

CAREConnections

Information and Inspiration for Caregivers

A Publication of Boulder County Area Agency on Aging

Sept/Oct 2018

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The Conversation

Dear Caregiver,

Sightings of the word *conversation* will be abundant throughout the following pages. That's because in this issue of Care Connections, we explore the value of planning and initiating "critical conversations" with those we are caring for... and others. Maybe there are several family members involved who are perceiving and experiencing this time of caregiving quite differently. Or it could be that it's time for a heart to heart with your loved one about changes that you are seeing in them. Whoever is a part of the dialogue and whether the call to speak up is related to driving safety, the need for more help, an uncomfortable diagnosis, or advanced directives...these conversations are usually not at all easy to have. It takes both bravery to bring up what needs to be spoken and a compassionate heart, to find a way to approach the subject with care. Almost always, the presence of mind to ask questions and listen is immensely helpful. So where do you start? How do you phrase your questions and concerns? What about putting forth your own needs and the importance of meeting those too? The articles here are filled with wisdom and tips to lead the way. We hope that they add light to your path.

The Editors

Engaging the Help of Physicians for Critical Conversations

By Jennifer Geiger PhD ABPP-CN

We all need to have critical conversations with our family members and friends from time to time. For some caregivers, critical conversations pertain to hot-button issues like driving safety and the need for additional help with complex activities like finances, medication management, household chores, and meal preparation. For other caregivers, critical conversations might pertain to the caregiver's own need for respite or a need to delegate specific caregiving responsibilities. As you are reading this, if the phrase "critical conversations" creates a pit in your stomach, you are not alone. After all, synonyms for the word critical include words like serious, perilous, and precarious. On the other hand, a critical conversation that finally addresses the elephant in the room could also be viewed as an opportunity for meaningful change or a pivot point





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– a point that creates clarity and reduces stress for everybody. Critical conversations, at their best, result in positive change and enhance wellbeing.

As a neuro-psychologist I am honored to frequently participate in these critical conversations between patients and caregivers about level of care, driving safety, and other daily issues. I know that primary care physicians, neurologists, and other medical professionals also readily participate in such critical conversations. It is part of our role as healthcare providers. We like to help caregivers emphasize what is healthy and safe because in the end it improves quality of life and patient care.

Every family and caregiving situation is unique. However, over my career I have concluded that two issues most commonly emerge as caregivers prepare to have a critical conversation, whether about driving, the need for additional help with activities of daily living, or any other important topic pertaining to wellbeing. The first issue is the need for support and validation. Emotions can run high during critical conversations, and often the need for these conversations brews for a while before one finally embarks on the topic to be discussed. Objective input from a healthcare professional can be extremely valuable if strong emotions need to be validated and diffused. For example, caregivers often tell me what a relief it is to know that they are not the only ones who are concerned about their loved one's driving safety and that it is helpful to bring a professional into the conversation from the start. They feel validated knowing that a professional with objective testing data shares their concerns.

The second issue is the very real need for resources, behavioral strategies, and other ways to manage daily life. With professional support, it is often easier to develop meaningful strategies for hot-button issues. These practical strategies are the bulk of what is discussed when we review the complete picture of cognitive strengths and weaknesses from a neuropsychological evaluation, but they are easily discussed during a regular checkup with a physician as well. All providers can share bits of expertise or tips that are helpful to address the "now what?" questions that inevitably emerge during critical conversations. For example, once it is decided that your loved one needs extra help to keep living at home, what actual steps should be taken in the upcoming weeks to make that happen?

If in your caregiving role you need to have a critical conversation, or if there has been a critical conversation brewing in your mind that

you are not sure how to start, remember that you are not alone. Physicians, neuropsychologists like myself, and other medical professionals are not just helpful for diagnoses and care planning. As members of your community we are here to help brainstorm, to provide comfort, and to remind you that you don't have to reinvent the wheel when it comes to obtaining community resources. Come on in. Let's chat.

Jennifer Geiger is a Clinical Neuropsychologist, with an office in Louisville. Her office can be reached at 303-655-2663.

The Stigma of Having Dementia: To Tell or Not to Tell



By Barbra Cohn

One of the hardest things about getting a diagnosis of Alzheimer's disease is deciding when and whom to tell. When my husband was diagnosed with younger-onset Alzheimer's disease at 60 years old we were afraid that people would treat him differently, and that our friends would write us off. Although we were excluded from some social events and intimate dinners by friends who didn't have the patience to listen to the same story repeated over and over, or by those who simply didn't know how to act around someone with dementia, most of our friends created a warm, caring cocoon that helped us feel safe and loved.

