



Natural Transitions

Volume 2, Issue 3

Conscious, holistic approaches to end of life



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The e-Caregiving Connection

by Lee Webster

Picture yourself in one of these scenarios:

- * Your father's dementia, while not severe, requires him to live with your sister in another state, and you don't know how to help from so far away.
- * Your neighbor down the street broke her leg on a slippery sidewalk and will be housebound in a cast for six weeks, followed by eight weeks of PT.
- * Your dearest friend has just learned that his cancer is back and there are no further treatment options.
- * Your minor elective surgery will keep you from lifting or moving anything—or driving—until you get the okay from outpatient rehab.
- * Your co-worker with a young family had an accident on the job that resulted in a permanent disability.
- * Your daughter discovers she is having not one, not two, but three babies.
- * Your son is deployed overseas on military duty, leaving his wife and family alone on base for his 18-month tour of duty.
- * Your son's 14-year-old best friend is waiting for an organ transplant and his family needs financial assistance.

Suddenly, your life as you've known it is over, at least for a while, possibly for a very long time. For most of us, just getting our bearings is a challenge, not to mention dealing with the ins and outs of the medical system or with potentially strained family dynamics. What in the world are you going to do? Like most of us, you'll probably head straight to your search engine.

That's right. The www. *More than half of us look to the web* to teach us what we need to know, show us ways to cope, and steer us in the right direction when it comes to caregiving issues. We choose consulting the Internet over health care professionals two to one.

Given that over *one-third of all Americans are caregivers at any point in time*, it is

small wonder that we are looking for ways to lighten our load. You might be surprised—and relieved—to learn that, although the degree to which we are Internet savvy is linked to age, location, and how much education and income we have, Internet use has not been limited substantially by any of these factors.

So what kind of support are you likely to find? Answer: caregiving management sites. Open 'round the clock and mostly cost-free, these specialized, social network caregiving sites provide tools and know-

how to manage the myriad of demands that tax a family or a group of friends when someone they love falls ill or needs extra support. Caregiving management sites provide ways for families and friends to stay connected, organize themselves, and even raise funds, all via the Internet. Think of it as Facebook for special circumstances with some awesome down-to-earth practical apps and people-connecting features.

Here's how these *online communities* work: Someone sees a need to get help



for a family member or friend. The organizer chooses an online provider [see next page], selects which services will be most helpful, sets up a free web page by following easy directions, and invites others to join and participate in organizing care. It's that easy.

All caregiving management sites include a calendar. Everyone on the contact list can contribute to this and can edit it to arrange whose turn it is to bring the casserole on Tuesday, mow the lawn Saturday morning, provide childcare after school, pick up groceries on Friday, or take care of other organizational tasks. This helps minimize the inevitable feelings of isolation for the person in need and prevents one person becoming overwhelmed with details—the primary cause of caregiver burnout.

With family, friends, neighbors, acquaintances, church members, and co-workers willing to help during a short-term crisis or long-term situation, privacy concerns are paramount. Most sites make it easy to restrict access to only those who have been invited.

Private community caregiver sites usually offer a bulletin board to relay messages of hope, prayers, or good wishes, relieving the family from well-meaning—but sometimes intrusive and time-consuming—phone calls or visits. This feature allows all concerned to maintain personal and timely contact with loved ones. Some offer photo-uploading capabilities as well.

Seem too virtual? Maybe for some of us who remember taking the whole family on a Sunday afternoon drive to drop in unannounced on folks who were ailing. But that custom has fallen by the wayside, and now, the younger the patient, the more comfortable he or she is with short bursts of communication that preferably don't require face-to-face contact.

In case of long and short hospital or rehab facility recuperations, patients benefit from regular contact while still receiving

the rest and medical attention they need. A message board might allow some friends to stay in touch more easily than sending a card or visiting in person.

Social caregiving websites can also be an efficient way to inform a group of concerned others of someone's rapidly changing health status, saving the time and energy of those who are dealing with a health crisis or life-threatening situation. When one person can keep a circle of loved ones posted from the bedside, everyone else can rest, in case they are needed later on. If death is imminent, a designated gatekeeper can send updates through the website, allowing the family to stay in charge and in the moment.

There are only four kinds of people in the world—those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.

—Rosalyn Carter

While most sites are designed to provide private access for the members included, open communities allow volunteers to join in supporting friends they have never met. As with private communities, the organizer has the ability to manage privacy settings with password protections, selecting only what he or she wants to be visible to volunteers. Sometimes medical crises come with unforeseen and potentially crippling financial burdens. Whole neighborhoods, towns, schools, and churches can rally round to help those in need. Many sites offer thoughtful ideas for both large- and small-scale fundraising activities as well as the tools to initiate them, including how to receive donations legally and easily.

