

# Together

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## Life after cancer

# Finding your way to stop feeling adrift

*We don't want to stop rowing, so we drift in circles for a time looking for guidance*

By Mary Amundsen

The last day of cancer treatment. Finally! Now I can get on with my life and everything will be back to normal. Cancer will be history and I can forget it ever happened.

As a nurse, cancer survivor and family member of cancer patients, I know those thoughts are common reactions to completing treatment. I also know that the reality of life after cancer is much different - it's usually a combination of surprise and bewilderment. It often feels like this...

During chemotherapy or radiation therapy, which typically follows surgery, we feel we're partners with our doctors and healthcare providers in an active process to defeat the cancer. We focus our energy on physical healing and we're part of a team working for that goal.

But like other graduations, the elation of reaching the goal soon wears off and we find ourselves feeling tired, vulnerable and really missing the medical team that was so much a part of our daily life. We don't trust our body and wonder if each ache and pain means the cancer is coming back. If we're not actively fighting the cancer, are we playing a waiting game? How do we get on with "our life" when we're not sure what that is anymore?

Feeling adrift aptly describes life after cancer. During treatment, we actively row the boat and see the other side where we want to be. When treatment ends, we feel like we're surrounded by a fog and can't tell which direction to go. We don't want to stop rowing, so we drift in circles for a time looking for guidance.

Adapting to all the changes from cancer can take months, sometimes years. The people around us want life to be like it was before cancer, but as much as we try, our old life doesn't fit us anymore. Things that we put on

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Mayo Clinic Cancer Center is part of Mayo Clinic. It is designated as a comprehensive cancer center by the National Cancer Institute. The mission of the cancer center is to provide compassionate state-of-the-art care for the cancer patient of today and continued advancements in the prevention, diagnosis, treatment and cure of cancer in the future. The programs and services of the cancer center span the three Mayo Clinic campuses in Rochester, Minn., Jacksonville, Fla., and Scottsdale, Ariz.

*Together* provides educational information for cancer patients treated at Mayo Clinic, their family members, caregivers and friends. Physicians and staff of the cancer center write the articles.

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## Stop feeling adrift

### Focus on the future with renewed hope

hold with our diagnosis now need to be addressed or resolved but some of those things don't have the same importance for us. Our priorities have changed.

These feelings of foundering surprise and bewilder us. But as with other major life changes and transitions, we can adapt to this challenge of getting on with life after cancer.

#### *These suggestions may help you in finding your way:*

■ First, know that feeling adrift is a normal part of the cancer journey. Most cancer survivors feel this way after they have completed their treatment.

■ Carefully planning your day may help you cope with fatigue. Prioritize your tasks and separate them into manageable pieces. Set small achievable goals to regain a sense of accomplishment and control.

■ Within your daily planning, allot time for thinking, grieving and playing. Find a way to express yourself in art, music or writing.

■ If you feel you need to talk with someone who understands what you're going through, consider joining a support group. Your healthcare provider or the American Cancer Society can tell you about support groups in your community.

Finally, focus on the future with renewed hope. Even though your life has changed, you have a wealth of courage and strength in you and from those who support you.



*Mary Amundsen is a registered nurse and a cancer survivor. She now works with Mayo Clinic Cancer Center's Women's Program as a study coordinator.*

## For Your Information

These books and Web sites provide more information about surviving cancer:

■ *Surviving Cancer Emotionally: Learning How to Heal*  
by Roger Granet, M.D.

■ *The New Cancer Survivors: Living with Grace, Fighting with Spirit*  
by Natalie Davis Spingarn

■ *Chicken Soup for the Surviving Soul: 101 Stories of Courage and Inspiration from Those Who Have Survived Cancer*  
by Jack Canfield, Mark Victor Hansen, Patty Aubrey and Nancy Mitchell, R.N.