In the beginning, I refrained from telling our children about their dad's diagnosis for an entire year, hoping to delay their heartache. Our youngest daughter had just gone off to college and we wanted her to have one year in which she could focus on her studies and friends, without worrying about her parents.

I tried my best to cover up my husband's gaffes, slips of memory, and awkwardness in social sit-

uations. Eventually, we withdrew from our old life because of the challenges that accompany dementia, and we socialized only with family and intimate friends. Our world became increasingly smaller as I became lonelier and more isolated.

When I look back at that time I find it naïve to think that divine intervention or a miracle would cure my husband. After all, I thought, why tell people about his diagnosis when perhaps he'll be cured as a result of taking myriad nutritional supplements and getting healings from alternative practitioners? It can remain our little secret.

It turns out that according to a survey published in the *World Alzheimer's Report 2012: Overcoming the Stigma of Dementia*, we weren't alone in trying to keep my husband's diagnosis a secret. (We did tell my parents, his brother, and a few very close friends.) Nearly one in four people with dementia (24 percent) who responded to the survey said they hid their diagnosis, citing stigma as the main reason. They expressed concerns that their thoughts and opinions would be discounted and dismissed, and that they would be treated more positively if they did not reveal their diagnosis.

Why worry about stigma when you've got so many other worries?

Identifying stigma is important because it:

- Gets in the way of receiving the proper help and care people with dementia need in order to live life optimally
- Leads to stereotyping and discriminating of the elderly and those with dementia
- Damages the fragile self-esteem of people with dementia
- Is a major cause of social isolation for the dementia patient and his or her family



- Is a barrier to the caregiver's utilization of community services and obtaining support from family and friends
- Reduces the depression and burden for the caregiver (once stigma is identified)

Doctors keep secrets, too. What happens when the doctor doesn't reveal a diagnosis? According to a report released March 24, 2015 by the Alzheimer's Association, just 45 percent of Medicare patients who'd been diagnosed with Alzheimer's said they were informed of the diagnosis by their doctor. By contrast, more than 90 percent of Medicare patients with cancer said they were told by their doctor. One reason doctors often cite for not telling patients is the time constraints of a typically short appointment, says Keith Fargo, director of scientific programs at the Alzheimer's Association. "It's difficult to disclose a diagnosis of a fatal brain disease in just a few minutes," he says. (The average length of time a doctor spends with a Medicare patient is just 8 minutes.) It's also hard for doctors to tell patients they have a disease that can't be stopped or even slowed down by a drug or surgery, Fargo says. And, he says, doctors often fear the emotional reaction an Alzheimer's diagnosis can cause.

However, the Alzheimer's Association believes that telling the person with Alzheimer's the truth about his or her diagnosis should be standard practice. Disclosure can be delivered in a sensitive and supportive manner that avoids unnecessary distress. And based on the principles of medical ethics, there is widespread agreement among health care professionals that people have the right to know and understand their diagnosis

Disclosing an Alzheimer's diagnosis has several benefits:

- Allows better access to quality medical care and support services

- Provides an opportunity for people with a diagnosis to participate in decisions about their care, including providing informed consent for current and future treatment plans
- Enables the patient to get the maximum benefit from available treatments
- Increases the chance of participating in clinical drug trials

What can you do? In response to the *World Alzheimer's Report 2012: Overcoming the Stigma of Dementia*, the Alzheimer's Association came up with these tips for coping with stigma created by people living with the disease. Current and former members of the Alzheimer's Association National Early-Stage Advisory Group developed these tips based on their personal experiences:

- Be open and direct. Engage others in discussions about Alzheimer's disease and the need for prevention, better treatment, and an eventual cure.
- Communicate the facts. Sharing accurate information is key to dispelling misconceptions about the disease. Whether a pamphlet or link to online content, offer information to help people better understand Alzheimer's disease.
- Seek support and stay connected. It is important to stay engaged in meaningful relationships and activities. Whether family, friends, or a support group, a network is critical.
- Don't be discouraged. Denial of the disease by others is not a reflection of you. If people think that Alzheimer's disease is normal aging, see it as an education opportunity.
- Be a part of the solution. Advocate for yourself and millions of others by speaking out and raising awareness. If you have the time and inclination, write letters to your state representatives, and to your newspaper.



