



## Resource List: Choosing Healthcare Services and Long-Term Care Facilities

Families face a variety of challenges when a loved one develops Alzheimer's disease (AD) or a related disorder, including finding home health and day care services, making decisions about placement in nursing homes or other long-term care facilities, and coping with financial and legal matters. This resource list gives an overview of helpful books, brochures, and manuals about available services and resources that may assist family members in the decision-making process.

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### Choosing Home Health and Day Care Services

#### 1. Alzheimer's Early Stages: First Steps for Family, Friends and Caregivers (2<sup>nd</sup> ed.)

Alameda, CA: Hunter House. 2003. 306 p.

Available from Hunter House Publishers. P.O. Box 2914, Alameda, CA 94501-0914. (800) 266-5592; (510) 865-5282; FAX: (510) 865-4295.

E-mail: [ordering@hunterhouse.com](mailto:ordering@hunterhouse.com). Website: [www.hunterhouse.com](http://www.hunterhouse.com). PRICE: \$15.95 paperback, \$27.95 hardcover. ISBN: 0897933974 paperback; 0897933982 hardcover.

This book offers information and support to the families and friends of people in the early stages of Alzheimer's disease (AD). Part 1 focuses on the medical aspects the disease. It discusses the need for an accurate diagnosis, symptoms of early AD, risk factors, and progress in treatment and prevention. Part 2 centers on caring for the loved one with AD. It discusses the changes in relationships and roles that take place and offers advice on making practical decisions, improving communication, planning for the future, and keeping the person with AD active and healthy. One chapter explores the experience of AD from the perspective of people with the disease. Part 3 offers suggestions to keep the caregiver healthy and positive. It suggests specific supports such as individual and family counseling, exploring spiritual resources, keeping a journal, and maintaining a sense of humor as well as community resources such as support groups, respite care, and adult day care. The book includes a suggested agenda for change in



public policy and a resource section with listings of AD Centers funded by the National Institute on Aging, print and video resources, and Internet sites. (AZBK09292).

## **2. And Thou Shalt Honor: The Caregiver's Companion**

Emmaus, PA: Rodale Books. 2002. 443 p.

Available from Rodale Books. 400 South Tenth Street, Emmaus, PA 18098-0099. (800) 848-4735; (610) 967-8964; FAX: (610) 967-8964. Website: [www.rodalestore.com](http://www.rodalestore.com). PRICE: \$15.95 and ISBN for paperback: 1579547745; ISBN for hardback: 1579545580.

This companion book to the Public Broadcast System (PBS) televised special program 'And Thou Shalt Honor' provides information and support for family caregivers of loved ones who are elderly or ill. It offers insights and advice about all aspects of providing care, including reaching out to a loved one in need of help, managing day-to-day caregiving tasks, accessing public and private caregiving resources, handling legal and financial matters, assembling a caregiver support network, understanding the changing family dynamic, and caring for oneself in the caregiver role. One chapter, on specific health problems, includes a section on caregiving for a loved one with Alzheimer's disease (AD). This section discusses the symptoms of AD, the importance of early diagnosis and treatment, tips for better communication, and a suggested daily routine. The book also has a comprehensive listing of web sites, books, and organizations for additional information and assistance. (AZBK09437).

## **3. Caregiver's Handbook: A Guide to Caring for the Ill, Elderly, Disabled...and Yourself**

Boston, MA: Harvard Medical School. 2004. 45 p.

Available from Harvard Health Publications, P.O. Box 421073, Palm Coast, FL 32142-1073. Website: [www.health.harvard.edu](http://www.health.harvard.edu). PRICE: \$16.00 for print or electronic versions.

