RENAL CELL CARCINOMA

A TREATMENT GUIDE FOR PATIENTS AND THEIR FAMILIES

CONTENT REVIEWED BY A DISTINGUISHED MEDICAL ADVISORY BOARD

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WHEN YOU HAVE KIDNEY CANCER, REMEMBER JUST ONE THING:

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**SURVIVOR | JAMES HOLMES**

I believe everyone has to do their part, especially when dealing with cancer.

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OVERVIEW

Learn about renal cell carcinoma

Receiving a cancer diagnosis often leads to many emotions, unanswered questions and concerns. This publication will help answer many of your questions, give you a better understanding of the disease and what you can expect, and offer valuable resources where you can find additional information. The more you know about your diagnosis, the more prepared you will be to make decisions about your treatment.

ABOUT THE KIDNEYS

Because renal cell carcinoma (RCC) affects the kidneys, it’s important to be familiar with the anatomy and function of normal kidneys (Figure 1). The kidneys are a pair of bean-shaped organs located in the back of the abdomen. There is one on each side of the spine, and they’re protected by the lower rib cage. Each kidney is about the size of a fist.

The kidneys are part of the urinary tract, and their main function is to filter the blood. All of the blood in the body passes through the kidneys many times each day, and the kidneys filter out excess water, salt and waste products. The end result of this filtering process is urine, which then travels to the bladder, where it’s stored until urination. The kidneys also play a role in controlling blood pressure and making red blood cells.

ABOUT KIDNEY CANCER

It is estimated that cancer of the kidney will be diagnosed in nearly 64,000 people in the United States in 2017. RCC is the most common type of cancer arising in the kidney, accounting for nearly 90 percent of all diagnoses. RCC is classified into subtypes according to what the tumor cells look like under a microscope. The most common subtype is clear cell RCC, which occurs in about seven of every 10 cases of RCC. Other subtypes include papillary, chromophobe, medullary and collecting duct RCC. The disease also can be “unclassified” when more than one type of cell is present and the cells don’t fit into any of the subtype classifications.

Knowing your particular subtype is helpful because treatment choices may differ according to your specific type of disease.

RCC begins when abnormal cells in the kidneys start to grow out of control and form one or more masses — or tumors — in the kidney. RCC may involve just one tumor in one kidney or may involve several tumors in both kidneys. The most common symptom of RCC is blood in the urine, also known as hematuria. However, sometimes tumors are found on imaging studies that are being done for another reason. More of these so-called “incidental” RCC tumors have been found as the use of imaging studies has increased. In some people, the cancer cells have already spread beyond the kidney at the time of diagnosis to one or more distant sites in the body; this is known as “metastatic” or “advanced” cancer. Treatment of metastatic cancer is directed at not only the primary site in the kidneys but also the metastatic site(s), or sites where the cancer has spread.

RISK FACTORS

The precise cause of RCC is unknown, but several risk factors may increase the chance of getting this disease. RCC occurs more often in men than women and is slightly more common in the African-American population than in the white population. In addition, the risk of RCC is slightly higher for people who have a close family member (especially a brother or sister) with the disease. Inherited conditions can also raise the risk. Von Hippel-Lindau (VHL) syndrome, a rare inherited disease caused by a mutation (abnormality) in the VHL gene, is associated with an increased risk of RCC. Testing can be done to determine if the VHL mutation is present in other family members.

Horseshoe kidney, which affects about one in every 500 children, is another inherited condition that can raise the risk of RCC. With this condition, the kidneys fuse together during development of the fetus to form a “U” shape — similar to a horseshoe — instead of developing normally.

Other risk factors for RCC include cigarette smoking, obesity and high blood pressure. Dialysis treatment, which removes toxins from the bodies of people whose kidneys are not working, increases the risk of RCC, as well.

New information about safe and effective cancer treatments is continuously discovered, so it’s wise to do your research and speak to several specialists before choosing the treatment that is best for you.

CANCER FACT

RCC is the most common type of cancer arising in the kidney, accounting for nearly 90 percent of all diagnoses.

IT’S OK TO SEEK A SECOND OPINION

You may decide that you would like to consult with another doctor before or even after you begin treatment. The process of seeking advice from a second doctor is called getting a second opinion.

A second opinion involves asking another cancer specialist or group of specialists to review your medical records, confirm or revise your doctor’s diagnosis and treatment plan, verify your pathology report and stage of cancer, and recommend a proposed treatment plan. Second opinions are a normal part of cancer care, and it’s important to discuss all of your treatment options and alternatives. Never shy away from seeking additional professional advice or worry about how your diagnosing physician may feel about it. Most doctors welcome opinions from other specialists. Some insurance companies even require that you obtain a second opinion before you can start treatment.

New information about safe and effective cancer treatments is continuously discovered, so it’s wise to do your research and speak to several specialists before choosing the treatment that is best for you.
In October 2010, I had occasional blood in my urine. Within a week, it was every time I urinated. My family doctor sent me for a CT. I knew it was bad because one of the technicians looked around the corner at me and it was not the “OK” look. I talked to the doctor on the phone. He told me I had a softball-sized tumor on my left kidney and multiple potential tumors in my lungs. I looked up renal cell carcinoma, which I had never heard of, on my smartphone. Those two hours reading about Stage IV kidney cancer were the worst two hours of my life.

I headed to my doctor’s office without an appointment, and he fit me in. He and his nurse prayed for me. I felt God’s presence, and I went through all the stages of grief by the time he finished his prayer. He made an appointment with an oncologist, and my daughter-in-law, who is a surgical tech, made an appointment with a surgeon for the same day. My tumor and left kidney were removed about a week later at a hospital near our home. After a few weeks of recovery, I traveled to a cancer center in another state with a referral from my oncologist.

Either luck or providence led me to one of the best oncologists for kidney cancer in the country. He believed chemotherapy would extend my life by only a few months, but he mentioned immunotherapy. Not many people with kidney cancer opted for it because of the poor odds, but it was being used by the melanoma department. He said that even if I could get approved for the treatment, he still gave it only a five percent chance of curing me — and a one percent chance of causing an earlier death. I met with the melanoma oncologist, and she agreed to give me the treatment. She later told me that my attitude and my physical fitness convinced her.

The treatment began in January 2011, and it was brutal. I was in ICU for a week, getting IV treatments every eight hours. I gained about 45 pounds in four days due to the continuous IV fluids. I had minor convulsions (entire body shaking) for 10 to 20 minutes after each treatment. If my vital signs and kidney function were okay, my nurses would ask if I was ready for another round. I was only 64 and I wanted to live, so I told them to sock it to me. I had nine treatments over three days before the effects on my kidney made it necessary to stop. I remained in ICU four more days recovering.

In May, I started another round of the drug. Between treatments, I worked out like I was preparing for a triathlon, and I discovered my secret to success. The treatments affected my internal thermostat, and I couldn’t handle weight training or the elliptical. My wife suggested swimming. The first time I got into the pool, something clicked. From then on, I swam every day. I had three treatments before I had to stop because of the effects on my kidney. Some of the tumors in my lungs were gone and four were in remission.

In February 2012, I began having trouble with my right leg and right arm. I had an upcoming dive trip. My wife was my dive buddy. I knew I’d endanger her if something happened during the dive, so I called the cancer center and my doctor. Both told me to get to the ER. A young ER doctor shared my MRI results with tears in his eyes. I had a tumor the size of a golf ball in the left side of my brain along with swelling. My daughter-in-law came to my rescue again. She contacted a brain surgeon whom she had assisted. He ordered MRIs and came in on his day off to see us. He said there was a 90 percent chance he could remove the tumor with no after-effects. To me, 90 percent felt like a sure thing so, on Monday, he removed the tumor. On Tuesday, I was walking around the ICU being entirely too cheerful. I was released the next day.

My condition changed recently. A tumor on my pancreas and two of the four tumors in my lungs are growing. New treatments, including other types of immunotherapies, are available now, and my oncologist is optimistic that I’ll be eligible for one of them.

