



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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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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We also thank the health professionals, consumers and editorial teams who have worked on previous editions of this title. This booklet is funded through the generosity of the people of Australia.

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 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.¹

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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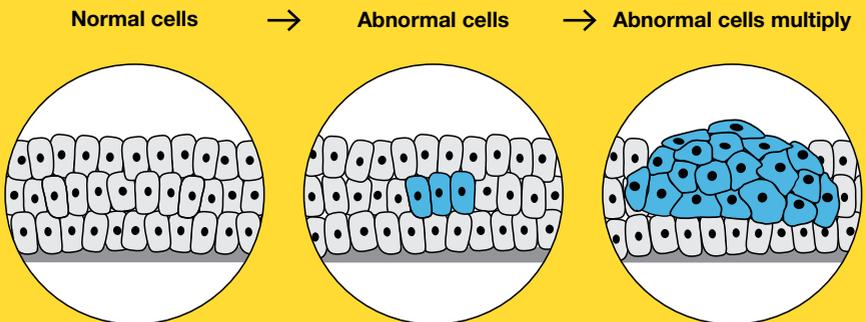
What is cancer?

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

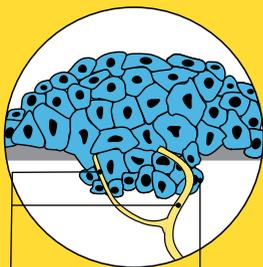
How cancer starts



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.

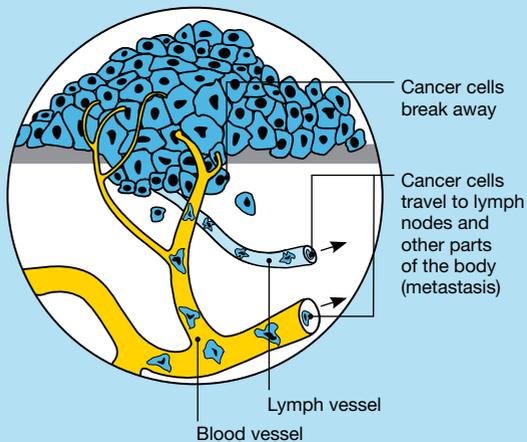
→ **Malignant cancer**



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. The kidneys are part of the body's urinary system.

What the kidneys do

The main role of the kidneys is to filter and clean the blood. Blood flows into each kidney through the renal artery and is filtered through tiny networks of tubes called nephrons. The clean blood then goes back into the rest of the body through the renal vein.

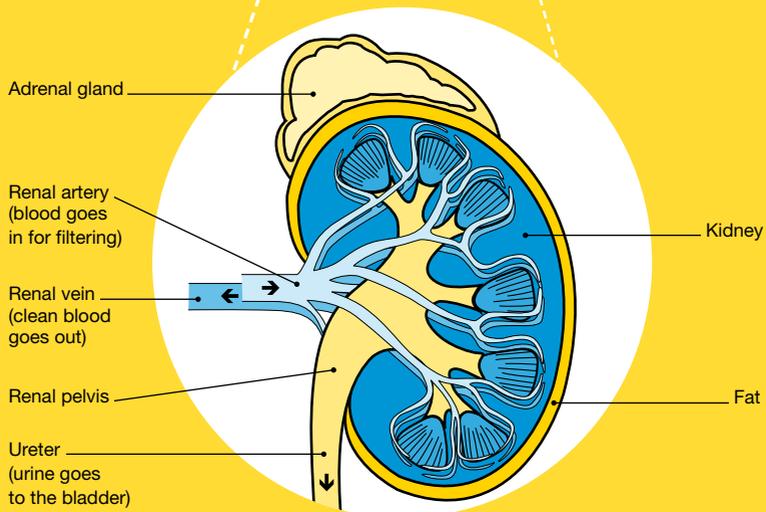
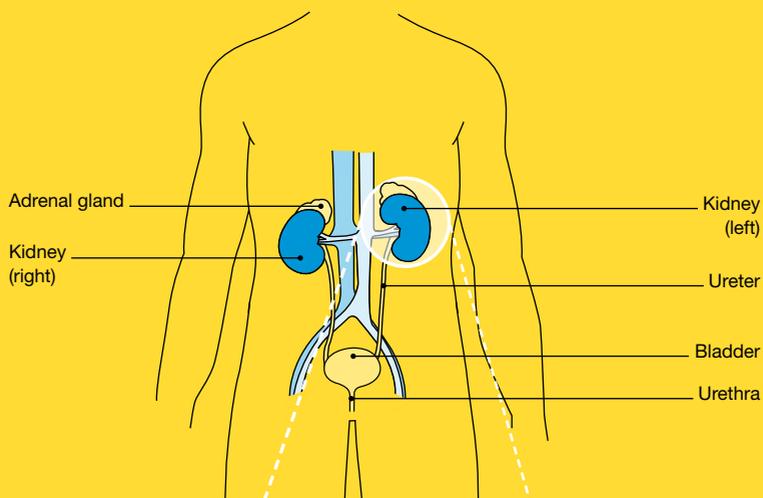
When the kidneys filter the blood, they remove excess water and waste products and turn these into urine (wee or pee). Urine travels from each kidney into a funnel called the renal pelvis, then through a long, thin tube called the ureter, and into the bladder.

