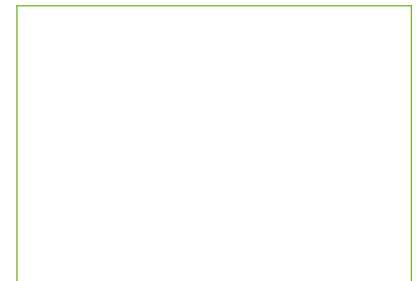
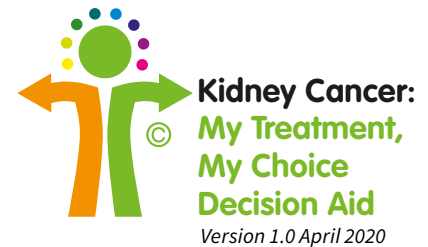


My Treatment, My Choice

A decision aid for people with small renal masses



Supporting you in the shared decision-making process with your healthcare team



Insert your organisation logo here

Insert your organisation logo, address and contacts here

This workbook belongs to:

Disclaimer

This decision aid is intended for patients to use alongside the advice of their healthcare team. It does not support any particular course of treatment over another. Use of this decision aid is voluntary.

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**Small Renal Masses:
My Treatment, My Choice
Decision Aid**

Version 1.0 April 2020



Perhaps you are reading this decision aid because you have a small renal mass (SRM) yourself, or someone you care about has one. Understanding what having a SRM means and figuring out the treatment options can be overwhelming. We have made this document to help you get through this challenging but important task.



As patients and patient advocates for kidney cancer worldwide, our strongest belief is that patients and their families have an essential role to play in healthcare decision-making that affects their lives.

This decision aid was written by a collaborative team of patients, patient advocates and medical professionals who have supported thousands of kidney cancer patients worldwide.

You may find that this decision aid contains a lot of medical information and new terms. If you find it difficult to read all at once, it might be helpful to read it in sections or re-read it again at another time.

We hope that you find this book helpful as you navigate the decisions ahead with your healthcare team.

*Sincerely,
Dr. Rachel Giles,
Chair, International Kidney Cancer Coalition*

*Dr. Michael A.S. Jewett,
Chair, IKCC Medical Advisory Board*

www.ikcc.org

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About this decision aid

This decision aid is for people diagnosed with a small mass, lesion or tumour in their kidney. Small renal masses are areas of abnormal tissue growth in the kidney that show up on scans. They are relatively small (less than 4 cm in diameter) when first discovered. They are treated as if they are a type of kidney cancer called renal cell carcinoma (RCC), unless proven otherwise.

At least 20% of small renal masses are found to be benign (non-cancerous) tumours, such as simple kidney cysts (sometimes called Bosniak cysts), papillary renal adenomas, oncocytomas or angiomyolipomas (AMLs). Simple kidney cysts can be diagnosed using a scan. A biopsy may be used to diagnose the other types of small renal masses. If the mass is removed with surgery, the final diagnosis is usually made after surgery.

You may have many appointments with your healthcare team and receive a lot of information about your treatment options. You will be faced with new challenges, concerns and questions, and you will need to make some personal decisions about your treatment and living with a small renal mass.

Access to treatments for small renal masses depends on which country you live in, or what your national healthcare system or insurance plan offers patients. You will need to take this into consideration when deciding on your treatment options.

This decision aid covers currently available treatments for small renal masses. Ask your doctor if there have been any changes.

This decision aid aims to help guide you through your conversations with your doctor by providing:

- Information about the treatment options available
- Details about possible benefits and potential risks of each option
- Advice on how to make a decision that will best suit your personal values and goals
- Questions you may want to ask your healthcare professionals
- Lists of resources where you can find support and further information.

Having a small renal mass that could potentially be malignant (cancerous) can be overwhelming. Learning about the disease and treatment options can empower you to become an informed patient and help you make the best decisions about your care and the various treatments available to you.

You may find this booklet useful when discussing your treatment options. You can print out this booklet and have it with you at your next appointment with your healthcare team.



My healthcare team

You may have one main doctor, or many healthcare professionals involved with your care and treatment.

However, the most important person in your healthcare team is actually you! With the help of this decision aid, you can work with your healthcare team to learn about the treatment options for small renal masses and choose the best option for you.

Who are the members of my healthcare team?

Your treatment may require the skills of many different healthcare professionals. The table on the right shows some of the healthcare professionals that your team might include. However, not all these healthcare professionals will be involved in your care.

Urologist/ uro-oncologist	A surgeon who specialises in treating diseases of the genitourinary system including renal cell carcinoma (RCC)
Oncologist	A doctor who has special training in diagnosing and treating cancer
Nephrologist	A doctor who specialises in kidney care and treating diseases of the kidney
General practitioner (GP) in primary care	A family doctor who is based in the community and treats patients with minor or chronic illnesses and refers those with more serious conditions to specialist doctors, usually at the hospital. Can help manage your symptoms, treat side effects, and assist with coordinating your care in the community
Pathologist	A scientist or doctor who studies cells under a microscope and who diagnoses the type of tumour you have
Clinical nurse specialist (CNS)	A specialist nurse who supports you throughout treatment and helps coordinate your care, administers medication, and provides information about your condition

Radiologist	A doctor who diagnoses diseases or conditions using x-rays, ultrasound, CT scans and MRI scans	Dietitian	Gives you advice about eating a healthy diet and staying nourished during your treatment and recovery
Interventional radiologist	A radiologist who uses minimally invasive procedures guided by CT or MRI scans, such as biopsies and ablation therapies, to diagnose and treat diseases	Physiotherapist	Helps manage pain and disability through exercise, massage and physical manipulation
Psychologist/ Counsellor	Helps you cope with the impact your diagnosis has on your emotional, psychological, and social wellbeing	Exercise physiologist	A healthcare professional who works with patients where exercise can help them achieve a better quality of life
Social worker	Provides help with the practical aspects of your life	Rehabilitation doctor	A doctor who specialises in providing rehabilitation after surgery or during treatment
Occupational therapist	Works with you to enable you to maintain your physical health and ability to participate in the activities of everyday life	Clinical trial coordinator	A nurse or scientist who recruits eligible people into clinical trials and organises the trial



My healthcare team

In some countries, these healthcare professionals work together in a multidisciplinary team (MDT). In other countries, these healthcare professionals might work separately.

You might find it helpful to keep a personal file of important reports and documents about your care and treatments, including the following:

- Important medical reports and documents
- A list of all the drugs you are taking with dose amounts, and any changes
- Contact information for your healthcare team
- Notes on clinical appointments and consultations
- Questions you want to ask your healthcare team
- A record of symptoms and side effects.



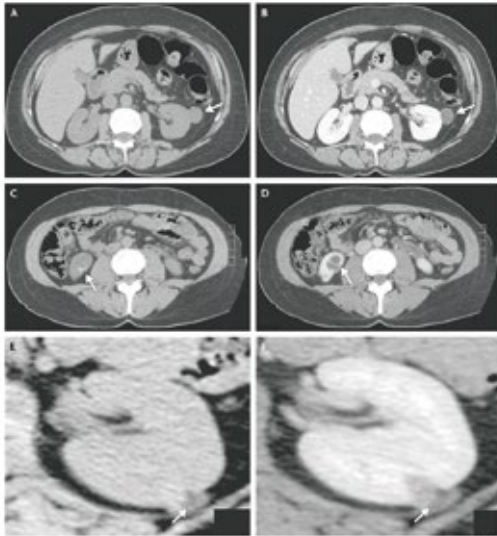
My diagnosis



Diagnostic imaging

What is involved?

Most small renal masses are diagnosed using an abdominal ultrasound (US) scan or a computed tomography (CT) scan, often performed for other medical reasons. Sometimes, you might have a magnetic resonance imaging (MRI) scan to diagnose your small renal mass. Small renal masses appear as either a solid mass or a fluid-filled sac (cyst) on a scan.



*small renal mass
on a CT-scan*

© Wikipedia commons

Most small renal masses are diagnosed accurately using a scan. US is more accurate for the diagnosis of kidney cysts, while malignant masses can be diagnosed using an MRI or CT scan with an injection of contrast agent to provide a clear picture (contrast-enhanced scan). If you are allergic to CT contrast agents or pregnant at the time of your scan, you will have an MRI or US scan instead. If you are concerned about gadolinium (contrast agent) accumulation after multiple contrast-enhanced MRI scans, a CT or US scan could be used as an alternative. For younger patients who are worried about the radiation exposure of frequent CT scans, US or MRI can be used as alternatives.



