WHAT YOU SHOULD KNOW ABOUT

Metastatic Kidney Cancer
Learning the basics of metastatic kidney cancer

If you or a family member has been diagnosed with metastatic kidney cancer (also known as metastatic renal cell carcinoma or mRCC), this brochure will provide information that can help you learn about the disease and help you focus on what matters most to you. There can be a lot of information to understand, but you are not alone. You have the help of your health care team, support from loved ones, and this booklet to keep you moving forward. Whether you have metastatic kidney cancer or are helping to care for a loved one who was diagnosed with the disease, you are taking a positive step by learning about mRCC and taking an active role in its treatment.

On the next pages, you will find information about metastatic kidney cancer and suggestions on how to speak with your health care team. Remember, always discuss any questions you may have with your doctor and health care team, and keep this resource on hand to refer to as you gather important information throughout your journey.

Your treatment glossary:

**Boldface** words are defined in a glossary on page 15. If there are words about your condition or treatment that you do not understand, ask your doctor or health care team to explain them further.
Understanding your kidneys

As you learn about metastatic kidney cancer, it is helpful to know what the kidneys do. The kidneys are a pair of bean-shaped organs about the size of a fist. They are on either side of the spine, attached to the back wall of the lower abdomen, and are protected by the rib cage. Each kidney has an adrenal gland attached to the top of it, which makes hormones that help control heart rate, blood pressure, and other important body functions. The adrenal glands and kidneys are wrapped in a mass of fatty tissue and an outer layer of fibrous tissue.

The kidneys are part of the urinary tract. Their main job is to filter blood and help your body get rid of extra water, salt, and waste products, which they turn into urine. Urine leaves the kidneys through long tubes called ureters that connect to the bladder. Your bladder stores the urine until you urinate.

The kidneys also make hormones that help control blood pressure and the production of red blood cells.
Understanding your kidneys (continued)
Understanding metastatic kidney cancer

Kidney cancer usually begins as a mass of abnormal cells in the kidney that begins to grow out of control and forms a growth, or a **primary tumor**. These cells can be found in more than one part of the kidney, or both kidneys, at the same time. These cancer cells can break away from the tumor, travel through the bloodstream or **lymph system**, and form a new tumor in other parts of the body. This spreading process is called **metastasis**, and your health care team may refer to this type of cancer as metastatic, or stage IV kidney cancer. Even though the cancer can spread and form new **metastatic tumors** in other parts of the body, the cells come from the primary tumor that originated in the kidney, so it is still considered kidney cancer.

**A genetic factor**

Although doctors don’t know exactly what causes kidney cancer, there are a few factors and one in particular is associated with the disease. It is called von Hippel-Lindau (VHL) syndrome. VHL is a rare condition caused by an abnormal VHL gene that can increase your risk of kidney cancer. Family members of someone with this syndrome can have a test to check for the abnormal VHL gene.
What are the stages of kidney cancer?

Stages are determined by the size of the tumor, lymph node involvement, and whether the tumor has spread. The stage of kidney cancer is an important factor when selecting treatment options.

**Stage I**
The tumor is 2 3/4 inches or smaller, and the cancer cells are found only in the kidney.

**Stage II**
The tumor is larger than 2 3/4 inches, and the cancer cells are found only in the kidney.
**Stage III** One of the following has occurred:

- The tumor is in the kidney, but cancer cells have spread to one nearby lymph node
- The tumor has spread to the adrenal gland, fatty tissue around the kidney, and/or a nearby vein

**Stage IV** One of the following has occurred:

- The tumor extends beyond the tissue surrounding the kidney
- Cancer cells are found in more than one nearby lymph node
- The cancer has spread to other places in the body, such as the lungs

Metastatic kidney cancer is considered stage IV, which means that it has spread to other places in the body. If you have any questions about your stage, ask your health care team, "Has the cancer spread to other parts of my body? If so, where?"
You’re unique, and so is your cancer

Although everyone with metastatic kidney cancer has cancer that has spread, cancer can affect people differently. This means that you will need to talk about your health and personal goals with your doctor and health care team to make sure that you are getting the maximum benefit from each and every medicine you decide to take. Some factors that may influence the type of treatment you and your health care team decide to choose include:

- Age
- Your physical health
- Stage of cancer
- Prior treatment
- Possible side effects of the treatment
- Your personal and treatment goals

Your health care team wants to know

Your health care team, which includes your oncologist, your primary care doctor or urologist, nurses, and your family members, plays a vital role in your treatment. When discussing and creating a plan to fight your cancer, be sure to tell your health care team how you feel. Let them know what you think about the therapies available to you. Every person approaches treatment differently, so try to work with your health care team to come up with the right plan for you.
Taking an active role

Even though you have metastatic kidney cancer, you still have a life to live. Taking an active role means doing everything you can do to feel better and to manage your treatment goals and plans. Here’s how you can start:

1. **Understand your treatment.** Know the anticancer treatments you are given and what to expect. Keep a record of your medicines, when to take them, and the possible side effects. Work with your doctor and health care team—ask questions so that you can understand how your medicines work. See the example questions on page 11 to get started.

