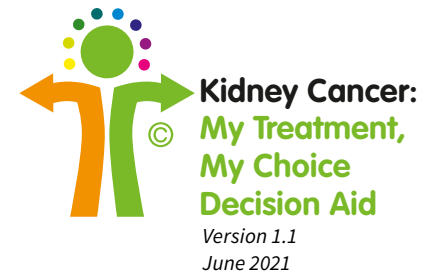


My Treatment, My Choice

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



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



Insert local patient support organisation logo here

Contents

This workbook belongs to:

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Disclaimer

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

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Locally Advanced Kidney Cancer:
My Treatment, My Choice
Decision Aid

Insert local patient support organisation logo here

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Perhaps you are reading this because you have locally advanced renal cell carcinoma (RCC) yourself, or someone you care about has kidney cancer. We understand that the diagnosis and the treatment options can be overwhelming. At the International Kidney Cancer Coalition, one of our strongest beliefs is that patients and their families have an essential role to play in healthcare decision-making that affects their lives.

There has never been a time with so many new discoveries in kidney cancer. Clinical trials have demonstrated the benefits of new treatments, especially immune checkpoint inhibitors that could potentially be used to complement surgery.

There are now more choices and patients can receive different treatments or combinations of treatments. Clinicians are getting more experienced and knowledgeable, and the role of surgery or ablation for locally advanced cancer is better understood. The use of robotic partial nephrectomy, better tools to predict how well patients respond to treatment, and the role of neoadjuvant and adjuvant therapy are all evolving rapidly. The basic biological mechanisms of kidney cancer are being untangled with the promise of biomarkers, new diagnostics and drug targets.

We are very excited to be participating in this rapidly changing and expanding field of medicine which promises real gains in the very near future.

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. For more information, and to help you understand the medical terms that are used, please also read our **Kidney Cancer Basics booklet**, which includes **My Kidney Cancer Dictionary** or see the glossary on page 85 of this decision aid.*

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
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*Dr. Michael A.S. Jewett,
Chair, IKCC Medical Advisory Board
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About this decision aid

This decision aid is for people diagnosed with a type of kidney cancer called renal cell carcinoma (RCC), including all subtypes of RCC. It is for people who have been initially diagnosed with locally advanced RCC, where the primary tumour has grown into nearby tissue, such as the adrenal gland, lymph nodes or blood vessels.

Locally advanced disease is defined as:
Patients who have stage III disease where the cancer has grown through the capsule and into the fat around the kidney
The cancer may have grown into one of the major veins close to the kidney (the renal vein or the vena cava) or into the adrenal gland
The cancer may have spread to the lymph nodes, or it might not have
Patients with a large primary tumour, usually > 10 cm in diameter
Patients who have positive margins on the tissue that was removed during surgery i.e., cancer cells at the edge of the tissue sample
Patients who might have 3 or 4 smaller tumours on one kidney.

There are different types of treatment for people who have locally 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 kidney cancer.

Access to treatments for RCC is different around the world. It depends on which country you live in, or what your national healthcare system or insurance plan offers patients with kidney cancer. You will need to take this into consideration when deciding on your treatment options.

This decision aid covers currently available treatments for locally advanced RCC. However, if your cancer does spread promising new treatments or combinations of treatments that can improve survival are now available in some countries and are in development.

This decision aid aims to help guide you through your conversations with your healthcare team. It can help you make treatment choices that will give you the best quality and quantity of life according to your personal goals.

This decision aid provides:

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

Having locally advanced RCC can be overwhelming. Learning about the disease and treatment options can empower you to become an informed patient and help you make the best decisions about your care and the various treatments available to you.

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

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



My healthcare team

My healthcare team

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

However, the most important person in your healthcare team is actually you! With the help of this decision aid, you can work with your healthcare team to learn about kidney cancer and treatment options. Together you can make decisions that may improve your health and wellbeing.

Who are the members of my healthcare team?

Treating locally advanced RCC can require the skills of many different healthcare professionals. The following table shows some of the healthcare professionals that your team might include. However, not all these healthcare professionals will be involved in your care.

In some countries, these healthcare professionals work together in a multidisciplinary team (MDT). The MDT meets regularly to discuss your treatment and care. In other countries, these healthcare professionals might work separately.

Urologist	A surgeon who specialises in treating diseases of the genitourinary system including renal cell carcinoma (RCC)
Uro-oncologist	A surgeon who specialises in treating cancers of the genitourinary system including RCC
Clinical oncologist	A doctor who has special training in diagnosing and treating cancer using radiation therapy and chemotherapy
Medical oncologist	A doctor who has special training in diagnosing and treating cancer using chemotherapy, hormonal therapy, biological therapy, and targeted therapy
Radiation oncologist	A doctor who specialises in using radiation therapy to treat cancer
Nephrologist	A medical doctor who specialises in kidney care and treating diseases of the kidney
General practitioner (GP) in primary care	A family doctor who is based in the community and treats patients with minor or chronic illnesses. Can help manage your cancer symptoms, treat side effects, and assist with coordinating your care in the community

