

Making a Real Impact: The CaringBridge Phenomenon



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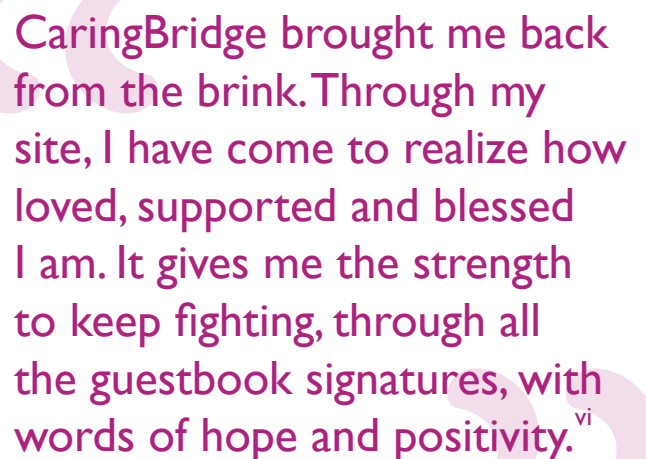
Every day, 10,000 people in the United States face cancer diagnoses, birth complications or serious injuries. Another 101,000 are awaiting a major organ transplant.ⁱ Countless others face debilitating conditions such as Lou Gehrig's disease, cerebral palsy or cystic fibrosis.

When diagnoses come, patients and their families begin looking for outside support. An abundance of online resources on any condition or diseases are available from WebMD, government agencies such as National Institutes of Health or Centers for Disease Control, and private healthcare providers like the Mayo Clinic. Online support groups are also gaining popularity. In 2010, three in four American adults were online, and over 60% turned to the Internet for health information.ⁱⁱ This means that 83% of Internet users can be classified as "e-patients," seeking, consuming and sharing information about their health and the health of their loved ones.

Information is helpful when facing a health event, however, according to research and medical authorities, the most significant impact comes from personally connecting with others.

The Value of Personal Connections to Healing

This connectivity may come through popular social networks such as Facebook, MySpace and others. But seven years before Facebook and more than five years before MySpace,ⁱⁱⁱ the nonprofit CaringBridge pioneered the use of the Internet as a powerful tool for building online social communities. Since 1997, more than 250,000 personal CaringBridge sites have been created, with over 1.8 billion site visits.^{iv} Each day, over 500,000 people connect through CaringBridge.^v In its history, the organization has seen the profoundly positive impact that a personal health social network can have on a person's healing process.



CaringBridge brought me back from the brink. Through my site, I have come to realize how loved, supported and blessed I am. It gives me the strength to keep fighting, through all the guestbook signatures, with words of hope and positivity.^{vi}

In a 2010 commissioned survey conducted by Forrester Consulting on behalf of CaringBridge, 91% of CaringBridge users who faced or are facing a health challenge such as cancer, premature birth or injury, said CaringBridge helped make their journey easier and 88% said it positively impacted their healing process.^{vii} In terms of the community-building aspects of CaringBridge, 99% of patients who responded said that reading the guestbook on their CaringBridge sites positively impacted their health journey, with 91% indicating that writing in their site's journal had a similar effect.^{viii}

The medical community has long agreed on the importance of connection to patients' healing. Tom Ferguson, MD, founder of e-patients.net, noted, "an individual's social network... has long been recognized as an important factor in maintaining health and managing disease more effectively."^{ix}

A June 2009 story from CNN notes that when facing cancer, social support can help a person live better and maybe even longer.^x That same story quotes Dr. Charles Raison, an assistant professor of psychiatry and behavioral sciences at Emory University School of Medicine and CNN.com's mental health expert as saying, "the jury is still out a little bit on whether social support helps you survive – but it definitely helps you live better," also adding that "when people provide each other with support and encouragement – that can make the difference in a person's life between... surrendering to hopelessness and... finding the gumption to keep going."^{xi}

The value of a network of family and friends, even during the healthiest of times, is well established. So, when facing a diagnosis and ongoing treatment, an individual's reliance on the support of his or her personal circle for emotional, and sometimes physical, strength becomes even more important. This is when CaringBridge communities rally.



CaringBridge is the single greatest tool in my recovery - it helps me maintain a positive attitude so that I can beat this cancer. I never knew I had so many supporters from even around the world.

