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Janet Schuler says it took time, but she has adapted to living with ovarian cancer.

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Cancer Care at Michigan Medicine

The University of Michigan Comprehensive Cancer Center might offer services closer to home or right in your neighborhood. Ask your care team about these services in the communities surrounding the main Cancer Center building.

Find our community locations: [www.uofmhealth.org/our-locations](http://www.uofmhealth.org/our-locations)

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<td><strong>LIVONIA CENTER FOR SPECIALTY CARE</strong></td>
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<td>Call: 877-758-2626</td>
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Additional oncology services are coming to the Brighton, East Ann Arbor and West Ann Arbor Health Centers in the next year.
The Transition From

What you need to know to get the best health care beyond cancer treatment

You got your diagnosis, endured treatment and are moving into the survivorship phase. What now? Which doctors do you see for follow up care? What if you have other illnesses besides cancer? What if you have long-term side effects from your cancer treatment and need treatment for those? Do you see your primary care physician or your oncologist?

The transition from cancer patient to cancer survivor is an occasion to celebrate, but also comes with questions and uncertainty.

As more patients survive cancer, the health care field faces a new challenge: How to best manage the ongoing care of cancer survivors. The population of cancer survivors is increasing—an excellent problem in that more people are surviving cancer, but one that must be addressed in order to give patients high-quality, coordinated and patient-centered care.

We sat down with Lauren Wallner, Ph.D., MPH, a researcher at the University of Michigan Comprehensive Cancer Center, to discuss the issues of survivorship that patients need to think about and what research has shown about providing cancer survivors with the best health care possible as they age.

Q: Why is survivorship care such a big area of focus in your research?

Thanks to curative therapy, early detection and prevention, patients are living longer. We need to think about the best way to care for them long term. We need to ensure they’re well cared for by the right doctors, without overloading doctors and resources needed for newly diagnosed cancer patients.

Q: What are some of the issues patients should be thinking about as they transition from patient to survivor?

There are quite a few, actually. In my recent study of breast cancer patients, women were questioned about follow-up screenings, such as annual mammograms and screenings for other cancers, their general care (think flu shots, annual physical), and what other health problems they are treated for, such as diabetes or heart disease. On top of that, which doctor do they prefer to see for each concern?

There are also survivorship issues related to managing worry of recurrence, anxiety about scans and depression that can come with cancer. They may have residual side effects from treatment, such as neuropathy. Some patients continue to have financial hardship long after treatment or employment issues. Many patients need support and resources for these issues.

We were interested in understanding—from the patient’s perspective—who they prefer to have direct their health care. Their oncologist? Their primary care physician? In order to deliver patient-centered care, we should address patient preferences. And, there’s an opportunity to counsel patients ahead of time on what will happen next with their care.

Q: Why is it complicated? Wouldn’t a patient see a cancer doctor for cancer-related issues and their primary care physician for other issues?

Clinical guidelines for survivorship care don’t specifically outline which provider handles which aspect of survivorship care. And again, surviving with cancer long-term is a fairly new phenomenon.
Primary care physicians deal with a collection of issues with aging patients. Cancer is one of many conditions a patient might have. PCPs can’t be expected to know it all. And, being a cancer expert is difficult when research keeps changing.

Developing new models of survivorship care depends a lot on us understanding the patient perspective on follow up care. We need to know what patients want, what access they have to certain doctors, how well their doctors are communicating with them and the patient’s level of trust in their providers.

Q: What did the patients you studied say they want for survivorship care?

The majority of women wanted oncologists to handle mammography and secondary cancer screenings, and their primary care physician to handle general care and care for other illnesses. It was not surprising that patients prefer their oncologist handle services related to cancer.

However, 21 percent of women wanted oncologists to provide their general care. Sixteen percent wanted oncologists to deliver care for their other illnesses. They weren’t the majority, but these are significant percentages. And importantly, primary care providers can handle all of these aspects of care for survivors. This tells us there is an opportunity to educate patients on the best doctors to see for care as they’re completing cancer treatment and transitioning to survivorship.

We also looked at how their answers varied by race, education, age and insurance status. We found that minority women and those with less than a high school education more often wanted to see their oncologist for primary care. So we may face some additional challenges in trying to improve survivorship care delivery in diverse populations.

