# CAREConnections Information and Inspiration for Caregivers

A Publication of Boulder County Area Agency on Aging

July/August 2017

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Opening the Doors of Understanding

## Dear Caregiver,

When confronted by a loved one's need for care, how do we respond? The "call to care" can come suddenly and loudly, after a loved one experiences a stroke, a fall, or some other calamity, or it can come gradually and quietly, as we slowly realize that our loved one is declining and can no longer manage alone. However the call comes, each of us responds in our own unique way.

This issue, about being confronted with the need for care, includes two articles that introduce basic principles of caregiving (important for all who become caregivers) and other articles, written by caregivers themselves, about the ways they responded to their loved ones' needs. Though all of us would prefer never to get the "call" that our loved one is ill or injured, it's likely to come to most of us, and responding to it gives us the opportunity to step up to the plate, to bring comfort to a loved one during a difficult time, and to learn just how strong we are.

Our best wishes to you. *The Editors* 



## **The Culture of Caregiving** by Stuart Feinhor

I f you are reading *Care Connections* (which you obviously are), then you are already in the Culture of Caregiving. And chances are that you were a member of it long before you even knew there was a name for it, a name for what you do, a name for who you are. If you give of your time, your compassion, your heart, your love to somebody in need, then you are a caregiver. If you focus your life, in even the smallest way, around helping ease and support the life of another human being who cannot manage on his or her own, then you are a caregiver. And since you are a caregiver, then you are an integral and vital part of what I call the Culture of Caregiving. It is among the most important, transformative, frustrating, fulfilling, and honorable cultures on the planet, and one with which more and more people will find themselves affiliated as time goes on.

No doubt like many of you, I was simply (*simply*!) "taking care of" somebody well before I knew I had become a caregiver. After my

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Reproduction of Care Connections articles is permitted with credit to Boulder County Area Agency on Aging. mother died in 1999, I became responsible for the daily, emotional, and logistical needs of my mother's sister. My Aunt Marilyn, who died in 2004 at the young age of 66, was a uniquely wonderful woman who was both mildly retarded and had a catalog of other physical and mental conditions. Over time I became her case manager, her advocate, her primary support system. We loved each other deeply, eternally. My story, like yours, is both exclusive to my experience as well as universally understandable to people who take care of other people.

It was as a result of one of Marilyn's many hospitalizations that I found out that I had been, unbeknownst to me, involved in this culture for a few years already. Equally unbeknownst to me, the "caregiver underground" was at work, and on my behalf. For somebody contacted somebody else who contacted Ina Rifkin (one of the co-facilitators of a local support group) who contacted me and asked if I would like to become part of a support group for caregivers. I remember, in addition to agreeing immediately to join what would become a lifesaving family of loving hearts, thinking "care-*what*-ing?" You mean there is a name for what I do? For who I have become? Yes, and yes. And thank God.

Typically, but by no means exclusively, one assumes or acquires or inherits the role of caregiver as a result of a family crisis. Your dad dies and your mom suddenly needs looking after, your child develops a debilitating and fatal disease and your life is turned upside down, you get diagnosed with an advanced stage of cancer and, being a single person, you find yourself requiring outside help. Alternatively, sometimes the caregiving role evolves over a period of time: your spouse develops Alzheimer's and your world slowly crumbles, your friend's previously controllable disability becomes unmanageable, somebody you love is simply (*simply!*) growing old. We know that our loved one needs help. But what we don't know is that we do too.

We know that caregiving is stressful, but we don't know that virtually half of all family caregivers suffer from depression. We know that most family caregivers describe their role in positive terms, but we don't know that more than two-thirds of us say that frustration is the emotion we experience most often. We know that most family caregivers find an inner strength previously untapped and unrecognized, but we don't know that more than twothirds of us don't get consistent help from other family members (well, maybe we do know that!). We know that we can't truly do this alone, but we don't know that very few of us participate in a

support group. Knowing these things helps normalize our shared experiences. Taking action brings us into a community.

One mantra dominates my caregivers' group: You can't take care of somebody else unless you take care of yourself. Sometimes we resist these words of wisdom and experience, and sometimes we permit ourselves to breathe in their nutrient-rich oxygen. We are a family, a culture of caregivers. We know what it means and we know that it matters. At the same time we need to remember that it is okay, indeed it is vital, that we caregivers, at least from time to time, become care-*takers*. Our culture has developed and continues to create resources that sustain and nourish. Don't forget to feed yourself.

This article first appeared in the September/ October 2005 issue, when Stuart Feinhor was a member of the Care Connections Editorial Advisory Committee.



