

Understanding Kidney Cancer



Kidney Cancer ranks as one of the top 10 most common cancers in the United States. This fact sheet will provide an overview of kidney cancer, details on diagnosis and treatment, and important members to have on your care team. It will also discuss the potential physical, emotional, and social impacts this cancer diagnosis may have on you and your loved ones.

WHAT IS KIDNEY CANCER?

Kidney Cancer is cancer located in one or both kidneys. The kidneys are bean-shaped organs located on either side of your spine near the lower part of your rib cage. Kidneys filter the blood and remove waste and any extra fluid from the body as urine. Most kidney cancers are Renal Cell Carcinomas (RCC). About 10% of kidney cancers are either Urothelial Carcinomas or other very rare types of kidney cancer. Benign, or non-cancerous, kidney tumors can also occur in people. Common signs and symptoms of kidney cancer include blood in the urine, pain in the lower back, unexplained weight loss, fatigue, fever, and night sweats. If you are experiencing any of these symptoms, speak to your doctor. Most of the time, kidney cancer is diagnosed incidentally, without you having any symptoms.

For more resources and additional information about kidney cancer, visit www.CancerSupportCommunity.org/Kidney-Cancer.

THERE ARE TWO MAJOR SUBTYPES OF RCC.

Clear Cell RCC - The most common subtype of RCC, making up about 80% of all kidney cancers

Non-clear Cell RCC - About 20% of all kidney cancers are not clear cell, and include papillary, chromophobe and many less common variants.

DIAGNOSING AND STAGING KIDNEY CANCER

There are some different procedures that your doctor may recommend to determine your specific kidney cancer diagnosis. They may have you complete imaging so that they can visualize the kidney. This may include a CT scan, MRI, or ultrasound. These imaging methods will help the care team diagnose and stage your type of kidney cancer. A biopsy on the affected area of the kidney may also be done. This is a procedure where a small needle is inserted that removes a sample of the cells in the tumor. Further analysis is performed in a lab that also provides information to make the exact diagnosis. For kidney cancer, a biopsy may sometimes be done before surgery or other treatment.

A staging system is used to help oncologists categorize kidney cancer. The stage is an important characteristic of the tumor that will inform the treatment process. The stages of kidney cancer include stage I (1), II (2), III (3), and IV (4). Stage I indicates the cancerous tumor is small and is contained within the kidney. Stage IV means that the cancerous tumor has spread, or metastasized, to other areas of the body. Kidney cancer is more commonly diagnosed in the earlier stages. Only a small fraction of kidney cancers have a hereditary link. Speak to your care team and ask them if your kidney cancer diagnosis has a genetic link. It may play a role in the type of treatment you receive, including clinical trials. The stage of your kidney cancer and other health factors, will influence the treatment options available for you.

TREATMENT FOR KIDNEY CANCER

Treatment for kidney cancer will depend on the stage, type, and other characteristics of your diagnosis. Your personal goals and health status are also important for determining your treatment plan. Be sure to share your preferences and work with your healthcare team to find the best treatment for you. If you are interested in clinical trials, also ask your healthcare team about this available option. Your care team will recommend the treatment that they believe is the best for your exact type of kidney cancer.

Surgery is the most common treatment for kidney cancer. The surgical procedure to remove a kidney is called a nephrectomy. There are two types of nephrectomy surgeries:

- **Radical Nephrectomy**- the entire kidney is removed. The adrenal gland and other nearby tissues and lymph nodes may also be removed.
- **Partial Nephrectomy**- only part of the kidney that contains the tumor is removed.

Radiation Therapy uses high energy x-rays to kill cancer cells in the kidney. It may also be used to relieve pain if the cancer has spread to other parts of the body.

Chemotherapy uses drugs that kill cancer cells. For treatment of kidney cancer, chemotherapy is not commonly used.

Targeted Therapy uses drugs that attack specific parts of cancer cells. Targeted therapy works differently than chemotherapy and may often lead to less severe side effects. This is a common first line of treatment for kidney cancer in advanced stages.

Immunotherapy is a treatment that uses the body's own immune system to fight cancer. Immunotherapy is used to treat almost all types of kidney cancer.

