

NCCN Guidelines for Patients®

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Kidney Cancer

Presented with support from: Kidney Caneer Association www.KidneyCancer.org

Available online at NCCN.org/patients



Kidney Cancer

Learning that you have cancer can feel overwhelming. The goal of this book is to help you get the best care. It explains which tests and treatments are recommended by experts in kidney cancer.

The National Comprehensive Cancer Network[®] (NCCN[®]) is a not-for-profit alliance of 26 of the world's leading cancer centers. Experts from NCCN[®] have written treatment guidelines for doctors who treat kidney cancer. These treatment guidelines suggest what the best practice is for cancer care. The information in this patient book is based on the guidelines written for doctors.

This book focuses on the treatment of kidney cancer. NCCN also offers patient books on breast, ovarian, and pancreatic cancer, as well as many other cancer types. Visit **NCCN.org/patients** for the full library of patient books as well as other patient and caregiver resources.



NCCN aims to improve the care given to patients with cancer. NCCN staff work with experts to create helpful programs and resources for many stakeholders. Stakeholders include health providers, patients, businesses, and others. One resource is the series of books for patients called the NCCN Guidelines for Patients®. Each book presents the best practice for a type of cancer. The patient books are based on clinical practice guidelines written for cancer doctors. These guidelines are called the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). Clinical practice guidelines list the best health care options for groups of patients. Many doctors use them to help plan cancer treatment for their patients. Panels of experts create the NCCN Guidelines®. Most of the experts are from NCCN Member Institutions. Panelists may include surgeons, radiation oncologists, medical oncologists, and patient advocates. Recommendations in the NCCN Guidelines are based on clinical trials and the experience of the panelists. The NCCN Guidelines are updated at least once a year. When funded, the patient books are updated to reflect the most recent version of the NCCN Guidelines for doctors.

For more information about the NCCN Guidelines, visit NCCN.org/clinical.asp.

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As an organization that strongly supports educating patients and physicians about renal cancer, the Kidney Cancer Association is proud to support this comprehensive resource for patients and their families. www.kidneycancer.org/

Supported by NCCN Foundation®



The NCCN Foundation supports the mission of the National Comprehensive Cancer Network® (NCCN®) to improve the care of patients with cancer. One of its aims is to raise funds to create a library of books for patients. Learn more about the NCCN Foundation at NCCN.org/foundation.



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Who should read this book?

This book is about treatment for renal cell carcinoma—the most common type of kidney cancer in adults. It does not discuss transitional cell carcinoma, Wilms tumor, or renal sarcoma. Patients and those who support them caregivers, family, and friends—may find this book helpful. The information in this book may help you talk with your treatment team, understand what doctors say, and prepare for treatment.

Does the whole book apply to me?

This book includes information for many situations. Thus, not everyone will get every test and treatment listed. Your treatment team can point out what applies to you and give you more information. As you read through this book, you may find it helpful to make a list of questions to ask your doctors.

The recommendations in this book are based on science and the experience of NCCN experts. However, each patient is unique and these specific recommendations may not be right for you. Your doctors may suggest other tests or treatments based on your health and other factors. This book does not replace the knowledge and suggestions of your doctors.

Making sense of medical terms

In this book, many medical words are included that describe cancer, tests, and treatments. These are words that you will likely hear from your treatment team. Some of this information may be new to you, and it may be a lot to learn.

Don't be discouraged as you read. Keep reading and review the information. Be sure to ask your treatment team to explain a word or phrase that you don't understand.

Words that you may not know are defined in the text or in the *Dictionary*. Words in the *Dictionary* are underlined when first used on a page. Acronyms are defined in the text when first used and are also defined in the *Glossary*. Acronyms are words formed from the first letters of other words. One example is CBC for **c**omplete **b**lood **c**ount.



Kidney cancer basics

NCCN Guidelines for Patients® Kidney Cancer, Version 1.2015

1 Kidney cancer basics

6	What are the kidneys?
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Learning that you have cancer can feel overwhelming and confusing. Part 1 explains some basics about kidney cancer that may help you better understand this disease. These basics may also help you start planning for treatment.

What are the kidneys?

The <u>kidneys</u> are a pair of organs found in the back part of the belly area (<u>abdomen</u>), just above the waist. One kidney is on the left side of the backbone (<u>spine</u>) and one is on the right side. **See Figure 1.1**.

Each kidney is about the size of an adult's fist. The kidney is covered by a thin layer of tissue, like the skin of an apple. This layer of tissue is called the renal capsule. The word "renal" refers to the kidneys or something related to the kidneys. For example, "renal disease" is a disease of the kidneys.

An <u>adrenal gland</u> sits on top of each kidney. The kidney and adrenal gland are surrounded by a layer of fat. Covering the fat is an outer layer of fibrous tissue called <u>Gerota's fascia</u>. See Figure 1.2.

What the kidneys do in the body

The kidneys are part of the <u>urinary system</u>, shown in **Figure 1.1.** The urinary system is a group of organs that remove waste from the body in the form of urine. This system includes the kidneys, <u>ureters</u>, <u>bladder</u>, and <u>urethra</u>.

The kidneys perform many jobs to keep your body healthy. They make <u>hormones</u> that help control blood pressure. They also make hormones that tell the body to make more <u>red blood cells</u>. The main job of the kidneys is to filter blood to remove waste and extra water the body doesn't need. They make urine from the waste taken out of the blood. By filtering the blood, the kidneys also control and balance the levels of fluids and chemicals in the body.



The kidneys are a pair of organs in the abdomen. The kidneys are the main organs of the urinary system. They filter waste out of blood and make urine. The ureters, bladder, and urethra hold and transport urine before it is released from the body.



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Figure 1.2 The kidney and adrenal gland

An adrenal gland sits on top of each kidney. The kidney and adrenal gland are surrounded by a layer of fatty tissue. Surrounding the fat is a layer of fibrous tissue called Gerota's fascia.



Derivative work of Kidney and Adrenal Gland by Alan Hoofring from NCI Visuals Online. Available at: https://visualsonline.cancer.gov/details.cfm?imageid=4355

How the kidneys filter and clean blood

The <u>renal arteries</u> carry blood with waste into the <u>kidneys</u>. See Figure 1.3. Blood then flows through tiny filtering tubes in the kidneys called <u>renal tubules</u>. Blood is "cleaned" as it flows through the renal tubules. The renal tubules take waste and other substances out of the blood. These substances are made into urine.

The clean, filtered blood flows out of the kidneys through the <u>renal veins</u>. The renal veins then merge with a larger <u>vein</u> called the <u>vena cava</u>. The vena cava takes clean blood back up to the heart.

Urine flows out of the renal tubules and collects in a hollow space in the middle of the kidneys. This hollow space is called the <u>renal pelvis</u>. Urine leaves the renal pelvis through long tubes called <u>ureters</u>. The ureters carry urine to the <u>bladder</u>. The bladder holds urine until it is released from the body—when you pee. A shorter tube, called the <u>urethra</u>, takes urine from the bladder to outside the body.

Most people have two kidneys. But, each kidney works on its own and does not need the other to function. This means that the body can often work well with less than one complete kidney. Many people live full, healthy lives with only one kidney.

Figure 1.3 The kidneys filter blood to remove waste

Blood travels throughout the body in a network of tubes called blood vessels. Blood with waste and extra water enters the kidney through the renal artery. In the kidney, renal tubules remove excess water and other waste from the blood to make urine. Urine drips out of the renal tubules into the renal pelvis then leaves the kidney through the ureter. Clean, filtered blood leaves the kidney through the renal vein.



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How does kidney cancer start?

Cancer is a disease of cells—the building blocks that form tissue in the body. Inside all cells are coded instructions for making new cells and controlling how cells behave. These coded instructions are called genes. Abnormal changes (mutations) in genes can turn normal kidney cells into cancer cells. Normal cells grow and divide to make new cells. New cells are made as the body needs them to replace injured or dying cells. When normal cells grow old or get damaged, they die. Cancer cells don't do this. The changes in genes cause cancer cells to make too many copies of themselves. **See Figure 1.4.** Cancer cells make new cells that aren't needed and don't die quickly when old or damaged. Over time, cancer cells grow and divide enough to form a mass called a <u>tumor</u>. The first tumor formed by the overgrowth of cancer cells is called the <u>primary tumor</u>.

Figure 1.4 Normal versus cancer cell growth

Normal cells divide to make new cells as the body needs them. Normal cells die once they get old or damaged. Cancer cells make new cells that aren't needed and don't die quickly when old or damaged.



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Where does kidney cancer start?

Almost all kidney cancers are <u>carcinomas</u>. Carcinomas are cancers that start in cells that line the inner or outer surfaces of the body. In the <u>kidneys</u>, carcinomas most often start in the cells that line the <u>renal tubules</u>. This is called <u>RCC</u> (**r**enal **c**ell **c**arcinoma) and it is the focus of this patient book. About 90 out of 100 kidney cancers are RCCs. See **Figure 1.5.** Because it is the most common type, RCC is often simply referred to as kidney cancer. There are three other, less common types of cancer that start in the kidneys. However, they do not act the same as RCC and are not treated the same as RCC. The less common types are: <u>TCC</u> (transitional cell carcinoma), <u>Wilms tumor</u>, and <u>renal sarcoma</u>. TCC starts in the cells that line the <u>renal pelvis</u>. Wilms tumor almost only occurs in young children. Renal sarcoma starts in the <u>blood vessels</u> or connective tissue of the kidneys. (For information about sarcoma, read *NCCN Guidelines for Patients: Soft Tissue Sarcoma*, available at www.nccn.org/patients.)

Figure 1.5 Common types of kidney cancer

RCC is the most common type of kidney cancer. About 90 out of 100 kidney cancers are RCCs. TCC accounts for 5 to 10 out of 100 kidney cancers. Renal sarcoma accounts for less than 1 out of 100. Wilms tumor is very rare and almost only occurs in young children.

Types of kidney cancer



How does kidney cancer spread?

Cancer cells act differently than normal cells in three key ways. First, cancer cells grow without control. Unlike normal cells, cancer cells make new cells that aren't needed and don't die when they should. The cancer cells build up to form a <u>primary tumor</u>.

Second, cancer cells can grow into (invade) other tissues. Normal cells don't do this. Over time, the primary <u>tumor</u> can grow large and invade tissues outside the kidney. It may invade nearby tissues like surrounding fat, blood vessels, the <u>adrenal gland</u>, and <u>Gerota's fascia</u>.

Third, cancer cells don't stay in one place as they should. Unlike normal cells, cancer cells can spread to other parts of the body. This process is called <u>metastasis</u>. Cancer cells can break away from the primary tumor and enter the bloodstream or <u>lymph</u> <u>vessels</u>. They can travel through blood or <u>lymph</u> to reach distant sites. The cancer cells can then form new tumors in other parts of the body. The new tumors are called <u>metastatic</u> tumors or <u>metastases</u>.

Kidney cancer tends to spread to distant sites such as the <u>lungs</u>, <u>lymph nodes</u>, bones, <u>liver</u>, and sometimes the brain. The uncontrolled growth and spread of cancer cells makes cancer dangerous. Cancer cells can replace or deform normal tissue causing organs to stop working.

Spread through lymph

Lymph is a clear fluid that gives cells water and food. It also has <u>white blood cells</u> that help fight germs. Lymph travels throughout the body in a network of small tubes like blood does. These small tubes are called lymph vessels. Lymph nodes are small groups of special disease-fighting cells. Lymph nodes filter lymph to remove germs. Lymph nodes are connected to each other by lymph vessels. Lymph vessels and nodes are found throughout the body. **See Figure 1.6.** Lymph nodes near the kidneys are called regional lymph nodes. Lymph nodes in other parts of the body are called distant lymph nodes.

Figure 1.6 Lymph vessels and nodes

Lymph nodes and vessels are found throughout the body. A lymph node is a small group of special disease-fighting cells. Lymph nodes are connected to each other by a network of small tubes called lymph vessels.



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Review

- The kidneys filter blood to remove extra water and other waste the body doesn't need.
- Renal tubules are tiny tubes in the kidneys that remove waste from blood and make urine.
- Cancer cells form a tumor since they don't die as they should.
- RCC (renal cell carcinoma) is cancer that starts in cells that line the renal tubules. RCC is the most common type of kidney cancer.
- Cancer cells can spread to other body parts through blood or lymph.



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2

Testing for kidney cancer



2 Testing for kidney cancer

15	General health tests
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Many kidney cancers are found by chance during imaging tests given for other health problems. Other times, testing is started when a person has signs or symptoms of kidney cancer. Part 2 describes the tests that are recommended when kidney cancer is first suspected or found. These tests are used to find and confirm (diagnose) kidney cancer and help plan treatment. This information will help you use the *Treatment guide* in Part 5. It may also help you know what to expect during testing.

General health tests

Medical history

Before and after cancer treatment, your doctor will assess your <u>medical history</u>. Your medical history includes any health events in your life and any medications you've taken. Your doctor will ask about any symptoms and health conditions that you have had. This information may affect which cancer treatment is best for you. It may help to make a list of old and new medications while at home to bring to your doctor's office.

Family history

Some health conditions can run in families. So, your doctor may ask about the medical history of your blood relatives. It's important to know who in your family has had what diseases. It's also important to know at what ages the diseases started. This information is called a family history.

Kidney cancer often occurs for unknown reasons. But, some people have <u>genetic</u> health conditions that increase the risk for kidney cancer. Genetic means that it is passed down from parent to child through genes. One example is VHL (**v**on **H**ippel-**L**indau) disease, also called VHL syndrome. This disease is caused by an abnormal change (mutation) in the VHL <u>gene</u>. People with VHL disease have a higher chance of getting kidney cancer and other types of cancer.

Physical exam

Doctors usually perform a <u>physical exam</u> along with taking a medical history. A physical exam is a review of your body for signs of disease such as infection and areas of unusual bleeding or bruising.

During this exam, your doctor may listen to your <u>lungs</u>, heart, and <u>intestines</u>. Your doctor may also feel parts of your body to see if organs are of normal size, are soft or hard, or cause pain when touched. Your <u>kidneys</u> sit deep inside your <u>abdomen</u> and normally can't be felt during a physical exam. But, your doctor may be able to feel a kidney that is enlarged or has a large <u>tumor</u>.

