Spring 2009

A Publication of the University of Michigan Comprehensive Cancer Center

THE SURVIVORSHIP ISSUE

Figuring out what comes next after cancer treatment



IN THIS ISSUE SPRING 2009

on the cover:

More than 11 million Americans are cancer survivors. As people live longer after cancer, they face new concerns that the medical community is just beginning to understand. Our special Survivorship Issue takes an in-depth look.

Photos by Lin Jones University of Michigan Photo Services



04 NOW WHAT? Survivorship experts Sheila Crowley and Marcia Leonard talk about getting the right care for you after cancer treatment ends.



06 GROWING PAINS Childhood cancer survivors continue to feel the impact of the disease into adulthood. That's why the U-M Cancer Center's Long-Term Follow-Up Clinic is here to help.



09 ON THE OTHER SIDE OF CANCER

Thrive talks with cancer survivors about their long-term concerns and what they plan to do to live well now that treatment is finished.



We want to know what you think. What kinds of stories would you like to read in Thrive? What type of advice would be helpful? Do you have tips for other patients? Let us know. E-mail us at ThriveMagazine@med.umich. edu or write to us at 2901 Hubbard, Suite 2600, Ann Arbor, Mich., 48109.



12 ONE STITCH AT A TIME

Survivor Harriett DeRose helped find meaning by quilting a self-portrait during cancer treatment. Find out how complementary therapies can help.



14 FRESH START Looking for ways to prevent recurrence? Start at the dinner table. Our dietitians offer tips.



15 RESEARCH **ROUND-UP**

A study finds cost is a barrier to cancer survivors getting follow-up care. A U-M study links childhood cancer treatment to higher osteoporosis risk.

WANT MORE? Here's what you'll find right now on our Web site, mcancer.org/thrive:

Check out our new Survivorship Web site. We're building an interactive resource center for people who have finished cancer treatment.

- Learn how to sign up for the U-M Cancer Survivors' Day Celebration, 1-3:30 p.m., Sunday, June 7, at Washtenaw Community College.
- Watch video of our popular Complementary Therapy programs. View clips from a yoga class. Follow our step-by-step instructions to make a wish doll commemorating your experience.

- Listen to our podcast with Sallie Foley, director of the U-M Center for Sexual Health.
- Click through the Cancer Center Recipes Just for You Web site for healthy eating ideas.

And don't forget, we have loads of tips on other cancer topics. Visit our online archive to learn more.

Better Care Through Research

STUDY SEEKS BETTER WAYS TO CARE FOR BREAST CANCER SURVIVORS

THE UNIVERSITY OF MICHIGAN COMPREHENSIVE CANCER CENTER HAS LAUNCHED A STUDY TO DETERMINE WHETHER BREAST CANCER PATIENTS BENEFIT FROM A ONE-TIME TRANSITION VISIT AT THE END OF STANDARD TREAT-MENT. DURING THE VISIT, AN ADVANCED PRACTICE NURSE PROVIDES A SUMMARY OF ALL CANCER TREATMENT THE PATIENT RECEIVED, EXPLAINS THE POTENTIAL LONG-TERM EFFECTS OF THE TREATMENT, DEVELOPS A SURVIVORSHIP CARE PLAN INDIVIDUALIZED TO SPECIFIC CONCERNS AND OFFERS REFERRALS TO OTHER CARE PROVIDERS.

The study is one of many planned as part of the Cancer Center's new survivorship initiative. Other future research initiatives will be based around a National Cancer Institute grant to investigate ways to use the Internet to help learn more about the best ways to care for people in this phase of survivorship. The Cancer Center plans to use this research in the future to develop evidence-based approaches to survivorship care for all cancer populations.

"It's very clear both from our own experience and the published medical literature that patients have issues after the completion of cancer treatment," said Jennifer Griggs, M.D., M.P.H., director of the U-M Breast Cancer Survivorship Program. "Cancer treatment itself is so intense and complicated, but patients are fairly well supported by family, friends and medical professionals during diagnosis and treatment. Then they enter this era we've termed 'survivorship,' and often they find support, including informational support, is lacking."



Breast cancer survivor Olga Muñiz felt she benefited from a posttreatment visit.



The new study is enrolling patients who have finished all forms of breast cancer treatment, except hormonal therapy, within the past nine months. The ultimate goal is to determine whether the visit helps patients to manage their own health care.

Olga Muñiz, who was diagnosed with breast cancer in December 2007, said she appreciated the opportunity to have an extended conversation about her concerns. She said she had been having problems with sleeping and was especially interested to know what she should do to prevent breast cancer recurrence.

"It was very helpful because I did have some questions, even though I do a lot of research on my own and read a lot," said Muñiz, a professor at Hillsdale College. "It's always good to discuss topics with someone else who is more knowledgeable. I was reassured."

Other women have different questions, Griggs said. For example, they may have concerns about fatigue, sexual side effects or changes in the size or shape of their breast. They may be coping with premature menopause, which requires management of symptoms like hot flashes. Or they may need a referral to PsychOncology to help work through anxiety, depression or other emotional issues.

