Stories of Survivorship
Finding your new normal after cancer treatment
Your Genes and Future Cancer Treatment

A Cancer Center study with an eye on personalized medicine

As advancements in cancer treatment occur over time, many patients are living longer, higher quality lives with metastatic disease. The problem for patients is that there is often no standard of care for their disease, or the standard of care has proven ineffective. At some point, treatment options run out.

Cancer researchers are looking for ways to understand advanced cancers in order to give patients personalized options for treatment. And, the more researchers understand individual cancerous tumors and how they change over time, the sooner new treatments can be developed.

MI-ONCOSEQ is a Cancer Center initiative where patients with metastatic or refractory cancer undergo a biopsy of their tumor so researchers can fully understand the genetic makeup of their cancer. Using advanced DNA and RNA sequencing technologies, the goal is to identify genetic mutations that may be a target for treatment. A team of experts meets regularly to discuss every patient’s results and recommends an existing treatment or a clinical trial that may work best. Since MI-ONCOSEQ launched three years ago, more than 400 adult patients and 80 pediatric patients have had their genes sequenced. Several significant discoveries have been made.

“Our is one of the few pioneering studies in this area and we hope to set the standards for the future when clinical sequencing becomes adopted as routine standard of care,” says Arul Chinnaiyan, M.D., Ph.D., director of the Michigan Center for Translational Pathology. “We have made tremendous advances in just the short time since initiating our study and we hope to make a significant impact in the treatment of cancer that will greatly benefit patients.”

Here are a few examples: Researchers discovered a new mutation in a patient with a rare cancer called solitary fibrous tumor. When they went back to examine 51 other patients with the same disease, they all had the same mutation. What does this mean for treatment? Patients with this tumor can now be diagnosed more easily, therapeutic interventions can begin earlier in the disease process and researchers can potentially develop new treatments that target this mutation.

More recently, researchers analyzed metastatic breast cancer patients who had received similar treatment and found several patients shared mutations in a specific region of a gene. After searching publicly available data in the Cancer Genome Atlas, researchers found similar mutations in patients with endometrial cancers. They determined that this mutation is an important aspect of why these cancers can become resistant to treatment. Now, researchers are conducting further studies to understand how this mutation leads to drug resistance and to identify alternate treatment options.

To learn more about MI-ONCOSEQ, call the Cancer AnswerLine at 800-865-1125 or email mi-oncoseq@umich.edu.

Cancer Center researchers are seeking interested patients with metastatic cancer or cancer that is resistant to treatment. If you think you might be a candidate, ask your physician. Each patient in the study receives genetic counseling ahead of time to talk about what type of information might be discovered through gene sequencing and how results might be used. For patients with advanced disease, participating in MI-ONCOSEQ is a way to help guide the future treatment of cancer.
Whether you’re a cancer patient in active treatment, a cancer survivor or a friend or family member of a person with cancer, flu season is upon us once again. Flu season lasts from October through May and often peaks in January and February. The Comprehensive Cancer Center receives many questions about influenza this time of year, especially about how flu can affect treatment and whether patients should get a flu vaccine.

We sat down with pharmacist Shawna Kraft, Pharm.D., from the U-M Comprehensive Cancer Center Symptom Management and Supportive Care Program to talk about what patients, survivors and loved ones need to know, common myths and tips for staying healthy this flu season.

**Q** What is influenza and what are its symptoms?

According to the Centers for Disease Control and Prevention, “Influenza (flu) is a contagious respiratory illness caused by influenza viruses. It can cause mild to severe illness.” Some people, such as people with cancer, are at higher risk of flu complications that can result in hospitalization or even death. Symptoms can include fever, cough, sore throat, body ache, headache and fatigue. Though it’s more common in children than adults, some flu patients have vomiting and diarrhea.

**Q** Should cancer patients in active treatment get a flu shot?

**YES!**

**Q** Why is getting a flu shot so important for cancer patients?

Cancer patients often have compromised immune systems and are at increased risk of complications if they do get the flu. The flu vaccine lowers the risk of death and complications from the flu.

**Q** Are there specific types of cancer patients who should NOT get a flu shot?

No, everyone should get the flu vaccine.

**Q** Is there a certain time cancer patients should receive the flu vaccine?

Preferred timing with chemotherapy is at least two weeks prior to the first treatment. If currently receiving chemotherapy, it should ideally be administered at the furthest possible time point away from treatment during a given cycle. However, timing should not prevent someone from getting a flu shot and the vaccine may be given at any time during the patient’s chemotherapy cycle.

**Q** What about cancer survivors?

Yes, cancer survivors should get vaccinated. The CDC recommends that everyone over 6 months of age receive an annual flu vaccination.

