



# CAREGIVER RESOURCES

An Infopeople Webinar

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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

# 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.



# 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

# 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

# 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.

# 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



# 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





# 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.

# 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

# 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](http://www.n4a.org/pdf/Conversations_on_Aging.pdf)

# 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.



# 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.

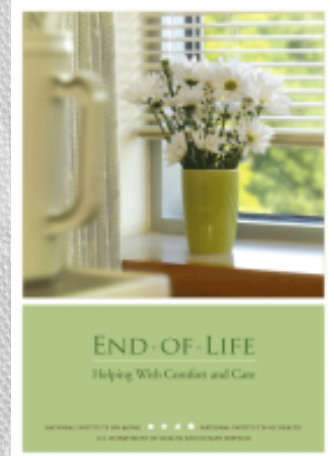
[http://www.healthinaging.org/agingintheknow/chapters\\_ch\\_trial.asp?ch=4](http://www.healthinaging.org/agingintheknow/chapters_ch_trial.asp?ch=4)

## Caring Connections

Information about Advance Directives and links to download state-specific forms

<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289>

# 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>

# Locating Services and Benefits

## Eldercare.gov

The Eldercare Locator from the U.S. Administration on Aging is a directory of services for older adults.



The screenshot shows the Eldercare Locator website. At the top, it says "Department of Health and Human Services" and "eldercarelocator Connecting You to Community Services". There is a search bar and a phone number "1-800-677-1116". Below the header, there are navigation tabs for "Home", "About", and "Resources". A welcome message states: "Welcome to the Eldercare Locator, a public service of the U.S. Administration on Aging connecting you to services for older adults and their families. You can also reach us at 1-800-677-1116." The main content area is titled "Find Help in your Community" and offers two search methods: "Search by Location" (with fields for Zip Code, City, and State) and "Search by Topic". The topic list includes: Alzheimer's Disease, Caregiver, Elder Abuse Prevention, Financial Assistance, Food & Nutrition, Health Insurance, Healthy Aging, Home Repair & Modification, Housing Options, In-Home Services, Legal Assistance, Long Term Care, Nursing Home & LTC Facilities, Transportation, and Volunteerism. On the right side, there are links for "Favorite Text", "Email Page", "Printer Friendly", "Download Reader", "Share", and "Tweet". There is also a "Facebook" link and an "Online Chat" section with a "Have a question? Speak with an Information Specialist" and "Monday - Friday 9am - 8pm ET, call 1.800.677.1116, Start Online Chat." Below that is a "Caregiver's Corner" section with links for "Caregiver Resources", "Ask Medicare", and "Caregiver Tips".

## BenefitsCheckup.org

A directory of benefit programs that can help pay for medications, health care, food, utilities and other necessities.



The screenshot shows the BenefitsCheckup.org website. At the top, it says "BenefitsCheckUp. Celebrating 10 Years" and "We have helped 3,053,194 people find over \$11.1 billion worth of benefits." There is a navigation bar with links for "Home", "Find Help", "About Us", "Our Sponsors", "News", and "Donate". The main content area is titled "Can I Get Help?" and says "It's easy to find out." Below that, it says "Answer some questions to find benefit programs that can help you pay for medications, health care, food, utilities and more. All from a reliable and trusted source. About Us." There is a "GET STARTED NOW" button. Below that, it says "I really just need help with..." and offers two options: "Paying for Medicine" (with a sub-section for "Medicare Rx Extra Help" and a "GET HELP NOW" button) and "Paying for Food" (with a sub-section for "Food Programs in Your State" and a "GO" button). On the right side, there is a "Stay Connected" section with a "SIGN UP" button and a "Bank of America" logo.

# 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.



# 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](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](http://www.payingforseniorcare.com/longtermcare/resources/state_health_insurance_programs.html)

# 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

# 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](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>



# 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>

# 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



# Some Basics for Special Situations

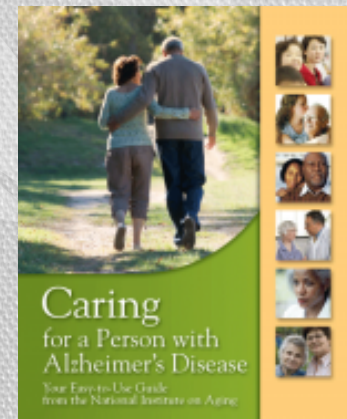
- Caregivers need to know the basics of the condition(s) their loved one is facing (diabetes, COPD, heart failure) in order to help provide appropriate care.
- Knowledge of quality health information sites such as MedlinePlus.gov can be very useful.
- Hospital social workers are very knowledgeable about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

# 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>



# 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

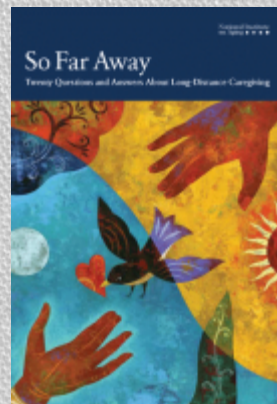
<http://www.als-mda.org/publications/alscare/>



# 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.



# 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

# MedlinePlus.gov Caregiver Health Topic

## Caregivers



Caregivers are people who take care of other adults, often parents or spouses, or children with special medical needs. Some caregivers are family members; others are paid. They help with:

- Food shopping and cooking
- House cleaning
- Paying bills
- Giving medicine
- Going to the toilet, bathing and dressing
- Eating
- Providing company and emotional support

Caregiving is hard, and caregivers of chronically ill people often feel [stress](#). They are "on call" 24 hours a day, 7 days a week. If you're caring for someone with mental problems like [Alzheimer's disease](#) it can be especially difficult. Support groups can help.

