



# Understanding Kidney Cancer

A guide for people with cancer,  
their families and friends

Cancer  
information

For information & support, call

**13 11 20**



## Understanding Kidney Cancer

A guide for people with cancer, their families and friends

First published June 2001. This edition November 2016.

© Cancer Council Australia 2016. ISBN 978 1 925136 25 8

*Understanding Kidney Cancer* is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

Editor: Jenni Bruce. Designer: Eleonora Pelosi. Printer: SOS Print + Media Group.

### Acknowledgements

This edition has been developed by Cancer Council NSW on behalf of all other state and territory Cancer Councils as part of a National Publications Working Group initiative.

We thank the reviewers of this booklet: Dr Craig Gedye, Medical Oncologist, Calvary Mater Hospital, Newcastle, and Senior Conjoint Lecturer, School of Biomedical Sciences and Pharmacy, The University of Newcastle, NSW; Gregory Bock, Urology Cancer Nurse Coordinator, WA Cancer and Palliative Care Network, WA; A/Prof Declan Murphy, Urologist, Chair of Uro-Oncology and Director of Robotic Surgery, Peter MacCallum Cancer Centre, VIC; Caitriona Nienaber, 13 11 20 Consultant, Cancer Council WA, WA; Jodie Turpin, Consumer.

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](http://cancer.org.au) or call your local Cancer Council.



### Cancer Council Australia

Level 14, 477 Pitt Street, Sydney NSW 2000

**Telephone** 02 8063 4100 **Facsimile** 02 8063 4101

**Email** [info@cancer.org.au](mailto:info@cancer.org.au) **Website** [cancer.org.au](http://cancer.org.au)

ABN 91 130 793 725

# Introduction

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 cancer in their kidney. 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, we hope this information will answer some of your questions and help you think about other questions to ask your treatment team.

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. You may also like to pass this booklet to your family and friends for their information.

## How this booklet was developed

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

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. Turn to the last page of this book for more details.



**Cancer  
Council  
13 11 20**

# Contents

<b>What is cancer?</b> .....	<b>4</b>
<b>The kidneys</b> .....	<b>6</b>
<b>Key questions</b> .....	<b>8</b>
What is the main type of kidney cancer? .....	8
Are there other types? .....	9
How common is kidney cancer? .....	9
What are the symptoms of kidney cancer? .....	10
What are the risk factors? .....	11
Which health professionals will I see? .....	12
<b>Diagnosis</b> .....	<b>14</b>
Imaging scans .....	14
Tissue biopsy .....	18
Grading kidney cancer .....	19
Staging kidney cancer.....	20
Prognosis .....	20
<b>Making treatment decisions</b> .....	<b>23</b>
Talking with doctors .....	23
A second opinion .....	24
Taking part in a clinical trial .....	24
<b>Treatment for early kidney cancer</b> .....	<b>25</b>
Active surveillance.....	25
Surgery .....	26
Other treatments .....	32

**Treatment for advanced kidney cancer..... 34**

Active surveillance..... 34  
Surgery ..... 35  
Targeted therapy..... 35  
Immunotherapy ..... 37  
Radiotherapy ..... 38  
Palliative treatment ..... 38

**Looking after yourself ..... 41**

Relationships with others ..... 42  
Sexuality, intimacy and fertility ..... 42  
Life after treatment ..... 43

**Seeking support ..... 46**

Practical and financial help ..... 46  
Talk to someone who's been there ..... 46

**Caring for someone with cancer ..... 48**

**Useful websites ..... 49**

**Question checklist..... 50**

**Glossary ..... 51**

**How you can help..... 56**



# What is cancer?

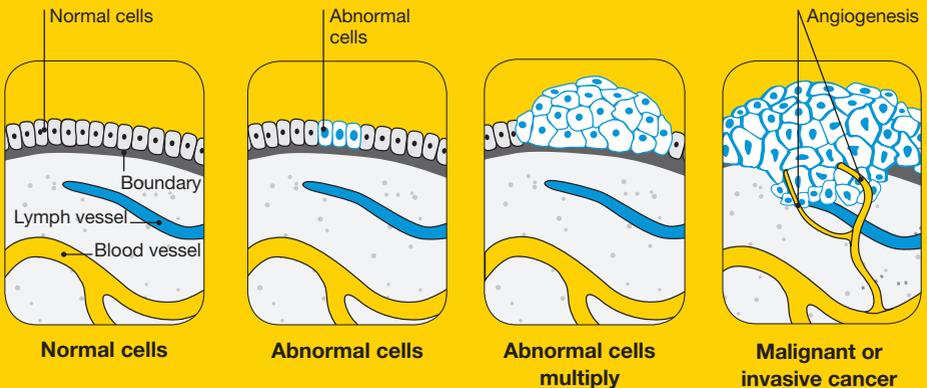
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

Sometimes cells don't grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

**Benign tumour** – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

**Malignant tumour** – This is made up of cancerous cells, which have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid).

## How cancer starts



The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised or early cancer. A tumour may invade deeper into surrounding tissue and can grow its own blood vessels, a process known as angiogenesis.

If cancerous cells grow and form another tumour at a new site, it is called a secondary cancer, advanced 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 person may be experiencing symptoms caused by problems in the lungs.

