

Strengthening Resident Social Support Systems

Margie Simon

Assisted living (AL) facility medical teams know how vital social support systems are for a patient's recovery—particularly for newly admitted patients coming from long-term hospital stays. What practitioners often don't know, however, is how to help rebuild those support systems when family members experience caregiving fatigue. Thanks to Sona Mehring, founder and executive director of CaringBridge, AL facilities now have a free tool to assist their patients and families.

CaringBridge is a 501(c)(3) non-profit organization offering free personalized Web sites for patients, families, and friends during significant life events. Sites connect family and friends to share information, love, and support during a healthcare crisis, treatment, and recovery.

"CaringBridge sites remove the isolation family members and patients often feel. Its simplicity adds to its value for both families and facilities. Friends or family can set up a site in just 2 minutes," explains CaringBridge staff member Kathy Tomlinson, who works exclusively with healthcare facilities. While no training is necessary, the organization offers a free introductory video for facilities and an awareness video for families. "These sites can transform the outlooks of families and friends. Facilities quickly see the uplifted spirits and the reduced call levels to the facility from friends and well-wishers, because CaringBridge becomes their resource, instead," she adds.

Tomlinson notes that these sites



A CaringBridge beneficiary: Harold Anderson and his mother-in-law, Joyce, at niece Erin's wedding, May 2005.

create a 2-way conversation between patient and family and their friends. Families update friends but can also request assistance for day-to-day needs from walking the dog or grocery shopping to taking their child to a birthday party or a game. Friends are eager to assist. Caregivers, in turn, are reinvigorated and transfer that energy to the patient.

CaringBridge's Birth

Mehring, a Web site designer, founded the organization in 1997 when a dear friend suffered a life-threatening condition during pregnancy. Mehring and her friends created a Web site to help the family communicate information to a wide circle of people without disturbing the mother's need for rest or placing extra demands on hospital staff.

Nearly 10 years later, friends and families have created more than 54,000 sites. Those sites have re-

ceived over 350 million visits and 8 million guestbook messages of hope and encouragement. And while its origins are hospital-based, CaringBridge is now a tool widely praised by hospitals, AL facilities, patients, families, and friends.

Use at Bethesda Rehabilitation

"We immediately saw the benefits of CaringBridge for our patients, their families and caregivers," says Lia Christiansen, director of marketing for Bethesda Rehabilitation Hospital in St. Paul, Minnesota, the largest rehabilitation hospital in the upper Midwest.

Family Benefits

"CaringBridge lets families communicate a tremendous amount of information to a large audience easily, quickly, and cost-free. The optional site password also lets families control who receives information about their loved one," says Christiansen.

With an average daily census of 130 patients, Bethesda has many opportunities to witness the value of the organization's services.

Patient Encouragement

As patients progress, they can read and respond to site visitors with help from family and friends. Bethesda provides computers for patients in its therapy, resource, and recreation rooms. Eventually, some patients can update their site independently. "What a powerful therapy to be able to respond personally to site guests... We see lots of smiles at those computers!" says Christiansen.

Caregiver Support

Bethesda finds CaringBridge to be a tremendous motivator and morale builder for AL caregivers too. The created sites reduce the volume of concerned calls from well-wishers wanting patient updates which, by law, facilities can't provide.

Christiansen adds that during site creation, the care facility logo is incorporated into each site, which enhances credibility as well as increases the facility's name recognition. In fact, Bethesda has expanded its name recognition, while enhancing its commitment to CaringBridge, by serving as a financial sponsor. Seventeen percent of CaringBridge's financial support comes from health-care sponsors and corporations.

"At Bethesda, we include information on CaringBridge in our patient and family 'welcome' book. Every day I see families using computers for that purpose. They quickly see the benefits. Friends and family feel so in touch, and patients feel so supported. CaringBridge becomes a real community supporting them," says Christiansen.

On-Site Computers Not Required

Chris Moquist, marketing and communications director for CaringBridge, notes that while computers for patients and families at health-care facilities are wonderful, their

research shows that 80% of those using these Web sites primarily use a computer at home or work to update their sites. Families and friends can then print out guestbook messages from loved ones at home, bring the greetings to the facility, and read them side-by-side with their loved one.

Maureen's Story

But perhaps the best testament to CaringBridge's value for an AL resident and family comes from a spouse who, just 1 month ago, lost her husband after a 3-month critical care and rehab facility stay due to congestive heart failure.

Harold and Maureen Anderson, from suburban St. Paul, were a loving couple, each from a family with

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9 children. Married for 27 years, their children, Ellen and Colin, are 16 and 23. When Harold's health deteriorated from congestive heart failure last October at age 57, Maureen had 30 family members and friends to update, while caring for their children as well. Harold's condition endured many ups and downs with prognoses ranging from 2 weeks to 4 years to live, to just days, all in a 3-month time span.

In early October, Harold's kidneys were failing and he was given 2 weeks to live. A new procedure performed at United Hospital, in St. Paul, restored his kidney function, although other organ damage had occurred. He was moved to New Brighton Health and Rehabilitation (formerly Trevilla Assisted Living Facility) in New Brighton, Minnesota, to recover. His rapid progress led to rehabilitation for an eventual

return home. The new year brought an optimistic outlook: Harold could have 2 to 4 years to live. Unfortunately, within 2 short weeks, complications developed. He returned to the hospital and died.

