

CAREConnections

Information and Inspiration for Caregivers

A Publication of Boulder County Area Agency on Aging

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INSIDE

1

Respecting the Need
to Choose

4

Visit with a Care Recipient

5

In Morris' Words:
What It's Like to Live
with Alzheimer's Disease

Compassionate
Conversations: How to
Talk with a Loved One

7

Advice from a
Wheelchair User

8

From the Care Receiver's
Perspective

10

Never Take Away
Anyone's Sovereignty

11

Community Resources

14

Receiving with Reluctance

Dear Caregiver,

In *Care Connections*, we usually focus on the experience of the caregiver, which, of course, is inescapably tied to the experience of the care recipient. Two sides of the same coin.

The experience of the caregiver can be intense: so many responsibilities, so many concerns for our loved one's needs. The experience of the care recipient is equally intense: illness or disability, reduced function, loss of independence (at least some of it), and reliance on others for care. Both the caregiver and the care recipient are in challenging circumstances, and the need for communication and understanding between them is great.

Probably any care recipient could understand their caregiver(s) better by reading any issue of *Care Connections*. But in this issue we look at helping the caregiver understand the experience of their care recipient. The more we can put ourselves in our loved one's shoes, the better able we are to provide care in a sensitive, respectful, and compassionate way.

We hope you'll find the articles inside both interesting and illuminating. Here's to understanding!

The Editors

Respecting the Need to Choose

by Kari Middleton



As a caregiver, you want what is best for the person for whom you're caring. So that goal should inform how you approach every decision and every action you take regarding your loved one, right? It sounds simple enough... except that it isn't. Care recipients have their own ideas about what's best for them, and they might not agree with yours. Sometimes a loved one may want something that simply isn't in that person's own best interest, perhaps even something that's harmful. As someone who has taken on the responsibility of keeping another person well, how should you respond in such circumstances? The truth is that these matters can be complicated. Sometimes a caregiver should intervene—and often a caregiver shouldn't.

First, we should recognize that competent people do get to make their own decisions, care recipients included. Aging does not equal incompetence. Nor do health challenges. An older adult who is very



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dependent on a caregiver due to serious illness or mobility challenges could still be perfectly capable of making reasoned judgments and have definite preferences. Just as it makes sense for younger adults to exercise as much control as possible over the course of their own lives, it makes sense for older adults to enjoy the same level of autonomy. Most of us probably want this for ourselves. Preserving some degree of independence may help a care recipient retain a sense of dignity and autonomy, or even a sense of self, while also potentially alleviating some of the burdens of the caregiver (maybe you really *don't* need to make all the decisions!). At a basic level, allowing people to direct their own lives as much as they are able is a matter of respect: it's treating them as whole people with interests, desires, and judgments of their own rather than merely as people who require care.

This remains true even when people choose things that aren't in their own best interest (we've all been there, making a decision that really wasn't best for us). Fostering independence necessarily entails risk. A care recipient might choose not to pursue treatment for a medical condition; might choose to take a solo walk and risk falling; might choose not to wear hearing aids even though the person's relationships deteriorate as a consequence; might choose to ignore medical instructions on diet, exercise, and lifestyle; and so on. One can, of course, encourage a loved one to take a healthier path. But the truth is that the decisions competent adults make are just one more thing outside one's control, among others (as anyone can attest who's had it rain on a perfectly planned outdoor event). If a person isn't competent—if dementia has severely impaired the person's ability to reason and make sound judgments, for instance—it is still possible to include that person in the course of his or her own life, *as much as the person is able*. For the really big things, such as Do Not Resuscitate orders, preferences for medical treatment when incapacitated or facing terminal illness, and similar matters, with luck a care recipient will have already spelled out preferences. But if not, and also when it comes to smaller things that give texture to our lives (food, recreation, where to live and with whom, etc.), consider your loved one's personality and past statements of personal preferences: would the person have wanted a certain course of treatment? Would your loved one have enjoyed some activities, or rather have gone to the dentist? Of course, personalities and preferences can change, so also think about what your loved one says now, especially repeated statements and statements made when the care recipient is experiencing relative mental clarity. Notice non-verbal cues as well.

If someone smiles and laughs whenever Elvis Presley is on the radio, it's a good bet that person enjoys listening to Elvis. If someone cries and pulls away whenever she is being led to the park, she may be telling you she doesn't want to go to the park.

So far so good, perhaps. But life is complicated: there may well be times when you do need to step in, when the right thing to do is to intervene in what your loved one chooses. Elvis and trips to the park are one thing, but what about shelter, food, water, medical care, or basic hygiene? If such basic needs are being neglected and the person is no longer competent, for example due to cognitive impairment, then those are indications that intervention is necessary. "Competent" here means genuinely and in a clinical sense lacking the capacity to direct one's own life; it doesn't mean sometimes making unwise decisions or decisions with which others disagree. (Competent people sometimes do make decisions that are irrational, or at least that seem irrational to others.)