Imaging tests

<u>Imaging tests</u> take pictures (images) of the inside of your body. Imaging tests are used to find and confirm (diagnose) <u>kidney</u> cancer. They are also used to assess the extent of the cancer to help plan treatment.

Imaging tests are often easy to undergo. Before the test, you may be asked to stop eating or drinking for several hours. You should also remove any metal objects that are on your body. Often there are no side effects.

CT scan

A <u>CT</u> (computed tomography) scan uses <u>x-rays</u> to take pictures of the inside of the body. It takes many x-rays of the same body part from different angles. All the x-ray pictures are combined to make one detailed picture of the body part. This type of scan is very good at showing kidney <u>tumors</u>.

A CT scan of your belly area (<u>abdomen</u>) and <u>pelvis</u> is recommended to check if there is a tumor in either of your kidneys. The pictures can clearly show the tumor size, shape, and location. This test can also show if the tumor has grown into nearby tissues.

Before the CT scan, you may be given a <u>contrast</u> dye to make the pictures clearer. The dye may be put in a glass of water for you to drink, or it may be injected into your <u>vein</u>. It may cause you to feel flushed or get hives. Rarely, serious <u>allergic reactions</u> occur. Tell your doctors if you have had bad reactions in the past. The contrast dye might not be used if you have a serious <u>allergy</u> or if your kidneys aren't working very well.

A CT scan machine is large and has a tunnel in the middle. **See Figure 2.1.** During the scan, you will need to lie face up on a table that moves through the tunnel. The scanner will rotate an x-ray beam around you to take pictures from many angles. You may hear buzzing, clicking, or whirring sounds during this time.

One x-ray scan is completed in about 30 seconds. But, the full exam may take 15 to 60 minutes to complete. More or less time may be needed depending on the part of your body being scanned. A computer

Figure 2.1 CT scan machine

A CT machine is large and has a tunnel in the middle. During the test, you will lie on a table that moves slowly through the tunnel.



will combine all the x-ray pictures into one detailed picture. You may not learn of the results for a few days since a <u>radiologist</u> needs to see the pictures. A radiologist is a doctor who's an expert in reading the pictures from imaging tests.

MRI scan

An <u>MRI</u> (magnetic resonance imaging) scan uses radio waves and powerful magnets to take pictures of the inside of the body. It does not use x-rays. An MRI scan is good at showing the <u>spine</u> and soft tissues like the kidneys and brain. It is also very useful for looking at <u>blood vessels</u>.

You may not be able to have a CT scan with contrast if you have an allergy to it or if your kidneys aren't working well. In such cases, an MRI scan of your abdomen may be used instead to check for a tumor in your kidneys. For an MRI scan, a contrast dye may still be used to make the pictures clearer. MRI scans use a different kind of contrast dye than CT scans. But, the contrast dye may not be given if your <u>kidney function</u> is below a certain level. In people with very poor kidney function, MRI contrast can cause a rare, but serious condition called <u>nephrogenic systemic sclerosis</u>.

Getting an MRI scan is similar to getting a CT scan. But, MRI scans take longer to complete. The full exam often lasts an hour or more. For the scan, you will need to lie on a table that moves through a large tunnel in the scanning machine. The scan may cause your body to feel a bit warm. Like a CT scan, you may not learn of the MRI scan results for a few days since a radiologist needs to see the pictures.

Ultrasound

An <u>ultrasound</u> is a test that uses sound waves to take pictures of the inside of the body. **See Figure 2.2.** This test can show if there is a mass in your kidneys. It can also show if the mass is solid or fluid-filled. Kidney cancer tumors are more likely to be solid.

For this test, you will need to lie down on an exam table. A gel will be spread on the area of skin near

Figure 2.2 Ultrasound

An ultrasound uses sound waves to make pictures of the inside of the body.



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your kidneys. Next, your doctor will place the <u>ultrasound</u> probe on your skin and guide it back and forth in the gel. The probe sends out sound waves that bounce off organs and tissues to make echoes. The probe also picks up the echoes. A computer uses the echoes to make a picture that is shown on a screen.

Ureteroscopy

Ureteroscopy uses a thin, tube-shaped tool called a scope that is inserted into your body to take pictures. Ureteroscopy is not used for kidney cancer. But, this <u>imaging test</u> may be used if your doctor suspects <u>TCC</u> or <u>bladder</u> cancer.

One end of the scope has a small light and camera lens to see inside your body. It allows your doctor to view your <u>ureters</u> and the middle part of your kidneys, called the <u>renal pelvis</u>. For this test, the scope will be inserted through your <u>urethra</u>. It will then be passed through your bladder, a ureter, and then into the renal pelvis of a kidney.

Blood tests

Doctors test blood to look for signs of disease and assess your general health. These tests are not used to confirm (diagnose) kidney cancer. But, abnormal results may signal there's a problem with your kidneys or other organs. Abnormal results may be caused by kidney cancer or other health conditions.

For a blood test, your doctor will insert a needle into a <u>vein</u> to remove a sample of blood. Blood is often removed from a vein in the arm. The needle may bruise your skin and you may feel dizzy afterward.

The blood sample will then be sent to a lab for testing. The blood tests used for kidney cancer are described below.

СВС

A <u>CBC</u> (complete blood count) measures the number of <u>red blood cells</u>, <u>white blood cells</u>, and platelets. Your doctor will want to know if you have enough red blood cells to carry oxygen throughout your body, white blood cells to fight infections, and platelets to control bleeding.

CBC test results are often abnormal in people with kidney cancer. Having a low number of red blood cells, called anemia, is common in people with kidney cancer. Your blood counts may be abnormal—too low or too high—because of kidney cancer or another health problem.

Blood chemistry tests

<u>Blood chemistry tests</u> measure the levels of the chemicals in your blood. Chemicals in your blood come from your <u>liver</u>, bones, and other organs and tissues. Your kidneys filter excess chemicals and waste out of your blood.

Doctors use blood chemistry tests to assess if certain organs and body systems are working well. Abnormal

levels of certain chemicals can be a sign that your kidneys aren't working well. Abnormal levels—too high or too low—may also be a sign that cancer has spread to other parts of your body.

Blood chemistry tests are given with other initial tests when kidney cancer is first found or suspected. They may also be given during and after cancer treatment to check treatment results.

A <u>blood chemistry panel</u> is a common test doctors give to people who have or might have kidney cancer. A blood chemistry panel measures many different chemicals in one sample of blood. Some of the main chemicals your doctor will assess with the blood chemistry panel are described in **Chart 2.1**. The panel will likely also include <u>liver function tests</u> to assess the health of your liver. Your liver does many important jobs, such as remove toxins from your blood. Liver function tests measure chemicals that are made or processed by the liver. Levels that are too high or low may be a sign of liver damage or cancer spread. One such chemical is <u>ALP</u> (alkaline **p**hosphatase). High levels of ALP may mean that the cancer has spread to the bone or liver. **See Chart 2.1** for details.

Chart 2.1 Blood chemistry tests

Calcium: Calcium is a mineral mostly found in bones. : High levels of calcium in your blood may be a sign that cancer has spread to your bones. : Abnormal levels of calcium may also be a sign that your kidneys aren't working well.Creatinine: Creatinine is waste from muscles that is filtered out of blood by the kidneys. : High levels of creatinine in the blood may be a sign that the kidneys aren't working well.Urea: Urea is a waste product made by the liver and filtered out of blood by the kidneys. : High levels of urea in the blood may be a sign that the kidneys aren't working well.Output: Urea is a protein found in most tissues in the body, including the liver and bones.	Chemical name	Why it's important
Creatinine• Creatinine is waste from muscles that is filtered out of blood by the kidneys. • High levels of creatinine in the blood may be a sign that the kidneys aren't working well.Urea• Urea is a waste product made by the liver and filtered out of blood by the kidneys. • High levels of urea in the blood may be a sign that the kidneys aren't working well.• ALP is a protein found in most tissues in the body, including the liver and bones.	Calcium	 <u>Calcium</u> is a mineral mostly found in bones. High levels of calcium in your blood may be a sign that cancer has spread to your bones. Abnormal levels of calcium may also be a sign that your kidneys aren't working well.
 Urea Urea is a waste product made by the liver and filtered out of blood by the kidneys. High levels of urea in the blood may be a sign that the kidneys aren't working well. ALP is a protein found in most tissues in the body, including the liver and bones. 	Creatinine	 <u>Creatinine</u> is waste from muscles that is filtered out of blood by the kidneys. High levels of creatinine in the blood may be a sign that the kidneys aren't working well.
• ALP is a protein found in most tissues in the body, including the liver and bones.	Urea	 <u>Urea</u> is a waste product made by the liver and filtered out of blood by the kidneys. High levels of urea in the blood may be a sign that the kidneys aren't working well.
• High levels of ALP in your blood may be a sign that cancer has spread to your liver or bones.	ALP	 ALP is a protein found in most tissues in the body, including the liver and bones. High levels of ALP in your blood may be a sign that cancer has spread to your liver or bones.

Urine tests

Doctors test urine to look for signs of disease and assess your general health. These tests are not used to confirm (diagnose) kidney cancer. But, abnormal results may signal there's a problem with your kidneys or other organs. Abnormal results may be caused by kidney cancer or other health conditions.

For a urine test, your doctor will ask you to fill a small container with your urine. You may only need to give one sample of urine for the test. Or, your doctor may want to collect your urine over a 24-hour period. The urine sample will be sent to a lab for testing. The urine tests that may be used for kidney cancer are described below.

Urinalysis

<u>Urinalysis</u> is a test that checks the content of urine using a <u>microscope</u> and chemical tests. Doctors use this test to look for small amounts of blood or other abnormal substances in urine that can't be seen with the naked eye. Blood in urine may be caused by kidney cancer or other health problems.

Urine cytology

Urine cytology is a test in which urine is examined with a microscope to check for cancer cells. Urine cytology is not used for kidney cancer. But, this test may be used if your doctor suspects <u>TCC</u> or <u>bladder</u> cancer.

Tissue tests

A <u>biopsy</u> is a procedure that removes samples of tissue from your body for testing. Doctors test <u>tumor</u> tissue to check for cancer cells and to look at the features of the cancer cells. A biopsy is the only way to confirm (diagnose) most types of cancer. For those cancers, a biopsy must be done before starting cancer treatment. Kidney cancer is different.

<u>Imaging tests</u> are very good at showing if a kidney tumor is cancer. Doctors can often confirm kidney cancer based on the imaging test results. Thus, a biopsy of the tumor is rarely needed before starting treatment. Instead, a biopsy may be done when the tumor is removed with <u>surgery</u>.

A biopsy may be done before treatment in some cases, such as when:

- A tumor is very small and might not be treated with surgery. In this case, a biopsy may be done to confirm kidney cancer and help to guide the treatment plan.
- Doctors think a tumor might be TCC. In this case, a biopsy may be done to confirm the cancer type.

There is more than one type of biopsy. For kidney cancer, a biopsy is done with a needle. This is called a needle biopsy. A needle biopsy uses a long, hollow needle that is inserted through your skin to remove a sample of the tumor.

Before the biopsy, the area of skin near your kidney will be cleaned. It will also be numbed with <u>local</u> <u>anesthesia</u>. Next, you may be asked to hold your breath while your doctor inserts the needle. Your doctor will push the needle through your skin and into the tumor in your kidney. Imaging tests such as a <u>CT</u> <u>scan</u> or <u>ultrasound</u> will help guide the needle to the



right spot. A sample of tumor tissue will be collected in the hollow center of the needle.

A needle biopsy may take up to one hour to complete. You may feel some pain in your belly area afterward. Rarely, serious problems like bleeding may occur.

Tissue samples removed with a biopsy or surgery will be sent to a <u>pathologist</u>. A pathologist is a doctor who's an expert in testing cells to find disease. The pathologist will view the tissue sample with a microscope to look for cancer cells. He or she will also assess the features of the cancer cells to find out the <u>subtype</u>.

Subtypes of RCC

<u>RCC</u> is the most common type of kidney cancer. There are also many subtypes of RCC, based on how the cancer cells look under a microscope. The most common subtype by far is <u>clear cell RCC</u>. Clear cells look very pale or clear when viewed with a microscope. Three other, less common subtypes are <u>papillary RCC</u>, <u>chromophobe RCC</u>, and <u>collecting</u> <u>duct RCC</u>. There are also a number of very rare subtypes of RCC. When the cancer cells don't look like any of the subtypes, it's called unclassified RCC.

2 Testing for kidney cancer

Review

- Your health history and a body exam inform your doctor about your health.
- Imaging tests are used to find and confirm kidney cancer.
- Blood and urine tests check for signs of disease.
- A biopsy removes small samples of tissue to test for cancer.
- Clear cell RCC is the most common subtype.



National Comprehensive Cancer Network[®]

3 Cancer staging

NCCN Guidelines for Patients® Kidney Cancer, Version 1.2015

3 Cancer staging

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Cancer staging is how your doctors rate and describe the extent of cancer in your body. The rating—called the cancer stage—is based on the results of certain tests. Doctors use cancer staging to plan which treatments are best for you. Part 3 describes the tests used for staging and defines the stages of kidney cancer. This information will help you use the *Treatment guide* in Part 5.

Staging tests

Doctors use certain tests to find out where and how much the cancer has grown and spread in your body. These are called <u>staging</u> tests. Some staging tests are recommended for all patients when <u>kidney</u> cancer is first found. Other staging tests are only recommended if you have certain signs or <u>symptoms</u> of cancer spread. The staging tests used for kidney cancer are listed in **Chart 3.1** and described next.

CT scan

A <u>CT scan</u> is an <u>imaging test</u> that uses <u>x-rays</u> to take pictures of the inside of the body. (See Part 2 on page 16 for more details.) A CT scan of your <u>abdomen</u> will show if the kidney <u>tumor</u> has grown into the attached <u>adrenal gland</u> or nearby <u>lymph nodes</u>. A CT scan of your chest is used to check if cancer has spread to your <u>lungs</u> or chest area. The lungs are one of the most common distant sites of kidney cancer spread. Thus, this test is often given when kidney cancer is first found. A CT scan of your brain may be used if you have symptoms that suggest the cancer has spread to your brain. Symptoms of cancer in the brain include chronic headaches, seizures, loss of balance, weakness on one side of the body, personality changes, and trouble with walking, speech, or vision.

