



# RESOURCES

FOR **PERSON-CENTERED DEMENTIA CARE**  
IN **LONG-TERM CARE SETTINGS**

# Resources for Person-centered Dementia Care in Long-term Care Settings

## Introduction

In the last decade or so, the term “person-centered” (or person directed) care has become a well-known term among long-term care settings, especially related to people with dementia. Person-centered care is an approach to care that focuses on a person’s autonomy (regardless of cognitive impairment), strengths, life story, and relationships with direct care worker(s). In a true person-centered setting, the person and his or her family are asked about their customary routines and preferences. The setting then adapts the person’s schedules and routines to provide individualized care.

This guide provides information on websites, books, professional organizations and services that can be valuable when developing and implementing a culture of person-centered care to communicate a philosophy of care through their policies and procedures, and staff training for their setting.

The Oregon Partnership to Improve Dementia Care has developed this resource guide. The partnership’s goal is to help long-term care settings develop person-centered practices that will enhance the quality of life for people with dementia. The partnership consists of representatives from the Oregon Health Care Association, LeadingAge of Oregon, Acumentra Health, Department of Human Services, the Alzheimer’s Association, Oregon Patient Safety Commission, Making Oregon Vital for Elders, and the Oregon Long-Term Care Ombudsman’s Office. Teri Fagan and William Simonson serve as consultant pharmacists.

**Please Note:** Although there are many resources listed, this is not a complete listing. For additional resources you can go to your local library or to the Green-Field Library at the Alzheimer’s Association. Access the library at [www.alz.org/library/index.asp](http://www.alz.org/library/index.asp).

This document can be provided upon request in an alternate format for individuals with disabilities or in a language other than English for people with limited English skills. To request this publication in another format or language, contact the State Unit on Aging, 1-866-535-8493 or 711 for TTY.

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## Resources for implementing person-centered care approaches to support people with dementia

Program name, book title or Web resource	Sponsoring organization or author	Description of organization, publication or website	Learning resource type	Website
Acumentra Health		Acumentra Health assists health care providers and clinicians in a wide range of initiatives to improve patient safety, effectiveness of care delivery and quality of care.	Offers consulting and quality improvement projects	<a href="http://www.acumentra.org">www.acumentra.org</a>
Nursing Home Quality Campaign	Advancing Excellence In America's Nursing Homes	This major initiative of the Advancing Excellence in Long-Term Care Collaborative assists all stakeholders of long-term care supports and services to achieve the highest practicable level of physical, mental and psychosocial well-being for all individuals receiving long-term care services.	Provides many tools including webinars, manuals and tool kits to implement person-centered programs	<a href="http://www.nhqualitycampaign.org/">www.nhqualitycampaign.org/</a>
CARES® Dementia Care Online Training	Alzheimer's Association	<p>This Alzheimer's Association training program for informal and professional caregivers offers the additional option of essentiALZ®. This online individual certification program recognizes individuals' knowledge of quality dementia care practices.</p> <p>The Alzheimer's Association is a national not for-profit organization with a 24-hour helpline for people with dementia and their care partners. The helpline connects them to local chapters for support. This organization is instrumental in assisting research efforts for treatments that will stop or slow the progression of Alzheimer's disease or other dementias.</p>	Offers online interactive training	<a href="http://www.hcinteractive.com/ProfessionalCARES?GroupID=3">www.hcinteractive.com/ProfessionalCARES?GroupID=3</a>
	Alzheimer's Association: Oregon Chapter	This not-for-profit organization operates within Oregon and Southwest Washington. It provides education and support to people with dementia, their care partners, health care professionals as well as the public at large. The organization also offers programs and activities that enhance the lives of people with dementia and those who support them.	Provides educational events/ programs for people with dementia and their care partners. Education topics include legal and financial planning, caregiving skills.	<a href="http://www.alz.org/oregon">www.alz.org/oregon</a>

