

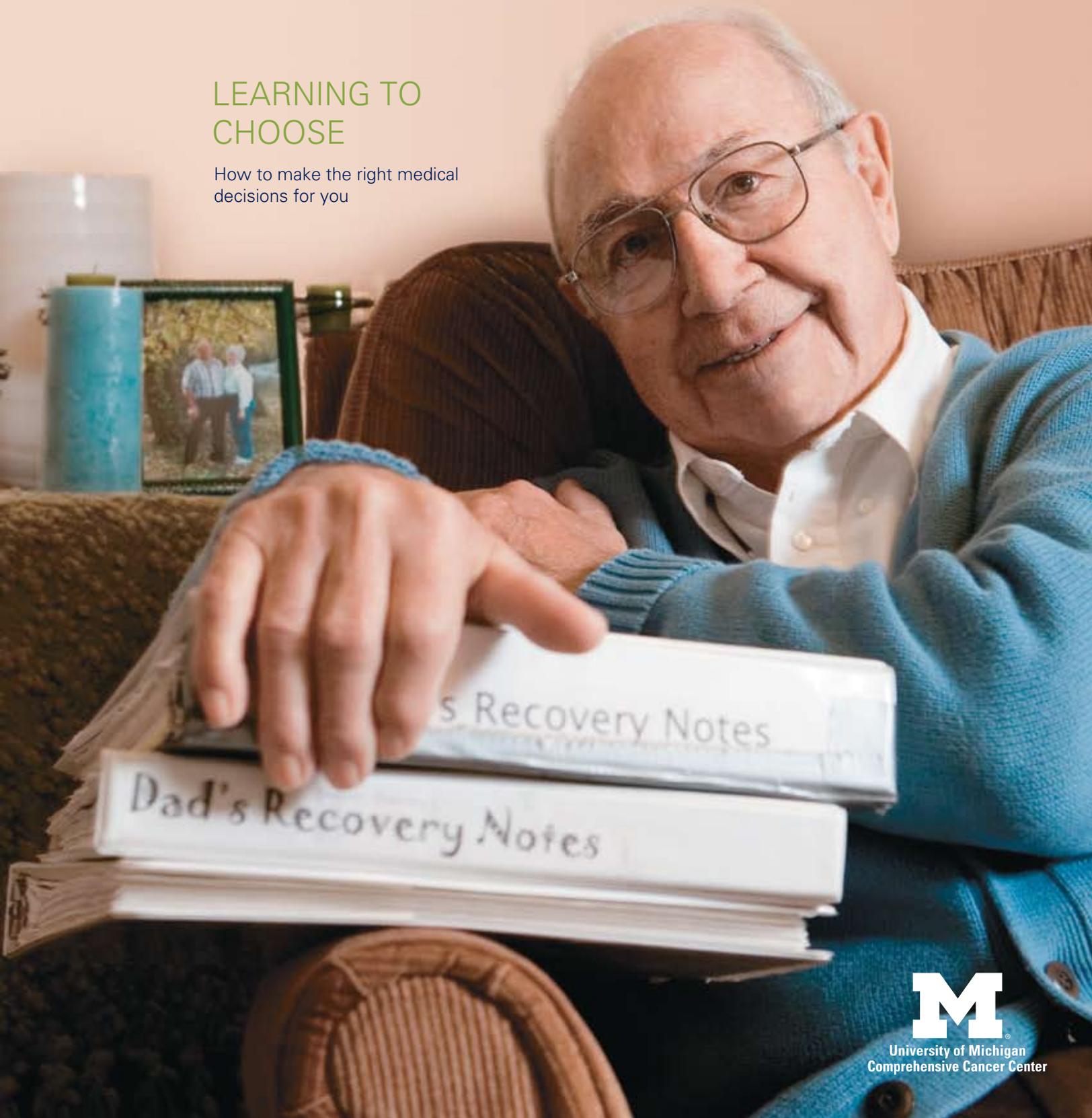
thrive

A Publication of the University of Michigan Comprehensive Cancer Center

Winter 2008

LEARNING TO CHOOSE

How to make the right medical
decisions for you



University of Michigan
Comprehensive Cancer Center

on the cover:

Louis Spino, a pancreatic cancer survivor, carefully considered his treatment options before choosing a plan offered by the U-M Cancer Center.

Photo by Martin Vloet, U-M Photo Services



04 TARGETING THE SOURCE

Cancer Center Director Max Wicha, M.D., discusses the promise of cancer stem cell research.



06 PEACE OF MIND

Thrive offers 10 strategies for coping with the financial impact of cancer.



10 LEARNING TO CHOOSE

How do you decide on a cancer treatment? Find out how Louis Spino found the best option for him.



WRITE

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.**



13 TELLING STORIES

Larry Hoffman, who has multiple myeloma, relives his days in the U.S. Air Force as part of his work with the Cancer Center's new Creative Writing Program.



14 A TEMPORARY FIX

What to expect when temporary tube feeding is necessary—and why, for some, it comes as a surprising relief.



15 RESEARCH ROUND-UP

U-M experts discuss the latest news in cancer research and what it means for you.

THE VIEW FROM ABOVE



On the four floors directly above the U-M Cancer Center's clinics, an army of researchers is working toward the same goal you are: To find a cure for your cancer.

We've given you a sneak peek inside a lab in this issue where research is underway that could change everything about cancer care. Max Wicha, M.D., the Cancer Center's director and a distinguished professor of oncology, is working to develop ways to target cancer stem cells—the cells that are the very roots of cancer. The research is vastly complex, but at its core is something profoundly intuitive: You can't kill weeds without getting at the roots.

Dr. Wicha, a pioneer in cancer stem cell research, plans the first human clinical trials in the near future.

Meanwhile, our clinics are already advancing cancer treatment with the help of patients who volunteer to participate in studies. In our cover story, we talk to a patient who decided to enroll in a clinical trial with our Multidisciplinary Pancreatic Cancer Clinic—one of the nation's leading centers for this type of cancer, in large part because of the research they conduct to find better methods to fight the disease.

The U-M Cancer Center is harnessing the power of its 350 faculty members who actively treat and research cancer along with \$79.5 million in funding from the National Institutes of Health. Physician researchers working in partnership with patients like you are developing the best in medical science—the best hope for a cure.

Growing Better

NEW CLINICS DEDICATED TO LIVER, NEUROLOGICAL CANCERS OPEN

THE CANCER CENTER RECENTLY ADDED TWO NEW PROGRAMS TO ITS ROSTER, FURTHERING THE UNIVERSITY OF MICHIGAN'S COMMITMENT TO PROVIDING PREMIER CARE TO PEOPLE WHO HAVE CANCER.

