

CAREConnections

Information and Inspiration for Caregivers

A Publication of Boulder County Area Agency on Aging

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Dear Caregiver,

November is National Family Caregivers Month, the officially designated time to celebrate our nation’s family caregivers, who number in the many millions (check out the statistics in the article that follows). There are thousands of family caregivers here in Boulder County, and we especially tip our hats to you.

Our definition of a family caregiver is intentionally broad: someone who provides any level of unpaid care to a relative, partner, or close friend who lives in their own home, in the caregiver’s home, or in an assisted living or skilled nursing home. It’s a big group, and every member of it deserves to be recognized, supported, and informed. That’s the goal of the caregiver programs of Boulder County Area Agency on Aging, including *Care Connections*. There are many other services that we’d love to tell you about (see the back page for ways to learn more).

If you’re a *Care Connections* subscriber, you’ve already self-identified as a family caregiver. But if you’re a new reader, one who’s just picked up this issue, you may not be familiar with the term “family caregiver” or know why it’s important to identify as one. When you’re caring for a parent, a spouse or partner, or another loved one, you’re more than a loving son or daughter, a loyal wife or husband, a trusted friend. You’re a family caregiver. You’re in a situation that challenges your skills, stretches your energies, and overwhelms your emotions—as well as rewards you with lasting gifts—and there are many services that have been designed to assist you during this uniquely intense time.

We honor all family caregivers for the extraordinary work they do. And we welcome you to this issue in celebration of the vast society of caregivers.

The Editors

The Vast Society of Caregivers

by *Emily Cooper*



According to Family Caregiver Alliance (FCA, www.caregiver.org), a leading national agency for caregivers, 29% of the U.S. adult population (in 2012), or 65.7 million people, are caregivers for



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someone who is ill, disabled, or aged. 43.5 million of those caregivers provide care for someone who is 50 years of age or older, and 14.9 million care for a loved one with Alzheimer's disease or another dementia. In 2009, the economic value of those volunteer caregiver services was \$450 *billion*. FCA predicts that the value of unpaid family caregivers will likely continue to be the largest source of long-term care services in the U.S., especially as the population of persons age 65 and older will more than double by 2030, increasing from 35.1 million (in 2000) to 71.5 million. That's an extraordinary number of people who are likely to turn to family members and other loved ones when care is required.

Following are other statistics from FCA (compiled from various surveys) that help us understand the breadth of family caregiving in the U.S.:

- An estimated 66% of caregivers are female, and one third of those take care of two or more people. Of the 43.4% of caregivers who provide care for older family members, 14.5 million are men. Research suggests that the number of male caregivers may be increasing and will continue to do so.
- While caregivers are found across the age span, the average age of caregivers is 48, and about 51% of caregivers are between 18 and 49. Of those caring for someone age 50 or older, the average age is 50 – 64. Not surprisingly, older caregivers are more likely to care for a spouse or partner.
- The percentage of caregivers caring for individuals over 85 years of age has increased. Parent care continues to be the primary caregiving situation for mid-life caregivers.
- Many caregivers of older people are themselves growing older. Of those caring for someone age 65 or older, the average age is 63, with one third of these caregivers in fair to poor health.
- 58% of care recipients live in their own home, and 20% live in their caregiver's home.
- 55% of caregivers report they have cared for three years or more. The average days per month spent on shopping, food preparation, housekeeping, laundry, transportation, and giving medication is 13, with 6 days per month spent on feeding, dressing, grooming, walking, bathing, and assisting with toileting. Nearly half of family caregivers perform medical and nursing tasks.

- On average, caregivers spend 204 hours per week providing care. Those who live with their care recipient spend 39.3 hours per week caring for that person.
- 72% of caregivers live within twenty minutes of their care recipient; 13% live within an hour of the care recipient. Long-distance caregivers, however, have the highest annual expenses related to caregiving, compared to caregivers who live with or near their care recipients.
- Among the caregiving U.S. adult population age 18 and over, 72% are Caucasian, 13% are African-American, 12% are Hispanic, and 2% are Asian-American.
- Between 13% and 22% of U.S. workers juggle a caregiving role with their jobs, and 70% of working caregivers suffer work-related difficulties due to their dual roles. 69% report having to rearrange their work schedule, decrease their hours, or take unpaid leave in order to meet their caregiving responsibilities. Work difficulties are even more challenging among those caring for someone with dementia.
- 10 million caregivers over 50 who care for their parents lose an estimated \$3 trillion in wages, pensions, retirement funds, and benefits.
- Regardless of employment status, caregivers report that positive activities in their daily life are reduced by 27.2% as a result of caregiving responsibilities, and the effect on their personal life is 3 times more than the effect on employment.
- 17% of caregivers feel their health in general has gotten worse as a result of their caregiving responsibilities. 17 – 35% view their health as fair to poor. However, 8% of caregivers feel their overall health is improved by caring for a loved one.

