Kidney Cancer Basics

An information booklet to compliment the IKCC My Treatment, My Choice series of decision aids for people with renal cell carcinoma (kidney cancer)



Supporting shared decision making between patients and healthcare professionals

KIDNEY CANCER
My treatment
My choice
Decision Aid
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Contents

Foreword P.03

About IKCC My Treatment, My Choice Decision Aids P.04

My kidney cancer P.05 - P.14

Understanding renal cell carcinoma (RCC) P.05 - P.07

What are the kidneys and what do they do? P.05
The urinary system P.05
What is kidney cancer? P.05
How common is kidney cancer? P.06
What are the risk factors for kidney cancer? P.06
What is localised renal cell carcinoma? P.06
What is locally advanced renal cell carcinoma? P.06
What is metastatic renal cell carcinoma? P.06
What is recurrent renal cell carcinoma? P.07

Understanding your diagnosis P.08 - P.11

What are the subtypes of renal cell carcinoma? P.08
What are the stages of renal cell carcinoma? P.09
What are the grades of renal cell carcinoma? P.10
Will I need a kidney biopsy? P.10
How is this information used? P.11
What is my prognosis? P.11

How is renal cell carcinoma treated? P.12 - P.13

Surgery P.12
Ablation P.12
Anti-cancer medications P.12
Radiotherapy P.13
Clinical trials and research P.13

My healthcare team P.14 - P.15

My kidney cancer dictionary P.16

Acknowledgements P.30

Foreward



Dr. Eric Jonasch,
Chair, IKCC Board of Directors



Rose Woodward, Founder,
Action Kidney Cancer in the UK and IKCC Board Ambassador

Perhaps you are reading this because you have kidney cancer yourself, or someone you care about has kidney cancer. We understand that the diagnosis, medical language 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.

A team of patients, patient advocates and healthcare professionals, who have supported thousands of kidney cancer patients, have collaborated to write this introduction to kidney cancer basics to compliment the IKCC *My Treatment, My Choice* series of decision aids for people with kidney cancer.

You may find that this booklet 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, share it with your friends and family, or re-read it at another time. The My kidney cancer dictionary is included to help you understand the medical terms that are used.

We hope you find this book helpful as an introduction to kidney cancer basics, and that it will support you with the decisions ahead regarding your treatment.

Sincerely,

Dr Eric Jonasch, Chair, IKCC Board of Directors
Rose Woodward, Founder, Action Kidney Cancer in the UK and IKCC Board Ambassador
www.ikcc.org

About IKCC My Treatment, My Choice Decision Aids



The IKCC *My Treatment, My Choice* decision aid booklets have been written for people diagnosed with a type of kidney cancer called renal cell carcinoma (RCC). The series includes decision aids that patients will find useful at various points of the kidney cancer pathway. There are different types of treatment for people who have 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.

The decision aids aim to help guide you through your conversations with the healthcare professionals involved in your care. They are also a tool to help you make treatment choices that will deliver the best quality of life for you according to your personal goals.

Having 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 future choices on your life.

Disclaimer
This Kidney Cancer Basics booklet is intended to compliment the IKCC *My Treatment, My Choice* series of decision aids for kidney cancer. The decision aids are intended for patients to use alongside the advice of their healthcare team. They do not support any course of treatment over another. Use of decision aids is voluntary.

My Kidney Cancer: Understanding renal cell carcinoma (RCC)

What are the kidneys and what do they do?
Your kidneys are a pair of bean-shaped organs located on either side of the backbone and under the rib cage. Most people are born with two kidneys. Healthy kidneys grow to be about the size of an adult fist.

The kidneys form part of the body's urinary system. The urinary system creates, stores and gets rid of liquid waste (urine).

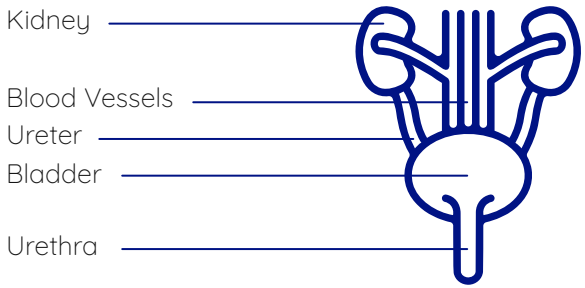
Kidneys are responsible for removing waste products and extra water and salts from your body. The parts of the kidney that filter the blood are called nephrons.

Kidneys also make hormones that play an important role in controlling your blood pressure and keeping your bones and blood healthy.

You can live a perfectly healthy life with one kidney. Some people are born with one kidney and lead a perfectly normal life. If one kidney is removed because of cancer, initially there may not be any significant loss of function in the remaining kidney. However, when possible, surgeons may try to preserve kidney function by removing only the tumour (partial nephrectomy) to prevent loss of kidney function over time.

The word 'renal' is used to describe terms relating to the kidneys.

The urinary system



What is kidney cancer?
Kidney cancer is a type of cancer that starts from the cells of the kidney. The cells divide and grow out of control and create a mass or a tumour.

Sometimes the mass or tumour is not cancer. These are benign tumours. One type is a renal oncocytoma. These make up about 5 in every 100 kidney tumours.

Usually, there is only one tumour in one kidney. Less commonly, two or more tumours may occur in the same kidney or in both kidneys (bilateral kidney cancer).

There are different types of kidney cancer. The most common type of kidney cancer is renal cell carcinoma (RCC). About nine out of ten kidney cancers are RCC. RCC affects the cells in the lining of very small tubes in the parts of the kidney that filter the blood.

There are other types of kidney cancer, including transitional cell carcinoma (TCC), renal sarcomas and Wilm's tumour. Sometimes, non-cancerous (benign) tumours may grow in the kidney. These are called renal oncocytomas.

Also, small sacs of fluid, called renal cysts, may occasionally develop. There are some significant differences in treatment for the various types of kidney cancer.

The IKCC *My Treatment, My Choice* series is for people who have RCC. If you have another type of kidney cancer, talk to your doctor for more information.

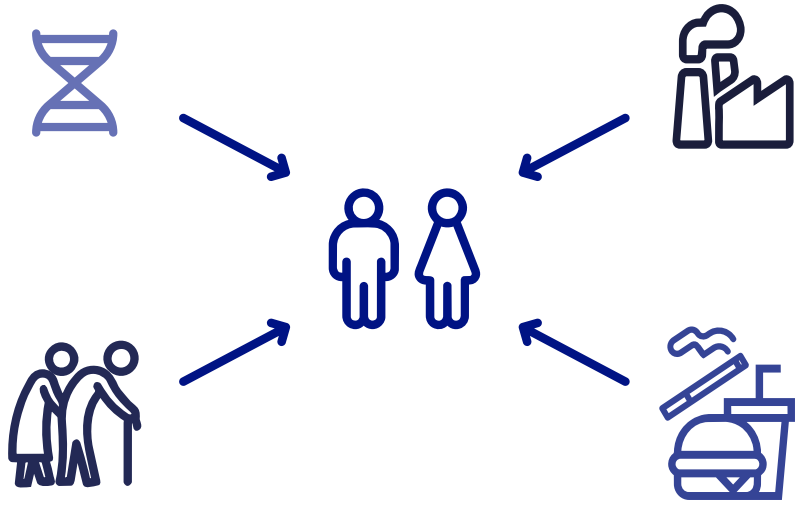
My Kidney Cancer: Understanding renal cell carcinoma (RCC)

How common is kidney cancer?
Kidney cancer is a less common cancer – for every 100 people with cancer in the world, only 2-3 of them will have kidney cancer. At the time of diagnosis, about a quarter of all kidney cancers will have spread beyond the kidney and are at an advanced stage.

What are the risk factors for kidney cancer?
Cancer can start when genes in the cells of the body change (called mutations). Certain risk factors are linked to an increased risk of developing kidney cancer:

- **Age and gender** - tumours in the kidney are most common in people over 60, and more common in men than women
- **Lifestyle factors** – the major risk factors are being overweight or obese and cigarette smoking. Cigarettes contain chemicals (carcinogens) that damage the genes of kidney cells
- **Certain medical conditions and treatments** – such as cystic kidney disease, dialysis, renal stones, high blood pressure (hypertension), previous radiotherapy, long-term use of non-steroidal anti-inflammatory medications, and hepatitis C infection can increase the risk of developing kidney cancer
- **Inherited conditions** – such as von Hippel-Lindau (VHL) syndrome, Birt-Hogg-Dubé syndrome, tuberous sclerosis and hereditary papillary RCC (HPRCC), or a family history of kidney cancer
- **Workplace chemicals or processes** – such as cadmium, lead, asbestos, trichloroethylene, blast furnaces or coke-ovens in the steel and coal industries.

