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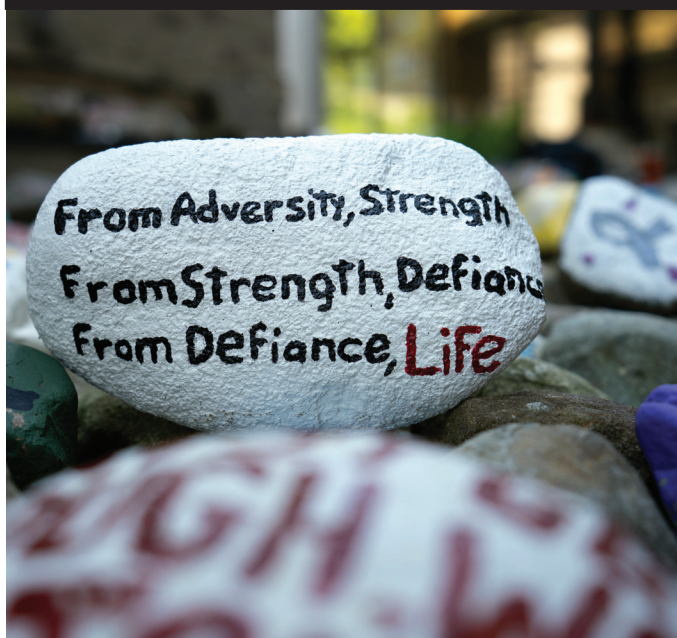


After an advanced cancer diagnosis, Scott Ward began documenting his family's past — while staying hopeful about the future.

Determined

Also: The benefits of palliative care; how a chaplain can help

thrive



THIS ISSUE'S THEME

Advanced Cancer

What it's like to live with cancer that's spread —
and the resources we can offer to help.



On the cover

Artistic hobbies like writing and photography have helped Scott Ward ride the roller coaster of advanced cancer.

Cover photo
by Erica Reist Bass

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Supportive sentiments

People who've had advanced cancer share words of hope and advice for those with new diagnoses.

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Riding a roller coaster

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The perks of palliative care

Palliative care providers do more than discuss the end of life. Here's how they can help.

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You're Stronger Than You Realize

And other words of hope and advice from patients who have been diagnosed with or treated for advanced cancer at Rogel.

"If you can, find a purpose - something to do that occupies your time and your mind so you're not always concentrating on the cancer."

Diane Detter

"If you think things are going to go right, you're probably right. If you think things are going to go wrong, you're probably right."

John Schaeffer

"If there's an experience you want to have, go for it. Try not to put things off. Do what you can to not let cancer be your whole life."

Darlene Nichols

"We're more than our cancer diagnosis. I'm still Bill Guisinger at my heart."

Bill Guisinger

**"You're stronger
than you ever
realized, without
a doubt."**

Theresa Gougeon

"You can be sad. You can go there. But you can't stay there. Try to set your intention to get through the day and be as present as you can be."

Heather Jose

"Sometimes, when I feel alone in the whole situation, I'll go to YouTube and watch some of the meditations by [guided imagery specialist] Claire Casselman and [art therapist] Sandra Drabant, and that makes me feel a lot better."

Maggie Smallwood

"We all know what that isolation of a cancer diagnosis feels like. Hearing other people's stories and the dimensions that happen on their paths can make you feel less alone and remain positive."

Wendy Passer

Resources

Check out:

► Heather Jose's podcast **"I'm Still Here: Lessons From Life With Metastatic Breast Cancer"** on YouTube and popular podcast services

► Maggie Smallwood's TikToks detailing her experience with stage 4 cancer under the handle **maggietycypk**



Guiding Spirit

Chaplains Shama Mehta and Bruce Paul go where patients need to go — emotionally, mentally and spiritually.

By Eric Olsen

When Bruce Paul meets a patient for the first time, he pulls up a stool and says, “Tell me about yourself.” It’s the beginning of a conversation about the person’s struggles and strengths – and the resources they have, both internally and externally, to help them navigate the experience of cancer.

