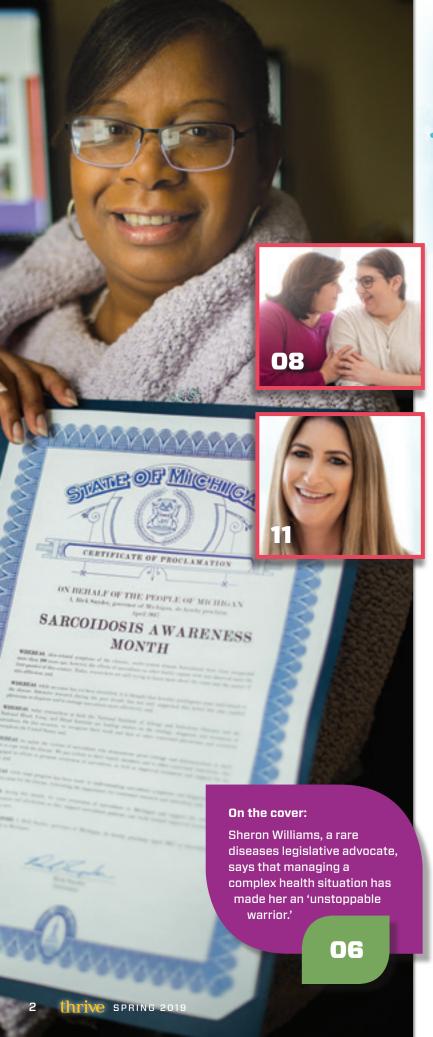
A Publication of the University of Michigan Rogel Cancer Center | SPRING 2019 **Helping You** Through Your guide to support services that complement medical treatment ROGEL CANCER CENTER MICHIGAN MEDICINE



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Published twice a year by the University of Michigan Rogel Cancer Center, 1500 E. Medical Center Dr., Ann Arbor, MI 48109-5944. If you have questions or a story idea for *Thrive*, please call Beth Johnson at 734-764-8311.

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For more information about the stories in *Thrive* or any other cancer-related information, please call the Cancer AnswerLine at 800-865-1125.

A letter from the Thrive editor

Hello Rogel Cancer Center patients,

And, hello to the friends, families and loved ones of our patients.

I'm so glad you have found our patient magazine. Cancer is never easy and these pages aim to give you information and stories about living with a cancer diagnosis in the way that works best for you.

In the seven years I have been editor of *Thrive*, I've interviewed many patients about their cancer experiences. In this issue of the magazine, my goal was to share some of the common themes I hear about that help and inspire patients the most.

Claire Casselman is a perfect example. Claire is a social worker at the Rogel Cancer Center whose name I hear regularly from patients, who say her work in guided imagery and elsewhere made a huge difference in easing their worries during treatment.

If you're feeling down when you come into our doors, try saying hello to Linda Diroff at our information desk. Linda is never without a smile, kind words and directions on which way to go.

Even if you don't have time to read *Thrive* today, flip to the back page of the magazine for our list of telephone numbers for a variety of resources that are available to you as patients.

Whether you need help to guit smoking, are struggling with side effects or need rides to treatment, there are numbers to call for people within this large health system whose goal is to meet your needs.

If you ever have a question and are unsure who to call, the Cancer AnswerLine is a great starting place. Our registered nurses will either answer your question or put you in touch with the person who can. Their number is 1-800-865-1125.

If you're inspired at the Rogel Cancer Center, I hope you'll let me know so I can write about it in the magazine for others. Email me at eaj@med.umich.edu.

Best wishes,

Beth Johnson Editor



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Your Emotio

Finding the tools to stay grounded during

The sheer impact of the word cancer carries many emotions, such as fear, shock and worry.

There are times of waiting for further information and times when a patient and family must carefully but quickly weigh options. It can be challenging to make sense of all the information and put some order to it.

We sat down with Donna Murphy, LMSW, director of Patient and Family Support Services at the Rogel Cancer Center, to talk about the importance of emotional well-being during cancer treatment and where to turn to find it.

