

FINDING YOUR WAY

QUESTIONS TO ASK YOUR DOCTOR :

What are my treatment options?

What are the side effects of the treatments you are recommending? How will they affect me and my family?

Are there any support groups available for people with my disease and their families?

What symptoms might arise suddenly? What medicines should I have on hand for these? What plans can we make in advance for these possible complications?

What treatments will help my symptoms even if they don't cure what I have?

What are the likely outcomes of resuscitation or life-support machines for someone with my medical problems?

I know you can't say how long I have to live, but would it surprise you as my doctor if I died within the next year or two?

How can you help me plan for the worst while I hope for the best?

What is your philosophy and practice on prolonging life versus enhancing the quality of life that remains?

If your illness is advanced, ask: "How will we know when death is near? What signs should my family look for and what can they do for me?"

WEB SITES

Partnership for Caring: It's All About Talking page: Download the booklet "Talking About Your Choices," which introduces you and your loved ones to the issues surrounding end-of-life decision making. www.partnershipforcaring.org/Talking/index.html

Aging with Dignity, the Five Wishes Project: Offers advance directive forms that can be used by residents of 33 states: www.agingwithdignity.org

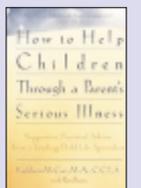
AARP: Order free copy of "Start the Conversation: Modern Maturity's Guide to End-of-Life Care" (D17219) by sending a postcard or letter to AARP Fulfillment, 601 E Street NW, Washington, D.C. 20049. Visit the AARP End-of-Life page at www.aarp.org/mmaturity/sept_oct00/conversation.html

BOOKS

"Dying Well: The Prospect for Growth at the End of Life," by Dr. Ira Byock (Riverhead Books, 1997; \$24.95).

"Handbook for Mortals: Guidance for People Facing Serious Illness," by Joanne Lynn and Joan Harrold (Oxford Press, 1999; \$28).

"How to Help Children Through a Parent's Serious Illness," by Kathleen McCue and Ron Bonn (St. Martin's Press, 1996; \$12.95).



"Peaceful Dying: The Step-by-Step Guide to Preserving Your Dignity, Your Choice, and Your Inner Peace at the End of Life," by Daniel Tobin (Perseus, 1999; \$14).

For more resources, go online to www.findingourway.net

ABOUT THE AUTHOR

Dale G. Larson, Ph.D., is associate professor, department of counseling psychology at Santa Clara University. A clinician and former Fulbright Scholar, Larson has published extensively in the end-of-life, counseling and health psychology areas. He is the author of "The Helper's Journey: Working With People Facing Grief, Loss, and Life-Threatening Illness."



Jim, Jeffrey and Janet Fossett of Delmar, N.Y., learned to have conversations about cancer after Janet was diagnosed with stage III breast cancer in April 2000.

PHOTO BY LAURIN TRAINER/COURTESY OF THE PARTNERSHIP FOR CARING

It's time to talk

The most important conversations often are the most difficult to have

BY DALE G. LARSON

It was a conversation Janet Fossett never expected or wanted to have: The doctor was alarmed. The cancer in her breast had reached an advanced stage. And it was spreading.

She was 46, a wife and a mother. But with that doctor's office visit, the university professor from Delmar, N.Y., became one more member of an aging nation forced to wrestle in words with her own mortality.

As Janet was about to learn, even though these conversations can be grueling in their candor, advocates say they can also bring dignity to dying and a precious sense of control. But while Americans say they want quality at the end of life, they avoid the discussions that make dying well possible.

"I was very scared," said Janet, recalling the day in April 2000 when she was diagnosed with stage III breast cancer. By the time her doctors detected it, the cancer had spread to her lymph nodes.

"I was scared of what test results would show, scared of having drugs injected into my veins, scared of major surgery, scared that I would soon die," she said.

Perhaps most of all, Janet was scared of talking about it. She's not alone. Most Americans dread these conversations. Physicians avoid them. Patients are reluctant to ask the very questions that would help them plan for what lies ahead. Relatives try to "stay positive" or have no idea what to say.