If you or a loved one have received a diagnosis of dementia or Alzheimer's disease I encourage you to not keep it a secret as I did. Be open and share your feelings with your family and friends. Unfortunately, because Alzheimer's disease is predicted to become an epidemic for the Baby Boomer generation, almost everyone will be touched by it in one way or other. It's important that we do our best to educate the public and the best place to start is within our circle of family and friends—because ignorance leads to fear and understanding leads to compassion.

Barbra Cohn is a member of the Care Connections Editorial Advisory Committee, is the author of Calmer Waters: The Caregiver's Journey Through Alzheimer's and Dementia, and writes the [healthy-caregiverblog at barbracohn.com](http://healthy-caregiverblog.at/barbracohn.com).

Having the Conversation about Driving

by Julia Spigarelli

There are many adjectives to describe the topic of giving up the car keys as it brings out a range of emotions both on the part of the senior who is asked to stop driving as well as the family member or professional who is doing the asking. Many people find this subject too sensitive or challenging to discuss, and, as a result, the conversation either never happens or happens too late. **When asked to give up driving, an older driver may feel:**

- Angry – “What gives you the right to tell me what to do?”
- Frustrated – “There's nothing wrong with my driving. I've been driving since I was 13 years old.”
- Resentful – “I've given up everything. Now you're taking my car away?”
- Sad – “Now I have to depend on others. I feel so useless.”

And family members may experience:

- Frustration – “I don't know what to say or how to say it.”
- Guilt – “I'm depriving Dad of the one thing that he really loves. Will he resent me for this?”
- Fear – “If I don't do this, I'm afraid Mom will be injured or will injure others.”

For many older seniors, driving may represent the last bit of independence that they can hold on to. They do not want to feel like they are giving up control or are having to depend on others. They want the freedom to come and go as they wish, even if it means just a short trip to church, to the doctor, or to the grocery store. They may also be in the role of a caregiver for friends and enjoy offering transportation to them as well. If you consider that an older person may have already experienced the loss of family, spouse, home, health, and more, you can understand why the conversation about driving must be handled in a caring, compassionate, and respectful manner. However, though this challenging interaction may be uncomfortable, it should not be avoided!

Statistically, many older adults are safe drivers who wear their seat belts, observe speed limits, have fewer incidences of alcohol-related charges, and do not talk or text while driving. So why is the risk of accident and injury increased?

- Age – Drivers over the age of 75 are at higher risk for collision
- Medical Conditions – Diminished vision, hearing, cognition, and motor skills
- Medication use – May be taking many medications for complex issues



- Reduced Reaction Time – Reflexes are not what they used to be

Hearing sensitive information from the right person can also make a difference. Selecting the right person, not necessarily a family member, can be instrumental in achieving success. Some non-family choices may be a doctor, close friend, social worker, therapist, police officer, or faith community leader.

Conversation openers may include:

- “I almost had an accident today. Thank goodness I reacted quickly enough to avoid a collision.”
- “Dad, what did the doctor say yesterday during your eye examination?”
- “I’m concerned about your safety, Mom.”
- “You said that new medication makes you dizzy at times. Let’s talk with your doctor about this.”

Once again, the conversation about limiting driving or giving up the keys should never be delayed. Ideally, it should begin before driving becomes a problem, but it definitely must take place **when a problem arises:**

- An actual accident – “I had a fender-bender today, but I don’t think it was my fault.” *Response:* “Even if you were not at fault, you could have been seriously injured.”
- A near miss – “I nearly got hit today in the grocery store parking lot.” *Response:* “It’s nearly time for your regular doctor appointment. Let’s get a good checkup. I know you would feel awful if you got hurt or injured someone else.”
- Health changes – “I don’t seem to see so well at night.” *Response:* “Let’s make an eye appointment and get those eyes checked out.”
- Signs of confusion – “I got lost going to church this morning. I guess I wasn’t paying attention.” *Response:* “Why don’t we go

together to church next week? You can drive and pick me up.”

