



thrive



How genetic testing results revealed invaluable information that empowered the Argyle family.

Together

Also: Talking to loved ones about a diagnosis; preserving fertility during cancer treatment

thrive



THIS ISSUE'S THEME

Family

A cancer diagnosis impacts the whole family.
Find guidance to help you navigate.



On the cover

Genetic testing helped Ray and Cathleen Argyle make choices about their health so they can continue enjoying activities like bike-riding together.

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by Erica Reist Bass

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Mary Clare Fischer, editor
Contributing writers: Anna Megdell, Eric Olsen and Jessica Webster-Sendra
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Photographers: Erica Reist Bass, Linus Brush-Mindell, Doug Coombe
Illustrators: Ellen Weinstein

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How to Tell Your Loved Ones You Have Cancer



**Families Facing Cancer program coordinator
Madison McTevia shares some tips.**

By Mary Clare Fischer

One of the unexpected challenges of a cancer diagnosis is how to talk about it with your family and friends.

“Even for adults, there are misconceptions when it comes to the word ‘cancer,’” says Madison McTevia, a certified child life specialist who manages Rogel’s Families Facing Cancer program. “A lot of times, we only have information from what we read in books or see on *Grey’s Anatomy*. I think that’s one of the reasons it can be so tricky to start the conversation.”

However, McTevia notes that it’s often better when people you care about hear the news directly from you, rather than finding out through word of mouth or other means.

Resources

To make an appointment with Madison McTevia, call 734-615-6952 or email mmctevia@med.umich.edu.

Plus, the information about your cancer might be helpful for your family to know for their own benefit. Although the majority of cancer cases are random occurrences, some people possess genetic mutations that increase their likelihood of certain cancers; your diagnosis could be the impetus to undergo genetic testing.

To help patients navigate this conversation, McTevia suggests thinking about how you communicate with different family and friends. Ask yourself questions like:

- › Does your family openly talk about emotions and stressors? If not, why is that?
- › Would your loved ones have noticed anything off about the way you’ve been acting? Is there anything in your routine that’s shifted that could be a jumping-off point for the conversation?
- › Where would you feel most comfortable having this discussion?
- › What are your boundaries around this topic? How much do you want to share?

McTevia recommends being as direct as possible, but she says there’s no wrong way to have the conversation. And it’s always good to remember why you’re sharing the information.

“Patients can feel encouraged by thinking about the reasons they’re doing this,” McTevia said. “And fortunately, getting everything out in the open often makes them feel better.” ☑



Preserving Possibilities

Certain cancer treatments can affect fertility, but Rogel offers ways to preserve your ability to have children before starting treatment for your disease. Molly Moravek, M.D., outlines the options.

By Jessica Webster Sendra

Ask Molly Moravek, M.D., why she pursued a career in fertility preservation for patients with cancer, and she'll tell you it's because her heart breaks whenever she sees a patient who's had their ability to have children taken away from them.

"It's the patient who was never told that their cancer treatment was going to affect their fertility or who is here once they've already started treatment and I can't offer much," says Moravek, director of U-M Health's Fertility Preservation Program. "Or maybe a provider mentioned it but didn't really emphasize it. And then I'm the one who has to tell the patient that their reproductive organs are no longer working properly, and they will probably never be able to use them to have a baby."

Chemotherapy, radiation and some immunotherapies can interfere with a patient's reproductive system and affect their ability to have children. The option to preserve eggs or sperm prior to treatment has long been available, but it's often not communicated to patients early enough in the process.

Moravek wants to change that.

She's built a program in partnership with U-M Health's

Center for Reproductive Medicine and the Rogel Cancer Center that works with patients and their oncologists to preserve patients' opportunity to have children.

Moravek spoke to *Thrive* about cancer fertility preservation and what makes U-M Health's offerings unique.

Who is cancer fertility preservation for?

People of reproductive age who are getting ready to undergo chemotherapy, radiation or removal of their ovaries or testes. We can freeze their eggs or sperm, or if they have a partner, we can freeze embryos. We also have medical options to offer them, although they are not as effective.

What does cancer fertility preservation involve?

The quickest and easiest option for people with ovaries is an injection that shuts the ovaries down – the thought being that chemotherapy attacks rapidly dividing cells, and if we can make the ovary quiet, then maybe it won't be as susceptible to chemotherapy. This option is considered experimental.

