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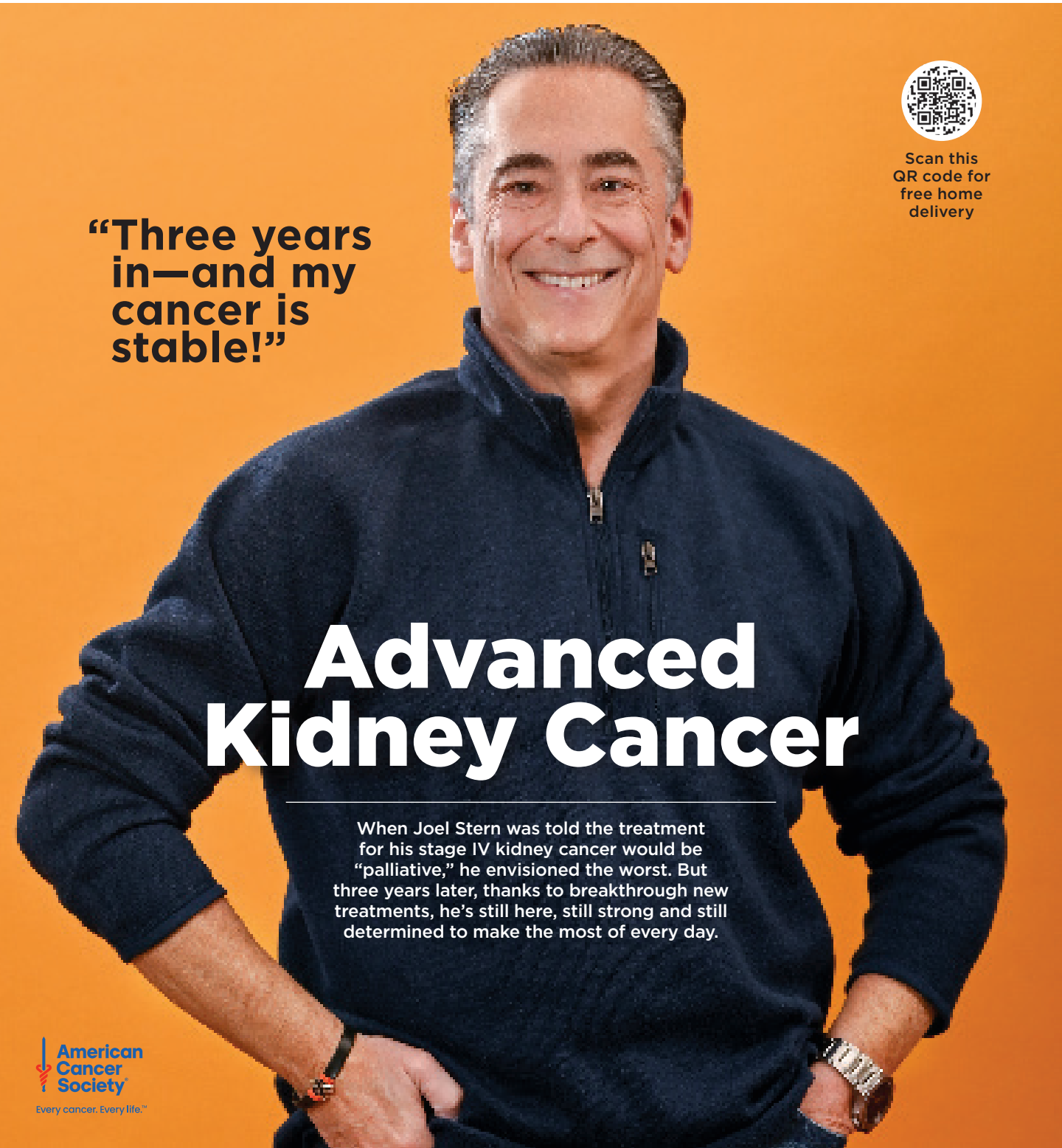
Health Monitor® Living



"Three years in—and my cancer is stable!"

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Advanced Kidney Cancer

When Joel Stern was told the treatment for his stage IV kidney cancer would be "palliative," he envisioned the worst. But three years later, thanks to breakthrough new treatments, he's still here, still strong and still determined to make the most of every day.

American Cancer Society®
Every cancer. Every life.™

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SPECIAL THANKS TO OUR MEDICAL REVIEWER

Christian Paul Pavlovich, MD, Bernard L. Schwartz Distinguished Professor in Urologic Oncology, Professor of Urology, Johns Hopkins

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RPA23

Cover photo by Chris Ocken

Keep looking ahead!

With today's treatment breakthroughs, there's every reason to believe you can get the upper hand on your advanced kidney cancer.

These days, Stanley H. is focused on three things: his fishing game, his garden and spending time with grandson Theo. Not making that list? His advanced renal cell carcinoma.

After his diagnosis last year—triggered by symptoms including lower back pain and weight loss—Stanley was immediately put on a combined treatment featuring both an immunotherapy, which helps his body's own immune system find and attack the cancer, as well as a targeted therapy, which works by blocking a protein cancer cells need to multiply. The result? Since starting treatment, Stanley's tumors have either shrunk completely or stabilized, meaning the cancer is no longer growing.

"I feel blessed that I was diagnosed at a time when stage IV cancer is no longer the death sentence it used to be. Hearing 'you have cancer' still changes your whole world, yet the follow-up: 'but we can treat it!' shifts everything back into focus!" ►

Where do you fit in?

Whether you've been newly diagnosed with advanced kidney cancer, your disease has progressed despite being treated or recurred following treatment, you have good reason to be as hopeful as Stanley. The latest treatments can stabilize and even eradicate the cancer, transforming advanced kidney cancer into a chronic illness that may be managed for years.

Ready to take aim at your cancer? Keep reading this guide, then discuss all your options with your oncologist.

Understanding kidney cancer

Your kidneys filter blood to remove impurities, excess minerals and salts, and extra water from the body. Kidney cancer develops when abnormal cells in the kidneys begin to multiply. Most often, a tumor forms in one kidney, although two or more tumors can develop in one or both kidneys.

The most common type of adult kidney cancer is renal cell carcinoma (RCC), accounting for nine in 10 cases. RCC develops in the renal tubules, the tubes that collect urine. There are different subtypes of RCC. Seventy percent of people with RCC have clear cell renal cell carcinoma. Less common subtypes include papillary renal cell carcinoma and chromophobe renal cell carcinoma.