Urine is stored in the bladder until you need to urinate, when it leaves the body through a tube called the urethra. In females, the urethra is a short tube in front of the vagina. In males, the tube is longer and passes through the prostate and penis.

Hormone production – The kidneys also help your body control how much blood it needs. They do this by making hormones that 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 cell adenocarcinoma. RCCs start in the cells lining tiny tubes in the kidney's nephrons. The information in this booklet is about RCC.

In the early stages of RCC, the tumour is in the kidney only. Usually one kidney is affected, but in rare cases there is a tumour in both kidneys. As the cancer grows, it can spread to areas near the kidney, such as the surrounding fatty tissue, veins, adrenal glands, lymph nodes, 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 how the cells look under a microscope.

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

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

➤ Visit childrenscancer.canceraustralia.gov.au.

Secondary cancer – Very rarely, cancer can spread from the original (primary) cancer to the kidney. This is known as secondary cancer (metastasis). This secondary 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 3600 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 as in women, and is the sixth most diagnosed cancer in Australian men. The risk of kidney cancer increases with age, and most cases occur in people over 50.²

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 include:

- blood in the urine (haematuria) or change in urine colour – can be 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 testing can confirm a 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 exact causes of kidney cancer are not known. The factors listed below may increase the risk of developing kidney cancer. Having these risk factors does not mean you will develop kidney cancer, some people develop kidney cancer without having any known risk factors. If you are concerned talk to your doctor.

Risk factors include:

- **smoking** – people who smoke have almost twice the risk of developing kidney cancer as nonsmokers. About 1 in 3 cases of all kidney cancers are thought to be related to smoking; the longer a person smokes and the more they smoke, the greater the risk
- **obesity** – too much body fat may cause changes to some 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 with a parent, brother or sister (first-degree relative) with kidney cancer are at increased risk
- **inherited conditions** – about 2–3% of kidney cancers develop in people who have particular inherited syndromes, including von Hippel–Lindau disease, hereditary papillary RCC, Birt–Hogg–Dubé syndrome and Lynch syndrome
- **exposure to toxic substances at work** – the risk may be higher after regular exposure to chemicals, such as some metal degreasers, arsenic or cadmium, which are used in mining, farming, welding and painting.

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

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

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.

cancer care coordinator	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)
social worker	links you to support services and helps you with emotional, practical and financial issues
physiotherapist, exercise physiologist	help restore movement and mobility, and improve fitness and wellbeing
occupational therapist	assists in adapting your living and working environment to help you resume usual activities after treatment
dietitian	recommends an eating plan to follow during treatment and recovery
psychiatrist*, psychologist, counsellor	help you manage your emotional response to diagnosis and treatment
palliative care specialist* and nurses	work closely with the GP and cancer team to help control symptoms and maintain your quality of life

* Specialist doctor



Diagnosis

Most kidney cancers are found by chance (incidentally) when a person has an ultrasound or another imaging 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.

Blood and urine tests

You will probably have urine and blood tests to check your general health and look for signs of a problem in the kidneys. These tests do not diagnose kidney cancer. They may include:

- a complete count of the three types of blood cells: red blood cells, white blood cells and platelets
- tests to check how your kidneys are working
- blood chemistry tests to measure certain chemicals – high levels of the enzyme alkaline phosphatase could be a sign that kidney cancer has spread to the bones.

