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## Staying 'ill' informed

### CaringBridge's free Web sites are a lifeline for people dealing with health crises

**BY KIMBERLY DISHONGH SPECIAL TO THE DEMOCRAT-GAZETTE**

When Laura Newman was diagnosed with invasive lobular carcinoma — breast cancer — in April 2006, her phone began ringing off the hook. People who cared about her were reaching out, offering to help in any way they could as she fought for her life.

She was grateful for their attention and thankful for their support, but she was too tired and too sick to talk with all of them.

"As I was telling friends about my diagnosis, I was, of course, bursting into tears and they were crying, and it was just too hard," the Little Rock resident says. "Plus, I was swept up in this flurry of tests and doctor visits and just had to put my immediate attention on all of that, but I needed to let friends and family, especially those who were out of town, know what was going on."

Not long after that, she heard about CaringBridge.org, a nonprofit organization that offers free Web sites to people who want to keep friends and family updated about themselves or a loved one who is going through a health crisis or recovering from an injury.

Newman set up her site right away — [www.caringbridge.org/visit/lauralouie](http://www.caringbridge.org/visit/lauralouie) — updating with news of chemotherapy, radiation and surgery and giving readers insight into her state of mind.

Updating the site became as important to her as it was to those who cared about her and wanted to know how she was doing.

"It really did become therapeutic," she says. "I would see responses from people who had written things and that made it really special. There's one friend who truly expected me to write and I knew she was counting on me, so I would get up out of bed [and write] because I knew she needed to know. It really made me feel that I was getting well to know that someone was expecting me to write something."

Newman's is one of more than 75,000 CaringBridge Web sites in the United States and one of about 400 in Arkansas.

The statistic CaringBridge founder and executive director Sona Mehring likes to share is that a new CaringBridge site is created every 10 minutes.

CaringBridge users can choose from three levels of privacy, and their sites cannot be found through Internet search engines.

"There are other ways of creating a Web site that people can use to share their journeys," Mehring says. "What CaringBridge does is take care of the technology. We make it extremely easy for anyone to create a Web site in a short amount of time, and we worry about the security and privacy behind it and make sure it's up 365 days a year. Really, all they have to worry about is what information they're sharing and getting in touch with their friends and sharing photos."

Mehring created a Web site in 1997 for a close friend who had a troubled pregnancy and who remained in critical condition after her baby was born almost three months' premature. The baby died nine days after birth. The site allowed her friend's and family to communicate information to others without putting demands on her or the medical staff that was caring for her, and the response to her Web site prompted the creation of CaringBridge.

Mehring, based in Eagan, Minn., has a background in technology and has received numerous awards recognizing her work in creating CaringBridge.

"It has been a wonderful journey," she says. "Being able to use that technology background to help people — I love to call it compassion technology — has been a wonderful personal experience. My joy is that I can help people."

Mehring hears from people often about CaringBridge's value. One woman told her the Web site turned her husband's life around. The man had been depressed and without hope, but when she showed him how many people had signed his guest book and he realized how many people were thinking about him, he found the strength to continue his struggle toward better health.

Sites can be deactivated by the author when a health crisis has passed or when a patient has died, but they can remain up as long as they are needed, Mehring says. Some people have written about babies born prematurely and then continued for years to tell of their children's progress, even telling readers about the children's first days of kindergarten.

Michelle Ford of Conway created a site for her daughter, Kaitlyn, who was diagnosed in October 2005 with medulloblastoma, a type of brain tumor.

"Especially when she was sick, we would have a lot of people sign the guest book," Ford says of the site, [www.prayforkaitlyn.com](http://www.prayforkaitlyn.com).

"We were in the hospital with her for five months straight, living at the hospital. When we could open the site and see that people were checking on her every day and leaving messages and praying for her — it gave us strength to keep on going."

Katie died on July 11, 2006, following a stem-cell transplant at Arkansas Children's Hospital in Little Rock, but her Web site remains active and Ford posts often with updates about how the family is doing.

"It helps me to vent a little bit about my feelings, but it's also a way for me to make sure that she's not forgotten and to keep her memory alive," she says.

In the journal, Ford writes about the baby boy she gave birth to while Katie was undergoing treatment and about how she tried to figure out how to split time between both children.

Some of her entries are warm and funny — sharing her spunky daughter's "quote of the day," and singing "You Are My Sunshine" to her girl every night before bed.

Others are raw and painful, like the ones she updated multiple times about Katie's last hours.

"We're just holding Katie's hand. Being in her presence. Waiting on the time to come," reads the post from 8 a.m. July 10, 2006.