*kidney cysts
on a CT-scan*

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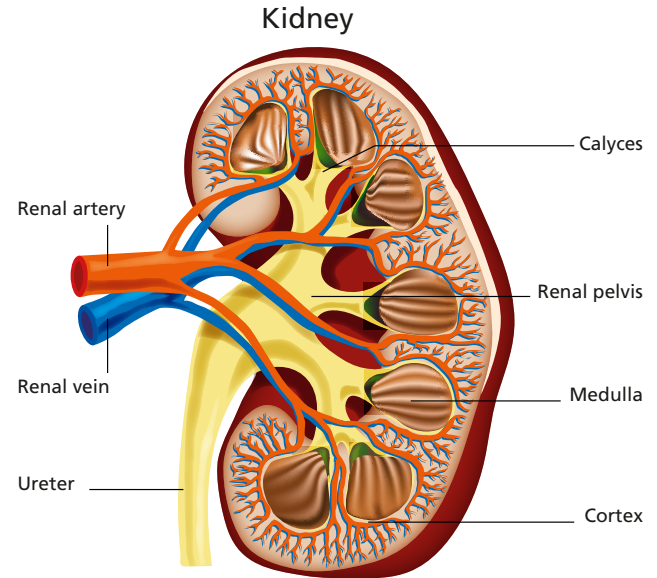
Possible findings from diagnostic imaging

Kidney cysts

Kidney cysts are classified as simple (Bosniak classification I and II) or complex (Bosniak classification IIF – IV) based on how they look on a contrast-enhanced CT scan.

Simple kidney cysts are the most common non-cancerous condition of the kidney and account for around 70% of benign tumours. A simple cyst is a round or oval fluid-filled sac. One or more cysts can develop in a kidney. Simple kidney cysts are very common in people over the age of 50 and most are found when a scan is done for other medical reasons. Simple kidney cysts are distinguished from other small renal masses by their smooth, well-defined and rounded edges on a CT or MRI scan. Simple kidney cysts do not need treatment if they are not causing any symptoms. However, if they bleed, cause pain or become infected, the cysts can be drained using a long needle or removed by surgery.

Complex kidney cysts are round or oval fluid-filled sacs divided into smaller sacs to form a honey-comb appearance on a scan. These cysts can be malignant. Complex Bosniak cysts IIF do not require treatment unless they are causing symptoms, but they require active surveillance to monitor growth. Complex Bosniak cysts III and IV are removed with surgery or ablation.



Papillary renal adenoma

Papillary renal adenoma is the most common non-cancerous solid kidney tumour. These tumours are small, grow slowly and usually don't cause any symptoms. They are often found during a scan done for other reasons.

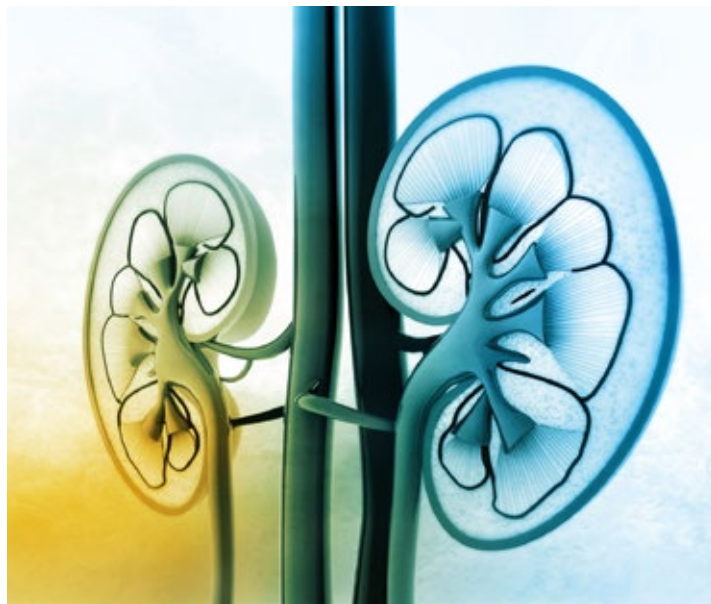
Oncocytoma

Oncocytomas grow in the cells of the collecting ducts of the kidney. These tumours can grow quite large. Very rarely, an oncocytoma can be diagnosed as malignant. In these cases there can be several oncocytomas in one or both kidneys. Oncocytomas may be found at the same time as a malignant tumour.

Angiomyolipoma

Angiomyolipoma (AML) is a non-cancerous tumour made up of fat, blood vessels and smooth muscle tissue. They often develop in people with a condition called tuberous sclerosis, a genetic condition that causes non-cancerous tumours to form in many organs, including the eyes, skin, brain, lungs, heart and kidneys. Even though these tumours are non-cancerous, they can spread and destroy surrounding tissue. Tumours larger than 4 cm in diameter can also cause sudden bleeding (called haemorrhage) from the kidney into the abdomen.

Papillary renal adenoma, oncocytoma and angiomyolipoma do not need treatment if they are not causing symptoms. However, they will need to be followed-up (active surveillance) and might need to be removed with surgery or ablation if they bleed, cause pain, get infected or interfere with kidney function due to size or location in the kidney.

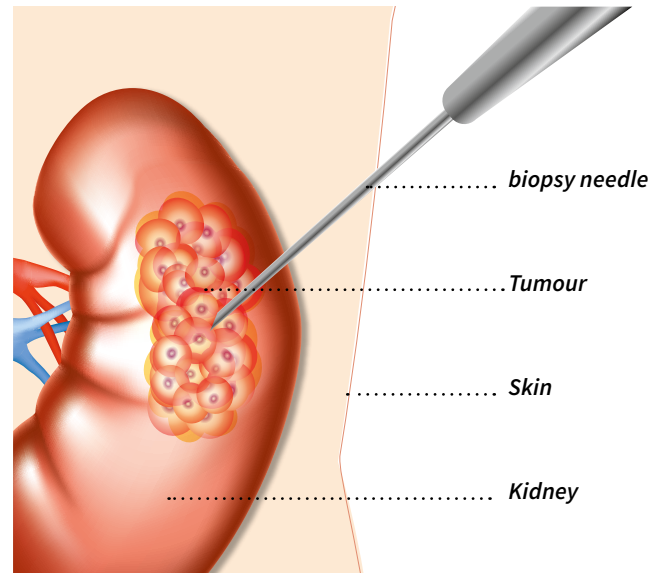


Kidney tumour biopsy

What is involved?

In some cases, your doctor might recommend a kidney tumour biopsy before you have surgery. This biopsy is done under a local anaesthetic and you will be awake for the procedure. Occasionally, a general anaesthetic may be offered. A sample of tissue is taken from the tumour using a sheathed needle through the skin and sent to a laboratory. A pathologist examines the tumour tissue sample under a microscope to diagnose the tumour as benign or malignant, as well as the type of tumour. This information is then used as a guide to treatment decision-making.

A biopsy is not always able to confirm if a tumour is cancer or not, so in some cases it may not help. The main side effects of a kidney biopsy are minor bleeding and pain or discomfort. In very rare cases, cells from the tumour might be transferred from the biopsy needle to the surrounding healthy tissue causing another tumour to grow (this is called tumour seeding).



Possible benefits of kidney tumour biopsy

1. Diagnosis of small renal masses

In most cases distinguishes between benign (non-cancerous) and malignant (cancerous) small renal masses

2. Relatively non-invasive diagnostic technique

No requirement for surgery and general anaesthesia

3. Informs subsequent treatment pathway

Results from a kidney tumour biopsy can be used as a guide for subsequent treatment decision-making

4. Reduces exposure to radiation

No requirement for CT scan to collect further information about the small renal mass. You can have a needle biopsy if you are pregnant or lactating, and if you are young and worried about exposure to radiation

5. Avoids exposure to contrast agents

Kidney tumour biopsy can be used for diagnosis of small renal masses if you are allergic to CT or MRI contrast agents

Possible disadvantages of kidney tumour biopsy

1. Anxiety

You may feel uncomfortable or anxious about having the test to potentially diagnose cancer. You might also feel uncomfortable or anxious about having injections for the local anaesthetic or you might have a phobia about needles

2. Injection of biopsy needle

During the biopsy procedure, a long biopsy needle will be inserted through your skin. You might feel uncomfortable or anxious about having this procedure

3. Side effects to biopsy

Possible side effects to kidney tumour biopsy include pain, bruising, swelling or infection at the site of biopsy. Occasionally, nearby organs might be damaged by the needle causing pain and bleeding

4. Biopsy sampling

Kidney tumour biopsy only removes very small core samples of tissue. Because kidney tumours can be very diverse (heterogenous), there is a possibility that the small renal mass is missed or you have a false negative diagnosis leading to inaccurate decision-making

My treatment options



What are the goals of treatment for small renal masses?

Depending on your individual case, the goals of treatment may be to:

- Determine whether your small renal mass is benign (non-cancerous) or malignant (cancerous)
- Determine the nature of your small renal mass. This will give your doctors an indication of how fast your tumour is growing and whether it is likely to spread
- To prevent unnecessary surgical procedures later in your course of treatment
- If your mass is found to be benign, remove your small renal mass and cure you of your disease
- If your mass is found to be malignant, achieve long-term remission (no visible evidence of disease) or cure your cancer (this is possible in more than 95% of cases)
- Prolong your life and improve overall survival
- Allow you to lead as normal a life as possible for as long as possible

- Improve your quality of life.

Currently available treatments for small renal masses aim to:

- Remove or destroy the small renal mass so that there is no evidence of disease
- Relieve any symptoms associated with the small renal mass
- If your mass is found to be malignant, put the cancer into long-term remission.

New treatments are constantly being developed and tested to further improve patient outcomes and quality of life. See page 41 on Clinical trials and research.

What you need to consider when deciding on treatment

There are several treatment options for people with small renal masses. See pages 21 and 25 - 38 for information about the most common types of treatment.