Early and advanced kidney cancer

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 meet 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-ray beams 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 find any tumours in the kidneys, and provide information about the size, shape and position of a tumour. The scan also helps check if a cancer has spread to nearby lymph nodes or to other organs and tissues.

CT scans are usually done at a hospital or radiology clinic. You may be asked to fast (not eat or drink) for several hours before the scan to make the pictures clearer and easier to read. Before the scan, a dye may be injected into a vein in your arm. This dye, known as contrast, helps make the pictures clearer. It travels through your bloodstream to the kidneys, ureters, bladder and other organs. The dye might make you feel flushed and hot for a few minutes and you could feel like you need to pass urine. These effects won't last long.

For the scan, you will lie flat on a table that moves in and out of the CT scanner, which is large and shaped like a doughnut. This painless test takes about 30–40 minutes.

MRI scan – An MRI (magnetic resonance imaging) scan uses a powerful magnet and radio waves to create 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 cancer has spread from the kidney to the renal vein or spinal cord.

Let your medical team know if you have a pacemaker, as the magnet in an MRI scanner 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 cannot have the dye.

During the scan, you will lie on an examination table that slides into a large metal tube that is open at both ends. Lying within the noisy, narrow machine makes some people feel anxious or claustrophobic. If you think you may become distressed, mention this beforehand to your medical team. You may be given a mild sedative to help you relax, and you will usually be offered headphones or earplugs. The MRI scan may take between 30 and 90 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 have diabetes or other kidney disease or are pregnant.

Radioisotope bone scan – Also called a nuclear medicine bone scan or simply a bone scan, a radioisotope scan can look for changes in the bones. It's used only if you have bone pain or blood tests results show high levels of alkaline phosphatase. These may be a sign that the cancer has spread to the bones. If cancer is found in the bones, the scan can also be used to check how the cancer is responding to treatment.

A radioisotope bone scan uses a very small amount of a radioactive solution. Before you have the scan, the solution is injected into a vein, usually in your arm. You will need to wait for a few hours while the solution moves through your bloodstream to your bones. 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. After the scan, you need to drink plenty of fluids to help remove the radioactive substance from your body through your urine. You should avoid contact with young children and pregnant women for the rest of the day. Your treatment team will discuss these precautions with you.

PET scan – A PET (positron emission tomography) scan is a specialised imaging test. It uses an injection of a small amount of radioactive solution to help cancer cells show up brighter on the scan. A PET scan is useful for some cancers, but kidney cancer does not always show up well on a standard PET scan. Newer solutions are currently being studied and a PET scan may be used to look for kidney cancer in the future.

Cystoscopy

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 or 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

A biopsy involves removing a tissue sample for examination under a microscope. It is a common way to diagnose cancer, but it is not often needed for kidney cancer before treatment. This is because imaging scans are good at showing if a kidney tumour is cancer.

For many people with kidney cancer, the main treatment is surgery (see pages 26–31). In this case, the tumour removed during surgery is tested to confirm that it is cancer.

A biopsy may be done before treatment when:

- surgery is not an option because the tumour is very small and active surveillance is suggested – a biopsy will help work out what other treatment is needed
- the tumour is large, looks irregular on the scan, or has obviously spread to the renal vein, adrenal gland or nearby lymph nodes.

If a biopsy is done, it will be a core needle biopsy. For this procedure, you will have a local anaesthetic to numb the area, and then an

interventional radiologist (see page 12) will put 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 look at the sample under a microscope to check for any cell changes.

In some cases, a kidney tumour will turn out to be benign (not cancer). Benign kidney growths, including oncocytoma and angiomyolipoma, can cause problems, and treatment may be similar to the treatment for early kidney cancer.

Grading kidney cancer

By examining under a microscope a tissue sample taken during a biopsy or after surgery, doctors can see how similar the cancer cells look to normal cells and estimate how fast the cancer is likely to be growing. This is called grading. It helps the doctors 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 14–19 to assign a stage of 1 to 4 (see the box on the opposite page for more detail):

- stages 1–2 are considered early kidney cancer
- stages 3–4 are considered advanced kidney cancer.

Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis with your doctor, but it is not possible for anyone to predict the exact course of the disease. Your doctor can give you an idea about common issues that affect people with kidney cancer.