- 40 - 70% of family caregivers have clinically significant symptoms of depression, with about one-fourth to one-half of these meeting the diagnostic criteria for major depression.
- 49% of caregivers report use of at least one type of help on behalf of their care recipient. 12% have requested respite assistance.
- 19% of caregivers report having had training, but 78% say they need more help and information with at least 14 topics related to caregiving.

These statistics (and many others on caregiving) are illuminating and can certainly be sobering. While they're important for grasping the impact of caregiving on individuals and our society, they don't capture the unmeasurable gifts of caring for a loved one that can make caregivers' efforts feel worthwhile.



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Creating a Community of Caregivers

by Brandy Queen, LPC

Being the sole, 24/7 care provider for a loved one is often said to be the most difficult aspect of caregiving. I would like to share some of the ways I have seen caregivers break the mold and create a community of caregivers in their lives. There are a few key factors that I believe contribute to this struggle. Our cultural norms of maintaining a high level of independence can make it very difficult for caregivers to create community and to ask for help. However, we are interdependent human beings who all need help and support from others. It is impossible for one person to carry the burden of caregiving alone forever. Caregivers often feel that their family, friends, and faith communities simply do not understand the depth of struggle involved in being a solo caregiver. If someone has never been a caregiver themselves or has never been close to a caregiver, it may be hard for them to understand without some honest discussion.

Engaging others for help may require that you risk the vulnerability of sharing your caregiving experience in order to help those close to you understand what it is like. It is very powerful to hear a caregiver say, “This is not just like being a parent. My kids grew up, but my spouse with dementia loses more of his abilities every year,” or, “It is exhausting to have to manage every detail of her appointments, changing Depends, shopping, cooking, cleaning, everything—and I haven’t felt rested in years.” If you are willing to share your experience honestly, to trust that others can in fact help your loved one, and to ask for help, the results can be amazing both for you and your care recipient. I have often seen caregivers who thought their loved one would not accept help from anyone else be shocked to discover that they are able to build relationships between their care recipient and other caregivers, and that their loved one may actually “listen

better” to those caregivers, especially if they are professionals.

I have seen many caregivers successfully build communities of care, and these are a few of their choices that I’d like to highlight:

- Ask other relatives to take the care recipient to medical appointments and track what happens at those appointments for you
- Have family or neighbors do yard work once per month
- Hire home care or apply for Long-Term Care Medicaid so that breaks in caregiving are routinely provided by professionals
- Apply for respite funds to reimburse a paid caregiver
- Allow faith community members to come once a week to provide meals, cleaning, or a chance for the caregiver to leave the house
- Have out-of-state relatives fly in periodically to be the caregiver for a week or more (even a month in one case!)
- Partner with other caregivers to give each other breaks
- Find ways to meet other caregivers such as by attending caregiver support groups or the Lunch Bunch (in Longmont)
- Travel together with friends and family who can help with caregiving during trips
- Connect with a respite volunteer through Boulder County Area Agency on Aging
- Ask family members who cannot provide caregiving to assist financially with hiring more care
- Tour an adult day care program to learn about their services (and then hopefully find that the care recipient blossoms in that environment)

The relief is palpable when caregivers coordinate regular outside care into their lives. I see people both cry and laugh with relief, and they say they wish they had gotten help sooner. Often caregivers have told me they don’t remember what they used to do for just themselves

and that the break from caregiving gives them time to learn again. Being refreshed also makes them feel like much better caregivers.

Finally, the biggest fear of many caregivers is what will happen to their loved one if something ever happens to them. A great way to address this fear proactively is to involve others in the loved one's care so that more than one person knows about and provides for their needs. Family meetings are another excellent way to create backup plans for the possibility that the primary caregiver may one day be unable to provide care at the same level or perhaps even at all.

