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MetLife

Resources for Caregivers 2004

*MetLife's Resource Guide
for Caregivers*



*MetLife Mature
Market Institute
and
National Alliance
for Caregiving*



As a caregiver, you are not alone. Approximately 22.4 million households (one out of every four) provide unpaid care to someone over the age of 50.¹ Family caregivers provide on average 18 hours of care weekly, some for a period of five years.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 \$257 billion annually.³



In 1996, close to two in three caregivers were employed, 52 percent full-time and 12 percent part-time.⁴ Family caregiving will present an even greater challenge to society in the years ahead. The number of households providing care by the year 2007 is estimated to increase to 39 million.⁵ In the past, responsibilities for caregiving almost exclusively belonged to women but currently at least 25% of men are now actively involved in caregiving.⁶

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 10/03. 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 (DI7051)
- Choosing Good Care: A Family Guide to Finding a Nursing Home (DI7064)
- Getting By With a Little Help: Community Services to Meet Changing Needs (DI7046)
- Navigating Your Way to a Quality Assisted Living Facility (DI7037)

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

AARP Fulfillment

601 E Street, NW

Washington, DC 20049

Call Toll free: 800-424-3410 or write to

member@aarp.org. Include the publication title and stock number and your postal mailing address.

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. (2000). New York, NY:

United Hospital Fund of New York City.

ISBN: 1881277534

Suggested retail price is \$2000.



Caregiver's Handbook: A Complete Guide to Home Health Care

The pictures, charts, glossaries and sample documents in this book make it easy for a home caregiver to gain needed skills to help keep a loved one at home and save on certain costs by supplementing the work of health care aides. It explains how to perform tasks such as washing, toileting, transferring, maintaining mobility, bed comfort, home adaptations and wound care.

Visiting Nurse Associations of America (1998). New York, NY: DK Publishing, Inc.

ISBN: 0789419696

Suggested retail price is \$14.95.

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

Caregiving: The Spiritual Journey of Love, Loss and Renewal

A guide for caregivers or those who anticipate providing care which includes advice from leaders in the fields of aging, medicine, finance and spirituality. A list of resources is included.

Witrogen-Mcleod, B. (1999). New York, NY:

John Wiley & Sons.

ISBN: 0471254088

Suggested retail price is \$22.95.

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). Sterling, VA: 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 Web site, www.caregiving.org/care.pdf and FRIA's Web site at www.fria.org.

The Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers – Second 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. (2002). Portland, OR: Caretrust Publications, ISBN: 0966476735 Suggested retail price is \$2000.

One quarter of US households contain at least one caregiver caring for someone at least 50 years old.⁷

The Complete Guide to Eldercare Consumer Reports: Complete Guide to Health Services for Seniors

This book contains a wealth of information specifically targeted to long-term care issues. It offers an overview of long-term care and addresses frequently asked questions about finding and paying for long-term care services for a loved one. It also provides information for caregivers on how to manage the health care bureaucracy. Lieberman, T. (2000). New York, NY: Three Rivers Press. ISBN: 0812931475 Suggested retail price is \$1397.



Helping Yourself Help Others: A Book for Caregivers


A book by former First Lady Rosalynn Carter that 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. (1994). New York, NY: Random House. ISBN: 0812925912 Suggested retail price is \$11.00.

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 Adult Day Centers, Choosing an Assisted Living Facility, Falls and Fall Prevention, Family Caregiving, Hiring An Independent Caregiver, Making the Nursing Home Choice, Medications and the Older Adult, and Understanding Home Care Agency Options. 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 VHS of the two-hour PBS original broadcast entitled & Thou Shalt Honor. McLeod, B. (2003). Rodale Press. ISBN: 1579547745 Suggested retail price is \$11.00.



“It’s a strain on you physically and mentally. You don’t have a life because you neglect a lot of your own personal needs because you’re so wrapped up with taking care of their needs.”⁸

INTERNET SITES

Caregiving Online

Caregiving Online, sponsored by Caregiving Newsletter, helps caregivers stay well by providing information about support and resources. It offers a Caregivers Discussion Group and an Online Caregiving Journal.
www.caregiving.com

Careguide

Careguide features information on finding and paying for care and legal planning for older adults. A searchable directory of eldercare facilities and home care by city and state is provided, as well as tools and check-lists for financial planning, long-term care insurance and nursing home placement.
www.careguide.net

Family Care Resource Connection

At the Family Care Resource Connection, family caregivers can search a database of over 700 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, click on *Family Resource Connection* and then click on *Search for Resources*.

