

# Resources for Implementing the Alzheimer's Association's Phase 3 Dementia Care Practice Recommendations on End-of-Life Care

This list is a reviewed collection of items prepared by the Alzheimer's Association Green-Field Library staff. Contact your local chapter or local library for availability of the items.

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### Alzheimer's Association Publications

*Dementia care practice recommendations for assisted living residences and nursing homes. Phases 1 & 2.*

Chicago, IL: Alzheimer's Association National Office; 2006.

[http://www.alz.org/national/documents/brochure\\_DCPRphases1n2.pdf](http://www.alz.org/national/documents/brochure_DCPRphases1n2.pdf).

*Dementia care practice recommendations for assisted living residences and nursing homes. Phase 3 end-of-life care.*

Chicago, IL: Alzheimer's Association National Office; 2007.

[http://www.alz.org/national/documents/brochure\\_DCPRphase3.pdf](http://www.alz.org/national/documents/brochure_DCPRphase3.pdf).

Tilly, J.; Fok, A. *Quality end of life care for individuals with dementia in assisted living and nursing homes and public policy barriers to delivering this care.*

Chicago, IL: Alzheimer's Association National Office, 2007.

[http://www.alz.org/national/documents/End\\_interviewpaper\\_III.pdf](http://www.alz.org/national/documents/End_interviewpaper_III.pdf)

Tilly, J.; Reed, P. Evidence of care for residents with dementia in nursing and assisted living facilities.

Chicago, IL: Alzheimer's Association National Office, 2004.

<http://www.alz.org/national/documents/dementiacarelitreview.pdf>

Volicer L. *End-of-life care for people with dementia in residential care settings.*

Chicago, IL: Alzheimer's Association National Office, 2005.

<http://www.alz.org/national/documents/endoflifelitreview.pdf>

### **Practice Recommendation Implementation**

Like practice guidelines, practice recommendations are based on the latest evidence for resolving problems in clinical settings and the experience of professional direct care experts. This section contains research and tools on implementing the Dementia Care Practice Recommendations.

### **Clinical Research & Discussion**

Colon-Emeric, C.S.; Lekan, D.; Utley-Smith, Q.; et al. The barriers to and the facilitators of clinical practice guidelines in nursing homes. *Journal of the American Geriatric Society*. Sep 2007; vol. 55(9), pp. 1404-1409.

Green-Field Library owns.

Resnick, B.; Quinn, C.; Baxter, S. Testing the feasibility of implementation of clinical practice guidelines in long-term care facilities. *Journal of the American Medical Director's Association*. Jan-Feb 2004; vol. 5(1), pp. 1-8.

Green-Field Library does not own.

### **Tools**

Davis, D.; Goldman, J.; Palda, V.A. *Handbook on clinical practice guidelines.*

Ottawa, ON: Canadian Medical Association, 2007.

<http://www.cma.ca//multimedia/CMA/Content/Images/ClinicalResources/PDF/English/CPGHandbook.pdf>

*Toolkit: implementation of clinical practice guidelines.*

Toronto, ON: Registered Nurses Association of Ontario, 2002.

<http://www.rnao.org/Page.asp?PageID=924&ContentID=823>.

Tuch, H., Parrish, P., Romer, A.L. Integrating palliative care into nursing homes: An interview with Howard Tuch and Pam Parrish. *Innovations in End-of-Life Care*. 2002;4(2) <http://www2.edc.org/lastacts/archives/archivesMarch02/featureinn.asp>.

### **Communication with Residents and Family**

#### **Clinical Research & Discussion**

Burgio, L.D.; Allen-Burge, R.; Roth, D.L.; et al. Come talk with me: improving communication between nursing assistants and nursing home residents during care routines. *Gerontologist*. Aug 2001; vol. 41(4), pp. 449-460.  
Green-Field Library owns.

Dijkstra, K.; Bourgeois, M.; Burgio, L.; et al. Effects of communication training on the discourse of nursing home residents with dementia and their nursing assistants. *Journal of Medical Speech-Language Pathology*. Jun 2002; vol. 10(2), pp. 143-157.  
Green-Field Library does not own.

Kettl, P. Helping families with end-of-life care in Alzheimer's disease. *Journal of Clinical Psychiatry*. Mar 2007; vol. 68(3), pp. 428-429.  
Green-Field does not own.

