



thrive

Unstoppable

Jennifer Watson put exercise and self-advocacy at the center of her cancer journey

Also: How to get better sleep, cancer's financial fallout

thrive



THIS ISSUE'S THEME

Survivorship

Life doesn't stop for cancer — our patients and experts share strategies to get your groove back.



On the cover

Keeping fit and maintaining a positive outlook helped Jennifer Watson navigate a stage 4 cancer diagnosis.

Cover photo
by Leisa Thompson

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Eric R. Fearon, M.D., Ph.D., director
Julie Brabbs, M.B.A., chief administrative officer
Nicole Fawcett, director of communications
Ian Demsky, editor
Mary Clare Fischer, associate editor
Shelley Zalewski, contributing writer
Paul Wallen, art director, Dog Ear Consultants

Executive Officers of Michigan Medicine
Marschall S. Runge, M.D., Ph.D., CEO of Michigan Medicine, which includes serving as dean of the U-M Medical School and chief executive of University of Michigan Health, and the executive vice president of medical affairs for U-M; David C. Miller, M.D., M.P.H., president, University of Michigan Health System, executive vice dean for clinical affairs; Patricia D. Hurn, Ph.D., R.N., dean, U-M School of Nursing.

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On the Horizon

7 Things to Know About 'Chemo Brain'

By Ian Demsky

Many people who have undergone treatment for cancer, especially chemotherapy, report they just don't seem to be able to think as clearly as they used to. N. Lynn Henry, M.D., Ph.D., the breast oncology disease lead at the Rogel Cancer Center, shares the latest research findings on "chemo brain."

It's real

Forgetfulness, trouble concentrating, difficulty multitasking — about 1 in 3 patients experience mental changes following cancer treatment. Researchers have been giving the topic serious study since the mid-1990s.

Doctors don't like the term 'chemo brain'

It sounds pretty scary — and they don't want fear of the mental side effects deterring patients from getting effective treatments for their cancer. Your doctor might use the term "cancer-related cognitive impairment" instead.

There can be many factors involved

Cognitive impairment is most commonly associated with chemotherapy, but other types of treatment can also affect thinking. Older age, pain, depression, trouble sleeping and other health problems can also play a role.

Testing exists — but it's complicated

Doctors have questionnaires and formal tests to measure mental changes, but the results don't always line up with what patients say they're experiencing. Considerable research is being done to develop better, more reliable tests.

Help is available

Care teams can help patients manage mental side effects from cancer treatment just like they do with physical side effects.



Working on certain risk factors may lessen the effects

Directly addressing a patient's anxiety, pain, trouble sleeping and fatigue can help improve symptoms.

Research shows several effective treatments

There is no standard treatment for chemo brain, but a growing body of research shows that cognitive rehabilitation and behavioral therapy programs, exercise, and mindfulness programs each were associated with perceived and objective improvements. Some medications, like anti-dementia drugs, appear promising, but more research is needed. ☑

Resources

► Our Cancer Rehabilitation Program offers a team-based approach to help people get back on track before, during and after cancer treatment.
michmed.org/cancer-rehab

Fighting Financial Toxicity

Patients often find themselves juggling new financial worries at the same time as a cancer diagnosis — Rogel researchers are tackling the issue

By Ian Demsky

The financial burden of cancer care is a growing issue. In fact, the topic has even sprouted a name to reflect its seriousness — financial toxicity — likening it to the toxicities of the treatments that kill cancer cells.

It's a fitting term. Slightly more patients were worried about the high financial burden of their cancer care than of dying from cancer, one 2018 survey found. But the medical community is stepping up to research and address the challenge more than ever before.

“We have made a lot of progress in many types of cancer treatment, which is wonderful. But we must turn our efforts to confronting the financial devastation many patients face,” says **Reshma Jagsi, M.D., D.Phil.**, a radiation oncologist at the Rogel Cancer Center who studies the issue.