If we have more time, I can freeze eggs or embryos in as little

as two weeks. We can get them right back to the oncologist, and patients can start chemotherapy the next day.

Preserving sperm is easier. The problem is: A lot of people with testes who have cancer will have decreased sperm count or difficulty producing a sample. Our reproductive urologists can help with that. They can also counsel those patients on how many samples they should freeze given their number of sperm.

How is U-M Health's program different from other fertility programs?

We're not just a fertility clinic that freezes eggs, embryos and sperm. We are a comprehensive program with doctors trained in different chemotherapies and their risk profiles, nurses comfortable with the accelerated schedule of a patient with cancer, fertility-trained mental health professionals and a fertility preservation program manager.

We're focused on making this as patient-friendly as possible, and a big part of that is our program manager. She communicates with the patient's oncologist and helps incorporate fertility preservation into their cancer treatment plan. She also helps patients schedule appointments and figure out their prescriptions and insurance coverage. We don't want fertility preservation to be one more hard thing a patient has to do.

Why is it important to offer fertility preservation to patients facing cancer treatment?

Lots of patients are shocked by the loss of fertility at the end of their treatment; multiple studies show this is one of the most pervasive regrets for patients. They either feel guilty that they didn't do it, or they feel angry that nobody talked to them about it.

Studies show that even fertility counseling matters. For those patients who chose not to preserve their fertility, the chance to make an informed, educated decision still mattered when asked about their decision after their cancer treatment.

I see fertility as a health issue, not a luxury. I think everyone should have the right to have a baby. If we know we're doing something with a high likelihood of taking that away from them and we can intervene, why wouldn't we?

When you're going through cancer treatment, having hope is important. Your oncologist sent you to me because we're talking about life after cancer treatment. That's a good thing. If they didn't think we could be talking about your life after cancer, they wouldn't be sending you. Let's talk about the good things to come. ☑

Resources



To learn more about fertility preservation, contact Fertility Preservation Program Manager Erin Ellman at 734-232-9710. Scan this QR code for resources, including LGBTQIA+-specific resources, around fertility preservation and cancer.

Working Toward Inclusivity

By Eric Olsen

WHEN MICHIGAN MEDICINE researcher Emily Walling, M.D., conducted a fertility preservation study with adolescent and young adult (AYA) cancer patients, some reported that Rogel's fertility preservation program was often at odds with their identities, intimate relationships and family planning goals.

"They were vocal," says Walling, co-medical director of U-M Health's AYA Oncology program. "They made sure we understood that the program was not meeting their needs as queer-identifying people."

When the team searched for other studies in the area of queer fertility, they discovered that virtually no research had been conducted.

In response, Walling and co-investigator Nina Jackson Levin launched the Sexual and Gender Minority Oncofertility study to recruit patients and survivors who do not identify as cisgender or heterosexual.

"We ask about how we approach the conversation around fertility, and if there are things we could be doing better to be more inclusive," Walling says. "Our goal is to improve our approach to be more inclusive, including the language we use. We want everyone to feel heard and seen, less marginalized, and more likely to consider fertility preservation services."



After Cathleen Argyle and her mother, Diane, developed breast cancer, the pair decided to get genetically tested. What they discovered would shape the health decisions of their whole family.

All Three of Us

By Mary Clare Fischer



Photos by Erica Reiss Bass

ON MARCH 3, 2018, Cathleen Argyle called the University of Michigan Rogel Cancer Center to get her results.

The 51-year-old wasn't waiting to see whether she had cancer. In fact, she'd already been diagnosed with early-stage breast cancer a month or so earlier and undergone a lumpectomy to remove the tumor. Instead, Cathleen was about to find out whether she carried a genetic mutation that increased her risk of certain cancers.

Cathleen's mother, Diane, had previously developed cancer. So had several of Diane's relatives. So, when Cathleen, too, joined that group, Diane decided it was time to undergo genetic testing.

Cathleen's results came back first: Positive. Cathleen had a rare mutation in the ATM gene complex, which repairs damaged DNA, that increased her risk for several cancers, including breast.





Top: Diane Argyle lived for 15 years after her breast cancer diagnosis. **Bottom:** Ray shows Cathleen the 1929 Ford pickup he bought with her son, Adam.

“I was a bit shocked, quite frankly,” Cathleen says. The shocks kept coming: Diane, the family learned, wasn’t the carrier of the mutation.

“So, if it wasn’t Diane, then who was it?” Cathleen says. “Well, it’s gotta be Ray.”