I believe everyone has to do their part, especially when dealing with cancer. I know God has a plan for me; however, that isn’t enough. My wife and I did a lot of research about diet. She makes me a smoothie every morning that is full of antioxidants and about 25 ingredients. My diet is abundant with fruits and vegetables. I was a minor social drinker but now avoid alcohol. I’ve never smoked. If I had, I wouldn’t have been eligible for the treatment and wouldn’t be here today. I’ve also stepped up my exercise regimen. I swim two miles on Monday and a mile of sprints on Thursday. I strenuously work out with weights on Tuesday and Wednesday and spend an hour on the elliptical. Friday is an optional workout day.

Look for the silver linings. Mine were getting closer to my three children and their families. My wife — my soul mate — was the angel in the room during treatments. I enrolled my two granddaughters into a swim club and taught them to swim. I cannot tell you how fulfilling it is to teach your grandchildren about a sport. Live every day like it is your last, and appreciate all that you have.
Doctors may use several tests that examine the abdomen and kidneys to diagnose your specific type of renal cell carcinoma (RCC). Following your diagnosis, your doctor also uses these test results to determine the extent of the disease, a process called staging. Accurately diagnosing and staging your RCC helps your doctor recommend the best treatment options for you, which may spare you from treatment that is unlikely to be effective.

**PHYSICAL EXAM AND LABORATORY TESTS**

Your doctor and health care team will obtain your complete medical history and perform a thorough physical examination. During the physical exam, the doctor will press on your abdomen to see if he or she can feel a mass or enlargement of nearby lymph nodes, where a cancer may spread. Laboratory tests, including blood and urine tests, may also be done. These results will provide your doctor with a baseline measurement of your overall health, kidney function and cancer status.

**Urine tests**

Your doctor may order a urinalysis and/or a urine cytology test. A urinalysis is a test done on a sample of your urine to see if blood or other indicators of an abnormality, such as sugar, proteins or bacteria, are present. For a urine cytology test, the urine sample is viewed through a microscope and examined for cancer cells.

**Blood tests**

Further laboratory evaluation will include blood tests. A complete blood count (CBC) is a measure of the number of red and white blood cells and platelets in the blood. CBC results may be abnormal in people with kidney cancer. A comprehensive metabolic panel, which is a group of blood tests, is usually done and can provide doctors with an overall picture of the body’s chemical balance, including information about how your kidneys and liver are working. Abnormal results can indicate a variety of medical conditions, including problems with the kidneys.

**IMAGING STUDIES**

Imaging studies are used primarily to help define the size, shape, location and spread of the tumor. They are also useful for assessing other parts of the body to see if the cancer has metastasized (spread) beyond the kidney, which helps define the stage of the disease. You may not need to have every diagnostic imaging study. Your doctors will consider the results of your physical examination and your general health status in deciding which tests will provide the most useful information.

**Computed tomography (CT)**

CT produces three-dimensional, cross-sectional X-ray images, so it can provide more precise details than a standard X-ray. For this test, a special dye (called a “contrast”) may be injected into your vein, and you will likely be asked to swallow another type of dye. These dyes help better define organs and tissues on the images. CT is excellent for assessing the size of the lymph nodes, as well as the presence of abnormalities in the liver, bones or lungs; however, the size of lymph nodes does not always indicate whether or not the nodes contain cancer. Thus, other studies to evaluate the lymph nodes may be done. In cases of RCC, CT scans of the abdomen, pelvis and chest, and sometimes the brain, are often necessary.

**Magnetic resonance imaging (MRI)**

MRI involves the use of strong magnets and magnetic waves to produce images. An MRI of the abdomen will provide images of the urinary tract, liver, bones, intestines and lymph nodes. These can show cancer in the kidneys, lymph nodes or other nearby tissues. An MRI is often done instead of CT for people who cannot tolerate the contrast dye used with CT because of an allergy or poor kidney function.

**Positron emission tomography (PET)**

PET images are not as finely detailed as those

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** TABLE 1  **

**AJCC TNM CLASSIFICATION FOR KIDNEY CANCER**

<table>
<thead>
<tr>
<th>Classification</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tumor (T)</td>
<td></td>
</tr>
<tr>
<td>TX</td>
<td>Primary tumor cannot be assessed.</td>
</tr>
<tr>
<td>T0</td>
<td>No evidence of primary tumor.</td>
</tr>
<tr>
<td>T1</td>
<td>Tumor ≤ (less than or equal to) 7 cm in greatest dimension, limited to the kidney.</td>
</tr>
<tr>
<td>T1a</td>
<td>Tumor ≤ (less than or equal to) 4 cm in greatest dimension, limited to the kidney.</td>
</tr>
<tr>
<td>T1b</td>
<td>Tumor &gt; (more than) 4 cm but ≤ (less than or equal to) 7 cm in greatest dimension, limited to the kidney.</td>
</tr>
<tr>
<td>T2</td>
<td>Tumor &gt; (more than) 7 cm in greatest dimension, limited to the kidney.</td>
</tr>
<tr>
<td>T2a</td>
<td>Tumor &gt; (more than) 7 cm but ≤ (less than or equal to) 10 cm in greatest dimension, limited to the kidney.</td>
</tr>
<tr>
<td>T2b</td>
<td>Tumor &gt; (more than) 10 cm, limited to the kidney.</td>
</tr>
<tr>
<td>T3</td>
<td>Tumor extends into major veins or perinephric tissues, but not into the ipsilateral adrenal gland (a small gland on top of each kidney) and not beyond Gerota’s fascia (an envelope of tissue that surrounds the kidney).</td>
</tr>
<tr>
<td>T3a</td>
<td>Tumor extends into the renal vein (the large blood vessel leaving the kidney) or its segmental branches, or invades the pelvicalyceal system, or invades perirenal (surrounding the kidney) and/or renal sinus (within the kidney) fat but not beyond Gerota’s fascia.</td>
</tr>
<tr>
<td>T3b</td>
<td>Tumor extends into the vena cava (the large vein leaving the heart) below the diaphragm (the muscle under the lungs that helps with breathing).</td>
</tr>
<tr>
<td>T3c</td>
<td>Tumor extends into the vena cava above the diaphragm or invades the wall of the vena cava.</td>
</tr>
<tr>
<td>T4</td>
<td>Tumor invades beyond Gerota’s fascia (including contiguous extension into the ipsilateral adrenal gland).</td>
</tr>
<tr>
<td>Node (N)</td>
<td></td>
</tr>
<tr>
<td>NX</td>
<td>Regional lymph nodes cannot be assessed.</td>
</tr>
<tr>
<td>N0</td>
<td>No regional lymph node metastasis.</td>
</tr>
<tr>
<td>N1</td>
<td>Metastasis in regional lymph node(s).</td>
</tr>
<tr>
<td>Metastasis (M)</td>
<td></td>
</tr>
<tr>
<td>M0</td>
<td>No distant metastasis.</td>
</tr>
<tr>
<td>M1</td>
<td>Distant metastasis.</td>
</tr>
</tbody>
</table>

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*Used with permission of the American Joint Committee on Cancer (AJCC), Chicago, Illinois. The original and primary source for this information is the AJCC Cancer Staging Manual, Eighth Edition (2017) published by Springer Science+Business Media.*
from CT, but they can help doctors decide whether a mass contains cancer and sometimes disclose whether there are deposits of abnormal cells not seen on CT or MRI scans. Currently, however, PET is not a standard tool used during the diagnosis of RCC.

**Ultrasound**
Ultrasound involves the use of sound waves to produce images of the organs inside the abdomen, including the kidneys and nearby tissues. The images can also show a tumor in the kidney.

**Intravenous pyelogram (IVP)**
For this test, a dye is injected into a vein in your arm, and X-rays are taken as the dye travels through the bloodstream into the kidneys, ureters and bladder. The dye will highlight any tumor that is present.

**Bone scan**
A bone scan is done to see if RCC has spread to bone. A small amount of a radioactive material that is preferentially deposited in damaged bone is injected through a vein in the arm, and a special camera is used to see if the radioactive material has deposited in bone. This radioactive material will not make your body radioactive, and the dose of radiation the patient is exposed to during regular X-rays is much lower.

**Renal arteriography**
Also called renal angiography, renal arteriography is a test to examine the blood vessels that feed the kidney and a tumor. A contrast dye is injected through a vein in your arm, and a catheter is then inserted into the renal artery, a large artery near the groin that leads to the kidney. A dye is also injected directly into the arteries into the kidneys. The dye defines the blood vessels in the normal kidney and any tumor present so it can be seen more clearly on X-rays. Renal arteriography can help your doctor plan surgery to remove a tumor.