Risk factors for kidney cancer



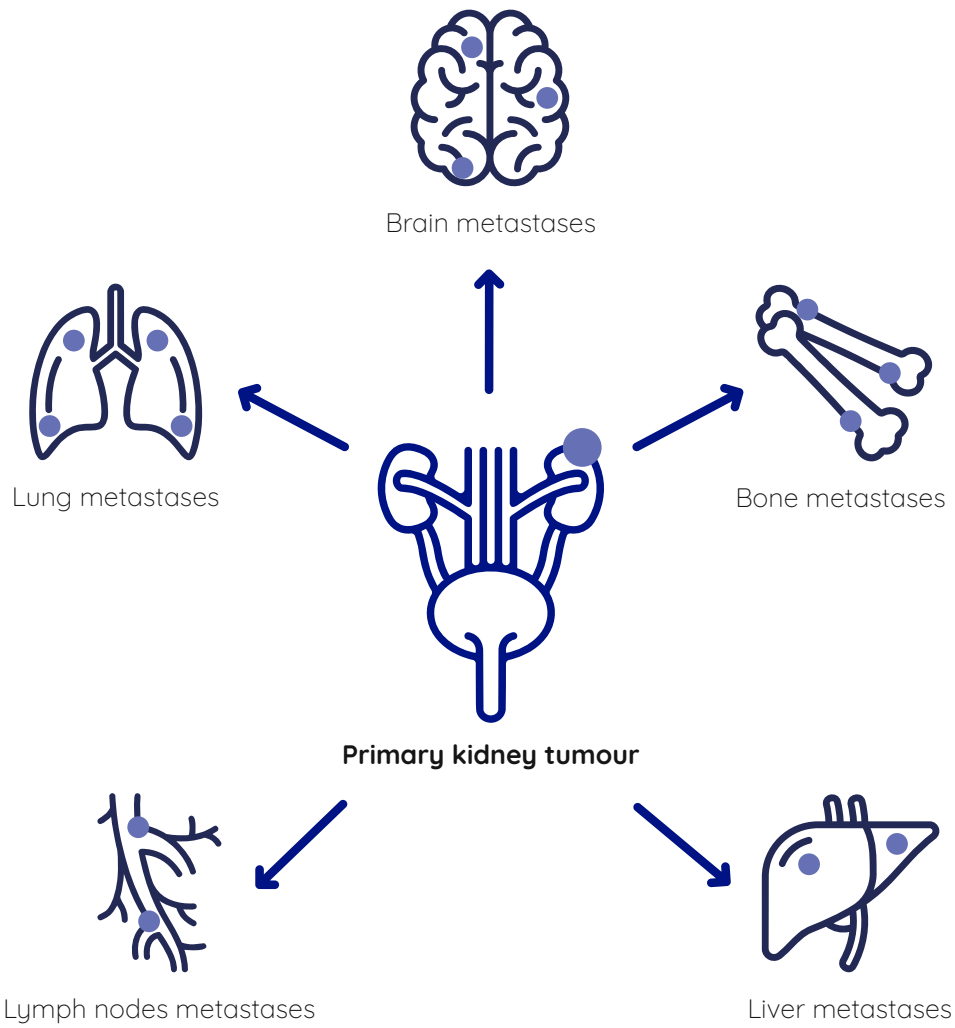
What is localised renal cell carcinoma?
Localised RCC is cancer that is contained within the kidney and has not spread to other parts of the body, such as the lymph nodes or other organs.

What is locally advanced renal cell carcinoma?
Locally advanced RCC is cancer that has spread from the kidney to nearby lymph nodes, blood vessels or nearby tissues.

What is advanced or metastatic renal cell carcinoma?
Advanced (aRCC) or metastatic RCC (mRCC) is when the cancer has spread to other organs or tissues in the body away from the kidney. The most common sites for RCC to spread are the lymph nodes, lungs, bones, liver, other kidney and brain.

My Kidney Cancer: Understanding renal cell carcinoma (RCC)

Metastatic renal cell carcinoma



What is recurrent renal cell carcinoma?

Like many cancers, RCC can return after treatment. This is called recurrent RCC. RCC may come back near the site of the original cancer, known as local recurrence, or in another part of the body. If it returns in another organ, such as the lungs, it is still kidney cancer because it is caused by kidney cancer cells that have spread to other organs. This is called advanced or metastatic RCC.

My Kidney Cancer: Understanding your diagnosis

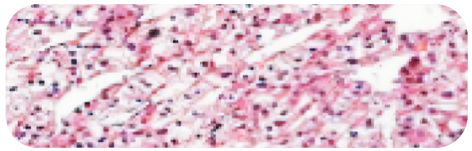
The first thing to understand is the subtype of renal cell carcinoma that you have been diagnosed with.

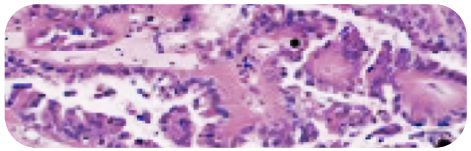
What are the subtypes of renal cell carcinoma?
There are different subtypes of RCC, based on what the cells look like under a microscope. The most common subtype of RCC is clear cell RCC.

Subtypes of renal cell carcinoma (RCC)	
Subtype name	**How common is this subtype of RCC?**
Clear cell RCC	65 to 70 out of 100 patients have this type
Papillary RCC	15 out of 100
Chromophobe RCC	5 to 7 out of 100
Translocation RCC, e.g. Xp11 translocation	1 to 4 out of 100
Clear cell papillary RCC	1 to 4 out of 100
Collecting duct carcinoma	1 to 2 out of 100
RCC, unclassified	1 to 5 out of 100
Mucinous tubular and spindle cell carcinoma	0 to 1 out of 100
Multilocular cystic neoplasm of low malignant potential	0 to 1 out of 100
Tubulocystic RCC	0 to 1 out of 100
Succinate dehydrogenase deficient RCC	0 to 1 out of 200
Acquired cystic disease associated with RCC	Extremely rare
Hereditary leiomyomatosis and RCC (HLRCC)	Extremely rare
Renal medullary carcinoma	Extremely rare

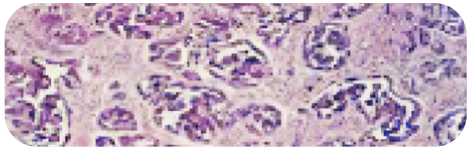
Bilateral kidney cancer
Bilateral kidney cancer is when kidney cancer is found in both kidneys. It is relatively uncommon, affecting about 1 to 5 out of 100 of all patients with kidney cancer. It is often associated with hereditary conditions, such as von Hippel-Lindau disease, hereditary papillary RCC, and hereditary clear cell RCC. However, a small proportion of bilateral kidney tumours can occur spontaneously and are not inherited.

Sarcomatoid kidney cancer
Sarcomatoid kidney cancer is a rare form of kidney cancer. Almost any type of RCC can become sarcomatoid. This means that the cells look like the cells of a sarcoma. Sarcoma is cancer of tissues, such as muscles, nerves, fat, blood vessels and fibrous tissue. Sarcomatoid kidney cancer tends to grow more quickly than other types of kidney cancer and is more likely to spread to other parts of the body. This makes sarcomatoid kidney cancer more difficult to treat.


Clear cell carcinoma


Papillary RCC


Chromophobe RCC


Collecting duct carcinoma

The RCC subtypes can be treated differently. It is, therefore, important to know what subtype of RCC you have so you receive the right treatment. After your operation, ask your doctor to see the pathology report about your tumour, which should explain the subtype you have. Most people have clear cell RCC.

My Kidney Cancer: Understanding your diagnosis

What are the stages of renal cell carcinoma?
Before your healthcare team can discuss treatment options with you, they need to know how big your tumour is and how far your cancer has spread. This is called staging. Information from the tests and scans used to diagnose your cancer is also used to stage your disease. There are a number of staging systems for 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 size and spread of the cancer.

TNM staging system for kidney cancer	
T	**Primary tumour**
TX	Primary tumour cannot be assessed
T0	No evidence of primary tumour
T1	Tumour is 7 cm or smaller at its widest point and is only in the kidney
T1A	Tumour is 4 cm or less
T1B	Tumour is bigger than 4 cm but no bigger than 7 cm
T2	Tumour is bigger than 7 cm at its widest point and is only in the kidney
T2A	Tumour is bigger than 7 cm but no bigger than 10 cm
T2B	Tumour is bigger than 10 cm but is only in the kidney
T3	Tumour has grown into major veins or tissue surrounding the kidney, but not the adrenal gland or beyond the tissue surrounding the kidney (the Gerota Fascia)
T3A	Tumour has grown into the renal vein, or the renal pelvis, and/or the fat surrounding the kidney, but not beyond the Gerota fascia
T3B	Tumour has grown into the vena cava below the diaphragm (a dome-shaped sheet of muscle the sits below the lungs)
T3C	Tumour has grown into the vena cava above the diaphragm or the wall of the vena cava
T4	Tumour has spread beyond the Gerota fascia and/or the adrenal gland

TNM staging system for kidney cancer	
N	**Regional lymph nodes**
NX	Regional lymph nodes cannot be assessed
N0	No regional lymph node metastases
N1	Metastases in regional lymph node(s)
M	**Distant metastases**
M0	No distant metastases
M1	Distant metastases

When doctors know the T, N and M categories, they combine this information to give the cancer an overall stage from I to IV. The stage helps describe how advanced the cancer is and can guide decisions about treatment and what to expect.