The transition from active treatment to survivorship can also spark questions about the risk of cancer in other family members.

"Things happen quickly after a cancer diagnosis," Griggs said. "This is the time to reflect upon what they've been through and what this means to their life story."



Your oncology team will work with you to determine when a transfer to the Survivorship Program is appropriate. To learn more about survivorship research, please visit **mcancer.org/thrive** or call the Cancer AnswerLine at **800-865-1125**.

Now What?

OUR EXPERTS TALK ABOUT THE TRANSITION FROM PATIENT TO SURVIVOR

YOU LONG FOR THE DAY WHEN YOUR CANCER TREATMENT IS FINISHED. BUT FOR MANY, THAT DAY IS LESS TRIUM-PHANT THAN THEY HAD ENVISIONED. THE WORRIES ARE STILL THERE. AND THEN THERE ARE THE LINGERING SIDE EFFECTS: THE FATIGUE, DIFFICULTY SLEEP-ING, MAYBE SOME CHANGES IN BODY IMAGE.

Put simply, life is just different than it was before.

That's why the University of Michigan Comprehensive Cancer Center has established a new donor-supported program to help ease the transition from regular treatment to less frequent follow-up care. We talked with Sheila Crowley, Ph.D., R.N., and Marcia Leonard, R.N., P.N.P., co-directors of the Survivorship Program, to find out more.

Q: The term "cancer survivor" means different things to different people. How do you define it?

CROWLEY: There are many different definitions of the term. For the National Coalition of Cancer Survivors, everyone who has been diagnosed with cancer is considered a survivor from that day forward. People who are impacted by cancer—family, friends and caregivers—are also considered survivors. In the health-care realm, the idea of "survivorship care" stems from research initiated by the Institute of Medicine and the National Cancer Institute to examine the issues people face after completing cancer treatment.

At the University of Michigan Comprehensive Cancer Center, our initial aim is to ease the transition that follows after active treatment ends. We find that patients often feel a bit unsettled after their cancer treatment and are not sure how best to move forward after it is completed. Our goal is to provide them with an individualized survivorship care plan, which provides information on how to manage their care in the future, as well as strategies to optimize their overall health and wellness after cancer treatment. We also are working on research to better understand issues cancer survivors face so we can develop better wavs to address them.

Q: What types of issues do patients face at this stage in their care?

CROWLEY: It depends on what type of cancer and what types of treatment a patient has received. But almost all of our patients are concerned about recurrence. What can they do to prevent the cancer from returning? Some may be coping with side effects of treatment, such as fatigue, sleep disturbances, peripheral neuropathies, changes in appetite, changes in body image and problems with sexual health—to name a few. Others are challenged by feelings of anxiety, depression or sadness. And still others want to be educated about what they can do to limit or manage long-term treatment effects. Survivorship experts Marcia Leonard, R.N., P.N.P., left, and Sheila Crowley, Ph.D., R.N., say recurrence is a top concern for patients finishing treatment.



LEONARD: The detrimental effects of treatment are of particular concern in childhood cancer survivors. Because the organs of children are actively growing during cancer treatment, they are at higher risk for long-term complications. Depending on the treatment children receive, normal growth may be affected. Puberty may be delayed, and the ability to have children of their own may be problematic. Children who receive treatment that affects the brain are at risk for residual learning disabilities. The risk of secondary cancers—although small—is real.

Q: What does the Cancer Center offer patients who are facing this transition in care?

LEONARD: All children who undergo cancer treatment can be seen in our multidisciplinary Long-Term Follow-Up Clinic. Because the medical community's earliest successes in treating cancer were in the pediatric realm, we've had the benefit of having years of research to guide us in what the long-term needs of our patients are. Our patients meet with our nurse practitioner, a child psychologist, a dietitian and a social worker, who are specialists in childhood cancer survivor care. The team helps ensure children and adolescents treated for cancer receive the resources they need to grow into healthy, well-functioning adults.

CROWLEY: Survivorship care is a newer concept for adults. We are piloting programs with breast cancer and prostate

cancer patients to determine how best to address their concerns before expanding the program to other cancer populations. The Cancer Center's goal is to expand the program to benefit all cancer patients, but in the meantime, we have other means of connecting patients with helpful resources. We've found that a good starting point is an educational booklet from the National Cancer Institute called "Facing Forward: Life After Cancer." *(Visit mcancer.org/thrive to view it.)*

Q: What should people entering this phase of treatment do to ensure they get the type of care they need?

CROWLEY: The first thing to do is to talk with your oncology health-care team about a summary of your treatment. Discuss which longterm effects you should be concerned about as well as their recommendations for routine follow-up care and screening tests. Take this information to your primary-care doctor and have a discussion about it. This is important since your primary-care doctor will continue to manage your overall care. Our Patient & Family Support Services are available during and after treatment. If you are experiencing anxiety, sadness or depression, consider making an appointment with the Cancer Center's PsychOncology Program. Also consider seeking out help from a peer counselor or using one of the many services offered by our Complementary Therapies Program.