Flu shots are typically covered by insurance.
Are cancer patients more likely to get the flu than others?
We don’t know that specifically but we do know that since cancer patients have a compromised immune system, their risk is higher and the complications from flu are more likely.

What exactly is a flu vaccine?
Each year, health professionals research what strains of flu will be most common during the coming flu season. A variety of drug companies develop vaccines that cause antibodies to build up in the body, resulting in better protection against infection. There are egg-based, cell-based and recombinant (genetically made) flu vaccines. All must be developed according to regulations by the U.S. Food and Drug Administration.

What type of flu vaccines should people with cancer get?
All patients should receive vaccination with quadrivalent inactivated influenza. Patients should NOT receive vaccination with live attenuated influenza vaccine, also referred to as LAIV. This is the nasal spray version of the vaccine.

What about family members of cancer patients?
People in the same household and close contacts should be vaccinated based on CDC recommendations, preferably with an inactivated influenza vaccine. Vaccination with live attenuated influenza vaccine (LAIV) should be avoided by anyone in contact with immunosuppressed patients who are hospitalized and receiving care in a protected environment (i.e. bone marrow transplant or leukemia patients).

What about anti-viral medication such as Tamiflu and Relenza?
These medications may be appropriate for some patients who have a confirmed flu infection and are generally safe for cancer patients. Ask your doctor first.

What are some common myths about cancer and the flu shot that you’d like to debunk?
You cannot get the flu from the flu vaccine, especially the inactivated flu vaccine. The risk of death and complications from the flu is more concerning than the possibility of fever or muscle pain from the injection itself. Since flu season is often during a time of increased respiratory infections, many think they have gotten the flu without a confirmation that it is the flu from their doctor’s office. Most likely it’s a different viral infection.

What tips can you offer to prevent getting the flu?
First, get a flu shot every year. Be sure to wash your hands often. Don’t touch your eyes, nose or mouth. Do your best to stay away from other people with the flu. If you’re sick, stay home to prevent spreading the infection to other people.

How should a Cancer Center patient go about getting a flu shot?
Flu shots are available now at the Cancer Center. Talk to your cancer care team about scheduling yours.
“True courage and strength is not measured in a yoga studio or on a mat. Yoga gives you tools so when you are in the world, you can embrace life’s challenges. This requires focus, humility, strength, courage to stay balanced and being true to yourself.”

—Flora Migyanka

SHARING THE Light

A breast cancer survivor finds peace of mind to reclaim her life
Yoga had been a part of Flora Migyanka’s life for years, but after she was diagnosed with breast cancer and had a double mastectomy, yoga became her go-to therapy for relieving stress and pain.

“I was doing OK, but when I had my one-year checkup with Dr. Newman, she said, ‘You have to let go of the stress in your life because it will increase your inflammation markers.’ For her to say that to me, I knew I had to change something,” Migyanka says.

But just deciding to lower your stress level is easier said than done, especially when you’re a wife and mother of two young children and you hold a full-time job. In addition, Migyanka had issues with her arm and back, some muscle wasting in her back and some painful scar tissue. She also has lymphedema or swelling in her arm from having 11 lymph nodes removed.

Excuses aside, she took her doctor’s advice and dove back into her practice of yoga and participated in a six-week support program for cancer survivors and their partners: the FOCUS Program through the Cancer Support Community of Greater Ann Arbor. The program emphasizes improving communication, emotional support and quality of life for people with cancer and their loved one. “Being in a support group with your significant other helps you and helps grow your relationship.”

Migyanka notes, “My life is different now. It will always be different. But yoga has given me the keys to accept the situation, in being present and being able to breathe.”

She is still in occupational therapy for her arm, which she says is a constant reminder of having cancer. “It’s like the ebb and flow of life. Sometimes the pain is there and sometimes it’s not. Yoga helps me listen to my body.”

And, like many cancer survivors, the recurrence of cancer is on her mind. “I think it never goes away, but it dissipates over time,” she says.

Migyanka’s surgeon, Lisa A. Newman, M.D., director of the University of Michigan Breast Care Center, says, “Many women are haunted by fears of recurrence or of developing a new cancer. The ongoing, routine demands of daily work and personal responsibilities can actually be a welcome distraction for our patients as they move beyond the acute phases of the breast cancer diagnosis and treatment experience. It also helps if you find new distractions as well.”

She adds, “It’s essential for patients to remember that after treatment, most women will indeed continue living long, productive lives. However, patients have to reclaim their lives after completing breast cancer treatment.”