Paul and Shama Mehta, the Rogel Cancer Center chaplains, are trained to provide care for patients and their families through an interfaith lens, which allows them to help people of any spiritual persuasion. We sat down with Paul and Mehta to learn more about how they interact with patients, what separates patients with cancer from those with other health issues and the strategies they use to help people with advanced cancer.

What are your interactions with patients like?

Bruce Paul: In our caregiving, we really sit and listen. We continue to let the patient tell us who they are and what’s going on with them. We let the patient lead and find out through that listening experience.

Shama Mehta: It’s basically empathizing with what they’re going through. I ask them to tell me more, tell me what it’s like for you. Even though you’re dealing with this situation right now, your strengths have not left you. How can you use them? It could be spirituality; it could be religion. And when we’re navigating spirituality, what we mean is that we’re also looking at what is their life’s meaning and purpose. But again, giving it back to them as something they can rely on while navigating what they’re dealing with.

What types of issues often come up for people with cancer?

Mehta: The aspect that differs slightly for patients with cancer, in my opinion, is at times the suddenness of the diagnosis that can create turmoil in one's life. How spiritual distress shows up in an individual with cancer is unique to who they are.

Paul: Most everyone who gets a cancer diagnosis experiences thoughts about their own mortality. They start to look at life differently — with an urgency. What people want to do when they have limited time really pulls into focus what moves them spiritually, what's most important to them.

Strong emotions can often be a part of the conversation for those with advanced cancer. How do you help people work with these feelings?

Paul: Really, identifying the emotions is key. Once we understand what they are feeling, then it's easier to start to discern why they are experiencing those emotions. I would say that patients with advanced cancer are often willing to go deeper into these areas quicker.

How do you approach end-of-life conversations with patients and their families?

Mehta: When patients or families want to discuss death and dying, I stay with them in those moments to assess which aspect is bothering them the most. With a cancer diagnosis, I have noticed that a lot of the questions regarding end of life tend to be a concern with what happens to someone physically.

Paul: I often simply ask how they are feeling about the prognosis and how they would like to best use whatever time they have. Are they afraid of something specific or something unknown? And I try to see if there is a ritual or activity that will be helpful in lessening the fear.

Why do you enjoy working with people who have cancer?

Mehta: I really enjoy the relationships that we develop with patients and their families.

For example, I had a patient once who was in and out of the hospital quite a lot with her disease. I developed a relationship not only with the patient but also with the family. They were there alongside as we navigated this journey with her up to the very end, and even now the family are friends. They would reach out every once in a while and check in and ask for prayers. It was that kind of relationship that makes you figure out we are truly a part of the same world, and we have the same human experience. ☐

Resources

The Rogel chaplains launched a spiritually focused expressive writing group earlier this year. If you're interested in signing up for the spring 2023 group, email: cancer-support-services@med.umich.edu

Sometimes, what you need

to get through the tough moments of cancer treatment is a peaceful place for reflection or prayer. Michigan Medicine has several dedicated spaces for just that, including both nondenominational chapels and quiet rooms.

Room 2A215 at University Hospital.

Access the chapel from the cancer center by taking the elevator to the second floor and making a left. The chapel will be on your left at the end of the long hallway, shortly after the gift shop.

Room 2780 on the second floor of C.S. Mott Children's Hospital.

The Helen and Mike Vlasic Family Chapel is right outside the Mott lobby, between Big Bird and the Taubman Center.

Room 001B on floor 2A and room 4141 on the fourth floor in the Cardiovascular Center. Take elevator 12 from the CVC's second floor (which connects to all the other hospitals, including the cancer center). The quiet rooms are directly to the right of the elevator on both 2A and four.



The Helen and Mike Vlasic Family Chapel at Mott



*Go
Not*

quietly

By Mary Clare Fischer
Photographs by Erica Reist Bass

The four years since Scott Ward was diagnosed with stage 4 prostate cancer have been a roller coaster. But, amid side effects and surgeries, he's found solace in creating art and memorializing his family's stories.

