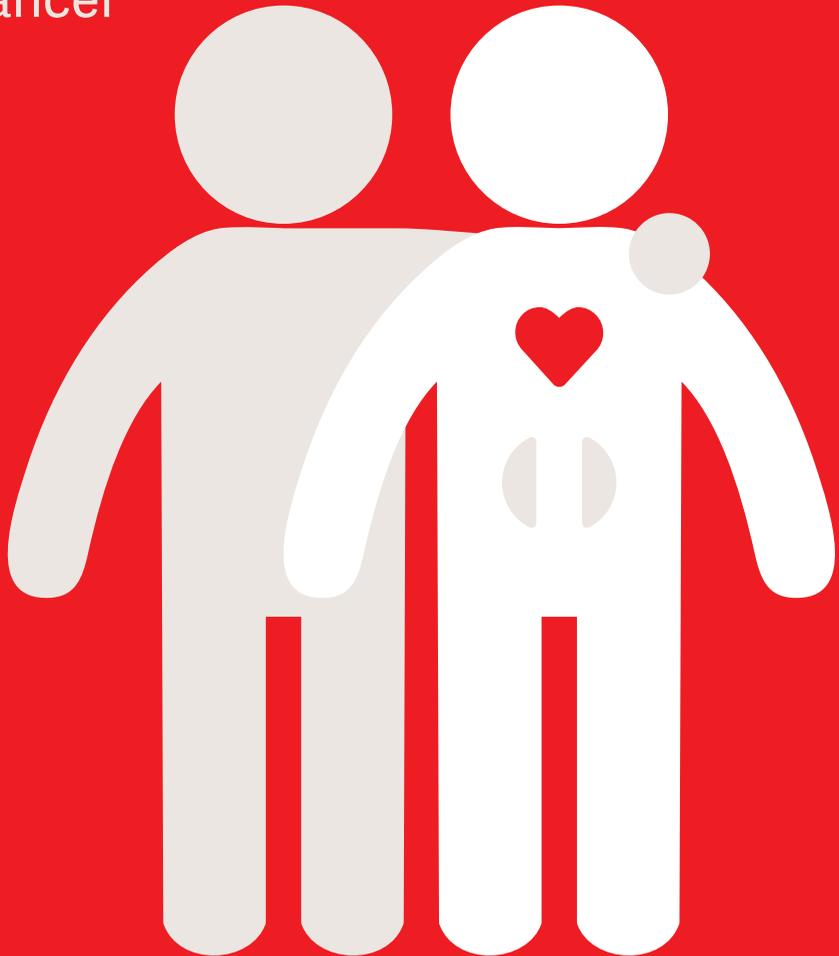


My Kidney Cancer My Health



Living with advanced
kidney cancer



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Foreword



***My Kidney Cancer, My Health* is designed specifically for people newly diagnosed with advanced kidney cancer and their families.**

If you are reading this for the first time it may be that you have just received news of your diagnosis or you are supporting a loved one who needs more information about their kidney cancer.

My Kidney Cancer, My Health is designed to help you navigate your way around your diagnosis and assist you to manage and take control of your own health. The aim is to provide you with information and support to empower you to be as healthy, active and positive as you can possibly be.

Kidney Health Australia is here to support you throughout your journey and our fully qualified team of nurses and allied healthcare professionals are only a phone call away should you wish to speak to someone confidentially.

I hope this handbook proves to be an invaluable companion, giving you direction on the challenging road ahead.

Mikaela Stafrace
CEO
Kidney Health Australia



JAMES' STORY

By the time you read this I may be dead. That is the nature of advanced kidney cancer, one moment you are ok, and the next moment your cancer has broken out again and you are once again confronted with your own mortality.

My name is James and I started my story this way to get your attention.

Like most people with kidney cancer, my kidney cancer was found by accident, when I had an ultrasound scan to examine a lump on my chest. I then had a CT scan that showed the cancer had already metastasised to my lungs. I had no symptoms to indicate that I had cancer – it was a total shock. I had my right kidney removed and I commenced my *cancer journey*.



It's now June 2016 and I am in my 7th year with stage 4 kidney cancer and I intend to be around a lot longer yet.

My wife and I said we will fight my cancer, we will win, and we will beat it. We would not accept that 95% of people with stage 4 kidney cancer are dead 5 years after diagnosis. So we started looking on the internet, hoping beyond hope there was a cure. We found a lot of strange *treatments*, with all sorts of promises, and some for outrageous prices.

But we also found some really useful websites with information about kidney cancer, treatment options and clinical trials, such as Kidney Health Australia and Kidney Cancer Association Canada. These websites helped us understand what we were confronting. Our attitude changed and we adopted a new philosophy. We realised that there is no cure, but what we could do, is **live with cancer**.

What does this involve? Enjoy every day, don't put anything off that you want to do; stay positive; manage your treatment side effects as best as you can, and do whatever you can to keep yourself as strong and fit as possible. For me, living with cancer is also about staying alive until the next new drug is developed to extend my life.

I hope this handbook can help you, and your family, through your diagnosis of advanced kidney cancer by helping you to discover the many ways to really **live** with your cancer.

James

About this handbook

Welcome to the *My Kidney Cancer, My Health* handbook. This handbook has been created to answer some questions that you may have about kidney cancer, and help support you through your journey. You may be the person who has just received a diagnosis of kidney cancer, or you may be a loved one.



Information

Understand advanced kidney cancer and its treatment



Taking control

How to look after yourself physically and emotionally



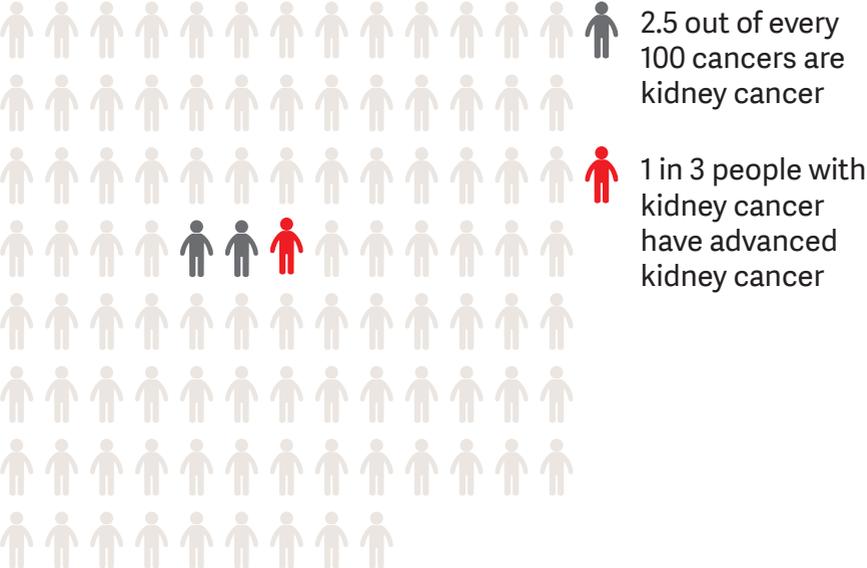
Support

You are not alone – how others can help you and you can help them

Introduction

Kidney cancer is a relatively rare cancer – for every 100 people with cancer in Australia, only 2 to 3 of them will have kidney cancer. Every year around 3000 people are diagnosed with kidney cancer in Australia. About 1 in 3 of them will have advanced kidney cancer.

In some other more common cancers, such as breast and prostate cancer, there are lots of resources to support people on their cancer journey. In kidney cancer there are fewer resources and people can often feel very alone and unsupported. The *My Kidney Cancer, My Health* handbook aims to fill this gap.



How to use this handbook

***My Kidney Cancer, My Health* gives basic information about:**

- The kidneys
- Kidney cancer
- Tests for kidney cancer
- Treatment of advanced kidney cancer
- Clinical trials
- Palliative care
- Taking control of your own health
- Dealing with the side effects of medications
- Physical wellbeing
- Coping emotionally
- Your health care team
- Your family and friends
- Information for carers
- Where to get support

More importantly at the end of each section there is a resource box. This gives you a list of resources, networks, and organisations that can provide you with extra information, guidance, peer support, and a sense of community.



REMEMBER

Highlights important and encouraging information to keep in mind as you begin your kidney cancer journey.



CALL TO ACTION

Contains simple actions you can do now to begin taking control of your health.