Robison, J.; Curry, L.; Gruman, C.; et al. Partners in caregiving in a special care environment: cooperative communication between staff and families on dementia units. *Gerontologist*. Aug 2007; vol. 47(4), pp. 504-515.  
Green-Field Library owns.

#### **Tools**

##### *Communication.*

Chicago, IL: Alzheimer's Association Green-Field Library, 2007.

A bibliography of print and electronic resources compiled for professional, trainers, family caregivers, and anyone seeking research materials in a broad range of topics on communicating effectively with the person with Alzheimer's disease. Prepared by the Alzheimer's Association Green-Field Library.

[http://www.alz.org/national/documents/Communication\\_RL2007.doc](http://www.alz.org/national/documents/Communication_RL2007.doc)

Parenteau, P. Communication with Alzheimer patients: a matter of time, caring and contact. *Canadian Alzheimer Disease Review*. Nov 2000; vol. 4(2), pp. 5-7.

[http://www.stacommunications.com/customcomm/Back-issue\\_pages/AD\\_Review/adPDFs/november2000/05.pdf](http://www.stacommunications.com/customcomm/Back-issue_pages/AD_Review/adPDFs/november2000/05.pdf)

Toseland, R.W.; McCallion, P. *Maintaining communication with persons with dementia: an educational program for nursing home staff and family members: workbook.*

New York, NY: Springer Publishing Company, 1998. ISBN-10: 0826112307.

Identifies stages of communication decline in the persons with dementia, general communication guidelines, communication strategies in the severe stage, activities, and more. Additionally the program helps nursing home staff and family members identify their own communication styles.

Green-Field Library Call No.: WM 220 T714 1998

## **Decision Making**

### **Clinical Research & Discussion**

Lacey, D. End-of-life decision making for nursing home residents with dementia: a survey of nursing home social services staff. *Health Social Work.* Aug 2006; vol. 31(3), pp. 189-199.

Green-Field Library does not own.

Lambert, H.C.; McColl, M.A.; Gilbert, J.; et al. Factors affecting long-term care residents' decision-making processes as they formulate advance directives. *Gerontologist.*

Oct 2005; vol. 45(5), pp. 626-633.

Green-Field Library owns.

White, C. An exploration of decision-making factors regarding advance directives in a long-term care facility. *Journal of the American Academy of Nurse Practitioners.* Jan 2005; vol. 17(1), pp. 14-20.

Green-Field Library does not own.

## **Tools**

*Project GRACE advance care plan document.*

Clearwater, FL: Project GRACE, 2000.

Project GRACE has prepared an advance directives document that allows the person to make choices about specific medical treatment for end stage disease, unconscious state, permanent confusion, or total dependence.

[http://www.projectgrace.org/acp\\_doc.htm](http://www.projectgrace.org/acp_doc.htm).

*Five wishes.*

Tallahassee, FL: Aging with Dignity, 2007.

Accepted in 40 states, Five Wishes allows the person to define what life support means to them, name the kind of medical treatment they want and don't want, name the tasks they want their agents to do, and how they want to be treated.

<http://www.agingwithdignity.org/5wishes.html>.

*Caring connections, state advance directives.*

Alexandria, VA: National Hospice and Palliative Care Organization.

Provides free advance directives and instructions for each state.

<http://www.caringinfo.org/stateaddownload>.

Pearlman, R.; Starks, H.; Cain, K.; et al. *Your life your choices: planning for future medical decisions. How to prepare a personalized will.*

Seattle, WA: Veterans Administration Medical Center.

A 52-page manual outlining the situations and decisions people commonly face and preferences under different health conditions. Also included are thought-provoking exercises and discussion on how to talk about your wishes.

[http://rihlp.org/pubs/Your\\_life\\_your\\_choices.pdf](http://rihlp.org/pubs/Your_life_your_choices.pdf)

Green-Field Library Call Number: KF 3827 P359

*Understanding life plans.*

Baltimore, MD: Video Press, 2001.

1 videocassette (20 min.)

Aimed at informing healthcare professionals about such end-of-life options for elders as feeding tubes, limiting treatment, and hospice care.