Migyanka says, “Yoga has helped to give me back my life. It’s given me peace. I feel that once you have peace, it’s almost an inner attitude that helps you to calm yourself and silence your mind. This, in turn, has diminished both the stress and the pain.”

Two years into her survivorship, Migyanka wants to help other cancer survivors. After taking a 200-hour teacher-training program and engaging in intense yoga practice of 15 hours a week, she is now a certified yoga instructor. “There’s a silver lining in my story,” she says. “I’ve been given a light that I want to share with others. I find love and peace in that. It’s really my happy place.”
COPING WITH THE FEAR OF RECURRENCE
Lisa A. Newman, M.D., says, “Patients should be aggressive about reaching out and embracing any strategy that helps them conquer the psychological baggage that might be weighing them down. For some patients, these strategies might include yoga. For others, it might be some alternative exercise regimen, or professional psychotherapy, or a hobby or social activity, or even a pet. For many survivors, being able to provide guidance to other, newly diagnosed patients can also be an effective coping strategy.”

Tips:
• Education is key. Talk with your doctor for a list of common signs of recurrence for your type of cancer. Make sure you understand the frequency and type of follow-up care you need, as well as the likelihood of recurrence given your condition.
• Talk with your friends and loved ones about your concerns.
• Find a cancer support group.
• Focus on wellness and what you can do now to stay as healthy as possible. Try to make healthy diet changes. If you are a smoker, this is a good time to quit.
• Be as physically active as you can.
• Control what you can.
• Work toward having a positive attitude.
• Take in the present moment.
• Find ways to relax and feel peaceful.

If the feelings persist or become overwhelming, ask your health care team for a referral to the PsychOncology Clinic or call 877-907-0859 and ask to speak with the PsychOncology intake coordinator.

Karen Pitton, an endometrial cancer survivor

On hearing the news from her gynecologist:
She told me they looked at the results and saw cells that were consistent with endometrial cancer. She didn’t come right out and say it. It wasn’t until later in the conversation that I said to her, “So what you’re telling me is that I have endometrial cancer?” She said yes.

On telling her family:
I called my mother the next morning and it was the hardest phone call I have ever had to make. I found myself saying the exact same thing the doctor said to me. I used the same phrases and terminology. I wondered if my mother actually knew I had cancer or if she thought it was all precautionary. She knew.

In an ideal world:
I liked that my doctor spent a lot of time on the phone with me. She called at night and I suspect she wanted to ensure she had enough time to spend on the phone. I asked questions. It was a discussion.

Instead of her saying the cells were consistent with cancer, I wanted to hear it straight out.

ONLINE EXCLUSIVE
Visit mCancer.org/thrive to share your story on breaking the news.
Diane Drago, whose husband, Bud, passed away from kidney cancer complicated by Parkinson’s Syndrome

On receiving difficult news:
I asked the oncologist if this was the beginning of the end. He replied, “No, you’re really in the middle of the end and you need to prepare.” Not everyone wants to hear it, but I did.

We had a final meeting with the oncologist, neurologist, rehab team and social worker. Everyone knew why we were there, but the elephant in the room remained. It was clear my husband was waiting for someone to say it.

Finally, his oncologist paused and quietly said, “Bud, we just don’t have the tools to fix what’s wrong with you. I’m sorry.” My husband visibly relaxed. He had permission to stop fighting and was finally at peace.

Upon reflection:
The oncologist and Bud established a great bond quickly. Their communication was straightforward and thorough from the start — exactly what he needed. Even the processes of chemo preparation and resulting wait time were explained at the outset.

When I hear other people’s stories, I’m often saddened. Not everyone is fortunate to have the kind of care team we did.

Alon Weizer, M.D., a urologist and medical director of the U-M Comprehensive Cancer Center

On delivering the news:
Delivery of the news of a cancer diagnosis is never easy. It is also not a skill set that is taught in medical school. I believe it is critical to get to know the patient both from a medical and personal standpoint. I assess a patient’s understanding of the current circumstance. It is important I do my homework before having the conversation so I can tell them about the disease and what options are available to them.

What you’ve learned:
When I let emotion rise to the top of the discussion, I failed to give my patient the information needed to make a good decision.

I like to discuss the treatment options available based on the facts. Broad discussions around treatment options are not helpful because we could be having discussions about treatment choices that are not appropriate based on the stage and grade of the cancer.

Speculation should never be part of the conversation.

The best scenario:
I must be prepared to discuss the specifics of the cancer, the need for additional diagnostic tests, the treatment and who will be responsible for the aspects of treatment.

