



# Network

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### In this issue:



#### **Patient profile:**

Tom Mitchell faces a rare cancer  
p. 3



#### **Research feature:**

Colorectal cancer  
p. 4



#### **Doctor, doctor:**

Yoga and cancer patients  
p. 6



#### **Survivorship issues:**

Treating neuropathy  
p. 7

## Opening the circle: **Caring for the caregiver**

As the mother of two small boys — a 9-month-old and a 6-year-old — Dawn Maxwell wasn't prepared to be a full-time caregiver when her husband was diagnosed with melanoma.

"We had good health insurance, but we still had outrageous expenses," she says. "Ken had only been on his job six months, so when he took off he wasn't getting paid. I was concentrating on just paying our bills and putting food on the table. And then there were the children. I felt sorry for Ken, but at the same time I was angry."

In her darkest days, she even made plans to be a widow. "No one was giving us hope. I was going to be a single mother, without my husband."

While Dawn is one of 44.4 million unpaid caregivers in the United States, 8 percent of whom give direct care to a cancer patient, she often felt alone in this journey, not realizing that the emotional and financial issues she faced are relatively common. Among them are sadness, anger, powerlessness, worry, uncertainty, anxiety, depression and being overwhelmed with the responsibility of running a house, often alone, with little income.

Then, she read Lance Armstrong's book, "It's Not About the Bike," and decided that if he could make it, so could her husband. She went online and found all the information she could. Her greatest discovery, she says, was the Melanoma Patients Information Page at



*With life returning to normal, the Maxwells — Brooks, 12, Austin, 6, Dawn and Ken — enjoy a cruise together.*

www.mpip.org that led them to M. D. Anderson. Today, Ken is a 4½-year survivor. And he credits his wife and her caregiving to his being here.

### **The caregiver burden: is it real?**

Maxwell's answer to the question of whether the caregiver burden is real is an unequivocal "yes." While there are countless studies researching the causes and possible cures for the 100-plus diseases that make up cancer, very little attention has been paid to those who carry the burden of care and the distress they experience.

Laurel Northouse, Ph.D., R.N., a nurse researcher at the University of Michigan, has

*continued on page 2*

Sharing hope, support and understanding with anyone diagnosed with cancer regardless of where treatment is or was received, the Anderson Network is a program of the Department of Volunteer Services at M. D. Anderson.

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## Tips for caregivers

“Caregiving is an extremely stressful situation, which involves assuming a sudden, expansive and unpredictable scope of responsibilities,” says Phyddy Kettler, an advanced practice nurse in Psychiatry at M. D. Anderson. “Though these responsibilities can render caregivers physically and emotionally exhausted, it is crucial that they take care of themselves so that their overall health does not suffer. Caregivers often are hesitant to ask for help or feel too guilty to take any time for themselves, but it is vital that they do so.”

She recommends:

- Join a caregiver support group — Seek support with other caregivers. Great comfort can be had in being with fellow comrades in this fight against cancer.
- Do something for yourself every day — Take a 10-minute walk, read for a few minutes, watch a movie or call a friend. Doing something pleasurable for yourself, even for a short time, is a good thing as it fortifies and restores strength for the next day.
- Keep in close contact with others — Don't isolate yourself. Caregivers often feel a profound sense of loneliness. Seek the companionship of others.
- Maintain physical and mental health — Caregivers often feel physically and emotionally exhausted. Make time to eat and get as much sleep as possible. Seek professional help if stress becomes overwhelming.
- Learning to live, really live, one day at a time is one of the greatest stress management tools — Focus on today, or even 15-minute periods at a time during moments of crisis, to combat fears of the future. Don't dwell on imaginary scenarios of what “might” happen that may not occur.

“Caregiving can be the most stressful role you will ever be called upon to perform,” Kettler says. “But many caregivers report that they have discovered hidden blessings along the way.”