The Cancer Center also allotted additional space to many existing clinics within the building.

The new programs will focus on cancers of the nervous system and liver. The American Cancer Society estimates that about 20,500 people are diagnosed annually with cancers of the brain or nervous system; another 19,160 people are diagnosed with liver or bile duct cancers.

“By bringing these new programs under the Cancer Center’s umbrella, we will be able to provide a new level of care to patients with these types of cancer,” said Douglas Blayney, M.D., the Cancer Center’s medical director. “The clinics provide a multidisciplinary approach—the gold standard in cancer care—in a setting that offers convenient access to related services, such as infusion and Patient & Family Support Services.”



Photo by Lin Jones, U-M Photo Services

Amy Dorr checks in at the Level 1 reception desk, which also serves neuro-oncology patients.

A multidisciplinary approach is rooted in the philosophy that collaboration among cancer specialists will lead to the best quality care. The defining feature of this approach is the tumor board.

Tumor boards are meetings where physicians from numerous specialties—including medical oncology, surgical oncology, radiation oncology, radiology and pathology—meet to discuss an individual patient’s case. By the conclusion of the meeting, the physicians come to consensus about what they believe to be the best course of action. That recommendation is then presented to the patient for consideration. Meanwhile, the patient comes to only one appointment.

In addition to the new clinics, infusion services in the U-M Canton Health Center are continuing to grow. After a successful first year, the center has expanded from six chairs to nine chairs to accommodate more patients.

Located at 1051 N. Canton Center Road, near the Interstate-275 Ford Road exit, the Canton branch is designed to provide Detroit-area patients easier access to frequent chemotherapy treatments.

“We know that our patients are looking for care closer to home, and we know that approximately 15 percent of our infusion patients come from the I-275 corridor,” Blayney said. “While cancer treatment is complex, new procedures make it safe to administer chemotherapy at satellite centers. We hope the expansion will make treatment a little easier on our Detroit-area patients and those patients whose primary care doctors already practice at the U-M Canton Health Center.”



CALL

For more information about the Liver Cancer or Neuro-Oncology clinics, please call the Cancer AnswerLine at 800-865-1125. To schedule an infusion appointment at the Canton Health Center, talk to your physician.

Targeting the Source

CANCER STEM CELL
RESEARCH OFFERS
HOPE FOR CURE



Max Wicha, M.D., studies cancer stem cells in the hope of developing more effective treatments.

Photo by Lin Jones, U-M Photo Services

DESPITE BILLIONS OF DOLLARS SPENT ON RESEARCH, CANCER REMAINS THE NO. 2 CAUSE OF DEATH IN THE UNITED STATES.

Today's doctors have better ways to find and treat early stages of the disease. But once cancer spreads, current treatments too often don't work. Why haven't we cured cancer yet?

We talked to Max Wicha, M.D., founding director of the Cancer Center and Distinguished Professor of Oncology, about research on cancer stem cells. Many scientists now believe cancer begins when these stem cells divide abnormally and grow out of control. Cancer Center scientists are developing new treatments to target these stem cells. Wicha believes this research will revolutionize the way physicians treat cancer.

Q: What are cancer stem cells?

A: Most cells in the body live for a short time, so we need a regular supply of new cells to replace old ones. These new cells come from the division of what scientists call "adult" stem cells, which are found in every organ in the body. Breast stem cells make new cells in breast tissue, for example. Liver stem cells make new liver cells.

Cancer stem cells are adult stem cells found in different types of cancer. When cancer stem cells divide, they make more cancer cells. They divide abnormally and too often. We believe this uncontrolled division of cancer stem cells is responsible for the development, growth and spread of cancer.

Q: How common are cancer stem cells?

A: On average, only about 1 percent of the millions of cells in a cancer are true cancer stem cells. But we believe they exist in all types of cancer. They were first discovered



in 1994 in leukemia. In 2003, U-M Cancer Center scientists were the first to find them in breast cancer tumors.

Q: Why are these cells so important?

A: Cancer stem cells are responsible for the development, growth and spread of cancer. If we had a way to destroy or control these stem cells, we could cure cancer. Unfortunately, traditional therapies like chemotherapy don't work. They kill most cells in the tumor, but not stem cells. So, the cancer often returns. We want to develop new treatments targeted at cancer stem cells, because if these cells are eliminated, the cancer won't grow and spread to other parts of the body.

Q: Will cancer stem cell research change how doctors treat cancer?

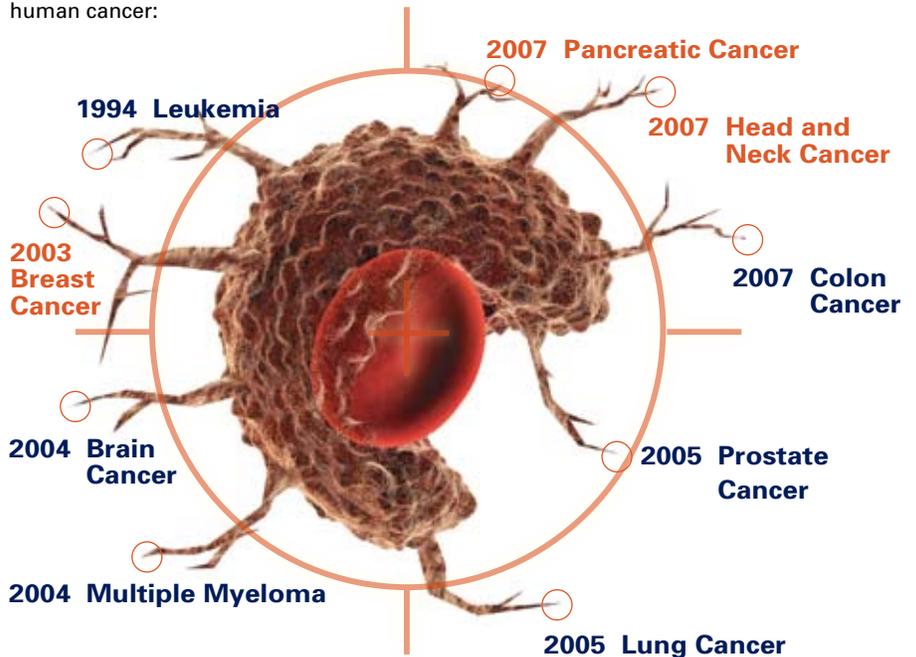
A: This research could change everything. Analyzing the stem cells in a patient's tumor will help us predict how aggressive the cancer will be and determine the best treatment plan for each patient. Most importantly, killing cancer stem cells could stop the disease from coming back. It's our best hope for a real cure. Also, new therapies that target and kill stem cells could eliminate side effects.

