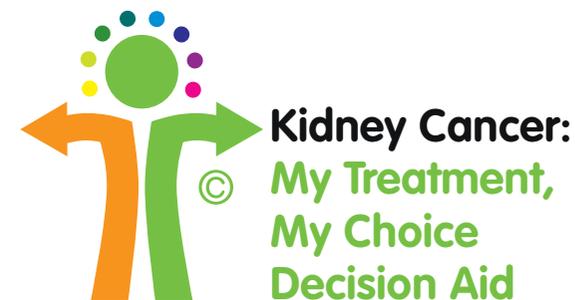


My Treatment, My Choice

A decision aid for people with advanced renal cell carcinoma (kidney cancer)



Supporting shared decision making with your healthcare team





This workbook belongs to:

.....

.....

.....

.....

.....

.....



Kidney Cancer: **My Treatment,** **My Choice** **Decision Aid**

Version 1.0 April 2017

Disclaimer

This decision aid is intended for use with the advice of your healthcare professionals. It does not support any particular course of treatment over another. Use of this decision aid is voluntary.

© by IKCC International Kidney Cancer Coalition

Foreword	6
----------	---

About this decision aid	7
-------------------------	---

My kidney cancer	9
-------------------------	----------

<i>Understanding advanced renal cell carcinoma</i>	10
<i>Understanding your diagnosis</i>	12
<i>Your healthcare team</i>	16

My treatment	17
---------------------	-----------

<i>What are the goals of advanced renal cell carcinoma treatment?</i>	18
<i>What is considered when making a decision about treatment?</i>	19
<i>What are the main types of treatment for advanced renal cell carcinoma?</i>	21
<i>Types of treatment</i>	22
<i>Active surveillance</i>	22
<i>Surgery – nephrectomy</i>	23
<i>Anti-cancer medications</i>	25
<i>Surgery – metastasectomy</i>	31
<i>Stereotactic radiotherapy</i>	32
<i>Ablative treatments</i>	34
<i>No active treatment</i>	36
<i>Stopping active treatment</i>	37
<i>Palliative care</i>	38
<i>Supportive care</i>	39
<i>Support</i>	39
<i>Clinical trials</i>	40
<i>How do I know that I am receiving the best possible care?</i>	42
<i>Will there be any financial costs?</i>	42

My questions

43

My decision

51

<i>Summary</i>	52
<i>Worksheets</i>	54
<i>Am I ready to make a decision?</i>	62

My resources

63

<i>Clinical guidelines</i>	64
<i>Kidney cancer websites</i>	64
<i>Clinical trial registries</i>	64

My kidney cancer dictionary

65

Acknowledgements

73



Perhaps you're reading this because you have advanced renal cell carcinoma yourself, or someone you care about has kidney cancer that may have spread. We understand that the diagnosis and the treatment options can be overwhelming. 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. The 'My kidney cancer dictionary' is included to help you understand the medical terms that are used.



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

www.ikcc.org

This decision aid has been written for people diagnosed with a type of kidney cancer called renal cell carcinoma (RCC). It is for people who have advanced renal cell carcinoma (advanced RCC). This means the cancer has:

- spread from where it started (metastatic kidney cancer), or
- come back after treatment (recurrent kidney cancer).

There are different types of treatment for people who have advanced RCC. You will probably 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 this condition.

This decision aid aims to help guide you through your conversations with the healthcare professionals involved in your care. It is also a tool to help you make treatment choices that will deliver the best quality and quantity of life for you according to your personal goals.

It provides:

- information about the options available
- details about possible benefits and risks of each option
- advice on how to make a decision that will best suit your values and goals
- questions you may want to ask your healthcare professionals
- a list of resources where you can find further information.

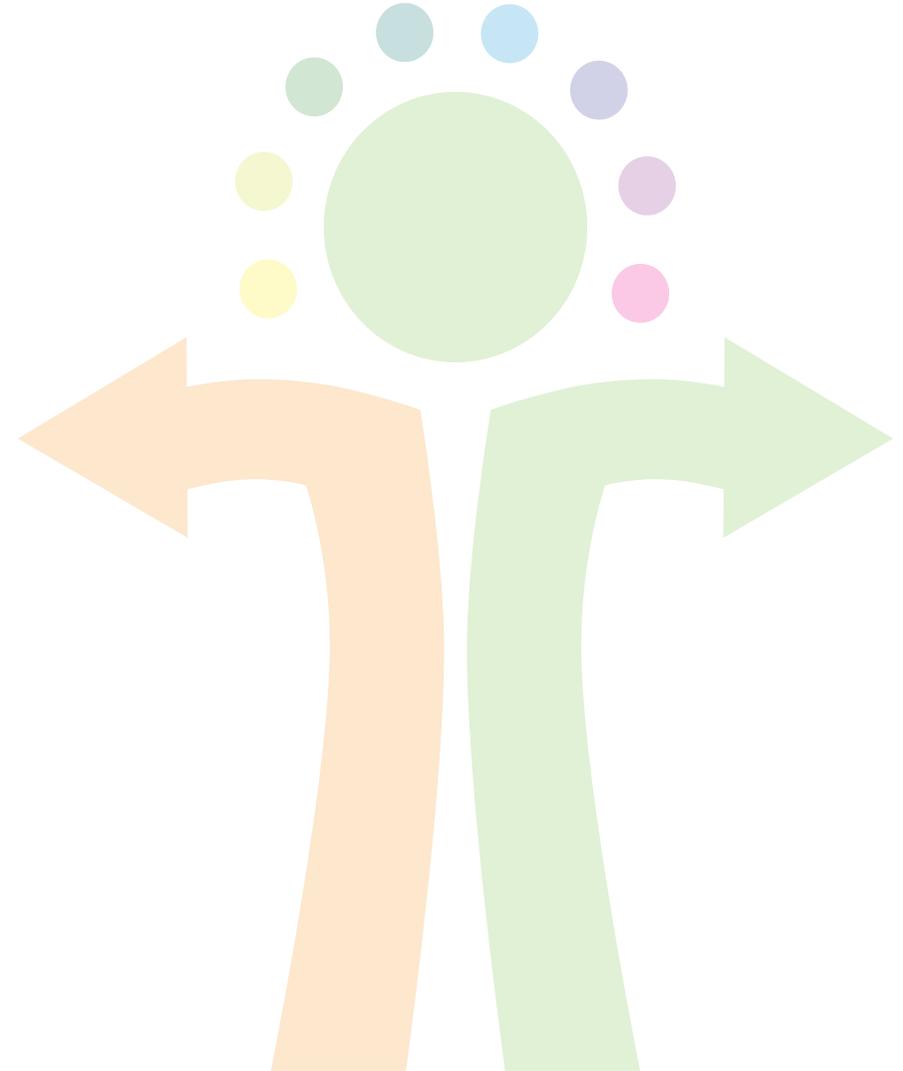
Having advanced RCC can be overwhelming. However, learning about the disease and treatment options can empower you to become an advocate in your own care.

You are the most important and powerful person involved in your own healthcare. Only you understand the impact of choices on your life.

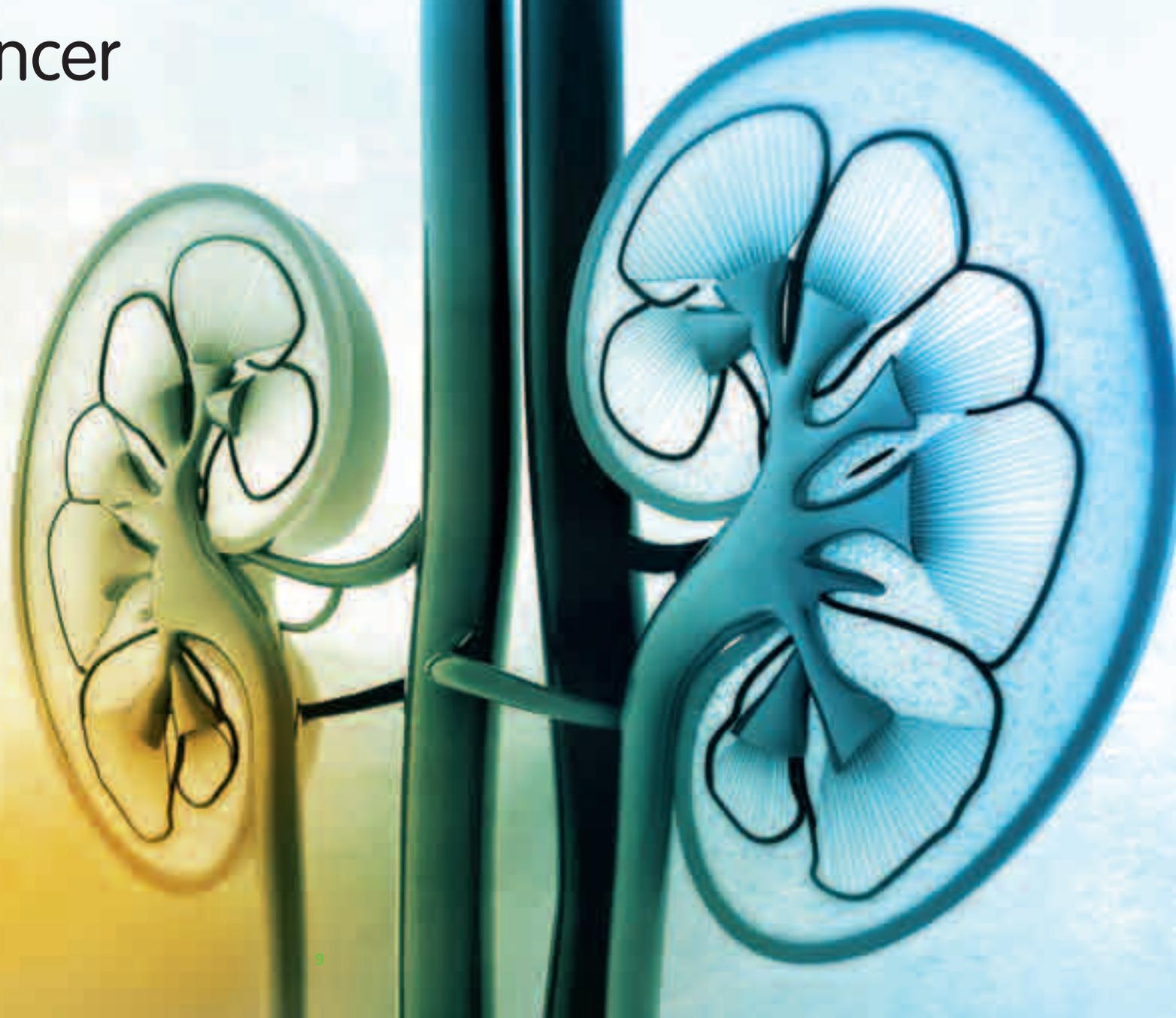


About this decision aid

Remember to bring this decision aid with you to your next appointment with your healthcare team. Having it on hand may be useful when discussing your treatment options.



