

thrive

THE ENGAGED PATIENT

10 things you can do to take
charge of your medical care



thrive

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For more information about the stories in *Thrive* or any other cancer-related information, please call the Cancer Answer Line at 800-865-1125.

On the cover: Rosemary Ireland Black knew something was wrong, but was shocked to discover she had pancreatic cancer. She pushed to get the medical attention she needed and is now cancer free.



A new kind of support

U-M Cancer Center develops program with Cancer Support Community to help patients and caregivers cope

For 44 years of marriage, Karen and Larry Ganzini have balanced each other. Karen is a talker; Larry is quiet. Larry isn't keen to show his soft side; Karen feels worse when she bottles up emotions.

Nearly 10 years ago, Karen was diagnosed with breast cancer. Although Karen says that cancer almost feels like second nature now, issues due to the couple's differing communication styles have cropped up as the disease has progressed to stage IV. Karen and Larry support each other, but it was still difficult to talk about certain aspects of Karen's cancer.

When Karen learned about a new pilot program to help patients and their caregivers cope better, the Ganzinis signed up. The program was offered by the Ann Arbor branch of the Cancer Support Community, a non-profit organization dedicated to providing education and support to people with cancer.

"I asked the question about hospice, and my husband really didn't want to go there at this point. He doesn't like to talk about the end, and I understand that," Karen said. "But I need to know what it's going to be like."

By enrolling in the pilot program, Karen got her answers, and both Ganzinis agreed that the experience helped them feel better about their situation. The program, called FOCUS, is based on University of Michigan Comprehensive Cancer Center research that has shown that patients and caregivers benefitted from meeting with a nurse to provide them with information and support.

"In our earlier studies, we found that caregivers often received more benefits from the program than patients, possibly in part because caregiver needs are not typically addressed in traditional clinic settings," said Laurel Northouse, Ph.D., R.N., co-director of Socio-Behavioral Research at the U-M Cancer Center. Caregivers reported better mental and physical quality of life, less negative views of caregiving and more active

copied strategies. Both patients and caregivers reported better communication and less uncertainty about cancer.


In order to offer the program in a community setting, it has evolved to become a series of group meetings facilitated by a social worker, Northouse said.

"This is an important step to move the FOCUS program forward so that more people can benefit from it," Northouse said. "It doesn't help anyone if the results of our research just get filed away. It's really wonderful to be able to collaborate with the Cancer Support Community to implement this program."

Three or four pairs of patients and caregivers meet together in weekly two-hour group sessions for six weeks, said Bonnie Dockham, L.M.S.W., a social worker for the Cancer Support Community who is leading the pilot program. Topics of discussion include communication and coping tools, strategies for handling uncertainty, and practical concerns, such as symptom management. All

participants complete surveys at the beginning, end and one month after the program to assess its impact.

If the pilot program, which is funded by the Rosalynn Carter Institute for Caregiving, is beneficial, the FOCUS program may be disseminated throughout the Cancer Support Community's 50 affiliates and 100 satellite locations nationwide.

"The program is for people who are coping well with cancer, in addition to those who may want to learn new strategies for dealing with their cancer-related stress. We try to create a middle ground for dealing with the cancer together, as a team," Dockham said. "We talk about taking this team approach, because cancer affects the whole family." 



Patients and caregivers facing any type of cancer are eligible to participate. To learn more, visit mCancer.org/thrive or call 734-975-2500.



Karen and Larry Ganzini said the FOCUS program helped them both to cope better with the uncertainties of cancer.



DEMANDING BETTER

U-M Breast Cancer Advisory & Advocacy Committee members work to improve care for future survivors

Every October, the world glows pink with Breast Cancer Awareness Month. That pink is as synonymous with breast cancer as orange is with Halloween wouldn't have been possible without the tireless advocacy of breast cancer survivors.

Each year, millions turn out to support efforts to put an end to breast cancer. We talked with Ruth Freedman and Maria Lyzen, co-chairs of the University of Michigan Comprehensive Cancer Center's Breast Cancer Advisory and Advocacy Committee, to find out what can be learned from the power of the pink ribbon movement.

Q: LET'S START BY TALKING ABOUT WHAT KIND OF WORK THE BREAST CANCER ADVISORY AND ADVOCACY COMMITTEE DOES.