Q: How much U-M Cancer Center research involves cancer stem cells?

A: Our goal is to become the world's leader in research on cancer stem cells and in the development of new cancer therapies, so we have committed significant resources to this research. We have teams of scientists studying stem cells in most types of common cancers, including leukemia, melanoma, myeloma, adrenal, breast, colon, head and neck, lung, pancreatic, prostate and thyroid cancers.

TYPES OF CANCER STEM CELLS FOUND

During the past 14 years, cancer stem cells have been found in many types of human cancer:



■ Discovered at the University of Michigan Comprehensive Cancer Center

I am pleased to report that we also have support from federal funding agencies and private donors, including a recent gift from the Taubman Medical Research Institute.

Q: When will stem cell-based treatments be ready for use in patients?

A: Before they are approved, new treatments must be tested to prove they are safe and effective. This process takes several years. Currently, Cancer Center researchers are conducting a small study in patients of a treatment aimed at stem cells in multiple myeloma. Next year, we hope to begin the first human trials of a treatment targeted at breast cancer stem cells. We aren't recruiting for these studies now, because they involve just a few patients with advanced cancer that has not responded to traditional therapy. But within the next few years, we hope to begin larger clinical trials of stem cell-based treatments for several types of cancer.



Learn more about stem cells with our new online tutorial. Visit mcancer.org/thrive.



Peace of Mind

10 STEPS TO COPE WITH THE
FINANCIAL IMPACT OF CANCER

NEARLY THREE-QUARTERS OF AMERICANS SAY MONEY IS A SIGNIFICANT SOURCE OF STRESS, ACCORDING TO A RECENT AMERICAN PSYCHOLOGICAL ASSOCIATION POLL.

BUT YOU DIDN'T NEED THEM TO TELL YOU THAT.

When a cancer diagnosis slams into your pocketbook, financial jitters quickly mount. Having a firm sense of how to handle it can help you focus on yourself, your family and your well-being.

We've assembled some tips to stretch a dollar.

1 Get organized.

Disorganization costs money: You buy things you forgot you had. You think a bill is wrong, but can't find receipts to doublecheck. Life gets more complicated when medical bills enter the picture.

Appoint a family member or close friend to monitor billing, deal with insurance companies and make sure you are taking advantage of benefits your employer offers. Ask your friend to help you keep good records to deal effectively with insurance companies. If you need help understanding a charge or you'd like copies of bills from the U-M Health System, Sue Thornton, the Cancer Center's financial counselor, can help. (Call 734-647-8663.)

2 Just say yes.

When people ask, "How can I help," they mean it. It often helps friends and family feel better to find ways to pitch in. It's OK right now to lean on people.

Create a list of things that would be useful to you so you can have a response ready, said Sheila Morris, a Cancer Center child life specialist. Ideas may include casseroles, grocery shopping, a ride to chemotherapy or help with fees for your

children's after-school activities. If your employer allows it, co-workers may be willing to donate extra vacation days to your leave bank.

3 Make it easy for friends and family to contribute.

People think nothing of bringing gifts to birthday parties; so why not celebrate life with gifts when it matters most? Amazon.com offers a "wishlist" service that functions much like a gift registry—and allows friends and family to help with the click of a mouse.

Select household goods, like paper towels and laundry detergent, or nutritional supplements, like Boost and multivitamins. Add them to your wishlist. Enter an address so items can be shipped directly to you or a friend who can organize the effort.

Then send a link to the wishlist via e-mail with a brief explanation to friends and family. This won't pay your medical bills, but cases of nutritional drinks and household expenses add up fast.

4 Host a party; raise some cash.

After Trisha VanDerBos's daughter, Laura, was diagnosed with stage IV neuroblastoma, her family banded together to organize a golf outing. VanDerBos's brother and sister-in-law, Scott and Brandi Warner, got together with Brandi's brother and sister-in-law, Adam and Lisa Priest, to round up donations for raffle and door prizes. In the end, several hundred people attended, raising enough money for VanDerBos to feel comfortable about covering costs that insurance wouldn't pay as well as household and travel expenses.

"It's so hard to accept help. I've really struggled with it," VanDerBos said. "But the thing that really helped

me to get over it is that people want to help in so many ways, but they don't know how. I'm very fortunate to have so much support. If I didn't have that support, I couldn't focus on what was most important now, which is taking care of Laura."

5 Demand better rates.

Unless you're a bargain hunter, you probably pay your monthly bills without a whole lot of comparison shopping. Review regular bills to make sure you're paying the lowest rates. Consider:

- ▶ Can you get a better cell phone plan?
- ▶ Do you belong to unions or other organizations that qualify you for discounts?
- ▶ Can you get new quotes on car and homeowners' insurance?
- ▶ Have the interest rates on your credit cards crept up? Try calling credit card companies to negotiate lower rates.
- ▶ Talk to your utility companies. Do they have different payment options to equalize charges throughout the year so you don't get hit by high heating bills during winter months?
- ▶ Could you pare back on cable or broadband services?
- ▶ Should you refinance mortgages or student loans?



6 **Get the kids involved in the conversation.**

Help your children understand the new challenges your family is facing so that they aren't surprised if you need to cut back in ways that affect them. Get them involved in decision-making. Challenge them to help find ways to save: Perhaps you could rent a DVD and pop popcorn at home, rather than going out to the movies. This can be a good opportunity to help them learn to be responsible with money.

Also, do your kids really enjoy all the activities they're involved in? After-school commitments can be financially draining. If you need to cut back on them, ask your kids what's most important to them. Simplifying obligations often leads to less stress and more family time.

7 **A balanced mind equals a balanced checkbook.**

The more emotionally equipped you feel, the better you're able to handle financial stresses. If you're feeling depressed or anxious—whether it's about money or other worries—the Cancer Center offers a number of free programs to help cope. Consider counseling through the Psych-Oncology Program or a social worker. Patient & Family Support Services' Complementary Therapies program also offers several other options, including guided imagery, art therapy, music therapy and creative writing.

8 **Balance finances with the urge to go organic.**

Organic food is more expensive, but do you need to buy it? Joan Daniels, a Cancer Center dietitian, said that the most important goal is to try to eat more vegetables and fruits—organic or not. If you would like to include some organic foods in your diet, but don't want to break the bank, choose foods that generally have the highest levels of pesticide residue when grown conventionally, including apples, bell peppers and potatoes. Whether you buy organic or not, be sure to wash food thoroughly before eating it.