## Caring for the caregiver *continued from page 1*

spent the last 20 years looking at the effect of cancer on the family. This research indicates that distressed family caregivers — which seem to account for roughly 20 percent of families dealing with cancer — hinder the adjustment of patients. This finding makes it important to identify high-risk families early in the course of the disease and design interventions to help them.

“The most important thing to remember is that cancer is a family disease,” she says. “It affects the entire family, not just the patient. Even though caregivers don't have cancer in their bodies, they suffer the emotional, social and spiritual aspects of the disease. They must face their own challenges.”

A determined woman, Maxwell faced her financial challenge by starting an online business that allowed her to be home with her children and care for her husband. But she wasn't good at accepting support from others, or even knowing what to ask for. That's why her mother taking the kids for an outing or the friend who just showed up with Happy Meals for the kids and a sack of groceries were such a blessing.

“When people ask what they can do, you tend to say nothing,” she says. “Now the things I would have liked done for me, Ken and I do for others: bringing meals, mowing lawns and taking care of the patient while the caregiver goes out for a manicure or lunch.”

### What does the research say?

As a social psychologist and instructor in the Department of Behavioral Science at M. D. Anderson, Hoda Badr, Ph.D., has been intrigued by spousal and familial relationships and communication. But her first-hand experience with her mother's cancer brought her to focus more specifically on how health influences that dynamic.

“Because the patient doesn't cope in a vacuum, but with significant others, the patient becomes somewhat dependent on how others cope with illness and the communication between them,” she says.

That has led to her current research into factors that may affect a patient's pain experience. In the first part of the study, both partners carry a hand-held computer to record pain and spousal response to pain. The second part assesses the psychological and relationship functioning of the couple. She hopes to collect data that will allow her and her colleagues to analyze adaptive and maladaptive interactions between spouses or significant others, and then design interventions that may help them cope.

In the future, Badr hopes to move beyond the self-report system of computers and bring couples into the lab where their discussion of a cancer-related issue could be observed in the moment. She also would like to study the physiological responses: for example, how the endocrine system functions in these situations, what the brain activity is and if the heart rate increases.

“This research is in its infancy, but it is a provocative issue,” Badr says. “The ultimate goal is to have good quality of life outcomes for the patient, the spouse and the rest of the family.”

Understanding the importance of communication has helped the Maxwells, a point they share willingly with others. And now that they feel like a “normal” family again, they've bought a new house, built a pool and are putting money away for college.



## A trombone, a hole-in-one and a rare cancer

Tom Mitchell suffers from a cancer so rare that the hole-in-one he recently hit was “like making a 10-foot putt,” according to his M. D. Anderson doctor and fellow golfer, Paul Mansfield. For the last three years, they have played together in the Golfers Against Cancer tournament in Houston.

It’s a relationship that Mitchell treasures because Mansfield was the surgeon who spent 11 hours 4½ years ago trying to remove a rare cancer that had spread through his abdomen.

“Rather than just being doctor and patient, it’s been golfer and golfer,” says Mitchell who travels from his home in Alabama to play in the tournament. “I made that shot with a driver into the wind on a 200-yard par 3! It was the best shot I’ve ever hit in my life. It shouldn’t have happened, but it did.”

### A change in diagnosis

Fatigue and a distended belly button were the beginning of Mitchell’s cancer journey in 2001. At first, doctors thought it was pancreatic cancer and told him he had three months to live. Then, a needle biopsy showed that it was pseudomyxoma peritonei, a cancer in the abdominal area.

“A lot of people were praying for me,” he says. “And many of them told me I was going to go to M. D. Anderson. I’d never been to Houston and only knew there was some kind of cancer center out in Texas. So my doctor told me to go home for a couple of hours while she did some research on the Internet. Then, she called and said there were four doctors that treat this and she had signed me up for Paul Mansfield.”

When Mitchell had his first consult in April that year, Mansfield warned him that the surgery would not be easy and that he was welcome to get a second opinion. But Mitchell was convinced that Mansfield, professor of surgical oncology, was the right doctor.

In May, he returned to Houston, underwent surgery and ended up spending the summer at M. D. Anderson after complications developed. Then, for six months he was unable to eat anything by mouth. Today he can eat anything he wants.

