Cancer Council

CANCER TYPE

Understanding
Kidney Cancer

A guide for people with cancer, their families and friends

For information & support, call **13 11 20**

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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 or call your local Cancer Council.

Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.

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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). (The term renal means related to the kidneys.)

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 also include information about support services.

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 or concerns, 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).

Contents

Key to icons

Icons are used throughout this booklet to indicate:

🔍 More information
❗ Alert
💬 Personal story
💡 Tips

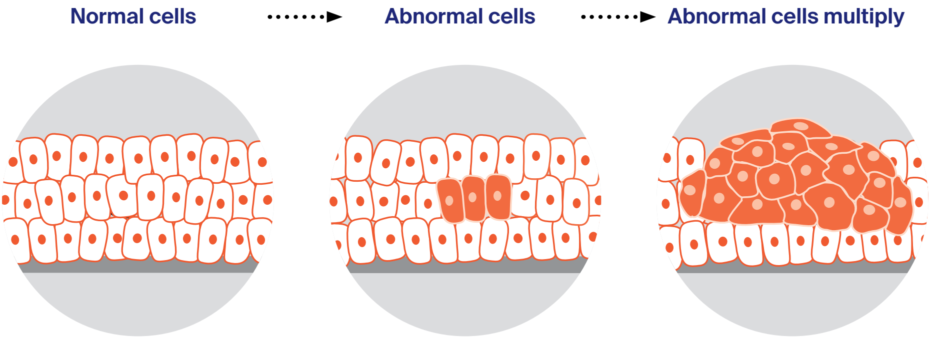
What is cancer?

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. These abnormal cells may turn into cancer.

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.

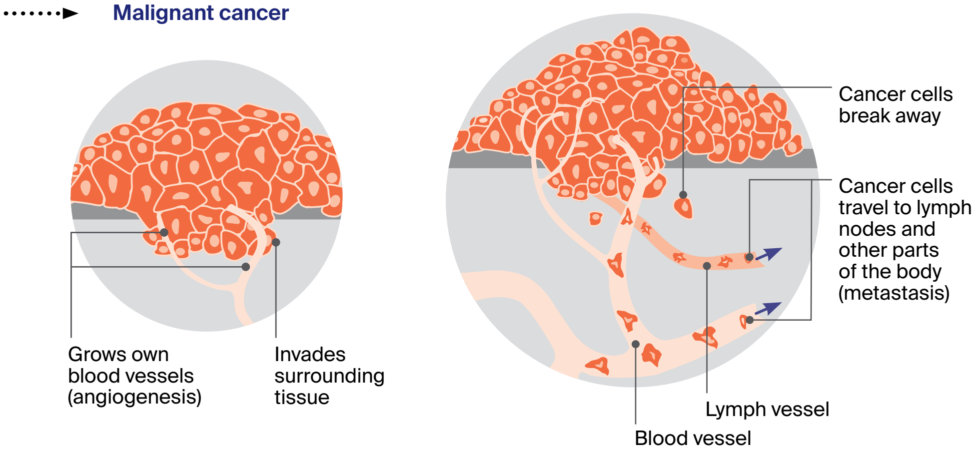
How cancer starts



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 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.

How cancer spreads


Malignant cancer

The kidneys

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

The kidneys are part of the body's urinary system, which also includes the:

- **ureters –** tubes that take urine from the kidneys to the bladder
- **bladder –** a hollow sac that stores urine (wee) until you need to urinate
- **urethra –** a tube that takes urine from the bladder to outside the body.

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.