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

The Caregiver Resource Directory: A Practical Guide for Family Caregivers

Sections of this online directory include: *Navigating “The System” Building Skills, Symptom Management at Home, Goals of Care in Progressive Illness, You Have Needs Too, Specific Illnesses and Where to Find Help*. There is also an extensive resource listing containing addresses and URLs for advocacy groups, financial/legal assistance, respite care and volunteer services and caregiver Web sites.

www.stoppain.org/caregivers/index.html#caregiver

The Center for Family Caregivers

The Center for Family Caregivers, a nonprofit organization, provides online support and educational materials to family caregivers.
www.familycaregivers.org


ASSOCIATIONS AND ORGANIZATIONS

AARP

601 E Street, NW
Washington, DC 20049
Toll free: 424-3410 TTY: 877-434-7598
AARP is a nonprofit organization that offers educational programs, services and support for adults 50 and older. The AARP Web site 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. E-mail: member@aarp.org
www.aarp.org/indexes/health.html#caregiving

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

2519 Connecticut Ave., NW
Washington, DC 20008
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.⁹

Assisted Living Federation of America (ALFA)

11200 Waples Mill Road, Suite 150

Fairfax, VA 22030

703-691-8100 Fax 703-691-8106

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 Web site provides an online directory of homes and services by city and state. [E-mail: info@alfa.org](mailto:info@alfa.org)

www.alfa.org

Children of Aging Parents (CAPS)

1609 Woodbourne Road, Suite 302A

Levittown, PA 19057-1511

215-945-6900 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 Web site. Support groups are available in some areas of the country.

www.caps4caregivers.org

Family Caregiver Alliance

690 Market Street, Suite 600

San Francisco, CA 94104

415-434-3388 Fax 415-434-3508

The Family Caregiver Alliance is a comprehensive support organization for caregivers. Its Web site 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](mailto: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."¹⁰

National Adult Day Services Association (NADSA)

8201 Greensboro Drive, Suite 300

McLean, Virginia 22102

Toll free: 866-890-7357 or 703-610-9035

Fax: 703-610-9005, [E-mail: info@nadsa.org](mailto:info@nadsa.org)

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

www.nadsa.org

National Association of Area Agencies on Aging (n4a)

Suite 1200

Washington, DC 20036

new phone Fax new fax available 11/5 MOVING ON 11/2

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 (NAHC)

228 Seventh Street, SE
Washington, DC 20003
202-547-7424 Fax: 202-547-3540

The National Association for Home Care 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 Web site 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.¹¹

National Association of Professional Geriatric Care Managers

1604 North Country Club Road
Tucson, AZ 85716-3102
520-881-8008 Fax: 520-325-7925

The National Association of Professional Geriatric Care Managers is a nonprofit organization of geriatric care managers. 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.

www.caremanager.org



National Family Caregivers Association

10400 Connecticut Avenue, #500
Kensington, MD 20895-3944
Toll free: 896-3650 Fax: 301-942-2302

The National Family Caregivers Association is a nonprofit organization dedicated to providing support and assistance to caregivers through information, education, public awareness and advocacy. They offer caregiving tips, caregiver advocacy updates and resources on-line. 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 Foundation

63 West Main Street, Suite H
Freehold, NJ 07728
212-685-8815 Toll free: 800-838-0879
Fax: 732-577-8644

The Well Spouse Foundation is a national, nonprofit membership organization that gives support to wives, husbands and partners of the chronically ill and/or disabled. 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 every day.

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.”¹²



VIDEOTAPES

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 \$9900.

To order, call toll free: 888-777-5585 or 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 \$2495.

To order, call toll free: 888-777-5585 or visit

www.agingparents.com.