Brandy Queen is a Licensed Professional Counselor with Longmont Senior Services, where she co-facilitates caregiver support groups, provides one-on-one caregiver consultations and family meetings, and coordinates the Lunch Bunch.



The “Natural” Caregiver

by Emily Cooper

I often talk to family caregivers who think they're somehow *less* because they don't always feel good about caregiving. They think there's something wrong with them because caregiving doesn't come “naturally” to them, or they wonder if they're missing the compassion gene because they really don't like all the tasks of providing care for another person. I tell them, “Guess what? There's no such thing as a ‘natural’ caregiver, and all of us have difficulty with many aspects, if not all aspects, of caregiving.”

It's been amusing (okay, sometimes irritating) to me when someone, often a family member, has told me, “You're just a natural caregiver. I could never do what you do.” Do they really think it's easy, for *anyone*, to change an adult's messy diaper, or to be patient with a parent with dementia, or to be so exhausted you can't think about doing anything for yourself? Those things, and many

other aspects of caregiving, are hard for *all* of us who care for another person, and I doubt that anyone feels like a natural when they're dealing with them. If someone tells me I'm a natural-born caregiver, of course I say thanks, but inside I translate their statement to, “I'm so glad this comes naturally to you, because that means I won't have to step out of my comfort zone to help.” Perhaps that's ungracious, because of course it's tempting for all of us to protect ourselves from doing things that are difficult by imagining they're so much easier for someone else.

No one is born knowing how to be a caregiver, knowing how to comfort a loved one in physical or emotional pain, knowing how to walk along with someone as they near and meet death. Some of us come from a family with a history of caring for its elders, and we had the valuable childhood experience of seeing that care provided. But many of us did not have that experience, and we certainly didn't learn how to care for older loved ones in our formal schooling—though caregiving is something the majority of us are likely to do at some time in our lives. Thankfully, there are many other ways to learn about caregiving, and it's never too late to get the training we need to feel more prepared and competent to provide care.

Caregivers are not born; they're made, after someone makes the brave choice to give caregiving a try. Think of this formula: Opportunity + Willingness + Training = Competent Caregiver. The Opportunity is when an older loved one (or anyone else) becomes sufficiently frail, ill, injured, or confused to need occasional or daily assistance. The Willingness is the choice to help meet the loved one's needs, in spite of misgivings or fears about one's aptitude for the job. The Training is everything that's learned purposefully or by trial and error along the way. Put the three together and you've got a competent caregiver—as competent as any of us can be when dealing with the unpredictability and complexity of another person's health.



Even when someone has chosen to be a caregiver, and has received training, he or she is likely to feel uncomfortable with some tasks. We all have strengths in some areas more than others, though we can usually muddle through in any area if the need is urgent enough and we're willing to try. Luckily, when we combine our efforts with other caregivers in the family or community, it's easier to designate tasks according to strengths: if you're not good at one thing, it's likely that someone else will be. When caring for my mother, I could handle personal tasks like helping with toileting (didn't like it, but I could do it); my sister really didn't want to help with that, but she could tolerate making tedious phone calls to insurance companies or doing paperwork that I had no patience for. My brother wasn't comfortable sitting and listening to Mom's woes (which I could do), but he could shop for groceries or do maintenance on her home. The more you spread out the caregiving, the more talents and tolerances you'll be able to draw from. No one person needs to do it all; everyone has something of value to pitch in, and every little bit helps.

So, please don't worry if you feel badly—at least at times—about caregiving. We all do. It's some of the hardest work anyone can ever do, and you've made the choice to do it. Don't think you had a choice? Of course you did. You could have walked away, but you're there, you're helping, and you're making a difference. That can feel very "unnatural," but you've had the courage to take on responsibilities that force you to uncomfortable places every day. There are no "natural" caregivers; there are only folks like you who are doing their best for someone who needs their help. We applaud you.

Emily Cooper is Information & Referral Specialist for Caregiver Programs and Editor of "Care Connections" with Boulder County Area Agency on Aging.



May Someone Learn from My Mistakes!

by Jane Seaton, PhD

With hindsight, I made a mess out of being a primary caregiver in some significant ways and wish I had known then what I know now.

