

Resources for Caregivers

2007

MetLife[®]



MetLife Mature Market Institute[®]
and
National Alliance for Caregiving
in cooperation with the
National Association of Area Agencies on Aging



As a caregiver, you are not alone. Approximately 22.9 million households provide unpaid care to an adult family member or friend who is age 18 and older.¹ On average, caregivers provide 21 hours of care per week.² This “free” care, however, is not without cost; many family caregivers feel isolated, stressed by balancing work, family, and caregiving, and perhaps even depressed. The value of family caregiving to society has been estimated to be \$306 billion annually.³

Nearly 60% of those caring for an adult over age 50 are working, the majority of them full time.⁴ In the past, responsibilities for caregiving almost exclusively belonged to women, but currently about 39% of caregivers are men.⁵

Resources for Caregivers was prepared by the National Alliance for Caregiving and the MetLife Mature Market Institute, in cooperation with the National Association of Area Agencies on Aging (n4a), to help individuals and families who have assumed the role of caregiver or anticipate future caregiving. This brochure should be viewed as a starting point in your pursuit of resources. It provides mailing addresses, phone numbers and Internet addresses of national associations and organizations, plus an annotated list of caregiver-related books, videos and Web sites. Retail prices of books, tapes and videos are listed. The items in this guide are generally available at any bookstore. Other materials can be ordered using the addresses listed in the guide.

This guide was revised in 12/06. All information is time-sensitive and subject to change.

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Resources for Caregivers

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CAREGIVER SERVICES AND SUPPORT

BOOKS AND GUIDES

AARP Publications

- Assisted Living: Weighing the Options (D17051)
- Choosing Good Care: A Family Guide to Finding a Nursing Home (D17064)
- Getting By With a Little Help: Community Services to Meet Changing Needs (D17046)
- Navigating Your Way to a Quality Assisted Living Facility (D17037)

Single copies of these booklets for caregivers and their families are free from:

AARP Fulfillment
601 E Street, NW
Washington, DC 20049

Include the publication title and stock number and your postal mailing address. You may also call them toll free at 1-888-OUR-AARP or 1-888-687-2277 to request these publications.

Nearly two-thirds of caregivers are employed full or part-time.⁶

Always On Call: When Illness Turns Families Into Caregivers

This book is a compilation of chapters from 12 authors—caregivers, advocates and health care professionals—that aims to advance the understanding of family caregiving and enhance advocacy measures. It contains personal narratives and a resource guide and addresses work, family and insurance issues.

Levine, C. (2004)
United Hospital Fund of New York City
ISBN: 0826514618
Suggested retail price is \$24.95.

Caring for Your Parents: The Complete AARP Guide

This book discusses innovative ways that others have approached caregiving issues and concerns. It explores a variety of caregiving topics, includes many helpful tips and contains a listing of resources related to each chapter.



Delahanty, H., Ginzler, E. and Pipher, M. (2005)
AARP
ISBN: 1402717393
Suggested retail price is \$19.95.

***Caring for Yourself While Caring for Your Aging Parents:
How to Help, How to Survive, 3rd Edition***

This book contains information and tips from other caregivers. It explores a variety of topics including long-distance caregiving, financial issues and addressing the needs of caregivers.

Berman, C. (2006)
Owl Press
ISBN: 0805079750
Suggested retail price is \$22.00.

***Give yourself credit for the things you do well
and be realistic about what may
or may not be possible.⁷***

The Eldercare 911 Question and Answer Book

This book, written in a question and answer format, discusses a variety of eldercare issues. It gives answers to questions other caregivers have asked and looks at the roles of both men and women as caregivers. It explores the impact of caregiving and provides guidance to caregivers to help them cope with many of the issues they may be facing. The book also contains helpful checklists and a listing of resources for caregivers.

Beerman, S. and Rappaport-Musson, J. (2005)
Prometheus Books
ISBN: 1591022932
Suggested Retail Price is \$20.00.

How to Care for Aging Parents

A compassionate, single-volume reference to the many topics associated with caring for aging parents. It covers such areas as nursing homes, finances, finding a good doctor, legal arrangements, redefining parental relationships and handling emotional issues.

Morris, V. (2004)
Workman Publishing Company
ISBN: 0761134263
Suggested retail price is \$18.95.



Love, Honor & Value

This book, written by Suzanne Mintz, the President and Co-Founder of the National Family Caregivers Association, relates her own experiences as a family caregiver and discusses the physical, emotional and financial effects of caregiving on the entire family. The book contains a chapter devoted to resources that can help with caregiving, finances, and family issues and also offers short tip sheets on caregiving-related considerations, such as selecting home care, a nursing home or health care, tax issues and wills.

Mintz, S. (2002)

Capital Books Inc.

ISBN: 1892123568

Suggested retail price is \$14.95.

Palliative Care: Complete Care Everyone Deserves

This 16-page booklet is produced by the National Alliance for Caregiving (NAC) and Friends and Relatives of Institutionalized Aged (FRIA) of New York. It provides an easy-to-understand definition of palliative care, and descriptions of who can benefit from palliative care, the elements of good palliative care, advice on how to obtain such care and a list of related resources. A free copy of the booklet may be obtained by sending an e-mail to info@caregiving.org.

The booklet may also be downloaded at no cost from NAC's website, www.caregiving.org/care.pdf and FRIA's website at www.fria.org.

The Comfort of Home™: A Complete Guide for Caregivers – 3rd Edition

A guide that starts with the basics and contains information that caregivers can use at all stages of caregiving. It helps caregivers learn how to make the home safe and comfortable and handle everyday activities like toileting, bathing and wheelchair transfers.

Meyer, M.M. and Derr, P. (2007)

CareTrust Publications, LLC

ISBN: 0966476794

Suggested retail price is \$24.95.

The most frequently reported unmet need of caregivers is finding time for themselves (35%).⁸



Helping Yourself Help Others: A Book for Caregivers

This book by former First Lady Rosalynn Carter addresses the social issues that have created what she calls a “caregiving crisis.” Practical solutions are offered to the problems caregivers typically experience, such as isolation, burnout, anger and helplessness.