*I am defiant
Though my life will be shorter
Memory will last*

—Scott Ward

By the time the doctors found the cancer, it had spread. Lymph nodes, ribs, lungs, pelvis — all were playing host to cells that had migrated from the tumor in Scott Ward's prostate to become stage 4 cancer.

Scott was devastated. One of his grandfathers and two of his uncles had died from prostate cancer at relatively young ages, so he assumed his diagnosis was as good as a death sentence.

And, at 54, he wasn't ready to die yet. He wanted to spend more time with his wife and teenage son. To eventually retire and do more of the things he actually wanted to do instead of work. To maybe even build a close relationship with a grandchild

like his grandparents had done with him.

Plus, as his family's historian, he worried about what would happen if no one was around to remember the Ward lore.

"All this negative stuff was in my mind," Scott says. "I was visiting a dark place and mucking around there for a while. But what I came to realize was: It does nobody good to stay down there."

Instead, with help from a Rogel therapy group for people with advanced cancer, Scott has figured out the legacy he wants to leave behind. Amid the swings of worrisome news and the jubilation of discovering new treatment options, he's documented his experiences and memories in photos, haikus, short stories





Scott Ward laughs with his wife, Kathleen, and son, Ethan, in their Ann Arbor home.

and even tattoos, while holding onto hope that perhaps he'll have more time left than expected.

"If there wasn't anything I could do about cancer necessarily, I wanted to live as fruitful and joyous a life as I could," he says. "And mentally, that's where I've tried to stay as much as possible. I didn't think I was going to be here, and I am."

What possible plan Can there be when faced with Terminal illness?

THE FIRST COURSE of treatment was a shot in the butt.

Testosterone is the primary way that prostate cancer grows and spreads, so Rogel Cancer Center urologic oncologist Zachery Reichert, M.D., Ph.D., first gave Ward an injection to lower the amount of the hormone made by Scott's testicles.

Reichert warned Scott about some of the side effects of this androgen deprivation therapy. (Scott's wife, Kathleen Folger, remembers laughing in the doctor's office at the mention of hot flashes.) But the symptoms were worse than Scott had expected. He lost most of his hair, including a bushy beard, and his testicles "shrank to the size of acorns." The hot flashes came every 30 minutes.

"Welcome to my world," Kathleen had said.

Reaching into the Unknown, one seeks to be heard Open, one learns grace

YET, AS SCOTT lost some elements of his identity, he added others he'd felt he couldn't explore before his diagnosis. He got one ear pierced and then the other. Next came the forearm tattoos: the Latin phrase "Ex adversis, viribus," which translates to, "From

adversity, strength," and an arrow that doubles back on itself.

Finally, he designed a larger tattoo for his chest. The artwork is made up of several symbols that represent concepts ranging from durability, a word Reichert used to describe what he was hoping to see from the series of cancer treatments Scott would undergo, to balance, which is all Scott says that he can reasonably hope for.

Kathleen was surprised but understood that these positive affirmations helped him find the motivation to keep going.

"After the second or third tattoo, I said, 'I've never dated a bad boy,'" she recalls with a grin, "but somehow I find myself married to one."

Living one's passion Is an act of defiance Go not quietly

IT WAS THE first day of spring. The sun was out and the temperature had climbed enough for Scott to sit outside in his front yard on the west side of Ann Arbor.

Resources

To see if the meaning-centered support group for patients with advanced cancer could help you on your cancer journey, call 877-907-0859. All complementary therapies are free for Rogel Cancer Center patients.

For more on how the Michigan Oncology Sequencing Center is transforming treatment for patients with metastatic cancer, scan this QR code:



He'd started taking two oral medications to treat his cancer and had just completed his second cycle of chemotherapy. Research had shown that adding additional treatments to the androgen deprivation therapy can help people with prostate cancer live significantly longer, and Reichert thought Scott might tolerate them well, given his relatively young age. (The average age of diagnosis for prostate cancer is 66.)

Under the fledgling sun, a haiku popped into his head fully formed. He wrote it down and set it aside, but the words wouldn't stop coming. Throughout the summer, he kept a pad of paper and a pencil next to his bed to jot down the steady stream of poetry that flowed from his mind.

