



# Natural Transitions

Conscious, holistic approaches to end of life

Volume 2, Issue 3



Share The Care: Don't Do It Alone!

Reflections of a Lesbian Caregiver

"The Hardest Thing": Hospice in China

Caregivers in the Workplace

Quakers: Departing in the Company of Brethren

Caregiving and Receiving



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DEPARTMENTS

EDITORIAL

- 4 Relief for the Caregiver  
by Karen van Vuuren

COMMUNITY FORUM

- 5 Letters from Canada and Minnesota

IN SPIRIT

- 23 What Makes a Full Life?  
by Bodhi Be

MEDIA

- 24 Video Review: Dying into Love  
by Lee Webster

CULTURAL CONNECTIONS

- 25 “The Hardest Thing”: Hospice in China  
by Lyn Gould

A TIME TO DIE

- 28 Dove: Releasing Me into the Now  
by Shana Stanberry Parker

LAST WORDS

- 35 Learning to Fall  
by Philip Simmons

FEATURES

- 6 Redefining Normal  
by Kelley Brunn

- 7 Reflections of a Lesbian Caregiver  
by Mary Jo Osterman

- 9 The e-Caregiving Connection  
by Lee Webster

- 12 Don't Do It Alone! Share The Care  
by Sheila Warnock

- 17 Rippling through the Islands:  
Kauai's Share The Care Model  
by Deborah Duda

- 19 Caregiving Goes Both Ways  
by Kate Semerad

- 20 Caregiving in the Workplace:  
Burdens, Challenges, and Solutions  
by Jennifer Ballentine

- 30 Undertaking with Love:  
Organizing a Faith Community  
by Donna Belk

- 32 Quaker Burial Societies:  
Departing in the Company of Brethren  
by Ashana Marie Larsen

Cover photo: After a hospice nurse suggested that Pauline “Pinky” Cassler-Jones had about six months left, her daughters gathered for a ceremony to “say all they needed to say.” Part of the ceremony included washing her feet. Photo by Katherine Jones







## Relief for the Caregiver

by Karen van Vuuren

Suddenly there was not enough of me to go around. Over the course of a week, I'd received pleas for help from three friends with relationship crises, two with broken limbs, and one with a life-threatening illness. On the home front, I was trying to avoid being sucked into my own minor maelstrom with my high school senior as she prepared for exams and completed college applications. I felt guilty and frustrated that I simply couldn't do it all. The irony was not lost on me that, at the same time, I was also putting together this issue of NTM with its focus on caregiving and receiving.

Sharing the burdens and the blessings of supporting those in need is more important than ever, for both our personal physical and mental well-being and our social and cultural health. When our family support networks and our financial resources fall short of our needs, we must create these new support communities. Share The Care founder, Sheila Warnock, has long exhorted Americans to "return to the barnstorming mentality of yesteryear," and she repeats her call for community in her article for this issue, *Don't Do It Alone!*

We've devoted much of this issue of NTM to the caregiver's needs. But clearly a healthy caregiving scenario, in which the caregiver does not buckle under the weight of his or her role, will positively impact the care recipient as well. Although the newly coined diagnosis, *caregiver stress*, is not yet in the Diagnostic and Statistical Manual of Mental Disorders, it is increasingly acknowledged and recognized by medical professionals. Exhaustion, depression, anger, guilt, and a decline in one's own health can all dog the caregiver who experiences "unrelieved" caregiving. This issue of NTM is in honor and support of those who care for the sick and the dying—and for the newly emerging circles of those who care for the dead (see *Undertaking with Love* and *Quaker Burial Societies*). Please send your comments to [mag@naturaltransitions.org](mailto:mag@naturaltransitions.org) for inclusion in our new Community Forum letters page.

*Karen van Vuuren*



## Natural Transitions

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### OUR VISION

- Acceptance of death, loss, and grief as a natural part of life

### OUR MISSION

- To share holistic approaches to end of life
- To provide a forum for end-of-life caregivers and educators

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## Death Care Toolkit for Canadians



Here in Canada a group of nine Canadian death midwives, thanadoulas, end-of-life educators, memorialists, celebrants, home funeral guides and funeral directors is currently collaborating on a toolkit to help Canadians get their final affairs in order and identify their end-of-life wishes (including post-death care).

This unique toolkit is composed of a variety of modules that explore practicalities like finances, as well as conscious dying, body care, ceremony, home vigils, disposition alternatives, and memorials. The working title of the project is *Beyond My Will: Holistic, Comprehensive Advance Care Planning for Canadians*. Once it is complete, members of our group will bring the toolkit to our own communities across the country.

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## Minnesota – Moving Along



In Minnesota change is happening faster than we anticipated. Mound Cemetery of Brooklyn Center became Minnesota's first cemetery to be certified by the Green Burial Council. It's a hybrid burial ground in which eco-friendly graves are mixed in with conventional graves. There are now at least three options for green burial in the metro area. This summer, the first commercial "green cremation"—alkaline hydrolysis—facility in the US opened in Stillwater, MN.

Minnesota Threshold Network members were featured in the PBS affiliate documentary series *Honoring Choices*. We also presented at several hospice and palliative care programs, a number of churches, a mortuary science seminar for medical examiners and funeral directors, and the University of Minnesota School of Mortuary Science. In June MTN had the largest turnout it has ever had at our annual free information forum.

And thanks to *Natural Transitions* for helping to widen our horizons and inspire us here in the Midwest. The last issue of *Natural Transitions* was gorgeous. Every article was inspiring!

Nancy Manahan  
Minnesota Threshold Network

*Natural Transitions* has always focused on building community. With that goal in mind, we introduce our new Community Forum page to encourage communication among our subscribers and within this movement for more conscious, holistic, and greener approaches to end of life. We welcome comments on the articles and sharing news and inspiration from your part of the world! Email your letters to [mag@naturaltransitions.org](mailto:mag@naturaltransitions.org).

# Redefining NORMAL

by Kelley Brunn

High school kids come bursting through the front door. “Hi, Mom, we’re home.” As they head back to Stacy’s room, they wave and shout to my husband, “Hi, Mr. Brunn!” I sit in the family room chair with a smile on my face. Of the five enthusiastic young people, only one of them, Stacy, is actually our child. Yet they act like they’re entering a normal home. Is that possible? Is it possible that we have created a normal life in the most abnormal of circumstances?

I never thought anyone would want to burst through our front door. In fact, fewer and fewer people seemed comfortable with my husband Bill’s declining health. I imagined people entering our door felt like they were climbing on a horror ride at an amusement park when they saw Bill’s hospital bed—with him in it—right in the middle of the family room. Bill has multiple sclerosis, most definitely an uninvited guest.

In the early years of our relationship and marriage, Bill played tennis and golf and jogged five days a week. He was the most fit and healthy person in both our families. Occasional tingling in his extremities and problems with balance and tripping just seemed like insignificant, minor distractions. Then these distractions grew into more serious falls, bladder dysfunction, and extreme fatigue. When the symptoms escalated, Bill’s doctor ordered a battery of tests that seemed extreme. We thought the test results were going to confirm that Bill just needed to get more rest and be careful, especially since, after two weeks, most of the symptoms had subsided.

I was waiting for Bill when he walked out of the doctor’s office, his hands full of papers and publications, his face stone white. As we left he whispered, “I have multiple sclerosis.”

My heart raced. My mind swirled with thoughts. “What? That can’t be. My mom is wheelchair-bound with MS. Our daughter is two months old. No

way!” I put Stacy in the car seat, and Bill started to drive home, then stopped the car and burst into tears, “This can’t be happening.” But it was.

The next few months and years were filled with a strong determination to “beat the odds” and to continue on with life as “normal.” What living with chronic illness has taught us, however, is to create our own normal—within the boundaries of the disease’s limitations.

## *Friends and family experienced initial shock when they walked through the front door and saw Bill’s bed right in the center of everything.*

As the MS progressed and little inconveniences became bigger obstacles, the voids and losses began. The former jogger and tennis player struggled to walk long distances. Mood swings and loss of bladder control became more frequent. Then we hit our first huge transition. Bill collapsed in the driveway, and after evaluation in the ER, it was determined he was having a major MS exacerbation. A new MS lesion in the center of his spinal cord was causing increased disability. Thirty days later he was discharged from neurological-rehab. He came home in a wheelchair.

We gradually became aware that MS was directing our lives. Almost all decisions—financial, personal, business, and educational—were made with MS as a component. How much ability would the disease take from Bill? How should we prepare for further decline? Was preparing for decline giving up? Finally, we just held to the motto: “We’ll hope and fight for the best while preparing and planning for the worst.” Denial is a short phase of facing chronic illness; when reality sinks in, maintaining hope and not dwelling on the bad become critical. Especially because dwelling on the bad can be all-consuming.

Bill’s disease affected every aspect of my life and Stacy’s. But even though our lives were dramatically different from most, we had to define how best to construct them. The only other option was for the healthy individuals in our family to pack up and start a new life without Bill, one too painful to entertain, let alone execute. But without some serious changes, it might have become the only option.

After living with Bill’s illness for ten years, I made my first visit to the local Well Spouse Association Support Group. The expertise of fellow caregivers—who emphasized that the key was to balance my mental, physical, spiritual, and emotional being—was so helpful. Taking care of myself, the caregiver, became one of my priorities. After all, if I sacrificed all of myself to Bill’s illness, eventually I’d be no good to anyone, sick or healthy.

I had already found great release in just going for walks around the neighborhood a few days a week, using that time to solve work issues, pray, or just release the emotions and tears. Bill saw the benefits: I was less stressed and more gentle in dealing with issues at home.

Bill and I were extremely sensitive to encouraging Stacy’s activities because she had already dealt with three years of her own health issues from ages one to four. Realizing the gift of her second chance encouraged her to stay active. As a freshman in high school she started running cross-country. She discovered running to be a great way to release stress, and it also gave her time alone to think. She received an award for most improved runner for the season. That led to more confidence and the ability to keep her dad’s illness in perspective and not make it an all-consuming element in her life. Many times Stacy and I combined our “alone” time: I walked the track while she ran.

Sometimes I used that time to entertain new ideas and force myself to think

*continued on page 27*

# Reflections of a Lesbian Caregiver

by Mary Jo Osterman, PhD

My partner, DJ, and I were together for nearly 50 years. “Being together” meant a number of different things over five decades: living 600 miles apart and talking on the phone every night, living in the same city but in separate apartments, living together as “friends” or “roommates.” Finally in 1992—after 30 years and DJ’s retirement from a United Methodist seminary—we moved to Louisville, CO, into a house together, and we slowly began to deal with our relationship, cautiously (for DJ) affirming our identity, speaking our love to each other, and acknowledging within our small old lesbians’ support group that we were a lesbian couple.

Myself, I came out in 1981 and had another short, very public lesbian relationship that ended when my partner, Phyllis, committed suicide after losing a battle to become ordained as a United Methodist minister. Through it all, DJ remained closeted, yet she and I remained closely connected. Over the years I’m sure people guessed the nature of our relationship, but we never said.

In the fall of 1997, I began to notice that DJ’s memory was beginning to fail. Her brother noticed that she wasn’t responding to his emails as thoroughly. Daily tasks became harder. She left water running or the stove on, forgot that the dishwasher needed a special kind of soap and constantly misplaced things. Driving and managing money became huge issues, and tasks I slowly and indirectly began to take over, while trying to leave DJ with as much dignity as possible. She remained in total denial of her memory loss, becoming frustrated and then angry, blaming me for all the problems. She began not wanting to go anywhere and making numerous repeat phone calls to people. We lost contact with friends, stopped going to church, and became more and more isolated. However, for several years DJ could pass the short memory test given by her doctor, so I began making notes and sending them to her doctor before her next appointment. Finally, we got a diagnosis of dementia (possibly Alzheimer’s disease).

My stress level increased until finally, in 2001, I reached out to our local senior center and to its Alzheimer’s Association caregiver support group, and that’s when my learning really began! Now I had to decide whether or not to be honest about my relationship with DJ. Someone at the senior center advised me not to come out, so at the first meeting I spoke of DJ as a longtime friend who lived with me. However, as I listened to others share the details of their lives with their loved ones, I realized I couldn’t get any real support if I lied. I didn’t return to the group for a whole year. Finally, desperate for help, I returned and identified myself as a caregiver with a lesbian partner. I was accepted—cautiously at first—then more and more naturally.

By 1992 DJ could not be left alone in the house, so a friend offered to come and visit with her once a month while I went to my support group. Much later that friend told me how every month she saw changes in DJ such as less ability to play canasta or Scrabble or work on small jigsaw puzzles.

Being a lesbian caregiver meant constantly coming out. Every time a new person joined the support group, I had to come out. Doctors, lawyers, insurance people, and memory care facility staff and caregivers—I had to let them know that I had an active power of attorney as I made decisions to accommodate DJ’s illness.

## *Usually I took a deep breath and said, “No, DJ is my partner.”*

For a long time I put off seeking day care for DJ (and respite for me!) because I wasn’t sure how the various facilities in our county would accept us as a couple. I had heard horror stories of other gay and lesbian elders around the country who were refused admission or who were taken in but then neglected or harassed. In my visits to facilities, I came out to staff and asked questions about their knowledge of and experience with

lesbian, gay, bisexual, transgender (LGBT) elders, and received mixed responses—some obviously uncomfortable, others not picking up on the discrimination and adequate care issues that I had.

Ultimately I chose a secured assisted living facility, Balfour Cherrywood. Forty minutes into the interview, Debbie had still not asked about or assumed what my relationship was to DJ. When I commented on that, she said, “Well, I assumed you would tell me sooner or later.” When I expressed my concerns, Debbie was open, accepting, and caring. She said, “If there’s a problem with staff acceptance, they won’t be here very long!” In the fall of 2004, DJ began day care and I met the staff, diverse and compassionate. DJ was thoroughly integrated into the community and much loved.