Carter, R. (1995)

Random House

ISBN: 0812925912

Suggested retail price is \$14.00.

Since You Care

The MetLife Mature Market Institute, in cooperation with the National Alliance for Caregiving, has produced an ongoing series of guides that provide practical suggestions and useful tools on a variety of specific care-related subjects.

Currently available are: *Alzheimer’s Disease – Caregiving Challenges, Becoming an Effective Advocate for Care, Choosing an Assisted Living Facility, Community Services, Falls and Fall Prevention, Family Caregiving, Final Arrangements, Hiring an Independent Caregiver, Hospice Care, Legal Matters, Long Distance Caregiving, Making the Nursing Home Choice, Medicare and Medicaid Programs – The Basics, Medications and the Older Adult, Preventing Elder Abuse, and Understanding Home Care Agency Options.*

The guides can be downloaded and printed at

www.maturemarketinstitute.com. Hard copies of the

guides may be obtained by writing to:

maturemarketinstitute@metlife.com

or to:

MetLife Mature Market Institute

57 Greens Farms Road

Westport, CT 06880



‘Thou Shalt Honor...The Caregiver’s Companion

This is a comprehensive book that contains resources, checklists, and medical and support information that can help individuals who are caring for family members or who foresee the need for care in the future. The book includes personal stories from caregivers that reveal the emotional aspect of providing care for a loved one. It is a companion to a DVD of the two-hour PBS original broadcast entitled *‘Thou Shalt Honor*.

McLeod, B. W. (2005)

Diane Publishing Company

ISBN: 0756785618

Suggested retail price is \$16.00.

INTERNET SITES

Family Care Resource Connection

At the Family Care Resource Connection, family caregivers can search a database of over 1,000 items by topic or key word and find an abstract, a rating and ordering information for each item. The materials are submitted by non-profit organizations, caregiver advocacy groups, disease-specific groups, government agencies and for-profit companies.

Go to www.caregiving.org/tips/, click on “Family Care Resource Connection.”

One third (35%) of caregivers say they experience emotional stress⁹

Family Caregiving 101

This is an educational website for caregivers which is co-sponsored by the National Alliance for Caregiving and the National Family of Caregivers Association with support from Eisai Inc. It provides assistance and information for family caregivers on a variety of issues related to caregiving as well as resources for locating needed services.

www.familycaregiving101.org



Health Compass

Health Compass, developed by the American Federation for Aging Research and the Merck Institute of Aging & Health, offers older adults and their caregivers a way to search and evaluate health information on the Web in order to make informed healthcare decisions. A section on improving communication with medical personnel is also included.

www.healthcompass.org

Strength for Caring

This award-winning website provides a wealth of information for caregivers on topics such as financial planning, legal issues, insurance and daily care. It includes links to other caregiver websites and the ability to download and print caregiving brochures from a variety of organizations. Caregivers will also find helpful worksheets and tips including a “Doctor’s Office Visit Checklist” from the National Family Caregivers Association. In addition, the website has a listing of statewide and local caregiving and healthcare resources as well as support information for each of the 50 states. www.strengthforcaring.com

ASSOCIATIONS AND ORGANIZATIONS

AARP

601 E Street, NW

Washington, DC 20049

Toll free: 888-687-2277 TTY: 877-434-7598

AARP is a nonprofit organization that offers educational programs, services and support for adults age 50 and older. The AARP website contains an extensive caregiver section that provides information on caregiver support, long-term care, home care and housing. Publications are available online and can also be mailed free upon request. Access their website at www.aarp.org/families/caregiving.



American Association of Homes and Services for the Aging (AAHSA)

2519 Connecticut Ave., NW

Washington, DC 20008

Telephone: 202-783-2242 Fax: 202-783-2255

The American Association of Homes and Services for the Aging represents nonprofit nursing homes, assisted living residences, senior housing and community service organizations for older adults. It offers free publications on selecting housing and care options and provides lists of accredited care communities, as well as information on contacting individual state associations of AAHSA.

www.aahsa.org

Assisted living residences may have as few as three or four rooms or as many as 200. Most have between 25-125 units.¹⁰

Assisted Living Federation of America (ALFA)

1650 King Street, Suite 602

Alexandria, VA 22314

Telephone: 703-894-1805 Fax 703-894-1831

The Assisted Living Federation of America is a trade association that represents the assisted living industry. ALFA provides information and education to consumers, industry partners and researchers. Its website provides an online directory of homes and services by city and state. E-mail: info@alfa.org. www.alfa.org



Children of Aging Parents (CAPS)

P.O. Box 167

Richboro, PA 18954

Toll free: 800-227-7294

Fax: 215-945-8720

CAPS is the country's oldest information resource helping adult children understand the needs and concerns of both the parent and the adult child. Extensive national information resource files and publications on a variety of caregiver issues are available. CAPS is a membership organization with approximately 2,200 members across the United States. Members receive a newsletter and can obtain information from the website. Support groups are available in some areas of the country.

www.caps4caregivers.org

Family Caregiver Alliance

180 Montgomery Street, Suite 1100

San Francisco, CA 94104

Toll free: 800-445-8106

The Family Caregiver Alliance is a comprehensive support organization for caregivers. Its website offers research, publications, statistics, fact sheets, public policy news and information on a variety of long-term care concerns. It also offers an online support group in a listserv (e-mail) format. E-mail: info@caregiver.org. www.caregiver.org

“I don't know what I would do without the adult day care center. My mother is busy during the day and I get a break. It helps me keep going.”¹¹

National Adult Day Services Association (NADSA)

2519 Connecticut Avenue NW

Washington, DC 20008

Toll free: 1-800-558-5301 Fax: 1-202-783-2255

NADSA is a 20-year-old organization that serves as the national voice for adult day service providers. You can search the NADSA website for adult day services in your area. The site also includes a guide to selecting an adult day center.