**Biopsy Procedures**
Because doctors can usually diagnose RCC with imaging tests, a biopsy is often not needed. However, a biopsy may be done if imaging tests have not shown for sure whether cancer is present. Two types of biopsy may be done to help diagnose RCC: fine needle and core needle. During a fine-needle procedure, the doctor inserts a thin needle into the suspected tumor, using CT or ultrasound to help guide the needle. Fluid or small pieces of tissue can be removed through the needle. In a core-needle biopsy, the needle is larger and a small cylinder of tissue can be removed. For both types of procedure, the area where the needle will be inserted is first numbed with a local anesthetic so that you won’t feel much pain.

Samples of tissue obtained during a biopsy are examined by a pathologist (a doctor who specializes in the analysis of body tissues and the diagnosis of diseases), who will look to see if cancer cells are present and, if they are, to determine the specific type of cancer cells. In some instances, the pathologist may not be able to identify the type because the tissue sample is too small. When this happens, another biopsy may be necessary. If imaging tests show a solid and growing mass, surgeons may remove the tumor first. In completing a pathology report following the operation to remove the cancer, the pathologist will note the size and location of the tumor, whether lymph nodes contain cancer cells, and other important facts about the cancer. The pathologic evaluation of biopsy samples offers the most valuable information for the diagnosing and staging of RCC.

**Staging**
As with most cancers, identifying the stage of RCC is essential for determining the prognosis (likely outcome) and for planning treatment. Staging helps doctors describe where the cancer is located, whether it has spread and whether other organs in the body are affected by it.

**Table 2: Stages of RCC**

<table>
<thead>
<tr>
<th>Stage</th>
<th>TNM classifications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage I</td>
<td>T1, N0, M0</td>
</tr>
<tr>
<td>Stage II</td>
<td>T2, N0, M0</td>
</tr>
<tr>
<td>Stage III</td>
<td>T1 or T2, N1, M0, T3, N0 or N1, M0</td>
</tr>
<tr>
<td>Stage IV</td>
<td>T4, Any N, M0, Any T, Any N, M1</td>
</tr>
</tbody>
</table>

RCC may be staged in two ways. First, your doctor will evaluate the results of your physical exam and imaging tests and determine a clinical stage. Then, if surgery is performed, a pathologist will examine tissue taken from the tumor and nearby lymph nodes and assign a pathologic stage, which provides much more detail about the cancer.

The enhanced detail of the pathologic stage is important to determine the best treatment options and to predict the prognosis; however, sometimes the clinical staging provides sufficient information to guide therapy.

RCC is classified according to the tumor, node and metastasis (TNM) system developed by the American Joint Committee on Cancer (AJCC) (Table 1). Doctors categorize the tumor (T) according to its size and location, whether cancer cells are found in nearby lymph nodes (N) and whether the cancer has metastasized (M) – or spread – to other parts of the body. Once the RCC has been classified with the TNM system, an overall stage is assigned (Table 2). RCC is staged from Stage I to Stage IV. If the RCC is diagnosed as Stage I, II or III, it is non-metastatic or localized, meaning it hasn’t metastasized, or spread, to other parts of the body. Stage IV RCC is considered metastatic and has spread beyond the kidney and surrounding lymph nodes.

The Fuhrman grade of cancer is also an important tool in assessing RCC. This grade refers to how closely the cancer cells resemble normal cells under the microscope. The grading scale ranges from 1 to 4, with 1 representing cancer cells that look similar to normal cells and 4 representing cancer cells that look vastly different from normal cells. The lower the grade, the better the outlook is for the person with RCC.

**Metastatic RCC**
If the RCC is diagnosed as Stage IV, it is metastatic, which means it has spread from the kidney to another part of the body (called a “metastatic site”). The most common metastatic sites for RCC are the lungs, lymph nodes, bones, brain and liver.

Metastatic tumors have the same type of abnormal cells as the primary (original) tumor and are referred to by the same name. So, if RCC metastasizes to the liver, for example, the cancer cells in the liver are still RCC cells and the disease is called metastatic RCC rather than liver cancer. The metastatic disease is also treated as RCC, not as liver cancer.

Throughout the diagnosis and staging processes, talk openly with your health care team. Ask any questions you may have so you can better understand your specific cancer and the best options for you.

**Additional Resources**
- American Cancer Society: www.cancer.org
  Early Detection, Diagnosis and Staging
- American Society of Clinical Oncology: www.cancer.net
  Kidney Cancer: Stages
- Kidney Cancer Association: www.kidneycancer.org
STAGES OF RENAL CELL CARCINOMA

Stage I
The tumor is 7 centimeters or smaller in greatest dimension and is limited to the kidney.

Adrenal gland
Renal artery
Renal vein
Ureter

Kidney
Cortex

T1 tumor

Stage II
The tumor is larger than 7 cm in greatest dimension and is limited to the kidney.

Adrenal gland
Renal artery
Renal vein
Ureter

Kidney
Cortex

T2 tumor

Stage III
The tumor may be 7 cm or smaller (T1) or larger than 7 cm (T2) and limited to the kidney, has spread to lymph nodes but not distant parts of the body; or the tumor may be any size and has spread to major veins or surrounding tissue, not including the adrenal gland and not beyond Gerota’s fascia (T3), may have spread to lymph node(s) but not distant parts of the body.

Adrenal gland
Renal artery
Renal vein
Ureter

Kidney
Cortex

T3 tumor

Gerota’s fascia

Stage IV
The tumor has spread beyond Gerota’s fascia, including the adrenal gland (T4), and may have spread to nearby lymph nodes but not distant parts of the body; or the tumor may be any size, may have spread to nearby lymph nodes and has spread to distant parts of the body.

Adrenal gland
Renal artery
Renal vein
Ureter

Kidney
Cortex

Tumor

Gerota’s fascia

Metastasis

Brain
Lung
Liver
Bone
To advance medical knowledge, research is needed, and much of that research is done through clinical trials. The advancements made through clinical trials save lives and help health care providers develop the best standards of care.

Clinical trials to test new medications or approaches as first-line therapy (the primary treatment prescribed by your doctor), second-line therapy (the second treatment suggested if the first treatment stops working or if you’re experiencing unmanageable side effects) and adjuvant therapy (treatment given in addition to the primary treatment) for renal cell carcinoma (RCC) are ongoing. These trials are usually carried out at hospitals, universities, doctors’ offices and community clinics and can be in both large cities and rural towns.

You may consider participating in a clinical trial for any of the following reasons:
1. Your current treatment may not be working as well as expected, and a clinical trial may be a worthwhile alternative.
2. A clinical trial may significantly improve your quality of life. Discuss your situation with your medical team so they are aware of your expectations regarding side effects.
3. You may have a rare type of RCC that hasn’t been studied as much as other types.
4. By simply participating, you play an integral role in helping refine and improve the way millions of people with all types and stages of cancer are treated. You will not only help identify treatments that work, you’ll help eliminate those that don’t.

Learning more about clinical trials by talking with other people who have participated in a clinical trial may encourage you to volunteer. Keep in mind that not everyone responds to treatments in the same way, so you cannot expect an identical experience in terms of response to treatment, side effects, etc. But you can find out what it’s like to receive care within a clinical trial. Ask your doctor if a clinical trial is a treatment option for you. Regardless of the opinions and research you gather, participating in a clinical trial is ultimately your decision.

FIND A CLINICAL TRIAL
Clinical trials are essential for evaluating new treatments for people with RCC. They are conducted under the care of physicians and other research professionals and are sponsored by government agencies, by individual doctors and health care groups, or by the pharmaceutical or biotechnology companies that developed the treatments. Begin to research potential clinical trials on your own, and share the information you find with your doctor. For a list of clinical trial resources to explore, see page 16.

UNDERSTANDING INFORMED CONSENT

Before volunteering for a clinical trial, potential participants receive detailed information about the clinical trial in an Informed Consent form. This form details the purpose of the research, including what the participant’s role will be in the trial and how the trial will work. It also includes risks, benefits and other pertinent information to answer a potential participant’s questions. To ensure they fully understand what they are agreeing to, potential participants are required to review the form during the Informed Consent process.

