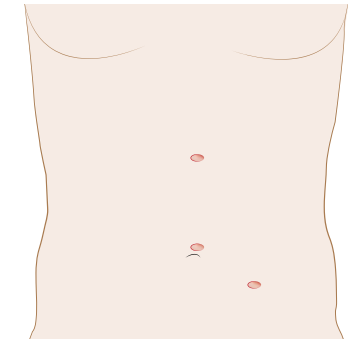
Open surgery is where the surgeon operates through a cut (incision) near your bottom ribs. It is a more invasive procedure than keyhole surgery and recovery is longer.



During surgery you may have an epidural tube placed in your back to help relieve pain after the operation. See page 51 for more about pain relief and what to expect after surgery. Your recovery will be supported by a number of specialties, if you need them, such as a physiotherapist or dietitian.

Keyhole surgery

For many patients it is possible to remove the kidney or part of the kidney using keyhole surgery. All you need are small cuts in your skin rather than the large cut you have with open surgery. This means less pain and quicker recovery.



Keyhole (laparoscopic) nephrectomy cuts

Keyhole surgery can be performed in two ways – laparoscopic or robotic. Robotic surgery is where the surgeon uses a robotic device to help perform minimally invasive surgery. Both ways can achieve the same result, but robotic is the more common approach. Keyhole surgery is not suitable for everyone and can depend on the size and stage of the cancer.

The main benefits of keyhole surgery compared to open surgery are:

- A shorter stay in hospital
- Less pain afterwards
- Faster recovery
- Quicker return to work
- Fewer complications

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.

Getting ready for surgery

Your surgical team and specialist nurse will tell you about your surgery. It is natural to feel very anxious about having surgery. Talk to your doctor or nurse if you are feeling anxious. If there is anything that you don't understand, ask again. Your doctor or nurse will be happy to answer your questions. They will tell you what you can expect after the operation and help you find ways to cope. You can also call our Support Line on 1800 200 700.

Tests

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

Exercises

A physiotherapist or nurse will show you how to do special breathing and leg exercises. These will help to prevent you getting a chest infection or blood clot after your operation.

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

You may be given elastic stockings to help prevent blood clots. You may also get a course of anti-clotting injections (such as heparin) after the operation, as you will be less mobile for a few days.



After the surgery

When you wake up, you will have some tubes attached to your body. Don't be alarmed as this is fairly standard after an operation like this. You may have:

- A drip in a vein in your arm. You will be given fluids through this until you can drink again.
- An oxygen mask over your face, for a short while after the operation.
- A small tube (catheter) draining urine from your bladder into a bag.
- A thin tube from your wound which will drain excess fluid (mostly blood) and help your wound to heal.

Pain

You may have some pain afterwards, especially when you cough or move. Your nurse can give you pain relief if you need it. There are various ways to relieve pain. 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.

Feeling sick

After your surgery you won't eat for a while. You will start taking sips of fluid and if you're feeling ok, the nurse will give you light food. Some people can feel sick after the operation. Some pain medication can also make you feel sick. The nurses can give you medication to stop you feeling sick or getting 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 or physiotherapist will help you out of bed and take you for a short walk. As you get better, you will be able to walk on your own for longer distances.

Risks of surgery

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

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

If any of these complications develop, they can be treated by your surgeon. Let your medical team know if you feel unwell, notice any bleeding or redness around the wound, have any swelling or develop any other symptoms.

Going home

Depending on the kind of surgery you had – open or keyhole – most people are ready to go home 2-7 days after surgery. Before you go home, you will be given a date to come back for a check-up about 2-4 weeks after your operation.

Help at home

If you live alone or have problems getting around the house, talk to the medical social worker or nurse on your ward as soon as you are admitted. That way, they can organise the community services you may need after you leave hospital.

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 73 for more about follow-up.

Email: supportline@irishcancer.ie

Alternatives to surgery



If surgery is not possible or recommended for you, your doctor may discuss 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 and you cannot have surgery. This procedure takes about 20 minutes under a general anaesthetic and 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.