What are some of the concerns patients face when diagnosed with cancer?

Adults have many roles and responsibilities, such as parenting, work and relationships. They worry about changes in health and ability, and the idea of becoming less independent. Patients may have financial concerns, a need to stop work temporarily or permanently, no transportation to and from appointments, or side effects from treatments.

One of the most difficult challenges I hear patients talk about is living with the unknown. Very few cancer diagnoses follow a specific path. The experience and side effects of treatment are different based on the person.

Cancer is an abrupt change in the course of one's life. Yet people are faced with responsibilities, big decisions and changes in their lifestyle. It is important for you to find what is right for you in managing this new information.

Why is it so important to stay on top of your emotional well-being during cancer treatment?

Grief, fear and worry are common emotions connected to cancer. People can also be hopeful and take on a positive outlook that might enhance healing. Maintaining a positive energy, both physically and emotionally, is one way to create a sense of control over something we can't always see or feel.

Not all people are wired to feel optimistic in the face of difficult news; we often say that peoples' way of managing a cancer diagnosis is similar to how they have managed other life challenges. It can help to have the support of those you trust and create ways to share your emotions.

It is important to care gently for yourself. Being able to ask for what you need from those you trust is key.

How can emotional distress hinder cancer treatment?

Distress responses release hormones that help us cope in the moment (the fight or flight response), but when repeated over the long term, they can be less beneficial to our bodies. If you find ways to help your emotions stay more stable (rather than sharp spikes of emotions) and increase the pleasure you experience, the body and mind will respond better.



Donna Murphy, LMSW

nal Well-being

cancer and treatment



What are some options for patients who are struggling with their emotions?

Certain lifestyle behaviors can be a good start, such as healthy eating, moving your body as much as possible, taking in nature or interacting with loved ones.

If an activity has brought you joy before, it may do so again. Some people find that their time in cancer treatment brings forth new forms of expression due to the life shift that happens when faced with a serious illness. Ideas to try include writing, breathing exercises, creating art, needlepoint, reading or gardening, to name a few.

At the Rogel Cancer Center, our Patient and Family Support Services are designed to reduce anxiety and worry, teach new ways of coping and provide a confidential outlet for feelings and emotions. Patients can try art therapy, music therapy or guided imagery, or talk about faith or spiritual needs. We can support those who need to speak to their children about a cancer diagnosis.

We also have clinical social workers and psychiatrists to help with exploring the deeper concerns when worries do not ease. Faith appears to be a framework for most people, either through a specific religion, spiritual practices or belief in a higher power that is bigger than themselves.

Try these online resources:

The American Cancer Society www.cancer.org

The Cancer Support Community of Greater Ann Arbor www.cancersupportannarbor.org

Imerman Angels (a peer matching group), imermanangels.org

Search for apps using these terms:

Cancer

Relaxation

Positivity

Humo

Murphy suggests: Be selective with social media groups. Make sure it is a positive group and you aren't left feeling more concerned or worried.



How can taking care of their emotional well-being benefit patients in the long run?

There are many people on your treatment team who can help during your time as a cancer patient. Remind yourself of the things that are most important in your life, your unique values and qualities, and remember that you are never defined by an illness. You are also not defined by your worries or concerns.

Feelings that come with an illness might challenge your confidence, but illness doesn't take away your competence as a parent, partner, worker, helper or friend. Moreover, you may find yourself feeling stronger, more resilient and wiser because of your diagnosis.

The Power of

Guided imagery helps one patient find her footing during treatment



Claire Casselman, LMSW



Visit **rogelcancercenter.org/thrive** for our free library of guided imagery podcasts.



Call **877-907-0859** to schedule an appointment to learn guided imagery and mindfulness techniques customized for you.

WEB EXCLUSIVE:

Visit **rogelcancercenter.org/thrive** to learn the Five Things list to help yourself when you feel anxious.



After 26 years with a rare inflammatory disease called sarcoidosis, Sheron Williams had learned to cope with a chronic illness that impacts her liver, skin, lungs and uvula and requires portable oxygen. Adding a breast cancer diagnosis to her already complex health situation left her stunned.

