

DEMENTIA RESOURCES COMPENDIUM



2018

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NEW Dementia Care Practice Recommendations:

☀ The new Alzheimer's Association *Dementia Care Practice Recommendations* were released and published in *The Gerontologist* (Jan. 2018). The recommendations, **plus several related dementia care articles are accessible free at:**

https://academic.oup.com/gerontologist/issue/58/suppl_1

2018 DEMENTIA CARE PRACTICE RECOMMENDATIONS



alzheimer's  association®

Short summary - 2018 press release: <https://www.geron.org/press-room/press-releases/2018-press-releases/842-latest-dementia-care-practice-recommendations-emphasize-person-centered-care>

Basics

National Institutes of Aging. (2016). *Alzheimer's Fact Sheet*.
<https://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-fact-sheet>

Alzheimer's Association. (2017). *Get the Facts*. Check out the short video and infographic. <https://www.alz.org/facts/overview.asp>

☀ Alzheimer's Association. (2017). *2017 Alzheimer's Disease Facts and Figures*. (88 pages, including state-by-state data). https://www.alz.org/documents_custom/2017-facts-and-figures.pdf

☀ Dementia Action Alliance. (2016). *Living With Dementia: Changing the Status Quo*. (40 pages). https://daanow.org/wp-content/uploads/2016/04/Living_Fully_With_Dementia_White-Paper_040316.pdf

What is Alzheimer's Disease? (2010). (video, 3.14 min.). With David Hyde Pierce as narrator. https://www.youtube.com/watch?v=7_kO6c2NfmE

Understanding Dementia From the Inside

☀ Alzheimer's Association (2018). *A Guide to Quality Care From the Perspectives of People Living With Dementia*. (20 pages). https://alz.org/dementia-care-practice-recommendations/downloads/qualitycare_plwd.pdf

Dementia Action Alliance. (2015). *Words Matter: See ME Not my Dementia*. (12 pages). https://daanow.org/wp-content/uploads/2016/03/Words_Matter-See-Me-Not-My-Dementia.pdf

Dementia: A month in the life (FULL documentary) - BBC News (2015) (13:00 min.)
<https://www.youtube.com/watch?v=zJObR8TqBIM>

Newton-Small, J. (2018). What it's like to live in a dementia care unit. *Next Avenue*.
<https://www.nextavenue.org/live-dementia-care-unit/>

Supporting Individuals with Dementia

Graham, J. (2017). How to help Alzheimer's patients enjoy life, not just 'fade away.' *Kaiser Health News*. <https://khn.org/news/how-to-help-alzheimers-patients-enjoy-life-not-just-fade-away/>

Singleton, D. (2017, Dec. 28). 9 Tips on Visiting Someone With Dementia. *Next Avenue*.
<https://www.nextavenue.org/visiting-someone-dementia/>

Swanson, D. (2017). What to Tell the Kids About Their Grandparent's Dementia. *Next Avenue*: https://www.nextavenue.org/tell-kids-grandparents-dementia/?utm_content=buffer1513&utm_medium=social&utm_source=facebook.com&utm_campaign=buffer

The Best Friends™ Approach. <http://bestfriendsapproach.com/about/about-the-best-friends-approach/>

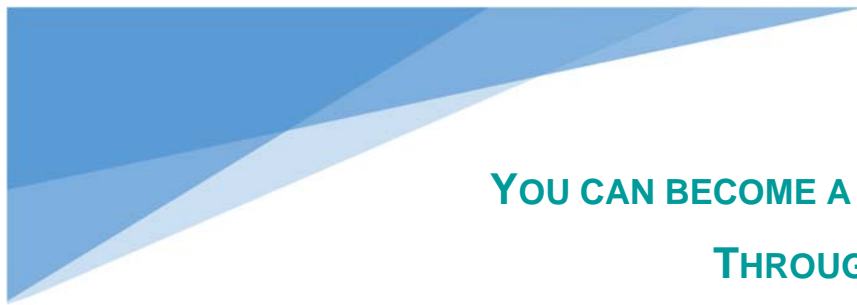
Dementia Friendly Community

Dementia Friendly America. <http://www.dfamerica.org/>

Glavin, G. (2018, Feb. 1). A quest to become dementia-friendly. *U.S. News & World Report* online. <https://www.usnews.com/news/healthiest-communities/articles/2018-02-01/minnesota-leads-states-in-fostering-dementia-friendly-communities>