This is how it began. Sue and I, a still fairly new couple, were in the process of relocating from New Mexico when her longtime hepatitis-C caused a massive esophageal bleed. There had been no prior warning, and statistically she had almost no chance of surviving such a bleed.

But ten days later I took her home to our half-packed boxes. She was very, very sick, and we were both profoundly stunned, with our whole known worlds unraveling. I had just gone from excitedly preparing, after an extended sabbatical, to come home and pick up my career, to suddenly becoming a primary caregiver.

All we could do was put one foot in front of the other, with almost no comprehension of what had just happened to either of our lives. Sue insisted we relocate anyway, so two months later, we found ourselves in a small Colorado apartment. Sue signed up for hospice care and permanent disability. As she chose not to do Interferon or seek a liver transplant, we initially were given short probable timelines for her life expectancy—perhaps three to four months. So I put her needs first, postponed recreating my work life to be with her for the little while we thought we had left. But hepatitis-C is a classically unpredictable illness, and despite well-meant medical guesstimates, there was no way of truly knowing when or how this would play out, though neither of us yet understood that.

While trying to adapt to being a caregiver, with its endless practical, organizational, emotional,

(continued on page 7)



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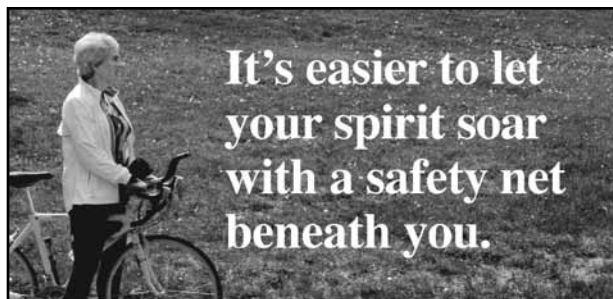
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May Someone Learn from My Mistakes!

(continued from page 6)

even legal components—my own professional plans supposedly only briefly postponed—I discovered that complex anticipatory grief can awaken long-buried feelings from unresolved previous losses. I finally fell into fifty years of unresolved grief about my mother’s death from breast cancer when I was eleven. I had terrifying fantasies of an immense black cliff looming over me with unimaginably threatening power; there was no way away from or around it. Many months later I would understand this cliff as a symbol of how trapped I felt, as the only person taking responsibility for being with Sue, and how this cliff also represented a young girl’s lonely terror faced with her mother’s death.

I was a far from ideal caregiver during the following winter, not always calm and kind. I went through a six-month undiagnosed nervous breakdown, from sudden traumatized loss of my own life. Lack of education about balancing caregiving with my own needs had created a gut-wrenching dilemma: I was utterly torn between standing by Sue and feeling completely blindsided, my own life on hold now for longer and longer. Later, I understood that not having taken care of myself financially, especially, and having somehow fallen through all the cracks of social services resources, severe caregiver burnout and compassion fatigue were eventually inevitable.

In the end, feeling like a traitor and a failure, I discussed living apart, since I was now functionally unable to find work. To my immeasurable relief, Sue understood and soon genuinely agreed. I found her a low-income apartment and began to wake up feeling halfway sane. Several wonderful professional opportunities showed up right on time. We gradually sorted

out a new relationship dynamic so she could live the remainder of her life more peacefully, with a new hospice taking care of daily practicalities, and I could balance caregiving *and* recreating my own life.

In hindsight, I regret having put my needs second through my fierce commitment to doing all that I could for Sue. Some have judged me for eventually creating boundaries around what I reasonably could and could not do; yet in finally taking care of myself, I have become a much better life-and-death companion. The love between Sue and me has somehow survived the proverbial thick and thin, through our unceasing commitment to living honesty-with-compassion. We continue to negotiate what is right for us rather than following others’ ideas of what this should look like. Our love and our walking this walk together to the end have actually grown deeper—and definitely wiser.

In the past eighteen months, I have learned many things. Never assume a terminal illness will play out how the medical folks indicate that it will or may. Never ignore one’s own common sense needs because of stressed-out caregiving; to do so is to burn out badly, as I did. Get enough support, and never underestimate the power of love. When Sue dies, whether that’s next week or next year, I’ll miss her like hell, but I’ll survive to grieve and move on, for now I feel that she will always be with me in spirit.