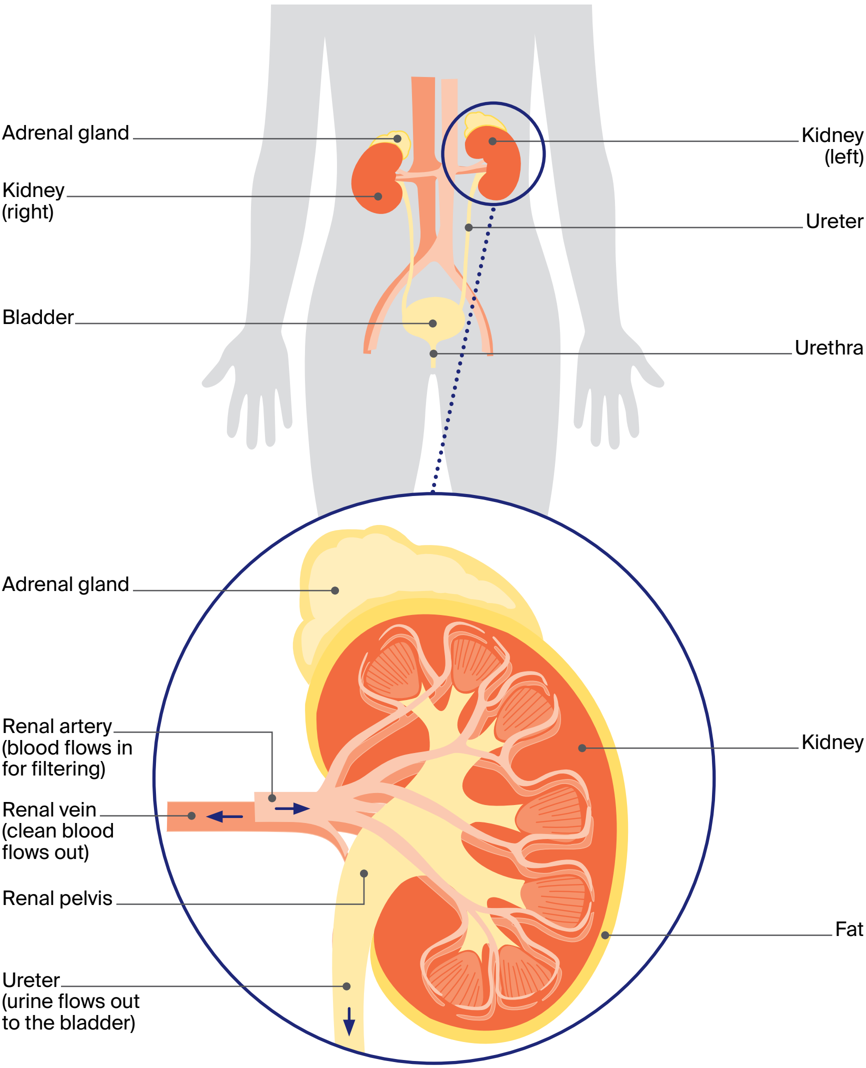
What the kidneys do

Filter blood – The main role of the kidneys is to filter and clean the blood. Blood flows through the renal artery into each kidney, where it is filtered through tiny networks of tubes called nephrons. The clean blood then flows out through the renal vein to the rest of the body.

Make urine – When the kidneys filter the blood, they remove excess water and waste products to make urine (wee or pee). The urine collects in an area of each kidney called the renal pelvis, and then flows through the ureters into the bladder.

Produce hormones – 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.

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 the tiny tubes found in the nephrons.

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, bones or brain.

Subtypes of renal cell carcinoma (RCC)

clear cell	• makes up about 75% of RCC cases • cancer cells look empty or clear
papillary	• makes up about 10–15% of RCC cases • cancer cells are arranged in finger-like fronds
chromophobe	• makes up about 5% of RCC cases • cancer cells are large and pale
other types of RCC	• 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 of kidney cancer?

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. It is also known as upper tract urothelial cancer.

▶ See our *Understanding Upper Tract Urothelial Cancer* fact sheet.

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 a primary cancer somewhere else in the body to the kidney. This is known as secondary cancer (metastasis). This secondary cancer is not kidney cancer and it behaves more like the primary cancer.

▶ See the Cancer Council booklet about the primary cancer.

This booklet is about RCC. Other less common types of cancer can start in the kidney, including some sarcomas and lymphomas. These types of cancer aren't included in this booklet. For more information, call Cancer Council 13 11 20.

Q: How common is kidney cancer?

A: Each year about 4500 Australians are diagnosed with kidney cancer. Men are twice as likely as women to be diagnosed with kidney cancer. It is the sixth most common cancer in men and the tenth most common cancer in women (excluding non-melanoma skin cancers). It is more common in people over 50, but it can occur at any age.[2]

“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 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. If symptoms occur, they usually include:

- blood in the urine (haematuria) or a change in urine colour – it may look red, dark, rusty or brown
- pain in the lower back or side not caused by injury
- a lump in the side or abdomen (belly)
- 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). If this affects blood production, it can 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 (belly) 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).

Q: What are the risk factors?