There are many factors that you and your healthcare team may consider when making a decision about treatment:

1. What type of small renal mass you have

If you are found to have a malignant small renal mass, it is most likely to be a type of kidney cancer called renal cell carcinoma (RCC). It could also be a less common type of kidney cancer, such as transitional cell carcinoma, sarcoma, or lymphoma. Once it is established that the mass is malignant, it is important to know the subtype, stage and grade of the cancer. Knowing the subtype of RCC and its stage and grade will help determine which treatment options are best suited to your type of kidney cancer.

If you are diagnosed with a benign small renal mass, it could be a simple kidney cyst, papillary renal adenoma, oncocytoma or angiomyolipoma. Knowing the type of benign renal mass will determine whether you have treatment and which treatment options are best for you.

2. Your general state of health

People who have good health can normally cope better with major surgery and the possible side effects of medications. However, if you have multiple medical problems (co-morbidities), you may find it more difficult to cope with some forms of treatment and recovery.

3. Side effects and risks of treatment

All treatments have possible side effects and/or risks. A side effect is an unwanted outcome from a treatment, such as pain, nausea, or fatigue. A risk is a potential danger or harm (adverse event), such as a blood clot following surgery.

Not all treatment options will be available at every hospital. Your doctor or nurse will talk to you about the possible side effects and risks of the available treatments. You can then take some time to consider those that you are prepared to accept and those you would like to avoid. This is an important part of the decision-making process. Your preferences and choices must be taken into account when any treatment decision is made.

4. Quality of life versus how long you will live (overall survival)

How much a particular treatment will extend your life is not the only factor to consider when you are thinking about different treatment options. You will also need to look at how a treatment will affect your overall wellbeing – **your quality of life**.

Examples of things that may affect your quality of life include:

- Whether the treatment relieves the symptoms of the small renal mass, such as pain and discomfort
- Coping with side effects of the treatment
- Consequences of length of treatment, 5 days in hospital and 6-8 weeks recovery for some types of surgery
- How well you can cope at work or home or financially
- How much support you have at work or at home?

Deciding which treatment to choose, or even whether or not to have treatment, will make a big impact on your life. You and your healthcare team will look at your quality of life during and after treatment and the length of life each treatment might give you.

5. Your priorities, values and goals

Your doctor can explain the various treatments available. Before you make any decisions, it is important to consider what is important in your life – your personal priorities, values, beliefs and goals.

6. Access to treatments

Around the world, access to diagnostic services and treatment differs. It may even depend on which hospital you are treated in and the experience of your health care team, which region of a country you live in, or what your national healthcare system or insurance plan offers patients.

You may need to take into account the cost of treatments and how this will affect you and your family. In some countries, the government pays for healthcare through the tax system. In other countries, you may need private health insurance, or a combination of private and government funding. You may also need to pay for some treatments yourself or with the help of local charities and other organisations. You can contact your local or national cancer patient support organisation for information about the availability of treatments in your country.

Choosing a treatment plan that's right for you

Your doctor will discuss the evidence supporting the clinically recommended treatment options with you, including what you can expect from treatment. However, which treatment and even whether or not to have any treatment is your decision. You are the expert in your own life and know best how you would manage risks and benefits when it comes to your health and wellbeing.



What are the main types of treatment for small renal masses?

Treatment types

The different types of treatment available for small renal masses are;

- Active surveillance (regular monitoring, no immediate treatment or surgery)
- Surgery (full or part removal of the kidney)
- Ablative therapies (a needle-like probe inserted through the skin into the tumour to destroy it)
- Arterial embolisation (blocks the blood flow to the tumour to destroy it).

Researchers have made tremendous progress over the past decade developing new treatments. This has provided doctors with a variety of treatments for their patients. Your doctor can explain which treatments would be suitable for your particular clinical situation. Together and working in partnership you can decide the best treatment for you.

Treatment choices

When you talk with your doctor about treatment choices, they may also offer you the option of “active surveillance” instead of starting treatment immediately. We discuss what this means in the following pages.

You might be offered the opportunity to join a clinical trial to test a new type of medication, medical procedure, or new way of delivering care. These trials test whether a new treatment is safe, effective and better than existing (standard) treatment.

You might not want to have any treatment. This is your choice. Talking about it with your doctor and your family may help clarify your thinking and ensure the decision you make is the right one for you.

Making a decision about your treatment

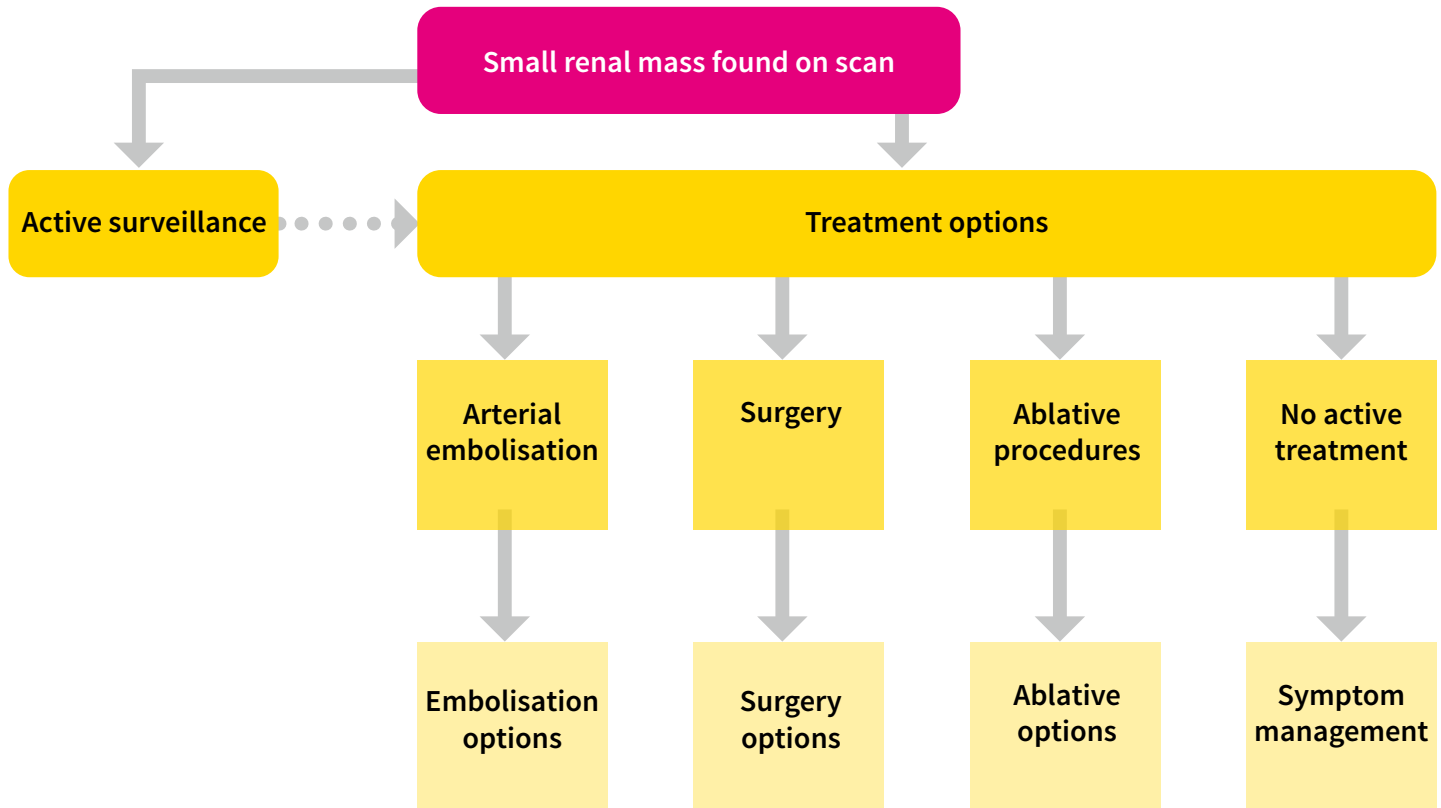
One way to think about the different treatments available is to imagine a toolbox full of different tools. Each tool (treatment) is designed to do a specific job. You and your doctor will gather as much information about your situation as possible to make sure you choose the right tool (treatment) for the job at the right time. Your doctor should help you find all the information you need to make the right decision for you.

You may want to contact your local or national kidney cancer patient support organisation to get up-to-date information before making your decision. You may find it useful to talk about your situation with other patients who have faced a similar situation. They may be willing to share their experiences with you.

You can call on other types of support from your healthcare team to help you manage the disease on a day-to-day basis. If your healthcare system doesn't provide this option, contact your local or national kidney cancer patient support organisation for advice; they will usually know the best way to access these support services.

You may need to discuss with your doctor which treatment options or ‘tools’ are suitable and available to you at your hospital, or those you might need to travel for. You may need a combination of treatments, or you may decide to have none at all. It is important to discuss these issues with your family and your doctor. Always ask for additional information if you feel you need it.

Decision Map: Options for people who are told they have a small renal mass



The following pages deal with these topics in greater depth and provide more information, including some of the benefits and disadvantages for each treatment option.

