FALL 2012

Insight

An educational newsletter from LBBC

LIVING BEYOND BREAST CANCER®

LBBC.ORG

Telling Others About Your Breast Cancer Diagnosis

BY ROBIN WARSHAW, FOR LBBC

Stacey Barber began the day with an ultrasound for a possible breast cyst. That led to a mammogram; then, a biopsy.

STACEY BARBER

As she was making dinner for her family in Homewood, Ill., the surgeon called and said the cyst was a tumor. "She never said the words, 'breast cancer,'" recalls Stacey, then 38.

Both she and her husband had been on the phone for the surgeon's call. Now it was time to think about telling the people closest to her: her parents, her best girlfriends and her children, then ages 7, 5 and 2.

When should she tell them, how should she deliver the news and what should she say? She worried about causing stress for her parents and protecting her children from information that might scare them.

The answer, for Stacey, was clear: "I decided I wasn't going to tell anyone until I knew exactly what was going on and how serious it was," she says.

Start Slowly

Deciding if, when and how to make your breast cancer diagnosis known to others—and who to tell—is "a process that unfolds," says **Kauser Ahmed, PhD**, a clinical psychologist at the Simms/Mann UCLA Center for Integrative Oncology in Los Angeles. That decision-making process applies whether you're newly diagnosed, in treatment or beyond.

With a new diagnosis, you're likely to tell the people you live with almost immediately. Dr. Ahmed suggests waiting a bit, as Stacey did, before talking with others who are important in your life but don't live with you.

"You need to have some time and space with it yourself," Dr. Ahmed says. You might choose to wait until after you receive a definitive diagnosis, or choose doctors, or establish a treatment plan, or have your first procedure.

Telling others can bring you emotional and physical support. Not disclosing keeps that support away, but it also lessens your exposure to insensitive comments or upsetting behavior from other people.

It's not an either/or choice. You can decide to tell certain individuals and not tell others. As you move forward, you may decide to reveal your diagnosis more often or less often.

"It's very difficult to keep something like this a secret but relatively easy to keep it private," says Dr. Ahmed. "You have a right to decide what your level of privacy is."

WORDS THAT MIGHT HELP

I've been diagnosed with breast cancer, and I am in treatment. I'd appreciate it if you don't talk about this with others.

Delivering Information

Think about what you want to share, and with whom. Some women write a one- or two-line explanation of what they are comfortable letting people know.

Create a list of a few close and trusted people you want to tell first. You may want to include those who can be helpful to you, such as co-workers, babysitters or teachers.

Notifying people can be hard. "Dealing with everyone else's emotions and stuff is really draining when you're

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Dear Friends:

I was saddened to learn earlier this summer that a forerunner in the breast cancer world, Y-ME, made the difficult decision to close its doors.

Y-ME was founded 35 years ago when there was little support for women with breast cancer. The organization played a key role in encouraging women to share stories and support each other. In many ways, LBBC builds on what Y-ME started. Its closing marks the end of an era. But fortunately, today women have many places to turn, including LBBC. We are poised to extend our services to anyone in need.

We are preparing a number of educational programs and special events to raise awareness and funds key to our financial health. Topics to be addressed this fall range from fertility to nutrition to updates on metastatic disease. If you are unable to attend, you can listen to podcasts on lbbc.org at convenient times for you. And if you want support from a woman who has been there, call our Survivors' Helpline at (888) 753-LBBC (5222).

Please take a moment to read about our corporate partners, and check out the products being sold this October to benefit LBBC on our Shop to Support page on lbbc.org. There, you can download a special catalog with all products for easy reference and order information.

Finally, if you or someone you know is a federal employee, you can support LBBC via the Combined Federal Campaign. LBBC has been selected to participate for the second year, and we have been assigned CFC's giving donation code #78012.

As always, thank you for your continued support.

Warmly,

Jean A. Sachs, MSS, MLSP


Laurie Beck Photography

LIVING BEYOND BREAST CANCER

Empowering all women affected by breast cancer
to live as long as possible with the best quality of life.

Saying Goodbye to My Mother: A Caregiver's Story

BY KELLY BALDWIN HEID, AS TOLD TO ANNA SHAFFER

This is a photo of my mom and me on my wedding day, December 21, 2011. She died on February 25, 2012, at age 58. This really was her last "good" day.

My mom used to say that having cancer was like wearing a backpack.

Sometimes the backpack was heavy and slowed you down, while other times it was empty and you hardly noticed it. But it was always there, always with you.