This treatment is easier on the body than surgery, but there is a slightly higher risk that some cancer cells will remain active after treatment, meaning you might need a second treatment. Although this treatment method seems attractive, it is only used in very specific situations and often depends on the location of the cancer. It is sometimes used for older patients or for people who are not fit for surgery.

Arterial embolisation

A treatment called arterial embolisation is occasionally 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 help to stop it growing.

This procedure is done under local anaesthetic 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.

Stereotactic radiotherapy

Radiotherapy uses high-energy rays to kill cancer cells. Stereotactic radiotherapy uses smaller, more precise radiation beams than standard radiotherapy. These beams are targeted at your tumour from several angles, which combine to give a high dose of radiation. It may be used for small tumours that are not suitable for surgery.

Drug treatments

If your cancer has spread or is advanced, your doctor may recommend targeted therapies or immunotherapy. See page 56 for more on drug treatments.

Email: supportline@irishcancer.ie

Treating cancer that has spread (metastatic cancer)

If the cancer spreads to another part of your body, it is called metastatic, advanced or secondary cancer. Your cancer may be in more than one part of your body when it is first diagnosed.



If the cancer has spread, it can still be treated. Treatment is usually to try to control the cancer rather than to cure it. Targeted therapy drugs are often used to keep metastatic kidney cancer under control (see page 56). Or you may have one of the treatments listed on the previous page, such as arterial embolisation or radiotherapy.

You may also have surgery to reduce the size of the cancer (see cytoreductive nephrectomy on page 60).

There may also be treatments that you can have as part of a clinical trial (see page 61). Your doctor will tell you if there are any clinical trials that might be helpful for you. You can also have treatment to help with any symptoms.

You may be referred to the palliative care team, who are experienced in managing the symptoms of metastatic cancer. Palliative care makes sure you have the best quality of life possible. (See page 62 for more on palliative care.)

Drug treatments

- Targeted therapies are drugs that block the growth and spread of cancer by interfering with specific molecules that help the cancer to grow.
- Immunotherapy drugs boost your body's immune system to fight cancer.
- Side-effects depend on the drugs being used and vary from person to person.

Your doctor may recommend targeted therapy or immunotherapy drugs for you:

- If the cancer has spread
- If the kidney cancer returns after surgery



Targeted therapies

Targeted therapies are drugs that work by 'targeting' certain parts of cancer cells that make them different from other cells. In other words, they take advantage of differences between normal cells and cancer cells.

The main type of targeted therapies used to treat kidney cancer are:

- Cancer growth inhibitors
- Angiogenesis inhibitors

Cancer growth inhibitors

Cancer cells need to communicate with each other to grow and multiply. They do this through a series of chemical signals.

Cancer growth inhibitors interrupt the communication process and prevent the cancer from developing. The main group of targeted therapy drugs used for metastatic (advanced) kidney cancer is tyrosine kinase inhibitors (TKIs). These drugs block chemicals called tyrosine kinases. Tyrosine kinases help cells to grow, so blocking them stops cells growing and dividing.

Examples of these are: sunitinib (Sutent®), axitinib (Inlyta®), pazopanib (Votrient®), sorafenib (Nexavar®), cabozantinib (Cabometyx®), tivozanib (Fotivda®) and belzutifan (Welireg®).

Cancer growth inhibitors are usually given as tablets.

Angiogenesis inhibitors

Angiogenesis inhibitors interfere with the growth of blood vessels. This means that the cancer is unable to receive the oxygen and nutrients it needs to survive. Angiogenesis inhibitors are usually given as an injection into a vein. Examples include: bevacizumab (Avastin®), everolimus (Afinitor®) and temsirolimus (Torisel®).

Immunotherapy

Immunotherapy helps your immune system to work better to fight cancer cells. Our immune system is often not good at recognising or clearing cancer cells from our body. Sometimes cancer cells find a way of hiding from the immune system, allowing cancer to develop or spread. Immunotherapy treatments can change certain immune cells to help them attack the cancer directly.

Monoclonal antibodies

Monoclonal antibodies attach to specific proteins on cancer cells, and 'lock' onto them like a key in a lock. Once the monoclonal antibody has 'locked' into a protein it can:

- Block signals telling cancer cells to divide
- Carry a chemotherapy drug straight to a cancer cell

Some monoclonal antibodies are also checkpoint inhibitors.

