

**American College of Physicians
Ethics, Professionalism and Human Rights Committee**

Information Resources for Physicians Supporting Family Caregivers

This appendix of resources was developed in conjunction with the American College of Physicians Position Paper “Family Caregivers, Patients and Physicians: Ethical Guidance to Optimize Relationships” which was published online in the *Journal of General Internal Medicine* in January 2010 (available on SpringerLink at: <http://www.springerlink.com/openurl.asp?genre=article&id=doi:10.1007/s11606-009-1206-3>).

General Resources

**American College of Physicians Center for Ethics and Professionalism
Patient Education and Caring: End-of-Life (PEACE) Series**

http://www.acponline.org/patients_families/end_of_life_issues/

These educational materials can be used to facilitate conversations between physicians, patients, and their families about coping with serious illness near the end of life.

American College of Physicians *Home Care Guide for Advanced Cancer*

http://www.acponline.org/patients_families/end_of_life_issues/cancer/

Problem-solving approach for family, friends, and hospice workers caring for patients with advanced cancer that are living at home. Provides information needed for dealing with caregiving problems while working cooperatively with a team of health professionals

American College of Physicians. *Ethics manual: fifth edition*

http://www.acponline.org/running_practice/ethics/manual/

The American College of Physicians *Ethics Manual: Fifth Edition* provides an ethical framework to facilitate the process of making ethical decisions in clinical practice and medical research.

AARP (formerly known as American Association of Retired Persons)

<http://www.aarp.org/families/caregiving/>

http://www.aarp.org/health/staying_healthy/prevention/caregiver_health.html

The AARP provides many resources on financial, legal and health issues relating to caregiving.

Administration on Aging Eldercare Locator

<http://www.eldercare.gov/Eldercare.NET/Public/Home.aspx>

The Eldercare Locator provides for entering a zip code or city and selecting an eldercare topic and linking to a local source of service information. Topics include: General Information and Assistance, Aging & Disability Resource Center, Medicare, Elder Abuse Prevention, Health Insurance Counseling, Legal Assistance, Long-term Care Ombudsman and Prescription Assistance

Alzheimer’s Association

<http://www.alz.org>

The Alzheimer’s Association provides extensive educational resources and support for family caregivers. The site section for professionals offers an extensive selection of downloadable patient-education resources as well as information for physicians on working with the caregiver in treating the Alzheimer patient, counseling families, and coding for insurance reimbursement.

AMA Caregiver Self-assessment Questionnaire

Designed to help caregivers assess their own behavior and health risks and work with their physicians to make decisions for the benefit of both patient and caregiver. The Questionnaire enables physicians to identify and provide preventive services to at-risk caregivers and improve the physician-family caregiver partnership.

English: <http://www.ama-assn.org/ama/upload/mm/36/caregivertooleng.pdf>

Spanish: <http://www.ama-assn.org/ama/upload/mm/36/caregivertoolspan.pdf>

American Brain Tumor Association

http://www.abta.org/Care_And_Support/48

<http://www.abta.org/siteFiles/SitePages/655551427C5999B6010EBA4B82675F09.pdf>

A helpful collection of resources for both patients and caregivers

American Geriatrics Association Eldercare at Home Guide for Caregivers

http://www.healthinaging.org/public_education/eldercare

This book written by experienced health professionals presents a problem-solving approach to managing care at home.

Caregivers Count Too. A Toolkit for Helping Practitioners Assess the Needs of Family Caregivers

http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1695

This Toolkit facilitates assessment of caregiver needs in service delivery settings.

Caring From a Distance

<http://cfad.org/>

User friendly website offers an abundance of resources that address the unique needs of long distance caregivers ranging from service directories to communication tools for assistance with development of a caregiving plan. Links to information for military families, and many other resources.

Centers for Medicare and Medicaid Services Ask Medicare Caregiver Initiative

http://www.cms.hhs.gov/Partnerships/25_CaregiverInitiative.asp

The *Ask Medicare* initiative provides information, tools and materials to assist the caregiver and their loved ones in making informed healthcare decisions.

