



IssueBrief

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Becoming aware: Six things every case manager needs to know about dementia

Are you *dementia-aware*? Are you sure?

Given that roughly 5.8 million Americans lived with Alzheimer's and other dementia in 2019¹, we can readily assume it directly affected more than 12 million people. And that will grow—both in raw numbers and as a percentage of the population—as Boomers and Gen X'ers continue to age.

So yes: We all know *about* dementia. Most of us have been touched by it. And yet, as a society, we are not *dementia aware*, warns dementia-care expert Laura Wayman, author of *A Loving Approach to Dementia Care*. It's not just that there are misconceptions—there *are* many—around dementia. It's our basic understanding that's lacking.

"We can't stop, fix or change dementia, but we can manage it and have more positive interactions as we begin to understand what's behind dementia symptoms," Wayman says. We must change our care approach in order to successfully connect, engage and communicate with any individual with dementia symptoms—and to support caregivers.

Professional case managers stand ready to do that. "We have an important role to play to help caregivers make sense of the clinical, behavioral and mental health issues that arise during the progression of this devastating disease," says Michelle Baker, chair of the Commission for

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¹ Alzheimer's Association. 2019 Alzheimer's Disease Facts and Figures. *AlzheimersDement*2019;15(3):321-87. <https://www.alz.org/media/documents/alzheimers-facts-and-figures-2019-r.pdf>

Case Manager Certification. But they need to be *dementia aware*.

To increase your dementia awareness, here are six things you need to know.

1. Dementia is a collection of symptoms, not a diagnosis.

Think of dementia as something akin to pain, Wayman explains. "Pain is your body saying, 'Hey, something's wrong.'" If you tell your physician that you're experiencing a sharp pain, she's not going to say, "Well, yes, you have pain; that is my diagnosis." Pain is a symptom. The same is true of dementia. More accurately, dementia is a list of symptoms. Alzheimer disease may be the number one cause, but there are at least 100 others, including Lewy body dementia, Parkinson disease, stroke, AIDS and traumatic brain injury.

This means there's no roadmap, no checklist. Each person with

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dementia declines in a different way. "So, if you've met one person with dementia symptoms, you've met one person with dementia symptoms," Wayman says.

2. Dementia is much more than memory loss

Thousands of dementia symptoms often go unrecognized because of our current focus on memory loss, she says. "We've been so programmed to look just for that, but dementia is not just about memory loss. It's about processing and much deeper than memory loss."

Dementia symptoms prevent the individual from properly processing, understanding and retaining information.

Essentially, the individual with dementia symptoms has a "broken thinker," she says. They receive data, but they can't process it in a normal way. "So, what they hear, what they say, see, what they touch, how they move, suddenly there's gaps in that normal process that we with a healthy brain take for granted."

3. For those with dementia, less information is better

"When someone has a broken thinker, it is kinder to watch for ways to 'think for them,'" she says. Don't overwhelm them with options—or with questions.

That may be a difficult adjustment to make for anyone in health or social services "because the way that we find out how people are

doing is we ask questions," she says. But asking too many questions shuts people down, it makes them anxious.

She offers the example of asking someone about eating. Instead of—or in addition to—questions such as, "Have you eaten?" "Are you hungry?" or "What would you like for dinner?" consider something along the lines of the following:

- "It has been a while since we ate, I bet you are hungry."
- "Come sit and have dinner with me."
- "I always enjoy breakfast/lunch/dinner more when we eat together."
- "I made your favorite fried chicken, let's eat."

She offers another example: Instead of greeting somebody with, "How are you?" or "What is your name?" consider the following:

- "It's so nice to meet you."
- "You have such a nice smile."
- "Oh, I so enjoy spending time with you."
- "You know, that color looks good on you."

Activity directors in senior centers and dementia facilities struggle with this, too, she says. "Would you like to come listen to the music?" may be hard to process and lead to a "No, thank you." A better

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option would be, “Oh, I love it when you come with me. All of your friends are listening to music. They’re waiting for you.”

Keep it simple, clear, to the point. Use actions. Hold out your hand. “It’s show and tell now.”

4. Someone with dementia isn’t like a child

It can be tempting to speak to someone with dementia as if they were a small child. Don’t. “With a child, we’re still teaching them; we’re still trying to help them learn. With someone who has this loss as an adult, we can’t make them learn because we can’t give it back to them,” she explains. And yes, there are comparisons—such as limiting the amount of information shared.

It can be challenging, because talking to someone with dementia isn’t like talking to an adult with a healthy brain. It is, she says, “a very different dementia dialect.”