I was a caregiver for my mother, who fought breast cancer for 25 years and died on February 25, 2012. For the last two years, I called her almost every day on my lunch break and tried to be there for her. I live in Philadelphia, so I went home to Michigan a lot. When the cancer spread to her brain and she decided not to have further treatment, I supported her.

I have kept a journal since I was in middle school, and I often wrote about how difficult this time was. On October 31, 2011, I wrote, *"Some days are better than others, but it's always with me. I cry a lot. But I just can't summon the strength or stamina to express my feelings of deep fear and almost manic desperation to her. If I go to call my mom at lunch, and I can't reach her for some reason, my anxiety flies off the charts, and I become literally obsessed with talking to her and hearing her voice."*

> **"One of the last things my mom said to me was, 'You have to be brave.' And she was right. Caregiving requires a lot of courage."**

In November 2011, we found out that the chemotherapy did not work. After that, I found myself writing down the most basic things I was grateful for—this, I got from my mother. She was the type of woman who would exclaim, "I just *love* yogurt," as if it was a pot of gold. She would break into song about asparagus or getting the mail. I wrote about being grateful for 2 percent milk, my gym, art, warm pants and the shining sun.

That November I wrote my mom a letter and asked if she felt that she was dying. She called me to talk about it, and her answer was yes. I didn't feel better after speaking with her about it, but at least I knew where she stood. Lesson: ask everything, ask anything, and ask often. Fear of the answer is not a good reason to keep quiet. I draw on the big conversations as much as the little exchanges now that she is gone. Asking questions might also help the sick person express herself in a way she wouldn't be able to otherwise. I felt part of my role was to ask my mom things other people might be afraid to ask but that she might want to talk about, like how her body and mind felt as she was dying.

When I relocated to Michigan for the two months preceding her death, my role expanded significantly. I went from providing emotional support to providing physical support. I also had to adjust from being a part-time caregiver to doing it full-time.

I and her other caregivers did everything for her. We were her voice, and we knew where she stood. She had always said she wanted to die with dignity, and we advocated for her. While in Michigan, I felt less emotionally reliable because of the exhausting and all-consuming demands of hands-on caregiving. It meant the world to me when my family and friends would tell me I was doing a good job. We—my dad, sister, husband, brother-in-law, aunts, uncles, friends and I—relied on each other so that we could give 100 percent to my mom.

My mom was often sleeping, and I would spend hours staring at her and memorizing her features. There were mornings when I was sure she would not make it another hour, and I would hold her hand and cry into her shoulder. I am not ashamed to admit that I prayed for two things every morning: that I would have the strength to make it through the day, and that my mom would have the strength to die.

My caregiving experience had many contradictions: I wanted to hold tightly to her warm body, but hearing her labored breathing was agonizing. I wanted her to be at peace, but I didn't want to live without her. And then she died. Five months later, I can't believe she is *still* dead.

One of the last things my mom said to me was, "You have to be brave." And she was right. Caregiving requires a lot of courage. Caring for someone with cancer or any ailment is hard, complicated work. And at the risk of sounding cliché, it is also indescribably rewarding and life-changing work. The ability to give someone you love what they need feels good, and I am proud I was able to do that for my sweet mother.

In honor of National Caregiver Month in November, LBBC would like to acknowledge Kelly and all those who care for loved ones diagnosed with breast cancer. Thank you for all that you do.

Drug Shortages in Breast Cancer: How They Impact You

BY JANINE E. GUGLIELMINO, MA


SHAUNE O'NEIL

Shaune O'Neil, 50, wanted the "bestest, baddest" treatment after her January 2011 diagnosis with triple-negative breast cancer.

The Palmer, Alaska, woman consulted her doctor, who recommended a dose-dense regimen of doxorubicin and cyclophosphamide, followed by paclitaxel. The combination, known as ACT (for Adriamycin, Cytoxan and Taxol), is standard therapy for early-stage breast cancer.

But after Shaune agreed, her doctor delivered surprising news. "She told me she had two other patients with leukemia who also needed the Adriamycin, and she didn't have enough," Shaune says.

Like thousands of Americans, Shaune was forced into a situation when drug shortages robbed her of her first-choice treatment. Shortages tripled in the last five years, most involving generic, injectable medicines like chemotherapy. For you and your doctors, that means planning ahead—and asking questions about what can be done.

A Complex Issue

At press time, doxorubicin remains among the several cancer medicines in short supply, FDA reports. Also recently listed were paclitaxel, cisplatin (Platinol) and pegylated liposomal doxorubicin (Doxil), sometimes used in metastatic breast cancer. (See the list at fda.gov/Drugs/DrugSafety/DrugShortages.)

