Delivering Care to 
Dementia & Alzheimer’s Clients 
Over the Next Quarter Century

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13.8 million people are projected to be diagnosed with Alzheimer’s type dementia in 2050. That’s almost double the number of breaths you take in a year and just about the total minutes you will sleep in your lifetime. One out of every nine seniors over the age of 65 has Alzheimer’s disease. The cost of care for people diagnosed is staggering. In 2016, an estimated $236 billion was paid for health care, long-term care, and hospice, and it is estimated to jump to $1.2 trillion in 2050. An estimated $221.3 billion in unpaid care was also provided by family and friends last year. Yet the ability to provide family support will decline from a current ratio of 7 care providers to 1 senior needing assistance to a projected ratio of 3:1 in 2050. Part of this is the transitory nature of our society, the nearest child living on average 280 miles from their parents, and the average family size getting smaller. So how do we help the 90% of Americans over the age of 65 stay in their homes and cope with the added concerns of dementia?

Family Education and Support

Understanding that dementia is a disease of relationships is essential to providing phenomenal care. As with many illnesses and diseases, when people
find out someone they know has been diagnosed with dementia they often offer help and support. However, most people when diagnosed are still very capable of caring for themselves. As the disease progresses, the family care partner takes on an increasing number of tasks, not acknowledging or realizing how much they are doing. The need for the caregiver to do more and more and the decreased abilities of the person diagnosed starts to isolate the care partner and person diagnosed alike. The support systems of family and friends, social groups, exercise regiments, and religious organizations fall away. Often family care partners eventually feel the need for respite but are embarrassed by the behavior of the person diagnosed. They may not trust that a paid caregiver will be able to care for their loved one as well, or they have lost so much of their personal identity they don’t know what to do with the free time. In fact, many do not seek or accept help until there is a catastrophic event.

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Care partners need reassurance that any challenging behaviors are not uncommon for a person with dementia and paid providers understand this is the disease, not the person. It’s an opportunity to educate families on interpreting behaviors as communication and changing communication styles so interactions are more positive and challenging behaviors are minimized. Instruction regarding modifying daily routines and activities so the person diagnosed can continue to be successfully involved can help support the care partner emotionally as they see decline. Care partners need to be encouraged to have regular time away meeting with friends, attending a

ABOUT THE AUTHOR

Michelle is the Director of Memory Care Programs at Cypress HomeCare Solutions in Phoenix, AZ. Michelle earned her Master of Social Work in 1997 from Arizona State University, then in 2011 Michelle earned her Master of Education in Human Resource Development from the University of Illinois. The majority of Michelle’s work experience has been with the elderly population managing memory care units in both skilled nursing facilities and assisted living facilities. At Cypress HomeCare Solutions she has implemented a dementia training program for their caregivers, a family support and education program for the family members of those diagnosed, and provides public educational sessions. Michelle has also been a support group facilitator for the Alzheimer’s Association and other community groups since 2013.

Michelle Toft is a respected speaker on dementia care in the Phoenix area, providing education to community, religious, and professional groups and organizations on a regular basis.
support group, exercising, or doing something that fulfills them. As you have been given the highest level of trust by being allowed to enter their home, your modeled behavior and guidance can teach positive relationships with this changed person.

**Caregiver Training**

To do this requires the paid caregiver be extensively trained in dementia. They are the eyes and ears in the home and the example for the family. Caring for a person with dementia is vastly different than other types of care. Since dementia affects the person’s ability to communicate, make decisions, problem solve, and care for one’s self, the caregiver must notice deficits and initiate activity. Whereas other clients are able to guide the course of their care, the person with dementia needs someone capable of guiding the care while at the same time allowing as much independence as possible. This is a fine line that constantly changes; too much help and the person feels demeaned, too little help and they feel incapable. The caregiver should be skilled at noticing emotional and behavioral changes, validating the client, and redirecting the behavior. The caregiver must live in the client’s world and be able to think quickly and guide the client to meeting their care needs in a manner that is not confrontational. During the course of the daily routine, the caregiver is responsible for maintaining client involvement, initiating activities to keeping the body and mind active, and ensuring the client feels their life still has purpose. These are skills that require both a comprehensive training program and ongoing client-specific coaching.

**Technology**

Many programs are available to help the caregiver and with technology they can have instant access to activities and ideas to make the day more enjoyable and advanced curriculum to maintain brain health. Programs
are available to help monitor safety, give daily reminders for medications, and prevent injury.\(^2\)

As technology developers think outside of the box, we will only see this expand. We need to constantly be monitoring for new innovations that will assist our clients. The paid caregiver needs to feel comfortable knowing that this technology enhances the care being given and not replaces it. Teach the family caregiver to try technology she/he may not feel comfortable using.

**Community Education**

And finally, we can’t do it alone. Dementia isn’t a disease that just takes away a person’s memory, it often diminishes a person’s ability to communicate, to care for their personal needs, to manage their home and finances, and to maintain personal relationships. It takes a community who understands the disease process and takes an active role in helping support to maintain safety for all members. Many of the fears experienced by families can be negated if the cashier at the store understands that the client didn’t mean to steal the candy bar but just has lack of judgement due to dementia, or if the other members of their faith community understand that they don’t intend to disrupt the service but are overwhelmed by the music and couldn’t help but belt out the words as loud as their voice could carry.\(^3\) Everyone needs to understand this is a disease that causes someone to not remember social norms and practicing patience will help them, the client, and the family.

With the staggering projected number of people being diagnosed with dementia, home care of the future is about quality care for all those affected, which includes the family and community. The expectation is that paid caregivers are the experts in completing a job the family may be struggling with. Lovingly coaching and guiding those in the home and in the community to understand the disease process, will ensure success for all affected.

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**Notes**