Once DJ moved into Cherrywood, I realized I had to come out to each new staff person, caregiver, housekeeper, as well as visiting family members of residents. Otherwise they often assumed that DJ was my mother since she was older than I am. Each time there was that momentary panic and internal thought process: *Do I come out and correct them? Or let the error stand and perhaps compound the situation?* Usually I took a deep breath and said, “No, DJ is my partner. We’ve been together X number of years.” In most instances, our relationship was accepted and meaningful conversations followed.

DJ remained at Balfour Cherrywood for four years, declining slowly. At one point the director, Megan, told me that when she was talking to another resident about his disease, DJ would come around to listen—for the first time seeking information.

By 2009, DJ had experienced falling episodes and needed pureed food and help with feeding, so I moved her to Cherrywood’s secured nursing facility, The Reserve. There I found new, highly diverse, and compassionate staff and caregivers. I also began relating to a hospice team off and on (another understanding group). In 2010, DJ began

to use a hospice-provided wheelchair. She lost interest in drinking and swallowing (or perhaps her ability). On Christmas day I found her agitated and seemingly in pain. After I put her in bed, she never got up again. Hospice and reserve caregivers supported my carrying through with DJ's decisions made before her illness about the last few days of her life. I was with her when she died early in the morning on January 3, 2011.

Over 14 years of caregiving, I realized that most of the Alzheimer's-related issues DJ and I faced were physically no different than those faced by others. *The disease doesn't discriminate; people do.* However, what happened to us often was not outright discrimination but rather a subtle but pervasive heterosexual bias built into human interactions: the bias on forms that left me without a box to check my relationship status; the bias in strangers who routinely assumed two women of different ages must be mother-daughter; the bias in videos and stories used with dementia residents that always identified two same-sex people as mother-daughter, father-son, sisters, or brothers. These

biases affected me. But more importantly, they affected DJ because they influenced how caregivers worked with her to either affirm or deny her diminishing sense of self.

## *I had to come out to each new staff person, caregiver, housekeeper, as well as visiting family members of residents.*

As I watched family, friends, neighbors, senior center staff, medical personnel, and caregivers try to find language to include us, I also began to realize how bound to heterosexual language our culture is. To be more inclusive, people would say "your friend" and often then revert to their usual heterosexually-based language. Perhaps my musings below will help others as we all try to use inclusive language in ALL situations, not just when working with those with dementia.

When we talk to someone who has some form of dementia, it is important to try to connect with familiar things from her past. If we are reading a story, describing a picture, or showing slides, we can try to think outside our usual—perhaps heterosexist—assumptions

of relationships. Heterosexism is the act of approaching the world from an exclusively heterosexual viewpoint: *It discriminates against LGBT people.* So when trying to expand our language to be more inclusive, we can mix up the images.

Which words or images will stir memories in the minds of LGBT persons with dementia? It can be very surprising what a dementia resident might say! Perhaps give a resident's partner an opening to tell you the truth. It's all in asking the right questions. It is important to help everyone feel visible, included, and valued.

A final musing: The LGBT community does not all use the same words, so it's always appropriate to ask: "What would be the appropriate word for me to use?" And to my LGBT friends, keep educating until everybody has enough language to include you!

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### *Instead of asking:*

Do you have a husband?

Are you married?

Is that your friend? Your companion?  
*(for two men or women)*

Is that your mother/daughter or father/son?  
*(for people of differing ages)*

Is that your child?  
*(of any age)*

Tell me about your grandchildren.

### *Ask:*

Who is in your family? Who is important to you? Do you have a spouse, mate, partner, loved one? or significant other?

Is there someone with whom you share your life? Are you in a committed relationship or partnership?

Who is that person to you? How are you related?  
*(life partner, daughter, other relative, or friend)*

Are you related? If so, how?

This child seems special to you. Who is she/he to you?  
*(niece, nephew, special friend, neighbor's child, cousin, etc.)*

Are there any children in your life who are very special to you? Tell me about them.

## Coma Communication



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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 from 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.***

***—Rosalynn 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.

Natural Transitions Magazine

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•SHARE your stories  
•SPREAD the word

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## Some Top e-Community Caregiver Websites



[www.sharethecare.org](http://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](http://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](http://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](http://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](http://www.lotsahelpinghands.com)

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



Lotsa Helping Hands



[www.carerunner.com](http://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](http://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](http://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%).



# Don't Do It Alone!

by Sheila Warnock

Founder and President, ShareTheCaregiving, Inc.

Historically, Americans have pulled together, not only when this country was being settled, but also in times of great stress (World War II, 9/11, Hurricane Katrina, among other disasters). Our spirit of volunteerism is being tested yet again in these difficult economic times. Indeed, the national climate is ripe for grassroots solutions to help overcome many of our country's problems. This is particularly true of caregiving.

At present, nearly one third of the US population is serving as caregivers, and the need for caregiving support will explode over the next several decades because the vast, aging population will double in size. It's almost a sure thing that every one of us will, at some time, be touched by this issue.

Share The Care™ is a grassroots model that empowers ordinary people with a solid step-by-step plan on how to organize and maintain a "caregiving family" to help themselves and each other deal with the care of people they know who are ill, disabled, or struggling with the challenges of aging that can overwhelm a lone caregiver. This model is meant to care for the entire family of that person as well. And, if someone has no family, then nearby friends, co-workers, and neighbors bond to become the "family."

After 17 years of field-testing, the model and philosophy have proven their worth, and the time is now for them to be shared and more widely supported. It is our dream that people everywhere involved in making caregiving decisions will view Share The Care as a viable and rewarding option. Already it's being used for some unique circumstances: support for widow(ers) with small children, grandparents raising children, difficult pregnancies, preemies or multiple births, and in times of bereavement.

Share The Care was born in 1988 when 12 women (mostly strangers to each other) came together for three and a half years to care for a mutual friend with a rare terminal cancer. Over that time, the group developed ways of working and rotating responsibilities so no one person was overwhelmed. Later, when asked to help others form similar groups, two of us, the late Cappy Capossela and myself, decided to document our techniques, systems, principles, and step-by-step instructions into a handbook, *Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill*.

***[I]f someone has no family, then nearby friends, co-workers, and neighbors bond to become the "family."***

Tragically, in 2002, Cappy was diagnosed with a terminal brain tumor, and I was called on to spearhead yet another group. Following Cappy's death (my third experience as a primary caregiver), I abandoned my career and life direction to establish our non-profit organization, ShareTheCaregiving, Inc., to take our model to the next level.

ShareTheCaregiving secured 501(c)(3) status in July 2004. In 2008, we made the decision to hibernate our 501(c)(3) and operate under the fiscal umbrella of the National Center for Civic Innovation. In compliance with IRS regulations, the *Share The Care* book rights were signed over to ShareTheCaregiving.

In 2004, my main focus was to update and revise the book for a second printing and build our website at [www.sharethecare.org](http://www.sharethecare.org). Based on the experience and research that indicate caregivers turn most often to health professionals for information and suggestions with caregiving, I recognized the need for a full-day Share The Care professional training as a way to reach more patients and families in need. The New York State



Nurses Association currently accredits this training.

Our vision at Share The Care is of a society where family caregivers are not left on their own to manage the complex stressors that inevitably lead to burnout. Using our model, a group of eight to 30 (sometimes more) friends and family share the caregiving and make best use of their team's combined resources, skills, contacts, and talents. Share The Care tools guide friends of someone in need to form their own group with relative ease.

There is no limit to the potential reach and value of our model. The exigencies of caregiving cut across racial, geographic, gender, and socioeconomic lines. Share The Care has been expanding

as a powerful grassroots movement throughout the United States, and it is spreading globally. We can document use of the model in 48 states, one territory, and nine countries.

Through our "Seeding Share The Care in Communities" training (for up to 50 professionals), it is possible for a local organization to establish a Share The Care program and station to bring awareness into their community. A trained station manager (professional or volunteer with caregiving experience) can provide information and/or coaching to anyone who calls the hotline listed on specially designed advertising. The station manager's responsibilities also include making local presentations at community centers, clubs, non-profit organizations, and faith communities.

There is currently a statewide effort to establish stations in rural Wisconsin through the Greater Wisconsin Agency on Aging Resources. Led by a Share The Care coordinator, five stations have been established and two more are in the works. Following a training in Monterey, CA, a community effort



led by a group of professionals known as the MoCo, Monterey County Share The Care Council has two stations in operation. Mercy Hospital in Springfield, MO, hosted a training in January for hospital staff and established a station and hospital coordinator to help patients and outpatients. In Ontario, five stations in various parts of the province are working to sustain Share The Care in their communities following an 18-month initiative funded by the Community Care Access Centers.

As we move forward, we seek to have Share The Care incorporated into the curriculum for student nurses and social workers. We would welcome a research study that explores the physical, psychological, and emotional benefits derived for everyone involved in a group (care recipient, primary caregiver, family, and friends). Such a study could help establish how the model supports people to create and sustain a powerful team, to carry on through the darkest of times and prevail (sometimes for years), and to imbue the experience with light and love.

To follow are some of the caregiving lessons I've learned through my personal experiences of helping family and friends over the years. I have chosen to illustrate them through our list of The Seven Principles of Share The Care™ that appear in full at the end of this article. My lessons are in order of their occurrence—not in order of the Principle as it appears on the list.

These principles are the glue that holds together a Share The Care team and help it operate smoothly over time (years). How they apply and are applied will, of course, vary from person to person, group to group, experience to experience. They really do work!

### Caregivers are made, not born.

When I was in my 20s and at my first job in advertising, a co-worker became gravely ill and was in the hospital for months. I sent him cards and flowers, yet I could never get myself to go visit. I was afraid I wouldn't know what to say. He died. And I never got to say anything.

Now, decades later, when I tell audiences about that experience, it's to illustrate a fear that is more common among us than one might believe. No one teaches us how to *be* with someone who is seriously or terminally ill. Had I been lucky, I would have found another person to accompany me for a visit and thus had my first lesson in supporting someone who is ill.

We believe Share The Care offers a solid avenue for people who may be hesitant or fearful to offer a hand to a friend, neighbor, or co-worker. With a group, any first-time caregiver can be paired with a veteran to learn the ropes. Most people *do* want to make a difference. Sometimes all they need is a bit of confidence to get going.

*Anyone who wants to help should be encouraged.*

### Take care of yourself in times of great stress.

I remember vividly being thrown into the lion's cage of caregiving in the mid-1980s when my widowed mother needed me. What I experienced was typical of so many first time caregivers: I totally burned out.

First, I had to learn quickly and in great depth the many medical issues that were plaguing my mom as I journeyed with her through the numerous and varied stages of her deterioration. And both of us also had to learn to let go of so much.

She lived some distance from me, a five-hour bus ride, so for starters I was a long-distance caregiver. Living far from my mom was particularly frightening because my imagination was always working overtime, especially if there were health crises that required hospitalizations.

Living in upstate New York during the snowy winters can be overwhelming for an older person in poor health, but I worked hard to convince my mom to sell her house and move to a retirement community in New Jersey. She had fractured her wrist during a fall on the ice that, combined with arthritis, made using her hands difficult. Finally she agreed to relocate to a gated community with grassy lawns and duck-filled ponds, and all kinds of outings and activities. *Ahhhh*, I thought, my travel time will be cut considerably—to less than two hours. But first we had to secure a buyer for her home and sell most of the treasures she and my late dad had accumulated over 25 years of living in Europe.

Downsizing from a large house to a one-bedroom condo called for a true lesson in letting go, and Mom handled it with grace. The next hurdle came for me when I needed to increase the number of my visits from weekends (oops, there went my entire social life!) to four days a week. My mom had wisely stopped driving and so became totally dependent on me to take her everywhere. I also had to let go of my dreams of pursuing an acting

career. This was especially hard since I had earned all of my credentials: SAG, AFTRA, AEA. But I simply had no time for auditions or for film or TV work when called.

Over a period of three years, I did an admirable job of taking care of my mother. I was, however, doing a lousy job of taking care of myself. I lived on the brink of tears, in a state of constant anxiety. I could no longer work as a freelance art director or as an actor and was subsequently running out of money.



*Sheila and her mom on her 80th birthday*

My friends had no concept of what was involved in helping a parent in declining health and were no help during this time. As a result, I evolved into a classically depressed, frustrated, isolated caregiver, a breath away from a breakdown.

It never occurred to me to ask for help. Who would I ask? My brother and his family lived in Japan and back in the 1980s, making a transatlantic phone call was a big deal. My brother and I communicated via lengthy airmail letters, and he did what he could from afar—sending money for outings and things our mom needed.

Then everything shifted from bad to worse. During the course of her one year in the retirement community, my mom showed signs of confusion and began to fall frequently. She needed aides with her during the three days I was at my home in New York City. The realization that she could no longer live alone was staring me in the face. We talked about options as her money was running out and I wasn't making any. Our only resort was a nursing home; finding one was yet

another mountain to be climbed. Finally, I relocated her to a nursing home across the Hudson River in Jersey City, where she was a resident for the next seven years while I continued as her caretaker, advocate, daughter, and “mother.”

There were more stages of letting go to come. A particularly difficult one for me was donating or getting rid of just about everything Mom owned after she moved into a shared room at the nursing home. I cried and cried, and then I stored what was left of her most prized possessions. Later I gave everything to her two granddaughters. It was painful to get rid of my mom’s personal belongings, especially her clothes; it felt as if she were already dead.