A few weeks later, after subsequent testing, Cathleen’s father called to confirm her hypothesis.

“Sorry to tell you, this, kiddo,” Ray Argyle had said. “But I’m the one who gave it to you.”

The news was a lot to handle. But the information the father and daughter gained about their risk of cancer would help them in significant ways: Cathleen to make important decisions about her cancer treatment and Ray to get worrisome symptoms checked out sooner than he otherwise might have.

“I’m really grateful,” Ray says. “It’s good to be alive.”

Diane and Cathleen

The conversations with Rogel’s Breast and Ovarian Cancer Risk Evaluation Clinic started before that poignant phone call.

In advance of the testing, Diane and Cathleen spoke with genetic counselor Kara Milliron, M.S., C.G.C., who reviewed their medical and family histories.

Cathleen was the fifth or sixth person in her extended family to be diagnosed with cancer — enough of a repeating pattern that it seemed there could be a shared clue hidden among the family’s genes.

But Milliron cautioned that 90% to 95% of cancer cases are “unfortunate random chance events.” As a result, the majority of genetic tests the clinic conducts come back negative for known mutations that increase cancer risk.

Even when tests come back positive, that doesn’t mean the person with the mutation is guaranteed to develop cancer, she noted.

“No one has a perfect genome,” Milliron says. “We all have about five or six mutations that we’re blissfully unaware of unless we have a child with someone who just happens to have a mutation in that same gene or something like this happens where you get a cancer diagnosis at a young age.”

Before the consult wrapped up, Sofia Merajver, M.D., Ph.D., the medical director of the clinic, joined Milliron to answer the Argyles’ questions.

“I look forward to these conversations because education is such a huge part of what we do in genetics,” Merajver says. “We are here to educate patients about the advantages of living in a society that respects science and the great possibilities that we are opening up for their loved ones.”

Cathleen

A few weeks later, Cathleen was left to deal with the answer to the primary question she’d been asking: Did she have a genetic mutation?

The ATM mutation is much less talked about than those on the BRCA1 and BRCA2 genes. That’s partially because it’s rare: Less than 0.5% of people carry an ATM mutation.

And for those who have it, like Cathleen and Ray, the increased risk of cancer is not as high as might be assumed. The ATM mutation means Cathleen has a 30% lifetime risk of developing breast cancer, compared to 12.5% for the general population.

But Cathleen did get breast cancer, and she was at a higher risk of developing additional cancers in the future, including colorectal and pancreatic cancers.

During Cathleen’s post-testing visits, Milliron



Cathleen, Ray and Adam regard a tapestry Diane created from old T-shirts.

and Merajver talked about tailored cancer screening. More frequent colonoscopies could help catch early signs of colorectal cancer, for instance. U-M Health had also been an early adopter of a novel method to screen for pancreatic cancer in certain patients with high genetic risk.

And before then, Cathleen could undergo additional treatment to increase the likelihood that her breast cancer wouldn't return.

Ultimately, her choices came down to radiation or surgery. Her ATM mutation meant that, if she chose radiation, there was an increased chance of developing a second breast cancer in the future.

Surgery, though, carried its own risks and would involve removing one or both breasts.

"It was disheartening," Cathleen recalls. "I kept thinking, 'What do I do?' The easy way out would have been to have the radiation and be done with it. But since this ATM gene was thrown into the mix, it made for a challenging time. I don't know that I've ever thought so much about a decision."

"Some women choose to have mastectomies because they don't want to ever go through cancer treatment again," says Megan Williams-Morad, PA-C, a physician assistant with the breast oncology

clinic at the Rogel Cancer Center who was part of Cathleen's treatment team. "But some people say that unless a mastectomy is going to save their life, they don't want to have it. It's about what the meaningful benefit is to you as the patient.

"What I really like about Cathleen is she asks those important questions and makes decisions with all that information in mind," Williams-Morad adds.

Eventually, Cathleen decided to have both breasts removed, which would reduce her risk of developing breast cancer again by 90% to 95%. She also chose a breast reconstruction procedure called a DIEP flap that would transfer the fat from her belly up to her chest and use it to reshape her breasts.

"Many times we're able to reconstruct these organs that were taken away for cancer reasons to a point where they look very realistic," says Adeyiza O. Momoh, M.D., Cathleen's plastic surgeon. "Based on the feedback we get from patients, they're often very pleased with what we can accomplish."

Cathleen concurs.