MARIA: The committee was formed to provide input to University of Michigan researchers as they design new studies. Our goal is to represent the patients' point of view: How can we make it easier for



Maria Lyzen, left, and Ruth Freedman lead the U-M Comprehensive Cancer Center's Breast Cancer Advisory and Advocacy Committee.

patients to participate in a clinical trial? Could a researcher consider reducing the number of scans required for a study so that a patient would only have to travel to the Cancer Center three times instead of four times?

RUTH: We see our role as working on projects to improve breast cancer care as a whole. For example, we learned from an excellent U-M occupational therapist that many insurance companies don't provide adequate coverage for treatment of lymphedema, a common side effect of breast cancer surgery that causes painful swelling in the arms. We worked with this occupational therapist to gather scientific evidence to show that certain interventions to treat this condition should be covered by insurance. We convinced the University of Michigan to include this coverage for its employees—both going forward and retroactively. We hope that this will become a model for other insurance programs.

Q: BREAST CANCER SURVIVORS, IN GENERAL, SEEM TO BE LEADING THE CHARGE IN TERMS OF ADVOCACY. WHY DO YOU THINK THAT IS?

RUTH: We're all assertive women and not afraid to speak up about issues that are important to us. We owe a lot to the founders of the National Breast Cancer Coalition (NBCC), a grassroots organization formed 20 years ago to raise awareness, provide scientific and advocacy education for the lay person, lobby for increased research funding and participate in scientific and regulatory decisions impacting breast cancer survivors.

MARIA: Also, women are often the pillars

of their families. Sometimes we've seen that women with breast cancer don't get the support they need from spouses or children, so women have bonded to form a support network to help other women.

Q: SO YOU THINK THAT BREAST CANCER ADVOCACY IS UNIQUE IN SOME WAYS BECAUSE OF ITS SPECIFIC IMPACT ON WOMEN?

RUTH: I think it's part of our acculturation as women to be caretakers, to be nurturing. We do this for ourselves, our daughters and our sisters. I really do think we need to give credit to the NBCC, though, as they've really helped to politicize women and empower them to be assertive.

Q: WHY DID YOU PERSONALLY BECOME INVOLVED IN ADVOCACY?


MARIA: After working in public health as a nurse, I was startled to find that the same two drugs I'd seen administered for breast cancer when I was a student in 1964 were the same two drugs I received when I was diagnosed in 2001. There has been some progress, but why hasn't there been more? I also watched as younger women were diagnosed with breast cancer. They had to take two years out of their lives for treatment, which was often devastating to their family lives and their financial stability. I wanted to get involved to help draw attention to this important problem.

RUTH: For me, I come from a very political background. It's in my roots. I believe in community organizing. When I learned about breast cancer advocacy, it seemed natural to put my energy behind it.

Q: WHAT DO YOU THINK SURVIVORS GAIN FROM IT?

MARIA: For me, it's about being of service to others. At first, I didn't want to think about breast cancer after I had finished treatment. But after I was healed and well enough, the question of how I could be of service to others kept bubbling up. I was never taught to lead or be an advocate, but this became my passion.

Q: WHAT DO YOU NEED TO KNOW TO BECOME AN ADVOCATE? HOW CAN YOU EDUCATE YOURSELF?

RUTH: Breast cancer survivors are welcome to join our committee. We also recommend educational opportunities offered by the National Breast Cancer Coalition's Project LEAD course, which provides scientific and advocacy background information. The National Coalition for Cancer Survivorship also offers advocacy training for people with interest in other cancer types. Also, talk to your doctor, as we have found that faculty members are often interested in partnering with patients to advance research. Empowering yourself to become an assertive, knowledgeable patient can only help to further the cause. 



To learn more about advocacy in general, the Breast Cancer Advisory and Advocacy Committee, or the U-M Head and Neck Cancer Patient Advocacy Group, please visit mCancer.org/thrive.



The engaged

10 things you can do to take charge of your medical care

Rosemary Ireland Black insisted on a CT scan that ultimately led to an early, lifesaving diagnosis of pancreatic cancer.

The culture of medicine has changed: Gone are the days when doctors dispensed treatment with a paternalistic air. As medicine has advanced, patients have more choices about how they can approach their care. Combined with the vast amount of health information available on the Internet, patients are educating themselves and partnering with their physicians to make informed medical decisions.

Consider Rosemary Ireland Black's story. She's a tall, willowy woman, but her stomach suddenly started to bloat. She went to the doctor twice, and he said nothing was wrong. So she went back a third time and demanded a CT scan.