"It was like a muse was whispering to me on a daily basis," Scott says.

*Then I remember
There is much to live for now
Legacy calls me*

SQUARES OF BOBBING heads filled the computer screen as people with advanced cancer logged onto Zoom. It was June 2020, and a new cohort of the meaning-centered support group at the Rogel Cancer Center was coming together for the first time.

The main topic of discussion was legacy, a mental road that Scott had traveled a bit already. He voiced his fears about how he could remain a presence in his son's life and whether it was possible to preserve the family stories that his son might appreciate more when he's older. Could there be a way for him to translate the past for his family, he wondered, even when he wasn't here anymore?

Others in the group had similar thoughts.

"Telling your story to your survivors was the biggest theme we all talked about," Scott says. "Everybody had their own way of doing so, but they all felt they would be able to leave an imprint of their own for family and friends."

For Ward, that meant delving back into photography and exploring writing, another hobby he'd always wanted to pursue but felt constrained from trying. Getting cancer, though, had freed him up to experiment.

*The well is too deep
Despair, I think to myself
How can I get out?*

JUST AS SUDDENLY as Scott's creative inspiration started, it stopped. The timing may not have been coincidence. The chemo wasn't working. In fact, the cancer had spread to Scott's liver, an ominous sign.

"What's left?" Scott asked Reichert.

Reichert very kindly "did not pull any punches," as Scott says.

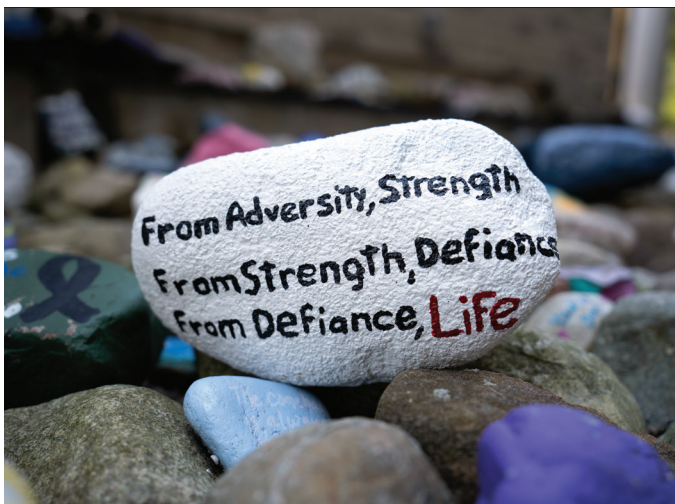


Scott has begun writing stories to preserve his family's legacy; a snapshot Scott, a photographer himself, took in Acadia National Park; photos of his ancestors.

"Essentially, we are looking at a very short time horizon unless a second chemotherapy works," Reichert responded.

After their virtual appointment ended, Scott got off the phone and emerged from the basement. He couldn't stop crying.

*Spend time in the dark
Opine for your lost life, then
Claw your way to light.*



Scott's painted rock in the garden near radiation oncology.

SCOTT WENT INTO what he calls engineer mode. He wrote down all the logistical tasks he needed to complete before he died — write his obituary, buy a cemetery plot — and threw all his energy toward his to-do list.

Meanwhile, he started on a combination of two new chemotherapies. Reichert knew of research that had found this specific pairing was more effective than just one of the two drugs by itself.

And for Scott, that proved to be the case. After 10 cycles of the dual-agent chemo, Reichert could find no evidence of active cancer on Ward's scans.

"That was the game changer," Scott says.

"His quality of life was so good that we decided to stop chemotherapy," Reichert says. "The goal is to use chemotherapy to live, not to live to get chemotherapy."

Raise hands in triumph.

Revel in spring renewal.

Life and hope are one.

WITH THE GOOD news in hand, Scott felt a renewed sense of purpose. He started entering online photography competitions and doing well. His work was featured in the cancer center's Voices Art Gallery, which showcases art from patients living with cancer.

