# ibrive e

Personal Treatment Decisions

Allowing yourself time to make informed choices



UNIVERSITY OF MICHIGAN



# TOTIVE CONTENTS CONTENTS

# 04

# **Method of Operation**

A Cancer Center partnership with engineers to improve your care

### 16

# Vegetables Pack a Punch

Our dietitians offer guidance on the rising popularity of superfoods and their benefits

# 07

# Diagnosis. Pause. Decision.

Decision-making in cancer treatment and one patient's personal checklist for an informed choice

# 10

# **Trust Your Instincts**

How one patient tracked the history of cancer in her family to a genetic condition

# 12

# Life at the End of Life

A sister looks back in gratitude as we share U-M Health System resources for end-of-life care

# 15

# **Research Round-Up**

Learn about the latest in research at the U-M Comprehensive Cancer Center

Published quarterly by the University of Michigan Comprehensive Cancer Center, 1500 E. Medical Center Dr., Ann Arbor, MI 48109-5944. If you do not wish to receive future issues of Thrive, please call Beth Johnson at 734-764-8311.

Max S. Wicha, M.D., director

Marcy B. Waldinger, M.H.S.A., chief administrative officer

Nicole Fawcett, manager of cancer communications

Beth Johnson, editor and senior writer

Cathy Mellett, contributing writer

Karen Moeller, art director, MOEdesign

Chas Moeller, project management, MOEdesign

Edda Pacifico, photographer, Edda Photography

Executive Officers of the University of Michigan Health System: Michael M.E. Johns, M.D., Interim Executive Vice President for Medical Affairs; James O. Woolliscroft, M.D., Dean, U-M Medical School; T. Anthony Denton, J.D., MHA, Acting Chief Executive Officer, U-M Hospitals and Health Centers; Kathleen Potempa, Dean, School of Nursing.

# The Regents of the University of Michigan:

Michael J. Behm, Laurence B. Deitch, Shauna Ryder Diggs, Denise Ilitch, Andrea Fischer Newman, Andrew C. Richner, Katherine E. White, Mark S. Schlissel, *ex officio*.

The University of Michigan is a non-discriminatory, affirmative action employer.

© 2015 Regents of the University of Michigan.

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

# Spiritual Care for Patients and Families

# Whenever It is Needed

N ever are spiritual concerns more present or more urgent than during a serious illness or at the end of life. The University of Michigan Health System's Department of Spiritual Care chaplains walk that journey with patients and families all day, every day.

"We're here to meet them wherever they are on their journey. We're trained and we have the skills to do so in a caring, empathetic way," says Rev. Lindsay Bona, the clinical coordinator for the Spiritual Care Department.

The chaplains represent a wide variety of religions and faith traditions. If there is not a chaplain of your faith currently on staff, the department has strong connections with local congregations and faith resources, and they can arrange a visit from a religious leader of your

choosing.

"No matter what time of the day or night, there's always someone available," says Bona.

In addition to providing ritual support such as prayers, communion, anointing, baptism, blessing and reconciliation, they also provide worship services and bereavement consultations.

Bona says, "Sometimes a patient is doing really well but they feel that their family is not. We're here for patients and families, including those who have children or if the patients are children. Several of our staff are trained in pediatrics and children's spiritual life, and we can help whether the child is the patient, the sibling, or the son or daughter of those who are dying."

Cancer Center Chaplain Deacon Wayne Charlton says that it is important for people to use whatever resources are available within their faith tradition and that talking with a chaplain is not just for people of faith.

Charlton, who has been a U-M chaplain for 24 years, says that meeting with a chaplain can benefit anyone who is going through a serious illness or end-of-life issues.

"Some of the most profound experiences I have witnessed are with people who don't identify with a particular faith tradition," he says. "They may relate more to science or nature, but during their disease seek something to help them understand what is going on in a profound way. We all yearn for that connection."

mat connection.



Visit www.uofmhealth.org/our-chaplains for information about our chaplains.



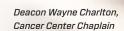
A clinically trained chaplain is available 24/7/365 in-house or on-call. Call **734-936-4041** for more information.