Q: How do you think survivorship care will look for patients in the future?

Health care experts are calling for “team-based cancer care.” This means sharing a patient’s care between oncologists, primary care physicians and any other specialists involved in treating different illnesses as needed. It requires a high level of coordination among doctors. Communication among the care teams is critical.

Also, communication between patients and their doctors will continue to be extremely important. Patients deserve high-quality care that is well coordinated and centered around their individual health situation.

Patients should feel empowered to speak with their doctors and ask questions. The patient is an essential part of the health care team. They should actively participate in the process.
A stage 4 prostate cancer patient changes careers for human connections

Jeff Smith has always been interested in self-improvement but back in 2014, at age 53, he was so busy juggling his sons’ sporting events, his own wealth management firm and family life with his wife, Lisa, that he didn’t have much free time for himself.

He’d never thought about the level of stress caused by his job, but a stage 4 prostate cancer diagnosis made him stop and rethink everything.

“Cancer makes you ask, ‘Why do you want to live? Are you willing to do everything possible to take care of yourself,’” Smith says. “My greater purpose was my family. I wanted to do anything I can.”

Smith entrusted his cancer care to the University of Michigan Comprehensive Cancer Center and went through six rounds of chemotherapy at three-week intervals.

Smith’s oncologist, David C. Smith, M.D., explains that the past few years have brought major improvements in the care of men with prostate cancer. There are six approved therapies for cancer that continues to grow despite reduced levels of testosterone in the body (called castrate or castration-resistant prostate cancer).

Treatment options range from immunotherapy that uses the body’s immune system to deprive cancer cells of testosterone to radiation therapy and chemotherapy to kill cancer cells.

During his chemotherapy treatment, Smith became familiar with many of the complementary therapies offered to patients of the Cancer Center, such as using guided imagery to relax.

He spoke to a nutritionist on the best ways to fuel his body and reached out to a therapist in the PsychOncology Clinic to help cope with the difficult emotions that accompany a cancer diagnosis.

“I knew that the PsychOncology group could help with my journey of discovery. What do you know that I don’t? They’re the experts. People should be open to self-reflection,” Smith says.

Combined, the medical treatment and complementary therapies gave him a sense of control over his situation. He began to realize, however, that the stress of managing other people’s life savings didn’t seem like a healthy approach to recovering from cancer treatment.
Visit mCancer.org/thrive for some of Jeff Smith’s favorite self-improvement resources and links to Cancer Center prostate cancer resources.
“One of the opportunities as I learned how to deal with cancer was that I saw how the body is designed to heal, regenerate and be healthy. Even though I really liked what I did, I saw the responsibility of taking care of someone’s money was going to cause too much stress,” Smith says.

He decided to leave behind all of those aspects of his life he didn’t love and start a new journey based on human connections. He sold his firm.

Smith completed treatment in 2015. His PSA level, an indicator of prostate cancer, has been undetectable since that time.

A DIFFERENT, THRIVING FUTURE

With his prostate cancer controlled, Smith returns to the Cancer Center for regular screenings. He describes his oncologist, Dr. Smith, as the chief executive officer of his medical treatment.

“All the caregivers at the University of Michigan deal with this on a daily basis. There is so much hope to have and information to learn. Be in partnership with your doctor. There is gold under your feet that you can mine,” he says.

“Men can still have a long and enjoyable life after prostate cancer,” says Dr. Smith. “Dealing with uncertainty becomes a major focus of people’s lives, but patients often make changes to reestablish control to some degree when their future is threatened. It is possible for patients to apply some alternative principals earlier in the process of the disease to improve their quality of life.”

Smith has taken his passion for learning and self-development and currently works with family businesses on executive coaching and succession planning. He has become certified as a Lifeline business development coach and a Conversational Intelligence coach. He also participates in a monthly radio show on WJR called The Family Business Forum.

His sons, 16 and 19 at the time of his diagnosis, are now both in college. Lisa continues to lead her public relations firm, Airfoil Group. And Smith expresses daily gratitude for the human connections that are now the focus of his life.

“Lisa and I had all kinds of thoughts and ideas of our life together. We had to let go of some dreams and that was painful. The reality was we had to deal with the cancer. Now I have an appreciation of how much positive, loving, grateful energy we have inside of us. When you go through a journey, you can make the best of it.”
Janet Schuler, 50, doesn’t buy into the belief that ovarian cancer is a silent killer, with quiet symptoms that don’t speak up until it’s so advanced that a cure is not possible.