Because early RCC does not always cause obvious symptoms, the disease is often not detected until it is at an advanced stage: In stage III kidney cancer, the cancer has spread to lymph nodes near the kidney, a main kidney blood vessel, or fatty tissue around the kidney. In stage IV kidney cancer, the cancer has spread to another organ or to other lymph nodes or tissue. Signs and symptoms may include:

- Blood in the urine
- A mass or lump on your abdomen, your side or your lower back
- Persistent lower back pain or pressure on your side
- Loss of appetite
- Unexplained weight loss
- Anemia (low red blood cell count)
- Swollen ankles and legs
- Fatigue
- Persistent fever not caused by infection
- In men, enlarged veins around a testicle (i.e., varicocele)

How is advanced kidney cancer (RCC) detected?

To diagnose a case of kidney cancer that is already advanced, your doctor will ask about your symptoms, perform a physical exam and inquire about your personal and family medical history. Your doctor may also order blood and urine tests, as well as a biopsy, in which a tissue sample is removed and examined for malignant cells. To determine if cancer has spread, and where, your doctor may order one or more of the following imaging tests: a CT scan, MRI (magnetic resonance imaging), X-ray, ultrasound or bone scan.

How is advanced kidney cancer treated?

When determining your treatment plan, your oncologist will consider several factors, including your cancer's stage, your age and overall health, the likelihood that a particular treatment will work and your feelings about it. Your doctor will also consider any treatments you've already had. Options such as immunotherapy and targeted treatments may also be combined to attack the cancer from multiple angles.

Current treatments for advanced kidney cancer include:

- ***Immunotherapy.*** This treatment boosts the body's immune system to destroy cancer cells.
- ***Targeted therapy.*** This treatment targets specific gene mutations that enable cancer to grow. (Learn more about immunotherapy and targeted therapy on p. 8)
- ***Chemotherapy.*** This treatment enters the blood-

ARE YOU A POC?

Black people are currently at the highest risk for kidney cancer, according to the journal *BMC Cancer*, with Hispanic people and Native Americans also at greater risk than White people.

Researchers are still looking into why, and are researching if high blood pressure and/or chronic kidney disease—two conditions also more prevalent in POC—may be a contributing factor in addition to genetics. Because smoking and obesity also increase risk, it can be especially important for POC to shun tobacco and maintain a healthy weight.

If you are experiencing any of the potential symptoms of kidney cancer (see the list, *above*), or you have a family member who has been diagnosed, ask your healthcare provider if a kidney screening might be right for you.

stream and fights cancer cells body-wide. It is not a standard treatment for advanced kidney cancer, and is usually used only if targeted therapy or immunotherapy have failed.

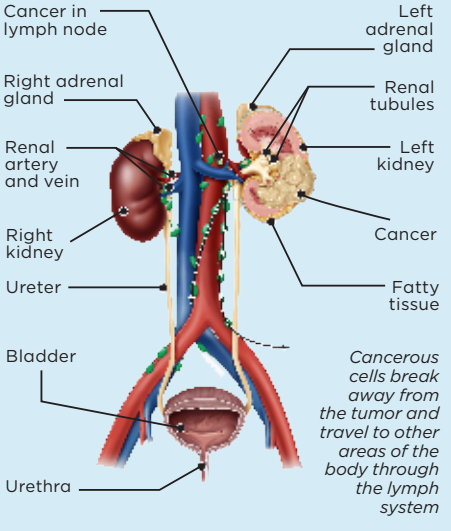
- ***Surgery.*** Surgery may be used to remove a kidney and surrounding tissue (radical nephrectomy), part of a kidney containing a tumor (partial nephrectomy) or cancer cells that have spread elsewhere (metastasectomy). Laparoscopic (using smaller incisions and instruments than those used in open surgery) and robot-assisted laparoscopic approaches (requiring special equipment) may also be used.
- ***Thermal ablation.*** Ablative treatments may be used when surgery is not recommended. These are typically delivered via probe(s) inserted into the tumor through which either cold (e.g. cryosurgery) or heat energy (e.g. radiofrequency) is delivered. With cryosurgery, freeze/thaw cycles are used to destroy the cancer cells, while with radiofrequency ablation, current is used to heat and destroy the tumor.
- ***Radiation.*** High-energy X-rays target and destroy cancer cells; in advanced kidney cancer, this therapy is mainly used in areas where malignant cells have spread.

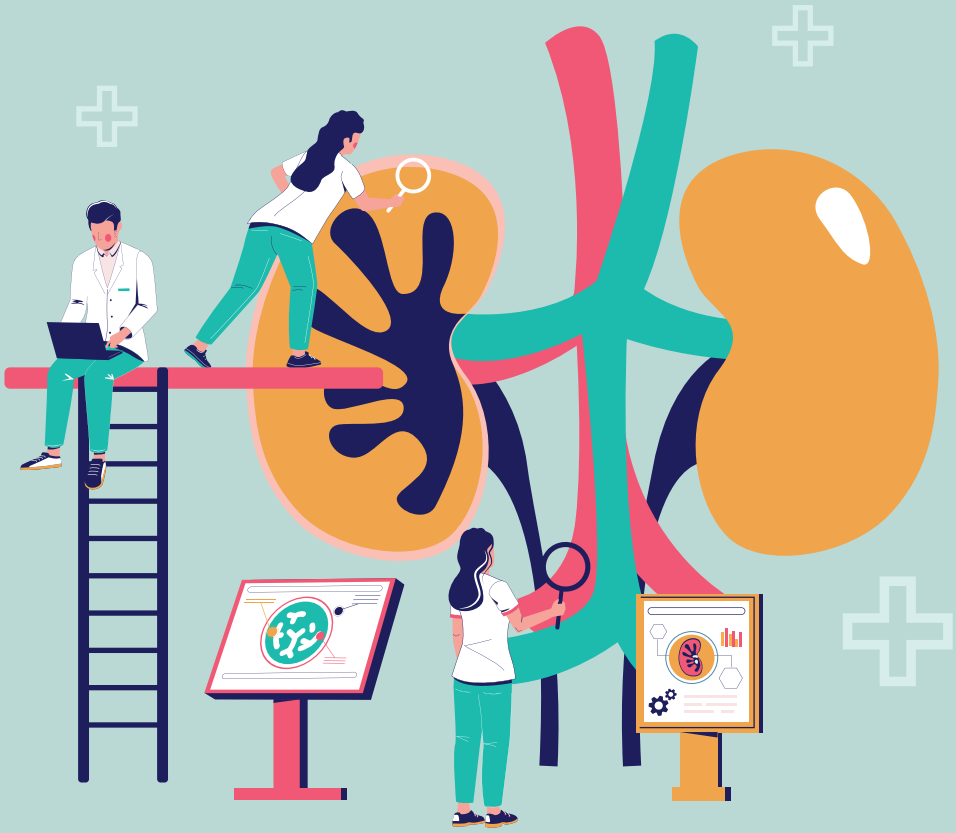
Some people may also consider taking part in a clinical trial, which contributes to cancer research. (Learn more on p. 7.)