As an example, CaringBridge sites created for cancer demonstrate how active these communities are. Each site has an average of 145 registered users (and this doesn't take into account the significant number of non-registered users) and 29 visits per day, with 2-3 of those visitors signing the guestbook, usually on behalf of a family or community.^{xii} Think about how that would translate to visits and conversations: nearly 150 people reaching out to you and 30 visits per day. Of course, that amount of in-person visits isn't feasible – having family and friends nearby is oftentimes impossible, whether for reasons of distance, "visiting hour" regulations, personal sanity concerns or sheer logistics.

Nearly all patients surveyed by CaringBridge said that the service was an easy way to update family and friends (98%), centralized and eased the communication burden (98%), saved time and emotional energy (96%) and enabled love, compassion and hope (95%).^{xiii}

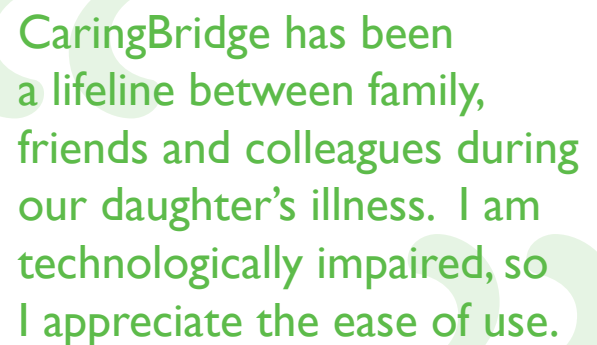
While not originally described as a social network, CaringBridge truly was the first social network dedicated to an individual's health journey. As a nonprofit organization, CaringBridge is completely focused on making health journeys easier rather than building profitability or providing an advertising medium for companies. Fueled almost exclusively by donations from the grateful families who use this service, the mission of CaringBridge is to amplify the love, hope and compassion in the world, making each health journey easier.

Accessible to All

In 1997 when CaringBridge was founded, Internet use was not nearly as prolific as it is in 2011. In 2000, statistics show that only 46% of American adults had access to the Internet, and only 25% went online in search of health information.^{xiv} CaringBridge had to be, and was, designed for anyone to easily create and maintain a site, post journal entries, sign the guestbook, and soak in the love and support of family and friends.

Even today, CaringBridge site visitors, who account for more than 95% of its users, tend to be less active in social media: only 12% have previous experience creating social media content and rank lower than the average U.S. online adult in all aspects of active social media engagement.^{xv}

CaringBridge has actually become many individuals' introduction to deeper online and social media engagement, and has served as a catalyst for many to become more socially active online.



CaringBridge has been a lifeline between family, friends and colleagues during our daughter's illness. I am technologically impaired, so I appreciate the ease of use.

The Growth of Social Networking

As the Internet adoption rate has risen, social networking sites like Facebook, MySpace, LinkedIn and Twitter have proliferated, connecting millions of people every day. Consider that in just a ten-month span, from December 2008 to September 2009, the percentage of Internet users who said they use a social networking site jumped from 35% to 47%.^{xvi} As of May 2010, 38% of Internet users visited a social networking site every day,^{xvii} up from just 27% a year prior.^{xviii}

“The use of social media in the service of health communication is likely to rise as usage patterns increase across age groups in the future,” said Bradford W. Hesse, Ph.D., chief of the health communication and informatics research branch of the National Cancer Institute and National Institutes of Health.^{xix}

CaringBridge site creators (who more often are not the patients themselves) tend to be significantly more active in social media activities than the average individual: CaringBridge site authors are nearly twice as likely (31% of individuals) to have experience creating social media content such as publishing a blog, a personal website, uploading video or music, posting original articles than the overall population of U.S. online adults (16%).^{xx}

When she was first diagnosed, and after surgery, chemo, scan, etc. I would spend the rest of the day on the phone with family, church, friends, etc. Finally I realized that I could put it on CaringBridge and say it once for everyone... it gave me much more time to focus on my daughter's health.

According to the CaringBridge survey, more people facing a significant health challenge would prefer to use a personal and private health website like CaringBridge than a general social network such as Facebook, a blog or a micro-blogging platform like Twitter.^{xxi}

Regardless of the platform one chooses, though, the impact of the Internet – and specifically of social networking sites – on the healing and recovery process can be profound. Through CaringBridge, everyone, including patients, caregivers and support community, benefits.