Though this period was one of the most painful in my life, it was also filled with great learning. It allowed me time to heal the things that can come between mother and daughter. Even more wonderful was the experience of total unconditional love that I saw in my mom’s eyes every time I walked through her door in that nursing home. After years of criticizing me, she stopped, and everything I did was just fine.

My experiences of being a solitary, long-distance caregiver, contrasted with my membership in the first Share The Care group, fuel my passion to teach this powerful model of caregiving, and remind caregivers of an important lesson:

*Keep your own life in good working order.*

## Learn to share everything.

One chilly, windy night in March 1988, a group of 12 of us got together following a call from our mutual friend Susan, a divorced, working mom suffering from a rare cancer. Most of us didn’t know one another. Little did we suspect we’d end up pioneering a caregiving system that has impacted the lives of patients, caregivers, and concerned friends around the world.

Our meeting was profound on many levels, and I remember it as if it happened yesterday. At the suggestion of her therapist, Susan had finally reached out to her friends for help. Though we had been aware of her first bout with cancer four years earlier, most of us had no idea that it had continued to plague her through several more surgeries and radiation treatments. She had kept it a secret from

nearly all of us, and she had sworn me to secrecy as well.

That evening each of us arrived in some kind of an emotional state: shock, fear, distress, anxiety, skepticism, or concern, to name a few. As the evening unfolded, the mood began to change dramatically. First Susan spoke about her illness and her fears about the future. She could lose her job, she might not be able to walk. She cried. We cried. Then we all took turns, introducing ourselves, explaining how we knew Susan and what we did for



*Susan’s Funny Family, the first STC group (1991)*

a living. One thing we had in common was our resolve to be there for Susan and her young teenage daughters, no matter what happened. We just needed to figure out how. That night this little group gave birth to one of the key components of Share The Care: the Rotating Captains System.

We made it simple: Two people (captains of the week) would contact Susan to learn her needs for the coming week. (That way she NEVER had to ask for help.) The captains would call the others to fill the jobs and make a schedule so Susan would know who was coming when, to do what, and for how long. Since everyone had very diverse occupations, responsibilities, and available time, we decided on two captains so, in case something came up for one, the whole system would stay on track through the efforts of the other. Then the following week another set of captains would rotate in. With 12 people we had six captains teams. That meant each of us was a captain only once every six weeks. This felt doable.

We started the very next day, and for the next three and a half years, we kept things on track, doing everything from cooking, cleaning, laundry, and going to doctors appointments, to more unusual

jobs: taking Susan for weekly visits to an Indian healer, getting her set up in an apartment, and providing the needed companionship for several months at an alternative cancer clinic in the Bahamas, to our most memorable achievement—organizing her younger daughter’s wedding. By this time we were widely known as Susan’s Funny Family.

We lost Susan in late 1991, and after an emotional closing meeting, we all returned to our lives, knowing we had given our best. One afternoon we got a call from Francine, a woman Susan had met at CancerCare. Like Susan, Francine was divorced with a young daughter and an elderly mother. She was scheduled for a bone marrow transplant that would require intensive care during recovery, and she knew her family would not be able to cope. However she had 20 friends who wanted to help, and she asked for advice on creating a “funny family.”

Cappy and I rallied Susan’s group for a meeting to teach Francine’s friends what we had done, how we had done it, and how much we had gained personally from our experience. We just didn’t expect what happened next.

As her friends arrived it was like déjà vu—we saw ourselves in our first meeting back in 1988. Her friends (both men and women) didn’t say a word, yet we could read their faces. They were scared, nervous, fearful, skeptical, and concerned. Throughout the evening, as we explained our systems and forms, we watched as they physically began to relax and imagine themselves as a team. What struck me was the LOVE in the room centered around Francine. It was like an aura...magnificent. I knew that night that we had to put it all down on paper so no one would ever have to reinvent the wheel.

Cappy and I worked every spare minute to write our book. It was a real eye-opener to realize how smoothly our “funny family” had operated, especially during stressful times. For example, we had



held a second meeting when Susan's cancer had completely metastasized to her skeleton, causing her extreme pain and emotional havoc. She had become difficult to be with due to the high doses of morphine she was taking. At this second meeting we dealt with our feelings, readjusted how we were working together, and got back on track. We also made the conscious effort to support one another through these last months with Susan because, at that point, we were way beyond being strangers...we were truly sisters.

*Sharing the responsibility is the key to not burning out.*

## Never say never.

For the first Share The Care meeting, we were given an exercise by Susan's therapist, Dr. Sukie Miller, who was also in attendance. She asked the question: *What do you think you will get out of helping Susan?* It's a critical element of Share The Care because the care recipient can hear how each individual can benefit from being part of the group. I felt put on the spot and insisted, "I'm here to help Susan, not to get something for myself." Although I put up a lot of resistance, Dr. Miller asked me to "just make up something," and I have absolutely no recollection of what I said.

I do, however, remember what I shared at Francine's meeting when it was my turn to say what I had gotten out of being a part of Susan's Funny Family. I told them I had learned how to be a better caregiver. I had learned to take care of myself and to share the workload. I was not only able to help care for Susan, but I could continue as my mother's advocate (in the nursing home), go back to working full time in advertising, and have a social life. Imagine that!

Now, nearly 25 years later, I'm still a living example of what you can get from a Share The Care experience. It has become for me so much more profound than I ever could have imagined.

Working with caregivers, patients, and professionals was never in my plans. Who knew I would end up co-authoring a book and starting an organization? All my experiences have made going to work in the morning both a gift and a privilege. I am blessed to hear the many, many stories of how Share The Care has made a difference in peoples' lives.

*It won't work unless everyone gains something personally.*

## Having boundaries

One of the free-floaters (someone who can help out only occasionally) in the Share The Care group we convened for Cappy had very definite boundaries: She did not want to be the person responsible in the case of any medical emergency. It is important to respect individual boundaries.

Then, as fate would have it, just when this woman was visiting, Cappy experienced a seizure. She called me (as I was a captain that week), and I assured her that I was on my way and another member was already en route to start her shift. I asked only that she call 911. I arrived minutes later, the EMS and relief person got there as well, and we accompanied Cappy to the emergency room. It was a long night of waiting until morning when Cappy was admitted to the hospital for observation. Her full-time aide came to the hospital to relieve us and get Cappy situated.

## *Twelve women (mostly strangers to each other) came together to care for a mutual friend.*

I learned that my boundaries were pretty flimsy at the time, and I was impressed that someone had them and stood by them.

If you know you are uncomfortable about something or don't like doing it, make sure your boundaries are clear to the others in the group. At our first meetings, we provide an individual data form to collect contact information and offer each person the opportunity to rate themselves on specific jobs. When a new group is getting to know each other, it helps for the captains to know the skills, talents, and boundaries of the individuals in the group.

*Know your limits and stick to them.*

## We need each other.

The folks who settled this country (or any country) had to work together to survive and build a life. Routinely, people were present in each other's lives during times of birth, illness, and death to help in any ways they could. They pitched in to raise a barn or build a log cabin before the freeze of winter set in, or harvest a crop before the first frost. These events were also opportunities for people to socialize, celebrate, and remember their connectedness.

Today we need each other more than ever. We have to find our way back into that barn-raising mentality, albeit redefined for the 21st century. Our lives are filled with cell phones, televisions, computers, and iPads, Facebook, and Twitter. Yet technology, though connecting us, has also kept us further apart. We communicate in sound bites.

In times of great stress we need to come face-to-face and connect on a real-life, heart level. How can you tell in a tweet that someone needs a comforting word or hug? You need to be able to look your team mates in the eye. Being there for someone else and for each other is what Share The Care is all about.

In just a few short decades, the number of people over the age of 65 will double to over 77 million people. There will be fewer younger people to fill the role of caregiver for all those in need of help. Nor will the number of health professionals be sufficient to cope with everyone who is ill or disabled. And who knows what the state will be of healthcare, nursing homes, institutions, and government health-related programs in the year 2020, 2030, or 2050?

One way we can make a difference is by taking charge of our own needs and not waiting for the government to fix the problem. If we begin to volunteer routinely to be part of a Share The Care group for someone we know, then we can and will accomplish great things. By example we can instill a deep sense of compassion back into our society.

Share The Care has been passed along over the years by word of mouth and by people who have experienced being in a group. Some of these individuals have gone on to help others start groups. It doesn't get any better than that!

It is not uncommon to find a special, unexplainable energy surrounding a Share The Care group. There is something about doing good together that attracts others people who want to pitch in, even if they don't know the care recipient. Men, women, children, teens, the elderly, and even those with their own health problems—all have something they can contribute. Find a way to make it possible for them to do so. There are ways we can all make this a better world.

*Trust the group; support each other.*



## Life and death

Over 20 years ago, for some reason, I was asked to draw a picture of how I envisioned my own death. What I drew was a crayon sketch of me holding someone's hand (I don't know whose) as we looked at my tombstone.

I guess the hand-holding went back to when I was four years old and going to the dentist. I could put up with anything as long as one of my parents was there to hold my hand. That connection provided the courage I needed to feel that everything would be okay.

When Cappy was dying, I thought I could help her with her transition and “hold her hand.” But she wasn't interested in hand-holding, talking, praying, meditating, or even thinking about dying. She wanted to think only about *living*. No matter that she was unable to speak, walk, or even move her body without the help of a few of us armed with a draw sheet. Every day, rain or shine, she got someone in her group—known as Cappy's Brain Trust—to take her out to the movies or a museum, to a restaurant for a meal, and even to her beloved summer house in Fair Harbor on Fire Island. Her final journey to the beach required an hour's trip via ambulette, then a 25-minute ride on the ferry, followed by a rickety journey in her wheelchair, high on the wooden boardwalks. (There are no roads or cars on the island.) It took seven of us to transport the huge array of food, clothes, medical equipment, and various entertainment paraphernalia for that weekend at the beach. It was her most cherished place on earth.

The 10—often frightening and grueling—months while helping Cappy were yet another big lesson for me personally. Each of us will have his or her own way of approaching death and letting go. Though I'm not sure how I will actually be at the time I stand on that threshold, my experiences with dying friends have opened my eyes to the fact that we do have a choice.

No matter what any of the 33 friends and family in Cappy's Brain Trust thought, Cappy did exactly what she wanted to

do. She died on a beautiful, sunny, warm October morning when the aide, hospice nurse, and her friends just happened to be out of the room.

Ironically, her dad, Carmen, who had been diagnosed with the very same condition at the very same time (an

advanced glioblastoma) had passed just 12 hours earlier the previous night. To this day, I swear he made the transition first so that he could be there for Cappy. He just may have been the one she needed to “hold her hand.”

*There's no one right way to do it.*

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## The Seven Principles<sup>©</sup> for Group Caregivers

During the first (scripted) Share The Care meeting, there is an exercise in which everyone in the room draws a folded index card from a bowl. Each card contains one of the Seven Principles. (Some of the principles are repeated more than once.) After choosing a card, each person reads it to the other members and is responsible for reminding them of the principle, should they forget it.

### Principle #1: Sharing responsibility is the key to not burning out.

- No one person has to be in charge all the time.
- No one person has to deal with every crisis.
- No one person has to be on call every single day.
- No one person has to make all the decisions, all the time.
- No one person has to try to run his or her own life plus the entire, complex life of his or her loved one.
- Let the others do their share. They want to. They need to.

### Principle #2: It won't work unless everyone gains something personally.

- Recognize the importance of personal rewards.
- The patient will feel too guilty unless you gain something too.

### Principle #3: Know your limits and stick to them.

- Whatever you can do to help is enough.
- If you can't or don't want to do something, don't. (Someone else is probably good at it, or loves to do it.)

### Principle #4: There's no one right way to do it.

- If there are ten members, there will be ten ways to do it.
- It's okay to disagree.
- Agree on basics, then follow the rules. You may learn some amazing things.

### Principle #5: Anyone who wants to help should be encouraged to do so.

- A minimum of eight is needed, but ten is better.
- If main caregivers are “real” family, they must be willing to broaden the circle.
- Free-floaters (people who can help only occasionally) are important to include.

### Principle #6: Trust the group; support each other.

- The group has power.
- Someone has the talent or the answer.
- Go on vacation. The others are there.
- Share your feelings; share the goal.
- Spend time together; acknowledge each other.

### Principle #7: Keep your own life in good working order.

- Take care of yourself or you won't be able to take care of the patient.
- Exercise, rest, stay in “life.”
- Lighten the rest of your load.
- Don't forget about your own family and friends.
- Let your friends, your boss, and your own family know what you are doing.



Sheila Warnock and Cappy Capossela, *Share The Care: How to Organize a Group to Care for Someone Who Is Seriously Ill*, 1995 and 2004, Simon and Schuster's imprint, Fireside Books.



## RIPPLING THROUGH THE ISLANDS:

# Kauai's Share The Care Model *by Deborah Duda*

Melia Miracle, a beautiful 20-year-old, suffered brain asphyxiation from a drug overdose. Although she understands everything that's said, she can't speak. When asked, she moves her limbs only slightly, with great effort. Her mother Espi, short for Esperanza de la Luz (hope of the light), was driving 80 miles roundtrip to visit her daughter in a nursing home and was exhausted.

The first day Espi met her Share The Care (STC) family and understood that we wanted to help her, free of charge, tears ran down her face. Melia's extended family has now grown from six to 14. On a volunteer's recommendation, she was moved to a rehab center 20 miles closer to home. Besides doing range-of-motion exercises taught them by her physical therapist, volunteers read to Melia, laugh with her, and play music. Two acupuncturists have also been recruited to treat her.

