

SINCE YOU CARE

A Series of Guides from **MetLife** in Cooperation with the National Alliance for Caregiving

Family Caregiving

Are You a Caregiver?

If you provide assistance to someone who is disabled or who needs help with day-to-day activities because of a chronic condition, cognitive limitations, or aging, you are a caregiver. Caregiving can mean shopping for groceries once a week for a homebound relative or neighbor, helping an aging parent with his or her finances, or providing hands-on care for a member of your household. And you are not alone. According to the National Alliance for Caregiving:

- More than 22 million households provide care for a family member, friend, or loved one.¹
- More than seven million older adults require some type of long-term care.²
- At least 10 million will have such needs by 2020 and 14 million by 2040.³
- 1.4 million children ages 8 to 18 provide care for an adult relative; 72% are caring for a



MetLife

Caregivers face many challenges as they search for information and make decisions about how best to provide care to their loved ones. To help meet their needs,

MetLife offers SinceYouCare® — a series of guides which provide practical suggestions and useful tools on a variety of specific care-related products.

parent or grandparent.

Fortunately, most are not the sole caregiver.⁴

People of all ages—a child, a disabled person, or an aging individual—can require long-term care. As a family caregiver, you give of your time, energy, strength, and personal resources on an ongoing basis without financial compensation.

Caregivers can be any age, male or female, working outside the home, or in the home full-time. Statistics of caregivers show:

- Of those actively involved in caregiving, 39% are men and 61% are women.
- Fifty-nine percent of caregivers either work or have worked while providing care.
- Of those providing care 26% are age 18-34, 32% age 35-49, 30% age 50-64, and 13% age 65 and over.⁵

Caring for the Caregiver

It is very easy to lose sight of your physical and emotional needs when you are performing the rewarding but difficult task of providing care. Emotions such as guilt, anger, regret and hopelessness—“burnout”—can erode your physical and emotional state if you do not allow time for your own needs. According to Barry Jacobs, author of *The Emotional Guide for Caregivers*:

Looking After Yourself While Helping an Aging Parent, “Empathy is the currency of emotional support—to feel heard, understood, and cared for. If others are accurately and empathetically attuned to your feelings, you’ll likely be able to sustain yourself while shouldering heavy burdens.”⁶ While it is easy to get lost in the many issues of caregiving, it is critical to maintain your own life, complete with social, physical, and emotional interactions. You need it, and deserve it. When you are at your best, you will be more effective in carrying out your caregiving responsibilities.

Things You Need to Know

Assessing Care Needs

If you are responsible for providing care to a family member, it is important to first assess your loved one’s functional ability. Different people will have different care needs and thus require varying levels of care. A care recipient who is unstable on his or her feet, forgetful (forgetting to turn the stove off or neglecting to take his or her prescription medicine), or unable to eat, move about, or use the toilet without help will need a higher level of care than someone who simply requires occasional assistance with tasks such as bill paying,

housekeeping, or meal preparation. See the *Functional Assessment Tool* in this guide.

Communication

Good communication skills help caregivers adapt to change by enabling them to obtain and share information, ask for what they need, and stay connected to others. Frequently caregivers express frustration when their loved ones resist accepting help, and find themselves at a loss in dealing with the changing family dynamics. Talking with your loved one and involving him or her in the decisions will go a long way toward creating a team approach in addressing your loved one’s issues.

Emotions like fear and anger may cause confusion or communication barriers. Listen for the meaning behind your loved one’s words. Try to place yourself in his or her shoes, and to imagine how you might feel if you were in his or her position. Next, express understanding of your family member’s feelings. We all want to be heard, and by acknowledging your loved one’s fears, concerns, or other emotions you will provide him or her with a measure of comfort. Find common ground and express agreement whenever possible. If you can both agree on the problem, you will stand a better chance of coming up with solutions that are acceptable to both parties.

Know your limitations as a caregiver. A family member, parent, or significant other may want you to be the only caregiver. However, they must understand that this is not always possible, and that you may need to enlist the services of others from outside the home. Setting limits may be difficult at first, but once you do, you may find that family members worry less, knowing that you are taking care of yourself. Also, by effectively communicating your limits, you will take much of the guesswork out of planning and problem solving.