Shortages have not just affected chemotherapy. Antibiotics, anesthetics, vaccines, pain medicines and nutritional supplements fill the agency's 100-plus-item list. Although federal law allows FDA to address shortages, until recently it did not require manufacturers to report them. Some did so voluntarily, but the system left doctors uncertain about supply.

"When we decide a treatment regimen, we now add to the list [of issues to consider] how available is this drug going to be in the next three or six months," says **Rick Frame, MD**, a medical oncologist at Utah Cancer Specialists in Salt Lake City. "We find ourselves living in this environment of, what next? When? And the 'why' is even more complicated."


RICK FRAME, MD

Experts point to multiple causes. Consolidation in the drug industry means nearly three-quarters of generics are made by just three companies. A quality-control problem at just one plant—such as fungus or glass in medicine—can halt production for multiple drugs. And if that medicine is made by only one company, it could take months for supply to recover. Even worse, some companies stop making older, well-studied generics because they yield little profit.

Injectable medicines like chemotherapy are complex to make and have a short shelf-life. Sometimes ingredients run low or run out. Typically, practices buy only what they need, but shortages may have led to hoarding. FDA is cracking down on so-called "gray markets," when unscrupulous people buy up generics and charge buyers as much as 3,000 percent above market value.

Also contributing to shortages is the 30-month wait time, on average, for FDA to approve New Drug Applications (NDAs) for generics. Others point to 2003 legislation that caps Medicare reimbursement for generics at 6 percent above the average wholesale price. That fails to cover administrative costs, so practices use brand-name drugs instead, squeezing the generics market further.


MUSA MAYER, MS, MFA

Impact in Breast Cancer

Due to the complex causes, drug shortages are unlikely to go away anytime soon. But as a woman with breast cancer, you may be less likely than others to face a shortage yourself.

"We are fortunate in breast cancer, because we have a lot of approved regimens," says **Ruth O'Regan, MD**, a medical oncologist at Emory's Winship Cancer Institute, in Atlanta. "It's been inconvenient in breast cancer, but in something like Kaposi's sarcoma or refractory ovarian cancer, we have fewer options."

The Doxil shortage is concerning to women with metastatic breast cancer, says **Musa Mayer, MS, MFA**, the longtime advocate who runs AdvancedBC.org and monitors the message boards of BCMETS.org. Doxil is not FDA approved in breast cancer, but it is sometimes used when cancer progresses after other therapies.

"These women know there are a finite number of treatments that will work for them, and they want to stay on a treatment that is working for as long as they possibly can," Ms. Mayer says.

Dr. O'Regan, who practices at both Emory and Grady Memorial Hospital, has faced shortages of Doxil at both locations. For two women, that meant switching treatment: the first, to a clinical trial; the second, to eribulin (Halaven), a new chemotherapy.

In some cases, Doxil may be the last treatment option. But much of the time you will have many choices. There is no standard sequence for treatments in metastatic disease, so you can move among therapies. If you are taking Doxil and have to stop, you might be able to take it again; Dr. O'Regan switched one woman back after Doxil returned to stock.

Community practices may feel shortages more acutely than large institutions, says **Eric Winer, MD**, a medical oncologist at Dana-Farber Cancer Institute in Boston. With 84 percent of people receiving treatment at local clinics, according to the Community Oncology Alliance, the number of women with breast cancer adds up.

Still, drug shortages in breast cancer have not reached a crisis level. "It seems that most oncologists have been able to navigate the issue, by either finding another drug or finding another source for the drug they need," Ms. Mayer says.

Shaune's doctor recommended she take epirubicin (Ellence), which is similar in structure to doxorubicin, because it works just as well and has fewer side effects on the heart.

"Knowing I had an alternative, I felt confident I was going to come out of treatment as good as I could," Shaune says.

Hidden (And Not So Hidden) Costs

Other generics in shortage have similar brand-name equivalents. With paclitaxel, for instance, your doctor can use nab-paclitaxel (Abraxane) or the generic docetaxel (Taxotere). All medicines have differences, so ask about effectiveness and side effects.

Brand-name medicines have higher co-pays than generics, a cost that gets passed along to you. If you don't have insurance, talk with your care team about patient assistance programs. But even with insurance, you can run into problems. Shaune faces $40,000 in bills because her claim was denied.

"In the middle of treatment, they called and said [the epirubicin] wasn't approved," Shaune says. "The emotional slam and mental burden [of that news] was almost as bad as the treatment. I continued, and I appealed. Finally, I hired a lawyer."