E-mail: info@nadsa.org. www.nadsa.org



National Alliance for Caregiving (NAC)

4720 Montgomery Lane

5th Floor

Bethesda, MD 20814

E-mail: info@caregiving.org

The National Alliance for Caregiving website contains research on caregiving as well as practical assistance for caregivers including a guide to hospital discharge planning, a guide for caring for aging parents and a guide specific to palliative care. www.caregiving.org

National Association of Area Agencies on Aging (n4a)

1730 Rhode Island Avenue, NW, Suite 1200

Washington, DC 20036

Telephone: 202-872-0888 Fax 202-872-0057

The National Association of Area Agencies on Aging (n4a) is the umbrella organization for our nation's 655 area agencies on aging (AAAs) and the representative body in Washington, DC, for the interests of 240 Title VI - Native American aging programs. Through its presence in Washington, n4a advocates on behalf of the local aging agencies to ensure that needed resources and support services are available to older Americans and their caregivers. www.n4a.org

National Association for Home Care and Hospice (NAHC)

228 Seventh Street, SE

Washington, DC 20003

Telephone: 202-547-7424 Fax: 202-547-3540

The National Association for Home Care and Hospice is a trade association that represents the interests of home care agencies, hospices and home care aide organizations. Membership in the association is offered at six different levels, from agencies to individuals. Members receive the latest news on the NAHC Member Network listserv, weekly news in the NAHC Report and a monthly magazine, *Caring*, as well as other services. NAHC's website has a consumer section devoted to choosing a home care provider. www.nahc.org



Sometimes an individual's ability to remain in their own home, which helps them preserve self-sufficiency and dignity, may be achieved with services that are basic but can make a big difference to the older adult.¹²

National Association of Professional Geriatric Care Managers

1604 North Country Club Road
Tucson, AZ 85716-3102

Telephone: 520-881-8008 Fax: 520-325-7925

Geriatric care managers assist families and older adults in coordinating and managing long-term care plans and arrangements. They can help with long-distance caregiving, crisis intervention, counseling and support and other tasks. Many are trained in therapy or daily money management. There is a searchable database of care managers available by state. The National Association of Professional Geriatric Care Managers is a non-profit organization of geriatric care managers.

www.caremanager.org

National Family Caregivers Association (NFCA)

10400 Connecticut Avenue, Suite 500
Kensington, MD 20895-3944

Toll free: 800-896-3650 Fax: 301-942-2302

The National Family Caregivers Association is a non-profit organization dedicated to providing support and assistance to caregivers through information, education, public awareness and advocacy. NFCA offers caregiving tips, caregiver advocacy updates and resources online. A quarterly newsletter called *Take Care! Self-Care for the Family Caregiver*, a support network and resource guides are available online for members. Membership is open to individuals as well as corporations and ranges from \$20 to \$200 annually, and is free for family caregivers. E-mail: info@nfcacares.org. www.nfcacares.org



The Well Spouse Association

63 West Main Street, Suite H

Freehold, NJ 07728

Toll free: 800-838-0879 Fax: 732-577-8644

The Well Spouse Association is a national, nonprofit membership organization that gives support to wives, husbands and partners of people with chronic illnesses and/or disabilities. They provide a bimonthly newsletter, *Mainstay*, mutual aid support groups in many areas, letter writing support groups, an annual conference and other regional and weekend meetings around the country. The organization also works to make health care professionals and the general public aware of the great difficulties caregivers face everyday.

E-mail: info@wellspouse.org

www.wellspouse.org

“When they asked me at the adult day care center to come to this meeting, I didn’t know why. I don’t consider myself a caregiver. I take care of my wife.”¹³

VIDEO AND AUDIO RESOURCES

Aging Parents: The Family Survival Guide

The Family Survival Guide examines many caregiving situations and offers the viewer advice and information on long-term care planning as well as support. It includes two videos (3 1/2 hours total), 180-page action guide, medical, legal and insurance forms, referrals and references.

Lifetapes Communications.

Suggested retail price is \$18.00.

To order visit www.agingparents.com.



Aging Parents: Planning for the Future

This video offers insights from several families who have experienced the aging of their parents. It includes practical suggestions on identifying the changes that the family will experience and how to respond to them in a manner that is beneficial to everyone.

Lifetapes Communications.

Suggested retail price is \$24.95.

To order visit www.agingparents.com.

The Educated Caregiver™

This three-video series offers an encyclopedia of information, an instruction guide and a video support group. The Educated Caregiver is formatted to accommodate the time constraints that caregivers face. Information is arranged in concise sections. All three videos can be purchased for \$49.95 or separately for \$24.95 each. To order, contact:

LifeView Resources

PO Box 290787

Nashville, TN 37229-0787

Toll free: 800-395-LIFE (800-395-5433)

Fax: 615-781-9692

E-mail: info@lifeviewresources.com

www.lifeviewresources.com

***Stay involved and visible in your family member's life.
Speak up for what you feel is important and don't be
afraid to reassess the situation and make changes
if you feel they are appropriate.¹⁴***



The Family Guide to Long-Term Care®

This is a six-video set that discusses the many aspects of long-term care: assessing the need for care, evaluating residential options, how to monitor your family member's care, understanding long-term care insurance, legal issues and financial planning. All six videos can be purchased for \$124.95, or separately for \$24.95 each.

To order, contact:

LifeView Resources

PO Box 290787

Nashville, TN 37229-0787

Toll free: 800-395-LIFE (800-395-5433)

Fax: 615-781-9692

E-mail: info@lifeviewresources.com

www.lifeviewresources.com

Hardship into Hope – The Rewards of Caregiving

This audiotape, produced by NPR reporter Connie Goldman, contains interviews with former First Lady Rosalynn Carter, Dana Reeve and others who talk about their caregiving experiences and rewards. Suggested retail price is \$12.00, including shipping and handling. Specify Hardship into Hope and make check payable to:

Connie Goldman Productions

217 West Canyon Drive

Hudson, WI 54016

Telephone: 715-531-0390 Fax: 715-531-0391

E-mail: congoldman@aol.com www.congoldman.org

When Your Parent Needs You: A Guide to Positive Growth When Caring for Aging Parents

This DVD features two caregiving and aging specialists, Beth Witrogen McLeod and Avrene Brandt, who address the challenges and issues facing adult children who provide care for their older parents. It discusses practical matters such as balancing work and personal life and underscores the fact that parent and child can experience personal growth and healing during the caregiving years.