We spoke with Jagsi to understand more about how financial toxicity affects patients and what resources patients can turn to.

Resources

National

American Cancer Society

► 24/7 helpline, help finding national and local resources
cancer.org
800-227-2345

Cancer Financial Assistance Coalition

► Organizations providing financial or practical help
cancerfac.org

National Cancer Institute

► Information on managing costs
www.cancer.gov/about-cancer/managing-care/track-care-costs
800-4-CANCER
► Support organization index
supportorgs.cancer.gov

Reshma Jagsi, M.D., D.Phil., is an internationally recognized radiation oncologist who studies ethics and equity in medicine.



Q. You recently published a study looking at financial toxicity in patients with breast cancer. What did you observe?

Our team interviewed 32 patients who received financial assistance from The Pink Fund, a Michigan-based nonprofit, during their treatment, and studied the patterns and themes that emerged in those conversations. We purposefully selected a group that was diverse in terms of race, income, education and whether they were raising children.

Over and over, the participants talked about the awful double whammy of facing financial difficulties at the same time as they were trying to manage a scary cancer diagnosis.

Q. What was your most important finding?

We found that patients' expectations going into treatment significantly affected their experiences — both in terms of actual financial burdens as well as how much distress they felt. That's not something that doctors and researchers have really accounted for.

Some patients, for example, expected to be back at work much sooner than they were able to return, and then found themselves facing a lot of additional stress and financial trouble.

Others were caught off guard by costs that weren't related to treatment — how much they had to pay for gas, food and parking during frequent hospital visits, for lotions or wigs after treatment, for duties like child care they could no longer fully do themselves.

In the end, we identified four important gaps patients often experience: unclear treatment expectations, few conversations with providers about costs, not knowing how to access financial resources, and lack of support in navigating the health care system.

We believe focusing health systems' attention on each of these four areas could really make a big difference in patients' lives. ☑

Q. What is financial toxicity?

It's not just about the high dollar amounts. It's also important to recognize the high level of emotional distress that financial worries cause for patients and their families — and they come at the worst time.

In order to develop new approaches to ease the burden, researchers like myself and my colleagues are working to better understand the many complex factors involved.

Tips for Patients

Start a conversation with your provider.

You might say, “Is there someone available who can help me understand what my treatment is going to cost?” Or, “Can you refer me to a social worker who can help me find resources and support services?”

Make a financial plan.

Making a budget that lists your income, savings and expected expenses can help you get organized — and to identify questions you may need help answering: How soon can I return to work? How much will my co-pays be? How much is parking at the cancer center? Will I need to budget for extra child care?

Don't be afraid to ask for help.

While there are many types of resources available to patients with cancer, they're not always easy to find and access. Your health care provider, local patient support groups and local chapter of the American Cancer Society are great places to start.





Paying it Forward

Olivia Goff is now a nurse on the same pediatric unit where she received treatment for lymphoma

By Mary Clare Fischer

Photographs by Leisa Thompson

On May 11, 2012, a pediatrician pulled Olivia Goff's mother into an exam room and told her to take her daughter to the emergency room.

A few weeks earlier, the 17-year-old Goff had woken up with a lump on her neck. An ultrasound had revealed abnormal findings, but additional tests were needed to determine what was wrong.

May 11 was the day the results came back, revealing that Goff had Hodgkin lymphoma, a type of cancer that begins in the immune system.

"I didn't know what that was," Goff says. "I didn't know it was cancer."

The mass under Goff's collarbone was so large that the pediatrician was concerned about its potential to cause breathing problems. That's how Goff found herself in Michigan Medicine's main emergency room, afraid that a tumor would keep her not only from enjoying adolescent milestones like prom, but also from fulfilling her adult goal of becoming a nurse.

It would take aggressive chemotherapy and a stem cell transplant to get rid of what would end up being two bouts of cancer.

Nine years later, not only is Goff cancer-free, she also works as an oncology nurse at the University of Michigan Health C.S. Mott Children's Hospital — on

the same floor where she received cancer treatment as a patient.