For Christmas, Scott's nephew bought him a subscription to Storyworth, a startup that provides questions designed to capture family history and then compiles the answers in a keepsake book.

Scott turned out one Storyworth response a week for seven weeks, writing detailed, 10-page entries. One of his pieces is titled "Adventures in Dynamite" and chronicles several family stories that feature TNT.

"My grandfather, trying to shift a large boulder in the basement of the family farmhouse, thought it would be a good idea to use dynamite to do so — with my grandmother still in the house," Scott shared. "It lifted the house right off the foundation, skewing it slightly off true. She was fine and had no idea what he had tried to do."

Dark thoughts fill my days

I will not have a full life

Things left unfinished

IN MAY 2022, Scott's world exploded again. He began falling down, unable to stand on his left leg without toppling over. There were cognitive issues, too; he once got lost on the way home from work for two hours.

The culprit was a racquetball-size tumor in Scott's brain. His doctors thought that because chemotherapy doesn't get into the brain very well, the treatment might have worked elsewhere in his body but never made it to his brain — especially because they could tell the tumor had metastasized from the original cancer in Scott's prostate. He would need surgery.

"Cancer wasn't a walk in the park," Scott says, "but come on, a brain tumor? You've got to be kidding me."

Live now, in the now

Tomorrow will bring new joys

New chances for growth

THE OPERATION WENT well as did the radiation that Scott received three weeks later.

It took him a few months to get back to doing normal activities, but the symptoms produced by the tumor have now resolved.

"It's unbelievable how well he's doing," Kathleen says. "Brain surgery seems like the most frightening and terrible thing, but he's doing great."

Another unexpected bright side: The Michigan Oncology Sequencing Center (MI-ONCOSEQ) at Rogel was able to genetically sequence Scott's tumor once it was removed.

The researchers learned that Scott's tumor didn't have germline mutations — ones that had been passed down from his ancestors. Instead, it had mutations that occurred at random. This explained why Ward had responded so well to certain types of chemotherapy and suggested options for more targeted treatments that might do an even better job of getting rid of Ward's cancer.

The positive outlook lifted Scott into a creative upswing. His photos have been displayed at the Michigan Fine Arts Competition, and he's writing again, mostly fictionalized versions of his family stories.

His words are rich with imagery, transporting readers back to the days of yesteryear through his own unique lens.

Take the beginning of one story, which he stresses is still an unfinished draft, that's set on his family's 200-year-old farm.

"The spring on the old screen door registered its outrage at being disturbed after such a long time, making that ting-ting-ting sound at an ever-increasing pitch as it stretched past its physical limit... Suddenly, its distress ignored for too long, the spring snapped noisily and finally, both ends rebounding back to door and frame..."

"The door itself was fine," he continues, "maybe now with a few additional marks to add to those of the last century." ■

When Lori Robertson's cancer recurred and spread, her doctors noted she might have a year left to live. But a U-M-led clinical trial made her options look brighter.

A woman with short brown hair, wearing a teal t-shirt with a 'GLACIER NATIONAL PARK' logo, dark pants, and a purple backpack, is hiking through a forest. She is holding two trekking poles and looking upwards with a smile. The background is a dense forest with green foliage and tree trunks.

A Glimmer of Hope

By Mary Clare Fischer
Photographs by Erica Reist Bass

Lori Robertson and her husband, Robb, have been to 27 national parks; the couple like to birdwatch on their hikes; Lori's friend Diane Haroutunian-Brus created signs with Lori's initials to show support



W

hen Lori Robertson met with Rogel Cancer Center medical oncologist Vaibhav Sahai, M.B.B.S., M.S., to talk about cancer treatment options, she remembers little of what he said.

Lori had just found out her rare bile duct cancer had not only returned several years after undergoing surgery but had also spread to the lining of her abdomen. She and her family had recently gone hiking in Denali National Park and Preserve, and even with the strenuous exercise, she'd felt fantastic. So she was shocked to hear that she had cancer again.