Stress from drug shortages can affect your relationships with your providers. But your care team probably feels just as frustrated as you.

"[Drug shortages] didn't register for me until I had to sit down with one of my patients, look her in the eye, and say, 'I can't get Doxil for you,'" says Dr. Frame, recalling a woman with ovarian cancer. "She couldn't believe it. And neither could I."

Planning Ahead

Trust in your care team is key. Shaune's doctor looked at alternate regimens and clinical trials but felt the epirubicin combination would give Shaune the best results.

"If your doctor won't tell you that, or you don't trust your doctor when she tells you that, then you need to find a new doctor," Shaune says.

Ask questions. Your doctors should be prepared with, or willing to get, answers for you. "We try to anticipate future shortages, or avoid regimens where there is going to be trouble getting the drugs," Dr. Frame says.

Educate yourself about treatment options. A good place to start is nccn.org, the website of the National Comprehensive Cancer Network, says Ms. Mayer. NCCN maintains treatment guidelines, which include level of evidence for each therapy. Among the questions to ask your team:

- Will this medicine be available throughout my treatment?
- If it runs out, what are my other options? Are they similar to my original therapy?
- Why is it unavailable? When will you have it again?
- What are the differences in effectiveness with the new medicine?
- What are the differences in side effects?
- Will insurance pay for this treatment? If not, what resources exist to help?
- Can I get treatment through a clinical trial?
- If I switch treatments, can I return to my original therapy when you get it again?

Even if you never personally face a shortage, consider what you can do to help others.

"As a whole, drug shortages are clearly a problem," Dr. Winer says. "That it's less of a problem for women with breast cancer shouldn't make us take it any less seriously."

How to Get Involved

Congress, government and advocates are working to address drug shortages. In July, President Obama signed a law which for the first time charges companies a fee to make generics. Money goes toward speeding FDA reviews of manufacturing plants and New Drug Applications. The law also requires companies to report known or anticipated shortages at least six months in advance.

The American Society for Clinical Oncology and American Cancer Society work to raise awareness of shortages, as does CPAN, the Community Oncology Alliance Patient Advocate Network. Dr. Frame, who serves as CPAN's medical chairman, says women help because "when the doctor says something, it's not as powerful as when the patient says it." You can also write to your legislators, Dr. Winer says.

To learn more about getting involved, visit asco.org, cancer.org and coaadvocacy.org.

Photo: Tim Sharp Photographic Services

Programs, Events Grow to Meet Your Needs

BY JOSH FERNANDEZ

Resources for Living Well

Join us as we kick off Breast Cancer Awareness Month with our fall conference, **News You Can Use: Breast Cancer Updates for Living Well**, on Saturday, Sept. 29, at the Loews Philadelphia Hotel.

Larry Norton, MD, of Memorial Sloan-Kettering Cancer Center, is back by popular demand and will start the day by discussing how modern medicine is changing the way we think about breast cancer and overall breast health. Our closing keynote features **Debra Jarvis**, a minister of the United Church of Christ and author of *It's Not About the Hair: And Other Certainties of Life and Cancer*, on the importance of self-discovery and self-awareness during your breast cancer journey.

Get information and practical resources for yourself, your caregivers, family and friends at workshops covering what to expect when you're newly diagnosed; cultural myths in communities of color; managing scan and test anxiety while living with metastatic breast cancer; reducing risk of triple-negative breast cancer recurrence and more.

The $50 per person registration fee includes access to educational programs, workshops and the exhibitor hall, and a continental breakfast, lunch and networking reception. Register at lbbc.org or by calling our office.

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Metastatic News and Awareness

LBBC is holding a teleconference series just in time for Metastatic Breast Cancer Awareness Day on October 13.

On October 8, **Hope Rugo, MD**, of the University of California, San Francisco, will cover medical updates. Learn about the latest research and treatment developments in metastatic breast cancer, and get information on clinical trials. During the second teleconference on October 22, **Wendy G. Lichtenthal, PhD**, of Memorial Sloan-Kettering Cancer Center, will discuss managing your emotions. Learn practical tips for getting emotional support. Check lbbc.org for updates and to register.

October 13 is also the target release date for our new ***Metastatic Breast Cancer Series: Guide for the Newly Diagnosed***. The guide, developed and distributed in partnership with the Metastatic Breast Cancer Network, will help you learn about treatment options and emotional concerns in the first few days, weeks and months after you are diagnosed with metastatic breast cancer. Preorder your free copies through lbbc.org's online marketplace.