"I always said, 'When I'm a nurse on 7 East at Mott,'" Goff says, "then I've made it."

A persevering teen

It wasn't as bad as they thought.

The biopsy results showed that Goff's tumor wasn't compromising her airway. The cancer was stage 2, meaning it had been found in at least two of her lymph nodes, but hadn't spread to the rest of her body.

In fact, Goff was still able to go to her senior prom a week later. She'd been worried that the scar from her biopsy would be visible in pictures from the dance, but her surgeon had promised he'd "make it look nice," she recalls.

In photos from that night, any incision is far outshone by Goff's bright smile and the shimmering crown on her head; she and her boyfriend, Connor, had been voted prom queen and king.

Ray Hutchinson, M.D., Goff's oncologist at the time, also told Goff she could wait an extra week to start her four rounds of chemotherapy, so she could go on a long-awaited cruise to the Bahamas with her mother, Julie Hawley.

And Goff was determined that cancer wouldn't stop her from doing the things she loved once she started treatment, either.

A week after her first round of chemo, for instance, she performed a solo and 13 group dances in her dance studio's annual recital. In between numbers, she inhaled water, Tylenol, and Motrin backstage as Hawley peeled the costumes off her skin that was dripping with cancer- and chemo-induced sweat.

"I honestly don't know how she did it," Hawley says. But her can-do attitude and support from her family got her through. By October, her perseverance had paid off: She was in remission.

Bringing out the 'big guns'

Then, almost two years later, Goff began experiencing terrible back pain — but only when she drank alcohol.

Initially, they thought it might be kidney stones. Instead, the cancer was back.

"That second diagnosis was a lot more devastating for me," Goff says, "because I knew what was to come."

This time, there were multiple tumors: in Goff's lymph nodes again as well as in her lungs and, most peculiarly, on her spine.

"Her relapse was fairly odd," Hutchinson says. "Bone involvement occurs with Hodgkin's disease, but it's uncommon. And it would be really uncommon if the patient didn't have it initially."

Because of the rare elements of Goff's cancer and its various locations, Hutchinson and the rest of Goff's care team decided to give her a more aggressive chemo regimen and then a stem cell transplant that used her own cells to replace her bone marrow.

"To be able to cure her of her disease, we had to hit her with



the big guns, so to speak," Hutchinson says.

Goff stayed in the hospital for extended periods — a week at a time for chemo, a month for her stem cell transplant.

She celebrated her 21st birthday on the seventh floor at Mott, listening to the nursing staff sing "happy birthday" as they gave her a T-shirt they all signed. She wore a plastic crown that read, "21st birthday."

But she didn't have the same energy she'd had the last time she wore a crown.

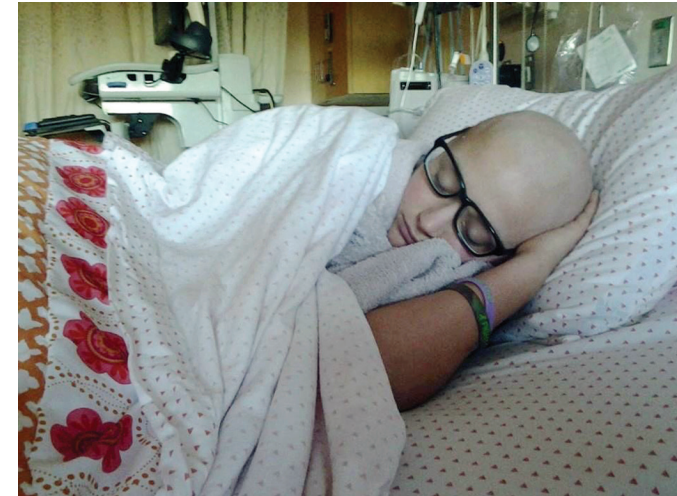
The side effects of the treatment made it difficult for her to concentrate, so she took time off from college, where she planned to study nursing.