The treatment journey is different for every person; but the good news is that today's options are more varied and advanced than ever. By working closely with your cancer care team, chances are that they will find a treatment that works for you. And, like Stanley, you'll probably find that advanced kidney cancer is no reason to put your life on hold!

ADVANCED KIDNEY CANCER

In stage III kidney cancer, the cancer has spread to lymph nodes near the kidney, a main kidney blood vessel, or fatty tissue around the kidney. In stage IV kidney cancer, the cancer has spread beyond the fatty tissue around the kidney or to another organ, such as the brain, lungs or bones, or to distant lymph nodes or tissue.





Your advanced kidney cancer healthcare team

These medical professionals can diagnose and help treat advanced kidney cancer.

Nephrologist:
MD who specializes in diseases that impact the kidney, who may have diagnosed your cancer and can provide ongoing care

Nephro-oncologist:
MD who specializes in treating kidney cancer

Urologic oncologist/urologist:
MD who specializes in cancers of the genitourinary tract

Medical oncologist:
MD who specializes in treating cancer using systemic treatments such as chemotherapy, immunotherapy and targeted therapy

Radiation oncologist:
MD who specializes in treating cancer using radiation therapy

Surgical oncologist:
MD who specializes in treating cancer using surgery

Pathologist:
MD who looks at tissue obtained by biopsy or surgery to help diagnose kidney cancer

Palliative care doctor:
MD who specializes in preserving quality of life through pain management and symptom relief

Radiologist:
MD who may perform X-rays, MRI scans, CT scans and nuclear medicine studies

Oncology nurse:
nurse who provides care, support and education during cancer treatment

Infusion nurse:
nurse who administers medications, such as chemotherapy, through infusions and/or injections, and supportive care

Nurse navigator:
nurse who educates and provides resources you may need during treatment

Clinical trials: *Are you a candidate?*

Astounding progress is being made in the treatment of advanced kidney cancer. By participating in a clinical trial, you may be able to benefit from the latest breakthroughs.

Here's what you can do:

1. Search for trials

Clinical trials are run by many different sponsors—private companies, the U.S. government, hospitals, etc.—so there is no single list that includes them all, but the search tools at the National Cancer Institute's website, *Cancer.gov/clinicaltrials/search*, and at the U.S. National Library of Medicine's site, *ClinicalTrials.gov*, are two of the most comprehensive and reliable.

2. Read the summaries

Trial summaries will give you the facts about the study so you can determine if you're a good fit. What to consider:

- Do you meet all the criteria? Clinical trials are often looking for people who fit specific traits—they may only want patients who have tried and failed to respond to a certain type of treatment, for example, or someone with a specific genomic mutation.
- Location of the trial
- Length of the trial
- What is the trial objective?

3. Contact the trials

Ask to speak with the trial coordinator, the referral coordinator or the protocol assistant. It's also possible to have your healthcare provider call for you, as they might be better able to answer any of the trial representative's questions to determine if you're eligible. Some questions you or your healthcare provider should ask:

- What are the risks, benefits and potential side effects?
- Is the trial randomized?
- Could you be given a placebo?
- Who will cover costs (such as travel)?
- Will it affect your everyday life?
- Are similar trials or drugs available through your own oncologist?

A closer look at immunotherapy and targeted therapy

Thanks to groundbreaking new treatments, more than 15.5 million people are now cancer survivors. Read on to learn more about two of the newest developments in cancer treatment: immunotherapy and targeted therapy, which are changing prognoses and improving quality of life for many, even those with advanced kidney cancer.

IMMUNOTHERAPY

- **What is it?** Immunotherapy treatments stimulate a person's own immune system to identify and destroy cancer cells.
- **How do immunotherapy medications work?** Immunotherapies "mark" cancer cells so the immune system can more easily find and destroy them. Immunotherapies also give the immune system a boost, so it can better fight cancer cells.
- **How is immunotherapy different from chemotherapy?** Chemotherapy is aimed at all rapidly dividing cells, whether cancerous or not. Immunotherapy is aimed at immune cells, enabling them to attack cancer cells.
- **Can an immunotherapy medication treat advanced kidney cancer?** Yes. Immunotherapies are already approved by the Food and Drug Administration to treat advanced kidney cancer. (Sometimes two immunotherapies are given in combination.) Ask your doctor if you may be eligible.

Immunotherapies—at a glance

THERAPIES	HOW THEY WORK
Monoclonal antibodies	These man-made versions of immune system proteins can be used to target a specific part of a cancer cell. Many monoclonal antibody medications are checkpoint inhibitors. (See below.)
Checkpoint inhibitors	Cancer cells can sometimes manipulate molecules (aka "checkpoints") on immune cells so the immune cells won't recognize and attack them. Checkpoint inhibitors target these molecules, enabling the immune system to recognize and attack the cancer.
Cancer vaccines	Treatment (vs. preventive) vaccines boost your immune system's response to cancer cells.
Cytokines	Cytokines help your immune system fight cancer cells; they may be used alone or in combination with other treatments, such as chemotherapy.
Other immunotherapies	Additional therapies to fight a variety of cancers are available; some are being studied in clinical trials.