LEONARD: The goal is to educate yourself and your family so you can be fully prepared if problems do arise in the future. While it's true that cancer treatment can have long-term effects, it's equally true that getting help for these effects earlier rather than later can have long-lasting impact on quality of life as well.



For more resources on coping with survivorship, please visit mcancer.org/ thrive.

FEATURE STORY

Growi

Sixteen years after her cancer diagnosis, Laura Selecki practices ballet in hopes of gaining a spot in Grand Valley State University's dance program.

ng Pains

CHILDHOOD CANCER SURVIVORS COPE WITH LONG-TERM EFFECTS OF TREATMENT

JARRED DUNCAN AND LAURA SELECKI DON'T REMEMBER MUCH ABOUT WHAT IT WAS LIKE TO HAVE CANCER. DUNCAN WAS DIAGNOSED WITH A WILMS TUMOR WHEN HE WAS 10 MONTHS OLD; SELECKI WAS A LITTLE OLDER THAN 2 WHEN DOCTORS TOLD HER FAMILY SHE HAD RHABDOMYOSARCOMA. NOW THE UNIVERSITY OF MICHIGAN COMPREHENSIVE CANCER CENTER IS HELPING THEM LEARN ABOUT WHAT THEY DON'T REMEMBER—AND HOW IT WILL AFFECT THEM AS THEY GROW OLDER.

Duncan, now 10, has only one kidney, so he's extra careful when he plays sports. It doesn't stop him from bragging about having had the most stitches of anyone in his class, though. He and his mom, Josie, pay close attention to how much protein he eats. And he wonders if the chemo has something to do with why his teeth are so yellow and full of cavities.

Selecki doesn't think too much about having had cancer, but she knows she has to take extra good care of herself. She spends hours each week in ballet classes so she can win a spot in Grand Valley State University's dance program. She understands that she won't be able to have children as a result of cancer treatment, but it doesn't bother her—yet.

"Maybe later it will," said Selecki, 18, of Manchester, Mich. "But I know there are other options."

As the University of Michigan Comprehensive Cancer Center's Pediatric Long-Term Follow-Up Clinic celebrates its 10th anniversary this year, its work has become a model for survivorship care. The clinic evolved out of need and a commitment: Patients should fully understand their risks and how best to address them. Researchers are beginning to take lessons learned from early successes in treating pediatric cancer survivors and apply them to adult populations.

By following childhood survivors closely as part of a national consortium of pediatric cancer research institutions, doctors have learned how to fine-tune treatment to prevent many types of unanticipated long-term effects. For example, radiation to the chest, neck and armpit lymph nodes was at one time routinely used for all patients with Hodgkin's disease, said Marcia Leonard, R.N., P.N.P., director of Childhood Cancer Survivorship at the U-M Cancer Center. But long-term follow-up showed that girls who received radiation to the chest were 35 times more likely to develop breast cancer. Treatment protocols have been changed as a result.

"We've learned a lot from following our patients for many years," Leonard said. "Part of my job is to remind our physicians not just to focus on this minute, but to try to picture the rest of a child's life. We need to inform our current patients what may happen in the future so they're prepared.

"Ten years ago when we first started seeing patients in the Long-Term Follow-Up Clinic, we saw too many 18-year-olds who were shocked to learn of the possibility of infertility because no one had told them that their treatment was likely to cause such problems. Even when we can't prevent these effects, we need to educate our patients about them."

Fleeting Chances

The key to managing the long-term effects of cancer treatment is the same as the key to surviving cancer: early diagnosis. When families are referred to the Long-Term Follow-Up Clinic three to five years after cancer treatment ends, they meet with a multidisciplinary team of specialists, including Leonard; social worker Peg Woehrle, M.S.W.; child psychologist Catherine Peterson, Ph.D.; dietitian Nancy Burke, R.D.; and, if needed, an on-call physician.

These visits are important because they can ferret out problems that may not be obvious. Each family or young adult receives a treatment summary including all

FEATURE STORY

chemotherapy drugs and doses, radiation port and dose, and surgical treatments. More importantly, a care plan specific to the needs of each child is developed. The plan takes into account the child's age, the known risks associated with specific treatments the child received and the individual needs of the child and family.

Beyond possible medical complications, clinic staff members help educate families about the psychosocial impacts of cancer: the long-range effect on siblings; the difficulties in maintaining reasonably priced health insurance after a childhood cancer survivor turns 21; the impact of indulging a child's every wish—or of letting them slack off in school—because of a cancer diagnosis.

Academic performance is a focal point for the Long-Term Follow-Up Clinic, particularly if chemotherapy was administered directly into the spinal fluid or if cranial radiation was part of a child's treatment. Peterson intervenes and evaluates school-age children to determine whether a child is having problems with cognitive functioning as a result of treatment. This will help parents work with schoolteachers to develop individualized education plans to help the child succeed in class.