My kidney cancer



What is locally advanced renal cell carcinoma?

Locally advanced RCC is cancer that has spread from the kidney to the local lymph nodes, blood vessels or surrounding tissues.

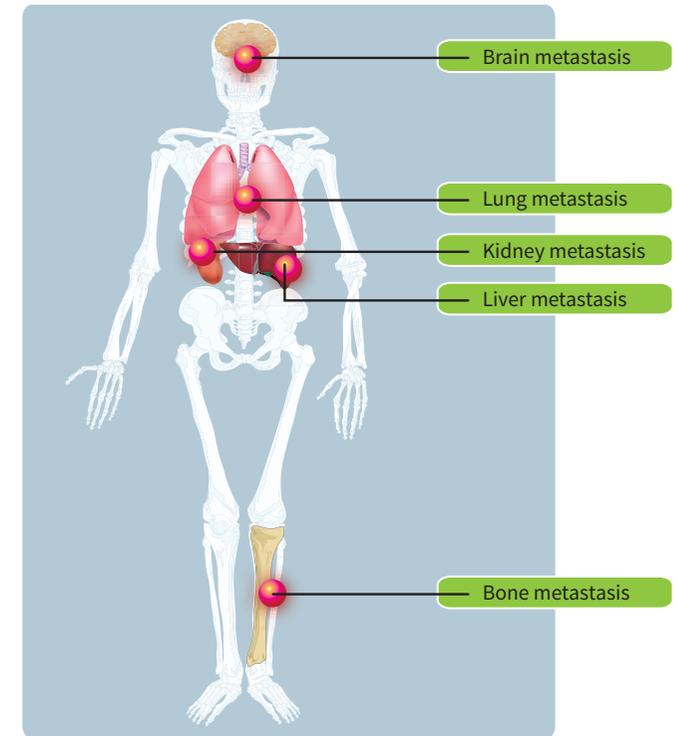
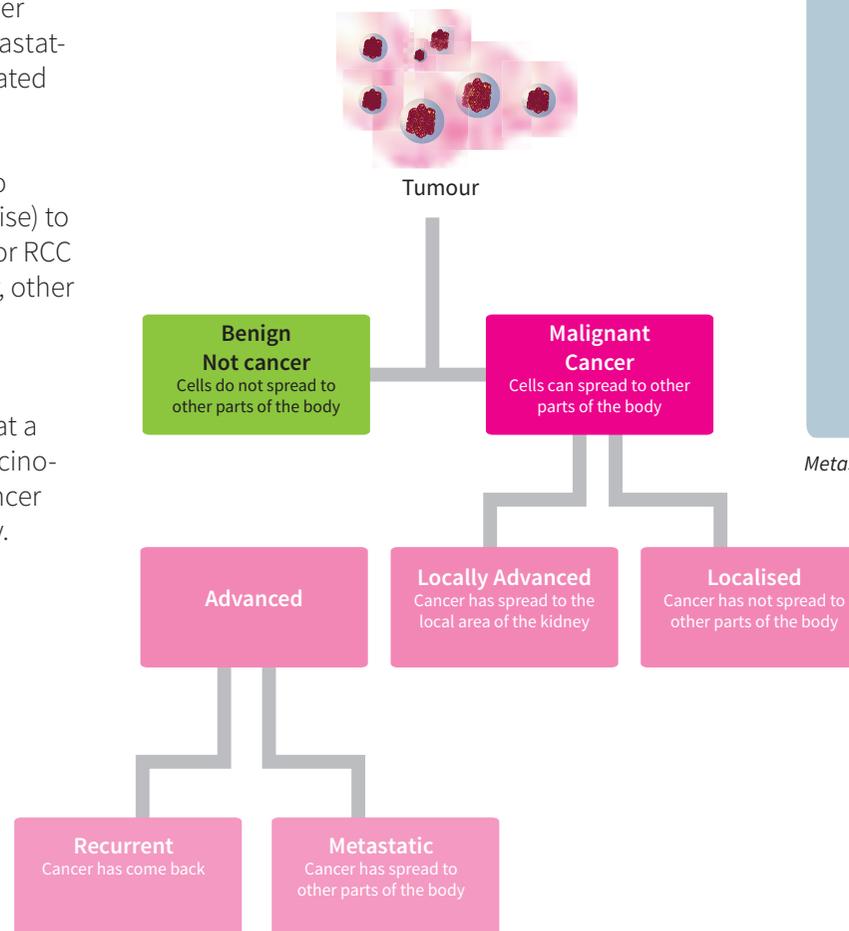
What is advanced renal cell carcinoma?

Advanced RCC (aRCC) is when the cancer has either spread to a distant site away from the kidney (metastatic RCC), or has come back some time after first treated (recurrent kidney cancer).

Metastatic RCC (mRCC): It is possible for cancer to break away from the kidney and spread (metastasise) to other parts of the body. The most common sites for RCC to spread are the lymph glands, lungs, bones, liver, other kidney and brain. This is called metastatic RCC.

Recurrent renal cell carcinoma

Like many cancers, it is possible for RCC to return at a later time. This is known as recurrent renal cell carcinoma. RCC may recur in the region of the original cancer (local recurrence), or in a different part of the body.

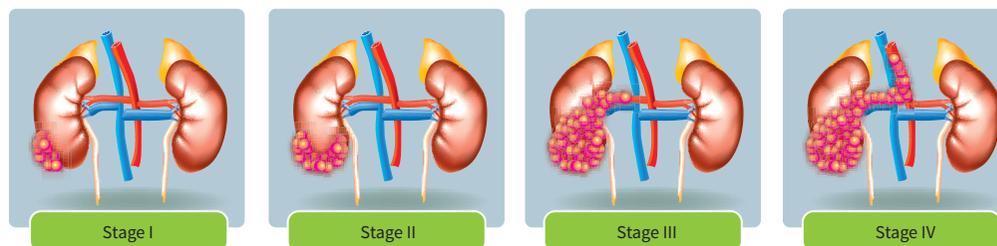


Metastatic renal cell carcinoma

What is the stage of the cancer?

Your healthcare team will use a standard staging system to describe the extent of the cancer.

There are a number of ways to stage RCC. The most common one is known as the TNM system. This stands for tumour, nodes and metastasis. Each letter is assigned a number to describe the cancer.



TNM staging system for kidney cancer

T (tumour) 1-4 or Tx	Indicates the size of the main kidney tumour and whether it has spread into nearby areas. A higher T number means that the tumour is larger or has spread to areas around the kidney. Tx means the tumour can not be assessed.
N (nodes) 0-1 or Nx	Indicates if the cancer has spread to nearby lymph nodes (part of the immune system). 0 means the cancer has not spread; 1 means that cancer has spread. Nx means that the lymph nodes can not be assessed.
M (metastasis) 0-1	Indicates whether the cancer has spread (metastasised) to distant parts of the body. 0 means the cancer has not spread; 1 means the cancer has spread.

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

Once the T, N and M categories have been assigned, this information is combined to assign an overall stage of I, II, III, or IV. The stages identify cancers that have a similar prognosis (predicted outcome of the cancer, such as how long you are likely to live) and similar treatments.

What are the different grades of RCC?

The different grades of RCC indicate how the cells look and how fast they are likely to grow (how aggressive they are).

The Fuhrman Nuclear Grade is the most commonly used grading system for RCC.

Fuhrman Nuclear Grade system for grading kidney cancer

Grade 1	The cancer cells look fairly normal. They are probably slow growing and are less likely to spread.
Grade 2	The cancer cells appear slightly abnormal and might grow more rapidly.
Grade 3	Most cells appear abnormal and the cancer might grow quickly.
Grade 4	No cancer cells look normal and they are more likely to grow and spread rapidly.

Will I need a kidney biopsy?

Some types of medications for advanced kidney cancer are only effective or recommended for specific subtypes of RCC. Your healthcare team will therefore need to know which subtype of RCC you have. They can find this out by looking at a sample of your cancer under a microscope.

There are two ways to get a sample of your kidney cancer:

■ **1. A kidney biopsy:** A kidney biopsy is usually done as an outpatient using local anaesthetic to numb your skin. A small sample of your cells is then removed using a fine needle. The sample is sent to a lab so the cells can be examined under a microscope by a pathologist, to determine the subtype and grade of RCC you have.

A biopsy can be taken from the kidney, or if the cancer has spread (mRCC), it may be possible to take a biopsy of the metastasis.

■ **2. During surgery:** If you are going to have surgery or have had surgery for kidney cancer, the tissue sample can also be taken from the tumour after it is removed.

How does my healthcare team use the information about the cancer?

Information about the subtype, stage and grade of the RCC will help the healthcare team to:

- recommend treatment(s) that would be suitable
- determine if you would be eligible for any clinical trials
- predict the expected course of the cancer based upon others with a similar diagnosis
- understand the impact on your quality of life.

What is my prognosis?

Before considering your treatment options, you may want to discuss your prognosis with your healthcare professional. Your prognosis is the health professional's **estimate** of how long you are likely to live. It is not possible for any doctor to predict the exact course of your illness.

There are a number of different prognosis scoring systems. In general, they take into account the stage and grade of the cancer, blood test results and your overall health and well-being. If you have already had treatment for RCC, your prognosis may also be based on how you responded to treatment.

Understanding your individual prognosis can help you make an informed choice about your care and make decisions according to your values. For example, if your prognosis is very good, good, or intermediate, you may wish to take some time to evaluate the best treatment options, including clinical trials that may be available. If, however, your prognosis is quite poor, you may choose not to have active treatment and enjoy the best quality of life that you can for as long as possible without the risk of side effects.