Supporting Caregivers

The value a personal health social network provides goes well beyond the individual facing a significant health challenge like cancer, a transplant or accident recovery. Often, the diagnosis, treatment and recovery journey takes an emotional, physical and mental toll on the immediate caregiver. The communication burden, time commitment and emotional drain of updating family and friends only add to this challenge. That may explain why 70% of CaringBridge sites are created by caregivers, whether a spouse, parent, child or friend. With less time dedicated to communicating, more time can be spent where it's needed most: caring for a loved one.

By enabling the love, hope and compassion that is needed to face a serious health challenge, CaringBridge makes the journey easier for not only the patient, but also the primary caregiver, family and friends.

I am the point of contact for my dad, and I can't even imagine how exhausted I would be if I had to continue to update everyone every day. This website saved my sanity!

Conclusion

Ninety-eight percent of CaringBridge users surveyed expressed high or very high satisfaction with the site and 95% of all users who responded have or would recommended it to others.^{xxii} Further, 99% of all users polled believe CaringBridge to be “valuable” or “very valuable.”^{xxiii} But what really reflects the value CaringBridge provides is the feedback received from site creators and authors, patients and visitors alike. Those quoted here are only a small representation of users who express their gratitude for the connections CaringBridge provides – connections that positively impact the lives of those affected, supplying love, hope and compassion to stay strong in the face of life's challenges.

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- i <http://www.organdonor.gov/>
- ii Susannah Fox & Sydney Jones, Pew Internet & American Life Project, "The Social Life of Health Information." June 2009.
- iii Boyd, D. M., & Ellison, N. B. (2007). Social network sites: Definition, history, and scholarship. *Journal of Computer-Mediated Communication*, 13(1), article 11. <http://jcmc.indiana.edu/vol13/issue1/boyd.ellison.html>.
- iv CaringBridge "Fast Facts," March 2011.
- v <http://www.caringbridge.org/about>
- vi All quotes in this white paper are from actual CaringBridge users, captured as part of the CaringBridge Custom Online Survey, Q3 2010 commissioned survey conducted by Forrester Consulting on behalf of CaringBridge, October 2010.
- vii CaringBridge Custom Online Survey, Q3 2010 commissioned survey conducted by Forrester Consulting on behalf of CaringBridge.
- viii CaringBridge Custom Online Survey, Q3 2010 commissioned survey conducted by Forrester Consulting on behalf of CaringBridge.
- ix Tom Ferguson, MD, "e-patients: how they can help us heal health care." 2007.
- x Leslie Wade, CNN, "Social support can be a lifeline during health crisis." June 15, 2009. Available at: <http://www.cnn.com/2009/HEALTH/06/15/social.support.benefit/index.html?iref=allsearch>
- xi Leslie Wade, CNN, "Social support can be a lifeline during health crisis." June 15, 2009. Available at: <http://www.cnn.com/2009/HEALTH/06/15/social.support.benefit/index.html?iref=allsearch>
- xii CaringBridge Site Analytics, November 2010.
- xiii CaringBridge Custom Online Survey, Q3 2010 commissioned survey conducted by Forrester Consulting on behalf of CaringBridge.
- xiv Susannah Fox & Sydney Jones, Pew Internet & American Life Project, "The Social Life of Health Information." June 2009.
- xv CaringBridge Custom Online Survey, Q3 2010 commissioned survey conducted by Forrester Consulting on behalf of CaringBridge.
- xvi Susannah Fox & Kristen Purcell, Pew Internet & American Life Project, "Chronic Disease and the Internet." March 24, 2010.
- xvii Pew Research Center's Internet & American Life Project, April 29-May30, 2010 Tracking Report. May 2010.
- xviii Pew Research Center's Internet & American Life Project, Usage Over Time Report, May 2010.
- xix Bradford W. Hesse, Ph.D., National Cancer Institute, National Institutes of Health, "Technology-Mediated Social Participation in Health and Healthcare." January 18, 2010.
- xx CaringBridge Custom Online Survey, Q3 2010 commissioned survey conducted by Forrester Consulting on behalf of CaringBridge.
- xxi CaringBridge Health Communication Research Poll, Ipsos Public Affairs, September 2010.
- xxii CaringBridge Custom Online Survey, Q3 2010 commissioned survey conducted by Forrester Consulting on behalf of CaringBridge.
- xxiii Proprietary CaringBridge Brand Positioning Survey Report, April 2010.