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“Excellence in Care”	Alzheimer’s Foundation of America (AFA)	This nonprofit foundation is comprised of member and associate member organizations across the United States that are dedicated to meeting the educational, social and emotional needs of individuals with Alzheimer’s disease and related illnesses. The foundation also serves their families and caregivers. AFA raises public awareness about the disease, lends expertise to health care professionals and provides grants to nonprofit member organizations to enhance local services.	AFA Excellence in Care specialists partner with a care setting to meet the program’s standards	<a href="http://www.alzfdn.org">www.alzfdn.org</a>
	Alzheimer’s Network of Oregon: Serves Marion, Polk, Linn and Benton counties.	This not-for-profit organization serves people with dementia and their care partners through educational and support programs. It is an associate member of the Alzheimer’s Foundation.	Sponsors educational events on caregiving, legal and financial planning	<a href="http://www.alznet.org">www.alznet.org</a>
“Dining with Friends: An Innovative Approach to Dining for People with Dementia”	Alzheimer’s Resource Center of Connecticut, Inc.	This 20-minute DVD and other tools provide creative and respectful methods that encourage a community to provide a more socially stimulating dining experience as well as encourage resident independence and ideas on nutritious and visually appealing meals, even when food must be chopped or pureed.	DVD, workbook, dining audit tool and recipe cards	<a href="http://bit.ly/1cyvke0">http://bit.ly/1cyvke0</a>
“The Art of Dementia Care”	Daniel Kuhn and Jane Verity	This practical guide for those who provide support to people with dementia uses the relationship model. Examples from the authors’ clinical situations provide insight on recognizing the limits of people with dementia while focusing on their strengths and abilities.	Book	<b>Can be purchased at Amazon.com:</b> <a href="http://amzn.to/1aar4I1">http://amzn.to/1aar4I1</a> ; <b>or Barnes &amp; Noble:</b> <a href="http://bit.ly/17P0ts9">http://bit.ly/17P0ts9</a> .

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“Bathing Without a Battle”	Ann Louise Barrick, Ph.D.; Joanne Rader, M.N., R.N., F.A.A.N.; Beverly Hoeffler, D.N.Sc., R.N., F.A.A.N.; Phillip D. Sloane, M.D., M.P.H.	This resource provides person-centered approaches to keeping people clean.	DVD and book	<b>DVD can be purchased at</b> <a href="http://bathingwithoutabattle.unc.edu/">http://bathingwithoutabattle.unc.edu/</a> ; <b>or</b> <b>Pioneer Network:</b> <a href="http://www.pioneernetwork.net/Store/BathingDVD/">www.pioneernetwork.net/Store/BathingDVD/</a> . <b>Book can be purchased at Amazon.com:</b> <a href="http://amzn.to/19PmmFw">http://amzn.to/19PmmFw</a> .
“Mouth Care Without a Battle”		This evidence-based program was developed by an interdisciplinary team of the University of North Carolina. It provides person-centered approaches to mouth care.	DVD	<b>Can be purchased at</b> <a href="http://bit.ly/1as9UN2">http://bit.ly/1as9UN2</a> .
“The Best Friends Approach to Alzheimer’s Care”	Virginia Bell and David Troxel	These authors of several books emphasize a person-centered care philosophy for family and formal care givers. The approach is easy to learn and apply. It transforms our relationship with the person, from caregiver to a friend.	Books	<b>Books may be purchased at:</b> <a href="http://bestfriendsapproach.com">http://bestfriendsapproach.com</a> ; <b>or</b> <b>Best Friends website</b> <b>Health Professions Press:</b> <a href="http://bit.ly/1fFYf10">http://bit.ly/1fFYf10</a> ; <b>or</b> <b>Amazon.com:</b> <a href="http://amzn.to/GSLMLW">http://amzn.to/GSLMLW</a> .
“Creating Moments of Joy/Enhanced Moments”	Jolene Brackney	This philosophy is based on creating moments that will trigger positive memory for people with dementia or put a smile on their face. Even though they may not remember what was said, they will remember the happy feeling it created.	Books and DVD	<b>Can be purchased at</b> <a href="http://enhancedmoments.com/">http://enhancedmoments.com/</a> .

