


Caregiver Resources



CAREGIVER RESOURCES

An Infopeople Webinar
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Presented by Kelli Ham

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Objectives

- Understand the spectrum of caregiving topics, from daily tasks to the issues and challenges facing people who are in caregiver situations
- Be aware of caregiver resources for specific conditions, such as Alzheimer’s disease
- Be able to find resources regarding financial issues and housing decisions
- Be able to provide support resources for the health and wellbeing of the caregiver

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Overview

- People are living longer with chronic or debilitating conditions
- Adults often find themselves in caregiver roles for parents or spouse, a child or disabled person
- Most people are unprepared and untrained for this role
- Providing care for a loved one can take a tremendous toll on the caregiver, in terms of emotional health, physical health, and financial status.



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Caregiver Resources

Statistics: Numbers and Health

More than 65 million people, 29% of the U.S. population, provide care for a chronically ill, disabled or aged family member or friend during any given year and spend an average of 20 hours per week providing care for their loved one.

Nearly three quarters (72%) of family caregivers report not going to the doctor as often as they should and 55% say they skip doctor appointments for themselves. 63% of caregivers report having worse eating habits than non-caregivers and 58% indicate worse exercise habits than before caregiving responsibilities.

Evercare Study of Caregivers in Decline: A Close-Up Look at Health Risks of Caring for a Loved One, National Alliance for Caregiving and Evercare, 2006

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Statistics: Work and Finances

Among employed caregivers (73%), two-thirds have gone in late, left early, or taken time off during the day to deal with caregiving issues (66%). One in five took a leave of absence.

Caregiving in the United States, National Alliance for Caregiving in collaboration with AARP, November 2009

47% of working caregivers indicate an increase in caregiving expenses has caused them to use up ALL or MOST of their savings.

Evercare Survey of the Economic Downturn and Its Impact on Family Caregiving, National Alliance for Caregiving and Evercare, March 2009

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Your Thoughts

For those of you who have been a caregiver or know about caregiving from another perspective, please use the chat box and write in a word or phrase that comes to your mind when thinking about the experience.

You may submit more than one entry. After we get a number of entries, we will discuss the common themes.

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Caregiver Resources

Range of Emotions is Normal


- Common emotions are both positive and negative
- Guilt, anger, sadness, feelings of helplessness
- Also feelings of gladness from being there for loved one, comfort, opportunity to spend quality time
- Feeling of usefulness, worth, being helpful



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Mental and Physical Effects

- Enormous stress
- Clinical depression
- Physical injuries, such as back strain
- Lowered immune system
- Sleep disorders
- Health issues from not exercising, poor nutrition, skipping routine checkups and tests



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When the Caregiver Comes to the Library

- As librarians know, people with health questions can be upset about a scary diagnosis, angry or fearful. The caregiver is facing these and other issues – worry, own health issues, and under stress.
- Learn as much as possible about the caregiver’s individual situation.
- Offer resources specific to situation and also refer to general resources that will provide help as the situation progresses.

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Caregiver Resources

The Good News

While it won't fix problems, having access to information and knowledge about services can go a long way towards helping the caregiver!

What follows –

- The big picture – legal and ethical issues, starting the conversation
- Resources about caregiving tasks – what needs to be done on a day by day basis such as learning how to lift or bathe a person, managing meds, or even choosing a nursing home
- Resources to help care for the caregiver

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Starting the Conversation

Talking with parents or a loved one about sensitive issues can be difficult, but extremely important. Here is a resource to help get started:



FACE THE FACTS: Must-Have Conversations About Aging
http://www.n4a.org/pdf/Conversations_on_Aging.pdf

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The Bigger Picture

The best case scenario is when the person who needs care has already made decisions and provided instructions about their care, or is willing to take that step.



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Caregiver Resources

Resources for Legal Issues

Family Caregiver Alliance
Good place to start for information about advance directives, living wills, and legal issues such as LGBT caregiving situations.
<http://www.caregiver.org>

AGS Foundation for Health in Aging
Well-organized and easy to use, explaining all of the issues related to choices for life sustaining treatment and much more.
http://www.healthinaging.org/agingintheknow/chapters_ch_trial.asp?ch=4

Caring Connections
Information about Advance Directives and links to download state-specific forms
<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289>

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End-of-Life Issues





End of Life: Helping With Comfort and Care
This 68-page guide discusses key issues at the end of life. Topics include finding hospice care, what happens at the time of death, managing grief, and preparing advance directives along with resources for more information. Free; also available as a PDF.
<http://www.nia.nih.gov/health/publication/end-life-helping-comfort-and-care>

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Locating Services and Benefits

<p>Eldercare.gov The Eldercare Locator from the U.S. Administration on Aging is a directory of services for older adults.</p>	<p>BenefitsCheckup.org A directory of benefit programs that can help pay for medications, health care, food, utilities and other necessities.</p>
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Caregiver Resources

Medicare and Medicaid Information

Medicare.gov is the primary source of information for all Medicare questions, including choosing a nursing home. The 4-minute video on the Caregivers website is worth watching:
<http://medicare.gov/caregivers/>

Medicaid.gov has basic information about Medicaid. For state-specific information, click on the map to drill down to information on Medicaid programs in each state.