# CHAPELS AND QUIET ROOMS

The University Hospital Chapel is located on the second floor of University Hospital, room 2A215.
The C.S. Mott Children's and Von Voigtlander Women's Hospital Chapel is located on the second floor of that hospital, room 2780.

There are also quiet rooms in the Cardiovascular Center located on floor 2A, room 001B, and floor 4, room 4141.

All are open 24 hours a day.



WINTER 2015

# Alethod

# THE CANCER CENTER TEAMS UP WITH EN

As a nationally designated comprehensive cancer center and part of a world-class health system, the University of Michigan Comprehensive Cancer Center is a big place. Our patients have high expectations, not only for positive health outcomes, but also for their personal experiences receiving care here. And rightly so! Creating the ideal patient care experience is at the core of the U-M Health System's mission. It only makes sense for the Cancer Center to live up to its reputation.



Amy Cohn, Ph.D.

That's why the Cancer Center partners with industrial engineers to review—step by step—how a patient travels through our system. Together, they look for kinks in the system, places where a patient's experience could be better, faster or more efficient. Additionally, the Cancer Center is financially invested in improving the system and has hired an engineering master's student part-time.

We sat down with Amy Cohn, Ph.D., associate director at the U-M Center for Healthcare Engineering and Patient Safety (CHEPS), to talk about her expertise in large health care settings and how multidisciplinary teams of students, faculty, and caregivers are working to implement positive change for our patients.





Healthcare Engineering and Patient Safety students (from left) Matt Rouhana, Vera Lo, Stephanie See and Sarah Bach

# oeration GINEERS TO IMPROVE YOUR PATIENT CARE EXPERIENCE

How is the Center for Healthcare Engineering and Patient Safety (CHEPS) qualified to help improve care at the Cancer Center?

Our program has students ranging from undergraduates to doctoral candidates working hand-in-hand with caregivers in the Cancer Center. What is valuable is that the students have strong technical skills; we're the No. 2 industrial engineering program in the country. When you take these strong technical skills and put them in the health care setting along with patients and caregivers, real improvements can be made. The partnership between the Cancer Center and CHEPS is extraordinary because we are learning from a network of collaborators with various backgrounds.

We focus on real problems that affect our patients, conducting hands-on projects with immediate and measurable impact. Our expertise is taking complex systems, studying how they work and making the parts fit together better.

What specific issue are the engineers working on to improve at the Cancer Center?

Because we know infusion is a complex part of the Cancer Center, our current goal is to reduce delays to infusion patients while maintaining safe, high-quality care. We're looking at all aspects of infusion, which gives a lot of avenues to explore. By evaluating steps in the process, such as waiting for blood work, mixing medication and how patients are scheduled, our data tells where there are bottlenecks and how we might change things to make patients happier with the overall process.

You mentioned data. What does that have to do with improving patient care?

Engineers do very technical work. We build computer programs to show patient flow, take time measurements at each step, and talk about specific patient circumstances that add variability.

This lets us help caregivers understand how delays occur. As a result, we can reallocate resources, change the way patients receive blood work, or schedule patients differently. We can show with computer simulation where problems arise, shine light on it and address how to fix it.

How do engineers take into account the human element of health care and that our goal is to treat patients, rather than something like build cars?

A key part of CHEPS' mission is to train future generations of engineers specifically interested in health care. By working side by side with physicians, other care providers and in consultation with Patient and Family Advisory Board members, these engineers take into account the actual patient and the ideal patient experience.