■ National Coalition for Cancer Survivorship  
([www.canceradvocacy.org](http://www.canceradvocacy.org))

■ Cancervive: Dedicated to Life after Cancer ([www.cancervive.org](http://www.cancervive.org))

# Tending to your spirit amid physical change and distress

By Phillis Bennett

*Spirituality is a way to relate on a deeper level to self, God, other people, and all of creation.*

I recently asked a patient with cancer to close her eyes and go to her favorite place in her mind. When I asked where she was, she said she was looking out over the Grand Canyon. I asked her to see herself as an eagle and fly over what she saw. She gasped and even with her eyes closed I could see that she was letting go of her cancer pain and anxiety and soaring if only for a moment over the beauty of nature.

This example illustrates that in times of physical illness and distress, the spirit - that energy deep within us - can help us cope with the realities and difficulties of our lives.

Spirituality is the search for meaning and purpose. It is a way to relate on a deeper level to self, God, other people, and all of creation. Spirituality is a dynamic relationship - a living thing that is influenced by life experiences - joys and sorrows, victories and defeats. Because spirituality is alive it needs tending and nurturing.

A person dealing with cancer may not be able to control the physical affects of the disease, but they can take charge of their spiritual life.

*These activities may help heal or strengthen your spirit:*

- Walk in nature if you are able; sit by a window in the warm sun; share a sunset with someone you love. These kinds of simple pleasures sustain us.
- Participate in guided meditation or relaxation techniques, such as in the example, to connect to your spirit. Sitting quietly, focusing on your breathing and using a prayer word or phrase to hold your attention can get you started. A phrase might be "I am one with God." Or try breathing in "peace" and exhaling "let go."
- Pray. Simply talking to God or a higher power can bring a measure of peace and connectedness that may help you deal with pain and suffering.
- Maintain relationships with family, friends and a community, whether church or a support group, to nourish your spirit.



*Phillis Bennett is a chaplain at Mayo Clinic and works primarily with cancer patients and their families.*

*Spirituality is the search for meaning and purpose.*

**For Your Information**

## Introducing Patient Partners

The American Cancer Society's *Patient Partners* program helps cancer patients, survivors and their caregivers adapt to the life changes that cancer brings and cope with issues that arise from a cancer diagnosis. Two types of volunteers comprise *Patient Partners* — survivor volunteers and support volunteers. Survivor volunteers are cancer survivors who are carefully screened and trained to address the concerns of cancer patients and survivors. Support volunteers are family members or caregivers of someone who has had cancer. They provide a listening ear and information to other caregivers. They are not necessarily cancer survivors. For more information about the *Patient Partners* program, call the American Cancer Society, 1-800-ACS-2345.

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# Bill Sands

# SURVIVOR

*“Each day you need to get out of yourself and see what you can enjoy because every day above ground is a good day.”*

**B**ill Sands of El Prado, New Mexico, doesn't live in fear of death. Instead he's found a new and better life with a great sense of peace and freedom.

That's how Bill describes the outcome of his experience with cancer. He credits the love of his wife, Martha, and the help of several people he calls his heroes for bringing him through his ordeal and to his changed attitude.

Now age 64, Bill was born in Indiana and raised in Delaware, but his life's values come from North Dakota and Minnesota where he attended college and began his career. Before his cancer diagnosis, his life had its ups and downs but he lived it pretty much on his terms. His 30-year career in the legal and sales departments of National Farmers Union Insurance Companies (NFUIC) challenged him. Getaway trips to northern Minnesota a couple of times a year energized him.

In 1993, Bill left the corporate world in Colorado where he had relocated with NFUIC. Martha, his wife of 15 years and a former insurance company executive, continued her career while Bill opened a small sandwich shop in Aurora. He used the shop to help troubled teenagers by giving them jobs and guidance in furthering their education.

On the eve of Good Friday in 1995, while doing the work schedule for his employees, Bill felt a slight bump on the left side of his neck. He dismissed it as an insect bite, but an hour later, the bump was the size of a hardboiled egg

and he went to the local emergency department to have it checked. The doctor told him the bump could be either an infection of a lymph node or a tumor. He wrote Bill a prescription for an antibiotic and gave him the name of a specialist in ear, nose and throat (ENT) problems.