The Informed Consent information should be explained in easy-to-understand language and will describe the study’s purpose, the length of time of the study, predictable risks, possible benefits, expectations, protocols, alternative beneficial procedures or treatments, the research subject’s rights, where more information can be found and additional questions about the research. The document will include some of the following information:

- The trial and its goals.
- How the participant will be monitored and what side effects to expect.
- The best standard regimen of care for the participants’ stage of disease, regardless of the doctor or institution.
- The safeguards in place. All clinical trial participants are protected by rules that apply nationwide to all facilities.
- How to withdraw from the trial at any time.

The Informed Consent process should give the potential participants a reasonable amount of time to review the trial’s information and ask questions before volunteering. They should use this time to check with any insurance providers to determine what procedures are covered and what they are expected or required to pay out of pocket. Although many trials cover the costs of certain treatments, other expenses may be the responsibility of the participants, which would best be discovered before starting a trial.

Potential participants need to understand their role as “subjects of research” and not as patients. Although they may receive personal treatment, they are not guaranteed to benefit from the study. They may be exposed to unknown risks, and they are entering a study that may be very different from current standard medical practices.
For a partial nephrectomy, the surgeon removes only the cancerous tumor, as well as some of the kidney tissue around the tumor. The goal of a partial nephrectomy is to preserve kidney function and decrease the risk of complications compared with a radical nephrectomy. In addition, research has shown that a partial nephrectomy provides outcomes similar to those after a radical nephrectomy. Because of this, more people with RCC are now being treated with a partial nephrectomy.

However, a radical nephrectomy is still needed in some cases, especially for large tumors or when the tumor has spread beyond the kidney. With this procedure, the surgeon removes the entire kidney, some nearby fatty tissue and, in some cases, the attached adrenal gland as well. Many people will still have normal kidney function with only one kidney. During the procedure, the surgeon will often remove some of the surrounding lymph nodes to more accurately stage the cancer and predict prognosis.

A partial or radical nephrectomy can be done with one of three techniques.

- **Open surgery.** Using this approach, the surgeon removes the tumor or kidney through a large incision in the abdomen or the flank (side). After the procedure, the incision is closed with stitches.

- **Laparoscopic surgery.** This less-invasive technique involves passing a laparoscope (a wand-like camera) and small instruments through a series of small incisions in the wall of the abdomen to remove the tumor or kidney. Laparoscopic surgery can preserve the muscles and/or nerves in the area and generally offers a shorter recovery time and fewer postoperative complications than open surgery.

- **Robotic-assisted surgery.** With this approach, the surgeon controls a robotic system that includes a camera and small instruments that are inserted into the body through several small incisions. Like laparoscopic surgery, robotic-assisted surgery is less invasive than open surgery. This type of operation provides a wider view of the kidney and nearby area than laparoscopic surgery.

Studies have shown that the outcomes are similar for all three surgical approaches when done by surgeons who have expertise in the specific techniques, so talk to your doctor about which choice is best for you. With any of these operations, you will receive a general anesthetic to keep you asleep and pain-free during the surgery. In general,
cold produces an ice ball that kills the tumor. Another ablative technique is known as radiofrequency ablation. Instead of cold gas, the surgeon passes high-energy radio waves through the needle to heat the tumor and kill the cancer cells. Ablative techniques are not standard treatment for RCC, but they may be used for older individuals or for people with other health risks.

**RADIATION THERAPY**

Radiation therapy is the use of high-energy X-rays to kill cancer cells. RCC typically doesn’t respond well to radiation therapy, but it’s sometimes used for people who cannot have surgery because of health problems. More often, radiation therapy is used to relieve the symptoms of RCC, including bleeding, pain and problems related to metastasis to the bones or brain. If your doctor includes radiation therapy in your treatment plan, a radiation oncologist will oversee it. He or she will carefully plan your radiation therapy to calculate the appropriate dose and determine the optimum treatment schedule before treatment begins.

**CHEMOTHERAPY**

Chemotherapy drugs, also called cytotoxic drugs, are used to stop the growth of cancer cells. Chemotherapy is sometimes referred to as conventional chemotherapy to distinguish it from targeted therapy, which relies on more recently developed drugs that target specific molecules in RCC. RCC is generally resistant to standard chemotherapy; however, these drugs can be more effective for certain RCC subtypes, especially when used in combination with other chemotherapy drugs (see Commonly Prescribed Medications for RCC).

**TARGETED THERAPY**

Researchers have learned about the cell pathways that can lead to many types of cancers and also have learned how to develop drugs that block those pathways. These drugs are known as targeted drugs (or agents), and treatment is known as targeted therapy. Although all cancer treatments target specific pathways, these targeted therapies are directed at more recently recognized targets, which are often more specific to the cancer cells or the mechanisms encouraging their growth. Targeted therapy drugs block the signals that proteins and other molecules send, which directs basic cancer cell functions, such as cell growth, division and death.

Effective targeted therapy (and, in fact, any therapy) depends on two factors: identifying targets that play an important role in the growth and survival of cancer cells, and developing agents that can attack those targets. Two important targets for RCC that researchers have identified are vascular endothelial growth factor (VEGF) and platelet-derived growth factor (PDGF). These growth factors activate proteins in and around the cancer cells that stimulate new blood vessel growth; these blood vessels then help tumors grow and spread. Targeted therapy drugs have been developed to inhibit these proteins in order to delay cell growth and possibly shrink tumors.

Targeted therapy drugs are widely used as first-line and second-line therapies for advanced RCC (see Commonly Prescribed Medications for RCC). First-line therapy is any treatment that is given first; second-line therapy is given if the first-line therapy fails.

Cancer cells often become resistant to targeted therapy drugs, making the drugs less effective over time. Researchers continue to explore ways to overcome resistance, identify new pathways to target and develop new...
agents to interrupt the growth of RCC cells (see Understanding Clinical Trials, page 7).

**IMMUNOTHERAPY**

Immunotherapy uses the body’s immune system to help fight RCC cells. Different types of immunotherapy, including checkpoint inhibitors and cytokine therapy, involve promoting, strengthening or re-engaging an immune response against RCC. The checkpoint inhibitor used to treat RCC targets PD-1, a protein on immune system cells called T-cells that normally helps keep these cells from attacking other cells in the body. By blocking PD-1, the checkpoint inhibitor boosts the immune response against cancer cells. This can shrink some tumors or slow their growth. Used as second-line therapy to treat RCC, this checkpoint inhibitor is given intravenously (through a vein in the arm or hand).

Cytokines are proteins in the body that activate the immune system. The biologic drugs used in cytokine therapy are versions of those proteins that have been made in a laboratory. The goal of cytokine therapy is to shrink the RCC tumor or slow its growth. These biologic drugs are used only in a small percentage of people with RCC because the drugs can have serious side effects and are often not effective in getting a response from the tumor. However, when a response does occur, it may be long-lasting. Cytokine therapy is given either intravenously (through a vein in the arm) or subcutaneously (by injection under the skin) and may be used in combination with or following targeted therapy.

**ORAL AND INTRAVENOUS TREATMENT MEDICATIONS**

→ **Some drugs to treat RCC** are taken orally (by mouth), and others are given intravenously (through a vein in the arm or hand). These treatments are considered “systemic” because the drugs travel through your entire body to kill cancer cells; because of this, some of the side effects can be similar (see page 12).

▼ **Oral Medications**

Oral medications can be in many forms, including liquid, tablet or capsule. Your treatment team will provide you with clear instructions on how to take your oral drugs, but it’s up to you to follow those instructions at home. You will see your treatment team at regular intervals to track how the RCC is responding to the medications, but the success of the treatment depends in part on medication adherence.

**Medication adherence**

Medication adherence refers to the extent to which a person follows instructions and guidelines for medications, as prescribed by the health care provider.

There are four key factors to proper medication adherence:

1. Taking the right drug
2. At the right dose
3. At the right time
4. On the right schedule

When people don’t follow their prescribed regimen exactly as prescribed, it’s called non-adherence. Most often, non-adherence is unintentional. If you miss one or more doses of your medication because you forgot to take it, let your health care provider know. If you are frightened about side effects, be sure to discuss your concerns with your medical team so they can assist you with your adherence.