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Save the Date: C4YW 2013

Mark your calendars and spread the word! LBBC and **Young Survival Coalition** are thrilled to announce the **Annual Conference for Young Women Affected by Breast Cancer (C4YW)** will be held February 22-24, 2013, at the Hyatt Regency Bellevue on Seattle's Eastside. This three-day educational program for women diagnosed before age 45 offers a plethora of networking opportunities and workshops on topics such as clinical trials, nutrition, metastatic breast cancer, managing side effects, fertility and pregnancy and caregiving.

Now on the schedule is opening plenary speaker **Julie R. Gralow, MD**, director of breast medical oncology at Seattle Cancer Care Alliance. Dr. Gralow will discuss "Young Women and Breast Cancer: The Facts, the Research, and the Future of Care." Closing plenary speakers **Nancy Buermeyer** and **Connie Engle, PhD**, of Breast Cancer Fund, will discuss "Going Green: Making Informed Environmental Choices." More speakers will be announced in the winter issue of *Insight*.

Check out c4yw.org for updates. We'll see you in the Emerald City!

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Young Women's Initiative Update

We recently completed a needs assessment for our **Young Women's Initiative**. The four-part needs assessment included a nationwide survey of more than 1,500 women diagnosed with breast cancer before age 45. **Kimlin Ashing-Giwa, PhD**, of the City of Hope National Medical Center in Duarte, Calif., will present the assessment's findings at our fall conference. **Arin Ahlum Hanson, MPH, CHES**, manager of the Young Women's Initiative, is excited to share the results and develop new programming for young women

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in 2013. The needs assessment consists of a national survey; key informant interviews with 12 healthcare providers and advocates; four focus groups with 34 women; and an environmental scan of 29 organizations with programs for young women. One key finding shows a need for more support and programs, especially for underserved young women.

"It was truly inspiring to have so many young women from across the country participate," Arin says. "The response was much larger than we had predicted."

The Young Women's Initiative is funded through a multiyear grant from the **Centers for Disease Control and Prevention**, an agency of the U.S. Department of Health and Human Services. In the first year, federal funding for the program totals $250,000. Visit lbbc.org for more information.

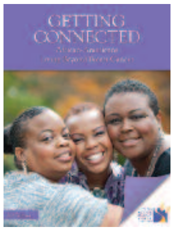
Reading Reminder

The newest editions in our popular *Guides to Understanding* series will debut soon and are available to order.

In ***Hormonal Therapy***, get the basics of treatments for hormone-sensitive breast cancers, whether you are pre-, peri- or postmenopausal. ***Intimacy and Sexuality*** provides tips on how to recapture feelings of happiness and pleasure and practical tools to talk with partners and doctors. ***Yoga and Breast Cancer*** is out just in time for our signature education and fundraising event, **Yoga on the Steps: Washington, DC**. The October 14 event incorporates the life-enhancing benefits and techniques discussed in the guide and raises funds and awareness for LBBC's programs and services.

Order these guides and learn about our other titles at lbbc.org.

Getting Connected



Our culturally relevant booklet ***Getting Connected: African-Americans Living Beyond Breast Cancer*** is a terrific resource for African-American women affected by breast cancer, healthcare providers and community advocates.

In May, LBBC's **Arin Ahlum Hanson, MPH, CHES**, gave a presentation on the development of the second edition of *Getting Connected* to healthcare professionals and researchers at the Moffitt Cancer Culture and Literacy Biennial Conference. The new edition was informed by five focus groups held in Philadelphia, Chicago and Little Rock. *Getting Connected* now highlights the unique needs of young women and has an updated look, a new section on managing and accessing information, a new chapter about the end of active treatment, an updated "Making Medical Decisions" chapter and quotes from focus group participants that represent a wider diversity of perspectives.

Are there other groups you think could benefit from this publication? Let us know at publications@lbbc.org or by calling our office at (610) 645-4567. Visit our website to learn more or to order copies.

Ask Our Experts

Have questions about medical or quality-of-life issues? Explore new treatments, clinical trials, medical findings from leading conferences, emotional issues and more by listening to an LBBC teleconference.

These free programs are scheduled at convenient times and give you the opportunity to ask questions and get information that helps you live well. Upcoming programs focus on navigating your "new normal" (September 11), metastatic breast cancer (October 8 and 22), nutrition (November 7) and fertility and pregnancy (December 12).

Can't listen live by phone? Access our online archive to download past programs to your smartphone or computer. You can also ask questions of experts via our online ask-the-expert series. Each month, a breast cancer expert responds to questions on a specific topic on lbbc.org. In September, November and December, ask-the-expert topics will be the same as teleconference topics so you have additional opportunities to get your questions answered.