RESOURCES

Highlights available resources to learn more and help you manage your health.

-  Fact sheets including Kidney Health Australia fact sheets which can be freely downloaded from www.kidney.org.au
-  Booklets and handbooks
-  Videos
-  Health or government websites
-  Phone apps, to help manage your health
-  Social and support groups
-  Freecall national phone services including the Kidney Health Information Service (KHIS) **1800 454 363***

This handbook is meant as an introduction only and does not replace advice from your healthcare team. Always consult your healthcare team for more advice.

*KHIS is a free service that offers information, support, referral and advice to those affected by kidney disease, including kidney cancer, and healthcare professionals. The KHIS service can draw upon the vast knowledge and experience of the Kidney Health Australia kidney cancer advisory board.

Information



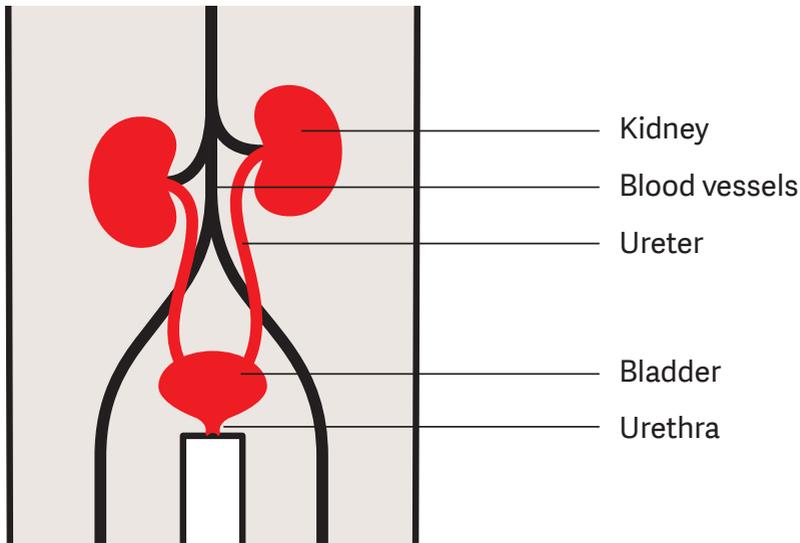
Understand advanced kidney
cancer and its treatment

Healthy kidneys

What are kidneys?

Most people are born with **two kidneys**, each growing to the size of your fist. Your kidneys are positioned on either side of your backbone (spine), just under your rib cage.

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



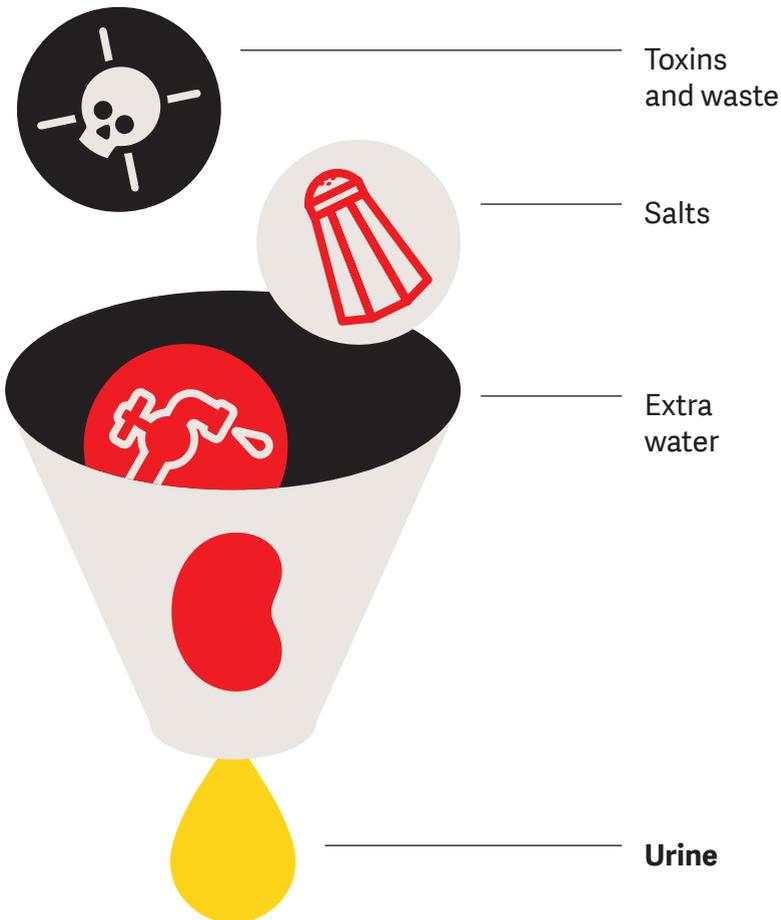
What do healthy kidneys do?

Kidneys are the unsung heroes of the body! Your kidneys have many important roles in keeping your body healthy and getting rid of body wastes.

Making urine

Every day you drink and eat food that is absorbed from your stomach (*tummy or belly*) into your blood. This becomes energy for your body to use.

However there is lots of leftover waste that your body does not need and has to get rid of. This is where your kidneys come in.

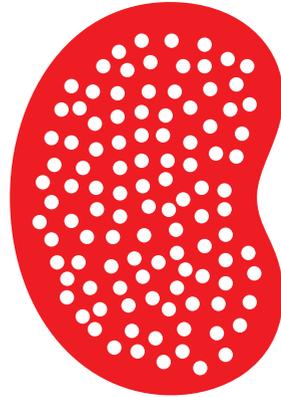


The kidneys have over a million tiny filters (*nephrons*) that clean the blood removing the extra water, salts and waste products. This becomes your urine (*wee*).

Urine leaves your kidneys and flows down through narrow tubes called ureters to the bladder where it is stored.

When your bladder is full you feel the need to pass urine.

When you go to the toilet urine passes out of your body through a tube from the bladder called the urethra.



What else do kidneys do?

Improve health of bones and blood

Kidneys activate vitamin D which is needed to keep your bones strong. They also make a hormone, erythropoietin (*EPO*) that tells your bone marrow to make more red blood cells.

Controlling blood pressure

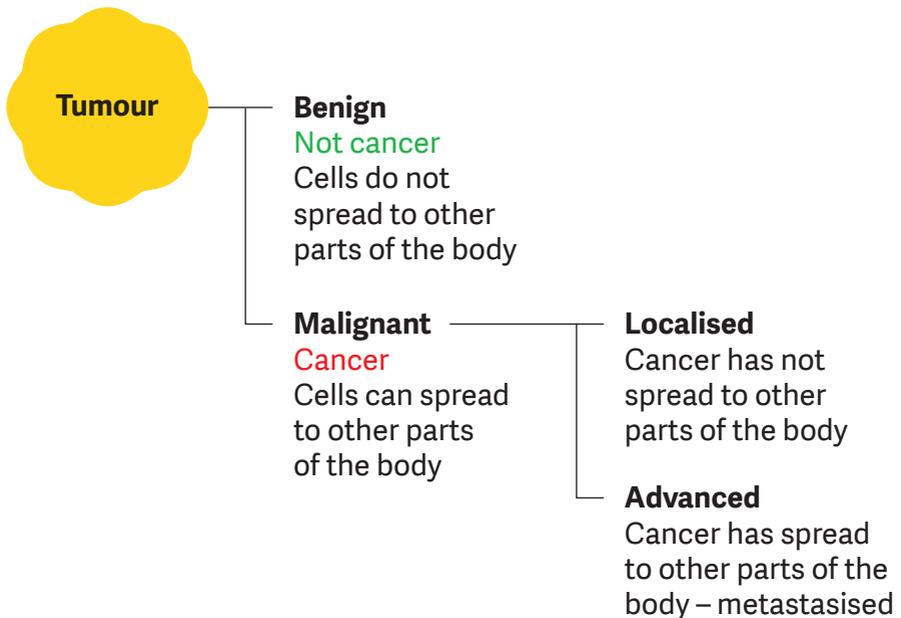
Kidneys make hormones that control how well your blood vessels expand and contract. This controls your blood pressure.

Kidney cancer

What is cancer?

Cancer is a disease of the cells. We are made up of trillions of cells, which are the building blocks that make up our bodies. Our cells are constantly growing and dividing to make new cells, to replace old or damaged ones. If our cells do not grow and divide in their normal and ordered pattern they can form a lump known as a tumour.