## How cancer spreads

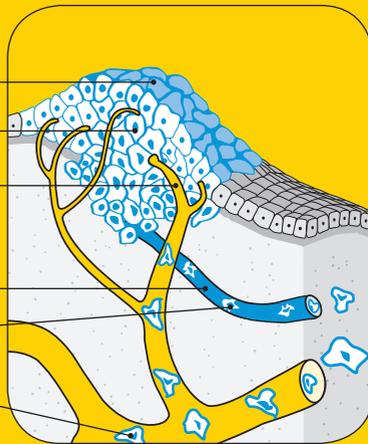
Primary cancer

Local invasion

Angiogenesis –  
tumours grow their  
own blood vessels

Lymph vessel

Metastasis –  
cells invade other  
parts of the body via  
blood vessels and  
lymph vessels





# The kidneys

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

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

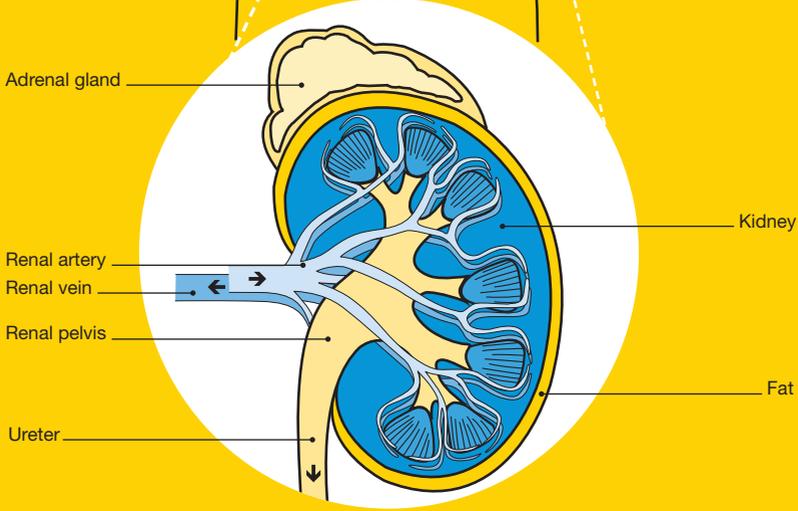
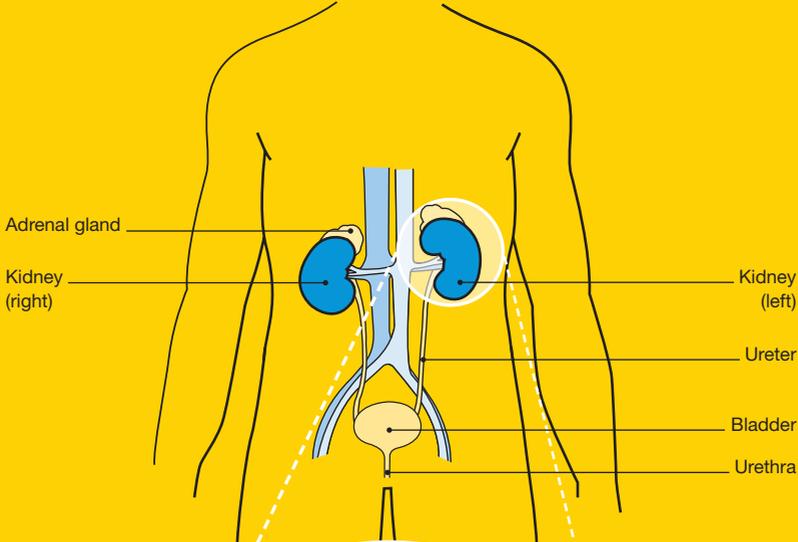
**The urinary system** – The kidneys are part of the body's urinary system. When they filter the blood, they remove excess water and waste products and turn these into urine. Urine travels from each kidney into a funnel called the renal pelvis, then through a tube called the ureter, and into the bladder.

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

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

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

# The urinary system





# Key questions

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

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

In the early stages of RCC, the primary cancer forms a tumour that is confined to the kidney. In almost all cases, only a single kidney is affected, but in rare cases, both can be affected. As the cancer grows, it may invade structures near the kidney, such as the surrounding fatty tissue, veins, adrenal glands, ureters or the liver. It might 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 renal cell carcinoma, based on the way the cells look under the microscope. The most common RCC is clear cell carcinoma.

<b>Clear cell carcinoma</b>	<ul style="list-style-type: none"><li>• makes up about 75% of RCC cases</li><li>• cancer cells look empty or clear</li></ul>
<b>Papillary renal cell carcinoma</b>	<ul style="list-style-type: none"><li>• makes up about 10–15% of RCC cases</li><li>• cancer cells are arranged in finger-like fronds</li></ul>
<b>Chromophobe renal cell carcinoma</b>	<ul style="list-style-type: none"><li>• makes up about 5% of RCC cases</li><li>• cancer cells are large and pale</li></ul>
<b>Other types of RCC</b>	<ul style="list-style-type: none"><li>• include renal medullary carcinoma, collecting duct carcinoma, XP11 translocation RCC, sarcomatoid RCC and other very rare types</li><li>• together make up about 5–10% of RCC cases</li></ul>

## Q: Are there other types?

**A:** RCC is the most common type of kidney cancer, but there are other types. An uncommon type is 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. For more information, call 13 11 20 for a free copy of *Understanding Bladder Cancer*, or download a digital version from your local Cancer Council website.

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

The most common type of kidney cancer in younger children is called Wilms tumour (or nephroblastoma), but this is still a rare cancer. Visit Cancer Australia's website at [childrenscancer.canceraustralia.gov.au](http://childrenscancer.canceraustralia.gov.au) for more information.

## Q: How common is kidney cancer?

**A:** More than 3000 Australians are diagnosed with kidney cancer each year. It makes up about 2.5% of all cancers and is the 10th most common cancer in Australia. The risk of kidney cancer increases with age, and it is rare in people under 40. Men are almost twice as likely to be diagnosed with kidney cancer as women are.<sup>2</sup>

## Q: What are the symptoms of kidney cancer?

- A:** Most people with kidney cancer have no symptoms and many are diagnosed with the disease when they see a doctor for an unrelated reason. Symptoms can, however, include:
- blood in the urine (haematuria) – this may be obvious or the urine may just look dark, rusty or brown
  - pain in the lower back or side not caused by injury
  - a lump in the abdomen
  - constant tiredness
  - unexplained weight loss
  - fever (not caused by a cold or flu).

Cancer can affect the kidneys' production of hormones (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 blood calcium (hypercalcaemia). Sometimes these problems can cause symptoms such as fatigue, dizziness, headaches, constipation, abdominal pain, and depression.