MRI scan

An <u>MRI scan</u> is an imaging test that uses radio waves and powerful magnets to make pictures. (See Part 2 on page 17 for more details.) An MRI scan of your abdomen can clearly show the <u>blood vessels</u> near your kidneys. It is used to check if the cancer has spread to major blood vessels like the <u>vena cava</u>. MRI scans take better and clearer pictures of blood vessels than CT scans. MRI is also very useful for viewing the brain. An MRI of your brain may be used if you have symptoms that suggest the cancer has spread to your brain.

X-ray

An x-ray is a test that uses small amounts of radiation to make a picture of the inside of the body. An x-ray of your chest is used to check if cancer has spread to your lungs. X-rays are good at showing bones and some soft tissues like the lungs. But, pictures from a regular x-ray are not as detailed as pictures from a CT scan of the chest. An x-ray is painless and takes about 20 minutes. Often, two pictures are taken—one from the back of your chest and one from the side.

Bone scan

A <u>bone scan</u> is an imaging test that can show if cancer has spread to your bones. This test is only used if you have certain symptoms such as bone pain or high levels of <u>ALP</u> in your blood. These symptoms may signal that the cancer has spread to your bones.

A bone scan uses a <u>radiotracer</u> to make pictures of the inside of bones. A radiotracer is a substance that releases small amounts of radiation. Before the pictures are taken, the tracer will be injected into your <u>vein</u>. It will take about 3 hours for the tracer to enter your bones. For the scan, you will need to lie very still on a table. A special camera will take pictures of the tracer in your bones as it moves over your body. It takes about 45 to 60 minutes to complete the pictures. Areas of bone damage use more radiotracer than healthy bone and thus show up as bright spots on the pictures. Bone damage can be caused by cancer or other health problems.

Chart	3.1	Staging	tests
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Staging tests for everyone	Staging tests based on symptoms
CT scan of the abdomen	CT scan of the brain
CT scan of the chest	MRI scan of the brain
X-ray of the chest	Bone scan
MRI scan of the abdomen	

TNM scores

The AJCC (**A**merican **J**oint **C**ommittee on **C**ancer) <u>staging</u> system is used to stage kidney cancer. In this system, each letter—T, N, and M—describes a different area of cancer growth. Your doctors will assign a score to each letter, based on the results of cancer tests. These scores will be combined to assign the cancer a stage.

T = Tumor

The T score describes the growth of the <u>primary</u> <u>tumor</u>. This score tells you how large the <u>tumor</u> has grown. It also tells you if the tumor has grown into nearby tissues. The tumor size is measured in cm (**c**enti**m**eters). It may help to compare the measurement to everyday objects. For example, a green pea is about 1 <u>cm</u> wide. A golf ball is a little more than 4 cm wide. A baseball is a little more than 7 cm wide. T scores for kidney cancer include:

- **T1** tumors are only in the kidney and are not larger than 7 cm at the widest point.
 - **T1a** tumors are 4 cm or smaller.
 - **T1b** tumors are more than 4 cm but not larger than 7 cm.
- **T2** tumors are only in the kidney and are larger than 7 cm at the widest point.
 - **T2a** tumors are more than 7 cm but not larger than 10 cm.
 - **T2b** tumors are larger than 10 cm.
- T3 tumors extend beyond the kidney. They have grown into a major vein, like the renal vein or vena cava, or into fatty tissue around the kidney. The renal veins carry blood out of the kidneys then merge with the vena cava. The vena cava is a large vein that carries blood up to the heart. T3 tumors have not grown into the adrenal gland on top of the kidney or beyond Gerota's fascia.

- **T3a** tumors have grown into the fat in or around the kidney, or into the renal vein or muscles of the vein, or both.
- **T3b** tumors have grown into the vena cava below the diaphragm, a sheet of muscles under the ribs that helps a person to breathe.
- **T3c** tumors have grown into the vena cava above the diaphragm or into the wall of the vena cava.
- **T4** tumors have grown beyond Gerota's fascia and may extend into the adrenal gland on top of the kidney with the tumor.

N = Nodes

The N score describes how much the cancer has spread within nearby <u>lymph nodes</u>. Lymph nodes are small groups of special disease-fighting cells found all over the body. N scores for kidney cancer include:

- **N0** means the cancer hasn't spread to nearby lymph nodes.
- **N1** means the cancer has spread to nearby lymph nodes.

M = Metastasis

The M score tells you if the cancer has spread to distant sites. Kidney cancer tends to spread to the <u>lungs</u>, <u>liver</u>, brain, bones, and distant lymph nodes. M scores for kidney cancer include:

- **M0** means the cancer has not spread to distant sites.
- M1 means the cancer has spread to distant sites.

Kidney cancer stages

The kidney <u>cancer stages</u> are labeled by Roman numerals I to IV. Kidney cancers of the same stage tend to have a similar outcome (<u>prognosis</u>) and thus are treated in a similar way. In general, earlier cancer stages have better outcomes. But, doctors define cancer stages with information from thousands of patients, so a cancer stage gives an average outcome. It may not tell the outcome for one person. Some people will do better than expected. Others will do worse. Other factors not used for <u>cancer staging</u>, such as your general health, are also very important.

The kidney cancer stage groupings are described next. The stage groupings are defined by the TNM scores according to the AJCC staging system.

Stage I kidney cancer

T1, N0, M0: The tumor is only in the kidney and is not larger than 7 cm (T1). Cancer has not spread to nearby lymph nodes (N0) or to other tissues in the body nearby or far away (M0).

Stage II kidney cancer

T2, N0, M0: The tumor is larger than 7 cm but is still only in the kidney (T2). Cancer has not spread to nearby lymph nodes (N0) or to other tissues in the body nearby or far away (M0).

Stage III kidney cancer

T3, **N1** or **N0**, **M0**: The tumor extends beyond the kidney into certain nearby tissues (T3). Cancer may or may not have spread to nearby lymph nodes (N1 or N0), but it has not spread to distant sites (M0). The tumor has not grown into the adrenal gland or beyond Gerota's fascia.

T1 or T2, N1, M0: The tumor is only in the kidney (T1 or T2), but cancer has spread to nearby lymph nodes (N1). Cancer has not spread to other tissues in the body nearby or far away (M0). The tumor has not grown into the adrenal gland or beyond Gerota's fascia.

Stage IV kidney cancer

T4, N1 or N0, M0: The tumor has grown beyond Gerota's fascia and maybe into the adrenal gland (T4). Cancer may or may not have spread to nearby lymph nodes (N1 or N0). Cancer has not spread to distant sites in the body (M0).

T1-T4, N1 or N0, M1: The tumor is of any size and may or may not extend beyond the kidney (T1-T4). Cancer may or may not have spread to nearby lymph nodes (N1 or N0). But, cancer has spread to distant sites in the body (M1).

3 Cancer staging

Review

- Cancer staging is how doctors rate and describe the extent of cancer in the body.
- Kidney cancer is grouped into stages to help plan treatment.
- Cancer stages are defined by the growth and spread of the tumor.
- Doctors use certain tests, called staging tests, to find out how much the cancer has grown and spread.





Overview of cancer treatments

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4 Overview of cancer treatments

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There is more than one treatment for kidney cancer. The main types are described on the next pages. This information may help you use the *Treatment guide* in Part 5. It may also help you know what to expect during treatment. Not every person with kidney cancer will receive every treatment listed.

Surgery

<u>Surgery</u> is an operation to remove or repair a body part. Surgery is used as <u>primary treatment</u> for most <u>kidney</u> cancers. Primary treatment is the main treatment given to rid the body of cancer. Thus, the goal of surgery is to remove all of the cancer from your body. To do so, surgery will remove all or part of the kidney with the <u>tumor</u> and maybe other nearby tissues.

There is more than one type of surgery for kidney cancer. The type and extent of surgery you will have depends on many factors. This includes the tumor size, tumor location, and how much the cancer has spread. The main types of surgery used to treat kidney cancer are described next.

Partial nephrectomy

A <u>partial nephrectomy</u> is surgery that only removes the part of the kidney with the tumor. With this surgery, the healthy part of your kidney and the

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nearby tissues are left in your body. It is also called nephron-sparing or kidney-sparing surgery since it saves (spares) as much of your kidney as possible.

The kidney can still work (function) and do its job in the body after part of it has been removed. Thus, a benefit of partial nephrectomy is that it preserves <u>kidney function</u>. This surgery is ideal for patients who have or are at risk for poor kidney function. This includes patients who have only one kidney, limited kidney function, or tumors in both kidneys. But, this surgery is used for other patients as well.

Partial nephrectomy is often used for early-stage kidney cancer—when the tumor is small and only in the kidney. This surgery is the preferred treatment for very small tumors no more than 4 <u>cm</u> wide. It may also be used to treat small tumors up to 7 cm wide. For most small tumors, a partial nephrectomy can remove all the cancer with good long-term results. But, the <u>surgeon's</u> skill and experience is a key factor.

Partial nephrectomy is a complex surgery. It is more technically difficult than surgery that removes the whole kidney. A partial nephrectomy should only be done by an expert surgeon who does this type of surgery often. Careful patient selection, based on factors such as the tumor size and location, is also important. This surgery should only be done when the entire tumor can be safely removed, leaving the healthy part of the kidney intact.

Before the surgery, you will be asked to stop eating, drinking, and taking some medicines for a short period of time. If you smoke, it is important to stop. This surgery is done under <u>general anesthesia</u>—a controlled loss of wakefulness from drugs. There is more than one way to perform a partial nephrectomy. The surgery methods that may be used are described on page 33.

Risks and side effects of partial nephrectomy

With any type of surgery, there are some health risks and <u>side effects</u>. A side effect is an unhealthy or unpleasant condition caused by treatment. Some possible side effects of a partial nephrectomy include infections, bleeding, pain from the surgical cuts, and urine leaking from the kidney.

Radical nephrectomy

A <u>radical nephrectomy</u> is surgery that removes the whole kidney with the tumor and the fatty tissue around the kidney. This surgery may also remove the <u>adrenal gland</u> on top of the kidney and nearby <u>lymph</u> <u>nodes</u>. How much tissue is removed depends on the extent of the tumor.

Surgery to remove an adrenal gland is called an adrenalectomy. The attached adrenal gland may be removed if it looks abnormal on <u>imaging tests</u>. It may also be removed if the tumor is near the top part of the kidney where the adrenal gland sits.

Surgery to remove nearby lymph nodes is called a lymph node dissection. A lymph node dissection is not often done as part of a standard radical nephrectomy. Nearby lymph nodes may be removed if they look enlarged on imaging tests or feel enlarged during the <u>physical exam</u>.

If the tumor has grown into the <u>renal vein</u> and <u>vena</u> <u>cava</u>, then the <u>veins</u> may be cut open to remove all of the cancer. Your heart may need to be stopped for a short time for surgery on the vena cava. While the heart is stopped, a heart-lung machine is used to circulate blood in the body. This is a very difficult and complex procedure. It should only be done by a team of experts who have a lot of experience.

Radical nephrectomy is the standard treatment for patients with stage II or stage III kidney cancer. It is also the preferred treatment for tumors that extend into the vena cava. A radical nephrectomy can be complex and should only be done by an expert <u>surgeon</u> who does this type of <u>surgery</u> often.

Before the surgery, you will be asked to stop eating, drinking, and taking some medications for a short period of time. If you smoke, it is important to stop. This surgery is done under <u>general anesthesia</u>—a controlled loss of wakefulness from drugs. There is more than one way to perform a <u>radical nephrectomy</u>. The surgery methods that may be used are described on page 33.

Risks and side effects of radical nephrectomy

With any type of surgery, there are some health risks and <u>side effects</u>. A side effect is an unhealthy or unpleasant condition caused by treatment. Some possible side effects of a radical nephrectomy include infections, bleeding, pain from the surgical cuts, and reduced <u>kidney function</u>. Since the whole kidney is removed, this surgery also increases the risk for chronic kidney disease. Chronic kidney disease is when kidney function slowly gets worse over a long period of time.

Cytoreductive nephrectomy

A <u>cytoreductive nephrectomy</u> is surgery to remove the whole kidney with the <u>primary tumor</u> in the presence of <u>metastatic</u> disease. Metastatic means the cancer has spread to distant parts of the body and formed new <u>tumors</u>. New tumors that formed far from the primary tumor are called <u>metastases</u>. It isn't possible to remove all of the cancer from your body with surgery when there are many metastases. But, removing at least some of the cancer can still be helpful for some patients.

The goal of cytoreductive surgery is to reduce the amount of cancer in your body. This surgery may be used for patients who have many metastases if the primary tumor can be completely removed. Some patients may benefit from having a cytoreductive nephrectomy before treatment with drugs. Removing the primary tumor may improve how well other treatments work against the remaining cancer and metastases.

Metastasectomy

A <u>metastasectomy</u> is surgery to remove metastases tumors that formed far from the first tumor. This surgery may be used when the primary tumor can be completely removed and there is only one <u>metastasis</u>. But, not all metastases can be removed by surgery. The location is a key factor. This approach works best for metastases in the brain, bone, or <u>lung</u>.

A metastasectomy may be done at the same time as surgery to remove the primary tumor. Or, it may be done during a separate operation. The amount of time needed for the surgery and recovery depends on many factors. Some factors include the size and location of the metastasis.





Surgery Methods

A <u>nephrectomy</u>—partial or radical—can be done with one of two surgery methods. The first method is called <u>open surgery</u>. The second method is <u>laparoscopic surgery</u>, also called minimally invasive surgery.

Open surgery

Open surgery removes tissue through one large surgical cut below your ribs. The cut may be made in your belly (<u>abdomen</u>), side, or lower back. The large cut lets your doctor directly view and access the tumor in your kidney to remove it. Open surgery may take several hours or longer. After the surgery, you will need to stay in the hospital for several days or maybe longer to recover. You may have some pain in your side for a few weeks or months after the surgery.

Laparoscopic surgery

Laparoscopic surgery uses a few small incisions instead of one large one. Small tools are inserted through each of the cuts to perform the surgery. One of the tools, called a laparoscope, is a long tube with a video camera at the end. The camera lets your doctor see your kidney and other tissues inside your abdomen. The other tools are used to remove all or part of the kidney with the cancer. Laparoscopic surgery can also be done using robotic arms to control the surgical tools. This is called robot-assisted laparoscopic surgery.