Tumours can be divided into benign (not cancer) and malignant tumours (cancer). Malignant tumours (cancer) can be divided into primary cancer and secondary cancer.



What is kidney cancer?

Kidney cancer is a type of cancer that starts from the cells of the kidney.

Usually there is only one tumour in one kidney. More unusually, two or more tumours occur in the same kidney or in both kidneys.

What is the difference between primary and secondary cancer?

A primary cancer is the original cancer – the cancer that has formed in the kidney.

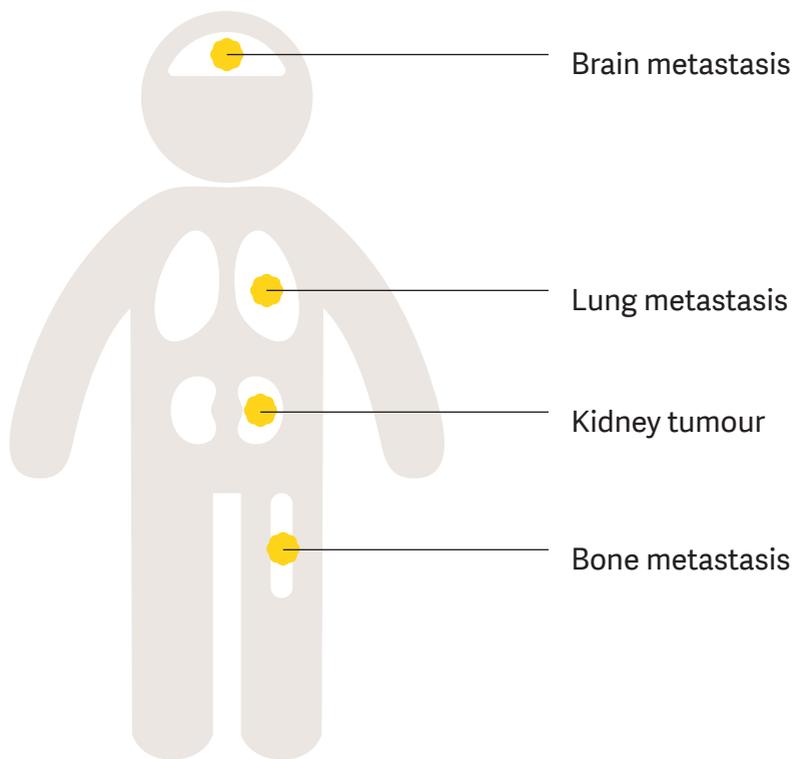
If cells from the primary cancer break away (metastasise) and are carried to other parts of the body, a new secondary cancer (metastasis) may form somewhere else in the body. The most common sites for a kidney cancer to spread are the brain, bones and lungs.

What is the difference between localised and advanced cancer?

Localised kidney cancer is a cancer that has not spread from the kidney.

Advanced kidney cancer is a cancer that has spread from the kidney to somewhere else in the body. It is also known as metastatic kidney cancer.

Metastatic kidney cancer



What are the stages of kidney cancer?

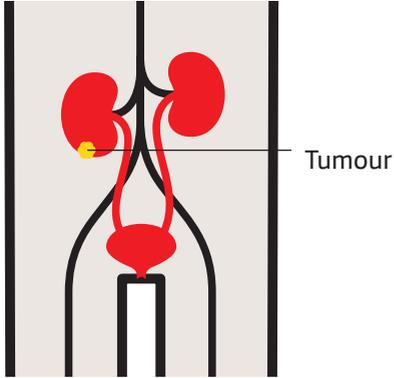
The stage of kidney cancer is a standard way of describing how large the cancer is and how far it has spread. Ask your doctor if you want more information about the stage of your cancer.

STAGE	Stage I	Stage II	Stage III	Stage IV
STAGE	Localised	Localised	Locally advanced	Advanced
SIZE	Less than 7cm	Larger than 7cm	Any size	Any size
LOCATION	Only in the kidney	Only in the kidney	Spread to local lymph nodes, blood vessels and tissues	Spread beyond the kidney – metastasised
TREATMENT	If the cancer can be removed, surgery is a good treatment option	If the cancer can be removed, surgery is a good treatment option	The chance of being cured by surgery is lower but not zero; medication may be used	Unlikely to be cured but various treatment options may improve quality of life, and for some prolong life
SURVIVAL				

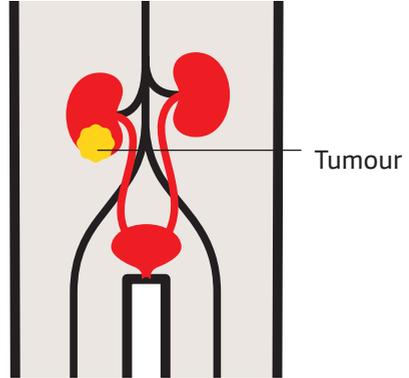
Survival decreases as stage increases

Stages of kidney cancer

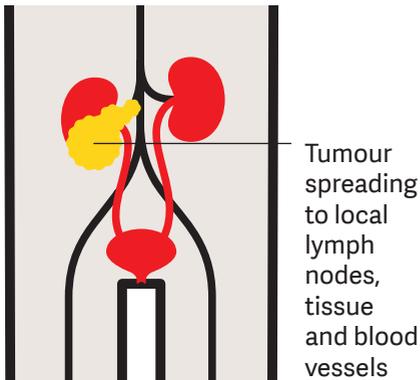
Stage I



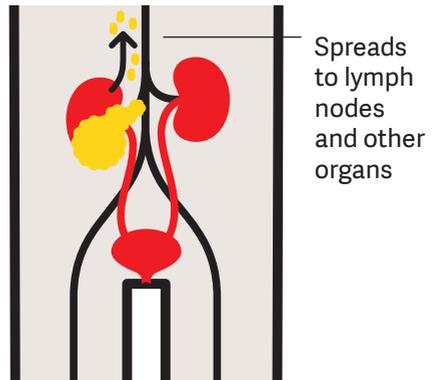
Stage II



Stage III



Stage IV



What increases the risk of getting kidney cancer?

Several factors are known to increase the risk of developing kidney cancer:



Males twice as likely as females



Increasing age



Very overweight or obese (Body Mass Index BMI – over 30 kg/m²)



Smoke cigarettes



High blood pressure



Family members with kidney cancer



Toxic substances



Specific genetic and hereditary conditions



Long term dialysis and acquired cystic disease



Kidney stones



REMEMBER

Many people who get kidney cancer do not have any risk factors, and many people who have known risk factors don't develop kidney cancer.

Tests

What tests will I need?

The tests used to diagnose kidney cancer and plan treatment can be divided into blood and urine tests, cystoscopy, imaging and kidney tissue biopsy.

If you are reading this handbook, then it is likely you have already had some of these tests. You will not necessarily need to have all of the tests, what you have will depend on your particular situation.



RESOURCES

-  **Kidney Cancer** – Kidney Health Australia
Diagnosis and Types of Kidney Cancer – Kidney Health Australia
-  **Understanding Kidney Cancer** – Cancer Council
-  www.kidney.com.au > your kidneys > support > kidney-cancer – Kidney Health Australia
- www.ikcc.org – International Kidney Cancer Coalition
- www.kidneycancer.org – Kidney Cancer Association United States website
- www.kcuk.org.uk – Kidney Cancer UK



Blood and urine tests

- Blood tests work out how well your kidneys are working and can detect findings associated with cancer
- Urine tests can show blood in the urine



Cystoscopy

- If you have blood in your urine you may have a cystoscopy
- Your doctor will use a special telescope to look into your bladder and urethra to see where the blood in your urine is coming from



Imaging

- Imaging is very important for the diagnosis of kidney cancer
- The most common imaging techniques used are ultrasound scans, computer tomography (CT) scans, and magnetic resonance imaging (MRI) scans
- Each type of scan gives different information about your kidney tumour. You may have more than one type of scan