Research has shown that childhood cancer survivors tend to fall behind in terms of socioeconomic status as adults, said Rajen Mody, M.D., an assistant professor of pediatric hematology oncology. They have trouble finding and keeping jobs, he said, which may be because they missed a lot of school or had trouble keeping up because of the cognitive effects of treatment.

"That's where early diagnosis comes into play," he said. "Once we identify these problems, we can work with families to lessen the impact so a child has a better chance to succeed in school and in a future career as an adult."

Surviving into Adulthood

The transition to adulthood is difficult for any kid, but even more so for childhood cancer survivors. Health insurance often comes at a premium when cancer is considered a preexisting condition. Even finding a primary-care doctor who is willing and able to provide care for a survivor can be difficult, Mody said.

Laura Selecki is excited about becoming more independent and going to college—and a little scared, as any 18-year-old is. She knows she has a higher risk of developing another cancer, but she's not too worried. Her mom, Carol, said her family has been discussing concerns related to her diagnosis, especially as she's grown into a young woman.

"She's always taken things as they come," Carol Selecki said. "We probably worry about it more than she does. I don't think it's a big concern for her. She's always had the attitude that she's going to make the most of her life."

The Long-Term Follow-Up Clinic continues to see patients, even as adults, to ensure they receive the care they need. Generally, patients are seen in the clinic for 10 years after the end of cancer treatment—or 15 years, if a blood stem-cell transplant was involved.

Often, it isn't until patients start coming to the clinic as young adults without their parents that they start asking questions of their own, Leonard said. Starting college, getting married, trying to have children and other milestones often prompt questions patients didn't realize they had. And it's still not well known how natural aging affects childhood cancer survivors.

But with time, researchers and health-care providers hope to have better answers.

"It's not uncommon for children with adverse cancer treatment effects—for those who aren't quite as tall or who don't do quite as well in school or who are infertile—to be told that they should just 'be happy that you're alive,'" Leonard said. "We recognize quality of life is of paramount importance. Cure is not enough."



For more information on the Pediatric Long-Term Follow-Up Clinic, please visit **mcancer.org/thrive** or call **800-865-1125**.

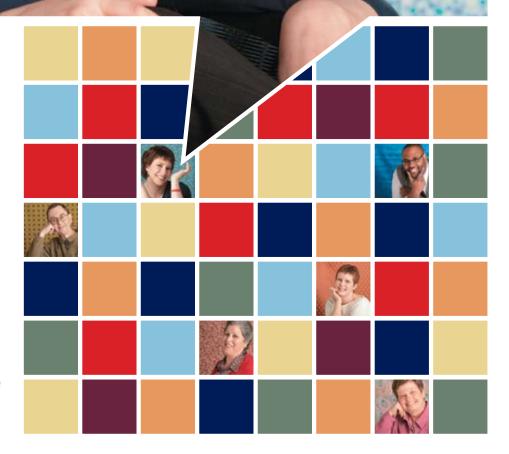
On the Other Side of Cancer

SURVIVORS TALK ABOUT THE CHALLENGES OF LIFE AFTER CANCER

CANCER IS SOMETHING TO FIGHT, SOMETHING TO CONQUER. BUT WHAT HAPPENS WHEN IT'S GONE? WHAT DOES IT LEAVE BEHIND? HOW DOES IT ALTER A LIFE? AND, PERHAPS THE MOST UNSETTLING QUESTION: WILL IT COME BACK?

We talked with people who completed cancer treatment at the University of Michigan Comprehensive Cancer Center about their concerns as they enter survivorship. The Cancer Center is starting a conversation that aims to improve care for patients once cancer treatment is finished and to help them anticipate changes in their lives as a result of the disease. As we learn more about survivorship, our researchers will find better ways to prevent and treat the long-term effects of cancer and its treatment.

"There are universal challenges for people who have been through cancer treatments and are trying to establish a new normal in their lives," said Karen Hammelef, M.S., director of Cancer Center Patient & Family Support Services. "We want patients to feel empowered to tell us what they're experiencing so we can help to address those issues."



Brandy Terwilliger

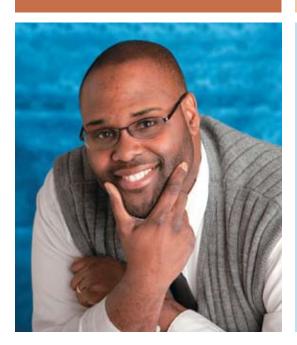
Age: 28 Hometown: DeWitt, Mich. Survived: Hodgkin's Disease Major Concern: Anxiety

Brandy Terwilliger can't stop thinking about cancer. It's hard to get to sleep. It pops into her mind when she gets up to go to the bathroom in the middle of the night. She has broken down and cried at work.

Cancer is gone from Brandy's body, but not from her thoughts.

Since finishing active treatment for Hodgkin's disease, Terwilliger has noticed her mood can change rapidly. She said she feels like few people understand what she's going through.