Remember that an illness such as Alzheimer's disease affects the care recipient's memory and frequently complicates his or her ability to respond effectively. To mediate a difficult situation, consider accessing the services of a trusted third party such as a doctor, clergy person, or social worker.

Planning

Exploring your options and planning ahead will reduce your anxiety related to becoming a caregiver. To help plan ahead:

- See if other family members and friends are available for specific duties and assistance.
- Check to see what community options are available.
- Know where your family member's medical history is kept and where you can locate important documents.
- Keep your records organized as it will help you to be more productive and effective in your caregiving.
- Find out about home care agencies in your area should you need one to supplement the care you are providing.

Health Effects of Caregiving

A study done by the National Alliance for Caregiving and AARP

found that 15% of those caring for someone identified a worsening of their own health and 35% reported emotional stress and strain.⁷ Generally, stress is what you feel when the demands on your life exceed your ability to meet those demands. In a recent study from a nearly three-decade-long program at Ohio State University, results link the psychological stress of family members caring for an Alzheimer's disease patient and a weakened immune status.⁸ The study confirmed that this kind of stress can make you more susceptible to getting ill yourself. Physical reactions to prolonged stress can show up as cardiovascular disease or worsening of existing chronic conditions such as asthma, high blood pressure, and gastrointestinal problems.

Physical Health

It is important to take care of your physical health. Try to limit your consumption of soft drinks, sweets, and other high-carbohydrates, high-fat foods, and alcohol. These foods usually offer only empty calories and little nutritional value. Make time for exercise, even if it's only 10-15 minutes each day. Exercise helps you feel better, keeps your muscles strong, and can help prevent disease. Exercise does not need to be intense or difficult. Taking a walk, riding a bike, dancing, or



doing low impact aerobics in your home are good ways to exercise. Getting enough rest is also important. A good night's sleep and allowing yourself to relax during the day are both critical to your overall health and effectiveness as a caregiver.

Psychological and Emotional Health

If you find yourself with high stress levels, you may be at risk for depression and/or anxiety, leading to other health problems. Studies have shown that family caregivers consistently report higher levels of depression than their non-caregiving peers.⁹ Other symptoms reported by caregivers include lack of energy/sleep, stress/panic attacks, pain, headaches and weight gain/loss.¹⁰ It is no wonder that caregivers experience prolonged feelings of sadness as they often face the issues of mortality and loss in isolation, while navigating the healthcare system and coping with many other added responsibilities.

If you find that sadness is interfering with daily life, it may be advisable to obtain an evaluation for depression, which is a treatable condition. Social connections and support groups are also key to maintaining your psychological health. Respite care offers temporary relief, giving caregivers greatly needed breaks. Check out adult day cen-

ters, home care agencies, or nursing homes. Finding respite care for your loved one allows you the freedom and time to relax and invest in your own health and emotional well being. See *Resources to Get You Started* at the back of this guide.

Signs You May Need Assistance

Be aware of the signs that point to caregiver "burnout." Watch for:

- Excessive use of alcohol, medications, or sleeping pills.
- Appetite changes—either eating too much or too little.
- Depression—hopelessness, feelings of alienation, lack of energy to do new things.
- Thoughts of death.
- Losing control physically or emotionally.
- Neglect or rough treatment of the person for whom you are caring.
- Trouble falling or staying asleep.
- Difficulty concentrating, missing appointments.

When possible, obtain training in skills such as the proper way to transfer someone from bed to chair, how to do wound care, behavioral management, and home safety.

Get support for yourself and never underestimate the importance of your own well-being. Having a healthy mind, body, and spirit are all positives that you bring into a caregiving relationship. They benefit both you and your loved one.

Caregiving and the Workplace

Caregiving responsibilities often have a more severe effect on job obligations and free time than individuals first realize. In a national study, over 40% of caregivers had been providing assistance for 5 or more years, and nearly one-fifth had been doing so for 10+ years.¹¹ It is estimated that the work of unpaid caregivers would be worth \$350 billion per year if caregiving were performed by paid home care workers.¹² Caregiving frequently starts out by simply doing errands, and over time, it can develop into more complex care, resulting in increasing pressure, and conflicting demands between work and family.

