

# Lifeline

A Quarterly Publication of Y-ME National Breast Cancer Organization



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## Running the Caregiver Marathon

To paraphrase Charles Dickens, caregiving can be the best of times and it can be the worst of times. There are tremendous rewards that come from stepping in to help someone going through the experience of breast cancer. Caregivers not only assist with everyday tasks that can seem impossible to someone in the midst of cancer treatment, but these quiet heroes offer support and a sense of connection at a time when patients can feel alone and frightened. In the words of so many breast cancer survivors to their caregivers, “I couldn’t do it without you.”

But there are risks to being a caregiver, too.

“So many caregivers just won’t take care of themselves,” says Michele Johns, executive director of the Cancer Community Center in South Portland, Maine. She notes that her organization has repeatedly tried to organize support groups for caregivers but hasn’t had success. “They’re too busy caring for the patient,” Johns says. “Even monthly meetings are too much of a time commitment. And there’s often the belief that ‘it’s not about me.’”

Such selflessness, however, often comes at the expense of the caregiver’s own health and well-being. When caregivers

don’t take good care of themselves, they can experience stress, depression, frustration, resentment, illness and, ultimately, burnout.

### Self-care isn’t selfish

Self-care isn’t selfish, emphasize the experts on WebMD.com, who offer a series of caregiving tips at [www.webmd.com/balance/tc/Caregiver-Tips-Caregiver-Tip-Number-1-Take-Care-of-Yourself-First](http://www.webmd.com/balance/tc/Caregiver-Tips-Caregiver-Tip-Number-1-Take-Care-of-Yourself-First). Rather, it’s an investment in your own well-being that allows you to continue to give good care to someone else.

“Being a caregiver is like running a marathon,” says Marc Silver, author of *Breast Cancer Husband: How to Help Your Wife (and Yourself) Through Diagnosis, Treatment and Beyond*. Silver’s wife, diagnosed with breast cancer in 2001, underwent surgery, chemotherapy and radiation treatments, and today is in good health. “You need to pace yourself, and recharge in whatever way you need to in order to keep going.

“It’s helpful just to have time to yourself,” he continues, acknowledging that it can be difficult if you are holding

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## Patients Weigh in on Caregiving

When well-meaning family members and friends “just want to help” someone going through breast cancer, here are a few pointers from survivors and caregivers who have been there.

“If there’s one piece of advice I would give men who are caring for a woman with breast cancer, it’s to shut up and listen,” says Marc Silver, author of *Breast Cancer Husband: How to Help Your Wife (and Yourself) Through Diagnosis, Treatment and Beyond*. “I had to learn to not try to take charge and ‘fix it.’ Instead, I needed to pick up on cues from

my wife, ask her what she wanted and needed, and not assume that I knew better.

“I also had to learn to listen more and not try to force my wife to cheer up or negate her feelings,” he continues. “I needed to let her say, ‘I’m depressed, down.’”

“Being able to express my feelings was crucial, at the top of the list,” says Jill Nell of Palm Desert, Calif. A nurse, wife and mother of two young sons, Nell was first diagnosed at

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## message from margaret



Dear Readers,

Taking care of a loved one as she goes through the breast cancer journey can be a rewarding—and difficult—experience. Caregivers can become so focused on helping the patient that they lose sight of the care they need themselves. Because of that, it's important to recognize that you can't provide care for others if your own needs aren't met. In our cover story, "Making the Most of the Caregiver Experience," we help caregivers think about their role in a new light and provide practical ways to cope with the stresses of breast cancer.

Even if you aren't a primary caregiver, you might know someone who is touched by the disease. Often I am asked, "My friend (or co-worker, cousin, etc.) just got diagnosed. What can I do for her?" My suggestion is to act from the heart. Although everyone's needs are different, try putting yourself in her shoes and imagining what you would want from a loved one.

It's helpful to be specific in your offer to help so the patient doesn't feel she has to ask directly. For example, you could tell your friend you'll be bringing over dinner, and then ask if Monday is better than Tuesday. Other options include driving to treatment appointments or picking up the kids from sports practice. For more ideas on ways you can help, call the 24/7 Y-ME Hotline at 800-221-2141 and speak with a breast cancer survivor who can give you insight.

Another service offered by the Y-ME Hotline is the Partners Match Program. Husbands and partners of breast cancer survivors can be paired with individuals who have been caregivers. Sometimes a person has thoughts he doesn't want to share with his wife, including rage or frustration. One man told us he was angry that his wife might die and leave him alone to start dating again (his wife has since recovered and is doing well). Whatever the topic, we have match peer counselors who can discuss your concerns.

Connecting with others who are going through similar experiences can ease fear and provide comfort when it's needed most. This holiday season, consider reaching out to help a caregiver or family touched by breast cancer. Now is also a good time to make a year-end gift to Y-ME in support of our mission to ensure no one faces breast cancer alone. Your donation will help Y-ME continue serving as a premier resource for anyone touched by breast cancer.

Best wishes for a wonderful holiday,

A handwritten signature in cursive script that reads "Margaret C. Kirk". The ink is dark and the signature is written in a fluid, personal style.

Margaret C. Kirk  
Chief Executive Officer

## On Survivorship

### Don't sweat the small stuff

I am a breast cancer survivor since 1983 and have had many recurrences all in bone. Survivorship is an important issue and I enjoy reading thoughts of those many women (*Editor's note*: see the summer 2007 issue of *Lifeline*). Living with advanced cancer is not easy. I feel some good has come out of it all—I don't sweat the small stuff anymore. It has shown me what is the most important in life for all of us—love, family and friends, and most of all good health. I hope I will live long enough to see a cure for this horrible disease.

~ Marcella Malamut  
Mount Laurel, New Jersey

P.S. I enjoy your informative and uplifting issues.

### Forgetting the disease

The term "survivor" suggests that we are seeking some type of special treatment, praise or pity because we have or had a disease and it hasn't killed us yet. I don't feel that way. Most of us would like to forget that we have this disease and live our lives as normally as possible. Normal people don't define themselves by the hardships they have lived through, but by their vision for the future. We can discuss our fears, experiences and hopes among ourselves, but we shouldn't present ourselves to the public as a group of whiners.

Can you imagine people who have survived other potentially fatal diseases walking around with labels—"Motor Vehicle Accident Survivor," "Appendicitis Survivor," "Hepatitis Survivor"... Who cares?

~ Linda Ruth  
Coventry, Connecticut

### Thank you for ASCO *Lifeline*

I want to thank you and Y-ME for the ASCO issue of *Lifeline*. I read it cover to cover, and found it to be very informative. I was particularly interested in the article, "Genomics of Tumor Cells in Metastatic Breast Cancer." I was also surprised that in the article, "Breast Cancer Survivorship: Long-Term Effects of Therapy," Dr. Barton did not address lymphedema.

I look forward to reading more about some of the research covered in this issue of *Lifeline*.

~ Best regards,  
Marion Thurnauer  
Boulder, Colorado

*Editor's note*: Visit [www.y-me.org/lymphedema](http://www.y-me.org/lymphedema) for information on lymphedema, which is a swelling of the arm on the side of the body where breast or lymph node surgery was performed. To read ASCO *Lifeline*, visit [www.y-me.org/publications/lifeline.php](http://www.y-me.org/publications/lifeline.php).

