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Patient Betsy de Parry was losing hope when a breakthrough treatment cured her cancer 11 years ago.
All in the Family

New program helps children adjust to a parent’s cancer diagnosis

One of the first questions a parent might ask when diagnosed with cancer is, “What will I tell my child?” Likewise, a child might ask, “What’s going to happen to my parent?”

Because cancer affects everyone in a family, the U-M Comprehensive Cancer Center now offers Families Facing Cancer, a program dedicated to helping children of all ages who have a parent or other adult family member diagnosed with the disease. The program is funded through the generosity of donors.

“Fear of the unknown is a concern for patients and their children,” says Program Coordinator Sheila Morris, a child-life specialist from Patient and Family Support Services. “There are many ways we can help by offering suggestions for having conversations with children, information about parenting during illness, developmentally friendly resources, and interactive programs that support children in their understanding and abilities to cope.”

For patients who are parents or grandparents, the program has a resource kit for talking with children and aged-based activity books. Kits are available at the Cancer Center’s Patient Education Resource Center.

“Come and Visit” Cancer Center tours are hosted periodically for children ages 5-12. The Saturday morning program invites children to visit the Cancer Center, learn about their family member’s care and meet the medical team. Children also participate in a fun art activity with beads and receive special recognitions.

“Hand in Hand beads honor children and the bonds shared with a parent or grandparent,” Morris says. “Beads are strung on a cord and represent the child’s unique qualities, significant moments and positive interactions during a loved one’s care. The child is encouraged to ask questions and express feelings.”

Future elements of the Families Facing Cancer Program include a website for children with an adult family member undergoing care, family portraits coordinated by Patient and Family Support Services and opportunities for children to participate in cancer-related service projects.

“What will I tell my kids?”
When Support

What you can do and things to say when you need

Communicating with friends, family and loved ones is hard enough when you aren’t sick, but add a cancer diagnosis to the mix and oftentimes people simply don’t know what to say. We sat down with Donna Murphy, co-director of the PsychOncology Program at the U-M Comprehensive Cancer Center, to talk about the issues cancer patients face when friends and family fall short in providing the support you need to face your illness.

Q. Why is it so hard for people to be there when someone they love has cancer?

I don’t think it’s human nature for people to turn away. However, many people show support in ways that aren’t face to face or in words. Some of this comes from fear of being a bother, saying the wrong thing or making someone cry. Or, they might be better at housecleaning, weeding or picking up kids from activities. These are all acts of caring and support.

Examining the expectations you have of others is a good thing. That way, you can state your needs or wishes and have help getting them met.

Q. What are some of the difficult issues facing friends and families of a person with cancer?

Your friends and loved ones are scared and worried about the cancer, too. Hearing the news of someone they care about having cancer can be devastating. Maybe they don’t know how to help or what to say so they do nothing at all. To the person who’s ill, it’s the sound of silence. But to think they don’t care could be the wrong assumption.

It’s not uncommon to be uncertain and bewildered with how to face a cancer diagnosis for patients and loved ones alike.

Q. How can a person with cancer communicate his or her needs to loved ones?

One of the first things a patient can do is pay attention to who IS there to support you instead of focusing on who is not offering you support. A spouse or friend may be rallying and always at your side, but it won’t be helpful if you are paying attention to the one person who hasn’t shown up. Focus on those supporting you in the here and now.

Consider assigning a friend or family member as spokesperson to communicate your needs, such as prayers, meal plans or chores around the house. This person can help identify specific ways other people can support you. Your best friend might not know what to say or do, but now your spokesperson has told her what you need. Many people are great at behind-the-scenes task work. This is the perfect place for those “not good with words” to show their love and support.
Q. What qualities make up a good spokesperson?

In this day and age, it’s often someone tech savvy who can get the word out via email or social media like Facebook. Look for a trusted person who is good with words and will share just the right amount of information based on your wishes.

There are websites created specifically for communicating about an illness, such as CarePages.com and CaringBridge.com. Your spokesperson can post messages and photos and might take a little time daily for updates about your needs.

Q. Where can patients turn for more support if they need it?

I ask patients where they turned for support before they had cancer. Perhaps you participated in a running club or volunteered at your child’s school. Someone in the group will almost always answer the call for help. Find the circle you existed in before you ever heard your doctor say the word cancer.

Within the Cancer Center, social workers, complementary therapists and spiritual care staff work with patients with concerns, fears and needs. They can identify community resources just for you. Some agencies have assigned volunteers to help people who are sick. Almost all hospices have great resources. There are support groups.

There are many places you can go for information, like the local library or the Cancer Center’s Patient Education Resource Center.