Pathologist	A scientist or doctor who studies cells under a microscope and who diagnoses the stage, grade and type of kidney cancer you have
Cancer nurse/ clinical nurse specialist (CNS)	A specialist nurse who supports you throughout treatment and helps coordinate your care, administers medication, and provides information about your kidney cancer
Radiologist	A doctor who specialises in diagnosing disease by using x-rays, ultrasound, CT scans and MRI scans
Interventional radiologist	A radiologist who uses minimally-invasive procedures guided by CT or MRI scans, such as biopsies and ablation therapies, to diagnose and treat diseases
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 a diagnosis of cancer has on your emotional, psychological, and social wellbeing

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	Gives you advice 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	A healthcare professional who works with patients with diseases where exercise can help them achieve a better quality of life
Rehabilitation doctor	A doctor who specialises in providing rehabilitation after surgery or during cancer treatment
Clinical trial coordinator	A nurse or scientist who recruits eligible people into clinical trials and organises the trial

My healthcare team

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

- Important medical reports and documents
- A list of all the drugs you may be prescribed
- Contact information for your healthcare team
- Notes on clinical appointments and consultations
- Questions you want to ask your healthcare team
- A record of symptoms and side effects.

My treatment options



What are the goals of treatment for locally advanced renal cell carcinoma (RCC)?

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

- Achieve long-term remission of your cancer
- Prolong your life and improve overall survival
- Allow you to lead as normal a life as possible for as long as possible
- Improve your quality of life
- To prevent a recurrence of your kidney cancer
- To prevent your kidney cancer from spreading
- To shrink your primary tumour to make surgery possible.

Currently available treatments for locally advanced RCC aim to:

- Prevent the spread of the cancer
- Put the cancer into long-term remission (no visible evidence of disease)
- If the cancer spreads (metastasises), slow down or reduce the spread of the cancer, reduce the size of the metastases or tumour(s) and slow down or reduce cancer symptoms.

New treatments are constantly being developed and tested to further improve patient outcomes, offering every reason for patients to remain hopeful. See page 40 on clinical trials and research.

What is considered when deciding on treatment?

There are several different treatment options for people with locally advanced RCC. See page 21 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 RCC you have

The subtype of RCC and its stage and grade will help determine which treatment options are best suited to your type of kidney cancer.

2. Your prognostic score

Doctors often use a scoring system to determine the risk of your cancer spreading. There are a number of scoring systems that are used for kidney cancer. These systems use results from blood tests and assessments of your overall health to score your risk as poor, intermediate or favourable. The most common prognostic scoring systems used for kidney cancer are; the Leibovich scoring system, the International Metastatic RCC Database Consortium (IMDC) risk model and the Memorial Sloan-Kettering Cancer Centre (MSKCC) criteria for RCC risk.

3. Your current state of health

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

4. Side effects and risks of treatment

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

Your doctor or nurse will talk to you about the possible side effects and risks of the available treatments. You can then take some time to consider those that you are prepared to accept and those you would like to avoid. This is an important part of the decision-making process. Your preferences and choices should be taken into account when any treatment decision is made.

5. Quality of life versus how long you will live

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

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

- Whether the treatment relieves the symptoms of the cancer, such as pain
- Coping with side effects of the treatment (surgery and/or medication)
- Length of treatment, for example a few weeks for recovery from surgery versus a year or more on medication
- Where you will have the treatment, for example in hospital for surgery or at home for medication
- How well you can cope at work or home
- How much support you have from family and friends?

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

We know that most people want to live as long as possible with the best quality of life as possible. Your healthcare team will help you to manage the side effects of treatment to give you the best possible quality of life while on treatment.

6. Your priorities, values, beliefs and goals

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

7. Access to treatments

Around the world, access differs for diagnostic services and cancer treatments. It may even depend on which region of a country you live in, or what your national healthcare system or insurance plan offers patients with kidney cancer.

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

Choosing a treatment plan that’s right for you

The aim is always to have treatment that is tailored to your personal situation. Your medical details, such as your subtype of RCC, 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 doctor will discuss the clinically recommended treatment options with you, including what you can expect from treatment. However, which treatment and even whether or not to have any treatment is your decision. You are the expert in your own life and know best how you would manage risks and benefits when it comes to your health and wellbeing.



What are the main types of treatment for locally advanced RCC?

Treatment types

The different types of treatment available for locally advanced RCC are:

- Active surveillance
- Surgery
- Ablative treatments
- Systemic anti-cancer medication (neoadjuvant and adjuvant therapy)
- Clinical trials and research

Researchers have made tremendous progress over the past decade developing new treatments. This has provided clinicians with a variety of treatments for their patients. There are also a number of new and exciting medications, specialised radiation therapy and surgical techniques in development. Each type of treatment is used for a different reason. Often, a combination or a particular sequence of treatments is used. Your clinician can explain which treatments would be suitable for your particular clinical situation.

Together you can decide the best treatment for you.

Treatment choices

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

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

You can discuss with your healthcare team whether you want to have treatment at all. This is your choice. Talking about it with your doctor and your family may help clarify your thinking and ensure the decision you make is the right one for you.