Graham, J. (2018, Feb. 8). Changing the way we look at dementia. *Kaiser Health News*. <https://khn.org/news/changing-the-way-we-look-at-dementia/> [BECOME A “DEMENTIA FRIEND!”]

Markwood, S. (2017, Nov. 27). Needed: More community support for people with dementia. *Next Avenue*. <https://www.nextavenue.org/community-support-dementia/>



YOU CAN BECOME A “DEMENTIA FRIEND”

THROUGH A LOCAL TRAINING

OR

GO TO [HTTPS://DEMENTIAFRIENDSUSA.ORG/](https://dementiafriendsusa.org/)

(1) WATCH AT LEAST TWO SHORT VIDEOS THAT FOCUS ON HOW TO HELP PEOPLE WITH DEMENTIA FUNCTION IN THE COMMUNITY.

(2) REGISTER AS A DEMENTIA FRIEND.

NOTE: *Dementia Friends* training will soon be available locally.

Being a Caregiver

AARP. *Help Caring for a Loved One with Dementia*. <https://www.aarp.org/caregiving/care-guides/dementia/?intcmp=AE-CAR-R4-C2-LL5>

Goyer, A. (2013). *Balancing work and caregiving*. AARP. <https://www.aarp.org/caregiving/life-balance/info-2017/balancing-demands-ag.html?cmp=SNO-ICM-FB-AO-WJ&socialid=1256583261&kenshoolID=141574155>

Graham, J. (2017, March 23). Video help is on way for family caregivers. *Kaiser Health News*. <https://khn.org/news/video-help-is-on-way-for-family-caregivers-who-must-draw-blood-or-give-injections/>

Johansen, B. (2017, Oct. 10). How to prepare to care for someone with dementia. *Next Avenue*. <https://www.nextavenue.org/prepare-care-someone-dementia/>

Reinhard, S. C., Levine, C., & Samis, S. (2012). *Home Alone: Family Caregivers Providing Complex Chronic Care*. (50 pages). AARP/United Hospital Fund. https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf

→A shorter summary of this report is available here:

Reinhard, S. C., Samis, S., & Levine, C. (2014). Family caregivers providing complex chronic care to people with cognitive and behavioral health conditions. (13 pages). *Insight on the Issues*. Washington, DC: AARP and United Hospital Fund with support from the John A. Hartford Foundation. https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/2014/family-caregivers-cognitive-behavioral-AARP-ppi-health.pdf

Medication Issues

Ellis, B. & Hicken, M. (2017, Oct. 12). *The little red pill being pushed on the elderly*. CNN. <http://www.cnn.com/2017/10/12/health/nuedexta-nursing-homes-invs/index.html>

Kernisan, L. (2016, April 21). 7 common drugs linked to higher risk of dementia. *Next Avenue*. <https://www.nextavenue.org/7-common-drugs-are-toxic-your-brain/>

Kennedy, S. (2017). Medication management for people with dementia. This 9 minute **video** is part of a series, *Supporting Family Caregivers: No Longer Home Alone*. <https://journals.lww.com/ajnonline/Pages/videogallery.aspx?videoId=102&autoPlay=true>

Videos for Caregivers

Suzanne Fitzsimmons (2015). Series of short videos on the use of Non-pharmacological Interventions for the Treatment of Behavioral and Psychological Symptoms of Dementia. Many are also useful for pain, sleep, apathy, and anxiety.
https://www.youtube.com/watch?v=E9fb_41tcAs

Kristin Belfry (2016).