## We Want to Hear From You

We welcome your reactions, comments and thoughts. Please e-mail us at [contact@y-me.org](mailto:contact@y-me.org), write via the Web site—[www.y-me.org](http://www.y-me.org)—or mail to Y-ME,

Attn: *Lifeline* Editor,  
212 W. Van Buren Street, Suite 1000,  
Chicago, IL 60607

Please include the city and state where you live. Letters may be edited for length and clarity. All names and locations will be included unless otherwise requested.

## Men get breast cancer, too

I looked through *Lifeline* to find or should I say NOT FIND anything saying "MEN GET BREAST CANCER, TOO." This really upsets me since it was National Breast Cancer Awareness Month and the fact men get breast cancer wasn't even mentioned. The numbers are going up for breast cancer in men and to not mention anything about this is not right. Men need to know they can get breast cancer so they don't have to feel alone or think they are freaks.

My husband, Brock, died three years ago. If only information had been available maybe he would have had a chance to survive. Fathers that get breast cancer can pass it on to their daughters. Isn't it time to put some blue on the pink ribbon? Please put on every Web page and on every page of *Lifeline* that MEN GET BREAST CANCER, TOO. Breast cancer isn't just a woman's disease.

~ Sincerely,  
Kriss M. Bowles  
Land O' Lakes, FL

*Editor's note*: With about 2,030 new cases of breast cancer expected in men in 2007\*, we agree with you that increased awareness is needed so people know that men can get the disease, too. For more information on male breast cancer, visit [www.y-me.org](http://www.y-me.org) and click on breast cancer information.

\*American Cancer Society

## The Courage to Ask

I am a single woman, living alone in Tulsa, Okla. I asked myself, "How was I going to manage the next nine months of surgeries, chemotherapy, and radiation treatment?" Although, I do a lot on my own, clearly this was impossible without a lot of support and help from others. Fortunately, it never occurred to me to try to do this on my own. Knowing I needed help and support was the beginning.

One snowy Sunday, I gathered friends for a meal in my home. We created a list of names, phone numbers (home, work and cell) and e-mail addresses. I would identify what I needed and send the list to the coordinator who would broadcast it to my "Circle of Friends." Individuals would then look at the list of needs, check their calendars, and respond with accepting tasks that would be a fit for them and their schedule. I had been a little reluctant to invite my Tai Chi teacher who I had just met. She not only came, but volunteered to be my e-mail coordinator! A job I thought no one would want.

I credit Anne Wilson Schaefer, author and mentor, with teaching me to ask for what I need with no expectations. I began to risk, to ask and to trust this process. Throughout my treatment, I was filled with gratitude that when I was diagnosed I had the courage to ask.

~ Dianne Marie Bostic, Breast Cancer Survivor  
Tulsa, Oklahoma

*Editor's note*: If you're looking for a way to juggle needs with offers to help, check out Y-ME's CarePages at [www.y-me.org/carepages](http://www.y-me.org/carepages) to create your own Web page for communicating with family and friends.

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down a regular job, have children and additional responsibilities around the house along with being a caregiver. “So I’d ask my wife if it was OK to do the things I wanted to do, like running or biking. And when she said yes, then I’d ask if she really meant it, and wasn’t just trying not to be a burden out of guilt.”

### Get moving

Exercise, in fact, is one of the most important things for which caregivers need to find the time. It is a tremendous stress reliever that gives a boost to both physical and mental health by increasing endorphin production (the brain’s “feel-good” chemicals), lowering stress hormone levels and activating T-cells, one of the body’s defenses against viruses.

“I’d go running and for those 40 minutes, it was a great relief not to think about the cancer,” Silver says.

But you don’t have to be a runner to realize the physical and mental benefits of exercise. Even a walk around the block or 20 minutes of yoga can make a difference. Or consider tai chi, a form of traditional Chinese mind/body exercise and meditation that uses slow body movements and controlled breathing. It has been shown to elevate moods and drop cortisol (the stress hormone) levels as effectively as brisk walking; in one study, tai chi practitioners had similar heart rate and blood pressure levels as participants who walked six kilometers per hour.

### Eat right

More food for thought: a healthy diet is vital to fuel the stamina that caregiving requires. While takeout fast food may seem a good option for the time-starved, it simply doesn’t provide adequate nutrition to meet your energy needs throughout the day. Eating well-balanced meals and drinking plenty of non-alcoholic fluids are essential elements of good self-care.

### Do what you love

Pursuing personal interests is another tried-and-true stress buster. If you have a hobby or activity you enjoy—such as crafts, knitting, reading or gardening—make some time each day for these pleasurable pursuits. Even if you spend just a few minutes, the time to yourself can help restore a sense of balance. Or ask a friend or family member to stay with your loved one for an hour or two so you can do these things, or treat yourself to a massage or a movie. Remember: It’s not being selfish to take good care of yourself.

### Don’t go it alone


Too often, caregivers think that they have to do everything themselves. Or, even if friends and family are eager to help with chores, organizing all those people and tasks can feel overwhelming. One solution is a free online service offered by Y-ME called CarePages ([www.y-me.org/carepages](http://www.y-me.org/carepages)).

This easy-to-use group calendar is specifically designed for organizing helpers who want to pitch in with meals, rides and other necessary tasks. Needs are posted on a private, personalized Web site where the group calendar is automatically updated. Members sign up to help and the calendar automatically tracks that, sending notification and reminder e-mails to the appropriate parties. With this service, caregivers—and the person they are caring for—can get help without having to directly ask for it. Another benefit is that loved ones and friends who want to help out can do so without feeling intrusive.

Other resources to consider are respite care services, which can provide someone to stay with your loved one when you need a break. If the person you’re caring for needs routine medical attention, many nursing homes offer respite care. Hospice programs provide social, personal and medical services to terminally ill patients who wish to spend their remaining time at home (see Page 17 for more information). Support groups provide an opportunity to discuss problems or concerns with other caregivers; some cancer organizations even offer a telephone buddy system or online chat rooms so caregivers can get support without leaving home.

### Stay connected

Finally, don’t lose touch with friends. “I didn’t do much socially when my mother [who had metastatic breast cancer] was living with me,” says Anita Jones of Monterey, Calif. “That went on the back burner, after my job, cleaning house and caring for a teenage daughter. I had to constantly remind myself to have fun.”

We need our connection with others not only for enjoyment but for comfort and support. Make regular weekly dates with friends to meet for coffee, a manicure or even a phone call. “Connect in any way you can to not feel alone and isolated,” adds Silver. 

## Bat Mitzvah Project Supports Y-ME National Breast Cancer Organization



*Melissa Kahn proudly standing in front of some of the many baskets of pink toiletries she collected and made for breast cancer patients.*

Melissa Kahn, 13, of Woodbridge, Conn., celebrated her Bat Mitzvah on June 9, 2007. As part of her Mitzvah project, she collected pink toiletries for the Connecticut Affiliate of Y-ME Breast Cancer Organization. The toiletries are being given to women going through breast cancer treatment.

Melissa became aware of how breast cancer affects families because several of her friends' moms had the disease. She felt she needed to do something meaningful for these women and others. Melissa wanted to be able to make someone's life a little bit happier while they are going through a difficult time.

Interested in hosting your own event to benefit Y-ME? We'd love to work with you. For details, visit [www.y-me.org](http://www.y-me.org) and click on "Events" then "Third Party Events."

### Breast Cancer around the World

Many thanks for your *Lifeline* publication, I read it cover to cover. Your articles are very informative and keep me up on current issues and topics of interest. The fall 2007 issue on "Breast Cancer around the World" was extremely interesting to me. I am a retired R.N. who at one point in my career worked on oncology. The story about the woman in the Philippines took me a while to imagine what she and her family had gone through. Not knowing beforehand what surgical treatment was performed, and not given any options is criminal. To think that the physicians have that power seems illegal, that article was a real eye opener.