It is very helpful when patients come with a list of questions and a person who can be a second set of ears that they trust.
Diagnosis First,

Education to help Cancer Center patients manage home-related treatment

You just learned that you have cancer and need to begin chemotherapy as soon as possible. The idea of being sick is overwhelming. For the first time, you question your mortality. Just as you begin to think about how you’re going to tell your family, you realize the doctor is saying something about a chemotherapy pump you’ll wear at home. Paying attention would be great, but your mind is racing. Thankfully, you hear the doctor say they’re sending you to a Cancer Center clinic where skilled nurses will teach you everything you need to know.
FACING SIDE EFFECTS | Diagnosis First, Treatment Next

Treatment Next

To ensure that Cancer Center patients are informed and prepared for home-related treatment, the Cancer Center Education Clinic houses five nurse educators who meet with patients one-on-one to discuss treatment plans and any home care that’s required. The nurse educators give patients thorough training to be confident and able to perform any and all tasks required to ensure successful treatment.

Nursing supervisor Marie Richards, R.N., B.S.N., explains that getting a cancer diagnosis and understanding treatment are two very different things.

“It’s a separate kind of coping,” Richards says. “Patients are overwhelmed during their physician appointment when they hear they have cancer and need treatment. We offer a quiet, patient-friendly place for them to learn how to actually manage their treatment.”

As cancer care advances and more treatment options become available, many cancer patients are finding themselves responsible for managing some aspect of their care from home. This can be overwhelming, whether it involves wearing a home chemotherapy pump, giving yourself an injection or keeping a catheter or pick line clean. In some cases, patients begin treatment immediately following diagnosis, before they have time to process the information or think of questions to ask.

The Cancer Center Education Clinic counsels patients on everything from continuous infusion pumps, caring for a chemo port, flushing a catheter, self-injections, how to read a glucometer, caring for wounds, education on fertility issues and more. In addition to education and training, the Education Clinic can assess other patient needs and make referrals to social work or the Practical Assistance Center for dealing with issues like childcare, paying for gas and other common concerns.

“When you’re new to chemo, a patient is scheduled in the Cancer Center Education Clinic,” Richards says. “We also see patients who have gone through a change in treatment. We try to capture every patient with something new to learn.”

Patients receive written materials specific to their treatment, as well as guidance to handle questions and issues that arise.

“A lot of our job is helping people manage the anxiety associated with their treatment,” Richards says. “We give them tools to manage their biggest fears, especially who to call if something happens late at night or outside of regular business hours.”

The five nurse educators at the Education Clinic aim to be a valuable source of information for patients and a positive contact whom patients can call with questions.

“When you tell a patient they’re going to go home on a pump, they’re often very scared,” says Louise Rushlow, R.N., one of the Education Clinic nurses. “Patients are apprehensive. We’re there to help reassure.”

The Cancer Center Education Clinic is housed alongside other symptom management programs and resources to help patients through the emotional aspect of cancer and treatment. Another perk is that its nurses can help connect patients with clinical trials.

For more information on the Cancer Center Education Clinic, call 877-907-0859.
Laws of Survivorship

One patient’s story of recovery after prostate cancer
Even though he’s a Michigan Law graduate, George Campbell’s path to the University of Michigan for health care was somewhat circuitous.

When the East Lansing resident started having prostate trouble several years ago, he went to see an area physician. Campbell says, “The doctor told me, ‘This is a problem of old men. Don’t worry about it.’ He didn’t operate on men over 75. I was 73.”

But Campbell’s problem worsened, prompting him to travel out of state to visit a prominent national hospital. That doctor recommended “aggressive observation” and referred him to someone closer to home: the Comprehensive Cancer Center’s John Wei, M.D., who specializes in prostate cancer detection.

“Luckily, Dr. Wei had a new way of doing a biopsy. When the results came back, he said, ‘You should deal with this promptly instead of just watching it.’”

U-M surgeon John Hollingsworth, M.D., performed a radical prostatectomy to remove all of the prostate gland. “The first day after surgery, I felt like a truck had run over me, but I could see the benefits quickly. Before that, I had to use catheters to urinate,” Campbell says.

Like most prostate cancer survivors, Campbell had to deal with the side effects of incontinence and erectile dysfunction (ED). Fortunately, he had help.

“At U-M, after the operation they don’t just tell you to go home,” he says. “They’re there with you for support. With information. They let you know when something is to be expected or is a symptom of something else. It helps to talk with someone who knows what they’re talking about.”

For Campbell and his wife, Paula, that someone was Daniela A. Wittmann, Ph.D., a social worker and certified sex therapist, who specializes in the area of sexual recovery after chronic illness, with particular emphasis on prostate cancer.