It’s extremely important for a cancer patient to identify the need for help and ask for it, even if it’s simply telling someone on your treatment team that you feel isolated.

Q. How can I help my friends, family and loved ones know what to say about my cancer?

There are many things you can do to help them, such as:

- Don’t be afraid to tell people what they can do to help, especially if they ask.
- Be specific about what you need and what you do or do not want.
- Give yourself permission to talk or not talk about certain things when others call or visit.
- Develop a CarePages website so friends and family can learn about your needs and help you.
- Refer people to your spokesperson or website if you don’t feel like telling the whole story over and over.

Tips for friends and loved ones who don’t know what to say:

- Listen first. Try to understand the needs of the patient and how you might be helpful right now.
- Let the patient know you are there and offer specific ways you can help.
- Don’t feel the need to talk about cancer. Most people just want to talk about life where you last left off.
- Listen for cues and ask questions to give the patient a chance to open up and talk about what he or she chooses.
At the time of her diagnosis, Cristina Reed had a husband and young children to live for.

What makes a good board member?

- Experience in adult cancer care
- Good listener and communicator
- Has time to give back and participate
- Offers a positive approach, even to negative experiences
- Works well in groups of people

Applications are always accepted. Visit mCancer.org/thrive for more information and to apply.
For Cristina Reed, cancer survivorship can be difficult. Though she’s had stage 4 non-Hodgkin’s lymphoma, the doctors caught it and used chemotherapy to get the disease on track. Sometimes, even now after her five-year scan came back clear, she feels guilty for surviving. “Do I dare say my cancer experience was ideal,” Reed says. “Yes, my kids were little, but I am still around. My oncologist was very proactive with me. My husband did the research and sought information to ensure I got to U-M. I responded well to chemo.”

Reed decided the best way to make sense of her eight-month stint as a young mom battling cancer was to try to ease the path for the next person who has to walk in her shoes. She joined the U-M Comprehensive Cancer Center’s Patient and Family Advisory Board for a two-year term.

The PFAB is a group represented by both patient advisors and Cancer Center staff that meets monthly with the goal to assure the delivery of the highest standard of patient-family centered care. Advisors also work on sub-committees to delve into more specific projects, such as finding ways to better educate Cancer Center caregivers, patients and family members about valuable resources available to patients that can ease some of the many burdens cancer can bring. “Patients and their family members have an essential role in guiding the work we do at the Cancer Center and throughout the University of Michigan Health System,” says Karen Hammelef, D.N.P., R.N., director of Cancer Center Patient and Family Support Services and co-chair of the PFAB. “This partnership with Cancer Center faculty, staff and patient advisory board members will promote excellence in cancer and family-centered care.”
Sarah Tupica Berard joined the PFAB after watching her father go through treatment for a rare, advanced cancer in his jaw.

“I was excited to join because it focuses on helping the patient and family. They are very much linked. If my dad was in distress, so were we,” Berard says. “I’d like to help make patients and families’ lives better through more information and access to information so the next girl can support her dad and feel a little more empowered.”

Berard and her siblings were frequent visitors at the Cancer Center, bringing care packages to their father and stepmother each day during his chemotherapy treatments. During radiation, her dad stayed at her house in Berkley because he was too fatigued to drive home to Wheeler, Mich. Now, almost two years post-treatment, her father comes to the Cancer Center for scans every four months.

“The PFAB experience has definitely helped me heal,” she says. “I wanted to give back specifically to U-M because they saved my dad’s life. Sarcoma is rare. He had to go there. I feel indebted to the university, the work they’re doing and the services they gave us.”

Berard is on the Patient and Family Support Service sub-committee and is excited to help revamp the patient toolkit. As the daughter of a patient, she offers her unique perspective and feels enriched by the experiences of other board members.

“It’s nice to walk into the Cancer Center for something positive,” she says. “I was able to meet other people with similar passions and interests, but different perspectives. Everyone is there for really pure purposes.”
Guided imagery engages the senses to cope with cancer

Kris Snow grew up skiing in the mountains of Utah and associates them with fond memories, peace and spirituality. With her entire family still living out West, being diagnosed with stage 3 breast cancer in 2011 after moving to Michigan left her feeling even farther away from the people and place she loved.

“The mountains and nature are really my church,” she says. “I feel calm there and can put things in perspective. Being so far away was hard.”

During the process of chemotherapy treatment, Snow imagined a fight in her body: the cancer cells were the enemies, her caregivers were the generals and the infusion treatments were the soldiers going in for battle.

“I’m a very visual person,” Snow says. “I literally pictured the cancer cells blowing up. Treatment was my time to do battle.”