TARGETED THERAPY

- **What is it?** Targeted therapy blocks specific molecules that signal cancer cells to multiply and spread. It is used to slow the growth of cancer, kill cancer cells or relieve symptoms caused by cancer. Targeted therapy is primarily used for cancers that overproduce specific proteins or have certain gene and protein mutations.
- **How do targeted therapies work?** Targeted therapies work in different ways depending on if they target a molecule within or on the surface of the cancer cell. Some attach to proteins inside a cancer cell to block the process that tells cells to grow, and some block enzymes that cancer cells use to reproduce.
- **How is targeted therapy different from chemotherapy?** Chemotherapy is aimed at all rapidly dividing cells, whether cancerous or not. Targeted therapy is aimed at specific aspects of cancer cells to stop them from growing and dividing.
- **Can a targeted therapy treat advanced kidney cancer?** Yes. Targeted therapies are already approved by the Food and Drug Administration to treat advanced kidney cancer, and are usually given along with other types of therapies, including immunotherapies. Ask your doctor if you may be eligible.

Targeted therapies—at a glance

THERAPIES	HOW THEY WORK
Angiogenesis inhibitors	These drugs block the cancer's ability to grow new blood vessels that contain nutrients it needs to grow.
Hormone therapies	These drugs either block or stop the production of hormones certain cancers need to grow, such as breast and prostate cancers.
Signal transduction inhibitors	These drugs block signals and enzymes that tell cells to continue to divide and grow.
Gene expression modulators	These drugs change the proteins that control the way gene instructions in cancer cells get carried out.
Apoptosis inducers	These drugs cause cancer cells to go through the natural process of cell death.

“THREE YEARS IN—AND MY CANCER IS STABLE!”

When Joel Stern was told the treatment for his stage IV kidney cancer would be “palliative,” he envisioned the worst. But three years later, thanks to breakthrough new treatments, he’s still here, still strong and still determined to work on his tennis game.

—BY DANIELLE TUCKER

CONTINUED ON P. 12


"I'm just living every day like it might be my last and making the most of it...I have stage IV cancer and surprisingly? I'm content!"

When Joel Stern isn't spending time with Donna, his wife of 35 years, his kids or his grandsons, you're likely to find the 63-year-old retired legal professional on the tennis court perfecting his swing, figuring out how to use his new Peloton bike or jogging around his neighborhood in Chicago. And if that sounds exhausting enough, consider he's doing all that while battling stage IV clear cell renal cell carcinoma (RCC).

Joel's issues began in the fall of 2020, when knee and hip pain began to impact his tennis game. By mid-November, even simple movements like getting in and out of his car were becoming increasingly difficult, forcing him to call the orthopedic surgeon who had previously treated him for knee issues.

After routine X-rays and an MRI, Joel assumed the diagnosis would be one more "old fart" ailment. But on the Monday before Thanksgiving, the phone rang. Joel recalls the cold bluntness of the doctor's words: "You have a very large lesion on your iliac bone, which is suspicious for cancer that has metastasized from somewhere."

"I thought I only had weeks or days left"

The word "cancer" was not a new one for Joel. He'd watched his mother fight her own 15-year battle. His father had also been diagnosed with prostate cancer, and in 2007 Joel received the same diagnosis. Thankfully, it was caught early, and with surgery, Joel was considered cured. A few years later, he learned that he had the BRCA 1 gene mutation, which increases the risk for several cancers in men, including breast, prostate, pancreatic and kidney.

"Despite all that, the stage IV diagnosis was a great shock," Joel recalls. "I wish I could say the earlier cancer diagnosis helped me deal with it, but it was so different."

With great empathy, the oncologist explained to Joel that stage IV disease meant there wasn't a cure, and that Joel's care would be "palliative."

"I had always thought of that word as the equivalent of hospice—in other words, I thought it meant I was dying," reflects Joel.

"I was ready to fight!"

Luckily, Joel's cancer care team was able to soften the blow, and his doctors explained that while his kidney cancer wouldn't be "curable" like his prostate cancer had been, it was still treatable—today, in fact, he had more options than ever.

In the days following his initial diagnosis, Joel's medical team developed a plan of action to eradicate, shrink and stabilize his cancer. He started with a monthly regimen of intravenous targeted and immunotherapy drugs, as well as radiation to shrink the painful tumor on his iliac bone.

"The combo of the infusions and radiation was rough; I felt like a couch-ridden 'corpse' and was struggling with self-pity and anxiety," Joel recalls. "I have always told my children that anxiety is worse than reality, and I eventually realized I wasn't listening to my own advice." Thankfully, in the weeks following the conclusion of radiation treatments, Joel's hip pain slowly improved, and treatment side effects were much more manageable.

Even better? The medication combination was working, and ongoing scans have shown his cancer has remained stable. Eventually he was even able to have surgery to remove the primary tumor on his kidney.

As Joel enters year three of living with cancer, he's now focused on adding items to his "bucket list," including sporting events, concerts and vacations, which he says gives him something to look forward to and keeps him focused on the future. "Maybe I'll still live to 100? Who knows. I'm just living every day like it might be my last and making the most of it. I'm less stressed, and I don't fear death anymore, which is crazy. I have stage IV cancer and surprisingly? I'm content!"

> "I've always told my children that anxiety is worse than reality, and I eventually realized I wasn't listening to my own advice."

Yes, you *can* thrive despite advanced kidney cancer!

Here, Joel shares the tips that have helped him manage life while undergoing treatment.

Find your healthcare "captain."

Joel can't thank his medical team enough for guiding his treatment, especially the "captain of his ship," Dean G. Tsarwhas, MD, medical director of the Cancer Center at North Region Northwestern Medicine. "We're partners. He listens to me. I challenge him. I ask questions. Sometimes I disagree with him, but we have a great relationship. Every patient needs a captain!"

Find a purpose.

Retired from the legal profession, Joel has a history of advocacy. Today, the former CEO of the National Association of Minority and Women-Owned Law Firms uses his experience to advocate for patients and families touched by RCC. His newly released book, *My Journey with Stage IV Renal Cell Carcinoma: How To Make the Most of a Dire Diagnosis*, was a true "labor of love." Six months after his diagnosis, Joel became active in the "Our Stage IV Journey with Renal Cell Carcinoma" Facebook group and started posting a "Thankful Friday" post each week, encouraging himself and others to post something they were thankful for that week. The positive words became a highlight among the members, and at the urging of the group and his family, Joel eventually compiled 18 months of posts into a book with all proceeds funding kidney cancer research. He considers it his legacy and hopes the words comfort and support others facing challenging circumstances.