Checkpoint inhibitors

Checkpoint inhibitors are a type of immunotherapy treatment used to treat kidney cancer. Checkpoint inhibitors work by blocking the proteins that stop the immune system from killing cancer cells. Examples of checkpoint inhibitors used to treat metastatic kidney cancer include ipilimumab (Yervoy®) and nivolumab (Opdiva®).

Cytokines

Cytokines are proteins or chemicals in our body that control the activity and growth of immune system cells. Examples of cytokines used for advanced kidney cancer are interleukin or interferon.

Understanding your drug treatment



It's important that you understand the drugs you have been given. Ask your doctor or specialist nurse for more information about your drug treatment and any possible side-effects. They should give you a printed sheet to take home with you. If you know the name of your chemotherapy drug, visit the Health Product Regulatory Authority's website at www.hpra.ie for more information about the drug and possible side-effects. If you have any questions or need any more information, you can speak to our cancer nurses by calling our Support Line on 1800 200 700.

Side-effects of targeted therapies and immunotherapy

Side-effects depend on the drugs being used and vary from person to person. Your doctor and nurse will explain your treatment to you in more detail and tell you about any likely side-effects. Some possible side-effects include:

- Increased risk of infection
- Difficulty sleeping
- Tiredness or fatigue (see page 65)
- Breathlessness
- Bruising and bleeding, such as nosebleeds
- Diarrhoea or constipation
- Hoarseness
- Taste changes
- Headaches or dizziness
- 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 get blisters
- Raised blood pressure – you may need to take tablets to control your blood pressure during treatment
- Low levels of thyroid hormone
- High temperature
- Aches and pains
- Mouth sores
- Indigestion
- Feeling sick or getting sick
- Loss of appetite

Always tell your doctor or nurse if you don't feel well or if you are having any symptoms that are troubling you. We also have advice about managing side-effects on our website www.cancer.ie. For more information on drug treatments and their side-effects, or for a copy of the booklet *Understanding chemotherapy and other cancer drugs*, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

New developments

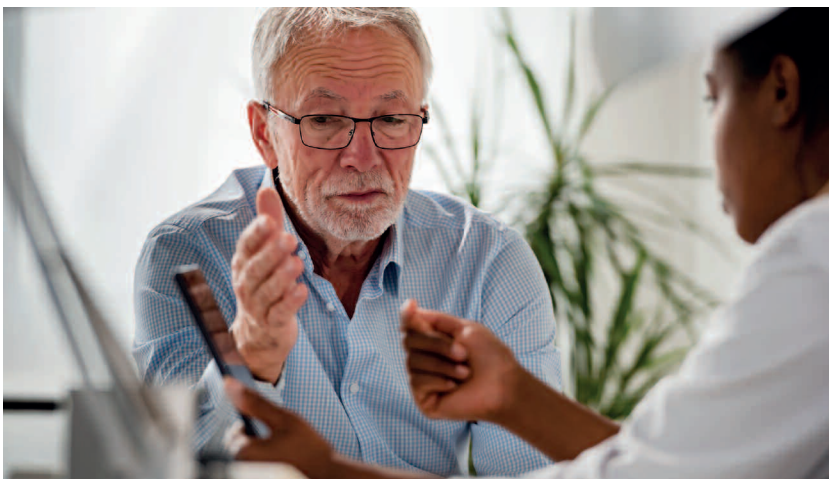
New drugs are being developed all the time and existing therapies are being used in new ways. You may also be given a drug as part of a clinical trial (see opposite). Ask your doctor if there are targeted therapies or immunotherapies available to treat your cancer or if there are any trials suitable for you.

Surgery

Cytoreductive nephrectomy

Your specialist team may recommend a cytoreductive nephrectomy as a palliative treatment rather than as a cure for your illness.

A cytoreductive nephrectomy is an operation to remove the kidney when the cancer has spread to other areas. The removal of the kidney can help control your cancer symptoms and may help other treatments to work better. This is a significant operation and is not suitable for everyone. Your doctors will tell you if they think it is an option for you. They will also discuss the advantages and disadvantages of this kind of surgery.