"She was angry at the cancer," Hawley says. "She was angry at life. And she had every right to be."

"There were periods where she just wasn't sure how it would turn out, if she could keep going, if she was strong enough," says Jana Thomas, R.N., one of Goff's nurses. "For someone who's so sweet and tender and cares about everybody else so much, it was really hard for her to focus on herself and be in the moment of being treated and healing instead of being out doing like all the other college kids."

But then, Goff would look out the window of her hospital room into the hallway. Frequently, she saw small children

A family photo (top) is a reminder it wasn't so long ago that Olivia Goff was a patient at Mott, where she now cares for kids with cancer. Outside of the hospital, she enjoys spending time with her mother, Julie Hawley, husband Connor, and pups Finley and Frankie.



"walking around and smiling and playing, with their little bald heads," as she says.

Goff asked Hawley to buy the kids headbands and even a fedora for one little boy who was always running around. And she kept going.

"The kids just live," Thomas says. "They don't worry about tomorrow. That was a huge inspiration and something she drew strength from."

"If they could do it," Goff says, "then I could do it."

Sharing hope

And she did do it.

May 11, 2021, marked nine years since Goff's first diagnosis of cancer, and she's spent more than five years cancer-free.

"She never lost sight of the fact that she could get over cancer," Hutchinson said. "It was a privilege and an honor to see how she did."

Ironically, Goff spent most of those cancer-free years at Mott — but not for treatment.

Goff's husband, Connor (yes, the same boyfriend she took to prom), has cystic fibrosis, and spending time with him while he was hospitalized at Mott had endeared her to the nursing field before she was ever told she had lymphoma. Her own experience at the children's hospital triggered an interest in pediatric oncology. She wanted to work with the same kids who had gotten her through her cancer journey, to support them in more ways than just buying them hats.

After networking her way into a position as a patient care technician in the cardiology department at Mott during college, Goff spent a year messaging on Facebook with the nurses who'd taken care of her, asking about possible job openings on the pediatric cancer floor. The manager eventually asked Goff to come in for an interview, and she was offered the role on the spot.

"I remember that day so vividly," Goff says. "It felt surreal to know that I was going to be working on the floor I was treated on."

"When I see her on the floor, it fills me with joy that someone who's gone through what she has gone through is there now giving," says Rama Jasty-Rao, MBBS, who took over Goff's care after Hutchinson retired. "It makes her a very special person because she has experienced what these kids have experienced."

Goff says that something as seemingly minor as knowing that getting your port flushed can provoke nausea helps her help her patients (she provides mints or Jolly Ranchers for patients to suck on during the process).

She doesn't tell all her patients that she had cancer but sometimes mentions it if the conversation flows in that direction.

"I hope that when I do say it, it gives these parents and families hope that there is an end," she says, "that there's a light at the end of the tunnel." ☒

‘They Called Me The *Zumba Lady*’

**Jennifer Watson put exercise and
self-advocacy at the center of her journey
with stage 4 cancer**

By Shelley Zalewski

Photographs by Leisa Thompson

Jennifer Watson had always been very active.

“I just took for granted that I’d always have enough energy for anything and everything I wanted to do,” says Watson, who lives in East Lansing, Michigan. That included hitting a “boot camp” exercise class six times a week.

After having no trouble keeping up with the class for two years, Watson hit a wall in the summer of 2016 when, at age 59, she became too tired to make it through the half-hour session. One Saturday, she headed to a local urgent care clinic instead of to the class.

“I was exhausted, and my heart was racing,” she recalls. Unable to diagnose the problem, the clinic

sent her to a nearby hospital.

After a day-long battery of tests, Watson was diagnosed with anemia, likely the result of internal bleeding. A colonoscopy and CT scan suggested the presence of cancer. In late July, she had a portion of her colon removed, which confirmed early stage colon cancer.