While the cancer recurred in 2004 and Mitchell spent a year on chemotherapy, he still feels blessed and is optimistic about a clinical trial with Erbitux® that he’s on at the University of Cincinnati. After 30 weeks, his CT scans indicate that the disease has remained stable.

### First and last: a music man

Before cancer, Mitchell spent 25 years as a band director at Challenger Middle School in Huntsville, Ala. He’s proud to say that in a school of 650 students, more than 300 kids took band. “And we worked hard,” he says. “I didn’t pass out candy!”

Though retired from teaching, he continues to play trombone with the Huntsville Symphony Orchestra. And last fall, he had the honor of conducting the University of Alabama band in the national anthem at the Alabama-Tennessee football game.

“Being in that setting and having gone to school there made the invitation a real honor,” he says. “And Alabama won 6-3!”



*Tom Mitchell conducts the University of Alabama marching band in the national anthem.*

“Tom Mitchell’s Miraculous Hole-in-One,” written by Paul Mansfield, M.D., is posted on the Golfers Against Cancer Web site at [www.golfersagaincancer.org](http://www.golfersagaincancer.org). Click on the headline in the right-hand column under “GAC News.”

### Network

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# Colorectal cancer: From prevention to treatment of advanced disease

Colorectal cancer refers to the presence of cancerous cells in the colon and the rectum, and is the fourth most frequently diagnosed internal cancer in the United States, after prostate, breast and lung cancer. In 2005, there were approximately 145,000 new cases and 56,000 related deaths, second only to lung cancer.

The worldwide figure is even more daunting. Globally, it is the fourth most common cancer in men and the third most common in women. In 2000, 945,000 new cases were reported, or 9.4 percent of the world cancer total.

The challenge is that these figures exist in a disease for which doctors now have the technology for early diagnosis and treatments that can offer a 90 percent five-year survival rate when it is detected early. However, less than 40 percent of cases are diagnosed before the cancer spreads.

This is why M. D. Anderson's colorectal program, under the direction of Robert S. Bresalier, M.D., professor and chair of the Department of Gastrointestinal Medicine and Nutrition, puts a keen emphasis on the importance of screening and early detection. At the same time, research moves forward to help those with advanced or recurrent disease.

## Causes

Slowly physicians and scientists are teasing out the causes of colorectal cancer. They know that the incidence of the disease varies regionally: higher in the Northeast and North Central United States than in the South and West; higher for urban residents; higher in the African-American population compared with the Caucasian population; and higher in populations that migrate from areas or countries of low risk to those of high risk. These differences suggest that environment plays a role in the development of the disease, a concept supported by migrant studies and rapid changes in incidence in countries assimilating Western practices.

Other factors also can play a role. Strong evidence exists that there is a link between diet and colorectal cancer. And certain individuals

with a family history of colorectal cancer can have a genetic predisposition to develop the disease, the most dramatic examples being familial adenomatous polyposis (FAP) or hereditary non-polyposis colon cancer (HNPCC).

## Screening

"Screening a low-risk population for any disease is worthwhile," Bresalier says, "if one, the disease represents a major health problem; two, effective therapy is available if the disease is found; three, a sensitive and specific screening test is available that is readily acceptable to patients and physicians; and four, the screening test is cost-effective. Colorectal cancer fulfills at least the first two of these conditions."

Current evidence, he continues, indicates that screening for colorectal cancer reduces related mortality. This finding has resulted in a recommendation by the United States Preventive Services Task Force that screening for colorectal cancer should be performed in all persons age 50 and older. With at least four million people a year turning 50, that brings to the fore the need for cost-effective strategies for screening.

Current recommendations include a menu of options: an annual fecal occult blood test (FOBT); a flexible sigmoidoscopy every five years or a combination of FOBT and flexible sigmoidoscopy; a colonoscopy every 10 years; or air contract barium enema every five years.