Intentional nonadherence includes deliberately not refilling your prescriptions or taking less than recommended. Nonadherence can have a serious impact on your cancer care and can lead to increased side effects, unnecessary changes to the treatment plan, hospitalization and poor outcomes.

The most serious consequence of medical nonadherence is running the risk that your treatment will be ineffective. Studies show that not taking cancer medication as prescribed by a doctor can lead to cancer progression or recurrence. Because of how the drugs work, even small alterations to a treatment regimen can lead to failure.

It’s important to stick to your treatment plan exactly as your doctor prescribed. The only people who should alter it are members of your health care team. Treatment regimens are the most beneficial if decisions are shared by you and members of your health care team, so communicate often with them about any questions or concerns you have to be sure you’re taking your medication as prescribed.

▼ **Intravenous Medications**

Intravenous (IV) treatments can be given as either a short infusion (an “IV push”), in which the drugs are pushed from a syringe through a catheter (slender tube) for just a few minutes, or by an IV infusion, in which a drug solution steadily flows into your body for anywhere from a half hour to several hours.

On the day of your IV treatment, you may want to bring a friend or family member with you for support, and/or something to keep you busy, such as a book or knitting materials.

When you arrive at the medical facility, you will meet the health care professional who will give you your treatment. He or she will check your vital signs (temperature, blood pressure, pulse and respirations), measure your height and weight, and insert the IV catheter into a vein in your arm. You may have a blood sample drawn and tested to make sure your body is strong enough to receive treatment that day. (A sample of blood may be drawn instead before your vital signs are checked.) After the initial discomfort of the needle stick, you usually don’t feel any pain, burning, coolness or anything unusual as the drug infuses.

When your treatment session ends, the health care professional will remove the IV catheter and needle and discuss the potential side effects again. It can be helpful to drink plenty of fluids for several hours after your treatment to flush the drugs through your body. Talk to your doctor about what to expect from your specific treatment plan.

**ADDITIONAL RESOURCES**

- **American Cancer Society:** [www.cancer.org](http://www.cancer.org)
- **Kidney Cancer Association:** [www.kidneycancer.org](http://www.kidneycancer.org)
- **Therapies for Advanced Kidney Cancer**
- **National Cancer Institute:** [www.cancer.gov](http://www.cancer.gov)
- **What You Need to Know About Kidney Cancer**
Now that you have learned about the treatments available to treat renal cell carcinoma (RCC), you can talk with your doctor about which option may work best for you. Before making a recommendation, your doctor will consider your overall health along with the results of staging procedures and other tests. It’s possible your treatment plan may change, too. For example, if the pathologist finds cancer cells in the lymph nodes or the surgical margins after surgery, you may need additional treatment. Or, if your doctor determines that your kidney function is poor, some types of treatment may no longer be appropriate.

The options listed here by stage provide basic information about how your RCC may be treated. Many other details are involved, so make sure you discuss them with your treatment team.

**STAGE I**

A partial nephrectomy is the preferred treatment for Stage I RCC when the tumor is less than 4 centimeters (about 1.5 inches). If a partial nephrectomy is not possible because of where the tumor is located or other factors, a radical nephrectomy is the most common alternative. Ablative techniques, such as cryotherapy or radiofrequency ablation, are also options for tumors of this size, especially for people who cannot have surgery because of their overall health status. (However, ablative techniques have been associated with a higher risk of the cancer coming back.) A partial or radical nephrectomy is done for larger Stage I tumors (up to 7 centimeters, which is almost 3 inches).

A clinical trial may be an option (see Clinical Trials, page 16, for resources). Radiation therapy or arterial embolization may be used as palliative therapy or treatment to relieve symptoms.

**STAGE II**

A radical nephrectomy is the standard of care for Stage II tumors. A clinical trial may be an option (see Clinical Trials, page 16, for resources). Radiation therapy or arterial embolization may be used as palliative therapy.

**STAGE III**

A radical nephrectomy is the standard of care for Stage III tumors. A clinical trial may be an option (see Clinical Trials, page 16, for resources). Arterial embolization, surgery or radiation therapy may be used as palliative therapy.

**RECURRENT DISEASE AFTER SURGERY**

RCC recurs (returns) in approximately 20 to 30 percent of people with Stage I, II or III tumors that have been surgically removed. When RCC recurs, it’s usually within the first three years after surgery, and the recurrence may be in the kidney or at a distant site in the body. If the cancer recurs in the kidney and can be removed, a partial or radical nephrectomy may be done, assuming enough time has passed after the first procedure. If the cancer comes back outside the kidney, the treatment options are the same as for cancer that is Stage IV at the time of diagnosis.

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**SURVIVOR STORY | WILLIAM “BILL” BRO**

*Bill Bro was diagnosed with renal cell carcinoma in 1989, while his wife, Johanna, was pregnant with their second child. He conquered it, and strongly encourages others who are diagnosed with RCC to learn all they can about the disease and the resources available to provide support.*

I saw some blood in my urine while out to dinner with some friends who were visiting from Europe, so I drove myself to the hospital to get it checked. Once there, I passed out in excruciating pain. The next day, I received the cancer diagnosis, which weighed heavily on both Johanna and me. We were determined to conquer it, however, so I could be around for my young family.

Our first step was to find a new urologist. The urologist who initially diagnosed me had a less-than-desirable bedside manner. At the hospital, in fact, he told me, “You can only get a fatal disease once.” I fired him on the spot and began to search for other experts. I eventually found a new urologist, and during the week of Christmas 1989, I was successfully treated by a radical nephrectomy. The recovery from the surgery took about six weeks. Through everything, my family was very supportive. I needed the help of family and friends because my mobility was limited and I couldn’t drive. After about eight weeks, I returned to work full time.

If you are faced with an RCC diagnosis, I recommend contacting an organization such as the Kidney Cancer Association (KCA) to gain access to the latest information about diagnosis and treatment, along with support resources. It funds, promotes and collaborates on research projects with the National Cancer Institute, the American Society of Clinical Oncology, the American Urological Association and other institutions. KCA is made up of patients and their family members, physicians, researchers and other health professionals from around the world. It works to educate families and physicians and serves as an advocate on behalf of patients at the state and federal levels in the United States and globally.

I encourage you to build a support network and lean on your resources — because you are not alone.
Fears about the side effects of treatment can increase the stress of a renal cell carcinoma (RCC) diagnosis. These fears are often made worse by a belief that the discomfort of side effects cannot be relieved. However, it’s now possible to manage the common side effects of RCC treatment. Managing side effects is important because if you feel better, you’re more likely to complete your treatment as planned by your treatment team.

The side effects of cancer treatment differ in many ways. First, not all people treated for cancer will have the same side effects. A friend or relative may have had a certain side effect after treatment, but that does not mean you will experience the same side effect. Whether or not you have a side effect depends on many factors, including your age, your overall health and your specific treatment plan. Second, side effects vary in severity. Some cause minor inconvenience or discomfort, and others may cause more discomfort, pain and/or emotional distress. Lastly, side effects differ according to the type of treatment you receive.

### RECOVERING FROM SURGERY
Common side effects of surgery to treat RCC are weakness, fatigue, pain and discomfort, which usually lessen after a few days. Depending on how severe your pain is, your doctor may prescribe a pain medication or recommend over-the-counter pain relievers. Your doctor will also suggest that you get plenty of rest and avoid doing too much. It’s important to know that your mobility may be limited for a brief time after surgery. In addition, you should drink plenty of fluids and eat healthy foods while you’re recovering from surgery.

Your doctor will look for any signs of bleeding, infection or other complications that can occur after surgery and will treat any issues that come up.

If one kidney is entirely removed, it may take some time for your remaining kidney to adjust to its new workload. One kidney is typically able to handle the work of two kidneys, but that’s not always the case. If your remaining kidney cannot properly clean your blood, you may need either dialysis or a kidney transplant.

### SIDE EFFECTS OF CANCER MEDICATIONS
Although the side effects from chemotherapy, immunotherapy and targeted therapy have some differences, several of their most common side effects are the same.