5. It’s permanent

Part of learning to think for a loved one—and really, part of dementia awareness—is dementia *acceptance*. “It’s recognizing and accepting this loss is permanent, that we can’t give it back to them.” Dementia involves relentless cognitive deterioration.

And yet, there’s a balance: They still have some ability to think. The key is to work on finding ways to support the thinking processes that they still have, she says.

Currently, no medications have been proven to successfully slow the overall progression of all dementia symptoms. Some medications slow *some* of the symptoms in some people. “But in the twenty years of working with hundreds of caregivers in different parts of their dementia journeys, I have never had a caregiver come up to me and say that a medication made a huge noticeable difference in the quality of life for either one of them,” she says.

6. It’s ok to fib sometimes

Brutal honesty can be unnecessarily, well, brutal. Yet, not all that long ago, many experts called for a strict “reality orientation.” So, if your client thought his parents were alive, you were advised to tell him the truth—that they were dead. But telling the hard truth can be needlessly cruel. Therapeutic fibbing has become more common.

Wayman acknowledges that the exhortation against lying is tough to shake. So, she talks about

creative intervention. “We’re not lying. We’re reframing the truth so that it is more palatable to this person who can’t process what we believe is normal. Their normal has changed.”

In a sense, you are titrating information. “You wouldn’t give a small child too much information if they asked you a question involving violence or death because they have not yet learned a way to

Dementia in the era of COVID-19



Increasingly, Wayman fields questions such as this one: “How can I talk to my mother over the phone now that her facility is in lock down because of coronavirus?”

She recommends multiple short, upbeat conversations throughout the day. “Instead of one phone call a day, try one in the morning, one at lunch and one after dinner. That will help the day go by.” And she offers this reminder: “No questions or options.”

Conversations won’t always remain upbeat. Both parent and child likely feel isolated and alone. “So, don’t be afraid to join each other in these feelings and share.” She offers an example: “I miss being with you in person, but I am so happy we can talk on the phone. You sound so good, and I know you and I are both safe. Tell me about your day. Let’s get through this together, and very soon we will be able to be together.” ■



Mrs. A moves in

Wayman shared a case example, with the details changed:

Mrs. A is 78 years old. She's exhibiting dementia symptoms. She was admitted into memory care when all attempts to support her remaining in her own home were unsuccessful. Due to her loss of processing, disorientation and lack of understanding of risks, she had begun to neglect herself. She would frequently leave her own home and get lost—often in the middle of the night. Perhaps most concerning, she had a tendency to tell complete strangers that she lived alone and where she lived.

When Mrs. A arrived at the memory care facility, she was very frightened and angry. She couldn't understand why she had to leave the home she'd lived in for more than 20 years. She became suspicious of everyone, believing they were all in some way to blame for what was happening to her.

The memory team gathered as much information about her as they could, talking to neighbors and friends. (They couldn't ask Mrs. A questions at this point.) Collecting this information allowed the care team, the staff—everyone tasked with building this new life for Mrs. A—to adapt dementia-aware techniques specifically for her.

The memory care team immediately adopted the appropriate dementia-aware techniques. These included educating the staff to not expose the person's weaknesses or loss, working with all feelings expressed, including anger—which can be frequent and sudden in onset—keeping their distance until invited to get closer and acknowledging and joining feelings rather than ignoring them or taking things personally.

Most importantly, they acknowledged Mrs. A's lifetime of experience as a senior nurse, inviting her opinions on simple issues where they knew she would be able to feel that her input was valued and helpful. Soon, she began confiding in staff members. Over the course of about four weeks, Mrs. A's behavior started to change; she appeared to be more comfortable in her new setting.

It all comes back to talking to the feelings, Wayman explains. "They helped make her feel more safe, secure, loved, valued and comfortable." ■

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One creative intervention is to *join* the person's feelings. If your client or loved one is upset and wants to see his own (dead) mother, he's likely missing her—or perhaps thinking about something from the past that he wants to resolve. "Try *joining* his feelings by saying, 'It sounds like you're thinking about your mother. Tell me more about her.'" Chances are, he will begin to feel the love for his mother and forget why he was upset.

"By honoring and sharing his feelings, you're not lying to him. You aren't agreeing or disagreeing

with his belief that his mother is alive. You're just joining in the moment."

Dementia symptoms prevent the individual from properly processing, understanding and retaining information. "And if they can't process what information you're giving them and store it for later use, it means they probably can't retrieve what you said in the conversation, so those feelings will come up again and again. Telling the truth each time forces them to experience fresh distress, fresh anxiety, fresh confusion over and over again," she says.