“Ovarian cancer does speak,” she says. “We just need to know how to listen.”

Schuler was 42 in 2009 when she began to feel bloated. A wife, mother and registered nurse working full-time with special needs children, she was busy living and going to school to become a nurse practitioner. She also noticed some changes in her bowel habits and an increase in gas.

These are symptoms of ovarian cancer, but they are also commonly seen in perimenopause and in gastrointestinal problems. Schuler saw her primary care doctor and was tested for celiac disease. Her lab tests came back normal.

At a visit with her gynecologist, he suspected perimenopause.

Schuler’s symptoms persisted for eight months, a period of time when she tried to live with being bloated and gassy, a time when she cancelled another doctor’s appointment because she prioritized other things.

Finally, a gastrointestinal specialist found and drained 2.5 liters of fluid from her abdomen. She was diagnosed with stage III C ovarian cancer.

Her first step was debulking surgery, common in ovarian cancer patients, to remove as much cancer as possible throughout the abdomen.

“Had my diagnosis been made when I first had symptoms, it could have made the difference between a cancer that is curable and one that is seemingly not,” she says. “If new and unusual symptoms persist longer than two to three weeks, see your doctor, preferably a gynecologist.”

CANCER BRINGS PROFOUND CHANGE

Schuler never expected to live seven years after her diagnosis. She has adapted from being a caregiver to being the patient. She undergoes regular chemotherapy treatments at the University of Michigan Comprehensive Cancer Center.

“Due to the challenges of detecting ovarian cancer at early stages, most women have stage III disease at diagnosis,” says Karen McLean, M.D., Ph.D., an oncologist and cancer biologist at the Cancer Center. “Significant research efforts are underway to both increase early detection and improve treatment options.”

A pap test screens for cervical cancer, not ovarian cancer.

Visit mCancer.org/thrive for more information on MIOCA and links to ovarian cancer resources.
In 2014, Schuler took a medical retirement in order to focus on her health and family. She set a goal to watch her youngest daughter graduate high school. She has alternated between infusion and oral chemotherapy and undergone several surgeries.

“As time went on, I realized the importance of being my own health advocate. I also try to advocate for other women with ovarian cancer. Instead of working as a nurse, I now take my nursing background and educate people about ovarian cancer,” she says.

Schuler met Pam Dahlmann, a registered nurse who established the Michigan Ovarian Cancer Alliance in 2011 after losing her mother and grandmother to ovarian cancer. The goal of MIOCA is to save women’s lives by promoting the early detection of ovarian cancer and research for better treatment outcomes. They also have support groups in four cities across Michigan.

“When my mother was diagnosed, there were no support groups. Thanks to volunteers and advocates like Janet, we now offer support to women, including Janet. She is reaping the benefits of what she’s helped create,” Dahlmann says.

Schuler co-facilitates the Teal Sisters support group at the Ann Arbor Regent Hotel and Suites, which meets the fourth Wednesday of each month at 6:30 p.m. Teal is the color of the ribbon that represents ovarian cancer. She also volunteers to educate health professionals and the general public about signs and symptoms of ovarian cancer.
Unlike many cancers, ovarian cancer does not have a screening test, such as mammography for breast cancer. Because ovarian cancer is less common and less talked about than breast cancer, research funding has lagged behind. A breast cancer diagnosis is 10 times more common than ovarian cancer.

“Hopefully research can unveil new strategies for ovarian cancer prevention and early detection so that we can improve patient outcomes,” says McLean.

“I want research for ovarian and other aggressive cancers to be as visible as breast cancer. I want to watch the mortality rates decrease as much as our pink counterparts have,” Schuler says.

Schuler attended her youngest daughter’s graduation last spring. She is planning to attend college to become a nurse. Schuler’s oldest daughter is in medical school.

“Last summer I was dealing with a chronic bowel obstruction and was not feeling hopeful. Through God’s grace and a wonderful medical team, I got past it and ended up having a great year,” she says. “Right now I’m feeling good and will stay involved with MIOCA because it’s a great way to help.”