Visit lbbc.org to register for teleconferences, submit an ask-the-expert question or get updates.

Help Is a Toll-Free Call Away

Living Beyond Breast Cancer's **Survivors' Helpline** is there when you have questions or need support and don't know where to turn. Assistance is just a toll-free call away at (888) 753-LBBC (5222).

A woman affected by breast cancer will answer the phone live on Tuesdays from 11:00 a.m. to 3:00 p.m. ET. At any other time, leave a message or submit your questions using our online form on lbbc.org, and a Helpline volunteer will return your call within 24 hours.

Photos: James Murphy of Creative Images, Epaul Julien Photography, Doug Seymour, Laurie Beck Photography

Shop to Support: One-of-a-Kind Products Benefit LBBC

BY KEVIN GIANOTTO AND RACHEL PINKSTONE-MARX

Each October the media recognizes Breast Cancer Awareness Month, and retailers across the country offer customers the chance to support the work of organizations that address the needs of women affected by breast cancer.

"LBBC is thrilled to present a few items that you'll see this fall from some of the corporate partners in our **Shop to Support** program," says **Sandy Martin**, director, development and communications at LBBC. "Each of the featured products gives back to LBBC when you purchase them because a percentage of the proceeds supports our programs and resources."

jane iredale—THE SKIN CARE MAKEUP®

jane iredale celebrates its Rise Above with Love® campaign by continuing its partnership with LBBC for the fifth year in a row.

"This year we're introducing Cherish Lip Fixation, a versatile two-in-one product with a lip stain in a universally flattering pink and a complementary gloss," says **Jane Iredale**, president and chief executive officer of Iredale Mineral Cosmetics. "It's an uplifting indulgence for every woman."

The product comes with a zip pouch adorned with two whimsical shoe charms that evoke the campaign tagline, "Cherish yourself and kick up your heels!"

jane iredale will donate 100 percent of profits from the sale of Cherish to LBBC. Cherish Lip Fixation retails for $34 and can be purchased at shop.janeiredale.com and at fine spas and salons, resorts, apothecaries and medical offices. Available while supplies last.

Everything But Water

Returning partner **Everything But Water** offers one of the most unique products that supports LBBC this year—a beautiful smartphone wristlet/wallet by Deux Lux.

The gray-woven zippered wristlet with pink contrast zipper tape was custom designed with innovation in mind. In addition to protecting your smartphone, the wristlet features a zippered coin pouch for storing cash and credit cards, as well as a special ring for easy access to your keys. The wristlet is versatile—use it as a fashionable alternative to a purse to carry streamlined necessities, or as a wallet inside your purse.

The smartphone wristlet retails for $44 and is available in stores October 1. Everything But Water will donate 25 percent of proceeds to LBBC. If you prefer to purchase online, pre-orders began September 1 at everythingbutwater.com.

Cline Cellars

The **Cline Cellars** winery in Sonoma, Calif., a producer of award-winning Rhone-style wines and Zinfandels, has offered its winemaking expertise to support LBBC since 2011.

"Through countrywide sales of Cashmere—a unique and refined wine blending Grenache, Syrah and Mourevédre—Cline will support the one-of-kind resources LBBC provides to women affected by breast cancer," says Cline Cellars owner **Nancy Cline**. "We selected LBBC because we were inspired by their focused mission and active outreach to women diagnosed at all stages and ages, and we were moved by the care and attention to detail that LBBC brings to every program."

In addition to a guaranteed donation of $25,000, Cline Cellars will provide the chance for customers to donate a special $2 rebate coupon back to LBBC during October.

Cashmere can be found at better wine shops across the country or online at clinecellars.com.

White House | Black Market

A major supporter of LBBC since 2004, **White House | Black Market** has a profound commitment to making a difference for women affected by breast cancer. This October, the company will introduce several new items in its Give Hope Collection, for which proceeds of up to $250,000 will benefit LBBC.

Shop to support LBBC at White House | Black Market locations across the country this October by purchasing these exclusive items: The Butterfly Tee, retailing for $40; the Give Hope Bracelet, retailing for $20; and the Butterfly Charm Bracelet, also retailing for $20. For the location nearest you, visit whbm.com.

essie

essie has named LBBC as the recipient of a $50,000 donation in support of our programs and services. Promotion of the partnership begins when essie launches its 2012 Breast Cancer Awareness Collection.