She mentioned the imaginary battle to Jennifer Griggs, M.D., and other members of her care team, who referred her to Claire Casselman and the Guided Imagery Program to learn more ways to use her imagination to cope with stressors associated with her cancer.

“Guided imagery is a way to tap into the power of your imagination and use your senses to release uncomfortable feelings or thoughts and then refocus,” says Casselman, a clinical social worker in the Complementary Therapies Program. “With Kris, it made sense to utilize her love of skiing and the mountains as a way to manage stress and regain a sense of control as she faced some bigger life issues related to her diagnosis.”

Casselman holds one-on-one sessions with her patients to get to know them, ask questions and develop personalized guided imagery resources they can use anywhere.

Snow received a CD, scripted and recorded by Casselman, that included sensory prompts to take her back to Utah and the mountains. She listened to the CD during infusion, after surgery, during radiation and even at night during bouts of insomnia.

“As I was laying there, I would take myself to the top of that mountain,” Snow says. “I would think of the sound of skis swishing on snow. I’d remember the shining of the sun and the warmth it provides even though it’s winter. I’d picture that physical, good fatigue you get from exercise and being with friends. It works. It calms you down. I never felt anxious about what the treatment was doing to my body.”

Snow worked with Casselman to develop two CDs during her treatment and now, in the recovery and rebuilding phase after cancer, thinks she’s ready for a return guided imagery session to create a third.

“During treatment you’re facing the physical aspect of things,” Snow says. “There’s a huge emotional component in healing. The mental part is beyond scary when you don’t see the physician for three months. Sometimes reentering regular life is hard.”

Casselman says the Guided Imagery Program is beneficial to patients at all points during and after treatment. The key is to engage your senses to corral the power of the imagination to affect the body and mind in a positive way.
When the U-M Comprehensive Cancer Center received its formal designation from the National Cancer Institute in fall 1988, cancer affected more than 1.3 million people in the United States annually. Director Max Wicha, M.D., stressed the importance of taking research developments from the labs and applying them to patient care in the clinics.

Twenty-five years later, the number of annual cases has risen to 1.6 million, but advances in cancer treatment have led to better outcomes, more cures and more people living quality lives with cancer: there are 14 million survivors in this country. Some cancers with very low survival rates can now be treated and cured in many cases. Clinical trials and new therapies can be used as stepping stones, forging a path toward a longer life and potential cures in the future.

Here are the stories of two Cancer Center patients with very different journeys.
CURED IN THE NICK OF TIME

Even though Betsy de Parry, 62, jokes about the state of Michigan being “geographically undesirable” compared to her previous home of West Palm Beach, Fla., she wouldn’t move back because of the security she feels living near the Comprehensive Cancer Center since her diagnosis in 2002.

“I will never forget the day I walked into that Cancer Center, sat in the waiting room wondering what we were doing there and walked out as a very scared cancer patient,” de Parry says. “Today I walk into the Cancer Center and it’s a place of healing and comfort. I know that if I ever got cancer again, everyone there would treat my future as if it were their own.”

When de Parry was diagnosed with non-Hodgkin’s lymphoma, treatment options were not what they are today. Starting with a clinical trial, her cancer simply did not respond to the chemotherapy she received.

“There were times my mind went to that dark place,” de Parry says. “My husband and I always believed I would beat this. At least we tried to say we believed it, but I remember one time walking into my closet to get dressed, wondering what to wear and collapsing in a pool of tears. I wasn’t ready for my life to end.”

A new therapy, radioimmunotherapy, became available just in the nick of time and de Parry’s oncologist, Mark S. Kaminski, M.D., who discovered and developed the therapy, encouraged her to pursue it. She took two doses a week apart and was cured. Her cancer has never relapsed.

“Cutting-edge research saved me and Michigan is at the forefront,” she says. “I’m in awe of the people willing to spend hours in a lab, day after day, year after year, to save people like me. I wasn’t ready for my life to end.”

Today de Parry has been cancer-free for 11 years and still works side by side with her husband and best friend, Alex, at Ann Arbor Builders. A byproduct of her cancer, she says, was being able to put context to compassion.

“Doctors can never make guarantees and I know that,” she says. “But Dr. Kaminski and (nurse practitioner) Judy Estes always kept my hope alive. Somehow they found a way to rekindle that hope when they saw it starting to go out. It would have been a much more difficult time emotionally had they not been there for me.”

“The idea of treating patients with smart therapies that don’t hurt the rest of their bodies has been the holy grail in treatment of patients with cancer. They’re seeing every time they turn around, there is something new on the horizon and that gives a tremendous amount of hope for these patients.”