The retail price is \$29.95.

Paraclete Press (2002)

ISBN: 1557252777

To place an online order, go to www.ParacletePress.com

or call toll free: 800-451-5006 for more information.



CARING FOR LOVED ONES WITH...

AIDS

BOOKS AND GUIDES

Sometimes My Heart Goes Numb: Love and Caregiving in a Time of AIDS (2003)

This book provides profiles of 20 caregivers, caring for a loved one with AIDS, and looks at the challenges they faced. It also explores caring for the caregiver and provides guidance for a caregivers related to setting limits, avoiding burnout and grappling with issues of life and death when caring for someone with HIV/AIDS.

Garfield, C. and Spring, C. (2003)

Harvest Books

ISBN: 015600495X

Suggested retail price is \$17.00.

INTERNET SITES

AIDS–HIV Resource Center at HealingWell.com

This site offers book lists, discussion groups and access to current information on research and treatments.

www.healingwell.com/AIDS/

AIDSinfo

Among other services, AIDSinfo provides a comprehensive glossary of terms used in the origin and development of the disease, associated treatments and medical management of HIV and related conditions.

There is also an extensive listing of other federal resource organizations that provide services such as hot line education and information, clinical trials, a document database and telephone consultation. www.aidsinfo.nih.gov

ASSOCIATIONS AND ORGANIZATIONS

National Association of People With AIDS (NAPWA)

Founded in 1983, the National Association of People with AIDS is a non-profit membership organization that advocates on behalf of all people living with HIV and AIDS in order to end the pandemic and the human suffering caused by HIV/AIDS. It is the oldest national AIDS organization in the United States and the oldest national network of people living with HIV/AIDS in the world. www.napwa.org



ALS

BOOKS AND GUIDES

Amyotrophic Lateral Sclerosis: A Guide for Patients and Families, 2nd Edition

This guide features discussions related to features of the disease, diagnosis, patient care, financial resources and the role of support groups. Additional sections deal with hospice care, life support systems and the legal, ethical, psychosocial and spiritual aspects of dealing with the disease.

Mitsumoto, H., Munsat, T.L. (2001)

Demos Medical Publishing

ISBN: 1888799285

Suggested retail price is \$39.95.

Living with ALS Manuals®

The ALS Association offers a series of six manuals to assist individuals with ALS and the families who care for them. They address many of the concerns and issues families living with ALS face. They can be downloaded and printed from the website at www.alsa.org and going to the “Patient, Family, Caregivers” section. They are also available in printed booklets, VHS video and DVD and can be ordered through the website using their library order form or by calling toll free at 800-782-4747.

ASSOCIATIONS AND ORGANIZATIONS

ALS Association

27001 Agoura Road, Suite 150

Calabasas Hills, CA 91301

Information & Referral Service:

Toll free: 800-782-4747

The ALS Association (ALSA) is a non-profit agency that provides education, advocacy and information about amyotrophic lateral sclerosis (Lou Gehrig’s disease) to patients, families, caregivers, researchers and health care professionals. The website allows a search for local ALSA chapters and contains a wealth of information for caregivers. ALSA’s National Office telephone information and referral service is available Monday through Friday from 7:30 a.m. to 4:00 p.m. pacific time. Family caregivers can call for information on a wide variety of issues including where to get products and assistance, insurance questions, physician



resources or to talk with someone about their caregiving responsibilities and how to cope. Most local ALSA chapters loan a range of equipment to ALS families and provide respite programs for family caregivers.

E-mail: alsinfo@alsa-national.org. www.alsa.org

ALZHEIMER'S DISEASE

BOOKS AND GUIDES

The 36-Hour Day: Family Guide to Caring for Persons with Alzheimer's Disease and Other Dementias and Memory Loss in Later Life, 4th Edition

A guide designed for people who are caring for individuals with Alzheimer's disease at home. Topics include medical, legal, emotional and financial issues related to caregiving.

Mace, N.L. and Rabins, P.V. (2006)

Warner Books

ISBN: 0446618764

Suggested retail price is \$9.99.

The Loss of Self: A Family Resource for the Care of Alzheimer's Disease and Related Disorders, Revised Edition

This book explores all aspects of Alzheimer's disease for patients, families, caregivers and professionals. The authors discuss medical, social and financial issues, and also recognize the emotions of patients and family members using case studies and personal stories. The authors are recognized internationally as leading Alzheimer's researchers.

Cohen, D. and Eisdorfer, C. (2002)

Norton, W.W. & Company, Inc.

ISBN: 0393323331

Suggested retail price is \$16.95.

INTERNET SITES

Alzheimer's Disease.com

Sponsored by Novartis and the Mayo Clinic, this site is an online resource for information about Alzheimer's disease. It contains *Caregiver's Corner*, a monthly column designed to address caregiving issues, and includes a link to the Alzheimer's Resource Center at the Mayo Clinic.

www.alzheimersdisease.com



ALZwell - Alzheimer's Caregiver Page

This site provides categorized book recommendations, caregiver stories, information related to a variety of topics including care options and legal and financial matters and news updates related to Alzheimer's disease. Additionally, caregivers can search for resources within their state.

www.alzwell.com

ASSOCIATIONS AND ORGANIZATIONS

Alzheimer's Association

225 North Michigan Avenue

17th Floor

Chicago, IL 60601

Toll free: 800-272-3900

The Alzheimer's Association provides resources for families and caregivers of those suffering from Alzheimer's disease. It also supports research efforts and provides information on advocacy, conferences and programs. A database of local chapters is searchable by zip code. E-mail: Info@alz.org

www.alz.org

A study done by the Alzheimer's Association reported that Alzheimer's disease costs businesses \$61 billion annually in terms of caregivers' time, loss of productivity and medical expenses.¹⁵

Alzheimer's Disease Education and Referral Center (ADEAR)

ADEAR provides research, information, publications and a clinical trials database. It is a service of the National Institute on Aging, one of the National Institutes of Health. The site features links to Federal resources and includes a consumer publication *Understanding Alzheimer's Disease* which can be downloaded and printed from the website at www.nia.nih.gov/alzheimers or ordered by calling 1-800-438-4380. Information specialists at the toll free number can also answer questions about Alzheimer's disease and provide referrals to local support services.