While you're in treatment, getting enough protein is important, but that doesn't mean you need to buy steaks. Consider foods like peanut butter that will give you the best bang for your buck. Adding skim milk powder is an economical way to get more out of a glass of milk or a serving of mashed potatoes.

9 **Don't be taken in by scams.**

You won't find the cure for cancer on the Internet. Unfortunately, plenty of people are willing to exploit people with cancer to make a fast buck. If you are interested

in exploring alternative therapies, before you invest in them, make sure their claims are supported by evidence-based research published in respected medical journals, like the *New England Journal of Medicine*. Contact the Cancer Center's Patient Education Resource Center at 734-647-8626 to help you make good choices.

10 **Seek formal assistance.**

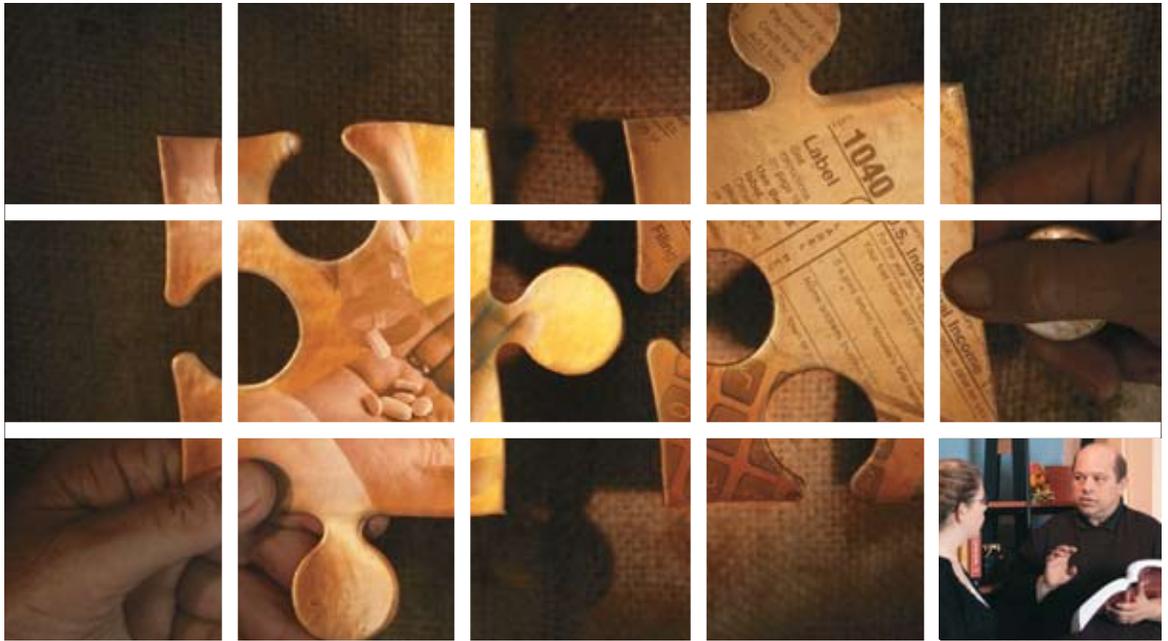
If you're not able to make ends meet, you may be eligible for financial assistance provided by government or non-profit agencies. Cancer Center social worker Dawnielle Morano advises patients who may be out of work for six months or more to apply for Social Security Disability immediately.

Depending on your diagnosis and your need, some organizations—such as the Patient Advocate Foundation or the Leukemia & Lymphoma Society—may provide co-pay assistance or reimbursement for travel expenses, medications or procedures. Pharmaceutical companies also have assistance programs. For more information, contact Social Work at 800-888-9825. Those who travel by air to the University of Michigan for cancer treatment may qualify for free flights through the Corporate Angel Network.

TIP

Nancy Burke, a Cancer Center dietitian, said patients should let her know if they are having trouble paying for nutritional supplements. Many companies offer free cases or samples for those in need.





With the April 15 tax deadline fast approaching, we asked accountant Jim Palazzolo, of Arbor Accountancy, in Ann Arbor, to give us the lowdown on medical expense deductions. Here's what he told us.

Q Who can claim medical expense deductions?

The IRS allows medical deductions if you meet two criteria. The first hurdle is whether it makes sense to itemize deductions. So you need to figure out which is bigger: the standard deductible—a figure established annually by the federal government—or the sum total of allowable itemized deductions, including eligible medical expenses, taxes, interest, charitable contributions, casualty and miscellaneous expenses. If the standard deduction is larger than all of these itemized deductions, there is no reason to itemize. One strategy is to bunch up deductions like real estate taxes or charitable contributions into every other year so that your itemized deductions exceed the standard deduction. Remember, you can claim a deduction based on when you pay the bill, rather than its due date, so it may make sense to pay deductible taxes early.

Q What's the second hurdle?

Next, you need to overcome the 7.5 percent medical expense deduction floor. Only allowable medical expenses exceeding 7.5 percent of your adjusted gross income can be deducted. Your adjusted gross income is all of your wages minus allowable deductions. If you take a loan to pay expenses, the loan is deductible. Prepayments toward medical expenses are not deductible, except in rare cases. Cashing in part of your tax-deferred accounts for medical bills may allow you to avoid some portion of withdrawal penalties.

Q Which medical expenses are deductible?

In general, deductible medical expenses are the taxpayer's unreimbursed costs for the diagnosis, treatment or prevention of disease. Transportation that is essential to medical care as well as qualified long-term services and insurance premiums qualify.

Q For whom can you claim a medical expense?

Ahh, sweet relief. The IRS actually does something kindly by allowing you to claim not only expenses paid for your spouse and your tax dependents, but also expenses paid on behalf of a person whom you could have claimed as a dependent. For example, you are allowed to take medical expenses you paid on behalf of a parent, even if your parent files a tax return, provided all other dependency requirements are met. Domestic partners or others who live with you for the entire year also may qualify.

Q Any tips for planning for the coming year?