Stage	Spread	Size of primary tumour	Location of tumour	TNM
Stage I	Localised	7 cm or smaller	Only in the kidney	T1 N0 M0
Stage II	Localised	Bigger than 7 cm but no bigger than 10	Only in the kidney	T2 N0 M0
Stage III	Localised advanced	Any size	Spread to nearby (local) lymph nodes, blood vessels, or tissues	T3 N0 M0 T1 N1 M0 T2 N1 M0 T3 N1 M0
Stage IV	Advanced or metastatic	Any size	Spread beyond the kidney to other organs and tissues in the body (metastasised)	T4 Any N M0 Any T Any N M1

Finding the stage of your cancer helps you to understand how advanced your cancer is and helps with decisions about treatment options. It also describes the cancer, which can be useful for clinical trials.

My Kidney Cancer: Understanding your diagnosis

What are the grades of renal cell carcinoma?
Doctors grade RCC to show how fast the cancer is likely to grow and spread (how aggressive it is).

Cells from a sample of the cancer (a biopsy) are looked at under the microscope or tested in other ways. By looking at certain features of the cells, the cancer can be graded 1-4. This system is called the Fuhrman Nuclear Grade and 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 slow growing, less agressive and are less likely to spread
Grade 2	The cancer cells appear slightly abnormal, might grow more rapidly, are moderately agressive and could spread
Grade 3	Most cells appear abnormal, the cancer might grow quickly, tends to be more aggressive and is more likely to spread
Grade 4	The cancer cells look very abnormal, are more likely to grow rapidly, are extremely aggressive and are very likely to spread

The subtype, stage and grade of your cancer can affect:
- How fast the tumour grows and how likely it is to spread
- Which treatments (if any) you should have
- Your prognosis or outcome
- Which clinical trials you can take part in.

Will I need a kidney biopsy?
Different countries have different guidelines about when a biopsy is needed. Please speak with your healthcare team about what is right for you.
Your healthcare team can often make a diagnosis of kidney cancer from a CT or MRI scan. On finding a tumour in the kidney some people have surgery to remove the whole kidney or part of it. Diagnosis of kidney cancer is confirmed from the tissue removed during surgery.

Removing all or part of a kidney can affect a person's quality of life. A biopsy before surgery can confirm whether the tumour is cancer. The accuracy of the biopsy depends on the size of the tumour. For smaller tumours the accuracy of diagnosis is close to 90%. If the tumour is not cancer, the doctor and the patient can use this information to decide whether surgery is still needed. This can help avoid unnecessary surgery for benign tumours.

Because some medications for kidney cancer are recommended for specific subtypes of RCC, your healthcare team will 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.

A biopsy can:
- Confirm the diagnosis of kidney cancer
- Confirm the subtype of RCC
- Determine the grade of kidney cancer
- Help your doctor recommend treatment options
- Help avoid unnecessary surgery for benign tumours.

There are two ways to get a sample of your tumour:

1. **A kidney biopsy** is usually done as an outpatient procedure using local anaesthetic to numb your skin. A thin needle is put through the skin and muscle into the kidney to remove a small sample of tumour cells. The sample is sent to a laboratory so the cells can be examined under a microscope by a pathologist. This will tell the doctor the subtype and grade of RCC.

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

2. **During sugery:** 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.

My Kidney Cancer: Understanding your diagnosis



How is this information used?
Information about the subtype, stage and grade of the RCC will help you talk about your cancer with family, friends and other patients. It will also help your healthcare team to:

- Recommend treatment(s) that would be suitable for you
- 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 of the cancer on your quality of life.

What is my prognosis?
Your prognosis is the healthcare 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, since every patient is an individual. However, **the earlier your cancer is detected, the better your chances of long-term survival.**

There are several different scoring systems for prognosis, e.g. the Leibovich prognostic scoring system. In general, these scoring systems consider the stage and grade of the cancer, blood test results, and your overall health and wellbeing. 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 personal wishes and values. For example, if your prognosis is 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 from treatment.

My Kidney Cancer: How is renal cell carcinoma treated?

Surgery

Surgery to remove the tumour and the kidney is called nephrectomy. It is usually the first thing doctors consider. It can successfully treat early-stage kidney cancer. The tumour can be removed in one of two ways:

- A partial nephrectomy (or nephron-sparing surgery) will remove only the portion of the kidney containing the tumour. A margin of tissue that is free of cancer is also removed from around the tumour.
- A radical nephrectomy will remove the whole kidney together with the tumour.

Nephrectomies may be carried out using open surgery or keyhole (laparoscopic) surgery. These days more partial nephrectomy is performed, sometimes using a robot to assist the surgeon help preserve the kidney (robot assisted surgery).

Ablation

Some small kidney tumours (4 cm or less) can be removed using methods that destroy the tumour without removing the kidney. These are called ablative treatments, and include freezing the tumour (cryotherapy), heating it (radiofrequency ablation), or using high intensity ultrasound. High intensity, focused radiotherapy can also be used to destroy small tumours or metastases. This is called stereotactic ablative radiotherapy (SABR) (see section on Radiotherapy below). These treatments are less invasive than surgery, which means they involve smaller procedures and have shorter recovery times.

Anti-cancer medications

Anti-cancer medications are usually given to patients whose cancer has spread (advanced or metastatic kidney cancer). Anti-cancer medications reduce symptoms and prolong life. They can also be given to some patients after surgery to try to prevent their cancer returning. This is called 'adjuvant' treatment and is usually given for one year after surgery.

Anti-cancer medications work by killing cancer cells, stopping or slowing down tumour growth, or shrinking tumours. There are two main types of anti-cancer medication for kidney cancer: targeted therapies or immunotherapies. Targeted therapies are usually taken daily as tablets or capsule. Immunotherapies are usually given as a drip into a vein (intravenously) in the arm very 2-6 weeks. Some can be injected just under the skin (subcutaneously). These anti-cancer medications can be given alone or in combination.

1. **Targeted therapies**

   Targeted therapies block the growth of new blood vessels (angiogenesis) needed for cancer cells to grow and spread. They also block signals within the cancer cells that trigger cell growth.

   Targeted therapies include vascular endothelial growth factor receptor (VEGFR) inhibitors (tyrosine kinase inhibitors), mTOR inhibitors, monoclonal antibodies, and hypoxia-inducible factor-2 alpha (HIF-2α).

   Targeted therapies are taken daily as tablets or capsules. These are taken at home according to a regular schedule.

2. **Immunotherapies**

   Immunotherapies, such as checkpoint inhibitors, block proteins called PD-1/PD-L1 and CTLA-4 on cancer cells. By blocking these proteins, these medicines help the immune system find and kill the cancer cells.

   Immunotherapies are usually given as a drip into a vein (intravenously) in the arm very 2-6 weeks. Some can be injected just under the skin (subcutaneously). Immunotherapies are administered by a nurse in the hospital during an outpatient clinic appointment.

My Kidney Cancer:
How is renal cell carcinoma treated?



Radiotherapy

Kidney cancer is often less responsive to traditional radiotherapy than some other cancers. However, new radiotherapy techniques may still be helpful for some patients with RCC. Radiotherapy can help control symptoms and slow the growth of cancer that has spread to the brain, liver, lungs and pancreas. One type of radiotherapy, called stereotactic radiotherapy (SABR or SBRT) uses very focused, high doses of radiation aimed directly at the cancer. This can help treat the cancer, reducing damage to nearby healthy tissue.

Clinical trials and research

Research into new treatments for kidney cancer remains very exciting, especially with new combinations of anti-cancer medications and the development of new immunotherapies and targeted therapies in recent years. Combinations of checkpoint inhibitors and targeted therapies bring renewed hope for the treatment of advanced RCC, and clinical trials with cancer vaccines and more potent targeted therapies show promise.

Clinical trials are ongoing in several countries with these products. Be sure to ask your healthcare team about research and clinical trials which might be suitable for you. Your local patient support organisation can also help you find out more about clinical trials in your area.

My Kidney Cancer: 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 the IKCC *My Treatment, My Choice* decision aids, you can work with your healthcare team to learn about kidney cancer and treatment options. Together you can make decisions that improve your health and wellbeing.

Who are the members of my healthcare team?

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

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 or medical oncologist	A doctor who has special training in diagnosing and treating cancer using radiation therapy and chemotherapy, targeted therapies, immunotherapy, hormone therapy and palliative care
Radiation oncologist	A doctor who specialises in using radiation therapy to treat cancer
Nephrologist	A doctor who specialises in kidney care and treating diseases of the kidney
General practitioner (GP) in primary care	A family doctor who is based in the community and treats patients with minor or chronic illnesses and refers those with more serious conditions to specialist doctors, usually at the hospital. Can help manage your 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)/ navigator nurse	A specialist nurse who supports you throughout treatment and helps coordinate your care, administers medication, and provides information about your kidney cancer. Navigator nurses will direct you to specific specialties or distinct steps of your kidney cancer treatment pathway, saving time, and optimising your journey
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
Supportive care doctor	A doctor who helps relieve symptoms, manage pain and improve your quality of life
Supportive care nurse	Works with the supportive care doctor to help relieve symptoms, manage pain and improve your quality of life

My Kidney Cancer:
My healthcare team

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

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.