Get Caregivers updates by email



[What's this?](#)

### Start Here

- [Information for Caregivers](#) (American Academy of Family Physicians)  
Also available in [Spanish](#)



### Related Topics

- [Alzheimer's Caregivers](#)
- [Child Care](#)
- [Home Care Services](#)
- [Health System](#)
- [Social/Family Issues](#)

### National Institutes of Health

The primary NIH organization for research on *Caregivers* is the [National Institute on Aging](#)

### Languages

- [Chinese - Simplified](#) (简体中文)
- [Chinese - Traditional](#) (繁體中文)

# 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)

# MedlinePlus Resources – Continued...

## Related Issues

- [Adult Day Care](#)(Administration on Aging)
- [Assistive Technology](#)(Family Caregiver Alliance)
- [Caregiving 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)

# 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](http://www.aoa.gov/AoAroot/Press_Room/Products_Materials/fact/pdf/Taking_Care_Yourself.pdf)

# 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.



# Make Time

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





# 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](http://www.heart.org/HEARTORG/Caregiver/Caregiver_UCM_001103_SubHomePage.jsp)

- Wonderful resources, including a set of Journal pages for the caregiver.



# 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



# 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](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/nehep/about/partnership/nehep\\_partnership\\_organizations.pdf](http://www.nei.nih.gov/nehep/about/partnership/nehep_partnership_organizations.pdf)

# 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>

# Caregiver DVDs



The screenshot shows the website for 'The Savvy Caregiver' by HealthCare Interactive. The header includes the company logo and contact information. The main title is 'The Savvy Caregiver™' with a navigation menu containing 'HOME', 'BACKGROUND', 'PRODUCT INFO', and 'PRICING'. The central content area features four DVD covers on the left and a text block on the right. The text block describes the program as a 4-DVD set designed to help caregivers of people with memory loss or dementia. It lists four key benefits: teaching practical skills, increasing knowledge, providing a sense of competence, and reducing stress.

HEALTHCARE INTERACTIVE® Order online, or call 1-888-860-4295.

## The Savvy Caregiver™

HOME BACKGROUND PRODUCT INFO PRICING

Helping family members of someone with memory loss or dementia regain control of their lives.

The Savvy Caregiver program is a 4-DVD set that provides training for family members or friends of someone with the early stages of memory loss, any form of dementia, or even Alzheimer's disease. It's designed to help empower you by:

- Teaching you real-world, practical skills you can use every day
- Increasing your knowledge about memory loss
- Giving you a sense of competence needed for caregiving
- Reducing the stresses of caregiving

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

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

# Tip: Quick Path to Information

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



A service of the U.S. National Library of Medicine  
NIH National Institutes of Health

[Home](#) [About MedlinePlus](#) [Site Map](#) [FAQs](#) [Contact Us](#)

Search MedlinePlus

GO

Health Topics

Drugs & Supplements

Videos & Cool Tools

ESPAÑOL

## Refine by Type

All Results (28)

- Health Topics (1)
- External Health Links (23)
- Drugs and Supplements
- Medical Encyclopedia (1)
- Videos and Tutorials
- News
- MedlinePlus Magazine
- Other Resources (3)
- Multiple Languages

Results 1 - 10 of 28 for caregiver huntington

[Search Help](#)

1. [Caregiver's Guide to Huntington's Disease](#) (We Move) (Huntington's Disease Society of America) - PDF  
A Caregiver's Guide to Huntington's Disease March 2011 www.hdsa.org www.wemove.org Introduction to Caregiving.....3 What is Huntington's Disease ( ... distribute this publication to the hd community. A Caregiver's Guide to Huntington's Disease | ©WE MOVE™ | MARCH 2011 2 A Caregiver's ...  
[www.mdvu.org/downloads/HD\\_CGG\\_4.pdf](http://www.mdvu.org/downloads/HD_CGG_4.pdf) - External Health Links
2. [Huntington's Disease](#) (National Library of Medicine)  
Huntington's disease (HD) is an inherited disease that causes certain nerve cells in the brain to waste away. People are born with the defective gene, but symptoms ...  
[www.nlm.nih.gov/medlineplus/huntingtonsdisease.html](http://www.nlm.nih.gov/medlineplus/huntingtonsdisease.html) - Health Topics
3. [We Move](#) (We Move)  
... of movement disorder activities on the web. A Caregiver's Guide to Huntington's Disease (PDF) How to Create a Care Notebook (

# 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](http://www.thefamilycaregiver.org/who-are-family-caregivers/care-giving-statistics.cfm)



# Thank You!

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<http://nnlm.gov/psr/>

1-800-338-7657



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