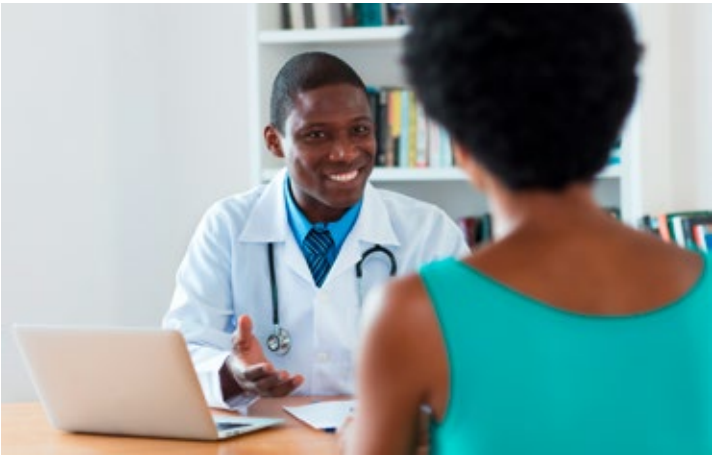
Making a decision about your treatment

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

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

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

You may need to discuss with your healthcare professional which treatment options or 'tools' are suitable and available to you at your hospital, or those you might need to travel for. You may need a combination of treatments, or you may decide to have none at all. It is important to discuss these issues with your family and your healthcare team. Make sure you have sufficient information to be able to make an informed decision. Always ask for additional information if you feel you need it.

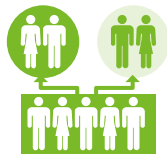


The following pages deal with these topics in greater depth and provide more information, including some of the benefits and disadvantages for each treatment option.

Active Surveillance	page 22
Neoadjuvant therapy (drugs)	page 24
Surgery	page 26
Ablative treatments	page 30
Adjuvant therapy (drugs)	page 32
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Supportive/palliative care	page 36
Getting additional support	page 38
Clinical trials and research	page 40



Active surveillance	Neoadjuvant therapy	Surgery	Adjuvant therapy	Ablative treatments	No active treatment
	Targeted therapy	Nephrectomy	Targeted therapy	Radiofrequency ablation	
	Immunotherapy		Immunotherapy	Microwave ablation	
				Cryoablation	



Supportive and palliative care	Getting additional support	Clinical trials and research

Types of treatments



Active surveillance



What is involved?

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

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

Is active surveillance a suitable option for me?

- Active surveillance may be particularly suitable if you:
- Have slow-growing kidney cancer and are currently symptom-free
 - Have other multiple health problems that may make treatment difficult (co-morbidities)
 - Were born with one kidney or have had a nephrectomy
 - Wish to continue working or have significant family responsibilities, such as caring for a family member.

By delaying active treatment of locally advanced RCC, you may be able to delay significant treatment side effects or other problems for some time. If your RCC is slow growing a delay in starting treatment is not likely to affect how long you live. Ask your doctor to help you assess this option.



Possible benefits of active surveillance	Possible disadvantages of active surveillance
1. No treatment side effects All active treatment options have risks and side effects. Some side effects may be physically and mentally exhausting and may significantly interfere with your life. By delaying starting treatment, you can potentially delay the onset of these side effects	1. Anxiety You may feel uncomfortable or anxious about not having active treatment for your 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 affect how long you live. However, there is a risk that your kidney cancer will grow. Ask your doctor to help you assess this risk
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)	3. Doctor anxiety Your doctor might feel uncomfortable or anxious about not giving you treatment for your cancer. Remember that you or your doctor can ask for a second opinion with a renal cancer specialist

Types of treatments

Neoadjuvant therapy



What is involved?

Neoadjuvant therapy is anti-cancer medication (medication to treat the cancer) given to patients before surgery. For people with high risk locally advanced RCC, the aim of neoadjuvant therapy is to shrink the tumour before surgery to make it easier to remove. Neoadjuvant therapy can also be used to treat any micrometastases that do not show up on scans. Currently, neoadjuvant treatment is only available in clinical trials and none of the drugs used for the treatment of RCC have been approved for use as a neoadjuvant treatment.

Several drugs are currently being investigated in clinical trials as potential neoadjuvant treatments. Clinical trials are looking at targeted therapy, such as sunitinib, and immunotherapy alone or in combination with targeted therapy as potential neoadjuvant therapies.

Clinical trials change frequently, so be sure to ask your patient support organisation what neoadjuvant trials are available in your country.

Possible side effects of neoadjuvant therapy

Each anti-cancer medication has different possible side effects. Not everybody will have side effects. If they do occur, they may be mild or temporary, but others may be serious and long lasting and need medical attention.

If you are on a clinical trial for neoadjuvant therapy and notice any side effects, do not wait - tell your clinical trial healthcare professional immediately. Early reporting can help to minimise the impact of side effects on your health and quality of life and may help you stay on medication longer.

Your clinical trial doctor can discuss with you any possible side effects to the neoadjuvant therapy that you are on and help you manage them.

Is neoadjuvant therapy a suitable option for me?