Clinical Trials are research studies that test new treatments or learn how to use existing treatments better. They find new and better ways to prevent or treat cancer. The Food and Drug Administration (FDA) oversees all clinical trials to keep all patients safe.

Ablation procedures are when a probe, a needle-like device, is inserted into the tumor area. There are 2 types of ablation procedures:

1. *Cryoablation* is when the needle is inserted into the kidney tumor and cold gas is released to freeze the cancer cells.
2. *Radiofrequency ablation* is when the needle is inserted into the kidney tumor and an electrical current is released to heat and burn the cancer cells.

Arterial Embolization cuts off blood supply and is occasionally done before an operation to make the surgery easier or to provide pain relief when tumor removal is not possible.

GETTING A SECOND OPINION

At any point in your care, you can ask for a second opinion. Many people may seek out a third opinion to confirm their diagnosis and review all available treatment options. Another hospital or doctor may offer a different treatment, including clinical trials, or more useful support services. They may be a better fit for you in other ways, such as being closer to your home. Do not worry about hurting feelings. You can always return to the first doctor if you want. Remember, timely cancer treatment is key, you are entitled to decide what is best for you and your goals.

OPEN TO OPTIONS®

If you are facing a cancer treatment decision, the Cancer Support Community's Open to Options program can help you prepare a list of personalized questions to share with your doctor. Our Open to Options® specialists can help you create a written list of specific questions about your treatment plan for your doctor. Call 888-793-9355 to schedule an appointment or to find a Cancer Support Community near you.

KIDNEY CANCER CARE TEAM

Navigating your treatment plan can be complex, and you may feel overwhelmed. The recommended treatment options may change over time because of new discoveries. It is important to have a care team that you can trust and speak with about your best treatment options. Your care team may consist of various healthcare professionals that work together including:

Urologist

A Urologist is a doctor that focuses on the health of the genitourinary tract. This would include the kidneys, bladder, genitals, prostate, and testicles.

Urologic Oncologist

A Urologic Oncologist specializes in treating cancers of the genitourinary system (includes bladder, kidney, prostate, genitals, and testicles).

Medical Oncologist - A Medical Oncologist treats cancer with systemic (or whole-body) treatments using medications. Some examples are immunotherapy, chemotherapy and targeted therapy.

Radiation Oncologist - A Radiation Oncologist treats cancer using radiation therapy. This is when high energy x-rays target the specific area of the tumor to help with pain or kill the cancer cells.

Nurse Practitioner (NP), Physician's Assistant (PA), Nurse (RN) - These are healthcare professionals that work alongside your oncologists to provide care. At times, you may speak more with a nurse practitioner or nurse more than your oncologist.

Registered Dietician - A Registered Dietician (RD) is trained to recommend foods and other ways to make sure your body gets the nutrients it needs. Make sure to find a RD who specializes in cancer nutrition.



Social Worker - A Social Worker is trained to help you and your caregiver with your emotional and logistical needs. They can help navigate appointments and find other support resources you need.

Physical and Occupational Therapists - Physical Therapists (PTs) and Occupational Therapists (OTs) provide therapy to maintain or improve your physical functioning and ability to perform activities of daily living.

Financial Navigator - A Financial Navigator helps you and your loved ones understand the cost of different treatments and how your insurance plan may help cover costs. They may also help find financial assistance programs or payment plans to help ease the burden of receiving treatment.

Oncology Pharmacist - An Oncology Pharmacist is an expert on medicines used to treat cancer. They can educate you on any associated side effects and how to manage them. They can also help you understand how to best take different medications if you have multiple at once.