Alzheimer's Foundation of America (AFA)

322 8th Avenue, 6th Floor

New York, NY 10001

Toll free: 866-AFA-8484 (866-232-8484)

AFA is a national organization which offers information about brain health, Alzheimer's disease and other forms of dementia as well as tips for caregivers. The AFA is staffed by certified social workers and other professionals knowledgeable about Alzheimer's disease and other similar disorders. It is available to assist with questions caregivers may have as well as to provide information about local resources to assist individuals with Alzheimer's disease and their families. www.alzfdn.org

CANCER

BOOKS AND GUIDES

Facing Cancer: A Complete Guide for People with Cancer, Their Families and Caregivers

This book provides pertinent information related to cancer and its treatment in a question and answer format. Written by physicians from the fields of oncology and psychiatry it combines medical information with a caring approach to dealing with the emotional impact of the disease. It provides guidance on available resources and advice on coping with the illness.

Stern, T. and Sekeres, M.A. (2003)

McGraw-Hill Professional Publishing

ISBN: 0071414916

Suggested Retail Price is \$19.95.



INTERNET SITES

Cancer Survival Toolbox:

An Online Audio Resource Program

This is a free online audio program that will help cancer survivors and their caregivers cope with the challenges of cancer, including diagnosis and treatments. Transcripts of this program and other downloadable materials are available on the site.

National Coalition for Cancer Survivorship

1010 Wayne Avenue, Suite 770

Silver Spring, MD 20910-5600

E-mail: info@canceradvocacy.org

www.canceradvocacy.org

ASSOCIATIONS AND ORGANIZATIONS

American Cancer Society

1599 Clifton Road, NE

Atlanta, GA, 30329

Toll free: 800-ACS-2345 (800-232-2345)

The American Cancer Society offers an array of cancer-related information and sponsors a wide range of services for cancer patients and their families, including self-help groups, transportation programs and limited financial aid. Additional resources can be found on its website,

www.cancer.org.

CancerCare

275 7th Avenue

Floor 22

New York, NY 10001

Toll free: 800-813-HOPE (800-813-4673)

CancerCare is a national non-profit organization whose mission is to provide free professional help to people with all cancers through counseling, education, information and referral and direct financial assistance. CancerCare's services include a toll free counseling line, telephone education workshops and regularly scheduled online educational chat sessions. www.cancercare.org



The National Cancer Institute

NCI Public Inquiries Office

6116 Executive Boulevard

Room 3036A

Bethesda, MD 20892-8322

Toll free: 800-4-CANCER (800-422-6237)

The National Cancer Institute coordinates the National Cancer Program, which conducts and supports research, training and health information dissemination with other programs related to the cause, diagnosis, prevention and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients. www.cancer.gov

The National Cancer Institute (NCI) has developed the following three caregiver publications based on focus groups from caregivers with loved ones in treatment and post-treatment, as well as those who had recently lost someone. The booklets focus on the caregiver, not how to take care of the patient. Although specific to cancer, the information translates for any disease or condition. The publications can be downloaded in PDF from the web or ordered by calling 1-800-4-CANCER. The publications are free.

When Someone You Love Is Being Treated for Cancer

www.cancer.gov/cancertopics/When-Someone-You-Love-Is-Treated

When Someone You Love Has Advanced Cancer: Support for Caregivers

www.cancer.gov/cancertopics/When-Someone-You-Love-Has-Advanced-Cancer

Facing Forward: When Someone You Love Has Completed Cancer Treatment

www.cancer.gov/cancertopics/Facing-Forward-When-Someone-You-Love-Has-Completed-Cancer-Treatment



CEREBRAL PALSY

BOOKS AND GUIDES

Cerebral Palsy: A Complete Guide for Caregiving, 2nd Edition

Written by a team of experts associated with the Cerebral Palsy Program at the Alfred I. duPont Institute, this book addresses the complexities and uncertainties of cerebral palsy and provides helpful information about the condition. It is a comprehensive resource for caregivers and health professionals, as well as adolescents and adults with cerebral palsy.

Miller, F. and Bachrach, S.J. (2006)

Johns Hopkins University Press

ISBN: 0801883555

Suggested retail price is \$18.95.

Children With Cerebral Palsy: A Parents' Guide, 2nd Edition

This guide offers chapters on subjects such as the definition of the disease, what to expect as a child with cerebral palsy grows, the legal rights of individuals with disabilities and how to be an advocate for individuals with disabilities. The book also includes a resource guide, a reading list and a list of special equipment suppliers.

Geralis, E. (Editor) (2003)

Woodbine House

ISBN: 0933149824

Suggested retail price is \$18.95.

ASSOCIATIONS AND ORGANIZATIONS

United Cerebral Palsy (UCP)

1660 L Street, NW, Suite 700

Washington, DC 20036

Toll free: 800-872-5827

Fax: 202-776-0414

TTY: 202-973-7197

United Cerebral Palsy's national office serves people with disabilities and others through programs, an information and referral service, legislative advocacy, technology initiatives and research. The site includes a UCP One-Stop Resource Guide for each state.

E-mail: ucpnatl@ucp.org

www.ucp.org



DIABETES

BOOKS AND GUIDES

Diabetes Mellitus: A Practical Handbook

This book focus on everyday concerns related to diabetes including diet, medication and exercise to promote optimal health. Now in its 9th edition this guide includes charts, tables and worksheets to help in managing the disease.