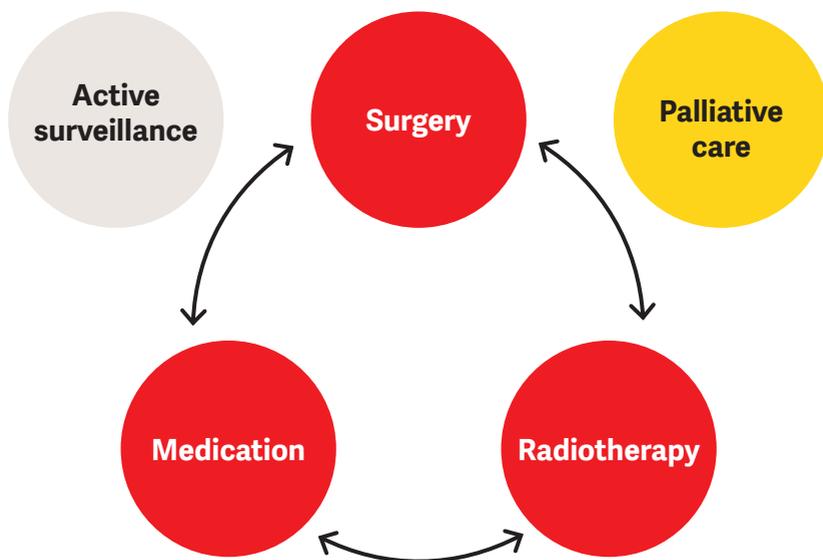
Kidney biopsy

- Small samples of your kidney tumour are taken using a fine needle. The cells of the tumour can be looked at using a microscope
- This gives more information about what type of kidney tumour you have

Treatment

In people with advanced kidney cancer, the cancer is not usually curable. The goal in advanced kidney cancer is therefore to make life as long and as normal as possible.

This is achieved through a combination of different treatments and support services which will be tailored to your individual needs.



Active Surveillance

Surveillance is where no treatment is given but instead you are monitored carefully with scans and other tests to see if the cancer is actually growing and likely to cause problems. Active surveillance is also known as watchful waiting or observation.

When is active surveillance appropriate?

- The cancer is a type that usually grows very slowly. This is especially the case when the cancer has been discovered by accident
- You would prefer not to have surgery or other treatments because of other health issues or your current personal situation

If the cancer does not grow significantly active surveillance will continue. If the cancer starts to grow quickly or cause symptoms then active treatments will be recommended.

Surgery

Although surgery can often cure localised kidney cancer, it does not usually cure advanced kidney cancer.

Why is surgery offered in advanced kidney cancer?

- It may prevent symptoms and problems from the cancer
- In some cases removing the primary kidney cancer improves survival and helps other treatments work better

What are the different types of surgical options that may be offered?

The surgery option you will be offered depends on your situation and include:

- *Cytoreductive nephrectomy* – removal of the kidney to remove as much of the cancer as possible. Also known as debulking surgery
- *Nephrectomy plus removal of other organs* – removing the kidney and other organs such as the spleen, part of the pancreas, or part of the intestines or the liver
- *Metastasectomy* – removal of metastases (secondary tumours). This is only possible if the cancer has spread to just one or two places

Medication

In advanced kidney cancer medications are either used together with surgery, or on their own. There are a number of different types of medications. The different medications attack the cancer in different ways.

There are 2 main types of medications used in advanced kidney cancer:

Targeted therapy

- Medications that block specific *targets* in cancer blood vessels or cells. This stops or slows down the growth of the cancer
- 2 types available: tyrosine kinase inhibitors (TKIs) and mammalian target of rapamycin (mTORs)

Immunotherapy

- Medications that use the immune system to attack cancer cells
- Older immunotherapy used injections of interferon or interleukin. Although they can be effective in a small number of people, they are not used as standard treatment in Australia because they have serious side effects
- The new immunotherapy medications are called *checkpoint inhibitors*. They stop or slow down the growth of cancer



You will be started on one type of medication (first line treatment), and if that doesn't work or stops working, then you may be offered a different type of medication (second-line treatment).



REMEMBER

All medications can cause side effects, although not everybody gets them. If they do occur they may be minor and temporary. However, some may be more serious and need medical attention.



CALL TO ACTION

If you do notice any side effects do not delay in telling your doctor or other healthcare professional. They can work with you to minimise the impact of side effects on your health and quality of life.

Radiotherapy

Radiotherapy uses high energy X-rays to kill cancer cells.

When is radiotherapy used in advanced kidney cancer?

Radiotherapy is used to control and relieve symptoms caused by the primary tumour or from metastases.

For example, to control bleeding from the kidney, reduce pain from cancer in the bones, or to control symptoms due to cancer in the brain.

A newer form of precise, high dose radiotherapy can be used in a small number of people. It is called stereotactic body radiotherapy (SBRT) and stereotactic radiosurgery (SRS). It is used to control limited sites of cancer spread (metastases) in the body (SBRT) or in the brain (SRS). It can also be used to treat the primary kidney tumour in certain people.



RESOURCES

-  **Advanced Kidney Cancer** – Kidney Health Australia
- Localised Kidney Cancer** – Kidney Health Australia
-  **Radiotherapy** – Cancer Council
- Surgery** – Cancer Council
- Surgery** – Peter MacCallum Cancer Centre
-  **www.10forio.info** – International Kidney Cancer Coalition (IKCC). A summary of immuno-oncology

What is a clinical trial?

Doctors and scientists are always looking for better ways to care for and treat patients. To do this research studies involving volunteers, called clinical trials, are carried out. A clinical trial is a way of testing new treatments or old treatments used in a new way to find out if they are safe, effective, and possibly better than the current (standard) treatment.

Should I go on a clinical trial?

If a clinical trial is available, it can be an interesting opportunity to consider. However, clinical trials are not right for every person and not every person is right for a clinical trial.

Advantages

- May be the best treatment option available
- May give access to a medication before it becomes available
- Participating in a clinical trial means helping to make medical advances
- Additional care from the medical team

Disadvantages

- You may not receive the new treatment
- The new treatment may not work as well as the current treatment
- There may be more side effects with the new treatment
- You may have to visit the hospital or clinic more often and have more tests



CALL TO ACTION

If you are interested in going on a clinical trial, talk to your doctor to find out if a clinical trial is right for you.



REMEMBER

If you do decide to go on a clinical trial, you may stop at any time for any personal or medical reason.



RESOURCES



Consumer Guide to Clinical Trials – Consumer Health Forum of Australia



Clinical Trials – Cancer Council



www.anzup.org.au – Australia and New Zealand Urogenital and Prostate cancer trial group

www.australiancancertrials.gov.au – A consumer friendly website providing information about clinical trials. It also includes lists of clinical trials available in Australian and New Zealand

www.clinicaltrials.gov – A world wide list of available clinical trials (a service of the US National Institutes of Health)

www.kidney.org.au > your-kidneys > support > kidney-cancer > cancer-clinical-trials – Kidney Health Australia has a list of available clinical trials for kidney cancer in Australia and New Zealand

Changing needs

As your cancer journey progresses your needs are likely to change.

- Sometimes one form of treatment becomes ineffective and a change in treatment is recommended
- At some point you may need to consider that treatment is not likely to improve your health or change your survival and your quality of life may be better if you stop treatment altogether
- You may need to decide whether the possible limited benefits of continuing treatment outweigh the possible downsides, including treatment side effects



REMEMBER

At some point you may decide that the side effects of medications outweigh the benefits. Your quality of life may be better if you stop treatment all together.

Palliative care

At all stages of your cancer journey you need to feel as good as you can – your quality of life needs to be as good as it possibly can. This is achieved through palliative care.

Palliative care offers a huge range of services including:

- Emotional and social support
- Cancer symptom management
- Side effects of treatment management
- Support during the dying process

When will palliative care be recommended?

Palliative care may be recommended at any time during your treatment. It is often recommended early in your treatment plan. You can choose to stop using the service at any stage, for example if your cancer stabilises.

Who provides palliative care?

Palliative care is provided by the healthcare professionals involved in your day-to-day care, such as your GP, medical oncologist, nurse and social worker. If needed, you may also be referred to a specialist palliative care team.

Do I have to go to hospital to have palliative care?

No, palliative care can be provided at home, a hospice or in hospital.



REMEMBER

Palliative care is not just for people who are about to die. It is for anyone who has advanced illness. The aim of palliative care is to improve your quality of life so that you can live as well as possible for as long as possible.