"I went through radiation and I was okay with that. I thought, 'If there's anything there, they're probably zapping it, so I'm good," she said. "But to go three months without seeing a doctor is a huge deal. I feel like they're my security blanket."





Take Action:

Many patients have similar concerns after treatment. Often, they seek out the U-M PsychOncology Clinic, designed specifically to provide counseling to people coping with cancer—even after treatment ends. Complementary therapies—such as guided imagery, art therapy or music therapy—may also help to alleviate anxiety.

"It's very normal for patients to seek help to cope with all that has happened to them," Hammelef said. "After treatment, people think they're supposed to be back to normal, and they're not. We can help with that."

Darrin Patterson

Age: 34 Hometown: Ypsilanti Survived: Sarcoma Concern: Changes in Body Function

When Darrin Patterson rolls up his left sleeve, you see the six-inch scar along his wrist and forearm. Just beneath it is the metal plate surgeons used to fuse his wrist in place after removing a tumor.

Patterson is the most positive guy you'll ever meet (and you may have met him—he works at the desk in the infusion waiting room on Level B-1). But every once in a while—say, when he picks up his 2-year-old daughter the loss of mobility in his hand and wrist bothers him. "I'm right-handed, which is a blessing, but I used my left hand a lot more than I realized," he said.

Take Action:

By lifting weights, Patterson has helped to increase strength—and lose 40 pounds. Patterson also credits faith, music and sense of purpose with helping him cope with the change in his life.

"I'm still here in the lives of my family. You only get one life so why would I carry myself in pity?" he said. "It's just something I have to accept. It's humbling, but once I embraced it, I knew it would be something I could use to help someone else."

Ron McCready

Age: 60 Hometown: Ann Arbor Survived: Nasopharyngeal Cancer Major Concern: Fatigue

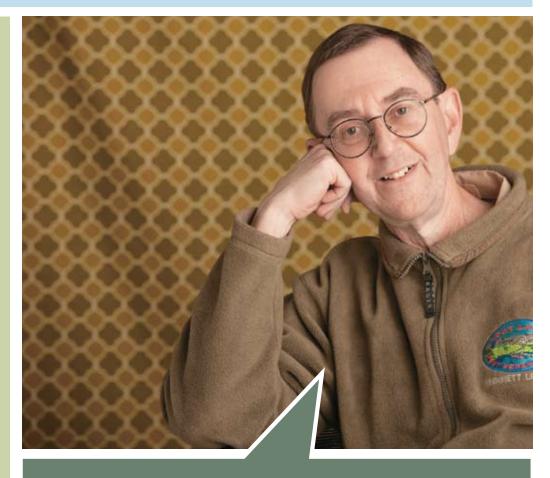
After Ron McCready finished cancer treatment, one of his goals was to have enough endurance to take the Boy Scout troop he leads to the Straits of Mackinac. It's a weeklong trip to an island without electricity. Each day follows the sun's rhythms: It starts before 6 a.m. and finishes after 10 p.m.

After six months of physical therapy and working out at the gym, McCready got his strength back and made the trip.

"I still go to the gym, but I know I don't have anywhere near the stamina I did," McCready said. "The difference between getting tired and getting exhausted is a heartbeat."

Take Action:

Research has shown that exercise, meditation, yoga and spending time in nature can measurably reduce fatigue. McCready worked with a personal trainer to develop a fitness routine. Talk with your health-care team about exercise. Or consider the Cancer Center's yoga class designed especially for people affected by cancer.



"I still go to the gym, but I know I don't have anywhere near the stamina I did," McCready said. "The difference between getting tired and getting exhausted is a heartbeat."



AnnaMarie Kish Age: 48 Hometown: Taylor Survived: Ovarian Cancer Concern: Family Risk

No one in AnnaMarie Kish's family had ever had cancer. So it's unlikely that her ovarian cancer was inherited. But it doesn't stop her from worrying about her 19-year-old daughter.

"I don't want her to be concerned," Kish said. "But there's still a certain degree of anxiety. Is it going to pop up down the road, and yes, she should've been tested?"

Take Action:

Doctors confirmed that Kish's cancer was unlikely to be genetic. However, genetic counseling is available at the U-M Cancer Center for people with many types of cancer. To learn more about genetic risk factors, **visit mcancer.org/thrive** or call the Cancer AnswerLine at **800-865-1125**.

James Muir

Age: 67 Hometown: Farmington Hills Survived: Prostate Cancer Concern: Erectile Dysfunction

James Muir didn't have much doubt that surgery was the right treatment for his prostate cancer. But one of the side effects of surgery is still with him: erectile dysfunction.

"That was a little discouraging," he said. "They're telling me it could be a year or two before that comes back, but there's no guarantee that it will."