Dunn-Long, B. and Milchovich, S.K. (2006)

Bull Publishing Company

ISBN: 1933503076

Suggested retail price is \$14.95.

American Diabetes Association Complete Guide to Diabetes, 4th Edition

This clearly written book encourages diabetics “to mesh the day-to-day management of diabetes” into the routine of their lives. It has been revised to provide the information people need to live active, healthy lives with diabetes. Chapters move from “What Is Diabetes?” (with discussion of causes and effects of Type I, Type II and gestational diabetes) to a glossary, an appendix on self-monitoring and injection techniques and a list of resources and organizations.

American Diabetes Association (2005)

ISBN: 1580402372

Suggested retail price is \$29.95.

ASSOCIATIONS AND ORGANIZATIONS

American Diabetes Association

1701 North Beauregard Street

Alexandria, VA 22311

Toll free: 800-DIABETES (800-342-2383)

The American Diabetes Association provides news, information and research findings on diabetes to patients, families, caregivers and health care professionals. A database of local chapters is searchable by zip code.

E-mail: askada@diabetes.org. www.diabetes.org



HEART DISEASE

ASSOCIATIONS AND ORGANIZATIONS

American Heart Association

National Center

7272 Greenville Avenue

Dallas, TX 75231

Toll free: 800-AHA-USA1 (800-242-8721)

The American Heart Association provides information on fighting heart disease and stroke. Its website features a section on heart related conditions such as heart failure and a support section for caregivers.

www.americanheart.org

MENTAL ILLNESS

BOOKS AND GUIDES

What Every Patient, Family, Friend, and Caregiver Needs to Know About Psychiatry, 2nd Edition

This layperson's guide contains information on the gamut of adult psychiatric disorders. It is written for patients and caregivers including family, friends and professionals.

Roukema, R.W. (2003)

American Psychiatric Publishing, Incorporated

ISBN: 1585621102

Suggested retail price is \$20.95.



ASSOCIATIONS AND ORGANIZATIONS

Mental Health America

2000 N. Beauregard Street, 6th floor

Alexandria, VA 22311

Toll free: 800-969-6642

TTY: 800-433-5959 Fax: 703-684-5968

Mental Health America, formerly known as the National Mental Health Association, is a nonprofit organization with 320 affiliates throughout the country dedicated to helping all people lead mentally healthier lives. The website includes FAQs, a section related to specific mental disorders and their treatment and facts about medications used to treat mental illness. The site also includes a “Help” section which provides individuals and their caregivers with information about various treatment options and support groups and allows them to search for local resources including MHA affiliates and mental health professionals. www.mentalhealthamerica.net

MULTIPLE SCLEROSIS

BOOKS AND GUIDES

Multiple Sclerosis: A Guide for Families, 3rd Edition

This book provides information, advice and resources for families dealing with the issues that accompany Multiple Sclerosis. This third edition contains a new chapter entitled “Planning for Possible Care Needs.” The book draws on information from specialists as well as individuals living with the disease. It includes resources and additional readings related to each chapter.

Kalb, R. (2005)

Demos Medical Publishing

ISBN: 1932603107

Suggested retail price is \$24.95.



ASSOCIATIONS AND ORGANIZATIONS

The National Multiple Sclerosis (MS) Society

733 Third Avenue

New York, NY 10017

Toll free: 800-Fight-MS (800-344-4867)

The National Multiple Sclerosis Society provides advocacy, research and information about living with MS and a list of local resources. A database of local chapters is searchable by zip code. E-mail: info@nmss.org. www.nmss.org

PARKINSON'S DISEASE

BOOKS AND GUIDES

The Comfort of Home™ for Parkinson Disease: A Guide for Caregivers

This guide is intended to help caregivers, family members and individuals with Parkinson's disease understand the issues that confront those with the illness and their families. It focuses on the practical aspects of caregiving and includes tips for both caregivers and individuals who have Parkinson's disease.

Meyer, M.M., Derr, P., and Imke, S.C. (2007)

CareTrust Publications, LLC

ISBN: 0966476778

Suggested Retail Price is \$24.95.

“Initially, I didn't think I'd have to modify anything [at work], but as time wore on I did...”¹⁶

Parkinson's Disease: A Complete Guide for Patients and Families, 2nd Edition

This book outlines Parkinson's treatments including new drugs, surgery and other therapies (diet, speech therapy, acupuncture). The book also advises patients about less clinical but equally important matters such as dealing with health insurance companies and informing employers. There is also a Q&A section and a resource directory.

Weiner, W.J., Shulman, L.M., Lang, A.E. (2006)

Johns Hopkins University Press

ISBN: 0801885469

Suggested retail price is \$17.95.



ASSOCIATIONS AND ORGANIZATIONS

National Parkinson Foundation, Inc.

1501 NW 9th Avenue
Bob Hope Road
Miami, FL 33136-1494
Toll free: 800-327-4545
Fax: 305-243-4403

The foundation provides educational and medical information to Parkinson patients, their families, neurologists and general medical practitioners. An extensive list of patient and caregiver resources can be found on its website.

www.parkinson.org

STROKE

BOOKS AND GUIDES

The Comfort of Home™ for Stroke: A Guide for Caregivers

This guide is intended to help caregivers, family members and individuals with who have suffered a stroke to understand the issues that accompany a stroke and ways to address them. It focuses on the practical aspects of caregiving and provides guidance and additional resources for both caregivers and the individuals to whom they are providing care.

Meyer, M.M., Derr, P., and Caswell, J. (2007)

CareTrust Publications, LLC

ISBN: 0966476778

Suggested Retail Price is \$24.95.