The writing was cathartic. Ford kept a journal, too, where she could write things that she didn't want Katie to read, including how afraid she was of losing her child.

Sometimes strangers approach Ford, introduce themselves and tell her how Katie's story has affected their lives.

"I think it's great that Katie was memorable and her story meant something to someone, enough that they kept coming back," she says.

CaringBridge sites serve practical purposes, too. Ford used it to let everyone know when it wasn't safe for Katie to have visitors because her immune system was weakened. Some use their sites to recruit bone marrow and blood donors, publicize fundraisers and network with others dealing with similar diseases or injuries.

Katie's site includes a link to Elijah Talley's. Katie met 6-year-old Elijah of Little Rock in the hospital during treatment, and they became friends.

Elijah's mom, Dawn Talley, knows that there are many people praying for her son; there have been 143,150 visits to his Web site — [www.prayforelijah.com](http://www.prayforelijah.com) — since his diagnosis in August 2005.

"At first it was a little bit strange, but the people who check on him regularly are the people who genuinely care for him and people who pray for him," she says. "We tell people, share his Web site with anybody you know, to try and get more people to hear his story and to bring more awareness to childhood cancer and specifically neuroblastoma, what Elijah's fighting. The more prayers the better, we think."

CaringBridge makes it easier for the family to accept help from those who readily offer it.

"When you're in a situation like this, you know you need help, but it's very difficult to say, 'I really wish you could bring us dinner' or 'could go run this errand for me,'" Talley says. "It's a lot easier to put on the Web site, these are a few things that we need, if you would like to help us with any of these, we would be forever grateful. It's just easier to put it out there in kind of a blanket thing instead of telling one person specifically."

The Talleys hosted an Alex's Lemonade Stand in west Little Rock last summer, so named for Alexandra Scott, who raised \$1 million for childhood cancer research before she died in 2004 at the age of 8.

"We had people that came ... halfway across Arkansas to the lemonade stand, just because they had read about Elijah on his CaringBridge site and wanted to meet him," Talley says.

Elijah is friends with Chase Wellenberger, and there's a link to Chase's page, [www.prayforchase.com](http://www.prayforchase.com), on Elijah's.

Chase Wellenberger, 9, of England, was diagnosed with acute lymphoblastic leukemia when he was 4, and his mother, Carrie Wellenberger, started his Web site in April 2005.

"It was my lifeline," she says. "It can be very stressful to repeat the same story 15 times to 15 people."

With CaringBridge, she could post the stories one time. Chase loves reading the site's guestbook entries.

A recent one, written by his grandfather when Chase reached remission, read: "Sir Chase Justin, Knight of the Realm, Slayer of Dragons, Special Knight to the Kingdom of Sugarloaf Mountain, and Ambassador for the 3rd Grade Class of England. Golly Booter-Bear, you sure have a lot of titles. I especially like the last one. You must really be getting along well with your classmates if they elected you Ambassador ... It seems all is going great and you are having loads of fun. You deserve it. Love you, Bob-Bob. P.S. I left out one of your titles — My Hero."

Bob Wellenberger, or Bob-Bob as he is known by Chase, lives in Rockwall, Texas, and although he hears most Chase-related news directly, he and his wife, Carolyn — aka Nannie — do sometimes depend on the CaringBridge site for timely news.

“When Carrie and Chase are in the hospital, the site becomes very important to all of us because she cannot use her cell phone in the hospital most of the time,” he says. “They have computer access at the hospital and she can [put news] out through the Web site and she doesn’t have to leave Chase to do that.”

Chase keeps up with his friends, many of whom have CaringBridge sites linked through his. His mom added the links to several of the families she and Chase had met in the hospital, and she and several other CaringBridge authors are quick to direct readers to sites of people who have immediate needs.

People Chase had never even met sent him cards or small gifts — dragons, which are prominently featured on his Web site; Hot Wheels cars and the like — to cheer him up when he was really sick and to let him know he was inspiring them through his fight with leukemia.