For example, someone who is in the middle stages of Alzheimer's may no longer be capable of rational thought or have a firm grasp of reality. If such a person insists on taking a walk in freezing temperatures while wearing sandals, shorts, and a t-shirt, he or she should be prevented from doing so (that is, either redirected or coaxed to wear weather-appropriate clothing). Similarly, someone who is cognitively impaired in such ways and who has open wounds or other injuries should be given medical care even if the person resists it. (A diagnosis of dementia does not automatically render a person incompetent; someone in the early stages, for instance, could still have enough cognitive capacity to make an informed decision about his or her own medical treatment. For example, a recent news story detailed what it was like for a man living with the early stages of Alzheimer's. The care recipient, a writer, refused to take medication intended to stabilize his mood,

complaining that it disrupted his ability to write, a decision his family—who after all was affected by his emotional wellbeing, too—wasn't necessarily happy with, but accepted.)

When a competent care recipient makes a decision not in that person's best interest, it can be stressful for the caregiver. If fostering independence necessarily entails risk, risk probably entails that a caregiver feels uncomfortable. No one wants to see a loved one hurt. Basic prescriptions for self-care apply here: take breaks, attend to your own health, establish or maintain a support network, perhaps learn some de-stressing or relaxation techniques. It may also be helpful to recognize that your loved one's decisions, even when they are not what you would have chosen, do not represent a failure on your part. They aren't about you at all—they're about your loved one's own individual wants and interests. Be flexible: realize that things aren't always going to go as you want them. Again, some things are outside of one's control. When it does rain on your perfectly planned event, you can't control the weather, but only your response to it—and it's still possible for the event to go well, even if not the way you envisioned, and even if it means redefining what it means to go well. A similar point relates to your care recipient's decisions. Keep things in perspective, and remember that humor is a powerful tool. If laughter isn't the best medicine, it's surely among the best. And, finally, perhaps consider again your role as a caregiver: maybe it isn't simply to keep the care recipient as safe and well as possible. Maybe instead it's to help the care recipient live as safely and as well as possible the life the care recipient wants to live (or if cognitively impaired, would have wanted to live).

Kari Middleton is the Respite and Companion Volunteer Program Coordinator and also helps provide elder rights training for Boulder County Area Agency on Aging.



VISIT WITH A CARE RECIPIENT

Margaret Boeckmann is a retired policy analyst who taught social science research on the university level and worked with government agencies assessing the effectiveness of social programs. She lives with her husband and two nearby daughters and grandchildren. Margaret began to experience vision loss 15 years ago and has been adapting to a continual deterioration of her retina, so that now she has no central vision and is legally blind. She no longer drives and cannot read without significant magnification. She has been seen by doctors at low vision centers where she has learned how to use readily available technology, such as iPhone and iPad, as well as devices designed for individuals with low vision. Accepting her diminished ability to read, Margaret decided to discard a lifetime's accumulation of professional documents, notes, magazines, and books. To accomplish this she needed help.

Care Connections: How did you go about finding help?

Margaret: Although I have two daughters close by, I realized that they have very full lives and would not have time to spend helping me. Further, my husband is still working, and it would be difficult for him to help me. Living within walking distance of several schools, I contacted the closest university's office for student employment. I wrote a job description specifying the skills required to meet my specific needs, which included strong computer literacy and willingness to read documents and other materials. I included a description of the work environment, the amount I was paying, and the number of hours per week to work. I interviewed seven candidates and decided on the one that I felt most comfortable with, a freshman named Autumn.

CC: How did that work out?

Margaret: Very well. Initially, she worked four hours a week and we focused on clearing out the paperwork and books. In addition, she read emails, caught me up with Facebook, paid online bills, and downloaded audible books. During school breaks, she could work more hours and she has scanned old photos into the computer and transferred old tapes to DVDs. As my vision has deteriorated, she helps me with laundry (as she can see stains that I can't), organizing my closets, and other things around the house. She has put labels on my cosmetics and other packaging that has impossibly small print. Autumn has been with me for two years now, and the relationship has evolved. We respect one another and frequently discuss the material she reads to me. Currently, I take classes at the school Autumn attends. She helps me download assignments such as poetry onto my iPad so that I can read them. Sometimes she reads the poems and other materials to me. Frequently, we have discussions about what we are reading.

CC: This seems to be working out. Any advice for others who are thinking about hiring help?

Margaret: The most important thing is to identify what it is that you need help with. Be realistic and specify the skills that the person must have. For me, it was vital that the person be extremely good with technology since I needed to learn how to use available technology. It is also important to find a person you can relate to and feel comfortable with. I was impressed with Autumn's maturity and sense of humor. In the interview I found her to be smart and confident.

CC: That sounds like an ideal balance. Thanks, Margaret.

This interview was conducted by Lynn Malkinson, Care Connections Editorial Advisory Committee member.

In Morris's Words: What It's Like to Live with Alzheimer's Disease

by Morris Cohn

Morris was 67 when he told his wife, author Barbara Cohn, about his experience of living with Alzheimer's. He passed away three years later.