It’s extremely important to talk openly with your doctor about any side effects you have. Keep a journal about your symptoms, and list what the side effect is, when it started, how severe it is and any other relevant information. Take your journal with you and share it with your doctor at every office visit. Your doctor will tell you when you should call your treatment team about specific side effects.

If you are receiving immunotherapy, as with any cancer treatment, partnering with your doctor to monitor for complications is vital. Your doctor likely will perform baseline assessments to determine what is normal for you; the results of these assessments can be compared with those obtained throughout treatment. You will play a key role in detecting what is abnormal for you and communicating that to your doctor immediately, so it is important to know how to recognize serious side effects, known as immune-mediated adverse reactions, as some of these reactions may not produce obvious symptoms.

All medications have different side effect profiles, so be sure to read about the specific

### WHAT YOU CAN DO TO MANAGE SIDE EFFECTS

#### MANAGING FATIGUE
- Increase activity. Most people think more rest will help relieve fatigue, but the opposite may be true.
- Perform regular exercise (such as walking or riding a bike).
- Follow your doctor’s recommendations. For severe fatigue, your doctor may recommend taking a psychostimulant drug for a short period of time. This type of drug helps improve alertness during the day and raise your energy level while also decreasing fatigue.

#### MANAGING NAUSEA AND VOMITING
- Take antiemetics as recommended by your doctor. If you will be receiving treatment that is likely to cause nausea and vomiting, your doctor may recommend antiemetics, which are drugs that prevent and control nausea and vomiting. Most antiemetics can be given as either a pill or an intravenous injection.
- Try some nondrug approaches to further protect yourself against nausea and vomiting. These approaches include progressive muscle relaxation, biofeedback, guided imagery, self-hypnosis and acupuncture.
- Eat several small meals a day rather than a few big meals.
- Drink plenty of fluids to stay hydrated.
- Avoid unpleasant odors.

#### MANAGING DIARRHEA
- Follow a diet of only clear liquids so the lining of your intestines can heal. Once diarrhea begins to improve, you can slowly add solid foods to your diet, starting with low-fiber foods such as white rice or boiled potatoes.
- Avoid foods that can worsen diarrhea, including dairy products; spicy, greasy or fried foods; raw fruits or vegetables; or foods high in fiber.
- Ask your doctor if you can take over-the-counter medicines and supplements and if you can follow the instructions on the drug label.
- Follow your doctor’s recommendations. If diarrhea is severe, your doctor may prescribe other medications or choose to stop treatment temporarily until your diarrhea is controlled.

#### MANAGING MOUTH SORES
- Keep your mouth and lips moist by using lip balm, sipping on water, sucking on ice chips and drinking through a straw.
- Choose soft, moist foods that are easy to swallow, such as mashed potatoes and scrambled eggs, and always let your food cool down to room temperature before you eat.
- Avoid hot, spicy, acidic, greasy, fried, coarse or rough-textured foods.
- Avoid alcoholic beverages and tobacco products.

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**SURVIVOR VOICE**

Rose C.

"Take advantage of all the support that’s available, and focus on eating cancer-fighting foods."
side effects associated with your treatment and always remember to talk to your doctor — ideally before treatment begins — about the best ways to manage them. Also, make sure your treatment team and all of your other health care professionals (primary care clinician, dentist, etc.) know all the drugs you’re taking. Tell your cancer treatment team about any medications you take for other health issues, as well as herbal supplements you may take, as some may interfere with your cancer treatment.

**Fatigue**

Treatment-related fatigue occurs primarily because the body needs extra energy to repair the healthy tissue damaged by cancer treatment. In addition, other side effects of treatment, such as pain, nausea and vomiting, can cause or worsen fatigue.

**Nausea and vomiting**

Nausea and vomiting occur as the result of a series of reactions between your stomach and your brain, and these reactions start when cancer drugs damage the cells lining the inside of the stomach. The cells send signals to an area in your brain that sends signals to trigger nausea and vomiting. Nausea and vomiting are easier to prevent than to control once they’ve started.

**Diarrhea**

Diarrhea is the passing of loose or watery stools three or more times a day and may be accompanied by cramps in the abdomen and pain or discomfort in the rectum. When mild, diarrhea is an inconvenience, but, left untreated, it can lead to serious problems, such as dehydration, loss of important nutrients, weight loss and fatigue. Treatment-related diarrhea is a short-term side effect that typically occurs within the first few days after treatment starts and usually resolves within a few weeks after treatment stops.

**Mouth sores**

Mouth sores may form in the lining of the inside of the mouth and can affect the gums, tongue, roof of the mouth or lips. Mouth sores sometimes begin as mild pain or burning, followed by the development of white patches that may become large red lesions. Pain may range from mild to severe, making it difficult to talk, eat or swallow. Also, infection may develop if bacteria enter the open sores. Taking good care of your teeth and gums is essential to managing mouth sores, and you should brush and floss several times a day. Your doctor may suggest rinsing with special solutions or may prescribe a medication that coats the lining of your mouth or pain medications that can be topically applied.

**Skin reactions**

Talk to your treatment team about possible skin reactions, as some may be more serious than others. Skin reactions to cancer treatments are common and include redness and irritation (similar to sunburn), rash, or dry, flaky skin. These reactions often cause itchiness and discomfort, and most are mild to moderate; however, some reactions can become severe if not treated early. If a rash develops that causes itchiness or pain, your doctor may prescribe a mild corticosteroid cream or an antibiotic gel. Severe rashes are usually treated with an oral antibiotic and perhaps an oral corticosteroid. When a rash is severe, the dose of the cancer drug(s) may be reduced or temporarily stopped and then restarted if the rash gets better within two weeks.

**Metabolic issues**

Metabolic issues, such as hyperlipidemia and hyperglycemia, may arise from some RCC therapies. Hyperlipidemia is a condition of excess lipids (fats) in the bloodstream and occurs when total cholesterol, low-density lipoprotein (LDL) and triglyceride levels are high. Hyperglycemia is a high level of sugar in the bloodstream; it occurs when the body does not have enough insulin and begins using fatty acids instead of glucose (sugar) as its energy source. Hyperglycemia can result in diabetes if it’s not treated in time. Your doctor will regularly monitor for both of these issues and may recommend weight loss, more exercise, or avoidance of simple sugars and alcohol to manage them. Medications to lower your lipid or sugar levels in the blood are also available if your doctor thinks they’re necessary.

**RECOVERING FROM RADIATION THERAPY**

Although radiation therapy is not typically used to treat RCC, it may be used in some treatment plans and is often associated with certain side effects. Because radiation is delivered directly to the kidneys from outside the body, the skin and underlying tissues in the area being treated may become sensitive. This can lead to redness, dryness, peeling and itchiness. This sensitivity is short term and usually resolves gradually within two months after treatment stops. Other side effects include fatigue, anemia, hair loss in the area treated, nausea and vomiting. No matter which treatment you have, frequent communication with your health care team is important for monitoring your symptoms. Seek treatment immediately, regardless of time of day, for any medical emergencies, including high fever, inflammation, swelling, severe abdominal pain or shortness of breath.

**POSSIBLE SIDE EFFECTS BY TREATMENT TYPE**

<table>
<thead>
<tr>
<th>CHEMOTHERAPY</th>
<th>IMMUNOTHERAPY</th>
<th>TARGETED THERAPY</th>
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<tr>
<td>Anemia</td>
<td>Bumpy or itchy red rash</td>
<td>Diarrhea</td>
</tr>
<tr>
<td>Cognitive dysfunction (“Chemo brain”)</td>
<td>Cough</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Constipation</td>
<td>Depression</td>
<td>Hand-foot syndrome</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>Dyspnea (difficulty breathing)</td>
<td>Diabetes</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Flu-like symptoms (headache, muscle aches, fever)</td>
<td>Nausea</td>
</tr>
<tr>
<td>Hair loss</td>
<td>Nausea and vomiting</td>
<td>Swelling</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>Skin reactions</td>
<td>Weakness</td>
</tr>
<tr>
<td>Mouth sores</td>
<td>Skin and nail changes</td>
<td>Weakness</td>
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<tr>
<td>Neutropenia</td>
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<td>(low white blood cell count)</td>
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**MAKE A PEER-TO-PEER CONNECTION**

Get introduced to another RCC survivor.
Sign up for the Patient Matching Service at PatientResource.com
Some types of treatment can remove or destroy kidney cancer, but care for people with renal cell carcinoma (RCC) doesn’t end when active treatment is completed. Your health care team will follow up with you on a regular basis to monitor your overall health, make sure the cancer has not metastasized (spread) or returned (called recurrence) and manage any side effects or late effects. This is known as follow-up care.