Focus on what's important.

Between his service as a Kidney Cancer Association board member, executive coach, and government research grant adviser, Joel prioritizes spending as much time as possible with his family. Mondays and Fridays are high points each week as he spends quality time with his grandsons. Planning trips keeps Joel active and gives him something to anticipate—and there are even whispers of a future skydiving excursion.

Put a limit on anxiety.

Joel realized he couldn't just make his anxiety go away entirely, so today he allows himself to have anxious thoughts for a dedicated 30 minutes a day. The rest of the time? "I'm too busy to be anxious!"

Speak up about side effects.

When one medication caused Joel to develop a rash, he was open and honest with his care team, who helped him by tapering down the dosage. He also overcomes fatigue with frequent naps and goes in for regular scans to monitor his blood pressure, thyroid levels and creatine levels, all of which can be impacted by his current treatment.

Photos by Chris Ocken

Keep track of your symptoms

Check the boxes to indicate any symptoms or side effects you're experiencing and how often they are affecting your life, then share this page with your care team so they can help you feel your best:

SYMPTOM	Doesn't affect me	Rarely	A few times a week	Daily	Multiple times a day
Diarrhea	☐	☐	☐	☐	☐
Stomach cramping	☐	☐	☐	☐	☐
Nausea/vomiting	☐	☐	☐	☐	☐
Constipation	☐	☐	☐	☐	☐
Skin rash	☐	☐	☐	☐	☐
Difficulty breathing	☐	☐	☐	☐	☐
Rapid heartbeat	☐	☐	☐	☐	☐
Dizziness	☐	☐	☐	☐	☐
Headache	☐	☐	☐	☐	☐
Joint pain	☐	☐	☐	☐	☐
Fatigue	☐	☐	☐	☐	☐
Feeling down or depressed	☐	☐	☐	☐	☐
Other (please specify):	☐	☐	☐	☐	☐

List the current medications you are taking, including anything over-the-counter or any supplements:

_____

_____

List any conditions (e.g., diabetes, heart disease, etc.) you've been diagnosed with since your last visit:

_____

_____

List any major life events (e.g., job change, divorce, moving) that have occurred since your last visit:

_____

_____

WATER CONSUMPTION My father is undergoing treatment for advanced kidney cancer—should he drink more or less water to help his kidneys function more easily?

Q

A

Answers to your questions about advanced kidney cancer

A: Your father will either undergo (or has undergone) surgery to remove the cancer in his kidney, systemic (body-wide) therapy for kidney cancer metastases, or a combination of these treatments (surgery + systemic therapy). Kidney cancer surgery causes loss of kidney tissue, whether an entire kidney is removed or just the part containing the cancer, which results in diminished kidney function. It is important to stay well-hydrated after such procedures to allow good blood flow to the remaining kidney tissue. It is equally important to adopt a low salt diet (we typically recommend a "no added sodium" diet, as there is quite a bit of salt in most foods already), and to favor vegetable rather than meat sources of protein, as they are easier for the kidneys to handle. If your father is undergoing systemic therapy rather than renal surgery, hydration can be important as well, as the kidney(s) help clear some of the therapies that may be administered. Hydration also ensures that medications will reach their targets through the bloodstream and is important in case there is therapy-related nausea, vomiting or diarrhea. Finally, good hydration helps prevent blood clots, which are more common in patients with cancer and in patients having surgery of any kind.

TREATMENT WORRIES

Q: *My oncologist recommended a combination immunotherapy/targeted therapy to treat my stage III renal cancer. The idea of multiple medications at once scares me—does that mean I'm going to have double the side effects? Am I going to lose my hair like with chemo?*

A: The systemic therapies used to treat advanced kidney cancer are not like traditional chemotherapy that destroys all fast-growing cells (such as those in the GI tract and scalp, which is why chemo can cause side effects like nausea, diarrhea and hair loss). Traditional chemotherapy does not work against advanced kidney cancer, but immunotherapy and targeted therapies do. These newer agents *only* attack pathways used by kidney cancer cells to grow and/or help the immune system "see" the cancer and attack it more effectively. It's quite common today for immunotherapies and targeted therapies to be given in combination because it's an effective treatment strategy for many people, and the good news is, even combined, these newer medications usually have much fewer side effects than chemo.

OUR EXPERT: Christian Paul Pavlovich, MD, Bernard L. Schwartz Distinguished Professor in Urologic Oncology, Professor of Urology, Johns Hopkins

Facing advanced kidney cancer (RCC)?

KEYTRUDA and LENVIMA are prescription medicines used together to treat a kind of kidney cancer called advanced renal cell carcinoma (RCC) as your first treatment when your kidney cancer has spread or cannot be removed by surgery.

It is not known if LENVIMA is safe and effective in children.

Important Safety Information for KEYTRUDA

KEYTRUDA is a medicine that may treat certain cancers by working with your immune system. KEYTRUDA can cause your immune system to attack normal organs and tissues in any area of your body and can affect the way they work. These problems can sometimes become severe or life-threatening and can lead to death. You can have more than one of these problems at the same time. These problems may happen any time during treatment or even after your treatment has ended.

Call or see your health care provider right away if you develop any signs or symptoms of the following problems or if they get worse. There are not all of the signs and symptoms of immune system problems that can happen with KEYTRUDA:

Lung problems: cough, shortness of breath, or chest pain.

Intestinal problems: diarrhea (loose stools) or more frequent bowel movements than usual; stools that are black, tarry, sticky, or have blood or mucus; or severe stomach area (abdomen) pain or tenderness.

Liver problems: yellowing of your skin or the whites of your eyes; severe nausea or vomiting; pain on the right side of your stomach area (abdomen); dark urine (tea colored); or bleeding or bruising more easily than normal.

Hormone gland problems: headaches that will not go away or unusual headaches; eye sensitivity to light; eye problems; rapid heartbeat; increased sweating; extreme tiredness; weight gain or weight loss; feeling more hungry or thirsty than usual; urinating more often than usual; hair loss; feeling cold; constipation; your voice gets deeper; dizziness or fainting; changes in mood or behavior, such as decreased sex drive, irritability, or forgetfulness.

Kidney problems: decrease in the amount of your urine; blood in your urine; swelling of your ankles; loss of appetite.