"He said, 'What for?'" Ireland Black said, recalling her doctor's skepticism. "And I looked at him and said, 'Because I want one.'"

The scan revealed a suspicious spot on her pancreas, so her doctor referred her to a surgeon in metro Detroit. During an appointment with the surgeon, Ireland Black's husband noticed the word "malignant" on one of his wife's medical reports. Until this moment, the couple hadn't realized they were dealing with pancreatic cancer.

The couple was in shock, but they knew this wasn't the right surgeon for Ireland Black. Ireland Black called a friend who is a doctor for advice. Her friend helped her research her condition

patient

and find a physician who is a leading expert on pancreatic cancer: Diane Simeone, M.D., a University of Michigan Comprehensive Cancer Center surgeon.

Simeone explained two surgical options to Ireland Black. After reading up on both procedures, Ireland Black said, she opted for a surgery that removed 45 percent of her pancreas as well as her spleen. Three years after facing one of the deadliest forms of cancer, no trace of the disease remains.

"Sometimes you just know when something isn't right. Do not let your doctors dismiss you," Ireland Black said. "I still go to my original doctor, but he's on the ball now. He actually thanks me for being my own advocate."

This shift toward becoming your own medical advocate has come to be known as the "e-patient movement," said Alexandra Sarkozy, the librarian who leads the U-M Cancer Center's Patient Education Resource Center. The term "e-patient" describes people who are "equipped, enabled, empowered and engaged in their



“The e-patient movement is not only helping to empower patients to be more active partners in their care, but offering them emotional support as they connect with other patients who have similar experiences.”


—Alexandra Sarkozy, Patient Education Resource Center librarian



Alexandra Sarkozy, a librarian who leads the Patient Education Resource Center, helps patients find quality information to make better choices about cancer care.

health and health-care decisions,” according to “E-patients: How They Can Help Us Heal Health Care,” a white paper by Tom Ferguson, M.D., and the e-Patient Scholars Working Group that serves as a blueprint of sorts for the movement.

The web is teeming with resources for e-patients: online support groups, forums, blogs and non-profit foundations have posted massive amounts of information for people who would like to become more assertive medical consumers.

“Cancer treatment is often difficult and requires big lifestyle changes,” Sarkozy said. “The e-patient movement is not only helping to empower patients to be more active partners in their care, but offering them emotional support as they connect with other patients who have similar experiences.” 



Call the Patient Education Resource Center at 734-647-8626 to research your condition or to receive a free patient tool-kit. Or visit the PERC on Level B-1 of the Cancer Center.

We’ve offered a few tips here to help you start thinking like an e-patient, but be sure to visit mCancer.org/thrive for a wide range of online resources.

- | | |
|--|---|
| <p>1 Assume responsibility. Think about the last car you bought. You didn’t hand that decision over to the salesman, did you? Only you know what medical choices are right for you. It’s up to you to get the information you need so that you can get the care you need.</p> | <p>6 Seek support. Patients often learn from other patients. Consider joining an online support group or forum, such as those hosted by the Association of Cancer Online Resources (www.acor.org), to glean information from others with similar experiences. Keep in mind that every person is not the same, though, and that any recommendations should be vetted by your health-care team before you pursue them.</p> |
| <p>2 Communicate with your health-care team. Your doctor may be the expert on treating cancer, but you’re the expert on how you feel. Speak up and be honest if things aren’t feeling right. Become comfortable with asking questions. Consider taking notes so you can go over them again later.</p> | <p>7 Be prepared. Make lists of questions before your appointments. If you read about a particular study that you think is relevant to your care, print it out and bring it with you.</p> |
| <p>3 Don’t be afraid to ask for second opinions. All too often, people are worried about offending their doctors. Don’t be. This is a routine part of medical care, and you have every right to get the information you need before making a medical decision.</p> | <p>8 Keep a patient tool kit. Keep all medical records and notes in a single, organized folder. The U-M Cancer Center provides every new patient with a filing box that features helpful information for navigating your care. In addition, consider keeping a diary to track how you are feeling.</p> |
| <p>4 Educate yourself. Learning about your condition can help you have better discussions with your doctors. Sifting through the vast amount of information online can be difficult—particularly since some online information isn’t credible—so consider visiting the Cancer Center’s Patient Education Resource Center. The staff can help you find the information you need.</p> | <p>9 Find your inner mama lion. Many of the best patient advocates are mothers. They will find a way to do what needs to be done for their children. Adopt a similar attitude about your own care.</p> |
| <p>5 Learn about clinical trials. Participating in a research study may be the right choice for some people with cancer. The U-M Cancer Center offers many opportunities. Talk to your doctor or visit UMClinicalStudies.org/cancer to find out more.</p> | <p>10 Enlist help. As much as you may want to be your own advocate, it can be difficult—particularly if you’re just not feeling up to it. Ask a trusted family member or friend to attend appointments with you and help you fill this role.</p> |

Handling the logistics

Practical Assistance Center offers patients practical resources





“ I came away with the feeling that U-M really cares.”