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“Dementia Beyond Drugs”	G. Allen Power, M.D.	Dr. Power provides a compelling case for creating a humane environment and eliminating most antipsychotic medications used to treat people with dementia.	Book	<b>Can be purchased at Health Professions Press:</b> <a href="http://bit.ly/1arSvnD">http://bit.ly/1arSvnD</a> ; or <b>Amazon.com:</b> <a href="http://amzn.to/1eunhAn">http://amzn.to/1eunhAn</a> .
“Dementia Beyond the Disease: Enhancing Well-Being”	G. Allen Power, M.D	In this new book, Dr. Power focuses on seven essential domains that challenge readers to think of new approaches to supporting people with dementia.	Book	<b>Can be purchased at Health Professions Press:</b> <a href="http://bit.ly/1r6eQlr">http://bit.ly/1r6eQlr</a> ; or <b>Amazon.com:</b> <a href="http://amzn.to/1mcno9X">http://amzn.to/1mcno9X</a>
“Dementia Reconsidered: the Person Comes First”	Tom Kitwood	This book places the person with dementia at the focal point of care and most importantly honors the person first through all stages of dementia.	Book	<b>Book may be purchased at Amazon.com:</b> <a href="http://amzn.to/H0dFlw">http://amzn.to/H0dFlw</a> ; or <b>Google Books:</b> <a href="http://bit.ly/H3NAIT">http://bit.ly/H3NAIT</a> .
Action Pact	Action Pact	This company focuses on culture change that helps develop the Household Model for residential senior environments. The model promotes decision making, autonomy and consistent staffing.	Training events, books, webinars, magazine (“Culture Change Now!”), consulting service	<a href="http://actionpact.com">http://actionpact.com</a>
Eden Alternative	William Thomas	Not-for-profit organization that provides education and consultation for establishments across the continuum of care. It emphasizes person-directed approaches to care and is dedicated to creating care environments that promote quality of life for elders and those who support them as care partners.	Webinars/online training, conferences, consultation, Certified Eden Associate training program	<a href="http://www.edenalt.org">www.edenalt.org</a>

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“Forget Memory”	Anne Davis Basting	This book emphasizes the importance of activities that focus on the present to improve the lives of people with dementia. Based on 10 years of research and practice, the author includes examples of innovative programs that stimulate growth, humor and emotional connection.	Book	<b>Book can be purchased at:</b> <b>Amazon.com:</b> <a href="http://amzn.to/17fNYJx">http://amzn.to/17fNYJx</a> ; or <b>Google Books:</b> <a href="http://bit.ly/17fO8k7">http://bit.ly/17fO8k7</a> .
GeriatricPain.org	Site developed by five John A. Hartford Centers of Geriatric Nursing Excellence	Website offers nurses who work in long-term care environments access to free best-practice pain assessment tools and resources to help them manage pain in older adults.	Website	<a href="http://www.geriatricpain.org">www.geriatricpain.org</a>
Green House Project	William Thomas	This innovative model of care focuses on small residential home settings, person-centered care, meaningful activities and empowered staff.	Webinars, workshops	<a href="http://thegreenhouseproject.org">http://thegreenhouseproject.org</a>
Hand in Hand: A Training Series for Nursing Homes	Centers for Medicare/Medicaid Services (CMS)	The training curriculum developed by CMS for nursing home staff emphasizes the basics of person-centered care, staff empowerment, relationship building and team involvement. Community settings will also benefit from this training.	DVD and online	<a href="http://www.cms-handinhandtoolkit.info">www.cms-handinhandtoolkit.info</a>
INTERACT	Interventions to Reduce Acute Care Transfers	This quality improvement program focuses on better management of acute change in condition of people living in long-term care settings; this includes nursing homes and community-based settings.	Online training, webinars	<a href="http://www.interact2.net">www.interact2.net</a>
MOVE	Making Oregon Vital for Elders	This culture change organization is a coalition of organizations and individuals. MOVE is committed to changing how older adults feel about long-term care in Oregon.	Workshops	<a href="http://orculturechange.org">http://orculturechange.org</a>
Music & Memory		Music & Memory is a nonprofit organization dedicated to training elder care professionals to provide personalized music for people who have cognitive and physical challenges through using iPods and other digital devices.	Certification program and resource guide	<a href="http://musicandmemory.org">http://musicandmemory.org</a>