Clinical trials for neoadjuvant therapy might not be available to you in your country. Also, neoadjuvant therapy may not be suitable for people with multiple serious diseases/ conditions (co-morbidities). You will need to discuss your suitability for a clinical trial with neoadjuvant therapy with your doctor to make an informed decision about whether to take part.

At all points along the patient pathway, clinical trials may be available. Clinical trials can offer you access to additional treatment options.



Surgery - nephrectomy



What is involved?

Nephrectomy is surgery to remove a kidney. Often this is the first step in treating kidney cancer.

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

During a radical nephrectomy the whole kidney is removed, usually along with the surrounding fatty tissue. The extent of a radical nephrectomy can vary among patients. Nearby lymph nodes may be removed if they are enlarged. The adrenal gland will remain in place if there is no evidence that the tumour has spread to the adrenal gland. You can live perfectly well with just one working kidney. If both kidneys are removed because of bilateral RCC, or because they are not working, you will need dialysis for the rest of your life. You might be able to have a kidney transplant when you have been cancer-free for a few years.

Nephrectomy is major surgery and you could be in hospital for up to 7 days. Check with your doctor how long you can expect to be in hospital. Full recovery may take 6-12 weeks or longer, depending upon the type of surgery and your general health and wellbeing.

Partial nephrectomy aims to save healthy kidney tissue.

It is usually carried out for people who have:

- A small (7 cm or less) stage 1 tumour on their kidney
- One kidney
- Kidney disease
- Tumours in both kidneys (bilateral kidney cancer)

Specialist surgeons now aim to treat most small (stage 1) kidney tumours with partial nephrectomy, if possible.

Partial nephrectomy reduces the risk of losing kidney function. However, partial nephrectomy requires an experienced surgeon, takes longer to heal and is not available at all hospitals.

Radical or partial nephrectomy can be done as an open or laparoscopic (keyhole) surgery, with or without robotic assistance. The way the surgery is done will depend on:

- The size and position of the primary tumour
- The facilities available at the hospital
- The surgeon's preference and experience
- Your choice.

Open surgery

The surgeon normally makes a large incision or cut below the lower ribs on the side of the affected kidney. The kidney (or part of the kidney) containing the tumour can be assessed by the surgeon and removed through this incision.

Laparoscopic surgery (keyhole or minimally invasive)

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

Robot-assisted laparoscopic surgery (RAS) is similar, except the instruments are attached to robotic arms, which the surgeon controls from a workstation. The surgeon has a 3D view of the operating area. The improved view and advanced tools give the surgeon more precision and control.

Kidney biopsy

In some cases, your doctor might recommend a kidney biopsy before you have surgery. This biopsy is done under local anaesthetic. A fine needle is inserted through your skin (percutaneous) and into the tumour under guidance from a CT or ultrasound scan and a sample of tissue taken and sent to a laboratory. A pathologist examines the tumour tissue sample under a microscope to diagnose kidney cancer. Risks involved in the biopsy procedure are minimal.

In most cases, a sample of tissue is taken from your tumour during surgery under general anaesthetic. The tumour tissue sample is sent to a pathologist to diagnose the subtype of RCC that you have, as well as the stage and the grade of your cancer. This information is used as a guide to treatment decision-making.

Types of treatments

Technique	Open	Laparoscopic
Possible benefits	<ul style="list-style-type: none">• Surgeons are highly experienced with open surgery• Does not need to be done in a specialised hospital• Most primary tumours can be removed using this technique	<ul style="list-style-type: none">• Less requirements for pain medication• Shorter stay in hospital and recovery time• Less scarring and less potential for abdominal hernias
Possible disadvantages	<ul style="list-style-type: none">• Higher requirement for pain medications• Longer stay in hospital and recovery time• Greater risks associated with major surgery• More extensive scarring• Damage to nearby organs and/or blood vessels	<ul style="list-style-type: none">• More specialised and only available in some hospitals• Not all tumours can be removed using this technique• More expensive (if applicable)• Damage to nearby organs and/or blood vessels• Uncomfortable side effects relating to the gas injected into the abdomen

Is nephrectomy a suitable option for me?

If you have been diagnosed with locally advanced RCC and your general health is good, in most cases your entire kidney and tumour will be removed. Some people may be offered a partial nephrectomy, but this will only be considered if your tumour is small, if you have one kidney, if you have tumours in both kidneys, and if you have poor kidney function. You will need to discuss your suitability for surgery with your doctor to make an informed decision about which surgical treatment option to choose.

If your cancer is recurrent, you may have already had either radical or 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 are difficult to control, removing the primary tumour may be helpful	1. Hospital stay Your length of stay in hospital depends on how your surgery was done (open or laparoscopic) and any other medical conditions you have. On average it will be 3-7 days. Full recovery can take 6-12 weeks, or longer. If you are working, you will need to take time off – most people require at least 6-8 weeks leave. You may need to start back at work gradually
2. May improve survival If the kidney cancer is not causing a lot of problems, and your health is otherwise good, then removing the primary tumour and the kidney may improve survival and reduce the need for further treatment	2. Risks and side effects of major surgery 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. Avoids the use of anti-cancer medication If the cancer has not spread, there is no need for anti-cancer medication. This will avoid the possible side effects of these medications	3. May not be effective or may still require treatment If the surgery only removes the kidney tumour, you may still require further treatment to prevent the spread of the cancer. There is also no guarantee that surgery to remove the original tumour will improve survival. This is especially true if your cancer has spread to nearby lymph nodes or your overall health is poor
	4. May delay the start of potentially 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

Ablative treatments



What is involved?