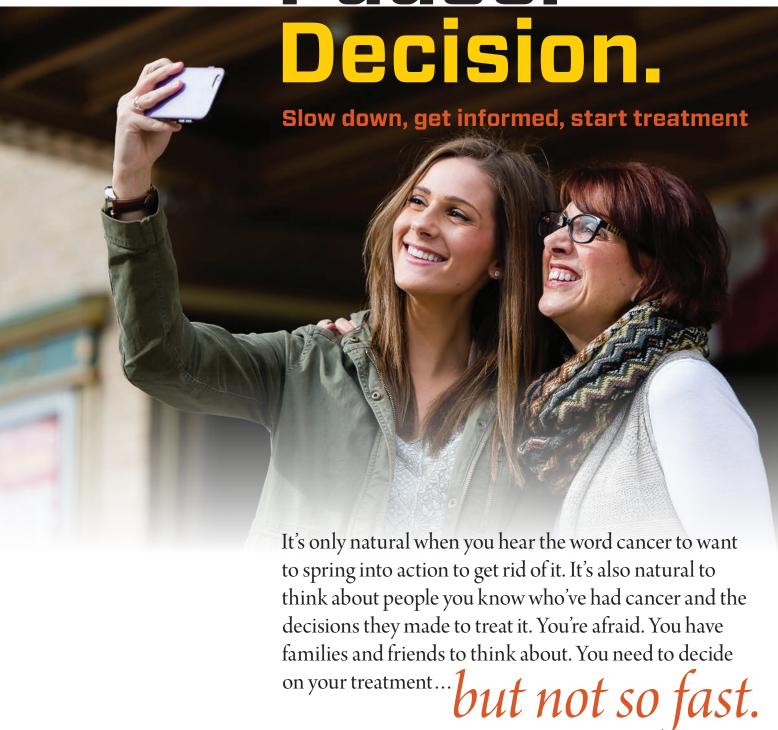




E-mail the Cancer Center's Patient and Family Advisory Board with suggestions on how to improve patient care: Cancer-Support-Services@ med.umich.edu.



# Diagnosis. Pause. Decision.



A cancer diagnosis is a whirlwind, says Steven Katz, M.D., M.P.H., co-director of the socio-behavioral research program at the U-M Comprehensive Cancer Center. Yet, even though few cancer decisions need to be made as if it is a medical emergency, most are treated as such.

"I'm not talking about waiting months," Katz says.
"I'm talking about an extra visit. Take time to discuss options with your spouse. Get a second opinion if you're not sure. We don't need to make all decisions during their first encounter with their doctor."

Katz leads a Cancer Center research team that studies treatment decision-making. Because breast cancer patients often face a variety of treatment options—surgery, chemotherapy, hormone therapy, radiation—studying them could help patients with other cancer types make decisions in the future.

### The researchers analyze topics like:

- Appropriate and personalized treatment for each patient
- How patient viewpoints impact decision-making and care
- How diagnostic test results influence decisions
- How quality of life during treatment and survivorship affects decisions

Katz says a good doctor helps patients navigate choices and evaluate factors like overtreatment (more than enough treatment) or undertreatment (a patient stops treatment too soon or refuses treatment).

# CONSIDERING: LIFE, HEALTH, BODY IMAGE, RECURRENCE

Lynn Dworzanin had been an oncology nurse practitioner for 24 years, so getting an annual mammogram was a way of life. What looked like sea salt on her scan was ductal carcinoma in situ, the most common form of non-invasive breast cancer. DCIS isn't life threatening, but having it upped the chances of an invasive cancer in the future.

Treatments include lumpectomy with radiation therapy or single mastectomy. Because of the size of her DCIS, it was recommended that she have a quadrantectomy, a surgery that removes one-quarter of the breast.

Making matters more stressful, her Cancer Center physician, Lisa A. Newman, M.D., was concerned about possible cancer in the opposite breast. Multiple biopsies were required to know for sure.

"The first thing you think of when diagnosed with cancer is *I want to live and be here for my children,*" Dworzanin say.

In addition to the fear of cancer in her second breast, Dworzanin knew having a quadrantectomy would result in dramatic asymmetry of her breasts. Both factors weighed heavily on her mind.

### What issues did she take into consideration?

- She was only 50, married and a mother of two daughters.
- The constant worrying about a potential future cancer in her second breast.
- Developing cancer again meant more treatment, possibly chemotherapy, radiation and hormone therapy.
- Quadrantectomy or a single mastectomy would result in less than desired cosmetic outcome and poor body image.
- image.
  A double mastectomy might not be medically necessary.
- A double mastectomy would alleviate worries about future breast cancer.
- A double mastectomy would allow her to have a better cosmetic outcome and improved quality of life.

# INFORMED DECISIONS, SOUND DECISIONS

Dworzanin chose the double mastectomy.

"When you have early stage breast cancer, you don't ever want it to come back and have the potential need for chemotherapy," Dworzanin says. "Every woman's situation is different. For me, it was eliminating the fear and worries, avoiding the need for additional cancer treatment and quality of life by having a good cosmetic outcome."