A: The exact cause of kidney cancer is not known. Research shows that people with certain risk factors are more likely to develop kidney cancer. Having a risk factor does not mean you will develop kidney cancer, and some people develop kidney cancer without having any known risk factors. If you are concerned, talk to your doctor.

Risk factors for kidney cancer include:

- **smoking –** people who smoke have almost twice the risk of developing kidney cancer as those who don't smoke. About 1 in 3 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, hereditary leiomyomatosis RCC, tuberous sclerosis, and Lynch syndrome.

If you are worried about your family history or whether you have inherited a particular syndrome, talk to your doctor about having regular check-ups or ask for a referral to a family cancer clinic. To find out more, call Cancer Council 13 11 20.

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*	diagnoses and treats diseases of the urinary system, 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 your 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 MDT, 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	helps with nutrition concerns and recommends changes to diet 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 quality of life

* *Specialist doctor*

Diagnosis

Most kidney cancers are found by chance 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 full blood count to check the levels of red blood cells, white blood cells and platelets
- tests to check how well your kidneys are working
- blood chemistry tests to measure the levels of certain substances in the blood (e.g. high levels of the enzyme alkaline phosphatase could be a sign that kidney cancer has spread to the bones).

Imaging scans

Various imaging scans can create pictures of the inside of your body and provide different types of information. You will usually have at least one of the following imaging scans.

Ultrasound – An ultrasound uses soundwaves to create pictures of your internal organs. These might show if there is a tumour in your kidney. During an ultrasound, you will lie on a bench and uncover your abdomen (belly) or back. A cool gel will be spread on your skin, and a small handheld device called a transducer will be moved across the area. The transducer creates soundwaves that echo when they meet something solid, such as an organ or tumour. A computer turns the soundwaves into a picture. An ultrasound scan is painless and usually takes 15–20 minutes.

CT scan – A CT (computerised tomography) scan uses x-ray beams and a computer to create a detailed picture of the inside of the body. 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.

During the scan, you will need to lie still on a table that moves in and out of the scanner, which is large and round like a doughnut. This painless test takes about 30–40 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 or breastfeeding.

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. Most people with kidney cancer won't 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 or any other metallic object in your body. If you do, you may not be able to have an MRI scan, although some newer devices are safe to go into the scanner. Before the MRI, you may be injected with a dye to help make the pictures clearer. 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 takes between 30 and 90 minutes.

Radioisotope bone scan – Also called a nuclear medicine bone scan or simply a bone scan, this scan can show if kidney cancer has spread to your bones. It's used only if you have bone pain or if blood tests show high levels of alkaline phosphatase. If cancer is found in the bones, the scan can also be used to check how the cancer is responding to treatment.

Before the scan, a tiny amount of a radioactive substance is injected into a vein. The substance collects in areas of abnormal bone growth. You will need to wait for a few hours while it moves through your bloodstream to your bones. Your body will be scanned with a machine that detects radiation. A larger amount of the substance will usually show up in any areas of bone with 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 after your scan. 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, so most people don't need one.

Looking inside your bladder, ureters or kidneys

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) or kidneys (pyeloscopy).

You will have an anaesthetic before these procedures. This will usually be a local anaesthetic for a cystoscopy and a general anaesthetic before a ureteroscopy or pyeloscopy.

For a few days after these tests you may see some blood in your urine and feel mild discomfort when urinating. These procedures help rule out urothelial carcinoma, which can start in the bladder, a ureter or part of the kidney. They may not be needed if imaging scans have found a kidney tumour.

▶ See our *Understanding Bladder Cancer* booklet and *Upper Tract Urothelial Cancer* fact sheet.

Tissue biopsy

A biopsy is when doctors remove a sample of cells or tissue from an area of the body. It is a common way to diagnose cancer, but it is not always needed for kidney cancer before treatment. For many people with kidney cancer, the main treatment is surgery (see pages 26–31). In this case, the tissue removed during surgery is tested to confirm that it is cancer.

A biopsy may be done before treatment when:
- it is uncertain if the tumour is cancerous or benign
- alternative treatments (such as ablative therapy, active surveillance or radiation therapy) are recommended – a biopsy will help work out what other treatment is needed
- it appears that the cancer has spread beyond the kidney and a biopsy will be helpful to guide systemic drug therapy (see pages 35–37).

