Long-term care (LTC) options for people living with dementia

Jan Karlen

Jan has worked for the Department of Human Services (DHS) since 1998. In her current position as a policy analyst, Jan has varied responsibilities, including coordinating and participating in several workgroups connected with the State Plan on Alzheimer’s Disease, overseeing the Family Caregiver Support Program, and coordinating and participating in the Oregon Partnership to Improve Dementia Care. In her tenure at DHS she has worked with the licensing of residential care and assisted living facilities and endorsement of memory care communities.

Making decisions about how to support a loved one with dementia can be difficult. It is recommended to have discussions with the person shortly after their diagnosis to understand what they want and expect; however, this is not always done. Family members can make promises about caring for their loved one at home, but circumstances can change and it is not always possible to carry through with that promise.

In-home care services allow people to stay in their homes longer. In-home services are available either through in-home care agencies or the Oregon Home Care Commission. These services can include assistance with activities of daily living (ADL) such as, housekeeping, shopping, transportation, medication management and meal preparation.

Adult day service programs provide health and social-related services during part of the day. Some programs are open five to six days a week all day and others have more limited days and hours. These programs provide socialization for the person and respite for their caregiver.

Adult foster homes are single-family homes that consist of five or fewer residents. There are different categories of care. Meals, assistance with ADL care, medications and activities are provided. Registered nurse (R.N.) consultation, assessment and delegation are also available. Skilled care is not provided, but the home can coordinate with home health and hospice care services when needed.

Assisted living (ALF) and residential care facilities (RCF) provide services to six or more residents. The rules for each of these settings are the same except for building requirements. People living in an ALF will have their own apartment equipped with a bathroom, kitchenette and living and bedroom space. RCFs may also have apartments, or they can be a large home and can have shared rooms. Both settings provide

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In our last newsletter, I advised caregivers to engage in “Pleasant Events” (Teri and Logsdon, 1991) with their family members with dementia. For this newsletter, try extending the pleasant events to you. You know, as caregivers, that you are at risk for developing anxiety, depression, high blood pressure, insomnia (etc., etc.). Protect yourself by taking care of yourself. Remember, pleasant events do not need to be elaborate. Write a list of pleasant events for you. Use this list when you need a boost during the day, or when a friend calls and says, “Can I help?” (You say “Yes!” and leave the house for an hour).

To get you started, here are some ideas. I left some lines for you to write in your own ideas. Keep the list handy for your reference. Email me your ideas so I can share these with other caregivers. Send me your ideas and we can work on a list together: lindauer@ohsu.edu.

- Get a pedicure (yes, guys, you can get a pedicure too!)
- Cook a favorite meal
- Take a walk
- Take a nap
- Watch a favorite movie
- Call a friend
- Read the newspaper
- Play an instrument
- Look at travel brochures
- Pet the dog (cat, gerbil, stuffed animal)
- Take five deep breaths
- Look at yourself in the mirror and say “Thank you for all you do.”
The Oregon Research Center for Complementary and Alternative Medicine in Neurological Disorders (ORCCAMIND)

Barry S. Oken, M.D., Ph.D.

Professor, departments of neurology, behavioral neuroscience and biomedical engineering; director, Oregon Center for Complementary and Alternative Medicine in Neurological Disorders; and associate director, Layton Aging and Alzheimer’s Disease Center

The Oregon Research Center for Complementary and Alternative Medicine in Neurological Disorders (ORCCAMIND) began in 1999 under the leadership of Barry Oken, M.D., Ph.D., with a center grant from the NIH National Center for Complementary and Alternative Medicine (currently named the National Center for Complementary and Integrative Health). ORCCAMIND has supported research projects and also has had a major emphasis on training researchers. Since 2005, an NIH institutional training grant, “CAM Research Training in Neuroscience and Stress,” has helped OHSU train over 30 postdoctoral fellows. Research by these fellows has extended from basic science to health services research. The original ORCCAMIND center grant and the T32 training grant have provided funding for many investigators at various stages of their careers. Besides Dr. Oken, this has included many NIH-funded investigators associated with the Layton Aging and Alzheimer’s Center: Drs. Jeffrey Kaye, Joseph Quinn, Amala Soumyanath, Lynne Shinto, Gene Bowman, Nora Gray and Jeff Proulx. Besides researchers involved in aging and Alzheimer’s, ORCCAMIND-affiliated researchers have been involved in research on fibromyalgia, nicotine addiction, multiple sclerosis, post-traumatic stress disorder, and sleep disorders using various integrative medicine interventions: dietary supplements, yoga, meditation, hypnotherapy, acupuncture, naturopathy and chiropractic.

