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What makes your loved one great?

Written by Darlene Rabb-Kerr, RN

Soon after Larry was diagnosed with Alzheimer's disease he became listless. The spark went out from his eyes. Karen knew he was depressed, understandably so, but she just could not reach him. She made arrangements for all of his care, and made sure that everything was covered. She tried to involve Larry in the planning, but he would have none of it. She tried to keep him active with puzzles and games, but he would just stare out the window, despondent.

Larry was an expert mechanic all of his life. He came by it honestly; growing up on a dairy farm in the 1930's with four brothers there was always a small engine to repair. In those days, you didn't buy a new one, you figured out how to fix it. He loved it and was good at it. Later in life, he made it his profession and opened his own auto mechanic shop. On weekends he volunteered with the Boy Scouts and taught small engine repair. There wasn't an engine made that he couldn't fix.

Karen was heartbroken. Caring for Larry was what mattered most, but even though his needs were met, he was distant. Karen and Larry's experience is not unusual. When caring for someone with Alzheimer's it is easy to get so wrapped up in schedules, medications and personal care that we forget what it was that made that person happy. That is, who they were, and how they liked to spend their time.

In the past, health and social services professionals would recommend care practices that were most practical and efficient for the person providing the care. Person-centered care is exactly the opposite. Instead of efficiency, the focus is on flexibility with the goal being to meet the needs of the person in a manner that is best for them. Making the focus of the care the person, their values, beliefs and preferences—person centered care—builds on the strengths and abilities of the person with Alzheimer's.

What is person-centered care?

Person-centered care is a way of thinking and doing things that makes your loved one an equal partner in planning, developing and monitoring care to make sure it meets their needs. It puts them at the center of their care, honoring their values, choices and



preferences, rather than focusing on their current level of ability, or abilities they have lost. Person-centered care is not just about giving people whatever they want or providing information. It is compassionate care that considers a person's desires, values, and lifestyle. One sees the person as an individual, and works together with them to develop the best solution. This might be done through sharing decisions with the person with dementia and helping them manage their health, when to go to bed, or how to spend an afternoon—but person-centered care is not just about activities. It is as much about the way you and your loved one think about care and your relationship as the actual care that is provided. It is grounded in mutually beneficial partnerships established between people with dementia and their caregivers.

Patient centered care reduces the amount of time spent in the doctor's office as well. Studies have found that people with Alzheimer's who received person-centered care needed fewer doctors' visits and were referred less for tests. This is attributed to a sense of greater connectedness that the person with Alzheimer's has with their environment and the people in it. In essence, things aren't quite so confusing because they are working with someone with whom they are familiar (*Stewart, et al., 2000*).

There are many different ways to take care of the person with Alzheimer's in a person-centered effort:

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- Discuss and identify what the person values and focus those values in their daily routines.
- Consider the person's preferences and needs.
- Work together to ensure there is good communication, information and education for both the person with Alzheimer's and the caregiver.
- Make sure the person with Alzheimer's is physically comfortable and safe.
- Provide emotional support.
- Involve friends, family and the community.
- Make sure the person has appropriate care when they need it.

Karen realized that games and puzzles so often recommended by healthcare consultants recommended were never his thing. For Larry to be engaged he had to be working on something. Using his hands to build something. Karen and Larry scoured flea markets for old vacuum cleaners and lawnmowers—anything with a motor—that Larry could work on in the garage. She worked with Larry and their son Rob to set up the garage to make it safe. Larry agreed that safety is always a priority in small engine repair.

Soon the light came back to Larry's eyes. She helped him set up a project to work on the card table, and was close by if he needed anything. Larry was engaged and smiling. He loves working on engines to this day.

⇒ Stewart, M., Brown, J.B., Donnor, A., McWhinney, I.R., Oates, J., Weston, W.W., & Jordan, J. (2000). The impact of patient-centered care on outcomes. *The Journal of Family Practice*, 49 (9); https://www.researchgate.net/profile/Wayne_Weston/publication/12292586_The_impact_of_patient-centered_care_on_outcomes/links/004635260327e8a432000000.pdf

Person Centered Care Core Concepts

Person-centered care is founded on an interactive process, in which people with dementia are active participants in their own care throughout the various stages of the disease and family members play a vital role in ensuring the health and well being of their relative.

Dignity and Respect: Like all individuals, people diagnosed with dementia are people first. Listen to them and honor their perspectives and choices. They have an inherent dignity, value and personhood which remains with them throughout the whole course of the disease and should be respected at all times.

Information Sharing: Communicate and share complete and unbiased information with people with dementia and their families in ways that are affirming and useful. People with dementia and their families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

Participation: People with dementia and families are encouraged and supported in participating in care and decision-making at the level they choose. This therapeutic relationship is based on the participation of the person with dementia, regardless of their level of cognitive or physical impairment. The goal is to focus the relationship on the person, without excluding family members.

Collaboration: People with dementia and families are also included on an organization-wide basis. Care home managers collaborate with people with dementia and families in policy and program development, implementation, and evaluation; in health care home design; and in professional education, as well as in care planning.

 **Tips &  Tools: Respite Grants Available**

The toll of caring for a loved one suffering from dementia builds up gradually. To help avoid becoming overwhelmed, include as many people as you can in the care of your loved one earlier, rather than later. Respite care can come in different forms:

In your home: A friend, other family member, volunteer or paid service can offer companionship, assistance with personal care such as bathing, dressing, laundry and shopping. Skilled care can also be provided at home, such as assistance with administering medication.

Adult day centers: These centers offer the person with dementia a safe place to socialize and participate in directed activities. Transportation and meals are often provided.

Residential facilities: Options may include an overnight stay, a few days, or a few weeks, allowing the caregiver a chance to take an extended break or vacation.

There are costs involved. Consider asking about financial assis-

tance, which may come in the form of scholarships, sliding-scales, or government programs.

Respite Care Grants are available to low-income family caregivers in need of respite care for their loved ones with Alzheimer's disease or other forms of dementia. Funds received through our grants are restricted, intended solely to help caregivers obtain a much needed break from caregiving duties.

These grants are made possible by the Mary Oakley Foundation and the Alzheimer's Association California Central Chapter. To find out more about our grants and to learn if your family qualifies, please contact:

- **Ventura County:** Araksi Kirakosyan at 805.494.5200
- **Santa Barbara County:** Donna Beal at 805.892.4259
- **San Luis Obispo County:** Rayleen Moran at 805.547.3830
- **Kern County:** Judy Ardray at 661.794.6948