If a biopsy is done, it will be a core needle biopsy. 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 but you may need to rest for a few hours before you can go home. You may also have some discomfort or notice some blood in your urine.

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). Small benign kidney growths, including oncocytoma and angiomyolipoma, may not need treatment. If they do, it may be similar to the treatment for early kidney cancer.

Grading kidney cancer

By examining a sample of kidney tissue, doctors can see how similar the cancer cells look to normal cells and estimate how fast the cancer is likely to grow. This is called grading.

Grading helps the doctors decide what follow-up treatment you might need and whether to consider a clinical trial (see page 24).

In Australia, both the Fuhrman system and the newer International Society of Urological Pathology (ISUP) system may be used to grade kidney cancer.

Both systems grade kidney cancer from 1 to 4, with grade 1 the lowest and grade 4 the highest. As the grade increases, the cancer cells look less similar to normal cells. Higher-grade cancers tend to be more aggressive than lower-grade cancers.

Staging kidney cancer

The stage of a cancer describes how large it is, where it is, and whether it has spread beyond the kidney. 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 14–18 to assign a stage of 1 to 4 (see the box on the next page for more detail):

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

How kidney cancer is staged

The most common staging system for kidney cancer is the TNM system, which 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, but has not spread outside the kidney.	early
stage 3	The cancer is any size and has spread to the major kidney veins, into the fat around the kidney, or to nearby lymph nodes.	locally advanced
stage 4	The cancer has spread to surrounding tissue outside the kidney, to the adrenal gland or to more distant parts of the body (such as the distant lymph nodes, the liver, lungs, bone or brain).	advanced (metastatic)

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 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 for some time.

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.

Preparing for treatment

Talk with your doctors about whether you need to do anything to prepare for treatment and help your recovery.

They may suggest that you exercise, eat a healthy diet or drink less alcohol. You may also find it helpful to talk to a counsellor about how you are feeling.

If you smoke, you will be encouraged to stop. Research shows that quitting smoking before surgery reduces the chance of complications. To work out a plan for quitting, talk to your doctor or call the Quitline on 13 7848.

Preparing for treatment in this way – called prehabilitation – may improve your strength, help you cope with treatment side effects and improve the results of treatment.

Key points about diagnosing kidney cancer

What it is	The main type of kidney cancer is renal cell carcinoma (RCC). Subtypes 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. • Some people have a core needle biopsy to take a tissue sample from the kidney.
Key information about the cancer	• The grade describes how similar the cancer cells look to normal cells. Higher-grade cancers are more likely to spread outside the kidney. • The stage shows how far the cancer has spread throughout the body. Early kidney cancer has not spread outside the kidney (stages 1 and 2). Advanced kidney cancer has spread outside the kidney (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, as it may not 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 says you have cancer, you may not remember everything you are told. Taking notes can help. If you would like to record the discussion, ask your doctor first. 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. The main treatment for early kidney cancer is surgery (see pages 26–31). Less often, thermal 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

Your doctor may suggest monitoring the cancer closely rather than starting treatment. This approach is known as active surveillance. The aim is to maintain kidney function and avoid unnecessary treatment, while looking for changes that mean treatment should start.

Active surveillance may be suggested if the tumour is less than 4 cm in size. It 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 14–15). If these imaging tests suggest that the tumour has grown, you may be offered active treatment (usually surgery). Ask your doctor how often you need check-ups.

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 19–20), and your general health, you might have surgery to remove part or all of a kidney.

Partial nephrectomy – This removes the cancer and a small part of the surrounding tissue, leaving some healthy tissue in the affected kidney. This operation may be recommended for tumours smaller than 7 cm that are in the kidney only. It may also be used for people who have existing kidney disease, cancer in both kidneys, or only one working kidney.

A partial nephrectomy is a more complex operation than a radical nephrectomy. Whether it is possible depends on where the tumour is in the kidney, as well as the expertise of the surgeon and hospital.

Radical nephrectomy – 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. This is the most common operation for large tumours.

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.