Despite knowing there are no survival advantages to undergoing a double mastectomy, she has no regrets and is happy with her surgical outcome and body image. Learning she was cancer free after surgery was a huge relief.

Dworzanin's sentiments echo what Katz has learned through research: Take your time and be informed.

"I think sometimes people regret a decision if they make it too quickly," Dworzanin says. "Get a second opinion. Talk to other women. It's your own personal journey so take the time to get all your information. Whatever decision you make will be the right one for you."





# Trust Your Instincts

# How one patient tracked her family's history of cancer



Sylvest and
Elena Stoffel, M.D.,
director of the Cancer
Genetics Clinic, created
a U-M event for patients
and families with genetic
conditions. "Empower
Yourself: Updates on
Lynch Syndrome, FAP and
Familial Colon Cancer"
took place last October.

Lisa Sylvest, a gastrointestinal nurse and mother of two, knew cancer ran in her family. Her father had been treated for colon cancer in 1992, but before that, many relatives on her father's side faced the disease in their 50s: her grandmother from Denmark, an uncle and an aunt.

Sylvest herself was diagnosed with endometrial cancer at age 40, in 1998, adding to her suspicion that the prevalence of cancer in her family seemed connected in some way.

"I always knew this wasn't a coincidence," she says. "Maybe it started as a gut feeling, but as I became a GI nurse, I learned more."

She suspected Lynch Syndrome, a hereditary genetic condition that greatly increases the chances of colon and other cancers, including endometrial, earlier in life than what is considered typical.

In 2005, Sylvest traveled to Denmark to honor the one-year anniversary of her father's passing. While there, she learned crucial information from a cousin: an uncle she thought had died of brain cancer actually had colon cancer that metastasized to the brain.

"I knew at that moment we had Lynch Syndrome," Sylvest said. "It was the missing piece of the puzzle."

Sylvest went for genetic testing at the University of Michigan Cancer Genetics Clinic. She worked with a genetics counselor to understand the process and how to proceed when she tested positive for Lynch Syndrome.

"We suspect 5-10 percent of cancer diagnoses may be caused by inherited risk," says Jessica Everett, a certified genetics counselor at the clinic. "Many patients opt to have genetic testing to gain information for their families. Identifying a genetic explanation for cancer can allow us to offer them strategies for risk reduction and early detection."

After Sylvest's diagnosis, her sister also tested positive for Lynch Syndrome. Upon having an endometrial biopsy, Sylvest's sister was diagnosed with endometrial cancer in 2010. She underwent a radical hysterectomy and has been cancer-free for nearly five years.

"My sister says my genetic testing saved her life," Sylvest says. "I've also realized that some families don't like to talk about cancer. Like mental illness, I would argue that many conditions are a stigma."

Sylvest believes that when someone in a family has cancer, it is everyone's business. For that reason, she traveled to Denmark again in 2010 to inform her five male cousins about her genetic condition. Some have opted to be tested for Lynch Syndrome and others have not.

Sylvest is going on 16 years as a cancer survivor. Each year she gets a pap test, an upper endoscopy and colonoscopy; no new cancer has appeared. She is thankful her adult son and daughter both tested negative for Lynch Syndrome.



Visit mCancer.org/thrive for more information on the Cancer Genetics Clinic.