2. **Talk to your doctor about your treatment goals.** Share your medical history with your doctor, and share your goals for treatment. Some discussions may feel uncomfortable because you are sharing personal information, but being honest about what you want from your treatment can help ensure that you get the best treatment available for you.

3. **Share how you’re feeling with your health care team.** Keep track of how you’re feeling, and write down any side effects you notice in a notebook. Then talk to your health care team so they can provide the best care for you. They may be able to help you feel better.

4. **Stay involved in all decision making.** Learn as much as you can about kidney cancer by seeking out information or talking with other people with metastatic kidney cancer. The following pages have contact information to help you learn more about metastatic kidney cancer. Knowing more about your disease will help you and your health care team make the best possible treatment decisions for you.
Staying on therapy

Doing everything you can do to move forward with your therapy includes following your treatment plan as closely as possible. This means sticking to your doctor’s directions and staying on therapy for as long as needed.

If you experience a side effect that makes it difficult to stay on therapy, talk to your doctor or health care team about figuring out a way to make it easier. A member of your health care team should be able to help you manage some of your side effects that bother you or that do not go away, such as nausea or vomiting.
Questions to ask your health care team

Having open, honest discussions with your health care team means asking questions and understanding what will happen before, during, and after your treatments. Here are a few questions to help you get started:

1. Which treatments will I be receiving, and what will they do?
2. What can I do to take care of myself during treatment?
3. Should I change my diet?
4. What is the schedule of my treatments?
5. Where will I go for treatment?
6. How long will I be on each treatment?
7. How will I know if the treatment is working?
8. Which side effects should I look out for?
9. Whom do I call if I want more information and support?
Many people living with cancer find that they can learn and get the support they need when they read about cancer or talk to others who are also living with cancer. Remember that you are not alone in your fight against cancer. Here are some ways to connect with other people and get and give support:

- Join a support group, either in person or on the Web
- Volunteer to help others with kidney cancer—offer your story
- Become a kidney cancer educator or speaker
- Attend social events to meet other people who are living with kidney cancer
- Ask a member of your health care team if you could call him or her for support. Calling a health care professional who has a strong presence in your care may help you stay connected and feel less alone
Where to find support groups and resources

Many national organizations offer local and online support groups for people with cancer and their family members or friends. Some places to start your search for a local group include:

**Kidney Cancer Association***
Provides education about kidney cancer, as well as support groups and physician referral information to cancer patients and their families.
1-800-850-9132
www.kidneycancer.org

**CancerCare***
Provides free counseling, education, financial assistance, and practical help to those with cancer and their caregivers.
1-800-813-HOPE (1-800-813-4673)
www.cancercare.org

**Cancer Wellness Center***
Offers professionally led support groups and patient counseling regarding the emotional issues of living with cancer.
1-866-292-9355
www.cancerwellness.org

**Cancer Support Community***
Professionally led support groups, educational workshops, nutrition and exercise programs, and mind/body classes.
1-888-793-WELL (1-888-793-9355)
www.cancersupportcommunity.org

**American Cancer Society***
Cancer information services, community programs, and research and advocacy resources.
1-800-ACS-2345 (1-800-227-2345)
www.cancer.org

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Local hospitals and cancer clinics are also good sources for finding support groups. Doctors, nurses, and hospital social workers may have information about support groups such as their location, size, type, and how often they meet. Hospitals also have social services departments that usually can provide information about cancer support programs.

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Glossary

**Abdomen:** The area of the body that contains the pancreas, stomach, intestines, liver, gallbladder, and other organs. (See page 3.)

**Adrenal gland:** A small gland on top of each kidney that makes steroid hormones, adrenaline, and noradrenaline. These hormones help control heart rate, blood pressure, and other important body functions. (See page 3.)

**Lymph node:** A rounded mass of lymphatic tissue that is surrounded by a capsule of connective tissue. (See page 6.)

**Lymph system:** The tissues and organs that produce, store, and carry white blood cells that fight infections and other diseases. (See page 5.)

**Metastasis (metastatic):** The spread of cancer from the primary site or origin to distant sites in the body. (See page 5.)

**Metastatic tumor:** A tumor that develops in a different location than the primary tumor as a result of the spreading of the primary tumor cells. (See page 5.)

**Primary tumor:** The original tumor (eg, a primary kidney tumor is one that first appears in the kidney as opposed to a metastatic tumor, which would develop in a different location as a result of the spreading of the primary tumor cells). (See page 5.)

**Tumor:** An abnormal lump or mass of tissue, which can be cancerous (malignant) or noncancerous (benign). (See page 5.)

**Ureters:** The tubes that carry urine from the kidneys to the bladder. (See page 3.)

**Urinary tract:** The organs of the body that produce and discharge urine. It includes the kidneys, ureters, bladder, and urethra. (See page 3.)

Some of the glossary definitions were adapted from the National Cancer Institute’s *Dictionary of Cancer Terms.*
Resources

There are many resources with useful information for people with cancer and their families. Take advantage of all the information to help you learn more and stay well informed.

**American Cancer Society**
Cancer information services, community programs, and research and advocacy resources.
1-800-ACS-2345 (1-800-227-2345)
www.cancer.org

**National Cancer Institute**
Current information about cancer, clinical trials, and resources.
1-800-4-CANCER (1-800-422-6237)
www.cancer.gov

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