- *How to talk so Alzheimer's can hear you.* (14.56 min.)
<https://www.youtube.com/watch?v=X6UMQmi09Ms&t=20s>
- *Alzheimer's – Combative Behavior* (11:37 min.)
<https://www.youtube.com/watch?v=XMfItlc8hL0>

Teepa Snow

Teepa Snow is a renowned specialist in helping those who are caregiving for people with dementia. She has a unique way of demonstrating behaviors and involving her audience in role play. Her videos are highly recommended.

- Teepa Snow describes the "Gems" - her dementia characteristic and ability model (9.03 min.). <https://www.youtube.com/watch?v=5Qv2nIB-6Qw>
- Teepa Snow discusses the *Ten Early Signs of Dementia* (17.00 min.).
<https://www.youtube.com/watch?v=pqmqC-702Yg>
- We have TEEPA SNOW available for streaming at the UNCW library:
<https://www.pineseducation.org/product/in-home-dementia-care-tips-techniques-with-teepa-snow-2-dvd-set/>

Supporting Family Caregivers: No Longer Home Alone Caregiving videos - part of a series: <https://journals.lww.com/ajnonline/Pages/videogallery.aspx?videoid=102&autoplay=true>

Family Caregiver Alliance. (2011). *Caregiver College*. (8 video series)
https://www.youtube.com/watch?v=xUjOarB8XUc&list=PLa1B8idpEiEplIAyH_swKvZvTQ9yAKH6t

Family Caregiver Alliance. (2013). *SafeAtHome: A Caregiver's Guide* (10 video series)
<https://www.youtube.com/watch?v=Z6U-11oCfjl&list=PLa1B8idpEiEq0sSCLNxW8f4hsJ0s75etM>

Another caregivers' video series, specific to dementia care, is available through the Office of Rural Health and The Veterans Rural Health Center.

<https://www.ruralhealth.va.gov/vets/resources.asp> (scroll down the page)

Molly & Joey. (2017-present). A continuing video series in which a man chronicles his experiences with his mother who has Lewy Body dementia.

<https://www.youtube.com/channel/UCNIXVpLqgOOKKdNpPwvECzA>

Assessment

Screening for Dementia (2011). With Lee Hyer, Ph.D., and Richard Ackerman, M.D., Mercer University School of Medicine, produced by the University of Georgia Institute of Gerontology.

- Screening for Dementia 1: Geropsychology (4:37 min.)
<https://www.youtube.com/watch?v=4gfTOJWYMrY>
- Screening for Dementia 2: Conference with Patient & Caregiver (3:45 min.)
<https://www.youtube.com/watch?v=15GkEwJx-NQ>
- Screening for Dementia 3: Patient Assessment (9:46 Min.)
https://www.youtube.com/watch?v=_hRBPrfDQVI
- Screening for Dementia 4: Diagnosis & Treatment (8:05 min.)
<https://www.youtube.com/watch?v=639vYxssYE>

U.S. Preventive Services Task Force. (2014). *Cognitive Impairment in Older Adults: Screening*

<https://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/cognitive-impairment-in-older-adults-screening>

Driving

AARP. (n.d.) *We Need to Talk*. An online seminar with three-modules. Free but requires registration. <https://www.aarp.org/auto/driver-safety/we-need-to-talk/>

Driving and Alzheimer's Disease. (n.d.) National Highway Traffic Safety Administration. <https://www.nhtsa.gov/sites/nhtsa.dot.gov/files/10900a-drivewell-handout-alzheimers.pdf>

See also other online driving resources provided by AARP at <https://www.aarp.org/auto/driver-safety/we-need-to-talk/additional-publications/>

Pain

Hunt, L. J., Covinshky, K. E., Yaffe, K., et al. (2015). Pain in community-dwelling older adults with dementia: Results from the National Health and Aging Trends Study. *Journal of the American Geriatrics Society*, 63(8), 1503-1511.
<http://onlinelibrary.wiley.com/doi/10.1111/jgs.13536/full>