Thanks to recent advances in research and treatments, many people are living longer with metastatic cancer and with a better quality of life.

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. Patients with cancer are sometimes asked to consider taking part in a clinical trial. This means that instead of the standard treatment you may get a new trial drug. Or you may be given existing treatments used in different ways. For example, giving a different dose of a drug or using two treatments together.

Because the drugs are still in trial, you'll be very closely monitored for unexpected side-effects and may have extra tests and appointments.

Trials often investigate very specific features of a particular cancer or treatment, so you may not be suitable for a trial, even if it is researching your particular cancer. Your doctor can advise you about this.

More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial. For more information, you can read our factsheet *Cancer and Clinical Trials*. It's available to read or download on our website, www.cancer.ie. You can also get a free copy by calling our Support Line on 1800 200 700 or by dropping into a Daffodil Centre. You can see a list of current cancer trials at www.cancertrials.ie

Palliative care

Palliative care helps you to manage your symptoms and improve your quality of life. Palliative care includes end-of-life care, but your doctor may also recommend palliative care to relieve symptoms earlier in your illness.

The palliative care team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, chaplains and counsellors. Palliative care can be arranged by your family doctor (GP), public health nurse or by the hospital. Palliative care is a free service for all patients with advanced cancer. You don't need medical insurance.



Managing side-effects and symptoms

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How can I cope with fatigue?

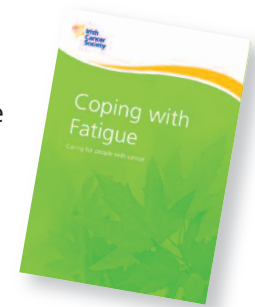
- Fatigue means feeling extremely tired.
- There are things that can improve fatigue, depending on what is causing it.

It's common to feel exhausted when you have cancer. This extreme tiredness (fatigue) can be caused by many things, including:

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

Usually fatigue starts to improve once treatment is over, but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you, so that they can help you. Finding out what is causing your fatigue makes it easier to treat. For example, if you have a low red blood cell count, a transfusion can make you feel better. If you are not eating well, a dietitian may be able to give you some advice to help you.

Our booklet *Coping with fatigue* has more advice. Call our Support Line on 1800 200 700 or drop into a Daffodil Centre for a free copy. It's also on our website www.cancer.ie



Support Line Freephone 1800 200 700



- **Ask your doctor about exercising.** Being active can help with fatigue. Your doctor may also be able to recommend an exercise programme for you.
- **Get to know when your energy levels tend to be better.** You may have to decide which tasks are important to finish and do them over the course of the day or when you have most energy.
- **Ask for help at work or at home** with any jobs that you find tiring.
- **Try to eat a well-balanced diet.** Eat little and often if your appetite is poor. Our *Diet and Cancer* booklet has tips to help.
- **Try to avoid stress.** Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling (see page 80) may help too.
- **If you are not sleeping well, have a good bedtime routine and try relaxation techniques.** Avoid stimulants like caffeine and alcohol in the evening and try not to use electronic devices for an hour before bedtime.
- **Short naps (less than an hour) and rest periods can be helpful,** as long as they don't stop you from sleeping at night.
- **Try complementary therapies** such as meditation, acupuncture or massage, if your doctor says they're safe for you.

Will treatment affect my sex life and fertility?

Sex and sexuality

Cancer can affect how you feel about sex and your relationships. Coming to terms with the fact that you have cancer can take quite a while. 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 treatment and lose interest in sex as a result.

There is no right or wrong way to feel about your sexuality and sex life. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner.

You may find that talking about your feelings eases any worries you have. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. Our Support Line 1800 200 700 and our Daffodil Centres can help you to find accredited therapists and supportive information if you would like to talk to someone. Therapy can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

There is no set time for you to be ready to have sex again. It varies from person to person. 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.

Contraception

It is best to use a reliable method of contraception if you are having treatment with targeted 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.

Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse specialist. Your doctor and nurse are well used to talking about these matters, so try not to feel embarrassed. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at supportline@irishcancer.ie

Will treatment affect my fertility?