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**“Caregiving often calls us to lean into
love we didn’t know possible.”**

— Tia Walker, *The Inspired Caregiver*



COMMUNITY RESOURCES

This column provides information about events and classes, services, and other resources that may be of interest to family caregivers in Boulder County. Please remember that it is each person's right and responsibility to research a service provider or event before taking action. See "Information and Assistance in Boulder County" on the back page for ways to learn more about these and other resources. (To share information about a resource for family caregivers, email InfoCaregiver@bouldercounty.org or call 303-678-6116. The deadline for the January/February 2016 issue is November 20.)

Medicare Counselors with Boulder County Area Agency on Aging hold **Medicare Basics Classes** for anyone wanting to learn more about enrollment, benefits, costs, and choices under Medicare, on Thursdays, November 5 or December 3, 2 – 4 p.m., at East Boulder Senior Center, 5660 Sioux Drive, Boulder (call 303-441-1546 to register); on Tuesday, November 17, or Monday, December 21, 10 a.m. – 12 p.m., at Longmont Senior Center, 910 Longs Peak Avenue, Longmont (call 303-651-8411 to register); on Friday, November 20, 1:30 – 3:30 p.m., at Lafayette Senior Services, 103 S. Iowa Avenue, Lafayette (call 303-665-9052 to register); and on Wednesday, December 2, 1:30 – 3:30 p.m., at Louisville Senior Center, 900 W. Via Appia, Louisville (call 303-666-7400 to register). There is no charge, but donations are appreciated.

Medicare Open Enrollment Period, the time to review and make changes to Medicare Part D (prescription drug) or Medicare Advantage/Health Plans, is October 15 – December 7. Call to schedule an appointment with a BCAAAMedicare Counselor for an individual review of your plan at

clinics held at local senior centers on Wednesdays, November 4 or 18, 9 a.m. – 12 p.m., at West Boulder Senior Center, 909 Arapahoe Avenue, Boulder (call 303-441-3148 to register); on Thursdays, November 5 or 19, or December 3, 9 a.m. – 12 p.m., at East Boulder Senior Center, 5660 Sioux Drive, Boulder (call 303-441-4150 to register); on Fridays, November 13 or December 4, 9 – 11 a.m., at Lafayette Senior Services, 103 S. Iowa Avenue, Lafayette (call 303-665-9052 to register); on Mondays, November 2, 9, 16, 23, or 30, or December 7, 9 a.m. – 12 p.m., at Longmont Senior Center, Longmont (call 303-651-8411 to register); and on Wednesdays, November 11 or 18, or December 2, 9 a.m. – 1 p.m., at Louisville Senior Center, 900 W. Via Appia, Louisville (call 303-666-7400 to register). Pre-registration is required. For more information, call 303-441-1546 or go to www.bouldercountymedicarehelp.org.

Alzheimer's Association of Colorado offers **Effective Communication Strategies**, a class about decoding verbal and behavioral communication by someone with Alzheimer's or other dementia, on Wednesday, November 11, 10 a.m. – 12 p.m., at Kaiser Baseline Clinic – Chautauqua Room, 580 Mohawk Drive, Boulder. Pre-registration is required, at 1-800-272-3900. The Association also offers **Memory Café**, a social gathering place for people with memory loss and their families, with coffee and treats provided, on Friday, November 13, 10 a.m. – 12 p.m., at Boulder Public Library – Main Branch, 1001 Arapahoe Avenue, Boulder. Pre-registration is required; call Kera at 303-813-1669.

AgeWell, a service of Longmont United Hospital, offers **Advance Directives workshops**, about



considering and clarifying one's wishes for medical treatment in the event of incapacitation, with Program Coordinator Peggy Arnold, MA, on Thursdays, November 12 and December 10, 9:30 – 11 a.m., at Longmont Senior Center, 910 Longs Peak Avenue, Longmont. Pre-registration is required; call 303-651-8411. There is a \$5 fee for Longmont residents, \$6 for non-residents.

Boulder County Area Agency on Aging presents the **15th Annual Lavender Gala**, a celebration for the LGBT community age 60 and better (and their friends, families, and allies), on Sunday, December 6, 1 – 4 p.m., at Nissi's Bistro, 2675 North Park Drive, Lafayette. Register at www.lavendergala15.eventbrite.com.