Some sites include the capability to download medical files, drug databases, advanced directives, forms, and permissions. This feature was made possible, in part, by legislation in the late 1990s giving individuals access to their personal health records. This can be a tremendous aid in managing patients

with terminal or lingering diseases whose care involves complicated medication schedules. However, some of these programs are limited in scope and have hidden or delayed charges, so consumer, beware!

As somewhere between 72 and 79 million Baby Boomers age, caregivers' needs for simple, easy-to-access support at their fingertips will increase exponentially. And as the first generation to embrace personal computers, these caregivers will find the right web tools to do just that. Add to that the rise of the Sandwich Generation—adult children caring for their parents and their own children simultaneously (usually in their own home)—and time constraints alone will dictate getting information and support from the most readily available source.

Most importantly, caregivers universally experience similar doubts, fears, guilt and shame. Everyone needs help working through these emotions, along

with help developing action plans and finding practical solutions.

Online caregiver communities provide a new way to transmit information with ease and accuracy and to create real connections between people as we care for those we love. So the next time someone says, "Please let me know if I can help," tell them exactly how they can: by going online to sign up for their weekly casserole drop-off.

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Some Top e-Community Caregiver Websites



Share The Care

www.sharethecare.org

Share The Care is a step-by-step program for organizing support based on a team-building model that provides care for the patient, the primary caregiver, and family members. Details about this cost-effective, supportive, community-based support system model are available in a book by the same name. Members of Share The Care are available to give presentations around the country. (see related article page 12)



www.caringbridge.org

CaringBridge has been around for 15 years, and is thus one of the grandmothers of caregiver management. CaringBridge partners with over 500 hospitals and nearly 100 health-based nonprofits. The support planner feature helps family and friends coordinate care and organize tasks that keep a household running and everyone on schedule. CaringBridge also provides personal, free, online space in which to post health updates, receive supportive messages in a guestbook, and keep everyone in the communication loop.



www.carecentral.com

The American Pain Foundation sponsors a free online service called CareCentral designed to help caregivers caring for a loved one who is experiencing chronic pain. This online community includes the provision of:

- An online journal where a caregiver can keep family and friends updated.
- A calendar that all volunteers can access to sign-up to provide services or ask for help.
- A newsfeed to keep members informed.

www.manystrong.com

Hosted by United Health Group (the parent company for United HealthCare, servicing more than half the Fortune 500



companies and a fifth of all Medicare recipients), this site is beautifully laid out, easy to navigate, and covers the basics of message boards, event and task calendars, and fundraising methods. Of particular interest are the tools for soliciting and managing donations. This service is particularly helpful to families whose loved one is being cared for at a distance or someone needing financial help more than physical support.

www.lotsahelpinghands.com

With services that include message boards, a photo gallery, event organization,



Lotsa Helping Hands

personal blogs, its own Well Wishes board, and a help calendar, Lotsa Helping Hands goes beyond the standard features to offer both private and open community support and a program on which to keep important information organized and stored safely. The LHH program is especially effective for open volunteer activity from people outside an immediate care circle.



www.carerunner.com

In addition to the organizational tools available on most caregiver sites, CareRunner also offers expert advice regarding specific conditions such as Alzheimer's, Parkinson's, amyotrophic lateral sclerosis, and multiple sclerosis. A community journal and private messaging service accessed through a personal dashboard allows one user to belong to several communities at once in varying capacities. CareRunner is well suited to individuals with aging parents, but designed for any caregiver situation.



www.carepages.com

For families with loved ones battling cancer, this site is an e-community and a research bonanza all in one. The care support circle pages keep family and friends up-to-date on progress or changes while a loved one is in the hospital. There are also discussion forums, blogs, advice on how to best support patients and how to care for oneself, plus the latest cancer treatment facts and research information.

Caregivers In and Out of the Workplace

There were approximately 66 million unpaid caregivers in the US in 2009.

Eighty percent of all long-term health care in the US is provided by family and friends.

This unpaid value is estimated at approximately \$300 billion annually.

Productivity and revenue losses are estimated to be between \$17 billion and \$35 billion as the result of workers' caregiver obligations.

National Alliance for Caregiving Survey 2009 "Caregiving in the U.S. Executive Summary"
www.caregiving.org/data/04finalreport.pdf

Who Is Helping the Helpers?

29% of all caregivers use the Internet as their main source of information and organizational support.

28% use doctors, nurses, hospitals, hospices, and other health professionals (combined).

53% use the Internet as a supplementary form of support.

The most prevalent form of technology used by caregivers is an electronic organizer or calendar (24%).