My kidney cancer – My healthcare team

Depending upon where you live, you may have one main doctor or many health professionals involved your care and the treatment of your advanced RCC.

However, the most important and powerful person in your healthcare team is actually you! You can work with the healthcare team to learn about advanced renal cell carcinoma and treatment options, and improve your own health and well-being.

Who are the members of my healthcare team?

Treatment of advanced kidney cancer often requires skills from many different types of healthcare professionals. The table on the right shows some of the healthcare professionals that your team might include.

In some countries, these healthcare professionals work together in a multidisciplinary team (MDT). The MDT meets to discuss your treatment and care. In other countries, these healthcare professionals might work separately. You will need to play an important role organising your care in keeping everyone on your healthcare team informed.

Many patients recommend keeping a personal file or diary of important reports and documents about your condition and treatment.

Urologist	A surgeon who specialises in treating diseases of the genitourinary system.
Uro-oncologist	A surgeon who specialises in treating cancers of the urinary system genitourinary
Medical oncologist	Assesses the role of cancer medications and prescribes them to treat the cancer.
Radiation oncologist	Assesses the role of radiation therapy to treat the cancer and plans treatment.
Nephrologist	A specialist kidney doctor who often advises people at risk of developing chronic kidney disease.
General practitioner (GP)	Refers you to specialist doctors, helps manage cancer symptoms and treatment side effects, and assists with coordinating your care.
Pathologist	Studies cells under a microscope to determine the type of kidney cancer you have and its features.
Cancer nurse	Provides education about kidney cancer, administers medication, supports you throughout treatment and helps coordinate your care.
Radiologist	Specialises in diagnosing disease by using x-rays, ultrasounds, CT scans and MRI scans.
Palliative care doctor	Helps relieve symptoms, manage pain and improve your quality of life.
Palliative care nurse	Works with the palliative care doctor to help relieve symptoms, manage pain and improve your quality of life.
Psychologist/ Counsellor	Helps you cope with the impact cancer has on your mental health and relationships.
Social worker	Provides help with the practical aspects of living with cancer.
Occupational therapist	Works with you to enable you to maintain your physical health and ability to participate in the activities of everyday life.
Dietitian	Advises you about eating a healthy diet and staying nourished during your treatment and recovery.
Physiotherapist	Helps manage pain and disability through exercise, massage and physical manipulation.
Exercise physiologist	Develops a clinical exercise program tailored to you.
Rehabilitation doctor	Provides rehabilitation after surgery or during cancer treatment.
Clinical trial coordinator	Recruits eligible people into clinical trials and organises the trial.
Patient organisations	Connect people who can share their experiences with kidney cancer and provide information and support.

My treatment



My treatment – What is considered when making a decision about treatment?

There are several different treatment options for people with advanced renal cell carcinoma. See pages 21-41 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 advanced renal cell carcinoma you have

The subtype of renal cell carcinoma and its stage and grade will determine the range of treatment options suitable for you.

2. Your current state of health

People who are generally fit and well can normally cope with major surgery and the side effects of medications. However, if you are not fit and well and have lots of other medical problems (co-morbidities), you may not be able to cope with active treatment.

3. Side effects and risks of treatment

All treatments for advanced renal cell carcinoma (RCC) have possible side effects and/or risks. A side effect is an unwanted outcome of a treatment, such as nausea or a rash. A risk is a potential danger or harm (adverse event), such as getting a blood clot after an operation.

Your doctor will talk to you about the possible side effects and risks of the available treatments. You can then consider the side effects or risks that you are prepared to accept and those you would most like to avoid.

4. Quality of life versus quantity of life

All cancer treatments are different and will affect your life in different ways. How much a particular treatment will extend your life – your **quantity of life** – is not the only factor you need to take into account when you are weighing up different treatment options. You will also need to look at how a treatment will affect your overall well-being – your **quality of life**.

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

- whether treatment will alleviate the symptoms of the cancer
- any treatment side effects
- whether it is a short-term treatment, such as surgery or radiation, or longer-term treatment, such as medication
- how well you are coping and how much support you have.

Deciding whether or not to have a treatment (and which treatment to choose) can be a balancing act between the quality of life you are happy with and the quantity of life the treatment gives you. Most people want both quality and quantity, however sometimes you may need to favour one over the other.

The diagram below shows a divide between quality and quantity of life. Where would you put yourself when balancing quality of life with quantity? Mark a cross on the middle line where you lie.



6. Priorities, values and goals

Your healthcare professional can explain what various treatments involve. But before you make any decisions about treatments, it is important to consider what is important in your life – your personal priorities, values and goals.

7. Cost and availability of treatments

Access to diagnostic services and treatments for advanced RCC is different around the world. It may even depend on which region of the country you live in or what your insurance plan will cover.

The cost of treatments will also vary. In some countries, treatments depend on government funding. In other countries, you may have access to treatments through private insurance. There may also be a combination of government, private insurance funding and self-funding.

Customising a plan that's right for you

You will need a treatment that is tailored to your goals. Medical details such as your exact type of renal cell carcinoma, your current state of health and where you live in the world will determine to some extent which treatment options will be available for you. Your healthcare professional will be able to discuss the recommended treatment options with you, including what you can expect from treatment and realistic goals you can set. However, whether or not to have treatment, and what type, is your decision. You are the expert in your own life and you best know how you cope with illness, side effects and risks.



My treatment – What are the main types of treatment for advanced renal cell carcinoma?

A number of different treatments are available for advanced renal cell carcinoma. Each one is used for a different reason and often a combination or sequence of treatments is used.

A way to think about the treatments for advanced renal cell carcinoma (RCC) is thinking about a garden shed full of different tools. Each tool represents an available treatment. Just as you would not use a hammer to cut a piece of wood, not all treatment options will be suitable for specific problems in advanced RCC.

To support and protect the tools in the garden shed, the shed has walls and a roof. For advanced RCC, this represents other aspects of your overall care, such as supportive and palliative care.

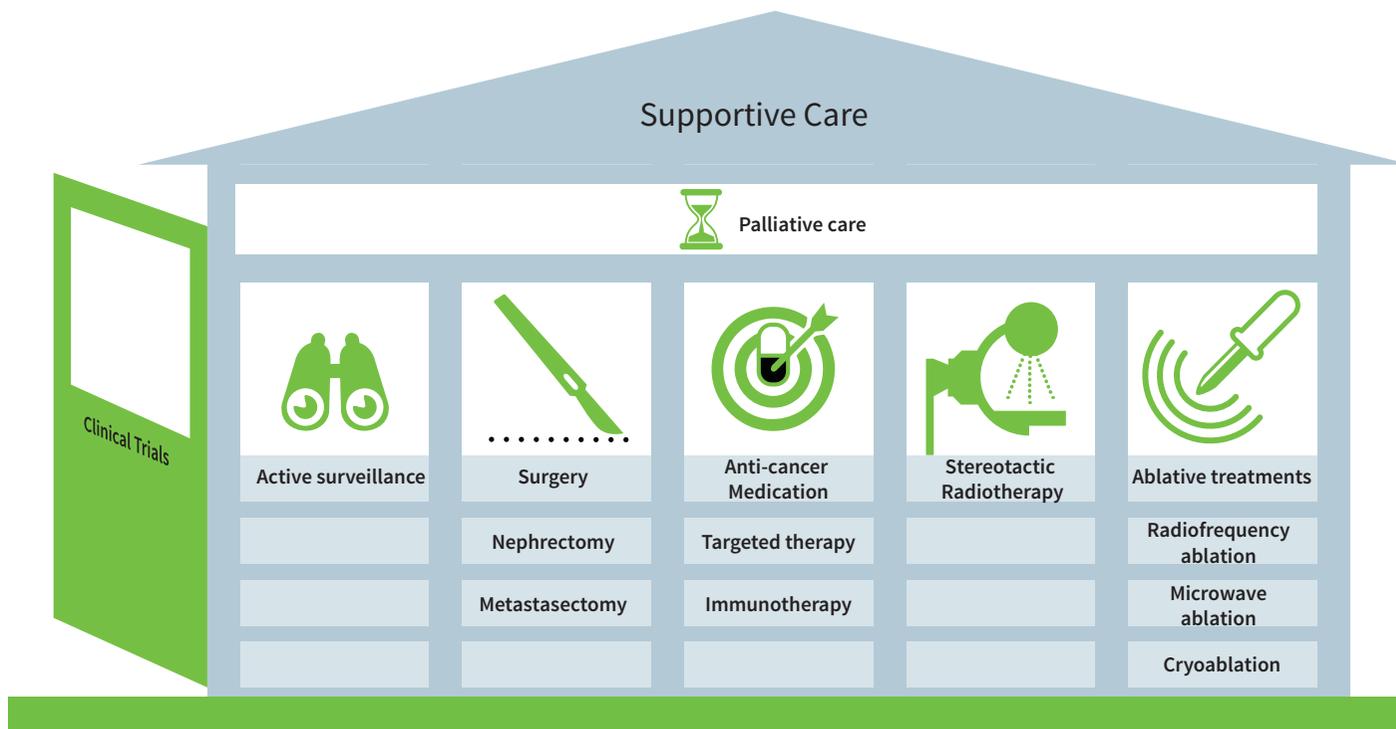
The door of the garden shed symbolises clinical trials, which may be a 'gateway' to accessing treatments that would not otherwise be available to you.

The different treatment options are shown in the diagram below. Remember you will need to discuss with your healthcare professional which treatment options or 'tools' are suitable and available to you locally, or those you might be able to travel for.

The following sections provide more information about each different treatment option. This includes if they might be a suitable choice for your type of advanced RCC and possible advantages and disadvantages of each.

Remember that you may need a combination or sequence of treatments, and every option listed in this decision aid may not be suitable. It is important to talk to your healthcare professional about your situation and ask for additional information.

The 'garden shed' of treatments for advanced renal cell carcinoma





What is involved?

Instead of starting kidney cancer treatment immediately, active surveillance involves closely monitoring the cancer. This involves having regular visits to your doctor for an examination and diagnostic tests.

People on active surveillance can decide to start active treatment at any time. For example, you may decide to have treatment if the cancer starts to grow or you start to have symptoms.

Is active surveillance a suitable option for me?

Active surveillance may be particularly suitable if you:

- have slow-growing kidney cancer and are symptom-free
- have other health problems
- are older
- only have one kidney.

