



# Understanding Kidney Cancer

A guide for people with cancer,  
their families and friends

Cancer  
information

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**13 11 20**



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A guide for people with cancer, their families and friends

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*Understanding Kidney Cancer* is reviewed approximately every two years.

Check the publication date above to ensure this copy is up to date.

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### Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

### Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit [cancer.org.au](http://cancer.org.au) or call your local Cancer Council.



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# About this booklet

This booklet has been prepared to help you understand more about the most common type of kidney cancer, renal cell carcinoma (RCC). Many people feel shocked and upset when told they have kidney cancer. We hope this booklet will help you, your family and friends understand how kidney cancer is diagnosed and treated.

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, this information may answer some of your questions and help you think about what to ask your treatment team (see page 50 for a question checklist).

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary (see page 51). You may also like to pass this booklet to family and friends for their information.

## How this booklet was developed

This information was developed with help from a range of health professionals and people affected by kidney cancer. It is based on international clinical practice guidelines for kidney cancer.<sup>1</sup>

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. You can also visit your local Cancer Council website (see back cover).



**Cancer  
Council  
13 11 20**

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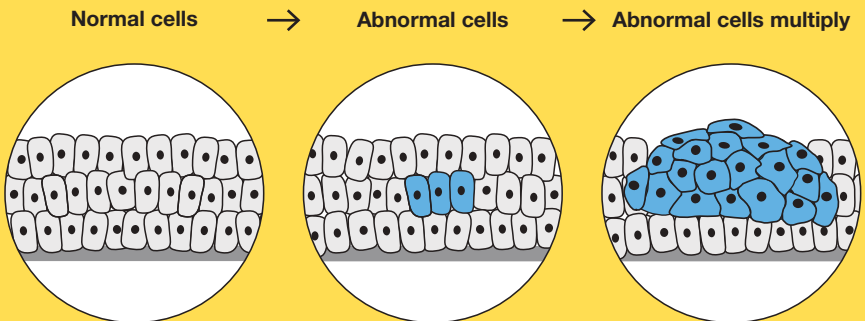
# What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. In solid cancers, such as kidney cancer, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into

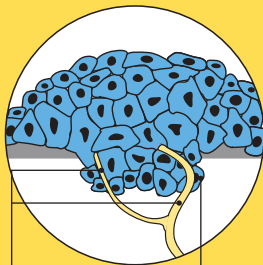
## How cancer starts



cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops is called the primary cancer. It is considered localised cancer if it has not spread to other parts of the body. If the primary cancer cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, kidney cancer that has spread to the lungs is called metastatic kidney cancer, even though the main symptoms may be coming from the lungs.

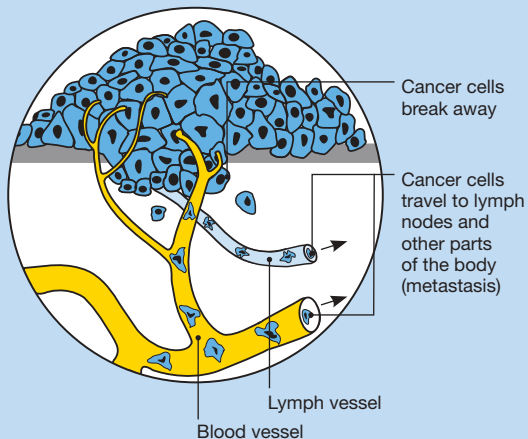
### → Malignant cancer



Grows own  
blood vessels  
(angiogenesis)

Invades  
surrounding  
tissue

### How cancer spreads



Cancer cells  
break away

Cancer cells  
travel to lymph  
nodes and  
other parts  
of the body  
(metastasis)

Lymph vessel

Blood vessel



# The kidneys

The kidneys are two bean-shaped organs, each about the size of a fist. They are deep inside your abdomen, positioned near the middle of your back, on either side of the spine.

**Blood filtering** – The main role of the kidneys is to filter and clean the blood. Blood goes into each kidney through the renal artery and is filtered through millions of tiny sieves called nephrons. It then goes back into the rest of the body through the renal vein.

**The urinary system** – The kidneys are part of the body's urinary system. When they filter the blood, they remove excess water and waste products and turn these into urine. Urine travels from each kidney into a funnel called the renal pelvis, then through a tube called the ureter, and into the bladder.

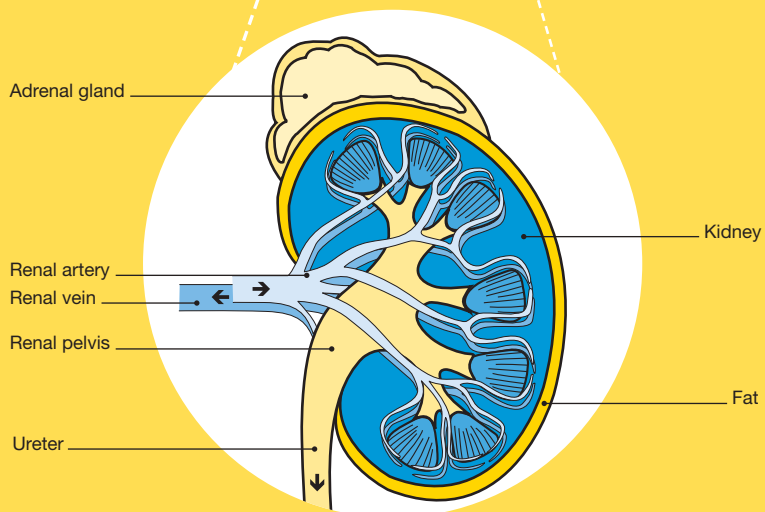
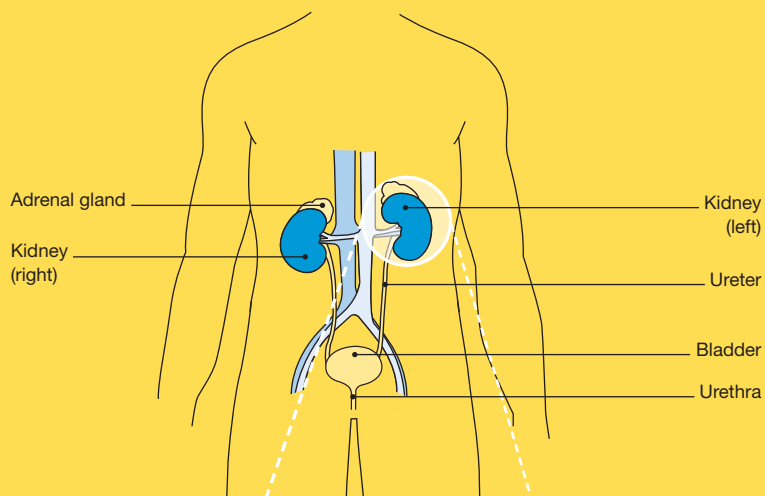
Urine is stored in the bladder until urination, when it leaves the body through a tube called the urethra. In women, the urethra is a short tube in front of the vagina. In men, the tube is longer and passes through the prostate and penis.

**Hormone production** – The main function of the kidneys is to cleanse the blood, but they also help your body control how much blood it needs. They do this by making hormones that help regulate blood pressure and trigger the production of red blood cells.

**Adrenal glands** – An adrenal gland sits above each kidney. The adrenal glands produce a number of hormones. Although these glands are not part of the urinary system, kidney cancer can sometimes spread to them.



## The urinary system





## Key questions

### Q: What is the main type of kidney cancer?

**A:** Kidney cancer is cancer that starts in the cells of the kidney. About 9 out of 10 kidney cancers are renal cell carcinoma (RCC), sometimes called renal adenocarcinoma. RCCs start in the cells lining small tubes in the kidney's nephrons. The information in this booklet is about RCC.

In the early stages of RCC the primary cancer forms a tumour that is confined to the kidney. Usually only a single kidney is affected, but in rare cases both kidneys can be affected. As the cancer grows, it can spread to areas near the kidney, such as the surrounding fatty tissue, veins, adrenal glands, ureters or the liver. It may also spread to other parts of the body, such as the lungs or bones.

#### Types of renal cell carcinoma (RCC)

There are several types of RCC, based on the way the cells look under a microscope. The most common type is clear cell renal cell carcinoma.

