

## Resources Page for Webinar #5: Advanced Stage Dementia and Palliative Care

- 1) **“Welcome”** (Basil Eldadah, MD, PhD, Division of Geriatrics and Clinical Gerontology, NIA)
  - “Advancing the Science of Geriatric Palliative Care”
    - <http://grants.nih.gov/grants/guide/pa-files/PA-13-354.html>
    - <http://grants.nih.gov/grants/guide/pa-files/PA-13-356.html>
    - <http://grants.nih.gov/grants/guide/pa-files/PA-13-355.html>
  - “Pain in Aging”
    - <http://grants.nih.gov/grants/guide/pa-files/PA-13-058.html>
    - <http://grants.nih.gov/grants/guide/pa-files/PA-13-060.html>
    - <http://grants.nih.gov/grants/guide/pa-files/PA-13-059.html>
  - Alzheimer’s Disease Research Centers
    - <http://www.nia.nih.gov/alzheimers/alzheimers-disease-research-centers>
  - Claude D. Pepper Older Americans Independence Centers
    - <https://www.peppercenter.org/public/home.cfm>
  - Resource Centers for Minority Aging Research
    - <http://www.nia.nih.gov/research/dbsr/resource-centers-minority-aging-research-rcmar>
  
- 2) **“Overview”** (Susan L. Mitchell, MD, MPH, Professor of Medicine, Harvard Medical School, and Senior Scientist, Hebrew SeniorLife Institute for Aging Research)
  - Mitchell, S.L., Teno, J.M., Miller, S.C., & Mor, V. (2005). National Study of the Location of Death for Older Persons with Dementia. *Journal of the American Geriatrics Society*, 53(2), 299–305. DOI: 10.1111/j.1532-5415.2005.53118.x <http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2005.53118.x/abstract;jsessionid=3500F2D805712733D02765BCECA7C9D8.d03t01>
  - Reisberg, B., Ferris, S.H., de Leon, M.J., & Crook, T. (1982). The Global Deterioration Scale for assessment of primary degenerative dementia. *The American Journal of Psychiatry*, 139(9), 1136-9. <http://www.ncbi.nlm.nih.gov/pubmed/7114305>
  - Mitchell, S.L., Miller, S.C., Teno, J.M., Kiely, D.K., Davis, R.B., & Shaffer, M.L. (2010). Prediction of 6-month survival of nursing home residents with advanced dementia using ADEPT vs hospice eligibility guidelines. *The Journal of the American Medical Association*, 304(17), 1929-35. doi: 10.1001/jama.2010.1572 <http://www.ncbi.nlm.nih.gov/pubmed/21045099>
  - Mitchell, S.L., Teno, J.M., Kiely, D.K., Shaffer, M.L., Jones, R.N., Prigerson, H.G., Volicer, L., Givens, J.L., & Hamel, M.B. (2009). *The clinical course of advanced dementia. The New England Journal of Medicine*, 361(16), 1529-38. doi: 10.1056/NEJMoa0902234. <http://www.ncbi.nlm.nih.gov/pubmed/19828530>
  - Givens, J.L., Kiely, D.K., Carey, K., & Mitchell, S.L. (2009). Health Care Proxies of Nursing Home Residents with Advanced Dementia: Decisions They Confront and Their Satisfaction with Decision-Making. *Journal of the American Geriatrics Society*, 57(7), 1149–1155. doi: 10.1111/j.1532-5415.2009.02304.x <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2796114/>
  - Gillick, M.R. (2001). Choosing appropriate medical care for the elderly. *Journal of the American Medical Directors Association*, 2(6), 305-9. <http://www.ncbi.nlm.nih.gov/pubmed/12812536>