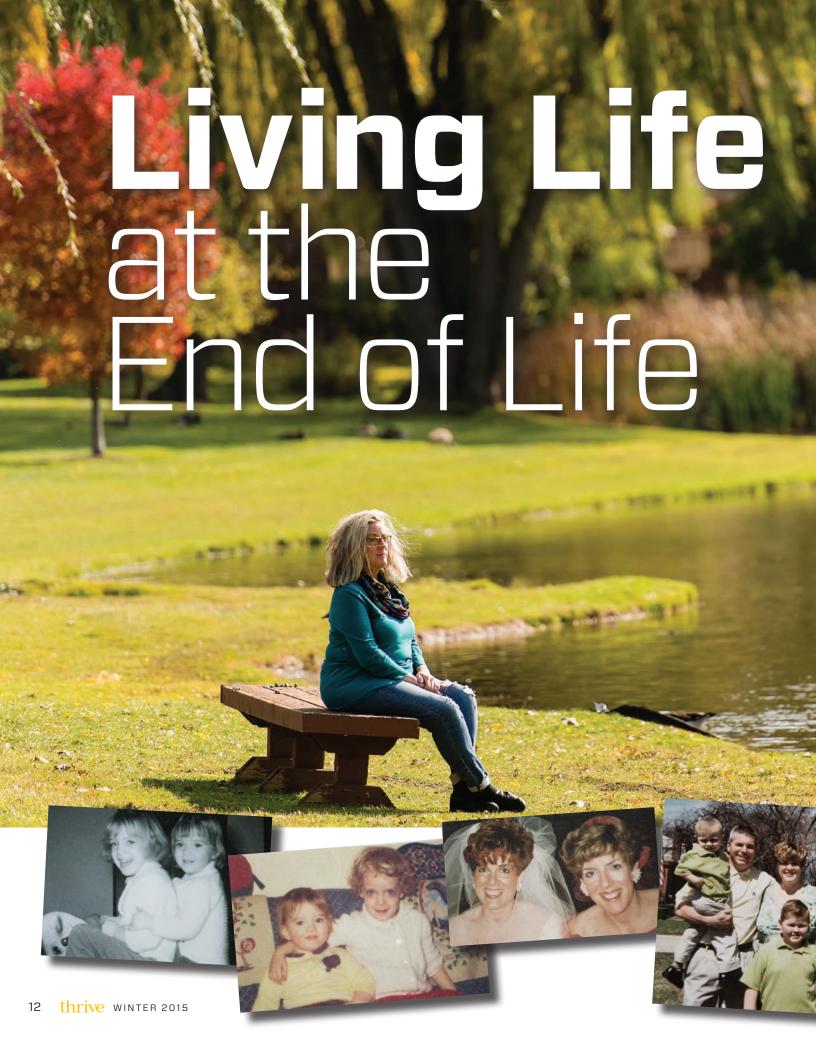
# FEATURE | Trust Your Instincts thrive WINTER 2015 11

# Basic steps of genetic testing

Meet with a genetics counselor and physician to:

- Review your medical and family history
- Determine whether a genetic condition may be present
- Determine what genes might be involved
- Provide a blood sample\*
- Identify who else in the family may be at risk
- Discuss strategies to reduce risk and detect cancer early

\*In some cases, a physical exam also takes place.





"I believe there is such a thing as a good death, and I know my sister had one," says Ann Fitzsimons. "For some, completion of end-of-life activities is an important part of a cancer journey that can benefit both the patient and their loved ones."

Her sister, Maureen Neary Dooley, was only 44 when she was diagnosed with late-stage colorectal cancer. Fitzsimons became the champion who motivated her to do what was necessary and meaningful as she approached death.

"Cancer takes so much from people. Preparing for the end of their life on their terms, helps them regain some lost control," says Fitzsimons who is a member of the U-M Comprehensive Cancer Center's Patient and Family Advisory Board.

"You have to find the person who can complete the hard work with you and, importantly, without you, if you can't do it yourself. Your spouse or best friend may not yet have accepted this as the beginning of the end. So, you need to find someone who can help you do what you want and need to, just in case this doesn't turn out the way you're hoping it will."

With Fitzsimons' help, Dooley preplanned her funeral, set up trusts for her children and even prepared a family budget because she handled the money in the family.

"Doing these things helped her immensely," says Fitzsimons. "She needed to make sure that her family was well-cared for after she was gone."

Dooley also did a lot of legacy work, creating scrapbooks, videos, milestone cards and gifts for each of her three children and her husband. These projects provided a sense of purpose at a time when cancer can devalue a patient's self-worth. They also helped her realize she had lived a very full life.

Fitzsimons realizes her sister's death was exceptionally positive and many aren't able to plan and prepare so well. These conversations are difficult, and identifying what health care resources are available can be challenging. She advises asking the health care team for a palliative care consult to provide an extra layer of care for the patient and family. "You have to empower yourselves," she says, "and the earlier at the end-of-life, the better."