■ Active surveillance	page 26
■ Surgery	page 28
■ Ablative treatments	page 32
■ Arterial embolisation	page 34
■ No active treatment	page 36
■ Supportive and palliative care	page 38
■ Getting support	page 40
■ Clinical trials and research	page 41

Types of treatments



Active surveillance



What is involved?

Active surveillance involves closely monitoring the small renal mass until there is evidence it has started to grow or until you have symptoms. This involves having regular visits to your doctor for examinations and diagnostic tests.

People on active surveillance can decide to have treatment at any time. For example, you may decide to have treatment if the tumour starts to grow, you start having symptoms, or if the situation becomes too stressful for you and your family.

Is active surveillance a suitable option for me?

Active surveillance may be particularly suitable if you:

- Have a benign small renal mass that is not causing you any problems
- Have a slow-growing malignant small renal mass and are currently symptom-free
- Have other health problems that may make treatment difficult (co-morbidities)
- Were born with one kidney or already have had one kidney removed (nephrectomy)
- Wish to continue working or have significant family and financial responsibilities, such as caring for a family member.

By delaying treatment, you may be able to delay significant treatment side effects or other problems for some time. A delay in starting treatment is not likely to affect how long you live if your small renal mass is found to be slow growing from regular scans. Ask your doctor to help you assess this option and talk with your family and/or friends about this option too. You can change your mind about this option at any time and discuss alternative treatment options with your doctor if you do not feel comfortable with your decision.



Possible benefits of active surveillance

1. No treatment side effects

All treatment options have risks and side effects. Some may be associated with significant health problems and may interfere with your life. By delaying starting treatment, you can potentially delay the onset of these side effects

2. Ability to focus on quality of life

As you will not be receiving treatment, the only impact on your daily life will be taking time out for medical appointments. You will be able to just get on with your life without dealing with side effects. You can spend more time with your family and friends, work if you feel well enough, travel and enjoy leisure activities

3. Financial benefits

Depending upon your situation, treatments can be expensive. The only expenses you will have during active surveillance will be for the doctor's appointments and the tests/scans (if these are not covered by your healthcare system)

Possible disadvantages of active surveillance

1. Anxiety

You may feel uncomfortable or anxious about not having treatment for your small renal mass

2. Risk of the cancer growing or spreading

A period of active surveillance is not likely to affect how long you live. However, there is a small risk that your small renal mass will grow causing symptoms, such as pain and sudden bleeding (haemorrhage) or spread (metastasise). Ask your doctor to help you assess this risk

3. Doctor anxiety

Your doctor might feel uncomfortable or anxious about not giving you treatment. Remember that you or your doctor can ask for a second opinion with a specialist

Surgery - nephrectomy



What is involved?

Nephrectomy is surgery to remove a kidney. Often this is recommended if the small renal mass is growing and causing you to have symptoms, such as bleeding (blood in urine) or pain, or you have had a biopsy that confirms an aggressive type of kidney cancer.

When the whole kidney is removed it is known as a radical or total nephrectomy. If only part of your kidney is removed, it is known as a partial nephrectomy or nephron-sparing nephrectomy. You will need to have a general anaesthetic for both radical and partial nephrectomy.

During a full **radical nephrectomy**, the whole kidney is removed, usually along with the surrounding fatty tissue, the adrenal gland, and nearby lymph nodes. The extent of a radical nephrectomy can vary among patients. You can live perfectly well with just one working kidney. However, you will need to look after your kidney to preserve kidney function, which may decline with time. If both kidneys are removed because they both have tumours, or because they are not working, you will need dialysis for the rest of your life or a kidney transplant.

Radical nephrectomy might be used when a small renal mass is challenging to remove due to its location in the kidney, or you have multiple small renal masses or cysts in one kidney. Tumours that are deeper in the kidney may be harder to remove because they are near the urine drainage system and/or major blood vessels.

Partial nephrectomy aims to save healthy kidney tissue and reduces the risk of losing kidney function. It is usually carried out for people who have:

- One kidney
- Kidney disease (or a condition that increases the risk of kidney disease, e.g., diabetes, lupus, family history)
- Small renal masses in both kidneys (bilateral kidney tumours)

Specialist surgeons now aim to treat most small renal masses with partial nephrectomy, if possible. Partial nephrectomy requires an experienced surgeon and is not available at all hospitals.

Possible benefits of nephrectomy	Possible disadvantages of nephrectomy
1. Prevents symptoms <p>If the small renal mass is found to be malignant and is causing symptoms and problems such as pain, bleeding, and high blood pressure, which are difficult to control, removing the primary tumour may be helpful</p>	1. Hospital stay <p>How long you will have to stay in hospital depends on how your surgery was done (open or laparoscopic) and any other medical conditions you have. On average it will be 3-7 days. Full recovery can take 6-12 weeks, or longer. If you are working, you will need to take time off – most people require at least 6-8 weeks leave. You may need to start back at work gradually</p>
2. Avoid anti-cancer medication <p>If the small renal mass is found to be malignant, removal of the kidney and small renal mass will avoid the need for anti-cancer medication</p>	2. Risks and side effects of major surgery <p>Major surgery is associated with significant health problems (morbidity) such as heart and lung problems. There is also a small but not insignificant risk of death (mortality)</p>
3. May improve survival <p>If the small renal mass is found to be malignant, removing it improves chances of survival for most patients</p>	3. Long-term effects of nephrectomy <p>A few months or maybe even years after nephrectomy, you could still have pain or discomfort around the site of surgery. You might develop a hernia, high blood pressure or chronic kidney disease (decrease or loss of kidney function)</p>
4. Emotional burden <p>You do not have to live with the burden of knowing you have a tumour inside you which might change/burst/spread at any time</p>	

Nephrectomy can be done as an open or laparoscopic (keyhole) surgery, with or without robotic assistance.

This will depend on:

- The size and position of the small renal mass in the kidney
- The facilities available at the hospital
- The surgeon's preference and experience
- Your choice.

Is nephrectomy a suitable option for me?

Most people with a small renal mass will be offered a partial nephrectomy. Partial nephrectomy will also be offered if you have one kidney, if you have tumours in both kidneys, and if you have poor kidney function. If the location of your tumour makes partial nephrectomy difficult or impossible and your general health is good, you might be offered a radical nephrectomy to remove your entire kidney. You will need to discuss your suitability for surgery with your doctor to make an informed decision about which surgical treatment option to choose.

Open surgery

The surgeon usually makes a large incision or cut below the lower ribs on the side of the affected kidney. In cases where a cut below the lower ribs is not possible, the surgeon will suggest an alternative incision to access the kidney. The kidney (or part of the kidney) containing the small renal mass can be assessed by the surgeon and removed through this incision.

Laparoscopic surgery (keyhole or minimally invasive)

The surgeon makes several small incisions or cuts in the skin of the abdomen, rather than one large incision. A long thin tube with a camera and a light at the end is inserted through one of the cuts. This instrument is called a laparoscope. It sends a high-quality image of the operating area to a video monitor. Other small instruments are inserted through the other cuts and used to remove the kidney or part of the kidney containing the small renal mass, which is usually taken out of the body in a bag through one of the cuts.

Possible benefits of open surgery

- Techniques for open surgery have been established for a long time
- Does not need to be done in a specialised hospital
- Most small renal masses can be removed using this technique

Possible disadvantages of open surgery

- Higher requirement for pain medications
- Longer stay in hospital and longer recovery time
- Greater risks associated with major surgery
- More extensive scarring
- Wound bulge or hernia can be uncomfortable for some patients

Possible benefits of laparoscopic surgery

- Less requirements for pain medication
- Shorter stay in hospital and shorter recovery time
- Minimal scarring

Possible disadvantages laparoscopic surgery

- More specialised and only available in some hospitals
- Not all small renal masses can be removed using this technique
- More expensive
- Risks specific to laparoscopic surgery, such as damage to nearby organs and/or blood vessels
- Uncomfortable side effects relating to the gas injected into the abdomen

Robot-assisted laparoscopic surgery (RAS)

is also minimally invasive, but the instruments are smaller and attached to robotic arms. The surgeon controls the robotic arms from a console, which provides a highly magnified 3D view of the operating area. The improved view

and advanced tools give the surgeon more precision and control. As it becomes more accessible, RAS will eventually replace conventional laparoscopy for partial nephrectomy.

Ablative treatments



What is involved?

Ablation is a word used to describe the destruction of body tissue. Extreme heat or cold can be used to destroy small renal masses.

Radiofrequency ablation and **microwave ablation** use energy waves to produce extreme heat to destroy the tumour.

Cryoablation or **cryotherapy** uses liquid nitrogen, liquid carbon dioxide or argon gas to freeze and destroy the tumour.

The doctor inserts one or more fine needles or probes through the skin (percutaneous) and into the tumour. Argon gas, liquid nitrogen/carbon dioxide or an electric current is passed through the needles to freeze or heat the tumour, respectively. Regular scans are carried out during the procedure to ensure the needles are positioned correctly in the tumour and the entire tumour has been treated. Ablation can often be carried out with light sedation. Sometimes a general anaesthetic is required.

Ablation can also be done using open or laparoscopic surgery if the tumour is in a position that is difficult to reach by going through the skin. This requires surgery and a general anaesthetic.