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

Radiofrequency ablation and microwave ablation

use energy waves to produce extreme heat to destroy the tumour.

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

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

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

Is ablation a suitable option for me?

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

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

Possible benefits of ablative treatments

1. Does not destroy the entire kidney

Ablative treatments just target the tumour leaving the surrounding tissues healthy. It is a treatment option for people who only have one kidney, or who have kidney failure or multiple kidney tumours

2. Improves symptoms

Ablative treatments can reduce the symptoms associated with kidney cancer

3. Local control of cancer

In suitable patients, ablation of the tumour can control the growth of the cancer

4. Non-invasive

If done through the skin, there are no cuts made in your body and a general anaesthetic can be avoided. This makes ablation a treatment option for people with multiple other medical problems (co-morbidities)

5. Minimal time spent in hospital

If done through the skin, you will not have to stay in hospital overnight. You should be able to return to usual activities in a few days

Possible disadvantages of ablative treatments

1. Only suitable for small cancers

Ablative treatments are generally used for small tumours, those less than 4cm

2. Multiple treatments

You may require more than one session to treat the cancer

3. Cancer control

Ablative treatments may not control the cancer as well as other treatment options

4. Risks and side effects

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

Adjuvant therapy



What is involved?

Adjuvant therapy is anti-cancer medication (medication to treat the cancer) given to patients after surgery. For people with high risk locally advanced RCC, the aim of adjuvant therapy is to prevent spread of the cancer and recurrence of the disease. Currently, an immune stimulating therapy called pembrolizumab has been approved for use in some countries.

Treatments change frequently, so be sure to ask your patient support organisation what is available in your country. Pembrolizumab is taken as an intravenous infusion every three to six weeks for one year after surgery. Pembrolizumab enhances stimulation of various immune cells and may help to kill cancer cells or prevent their growth.

Possible side effects of adjuvant therapy

Each anti-cancer medication has different possible side effects. Not everybody will have side effects. If they do occur, they may be mild or temporary, but others may be serious and long lasting and need medical attention.

If you take pembrolizumab and notice any side effects, do not wait - tell your healthcare professional immediately.

Early reporting can help to minimise the impact of side effects on your health and quality of life and may help you stay on medication longer.

Common side effects to pembrolizumab are:

- Fatigue or feeling tired
- Diarrhoea
- Joint aches
- Skin rash
- Inflammation of the liver
- Inflammation of the kidney(s)
- Decrease or increase in thyroid function
- Inflammation of the lungs
- Nausea and/or loss of appetite

Your doctor can discuss with you any possible side effects and help you manage them.

Is adjuvant therapy a suitable option for me?

Adjuvant therapy might not be available to you in your country.

Adjuvant therapy may not be suitable for people with multiple serious diseases/conditions (co-morbidities). You will need to discuss your suitability for adjuvant therapy with your doctor to make an informed decision about which option to choose.

Clinical trials are currently testing new adjuvant therapies called immunotherapies, which may be beneficial to patients and have fewer and more tolerable side effects.

At all points along the patient pathway, clinical trials may be available. Clinical trials can offer you access to additional treatment options.

No active treatment

What is involved?

You may decide that you do not want to have active treatment for your cancer, such as surgery, or adjuvant therapy. 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, then having no active cancer treatment may be an acceptable option for you at any time. You would still receive what is known as ‘best supportive care’ to help you manage your symptoms.

Stopping active treatment

If you have started active treatment, you can decide at any time that you do not wish to continue.

You may be struggling with treatment side effects. Perhaps the disadvantages of treatment outweigh the possible benefits. You might decide your quality of life would be better without active treatment.

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

Important: If you would like to stop or take a break from your current treatment, discuss with your healthcare team first. There may be other active treatment options for you to consider, other ways to manage your side effects, or you may be able to have supportive or palliative care – see page 36.

Possible benefits of no active treatment	Possible disadvantages of no active treatment
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	1. Worsening cancer symptoms Because your cancer is not being treated it may progress 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
2. You can focus on your quality of life Without having side effects or recovery from surgery, you will be able to get on with your life. You may spend more time with family and friends, work if you feel well enough, travel and enjoy leisure activities	2. Anxiety You may feel uncomfortable or anxious about not having treatment
3. Less hospital trips and medical tests Although you will have occasional hospital appointments, you will not have to spend a lot of time visiting the hospital or having tests	3. Regret You may wonder what might have happened if you had chosen to have or continue with active treatment
4. May improve emotional wellbeing Making a decision not to have active treatment for a time, or to stop treatment altogether, 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 peace with your diagnosis	4. Pressure from others Your family and friends may not understand why you have chosen not to have or continue with active treatment. This may make you feel pressured to change your mind or make you feel guilty about your decision

Supportive/palliative care



What is involved?