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

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

## Q: What are the risk factors?

**A:** Several factors may increase the risk of a person developing kidney cancer:

- **Smoking** – People who smoke have almost twice the risk of developing kidney cancer as nonsmokers. Up to one-third of all kidney cancers are thought to be related to smoking.
- **Obesity** – Excess body fat may cause changes in certain hormones that can lead to kidney cancer.
- **High blood pressure** – Whether it is caused by being overweight or another medical condition, high blood pressure increases the risk of kidney cancer.
- **Kidney failure** – People with end-stage kidney disease have a higher risk of developing kidney cancer.
- **Family history** – People who have family members with kidney cancer, especially a sibling, are at increased risk.
- **Inherited conditions** – About 3–5% of kidney cancers occur in people with particular inherited syndromes, including von Hippel-Lindau disease, hereditary papillary RCC and Birt-Hogg-Dubé syndrome.
- **Exposure to toxic substances at work** – The risk may be higher after regular exposure to certain chemicals, such as some metal degreasers, arsenic or cadmium.

## Q: Which health professionals will I see?

**A:** Your general practitioner (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.

### MDT health professionals

<b>GP</b>	assists you with treatment decisions and works in partnership with your specialists in providing ongoing care
<b>urologist*</b>	specialises in treating diseases of the male and female urinary system and the male reproductive system; performs surgery
<b>nephrologist*</b>	specialises in caring for people with conditions that cause kidney (renal) failure or impairment; may be consulted by your urologist when planning surgery
<b>medical oncologist*</b>	specialises in treating cancer with drug therapies such as targeted therapy, immunotherapy and chemotherapy
<b>radiation oncologist*</b>	prescribes and coordinates the course of radiotherapy
<b>interventional radiologist*</b>	uses imaging scans to diagnose cancer, may perform a biopsy under ultrasound or CT, and delivers some treatments

If kidney cancer is diagnosed, the specialist will advise you about treatment options. You will then be cared for by a range of other health professionals who specialise in different aspects of your treatment. This is called a multidisciplinary team (MDT) and it may include some or all of the health professionals listed below.

<b>cancer care coordinator or clinical nurse consultant (CNC)</b>	coordinates your care, liaises with other members of the MDT and supports you and your family throughout treatment
<b>nurses</b>	administer drugs and provide care, information and support throughout your treatment
<b>physiotherapist, occupational therapist</b>	assist with physical and practical problems, including restoring a range of movement after surgery
<b>dietitian</b>	recommends an eating plan to follow while you are in treatment and recovery
<b>social worker</b>	links you to support services and helps you with emotional or practical issues
<b>psychologist, counsellor</b>	provide emotional support and help manage any feelings of depression and anxiety

\* Specialist doctor



# Diagnosis

Most kidney cancers are found unexpectedly – for example, when people have an ultrasound or scan for symptoms that turn out to be unrelated. If your doctor suspects kidney cancer, you may have some of the following tests, but you are unlikely to need all of them.

You will probably have urine and blood tests to check for changes that could be caused by kidney cancer, but these tests cannot provide a definite diagnosis. The main tests for diagnosing kidney cancer are imaging scans (see below) and tissue sampling (biopsy, see pages 18–19). Sometimes the doctor will also recommend an internal examination of the bladder (cystoscopy, see page 18).

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

## 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 a mass is present in your kidney.

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

## Early and advanced kidney cancer

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

Treatment for early kidney cancer

pages 25–33

Treatment for advanced kidney cancer

pages 34–40

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

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

As part of the procedure, you may have an injection of a dye (called contrast) into one of your veins before the scan. This dye

travels through your bloodstream to the kidneys, ureters, bladder and other organs, and helps make the pictures clearer. It might make you feel flushed and hot for a few minutes. Symptoms should ease quickly, but tell the medical team if you feel unwell. The contrast should be used only if your kidneys are functioning well, so this will have been checked during earlier blood tests.

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



The dye used in a CT scan usually contains iodine. If you have had an allergic reaction to iodine or dyes during a previous scan, let your medical team know beforehand. You should also tell them if you are diabetic, have kidney function problems or are pregnant.

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

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

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

**Radioisotope bone scan** – A radioisotope scan is another way to see if any cancer cells have spread to the bones. You might have this test if you have a very large tumour or advanced kidney cancer. The scan is also used during treatment to determine how the cancer is responding to the treatment.

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

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



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

## Tissue biopsy

A biopsy is when doctors remove a sample of tissue from the body so that it can be examined under a microscope to see if there have been any changes in the cells.

The biopsy used to check for kidney cancer is called a core needle biopsy and is performed by an interventional radiologist (see page 12) during an ultrasound or CT scan. You will have a local anaesthetic to numb the area, and then a sample of tissue will be removed from the kidney with a needle. The procedure usually takes about 30 minutes.

### Do I need a biopsy?

A diagnosis of kidney cancer cannot be positively made without looking at some of the tumour under a microscope. A core needle biopsy can provide a tissue sample for examination.

You may not need a biopsy if the doctor already knows enough from other tests, such as a CT scan, to immediately recommend surgery to remove the tumour (see pages 26–31). In this case, the removed tissue can then be tested to confirm that it is cancer. Surgery without a biopsy first is most likely to be recommended if

the tumour is large, looks irregular on the scan, or has obviously spread to the renal vein, adrenal gland or nearby lymph nodes.

In some cases, a mass on your kidney will turn out to be benign (not cancer). If the mass is confined to the kidney and is smaller in size, a biopsy can allow doctors to make a diagnosis. A benign mass may not need surgery at all. Benign growths on the kidney can include oncocytoma and angiomyolipoma.

A biopsy may also be done if there is a suspicion that a kidney cancer has spread, and the plan is to use targeted therapy or immunotherapy (see pages 35–37) rather than surgery. The biopsy helps plan treatment and may be required by the Pharmaceutical Benefits Scheme (PBS), which subsidises the cost of the drugs.