Although progress is slow, Melia now laughs a lot. Espi no longer feels like an island alone, caring for her daughter in a world going about business as usual. In Espi's own words: "Before Share The Care became part of our journey, I was left with the full weight and responsibility of my daughter's unfortunate reality. I felt defeated mentally. Although I was holding up pretty well, I knew sooner or later exhaustion would take its toll. God answered my prayers when Deborah Duda and the other wonderful STC volunteers met me that first day at the nursing home. It seemed too good to be true, but it wasn't. They have made this experience so much better for me and my family. My daughter is truly happy and has a wonderful sense of peace because of their thoughtfulness and amazing hearts. They are a tremendous resource."

## TAKING CARE OF OUR OWN

My mom was sort of a female Will Rogers, quite ordinary and extraordinary. She might easily have echoed Rogers' words,



"I never met a man I didn't like." I never met anyone who didn't like Mom. In simpler times, before women divided themselves between home and career, she devoted herself entirely to family and friends' happiness and well-being.

## *I didn't want other daughters and families to have to make painful choices alone.*

By her early 80s, Mom had advanced Parkinson's with some dementia. She handled her limitations with her customary grace, a blend of humor and stoicism. Often, I took Mom, wearing huge sunglasses, out to her favorite restaurant. A number of times, as I was pushing her wheelchair, someone said to her, "You look like Greta Garbo." Once she replied, "No. Greta Garbage." That nickname and her sense of humor stuck in my heart.

At one time in our family's caregiving saga, Mom came to live with me in Hawaii. By then she needed round-the-clock care. I did my best with the help of an aide, Shirley, who was on duty four hours a day, four days a week. Although caring for Mom was usually a joy, I was

not able to sleep through the night because she needed attention. After six months of sleep deprivation, my energy reserve was wearing thin.

One day, while I was holding her up from behind to help her down the stairs to her wheelchair, the thought crossed my mind, *If I just pushed her, I could sleep tonight.* In that moment, I got it that I was in over my head. I wasn't good, like many of us, at asking for help. A week later, Mom was in a nursing home in Texas. If I'd known then about Share The Care's group caring model, it would have been easy to form a caring team for her with the help of my friends.

One day 15 years later, when the fourth edition of my book *Coming Home: A Practical and Compassionate Guide to Caring for a Dying Loved One* was released, I was surfing the Internet to find caregiving groups that might benefit from knowing about my book. I clicked on a site called ShareTheCaregiving. While reading about Sheila Warnock, the founder, something clicked. I wrote her, she wrote me, we exchanged books, and a friendship began.

As I learned more about Sheila's work, I thought, "We need this group caring model on Kauai." In the Hawaiian and Asian cultures there is a strong respect for elders. Nevertheless, families caring for loved ones who need extra help are pretty much on their own, unless they have deep pockets. Assisted living and nursing homes cost between \$5000 and \$10,000 a month. Most of our residents can't afford them and want to stay at home anyway.

One day I was sitting at a sidewalk table outside a Mexican restaurant eating fish tacos with two friends: Lori Miller, executive director of Kauai Hospice, and Bodhi Be, a Sufi sheikh and death and dying educator from Maui. We were talking about stress on families caused by caregiving. Bodhi was already facilitating caring teams for friends on Maui. I told Lori and Bodhi about Sheila's work.

I knew she was going to be speaking soon at the 2011 American Conference on Aging in San Francisco and asked what Lori and Bodhi thought of inviting her to Kauai and Maui. They agreed it seemed like a great idea.

Lori wrote a grant and in September 2011, Sheila came to Kauai and gave an inspiring STC presentation. Afterwards, she and I both gave presentations on Maui. The next step was figuring out how to get her back to Kauai to train those interested in her group caring model. Lori wrote another grant, and in February 2012, 55 Kauaians, from a multitude of interests and occupations, were inspired by Sheila's training.

After that initial training, Lori, Jim Jennings (a hospice pastoral counselor), and I gathered to brainstorm about how to adopt and adapt the STC model to our island. We set our intention to not only work to prevent caregiver burnout, but also to deepen a sense of community among our residents. We formed a steering committee and divided our island into six regions, each with a coordinator. I volunteered to serve as overall coordinator. To prevent wearing ourselves out with drives of 40 to 60 miles to Lihue, our most central location, and to keep the project as simple as possible, we decided to meet only once a month. We'd communicate as much as possible by phone, e-mail, and newsletter. We deeply believed, and still believe, that if we each do a little, we can help a lot.

Well aware that government was not going help us and that we had to care for our own, we set about community development. We educated residents about STC and let them know that we were available to support caregivers. We enlisted referrals and recruited more volunteers. We exhibited at community health fairs. We briefed our county council and mayor, who both endorsed STC as one solution to the challenge of helping caregivers. We donated two copies of Sheila's book to each of our six libraries. I gave STC presentations to any group who'd have me: Rotary and Lions Clubs, neighborhood associations, the office of elderly affairs, the AARP board, senior centers, social clubs, and social workers from local hospitals. Our local newspapers and radio stations supported our efforts by doing interviews.

As we did the hard work of community organizing, I thought of my mom. I didn't

want other daughters and families to have to make painful choices alone about their loved one's care.

In implementing STC, we suspected (and were later proved correct) that:

- Many of our island caregivers don't have family, friends, etc., to organize into caring teams. We would need to create *hanai*, or extended families.
- We would meet resistance, even if the help was free of charge.
- On Kauai, many people have only one or two caregivers who are holding jobs as well as caregiving.

***[A]n already exhausted caregiver would not have to organize the caring group: We'd do it.***

So, we adopted Sheila's model, which focused on families with sufficient people and resources to organize into a caring team. Clearly, we were going to have to create extended families using volunteers.

In addressing resistance, we explained that an already exhausted caregiver would not have to organize the caring group: We'd do it. To address concerns about privacy—fear of their home being overrun with strangers—we explained that caregivers have only to call one person, a rotating team captain, about their needs or schedule changes.

In addressing psychological resistance to receiving help, we often repeated, "It takes a village to raise a child and a village to care for a loved one who needs extra help." We talked about the circle of compassion—giving and receiving. Many of us are skilled givers, yet not so skillful as receivers. When giving, we feel in control; when receiving, we feel vulnerable. We emphasized that in allowing ourselves to receive, we are giving others the gift of giving—joy.

In talking with caregivers about cultural beliefs underlying the resistance to receiving, I might say, "Sometimes for the wellbeing of a loved one, we may want to adjust our beliefs." Then I might add, "Would you prefer to receive care from someone who is relaxed and happy or someone exhausted, cranky, and irritable? If you, as a caregiver, are feeling good, you are likely to create beautiful memories for your family of this time in your lives of loving and caring."

STC receives referrals from individuals, medical professionals, hospital and hospice social workers, and our office of elderly care caseworkers. As STC continues on Kauai, we are challenged to juggle referrals and volunteers to meet families' needs. It's an ongoing adventure because each family has its own unique culture. Creative solutions are needed to reach out and build community.

STC has been adopted and adapted by a variety of Kauai groups. An Episcopal church has asked us to join them in brainstorming how they could adapt the STC model to their church's outreach program. A pastor who works at our island correctional facility plans to

create caring teams for newly released inmates. Betty Moore, residence board president, and Pat Simpson, already an STC volunteer extraordinaire, decided to organize their 180 residents at Sun Village, an apartment complex for people over 55. After being briefed on STC, they are dividing each building of the three-building complex into teams. Each floor of each building will have a captain to keep abreast of residents' needs. Pat is doing a door-to-door survey of residents' needs and what assistance they can share.

The STC pebble that Kauai has tossed into the pond is rippling out to the shores of the other Hawaiian islands. Recently, I was invited to give a presentation on STC to the Bereavement Network of Hawaii, a group representing 17 Honolulu non-profit organizations. We also shared the original grant proposal Lori wrote to bring Sheila to Kauai with the Veterans Administration hospice coordinator.

STC is a caregiving model that can be adapted by individuals and communities to meet their particular needs and cultures. Our compassionate and willing regional coordinators and volunteers make STC possible on Kauai. We're grateful to be part of this volunteer grassroots movement.



Deborah Duda is the author of *Coming Home: A Practical and Compassionate Guide to Caring for a Dying Loved One* and *Lighten Up: Seven Ways to Kick the Suffering Habit*. For more information visit [www.deborahduda.com](http://www.deborahduda.com).

# CAREGIVING GOES BOTH WAYS

BY KATE SEMERAD



The environment for caregiving isn't static. As an illness progresses or is prolonged, a greater energy output and percentage of the caregiver's time are required. While most caregivers are acutely aware of the increasing demands, most patients—who have slowly become used to having their needs met—become increasingly unaware of the demands their care places on their caregiver. As this gap in a couple's understanding of their reality widens, stress fractures begin to show in their relationship.

The patient, requiring more time and effort, often fails to be proportionately grateful. Meanwhile, the caregiver feels over-worked, under-appreciated, and more stressed. This is when someone needs to call, "Time out!"

A fundamental rule of spousal caregiving should be that "care" must go both ways. The recipient of care cannot be allowed to be either unaware of, or ungrateful for, the care he receives; the caregiver must receive recognition and gratitude for her services. Anything less than this basic understanding is unsustainable.

As my husband's needs began to require a greater portion of my time and attention, I slowly became aware that he was saying "thank you" less and less. This might seem like a small matter, but to me—at that time, I can guarantee you—it wasn't.

I would spend hours helping him get showered and dressed in the morning, worrying all of that time about the multitude of things on my own list that weren't getting done. Then, set for the day, he would leave the room without so much as a backward wave. When I finally realized I was being taken for granted, I was furious. I felt like the paid help, not a partner. Vowing to myself that this behavior had to change, I began to strategize.

*Care...should include making someone feel appreciated and loved.*

The first part of my strategy was to say, "You're welcome" after completing any caretaking task for him. At first this didn't seem to register. Then, after a few days of my "you're welcomes," he began to respond, "Thank you." Pretty soon he was saying thank you on his own. Even now, seven or eight years later, he frequently says thank you to me and to others who care for him.

The fact that caregiving in a relationship needs to go both ways should not be earth-shaking news; it's just common sense. Yet, when a partner falls ill, care seems to be defined as only what the well partner provides the ill partner. This understanding needs to change.

Care does not need to be defined as only putting on someone else's shirt or helping them brush their teeth. It should include making someone feel appreciated and loved. Care is also dealing with difficult situations with as much grace and humor as one can muster and not complaining when there is nothing that can be done to make a situation any better.

Spousal caregivers of ill partners must sacrifice a great deal to keep their vow of "...in sickness and in health." And the ill partner needs to recognize that the giving of care needs to go both ways and to show this in as many ways as possible.

*Kate Semerad lives in Washington, D.C. Her husband Roger was diagnosed with the chronic progressive form of multiple sclerosis in 1985. Their story of dealing with MS, as told in her blog, [www.keepingvows.com](http://www.keepingvows.com), speaks to the positive, transcending value that keeping our vows in the face of adversity has on our lives.*

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# Caregivers in the Workplace: Burdens, Challenges, and

by Jennifer Ballentine, MA

Marie remembers the phone call vividly. “I was about a week into a new job—the first office job I’d had after 15 years of contract work. When the cell phone rang, I jumped about a foot because it had never rung before. I’d only gotten it about a month earlier and the only people who had the number were my husband, my 13-year-old kid, and my mother.”

Marie’s mother, Ann, had been enrolled in home hospice care for about two months, with a diagnosis of COPD (chronic obstructive pulmonary disease). Her prognosis was uncertain; COPD progresses slowly but can be accelerated by acute “exacerbations,” secondary infections, or other complications. Ann had weathered one exacerbation since her enrollment in hospice, but was struggling with new medications that were causing confusion and prohibited her from driving.

Marie had been closely managing her mother’s care, in between launching her son into his second year in middle school, helping her husband with a start-up business, and working on the thesis which would complete the master’s degree she’d been pursuing for almost six years. She hadn’t intended to look for work in her new field until the degree was completed and her mother’s situation was more clear, but an opportunity had come her way that she felt she couldn’t pass up. The job was only half-time but could become full-time if she proved herself. To be sure her mother was secure and looked after during her working hours, Marie had hired a private duty care companion. Wendy’s wage pretty much consumed Marie’s paycheck, but it was worth the peace of mind. Which was why her heart sank when she opened the flip phone and saw her mother’s number on the caller ID.

“I was worried something had happened—that Wendy was calling to say Mom had had a fall or another exacerbation, but instead, I heard my mother’s voice—the one she always used

when she was mad or upset, the one that made me feel six years old again. She said, making each word distinct, ‘Wendy and I seem to have run out of things to do. Perhaps it’s time for her to go home now and for you to come over.’ It was awful—I couldn’t leave work for at least another couple of hours, my husband was meeting with potential clients, and Mom didn’t want him anyway. She was clearly unhappy and enough changed by the meds that I didn’t know how she would handle it. I didn’t know what to do.”

*The typical caregiver is just like Marie—a late-40s daughter who works outside the home, has a family, and provides care for her mother.*

This was the start of a six-month juggling act that ended only with Ann’s death. By that time, Marie had finished the master’s degree, but she had quit her dream job. Marie recalled, “It just wasn’t worth the stress of dreading the phone calls, hiring and firing the companions, dealing with Mom’s unhappiness on top of her illness and pain—I couldn’t put either of us through it.”

Four months after Ann’s death, Marie had major rotator cuff surgery on her right shoulder. “My physical therapist told me that the medieval herbalists and healers used to treat physical ailments by first figuring out what kind of ‘soul pain’ was being expressed. Any problem of the neck, shoulders, or back was likely caused by carrying too much emotional weight or stress. I don’t know if that’s true, but it sure felt right.”