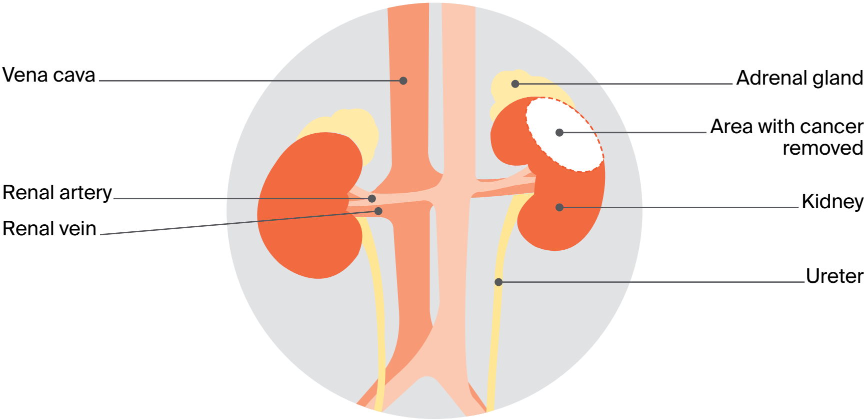
The remaining kidney – If a whole kidney or part of a kidney is removed, the remaining kidney usually does the work of both kidneys. Your doctor will talk to you about how to keep the remaining kidney healthy, which may include taking steps to reduce your risk of high blood pressure, heart problems and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

Types of surgery

◌ **Area removed**

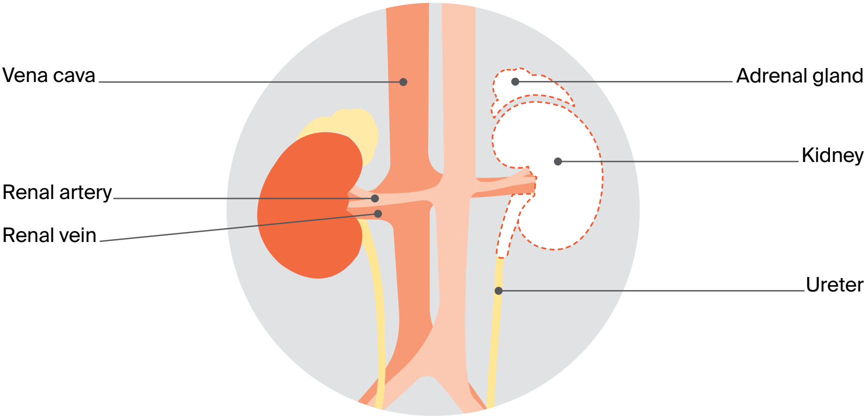
Partial nephrectomy

Removes part of the kidney



Radical nephrectomy

Removes the whole kidney and some surrounding tissue



How the surgery is done

If you have surgery for kidney cancer, it will be carried out in hospital. A nephrectomy is a major operation and you will be given drugs (general anaesthetic) to put you to sleep and temporarily block any pain or discomfort during the surgery.

One of the following methods will be used to remove part or all of the kidney (partial or radical nephrectomy). The method recommended for you will depend on the size and location of the tumour and your general health. Your surgeon will talk to you about the risks of the procedure.

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 a few small cuts in the skin, then insert a tiny instrument with a light and camera (laparoscope) into one of the cuts. The surgeon inserts tools into the other cuts to remove the cancerous tissue or kidney, using images from the camera as a guide.

Robot-assisted surgery – This is a type of keyhole surgery performed with help from a robotic system. The surgeon sits at a control panel to see a 3-dimensional picture and moves robotic arms that hold the instruments. Robotic surgery has meant that more partial nephrectomies can be performed with keyhole surgery, reducing complications and improving recovery time.

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 2 weeks and was back to driving in 3 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.

Making decisions about surgery

Talk to your surgeon about the types of surgery suitable for you. Ask about the advantages and disadvantages of each method. There may be extra costs involved for some procedures and they are not all available at every hospital.

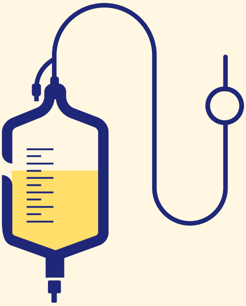
Compared to open surgery, both keyhole (laparoscopic) surgery and robot-assisted surgery usually mean a shorter hospital stay, less pain and a faster recovery time. But in some cases, open surgery may be a better option.

▸ See our *Understanding Surgery* booklet.

What to expect after surgery

After a nephrectomy, you will usually be in hospital for 2–7 days, but it can take 6–12 weeks to fully recover.

Drips and tubes



While in hospital, you will be given fluids and medicines through 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 flexible 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. When the catheter is removed, you will be able to urinate normally again.