## Grading kidney cancer

By examining a tissue sample taken during a biopsy or surgery, doctors can see how similar the cancer cells look to normal cells and estimate how fast the cancer would grow without any treatment. This is called grading. It helps them decide what follow-up 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 new system called the ISUP (International Society of Urological Pathology) system has now been introduced. Both systems grade kidney cancer from 1 to 4, with grade 1 indicating the slowest growing and grade 4 indicating 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 I–IV. Stages I–II are considered early kidney cancer, and stages III–IV are considered advanced. The diagrams opposite explain staging in more detail.

## Prognosis

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

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

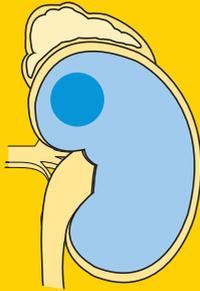
People who can have surgery to remove the cancer tend to have better outcomes. However, other factors such as your age, general fitness and medical history also affect prognosis.

## How kidney cancer is staged

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

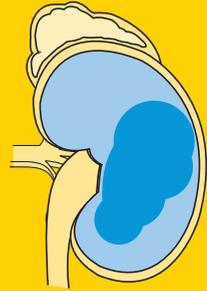
### Stage I

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



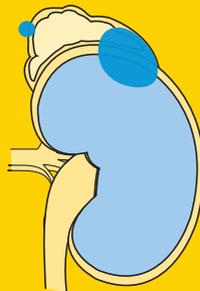
### Stage II

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



### Stage III

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



### Stage IV

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



## Key points

- Kidney cancer is most often discovered during a test or scan for an unrelated reason.
- Sometimes kidney cancer causes blood in the urine or pain in the side, but it often doesn't produce any symptoms. This means cancer might be present for some time before diagnosis and some kidney cancers have already advanced by the time they are diagnosed.
- The main tests for diagnosing kidney cancer are imaging scans (ultrasound, CT, MRI and/or bone scans) and tissue sampling (biopsy). Your doctor may also arrange blood and urine tests.
- The tests show what type of kidney cancer you have, as well as its grade and stage.
- The grade of the cancer indicates how quickly the cancer was growing. The Fuhrman system and ISUP system both grade kidney cancer using grades 1 to 4.
- The stage of the cancer shows if and how far the cancer has spread in the body. Kidney cancer is assigned a stage (I–IV) using the TNM system. TNM stands for tumour, nodes, metastasis.
- Knowing the stage and the grade helps doctors recommend the best treatment for you.
- Your prognosis is the expected outcome of the disease. It is based on the cancer's stage, and factors such as your age, medical history and fitness. Your doctor can discuss your prognosis with you.
- You will usually be cared for by a urologist or oncologist and other health professionals who work together as a multidisciplinary team.



# 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. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that's based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some people with more advanced cancer choose treatment even if it offers only a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so that they have the best possible quality of life.

## Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask questions – see page 50 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

## A second opinion

You may want to get a second opinion from another specialist to confirm or clarify your doctor's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this.

Your doctor can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have already started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the doctor who provided the second opinion.

## Taking part in 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.

It may be helpful to talk to your specialist or clinical trials nurse, or to get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call Cancer Council 13 11 20 and ask for a free copy of *Understanding Clinical Trials and Research*, or visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).



# Treatment for early kidney cancer

Early-stage kidney cancer (stages I and II) is localised – it is confined to the kidney or has not spread very far (see page 21). The main treatment is surgery (see pages 26–31). Less often, non-surgical treatments, such as radiofrequency ablation and stereotactic body radiotherapy (see page 32), are used to try to kill the tumour without removing it from the body. Sometimes the best approach for localised kidney cancer is not immediate treatment, but to watch the cancer carefully (active surveillance).

## Active surveillance

When small tumours (less than 4 cm in diameter) are found in the kidney, they are less likely to be aggressive and might not grow during a person's lifetime. In this case, your doctor might recommend active surveillance, also known as observation. This involves regular ultrasounds or CT scans (see pages 14–16). If these imaging tests suggest that the tumour has grown at any time, you will be offered treatment (usually surgery).

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

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

## Surgery

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

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

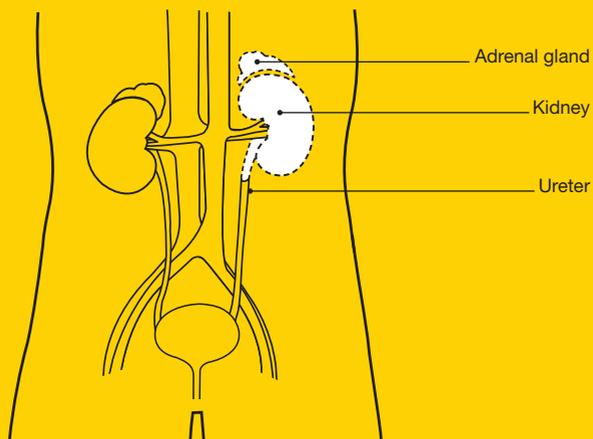
**Removing part of the kidney (partial nephrectomy)** – This is sometimes an option for tumours that are confined to the kidney, and is particularly useful for people with pre-existing kidney disease, cancer in both kidneys or only one working kidney. Only the cancer and a small part of the kidney are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



If a whole kidney or part of a kidney is removed, the remaining kidney usually carries out the work of both kidneys.

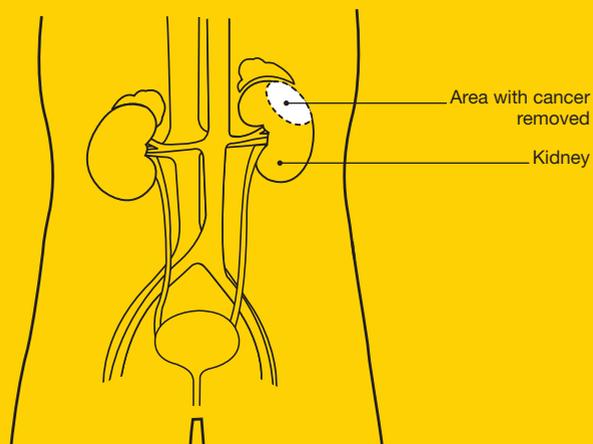
## Radical nephrectomy

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



## Partial nephrectomy

Part of the kidney is removed.