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“Palliative Care for Advanced Dementia”		Person-centered model that focuses on the person’s comfort; incorporates the person’s life story into his or her care plan; anticipates needs rather than responding to them; and empowers frontline caregivers to do whatever is needed to make residents comfortable.	Article	<a href="http://goo.gl/cxESVm">http://goo.gl/cxESVm</a>
Pioneer Network		This organization supports culture change in long-term care settings through educational tools and opportunities for learning. It also supports local and state coalitions in improving the lives of people living in long-term care settings. Pioneer Network has many resources for communities that are just starting the culture change journey. Those who want to enhance their person-centered practices are also served.	Webinars, DVDs, books, conferences	<a href="http://www.pioneernetwork.net">www.pioneernetwork.net</a>
Promoting Positive Behavioral Health: A Nonpharmacologic Toolkit for Senior Living Communities	Prepared for the Commonwealth Fund in collaboration with the Hartford Foundation	This tool kit promotes non-pharmacologic behavioral health strategies that address the behavioral symptoms of dementia. It has information on implementing person-centered best practices programs.	Links to several programs and services that promote culture change and person-centered care	<a href="http://www.nursinghometoolkit.com">www.nursinghometoolkit.com</a>
Teepa Snow		Teepa Snow is a nationally known presenter who provides a unique perspective on dementia and challenging behaviors. She has developed a new program, “Positive Approach to Care.” Teepa recently published “Dementia Caregiver Guide.”	DVDs, book, educational events	<a href="http://www.teepasnow.com">www.teepasnow.com</a> <b>To view clips of Teepa’s presentations on YouTube:</b> <a href="http://bit.ly/19bEFi9">http://bit.ly/19bEFi9</a> .
Virtual Dementia Tour	Second Wind Dreams	This is an experiential kit that puts you in the world of dementia. This will help individuals move from sympathy to empathy for people with dementia. It will also help caregivers better understand the behaviors and needs of the people they support.	Three VDT editions available; contents will vary.	<a href="http://www.secondwind.org/virtual-dementia-tour">www.secondwind.org/virtual-dementia-tour</a>

## Person-centered behavior intervention services

### Behavior Support Services (BSS)

Behavioral Support Services (BSS) is a service that can be provided in a person’s home, adult foster/ care home, assisted living or residential care facility to individuals with persistent and challenging behaviors. The service is provided by BSS specialists that are trained and certified in a set of evidence-based practices based on the philosophies of person-centered care, self-empowerment and autonomous decision making.

A BSS specialist is trained to do an in-depth review of the person with behaviors and work with staff on developing and implementing a plan. This service is available to both Medicaid clients and in certain areas of the state to private pay individuals. All Medicaid BSS must be referred and approved through the eligible client’s case manager. Private pay residents can contact the agencies (listed in the next column) that provide BSS directly.

### **Medicaid and private pay:**

#### **Altoris Behavioral Supports:**

Altoris provides services in Clackamas, Clatsop, Columbia, Multnomah, Tillamook and Washington counties.

**Woollard Ipsen Management:** Woollard Ipsen serves Benton, Coos, Curry, Crook, Deschutes, Douglas, Gilliam, Harney, Hood River, Jackson, Jefferson, Josephine, Klamath, Lake, Lane, Lincoln, Linn, Sherman, Wasco and Wheeler counties.

### **Medicaid only:**

**Yamhill County Health and Human Services** delivers behavioral support Services to eligible Medicaid clients in Yamhill, Polk and Marion counties.

**Center for Human Development** currently delivers Behavioral Support Services to eligible Medicaid clients in Baker, Grant, Malheur, Morrow, Umatilla, Union and Wallowa counties.

### **Altoris:**

Contact: Lori Ireland,  
503-254-8343 or  
[lireland@hwcg.com](mailto:lireland@hwcg.com).