This report is a guide to caring for elderly, ill, or disabled loved ones while attending to one's own needs. Although not specific to people with dementia, much of the information is applicable to caring for the confused elderly. First, it outlines the important elements of good caregiving and offers advice about developing a caregiving plan. It explains how to talk with the loved one to determine what care is needed, and provides a questionnaire that can be used to assess and document those needs. Then, it discusses the resources and documents that are useful for legal planning, financial planning, and medical planning. It also discusses the community services and professionals who can provide assistance, ways to involve family members, and tips for long-distance caregiving. Next, it offers suggestions for managing daily tasks and common problems such as mobility, meals, personal hygiene, confusion, urinary incontinence, and bowel incontinence. It also suggests strategies the caregiver can use to take care of his or her own needs. Finally, it describes options for care



when the loved one can no longer stay at home. The report includes a glossary and list of resources. (AZDC09639).

#### **4. Caregiver's Information-Pack**

Cookeville, TN: C-Mac Informational Services, Inc. 2003-2004. 28 p.

Available from C-Mac Informational Services, Inc. 120 Clinton Lane, Cookeville, TN 38501. E-mail: [caregiver\\_cmi@hotmail.com](mailto:caregiver_cmi@hotmail.com). PRICE: \$9.95.

This caregiver's information pack is designed to help families provide daily care for their relatives with Alzheimer's disease (AD) and make appropriate decisions and arrangements for their future well-being. First, it provides an overview of AD, its symptoms, and the changes that may occur as the patient progresses from the early through the middle and late stages of the disease. Then, it offers suggestions for planning ahead regarding legal and financial matters, dealing with caregiver stress, preparing to care for the patient at home, working with dementia patients on a day-to-day basis, and coping with common behavioral problems. Next, it discusses illnesses and injuries, the use of medications, making the home safe, adult day-care programs, the issue of when the dementia patient should stop driving, caring for the caregiver, selecting an attorney knowledgeable about elder law, and documenting the patient's wishes through advance directives. Finally, it discusses the decision to move the patient to an assisted living facility or nursing home. It includes a checklist for selecting a facility and advice about admitting the patient. (AZBR09530).

#### **5. Complete Eldercare Planner: Where To Start, Questions To Ask, and How To Find Help** (2<sup>nd</sup> ed.)

New York, NY: Hyperion. 2000. 273 p. Available from local and online book dealers. PRICE: \$19.95. ISBN: 0812932781.

This handbook is intended to help family members provide better care for their aging parents and other older relatives through effective planning. It offers guidance on getting organized and locating resources, determining when an older relative needs help, talking about sensitive subjects, sharing the care, preparing for emergencies, handling financial and legal matters, ensuring that the older relative has adequate insurance, determining the best housing option, ensuring the older relative's safety and security from a distance, encouraging a more healthy lifestyle, communicating with doctors, and getting an impaired older person to stop driving. It also includes suggestions for handling caregiver stress and preventing burnout, maintaining a high quality of life, and planning for the loved one's death. Each chapter includes a step-by-step planning guide, a list of low-cost and free resources, and an action checklist to help chart progress. A documents locator is included, which is a fill-in-the-blank list of legal documents, property titles, family medical histories, financial records, and other important



papers. This book includes lists of organizations and Web sites for additional information. (AZBK06528).

## **6. Fact Sheet: Alzheimer's Disease, Early Stage (2<sup>nd</sup> ed.)**

San Francisco, CA: Family Caregiver Alliance. January 2002. 6 p.

Available from Family Caregiver Alliance. 180 Montgomery Street, Suite 1100, San Francisco, CA 94104. (800) 445-8106; (415) 434-3388; FAX (415) 434-3508. E-mail: [info@caregiver.org](mailto:info@caregiver.org). Website: [www.caregiver.org](http://www.caregiver.org). PRICE: free online access, \$1.00 for print copy.

This fact sheet summarizes basic information about early-stage Alzheimer's disease (AD). It also discusses the nature of AD, what happens during the early stage, how it affects AD patients and caregivers, the diagnostic process, the benefits of early diagnosis and intervention, abilities that may be affected by AD, driving and household and financial management issues, research advances in the areas of medications and genetics, suggestions for coping with the effects of AD, and community resources for support and assistance. The document includes a recommended reading list, references, and list of resources. (AZDC08013).

