

SINCE YOU CARE

A Series of Guides from MetLife[®] in Cooperation with the National Alliance for Caregiving

Family Caregiving

About the Subject

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 their 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 now require some type of long-term care.²
- At least 10 million will have such needs by 2020 and 14 million by 2040.³



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

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. Recent 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.⁴

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 tasks of providing care. “Those who provide care to others often overlook their own needs, believing that they must take a backseat to their loved ones,” according to Dr. Steven Zarit, Ph.D., Professor of Human Development and Assistant Director of the Gerontology Center at Penn State University.⁵

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 rest and relaxation.

While it is easy to become lost in the many issues of caregiving, it is critical to maintain your own life, complete with social, physical and emotional interactions. There is no need to feel guilty about taking some time to take care of yourself. 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 the person’s functional ability. Different people will have different care needs and thus require varying levels of care. A care recipient who is unstable on her feet, forgetful (forgetting to turn the stove off or neglecting to take 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.

Talk with the care recipient and involve her with care decisions as much as possible. Keep the lines of communications open because problems or concerns are best addressed earlier than later.

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 this is not always possible and that you may need to enlist the services of others from outside the home. To help avoid miscommunication, be specific in your request of others.

Planning

Planning can help eliminate anxiety caused by the unknown. 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 care recipient’s medical history is kept and where you can locate support information.
- Try to stay focused and prioritize, 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.⁶ Generally, stress is what you feel when the demands on your

life exceed your ability to meet those demands. There can be physical reactions to prolonged stress such as immune system changes or cardio-vascular disease and it may worsen existing 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 sweets, cookies, and other high-carbohydrate, 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. Hiring someone to assist with caregiving during the night will help you get a good night's sleep.



Psychological and Emotional Health

Your emotional and psychological health is important and can affect your physical health. Feelings of guilt and inadequacy, while common, are not well founded. Give yourself credit for the things you do well and be realistic about what may or may not be possible. Recognize the anger-guilt-anger cycle and stop it immediately by forgiving yourself for being angry. It is very easy to become socially isolated from other friends and family, without even realizing it is happening. Give yourself adequate time each week for relaxation; ask for the assistance of others to make time for you or inquire about respite care provided by nursing facilities or home care agencies. Respite care offers temporary care to individuals so that the caregiver can rest or travel.

Impact on Job and Career

Caregiving responsibilities often have a more severe effect on job obligations and free time than individuals first realize. Caregivers spend, on average, eight years providing care and about one-third provide care for more than 10 years. Studies estimate that the work of unpaid caregivers would be worth

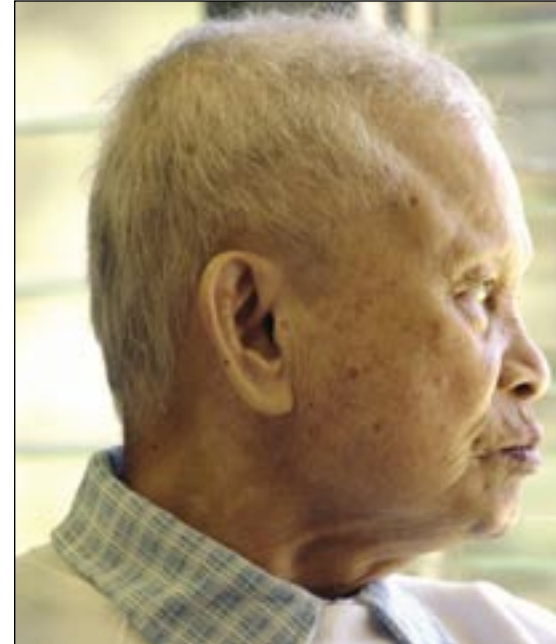
\$257 billion per year if caregiving were performed by paid home care workers.⁷ By 2007, employed caregivers are expected to number approximately 11-15.6 million working Americans, or one in ten employed workers.⁸

Working caregivers who go from full-time to part-time status or leave a job to perform caregiving responsibilities experience an average lifetime total wealth loss of \$659,139. This figure includes lost wages, Social Security and pension benefits.⁹

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, or home modification.

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 and benefit both the caregiver and receiver.

Helpful Hints

- Community resources for support, such as Meals on Wheels, Friendly Visitors or volunteers 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, or 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, flex-

ible scheduling and 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.

- Consider placing the individual in adult day care during working hours. This will provide you with a safe, caring environment for your loved one and significantly reduce the amount of time you would need to spend out of work. Some adult day care facilities provide transportation; others do not, so be sure you know what each offers before making a decision.

Resources to Get You Started

Books and Publications

And Thou Shalt Honor:

The Caregiver's Companion

This book is based on the PBS special, *And Thou Shalt Honor*, that aired October 2002. It contains useful checklists, tips and information for caregivers and their families. McLeod, B., Witrogen (ed). Rodale, Inc., 2002.

\$24.95 ISBN 1579545580

How to Care for Aging Parents: A Complete Guide

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. (1996). New York, NY: Workman Publishing Company.
\$15.95 ISBN: 1563954353

Resources for Caregivers

This guide was prepared by the National Alliance for Caregiving and the MetLife Mature Market Institute to assist individuals and families who have assumed the role of caregiver, or anticipate future caregiving. Single copies are available free from:

MetLife Mature Market Institute
57 Greens Farms Road
Westport, CT 06880

You may also call 203-221-6580 or e-mail MatureMarketInstitute@metlife.com.

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. (1998). Portland, OR: Caretrust Publications.