You and your doctor should work together to create a personalized follow-up care plan. You may choose to work with your oncologist or your primary care physician for follow-up care. Before making that decision, consider the type and stage of your cancer, potential side and late effects you may be facing, your health insurance and your comfort level.

Your follow-up care plan likely will include schedules and other information to manage the following.

ROUTE CARE AND RECURRENCE
Cancer recurs because small areas of cancer cells may remain undetected in the body, sometimes only showing up on test results or through symptoms after they have increased in number over time. As a result, it’s very important to attend all of your follow-up appointments. During those appointments, your doctor can give you personalized information about your risk of recurrence.

To track your condition, your doctor likely will order physical examinations and/or medical tests in your follow-up care. Routine follow-up care usually includes regular blood tests to check kidney function and chest X-rays, CT scans of the abdomen and chest and other imaging tests to watch for recurrence or metastasis (cancer that has spread to another part of the body). Your schedule for and type of follow-up appointments will depend on your original diagnosis and the type of treatment you received. If you had surgery to remove a kidney and are living with one kidney, for example, your kidney function will be monitored for the rest of your life.

Another reason to be diligent about follow-up appointments is because being treated for kidney cancer doesn’t mean you can’t get a different type of cancer. People who have had kidney cancer have an increased risk for a second kidney cancer (not a recurrence of the first cancer), bladder cancer, cancer of the ureter (the tube that connects the kidney to the bladder), prostate cancer, thyroid cancer and melanoma of the skin.

Communication is crucial to your follow-up care. Keep a list of your questions to take to your appointments. Use these appointments to talk to your health care team about any changes in your health or new problems or symptoms you notice, no matter how minor they may seem, in addition to any general questions or concerns you have. If you see doctors who were not directly involved in your cancer care, it’s helpful to share your cancer treatment summary and follow-up care plan forms with them.

SIDE EFFECTS AND LATE EFFECTS
Each type of treatment for kidney cancer has side effects that can last from a few weeks to a few months, throughout treatment or for the rest of your life (see Side Effects, page 12). Some side effects begin when treatment begins, and others may not appear until much later. These are known as late effects. Late effects can cause physical and emotional changes.

Talk with your doctor early on, if possible, about your risk for the development of side and late effects based on the type of treatment you had so you can be prepared for what to expect. Continually communicating with your health care team about your symptoms may help you manage these effects more successfully.

MEDICAL HISTORY
You may find yourself seeing a new doctor who is unaware of your RCC history. It’s important to be able to give your new doctor the details of your diagnosis and treatment. Gathering these details soon after treatment may be easier than trying to get them later. Keep copies of the following for any new doctor you see and for yourself:

- Pathology report(s) from any biopsies or surgeries
- Operative report (if you had surgery)
- Treatment summary (list of the drugs you received, including the dose and schedule, and details on radiation therapy, if you received it)

ADDITIONAL RESOURCES
- American Cancer Society: www.cancer.org
  What Happens After Treatment for Kidney Cancer?
- American Society of Clinical Oncology: www.cancer.net
  Kidney Cancer: Follow-Up Care
  Kidney Cancer: Survivorship
- Kidney Cancer Association: www.kidneycancer.org
- National Cancer Institute: www.cancer.gov
  What You Need To Know About Kidney Cancer

EMOTIONAL SUPPORT
Finishing treatment or moving to a less frequent treatment schedule may be exciting for some people but may cause worry for others. You may feel a variety of emotions during and after your cancer treatment:

- You may be anxious that your cancer will recur or that another type of cancer will develop.
- Without frequent doctor’s appointments, the additional free time you have in your schedule may make you feel unsettled.
- Going back to work and interacting with coworkers and friends may be a difficult transition.
- Financial concerns may weigh heavily on your mind.
- You may feel the need to re-evaluate the personal or business relationships in your life.

All of these emotions are valid. Just like during treatment, you are not alone. It’s important to remember that you don’t have to try to sort out these feelings on your own.

Different sources of support include friends and family members, religious or spiritual groups, local and online support groups or a counselor. Think about how you relate to others and whether you’d prefer one-on-one type of support or interacting with others in a group setting. Choose a forum that best fits your personality. If you aren’t sure where to get help, ask your health care team for a referral.
Living a healthy physical and emotional lifestyle is essential both during and after treatment for renal cell carcinoma (RCC). You can help yourself feel more in control by learning as much as you can about the specific characteristics of your subtype of RCC, your treatment options and the ways you can help make yourself healthier, both physically and emotionally.

Many people with RCC have credited a balance of regular exercise and plenty of rest to feeling better during and after treatment. Healthy eating habits are also beneficial, as they can help people achieve — and maintain — a healthy weight. Spending time with family and friends, getting involved in support groups and/or participating in religious or spiritual organizations are also helpful to many people treated for RCC.

Following are suggestions for managing some of the lifestyle obstacles you may face during treatment. Taking these actions can help you feel better both physically and emotionally, allowing you to better cope with the day-to-day challenges.

**MAINTAIN GOOD NUTRITION**
It’s important to make healthy choices when it comes to nutrition before, during and after treatment. This can be a challenge because you may not feel like eating if you have side effects, such as loss of appetite or nausea and vomiting. Or, you may find that foods don’t agree with you and these tips:
- **Eat** a wide variety of nutrient-rich foods, such as fruits and vegetables, and be sure you are getting enough protein.
- **Drink** plenty of liquids.
- **Eat** several small meals throughout the day instead of three big meals.
- **Try** drinking ginger ale or peppermint tea because ginger and peppermint can help with nausea.
- **Talk** to your doctor about whether you need calcium and vitamin D, either in your diet or as supplements. Some cancer treatments can cause loss of bone mass, and these vitamins help strengthen bones.
- **Conserv**e your energy. Plan activities at times of the day when you feel your best.
- **Take** a break from daily chores, such as cooking or cleaning, by accepting help from others.
- **If** you don’t get relief, talk with your health care team. Your doctor may change your medications if he or she thinks that drug interactions or side effects are contributing to your sleep problems. Your doctor may also recommend a medication to help you sleep.

**STAY EMOTIONALLY HEALTHY**
A cancer diagnosis can cause significant emotional reactions. Allowing yourself to express those emotions freely is vital to remaining emotionally healthy. Discovering ways to reduce and manage stress will strengthen your coping abilities. Try these tips:
- **Practice** meditation, guided imagery, muscle relaxation and yoga.
- **Relax** with ordinary “escapes,” such as reading, television or games.
- **Participate** in online or in-person support groups.
- **Maintain** relationships. Chat with a friend or family member about something completely unrelated to cancer. Maintaining relationships can go a long way toward good emotional health.
- **Stay** alert for signs of depression, and seek help if you experience a depressed mood and a loss of interest in normal activities.

**GET ENOUGH REST**
Sleep disturbances are common among people with cancer. One reason is that fatigue related to cancer and its treatment leads people to take frequent naps during the day, which then makes it difficult to sleep at night. Try these tips:
- **Set** aside time in your day to rest or take naps, but limit them to 20 to 30 minutes each.
- Avoid napping in the late afternoon or early evening.