"You know the old adage when you get your cancer diagnosis and you go to the doctor and they talk to you and you cannot hear what they're saying?" Lori says. "That's true. You look at the doctor and nod your head yes, but you can't really hear or retain anything."

What she did recall: She had the option to enroll in a phase 1 clinical trial, an early-stage research study that investigates the ideal dose for a potential new drug. Although the results for this trial were still preliminary and more testing needed to be done to say whether the treatment was effective, early signs had been promising for people with Lori's type of cancer.

"There's one open spot left," said Sahai, who is leading this multi-site trial. "It's yours if you want it."

Lori signed up for the trial that day.

"The prognosis was not too good, and when you're in that situation, you're willing to try anything," Lori says. "The trial gave us that glimmer of hope, that optimism that maybe we would come out of this on the other side."

On trial

Lori started coming into the cancer center for her trial treatment the week after she enrolled in the study.

There, she received two chemotherapies in combination with devimistat, an intravenous drug that blocks cancer cells from producing the energy the cells need to survive. (In phase 1 trials, every patient receives the study drug.)

"In theory, if you switch off their energy source, cancer cells should die," says Sahai, who leads the section of gastrointestinal medical oncology at Michigan Medicine and is a nationally recognized expert in bile duct cancer. "But that's not always the case."

The days at the cancer center were long — 12 hours at times. But, on Mondays, Lori's nurse was often Jessica Pott, R.N. The two both had children who attended Western Michigan University, and that personal connection helped Lori feel calmer.

"I would give her the plan for the day but then tried to draw her out a bit personally," Pott says. "I

Resources

Interested in enrolling in a clinical trial?

Head to: rogelcancer.org/clinical-trials/find-clinical-trials

Need to know more about how clinical trials work first? Scan this QR code:





Robb, Lori's husband, helped her through some anxious moments during her treatment.

think she then felt more comfortable opening up and telling me what she was scared of."

Lori had indeed fallen into despair. It was difficult for her to believe she might only have a year left to live. At one point, her anxiety levels were so high that she needed her husband, Robb, to be in physical contact with her when she sat on the couch, her leg on his, his hand resting on her arm.

"It was a tough year," Lori says. "Jess and Robb really pulled me through a lot of those bad days."

Her neighbors had a plan to help, too. Around Berkley, the community outside of Detroit where Lori lives, signs began appearing with a teal heart and her initials.

The signs were the brainchild of Diane Haroutunian-Brus, a friend of Lori's, who'd wanted to give Lori a boost and been amazed at the number of people who felt the same way.

"I still have people in my phone with the initials 'LR' next to them to remind me why I know them," Haroutunian-Brus says.

The neighborhood wasn't done yet. At 9 p.m. on Lori's birthday in mid-August, Robb suggested going for a walk. The couple walk frequently, so Lori wasn't expecting anything unusual — until she saw a group gathered at the end of her driveway and luminarias all the way down the street.

Lori started crying.

"I was sobbing and sobbing and sobbing," Lori says. "I think that was the release I needed."

"The trial gave us that glimmer of hope, that optimism that maybe we would come out of this on the other side."

Lori Robertson

Positive response

Luckily, fate seemed to have more positive things in store for Lori. By November, her tumor had shrunk significantly. On her January scans, it was no longer visible. There was now a possibility that the cancer could be surgically removed.

"Oftentimes, we'll have patients that do really well on clinical trials we're running and will need a surgeon as part of their care, even though originally they were not a good candidate for an operation," says Filip Bednar, M.D., Ph.D., a surgical oncologist who co-leads the peritoneal malignancy program at Michigan Medicine.

Lori was even eligible for heated intraperitoneal chemotherapy, or HIPEC, a form of chemo that is pumped into the abdomen during surgery to treat cancer that has spread to the abdominal lining.

HIPEC isn't typically a treatment option for patients with bile duct cancer because this type of cancer tends to come back in multiple regions of the abdomen or in other organs, like the lungs or liver.

"The patients that benefit the most from HIPEC have relatively low amounts of tumor in the abdomen," Bednar says. "Lori had such a good response, and she'd survived for so long with all of her other treatments that it was pretty reasonable for us to try to completely clear her disease."