Skin problems: rash; itching; skin blistering or peeling; painful sores or ulcers in your mouth or in your nose, throat, or genital area; fever or flu-like symptoms; swollen lymph nodes.

Problems can also happen in other organs and tissues. Signs and symptoms of these problems may include: chest pain; irregular heartbeat; shortness of breath; swelling of ankles; confusion; sleepiness; memory problems; changes in mood or behavior; stiff neck; balance problems; tingling or numbness of the arms or legs; double vision; blurry vision; sensitivity to light; eye pain; changes in eyesight; persistent or severe muscle pain or weakness; muscle cramps; lowered blood cells; bruising.

Important Safety Information for KEYTRUDA continued on next page.

KEYTRUDA + LENVIMA may be your first treatment

Two medicines. One combination that may help you fight advanced kidney cancer (RCC). Your doctor can help you decide if KEYTRUDA + LENVIMA could be right for you.

Ask your doctor if KEYTRUDA + LENVIMA is right for you
KeytrudaLenvima.com/AdvancedRCC

Important Safety Information for LENVIMA

LENVIMA may cause serious side effects, including:

High blood pressure (hypertension): High blood pressure is a common side effect of LENVIMA and can be serious. Your blood pressure should be well controlled before you start taking LENVIMA. Your healthcare provider should check your blood pressure regularly during treatment with LENVIMA. If you develop blood pressure problems, your healthcare provider may prescribe medicine to treat your high blood pressure.

Heart problems: LENVIMA can cause serious heart problems that may lead to death. Call your healthcare provider right away if you get symptoms of heart problems, such as shortness of breath or swelling of your ankles.

Problem with blood clots in your blood vessels (arterial): Get emergency medical help right away if you get any of the following symptoms: severe chest pain or pressure; pain in your arms, back, neck, or jaw; shortness of breath; numbness or weakness on one side of your body; trouble talking; sudden severe headache; sudden vision changes.

Liver problems: LENVIMA may cause liver problems that may lead to liver failure and death. Your healthcare provider will check your liver function before and during treatment with LENVIMA. Tell your healthcare provider right away if you have any of the following symptoms: your skin or the white part of your eyes turns yellow (jaundice); dark "tea-colored" urine; light-colored bowel movements (stools); feeling drowsy, confused or loss of consciousness.

Kidney problems: Kidney failure, which can lead to death, has happened with LENVIMA treatment. Your healthcare provider should do regular blood tests to check your kidneys.

Increased protein in your urine (proteinuria): Proteinuria is a common side effect of LENVIMA and can be serious. Your healthcare provider should check your urine for protein before and during your treatment with LENVIMA.

Diarrhea: Diarrhea is a common side effect of LENVIMA and can be serious. If you get diarrhea, ask your healthcare provider about what medicines you can take to treat your diarrhea. It is important to drink more water when you get diarrhea. Tell your healthcare provider or go to the emergency room, if you are unable to drink enough liquids and your diarrhea is not able to be controlled.

An opening in the wall of your stomach or intestines (perforation) or an abnormal connection (continued)

Important Safety Information for LENVIMA continued on next page.

Important Safety Information for [redacted] (continued)

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- Change in thyroid hormone levels. Your healthcare provider should check your thyroid hormone levels before starting and every month during treatment with LENVIMA.
- Wound healing problems. Wound healing problems have happened in some people who take LENVIMA. Tell your healthcare provider if you plan to have any surgery before or during treatment with LENVIMA.
  - You should stop taking LENVIMA at least 1 week before planned surgery.
  - Your healthcare provider should tell you when you may start taking LENVIMA again after surgery.
- Severe jawbone problems (osteonecrosis). Severe jawbone problems have happened in some people who take LENVIMA. Certain risk factors such as taking a bisphosphonate medicine or the medicine denosumab, having dental disease, or an invasive dental procedure may increase your risk of getting jawbone problems. Your healthcare provider should examine your mouth before you start and during treatment with LENVIMA. Tell your dentist that you are taking LENVIMA. It is important for you to practice good mouth care during treatment with LENVIMA. Tell your healthcare provider right away if you get signs or symptoms of jawbone problems during treatment with LENVIMA, including jaw pain, toothache, or sores on your gums. Tell your healthcare provider if you plan to have any dental procedures before or during treatment with LENVIMA. You should avoid having invasive dental procedures if possible, during treatment with LENVIMA. Stopping your bisphosphonate medicine before an invasive dental procedure may help decrease your risk of getting these jaw problems.
  - You should stop taking LENVIMA at least 1 week before planned dental surgery or invasive dental procedures.
  - Your healthcare provider should tell you when you may start taking LENVIMA again after dental procedures.

The most common side effects of LENVIMA when given with pembrolizumab include:

- decrease in thyroid hormone levels
- increased blood pressure
- tiredness
- diarrhea
- joint and muscle pain
- nausea
- decreased appetite
- vomiting
- mouth sores
- weight loss
- stomach-area (abdominal) pain
- urinary tract infection
- protein in your urine
- constipation
- headache
- bleeding
- rash, redness, flaking, or peeling of your skin on your hands and feet
- hoarseness
- rash

LENVIMA may cause fertility problems in males and females. Talk to your healthcare provider if this is a concern for you.

Your healthcare provider may need to reduce your dose of LENVIMA, or delay or completely stop treatment, if you have certain side effects.

These are not all the possible side effects of LENVIMA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How should I store LENVIMA?

- Store LENVIMA at room temperature, between 68°F to 77°F (20°C to 25°C).
- Keep LENVIMA and all medicines out of the reach of children.

General information about the safe and effective use of LENVIMA.

Medicines are sometimes prescribed for purposes other than those listed in a Patient Information leaflet. Do not use LENVIMA for a condition for which it was not prescribed. Do not give LENVIMA to other people, even if they have the same symptoms you have. It may harm them. You can ask your healthcare provider or pharmacist for information about LENVIMA that is written for health professionals.

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"Kidney cancer *CAN'T* SLOW US DOWN!"

Tracy and Michael know that living with advanced kidney cancer can be tough sometimes—but it doesn't have to limit your life! Read on for their tips on managing everyday tasks, stress, mental health, fatigue and more.
—BY LINDSAY BOSSLETT

"Tap your newfound strength—and seek joy!"

TRACY "TRA" POYNEER, 50
ANNE ARUNDEL COUNTY, MD

Stay positive.