One time I feel one way and another time I feel a different way. I cope by finding things to do. I read, talk to people, go out to lunch with my friends. I feel just like anybody else, but I'm limited in things that I want to do, or where I want to go. I have to have someone take care of me. I would rather be my own person and do what I can do as much as possible. It's not great having this [Alzheimer's] and there's not much I can do about it. But I do have lots of great friends and family, and I'm lucky to be able to think and act and live a partial life.

I'm not very happy at times. It's not easy for me, and my wife tries to help as much as possible. I feel frustrated. I can't have my car, which was taken away. I don't have as many options. We have our TM lunch*; one of the things I look forward to. That's a happy thing to do. Having people around is obviously good. I like watching movies and TV.

Sometimes I don't know what to do, or I forget things and have to depend on my wife. I've had things taken away from me. When I first got the diagnosis, I thought it was a bunch of crap. I didn't think the doctor had the right diagnosis and that I was pretty much okay. Now I understand that I have Alzheimer's disease and things are more difficult. That's the way it is. Having a support group is very important to me. Sometimes I get frustrated and sometimes I feel that I'm still a human being and that I can do things.

I know I'm taken care of. I'm able to just be a good person that other people want to be around. I'm already enlightened in my own way. I feel

like I'm my own being, my own person, and am living a life to the best of my ability. I like music and culture. I'm very lucky to have a support group of friends and family. In this life, I'm doing the best I can and I'll continue to with friends and family.

I want to be treated like any other human being. My message to others is try to find your own happiness and do the best you can. I still like to meditate and I like to take a nap every day. I am getting more tired. I can't do a lot or do as well as I used to do.

**About a dozen friends who practice Transcendental Meditation have been meeting regularly for lunch every Tuesday for the past 18 years.*

From Calmer Waters: The Caregiver's Journey Through Alzheimer's & Dementia," by Barbra Cohn. Used with permission.



Compassionate Conversations: How to Talk with a Loved One

by Claudia Helade, Ph.D.

If you've ever been sad or frustrated with your efforts to comfort, support, or "get through" to a loved one in your care, you are in the company of many on both sides of the conversation who would love to break the pattern. Communication freed of impediments to understanding is made less difficult with a few helpful tips that generate and support effective and loving connection.

Remembering that the goal of any communication is to understand the perspective of the one with whom you are interacting, whether verbally or by just being present, is essential. There may be additional reasons for communicating, but understanding another is the baseline for any successful communication. In order to understand we must come from the heart, and when we approach another with the intention to



understand their perspective, all manner of options become available from a respectful and open stance, free from reactivity and misunderstanding. A quote of artist Jack Carter, which I saw many years ago on the wall of an art gallery, has stayed with me as an essential reminder: “The move to approach the Stranger should not be made as a move to interpret his motives, but to grasp his predicament.” How compassionate! If we can do that for a stranger, would that approach not also receive a loved one?

Among the skills inherent in successful communication, asking with sensitivity rather than assuming what another feels or thinks is important. I am often surprised by the answers to a question about how my mother feels about a particular question or situation, even though I know her well and can often predict many of her patterned responses. At 94 she is still a growing and changing person and can have an opinion or perspective that I would not have predicted. It is easy to project our own mindset on others without inquiring about their current perceptions and feelings, and this projection often produces anxiety and misunderstandings. I sometimes come to our conversations from the perspective of not having previously heard her speak about a certain topic and am then able to hear a nuance or current feeling I would have otherwise overlooked, offering me an understanding of where she is now without judgment or stale predictability. What offers profound comfort to loved ones is the elicitation and validation of their feelings and perspectives, regardless of whether we agree or share the same viewpoint. When we shift from having the goal of communication to change or convince and just receive what we hear with an open heart, we can validate and encourage whatever our loved one is wanting to share. Our anticipation of the discomfort we can often feel when someone has a different opinion than our own prohibits us from really listening and letting what we hear be protected from

judgment, disagreement, or defensiveness. We can then understand at a deep level the reality of the other.

I ask my mother how she feels about what just happened, or what she heard someone say. I am direct and interested in her response, whatever it is, because I want to understand her and validate how she responds to what she perceives. I don’t “feed” her helpful prompts or disagree; I just ask for and hear what comes up for her. When she shares a feeling or thought, I explore it with her and always find it fresh and interesting. I try to proceed from the place of not knowing so there is space for her to tell me, and I am honored to have her confidence. So often loved ones are “managed” for the sake of expediency or efficient care and how they feel about their situation goes unasked and unacknowledged. The precious gifts of presence, connection, and understanding go unopened.

In every caregiving situation I have encountered, I have enjoyed with my care partner, at one point or another, a keen appreciation for the value of humor. The ironies and frailties and even indignities inherent in being the recipient of care are often opportunities to share humor—always with respect and acknowledgement of our shared vulnerabilities. When appropriate, humor lightens the load and indicates the beauty of seeing and being seen. Few human traits are as bonding and full of understanding as a laugh shared together. When we laugh with someone, as opposed to at them or their situation, we show our compassion in a profound way and can offer our loved ones courage for living as they continue their journey a little lighter and more anchored in our hearts.