Pain relief

You will have some pain and discomfort for several days after kidney surgery. This will be managed with pain medicines. You may be given tablets or injections, or you may have patient-controlled analgesia (PCA), which delivers a measured dose of pain medicine through a drip when you press a button. If you still have pain, let your doctor or nurse know so they can change your medicine as needed.

Blood clots

You will usually have to wear compression stockings to help the blood in your legs circulate and prevent blood clots developing. Depending on your risk of clotting, you may be given daily injections of a blood-thinning medicine.

Your recovery time will depend on the type of surgery you had, your age and general health. Once you are home, you will need to take some precautions.

Moving around

Your health care team will probably encourage you to walk the day after the surgery. A physiotherapist may explain how to move safely and show you exercises to do while you are recovering. Doing breathing or coughing exercises can help you avoid developing a chest infection.

It will be some weeks before you can lift heavy things, reach your arms overhead 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.

To help your body recover from surgery, try to eat a balanced diet (including proteins such as lean meats and poultry, fish, eggs, milk, yoghurt, nuts, seeds, and legumes such as beans).

Check-ups

You will need to visit your surgeon for a check-up a few weeks after you've returned home. You will usually leave the hospital with the details of your appointment. If you haven't been given an appointment time, check with your surgeon's rooms.

Other treatments

If surgery is not the best approach, other treatments may be recommended to destroy or control early kidney cancer.

Thermal ablation – This procedure uses heat to destroy small tumours. The heat may come from radio waves (radiofrequency ablation or RFA) or microwaves (microwave ablation or MWA). 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. The needle delivers either radio waves or microwaves into the tumour.

Thermal ablation is usually done under general anaesthetic in the x-ray department or the operating theatre. The procedure itself 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. You may have some bleeding or leakage of urine afterwards.

Stereotactic body radiation therapy (SBRT) – This specialised form of radiation therapy is also called stereotactic ablative body radiation therapy (SABR). It is a way of giving a highly focused dose of radiation therapy to an early kidney cancer when surgery is not possible. If you have SBRT, you will lie on a treatment table under a machine that directs radiation beams from outside the body to the kidney. SBRT is painless and is usually delivered over 1–3 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 many weeks until you can do your usual activities.
Other treatment options	Other options for early kidney cancer may include: • active surveillance – involves watching the cancer carefully through regular check-ups before starting treatment if the tumour changes • thermal ablation – 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 delivered from outside the body to destroy or damage cancer cells.

Treatment for advanced kidney cancer

When kidney cancer has invaded the major kidney veins or spread to nearby lymph nodes (stage 3 or locally advanced), you may still be able to have surgery to remove the tumour (see pages 26–31).

If kidney cancer has spread outside the kidney to other parts of the body (stage 4 or metastatic), treatment usually aims 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 things, including how soon after diagnosis you start systemic treatment (see opposite page), as well as your blood counts, blood calcium levels and general health.

Active surveillance

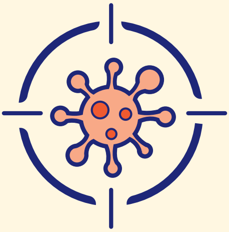
In some cases, kidney cancer grows so slowly that it won't cause any problems for a long time. Because of this, especially if the advanced kidney cancer has been found unexpectedly, your doctor may suggest looking at the cancer regularly, usually with CT scans (see page 15). This approach is known as active surveillance.

If the cancer starts to grow quickly or cause symptoms, your doctor may recommend active treatment.

Speaking to a counsellor about your feelings and individual situation can be helpful. You can also call Cancer Council 13 11 20 to talk to a health professional about your concerns.

Having systemic treatment

Drugs can reach cancer cells throughout the body. This is called systemic treatment.



Controlling kidney cancer

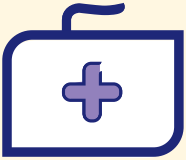
Targeted therapy and immunotherapy are the main types of systemic treatment used to control advanced kidney cancer (see next 2 pages). Chemotherapy is rarely used for kidney cancer these days. The types of drugs and combinations used are rapidly changing as clinical trials show better responses and improved survival with newer drugs.

Accessing new drugs

Talk with your doctor about the latest developments and whether you are a suitable candidate. You may also be able to get other drugs through clinical trials (see page 24).