## **7. How to Care for Aging Parents (2<sup>nd</sup> ed.)**

New York, NY: Workman Publishing Company, Inc. 2004. 691 p.

Available from the Workman Publishing Company, Inc. 708 Broadway, New York, NY 10003-9555. (212) 254-5900; FAX: (212) 254-8098. E-mail: [info@workman.com](mailto:info@workman.com). Website: [www.workman.com](http://www.workman.com). PRICE: \$15.95 and ISBN: 1563054353 for paperback; \$18.95 and ISBN: 0761134263 for book.

This book is a comprehensive resource for people caring for aging parents. It addresses such topics as talking with parents about their future, adjusting to new roles, caring for the caregiver, healthy aging, tips for daily living, getting help from family and friends, using community and home care services, working with the doctor, physical and mental problems in older age, coping with hospital stays, finance and insurance issues, legal matters, relocating to a new care setting, caring for a parent with dementia, terminal care, and grieving. The book includes new sections on housing options, alternative therapies, balancing career and caregiving, and dealing with difficult parents. Three chapters are devoted to Alzheimer's disease (AD) and related dementias. A chapter on the aging brain explains the differences between normal age-related brain changes and dementia, the early signs of dementia, the stages of AD, diagnosis, and treatment. Another chapter offers suggestions to help make living with dementia easier for both the caregiver and the parent. A third chapter provides tips for managing daily activities and coping with behavior problems. At the end of the book is a 100-page 'Yellow Pages' guide to resources and services in the eldercare industry. (AZBK09746).



## 8. Respite Care Guide: How to Find What's Right for You

Chicago, IL: Alzheimer's Association. 1995 [reprinted 2002]. 18 p.

Available from the Alzheimer's Association 225 North Michigan Avenue, Suite 1700, Chicago, IL 60601-7633. (800) 272-3900; (312) 335-8700; (312) 335-8882 (TDD); FAX (312) 335-1110. E-mail: [info@alz.org](mailto:info@alz.org) .

Website: [www.alz.org/resources/factsheets/respitecareguide.pdf](http://www.alz.org/resources/factsheets/respitecareguide.pdf).

PRICE: Free online access and single copies free. Order Number PF112Z.

This guide is designed to assist families of people with Alzheimer's disease (AD) in understanding and finding respite care services. It defines respite services, explains the ways they could be used, and presents some of the concerns about using them. The guide explains the different types of services, and how to choose one, and aids in family preparation for the use of such services. A detachable form is provided at the end of the guide. (AZDC05337).

## 9. Rush Manual for Caregivers (6th ed.)

Chicago, IL: Rush Alzheimer's Disease Center. 2004. 116 p.

Available from the Rush Alzheimer's Disease Center, Rush Presbyterian-St. Luke's Medical Center. 710 South Paulina Street, Suite 8 North, Chicago, IL 60612-3872. (312) 942-4463. E-mail: [info@alz.org](mailto:info@alz.org).

Website: [www.rush.edu/rumc/page-R12399.html](http://www.rush.edu/rumc/page-R12399.html) or

[www.rush.edu/Rush\\_Document/CaregiversManual.pdf](http://www.rush.edu/Rush_Document/CaregiversManual.pdf). PRICE: \$14.95 for printed version, and free online access.

This manual provides an overview of the issues that family members with relatives with Alzheimer's disease (AD) may need to address to cope with dementia. Chapters describe dementia and give the stages of AD; communication difficulties experienced and suggests ways to bridge the communication gap that dementia creates; the needs of the family in coping, including children and legal matters that may need attention; guidelines for providing daily care (hygiene, home safety, mobility and exercise, and nutrition); and important considerations when handling health and behavior problems. The manual's final chapter addresses ways to obtain outside help, such as from community-based and government resources, and considerations to be addressed when selecting a nursing home or hospice care. The manual concludes with lists of selected readings for families with a member who has dementia, and for professionals, concerning such areas as activities, public policy, and nursing home care. (AZBK04965).