Managing Treatment Side Effects

Every treatment type can result in side effects. The side effects you experience will vary based on the exact treatment you receive and your health. You may find it helpful to speak with your care team about what side effects you may experience before beginning treatment. This will allow you to feel more prepared and to better manage their impact on your physical and emotional health. After beginning treatment, managing side effects with the help of your care team will be important. Your care team, including your oncology pharmacist and palliative care specialist, can recommend ways to reduce your pain to maintain your quality of life. Below are some examples of side effects that you may experience:

Diarrhea - frequent and watery bowel movements

Nausea/Vomiting - discomfort in the stomach which may result in an urge to vomit

Fatigue - a sense of extreme tiredness or lack of energy

Skin rashes - an area of skin that appears irritated or different in color or texture

Mouth sores - an ulcer or sore in your mouth that may be red, white, or yellow

Loss of kidney function - the kidneys are no longer functionally as normal. Waste or extra fluid is built up in the blood instead of being emptied out of the body

Hand-foot syndrome - skin reaction in palms of your hands and soles of your feet

High blood pressure - your blood pressure levels are higher than normal

General pain - generalized pain or soreness felt in any part of the body

It is not uncommon for treatment to also impact your mental health. Speaking to your care team about any changes, both emotionally and physically, is very important. They may recommend other resources to support you, such as a social worker. Social workers can provide therapy and recommend ways to cope. Below are a few examples of emotional side effects of kidney cancer treatment:

Anxiety - a feeling of uneasiness, worry, or fear that usually occurs because of stress

Depression - a diagnosed condition. It can cause a persistent feeling of sadness or loss of interest in things you once enjoyed.

Overall distress - an unpleasant state that can affect how you think, feel, and act. This may include emotions such as fear, sadness, anger, and worry.

Fear of recurrence - a focused fear on cancer returning (recurring) or progressing to become worse. It may cause anxiety or worry about any new or change in symptoms.

PALLIATIVE CARE

Palliative Care is used to relieve symptoms or side effects, such as pain. Typically, palliative care involves treating the side effects of cancer and not the intent to cure the cancer. Seeing a palliative care specialist can help address side effects that arise during or after treatment. The goal of palliative care is to help you maintain your best possible quality of life. It is important to know that palliative care is different from end-of-life care. It is available to you at any point throughout your care.

CAREGIVING FOR KIDNEY CANCER

Caregivers play a vital role in cancer treatment. They provide important physical, emotional, and logistical support. Due to the challenges of caregiving, it is important that your caregiver(s) feel supported by the care team. Your healthcare team can provide support and recommend ways to manage your responsibilities. For more information and resources on caregiving, visit www.CancerSupportCommunity.org/Caregivers.



COPING WITH KIDNEY CANCER

Life may feel very different after a kidney cancer diagnosis for both you and your loved one. You may experience both physical and social changes which may now require additional help. You may need to adjust your lifestyle and establish a “new normal.” Your emotions may also be impacted in ways you did not expect. Seek assistance from your care team, family, friends and other loved ones when you feel overwhelmed. Navigating a cancer diagnosis is challenging and stressful. This is normal. Make sure to work with your healthcare team to seek the help that you or your loved ones need. Remember, there are multiple people and resources available to help you every step of the way during your kidney cancer treatment, through survivorship, and beyond.

CANCER SUPPORT HELPLINE

If you need help finding resources or want help getting information about cancer, call CSC’s toll-free Cancer Support Helpline® at 888-793-9355. It is staffed by community navigators and resource specialists who can assist you Monday – Thursday 11:00 a.m.- 8:00 p.m. ET and Friday 11:00 a.m.- 6:00 p.m. ET.



RESOURCES

KIDNEY CANCER RESOURCES

Kidney Cancer - Cancer Support Community ·
www.CancerSupportCommunity.org/Kidney-Cancer

KidneyCAN
www.KidneyCAN.org

National Cancer Institute (NCI) Kidney Cancer
www.Cancer.gov/Types/Kidney

NCI Clinical Trial Registry
www.ClinicalTrials.gov

National Kidney Foundation
www.Kidney.org

Kidney Cancer Association
www.KidneyCancer.org

American Cancer Society (ACS) Kidney Cancer
www.Cancer.org/Cancer/Types/Kidney-Cancer



Cancer Support Community Resources

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Thurs 11am-8pm ET and Fri 11am-6pm ET.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking about Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs — With the help of 190 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more:
www.CancerSupportCommunity.org/Find-Location-Near-You

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at www.MyLifeLine.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/Become-Advocate.

This publication is available to download and print yourself at www.CancerSupportCommunity.org/Kidney-Cancer

For print copies of this publication or other information about coping with cancer, visit Orders.CancerSupportCommunity.org

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