The tumor had grown into tissue around the colon, but had not spread to adjacent lymph nodes or nearby organs. At that stage, the standard of care is regular monitoring for signs of growth or spread. So Watson saw her oncologist every three months. In June 2017, imaging indicated a spot on her liver. Her



oncologist believed it was inflammation, not cancer.

A year later, a scan revealed the spot was indeed cancer that had metastasized to the liver. A difficult liver resection followed.

“The procedure was very painful,” she recalls. “It was an anxious time for me, a real low point. I had 33 staples in my stomach. I spent six days in the hospital. And I learned my cancer had advanced to stage 4.”

A new direction

As Watson recovered, she and her family struggled with the direction of her cancer treatment.

“We began to question whether we were with the right care team,” she explains. The surgeon and the oncologist seemed to disagree about both her treatment to date and her future prognosis. “Clearly, my doctors were not on the same page.”

Watson’s daughter researched other options, and the family sought treatment from the Rogel Cancer Center, at its Brighton Center for Specialty Care location.

“Michigan Medicine and the Rogel Cancer Center have a great reputation,” Watson notes. “When we learned we could access that level of care in Brighton – just an hour’s drive from our home – in a brand-new facility with the latest imaging equipment, we felt confident about making the change.”

In mid-September 2018, Watson met with John C. Krauss, M.D., medical director of the Multidisciplinary Colorectal Cancer Clinic, and his team in Brighton. After a thorough assessment, they confirmed the diagnosis.

“While every advanced cancer is life-threatening, several aspects of Jennifer’s prognosis gave us reason for optimism,” Krauss says. “Rather than cancer that had spread all over the body, hers recurred in one place and was surgically removed, so she started chemotherapy without symptoms from her cancer. Jennifer hadn’t previously received chemotherapy, so if there were any additional cancer cells in the liver or other organs, they would be more responsive to curative chemotherapy. Finally, Jennifer is one of the most active patients I have seen, and she is invested in returning to full activity after the setback of surgery and chemotherapy.”

Staying active

In early October, Watson began chemotherapy at the Brighton center. The standard of care for advanced



“I’ve made some major changes to my life. ... I devote more time to self-care.”

Jennifer Watson

metastatic colon cancer is a combination of drugs called FOLFOX, an abbreviation for folinic acid, fluorouracil and oxaliplatin.

FOLFOX is delivered every other week for 12 weeks. During treatment weeks, Watson would receive chemo at Brighton on Tuesday, and go home with a fanny pack that continued to deliver the drugs until Thursday, when a nurse would come to disconnect the pack.

True to form, Watson was anxious to get back to her active lifestyle as soon as possible, even during chemotherapy.

“I couldn’t stand just sitting around,” she remembers. “On the off weeks, Dr. Krauss said it was OK to return to work, and to exercise in moderation, which for me meant regular walks and a Zumba dance/exercise class after work. At the clinic, they called me the Zumba lady.”

Midway through treatment, as the chemotherapy built up in her system, Watson found it too difficult to exercise, and at times even to finish a day at work.

“I was very tired, and I developed neuropathy,” she explains. “It began with numbness and tingling in my fingers, and eventually impacted both my hands

Jennifer Watson looks through a family bible with her younger daughter, Jada Keas, works out with trainer Fizah Khan and takes a walk with her older daughter, Autumn Watson.