"That guy's amazing," she says of Momoh. "I



Ray and his grandson, Adam, bought a 1929 Ford pickup and spend time together fixing it up.

wouldn't have thought he could do all that plumbing, and oh my God, he did. And everything healed just fine."

Cathleen took eight weeks off from work to recover from the operation. By summer 2021, she was doing well enough to bike 90 miles with her son, Adam.

"If people ask what's the hardest thing you've done in your life, those choices were it for me," Cathleen says. "It wasn't to get married, have kids, buy a house. The hardest thing was to make a decision about my own well-being, what I thought would be the outcome of the future. But five years later, here I am."

Ray

And then there was Ray.

He didn't have a history of cancer and wasn't prone to significant illness. He ran 15 to 20 miles a week for decades, and he and Diane have scuba dived all over the world.

"I have a neighbor who's said to me, 'Damn you, you'll get a cold and you're over it the next day. I get a cold, and I'm in bed for a week,'" Ray laughs.

But in 2020, Ray's glucose levels shot up. Although he first attributed the uptick to too many jelly beans, it was clear when he lost 20 pounds in the span of two months that excess sugar wasn't the problem.

Thinking about his increased likelihood of cancer, Ray continued to push for more answers — and wasn't surprised when a CT scan showed he had pancreatic cancer.

Because he hadn't had very many health issues in the past, Ray believes he wouldn't have investigated his concerning symptoms as quickly if he hadn't known he had the ATM gene.

"Had I waited another two months and done nothing, it might have been too late," he says.

It's difficult to know whether that would have been the case. But pancreatic cancer's dismal survival rate — 11% five years after diagnosis — and the fact that it's frequently diagnosed at late stages, once the cancer has spread to distant areas of the body, makes early action crucial.

Ray's tumor was locally advanced, meaning that blood vessels outside the pancreas were involved, but it hadn't metastasized.

"If someone has a locally advanced, surgically inoperable pancreatic cancer like Ray, I send them for radiation and chemotherapy to seal the cancer in the hope that it doesn't grow further," says Thomas Enzler, M.D., Ph.D., Ray's medical oncologist at Rogel.

So far, Ray's response has been impressive. While



his periodic scans still detect cancer, his tumor has shrunk and continues to do so now that his 25 cycles of chemotherapy and radiation are complete, an outcome that Enzler calls “amazing.”

Although Ray has lingering numbness and tingling in his feet (a side effect of the chemotherapy), he’s still able to play golf, zoom around Ann Arbor on his e-bike and restore a 1929 Ford pickup truck he shares with Adam.

“We’re so fortunate to live here and have access to such top-notch medical care,” Ray says. “I love Michigan Medicine. Everyone there, from the guy that’s parking the cars to the person at the reception desk to the nurses administering the drugs to the doctors — they’re just the nicest people. You guys have done wonders for me.”

“And my mother and me,” Cathleen adds. “You saved all three of us.”

Diane

Diane Argyle always wanted to know more.

Once she became the director of the Ann Arbor Parks and Recreation ice skating program, she continued to take skating lessons herself for decades, “working at her skating like someone would work on a master’s degree,” former ice skating director Betty Jane Wilson told the Ann Arbor Observer.

And after Diane was treated for breast cancer in 2004, she took so many science classes at the University of Michigan that Max Wicha, M.D., her oncologist and Rogel’s founding director emeritus, would later write, “In my entire 40-year career of treating cancer patients, I can honestly say that she was unique in her passion for knowledge. She attended more lectures on cancer research than any of my students.”

“She always asked thoughtful questions,” Milliron remembers. “And she was very well read. She went to the primary literature and understood it. There were a couple of times where I’ve said, ‘Wow, I don’t remember that from that paper; I’m going to have to go back and look at it again.’ She was a brilliant, brilliant woman.”

Diane died in 2019. But she lived for 15 years after her breast cancer diagnosis and ultimately passed away from unrelated causes.

And her commitment to learning about her family’s genes left them with knowledge that may have changed the course of their lives — the best legacy she could have asked for.

“As my mother thrived, I am continuing to thrive,” Cathleen says, “and my father is beginning to thrive again.” ☑

Ray has lived a vibrant life full of hobbies, including woodworking (pictured) and scuba diving around the world.



Resources



To make an appointment at Rogel’s Breast and Ovarian Cancer Risk Evaluation Clinic, call 734-647-8902.