Is ablation a suitable option for me?

Ablative treatments can be used to treat small renal masses. An ablative treatment may be suitable if you:

- Have multiple other medical problems (co-morbidities)
- Are unable to tolerate a general anaesthetic
- Have renal failure
- Have multiple small renal masses
- Do not want to have surgery.

Possible benefits of ablative treatments	Possible disadvantages of ablative treatments
1. Does not destroy the entire kidney	1. Only suitable for small renal masses less than or equal to 4 cm in diameter
Ablative treatments target the small renal mass leaving the surrounding tissues healthy. This may be a suitable treatment option for people with a mass in a solitary kidney, or who have kidney failure or multiple small renal masses, or for people who are too frail for surgery or general anaesthesia	Ablative treatments are generally used for small renal masses less than 4 cm in diameter
2. Improves symptoms	2. Multiple treatments
Ablative treatments can reduce the symptoms associated with the small renal mass	You may require more than one session to treat the small renal mass
3. Local control of cancer	3. Cancer control
If your small renal mass is found to be malignant, ablation can control the growth of the cancer	If your small renal mass is found to be malignant, ablative treatments may not control the cancer as well as other treatment options
4. Non-invasive	4. Risks and side effects
If done through the skin, there are no cuts made in your body and a general anaesthetic can be avoided. This makes ablation a treatment option for people with multiple other medical problems (co-morbidities)	The treatment can be painful after the anaesthetic wears off. You may need painkillers for a few days afterwards. Some people develop a fever and flu-like symptoms. Other possible risks include bleeding around the kidney and damage to the ureter
5. Minimal time spent in hospital	
If done through the skin, you will not have to stay in hospital overnight. You should be able to return to usual activities in a few days	
6. Tumour biopsy can be taken	
A tumour biopsy can be taken before the start of the ablative treatment	

Arterial embolisation



What is involved?

Arterial embolisation involves injecting a substance into a blood vessel (artery) in the kidney. This substance blocks the blood supply and reduces the supply of oxygen and nutrients to the small renal mass. This can shrink the mass or stop it from growing to help control symptoms, such as pain or bleeding.

Arterial embolisation might be used if you are not able to have surgery. Arterial embolisation may also be used for the treatment of benign small renal masses with a rich blood supply, such as angiomyolipomas.

Your doctor or nurse might give you a mild sedative to help you relax before you have the treatment. The doctor will then numb an area of skin at the top of your leg (the groin) with an injection of local anaesthetic. A thin, plastic tube (catheter) is inserted into a blood vessel in the groin and guided into place using x-ray pictures. The catheter is placed in the artery that carries blood to the small renal mass in the kidney. The substance is injected through the catheter into the artery to block the blood supply. You may need to stay in hospital overnight, or possibly for a day or two.



Possible benefits of arterial embolisation	Possible disadvantages of arterial embolisation
1. Does not destroy the entire kidney	1. Only suitable for small renal masses with a rich blood supply
<p>Arterial embolisation targets the blood vessels supplying the small renal mass leaving the surrounding tissues healthy. Arterial embolisation is a treatment option for people with a small renal mass in one kidney, or for people who have kidney failure, or who are too frail for surgery or general anaesthesia</p>	<p>Arterial embolisation is generally used for small renal masses, less than 4 cm in diameter and with a rich blood supply, e.g. angiomyolipomas</p>
2. Improves symptoms	2. Multiple treatments
<p>Arterial embolisation can reduce the symptoms associated with the small renal mass, such as pain and bleeding</p>	<p>You may require more than one session to treat the small renal mass</p>
3. Local control of cancer	3. Cancer control
<p>If your small renal mass is found to be malignant, arterial embolisation can control the growth of the cancer</p>	<p>If your small renal mass is found to be malignant, arterial embolisation may not control the cancer as well as other treatment options</p>
4. Non-invasive	4. Risks and side effects
<p>Arterial embolisation involves an injection into an artery in the groin under local anaesthetic and mild sedative. There are no cuts made in your body and a general anaesthetic can be avoided. Arterial embolisation can be used as a treatment option for people with multiple other medical problems (co-morbidities)</p>	<p>The treatment can be painful after the anaesthetic wears off. You may need painkillers for a few days afterwards. Some people develop a fever and flu-like symptoms</p>
5. Minimal time spent in hospital	
<p>You may need to stay in hospital overnight, and possibly for 1-2 days. You should be able to return to usual activities in a few days</p>	

No active treatment

What is involved?

Active treatments are treatments like surgery or ablation that aim to get rid of your small renal mass or symptoms associated with it.

You may decide that you do not want to have active treatment for your small renal mass. You may feel that your quality of life will be better if you do not have active treatment. No active treatment (sometimes called “watchful waiting”) is often used for older patients or those with concomitant conditions where the risks of treatment exceed the benefits.

Is no active treatment a suitable option for me?

If you feel the disadvantages of active treatment outweigh the benefits for you, then having no active treatment may be an acceptable option for you at any time. You would still receive what is known as ‘best supportive care’ to help you manage your symptoms.



Possible benefits of no active treatment	Possible disadvantages of no active treatment
1. No treatment side effects <p>All active treatment options have risks and side effects. Side effects may be physically and mentally exhausting and significantly interfere with your life</p>	1. Worsening symptoms <p>Because your small renal mass is not being treated it may grow and you may experience symptoms such as pain, bleeding and depression or anxiety. However, your doctor or palliative healthcare team will be able to help you manage these symptoms</p>
2. You can focus on your quality of life <p>Without having side effects or recovery from surgery, you will be able to get on with your life. You may spend more time with family and friends, work if you feel well enough, travel and enjoy leisure activities</p>	2. Anxiety <p>You may feel uncomfortable or anxious about not having treatment – you might feel like you are ‘doing nothing’ to treat your condition</p>
3. Less hospital trips and medical tests <p>Although you will have occasional hospital appointments, you will not have to spend a lot of time visiting the hospital or having tests</p>	3. Regret <p>You may wonder what might have happened if you had chosen to have or continue with active treatment</p>
4. May improve emotional wellbeing <p>Making a decision not to have active treatment may help you come to terms with your situation and feel in control of it</p>	4. Pressure from others <p>Your family and friends may not understand why you have chosen not to have or continue with active treatment. This may make you feel pressured to change your mind or make you feel guilty about your decision</p>

Supportive/palliative care



What is involved?

At all stages of your treatment you need to feel as well as possible. You might need support to help relieve your symptoms, manage pain, and reduce side effects of treatment. You might also need emotional and social support. Supportive/palliative care focuses on improving quality of life for you and your family.

Supportive/palliative care services could include:

- Pain management
- Relaxation techniques, meditation and massage to help support your mental health and make you feel better
- Counselling and support to manage emotional problems, such as anxiety and depression
- Nutritional advice
- Practical help with tasks of daily living
- Help and advice regarding issues, such as powers of attorney and advanced care planning, according to your personal wishes.

Supportive/palliative care also aims to support others involved in your care, such as your family and friends.

When is supportive/palliative care recommended?

Many people mistakenly think that palliative care is just for people who are dying.

In fact, people with any type of serious condition can benefit from palliative care at any time during their treatment. For this reason, palliative care is often recommended early in your treatment plan. In some countries, palliative care has been more appropriately renamed ‘supportive care’.

If supportive/palliative care is started early, you can have your needs addressed quickly, which can improve your quality of life immediately and help prevent or reduce problems later on.

Who provides supportive/palliative care?

Supportive/palliative care can be provided by the health-care professionals involved in your day-to-day care, such as your GP, medical oncologist, nurse or social worker. You may also be referred to a specialist supportive/palliative care team.



Getting support



I have been diagnosed with a small renal mass.

Where can I get support?

Being diagnosed with a small renal mass that could potentially be cancer, and its subsequent treatment can have a huge physical and emotional effect on you. It is important to look after yourself. This includes eating a well-balanced and healthy diet, not smoking, doing regular exercise, and seeking help if you feel depressed or anxious. There are professionals who can help guide and support you with these aspects of your life.

Family and friends are an invaluable source of support, whether it's helping with the shopping, coming to doctor appointments with you or simply being with you. Let your family and friends support you. Your diagnosis will also affect your family and friends. It is likely that your closest family member or main caregiver may need help and support as well as you.

Many people find that it's helpful sharing their experiences and knowledge with other people in similar situations or talking to someone trained in supporting people with cancer. You may consider contacting a local or national patient support/advocacy group to get information about small renal masses and to help you navigate your way around the healthcare system in your country.

I am a carer for someone with a small renal mass.

What can I do?

Being a carer for a loved one with a serious medical condition can be rewarding, but it can also be tiring, stressful, and cause you a lot of worry. It is important that you look after yourself and take some time just for you. And it's important that you get some help and support too.

Clinical trials and research



Over the past decade, clinical trials and research have resulted in some major breakthroughs in the treatment of small renal masses. Ablation and laparoscopic surgery have improved recovery times from surgery and reduced the length of hospitalisation. Robot-assisted surgery has improved surgical precision and blood loss. Both laparoscopy and robot-assisted surgery result in minimal scarring, smaller incisions and less infections, pain and discomfort for the patient.