By delaying or not having treatment, you may be able to avoid significant treatment side effects or other problems. If your RCC is slow growing a delay in starting treatment is not likely to affect your long-term outcome.

Possible benefits of active surveillance	Possible disadvantages of active surveillance
1. No treatment side effects All active treatment options have risks and side effects. Side effects may be physically and mentally exhausting and significantly interfere with your life. By delaying starting treatment, you will avoid these side effects.	1. Anxiety You may feel uncomfortable or anxious about not having treatment – you might feel like you are ‘doing nothing’ to treat the cancer.
2. Ability to focus on quality of life As you will not be receiving active treatment, the only impact on your daily life will be taking time out for hospital 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.	2. Risk of the cancer growing A period of active surveillance is not likely to have an effect on your long-term outcome, however there is a risk that your kidney cancer will grow.
3. Financial benefits Depending upon your situation, active 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).	



What is involved?

A nephrectomy is an operation to remove a kidney. 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.

Nephrectomy can be done as an open or as a laparoscopic operation, with or without robotic assistance. The way the operation is done will depend on:

- the size and spread of the cancer
- the facilities available at the hospital
- the surgeon's preference and experience
- your choice.

Open surgery

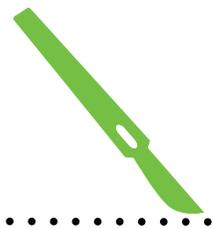
A large cut (incision) is made in the abdomen so the surgeon can see and directly access the kidney tumour.

Laparoscopic (keyhole or minimally invasive) surgery

Small cuts (incisions) are made in the abdomen. Long thin surgical instruments and a small telescope with a camera (laparoscope) are inserted through these cuts to do the surgery. The camera gives a high-quality image of the operating area on a video monitor.

Robotic assisted laparoscopic surgery is similar, except the instruments are attached to robotic arms which the surgeon controls from a work station. The surgeon has a 3D view of the operating area. The improved view and advanced tools gives the surgeon more precision and control.

Technique	Open	Laparoscopic
Possible benefits	<ul style="list-style-type: none"> • Traditional approach • Does not need to be done in a specialised hospital • Most cancers can be removed using this technique 	<ul style="list-style-type: none"> • Less requirements for pain medication • Shorter hospital stay and recovery time
Possible disadvantages	<ul style="list-style-type: none"> • Higher requirement for pain medications • Longer hospital stay and recovery time • Greater risks associated with major surgery 	<ul style="list-style-type: none"> • More specialised and only available in some hospitals • Not all cancers can be removed using this technique • More expensive (if applicable) • Risks specific to laparoscopic surgery



For advanced RCC, a nephrectomy is usually used together with medication and/or radiation therapy.

Nephrectomy is a major operation and you will be in hospital for around 3 – 7 days. Check with your doctor how long you can expect to be hospital. Full recovery may take 6 – 12 weeks depending upon the type of surgery.

Is a nephrectomy a suitable option for me?

If you have just been diagnosed with metastatic RCC and your general health is good, in most cases your entire kidney will be removed. In metastatic RCC this is known as a cytoreductive radical nephrectomy. Some people may be offered a partial nephrectomy but this will only be considered if your kidney cancer is small, if you have one kidney or if you have poor kidney function.

If your cancer is recurrent and you have had surgery in the past, you may have already had either a radical nephrectomy or a partial nephrectomy.

Possible benefits of nephrectomy	Possible disadvantages of nephrectomy
1. Prevents symptoms of the cancer If the kidney cancer is causing symptoms and problems such as pain, bleeding, and high blood pressure which is difficult to control, removing the cancer may be helpful. As well as making you feel better, it may also help you tolerate kidney cancer medication.	1. Hospital stay 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. If you are working you will need to take time off – most people require 6-8 weeks leave. You may need to start back at work gradually.
2. Helps other treatments work better If the kidney cancer is not causing a lot of problems, and your health is otherwise good, then removing the original cancer in the kidney helps other medications work better.	2. Risks and side effects of major operation 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).
3. Delays anti-cancer medication If the cancer has spread to 1-2 places and these are removed along with the primary kidney cancer, this may delay the need for anti-cancer medication.	3. May not be effective or may still require treatment If the surgery only removes the kidney tumour, and not the metastasis, you may still require further treatment. There is also no guarantee that surgery to remove the original cancer will improve survival. This is especially true if your cancer has spread to several places and your overall health is poor.
4. May improve survival Removing the original primary cancer may improve survival.	4. May delay or prevent helpful anti-cancer medication You will need to recover from the surgery and any complications before starting any anti-cancer medication. This may delay starting on anti-cancer medication.



What is involved?

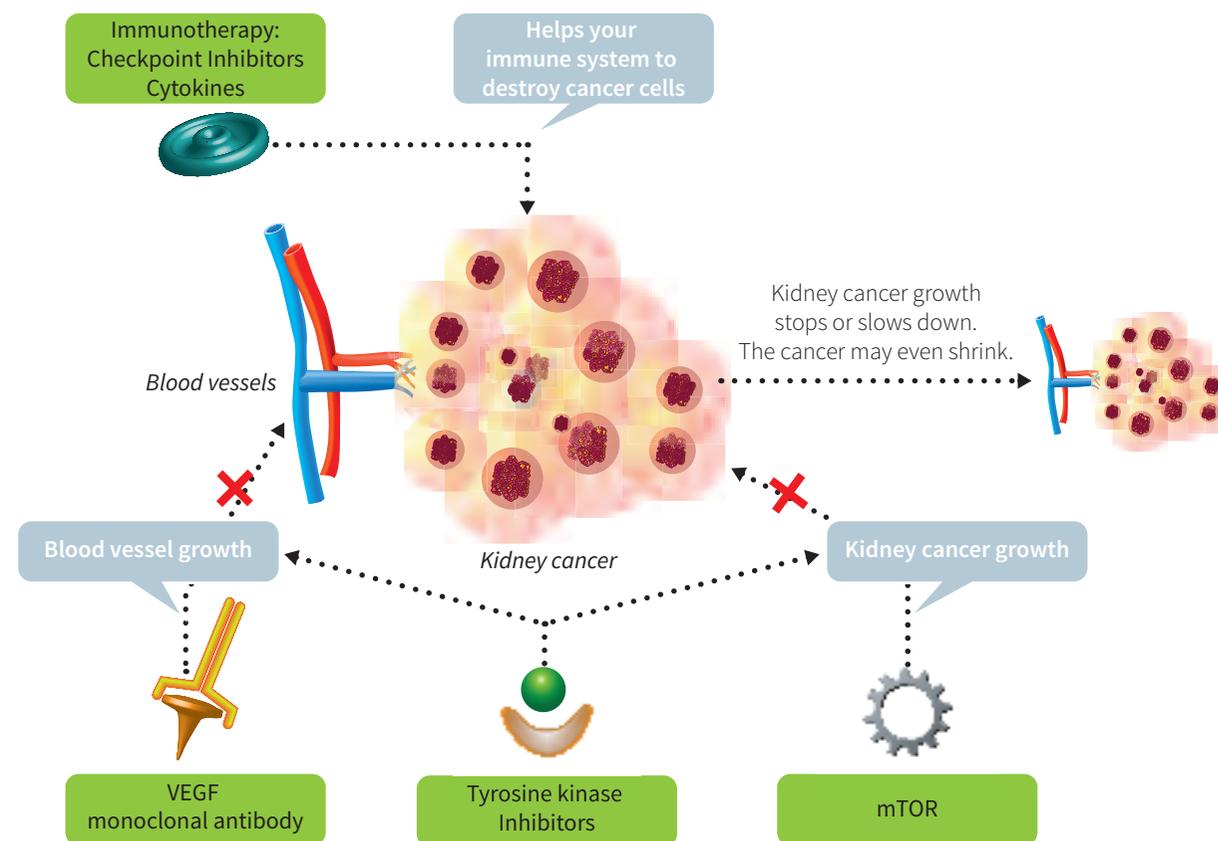
Anti-cancer medications are used to destroy cancer cells. The medication may stop or slow down cancer growth or shrink the cancer. The aim is to reduce symptoms and prolong life.

There are different types of anti-cancer medications used to treat advanced renal cell carcinoma. Each type of medication works in a unique way. The diagram shows how medications work. For more detailed information, please see **How exactly do anti-cancer medications work** on page 29.

Some anti-cancer medications are taken as tablets or capsules, while some are injected just under the skin (subcutaneously) or into a vein (intravenously). If you take tablets or capsules, you will take medication at home according to a regular schedule. Subcutaneous injections can also be done at home by yourself, about 3 times per week. You will be taught how to do this. If the anti-cancer medication is injected into a vein, this will be done by a nurse every 2-3 weeks as an out-patient in hospital.

For advanced RCC, anti-cancer medications can be combined with other forms of treatment. Medications may be the only treatment you receive, or might be used in combination with surgery or radiotherapy.

How do anti-cancer medications for advanced RCC work?



Note: not every type of anti-cancer medication may be available where you live. New anti-cancer medications for advanced renal cell carcinoma are undergoing clinical trials worldwide. Check with your local patient group for more information about clinical trials in your country.



Possible side effects of anti-cancer medications

There are a number of different anti-cancer medications for advanced renal cell carcinoma and each has different possible side effects. Not everybody will have side effects. If they do occur, they may be mild and temporary, but others may be serious and need medical attention.

If you take anti-cancer medication and notice any side effects, do not wait before telling your healthcare professional immediately. Early reporting can help to minimise the impact of side effects on your health and quality of life.

Your doctor can discuss with you the possible side effects of anti-cancer medications available to you.