Janet quickly found herself the center in this conspiracy of silence.

"My fears made it hard to function," she said. "I had to push myself to do what I knew I had to do: learn about my illness, find good doctors, undergo tests to determine how far the cancer had spread."

Through conversation, Janet found a path through her fears: She understood her illness. Her doctors helped hammer out treatment options. As she later realized, Janet had taken the first steps on what she would call her "breast cancer journey."

In physicians' offices, living rooms and community meetings across the country, people are learning how to break the silence. As America's burgeoning baby-boomer generation will soon find out, it's a three-step process:

When they're well, they can draw up so-called "advance directives," a formalized game plan for end-of-life medical care, including a living will and a durable-power-of-attorney form.

When serious illness strikes, a double set of conversations can kick in: one with health professionals to address not just the medical but the emotional and social needs of the patient. The other is with loved ones, whose support can make even the roughest end-of-life journey manageable.

Finally, when death draws near, conversation ascends to an almost spiritual state. By sharing the realities of dying, fear and denial can be replaced by intimacy and growth, a passage through the ultimate window of opportunity.

"Having direct talk, even about threatening issues like dying and death, can be reassuring," said Dr. David Spiegel, director of Stanford's Psychosocial Treatment Laboratory. "It makes people feel connected, rather than isolated. So an intimate conversation

about death can soften the terror."

Studies back that up. One survey by Dr. William Tierney of Indiana University found that patients came away happier from doctor visits where advance directives were discussed. Further down the road, conversation becomes even more crucial. It is here that perhaps the most crucial discussion takes place — how to move from cure to care, from the so-called "curative" stage of treatment to the "palliative," or comfort, stage where hospice help could eventually be considered.

The drive to get people talking, though, can be complicated by cultural considerations.

Each culture has its own set of rituals and taboos concerning death, and each varies in the extent to which its members can discuss death openly. But in the end, the decision always comes down to the individual.

And "it's your values that are most important in deciding if a treatment is right for you," says Dr. Laura Esserman, director of the University of California San Francisco's Carole Frank Breast Cancer Clinic. She advises patients "to remember the treatments and services are for you, not the physician."

Talking to her doctors, Janet said, was tough. But the conversation that followed was agony.

Janet and her husband, Jim, knew their son, Jeff, 9, would soon pick up on the frantic phone calls and skyrocketing anxiety in the house. How do you tell your own child that your life is in jeopardy?

For Janet, the answer began with a book. Janet and her husband met with a social worker in Boston who gave them "How to Help Children Through a Parent's Serious Illness." As Jim drove, Janet read aloud on their way back to New York.

"We learned a lot on that two-hour drive," said Janet. "We knew we couldn't delay the conversation any longer, that we needed to be truthful and use the 'C' word."

They got good advice: Keep it simple. Stress that cancer's not contagious. Assure Jeff that he had not, somehow, caused the illness. "Most of all," said Janet, "we needed to assure him he would always be loved and cared for. By the time we got home, we had a plan."

Jim and his son shot hoops in the driveway. Sitting on the front steps, Jim braced himself, then told his son what the doctors had found.

"You know how Mommy has been having lots of tests?" asked Jim. "Well, it turns out Mommy has breast cancer."

"Really?" said Jeff.

"Yes. But the doctors in Boston have good ideas about how to treat it. Mom and I can tell you more about it later."

Jeff asked a few brief questions. Then he changed the subject.

Later that evening, Janet drew Jeff a bath. She was on her knees with sleeves pushed up to the elbow. As Janet leaned over the tub, Jeff suddenly asked: "Mommy, are you going to die?"

Janet closed her eyes and took a deep breath.

Where to start

Here are tips to help you talk to doctors, loved ones — and yourself:

Know your stuff: Research your disease and bring a detailed list of questions to your doctor (see column at far right). If you need support, bring along a friend or family member. Ask to tape record the medical interview so you can remember all the details of the conversation.