Some employers are recognizing the need to assist employees with balancing work and family responsibilities, as the number of full time working caregivers is estimated at just under 16 million¹³ and represents almost one fifth (19%) of the workforce¹⁴. Check with your employer to see whether eldercare benefits are available through the human resources department or as part of a work-life program.

Helpful Hints

- Community resources for support, such as Meals on Wheels, Friendly Visitors, or respite programs can often be located by calling your local Area Agency



on Aging. (See *Resources to Get You Started*.) Many programs have a sliding fee scale adjusted to income; some are free.

- Look into respite programs with adult day care centers, assisted living, or nursing facilities that might be able to assist you with care on a periodic basis; consider a home care agency; or ask a family member to stay with your loved one.
- Check into support groups for caregivers. If the person has a disease such as Alzheimer's or Parkinson's, there are often support groups specific to these diseases, although anyone can attend. There are also on-line support groups. See *Resources to Get You Started* for the Internet addresses.
- Ask your employer if working from home on occasion, flexible scheduling, or employee counseling are available. You may want to look into the Family and Medical Leave Act, which grants employees unpaid leave to care for a sick parent or

spouse. You may be eligible for this if you work for a company with more than 50 employees.

- Some state and local communities have organized caregiving coalitions that serve the needs of family caregivers. The coalitions provide an advocacy voice for family caregivers and serve as a resource for caregivers in the community. To see if there is a caregiving coalition in your area visit the website for the National Alliance for Caregiving at www.caregiving.org.

Resources to Get You Started

Books and Publications

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. (2006). Sterling Publishing Company, Incorporated. \$12.95 ISBN: 9781402735592

Doing the Right Thing: Taking Care of Your Elderly Parents Even If They Didn't Take Care of You

This book is intended to help caregivers who are caring for parents with whom they have had a strained relationship. It provides insights for caregivers who find themselves struggling with this new role. It also addresses some of the issues that may arise with other family members related to this caregiving experience. Satow, Roberta, Ph.D. (2005). Penguin Group, \$14.95 ISBN: 1585423920

How to Care for Aging Parents

A compassionate, single-volume reference to the many topics associated with caring for aging parents, covering practical matters, including emotional, financial, and legal issues. Morris, V. (2004). Workman Publishing Co., \$18.95 ISBN: 0761134263

Resources for Caregivers

This 38-page booklet, prepared by the National Alliance for Caregiving and the MetLife Mature Market Institute, in cooperation with the National Association of Area Agencies on Aging lists tips, centers of information, and disease specific resources. You can obtain a complimentary copy by calling



203-221-6580, e-mailing maturemarketinstitute@metlife.com, or visiting www.maturemarketinstitute.com.

Share the Care: How to Organize a Group to Care for Someone Who is Seriously Ill

This book offers step by step guidelines, and specific suggestions for creating a “caregiving network” from friends, neighbors, and co-workers. The authors translated their personal experience caring for a dying friend into a model that demonstrates how to systematically organize pooled time and efforts of others to help family caregivers, and prevent caregiver burn-out. Capossella, C., Warnock, S. (2004). Simon & Schuster Adult Publishing Group, \$15.00 ISBN: 9780743262682

The Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers

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. (2007). Care Trust Publications, \$24.95 ISBN: 0966476794

The 36-Hour Day: A Family Guide to Caring for People with Alzheimer Disease, Other Dementias and Memory Loss in Later Life

A guide and narrative for anyone caring for an individual with Alzheimer disease or related dementias. Mace, N. and Rabins, P. (2006). John Hopkins University Press, \$16.95 ISBN: 9780801885099

Internet Sites

AARP

AARP is a nonprofit organization that offers educational programs, services, and support for adults 50 and older. The AARP website contains an extensive caregiver sec-

tion that provides information on caregiver support, long-term care, home care, and housing. Publications are available online at www.aarp.org or by calling 888-687-2277, TTY: 877-434-7598.

Administration on Aging (AoA)

This site, www.aoa.gov is maintained by the U.S. Department of Health and Human Services and provides resources, news, and developments for older adults and their families. Since 2000, with the establishment of the National Family Caregiver Support Program (NFCSP), states now provide basic services for family caregivers including information, assistance, counseling, support groups, respite, and supplemental services. Caregivers can access the information about their state’s resources at www.aoa.gov/pref/aoaprogram/caregiver/caregiver.asp by scrolling down, and clicking on State Caregiver Websites.