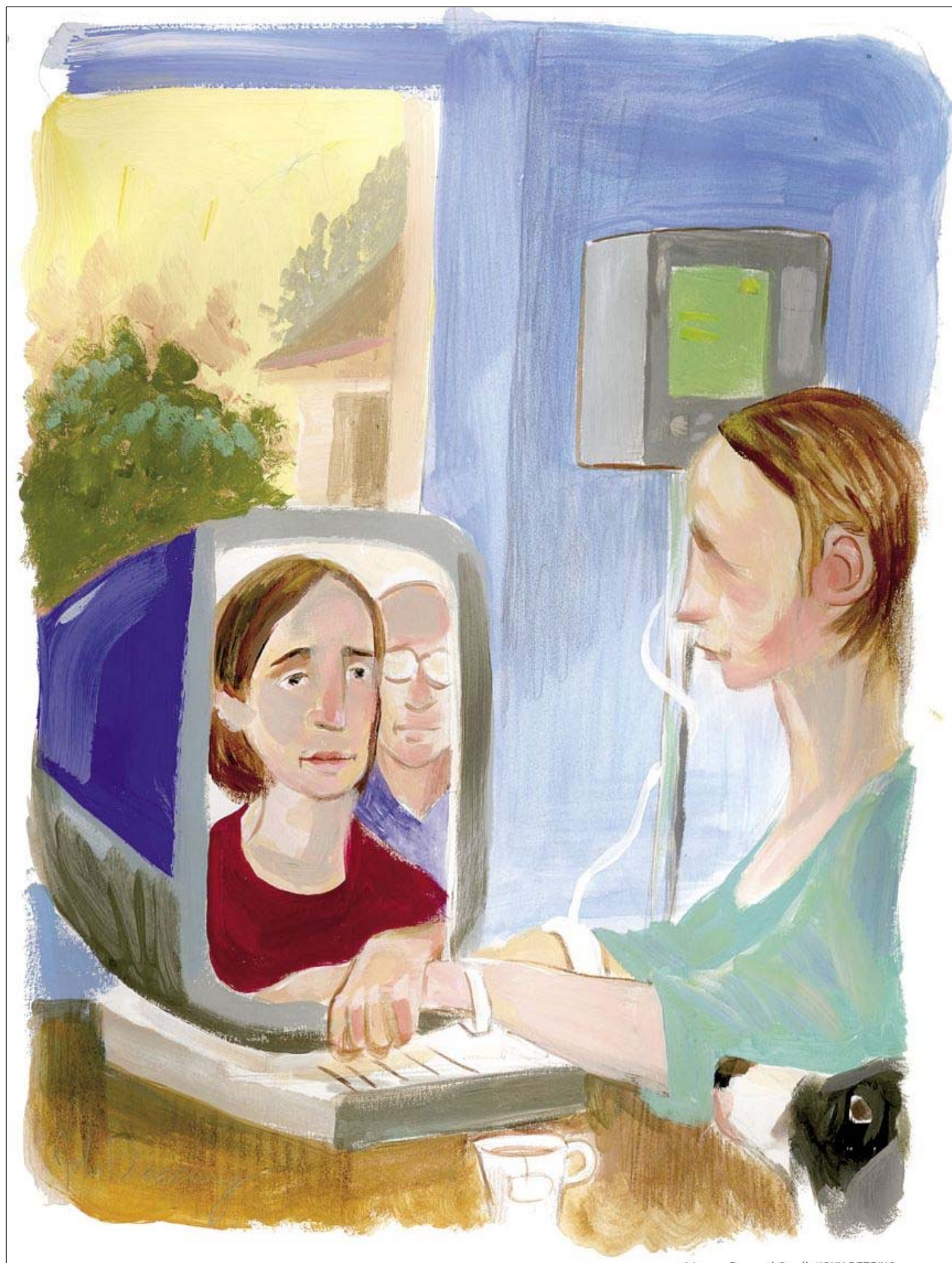
And Chase wants everyone to know that they should smile and send messages to cheer up friends who are fighting diseases.

Elijah, who has relapsed and is scheduled to go into the hospital in a few weeks for another transplant, loves getting mail and reading guest-book entries on his Web site and Chase hopes his friend will be inundated with messages and cards to boost his spirits.

Newman is in remission and doing well a year and a half after her breast cancer diagnosis, and she will forever be grateful for her friends and family’s support.

And she’s grateful to Caring-Bridge for helping her through, too. It not only kept her in touch with those who cared about her, it provided her with a sense of responsibility to them that buoyed her heart.

“Also a motivation [for updating the site] was that I didn’t want my friends and family to worry about me. I wanted to support them and not have them be all upset,” she says. “I wanted them to be able to read my words and hear my laughter through that journal, if I didn’t really feel like getting on the phone or anything.”



Arkansas Democrat-Gazette/JOHN DEERING



Arkansas Democrat-Gazette/STEVE KEESEE Laura Newman kept friends and family apprised of the progress of her treatment for breast cancer with a Web site at CaringBridge.org.



The home page of Elijah Talley's CaringBridge Web site.