The Grillo Health Information Center provides **free, confidential health information** in response to health questions submitted by phone, via its website, or in person. The staff of trained volunteers researches health topics using reliable, evidence-based databases and provides a packet of information to the individual requesting the research. The Center is in the Tebo Family Medical Pavilion, 4715 Arapahoe Avenue, at the Boulder Community Health Foothills Campus in Boulder. For more information, call 720-854-7293 or go to www.grillocenter.org.

Longs Peak Energy Conservation, a program of Boulder County, offers **free weatherization services** to qualifying residents who own or lease their home. Services include a free energy audit, furnace check, and carbon monoxide testing, and *may* include attic and/or wall insulation, air leak sealing, furnace repair or replacement, and refrigerator replacement, helping to lower heating and utility bills by improving energy efficiency. This level of service is provided only once to any

home. To qualify, you must receive LEAP, AND, TANF, SSI, SSDI, or OAP, or have a gross yearly income under \$31,860 (for a family of two). Call 720-864-6401 for more information and an application.

Elder Share provides **groceries for low-income seniors** at neighborhood sites throughout Boulder County (and Broomfield County). Members come to a site near their home at a specific day and time twice each month to pick up food; homebound individuals have groceries delivered to them at home. Every senior receives cheese, a variety of pantry items, fresh produce, and bread. To be eligible, you must be 60 or older, live in Boulder County (or Broomfield County), and have a household income that is at or below 130% of the federal poverty level (monthly income of \$1,276 for 1 person or \$1,726 for 2 persons). To request an application or for more information, call Community Food Share at 303-652-3663.

Care for Caregivers, a **drop-in community-style (group) acupuncture** for informal and professional caregivers, is offered on Sundays, 1 – 3:30 p.m., at 4710 Table Mesa Drive, Suite B (inside the Boulder Massage Clinic), Boulder, by acupuncturist Ian McPherson. The mission of this program is to provide an affordable way for caregivers of all kinds to give back to themselves, and to help them feel supported, nourished, and healthy. Suggested donation of \$10, but no one is turned away for lack of funds. Call 720-757-0100 for more information.

For a list of **caregiver support groups** that meet in Boulder County, call 303-678-6116 or email InfoCaregiver@bouldercounty.org.



May's Story

by Mary Jane Longanecker

May, a Vietnamese-American who has lived in the U.S. for almost ten years, became the primary caregiver for her seven-year-old daughter after a divorce. Then she became the caregiver for her parents when they came to the U.S. for the first time two years ago and moved into her home. Now, in addition to the normal stresses of caregiving, May has the challenges of a cultural tradition that shows respect for elders by giving them the final say in all matters of the household.

One of five children, May had a part in deciding that her parents would be better off in America. In Vietnam, it is traditional for several generations to live together until a child has enough money to purchase his or her own home. The children and grandchildren who continue to live in the family home are responsible for caring for the elders. Some of May's siblings have their own homes, and others remain in the family home and would care for their parents. Nevertheless, May encouraged her parents to move to the U.S. to live with her, primarily because of the availability of better health care. Now she tries to maintain respect for her parents while urging them to develop some independence. She admits the best solution might be if they had their own home next to hers.

There is a Vietnamese saying that sums up the expectation of the family's responsibility for aging parents: "If one mother can raise ten children, why then can't ten children care for one parent?" It is considered shameful to place a parent in a nursing facility (there is no assisted living in Vietnam), and it's only done as a last resort.

These cultural expectations translate into much emotional conflict for May, who works full-time and shoulders some of her parent's financial

obligations. She wishes she could have some aspects of a private life, such as social relationships, but traditionally even those relationships would be subject to her mother's approval. It further complicates matters that May depends on her parents to provide after-school care for her daughter.

Though neither of May's parents has chronic health problems, May has still used all of her sick leave in order to accompany them to medical appointments. Recently they found a Denver doctor who speaks Vietnamese—a real plus—but transportation to and from his office is difficult. Happily, May's parents attend a church near Denver and receive roundtrip rides each Sunday from a fellow parishioner.

May is caught in a constant emotional tug-of-war, not knowing whether to respect her parents in the traditional way or to strive to make them—and herself—more independent, thus eschewing cultural values. Though there has been some discussion among May's siblings about moving their parents back to Vietnam, for now everyone believes that they are better off in the U.S.

