

Fact sheet

Kidney Cancer – Make the most of your visit to the doctor

i

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 how you can get the most out of your visit to your healthcare professional.

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
- Advanced Kidney Cancer
- Support for Kidney Cancer
- Advanced Kidney Cancer – Dealing with the side effects of medication: targeted therapy

For more general information see our fact sheets:

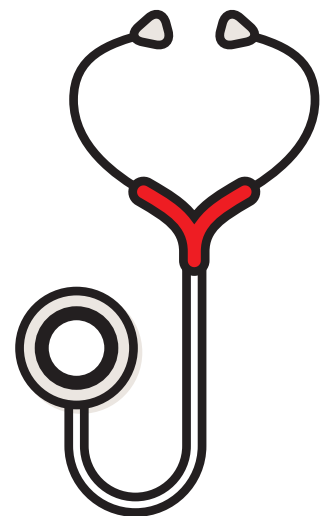
- Informed Consent for Medical Tests
- Using the Internet to Research Health Information

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.

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.



What can I do before I visit the doctor?

In many instances your time with your doctor may be limited. It is helpful to prepare for the visit in advance. This may include:

- Make a list of your questions so you don't forget anything. Rank your questions in order of importance in case you run out of time.
- Take a family member or friend with you when you go to see your doctor. They may remember questions you forgot in the moment and can help you review the information after your appointment.
- Know the name and dosage of all your medications including anything you buy 'over the counter' at the chemist or supermarket. Consider taking a list of your medications to your doctor or take all the bottles and packets with you if that is easier.
- Giving a written record of your major past medical and surgical events to the doctor on your first visit is an excellent idea. Knowing about your family's medical history is also helpful.
- If you don't know a lot about your condition, you may want to try to get some written information. This will help you understand and become familiar with the medical terms so that it's easier to discuss concerns with your doctor.

- Leave plenty of time to get to your appointment and if you are driving have a clear idea of where you are going to park. Many hospitals have information about parking on their websites. If you think it might be stressful to drive and try and park, consider asking a friend to drive you to your appointment.

Take a family member or friend with you when you go and see your doctor.

What can I do during the visit?

- Tell the doctor you have some questions
- Write down the answers – don't trust your memory. Most people remember less than half the information they are given. You may wish to ask your family member to record the information that is being discussed.
- Tell your doctor if you are getting advice or treatment from another healthcare professional including complementary therapies, vitamin supplements or herbal treatments.
- Your doctor should give a clear explanation of your condition, choice of available treatments, and advise you on the best treatment options for your situation. They should also detail the list of possible side effects.
- Ask your doctor to write names of any medications you must take and the details of any treatments.
- If you think you may not be able to follow any instructions tell your doctor immediately to avoid problems later.
- Make sure you have a clear idea of your treatment plan, including dates of any surgery, where and when to get any blood tests and imaging done.
- If you are having surgery make sure you know how to prepare for the operation. You must not eat, smoke or drink 6 hours before surgery. Some medications will need to be stopped several days before surgery.
- Ask for any written information that may help you understand your condition.

Write down information being discussed – ideally get your family member or friend to do this for you.

What can I do after the visit?

- Don't be afraid to call your doctor between visits with any concerns.
- Consider keeping a written record of your contact with healthcare professionals. You could keep a folder with all your appointments, test results and medications.
- Try using one of the smartphone applications (apps) to help you manage your cancer, such as the Cancer.Net app (available on iTunes or GooglePlay).
- Trust and respect is important in a doctor-patient relationship. If you don't feel comfortable with your doctor it may be worth getting another opinion. Different people are suited to different doctors so find someone you can relate to.
- Contact Kidney Cancer Support Service or the Cancer Council for more information and support.

Remember, you are responsible for your well being

What questions can I ask the doctor?

Good communication is important and asking questions can make your visit more useful. Remember that writing down questions and making notes about answers can be helpful when reviewing information after your visit.

Below is a list of questions you may want to ask to get a better understanding of kidney cancer and possible treatments. Tick the questions you want to ask and write down any others not listed.

Diagnosis

- What type of kidney cancer do I have?
- Has the cancer spread to other parts of my body?
- What type of symptoms can I expect?

Tests

- What sort of tests will I need to have?
- What will they tell us? Will they confirm my diagnosis?
- What can I expect during a test?

Optimal Care

- Can I get a second opinion?
- Are there any guidelines for the treatment of kidney cancer?
- Do you specialise in treating kidney cancer?
- Do you work in a multidisciplinary team?
- Are there other healthcare professionals that I need to see?

Treatment

- What sort of treatment will I need?
- When will I need to start treatment? Do I need to start straight away?
- Do I need to make a decision about treatment today?
- Is active surveillance an option for me?
- What are the benefits of this type of treatment?
- Are there any risks to this treatment?
- What is the success or failure rate of this treatment?
- Are there any immediate side effects to this treatment?
- Does this treatment cause any other long-term changes either physical, social, emotional, mental or sexual?
- Where will I have my treatment?
- What exactly is going to happen when I have my treatment?
- What should I do before, during, and after my treatment?
- How long will I have to undergo treatment?
- What sort of follow-up will I need?
- Are there any other treatment choices?
- What happens if I choose to have no treatment?
- What should I expect after treatment?

Clinical trials

- What is a clinical trial?
- What will happen if I enrol in a clinical trial?
- Are there any clinical trials suitable for me?
- What are the advantages for me in participating in a clinical trial? What are the disadvantages?

Prognosis

- What is the long-term survival with my kind of kidney cancer?
- What is the likely course of this kidney cancer?
- What is the likelihood of my cancer recurring after treatment?
- What is the aim of treatment? To cure my cancer, or control it and manage symptoms?
- How likely is the cancer to spread to other parts of my body if I don't have more treatment?
- How likely is the cancer to spread to other parts of my body if I do have more treatment?
- Is treatment going to improve my chance of survival?
- Is treatment going to improve the control of my cancer and improve my symptoms?

Costs

- How much is this treatment going to cost?
- Where can I get information about financial assistance?
- Is there any difference between having treatment in a public versus a private setting?

Support information

- Do you have any information that I can take with me?
- Where can I get more information about kidney cancer?
- Is there someone I can talk to who has had kidney cancer?
- Are there any support groups for me and my family?
- Would complementary therapies help my health?
- Do I need to change my lifestyle, e.g. diet, exercise, weight?

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