

# Dementia Curriculum for Health Care Professionals

## Module 4: References

Providing and Discussing a Dementia Diagnosis with  
Persons Living with Dementia (PLWD) and Their Care  
Partners



## Module 4 References

- Alzheimer's Association. (2011, February 11). [Blog post]. (2011). How do you convince your loved one with memory loss to see a doctor? Retrieved from <http://www.alzheimersblog.org/2011/02/14/convince-loved-memory-loss-doctor/>
- Aminzadeh, F., Molnar, F. J., Dalziel, W. B., & Ayotte, D. (2012). A review of barriers and enablers to diagnosis and management of persons with dementia in primary care. *Canadian Geriatric Journal, 15*(3), 85–94.
- Appelbaum, P.S. & Grisso, T. (1988) Assessing patients' capacities to consent to treatment. *New England Journal of Medicine, 319*(25):1635-1638.
- Bakker, C., de Vugt, M. E., van Vliet, D., Verbey, F., Pijnenburg, Y. A., Vernooij-Dassen, M. J., & Koopmans, R. T. (2014). Unmet needs and health-related quality of life in young-onset dementia. *American Journal of Geriatric Psychiatry, 22*(11), 1121–1130.
- Beusterien, K. M., Thomas, S. K., Gause, D., [Kimel, M.](#), [Arcona, S.](#), & [Mirski, D.](#) (2004). Impact of rivastigmine use on the risk of nursing home placement in a US sample. *CNS Drugs, 18*(15), 1143–1148.
- Black, B. S., Johnston, D., Morrison, A., Rabins, P. V., Lyketsos, C. G., & Samus, Q. M. (2012). Quality of life of community-residing persons with dementia based on self-rated and caregiver-rated measures. *Quality of Life Research, 21*(8), 1379–1389.
- Boise, L., Camicioli, R., Morgan, D. L., [Rose, J. H.](#), & [Congleton, L.](#) (1999). Diagnosing dementia: perspectives of primary care physicians. *Gerontologist, 39*(4), 457–464.
- Bunn, F., Goodman, C., Sworn, K., Rait, G., Brayne, C., Robinson, L., McNeilly, E., & Illiffe, S. (2012). Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: A systematic review of qualitative studies. *PLoS Med, 9*(10), e1001331.
- Carter, R. E., Rose, D. A., Palesch, Y. Y., & Mintzer, J. E. (2004). Alzheimer's disease in the family practice setting: Assessment of a screening tool. *Primary Care Companion to Journal of Clinical Psychiatry, 6*(6), 234–238.
- Centers for Disease Control and Prevention. (2003, April 11). *HIPAA privacy rule and public health: Guidance from CDC and the U.S. Department of Health and Human Services*. Retrieved from <http://www.cdc.gov/mmwr/preview/mmwrhtml/m2e411a1.htm>
- Cosentino, S., Metcalfe, J., Cary, M.S., De Leon, J., & Karlawish, J. (2011). Memory awareness influences everyday decision making capacity about medication management in Alzheimer's disease. *International Journal of Alzheimer's Disease, 1022*, 483897.
- Covinsky, K. E., Newcomer, R., Fox, P., [Wood, J.](#), [Sands, L.](#), [Dane, K.](#), & [Yaffe, K.](#) (2003). Patient and caregiver characteristics associated with depression in caregivers of patients with dementia. *Journal of General Internal Medicine, 18*(12), 1006–1014.
- Cummings, J. L., Schneider, L., Tariot, P. N., Kershaw, P. R., & Yuan, W. (2004). Reduction of behavioral disturbances and caregiver distress by galantamine in patients with Alzheimer's disease. *American Journal of Psychiatry, 161*(3), 532–538.

Dastidar, J. G., & Odden, A. (2011, August). *How do I determine if my patient has decision-making capacity?* Retrieved from <http://www.the-hospitalist.org/article/how-do-i-determine-if-my-patient-has-decision-making-capacity/2/>

Dhedhi, S. A., Swinglehurst, D., & Russell, J. (2014). “Timely” diagnosis of dementia: What does it mean? A narrative analysis of GPs’ accounts. *BMJ Open*, 4(3), e004439.