Speaking with others from one’s own authenticity elicits trust and comfort and supports everyone’s capacity to be authentic and real. In the article *Speak Your Truth: Three Tips for Communicating Authentically*, author Mike Robbins sug-

gests deepening the ability to speak one's truth with kindness, love, and authenticity by 1) being real, not right, 2) not managing others' feelings, and 3) practice. Authenticity is only available when we are fully present, in our hearts, and willing to hear. Each of those gifts is worth cultivating and will be rewarded with the gratitude and comfort of those who put their trust and faith in our hands and hearts. If we are not in a space where we can listen to another at a particular time, we can "clear our channels" and come to them when we are ready to be present with love.

Compassionate care is focused on the capacity to communicate with love and presence, participating as part of a team in the journey of care partners. If we authentically show up for that calling, we can share a unique and valuable piece of our lives in service of connection and love—surely a beautiful reason to be with one another. In the words of the once ubiquitous bumper sticker—"Be Kind – Everyone Is Fighting a Great Battle"—we find the ultimate reason to communicate with our loved ones with care, offer a precious grasp of their predicament, and comfort with words and presence.

Claudia J. Helade, Ph.D., is a psychotherapist, director of Into the Center, and member of the Care Connections Editorial Advisory Committee.

Advice from a Wheelchair User

by Mary Kathleen Rose



Many of us, as caregivers, have cared for people who need to use a wheelchair. It is important to acknowledge that not all wheelchair users are alike. For example, some people may be long-time users, because of a specific illness or injury. They may be largely independent, working, driving, and living a very active life. On the other end of the spectrum are people who require everyday caregiving to manage basic

activities of daily life. They may be elders who do not have the strength or stability to walk alone. Some people need to use a wheelchair as part of rehabilitation from injury, or due to a specific illness.

In my own practice and teaching of Comfort Touch in medical settings, I have worked with many people who are wheelchair users. Most were patients, but some were the nurses and doctors themselves. I've learned from all of them. I have also used a wheelchair on occasion myself, when it was medically necessary. For this article, I ask the question, "Can we do a better job of interacting with people who use wheelchairs?"

To help answer this question I turned to Duke Williams for his observations and advice. Duke has used a wheelchair since being injured in a hunting accident when he was a teenager in the 1950s. Despite the injury and the challenges of navigating in a wheelchair in the era before the Americans for Disabilities Act mandated accessible building design, he finished high school, continuing on to Michigan State University. After earning his degree in Foreign Relations, English, and Science, he was the first wheelchair user in the nation to be certified as a teacher.

Duke went on to teach and coach, eventually becoming a school administrator and superintendent. He earned a Masters Degree in Educational Leadership from the University of Michigan. Through his years in education and subsequent jobs in the private sector he witnessed changes in accessibility and attitude regarding his status as a wheelchair user. From the extreme difficulties he experienced in college with his "clunky wheelchair," he has seen much better designs, which make life easier.

"People are superstitious," Duke says. "They avoid people in wheelchairs, unconsciously thinking they may end up in one." In general, people fear disability, and do not see beyond the symbols they associate with the disability to the



reality of the person. “Some people show pity, patting you on the shoulder, like a dog.” This attitude is also not helpful.

So what is helpful? First of all, treating a person with consideration and respect is always appropriate. Duke shared an observation he made while visiting his grandmother in a skilled nursing facility. He said that sometimes “caregivers would come up behind a person in a wheelchair, and push them, without even greeting them.” It would be much better to talk to the person first, stating your intentions, letting her or him know what you are going to do.

In public situations or social situations, people often wonder if it is appropriate to offer help to the person using a wheelchair. Duke says he appreciates the offer, if it is made in a non-judgmental way. But he said that sometimes people act annoyed if he doesn’t accept help. For example, in a situation that is not totally accessible, such as a home or venue with steps, sometimes people are presumptuous and will say, “Oh, we can carry you.” That is “not okay with me!” Duke says. “Being carried makes you feel ‘less than.’” People are showing their lack of understanding of the safety issues involved, as well as the physical and emotional vulnerability of the person they think they are offering to “help.”

It is much better to simply ask the person what is helpful. There may be simple solutions, like clearing a path so the wheelchair user can navigate the space, or researching the accessibility of a building ahead of time. Some restaurants, for example, are very difficult. They have retrofitted accessibility, making it difficult to get around. On the other hand, Duke has had wonderful experiences when the staff gladly made an effort to make him feel welcome.

Duke commented on another issue he has encountered. “In the last five to seven years, people are more judgmental. The political climate has created an attitude about people getting free

stuff.” He mentioned being in a hardware store, and someone being overly dramatic about getting out of his way.

It is the simple, kind-hearted interactions that Duke appreciates. For example, as a caregiver, or a friend, take a moment to sit down when talking to someone who is in a wheelchair. It is nice to be on the same level, and it demonstrates a desire to connect person to person.

Duke also acknowledged his appreciation of his wife, Shirley, his partner of many years. When I talked with Shirley, she said, “Here’s the best advice I can give you: take Duke’s advice!”