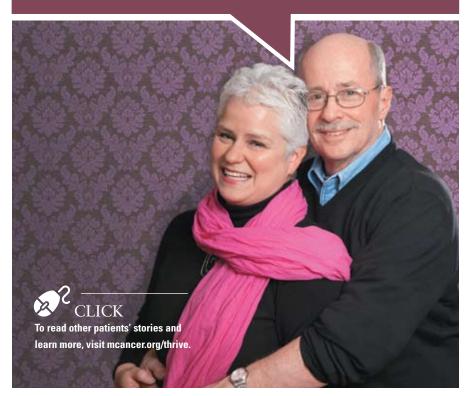
Muir and his wife, Janet, are participating in a new U-M Cancer Center Prostate Cancer Survivorship Clinic designed for men who have undergone radical prostatectomy. The clinic provides survivors with strategies to address their needs, including impotence.

Take Action:

Daniela Wittmann, a sex therapist for the U-M Prostate Cancer Survivorship Clinic, said many options exist to help men with erectile dysfunction, including medications and vacuum devices that create erections mechanically. Talking with a sex therapist can help couples make good choices—and address concerns women may be facing, particularly challenges to sexuality related to menopause.

"The goal is to make sure people know everything there is to know about how to maintain intimacy," Wittmann said.

"We are just very pragmatic. We just wanted to do whatever we could to get the best outcome," Muir said.



COMPLEMENTARY THERAPY



FOUR HASHMARKS ON THE POLE IN HARRIETT DEROSE'S BASEMENT STUDIO TRACK THE GROWTH OF HER GRANDDAUGHTERS. TO THEM, SHE'S "MANGI." TO HER HUSBAND, ANTHONY, SHE'S "THE MOST TALENTED PERSON" HE'S EVER MET. LOOK ACROSS THE ROOM, AND YOU'LL BE INTRODUCED TO A DIF-FERENT PART OF DEROSE: A QUILTED SELF-PORTRAIT THAT WAS KEY IN HELPING DEROSE FIND A WAY TO COPE WITH OVARIAN CANCER.



One Stitch at a Time

USING ART TO FIND MEANING IN SURVIVORSHIP

DeRose is now cancer-free, although she participates in a clinical trial to study the effectiveness of continued chemotherapy to prevent recurrence. But while she was in active treatment, she turned to quilting to help her make sense of everything she was going through.

"It was very, very cathartic for me," DeRose said of the five wall hangings she made to mark her cancer experience. "It's like in counseling when they say, 'Once you've said it, whatever it is isn't so bad.' I felt like having said it, I was able to relax a little about it."

In her self-portrait, "In My Mind's Eyes," DeRose sewed meaning into every detail: One eye is shut, while one remains wide open, signaling her struggle between wanting to educate herself completely about her diagnosis and wishing she could ignore it. She stitched a key over the spot where her port would be, representing her determination to maintain control of her care. And a block of bars sewn over her bald head indicates how she felt like a prisoner in her body and in her mind.

DeRose's wall hangings recently were on display in the Cancer Center's Voices Art Gallery.

Donna Murphy, director of Complementary Therapies at the University of Michigan Comprehensive Cancer Center, said art can play an important role in helping cancer survivors emotionally.

"People find that they need art or music or yoga to help them

reclaim their lives. They're saying, 'My life is different now,'" Murphy said. "When people are going through treatment, there isn't enough time to sort through what they're feeling. They want to go back to put the pieces together, to make their story comprehensive and to strengthen their sense of survivorship."

The Cancer Center offers a range of free activities for patients—all supported by generous donors—to help patients find a creative outlet for their emotions. For some, like DeRose, their own talents lead them naturally to projects that help them cope.

DeRose said she has also found that her quilting is useful for starting conversations with family and friends about what it means to have stage IV ovarian cancer.

"People are afraid to talk about cancer. They would say, 'You'll get over it,'" DeRose said. "I really needed to get my family on board and I didn't know how to do that. I needed to make them understand that people have to let me talk about what I was going through."

CLICK

To learn more about complementary therapies at the Cancer Center, visit **mcancer.org/thrive**, where you can also view more of Harriett DeRose's work online.

EAT WELL

Fresh Start

YOUR TREATMENT HAS ENDED, BUT YOU'RE LOOKING FOR WAYS TO KEEP UP THE FIGHT, TO STOP THE CANCER FROM COMING BACK. LOOK NO FURTHER THAN YOUR REFRIGERATOR.

Eating for treatment is quite different than eating for survivorship. During treatment, our goal is to help you maintain your weight as it is. Your appetite still may be diminished for some time after treatment ends. Food may continue to taste different for a while, too. But when you do start to feel more like eating, consider it an opportunity to take charge of what you eat.

A lot of studies have shown the nutrients in certain plant-based foods can help prevent cancer. But we're still learning how these chemicals work together. That's why we don't recommend nutritional supplements beyond a general multi-vitamin, if it's approved by your doctor.

For cancer prevention, the best advice is the simplest:



• Eat mostly plant foods, limit red meat and avoid processed meat.



 Be physically active however you can for at least 30 minutes per day.