Doody, R. S., Stevens, J. C., Beck, C., [Dubinsky, R. M.](#), [Kaye, J. A.](#), [Gwyther, L.](#), ... & [Cummings, J. L.](#) (2001). Practice parameter: Management of dementia (an evidence-based review)—Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*, 59(9), 1154–1166.

Dubois, B., Padovani, A., Scheltens, P., Rossi, A., & Dell’Agnello, G. (2015). Timely diagnosis for Alzheimer’s disease: A literature review on benefits and challenges. *Journal of Alzheimer’s Disease*, 49(3), 617–631.

Elson, P. (2006). Do older adults presenting with memory complaints wish to be told if later diagnosed with Alzheimer’s disease? *International Journal of Geriatric Psychiatry*, 21(5), 419–425.

Fisk, J. D., Beattie, B. L., Donnelly, M., Byszewski, A., & Molnar, F. J. (2007). Disclosure of the diagnosis of dementia. *Alzheimer’s & Dementia*, 3(4), 404–410.

Fowler, N. R., Frame, A., Perkins, A. J., Gao, S., Watson, D. P., Monahan, P., & Boustani, M. A. (2015). Traits of patients who screen positive for dementia and refuse diagnostic assessment. *Alzheimer’s & Dementia (Amsterdam)*, 1(2), 236–241.

Fowler, N.R., Perkins, A.J., Turchan, H.A., Frame, A., Monahan, P., Gao, S., & Boustani, M.A. (2015). Older primary care patients’ attitudes and willingness to screen for dementia. *Journal of Aging Research*, 2015, Article ID 423265.

Gattman, R., & Seleski, M. (Eds.). (1999). *Diagnosis, management and treatment of dementia: A practical guide for physicians*. Chicago, IL: American Medical Association.

Geldmacher, D. S., Frolich, L., Doody, R. S., [Erkinjuntti, T.](#), [Vellas, B.](#), [Jones, R. W.](#), ... & [Sano, M.](#) (2006). Realistic expectations for treatment success in Alzheimer’s disease. *Journal of Nutrition and Health in Aging*, 10(5), 417–429.

Geldmacher, D. S., Provenzano, G., McRae, T., [Mastey, V.](#), & [Ieni, J. R.](#) (2003). Donepezil is associated with delayed nursing home placement in patients with Alzheimer’s disease. *Journal of the American Geriatric Society*, 51(7), 937–944.

Gitlin, L. N., Belle S. H., Burgio L. D., Czaja, S. J., Mahoney D., Gallagher-Thompson D., ... & REACH Investigators. (2003). Effect of multi-component interventions on caregiver burden and depression: The REACH multi-site initiative at 6 months follow-up. *Psychology and Aging*, 18, 361–374.

Goodman R.A., Lochner K.A., Thambisetty M., Wingo T.S., Posner S.F., & Ling S.M. (2017). Prevalence of dementia subtypes in United States Medicare fee-for-service beneficiaries, 2011-2013. *Alzheimer’s Dementia*, 13(1): 28-37. doi: 10.1016/j.jalz.2016.04.002. Epub 2016 May 10. PMID: 27172148

Grossberg, G. T., Christensen, D. D., Griffith, P. A., Kerwin, D. R., Hunt, G., & Hall, E. J. (2010). The art of sharing the diagnosis and management of Alzheimer’s disease with

patients and caregivers: Recommendations of an expert consensus panel. *Primary Care Companion to Journal of Clinical Psychiatry*, 12(1), PCC.09cs00833. doi: [10.4088/PCC.09cs00833oli](https://doi.org/10.4088/PCC.09cs00833oli)

Guo, Z., Levy, B. R., Hinton, W. L., Weitzman, P. F., & Levkoff, S. (2000). The power of labels: recruiting dementia affected Chinese-American elders and their caregivers. *Journal of Mental Health & Aging*, 6, 103–112.