In order to prepare for this “Courageous Conversation,” you should always have your facts straight. Do not assume something just because the driver is older. Try to drive with them as a passenger on several occasions and observe. You may want to accompany your loved one to a medical appointment and have the physician administer tests for hearing, vision, cognition, reflexes, and flexibility. Investigate alternative transportation options and be supportive, open, and honest. And ask yourself this question: “If I couldn’t drive, what would I do and how would I feel?” Someday, someone is likely to have the difficult conversation about driving with *us*, and we’ll probably find it hard to deal with too.

This article first appeared in the July/August 2013 issue, when Julia Spigarelli worked with Centura Health – The Villas at Sunny Acres Senior Living Community.

VISIT WITH A CAREGIVER

Sarah is a poet, essayist, fiction writer, and former professor who lives with her partner, Richard. She was diagnosed with Alzheimer’s Disease several years ago, and is learning how to manage emerging symptoms. Richard is learning how he can support Sarah.

Care Connections: We spoke with you in 2014 about your assessment for memory loss. You and Richard underwent a day of intensive testing at National Jewish Hospital, resulting in the Alzheimer’s diagnosis. This issue of Care Connections is about difficult conversations, so I’m curious about that conversation three years ago, that led you to seek medical guidance.



Richard: Sarah initiated the conversation. She told me she was worried about increasing loss of memory and mental abilities such as spelling. She wanted a professional assessment. She presented this in a practical and straightforward way; it seemed like a reasonable thing to do.

CC: In the three years since the diagnosis, how have you, as a couple, communicated about changes observed and about decisions you have made. Have these conversations been difficult?

Sarah: I think we're both realistic and practical and want to face the future together as honestly as possible. The difficult part is the sadness of anticipating how the disease will affect us both and change our lives.

CC: Does the way you cope with what is often called the *new normal*, both personally and as a couple, reflect your personalities, attitudes, and ways of dealing with life in a recognizable way?

Sarah: I've been meditating for a long time, and fairly soon after the diagnosis I realized that I can use that practice to manage my experience as things change.

CC: You're also a poet and a writer so I would guess you are aware of your moods and thoughts, and are sensitive to what's going on around and within you. I've read some of your poetry and find it honest, direct, and generally unsentimental.

Richard: I've always tried to accept and be patient with problems and situations life brings us that I can only affect in a small way. I guess I'm a realist.

Sarah: He's also a perfectionist.

Richard: That's true. I often worry too much about details and getting everything right. I'm a scientist and she's a poet. But, there's also a lot of overlap. For example, I gave up meditation for

a long time but I've now started again, and we meditate together in the mornings.

Sarah: But on mornings like today, I get grouchy, irritable, and pretty distraught. Richard has lists of things that must be done in a certain order and that require a lot of preparation, such as finding my ID and credit card, and filling out forms. Many things to *not* forget. This is overwhelming. I process information slowly and things take longer to absorb. This is different from how I used to be, and that's important for him to understand.

Richard: I always want to stop talking about all these details, often for the umpteenth time, and just make a list, put it in my pocket and proceed.

CC: Is it that activities and interactions that used to be easier, requiring little discussion, and not creating anxiety or tension, now require more time and patience on your part?

Richard: Exactly. We periodically meet with Sarah's neurologist, and this time I told her about my observations of "Sarah's States." In what I call State A, she's peaceful, happy, and rational, more like her old self, and her cognitive functioning is higher. We enjoy each other, have good conversations, and it's lovely. But in State B, she's anxious, irritable, impatient, and less rational, and her general cognitive function declines.

Sarah: Like this morning's expedition. There was so much going on that I couldn't keep up, and I got more and more frustrated and grouchy, *and* angry. And another thing. When we walk together, he's much faster and always goes way ahead of me.

Richard: And if I slow down, then she slows down too and stays behind!

CC: Well, I suppose the only solution is to walk separately.

Richard: Or hold hands.



CC: So, Richard, are you generally the peacemaker?

Richard: I guess so. I don't like the feeling that an argument or disagreement is hanging between us, and I seem to have a reserve of patience for talking things out.

CC: Sarah, how do you respond to that?

Sarah: It's true. I'm very grateful for his patience and support, and sometimes I even tell him so.

CC: Thank you both so much for talking with us and sharing this piece of your story.

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

The Nuts and Bolts: Using the Assertive Style of Communication



By Faith Halverson-Ramos,
MA, LPC, MT-BC

Conversations about end-of-life planning are not conversations that most people want to have. Even though we know that we'll all die someday, we're reluctant to talk with others about our wishes. It's as though we think that if we never talk about it, it will never happen to us. Likewise, it can also be difficult for family members and caregivers to initiate such conversations, whether out of their own discomfort or fear of how the other person will respond.