Family Caregiver Alliance National Center on Caregiving

www.caregiver.org

This site is a comprehensive source of caregiver information, advice and links to resources and services for both families and providers.

Family Caregivers Online

www.familycaregiversonline.com

This site, created by several Texas area agencies on aging, provides fact sheets and other educational resources in both English and Spanish for caregivers of aging adults.

National Alliance for Caregiving

www.caregiving.org

This caregiver-centered site provides tip sheets, links and other resources for family caregivers.

The National Association of Area Agencies on Aging (n4a)

<http://www.n4a.org/>

Advocates on behalf of the local aging agencies to ensure that needed resources and support services are available to older Americans.

National Association of State Units on Aging

<http://www.nasua.org/>

Provides a compendium of information about family caregivers of older Americans and the state-level programs that serve them.

National Caregivers Library

<http://www.caregiverslibrary.org/Default.aspx?tabid=1>

One of the most extensive online libraries for caregivers. It consists of hundreds of articles, forms, checklists and links to topic-specific external resources.

National Family Caregivers Association

www.nfcacares.org

The National Family Caregivers Association educates, supports, empowers and advocates for family caregivers.

National Family Caregiver Support Program (NFCSP)

http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Caregiver/index.aspx#resources

The NFCSP, created by the Administration on Aging, provides grants to States and Territories to provide services that assist family and informal caregivers to care for their loved ones at home.

National Institute on Aging *Alzheimer's Caregivers Guide*

<http://www.nia.nih.gov/alzheimers/publications/caregiverguide.htm>

Offers strategies for dealing with difficult behaviors and stressful situations.

National Institute on Aging *Home Safety for People with Alzheimer's Disease*

<http://www.nia.nih.gov/Alzheimers/Publications/homesafety.htm>

Identifies potential problems in the home and offers solutions to help prevent accidents.

National Institute on Aging *Working with Your Older Patient: A Clinician's Handbook*

<http://www.nia.nih.gov/NR/rdonlyres/99913D0D-2676-43C3-B238-77A0D9A011B7/0/CliniciansHandbook.pdf>

Introduces physicians and other health care professionals to communication skills essential in caring for older patients and their families. Offers practical techniques and approaches to help with diagnosis, promote treatment adherence, make more efficient use of clinicians' time, and increase patient and provider satisfaction.

National Kidney Foundation, Inc.

<http://www.kidney.org/patients/pfc/caregiver.cfm>

Provides additional links to services to support the caregiver.

National Hospice and Palliative Care Organization – Caring Connections

<http://www.caringinfo.org/CaringForSomeone.htm>

Provides information and resources on caregiving at the end of life, finances, advance care planning, hospice and palliative care, and access to state-specific forms for executing advance directives.

National Multiple Sclerosis Society

<http://www.nationalmssociety.org/chapters/AAC/programs--services/caregivers/index.aspx>

The MS and Home Caregivers Page provides an array of resources for family caregivers and physicians working in partnership to support patients with MS.

United States Government Caregivers' Resources

<http://www.usa.gov/Citizen/Topics/Health/caregivers.shtml>

Official information and services from the U.S. government

The Wellness Community

<http://www.thewellnesscommunity.org/mm/Caring.aspx>

List of links to national organizations that offer information and help to people with cancer and their caregivers.