## How the surgery is done

If you have surgery for kidney cancer, it will be carried out in hospital under a general anaesthetic.

Whether all or part of the kidney is removed (radical or partial nephrectomy), different surgical methods may be used. Each method has advantages in particular situations.

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

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

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

## Making decisions about surgery

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

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

### 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.



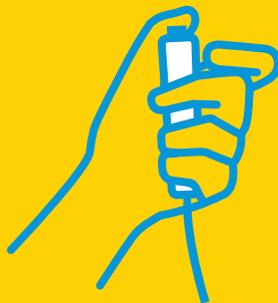
## What to expect after surgery

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.

### 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 and attached to a bag that collects urine. This is called a urinary catheter. Knowing how much urine you are passing helps hospital staff monitor the function of the remaining kidney. When the catheter is removed, you will be able to urinate normally again.



### Pain relief

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

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



### 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.

### Check-ups

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



### Movement

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 exercises that can help you avoid developing a chest infection.

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



## Other treatments

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

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

**Stereotactic body radiotherapy** – Radiotherapy uses radiation, such as x-rays, to kill or damage cancer cells. It is also known as radiation therapy. Standard radiotherapy (see page 38) is not effective in treating primary kidney cancer, but stereotactic body radiotherapy (SBRT) is looking promising and your doctor may recommend it in particular situations. This is a highly targeted form of radiotherapy that focuses thin beams of radiation onto the tumour from different angles.



Clinical trials are currently testing whether particular targeted therapy and immunotherapy drugs (see pages 35–37) should be given after surgery for early kidney cancer (adjuvant treatment).



## Key points

- If you have a small tumour (smaller than 4 cm), your doctor might recommend active surveillance rather than treatment. You will be monitored with regular check-ups, and treatment might be offered if the tumour changes.
- The most common treatment for early kidney cancer is surgery. You might have either a radical nephrectomy (removing the whole kidney) or a partial nephrectomy (removing part of the kidney).
- The surgery can be done using different surgical techniques. Open surgery involves one large cut, while laparoscopic surgery involves several smaller cuts and the use of a laparoscope, a tiny instrument with a camera and light. Robot-assisted surgery is a type of laparoscopic surgery. Each method has advantages in some situations, so discuss the options with your surgeon.
- Most people are in hospital for 2–7 days after surgery for kidney cancer, and it may be a number of weeks until you can safely return to your usual activities.
- The recovery time varies, depending on the type of surgery. Recovery after laparoscopic surgery is usually quicker than after open surgery.
- If the tumour is small and you are not well enough for surgery, you may have other treatments that aim to destroy the tumour without removing it.
- Radiofrequency ablation uses heat from a probe to kill the cancer cells.
- Stereotactic body radiotherapy uses highly targeted beams of radiation to destroy or damage the cancer cells.



# Treatment for advanced kidney cancer

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

Combinations of different treatments may be recommended by various members of your treatment team (see pages 12–13), including urologists, medical oncologists and radiation oncologists. The best sequence or combination of treatments depends on many factors, so the right treatment for each patient is different.

Watching and waiting (active surveillance) may be an option for some people. The main medical treatment to help control advanced kidney cancer is targeted therapy. Other possible treatments include immunotherapy and radiotherapy. Surgery to remove the kidney affected with cancer might also be recommended. Chemotherapy isn't usually used for treating kidney cancer – other treatments such as targeted therapy or immunotherapy appear to work better.

## Active surveillance

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

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

## Surgery

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

In some circumstances, surgery may improve survival, especially when given before targeted therapy (see below). It can also reduce current symptoms or the risk of future symptoms from the cancer in the kidney. Generally, surgery is not recommended if you are unwell or if the cancer has spread to many places in the body.

## Targeted therapy

If you have advanced kidney cancer that is growing quickly or causing symptoms, your doctor is likely to suggest targeted therapy. This works in a different way to chemotherapy. While chemotherapy affects all rapidly dividing cells and works by killing cancerous cells (cytotoxic), targeted therapy targets specific molecules within cells and often works by blocking cell growth (cytostatic).

Different types of targeted therapy drugs are used for advanced kidney cancer (see box, next page). Most are in the form of tablets that you take at home.

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

## Types of targeted therapy for kidney cancer

The main types of targeted therapy used for advanced kidney cancer are listed below. In Australia, some of these are available on the Pharmaceutical Benefits Scheme (PBS) as long as certain criteria are met. This means that the government covers most of the cost. Medicines or treatments that are not on the PBS are usually very expensive unless given as part of a clinical trial.

### tyrosine kinase inhibitors (TKIs)

- Tyrosine kinase inhibitors (TKIs) block the function of a group of enzymes called tyrosine kinases, in particular VEGFR (vascular endothelial growth factor receptor).
- To spread into surrounding tissue, a tumour has to grow its own blood vessels. This process is called angiogenesis. VEGFR TKIs are angiogenesis inhibitors, which means they block the growth signals to blood vessel cells. This cuts off blood supply to the cancer and stops the cancer growing.
- The main VEGFR TKIs currently used for kidney cancer in Australia are sunitinib, pazopanib, sorafenib and axitinib. Others, including lenvatinib and cabozantinib, have been shown to be beneficial in clinical trials, but are not yet available in Australia.

### mammalian target of rapamycin (mTOR) inhibitors

- Mammalian target of rapamycin (mTOR) is an enzyme that tells cancer cells to grow and spread; mTOR inhibitors block this enzyme.
- Everolimus is an mTOR inhibitor that is on the PBS in Australia, but it can be used only if kidney cancer has progressed after taking a VEGFR TKI.