ASSOCIATIONS AND ORGANIZATIONS

American Stroke Association

National Center
7272 Greenville Avenue
Dallas TX 75231

Toll Free: 888-4-STROKE (888-478-7653)

The American Stroke Association provides educational materials related to stroke, including a question and answer section for consumers, information on many of the issues individuals face in a section called “life after a stroke” and a free subscription to *Stroke CONNECTION Magazine*. The site also includes a database to search for local resources at www.local.strokeassociation.org. To order publications or if you have questions you may also call their toll free number above. www.strokeassociation.org



National Stroke Association

9707 E. Easter Lane
Englewood, CO 80112
Toll free: 800-787-6537
Fax: 303-649-1328

The National Stroke Association offers information about stroke risk reduction, symptoms, the effects of stroke and a list of regional resources for caregivers and survivors of stroke. www.stroke.org

FINANCIAL AND LEGAL RESOURCES

BOOKS AND GUIDES

The Complete Retirement Survival Guide: Everything You Need to Know to Safeguard Your Money, Your Health, and Your Independence.

This book, written by two attorneys, offers a practical and general guide to elder law. The authors present simple but accurate explanations of issues facing older adults such as finances, health matters and legal issues. Wills, trusts, powers-of-attorney, long-term-care issues and even Medicare and Medicaid are addressed.

Strauss, P., Ledermann, N. (2003)

Checkmark Books

ISBN: 0816048045

Suggested retail price is \$18.95

The Cost of Caring: Money Skills for Caregivers

A financial guide for caregivers, including action plans and money management tips. The guide looks at the challenges caregivers face, including money management. It provides advice on juggling personal finances and the costs related to caring for a loved one.

Johnson, A. and Rejnis, R. (1998)

Johy Wiley & Sons

ISBN: 0471239259

Suggested retail price is \$14.95



On average, caregivers pay \$200 per month out-of-pocket for groceries, medications, home modifications, etc., for the care recipient.¹⁷

ASSOCIATIONS AND ORGANIZATIONS

American Bar Association (ABA)

Commission on Law and Aging

740 15th Street, NW

Washington, DC 20005-1022

Telephone: 202-662-8690

The site offers information addressing the legal aspects of planning for incapacity, including considering durable and medical powers of attorney, living wills and trusts. It provides booklets on Medigap insurance, advance medical directives and housing rights of older persons.

www.abanet.org/aging

National Academy of Elder Law Attorneys (NAELA)

1604 North Country Club Road

Tucson, AZ 85716

Telephone: 520-881-4005 Fax: 520-325-7925

This site provides a national registry of attorneys specializing in elder law and a question and answer section related to finding and working with an elder law attorney. NAELA does not provide referrals to individual attorneys. www.naela.org



END OF LIFE CARE

INTERNET SITES

Five Wishes

Aging with Dignity

PO Box 1661

Tallahassee, FL 32302-1661

Telephone: 850-681-2010 Fax: 850-681-2481

Five Wishes is a living will and a durable power of attorney for health care, valid in the majority of states, that addresses not only an individual's medical wishes, but also their personal, emotional and spiritual needs. It is easy to understand and use. (Check with your state to see if it will honor the Five Wishes document.) The project was supported by a grant from The Robert Wood Johnson Foundation. To order, write to Aging with Dignity, call toll free: 888-5-WISHES (888-594-7437), or go to www.agingwithdignity.org for online ordering. Single copies are \$5.00 each; pricing for bulk orders is available.

ASSOCIATIONS AND ORGANIZATIONS

American Hospice Foundation

2120 L Street, NW Suite 200

Washington, DC 20037

Telephone: 202-223-0204 Fax: 202-223-0208

The American Hospice Foundation supports programs that serve the needs of terminally ill and grieving individuals. The site contains information related to hospice and palliative care and caregiver specific information on end of life care and grief.

www.americanhospice.org



***National Hospice & Palliative Care Organization
(NHPCO)***

1700 Diagonal Road, Suite 625

Alexandria, Virginia 22314

Telephone: 703-837-1500 Fax: 703-837-1233

This organization was established in 1978 as the National Hospice Organization and changed its name in 2000.

It is the largest non-profit hospice and palliative care organization representing programs and professionals in the United States. This site includes a wealth of information about resources. The NHPCO Helpline (800-658-8898) provides free consumer information on hospice care and puts the public in direct contact with hospice programs. www.nhpco.org

FOR PET OWNERS

Home for Life® Angel Care ProgramSM

P.O. Box 847

Stillwater, MN 55082

Toll free: 800-252-5918 Fax: 651-998-1512

The national “Home for Life Animal Sanctuary’s Angel Care Program” provides a safe, affordable residence for an individual’s pet if the owner dies, moves to a nursing home, or to another residence where pets are not allowed.

The animal is guaranteed a “Home for Life” when their owner meets the qualifications for enrollment of their pet in the program. Enrollment fees differ depending on the age of the individual. If the owner’s circumstances change and pet placement is necessary, Home for Life personnel arrange for air or ground travel or even retrieval to the sanctuary directly by Home for Life caretakers. Home for Life is a non-profit corporation.

E-mail: info@homeforlife.org www.homeforlife.org



GOVERNMENT RESOURCES

The U.S. Administration on Aging

The Administration on Aging (AoA) is an agency in the U.S. Department of Health and Human Services that provides resources and information for older adults and their caregivers. Its mission is to promote the dignity and independence of older people, and to help society prepare for an aging population. The AoA operates the Center for Communication and Consumer Services, which can be reached at 202-619-0724. Go to www.aoa.gov and click on “Elders and Families” for a list of consumer-friendly pages.

BenefitsCheckUp

This site was developed by the National Council on Aging (NCOA) and can assist seniors and their families in determining benefit eligibility for services in their area. Access the site at: <http://www.benefitscheckup.org/>

The National Family Caregiver Support Program (NFCSP), established as a result of the Older Americans Act Amendments of 2000, supports caregiver programs through area agencies on aging across the country. You can locate these services in your community by calling the Eldercare Locator at 1-800-677-1116.