We, for the most part, are not aware of these events happening in other countries. On the other hand, it is great to see such high standards of care for women in the U.K., Sweden and the Netherlands. The M.D. from Brazil was extremely honest about the health care system in his country, and still remains there to promote awareness and provide care.

I am a 12 year "survivor" of stage II breast cancer. Although it has been a long time since my treatment ended, thoughts of recurrence still remain with me, and probably always will. I don't like the term "survivor" as it puts a label on me. It is part of my life; it doesn't define who I am as a person.

I think it is nothing short of wonderful that your information is available in so many languages to raise awareness and provide critical information for those who otherwise would not have access to that information.

I look forward to receiving my monthly *Peer to Peer* via e-mail. Thank you for getting the word out!

~ Sincerely,  
Jacqueline Scully  
Oakdale, New York

Editor's note: For breast cancer information in seven languages, visit [www.y-me.org](http://www.y-me.org).

### Treat yourself, even on a budget

Taking care of yourself does not have to be expensive. Here are some tips for self-care that cost little but can deliver big rewards:

- Listen to music—especially classical music. Tunes with slow tempos of 60 beats per minute have been shown to cause brain activity similar to that found during deep relaxation and meditation.
- Meditate—Just 20 minutes of meditation can help reduce stress, depression, anxiety and anger. Or try deep-breathing exercises for relaxation.
- Keep a journal—Daily journaling is an effective "relief valve" for safely and privately expressing pent-up emotions.
- Take a bath—A warm bath can be a soothing, private ritual to "wash away" stress at the end of the day. Add calming lavender or chamomile oil to the water.
- Practice yoga or tai chi—Rent a video and follow along at home.
- Walk daily—Even a 15-minute walk through the neighborhood can be refreshing.
- Remember to be thankful—Identify at least three things each day to be grateful for; sometimes it may simply be that a difficult day is over.

## Have a Breast Cancer or Breast Health Question?

Feel free to call the Y-ME National Breast Cancer Hotline at 1-800-221-2141 or visit [www.y-me.org](http://www.y-me.org) to submit your questions. All online requests are answered promptly.

Transcriptions are available at [www.y-me.org/sharing](http://www.y-me.org/sharing). Topics of past calls include clinical trials, relationships and nutrition, among others.



## Join us for the ShareRing Network

Join us for a free, monthly teleconference featuring a breast health related presentation followed by a question and answer session. Participants are then divided into optional small groups for discussion, which are moderated by Y-ME peer counselors.

### **December 19, 2007**

“Relationships Challenged by Cancer”

Karen Kayser, M.S.W., Ph.D.  
Professor, Boston College  
Graduate School of Social Work

### **January 16, 2008**

“Scientific Breakthroughs”

Speaker TBA

### **February 20, 2007**

“Fertility and Intimacy Issues after Breast Cancer”

Speaker TBA

All calls are 7:00-8:00 p.m. CT.

[Register now!](#)

Everyone is welcome. Simply call us at 1-800-221-2141 or visit [www.y-me.org/sharing](http://www.y-me.org/sharing) to register and receive dial-in instructions.

*Continued from cover*

## Patients Weigh in on Caregiving

32, then had a recurrence 12 years later in July 2005. She underwent a double mastectomy and total hysterectomy. She credits her husband Chris with being a good listener—and a good communicator—throughout the entire process.


“The one thing I couldn’t deal with was being bombarded with phone calls,” Nell recalls. “It was just too much to explain over and over. I was grateful for everyone’s concern, but I just couldn’t be on the phone all the time. So Chris did the talking for me.”

“The most important thing for me was to make sure that life went on as usual for my kids,” Nell continues. “I could take care of myself after surgery; I wasn’t nauseated and the meds managed my pain. I didn’t need [Chris] to care for me, but to keep the kids on their schedule. I’m not into being coddled,” she adds.

Neither was Shelley Gaidos. The 49-year-old pharmaceutical representative from Massachusetts (who, incidentally, sells cancer therapy drugs) was diagnosed in December 2006, underwent a lumpectomy and completed radiation therapy in July. “I worked and drove myself to therapy appointments,” she says.

Nell, on the other hand, relied on friends to take her to and from chemotherapy. What’s the best way to determine if someone wants help with transportation or other tasks?

“Simply ask me what I need,” advises Nell to would-be caregivers. Or ask, “What are the things you hate most?” and then offer to take on an unpopular task.

What about patients who don’t have nearby family or friends to rely on? There are resources to which they can turn, including local hospital breast cancer programs, local chapters of organizations such as the American Cancer Society ([www.cancer.org](http://www.cancer.org)), Gilda’s Club ([www.gildasclub.org](http://www.gildasclub.org)) or The Wellness Community ([www.TheWellnessCommunity.org](http://www.TheWellnessCommunity.org)), home health care agencies, hospice and religious organizations. Of course, there is always Y-ME, committed to ensuring that no one faces breast cancer alone ([www.y-me.org](http://www.y-me.org)). 

## Got Caregiving Questions?

Who knows better what patients want from their caregivers than, well, patients? With a single phone call to Y-ME’s 24/7 Hotline, you can get tips and guidance from women who not only have walked the walk but are happy to share their experiences and insights about being on the receiving end of caregiving. Just call 1-800-221-2141 (English with interpreters in 150 languages) or 1-800-886-9505 (español).

# on the side: compassion fatigue

Compassion fatigue occurs when family and friends taking care of a loved one with cancer lose their ability to be compassionate as a result of emotional, spiritual and physical overload. The demands of caring for a person going through cancer treatment can be so stressful that the caregiver will experience overwhelming emotions and fears about issues such as their own mortality. According to Dr. Gail Gazelle of MD Can Help and Harvard Medical School, “If enough unresolved internal pain is experienced by the caregiver, compassion fatigue becomes inevitable.”

The demands of caring for a person going through cancer treatment can be so stressful that the caregiver will experience overwhelming emotions and fears about issues such as their own mortality.

## Common Signs



Caregivers should be aware of key signs that may indicate they are facing compassion fatigue. Matthew Loscalzo, M.S.W., director of the Sheri & Les Biller Patient and Family Resource Center at City of Hope, Duarte, Calif., said that the most common sign is when a caregiver is irritable and quick to anger. Some caregivers get so upset that they have thoughts about abusing the patient. These thoughts and feelings can become overpowering, often leading to shame and depression. Some other signs include:

- Physical exhaustion
- Illness
- Difficulty sleeping
- Trouble concentrating
- No longer finding any meaning or pleasure in the activities that they used to enjoy
- Going back to abusive behavior such as smoking or drinking excessively

Loscalzo also noted that compassion fatigue can manifest differently in men and women. He explained, “Men tend to be very focused on the physical functions of helping the patient, such as administering medications and taking them to doctor’s appointments, while women are committed in emotional and spiritual ways. Men can have trouble facing their emotions. Female caregivers have a difficult time when the male patient does not open up, which can lead to their own physical health problems.”

Although it is different for each person, compassion fatigue typically occurs at the end of active treatment

when both the patient and caregiver stop to catch their breath and recognize how tired they are.

## Getting Help

Once the signs of compassion fatigue are recognized, it is critical that caregivers seek help. According to Loscalzo, the most important thing that a caregiver can do is have open and honest communication with the patient and other family members about what they think and feel. Caregivers tend to protect the patient while they suffer internally. Compassion fatigue is more common for people who are isolated, so it is necessary for the caregiver to find a support system. This could include individual or group therapy, or simply calling on others to help with daily chores. Sometimes caregivers are so drained that it is best for them to step aside and appoint another person to fill the role.



