

Fact sheet

Advanced Kidney Cancer



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Introduction

Our series of kidney cancer fact sheets have been developed to help you understand more about kidney cancer. This fact sheet provides information about advanced kidney cancer. Advanced kidney cancer is cancer that has spread beyond the kidney to distant lymph nodes or to other organs.

For more information relating to other aspects of kidney cancer please see our other fact sheets:

- Kidney Cancer
- Diagnosis and Types of Kidney Cancer
- Localised Kidney Cancer
- Support for Kidney Cancer
- Advanced Kidney Cancer – Dealing with the side effects of medication: targeted therapy
- Kidney Cancer – Make the most of your visit to the doctor

These fact sheets are meant as an introduction only and are not meant to be a substitute for your doctor's or healthcare professional's advice. Always consult your doctor or healthcare professional for more advice.

Who is involved in my health care?

A range of specialised healthcare professionals 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 drug side effects, and coordinating your care.

Cancer nurse

A specialised cancer nurse will provide education about kidney cancer, administer drugs 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.

Occupational therapist

An occupational therapist will work with you to enable you to participate as much as possible in the activities of everyday life.

Psychologist

A psychologist will help you cope with the impact cancer has on your mental health and your relationships.

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.

Psychotherapist

A psychotherapist will help you manage pain and disability through exercise and manipulation.

Exercise physiologist

An exercise physiologist will develop an exercise program tailored to you.

How is advanced kidney cancer treated?

Advanced kidney cancer is not usually curable so the goal in advanced kidney cancer is to make life as long and as normal as possible. Your healthcare team will guide you through the range of treatments that may suit your individual needs.

The combination of different treatments options that you will be offered may include: active surveillance, surgery, medication, and radiation. There are also some general things you can do to stay healthy which will help you to continue with normal daily activities. It is important to eat healthy, continue to exercise and look after other aspects of your health.

Active surveillance

Active 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. A period of active surveillance has no bad effect on long term health.

Where 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?

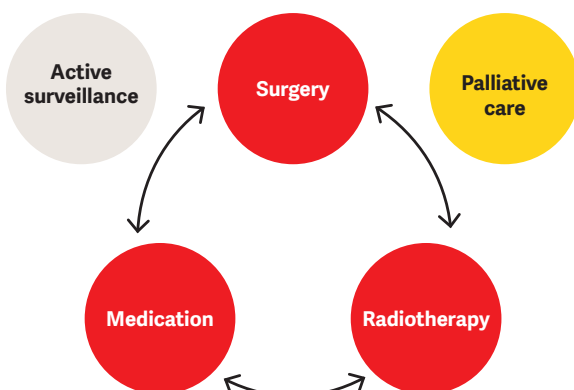
- It may prevent symptoms and problems caused by the cancer
- In some cases removing the primary kidney cancer improves survival and helps other treatments work better.

What are the different surgical options that may be offered?

- **Cytoreductive nephrectomy** – removal of the kidney to remove as much of the cancer as possible. Also known as debulking surgery.
- **Nephrectomy plus removal 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. This is only possible if the cancer has spread to just one or two places. It is done with a removal of the kidney (nephrectomy).

The different surgical options that you may be offered depend on your situation. Surgery is only possible if you are fit enough to have an operation and the tumour can be removed.

For more information about surgery in general see our fact sheet on *Localised Kidney Cancer*.



Medication

In advanced kidney cancer medications are either used together with surgery, or on their own. There are a number of different types of drug treatments. The different drugs attack the cancer in different ways. You will be started on one type of drug (first line treatment), and then if that doesn't work or stops working, then you may be offered a different type of drug (second-line treatment).

In advanced kidney cancer drug treatments are used on their own or with surgery.



1. Targeted therapy

Targeted therapies are medications that block specific targets in blood vessels or cancer cells. This stops or slows down growth of the cancer and can reduce its size. Because only the cancer is targeted, damage to healthy cells is limited.

Two types of targeted drugs, called tyrosine kinase inhibitors (TKIs) and mammalian target of rapamycin (mTORs) are currently available in Australia for people with advanced kidney cancer.

Tyrosine kinase inhibitors (TKIs):

- Block blood vessels and cancer cell growth and development
- Taken as tablets
- Side effects may include fatigue, diarrhoea, nausea, high blood pressure, and tenderness and sensitivity in the hands and feet, skin rashes, mouth ulcers, shortness of breath and chest pain
- Examples of this type of drug include: axitinib, cabozantinib, pazopanib, sorafenib, sunitinib.

mTOR inhibitors:

- Block cancer cells growth and development
- Taken as tablets or injected into a vein
- Side effects include diarrhoea, mouth ulcers, cough, changes in blood cholesterol, fats, phosphorus and anaemia.
- Examples of this type of drug include everolimus and temsirolimus.

2. Immunotherapy

The immune system defends the body against attack by foreign substances such as viruses (like the common cold) and bacteria, but it can also attack cancer cells. Immunotherapy medications treat cancer by activating your immune system to attack cancer cells.

The new immunotherapy drugs are known as *checkpoint inhibitors*. Checkpoint inhibitors act as a kind of switch that allows your immune system to attack cancer cells. This stops or slows down growth of the cancer and can reduce its size.

Because only the cancer is targeted, damage to healthy cells is limited.