Eldercare Locator

Toll free: 800-677-1116 (9 a.m.–8 p.m. ET)

The Eldercare Locator is a public service of the U.S. Administration on Aging. The service helps older adults and their caregivers find service in their area. The Eldercare Locator can be accessed through its toll free telephone line, staffed by trained information specialists, or through its website. www.eldercare.gov

FirstGov for Seniors

FirstGov for Seniors offers a wide range of information and government services. One of its objectives is to offer the convenience of conducting business with the government online, such as estimation of Social Security benefits. It also provides information related to a number of topics including health, housing for older Americans and consumer protection for seniors. www.seniors.gov

healthfinder[®]

Developed by the U.S. Department of Health and Human Services, *healthfinder* helps users locate selected online publications, clearinghouses, databases, websites and support and self-help groups, as well as government agencies and nonprofit organizations that produce reliable information for the public. Consumers can also take online quizzes related to a variety of health topics.

www.healthfinder.gov

Medicare.gov

This site is the official U.S. government consumer site for information on Medicare and is operated by the Centers for Medicare & Medicaid Services (CMS). At this site consumers can search for information on health plans, nursing homes, dialysis facilities, Medigap policies, Medicare activities, participating physicians and Medicare prescription drug plans in their area. The site also provides information on Medicare basics such as eligibility, enrollment, Medicare cards and replacement cards. Medicare publications may also be ordered. Some publications are available in large print, Spanish, Chinese, audiotope and Braille.

Toll free: 800-MEDICARE (800-633-4227)

www.medicare.gov



Medicare Basics: A Guide for Caregivers

This is an online resource produced by the Centers for Medicare & Medicaid Services (CMS) to help caregivers understand their care recipients' options under Medicare and guide them through eight decision points in the healthcare process. The guide is available at:

www.medicare.gov/Publications/Pubs/pdf/11034.pdf

National Institute on Aging (NIA)

The National Institute on Aging produces a number of publications that contain valuable information related to health issues that affect older Americans. Publication categories include sections on healthy aging, caregiving, planning and decision making, making sense of health information and a variety of disease specific conditions. The site currently offers a publication called *Talking With Your Doctor* at <http://www.nia.nih.gov/HealthInformation/Publications/TalkingWithYourDoctor/>, which is a guide for older people to help them to get the information they need when seeing the doctor. Other publications can be downloaded or ordered from <http://www.niapublications.org/>. For help with ordering publications you may also call 1-800-222-2225.



Endnotes

- ¹ *Caregiving in the U.S. – Findings from a National Survey*, National Alliance for Caregiving and AARP, April 2004.
- ² Ibid.
- ³ Arno, P., *Economic Value of Informal Caregiving*, Presented at the Care Coordination and Caregiver Forum, Department of Veterans Affairs, NIH, Bethesda, MD, January 25-27, 2006.
- ⁴ *Caregiving in the U.S. – Findings from a National Survey*, National Alliance for Caregiving and AARP, April 2004.
- ⁵ Ibid.
- ⁶ Ibid.
- ⁷ *Family Caregiving, Since You Care*, MetLife Mature Market Institute and the National Alliance for Caregiving, 2003.
- ⁸ *Caregiving in the U.S. – Findings from a National Survey*, National Alliance for Caregiving and AARP, April 2004.
- ⁹ Ibid.
- ¹⁰ *What Is Assisted Living?*, Consumer Information Center, Assisted Living Federation of America, Fairfax, VA, July 14, 2000.
- ¹¹ *Family Caregiving in the U.S. – Findings from a National Survey*, National Alliance for Caregiving and AARP, June 1997.
- ¹² *Understanding Home Care Agency Options*, Since You Care, MetLife Mature Market Institute and the National Alliance for Caregiving, 2003.
- ¹³ *Family Caregiving in the U.S. – Findings from a National Survey*, National Alliance for Caregiving and AARP, June 1997.
- ¹⁴ *Making the Nursing Home Choice*, Since You Care, MetLife Mature Market Institute and the National Alliance for Caregiving, 2003.
- ¹⁵ Koppel, R., *Alzheimer's Disease: The Costs of U.S. Businesses in 2002*.
- ¹⁶ *The MetLife Juggling Act Study – Balancing Caregiving with Work and the Costs Involved*, MetLife Mature Market Institute, November, 1999.
- ¹⁷ *Caregiving in the U.S. – Findings from a National Survey*, National Alliance for Caregiving and AARP, April 2004.



The MetLife Mature Market Institute®

MetLife Mature Market Institute® is the company's information and policy resource center on issues related to aging, retirement, long-term care and the mature market. The Institute, staffed by gerontologists, provides research, training and education, consultation and information to support Metropolitan Life Insurance Company, its corporate customers and business partners. MetLife, a subsidiary of MetLife, Inc. (NYSE: MET), is a leading provider of insurance and other financial services to individual and institutional customers.

National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a nonprofit coalition of national organizations that focuses on issues of family caregiving across the life span. The Alliance was created to conduct research, do policy analysis, develop national programs and increase public awareness of family caregiving issues.

National Association of Area Agencies on Aging

The National Association of Area Agencies on Aging (n4a) is the umbrella organization for our nation's 655 area agencies on aging (AAAs) and the representative body in Washington, DC, for the interests of 240 Title VI - Native American aging programs. Through its presence in Washington, n4a advocates on behalf of the local aging agencies to ensure that needed resources and support services are available to older Americans and their caregivers.



M A T U R E
M A R K E T
I N S T I T U T E

MetLife

MetLife Mature Market Institute

57 Greens Farms Road

Westport, CT 06880

203-221-6580

203-454-5339 Fax

MatureMarketInstitute@metlife.com

www.maturemarketinstitute.com

National Alliance for Caregiving

4720 Montgomery Lane, Fifth Floor

Bethesda, MD 20814

info@caregiving.org

www.caregiving.org

National Association of Area Agencies on Aging (n4a)

1730 Rhode Island Avenue, NW

Suite 1200

Washington, DC 20036

202-872-0888

202-872-0057 Fax

www.n4a.org

MetLife

Metropolitan Life Insurance Company

New York, NY

MMI00073(0107)

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