Please look at the IKCC *My Treatment, My Choice decision aids* for more information about the care and treatment of patients with metastatic RCC, locally advanced RCC, and small renal masses. These decision aids go into detail about potential treatment options for your kidney cancer. Together with your healthcare team, a decision aid can help you make an informed choice about your future treatment in accordance with your personal values opinions and beliefs.

My kidney cancer dictionary

During your discussions with your medical team, you will come across medical words or phrases that are difficult to understand. The following dictionary defines difficult medical language into easy-to-understand explanations of the medical terms.

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

Ablation: Removal of cancer by cutting, intense heating or cold.

Active surveillance: Closely monitoring a patient's condition in a predefined manner but withholding treatment (without causing any harm to the patient) until symptoms appear or change. Active surveillance can be used to avoid or delay the need for treatment, such as radiotherapy, chemotherapy or surgery, which can cause side effects or other problems.

Active treatment: Treatment that aims to prolong your survival.

Acute: Symptoms or signs that begin and worsen quickly.

Adenoma: A non-cancerous tumour.

Adenopathy: Large or swollen lymph nodes/glands.

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

Adrenal gland: A small gland that secretes hormones. These hormones help control the heart rate, blood pressure and other important body functions. There are two adrenal glands, one located on top of each kidney.

Adrenalectomy: Surgery to remove one or both adrenal glands.

Advanced or metastatic cancer: Cancer that has spread from where it started to another part of the body. 'Locally advanced' cancer usually means the cancer has grown outside the organ that it started in and into nearby body tissues.

Adverse event: Undesired effect that may or may not be related to treatment, such as dizziness, stomach ache or a rash. A symptom caused by the treatment is a side effect. Serious adverse events in clinical trial participants are reported to the national regulatory authority.

Anaemia: A condition in which the number of red blood cells are below normal.

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.

Analgesic: A drug that reduces pain, for example paracetamol, aspirin and ibuprofen.

Anaplastic: A term used to describe cancer cells that divide rapidly and have little or no resemblance to normal cells.

Angiogenesis: Growth of blood vessels. Growing cancers form new blood vessels from the surrounding tissue for their own blood supply.

Anti-angiogenic agents (or angiogenesis inhibitors): Agents that interfere with the development of blood vessels. In anticancer therapy, an angiogenesis inhibitor prevents the growth of blood vessels from surrounding tissue to a solid tumour.

Angiogenesis inhibitor: A substance that prevents the formation of blood vessels. In anticancer therapy, an angiogenesis inhibitor prevents the growth of blood vessels from surrounding tissue to a solid tumour.

Antibody: A protein produced in blood cells that help the immune system to identify and destroy infectious agents, such as bacteria and viruses.

Antibody therapy: Treatment with an antibody. An antibody is a substance that can directly kill specific tumour cells or stimulate the immune system to kill tumour cells.

Antigen: A protein or other substance that causes the immune system to respond and produce antibodies.

Anti-emetic: A drug that prevents or reduces nausea and vomiting.

Apoptosis: Normal series of events inside cells that leads to its death. Also called programmed cell death.

Arterial embolisation: A procedure in which the blood supply to the area of the kidney containing the tumour is blocked causing it to shrink.

Ascites: Abnormal buildup of fluid in the abdomen that causes swelling.

Asymptomatic: Having no symptoms of disease.

Atypical: Unusual or abnormal cells when looked at under the microscope.

Baseline: An initial measurement that is taken at the start of a study or just before the start of treatment. It is used for comparison over time to look for changes.

My kidney cancer dictionary

For example, the size of a tumour will be measured before treatment (baseline) and then afterwards to see if the treatment had an effect.

Benign: Not cancerous. Benign tumours can grow large but do not spread to other parts of the body.

Bilateral: Affecting both sides of the body.

Bilateral renal cell carcinoma/kidney cancer: Renal cell carcinoma/kidney cancer affecting both kidneys.

Biological therapy: Treatment that uses natural body substances or drugs made from natural body substances to treat cancer.

Biopsy: Removal of a small piece of body tissue to look at the cells under a microscope to see if they are cancer cells.

Birt-Hogg-Dubé (BHD) syndrome: A rare inherited genetic condition that is characterised by skin lesions on the face and neck. It is caused by a genetic mutation in the folliculin gene. Patients may also develop lung cysts or experience a collapsed lung, and a few develop kidney cancer.

Blinded: Clinical trial participants do not know which treatment they are receiving.

Blood urea nitrogen (BUN): A test that measures the amount of nitrogen in the blood that comes from the waste product urea. Urea is made in the liver when the body breaks down protein. Urea nitrogen is removed from the blood by the kidneys. Blood urea nitrogen (BUN) tests are sometimes done to see how well the kidneys are working.

Bone metastases: Cancer that has spread from the original site to the bone.

Bone scan: A diagnostic test using a mildly radioactive material to see whether the cancer has spread to the bones. A small amount of radioactive material is injected into a blood vessel and travels through the bloodstream where it collects in the bones and is detected by a scanning machine.

Cachexia: Loss of body weight and muscle mass resulting in weakness, which can sometimes occur in cancer patients, as well as other illnesses.

Cancer: A group of diseases in which there is an uncontrolled growth of abnormal cells, 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.

Cancer vaccine: A vaccine developed to help the immune system recognise and destroy cancer cells.

Carcinogen: Any substance that causes cancer.

Carcinogenesis: The process in which normal cells become cancer cells.

Carcinoma: A type of cancer that starts in the cells that line or cover all the organs in the body (the epithelial cells), including the skin.

Catheter: A thin, flexible tube that is passed into a body cavity or a blood vessel (usually a vein), to remove body fluids or administer medicines.

Cells: Every part of the body is made up of specialised, individual cells. Cancer starts with one cell becoming cancerous.

Cell proliferation: An increase in the number of cells as a result of cell growth and division.

Cell-to-cell signalling: The transfer of information from one cell to another through chemical transmitters.

Central nervous system: The brain and spinal cord.

Checkpoint inhibitor: Immunotherapies that affect the body's immune system to allow it to respond more aggressively against cancer cells.

Chemotherapy: The use of anti-cancer or cytotoxic drugs to destroy cancer cells (not often used for the treatment of kidney cancer).

Chromophobe RCC: A rare subtype of renal cell carcinoma, which accounts for 5% of RCC cases.

Chromosome: A threadlike structure of nucleic acids and protein (DNA) found in the nucleus of most living cells. Chromosomes carry genetic information in the form of genes.

Chronic: A disease or condition that persists or progresses over a long period of time.

Clear cell RCC: The most common subtype of renal cell carcinoma, which accounts for 75% of RCC cases. The cancer cells appear clear under the microscope and have large nuclei.

Clinical nurse specialist (CNS): An advanced practice nurse with a graduate qualification; clinical experts in the diagnosis and treatment of illness.

Clinical oncologist: A doctor who specialises in radiotherapy treatment for 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.

Collecting duct carcinoma: A rare subtype of renal

My kidney cancer dictionary

cell carcinoma, which develops in the cells that line the collecting ducts in the kidney cortex.

Combination therapy: Using two or more types of treatment, e.g. surgery and chemotherapy or chemotherapy and radiotherapy.

Co-morbidity: The presence of one or more additional diseases or disorders.

Complete remission: The disappearance of all signs of cancer in response to treatment. This does not always mean the cancer has been cured.

Complete response: No cancer can be detected after treatment; however, individual cancer cells or very small tumours that cannot be seen on scans may still be present and may cause a later relapse.

Compliance: Sticking to the treatment prescribed, or the treatment allocated in a clinical trial and, if appropriate, finishing the course.

Contralateral: Having to do with the other side of the body.

Contrast agent: A special dye, which is given during an X-ray or CT scan as an injection or in a drink. Contrast agents are opaque to X-rays and are used to give soft tissues and blood vessels contrast on an X-ray so that they can been seen.

Creatinine: A compound that is produced by the metabolism of creatine and excreted (expelled as waste) from the body in the urine by the kidneys. It is used to monitor kidney function.

Creatine: A compound produced by the metabolism of protein, which is present in living tissue. It is involved in the supply of energy for the contraction of muscles.

Cross-over trials: Clinical trials in which two different treatments are being compared, one in each of two groups of patients. After time, the patients cross over to have the treatment that the other group of patients received.

Cryotherapy/cryoablation: A method of killing cancer cells by freezing the tumour using a probe through the skin as an alternative to surgery.

CT (or CAT) scan or computerised tomography: A special type of X-ray examination in which a series of X-ray pictures of your body are taken from different angles. A computer puts the pictures together to give a detailed image of the inside of your body.

CTLA-4 inhibitors: A type of immune checkpoint inhibitor - an immunotherapy drug that helps in controlling the body's immune response to cancer. An example of a CTLA-4 inhibitor is ipilimumab.

Cyst: A closed sac that may contain air, fluids, or semi-solid material. Once formed, a cyst can go away on its own or may have to be removed through surgery. Most cysts are benign, but some are formed within tumours and may be malignant (cancer).

Cystoscopy: An investigation of the bladder. A surgeon puts a special camera called a cystoscope into the bladder and uses it to look inside the bladder and urethra to check if there is anything wrong.