Bigger and better than ever, the line this year includes four pinks created to inspire empowering "me time": i am strong (in powerful powder puff pink), good morning hope (in unstoppable, iridescent semi-sheer pink), check-up (in punchy pink dahlia) and we're in it together (in rosy petal pink).

"The breast cancer fight is deeply important to me, as too many women have been affected," says **Essie Weingarten**, founder and global creative director for essie. "I'm fully committed to help raise awareness and educate women. This is our second year collaborating with Living Beyond Breast Cancer. They have been a wonderful partner, whose main goal is to improve the quality of life in battling this disease. We chose to make a donation to LBBC in honor of our Raise Awareness collection. It's amazing what we can accomplish when we're in it together."

essie's Breast Cancer Awareness Collection will be available in October in salons and beauty destinations worldwide.

Thank you to our February 2012 – June 2012 contributors:

$100,000+

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Liz and Stephen Raynes

$20,000–$24,999

Centers for Disease Control and Prevention

$10,000–$19,999

Comcast-Spectacor Foundation
Genentech
Genomic Health Inc.
White House | Black Market

$5,000–$9,999

California Exotic Novelties
Deloitte LLP
Einstein Healthcare Network
essie
Fieldstone 1793 Foundation/ Mrs. Henry A. Jordan
Robert B. Golder
HealthAmerica Pennsylvania
Independence Blue Cross
John Harding Family Foundation
LIVESTRONG
Diane S. Raynes
Riedel Crystal of America Inc.
SmartWool Advocacy Program
Unite for HER
UnitedHealthcare
Veridex, LLB
Warnaco Inc.

$2,500–$4,999

Beneficial Bank
BJNB Foundation/ Jacqueline L. Allen
Cancer Treatment Centers of America at Eastern Regional Medical Center
Celebrate Wine/Wine by Design
Daniel Comer
Thomas Egan
GreaterGood.org
Hologic
Jade Yoga, a division of Jade Industries, Inc.
LympheDIVAs, LLC
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Meyer Capital Group
Patricia and George Miller
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Susie and Jay Shah
THOR•LO, Inc. & Subsidiaries
Valley Green Bank
Margaret and Andy Zuccotti

Continued from cover

trying to deal with your own," says **Natalie Palmer**, 50, an editor from Avon, Conn. Ask a relative or good friend to convey your information by phone, email, social media or websites such as caringbridge.org/partner/LBBC and carepages.com.


NATALIE PALMER

Natalie, who was diagnosed with stage IV breast cancer in 2005, noticed that people picked up on her cues. "If you're calm and feeling positive and confident, people will also be calm and tend to be more positive," she says. "If you're weepy or upset, people go right there with you."

Single women often worry about how to tell someone they've just started dating. Dr. Ahmed advises waiting until early interactions have moved on to genuine interest. Your breast cancer experience is "not necessarily the first thing anyone needs to know about you, but it's a significant part of your life you'd want the person to know," she says.

WORDS THAT MIGHT HELP

I feel good about the doctors I'm working with and my treatment plan. I was diagnosed with breast cancer a while ago. I'm focused on moving forward.

How Much To Tell?

You can set boundaries for how much to say about the specifics of your diagnosis. Just because someone asks for details doesn't mean you need to give them. "You don't ever have to abdicate your right to control the information," Dr. Ahmed says.


CICELY CREWS

If you are living with metastatic breast cancer, you might choose not to talk about ongoing treatment, a concept many people don't understand. Or you may see it as an opportunity to educate others.

If your diagnosis doesn't fit a common breast cancer profile, you might decide to limit what gets discussed. **Cicely Crews**, 31, a systems analyst from Jackson, Tenn., was diagnosed with stage II breast cancer last year. She told few people outside of her family about her triple-negative status.

"The only others I talked to about it in detail were other people who had experienced breast cancer. They were familiar with the term," Cicely says.

Stacey wanted to shelter her children from others' comments, so she told her babysitter she did not want to publicize her diagnosis. Later, while helping her son wash up at preschool, a mother she did not know asked how she was doing. The woman said the babysitter had told her about Stacey's diagnosis.

To an extent, "there's no way to keep that from happening," Dr. Ahmed says. If someone mentions your diagnosis and you don't want to talk about it, change the subject. "That level of control you always have, whether you disclosed to them or not," she adds.


ROSLYN REID

WORDS THAT MIGHT HELP

Thanks for asking, but I'd rather not go into the details. I'd like this time to not be about that experience, and I hope you can respect that.