At all stages of your cancer treatment you need to feel as well as possible. This can be achieved through supportive/palliative care. Supportive/palliative care focuses on improving quality of life for you and your family. Supportive/palliative care can be given at any time during your treatment pathway. In some countries, palliative care has been more appropriately renamed ‘supportive care’.

Supportive/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.

Supportive/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 tumour 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 to help with cancer-related weight loss or side effects
- Practical help with tasks of daily living
- Help and advice regarding issues, such as powers of attorney and advanced care planning, according to your personal wishes.

Supportive/palliative care 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 supportive/palliative care recommended?

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

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

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

Who provides supportive/palliative care ?

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

Where is supportive/palliative care provided?

Supportive/palliative care can be provided at home, in a hospital or in hospice.

Getting additional support



I am a kidney cancer 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 support you. Your cancer diagnosis will also affect your family and friends. It is likely that your closest family member or main caregiver may need help and support as well as you.

Many people find that it's helpful sharing their experiences and knowledge with other people who have kidney cancer or talking to someone trained in supporting people with kidney cancer. You may consider contacting a patient support organisation to get information about kidney cancer and to help you navigate your way around the healthcare system in your country. Depending on the healthcare systems in your country, you might also get support from social services.

I am a carer for someone with kidney 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.



Clinical trials and research



Over the past decade, clinical trials and research have resulted in some major breakthroughs in the treatment of locally advanced RCC. Surgical techniques are less invasive with shorter recovery times, radiation therapy and ablative techniques are improving in terms of accuracy and effectiveness, and immunotherapy is in clinical trials for adjuvant therapy after surgery to prevent recurrence. Current research may result in long-term survival with a good quality of life for some patients.

What is a clinical trial?

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

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

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

Should I join a clinical trial?

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



Am I eligible to join a clinical trial?

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

- The trial is not for your particular subtype of RCC
- Your general health is not good enough
- Your earlier treatment could affect the results of the trial
- You have other diseases (e.g. diabetes or 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 all clinical trials that may be right for you.

Where can I find a suitable clinical trial for me?

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

Types of treatments

Possible benefits of a clinical trial	
1. May be the best or only treatment option available	4. Helping others
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	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
2. High-level care	
Usually, you are seen by doctors and nurses who are experts in treating your condition. Patients who are treated in hospitals running a clinical trial often do better overall. For many patients, access to expert level care at a centre of excellence is a major benefit	
3. Free medication	
In most countries, the clinical trial centre will provide the costs of all medical care involved in the clinical trial (all tests, surgery, radiotherapy, and medication). If you receive medication as part of a clinical trial, you will normally continue that medication if the treatment proves to be effective. Be sure to ask about any potential costs that might affect your participation	

Possible disadvantages of a clinical trial	
1. You may not receive the new treatment	4. There may be more side effects
Some clinical trials are randomised, and others are not. Early phase trials provide the new treatment to all patients. Later trials compare the new treatment with standard treatment or placebo, and patients are randomly allocated to a treatment group	The new treatment might have fewer side effects than standard treatments, but it might also cause unpredictable or serious side effects. In some cases, these can be permanent. This is particularly relevant if you want to join a trial that is the first to test a medicine in humans (a Phase I trial)
2. Changing to a different healthcare team	5. More hospital or clinic visits
You will be seen by expert doctors and nurses who are involved in running the clinical trial. They may not be your original healthcare team. After the trial, you can return to your original team, which might be closer to home	If you join a clinical trial you may need more tests or more frequent appointments, as the researchers want to study the effects of the new treatment
3. The new treatment may not work as well as the standard treatment	6. Financial costs (if applicable)
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	Although you will not be paying for treatment, there may be financial costs to consider, such as the cost of travel and accommodation, or the cost of you or a caregiver taking time off work to go to the trial clinic. Always ask at the trial centre about any financial assistance that may be available

Clinical guidelines

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

Healthcare organisations worldwide produce clinical guidelines that outline how locally advanced RCC should be treated. These guidelines are based on the current best available evidence from international research. See **My resources** on page 81.

If you have doubts or questions about the medical advice you have received, discuss this with your healthcare team. You also have a right to ask for a second opinion from another doctor who specialises in kidney cancer.

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

Costs of treatment

Will there be any financial costs?

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

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

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



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

Good communication with your doctor and other 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.

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

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

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

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 these tests/scans?		
Are there any risks to having these tests/scans done?		
When and how will I receive the results?		

My treatment options	Please fill in your answers	<input checked="" type="checkbox"/>
What are all the treatment options available to me?		
What would each treatment option mean for me?		
For my subtype 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?		

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

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

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 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 wellbeing?		

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?		
How current are the data used to work out my prognosis?		
Is the recommended treatment likely to improve my length of survival?		
Is this treatment likely to improve my symptoms?		
What effect will this treatment have on my quality of life?		
Are there other ways to reduce my symptoms and side effects?		