Cytokine: Substances made by cells of the immune system in response to infection, injury or cancer. 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.

Cytotoxic: Substances that are toxic to cells.

DNA (deoxyribonucleic acid): A self-replicating material present in nearly all living organisms as the main constituent of chromosomes. It is the carrier of genetic information.

Debulking: The surgical removal of part of a tumour, which cannot be completely removed. This surgery can help reduce pain and symptoms due to the tumour, or to improve quality of life. It can also be used to enhance the effectiveness of radiotherapy or chemotherapy.

Dendritic cell: Antigen-presenting cells of the immune system. They are presenting foreign proteins to other immune cells, which then destroy the intruders.

Diagnosis: Finding out the nature of an illness or condition by examination of the symptoms.

Dialysis: An artificial way of filtering waste products and excess water from your blood when your kidneys aren't working properly.

Diaphragm: a dome-shaped sheet of muscle that sits below your lungs. It is the main muscle used for breathing. When you breathe in, it moves down to pull air into your lungs. When you breathe out, it moves up to push air out. It also separates your chest from your abdomen.

Diffuse: Spread out over a large area, widely distributed. The opposite to localised.

Disease free survival: Length of time after treatment during which no cancer is found. Can be reported for an individual patient or for a study population.

My kidney cancer dictionary

Disease progression: The course that a disease takes over time. When doctors talk about progress of disease, unfortunately they mean it has got worse.

Double blind clinical trial: The patient, their doctor, and the researchers running the trial do not know which treatment is received by each group of patients until all data have been recorded. This helps prevent bias.

Dysphagia: Difficulty swallowing.

Dysuria: Difficult or painful urination.

Eligibility criteria: Clearly defined criteria for who is eligible to take part in a clinical trial and who is not. These criteria are described in the inclusion and exclusion criteria of the trial.

Embolisation: A surgical procedure used to slow the growth or destroy cancer cells by blocking the blood supply to a tumour.

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.

Enucleation: The removal of an organ or tumour so that it comes out whole.

Epidemiological study (or observational study): A study that examines data on individuals with a specific condition and does not intervene in their care, as a clinical trial would. Epidemiological studies examine the effect of certain exposures (e.g. tobacco smoke, long duration of HIV infection) on health outcomes (e.g. cancer).

Epidural block: An injection of an anaesthetic drug into the space between the wall of the spinal canal and spinal cord (epidural space) often used for pain relief.

Epithelial tissue: Type of tissue that forms a covering or lining of all internal and external body surfaces, including the skin.

Epithelial carcinoma: Cancer that begins in the epithelial cells that line or cover an organ. Many kidney cancer tumours begin in the epithelial cells that line the small tubes in the kidney that transport urine.

Erythrocyte sedimentation rate (ESR): The rate at which red blood cells settle at the bottom of a test tube in one hour. It is a blood test that is used to detect inflammation associated with cancer, infection, autoimmune diseases, and diseases of the blood and bone marrow.

Erythropoietin: A hormone naturally produced by the kidneys, which stimulates the bone marrow to make red blood cells in response to falling levels of oxygen in the tissues. Synthetic forms are called epoetin alpha or epoetin beta.

Ethics committee: A committee of healthcare professionals and lay people who review clinical trials and research studies to ensure they are conducted to appropriate ethical standards. Recruitment for a clinical trial cannot start until ethics committee approval has been granted.

Evidence base: A collection of the best available scientific research currently available about a health condition. This is used to make decisions about how best to treat and provide care for individuals with that condition, or to prevent it.

Exophytic: A tumour that is growing outward, either externally to the body or on the surface of an organ or structure inside the body.

Excisional biopsy: A surgical procedure in which an entire lump or suspicious area is removed, and the tissue is examined under a microscope for diagnosis.

Exclusion criteria: These determine who is not eligible for a clinical trial. For example, many trials exclude women who are pregnant, or who may become pregnant, to avoid any possible danger to a baby, or people who are taking a drug that might interact with the treatment being studied (see also eligibility criteria and inclusion criteria).

False-negative test result: A test result that indicates that a person does not have a specific disease or condition when the person actually does have the disease or condition.

False-positive test result: A test that indicates that a person has a specific disease or condition when the person actually does not have the disease or condition.

Familial cancer: Cancer that occurs in families more often than would be expected by chance. These cancers often occur at an early age and may indicate a gene mutation that increases the risk of cancer. They can also be a sign of shared environmental or lifestyle factors.

Fatigue: Extreme tiredness which is not rectified by sleep.

Fine-needle aspiration: A procedure in which a fine needle is inserted into a tumour, cyst or tissue, under local anaesthetic, to obtain a sample of fluid or tissue for examination under a microscope. Also called needle biopsy.

First-line (or front-line) treatment: The first treatment given for a disease, often as part of a standard set of treatments. First-line treatment is usually the one accepted as the best treatment for the disease, and

My kidney cancer dictionary

if it doesn't work or causes severe side effects, other treatments may be added or used instead.

Five-year survival: A statistic indicating the percentage of people with a particular type of cancer who are living 5 years after the initial cancer diagnosis.

Frozen section: A technique in which tissue is removed and then quick-frozen and examined under a microscope by a pathologist.

Fractions: Daily radiotherapy treatments.

Full blood count (FBC): A blood test which provides important information about the type, number and appearance of cells in the blood, especially red blood cells, white blood cells, and clotting cells.

Gadolinium: A contrast agent/dye that is given intravenously before MRI scans to improve the quality of the picture.

Gamma irradiation: Used for sterilising or decontaminating surgical equipment by exposure to gamma rays, a type of high-energy electromagnetic radiation that destroys bacteria.

Gamma knife surgery (stereotactic radiosurgery or radiosurgery): Radiotherapy for brain metastases using high doses of radiation directed at the cancer using a head frame.

Gamma radiation: A very high frequency form of electromagnetic radiation that consists of high-energy photons emitted by radioactive elements. Gamma rays can injure and destroy body cells and tissue, especially cell nuclei. Gamma radiation is used in radiotherapy to treat cancer.

Gene: Pieces of DNA that contain the information for making a specific protein. Genes are passed on from parents to offspring in the sperm and egg cells.

Generic name: The chemical name of a drug, which refers to its chemical makeup.

Genetics: The study of genes, genetic variation, and heredity in living organisms.

Genetic marker: An alteration in DNA that may indicate an increase in the risk of developing a specific disease or disorder.

Gerota capsule/fascia: A fibrous envelop of tissue that surrounds the kidney. This is also called renal fascia or Gerota fascia.

Glomerular filtration rate (GFR): A test used to check how well the kidneys are working. Specifically, it estimates how much blood passes through the glomeruli each minute.

Good Clinical Practice (GCP): An international quality standard for the conduct of clinical trials. Randomised clinical trials are required by law to conform to GCP.

Grade: A description of a tumour that refers to how the cancer cells look and behave under a microscope. It describes how different the cancer cells look from normal cells, how quickly the cancer cells are growing and dividing, and how likely they are to spread.

Haematogenous: Originating in the blood or spread through the blood stream.

Haematuria: The presence of blood in the urine, which can be visible to the naked eye or through a microscope (non-visible haematuria).

Haemoglobin: The substance in red blood cells that carries oxygen. Used in blood tests to measure a person's red blood cell content.

Haemoptysis: Coughing-up blood.

Half-life: The time it takes for half of the total amount of a substance or drug to be eliminated from the body.

Hand-foot syndrome: Pain, swelling, numbness, tingling or redness of the hands or feet. It can occur as a side effect of some of the anticancer drugs.

Health economics: In some clinical trials the cost of all aspects of the treatments being compared is examined. This is particularly important when there is more than one effective approach to treating a condition.

Helper T cell: A type of white blood cell that helps stimulate immune system reactions. Helper T cells help activate cytotoxic T cells and macrophages by secreting cytokines. They also stimulate B cells to make antibodies.

Hereditary: The transfer of genes from a parent to their offspring. Genes contain information about the physical or mental characteristics of the individual.

High-grade: Cancers that tend to grow and spread quickly.

High intensity focused ultrasound (HIFU): A method of killing cancer cells by directing a strong beam of sound at the tumour. This technique is done using a probe through the skin thereby avoiding open surgery.

Hilar: The area where nerves and blood vessels attach to an organ.

Histopathology: The study of diseased cells or tissues using a microscope.

Hospice: A home for providing specialised care for people who are sick or terminally ill.

My kidney cancer dictionary

Hypercalcaemia: High levels of calcium in the blood.

Hyperplasia: An abnormal increase in the number of cells in an organ or tissue.

Hypertension: High blood pressure.

Hyperuricemia: A build-up of uric acid in the blood (this is a byproduct of metabolism). It can also be a side effect to some of the drugs that fight cancer.

Hypervascular: Having many blood vessels (common in renal cell carcinoma).

Hypotension: Low blood pressure.

Hypocalcaemia: Low levels of calcium in the blood. Immune response: The activity of the immune system against foreign substances.

Immune system: A complex groups of organs, tissues and cells that defend the body against infection and foreign substances. Organs include the thymus, bone marrow, and lymph nodes.