Mary Kathleen Rose (www.comforttouch.com) is a licensed massage therapist, health educator, and author of several books, including Comfort Touch of the Hands & Feet: A Guide for Family Caregivers. She is a member of the Care Connections Editorial Advisory Committee.

From the Care Receiver’s Perspective

by Emily Cooper

Many of us provide care for an older adult who is frail, physically disabled, chronically ill, or cognitively impaired—or a mixture of the four. When our care receiver grumbles, it’s easy from our perspective to think that they should improve their attitude, but none of us can truly understand the challenges of being in the position of needing care until we *are*. Until we’re there, we can’t imagine what it feels like to be dependent on someone else for our care, to know that we’re in the end years or days of our life, or to be unable to see, or hear, or walk, or do many of the things we effortlessly did before. But if we *could* know, if we could take a walk in our care receiver’s shoes, it would certainly bring greater awareness and clearer understanding to the care that we provide.

(continued on page 9)



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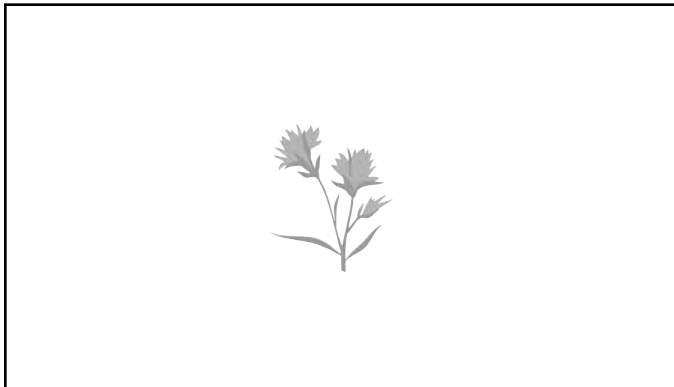
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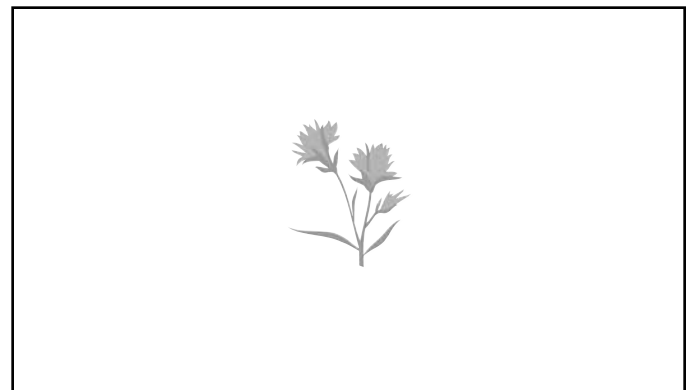
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From the Care Receiver's Perspective

(continued from page 8)

In an effort to understand the perspective of care receivers, the University of Denver Institute of Gerontology conducted a study [in 2004] that included interviews with dozens of older adults who rely on others for their care. The participants talked openly about their feelings on dependence and independence, and their comments offer a revealing glimpse into their worlds:

- *I've been so independent. I hate needing help.*
- *I feel like my freedom has been taken away.*
- *It all comes from the heavenly father. Have a good attitude.*
- *I just accept what God gives me. I don't expect anything.*
- *I remember all those people I've helped and think, now it's my turn.*
- *If you work hard every day of your life you're entitled to help when you need it.*
- *It [caregiving] is just something a daughter should do for any aging mother.*
- *I want to grow old gracefully. That means accepting and making the best of the situation.*
- *Not being able to drive means being a burden or giving up on getting to church, stores, seeing friends, or just enjoying the chance to get in the car and go somewhere.*
- *I will be glad with the time comes; I won't have to ask for help.*
- *I have a hard time asking my family for help. I don't want to be dependent. My children are not used to taking care of me and it is new to them too. They get scared.*
- *I do what I can. I'm a great potato peeler.*
- *We women are supposed to be the caregivers, not taking or needing someone to take care of us. I feel so useless.*
- *I believe that families used to take care of their elders, but today it is hard because they have to work. I don't want to bother my daughters because they live too far away and*

are busy every minute. They can't move here, and I want to stay in my own home.

- *Sometimes I'm anxious to "go beyond" so my daughter can live her life.*
- *After I have done all I can for myself, then the best thing I can do for everyone is to accept help and be grateful.*
- *I've taken care of enough old people, and I know what happens.*
- *I accept that I cannot stand on my own, so I willingly accept the help of others. It's easier now than a few years ago.*
- *I do what I have to do but try to make sure I don't worry about tomorrow—just live today and enjoy every minute of it.*
- *I've always helped others. I spent my life helping family members and friends who were in need. It's okay to help, and it's okay to receive help.*
- *I never thought I would need help. I always assumed that I'd still be the one giving the care and not be on the receiving end, so I really had no plans to receive care.*
- *I never wanted to think about it. I guess I thought my husband would take care of me, but he died eight years ago.*
- *We [care receiver and caregiver] have become closer than we ever were. I think it has made us appreciate the time we have together more. I have realized how important my family is, and I let them know every chance I get.*

As a caregiver, no doubt you have tried to put yourself in your care receiver's shoes, but you might also ask to have a conversation with your loved one about caregiving from their perspective. It could lead to helpful revelations and better understanding of the situation for both of you.