Betty DeGeneres, mother of comedian and talk show host Ellen, suggests that caregivers with compassion fatigue turn to support groups to share their experiences with others. When Ellen was just 16 years old, Betty was diagnosed with breast cancer. Fortunately, Betty was treated immediately with a mastectomy and has remained healthy for 34 years. Betty feels strongly that family support is critical for cancer patients and explained how her daughter helped her through that difficult time. “Not surprisingly, even at such a young age, Ellen used humor to help me get through cancer treatment and the recovery period,” Betty said. Ellen is now using her experience to reach out to cancer patients and their caregivers. She is part of an initiative called Pink Together ([www.pinktogether.com](http://www.pinktogether.com)), a Web site sponsored by General Mills that encourages people to share their stories about breast cancer. As Betty explains, sometimes just hearing other people’s stories can help patients and caregivers cope with their own battle against cancer. ✕

## Embracing Palliative Care When You Are Sick

With increased awareness and early detection, death rates for breast cancer have been dropping since 1990<sup>1</sup>. In addition, today's medications control many side effects far better than in the past. That said, there may be occasions when survivors can benefit from the compassionate attention of a team of professionals who can help manage their illness. Enter palliative care—an innovative subspecialty of internal medicine.



“We are trying to get the word out,” says internist Desiree Pardi, Ph.D., M.D., director, Palliative Care Services, New York-Presbyterian Hospital and assistant professor of medicine at Weill Cornell Medical College.

“Palliative care is interdisciplinary care with the purpose to prevent suffering and improve the quality of life for patients and their families. Palliative care reflects the same purpose or philosophy as hospice. They are different, however. Hospice is associated strictly with end-of-life care. In contrast, palliative care is focused on caregiving throughout the entire course of an illness from the *time of diagnosis* until, if necessary, the end of life.”

In other words, palliative care does not require a terminal diagnosis and can, and should, be delivered along with any treatment. The ultimate goal of palliative care is to help people live the best that they can with whatever disease that they may have.

“We focus on a variety of illnesses that are complex and chronic, just because that's where things that we do would be most required.”

Pardi sees palliative care as especially valuable for breast cancer patients for reasons that go beyond physical needs.

“If a woman is getting a lumpectomy, for example, it could change the way the breast looks,” she says, noting how upsetting this is for a woman. “When that distress gets out of hand, we can certainly jump on it and help a woman deal with it.

“Likewise, mastectomies change the way women think about themselves. We have social workers who are experts in counseling and will help women with these kinds of issues too.”

The idea, Pardi says, is to keep individuals who are going through chemo or other treatment in the best state of health, so they can live their everyday lives. Studies show that people who get holistic palliative care early on miss fewer treatments and do better overall.<sup>2</sup>

To find palliative care services, Pardi suggests starting with [www.getpalliativecare.org](http://www.getpalliativecare.org) to learn about local hospital offerings. Palliative care is still so new that most of these services are provided only through in-patient services.

“The more people ask for it, though, the more we will be able to get out-patient facilities or be able to work alongside oncologists in their offices.”

Pardi's enthusiasm for palliative care is deeply felt. Not only has she witnessed the effects of palliative care as a provider, but she has been on the receiving end as a survivor.

“After having breast cancer myself, palliative care has become one of my greatest passions.”

While formal palliative care programs were not in place when Pardi was diagnosed, she feels she received palliative care through great physicians who had an intuitive sense for compassionate caregiving. Wanting to pass this care to others, she did a fellowship in pain and palliative care management at Memorial Sloan-Kettering Cancer Center after her recovery and then returned to Cornell.

Pardi thinks palliative care is especially important for breast cancer patients, who may benefit from this care intermittently throughout their survivorship—particularly post-treatment.

“Often what happens is that a patient can get lost. She doesn't see her oncologist quite as much any more, yet she may have lingering physical, emotional, or financial symptoms. She needs someone who knows how to handle these things,” Pardi says. “That's what palliative care does.” ✂

### SOURCES:

1. [http://www.cancer.org/docroot/CRI/content/CRI\\_2\\_4\\_1X\\_What\\_are\\_the\\_key\\_statistics\\_for\\_breast\\_cancer\\_5.asp?sitearea=](http://www.cancer.org/docroot/CRI/content/CRI_2_4_1X_What_are_the_key_statistics_for_breast_cancer_5.asp?sitearea=)

2. Hearn J, Higginson IJ. Do specialist palliative care teams improve outcomes for cancer patients? A systematic review. *Palliat Med* 1998; 12:317-322.



### Looking for some comfort while going through treatment?

Call the 24/7 Y-ME Hotline at 800-221-2141 and talk about your issues with a peer counselor who's been there. Trained and certified peer counselors are all breast cancer survivors and are available anytime, day or night.

# Communicating with Children

## How to tell them what you need during your breast cancer journey



The entire family is likely to feel anxious when a loved one is diagnosed with breast cancer, and communication plays a key role in coping. However, children have unique fears and concerns when illness comes between them and a parent they depend upon for love, direction and security, making the dual roles of parent and patient a difficult road to navigate.

“It’s natural for parents to feel the need to protect a child from the fear and uncertainty that go along with breast cancer or any other serious illness by withholding information,” says Christine McGinnis, Psy.D., a family therapist in Roswell, Ga. “This is the wrong thing to do, because children then fill in the blanks with what they

Regardless of how large or small the contribution, children should receive recognition for their efforts. They need to hear that they have made a difference.

don’t know. By explaining your illness to your children, you can help them manage their fears and guide them toward accurate and hopeful interpretations of events during your journey toward recovery.”

Although families may make every attempt to maintain regular routines, it is important to acknowledge that certain changes may be required due to medical and emotional needs. Children should be informed that these needs may make you less available at times, and be reassured that they will have access to you again in the near future.



“Young children need to hear from you that Mommy isn’t feeling well, and that’s why she has to go to the doctor a lot and take medicine that makes her sick,” says Dr. McGinnis. “A teenager can handle a more detailed conversation in terms of the actual illness and what the treatment period is going to be like. But children of all ages need to hear that it’s okay to give you space during the times when you are feeling sick or just need a good cry by yourself.”

By setting expectations for your children, you send a reassuring message that you are still in charge and that they will not be left on their own. But with energy divided between your normal responsibilities and the demands of treatment, you still may have to rely on the assistance of family members and friends to complete certain tasks. Asking children to help is a logical way to ease your burden, and pitching in can contribute to children’s sense of purpose within the family.

However, it is important to be sensitive to how much your children want to be involved and to gauge their adjustment to additional expectations. “You have to remember that children are self-centered, and that this is what they need developmentally,” Dr. McGinnis cautions. “If you take away too much of that, they miss a part of parenting. And too much responsibility creates a danger that children might take on an adult role, which is not good for them.”

When you do ask for help, try to give children tasks they can safely and easily perform. Keep in mind that age matters not just in terms of what a child can accomplish, but in how they may prefer to contribute. Younger children may feel good about bringing you a glass of water or helping to take care of the family pet. Teens may be more open to tasks that recognize their growing maturity and independence, such as driving younger siblings to school or picking up a prescription.

Regardless of how large or small the contribution, children should receive recognition for their efforts. They need to hear that they have made a difference. They also need understanding when they resist giving the time that you ask for, even when the request seems small.