& Thou Shalt Honor

This is a video of the original two-hour PBS broadcast and contains profiles and interviews of current and former caregivers who provided care for friends, spouses and other family members prior to their death. Directed by: Harry Wiland and Dale Bell. The video costs \$2995 + \$4.00 s/h 11.00 from Rodale Press. Group discounts are available. To order online, go to www.thoushalthonor.org/books/pbs.html. To order by mail, make a check payable to Wiland-Bell Productions LLC and send to:

Orders

Wiland-Bell Productions

2125 Arizona Avenue

Santa Monica, CA 90404-1337



Terra Nova Films

Terra Nova Films has produced a variety of videotapes on caregiving and related issues such as death and dying and nursing home care. Visit www.terrannova.org or call or write for a catalog.

9848 South Winchester Avenue

Chicago, IL 60643

Toll free: 800-779-8491 Fax: 202-296-3368

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 \$4995 or separately for \$1995 each.

To order, contact:

LifeView Resources

PO Box 290787

Nashville, TN 37229-0787

Toll free: 800-395-LIFE or 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.¹³

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 \$119.70, three or more at a 20% savings, or separately for \$24.95 each.



To order, contact:

LifeView Resources

PO Box 290787

Nashville, TN 37229-0787

Toll free - 800-395-LIFE or 800-395-5433

Fax: 615-781-9692

E-mail: info@lifeviewresources.com

www.lifeviewresources.com

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

This video 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 parent. 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 \$3995, with an online discount price of \$31.96. Paraclete Press, ISBN: 1-55725-277-7

To place an online order, go to www.ParacletePress.com or call Toll free: 800-451-5006 for more information.

AUDIOTAPES

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 \$1000.

Specify Hardship into Hope and make check payable to:

Connie Goldman Productions,

217 West Canyon Drive


Hudson, WI 54016

715-531-0390

Fax: 715-531-0391

E-mail: congoldman@aol.com

www.congoldman.org



“There’s still a lot of happiness. My mother comes alive when she interacts with the grandchildren.”¹⁴

CARING FOR LOVED ONES WITH...

AIDS

BOOKS AND GUIDES

Living Well With HIV and AIDS – Second Edition

This book covers such topics as HIV and AIDS self-management, common symptoms, exercise, nutrition, communication, getting the most out of medicines, AIDS and the immune system, planning for the future and finding resources.

Gifford, A., Lorig, K., Laurent, D., Gonzalez, V.M. (2000). Palo Alto, CA: Bull Publishing Co.

ISBN: 0923521526

Suggested retail price is \$1895.

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/

INTERNET SITES

AIDSinfo

Among other services, the Web site, AIDSinfo, provides a comprehensive glossary of terms used in the pathogenesis, 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



ALS

BOOKS AND GUIDES

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

This guide features discussions of classifications and clinical features of the disease, diagnosis, patient care, therapeutic trials, speech problems, physical therapy, nutrition, environmental adaptations, respiratory care, nursing care, long-term 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).

New York, NY: Demos Medical

Publishing.

ISBN: 1888799285

Suggested retail price is \$3995.

ASSOCIATIONS AND ORGANIZATIONS

ALS Association

27001 Agoura Road, Suite 150

Calabasas Hills, CA 91301-5104

Information & Referral Service:

Toll free: 800-782-4747

All others: 818-880-9007

The ALS Association is a nonprofit agency that provides education, advocacy and information about amyotrophic lateral sclerosis (Lou Gehrig's disease) to patients, families, caregivers, researchers and health care professionals. [E-mail: alsinfo@alsa-national.org](mailto: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 Related Dementing Illnesses and Memory Loss in Later Life - Revised

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

Mace, N.L. and Rabins, P.V. (2001).

New York: Warner Books

ISBN: 0446610410

Suggested retail price is \$795.

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 \$1695.

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 and advocacy areas. Also posted on the site are schedules of Alzheimer's related chats at other Web sites, book excerpts, calls for manuscripts, an "anger wall" on which caregivers may express their feelings, memorial pages, resource links and legal articles and forms.

www.alzwell.com

ASSOCIATIONS AND ORGANIZATIONS

Alzheimer's Association

919 North Michigan Avenue,
Suite 1000

Chicago, IL 60611-1676

Toll free: 800-272-3900, 312-335-8700

Fax: (312) 335-1110

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](mailto: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.