<b>clear cell RCC</b>	<ul style="list-style-type: none"><li>• makes up about 75% of RCC cases</li><li>• cancer cells look empty or clear</li></ul>
<b>papillary RCC</b>	<ul style="list-style-type: none"><li>• makes up about 10–15% of RCC cases</li><li>• cancer cells are arranged in finger-like fronds</li></ul>
<b>chromophobe RCC</b>	<ul style="list-style-type: none"><li>• makes up about 5% of RCC cases</li><li>• cancer cells are large and pale</li></ul>
<b>other types of RCC</b>	<ul style="list-style-type: none"><li>• include renal medullary carcinoma, collecting duct carcinoma, MiT family translocation RCC, sarcomatoid RCC and other very rare types</li><li>• together make up about 5–10% of RCC cases</li></ul>

## Q: Are there other types?

**A:** RCC is the most common type of kidney cancer, but there are other less common types:

### **Urothelial carcinoma (or transitional cell carcinoma) –**

This can begin in the ureter or in the renal pelvis, where the kidney and ureter meet. Urothelial carcinoma of the kidney or ureter behaves and is treated like bladder cancer (another type of urothelial cancer), rather than like RCC.

➤ See our *Understanding Bladder Cancer* booklet.

**Wilms tumour (nephroblastoma) –** This is the most common type of kidney cancer in younger children, but it is still rare.

➤ Visit [childrenscancer.canceraustralia.gov.au](http://childrenscancer.canceraustralia.gov.au).

**Secondary cancer –** Very rarely, cancer in the kidney can be a secondary cancer (metastasis) from a primary cancer located in another part of the body. However, this type of cancer is not kidney cancer and it behaves more like the original cancer.

➤ See the Cancer Council booklet on the primary cancer.

## Q: How common is kidney cancer?

**A:** More than 3000 people are diagnosed with kidney cancer in Australia each year. It makes up about 2.5% of all cancers. It is twice as common in men than women, and is the ninth most diagnosed cancer for Australian men. The risk of kidney cancer increases with age, and most cases occur in people over 50.<sup>2</sup>


## Q: What are the symptoms?

**A:** Most people with kidney cancer have no symptoms and many are diagnosed with the disease when they see a doctor for an unrelated reason. Symptoms can, however, include:

- blood in the urine (haematuria) – this may be obvious or the urine may just look dark, rusty or brown
- pain in the lower back or side not caused by injury
- a lump in the abdomen
- constant tiredness
- unexplained weight loss
- fever (not caused by a cold or flu).

Cancer can affect the amount of hormones produced by the kidneys (see page 6), and this may lead to a low red blood cell count (anaemia), a high red blood cell count (polycythaemia) or high levels of calcium in the blood (hypercalcaemia). Sometimes these problems can cause symptoms such as fatigue, dizziness, headaches, constipation, abdominal pain, and depression.

The symptoms listed above can also occur with other illnesses, so they don't necessarily mean you have kidney cancer – only tests can confirm the diagnosis. If you are concerned, make an appointment with your general practitioner (GP).

“Kidney cancer can be a silent cancer until it is quite advanced, so I do feel thankful that it was discovered incidentally, when it was small and easier to treat.”  *Chris*

## Q: What are the risk factors?

**A:** The factors listed below may increase the risk of a person developing kidney cancer. However, having one or more of these risk factors does not mean you will develop cancer.

**Smoking** – People who smoke have almost twice the risk of developing kidney cancer as nonsmokers. Up to one-third of all kidney cancers are thought to be related to smoking.

**Obesity** – Excess body fat may cause changes in certain hormones that can lead to kidney cancer.

**High blood pressure** – Whatever the cause, high blood pressure increases the risk of kidney cancer.

**Kidney failure** – People with end-stage kidney disease have a higher risk of developing kidney cancer.

**Family history** – People who have family members with kidney cancer, especially a sister or brother, are at increased risk.

**Inherited conditions** – About 2–3% of kidney cancers occur in people who have particular inherited syndromes, including von Hippel-Lindau disease, hereditary papillary RCC and Birt-Hogg-Dubé syndrome.

**Exposure to toxic substances at work** – The risk may be higher after regular exposure to certain chemicals, such as some metal degreasers, arsenic or cadmium.

## Q: Which health professionals will I see?

**A:** Your GP will arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a specialist such as a urologist. The specialist will arrange further tests. If kidney cancer is diagnosed, the specialist will consider

### Health professionals you may see

<b>GP</b>	assists you with treatment decisions and works in partnership with your specialists in providing ongoing care
<b>urologist*</b>	treats diseases of the male and female urinary systems, and the male reproductive system; performs surgery
<b>nephrologist*</b>	diagnoses and treats conditions that cause kidney (renal) failure or impairment; may be consulted by your urologist when planning surgery
<b>medical oncologist*</b>	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy (systemic treatment)
<b>radiation oncologist*</b>	treats cancer by prescribing and coordinating a course of radiation therapy
<b>radiologist*</b>	analyses x-rays and scans; an interventional radiologist may also perform a biopsy under ultrasound or CT, and deliver some treatments

treatment options. Often these will be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting. During and after treatment, you will see a range of health professionals who specialise in different aspects of your care.

<b>cancer care coordinator</b>	coordinates your care, liaises with other members of the team, and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)
<b>nurse</b>	administers drugs and provides care, information and support throughout treatment
<b>physiotherapist, occupational therapist</b>	assist with physical and practical problems, including restoring movement and mobility after treatment and recommending aids and equipment
<b>dietitian</b>	recommends an eating plan to follow while you are in treatment and recovery
<b>social worker</b>	links you to support services and helps you with emotional, practical or financial issues
<b>psychiatrist*, psychologist, counsellor</b>	help you manage your emotional response to diagnosis and treatment

*\* Specialist doctor*



# Diagnosis

Most kidney cancers are found when people have an ultrasound or scan for an unrelated reason. If your doctor suspects kidney cancer, you may have some of the following tests, but you are unlikely to need them all.

You will probably have urine and blood tests to see how well your kidneys are working and to check for changes that could be caused by kidney cancer, but these tests cannot provide a definite diagnosis. The main tests for diagnosing kidney cancer are imaging scans (see opposite page) and tissue sampling (biopsy, see page 18). Sometimes the doctor will also recommend an internal examination of the bladder, ureters and kidneys (see box, page 18).

It may take up to a week to receive your test results. If you feel anxious while waiting for test results, try talking to a close friend or relative, or call Cancer Council 13 11 20 for support.

## Early and advanced kidney cancer

Some kidney cancers are diagnosed when they have already spread beyond the kidney (advanced kidney cancer). This may be because the primary cancer never caused obvious symptoms. The tests discussed in this chapter are used for diagnosing both early and advanced kidney cancer. The treatments are covered in separate chapters.

**early kidney cancer**



**see pages 25–33**

**advanced kidney cancer**



**see pages 34–40**



## Imaging scans

You will usually have at least one of the following imaging scans.

**Ultrasound** – In an ultrasound, soundwaves are used to produce pictures of your internal organs. These might show if there is a tumour in your kidney.

For this scan, you will lie down and a gel will be spread over your abdomen or back. A small device called a transducer is passed over the area. The transducer sends out soundwaves that echo when they encounter something dense, like an organ or tumour. An ultrasound is painless and takes about 15–20 minutes.

**CT scan** – A CT (computerised tomography) scan uses x-rays to take many pictures of the inside of your body and then a computer compiles them into one detailed, cross-sectional picture.

If kidney cancer is suspected on an ultrasound, your doctor will usually recommend a CT scan. This will help identify any tumours in the kidneys, provide information about tumour size, shape and position, and may show whether cancer has spread to other organs and tissues. The scan also helps identify enlarged lymph nodes that might contain cancer. Lymph nodes are small glands found in many parts of the body. If cancer is going to spread, it often spreads first to nearby lymph nodes.

Before the scan, you may have an injection of a dye (called contrast) into one of your veins to help make the scan pictures clearer. This dye travels through your bloodstream to the kidneys, ureters, bladder

and other organs. It might make you feel flushed and hot for a few minutes. This side effect should ease quickly, but tell the medical team if you feel unwell. The contrast should be used only if your kidneys are functioning well, so this will have been checked during earlier blood tests. If you are concerned about having the dye, check with the doctor that it is safe to have the dye injection with your level of kidney function.