“Children aren’t capable of comprehending your needs at an adult level,” Dr. McGinnis says. “They are struggling with knowing that their mother is sick, yet at the same time they really want Mom to make their breakfast and attend school activities. And it’s natural for them to want those things, even when they realize you’re not up to it.”





# RIDE TO Empower

## Think you have what it takes for Y-ME's Ride to Empower?

Y-ME's Ride to Empower™ is a destination bike ride, with route lengths ranging from a 100-mile century to less than 32 miles. The event will give participants the opportunity to meet the challenge of a long-distance bike ride and pay tribute to friends and loved ones touched by breast cancer, and to enjoy an empowering and memorable three-night and four-day experience.

The Ride will take place in Solvang, Calif., October 23-26, 2008, with the century ride taking place on October 25. Ride to Empower participants are required to raise a minimum of \$4,000, and in exchange for their successful fundraising efforts, riders will enjoy accommodations at a 3-star hotel, with meals included. Y-ME will provide riders with fundraising and training tips so they will be successful.

### About the route

Solvang, 130 miles north of Los Angeles, is a picturesque community with Danish-style architecture located in the heart of the Santa Barbara's wine country with the Santa Ynez mountains as a backdrop. The route offers something for every level of cycling ability—from rolling country

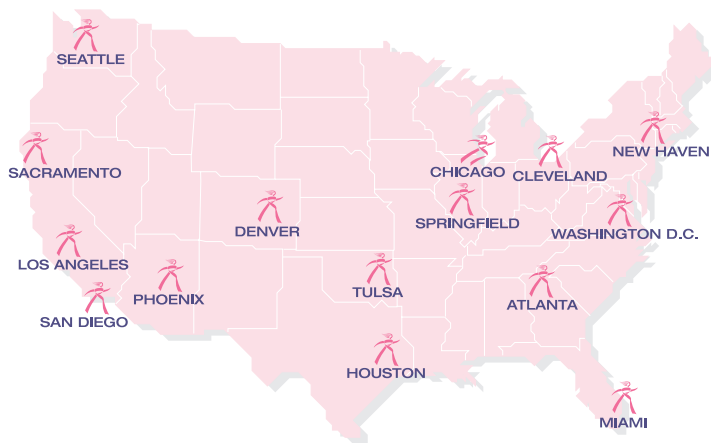
stretches past vineyards to challenging climbs into the mountains. Solvang, which means "sunny fields" in Danish, has an average of 340 days of sunshine per year. This area is a prominent training ground for professional cycling teams and serves as host for the Discovery Channel pro-cycling team's first training camp of the year. All of this will make Y-ME's Ride to Empower an event you won't want to miss.

For more information on the Ride to Empower, please visit <http://ride.y-me.org>, call (312) 873-2729 or e-mail [events@y-me.org](mailto:events@y-me.org).



## Save the Date!

Mother's Day  
Sunday, May 11, 2008  
[www.y-me.org](http://www.y-me.org)



### Lifeline Is Available Online

If you'd like to read the current or back issues of Y-ME's quarterly publication, *Lifeline*, you can do so by visiting [www.y-me.org](http://www.y-me.org) and clicking on Publications.



*“My loved one has breast cancer and I’m having a hard time coping. Can you help me?”*

Most people diagnosed with breast cancer today have an excellent prognosis, says breast cancer survivor Linda Seligman, Ph.D., faculty associate at Johns Hopkins University and author of 14 books on psychotherapy and related topics.



“With the great medications now available, chemotherapy is not what it used to be and recovery from surgery, even with a mastectomy, is usually brief. While there are exceptions, obviously, patients generally are not incapacitated for any length of time,” she says.

Still, survivors may battle fatigue, nausea or other side effects. Drained of the energy they once had, most of these individuals need a helping hand—a caregiver—to pitch in and do a little more.

The role of a caregiver is challenging, however. While the role of the survivor is simply to get treatment, the responsibilities of the caregiver are not well defined. According to Seligman, this ambiguity is difficult, because the caregiver wants to take away the pain and make things better, but what this person can do is limited. Emotionally, he or she feels powerless and is suffering along with the patient. One of the big challenges is knowing what to do.

Seligman, who received the 2007 Counselor Educator of the Year Award from the American Mental Health Counselors Association and has worked with countless couples and individuals dealing with breast cancer, has several suggestions for coping with the role of caregiver.

“The most important thing is for the survivor and the caregiver to have a dialogue and for the caregiver to ask the survivor how to help best.”

Communication is a two-way street though, Seligman adds. Often a patient wants something very specific, but may not share these wishes clearly, so the caregiver never knows. Requests go ignored and the patient thinks the caretaker does not care.

Likewise, a caregiver needs to listen and not presume that doing more is necessarily better. Specifically, temporary role shifts often occur within families when someone is ill and this can be a potential trouble spot. It is difficult for survivors to give up the role they once had. They may be

resentful because they cannot do something themselves and because their partners are not doing the task as well as they did.

“Caregivers should empower survivors to continue doing these tasks if they want to, rather than just taking things away by doing things themselves.”

Other suggestions for caregivers:

- Maintain normal activities and holiday traditions as much as possible, getting outside help if necessary. Routines are particularly important when there are children in a family.
- Be sensitive to the survivor’s moods and possible needs that you cannot provide. Along with the survivor and with that person’s permission, talk to the oncologist about treatment for depression or any symptoms that may be painful or disturbing.
- Encourage your loved one to share any feelings and any worries he or she may have.
- Support your partner after treatment is over. Breast cancer is never declared “cured,” so it is normal for survivors to worry about recurrence.

With so much attention directed to the breast cancer patient, caregivers often feel as though they are not entitled to feel bad themselves. But emotional pain is legitimate pain, Seligman points out. Caregivers need to talk about their feelings and can benefit from a support system, whether it is a therapist, an online or local support group, or a good friend they see on a regular basis.

Finally, Seligman encourages caregivers to pay special attention to little kindnesses, which she believes are exceptionally important. Remembering back 17 years to when she was receiving treatment for breast cancer, it was these little things that touched her the most, drawing her closer than ever to her husband.

“One of the things I used to like him to do was to bring me a cup of tea and a piece of cake at the end of the day,” she says. “And we’d just sit and talk. It was just a nice self-indulgent way to wrap up the day.” ❧

## The Y-ME Hotline offers coping tips

Don’t feel as if you have nowhere to turn! Y-ME peer counselors are available 24/7 at 800-221-2141 to address your concerns. Whether you are the loved one or the patient, you may benefit from speaking with one of our trained peer counselors who are breast cancer survivors.



## Introducing Y-ME South Florida

We are pleased to announce the launch of Y-ME South Florida, the newest addition to our growing Affiliate network. Building upon the success of the Miami Walk to Empower, this Affiliate will begin serving Palm Beach, Broward, Dade and Monroe counties during the next several months.

In November, we welcomed Marjorie Aloni as executive director for Y-ME South Florida. Marjorie has extensive experience in nonprofit administration and is delighted by the opportunity to build and grow this Affiliate. Most recently, Marjorie worked as the C.E.O of Florida Breast Cancer Coalition Research Foundation. She created the organization's first major gifts and planned giving programs. Marjorie directed all advocacy and legislative

efforts for the foundation on both state and federal levels. She developed a publicity campaign for the End Breast Cancer license plate, as well as created a new branding program for the organization. In addition, she worked at Aventura Turnberry Jewish Center as the director of member services and development; where she developed educational, cultural and social events for the congregation. Marjorie holds a master's degree in women's studies from American University. We welcome Marjorie and look forward to her contributions to our newest Affiliate and to our mission to ensure no one faces breast cancer alone.