Green-Field Library Call No.: WB 310 VC no. 728 2001

## **Care Provision, Coordination and Communication When Residents Choose Hospice Services**

### **Clinical Research & Discussion**

Carrie, S.; Keene, S. Hospice care for Alzheimer's disease: caring for the patient, family, and caregivers. *The Internet Journal of Geriatrics and Gerontology*. 2007; vol. 3(2), [online only]

<http://www.ispub.com/ostia/index.php?xmlPrinter=true&xmlFilePath=journals/ijgg/vol3n2/hospice.xml>

Kim, K.Y.; Yeaman, P.A.; Keene, B.S.; et.al. Practical geriatrics: end-of-life care for persons with Alzheimer's disease. *Psychiatric Services*. Feb 2005; vol. 56(2). [online only]

<http://ps.psychiatryonline.org/cgi/content/full/56/2/139?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&fulltext=peratical+geriatrics+end+of+life+care+dementia&searchid=1&FIRSTINDEX=0&sortspec=relevance&resourcetype=HWCIT>

Sachs, G.A.; Shega, J.W.; Cox-Hayley, D. Barriers to excellent end-of-life care for patients with dementia. *Journal of General Internal Medicine*. Oct 2004; vol. 19(10), pp. 1057-1063.

<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1492583>

Thompson, P.M. Communicating with dementia patients on hospice. *American Journal of Alzheimer's Disease and Other Dementias*. Sep-Oct 2002; vol. 17(5), pp. 299-302.

Green-Field Library owns.

Volicer, L. Goals of care in advanced dementia: quality of life, dignity, and comfort. *Journal of Nutrition, Health & Aging*. Nov-Dec 2007; vol. 11(6), p. 481.  
Green-Field Library does not own.

Weckmann, M.T. The role of the family physician in the referral and management of hospice patients. *American Family Physician*. Mar 15, 2008, vol. 77(6), pp. 807-817.  
Green-Field Library does not own.

Zimmerman, S.; Sloane, P.D.; Williams, C.S.; Reed, P.S. et al. Dementia care and quality of life in assisted living and nursing homes. *Gerontologist*. Oct 2005; 45 Spec No 1(1), pp. 133-146.  
Green-Field Library owns.

## Tools

*Caring for persons with Alzheimer's and other dementias: guidelines for hospice providers*.  
Alexandria, VA: National Hospice and Palliative Care Organization, 2007.  
Noteworthy are the sections on how to open hospice doors and the descriptions of dementia-specific programs.  
<http://www.nhpco.org/i4a/pages/Index.cfm?pageID=5397>

*End of life care*.  
San Marcos, CA: Advanced Healthcare Studies, LLC, 2004.  
1 videocassette (60 min.)  
Includes issues concerning caring for nursing home residents during the dying process.  
Green-Field Library Call No.: WY 152 VC no. 1007 2004

Hellen, C.R. Terminal care: final storm weathered. IN: *Alzheimer's disease: activity-focused care*. (2nd ed.), pp. 355-371.  
Boston, MA: Butterworth Heinemann, 1998. ISBN: 0750699086.  
Green-Field Library Call No.: WM 450 H477a 1998

*Hospice/nursing home interface. Guidelines for care coordination for hospice patients who reside in nursing homes*.  
Madison, WI: Wisconsin Department of Health and Family Services (DHFS), 2001.  
[http://dhfs.wisconsin.gov/rl\\_dsl/publications/pdfmemos/01042a.pdf](http://dhfs.wisconsin.gov/rl_dsl/publications/pdfmemos/01042a.pdf).

Medical guidelines for determining prognosis of dementia. IN: Medical guidelines for determining prognosis in selected non-cancer diseases, pp. 52-54. *The Hospice Journal*. 1996; vol. 11(2), pp. 47-63.  
Green-Field Library owns.

*Palliative dementia care resources.*

North Wales, PA: Polisher Research Institute.

Funded by the Farber Family Foundation, this Web site for professionals and family caregivers, provides educational materials related to palliative care for persons with advanced dementia. Noteworthy is the link to end-of-life care in nursing homes, which contains an online staff training module for palliative care, guidelines for developing quality indicators for end of life care, and more.

<http://www.pdcronline.com/index.php>

Rhodes-Kropf, J. Palliative care for patients with Alzheimer's dementia: advance care planning across transition points. IN: Blank, A.E.; O'Mahony, S.; Selwyn, A. *Choices in palliative care: issues in health care delivery*, 144-156.