### **Switching Gears** by Carol Spar, Psy.D.

**T** his article is written primarily for those who come into the role of caregiver in the face of an emergency, but it is hoped that all caregivers may find helpful information here. In any emergency, by definition, we must make a rapid assessment of the situation, make major decisions, and initiate bold actions. When the emergency involves the health and well-being of a family member, we can find ourselves dealing with unfamiliar situations, making decisions with insufficient information, and initiating action with consequences we cannot always predict but must, nonetheless, put into motion. When a spouse suddenly slumps in her chair and her speech becomes slurred and confused, we mobilize and set in motion a disorienting flurry of phone calls, ambulance, and emergency room, with numerous medical staff using words familiar to them but foreign to us, and yet of great import as procedures are decided upon and permission is given or withheld. When we visit an aging parent out of state, and it becomes clear that adequate meals are not being prepared, medication is not being taken correctly, or bills are not being paid, we recognize that we must now take charge of our parent's day-to-day existence. We quickly locate and hire resources in a city that may not be familiar to us so as to set up a short-term safety net while we begin to work on a long-term solution, all the while re-shuffling the other responsibilities of our life. In the face of a family member's crisis, we mobilize.

In its simplest form, mobilizing in a crisis is the familiar "Flight or Fight Response." In physical terms, when the mind perceives a threat, the brain sets in motion a surge of adrenaline throughout the body: we breathe rapidly to bring in lots of oxygen, and our heart pumps at a fast rate to get the oxygen to our large muscles for extra energy either to "do battle" or to "run for safety." Then, following the "Flight or Fight Response," the body is spent and must replenish its reserve of energy; we are physically exhausted and must rest.

Similarly, in psychological terms, when the mind perceives a threat, we shift into a "hyperalert" state with a sense of urgency about everything, as anything could mean something of great import that we must be ready to deal with, even if we feel that we are in over our heads.

Generally speaking, when there is a crisis, it is clear what to do and people do it. And then the situation is no longer a crisis. The situation may still be serious and difficult, but it is no longer an emergency. What can happen for a caregiver is that the situation has changed, often as a result of their effective efforts, but the caregiver's sense of urgency remains in high gear. Physically, the caregiver's body has moved through the "Flight or Fight Response," and the body is ready to rest, but psychologically the caregiver continues to respond to events as if each event is its own crisis or, quite commonly, as if each event contains the seeds of a crisis ready to burst onto the scene unless the caregiver mobilizes to avert the disaster with all the force he or she can muster. Such a relentless pattern of mobilizing the body and mind for "Flight or Fight" is exhausting, and it compromises the caregiver's physical health. And, after the initial crisis has passed, responding to everything as if it were a full crisis is like always firing a cannon when a fly swatter would do. Staying in this urgent, high gear mode helps neither the caregiver nor those around them.

So the task for the caregiver becomes making the psychological shift from high gear to lower gear, from a sense of hyper-alertness to an acceptance of what is now part of a new routine and reality. Fortunately, making this shift requires neither brilliance nor magic, which means that we ordinary folks can do it. It does require awareness and persistence. And it helps to frequently pause and take three deep, slow breaths.

The first step to making this shift is to observe oneself and ask:

- How am I feeling emotionally right now?
- What am I doing in this moment?
- What are my thoughts at this point in time?

These questions capture what is sometimes called the ABC's of functioning: "A" is for Affect, which means emotions; "B" is for Behavior, which is observable actions; and "C" is for Cognitions, which are thoughts, beliefs, and expectations.

In reverse order, it is important to observe our thoughts and "correct" what we recognize as no longer accurate, as an exaggerated perception, or as a belief that has been proven wrong. For example, if you hear yourself dictating, "I must take care of this immediately," you should ask, "Why immediately? What is the worst thing that can happen if I don't take care of this right now? Is that 'worst thing' dangerous, or just unpleasant, or just annoying, or not really a problem at all?" Remind yourself that no one can do *everything* "immediately." And you could and should take three deep, slow breaths before starting the next task.

It is important to be aware of our behaviors, from the basics of regular eating and sleeping to being in such continuous motion that we seem to forget to breathe (especially those three deep, slow breaths). For example, are you eating haphazardly, saying to yourself (and here one uses the skill of observing thoughts), "These other tasks are so important that I'll get to my breakfast after I just get this load of laundry started / leave a message for the doctor / get this Medicare paperwork taken care of ...," and then never getting to any food at all? Similarly, are you worn out at the end of the day, but saying to yourself, "I'll just do one more thing before bed ...," and then it is several hours later? Use self talk to commit to, to encourage, and, if necessary, to chide yourself to eat better, to go to bed earlier, to sleep fifteen minutes later, to stay in the hot shower five minutes longer. And notice as you do these things that the world does not stop spinning and fall off its axis, and neither does your family member's health become dangerously jeopardized because you have paused to take three deep, slow breaths, to eat a carrot, or to watch a butterfly flit through your backyard.

Finally, it is important to observe our emotions. We can begin to shift some of our emotional sates right away; others will take longer. The obvious example of an easier emotional shift is self-observing to see if you are feeling anxious or worried as if you were facing a crisis; and if the answer is "yes," then remind yourself that the crisis is over. You can invite yourself to feel a sense of accomplishment and some pride and confidence that you rose to the occasion. And you can take three deep, slow breaths. Emotions that may take longer to shift are the feelings of grief that come with any major loss, such as the loss of the person you now care for as you knew to be or the loss of the life you lived before the responsibility of caregiving. Grief does take time. It is a natural process that runs its course, and it is important that we do not avoid or obstruct the process by staying in "crisis mode."