International Design Ideas

Netherlands

- Lessons about dementia care from the Netherlands- A.P. Glass (video, 14.22 min.)
<https://www.youtube.com/watch?v=u5sgnUpENSk&feature=youtu.be>

DeHogeweyk, the unique Dementia Village in the Netherlands

- CNN's *World's Untold Stories: Dementia Village* (2013). With Dr. Sanjay Gupta
<https://www.youtube.com/watch?v=LwiOBlyWpko>
- World Economic Forum (2017). This Dutch village was built for people with dementia (1.19 min.). <https://www.youtube.com/watch?v=MVAbqvQGfdk>
- ☀ Yvonne van Amerongen | TEDxWarwick (2015). *Living with Dementia: To Be or Not To Be* (14:55 min.). <https://www.youtube.com/watch?v=6JnDfyOd6rM>
- <https://www.dementiavillage.com/>

Thailand

Dr. Steve Zarit and Dr. Judy Zarit, retired gerontology specialists, describe dementia care in Thailand in their blog, *The Gift of Aging* (2018, Feb. 20). <https://giftofaging.blogspot.com/>

United Kingdom

Design for Dementia Care: Ideas from the UK in a video series from OpenLearn from The Open University (2012).

- Public space: Design for dementia care (1/7) (6.12 min.)
<https://www.youtube.com/watch?v=KKIaAtPwMg4>
- Private space: Design for dementia care (2/7) (5.44 min.)
<https://www.youtube.com/watch?v=QPPAbP-4cWI&t=41s>
- The Market Square: Design for dementia care (3/7) (3.26 min.)
https://www.youtube.com/watch?v=M3Hrhzq9K_g
- Garden space: Design for dementia care (4/7) (5.33 min.)
<https://www.youtube.com/watch?v=l6gCCx9sM0g>
- Evaluating the success of the design: Design for dementia care (5/7) (4.08 min.)
<https://www.youtube.com/watch?v=G51bjo19qHo&t=25s>
- Refurbishing an existing care home: Design for dementia care (6/7) (10.08 min.)
<https://www.youtube.com/watch?v=cnfvCXsDnWE>
- Looking back on the refurbishment process: Design for dementia care (7/7) (3.23 min.) <https://www.youtube.com/watch?v=r16xl8H83Vc&t=9s>

End-of-Life Care

These two references provide useful summaries, but they do include references to services available outside the U.S.

- Alzheimer's Society of Canada. (2018). *Dementia and End-of-Life Care*. <http://alzheimer.ca/en/Home/Living-with-dementia/Caring-for-someone/End-of-life-care>
- Alzheimer's Society of the UK. (2017) *End of life Care Factsheet 531LP*. Note: https://www.alzheimers.org.uk/download/downloads/id/2267/factsheet_end-of-life_care.pdf

Glass, A. P. (2012, February). *End-of-life care experiences for individuals with Alzheimer's disease and their family caregivers*. Webinar, sponsored by Virginia Commonwealth University, AlzPossible Initiative, and Virginia Center on Aging's GTE Initiative. <http://alzpossible.org/newalzpossible/end-of-life-care-experiences/> (*many other webinars also accessible at this AlzPossible website*).

National Institute on Aging. (2017). *End-of-Life Care for People With Dementia*. <https://www.nia.nih.gov/health/end-life-care-people-dementia>

Policy and Projected Costs

Brown University (2017, Aug. 17). Simulation shows the high cost of dementia, especially for families. *Medical Xpress*. <https://medicalxpress.com/news/2017-08-simulation-high-dementia-families.html> (Original article published in *Journal of the American Geriatrics Society*.)