Other methods of detection also are being studied, among them CT colonography and stool-based genetic testing:

- "Virtual" colonoscopy, which uses CT scans to generate high-resolution images of the abdomen and pelvis, may provide an alternative to regular colonoscopy, but its sensitivity and efficacy is still being explored.
- The feasibility of detecting altered DNA in stool has been demonstrated and recent multicenter studies have compared this fecal DNA testing to a combined fecal occult blood test and colonoscopy. The fecal DNA testing detected a higher proportion of important lesions and suggests future promise for this method of testing.

## Chemoprevention

Chemoprevention is the use of natural or synthetic agents to reverse, suppress or prevent progression or recurrence of lesions.

“Over the last half-dozen years or so, we’ve started to see studies that show chemoprevention can be effective. We’ve had some positive trials with calcium, aspirin, the COX-2 inhibitors. In the future, we will probably use a combination of agents, because each alone may be positive, but the results are modest,” Bresalier says.

Most promising has been the use of aspirin and NSAIDs, he says. Clinical studies have shown a 40 percent to 50 percent reduction in colorectal cancer-related mortality in individuals taking aspirin and other NSAIDs on a regular basis compared with those not taking these agents. While the exact mechanism for cancer protection is unknown, it may relate to altered compounds that modulate a number of pathways that may affect cellular adhesion, growth and differentiation.

Other agents being studied include folate, hormones and fiber products.

While many think there is a connection between diet and colorectal cancer, prospective data have not supported the potential benefit of a low-fat, high-fiber diet. Two large randomized trials that examined the effects of fiber supplementation on adenoma recurrence failed to demonstrate that people following this regimen had less chance of developing colorectal polyps which are precursors to cancer. Another study that agreed with these findings was released in February this year.

## Surgery

Surgical resection is the treatment of choice for most colorectal cancer, and in selected patients, laparoscopically assisted surgery may be an acceptable alternative.

“Several studies indicate that though the age and physiologic status of a patient may affect operative mortality, advanced age, per se, does not affect tumor-associated mortality after surgery,” Bresalier says. “Therefore, resection of cancer should not be limited or denied on the basis of age alone.”

## Chemotherapy

While current standard of care for patients with stage III disease (metastatic to the lymph nodes) and high-risk patients with stage II disease (although this is more controversial) is adjuvant therapy with a combination of 5-fluorouracil and leucovorin administered after surgery, new agents are showing significant results.

Irinotecan (Camptosar®), oxaliplatin (Eloxatin®) and capecitabine (Xeloda®), and molecular-targeted agents such as cetuximab (Erbix®) and bevacizumab (Avastin®) have led to a rapid evolution in the treatment of advanced colorectal cancer.

The choice of therapy is individualized based on performance status, the type and timing of prior therapy, and the differing toxicity profiles of the drugs to be used in various regimens. Clinical trials also are evaluating the addition of anti-angiogenesis therapy (therapy that keeps the tumor from developing its own vascular system) by combining bevacizumab (Avastin) with traditional chemotherapy.

## Radiation

Radiation is considered standard treatment before and/or after surgery for patients with rectal cancers whose cancer has penetrated the bowel wall or who have regional lymph node involvement. The intent is to decrease local recurrence of the disease in those with high-risk rectal and rectosigmoid cancers. It also is used to shrink unresectable large tumors and those fixed to pelvic organs to make surgery a possibility.

Results of combined adjuvant radiation and chemotherapy following surgery for those with stage II and III rectal cancer are encouraging. A follow-up trial by the North Central Cancer Treatment Group strongly suggests that postsurgical combined-modality therapy decreases tumor relapse and improves survival over those with surgery alone or full-dose postoperative radiation therapy.

Xeloda (an oral 5-FU compound) is also being studied as an enhancer of radiation therapy in the preoperative setting.

## Immunotargeted therapy and immunotherapy

Preclinical and clinical evidence suggest that the immune system can be stimulated against cancer cells with active specific immunotherapy strategies. To date, these approaches are limited to clinical trials, but may hold promise for the future.