New York, NY: Springer Publishing Company, 2007. ISBN: 038770874X.

Green-Field Library Call No.: WB 310 C545 2007

Simard J. *The end-of-life Namaste Care Program for people with dementia.*

Baltimore, MD: Health Professions Press, 2007. ISBN: 9781932529340.

The Namaste Care Program is designed to provide guidance on implementing peaceful activities and sensory practices for persons with advanced dementia stressing their individuality and dignity.

Green-Field Library Call No.: WY 152 S588 2007

Stone, M.J. Goals of care at end of life. *Baylor University Medical Center Proceedings*. April 2001; 14(2), pp. 134-137.

Includes Tables outlining the goals and steps for negotiating care and how to frame language with positive connotations versus negative.

[http://www.baylorhealth.edu/proceedings/14\\_2/14\\_2\\_stone\\_cme.html](http://www.baylorhealth.edu/proceedings/14_2/14_2_stone_cme.html)

## **Assessment and Care for Physical Symptoms, Including Pain**

### **Clinical Research & Discussion**

Herr, K.; Bjoro, K.; Decker, S. Tools for assessment of pain in nonverbal older adults with dementia: a state-of-science review. *Journal of Pain Management*. Feb 2006; vol. 31(2), pp. 170-192.

Green-Field Library does not own.

Volicer, L.; Hurley, A.C.; Blasi, Z.V. Scales for evaluation of end-of-life care in dementia. *Alzheimer's Disease and Associated Disorders*. Oct-Dec 2001; vol. 15(4), pp. 194-200.

Green-Field Library owns.

## Tools

Cervo, F.A.; Raggie, R.P.; Bright-Long, L.E.; et al. Use of the Certified Nursing Assistant Pain Assessment Tool (CPAT) in nursing home residents with dementia. *American Journal of Alzheimer's Disease and Other Dementias*. Apr-May 2007; vol. 22(2), pp. 112-119.

Contains CPAT scale and validation for use by direct care workers.  
Green-Field Library owns.

*Pain assessment in older adults at the end of life.*

Herr, K.A.

Includes the consequences of unrecognized and untreated pain, barriers to pain assessment, and approaches to assessment for persons with advanced dementia who are nonverbal.

[http://www.epec.net/EPEC/Media/pdf/epecg/EPECg\\_pna.pdf](http://www.epec.net/EPEC/Media/pdf/epecg/EPECg_pna.pdf)

Snow, A.L.; Weber, J.B.; O'Malley, K.J. NOPAIN: a nursing assistant-administered pain assessment instrument for use in dementia. *Dementia and Geriatric Cognitive Disorders*. Mar 2004; vol. 17(3), pp. 240-246.

Contains NOPAIN scale and validation discussion for use by direct care workers. For a copy of the scale only (English and Spanish versions) visit

[http://prc.coh.org/Review%20of%20Tools%20for%20Pain%20Assessment/Review%20of%20Tools%202004/NOPPAIN/NOPPAIN\\_Indepth.pdf](http://prc.coh.org/Review%20of%20Tools%20for%20Pain%20Assessment/Review%20of%20Tools%202004/NOPPAIN/NOPPAIN_Indepth.pdf)

Useful tools: relieving pain. *Innovations in End-of-Life Care: An International Journal of Leaders in End-of-life Care*. [online only]

Includes a pain audit for customers with dementia and a pain flowchart.

<http://www2.edc.org/lastacts/pain.asp>

## Assessment and Care for Behavioral Symptoms

### Clinical Research & Discussion

Goy, E.; Ganzini, L. End-of-life care in geriatric psychiatry. *Clinical Geriatric Medicine*. Nov 2003; vol. 19(4), pp. 841-856, vii-viii.

Discussed here are depression, anxiety, and delirium, treatment versus burden of intervention, and the complications of behavioral disturbance in dementia.

Green-Field Library does not own.

Kovach, C.R.; Kelber, S.T.; Simpson, M.; et al. Behavior of nursing home residents with dementia: examining nurse responses. *Journal of Gerontological Nursing*. Jun 2007; vol. 32(6), 13-21.

Green-Field Library owns.

Volicer, L. Management of severe Alzheimer's disease and end-of-life issues. *Clinical Geriatric Medicine*. May 2001; vol. 17(2), pp. 377-391.