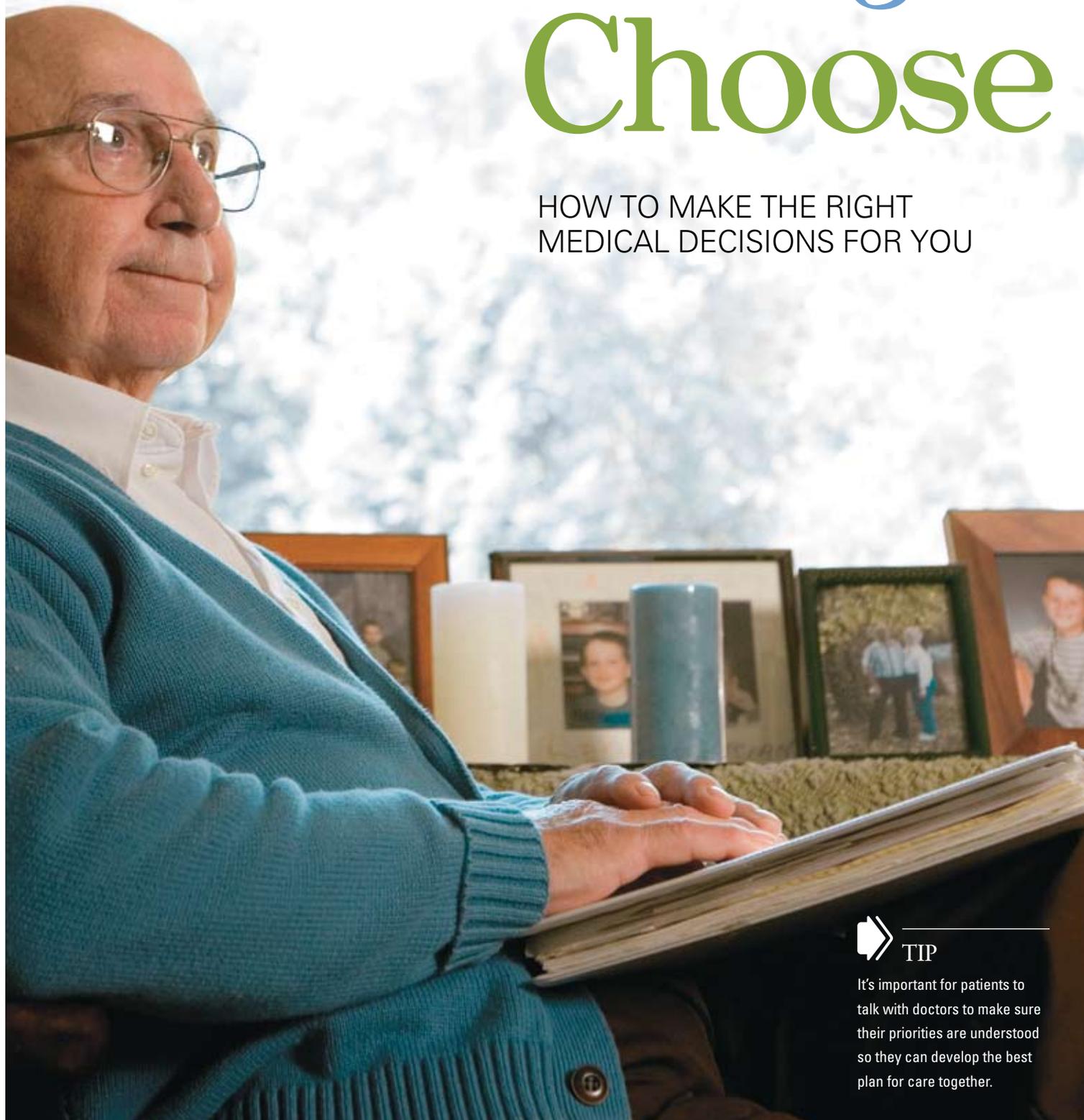
If you're not covered by a health-care plan, you might want to consider opening a Health Savings Account, an IRA-like account to pay medical expenses. The essence of an HSA account is that it provides tax benefits for those individuals who can't itemize and aren't covered by other health care.



For a full list of related resources, please visit mcancer.org/thrive or call the Cancer AnswerLine at 800-865-1125.

Learning to Choose

HOW TO MAKE THE RIGHT MEDICAL DECISIONS FOR YOU



Photos by Martin Vloet, U-M Photo Services



It's important for patients to talk with doctors to make sure their priorities are understood so they can develop the best plan for care together.

LOUIS SPINO WAS STILL RECOVERING FROM OPEN-HEART SURGERY IN 2005 WHEN HIS BUDDY ASKED HIM WHY HIS EYES WERE YELLOW. A CT SCAN CONFIRMED THAT SPINO, THEN 80, HAD PANCREATIC CANCER.

A local oncologist told Spino he needed to go somewhere where they see a lot of cases like his. So Spino's five daughters kicked into gear. They opened a third volume in a series of binders they were keeping about their father's health: Dad's Recovery Notes.

"We sat down that day and started calling people," said Margie Spino, who lives a block away from her father in Toledo, Ohio. "We weren't shy."

The Spinos talked to the nation's leading pancreatic cancer specialists at cancer centers in Chicago, Baltimore, Houston and Ann Arbor. Each offered opinions. The centers in Baltimore and Houston were eliminated first, given the distance. The decision came down to Lurie Comprehensive Cancer Center of Northwestern University and U-M. U-M recommended chemotherapy and radiation followed by surgery; Northwestern recommended surgery first.

As medicine advances, patients with all types of cancer are presented with more options for treatment. But sorting through those options and deciding what's best can be confusing and intimidating.

"Human beings are not always great decision-makers," said Peter Ubel, M.D., a Cancer Center researcher with the U-M Center for Behavioral and Decision Sciences and Medicine. "The best decisions are made when a patient and clinician together figure out what a patient cares about, and when there's more than one option, what fits that patient best."

“The best decisions are made when a patient and clinician together figure out what a patient cares about, and when there's more than one option, what fits that patient best.”

Assessing options

For Louis Spino, he wanted to treat the cancer aggressively.

"Regardless of what happened, I figured I'd do the best I can," he said.

The U-M Multidisciplinary Pancreatic Cancer Clinic—which consists of specialists in several fields—met to discuss Louis's case. He was clearly a candidate for a surgery called a "Whipple"—and could have had it immediately, as Northwestern had recommended.

But the procedure is complicated, lasting as long as five or six hours, said Diane Simeone, M.D., surgical director of the Multidisciplinary Pancreatic Cancer Clinic. During a Whipple, surgeons remove tumors located in the head of the pancreas, which is attached to several other critical organs, including the duodenum, the bottom half of the bile duct, the gall bladder and the bottom third of the stomach.

To help give Louis more time to recover from his heart surgery two months earlier, the U-M team recommended a clinical trial. Instead of having surgery immediately, Louis would have chemotherapy and radiation first to keep the tumor at bay.

