



## Web's caring connections

By Kim Painter

Published October 2, 2006



### Your Health

Kim Painter

#### ■ IT'S EASY TO DO

How easy is it to start your own website?

It's so easy that I started two - one at [caringbridge.org](http://caringbridge.org) and one at [carepages.com](http://carepages.com) - in about 20 minutes. The services appear to be as user-friendly as advertised - and both immediately e-mailed me access information I could forward to anyone I chose.

When a close friend of Sona Mehring gave birth to a premature baby, the Egan, Minn., website designer helped the way she knew best: She put up a site to post progress reports for friends and family members.

The site, which also allowed well-wishers to post messages, "instantly became the connecting point for all these people," she says.

When Eric and Sharon Langshur of Chicago learned that their newborn first child, Matthew, had a serious heart defect, they, too, put up a website. "By Matt's third surgery, when he was 18 months old, we were getting a few thousand unique hits a day," Eric recalls.

Mehring and the Langshurs could have kept their tech-savvy ideas to themselves. Instead, they turned their personal experiences into a now-

booming phenomenon: services that allow anyone who can fill in an online form to create their own Web page during a medical crisis or other life-changing event.

Mehring's non-profit service is called CaringBridge and is supported largely through donations, plus some hospital sponsors. The Langshurs' for-profit service is called CarePages and has licensing agreements with about 500 health care facilities, including top-tier hospitals such as the Mayo Clinic and Cleveland Clinic. The participating hospitals add their logos to patients' pages and get other benefits — including exposure to potential donors. Another service is theStatus.com.

Though details differ, all the services allow anyone with computer access — in or outside a hospital — to quickly, at no charge, set up a Web page to post updates and receive messages.

One important feature: These highly personal sites aren't detectable by search engines. Users can restrict who sees them — or broadcast access information as widely as they like.

Genevieve Riley, 53, a Catholic lay-minister-in-training from Clearwater, Fla., started her CarePage soon after she was diagnosed with breast cancer in May. She first invited family

and friends, then other cancer patients she met, to read her postings. Recently she opened her page to the public. (It's listed under *Profiles in Courage* at carepages.com.)

She has shared not just medical facts but coping strategies — including her decision to shave off her hair before chemotherapy and attempt to dye the stubble pink. (It didn't work — "too short," she posted on July 20.) On Aug. 20, after two chemo treatments, she wrote: "I look forward to the day when this is over and my head doesn't itch/annoy me, when the skin on my lips stops peeling off, when my taste returns to what it was before ... And I will be CANCER FREE for a very long time." Riley says the page has been a "really great outlet for me." And she hopes it's helping others.

Some medical update sites attract huge memberships — and mobilize armies of supporters.

Mike Holmstrom of Dartmouth, Mass., put up a CarePage shortly after his 17-year-old daughter, Carrie, was severely burned from the chest down in a car wreck in late April. The page address quickly spread through the area soccer community, where Carrie is known as a star goalkeeper.

By the end of last week, nearly 2,000 guests had visited the site more than 112,000 times — and had rallied together to raise money for Carrie's rehabilitation and to benefit Shriners Hospitals for Children-Boston, where she is being treated.

"One of the things I've gotten out of this is a renewed faith in mankind," Holmstrom says.

He posted updates as Carrie lost first her right foot, then part of her left, woke up from a three-month drug-induced coma and, more recently, battled a nasty infection. On Thursday, Holmstrom proudly announced Carrie's classmates had voted her homecoming queen. "The nurses are calling her 'your highness' and bowing when they enter the room," he wrote.

Then, on Friday, he updated readers as Carrie's doctors amputated more of both limbs, a needed step before she is fitted with prosthetic lower legs and feet.

The surgery brought Carrie closer to playing soccer again — something the doctors say can happen.

On Aug. 30, Holmstrom wrote that those doctors once thought she might not survive: "I clearly remember talking with (wife) Karen ... and both of us saying almost simultaneously, 'They don't know Carrie.' One thing is for sure ... They sure as hell do now!"

And so do nearly 2,000 other well-wishers.