"Am I really going down another journey with another diagnosis? How do I handle this?" she asked herself.

Williams' cancer diagnosis came after a routine mammogram, an annual screening she never misses. A biopsy confirmed a tumor the size of a Cheerio, triple-negative breast cancer.

Her surgeon at the University of Michigan Rogel Cancer Center, Jacqueline Jeruss, M.D., Ph.D., removed the tumor. Her oncologist, Aki Morikawa, M.D., Ph.D., recommended chemotherapy and radiation therapy to ensure her best chance of the cancer not returning.

Williams was pleased her sarcoidosis care team at Michigan Medicine communicated with her new cancer care team at the Rogel Cancer Center, but her anxiety grew when she learned she had to stop taking her sarcoidosis medication while on chemotherapy.

When a social worker called her at home to explain some of the free complementary therapies offered at the Rogel Cancer Center, Williams was interested in one called guided imagery. She asked to learn more.

"Guided imagery is about harnessing the power of the imagination and using it to feel more calm and in control," says Claire Casselman, LMSW, a clinical social worker in the Complementary Therapies Program.

Casselman met with Williams the day before her first chemotherapy appointment to teach her mind and body techniques for learning to manage anxiety related to her cancer treatment. She gave her two guided imagery CDs to take home.

"The benefits of guided imagery are apparent immediately. It's easy to learn and you'll likely notice the very first time that you feel better, more calm," Casselman says.

Williams hadn't expected to need guided imagery so soon, but an allergic reaction to her chemotherapy drugs made it difficult to breathe.

"It felt like someone was physically squeezing my body, but all of a sudden I stopped and remembered what Claire said yesterday. Breathe. Cancer doesn't have me. Listen to what the doctors are telling me," Williams says.

Casselman remembers the allergic reaction and how Williams helped herself through it using guided imagery techniques.

"She focused on her breath and 'finding her feet.' That's a mindfulness technique to literally feel more grounded by paying attention to where you are and what's available to you. Then Sharon could feel her strength," Casselman says.

Williams ended up changing to a new chemotherapy drug and is preparing to begin radiation therapy. She still listens to her guided imagery CDs around five times a week.

Imagination

"It really does work. You know it's positive when you can actually feel the positive energy replacing the fear or anger. I used to put up a wall to protect me. Now I don't need it," Williams says.

Williams feels well enough to continue her life's passion as a rare disease legislative advocate. She started an education-based support group called the Michigan Unstoppable Warriors Sarcoidosis Group. She is also a patient ambassador for the Foundation for Sarcoidosis Research and meets with legislators to educate them about the disease. Her goal is to have a law in Michigan for a sarcoidosis awareness month.





Inspiration

For other patients at the Rogel Cancer Center, art therapy is available with Art Therapists Sandra Drabant and Melinda Hallenback-Kosteky, who offer workshops, special projects, gallery opportunities and individual sessions during or outside of treatment.

"Being engaged in a creative process can provide a safe and gratifying way to explore difficult experiences and emotions. It can also be a way to express intention, gratitude, love and hope," Hallenback-Kostecky says.

TURNING NEGATIVE INTO POSITIVE

Hannah Thomas, 18, started radiation therapy with a reluctant attitude. She'd had surgery over the summer to remove most of the malignant tumor, medulloblastoma, in the floor of the fourth ventricle of her brain. Now, she and her parents had to travel from their home in Grosse Ile to Ann Arbor for 30 days for radiation therapy appointments that only took 10 minutes. Worse, school had started and she was missing her junior year.

She noticed the rock garden and saw other patients painting rocks, but had little interest in doing one. Painting a rock meant spending more time there when she really just wanted to go home.

"Dark clouds, despair and the thought of leaving is a very poor path to take. Keep smiling, laughing and enjoying life is a better one!"

- MARTY SCHULTZ, 65

Dear Cancer,
Nice try...
but I am
still here!