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Understanding Insurance

Health Insurance Counseling and Advocacy Program (HICAP)

HICAP is a federal program that assists people with information on Medicare, Medicare supplement insurance, managed care, long-term care planning and health insurance, and other health insurance concerns.

California: http://www.aging.ca.gov/programs/hicap_contacts.asp

In other states: Directory of State Health Insurance Counseling and Assistance Plans
http://www.payingforseniorcare.com/longtermcare/resources/state_health_insurance_programs.html

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Daily Caregiving: Wide Range of Activities

- Running errands
- Grocery shopping
- Preparing meals
- Housekeeping and yard work
- Bill paying
- Driving to appointments
- Help with getting dressed
- Brushing teeth and combing hair
- Assisting with getting in and out of chairs or bed
- Help in using the toilet
- Bathing
- Feeding

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Caregiver Resources

Day to Day Activities

Hands-on Skills for Caregivers
Five techniques to help caregivers take care of a loved one's physical needs.
http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=787

Dental Care Every Day: A Caregiver's Guide
Illustrated, step-by-step guide for providing daily dental care such as brushing and flossing.
<http://www.nidcr.nih.gov/OralHealth/Topics/DevelopmentalDisabilities/DentalCareEveryDay.htm>



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Day to Day Activities - Continued

Lifting Techniques for Home Caregivers
Illustrations and instruction for proper lifting and moving techniques to prevent injury to the caregiver
<http://orthoinfo.aaos.org/topic.cfm?topic=A00096>

Rehabilitation Tip Sheets
Step-by-step instructions and photo illustration for wheelchair positioning, assisted pressure relief, lifting and transfers, and swallowing strategies.
<http://www.spinalcord.uab.edu/show.asp?durki=90249>

Activities of Daily Living: Tips for the Family Caregiver
Helpful information about ADL assessments to determine needed levels of care, plus useful tips for the caregiver
<http://www.seniornavigator.org/virginiannavigator/DetailSN.aspx?contentid=51&f=1>

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Special Situations for Caregivers

- Disease or Condition
 - Alzheimer's Disease
 - Cancer
 - Many others
- Care Recipient
 - Special needs child
 - Elderly parent
 - Injured veteran
- Long Distance Caregiving



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Caregiver Resources

Some Basics for Special Situations

- Caregivers need to know the basics of the condition(s) their loved one is facing (diabetes, COPD, heart failure) in order to help provide appropriate care.
- Knowledge of quality health information sites such as MedlinePlus.gov can be very useful.
- Hospital social workers are very knowledgeable about resources through the hospital or community.
- Check with the patient’s healthcare institution to see if there is any specialized training for caregivers.

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Alzheimer’s Disease



Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide

This comprehensive, 136-page handbook from the National Institute on Aging offers easy-to-understand information and advice for at-home caregivers of people with Alzheimer’s disease. It addresses all aspects of care, from bathing and eating to visiting the doctor and getting respite care.

<http://www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease>

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ALS (Lou Gehrig’s Disease)

Muscular Dystrophy Association ALS Caregiver’s Guide

- Comprehensive 200 page guide from the Muscular Dystrophy Association
- Covers emotional and financial concerns, everyday care tasks and finding help
- Addresses topics such as nutrition, breathing, communication, finances, insurance accessibility and much more
- Can be ordered online; each section is also available as a separate PDF

<http://www.als-mda.org/publications/alscare/>

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Caregiver Resources

Caregiving from Afar

So Far Away: Twenty Questions and Answers About Long-Distance Caregiving

Using a question-and-answer format, this beautifully illustrated, 44-page booklet offers information about caregiving from afar. It explores topics such as complex family relationships, legal issues, housing options, and advance directives.



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Taking Care of the Caregiver

Caregivers often are the type of people who don't ask for help themselves; they are problem solvers, doers, and very capable people. They often find it hard to ask for help, or accept help. Support comes in many forms:

- Print and online resources
- Online support groups
- Mental health/social workers
- Respite
- Directories of services
- Personal support networks, friends, family

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MedlinePlus.gov Caregiver Health Topic



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Caregiver Resources

Examples of MedlinePlus Resources

Coping

- [Caring and Depression](#) (Family Caregiver Alliance), Also in [Spanish](#)
- [Caring for the Caregiver](#) (National Cancer Institute), Also in [Spanish](#)
- [Respite Care](#) (Administration on Aging)
- [Taking Care of You: Self-Care for Family Caregivers](#) (Family Caregiver Alliance)

Specific Conditions

- [ALS Caregiver's Guide](#) (Muscular Dystrophy Association)
- [Cancer: End-of-Life Issues for the Caregiver](#) (American Academy of Family Physicians), [Spanish](#)
- [Caring for Adults with Cognitive and Memory Impairments](#) (Family Caregiver Alliance), [Spanish](#)
- [Caring for Someone with AIDS at Home](#) (Centers for Disease Control and Prevention), [Spanish](#)
- [Caring for Someone with Developmental Disabilities](#) (Administration on Aging) - PDF
- [Caring for the Elderly: Dealing with Resistance](#) (Mayo Foundation for Medical Education and Research)
- [Families with Special Needs: Caregiving Tips](#) (Centers for Disease Control and Prevention)
- [Family Caregivers in Cancer \(PDQ\)](#) (National Cancer Institute)

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MedlinePlus Resources – Continued...