Alzheimer's Disease Education and Referral Center (ADEAR)

P.O. Box 8250

Silver Spring, MD 20907-8250

Toll free: 800-438-4380

ADEAR provides information, research, publications and a clinical trials database. It is a service of the National Institute on Aging, National Institutes of Health. The site features links to federal resources and a list of recent press releases. [E-mail: adear@alzheimers.org](mailto:adear@alzheimers.org)

www.alzheimers.org



Alzheimer's Foundation of America (AFA)

252 2. 37th Street, 8th floor

New York, NY 10018

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

AFA is a non-profit foundation dedicated to meeting the educational, social and emotional needs of individuals with Alzheimer's disease and their families and caregivers as well as raising public awareness about the disease and lending expertise to healthcare professionals. [E-mail: info@alz.org](mailto:info@alz.org)

www.alzfdn.org

CANCER

BOOKS AND GUIDES

Caregiving : A Step-By-Step Resource for Caring for People with Cancer at Home

This book includes sections on cancer treatments, managing care, emotional and physical conditions associated with cancer and living with cancer and cancer treatments. Provides step-by-step instructions on how to deal with situations or conditions that may occur when giving care to a person with cancer. Also contains a list of resources available to caregivers that will make the job easier.

Houts, P.S., Bucher, J., Nezu,

A.M. (2000). Atlanta, GA: American

Cancer Society

ISBN: 0944235204

Suggested retail price is \$1327.


When Cancer Strikes: A Tribute to the Family Caregiver

Developed through interviews and experiences with cancer patients and their families, this book offers a glossary of cancer terms, resources and practical advice. Hagag, N.G. (1999). Huntington, NY:

Nova Science Publishers, Inc.

ISBN: 1560725400

Suggested retail price is \$2495.



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, N.E.

Atlanta, GA, 30329

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

The American Cancer Society 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

Web site: www.cancer.org

Cancer Care

275 7th Avenue

New York, NY 10001

Toll free: 800-813-HOPE (4673)

Cancer Care 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.

Cancer Care's services include a toll-free Counseling Line, Telephone Education Workshops, and regularly scheduled online educational chat sessions.

CEREBRAL PALSY

BOOKS AND GUIDES

Cerebral Palsy: A Complete Guide for Caregiving

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. (1998).

Baltimore, MD: Johns Hopkins

University Press.

ISBN: 0801859492

Suggested retail price is \$1397.

Children With Cerebral Palsy: A Parents' Guide

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), second edition

Bethesda, MD: Woodbine House.

ISBN: 0933149824

Suggested retail price is \$11.87.

Forty-one percent of caregivers have one or more children under age 18 living in their households.¹⁵



ASSOCIATIONS AND ORGANIZATIONS

United Cerebral Palsy

1660 L Street, NW, Suite 700

Washington, DC 20036

Toll free: 800-872-5827

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.

202-776-0406

Fax: 202-776-0414

TTY: 202-973-7197

E-mail: ucpnatl@ucpa.org

www.ucpa.org

DIABETES

BOOKS AND GUIDES

Living with Juvenile Diabetes: A Practical Guide for Parents and Caregivers of Children with Type 1 Diabetes Mellitus

This book offers practical hints and ideas on how parents can deal with their child's diabetes and help their child cope with the condition on a daily basis. Topics covered include the latest facts and treatments, how to deal with the emotional roller coaster, how to prepare insulin and give injections, tips on exercise and nutrition, recipes and much more.

Peurrung, V. (2001). New York, NY:

Hatherleigh Press.

ISBN: 1578260574

Suggested retail price is \$1047.

The Ten Keys to Helping Your Child Grow Up With Diabetes: A Practical Guide for Parents & Caregivers

This problem-solving guide helps parents and caregivers of children with diabetes discover how to develop skills to cope with diabetes and stress, recognize the importance of open communication,

interact with health care professionals and more.

Wysocki, T. (1997). Alexandria, VA:

American Diabetes Association.

ISBN: 0945448740

Suggested retail price is \$1047.