—Judy Mackey

Judy Mackey worked with the Practical Assistance Center to connect with a program that would help her to afford Gleevec—a drug that costs \$5,100 per month.

Judy Mackey was already reeling from the news that she would have to take Gleevec every day for the rest of her life to keep gastrointestinal cancer at bay. But the news only got worse.

The pharmacist told her she had fallen into the notorious Medicare Part D doughnut hole, effectively leaving her without any prescription insurance. When Mackey learned that Gleevec costs \$5,100 per month, she was devastated.

The pharmacist recommended she go to the Practical Assistance Center, a new office on Level 1 of the University of Michigan Comprehensive Cancer Center, to find out whether she was eligible for financial assistance with her prescriptions. It was nearly 5 p.m. on a Friday, so Mackey didn't think she'd get help that day. But she was

surprised to find that social work assistant Maureen Marhofer, L.L.B.S.W., was not only willing to stay late to work through all of her questions, but was able to fax an application for financial assistance to Gleevec's manufacturer, Novartis.

By Tuesday, Mackey had learned she was eligible for a free supply of Gleevec.

“When you're facing this kind of diagnosis, you begin to feel like there's no answer to any of these problems. They become so overwhelming that you can't see through them to even think. Maureen did the thinking for me,” Mackey said. “I came away with the feeling that U-M really cares.”

In partnership with the U-M Health System's Guest Assistance Program and Cancer Center Business Services, the

Practical Assistance Center can help patients navigate the often complex logistics involved in cancer care, said Dana Selwitz-Zacks, L.M.S.W., program manager for practical assistance and guest amenities.

The Practical Assistance Center brings together several services in a single, convenient location within the Cancer Center. U-M social work resources, such as financial assistance for meals, lodging, transportation and parking, are available. The center handles questions about billing and works closely with the patient financial counselors.

In addition, Sarita Castro, a social services technician for the center, is dedicated to helping patients find community resources that may be useful. Castro also helps patients cut through red tape by helping to complete aid applications and acting as a

“We want to relieve any stress that we can to help patients and families focus on getting well.”

—Maureen Marhofer,
U-M social work assistant



Maureen Marhofer, Dana Selwitz-Zacks and Sarita Castro (from left) work with patients in the Practical Assistance Center.

liaison to clinics to help expedite the process.

“We found that, especially in the changing economy, more and more patients need assistance, and clinicians are devoting a lot of time to this,” Selwitz-Zacks said. “We figured that centralizing these services—as well as offering services that go above and beyond—would be helpful.”

Patients often are referred to the Practical Assistance Center by their health-care teams, but walk-ins are encouraged. Typically, patients meet with Marhofer, who conducts a brief assessment by asking questions. Marhofer can help determine what resources may be available based on a patient’s financial situation.

Often, patients don’t know about programs for which they are already eligible. For example, Marhofer said, many


patients are not aware that discounted drugs may be available or that Medicaid provides a transportation benefit.

“We want to relieve any stress that we can to help patients and families focus on getting well,” Marhofer said. “We try to eliminate any barriers to care.”

If a patient is not eligible for U-M programs, Practical Assistance Center staff can search a list of external resources that may be helpful. Many of these resources are specific to certain types of cancer. Other assistance may be more general, but no less important: For example, during the height of summer, Castro helped a patient find an air conditioner through the Salvation Army.

By providing a one-stop resource for practical assistance, the Cancer Center is freeing up more time for clinic social workers

to address patients’ emotional needs.

“These practical things really can be time-consuming,” Castro said. “That’s why we’re here to help.” 



To learn more about the Practical Assistance Center, visit mCancer.org/thrive or call 877-907-0859. Or just stop by the center, which is located on Level 1 of the Cancer Center.

A helping hand

Taking control of eating problems with tube feeding

By Nancy Burke, R.D.; Joan Daniels, R.D.; and Danielle Karsies, M.S., R.D.