OVER OME THRO GH COU AGE & STR NGTH

thrive SPRING 2019 9

FEATURE | Creating Inspiration

"Reading the quotes when you walk in puts you in a positive state of mind when you're feeling down and have no hope. It's a reminder the people in there have your back and are there to support you during the worst time."

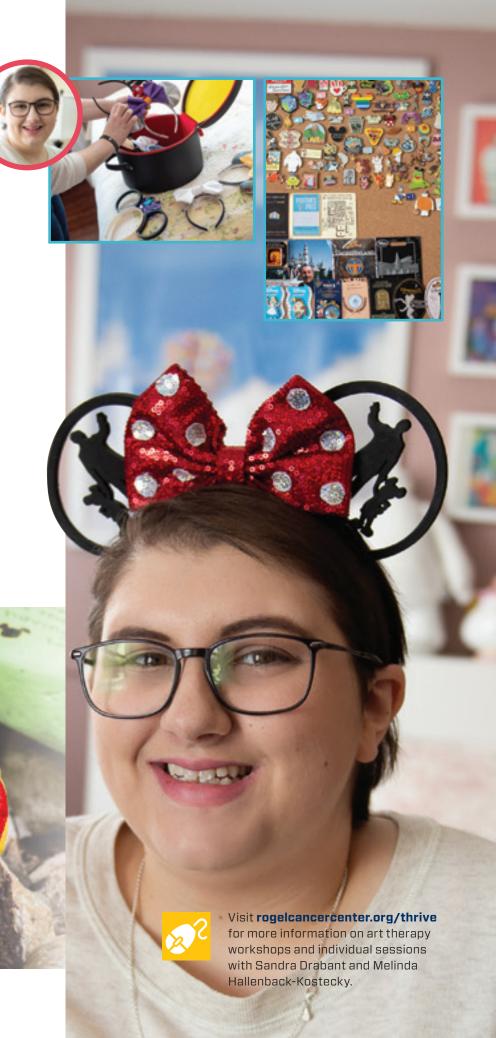
- HANNAH THOMAS, 18

"It seems like it's never going to end when you first start treatment," Thomas says. "But it goes by so fast if you think positive. Kristan and all the people in radiation were really nice. They made it go by quickly."

Thomas changed her mind about painting a rock as she bonded with her caregivers. When she went to the garden to select her rock, she picked one so large Freitag had to carry it inside for her.

The message on Thomas' rock is inspired by her family's love of Disney World, where they travel at least once a year. She painted a Walt Disney quote: "If you dream it, you can do it."

"I hope my message makes anyone who has to walk in there who is feeling down or sad, or doesn't think this whole thing is going to end, that there's hope," Thomas says. "If you think positive, it will go by so much faster and it will be so much better."



A Whole New Lifestyle

ichelle Peres was on a trip to Florida in 2016, simply pulling her hair into a ponytail when her friend noticed a small indentation form on her chest from lifting her arms. Further tests back home in Michigan revealed three small tumors: stage 1 breast cancer.

After having a mastectomy to remove it, Peres, now 49, was left feeling tired, with little energy for her work as the vice president of enrollment for a medical school. Her weight was the highest it had ever been. She wanted to feel healthy again for her husband, Ed, and their two teenage sons.

She began follow up cancer care at the Rogel Cancer Center, which included maintenance therapy of tamoxifen, a drug that blocks estrogen, and a monthly injection of Lupron, which puts the body into artificial menopause. Her oncologist referred Peres to Danielle Karsies, a registered dietitian, for guidance on using nutrition and lifestyle changes to improve how she was feeling.

"My body was really inflamed after surgery and I felt unhealthy," Peres says. "I didn't know what I was doing wrong. My old eating habits didn't work anymore."

Karsies works with a team of registered dietitians who counsel Rogel Cancer Center patients on how to use food as fuel during and after cancer treatment. One of the first things she tells patients dealing with excess weight is that 30 percent of cancers have a weight and obesityrelated risk.

The first step for Peres was to aim to fill half her plate at meals with fruits and vegetables. In addition to healthy nutrients and filling fiber, they make you feel full on fewer calories.