Includes discussion on the management of behavioral symptoms.

Green-Field Library does not own.

Wilden, B.M.; Wright, N.E. Concept of pre-death. Restlessness in dementia. *Journal of Gerontological Nursing*. Oct 2002; vol. 28(10), p. 24-29; quiz 50 - 51.

Family distress caused by behaviors in end-stage dementia can be lessened if symptoms of pre-death restlessness are recognized.

Green-Field Library owns.

## Tools

*Behavioral and psychological symptoms of dementia (BPSD) educational pack.*

Northfield, IL: International Psychogeriatric Association.

Among other behavioral symptoms, this tool provides guidance on apathy, anxiety, agitation, and delirium.

<http://www.ipa-online.org/ipaonlinev3/ipaprograms/bpsdarchives/bpsdrev/2BPSDfinal.pdf>

## Psychosocial and Spiritual Support of Residents

### Clinical Research & Discussion

McCurdy, D.B. Personhood, spirituality, and hope in the care of human beings with dementia. *The Journal of Clinical Ethics*. Spring 1998; vol. 9(1), pp. 81-91.

Green-Field Library owns.

Nelson-Becker, H.; Nakashima, M.; Canda, E.R. Spiritual assessment in aging: a framework for clinicians. *Journal of Gerontological Social Work*. 2007; vol. 48(3-4), pp. 331-347.

Green-Field Library owns.

Post, S.G. God and Alzheimer's: a neurological reflection on religious experience, self, and soul. *Park Ridge Bulletin*. 2001; Issue 19, pp. 9-10.

An online article discussing the relationship between personhood, self-identity, and God in a person with advanced dementia.

<http://www.parkridgecenter.org/Page482.html>

Richards, M. Spirituality and social work in long-term care. *Journal of Gerontological Social Work*. 2005; vol. 45(1-2), pp. 173-183.

Green-Field Library owns.

## Tools

### *Ethnicity online.*

Cambridge, UK: NHS Workforce Development Confederation (WDC) for Norfolk, Suffolk and Cambridgeshire, 2003.

Contains links to information about ethnic/religious groups, including summaries of their beliefs and customs on death, dying, and religious observance, along with healthcare-related advice.

[http://www.ethnicityonline.net/ethnic\\_groups.htm](http://www.ethnicityonline.net/ethnic_groups.htm)

Hellen, C.R. Maintaining personhood: psychosocial aspects of support. IN: *Alzheimer's disease: activity-focused care*. (2nd ed.), pp. 19-41.

Boston, MA: Butterworth Heinemann, 1998. ISBN: 0750699086.

Green-Field Library Call No.: WM 450 H477a 1998

### *Spiritual assessment.*

Oakbrook Terrace, IL: The Joint Commission, 2004.

[http://www.jointcommission.org/AccreditationPrograms/HomeCare/Standards/09\\_FAQs/PC/Spiritual\\_Assessment.htm](http://www.jointcommission.org/AccreditationPrograms/HomeCare/Standards/09_FAQs/PC/Spiritual_Assessment.htm)

## **Family Participation in Resident's End-of-life Care**

### **Clinical Research & Discussion**

Dijkstra, A. Family participation in care plan meetings: promoting a collaborative organizational culture in nursing homes. *Journal of Gerontological Nursing*. Apr 2007; vol. 33(4), pp. 22-29.

Green-Field Library owns.

McCallion, P. Supporting families of persons with dementia living in nursing homes: the family visit education program. IN: Gaugler, J.E. (ed.). *Promoting family involvement in long-term care settings: a guide to programs that work*, pp. 123-142.

Baltimore, MD: Health Professions Press, 2005. ISBN: 1932529071

Green-Field Library Call No.: WT 27.1 P965 2005

Piechniczek-Buczek, J.; Riordan, M.E.; Volicer, L. Family member perception of quality of their visits with relatives with dementia: a pilot study. *Journal of the American Medical Directors Association*. Mar 2007; vol. 8(3), pp. 166-172.

Green-Field Library owns.

Yamamoto-Mitani, N.; Aneshensel, C.S.; Levy-Storms, L. Patterns of family visiting with institutional elders: the case of dementia. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*. Jul 2002; vol. 57(4), pp. S234-S246.

Green-Field Library owns.