Your fertility may be affected by some of the treatments so that you may not be able to have a child in the future. Discuss any worries you have about infertility with your doctor before treatment starts. Your doctor can refer you to a specialist fertility clinic for advice, counselling and support if this is an option for you.

You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.

Cancer and complementary therapies

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

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

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

Integrative care



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

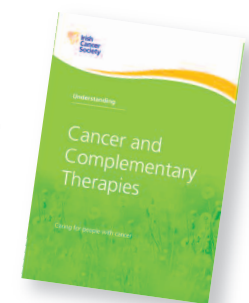
What's the difference between complementary and alternative therapies?

- Complementary therapies are used **together with** standard medical treatment.
- Alternative therapies are used **instead of** standard medical care.

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

More information

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





After treatment

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What follow-up will I need?

After your cancer treatment has ended you will still need regular check-ups. This is called follow-up. The follow-up may involve having a physical exam, blood and urine tests, chest X-rays, and ultrasound and chest CT scans. At first you will see your consultant 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.



It's important to go to your follow-up appointments. They give your doctor the chance to:

- Help with any side-effects that you may have
- Check for signs of new side-effects that may develop after you have finished treatment
- Check for signs of the cancer coming back (recurrence)

Tell your doctor or nurse how you have been since your last appointment. Remember to tell them about any new symptoms, aches or pains you have, or if you are finding it hard to cope.

Sometimes it helps to write down what you want to say before you see the doctor, so you don't forget anything.

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

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

What if the cancer comes back?

If cancer does come back, it can often be treated again. Your cancer doctor will advise you on your treatment options.

Life after treatment

It can take some time to adjust to life after cancer treatment. It's normal to feel quite low and lost after your treatment has ended, especially during the first few months. Feelings you may have include:

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

There is more about how to cope with these feelings and adjusting to life after cancer on our website www.cancer.ie. You can also call our Support Line or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 81 for other ways to get emotional support.

After-treatment workshops



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

Living a healthy lifestyle

Having a healthy lifestyle after cancer treatment is important as it can help you to:

- Feel better
- Heal and recover faster
- Keep up your energy and strength
- Reduce your risk of further illness

A healthy lifestyle includes:

- Exercising (see page 76)
- Eating well
- Trying to stay at a healthy weight
- Not smoking
- Avoiding alcohol
- Protecting yourself from the sun
- Getting any vaccinations recommended for you

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

Taking exercise

Try to remain active, and ideally take some exercise after your treatment. Research shows that there are many benefits to exercise:

- It helps to reduce the symptoms of fatigue, the side-effects of cancer treatments, and improves your overall quality of life.
- Regular exercise (ideally 30 minutes of moderate activity 3-5 times a week) builds up your physical fitness level, improves your energy, strength, balance, stamina and co-ordination.
- Exercise encourages your body to release endorphins. These are often called 'feel-good hormones'. When released, they can lift your mood and sense of wellbeing, and lower stress levels.

Start gradually if you have not been taking regular exercise before your cancer diagnosis. Remember a little exercise is better than none. Even a short walk is a good place to start. Your doctor, specialist nurse or physiotherapist can all give you advice. You might also be referred to a physical activity programme. Your local cancer support centre may run a physical activity programme or have information about one in your area. See page 102 for more about cancer support centres.

Coping and emotions

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How can I cope with my feelings?



Some people say that trying to cope with their thoughts and feelings is the hardest part of having cancer.

You may find it hard to come to terms with your diagnosis, you may blame yourself, resent other people who are healthy or feel very anxious or depressed. Emotions like sadness, fear, grief, hopelessness and anger can happen at different times, sometimes months or years after treatment.

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

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

Anxiety and depression

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

Your doctor may also suggest medication to help with anxiety or depression. Often a short course of medication can work well. Professional counselling can also be very helpful.

Counselling

If you're feeling very distressed or finding it hard to cope, a trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them.

It's not a sign of failure to ask for help or to feel unable to cope on your own.