Laparoscopic surgery may take a couple of hours or longer to perform. After the surgery, you will need to stay in the hospital, usually for about 1 to 2 days, to recover. Laparoscopic surgery often results in less pain, a shorter hospital stay, and shorter recovery time.

Active surveillance

<u>Active surveillance</u> consists of testing on a regular basis to watch for <u>tumor</u> growth so that treatment can be started later, if needed, instead of right away. This may be used for certain patients with a very small tumor (3 <u>cm</u> or smaller) that is only in the <u>kidney</u>.

Active surveillance may be an option for patients who are elderly or have other serious health problems. Such patients may not be healthy enough for <u>surgery</u> or other cancer treatments. Also, the cancer may not pose the greatest risk to their health.

All cancer treatments have some health risks and <u>side effects</u>. Older age and having other health problems increases the risk of severe side effects and complications. For these patients, the potential risks of treatment may be more dangerous than the cancer.

During active surveillance, your doctor will plan a testing schedule just for you. This may include <u>imaging tests</u>, such as <u>CT scans</u>, <u>MRI scans</u>, and <u>ultrasound</u>, every few months. But, these and other tests may be given more or less often. The tests and schedule will be based on a number of factors specific to you. Such factors include your age, health, personal wishes, and the size, appearance, and <u>growth rate</u> of the tumor.

Thermal ablation

<u>Thermal ablation</u> is a type of treatment that uses extreme cold or extreme heat to destroy cancer cells. It can destroy small tumors with little harm to nearby tissue. Thermal ablation may be used in certain cases when surgery is not a good option. Surgery may not be a good option for patients who are elderly or have other serious health problems. Thermal ablation works best for very small tumors—4 cm or smaller.

There are two main ways to "ablate" a kidney tumor. Cryoablation kills cancer cells by freezing them with a very cold gas such as liquid nitrogen. Radiofrequency ablation kills cancer cells by heating or "cooking" them with high-energy radio waves.

Both types of thermal ablation use a special needle called a probe—that is inserted into the tumor. With cryoablation, the probe releases cold gases to freeze the tumor and destroy it. With radiofrequency ablation, the probe emits radio waves to heat the tumor and destroy it.

The probe can be inserted through the skin and guided into place with CT scans, ultrasound, or other imaging tests. The probe can also be inserted and guided into place during <u>laparoscopic surgery</u>. Imaging tests are also used to monitor the tumor during treatment to make sure the whole tumor is destroyed. The probe will be removed when treatment is done.

Thermal ablation may be done with <u>local anesthesia</u> or <u>general anesthesia</u>. You may also be given a sedative—medicine to help you relax. Possible side effects of thermal ablation include bleeding and damage to the kidney or nearby tissues.
Targeted therapy

Targeted therapy is treatment with drugs that target a specific or unique feature of cancer cells. These drugs stop the action of molecules that help cancer cells grow. Targeted therapy is used to treat kidney cancer that has spread to other parts of the body. In the past 10 years, 7 targeted therapy drugs have been approved to treat advanced kidney cancer.

Targeted therapy drugs treat kidney cancer in a few different ways. Some target and block the signals that cause new blood vessels to form. Others block the signals that tell the kidney cancer cells to grow and make more cancer cells. Often, these drugs have more than one target. The different types of targeted therapy are named based on what they target.

Bevacizumab

Bevacizumab is a type of targeted therapy called an angiogenesis inhibitor. Angiogenesis is the growth of new blood vessels. Like normal cells, cancer cells need the food and oxygen in blood to grow. Kidney cancer cells are very good at getting new blood vessels to grow into the tumor to "feed" it. The cancer cells release high amounts of a protein called VEGF (vascular endothelial growth factor). VEGF binds to receptors on cells that form blood vessels. The binding sets off signals in the cells for new blood vessels to grow into the tumor.

Bevacizumab attaches to VEGF, which stops VEGF from binding to receptors on cells. This stops VEGF from sending signals for new blood vessels to form. Thus, bevacizumab slows or stops blood vessel growth and "starves" the tumor.



Bevacizumab is a liquid that is given by infusion. Infusion is a method of giving drugs slowly through a needle into a vein. It takes about 90 minutes to get the first dose and 30 minutes for later doses. It may be given alone or with interferon alfa, an immunotherapy drug (described on page 37).

Although bevacizumab targets tumor blood vessels, it can also affect normal blood vessels. This can result in side effects. A side effect is an unhealthy or unpleasant physical or emotional condition caused by treatment. Some side effects can be very serious while others can be unpleasant but not serious. Some common side effects of bevacizumab are high blood pressure, headache, nosebleeds, runny nose, taste changes, skin rash, dry skin, and back pain. Rare but serious side effects include stroke, heart attack, kidney damage, holes in the intestine, and bleeding within the body.

Sorafenib, sunitinib, pazopanib, and axitinib

Sorafenib, sunitinib, pazopanib, and axitinib are a type of targeted therapy called TKIs (tyrosine kinase inhibitors). Tyrosine kinases are proteins in cells that are important for many cell functions. This includes sending signals in cells for cell growth, survival, and death.

TKIs bind to tyrosine kinases in cells to block the signals that help kidney cancer grow and spread. There are many different types of tyrosine kinases. Some tyrosine kinases send signals that tell cancer cells to grow and divide to make new cells. Some tyrosine kinases send signals that tell new blood vessels to grow into the tumor.

Each TKI works in a slightly different way. Some TKIs target and block more than one type of tyrosine kinase. These are called multi-kinase inhibitors. Sorafenib, sunitinib, axitinib, and pazopanib are multikinase inhibitors. In kidney cancer, the main purpose of these drugs is to block the signals for blood vessel growth. Blocking these signals may slow or stop cancer growth and spread. It may also cause tumors to shrink.

Axitinib targets and blocks the signals that cause new blood vessels to grow into the tumor. By blocking these signals, axitinib "starves" the tumor. This may slow tumor growth or cause the tumor to shrink.

All four TKIs come as a pill that is swallowed. Sorafenib and axitinib are taken twice a day. Sunitinib and pazopanib are taken once a day.

Each of these drugs can cause side effects. Some side effects are caused only by one or a few of the TKIs. Other side effects are caused by all four TKIs, but may differ in how likely they are to occur. Some common side effects of TKIs used for kidney cancer include: skin rash, hand-foot syndrome, hair thinning, feeling tired or weak, abnormal bleeding,

change in skin or hair color, high blood pressure, diarrhea, nausea, vomiting, upset stomach, pain in belly area, mouth sores, taste changes, not feeling hungry, weight loss, cough, shortness of breath, voice changes or hoarseness, abnormal liver function tests, and pain or swelling in the arms or legs.

Everolimus and temsirolimus

Everolimus and temsirolimus are a type of targeted therapy called <u>mTOR inhibitors</u>. <u>mTOR</u> is a protein in cells that is important for cell growth and survival. mTOR moves chemicals, called phosphates, from one molecule to another. The phosphate "turns on" the second molecule. By transferring phosphates, mTOR sends signals that tell cells to grow and divide.

Everolimus and temsirolimus block mTOR from transferring the phosphate. This stops the cell from receiving signals to grow and divide. By blocking the action of mTOR, these drugs slow tumor growth.

Everolimus comes as a pill that is swallowed. It is taken once a day. Some of the most common side effects of this drug are: feeling tired or weak, cough, diarrhea, mouth sores, nausea, not feeling hungry, increased risk of infections, skin rash, and swelling from fluid buildup. A less common but serious side effect is lung damage. This can cause shortness of breath or other problems.

Temsirolimus is given by infusion once a week. The infusion takes about 30 to 60 minutes. Some people have an <u>allergic reaction</u> to the infusion. Symptoms of an allergic reaction include flushing, chest pain, and trouble breathing. Before the infusion, you will likely be given medicine to reduce the risk of allergic reaction. Some other common side effects of this drug are: nausea, not feeling hungry, mouth sores, feeling tired or weak, skin rash, and swelling from fluid buildup.



Erlotinib

Erlotinib is a type of targeted therapy called an <u>EGFR</u> (epidermal growth factor receptor) <u>inhibitor</u>. <u>EGFR</u> is a protein on the surface of cells that is involved in cell growth. It is found on both normal cells and cancer cells. Molecules outside of cells can attach to EGFR. When this happens, EGFR sends signals into the cell that tell the cell to grow.

Erlotinib blocks the signals from EGFR that tell cancer cells to grow. This slows or stops new cancer cells from being made. Erlotinib is given as a pill that is swallowed. Common side effects of this drug include skin rash, diarrhea, nausea, feeling tired, and not feeling hungry.

"It is very important for the patient and/ or caregiver to communicate with the medical team about any side effect and its severity. It may be a good idea to record this information in a journal to take to the doctor visit as well as to take notes during the visit for future reference."

- Patient Advocate Kidney Cancer Association

Immunotherapy

The <u>immune system</u> is the body's natural defense against infection and disease. The immune system includes many chemicals and proteins. These chemicals and proteins are made naturally in your body.

Immunotherapy is treatment that increases the activity of your immune system. By doing so, it improves your body's ability to find and destroy cancer cells. Immunotherapy is used to treat kidney cancer that has spread to other parts of the body. The immunotherapy drugs used for <u>advanced kidney</u> cancer are interferon alfa and IL-2 (interleukin-2).

Interferon alfa and IL-2 are proteins called <u>cytokines</u> that stimulate immune cells. Cytokines are made naturally in the body as part of the immune system. But, these proteins can also be made in a lab to use as treatment for cancer. Thus, interferon alfa and IL-2 are also called <u>cytokine therapy</u>.

Very high doses of IL-2 are used to treat kidney cancer. This can cause severe and sometimes lifethreatening side effects. Some of the most common side effects of IL-2 are: low blood pressure, abnormal kidney and <u>liver function tests</u>, confusion, shortness of breath, chills, nausea, vomiting, diarrhea, skin rash, feeling tired or weak, and low urine output. Rare, but serious side effects include breathing problems, low blood pressure, kidney damage, fast heartbeat, coma, bleeding, and infections.

Due to the serious risks, IL-2 is only used for certain patients who are healthy enough to handle the side effects. To consider this option, you must have good overall health. Your kidneys and other organs must also be working well. High-dose IL-2 should only be given at a center that has expertise and experience with this treatment. IL-2 is given as an <u>infusion</u> that takes about 15 minutes. You will likely need to stay in the hospital for several days during treatment. Interferon alfa is not used alone to treat kidney cancer. It is always given along with bevacizumab, a <u>targeted therapy</u> drug (described on page 35). Interferon alfa is a liquid that is injected under the skin with a needle. It is often given three times a week.

Interferon alfa also has <u>side effects</u>, but not as severe as <u>IL-2</u>. Side effects of interferon alfa often include flu-like symptoms such as fever, chills, feeling tired or weak, headache, and body aches. Other common side effects are diarrhea, nausea, vomiting, not feeling hungry, and depression.

Supportive care

<u>Supportive care</u> is treatment given to relieve <u>symptoms</u> of the cancer and side effects of cancer treatment. It doesn't treat the cancer itself. The goal of supportive care is to improve quality of life and relieve any discomfort you may have.

Supportive care is given at any stage of cancer, but is often the main type of care when the cancer is advanced. When used for <u>advanced cancers</u>, supportive care is often called <u>palliative care</u>.

Supportive care can address many needs. Some examples include treatment for physical and emotional symptoms, help with treatment decisions, and coordination of care between health care providers. Talk with your treatment team to plan the best supportive care for you. A few key supportive care options for patients with kidney cancer are described next.

Radiation therapy

<u>Radiation therapy</u> uses a beam of high-energy rays to kill cancer cells. Radiation therapy is not used as a standard or <u>primary treatment</u> for kidney cancer. Instead, it may be used to relieve symptoms caused by kidney cancer that has spread (metastasized) to distant sites in the body.

Radiation therapy is often given using a machine outside the body. This method is called <u>EBRT</u> (external beam radiation therapy). EBRT may be used to ease pain caused by <u>bone metastases</u>—cancer that has spread to the bones. It may also be used for <u>brain</u> <u>metastases</u>—cancer that has spread to the brain.

<u>Stereotactic radiosurgery</u> is a type of EBRT that may be used for a small or single <u>metastasis</u> in the brain. Stereotactic radiosurgery delivers a high dose of radiation to a very specific, small area of the body. Whole brain irradiation may be used for large or many <u>metastases</u> in the brain.

Drugs for bone health

When kidney cancer spreads to distant sites, it may spread to your bones. Your bones are at an increased risk for injury and disease when kidney cancer spreads to them. Such problems include bone <u>fractures</u>, bone pain, and squeezing (compression) of the <u>spinal cord</u>. High levels of <u>calcium</u> in the blood, called hypercalcemia, may also occur.

Drugs such as zoledronic acid (Zometa) and denosumab (Xgeva) may be given to treat bone problems. These drugs can help relieve bone pain and reduce the risk of other bone problems. They work by slowing or stopping bone breakdown. They also help increase bone thickness.

However, these drugs may cause damage to the jaw bone—a condition called osteonecrosis. Be sure to ask your doctor about this risk and other possible side effects. It is also recommended that you take these drugs with calcium and vitamin D.

Surgery

Even if all the cancer can't be removed, <u>surgery</u> may be used to help with symptoms caused by the cancer. This is called <u>palliative surgery</u>. Symptoms may be from the <u>primary tumor</u> or cancer that has spread to other body parts.

As a kidney <u>tumor</u> grows larger, it can cause severe symptoms such as pain and blood in the urine. Surgery to remove the kidney may be used to relieve these symptoms. This surgery is called a palliative nephrectomy.

Palliative surgery may be used to treat problems caused by cancer that has spread to your bones. Such problems may include bone pain, bone fractures, and spinal cord compression.

Clinical trials

New tests and treatments aren't offered to the public as soon as they're made. They need to be studied first. New uses of tests and treatments also need to be studied.

A <u>clinical trial</u> is a type of research that studies a test or treatment. Clinical trials study how safe and helpful tests and treatments are. When found to be safe and helpful, they may become tomorrow's standard of care. Because of clinical trials, the tests and treatments in this book are now widely used to help patients.