In sum, we can shift gears by observing ourselves and choosing to take a small step, and then another, and then persisting with those small steps. We can observe ourselves at any moment, in any location, with no one else the wiser, and we can in that moment resolve to make a small change in our thinking, in our actions, or in our feelings. Some changes will come sooner or more easily than others, but change will come if we persist. And we should always remember to breathe.

This article first appeared in the July/August 2010 issue, when Carol Spar, Psy. D., a Licensed Clinical Psychologist, was with the Mental Health Center Serving Boulder and Broomfield Counties (now Mental Health Partners).

#### Beneath

#### by Kika Dorsey

**S** he wanders about in the Alzheimer's unit, hunched over and unstable, taking dirty napkins from the tables and strewing them across the floors and fiddling with the residents' belongings in the rooms. She wears Depends and her hair gets greasy the day after it is washed. I used to be able to wash it in the sink when I visited her, but now she is unable to follow directions and won't lower her head. Her breath smells of decaying food and her clothing contains stains on her lap and shirt from spilling while eating. She eats salads with spoons, pours the orange juice onto her meal, then eats the soaked food. She speaks nonsense with occasional German words that make no sense. She stares without blinking. Her toenails are covered in fungus. She is only 71.

Living in Vienna with my father, she began to forget things, then she began to try to wander and escape from his watchful eyes, and then my father couldn't take it anymore and committed suicide, plunging headfirst from the third floor of a building. I rushed to Austria to bring her back to the states, and for a year I had to deal with immigration, social security, guardianship, and finding her a home. She lived with us for two weeks, a time of complete chaos. She hid things in drawers and tried to escape. We found items under mattresses, in closets, behind couches. We were always searching for our belongings. It was a relief when I found her a nursing facility.

But the stress continued. I received calls constantly. She escaped twice and I had to put a GPS on her wrist. She began attacking the caregivers and we had to put her in a mental facility and they put her on so many drugs that she became a zombie. Now they have weaned her off them and the only calls I get are when she falls. I dealt with my stress by drinking vodka. I am sober now, and I try to take care of myself. I have a well of despair in me that is unfathomable. I don't understand how a person can keep living without a mind. Or maybe there's a well of light beneath this surface that I cannot see. Because my mother is so young, she could live like this for another twenty years. It makes no sense to me.

I visit her every week but my visits get shorter. I used to take her out when she was first there. We would eat at Murphy's, and when she poured salad dressing into her coffee, I just ignored it. She would tell me she loved me, that I was beautiful. I miss the days she could talk. Now I sit next to her and hold her hand and tell her about my day. She gets up and wanders aimlessly. I follow her around some, then leave. 6

My only comfort is a sense of mystery, like the feeling one gets when watching the snow fall, or gazing at the blooms of young apple trees in the spring, or the waves of a sea that say look beneath, I am what you are unable to imagine.

*Kika Dorsey is a caregiver, poet, and professor* at Front Range Community College.

"For one human being to love another: that is perhaps the most difficult of all our tasks, the ultimate, the last test and proof, the work for which all other work is but preparation."

– Rainer Maria Rilke

### The Unfolding by Kaelin Kelly



any months ago When you were in transition Newly unable to live alone Or meet your own basic needs The emails flew "What will we do?" "Where can she go?" "WHAT"S GOING TO HAPPEN?" A roller coaster of emotion Burning in cyberspace.

In the midst of the chaos A quiet voice spoke Les, my sweet husband, said, "Bring her here to live with us." "She deserves it."

I remember the squawk That rose from my throat "What!," I croaked,

"We couldn't ..." "Too much ...' "Unknown ..."

That moment was the seed The thought of what might be With my husband's willingness We could make it happen Take this piece of our lives And devote it to Mom

I remember the moment It all came together "Mom," I asked, "Are you afraid of dying?" "No," you answered Then anguish filled your voice "But I don't want to die alone."

That was it. Such resolve filled my being Hesitation melted away A life of connection Deserves a death with connection A transition fully supported No matter how it plays out

Death may steal in When there's no one around There are no rules here Just a process unfolding

Regardless of the timing You won't die alone "Not alone" is more than A hand holding yours It's a resting in peace Knowing you're loved

From A Caregiver's Journey: Poetry by Kaelin Kelly.

# **Oh No, Not Me!** *by Gary LaCroix*

om was still living in her apartment in Boulder; but with her ever increasing dementia, my sisters and I knew the time for a move was close. It was becoming less and less safe for her to live alone. We decided, as a family, that she would live with my middle sister, who was happily married and living in Alabama with three children whom Mom loved. It seemed so logical a choice that builders were already pricing the remodel of the mother-in-law addition to my sister's home. But after our second trip to Alabama to see how the house would be changed to accommodate Mom, it was clear that the family of five completely confused her. There was just too much action. She kept asking, "What are we doing here?," "When can we go home?," "Please, I don't want to be here any longer!" We couldn't help but wonder if our long-time plans would have to be changed.