For more information on Y-ME South Florida, visit [www.y-me.org/southflorida](http://www.y-me.org/southflorida).

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## Affiliate Roundup

Here's a glimpse of what's happening at our Affiliates across the country. For more information and to find your local office, explore our Affiliate Web pages at [www.y-me.org/affiliates](http://www.y-me.org/affiliates). If you don't have Internet access, please call 800-221-2141.

### Chattanooga

Is celebrating its 15th anniversary. The affiliate has started a knitting group that doubles as a therapy group. The participants create hats for other breast cancer patients who lose their hair during chemotherapy.

### Connecticut

Is excited to host the first Walk to Empower in New Haven, Conn., Mother's Day 2008.

### Illinois

Is expanding its services to include outreach to women's prisons and halfway houses. The Affiliate is also starting outreach into the large Polish community in Chicagoland.

### Indiana

Continues to collaborate with other Indiana breast cancer organizations. Supporters were proud to host their 13th annual fashion show on October 13, 2007.

### Mid-Atlantic

Is planning to offer African-American outreach through A Day for You. The outreach will also serve the Caribbean, Ethiopian and other African communities in the national capital area.

### Northeastern Oklahoma

Continues to build relationships with the Native-American community in the region. The Affiliate is becoming more involved in breast cancer advocacy due to the efforts of a state senator who is a breast cancer survivor.

### Northern California

Is actively engaged in a strategic planning process to prepare for expanded programs and services.

### Rocky Mountain

Is expanding its services to include several new support groups and open door programs. This Affiliate is actively recruiting for its board of directors.

### Southern California

Is launching a teen program in high schools throughout Southern California to raise awareness of breast health; teens can take information home for their families.

### Texas Gulf Coast

Is exploring outreach to the homeless population in the Houston area. The Affiliate will soon offer a breast cancer support group for Chinese-speaking participants.

## Y-ME Announces Recipients of Annual Awards

Y-ME National Breast Cancer Organization is pleased to announce the recipients of its annual awards. The award ceremony followed Y-ME's annual board of directors meeting held Thursday, October 18th at Edelman Worldwide in downtown Chicago.



The **Sharon Rose Miller Spirit Award** is in honor of Sharon, a metastatic breast cancer patient who worked tirelessly on Y-ME's front lines, sharing her personal story to help others traveling the same path. The award was presented to **Leah Josiah**, a native of Nairobi, Kenya, who was

diagnosed with breast cancer in 2000 and now lives in Chattanooga, Tenn., where she is a peer counselor for the 24-hour Y-ME Hotline and a volunteer for Y-ME Chattanooga.

Given in memory of a doctor who left an enormous legacy of hope, compassion and dignity, the **Arthur G. Michel, M.D., Award for Excellence in Breast Cancer** went to **Dr. William Gradishar**, director of Breast



Medical Oncology and co-director of the Lynn Sage Breast Program at Northwestern. Dr. Gradishar recently provided expert commentary for the special ASCO edition of Y-ME's newsletter, *Lifeline*, and has provided valuable information to Y-ME's constituents including as a speaker for Y-ME's monthly teleconference, the ShareRing Network.

Each year, Y-ME's **Award of Distinction** is given to the organization or individual who made the largest financial contribution to Y-ME in the past year. This year, **sanofi-aventis** was honored for its \$750,000 in donations and its National Presenting Sponsorship of Y-ME's Mother's Day Events.

Fashion Designer Daniella Clarke of **Frankie B.**, in partnership with **Genentech**, were given Y-ME's **Media Award** for their efforts to bring the message of earlier detection and breast cancer awareness to the public.

Y-ME's **Cause Partnership Award** went to **Soft & Dri**, a brand of The Dial Corporation, for helping generate significant revenue and bringing attention to Y-ME's core programs and services. In addition to a national ad campaign announcing its \$100,000 commitment to Y-ME, Soft & Dri was a national official sponsor of Y-ME's Mother's Day Events and launched an online "Awareness Garden" in support of Y-ME.

The Y-ME National **Mother's Day Team Achievement Award** went to four companies that created fundraising teams with their employee bases throughout the country: **McDonald's**, **Grant Thornton, LLP**, **Walgreens** and **United Airlines**.

Y-ME's Hospitality Award was presented to **Edelman**.

Three Y-ME employees were given the **Every Day Every Way Award**, to recognize and reward individuals who demonstrate Y-ME's five core values: *Excellence, empowerment, customer focus, integrity and communication*. This year's winners, voted for by their peers, were: **Donna Pelletier**, Y-ME quality assurance manager; **Ana Venezia**, Y-ME contact center manager, 2nd shift, and **Kelly Bonen**, Y-ME Hotline volunteer manager.



In addition, the organization honored two board members whose tenure has ended: **Jane Perlmutter**, who served for six years, and **Marge Kauffman**, who represented the Northeastern Oklahoma Affiliate for two years. ♪

## theme for the spring issue of *Lifeline*

All you ever wanted to know about nutrition and exercise





## Know Your Rights as a Caregiver

Did you know there are laws that protect and give rights to caregivers? Read on for a summary of the latest legislation that has already been passed into law and the acts for which we're still advocating.

The following acts **have not been passed** by Congress:

### Healthy Families Act

(Senate Bill 910/ House Bill 1542):

**What the bill would do:** The Healthy Families Act would require employers with at least 15 employees to provide an annual minimum of seven days paid sick leave for those who work at least 30 hours per week. For those who work 20-30 hours per week, a lesser amount of paid sick days would be allowed. The paid sick leave would allow workers to care for their own medical needs or to care for a sick relative.

**How you can help:**

Visit [www.y-me.org/caregiversalerts](http://www.y-me.org/caregiversalerts) and send your elected officials a letter urging them to support the Healthy Families Act.

### Family Leave Insurance Act of 2007

(Senate Bill 1681)

**What the bill would do:** The Family Leave Insurance Act of 2007 would establish a Family and Medical Leave Insurance Program through the Department of Labor. The program is designed to provide up to eight weeks of paid leave to workers for the birth or adoption of a child, to care for a child, spouse or parent with a serious illness or to care for their own serious illness. The Department of Labor would reimburse employers through an insurance fund once payment is made to their employees. Businesses with 50 or more employees would be required to participate, while small businesses could choose to opt in.

**How you can help:**

Visit [www.y-me.org/caregiversalerts](http://www.y-me.org/caregiversalerts) and send your elected officials a letter urging them to support the Family Leave Insurance Act.



Take advantage of the following legislation that **has been passed** by Congress:

### Older Americans Act Amendments of 2006

(P.L. 109-365)

**What the bill does:** Older Americans Act Amendments of 2006 reauthorized the Older Americans Act, which includes the National Family Caregiver Support Program (NFCSP). The Older Americans Act Amendments of 2006 includes provisions to expand the number of family caregivers eligible for support services by:

- 1) Decreasing the age of a qualified grandparent or relative caregiver caring for a child from 60 to 55 years old;
- 2) Including adopted children in the list of individuals to whom a grandparent may provide care.

The NFCSP calls for all states, working in partnership with local area agencies on aging and faith and community-service providers and tribes to offer five direct services that best meet the range of caregivers' needs, including: information; assistance; individual counseling; organization of support groups, and caregiver training; respite (relief) care; and supplemental services.