Tests and treatments go through a series of clinical trials to make sure they're safe and work. Without clinical trials, there's no way to know if a test or treatment is safe or helpful. Clinical trials are done in a series of steps, called phases. The four phases of clinical trials are described next using the example of a new drug treatment:



Phase I trials aim to find the best dose and way to give a new drug with the fewest side effects. If a drug is found to be safe, it will be studied in a phase II trial.

Phase II trials assess if a drug works for a specific type of cancer. They are done in larger groups of patients with the same type of cancer.

Phase III trials compare a new drug to the standard treatment. These are randomized, meaning patients are put in a treatment group by chance.

Phase IV trials test new drugs approved by the <u>FDA</u> (U.S. Food and **D**rug **A**dministration) to learn about short-term side effects, long-term side effects, and safety. They involve many patients with different types of cancer.

Joining a clinical trial has benefits. First, you'll have access to the most current cancer care. Second, you will receive the best management of care. Third, the results of your treatment will be carefully tracked. Fourth, you may help other patients with cancer. <u>Clinical trials</u> have risks, too. Like any test or treatment, there may be <u>side effects</u>. Also, new tests or treatments may not work better than current treatments. Another downside may be that paperwork or more trips to the hospital may be needed.

To join a clinical trial, you must meet the conditions of the study. Patients in a clinical trial often have a similar cancer type and general health. This helps ensure that any response is because of the treatment and not because of differences between patients. You also must review and sign a paper called an informed consent form to join a clinical trial. This form describes the study in detail, including the risks and benefits.

Ask your treatment team if there is an open clinical trial that you can join. There may be clinical trials where you're getting treatment or at other treatment centers nearby.

Review

- Primary treatment is the main treatment used to rid the body of cancer.
- Surgery is often used as primary treatment for kidney cancer.
- A partial nephrectomy is surgery that only removes the part of the kidney with the tumor.
- A radical nephrectomy removes the whole kidney with the tumor, and possibly other nearby tissues like the adrenal gland and lymph nodes.

- Targeted therapy is treatment with drugs that target a specific or unique feature of cancer cells.
- Immunotherapy, also called cytokine therapy, helps the immune system fight off cancer cells.
- Supportive care is treatment given to relieve symptoms of the cancer and side effects of cancer treatment.
- A clinical trial studies a test or treatment to see how safe it is and how well it works.



5 Treatment guide



5 Treatment guide

44 5.1 Stage I kidney cancer

Presents the recommended treatments and follow-up for tumors that are very small and only in the kidney.

50 5.2 Stages II and III kidney cancer

Presents the recommended treatments and follow-up for tumors that are a little larger, but are still only in the kidney or certain nearby tissues.

52 5.3 Stage IV and relapsed kidney cancer

Presents the recommended treatments and follow-up for kidney cancer that has grown beyond the kidney, spread to distant sites in the body, or come back after treatment.







Part 5 is a guide through the treatment options for patients with kidney cancer. It shows which tests and treatments are recommended under which conditions. This information is taken from the treatment guidelines written by NCCN experts for kidney cancer doctors.

The treatment options are organized by cancer stage. Much effort has been made to make this guide easy to read. Charts list the treatment options and map the steps through the treatment process. The text along with each chart explains the information presented in the chart. Some words that you may not know are defined on the page or in the *Dictionary* on page 72. More information about the tests and treatments in this guide can be found in Parts 2 through 4.

5.1 Stage I kidney cancer

Chart 5.1.1 Primary treatment

Stage and tumor size	Primary treatment
Stage I (T1a) Tumor is 4 cm or smaller	 Partial nephrectomy (preferred), Radical nephrectomy, Active surveillance, or Thermal ablation
Stage I (T1b) Tumor is 4.1 cm to 7 cm	Partial nephrectomy, orRadical nephrectomy

Chart 5.1.1 shows the <u>primary treatment</u> options for stage I kidney cancer—when the <u>tumor</u> is 7 <u>cm</u> or smaller and cancer is only in the <u>kidney</u>. Primary treatment is the main treatment used to rid the body of cancer. <u>Surgery</u> is the most common primary treatment for stage I kidney cancer. But, there is more than one type of surgery. And, you may have a few other options to choose from.

The tumor size is a key factor that affects your primary treatment options. Stage I is divided into two smaller groups, based on the size of the tumor. T1a tumors are 4 cm or smaller. T1b tumors are more than 4 cm but not larger than 7 cm.

Primary treatment

For stage I (T1a), there are four primary treatment options to choose from. The preferred option is a <u>partial nephrectomy</u>. A partial nephrectomy is surgery that only removes the part of the kidney with the

tumor. (See page 30 for more details.) For very small tumors, all the cancer can often be removed without taking out the whole kidney. When only part of the kidney is removed, more <u>kidney function</u> is preserved. Thus, this surgery is ideal for patients who have only one kidney, poor kidney function, or tumors in both kidneys.

But, sometimes a partial nephrectomy can't be done. This may be because the tumor is near the middle of the kidney or very close to major <u>veins</u>. If a partial nephrectomy can't be done, then another option is to have a <u>radical nephrectomy</u>. A radical nephrectomy is surgery that removes the whole kidney with the tumor. This surgery may also remove the attached <u>adrenal</u> <u>gland</u> and nearby <u>lymph nodes</u>. How much tissue is removed depends on the extent of the tumor. (See page 31 for details.)

Surgery may not be a good treatment option for everyone. Your doctor will look at many factors to decide if you are healthy enough to have surgery. Such factors include your age, general health, other current health problems, and how well your <u>lungs</u>, heart, and other organs are working. Based on these and other factors, your doctor may decide that surgery isn't a good option for you.

Besides surgery, there are two other primary treatment options for very small tumors. One option is <u>active surveillance</u>. Active surveillance consists of testing on a regular basis to watch for tumor growth. Treatment may be started later if needed, based on the results of tests, instead of right away. This may be a good option if you are elderly or have other serious health conditions. Both are factors that increase the risk of serious problems during and after surgery.

<u>Thermal ablation</u> is another option for patients who aren't healthy enough for surgery. Thermal ablation uses extreme heat or extreme cold to destroy small tumors. This type of treatment causes very little damage to nearby tissues. It is much less invasive and has fewer <u>side effects</u> than surgery. (Read more about thermal ablation on page 34.)

For stage I (T1b), surgery is used as primary treatment. You may have a partial or radical nephrectomy, as described above. Your doctor will consider a number of factors to help decide which type of surgery is best for you. Such factors include your general health, how well your kidneys are working, and the size, location, and extent of the tumor. NCCN experts recommend that a partial nephrectomy should always be used when possible. But, sometimes a partial nephrectomy can't be done. This may be because the tumor is larger in size, near the middle of the kidney, or very close to major veins. In such cases, a radical nephrectomy may be the best option.

Next steps: 🔵

After primary treatment for stage I kidney cancer, you will begin followup testing. For recommended testing during active surveillance, see Chart 5.1.2 on page 46. If you had a partial nephrectomy, a radical nephrectomy, or thermal ablation, see Chart 5.1.3 on page 48 for recommended followup tests.

Chart 5.1.2	Testing	during	active	surveillance
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Tests	Schedule
Medical history and physical exam	Every 6 months for 2 years, thenOnce a year for up to 5 years after diagnosis
Blood chemistry panel and other blood tests	Every 6 months for 2 years, thenOnce a year for up to 5 years after diagnosis
Imaging tests of the abdomen	 CT or MRI within 6 months of starting surveillance, then CT, MRI, or ultrasound at least once a year thereafter
Imaging tests of the chest	CT or x-ray once a year, if cancer confirmed by biopsy
Imaging tests of the pelvis	As needed
CT or MRI of the head or MRI of the spine	As needed
Bone scan	As needed

Chart 5.1.2 shows the tests that are recommended during <u>active surveillance</u> for <u>tumors</u> 4 <u>cm</u> or smaller. Active surveillance consists of frequent testing on an ongoing basis to watch for tumor growth. Many of the tests used for <u>diagnosis</u> and <u>cancer staging</u> are repeated during active surveillance. (See Part 2 on page 14 and Part 3 on page 24 for more details about each test in the chart.)

But, no single follow-up plan is right for all patients. The tests and schedule should be tailored for each patient. You may need more or less frequent testing than someone else. The timing and duration of followup testing should be based on factors specific to you. Such factors include your age, general health, the tumor size, and the tumor location. You will have a number of different tests to monitor the cancer so that treatment can be started when, or if, needed. The <u>medical history</u>, <u>physical exam</u>, and blood tests will tell your doctor about your overall health. <u>Blood chemistry tests</u> will also show if your organs, such as your <u>liver</u> and <u>kidneys</u>, are working well. (See page 18 for more details on blood tests.)

<u>Imaging tests</u> of your <u>abdomen</u> are used to check if and how much the tumor grows over time. The first few imaging tests will help your doctor assess the <u>growth rate</u>. The growth rate is a measure of how much the cancer grows over a set period of time. Ongoing imaging tests are used to watch the growth rate to see if anything changes. Imaging tests of your chest are used to check if the cancer has spread to your <u>lungs</u>. Imaging tests of your <u>pelvis</u>, head, <u>spine</u>, or bones are not recommended as standard <u>follow-up tests</u> for all patients. These tests may be done as needed such as to check out certain signs or <u>symptoms</u>. Imaging tests of your head or spine may be done to show if cancer has spread to your brain. Some symptoms of cancer in the brain are chronic headaches, seizures, loss of balance, and weakness on one side of the body. If you have bone pain or high levels of <u>ALP</u> in your blood, then a <u>bone scan</u> may be done to show if cancer has spread to your bones. See page 16 and page 24 for more details about how and why imaging tests are given.

How often tests are done may change over time. This may be due to changes in the tumor growth rate or other factors. If the tumor grows more slowly or not at all, then tests may be done less often. If the tumor grows faster, then tests may be done more often. If the tumor keeps growing larger or faster, then treatment may be needed. But, these decisions must be made on an individual basis.

Next steps: 🔵

If your doctor decides that treatment is needed, see Chart 5.1.1 on page 44 for recommended treatments for stage I kidney cancer.

Chart 5.1.3 Follow-up testing after treatment

Tests	Schedule
Medical history and physical exam	Every 6 months for 2 years, thenOnce a year for up to 5 years after diagnosis or surgery
Blood chemistry panel and other blood tests	 Every 6 months for 2 years, then Once a year for up to 5 years after diagnosis or surgery
Imaging tests of the abdomen	 After partial or radical nephrectomy Baseline CT, MRI, or ultrasound within 3 to 12 months after surgery, then If no signs of cancer at baseline: After partial nephrectomy, possible testing once a year for 3 years based on the risk of recurrence After radical nephrectomy, possible testing beyond 12 months as doctor sees fit After thermal ablation CT or MRI at 3 and 6 months after ablation, then CT, MRI, or ultrasound at least once a year for 5 years
Imaging tests of the chest	 After partial or radical nephrectomy CT or x-ray once a year for 3 years, then As needed After thermal ablation CT or x-ray once a year for 5 years
Repeat biopsy	After thermal ablationAs needed based on results of imaging tests
Imaging tests of the pelvis	As needed
CT or MRI of the head or MRI of the spine	As needed
Bone scan	As needed

Chart 5.1.3 shows the <u>follow-up tests</u> that are recommended after treatment for stage I kidney cancer. Doctors use follow-up tests to monitor your health and to look for signs of cancer return or spread (<u>metastasis</u>)

after treatment. The return of cancer after treatment is called a <u>relapse</u> or <u>recurrence</u>. Follow-up tests are also used to check your <u>kidney function</u> and watch for treatment <u>side effects</u>. Many of the tests used for

<u>diagnosis</u> and <u>staging</u> are repeated during follow-up. (See Part 2 on page 14 and Part 3 on page 24 for more details about each test.)

No single follow-up plan is right for all patients. Your doctor will adjust the follow-up plan based on a number of factors specific to you and the <u>tumor</u>. Some key factors are the type of treatment you had, the size and extent of the tumor, and your overall health. You may need more or less frequent testing than someone else. The timing and duration of follow-up testing should be based on the chance (risk) of recurrence and other factors specific to you. Follow-up testing may be extended beyond five years as your doctor sees fit.

Follow-up tests

Regular <u>medical history</u> check-ups, <u>physical exams</u>, and blood tests will tell your doctor about your general health. <u>Blood chemistry tests</u> will also show if your organs, such as your <u>liver</u> and <u>kidneys</u>, are working well. Abnormal results may be a sign that the cancer has come back or spread to other parts of your body.

<u>Imaging tests</u> of your <u>abdomen</u> are used to check for signs of <u>local recurrence</u>. A local recurrence is when cancer comes back in or near the same place as the <u>primary tumor</u>. A baseline imaging test of your abdomen should be done within 3 to 12 months after a partial or <u>radical nephrectomy</u>. A <u>baseline test</u> is a starting point to which future tests are compared.

If there are no signs of cancer at <u>baseline</u>, the next follow-up tests may be done less often. After a <u>partial</u> <u>nephrectomy</u>, you may have tests once a year for 3 years. How often and how long follow-up tests are needed is based on the risk of recurrence. Larger tumors have a slightly higher risk of recurrence than smaller tumors. Thus, more frequent follow-up may be needed. After a radical nephrectomy, your doctor will decide how often follow-up testing is needed. Imaging tests of your abdomen are recommended more often and for a longer period of time after <u>thermal</u> <u>ablation</u> than <u>surgery</u>. This is because there is a slightly higher chance of <u>local recurrence</u> after thermal ablation than surgery. The initial imaging tests should be done with and without <u>contrast</u> to make the pictures clearer. If the imaging tests show signs of tumor growth, spread, or return, then a <u>biopsy</u> is recommended.

An <u>x-ray</u> or <u>CT scan</u> of your chest will show if cancer has spread to your <u>lungs</u>. Imaging tests of your chest are important since the lungs are the most common site of <u>distant recurrence</u>. Imaging tests of your chest should be done once a year for the first few years after treatment. After that, they may be used as needed to check out signs or <u>symptoms</u> of cancer in your lungs.

Imaging tests of your <u>pelvis</u>, head, <u>spine</u>, and bones are not recommended as standard follow-up tests for all patients. These tests may be done as needed such as if there are signs or symptoms of cancer spread. A CT or <u>MRI scan</u> of your head may be done to show if cancer has spread to your brain. Some symptoms of cancer in the brain are chronic headaches, seizures, loss of balance, and weakness on one side of the body. If you have bone pain or high levels of <u>ALP</u> in your blood, then a <u>bone scan</u> may be done to show if cancer has spread to your bones. (See page 25 for more details about these tests.)

