

CaringBridge: A Valuable Tool for Social Workers and Those With Critical Illness

Contributed by Karen Zgoda, MSW, LCSW

Editor's Note: In this issue, I am pleased to welcome our new technology columnist, Karen Zgoda. In this newly-titled SW 2.0 column, Karen will bring us news of the latest, most up-to-date tech topics for social workers!

CaringBridge: A Valuable Tool for Social Workers and Those With Critical Illness, In Treatment, or in Recovery

A woman smiling with brown curly hair, holding a candle in each hand, one candle a "4" and the other a "0," and a diagnosis of Hodgkin's Lymphoma. A newborn baby sleeping peacefully in an intensive care unit (ICU), surrounded by soft, cuddly stuffed animals, multiple tubes coming out of his small body, the unfortunate result of a congenital heart condition. A U.S. Marine Corps soldier back from Iraq without his legs and injuries to other parts of his body. The 14-year-old girl who developed obsessive compulsive disorder (OCD) over the course of a few months and needed to spend two months in a treatment center. A young woman who recovered from a brain aneurysm but who can no longer drive and needs to ask for rides without feeling like a burden to friends and family.

It may seem hard to believe that all these individuals are able to provide regular updates on their conditions, recovery, and maintain relationships with their friends and loved ones. In fact, each of the individuals can receive messages of love and support from their friends and loved ones 24 hours a day, 7 days a week, for free. Using a unique technology-driven tool, each of these vibrant, beautiful people struggling and fighting for their health and happiness has his or her own CaringBridge online community (<http://caringbridge.org/stories>).

According to the CaringBridge Web site (<http://caringbridge.org/about>): CaringBridge® is a 501(c)(3) nonprofit Web service that connects family and friends during a critical illness, treatment, or recovery. A CaringBridge Web site is personal, private, and available 24/7. It helps ease the burden of keeping family and friends informed. Patients and caregivers draw strength from loved ones' messages of support.

150,000 families have created free, personalized CaringBridge Web sites
 Over half a billion visits by families and friends
 20+ million guestbook messages of hope and encouragement
 150+ new personal CaringBridge communities created daily
 Used in 190+ countries around the world

Sona Mehring created CaringBridge in 1997. At the time, a friend of Sona's had serious complications with her pregnancy. After the birth, the mother remained in critical condition while her baby was born nearly three months premature. Sona then created a Web site to help keep friends and family members informed about their condition. Posting updates on the Web site allowed the mother to rest and the hospital staff to focus on care, rather than address a constant stream of information inquiries. In addition to offering daily news on the mother and baby's condition, a guestbook feature was added to the Web site, so guests could leave messages of support and encouragement. Unfortunately, the small baby survived only nine short days and passed away during surgery. The Web site Sona created was then used to share news of the baby's passing to help alleviate the heavy burden of sharing the news with multiple friends and family members. The parents also used the site to write a final message about their daughter and thank visitors. As a result, a memorial fund was established at Children's Hospital in St. Paul, Minnesota, to provide a computer with Internet access so that patients and families could create their own CaringBridge online communities.

Lisa Gebo, an editor and friend of many in the social work community, was diagnosed with Stage IV breast cancer and has used CaringBridge since 2006. Here is her story in her own words:

I was first introduced to CaringBridge® when one of my former colleagues invited me to join his circle of friends and family when his young son became very ill. I was honored to be invited (by way of a simple e-mail to a link where I then completed an easy on-line guest registration process). I was impressed by the growing social support network that the family's Web page came to represent. As my colleague had updates regarding his son's health status, I would get an automatic notice in my e-mail. I could then go to the family's personalized site, read the latest news, enjoy adorable pictures of this boy I have never met but love nonetheless, and post encouraging notes to my friend and his family in the guest section.