For the scan, you will need to lie still on a table that moves in and out of the CT scanner, which is a large, doughnut-shaped machine. The whole procedure takes about 30–45 minutes.



Before having scans, tell the doctor if you have any allergies or have had a reaction to contrast during previous scans. You should also let them know if you are diabetic, have kidney disease or are pregnant.

**MRI scan** – An MRI (magnetic resonance imaging) scan uses a powerful magnet and radio waves to build up detailed, cross-sectional pictures of the inside of your body. Only a few people with kidney cancer need an MRI, but it might be used to check whether the cancer has spread to the renal vein or spinal cord.

Let your medical team know if you have a pacemaker, as the magnet can interfere with some pacemakers. As with a CT scan, a dye might be injected into your veins before an MRI scan. An MRI without dye may be used instead of a CT scan if you have pre-existing kidney problems and are concerned about having the dye.

During the scan, you will lie on an examination table inside a large metal tube that is open at both ends. The noisy, narrow machine makes some people feel anxious or claustrophobic. If you think you may become distressed, mention it beforehand to your medical team. You may be given a medicine to help you relax, and you will usually be offered headphones or earplugs. The MRI scan may take between 30 and 90 minutes.

**Radioisotope bone scan** – A radioisotope scan is used to see if any cancer cells have spread to the bones. It may also be called a nuclear medicine bone scan or simply a bone scan. You might have this test if other scans show you have a very large tumour or advanced kidney cancer. The scan is also used to check how the cancer is responding to the treatment.

A very small amount of radioactive substance is injected into a vein, usually in your arm. You will need to wait while the substance moves through your bloodstream to your bones, which can take about 3–4 hours. Your body will be scanned with a machine that detects radioactivity. A larger amount of radioactivity will show up in any areas of bone affected by cancer cells. Radioisotope bone scans generally do not cause any side effects. However, tell your doctor if you are pregnant, as it may not be safe for you to have this type of scan.

The amount of radioactive substance used for this bone scan is small and disappears from your body through your urine within a few hours. After the scan, you should drink plenty of fluids and avoid contact with young children and pregnant women for the rest of the day. Your treatment team will discuss these precautions with you.



If you have blood in your urine, your doctor might use a thin tube with a light and camera to look inside your bladder (cystoscopy), ureters (ureteroscopy) and kidneys (ureterorenoscopy). These procedures rule out urothelial carcinoma of the bladder, kidney and ureters, but they may not be needed if an ultrasound and CT scan have already shown there is a tumour on your kidney.

## Tissue biopsy

Removing a tissue sample from the kidney for examination under a microscope is the only way to confirm a diagnosis of kidney cancer. This is known as a biopsy. The procedure used to check for kidney cancer is called a core needle biopsy.

You will have a local anaesthetic to numb the area, and then an interventional radiologist (see page 12) will insert a hollow needle through the skin. They will use an ultrasound or CT scan to guide the needle to the kidney and remove a sample of tissue. The procedure usually takes about 30 minutes.

The tissue sample will be sent to a laboratory, and a specialist doctor called a pathologist will examine the sample under a microscope to see if there have been any changes in the cells.

You may not need a core needle biopsy if the doctor already knows enough from other tests, such as a CT scan, to immediately recommend surgery to remove the tumour (see pages 26–31). In this case, rather than testing a tissue sample, the removed tumour is tested to confirm that it is cancer.

Surgery without a biopsy first is most likely to be recommended if the tumour is large, looks irregular on the scan, or has obviously spread to the renal vein, adrenal gland or nearby lymph nodes.

In some cases, a tumour on your kidney will turn out to be benign (not cancer). If it is confined to the kidney and is smaller in size, a biopsy of the tumour can allow doctors to make a diagnosis. Benign kidney growths, including oncocytoma and angiomyolipoma, can cause problems, and treatment may be similar to early kidney cancer.

A biopsy may also be done if your doctor suspects that the cancer has spread, and the plan is to treat it with ablation techniques (see page 32), targeted therapy or immunotherapy (see pages 35–38), rather than surgery. The biopsy results will help your doctors identify suitable drug therapies.

## Grading kidney cancer

By examining a tissue sample taken during a biopsy or surgery, doctors can see how similar the cancer cells look to normal cells and estimate how fast the cancer would grow without any treatment. This is called grading. It helps them decide what follow-up treatment you might need and whether to consider a clinical trial (see page 24).

There are different systems for grading kidney cancer. The Fuhrman system has been widely used in Australia, but a newer system called the International Society of Urological Pathology (ISUP) system has been introduced. Both systems grade kidney cancer from 1 to 4, with grade 1 being the slowest growing and grade 4 the fastest growing.

## Staging kidney cancer

The stage of a cancer describes how large it is, where it is, and whether it has spread in the body. Knowing the stage of the kidney cancer helps doctors plan the best treatment for you. The stage can be given before surgery (clinical staging), but may be revised after surgery (pathologic staging).

If you have kidney cancer, your doctor will use the results of the tests described on pages 15–19 to assign a stage of I–IV (see the table on the opposite page for more detail):

- stages I–II are considered early kidney cancer
- stages III–IV are considered advanced kidney cancer.

## Prognosis

Prognosis means the expected outcome of a disease. It is not possible for anyone to predict the exact course of the disease, but your medical team can give you an idea about common issues that affect people with kidney cancer.

The stage of the cancer is the main factor in determining prognosis. In most cases, the earlier that kidney cancer is diagnosed, the better the chance of successful treatment. If the cancer is found after it has spread to other parts of the body, it is very unlikely that all of the cancer can be removed, but treatment can often keep it under control.

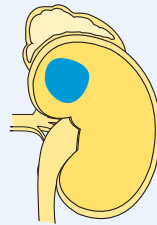
People who can have surgery to remove the cancer tend to have better outcomes. However, other factors such as your age, general fitness and medical history also affect prognosis.

## How kidney cancer is staged

In Australia, the TNM system is the method most often used for staging kidney cancer. The TNM gives numbers to the size of the tumour (T1–4), whether or not lymph nodes are affected (N0 or N1), and whether the cancer has spread or metastasised (M0 or M1). Based on the TNM numbers, the doctor then works out the cancer's overall stage (I–IV).

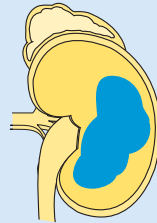
### Stage I

The cancer is confined to the kidney and measures less than 7 cm.



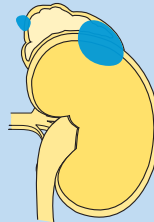
### Stage II

The cancer is larger than 7 cm, may have spread to the renal vein or the outer tissue of the kidney but no further, and has not spread to any lymph nodes.



### Stage III

The cancer is any size and has spread to nearby lymph nodes, or the cancer has spread to the adrenal gland.



### Stage IV

The cancer has spread beyond the kidney, adrenal gland and nearby lymph nodes, and is found in more distant parts of the body, such as the abdomen, distant lymph nodes, or organs such as the liver, lungs, bone or brain. Stage IV may also be called metastatic kidney cancer.



## Key points about diagnosing kidney cancer

### What it is

The main type of kidney cancer is renal cell carcinoma (RCC). Types of RCC include clear cell, papillary and chromophobe.

### How is it found

Kidney cancer is most often discovered during a test or scan for an unrelated reason. Because kidney cancer often doesn't produce any symptoms, it may be present for some time before it is found. This means some kidney cancers are diagnosed at an advanced stage.

### Main tests

The main tests to diagnose kidney cancer are:

- imaging scans (ultrasound, CT, MRI and/or bone scans) to show the location of the cancer and whether it has spread
- a core needle biopsy to take a tissue sample from the kidney.

### Other tests

Other tests can give more information about the cancer. These tests may include urine and blood tests to see how well your kidneys are working and to look for changes caused by cancer.

### Key information about the cancer

- The grade indicates how fast the cancer is likely to grow. The higher the grade, the faster the cancer cells are growing.
- The stage shows how far the cancer has spread throughout the body. Early kidney cancer is stages I and II, while advanced kidney cancer is stages III and IV.





# Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast, or you might be anxious to get started. Check with your specialist how soon treatment should begin – often it won't affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

**Know your options** – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see page 13) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

**Record the details** – When your doctor first tells you that you have cancer, you may not remember everything you are told. Taking notes or recording the discussion can help. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

**Ask questions** – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 50 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

**Consider a second opinion** – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of

your options. Specialists are used to people doing this. Your GP or specialist can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the second specialist.

**It's your decision** – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.

➤ See our *Cancer Care and Your Rights* booklet.

### Should I join a clinical trial?

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment. Over the years, trials have improved treatments and led

to better outcomes for people diagnosed with cancer.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time.

For more information, visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).

➤ See our *Understanding Clinical Trials and Research* booklet.



# Treatment for early kidney cancer

Early kidney cancer (stages I and II) is localised. That means the cancer is found only in the kidney or has not spread very far (see page 21). The main treatment is surgery to remove the tumour from the body (see pages 26–31). Less often, non-surgical treatments, such as radiofrequency ablation and stereotactic body radiation therapy (see page 32), are used to try to kill the tumour. Sometimes the best approach for localised kidney cancer is not immediate treatment, but to watch the cancer carefully (active surveillance).

## Active surveillance

When small tumours (less than 4 cm in diameter) are found in the kidney, they are less likely to be aggressive and might not grow during a person's lifetime. In this case, your doctor might recommend active surveillance, also known as observation. This involves regular ultrasounds or CT scans (see pages 15–16). If these imaging tests suggest that the tumour has grown at any time, you will be offered treatment (usually surgery).

Active surveillance might help to avoid the loss of kidney function and other side effects you may experience after surgery. It can also be a reasonable option if you are not well enough for an operation and the tumours are small.

You might feel anxious about not treating a cancer in your body right away. However, active surveillance is a common approach for early kidney cancer and will only be recommended if the doctor thinks it is the best thing to do. If you are worried, discuss your concerns with your urologist, GP or a counsellor.

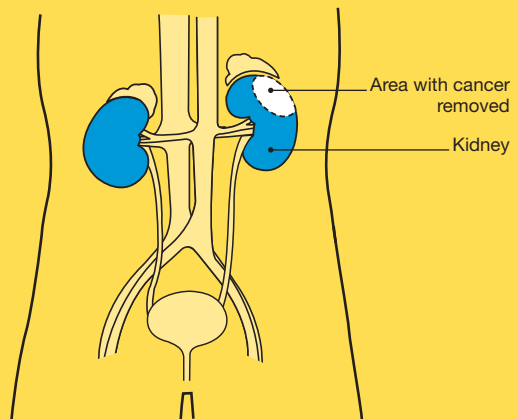
## Surgery

Surgery is the main treatment for kidney cancer that has not spread outside the kidney. Depending on the type of kidney cancer, the grade and stage of the cancer (see pages 19–21), and your general health, you might have one of the following operations:

**Removing part of the kidney (partial nephrectomy)** – This is the preferred option for small tumours that are confined to the kidney. It may also be used for people with pre-existing kidney disease, cancer in both kidneys or only one working kidney. Only the cancer and a small part of the kidney are removed, which means more of the kidney's function is preserved. A partial nephrectomy is a more difficult operation than a radical nephrectomy, and whether it is possible depends on the position of the tumour.

### Partial nephrectomy

A small part of the kidney is removed.



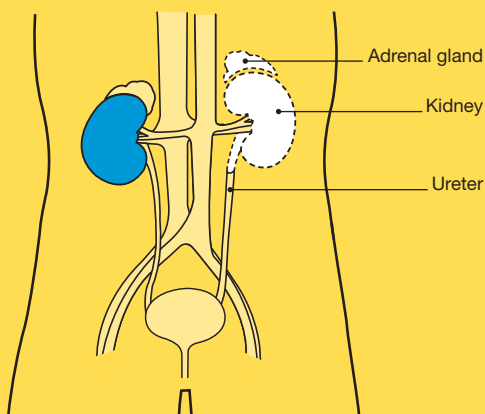


If a whole kidney or part of a kidney is removed, the remaining kidney usually carries out the work of both kidneys. Your doctor will talk to you about any steps you need to take to protect the remaining kidney.

**Removing the whole kidney (radical nephrectomy)** – This is the most common operation for large tumours. The whole affected kidney, a small part of the ureter and the surrounding fatty tissue are removed. The adrenal gland and nearby lymph nodes might also be removed. Sometimes the kidney cancer may have spread into the renal vein and even into the vena cava, the main large vein that runs up the body next to the spine. Even if the cancer is in the vena cava, it is sometimes possible to remove all the cancer in one operation.

### Radical nephrectomy

The kidney and a small part of the ureter are removed. The adrenal gland and nearby lymph nodes might also be removed.



## How the surgery is done

If you have surgery for kidney cancer, it will be carried out in hospital under a general anaesthetic. Your surgeon will talk to you about the risks of the procedure.

Your surgeon will use one of the following methods to remove part or all of the kidney (partial or radical nephrectomy). Each method has advantages in particular situations.

**Open surgery** – A long cut (incision) is made at the side of your abdomen where the affected kidney is located. In some cases, the incision is made in the front of the abdomen or in another area of the body where the cancer has spread. If you are having a radical nephrectomy, the surgeon will clamp off the major blood vessels and tubes in the affected kidney before removing it.

**Laparoscopic surgery** – This is sometimes called keyhole or minimally invasive surgery. The surgeon will make several small cuts in the skin and insert a tiny instrument with a light and camera (laparoscope) into one of the cuts. The laparoscope takes pictures of your body and displays them on a TV screen. The surgeon inserts tools into the other cuts and performs the surgery using the images on the screen for guidance.

**Robot-assisted surgery** – This is a type of laparoscopic surgery. A surgeon makes small cuts in the abdomen, and the camera and instruments are inserted through the cuts to perform the surgery. The surgeon has a 3D view that can be magnified up to 10–12 times and carries out the surgery using a machine to control the robotic arms.

## Making decisions about surgery

Talk to your surgeon about the types of surgery available to you, and the pros and cons of each option. If your surgeon suggests robot-assisted surgery, check what fees are involved – unless you are treated as a public patient in a hospital or treatment centre that offers this at no extra cost, it can be an expensive operation.

Compared to open surgery, both standard laparoscopic surgery and robot-assisted surgery usually mean a shorter hospital stay, less pain and a faster recovery time. However, open surgery may be a better option in some situations.

► See our *Understanding Surgery* booklet.



### Chris's story

A few years ago, I became very unwell with appendicitis and had to have my appendix removed. While in hospital, a scan picked up a lump at the bottom of my left kidney. This was an incidental finding – I had symptoms of appendicitis but no symptoms of kidney cancer.

The urologist talked through the options with me. Because it was a small tumour, only part of the kidney needed to be removed. I could choose between open and

laparoscopic surgery. I opted for laparoscopy because it would have a quicker recovery and I knew our hospital had a good track record with it. I was only in hospital for one and a half days. I felt better in two weeks and was back to driving in three weeks, although it took a few months to feel back to normal.

The pathology tests on the tumour confirmed that it was renal cell carcinoma, but it was a type with a good prognosis.

## What to expect after surgery

After surgery, you will usually be in hospital for 2–7 days. Once you are home, you will need to take some precautions while you recover. Your recovery time will depend on your age, general health and the type of surgery that you had.



### Drips and tubes

While in hospital, you will be given fluids and medicines via a tube inserted into a vein (intravenous drip). You will also have other temporary tubes to drain waste fluids away from the operation site.

For a few days, you will most likely have a thin tube inserted in your bladder that is attached to a bag to collect urine. This is called a urinary catheter. Knowing how much urine you are passing helps hospital staff monitor the function of the remaining kidney. When the catheter is removed, you will be able to urinate normally again.



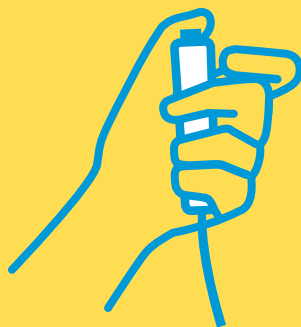
### Blood clots

You may have to wear compression stockings to help the blood in your legs circulate and prevent blood clots.