“For the next few days, I hoped the bump was an infection, but it wasn't going away,” Bill says. He went to the ENT doctor, who referred him to an ENT oncologist. Martha went with him to that appointment.

The oncologist confirmed Bill's fear. He told him he had a rare cancer of the nasal system, called nasopharyngeal cancer, also known as NPC. He also told Bill that without treatment he might live six months; with radiation and chemotherapy he might have one year.

“I was shocked,” Bill says.

Martha also was stunned, but her years as a decision-making executive started her thinking about options. She said to Bill and the oncologist, “We're going to Mayo Clinic for a second opinion.”

“It seemed logical because Bill had been to Mayo a few years before for another problem that no other place could help him with,” Martha says.

The Colorado oncologist suggested they see H. Bryan Neel, III, M.D., Ph.D, specialist in ear, nose and throat problems at Mayo Clinic. He had heard Dr. Neel speak at



*Nearly eight years after his battle with cancer, Bill Sands and Martha, his wife, enjoy a normal, active lifestyle. Martha is now an adjunct professor at the University of New Mexico in Taos, and Bill does some substitute teaching and volunteer work. Each year Bill comes to Mayo Clinic for checkups. He continues to take an annual canoe trip in the boundary waters as he has done for 45 years. He also cross-country skis in the winter and bicycles in the summer to stay physically fit and keep his mind off the cancer.*

a medical conference about the type of cancer Bill had. (Dr. Neel and other Mayo researchers have conducted a lot of basic and clinical research on nasopharyngeal cancer.)

Bill and Martha drove the nearly 1,000 miles to Rochester, Minn., and Mayo Clinic. Although they cried a lot during the drive, they also talked about being positive. "We felt like the whole world around us had disappeared," Bill says. They had packed clothes for only a few days not really knowing what the results of the Mayo Clinic visit would bring.

Then they met Dr. Neel.

One of the first questions Dr. Neel asked Bill was what he had been told about his condition. Bill reported the grim prognosis and added he wasn't sure he wanted to undergo the difficult treatments for only a few more months of life. He would rather take a long meditative canoe trip and enjoy his last remaining days with his family.

"As I talked, I saw Dr. Neel stiffen and the hair on the back of his neck seemed to stand out," Bill recalls. "Then



*H. Bryan Neel, III, M.D., Ph.D.*

he said nobody really knows how long anybody has to live, and that from his research and experience, I did not need chemotherapy because that didn't work on my type of cancer. He said I needed conventional, and intense, radiation treatments and he talked with a radiation oncologist. Surgery to remove scar tissue from the neck would come later.

"For the first time since being told I had cancer, I felt relief and a lot more confident," Bill says. "I received a glimmer of hope. Right then and there Dr. Neel became one of my heroes."

Bill met another of his new heroes the next day – James Bonner, M.D., (now at the University of Alabama in Birmingham) and later Robert Foote, M.D., both radiation oncologists.

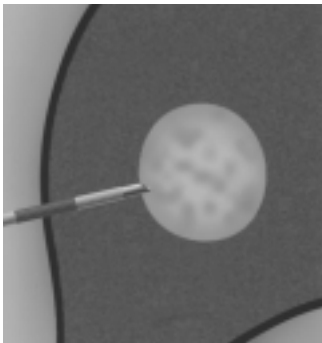
"I thought that after talking with Dr. Bonner, Martha and I would go back home to either stay or arrange to return to Mayo for treatment, but instead Dr. Neel and Dr. Bonner were eager to get started right away with the treatments," Bill says.

Martha adds, "Although Bill was reluctant to stay, our meetings with both doctors convinced me that Bill was in the right place."