Research is ongoing to determine whether this approach is more effective than doing surgery first, said Mark Zalupski, M.D., medical director of the Multidisciplinary Pancreatic Cancer Clinic. However, there's a risk that a patient's cancer may spread before surgery; in those cases, researchers believe the cancer may be so aggressive that surgery wouldn't have benefited the patient anyway.

Ultimately, the Spino family chose the University of Michigan.

"It's so hard. You're lay people trying to make the best decision you can," Margie said. "How do you make that decision? I think it came down to proximity. It seemed to make sense."

'Best' vs. right and wrong

When there's more than one viable option for medical care, it's not always easy to identify the right choice, said Ubel, who researches the best ways to communicate with patients. His team is looking at developing decision aids that use different types of pictures and graphs to help clarify risks and benefits to patients.

It's important for patients to talk with doctors to make sure their priorities are understood so they can develop the best plan for care together. It gets tricky, though. For example, Ubel studied perceptions of having to live with a colostomy—a procedure that reroutes the intestine to an opening in the abdominal wall so that

COVER STORY

stool is collected in a bag outside the body. People who had never had the procedure often believed a colostomy would negatively impact quality of life more so than people who were actually living with a colostomy.

“Doctors know that patients with colostomies do pretty well, but sometimes things sound gross,” Ubel said. “That’s when it’s appropriate for a doctor to use a little bit of persuasion. We’re not just data dumpers.”

With pancreatic cancer, Zalupski said, he doesn’t feel a need to push patients in any direction because the options are roughly equivalent. He presents treatment plans honestly and then answers questions.

Because pancreatic cancer can be very hard to control, patients often feel pressured to make decisions immediately, said Janet Hampton, clinic coordinator. She helps patients talk through options and encourages them to take time to think about their decision.

“Often times, people feel pushed by their diagnosis. They feel like they have to get going, they have to get treatment,” she said. “But you can take time to think about it. A few days or a week is not going to be critical in changing the course of the disease.”

Living with the Decision

For the Spinós, they had a different time concern: Louis’s age. Louis, now 82, wanted to treat the cancer aggressively. But his daughters ran into some ageism along the way.

Zalupski said fitness, rather than age, is more important in assessing options.

“It makes you feel so much better,” said Cherie, another Spino daughter. “Some people gave us the feeling that they couldn’t believe we were putting Dad through this at that age.”

Louis underwent surgery in August 2005, following a two-month regimen of chemotherapy and radiation. After the Whipple, he had additional chemotherapy. Since finishing treatment in December 2005, he has been disease free.

It’s all there in the binders, the Spino daughters’ meticulous notes about their father’s health. Just after Louis’s diagnosis, the five sisters fretted over which clip art to choose for the cover—something Margie and Cherie laugh about now.

“That’s what keeps me going,” Louis said, gesturing to his daughters. “It ain’t just medicine.”

TIPS FOR MAKING DECISIONS

Whether you have prostate cancer and you’re trying to decide between surgery and radiation, or you have breast cancer and you’re trying to decide between a mastectomy and breast-conserving therapies, the same tips for making medical decisions apply.

▶ **Make sure your doctor understands**

where you’re coming from. Talk to your doctor about what’s most important to you.

▶ **Don’t hesitate to get a second opinion.**

The Spino family continued to consult with a physician at Johns Hopkins Sidney Kimmel Comprehensive Cancer Center even after they had ruled out traveling to Baltimore.

▶ **Seek out doctors** who have treated many cases like yours. This ensures high levels of physician expertise as well as an environment prepared to deal with any complications that may arise.

▶ **Don’t be shy** about asking questions. Take notes or record conversations so you can go back to it later or share it with family members.

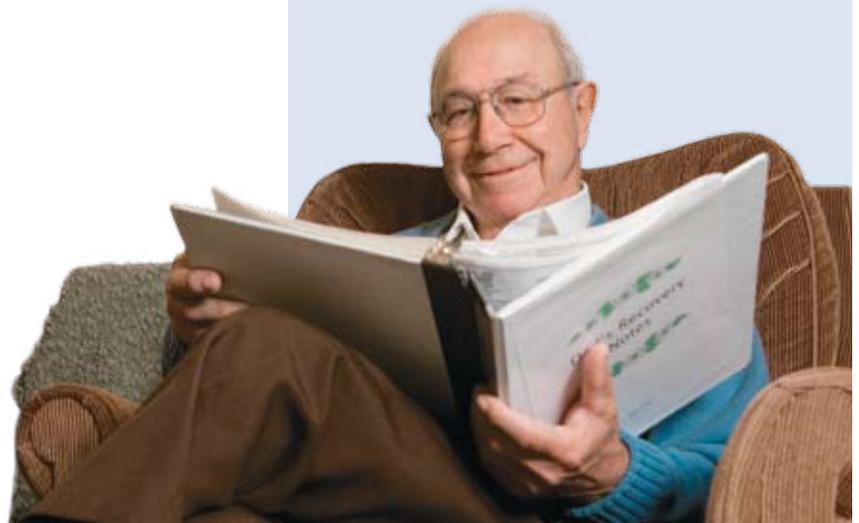
▶ **Push for time.** There’s benefit in taking time to sleep on it. Even when you are not consciously thinking about issues, thoughts and opinions can mature and become clear.

▶ **Don’t be afraid** to change your mind. Melissa McKenna, a bladder cancer survivor, initially agreed to participate in a clinical trial, but decided on the way to an appointment that she didn’t want to delay surgery. She told her doctor and rescheduled her operation for an earlier date.



CLICK

For more information about making decisions about your care, visit mcancer.org/thrive.



Telling Stories

“ I ONLY CRASHED ONCE. IT WAS DURING FLIGHT TRAINING SCHOOL ”

SO BEGINS A SEGMENT OF LARRY HOFFMAN’S ORAL HISTORY—A HISTORY THAT STRETCHES FROM HIS BOYHOOD IN INDIANA, THROUGH FOUR TOURS OF DUTY AS A U.S. AIR FORCE PILOT IN VIETNAM, TO HIS LIFE NOW IN COLDWATER, MICH. HOFFMAN, WHO HAS MULTIPLE MYELOMA, IS WORKING WITH THE CANCER CENTER’S NEW CREATIVE WRITING PROGRAM TO DOCUMENT THE STORIES OF HIS LIFE.



Larry Hoffman works with the Cancer Center’s Creative Writing Program to record his memories.

Led by Dave Karczynski, a graduate of the U-M master of fine arts program, and M.F.A. student Kodi Scheer, the Cancer Center’s Creative Writing Program helps patients develop language skills to capture their thoughts, feelings and memories. Hoffman said he wishes he knew more about his own family, which is why he’s taking the time to record his history.