For more on breast reconstruction options available at Rogel, scan this QR code to listen to our Cancer Wise podcast.



Finding out that she had stage 3 melanoma was enough of a shock for Leah Koskinen. Hearing that she might need to delay pregnancy as a result was even more stressful.

Navigating the unknown

By Cecilia Warchol and Mary Clare Fischer
Photographs by Erica Reist Bass and Linus Brush-Mindell

Leah Koskinen never imagined she would be a stay-at-home mom in her mid-20s. She used to think, if anything, her husband would stay home while she became the breadwinner. But after being home with her newborn son for two months, she couldn't imagine not being around to raise him.

The phrase, "Because you're a mom now..." was all Leah needed to hear from her own mother to be convinced that she should start seeing a dermatologist. Her fair skin and number of moles gave her extra reasons to make an appointment for a check-up.

One of the spots Leah was hoping the doctor could examine was a mole that had recently popped up on her left shoulder, noticeable because it was right where her bra strap lay.

The dermatologist didn't think the spot was an issue, but just to be safe, she removed it and sent the cells off for analysis.

A week and a half later, the dermatologist called. Leah had melanoma, a type of skin cancer — and because of the depth of the cancer, the doctor was concerned that cancerous cells had moved elsewhere in Leah's body. The dermatologist was referring her to the Rogel Cancer Center, with hopes she could see an oncologist as soon as possible.

"I don't know how we survived," Leah says. "I was worrying about myself but then also worrying about my son, thinking, 'What if this goes really bad and I'm not here?'" Up until we had all these appointments at Rogel and



Leah Koskinen spends time with her husband, Scott, and their son, Boden. In 2022, they welcomed a daughter, Kenzie, into their family.

had a better idea of what we were working with, the unknowns and the what ifs totally took over.”

Leah would go on to have successful surgery. But it would take a team of people and several years for her to manage her anxiety around heading back out into the sun — and whether to become a mother for the second time.

‘It feels like forever’

When Leah arrived at the cancer center, she underwent more testing. Cancer had spread to one of her lymph nodes, so she was diagnosed with stage 3 melanoma.

Melanoma is one of few cancers that can, although very rarely, spread to the fetus, Leah’s care team told

her. If she and her husband were considering having another child, the conservative choice would be to wait for at least five years.

“Being told five years...that’s a big chunk of time when you’re thinking about your family and how old you’re going to be when you have the kid,” Leah says.

While trying to accept this new reality, she also had to undergo surgery. In May 2018, Lesly Dossett, M.D., the division chief of surgical oncology at University of Michigan Health, removed the tissue around where the cancerous spot had been as well as the lymph node with signs of cancer.

For four to six weeks afterwards, Leah couldn’t pick up her son. She was unable to even lift her left arm above shoulder height.

She didn’t need to see a physical therapist, though, and was back to her usual routine within three months.

“Looking back, that’s actually really impressive,” Leah says. “At the time, it feels like forever, like it’s never going to end.”

How to reflect deeply and mindfully

The stress and anxiety lingered. Leah grew frustrated with people who couldn’t relate to what she had been through. Although she knew it was well-intended, it was hard for her to listen to others tell her that “Everything will be fine” and “Everything will work out.”

About a year after her diagnosis, she mentioned to one of her doctors that her worries were still there. She thought it might be helpful to talk about her experience with someone who wasn’t her husband or a friend.

And it was. Claire Casselman, L.M.S.W., a social worker and guided imagery specialist on Rogel’s Patient and Family Support Services team, was “phenomenal,” Leah says, especially as she and her husband began to think about when to grow their family.

Advanced melanoma is uncommon at Leah’s age, so there wasn’t much evidence to help her and her husband decide when to try to conceive again.

“Our conversations surrounded how she could reflect deeply and mindfully about the decision,” Casselman says. “Could she sit with the worst-case scenario? Could she engage her husband in this conversation, with eyes wide open?”

At three and a half years post-diagnosis, all of Leah’s testing came back with good news — neither a CT scan nor an ultrasound nor MRI showed signs of cancer. She and her husband made their choice.



‘Using what happened for good’

In November 2021, Leah became pregnant.

“I’m proud and excited that we finally made a decision to have another baby,” she says. “It absolutely felt like a goal had been conquered.”

Doctors monitored Leah throughout her pregnancy. She took pictures of anything suspect and her dermatologist removed those moles, even if they were likely benign.