But these kinds of conversations are incredibly important to have. Not only does it help you communicate clearly what you want for yourself, it also ensures that everyone involved with your care is on the same page. In other words, these are not the conversations you want to have when it's too late for you to express yourself. As well,

if you're a caregiver, you don't want to find yourself in a situation where you don't know what the wishes of the person you care for are, when there's no way to find out.

This article looks at how the assertive style of communication can help make conversations about advance directives easier to have. This style of communication is one of the tools taught in the Powerful Tools for Caregivers class offered by the Boulder County Area Agency on Aging.

Assertive Style of Communication

You can use the assertive style of communication to express your personal needs, feelings, and concerns in a positive way. It helps you with speaking in a direct way to another person. Communicating with an assertive style can also help you in getting all the information you may need, which can be beneficial when speaking with healthcare providers.

At the foundation of the assertive style of communication are "I" statements. "I" statements show that you take ownership of your feelings, needs, and motives. They also help you clarify your point of view and express what you want.

The assertive style of communication is also built around four steps. These steps are:

Describe: Describe an observable behavior or problem using "I" statements.

Express: Express how you feel using an "I" statement.

Specify: Tell the other person specifically what needs to happen or what needs to be done using an "I" statement.

Consequence: Explain the consequences of the behavior using an "I" statement.

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The Nuts and Bolts: Using the Assertive Style of Communication

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Assertive Style of Communication in Action

In this scenario, an adult son wants to talk to his Mom about a Living Will. He is her Medical Durable Power of Attorney, but they've never talked about what her advance directive wishes are. This is because in addition to his own personal discomfort around bringing up the topic, he suspects that she is also reluctant to have such a conversation.

But he wants to make sure that he knows what his Mom's wishes are in the case that he may have to advocate for her in the future. He's been noticing some changes in her memory and is concerned that she may be in the early stages of Alzheimer's. He knows that they need to have this conversation sooner, rather than later. Likewise, he knows that ultimately his mother would want him to know how he can best support her quality of life.

Using the assertive style of communication, he might bring up the conversation like this:

(Describe) "Mom, I notice that you seem to be having a harder time remembering things."

(Express) "I worry because I realize that I don't know what you'd want if something were to happen to you and you couldn't tell me."

(Specify) "I'd like for us to work on your Living Will so that we can talk about what you'd like if something were to happen to you and I had to be your voice."

(Consequence) "I think we'll both feel better if we can get your wishes written down in a Living Will. I'll make sure that your doctors get a copy so that they also know your wishes."

While conversations about advance directives may be difficult or uncomfortable, they are important to have. The assertive style of communication can help make these conversations easier. If you find yourself in the situation of needing to talk with someone about their advance directives and you're reluctant to do so, consider using this style of communication.

Faith Halverson-Ramos serves as a Music Therapist through her company Soundwell Music Therapy and as a teacher of Powerful Tools for Caregivers, a course for family caregivers, offered by Boulder County Area Agency on Aging.



Strategies for Working with Resistance to Care

By Rachel Harrison and Audra Belden, RN, BSN

As you age, or as a family member with an aging loved one, how do you start the conversation about whether someone needs care or assistance with activities of daily living in order to maintain quality of life and safety. When in need, many times, we resist asking for or accepting help. We believe we are taking care of ourselves by not asking or telling anyone about it, when we may need assistance.

What if your loved one won't admit they need more care? It can be hard to balance what your aging parent wants and what they may need. The best timing to have a conversation rarely comes. What if there are multiple adult children or family members involved—how do you work together? Sometimes it is helpful to designate one person that is the point of contact and responsible to communicate to the group. If there is more than one decision maker, be willing to compromise and work together. Remember the primary goal is the safety and quality of life of someone you both love.



It is often best to start the conversation before care is needed or before a crisis hits. Noticing small vulnerabilities such as difficulty paying bills, missing meals, frequent falls, decreased personal hygiene, difficulty with medication management, or general forgetfulness are all indicators that additional assistance or oversight may be beneficial. The sooner the conversation is started, the better for all involved.

So where do you start? How do you overcome resistance to care? One of the first steps that may help initiate a conversation is to identify the root of their resistance. Is it financial concern? Are they worried they're becoming a burden? Last, but not least, are fear and concern about loss of independence or control.