—Mark S. Kaminski, M.D.
MEDICINE AS AN ART FORM

Tom Shumaker, an attorney from Grosse Pointe, was just 47 when diagnosed with kidney cancer in 1995 by his father Edward, the former chair of urology at Harper Hospital. When the referred surgeon wasn’t immediately available, Shumaker became even more anxious.

“Growing up in a surgeon’s home, my father’s philosophy was if you have cancer and you can operate, cut it out,” he says. Shumaker’s brother knew their high school buddy, James S. Montie, M.D., had recently been selected to lead urology at U-M. Montie scheduled Shumaker for surgery and within days removed his left kidney along with numerous affected lymph nodes.

For the past 18 years, Shumaker has enjoyed periods when his cancer remained dormant and periods of recurrence that led to additional surgeries and treatments. Bruce G. Redman, D.O., joined his treatment team in 2005 and oversaw an aggressive form of immunotherapy and a drug regimen that interferes with the growth of his cancer cells.

“I’m fortunate to have developed relationships with people rather than an institution,” Shumaker says. “The pure people in medicine, like Dr. Montie, Dr. Redman, their immediate staff and others, know it’s not just a science. There is still an art in taking care of patients.” Shumaker has managed metastatic renal cell cancer for close to four years on a drug regimen. He’s watched his two sons grow into adults, he became a grandfather and he enjoys life with his “bride of almost 37 years.” At 65, he works in property management and is an avid player of sports involving the modern-day racquet and old-fashioned racket.

“I love life,” Shumaker says. “That’s why I’ve lived with cancer. Every day is a gift. It’s not to say there aren’t peaks and valleys, but there are all kinds of goodness in the world.”
“I knew I wanted to get back into academics and fortunately was able to land at U-M. That is why I am here: the challenge of the most difficult cases, the most perplexing questions, the most complex management issues, new ideas—not just state of the art. But to realize such aspirations, it is clear that one has to be part of a larger group with similar values.”

— James Montie, M.D.
Exercise
Another weapon in the fight against cancer

An Internet search on exercise will result in numerous articles about how to whittle your middle and tone your trouble spots. But exercise is not just for weight loss. Studies have shown that physical activity is beneficial during and after cancer diagnosis and treatment.

Exercise is not only safe and feasible during cancer treatment, it can improve your ability to tolerate your treatment, perform your daily activities, minimize fatigue, and decrease stress and depression. It can also minimize post-treatment bone and muscle loss, speeding recovery. If you were not active before diagnosis, start low and go slow. Focus on low-intensity activities such as walking or stretching for at least 10 minutes at a time. If you are a regular exerciser, remember you may need to lower the intensity and duration of exercise during treatment.

Once treatment is completed, regular physical activity has been shown to reduce the risk of cancer recurrence and death in people with breast, colorectal, prostate and ovarian cancer. But some cancer treatments can leave you feeling weak and unsteady. Exercise, including aerobic and resistance training can improve muscle strength, cardiopulmonary fitness and balance. Check with your physician before starting an exercise routine to see if you should take extra precautions, especially if you are severely anemic, have a compromised immune system, have longer-term catheters or feeding tubes, or have peripheral neuropathies.

Your take-home message:
• avoid inactivity during treatment
• stay as physically active as possible during treatment
• increase the intensity and duration of physical activity once treatment is complete

Work towards a goal of 150 minutes of moderate intensity activity with at least two days of muscle strengthening exercises per week. Remember that some activity is better than no activity, so whether you get 10 minutes or 60 minutes in a day, just move.

Examples of moderate activities:
• Ballroom and line dancing
• Biking on level ground or with few hills
• Canoeing
• General gardening
• Doubles tennis
• Walking briskly
• Water aerobics
• Using a manual wheelchair
• Using hand cyclers

Visit mCancer.org/thrive for exercise precautions for some cancer survivors.
25% DON’T COMPLETE RECOMMENDED BREAST CANCER TREATMENT

One-quarter of women who should take hormone-blocking therapies as part of their breast cancer treatment either do not start or do not complete the five-year course, according to a new study led by University of Michigan Comprehensive Cancer Center researchers.

Five years of daily tamoxifen or aromatase inhibitors—two types of endocrine therapy that are taken as a pill—is recommended for many women whose breast cancer expresses the hormones estrogen or progesterone. The drugs have been shown to reduce cancer recurrence and increase survival. And recent studies suggest there may be even more benefit for some women to continue this therapy for 10 years.

Despite this, the study of 743 women eligible for endocrine therapy found that about 11 percent never initiated the treatments and 15 percent stopped taking it early. Results appear online in Breast Cancer Research and Treatment.