“Kids and grandkids don’t know what went on before them, but this is one way of preserving it and giving it as a gift to the family,” said Hoffman, 68. “Most people just put it off.”

Writing about emotional experiences has been shown to promote health and well-being. Early research suggests that some types of immune system function improve after writing. Participants in a study published in *Psychological Science* also reported long-term improvement in mood and well-being, despite initial pain related to writing about

upsetting experiences.

Karczynski and Scheer talk with hospitalized patients to develop oral narratives through the program, which is supported in part by Cancer Center donors. Karczynski also runs a weekly creative writing seminar in the Cancer Center’s Patient & Family Center, on Level 1.

As an undergraduate, Scheer intended to go to medical school, but had an epiphany while working on an honors thesis in cognitive neuroscience: She was more interested in patients’ stories than in the diseases they had. Karczynski thought he could make an impact in people’s lives while he works on his own novel.

“There are easy tricks we can teach people to help them improve the effect of their writing: how to communicate images in your head, how to describe a person so he really comes alive to the reader,” he said.

For Hoffman, the images included a fiery plane crash.

“ It was definitely an emergency situation, and we responded accordingly. You’ve got to burn fuel, get Pedro the rescue helicopter, cinch your parachute tight in case you have to eject. When the time got close to landing, they asked us if we wanted the runway foamed, in case of fire. We said no. We touched down.

I have to admit that I was enjoying it—the danger, the intensity, everything. My trainer did a good job on the landing. He kept the right wing (the damaged side) off the ground as long as he could, but of course when it came down, the tire shredded apart, unraveled and flew into the engine. The bare wheel ground down into its magnesium core; the fuel caught fire and we had 60 feet of flame. Pedro was right above us, the plane shuddering with the chopper’s thumping.

My trainer bailed out first, then me, but we both had forgotten to uncinch our parachutes. We ran away from the flames to the grass on the side of the runway. We made it. They put the fire out.

I was alive; everything was good. ”

—Larry Hoffman

A Temporary Fix

WHAT TO EXPECT WHEN TUBE FEEDING IS NECESSARY

By Joan Daniels, R.D., and Nancy Burke, R.D.

THINK QUICK: WHAT'S THE FIRST THING YOU THINK OF WHEN YOU HEAR THE WORD "CALORIES"? IS IT "FOOD"? OR MAYBE "DIET"? Unless you're a chemist or a dietitian, you probably don't think about what calories really are: a unit of energy. Taken together, all these little units of energy fuel your body so that it functions well.

But sometimes when you're going through treatment for cancer, it's difficult to consume enough food and fluids to get the energy your body needs. Most cancer patients maintain their weight by eating smart and adding a nutritional supplement, like Boost or Ensure. But if you're rapidly losing weight and having significant problems with appetite, nausea and swallowing, that's when it's time to consider talking with your physician about tube feeding.

Tube feeding sounds intimidating, but for some, it can actually come as a relief. It may take time to adjust, but you can still enjoy many of the same daily activities. Eating gets stressful when you don't have an appetite or when food just tastes bad. Some people obsess about what they are going to eat or whether they'll be able to eat.

For most, tube feeding is a temporary fix to help get through treatment. Losing too much weight can make your body too weak for treatment. Not getting enough protein can slow the healing process and may lead to more severe side effects, such as a weakened immune system.

If you require only temporary help, your health-care team may recommend a nasogastric tube,

sometimes called a "dobhoff" tube. Your team will insert a tube through your nose and down into either your stomach or small intestine. The tube will not interfere with talking. And although you may be able eat small amounts with the tube, some people find it bothersome and limit themselves to fluids.

If you need alternative nourishment for two months or more, your team may recommend surgery to place a feeding tube directly into the stomach. This option—called a "gastrostomy" or "PEG tube"—is more discreet, allows for easier eating and avoids throat irritation that may occur with a dobhoff tube.

Once a tube is in place, you can feed yourself in the comfort of your home using a dietary formula that flows directly into the digestive system via a gravity drip, pump or syringe. When you are able to meet 75 percent of your daily nutritional needs through normal eating,

your team may consider removing the tube.

Talk about the options with your doctor to see what's right for you. Most cancer patients will be able to get the calories they need by making adjustments to their diet. But if you're continuing to lose weight, it's important to take action to get your body the energy it needs.



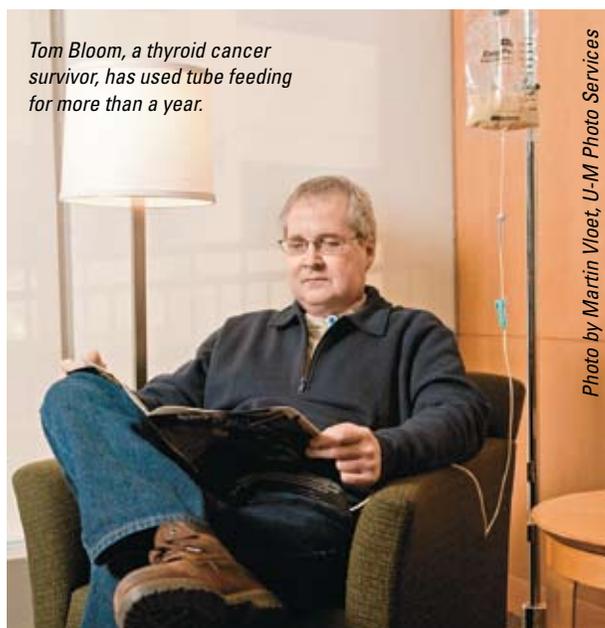
CALL

To make an appointment with a Cancer Center dietitian, call **734-936-6000**.

TIPS

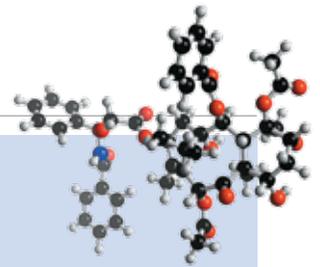
Eating is about more than consuming energy. If you're feeling up to it, use these tips to help you enjoy the rituals of food—without actually eating it—during your tube feeding.

- ▶ **Maintain your mobility.** With portable feeding pumps, you can take tube-feeding almost anywhere.
- ▶ **Consider** taking your tube feeding at the dinner table with your family. Stay involved and lead the conversation.
- ▶ **If your condition allows** you to eat some food orally and you still enjoy the taste of it, consider chewing a bite and then spitting it out.
- ▶ **Now that you don't have to worry** about what to eat, find other activities to distract you. If you used to snack in front of the TV, consider taking up knitting or working a puzzle instead.
- ▶ **Keep swallowing.** You may not realize how many muscles are involved in everyday eating, but it's important to keep exercising them. If you're able, consider swallowing sips of water, chewing sugar-free gum or sucking on mints.



