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Support for Patients, Just a Mouse Click Away

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Not long after Susan Butcher, a four-time Iditarod champion, received a diagnosis of [leukemia](#) in Seattle last December, her husband, David Monson, sat down at his computer to tell everyone.

By filling out a simple online form, he was able in a few minutes to set up an interactive Web page so Ms. Butcher could keep far-flung friends and family abreast of her condition and treatment. Concerned supporters could respond online night or day without worrying about intruding.

The company behind the Web site, www.thestatus.com, is one of several that have sprung up in recent years to help people with serious illnesses and their families stay easily connected to a broad network of loved ones without being swamped by well-meant visits or phone calls at the end of exhausting days.

And although Ms. Butcher and her husband chose to leave their Web site open to any visitor, companies have equipped the sites with password protection. Strangers cannot happen upon them by plugging a patient's name into an Internet search engine, and only those invited are allowed to view them or leave a message.

In an era when many people are traveling far from home for medical treatments that can in themselves be isolating and debilitating, a patient's need to stay in touch — but on his or her own terms — can be profound.

"When you're facing something like [cancer](#), a bone marrow transplant or other major illness, all the people who care about you need to be attended to," Mr. Monson said. "They're grief-stricken and need healing, too."

He added: "But you can't explain what happened that day 10 times. You can't even do it five times. You have to do it once, because that's all the energy you have, all the grieving you can do in one day."

Before Ms. Butcher died on Aug. 5 in a Seattle hospital from cancer and complications of a bone marrow transplant, she and her husband had posted more than 100 entries in their Web chronicle. They had also received thousands of messages from well-wishers in dozens of countries.

On good days, the couple's entries were light-hearted or tender — recounting a friend's misadventures with a bear in a barn or a beautiful hike with their young daughters between treatments — the singular joys of "a normal day" in the midst of the pain. Even later, when the medical news grew increasingly grim, Ms. Butcher kept the illness from defining her. By including photos from happier times and posting links to marrow donor registries and other Web sites, she was able to frame her story in the way an old-fashioned telephone tree with simple medical updates never could.

"For me," Mr. Monson said, "it was therapeutic just to write it all down."

The Web sites, free to patients and visitors, are typically paid for by private donations or foundation grants or by hospitals that realize the public relations benefit of having their name attached to such a conduit of good will. The e-mail addresses of patients and visitors are never sold, rented or otherwise disclosed without patient approval, the Web companies say, and hospital staff members and administrators cannot look at a site unless the patient invites them.

Some sites come with bells and whistles. For example, CarePages.com, a for-profit company whose 500 hospital affiliates include the Mayo Clinic, the Cleveland Clinic and Massachusetts General Hospital, offers newsletters; educational materials specific to the patient's illness; links to the hospital florist, gift shop or medical foundation; and even a button that allows patients and visitors to send compliments to nurses or other staff members who have been particularly helpful.

There is no analogous button to register complaints about care. In fact, to reduce any libel risk, site managers and visitors on all the Web sites are required, as a condition of registration, to promise not to defame or in some cases even print the names of hospital staff members or other patients.

But the sites do not tend to foster rants, in any event, said Michael Hubner, a director of social work at the Dana-Farber/Brigham and Women's Cancer Center in Boston, which is a sponsor of a nonprofit online service, www.caringbridge.org. In the first 18 months the center kept data, 137 patients set up Web sites, Ms. Hubner said, drawing 256,953 visits from 14,842 invited guests. "The multiplier effect here in terms of lives touched is extraordinary," she said.

The patient Web pages are not a replacement for traditional get-well cards and casserole brigades, Ms. Hubner added, but rather another tool — a way to let those who want to help know what is most needed minute to minute, whether that is food, prayer or privacy.

Chuck Aitken availed himself of a call for privacy last spring when he wanted to surprise his wife, Marge, with a specially prepared romantic dinner on their 28th anniversary. At the time, Ms. Aitken was hospitalized with non-Hodgkin's lymphoma at the University of Pennsylvania, and their daughter, Jessica, was able to ensure that the couple would not be disturbed by sending a quick alert via the CarePages Web site to more 70 friends and family members advising them not to call or stop by the hospital after 5 p.m.

It worked. "We had a lovely, quiet dinner," Ms. Aitken said.

Today, Ms. Aitken is back home and healthy by every measure. She said her CarePages Web site not only strengthened her network of close friends during the medical ordeal, but also enlarged the group.

Some people, including her husband, said that by writing, they were able to be more vulnerable and candid about their feelings and needs than they could ever have been in person or on the phone, when a cracked voice or tears might have cut them off. And Ms. Aitken reports that largely because of supportive exchanges that began online, she now counts as dear friends several people she had considered merely co-workers of her husband's before her illness.

The multiplier effect continues. Mr. Aitken, a hospital administrator at the University of Pennsylvania, said his employer planned to offer wireless public Internet access throughout the hospital within a year. Lobbies, surgical waiting rooms and cafeterias could be ready much sooner, and family waiting rooms on many floors already have Internet kiosks.

Ms. Aitken said she was looking forward to volunteering at the hospital one day a week, specifically to help Internet-shy patients and their families set up CarePages of their own.