Dr. Oken’s research has been focused on mind-body approaches for stress reduction, beginning with yoga but for the last 10 years focused on mindfulness meditation. Mindfulness training has two components: bringing your attention to your current moment and not overreacting emotionally to experiences (being non-judgmental). For example, if your spouse starts yelling at you because they have dementia, the goal is to almost shrug your shoulders and not attach an emotional tag to the experience. Dr. Oken’s studies have utilized healthy older adults, dementia caregivers and stressed older adults. The mind-body interventions have produced consistent improvements in quality of life and mood. We have had limited success in improving cognition by reducing stress but were successful in one condition where there is excessive stress: family caregivers of people with dementia. As part of his research, Dr. Oken received an NIH career development grant that advanced his ability to utilize advanced signal analysis to improve mind-body medicine research.
Oregon Tax Checkoff for Alzheimer’s Research 2017 Grants

The Oregon Tax Checkoff Alzheimer’s research fund is administered by the OHSU Layton Aging and Alzheimer’s Disease Center on behalf of the Oregon Partnership for Alzheimer’s Research. These funds are made available through Oregonians donating part of their tax refund to Alzheimer’s research.

Priority for funding is given to investigators just entering the field of dementia research. Applicants may be investigators in Oregon who are launching their careers, including senior graduate students (for doctoral dissertation research), fellows and junior investigators.

Grants may be awarded to clinical, basic or social scientists for support of research that will advance the understanding, treatment or prevention of Alzheimer’s disease. Potential fields for research include the basic neurosciences, genetics, nursing, social work, epidemiology, sociology, psychology, psychiatry, public health, economics, counseling, delivery of health care services, and others relevant to Alzheimer’s research or practice.

The 2017 research grants were awarded to:

Iris Wernher, Dipl.-Psych.; Ph.D. student, graduate research assistant, Portland State University, Institute on Aging: Defining “dementia-friendly communities” from the perspective of those affected

Vivek K. Unni, M.D., Ph.D., assistant professor, neurology: Lewy body-associated neurodegeneration in dementia

For information about this program, contact Allison Lindauer, lindauer@ohsu.edu, 503-494-6370.

More than 62,000 Oregonians have Alzheimer’s disease. You can help.

When filling out your tax return this year, please check the designated box to donate a portion of your state tax return to fighting Alzheimer’s disease.

Every dollar of donated Tax Checkoff funds goes to researchers in Oregon. Funds are administered through OHSU under the direction of the Oregon Partnership for Alzheimer’s Research.

For more information, visit www.ohsu.edu/alzcheck.
If a patient has a brain disease, usually the family will donate the brain for study after death for a couple of reasons. The first is to find out the final diagnosis. The second is to understand what this means for other family members, usually children or siblings. They want to know what are the chances that others in the family will get this or a similar brain disease?

Contrary to common belief, Alzheimer’s and most other age-related brain diseases are not always inherited. There are a few gene mutations that produce Alzheimer’s disease but these are estimated to account for only around 5 or 10 percent of Alzheimer’s patients. Patterns of inheritance of a combination of other non-mutated genes contribute to about 40 to 50 percent of the risk of Alzheimer’s disease, but do not typically lead to the disease. Unfortunately, no amount of testing of these genes can predict with certainty whether a person will develop Alzheimer’s disease.

So it appears that, taken together, genetic factors determine only about half of the cases of Alzheimer’s disease. So what causes disease in others? We assume that the disease in these people is triggered by something, or a combination of things, in the environment. However, what these are, when they have their effects, and how these work on the brain to produce disease remains completely unknown. In this way, brain diseases are similar to many other diseases such as cancer that have known risk factors but that still appear somewhat random in terms of who precisely gets a disease versus who does not.

Our limited understanding of what exactly causes brain disease makes us want to learn more so we can prevent them or find a cure. Most age-related brain diseases are incurable and ultimately fatal. Families feel powerless when they watch a loved one lose their mental capabilities and often their identity. Donating brain tissue for research can provide a sense of empowerment and purpose to those left behind, often tempering the grieving process and sense of loss.

For more information on brain donation, contact Randy Woltjer, M.D., Ph.D., at 503-494-0100.
We are excited to announce that we have three EXITO scholars joining our team at the OHSU Layton Aging and Alzheimer’s Disease Center: Juell Towns, Mustafa Ahmed and Sabrina Shofner. They are all juniors at Portland State University.

EXITO is an undergraduate research training program. PSU received a grant from the National Institutes of Health to serve as a center for innovation to help undergraduates, including those from diverse backgrounds, become successful health researchers. OHSU serves as the research-intensive partner, providing crucial support, guidance and expertise.