## **Choosing Long-Term Care Services**

### **10. Age Page: Long-Term Care: Choosing the Right Place**

Bethesda, MD: National Institute on Aging. September 2003. 1 p. [14 panels].

Available from the NIA Information Center (NIAIC), P.O. Box 8057, Gaithersburg, MD 20898-8057. (800) 222-2225; TTY: (800) 222-4225.

Website: [www.niapublications.org/engagepages/longterm.asp](http://www.niapublications.org/engagepages/longterm.asp) (English) and [www.niapublications.org/spnagepages/longterm-sp.asp](http://www.niapublications.org/spnagepages/longterm-sp.asp). PRICE: free print copies and free online access.

This pamphlet distributed by the National Institute on Aging discusses choices in long-term care for the elderly. It presents information on planning ahead, the need for additional care in the home, assisted living facilities, skilled nursing facilities, how to find the right facility, and making a smooth transition. Additional resources are listed. (AZBR07241)

### **11. Home Away From Home: Relocating Your Parents**

San Francisco, CA: Family Caregiver Alliance. 2003. 6 p.

Available from the Family Caregiver Alliance. National Center on Caregiving. 180 Montgomery Street, Suite 1100, San Francisco, CA 94104. (800) 445-8106; (415) 434-3388; FAX: (415) 434-3508. E-mail: [info@caregiver.org](mailto:info@caregiver.org). Website: [www.caregiver.org](http://www.caregiver.org). PRICE: free online access, and \$1.00 for print copy.

This fact sheet offers advice and summarizes the issues to consider before relocating an elderly parent. First, it outlines some of the topics to cover in family discussions about the decision to relocate a parent. These include determining how the parent's care needs will be met and resolving family dynamics issues such as conflicts between family members. Then, it describes different types of living arrangements that might be appropriate for the parent, including a nearby apartment or retirement community, assisted living facility, residential care facility, intermediate care facility, and skilled nursing facility. Finally, it discusses issues to consider before moving a parent into your own home, including the change of family roles, lifestyle differences, loss of time to caregiving, physical living arrangements, financial arrangements, and emotional adjustment for the relocated parent. The fact sheet includes a list of recommended readings and resources for additional information and support. (AZDC09664)

### **12. Family Guide to Alzheimer's Disease. Volume 5: Transitions**

Nashville, TN: LifeView Resources, Inc. 2004. (videocassette, guidebook, 10 p.).

Available from LifeView Resources, Inc., P.O. Box 290787, Nashville, TN 37229-0787. (800) 395-5433. Website: [www.lifeviewresources.com](http://www.lifeviewresources.com). PRICE: \$24.95, or \$99.95 for 5-volume set.



This videotape, part of a series for families affected by Alzheimer's disease (AD), addresses some of the difficult transitions families face as the disease progresses. First, it explains how to adapt social activities to accommodate the loved one's increasing disability and isolation, and how maintaining ties to religious rituals and places of worship can offer comfort and meaning. Then, it explores issues involved in the transition to a care facility, including knowing when it is time to move the loved one, finding a good facility, making the move, and staying connected after the move. Finally, it offers insights from others who have gone through the process of grieving the loss of a loved one for whom they have provided years of care. The videotape comes with a guide booklet that summarizes the material. (AZAV09661).

### **13. Guide To Choosing a Nursing Home**

Baltimore, MD: Centers for Medicare and Medicaid Services (CMS). September 2004. 61 p.

Available from U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services (CMS). 7500 Security Boulevard, Baltimore, MD 21244-1850. (800) 638-6833. Website: [www.medicare.gov/publications/](http://www.medicare.gov/publications/). PRICE: Free print and online versions. Publication number: CMS 02174; also available in Spanish, Braille, and audiotape.