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TIPS TO GET STARTED WITH A HEALTHY LIFESTYLE

Some activity is better than none. Get 10 minutes in at a time and just move.

Try moderate activities like brisk walking, gardening or ballroom dancing. Fill half of your plate with fruits and vegetables.

Try a plant-based diet of mostly fruits, vegetables, whole grains and legumes. Limit high-calorie foods and beverages if you need to lose weight.

Limit alcohol to 1 drink for women, 2 drinks for men daily.

Limit red or processed meats to 18 ounces per week.

Find alternatives to processed meat, as these should be avoided.



"I eat a lot of plant-based foods now," Peres says. "I eat broccoli at least four times a week, a lot of legumes. I love bean salads and quinoa."

Gradually, she also cut out red meat and alcohol, which have been associated with increased risk of certain cancers.

"While no one food can cure or cause cancer, experts agree that eating 18 ounces or less of red meat a week is preferred. When eating meat, patients should always choose lean cuts," Karsies says. "Not all patients cut out meat entirely like Michelle did, but filling up half your plate with fruits and vegetables and a quarter of your plate with whole grains ensures your meat portions are small."

With her new eating plan in place, Michelle spoke with Karsies about getting back to exercise as part of her recovery.

"Getting your body back together after such a large surgery can be very traumatic," Peres says. "I felt like my body was a mess. I had to go to physical therapy. I needed to get my mind and body connected. Eating healthy. Exercising. Massage therapy."

Because of her busy work schedule, she decided to try a noontime Pilates class twice a week at a studio near her home in West Bloomfield. On the weekends, she goes to the gym for a stretching class and to use the elliptical machine. In the summer, she walks several miles a week outdoors.

in people with breast, colorectal, prostate and ovarian cancer," Karsies says. "Some cancer treatments can leave you weak and unsteady. Exercise, including aerobic and resistance training, can improve muscle strength, cardiopulmonary fitness and balance."

Karsies says the goal for exercise is 150 minutes of moderate intensity per week. Patients should always check with their physician before starting an exercise routine. Water activities, such as swimming or water aerobics, can be helpful with balance issues or neuropathy.

Using the nutritional and lifestyle guidance from Karsies, Peres has lost 30 pounds and, over the past two and a half years, has stuck with it. She still meets with Karsies during her appointments at the Rogel Cancer Center to check in and make adjustments for her food allergies.

"It all made me feel better and whole again," she says. "I am energized. I feel that I've taken control of my body, which is what you want to do when you have a cancer diagnosis."

Peres hopes sharing her story about lifestyle changes will help other women and men feel empowered, healthy and strong.



The **Language** of Cancer

The history of military language to describe cancer inspires some, burdens others

Why is it that people often use terms associated with war when they're talking about cancer? More so than other illnesses, you're likely to hear it described as a "battle."

And, if someone passes away from their disease—such as the recent high profile instances of politician John McCain or singer Aretha Franklin—it is reported that they "lost their battle" with cancer.

Michelle Riba, M.D., director of the PsychOncology Program at the University of Michigan Rogel Cancer Center, suggests that using this type of language can put an unfair burden on some cancer patients.

After all, cancer and its treatment can be grueling. Patients can experience fatigue, nausea or other side effects that make day-to-day living difficult, let alone allow them to muster enough energy or enthusiasm for the "fight of their life."

"This has become common in our lexicon, and we read about it, yet it is very negative for a lot of people to really think about this as a fight," Riba says. "We are trying to use different language these days, but still we don't even think about how often these kinds of terms are used in reading and watching TV."

Riba points out that it is far less common to describe other illnesses, such as heart disease or diabetes, using language connected to the military.

SOME HISTORY: "THE WAR ON CANCER"

In 1971, President Richard Nixon declared the "war on cancer," which had become the second leading cause of death in the United States after heart disease. In addition to establishing the National Cancer Institute, the war on cancer included the creation of cancer centers, dedicated research teams and a renewed financial commitment to understanding cancer cells in order to develop new treatments.