After we got back to Boulder, Mom again seemed fine, and it occurred to me that maybe it would be best for her to move in with me. She was familiar with my home and had visited me there for the fifteen years I'd lived in Boulder. We reasoned that her adjustment to the move out of her apartment might be much easier because of that familiarity. My sisters were more than willing to be a part of her care and to support my caregiving, so I knew I wouldn't be entirely on my own, but there also were questions that weren't so much about her adjustment as they were about mine. Could I stand it? Would it work? I would be a son taking care of an elderly, increasingly confused, and eventually physically debilitated mother. "Oh no, not me."

Even with these thoughts going through my head, I still found myself making plans. It would be easy to remodel the garage. I started drawing, made a set of plans, talked to contractors, and began getting bids. It was a long time — months — before the contracts were finally signed and the crew started tearing down walls.

In the meantime, Mom was outwardly failing. It was just a few months, but there were many changes in her. By this time I was going to her apartment two or three times a day to prepare food and assist her. I had already unplugged the stove after a scary call: "I can't remember how to turn it off!" (Thankfully, she could still use the phone ... or maybe not so thankfully. One day I had 100 calls on my voice mail. She didn't remember making any of them.) Mom was a loving person and always appeared happy, but questions still remained: What was I getting into? Could I handle it?

I realized I needed help, especially after others kept asking me things like, "Do you know what you're getting yourself into here?" I went to several Alzheimer's support group meetings and participated in an 8-week workshop at the senior center which focused on caring for aging parents. As a result, I found myself becoming more and more positive about my plans as the weeks passed. I changed my work schedule to fit that of a caregiver, which was possible because I am an artist and freelance designer and arrange my own appointments. By the time the remodel was finished and Mom moved into my home, things were organized and I was ready—ready for my new lifestyle.

There were many delays, but the move happened in spite of them. Mom lived with me for almost two years until she passed away in her own bed, among her own things, with her family at her side. I believe her transition was as she wanted. I think of her often and find that I'm forgetting the hard times and remembering the fun and laughter.

This article first appeared in the September/ October 1995 issue.



# **An Unexpected Gift** *by Sharon Schwoch*

**M** y mother did me a favor. I didn't realize it at the time—I was scared. Scared about many things: about how we would get along, about losing touch with friends, about emergencies that were bound to arise, and about her eventual death.

After my father passed away in October 2006, I helped my mother move into an apartment the following spring. I was concerned about how she would adjust after being married 67 years, but she flourished—made new friends, joined the Red Hat Ladies, had her first massage, and started doing needlework again.

There were also a few emergencies and a new diagnosis of myelodysplasia. After an episode in April 2009, her doctor told her in no uncertain terms that she could not live alone anymore.

My husband and I offered her the option of living with us. It would, however, mean moving 1,200 miles away from most of her family, friends, and physicians. Her other option was assisted living. She and I spent a month visiting facilities and weighing their pros and cons. She eventually chose a lovely place with a view of Lake Superior. My brother joined my mother and me to make a final inspection of the apartment the day before I was to return home. The nurse manager told Mom she would have a few more days before making her deposit.

That night, however, my mother confessed that she couldn't really see herself living there. I said she could still change her mind. She replied hopefully, "I can?"

So I called my husband and said to be ready to drive to Wisconsin in ten days. As soon as I got home, we began shifting furniture around so Mom could move into the master bedroom. I visited the county Medicare Ombudsman [now Medicare Counselor] office to find the best drug plan for her, made an appointment with a physician who was accepting new Medicare patients, reserved a rental truck for the move, arranged to have the bedroom painted while we were gone, and headed back to pack Mom's things.

After taking three days to move and the next few weeks to unpack, we had Mom settled in. We still had time to enjoy the rest of the summer. Mom liked sitting on the patio, going to the library and bookstores, shopping at the Farmers Market, trying new restaurants, and not being alone—especially at night.

Then, in mid-September, Mom had carotid artery surgery. She recovered so well that she came home two days later. She had a small stroke, however, and we brought her back to the hospital, where she stayed for a week. For the next month, a nurse, an aide, and therapists visited her several times a week. Her speech therapist said she was one of the few clients who not only completed but also enjoyed her homework. In addition, Mom often practiced her speech by reading poetry or passages from one of her current novels aloud. Mom demonstrated yet again that she had a lot of *sisu*, Finnish for perseverance or determination.

Having lived in Colorado since 1970, I missed celebrating many birthdays and holidays with my parents. In 2009, however, we made up for that. In October we celebrated Mom's 91st birthday. Not long after, she began looking forward to Thanksgiving. In early December, we attended one of my favorite holiday activities, the annual Christmas service at Ryssby church. It reminded Mom of the church in Minnesota that her father helped build. As December 25 got nearer, Mom was like a little kid—wearing her Santa hat and feeling her Christmas stocking to determine what was in it. We made New Year's Eve special by having a smorgasbord by candlelight.

