

A Change of Plans: The gift of an early diagnosis

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There is no prevention, treatment, or cure for the many diseases that cause dementia. As a result, many people question why they should seek a diagnosis if experiencing occasional memory lapses or confusion. There are many reasons to explore the cause for these early symptoms. First and foremost—it *may not* be a progressive dementia such as Alzheimer's at all. The symptoms might be the result of a treatable condition that can be reversed or controlled, such as depression, hyperthyroidism, dehydration, stress, or sleep apnea.

However, if the diagnosis *is* progressive dementia, knowing this will provide one with the opportunity to prioritize plans for the future and consider options that will improve the quality of life for oneself and his loved ones throughout the progression of the disease. A diagnosis doesn't mean that all prior plans must be discarded, but that they may need to be adjusted.

A person diagnosed with progressive dementia will live, on average, another four to six years. An early diagnosis may allow a person to fulfill some of her "maybe someday" dreams during the early stages—perhaps fulfill that once-in-a-lifetime adventure, go to a live sporting event they have wanted to see that had been put off until the "right" time; or perhaps make more opportunities to spend quality time with loved ones. Importantly, the diagnosed person will have opportunities and choices while still healthy.

Knowledge of one's having progressive dementia may also allow a person to



participate in research for treatment or a cure. The Alzheimer's Association offers **TrialMatch**, a service that connects diagnosed people and healthy participants to research. Participants in research trials receive high quality care and their participation can give them a sense of purpose and meaning, knowing that they are contributing to better treatment or a future cure.

For those who are still working, being able to discuss one's diagnosis with an employer may save one's job or provide retirement without losing benefits. If a person experiences memory loss and confusion on the job and there is no explanation for the change in performance, it may result in job loss. However, a diagnosis of progressive dementia may provide ADA protections so the cognitive handicap can be accommodated and the person can continue to work for a longer time. Once retirement is necessary, he will be eligible to apply for Social Security benefits. Without a diagnosis, those benefits would not be available.

An early diagnosis will allow the diagnosed person to make decisions about financial and legal matters such as wills, advance

alzheimer's association®

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Chapter

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San Luis Obispo County
71 Zaca Ln Suite 110
San Luis Obispo, CA 93401
Tel: 805.547.3830

Ventura County
2580 E. Main St Suite 201
Ventura, CA 93003
Tel: 805.494.5200

24-Hour Helpline:
800.272.3900

alz.org/CaCentral

Plan Ahead

Tips



- Develop a support team ahead of time.
- Ask for help
- Learn or update caregiving skills
- Join a support group
- Learn how to manage stress

Tools



Map out a plan to approach dementia.

Create a simple personalized action plan and link your information, support and local resources: alzheimersnavigator.org

- Working with your doctor
- Identify symptoms.
- Safety
- Legal planning
- Knowledge
- Financial planning
- Caregiver support
- Care options
- Activities of daily living

healthcare directives, naming a power of attorney, and developing a plan for financial stability. Having these legal documents in place ensures that the diagnosed person can make her wishes known and are carried out, and that her loved ones are not left trying to guess what she might have wanted. It also enables the family to plan for the long-term care of the diagnosed person. Together, patient and caregiver may plan for future care, including the selection of a residential care facility. Further, the diagnosed person may connect with programs through Aging and Adult services or the Veteran's Administration, that will help identify financial resources that may be available.

An early plan may allow a person to fulfill "maybe someday" dreams.

Education and support are key to creating the best circumstances for those living with progressive dementia. The sooner one is aware of his diagnosis, the sooner he can begin to build a support team of family, medical professionals, and friends or begin to learn about Alzheimer's. Online support and education are available 24-hours a day at alz.org, and at the Alzheimer's Association Helpline, 1-800-272-3900. In addition, many communities have in-person classes, support groups, and engagement opportunities for people in early stages.

Education is especially valuable to care partners as the disease progresses. Educational classes can help caregivers gain an understanding of the physical and behavioral changes that may occur throughout the stages of the disease. Classes will also help the caregiver develop skills for better communication and caregiving techniques that will improve the quality of life for the afflicted loved one and provide greater peace of mind for the caregiver.

Participation in a support group can give the caregiver practical information from others who share similar caregiving

experiences, thus relieving the feelings of isolation that can result from long-term caregiving. Whether online or at a local meeting, the sense of community that develops in a support group can remind a caregiver that he is not alone in his journey.

Learning that a person has progressive dementia helps to develop a care team and to develop a strategy for the future. By sharing the diagnosis

with others, it can de-stigmatize the illness and create a larger circle of support. Close friends are given the opportunity to learn about the illness and continue to offer friendship and support to both patient and caregiver.

When the patient's health-care team is made aware of the diagnosis, it can offer the best medical care based on the individual's changing needs.



Having a plan in place can be a great comfort to anyone living with a long-term chronic disease. Once plans are prioritized and the person with dementia has been able to participate in future planning, it will be up to the caregiver to make new plans and adjust for the challenges of unforeseen circumstances as the disease progresses.

Despite the dread of having an early diagnosis that might confirm one's greatest fear that indeed, it is a cognitive problem, once the diagnosis is made it allows the diagnosed person to give the gift of shared planning to one's care partners—eliminating any uncertainty in making plans and future decisions on behalf of the afflicted person.