RESOURCES

-  **Understanding Palliative Care** – Cancer Council
-  **www.advancecareplanning.org.au** – Advance Care Planning, Australia
- www.caresearch.com.au** – Care Search – Palliative care knowledge network
- www.palliativecare.org.au** – Palliative Care Australia
- www.pcis.org.au** – Palliative Care Information Service
- www.pallcareact.org.au** – Palliative Care ACT
- www.palliativecarensw.org.au** – Palliative Care NSW
- www.palliativecareqld.org.au** – Palliative Care QLD
- www.pallcarevic.asn.au** – Palliative Care Victoria
- www.pallcare.asn.au** – Palliative Care SA
- www.tas.palliativecare.org.au** – Palliative Care Tasmania
- www.palliativecarewa.asn.au** – Palliative Care WA
-  Palliative Care Information Service **1800 772 272**

Complementary therapies

Complementary therapies can work with established medical treatments to improve quality of life and symptoms.

Complementary therapies include:

- Remedial massage therapy
- Yoga
- Acupressure
- Acupuncture
- Aromatherapy
- Chiropractic
- Osteopathy*
- Relaxation techniques
- Mindfulness meditation
- Homoeopathy
- Prayer

*If there were any chance that the kidney cancer has spread to bones, chiropractic or osteopathy is not advisable. Please talk to your healthcare professional to decide if complementary therapy is safe for you.

Alternative therapies

Alternative therapies are *therapies* that are not scientifically proven to cure cancer or help. In fact some alternative therapies are harmful and can also interfere with the medications prescribed by your doctor.

Examples of alternative therapies are mega-dose vitamins, herbal products, extreme diets and crystals.





CALL TO ACTION

Inform your doctor if you are considering taking an alternative therapy.



RESOURCES



Acupuncture – Better Health Channel

Aromatherapy – Better Health Channel

Complementary and alternative therapies: what are they and should I use them? –

Peter MacCallum Cancer Council

Complementary therapies – Cancer Council

Relaxation: learning to relax – Cancer Council

Wellbeing therapies at Peter Mac –

Peter MacCallum Cancer Centre



Massage and cancer – Cancer Council



www.quackwatch.org – a list of alternative therapies that have been discredited



DR DAN'S TIPS

Stay positive – symptoms can be well controlled, and even if your cancer is incurable, with newer treatments many cancers can be put into remission for a number of years.

Stay healthy – a body in good shape is better placed to fight the cancer and tolerate treatments that may be required.



Explore options – everyone is different and will benefit from treatment tailored to their situation. For example, some patients will benefit from removing the primary kidney cancer, others may not. Some may require immediate medication, in others a *wait and watch* approach may be best. Ask whether you could be eligible for any clinical trials that may offer newer medications.

Don't do it alone – Family and friends will want to help but may not know how to ask or what you need. Involving those close to you in treatment decisions can help you gain invaluable support at what is a stressful time for everyone. Organisations such as Kidney Health Australia can be a source of information and support.

Dr Dan

Where can I get more information about advanced kidney cancer?

This handbook contains introductory information about advanced kidney cancer. If you would like to get more information here are a few suggestions:



RESOURCES



www.kidney.org.au

www.cancer.org.au

www.ikcc.org

www.kcuk.org.uk

www.kidneycancer.org

www.kidneycancercanada.ca

Taking control



How to look after yourself
physically and emotionally

Taking control of your own health

What are my rights as a patient?

When you visit any healthcare professional, remember they are there to advise you about your condition so that you can make an informed choice. As a patient you have the right to:

- Ask questions about your treatment
- Be informed about details of your care (for example what it may cost you)
- Be informed about treatment options
- Get a second medical opinion (doctors expect and understand, and in some instances suggest their patients get a second opinion. Don't worry about hurting the doctor's feelings if you ask for one)
- Get information from other sources about your condition and its treatment

How can I make the most of my visit to the doctor?

In many instances your time with your doctor may be limited and you may be stressed. It is therefore helpful to:

- Take a family member or friend with you
- Make a list of questions and take it with you so you don't forget anything
- Write down information being discussed
- Ask the doctor for any written information that may help explain your cancer

What is shared decision making?

Shared decision making is as simple as talking to your health care team about your choices and making decisions together.

Your health care team are the experts on cancer and its treatment. However, you are the expert of *you* – your quality of life, what is important to you and how your body feels.

You can talk to your health care team about the test and treatment choices you may have. It involves sharing information about options, lifestyle, outcomes, and using this together to make decisions.

If you make decisions with your doctor you are more likely to:

- Follow that treatment
- Work out the best option for you so that you can get the best quality of life for you
- Understand your choices and feel that the decision is right



RESOURCES

- 📄 **Kidney Cancer – Make the most of your visit to the doctor** – Kidney Health Australia
- 📄 **Advanced Kidney Cancer Decision Aid** – International Kidney Cancer Coalition

Dealing with the side effects of medications

A side effect is a secondary and normally unwanted effect of a treatment or medication. All medications can cause side effects, although not everybody gets them. If they do occur, they may be minor and temporary. However, some may be more serious and need medical attention.

What are the common side effects of kidney cancer medications?

- Fatigue
- Taste problems
- Mouth problems
- Hand and foot problems
- Skin and nail problems
- Nausea and vomiting
- Diarrhoea
- Constipation
- Swelling (oedema)
- Cough and shortness of breath
- Insomnia

More information about what you can do to manage your side effects see our fact sheet *Advanced Kidney Cancer – Dealing with the side effects of medications*.



REMEMBER

It is important to remember that you may not have any side effects, you may have one or more of the side effects listed here, or you may have a side effect not listed here. All side effects can vary from very minor to more serious.

What should I do before starting medication?

Before you start taking a medication talk to your doctor or nurse about possible side effects. You may find it useful to get a diary to record any side effects and how bad they are, and take it to your medical appointments.

You could consider putting together a *self-care kit* with some or all of the following items:

- Lip balm
- Fragrance free body, hand & foot creams
- Mild, soap-free cleansing bars
- Fragrance-free shower gel
- Soft-bristle toothbrush
- Non-abrasive toothpaste
- Cotton gloves
- SPF 30+ sunscreen for sensitive skin

What should I do while taking a medication?

Don't stop taking your medication because of side effects until you talk with your doctor or nurse. You may decide that the side effects of your medication outweigh the benefits of continuing medication. If you feel that this is true for you talk to your doctor about trying a different medication or stopping all together.



CALL TO ACTION

If you do notice any side effects do not delay in telling your doctor or healthcare professional. They can work with you to minimise the impact of side effects on your health and quality of life.



RESOURCES



Advanced Kidney Cancer – Dealing with the side effects of medications – Kidney Health Australia

Consumer Medicines Information (CMI) – A leaflet containing information on the safe and effective use of prescription or specified over-the-counter medicine. Ask your healthcare professional for the CMI for your medication or download from www.tga.gov.au/consumer-medicines-information-cmi

Mouth care: caring for your mouth during cancer treatment – Peter MacCallum Cancer Centre

Taste and smell changes – Cancer Council

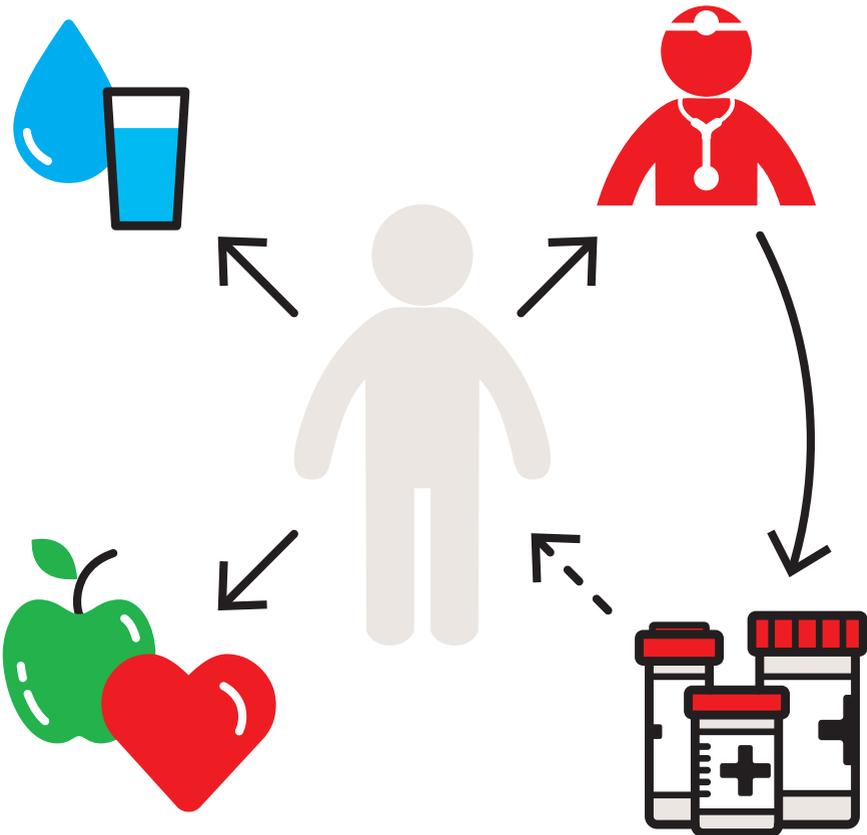
Looking after yourself

Cancer and its treatment can have a huge physical and emotional effect on you.