People of all ages – a child, a disabled person, or an aging individual – can require long-term care.¹⁹

ASSOCIATIONS AND ORGANIZATIONS

American Diabetes Association

1701 North Beauregard Street

Alexandria, VA 22311

Toll free: 800-DIABETES or 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 or 800-242-8721

The American Heart Association provides information on fighting heart disease and stroke. Its Web site features a section called Living with Heart Failure, an information and support section for caregivers.

www.americanheart.org home page



MENTAL ILLNESS

BOOKS AND GUIDES

Helping Someone With Mental Illness: Compassionate Guide for Family, Friends, and Caregivers

Building on 25 years of experience as an advocate for the mentally ill, former First Lady Rosalynn Carter discusses the latest treatments and research as well as effective caregiving and advocacy.

Carter, R. (1998). New York, NY: Times Books.

ISBN: 0812928997

Suggested retail price is \$24.00.

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

This layperson's guide contains information on the gamut of adult psychiatric disorders. Aimed at patients and caregivers: family, friends and professionals.

Roukema, R. W. (2003). Washington,

DC: American Psychiatric Press, second edition

ISBN: 1585621102

Suggested retail price is \$36.00.

ASSOCIATIONS AND ORGANIZATIONS

National Mental Health Association

2001 Beaugard Street, 12th floor

Alexandria, VA 22311

703-684-7722

Toll free: 800-969-NMHA or 800-969-6642

Fax: 703-684-5968

(Mental Health Information Center) The National Mental Health Association promotes mental health through education and research efforts. NMHA provides information and advocates for those suffering with mental illness. The NMHA Web site offers fact sheets, legislative alerts, discussion boards, a newsletter and publication list and an event calendar.

www.nmha.org

TTY: 800-433-5959



MULTIPLE SCLEROSIS

BOOKS AND GUIDES

Multiple Sclerosis: The Facts

You Need This book is a comprehensive guide to living with MS, supported by diagrams, case histories, a drug table and an extensive list of helpful books and organizations. Topics include what MS is and who gets it; how MS is diagnosed as “possible,” “probable” or “definite”; why the disease affects different people in different ways; how “relapsing remitting” MS differs from “progressive” MS; how people with MS and their families can adapt their homes, careers and lifestyles to cope with the disease; which treatments work, which don't and what help is on the horizon.

O'Connor, P. (1999). Westport, CT: Firefly Books.

ISBN: 1552093670

Suggested retail price is \$14.95.

Multiple Sclerosis: The Questions You Have—The Answers You Need

This book is a guide for everyone concerned with multiple sclerosis from those who have the disease, to those who share their lives with someone who has it, and to those health care professionals involved with its management. Kalb, R. (2000). New York, NY:

Demos Medical Publishing.

ISBN: 1888799439

Suggested retail price is \$39.95.

ASSOCIATIONS AND ORGANIZATIONS

The National Multiple Sclerosis (MS) Society

733 Third Avenue

New York, NY 10017

Toll free: Fight-MS or 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](mailto:info@nmss.org)

www.nmss.org



PARKINSON'S DISEASE

BOOKS AND GUIDES

Parkinson's Disease: A Complete Guide for Patients and Families

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. (2001). Baltimore, MD: Johns Hopkins University Press.

ISBN: 0801865565

Suggested retail price is \$16.95.

"Initially, I didn't think I'd have to modify anything [at work], but as time wore on I did..."¹⁷

Caring for the Parkinson Patient : A Practical Guide

This guide discusses diagnosis and treatment, new research, communication, physical and occupational therapy, nursing care, problems faced by caregivers and more.

Hutton, J.T., Dippel, R.L., Slewett, N. (1999). Amherst, NY: Prometheus Books.

ISBN: 1573926841

Suggested retail price is \$22.00.

ASSOCIATIONS AND ORGANIZATIONS

National Parkinson Foundation, Inc.

Bob Hope Parkinson Research Center
1501 N.W. 9th Avenue

Bob Hope Road

Miami, FL 33136-1494

305-547-6666 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 Web site.

www.parkinson.org

STROKE

ASSOCIATIONS AND ORGANIZATIONS

National Stroke Association

9707 E. Easter Lane

Englewood, CO 80112

303-649-9299 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 RESOURCES

BOOKS AND GUIDES

Protect Your Parents and Their Financial Health... Talk With Them Before It's Too Late


A financial planning book for adult children and their parents. Topics include establishing a power of attorney, preparing for the future and managing health care costs.