Immuno-oncology: The use of immunotherapy drugs to treat cancer. See immunotherapy.

Immunomodulating: Adjusting the immune response to the desired level using immunotherapy drugs.

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.

Inclusion criteria: A set of criteria that clearly indicate who can join a clinical trial or research study, e.g. the condition and stage of disease they are already at, and their age. See also eligibility criteria and exclusion criteria.

Indolent: A type of cancer that grows slowly.

Inferior vena cava: A large vein that carries deoxygenated blood from the lower body (legs, feet and organs in the abdomen and pelvis) into the heart.

Informed consent: Written permission given before surgery, clinical trials, research or other kinds of treatments and tests. The individual, or a parent or guardian, must understand the treatment and legally agree to any risks involved.

Inpatient: A patient who stays overnight in hospital to receive care.

Intensity-modulated radiotherapy (IMRT): Three-dimensional radiotherapy that uses computer-generated images to show the size and shape of the tumour. Thin beams of radiation of different intensities are aimed at the tumour from many angles. This type of radiotherapy reduces the damage to the healthy tissue surrounding the tumour.

Interferon: A naturally occurring protein produced and secreted by cells in the body to help stimulate the immune system to fight infection and disease. Interferon works by helping to stop the cancer cells from growing, and by boosting the immune system to attack the cancer. Interferon is a type of immunotherapy. The form of interferon used to treat cancer is interferon alpha-2a.

Interim analysis: An analysis of trial data, which is undertaken before the end of the trial.

Interleukin (IL 2): A naturally occurring protein produced and secreted by cells in the body to help stimulate the immune system to fight infection and disease. Interleukin works by stimulating a type of white blood cell, called a T cell, to attack the cancer. T cells are part of the immune system and interleukin is a type of immunotherapy. The form of interleukin used to treat cancer is interleukin 2 (IL 2).

Intervention: A measure that is introduced and evaluated through a clinical trial with the aim of improving health. It could be a treatment (e.g. drug A vs. drug B), a treatment strategy (e.g. a drug vs. a surgical technique), a different screening approach, or prevention measure.

Intravenous: An injection into a vein.

Intravenous pyelogram (IVP): A special X-ray examination of your urinary system (kidneys, ureters and bladder). The X-rays are taken after a contrast agent, or dye is injected into a blood vessel. The dye is concentrated in the urine, which outlines the kidneys, ureters, and bladder on the X-rays. Also called intravenous urogram (IVU).

Intravenous urogram (IVU): A special X-ray examination of your urinary system (kidneys, ureters and bladder). The X-rays are taken after a contrast agent, or dye is injected into a blood vessel. The dye is concentrated in the urine, which outlines the kidneys, ureters, and bladder on the X-rays. Also called intravenous pyelogram (IVP).

Investigational drug: A substance that has been tested in a laboratory and has regulatory approval to be tested in people in clinical trials. A drug may have a license for use in one disease/condition but be considered investigational in other diseases/conditions. Also called an experimental drug.

Jaundice: A condition in which the skin and the whites of the eyes become yellow, the urine darkens, and the stool becomes a lighter colour than normal. It is usually

My kidney cancer dictionary

associated with gallbladder or liver problems.

Karnofsky index: A scale for the measurement of performance status to quantify the general wellbeing and activities of daily life of cancer patients. Patients are scored from 100 to 0, where 100 is «perfect» health, and 0 is death. Doctors occasionally assign performance scores in between standard intervals of 10. The primary purpose of the Karnofsky index was to evaluate a patient's ability to survive chemotherapy for cancer.

Keloid: A thick irregular scar caused by excessive tissue growth at the site of an incision (cut).

Kidney cancer: Cancer that forms in tissues of the kidneys, including renal cell carcinoma (RCC), transitional cell carcinoma (TCC) (also called renal pelvis carcinoma), and Wilms' tumour, a rare type of kidney cancer that usually develops in children under the age of 5.

Killer cell: A white blood cell that attacks and destroys cancer cells and infected cells.

Lactic acid dehydrogenase: An enzyme found in the blood and other body tissues which is involved in energy production in cells. An increased amount in the blood may be a sign of tissue damage, and some types of cancer or other diseases. Also called lactate dehydrogenase.

Laparoscope: A thin, tube-like instrument used to look at tissues and organs inside the abdomen. It has a light and a lens at the end for viewing tissues and organs, and tools for the removal of tissue samples.

Laparoscopic nephrectomy: Keyhole surgery to remove the kidney through a small cut in the abdomen.

Laparoscopy: A procedure that uses a laparoscope inserted through the abdominal wall to examine inside the abdomen.

Laparotomy: A surgical incision that is made in the wall of the abdomen to gain access to the abdominal cavity.

Latent: Describes a condition that is present but not active or causing symptoms.

Leibovich score: A scoring algorithm that can be used to predict cancer-specific survival for patients with clear cell renal cell carcinoma (RCC). The scoring system is based on stage of disease, spread to the lymph nodes, tumour size, nuclear grade and tumour necrosis. A low score (0-2) is a good prognosis, whereas a high score (6-11) is a poor prognosis.

Lesion: An area of abnormal tissue that may be benign (not cancer) or malignant (cancer).

Leukocyte: General term for a variety of cells responsible for fighting invading germs, infection, and allergy-causing substances. Also called a white blood cell. These cells help the body fight infection and diseases.

Leukopenia: A low number of white blood cells.

Liver function test: A blood test to measure the blood levels of some of the enzymes released by the liver. Abnormal levels of these enzymes can indicate liver disease.

Liver metastasis: Cancer that has spread from the original or primary site of the tumour to the liver. Also called liver secondaries.

Localised: Restricted to the original (primary) site, with no evidence of spread. A localised kidney tumour is confined to the kidney.

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

Low grade: Cancerous cells look nearly normal under a microscope. These are least likely to grow and spread rapidly.

Lymph: The fluid that circulates through the lymphatic system. Contains white blood cells, such as lymphocytes (T cells and B cells) that fight infection and foreign substances.

Lymph node: A small, bean-shaped swelling in the lymphatic system where lymph is filtered and lymphocytes (white blood cells) are formed. There are hundreds of lymph nodes distributed widely throughout the body, including the armpit, neck and abdomen, linked by lymphatic vessels. They form part of the body's defence against infections and cancer.

Lymphatic system: Part of the immune system, comprising a network of lymphatic vessels (a network of thin tubes) that carry a clear fluid called lymph round the body and towards the heart. Lymphatic vessels branch, like blood vessels, into all the tissues of the body.

Lytic lesion: The damaged area of a bone that shows up as a dark spot on an X-ray when the healthy bone is destroyed by cancer. Lytic lesions look like holes in the bone and are evidence that the bone is being weakened.

Magnetic resonance imaging (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.

Magnetic resonance spectroscopic imaging (MRSI): A type of MRI scan that provides information about

My kidney cancer dictionary

tumour metabolism. In addition to information about the shape and size of the tumour, MRSI can also provide additional information about the metabolism of the tumour.

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

Malignant ascites: A condition in which there is a fluid build-up in the abdomen in which there are cancer cells.

Mammalian target of rapamycin (mTOR) inhibitors: Protein kinase inhibitors that are used to treat cancer by interfering with the signalling pathway that controls tumour cell growth and angiogenesis. Examples include everolimus and temsirolimus.

Margin: Border of tissue surrounding a tumour that is removed during surgery. If the pathologist describes the margin as negative or clean, it suggests that all the cancer has been removed. If the margin is considered positive, it means that the cancer cells are found at the edges, and not all the cancer has been visibly removed.

Mean: A statistical term for the average value in a set of measurements. The mean is the sum of a set of numbers divided by the total number of observations.

Mean survival time: The average time patients in a clinical study remain alive. The time is measured from time of diagnosis or start of treatment.

Medical oncologist: A doctor who specialises in the medical treatment of cancer.

Meta-analysis: A means of quantitatively combining the results of several research studies to provide an average estimate of the treatment effect.

Metastasectomy: Surgical removal of metastases.

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: When cancer spreads from one part of the body to another.

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

Molecule: A group of two or more atoms bonded together, representing the smallest unit of a chemical compound that can take part in a chemical reaction. Biological molecules, such as proteins, carbohydrates, lipids and nucleic acids, can be made up of hundreds of atoms.

Monoclonal antibody: Man-made antibodies that specifically bind to signalling proteins which control various biological functions, such as angiogenesis, and interfere with their actions. Monoclonal antibodies can be used alone, or they can be used to deliver drugs, toxins or radioactive material directly to the tumour. Examples include bevacizumab, nivolumab and pembrolizumab.

Morphine: A narcotic drug used in the treatment of pain.

Mortality: The state of being subject to death.

Mucinous tubular and spindle cell carcinoma: A rare subtype of renal cell carcinoma, which develops in the mucinous and spindle cells of the renal cortex.

Mucositis: Inflammation of the lining of the digestive system, often seen as sores in the mouth. Can be a complication of some cancer treatments.
Multidisciplinary team (MDT): The name given to the healthcare professionals working as a team to look after you.

Multifocal: More than one tumour, each having arisen from the original (primary) tumour.