(continued on page 9)



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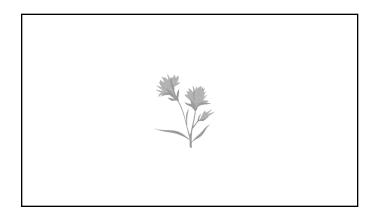




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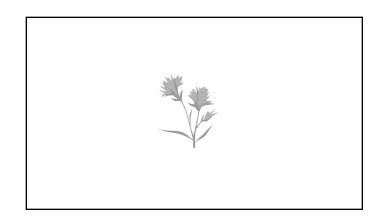
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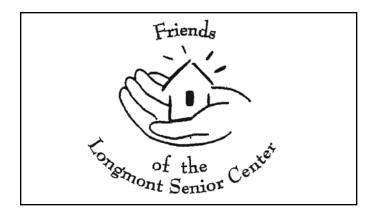
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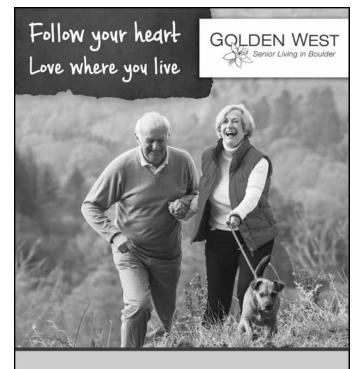
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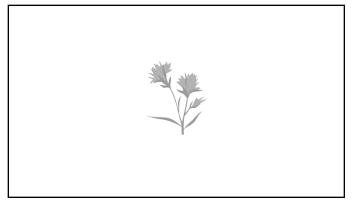




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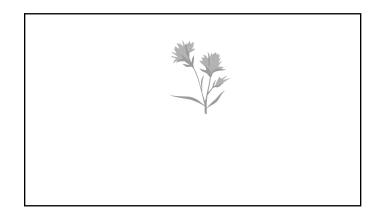
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# **An Unexpected Gift** (continued from page 8)

Mom passed away in February not quite seven months after she came to live with us. During that time, I felt such a sense of purpose. I told Mom before she died that it was an honor to have taken care of her. The caregiving experience has given me more peace than I could have imagined.

This article first appeared in the November/ December 2010 issue.



# Last Dance with My Father

by Maria B. Greco, Ph.D.

W hen my father's days were growing short, he decided to leave his home of almost fifty years, a home which he had shared with my mother for most of that time. I remember being worried when my mother died that my dad would not be able to carry on without her. Though he missed her, he still was able to maintain his life without help and to welcome us home with the same hospitality and generosity of spirit that we had known when my mother was alive.

The day did come, though, when he became too weak to carry on alone. My sister lovingly opened up her home and her heart to him for the last two years of his life. Since my roots are on the East Coast and I was already living in Colorado, my home was not an option. Dad wanted to be on familiar territory for the last days of his journey.

Because my sister has always been a traveler, she looked to me to be with our dad when she was away. This became one of my life's greatest gifts. Being one of five children, I did not often get my father to myself. Having this time alone with him was unique, special, and restorative.

Over the years, we traveled a rocky road together. My father was a devout Catholic and truly felt responsible for the safe delivery of my soul at my life's end. So, because I had made mistakes in life, I had disappointed and confused him. My dad was a very black-and-white kind of guy at first. Somehow, though, in those last times together, he became the most beautiful shade of gray. At that point, we became more than father and daughter; we became friends. In the process, I learned much about a life well lived, and I learned not to fear death. My father learned that despite my mistakes, I was a daughter for whom he might actually receive a "well done, my good and faithful servant" at the final tally of his life. In our time together, he allowed me to capture his life story on video so that we might have it as a lasting memory. I cannot believe how much I did not know about my dad before that taping. It was a rare, precious look into the landscape of his long lifetime, one that spanned 88 years.

As my dad grew weaker and it became apparent that we would not share many more times together, I often asked him if he was afraid to die. He always said the same thing: "I am ready when the Lord calls me." When his time did come, he was ready and he was at peace. Somehow, in his peaceful passing my fear of dying disappeared.

That truth was tested within five years when I was diagnosed with ovarian cancer, an out-of-theblue diagnosis, one that is often deadly. Somehow, despite that fact, I was filled with peace and hope. I was not often afraid of what the future held for me. I have been fortunate to become a long-term survivor of that illness. I will be forever grateful for my father's example as it sustained me in my time of uncertainty and upheaval.

More recently, I have been working as a chaplain at an assisted living residence. I feel fortunate to have taken my experience with my father into my heart. Each new person I meet is a sweet reminder of the times I shared with my father. Each meeting is filled with the joy of recognition. There is so much to be learned from those who precede us on the journey. It is an opportunity and a gift. I once read that in order to know about the road ahead, we

should ask someone on the way back. Though our elders are still on the journey, there is much to be learned from their travels.

I was lucky that my family situation forced me to show up when I might have chosen not to. I also realize that the actual geographic distance between me and my father enabled me to compartmentalize my relationship with him. When I was with him, I was completely with him. When I was not, I was free to resume my normal routine without guilt.