What is a clinical trial?

A clinical trial is a research study that tests a new treatment or procedure to find out if it is safe, effective and better than the existing (standard) treatment.

The treatment being tested can be a medication, a new way of giving radiotherapy or performing surgery or something as simple as a different way of caring for patients. Sometimes the clinical trial tests a new combination of medications or treatments to see if two treatments combined are better than one.

Clinical trials are used to help improve treatment. There is always uncertainty about whether the new treatment will be better or worse than standard treatment. Clinical trials answer that question.

Should I join a clinical trial?

Joining a clinical trial is a big decision. There are several factors you need to think about as you decide. You might like to consider the following:



Possible benefits of a clinical trial

1. May be the best or only treatment option available

Sometimes the only way for you to get access to a new type of treatment is by taking part in a clinical trial

2. High-level care

Usually, you are seen by doctors and nurses who are experts in treating your condition. Patients who are treated in hospitals running a clinical trial often do better overall. For many patients, access to expert level care at a centre of excellence is a major benefit

3. Free medication

In most countries, the clinical trial centre will provide the costs of all medical care involved in the clinical trial (all tests, surgery, radiotherapy, and medication). If you receive medication as part of a clinical trial, you will normally continue that medication if the treatment proves to be effective. Be sure to ask about any potential costs that might affect your participation

4. Helping others

Participating in a clinical trial means you are making a valuable contribution to medical research and helping others who are diagnosed with a small renal mass in the future

Possible disadvantages of a clinical trial

1. You may not receive the new treatment

Some clinical trials allocate patients to the new treatment or other treatment options, so it is important to read any information the trial team provide

2. Changing to a different healthcare team

You will be seen by expert doctors and nurses who are involved in running the clinical trial. They may not be the original healthcare team you chose. After the trial, you can return to your original team, which might be closer to home

3. The new treatment may not work as well as the standard treatment

Despite the hopes of the researchers running the trial, the new treatment might not work as well as the standard treatment that is already available. The new treatment might not work at all for you

4. There may be more side effects

The new treatment might have fewer side effects than standard treatments, but it might also cause unpredictable or serious side effects. In some cases, these can be permanent. This is particularly relevant if you want to join a trial that is the first to test a medicine in humans (some phase I trials)

5. More hospital or clinic visits

If you join a clinical trial you may need more tests or more frequent appointments, as the researchers want to study the effects of the new treatment

6. Financial costs (if applicable)

Although you will not be paying for treatment, there may be financial costs to consider, such as the cost of travel and accommodation, or the cost of you or a caregiver taking time off work to go to the trial clinic. Always ask at the trial centre about any financial assistance that may be available

7. Jeopardising access to future treatments

Situations may occur where testing a new drug in a clinical trial might restrict access to future treatment options. This needs to be discussed with your doctor before taking part in the trial

Am I eligible to join a clinical trial?

It is not always possible to join a clinical trial, even if you want to. When researchers design clinical trials, they usually have a strict set of criteria to help them choose who can take part. You might not be eligible to take part in the trial if:

- The trial is not for your particular type of renal mass
- Your general health is not good enough
- Your earlier treatment could affect the results of the trial
- You have other diseases (e.g. diabetes or autoimmune diseases) which could make you more likely to have side-effects or affect the results of the trial
- You have had another kind of cancer at some time in the past
- Your country is not taking part in the trial.

Talk with your doctor about clinical trials that may be right for you.

Where can I find a suitable clinical trial for me?

Ask your doctor or a member of your healthcare team for information about clinical trials that you might be able to join. Alternatively, there are websites where you can find out more information and search for a suitable clinical trial in your area. See the **My resources** on page 81 for a list of useful clinical trial registries and patient support websites.

Clinical guidelines

How do I know I am receiving the best possible care?

Healthcare organisations worldwide produce clinical guidelines that outline how small renal masses, including kidney cancer should be treated. These guidelines are based on the current best available evidence from international research. See **My resources** on page 81.

If you have doubts or questions about the medical advice you have received, discuss this with your doctor. You also have a right to ask for a second opinion from another doctor who specialises in the treatment of small renal masses.

Some people seek support from a patient support organisation and ask other patients who have been in a similar situation to share their experiences and thoughts.

Costs of treatment

Will there be any financial costs?

Depending on the healthcare system of the country that you live in, there may be costs associated with the different treatment options. This may include the cost of appointments, tests/scans, hospital stays and the treatment itself.

In some countries, these costs will be completely covered by government funding. In other countries you may have to rely on private insurance or your own funds. There may also be a combination of government, private insurance and self-funding.

In some countries, patients can obtain some financial assistance from local charities, foundations, and patient groups.

My Notes:

[illegible]

My questions



The information you have learned about small renal masses has probably raised some questions. Write them down at the appropriate pages in this book. By talking them through with your doctor and healthcare team, your questions can help you decide which options are right for you.

Good communication with your doctor and other health-care professionals is vital. The more questions you ask, the more you will be informed and understand, and the more in control and confident you will feel about decisions you make.

Talking with your doctor and healthcare team will also help them understand your priorities and points of view. Tell your doctor what you are concerned about and what matters most to you.

The list of questions on the following pages may help you get a better understanding of small renal masses and treatment options. You may like to select the questions you want to ask and write down the answers in the space provided. Add any other questions you would like to ask which are not listed. Making notes about answers can be helpful, especially if you are reviewing information after your visit. Taking someone with you to appointments can be really useful, as they can take notes while you concentrate on what the doctor is saying. You may also ask your doctor for permission to record the conversation so you can listen again later.

Contact your local kidney cancer patient organisation for good up-to-date information and support. See *My resources* on page 81 for a list of patient organisations.

About my kidney cancer	Please fill in your answers	<input checked="" type="checkbox"/>
Is my small renal mass benign (non-cancerous) or malignant (cancerous)?		
If benign, what type of renal mass is it?		
If malignant, what is the stage and grade of my kidney cancer?		
If malignant, has my kidney cancer spread to other parts of my body?		
Is my small renal mass hereditary (passed down in my family)?		
What symptoms can I expect from my small renal mass?		
Where can I get further help?		

Diagnosis	Please fill in your answers	<input checked="" type="checkbox"/>
What tests or scans will I need to have and why? Will I need a biopsy?		
What can I expect during these tests/ scans?		
Are there any risks to having these tests/scans done?		
When and how will I receive the results?		

My treatment options	Please fill in your answers	<input checked="" type="checkbox"/>
What are all the treatment options available to me?		
What would each treatment choice mean for me?		
Do you recommend a certain sequence of treatments?		
What effect will this treatment have on my quality of life?		
What are the potential benefits of this type of treatment over any other types of treatment?		
Are there any risks to this treatment? How likely are they to occur?		
What are the side effects of this treatment?		

My treatment options	Please fill in your answers	<input checked="" type="checkbox"/>
Does this treatment cause any long-term or permanent changes (physical, social, emotional, mental or sexual)?		
What happens if I choose not to have treatment?		
Is active surveillance an option for me?		
If I stop having active treatment, or choose not to continue, what will happen to me?		

Making a decision	Please fill in your answers	<input checked="" type="checkbox"/>
How much time do I have to make a decision about treatment?		
If I would like to have a second opinion before I start treatment, can that be arranged?		
How many cases like mine are treated at this hospital every year?		

Having my treatment	Please fill in your answers	<input checked="" type="checkbox"/>
Where will I have my treatment?		
Is there anything I should do before, during and after my treatment?		
How long will I undergo treatment and need to stay in hospital?		
How long will it take to recover from my treatment?		
Will there be any follow-up visits to the hospital? If so, when will these take place?		
Do you recommend that I change my lifestyle, e.g. diet, exercise, weight, smoking, work hours?		
Would complementary therapies support my treatment and overall wellbeing?		

Prognosis of my small renal mass	Please fill in your answers	<input checked="" type="checkbox"/>
Is it possible to estimate how long people live with my kind of small renal mass?		
How current are the data used to work out my prognosis?		
Is the recommended treatment likely to improve my length of survival?		
Is this treatment likely to improve my symptoms?		
What effect will this treatment have on my quality of life?		
Are there other ways to reduce my symptoms and side effects?		

Participating in a clinical trial	Please fill in your answers	<input checked="" type="checkbox"/>
Where can I find out more information about clinical trials?		
Are you aware of any clinical trials suitable for me?		
How do I join a clinical trial?		
What will happen if I join this clinical trial?		

Cost of my treatment	Please fill in your answers	<input checked="" type="checkbox"/>
Is there a financial cost of this treatment for me?		
Where can I get information about financial assistance?		
Can I travel to another part of the country or a different country for treatment?		
In some countries: Is there any difference between having this treatment in a public versus a private setting?		

Supportive/palliative care	Please fill in your answers	<input checked="" type="checkbox"/>
When will supportive/palliative care be offered to me?		
Is there someone I can talk to about how I am feeling?		
Is there someone my family can talk to about their feelings?		
Where can I get nutritional/dietary advice?		
Can I have practical help with day-to-day living? Do I qualify for financial assistance?		

Supportive/palliative care	Please fill in your answers	<input checked="" type="checkbox"/>
Where can I get help with returning to work?		
How do I access complementary therapies, such as relaxation techniques, mediation, or massage?		