Doraiswamy, M., Kuriakose, J. R., & Zannas, A. (n.d.). The global threat of Alzheimer's disease: Ready nations for the challenge. *Huffington Post*. https://www.huffingtonpost.com/murali-doraiswamy/the-global-threat-of-alzh_b_4652107.html

Gurnon, E. (2017, March 7). Costs exploding for Alzheimer's and other dementias. *Next Avenue*. <https://www.nextavenue.org/costs-exploding-alzheimers-dementias/>

Reinhard, S., Feinberg, L. F., Choula, R., & Houser, A. (2015). *Valuing the Invaluable 2015 Update: Undeniable Progress, but Big Gaps Remain*. AARP Public Policy Institute. <https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html>

UNECE Policy Brief on Aging No 16 (2015). *Dignity and non-discrimination for persons with dementia*. https://www.unece.org/fileadmin/DAM/pau/age/Policy_briefs/ECE-WG.1-23.pdf

For Healthcare Professionals

Assessment:

Dementia Screening Indicator Tool: <http://ars.els-cdn.com/content/image/1-s2.0-S1552526013029403-gr2.jpg>

Carolina Memory CareNet. (2016). *Screening for Cognitive Impairment* (video, 7.43 min.) <https://www.youtube.com/watch?v=2NowRAFsXkU>

Cordell, C. B. et al. (2013). Alzheimer's Association recommendations for operationalizing the detection of cognitive impairment during the Medicare Annual Wellness Visit in a primary care setting. *Alzheimer's & Dementia*, 9, 141-150. [http://www.alzheimersanddementia.com/article/S1552-5260\(12\)02501-0/pdf](http://www.alzheimersanddementia.com/article/S1552-5260(12)02501-0/pdf)

Medicare Learning Network. (2017). *The ABCs of the Annual Wellness Visit (AWV)*. https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/downloads/AWV_chart_ICN905706.pdf

U.S. Preventive Services Task Force. (2014). *Cognitive Impairment in Older Adults: Screening* <https://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/cognitive-impairment-in-older-adults-screening>

Caregivers:

Levine, C. & Reinhard, S. C. (2016). *"It All Falls on Me" Family Caregiver Perspectives on Medication Management, Wound Care, and Video Instruction*. (19 pages). Washington, DC: AARP Public Policy Institute. https://www.aarp.org/content/dam/aarp/ppi/2016-08/AARP1078_FamilyCaregiver_SpotlightSep6v5.pdf

Driving:

American Geriatrics Society. (2015). *Clinician's Guide to Assessing and Counseling Older Drivers, 3rd Edition*. <https://geriatricscareonline.org/ProductAbstract/clinicians-guide-to-assessing-and-counseling-older-drivers-3rd-edition/B022>Barco, P. P., Baum, C. M., et al. (2015). Driving errors in persons with dementia. *Journal of the American Geriatrics Society*, 63, 1373-1380. <http://onlinelibrary.wiley.com.liblink.uncw.edu/doi/10.1111/jgs.13508/epdf> (may require special access)

Jouk, A., & Tuokko, H. (2017). Development of "down the road": An interactive toolkit about driving cessation for dementia caregivers. *Educational Gerontology*, 43(10), 499-510. <http://www.tandfonline.com.liblink.uncw.edu/doi/pdf/10.1080/03601277.2017.1355669?needAccess=true> (may require special access)

Moorhouse, P., & Hamilton, L. M. (2014). Not if, but when: Impact of a driving and dementia awareness and education campaign for primary care physicians. *Canadian Geriatrics Journal*, 17(2), 70-75. <https://search-proquest-com.liblink.uncw.edu/docview/1536488725/fulltextPDF/FFF3399970454DF3PQ/1?accountid=14606> (may require special access)

Nurses:

Supporting Family Caregivers: No Longer Home Alone, is a collection of articles and videos to help nurses provide caregivers with the tools they need. Topics include medication management, fall prevention, managing complex medication regimens, and skin care, at <https://journals.lww.com/ajnonline/pages/collectiondetails.aspx?TopicalCollectionID=38>

Flanagan, N. M. (2011). Driving and dementia: What nurses need to know. *Journal of Gerontological Nursing*, 37(8), 10-13. <https://search-proquest-com.liblink.uncw.edu/docview/879695814/fulltextPDF/70AEBB9862D2426DPQ/1?accountid=14606> (may require special access)