I have seen family members at all points of the spectrum. There are those who put their own lives on hold for their loved ones. There are those who avoid spending time with them. There are those who have learned to balance their own lives with the times they share. This is never easy as one's own feelings of guilt or the overwhelming needs of the other make it difficult to achieve a balance. Sometimes there are aspects of spending time with our parents in their declining years that are fear provoking. This is especially true if they do not even remember us. It might feel easier to keep our distance. In the end, when our parents have left us, what we hope for most is a feeling of peace and completion. Each person must decide what it will take to achieve this.

I know from my memory of the time I spent with my father and my day-to-day experiences as a chaplain that this period is often filled with many life lessons and sweet surprises.

This article first appeared in the September/ October 2013 issue, when Maria Greco, Ph.D., Licensed Professional Counselor, was an assistant chaplain at Balfour Assisted Living.

#### "Flow with whatever may happen and let

your mind be free. Stay centered by accepting

whatever you are doing. This is the ultimate."

#### VISIT WITH A CAREGIVER

Linda is a "long-distance caregiver" who has traveled dozens of times from her home in Erie to her childhood home in Iowa to care for her mother and elderly grandfather. For a while she spent as much as half of her time there, and she learned about the special challenges—and rewards—of being a caregiver across the miles.

**Care Connections:** Linda, when did you first become a caregiver?

**Linda:** In the fall of '97, my mother was diagnosed with lymphoma. She's divorced and her only relatives were her elderly father and an older sister, so caring for her fell to me, an only child. I stayed with her for two weeks during the initial biopsies and tests, and then I went back to be with her half of every month for the next six months while she had chemotherapy.

**CC:** How did you manage to spend so much time there?

**Linda:** Fortunately, I wasn't working at the time. And my husband is mellow and understanding. We're both independent individuals, and we're okay being apart.

**CC:** Were you able to get any help caring for your mother?

Linda: Mom lived out in the country on a farm, so she had no access to services and she was twenty minutes from the Cancer Center. I was the only one making decisions, but at one point, when I had to leave and Mom needed more care, I did ask her older sister to help out. There had always been the understanding in the family that she was the "non-helper," but I told her I was bringing my mom over and she took her in.

– Chuang Tsu

(continued on page 13)



## COMMUNITY RESOURCES

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This column provides information about events, classes, services, and other resources of interest to family caregivers in Boulder County. Please remember that it is each person's right and responsibility to research a service provider 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, please email InfoCaregiver@bouldercounty.org or call 303-678-6116. The deadline for the September/ October 2017 issue is July 27.)

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, July 6 and August 3, 2 - 4 p.m., at East Boulder Senior Center, 5660 Sioux Drive, Boulder (call 303-441-1546 to register); on Mondays, July 17 and August 21, 10 a.m. - 12 p.m., at Longmont Senior Center, 910 Longs Peak Avenue, Longmont (call 303-651-8411 to register); and on Friday, August 18, 1:30 - 3:30 p.m., at Lafayette Senior Center, 103 S. Iowa Avenue, Lafayette (call 303-665-9052 to register). There is no charge, but donations are appreciated. For more information, visit www. bouldercountyMedicarehelp.org.

The Alzheimer's Association has recently added new regular programs in Boulder County: **Caregiver Support Group**, for persons caring for a loved one with Alzheimer's disease or other form of dementia, on the second Tuesday of each month, 12:30 - 2 p.m., at Longs Peak United Methodist Church, 1421 Elmhurst Drive, Longmont; another **Caregiver Support Group**, on the first Wednesday of each month, 5:30 - 7p.m., at Niwot United Methodist Church, 7405 Lookout Road, Niwot; and **Memory Café**, a place for persons with dementia, with their friends or family, to enjoy socializing in a comfortable setting, on the third Monday of each month, 1 – 2:30 p.m., at First United Methodist Church, 1255 Centaur Village Drive, Lafayette. For more information, call Ralph Patrick, Boulder County Regional Director, at 303-813-1669.

The Alzheimer's Association of Colorado offers Know the 10 Signs: Early Detection Matters, on Wednesday, July 26, 2 – 3:30 p.m., at The Carillon at Boulder Creek, 2525 Taft Drive, Boulder; and on Thursday, July 27, 10 - 11:30 a.m., at West Boulder Senior Center, 909 Arapahoe Avenue, Boulder; The Basics: Memory Loss, Dementia, and Alzheimer's, on Tuesday, July 11, 3 – 4:30 p.m., in Spanish, at Longmont Senior Center, 910 Longs Peak Avenue, Longmont; on Wednesday, July 12, 6-8 p.m., at Broomfield Community Center, 280 Spader Way, Broomfield; on Tuesday, July 18, 2 - 3:30 p.m., at Kaiser Permanente Baseline Clinic, 580 Mohawk Drive, Boulder; on Tuesday, July 25, 3 - 4:30 p.m., at Longmont Senior Center (address above); on Tuesday, July 25, 6 -7:30 p.m., at Longmont Senior Center (address above); on Tuesday, August 22, 2 - 3:30 p.m., at Kaiser Permanente, 280 Exempla Circle, Lafayette; and on Wednesday, August 23, 12:15 -1:30 p.m., at Walt Self Building, 432 5th Avenue, Lyons; Living with Alzheimer's for Caregivers: Middle Stage (2-part), on Mondays, July 24 and July 31, 1 – 4 p.m., at Longmont Senior Center (address above); Effective Communication Strategies, on Tuesday, July 25, 6 – 8 p.m., at The Villagio, 11592 Gray Street, Broomfield; and on Wednesday, August 9, 6 - 8 p.m., at Broomfield Community Center (address above); Understanding and Responding to Dementia-Related Behaviors, on Tuesday, July 11, 7-8:30 p.m., at Niwot United Methodist Church, 7405

