



Caregiver Self-assessment Questionnaire

How are YOU?

Caregivers are often so concerned with caring for their relative's needs that they lose sight of their own well-being. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have...

- | | |
|---|--|
| <p>1 Had trouble keeping my mind on what I was doing. <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>2 Felt that I couldn't leave my relative alone. <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>3 Had difficulty making decisions. <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>4 Felt completely overwhelmed. <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>5 Felt useful and needed. <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>6 Felt lonely. <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>7 Been upset that my relative has changed so much from his/her former self. <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>8 Felt a loss of privacy and/or personal time. <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>9 Been edgy or irritable. <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>10 Had sleep disturbed because of caring for my relative. <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>11 Had a crying spell(s). <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>12 Felt strained between work and family responsibilities. <input type="checkbox"/> Yes <input type="checkbox"/> No</p> | <p>13 Had back pain. <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>14 Felt ill (headaches, stomach problems or common cold). <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>15 Been satisfied with the support my family has given me. <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>16 Found my relative's living situation to be inconvenient or a barrier to care. <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>17 On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress.
_____</p> <p>18 On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year. _____</p> |
|---|--|

Self-evaluation

To determine the score:

- Reverse score questions 5 and 15. *(For example, a "No" response should be counted as "Yes" and a "Yes" response should be counted as "No.")*
- Total the number of "yes" responses.

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It Starts with a Conversation...

Are you worried about having “the talk” with an elder about his or her future? Here are some tips on how to start.

Talk with other family members first. Give everyone a chance to discuss his or her concerns so that you all agree on the need for the conversation.

Decide who should be there. You may or may not want to include other family members, such as siblings. A favorite family member may help ease the tension, but having too many people may feel overwhelming. The elder’s doctor can also help you begin the conversation.

Be prepared. What issues do you want to talk about? If you are proposing a solution to something, do your homework and come with the necessary information.

Find a comfortable place and time. Where does the elder like to relax—at the dinner table, in the garden, or on a walk? It may be helpful to start the conversation there.

Introduce the topic by talking about an article, television show, or a friend whose parent may be having a similar problem. The elder will be reminded that he or she is not the only person whose life is changing.

Don’t assume that you are the only one who needs to talk. You may be surprised that the elder is relieved to start the conversation.

Start with small steps, small decisions, and small changes. If you are worried about the elder’s health, safety, or cleanliness, focus on that particular issue. Don’t overwhelm the elder.

It’s a conversation, not a lecture. Seek the elder’s input and listen to his or her perspective. Be patient. Discuss solutions together.

Respect the elder’s feelings and concerns. The elder may deny that there is a problem. Be supportive and sympathetic. Arguing will just make it worse.

Suggest a follow-up conversation. It’s a lot to take in at once. Give the elder—and yourself—time to think about the options.

End the conversation on a good note. You have made progress just by getting the issues out in the open.

At the Doctor's

Gathering, understanding, and managing medical information for an elder is one of the caregiver's major tasks. Here are some tips on how to get the most out of visiting the doctor with the elder in your care.

Before the Appointment

- 1 Write down questions or issues that you'd both like to discuss with the doctor.
- 2 Prioritize the questions so that you are sure to cover the most important questions first.
- 3 Make a list of any changes since the last visit: physical (bumps or bruises, new glasses or hearing aids, difficulty sleeping, etc.) and emotional (a move, an accident, the loss of a loved one).
- 4 Bring along all medications, the dosages, and who prescribed them. Include any natural remedies, supplements, and over-the-counter drugs. (If you can't bring them all, make a list.) Include the pharmacy's name and phone number.

At the Appointment

- 1 Find out how the doctor's office works: the names of his or her office staff, nurses, or physician's assistant; office hours and locations; lab procedures; emergency coverage; and hospitals you will be referred to.
- 2 Remember to get several copies of the doctor's card to keep at home, at work, and so on.
- 3 Ask to be present during the initial consultation (and the examination if possible).
- 4 After the examination, ask to be included in the discussion about findings and treatments.
- 5 Ask questions until you understand all the information the doctor is giving you. Don't let him or her rush you out. There is no such thing as a wrong or stupid question!
- 6 If a drug or treatment is recommended, ask why it's being prescribed, what its potential side effects are, what the expected outcomes are, and what other options are. The doctor or staff may also know about insurance coverage or payment options.
- 7 Take careful notes. Ask if there are pamphlets or Web sites that can provide more information.
- 8 Find out who you can call, and when, if you have additional questions after your visit.