## Caregiving in the United States

Marie’s story is true, and it is typical of the American caregiver. Our population is aging and more of us are experiencing—and ultimately dying from—chronic and progressive disease, often several diseases at a time. Currently, US nursing home residents suffer from a median of 6.2 concurrent chronic conditions, and many

elders still living in the community are struggling with physical, functional, and social challenges. An assessment of older adults conducted in 2010 in Colorado by the National Research Center found that 59% had problems with health, and 31% needed assistance in performing everyday tasks such as dressing, bathing, cooking, shopping, and getting around.

In 2009 almost 66 million people provided care at some point during the year for another adult—that’s about one third of the total adult population—for an average of 20 hours per week. The typical caregiver is just like Marie—a late-40s daughter who works outside the home, has a family, and provides care for her mother. Sixty percent of caregivers providing intense care for a family member or loved one are women, which means 40% are men. Male caregivers are additionally burdened by lack of support for their role as caregiver, weaker social support systems, and reluctance to seek help.

## The Economic Impact of Caregiving

Marie is somewhat atypical, however, in that she was able to quit her job without major economic disruption to her household. She continued with her contract work, which allowed her more flexibility in scheduling and time to be with her mother during most of the day. An estimated 60% of adult caregivers are employed part- or full-time, increasing the strain on all parties, and nearly one in four persons in any workplace is likely to be providing care for another adult. The burdens of caregiving on working adults have a significant impact on productivity, workplace relationships, career paths, and ultimately, the economic bottom line.

In 2009 the economic value of informal caregiving—that is, the amount of money that would be required to pay minimum wage for the hours provided by family and friends—was estimated at \$450 billion, up from \$350 billion in 2007,



# Solutions

a 20% increase in just two years. The \$450 billion value of caregiving in 2009 was gaining on the total of all Medicare spending in that year (\$509 billion), exceeded the total amount of Medicaid spending, and was *four times* the amount of Medicaid spending on long-term services and supports. It also exceeded the total sales of Walmart and the three largest publicly traded automobile companies *combined*. Conservatively applying the same rate of increase from 2009 to 2012, the economic value of caregiving this year could be at least \$585 billion, and is most likely to be more.

## Caregiving Burden in the Workplace

The direct cost to employers of the caregiving burden borne by employees is nearly \$36.6 billion, or \$2110 per employee. When surveyed about the impact of caregiving on their working lives, many respondents indicated that they had had to make adjustments to work schedules: 10% had reduced hours, 9% left their jobs, 6% left the workplace, 3% opted for early retirement. In addition to the immediate hardship of lost wages, these workers lost retirement benefits, health insurance, and social security benefits, adding up to hundreds of thousands of dollars lost over the course of a career.

The personal toll of the caregiving burden for those who stay on the job is equally huge, if less quantifiable. Stresses manifest in absenteeism, presenteeism (being at work physically but not mentally), interruptions, additional supervisory time, extra burden on other employees and teammates, hiring of temporary workers to pick up slack, unpaid leave, and the costs of replacing employees and training new recruits.

Another significant cost is in increased healthcare utilization for the caregivers: 60% of caregivers report negative health impacts, and 69% report feeling overwhelmed. Almost 40% report conflicts with other family members about the care recipient; 80% say that caring for an elderly parent has strained

their marriages; and 25% cite that strain in their divorce. A significant percentage of caregivers suffer from clinical depression (33% of caregivers for persons with Alzheimer's or other dementias; almost 40% of spouses of persons with advanced cancer), and studies indicate that even just a hospitalization—not necessarily a death—of an ill spouse raises the risk of death for the caregiving spouse.

Complicating these challenges is a perception on the part of many working caregivers that they cannot be candid with their employers, supervisors, or teammates for fear of being discriminated against in assignments, promotions, expectations, or compensation. Many will make elaborate efforts to conceal or avoid discussing their caregiving responsibilities, taking personal sick days or making excuses for early departures, late arrivals, errors, and inattention. And yet a recent study from the National Alliance for Caregiving and AARP found that most employers are sympathetic to caregiving demands—likely because many are struggling with the same demands as well!

## Workplace Responses to the Caregiving Burden

As long ago as the 1980s, employers began responding to the needs and burdens of caregivers in the workplace. In concert with the movement to make more accommodation for working parents, employers recognized that other family challenges required support. Early responses included flex time; job sharing; telecommuting; referrals to outside services and resources; employer-funded long-term care insurance; on-site or contract geriatric care managers; discounted in-home or respite care; wellness programs addressing stress reduction and bereavement support; even on-site adult day care. The 1993 passage of the Family and Medical Leave Act allowed eligible workers up to 12 weeks per year in unpaid leave for family caregiving—whether of a new baby, ill

spouse, or dying parent—while retaining job security and benefits (a big step in the right direction, to be sure, except for the unpaid part). By 1997, at least a quarter of all employers offered at least referrals and resource services, while only the largest and most progressive companies provided the more elaborate benefits.

Some of these early efforts were frustrated by lack of use; perhaps some of the offerings were just a bit ahead of their time. In the past five years of economic downturn, even the few companies that offered the most robust benefits have scaled back or eliminated programs, just when expansion and innovation in eldercare services are most sorely needed. In 2011, only 9% of companies even



offered referrals and resources, and less than 2% offered any care service backup.

In March 2012, the National Alliance for Caregiving issued a report outlining best practices for eldercare support in the workplace, including familiar suggestions such as paid time off specifically for caregivers, flexible scheduling, and access to geriatric care managers and consultants. However, the report stressed the importance of tailoring offerings to the specific needs of the particular workplace population by use of needs assessments, follow-up satisfaction surveys, and evidence-based support programs. It also emphasized the importance of “equitable, accessible services and programs that respect privacy, are mission-driven, provided by competent, qualified and trained professionals.” In other words, support programs should not be just an informal “casserole brigade,” but validated and expertly delivered interventions.

### **Creating a Culture of Caring in the Workplace**

The ability of employers to respond effectively to the crushing personal and economic burdens of caregiving is unfortunately compromised by the current economic climate. “Luxuries” of additional benefits like job sharing and flexible scheduling, let alone onsite care managers or adult daycare, are outside the reach of even the best-intentioned business owners. However, many also recognize the longer term value of retaining effective workers and maintaining their mental and physical health through supportive programs. This need not require offering expensive perks; the first step is to create a culture of caring in the workplace.

#### **A culture of caring includes:**

- An attitude of support for caregiving challenges, communicated through HR policies and supervisors, such as:
1. Explicit discussion by supervisors about their openness to working with employees to meet caregiving challenges should they arise.

2. Explicit mention of caregiving for adult family members as an appropriate use of FMLA leave or other time off.
3. If possible, flex time, job-sharing, and telecommuting options.
4. Paid time off rather than “sick days” to allow employees to use time off/vacation as they need, without creating fictions about personal illness.

### ***In 2009 the economic value of informal caregiving...was estimated at \$450 billion.***

- Leadership training to foster an attitude of respect for personal challenges of all kinds, including caregiving.
1. Acknowledgement that employees have commitments outside the workplace that may impinge on work responsibilities.
  2. Developing solutions to conflicts between work and home without explicitly or implicitly penalizing the employee.
- An emphasis on wellness and self-care, including stress management and coping.
  - A safe forum in which employees can share their burdens and gain from colleagues’ past experience or wisdom (e.g., Caregiver’s Lunch Club; facilitated support group).
  - A robust library of resources and information on available community services, such as geriatric care managers, patient navigators, in-home care providers, etc.; if possible a subsidy option in which the employer pays a portion of the cost for paid support.
  - Education for caregivers on coping skills, practical techniques, emotional support, and care management and communal care sharing.

Exploring and explaining each of these items in detail exceeds the scope of this article, but the list should offer employers

some concrete tools with which to support their caregiving employees. A good 25% of any workforce is struggling with these challenges right now or will be soon. At the very least, communicating that it’s okay to acknowledge and share caregiving burdens and providing emotional and some practical support will go a long way toward maintaining a healthier, more productive workplace and ensuring better care for the elderly and ill among workers’ families.

As hard as the six months of her mother’s final illness was, Marie knows she was lucky. Her family was not dependent on her job, her mother’s illness was relatively brief, and—as it turned out—her employer was sympathetic and offered her another opportunity after her mother’s death. Many caregivers are not so lucky.

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# What Makes a Full Life?

by Bodhi Be

After 20 years of teaching, it has become clear to me that asking a good question—helping people to ask themselves good questions, helping them turn a good question into a better question—turns out to be much more valuable than me giving a good answer to someone’s good question. My answer will be an answer for me, coming from my life experiences, insights, understandings, and guidance. It may not be your answer. Living with a good question, finding an even better question, pulls one forward with direction and intention. What is your intention that provides you the motivation to live forwards?

This notion of a “full life” shows itself sharply when a child dies and someone is heard to say, “How sad, he/she didn’t get to live a full life.” Where does this conclusion come from? Maybe it comes from an underlying sense of entitlement, that we, as modern folk, are entitled to at least 75 to 80 years of life, and if we fall short of that, we haven’t lived a full life.

This is not at all to diminish how difficult it can be when a child dies. Of all deaths, the death of one’s child, especially a sudden, unexpected death, can be the most difficult and painful of all, and asks for deep grieving.

So then, what exactly is a “full life”? Are you living a full life now? Would your children think they were living a full life? Would they even be able to make sense of the concept or question? What would a full life look like? Could someone dying at the age of seven, for example, have lived a full life? If we step back, to the view of souls and incarnations, how can we know how much time a soul needs in a new incarnation?

In my work as an ordained interfaith minister in the Sufi lineage of Hazrat Inayat Khan and Sam Lewis, and as a funeral director and hospice volunteer, as well as a parent and grandparent, some things have become quite clear:

A whole life, a full life, includes its death. And too, there is no death.

We are all the Buddha, Jesus, Pure Awareness, Holy Spirit, The Infinite Radiant Is, or whatever name you give to that which is beyond all names.

It is true, there is nothing we need to do.

Look around in the natural world where life and death dance together entwined, death feeding life, continuously. We will all die from the same thing, the failure to inhale.

## *[A]voidance of our approaching death can only lead to “life-phobia.”*

To love your life fully, you must love its end, its death. You will die and you don’t know when. Everyone you know will die, your relationships will end, your career will end, your friendships. Most of us think we will die in the distant future. We might think, “I’ll just deal with it when I get there.” Most everyone who will die today had no idea that yesterday was the last day of life.

How you use this information will determine your ability to live fully, whole-heartedly, and in a sacred manner. Starting now. It may be the most powerful spiritual transformation tool you’ll find. To live otherwise is to live with a “hole” rather than “whole.” To live in aversion, denial, and avoidance of our approaching death can only lead to “life-phobia,” the inability and unwillingness to be fully alive. To be fully alive requires an honest and living relationship to our approaching death.

Try it on. Breathing in: “Death is inevitable.” Breathing out: “I too will die.” See what happens to your breathing, your thoughts. See if some version of spiritual override kicks in as a form of denial and avoidance. And too, some of the denial is knowing we don’t die.

We do and we don’t, and the realization and embodiment of these two seemingly opposites changes everything. Denying either truth is to deny the human experience of sorrow and joy, or to

deny something larger and greater than ourselves and this one life.

There is more that makes this “hole.” Many of us have changed our residence a number of times or have never felt grounded enough to feel at home in our bodies or on this earth; consequently many of us feel homeless. Witness how we often relate to nature and the environment as “out there,” how often we feel separate and alone. Too, many of us have lost any real connection to our ancestors; witness how when someone close dies, we often say, I lost so and so. How did we lose them?

Sufis speak of our primary and secondary wounds. The secondary wound, for many of us, is not being good enough, or not being seen or heard, or having shame and self-guilt and self-judgment. Too often, at the bedside of the dying, I see that people wish deeply to be forgiven. The largest part of the hole is often caused by the primary wound, our disconnect from the holy. This leaves many of us as orphans and homeless, craving something we often call “community.”

This hole in our being-ness leaves us desperately hungry and needy. Without acknowledging this hole, we will continue to “consume the earth,” being hard on the people around us and all other life, even while we are all recycling and driving electric cars.

My experience, understanding, and insight confirm this is so. Acknowledging and befriending the hole is an important step towards wholeness, and to what shows up as full life. May you live a deep and holy, whole life filled with service to all, and may you die on a good day.

*Bodhi Be is a teacher and guide in Sufi Ruhaniat International, the executive director of Doorway into Light ([www.doorwayintolight.com](http://www.doorwayintolight.com)), and the founder and president of TheDeathStore. He is an independent funeral director, coffin maker, crematory apprentice, off-the-grid organic homesteader, and end-of-life and bereavement counselor based in Hawaii.*



## Video Review

### Dying into Love

Reviewed by Lee Webster

“We all die of the same thing: failure to inhale.”

So begins this dynamic, sobering, and often profound collection of teaching moments, introduced by Bodhi Be and filmed during an all-day retreat workshop in Maui. The series of video segments, available online, features pioneers in the exploration of death, including Ram Dass, Joan Halifax, Dale Borglum, and Bodhi Be, with an ever-present nod of gratitude to Stephen Levine. Guided meditations are interspersed with the teachings of various spiritual traditions and the enlightened writings of poets and sages to allow each participant to approach the difficult and rewarding work of conscious dying from a variety of angles and purposes. In a beautifully choreographed presentation, the principle speakers weave personal and universal discoveries to overcome fear in order to experience the human needs and spiritual awakenings that are present in the transition called death.

The full day’s workshop is organized in easily digestible, distinctive sections that are seamless when taken in order and well-labeled when looking for specific subjects. As a whole, the video segments represent a cohesive pattern of inquiry and wisdom, spanning both philosophical thought and down-to-earth concerns for ourselves and for our loved ones.