In early 2020, Tracy "Tra" Poyneer came down with pneumonia. While in the hospital, she discovered two things: She had COVID, and she had stage III kidney cancer. "It was devastating," recalls the retired real estate marketing exec. "There I am in quarantine, alone, coping with what–at the time–was a frightening new illness, and then they discover my d-Dimer [a test that looks for blood clotting issues] results are too high, so they sent me for a CT scan to check for clots and discovered I had a 9-cm mass on my kidney." Tra, who refers to her primary tumor as "Karen," was determined to look on the bright side. "I'm very thankful for my ER doctor, Dr. Todd Rosen of the University of Maryland. He took a chance when he sent me for that CT scan, because ERs had stopped routinely scanning COVID patients for clots at that time. If not for that, we wouldn't have caught 'Karen' when we did."

Seek a second opinion.

"I was diagnosed with stage III chromophobe (a.k.a. non-clear cell) renal cell carcinoma at the University of Maryland Tate Cancer Center, but I decided to switch to the Lombardi Cancer Center in Georgetown, MD, because they have oncologists who specialize in kidney cancer, and non-clear cell is more rare. There, I was able to have genetic testing done that revealed a defect in my SDHB

gene. More testing is being done today to see if that defect is linked to my RCC, which could impact treatments in the future. It's important to feel like you and your cancer care team know all they can about your condition—there is always something to learn, especially when genetics plays a role."

Focus on the "now."

"To cope with everything, I've been working on honing my fishing, crabbing and boating skills," says Tra, who lives off Maryland's Magothy River. "Being on the water provides me tranquility, and I learned that healing from cancer *can* mean finding new strength and joy. It changed the way I've viewed life's unexpected challenges and helped me let go of all the negativity I had been carrying."

Join a support group—or all of them!

"I think I reached out to every support group available," Tra laughs. "But they were helpful in so many ways, including getting me involved in the kidney cancer community. I'm proud to say I was part of a six-woman team that raised $50,000 for the first-ever patient-led research grant for my type of RCC through the Kidney Cancer Research Alliance [*kccure.org*]. Today I feel honored to be able to connect with other rare RCC patients to help them along their journey and keep advocating for funding for non-clear cell research."

Avoid the "Google trap."

"Researching your cancer online will only generate worse-case scenarios. Reach out to oncology specialists who are knowledgeable and who treat others with your RCC subtype. RCC social media support groups can be helpful in this regard, too. You'll find others that have gone through a similar situation or can point you in the right direction."

Rely on others.

"Having a reliable caregiver, support system and partner was (and is) critical in my journey," Tra says. "It's hard enough processing a new diagnosis, and the overwhelming amount of anxiety over upcoming scans, without going it alone. My community rallied around me by providing meals during surgeries, and sending me cards, care packages and uplifting words."

Find a hero.

"My diagnosis has brought me closer to my husband and even extended family members. I've also learned that I can push myself in ways I never thought possible, both mentally and physically. My parents live on the Eastern Shore in Cambridge, MD, which is Harriet Tubman's birthplace and I've had the privilege of visiting there often. Her story, her strength, her determination, her beauty, her courage and faith have inspired me to keep pushing. She was a remarkable woman and taught me to *#HoldSteady* when you think you can't go on anymore."

"One positive to my diagnosis is it's brought me closer to the people in my life," says Tra with husband A.F. and their dog, Latke.

Photo by O'Doherty Photo

“Stay strong—and stay hopeful!”

MICHAEL WHITLEY, 45
HUNTSVILLE, AL

Listen to your body.

Everything changed for Michael Whitley on September 3, 2019. “That’s the day my friend, a nephrologist, officially diagnosed my kidney cancer. I’ve been on treatment, including both immunotherapy and targeted therapy, ever since.” Michael dismissed his initial symptoms, which began in January of that year, as kidney stones, passing “several,” which turned out to be blood clots. “Finally, in September I agreed to go to my friend’s clinic for bloodwork and urinalysis. Both came back normal. She pushed me to get a CT scan, and I got a copy of my images when I left the scan center. I texted her an image because I thought my left kidney was ‘inflamed.’ Turns out it was a massive tumor—I’m definitely glad I finally listened to her about getting that scan!” Subsequent tests determined Michael had stage IV clear cell renal cell carcinoma.

Seek a coping mechanism.

My vision completely narrowed, and I became hyper focused when I was diagnosed. My goal became to learn as much as possible about this cancer and be the best patient possible. So for the first three months, I processed my emotions by doing intense research, looking up journal articles and watching and reading everything I could about kidney cancer. I didn’t fully ‘feel’ the impact of the diagnosis until around December 2019. Then I worked to process my emotions by talking about them with friends and family and making plans for the future regarding my treatment. Having a plan has always made me feel more secure!”

Find your new “normal.”

“When I was diagnosed, I was halfway through an MBA and running my engineering firm, EngeniusMicro. I was completely transparent with my employees and customers. Luckily, I still finished my MBA and was able to keep working while in treatment. I could not have done any of this without my business partners and employees helping to shoulder the load when things were tough.”

Reach out.

“I find support through online forums such as SmartPatients *[smartpatients.com]* and connections I have made with other kidney cancer patients, advocates and researchers. Working on ‘doing’ rather than just ‘talking’ makes me feel more in control of my disease, so I’ve recently become active in a patient advocate role, helping to advise newly diagnosed patients, perform research reviews for funding organizations and advocate for additional research funding for kidney cancer through organizations like the Kidney Cancer Association [*kidneycancer.org*].”

Find a doctor you trust.

“I sought a second opinion from a kidney cancer expert after my initial diagnosis. Having confidence in my care team is critically important to reducing anxiety about my future treatments. There is so much uncertainty with cancer treatments and it is important to have trust that the team you have assembled is providing you the best advice possible.”

Photo by Christopher Analista

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Find the EMOTIONAL CARE you need

Cancer doesn't only have a bodily impact; it can also cause mental distress. Studies show that anxiety and depression can interfere with a person's adherence to treatment. If you're down, on edge, irritable, or out of sorts, read on to find the right support! —BY MARISSA PURDY

IN-PERSON THERAPY

What it is: A psychologist, psychiatrist, licensed therapist or social worker can work with you to develop a personalized plan specific to your needs using methods such as psychoanalysis, cognitive behavioral therapy, holistic therapy and more.