### Pain relief

You will have some pain in the areas where the cuts in the skin were made and where the kidney (or part of the kidney) was removed.

If you are in pain, ask for medicine to help control it. You might have an anaesthetic injected into the area around your spine (epidural), painkillers injected into a vein or muscle, or a patient-controlled analgesia (PCA) system. The PCA system delivers a measured dose of pain relief medicine when you push a button.







### Movement

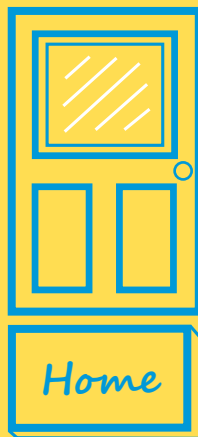
Your health care team will probably encourage you to walk the day after the surgery.

You may see a physiotherapist while you are in hospital. They can explain the safest way to move and show you exercises to do while you are recovering. These might include breathing or coughing exercises that can help you avoid developing a chest infection.

It will be some weeks before you can lift heavy things, drive, or return to work. Ask your doctor how long you should wait before attempting any of these activities.

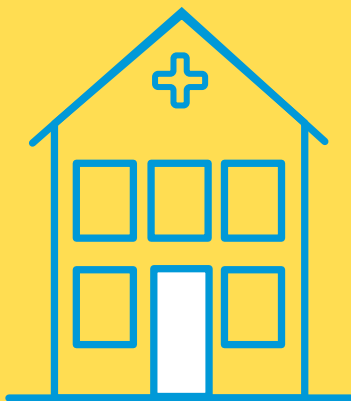
### Returning home

When you get home, you will need to take things easy and only do what is comfortable. Let your family and friends know that you need to rest a lot and might need some help around the house. Focus on eating a balanced diet (including proteins such as lean meats and poultry, fish, eggs, milk, yoghurt, nuts, seeds and legumes/beans) to help your body recover from surgery.



### Check-ups

You will need to visit the hospital for a check-up a few weeks after you've returned home. You can do this on an outpatient basis.



## Other treatments

Surgery is the most accepted treatment for early kidney cancer. However, if you are not well enough for surgery and the tumour is small, your doctor may recommend another type of treatment to destroy or control the cancer.

**Radiofrequency ablation (RFA)** – Radiofrequency ablation uses high-energy radio waves to heat the tumour. The heat kills the cancer cells and forms internal scar tissue. For this procedure, the doctor inserts a fine needle into the tumour through the skin, using a CT scan as a guide. An electrical current is passed into the tumour from the needle. The treatment takes about 15 minutes and you can usually go home after a few hours. Side effects, including pain or fever, can be managed with medicines.

**Stereotactic body radiation therapy (SBRT)** – Radiation therapy uses a controlled dose of radiation, such as x-ray beams, to kill or damage cancer cells. Standard radiation therapy (see pages 38–39) is not effective in treating primary kidney cancer and is given primarily to control symptoms such as bleeding or pain. Some studies, however, show promising results for SBRT as a treatment for kidney cancer and your doctor may recommend it in particular situations. SBRT is a highly targeted form of radiation therapy that delivers tightly focused beams of high-dose radiation precisely onto the tumour from many different angles. SBRT is sometimes called stereotactic ablative body radiation therapy (SABR).



## Key points about early kidney cancer

### What it is

Early kidney cancer is cancer that has not spread outside the kidney. It is known as localised cancer or stage I or II.

### The main treatment

The main treatment is surgery to remove the whole kidney (radical nephrectomy) or part of the kidney (partial nephrectomy).

### How surgery is done

Surgery for kidney cancer may be done as:

- open surgery – one large cut
- laparoscopic surgery – several smaller cuts and the use of a tiny surgical instrument with a camera and light
- robot-assisted surgery – a type of laparoscopic surgery.

Recovery time varies. Most people are in hospital for 2–7 days after surgery for kidney cancer, and it may be several weeks until you can safely return to your usual activities.

### Other treatment options

For small tumours, other options may include:

- active surveillance – watching the cancer carefully through regular check-ups before having treatment if the tumour changes
- radiofrequency ablation – uses heat from a needle to kill the cancer cells
- stereotactic body radiation therapy – uses highly targeted radiation to destroy or damage the cancer cells.



# Treatment for advanced kidney cancer

When kidney cancer has spread outside the kidney to other parts of the body, the usual goal of treatment is to control the cancer, to slow down its spread and to manage any symptoms.

A combination of different treatments may be recommended by your treatment team (see pages 12–13). The best combination of treatments depends on many factors, so the right approach for each person will vary:

- Watching and waiting (active surveillance) may be an option for some people.
- Systemic treatment with targeted therapy or immunotherapy drugs is the main medical treatment to help control advanced kidney cancer. Since the development of these more effective treatments, chemotherapy is rarely used.
- Radiation therapy may be suitable for some people.
- Surgery to remove the affected kidney might be recommended in certain circumstances, for example, if the cancer is causing symptoms.

## Active surveillance

In some cases when kidney cancer has spread, the cancer grows so slowly that it won't cause any problems for a very long time. Because of this, especially if the advanced kidney cancer has been discovered unexpectedly, your doctor may suggest observing the cancer at regular intervals, usually with CT scans (see pages 15–16). This approach is known as active surveillance or observation.

If the cancer starts to grow quickly or cause symptoms, active treatment will be recommended.

## Surgery

Surgery to remove kidney cancer when the cancer has spread is called cytoreductive surgery. This can involve removing the primary cancer in the kidney by nephrectomy (see pages 26–29), or removing some or all of the tumours that have spread (metastasectomy).

Recent studies suggest that treatment with targeted therapy alone is as effective as surgery followed by targeted therapy, and many people with advanced kidney cancer are now managed with targeted therapy alone (see below). Cytoreductive nephrectomy may still be offered in certain circumstances, such as when the kidney cancer is causing symptoms, or in people who have very little cancer spread outside the kidney. Generally, surgery is not recommended if you are unwell or if the cancer has spread to many places in the body.

## Targeted therapy

This is a type of drug treatment that attacks specific features of cancer cells to stop the cancer growing and spreading. The type of targeted therapy most frequently used to treat advanced kidney cancer is a group of drugs called small molecule inhibitors. These drugs can get inside cancer cells and block certain enzymes and proteins that tell cancer cells to grow, multiply and spread.

Most small molecule inhibitors are in the form of tablets that you take at home. They are commonly given in repeating cycles, with rest periods in between. Some may be taken daily for many months or even years. How long you take the drugs will depend on the aim of the treatment, how the cancer responds, and the side effects you have.

The two main types of small molecule inhibitors used for advanced kidney cancer in Australia are:

- **Tyrosine kinase inhibitors (TKIs)** – these drugs block a group of enzymes called tyrosine kinases from sending signals that tell cancer cells to grow. Without this signal, the cancer cells die. The main TKIs used are sunitinib, pazopanib, cabozantinib, sorafenib and axitinib.
- **mTOR inhibitors** – these drugs block mammalian target of rapamycin (mTOR), an enzyme that tells cancer cells to grow and spread. Everolimus is an mTOR inhibitor approved for use for some types of advanced kidney cancer that have not responded to TKIs.

The Pharmaceutical Benefits Scheme (PBS) subsidises the cost of these targeted therapy drugs as long as certain criteria are met. Medicines or treatments that are not on the PBS are usually very expensive unless given as part of a clinical trial.

Cancers often become resistant to particular targeted therapy drugs. If this happens, your doctor will usually suggest trying another targeted therapy drug or another treatment.

- See our *Understanding Targeted Therapy* fact sheet or listen to our podcast episode “New Cancer Treatments”.

## Side effects of targeted therapy

Ask your doctor what side effects you may experience and how long your treatment will last. Targeted therapy drugs minimise harm to healthy cells, but can still cause side effects. These vary depending on the drug used and how your body responds, but may include fatigue, mouth ulcers, changes in appetite, fevers, allergic reactions, skin rashes, diarrhoea, blood-clotting issues and blood pressure changes.



It's important to discuss any side effects of targeted therapy or immunotherapy drugs with your medical team as soon as they appear, so they can be managed appropriately. Early treatment is likely to shorten the length of time a side effect lasts.