When May reflects on the desire she had to be a helpful, compliant daughter before her parents' arrival, she realizes that the resulting situation has been much more difficult than expected. And after experiencing an independent American lifestyle with her ex-husband and daughter, the constraint of her current situation is all the more pronounced. For now, as her parents inch toward acclimation, May daily addresses the realities of her caregiving role and does her best to straddle two vastly different cultures.

This article first appeared in the September/October 2006 issue when Mary Jane Longanecker was Respite Services Coordinator for Boulder County Area Agency on Aging.



The Hardest Thing

by Stuart Feinhor

The easiest thing I have ever done was to love my Aunt Marilyn. The best thing I ever did was to take care of her. And the hardest thing was to say goodbye on August 31, 2004.

Marilyn was that rare gift of a person who is so easy to love. She just made it so easy. You met her once and you were hooked: on her cheerfulness, her love of life, her gratitude, her politeness, her humor, her consideration of others, her generosity.

And it didn't take much for her to love you back: a kind word, a friendly smile, treating her with respect, and caring for her with affection. She had a way of making a lasting and positive impact on people, and that is a source of comfort to me. She made the world a better place by being who she was while she was here, and I know that her legacy will live on through the many people she touched. Marilyn was unforgettable. And there is a tremendous hole in my life where she used to be with me.

Marilyn didn't always have an easy time of it, and she certainly didn't always make it easy to take care of her. She was born mentally retarded and had a list of other mental and physical conditions, all of which conspired to bring her life to a close at the young age of 66. But we were able to celebrate the fact that she had outlived—"over-lived," she would say—both of her parents and her sister, my mother, and that was quite an achievement.

While Marilyn was a constant presence and an integral part of my entire life, we were together as a unit for the past five years. She was my aunt, my friend, my companion, my champion, my "Moomie." I assumed full responsibility for her upon my mother's death in 1999, but the last three and a half years were the most challenging. She developed a condition in her spine that rendered her unable to walk, to feed herself, even to sit up.

So, she underwent surgery in San Francisco and was able to be rehabilitated to the point where she could do most things by herself. And the things she still could not do for herself, she asked for help with—something many find almost unbearable. But she did it, for as long as she could. We did it together. It was not easy, and there were times I was not sure I would be able to manage it. But her determination and perseverance and will were also the factors that spurred me on to do all that I could to take care of her.

But I did not do it completely on my own, even if it often felt that way. Among those I thank are the nurses and doctors and social workers and others whose skill and compassion and patience helped Marilyn live a happy and comfortable life. And all the aides—they are the heroes I pay tribute to for contributing as much as, if not more than, anybody else in caring for my aunt. And I definitely could not have survived without the loving support and empathic understanding of the people in my caregivers' group. They became the family I needed to sustain me over the past year and a half. All of these wonderful people tolerated my ranting, supported my concerns, and acknowledged my efforts to provide Marilyn with the best care possible.

The easiest thing I have ever done was to love my Aunt Marilyn. The best thing I ever did was to take care of her. And the hardest thing was to say goodbye.

This article, slightly adapted here, first appeared in the November/December 2004 issue of Care Connections.

“Sometimes our work as caregivers is not for the faint of heart. But, you will never know what you are made of until you step into the fire. Step bravely.”

— Deborah A. Beasley

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INFORMATION AND ASSISTANCE IN BOULDER COUNTY

Within Boulder County, there are several ways to access information and assistance about resources and services for older adults and their family caregivers:

- Check out **Network of Care for Seniors and People with Disabilities**, a comprehensive online service directory, at www.BoulderCountyHelp.org
- Call the **ADRC Help Line**, at 303-441-1617, and Boulder County Area Agency on Aging staff will respond to your message.
- Call the **resource specialist** in your community (numbers below). Services vary by community but include identifying needs, exploring options, finding solutions, and providing in-depth assistance.

Allenspark area	303-747-2592
City of Boulder	303-441-4388 (bilingüe: 303-441-3918)
City of Lafayette	303-665-9052, ext. 2
City of Longmont	303-651-8716 (bilingüe), 303-774-4372
City of Louisville	303-335-4919
Erie	303-441-1617
Lyons area	303-823-9016
Nederland area	303-258-3068
Niwot area	303-441-1617
Superior	303-441-1617