It might work best for you if: You're not comfortable speaking up in a crowd, you prefer more personalized attention or you're also looking to work through emotional issues not related to your cancer.

How to get started: You can find a licensed practitioner that works for you on *psychologytoday.com* or *goodtherapy.org*.

TELEHEALTH COUNSELING

What it is: The same type of one-on-one session as in-person therapy but conducted online or via phone or text.

It might work best for you if: You live in a remote area, lack transportation or have mobility issues.

How to get started: Visit Teladoc, an online search engine that can help you get matched with a therapist that fits your lifestyle, or ZocDoc, a platform you can use to find a variety of online healthcare specialists.

SUPPORT GROUPS

What they are: These meetups can sometimes involve people only with your type of cancer, cancer in general or people dealing with any type of chronic health condition. They often gather at hospitals, wellness centers, community centers or churches and are sometimes run by trained professionals.

They might work best for you if: You're looking for information or affirmation from others going through a similar situation as you.

How to get started: Look for flyers at your local hospital, cancer care center or community center, or try searching on *meetup.com* to find meetings near you.

SOCIAL MEDIA GROUPS

What they are: Online peer support groups where you can connect with people virtually.

They might work best for you if: You're seeking the same type of support as a support group but want to be able to reach out to anyone at any time. These can also be helpful for those who live in remote areas or who otherwise might have difficulty getting to a meeting.

How to get started: Search for "kidney cancer support" or #kidneycancer on social media sites like Facebook, Instagram and Twitter.

Need help paying for mental health care?

TRY THESE RESOURCES:

- Cancer Financial Assistance Coalition ***cancerfac.org***
- National Patient Advocate Foundation ***npaf.org***


American Cancer Society
Regular cancer screening can help keep people together.
Call the American Cancer Society at 1-800-227-2345 or visit cancer.org.
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5 EASY WAYS to lower

Recurrence anxiety—the fear of cancer coming back—impacts nearly 70% of cancer patients, with close to 40% reporting depression as a result, according to a study in the journal *Neuropsychiatric Disease and Treatment*. One of the most effective methods for managing those emotions? Gaining back a sense of control. Read on for the common risk factors you can take charge of to lower your risk of recurrence, and see if they could work for you!

—BY MARISSA PURDY

KICK THE BUTTS

Smoking is not just a risk factor for lung cancer—it raises your risk for *any* form of cancer recurrence, according to the American Cancer Society (ACS). That's because smoking exposes you to cancer-causing chemicals, including PAH, N-nitrosamines, aromatic amines, 1,3-butadiene, benzene, aldehydes and ethylene oxide, which are absorbed directly into the bloodstream and circulated throughout the body. Today, there are many effective methods to help you cut the habit for good, including medications, addiction counseling and more. Visit *smokefree.gov* for some tips to help get you started.

STAY ACTIVE

You probably already know the American Heart Association recommends 150 minutes a week of physical activity to keep your ticker in top shape, but this recommendation extends to cancer patients in remission, as well. A study by the *Journal of Cancer Survivorship* found that cancer patients in recovery who maintained regular physical activity had a profoundly improved outcome—getting moving not only lowered rates of recurrence and increased survival rates, it also lowered anxiety and depression. The moral? Staying active can significantly improve your mood *and* help stop cancer from returning. And luckily that doesn't mean training for a marathon—study subjects saw improvements using a range of activities, including walking, dancing, yoga and strength-building exercises.

your recurrence risk!

LIMIT ALCOHOL INTAKE

Much like smoking impacts more than the lungs, drinking excess alcohol can increase health risks to more than just your liver. In fact, the World Health Organization estimates that anywhere from 4% up to 25% of cancers worldwide are attributable to alcohol. That's because the alcohol we drink—whether beer, wine or liquor—is comprised of ethanol, which can damage our DNA, causing cancer cells to develop. Alcohol also increases risk in other ways, including preventing the absorption of certain antioxidants, and increasing estrogen levels, which can promote the growth of certain estrogen-receptor positive cancers. Luckily, lowering your alcohol-related risk typically does not mean giving up happy hour completely—just keep the amounts you drink within the recommended levels. The Centers for Disease Control and Prevention recommend two drinks or less in a day for men or one drink or less in a day for women, but ask your cancer care team what levels are safe for you.

TASTE THE RAINBOW

By upping your intake of colorful fresh fruits and veggies, that is. In general, the same eating plan recommended for a healthy heart and lifestyle applies to lowering your cancer risk, as well. Several studies have linked high consumption of red meat, cured meats, sugar, canned goods (which can contain the carcinogen BPA), fried foods and high-fat dairy to increased risk of dozens of types of cancer. After completing treatment, the ACS recommends filling your plate with whole fruits and vegetables, lean protein (such as chicken and fish), beans, nuts and whole-grain carbs like brown rice.

DON'T MISS FOLLOW-UP SCANS

More so than anything else, adhering to your care team's recommended screening schedule can help you detect any signs or symptoms of recurrence before they progress. The Centers for Disease Control and Prevention (CDC) suggest a great way to stay on top of your care is to create a "survivorship care plan" with your team, which includes a record of your treatment history, a schedule for exams and future testing, and different ways they recommend specifically for you to stay healthy. And if a recurrence does occur? Take heart—with today's treatment options, you have every reason to believe you can beat this episode of cancer, as well, and get back to living in remission!

How often should I go for follow-up screenings?

Exact recommendations can vary from patient to patient, but generally speaking most patients with advanced stage cancer who achieve a full response from treatment will need scans **every 3 to 6 months for the first 3-5 years after treatment and every 6 months to every year going forward.**

Health Monitor Living

Questions to ask at today's exam

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What are the results of my latest tests and scans, and what do they indicate about my current treatment?

What should I know about immunotherapy or targeted therapy? Are either or both an option for me?

Is there a clinical trial that can help me? What are the pros and cons of participating in a trial?

Are there any side effects that I should report to you immediately?

If this treatment doesn't work, what are my next options?

What future tests will I need to track my progress?

What are the side effects I can expect?

Can I still work while undergoing treatment?

Do you know of any support groups I can join?

On treatment and need help covering the cost?

Ask your healthcare provider about patient assistance programs or call the manufacturer of the treatment you have been prescribed. Many pharmaceutical companies offer copay assistance programs that can make treatment more affordable.