Cancer Center Chaplain Deacon Wayne Charlton says hospice is a marvelous resource. "So many people say, 'We took our mother to hospice and she died three days later,'" Charlton says. "Unfortunately, we often wait too long to get people into hospice. The sooner hospice is involved, the sooner the patient can be surrounded by friends and family in an environment built just for them."

Part of being prepared is having a Durable Power of Attorney for Healthcare and/or a Do-Not-Resuscitate (DNR) Declaration. Patients and families can get printed copies of the booklet and forms at the Cancer Center's Patient Education Resource Center on level B2; a U-M health center or clinic; any inpatient unit; the Guest Assistance Program, 800-888-9825; the Office of Clinical Safety, 877-285-7788 or online at uofmhealthsystem.org/documents/adult/ AdvanceDirectiveBooklet.pdf.

Charlton also suggests that patients plan as much of their own funeral as they can, including readings and hymns. "Patients often tell me what wonderful emotions and experiences surfaced because of that."

"Maureen's last few days were nothing short of miraculous," Fitzsimons says. "She held court, and friends and coworkers came in with lunch. She was at peace and had no regrets as everything had been done. She had done the preparatory work and it had all been worth it."

Charlton says, "I encourage patients and families to continually look for the miracle but don't try to define it. In other words, if the only miracle we are looking for is the big one—the one where there is a miraculous cure—then we will most likely miss the other miracles that are unfolding before our very eyes, each and every day."

The U-M Comprehensive Cancer Center offers several services to support patients and families through their cancer journey to end of life.

# Adult Palliative Medicine Program

Can be requested by patient or physician to assist in managing quality of life issues. Helps with physical and emotional issues as well as legal, faith and relationship matters.

734-936-8357

# **Grief and Loss Program**

Offers assistance for those experiencing loss related to cancer—whether it is the patient's personal loss or the family member's loss of a loved one.

1-877-907-0859

# Michigan Visiting Nurses Palliative Care Services

A specialized program that emphasizes pain control and symptom management, and enables patients and families to continue to function in their homes for as long as possible.

734-677-1515

# Symptom Management and Supportive Care Program

Available to any Cancer Center patient at any stage in their treatment who is experiencing treatment- or cancer-related side effects, or dealing with transition of care due to advancing cancer.

877-907-0859





# U-M SPECIALIST AT FOREFRONT OF EFFORT TO BRING LUNG SCREENING TO THOSE AT HIGH RISK

The Centers for Medicare and Medicaid Services announced that lung cancer screening with CT scans will be covered for people at high-risk of developing lung cancer.

"This is a victory for cancer prevention and for the well-being of thousands of Americans at high-risk of lung cancer," says Ella Kazerooni, M.D., director of cardiothoracic radiology at the University of Michigan Health System. "Lung screening is a life-saving health measure for the No. 1 cause of cancer death in the United States today."

Kazerooni has been at the forefront of national efforts to urge CMS to approve Medicare coverage. As chair of the Committee on Lung Cancer Screening for the American College of Radiology, she worked to forge alliances with major professional and advocacy organizations, culminating in a letter signed by 78 organizations across the country urging lung screening coverage.

The CMS decision stems from the National Lung Screening Trial, a large-scale clinical trial funded by the National Cancer Institute. It found that among 53,000 heavy smokers at high risk of lung cancer, CT screening demonstrated a 20 percent reduction in lung cancer deaths.

The results led to the U.S. Preventive Services Task Force (USPSTF), the government body that evaluates cancer screening tools, to recommend lung cancer screening for people age 55-80 who have smoked at least 30 pack years, and are either current smokers or quit within the last 15 years.

Under the Affordable Care Act, the USPSTF recommendation requires insurance companies to include the service as an essential covered benefit. This became effective for lung cancer screening in January 2015.

CMS's decision includes annual lung screenings for people age 55-74 who have smoked at least 30 years and are either current smokers or quit within the last 15 years.

Visit **mCancer.org/lung-cancer/resources** for lung cancer screening information.

# SARCOMA SURVIVORSHIP CLINIC PUTS CANCER, HEART SPECIALISTS SIDE-BY-SIDE TO MONITOR, TREAT LONG-TERM SURVIVORS

A new clinic at the University of Michigan Health System aims to help adults who were treated for sarcoma, a cancer of the bone and connective tissue.