REMEMBER

It is important to look after your physical and emotional wellbeing during treatment.



Physical wellbeing

Why should I quit smoking if the damage has already been done?

It is never too late to quit smoking. Research has shown that people with kidney cancer who do not smoke live longer than those who do smoke.



CALL TO ACTION

Quitline doubles your chance of quitting smoking for good. Call 13 78 48.

How will exercise help?

Recent research has shown that exercise is beneficial for people with cancer. Moderate regular exercise has been shown to:

- Increase your energy levels
- Elevate your mood
- Help you cope with the side effects of medications
- Boost your immune system to help it fight your cancer
- Help control weight – gaining weight during and after cancer treatment may increase the risk of cancer recurrence

What is more – there are no harmful effects of moderate exercise. The sooner you start the better you will feel.

Exercise tips:

- Do not over do it at the start, you may become discouraged and stop all together
- If you exercised regularly before cancer, lower the intensity of your workouts for a while
- Aim to be as physically active as you can. Try to do at least 30 minutes of moderate exercise on most days of the week
- If you don't have the energy to exercise for a full 30 minutes, break it down into three 10 minute sessions
- Exercise with a friend to keep you motivated and make it more fun
- Drink plenty of water
- Warm up with some gentle stretches
- Don't exercise if you feel unwell



CALL TO ACTION

Ask if your hospital has a special exercise program for people with cancer or if they can refer you to a specialised exercise physiologist. Talk to your doctor before starting an exercise program.

Is healthy eating important?

Yes. Eating a healthy, well-balanced diet is especially important if you have cancer. Both cancer and its treatments can change which nutrients and how much energy your body needs. You may also not be able to tolerate certain foods.

Eating a healthy well-balanced diet might help you:

- Feel better
- Keep up your energy and strength
- Maintain a healthy body weight and your body's store of nutrients
- Cope with side effects better
- Lower your risk of getting an infection
- Heal and recover faster

A healthy, well-balanced diet involves eating a variety of foods from each food group daily, in the recommended amounts. These food groups include proteins, carbohydrates, fats, vitamins and minerals.



CALL TO ACTION

The nutrient needs of people with cancer vary from person to person. Talk to a dietitian or your doctor to help you plan a well-balanced diet to help you fight cancer.



RESOURCES

- 📄 **Healthy eating to reduce cancer risk** – Cancer Council
- Nutrition information for people with cancer, their families and friends** – Peter MacCallum Cancer Centre
- Fatigue: coping with cancer fatigue** – Cancer Council
- Fatigue: practical ways of dealing with cancer-related fatigue** – Peter MacCallum Cancer Centre
- Sleep problems in cancer** – Peter MacCallum Cancer Centre
- 📄 **Exercise for people living with cancer** – Cancer Council
- Nutrition and Cancer** – Cancer Council
- 📄 **www.icanquit.com.au** – Learn about the benefits of quitting smoking, and to keep you motivated during your quit smoking journey
- www.quitbecauseyoucan.org.au**
- www.quit.org.au** – Quit
- ☎️ **National Quitline 13 78 48**

Sexuality

Cancer and its treatments can affect your sexuality. This can be for many different reasons. It may be because of your emotional state, low self-confidence, decreased energy levels, medication side effects or your relationship with your partner.

Even if you don't have sexual intercourse with your partner it is important to maintain intimacy and closeness.



REMEMBER

Maintain intimacy and closeness with your partner though holding hands, hugging or massage.

What can I do to look after my health and well-being?



Learn about kidney cancer



Exercise regularly



Take control of your health



Eat healthy



Stop smoking



Look after your emotional wellbeing

Emotional wellbeing

Anxiety and depression are quite common in people who have or had cancer.

Could I be suffering from anxiety?

Anxiety is more than a passing feeling of being worried. Do you often feel like you:

- Do you constantly feel *stressed*?
- Are constantly agitated or angry?
- Have difficulty sleeping?
- Have difficulty concentrating or making decisions?
- Avoid distressing issues and situations?
- Have a need to be constantly reassured?

If you answered yes to any of these you may be suffering from anxiety.

Could I be depressed?

Depression is more than a passing phase of being happy or sad. Do you often feel like you:

- Cannot get out of bed?
- Have lost motivation to do anything, including things that used to give you pleasure?
- Have a black cloud hanging over your head?
- Are unreasonably moody or angry or anti-social?
- Are not interested in how you look?
- Want to end your life?
- Eat excessive amounts of food or drink excessive amounts of alcohol?

If you answered yes to any of these you may be depressed.



CALL TO ACTION

You need to talk to someone you trust who can assess you properly. Your GP is a good option. Your GP will be able to recommend counselling or medication to treat your depression or anxiety.



RESOURCES

-  **Anxiety: understanding and managing anxiety when living with cancer** – Peter MacCallum Cancer Centre
- Depression: understanding and managing depression in cancer** – Peter MacCallum Cancer Centre
- Cancer – how are you travelling? Understanding the emotional and social impact of cancer** – Cancer Australia
- Chronic physical illness, anxiety and depression** – Beyond Blue
- Coping with a serious health event: how to keep mentally well** – Beyond Blue
- Questions you may wish to ask about the time after treatment** – Australian Cancer Survivorship Centre
-  **Emotions and Cancer** – Cancer Council
- Loss and grief** – Cancer Council
- Understanding Grief** – Cancer Council
-  **www.beyondblue.org.au**
- www.cancer.org.au**
- Better Access Initiative: Medicare-subsidised referral to psychologist through your GP
- www.health.gov.au/mentalhealth-betteraccess**
-  Beyond Blue **1300 224 636**
- Life Line **13 11 14**
- Cancer Council **13 11 20** – The Cancer Council offer a free and confidential intimacy counselling service for men, women and partners

Support



You are not alone – how others can help you and you can help them

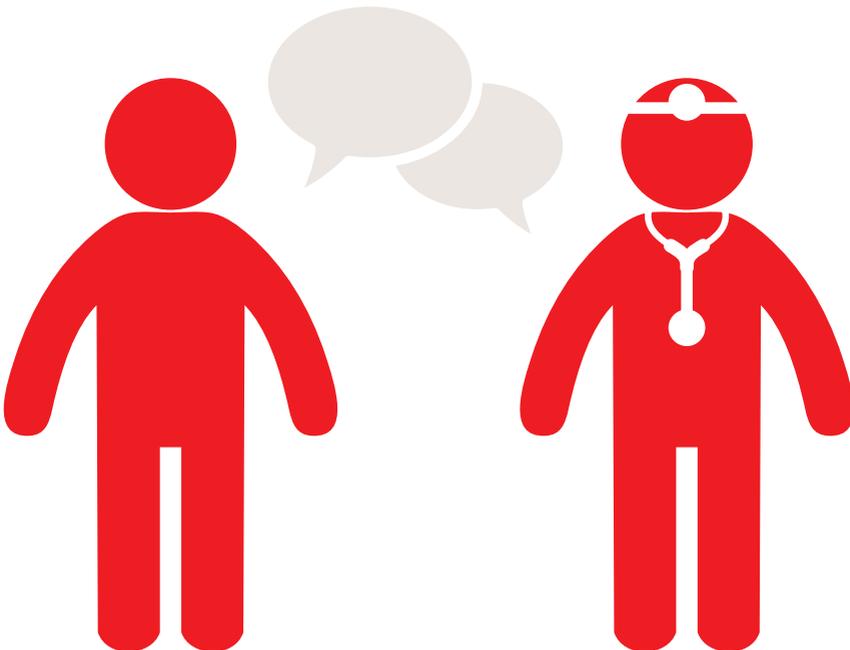
You are not alone

Your health care team is there to support you

The most important and powerful person in your health care is actually **you!** There are many steps that you can take to become an advocate in your own health care and this handbook is designed to help you. Learning about kidney cancer and understanding the things that you can do to maximise your own health and well-being are incredibly valuable. However, **you are not alone!**

Who is involved in my healthcare?