Emily Cooper is Information & Referral Specialist for Caregiver Programs and Editor of Care Connections for Boulder County Area Agency on Aging. This article first appeared in the May/June 2004 issue.

Never Take Away Anyone's Sovereignty

by Terri Malucci

Years ago when my friend Lucy was dying of a brain tumor, I went to see her at home. Her hospital bed was set up in the living room, and she was comfortably surrounded by her desk, favorite chair, and windows, so she could keep an eye on the weather and garden. On the afternoon of our visit, she had suffered a seizure, home alone feeling confused and afraid. When she called, since I only lived across the street, I ran over to sit with her.

In addition to the physical distress she was experiencing, she was quite agitated and upset about the most recent visit from her daughter. While making her weekend pilgrimage to see her mother, this well-meaning adult child had taken it upon herself to clean off Lucy's desk, as if its owner was already gone. Out went magazines, clippings, catalogs, old letters, greeting cards, and receipts.

"You don't need all this stuff, Mom. Let's get rid of all this clutter!" Into the trash it went, amidst Lucy's protests.

Lucy said, "She didn't acknowledge that those catalogs were my only way of shopping, my link to the outside world. I can still order gifts for special people, still see what's new, and feel a part of life as I knew it." And then she turned to me and said, "Remember, don't ever rob another person of their sovereignty."

Since I've become caregiver to my aging parents, Lucy's words have guided me through difficult challenges. Times when I have just wanted to make decisions for them and be done with it. Then I hear that voice: "Don't ever take away another person's sovereignty." Sovereignty—meaning freedom from external control. Self-governing.

My philosophy of caregiving has evolved into this: If it is not mine to throw away, don't. If those boxes of papers and greeting cards from

long ago are taking up lots of space, be quiet. They are links to the past and to fond memories. There will be time enough to clear the clutter, later.

If the bookcase is brimming with *National Geographic* issues from 30 years ago. "I've had *National Geographic* in my life forever, and I love looking at them some days." Let them be. Are they yours to toss?

Does it matter if those pants don't go with that shirt? Does it really make a difference if he won't eat that casserole I prepared? Maybe he doesn't feel like eating at all, but doesn't want to come out and say it for fear of worrying you. Let it go.

If what I am stressing over is not a threat to Mom or Dad's health, cleanliness, safety, or contentment, let it go. Some decisions are not mine to make. My job as caregiver and daughter is to make life as easy for them as possible, to carry them to the doctor, or to make sure they're drinking enough water, taking their meds. It is to help them maintain a sense of dignity and independence, to be rulers of their own domain.

Try to let it go, to create a sense of independence and empowerment. And never, never take away another person's sovereignty.

This article first appeared in the November/December 2009 issue.

**"The most precious gift we can offer others
is our presence.**

**When mindfulness embraces those we love,
they will bloom like flowers."**

— *Thich Nhat Hanh*



COMMUNITY RESOURCES

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 November/December 2017 issue is September 25.)

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, September 7 or October 5, 2 – 4 p.m., at East Boulder Senior Center, 5660 Sioux Drive, Boulder (call 303-441-1546 to register); on Monday, September 18, or Tuesday, October 17, 10 a.m. – 12 p.m., at Longmont Senior Center, 910 Longs Peak Avenue, Longmont (call 303-651-8411 to register); and on Wednesday, September 20, 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. For more information, visit www.bouldercountyMedicarehelp.org.

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 Boulder County Medicare Counselor for an individual review of your plan at clinics held in local communities, at West Boulder Senior Center, 909 Arapahoe Avenue, Boulder, on October 25, and November 8 and 29, all 9 a.m. – 12 p.m. (call

303-441-4388 to register); at East Boulder Senior Center, 5660 Sioux Drive, Boulder, on October 19, and November 2, 16, and 30, all 9 a.m. – 12 p.m. (call 303-441-4388 to register); at Lafayette Senior Center, 103 S. Iowa Avenue, Lafayette, on October 20, November 3, and December 1, all 9 a.m. – 12 p.m. (call 303-661-1492 to register); at Longmont Senior Center, 910 Longs Peak Avenue, Longmont, on October 16, 23, and 30, November 6, 13, 20, and 27, and December 4, all 9 a.m. – 12 p.m. (call 303-651-8411 to register); at Louisville Senior Center, 900 W. Via Appia, Louisville, on October 19, and November 2, 16, and 30, all 9 a.m. – 1 p.m. (call 303-666-7400 to register); at Boulder County Public Health, 3482 N. Broadway, Boulder, on November 1, 9 a.m. – 12 p.m. (call 303-441-1546 to register); and at St. Vrain Community Hub, 515 Coffman Street, Longmont, on December 5, 9 a.m. – 12 p.m. (call 303-441-1546 to register). Note: This annual open enrollment period is not for enrolling in Parts A and B or Medigap plans. For more information, call 303-441-1546.