Cost of drugs

The Pharmaceutical Benefits Scheme (PBS) subsidises the cost of some 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.



Reporting side effects

Your doctors will explain the possible side effects of the different drugs. It is important to tell your treatment team about any side effects you have from drug therapies. Side effects can be better managed when they are reported early. If left untreated, some can become life-threatening.

Targeted therapy

This is a type of drug treatment that attacks specific features of cancer cells to stop the cancer growing and spreading. Targeted therapy drugs are used as the first treatment for advanced kidney cancer (first-line treatment), often in combination with immunotherapy drugs (see opposite page).

These drugs are usually taken daily as tablets. They may be taken for many months and sometimes even years. There are different drugs available and your medical oncologist will discuss which combination of drugs is best for your situation.

Cancer cells often stop responding to targeted therapy drugs over time. If the first-line treatment stops working, your oncologist may suggest trying another targeted therapy or an immunotherapy drug.

Side effects of targeted therapy

The side effects of targeted therapy will vary depending on the drug used. Common side effects include fatigue, skin rash, mouth sores, nausea, diarrhoea, joint pain and high blood pressure.

Managing side effects of drug therapies

Your doctor may be able to prescribe medicine to prevent or reduce side effects of targeted therapy and immunotherapy drugs. In some cases, your doctor may delay treatment or reduce the dose to lessen side effects.

For more information, see our *Understanding Targeted Therapy* and *Understanding Immunotherapy* fact sheets. You may also find our podcast episode “New Cancer Treatments – Immunotherapy and Targeted Therapy” helpful.

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 may be used at different stages of advanced kidney cancer:
- as the first-line treatment for advanced kidney cancer, either on their own or in combination with targeted therapy drugs
- as a second-line treatment when targeted therapy has stopped working
- as long-term treatment to try to control the cancer's growth (maintenance treatment).

The drugs are usually given into a vein through a drip (intravenously) and the treatment is repeated every 2–6 weeks. How many infusions you have depends on how you respond to the drug and whether you have any side effects. You may keep having the drugs for many months and sometimes even years.

The drugs used for kidney cancer are rapidly changing as clinical trials test newer drugs. Your medical oncologist will discuss which combination of drugs is best for your situation.

Side effects of immunotherapy

The side effects of immunotherapy can vary – not everyone will react in the same way. Immunotherapy can cause inflammation in any of the organs of the body. This can cause side effects such as fatigue, skin rash, joint pain 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

Also known as radiotherapy, radiation therapy uses a controlled dose of radiation to kill or damage cancer cells. Conventional external beam radiation therapy may be used if you are not able to have surgery. It may also be used in advanced kidney cancer to shrink a tumour and relieve symptoms such as pain and bleeding (palliative treatment, see next page).

Some people may have stereotactic body radiation therapy (SBRT) to treat some or all of the tumours that have spread. This may be offered when the cancer has spread to only a few places outside the kidney.

If you have radiation therapy, you will lie on a treatment table under a machine called a linear accelerator. The machine directs radiation beams from outside the body to the kidney. The treatment is painless and takes only a few minutes.

The total number of treatment sessions depends on your situation. 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.

Side effects – 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 possible side effects and ways to manage them.
▸ See our *Understanding Radiation Therapy* booklet.

Surgery

Surgery to remove kidney cancer that has spread is known as cytoreductive surgery. Generally, surgery is not recommended if you are unwell or if the cancer has spread to many places in the body.

Two types of cytoreductive surgery may be possible in some situations:

- **nephrectomy –** to remove the primary cancer in the kidney (see pages 26–29). This 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
- **metastasectomy –** to remove some or all of the tumours that have spread. This may be offered when the cancer has spread to only a few places outside the kidney.

Palliative treatment

In some cases of advanced kidney cancer, the medical team may talk to you about palliative treatment. This is treatment that aims to slow the spread of cancer and relieve symptoms without trying to cure the disease. You might think that palliative treatment is only for people at the end of their life, but it may help at any stage of advanced cancer. It is about living for as long as possible in the most satisfying way you can.

Treatments given palliatively for advanced kidney cancer may include radiation therapy, arterial embolisation (a procedure that can reduce blood in the urine by blocking the blood supply to the tumour), targeted therapy or immunotherapy.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aims to meet your physical, emotional, practical, cultural, social and spiritual needs. The team also provides support to families and carers.