The stage of the cancer is the main factor in working out 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 kidney cancer tend to have better outcomes. 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. TNM stands for tumour–nodes–metastasis. This system 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 (1–4).

stage 1	The cancer is found in the kidney only and measures less than 7 cm.	early
stage 2	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.	early
stage 3	The cancer is any size and has spread to nearby lymph nodes, or the cancer has spread to the adrenal gland.	locally advanced
stage 4	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.	advanced (metastatic)



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 it is found

Kidney cancer is usually 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

Imaging scans (ultrasound, CT, MRI, bone scans) are used to show the location of the cancer and whether it has spread.

Other tests

- Other tests can give more information about the cancer. They may include urine and blood tests to: see how well your kidneys are working; look for changes caused by cancer; and measure for chemicals that could be high if there is cancer.
- Core needle biopsy to take a tissue sample from the kidney.

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 1 and 2, while advanced kidney cancer is stages 3 and 4.



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 can help or you might like to ask if you can record the discussion. 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.
► See our *Understanding Clinical Trials and Research* booklet.



Treatment for early kidney cancer

Early kidney cancer (stage 1 or 2) is localised. That means the cancer is found in the kidney only or has not spread very far. The main treatment is surgery (see pages 26–31). Less often, radiofrequency ablation, cryotherapy and stereotactic body radiation therapy (see page 32) are used. Sometimes the best approach for early kidney cancer is to watch the cancer over time (active surveillance).

If you are a current smoker, your health care team will advise you to stop smoking before you start treatment. To work out a plan for quitting, talk to your doctor or call the Quitline on 13 7848.

Active surveillance

Also known as observation, active surveillance is a way of monitoring kidney cancer. The aim is to avoid affecting how your kidney works and other side effects you may experience if you have surgery. It may be suggested if the tumour is less than 4 cm in diameter. Active surveillance might also be an option if you are not well enough for surgery and the tumours are small, or if you are older.

Active surveillance involves having regular ultrasounds or CT scans (see pages 15–16). If these imaging tests suggest that the tumour has grown, you may be offered active treatment (usually surgery).



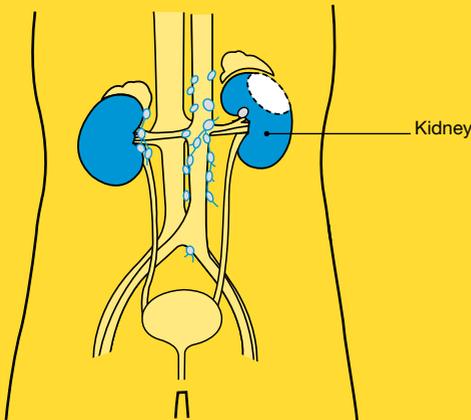
Choosing active surveillance avoids treatment side effects, but you might feel anxious about having a cancer diagnosis without active treatment. Talk to your doctors about ways to manage any worries.

Surgery

Surgery is the main treatment for early kidney cancer. 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 operations described below.

Types of surgery

Surgery for kidney cancer may remove part or all of a kidney.



● Lymph nodes

○ Area removed

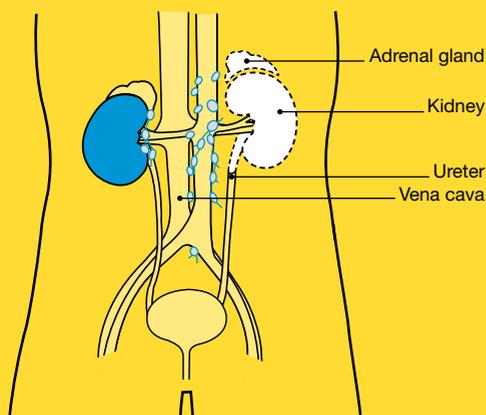
Partial nephrectomy

This is the most common operation for tumours 7 cm or smaller that are found only in the kidney. It may also be used for people who have existing kidney disease, cancer in both kidneys or only one working kidney.

Only the cancer and a small part of the surrounding kidney are removed.

A partial nephrectomy is a more difficult operation than a radical nephrectomy. Whether it is possible depends on where the tumour is in the kidney.

If a whole kidney or part of a kidney is removed, the remaining kidney usually does the work of both kidneys. Your doctor will talk to you about how to keep the remaining kidney healthy, which may include reducing your risk of high blood pressure, heart problems and diabetes.