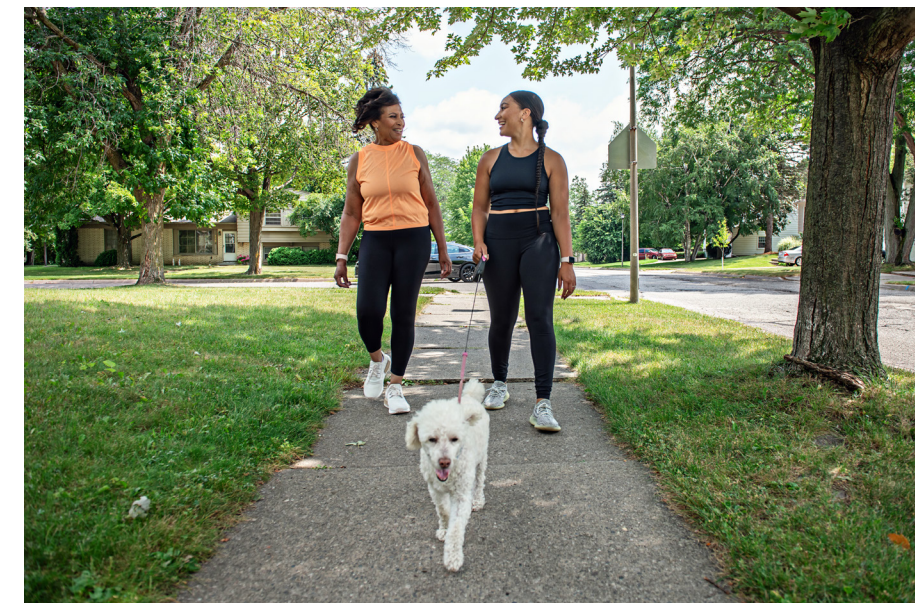
and my feet. At first, exercise gave me some relief, but eventually, I reached a point where I couldn’t comb my hair or button my shirt.” To help manage her symptoms, Krauss adjusted her medications.

Watson completed treatment in March 2019. Since then, scans have continued to show no evidence of disease.

‘She’s a real inspiration’

With chemotherapy behind her, Watson turned her attention to reclaiming her overall wellness. “When I had to stop exercising, I gained weight,” she says, “so I jumped right back to it as soon as I could.” She sought help from a local wellness consultant and cancer survivor, who coached her through a lifestyle overhaul including not only exercise, but nutrition, personal care and much more.

“I’ve made some major changes to my life,” says Watson. “I’m making smarter choices about what I eat and the products I use on my body and in my home,



and I devote more time to self-care. And of course, I’m more committed than ever to staying physically active. I’ve lost 20 pounds and I feel terrific.”

From the first consultation in Brighton, Watson and her family were impressed with the Rogel team, the Michigan Medicine Brighton facility, and the approach to her treatment and follow-up. “They were both realistic about my diagnosis and optimistic about my treatment plan. Right away that helped us feel more hopeful about the future,” she recalls.

“For this type and stage of cancer, we delivered the same chemotherapy treatment Jennifer would have received at another center,” says Krauss. “What I think sets us apart is the trust we build with our patients.”

“You couldn’t ask for a better patient partner than Jennifer Watson,” he adds. “She is very engaged and proactive. She worked so hard to stay active during treatment, and she continues to put in the effort to maintain the good habits that will lower her future cancer risk. She’s a real inspiration.”



Sleeping Soundly

How to cope with sleep issues during cancer treatment

By Mary Clare Fischer

We'll start with the bad news: **Sean Smith, M.D.**, the medical director of the Rogel Cancer Center's Cancer Rehabilitation Program, estimates that between one-third and half of patients he sees in his clinic are dealing with a sleep-related problem. Psychological distress and fatigue often lead to poor sleep habits and keep those with a history of cancer from snoozing soundly, while others wake up regularly because of pain or develop sleep apnea.

The good news is that all of these issues are treatable, and care providers can help you find solutions to your sleep woes.

Medication

The medications that Smith's team typically uses to address insomnia are trazodone and mirtazapine. These can send patients into a deep, restorative sleep. He frequently has to explain why patients shouldn't use certain sleep drugs, which may be creating more problems than they solve. Take melatonin; there's little evidence about the optimal dose, so it's tough for providers to tell you how to take it, and ongoing use can actually disrupt your sleep. So only turn to this well-known supplement to occasionally reset your clock, unless your provider recommends it for your specific problems.