BenefitsCheckUp

This is a free, confidential service that helps older adults find programs that may help pay for some of the costs associated with prescription drugs, health care, utilities, and other essential items or services. It requires completion of a simple form that asks for no personal information other than your zip code, using it to locate programs in your area. www.benefitscheckup.org

Important Information: Keep this form handy and accessible to all caregivers, so that it can be given to healthcare professionals in the event of an emergency.

Name _____

Date of Birth _____

Social Security Number _____

Doctor _____

Phone & Address _____

Hospital _____

Phone & Address _____

Directions _____

Pharmacy _____

Phone & Address _____

Insurance Company _____

Health Insurance (Company) _____

(Policy Number) _____

Long-Term Care Insurance (Company) _____

(Policy Number) _____

Life Insurance (Company) _____

(Policy Number) _____

Legal and Medical Papers _____

Power of Attorney (Name) _____

Where is it filed? _____

Health Care Proxy _____

Where is it filed? _____

Living Will _____

Where is it filed? _____



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Important Information: Keep this form handy and accessible to all caregivers, so that it can be given to healthcare professionals when receiving treatment from a new doctor or emergency care.

Medical History

<p style="text-align: center;"><u>Current Prescriptions</u></p>	<p style="text-align: center;"><u>Over-the-Counter Drugs/Herbals</u></p>								
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Functional Assessment Checklist

Activities of Daily Living (ADLs)

Instrumental Activities of Daily Living (IADLs)

ACTIVITY	Needs No Assistance	Needs Some Assistance	Unable to Do	ACTIVITY	Needs No Assistance	Needs Some Assistance	Unable to Do
1. Eating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8. Prepare Light Meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Transferring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	9. Prepare Full Meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Dressing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	10. Light Housekeeping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Bathing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	11. Personal Laundry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Toileting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	12. Handling Money	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Continence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	13. Using Telephone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cognitive Assessment				Appliance/Aids Special Equipment Used by Patient			
ACTIVITY	Needs No Assistance	Needs Some Assistance	Complete Assistance	Prosthetic Device	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Cognitive Independence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Pacemaker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				Hearing Aid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				Tub Stool	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				Glasses/Lenses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				Hospital Bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				Commode	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				Special Dressing Equipment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				Colostomy Bag	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				Cane			<input type="checkbox"/>
				Dentures			<input type="checkbox"/>
				Walker			<input type="checkbox"/>
				Grab Bar			<input type="checkbox"/>
				Catheter			<input type="checkbox"/>
				Oxygen			<input type="checkbox"/>
				Wheelchair			<input type="checkbox"/>
				Leg Brace			<input type="checkbox"/>
				Other			<input type="checkbox"/>

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Caregiving Help

This website provides information, links, and educational videos that address many diverse caregiving situations. The information is arranged into five categories: services and benefits, help for caregivers, care alternatives, disease specific information, and more detailed discussion topics. State specific information is provided as well as information on financial, legal, housing, and many other topics of concern. Caregivers can also communicate with others using the message board. See www.e-careonline.net/resources.

Caregiving Online

An online resource, this website offers a number of online support groups addressing the needs of long distance caregivers, sandwich generation, male caregivers, and others. Caregivers can also participate in online book clubs, find answers to questions/concerns, and obtain advice. For more information visit www.caregiving.com.

Family Caregiver Alliance (FCA)

Founded in 1977, the FCA is a public voice for caregivers, offering assistance through education, services, research, and advocacy. The site contains many valuable resources such as fact sheets, publications, a newsletter, and a public policy section. You can also do a search for caregiver assistance and support services on a state by state basis. Visit www.caregiver.org.