When Lori underwent surgery, Bednar found microscopic bits of cancer, but otherwise, the rest of the tumor had died — even before he administered HIPEC.

"Lori's type of tumor is typically very challenging to treat," Sahai says. "It's unique to see such a high degree of response. Her story highlights the need for us to identify the exceptional scenarios and what makes these patients so responsive to this particular therapy."

To help others

In August, Lori's first scans since her surgery came back clean. She says she expects round three of her cancer to come eventually but hopes that day won't be for many years.

She's been open about her experience, sharing on her personal Facebook page and in support groups.

"I share because 1) it helps me to get it off my chest but 2) it could help somebody else," Lori says. "I'm constantly telling people to get a second opinion, to look into Dr. Sahai, to look into Michigan Medicine. That slogan, 'the leaders and best' — that's true." ■

How Palliative Care Can Help

The team has an "amazing toolbox" of options to help you navigate a host of cancer-related issues.

By Mary Clare Fischer and Anna Megdell

Palliative care has become known as the discipline that deals in tough conversations about the end of life. To some extent, that's true; Ketti Petersen, M.D., the physician lead for the Palliative Care and Supportive Oncology Clinic at Rogel, acknowledges that the palliative care providers don't shy away from asking challenging questions — but really, the discussions are just as much about how patients want to live as their preferences about death.

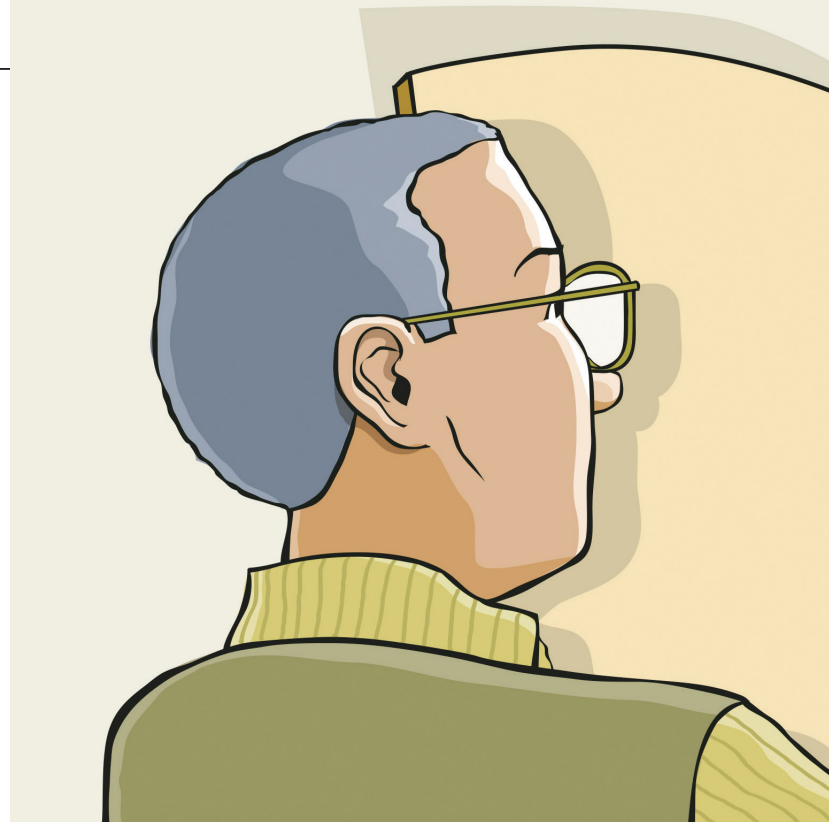
"We try to help people live as well as they can, for as long as they can, given the limits of their body and their disease," Petersen says.

That goal doesn't change for the team's patients who have been diagnosed with advanced cancer, some of whom are living with chronic, stable disease — or even no active signs of cancer — but are still coping with the effects of their treatment.

Katie Patterson, N.P., a nurse practitioner in palliative care, says common side effects for patients include pain, nausea, fatigue and tingling in the hands and feet.