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Lookout Road, Niwot; Legal and Financial Planning for Alzheimer's, on Tuesday, August 22, 6 - 8 p.m., at MorningStar Assisted Living, 575 Tantra Drive, Boulder; Healthy Living for Your Brain and Body, on Wednesday, August 23, 2 - 3:30 p.m., at West Boulder Senior Center (address above); and Spirituality and Dementia, on Sunday, July 30, 10:45 – 11:45 a.m., at First Presbyterian Church, 1820 15th Street, Boulder. See class descriptions at *www.alz.org/co* (Classes and Workshops / Boulder). Pre-registration is required, at the website above, by calling the 24/7 helpline at 1-800-272-3900, or by emailing *hvolden@alz.org*.

Erie Community Center offers an Alzheimer's Association Caregiver Support Group, for current or former caregivers, family, and friends of persons with dementia, on the first Thursday of each month, 4 – 5:30 p.m. (register at 303-813-1669; and Medication Management, about considerations for safe and effective use of medications, with Dr. Megan Moini, Avista Family Medicine, on Tuesday, July 25, 11 a.m. – 12 p.m.; both at 450 Powers Street, Erie. Register at 303-926-2795.

Longmont Senior Services presents Adjusting to Life's Changes Support Group, for persons dealing with changes (such as caregiving) and working to find a "new normal," on Thursdays, July 13 – August 31, 3:30 – 5 p.m. (schedule an intake with Brandy Queen, at 303-651-8414); Early Stage Dementia Support Group (sponsored by Alzheimer's Association), an 8-week series for people with early stage dementia and their family care partners, who meet separately, on Fridays, July 21 – September 8, 2 – 3:30 p.m. (schedule a screening interview with Ralph Patrick, at 720-974-1586 or *rpatrick@alz.org*); and TRU PACE: A Program of All-Inclusive Care for Seniors, about the program which provides and coordinates all healthcare services and support for seniors who would otherwise need

a nursing home level of care, with Leslie Mader, Outreach and Enrollment Manager, on Thursday, August 17, 10 – 11 a.m. (register at 303-651-8411). Programs are at Longmont Senior Center, 910 Longs Peak Avenue, Longmont.

AgeWell, a program of Longmont United Hospital / Centura Health, holds Advance Directives workshops, about considering and clarifying one's wishes for medical treatment in the event of incapacitation, on Thursday, July 13, or Thursday, August 10, both 9:30 -11 a.m. (\$5 fee for Longmont residents, \$6 for non-residents); and Pain Sucks, but Life Goes **On: A 5-Week Course in Solution-Focused** Chronic Pain Management, about discovering what you can do for yourself to live the life you can still live in spite of chronic pain, with Jay E. Valusek, M.Ed., starting with an information session on Thursday, July 13, 3 - 4 p.m. (free, but registration needed), and continuing with class sessions on Thursday, July 20, 3 – 5:30 p.m., and Thursdays, July 27 and August 3, 10, and 17, 3 – 5 p.m. (\$50 fee for Longmont residents; \$60 for non-residents). All are at Longmont Senior Center, 910 Longs Peak Avenue. Pre-registration is required, at 303-651-8411.

Boulder County CareConnect provides nocost services to Boulder County residents age 60 or over. Volunteer-provided services include escorted rides to and from medical appointments, escorted rides for veterans to VA facilities, grocery shopping and delivery, minor home repairs, yard cleanup, and snow shoveling. For more information, call 303-443-1933 or visit www.careconnectbc.org.

Boulder County Area Agency on Aging sponsors the **National Caregiver Training Program**, an 18-hour course taught by a registered nurse that helps family caregivers acquire the practical skills needed to provide safe, confident home care for



frail older loved ones, on Thursdays, July 20 – August 31, 1:30 – 4:30 p.m., in Boulder. The course is open to Boulder County residents who provide any level of care for a relative, partner, or friend who is age 60 or over, or of any age if the person has dementia. (The course is not open to professional caregivers.) There is no charge, but donations are appreciated. Financial assistance for respite care (substitute elder care during class periods) is available. Preregistration is required, at 303-678-6116 or *InfoCaregiver@bouldercounty.org*.