Think of any celebration, and the first thing that probably comes to mind is food. The aroma, taste and texture of food give us pleasure and satisfaction—but cancer and its treatment can temporarily interfere with our ability to enjoy it.

Some people with cancer may experience loss of appetite or taste. Others may not be able to eat because of a blockage or pain when swallowing. No one wants to give up eating, but when it becomes more of a hindrance or a burden, a feeding tube may offer relief. In fact, we've found that many people who opt for tube-feeding say that they wished they had done so sooner, as they feel better overall, more energetic and less burdened by not having to force themselves to eat.

Tube-feeding should not be thought of as defeat or failure; it's a temporary way to help you regain control. It can be a shortcut to getting the food, fluid and medications your body needs. Tube-feeding may reduce the need for hydration infusions and decrease the number of pills you need to take if medications can be administered via the feeding tube.

If you are losing weight rapidly, don't put off having a feeding tube placed. Waiting until you have lost a significant amount of weight only leads to possible postponed treatments and longer recovery time. Be proactive and ask your doctor if a feeding tube is right for you. A registered dietitian will develop a nutrition prescription for the type and amount of formula that is needed to meet your nutrition goals and promote optimal nutrition status.

Having a feeding tube placed should not hinder you from living your normal life.

You can continue to participate in your favorite hobbies and activities. Also, if it's pleasurable and medically feasible, you can supplement your nutrition by eating while on tube-feedings.

Feedings can be given many different ways: Some people use feeding tubes at regular meal times to maintain family routines; others use a portable feeding pump that they carry in a backpack to provide gradual feedings in 24-hour increments.

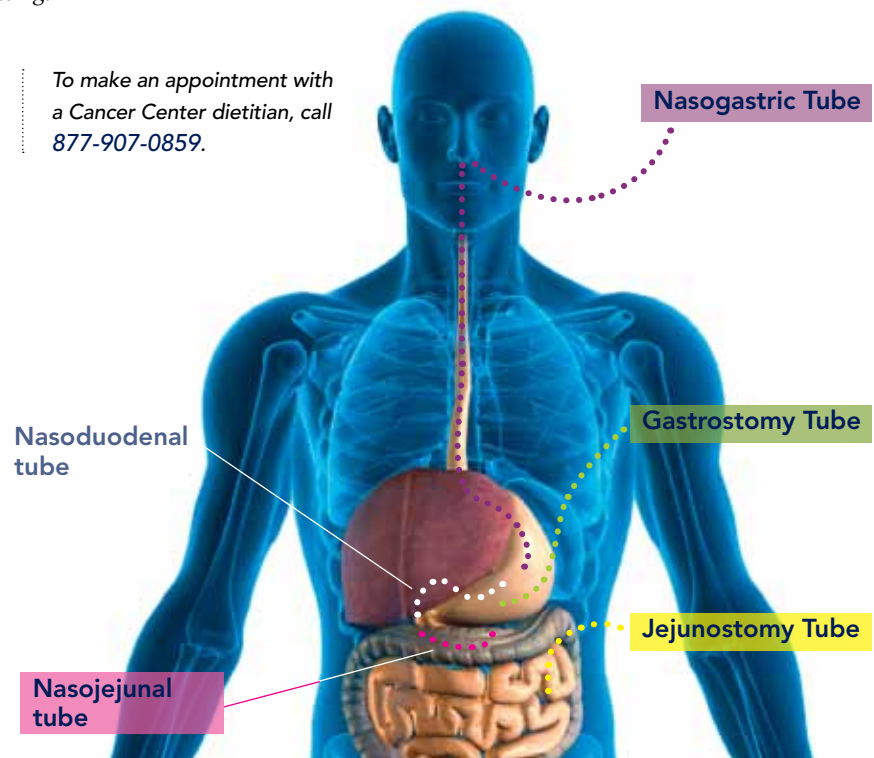
Maintaining good nutrition is essential to maintaining overall strength and well-being, and to minimizing recovery time. Tube-feeding can help you focus on the things you love, rather than worries about eating. **i**

OPTIONS

TYPES OF FEEDING TUBES: A nasogastric tube or a "dohhoff tube" is a small, thin tube that is inserted through the nose and down into the stomach or small intestine. A gastrostomy (or "PEG") tube or a jejunostomy (or "J") tube is placed surgically and is often used when feedings are going to be required for two months or more. All these tubes are temporary and are removed when they are no longer needed.