Hinton, L. Chambers, D., Velasquez, A., Gonzalez, H. & Haan, M. (2006). Dementia neuropsychiatric symptom severity, help-seeking patterns and family caregiver unmet needs in the Sacramento Area Latino Study on Aging (SALSA). *Clinical Gerontologist*, 29(4), 1–15.

Hinton, L., Franz, C. E., Yeo, G., & Levkoff, S. (2005). Conceptions of dementia in a multi-ethnic sample of family caregivers. *Journal of the American Geriatrics Society*, 53(8), 1405–1410.

Holmes, S. B., & Adler, D. (2005). Dementia care: Critical interactions among primary care physicians, patients, and caregivers. *Primary Care*, 2005323, 671–682.

Karlawish J. (2008). Measuring decision-making capacity in cognitive impaired individuals. *Neurosignals*, 16, 91–98.

Kim, S. Y., Karlawish, J. H., Kim, H. M., Wall, I. F., Bozoki, A. C., & Appelbaum, P. S. (2011). Preservation of the capacity to appoint a proxy decision maker: Implications for dementia research. *Archives of General Psychiatry*, 68(2), 214–220.

Lecouturier, J., Bamford, C., Hughes, J. C., Francis, J. J., Foy, R., Johnston, M., & Eccles, M. P. (2008). Appropriate disclosure of a diagnosis of dementia: Identifying the key behaviours of “best practice.” *BMC Health Services Research*, 81(1), 95.

MacRae, H. (2010). Managing identity while living with Alzheimer’s disease. *Quality Health Research*, 20, 293–305.

Markowitz, J. S., Gutterman, E. M., Sadik, K., & Papadopoulos, G. (2003). Health-related quality of life for caregivers of patients with Alzheimer disease. *Alzheimer’s Disease and Associated Disorders*, 17(4), 209–214.

Min, A. A., Spear-Ellinwood, K., Berman, M., Nisson, P., & Rhodes, S. M. (2016). Social worker assessment of bad news delivery by emergency medicine residents: a novel direct-observation milestone assessment. *Internal and Emergency Medicine*. Advance online publication. doi: [10.1007/s11739-016-1405-y](https://doi.org/10.1007/s11739-016-1405-y)

National Institute on Aging. (2016 April). *Talking with patients about cognitive problems*. Retrieved from <https://www.nia.nih.gov/health/publication/talking-your-older-patient/talking-patients-about-cognitive-problems>

Orgeta, V., Orrell, M., Hounscome, B., Woods, B., & the REMCARE team. (2015). Self and carer perspectives of quality of life in dementia using the QoL-AD. *International Journal of Geriatric Psychiatry*, 30, 97–104.

Ortman, J. M., Victoria A. Velkoff, V. A., & Hogan H. (2014). *An Aging Nation: The Older Population in the United States* (Current Population Reports, P25-1140). Washington, DC: U.S. Census Bureau.

Ouimet, M. A., Dendukuri, N., Dion, D., [Beizile, E.](#), & [Elie, M.](#) (2004). Disclosure of Alzheimer's disease: Senior citizen's opinions. *Canadian Family Physician*, *50*, 1671–1677.

Phillips, J., Pond, C. D., Paterson, N. E., Howell, C., Shell, A., Stocks, N. P., .... & Marley, J. E. (2012). Difficulties in disclosing the diagnosis of dementia: A qualitative study in general practice. *British Journal of General Practice*, *62*(601), e546–e553.

Psota, G. (2015). Social psychiatric aspects of dementia. *Psychiatria Danubina*, *27*(4), 432–438.

Robinson, S. M., Canavan, M., & O'Keeffe, S. T. (2014). Preferences of older people for early diagnosis and disclosure of Alzheimer's disease (AD) before and after considering potential risks and benefits. *Archives of Gerontology and Geriatrics*, *59*(3), 607–612.