“Dr. Wittmann made a big difference in my recovery,” Campbell says. “She let me know that yes, life is no longer ‘normal,’ and that you just have to realize things will be different for a while. My wife came to like the meetings with her and now says they’ve been very beneficial.”

Wittmann says, “Many urologic cancer treatments have short- and long-term side effects. Common issues such as urinary, bowel, sexual health and emotional health can affect anyone, and probably all people struggle with at least one of these to some degree. That is why survivorship support is important. It’s also important to include the caregiver and partner who has a special role in the patient’s recovery.”

Today, Campbell is cancer-free and still working at his law practice, but is making more time for golf and other activities he thought he’d enjoy in retirement. He is enjoying life: as a husband, a father, a grandfather to five and a part-time lawyer.

“I want men to know that it really does get better. Mostly, I live life as I did before the diagnosis and the operation.”

—George Campbell
Campbell says that he will continue to have the prostate specific antigen (PSA) test at his annual physicals. “And I still follow the exercises my physical therapist taught me, and which the doctor said I’ll have to do for the rest of my life.

“The way I look at it, the problems are not major. The side effects have decreased. Right now, they can be worked around and lived with, and I have hope that the problems will go away altogether.”

Campbell says it also helps him to be of help to others. “I belong to a coffee group of old lawyers,” he says. “We meet on a regular basis, and at least two of the men have had operations since I had mine. It was great to be able to talk with them, to let them know my experiences and to share with them that it will indeed get better with time.

“I want men to know that things really do get better — and they get better fairly rapidly. Don’t get discouraged.

“Mostly, I live life as I did before the diagnosis and the operation.”

SURVIVOR RESOURCES
U-M has several resources for cancer survivors who are having trouble with incontinence or sexual functioning:

U-M Center for Sexual Health
The center is geared toward anyone having sexual difficulties, including people who have experienced illness or a medical treatment. Call 734-763-4963 to make an appointment.

U-M Sexual Recovery Clinic
The clinic specializes in patients who have had breast or genitourinary cancers (prostate and bladder) or who have had chemotherapy. Call 734-647-8903 to make an appointment.
U-M RESEARCHERS FIND PROTEIN THAT FUELS REPAIR OF TREATMENT-RESISTANT CANCER CELLS

Imagine you’re fighting for your life but no matter how hard you hit, your opponent won’t go down.

The same can be said of highly treatment-resistant cancers, such as head and neck cancer. Now, University of Michigan researchers have found that a particular protein — TRIP13 — encourages those cancer cells to repair themselves. And, they have identified an existing chemical that blocks this mechanism for cell repair.

“This is a very significant advance, because identifying the function of the protein that fuels the repair of cancer cells and having an existing chemical that blocks this process, could speed the process of moving to clinical trials,” said principal investigator Nisha D’Silva, U-M professor of dentistry and associate professor of pathology.

If cell DNA is damaged and the cell cannot repair the damage, the cell dies. In head and neck cancers, D’Silva and colleagues showed that cancer cells that overexpress TRIP13 were able to repair their DNA enough to survive and continue to grow as cancer.

“Targeting this repair mechanism with specific drugs could increase effectiveness of treatment and improve survival of cancer patients,” D’Silva said. “And given the overexpression of TRIP13 in several treatment-resistant cancers, this strategy will likely be important for multiple cancers.”
The media is ripe with new ways to prevent cancer through “super” foods, but often these recommendations are based on a single promising study and lack sufficient evidence to support the claims with confidence. A recent article in the *Journal of the American College of Nutrition* released diet recommendations for the prevention of cancer based on a review of many studies.

**FOODS TO INCLUDE**

1. Fruits and vegetables: Strive for at least five servings of colorful fruits and vegetables daily to reduce cancer risk.
2. Whole soy products: These include soymilk, tofu, tempeh and edamame. If you have a history of prostate or breast cancer, consider adding soy foods to your diet.

**FOODS TO LIMIT OR AVOID**

1. Alcohol: Even a small amount has been associated with increased risk of certain cancers. Avoidance is recommended.
2. Red and processed meats: This includes all beef, lamb and pork products, as well as processed meats, including bacon, sausage, ham and lunchmeat. Limit red meat to 18 ounces per week. Avoid processed meats.
3. Grilled, fried and broiled meats: These high-heat cooking methods cause red meat, poultry, game and fish to produce cancer-causing compounds, especially meats that are high in fat. Limit cooking time, keep temperatures low and cook only low-fat meats.

While no one food can cure or cause cancer, experts agree that each meal and snack should be focused on plant foods, which include a variety of vegetables, fruits, whole grains, whole soy foods, beans and nuts.