Communicating his widely varying condition proved daunting for Maureen. "It was not easy to keep repeating his situation to 30 different people over the phone!" A close friend, seeing her dilemma, created a CaringBridge site for Harold (Figure 1).

An Umbrella of Caring

"I was astonished," says Maureen. "I E-mailed the link; recipients sent it to friends, and it just mushroomed! Suddenly I was flooded with caring messages, both on the site and in E-mails, from people hearing about Harold from his CaringBridge site. In no time, friends I hadn't had time to contact were showing up at New Brighton Health and Rehabilitation, or bringing over food, or even repairing my snow blower and blowing my driveway. It was like this umbrella of caring, support, and love had suddenly enveloped us."

Maureen adds, "My husband touched a lot of lives. Residents, watching Harold's steady parade of guests, teased him, amazed that 1 person could have so many visitors. Some days Harold had to say, 'I'm sorry, I can't visit any more today. I've just got to get some rest.'"

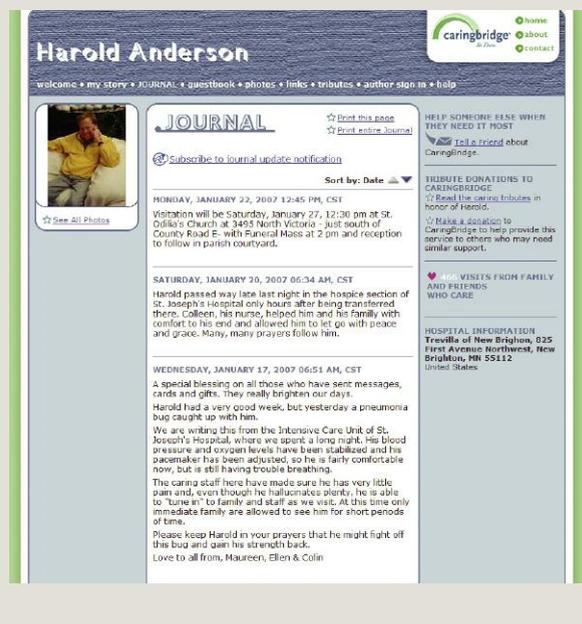
A Legacy of Memories

Although the rehab facility did not have a computer on site for patients or families, Maureen reviewed the site at home before heading out each day. "I'd print out the Web site messages from family and friends to share with Harold. The joy and comfort those messages provided was awe-inspiring." Each greeting meant so much to Harold. "We were all so touched," Maureen says. "We have all those memories to keep, and they're all from a free service that one could expect to pay considerable money for."

Figure 1.
The welcome page of the CaringBridge Web site created for Maureen Anderson's use in communicating about her husband Harold.



Figure 2.
Maureen Anderson's messages to friends and family about Harold's condition.



Friends and family visited Harold's site 450 times during the 3-month period. But as Maureen points out, "The site's activity is just a small fraction of the contacts that result from CaringBridge." Many people privately contacted Maureen by E-mail after receiving updates on the site. Still others were in touch after hearing from friends who visited the site. CaringBridge's support grows exponentially. "Even as I drove to and from New Brighton Rehab or the hospital, thoughts of the kind things people said sustained me."

CaringBridge Benefits

Maureen says, "The amount of time CaringBridge Web sites save is priceless. The less time I needed to call people, the more time I could be with Harold and my kids." This also gave Maureen more time to process and recover from Harold's downturns.

In turn, the site helped prepare friends and associates for Harold's pending death. People followed his condition on the site without even contacting Maureen (Figure 2).

They knew when he was transferred to hospice care, when he died, and when the funeral and visitation would be.

Another benefit is privacy. "Rather than calling people from Harold's hospice room and interrupting a roommate or discussing his health in a roomful of strangers, the Web site allowed me to be completely 'in the moment' with Harold when he was awake. While he slept, I went to the visitors lounge, logged onto the site, and updated friends and family all at once from the privacy of the computer," says Maureen.

"One unforgettable moment was at the hospice. I left to make a quick update on Harold's site, allowing everyone to know at once his condition, while saving me so much time. When I finished I returned to the room and Harold's side. I was with him when he died about 5 minutes later."

More Stories

A quick visit to the organization's Web site, www.CaringBridge.org,

reveals story after story of people and families whose lives were transformed by the organization's services. When the late Bob Moog, inventor of the Moog Synthesizer, was diagnosed with brain cancer, his son Matthew established a site. The Moog family CaringBridge Web site address quickly found its way around the world. "I created the site on July 1, 2005, and a few days later there were thousands of visitors to the site. This was completely unanticipated by the entire family," Matthew adds.

Today, Matthew considers CaringBridge a profound conduit for support and encouragement. "I think it is the best example of a virtual community, where one can be instantly connected with people who are passionate and caring about one person. My family will be forever grateful for CaringBridge."

AL facilities needing assistance from Kathy Tomlinson can contact her directly at 651.789.2304 or ktomlinson@CaringBridge.org. ALC

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