Build teams: When you talk to your doctor, nurses, social workers, clergy, and other care-providers, think of them as colleagues, all interested in the same thing — helping you live your life to the fullest in the time you have left.

Learn from others: Call up a local hospice or hospital to find nearby support groups or educational programs for people facing the same medical or care-giving challenges.

Share experiences: Get your group — say, church or senior center — to discuss the experiences (good and bad) that members have had with friends and family who have died recently.

Plan proactively: Discuss a treatment plan for your remaining time with your loved ones. Discuss your medical options (living will and health-care proxy) and desired funeral arrangements. Give your doctor a copy of your completed directives.

Don't waste time: Share with your loved

ones what you'd like to do with the remaining time in your life — travel, getting together with old friends, for example. Be realistic, but set down your plans in detail and take action.

Tie up loose ends: Think about what the unresolved issues are for you with your family, and what you can do to achieve some closure. For example, tell someone you forgive him or her for a past conflict. Get closure for the unfinished parts of your life.

Tell your story: Make a video or audiotape for your children or grandchildren, telling them stories of your life and candidly sharing your feelings for them.

Write it down: Think of writing as a conversation with yourself. Writing about your life in its final stages may not cure your illness, but finding words to describe what you're feeling can be emotionally comforting and help you find meaning.

Look for the window of opportunity: If your illness worsens and you are trying to balance life-prolonging treatments with your quality of life, it might be time for you to consider dying as the next stage of your life. The more you talk with others and prepare, the more likely you will be able to maintain control and dignity and achieve a sense of peacefulness in the time that remains.

— Dale G. Larson

"Actually," she began, "I really don't know. I've got great doctors and they're going to help us figure out how to treat my cancer. I sure hope I don't die. And I want you to join me and Daddy in hoping for this, too."

It was the talk she dreaded, "the most frightening conversation of my entire life," she called it. And even then, it didn't include all the upsetting details — her treatment plan included chemotherapy, a mastectomy, radiation and hormonal therapy. But as dreadful as the conversation had seemed beforehand, it was over and done with in a heartbeat.

"I worried whether we'd fumbled these initial conversations," she said later. "But we were sure that talking about this stuff with our son was better than not talking about it."

But it was just the first of many conversations to come, conversations that continue today, 17 months after her cancer was diagnosed, as Janet struggles to live the fullest life possible in a lifetime still impossible to measure.

Said Janet: "If I should develop stage IV cancer, which is so often eventually fatal, then I guess we'll find ways to talk about that as well."

There is no way around the reality of death and dying. But Americans are learning that end-of-life conversations can be a pathway leading them to a better way of dying. The end of life, say experts, need not be all angst and agony, but a time of personal growth.

Americans are clear in surveys about what they want as they die: Maintain dignity. Be comfortable. Say goodbye to important people. Make peace with whatever higher power they choose. What they may not know, though, is that the healing power of these challenging conversations is one of life's greatest gifts. A few words — words perhaps never before uttered — can lift the burden of a lifetime of disappointment, of a shameful personal secret, of an unexpressed love.

In everyday words, it can sound as simple as this:

*I forgive you.
Please forgive me.
Thank you.
I love you.
Goodbye.*

Janet Fossett is not ready to say goodbye to anyone. But if her cancer worsens, as it could well do, she already has learned the lexicon that will help her find a way to live with dying.

"I've recently begun writing a little bit about my life, things I'd like my son to know," she said. "No matter what may happen to me, this will be a part of myself that I can always share with him."

In her education, Janet has had some powerful teachers — from authors to Webmasters, social workers to medical specialists, and most of all, family and friends. Her time facing death has enriched her life in many ways.

"No one knows what the future holds," said Janet. "But this uncertainty is also a gift that allows us to be hopeful for my future."

As she moves into it, she takes with her the greatest lesson of all.

"I learned," said Janet, "that I did not have to face these conversations alone."

For more resources and contacts, go online to www.findingourway.net