- Lymph nodes
- Area removed

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 large vein that takes blood to the heart. Even if the cancer has spread to the vena cava, it is sometimes possible to remove all the cancer in one operation.

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.

One of the following methods will be used to remove part or all of the kidney (partial or radical nephrectomy). Each method is suitable in particular situations.

Open surgery – This is usually done with a long cut (incision) 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 and divide the major blood vessels and tubes to the affected kidney before removing it.

Keyhole surgery – This is also called minimally invasive surgery or laparoscopic 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 openings. The laparoscope sends images of your body to a video monitor. The surgeon watches the images on the monitor for guidance during the operation.

Robot-assisted surgery – This is a type of keyhole surgery using a robotic device. The surgeon sits at a control panel to see a three-dimensional image and moves robotic arms that hold the instruments. Robotic surgery has allowed more partial nephrectomies to be performed with keyhole surgery, reducing complications and improving recovery time.

Making decisions about surgery

Talk to your surgeon about the types of surgery suitable for you, and ask about the advantages and disadvantages of each method. If your surgeon suggests robot-assisted surgery, check what you have to pay. Unless you are treated as a public patient in a hospital or treatment centre that offers this at no extra cost, it can be a more expensive operation.

Compared to open surgery, both keyhole (laparoscopic) surgery and robot-assisted surgery usually mean a shorter hospital stay, less pain and a faster recovery time. But in some cases, open surgery may be a better option.

► 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 how the remaining kidney is working (functioning). When the catheter is removed, you will be able to urinate normally again.



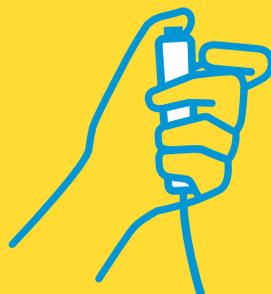
Blood clots

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

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 medicine when you push a button.





Moving around

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, reach high with your arms or drive. Ask your doctor how long you should wait before attempting any of these activities or returning to work.

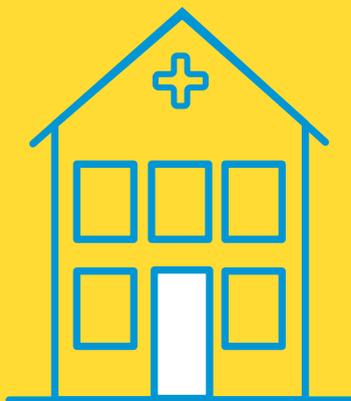
Returning home

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. Try to eat a balanced diet (including proteins such as lean meats and poultry, fish, eggs, milk, yoghurt, nuts, seeds and legumes or 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.



Other treatments

If you are not well enough for surgery and the tumour is small, other treatments to destroy or control the cancer may be recommended.

Radiofrequency ablation (RFA) – This procedure uses high-energy radio waves to heat the tumour. The heat kills the cancer cells and forms internal scar tissue. 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. RFA 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.

Cryotherapy – Also known as cryosurgery, cryotherapy kills cancer cells by freezing them. This treatment is not widely used in Australia. Under a general anaesthetic, a cut is made in the abdomen. The doctor inserts a probe through the cut into the tumour. The probe gets very cold, which freezes and kills the cancer cells. Cryotherapy takes about 60 minutes. Side effects include bleeding and leaking urine.

Stereotactic body radiation therapy (SBRT) – This is also called stereotactic ablative body radiation therapy (SABR) and is a specialised form of radiation therapy. It is a way of giving a highly focused dose of radiation therapy to a primary kidney cancer when surgery is not possible due to other health conditions. SBRT is painless and is usually delivered over one to three days.



Key points about early kidney cancer

What it is

Early kidney cancer is cancer that is found only in the kidney. It is known as localised cancer or stage 1 or 2.

Main treatment

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

How surgery is done

Surgery for kidney cancer may be done as:

- open surgery – one long cut
- keyhole surgery – several smaller cuts and the use of a tiny surgical instrument with a light and camera (laparoscope)
- robot-assisted surgery – a type of keyhole surgery using a robotic device.