Checkpoint inhibitors:

- Given into a vein (intravenously) every 2–3 weeks, usually for as long as it controls the cancer
- Side effects include fatigue, skin reactions, diarrhoea, abdominal pain, loss of appetite, anaemia, fever, stiff or painful joints, sore and red eyes, shortness of breath and chest pain
- Examples of this class of drug are atezolizumab, avelumab, bevacizumab, nivolumab, pembrolizumab.

Older immunotherapy used injections of interferon or interleukin. Although they are effective in a small number of people, they are not used as standard treatment in Australia as they have serious side effects.

3. Chemotherapy medications

Chemotherapy works by killing dividing and growing cells including cancer cells. However, chemotherapy medications are not usually used for treating kidney cancers (except urothelial carcinoma and Wilms tumour) as other treatments work better.

Some of the medications above are not available in Australia or listed on the Pharmaceutical Benefits Scheme (PBS) (i.e. at regular prescription costs). However it is sometimes possible to get access to them in a clinical trial. More information about clinical trials is given in the next section.

Radiotherapy

Radiotherapy uses high energy X-rays to kill cancer cells. In kidney cancer radiation can be 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
 - control symptoms due to cancer in the brain.
- Control limited sites of cancer spread (metastases) or the primary cancer to slow down cancer progression. This is done using precise, high dose specialised forms of radiotherapy. These are:
 - Stereotactic body radiotherapy (SBRT) for metastases or the primary tumour
 - Stereotactic radiosurgery (SRS) for metastases in the brain

Treatment is given as an outpatient either as a single dose of radiation or divided up into several doses, in which case you would need to visit the hospital several times. You might have some side effects such as fatigue, nausea, appetite loss, diarrhoea, tiredness and skin irritation.

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. There are advantages and disadvantages to participating in a clinical trial that you will need to consider.

Advantages:

- A clinical trial may be the best treatment option available
- The trial may give you access to a new treatment before it becomes widely available
- You will receive additional care from your healthcare team
- Just participating in a trial means that you are helping make medical advances.

Disadvantages:

- You may not receive the new treatment. You may receive the standard treatment that the new treatment is being compared with in the trial
- The new treatment may not work as well as the standard treatment
- There may be more side effects with the new treatment
- You may need to visit the hospital or clinic more often and have more tests.

If you do decide to participate in a clinical trial you may stop participating at any time for any personal or medical reason.

For more information about clinical trials and a list of currently available clinical trials in Australia visit our website at www.kidney.org

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

How will my ongoing care be organised?

There will be a lot to think about and organise as you proceed on your cancer journey and you are likely to need some help and support with this.

- In some hospitals cancer care coordinators are available to help you with planning and treatment
- Your GP will be invaluable to help you to manage symptoms, coordinate referrals and provide other assistance
- For more information on how to best manage your visits to healthcare providers and organise your cancer treatment see our fact sheet *Kidney Cancer: How to make the most of your visit to the doctor.*

Will my needs change?

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.

At some point you may decide that the side effects of treatment outweigh the benefits.



What is 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 includes:

- Cancer symptom management
- Side effects of medication management
- Helping with other physical problems
- Providing emotional and social support
- Extensive support to both you and your family during the dying process.

Palliative care helps you feel as good as you possibly can.

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.

Starting palliative care early can prolong your life.

Who can I contact for more support & information?

Both Kidney Health Australia and the Cancer Council offer a free and confidential service for further support and information.

Kidney Health Australia Cancer Support & Information Service
Kidney Health Australia provides support and information for kidney cancer patients, their families and carers in a variety of different ways.

Free call: **1800 454 363**
kidneycancer@kidney.org.au
kidneycancer.org.au
forum.kidney.org.au



Cancer Council offers reliable cancer information and support to anyone affected by cancer, including patients, carers, families, friends, and healthcare professionals. They can connect you with others who have been through a similar experience and link you to practical, emotional and financial support in your area.

Free call: **13 11 20**
cancer.org.au



For more information about kidney or urinary health, please contact our free call Kidney Health Information Service (KHIS) on 1800 454 363.

Or visit our website **kidney.org.au** to access free health literature.

This is intended as a general introduction to this topic and is not meant to substitute for your doctor's or healthcare professional's advice. All care is taken to ensure that the information is relevant to the reader and applicable to each state in Australia. It should be noted that Kidney Health Australia recognises that each person's experience is individual and that variations do occur in treatment and management due to personal circumstances, the healthcare professional and the state one lives in. Should you require further information always consult your doctor or healthcare professional.



If you have a **hearing or speech impairment**, contact the National Relay Service on **1800 555 677** or **relayservice.com.au**

For all types of services ask for 1800 454 363

What does that word mean?

Checkpoint inhibitor – An immunotherapy drug.

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.

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

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

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

Immunotherapy – A way to treat cancer by activating your immune system to attack cancer cells with less harm to normal cells.

Mammalian target of rapamycin (mTOR) inhibitors – Targeted drugs 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. If there is more than one metastasis they are known as metastases.

Metastasis – The spread of cancer cells from the primary cancer to other parts of the body to become secondary cancers or metastasis.

Multidisciplinary team – The name given to all the health professionals involved in looking after you.

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

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

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.

Second line treatment – A treatment that is used if a first line treatment doesn't work or stops working.

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.

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