Next steps: 🔵

If follow-up tests show that cancer has come back, see Chart 5.3.2 on page 54 for recommended treatments for relapsed kidney cancer.

5.2 Stages II and III kidney cancer

Chart 5.2 Primary treatment and follow-up tests

Primary treatment	Follow-up testing schedule
Radical nephrectomy	 Medical history and physical exam Every 3 to 6 months for 3 years, then Once a year for up to 5 years after surgery, then As needed
	 Blood chemistry panel and other blood tests Every 6 months for 2 years, then Once a year for up to 5 years after surgery, then As needed
	 Imaging tests of the abdomen Baseline CT or MRI within 3 to 6 months after surgery, then CT, MRI, or ultrasound every 3 to 6 months for at least 3 years, then Once a year for up to 5 years, then As needed, and Site-specific imaging tests as needed to check out symptoms
	 Imaging tests of the chest Baseline CT within 3 to 6 months after surgery, then CT or x-ray every 3 to 6 months for at least 3 years, then Once a year for up to 5 years, then As needed based on the patient and risk of recurrence
	Imaging tests of the pelvis as needed
	CT or MRI of the head or MRI of the spine as needed
	Bone scan as needed

Chart 5.2 shows the <u>primary treatment</u> and <u>follow-up</u> <u>tests</u> that are recommended for patients with stage II or stage III kidney cancer. Stage II kidney cancer is when the <u>tumor</u> is larger than 7 <u>cm</u> but is still only in the <u>kidney</u>. Stage III kidney cancer is when the tumor has grown into fatty tissue in or around the kidney, nearby <u>veins</u>, and/or nearby <u>lymph nodes</u>. (See page 27 for more details about each <u>cancer stage</u>.)

Primary treatment

Primary treatment is the main treatment used to rid the body of cancer. A <u>radical nephrectomy</u> is the preferred and only option recommended as primary treatment for stage II and III kidney cancers. A radical nephrectomy is <u>surgery</u> that removes the whole kidney with the tumor. The attached <u>adrenal gland</u>, nearby lymph nodes, and other tissues may also be removed. How much tissue is removed depends on the extent of the tumor. (See page 31 for more details.)

Follow-up tests

After primary treatment, you will begin follow-up testing. Follow-up tests are used to monitor your health after treatment. Doctors use follow-up tests to look for signs of cancer return or spread (metastasis) after treatment. The return of cancer after treatment is called a <u>relapse</u> or <u>recurrence</u>. Follow-up tests are also used to check that your remaining kidney and other organs are working well. Many of the tests used for <u>diagnosis</u> and <u>staging</u> are repeated during follow-up. (See Part 2 on page 14 and Part 3 on page 24 for more details about each test.)

No single follow-up plan is right for all patients. Your doctor will adjust the follow-up plan based on a number of factors specific to you and the tumor. Some key factors are the type of treatment you had, the size and extent of the tumor, and your overall health. You may need more or less frequent testing than someone else. The timing and duration of follow-up testing should be based on the risk of recurrence and other factors specific to you. Follow-up testing may be extended beyond 5 years as your doctor sees fit.

Regular <u>medical history</u> check-ups, <u>physical exams</u>, and blood tests will tell your doctor about your general health. <u>Blood chemistry tests</u> will show if your organs, such as your <u>liver</u> and kidneys, are working well. Monitoring the health of your remaining kidney is very important. Poor <u>kidney function</u> can increase the risk of other health problems. Abnormal results of blood chemistry tests may be a sign of organ damage. Abnormal results may also be a sign that the cancer has come back or spread to other parts of your body.

<u>Imaging tests</u> of your <u>abdomen</u> are used to check for signs of <u>local recurrence</u>. A local recurrence is when cancer comes back in or near the same place as the <u>primary tumor</u>. A baseline <u>CT</u> or <u>MRI scan</u> of your abdomen should be done within 3 to 6 months after surgery. A <u>baseline test</u> is a starting point to which future tests are compared. Imaging tests of your abdomen are recommended on a regular basis for up to 5 years. After 5 years, further testing may be done as needed. Imaging tests may also be done to check out signs or <u>symptoms</u> in a certain part of your abdomen. This is called site-specific imaging.

Imaging tests of your chest are important since the <u>lungs</u> are the most common site of <u>distant recurrence</u>. An <u>x-ray</u> or CT scan of your chest will show if cancer has spread to your lungs. A baseline CT scan of your chest is recommended within 3 to 6 months after surgery. After the baseline test, an x-ray or CT scan should be done on a frequent basis for the next few years. After 5 years, imaging tests may be done as needed based on the risk of recurrence and other factors specific to you. The cancer stage and tumor size are two key factors that affect the risk of recurrence.

Imaging tests of your <u>pelvis</u>, head, <u>spine</u>, and bones are not recommended as standard follow-up tests for all patients. These tests may be done as needed such as if there are signs or symptoms of cancer spread. A CT or MRI scan of your head may be done to show if cancer has spread to your brain. Some symptoms of cancer in the brain are chronic headaches, seizures, loss of balance, and weakness on one side of the body. If you have bone pain or high levels of <u>ALP</u> in your blood, then a <u>bone scan</u> may be done to show if cancer has spread to your bones. (See page 25 for more details about these tests.)

Next steps: 🔵

If follow-up tests show that cancer has come back after treatment, see Chart 5.3.2 on page 54 for recommended treatments for relapsed kidney cancer.

5.3 Stage IV and relapsed kidney cancer

Chart 5.3.1 Primary treatment

Test results	Primary treatment options
Primary tumor can likely be removed by surgery + Only one metastasis	Nephrectomy + metastasectomy
Primary tumor can likely be removed by surgery + Many metastases	Cytoreductive nephrectomy prior to treatment with drugs
Primary tumor can't be removed by surgery	Treatment with drugs

Chart 5.3.1 shows the <u>primary treatment</u> options that are recommended for stage IV kidney cancer. Stage IV kidney cancer is when the <u>tumor</u> has grown outside the <u>kidney</u> and <u>Gerota's fascia</u>, cancer has spread to a distant site, or both. (See page 27 for more details about each kidney <u>cancer stage</u>.)

Primary treatment is the main treatment used to rid the body of cancer. There are three main treatment options to choose from. Which primary treatment option is best for you depends on a number of factors. One important factor is the size and extent of the <u>primary tumor</u>. Another important factor is the number of <u>metastases</u>. Metastases are tumors that formed in parts of the body far from the first <u>tumor</u>.

Your doctor will assess the size and extent of the primary tumor to decide if it can likely be removed by <u>surgery</u>. If the entire primary tumor can't be removed by surgery, then treatment with drugs is recommended. If the entire primary tumor can be removed by surgery, then the treatment options depend on the number of metastases.

If there is only one metastasis, then surgery to remove the primary tumor and the <u>metastasis</u> is recommended. A <u>nephrectomy</u> is surgery to remove the whole kidney with the tumor. A <u>metastasectomy</u> is surgery to remove the metastasis. These surgeries may be done at the same time or during different operations. Other nearby tissues may also be removed during the nephrectomy. How much tissue is removed depends on the extent of the primary tumor. (See page 31 and page 32 for details about these surgeries.)

But, this may not be a good option for everyone. Your doctor will consider factors like your general health and ability to do daily activities. This is to make sure you are healthy enough to have surgery. Your doctor will also look at the location of the metastasis to decide if it can be safely removed.

If there are many metastases, then surgery to remove the primary tumor (but not the metastases) is generally recommended. Treatment with drugs is recommended after surgery. A <u>cytoreductive</u> <u>nephrectomy</u> is surgery to remove the whole kidney with the tumor. This surgery aims to reduce the amount of cancer in your body. Since all the metastases can't be removed by surgery, treatment with drugs is used next. Removing the primary tumor first may improve how well drugs work against the metastases.

But, this may not be a good treatment option for everyone. Your doctor will assess your general health and ability to do daily activities. This is to make sure you are healthy enough to have surgery. Your doctor will also look at the location of metastases and other factors to decide if this is a good option for you.

Next steps: 🔵

If you had a cytoreductive nephrectomy or surgery wasn't possible, see Chart 5.3.2 on page 54 for recommended drug treatments.

If you had a nephrectomy and metastasectomy, see Chart 5.3.3 on page 56 for recommended follow-up tests.

Chart 5.3.2 First-line treatment with drugs

Cell subtype	Treatment options		
	Clinical trial,		
	• Sunitinib,		
	Temsirolimus (for certain patients),	L Dect currentive core	
Clear cell	Bevacizumab + interferon alfa,		
	• Pazopanib,	+ Desi supportive care	
	• High-dose IL-2 (for certain patients),		
	Axitinib, or		
	Sorafenib		
	Clinical trial (preferred),		
	Temsirolimus (for certain patients),		
	• Sorafenib,		
	• Sunitinib,		
Non-clear cell	• Pazopanib,	+ Best supportive care	
	• Axitinib,		
	• Everolimus,		
	Bevacizumab, or		
	• Erlotinib		
Clear cell Non-clear cell	 Temsirolimus (for certain patients), Bevacizumab + interferon alfa, Pazopanib, High-dose IL-2 (for certain patients), Axitinib, or Sorafenib Clinical trial (preferred), Temsirolimus (for certain patients), Sorafenib, Sunitinib, Pazopanib, Axitinib, Everolimus, Bevacizumab, or Erlotinib 	+ Best supportive care	

Chart 5.3.2 shows the <u>first-line treatment</u> options for kidney cancer that can't be removed by <u>surgery</u> or that came back (<u>relapsed</u>) after surgery. First-line treatment is the first drug or set of drugs used to treat cancer. There are many first-line treatment options to choose from. Which option is best for your depends on a number of factors. One key factor is the cell <u>subtype</u>. The most common subtype is <u>clear cell</u> <u>RCC</u>. The other subtypes are much less common. Therefore, they are simply referred to as "non-clear cell." (See page 21 for more details.)

First-line treatment

Treatment within a <u>clinical trial</u> is an option for all patients. Many new drugs have been approved for kidney cancer in the past 10 years because of clinical trials. But, most of the studies focused on clear cell <u>RCC</u>. More research is needed to find the best treatment options for <u>non-clear cell RCC</u>. Thus, treatment on a clinical trial is the preferred option for patients with non-clear cell RCC. (See Part 4 on page 30 for more details about each treatment.) **For clear cell RCC,** there are several treatment options to choose from besides a clinical trial. Most of the options are types of <u>targeted therapy</u>. Sunitinib, pazopanib, axitinib, and sorafenib are a type of targeted therapy called <u>TKIs</u>. They block signals in cells that help kidney cancer grow and spread. Each TKI works in a slightly different way and can cause <u>side</u> <u>effects</u>. Each drug may be a good option for different reasons. It is important to weigh the risks and benefits of each drug to choose the best option for you.

Temsirolimus is a type of targeted therapy called an <u>mTOR inhibitor</u>. It may be a good option for certain patients, such as those with three or more <u>poor risk</u> <u>factors</u>. A poor risk factor is something that increases the risk that cancer will be aggressive and progress quickly. Poor risk factors include having trouble with daily activities or work, <u>metastases</u> in two or more organs, too much <u>calcium</u> in the blood, and starting drug treatment less than one year after <u>diagnosis</u>.

Another option is to receive bevacizumab and interferon alfa. Bevacizumab is a type of targeted therapy called an <u>angiogenesis inhibitor</u>. Interferon alfa is a type of <u>cytokine therapy</u> (also called <u>immunotherapy</u>). Interferon alfa works better against kidney cancer when it's given along with bevacizumab. But, each drug has side effects and they may be more severe when both drugs are given.

High-dose <u>IL-2</u> is another type of cytokine therapy that may be an option for some patients. Due to the risk of severe side effects, high-dose IL-2 is not a good option for everyone. It is only recommended if your overall health is good, your organs are working well, and you are able to do normal daily activities well.

For non-clear cell RCC, there are also several treatment options to choose from. Many of the options are the same as those recommended for clear cell RCC. This includes temsirolimus, all four TKIs, and bevacizumab, but not interferon alfa.

Everolimus and erlotinib are two more options that are only recommended for patients with non-clear cell RCC. Both are targeted therapy drugs—everolimus is an mTOR inhibitor and erlotinib is an <u>EGFR inhibitor</u>. These drugs work in slightly different ways to block the signals that tell cancer cells to grow.

Supportive care

<u>Supportive care</u> is recommended along with first-line treatment for all patients. Supportive care is treatment given to relieve the <u>symptoms</u> of cancer or side effects of cancer treatment. It aims to improve quality of life and relieve any discomfort you may have.

Supportive care may include <u>radiation therapy</u>, surgery, drugs, or other treatments. Radiation therapy may be used to relieve pain from cancer that has spread to your bones or brain. Drugs that strengthen your bones may also help with pain and other problems caused by <u>bone metastases</u>.

Surgery to remove the <u>primary tumor</u> may be used to ease symptoms like pain or blood in the urine. Surgery to remove metastases may also help relieve symptoms. (See page 38 for more details about supportive care.)

Next steps: 🔵

For recommended follow-up tests to check how well treatment is working, see Chart 5.3.3 on page 56.

Chart 5.3.3	Follow-up	testing	during	treatment	wtih drugs
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Tests	Schedule
Medical history and physical exam	Every 6 to 16 weeks during drug treatment, orMore frequently as needed based on the drug given
Blood chemistry panel and other blood tests	As needed based on the drug given
Imaging tests of the chest, abdomen, and pelvis	 Baseline CT or MRI before starting treatment or observation, then Tests every 6 to 16 weeks based on the doctor's judgment and cancer status
CT or MRI of the head	 Possible baseline test before treatment, then As needed, and Possible testing once a year based on doctor's judgment
MRI of the spine	As needed
Bone scan	As needed

Chart 5.3.3 shows the <u>follow-up tests</u> that are recommended during and after treatment with drugs. These tests are also recommended after a <u>nephrectomy</u> and <u>metastasectomy</u> for stage IV kidney cancer.