Recovery time varies. You may be in hospital for 2–7 days after surgery, and it may take a few weeks until you can do 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 (RFA) – passes heat through a needle to kill cancer cells
- cryotherapy – kills cancer cells by freezing them
- stereotactic body radiation therapy (SBRT) – uses a highly focused dose of radiation to destroy or damage cancer cells.



Treatment for advanced kidney cancer

When kidney cancer has spread outside the kidney to lymph nodes or other parts of the body (stage 3 or 4), it's known as advanced or metastatic cancer. The aim of treatment is to slow the spread of the cancer and to manage any symptoms.

A combination of different treatments may be recommended. Which combination is suitable for you will depend on several factors, including how soon after diagnosis you start systemic treatment, blood counts, blood calcium levels and your general health.

Systemic treatment

Drugs that reach cancer cells throughout the body are called systemic treatments. These can include chemotherapy, targeted therapy and immunotherapy.

Targeted therapy and immunotherapy are the main systemic treatments used to control advanced kidney cancer. The types of drugs and combinations used are rapidly changing as clinical trials show better responses and improved survival with newer drugs (see page 24). Since the development of these more effective systemic treatments, chemotherapy is rarely used for kidney cancer.

Talk with your doctor about the latest developments and whether you are a suitable candidate. Ask them about the side effects you might have. Most side effects can be managed, and treating them early is likely to reduce how long side effects last.

The Pharmaceutical Benefits Scheme (PBS) subsidises the cost of targeted therapy or immunotherapy 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.

Active surveillance

In some cases, kidney cancer grows so slowly that it won't cause any problems for a long time. Because of this, especially if the advanced kidney cancer has been found unexpectedly, your doctor may suggest looking at the cancer regularly, 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.

Targeted therapy

This is a type of drug treatment that attacks specific features of cancer cells to stop the cancer growing and spreading. The main groups of targeted therapy drugs for advanced kidney cancer are tyrosine kinase inhibitors (TKIs) and mTOR inhibitors. These drugs can get inside cancer cells and block certain enzymes and proteins that tell cancer cells to grow, multiply and spread. See next page for details.

Targeted therapy drugs are usually used as the first treatment for advanced kidney cancer (first-line treatment).

Kidney cancer often stops responding to particular targeted therapy drugs. If this happens, your doctor will usually suggest another targeted therapy drug or immunotherapy combination (see page 37). Research shows that having targeted therapy drugs together with immunotherapy has led to better response rates in certain people.

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

Types of targeted therapy drugs used for advanced kidney cancer

	tyrosine kinase inhibitors (TKIs)	mTOR inhibitors
How they work	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	drugs block the mammalian target of rapamycin (mTOR), an enzyme that tells cancer cells to grow and spread
When they are used	approved for use for some types of advanced kidney cancer	approved for use for some types of advanced kidney cancer that have not responded to TKIs
How they are given	taken as daily tablet; often given in repeating cycles, with rest periods in-between; some may be taken for many months or even years	taken as daily tablet; may be taken for many months or even years; may be given alone or with a TKI
Examples (may also be known by their brand name)	sunitinib, pazopanib, cabozantinib, sorafenib, axitinib, lenvatinib	everolimus
Side effects	fatigue, mouth ulcers, changes in appetite, fevers, allergic reactions, skin rashes, diarrhoea, blood-clotting issues, blood pressure changes	diarrhoea, fatigue, skin rash, mouth sores, high blood sugar

Immunotherapy

There have been many advances in treating advanced kidney cancer with immunotherapy drugs known as checkpoint inhibitors. These use the body's own immune system to fight cancer.

Checkpoint inhibitors approved to treat advanced kidney cancer include ipilimumab and nivolumab. The drugs are usually given into a vein (intravenously). Taking these drugs together has been shown to work well as a first-line treatment for advanced kidney cancer. In people with advanced kidney cancer previously treated with a tyrosine kinase inhibitor, nivolumab has been shown to work well as a second-line treatment.

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 together with existing kidney cancer drugs, such as in combination with TKIs. Clinical trials are also testing new types of immunotherapy and targeted therapy drugs.

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

Side effects of immunotherapy

The side effects of immunotherapy can vary – not everyone will experience the same effects. Immunotherapy can cause inflammation in any of the organs of the body, leading to side effects such as fatigue, skin rash and diarrhoea. The inflammation can lead to more serious side effects in some people, but this will be monitored closely and managed quickly.