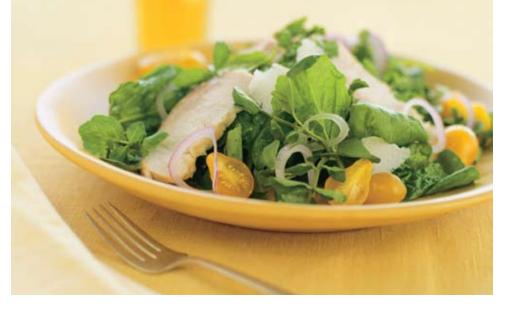


Aim for a healthy weight throughout your life.

These are the general guidelines offered by the American Institute for Cancer Research. What does it mean to eat mostly plant foods?

CHANGING EATING HABITS MAY HELP KEEP CANCER AT BAY

By Joan Daniels, R.D., and Nancy Burke, R.D. U-M Comprehensive Cancer Center Dietitians



Think of your dinner plate. Now, start to consider all the vegetables, fruits, whole grains, beans, peas and lentils you could put on that plate. Pick vegetables from a variety of colors: dark green spinach, red beets, orange carrots, yellow squash. Go for a new whole grain, like quinoa or whole-wheat pasta. Puree some navy beans or make some lentil soup.

Then, once you've stocked your plate at least two-thirds full of these food groups, consider poultry or fish. Limit red meat (that includes pork) to no more than 18 ounces per week. And leave the hotdogs and bacon for special occasions.

This is a good time to experiment. Talk to your family about your goals and get them on board with finding delicious new approaches to foods you haven't tried before. If you need ideas, check out the Cancer Center's Recipes Just for You Web site at **mcancer.org/recipes**.

If you want to lose weight, take this approach first. Your goal now isn't just to lose weight, but to find a way to eat healthfully for the rest of your life. The weight loss will naturally follow, especially if you make a point of being physically active for 30 minutes a day.

We asked our colleague, Ronald Sayre, a University of Michigan physical therapist, for his tips on getting into gear with exercise. Visit **mcancer.org/thrive** to see what he has to say. It's the first step to taking back control.



To make an appointment with a Cancer Center registered dietitian for personalized counseling, call **734-647-8902**.

CURIOUS ABOUT SUPPLEMENTS?

Send your questions to **ThriveMagazine@med.umich.edu**. We'll address them in an upcoming story. And remember, always tell your health-care team if you are taking supplements.

RESEARCH ROUND-UP

COST BLOCKS SURVIVORS FROM FOLLOW-UP CARE, STUDY FINDS

As many as 2 million American cancer survivors may be going without health care because of its expense, according to a recent National Cancer Institute study.

Based on the National Health Interview Survey that collected data between 2003 and 2006 from 40,000 households, the NCI examined health-seeking behaviors of 6,602 adult cancer survivors as compared with 104,000 adults without a cancer history.

Survivors younger than 65 were almost twice as likely to go without medical care as were people in the same age group who had never had cancer.

Douglas Blayney, M.D., medical director for the University of Michigan Comprehensive Cancer Center, said it's critical for cancer survivors to seek regular medical care.

"We know that some people who have one cancer are

at high risk for getting a second cancer, either from innate susceptibility or as a side effect of treatment. Part of survivorship care is targeting those who are most at risk so that we catch cancers early when they're more likely to be treatable," said Blayney, who was not involved in the NCI study. "If it's important for the general population to be screened



Douglas Blayney, M.D., is medical director for the University of Michigan Comprehensive Cancer Center.

to catch cancers early, then it's even more important for cancer survivors because of their increased risk for developing second cancers."

The NCI study found that almost 8 percent of the cancer survivors went without medical care because of cost. Nearly 11 percent went without dental care, 3 percent went without mental health care and 10 percent failed to fill prescriptions for the same reason.

African-American and Hispanic cancer survivors appeared to be disproportionately affected by cost: Hispanic survivors were twice as likely as white survivors to go without prescriptions, while African-Americans were 87 percent more likely than whites to do that.

"There are certainly a lot of things we don't know about survivorship care. This study points out that cost

is one barrier to care, but there may be others we don't understand," Blayney said. "One of the ways we can address this within the medical community is to be more directed in our testing so that we can target those people we know are at risk. That way, we can be more efficient in our use of health-care dollars."

ADULT SURVIVORS OF CHILDHOOD CANCER HAVE LOWER BONE-MINERAL DENSITY

Men who survived childhood leukemia treatment into adulthood were more likely to have lower bone-mineral density than other adults their age, putting them at risk for bone fractures and osteoporosis, a bone disorder common in older adults, according to a new study.

Researchers led by James G. Gurney, Ph.D., of the University of Michigan Comprehensive Cancer Center, found that 24 percent of the 74 survivors studied had abnormally low bone-mineral density, a measure of bone strength. The average age of the survivors was 30, and they had been treated an average of 24 years ago for the most common type of childhood cancer, acute lymphoblastic leukemia.

According to the World Health Organization, in the general population, 11 percent of 30-year-old men and



19 percent of 30-year-old women on average have low bone-mineral density, a condition known as osteopenia. In this study, published in the journal *Cancer*, 36 percent of men and 16 percent of women had low bone-mineral density.