Shinagawa, S., Catindig, J. A., Block, N. R., Miller, B. L., & Rankin, K. P. (2016). When a little knowledge can be dangerous: False-positive diagnosis of behavioral variant frontotemporal dementia among community clinicians. *Dementia and Geriatric Cognitive Disorders*, *41*(1–2), 99–108.

Spiegel, W., Zidek, T., Maier, M., Vutuc, C., Isak, K., [Karlic, H.](#), & [Micksche, M.](#) (2009). Breaking bad news to cancer patients: survey and analysis. *Psycho-oncology*, *18*(2), 179–86.

Steehan, E., Godderis, J., Grypdonck, M., De Bal, N., & Dierckx de Casterle, B. (2007). Living with dementia from the perspective of older people: Is it a positive story? *Aging and Mental Health*, *11*, 119–130.

Stokes, L. A., Combes, H., & Stokes, G. (2014). Understanding the dementia diagnosis: The impact on the caregiving experience. *Dementia (London)*, *13*(1), 59–78.

Tunzi, M. (2001). Can the patient decide? Evaluating patient capacity in practice. *American Family Physician*, *64*(2):299-306.

Turnbull, Q., Wolf, A. M., & Holroyd, S. (2003). Attitudes of elderly subjects toward “truth telling” for the diagnosis of Alzheimer's disease. *Journal of Geriatric Psychiatry and Neurology*, *16*(2), 90–93.

Van den Dungen, P., van Kuijk, L., van Marwijk, H., van der Wouden, J., van Charante, E. M., van der Horst, H., & van Hout, H. (2014). Preferences regarding disclosure of a diagnosis of dementia: A systematic review. *International Psychogeriatrics*, *25*(10), 1603–1618.

Wald, C., Fahy, M., Walker, Z., & Livingston, G. (2003). What to tell dementia caregivers: The rule of threes. *International Journal of Geriatric Psychiatry*, *18*(4), 313–317.

## Module 4 Resources

Alzheimer's Association 24-hour HELPLINE (1.800.272.3900) or Web site (<http://www.alz.org>) This Web site is a national resource, with portals in multiple languages containing excellent, easy-to-understand information about dementia and

Alzheimer's disease—from diagnosis through treatment. There is information for family care partners, support groups located all throughout the United States, end-of-life planning, tips for managing stress, as well as links to other on-line, print and video resources.

Local senior centers

<http://www.alz.org/espanol>: Spanish language portal for information on Alzheimer's disease.

Note: There are other portals in different languages: Chinese, Japanese, Korean, Vietnamese, Arabic, Hindi, and Russian.

American Psychological Association: <http://www.apa.org> Caregiver assessment tools; coping with caregiver stress and burden. Within the APA Web site, Publications and Databases tab; "Caregiver toolkit". Look under Assessment tools, Caregiver assessments, and/or coping with caregiver stress and burden for a comprehensive resource on the topic of caregiver assessment.

Center for Quality Assessment and Improvement in Mental Health. PHQ2. <http://www.cqaimh.org>. The PHQ2 is a very brief screening tool for depression; if a person screens positive, the full PHQ9 can be given; if the score is above the validated cut-offs, the persons should be referred to a mental health provider for further assessment and treatment.

Cultural Competency: Engebretson, J., Mahoney, J., & Carlson, E. D. (2008) Cultural competence in the era of evidence-based practice. *Journal of Professional Nursing*, 24(3), 172–178.

Easy to print and understand version of the Caregiver Self-Assessment Questionnaire, a tool developed by the AMA. Available at:

<http://web.mit.edu/workplacecenter/hndbk/sec4.html>

Hand-under-Hand: <http://www.teepasnow.com>

HealthinAging.org: contains caregiver self-assessment tools in several languages; free, downloadable, easy to use

National Institutes of Health. (2016, July 29). Cultural Respect. Retrieved from: <https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/cultural-respect>

Positive Approach to Care: <http://www.teepasnow.com>

Positive Physical Approach: <http://www.teepasnow.com>

Rosalynn Carter Institute for Caregiving: <http://www.rosalynncarter.org>). Information on evidence-based programs including multiple adaptations of the REACH program used nationally.