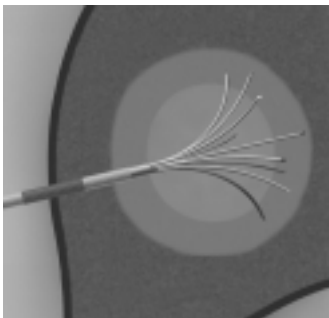
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*Radio-frequency ablation does not cure cancer, but according to a Mayo Clinic research study, it can safely and effectively reduce the severe pain some patients experience when their cancer has spread to the bone.*

## Intense heat stops severe pain



*The radio-frequency ablation needle is directed to a tumor in the bone.*



*The electrodes spread out through the needle, causing a zone of intense heat to the tumor in the bone and alleviating the pain.*

Even though it was two years ago, Heather Henrichs of Billings, Mont., remembers the unbearable pain she felt in her left shoulder after lifting a laundry basket as if it were yesterday.

“The pain just took my breath away,” recalls Heather. “I had to lie on the basket because I couldn’t get up.”

Now 29 years old, Heather was diagnosed seven years ago with paraganglioma, a rare cancer of the endocrine system. She received the diagnosis at about the same time she learned she was pregnant with her son, Tristan. The pain she felt resulted from the cancer having spread to her shoulder bone.

Cancer spreading to bone is a common problem for cancer patients. Although the spread of cancer to bone is usually not life threatening, it can cause excruciating pain and severely affect a patient’s quality of life. For some patients the pain can become so extreme that it becomes difficult, if not impossible, to walk, sit or lie down.

Treatments used routinely to control cancer pain include radiation therapy, surgery, chemotherapy, hormonal therapy and pain-relieving drugs such as morphine. These treatments work well, but all of them have limitations or side effects.

Now another method is helping to alleviate pain for some patients like Heather. A research study led by Mayo Clinic and involving researchers at nine other cancer centers in the United States and Europe has found that a fairly simple radiological technique can provide huge benefits to some patients with severe bone cancer pain. The technique is called radio-frequency ablation, or RF ablation, and it uses heat to kill cancer cells in the bone and thereby greatly reduce the pain.



*Ultrasound is used to guide the radio-frequency ablation needle to the site of the cancer in the bone. Dr. Charboneau, right, maneuvers the ultrasound device while he and Dr. Callstrom watch the monitor on the ultrasound machine to pinpoint the destination for the needle.*

The study has thus far involved 62 patients with cancer that had spread to the bone. These patients either were not helped or were not eligible for the standard pain-relieving treatments. After receiving RF ablation, 95 percent of these patients had a significant reduction in their pain. These patients were asked to report their pain on a standard 10-point pain rating scale before and after the procedure with 10 being pain "as bad as you can imagine." More than 50 percent of the patients reported significant relief four weeks after the procedure. At 24 weeks after the procedure, the average pain reduction was 69 percent. Follow-up on these patients indicates they continue to enjoy significant pain relief six months to a year after their treatment.

"RF ablation is actually remarkably effective at reducing pain," says William Charboneau, M.D., a Mayo Clinic radiologist and researcher on the study. "It was really quite amazing that patients can go from so much pain to resuming a near-normal life."



*William Charboneau, M.D.*

"Our study provides evidence that the RF ablation procedure is safe, the relief from pain dramatic and the treatment should provide an alternative for the treatment of painful bone metastases when standard treatments fail," says Dr. Charboneau.



*Matthew Callstrom, M.D.* According to Matthew Callstrom, M.D., also a Mayo Clinic radiologist and researcher on the study, "On a scale of 10, our patients typically begin with about a 7 pretreatment pain score and then drop down to an average score of 2. Many patients' pain levels have dropped to 0." "A score of 7 generally means that pain is the dominant concern, with the patient watching the clock between medication doses and requiring as much pain medication as can be tolerated," says Dr. Callstrom. "Through RF ablation we have been able to reduce fairly severe pain down to the point where pain is not controlling our patients' every thought. They have a good quality of life."

The procedure takes about an hour to perform under general anesthesia. With the aid of computed tomography (CT) or ultrasound guidance, electrical energy is transmitted through a long thin needle inserted through the skin directly into carefully targeted tissue around the tumor. The high-frequency currents heat and destroy a large part of the tumor.