Medication type	Targeted therapy			
	Tyrosine kinase inhibitors (TKI)	Vascular endothelial growth factor (VEGF) inhibitors (antibodies)	Mammalian target of rapamycin (mTOR) inhibitors	
How does it work?	Prevents growth of cancer cells and blood vessels	Prevents growth of cancer cells and blood vessels	Prevents growth of cancer cells	
Examples of this medication	axitinib, cabozantinib, lenvatinib, pazopanib, sorafenib, sunitinib	bevacizumab (taken with interferon-alpha – next page)	everolimus	temsirolimus
How is it given?	Tablets on a daily basis or with a regimen of breaks	Bevacizumab is injected into a vein every 2 weeks. Interferon needs to be injected under the skin 3 times a week.	daily tablet	injected into a vein once a week
What are the more common side effects?	Fatigue, diarrhoea, nausea and vomiting, stomach pain, weight loss, high blood pressure, tenderness and sensitivity in the hands and feet (hand - foot syndrome), skin rash, mouth sores, taste changes, pain and swelling in arms or legs (oedema), chest pain and breathing problems.	Headache, back pain, diarrhoea, loss of appetite, cold symptoms (stuffy nose, sneezing, sore throat, dry or watery eyes), dry or flaky skin, hair loss, changes in your sense of taste, jaw pain, swelling, numbness, loose teeth and gum infection	Fatigue, diarrhoea, decreased appetite, nausea, diabetes, mouth sores, skin rash, swelling in arms or legs (oedema), cough, breathing problems and possible allergic reaction (temsirolimus)	

Medication type	Immunotherapy		
	Cytokines		Checkpoint inhibitors (PD/PD-L1 inhibitors)
How does it work?	Helps your immune system attack the cancer cells	Helps your immune system attack the cancer cells	Helps your immune system attack the cancer cells
Examples of this medication	high dose interleukin (IL-2)	interferon-alpha (sometimes given in combination with bevacizumab)	nivolumab
How is it given?	Injected into a vein 3 times a day for several weeks	Injected under the skin or into a vein 3 times a week	Injected into a vein every 2 weeks
What are the more common side effects?	Side effects can be severe and dangerous. IL-2 is only given in some countries and select hospitals. Side effects include extreme fatigue, fever, low blood pressure, breathing and heart problems and intestinal bleeding	Flu-like symptoms, fatigue and nausea. Side effects are not as severe as IL-2	Fatigue, rash and other skin reactions, diarrhoea, abdominal pain, loss of appetite, anaemia, fever, stiff or painful joints, numbness, weakness, shortness of breath, chest pain, and sore and red eyes



Is anti-cancer medication a suitable option for me?

Taking an anti-cancer medication is an option for most people with advanced RCC.

How are anti-cancer medications sequenced?

If you chose to have anti-cancer medication you will be started on one type of medication. This will be called your first-line treatment. Clinical guidelines in your country specify which medications are approved as first-line treatments, based upon evidence from clinical trials.

If the first medication doesn't work, causes unbearable side effects or stops working, you may be offered a different type of medication. This is known as a second-line treatment. Types of second-line treatment will also be specified by guidelines in your country.

The number of lines of treatment and sometimes the sequence varies. New treatments are being introduced that may change treatment guidelines. Some countries may only have one treatment available, while others may have many more. Clinical trials in most countries also offer patients additional treatment options.

Possible benefits of kidney cancer medication	Possible disadvantages of kidney cancer medication
1. May prolong life Currently, anti-cancer medications do not cure advanced kidney cancer. However, all of the medications have the capacity to prolong life to some degree.	1. Side effects All anti-cancer medications have side effects. They are different depending on the type of medication.
2. Symptom relief By slowing or stopping cancer growth (or even shrinking the cancer), medication can reduce the symptoms associated with primary kidney cancer and metastases.	2. Unavailability Not all anti-cancer medications are available in each country. In some countries, there may not be any medications available outside of clinical trials.
3. Sequencing medication offers extended treatment time If one type of medication stops working, you may be able to start a different type. In some countries, sequencing involves many different types of medications used over time according to clinical guidelines and availability of treatments.	3. Medication may stop working Sometimes the cancer cells become resistant to the medication and it stops having an effect. In this case, a different medication can be tried or the same medication can be re-tried after a break (known as a re-challenge).
	4. Medical appointments Some medications can be taken at home. For others that must be injected into a vein, treatment will require travel and medical appointments.

How exactly do anti-cancer medications work?

Targeted therapy

Tyrosine kinase inhibitors (TKI)

Tyrosine kinases are proteins in cells that are important for cell growth and survival. Tyrosine kinase inhibitors (TKIs) attach to tyrosine kinases in cells and block (inhibit) the signals that help kidney cancers grow and spread. All TKIs block more than one tyrosine kinase, but each TKI blocks different ones. The main targets for TKIs are:

1. Cancer blood vessels

TKIs target a cancer cell protein called vascular endothelial growth factor (VEGF). This protein helps cancers grow blood vessels. Blocking the growth of blood vessels to the cancer cuts of the supply of nutrients and oxygen to the cancer so that the cancer stops growing. Growth of blood vessels is known as angiogenesis. These medications are also known as 'anti-angiogenic' medications.

2. Cancer cells

Many TKIs also block other factors which are needed for a cancer to grow and divide.

Vascular endothelial growth factor (VEGF) inhibitors (antibodies)

Vascular endothelial growth factor (VEGF) is a protein in cells that is important for the growth and development of blood vessels. VEGF inhibitors bind to VEGF and blocks (inhibits) the growth of blood vessels to the cancer. This cuts of the supply of nutrients and oxygen to the cancer so that the cancer stops growing.

These medications are also known as 'anti-angiogenic' medications.

Mammalian target of rapamycin (mTOR) inhibitors

Mammalian target of rapamycin (mTOR) is a protein in cells that is important for cell growth and survival. It is involved in signalling cells to grow and divide (signal transduction). mTOR inhibitors block these signals, preventing growth and development of cancer cells.



How exactly do anti-cancer medications work?

Immunotherapy	
Cytokines	Checkpoint inhibitors (PD/PD-L1 inhibitors)
Help your immune system attack the cancer cells by: <ul style="list-style-type: none">• interfering with the way cancer cells grow and multiply• stimulating the immune system to attack cancer cells• encouraging cancer cells to produce chemicals that attract immune system cells to them.	Also known as immuno-oncology medications. Immune cells have a number of 'checkpoints' that help them work properly. Cancer cells sometimes use these checkpoints to stop your immune system recognising cancer cells. Checkpoint inhibitors are medications that block this so that the immune system is freed up to fight cancer cells.



What is involved?

A metastasectomy is a surgical operation to remove cancer that has spread from the kidney (metastasised). A metastasectomy may be done together with a nephrectomy (see page 23 – nephrectomy), or it may be done on isolated secondary cancers at a later time.

You will need to stay in hospital and have a period of recovery afterwards. Your length of time in the hospital will depend upon the extent of the surgery.

Is metastasectomy a suitable option for me?

The aim of metastasectomy is to control cancer symptoms, slow down the progression of your cancer and prolong your survival.

If the cancer has spread (metastasised) to just 1-2 places, it may be possible to try to remove (or ablate) the cancer.

Limited sites of metastases can also be treated using a specialised form of radiotherapy called stereotactic radiotherapy (see the next section).

Possible benefits of metastasectomy	Possible disadvantages of metastasectomy
1. Improves symptoms of the metastases If you are eligible for this treatment, removing metastases should improve your symptoms.	1. Hospital stay You will have to stay in hospital (the length of time depends on the part of the body affected, the extent of the surgery and your general health). Depending upon the surgery, full recovery can take several weeks or longer. If you are working you will need to take time off. Ask your surgeon how much time off you might require.
2. Improves survival Removing metastases along with the original cancer may delay the cancer progression and improve your survival.	2. Risks and side effects of major operation Major surgery is associated with significant health problems (morbidity) such as heart and lung problems. With any surgery, there is also a small but not insignificant risk of death (mortality).



What is involved?

Radiation therapy (radiotherapy) uses high-energy x-rays to kill cancer. Stereotactic radiotherapy is a specialised form of radiotherapy used to treat the primary RCC and/or metastases. A precise, high dose of radiation is targeted at the cancer. This aims to kill all the cancer in that area while limiting damage to healthy surrounding tissue.

There are two types of stereotactic radiotherapy:

- Stereotactic body radiotherapy (SBRT) – Used to treat small kidney cancers or metastases (for example bone, lungs or liver). It is given using a Linear Accelerator, CyberKnife® or Tomotherapy.
- Stereotactic radiosurgery (SRS) – Used to treat small metastases in the brain. SRS is not surgery, but the name reflects its ability to target the tumour. Also known as Gamma Knife® or CyberKnife®.

SBRT and SRS are given in a specialised hospital as an outpatient. It may be given in a single treatment or as up to 5 treatments.

Each treatment can take 30-60 minutes.

Is stereotactic radiotherapy a suitable option for me?

Stereotactic radiotherapy is an option if the cancer cannot be treated by surgery or if the cancer has metastasised to only a few places and these secondary cancers are reasonably small.

Stereotactic radiotherapy is only offered in specialised cancer centres.

Possible side effects of radiotherapy

The radiation used to destroy cancer can also damage the surrounding healthy tissues which can cause side effects.

Radiation can cause early side effects during or immediately after treatment. They tend to disappear gradually after radiation is complete.

Possible early side effects include:

- tiredness (fatigue)
- reddening, irritation and swelling of the skin in the treatment area
- loss of body hair in the treatment area
- feeling or being sick (nausea and vomiting)
- diarrhoea
- headaches.

Radiation can also cause late side effects which may be months to years after you had the treatment. This is because the radiation damage gradually builds up over time. Possible late side effects, depending on the area radiated, include:

- brain changes
- colon and rectal changes
- urinary and bladder changes
- infertility
- secondary cancer.

Stereotactic radiotherapy is very precise. It targets the cancer with limited damage to healthy surrounding tissue. This minimises the side effects of the treatment.

Possible benefits of stereotactic radiotherapy	Possible disadvantages of stereotactic radiotherapy
1. Delays cancer progression or prolongs survival	1. Side effects
If you are suitable for this treatment, it may delay the progression of your cancer and improve your survival.	The higher dose of radiotherapy aims to kill cancer, but it may be associated with some side effects and, uncommonly, significant complications.
2. Improves symptoms	2. Availability
Stereotactic radiotherapy can reduce the symptoms associated with primary RCC and the metastases.	Such specialised treatment is not available at all radiation therapy treatment centres.
3. Non-invasive	3. Delayed effect
This is not a surgical procedure (no cuts are made in your body).	It takes time for the damage that the radiation causes to build up (it can take weeks to months for the full effect of the treatment).
4. Precise	4. Trips to hospital
A high dose of radiation is delivered in a targeted way. This maximises the effect on the cancer cells and limits the damage to healthy tissues.	Treatment requires 1-5 outpatient visits.
5. Minimal time spent in hospital	
You do not have to stay in hospital.	