Four common signs and symptoms of ovarian cancer:
• bloating
• pelvic or abdominal pain
• difficulty eating or feeling full quickly
• urinary symptoms (frequency, urgency)
Michele Galgoul, 66, was trying to rebuild her life after the worst economic downturn in recent history. Then she received the news of a stage 3 breast cancer diagnosis. It couldn’t have come at a worse time. She and her husband, Steve, had given up their flooring business and their dream home, and had downsized to a rental house in a new town. Though they both had new jobs, they did not have health insurance.

“Honestly, my first thought was I was going to die,” Galgoul says. “Having no insurance, I didn’t think I could be treated. I’m very strong when it comes to others, but when it comes to me, I fall apart.”

Galgoul’s two adult sons and daughter-in-law encouraged her to call the University of Michigan Comprehensive Cancer Center. Though she doubted she could be treated with no insurance or savings to pay, she went to her first appointment with oncologist Jennifer Griggs, M.D., MPH.

Two things happened: Griggs assured her the cancer was treatable and put her in contact with Veronique Mosby, LBSW, a social worker at the Cancer Center’s Patient Assistance Center, who told Galgoul there were options to pay for her treatment.

“A patient going through cancer treatment is under a tremendous amount of stress. To have the added worry of paying for cancer care, including medications to manage the side effects of treatment, is yet one more burden on them and their families. As an oncologist, I can see this burden on their faces and the weight of this worry on their shoulders,” Griggs says.

The Patient Assistance Center, located on level 1, room 1139 at the Cancer Center, provides many services in a single, convenient location to help patients dealing with barriers to health care. U-M social work resources, such as financial assistance for meals, prescription assistance, lodging, transportation and parking, are available.

“We offer assistance for just about any barrier to care that a patient might have, such as no transportation or health insurance,” Mosby says.
In Galgoul’s case, Mosby went to work helping her apply for Medicaid to pay for medical costs. She later connected her with Shades of Pink and The Pink Fund, grants that help patients in financial need. When Galgoul lost her hair from chemotherapy treatment, Mosby let her know that every patient at the Cancer Center is eligible for a complimentary wig through the PAC’s wig bank.

“Veronique was my lifesaver. She calmed me down more than anyone else ever could. I would always stop by to see her when I went for infusions at the breast center,” Galgoul says.

Patients can be connected to the PAC by their physician or anyone else on the health care team. Or anyone is welcome to walk in for an appointment. The center exists primarily for people with financial need or anyone whose financial situation has been challenged, often because of their health care situation.

“A burden is always lighter when it’s shared. Letting their cancer care team know that they are concerned about costs can help,” Griggs says. “Our patient navigators, social work colleagues, financial assistance partners and community resources are available to help patients. Open communication with us is the first way to start sharing the burdens and worries.”

Galgoul did not have an easy time during treatment, experiencing nausea, dizziness and anemia that delayed treatments. She finally had surgery—a lumpectomy and removal of 24 lymph nodes—and radiation therapy. She is hopeful her cancer was removed surgically and the chemo and radiation killed any remaining cancer cells. Her next mammogram is in several months.

With cancer treatment behind her and the economy on the rise, Galgoul and her husband purchased a new home in Farmington and enjoy spending time with their grandchildren: Logan, 6, Liliana, 5, and Liam, 4.

Aside from the support of her care team at the Cancer Center, she says her grandkids were what kept her going during the difficult financial times and when she was not feeling well. Liliana decided she liked her “Nomie” with a bald head instead of the wig and was so concerned about her chemotherapy port that she told other patrons at a restaurant about it.

“We live for our grandkids. They’re so much fun. One day Liliana threw her arms up in the air and yelled, ‘They’re back!’ My eyelashes. I hadn’t even noticed,” Galgoul says.

Visit mCancer.org/thrive for links to the Patient Assistance Center and other financial resources at the Cancer Center.
Eating Better: Anti-cancer foods can bring lifelong, positive change

BY NANCY BURKE, R.D., DANIELLE KARSIES, M.S., R.D., CSO, AND MELISSA SHANNON-HAGEN, R.D., CSO, U-M COMPREHENSIVE CANCER CENTER SYMPTOM MANAGEMENT AND SUPPORTIVE CARE PROGRAM

Cancer changes a person’s life and the shock of a diagnosis can bring feelings of losing control.