To make an appointment with a Cancer Center dietitian, call 877-907-0859.

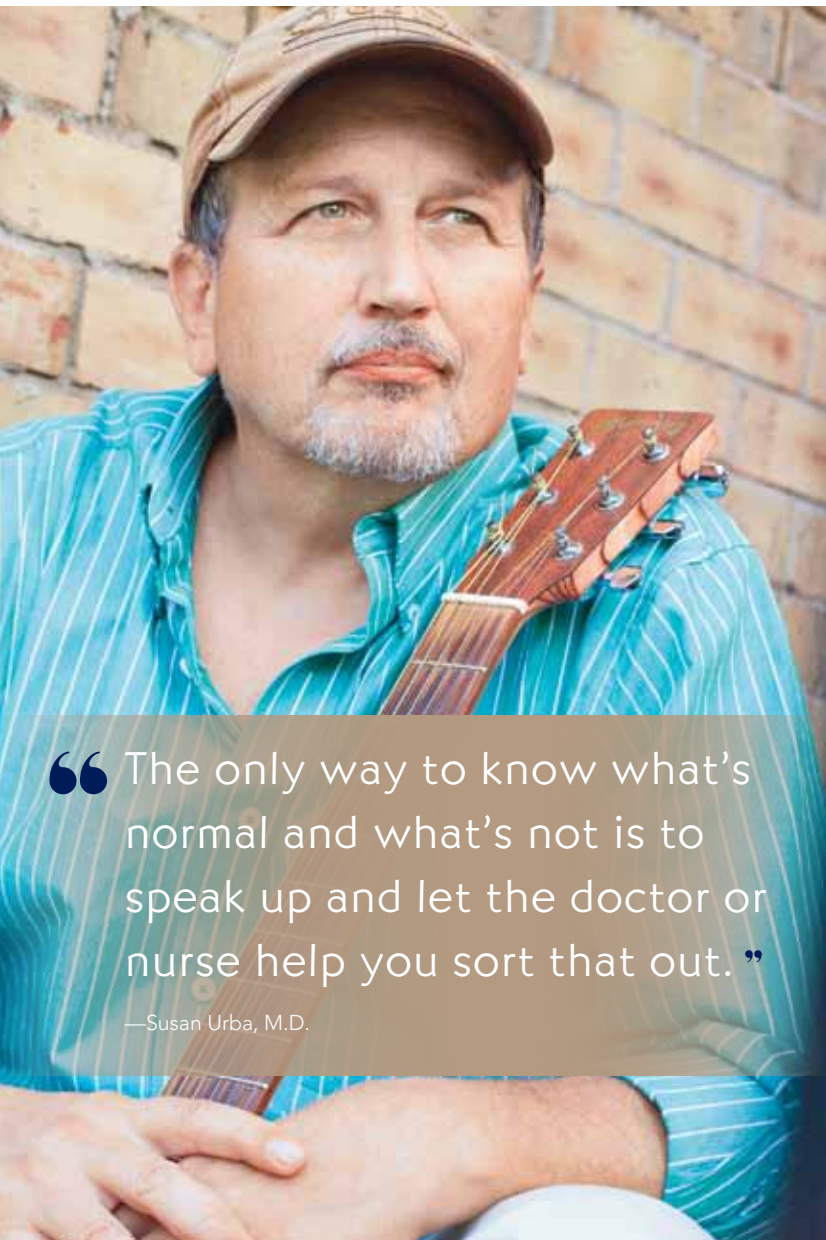




Larry Stone is back to playing the guitar after the U-M Symptom Management & Supportive Care Clinic helped him find relief from pain and numbness.

When to ask for help

Talking about symptoms is first step in treating them



“The only way to know what’s normal and what’s not is to speak up and let the doctor or nurse help you sort that out.”

—Susan Urba, M.D.

Larry Stone joined a clinical trial in fall 2009 to test a medication that offered the possibility of prolonging the effectiveness of the hormone therapy he was taking to stave off prostate cancer.

When he started to experience mild numbness in his hands and feet later that spring, he didn’t think too much about it. But by June, pain and swelling sent him to the hospital overnight.

His hospital stay relieved his pain somewhat, but it prompted him to ask his oncology team a question: “Is there a specialist I can see?”