Exercise

Exercise can be a Catch-22 for cancer survivors when it comes to sleep, Smith says. "If you don't sleep, you're not going to exercise and if you don't exercise, you're not going to sleep well," he says. "So you have to sort of break the cycle." His prescription involves 45 minutes of aerobic exercise, the kind that gets your heart rate up and makes you sweat, three days a week.

Sleep hygiene

Cancer survivors who manage chronic fatigue often take naps during the day, which can leave the brain confused about when it's time to sleep. The following methods to optimize sleep hygiene can reduce such daytime foggy over time: create a regular bedtime routine, limit naps and keep them short, and avoid screens before bed (or invest in a pair of blue-light blocking glasses if you watch screens in the evening). Smith also recommends buying a comfortable pillow and creating a calm environment in your bedroom.

Counseling

Many sleep issues for cancer survivors can be traced to anxiety and sometimes even untreated post-traumatic stress disorder from having been diagnosed with cancer, Smith says. He recommends patients find a professional counselor to talk to — or a team-based program like the one at U-M, which has a social work team that includes rehabilitation psychologists and psychiatrists who are experts at helping patients work through their unprocessed stress and fear around the cancer experience that may be keeping them from a restful night.

Speaking up

Unless you've sought out a sleep medicine clinic, there's not always a clear provider with whom to discuss sleep issues — but, in fact, you can bring up the problem to anyone on your medical team, and they can get you the help you need. "You might be talking to your medical oncologist about whether your cancer is still in remission, or your primary care physician about your blood pressure, and to me for your shoulder pain and not thinking that any of us will discuss sleep," Smith says. "But hopefully patients can read this and speak up, knowing that we're all here to help." ❏

Resources

- ▶ The Rogel Cancer Rehabilitation Program offers a team-based approach to help people get back on track before, during and after cancer treatment. michmed.org/cancer-rehab
- ▶ The U-M Sleep Disorders Center provides evaluation and treatment of sleep disorders by addressing behavioral, psychological and physiological factors. michmed.org/sleepdisorders

Finding Your New Groove

Overcoming sexual challenges after cancer

By Mary Clare Fischer and Ian Demsky

Sexual health during and after cancer treatment isn't talked about enough.

Surgery, chemotherapy, radiation or other cancer treatments can impair sexual function, as well as create issues with sexual desire and arousal. Some patients may question whether sexual pleasure is still possible. And there are often emotional challenges as well as physical ones.

"It's our job as health care providers to include sexual health and recovery in our care," says **V. Bernadene Stody, M.D., M.Sc.**, an adolescent medicine fellow at Michigan Medicine. "I want patients and caregivers to know that education and resources are available that can empower them to ensure that their needs as a whole person are being met."

Just because you've been diagnosed with cancer doesn't mean your sex life is taken out of the equation, she informed an audience of young adult cancer patients and survivors during a recent presentation. "Good sex is important," she told them.