Getting the right nutrition, however, is something you can control during this difficult time. This is not to say that eating doesn’t come with challenges during cancer treatment. It can be very difficult to eat when food doesn’t taste good or if you have side effects like nausea or diarrhea.

But, most side effects are temporary and patients get to choose how to fuel their bodies. Think of food as fuel during cancer treatment. It’s going to get you through the beginning to the end of treatment.

How we choose to nourish our bodies is a way patients can gain some control back.

And, the silver lining of an anti-cancer diet is that sticking to it for the long term can reduce your risk of recurrence, as well as many other chronic diseases.

Here are tips to give your body the best chance to respond to treatment, nutritionally speaking:

1. Start by getting enough calories and protein to maintain your weight
2. This is not a time to make drastic dietary changes
3. Add fruits, vegetables, whole grains, legumes and beans to your plate
4. Avoid sugary beverages and calorie-dense junk food
5. Reduce red meat to less than 18 oz. per week

After cancer treatment, stick to the plate method, which includes on your plate:
- ¼ protein rich foods
- ¼ whole grain foods
- ½ fruits and vegetables

Treatment for any chronic disease—from cancer to heart disease to diabetes—follows similar nutritional guidelines. Sticking to these healthy eating habits puts you on the path for better health.

Call Cancer Center Nutrition Services at 877-907-0859 for an appointment with a registered dietitian.
‘VERY HIGH RISK’ OF BLOOD CLOTS IN OVARIAN CANCER PATIENTS WHO HAVE CHEMO BEFORE SURGERY

A new study sheds light on the risk of blood clots at all stages of ovarian cancer and the potential need for preventive blood thinners during pre-surgery chemotherapy.

More than 25 percent of patients undergoing chemotherapy before and after surgery for ovarian cancer develop blood clots, according to a new retrospective cohort study from researchers at the University of Michigan Comprehensive Cancer Center.

The findings were published in Obstetrics & Gynecology.

It has long been understood that patients with ovarian cancer are at a much higher risk of blood clots than the general population, but no previous studies had looked at patients who receive chemotherapy before surgery. The results were surprising — and indicate opportunities for intervention in such patients to prevent clots.

“If you asked me for a guess before we examined the data, we would have thought the number was 10 percent,” says senior author Shitanshu Uppal, M.D. “It was quite a surprise to see that what we were talking about was more than 25 percent.”

The study suggests providers should consider using prophylactic blood thinners before and after surgery to decrease the incidence of blood clots and improve outcomes.

“Historically, patients have been given blood thinners during postoperative chemotherapy, but what we’re seeing is that nearly half of those diagnosed with clots in this study were diagnosed before surgery,” says Uppal.

If a patient develops a blood clot prior to surgery, she must be on a much higher dose of blood thinner and for a much longer time, he says.

COMPREHENSIVE SEQUENCING PROGRAM SHOWS PROMISE OF PRECISION MEDICINE FOR ADVANCED CANCER

In one of the largest and most comprehensive efforts to examine the genetic and molecular landscape of advanced cancer, researchers at the University of Michigan Comprehensive Cancer Center sequenced the DNA and RNA of 500 patients with metastatic cancer. The results are published in Nature.

“This is a more comprehensive approach than most commercially available clinical sequencing programs. Our results suggest value on several levels to this more detailed approach,” says senior study author Arul Chinnaiyan, M.D., Ph.D., director of the Michigan Center for Translational Pathology.

The data reflect the first 500 patients with solid tumors to enroll in the Michigan Oncology Sequencing Program, research that began in 2010, sequencing the DNA and RNA of metastatic cancers and normal tissue to identify alterations that could help drive treatment.

The adult patients represented in the Nature paper spanned more than 30 types of cancer, with metastases in 22 organs.

Researchers found a significant increase in the number and type of mutations between patients’ metastatic cancer and primary cancer. Nearly every case of metastatic cancer had more mutations, they found. This likely reflects that metastatic cancers are more aggressive. They’ve had more time to develop additional mutations, and treatments designed to kill the cancer have caused more mutations.

“Our findings emphasize the importance of getting a fresh biopsy of the metastatic tumor,” Chinnaiyan says. “Tumors are evolving as part of metastasis and under therapy. We need to biopsy the metastatic tumors and then suggest therapies, rather than using archival tissue from the primary tumor.”