The Older Americans Act Amendments of 2006 gives priority for NFCSP services to family caregivers who provide care for older individuals with Alzheimer's disease or related disorders and to grandparents or older relative caregivers who provide care for children with severe disabilities.

For more information on the NFCSP visit [www.y-me.org/caregiversalerts](http://www.y-me.org/caregiversalerts).

### Lifespan Respite Care Act (P.L. 109-442)

**What the bill does:** the Lifespan Respite Care Act created grants for state agencies and organizations that administer programs under the Older Americans Act (see above) to:

- 1) Develop lifespan relief care at the state and local level;
- 2) Provide relief care services for family caregivers caring for children or adults;
- 3) Train and recruit relief care workers and volunteers;
- 4) Provide information to caregivers about available relief or support services; and
- 5) Assist caregivers in gaining access to such services. **Y**

\*Respite care is provided to caregivers to temporarily relieve them from common tasks associated with caregiving, such as adult day care and in-home assistance.

## FMLA Helps People Juggle Work and Caregiving

According to the U.S. Department of Health and Human Services, more than 50 million people in the U.S. provide care for a chronically ill, disabled or aged family member or friend during any given year. Being a caregiver is often a full-time job. For many, balancing one's career and caregiving can be a daunting, if not impossible, task. However, in 1993 then President Bill Clinton signed into law the Family and Medical Leave Act (FMLA) to help Americans cope with the demands of work and family.

FMLA requires certain employers to grant eligible employees up to 12 work weeks of unpaid, job-protected leave during any 12-month period for the birth and care of an employee's newborn child; for placement with the employee of a son or daughter for adoption or foster care; to care for an immediate family member with a serious health condition; or to take care of the employee's personal health due to a serious condition that prohibits the employee from performing his/her essential functions at work.

Are you eligible under the Family and Medical Leave Act?

FMLA applies to all:

- Public agencies, including state, local and federal employers, local education agencies (schools)
- Private-sector employers who employed 50 or more employees in 20 or more work weeks in the current or preceding calendar year and who are engaged in a business related industry (buying/trading/selling)

To be eligible for FMLA benefits, an employee must:

1. Work for a covered employer;
2. Have worked for the employer for at least a total of 12 months;
3. Have worked at least 1,250 hours over the previous 12 months; and
4. Work at a location in the United States or in any territory or possession of the United States where at least 50 employees are employed by the employer within 75 miles.

For more information on the Family and Medical Leave Act, visit [www.y-me.org/caregiveralerts](http://www.y-me.org/caregiveralerts).<sup>Y</sup>

\*Above information obtained from the U.S. Department of Labor and the U.S. Department of Health and Human Services.



Want to be in the know on Y-ME Advocacy issues? Sign up for our monthly eNewsletter and learn the latest. Visit [www.y-me.org](http://www.y-me.org) today.

## October is Y-ME Month

Just call October "Y-ME Month." In 2007, National Breast Cancer Awareness Month was also named Y-ME Month in seven states across the country. Y-ME was recognized for the programs and services we provide year 'round to ensure that no one faces breast cancer alone.

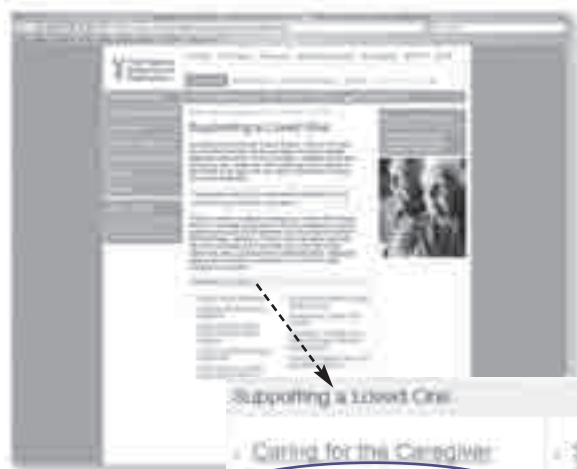
States and cities with an official "Y-ME Month" are Arizona, Colorado, Connecticut, Illinois, Maryland, Cleveland and Washington. Y-ME received a letter of commendation from the Governor of Georgia praising our efforts in the great "Peach State."<sup>Y</sup>





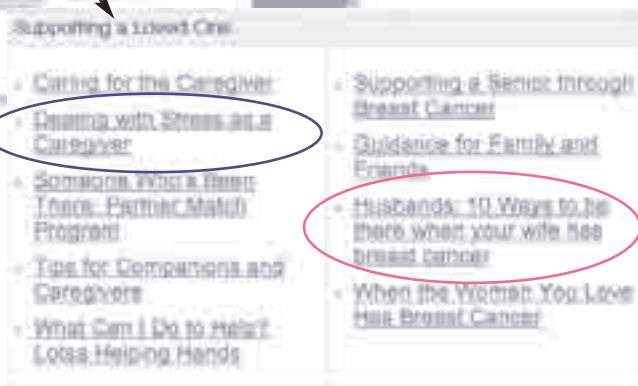
## Information you can trust...with a survivor's touch

Y-ME's online resources are there for you anytime you need them.  
Just visit us at [www.y-me.org](http://www.y-me.org) to see the latest.



### Support for caregivers

From dealing with stress to providing tips for supporting a senior or your wife through breast cancer, we have caregivers covered. Here's just an excerpt of what you'll find when you visit [www.y-me.org/caregivers](http://www.y-me.org/caregivers).



**"I'm taking care of my partner who is being treated for breast cancer and I am feeling a lot of stress. What should I do?"**

Psychiatrist David Spiegel, M.D., says that it is a good thing for partners to acknowledge that they, too, are under stress. Spiegel says there tends to be the feeling that the person with the cancer is the only one who has any real stress. It is, however, important to recognize that partners of people with cancer have their own set of burdens. These are related, but different.

For the full story, visit [www.y-me.org/caregivers](http://www.y-me.org/caregivers).

**Breast cancer is a life-threatening and relationship-threatening trauma. Peter J. Flierl, M.S.W., offers 10 tips for husbands of patients with breast cancer.**

#### **Tip #2 Say yes**

When someone, anyone, asks if they can do anything to help, just say "Yes." Friends, family, neighbors, colleagues and others want to be there for you and for themselves. I know, I know. You're a man and never ask for help, not even simple directions. Understand that the people asking to help need your "Yes" as much as you. It gives them some sense of being able to do something positive.

For the other nine tips, visit [www.y-me.org/caregivers](http://www.y-me.org/caregivers).

## We're here if you ever need us

You can submit your breast cancer and breast health questions online at [www.y-me.org](http://www.y-me.org) when you click on the "Ask Y-ME" button. A trained peer counselor who is also a breast cancer survivor will get back to you quickly.

## Spotlight on Hospice

### A high-quality option for end-of-life care

Hospice is a philosophy of compassionate caregiving designed to help individuals with chronic illnesses and their families cope with end-of-life issues, so they don't have to face them alone.



"Hospice care is about keeping people as comfortable as possible when they decide they are not going to pursue further therapy," says Linda T. Vahdat, breast cancer oncologist. "I see it as an optimal way to achieve the best quality of life at the end of life."

Vahdat, medical director of the Breast Cancer Research Program at Weill Cornell Medical College, explains that there are two kinds of hospice: inpatient and home-based.

**Staying at home means having the support of a family member or other caregiver who can administer pain medication, if needed, and basically assume all caregiving, around the clock, every day.**

Home-based hospice is for people who wish to spend their last days at home. The most important concern for many patients at the end of life is to be pain free, she says. Staying at home means having the support of a family member or other caregiver who can administer pain medication, if needed, and basically assume all caregiving, around the clock, every day.