“One of the advantages of M. D. Anderson,” says Bresalier, who joined the faculty three years ago, “is that we’re on the cutting edge and have something for patients with all levels of disease.”

For more information about colorectal cancer and what treatments are available at M. D. Anderson, log on to the Web site at [www.mdanderson.org/diseases/colorectal](http://www.mdanderson.org/diseases/colorectal).



## Current research, ancient tradition: **Yoga**



*Lorenzo Cohen, Ph.D.*

M. D. Anderson's Integrative Medicine Program, under the direction of Lorenzo Cohen, Ph.D., is taking a serious look at how an ancient tradition may help today's cancer patients. To date, Cohen has led studies to determine the effects of the practice of yoga on those with lymphoma and breast cancer. When a seven-session pilot program affirmed the feasibility of yoga to improve sleep and lessen fatigue in breast cancer patients, the National Cancer Institute awarded M. D. Anderson a large grant to continue this work in a Phase III study over the next five years.

### **Why yoga?**

As a comprehensive cancer center, we don't just treat cancer, we treat people who have cancer. It is incumbent on us to explore the potential benefit of therapies that have some evidence of efficacy, even non-conventional therapies such as yoga. Yoga incorporates stress-reduction techniques including regulated breathing, visual imagery and meditation, as well as various postures. And research suggests that stress-reduction programs tailored to cancer treatment may help patients cope with the acute effects of treatment and improve quality of life after treatment.

### **What did you discover about yoga for patients with lymphoma?**

We examined the effects of the Tibetan yoga practices of Tsa lung and Trul khor, which incorporate controlled breathing and visualization, mindfulness techniques and low-impact postures. We found that using Tibetan yoga with patients with cancer was feasible and that such a program significantly improved sleep-related outcomes.

### **Why did you choose to study patients with breast cancer?**

Cancer and its treatment are associated with considerable distress, impaired quality of life, poor mental health and

reduced physical function. This is particularly true for women with breast cancer who receive a combination of treatments over an extended period of time. Our newly funded study will assess the physical and psychological benefits of a Tibetan yoga program for women with breast cancer undergoing chemotherapy.

### **How will the trial be run?**

Women with stage I-III breast cancer who are scheduled to undergo chemotherapy will be randomly assigned to either a Tibetan yoga group, a stretching group or a wait-list control group. Those in the yoga group will learn the Tibetan yoga practices of Tsa lung and Trul khor. Those in the stretching group will learn some simple stretches and relaxing exercises that are useful for women with breast cancer. Women in the wait-list control group will receive the standard of care and will be able to participate in the yoga or stretching program at the end of the study.

### **What do you hope to discover?**

We hope to find that Tibetan yoga improves sleep and lessens fatigue. In this larger trial we will be incorporating objective measures of sleep quality as well as assessing the physical benefits of the program through the use of goniometric measurements. We hope that other aspects of quality of life

and mental health will be improved as well. We also will be exploring some plausible factors that may mediate the benefits of yoga, including cognitive and emotional processing, coping, spirituality and benefit finding.

### **Are other types of yoga being studied at M. D. Anderson?**

In April 2005, we announced our collaboration with the Swami Vivekananda Yoga Anusandhana Samsthana (SVYASA Research Foundation), in Bangalore, India, to study the benefits of Hatha yoga for people with cancer. They are the largest yoga therapy research Health Home Arogyadhama in India. The foundation has published 45 research papers on yoga therapy and other yoga applications, trained nearly 3,500 yoga teachers and reached 20 countries with collaborative research projects in the United Kingdom and the United States.

We are currently conducting our second study with SVYASA. We are incorporating yoga into the treatment plan for women with breast cancer undergoing radiation treatment. In a related line of research, we hope to utilize brain-imaging technology in an effort to pinpoint precisely where changes take place in the brain and to confirm previous research that showed certain brain regions were affected by meditation-based programs.



## Closing in on a treatment for neuropathy

One of the most difficult side effects that many cancer patients deal with is neuropathy, a burning sensation in the hands and feet. And if it intensifies, it can affect sensory motor functions, like holding things between the index finger and thumb or walking.