Related Issues

- [Adult Day Care](#) (Administration on Aging)
- [Assistive Technology](#) (Family Caregiver Alliance)
- [Caring and Sibling Relationships: Challenges and Opportunities](#) (Family Caregiver Alliance)
- [Community Care Options](#) (Family Caregiver Alliance), Also available in [Spanish](#)
- [Emergency Readiness for Older Adults and Caregivers](#) (Administration on Aging) - PDF
- [Guidelines for Better Communication](#) (Family Caregiver Alliance)
- [Hands-On Skills for Caregivers](#) (Family Caregiver Alliance)
- [Holding a Family Meeting](#) (Family Caregiver Alliance)
- [Information Caregivers Can Use on: Speaking with a Friend or Family Member's Doctor During an Office Visit](#) (Centers for Medicare & Medicaid Services) - PDF
- [Information for Caregivers](#) (American Health Information Management Association)
- [LGBT Caregiving: Frequently Asked Questions](#) (Family Caregiver Alliance)
- [Lifting Techniques for Home Caregivers](#) (American Academy of Orthopaedic Surgeons)

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Basics of Caring for Yourself

- Educate yourself about the disease or medical condition
- Become part of the healthcare team
- Consult with other experts if necessary (legal, financial)
- Tap your social resources
- Take time for relaxation and exercise
- Use community resources
- Maintain your sense of humor
- Set realistic goals
- Explore religious beliefs and spiritual values



http://www.aoa.gov/AoARoot/Press_Room/Products_Materials/fact/pdf/Taking_Care_Yourself.pdf

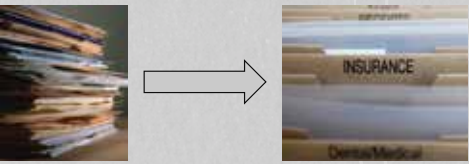
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Caregiver Resources

A Few More Things


- Creating and maintaining an organized filing system reduces stress
- Person handling the affairs of another will need power of attorney to speak to doctor, bank, insurers, even the cable company.



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Make Time


- Caregivers need to make time for the others in their life; it's vital for everyone



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Resources for the Caregiver

- Nicely designed page for caregivers of people with heart disease, but information applies to caregivers in all situations.
http://www.heart.org/HEARTORG/Caregiver/Caregiver_UCM_001103_SubHomePage.jsp
- Wonderful resources, including a set of Journal pages for the caregiver.



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Caregiver Resources

Finding Support Groups

- Local resources – hospital social worker, community organizations
- Area Agency on Aging
- Online resources for specific conditions – often have support group directories
- Online support groups



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Seek Out Local and State Services

Area Agency on Aging

- California divided into 33 PSAs (Planning and Service Areas)
http://www.c4a.info/index.php?option=com_content&view=article&id=4&Itemid=4

California Caregiver Resource Centers

- 11 non-profit centers throughout state
<http://www.californiacrc.org/californiacrc/jsp/home.jsp>

The National Family Caregiver Support Program

- Provides information about caregiver programs and services, counseling, training services and respite
http://www.nei.nih.gov/nehcp/about/partnership/nehcp_partnership_organizations.pdf

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Building a Small Collection

The National Institutes of Health
Free and low-cost publications for consumers

Examples:

National Diabetes Information Clearinghouse
<http://diabetes.niddk.nih.gov/>

National Cancer Institute
"What You Need to Know About" series
<http://www.cancer.gov/cancertopics/wyntk>

Building & Running a Small Resource Center: a toolkit
Published by the Alzheimer's Association, the guide includes information useful to any organization interested in building and running a small resource center.
<http://www.alz.org/library/downloads/BuildingSmallResourceCenter2.10.pdf>

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Caregiver Resources

Caregiver DVDs



The Savvy Caregiver program is a training program for caregivers of persons with memory loss or dementia.

<http://www.memorylossdvd.com/>

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Tip: Quick Path to Information

Remember to use MedlinePlus for quick checks on caregiver information for just about any topic



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This Affects All of Us

Caregiving is probably affecting library staff members at any given time. Identify resources in your own institution:

- Flexible spending accounts for dependent care
- Family leave time
- community resources

http://www.thefamilycaregiver.org/who_are_family_caregivers/care_giving_statistics.cfm



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Thank You!

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