That simple question triggered a referral to the University of Michigan Comprehensive Cancer Center’s Symptom Management and Supportive Care Clinic. Stone met with Susan Urba, M.D., and Suzette Walker, F.N.P.-A.O.C.N.P.—the clinic’s leaders—as well as

pharmacist Emily Mackler, Pharm.D. Together, the team mapped out a program to reduce Stone’s discomfort.

“That was the start of a great relationship,” Stone said.

All too often, people who live with cancer suffer with symptoms that could be eased with aggressive management, Urba said. The reasons for this vary.

Some people are naturally inclined to downplay how sick they are feeling, particularly in front of family members whom they’re trying to protect emotionally, Urba said. Other times, patients downplay new symptoms because they are afraid it means the cancer has returned or is growing. Some patients may fear that reporting symptoms will delay treatment.

And in some cases, the reason may be even plainer: People don’t realize there are options to ease their symptoms.

“The only way to know what’s normal and what’s not is to speak up and let the doctor or nurse help you sort that out,” Urba said. “A recent study showed that people didn’t tell their doctors that they were experiencing fatigue. They thought there wasn’t much that could be done about it, so why bring it up? But, in fact, there are options for treating fatigue.”


For some symptoms, many interventions exist, but it may take time to figure out which one works best for the individual. For example, with fatigue, altering medications may be helpful in some situations, while working with a physical therapist or taking a gentle yoga class may work for others. Clinicians who work with the Symptom Management and Supportive Care Program specialize in helping patients find the right solutions for them.

Patients should always discuss all symptoms with their oncology team first. But it can often be difficult to address numerous symptoms during a routine visit to the oncologist, since there’s already a lot to discuss regarding the cancer and its treatment. One of the benefits of visiting the Symptom Management and Supportive Care Clinic is having dedicated time to sort through the often complex issues surrounding symptoms, Walker said.

“Many physicians are glad to collaborate with us in managing patients’ symptoms, particularly if the symptom is resistant to initial interventions,” Walker said. “Sometimes, they may not realize how badly a patient is feeling.”

In addition, the clinic partners with other subspecialties that can help manage symptoms, such as the Pain Clinic and Physical Therapy. This means the team can cut through red tape to get a consultation scheduled immediately.

For Stone, visiting the Symptom Management and Supportive Care Clinic has helped him regain the use of his hands. He’s back to his longtime passion—playing the guitar.

“Dr. Urba and Suzette and Emily are very attentive to detail as well as conscientious and caring,” Stone said. “I’m so glad I got that referral.” 



To make an appointment for symptom management, call 877-907-0859.



U-M STUDY: MEN HAVE OVERLY OPTIMISTIC EXPECTATIONS ABOUT RECOVERY FROM PROSTATE CANCER SURGERY

Nearly half of men undergoing surgery for prostate cancer expect better recovery from the side effects of the surgery than they actually attain one year after the operation, a University of Michigan Comprehensive Cancer Center study finds.

In addition, prior to surgery, a small proportion of men had expected to have better urinary continence and sexual function a year after the surgery than they had before it—the opposite of what typically happens.

“This is a belief that does not reflect preoperative counseling, which, on the contrary, alerts men to urinary and sexual problems after surgery,” says study author Daniela Wittmann, M.S.W, sexual health coordinator at the U-M Prostate Cancer Survivorship Program.

The study, published in a recent issue of the *Journal of Urology*, surveyed 152 men undergoing radical prostatectomy, an operation to remove the prostate. All of the men filled out questionnaires before surgery, after receiving preoperative counseling.

The study showed that for the most part, men’s expectations of hormonal and bowel function matched what happened one year after surgery. But, when it came to urinary incontinence only 36 percent of the men’s expectations corresponded to what happened one year post-surgery.

In addition, only 40 percent of men found what they expected for sexual function to be true one year post-surgery.

“When we provide preoperative education, we can only inform men in terms of overall statistics. We can’t predict for the individual,” Wittmann said. “This may mean that, if in doubt, people tend toward being hopeful and optimistic; perhaps overly optimistic.”

The researchers suggest that it is important to provide men with tools for urinary and sexual recovery after surgery and with support that will lead to the best possible outcome. Patients who undergo surgery for prostate cancer at U-M participate in the Prostate Cancer Survivorship Program. The program includes partners as well. It is designed to provide men with excellent surgical care along with tailored, couples-oriented support both before and after surgery to help ease recovery from the side effects of surgery.