By May 1971, Nixon had secured an additional \$100 million in funding for the purpose of seeking a cure for cancer.

The news media and health care organizations reported on Nixon's declared war against a dangerous illness. Over time, using militaristic language connected to the disease was common.

SOME PATIENTS WANT TO BATTLE, OTHERS DON'T

It is not to say that many patients aren't inspired by the idea they are fighting for their lives. And, if this is the case, patients and their families and loved ones should proceed using the words that connect with getting through treatment and aiming to become healthy.

Riba points out that the needs of individual patients can be varied, not just in how they live their lives with cancer but also in the language that resonates with them.

"For some, referring to cancer as a battle could be motivating: a warrior trying to slay a dragon. It is time, however, that we consider the people who might feel burdened by it and offer some alternative terminology, such as 'living with cancer.'"

And, she adds, "At no time should we refer to someone losing his or her battle with this disease. We are not talking about a battle in a war or a basketball game; we are talking about the entirety of patients' lives, and they deserve better."

Experts at the Rogel Cancer Center are working on recommended language to use in place of



FINDING CANCER PREVENTION CLUES IN FOREIGN DIETS, LIFESTYLES

In a global tour under the Fulbright Global Scholar Award, Michigan Medicine cancer researcher Zora Djuric, Ph.D., studied eating habits in Serbia, Guatemala and Australia.

The goal: to understand how different cultures' menus impact cancer risk factors — and ways those findings might be applied in American kitchens to improve cancer prevention and outcomes.

"We do have personal control over the food we eat, and that made me interested in how we can use that to prevent cancer," says Djuric, also a research professor of family medicine and nutritional sciences at the University of Michigan.

Obesity increases the risk of at least half a dozen cancers, notes Djuric. So if a healthy diet prevents weight gain, then it could also help prevent cancer.

Djuric first worked with the Center of Excellence in Nutrition and Metabolism Research at the University of Belgrade in Serbia, headed by Marija Glibetić, Ph.D., where she looked at the dietary components and timing of meals in preventing obesity.

Serbians tend to eat their big meal in the middle of the afternoon, around 3 or 4 p.m., Djuric found. Later, they eat a very light dinner, almost like a snack.

That schedule means Serbians are more likely to metabolize (or burn off) the food before going to sleep. And most of their meals are home-cooked with fresh market foods instead of prepackaged or ready-made ingredients.

Serbians typically eat a nutritious, mixed meal with lots of vegetables and a little meat in a large soup bowl. "Think goulash or one-pot stew," Djuric says.

But we don't have to copy Serbian eating patterns to prevent cancer, she says. We can just be inspired by it. The challenge she offers is to make vegetables the biggest part of the meal.

Djuric says the Fulbright scholarship, which sponsors U.S. and foreign participants for international exchanges in many fields to advance mutual understanding, provides a unique opportunity.

"The program enriches my own research into different directions and also helps me with my existing projects," she says. "Because the United States tends to be isolated from the world, Fulbright gives us the chance to see different ways of doing things, different attitudes and different values."

Djuric visited Guatamala and Australia in late 2018, with her findings forthcoming.

MAJOR STRIDES IN PANCREATIC CANCER GIVE 'ACTUAL REASONS FOR HOPE'

When the five-year survival rate for pancreatic cancer hit 9 percent last year, it represented a near doubling from 5 percent just five years earlier.

While progress is exciting, researchers remain unsatisfied. So much work remains to be done.

"There's actual reason for hope now. For the longest time, we were throwing around the word 'hope,' but now we have scientific reason for hope," says Clifford Cho, M.D., a pancreatic cancer surgeon at the University of Michigan Rogel Cancer Center.

"I feel there's momentum right now. Scientists are working tremendously hard on this question. There is an accelerating momentum. Our patients deserve that," says Cho, C. Gardner Child Professor of Surgery and chief of hepatopancreatobiliary and advanced gastrointestinal surgery at Michigan Medicine.

