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Home Care



# THRIVING WITH DEMENTIA

With the right at-home training and tools, caregivers can help clients with dementia live full lives

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Dementia Care Specialists



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Living well with dementia is not only possible, it is a realistic and achievable goal.

That's the word from Kim Warchol, president and founder of Dementia Care Specialists at Crisis Prevention Institute based in Milwaukee, WI. Dementia Care Specialists offers training, certification and support to help dementia caregivers provide person-centered dementia care. Crisis Prevention Institute offers de-escalation training to keep individuals living with dementia and their caregivers safe.

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“Just because a person's cognition is changing doesn't mean that suffering is inevitable,” Warchol said. “If we can help people living with dementia stay successfully and safely engaged in meaningful life activities at their best ability, then we can optimize their level of independence, their health and their quality of life.”

### THE BENEFITS OF HOME CARE

Warchol noted that thanks to the availability of home care services increasing, people with dementia are living

in their own homes. Although memory care communities can be a good choice for people living with dementia, opting to keep those individuals at home, if possible, plays to one of their core strengths: long-term memory.

“Being in a familiar environment, where they know where their bathroom is, and they know where their daily care supplies are located, can be very helpful for someone with dementia,” she said.

Warchol explained that there are two general types of home care: medical home care that begins after a person returns home from the hospital after an acute medical event, and personal care, which is longer-term and relationship-based. Medical home care usually is covered by insurance, whereas personal care often is private pay.

Both types are growing exponentially – medical home care because people are being sent home from hospitals “quicker and sicker,” and personal care because older adults increasingly are choosing to remain at home longer rather than move into assisted living or memory care communities.

Staffing shortages in senior living and memory care also may have played a role in the growth of home care services for people living with dementia, as has the COVID-19 pandemic: With lockdowns forcing families to become separated from loved ones in congregate living for extended periods of time, families have decided to look into home-based solutions.

The services provided for the two different types of home care are different. Medical care focuses mainly on providing positive medical and rehabilitation outcomes, whereas personal care focuses on creating long-term relationships with both the individual living with dementia and his or her family.



“The goal [of personal care providers] is to really get to know the day-to-day living situation of the person living with dementia in order to get the best daily life outcomes,” Warchol said.

“In addition, how are we supporting the family members who may have a significant role in helping to keep their loved one with dementia at home?” she added. “How are we supplementing the care those family members are providing so they have the time they need to stay healthy?”

Warchol pointed out that although the goal of medical home care is to provide the best outcomes after a hospital stay and prevent recurring hospitalizations, providers of medical home care often play a large role in dementia care. With more than 6 million people living with dementia in the U.S., it is a common comorbidity in medical home care.

“When an elderly patient is going home after a hip replacement, for example, the medical home care provider might notice that the person has some difficulty learning or making good judgments,” Warchol said. “So whether or not the person has been diagnosed with dementia, there are many seniors who have cognitive challenges who need support.”

That means medical home care providers should also be checking on patients’ cognition to ensure that they have the ability to understand how to take new medications and follow through on other medical interventions. As always, the common goal — no matter who the care



Photo: Rob Melnychuk/DigitalVision/Getty Images Plus

Understanding a person’s stage of dementia and their life story is the best way to start caring for that person.

provider might be — is to rally around people who are living with dementia to help them live well.

**UNDERSTANDING THE STAGES**

Warchol advocates for a society in which a wider understanding of the stages of dementia leads to better care planning and better outcomes.



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“You can’t really develop a plan of care or goals of care without knowing a person’s stage of dementia and what their cognitive abilities and challenges are, based on that stage,” she said. “On the other hand, if we understand the stages of dementia and what they mean in terms of a person’s capabilities, they become a powerful roadmap for the best way to provide successful care.”

Warchol added that it’s important to focus on an individual’s remaining abilities and not get lost in a “sea of negativity” when someone receives a diagnosis of dementia. People living with dementia are going to lose capabilities, but not all at once, and some abilities are still going to remain at each stage of the disease. As care providers, the key is to find those remaining abilities and put them to good use. That means thoroughly screening, assessing and monitoring the person’s cognitive level.

According to Warchol, a big piece of the dementia care movement is person-centered care so that the person living with dementia is never reduced to a diagnosis. The best way to provide person-centered care is to prioritize learning the person’s life story.

“Before we do anything with that person, what makes them tick?” she asked. “Who are they? What do they want and need to do every day? And how do we help them do those things successfully? That has to be the priority of our care. We understand the diagnosis and we support it, but the person is our focus.”

**ADAPTING COMMUNICATION, ACTIVITIES**

Adapting communication and activities to a person’s



Photo: Morsa Images/Digital Vision/Getty Images Plus

Personality traits needed in a dementia caregiver: Empathetic, patient, kind, a good listener and committed.

stage of dementia and level of independence is an important skill for caregivers. The goal is to provide meaningful activities in a safe and supportive environment. Warchol compared it with the type of adaptation that commonly is used for children.

“We’re always adapting to and enabling a child at the different phases of their development,” she said. “We know how to adapt the way we communicate. We know how to simplify activities. We know how to have the right expectations for their level of independence. You know that the developmental age is like a guide to helping us understand how we support a child so they can be the best they can be. It’s the same concept in dementia care.”

Adapting communication for a person who is living with dementia is important, as is understanding their communications, because misunderstandings can trigger a distress behavior reaction. This, unfortunately, is an area when many caregivers often are not properly trained, according to Warchol.

“Quite frankly, staff are often are not well-trained in understanding common distress behaviors, like anxiety and agitation and resistance, as a form of communication,” she said. “So we need to make sure that staff is very well-trained in how to look at behavior as a form of communication as a starting point. When a person living with dementia is anxious or resistive, or maybe even hitting or crying or threatening, they’re telling us some-

thing is wrong. They’re telling us through that distress communication. We have to make sure the person understands what we’re saying, and we must understand what they’re trying to communicate to us.”

## NEW FRIENDS WANTED

Warchol concluded that anyone who is providing care for a person living with dementia needs to be the right person for the job. They need to be empathetic, patient, kind, a good listener, and willing to build trusting relationships.

She noted that a great benefit of home care providers is that, unlike family members, they are not going through the stages of grieving that can follow a dementia diagnosis.

“We don’t have that past relationship with the person in care in which we’re saddened about the way the role or the relationship has changed,” she said. “We’re just meeting that person in the moment and being their new friend.”

The positivity that home care providers bring to the situation must apply to the families, too. Families caring for a loved one with dementia will need to make some tough decisions. Home care providers can be a great resource in helping to reduce their burden of care and their stress and helping them get connected to the right



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medical team members and other resources in the community such as elder care lawyers or support groups.

“At the end of the day, I think this is one team, and we all need to remember that we’re trying to help an individual live well with dementia,” Warchol said. “It’s very much possible if we can lock arms and share goals and beliefs and work together.” ■