Support and information to help manage my small renal mass	Please fill in your answers	<input checked="" type="checkbox"/>
Are there any support groups for my family and me?		
Do you have any printed information that I can take away with me?		
Where can I get more information about small renal masses?		
Can you put me in touch with someone else who has a small renal mass like mine?		
Who should I call if I have questions after our appointment today?		

Other questions







Other questions	
	<input checked="" type="checkbox"/>

My decision



Summary

Opposite is a summary of the possible benefits and disadvantages of each treatment option.

		What is involved
	Active surveillance	No active treatment is given – close monitoring with examinations, tests and scans
	Nephrectomy	Surgical removal of the primary tumour and part or all of your kidney
	Ablative treatments	Extreme heat or cold is used to destroy the small renal mass.
	Arterial embolisation	Injection of a substance into a blood vessel (artery) in the kidney to block the blood supply and control the growth of the mass
	No active treatment	Not having any active treatment

Possible benefits	Possible disadvantages
<ul style="list-style-type: none"> • No treatment side effects • Ability to focus on your quality of life • Financial benefits if you can continue to work 	<ul style="list-style-type: none"> • Anxiety that you are not having treatment • There is a risk the small renal mass has a chance to grow • There is a chance a benign small renal mass will become cancerous
<ul style="list-style-type: none"> • Prevents symptoms of the small renal mass • Delays the need for other treatment • May improve survival • For some types of small renal mass, nephrectomy may prevent the development of cancer 	<ul style="list-style-type: none"> • Requires a hospital stay • There are risks and side effects of surgery
<ul style="list-style-type: none"> • Does not destroy the entire kidney • Improves symptoms • Local control of the small renal mass • Non-invasive • Minimal time spent in hospital 	<ul style="list-style-type: none"> • Only suitable for small renal masses • Multiple treatments • Risks and side effects • May not destroy small renal mass entirely • If your small renal mass is found to be malignant, ablation may not control
<ul style="list-style-type: none"> • Does not destroy the entire kidney • Improves symptoms • Local control of the small renal mass • Non-invasive • Minimal time spent in hospital 	<ul style="list-style-type: none"> • Only suitable for small renal masses with a rich blood supply • Multiple treatments • Risks and side effects • May not destroy small renal mass entirely • If your small renal mass is found to be malignant, arterial embolisation may not control the cancer as well as other treatments
<ul style="list-style-type: none"> • No side effects from treatment • You can focus on your quality of life • Fewer hospital trips and medical tests • May improve emotional well-being 	<ul style="list-style-type: none"> • Your symptoms may worsen • Anxiety that you are not having treatment • Regret that you are not having treatment • Pressure from others to have active treatment

My decision

By the time you come to this section you should have a good understanding of the different treatments for small renal masses and their potential benefits, disadvantages and side effects.

Following the discussions you have had with your doctor, you should also now have a clear understanding of which treatment options are currently available to you.

If you feel that you still don't understand your options, talk to your doctor or patient organisation for more information before you make a choice.



My decision aid

The following pages have worksheets for you to go through to help you think through the possible benefits (pros) and disadvantages (cons) of each treatment option.

For each pro and con statement, there are three options about how important you consider the issue to be. By circling one of the options you can indicate how important each issue is to you.

- **Circle 1:** Indicates the issue is not important.
This means it is not a concern to **you**.
- **Circle 2:** Indicates the issue is somewhat important.
This means it is a small concern **you**.
- **Circle 3:** Indicates the issue is very important.
This means it is a big concern to **you**.

Not all these treatments are available or appropriate for everyone. There are strict guidelines in most countries for the use of some of these treatments. Therefore, before using these worksheets, find out from your doctor the treatments that are available to you and most appropriate. For example, ablative treatment is only available at specialist centres in some countries.

PROS of active surveillance				
Points to consider	My thoughts	Level of importance <i>(how important each point is to you)</i>		
No treatment side effects		1	2	3
Ability to focus on your quality of life		1	2	3
Financial benefits if you continue to work		1	2	3
Other pros		1	2	3

CONS of active surveillance				
Points to consider	My thoughts	Level of importance <i>(how important each point is to you)</i>		
Anxiety that you are not having treatment		1	2	3
There is a risk the small renal mass has a chance to grow		1	2	3
There is a chance a benign small renal mass will become cancerous		1	2	3
Other cons		1	2	3

Overall, are the pros or cons more important to me? *(please circle)*

PROS more important

CONS more important

PROS of surgery - nephrectomy				
Points to consider	My thoughts	Level of importance		
Prevents symptoms of the small renal mass		1	2	3
Delays the need for other treatment		1	2	3
May improve survival		1	2	3
For some types of small renal mass, nephrectomy may prevent the development of cancer		1	2	3
Other pros		1	2	3

CONS of surgery - nephrectomy

Points to consider	My thoughts	Level of importance		
Requires a hospital stay		1	2	3
There are risks and side effects of surgery		1	2	3
It may not be effective or you may still require treatment		1	2	3
Other cons		1	2	3

Overall, are the pros or cons more important to me? *(please circle)*

PROS more important



CONS more important

PROS of ablative treatment				
Points to consider	My thoughts	Level of importance		
Does not destroy entire kidney		1	2	3
Improve symptoms		1	2	3
Local control of small renal mass		1	2	3
Non-invasive		1	2	3
Minimal time spent in hospital		1	2	3
Other pros		1	2	3

CONS of ablative treatment

Points to consider	My thoughts	Level of importance		
Only suitable for small renal mass		1	2	3
Multiple treatments		1	2	3
Risks and side effects		1	2	3
It may not be effective or you may need further treatment		1	2	3
Other cons		1	2	3

Overall, are the pros or cons more important to me? *(please circle)*

PROS more important



CONS more important

PROS of arterial embolisation				
Points to consider	My thoughts	Level of importance		
Does not destroy entire kidney		1	2	3
Improve symptoms		1	2	3
Local control of small renal mass		1	2	3
Non-invasive		1	2	3
Minimal time spent in hospital		1	2	3
Other pros		1	2	3

CONS of arterial embolisation

Points to consider	My thoughts	Level of importance		
Only suitable for small renal mass with a rich blood supply		1	2	3
Multiple treatments		1	2	3
Risks and side effects		1	2	3
May not destroy small renal mass entirely		1	2	3
Other cons		1	2	3

Overall, are the pros or cons more important to me? *(please circle)*

PROS more important



CONS more important

PROS of no active treatment				
Points to consider	My thoughts	Level of importance		
No side effects from treatment		1	2	3
You can focus on your quality of life		1	2	3
Fewer hospital trips and medical tests		1	2	3
May improve emotional well-being		1	2	3
Other pros		1	2	3

CONS of no active treatment				
Points to consider	My thoughts	Level of importance		
Your symptoms may worsen		1	2	3
Anxiety about not having treatment		1	2	3
Regret about not having treatment		1	2	3
Pressure from others to have active treatment		1	2	3
Other cons		1	2	3

Overall, are the pros or cons more important to me? *(please circle)*

PROS more important
 ☐
☐
☐
☐
☐
 CONS more important

My decision

Am I ready to choose my preferred treatment plan?

Based on the worksheets on the previous pages, you may feel ready to write down your preferred treatment choices.

You may want to ask yourself:

- Have I spoken to my doctor about all the available options?
- Do I understand all of my treatment options?
- Have I spoken to my family or friends for their input?
- Do I still need more information to help me make my decision?
- Is there anyone else who can help me make my decision, such as another patient?
- Do I feel I have unanswered questions?
- Do I feel I need to seek a second opinion before I decide?

If you have identified your preferred treatment options, write them down in the table. Remember that you can change your mind and add to your treatment plan over time.

If you are not ready to choose a preferred treatment plan at this time, think about what might help you.

Many patients find it helpful to speak to another doctor, family and friends, another patient, or a patient organisation.



**Whatever you decide,
there are no wrong decisions,
only decisions
that are right for you.**

Date	My Preferred Option	Reason

Date	My Preferred Option	Reason

My resources





Clinical guidelines

The most widely used clinical treatment guidelines worldwide are published by the European Association of Urology (EAU) and are updated regularly. Although these guidelines are for renal cell carcinoma, the treatment of small renal masses is also covered:

European Association of Urology (EAU).

Guidelines on renal cell carcinoma.

www.uroweb.org/guideline/renal-cell-carcinoma/

For treatment guidelines specific to your country, please contact your local patient organisation or the International Kidney Cancer Coalition.