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

## **Visit With a Caregiver** (continued from page 10)

Eventually Mom decided to sell the farm and move into town where there was transportation to treatment, Meals on Wheels, and other services. Leaving the farm was hard, but we both felt it was a blessing afterwards. She was closer to her friends, had more income, and felt less isolated and depressed.

**CC:** Was it hard for you when you couldn't be with your mom?

Linda: There were no direct flights to her town, and it was a 9 ½ hour drive there, so I worried that something serious would happen and I wouldn't be able to get there quickly enough. I remember one Christmas when a friend of hers called and said that Mom was dying. Of course it terrified me, but I called the Cancer Center and they reassured me that she was doing fine. It really helped to have someone more objective than friends or family who could tell me how she was.

**CC:** And after your Mom got better, you started caring for your grandpa?

Linda: Yes. His wife had Alzheimer's disease, and they had both moved to a long-term care facility. He was 96, and after she died, his health also went downhill. But he didn't think of himself as old. He wanted to get better and do things, but he couldn't.

**CC:** Did you feel good about your contribution as a caregiver?

**Linda:** Yes, especially with my grandpa. I don't think I've ever done anything as important for anyone. I helped him feel safe, especially when he needed protection during some difficult family interactions. I know I did a good job and that things worked out as well as possible. I also advocated for him with his physicians.

**CC:** What were your strengths as a caregiver?

Linda: I'm a social worker, so that helped a lot. The family certainly turned to me as the "expert" on social services. And I've always been good at imagining others' feelings and putting myself in their shoes. I could feel what it would be like to be 96, and to see all of your things sold, and to have your world reduced to one little room. I knew that Grandpa needed to keep things that had special memories for him ... he needed to feel connected to his former life. There were big photos of flowers that he had taken, and I moved them to his room at the nursing home. He was pleased when he saw them there, and he'd proudly tell the staff, "I took those photos." I told the staff things about him too; I think it's important for them to know their residents as persons who've had full lives.

**CC:** It sounds like you were close to your Grandpa. He was a lucky man to have you in his life.

This interview first appeared in the January/ February 2003 issue.

## **Opening the Doors of Understanding** *by Bryce Holloway*

**M** y name is Bryce, the husband of Fran, who passed away October 2, 1992, having fought a two-year battle with renal cell carcinoma, a form of cancer for which there's no known cure. Many questions have been asked of me. When Frances was first diagnosed, how did I feel? What did I do? Well, it's kind of like getting hit on the head with a baseball bat. You pick yourself up and go from there because you really don't know how to feel. Not many of us have had the displeasure of going through this before.

We received the finest of care and tried many experiments and new medicines, hoping always that one would work. As the disease progressed, it settled in her spine and finally broke it. She had a spinal fusion, but after her spine broke a second time, I remember her looking up and saying she wanted to come home from the hospital. She came home. That is when hospice entered our lives. Everyone there made us a part of their family. Whether it was giving advice on how to proceed with legal matters or providing care, they were always there. Each and every one of them gave their fullest available time to my wife and me, answered every question, and never said, "I'm too busy."

With the exception of chemotherapy, I administered the medicines and gave the shots. I did everything humanly possible to take care of Frances. When the nurse said the time had come to have a hospital bed, I fought because I thought giving in would be an indication to my dear wife of nearly 40 years that the end was in sight. We both knew it, but I didn't like to admit it. As things progressed, we realized this was a dead-end street, and we began to have a very intimate conversation. "What will you do if I'm gone? ... What I want you to do is this ..." This was very hard for both of us, because the last thing I wanted her to do was give up. But with the help of the hospice social worker and staff, we tried to wrap up our loose ends and answer questions so Fran could go in peace, and so I could go on with my life for as long as the man upstairs gave me. I was fortunate enough to have a partner who wanted to do this. So a lot of questions were answered before she left. It has helped me a tremendous amount, and her wishes were followed to the letter.

If I could say anything to someone who's approaching this same situation, it would be to try to open the doors of understanding, to try to have a conversational relationship so that both sides can express their feelings. You're not going to like what you hear, it's going to hurt, but it will be so much easier afterwards if you know that their questions have been answered and you know their wishes for the time ahead. It makes it so much easier to open that door the next morning. I know that some of us want to slam that door and say we'll never open it again, but unless you want to go with them, you've got to go on with your life. You've got to get through this bereavement period, and it can be done.

If you're still in the period of hoping for a turnaround, never give up that hope, but don't put off things you need to take care of. Talk to each other. Use the time, whether it's three days or three months. Because the opportunity is going to go, and you can't back up the film. There's no rewind on life.

This article first appeared in the January/February 1995 issue.



CARE Connections Boulder County Area Agency on Aging P. O. Box 471 Boulder, CO 80306



# -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	303-441-4388/303-413-7494 (bilingüe)	
City of Lafayette	303-661-1499	
City of Longmont	303-774-4372/303-651-8716 (bilingüe)	
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	Aging and Disability Resources for Colorado
Superior	303-441-1617	Resources for Colorado