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 may also be used in advanced kidney cancer to shrink a tumour and relieve symptoms such as pain and bleeding (palliative treatment, see opposite page).

If you have radiation therapy, you will lie on a treatment table under a machine called a linear accelerator. The treatment is painless and takes only a few minutes. Each session usually lasts for 10–20 minutes. You will be able to go home once the session is over, and in most cases you can drive afterwards.

The total number of treatment sessions depends on your situation. You might have some temporary side effects, such as fatigue, nausea, loss of appetite, diarrhoea, tiredness and skin irritation. The radiation oncologist can talk to you about side effects you are likely to experience and give you advice about how to manage them.

› See our *Understanding Radiation Therapy* booklet.

Surgery

Surgery to remove kidney cancer that has spread is known as cytoreductive surgery. This can involve removing the primary cancer in the kidney by nephrectomy (see pages 26–31), or removing some or all of the tumours that have spread (metastasectomy).

Recent studies suggest that treatment with targeted therapy is as effective as targeted therapy combined with cytoreductive surgery.

Cytoreductive nephrectomy may be offered when the kidney cancer is causing symptoms, or when there is very little cancer spread outside the kidney. It can also be used in some people who have responded well to systemic treatment. Generally, surgery is not recommended if you are unwell or if the cancer has spread to many places in the body.

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 aims to meet your physical, emotional, cultural, spiritual and social needs.

As well as slowing the spread of cancer, palliative treatment can relieve pain and help manage other symptoms. Treatments may include radiation therapy, arterial embolisation (a procedure that blocks the blood supply to the tumour) to reduce blood in the urine, 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 lymph nodes or other parts of the body or come back after the initial treatment. It is known as stage 3 or 4.

Treatment goal

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

Systemic treatment

Systemic treatment uses 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 having treatment
- radiation therapy – shrinking the tumour if it is causing symptoms
- surgery – removing the primary kidney cancer (cytoreductive nephrectomy), and sometimes removing some or all of the cancer that has spread (metastasectomy)
- 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 medication – 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 Beyond Blue 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 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. 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, which will depend on the risk of the cancer coming back.

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. If the cancer recurs in the kidney (after a partial nephrectomy), 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 35–39).



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 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 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.



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	cancer.org.au
Cancer Council Online Community	cancercouncil.com.au/OC
Cancer Council podcasts	cancercouncil.com.au/podcasts
Cancer Australia	canceraustralia.gov.au
Carer Gateway	carergateway.gov.au
Department of Health	health.gov.au
eviQ Cancer Treatments Online	eviq.org.au
Healthdirect Australia	healthdirect.gov.au
Kidney Health Australia	kidney.org.au
Services Australia	servicesaustralia.gov.au

International

American Cancer Society	cancer.org
Cancer Research UK	cancerresearchuk.org
Macmillan Cancer Support (UK)	macmillan.org.uk
National Cancer Institute (US)	cancer.gov
International Kidney Cancer Coalition	ikcc.org



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.

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 Australia – Carers Australia provides information and advocacy for carers, and is the national peak body representing them to the Australian Government. Visit 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 and kidneys. Also known as the belly.

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 after the main treatment to lower the risk that the cancer will come back.

adrenal glands

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

advanced cancer

In most cases, the cancer has spread to other parts of the body (secondary or metastatic cancer). Treatment can often still control the cancer and manage symptoms.

alkaline phosphatase

An enzyme in the blood that helps break down proteins.

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.

arterial embolisation

Blocking the artery that supplies blood to a tumour.

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. A urinary catheter drains urine.

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 helping the immune system to recognise and attack the cancer.

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 with a wide needle.

cryotherapy

The process of inserting a probe into a tumour to freeze and destroy cancer cells.

CT scan

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

cystoscope

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

cystoscopy

A procedure using a cystoscope to see inside the urethra and bladder.

cytoreductive nephrectomy

Surgical removal of a kidney. This may be used when cancer has spread.

first-line treatment

The initial treatment used to target cancer.

grade

A score that describes how quickly a tumour is likely to grow.

haematuria

Blood in urine.

hormones

Chemicals in the body that send information between cells. Hormones control many of the body's functions, including how people grow, develop and reproduce.