Reactions Vary

Roslyn (Roz) Reid went to a yoga retreat after finishing radiation therapy for stage I breast cancer 21 years ago. When she disclosed her diagnosis to the retreat organizer, "her face fell completely to the floor," says Roz, 65, of Trenton, Maine. "She was stunned into silence. It was very uncomfortable."

Roz went to her room but couldn't shake the effect of the woman's response. She decided to leave. "It kind of blindsided me. I felt they would be supportive."

While negative experiences do happen, "the majority of women are pleasantly surprised and touched by the kindness of most people in their lives," Dr. Ahmed says.

Because she's young, Cicely often gets questions about her diagnosis. She says that talking with other people has been good. "It just seems that when people ask you and you tell them, it ends up being a positive interaction."

WORDS THAT MIGHT HELP

What you've said (or done) isn't helpful. What I need from you is [fill in what applies].

Talking With Your Employer

At work, you will probably need to tell your human resources department and your supervisor about your diagnosis if you plan to ask for time off or flexible or reduced hours. By law, your employer must keep your information private.

You might choose to tell some of your co-workers as well, but the law does not require them to protect your privacy. At first, Natalie didn't care if people at work knew. As word spread, "I became part of this club I didn't want to be part of," she says. "I think I would be more careful about it now."

Cicely told her manager about her diagnosis almost immediately because surgery was scheduled soon. Her manager asked Cicely's permission to tell her co-workers. "I told her she could share my diagnosis, but I would rather them not know the details of the surgery." That request was respected.

You can set boundaries for how much to say about the specifics of your diagnosis. Just because someone asks for details doesn't mean you need to give them.

WORDS THAT MIGHT HELP

My doctor says I should recuperate for [fill in time length], and then I can return to work. My plan is to work around my treatment schedule.

Telling Children

It's important to talk with your children about your diagnosis using simple words they can understand at their age level. Prepare by writing down a few points. Talk when children are rested and there's time to answer questions or comfort them.

Experts advise telling children you have breast cancer, rather than saying you are sick, to avoid confusion with everyday illnesses. Reassure children that nothing they did caused you to develop breast cancer and that it is not contagious. Let them know who will take care of them.

Some parents want to keep a diagnosis secret to protect children from becoming upset. Yet children sense family stress, hear things and worry when they don't understand what is happening. They do better when they hear the news, with supportive guidance, from you.

Because Cicely was having surgery quickly and her 16-year-old son lived away during the week, her sister and mother told him about her diagnosis. Cicely and her husband told their 6-year-old daughter. It had been only a few days since diagnosis, but her daughter had already overheard a telephone conversation and asked Cicely if she had cancer.

Natalie told her two sons, ages 12 and 15, together and then told her daughter, a senior in high school. In those first conversations, she didn't provide a lot of details. She told the children enough "so they would know I was going to be OK. That I would be sick with chemo, but that was part of the healing process," she says.

WORDS THAT MIGHT HELP

There is something in my breast that shouldn't be there. It's called breast cancer. The doctors are going to take it away with an operation. Then I will take medicine to help me get better.

RESOURCES

American Cancer Society: Talking With Friends and Relatives About Your Cancer, cancer.org/Treatment/UnderstandingYourDiagnosis/TalkingaboutCancer/talking-with-friends-and-relatives-about-your-cancer

Cancer and Careers: cancerandcareers.org

LBBC: Ask the Expert: Communicating With Loved Ones, lbbc.org/Learning-From-Others/Ask-the-Expert/2010-12-Communicating-With-Loved-Ones

FALL 2012

Insight

An educational newsletter from LBBC

LIVING BEYOND BREAST CANCER
LBBC.ORG

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IN THIS ISSUE

Calendar

Educational Programs

Teleconferences

OCTOBER 8, 2012
Living with Metastatic Breast Cancer: Medical Update

OCTOBER 22, 2012
Living with Metastatic Breast Cancer: Emotional Impact

NOVEMBER 7, 2012
Eating Well During and After Treatment

DECEMBER 12, 2012
Fertility and Pregnancy

Conferences

SEPTEMBER 29, 2012
Annual Fall Conference: News You Can Use
Philadelphia, PA

FEBRUARY 22–24, 2013
C4YW—Annual Conference for Young Women Affected by Breast Cancer
Bellevue, WA on Seattle's Eastside

Special Events

OCTOBER 14, 2012
Yoga on the Steps: Washington, DC

NOVEMBER 10, 2012
The Butterfly Ball Philadelphia, PA

Check **lbbc.org** for the latest program information

Photos: Laurie Beck Photography, James Murphy of Creative Images