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

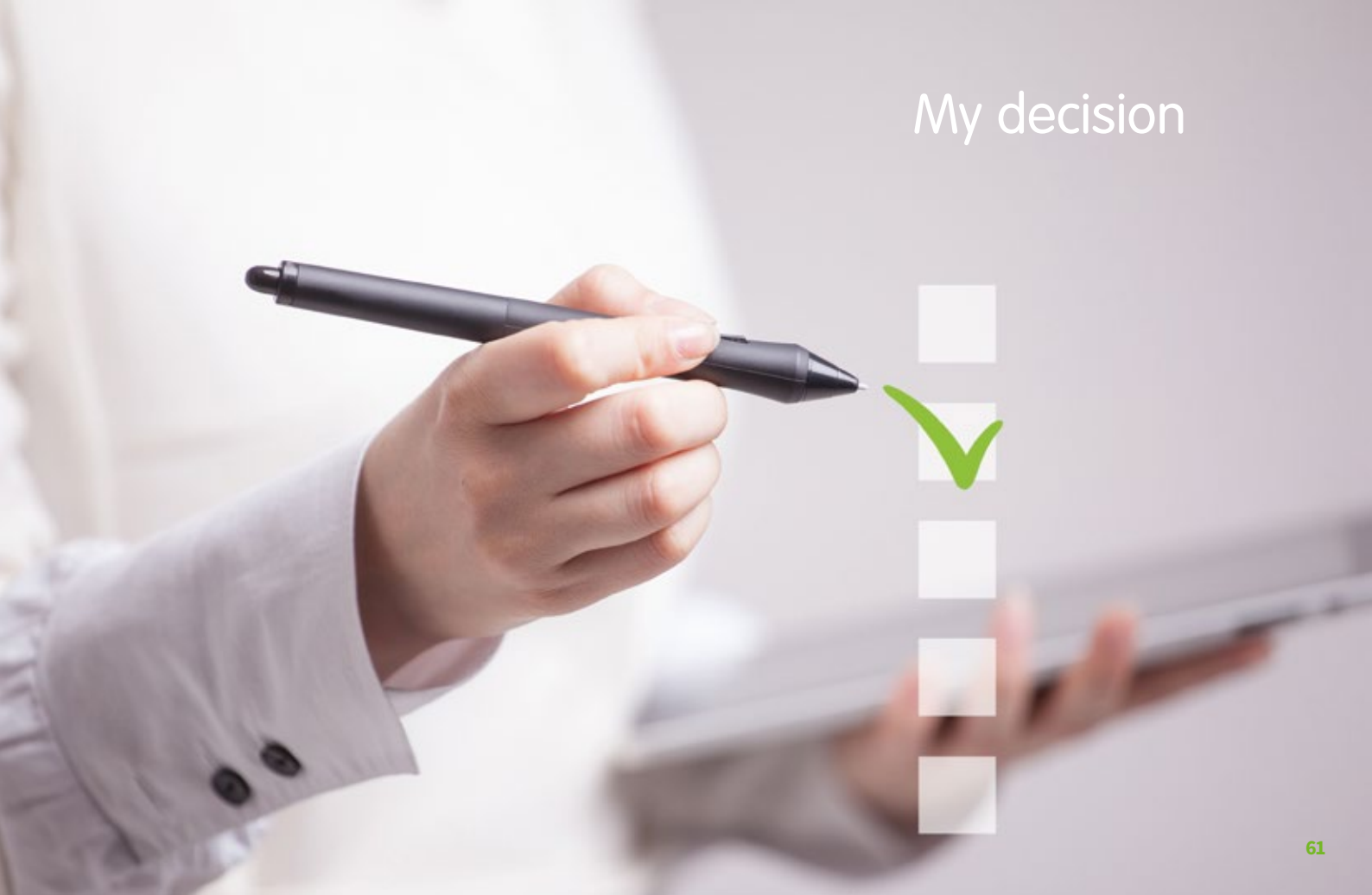
Supportive/palliative care	Please fill in your answers	<input checked="" type="checkbox"/>
When will palliative or supportive care be offered to me?		
Who will provide supportive/palliative care? Specialist supportive care team or other healthcare professional?		
Where will I receive supportive care?		
Is there someone I can talk to about how I am feeling?		
Is there someone my family can talk to about their feelings?		

Supportive/palliative care	Please fill in your answers	<input checked="" type="checkbox"/>
Where can I get nutritional/dietary advice?		
Can I have practical help with day-to-day living?		
Do I qualify for financial assistance?		
Where can I get help with returning to work?		
How do I access complementary therapies for my cancer, such as relaxation techniques, meditation, exercise or massage ?		

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

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

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








Summary

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

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

Following discussions you have 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.

		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
	Neoadjuvant therapy	Medication to destroy cancer cells before surgery	<ul style="list-style-type: none"> • May shrink the tumour to make it easier to remove • Only available as part of a clinical trial 	<ul style="list-style-type: none"> • Not available outside clinical trials • Not yet proven to be beneficial • There are side effects to the medication • Not all medications are available as neoadjuvant therapy
	Nephrectomy	Surgical removal of the primary tumour and 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
	Adjuvant therapy	Medication to destroy cancer cells and prevent recurrence of cancer after surgery	<ul style="list-style-type: none"> • May prolong life • Not proven to be beneficial with current targeted therapies 	<ul style="list-style-type: none"> • There are side effects • Not all medications are available • Medication may stop working. Changes to medication may bring different side effects • Requires medical appointments
	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 • Risks and side effects
	No active 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



Decision aid

The following pages have worksheets for you to go through to help you think about 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 a concern to *you*.
- **Circle 2:** Indicates the issue is a small concern to *you*.
- **Circle 3:** Indicates the issue 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.