Primary care clinicians are often the first to see older adults with memory loss or other signs of cognitive impairment. The National Institute on Aging offers guidance to healthcare providers to assess, manage, and support their patients with memory complaints or impairment: https://www.nia.nih.gov/health/alzheimers-dementia-resources-for-professionals?utm_source=20171031_proresources&utm_medium=facebook&utm_campaign=ealert

Palliative Care

Bharadwaj, P., Chandra, A. Fitzgerald, G., & Ward, K. (2015). *Palliative Care for Dementia Patients: Practical Tips for Home Based Programs*. National Hospice and Palliative Care Organization. https://www.nhpco.org/sites/default/files/public/palliativecare/PALLIATIVECARE_Dementia%20Patients.pdf

Mitchell, S. L. (2018). *Palliative care of patients with advanced dementia*. UpToDate. <https://www.uptodate.com/contents/palliative-care-of-patients-with-advanced-dementia>

Training Modules

☀ Health Resources & Services Administration. (2017). *Training Curriculum: Alzheimer's disease and Related Dementias*. Washington, DC: US Department of Health and Human Services. <https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum>

- 16 Modules for the primary care workforce (Modules 13-16 for specific health care professions)
- 4 Supplemental modules for providers, addressing meeting caregiver needs
- 5 Modules for caregivers

Is It Dementia?

Johns Hopkins Medicine. *Memory Lapse or Dementia? 5 clues to Help Tell the Difference*
https://www.hopkinsmedicine.org/health/healthy_aging/healthy_mind/memory-lapse-or-dementia-5-clues-to-help-tell-the-difference

MARS Memory-Health Network. *Do I have a Memory Problem?*
<http://marsmemory.com/memory-health/do-i-have-a-memory-problem/>

Scott, P. S. (2016, May 5). 8 Common Myths About Alzheimer's. *Next Avenue*.
<https://www.nextavenue.org/8-common-myths-alzheimers/>

See also *Alzheimer's Association* and other basic sites.

What is Mild Cognitive Impairment (MCI)?

Harvard Health Online. (2017). *What to do about mild cognitive impairment*.
<https://www.health.harvard.edu/mind-and-mood/what-to-do-about-mild-cognitive-impairment>

MedLine Plus. (2017). *Mild Cognitive Impairment. (Also called: MCI)*. U.S. National Library of Medicine. https://medlineplus.gov/mildcognitiveimpairment.html#cat_79

National Institute on Aging. (2017). *What Is Mild Cognitive Impairment?*
<https://www.nia.nih.gov/health/what-mild-cognitive-impairment>

More on the MIND Diet

MIND diet. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4532650/>

Organization Websites

AARP Family Caregiving Resources. <https://www.aarp.org/caregiving/>

Alzheimer's Association. <https://www.alz.org/>

Alzheimer's Association Eastern North Caroling Chapter Event Calendar.
<https://www.calendarwiz.com/calendars/calendar.php?crd=enc&op=cal&month=2&year=2018>

AlzNC. <https://www.alznc.org/>

Dementia Action Alliance. <https://daanow.org/>

Eldercare Locator. www.eldercare.gov or 1-800-677-1116 (toll-free)

Eldercare Disability Resources listing provided by CCAL. <http://www.ccal.org/eldercare-disability-resources/eldercare.shtml>

Local Resources

MARS Memory-Health Network. <http://marsmemory.com/>

UNCW Gerontology Program Facebook page. <https://www.facebook.com/UNCWGerontology/>

Cape Fear Council of Governments Area Agency on Aging: <http://capefearcog.org/area-agency-on-aging/>

Family Caregiver Support Program – Holly Henderson Pilson, Caregiver Resource Specialist. Contact at 910-395-4553 Ext. 204 or hpilson@capefearcog.org

New Hanover County Senior Resource Center. <https://src.nhcgov.com/>

Brunswick Senior Resources Inc. <http://www.bsrinc.org/>

NOTE: *Dementia Friends* training will soon be available locally.

**NOTE: This selection of free web-based resources was compiled by
Anne P. Glass, Ph.D., Gerontology Program Coordinator.**

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