What are our greatest fears? According to Bodhi Be, they are the fear of losing control (usually physical) and the fear of being a burden. He says people are more afraid of pain and suffering than of death itself. How can we, he asks, have robbed ourselves of the opportunity for meaningful connection by allowing businesses and institutions to take over the essential community-building acts of caring for our elders, in life and after death? Despite their highly individualized views on the subject, each panelist is dedicated to assisting others in their heartfelt search for answers to this and other questions about death.

Borglum describes his work with the Living/Dying Project as an opportunity for his own heart to open, to experience compassion with all of its healing power. To sit with the dying, he says, “calls out the best in me.” He revels in those moments when dying people he is attending are, at last, the persons they truly are, not the persons they may have thought they were.

This connection by caregivers to authenticity, to embracing whatever is necessary to be fully present, and to the willingness to make room for true compassion is what creates space and energy for awakening, the major theme each speaker returns to time and again. As Ram Dass says, “There are dying people and there are caregivers to the dying, and they are both engaged in the same work: the work of waking up.”



*Joan Halifax and Ram Dass*

And waking up sometimes requires the help of some not-so-subtle hints. Caregivers often experience burnout, a serious, debilitating fatigue that interferes with the ability to be present in any capacity. All of us are susceptible to wounds when being with the dying, and our challenge is to offer healing and also find it for ourselves. Borglum says we have three reactions when suffering arises: We try to push it away, we try to identify and share it, or we empty our hearts to increase our capacity for compassion.

The panelists also tackle the complexities of the nature of grief: Is grief simply a negative reaction to loss or separation? Or is it a reaction to all the little changes in our lives that prepare us for the larger void? Grief, they agree, can and should be a heart-opening experience, not the impetus to shut down and withdraw.

How can we learn to work with suffering in a compassionate, fulfilling way? Will leading a mindful life prepare us to die a good death? How can we learn to fully live and die into the next breath that may be our last? For anyone searching for either a way to be with the dying or a way to be with oneself in the face of death, the questions being asked here both inform and nurture the asker, while the answers proffered by these luminaries nudge us that much closer to understanding and acceptance.

Video: [www.dyingintolove.com](http://www.dyingintolove.com)  
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## “The Hardest Thing”: Hospice in China

by Lyn Gould, founder, Butterfly Children’s Hospices

People ask me how I can work with dying children in China. They say they couldn’t do it because they would just cry all the time. But I can’t *not* do it.

There is no free health service in China, and health insurance is not universally available or affordable. Even if a child needs surgery to help him or her live, if the family can’t pay for it, it won’t be done. To give that child any kind of care, even if it’s available or life-saving, costs more than most people have. For many, abandonment is the only hope that their child will get the medical attention needed.

We set out to build a model of palliative care for children that could work in China. The Chinese are superstitious, and some consider it bad luck to have a very ill child. Parents are thought to be cursed, and by mixing with them, the curse might be passed on.

As in many developing countries, there is no palliative care here. Projects like Butterfly Children’s Hospices usually start with individuals who have the vision and form a charity to fund the service. It will take many years for palliative care to become an accepted part of their culture.

And yet, this is my childhood dream. My mum took me to see the film, *The Inn of the Sixth Happiness*, the story of Gladys Aylwood, an English missionary to China who rescued children. Even when I was eight years old—I am now 63—I was inspired and thought, “One day I will go to China and look after children.”

Although China was closed when I was a child and not much news was reaching the West, I was fascinated with the country. I grew up, got married, and had three children, but the fascination never went away. When I was 45 and my children were grown, I was working as a nurse at the Royal Devon and Exeter Hospital in the southwest of

England. I decided to go to China as part of a team to work in orphanages for three weeks.

That was 1994 and I remember clearly walking across the border from Hong Kong into China and thinking, “This is my dream come true.” Actually it was more like a nightmare. I’d grown up in Exeter and, although my parents weren’t wealthy, we also weren’t poor. What I saw in China was complete poverty. I was very culture shocked.

But I returned every year. My husband Alan and I realized that if we were going to make a difference, we’d have to live there. So we sold our house. I took early retirement in 2004, and we moved to Changsha in Hunan province in 2006.

As a first step, we set up a children’s hospice in an orphanage, working within the established system. A lot of NGOs

(non-governmental organizations) who work outside the system have lovely children’s homes. They take in orphans, fix them up, and get them adopted—which is fantastic—but we wanted to help the kids who were being left behind or left to die in terrible circumstances.

In 2010 we established the Butterfly Home. Since then we’ve cared for 48 children, of which 29 have died and seven have had life-changing surgery. We’ve also arranged four adoptions—remember these were all children who were dying—and another seven are awaiting adoption, two of whom have been matched to families and their papers are being prepared.

That first home opened two years ago. It seems like a lifetime, but in some ways only yesterday. We celebrated our second anniversary here at the original Butterfly Home and were delighted to hang up

a beautiful painting created especially for the occasion by two of our Chinese volunteers. The picture includes 40 butterflies, each depicting one of the 40 children we have cared for here since we opened, although since then we have taken in another eight. Paper “wish flowers” were filled with memories, hopes, and blessings and attached to the picture as well. This is our way of honoring the memories of all the children who have touched our hearts and of giving voice to those who work here or have visited, bringing with them their time, skills, and love.

When sweet, quiet Ysmael came to live with us, he had a small surgical incision on his stomach. It looked like he had had surgery in an attempt to repair his condition, but the surgery was unsuccessful. It’s impossible to imagine how his parents must have suffered as they realized that their beautiful son would not live long. They left their boy and he became an orphan. He was welcomed into the Butterfly



Home at age two months, in considerable pain, with his liver and spleen enlarged due to biliary atresia.

Although Ysmael was never to enjoy a long life, it was important that he enjoyed what he had and be made as comfortable as possible. He was never mobile, but enjoyed being carried, spending time outdoors, listening to music, and watching the antics of the other children as they played. On his last day he was “dancing” in his walker and enjoying his bottle of milk. After suffering a large hemorrhage, he died peacefully in a caregiver’s arms. He was 18 months old.

And while we are providing every dying child the love and care they need to die peacefully and free from pain, our greatest joy is that some of them get better and recover with proper medical care.

Born prematurely, Zoe was admitted weighing just 2.6 pounds. Her face was pinched, her skin was dry, and she was unable to maintain her body temperature because her nervous system was still maturing. Without specialized care, she would not have lived much longer. Zoe was in the cot named “Hope”—all our cots are named and are open for sponsorship. There was a small bassinet fitted inside the cot to make things a bit cozier, and the room was kept very quiet. Too much stimulation is not good for preemies until they are a little more ready for the world.

In only a short time her weight increased significantly. She is now drinking well and lets us know with a lusty cry when she is hungry. She is getting lots of cuddles, and is starting to come out of her quiet room for short periods. There is a sweet roundness to her little cheeks, and we can see that she is going to be a beauty. Prematurity brings a higher risk of problems with breathing, cerebral palsy, retinal issues, and multiple other conditions, so we will be watching Zoe’s progress carefully. Quite likely she will grow to be a healthy child. All she needed was a bit of extra care and some understanding of her needs.

The reality of the Butterfly Home is very different than my childhood dream. I don’t sleep well because I’m overtired



most of the time. In my sleeplessness, I lie in bed, staring at the ceiling, thinking this is the maddest thing I’ve ever done in my life. I question my ethics whenever we have to choose which child to help when we have an empty cot. Physically I’ve lost fitness. But it’s incredibly rewarding on a personal level to see a child’s face full of joy and life, even if that child isn’t going to live very long.

### *I question my ethics whenever we have to choose which child to help.*

One of our children—sweet, cheerful Annie—has captured the hearts of many around the world. She has cerebral palsy and when she arrived at the Butterfly Home as a baby, her back was arched so far backwards that her head was touching her feet. Now at age two she is a bright and charming part of our “family” who works so, so hard with us to develop her range of movement and communication skills.

Everyone who visits adores Annie. She so captured the heart of one of our supporters that he initiated a fundraiser to buy her a customized wheelchair. We are so grateful to Andy, the Hong Kong Scouts, and to all friends who have contributed to this gift. Now this unique and precious child can feel the joy of greeting her friends at eye level instead of always looking up. She has the ability to move within her environment instead of having to wait and hope that others will move towards her. Her body is supported in a comfortable and secure harness, and

the headrest gently keeps her head stable. She feels like the big girl that she is, no longer on the floor with the babies.

We are a very small organization and we always need more volunteers from around the world who can share whatever skills they have by raising funds, working on the website, or attracting publicity. Further we need a long-term Western-trained nurse who can commit for a year or more, so we can start training Chinese nurses. Then we will be able to expand our service into the community; a Western nurse going into the community will inevitably attract attention.

Cultural sensitivities make it difficult for Chinese people

to step forward willingly as volunteers—it cannot be underestimated how very different this country is from the United Kingdom or the United States. Recently, one volunteer, Emily, came to us from Australia for a month and wrote very movingly about what she experienced in her time with us. “It was cold, but my heart and life have now been forever warmed. Those dear orphans changed me. Yes, I applied my pediatric nursing skills, but I also played, laughed, cried, and hoped, and received far more than I could have ever given.

“I saw this ‘non medical’ prescription cause a baby’s eyes to come to life and choose to fight, to hope again for a future that was not bleak and dark. I saw love fill out a skinny baby’s face as he was fed by staring into his caregiver’s loving eyes.

“I saw love take a Butterfly to a world where there would be no more suffering. I saw love take him there pain-free, celebrated, counted, and adored. I saw love in those who have chosen to care for the ‘least of these’ because they have responded to their need.

“Coming from a cutting edge hospital of abundance in Australia, I can honestly say that the best medical care I gave at Butterfly was pure love. For me, the Butterflies and this special home showed me what true love is. It is pure, it is freely given, and it saves lives that were once forgotten.”



These strong words coming from a 26-year-old nurse brought tears to my eyes. What we take for granted as rights in developed countries can be very different in places like China. We often get angry and it's difficult not to be critical. I'll never ever understand it and I definitely will never accept that it's okay, and that's what makes me want to do something about it.

Yes, I cry every day. But when I see the results of the Butterfly Home, I hope we're sowing seeds of future change that will grow and benefit all the children in China, not just the few that we are able to touch now. We know we're doing the right thing. We won't live long enough to see a true shift happen, but we can make a start. There is a Greek proverb: "It is a wise man who plants a tree in the shade of which he knows he will never sit." That shade is what I hope to bring, eventually, for all the children and their families who need it.



kind of palliative care service for children with cancer.

Also, the directors of Butterfly Children's Hospices are supporting the development of three pediatric palliative care services in Xian, Nanjing, and Shanghai. These have been inspired by hospital doctors who recognize the need for this service and have asked us to assist and develop a model to fit their circumstances.

We are hoping to provide another six beds and three high-dependency cots by April 2013. We are investigating the possibility of opening a foster home for those children who have recovered sufficiently to be adopted, a place where they can make progress away from the sicker children. In the future, we plan to establish a community hospice service, where families will be welcomed and offered the resources they need to continue caring for their children. It is exciting to watch our work grow.

The exciting thing is how much publicity we've been allowed by the government. They've done documentaries on us, and as a result, about half of our income actually comes from within China. This means

our work has captured the hearts of the people, and that is what we want and need. For example, we are working with a pediatric oncologist and an orthopedic consultant in Shanghai Children's Hospital who want us to help them establish some

*Lyn Gould is the founder of the Butterfly Children's Hospices in China. To find out more and support Butterfly Children's Hospices, visit [www.butterflych.org](http://www.butterflych.org).*

## Redefining NORMAL

*from page 6*

outside the box. I found comfort in thinking up possible solutions or ways to emphasize the positive while watching the negatives gaining on us in the rearview mirror. When I felt I was limiting my thinking, I brainstormed with friends and co-workers for new ideas on how to do things.

When Bill became too weak to safely transfer himself in and out of his wheelchair, the frustration and disruption to all our lives escalated. Eventually he was unable to stay in the wheelchair for long periods of time, and we all knew then that we were at a breaking point. Stuck in the bedroom, Bill was missing out on too much daily life. He wanted us to come in and share what was happening, but it just wasn't working.

I made a bold move. When Bill returned from a hospital stay, I had his hospital bed

delivered into the family room. What's more "family" than Bill the husband, Bill the father? Since our kitchen was completely open to the family room, it also meant that Bill would be part of many daily and evening activities. He liked the psychological change of being in the center of activity. Although he was now more disabled, he felt less "sick." Stacy and I didn't need to make any more modifications to fix and eat dinner, work on homework, or constantly interrupt activities to visit with Bill. We were all sharing the time and space together.

Admittedly many friends and family experienced initial shock when they walked through the front door and saw Bill's bed right there in the center of everything, but over time it became our normal. As it became more normal for us, others also accepted that this was our life.

On many days my closest friend in this well-spouse journey is my journal because the feelings are just too raw and frightening to share with anyone else.

Hope sometimes seems impossible to find. There are other days, though, when kids come bursting through the front door as though nothing at all is wrong—and I find comfort in that. It's those times when a deep sense of accomplishment fills my heart. It doesn't erase the disease. It doesn't eliminate the fear. But it provides the motivation to continue to face the changes that go with chronic illness in the house.

There isn't one answer on how to cope, and there is certainly no magic solution to dealing with all the emotions, loss of dreams, and hurt. However, defining your own normal is a good place to start.

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# Dove: Releasing Me into the Now

by Shana Stanberry Parker, ScD

At age 38, I was a mother with a loving husband and living in the glory of Aspen, Colorado. My life was filled with grace. But as they say, “When the student is ready, the teacher appears,” and she was already in my life. A few days before my daughter Dove’s first birthday, on our way home from an idyllic Hawaiian vacation, we stopped at Children’s Hospital in Denver to consult a movement doctor about a peculiar curve in her spine.