## Side effects of targeted therapy

Targeted therapy drugs minimise harm to healthy cells, but they can still have side effects. These vary depending on the drug used, but may include fatigue, mouth ulcers, changes in appetite, fevers, allergic reactions, rashes, diarrhoea, blood-clotting issues and blood pressure changes.

## Immunotherapy

Immunotherapy is treatment that works by enhancing the body's own immune system, in the hope that it will then attack the cancer. Some older immune therapies like interferon alpha and interleukin-2 were successful in some kidney cancer patients, but were very toxic and so are now rarely used.

A new family of immunotherapy drugs work by permitting the immune system to bypass 'checkpoints' set up by the cancer that block the immune system. Several of these checkpoint immunotherapy drugs are already approved for the treatment of other cancers like melanoma, lung cancer and bladder cancer. Nivolumab is a checkpoint immunotherapy drug that has been shown to be effective in people with advanced kidney cancer previously treated with a VEGFR TKI. However, it is not currently reimbursed for kidney cancer in Australia (as of 2016).

Clinical trials (see page 24) are testing checkpoint immunotherapy at many stages of kidney cancer – after surgery (adjuvant treatment), as the first treatment for advanced kidney cancer, and in combination with existing kidney cancer drugs like TKIs.

## Radiotherapy

Radiotherapy uses radiation, such as x-rays, gamma rays, electron beams or protons, to kill or damage cancer cells. It is also known as radiation therapy. Radiotherapy might be used in advanced kidney cancer to shrink a tumour and relieve symptoms (palliative treatment, see below).

If you have radiotherapy, you will lie on a treatment table under a machine called a linear accelerator. The treatment itself takes only a few minutes, but each session may last 10–20 minutes because of the time it takes to set up the equipment. You will be able to go home once the session is over.

The total number of treatments and their duration depend on your situation. You might have some side effects, such as fatigue, nausea, appetite loss, diarrhoea, tiredness and skin irritation.

Talk to your doctor and nurses about any side effects you experience so you can get advice about managing them. You can also read the *Understanding Radiotherapy* booklet – call Cancer Council 13 11 20 for a free copy or download a digital version from your local Cancer Council website.

## Palliative treatment

In some cases of advanced kidney cancer, the medical team may talk to you about palliative treatment. Palliative treatment helps to improve quality of life by alleviating symptoms of cancer. It can be used at any stage of advanced cancer.

As well as slowing the spread of cancer, palliative treatment can relieve pain and help manage other symptoms. Treatment may include radiotherapy, arterial embolisation (a procedure that blocks the blood supply to the kidney and the tumour inside it), or drug therapies.

Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, emotional, practical and spiritual needs.

For more information, you can read Cancer Council's booklets *Understanding Palliative Care* and *Living with Advanced Cancer*. You may also be interested in the booklet and DVD *Overcoming Cancer Pain*, as well as our relaxation and meditation CDs. Call 13 11 20 to request free copies of these resources, or download the booklets from your local Cancer Council website.



## Key points

- Advanced cancer means the cancer has spread from where it started to another part of the body, or it has come back some time after you were first treated.
- In some people, the cancer may be growing so slowly that the doctor suggests active surveillance. This means checking the growth of the cancer with regular scans.
- If the primary kidney cancer is the largest site of disease and the cancer has not spread very much, the primary kidney cancer may be removed (cytoreductive nephrectomy).
- In some cases, surgery can remove some or all of the cancer that has spread (metastasectomy).
- Targeted therapy drugs target specific molecules within cells and often work by blocking cell growth.
- The most commonly used targeted therapies for advanced kidney cancer are VEGFR tyrosine kinase inhibitors (TKIs) and mTOR inhibitors.
- Immunotherapy uses drugs that encourage the immune system to fight the cancer cells. These checkpoint immunotherapy drugs are the focus of many clinical trials.
- Radiotherapy may be used to shrink a tumour that is causing symptoms in people with advanced kidney cancer.
- Some people might be offered palliative treatment, such as radiotherapy and arterial embolisation. Palliative treatment is given to ease the symptoms of the cancer.
- All of the treatments can cause side effects, such as pain, fatigue or diarrhoea. Talk to your doctor about how to manage any side effects.



# Looking after yourself

Cancer can cause physical and emotional strain. It's important to try to look after your wellbeing as much as possible.

**Nutrition** – Eating healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet.

**Staying active** – Physical activity may help to reduce tiredness, improve circulation and elevate mood. The amount and type of exercise you do depends on what you are used to, how you feel, and your doctor's advice. Cancer Council's *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

**Complementary therapies** – These therapies are used with conventional medical treatments. You may have therapies such as massage, relaxation and acupuncture to 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.

Alternative therapies are used instead of conventional medical treatments. These therapies can include coffee enemas and magnet therapy. These can be harmful or may mean you decline a treatment that is known to offer benefit. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet, or visit your local Cancer Council website.

## Relationships with others

Having cancer can affect your relationships with family, friends and colleagues. This might be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities, or outlook on life.

Give yourself time to adjust to what's happening, and do the same for others. People might deal with the cancer in different ways, for example, by being overly positive, playing down fears, or keeping a distance. It might be helpful to discuss your feelings with each other.

## Sexuality, intimacy and fertility

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 might not always be possible, closeness and sharing can still be part of your relationship.

If you are able to have sex, you might be advised to use certain types of contraception to protect your partner or avoid pregnancy for a certain period of time. Your doctor will talk to you about the precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before starting treatment.

Call 13 11 20 for free copies of *Sexuality, Intimacy and Cancer*, *Emotions and Cancer* and *Fertility and Cancer*, or download the booklets from your local Cancer Council website.

## Life after treatment

For most people, the cancer experience doesn't end on the last day of treatment. Life after cancer 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', but they don't want life to return to how it was before cancer. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace.

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.

## 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 or have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible.

The organisation [beyondblue](http://beyondblue.org.au) has information about coping with depression and anxiety. Visit their website at [beyondblue.org.au](http://beyondblue.org.au) or call 1300 22 46 36 to order a fact sheet.