Mutation: Any change in the DNA of a cell. Mutations may be caused by mistakes during cell division, or they may be caused by exposure to DNA-damaging agents in the environment.

Myalgia: Pain in a muscle or group of muscles.

Natural killer cell (NK cell): A type of white blood cell called a lymphocyte that forms part of the immune system. Plays a major role in the destruction of cancer cells and infected cells.

Nausea: Feeling sick. Nausea can be the side effect of some cancer treatments.

Necrosis: Refers to the death of living tissue.

NED or No Evidence of Disease: Medical phrase to indicate that the doctors cannot detect any sign of disease or cancer with current testing methods.

Needle biopsy: The removal of tissue or fluid with a needle for examination under a microscope. Also called fine-needle aspiration.

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.

Neoplasm: 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

My kidney cancer dictionary

cancerous), or malignant (cancerous). Also called a 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.

Nephron: Tiny structures in the kidney that filter the blood to form urine.

Nephron-sparing surgery: Surgical removal of part of the kidney containing the tumour to keep as much normal kidney tissue as possible so that the remaining kidney is still able to work. Also called partial nephrectomy.

Nephrotoxic: Poisonous or damaging to the kidney.

Neuropathic pain: Pain that comes from problems with the signalling from nerves.

Nil per os (NPO): Medical phrase for 'nothing by mouth'.

Non-steroidal anti-inflammatory drug (NSAID): An analgesic drug that decreases fever, swelling, pain, and redness.

Objective response: A measurable response.

Observational study: A type of study in which individuals are observed or certain outcomes are measured. No attempt is made to affect the outcome (for example, no treatment is given). See epidemiological study.

Oedema: Swelling caused by excess fluid in body tissues.

Off label: The legal use of a prescription drug to treat a disease or condition for which the drug has not been licensed for use.

Oncogene: A gene that in some circumstances can transform a normal cell into a cancer cell. In tumour cells, they are often mutated (changed) or expressed at a high level. Oncogenes can be inherited or caused by exposure to environmental/lifestyle substances that cause cancer.

Oncologist: A doctor who specialises in the diagnosis and treatment of cancer.

Oncology: The study and treatment of cancer.

Open label trials: A clinical trial in which participants and their doctors know which treatment (or treatment strategy) they are receiving.

Opiate: A drug used to treat pain. It contains opium or a substance made from opium (such as morphine).

Outcome measures: Outcomes are measures of health, e.g. response to treatment, occurrence, or recurrence of disease, a measure of wellbeing.

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

Overall survival: The length of time from either date of diagnosis or start of treatment that people diagnosed with cancer (or another disease) are still alive.

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: The relief of symptoms, especially pain, caused by serious life-threatening disease, such as cancer. Palliation can help a patient feel more comfortable and improve their 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 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.

Palliative therapy: Treatment given to relieve symptoms, especially pain, caused by serious life-threatening disease, such as cancer. Palliative care therapies can be given together with other cancer treatments, from the time of diagnosis through treatment, survivorship, recurrent disease, and end of life.

Papillary (or chromophilic) RCC: A subtype of renal cell carcinoma (RCC), which accounts for about 10-15% of RCC cases. The tumours have characteristic papillae or nodules on the surface. Papillary RCC is sub-divided into type 1 and type 2. Type 2 tumours are larger, more common in younger patients, and more frequently stages 3 or 4 than type 1 tumours.

Paracentesis: Removal of fluid from the abdomen using a needle and syringe, conducted using local anaesthetic.

Partial nephrectomy: Surgical removal of part of the kidney containing the tumour to keep as much normal kidney tissue as possible so that the remaining kidney is still able to work. Also called nephron-sparing surgery.

My kidney cancer dictionary

Partial response: A decrease in the size of a tumour or in the extent of the cancer in response to treatment. This is also called partial remission.

Pathologist: A doctor who identifies disease by studying cells and tissues under the microscope.

Pathological fracture: A break in a bone usually caused by cancer or disease.

Patient advocate: A person who guides a patient through the confusing maze of health care with caring and sensitivity. A patient advocate focuses exclusively on the patient's needs and helps the patient resolve concerns about the quality of their care, get the care the patient needs, and ensures the patient's voice is heard and that they are included in decision-making. Patient advocacy groups try to raise public awareness about important cancer issues, such as the need for cancer support services, education, and research. Such groups work to bring about change that will help cancer patients and their families.

Patient-controlled analgesia (PCA): Pain relief that is directly controlled by the patient. When pain relief is needed, the patient receives a pre-set dose of pain medicine by pressing a button on a computerised pump that is connected to a small tube in the body.

PD-1/PD-L1 inhibitors: A type of immune checkpoint inhibitor - an immunotherapy drug that helps in controlling the body's immune response to cancer. Examples of PD-1 inhibitors are nivolumab and pembrolizumab.

Percutaneous: A medical procedure carried out or occurring through the skin.

Peri-operative: Around the time of surgery. This usually lasts from the time the patient goes into the hospital or doctor's office for surgery until the time the patient goes home.

Pericardial effusion: Increased amounts of fluid within the sac surrounding the heart, usually due to inflammation.

Peripheral neuropathy: A condition of the nervous system that causes numbness, tingling, burning or weakness. It usually begins in the hands or feet and can be caused by certain anticancer drugs.

Positron emission tomography (PET) scan: A procedure in which a small amount of radioactive glucose is injected into a vein and a scanner is used to make detailed computerised pictures of areas inside the body where the glucose is used. Because cancer cells often use more glucose than normal cells, the radioactive glucose accumulates in active cancer cells, and these areas are highlighted on the scan.

Photodynamic therapy: Treatment with drugs that are activated by exposure to light. These drugs kill cancer cells.

PICC-line: A long, thin, flexible tube (catheter), which is put into a vein above the bend in the elbow and pushed through the vein until the tip of the catheter sits in the large vein just above the heart. It is used to give chemotherapy or other medicines and can stay in place until treatment is finished.

Placebo: A dummy treatment that is designed to be harmless and to have no effect. It looks, smells and tastes like the treatment being tested, so that trial participants do not know if they are taking the dummy treatment or the treatment itself, i.e. they are blinded to the treatment they are taking. The effects of the active drug are compared to the effects of the placebo.

Pleura: A thin layer of tissue, or membrane, covering the lungs and lining the interior wall of the chest cavity. It protects and cushions the lungs. This tissue secretes a small amount of fluid that acts as a lubricant, allowing the lungs to move smoothly in the chest cavity while breathing.

Pleural cavity: The space enclosed by the pleura, which is a thin layer of tissue, or membrane, that covers the lungs and lines the interior wall of the chest cavity.

Pleural effusion: An abnormal collection of fluid between the membranes (pleura) lining the lung and the wall of the chest cavity.

Port: A catheter connected to a small disc that is surgically placed just below the skin in the chest or abdomen. The tube is inserted into a large vein directly into the bloodstream. Fluids, drugs, or blood products can be infused, and blood can be drawn through a needle that is stuck into the disc. Also called a port-a-cath or infusaport.

Postoperative: After surgery.

Primary tumour: The original site of the tumour.

Prognosis: The likely outcome or course of a disease. The factors that affect a patient's prognosis include the type of cancer, its stage, grade, and response to treatment.

Prognostic factor: A situation or condition, or a characteristic of a patient, which can be used to estimate the chance of recovery from a disease, or the chance of the disease recurring (coming back).

Programmed cell death: A type of cell death in which a series of molecular steps in a cell leads to its death. This is the body's normal way of getting rid of unneeded or abnormal cells. The process of programmed cell death may be blocked in cancer cells. Also called apoptosis.

My kidney cancer dictionary

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

Progression-free survival (PFS): The length of time a patient lives without their cancer getting worse (progressing). PFS is a measurement used in clinical trials to help determine whether a new treatment is effective.

Progressive disease: Cancer that is growing, spreading, or getting worse.

Protocol: The plan for a research study or clinical trial. Protocols need to be approved by an ethics committee before the study begins to recruit participants. They provide information on the question being addressed by the study, the treatments under investigation, the eligibility criteria, and the visit schedule and type of tests for trial participants.

Physical examination: The process by which a doctor investigates the body of a person for signs of disease.

Polycythaemia: Thickening of the blood caused by an increase in red blood cells due to an abnormality in the bone marrow, or a decrease in the volume of plasma, the fluid that carries the red blood cells.

Primary cancer (primary tumour): Where the cancer started. The type of cell that has become cancerous will be the primary cancer; for example, if a biopsy from the liver or lung contains cancerous kidney cells, then the primary cancer is kidney cancer.

Prophylaxis: Any measure to prevent a health condition, rather than curing or treating it, such as vaccination and use of anti-malaria drugs.

Protein kinase inhibitors: Small molecules that work inside the cell to inhibit kinases - proteins which are part of the signalling system that tells cells when to divide and grow and produce new blood vessels.

Pruritus: Severe itching of the skin/unpleasant sensation that causes the desire to scratch.

Quality of life: As well as measuring the physical effects of a treatment (for example changes to blood pressure), many trials now try to assess the impact of treatments on people's quality of life. For example, a 'quality of life' study might ask about; mood and general sense of wellbeing, fatigue, sleep patterns, and ability to carry out daily activities.