AgeWell – Longmont United Hospital holds **Advance Directives workshops**, about considering and clarifying one's wishes for medical treatment in the event of incapacitation, on Thursdays, September 14 or October 12, 9:30 – 11 a.m., at Longmont Senior Center, 910 Longs Peak Avenue, Longmont. Pre-registration is required, at 303-651-8411 (\$5 fee for Longmont residents, \$6 for non-residents). AgeWell also offers **What's New in Integrative Medicine? ... There's More!**, with additional information (after an earlier presentation) about alternative therapies and what's available at Centura Health Integrative Medicine, on Wednesday, September 20, 5:30 – 7 p.m., at 1380 Tulip Street, Longmont. Pre-registration is required, at 303-651-5188.



The **8th Annual Boulder County Senior Law Day**, providing education and legal resources to seniors and those who care about them, is on Saturday, September 23, 8 a.m. – 3 p.m., at the Plaza Conference Center, 1850 Industrial Circle, in Longmont. Speaker topics include estate planning basics, Medicaid for long-term care, fraud protection, safety for seniors at home, advance medical directives, picking the right senior community, choosing your fiduciaries, and many others (four in Spanish). The registration fee of \$10 provides a copy of the *Senior Law Handbook*, a boxed lunch, and the opportunity to sign up for a free consultation with an attorney. Go to www.bouldercountyseniorlawday.org to register through Eventbrite or call 303-441-1685 to register by phone and then pay at the door. The event agenda is available on the website above.

Louisville Senior Center holds a free **Wellness and Resource Fair**, with a variety of vendors with information on transportation, nutrition, fraud prevention, housing, home care, caregiving, support groups, and more, on Friday, October 6, 9 – 11 a.m., at Louisville Senior Center, 900 W. Via Appia, Louisville. Registration is not required; for more information, call 303-666-7400.

TRU Community Care hosts its inaugural **Fall Symposium**, to provide education and prompt conversations on the health of the Boulder area community, the phases of end-of-life care, and the role that TRU plays in caring for elders, on Tuesday, October 10, and Wednesday, October 11, in Boulder. The featured guest speaker is Dr. Timothy G. Ihrig, MD, MA, nationally recognized expert on community-based palliative care program development and innovation, who will present the keynote address at a reception and dinner hosted by Academy Senior Living, 970 Aurora Avenue, on October 10, and facilitate a day of learning at Boulder Jewish Community Center, 6007 Oreg Avenue, on October 11. For

more information, contact Kristen Obenchain, at 303-604-5358 or kristenobenchain@trucare.org. Sponsorships and tickets are available.

The Town of Erie offers **COAW: Living a Healthy Life with Chronic Conditions**, a free course in which mutual support and success build participants' confidence in their ability to manage their health and maintain active and fulfilling lives, with four visits with a self-management coach included, on Mondays, September 11 through October 23, 5:30 – 8 p.m., at Erie Community Center, 450 Powers Street, Erie. Pre-registration is required, at 303-984-1845 or maripat@coaw.org.

Longmont Senior Center presents **You Can Become a Savvy Caregiver**, a free training program for family caregivers of persons with early to middle stage memory loss, which helps them understand dementia, increase their confidence, and reduce the adverse effects of caregiving, with Jessica O'Leary, MA, CVW, a Gerontologist and dementia specialist, on Wednesdays, September 13 through October 18, 6 – 8 p.m. (attendance at all classes required); **The Power of Resilience: The Five Steps of Conscious Caregiving**, about the steps that can help a caregiver move through their caregiving journey with ease and grace, with Nadine Roberts Cornish, CSA, caregiver coach and author, on Wednesday, September 27, 10 – 11 a.m.; **Intimacy: The Silent Casualty**, about the common loss of intimacy for caregivers and care recipients and looking at barriers, solutions, and more, also with Jessica O'Leary (see above), on Thursday, October 5, 1 – 2:30 p.m.; **Virtual Dementia Tour and Presentation**, an up close, hands-on experience that provides critical insight to family caregivers of persons with dementia, with Colleen Daugherty, Care Manager, Senior Life Solutions, on Thursday, October 12, 10 a.m. – 12 p.m. or 1 – 3 p.m. (register with Brandy



Queen, at 303-651-8414); and **Caring for the Caregiver**, about the essential aspects of caregiver wellness and developing specific strategies to enhance well-being, with Mary Sean O'Halloran, psychologist and professor of counseling psychology, on Thursday, October 19, 12:30 – 2 p.m.. All presentations are at Longmont Senior Center, 910 Longs Peak Avenue, Longmont. There is no charge, but pre-registration is required; call 303-651-8411 unless otherwise noted above.

The Holistic Homestead, with a grant from The Mountain Forum for Peace, initiated a **Used Durable Medical Equipment Program** in response to the need for affordable and accessible medical supplies in local mountain communities, ran a community-wide campaign asking residents to donate used medical equipment, and now has a wide range of items (crutches, walkers, braces, grab bars, shower chairs, toilet risers, commode, wheelchair, etc.) available for loan to residents in the Peak to Peak corridor between Evergreen and Estes Park. To learn more, call 303-582-3001 or connect@theholistichomestead.org. Free delivery is available.