Another conversation starter may be to use the Colorado Advance Directives website colorado-advancedirectives.com as a guideline for your loved one's wishes. Here you will find information on Living Wills, Durable and Medical Power of Attorney, and Medical Orders for Scope of Treatment (MOST — formerly DNR).

Sometimes loved ones will accept care under the auspices of companionship. If your loved one is resisting extra help around the house, an ice breaker may be to offer a companion — someone who comes in once or twice a week without a specific agenda or tasks.

How do I know if I need more care? As we age, we often develop coping mechanisms without realizing it. Be honest with yourself and be willing to speak with your loved ones or physician about if it may be time to accept additional help into your home. Here are some signs you may need extra help:

- You use furniture or the wall to steady yourself as you stand or walk
- You've had more than two falls within the past six months
- Difficulty in bathing or dressing
- Difficulty reading or understanding directions or medication labels
- Relying on family members, friends, and neighbors frequently
- Difficulty managing meals
- Difficulty managing transfers, particularly, getting in and out of the shower

Remember, there are a variety of care options, both medical and non-medical agencies, private care providers, and community resources that provide a broad scope of assistance. Your physician will have a list of local agencies and resources. In addition, check with your local Area Agency on Aging or Senior Center. We are fortunate to live in a community with many supports for our aging population.

Working together as a family can make the transition smoother and prevent any one person or family member from becoming overwhelmed, or feeling like a burden. When working together, remember the primary goal is the safety and quality of life of our loved one. How that is achieved will vary, but will almost always requires cooperation and excellent communication.

Rachel Harrison and Audra Belden are both with Dignity Care, Rachel serves as Office Manager and Audra as a Case Manager.

**“People almost never change
without first feeling understood.”**

-- Douglas Stone



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 2018 issue is September 21.)

During **Fall Prevention Week**, September 17 – 21, educational and fun activities that reduce the risk of falling will be offered throughout the county. See the full schedule at www.bouldercountyhealthyaging.org and at local senior centers.

Longmont Senior Center presents **You Can Become a Savvy Caregiver**, a free training program for family caregivers of persons in the early to middle stages of 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 19 – October 24, 6 – 8 p.m., at Longmont Senior Center, 910 Longs Peak Avenue, Longmont. Attendance at all classes is required. Pre-register at 303-651-8411.

The 9th Annual **Boulder County Senior Law Day**, providing education and legal resources to seniors and those who care about them, is on Saturday, September 29, at the Boulder Jewish Community Center, 600 Oreg Avenue in Boulder. For more information, visit www.bouldercountyhealthyaging.org or on

Facebook: www.facebook.com/bouldercounty_seniorlawday.

The Wisdom Series at Balfour offers three Thursday evening sessions focusing on the emotional and spiritual challenges of aging and caregiving: **How Caregivers Survive and Thrive**, a caregiver panel with Paula Enrietto of Affirmicare and Jessica O'Leary of Halcyon Hospice, September 6; **A Deeper Perspective on Alzheimer's and Related Dementias**, with Megan Carnarius, Alzheimer's specialist and author, September 20; and **Losses Along the Way**, a talk and discussion for caregivers with Kim Mooney, end of life and grief specialist, and founder of Practically Dying, October 4. Each presentation begins at 6:30 p.m and will be followed by community conversations and refreshments. Held at The Lodge Theatre at Balfour's Louisville Campus, 1331 E. Hecla Drive. Sessions are free and open to the public. Please call 303-867-6381 to reserve your seat.

Boulder County Area Agency on Aging offers **A Matter of Balance**, an 8-week health education class designed to help people manage their risk of falling, reduce their fear, and strengthen their bodies. On Tuesdays, September 25 – November 13, 1 – 3 p.m., at Longmont Senior Center, 910 Longs Peak Avenue, Longmont; Thursdays, September 27 – November 15, 1 – 3 p.m. at Lafayette Senior Center, 103 S. Iowa Avenue, Lafayette; and on Thursdays September 27 – November 15, 2:30 – 4:30 p.m. (*in Spanish), at Lashley Street Station, 1200 Lashley Street, Longmont. Also offered is **Diabetes Prevention Program**, a year-long program for those who have been diagnosed with prediabetes to get the support they need — and make healthy lifestyle changes, on Tuesdays, 5 – 6 p.m., beginning



September 11, at 3482 Broadway, Boulder and on Thursdays, starting September 13, 12 – 1 p.m., at East Boulder Senior Center, Boulder. Call for information about joining this program, and if you are wondering if you might have prediabetes take the test at www.BoulderCountyDPP.org. These programs are free, but donations are appreciated. Pre-registration is required at 303-441-3500 or mpruitt@bouldercounty.org.