The Caregiver's Handbook: A Companion Resource to Caring for Your Parents at pbs.org/caringforyourparents/community/index.html contains a wealth of information about all aspects of caregiving, including health care and home care issues.

Additional Resources

- “Talking with Your Doctor” from the National Institutes of Health’s Senior Health Web site explains how to prepare for the visit, and how to understand the more technical aspects of health care, such as diagnoses and follow-up lab tests. Go to <http://nihseniorhealth.gov/talkingwithyourdoctor/toc.html>.
- “Be Prepared for Medical Appointments” from the Department of Health and Human Services’ Agency for Healthcare Research and Quality contains a list of questions you can print and take with you to the doctor’s office. Go to www.ahrq.gov/qual/beprepared.htm or call 301-427-1364 and request AHRQ Publication No. 07-0039-A, May 2007.
- “Talking with Your Doctor” from the Medline Plus Web site at www.nlm.nih.gov/medlineplus/talkingwithyourdoctor.html has resources and links in both English and Spanish.

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List of Important Documents

	Where to find it	Notes and updates
Health Insurance Policies		
Primary Health Insurance	_____	_____
Supplemental Medical Insurance	_____	_____
Medicare Card	_____	_____
Long-term Care Insurance	_____	_____
Disability Insurance	_____	_____
Life Insurance (Agent, Beneficiaries)	_____	_____
Funeral Insurance Policy	_____	_____
Financial Accounts and Valuables		
Safety Deposit Box and Keys	_____	_____
Checking and Savings Accounts	_____	_____
Brokerage Accounts	_____	_____
Stocks and Bonds	_____	_____
Jewelry/Coins	_____	_____
Appraisals and Inventory Lists	_____	_____
Retirement and Benefit Plans		
401k Plans	_____	_____
Profit Sharing/Pension Plans	_____	_____
IRA Accounts	_____	_____
Military Benefits/Records	_____	_____
Social Security Records	_____	_____
Debt		
Credit Cards	_____	_____
Outstanding Bills/Loans	_____	_____
Taxes		
Annual Income Tax Records	_____	_____
Property Tax Records	_____	_____

LIST OF IMPORTANT DOCUMENTS

	Where to find it	Notes and updates
Personal Legal Documents		
Birth Certificate	_____	_____
Passport	_____	_____
Citizenship Papers	_____	_____
Marriage Certificate/Divorce Records	_____	_____
Will	_____	_____
Other Legal Documents		
Contracts	_____	_____
Partnership Agreements	_____	_____
Deed to House	_____	_____
Mortgage (or Rental Lease)	_____	_____
Homeowner's Insurance	_____	_____
Automobile Title	_____	_____
Automobile Insurance	_____	_____
Driver's License	_____	_____

Legal and Financial Advisers

ACCOUNTANT Name: _____

Address: _____ Phone: _____

ATTORNEY Name: _____

Address: _____ Phone: _____

EXECUTOR/TRUSTEE Name: _____

Address: _____ Phone: _____

CO-EXECUTOR/TRUSTEE Name (if any): _____

Address: _____ Phone: _____

OTHER: _____

Address: _____ Phone: _____

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Selected Books and Web Sites

In addition to the extensive information in *The Caregiver's Handbook: A Resource Companion to Caring for Your Parents* (pbs.org/caringforyourparents/community/index.html), these books and Web sites will help you cope with the challenges of caregiving.

American Medical Association Guide to Home Caregiving. Wiley, 2001.

This sourcebook describes the emotional and practical aspects of home care and includes a section on organizations and resources.

Caring for Your Parents: The Complete AARP Guide, by Hugh Delehanty and Elinor Ginzler. AARP Books, 2008.

Filled with tips, advice, and strategies, this book helps readers with practical issues as well as how to transform caregiving into an act of spiritual growth and personal discovery.

The Caregiver's Survival Handbook: How to Care for Your Aging Parent Without Losing Yourself, by Alexis Abramson. Perigree, 2004.

Aimed primarily at the millions of women who are caregivers, this book offers insights into how to cope with the emotional and psychological demands of caregiving.

The Complete Eldercare Planner, Second Edition: Where to Start, Which Questions to Ask, and How to Find Help, by Joy Loverde. Three Rivers Press, 2000.

This workbook covers common issues, checklists, and action steps for caring for elders, including finances, legal concerns, insurance, housing, medical care, and death and dying.

Coping with Your Difficult Older Parent: A Guide for Stressed-out Children, by Grace Lebow, Barbara Kane, and Irwin Lebow. Harper, 1999.