## Immunotherapy

Immunotherapy is a type of cancer drug treatment that focuses on using the body's own immune system to fight cancer. Some cancer cells create barriers known as “checkpoints” to block the immune system. Drugs called checkpoint inhibitors help make the cancer cells visible to the body's own immune system. Once the barrier is removed, the immune system can recognise and destroy the cancer.

Nivolumab is a checkpoint inhibitor used to treat advanced kidney cancer. Nivolumab is usually administered into a vein (intravenously). It has been shown to be effective in people with advanced kidney cancer previously treated with a tyrosine kinase inhibitor.

Clinical trials (see page 24) are testing checkpoint immunotherapy at many stages of kidney cancer – after surgery (adjuvant treatment), as the first treatment for advanced kidney cancer, and in combination with existing kidney cancer drugs. In particular, using nivolumab combined with ipilimumab, has been shown to be an effective first treatment for advanced kidney cancer. This combination of drugs is not currently subsidised on the PBS for kidney cancer, however, this may change in 2019.

- See our *Understanding Immunotherapy* fact sheet or listen to our podcast episode “New Cancer Treatments”.



Many more targeted therapy and immunotherapy drugs are being studied in clinical trials (see page 24). Talk with your doctor about the latest developments and whether you are a suitable candidate.

## Side effects of immunotherapy

The side effects of immunotherapy can vary – not everyone will experience the same effects. Common side effects include fatigue, skin rash and diarrhoea. Because immunotherapy drugs stimulate the immune system, they can cause reactions such as dermatitis, hepatitis and colitis.

## Radiation therapy

Radiation therapy uses a controlled dose of radiation, such as focused x-ray beams, to kill or damage cancer cells. It is also known as radiotherapy. Radiation therapy might be used in advanced kidney cancer to shrink a tumour and relieve symptoms (palliative treatment, see opposite page).

If you have radiation therapy, you will lie on a treatment table under a machine called a linear accelerator. You will not feel anything during the treatment, which will only take a few minutes. Each session may last 10–20 minutes because of the time it takes to set up the equipment. You will be able to go home once the session is over.

The total number of treatment sessions depends on your situation. You might have some side effects, such as fatigue, nausea, appetite



loss, diarrhoea, tiredness and skin irritation. Talk to your radiation oncologist about any side effects you experience so you can get advice about how to manage them.

- See our *Understanding Radiation Therapy* booklet.

## Palliative treatment

In some cases of advanced kidney cancer, the medical team may talk to you about palliative treatment. Palliative treatment helps to improve people's quality of life by managing the symptoms of cancer without trying to cure the disease. It is best thought of as supportive care.

Many people think that palliative treatment is for people at the end of their life, but it may be beneficial for people at any stage of advanced kidney cancer. It is about living for as long as possible in the most satisfying way you can. Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, emotional, practical, spiritual and social needs.

As well as slowing the spread of cancer, palliative treatment can relieve pain and help manage other symptoms. Treatment may include radiation therapy to reduce pain from cancer that has spread to the bone, arterial embolisation (a procedure that blocks the blood supply to the kidney and the tumour inside it), targeted therapy or immunotherapy.

- See our *Understanding Palliative Care, Living with Advanced Cancer* and *Overcoming Cancer Pain* booklets, and *Understanding Secondary Bone Cancer* fact sheet.



## Key points about advanced kidney cancer

### What it is

Advanced kidney cancer is cancer that has spread from the kidney to another part of the body or come back after the initial treatment.

### Treatment goal

The usual goal of treatment is to control the cancer, slow down its spread and manage any symptoms.

### The main treatment

The main treatment is with drugs that reach cancer cells throughout the body to control the cancer's growth and stop it spreading:

- targeted therapy drugs block cancer cell growth by targeting specific features of cancer cells
- immunotherapy drugs use the body's own immune system to fight cancer.

### Other treatment options

Other options might include:

- active surveillance – watching the growth of the cancer through regular check-ups before giving treatment
- surgery – removing the primary kidney cancer (cytoreductive nephrectomy), and sometimes removing some or all of the cancer that has spread (metastasectomy)
- radiation therapy – shrinking the tumour if it is causing symptoms
- palliative treatment – using medical treatments to ease cancer symptoms.



# Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more, or visit your local Cancer Council website (see back cover).

**Eating well** – Healthy food can help you cope with treatment and side effects. A dietitian can explain how to manage any special dietary needs or eating problems and choose the best foods for your situation.

➤ See our *Nutrition and Cancer* booklet.

**Staying active** – Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel, and your doctor's advice.

➤ See our *Exercise for People Living with Cancer* booklet.

**Complementary therapies** – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

➤ See our *Understanding Complementary Therapies* booklet.



Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

**Work and money** – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check with a social worker or Cancer Council whether any financial assistance is available to you.

➤ See our *Cancer and Your Finances* and *Cancer, Work & You* booklets.

**Relationships** – Having cancer can affect your relationships with family, friends and colleagues in different ways. Cancer is stressful, tiring and upsetting, and this may strain relationships. It may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for those around you. It may help to discuss your feelings with each other.

➤ See our *Emotions and Cancer* booklet.

**Sexuality** – Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

➤ See our *Sexuality, Intimacy and Cancer* booklet.

**Contraception and fertility** – If you can have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, discuss the options with your doctor before starting treatment.

➤ See our *Fertility and Cancer* booklet.



# Life after treatment

For most people, the cancer experience doesn't end on the last day of treatment. Life after cancer treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry that every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to “normal life”. It is important to allow yourself time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

Cancer Council 13 11 20 can help you connect with other people who have had cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

► See our *Living Well After Cancer* booklet.

## Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression.

This is quite common among people who have had cancer.

Talk to your GP, as counselling or medicine – even for a short time – may help. Some people

can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call **beyondblue** on **1300 22 4636** or visit **beyondblue.org.au**. For 24-hour crisis support, call Lifeline **13 11 14** or visit **lifeline.org.au**.

## Follow-up appointments

After treatment for early-stage kidney cancer, you will need regular check-ups to monitor your health, manage any long-term side effects and check that the cancer hasn't come back or spread. If your doctor recommends active surveillance (see page 34), you will also have regular check-ups. During these check-ups, you will usually have a physical examination and you may have ultrasounds, CT scans or blood tests. Your doctor will talk to you about the follow-up schedule.

If you have advanced kidney cancer, you will have appointments with your treatment team on an ongoing basis.

When a follow-up appointment or test is approaching, many people find that they think more about the cancer and may feel anxious. Talk to your treatment team or call Cancer Council 13 11 20 if you are finding it hard to manage this anxiety.

Check-ups will become less frequent if you have no further problems. Between follow-up appointments, let your doctor know immediately of any symptoms or health problems.

## What if the cancer returns?

For some people, kidney cancer does come back after treatment, which is known as a recurrence. It is important to have regular check-ups, so that if cancer does come back, it can be found early. Recurrence can be locally in the kidney (if you had a partial nephrectomy) and you may be offered more surgery. If the cancer has spread beyond the kidney, your doctor may suggest targeted therapy, immunotherapy or radiation therapy, or occasionally surgery (see pages 35–38).



## Jodie's story

I had not been well for about a year, and one day I saw blood in my urine. By the end of the day, I was in such pain I ended up in emergency, where I was told it was kidney stones that should pass in a couple of days. When they didn't, I followed up with my doctor, who sent me for further scans.

I was in shock when the specialist said I had kidney cancer. I was booked in for surgery about three weeks after the initial diagnosis, but within a week I couldn't pass urine and ended up back in emergency, where I stayed until my surgery.

After the surgery, I was in quite a bit of pain and discomfort, and had lots of trouble going to the toilet.

My greatest concern has been about the cancer coming back. For a while it was my first waking thought. Time has helped me deal with this. Every check-up has reassured me that things are okay.

I had six-monthly check-ups at first, but now they're yearly. My family was great during this period; both my husband and son were very supportive. I was concerned I was driving my family crazy because I found the experience so consuming it was all I could talk about.

I couldn't find information and there was no support group that I was aware of, except online – that's why, once I was well again, I felt it important to become a volunteer in a peer support program. I always tell people that it was a really scary experience, but that it's okay to be afraid.

At the time of the diagnosis, I was working as an office manager, but afterwards we reassessed our life. I changed jobs and we moved house.