- Mitchell, S.L., Kiely, D.K., Hamel, M.B., Park, P.S., Morris, J.N., & Fries, B.E. (2004). Estimating Prognosis for Nursing Home Residents With Advanced Dementia. *The Journal of the American Medical Association*, 291(22), 2734-2740. doi:10.1001/jama.291.22.2734. <http://jama.jamanetwork.com/article.aspx?articleid=198894&resultClick=3>
- Mitchell, S.L., Teno, J.M., Roy, J., Kabumoto, G., Mor, V. (2003). Clinical and Organizational Factors Associated With Feeding Tube Use Among Nursing Home Residents With Advanced Cognitive Impairment. *The Journal of the American Medical Association*, 290(1), 73-80. doi:10.1001/jama.290.1.41. <http://jama.jamanetwork.com/article.aspx?articleid=196851&resultClick=3>
- Kuo, S., Rhodes, R.L., Mitchell, S.L., Mor, V. (2009). Natural History of Feeding-Tube Use in Nursing Home Residents With Advanced Dementia. *The Journal of the American Medical Association*, 10(4), 264-270. [http://www.jamda.com/article/S1525-8610\(08\)00412-X/abstract](http://www.jamda.com/article/S1525-8610(08)00412-X/abstract)
- Mitchell, S.L., Kiely, D.K., & Lipsitz, L.A. (1997). The risk factors and impact on survival of feeding tube placement in nursing home residents with severe cognitive impairment. *Archives of internal medicine*, 157(3), 327-32. <http://www.ncbi.nlm.nih.gov/pubmed/9040301>
- Teno, J.M., Gozalo, P.L., Mitchell, S.L., Kuo, S., Rhodes, R.L., Bynum, J.P., & Mor, V. (2012). Does feeding tube insertion and its timing improve survival? *Journal of the American Geriatrics Society*, 60(10), 1918-21. doi: 10.1111/j.1532-5415.2012.04148.x. <http://www.ncbi.nlm.nih.gov/pubmed/23002947>
- Teno, J.M., Gozalo, P., Mitchell, S.L., Kuo, S., Fulton, A.T., & Mor, V. Feeding Tubes and the Prevention or Healing of Pressure Ulcers. *Archives of internal medicine*, 172(9), 697–701. doi: 10.1001/archinternmed.2012.1200 <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3555136/>
- Gillick, M.R. (2000). Rethinking the Role of Tube Feeding in Patients with Advanced Dementia. *The New England Journal of Medicine*, 342, 206-210. DOI: 10.1056/NEJM200001203420312 <http://www.nejm.org/doi/full/10.1056/NEJM200001203420312>
- Finucane, T.E., Christmas, C, & Travis, K. (1999). Tube Feeding in Patients With Advanced Dementia. A Review of the Evidence. *The Journal of the American Medical Association*, 282(14), 1365-1370. doi:10.1001/jama.282.14.1365. <http://jama.jamanetwork.com/article.aspx?articleid=191992>
- Van der Steen, J.T., Ooms, M.E., Mehr, D.R., van der Wal, G., Ribbe, M.W. (2002). Severe dementia and adverse outcomes of nursing home-acquired pneumonia: evidence for mediation by functional and pathophysiological decline. *Journal of the American Geriatrics Society*, 50(3), 439-48. <http://www.ncbi.nlm.nih.gov/pubmed/11943038>
- Gillick, M.R. (2001). Choosing appropriate medical care for the elderly. *Journal of the American Medical Directors Association*, 2(6), 305-9. <http://www.ncbi.nlm.nih.gov/pubmed/12812536>
- D'Agata, E., & Mitchell, S.L. (2008). Patterns of Antimicrobial Use Among Nursing Home Residents With Advanced Dementia. *Archives of internal medicine*, 168(4), 357–362. doi: 10.1001/archinternmed.2007.104 <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2670184/>
- Givens, J.L., Jones, R.N., Shaffer, M.L., Kiely, D.K., & Mitchell, S.L. (2010). Survival and Comfort After Treatment of Pneumonia in Advanced Dementia. *Archives of internal medicine*, 170(13):1102-1107. doi:10.1001/archinternmed.2010.181. <http://archinte.jamanetwork.com/article.aspx?articleid=225757#ioi05016t2>
- Pop-Vicas, A., Mitchell, S.L., Kandel, R., Schreiber, R., & D'Agata, E.M. (2008). Multidrug-resistant gram-negative bacteria in a long-term care facility: prevalence and risk factors. *Journal of the American Geriatrics Society*, 56(7), 1276-80. doi: 10.1111/j.1532-5415.2008.01787.x. <http://www.ncbi.nlm.nih.gov/pubmed/18557965>

- Advanced Dementia – A Guide for Families:  
[http://www.hebrewseniorlife.org/workfiles/IFAR/Palliative\\_Care\\_Dementia\\_Booklet.pdf](http://www.hebrewseniorlife.org/workfiles/IFAR/Palliative_Care_Dementia_Booklet.pdf)

3) **“Research in home and community-based settings”** (Greg Sachs, MD, FACP, Professor of Medicine, Chief, Division of General Internal Medicine and Geriatrics, Department of Medicine, Indiana University School of Medicine, Scientist, IU Center for Aging Research, Regenstrief Institute, Inc., Service Line Leader for Palliative Care, IU Health Physicians)