This guide is designed to help older people and families choose a good nursing home. It may be of interest to families of people with Alzheimer's disease who can no longer care for their relative at home. It discusses the importance of building a network of partners to share in the decision, the types of long-term care options that are available in the community, sources of information, the types of information to get from nursing homes, sources of payment for nursing home care, the rights of residents in a nursing home, and the rights of relatives. A section on visiting nursing homes offers suggestions for assessing whether the home is sensitive to quality of life and is providing high quality care. The booklet also provides lists of telephone numbers for long-term care ombudsmen, survey agencies, and Insurance Counseling and Assistance programs in the 50 states and territories, as well as a checklist for evaluating and comparing nursing homes. Index, and glossary of terms. (AZDC07153).

### **14. How To Select a Special Care Unit: A Consumer's Guide to Special Care Units For Persons With Dementia**

Topeka, KS: Kansas Department on Aging. 2002. 13 p.

Available from Kansas Department on Aging, 503 South Kansas Avenue, Topeka, KS 66603-3404. (800) 432-3535; (785) 296-4986. Website: [www.agingkansas.org/kdoa/publications/requestform.htm](http://www.agingkansas.org/kdoa/publications/requestform.htm). PRICE: Single copy free.

This booklet is designed to help families select a special care unit for a loved one with dementia. The information can be used in discussions with the nursing home



administrator and staff about the services and programs offered. The first section provides a brief overview of Alzheimer's and related dementias. The second section provides guidelines for evaluating a special care unit (SCU). It includes questions to ask the SCU administrator about the unit's philosophy and goals; policies, management, environment, daily resident care; therapeutic activity programming; and costs. A list of resources is provided. (AZBR09768)

## **15. Matter of Rights: A Guide to Your Rights and Responsibilities as a Resident**

Seattle, WA: Caresource Healthcare Communications. 2003. 31 p.

Available from Caresource Healthcare Communications. 426 Yale Avenue, North, Seattle, WA 98109. (800) 448-5213; FAX: (206) 682-2901. E-mail: [service@caresource.com](mailto:service@caresource.com). Website: [www.caresource.com](http://www.caresource.com). PRICE: \$1.69 each for nonmember, \$1.65 each for member for 1-99 copies; \$1.49 each for nonmember, \$1.40 each for member for 100-249 copies. Item number: AMR001 in English; AMR002 in Spanish.

This booklet is a general guide to the rights and responsibilities of residents and patients in long-term care facilities. The information is applicable to all residents, including those with cognitive impairment. It outlines residents' rights and generic facility policies and procedures in the following areas: (1) dignity and respect; (2) ready access to information; (3) freedom of choice; (4) money and property; (5) privacy, confidentiality, and the Health Insurance Portability and Accountability Act of 1996; (6) grievance procedures; (7) groups and activities; (8) visitors and communications; and (9) admission, transfer, and discharge. A final section explains resident responsibilities regarding other residents, staff, and the facility. The booklet includes an index. (AZBR09699)

## **16. Nursing Homes: Getting Good Care There** (2nd ed.)

Burger, S.G. et al. San Luis Obispo, CA: Impact Publishers, Inc. 2001. 176 p.

Available from Impact Publishers, Inc. PO Box 6016, Atascadero, CA 93423-6016. (805) 466-5917; WEB: [www.impactpublishers.com](http://www.impactpublishers.com). PRICE: \$14.95. ISBN: 0915166976.

This advocacy handbook and resource guide for families and friends of nursing home patients was produced by the National Citizen's Coalition for Nursing Home Reform. The book provides specific instructions and suggestions for advocating for good care practices, residents' rights, and staff responsibilities. Topics include: the individual experience of entering a nursing home; residents' struggles to retain individuality within an institutional routine; the residents' rights, including financial affairs, treatment options, and transfer/relocation; patient assessment; the potential dangers of physical and chemical restraints; quality of life issues; problem solving; and how good leadership ensures excellent care. (AZBK05852)





## **17. Residential Care: A Guide for Choosing a New Home**

Chicago, IL: Alzheimer's Association. 1998 [reprinted 2001]. 25 p.