## Tools

*Advancing the practice of patient-and-family-centered care: how to get started.*

Bethesda, MD: Institute for Family-Centered Care.

This tool for hospitals can be useful for creating working partnerships between residences and families.

<http://www.familycenteredcare.org/tools/downloads.html>

*Family involvement in care for persons with dementia (FIC).*

Iowa City, IA: University of Iowa, College of Nursing, 2001.

An intervention guideline designed for families and front-line staff who care for elders and provide support to their families in nursing homes. Also for care managers who develop policy and procedures in nursing homes. Includes the *Family Bereavement Support Policy and Family Bereavement Survey*, other assessment tools and materials. Available for a nominal fee. Order form:

[http://www.nursing.uiowa.edu/products\\_services/documents/orderform06-07NEWPRICES.pdf](http://www.nursing.uiowa.edu/products_services/documents/orderform06-07NEWPRICES.pdf)

Specht, J.P.; Reed, D.; Maas, M.L. Family involvement in the care of residents with dementia: an important resource for quality of life and care. IN: Gaugler, J.E. (ed.). *Promoting family involvement in long-term care settings: a guide to programs that work*, pp. 163-196.

Baltimore, MD: Health Professions Press. 2005. ISBN: 1932529071

Green-Field Library Call No.: WT 27.1 P965 2005

## Staff Training

### Clinical Research & Discussion

Hernandez-Medina, E.; Eaton, S.; Hurd, D.; et al. *Training programs for certified nursing assistants: research report.*

Washington, DC: AARP, April 2006.

[http://www.aarp.org/research/longtermcare/nursinghomes/2006\\_08\\_cna.html](http://www.aarp.org/research/longtermcare/nursinghomes/2006_08_cna.html).

*Nurse aide turnover: literature review of research, policy, and practice.*

Tampa, FL: University of South Florida, Policy Exchange Center on Aging, 1999.

A study "to identify the factors affecting the recruitment, training, employment, and retention, of qualified certified nurse aides within the nursing home industry."

[http://fpeca.usf.edu/chlrc/data/Nurse\\_Aide\\_Turnover\\_Literature\\_Review\\_of\\_Research\\_Policy\\_and\\_Practice.pdf](http://fpeca.usf.edu/chlrc/data/Nurse_Aide_Turnover_Literature_Review_of_Research_Policy_and_Practice.pdf)

Parks, S.M.; Haines, C.; Foreman, D.; et al. Evaluation of an educational program for long-term care nursing assistants. *Journal of the American Medical Directors Association*. Jan-Feb 2005; vol. 6(1), pp. 61-65.

Green-Field Library does not own.

Tellis-Nayak, V. A person-centered workplace: the foundation of person-centered caregiving in long term care. *Journal of the American Medical Directors Association*. Jan 2007; vol. 8(1), pp. 46-54.  
Green-Field Library owns.

Zimmerman, S.; Williams, C.S.; Reed, P.S.; et al. Attitudes, stress, and satisfaction of staff who care for residents with dementia. *Gerontologist*. Oct 2005; vol. 45 Spec No. 1(1), pp. 96-105.  
Green-Field Library owns.

## Tools

Comer, S. Alzheimer's disease. IN: *Delmar's geriatric nursing care plans*, (3rd ed.), pp. 82-99.  
Clifton Park, NY: Thomson Delmar Learning, 2005. ISBN: 0766859924  
Green-Field Library Call No.: WY 152 D359 2005

*Is Mrs. Jones okay?*  
Baltimore, MD: Video Press, 2001.  
1 videocassette (20 min.).  
In this video "staff relate specific guidelines for appropriate checking. They emphasize the need to check vital signs and look for change, and point out the need to recognize individual differences of residents."  
Green-Field Library Call No.: WY 100 VC no.729 2001

*Knowledge and skills needed for dementia care: a guide for direct care workers.*  
Okemos, MI: Michigan Dementia Coalition, Michigan Public Health Institute, 2006.  
A 74-page online manual covering knowledge of dementia, person-centered care, care interactions, enriching person's life, understanding behaviors, interacting with families, and the care for the direct care worker.  
[http://www.mi.gov/documents/miseniors/Dem\\_CompGuide\\_-\\_Everyday\\_Lang\\_3.4.08\\_228172\\_7.pdf](http://www.mi.gov/documents/miseniors/Dem_CompGuide_-_Everyday_Lang_3.4.08_228172_7.pdf)