Follow-up tests are used to monitor your health and check how well treatment is working. An outcome or improvement related to treatment is called a treatment response. Doctors use follow-up tests to look for signs of cancer return or spread (metastasis) after treatment. The return of cancer after treatment is called a <u>relapse</u> or <u>recurrence</u>. Follow-up tests are also used to check your <u>kidney function</u> and watch for treatment <u>side effects</u>. Many of the tests used for <u>diagnosis</u> and <u>staging</u> are repeated during follow-up. (See Part 2 on page 14 and Part 3 on page 24 for more details about each test.) No single follow-up plan is right for all patients. Your doctor will adjust the follow-up plan based on a number of factors specific to you. Some key factors are your overall health, the extent of the cancer, and the type of drug you receive. You may need more or less frequent testing than someone else. How often tests are done may change over time. This may be due to changes in cancer growth, response to treatment, or other factors.

Regular <u>medical history</u> check-ups, <u>physical exams</u>, and blood tests will tell your doctor about your general health. <u>Blood chemistry tests</u> will also show if your organs, such as your <u>liver</u> and <u>kidneys</u>, are working well. Abnormal results may be a sign that an organ isn't working well. Abnormal results may be caused by the cancer, treatment, or another health problem. Certain blood tests may be needed more often based on the type of drug given. For example, blood tests to check <u>liver function</u> may be needed more often if you receive pazopanib. This is because pazopanib can cause much damage to your liver. Other blood tests may be needed to watch for certain side effects of other drugs.

<u>Imaging tests</u> of your chest, <u>abdomen</u>, and <u>pelvis</u> are an important part of follow-up. Each type of imaging test works in a slightly different way. (See page 16 for details.) These tests help your doctors watch for any changes in the cancer size or location during treatment.

A baseline <u>CT</u> or <u>MRI scan</u> should be done before starting treatment. A <u>baseline test</u> is a starting point to which future tests are compared. After the baseline test, ongoing imaging tests are used to show if the cancer grows or shrinks over time.

Imaging tests of your head will show if the cancer has spread to your brain. Your doctor may want to do a baseline CT or MRI scan of your brain before starting treatment. After that, you may have a CT or MRI scan of your head once a year. Imaging tests should also be done as needed such as to check out certain <u>symptoms</u>.

Other imaging tests, such as a <u>bone scan</u> or MRI scan of your <u>spine</u>, aren't recommended as standard follow-up tests for all patients. These tests may be done as needed such as if there are signs or symptoms of cancer spread. An MRI of your spine may be done if you have symptoms that suggest cancer has spread to your brain or <u>spinal cord</u>. Some symptoms of cancer in the brain are chronic headaches, seizures, loss of balance, and weakness on one side of the body. If you have bone pain or high levels of <u>ALP</u> in your blood, then a bone scan may be done to show if cancer has spread to your bones.

Next steps: 🔵

If follow-up tests show that the cancer has come back after a nephrectomy and metastasectomy, see Chart 5.3.2 on page 54 for drug treatments.

If the cancer grows during or after first-line treatment for clear cell RCC, see Chart 5.3.4 on page 58 for recommended treatments.

If the cancer grows during or after first-line treatment for non-clear cell RCC, then you may receive a different drug listed in Chart 5.3.2.

Chart 5.3.4 Treatment after first-line for clear cell RCC

First-line treatment	Next treatment options	
TKI therapy (axitinib, pazopanib, sorafenib, or sunitinib)	 Clinical trial or Targeted therapy with: everolimus, axitinib, sorafenib, pazopanib, temsirolimus, or bevacizumab or Cytokine therapy: high-dose IL-2 (for certain patients) 	+ Best supportive care
Cytokine therapy (interferon alfa or high-dose IL-2)	 Clinical trial or Targeted therapy with: axitinib, sorafenib, sunitinib, pazopanib, temsirolimus, or bevacizumab 	+ Best supportive care

Chart 5.3.4 shows the next treatments that are recommended for <u>clear cell RCC</u> that grew during or after <u>first-line treatment</u>. Which treatment is recommended next depends on the type of drug you received as first-line treatment. This is because some drugs may work better when taken after certain other drugs.

If you had a <u>TKI</u> as first-line treatment, then you have three main options to choose from. The first option is to receive treatment within a <u>clinical trial</u>. A clinical trial is a type of research that studies how safe and helpful a treatment is.

The second option is to receive one of the following <u>targeted therapy</u> drugs: everolimus, axitinib, sorafenib, pazopanib, temsirolimus, or bevacizumab.

Each targeted therapy drug works in a slightly different way and can cause <u>side effects</u>. Each of these drugs may be a good option for different reasons. It is important to weigh the risks and benefits of each drug to choose the best option for you. (See page 35 for more details about targeted therapy.)

The third option is high-dose <u>IL-2</u>, a type <u>cytokine</u> <u>therapy</u> (also called <u>immunotherapy</u>). Due to the risk of severe side effects, high-dose IL-2 is not a good option for everyone. It is only recommended if your overall health is good, your organs are working well, and you are able to do normal daily activities well.

If you had cytokine therapy as first-line

treatment, then you have three main options to choose from. The first option is to receive treatment

within a clinical trial. The other option is to receive one of the following targeted therapy drugs: axitinib, sorafenib, sunitinib, pazopanib, temsirolimus, or bevacizumab.

Supportive care is recommended along with cancer treatment for all patients. <u>Supportive care</u> is treatment given to relieve the <u>symptoms</u> of cancer or <u>side effects</u> of cancer treatment. It aims to improve quality of life and relieve any discomfort you may have.

Supportive care may include <u>radiation therapy</u>, <u>surgery</u>, drugs, or other treatments. Radiation therapy may be used to relieve pain from cancer that has spread to your bones or brain. Drugs that strengthen your bones may also help with pain and other problems caused by <u>bone metastases</u>. Surgery to remove <u>metastases</u> may also be used to ease symptoms. (See page 38 for more details about supportive care.)

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rehensive r rk® Making treatment decisions

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6 Making treatment decisions

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Cancer can be very stressful. While absorbing the fact that you have cancer, you must also learn about tests and treatments. And, the time you have to decide on a treatment plan may feel short. Parts 1 through 5 aimed to teach you about kidney cancer, its treatment, and other challenges. Part 6 aims to help you talk with your doctor and make treatment decisions that are right for you.

Have a treatment plan

Learning you have cancer starts an unplanned journey to an unknown place. A <u>treatment plan</u> is like having a roadmap for your journey. It is a written course of action through treatment and beyond. It can help you, your loved ones, and your treatment team.

A treatment plan addresses all cancer care needs while respecting your beliefs, wishes, and values. It is likely to change and expand as you go through treatment. The plan will include the role of your doctors and how you can help yourself. A treatment plan often has the following parts:

Cancer information

Cancer can greatly differ even when people have cancer in the same organ. Test results that describe the cancer are reported in the treatment plan. Such test results include the cancer site, cell type, and <u>cancer stage</u>. See Part 2 and Part 3 to read more about the tests used for kidney cancer.

Your treatment team

Treating kidney cancer takes a team approach. A <u>urologist</u> is a doctor who's an expert in diseases of the <u>urinary system</u> and the male reproductive system. A <u>medical oncologist</u> is a doctor who's an expert in treating cancer with drugs. A <u>radiation oncologist</u> is an expert at treating cancer with radiation. A <u>surgeon</u> is an expert in operations to remove or repair a part of the body. A <u>pathologist</u> is an expert in testing cells and tissue to find disease.

Your primary care doctor can also be part of your team. He or she can help you express your feelings about treatments to the team. Treatment of other medical problems may be improved if he or she is informed of your cancer care. Besides doctors, you may receive care from nurses, social workers, and other health experts. Ask to have the names and contact information of your health care providers included in the treatment plan.

Cancer treatment

There is no single treatment practice that is best for all patients. There is often more than one treatment option, including <u>clinical trials</u>. Clinical trials study how well a treatment works and its safety.

A guide to kidney cancer treatment options can be found in Part 5. The treatment that you and your doctors agree on should be reported in the treatment plan. It is also important to note the goal of treatment and the chance of a good treatment outcome. All known <u>side effects</u> should be listed and the time required to treat them should be noted. See Part 4 for a list of some of the possible side effects of kidney cancer treatments.

Your treatment plan may change because of new information. You may change your mind about treatment. Tests may find new results. How well the treatment is working may change. Any of these changes may require a new treatment plan.

Stress and symptom control

Cancer and its treatments can cause bothersome symptoms. The stress of having cancer can also cause symptoms. There are ways to treat many symptoms, so tell your treatment team about any that you have.

You may lose sleep before, during, and after treatment. Getting less sleep can affect your mood, conversations, and ability to do daily tasks. If possible, allow yourself to rest, let people do things for you, and talk with your doctor about sleep medication. Behavioral sleep medicine—a type of talk therapy—may also help.

Feelings of anxiety and depression are common among people with cancer. At your cancer center, cancer navigators, social workers, and other experts can help. Help can include support groups, talk therapy, or medication. Some people also feel better by exercising, talking with loved ones, or relaxing.

You may be unemployed or miss work during treatment. Or, you may have too little or no health insurance. Talk to your treatment team about work, insurance, or money problems. They will include information in the treatment plan to help you manage your finances and medical costs.

Survivorship care

Cancer survivorship begins on the day you learn of having kidney cancer. For many survivors, the end of active treatment signals a time of celebration but also of great anxiety. This is a very normal response. You may need support to address issues that arise from not having regular visits with your cancer care team. In addition, your treatment plan should include a schedule of follow-up cancer tests, treatment of longterm side effects, and care of your general health.

Advance care planning

Talking with your doctor about your <u>prognosis</u> can help with treatment planning. If the cancer can't be controlled or cured, a care plan for the end of life can be made. However, such talks often happen too late or not at all. Your doctor may delay these talks for fear that you may lose hope, become depressed, or have a shorter survival. Studies suggest that these fears are wrong. Instead, there are many benefits to advance care planning. It is useful for:

- Knowing what to expect,
- Making the most of your time,
- · Lowering the stress of caregivers,
- · Having your wishes followed,
- Having a better quality of life, and
- · Getting good care.

Advance care planning starts with an honest talk between you and your doctors. You don't have to know the exact details of your prognosis. Just having a general idea will help with planning. With this information, you can decide at what point you'd want to stop cancer treatments, if at all. You can also decide what treatments you'd want for symptom relief, such as <u>radiation therapy</u>, <u>surgery</u>, or medicine.

Another part of the planning involves hospice care. Hospice care doesn't include treatment to fight the cancer but rather to reduce symptoms caused by cancer. Hospice care may be started because you aren't interested in more cancer treatment, no other cancer treatment is available, or you may be too sick for cancer treatment. Hospice care allows you to have the best quality of life possible. Care is given all day, every day of the week. You can choose to have hospice care at home or at a hospice center. One study found that patients and caregivers had a better quality of life when hospice care was started early.



"I would encourage each patient to be as active an advocate as they possibly can and to be as involved in the treatment and decision-making process as they are able to."

- Patient Advocate Kidney Cancer Association

An advance directive describes the treatment you'd want if you weren't able to make your wishes known. It also can name a person whom you'd want to make decisions for you. It is a legal paper that your doctors have to follow. It can reveal your wishes about lifesustaining machines, such as feeding tubes. It can also include your treatment wishes if your heart or lungs were to stop working. If you already have an advance directive, it may need to be updated to be legally valid.

Your role in planning

The role patients want in treatment planning differs. Your doctors and treatment team will give you the information you need to make informed choices. But, you may prefer to let others take the lead in deciding your treatment. This may be due to a high level of stress. It may be hard to hear or know what others are saying. Stress, pain, and drugs can limit your ability to make good decisions. You may have never heard the words used to describe kidney cancer, tests, or treatments. Likewise, you may think that your judgment isn't any better than your doctors'.

You may rely on your doctors alone to make the right decisions. You can also have loved ones help. They can gather information, speak on your behalf, and share in decision-making with your doctors. Even if others decide which treatment you will receive, you still have to agree by signing a consent form.

On the other hand, you may prefer to take the lead or share in decision-making. In shared decision-making, you and your doctors share information, weigh the options, and agree on a treatment plan. Your doctors know the science of treating kidney cancer. But, you know your personal concerns and goals. By working together, you may feel more comfortable and satisfied with your care and treatment plan. You'll likely get the treatment you want, at the place you want, and by the doctors you want.

Getting a 2nd opinion

The time around a cancer <u>diagnosis</u> can be very stressful. People with cancer often want to start treatment as soon as possible. They want to make the cancer go away before it spreads any farther. While cancer can't be ignored, there is time to think about and choose which <u>treatment plan</u> is best for you.

You may wish to have another doctor review your test results and the treatment plan your doctor has recommended. This is called getting a 2nd opinion. You may completely trust your doctor, but a 2nd opinion on which treatment is right for you can help.

Copies of all of the test results need to be sent to the doctor giving the 2nd opinion. Some people feel uneasy asking for copies from their doctors. However, a 2nd opinion is a normal part of cancer care.

When doctors have cancer, most will talk with more than one doctor before choosing their treatment. What's more, some health plans require a 2nd opinion. If your health plan doesn't cover the cost of a 2nd opinion, you have the choice of paying for it yourself. Choosing your cancer treatment is a very important decision. It can affect length and quality of life.

Questions about testing

- 1. What tests will I have? How often will I be tested?
- 2. Where will the tests take place? Will I have to go to the hospital?
- 3. How long will it take? Will I be awake?
- 4. Will it hurt? Will I need anesthesia?
- 5. What are the risks? What are the chances of infection or bleeding afterward?
- 6. How do I prepare for testing? Should I not take aspirin? Should I not eat beforehand?
- 7. Should I bring a list of my medications? Should I bring someone with me?
- 8. How long will it take for me to recover? Will I be given an antibiotic or other drug afterward?
- 9. If a biopsy is done, will I get a copy of the results?
- 10. How soon will I know the test results and who will explain them to me?
- 11. Who will talk with me about the next steps? When?