\$23.00 ISBN: 0966476700

The Complete Guide to Eldercare

This book offers advice on how to provide for elders' everyday needs and how to cope with illness. It also includes a section on financing eldercare. Resource appendix included. Directed at consumers, but a helpful guide for professionals. Jones-Lee, A. and Callender, M. (1998). Woodbury, NY: Barron's Educational Series.

\$14.95 ISBN: 0764101730

The 36 Hour Day

A guide and narrative for anyone caring for an individual with Alzheimer's Disease or related dementias. Mace, N. and Rabins, P. (2001). Warner Books \$7.99 ISBN: 0446610410. A large-print edition is available for \$13.97. (2001). Johns Hopkins Univ. Press ISBN: 0801865212

Internet Sites

AARP

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. Write AARP, 601 E Street, NW, Washington, DC 20049, call 800-424-3410 TTY: 877-434-7598, or access their Web site at www.aarp.org.

Administration on Aging (AoA)

This site is maintained by the U.S. Department of Health and Human Services and provides resources, news and developments and information for older adults. www.aoa.dhhs.gov

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

Caregiving Online

Caregiving Online, sponsored by *Caregiving Newsletter*, helps caregivers stay well by providing information about support and resources such as an online *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 checklists for financial planning, long-term care insurance and nursing home placement. www.careguide.com

Family Caregiver Alliance (FCA)

Founded in 1977, the FCA is a public voice for caregivers, help-

ing them through their daily challenges and offering them needed assistance and championing their cause through education, services, research and advocacy. The site contains many resources such as fact sheets, publications, a newsletter and a public policy section. 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. The Alliance was created to conduct research, do policy analysis, develop national programs and increase public awareness of family caregiving issues. The Web site 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, provides callers with information about local services by zip code. Call 800-677-1116, 9:00 a.m.-8:00 p.m. ET, or go to www.n4a.org.

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 open to individuals as well as corporations and ranges from \$20 to \$200 annually. 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.

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

About the Authors of Since You CareSM

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

MetLife Mature Market InstituteSM is the company's information and policy resource center on issues related to aging, retirement, long-term care and the mature market.

MetLife Nurse Care Managers are available to MetLife's long-term care customers and their caregivers, on a daily basis, to help identify and resolve caregiving questions and concerns through counseling and referral.

National Alliance for Caregiving is a non-profit coalition of 38 national organizations that focuses on issues of family caregiving.

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This information is general in nature. It is not a substitute for obtaining guidance from a healthcare, financial or other professional.

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 *Caregiving in the U.S.*, National Alliance for Caregiving and AARP, April 2004.
- ⁵ National Alzheimer's Association Advances Newsletter, 2001.
- ⁶ *Caregiving in the U.S.*, National Alliance for Caregiving and AARP, April 2004.
- ⁷ Arno, P., *Economic Value of Informal Caregiving: 2000*, Presented at the American Association for Geriatric Psychiatry, February 24, 2002.
- ⁸ *The MetLife Juggling Act Study - Balancing Caregiving with Work and the Costs Involved*, MetLife Mature Market Institute, November 1999.
- ⁹ Ibid.

Important Information

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?

Important Information

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>			
<p style="text-align: center;"><u>Chronic Conditions</u></p>	<table><thead><tr><th data-bbox="933 934 997 961"><u>Date</u></th><th data-bbox="1077 898 1220 926"><u>Surgeries</u></th><th data-bbox="1268 934 1364 961"><u>Reason</u></th></tr></thead></table>	<u>Date</u>	<u>Surgeries</u>	<u>Reason</u>
<u>Date</u>	<u>Surgeries</u>	<u>Reason</u>		
<table><thead><tr><th data-bbox="231 1495 295 1522"><u>Date</u></th><th data-bbox="327 1459 566 1486"><u>Hospitalizations</u></th><th data-bbox="566 1495 662 1522"><u>Reason</u></th></tr></thead></table>	<u>Date</u>	<u>Hospitalizations</u>	<u>Reason</u>	<p style="text-align: center;"><u>Allergies</u></p>
<u>Date</u>	<u>Hospitalizations</u>	<u>Reason</u>		

Functional Assessment Checklist

Activities of Daily Living (ADLs)

ACTIVITY	Needs No Assistance	Needs Some Assistance	Unable to Do
1. Eating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Transferring	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Dressing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Bathing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Toileting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Continence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Instrumental Activities of Daily Living (IADLs)

ACTIVITY	Needs No Assistance	Needs Some Assistance	Unable to Do
8. Prepare Light Meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Prepare Full Meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Light Housekeeping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Personal Laundry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Handling Money	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Using Telephone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Cognitive Assessment

ACTIVITY	Needs No Assistance	Needs Some Assistance	Complete Assistance
7. Cognitive Independence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appliance/Aids Special Equipment Used by Patient

Prosthetic Device	<input type="checkbox"/>	Cane	<input type="checkbox"/>
Pacemaker	<input type="checkbox"/>	Dentures	<input type="checkbox"/>
Hearing Aid	<input type="checkbox"/>	Walker	<input type="checkbox"/>
Tub Stool	<input type="checkbox"/>	Grab Bar	<input type="checkbox"/>
Glasses/Lenses	<input type="checkbox"/>	Catheter	<input type="checkbox"/>
Hospital Bed	<input type="checkbox"/>	Oxygen	<input type="checkbox"/>
Commode	<input type="checkbox"/>	Wheelchair	<input type="checkbox"/>
Special Dressing Equipment	<input type="checkbox"/>	Leg Brace	<input type="checkbox"/>
Colostomy Bag	<input type="checkbox"/>	Other	<input type="checkbox"/>