Tom Bloom, a thyroid cancer survivor, has used tube feeding for more than a year.

Photo by Martin Vloet, U-M Photo Services



STUDY DEMONSTRATES WAY TO PREDICT CHEMOTHERAPY SUCCESS IN BREAST CANCER

Researchers have found they can potentially target chemotherapy for breast cancer to only those women most likely to benefit, sparing the majority of patients from unnecessary side effects.

The multicenter study, led by University of Michigan Comprehensive Cancer Center researchers, found women whose breast cancer expressed a protein called HER-2 were most likely to benefit from adding the drug Taxol to the chemotherapy regimen, while women whose tumors were fueled by estrogen but did not express HER-2 did not get any benefit from the added Taxol. About 15 percent to 20 percent of breast cancers express HER-2, and as many as three-quarters of breast cancers are so-called estrogen-receptor-positive.

Results of the study appear in the Oct. 11 issue of the *New England Journal of Medicine*.

"In general, chemotherapy for breast cancer has been a one-size-fits-all approach. Our decision to recommend it is based on whether a woman is at

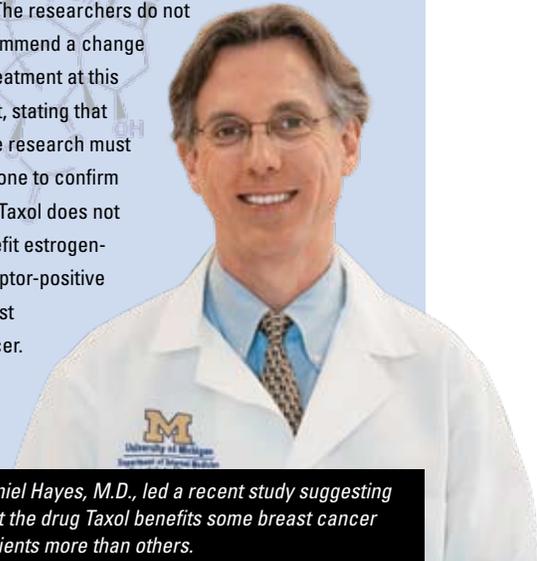
high risk of the breast cancer recurring, without any idea of whether she would benefit from the additional therapy. With this data we hope we will be able to focus chemotherapy on patients whom it's most likely to help," said lead investigator Daniel Hayes, M.D., clinical director of the breast oncology program at the Cancer Center.

The study looked at tissue samples and data from 1,500 women who had previously participated in a study looking at the benefit of adding Taxol after four cycles of the drugs Adriamycin and Cytosin, so-called AC chemotherapy. Cancer had spread to the lymph nodes in all of the women, which is a standard indication to recommend chemotherapy. All the women were given AC chemotherapy for four cycles, after which half the women received four cycles of Taxol and the other half did not receive any more chemotherapy.

Researchers found that the addition of Taxol improved survival rates in women who were HER-2-positive, regardless of their estrogen receptor status.

But women whose tumors were HER-2-negative and estrogen-receptor-positive had no additional benefit from the Taxol. More than half of the patients in the study fell into this category.

The researchers do not recommend a change in treatment at this point, stating that more research must be done to confirm that Taxol does not benefit estrogen-receptor-positive breast cancer.



Daniel Hayes, M.D., led a recent study suggesting that the drug Taxol benefits some breast cancer patients more than others.

CANCER TREATMENT MAY AFFECT DRIVING PERFORMANCE, STUDY SHOWS



Some people undergoing treatment for cancer may need to exercise more caution when driving, according to a recent article published in the *Archives of Otolaryngology—Head and Neck Surgery*.

A small study, which was conducted at the Medical University of South Carolina, used a virtual reality driving

simulator to compare the skills of 10 head and neck cancer patients with the skills of 50 people who did not have cancer. People with cancer were significantly slower in braking and showed larger steering variability than those who did not have cancer.

However, no significant differences were reported be-

tween the groups in average speed, number of collisions and a performance scale developed by researchers.

"I don't believe that patients should change their behavior because the study is so preliminary, but we will continue to advise our patients to avoid particularly challenging situations and carefully consider whether they are ready to drive," said Carol Bradford, M.D., co-director of the U-M Head and Neck Oncology Program.

Hon K. Yuen, Ph.D., the study's lead author, suggested that treatments that interfere with thinking may play a role in degrading driving performance. Bradford agreed, adding that patients need to be aware of all potential side effects of treatment, including the "chemo-brain" phenomenon.

"Chemo-brain" is short-hand for problems people encounter during treatment such as difficulty concentrating or juggling multiple tasks.

"One reason this study is important is that it tells us about one of the subtle ways treatment affects patients' lives," Bradford said. "This highlights why it's necessary to enter into a continuing dialogue with your doctor about the different forms of treatment, their success rate in controlling cancer and the expected side effects."

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., C.S., director of Patient & Family Support Services

Nicole Fawcett, communications lead

Jennifer Day, editor

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.

The Regents of the University of Michigan: Julia Donovan Darlow, Laurence B. Deitch, Olivia P. Maynard, Rebecca McGowan, 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, 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 for 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.

*Includes discrimination based on gender identity and gender expression.

Copyright ©2008 The Regents of the University of Michigan, Ann Arbor, Michigan 48109

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

JUST A PHONE CALL AWAY



CLICK

Would you like to learn how you can give back to the U-M Comprehensive Cancer Center? Please visit www.mccancer.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: **734-764-8663**

Fertility Counseling and Gamete Cryopreservation: **734-615-8143**

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: **734-936-6000**

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: **734-647-8906**

Ronald McDonald House: **734-994-4442**

Skills Lab: **734-763-9642**

Speech-Language Pathology: **734-763-4003**

Social Work: **800-888-9825**

Volunteer & Community Resource Program: **734-936-8307**

My Best Advice

“Just take that extra moment for a handshake or a smile.”

—Susan Zerweck, a 74-year-old Ann Arbor woman who has acute myelogenous leukemia

“Listen to your patients and don't talk down to them.”

—David Reynolds, a 54-year-old Ypsilanti teacher who has laryngeal cancer

“Be honest. Don't pull any punches. Tell us what you know.”

—Don Liptak, a 73-year-old Livonia man who has acute myelogenous leukemia

Q: What advice would you give health-care professionals?