Available from the Alzheimer's Association. 225 North Michigan Avenue, suite 1700. (800) 272-3900; (312) 335-8700; (312) 335-8882 (TDD); FAX (312) 335-1110; E-mail: [info@alz.org](mailto:info@alz.org). Website: [www.alz.org/resources/factsheets/guidenewhome.pdf](http://www.alz.org/resources/factsheets/guidenewhome.pdf). PRICE: free online access and free print copy. Order number: PF110Z.

This brochure is intended to educate caregivers about the types of residential care available for people with dementia, and to help them assess the quality of care provided in each one. The brochure opens with a description of the four major types of residential facilities: housing only; room, board, and minimal assistance; 24-hour care with skilled nursing services; and continuum-care retirement communities. A thorough evaluation of the patient's condition and special needs assists the caregiver in choosing a facility that provides the appropriate level of care. When selecting a home, caregivers should seek out specialized Alzheimer's disease and/or dementia programs, a well-trained and experienced staff, opportunities for family involvement, a stimulating activity program, and a safe and comfortable environment. A list of questions to discuss with staff of prospective facilities concludes the brochure. (AZBR07743)

## **Handling Financial and Legal Matters**

### **18. Age Page: Getting Your Affairs in Order**

Bethesda, MD: National Institute on Aging. June 2004. 1 p. (12 panels).

Available from the National Institute on Aging Information Center (NIAIC). P.O. Box 8057, Gaithersburg, MD 20898-8057. (800) 222-2225; (800) 222-4225 (TDD). Website: [www.niapublications.org/engagepages/affairs.asp](http://www.niapublications.org/engagepages/affairs.asp). PRICE: Free print copies and free online access.

This NIA fact sheet for patients, their families, and the general public provides practical information to aid aging people, their relatives and friends in planning for the future and managing their legal and financial affairs. Personal and legal records and documents to prepare are listed, and steps to take for future needs are given. The importance of establishing such files, especially if caregivers live far away, is discussed. Resources are listed that provide free legal and financial services to help older people and their families. (AZDC01116)

### **19. 10 Legal and Financial Issues Everyone Should Consider**

Reflections: Indiana Alzheimer Disease Center Newsletter. 9(1): 7-9. Winter 2002-2003.



Available from the Indiana Alzheimer Disease Center, Indiana University School of Medicine, 541 Clinical Drive, Suite CL 590, Indianapolis, IN 46202-5111.  
(317) 274-4939. E-mail: [smabbott@iupui.edu](mailto:smabbott@iupui.edu) .  
Website: <http://iadc.iupui.edu/htm/newsletter.htm> . PRICE: free.

This article from the Reflections newsletter of the Indiana Alzheimer Disease Center outlines 10 legal and financial issues people should consider as they age: (1) organizing and keeping important papers, (2) preparing health care advance directives, (3) designating a power of attorney, (4) estate planning, (5) reviewing and understanding health care insurance coverage, including Medicaid and Medicare, (6) pre-planning and possibly pre-paying the funeral, (7) reviewing property taxes, (8) planning for long-term care, (9) avoiding consumer scams, and (10) locating programs for seniors in need.(AZJA09508).

## **20. Medicare Advocacy Project.**

Chicago, IL: Alzheimer's Association. April 2002 (online version is current as of 2005).  
20 p.

Available from Alzheimer's Association. 225 North Michigan Avenue. Chicago, IL 60601-7633. (800) 272-3900 or (312) 335-8700. FAX: (312) 335-1110. E-mail: [info@alz.org](mailto:info@alz.org).  
Website: [www.alz.org/Resources/Medicare.asp](http://www.alz.org/Resources/Medicare.asp) . PRICE: free print copy and free online access to each of the Medicare resources listed.

This information kit contains several materials about Medicare benefits for people with Alzheimer's disease (AD) and their families. It includes the following papers and fact sheets: (1) a brief description of the Medicare Advocacy Project (a collaborative project of the Alzheimer's Association and the American Bar Association Commission on Legal Problems of the Elderly designed to respond to Medicare-related inquiries from local Alzheimer's Association chapters); (2) an outline of benefits under the original (fee for service) Medicare program; (3) recommended prescription drug benefit principles; (4) frequently asked questions about Medicare for people with AD; (5) frequently asked questions about Medicare's hospice benefit for people with AD; (6) what to do if Medicare refuses to pay for a medical service; and (7) a fact sheet about recent change affecting Medicare coverage. (AZDC09186).