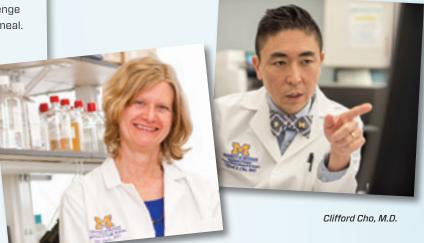
Better funding throughout the last decade from foundations and advocacy organizations has helped move the field forward. Working collaboratively within and across institutions, researchers are gaining new understandings of the unusual biology of pancreatic cancer and can now simulate it better in laboratory models.

The result: incremental yet significant improvements in surgery, radiation therapy and chemotherapy that have some patients with advanced disease living for years instead of months.

And on the horizon: a determination among researchers to manipulate the immune system so that pancreatic cancer patients can benefit from the immunotherapy treatments revolutionizing other hard-to-treat cancers.

"Immune therapy is the future. For the past 20 years, we've been using chemotherapy regimens with minor benefits. We need more tolerable medicines that allow for a good quality of life," says Howard Crawford, Ph.D., director of the Pancreas Disease Initiative and professor of molecular and integrative physiology and internal medicine at U-M.

Read the full report at michmed.org/EG3W5.



Zora Djuric, Ph.D.



Have a question for the pharmacist? Email us at ThriveMagazine@ med.umich.edu

Symptom Management Self-Care

Below are some common symptoms during cancer treatment, ways you can help yourself and when you should call your medical team.

NAUSEA

What you can do

- · Drink at least 8 cups of fluid per day
- Use anti-nausea medication prescribed by the clinic
- Eat smaller, more frequent meals/snacks
- Avoid an empty stomach
- · Eat bland foods

When to call the clinic

- Unable to stay hydrated or keep liquids down
- Over-the-counter remedies
- · Anti-nausea medication is not working
- · Ginger foods or drinks

FATIGUE/TIREDNESS

What you can do

- Don't over-exert yourself · Rest when you're tired
- Ask for help
- Eat and drink well

When to call the clinic

• Unable to perform normal daily activities

Over-the-counter remedies

· Exercise/activities

NEUROPATHY (Numbness, tingling, burning or weakness in the hands/fingers, feet/toes, legs)

- Tell your care team at your next visit, as this can worsen as treatment progresses.
- Discomfort that affects your ability to work or perform normal activities (i.e. unable to grasp a pen, button your shirt or feel the bottoms of your feet)
- Vitamin B6/B complex

TROUBLE SLEEPING/INSOMNIA

- Avoid napping during the day
- Avoid caffeine, nicotine and alcohol before bedtime
- · Establish a relaxing bedtime routine
- Exercise

- Unable to perform normal daily activities
- Melatonin
- · Chamomile tea

HEADACHES

- Use an over-the-counter pain medicine as directed by your care team
- · Headaches that do not resolve after 24 hours with over-the-counter medicine
- If directed by your care team, try acetaminophen (Tylenol) or ibuprofen (Motrin/Advil)

- 734-647-8911
 - **PsychOncology**

877-907-0859

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734-232-2621

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Music Therapy

877-907-0859

877-907-0859

734-232-2208

Center

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Nutrition Services

Patient Assistance

877-907-0859

Cancer AnswerLine 800-865-1125

Smoking Cessation Counseling

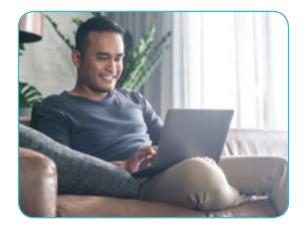
734-998-6222

Social Work

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Symptom Management and Supportive Care

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THRIVE ONLINE

rogelcancercenter.org/thrive

Thrive doesn't end here! Visit rogelcancercenter.org/thrive for more. Here's what you'll find:

- Information on art therapy workshops and sessions with Sandra Drabant and Melinda Hallenback-Kostecky
- · Guided imagery podcasts you can download for free
- · Links to events at the Rogel Cancer Center and in the community
- The Five Things list to help yourself when you feel anxious
- · Clinical trials looking for participants