“It happens because the nerves get sick during chemotherapy,” says Patrick Dougherty, Ph.D., associate professor in the Department of Anesthesiology and Pain Medicine at M. D. Anderson. “Pain from sick nerves — that’s the bottom line.”

Intrigued by what happens in the body when a certain treatment is used, Dougherty switched from medical school to graduate work in basic science, hoping to discover what causes sensitization in the brain. He was especially drawn to study immune signals, such as cytokines, proteins secreted by cells that regulate a variety of cellular processes, including the immune response.

“When sensory things happen to us, our body remembers that and later when the same sensory thing happens, the body is used to it. For example, when holding a tennis racket, the hand knows to assume a certain grip. The same thing happens when the body experiences pain,” Dougherty says.

“Sensitization is a process whereby, for example, one painful event can make the next painful event seem even more painful. I want to understand what is happening in the brain when this occurs.”

In his current work at M. D. Anderson, he is looking at the role these proteins play in chemotherapy-related neuropathy. “We want to see if we can detect which patients will develop this, what the neuro-function is and design an intervention to protect that group,” he explains.

His parallel research alternates between the laboratory and the clinic. First, his team tests the nerve function of patients in chemotherapy to identify which nerve is causing the pain. Then, they give the animal model the same chemotherapy that has caused the pain in the patient.

When the animal develops hypersensitivity that matches what is seen in the patient, then the team looks at the physiology of sensory neurons, scans the spinal cord and the brain, and performs chemical, serum and molecular studies.

They have been able to successfully model neuropathy generated by four of the most toxic chemotherapies: taxanes, platinum, vincristine and thalidomide. They also want to work with the drug bortezomib, which is an important treatment for leukemia and myeloma patients, but has high toxicity.

“We now have a set of data that seems to suggest that what contributes to the pain has to do with the biochemical and inflammatory responses that the body has to these chemotherapies,” Dougherty says. “We are close to testing one intervention in patients — an antibiotic called minocycline which has been successful in reducing neuropathy associated with taxol in animal models.”

While there are still many unanswered questions about what leads to neuropathy, Dougherty hopes that follow-up studies will validate these findings so this therapy — which may prevent or, at least, lessen the impact of a side effect that causes patients a heavy symptom burden — can be brought to patients in the next year or two.



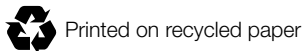
*Patrick Dougherty, Ph.D., is committed to understanding what happens in the body and the brain during chemotherapy.*



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## Page 8 Briefs



*Kent Roberts, an esophageal cancer survivor, shares hope with patients in Anderson Network's Hospitality Center and on the Telephone Support Line.*

### Would you be willing to share your cancer experience with newly diagnosed patients?

If so, call the Anderson Network at (713) 792-2553 or (800) 345-6324 and find out about becoming a member of the telephone committee that matches patients and caregivers dealing with similar diagnoses and treatment plans. Your story and willingness to listen could make the difference in another person's ability to cope with this life-threatening illness.

Now in its 20th year, the support line has helped more than 21,000 patients receive hope and understanding. And becoming a member is easy. There is no cost, only a profile that can be sent to you by mail or that can be filled out online at [www.mdanderson.org/andersonnetwork](http://www.mdanderson.org/andersonnetwork). Click on "Membership Profile" in the left-hand column.

### The 18th annual Living Fully With Cancer patient and caregiver conference

It's not too early to start planning for Anderson Network's annual conference, Sept. 7-9, at the Houston Marriott Westchase, 2900 Briarpark Dr., Houston.

This year's keynote speakers include Evan Handler, best known as Harry Goldenblatt on HBO's "Sex and the City" and a survivor of acute leukemia, and Leslie Mouton, the San Antonio news anchor who shared her journey through breast cancer with her viewers.

Watch for the summer issue of Network in June with the full agenda of breakout sessions, wellness workshops, mixers and banquet, as well as registration information.