Leah has developed strategies, like regularly reapplying sunscreen and sitting in the shade, that help her enjoy the outdoors. Her husband is there for her when she gets anxious about how long she’s been exposed to the sun, reassuring her that she’s fully covered in all the right areas. Each year, she gets a little better at standing outside for her son’s T-ball games.

Leah’s son was young at the time she underwent surgery, but now at 6 years old, he is more aware of her actions and asks questions about her scar.

Madison McTevia, a child life specialist for the Patient and Family Support Services team at Rogel, helped Leah figure out how to talk to him about her experience.

“I respect that Leah wanted to have open and

Resources

To learn more about guided imagery services, call 877-907-0859.

honest conversations with her son, especially as he gets older,” McTevia says. “So that’s what we practiced — how to have age-appropriate conversations about Mom’s diagnosis, so he doesn’t grow up afraid of the sun or fear that he will catch cancer.”

A new addition

Eventually, Leah will be able to have similar conversations with her daughter.

On July 22, 2022, the Koskinens’ baby girl was born by scheduled C-section. Leah’s doctors froze her placenta to send to the Rogel Cancer Center where it was tested for traces of melanoma.

About a week later, the Koskinen family received the news they’d been hoping for: Their healthy baby girl had no signs of cancer.

“A weight was instantly lifted,” Leah says. “I expected myself to cry happy tears, but it was almost hard to believe and process.”

Leah’s latest tests have revealed that she, too, remains cancer-free.

“I’ve learned that when it comes to your health, you are your best advocate,” she says. “No one can take care of you as good as you can.” ☑

Finding Foy in Community

A monthly peer discussion group for those genetically predisposed to colorectal and other cancers has created connection for an often isolated demographic.

By Anna Megdell

About 15 faces line the Zoom screen on a Thursday evening. Folks of all ages and backgrounds, across the country and in different phases of life, chat with warmth and care. They share details about their health, ask for advice, laugh.

One person admits they hadn't been feeling well but came to offer support to other members. Another says the meetings provide them with "opportunities to be in life."

This tight-knit group meets once a month to support those with hereditary colorectal cancer or genetic conditions, like familial adenomatous polyposis (FAP) and Lynch syndrome, that predispose them to developing cancer. Some members have had cancer, while others have undergone major surgeries to prevent cancer. Many receive colorectal and other cancer screenings multiple times a year.

Group co-founder Kevin Myers comes from a family with FAP. He and his four brothers were diagnosed with the condition in their early teens and have each had their colons and rectums removed.

He started the support group in 2015 after attending a Rogel-sponsored event for people with FAP and Lynch syndrome.

"I found so much joy and freedom by interacting with others who also have a hereditary genetic condition," he says.

Kevin facilitates the group alongside Rogel clinical research project manager Erika Koeppel, with support from U-M's Human

Genetics Department and the local chapter of the Cancer Support Community.

While discussions inevitably deal with the realities of cancer risk, the group differs widely from traditional cancer support groups, Koeppel says.

"Cancer can often be viewed as one and done," says Koeppel. "Folks in our group often cringe when people say, 'I beat cancer,' because they're dealing with lifelong conditions. They understand that cancer isn't something they will ever 'beat.'"

Conversations often revolve around how to adjust to dietary changes, have difficult conversations with family members who may also be at-risk, manage a slew of medical appointments and ease pain and exhaustion.

"It's about how to be your own advocate for conditions that reach into all areas of life and that many doctors are uneducated about," Koeppel says.

The group is open to those that care for members, too.

One couple attends together. The patient's husband wants to know more information than she does, so he's in charge of asking questions and learning about possible treatments to, ultimately, better advocate for his wife.

Toward the end of the meeting, one member shares concerns about working with a new physician and the possibility of surgery.

Resources

If you're interested in signing up for this peer discussion group or learning about educational opportunities related to hereditary cancer, contact the Cancer Support Community of Greater Ann Arbor: www.cancersupportannarbor.org/contact/



Another member has seen this physician and shares the positive experience and hope they received under the doctor's care. The first member exhales, relieved, and later shares that hearing this has changed their perspective on the coming months.

Hearing Kevin's story lifts group members' hopes, too. His father, who had FAP as well, didn't die until age 96 last year. Myers runs at least 10 miles on Saturday mornings and has completed three marathons.

"The circumstances of these conditions are unique," Koeppe says. "Many group members say they've gone their entire lives without ever meeting someone else with the same condition. Through the group, they can hear experiences like Kevin's and learn that this diagnosis is not necessarily a death sentence. They become inspired."