## Jodie's story

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

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

After the surgery, I was in quite a bit of pain and discomfort, and had lots of trouble going to the toilet. My greatest concern has been about the cancer coming back. For a while it was my first waking thought. Time has helped me deal with this. Every check-up has reassured me that things are okay. At first

I had six-monthly check-ups, but now they're yearly.

My family was great during this period; both my husband and son were very supportive. I was concerned I was driving my family crazy because I found the experience so consuming it was all I could talk about. I couldn't find information and there was no support group that I was aware of, except online – that's why, once I was well again, I felt it important to become a volunteer in a peer support program. I always tell people that it was a really scary experience, but that it's okay to be afraid.

At the time of the diagnosis, I was working as an office manager, but afterwards we reassessed our life. I changed jobs and we moved house. I now work in aged care, which I love, and we moved from a big house to a small apartment overlooking the sea. I learnt to go with the flow and that life will be all right.

## Follow-up appointments

After treatment for early-stage kidney cancer, you will need regular check-ups to confirm that the cancer hasn't come back. Your doctor will talk to you about the follow-up schedule. If your doctor recommends active surveillance (see page 25), you will also continue having regular check-ups.

During these check-ups, you may have ultrasounds, CT scans or blood tests. If these show no further problems, your appointments will become less frequent. Tell your doctor immediately about any health problems between check-ups.

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

“ I have the scan every March, and I spend February worrying about it. I call it ‘scanxiety’. You just have to say that even if it does come back, they will find it when it is still small, which is why you have the yearly scans. ” *Chris*

## What if the cancer returns?

For some people, kidney cancer does come back after treatment, which is known as a recurrence. This is why it is important to have regular check-ups.

Kidney cancer may have spread beyond the kidney. If it has spread, you may be offered other treatment, such as targeted therapy, immunotherapy or radiotherapy (see pages 35–38).



# Seeking support

Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. It can also cause practical and financial problems.

## Practical and financial help

There are many services that can help deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council offers free legal and financial services in some states and territories for people who can't afford to pay – call 13 11 20 to ask if you are eligible.

## Talk to someone who's been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

People often feel they can speak openly and share tips with others who have gone through a similar experience.

In a support group, you may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest in these support settings because they aren't trying to protect their loved ones.

## Types of support

There are many ways to connect with others for mutual support and to share information. These include:

- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** – such as Cancer Council Online Community at [cancercouncil.com.au/onlinecommunity](http://cancercouncil.com.au/onlinecommunity).

Talk to your nurse, social worker or Cancer Council about what is available in your area.

“ 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*



# Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your worries and concerns with somebody neutral, such as a counsellor or your doctor.

Many cancer support groups and cancer education programs are open to carers, as well as people with cancer. Support groups and programs can offer valuable opportunities to share experiences and ways of coping.

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

There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Visit [carersaustralia.com.au](http://carersaustralia.com.au) or call 1800 242 636 for more information and resources.

You can call Cancer Council 13 11 20 to find out more about carers' services and get a copy of the *Caring for Someone with Cancer* booklet.



# Useful websites

The internet has many useful resources, although not all websites are reliable. The websites below are good sources of information.

## Australian

---

Cancer Council Australia.....	<b>cancer.org.au</b>
Cancer Australia.....	<b>canceraustralia.gov.au</b>
Carer Gateway.....	<b>carergateway.gov.au</b>
Carers Australia.....	<b>carersaustralia.com.au</b>
Department of Health.....	<b>health.gov.au</b>
healthdirect Australia.....	<b>healthdirect.gov.au</b>
Kidney Health Australia.....	<b>kidney.org.au</b>

## International

---

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



# Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don't understand, ask for clarification.

- What type of kidney cancer do I have?
- How far has the cancer spread? How fast is it growing?
- What treatment do you recommend and why?
- Are there other treatment choices for me? If not, why not?
- What are the risks and possible side effects of each treatment?
- How long will treatment take? Will I have to stay in hospital?
- How much will treatment cost? How can the cost be reduced?
- Will I have a lot of pain with the treatment? What will be done about this?
- Are there any clinical trials or research studies I could join?
- How frequently will I need check-ups after treatment?
- Who should I go to for my check-up appointments?
- Are there any complementary therapies that might help me?
- Should I change my diet during or after treatment?
- Should I do more exercise?
- If the cancer comes back, how will I know?



# Glossary

## **abdomen**

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

## **active surveillance**

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

## **adjuvant treatment**

A treatment given with or shortly after the primary treatment to make the primary treatment more effective and try to stop the cancer coming back.

## **adrenal glands**

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

## **anaemia**

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

## **anaesthetic**

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

## **angiogenesis**

The formation of new blood vessels. This process enables tumours to develop their own blood supply, which helps them grow.

## **angiogenesis inhibitor**

A type of targeted therapy drug that attacks developing blood vessels so the cancer cells can't grow and spread to other parts of the body.

## **arterial embolisation**

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

## **artery**

A blood vessel that carries blood away from the heart.

## **benign**

Not cancerous or malignant.

## **biopsy**

The removal of a sample of tissue from the body for examination under a microscope to help diagnose a disease.

## **bladder**

The hollow muscular organ that stores urine.

## **catheter**

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

## **cells**

The basic building blocks of the body. A human is made up of billions of cells that are adapted for different functions.

## **checkpoint immunotherapy**

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

## **chemotherapy**

The use of anti-cancer drugs to treat cancer by killing cancer cells or slowing their growth.

**clinical trial**

A research study that tests new and better treatments to improve people's health.

**contrast**

A substance injected into the vein or taken orally 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 procedure in which tissue is removed from an organ or lymph node using a needle.

**CT scan**

A computerised tomography scan. This scan uses x-rays to create a detailed, cross-sectional picture of the body.

**cystoscope**

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

**cystoscopy**

A test using a cystoscope to examine the vagina, cervix, bladder and rectum. It is performed under a general anaesthetic.