The first-of-its-kind multidisciplinary clinic pairs a medical oncologist who specializes in treating sarcoma patients with a cardiologist who specializes in heart problems that can result from cancer treatment.



Patients will have a comprehensive exam by | Laurence Baker, D.O. both doctors. In addition, the clinic includes specialists in kidney disease, endocrinology, physical medicine and rehabilitation, and psychiatry to help manage the conditions most often seen in sarcoma survivors.

"Patients who are cured of sarcoma as teens should be able to live into their 80s. But we see many of these patients develop heart disease, renal disease or other late effects in their 30s or 40s. These are often treatable issues. We have a tremendous potential with this clinic to impact long-term survival for these patients," says Laurence Baker, D.O., professor of internal medicine at the University of Michigan Medical School. Baker, who has been treating sarcoma patients for more than 40 years, will see patients in the new clinic.

Because these issues are more typically seen in older adults, they often go undetected or misdiagnosed in sarcoma survivors, delaying treatment. Heart disease in a 30-year-old is rare; heart disease in a 30-year-old sarcoma survivor is not. In fact, heart disease is the main issue facing sarcoma survivors – nearly a third will develop a cardiac issue after treatment. Other conditions are also possible.

These illnesses can occur as early as two years after completing sarcoma treatment.

"Many of these issues can be treated effectively with early interventions using common, established techniques. What's different is that this particular population will face these issues at a younger age than you'd typically see. Because of that, our emphasis will be on early detection," says Monika Leja, M.D., assistant professor of cardiology and the cardio-oncologist who works side-by-side with Baker in the clinic. Leja specializes in preventing or minimizing heart damage caused by chemotherapy and radiation therapy for cancer.

To make an appointment, call 888-287-1082.

# Sticking to the Plan

Why taking your prescription medication as prescribed is so important



Shawna Kraft, Pharm.D.
Have a question for the
pharmacist? Email us at
ThriveMagazine@
med.umich.edu.



Do you take your medication exactly as prescribed by your health care provider? If you do, congratulations!

You are medication compliant or adherent.

However, non-adherence can occur very easily and most likely happens to everyone from time to time. Whether it is on purpose or by accident, missing doses can lead to your medication not working as well as it could.

### Some common reasons for non-adherence:

- Simply missing a dose
- Side effects from the medication
- Concerns about possible side effects
- Concerns about long term effects
- Don't think you need the medication anymore
- Don't think the medication is working
- Difficulty managing all the medicines you take
- Missed doses because of a busy schedule
- Tendency to forget things in your daily life
- Financial concerns about medication costs
- Pharmacy was out of the medication And, there may be other reasons.

Everyone can forget to take a dose. Don't be embarrassed to simply let your care team know. *Your issues are valid, and there are often solutions available to help,* such as pill boxes, financial assistance and treatment for side effects.

Taking your medications as directed is important. If it does seem that the medication isn't working or if you're experiencing side effects, your providers can make decisions assuming the medication was taken as prescribed. This will result in the best treatment plan for you.

Everyone at the Cancer Center is here to help you treat your cancer and symptoms. You, as the patient, are the center of that care. We need you to speak up and be honest so we can help you the best way we can.

# **Just a Phone Call Away**

**Art Therapy** 

877-907-0859

Cancer AnswerLine

800-865-1125

**Clinical Trials** 

800-865-1125

**Education Clinic** 

877-907-0859

**Fertility Counseling** 

877-907-0859

Financial Counseling

734-647-5120

**Guided Imagery** 

877-326-9155

Make a Donation

734-998-6893

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

**Smoking Cessation Counseling** 

734-998-6222

Symptom Management and Supportive Care

877-907-0859



# THRIVE ONLINE

mCancer.org/thrive

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

- Tips from our dietitians on buying superfoods and advice for prepping winter squashes and other veggies
- More information on the U-M Center for Healthcare Engineering and Patient Safety and its mission to improve patient care
- A link to frequently asked questions at the U-M Cancer Genetics Clinic
- Details on the many end-of-life services available throughout the U-M Health System
- The Cancer Center's resources for lung cancer screening, including a screening guide