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 6 and October 4, 2 – 4 p.m., at East Boulder Senior Center, 5660 Sioux Drive, Boulder (call 303-441-4150 to pre-register); on Mondays, September 17 and October 15, 10 a.m. – 12 p.m., at Longmont Senior Center, 910 Longs Peak Avenue, Longmont (call 303-651-8411 to pre-register). There is no charge, but donations are appreciated.

AgeWell – Longmont United Hospital holds **Advanced Directives workshops**, about considering and clarifying one's wishes for medical treatment in the event of incapacitation, on Thursdays, September 13, October 11, and November 8, from 9:30 to 11:00 a.m. (separate classes, not a series), at Longmont Senior Center, 910 Longs Peak Avenue, Longmont. Pre-registration is required, at 303-351-8411 (\$5 for residents, \$6 for non-residents).

Alzheimer's Association of Colorado offers an 8 week **Early Stage Support Group**, a safe environment where those sharing this journey can connect, offer support to one another, and discuss topics such as receiving and disclosing a diagnosis, changing relationships, and future planning, Mondays, September 10 – October 29, 1:15 – 2:45 p.m., West Boulder Senior Center, 909 Arapahoe Avenue, Boulder;

Understanding Alzheimer's and Dementia, Tuesday, September 25, 6:30 – 8 p.m., Sacred Heart of Mary Church, 6739, S. Boulder Road, St. Bernard Hall, Boulder; **Understanding and Responding to Dementia-Related Behavior**, Monday, September 24, 9 – 10:30 a.m., Erie Community Center, 450 Powers Street, Mitchell Room, Erie; and **Effective Communication Strategies**, Monday, September 10, 3 – 4:30 p.m., Balfour Senior Living, 1331 Hecla Drive, Theatre, Louisville. There is no cost for these programs. Schedule a screening interview with Ralph Patrick at 303-813-1669, ext. 362 or rpatrick@alz.org for the support group. Pre-registration also required for courses, at alz.org/co or 800-272-3900.

The Longmont Senior Center provides a **Dementia-Friendly Community Calendar** – the results of an effort, by several Longmont businesses and organizations, to become a more dementia-friendly community, extending a special welcome to people with dementia and their family caregivers for socializing together. Included on the calendar are free, weekly, activity-based **Lunch Bunch** gatherings, Mondays or Wednesdays, 11 a.m., for people with early to mid-stage dementia and their family caregivers. Contact Elaine Keiser at 303-335-6933 if you are interested in joining and for an intake meeting. Also offered is **Connections**, a free lunch group with a guided activity for those living with dementia and time for family caregivers to connect with each other separately. Contact Gemma Wilson at 720-745-8248 if you are interested in joining and for an intake meeting. Other events listed include self-guided group walks and ice cream socials. To receive the calendar via mail or email call 303-651-8411 or email Brandy.Queen@longmontcolorado.gov.



The Conversation

by Phyllis Coletta, JD



As a caregiver, you make decisions for your loved one every single day, and as he or she ages or illness progresses, those decisions may become more subtle, complex, and difficult. How do you know what's right? Should Mom undergo that test or not? What if Dad loses his mobility? Every day you are in a position of making decisions, often without input of the loved one if he or she is unable to communicate clearly or is on the spectrum of memory loss.

There is a free community resource in Boulder County focused only on helping you with this overwhelming task. The Conversation Project in Boulder County helps individuals and families engage in meaningful, values-based conversation around Advance Care Planning – that process of decision-making as we age or illness progresses. If your loved one is still able to engage, it may seem difficult to talk about topics like the extent of medical care or intervention they may want, or where they'd like to spend their last days. At The Conversation Project we have trained coaches who can walk with you, in complete confidence, in these difficult discussions.