"Studies such as this one stress the importance of monitoring for bone health in

these survivors, particularly since there may be some simple interventions, such as vitamin D and calcium, that may be beneficial," said study lead author Inas Thomas, M.D., a U-M pediatric endocrinology fellow.

The researchers also looked at levels of growth hormones, which are affected by leukemia treatment. Low growth-hormone levels can contribute to poor bone health. The researchers believe the disease itself or the treatments, such as radiation particularly to the brain—and chemotherapy may affect bone growth.

"We would argue that all adult survivors should be screened," Thomas said. "The disease, chemotherapy and cranial radiation—even if they do not lead to growth-hormone deficiency—may play a role in the development of osteopenia or osteoporosis."

thrive

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 Martha Towas at 734-936-0434.

Max S. Wicha, M.D., director

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

Karen Hammelef, M.S., director of Patient & Family Support Services

Nicole Fawcett, communications lead

Jennifer Day, editor

Lin Jones, photographer, U-M Photo Services

Enrique Cruz Jr., art director, GLC

Executive Officers of the University of Michigan Health System: Robert P. Kelch, Executive Vice President for Medical Affairs; James O.Woolliscroft, Dean, U-M Medical School; Douglas Strong, Chief Executive Officer, U-M Hospitals and Health Centers; Kathleen Potempa, Dean, School of Nursing.

The Regents of the University of Michigan: Julia Donovan Darlow, Laurence B. Deitch, Olivia P. Maynard, Denise Ilitch, Andrea Fischer Newman, Andrew C. Richner, S. Martin Taylor, Katherine E. White, Mary Sue Coleman (ex officio).

The University of Michigan, as an equal opportunity/affirmative action employer, complies with all applicable federal and state laws regarding nondiscrimination and affirmative action, including Title IX of the Education Amendments of 1972 and Section 504 of the Rehabilitation Act of 1973. The University of Michigan is committed to a policy of nondiscrimination and equal opportunity for all persons regardless of race, sex, color, religion, creed, national origin or ancestry, age, marital status, sexual orientation, gender identity, gender expression, disability, or Vietnam-era veteran status in employment, educational programs and activities, and admissions. Inquiries or complaints may be addressed to the Senior Director for Institutional Equity and Title IX/Section 504 Coordinator, Office of Institutional Equity, 2072 Administrative Services Building, Ann Arbor, Michigan 48109-1432, 734-763-0235, TTY 734-647-1388. For other University of Michigan information call 734-764-1817.

Copyright ©2009 The Regents of the University of Michigan, Ann Arbor, Michigan 48109

For more information about the stories in *Thrive* or any other cancerrelated information, please call the Patient Education Resource Center at 734-647-8626.

JUST A PHONE CALL AWAY



Would you like to learn how you can give back to the U-M Comprehensive Cancer Center? Please visit www. mcancer.org/giving or call 734-998-6893.



Cancer AnswerLine: 800-865-1125

Child and Family Life: 734-647-6418

Complementary Therapies Program or Patient & Family Support Services: 734-615-4012

Development: 734-998-6893

Discharge Planning Services: 734-764-0589

Customer Service/Billing: 734-615-0396

Fertility Counseling and Gamete Cryopreservation: 734-763-4323

Financial Counselor: 734-647-8663

Guest Assistance Program, Social Work, Peer Counseling or Wig Bank: 800-888-9825

Grief and Loss Program: 734-615-4012 Nutrition Services: 734-647-8902 Occupational Therapy: 734-936-7175 Patient Education Resource Center: 734-647-8626 Peer Counseling: 800-888-9825 Personal Touch Program: 734-973-2400 Physical Therapy: 734-936-7070 PsychOncology Clinic: 734-232-6366 Ronald McDonald House: 734-994-4442 Skills Lab: 734-232-6366 Speech-Language Pathology: 734-763-4003 Social Work: 800-888-9825 Volunteer & Community Resource Program: 734-936-8307

RESOU

RESOURCE EXCHANGE Tips and advice designed just for cancer patients

When we were talking to survivors for this issue, we met one who didn't want people to know she had had cancer. She wasn't ashamed—and in fact she was eager to talk with us about concerns she had faced in the hope that it would help someone else.

But she declined to be identified because she was worried she had been the victim of employment discrimination.

"There was one job where I really thought I nailed the interview," she said. "I got a 98 percent on the test, but when I called to ask why I wasn't hired, the interviewer told me, 'We didn't design the test for you to fail.' I think I told her too much. I'm not old enough to retire, but I feel like there was some kind of prejudice because I'd been ill." People who have a history of cancer are under no obligation to tell potential employers about their diagnosis. And, it is illegal for potential employers to ask. So where do you go if you have concerns about the legal ramifications of cancer?

Consider calling the Cancer Legal Resource Center, a free service based in California. The center provides confidential information and resources on a number of legal issues, including insurance coverage, employment discrimination, access to health care

and estate planning.



To learn more, visit mcancer. org/thrive or call the center directly at 866-843-2572.