I now work in aged care, which I love, and we moved from a big house to a small apartment overlooking the sea. I learnt to go with the flow and that life will be all right.



## Seeking support

A cancer diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer also often creates practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs
- counselling services.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost.

To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.

“ My family members don't really understand what it's like to have cancer thrown at you, but in my support group, I don't feel like I have to explain. ” Sam



## Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

### Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).



### Information resources

Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call **13 11 20** or visit your local Cancer Council website (see back cover).

### Practical help

Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.



### Legal and financial support

If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council **13 11 20** to ask if you are eligible.

### Peer support services

You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call **13 11 20** or visit [cancercouncil.com.au/OC](https://cancercouncil.com.au/OC).



## Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

### Australian

Cancer Council Australia	<a href="https://cancer.org.au">cancer.org.au</a>
Cancer Australia	<a href="https://canceraustralia.gov.au">canceraustralia.gov.au</a>
Cancer Council Online Community	<a href="https://cancercouncil.com.au/OC">cancercouncil.com.au/OC</a>
<i>The Thing About Cancer</i>	<a href="https://cancercouncil.com.au/podcasts">cancercouncil.com.au/podcasts</a>
Carer Gateway	<a href="https://carergateway.gov.au">carergateway.gov.au</a>
Carers Australia	<a href="https://carersaustralia.com.au">carersaustralia.com.au</a>
Department of Health	<a href="https://health.gov.au">health.gov.au</a>
Department of Human Services	<a href="https://humanservices.gov.au">humanservices.gov.au</a>
eviQ	<a href="https://eviq.org.au">eviq.org.au</a>
Healthdirect Australia	<a href="https://healthdirect.gov.au">healthdirect.gov.au</a>
Kidney Health Australia	<a href="https://kidney.org.au">kidney.org.au</a>

### International

American Cancer Society	<a href="https://cancer.org">cancer.org</a>
Cancer Research UK	<a href="https://cancerresearchuk.org">cancerresearchuk.org</a>
Macmillan Cancer Support (UK)	<a href="https://macmillan.org.uk">macmillan.org.uk</a>
National Cancer Institute (US)	<a href="https://cancer.gov">cancer.gov</a>
International Kidney Cancer Coalition	<a href="https://ikcc.org">ikcc.org</a>
10-for-1.O.: Understanding immuno-oncology for kidney cancer	<a href="https://10forio.info">10forio.info</a>



# Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with both the practical and emotional aspects of your caring role.

**Support services** – Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local services, as well as information and resources, through the Carer Gateway. Call 1800 422 737 or visit [carergateway.gov.au](http://carergateway.gov.au).

**Support groups and programs** – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

**Carers Associations** – Carers Australia works with the Carers Associations in each state and territory to provide information and services to carers. Call 1800 242 636 or visit [carersaustralia.com.au](http://carersaustralia.com.au).

**Cancer Council** – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

➤ See our *Caring for Someone with Cancer* booklet.



# Question checklist

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

## Diagnosis

- What type of kidney cancer do I have?
- Has the cancer spread? If so, where has it spread? How fast is it growing?
- Are the latest tests and treatments for this cancer available in this hospital?
- Will a multidisciplinary team be involved in my care?
- Are there clinical guidelines for this type of cancer?

## Treatment

- What treatment do you recommend? What is the aim of the treatment?
- Are there other treatment choices for me? If not, why not?
- If I don't have the treatment, what should I expect?
- How long do I have to make a decision?
- I'm thinking of getting a second opinion. Can you recommend anyone?
- How long will treatment take? Will I have to stay in hospital?
- Are there any out-of-pocket expenses not covered by Medicare or my private health cover? Can the cost be reduced if I can't afford it?
- How will we know if the treatment is working?
- Are there any clinical trials or research studies I could join?

## Side effects

- What are the risks and possible side effects of each treatment?
- Will I have a lot of pain? What will be done about this?
- Can I work, drive and do my normal activities while having treatment?
- Will the treatment affect my sex life and fertility?
- Should I change my diet or physical activity during or after treatment?
- Are there any complementary therapies that might help me?

## After treatment

- How often will I need check-ups after treatment?
- Who should I go to for my check-up appointments?
- If the cancer returns, how will I know? What treatments could I have?



# Glossary

## **abdomen**

The part of the body between the chest and hips, which contains the stomach, spleen, pancreas, liver, gall bladder, bowel, bladder and kidneys.

## **active surveillance**

When a person does not receive immediate treatment, but instead has their health monitored regularly, with the option of future treatment if necessary. Also called observation.

## **adjuvant therapy**

A treatment given with or shortly after another treatment to enhance the main treatment's effectiveness.

## **adrenal glands**

Triangular glands resting on top of each kidney that produce adrenaline and other hormones.

## **advanced cancer**

Cancer that is unlikely to be cured.

It may be limited to its original site (primary cancer) or may have spread to other parts of the body (secondary or metastatic cancer).

## **anaemia**

A reduction in the number or quality of red blood cells in the body.

## **anaesthetic**

A drug that stops a person feeling pain during a medical procedure. Local and regional anaesthetics numb part of the body; a general anaesthetic causes a temporary loss of consciousness.

## **angiogenesis**

The formation of new blood vessels.

This process enables tumours to develop their own blood supply, which helps them grow.

## **arterial embolisation**

A palliative treatment for advanced kidney cancer in which the artery that feeds the diseased kidney is deliberately blocked. This causes the kidney and the tumour inside it to die.

## **artery**

A blood vessel that carries blood away from the heart.

## **benign**

Not cancerous or malignant.

## **biopsy**

The removal of a sample of tissue from the body for examination under a microscope to help diagnose a disease. See also core needle biopsy.

## **bladder**

The hollow muscular organ that stores urine.

## **catheter**

A hollow, flexible tube through which fluids can be passed into the body or drained from it.

## **cells**

The basic building blocks of the body.

A human is made up of billions of cells that are adapted for different functions.

## **checkpoint immunotherapy**

The use of drugs that work by allowing the immune system to pass "checkpoints" set up by the cancer to block the immune system.

## **chemotherapy**

A cancer treatment that uses drugs to kill cancer cells or slow their growth. May be given alone or in combination with other treatments.

### **clinical trial**

A research study that tests new approaches to prevention, screening, diagnosis or treatment, to see if they are better than current treatments.

### **contrast**

A substance injected into a vein or taken orally before a scan (such as a CT or MRI scan), which helps make pictures clearer. Also called a contrast medium or dye.

### **core needle biopsy**

A type of biopsy where a tissue sample is removed using a wide needle from an organ or lymph node for examination under a microscope.

### **CT scan**

Computerised tomography scan. This scan uses x-rays to create cross-sectional pictures of the body.

### **cystoscope**

A thin viewing instrument with a light and camera that is inserted into the urethra and advanced into the bladder.

### **cystoscopy**

A procedure that uses a tool called a cystoscope to see inside the urethra and bladder.

### **cytoreductive nephrectomy**

The surgical removal of the kidney with the primary cancer. This technique is sometimes used when cancer has spread.

### **grade**

A number that describes how similar cancer cells look to normal cells, and how quickly a tumour is likely to grow.

### **haematuria**

Blood in the urine.

### **hormones**

Chemicals in the body that send information between cells. Some hormones control growth, others control reproduction.

### **hypercalcaemia**

Higher than normal levels of calcium in the blood.

### **immune system**

A network of cells and organs that defends the body against attacks by foreign invaders, such as bacteria and viruses.

### **immunotherapy**

Treatment that uses the body's immune system to fight cancer.

### **interventional radiologist**

A specialist doctor who uses imaging scans to diagnose cancer, may perform biopsy under ultrasound or CT, and delivers some treatments.

### **intravenous**

Injected into a vein.

### **kidneys**

A pair of organs in the abdomen. The kidneys remove waste from the blood and make urine. They also produce hormones that stimulate red blood cell production and control calcium levels.

### **laparoscope**

A thin viewing instrument with a light and camera that is inserted through a cut in the abdomen to look inside the abdomen and pelvis during laparoscopy.

### **laparoscopy**

Surgery done through small cuts in the

abdomen using a viewing instrument called a laparoscope. Also called keyhole or minimally invasive surgery.