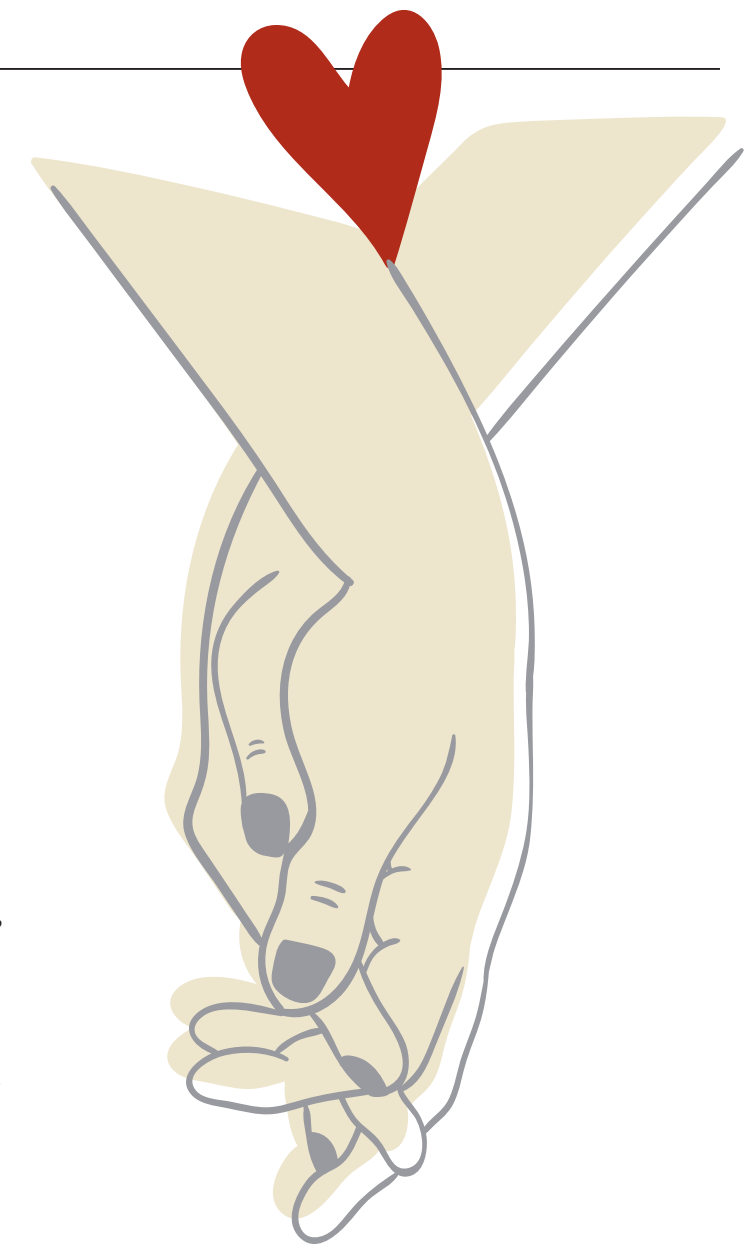
If your care team doesn't bring it up, cancer patients and advocates are encouraged to ask their medical team how their treatment may affect their sexual health, and what rehabilitation resources are available — such as meeting with a gynecologist or urologist who specializes in sexual medicine — as well as specialized counseling services.

The impacts of treatment can affect both patients and their partners, adds **Daniela Wittmann, Ph.D., M.S.W.**, a social worker and certified sex therapist at U-M who led a national team in developing an online support program for men recovering from prostate cancer treatment.

"Emotional challenges are just as important to recognize as physical ones," she says. "Working with a trained specialist can be very helpful for individuals and couples navigating these changes, which can come with feelings of loss and grief."

Sometimes progress doesn't come as fast as people would like, Wittmann notes. It can take time to adjust to a new way of experiencing sexual pleasure alone or with a partner. It may mean finding new opportunities to explore intimacy and find pleasure beyond intercourse if treatment has impaired sexual function. Orgasms may take longer to reach, and may require more or different types of stimulation.

Sex therapists and other professional counselors can provide



a uniquely safe and powerful space to explore challenges related to intimacy and pleasure, Stody adds.

Both experts pointed toward physical therapy as an avenue that may help with sexual rehabilitation in both male and female patients. Exercises that improve pelvic blood flow can enhance erection, and exercises that help to strengthen the pelvic floor can optimize pleasure and decrease vaginal and pelvic pain.

They also noted numerous safe and effective products are available to enhance sexual function. Medications, devices such as vacuum pumps and even implants can assist in achieving and maintaining erections; meanwhile lubricants and medications can increase sexual pleasure. ❏

Resources

- ▶ Learn more on the American Cancer Society's website michmed.org/ACS-sex-cancer
- ▶ Sexual recovery after prostate cancer online support program michmed.org/sexual-recovery

Inside: Learn how nurse Olivia Goff is giving back, caring for kids with cancer on the same pediatric oncology unit where she herself was once a patient.

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