*Lippincott's textbook for nursing assistants: a humanistic approach to caregiving.* Philadelphia, PA: Lippincott Williams & Wilkins, 2008. ISBN: 0781766850.  
Green-Field Library Call No.: WY 193 L765 2008

*Palliative care for advanced dementia: a self-instructional seven-part training program.*  
Phoenix, AZ: Alzheimer's Association Desert Southwest Chapter, 2006.  
Available in videocassette and DVD. Order from 602-528-0545.  
Green-Field Library Call No.: WM 220 VC no.843  
Green-Field Library Call No.: WM 220 DVD no.2

Stamp, N. *Supporting people with dementia: a training pack to use with care assistants working in care homes.*

Brecon, Powys: UK: Age Concern Books, 2005. ISBN: 086242349X.

Green-Field Library Call No.: WY 193 S783 2005

Walsh, D. *Dementia care training manual for staff working in nursing and residential settings.*

London, UK: Jessica Kingsley Publishers, 2006. ISBN: 1843103184

Green-Field Library Call No.: WY 193 W224 2006

## **Acknowledgement of Death and Bereavement Services**

### **Clinical Research & Discussion**

Doka, K. Grief and dementia. IN: *Living with grief: Alzheimer's disease*, pp. 139-153.

Washington, DC: Hospice Foundation of America, 2004. ISBN 1893349055.

This chapter explores grief in the person with dementia before death and caregiver mourning after.

Green-Field Library Call No.: WM 220 L785 2004

Murphy, K.; Hanrahan, P.; Luchins, D. Survey of grief and bereavement in nursing homes: the importance of hospice grief and bereavement for the end-stage Alzheimer's disease patient and family. *Journal of the American Geriatrics Society*. Sep 1997; vol. 45(9), pp. 1104-1107.

Nursing homes completed a structured telephone survey on sending sympathy cards, providing educational material, support groups, referral for counseling, attendance at the funeral, and contact with family after death. The study demonstrated few grief and bereavement services for families and recommended access to Medicare hospice where these services were unavailable.

Green-Field Library owns.

Volicer, L. End-of-life care and bereavement: effect on family carers. *Lancet Neurology*. Mar 2004; vol. 3(3), p. 144.

Green-Field Library does not own.

### **Tools**

*Ethnicity online.*

Cambridge, UK: NHS Workforce Development Confederation (WDC) for Norfolk, Suffolk and Cambridgeshire

Contains links to information about ethnic/religious groups, including summaries of their beliefs and customs on death, dying, and religious observance, along with healthcare-related advice.

[http://www.ethnicityonline.net/ethnic\\_groups.htm](http://www.ethnicityonline.net/ethnic_groups.htm)

*Family bereavement support before and after the death of a nursing home resident.* [practice guidelines].

Iowa City, IA: University of Iowa, College of Nursing, 2002.

"Intervention guidelines for a nominal fee designed to assist family members before and after the death of their loved one in nursing home settings. Intended for front-line staff (registered nurses, care attendants, social workers, chaplains) who care for the elderly, and provide support to the elders' families in nursing homes. Also intended for care managers who develop policy and procedures in nursing home settings. Includes the *Family Bereavement Support Policy and Family Bereavement Survey* along with other assessment tools and helpful materials."

[http://www.nursing.uiowa.edu/products\\_services/evidence\\_based.htm](http://www.nursing.uiowa.edu/products_services/evidence_based.htm)

Simard J. After-death care. IN: *The end-of-life Namaste Care Program for people with dementia*, pp. 141-145.

Baltimore, MD: Health Professions Press, 2007. ISBN: 9781932529340.

Green-Field Library Call No.: WY 152 S588 2007

*Standards for bereavement care.*

Keegan, O.

Dublin, IR: Education, Research and Training Manager, Irish Hospice Foundation.

Guidelines for bereavement care to ensure the work is ethical, safe, and appropriate for the situation.

[http://www.hospice-foundation.ie/up\\_documents/standards\\_bereavement\\_care.pdf](http://www.hospice-foundation.ie/up_documents/standards_bereavement_care.pdf)

## **Resources for Implementing the Alzheimer's Association's Phase 3 Dementia Care Practice Recommendations on End-of-Life Care**

A selected list of references compiled by

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