Richards, S. (1999). Chicago, IL:

Dearborn Financial Publishing.

ISBN: 0793127629

Suggested retail price is \$19.95.



The Cost of Caring: Money Skills for Caregivers

A financial guide for caregivers, including action plans and money management tips.

Johnson, A. and Rejnis, R. (1998). New York, NY:

John Wiley & Sons.

ISBN: 0471239259

Suggested retail price is \$14.95.

On average, caregivers pay \$171 per month out-of-pocket for groceries, medications, home modifications, etc., for the care recipient.¹⁸

FINANCIAL RESOURCES

ASSOCIATIONS AND ORGANIZATIONS

America Bar Association (ABA)

Commission on Law and Aging

740 15th Street, NW, 8th Floor

Washington, DC 20005

202-662-8690 Toll free: 800-285-2221

Offers information addressing the legal aspects of planning for incapacity and introducing durable and medical powers of attorney, living wills and trusts and 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

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

Provides a national registry of attorneys specializing in elder law and publishes brochures on legal issues affecting older adults. NAELA does not provide referrals to individual attorneys.

www.naela.org



National Senior Citizens Law Center (NSCLC)

1101 14th Street NW, Suite 400

Washington, DC 20005

202-289-6976

NSCLC provides a clearinghouse of information on legal problems of older adults covering such issues as Social Security, age discrimination, pension plans, Medicaid, Medicare, nursing homes and consumer products. The Center also provides free services including consulting and referrals to other sources. A variety of free documents are available.

www.nsclc.org

END OF LIFE CARE

Five Wishes

Aging with Dignity

PO Box 1661

Tallahassee, FL 32302-1661

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

Five Wishes is a living will and a durable power of attorney for health care, valid in 35 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 if you have an existing living will but prefer to use the Five Wishes document, all you need to do is complete Five Wishes and then destroy your current living will or durable power of attorney for health care. The project is supported by a grant from The Robert Wood Johnson Foundation. To order, write to Aging with Dignity, call (toll free: 888-5-WISHES (594-7437), or go to www.agingwithdignity.org for online ordering. Single copies are \$500 each; pricing for bulk orders is available.



Last Acts

Partnership for Caring, Inc
1620 Eye Street NW, Suite 202
Washington, DC 20006
202-296-8071 Fax: 202-296-8352

Last Acts is a campaign organized by a coalition of professional and consumer organizations whose mission is to improve end-of-life care and promote palliative care and pain management. Last Acts advocates for quality care for those who are dying and support for the family. The Web site contains publications for free downloads, newsletters, a bookstore, campaign news and other features.

www.lastacts.org

Partnership for Caring: America's Voice for the Dying

1620 Eye Street NW, Suite 202,
Washington, DC 20006
202-296-8071 Fax: 202-296-8352
Hotline: Toll free: 800-989-9455

This is a national, nonprofit organization that partners with individuals and organizations dedicated to raising consumer expectations for quality end-of-life care, Partnership for Caring is home to the only national crisis and information hotline that deals with end-of-life issues. State-specific living wills and medical powers of attorney form, also called Advance Directives, are available for download.

[E-mail: pfc@partnershipforcaring.org](mailto:pfc@partnershipforcaring.org) www.partnershipforcaring.org/HomePage/



FOR PET OWNERS

Home for Life® Angel Care ProgramSM

P.O. Box 847
Stillwater, MN 55082
Toll free: 800-252-5918 Fax: 651-351-0527

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 federal 501(c)(3) corporation.

[E-mail: info@homeforlife.org](mailto:info@homeforlife.org)

www.homeforlife.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 throughout the country. Funding is provided for five basic services for family caregivers, which include:

- ***Information about available services***
- ***Assistance in gaining access to services***
- ***Individual counseling, support groups and caregiver training***
- ***Respite care***
- ***Supplemental services to complement care provided by caregivers***



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.

CarePlanner

Developed for the Centers for Medicare and Medicaid Services (CMS), CarePlanner is a free online tool developed to help seniors, individuals with physical disabilities or chronic illnesses and caregivers plan for successful living and care choices. Through a series of questions on lifestyle preferences, income, and physical and mental condition, CarePlanner helps users develop a care plan that best fits their needs.

www.careplanner.org

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 Locator helps older adults and their caregivers find services in their area. The Eldercare Locator can be accessed through its toll-free telephone line, staffed by trained information specialists, or through its Web site.