After a couple of hours, the meeting ends. The members wave to each other from their living rooms, kitchens, cars. They wish each other peace and comfort until the next time they come together. ☐

"Cancer can often be viewed as one and done. Folks in our group often cringe when people say, 'I beat cancer,' because they're dealing with lifelong conditions. They understand that cancer isn't something they will ever 'beat.'"



Thrown Into Cancer Land

How a caregiver has navigated supporting her mother during brain cancer treatment.

By Jeanne Hodesh, as told to Mary Clare Fischer

We took my mother, Margaret Parker, to the emergency room in May 2022, two days after her 75th birthday. It was the worst day of my life.

This was after about four days of realizing something was off. My dad and I took her to her primary care doctor, who was pretty dismissive. So we went to the ER.

All day long, different doctors came in, and the various assessments escalated up until about 4 p.m., when they called in the neurosurgery department. That's when they told us she had a glioblastoma, a brain tumor.

It was this beautiful time of year. All the dogwood trees were blooming. It felt so unfair and otherworldly. I was just struck with grief.

So far, my family had managed to avoid cancer. I was

struck by how big, unfortunately, this community is, and that you're just thrown into cancer land, where no one wants to be, and there's a lot to learn.

My parents don't understand patient portals very well, and hospitals are complicated to navigate. My mom couldn't feed herself at first, and she was so confused about what was happening to her. So the caretaking was enormous, and to balance that with your own grief is quite extreme.

Before her surgery, I sent an email to 12 close family friends and relatives and made a couple of calls. I realized for me what would be helpful is to rally this team together and know they were thinking of us.

I've written plenty of sympathy cards over the years, but when people say, "I'm thinking of you. I'm holding you in my thoughts," it meant so much more than I ever imagined.

“As much as I was proud to celebrate our union, I was also proud to show off how far my mom had come. The whole thing went from being extremely scary to her being more empowered and thriving in a way. I can’t remember when I’ve seen her like this.”



That first night home, with this crazy regimen of pills, I got them all lined up, and I knew which one she was supposed to take and when. But she was looking at every pill bottle and trying to sound out the words on them. It reminded me of when my grandmother had dementia. The loop was really short.

And then there were home care visits — physical therapy and occupational therapy and speech therapy. So there was a lot of scheduling.

I started to hear from friends how important it was to advocate for ourselves. Someone suggested getting a second opinion.

We had a Zoom with Dr. Daniel Wahl, who would become her radiation oncologist at Rogel. He was just great. He listened. He took her seriously. He answered her questions and didn’t mind re-explaining.

We got off the Zoom, and she turned to me and said, “I want him to be my doctor.” I started crying. It was like a kid picking which college they want to go to. That’s the one I wanted for her.

In early June, we started going to Rogel to do her radiation treatment. Her chemotherapy and clinical trial drugs started at the same time.

Obviously, no one wants to spend their summer going to radiation every day. But I was so relieved that she was with us. I wanted to spend time with her, and this was just the activity we were doing.

The biggest challenge was paying attention to the idea that I was in charge, but she wanted to take care of herself. I was able to cede that control back in tiny increments. It was hard for me, but it was important to her and her healing.

In the beginning, I had all the doctors call my number, but we eventually got it switched back, so her number is the primary one for people to call. She started keeping track of all her appointments, all her medications

and just running with it.

I began to feel calmer and came back to myself as the months went on. Eventually she started being able to take walks, which is something we always did together before. We would go short distances, and then we went farther and farther, and now we’re back to our old long walk.

Two months before we took her to the ER, my husband and I had gotten engaged.

The wedding was in the backyard of my parents’ house on Oct. 1. The timing was great because by then my mom was getting better and more independent.

It felt so significant to have her there — and to have her fully there. She read an original poem. She wasn’t diminished.

As much as I was proud to celebrate our union, I was also proud to show off how far my mom had come. The whole thing went from being extremely scary to her being more empowered and thriving in a way. I can’t remember when I’ve seen her like this.

Her attitude has made it easy for the rest of the family to take a breath. This traumatic thing happened, but we’re getting through it, and there are surprises along the way that you would never expect. A lot of people who have cared for aging and dying parents have said, “I’m so sorry, it’s going to be really hard, but it will also be incredibly beautiful in ways you never could imagine.” And that is 100% true. ☑

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