## **End-of-Life Resources**

### **21. Living With Grief: Loss in Later Life**

Washington, DC: Hospice Foundation of America. 2002. 363 p.

Available from the Hospice Foundation of America. 1621 Connecticut Avenue, NW, Suite 300. Washington, DC 20009. (800) 854-3402; (202) 638-5419; FAX: (202) 638-5312; E-mail: [info@hospicefoundation.org](mailto:info@hospicefoundation.org) . Website: [www.hospicefoundation.org](http://www.hospicefoundation.org) . ISBN: 1893349039. PRICE: \$24.95, plus shipping fee.

This book explores how older people are affected by grief and loss. It features writings from renowned experts and professionals in the aging field as well as personal accounts of grief and loss from older individuals. Part 1 looks at death as a fact of older life. Part 2 addresses the fundamental losses and realities of growing old and dying. Part 3 discusses the many and particular losses experienced by older people, including the loss of a spouse, parent, and grandchild. It also examines the effects of loss on the survivor's health, suicide in older people, traumatic loss, cultural aspects of loss, and counseling strategies. One chapter focuses on the losses that accompany Alzheimer's disease (AD), the psychological impact of those losses, and the strategies caregivers can use to help the person with AD. Other chapters of special interest include one on the spectrum of long-term care options for older people and one on the concept of 'disenfranchised' or invalidated grief among older persons. Also available in VHS video and DVD formats. (AZBK09118)

### **22. Living With Grief: Alzheimer's Disease**

Washington, DC: Hospice Foundation of America. 2004. 290 p.

Available from the Hospice Foundation of America. 1621 Connecticut Avenue, Suite 300, N.W., Washington, DC 20009. Tel: (202) 638-5419; FAX: (202) 638-5312. E-mail: [info@hospicefoundation.org](mailto:info@hospicefoundation.org). Website: [www.hospicefoundation.org](http://www.hospicefoundation.org). PRICE: \$24.95 plus shipping fee. ISBN: 1893349055.

This book explains how hospice principles can improve care for patients with Alzheimer's disease (AD) and their families. Part 1 provides background information about AD and related dementias, including the impact of dementia on society, the biology of AD, promising therapies, dementias other than AD, cultural influences, and dementia in older adults with intellectual disabilities. Part 2 presents personal accounts of the experience of AD from both patients and family members. Part 3 is focused on helping patients and caregivers cope with loss in AD. It discusses the grief issues associated with the disease itself as well as the mourning that follows the death, grief counseling for people with cognitive impairment, assessing grief in family caregivers, caregiving styles, and spiritual issues. Part 4 looks at the future of dementia care, including the challenges of providing hospice care in dementia, barriers in the Medicare hospice benefit, ethical issues in end-of-life care, quality-of-life concepts in AD, and resources for



family members and caregivers. Also available in VHS video and DVD format. (AZBK09535)

### **23. Autopsy: A Lasting Gift for Your Family**

Chicago, IL: Alzheimer's Association. 1996. 1 page (8 panels).

Available from the Alzheimer's Association. 919 North Michigan Avenue, Suite 1000, Chicago, IL 60611-1676. (800) 272-3900; (312) 335-8700; (312) 335-8882 (TDD); FAX (312) 335-1110. E-mail: [info@alz.org](mailto:info@alz.org). Website: [www.alz.org](http://www.alz.org). PRICE: Free print copy. Order Number: PF209Z.