**ADDITIONAL RESOURCES**
- **American Cancer Society**: www.cancer.org Nutrition for the Person With Cancer During Treatment
- **American Society of Clinical Oncology**: www.cancer.net Healthy Living
- **National Cancer Institute**: www.cancer.gov Nutrition in Cancer Care

**HEALTHY LIVING**

**CHOOSE HEALTHY FOODS**

**SLEEP WELL**

**FOCUS ON EMOTIONAL HEALTH**
BASIC LIVING EXPENSES

Bringing Hope Home ........................................www.bringinghopehome.org, 484-589-8385
The CHAIN Fund Inc ...........................................www.thechainfund.com, 203-691-5955
Cleaning for a Reason (free house cleaning) ......www.cleaningforeason.org, 877-337-5348
Family Reach Foundation ...............................www.familyreach.org, 973-394-1411
Hugs and Kisses ..............................................www.hugsandkissesinc.org, 561-819-9471
Life Beyond Cancer Foundation .................www.needhelppayingbills.com, 281-791-7549
Team Continuum ........................................www.teammcontinuum.net, 846-569-5621
Zichron Shime Refuah Fund ............................www.zsrf.org, 718-GET-WELL

CANCER EDUCATION

Alex’s Lemonade Stand Foundation for Childhood Cancer ...............................www.alexlemonade.org
American Cancer Society ..........................................www.cancer.org
American Society of Clinical Oncology ...........................................www.cancer.org
CANCER101 ......................................................www.cancer101.org
CancerCare ..................................................www.cancer.org
cancer.org
CancerGuide ..................................................www.cancer.org
CancerQuest ..................................................www.cancerquest.org
Centers for Disease Control and Prevention (CDC) ..............................www.cdc.gov
The Gathering Place ........................................www.touchedbycancer.org
Get Palliative Care ........................................www.getpalliativecare.org
Global Resource for Advancing Cancer Education (GRACE) .............www.gracecancer.org
The Hope Light Foundation .......................................www.hopelightproject.com
LIVESTRONG Foundation ........................................www.livestrong.org
National Cancer Institute ..........................................www.cancer.gov
National Comprehensive Cancer Network (NCCN) .......................www.nccn.org
National LGBT Cancer Network ........................................http://cancer-network.org
OncoLink .....................................................www.oncolink.org
Patient Power ................................................www.patientpower.info
PearlPoint Cancer Support ...............................................www.pearlpoint.org
Pine Street Foundation ........................................www.pinenestfoundation.org
R.A. Bloch Cancer Foundation .........................................www.blochcancer.org
Scott Hamilton Cares Foundation ........................................www.scottcares.org
Triage Cancer ..................................................www.triagecancer.org

CAREGIVERS & SUPPORT

4th Angel Patient & Caregiver Mentoring Program ...............................www.4thangel.org
Bloom Cancer Hotline ...........................................800-433-0484
CanCare .........................................................www.cancercare.org
CANCER101 ......................................................www.cancer101.org
Cancer Action ..................................................www.canceractionlfc.org
Cancer and Careers ............................................www.cancerandcareers.org
CancerCare .....................................................www.cancer.org
Cancer Connection .............................................www.cancerconnection.org
Cancer Hope Network ...........................................www.cancerhopefoundation.org
Cancer Information and Counseling Line .........800-525-3777
Cancer Really Sucks! ........................................www.cancerreallylucks.com
Cancer Support Community ........................................www.cancersupportcommunity.org
Cancer Support Helpline ....................................888-793-9355
Cancer Survivors Network ........................................www.cancerlifescenter.org
Cancer Wellness Center ........................................www.cancerwellness.org
Caregiver Action Network ........................................www.caregiveraction.org
CaringBridge ....................................................www.caringbridge.org
Center to Advance Palliative Care .................................www.capc.org
Cleaning for a Reason ........................................www.cleaningforeason.org
Cooking with Cancer ..........................................www.cookingwithcancer.org
Cuddle My Kids .............................................www.cuddlemymkids.org
Family Caregiver Alliance ........................................www.caregiver.org
Fighting Chance ................................................www.fightingchance.org
Finding Comfort Cancer Support Network ......................www.findingcomfort.org
The Gathering Place ........................................www.touchedbycancer.org
Guide Posts of Strength, Inc .......................................www.cancer.org
The Hope Light Foundation ........................................www.hopelightproject.com
Imeman Angels .................................................www.imemanangels.org
Kidney Cancer Association........................................www.kidney.org
Support Community ........................................www.cancer.org
The LGBT Cancer Project – Out With Cancer ..................www.lgbtcancer.org
LIVESTRONG Foundation ........................................www.livestrong.org
LivingWell Cancer Resource Center ...............................www.livingwell.org
Lotsa Helping Hands ........................................www.lotsahelpinghands.com
MyLifeLine.org Cancer Foundation .....................................www.mylifeline.org
Patient Empowerment Network ........................................www.patientpower.org
PearlPoint Cancer Support ...............................................https://my.pearlpoint.org
SHARE Caregiver Circle ...........................................www.sharingcaring.org
Strike Out Cancer ..............................................www.strikeoutcancer.com
Stronghold Ministry .............................................www.stronghold.org
Support Groups ................................................www.supportgroups.com
Triage Cancer ..................................................www.triagecancer.org
Turning Point ..................................................www.turningpointtc.org
Vital Options International ........................................www.vitaloptions.org
Walk With Sally ................................................www.walkwithsally.org
Well Spouse Association ........................................www.wellsupecancer.org
weSPARK Cancer Support Center ......................................www.wespark.org
Wonders & Worries .............................................www.wondersandworries.org

CHILD CARE EXPENSES

Brenda Mehleng Cancer Fund (patients 18–40) .....................www.bmcf.net, 661-310-7940
Cancer Care ......................................................www.cancersupport.org, 800-813-HOPE
Family Reach Foundation ........................................www.familyreach.org, 973-394-1411

CLINICAL TRIALS

ACCESS ..........................................................www.access.cancer.gov
AccrualNet ................................................................http://accrualnet.cancer.gov
ACT (About Clinical Trials) ........................................www.learnaboutclinicaltrials.org
Center for Information and Study on Clinical Research Participation .............................................www.cancer.gov
CenterWatch ....................................................www.centerwatch.com
ClinicalTrials.gov ...............................................www.clinicaltrials.gov
Coalition of Cancer Cooperative Groups ........................................www.cancertrials.org
LIVESTRONG Foundation ........................................www.livestrong.org
PearlPoint Cancer Support ...............................................https://my.pearlpoint.org
MolecularMatch ..................................................www.molecularmatch.com
My Clinical Trial Locator ...........................................http://myclinicaltriallocator.com
National Cancer Institute ........................................www.cancer.gov
Stand Up To Cancer .............................................www.standup2cancer.org
TrialCheck ........................................................www_trialcheck.com

COMPLEMENTARY PROGRAMS & ALTERNATIVE MEDICINE

Believe Big ........................................................www.believebig.org
The Center for Mind-Body Medicine ........................................www.cbmi.org
National Center for Complementary and Integrative Health ........www.nccn.org
Society for Oncology Massage ........................................www.s4om.org
Touch, Caring and Cancer ........................................www.partnersinhealing.net

FERTILITY & CANCER

Alliance for Fertility Preservation ........................................www.allianceforfertility.org
American Society for Reproductive Medicine ........................................www.asrm.org
LIVESTRONG Foundation ........................................www.livestrong.org
RESOLVE: The National Infertility Association ........................................www.resolve.org
SaveMyFertility ................................................www.savedsfertility.com

GOVERNMENT ASSISTANCE

Administration on Aging ........................................www.aoa.gov, 202-401-4634
Benefits.gov .....................................................www.benefits.gov, 800-FED-INFO
Centers for Medicare & Medicaid Services .............................www.cms.gov, 888-MEDICARE
Hill-Burton Program .............................................www.hrsa.gov/gethealthcare/affordable/hillburton
Legal Services Corporation ........................................www.lsc.gov, 202-295-1500
Medicare Rights Center ........................................www.medicare.gov, 800-333-4414
Social Security Administration ........................................www.ssa.gov, 800-772-1213
Social Security Disability Resource Center ........................................www.ssdrc.org
State Health Insurance Assistance Programs ......................www.shiap.org
U.S. Department of Veterans Affairs ....................................www.va.gov/health/index.asp

HOUSING DURING TREATMENT EXPENSES

American Cancer Society (Hope Lodges) ........................................www.cancer.org, 800-227-2345
Brenda Mehleng Cancer Fund (patients 18–40) .....................www.bmcf.net, 661-310-7940
Fish House Foundation .............................................www.fishhouse.org, 888-294-8560
Hospitality Homes ..............................................www.hosp.org, 888-959-4678
Joe’s House ........................................................www.joeshouse.org, 877-563-7468
Healthcare Hospitality Network, Inc .....................................www.hhnetwork.org, 800-542-9730