International Kidney Cancer Coalition.

www.ikcc.org/kidney-cancer-demographics/national-guidelines-and-standard-of-care/



Kidney Cancer websites:

Listed below are the main English-language kidney cancer websites. Other websites may be more specific to the country that you live in. Many of these are listed on the IKCC website – ***www.ikcc.org***

International Kidney Cancer Coalition (IKCC)

www.ikcc.org

Action to Cure Kidney Cancer (USA)

www.ackc.org

Climb 4 Kidney Cancer (USA)

www.climb4kc.org

Judy Nicholson Foundation (USA)

www.jnfkidneycancer.org

Juliet Ibrahim Foundation (Ghana)

www.julietibrahimfoundation.org

KidneyCAN (USA)

www.kidneycan.org

Kidney Cancer Association (USA)

www.kidneycancer.org

Kidney Cancer Canada

www.kidneycancercanada.ca

Kidney Cancer Research Alliance KCCure (USA)

www.kccure.org

Kidney Cancer Scotland (UK)

www.kidneycancerscot.org

Kidney Cancer Support Network (UK)

www.kcsn.org.uk

Kidney Cancer UK

www.kcuk.org.uk

Kidney Health Australia

www.kidney.org.au

Kure It Cancer Research (USA)

www.kureit.org

National Kidney Foundation (USA)

www.kidney.org

Renal Medullary Carcinoma (USA)

www.rmcsupport.org

VCare (India)

www.vcarecancer.org

VHL Alliance

www.vhl.org/patients



Clinical trial registries

ANZUP

(Australia and New Zealand Urogenital and Prostate Clinical Trials Group)
www.anzup.org.au

Clinical Trials Registry, India

www.ctri.nic.in/Clinicaltrials

Clinical Trials worldwide

(a service of the
U.S. National Institutes of Health)
www.clinicaltrials.gov

Health Canada's Clinical Trials Database

(English and French)
[www.hc-sc.gc.ca/dhp-mps/
prodpharma/databasdonclin/
index-eng.php](http://www.hc-sc.gc.ca/dhp-mps/prodpharma/databasdonclin/index-eng.php)

European Union Clinical Trials Register

www.clinicaltrialsregister.eu

International Kidney Cancer Coalition

www.ikcc.org/clinical-trials-search

Kidney Cancer Support Network (UK)

[www.kcsn.org.uk/
clinical-trials-database/](http://www.kcsn.org.uk/clinical-trials-database/)

SmartPatients

www.smartpatients.com/trials



Glossary

abdomen

The abdomen is area of the body that contains the pancreas, stomach, intestines, liver, gallbladder and other organs.

ablate

Removal of cancer by cutting, intense heating or cold.

active surveillance

Closely monitoring a patient's condition but not administering treatment until symptoms appear or change.

active treatment

Treatment that aims to prolong your survival.

adverse event

An unwanted occurrence that results in harm.

anaesthetic

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

angiomyolipoma

A non-cancerous tumour composed of fat, blood vessels and smooth muscle. They often develop in people with a genetic condition called tuberous sclerosis.

autoimmune

A condition where your immune system mistakenly attacks your body. The immune system normally defends the body against infections and other diseases.

benign

Not cancerous, not malignant

biopsy

The removal of cells or tissues for examination by a pathologist. The pathologist may study the tissue under a microscope or perform other tests on the cells or tissue.

Bosniak cyst

A round or oval fluid-filled sac found in the kidney. Can be simple (a single sac) or complex (fluid-filled sac divided into smaller sacs to form a honeycomb appearance on a scan).

clinical trial

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

co-morbidity

The presence of one or more additional diseases or disorders.

cryoablation

A procedure in which tissue is frozen to destroy abnormal cells.

CT scan

A series of detailed pictures of areas inside the body taken from different angles using x-rays.

cyst (kidney)

A fluid-filled sac that occurs in the kidney. Most cysts are benign and do not need treatment if they are not causing symptoms.

dialysis

A treatment for kidney failure, which removes wastes and extra fluid from the blood by filtering through a special membrane. There are two types of dialysis, haemodialysis and peritoneal dialysis.

fatigue

A condition marked by extreme tiredness and inability to function due to lack of energy.

grade

A description of a tumour based on how abnormal the cancer cells look under a microscope and how quickly the tumour is likely to grow and spread.

hereditary

Transmitted from a parent to child through genetic information.

laparoscope

A thin telescope with a light and a lens that can be passed into the body. It is used to look at tissues and organs inside the abdomen.

laparoscopy

A procedure that uses a laparoscope to examine the organs inside the abdomen. Other tools are also passed through the abdominal wall to remove tissue (such as a kidney containing cancer). Also called keyhole surgery.

lymph node

A small swelling in the lymphatic system where lymph (clear fluid carrying immune cells) is filtered and lymphocytes (a type of white blood cell) are formed and stored.

malignant

A cancerous tumour that can invade and destroy nearby tissue and spread to other parts of the body.

microwave ablation

A procedure that uses microwaves to heat and destroy a cancer.

morbidity

The condition of being diseased.

mortality

The state of being subject to death.

MRI

A type of scan that uses a magnet, radio waves and a computer to make detailed pictures of the inside of the body. These pictures can show the difference between normal and diseased tissue.

multidisciplinary team

The name given to the healthcare professionals working as a team to look after you.

nausea

A feeling of sickness or discomfort in the stomach that may come with an urge to vomit. Nausea is a side effect of some types of cancer therapy.

nephrectomy

The surgical removal of all or part of the kidney.

Radical or total nephrectomy: The surgical removal of the whole kidney and the surrounding fat.

Partial or nephron-sparing nephrectomy:

The surgical removal of part of the kidney containing the tumour along with a small amount of normal (cancer-free) kidney surrounding the tumour.

oncocytoma

A small renal mass that grows in the collecting ducts of the kidney. They can grow quite large and very rarely diagnosed as malignant (cancer).

oncologist

A doctor qualified to diagnose and treat cancer.

outpatient

A patient who attends hospital for care but does not stay overnight.

overall survival rate

The percentage of people in a study who are still alive at a defined time after they started treatment for their cancer.

palliative care

Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of palliative care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment, and address any psychological, social, or spiritual concerns. Also called supportive care.

papillary renal adenoma

The most common non-cancerous solid small renal mass. These grow very slowly and usually don't cause any symptoms.

prognosis

The likely outcome or course of a disease; the chance of recovery or recurrence. Some of the factors that affect prognosis are the type of cancer, its stage and grade, and its response to treatment.

quality of life

The standard of health, comfort, and happiness experienced by a person.

radiofrequency ablation

A procedure that uses radio waves to heat and destroy a cancer.

renal

Having to do with the kidneys.

renal cell carcinoma (RCC)

The most common kind of kidney cancer. It arises in the small tubes of the kidneys. In the majority of cases, this is the clear cell subtype.

robot-assisted surgery (RAS)

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

side effect

An unwanted or undesirable effect resulting from treatment. Some common side effects of cancer treatment are fatigue, pain, nausea, vomiting, decreased blood cell counts, hair loss and mouth sores.

small renal mass

Areas of abnormal tissue growth in the kidney that show up on scans. They are relatively small when first discovered (<4cm in diameter).

stage

The extent of a cancer in the body. Staging is usually based on the size of the tumour, whether lymph nodes contain cancer, and whether the cancer has spread from the original (primary) site to other parts of the body.

supportive care

Care that focuses on relieving symptoms caused by serious illnesses like cancer. It can be given at any point during a person's illness to help them feel more comfortable. Includes pain management, relaxation techniques, counselling nutritional advice and practical help with tasks of daily living. Also called palliative care.

surgery

A procedure to remove or repair a part of the body or to find out whether disease is present. An operation.

symptom

An indication that a person has a condition or disease. Some examples of symptoms are headache, fever, fatigue, nausea, vomiting, and pain.

tissue

A group or layer of cells that work together to perform a specific function.

tumour

An abnormal growth of cells. Tumours can be benign (not cancer) or malignant (cancer).

ultrasound

A technology that uses high-energy sound waves to take pictures of internal organs and other structures like blood vessels.

urologist

A surgeon who specialises in treating diseases of the genitourinary system.

x-ray

A type of high-energy radiation. In low doses, x-rays are used to diagnose diseases by making pictures of the inside of the body. In high doses, x-rays are used to treat cancer.

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Edition 1.0 of this decision aid was developed by the International Kidney Cancer Coalition (IKCC) working in partnership with Kidney Cancer Support Network (KCSN).

The IKCC is an independent international network of patient organisations that focus on kidney cancer. It is legally incorporated as a Foundation in the Netherlands. The organisation was born from a very strong desire among various national kidney cancer patient groups to network, cooperate and share materials, knowledge, and experiences.

KCSN is an affiliate organisation of the IKCC. KCSN is a patient-led network of patients, carers and families affected by kidney cancer in the UK. They provide up-to-date news and information, help raise awareness and advocate for better care for kidney cancer patients. KCSN enables patients and carers to come together to share their experiences about the day-to-day reality of living with kidney cancer to help improve the lives of fellow patients.

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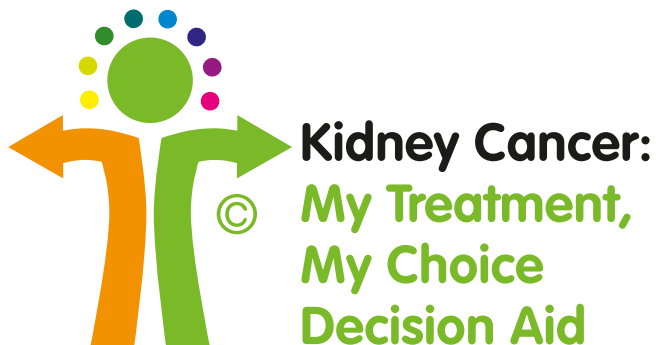
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