Radical nephrectomy: Surgery to remove an entire kidney, nearby adrenal gland and lymph nodes, and surrounding tissue.

Radiofrequency ablation (RFA): A procedure that uses radio waves to heat and destroy a cancer.

Radiologist: A doctor who specialises in diagnosing disease or medical conditions by using X-ray, CT scans, ultrasound scans or MRI.

Radiology: Medical speciality which uses imaging technology (such as X-ray, ultrasound, CT, MRI) to diagnose or guide the treatment of disease/medical conditions.

Radiosurgery: A radiotherapy procedure that uses special equipment, such as a head frame, to position the patient and precisely deliver a large radiation dose directly to a tumour, thus avoiding surrounding healthy tissue. This procedure does not use surgery. It is used to treat brain tumours and other brain disorders. It is also being studied in the treatment of other types of cancer, such as lung cancer and pancreatic metastases. Also called stereotactic radiotherapy or gamma-knife surgery.

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

Randomisation: Used in randomised controlled trials. A computer decides at random which treatment or treatment strategy a trial participant will receive. This ensures that each participant has the same chance of receiving the treatments or strategies being compared and avoids one treatment being given to someone because they are, for example, elderly or very sick. Randomisation ensures that the groups of people being compared in a trial are as similar as possible, except for the treatment they receive. This in turn ensures that differences seen between these groups after they have started their treatment are likely to be due to the treatments being compared.

Randomised controlled trial (RCT): A clinical trial in which the participants are assigned by chance to different treatment groups; neither the researchers nor the participants can choose which group they are in. Randomisation allows a fair comparison between trial groups to be made.

Recurrence: Cancer that has returned after a period of time during which the cancer 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.

Red blood cell: The blood cell that carries oxygen around the body.

Regression: A decrease in the size of a tumour or the extent of cancer in the body.

Relapse: The return of the signs and symptoms of cancer after a period of improvement.

Relative survival: A specific measurement of survival. For cancer, the rate is calculated by adjusting the

My kidney cancer dictionary

survival rate to remove all causes of death except cancer. The rate is determined at specific time intervals, such as 2 years and 5 years after diagnosis.

Remission: If a cancer is in remission, there is no sign of it on scans or during an examination. Doctors use the word 'remission' instead of cure when talking about cancer because they cannot be sure that there are no cancer cells at all in the body.

Renal: Having to do with the kidneys.

Renal artery: The main blood vessel that supplies blood to a kidney and its nearby adrenal gland and ureter. There is a renal artery for each kidney.

Renal capsule: The fibrous connective tissue that surrounds each kidney.

Renal cell carcinoma (RCC): The most common kind of kidney cancer. It arises in the small tubes of the kidneys. In most cases, this is the clear cell subtype.

Renal medullary carcinoma: A rare subtype of renal cell carcinoma, that develops in the cells in the renal medulla (the innermost part of the kidney).

Renal pelvis: The area at the centre of the kidney. Urine collects here and is funnelled into the ureter, the tube that connects the kidney to the bladder.

Renal translocation carcinoma: A rare subtype of renal cell carcinoma involving a mutation (change) in the Xp11.2 gene.

Residual cancer: Cancer cells that remain after attempts to remove the cancer have been made.

Response: An improvement in disease related to treatment.

Response rate: The percentage of patients whose cancer shrinks or disappears after treatment (responds to treatment).

Robot-assisted surgery: A type of keyhole (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 it 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.

Sedimentation rate: The rate at which red blood cells settle at the bottom of a test tube in one hour. It is a blood test that is used to detect inflammation associated with cancer, infection, autoimmune diseases, and diseases of the blood and bone marrow. Also called erythrocyte sedimentation rate (ESR).

Sequencing: The optimal order in which different drugs are administered to a patient for the treatment of cancer to maximise efficacy and minimise side effects.

Shared decision-making: A process that ensures individuals are supported to make decisions that are right for them. It is a collaborative process through which a clinician supports a patient to reach a decision about their treatment. The conversation brings together the clinician's expertise, such as treatment options, evidence, risks and benefits, and the patient's preferences, personal circumstances, goals, values and beliefs.

Side effects: 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. These are sometimes called adverse events.

Solid tumour: An abnormal mass of tissue that usually does not contain cysts (sacs containing fluid). Solid tumours may be benign (not cancerous), or malignant (cancerous). Solid tumours are named according to the type of cells that form them. Examples of benign tumours are adenomas and fibromas, and malignant tumours are sarcomas and carcinomas.

Stable disease: Cancer that isn't changing, i.e. the tumour(s) is not growing, and no new tumours have developed.

Stage/staging: A system used to describe the size of a tumour and the extent of spread of the cancer throughout the body.

Staging: A system used by doctors to describe how big a cancer is and how far it has already spread.

Stem cell: An unspecialised cell that can grow into any one of the body's more than 200 specialised cell types.

Stereotactic radiotherapy: 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: 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

My kidney cancer dictionary

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.

Survival rate: The percentage of people in a study or treatment group who are alive for a given period of time after diagnosis. This is commonly expressed as 1- or 5-year survival rates.

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. Also used to describe the supply of medicines through the circulatory system (blood) to the entire body.

Systemic treatment/therapy: A treatment that is delivered to the entire body through the circulatory system (blood). Most cancer drugs are systemic treatments.

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 staging: A system for staging cancer based on the presence of tumours (T), lymph node involvement (N) and metastases (M). Also called AJCC staging.

Toxicity: The extent to which something is poisonous or harmful.

Trade name: The name of a drug under which it is licensed and sold. Also called the brand name.

Transdermal: Absorption of a drug or medicine through the skin, for example, using adhesive patches.

Transitional cell: A type of epithelial cell that can vary in shape when stretched. They are found lining hollow organs that need to stretch to accommodate body fluid, such as the bladder.

Transitional cell carcinoma (TCC): Cancer that develops in the transitional cells that line the bladder, ureter, or renal pelvis (the part of the kidney that collects, holds, and drains urine).

Trial/treatment arm: One of the groups to which trial participants are assigned to in a randomised controlled trial. The group of people receiving the current standard of care are usually referred to as the control arm.

Trial phases: Clinical trials are conducted in phases from phase 1 through phase 4. Phase 1 trials aim to test safety and usually involve a small number of people. Phase 2 trials aim to evaluate effectiveness and usually involve a larger number of people. Phase 3 trials aim to compare two or more treatments or treatment strategies and monitor side effects. Results from phase 3 trials are used to license treatments for use by patients. Phase 4 trials are post-marketing studies and collect further information on use of treatments in clinical practice.

Tuberous sclerosis: A rare multi-system genetic disease that causes benign tumours to grow in the brain, kidneys, heart, lungs, eyes and skin.

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

Tumour burden/load: The number of cancer cells, the size of a tumour, or the amount of cancer in the body.

Tumour-specific antigen: A protein that is unique to cancer cells or is much more abundant in cancer cells. Usually found in the outer membrane of the cell and are potential targets for immunotherapy or other types of anticancer treatment.

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

Unclassified RCC: Rare subtypes of renal cell carcinoma that cannot be described as any other subtype of renal cell carcinoma.

Uric acid: A waste product left over from normal chemical processes in the body and found in the urine and blood. Abnormal build-up of uric acid in the body may cause a condition called gout. Increased levels of uric acid in the blood and urine can be a side effect of chemotherapy or radiation therapy.

Urea and electrolytes (U&E): A blood test that tests the function of the kidneys.

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

Urology: The study and treatment of the urinary tract in women and the urogenital system in men.

Vaccine: A naturally occurring biological substance that stimulates the body's immune system and provides immunity to a particular disease. A vaccine typically contains an agent that resembles the disease-causing virus or bacterium and is often made from weakened or killed forms of viruses or bacteria.

My kidney cancer dictionary

Vaccines have been developed to help the immune system recognise and destroy cancer cells.

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.

Von Hippel-Lindau (VHL) syndrome: A rare inherited genetic condition which causes abnormal growth of blood vessels. VHL is caused by a genetic mutation in the VHL gene and about 28-45% of VHL patients develop kidney cancer. VHL kidney cancer is clear cell and it can metastasise and become aggressive.
Wedge resection: A surgical procedure to remove a triangle-shaped slice of tissue. It may be used to remove a tumour and a small amount of normal tissue around it.

White blood cell: A type of blood cell, which has an important role in the immune system to help fight infections and foreign bodies. White blood cells are made in the bone marrow, lymph nodes or spleen, and are found in the blood and lymph (in lymphatic vessels). Examples of white blood cells include lymphocytes (T and B cells) and leucocytes.

Wilms' tumour: A very rare kidney cancer which affects children under the age of 5.

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



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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.

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Contributors:
Dr Sharon Deveson Kell
Ms Rose Woodward
Dr Saurabh Bhargava

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IKCC
International Kidney
Cancer Coalition

Registered Address:
Stichting International Kidney Cancer Coalition
Computerweg 22, 3542 DR Utrecht, The Netherlands

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

Search for us on
Facebook: ikcc
Instagram: @ikccfoundation
X: @IKCCorg
Youtube: @ikccorg
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BlueSky: @ikccorg.bsky.social

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