National Alliance for Caregiving (NAC)

Established in 1996, the NAC 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. The website has a clearinghouse with over 1,000 consumer materials, books, and videos. National Alliance for Caregiving, 4720 Montgomery Lane, Fifth Floor, Bethesda, MD 20814. www.caregiving.org

National Association of Area Agencies on Aging (n4a)

The n4a is the umbrella organization for the 655 Area Agencies on Aging throughout the United States which provide information and services, and coordinate and administer programs for older adults. The federally-funded Eldercare Locator, established by the U.S. Administration on Aging in 1991, and administered by n4a in partnership with the National Association of State Units on Aging, provides callers with information about local services by zip code. Trained professionals, including a Spanish-speaking information specialist and a 150-language line service, answer callers to the

Eldercare Locator. Call 800-677-1116, 9:00 a.m.-8:00 p.m. ET, or go to www.n4a.org/locator. TDD/TTY access also is available with instructions provided online.

National Family Caregivers Association (NFCA)

The NFCA is a nonprofit organization dedicated to providing support and assistance to caregivers through information, education, public awareness, and advocacy. A quarterly newsletter called *Take Care! Self-Care for the Family Caregiver*, a support network, and many resources are available online for members. Membership is free to all family caregivers, and professionals, associations, and organizations are invited to join NFCA through memberships and contributions. Write to 10400 Connecticut Avenue, #500, Kensington, MD 20895-3944, call 800-896-3650, fax: 301-942-2302 or e-mail: info@nfcacares.org or go to www.nfcacares.org.

Useful Tools

Enclosed are three tools to assist you with providing care.

- Important Information Form
- Medical History Form
- Functional Assessment Checklist

About the Authors of Since You Care®

Since You Care guides are prepared by the MetLife Mature Market Institute in cooperation with the National Alliance for Caregiving and MetLife's Care Coordinators.

MetLife Mature Market Institute®

Staffed by gerontologists, the MetLife Mature Market Institute, part of the company's Retirement Strategies Group, has been providing research, knowledge management, education, and policy support for over ten years to 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. For more information about the MetLife Mature Market Institute, please visit the Mature Market Institute's website at www.MatureMarketInstitute.com.

MetLife Care Coordinators are available to MetLife's long-term care customers and their caregivers to help identify and resolve caregiving questions and concerns through counseling and referral.

National Alliance for Caregiving

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This booklet offers general advice, however, it is not a substitute for consultation with an appropriate professional. Please see a health care professional, attorney, or other appropriate professional when determining how the information and recommendations discussed in this booklet apply to your specific situation.

Endnotes

¹ *Caregiving in the U.S.*, National Alliance for Caregiving and AARP, April 2004.

² *Toward a National Caregiving Agenda: Empowering Family Caregivers in America*, National Alliance for Caregiving with Partnership for Caring, July 2001.

³ Ibid.

⁴ National Alliance for Caregiving and the United Hospital Fund, *Young Caregivers in the U.S.*, 2005.

⁵ *Caregiving in the U.S.*, National Alliance for Caregiving and AARP, April 2004.

⁶ Jacobs, Barry J. 2006. "The Emotional Survival Guide for Caregivers: Looking After Yourself and Your Family While Helping an Aging Parent." The Guilford Press.

⁷ *Caregiving in the U.S.*, National Alliance for Caregiving and AARP, April 2004.

⁸ Amanda K. Damjanovic, Yinhua Yang, Ronald Glaser, Janice K. Kiecolt-Glaser, Huy Nguyen, Bryon Laskowski, Yixiao Zou, David Q. Beversdorf, and Nanping Weng, *Accelerated Telomere Erosion Is Associated with a Declining Immune Function of Caregivers of Alzheimer's Disease Patients*. Journal of Immunology, September 2007; 179: 4249-4254.

⁹ *Caregiver Health*, Family Caregiver Alliance, via the Internet at www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1822, accessed 12/07.

¹⁰ National Alliance for Caregiving and Evercare. *Caregivers in Decline*. September 2006.

¹¹ Donelan, K, C.A. Hill, C. Hoffman, K. Scoles, P.H. Feldman, C. Levine and D. Gould. 2002. *Challenged to Care: Informal Caregivers in a Changing Health System*. Health Affairs 21:222-231.

¹² AARP Issue Brief. *Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving*. June 2007.

¹³ *The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business*. MetLife Mature Market Institute, and National Alliance for Caregiving. July 2006.

¹⁴ AARP Issue Brief. *Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving*. June 2007.