**cytoreductive nephrectomy**

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

**grade**

A number that describes how similar cancer cells look to normal cells.

**haematuria**

Blood in the urine.

**hormones**

Chemical messengers in the body that send information between cells.

**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 invaders, such as bacteria and viruses.

**immunotherapy**

The prevention or treatment of disease using substances that alter the immune system's response.

**interventional radiologist**

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

**intravenous**

Injected into a vein.

**kidneys**

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

**laparoscope**

A thin viewing instrument with a light and camera that is inserted through a cut (incision) in the abdomen to look inside the abdomen and pelvis during laparoscopic surgery.

**laparoscopic surgery**

Surgery done through small cuts in the abdomen using a laparoscope

for viewing. Also called keyhole or minimally invasive surgery.

### **lymphatic system**

A network of tissues, capillaries, vessels, ducts and nodes that remove excess fluid from tissues, absorb fatty acids and transport fat, and produce immune cells.

### **lymph nodes**

Small structures that form part of the lymphatic system. Also called lymph glands.

### **malignant**

Cancer. Malignant cells can spread (metastasise).

### **mammalian target of rapamycin (mTOR) inhibitors**

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

### **medical oncologist**

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

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

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

### **MRI scan**

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

### **nephrectomy**

The surgical removal of a whole kidney (radical nephrectomy) or part

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

### **nephrologist**

A doctor who specialises in diagnosing and treating kidney disease.

### **nephrology**

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

### **nephrons**

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

### **observation**

See active surveillance.

### **oncologist**

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

### **open surgery**

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

### **palliative treatment**

Medical treatment for people with advanced cancer to help them manage pain and other symptoms of cancer.

For advanced kidney cancer, palliative treatment may include radiotherapy, arterial embolisation or drug therapies. It is an important part of palliative care.

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

An intravenous system that allows a person to administer a 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 predicted outcome of a person's disease.

### **prostate**

A gland in the male reproductive system that produces most of the fluid that makes up semen.

### **radiation**

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

### **radiation oncologist**

A doctor who specialises in treating cancer with 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.

### **radiotherapy**

The use of radiation, such as x-rays, to kill cancer cells or injure them so they cannot grow and multiply. Also called radiation therapy.

### **renal artery**

A blood vessel that carries blood to the kidney.

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

The most common type of kidney cancer. Also called renal adenocarcinoma. It begins in the kidney's nephrons. Types of RCC include clear cell carcinoma, papillary RCC, chromophobe RCC and sarcomatoid RCC.

### **renal pelvis**

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

### **renal sarcoma**

A rare cancer that affects the connective tissues of the kidney.

### **renal vein**

A blood vessel that carries blood away from the kidney.

### **staging**

Performing tests to determine how far a cancer has spread.

### **stereotactic body radiotherapy (SBRT)**

A highly targeted form of radiotherapy that focuses thin beams of radiation onto the tumour.

### **targeted therapy**

Treatment that attacks specific particles (molecules) within cells that allow cancer to grow and spread. The main types of targeted therapy drugs used for advanced kidney cancer are tyrosine kinase inhibitors (TKIs) and mammalian target of rapamycin (mTOR) inhibitors.

## tumour

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

## tyrosine kinase inhibitors (TKIs)

Targeted drugs that block the enzyme tyrosine kinase, which is a chemical messenger that tells cells when to divide and grow.

## ultrasound

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

## ureteroscopy

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

## ureters

The tubes that carry urine from each kidney to the bladder.

## urethra

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

## urinary system

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

## urologist

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

## urothelial carcinoma

Cancer that occurs in urothelial cells. It can start in the renal pelvis of the kidney, the ureter or the bladder. 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. They form a watertight lining. Also called transitional cells.

## urothelium

The inner lining of the bladder and the urinary system.

### Can't find a word here?

For more cancer-related words, visit:

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

## References

1. B Escudier et al. on behalf of the ESMO Guidelines Working Group, 'Renal cell carcinoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up', *Annals of Oncology*, vol. 25, suppl. 3, 2014, pp. iii49–iii56. doi:10.1093/annonc/mdu259.
2. Australian Institute of Health and Welfare (AIHW), *Australian Cancer Incidence and Mortality (ACIM) books: Kidney cancer*, AIHW, Canberra, 2016.



# 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 Pink Ribbon Day, 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.

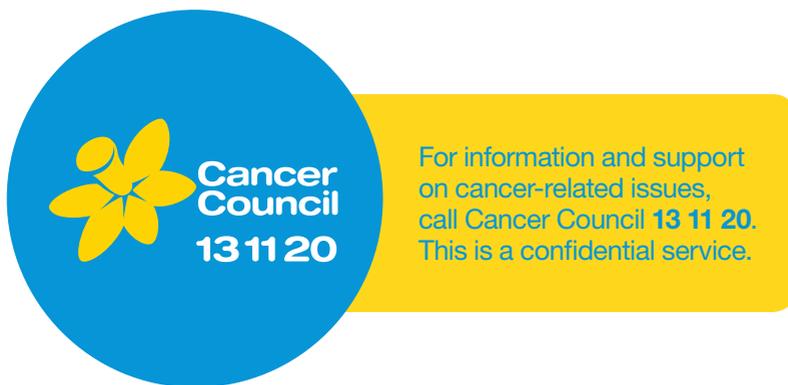
Cancer Council services and programs vary in each area.  
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



**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, contact us through the National Relay Service.**  
[www.relayservice.gov.au](http://www.relayservice.gov.au)



## Visit your local Cancer Council website

**Cancer Council ACT**  
actcancer.org

**Cancer Council NSW**  
cancercouncil.com.au

**Cancer Council NT**  
nt.cancer.org.au

**Cancer Council Queensland**  
cancerqld.org.au

**Cancer Council SA**  
cancersa.org.au

**Cancer Council Tasmania**  
cancertas.org.au

**Cancer Council Victoria**  
cancervic.org.au

**Cancer Council WA**  
cancerwa.asn.au

**Cancer Council Australia**  
cancer.org.au

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