- Reisberg, B., Ferris, S.H., de Leon, M.J., & Crook, T. (1982). The Global Deterioration Scale for assessment of primary degenerative dementia. *The American Journal of Psychiatry*, 139(9), 1136-9. <http://www.ncbi.nlm.nih.gov/pubmed/7114305>
- Mitchell, S.L., Teno, J.M., Miller, S.C., & Mor, V. (2005). National Study of the Location of Death for Older Persons with Dementia. *Journal of the American Geriatrics Society*, 53(2), 299–305. DOI: 10.1111/j.1532-5415.2005.53118.x <http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2005.53118.x/abstract;jsessionid=3500F2D805712733D02765BCECA7C9D8.d03t01>
- Callahan, C.M., Arling, G., Tu, W., Rosenman, M.B., Counsell, S.R., Stump, T.E., Hendrie, H.C. (2012). Transitions in Care for Older Adults with and without Dementia. *Journal of the American Geriatrics Society*, 60(5), 813–820. DOI: 10.1111/j.1532-5415.2012.03905.x <http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2012.03905.x/abstract>
- Sachs, G.A., Shega, J.W., Cox-Hayley, D. (2004). Barriers to Excellent End-of-life Care for Patients with Dementia. *Journal of General Internal Medicine*, 19(10), 1057–1063. DOI: 10.1111/j.1525-1497.2004.30329.x <http://onlinelibrary.wiley.com/doi/10.1111/j.1525-1497.2004.30329.x/full>
- Hickman, S.E., Nelson, C.A., Moss, A.H., Tolle, S.W., Perrin, N.A., & Hammes, B.J. (2011). *Journal of the American Geriatrics Society*, 59(11), 2091-2099. doi: 10.1111/j.1532-5415.2011.03656.x. <http://www.ncbi.nlm.nih.gov/pubmed/22092007>
- POLST website: <http://www.polst.org/>
- Assessment of Pain: <http://prc.coh.org/PAIN-NOA.htm>
- Shega, J.W., Hougham, G.W., Stocking, C.B., Cox-Hayley, D., & Sachs G.A. Pain in community-dwelling persons with dementia: frequency intensity, and congruence between patient and caregiver report. (2004). *Journal of Pain and Symptom Management*, 28(6), 585-92. <http://www.ncbi.nlm.nih.gov/pubmed/15589083>
- Shega, J.W., Hougham, G.W., Stocking, C.B., Cox-Hayley, D., Sachs, G.A. (2005). Factors associated with self- and caregiver report of pain among community-dwelling persons with dementia. *Journal of Palliative Medicine*, 8(3), 567-75. <http://www.ncbi.nlm.nih.gov/pubmed/15992198>
- Shega, J.W., Hougham, G.W., Stocking, C.B., et al. (2003). Barriers to limiting the practice of feeding tube placement in advanced dementia. *Journal of Palliative Medicine*, 6, 885–893. <http://www.ncbi.nlm.nih.gov/pubmed/14733680>
- Shega, J.W., Hougham, G.W., Stocking, C.B., Cox-Hayley, D., Sachs, G.A. (2008). Patients dying with dementia: experience at the end of life and impact of hospice care. *Journal of Pain and Symptom Management*, 35(5), 499-507. doi: 10.1016/j.jpainsymman.2007.06.011. <http://www.ncbi.nlm.nih.gov/pubmed/18261878>

- Miller, S.C., Lima, J., Gozalo, P.L., Mor, V. (2010). *The Growth of Hospice Care in U.S. Nursing Homes. Journal of the American Geriatrics Society, 58(8)*, 1481-1488. DOI: 10.1111/j.1532-5415.2010.02968.x <http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2010.02968.x/abstract>

4) **“Aging Network”** (Greg Link, Aging Services Program Specialist, Office of Caregiver and Supportive Services, Administration on Aging/Administration for Community Living)

- Alzheimers.gov: <http://alzheimers.gov/>
- National Alzheimer’s Call Center: <http://www.alz.org/>, 1-800-272-3900
- Advance Care Planning: An Introduction for Public Health and Aging Services Professionals: <http://www.cdc.gov/aging/advancecareplanning/care-planning-course.htm>
- Long Term Care Clearinghouse: <http://longtermcare.gov/how-to-decide/>
- Family Caregiver Alliance: <http://www.caregiver.org/caregiver/jsp/home.jsp>
- “Place of Death Among Older Americans: Does State Spending on Home and Community-Based Services Promote Home Death?": <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2708119/pdf/nihms-66857.pdf>
- ARCH National Respite Network - Fact Sheets and National Respite Locator: <http://archrespite.org/>