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, postage stamp purchases and express mail package tracking.

www.seniors.gov

healthfinder®

healthfinder®, developed by the U.S. Department of Health and Human Services, helps users locate selected online publications, clearinghouses, databases, Web sites and support and self-help groups, as well as government agencies and nonprofit organizations that produce reliable information for the public.

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 and 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 prescription drug assistance programs 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, audiotape and Braille.

Toll free: MEDICARE or 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



When Employees Become Caregivers: A Manager's Workbook

This online guide, prepared by the Centers for Medicare and Medicaid Reform (CMS) by the National Alliance for Caregiving, helps employers identify issues affecting employees who are caregivers. It also offers solutions for businesses that are low or no cost. An employer's workbook is also available.

www.cms.hhs.gov/partnerships/materials/brochure/Final_Workbook_online_version.pdf

Nearly two-thirds of caregivers are employed full or part-time.¹⁹

Endnotes

- ¹ *Family Caregiving in the U.S. – Findings from a National Survey*, National Alliance for Caregiving, AARP, June 1997.
- ² Ibid.
- ³ Arno, P., *Economic Value of Informal Caregiving: 2000*, Presented at the American Association for Geriatric Psychiatry, February 24, 2002.
- ⁴ *Family Caregiving in the U.S. – Findings from a National Survey*, National Alliance for Caregiving, AARP, June 1997.
- ⁵ Ibid.
- ⁶ *Selected Caregiver Statistics*, Family Caregiver Alliance, Accessed 10/2002.
- ⁷ *Family Caregiving in the U.S. – Findings from a National Survey*, National Alliance for Caregiving, AARP, June 1997.
- ⁸ Ibid.
- ⁹ *What Is Assisted Living?*, Consumer Information Center, Assisted Living Federation of America, Fairfax, VA, July 14, 2000.
- ¹⁰ *Family Caregiving in the U.S. – Findings from a National Survey*, National Alliance for Caregiving, AARP, June 1997.
- ¹¹ *Understanding Home Care Agency Options*, Since You Care, MetLife Mature Market Institute and the National Alliance for Caregiving, 2002.
- ¹² *Family Caregiving in the U.S. – Findings from a National Survey*, National Alliance for Caregiving, AARP, June 1997.
- ¹³ *Making the Nursing Home Choice*, Since You Care, MetLife Mature Market Institute and the National Alliance for Caregiving, 2002.
- ¹⁴ *Family Caregiving in the U.S. – Findings from a National Survey*, National Alliance for Caregiving, AARP, June 1997.
- ¹⁵ Ibid.
- ¹⁶ Ibid.
- ¹⁷ *The MetLife Juggling Act Study — Balancing Caregiving with Work and the Costs Involved*, MetLife Mature Market Institute, November 1999.
- ¹⁸ *Family Caregiving in the U.S. – Findings from a National Survey*, National Alliance for Caregiving, AARP, June 1997.
- ¹⁹ Ibid.



The MetLife Mature Market Institute

The MetLife Mature Market Institute is MetLife'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 MetLife, its corporate customers and business partners.

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. 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.

MetLife, a subsidiary of MetLife, Inc. (NYSE: MET), is a leading provider of insurance and other financial services to individual and institutional customers. The MetLife companies serve approximately 12 million individuals in the U.S. and provide benefits to 37 million employees and family members through their plan sponsors. For more information about MetLife, please visit the company's Web site at www.metlife.com.



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 Telephone

(203) 454-5339 Fax

MatureMarketInstitute@metlife.com

www.maturemarketinstitute.com

National Alliance for Caregiving

4720 Montgomery Lane, Fiftyth Floor

Bethesda, MD 20814

E-mail: info@caregiving.org

www.caregiving.org

National Association of Area Agencies on Aging (n4a)

1730 Rhode Island Avenue, N.W.

Suite 1200

Washington, DC 20036

202-296-8130

202-296-8134 Fax

www.n4a.org

MetLife

Metropolitan Life Insurance Company

New York, NY