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

PROS of active surveillance				
Points to consider	My thoughts	Level of importance <i>(how important each point is to you)</i>		
No treatment side effects		1	2	3
Ability to focus on your quality of life		1	2	3
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 neoadjuvant therapy				
Points to consider	My thoughts	Level of importance <i>(how important each point is to you)</i>		
May shrink the tumour to make it easier to remove		1	2	3
Only available as part of a clinical trial		1	2	3
Other pros		1	2	3

CONS of neoadjuvant therapy				
Points to consider	My thoughts	Level of importance <i>(how important each point is to you)</i>		
Not available outside clinical trials		1	2	3
Not yet proven to be beneficial		1	2	3
There are side effects to the medication		1	2	3
Not all medications are available as neoadjuvant therapy		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

My decision

PROS of adjuvant therapy				
Points to consider	My thoughts	Level of importance		
May prolong life		1	2	3
Not proven to be beneficial with current targeted therapies		1	2	3
Other pros		1	2	3

CONS of adjuvant therapy					
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. Changes to medication may bring different side effects		1	2	3	
Requires medical appointments		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
Improves 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
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 on the previous pages, you may feel ready to write down your preferred treatment choices.

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

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

If you are not ready to choose a preferred treatment plan at this time, think about what might help you. Many patients find it helpful to speak to another healthcare professional, family and friends, another patient, or a patient organisation.



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

Date	My Preferred Option	Reason

My decision

Date	My Preferred Option	Reason

My resources





Clinical guidelines

The most widely used clinical treatment guidelines world-wide 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 (RCC) guidelines specific to your country, please contact your local patient organisation or the

International Kidney Cancer Coalition.



Kidney Cancer websites:

Please visit our website for a list of patient organisations providing support to kidney cancer patients around the world.

www.ikcc.org



Clinical trial registries

ANZUP

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

Clinical Trials Registry, India

www.ctri.nic.in/Clinicaltrials

Clinical Trials worldwide

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

Health Canada's Clinical Trials Database

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

European Union Clinical Trials Register

www.clinicaltrialsregister.eu

International Kidney Cancer Coalition

www.ikcc.org/clinical-trials-search

Kidney Cancer Support Network (UK)

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

SmartPatients

www.smartpatients.com/trials

Glossary

abdomen

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

ablate

Removal of cancer by cutting, intense heating or cold.

active surveillance

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

active treatment

Treatment that aims to prolong your survival.

adjuvant therapy:

A treatment given in addition to the main treatment (for example, targeted therapy as well as surgery) to try to prevent cancer from coming back. Its purpose is to assist the main treatment. Also called adjunct/adjunctive therapy

advanced cancer

Cancer that has spread to other parts of the body (metastasised) or has grown back (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.

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.

checkpoint inhibitor

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

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.

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.

end of life care

Support for people in the last months or years of their life. End of life care should help you live as well as possible until you die with dignity. People who are approaching the end of life are entitled to high-quality care, wherever they are being cared for. See also palliative care and supportive care

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.

grade

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

hereditary

Transmitted from a parent to child through genetic information.

hospice care
Palliative care, supportive care or end of life care provided in a hospice or care home.

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

intravenous
An injection into a vein.

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

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

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

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

metastasis
A tumour formed by cells that have spread from the original (primary) tumour to other parts of the body. A metastatic tumour contains cells that are like those in the primary tumour, e.g. if kidney cancer spreads to the lungs, the metastasis in the lungs is kidney cancer, not lung cancer. The plural of metastasis is metastases.

metastasise
To spread from one part of the body to another.

metastasectomy
Surgical removal of metastases.

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

mortality
The state of being subject to death.

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

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

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

neoadjuvant therapy
Treatment given as a first step to shrink a tumour before the main treatment (usually surgery) is given. Can help to make surgery easier and/or possible.

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.

oedema
Swelling caused by excess fluid in body tissues.

oncologist
A doctor qualified to diagnose and treat cancer.

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

overall survival rate

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

palliative care

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

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.

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.

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 subtype.

response

In medicine, an improvement related to treatment.

robot-assisted 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/tumour

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.

stage

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

supportive care

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

surgery

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

symptom

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

systemic

Carried in the blood stream throughout 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.

tumour

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

ultrasound

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

urologist

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

x-ray

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

Notes, Questions:

[illegible]

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

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

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

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

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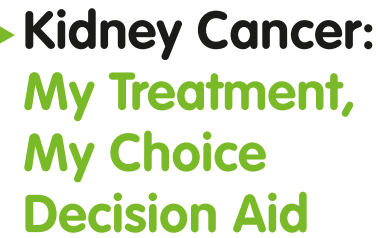
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Notes:

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