Generally, most clinical sequencing efforts focus on DNA sequencing only. While DNA sequencing reveals genetic alterations involved in metastatic cancer, researchers found RNA sequencing shed light on the underlying mechanisms that either turn on cancer-causing genes or turn off the genes meant to stop cancer. Their findings could help identify potential targets for treatment.
**When Symptoms Are Part of Your ‘New Normal’**

Cancer often creates a new normal for your life. Physical changes can occur as a result of surgery or treatment. Emotional changes may occur too, such as worry about progression or recurrence.

First, recognize your new normal and know that it is understandable to feel different.

Second, talk with your providers about what this new normal is for you. Some symptoms may last well beyond your last treatment. What symptoms would you like to address?

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<tr>
<th>Symptom</th>
<th>What you can do</th>
<th>When to consider treatment</th>
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</thead>
<tbody>
<tr>
<td>Peripheral neuropathy (Numbness, tingling, burning or weakness in the hands/fingers, feet/toes, legs)</td>
<td>If affecting your feet, see a specialist for special shoes</td>
<td>Discomfort that affects your ability to work or perform normal activities (examples: unable to hold a pen/pencil, unable to button your shirt, unable to feel the bottoms of your feet making walking difficult)</td>
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<tr>
<td>Fatigue (Tiredness)</td>
<td>Don’t over exert yourself</td>
<td>Unable to perform daily activities</td>
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<td>Rest when you're tired</td>
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<td></td>
<td>Eat and drink well</td>
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<td></td>
<td>If safe, increase your physical activity/exercising</td>
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<tr>
<td>Depression (Feelings of sadness, worthlessness, thoughts of suicide or death)</td>
<td>Discuss emotional effects with your provider</td>
<td>Unable to perform daily activities</td>
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<tr>
<td></td>
<td>See a mental health provider</td>
<td>Thoughts of suicide: CALL 911</td>
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<td></td>
<td>CALL 911 IF YOU'RE SUICIDAL</td>
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<tr>
<td>Hot flashes</td>
<td>Keep cool; dress in layers</td>
<td>Unable to perform daily activities</td>
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<td></td>
<td>Avoid caffeinated beverages and spicy foods</td>
<td>Disruptions in sleep</td>
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<td>Try relaxation techniques (deep breathing, meditation)</td>
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<td></td>
<td>Don’t smoke</td>
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<tr>
<td>Sexual health changes (Vaginal dryness, decreased libido)</td>
<td>Use vaginal lubricant</td>
<td>Affecting your well-being and personal relationships. Do not hesitate to discuss emotional and sexual effects with your provider</td>
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<tr>
<td></td>
<td>See a sexual health provider</td>
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<td></td>
<td>Visit: michmed.org/Egx34</td>
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**PHARMACISTS CORNER**

*Shawna Kraft, Pharm.D.*

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

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**Just a Phone Call Away**

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<thead>
<tr>
<th>Service</th>
<th>Phone Number</th>
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<tr>
<td>Art Therapy</td>
<td>877-907-0859</td>
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<tr>
<td>Cancer AnswerLine</td>
<td>800-865-1125</td>
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<td>Clinical Trials</td>
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<tr>
<td>Family Resource Center</td>
<td>734-647-8626</td>
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<td>Fertility Services</td>
<td>734-763-4323</td>
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<td>Financial Counseling</td>
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<td>Guided Imagery</td>
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<td>Make a Donation</td>
<td>734-764-6777</td>
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<td>Music Therapy</td>
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<td>Nutrition Services</td>
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<td>Patient Assistance Center</td>
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<td>Pharmacy</td>
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<td>PsychOncology</td>
<td>877-907-0859</td>
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<td>Smoking Cessation Counseling</td>
<td>734-998-6222</td>
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<td>Social Work</td>
<td>734-647-8901</td>
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<tr>
<td>Symptom Management and Supportive Care</td>
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**THRIVE ONLINE**

mCancer.org/thrive

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

- Information on the Michigan Ovarian Cancer Alliance
- Clinical trials looking for participants
- Links to the Cancer Center’s prostate cancer resources
- A list of Jeff Smith’s favorite self-improvement sources
- Resources available to cancer survivors: support groups and more
- A photo slideshow of the Patient Assistance Center