For many patients with advanced cancer, Petersen says it can start to feel burdensome to bring up yet another problem to their provider. Or they may feel the issue somehow lies with them.

"If a patient is saying to me, 'This chemotherapy is exhausting, and I spend all my time in bed, and I can't go to my kids' soccer



games,' and I ask them if they've shared that with their oncologist, the response is usually that they don't want the physician to stop their treatment," Patterson says. "I tell them there are always options."

Given the number and complexity of medications the team's patients often take, the symptom relief solution for one person may not work for someone else — and sometimes what worked once no longer does, especially for people who have been living with cancer for a long time.

That's when the team can step in to manage medications, provide referrals for procedures to address pain or connect patients with cancer rehabilitation physicians and physical therapists.

Sometimes, Madison Irwin, Pharm.D., is on the case. A pharmacist who is specialty trained in pain management and palliative care, she can lend her expertise to assist with managing complex drug regimens.

True and False



Fact: Very few people want to think about dying. "The truth is, it's just scary," palliative care nurse practitioner Katie Patterson affirms. But there are some common assumptions about end-of-life planning that are false. Here, we debunk two of these myths.

False: Bringing up advance care planning means that the end is near.

True: The most important element of advance care planning is choosing a durable power of attorney — someone who can make decisions on your behalf if you're not capable of doing so. "Realistically, all of us should have that because unexpected things happen," palliative care physician Ketti Petersen says.

False: You can't change your mind about your advance care plan.

True: Just because you've mentioned, say, that you wouldn't want to be intubated if you have a terminal disease does not mean that decision is final. "Physicians don't look at advance care planning documents as a definitive guide and limit to care," Petersen says. "It's more about understanding where you're coming from."



“Our whole goal as a palliative care team is to improve and optimize quality of life,” Irwin says. “The situation for these patients can change quickly, so being able to respond at a moment’s notice is really valuable.”

Sometimes the answer is more emotional support. Patterson once spoke to a young woman with metastatic cervical cancer and her husband every week for about two months. (Starting this past summer, two social workers are helping the palliative care team, too.)

This relationship building puts the palliative care team in a position to advocate for their patients. They have gone to patients’ oncology appointments and sent oncologists lists of questions to make sure patients’ needs are being heard across the care team.

“We have an amazing toolbox in palliative care of different tools that we can use,” Petersen says. “It’s all about finding the right tool for the problem.”

Provider Perspective

Family and palliative care physician and geriatrician Ayano Kiyota, M.D., Ph.D., has spent a decade explaining the goals and benefits of palliative care. In 2018, a breast cancer diagnosis added new dimension to her work. “I found it during a self-exam,” she says. “Cancer doesn’t run in my family, and I was relatively young. It was a shock.”

Though Kiyota had a strong support system, treatment remained a lonely experience, and years of working to be an independent adult prevented her from asking for help. Kiyota now brings this sensitivity to her patients. “I say, ‘When I went through my cancer, I felt isolated even when I had friends and family around me. Has that ever happened to you?’” she says. “I mention my experience in hope that they feel more comfortable being open with me and know that whatever they’re feeling is OK.”



The Ultimate Questions

Our experts are a virtual visit away from helping you create an advance care plan. If you’d like to start brainstorming on your own, though, our palliative care providers have passed along a few questions to consider.

- 1 What is most important to you? What brings you joy?
- 2 How do your personality, family history, culture, age or other factors play into that?
- 3 How can you make decisions based on those values?
- 4 At what point do you think you’d want to stop treatment?
- 5 Do you want to be at home during end-of-life care? Do you have financial, emotional and physical support to aid you in whatever decision you choose?
- 6 Who would you like to pass on a legacy to? What would you like them to do with your remains?
- 7 How can you celebrate the time you have left?

Resources

If you’re interested in palliative care, ask a Rogel provider or your primary care physician for a referral.

Inside: Lori Robertson thought she might have just a year left to live after she was diagnosed with advanced cancer. Now she's looking further down the road, with help from a clinical trial.

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