There is a range of specialised professionals that will become involved in your care and they will work together in what is known as a healthcare or multidisciplinary team. The particular healthcare professionals that make up your team will depend on your individual circumstances.



Here is a list of healthcare professionals that may be involved in your care and the role they will have:

Urologist	A urologist will perform your surgery if you need to have an operation for your kidney cancer.
Medical oncologist	A medical oncologist will use medication to treat your cancer. They will help to manage your overall health, cancer symptoms and medication side effects.
Radiation oncologist	A radiation oncologist will prescribe and coordinate radiation therapy to treat your cancer.
Nephrologist	You may see a nephrologist or specialised kidney doctor if you are at particular risk of developing chronic kidney disease.
General practitioner	Your general practitioner will be able to help with referrals to specialist doctors, managing cancer symptoms and medication side effects, and coordinating your care.
Cancer nurse	A specialised cancer nurse will provide education about kidney cancer, administer medication and support you throughout your treatment.

Cancer care coordinator	A central person to liaise with other members of your multidisciplinary team and support you and your family.
Palliative care doctor	A palliative care doctor will help to relieve suffering and improve your quality of life.
Palliative care nurse	A nurse will work with the palliative care doctor to coordinate your treatment and support plan.
Psychologist	A psychologist will help you cope with the impact cancer has on your mental health and your relationships.
Occupational therapist	An occupational therapist will work with you to enable you to participate as much as possible in the activities of everyday life.
Social worker	A social worker will provide help with the practical aspects of living with cancer.
Dietitian	A dietitian will advise you about eating a healthy diet during your treatment.
Physiotherapist	A physiotherapist will help you manage pain and disability through exercise, massage and manipulation.
Exercise physiologist	An exercise physiologist will develop an exercise program tailored to you.

Your family and friends are there to support you

Family and friends are an invaluable source of support, whether it's helping with the shopping, coming to doctor appointments or simply being with you. Let your family and friends, and anyone else who you think can help, be there for you.

How will my family and friends react to my cancer diagnosis?

Your cancer diagnosis will affect your family and friends and your relationship with them. Just as you will take time to adjust to your diagnosis so will your family and friends.

You may think that if you do not talk to your family and friends about your cancer and your feelings, that you are protecting them. However, not talking to them will only make them feel shut out and scared. Let them in – it will help you and help them.

Remember that people deal with bad news in different ways. Some people will try and pretend nothing has happened, others will be overly cheerful and positive, some will need to talk about what is going on and others may avoid you. Everyone will be different and cope in different ways. You may find it useful to talk about your cancer and your feelings with each other.



REMEMBER

Do not underestimate the role your partner or close friend will play in all aspects of your well being and motivation to stay positive. Do not forget they will be suffering too. They will need help and support as well as you.



CALL TO ACTION

Take a family member or friend along with you to your healthcare professional appointments.



SISTER EMMA'S TIPS

Everyday is different – I have heard people describe it as a rollercoaster. There are good days and bad days so try to cherish the good ones and keep the bad ones in perspective – every day is not the same.

In control – *Patients often tell me that they feel they have no control.* They are overwhelmed with the diagnosis and future. Focus on the smaller things you can achieve each day and praise yourself for these accomplishments.

Organised – There can be a many appointments, scans, medications to keep track of. Being organised can mean one less thing to think of. Keeping everything in one folder/bag minimises losing appointments, blood slips, scans. A diary may help, and your nurse can fill it in at each visit with the next tests that are due.

Sister Emma



I am a carer for someone with cancer. What can I do?

Being a carer for a loved one with cancer can be rewarding. But it can also be tiring, stressful, challenging and cause you a lot of anxiety. It is important that you make sure you look after yourself and take some time just for you. It is also important that you get some help and support too.

Here are some suggestions to help you look after yourself:

- Make sure you eat a healthy balanced diet with plenty of water
- Get some exercise – take a walk with a friend
- Ensure that you get enough sleep
- Make sure you do something you enjoy every day even if it is only for 15 minutes
- Keep in touch with your friends and socialise
- Organise some respite care for your loved one to give you both a break

There are a number of people and organisations that can provide you with more information and support. Your loved one's social worker is often a good person to talk to.



REMEMBER

Make sure you look after yourself. Take some time just for you.



CALL TO ACTION

Help and support is available – contact one of the carer support organisations.



RESOURCES



Caring for Someone with Cancer – Cancer Council



Cancer Council **13 11 20**

www.cancer.org.au

Carers Australia **1800 242 636**

www.carersaustralia.com.au

Provides information, advice, counselling, support groups, advocacy, education and training for carers. They also run the National Carer Counselling Program (NCCP) a short-term counselling program for carers delivered by qualified, professional counsellors either in person, by telephone, one-on-one or in a group. Ask for a free Carer Support Kit.

My Aged Care **1800 200 422**

www.myagedcare.gov.au

Information about the aged care system including respite care, help at home, after hospital care and residential care.

Commonwealth Respite and Carelink Centres

1800 052 222 (1800 059 059 for emergency respite)

www.dss.gov.au > Disability and carers > Programmes services > For carers > Commonwealth respite and carelink centres – Information about how to access respite care at home, in a centre, or at hospital.



BELINDA'S STORY

My daughter Bec was diagnosed with kidney cancer when she was 13 years old. A year after her surgery we found out it had metastasised. She died aged 19. My husband and I were her carers.

The role of carer is rewarding but can also be challenging. Here is some advice I would give to someone caring for a loved one with advanced kidney cancer.



Communication is key – Communication between the carer and patient is vital in keeping a positive and balanced relationship.

Support but don't smother – a difficult balance! It is important for the patient to be empowered and in control but also know that their carers are there to support and offer guidance if needed.

Planning for all appointments – It is critical to support the patient when they see a health professional. Go to appointments with them, ensure that key questions are asked and encourage them to speak up for themselves. Encourage them not just say everything is good when it isn't just because they feel they don't want to be a bother or a burden to their treating team, family or friends.

Plan for the good and bad times – The patient will have good and bad weeks and sometimes these can be predicted. Many of the advanced kidney cancer medications have side effects that can impact daily quality of life. However, the medications are often taken in a cycle, with a couple of weeks break in between. Take advantage of the breaks and plan *treats* for when you know they are going to feel at their best. It will also give them something to look forward to when struggling through the harder weeks.



During the *bad times* plan quieter in-house activities and get friends to visit. Never hesitate to tell people when would be a good time to visit.

Live life to fullest – Spend time with family and friends, go to the movies, go out to dinner, go on holiday. Try and make sure that important milestones are celebrated along the way. For us it meant debutante balls, formals, birthdays, schoolies. Just have fun.

Give each other space and time to forget about cancer – Make sure the patient spends time being *normal*, spending time with friends, doing activities they enjoy, and being just like everyone else whenever possible. Make sure you do the same. Try and forget about ‘cancer’ for a while.

Don’t forget other loved ones – Make sure that other family members are not left out, their important milestones are not missed, and they are loved. Everyone is as important as each other. This adds to the creativity of the carer’s balancing act.

Talk about end of life choices – Talking to each other about end of life choices is very challenging but crucial. You need to be able to carry out their wishes some of which can be done before they pass.



Our daughter brought special angel charms for her *besties* which she gave to them herself in the last few days. It meant a lot to everyone.

Accept help from other people – It is natural to want to be independent and *do* everything yourself. But please do accept help from family and friends. This will not only help you, but can also help those wanting to do something for you. They may otherwise feel useless and this can sadly affect your long term relationship with them.

So communicate, listen, support and take care of yourself as well.

Belinda

There are other people to connect with too

Most people know people who have had breast or prostate cancer, but because kidney cancer is relatively rare you may not know of anybody else who has had or has kidney cancer. This can make you feel very isolated and alone.

Some people find that it is enough to talk to family and friends. However, you may find it useful to talk to other people who have or had cancer, or to someone trained in supporting people with cancer.