Not long after that, my dear friend, hero, and former author, Len Gibbs, a social work educator who wrote with passion about evidence-based practice and who sadly died in 2008 after a brave struggle with prostate cancer, invited me to join his CaringBridge® community. Len and his wife, Betsy, took the Web site service to new heights by not only posting Len's health updates, including information on the clinical studies in which he was participating, but they also provided links (another great function built into all the personalized Web site templates), to important downloadable documents written by Len. Via this link, Len was able to share concrete direction for readers so that they could apply evidence-based practice to their own or their loved one's healthcare. Lives were literally saved by Len's detailed "lessons learned" guidelines, urging men to use evidence-based questioning with their doctors to help ensure that thorough and preventative measures were taken.

When I had my own cancer news, I knew that I wanted to set up a personalized CaringBridge® site. Most of my family

and childhood friends live back East, and my husband and I live in CA. When we first got my diagnosis, we were inundated by calls, letters, and e-mails from concerned loved ones as well as many beloved colleagues and authors with whom I had worked over the years as part of my role as an acquiring editor for two major publishers. Having a central place where people could go to receive my latest news and provide much appreciated support was very convenient. It was also psychologically helpful, as it saved repeating my devastating news over and over again with each phone call or e-mail.

My CB site (still going strong after almost three years now!) has provided an invaluable space for me to process and share my cancer experience. I began by focusing on medical details, but I soon started sharing my internal process by way of prose, poems, and cathartic rants, if you will.

While I don't write in the journal section every day, I do find that I check my site every morning to see if I've heard from anyone in the guest section. Even though I have a tremendous support system here comprised of my husband and close friends, it has been deeply comforting to retain contact by way of the site, with my family back East and my friends from all around the country. When it became necessary for me to stop working, the CB journal and guestbook became (and still is) an important lifeline to my former identity. After 18 years as an editor in social work, counseling, and psychology, I have come to profoundly admire the work and the people in these professions... and I derived a great deal of meaning from my work. I've been privileged to have made life-long friendships after attending all those BPD, CSWE, SSWR, and other conferences over the years. So, one of the biggest losses I've faced to date is not having daily exchanges with my friends in the field. In sum, my CB site has allowed me to stay in touch with my dearest friends and family, and this has contributed greatly to maintaining a positive outlook and coping with my disease.

For anyone dealing with an illness, (self, caregiver, partner, family member, close friend), I highly recommend setting up a personalized CaringBridge® site. I think that the service offers social workers an invaluable and potentially very creative resource to share with consumers.

All one needs is Internet access to set up a CaringBridge online community Web site. In fact, the site itself can be built in just three steps:

Setting up the account: Includes contact information, address, name of loved one needing care, care facility, and login information

Selecting a template or look for your web site

Setting privacy options for who can access your site

There is even a pop-up help menu (meaning clicking on the Help link opens in a new window) to help you with any questions you may have and walk you through the process of setting up a site.

The folks at CaringBridge say it should take about five minutes to set up your site. Sometimes it takes me five minutes just to log in to a Web site, so I find this to be most impressive. To see some sample Web sites, check out the Web Site Gallery (<http://www.caringbridge.org/stylegallery>). Each site contains a patient care journal where the person receiving care can update friends and family, a guestbook for site visitors, and a photo gallery. To get a sense about how these features are used, check out the Our Services page (<http://www.caringbridge.org/ourservice>). For a small fee, you can even create what is called a Caring Book, a full-colored book based on your CaringBridge site (<http://www.caringbridge.org/caringbook>).

Karen Zgoda, MSW, LCSW, is an ABD doctoral student at the Graduate School of Social Work at Boston College. Her research interests include the role of technology in social work, the effects of information communications technologies (ICTs) such as the Internet and e-mail, poverty and class, aging, social informatics, socioeconomic development, public policy, and community practice. Karen is the chief editor and founder of EditMyManuscript.com, providing manuscript editing services to students, faculty, and other social work professionals. Her Web site is <http://www.karenzgoda.org>.