▶ See our *Living with Advanced Cancer* and *Understanding Palliative Care* booklets.

Key points about advanced kidney cancer

What it is	Advanced kidney cancer is cancer that has spread from the kidney to the major kidney veins, 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 in the kidney if it is causing symptoms or, sometimes, causing some or all of the tumours that have spread to disappear • 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 for People Living with 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, may prevent successful treatment of the cancer and can be harmful. 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 whether any financial assistance is available to you by asking a social worker at your hospital or treatment centre or calling Cancer Council 13 11 20.
▸ 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. The experience of cancer 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 kidney 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, because counselling or medication – even for a short time – may help. Some people can get a Medicare rebate for sessions with a psychologist. 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 have regular appointments 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 3 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 6-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 by location.

Cancer Council 13 11 20

Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

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.

Information resources

Cancer Council produces booklets and fact sheets on more than 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.

Practical help

Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

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**
Guides to Best Cancer Care	**cancer.org.au/cancercareguides**
Cancer Australia	**canceraustralia.gov.au**
Carer Gateway	**carergateway.gov.au**
Department of Health and Aged Care	**health.gov.au**
eviQ Cancer Treatments Online	**eviq.org.au**
Healthdirect Australia	**healthdirect.gov.au**
Kidney Health Australia	**kidney.org.au**
Services Australia (including Centrelink and Medicare)	**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. 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, liver, bowel and kidneys. Also known as the belly.

active surveillance
When a person does not receive immediate treatment, but instead has the kidney cancer monitored regularly, with the option of future treatment if the cancer starts growing faster.

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

advanced cancer
Cancer that is unlikely to be cured. 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. High levels can indicate that cancer has spread to the bones.

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
Blocks the artery supplying 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 perform different functions.

checkpoint inhibitor
A drug that allows 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 approaches.

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

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

cryotherapy (cryosurgery)
The process of inserting a probe into a tumour to freeze and destroy cancer cells.

CT (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 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 surgery
Surgery to reduce the number of cancer cells in the body. May remove the kidney, lymph nodes or other tissue cancer has spread to.

first-line treatment
The first 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.

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 regulate blood pressure, trigger the production of red blood cells 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.

locally advanced cancer
Cancer that has spread to nearby organs or blood vessels.

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 found in groups throughout the body. They help protect the body against disease and infection.

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

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.

microwave ablation (MWA)
A treatment that uses microwaves to heat and destroy cancer cells.

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

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

nephrologist
A doctor who specialises in diagnosing and treating kidney disease.

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

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 symptoms. 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.

Pharmaceutical Benefits Scheme (PBS)
A government-funded scheme that subsidises some prescription medicines.

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 male reproductive system. 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 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
Surgical removal of a whole kidney and the fatty tissue around it. The adrenal gland and nearby lymph nodes may also be removed.

radiofrequency ablation (RFA)
A treatment that uses radio waves to heat and destroy cancer cells.

radioisotope bone scan
A scan using small amounts of a radioactive liquid to find areas of bone with cancer.

renal
Related to the kidneys.

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 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 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 type of radiation therapy that delivers high doses of precise radiation. 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 features of cancer cells to stop a cancer growing and spreading.

thermal ablation
Treatment that uses extreme temperatures (thermal) to destroy cancer cells without actually removing them from the body.

tumour
A new or abnormal growth of tissue on or in the body. A tumour may be benign (not cancer) or malignant (cancer).

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

ureteroscopy
A procedure 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 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.

urothelial carcinoma
Cancer that begins in the bladder, 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 kidney cancer that occurs almost exclusively in children. Also known as nephroblastoma.

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
- cancervic.org.au/glossary.

Notes

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. 706–20 (as amended up to T Powles et al. on behalf of the ESMO Guidelines Committee, “ESMO Clinical Practice Guideline update on the use of immunotherapy in early stage and advanced renal cell carcinoma”, *Annals of Oncology*, vol. 32, 2021, pp. 1511–19).
2. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia 2022*, AIHW, Canberra, viewed 20 July 2022, available from aihw.gov.au/reports/cancer/cancer-data-in-Australia.

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 experienced health professionals 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.

If you need information in a language other than English, an interpreting service is available. Call 131 450.

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

Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).

For information & support
on cancer-related issues,
call Cancer Council 13 11 20

Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
cancer.org.au/nt

Cancer Council Queensland
cancerqld.org.au

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