The astute doctor called in a geneticist, who looked at Dove’s sweet round face and suspected something for which he did a urine test. Shortly thereafter, he came to us and told us the news. “Your daughter has a terminal genetic illness called Hurlers Disease. Children with this disease die between the ages of two and ten. I am sorry.”

The room began to fade as reality blurred like a watercolor on wet paper. In that first moment the whole of my small human self felt the truth of my naked powerlessness. My overwhelming impulse was to reject this truth and reject death itself. Instinct took over, and what arose was an attempt to cover up my helplessness. I could have knocked over the table with the magazines and the brass metal lamp. Or slammed my fist into the desk. In that moment of temporary madness, I even had the impulse to throw Dove’s little body across the room. I imagined it smashing into the wall. Instead I held on to her tighter than ever. And I would continue to hold on to her for the rest of her life, no matter who I had to become. I remember handing Dove to Dan and sobbing as I walked to the ladies room, the blackness and dread consuming me. I sank onto the toilet, certain that no spark of joy would ever enter my body again, feeling that grace was dead, and I wanted to be too. Head in my hands, I sat sobbing for a long, dark time.

Then a voice inside me asked: “Look and see if you’re okay.” And in response I discovered an intact sense of myself: the quality of breath below my breathing, an awareness of being, surrounded by emotion. I got up, walked back to Dove, and was amazed to feel a spark of joy at her smile. This was the first door into a

new house of many rooms, a house I now call the house of grace. For the next two years our lives became a kaleidoscope of researching, international networking, and searching and praying for a cure.

Despite her developmental delays, Dove was exquisitely happy. She drank in life and love. She knew no distinction between good and evil. I remember seeing her little nose pressed up against the TV screen to kiss Ursula, the evil sea witch in *The Little Mermaid*. I remember her gleeful dance to “Knees up, Mother Brown,” with her crooked little legs and high orthopedic shoes. The present moment was her whole world. I tried to live there with her. There was no future to plan for, so I was released into the now with no place to go but the present moment.

Because there was no future, there was no need to strive, to mold the clay of her personality, to teach her something that might be necessary for “getting somewhere.” No manners to be concerned about, no spelling, no tests. It was all success and it was all about the present moment: the glint of sun off her little, flat nose and the ecstatic look on her face when the horse who came to the fence took the carrot she held out. The success was being in our love, and she made that easy.

After Dove’s fourth birthday, when our family had grown to four with the arrival of our daughter, Bodhi, I noticed that I was no longer obsessively driven to find a cure for Dove’s illness or for my own pain, even as I saw her capacity to dance and walk diminish and noticed her vocabulary slipping away slowly, word by word. She was getting younger as Bodhi was getting older. At night we would look adoringly into one another’s eyes. I would sing and she would just say, “Love, love.”

Dove would fall asleep and I would fall into the blackness of despair, the well of pain, the waves of feeling abandoned, falling, falling, allowing, surrendering into the grief of this precious, time-limited touch—until I came to the center, the still point from which all feelings emerged, the space before form, where grace still lived and always does.

I remember Dove, sitting on her knees by Bodhi’s cradle, her little, curved, deformed fingers patting her new baby sister on the back with the gentleness of a feather landing on a silk pillow. She would coo softly “Becca, Becca,” as though this was her gift to us. She was welcoming the one she herself would leave behind. At only four years old, her young life was already half over. No one knew exactly when our Dove would take flight, and yet by some miracle we allowed life to be full with the joys of caretaking two little ones.

It was sometime during her fifth year when I noticed Dove was breathing poorly. We discovered her airway was becoming narrower due to sulfate deposits, and her head was filling with fluid. We chose to let the doctors put in a shunt and drain the fluid from her brain. An hour into the operation, a doctor on the team came out to the waiting room and said they could not take the anesthesia tube out without causing her death. He asked if we would okay a tracheotomy or should they let her go. It was not hard for us to decide: Dan and I wanted Dove to have the choice to go or stay a while longer. They put in the trache. Now she had no voice except in my mind and my heart. This was the entrance to the next room in the house of grace.

Our relationship was stripped to its pure essence. Because Dove had no defenses and no resistance to loving or being loved, my heart was in a constant state of openness, constantly giving and receiving love. Dove could no longer walk or stand, and I noticed her vision was failing. Our home was filled with kids’ music, and I often found myself singing and dancing around the house. Our home was also filled with activity, care providers, homebound schoolteachers, physical therapists, speech therapists, even a massage therapist. Dove had a full life in her own, sweet world. I deepened into the moments of serving Dove and loving Bodhi. This purpose infused every day and altered every aspect of my life for the next two and a half years.

On Friday morning, May 5th, two weeks before Dove’s eighth birthday, I heard how labored her breathing had become.

Reality began to creep in. As I held Dove in my arms, I planted kisses all over her face, repeating, “I love you so much” over and over. I sang and cried and Dove breathed. I called the doctor and he came over and shook his head. “She could rally, but she might not make it through this.”

“We’re losing her,” I thought, and then she rallied for a few hours.

What happened next is difficult to describe in words. My precious Dove began to take flight. She began to breathe harder and harder and was using her mouth, which she had rarely done since getting the trache. She was gathering her energy—up, up from her toes, slowly all the way up through her body, and then out the top of her head. It felt like a labor, a birth of spirit. All the while I was saying, “Go, Dove, go, Dovie. It’s okay, baby. Fly free. The angels are waiting to greet you. You’ll be able to sing and dance again and run and play. It’s okay to go. And thank you for being the perfection you are. Thank you for coming to me. Don’t be afraid. The light will guide you.” As I held her on my lap, I could tell when she had left her body to stand somewhere above, high on a bridge between here and there. I held my breath. And then she came back into her body for another minute. I looked into her eyes. I felt our forever union. I was totally present for her as she worked hard to breathe herself free. And once more she left her body. This time was the last. I looked at her still form and then felt a wave, a current of electric energy that ran up through my body, and I let out a scream of release that was Dove’s scream. She was free. And I wanted to go with her. “Come back and meet me on the bridge when it’s my turn,” I whispered to her freed soul. And I know she will.

It was 9:40pm and Bodhi was asleep. The house was filled with the grace of a spirit finally set free from its form. I took my baby girl up to my bedroom and ran a bath for us. I took out her trache. We bathed together. I washed her precious body. I dressed her in the pink satin angel nightgown she had worn the last Christmas. And then I called some friends. They came over. We sang songs into the wee hours. And then I took Dove upstairs into bed with me, and I tried to sleep for a couple of hours. Then I put her little body back on her usual spot on her chaise in the living room. I got Bodhi up and brought her into bed with me for a snuggle. She was now 3½ years old. I said, “I have something important to tell



you, my sweet girl. Your sister Dove died last night. She left her body and went to be an angel. I don’t think she went too far. I think she’s going to be our guardian angel.”

“Can I see her?” Bodhi asked.

“Yes,” I said. “Her body is downstairs. Come and pat her and say goodbye.”

People started to come in waves of love with food and flowers. Children came by to pat Dovie and hand her a rose or whisper something in her ear and say goodbye. I wanted to keep her body in the house until it was time for her to go in the ground. I arranged with the mortuary to bring over a small white satin casket and some dry ice to put on Dovie so we could keep her at home.

Bodhi Rebecca sat on the floor by the coffin and gently patted her sister’s body. She put her little fingers on the shiny angel nightgown and looked sad. She spread her Mickey Mouse umbrella above her and sat like a little guardian angel herself. For the next three days Dove was never alone. On the third day many loved ones gathered as we laid her little body to rest. I threw dirt onto her coffin and I threw dirt onto myself.

In a single moment, the diagnosis of Hurlers had robbed my husband and me of future expectations, ironically bestowing us with the incredible gift of being released into the now. Some magical mind trick usually hides from us the truth of life’s fleeting moment, but because of the “terminal” nature of Dove’s condition, that awareness came

to the forefront for us. We had no way of knowing how long she would be with us, so there was nothing but the present, both the grief and the joy of her precious, time-limited touch. My relationship with Dove was stripped to its pure essence, feeling each other heart to heart and being together, sharing each moment. It’s been years since Dove’s passing. Each anniversary I give myself time to watch her on home videos, to laugh and cry and shine a full light on the heart we share.

By night I often ask Dove to come to me in my dreams. Perhaps some dreams are truly visitations to a place we can travel when the mind is asleep. Who knows how many times we do visit with each other, but only sometimes am I graced with the memory of it. One time I awoke having seen her face close to mine on the pillow. Her radiant state of bliss permeated me, as her face lit up with total joy.

For all of her nearly eight years, Dove remained small, never growing larger than a three-year-old. Yet when I think of her teachings, I see the enormity and the purity of what I learned from being her mother. My relationship with her was my initiation into relationship as a spiritual path. My relationship with her is about both being in the present and the moments beyond time and space. Through our relationship, I am able to glimpse what it is like to let go of fear of loss and embrace the eternal now. To be willing to dissolve my small boundary and become the love that is our very breath and binds and frees us all with every lapping wave beyond the mind.

*If the sin of dark despair  
Betrays you in the cold,  
The doubt that fills your heart with care  
Takes courage to behold.  
We can run and we can climb  
We’re as strong as we can be.  
But Dovie has what we’re looking for.  
She knows what all need.  
That love’s the angel’s mighty wings,  
Love’s the still small voice:  
That love’s the path that’s chosen us,  
That love’s the only choice,  
Oh, that love’s the only choice.*

– From “Song for Dove” by Joe Henry

*Shana Parker lives in Boulder, CO, with her husband, Doug. She is a licensed psychologist who infuses her work with couples and individuals with the lessons she has been taught by both her children.*



# Undertaking with Love: Organizing a Faith Community

by Donna Belk

The credit for *Undertaken with Love: A Home Funeral Guide for Communities and Congregations* goes to the late Holly Stevens, a passionate advocate of families' rights at death. Holly died in 2011 at age 55, after living with breast cancer for a third of her life. But her determination and organizing abilities allowed her to accomplish several major life goals, even after her stage IV diagnosis and subsequent paraplegia. This manual is one of her crowning achievements and now forms part of her legacy. Holly recruited six of us to write the chapters in the book, obtained permission to use the artwork, brought on a graphic designer to handle the layout, and arranged to make the book available as a free downloadable PDF or as hard copy. My job now is to ensure that this valuable resource remains accessible.

*Undertaken with Love* describes the formation and workings of what we call a "home funeral committee." This is a group within a church or community that is committed to helping families care for their own. Church groups often have respite care for those who are ill. The home funeral committee takes this one step further by providing guidance and assistance at death and thereafter. All the committee's members are volunteers. One person takes the lead as a home funeral guide or advocate for the group, but there are many other roles. Some of these roles relate to practicalities, such as researching laws and regulations and getting to know local officials. Others may be more intimately connected with the death itself, including care of the body after death, the coordination of meals, and acting as a point person for information.

The committee can also help the dying person plan for a more graceful death. Home funeral committee members can provide opportunities to deal with "unfinished business," allowing the dying one to say what he needs to say and

complete any projects he has begun. This is also a time when the dying person can share his or her memories and reflect on life. Sometimes family members are reluctant to initiate these conversations because they may uncover old wounds or disagreements. They fear that they will become too emotional when they hear what the dying family member has to say. It can be a great comfort for the terminally ill person to be able to speak openly to a committee member, someone who can listen without judgment.

Another possible role for a committee member is to talk with the patient about the meaning of dying. This might involve a conversation about "healing" and redefining death as something other than failure (as is too often the perspective of the medical community).

## *The committee can also help the dying person plan for a more graceful death.*

Home funeral committee members can become knowledgeable about signs of impending death and what to expect as the death draws near. When a family member wants to feed a failing patient her favorite food out of love, the dying one may simply agree to eat to avoid hurt feelings. Committee members can help the family understand that the patient may no longer have an appetite and that eating might increase discomfort.

*Undertaken with Love* contains six exercises for community groups to study before they begin working with members of their community. One of the exercises is to research state and local laws relating to after-death care and to visits with local officials who provide the paperwork for final disposition. Committee members might also visit local hospices and hospitals to let them know about their plans to serve their own community members. This will avoid any surprises

when a faith group member becomes a recipient of their services.

Home funeral committee members can also explore their own deathcare preferences, creating their own plans, sharing their own stories about loved ones who have died and their own experiences of these events. The home funeral committee that serves our local Buddhist community has taken on a more public function as well, offering classes on death and dying throughout the year and open to anyone. Buddhists believe we should be prepared to die with consciousness at any moment. The time to get ready for death is now, not when it is knocking at the door.

From what I have seen, the main Judeo-Christian religions in the US do not embrace home funerals as much as groups such as the Buddhists and the Quakers that have traditionally provided their own community-led care. An

exception to this is the branch of Judaism that serves its members through the *chevra kadisha* (literally, the holy society). Chevra kadisha caregivers perform body washing in accordance with traditional Jewish ritual and practice.


One of my most recent experiences with a community group was at a home funeral for a Wiccan priestess. Her Wiccan caregiver friends were not part of a formal home funeral committee, but they carried out their care mission with aplomb. As the priestess neared death, she became upset and agitated about her declining ability to care for herself. So her community of friends undertook a survey of care facilities in the area to see what she could afford. The information they delivered relieved this dying woman of a huge burden and her anxiety decreased. This isn't perhaps typical home funeral committee work, but it's worth remembering that we do not always know how we will be called to serve.