Alzheimer's Association of Colorado offers **Know the 10 Signs: Early Detection Matters**, on Wednesday, September 6, 12:15 – 1:30 p.m., at Walt Self Building, 432 5th Avenue, Lyons; on Wednesday, September 13, 4 – 5:30 p.m., at REMAX Boulder, 2425 Canyon Boulevard, #110, Boulder; and on Thursday, September 14, 3 – 4:30 p.m., at Sunrise Boulder, 3955 28th Street, Boulder; **The Basics: Memory Loss, Dementia, and Alzheimer's**, on Tuesday, September 19, 2 – 3:30 p.m., at Kaiser Permanente, 2345 Bent Way, Longmont; **Living with Alzheimer's for Caregivers: Middle Stage (two-part)**, on Wednesdays, September 6 and 13, 5 – 8 p.m., Broomfield Community Center, 280 Spader Way, Broomfield; **Living with Alzheimer's for Caregivers: Late Stage (two-part)**, on

Thursdays, September 21 and 28, 2 – 4 p.m., at Longmont Senior Center, 910 Longs Peak Avenue, Longmont; **Dementia Conversations**, on Tuesday, September 5 (Part 1), 10 – 11:30 a.m., at First United Methodist Church, 1255 Centaur Village Drive, Lafayette; and on Thursday, September 21 (Part 1), 7 – 8:30 p.m., at Niwot United Methodist Church, 7405 Lookout Road, Niwot; **Legal and Financial Planning for Alzheimer's**, on Thursday, September 21, 1 – 4 p.m., at Aspen Lodge at Anthem Ranch, 16151 Lowell Boulevard, in Broomfield; and **Healthier Living for Your Brain and Body**, on Tuesday, September 26, 3 – 4:30 p.m., at Natural Grocers (Vitamin Cottage), 1745 Main Street, Longmont. 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.

Boulder County Area Agency on Aging offers 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, October 12 through November 16, 1:30 – 4:30 p.m. (tentative), in Longmont. 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. Pre-registration 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

Receiving with Reluctance

by Susan Damon

My father did not come to terms with his lung cancer easily. The fierce independence and stubbornness that his family and friends knew so well were brought to bear on this enemy, keeping him ahead of the disease longer than his oncologist had predicted. But the cancer advanced and the time came when Dad no longer wanted to be left alone when my mother needed to leave the house to run errands. My sister Beth or I tried to stay with him then, but sometimes it just wasn't feasible and we needed more help.

Dad had accepted hospice care months earlier and had come to rely on Debbie, the visiting nurse, but he was reluctant to accept caregiving beyond that nursing care. Mom, however, was ready to have a volunteer come to the house so she could have the time she needed to go out—her world had also narrowed. Debbie made the arrangements for a volunteer to come one January afternoon.

Steve was a theology student at the local university. Under normal circumstances, my father would have been quite charming and welcomed this quiet young man into his home. And Dad was courteous, but my mother could tell that we wasn't comfortable with the idea of a stranger in his home, the home he had once so firmly guarded. One more indignity in the continual erosion of so many rights he had taken for granted. Over the past year, he had given up driving, working in his shop, even the ability to go anywhere by himself. Now he couldn't even stay in his own home alone.

My mother was gone for two hours, at the most, while Dad slept and Steve studied. Later, Dad told Mom that he hadn't slept at all, worrying about what Steve was doing and claiming he had heard the volunteer moving about the house. My mother didn't believe any of it—she already knew my father had slept most, if not all, of the time she was gone. But it was clear that having

Steve in their home was not worth the stress that it caused my father. Dad was nearly at the end of his difficult journey, and none of us wanted him to expend his limited energy worrying about problems that could be eliminated. Steve never came back, somewhat to my mother's disappointment. Mom resumed waiting to leave the house until one of her daughters or granddaughters was available to stay with Dad or she asked one of the two neighbors that Dad was comfortable with to sit with him.

My father tried to be as gracious as possible as his condition worsened and he had to rely on others for care, but there were some boundaries that he had trouble crossing until he died. He never became comfortable with the health aide who came to help him bathe, and he would only let the aide do a minimal job. Only immediate family and a few familiar neighbors put him at ease when my mother was absent and he needed constant care.

My father died relatively suddenly, shortly after the new caregivers entered his life. Beth and I believe that he crossed a personal threshold when he lost too much of his independence, losing the will to continue the incredible battle he had fought to stay alive as long as he did.

It is a privilege to share caregiving, but sometimes it is difficult for the recipient to accept the gift. Looking back, I would never have expected my father to accept as much caregiving as he did. So while the circle may not have been as large as we would have liked toward the end of his illness, it was larger than we would have predicted. Despite his frustrations, Dad appreciated all of the care that was offered him, as did his very grateful family.

Susan Damon volunteers in several capacities, including being a member of the Care Connections Editorial Advisory Committee, for Boulder County Area Agency on Aging. This article first appeared in the July/August 2005 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
Superior	303-441-1617