What is involved?

Ablation is a word used to describe the destruction of body tissue. Extreme heat or cold can be used to destroy kidney cancer and metastases.

Radiofrequency ablation and **microwave ablation** use energy waves to produce extreme heat to essentially cook and destroy the cancer.

Cryoablation or **cryotherapy** uses liquid nitrogen or liquid carbon dioxide to freeze and destroy the cancer.

The energy waves or gas are passed down a fine instrument into the cancer to destroy it. The needle can be inserted into the kidney cancer or metastasis through the skin (percutaneously). A CT or MRI scanner is used to locate the cancer's exact position. Local anaesthetic is given.

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

Is ablation a suitable option for me?

Ablative treatments can be used to treat the primary RCC or metastasis. An ablative treatment may be suitable if you:

- have multiple other medical problems (co-morbidities)
- are unable to tolerate a general anaesthetic
- have a single kidney
- have renal failure
- have multiple kidney tumours
- do not want to have surgery.

Possible benefits of ablative treatments	Possible disadvantages of ablative treatments
<p>1. Does not destroy the entire kidney</p> <p>Ablative treatments just target the kidney cancer leaving the remaining healthy kidney. This means it is treatment option for people with only one kidney, kidney failure or multiple kidney tumours.</p>	<p>1. Only suitable for small cancers</p> <p>Ablative treatments are generally used for small cancers, those less than 4cm.</p>
<p>2. Improves symptoms</p> <p>Ablative treatments can reduce the symptoms associated with metastases.</p>	<p>2. Multiple treatments</p> <p>You may require more than one session to treat the cancer.</p>
<p>3. Local control of cancer</p> <p>In suitable patients, ablation of the RCC can control the growth of the cancer.</p>	<p>3. Cancer control</p> <p>Ablative treatments may not control the cancer as well as other treatment options.</p>
<p>4. Non-invasive</p> <p>If done percutaneously 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).</p>	<p>4. Risks and side effects</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. Other possible risks include bleeding around the kidney and damage to the ureter.</p>
<p>5. Minimal time spent in hospital</p> <p>If done percutaneously you will not have to stay in hospital overnight. You should be able to return to usual activities in a few days.</p>	

What is involved?

Active treatments are treatments that aim to prolong your life, such as anti-cancer medications, surgery and stereotactic radiotherapy.

You may decide that you do not want to have active treatment for your cancer. It may be that your current state of health is not as good as it could be. You may feel that your quality of life will be better if you do not have active treatment.

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 cancer treatment may be an option for you.

Possible benefits of no active treatment	Possible disadvantages of no active treatment
<p>1. No treatment side effects</p> <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>	<p>1. Worsening cancer symptoms</p> <p>Because your cancer is not being treated it may grow and you may experience cancer-related symptoms such as pain, fatigue, nausea, constipation, loss of appetite, weight loss, difficulty passing urine, difficulty breathing and depression or anxiety. However, your doctor or palliative healthcare team will be able to help you manage these symptoms in other ways.</p>
<p>2. You can focus on your quality of life</p> <p>Without having side effects or recovery from an operation, 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>	<p>2. Anxiety</p> <p>You may feel uncomfortable or anxious about not having treatment – you might feel like you are ‘doing nothing’ to treat the cancer.</p>
<p>3. Less hospital trips and medical tests</p> <p>While you will have occasional hospital appointments, you will not have to spend a lot of time visiting the hospital.</p>	<p>3. Regret</p> <p>You may wonder what might have happened if you had chosen to have active treatment.</p>
<p>4. May improve emotional well-being</p> <p>Making a decision not to have active treatment may help you come to terms with the cancer and accept the next phase of your life. This may give you a sense of control and help you find inner peace.</p>	<p>4. Pressure from others</p> <p>Your family and friends may not understand why you have chosen not to have active treatment. This may make you feel pressured to change your mind or feel guilty about your decision.</p>

Stopping active treatment

If you have started active treatment, you may decide that you do not wish to continue.

You may be struggling with treatment side effects and feel that the disadvantages are outweighing the possible benefits of treatment. In this case, you may feel that your quality of life would be better if you stop active treatment.

You may feel that you need a break, or that you want to stop a medication or all active treatment altogether. This is a personal choice.

If you would like to stop your current treatment, discuss it with your healthcare team first. There may be other active treatment options for you to consider, or you may be able to have palliative treatment – see page 38.





What is involved?

At all stages of your cancer journey you need to feel as good as possible. This can be achieved through palliative care. The focus of palliative care is on improving you and your family's quality of life.

Palliative care includes a wide range of services, including:

- treatments and support to relieve cancer symptoms
- treatments and support to help manage pain
- treatments and support to reduce medication side effects
- emotional and social support
- specialised support at the end of life.

Palliative treatments and services include but are not limited to:

- medication – to control symptoms such as pain and nausea
- radiotherapy – to control growth of the cancer and relieve symptoms caused by the RCC or the metastases. For example, a low dose of palliative radiotherapy can reduce pain from cancer in the bones or control symptoms such as bleeding
- blood transfusions – to treat anaemia
- oxygen – to help with breathing difficulties
- 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, do not resuscitate orders and tissue donation.

Palliative care not only provides support to you, but it also aims to support others involved in your care, such as your family and friends.

When is palliative care recommended?

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

In fact, people with any advanced cancer can benefit from palliative care at any time during their journey. For this reason, palliative care is often recommended early in your treatment plan.

If 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. Early palliative care can also improve your survival.

Who provides palliative care?

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

Where is palliative care provided?

Palliative care can be provided at home, in a hospital or in hospice.



I am a patient. Where can I get support?

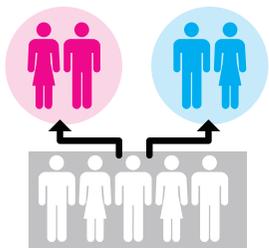
Cancer and its treatment can have a huge physical and emotional effect on you. It is important to look after yourself. This includes eating a well-balanced and healthy diet, not smoking, doing regular exercise, and seeking help if you feel depressed or anxious. There are professionals who can help guide 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 be there for you. Don't forget that your cancer diagnosis will also affect your family and friends. They will need help and support as well as you.

Some people find that it's helpful connecting with other people who have kidney cancer, or to talk to someone trained in supporting people with kidney cancer. You may want to consider contacting a patient support/advocacy group that is focused on kidney cancer.

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

Being a carer for a loved one with cancer can be rewarding, but it can also be tiring, stressful, 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.



What is a clinical trial?

A clinical trial is a type of research study that tests a new treatment, or other healthcare intervention, 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 an operation, or something as simple as a different way of caring for patients. Sometimes the clinical trial tests a combination of drugs or treatments that have not been tested before to see if two treatments combined are better than one.

When patients take part in clinical trials, there is always some uncertainty as to whether the new treatment is better or worse than the standard treatment. Clinical trials are the only way forward to improve cancer treatment.

Should I join a clinical trial?

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

Possible benefits of clinical trial

1. May be the best or only treatment option available

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

2. High-level care

You are often 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

The costs of all medical care involved in the clinical trial (all tests, surgery, radiation, and medication) will be provided by the clinical trial centre.

If you receive medication as part of a clinical trial, you will normally continue that medication if the treatment proves to be effective.

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 kidney cancer in the future.

Possible disadvantages of clinical trial

1. You may not receive the new treatment

Some clinical trials are randomised, others are not. For example, many Phase 1 or 2 medication trials provide the new medication to all patients, sometimes in different doses. Phase 3 trials randomise patients to receive either the current standard treatment or the new treatment.

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 drug in humans (a Phase I trial).

5. More hospital or clinic visits

If you do join a clinical trial you may need to have more tests or to have 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. If the trial would place undue costs on you, speak to the trial centre about any available financial assistance that may be available.

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 rules 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 RCC
- your general health is not good enough
- you have had treatment for your advanced RCC that could affect the results of the trial
- you have other diseases (e.g. diabetes or auto-immune 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.

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

There are a number of clinical guidelines produced by health organisations worldwide that outline how advanced RCC should be treated. These guidelines are based on the current best available evidence from international research.

See **My resources** on page 70.

If you are not sure you are being offered the best advice, you should discuss this with your healthcare team. You also have a right to ask for a second opinion from another doctor.

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

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 questions



My questions

The information you have learned about advanced RCC has probably raised some questions.

Asking your doctor and healthcare team these questions can help you decide upon which options are right for you.

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

Talking with your 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.

This list of questions on the following pages may help you get a better understanding of kidney cancer and treatment options. You may like to tick 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. You may also ask your doctor for permission to record the conversation so you can listen again later.

Contact your local patient organisation who can also provide good information and support. See *My resources* for a list of patient organisations.

About my kidney cancer	Please fill in your answers	<input checked="" type="checkbox"/>
What type of kidney cancer do I have?		
What is the stage and grade of my kidney cancer?		
How advanced is my cancer? Where in my body has it spread?		
Is my kidney cancer possibly hereditary (passed down in my family)?		
What type of symptoms can I expect?		

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

My questions

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?		
For my type of kidney cancer, 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?		
Are there any risks to this treatment? How likely are they to occur?		
What are the side effects of this treatment?		
Does this treatment cause any long-term or permanent changes (physical, social, emotional, mental or sexual)?		
Is active surveillance an option for me?		
How long do I have to make a decision about treatment?		
Are there any new treatment choices available to me?		
What happens if I choose not to have treatment?		
If I stop having active treatment, what will happen to me and how long am I likely to live?		

Having my kidney cancer treatment	Please fill in your answers	<input checked="" type="checkbox"/>
Where will I have my treatment? In hospital? At home?		
Is there anything I should do before, during and after my treatment?		
How long will I undergo treatment?		
How often will I be checked to make sure the treatment is working (follow-up)?		
Do you recommend that I change my lifestyle, e.g. diet, exercise, weight, smoking, work hours?		
Would complementary therapies support my treatment and overall well-being?		

My questions

Prognosis of my kidney cancer	Please fill in your answers	<input checked="" type="checkbox"/>
Is it possible to estimate how long people live with this kind of kidney cancer?		
Is this 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?		
What will happen if I enrol in 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?		