*Heather Henrichs has been living with cancer for seven years. Treatment with radio-frequency ablation helps her enjoy a near normal life with her husband and son.*

While the pain-relieving capability of RF ablation is noteworthy, Dr. Charboneau and Dr. Callstrom caution that RF ablation is not a cancer cure and not appropriate for every patient with bone cancer. While the procedure kills cancer cells, it is intended to treat the pain not the cancer. A patient with more than two or three painful bone metastases is not a good candidate for the procedure under its current use.

Meanwhile, Heather enjoys a near normal life with her husband, Scott, and their son, Tristan, at home and in her familiar surroundings of Billings.

"I feel kind of like my myself again," she says.

*The results of the study on radio-frequency ablation for relief of cancer pain in bone were published in the November 2002 issue of Radiology journal.*



## Will I get sick from my chemotherapy?

That question is easier to answer these days because of a class of effective anti-nausea drugs developed in the past decade. This class of drugs is called 5-HT3 blockers and includes Zofran™, Kytril™ and Anzemet™.

Oncologists, pharmacists and nurses at Mayo Clinic have developed an anti-nausea guideline for patients receiving chemotherapy. This guideline uses 5-HT3 blockers in combination with dexamethasone, a steroid, to control nausea and vomiting associated with the stronger chemotherapy treatments.

A few patients experience nausea after their first chemotherapy treatment, despite the 5-HT3 blocker and the dexamethasone (Decadron™). When the dosage of their anti-nausea medication is adjusted, these patients usually tolerate the remaining chemotherapy treatments without nausea.

Thankfully, nausea and vomiting have become the exception rather than the expectation with today's chemotherapy treatment.



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Oncology Nursing  
Supervisor

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## Bill Sands - Survivor

*"To my surprise and gratitude, Dr. Neel told me 'you're cancer-free.' I couldn't have asked for a better present."*



Bill Sands

After finding a small apartment and getting Bill settled in, Martha flew back to Colorado to her job and to take care of their business. Bill started treatments, twice a day, Monday through Friday, for 30 days. Along with the radiation treatments to his head and neck came the side effects of burns to his tongue and the loss of saliva. Emotionally, he took inventory of his life and sought spiritual guidance, but found himself feeling angry and depressed.

While struggling with coming to grips with having cancer, Bill's now long-time friend and cancer survivor, Wayland Eppard of Rochester, gave him some of the best advice he's ever received.

"I was at a point where I did not want to get another book on living with cancer," Bill says. "Wayland understood my struggle and told me that anybody can die from cancer but it takes courage to learn to live with it. He was a godsend to me because he didn't give me an inch of sympathy but lots of support. What he said made me take the position that I wanted to survive my cancer."

Bill turned to his physicians for information and trusted their skills.

"I had faith that they were the best at their work and knew what was best for me. For one time in my life, I did just as I was told instead of dwelling on dying," he says.

Bill completed his radiation treatments, and on Aug. 8, Dr. Neel checked him. That day also was Bill and Martha's wedding anniversary.

"To my surprise and gratitude, Dr. Neel told me 'you're cancer-free,'" Bill says. "I couldn't have asked for a better present."

Martha was equally relieved. "Through an experience like that you realize just how short life can be," she says.

Martha describes herself and Bill as people who like to keep working, doing things. They compartmentalized the cancer as an occurrence in their lives and got on with living. They sold their business in Colorado in 1999 and moved to the Taos area in New Mexico, a place they had always wanted to live, and built their new home. Both agree that they have become better partners and appreciate each other more as a result of the cancer experience.

"I'm so thankful that Martha insisted on going to Mayo Clinic and for the care and support I received there; otherwise I might not be here," Bill says.

After seven years, Bill is regaining saliva, and the senses of smell and taste, which were impaired during radiation treatment. Bill now lives by the philosophy that "each day you need to get out of yourself and see what you can enjoy because every day above ground is a good day."



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