Counselling can also give you emotional support, help you to make decisions and learn ways to cope better. Free one-to-one counselling is available through many local cancer support centres. To find out more about counselling call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at supportline@irishcancer.ie. A list of counsellors funded by the Irish Cancer Society is available at www.cancer.ie.

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

Ways to get emotional support



Find out about cancer support services in your area: Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 102 for more about cancer support services.

Join a support or educational group:

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

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

Ask about psycho-oncology services at the hospital:

Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope.

Your healthcare team can refer you to psycho-oncology services if they're available at your hospital.

Get online support: Special websites called online communities let you write questions, share stories, and give and receive advice and support. Visit www.cancer.ie/community to join the Irish Cancer Society online community.

Talk things through: It can be a great weight off your mind to share your feelings and worries. You could talk to a friend or family member if you feel comfortable doing so. You could also speak to the medical social worker at the hospital or to one of our cancer nurses.



Seek spiritual support: For some people spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation may help you to focus on what has value and meaning in your life.

If you need more information or help with finding support, call our Support Line on 1800 200 700 or drop into a Daffodil hospital or to one of our cancer nurses.

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

Survivor support

Survivor Support is the Irish Cancer Society's one-to-one support programme. You can be put in contact with a trained volunteer who has dealt with a cancer diagnosis. Volunteers give support, practical information and reassurance. Call 1800 200 700 for more information or visit a Daffodil Centre.

Positive feelings

In time, some people say they can find positive things in their cancer experience. They say that cancer brought them closer to the people around them or made them appreciate what's important in life.

Or it opened up new experiences and relationships. Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.

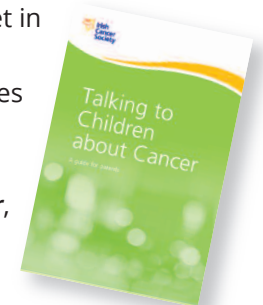
'I am very happy and content ... even though I have to live with this.'

You and your family

Every family deals with cancer in its own way. You may feel that you don't want your illness to upset family life, feel guilty that you can't join in as much as before, or that you're letting down your partner or children. You may also worry about the emotional impact your illness will have on your loved ones. Our booklet *Understanding the emotional effects of cancer* can help you to find ways to talk about your cancer and to ask for the help and support you need.

Further information and support

If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our cancer nurses. Call us on 1800 200 700 or visit a Daffodil Centre. The nurses can also support you if you have children and aren't sure what to say to them. You could also read our booklet *Talking to children about cancer*, which has practical advice about how to talk to children of different ages.



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

Further information and support

If you want more advice and support, you can ask your nurse or medical social worker. Or call our Support Line on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse in confidence.

Changing relationships



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



Advice for carers

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Supporting someone with cancer



Finding out someone you love has cancer and trying to care for them can be difficult. You might be unsure about how best to support them, practically or emotionally. You might also be struggling with your own feelings and responsibilities. Here are some things that can help to make life a little easier:

Learn about cancer

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

Share worries

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

Be kind to yourself

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

Try counselling

You might find it helpful to talk to a counsellor. Free one-to-one counselling is available to friends and family members through many local cancer support centres. Talk to your GP or see page 80.

Find out about support for carers

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



Support for you

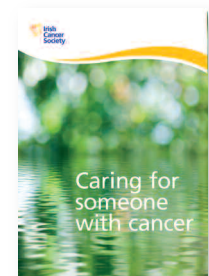


Our cancer nurses are there to support you. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information.

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

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

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



How to talk to someone with cancer

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


Our booklet, *Caring for someone with cancer*, has a section on how to talk to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative. You can pick up a copy at your local Daffodil Centre, or download it from our website.



Support resources

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Money matters

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

A diagnosis of cancer often means that you will have extra expenses, like car parking during hospital visits, medication, travel, heating and childcare costs. If you can't work or you are unemployed, this may cause even more stress. It may be harder for you to deal with cancer if you are worried about money.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Medicines
- Visits to hospital
- Medical aids and equipment (appliances), like wigs
- Overnight stays in hospital

How much you pay towards your medical expenses depends on whether or not you qualify for a medical card and what type of health insurance you have, if any.

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication. If you are over 70, you can get a free GP visit card.

Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

An emergency medical card may be issued if you are terminally ill and in palliative care, irrespective of your income.

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

If you have health insurance the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It's important to contact your insurance company before starting tests and treatment to check you're covered.

Benefits and allowances

There are benefits that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, Carer's Leave.

If you want more information on benefits and allowances, contact:

- **The medical social worker** in the hospital you are attending
- **Citizens Information** – Tel: 0818 074 000
- **Department of Employment Affairs and Social Protection (DSP)** – Tel: 0818 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are asking about entitlements and benefits. It's also a good idea to photocopy or take a photograph of completed forms before posting them.

If you have money problems

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0818 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice.

The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 99 for more details of our Volunteer Driver Service and the Travel2Care fund.

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



More information

Go to www.cancer.ie and see our **managing money** page for information on:

- **Medical costs and help available**
- **Benefits and allowances** that you or your family may qualify for
- **Travel services**
- **Ways to cope with the cost of cancer**

The Benefits Hub on our website has lots of information on government supports for people who are unwell and their carers. It also has advice on how to apply.

Irish Cancer Society services

Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including:

- Support Line
- Daffodil Centres
- Survivor Support
- Support in your area
- Patient travel and financial support services
- Night nursing
- Publications and website information

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information. The Support Line is open Monday–Friday, 9am to 5pm. You can email us at any time on supportline@irishcancer.ie or visit our Online Community at www.cancer.ie

For the deaf community, our Support Line is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: remote@slis.ie



Email: supportline@irishcancer.ie

Daffodil Centres

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



Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – you don't need an appointment. Just call in if you want to talk or need information on any aspect of cancer including:

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

You can email daffodilcentreinfo@irishcancer.ie or visit www.cancer.ie to find your local Daffodil Centre.

Survivor Support



Speak to someone who has been through a diagnosis similar to yours. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

Support in your area

We work with cancer support groups and centres and the National Cancer Control Programme to ensure patients and their families have access to high-quality confidential support in a location that's convenient to them. The Society funds professional one-to-one counselling (including telephone and video-call counselling) and group survivorship programmes in communities across the country.

For information about what's available near you, call our Support Line on 1800 200 700 or go to www.cancer.ie and search 'Find support'.

Patient travel and financial support services



We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:

- **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are travelling for cancer tests or treatment to one of the national designated cancer centres or their approved satellite centres. Patients must be travelling over 50km one way to access the fund.
- **Irish Cancer Society Volunteer Driver Service** is for patients undergoing chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments.

To access either of these services please contact your hospital healthcare professional.

Irish Cancer Society Night Nursing



We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is a unique service in Ireland, providing palliative nursing care at night between 11pm and 7am to cancer patients.

The health professional who is looking after your loved one can request a night nurse for you, so talk to your palliative care team member, GP or public health nurse about this.

Email: supportline@irishcancer.ie

Publications and website information



We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website www.cancer.ie or call our Support Line for free copies of our publications.

If you would like more information on any of our services, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients and their families, during and after treatment, many of which are free.

For example:

- **Professional counselling** (the Irish Cancer Society funds up to 8 sessions of free one-to-one counselling through many local cancer support services)



- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**
- **Stress management and relaxation techniques**, such as mindfulness and meditation

- **Complementary therapies** like massage and reflexology
- **Specialist services** such as prosthesis or wig fitting and manual lymph drainage
- **Mind and body sessions**, for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics



Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what's available.

You can call our Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or go to www.cancer.ie and search 'Find support'.

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.

Fatigue Ongoing tiredness often not helped by rest.

Grading Tests that look at the structure of cancer cells under the microscope.

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.

Neo-adjuvant Treatment 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.

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?

Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team!

Support people affected by cancer

Reaching out directly to people with cancer is one of the most rewarding ways to help:

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Survivor Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

Share your experiences

Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:

- Share your cancer story
- Tell people about our services
- Describe what it's like to organise or take part in a fundraising event

Raise money

All our services are funded by the public's generosity:

- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Contact our Support Line on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?

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

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Support Line Freephone 1800 200 700

Email: supportline@irishcancer.ie

Find us on Facebook

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