Support and information to help manage my kidney cancer	Please fill in your answers	<input checked="" type="checkbox"/>
Are there any support groups for me and my family?		
Do you have any printed information that I can take away with me?		
Where can I get more information about kidney cancer?		
Can you put me in touch with someone else who has had kidney cancer?		

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

My decision



My decision – summary

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

		What is involved	Possible benefits	Possible disadvantages
	Active surveillance	No active treatment is given – close monitoring with examinations, tests and scans	<ul style="list-style-type: none"> • No treatment side effects • Ability to focus on your quality of life • Financial benefits 	<ul style="list-style-type: none"> • Anxiety that you are not having treatment • There is a risk the cancer has a chance to grow
	Nephrectomy	Surgical removal of part or all of your kidney	<ul style="list-style-type: none"> • Prevents symptoms of the cancer • Helps other treatments work better • Delays the need for other treatment such as anti-cancer medications. • May improve survival 	<ul style="list-style-type: none"> • Requires a hospital stay • There are risks and side effects of surgery • It may not be effective or you may still require treatment • It may delay or prevent taking beneficial anti-cancer medications
	Anti-cancer medication	Medication to slow the growth or destroy cancer cells	<ul style="list-style-type: none"> • May prolong life • May relieve symptoms of the cancer • Sequencing medication offers extended treatment time 	<ul style="list-style-type: none"> • There are side effects • Not all drugs are available • Medication may stop working • Requires medical appointments
	Metastasectomy	Surgical removal of metastases	<ul style="list-style-type: none"> • Improves symptoms and problems from the metastases • Improves survival 	<ul style="list-style-type: none"> • Requires a hospital stay • There are risks and side effects of surgery
	Stereotactic radiotherapy	High-dose precise radiation targeted at sites of limited metastases	<ul style="list-style-type: none"> • Delays cancer progression and prolongs survival • Improves symptoms • Non-invasive • Precise • Minimal time spent in hospital 	<ul style="list-style-type: none"> • There are side effects • It is not available everywhere • There is a delayed effect • Trips to hospital as an outpatient
	Ablative treatments	Extreme heat or cold is used to destroy cancer cells	<ul style="list-style-type: none"> • Does not destroy the entire kidney • Improves symptoms • Local control of cancer • Non-invasive • Minimal time spent in hospital 	<ul style="list-style-type: none"> • Only suitable for small cancers • Multiple treatments • Cancer control • Risks and side effects
	No treatment	Not having any active (anti-cancer) treatment	<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 cancer symptoms may worsen • Anxiety that you are not having treatment • Regret that you are not having treatment • Pressure from others to have active treatment

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

Following the discussions you have had with your healthcare professionals, 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 healthcare professional or patient organisation for more information before you make a choice.

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 to you.
- **Circle 3:** Indicates the issue is very important. This means it is a big concern to you.

For example:

One of the cons of anti-cancer medications is the side effects. If you feel that you will be able to deal with these (i.e. the issue is only a small concern), you would circle 2, that it is ‘somewhat important’ for you.

There is a chance I might experience side effects

I think I will be able to deal with that

1

Indicates that the issue is not a concern for you

2

Indicates that the issue is a small concern for you

3

Indicates that the issue is a big concern to you

After rating how important you consider each statement, at the bottom of the worksheet you can indicate (by circling one of the 5 dots) which way you are leaning in your decision.

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

PROS more important



CONS more important

By circling the third dot, this person is indicating they are still unsure (50/50). They may need to further discuss the option with their healthcare professional or family.



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
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 cancer has a chance to grow		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 cancer		1	2	3
Helps other treatments work better		1	2	3
Delays the need for anti-cancer medications		1	2	3
May improve survival		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
It may delay or prevent starting anti-cancer medications		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 anti-cancer medications				
Points to consider	My thoughts	Level of importance		
May prolong life		1	2	3
May relieve symptoms of the cancer		1	2	3
Sequencing medication offers extended treatment time		1	2	3
Other pros		1	2	3

CONS of anti-cancer medications				
Points to consider	My thoughts	Level of importance		
There are side effects		1	2	3
Not all medications are available		1	2	3
Medication may stop working		1	2	3
Requires medical appointments		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 - metastasectomy				
Points to consider	My thoughts	Level of importance		
Improves symptoms and problems from the metastases		1	2	3
Improves survival		1	2	3
Other pros		1	2	3

CONS of surgery - metastasectomy				
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
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 stereotactic radiotherapy				
Points to consider	My thoughts	Level of importance		
Delays cancer progression and prolongs survival		1	2	3
Improve symptoms		1	2	3
Non-invasive		1	2	3
Precise		1	2	3
Minimal time spent in hospital		1	2	3
Other pros		1	2	3

CONS of stereotactic radiotherapy				
Points to consider	My thoughts	Level of importance		
There are side effects		1	2	3
It is not available everywhere		1	2	3
There is a delayed effect		1	2	3
Trips to hospital as an outpatient		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 cancer		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 cancers		1	2	3
Multiple treatments		1	2	3
Cancer control		1	2	3
Risks and side effects		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 cancer symptoms may worsen		1	2	3
Anxiety that you are not having treatment		1	2	3
Regret that you are 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

Am I ready to choose my preferred treatment plan?

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

You may want to ask yourself:

- Have I spoken to my healthcare professional about 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?
- Do I feel like I have unanswered questions?

If you have identified preferred treatment options at this time, 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 healthcare professional, to family and friends, or to a patient or patient organisation.

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

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:

European Association of Urology (EAU).

Guidelines on renal cell carcinoma.

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

For renal cell carcinoma guidelines specific to your country, please contact your local patient organisation or the **International Kidney Cancer Coalition**.

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

Action to Cure Kidney Cancer (USA)

www.ackc.org

International Kidney Cancer Coalition (IKCC)

www.ikcc.org

Juliet Ibrahim Foundation (Ghana)

www.julietibrahimfoundation.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 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

Renal Cancer Research Fund (UK)

www.renalcancerresearch.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 US 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

European Union Clinical Trials Register

www.clinicaltrialsregister.eu

International Kidney Cancer Coalition

www.ikcc.org

Kidney Cancer Support Network (UK)

www.kcsn.org.uk/clinical-trials-database/

Kidney Health Australia

www.kidney.org.au/your-kidneys/support/kidney-cancer/cancer-clinical-trials

SmartPatients

www.smartpatients.com/trials



My kidney cancer dictionary

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

advanced cancer

Cancer that has metastasised or recurred.

adverse event

An unwanted occurrence that results in harm.

anaemia

A deficiency of red blood cells or of haemoglobin in the blood. This reduces the capacity of the blood to carry oxygen causing fatigue, shortness of breath, pallor and heart palpitations.

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.

angiogenesis

Blood vessel formation. Tumour angiogenesis is the formation of new blood vessels that grow into the tumour, giving it nutrients and oxygen to assist its growth.

anti-angiogenic medications

Medications that prevent the growth of new blood vessels required for cancer growth.

antibody

An antibody is a type of cell that helps the immune system to identify and neutralise pathogens such as bacteria and viruses. The plural is antibodies

benign

Not cancerous. Benign tumours may grow larger but do not spread to other parts of the body. These tumours are also called non-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.

cancer

A term for diseases in which an uncontrolled growth of abnormal cells happens which can invade and destroy nearby healthy tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems.

carcinoma

Cancer that begins in the skin or in tissues that line or cover internal organs.

cell

The individual unit that makes up the tissues of the body.

checkpoint inhibitor

Medications that affect the body's immune system to allow it to respond more aggressively against cancer cells.

chromophobe renal cell carcinoma

A type of kidney cancer. This type accounts for only 5% of all kidney cancers. Chromophobe kidney cancer rarely spreads outside of the kidneys

clear cell renal cell carcinoma

A type of cell that looks clear inside when viewed under a microscope. Clear cell renal cell carcinoma is the most common type of kidney cancer.

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.

CyberKnife®

A non-invasive, stereotactic radiation treatment used to control small tumours in the brain or body. It uses many small x-ray beams, directed from many different angles, to deliver a precisely focused, high dose of radiation to the tumour(s) with the surrounding normal tissue receiving little radiation dose.

cytokine

Substances made by cells of the immune system in response to infection, injury or tumour. Some cytokines can boost the immune response and others can suppress it. Cytokines can also be made in the laboratory and used in the treatment of various diseases, including cancer. Interferon and interleukin-2 are types of cytokine therapies used in the treatment of kidney cancer.

cytoreductive nephrectomy

The removal of a kidney in a patient who has metastatic kidney cancer.

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.

disease progression

Cancer that continues to grow or spread.

fatigue

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

first-line treatment

The recommended medication that will be given first, until it is no longer effective.

follow-up care

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

Gamma Knife® therapy

A non-invasive radiation treatment used to control limited numbers of small brain metastases. It uses up to 190 small gamma ray beams (similar to high-energy x-rays), directed from many different angles, to deliver a precisely focused, high dose of radiation to the tumour(s) in a single treatment session. The surrounding normal tissue receives very little radiation dose.

genetic

Inherited; having to do with information that is passed from parents to offspring through genes in sperm and egg cells.

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.

grading system

A system for classifying cancer cells in terms of how abnormal they appear when examined under a microscope. The grading system is used to provide information about the probable growth rate of the tumour and its tendency to spread. For kidney cancer, doctors use the Fuhrman Nuclear grading system.

hand - foot syndrome

A condition marked by pain, swelling, numbness, tingling, or redness of the hands or feet. It sometimes occurs as a side effect of certain anti-cancer medication.

hereditary

Transmitted from a parent to child through genetic information.

hepatitis C

A viral infection causing inflammation of the liver resulting in chronic liver disease.

immune system

The complex group of organs, tissues and cells that defends the body against infections and other diseases.

immuno-oncology (IO)

A way to treat cancer by activating the immune system to attack tumour cells with less harm to normal cells. IO therapies are specifically designed to treat cancer (not other diseases).

immunotherapy

Treatment to boost or restore the ability of the immune system to fight cancer, infections and other diseases. Agents used in immunotherapy include monoclonal antibodies, growth factors, and vaccines. These agents may also have a direct anti-tumour effect.

inpatient

A patient who stays overnight in hospital to receive care.

interferon

A biological response modifier (substance that can improve the body's natural response to infections and other diseases). Interferons affect the division of cancer cells and can slow tumour growth. The body normally produces these substances. They are also made in the laboratory to treat cancer and other diseases.

interleukin

A group of related proteins made by leukocytes (white blood cells) and other cells in the body. Interleukins regulate immune responses. Interleukins made in the laboratory are used to boost the immune system in cancer therapy. An interleukin is a type of cytokine.

intravenous

An injection into a vein.

kidney

One of a pair of organs located behind the abdominal cavity. Kidneys remove waste from the blood (as urine), produce erythropoietin (a substance that stimulates red blood cell production) and play a role in blood pressure regulation.

