

Opinion Piece

Helping People Live, Not Just Exist, with Alzheimer's Disease; It's what We Do

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It is now estimated that over 5 million Americans have AD and one person is diagnosed every 67 seconds. Nursing home, staff tells me that about 80% of their residents have some type of memory loss. It was not that long ago that assisted living communities would discharge anyone with advanced dementia and now I find that in most states their residents "age in place" as long as they do not need skilled services. Often using the services of a hospice organization they can stay and die with people who know them and are with them at the end of life. Dedicated dementia communities are the fastest growing segment of the healthcare industry; we are the experts in caring for people with AD.

With no cure in sight or no "magic pill" that would significantly slow the progression of AD, we continue to be bombarded with bad news. The good news rarely gets reported but the good news is so exciting we should all be hounding the media with our stories. And the good news is? Healthcare workers know how to help people in all stages of memory loss live with quality in their lives, literally until they take their last breath. We do this every day, 24 hours a day. Our residents are rarely restrained, and the use of antipsychotics has decreased significantly. They smile very often, and it's not uncommon for a resident to say "I love you" to a care partner.

We help people LIVE not exist with memory loss, by making sure the basic care is only the beginning of how we provide care. Existing means residents are offered food and beverages and assisted as needed. They are bathed, groomed and given whatever medications and treatments that are prescribed. This is existing; and no one wants to simply exist. Most of us thrive on being loved and touched. We need to feel special, that the care partners know us as individuals, not as the resident in 12 B who has AD. Most of us also want to be needed, to be able to give as well as receive. Our residents feel the same way.

In spite of memory loss our residents can still laugh, enjoy special treats, engage in activities that are meaningful to them, and be touched by their spiritual or religious beliefs. A few months ago at the Lutheran Homes of Oshkosh, Wisconsin I saw Chaplain Cathie Vander Velden place her hands on the forehead of a resident with advanced dementia, and then to our amazement, the resident reached up and blessed her!

Healthcare professionals know how important it is to lower the

stress of a resident with mild memory loss. We print a daily list of activities so that they are not overwhelmed with the monthly calendar and trying to figure out what day it is. We use memory reminders of beauty shop days and other weekly notices. Many of our residents continue to engage in volunteer work. At EPOCH assisted living of Melbourne located in Pittsfield, Massachusetts a group of women who can still knit have a table with a sign declaring them the "Knit Wits". They sell the Afghans, baby blankets and other items, donating the money to a local hospice.

Activity professionals know the benefits of planning programs for people with early and moderate memory loss that keep them physically active. They also plan programs that stimulate them cognitively. A mixture of creative (right brain) activities and those that use the left brain like figuring out how to score bowling tournaments and engaging in a variety of word games keep residents busy and involved with others. Behaviors associated with dementia like wandering and hoarding disappear when residents are having a good time engaged in activities that are meaningful to them. The sounds of laughter fill the rooms where in spite of memory loss, residents are just having fun. They are definitely not just existing.

As residents transition to the advanced stage, they can continue to be engaged in activities that are meaningful to them. Programs such as Namaste Care™ offer residents an opportunity to continue to be in a group setting. Activities change as the resident can no longer participate in traditional physical and mentally stimulating programs. What they enjoy is someone touching them in a gentle and loving way. Just combing a resident's hair, telling them how beautiful they are, soaking their hands and feet in warm water, and moisturizing their skin brings smiles and joy to residents with advanced dementia. In a setting that is quiet and calming, residents can continue to experience quality in their lives until they are ready to leave this world.

When a resident is actively dying, families are helped to understand what is happening and what they can do for instance telling the resident that it is okay for them to go, massaging their hands or just sitting with them. If a resident has no family, staffs try to have someone with them so that no one dies alone. Hospice is often involved making sure that the resident is not uncomfortable on this final journey. Thankfully, futile medical interventions for residents with advanced dementia have decreased and rather than dying in a hospital, they are with staff that have loved and cared for them sometimes for many years. Even how residents leave the facility has changed in recent years. No longer are they whisked out the back door, but many will leave as they arrived, through the front door accompanied by staffs who then have an opportunity to say their final good-bye. The last time I saw a resident leave this way, one of the nursing assistant lovingly touched the hearse as the door closed. It was such a beautiful gesture, the love she felt for her resident was palpable.

The majority of long term care homes are just that, homes with caring staff that help residents with physical and cognitive disabilities, live not just exist. And, it's time we all help the public hear our stories.

Please share yours and let's help to change the negative picture that has been projected about living with dementia. We know how to help people live not just exist with AD, it is what we do!