"We have an important role in helping them assess and navigate through the difficult decisions they have to make as they consider what is best for their loved one and for themselves. As case managers, we support our client while, at the same time, help ensure that the caregivers' own health and needs are not forgotten along the way."

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Still, she draws a bright line between creative interventions—which have a grain of truth in them—and lying. "I don't want you to out and out lie because that almost always will threaten the relationship between the caregiver and that individual with whatever's causing their dementia symptoms."

Perhaps the person you're caring for insists there's a stranger in the bathroom singing to them. You're not going to say "Yes! That's Tony Bennett, and he's come to sing for you!" That would be an outrageous lie—one that your client or loved one may not believe.

Instead, she says, talk to their feelings. They really feel, for one reason or another, that someone's in the bathroom. So perhaps simply say, "I just checked the bathroom, and they must have left because there's no one there now, so we're safe."

Be aware, stand together

Wayman calls on professional case managers to find ways to instill dementia awareness, and case managers are more than ready to take up the challenge, Baker says. Case managers can—and do—help caregivers make sense of the clinical, behavioral and mental health issues that arise as dementia symptoms progress.

They are uniquely qualified to provide the caregivers with a specialized skill set and tools to support them through this often long and mostly painful dementia care journey.

"We have an important role in helping them assess and navigate through the difficult decisions they have to make as they consider what is best for their loved one and for themselves," Baker says. Too often, caregivers often sacrifice their own needs and well-being to provide care for their loved one. "As case managers, we support our client while, at the same time, help ensure that the caregivers' own health and needs are not forgotten along the way."

Wayman agrees, noting that dementia-aware systems, structures and supports are simply not in place. If you have any doubt, look no further than state Medicaid programs' lack of support for home care for dementia patients.

The situation is profoundly frustrating, and it makes supporting and equipping caregivers even more critical. "We need to help the family caregivers to become dementia-aware so we can all start to demand this level of understanding." Together, she says we can work to reshape and rebuild all community support services so that we can raise the bar for all dementia care.

In her ideal world, everyone—government, medical personnel, first responders, policy makers, etc.—are enlightened, providing the necessary support caregivers and individuals with dementia need. "But until then, it is going to have to start with individuals and grow to organizations to communities to states to the world. This is my mission and my vision." ■

About the Experts

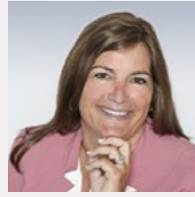


Laura Wayman, The Dementia Whisperer
Author, *A Loving Approach to Dementia Care*

Laura Wayman, The Dementia Whisperer, is an accomplished keynote speaker, international best-selling author, trainer, consultant and a dedicated gerontologist with an A.A. degree in gerontology and a social services designee certification. She has presented keynote speeches, workshops, in-services, classes, trainings and seminars across the U.S. on the significant subject of dementia care, continuing to share her essential message of “raising dementia-awareness” worldwide.

Her audiences have often given her the highest evaluations, singing her praises months and even years after her compassionate presentations. Each presentation is a representation of how much Laura enjoys her work. She is confident with every opportunity that she is “living her vision” of changing the dementia caregiving focus, one person, one family, one organization at a time. Laura grabs her audiences’ full attention in the first few minutes and holds it throughout with interesting stories, humor and relevant details that support and reinforce the message being delivered.

Her material will provide the opportunity for audience members to feel a full range of emotion, from tears to laughter, and comfortably relate to sometimes serious and disturbing information, leaving with a new sense of confidence, purpose and direction.



Michelle Baker, BS, RN, CRRN, CCM
2019.2020 Chair, Commission for Case Manager Certification

Michelle Baker is a registered nurse and associate director, Network Services for Paradigm Catastrophic Care Management. In this role, responsibilities include leadership in recruitment, application and selection process with Network business partner candidates, Network manager candidates, medical directors and clinical/medical specialist consultants.

Michelle’s professional background includes a variety of clinical leadership roles such as director of nursing, director of rehabilitation and senior case manager. Transitioning into rehabilitation and case management, Michelle had managed catastrophically injured workers for 13 years prior to becoming part of the management team at Paradigm in 2011.

Michelle first became a CCMC board member in 2016. Her service to CCMC includes participation in the 2009 and 2019 Role and Function Study and also includes multiple years as a volunteer and in leadership roles serving on the Program and Services Committee, the Governance and Nominations Committee, the Finance Committee, the New World Symposium Committee and on the Executive Committee of the CCMC Board.



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