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).

localised

Restricted to the primary (original) site, without evidence of spread. A localised kidney cancer is confined to the kidney.

locally advanced cancer

Cancer that has spread from where it originally started to nearby tissue or lymph nodes.

lymph

The clear fluid that travels through the lymphatic system and carries cells that help fight infections and diseases.

lymph node

A rounded piece of lymphatic tissue that is surrounded by a capsule of connective tissue. Lymph nodes filter lymph (lymphatic fluid) and store lymphocytes (a type of white blood cell). They are located along lymphatic vessels.

lymphatic system

The tissues and organs that produce, store, and carry white blood cells that fight infections and other diseases. This system includes the bone marrow, spleen, thymus, lymph nodes and lymphatic vessels (a network of thin tubes that carry lymph and white blood cells). Lymphatic vessels branch, like blood vessels, into all the tissues of the body.

malignancy

A tumour made up of cancerous cells.

mammalian target of rapamycin (mTOR) inhibitors

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

mass

A lump in the body. It may be caused by the abnormal growth of cells, a cyst, hormonal changes or an immune reaction. A mass may be benign (not cancer) or malignant (cancer).

metastasis

The spread of cancer from its original (primary) site to other parts of the body. A tumour formed by cells that have spread is called a "metastatic tumour" or a "metastasis." The metastatic tumour contains cells that are like those in the original (primary) tumour. The plural form of metastasis is metastases.

metastasise

To spread from one part of the body to another. When cancer cells metastasise and form secondary tumours, the cells in the metastatic tumour are like those in the original (primary) tumour. (For example, if a primary kidney cancer spreads to the lungs, the metastasis in the lungs is kidney cancer and not lung cancer.)

metastasectomy

Surgical removal of metastases.

microwave ablation

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

mortality

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.

neoplasm

An abnormal growth of cells. This term usually refers to a malignant tumour.

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.

nephrons

Structures in the kidney that filter blood and create urine.

non-malignant

Not cancerous (benign). Non-malignant tumours may grow larger but do not spread to other parts of the body.

non-steroidal anti-inflammatory medications

A class of analgesic medication that reduces pain, fever and inflammation.

oedema

Swelling caused by excess fluid in body tissues.

oncology

The type of medical practice that specialises in the diagnosis and treatment of 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.

palliation

Relief of symptoms and suffering caused by cancer and other life-threatening diseases. Palliation helps a patient feel more comfortable and improves the quality of life, but does not cure the disease.

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.

palliative therapy/treatment

Treatment given to relieve the symptoms and reduce the suffering caused by cancer and other life-threatening diseases. Palliative cancer therapies are given together with other cancer treatments, from the time of diagnosis, through treatment, survivorship, recurrent or advanced disease, and at the end of life.

papillary renal cell carcinoma

The second most common type of renal cell carcinoma. Approximately 10-15% of kidney cancers are this subtype.

PD-1/PD-L1 inhibitors

A type of checkpoint inhibitor immunotherapy that helps in controlling the body's immune response to cancer.

primary cancer/tumour

The place where the cancer first started in the body, or the original site of tumour.

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.

progression

The course of a disease, such as cancer, as it becomes worse or spreads in the body.

progressive disease

Cancer that is growing, spreading or getting worse.

protein

A molecule made up of amino acids that are needed for the body to function properly. They are the basis of body structures such as skin and hair and of substances such as enzymes, cytokines and antibodies.

quality of life

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

radiation therapy

The use of high-energy radiation from x-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink tumours.

radiofrequency ablation

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

rechallenge

A medical testing protocol in which a medication is given, stopped, then re-given, while being monitored for adverse events.

recurrence

Cancer that has come back, usually after a period of time during which it could not be detected. The cancer may come back to the same place as the original (primary) tumour or to another place in the body.

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 type.

response

In medicine, an improvement related to treatment.

robotic surgery

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

second line treatment

The recommended medication that will be given second if the first line treatment stops being effective or is not tolerated because of side effects.

secondary cancer

A term that is used to describe a cancer that has spread from its starting place to other another part of the body. This term is also used to describe a second primary that has been caused by the treatment of the first cancer.

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.

stable disease

Cancer that is neither decreasing nor increasing in extent or severity.

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.

staging

Performing exams and tests to determine the extent of the cancer within the body, especially whether the disease has spread from the original site.

stereotactic radiation therapy

The delivery of very precise, highly potent doses of radiation therapy, generally over 1-5 treatment sessions.

subcutaneous injection

An injection given just under the skin

supportive care

All forms of care and support that aim to improve the quality of life with people living with cancer.

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.

systemic

Affecting the entire body.

targeted therapy

A type of treatment that uses drugs or other substances, such as monoclonal antibodies, to identify and attack specific cancer cells.

tissue

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

TNM

A cancer staging system. This stands for tumour, nodes and metastasis

transitional cell carcinoma

A type of cancer that occurs in the urinary system arising from the transitional epithelium, a tissue that lines the inner surface of the bladder, the renal pelvis of the kidneys and the ureters. It is the second most common type of kidney cancer.

tumour

An abnormal mass of tissue that results when cells divide more than they should or do not die when they should. Tumours may be benign (not cancer) or malignant (cancer).

tyrosine kinase inhibitor (TKI)

A drug that interferes with cell communication and growth and may prevent tumour growth. Some tyrosine kinase inhibitors are used to treat cancer.

ultrasound

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

urologist

A doctor who specialises in diseases of the urinary organs in females and the urinary and sex organs in males.

vascular endothelial growth factor (VEGF)

A substance made by cells that stimulates new blood vessel formation.

VEGF inhibitor

A substance that blocks a growth factor needed to form blood vessels.

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.

Acknowledgements

This decision aid was conceived by patients, written in collaboration with patients, and for the benefit of other patients worldwide.

The decision aid was developed by the International Kidney Cancer Coalition (IKCC) working in partnership with Kidney Health Australia (KHA).

The IKCC is an independent international network of patient organisations that focus exclusively, or include a specific 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.

KHA is an affiliate organisation of the IKCC. KHA is a national health care charity with a vision 'to save and improve the lives of Australians affected by kidney disease'. As the national peak body, KHA promotes good kidney health through delivery of programs in education, advocacy, research and support.

The IKCC would like to acknowledge and thank the following multidisciplinary team of health professionals who contributed their professional and personal expertise to the development of this decision aid.

Contributors

Ms Julia Black

Ms Emma Birch

Ms Berit Eberhardt

Ms Debbie Fortnum

Dr Craig Gedye

Dr Rachel Giles

Dr Michael Jewett

Ms Deborah Maskens

Ms Margaret McJannett

Dr David Pryor

Dr Lisa Murphy

Dr David Pryor

Professor Penny Schofield

Dr Ben Tran

Ms Anne Wilson

Ms Rose Woodward

Ms Laura Wuellner

Dr Homi Zager

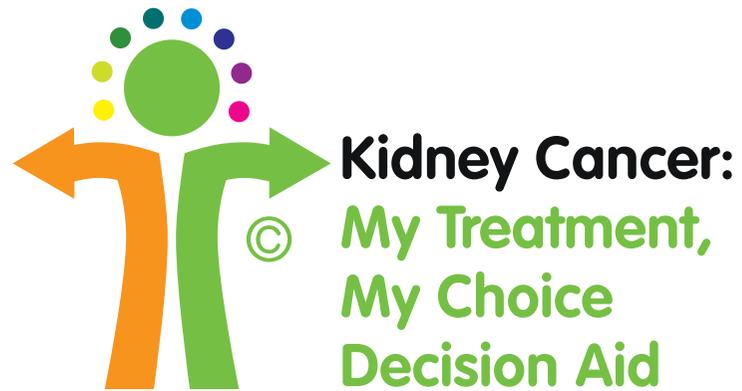
The value clarification exercises were adapted with kind permission from work done by Dr Ilona Jurásková and her team at the University of Sydney.

The IKCC is especially grateful to the patients and patient organisations who provided feedback during the development of this decision aid.

This project has been funded with grants from the following companies in full compliance with the Code of Conduct of the International Kidney Cancer Coalition:



Bristol-Myers Squibb



Citation:

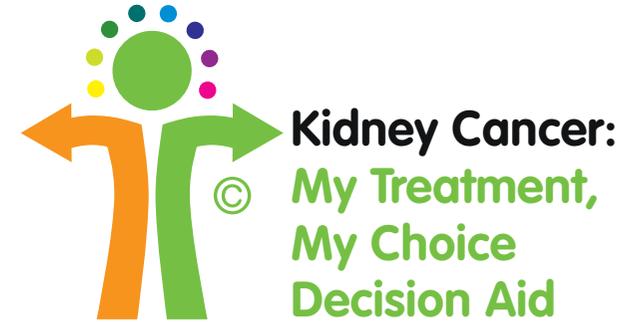
My Treatment, My Choice Decision Aid
A decision aid for people with
advanced renal cell carcinoma (kidney cancer).
Supporting shared decision making with
your healthcare team.
International Kidney Cancer Coalition, 2017

Copyright:

This decision aid is copyrighted. It may be reproduced in whole or in part for study or training purposes subject to the acknowledgement of the source. It may not be reproduced for commercial usage or sale. Reproduction for purposes other than those indicated requires written permission from International Kidney Cancer Coalition.

Design, Illustrations and typesetting:
Herbert Thum, Germany, www.viskon.de





International Kidney Cancer Coalition

Administrative Office
Caspar-Bender-Weg 31
61200 Wölfersheim-Södel
Germany

Email: info@ikcc.org
Website: www.ikcc.org

Search for us on Facebook as: [ikcc](#)
Follow us on Twitter: [@IKCCORG](#)

Registered in the Netherlands under:
Stichting IKCC
Reg.-No. KvK 62070665