A good in-patient hospice is clean and friendly, Vahdat says. It is somewhat like a hospital setting in that you have around-the-clock care, but it is homier and so much nicer than a hospital.

"The décor, for example, is prettier," she says. "Also, in-patient hospice is geared toward patient and family comfort, as opposed to being fully functional."

Hospice, which may be paid for by private insurance companies, as well as by Medicare or Medicaid, offers a variety of therapies performed by the patient's very own hospice team.

According to Vahdat, a hospice team is different from a treatment team. A hospice team includes specially trained palliative care doctors, nurses, pain management doctors, nurse anesthetists, social workers and clergy. These individuals are selected because of their desire and dedication to providing compassionate caregiving to those with chronic illness. The focus of this team is not only

making the patient comfortable and coordinating all care, but increasing the overall well being of the family.

Hospice is not for everybody, Vahdat says, but it is a good choice for end-of-life care, because it lessens the fear and discomfort of dying. "People are afraid of being in pain," Vahdat says. "With hospice, they control the pain."

According to the National Hospice and Palliative Care Organization, an estimated 1.2 million individuals are using hospice each year. Because of this growing popularity, patients and their loved ones are becoming increasingly aware of this option, often bringing it up themselves.

Bringing up the subject of hospice can be difficult, but it is important to discuss when a patient is deteriorating and every intervention does not seem to make her better. A patient might bring up the subject to ensure that she is as comfortable and pain free as possible. She might also welcome additional support for her family and friends who are caring for her.

A caregiver might talk about requesting hospice because it can help manage many of the symptoms a patient may have. Vahdat introduces the subject of hospice if no one else brings it up. She often approaches the topic indirectly by asking her patient a few key questions: Does she want to be resuscitated and put on life support if her heart stops beating? Who does she want to make her health care decisions, if she is incapable of making decisions on her own?

Initiating hospice services can be difficult for the caregiver, as well as for the survivor, because you are shifting gears. With this shifting of gears, the primary goal becomes making the patient comfortable, as opposed to shrinking the tumor. Hospice offers meditation and spiritual therapies too. They also help family and friends deal with grief and impending loss.

"Hospice is an integral part of how we care for patients today," Vahdat says. "It is important to keep open-minded communications with health care providers, so they can explore all options, including the right time for hospice, when appropriate."

"This is a difficult subject for many doctors to bring up, so I think sometimes patients and their families need to bring it up themselves. That makes everything easier." ❧

Statistics Source:  
[www.nhpc.org/templates/1/homepage.cfm](http://www.nhpc.org/templates/1/homepage.cfm)

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## Make their day with flowers

Who doesn't love to get flowers? Now you have the perfect excuse to send a bouquet to someone special in your life. From October 1 through May 31, FTD.com will donate 10 percent of the purchase price of its "Pink Ribbon Collection" bouquets to Y-ME. Let your caregiver know their efforts are appreciated, or send some cheer to a survivor. Visit [www.y-me.org/ftd](http://www.y-me.org/ftd) and click on the "Pink Ribbon Collection" image to begin shopping. ♪



 Y-ME National  
Breast Cancer  
Organization™

# mission

The mission of Y-ME National Breast Cancer Organization is to ensure, through information, empowerment and peer support, that no one faces breast cancer alone.

## Lifeline

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\*Interpreters available in 150 languages



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# Y-ME resources



## When the Woman You Love Has Breast Cancer

Y-ME's booklet is for the husband or the partner of a woman who has been diagnosed with breast cancer. From initial diagnosis through treatment and recovery, the publication addresses the common concerns of caregivers.

To view a pdf or request your free copy, visit [www.y-me.org](http://www.y-me.org) and click on "Publications."



## CarePages

CarePages are free, easy-to-use Web pages that help family and friends communicate when a loved one is receiving care. It takes just a few minutes to create a CarePage, share it with friends and family, and build a community of support.

For the next three months, CarePages will donate \$10 per active CarePage which is created through Y-ME's CarePage Web site at [www.y-me.org/carepages](http://www.y-me.org/carepages) up to a maximum of \$10,000.

# resources

In addition to our publications and our Web site, [www.y-me.org](http://www.y-me.org), Y-ME suggests the following resources for breast cancer information.

## books

***Windshifts***  
**Jane Grossman.**  
**Authorhouse, 2005.**



Have you ever dreamed of running away to a tropical island? In 1996, Jane Grossman left behind a comfortable life in Chicago and set off with her husband on their 34-foot sailboat, Iniki, to sail South America. What began as a chance to simplify their lifestyle and see the islands gradually evolved to a sojourn of self-discovery, renewal and triumph over breast cancer.

"Windshifts" is a true sailing adventure that chronicles the wonder and excitement, the difficulties and fears from a woman's perspective. Vivid details and delightful descriptions of exotic lands, cultural interactions and inevitable conflicts of a husband and wife confined to close quarters involve the reader with all of their senses. More importantly, it is a reflection on dealing with the unexpected challenges, including breast cancer, that confront us throughout our lives.

## organizations

**The American Cancer Society**  
**[www.cancer.org](http://www.cancer.org)**

ACS offers medical information, treatment decision tools, news updates and support resources.

**Gilda's Club**  
**[www.gildasclub.org](http://www.gildasclub.org)**

Gilda's Club provides meeting places where men, women and children living with cancer, along with their family and friends, can join with others to build a personal network of social and emotional support.


**Men Against Breast Cancer**  
**[www.menagainstbreastcancer.org](http://www.menagainstbreastcancer.org)**

MABC provides targeted support services to educate and empower men to be effective caregivers. The organization mobilizes men to be active participants in the fight to eradicate breast cancer.

**The Wellness Community**  
**[www.thewellnesscommunity.org](http://www.thewellnesscommunity.org)**


The Wellness Community is an international non-profit organization dedicated to providing free support, education and hope to people with cancer and their loved ones.

## Shopbop.com Marc Jacobs Bracelet Is Here for the Holidays

Fashion forward women's online retailer, Shopbop.com, debuted an exclusive Marc Jacobs Breast Cancer Awareness bracelet in the fall. Shopbop teamed up with the fashion designer to create a charity piece exclusively for its Web site to benefit those who can't wait for a breast cancer cure. Fifty percent of each bracelet purchase will benefit Y-ME. The Marc by Marc Jacobs bracelet was featured in some exciting press this fall: in *Glamour* magazine's October issue, *Teen Vogue's* October issue and in *People Style Watch*. The exclusive bracelet is sold at [www.shopbop.com](http://www.shopbop.com) for \$88.00. Don't miss this great opportunity! 



## Read ASCO Lifeline

Y-ME recently published a special edition of *Lifeline* that focused on the latest news in breast cancer that came out of the American Society of Clinical Oncology (ASCO) meeting in June. The issue is available online at [www.y-me.org](http://www.y-me.org) when you click on publications, then "Lifeline." 

# need to talk?

## 24-hour Y-ME National Breast Cancer Hotline

1-800-221-2141 (English)\*

1-800-986-9505 (español)

\*Interpreters available in 150 languages

[www.y-me.org](http://www.y-me.org)



Receiving duplicate  
newsletters?

Has your address  
changed?

Please let us know! We make every effort to send only one newsletter to each family. If you're receiving more than one copy, or if you prefer to stop receiving *Lifeline*, e-mail your request to [list@y-me.org](mailto:list@y-me.org) or call us at 312-986-8338.



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[www.y-me.org](http://www.y-me.org)

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