If you are caring for a loved one, hopefully he or she has appointed you or someone else as their Medical Power of Attorney (MDPOA). The MDPOA is a very simple document someone can fill out without an attorney, which specifically appoints another person to make medical decisions in the case of incapacity. If hospitalized and unable to make choices for him/herself, the MDPOA allows someone else to “step up to the plate” and help the doctors in charting a course of treatment that reflects what that individual would have wanted. This simple document (legal and effective when signed by the

individual), in conjunction with some clear and meaningful conversations, can go a long way in easing everyone's suffering in a crisis. Does the person you are caring for have a signed MDPOA? Do you? (Caregivers rarely think of themselves, but your future is just as important as your loved one's.) We can assist you for free, because the research shows that these conversations and the appointment of an informed medical decision-maker do in fact make a big difference in difficult situations.

My mother was a nurse, a first generation Italian who was fiery and strong. She had six children, two of whom became doctors. When she started getting confused and forgetful at the age of 66, we were worried about early Alzheimer's or the onset of some form of dementia. The truth was much worse – a diagnosis of Jacobs- Creutzfeldt's disease, commonly known as the human variant of “mad cow.” This is 100% fatal, and the process of swift decline involves paralysis, blindness, and a resultant vegetative state. Before we knew it, our dear wonderful mother was confined to a skilled nursing facility, unable to see, move, or interact in any way.

She had no written documents, “advance directives,” or even informal directions about what she would want in this kind of state, but here is what she did have: six children who knew her very well and wanted to do what was right for her. Many times in her life she had expressed to us her values about being able to connect with her, her fears around “losing her mind” and abilities, her anxiety around loss of control. All these things did, in fact, happen to her, so when the nursing home said they could no longer feed her and she would need a feeding tube, all six of us agreed very quickly that she never would want that. We knew her well. She had expressed herself early and often. And so she came to my house, and died peacefully on hospice.



No Living Will in the world can ever anticipate the hundreds of small decisions you have or will need to make for the loved one you care for, but if they can communicate in any way, you can still engage in exchanges that will help you understand who they really are, what brings them comfort, what they worry about most, and what makes life meaningful. This is the kind of information that will inform your decision-making, and we can help you begin those conversations with your loved ones and other family members. Even if your loved one suffers from some form of dementia or memory loss, we can help you and your family engage in conversations around what your loved one may want.

It is really important that all members of the family be engaged in this process, in order to avoid conflicts, guilt, and undue emotional suffering as your loved one ages or illness progresses. If you have any friends who have worked on an ICU, they can tell you just how awful it is when bereft families fight at the bedside about next steps, or when they are confused and bewildered because no one really knew the patient well enough to know his/her values.

I worked for three months as a chaplain in a Medical ICU and was deeply distressed at what I saw there – good people in very bad situations, with no direction or guidance, no understanding of what the patient might have decided, and thus feeling lost and overwhelmed by guilt. I knew we had to do better, and we can do better. We can avert these crises and the suffering they bring.

The Conversation Project operates under a two-year grant from The Colorado Health Foundation, as many organizations across the state are now addressing the dire need for education and support around Advance Care Planning. Aside from free confidential one-on-one coaching, we can come to your church group, social club, support groups, or

other places where people gather and introduce some very simple tools and resources to get these conversations started. We have copies of the MDPOA that you and others can fill out, and we have people willing to help you every step of the way.

As a caregiver, you may feel overwhelmed on a daily basis, particularly if you see a slow decline and don't know what is next. There can be great relief in talking with your loved one about next steps, and we are here to support you in that process. Don't hesitate to reach out to us right away, and we will connect you with a coach or some resources to ease your burden of decision-making.

This article first appeared in the January/February 2017 issue, when Phyllis Coletta was the director of The Conversation Project in Boulder County. Contact the Conversation Project at 303-442-0436 ext. 133 or visit theconversationprojectinboulder.org

“Courage does not always roar. Sometimes

courage is the quiet voice at the end of the day

saying, ‘I will try again tomorrow.’”

-- Mary Anne Radmacher

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INFORMATION AND ASSISTANCE IN BOULDER COUNTY

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

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

Allenspark area	303-747-2592
City of Boulder	303-441-4388/303-413-7494 (bilingüe)
City of Lafayette	303-661-1499
City of Longmont	303-774-4372/303-651-8716 (bilingüe)
City of Louisville	303-335-4919
Erie	303-926-2795
Lyons area	303-823-9016
Nederland area	303-258-3068
Niwot area	303-441-1617
Superior	303-441-1617