### **Woollard Ipsen**

Contact: Jana Hirsch,  
541-773-2771 or  
[janahirsch@woollardipsen.com](mailto:janahirsch@woollardipsen.com).

### **Yamhill County**

Contact: Krisan Pendleton,  
503-472-4022 or  
[pendlek@yamhill.or.us](mailto:pendlek@yamhill.or.us).

### **Center for Human Development**

Contact: Jon Landers,  
541-962-8819 or  
[jlanders@chdinc.org](mailto:jlanders@chdinc.org).

### **DHS website**

[www.oregon.gov/dhs/spwpd/apd-providers/bss/Pages/index.aspx](http://www.oregon.gov/dhs/spwpd/apd-providers/bss/Pages/index.aspx)

## Long-term care associations

American Health Care Association (AHCA)	National not-for-profit organization comprised of state health affiliates that include for-profit nursing facilities, assisted living and developmentally disabled and sub-acute care facilities. This website gives its members the latest information on best practices in long-term care.	<a href="http://www.ahcancal.org">www.ahcancal.org</a>
Oregon Health Care Association (OHCA)	OHCA is the Oregon affiliate of the American Health Care Association. Its membership is comprised of long-term care providers including nursing homes, assisted living and residential care facilities, in-home care agencies and senior housing communities.	<a href="http://www.ohca.com">www.ohca.com</a>
LeadingAge	This national organization's membership is made up of 6,000 not-for-profit organizations. They include adult day services, home health, hospice, community-based services, PACE, senior housing, assisted living residences, continuing care communities and nursing homes. Technology solutions and person-centered practices that support the overall health and well-being of seniors, children and those with special needs are also included.	<a href="http://www.leadingage.org">www.leadingage.org</a>
LeadingAge Oregon	Statewide organization of not-for-profit and other mission-directed organizations focusing on advancing quality aging services in Oregon. Tools include advocacy, education and fellowship. LeadingAge Oregon is an affiliate of the national LeadingAge organization.	<a href="http://www.oahs.org">www.oahs.org</a>
National Consumer Voice	The leading national voice representing consumers of long-term care, and working to ensure that consumers are empowered to advocate for themselves.	<a href="http://theconsumervoice.org/home">http://theconsumervoice.org/home</a>

## Professional organizations and resources

ABIM Foundation: Advancing Medical Professionalism to Improve Health Care Choosing Wisely® initiative	Choosing Wisely® is an initiative of the ABIM Foundation to help health care providers and patients make smart and effective care choices. The right-hand column includes links to some of their initiatives related to dementia care practices:	<p>Choosing Wisely, Five Things Physicians and Patients Should Question, in conjunction with the American Academy of Hospice and Palliative Medicine: <a href="http://bit.ly/HCYpvc">http://bit.ly/HCYpvc</a></p> <p>Choosing Wisely, Five Things Physicians and Patients Should Question, in conjunction with the American Geriatrics Society: <a href="http://bit.ly/1bePFUN">http://bit.ly/1bePFUN</a></p> <p>Choosing Wisely, Five Things Physicians and Patients Should Question, in conjunction with the American Psychiatric Association: <a href="http://bit.ly/1bavVUp">http://bit.ly/1bavVUp</a></p> <p>Choosing Wisely, Five Things Physicians and Patients Should Question, in conjunction with the Society of Nuclear Medicine and Molecular Imaging: <a href="http://bit.ly/1beQz3T">http://bit.ly/1beQz3T</a></p> <p>Choosing Wisely, Five Things Physicians and Patients Should Question, in conjunction with the American Medical Directors Association: <a href="http://bit.ly/HLC4ed">http://bit.ly/HLC4ed</a></p>
Alzheimer's Association: Health Care Professionals and Alzheimer's	This website provides information, assessment tools and instructional videos for health care professionals who conduct screenings for cognitive impairment. The Alzheimer's Disease Pocketcard app can be downloaded for free.	<a href="http://www.alz.org/health-care-professionals/health-care-clinical-medical-resources.asp">www.alz.org/health-care-professionals/health-care-clinical-medical-resources.asp</a>