A first step for a fledgling home funeral committee might be to consider how the community can help with respite for families caring for the sick and debilitated. With time, the committee may wish to take things further and provide support to people who are dying and then also after death. A strong home funeral advocate can take the lead in assigning roles and educating members. This coming together to figure things out fosters camaraderie and helps solidify the group. Experience with death has the same effect. When the time comes, and the committee helps with the community's first home funeral, members will feel the blessings of what is truly a sacred event.

This article is an edited adaptation of an interview with Donna Belk, co-author of *Undertaken with Love: A Home Funeral Guide for Communities and Congregations*, available at [www.undertakenwithlove.org](http://www.undertakenwithlove.org).



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# Quaker Burial Societies:

## Departing in the Company of Brethren

by Ashana Marie Larsen



*Every organization calls itself into being as a belief that something more can be accomplished by joining with others. At the heart of every organization is a self reaching out to new possibilities.*

*Life opens to more possibilities through new patterns of connection.*

*If we can be in the world in the fullness of our humanity, what are we capable of? ...What could we accomplish if we worked with life's natural tendency to organize? Who could we be if we found a simpler way?*

—From *A Simpler Way* by Margaret J. Wheatley and Myron Kellner-Rogers

All religions speak of being in communion with others in some way. As social beings, there are no greater times to be in union with others than when we reach seminal moments in our lives—births, weddings, deaths—that stir emotions larger than ourselves and call for the company of others to share our joy and our grief. There is a growing movement to return death, our last ritual, to the care of the family and our religious congregations, allowing us to depart this world, not in the hands of strangers,

but in the company of our like-minded brethren. Congregational burial societies are being created all over the country. Pennsylvania, in particular, has become an influential location in this new burial movement, with various denominations creating burial societies. Among these are the Old Order River Brethren, the Old German Baptist, the Fellowship Church, Rabbi Wasserman's Chevra Kadisha, the Schwenkfelders, the Bhutanese Hindu Community, and in the forefront, the Quakers.

David Morrison, a plain-clothed, conservative Quaker with a long, white beard and broad-brimmed straw hat, could easily be mistaken for Amish or law attorney and long time advocate for family-directed deathcare, he is not surprised by the growing interest in burial societies among many religious organizations. It feels both natural to him and the obvious choice. Morrison is a lifelong member of the Lancaster area congregation, Lampeter Friends.

The Lampeter meeting house was a well-used stop on the underground railroad and hasn't changed much since that

time. It still functions without electricity, running water, and heat. Its cemetery has always been green and, due to the work of Morrison and other friends, has recently been revitalized. Keeping it natural has been the priority. "We follow William Penn's burial guidelines from the 1600s—no funeral directors, hand-dug graves, shrouds or simple Amish-style coffins no more than 14 inches high to minimize dirt displacement," Morrison explained.

Morrison has been doing burials without a funeral director for more than 30 years. "I learned from Quaker Ernest Morgan," he recounts, "who took over his meeting's burial group in 1955." With an incredible memory for detail, Morrison knows everyone and sometimes talks so fast his mind seems ten paces ahead of his words. He keeps up an active law practice, is devoted to the Funeral Consumer Alliance and, despite how busy he is, somehow always has time to answer questions related to deathcare.

When I emailed Morrison about my father's impending death, his response came through a half hour later, detailing all the legal information I needed to know. He carefully numbered the steps in the process, one through eight. The last included the following advice: "If threatened by an FD [funeral director] just smile and say nothing. Pretend you are Elizabeth Cady Stanton."

In the beginning of his involvement with deathcare, Morrison worked with Mary McLane, a registered nurse, midwife, and fellow Quaker. Morrison took care of the green burials and McLane helped with the cremations and pacemaker removals. One of his life-long missions was, in his own words, to "empower and educate families to be able to direct their own funerals with the participation of all generations." After more than 30 years leading the Lancaster area deathcare movement, Morrison knew he couldn't continue without more help. He found the support he was looking in the soft-spoken, enthusiastic Debra Raudenbush, a member of the progressive Quaker Lancaster Monthly Meeting, which had an active environmental committee.



Ashana Larsen

David Morrison and Debra Raudenbush at their local green cemetery



Morrison and Raudenbush brought Penny Rhodes and Cheryl Clark to speak to the Lancaster Monthly Meeting. Rhodes and Clark are members of Natural Undertaking, a nonprofit advocacy group offering education on home and green funerals.

Clark, a member of Schuylkill Friends Meeting in Phoenixville, PA, was a founding member of Natural Undertaking. Because of the cathartic personal experiences she had caring for family members, she felt led to help religious communities learn to care for each other. “I believe that death is at the heart of every religion and it is in that threshold experience that we find the seeds to our humanity and our divinity,” Clark explained.

“Quakers are a society of friends who are part of an experiential and mystical religion. We were meant to bear witness to each other’s joys and trials. We have testimonies of simplicity and integrity and, to me, integrity means doing what needs to be done. Death is very fertile ground for growth, wisdom, and experience of the divine. I want to empower congregations to participate in this sacred threshold surrounded by friends who know each other and spiritually support each other instead of giving this sacred opportunity away to a funeral home.”

“I was really touched by Cheryl and Penny’s presentation,” Raudenbush explained, “and by the stories they told of what brought them to the ministry and the home funeral movement.”

Around the same time, Raudenbush learned about the film *Departures*, a moving story of an out-of-work Japanese musician. This young man takes a job out of desperation as a funeral assistant and finds a new vocation that changes his life. The movie portrays the ancient art of body care—performed in Japan for centuries—in which the body is prepared in a sacred ceremony at home. Raudenbush teamed up with Morrison to show the film to the Lancaster Meeting.



*Terry Wallace, keeper of the grounds, Lampeter Quaker Meeting House*

After these two events, Raudenbush had what she refers to in Quaker-speak as a *leading*, a sacred and divine calling to help families care for their loved ones at the time of death. “I was having almost daily ‘envisionings’ of me caring for deceased bodies of my loved ones,” she explained. “I processed this with some of the elders of the Quaker meeting and was invited to be the convener of a burial committee to investigate green burial, home funerals, and cremations.”

Initially, Raudenbush began to hold bimonthly meetings with about a dozen interested people, and the group composed a mission statement. They created a body preparation team and invited Rhodes and Clark to come again for a more detailed workshop on caring for the body. They held several sessions to practice what they learned, put together a body prep supply kit, and moved on to creating a body removal team. “I have a gift for organizing and facilitating,” Raudenbush explained, laughing.

In a short time, under her careful guidance, the Lancaster Friends Care Group for Death and Dying created six subgroups including a cremation team, a green burial team, and a vigil team with a roster of 30 people including eight men. At the heart of these is the visitation team, a group of members who do outreach to community members approaching the last stage of life. Before a person is actively dying, visitation team members visit and get to know the person so, at the time of death, they can help provide a more intimate experience for all involved.

Raudenbush knew she might not always be available when a call came about a death. She wanted to make sure as many others as possible were prepared to jump in when needed. “The understanding is that, when the need arrives, we have a call list and whoever is available can come forward,” Raudenbush explained. “If you are on the body removal team, then you are likely not to have the energy to do the body preparation, so that is a separate group. If you have worked to prepare the body, you might not have the energy to be present through the vigil, so we have another team that does that.”

When the first call came in, both Raudenbush and Morrison were out of town, but because of the careful planning, all aspects went smoothly. “Everyone involved said it was truly amazing,” recalled Raudenbush. “Although we didn’t have everything worked out, the pieces that weren’t in place just seemed to come together when needed.”

“The second call was for a man who was very large. We really needed strong men to carry him. Someone on the removal team started going down the list and calling people, and before we knew it, we had more than enough help.”

The teams called on Morrison’s expertise to help them with the myriad of details. They formed a research library, made contact with a local crematorium, and worked out special pricing for their members. For further research and inspiration, Raudenbush attended the National Home Funeral Alliance Conference in October 2010.

What advice would she give to other congregations starting out in this work? “Just do it!” She replied, smiling. “Personally for me, I like to keep things simple. Basically, we just worked with the information Rhodes and Clark shared with us and used their book, *When a Loved One Dies: Things You Should Know*, as our reference. I think the whole idea that we live in an Amish community where we have always taken care of our own gave us the confidence that we could do it. It is all very simplistic and in line with the Quaker testimony. This has kept us grounded and feeling pretty comfortable with the process. If you are just starting out, don’t worry about having a big plan. Just start learning everything you can and see who is interested.”

Raudenbush stressed the importance of not pressuring anyone since so many people today are not comfortable with the topics of death and dying. The visitation team is available for anyone dealing with a life-threatening illness, not just people who want a home funeral or a green burial. She feels our society in general has desensitized people, and so these ideas often need to be approached slowly. Within her working care group, the process of being able to talk openly about death and dying has brought them much closer to each other and helped build strong relationships. “It has raised the awareness of how death is a part of life.”

As both the interest and comfort level spread, she was asked to hold a study session for an hour each Sunday at Lancaster Meeting, which she has called “Conversations on Death and Dying.” “This really speaks to how the awareness has broadened and people have a desire to become comfortable with the whole idea of the death process.”



This fall Raudenbush stepped down as convener for the group, but she had laid a firm foundation, and the group continues to fine-tune its workings with such things as an obituary group, now in its formative stages.

For Raudenbush, this work continues to be her focus. For the time being she has been led to join Final Arrangements, a neighboring Mennonite community that started a deathcare study group. “Final Arrangements” at the Akron Mennonite Church is a course designed by Don Zeigler and Jerry Shank to investigate all the deathcare options available, with a special emphasis on exploring options for body care. Now in its third session, they have 30 attendees and have opened up the group to outsiders for the first time.

Although still a Quaker, Raudenbush is highly involved in the Mennonite community and has a long history with the church. “I planted the seed and got things started at Lancaster Friends and now I am with this group. I am just blown away by the interest level. People are coming with such gratitude and, I would say, even excitement. There is really a special energy created by claiming your own process, in being able to talk about death, embrace it, and plan for it.”

These two communities, working on similar missions, have found many ways to combine their efforts. The Mennonites have their own casket-making team and have made caskets available to the Quakers. The shroud-making committees of both groups have combined in a shroud burial support team. One man has created a body removal apparatus out of wood, and the two congregations have made themselves available for each other’s services.

The Quakers now maintain two historic green burial grounds in the Lancaster area that once belonged to the Amish, one in Lampeter and one in Cambridge. These cemeteries are open to other congregations as long as they are willing to abide by the natural burial rules. In February, Final Arrangements will be offering a class by Dr. Richard Weaver, a retired internist and surgeon, about natural dying.

When we begin to honestly look at what it means to be on this earth for a finite amount of time, embracing what we have and what we know we will eventually lose, we learn what it means to be in communion with others. The patterns of connection that are interwoven among people as they work together illuminate the healing that can come about when we allow ourselves to be vulnerable together and join together with integrity to do what needs to be done. As Raudenbush considered everything that has been accomplished by these two congregations in supporting both the physical side of death and fostering its spiritual side, she exclaimed, “It is really alive! It is birthing!”

### Mission Statement

Lancaster Care Group for Death and Dying

We, the participants in the Lancaster Friends Care Group for Death and Dying, desire to “wrap our arms around,” while being present to a dying Friend and the family of the Friend, during the time of the Friend’s transitioning through death, to the final disposition of the body, according to the Friend’s wishes.

Our ministry may include helping to process and prepare the details of one’s final arrangements; home and/or hospital visitations; removal of the body; preparation of the body for vigil, burial, or cremation; preparing and holding a vigil; organizing a green burial or cremation; notifying Care and Counsel for a memorial service—all without the use of a funeral director.

This ministry embodies the sacredness of death. It is spiritually led, reflecting and practicing our Quaker beliefs of simplicity, community and green consciousness, and fostering “conscious dying.”

*Ashana Marie Larsen is a freelance writer homesteading in a 240-year-old crooked house in Pennsylvania. She is a founding member of Natural Undertaking, a nonprofit organization offering information on home funerals and green burials. <http://naturalundertaking.org>.*



When we learn to fall, we learn that only by letting go our grip on all that we ordinarily find most precious – can we find, ultimately, the most profound freedom. In the act of letting go of our lives, we return more fully to them.

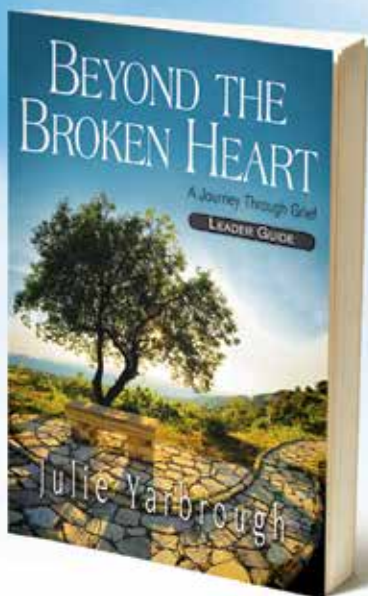
– Philip Simmons



Philip Simmons, writer and English professor, died in 2007 of complications of ALS (Lou Gehrig's disease). For more information about his book *Learning to Fall* and the documentary of the same name, visit [www.learningtofall.com](http://www.learningtofall.com).

Art: *Twilight* by Kathryn Field (wife of Philip Simmons)  
20" x 20", oil paint and 24-karat gold leaf on aluminum plate.  
Find out more at [www.kathrynfield.com](http://www.kathrynfield.com).





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by Julie Yarbrough

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—James W. Moore

Pastor in Residence

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### About the author:



**Julie Yarbrough.** Inspired by her personal experience after the death of her husband, Dr. Leighton Farrell, senior minister at Highland Park United Methodist Church for many years, Yarbrough established a support group for widows and widowers and began writing for persons who are grieving. She is president of Yarbrough Investments and lives in Dallas, Texas.

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