THYROID CANCER TREATMENT VARIES BY HOSPITAL, U-M STUDY FINDS

Where thyroid cancer patients go for care plays a large role in whether they receive radioactive iodine treatment, a new study from the University of Michigan Comprehensive Cancer Center finds.

“What hospital you go to makes a difference in the use of radioactive iodine. It doesn’t just matter what the tumor looks like, but where you go for care,” says lead study author Megan Haymart, M.D., assistant professor of internal medicine at the U-M Medical School.

Results of the study appear in a recent issue of the *Journal of the American Medical Association*. Thyroid cancer is one of the 10 most common cancers in the United States and is expected to become even more common in the next decade as more early stage cancers are uncovered.

Radioactive iodine following surgery to remove the thyroid is known to be an effective treatment for advanced or high-risk thyroid cancer that is very likely to return. But patients with small, low-risk disease often have an excellent prognosis without radioactive iodine treatment.

Researchers looked at data from 189,219 patients diagnosed with thyroid cancer between 1990 and 2008, as reported to the National Cancer Database.

Researchers found that radioactive iodine treatment is being used more frequently overall—56 percent of patients in 2008, compared to 40 percent of patients in 1990. Size and severity of the tumor did impact a patient’s likelihood to have radioactive iodine, accounting for about 21 percent of the variation in care.

In addition, factors such as whether the hospital saw a high volume of thyroid cancer patients played a role. But 29 percent of the variation between whether patients received radioactive iodine was attributable to hospital factors that could not be explained.

“Even among people who are high-risk—and the guidelines are clear that these patients should receive radioactive iodine—there is still variation,” Haymart says. This suggests doctors are unclear about the indications for radioactive iodine. We need randomized clinical trials that look at radioactive iodine in low-risk patients so that we can set better guidelines for its use.”

Radioactive iodine treatment can have long-term side effects, including risk of a second cancer or damage to nearby tissue such as salivary glands.

Learn more about the latest cancer research at the University of Michigan at mCancer.org/thrive.





Emily Mackler, Pharm.D.

To learn more about medication management, visit mCancer.org/thrive to watch a videocast with pharmacist Emily Mackler.

Art Therapy:
877-907-0859

Cancer AnswerLine:
800-865-1125

Clinical Trials:
800-865-1125

Fertility Counseling:
877-907-0859

Financial Counseling:
734-647-5120

Guided Imagery:
877-907-0859

Music Therapy:
877-907-0859

Nutrition Services:
877-907-0859

Patient Education Resource Center:
734-647-8626

Pharmacy:
734-647-8911

Practical Assistance Center:
877-907-0859

PsychOncology:
877-907-0859

Social Work:
800-888-9825

Skills Lab:
877-907-0859

Smoking Cessation Counseling:
734-998-6222

Symptom Management & Supportive Care:
877-907-0859

KEEPING TRACK OF MEDICATIONS

Keeping track of your medications and remembering whether or not a medication has been taken can be a daunting task. Many tools exist that can help you with this process, but what's important is to develop a system that works best for you. The following items—some of which are available in the Cancer Center's patient tool kit—may help you:

- A medication chart describing the medications, the reason you're taking them and the time they should be taken.
- A calendar that lists when to take medications each day.
- A check-off list allowing you to check off when a medication is taken (even better if it allows you to track side effects or make other notes to monitor how the medication is working for you).
- Pill boxes large enough to pre-fill a day's or week's worth of medication.
- An alarm system to remind you to take your medications.

The Cancer Center Symptom Management and Supportive Care Program offers a medication management clinic to help you develop a reliable routine to fit your pharmaceutical needs.

Emily Mackler discusses the services provided during a medication management appointment in a videocast available at mCancer.org/thrive.

Do you have a question for the pharmacist? Email us at ThriveMagazine@med.umich.edu.



If you'd like to schedule a medication management appointment, call 734-232-6366.

THRIVE ONLINE

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

- Interested in becoming a more engaged patient? We have a variety of resources to help you connect.
- Learn more about patient advocacy and how you can get involved.
- Find out more about how the FOCUS Program is helping caregivers and patients.
- Visit the Cancer Support Community's website to learn more about the services they offer patients.
- Check out Cancer Center Recipes Just for You. Visit the website and enter your food preferences, and the site will offer healthy recipes customized to your tastes.
- Learn more about the latest research under way at the U-M Comprehensive Cancer Center.

If you're new to *Thrive*, check out our archive at mCancer.org/thrive. We have lots of advice to share.