Talking to other people who understand what you are going through may help you feel less alone. Often it is easier to talk openly and honestly to someone who is not close to you. That way you can just worry about your concerns and not those of your family or friends.

What ways are there to get support?

- Telephone support – talk on the phone to someone trained in supporting people with cancer
- Online support communities – chat online to other people who have had kidney cancer using an online cancer forum
- Peer support groups – match you with someone who has had a similar cancer experience
- Telephone support groups – facilitated by trained counsellors
- Face-to-face groups – often held in community centres or hospitals
- A church or spiritual group – if you are a member of a church or spiritual group they can be a great source of support



RESOURCES



Kidney Health Australia Cancer Support and Information Service **Freecall 1800 454363**
www.kidneycancer.org.au



Cancer Council Australia **Freecall 131 120**
www.cancer.org.au – Information about a variety of support groups including:
Peer support groups – match you with someone who has had a similar cancer experience.
Telephone support groups – facilitated by trained counsellors.
Face-to-face groups – often held in community centres or hospitals one-on-one counsellors.

Connect with others using our Kidney Forum
www.kidney.org.au > Connect > Forum > Your kidney forum – Kidney Health Australia's kidney forum. Here you can relate your stories, ask questions, share practical information and, most of all, support each other.

www.cancerconnections.com.au

There are organisations that can offer financial and legal advice

Having cancer can be expensive and you may need to get some financial advice. The cost of treatment, transport and accommodation expenses may be made worse by possible loss of wages.

There are also a number of legal issues that you will have to manage such as wills, power of attorney, financial and employment issues.



RESOURCES



Australian Cancer Foundation **02 8001 6337**

www.acfoundation.com.au – Provides financial assistance and accommodation for cancer patients and their families.

Cancer Council **13 11 20**

www.cancer.org.au

Centrelink **132 717**

www.humanservices.gov.au > Carers >

Payments for carers – Offers financial support for people with a long-term illness and for primary carers.

Kidney dictionary



Medical terms, acronyms
and abbreviations

What does that word mean?

A

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

Active surveillance – A treatment plan that involves closely monitoring the kidney cancer but not giving any treatment unless the tumour gets larger. It is used to avoid or delay surgery or other treatments in certain circumstances.

Adrenal gland – triangular glands on top of each kidney that produce adrenaline and other hormones.

Anaesthetic – A medication that stops a person feeling pain during a medical procedure. A general anaesthetic affects the whole of your body by making you temporarily unconscious. A local anaesthetic affects only part of your body by making that area numb.

B

Benign tumour – Not cancer. A tumour that will not spread to the rest of the body.

Biopsy – Removal of a small sample of tissue from the body to be examined under the microscope to help diagnose a disease.

Bladder – the organ that stores urine.

Bone scan – A scan using small amounts of radioactive material to see if the cancer has spread to the bones.

C

Checkpoint inhibitor – A type of immunotherapy.

Clinical trial – A type of research study that tests how well new medical approaches work in humans. These studies test new methods of screening, prevention, diagnosis, or treatment of a disease.

Computer Tomography Scan (CT) – A scan using X-rays to get detailed pictures of the body.

Contrast medium/agent/dye – A substance injected into a vein before a scan that gives more information about the tumour.

Cystoscopy – A test using a special telescope to look into the bladder.

Cytoreductive nephrectomy – Surgical removal of as much of a tumour as possible. This surgery is used when the cancer has spread. Also known as debulking surgery.

F

First line treatment – The recommended treatment that will be tried first.

Follow-up care – Care given to a patient over time after finishing treatment for a disease. Follow-up care involves regular medical check-ups, which may include a physical examination, blood tests and scans. Follow-up care looks for the development of other health problems and recurrence of cancer.

G

Grading – A score that is used to describe how quickly (aggressive) a tumour is likely to grow.

H

Haematuria – Blood in the urine.

I

Immune system – A network of cells and organs that protect the body against attacks from foreign substances such as viruses and bacteria.

Immunotherapy (Immuno-oncology) – A way to treat cancer by activating your immune system to attack cancer cells with less harm to normal cells.

Incision – A surgical cut.

Intravenous – Injected into a vein.

L

Laparoscope – A small tube with a video camera which is used to see structures in the abdomen and pelvis during laparoscopic surgery.

Laparoscopic surgery – A method of surgery where the operation is done using thin surgical instruments and a laparoscope inserted through small incisions in the abdominal wall. Also known as keyhole or minimally invasive surgery.

Lymph nodes – A small round gland that makes up part of the lymphatic system. They contain white blood cells that remove bacteria, cancer cells and foreign particles from the body.

Lymphatic system – A network of tissues, vessels, ducts and nodes that remove excess fluid from tissues, absorb and transport fat, and produce immune cells.

M

Magnetic resonance imaging scan (MRI) –

A scan using magnetic and radio waves to produce a detailed pictures of the body.

Malignant tumour – Cancer. A tumour that grows continuously or in spurts. Malignant tumours can metastasise, which means they can spread to other organs.

Mammalian target of rapamycin (mTOR) inhibitors –

Targeted medications that block chemicals in the body connected to cell growth.

Metastasectomy – Surgical removal of metastases.

Metastasis/secondary cancer – A cancer that has spread from the primary cancer to other parts of the body.

Metastasise – Cancer cells can travel from the primary cancer to other parts of the body to become secondary cancers or metastases.

Multidisciplinary team – A group of healthcare professionals who work together to plan and coordinate your care.

O

Oncologist – A doctor who uses medications to treat cancer and will help to manage your overall health. Also called a medical oncologist.

Open surgery – The traditional type of surgery. A large incision is made in the skin and tissues for the surgeon to insert the instruments and get direct access to the operation field.

P

Palliative care – Treatments and support that improve the quality of life of patients and their families facing the problems associated with life-threatening illness.

Partial nephrectomy – Surgical removal of the tumour only, the healthy kidney tissue is left untouched. Also known as nephron-sparing surgery.

Primary cancer – The original cancer. The cancer is named after the part of the body the cancer starts.

Prognosis – The predicted outcome of a person's disease.

R

Radical nephrectomy – The surgical removal of the whole of the kidney. If the cancer has spread to the adrenal gland, surrounding fatty tissues and lymph nodes they may be removed as well.

Radiation – Energy waves or particles (X-rays, gamma rays, UV rays). This energy is harmful to cells.

Radiation oncologist – A doctor who prescribes and coordinates radiation therapy to treat cancer.

Radiotherapy – The use of radiation to kill cancer cells.

Renal – Another word for the kidney.

Renal cell carcinoma (RCC) – The most common type of kidney cancer. Also called renal adenoma.

Renal pelvis – The area where the kidney and ureter meet.

Robotic surgery – A type of laparoscopic surgery where the surgical instruments are attached to a robotic arm that the surgeon controls.

S

Secondary cancer/Metastatic disease – When the tumour has spread from the primary site to other organs or lymph nodes.

Side effect – A secondary and normally unwanted effect of a treatment or medication.

Staging – A score that is used to determine how far a cancer has spread.

Stereotactic body radiotherapy (SBRT) – A specialised form of precise, high dose radiotherapy used to treat tumours in the body.

Stereotactic radiosurgery (SRS) – A specialised form of precise, high dose radiotherapy used to treat tumours in the brain.

T

Targeted therapy – A type of treatment that uses medications or other substances to identify and attack specific elements of cancer cells with less harm to normal cells.

Tumour – An abnormal growth of tissue on or in the body. A tumour may be benign or malignant. Other words that may be used include growth, neoplasm, lump, mass, or shadow.

Tyrosine kinase inhibitors – Targeted medications that block the enzyme tyrosine kinase, a chemical messenger that tells cells when to divide and grow.

U

Ultrasound – A scan that uses soundwaves to generate a picture of parts of the body.

Ureters – Tubes that carry urine from each kidney to the bladder.

Urethra – Tube that carries urine from the bladder to the outside of the body.

Urinary system – The system that removes waste from the blood and gets rid of it from the body in the urine. It includes the kidneys, ureters, bladder and urethra.

Urologist – A doctor who specialises in treating diseases of the urinary tract. If you need to have surgery for your kidney cancer your urologist will do the operation.

Urothelial carcinoma – A kidney cancer that starts from the renal pelvis, the ureter or the bladder. Also known as transitional cell carcinoma (TCC).

Connect with us
www.kidney.org.au
Freecall 1800 454 363