## Professional organizations and resources

The American Geriatrics Society (AGS)	This national organization of health care professionals is devoted to improving the health, independence and quality of life of all older people.	<a href="http://www.americangeriatrics.org">www.americangeriatrics.org</a>
Oregon Geriatrics Society (OGS)	This medical society includes health care professionals that are community leaders in geriatric care. Focus is on education for geriatric health care professionals, and the continuum of care in long-term care settings. OGS is an official member of the Council of State Affiliates of the American Geriatrics Society.	<a href="http://www.oregongeriatricsociety.org">www.oregongeriatricsociety.org</a>
American Medical Directors Association (AMDA)	AMDA is a professional organization that provides education, advocacy, information and professional development to promote quality long-term care medicine delivery.	<a href="http://www.amda.com">www.amda.com</a>
American Society of Consultant Pharmacists (ASCP)	ASCP is a nonprofit international society dedicated to optimal medication management and improved health outcomes for all older people.	<a href="http://www.ascp.com">www.ascp.com</a>
Institute for Safe Medication Practices	This nonprofit organization is dedicated to educating the health care community and consumers on safe medication practices.	<a href="http://www.ismp.org">www.ismp.org</a>

## Books written by Oregon authors

“Dancing with Rose” by Lauren Kessler	Lauren Kessler is a journalist whose mother was diagnosed with Alzheimer’s disease. To better understand this disease, Kessler enlisted as a caregiver at an Alzheimer’s community and learned lessons that challenge what we think we know about Alzheimer’s.	<b>Amazon:</b> <a href="http://amzn.to/1rotkNN">http://amzn.to/1rotkNN</a> <b>Powell’s Books:</b> <a href="http://bit.ly/W7AJGF">http://bit.ly/W7AJGF</a> <b>Barnes and Noble:</b> <a href="http://bit.ly/1jv4rQ9">http://bit.ly/1jv4rQ9</a>
“Help is Here: When someone you love has dementia,” by Marion O. Hodges, M.D., M.P.H., and Anne P. Hill, J.D.	This is a practical guide for people with dementia and their families. This book tells you what you need to know about dementia, day-to-day living, and what you need to think about immediately as well as later. Most importantly, it discusses self-care for caregivers. It is a great book for health care providers to share with their patients and families. Funding is provided by Providence Portland Medical Foundation.	<a href="http://www.dementiahelphere.org">www.dementiahelphere.org</a>
“Underneath the Ash: An Alzheimer’s Story” by Kate Dyer-Seeley	This book profiles a daughter’s experience with her mother’s early onset Alzheimer’s disease while raising her young son.	<b>Amazon:</b> <a href="http://amzn.to/16ec86P">http://amzn.to/16ec86P</a>
“Unforgettable Journey: Tips to Survive Your Parent’s Alzheimer’s” by Anne Hill	The author provides practical tips from her experience in supporting her mother through all phases of Alzheimer’s disease. This book is a valuable resource for both the informal and formal caregiver.	<b>Amazon:</b> <a href="http://amzn.to/1g0TqVu">http://amzn.to/1g0TqVu</a> <b>Barnes and Noble:</b> <a href="http://bit.ly/19UloNc">http://bit.ly/19UloNc</a>

## Other resources

Alzheimer's Disease Education and Referral Center (ADEAR)	ADEAR is a service of the National Institute on Aging (NIA), which is part of the National Institute on Health (NIH). ADEAR's mission is to compile, archive and disseminate information on Alzheimer's disease. ADEAR also provides free publications on Alzheimer's disease and will provide referrals to local supportive services and research centers.	<a href="http://www.nia.nih.gov/alzheimers">www.nia.nih.gov/alzheimers</a>
Alzheimers.gov	The government's free information resource on Alzheimer's disease and related dementias provides links that discuss treatment options, paying for care and services, and caregiving.	<a href="http://www.alzheimers.gov">www.alzheimers.gov</a>
Dementia Action Alliance	CCAL is a nonprofit national consumer advocacy and education organization. It advocates for widespread implementation of person-centered living principles, policies and practices for in-home and community-based supports.	<a href="http://www.ccal.org">www.ccal.org</a>