### **lymphatic system**

A network of tissues, capillaries, vessels, ducts and nodes that removes excess fluid from tissues, absorbs fatty acids, transports fat, and produces immune cells. Includes the lymph nodes.

### **lymph nodes**

Small bean-shaped structures that collect and destroy bacteria and viruses.

### **malignant**

Cancerous. Malignant cells can spread (metastasise) and eventually cause death if they cannot be treated.

### **mTOR inhibitors**

Drugs that block mammalian target of rapamycin (mTOR), an enzyme which tells cancer cells to grow and spread.

### **medical oncologist**

A doctor who specialises in treating cancer with drug therapies such as targeted therapy, immunotherapy and chemotherapy (systemic treatment).

### **metastasis (plural: metastases)**

Cancer that has spread from a primary cancer in another part of the body. Also called secondary cancer.

### **MRI scan**

Magnetic resonance imaging scan. A scan that uses magnetism and radio waves to take detailed cross-sectional pictures of the body.

### **nephrectomy**

Surgical removal of a whole kidney (radical nephrectomy) or part of a

kidney (partial nephrectomy). In a radical nephrectomy, the adrenal gland, surrounding fatty tissue and nearby lymph nodes are sometimes removed as well.

### **nephrologist**

A doctor who specialises in diagnosing and treating kidney disease.

### **nephrology**

The branch of medicine relating to the function and diseases of the kidneys.

### **nephrons**

The tiny parts of the kidney that filter the blood. Nephrons also regulate blood volume, pressure and pH, and levels of electrolytes and metabolites.

### **observation**

See active surveillance.

### **oncologist**

A doctor who specialises in the study and treatment of cancer.

### **open surgery**

A surgical method that involves one large cut (incision) in the body to view and access the organs.

### **palliative treatment**

Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional symptoms. Palliative treatment may include radiation therapy, arterial embolisation or drug therapies. It is an important part of palliative care.

### **patient-controlled analgesia (PCA)**

An intravenous system that allows a person to administer a measured dose of pain relief by pressing a button.

### **polycythaemia**

A condition in which red blood cell levels are higher than normal.

### **primary cancer**

The original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form.

### **prognosis**

The expected outcome of a person's disease.

### **prostate**

A gland about the size of a walnut found only in men. It produces fluid that makes up part of semen.

### **radiation**

Energy in the form of waves or particles, including gamma rays, x-rays and ultraviolet (UV) rays. This energy is used in radiation therapy to destroy cancer cells.

### **radiation oncologist**

A doctor who specialises in treating cancer with radiation therapy.

### **radiation therapy**

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams. Also called radiotherapy.

### **radical nephrectomy**

See nephrectomy.

### **radiofrequency ablation (RFA)**

A treatment that uses radio waves to heat and destroy cancer cells.

### **radioisotope bone scan**

A scan using small amounts of radioisotope to find areas of bone where there is cancer.

### **renal artery**

A blood vessel that carries blood to the kidney.

### **renal cell carcinoma (RCC)**

The most common type of kidney cancer. Also called renal adenocarcinoma. It begins in cells lining small tubes in the nephrons. Types of RCC include clear cell, papillary, chromophobe and sarcomatoid.

### **renal pelvis**

A funnel-shaped structure where the kidney and ureter meet.

### **renal vein**

A blood vessel that carries blood away from the kidney.

### **staging**

Performing tests to work out how far a cancer has spread.

### **stereotactic body radiation therapy (SBRT)**

A specialised form of external beam radiation therapy that can deliver a few high doses of radiation very precisely. Also called stereotactic ablative body radiation therapy (SABR).

### **targeted therapy**

Drugs that attack specific particles (molecules) within cells that allow cancer to grow and spread. The main types of targeted therapy used for advanced kidney cancer are tyrosine kinase inhibitors (TKIs) and mTOR inhibitors.

### **tumour**

A new or abnormal growth of tissue on or in the body. A tumour may be benign or malignant.



### **tyrosine kinase**

A chemical messenger that tells cells when to divide and grow.

### **tyrosine kinase inhibitors (TKIs)**

A targeted therapy drug that blocks enzymes involved with cell growth.

### **ultrasound**

A scan that uses soundwaves to create a picture of part of the body.

### **ureteroscopy**

A test using a thin tube with a light and camera (ureteroscope) to examine the ureters. It is performed under a general anaesthetic.

### **ureters**

The tubes that carry urine from the kidneys to the bladder.

### **urethra**

The tube that carries urine from the bladder to the outside of the body. For men, the urethra also carries semen.

### **urinary system**

The system that removes wastes from the blood and expels them from the body in urine. It includes the kidneys, ureters, bladder and urethra.

### **urologist**

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

### **urothelial carcinoma**

Cancer that starts in the urothelium. Sometimes called transitional cell carcinoma (TCC).

### **urothelial cells**

Cells that line parts of the urinary tract, such as where the kidney joins the ureter, in the ureter itself, in the bladder and in some parts of the urethra. This forms a watertight lining. Also called transitional cells.

### **urothelium**

The inner lining of the bladder and the urinary system.

### **Can't find a word here?**

*For more cancer-related words, visit:*

- [cancercouncil.com.au/words](http://cancercouncil.com.au/words)
- [cancervic.org.au/glossary](http://cancervic.org.au/glossary)
- [cancersa.org.au/glossary](http://cancersa.org.au/glossary)

## **References**

1. B Escudier et al. on behalf of the ESMO Guidelines Committee, "Renal cell carcinoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up", *Annals of Oncology*, vol. 27, suppl. 5, 2016, pp. v58–v68.
2. Australian Institute of Health and Welfare (AIHW), *Australian Cancer Incidence and Mortality (ACIM) books: kidney cancer*, AIHW, Canberra, December 2017.



## How you can help

At Cancer Council, we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

**Join a Cancer Council event:** Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls' Night In and other Pink events, or hold your own fundraiser or become a volunteer.

**Make a donation:** Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

**Buy Cancer Council sun protection products:** Every purchase helps you prevent cancer and contribute financially to our goals.

**Help us speak out for a cancer-smart community:** We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

**Join a research study:** Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



# Cancer Council

## 13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

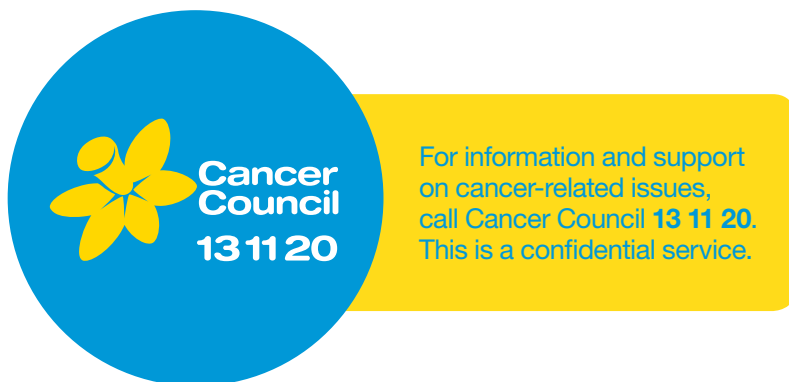
Cancer Council services and programs vary in each area.

13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



**If you need information in a language other than English, an interpreting service is available. Call 13 14 50.**

**If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. [www.relayservice.gov.au](http://www.relayservice.gov.au)**



## Visit your local Cancer Council website

**Cancer Council ACT**  
[actcancer.org](http://actcancer.org)

**Cancer Council NSW**  
[cancercouncil.com.au](http://cancercouncil.com.au)

**Cancer Council NT**  
[nt.cancer.org.au](http://nt.cancer.org.au)

**Cancer Council Queensland**  
[cancerqld.org.au](http://cancerqld.org.au)

**Cancer Council SA**  
[cancersa.org.au](http://cancersa.org.au)

**Cancer Council Tasmania**  
[cancertas.org.au](http://cancertas.org.au)

**Cancer Council Victoria**  
[cancervic.org.au](http://cancervic.org.au)

**Cancer Council WA**  
[cancerwa.asn.au](http://cancerwa.asn.au)

**Cancer Council Australia**  
[cancer.org.au](http://cancer.org.au)

*This booklet is funded through the generosity of the people of Australia.  
To support Cancer Council, call your local Cancer Council or visit your local website.*