This commonsense guide offers advice on how to deal with anger, guilt, frustration, and blame in order to make communicating with a challenging elder easier.

Eldercare 911: The Caregiver's Complete Handbook for Making Decisions, by Susan Beerman and Judith Rappaport-Musson. Prometheus, 2002.

Written primarily for women, this is a reassuring and comprehensive guide to caregiving issues.

How to Care for Aging Parents, by Virginia Morris and Robert M. Butler. Workman, 2004.

A thorough guide to the emotional, legal, financial, medical, and logistical issues in caring for elders, including a directory of services.

The 36-hour Day: A Family Guide to Caring for Persons with Alzheimer Disease, Other Dementia Illnesses, and Memory Loss in Later Life, by Nancy L. Mace and Peter V. Rabins. Johns Hopkins University Press, 2006.

Now in its fourth edition, this is a manual for family caregivers struggling to cope with these progressive diseases.

AARP

www.aarp.org

1-888-OUR-AARP (1-888-687-2277)

AARP is a nonprofit, nonpartisan membership organization that helps people 50+ have independence, choice, and control in ways that are beneficial and affordable to them and society as a whole. It produces *AARP The Magazine*, *AARP Bulletin*, *AARP Segunda Juventud*, and *NRTA Live & Learn*. Its Web site contains information on all aspects of aging and caregiving. It has staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.

Caring for Your Parents

www.pbs.org/caringforyourparents

This extensive Web site, to accompany the PBS film *Caring for Your Parents*, provides the complete video, plus a 30-minute follow-up discussion, “A Conversation About Caring,” led by Dr. Art Ulene. You can also download *The Caregiver’s Handbook*, a comprehensive compendium of advice and information at www.pbs.org/caringforyourparents/handbook.html.

Eldercare Locator

www.eldercare.gov

800-677-1116

This free, national service of the U.S. Administration on Aging (www.aoa.gov/) and the National Association of Area Agencies on Aging (www.naa.org/) is the key to finding information, referrals, and agencies in your community.

Family Caregiver Alliance

www.caregiver.org

800-445-8106

This national network addresses the needs of families and friends providing long-term care at home. The Web site includes information, free publications, and an online caregiver support discussion group.

National Alliance for Caregiving

www.caregiving.org

This nonprofit coalition of national organizations focuses on issues of family caregiving across the life span. Along with the National Family Caregivers Association, they have created “Family Caregiving 101” at www.familycaregiving101.org, a comprehensive “course” on caregiving.

National Association of Social Workers (NASW)

www.socialworkers.org

202-408-8600

A membership organization for social workers, this Web site offers advice and information on how to find support, including locating a licensed social worker at www.HelpStartsHere.org.

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Checklist of Activities of Daily Living (ADL)

Check the level of function of each activity of daily living listed below. This will help you determine how much assistance an elder needs.

FUNCTION	INDEPENDENT	NEEDS HELP	DEPENDENT	DOES NOT DO
Bathing				
Dressing				
Grooming				
Oral Care				
Toileting				
Transferring				
Walking				
Climbing Stairs				
Eating				
Shopping				
Cooking				
Managing Medications				
Using the Phone				
Housework				
Doing Laundry				
Driving				
Managing Finances				

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The Joys of Caregiving

Yes, caregiving can be confusing, stressful, and exhausting. But it can also bring you unexpected joys, experiences, and relationships.

Caregiving can bring you closer to the elder in your care. Whatever your relationship was in the past, caring for an elder can bring a new perspective for each of you, resulting in newfound respect, admiration, and understanding.

Caregiving can help you spend more quality time with an elder. You may be able to slow down and do things you may never have had time for before—talk, laugh, reminisce, watch TV or movies together.

Caregiving can get you in touch with your family history. Encouraging the elder in your care to talk about the past can bring new understanding to the events that helped shaped you and your family. Bring out those boxes of old photos and dive in.

Caregiving can sharpen your organizational and multitasking skills. Despite the burdens of caregiving, you may find that you are more competent than you thought.

Caregiving can bring you a deeper sense of your own values. As you talk about and experience end-of-life issues, you'll be able to better define what you believe in.

Caregiving may help you recognize your own support systems. Friends, relatives, coworkers, and health professionals who cheer you up, comfort you, and show concern may unexpectedly enrich your life.

Caregiving can make you more compassionate and loving. You may think you don't have the patience or the personality to care for an elder—but you do. Rising to the challenge of caregiving helps you recognize your own strengths and abilities.

Caregiving can help you plan for your own future. Your experience with aging and caregiving issues will make you better prepared to think and plan ahead for your own needs.

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