Caregiver Resources

Presented by Kelli Ham January 19, 2011

MedlinePlus.gov Health Topic Pages of Interest to Caregivers

Caregivers

http://www.nlm.nih.gov/medlineplus/caregivers.html

Alzheimer's Caregivers

http://www.nlm.nih.gov/medlineplus/alzheimerscaregivers.html

Advanced Directives

http://www.nlm.nih.gov/medlineplus/advancedirectives.html

Assisted Living

http://www.nlm.nih.gov/medlineplus/assistedliving.html

End of Life Issues

http://www.nlm.nih.gov/medlineplus/endoflifeissues.html

Home Care Services

http://www.nlm.nih.gov/medlineplus/homecareservices.html

Hospice Care

http://www.nlm.nih.gov/medlineplus/hospicecare.html

Nursing Homes

http://www.nlm.nih.gov/medlineplus/nursinghomes.html

Palliative Care

http://www.nlm.nih.gov/medlineplus/palliativecare.html

Statistics about Caregiving

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

http://www.caregiving.org/data/Caregivers%20in%20Decline%20Study-FINAL-lowres.pdf

Statistics: Work and Finances

Caregiving in the U.S, National Alliance for Caregiving in collaboration with AARP, November 2009 http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf

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

http://www.caregiving.org/data/EVC_Caregivers_Economy_Report%20FINAL_4-28-09.pdf

Statistics on Family Caregivers and Family Caregiving

This is a compilation of specific facts and figures from a variety of sources.

http://www.thefamilycaregiver.org/who are family caregivers/care giving statstics.cfm

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

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. Users can find local Area Agency on Aging listings here.

http://eldercare.gov/

BenefitsCheckup.org

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

http://www.benefitscheckup.org/

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/

http://www.medicare.gov/

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.

http://medicaid.gov/

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. Other states have similar services, although they may be known by other names/acronyms.

In 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

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

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/virginianavigator/DetailSN.aspx?contentId=51&.f=1

Special Situations 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.

 $\underline{\text{http://www.nia.nih.gov/alzheimers/publication/caring-person-alzheimers-disease}}$

ALS (Lou Gehrig's Disease) MDA ALS Caregiver's Guide

This comprehensive 200-page guide from the Muscular Dystrophy Association covers emotional and financial concerns, everyday care tasks and finding help for the caregiver. It addresses topics such as nutrition, breathing, communication, finances, insurance accessibility and much more. It can be ordered free of charge for family caring for ALS patient, otherwise the cost is \$15; each section is also available as a separate PDF.

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

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.

http://www.nia.nih.gov/health/publication/so-far-away-twenty-questions-and-answers-about-long-distance-caregiving-0

Caring for the Caregiver

This concise document from the Administration on Aging spells out the basic things caregivers need to do for themselves to stay physically and mentally healthy.

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

Resources for the Caregiver

Nicely designed page for caregivers of people with heart disease, but information applies to caregivers in all situations. Wonderful resources, including a set of Journal pages for the caregiver. http://www.heart.org/HEARTORG/Caregiver/Caregiver_UCM_001103_SubHomePage.jsp
Journal pages: http://www.heart.org/HEARTORG/Caregiver/Rights/JournalPages/Journal-Pages_UCM_301751_Article.jsp#.Txy8XV1pD90

Online Support Groups

Daily Strength

This online discussion forum may be useful for sharing information. Note: There is advertising on the site. Also, encourage users to review the privacy policy before posting to the site. http://www.dailystrength.org/c/Caregivers/support-group

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, each providing services targeted to service area. 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

Building a Small Collection

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

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

http://www.memorylossdvd.com/