The EXITO model aims to identify students early in their college careers and engage them in finding solutions to today’s major health problems. Students must be enrolled at PSU or one of the EXITO-partnering community colleges and universities. Our students will be at the Layton Center for two years. They will have hands-on research experience with their mentors, Raina Croff, Ph.D., Andre’ Pruitt, M.S.W., and Allison Lindauer, P.h.D., N.P.

You may see our scholars in clinic, at community events and at research visits. Please join us in welcoming them to OHSU.

To learn more: www.pdx.edu/exito/about-build-exito

Options
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assistance with ADL care, health-related services, meals and activities. Caregivers are trained, but not required to be certified nursing assistants (C.N.A.s). An R.N. is required for assessment and delegation as well as consultation, but is not required to be on-site 24/7. Skilled care is not provided, but the facility must coordinate with home health and hospice agencies when needed.

Nursing facilities (NF) are considered the most institutional option. They tend to focus on skilled services such as for rehabilitation and complex nursing care. Direct care staff must be C.N.A.s and licensed nurses are required 24/7. They are also required to have a medical director that would be an M.D. or D.O.

Memory care communities (MCC) are licensed as either an RCF, ALF or NF, and in addition to meeting licensing requirements, they must also meet the requirements for MCC endorsement. Individuals admitted to these secured settings must have a diagnosis of a progressive dementia. All staff who work in MCCs must receive dementia training. Nursing services and caregiver training will depend on the license of the MCC.

For more information about Oregon’s long-term care services and settings, visit the Aging & Disability Resource Connection at https://adrcforegon.org/consite/explore-in-a-facility.php. There are resource guides and tools that can help in choosing a long-term care setting.
Tele-Savvy study enrolling dementia family caregivers

Tele-Savvy is a study that aims to test the efficacy of an online program for family caregivers of persons diagnosed with Alzheimer’s disease or another dementia. Tele-Savvy is adapted from its in-person version, the Savvy Caregiver program, a training program for those providing care for a person living with Alzheimer’s. The Savvy Caregiver program has demonstrated its effectiveness in decreasing caregiver stress and burden and improving their sense of mastery. A pilot study of Tele-Savvy has shown similar positive results for caregivers. The goal of the Tele-Savvy program is to help caregivers gain additional skills that will help them decrease their depression, stress and caregiver burden, while maintaining optimal function and quality of life for their family members with dementia.

OHSU is one of the lead centers, recruiting over 270 caregivers nationwide to take part in the Tele-Savvy study. The Tele-Savvy program engages participants in professionally led, small-group 1.5-hour videoconferences held over seven consecutive weeks. Tele-Savvy also asks participants to view a series of video lessons meant to inform and improve caregiving. The daily videos are 10–25 minutes in length and can be viewed whenever, and as often as, participants wish.

All caregivers who take part in the study will have the opportunity to participate in the Tele-Savvy program. Some will be asked to take part immediately; others will be asked to take part six months after enrolling in the study. For those asked to wait six months, some will be asked to join a Healthy Living program and some will be asked just to continue with the care they usually receive. Like Tele-Savvy, Healthy Living involves seven weekly group videoconferences and daily video lessons, to be viewed at participants’ leisure. Tele-Savvy and Healthy Living videoconferences will be offered during business hours, evenings and weekends. Assignments to each of these conditions will be random (to Tele-Savvy, Healthy Living or regular care).

All who take part in the study will be asked to complete five study-related interviews over the course of 12 months, and some participants will be asked to participate in an additional in-depth interview about their experience in the program. To show appreciation and respect for the time involved, caregivers will be offered a $25 gift card for each interview in which they participate.

Interested caregivers can contact OHSU Site Coordinator Natasha Spoden at 503-494-6370 or email spoden@ohsu.edu.

Clinical research trial

OHSU is a study site for the Aware (AbbVie) study, a placebo-controlled clinical research trial designed to learn whether an investigational drug, ABBV-8E12 (an anti-tau antibody), is safe and can effectively block spreading of tau protein in the brain and slow down Alzheimer’s disease progression (cognitive and functional impairment). If you are 55-85 years of age and have a diagnosis of mild cognitive impairment or probable Alzheimer’s disease, you may be eligible to participate in this research effort.

To learn more, please call 503-494-7647.
(PI: Dr. Jeffrey Kaye | IRB 16347)

If you would like information about our current trials and research participation opportunities at the Layton Center, please call our research team at 503-494-7647 or email adresearch@ohsu.edu.
The Layton Aging and Alzheimer's Disease Center

The Layton Aging and Alzheimer's Disease Center is one of 30 NIA Alzheimer's Disease Centers in the U.S. and the only one of its kind in Oregon. Our center is recognized as a national leader in dementia care and research, and is committed to serving the needs of people throughout the Northwest.

The Layton Center is part of the OHSU Brain Institute (OBI). OBI is a national leader in neuroscience patient care, research and education.

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