Questions about treatments

- 1. Do I have to get treated?
- 2. What are my treatment options?
- 3. Will I have more than one treatment?
- 4. If surgery is an option, which type of surgery do you recommend? How often do you perform this type of surgery?
- 5. Is laparoscopic surgery an option?
- 6. What are the risks and benefits of each treatment for kidney cancer?
- 7. Will my age, general health, cancer stage, and other medical conditions limit my treatment choices?
- 8. What treatment do you recommend for me? How is this treatment given?
- 9. How soon should I start treatment? How long does treatment last?
- 10. Where will I be treated? Will I have to stay in the hospital or can I go home after each treatment?
- 11. What can I do to prepare for treatment? Should I stop taking my medications? Should I store my blood in case I need a transfusion?
- 12. How much will the treatment cost? How can I find out how much my insurance company will cover?
- 13. How likely is it that I'll be cancer-free after treatment?
- 14. What symptoms should I look out for while being treated for kidney cancer?
- 15. When will I be able to return to my normal activities?
- 16. What is the chance that the cancer will come back or spread?
- 17. What should I do after I finish treatment?
- 18. Are there supportive services that I can get involved in? Support groups?

Questions about clinical trials

- 1. Is there a clinical trial that I could take part in?
- 2. What is the purpose of the study?
- 3. What kinds of tests and treatments does the study involve?
- 4. What does the treatment do?
- 5. Has the treatment been used before? Has it been used for other types of cancers?
- 6. Will I know which treatment I receive?
- 7. What is likely to happen to me with, or without, this new treatment?
- 8. What are my other choices? What are their benefits and risks?
- 9. How might the study change my daily life?
- 10. What side effects can I expect from the study? Can the side effects be controlled?
- 11. Will I have to stay in the hospital? If so, how often and for how long?
- 12. Will the study cost me anything? Will any of the treatment be free?
- 13. If I'm harmed as a result of the research, what treatment might I get?
- 14. What type of long-term follow-up care is part of the study?

My notes

Websites

American Cancer Society www.cancer.org/cancer/kidneycancer/index

National Cancer Institute

www.cancer.gov/cancertopics/pdf/treatment/ renalcell/Patient

Kidney Cancer Association

www.kidneycancer.org/

National Kidney Foundation

www.kidney.org/atoz/content/kidneycancer

Urology Care Foundation

www.urologyhealth.org/urologic-conditions/ kidney-cancer

National Coalition for Cancer Survivorship www.canceradvocacy.org/toolbox

Cancer Support Community

www.cancersupportcommunity.org/MainMenu/ About-Cancer/Quality-of-Life

NCCN

www.nccn.org/patients/resources/default.aspx

Review

- A treatment plan can help you through treatment and beyond.
- It covers many issues—test results, treatments, and supportive programs.
- You can choose how active a role to have in planning your treatment.
- You may wish to get a 2nd opinion on your treatment plan.


Glossary

Dictionary Acronyms

NCCN Guidelines for Patients[®] Kidney Cancer, Version 1.2015

Dictionary

abdomen The belly area between the chest and pelvis.

active surveillance Frequent and ongoing testing to watch for cancer growth without giving active treatment.

adrenal gland A small organ on top of each kidney that makes hormones.

advanced kidney cancer Cancer that has spread to other parts of the body far from the first cancer site.

alkaline phosphatase (ALP) A protein found in most tissues in the body.

allergic reaction Symptoms caused when the body is trying to rid itself of invaders.

allergy

A condition in which the immune system has an abnormal reaction to something that is not harmful to most people.

angiogenesis The growth of new blood vessels.

angiogenesis inhibitor

A drug that blocks the growth of new blood vessels that feed cancer cells.

baseline A starting point to which future test results are compared.

baseline test The first test results to which future test results are compared.

biopsy Removal of small amounts of tissue from the body to be tested for disease.

bladder

An organ that holds and expels urine from the body.

blood chemistry panel

A test that measures the amounts of many different chemicals in a sample of blood.

blood chemistry test

A test that measures the amount of chemicals in the blood to check for signs of disease or organ damage.

blood vessel A tube that carries blood throughout the body.

bone metastases

Cancer that has spread from the first (primary) tumor to the bone.

bone scan

An imaging test that uses radioactive material to check for cancer or damage in bones.

brain metastases

Cancer that has spread from the first (primary) tumor to the brain.

calcium

A mineral needed for healthy teeth, bones, and other body tissues.

cancer stage

A rating of the growth and spread of cancer in the body.

cancer staging

The process of rating and describing the extent of cancer in the body.

carcinoma

Cancer that starts in cells that form the lining of organs and structures in the body.

chromophobe RCC

The third most common subtype of RCC (renal cell carcinoma) based on how the cancer cells look when viewed with a microscope.

clear cell RCC

The most common subtype of RCC (renal cell carcinoma) based on how the cancer cells look when viewed with a microscope.

clinical trial

Research on a test or treatment to assess its safety or how well it works.

collecting duct RCC

The fourth most common subtype of RCC (renal cell carcinoma) based on how the cancer cells look when viewed with a microscope.

complete blood count (CBC)

A test of the number of blood cells.

computed tomography (CT) scan

A test that uses x-rays from many angles to make a picture of the inside of the body.

contrast

A dye put into your body to make clearer pictures during imaging tests.

creatinine

A waste product of muscles that is filtered out of blood into urine by the kidneys.

cytokines

Proteins made naturally in the body or in a lab that boost or activate the immune system.

cytokine therapy

Treatment with drugs that are cytokines—proteins made in a lab that boost or activate the immune system to fight cancer.

cytoreductive nephrectomy

Surgery to remove the whole kidney with the tumor when cancer has spread to many distant sites and can't all be removed.

diagnosis

The process of identifying or confirming a disease.

distant recurrence

Cancer that has come back after treatment and is found in a part of the body far from the first (primary) tumor.

EGFR inhibitor

A drug that blocks the action of EGFR (epidermal growth factor receptor), a protein on the outside surface of a cell that sends signals inside the cell to grow.

epidermal growth factor receptor (EGFR)

A protein on the outside surface of a cell that sends signals inside the cell to grow.

external beam radiation therapy (EBRT)

Radiation therapy (use of high-energy rays to destroy cancer cells) received from a machine outside the body.

first-line treatment

The first drug or set of drugs given to treat cancer.

follow-up test

Tests done after the start of treatment to check how well treatment is working.

fracture A crack or break in a bone.

general anesthesia A controlled loss of wakefulness from drugs.

genes

A set of coded instructions in cells for making new cells and controlling how cells behave.

Gerota's fascia

The outer layer of fibrous tissue that surrounds the kidney.

growth rate

A measure of how much the cancer grows over a set period of time.

hand-foot syndrome

Redness, pain, swelling or blisters on the palms of the hands or soles of the feet.

hormone

Chemicals in the body that activate cells or organs.

imaging test

Tests that make pictures (images) of the inside of the body.

immune system

The body's natural defense against infection and disease.

immunotherapy

Treatment that activates or boosts the body's natural defense against disease (immune system) to fight cancer.

infusion

A method of giving drugs slowing through a needle into a vein.

intestine

The organ that eaten food passes through after leaving the stomach.

Dictionary

kidney function

A description of how well the kidneys are working.

kidneys

A pair of organs that filter blood and remove waste from the body through urine.

laparoscopic surgery

Surgery that uses small tools and a laparoscope—a thin tube with a light and camera at the end—inserted through a few small cuts in the belly area.

liver

An organ that removes waste from blood and makes a liquid that helps to digest food.

liver function A description of how well the liver is working.

liver function test

A blood test that measures chemicals that are made or processed by the liver to check how well the liver is working.

local anesthesia

A controlled loss of feeling in a small area of the body from drugs.

local recurrence

Cancer that has come back after treatment in or near the same place as the first (primary) tumor.

lungs

One of a pair of organs in the chest that is made of airways and air sacs and supplies the body with oxygen.

lymph

A clear fluid containing white blood cells that fight infection and disease.

lymph nodes

Small groups of special disease-fighting cells located throughout the body.

lymph vessels

Tubes that carry lymph—a clear fluid containing white blood cells that fight disease and infection—throughout the body and connect lymph nodes to one another.

magnetic resonance imaging (MRI) scan

A test that uses radio waves and powerful magnets to make pictures of the inside of the body.

medical history

All health events and medications taken to date.

medical oncologist

A doctor who's an expert in treating cancer with drugs.

metastasectomy

Surgery to remove tumors that formed far from the first site of cancer.

metastases

Tumors formed by cancer cells that have spread from the first tumor to other parts of the body.

metastasis

The spread of cancer cells from the first tumor to another body part.

metastatic

Containing cancer cells that have spread from the first tumor.

microscope

A tool that uses lenses to see very small things the eyes can't.

mTOR

A protein in cells that sends chemical signals for cell growth and survival.

mTOR inhibitor

A drug that blocks the action of mTOR—a protein in cells that sends chemical signals for cell growth and survival.

nephrectomy

Surgery that removes a kidney.

nephrogenic systemic sclerosis

A health condition that causes abnormal thickening and hardening of the skin and may affect other soft tissues.

non-clear cell RCC

Subtypes of RCC (renal cell carcinoma) other than clear cell, based on how the cancer cells look when viewed with a microscope.

open surgery

Removal of tissue through one large cut.

palliative care

Treatment for symptoms of a disease. Also sometimes called supportive care.

palliative surgery

Surgery that is used to relieve symptoms caused by the cancer.

papillary RCC

The second most common subtype of RCC (renal cell carcinoma) based on how the cancer cells look when viewed with a microscope.

partial nephrectomy

Surgery to remove a small part of the kidney with the tumor.

pathologist

A doctor who's an expert in testing cells and tissue to find disease.

pelvis The body area between the hip bones.

physical exam A review of the body by a health expert for signs of disease.

poor risk factor Something that increases the chance (risk) that cancer will be aggressive and grow (progress) quickly.

primary treatment The main treatment used to rid the body of cancer.

primary tumor The first mass of cancer cells in the body.

prognosis The likely or expected course and outcome of a disease.

radiation oncologist A doctor who's an expert in treating cancer with radiation.

radiation therapy Use of high-energy rays to destroy cancer cells.

radical nephrectomy

Surgery that removes the whole kidney with the tumor, the fatty tissue around the kidney, and possibly the attached adrenal gland and nearby lymph nodes.

radiologist

A doctor who's an expert in reading imaging tests—tests that make pictures of the inside of the body.

radiotracer

A substance that releases small amounts of energy (radiation) that is put into the body to make pictures clearer.

receptor

A protein inside or on the surface of cells to which substances can attach to cause a certain effect in the cell.

recurrence

The return of cancer after treatment. Also called a relapse.

red blood cell

A type of blood cell that carries oxygen from the lungs to the rest of the body.

relapse The return of cancer after treatment. Also called a recurrence.

renal artery The blood vessel that carries blood into the kidney.

renal cell carcinoma (RCC)

The most common type of kidney cancer. It starts in the cells that line the renal tubules—tiny tubes that filter blood and make urine.

renal pelvis

The space in the middle of the kidneys where urine collects before leaving the kidneys though long, thin tubes called ureters.

renal sarcoma

Cancer that starts in the blood vessels or connective tissue of the kidneys.

renal tubules

Tiny tubes in the kidneys that filter blood and make urine from the waste and extra water filtered out of blood.

renal vein

The blood vessel that carries clean blood out of the kidney.

side effect

An unhealthy or unpleasant condition caused by treatment.

spinal cord

The bundle of nerves in the spine (backbone) that carries messages between the brain and other parts of the body.

spine

The bones, muscles, and other tissues that reach from the base of the skull to the tailbone. Also called backbone.

staging

The process of rating and describing the extent of cancer in the body.

stereotactic radiosurgery

A type of radiation therapy that delivers a high dose of radiation to a small, specific area.

subtype

Smaller groups that a type of cancer is divided into based on how the cancer cells look under a microscope.

supportive care

Treatment given to relieve the symptoms of a disease. Also called palliative care.

surgeon

A doctor who's an expert in operations to remove or repair a part of the body.

surgery

An operation to remove or repair a part of the body.

symptom

A new or changed health problem a person experiences that may indicate a certain disease or health condition.

targeted therapy

Treatment with drugs that target a specific or unique feature of cancer cells.

thermal ablation

Treatment that destroys tumors using extreme heat or extreme cold.

transitional cell carcinoma (TCC)

Cancer that starts in the cells that line the renal pelvis—the middle part of the kidney where urine collects before leaving the kidney through a long tube called a ureter. TCC also arises in the ureter and in the bladder.

treatment plan

A written course of action through cancer treatment and beyond.

tumor

An abnormal mass formed by the overgrowth of cells.

tyrosine kinase

A type of protein in cells that is important for many cell functions, such as sending signals for cell growth and survival.

tyrosine kinase inhibitor (TKI)

A drug that blocks the action of tyrosine kinases—proteins in cells that send signals for cells to grow, divide, and survive.

U.S. Food and Drug Administration (FDA)

A federal government agency that regulates drugs and food in the United States.

ultrasound

A test that uses sound waves to take pictures of the inside of the body.

urea

A waste product made by the liver and filtered out of blood by the kidneys.

ureter

A long, thin tube that carries urine from the kidney to the bladder.

urethra

The tube that carries urine from the bladder to outside the body.

urinalysis

A test that assess the content of urine using a microscope and chemical tests.

urinary system

The group of organs that removes waste from the body in the form of urine. It is made up of the kidneys, ureters, bladder, and urethra.

urologist

A doctor who is an expert in treating diseases of the urinary system in men and women and sex organs in men.

vascular endothelial growth factor (VEGF)

A protein that binds to cells that form blood vessels.

vein

A blood vessel that carries blood back to the heart from all parts of the body.

vena cava

The main, large vein that carries blood back to the heart.

white blood cell

A type of blood cell that helps fight infections in the body.

Wilms tumor

A rare type of cancer that starts in the kidneys and almost only occurs in young children.

x-ray

Use of small amounts of radiation to make pictures of the inside of the body.

Acronyms

AJCC American Joint Committee on Cancer

ALP alkaline phosphatase

CBC complete blood count

cm centimeters

CT computed tomography

EBRT external beam radiation therapy

EGFR epidermal growth factor receptor

FDA U.S. Food and Drug Administration

IL-2 interleukin-2

MRI magnetic resonance imaging

RCC renal cell carcinoma

TCC transitional cell carcinoma

TKI tyrosine kinase inhibitor

VEGF vascular endothelial growth factor

VHL von Hippel-Lindau

NCCN Abbreviations and Acronyms

NCCN[®] National Comprehensive Cancer Network[®]

NCCN Patient Guidelines NCCN Guidelines for Patients®

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