This brochure is intended to help people with Alzheimer's disease (AD) and their families decide whether to have a brain autopsy done. It explains the purpose of a brain autopsy in AD and its potential benefits to the family. It discusses factors such as religious considerations, the effect of an autopsy on funeral arrangements, costs of an autopsy, and organ donation by people with AD. It further outlines steps to take in arranging an autopsy before the person with AD dies: locate a pathologist to conduct the autopsy; make arrangements with the pathologist; make transportation arrangements, if necessary; make sure everyone involved knows an autopsy is to be done; and periodically confirm the arrangements. The brochure also explains how the family may help with AD research by requesting that the physician list AD as the underlying cause of death on the AD patient's death certificate, and by donating brain tissue for research. (AZBR06318)

### **24. Palliative Care: Complete Care Everyone Deserves**

Bethesda, MD: National Alliance for Caregiving. 2003. 14 p.

Available from the National Alliance for Caregiving. 4720 Montgomery Lane, Bethesda, MD 20814. (301) 718-8444. E-mail: [info@caregiving.org](mailto:info@caregiving.org). Website: [www.caregiving.org](http://www.caregiving.org). PRICE: free online access and free print format for 1 to 10 copies; over 10 copies, pay postage.

This brochure discusses palliative care for people with advanced illnesses, including those with Alzheimer's disease and other types of dementia. First, it explains the purpose and characteristics of palliative care. Then, it describes the elements of good palliative care, including advance care planning, care coordination, pain management, psychological counseling, spiritual help, and flexibility. Finally, it suggests strategies for getting palliative care and working with nursing homes and other long term care facilities. The brochure includes case examples of the types of patients who could benefit from palliative care and a list of resources. (AZBR09363).

### **25. Steps to Caring for a Person with Late-Stage Alzheimer's Disease: Responding to the Individual's Increasing Needs**



Chicago, IL: Alzheimer's Association. 2000. 15 p.

Available from Alzheimer's Association. 225 North Michigan Avenue, Suite 1700, Chicago, IL 60601. (800) 272-3900. FAX: (312) 335-1110. PRICE: Single copy free, \$10 for 50 copies. E-mail: [info@alz.org](mailto:info@alz.org). Website: [www.alz.org](http://www.alz.org). Item number: ED486Z.

This brochure is designed to help families care for a loved one in the late stage of Alzheimer's disease (AD). It offers practical suggestions for encouraging food and liquid intake, maintaining a healthy skin and body, maintaining bladder and bowel function, decreasing the risk of infections and pneumonia, recognizing pain or illness, staying connected to the person with AD, and deciding to move the loved one to a long-term care facility. It concludes with general tips for caring for a person with late-stage AD and a list of educational resources. (AZBR08967).

## 26. Talking About Death

Chapel Hill, NC: Algonquin Books of Chapel Hill. 2004. 292 p.

Available from Workman Publishing. 708 Broadway, New York, NY 10003-9555. (800) 722-7202, (212) 254-5900. Website: [www.workman.com](http://www.workman.com). PRICE: \$14.95. ISBN: 1565124375.

This book combines personal stories with practical advice for families and individuals on how to communicate with and provide support to a loved one facing death. The author discusses ways for the patient and family to overcome cultural and personal barriers to openly discuss and prepare for death, such as staying informed about the prognosis, pain relief and palliative care. The book addresses the needs of a patient facing death to speak openly about emotional and spiritual feelings and the needs of the health care provider, whether at home or a hospital or nursing home, to make the patient and family aware of the nearness of death to allow them to express their last wishes. The book also provides practical subjects that need to be discussed among family members to better plan for death, such as personal finances, how to take care of the children's feelings and needs, business matters, legal documents, funeral and burial arrangements, or any organ donation. Other issues that need to be discussed are given, such as what kinds of medical treatment to use or withdraw, who should make the decision for such treatment, and what is involved in life support procedures, palliative care, pain medications, and ways to improve the doctor-patient-family relation in end-of-life care. (AZBK09843).

**For more information, contact the ADEAR Center:**

**Phone:** 1-800-438-4380

**Web:** [www.alzheimers.org](http://www.alzheimers.org)

**E-mail:** [adear@alzheimers.org](mailto:adear@alzheimers.org)

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