“We’re doing well with women taking endocrine therapy, but there’s work to do,” says lead study author Christopher Friese, Ph.D., R.N., assistant professor at the University of Michigan School of Nursing. “If guidelines begin to shift so that some women at high risk of breast cancer recurring need 10 years of endocrine therapy, then the number of women who persist with treatment will likely worsen. We need to develop better ways of supporting women through this therapy.”

The most common reason patients said they either discontinued or never started endocrine therapy was side effects. Many women experience menopause-like symptoms such as hot flashes or vaginal dryness, and both types of drugs, more commonly the aromatase inhibitors, can cause joint pains.

ON-AND-OFF APPROACH TO PROSTATE CANCER TREATMENT MAY COMPROMISE SURVIVAL

Taking a break from hormone-blocking prostate cancer treatments once the cancer seems to be stabilized is not equivalent to continuing therapy, a new large-scale international study finds.

Based on previous smaller studies, it looked like an approach called intermittent androgen deprivation therapy might be just as good as continuous androgen deprivation in terms of survival while giving patients a breather from the side effects of therapy. In fact, researchers believed intermittent therapy might help overcome treatment resistance that occurs in most patients with metastatic hormone-sensitive prostate cancer.

But this new study, which treated 1,535 patients with metastatic prostate cancer and followed them for a median of 10 years, finds that’s not the case. Results appear in the New England Journal of Medicine.

“We tried to see whether intermittent androgen deprivation is as good as continuous androgen deprivation, but we did not prove that. We found that intermittent therapy is certainly not better and moreover we cannot even call it comparable,” says lead study author Maha Hussain, M.D., FACP, a prostate cancer expert at the University of Michigan Comprehensive Cancer Center.

In the study, men with metastatic hormone-sensitive prostate cancer were given an initial course of androgen deprivation therapy (hormone therapy), which is standard therapy for this disease. Patients with a stable or declining PSA level equal to or below a cut-off of 4 ng/ml were then randomly assigned either to continue or to discontinue the hormone therapy. Patients were carefully monitored with monthly PSAs and a doctor’s evaluation every three months and therapy was resumed in the intermittent arm when PSA climbed to 20 ng/ml. The intermittent cycle continued on-and-off based on the PSA levels.

Survival among the two groups showed a 10 percent relative increase in the risk of death with intermittent therapy, with average survival of 5.8 years for the continuous group and 5.1 years for the intermittent group from the time of randomization.
MANAGING SIDE EFFECTS OF RADIATION

By Molly Brummond, R.N., U-M Department of Radiation Oncology, and Emily Mackler, Pharm.D., U-M Comprehensive Cancer Center Symptom Management and Supportive Care Program

About 60 percent of patients diagnosed with cancer will receive radiation therapy. Radiation in high doses damages cancer cells by interfering with the cell's ability to grow and reproduce. However, normal cells of the surrounding tissue can also be affected, leading to side effects. Side effects only occur in the area of the body that is receiving the radiation. The severity depends on your dose of radiation, whether you're also receiving chemotherapy and the size of the treatment field.

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<th>Side Effect</th>
<th>Ways to Manage</th>
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| Fatigue             | - Sleep at least 8 hours each night  
- Take extra rest periods  
- Let others help you  
- Get light exercise each day |
| Skin Changes        | - Wear sunscreen, wide-brimmed hats, and clothing to protect your skin  
- Keep the area clean and dry  
- Wear loose-fitted clothing and soft fabrics  
- Use a mild soap and no deodorants, powders or other products to the area receiving radiation  
- Discuss skin care products with your health care team |
| Mouth Sores/Pain    | - Keep your mouth clean  
- Rinse your mouth every 1-2 hours with a solution of salt and soda (1/4 tsp. baking soda + 1/8 tsp. salt in 1 cup of water)  
- Eat foods that are easy to chew and swallow  
- Use Magic Mouthwash, Mugard or Gelclair if prescribed  
- Take pain medications by mouth if prescribed  
- Tell your health care team if pain worsens or if it is difficult to swallow |
| Dry Mouth (Xerostomia) | - Use a saliva substitute  
- Sip on water often  
- Suck on ice chips  
- Discuss medications that may increase saliva production with your health care team |

THRI vE ONLINE mCancer.org/thrive

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

- Information on exercise precautions for some cancer survivors
- A link to apply to the Patient and Family Advisory Board
- Listen to our collection of guided imagery podcasts
- More resources and articles about communicating with friends and loved ones during your illness
- A link to the timeline of the Cancer Center’s history
- Tips on how to make exercise more fun
- Details on how to search for clinical trials that could help you become the future of cancer treatment