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

A type of drug treatment that uses the body's own 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 using imaging.

intravenous

Injected into a vein.

keyhole surgery

Surgery done through small cuts in the body using a thin viewing instrument with a light and camera. Also known as minimally invasive surgery or laparoscopic surgery.

kidneys

A pair of organs in the abdomen that 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 keyhole surgery.

laparoscopic surgery

See keyhole surgery.

lymphatic system

A network of vessels, nodes and organs

that removes excess fluid from tissues, absorbs fatty acids, transports fat and produces immune cells. Includes the bone marrow, spleen, thymus and lymph nodes.

lymph nodes

Small bean-shaped structures that collect and destroy bacteria and viruses. Also called lymph glands.

malignant

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

medical oncologist

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

metastasectomy

Surgical removal of tumours that have spread from cancer that started in another organ in the body.

metastasis (plural: metastases)

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

MRI scan

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

mTOR inhibitors

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

nephrectomy

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

nephrectomy). In a radical nephrectomy, the fatty tissue around the kidney and sometimes the adrenal gland and nearby lymph nodes are removed too.

nephrologist

A doctor who specialises in diagnosing and treating kidney disease.

nephrons

The tiny parts of the kidney that filter blood and form urine.

observation

See active surveillance.

open surgery

A surgical method that involves one large cut (incision) in the body.

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.

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 particular person's disease.

prostate

A gland in the reproductive system. It is about the size of a walnut and 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 cell adenocarcinoma. It begins in cells lining small tubes in the nephrons. Types of RCC include clear cell, papillary and chromophobe.

renal pelvis

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

renal vein

A blood vessel that carries blood away from the kidney.

second-line treatment

Treatment that is given if the first-line treatment doesn't work or the disease comes back.

staging

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

stereotactic body radiation therapy (SBRT)

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

systemic treatment

Cancer drugs that spread throughout the whole body. Includes chemotherapy, targeted therapy and immunotherapy.

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 (not cancer) or malignant (cancer).

tyrosine kinase

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

tyrosine kinase inhibitor (TKI)

A targeted therapy drug that blocks the enzyme tyrosine kinase.

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 long, thin tubes that carry urine from the kidneys to the bladder.

urethra

The tube that carries urine from the bladder, as well as semen from the male's sex glands, to the outside of the body.

urinary system

The group of organs that removes waste from the blood and then from the body in the form of urine. It includes the kidneys, ureters, bladder and urethra.

urine

Liquid waste from the body. Also known as wee or pee.

urologist

A surgeon who specialises in treating diseases of the male and female

urinary systems and the male reproductive system.

urothelial carcinoma

Cancer that begins in the ureter or in the renal pelvis. Sometimes called transitional cell carcinoma (TCC).

urothelial cells

Cells that line parts of the urinary tract, such as where the kidney joins the ureter, the ureter itself, the bladder and 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.

vena cava

A large vein that carries blood to the heart.

Wilms tumour

A rare cancer that occurs almost exclusively in children.

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
- cancervic.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. 30, 2019, pp. 706–720.
2. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia*, AIHW, Canberra, 2020, viewed 17 August 2020, available from aihw.gov.au/reports/cancer/cancer-data-in-Australia/contents/summary.



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.

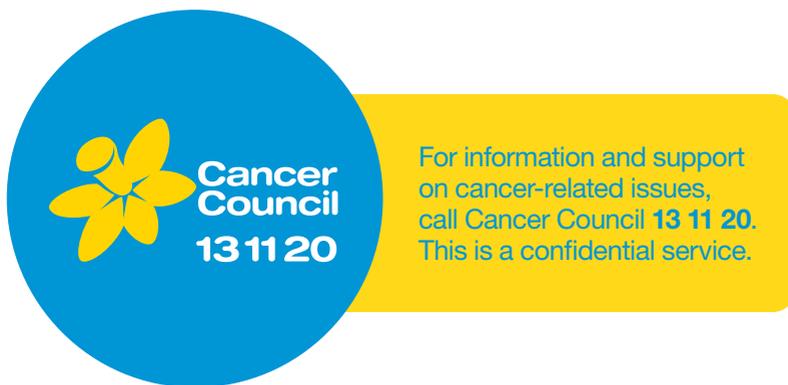
Cancer Council services and programs vary in each area.

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. communications.gov.au/accesshub/nrs



Visit your local Cancer Council website

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actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

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