State Government-Specific Resources

Alabama

<http://camellia.alabama.gov/default.aspx>

Alaska

<http://hss.state.ak.us/dsds/grantservices/hcbforms.htm>

Arizona

<https://egov.azdes.gov/cmsinternet/main.aspx?menu=8&id=40>

Arkansas

<http://www.choicessinliving.ar.gov/>

California

<http://www.ca.gov/Health/Caregivers.html>

http://www.aging.ca.gov/programs/family_caregiver.asp

http://www.aging.ca.gov/tools_tips.asp

Colorado

http://www.cdhs.state.co.us/aas/agingservicesunit_caregiver.htm

Connecticut

<http://www.ct.gov/agingservices/cwp/view.asp?a=2513&q=313064>

Delaware

<http://www.dhss.delaware.gov/dhss/dsaapd/care.html>

District of Columbia

<http://dcoa.dc.gov/dcoa/site/default.asp?dcoaNav=|31409|>

Florida

<http://elderaffairs.state.fl.us/english/caring.php>

Hawaii

<http://hawaii.gov/health/eoa/CG.html>

<http://www.honolulu.gov/dcs/2008familycaregivingguide.pdf>

Idaho

<http://www.idahoaging.com/IdahoCommissiononAging/ICOAProgramsandServices/CaregiverSupportServices/tabid/133/Default.aspx>

Illinois

<http://www.state.il.us/aging/1caregivers/caregivers-main.htm>

Indiana

<http://www.in.gov/fssa/da/3470.htm>

Iowa

<http://www.aging.iowa.gov/living/caregiver.html>

Kansas

<http://www.agingkansas.org/Choices/Programs/progdescriptions.htm>

Kentucky

<http://chfs.ky.gov/dail/familycaregiver.htm>

Louisiana

<http://goea.louisiana.gov/index.cfm?md=pagebuilder&tmp=home&pid=34&pnid=20&nid=46>

Maine

<http://www.maine.gov/dhs/beas/caregivers.htm>

Maryland

<http://www.mdoa.state.md.us/caregiver.html>

Massachusetts

http://www.mass.gov/portal/site/massgovportal/menuitem.14191bdddbe631c14db4a11030468a0c/?pageID=eldersterminal&L=2&LO=Home&L1=Caregiver+Support&sid=Elders&b=terminalcontent&f=csp_overview&csid=Elders

Michigan

<http://www.michigan.gov/miseniors/0,1607,7-234-43803---,00.html>

Minnesota

<http://www.mnaging.org/advisor/caregiver.htm>

http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id_005741

Mississippi

http://www.mdhs.state.ms.us/aas_mfcsp.htm

Missouri

<http://moaging.com/Public/Default.aspx>

Montana

<http://www.dphhs.mt.gov/sltc/>

Nebraska

<http://www.dhhs.ne.gov/HCS/Services/Respite.htm>

Nevada

<http://www.nevadacareconnection.org/>

New Hampshire

<http://www.dhhs.nh.gov/DHHS/BEAS/caregivers.htm>

New Jersey

<http://www.state.nj.us/caregivernj/>

New Mexico

<http://www.nmaging.state.nm.us/talk.html>

New York

<http://www.aging.ny.gov/Caregiving/Programs/GetHelp.cfm>

North Carolina

<http://www.ncdhhs.gov/aging/fc-resources.htm>

North Dakota

<http://www.nd.gov/dhs/services/adultsaging/caregiver.html>

Ohio

<http://aging.ohio.gov/resources/nationalfamilycaregiversupport/>

http://olrs.ohio.gov/ASP/olrs_Caregiver.asp

Oklahoma

<http://www.okrehab.org/guide/Ch13/13-01E.asp>

Oregon

<http://www.oregon.gov/DHS/spwpc/caregiving/home.shtml>

Pennsylvania

http://www.portal.state.pa.us/portal/server.pt/community/what_is_a_caregiver_family_support/9097

Rhode Island

<http://adrc.ohhs.ri.gov/caregivers/index.php>

South Carolina

<https://scaccess.communityos.org/cms/>

South Dakota

<http://dss.sd.gov/elderlyservices/services/caregiver.asp>

Tennessee

<http://www.state.tn.us/comaging/caregiving.html>

Texas

<http://www.dads.state.tx.us/services/agingtexaswell/caregiving/index.html>

Utah

http://www.hsdaas.utah.gov/caregiver_support.htm

Vermont

<http://www.vermont.gov/portal/health/index.php?id=229>

<http://www.ddas.vermont.gov/ddas-programs/programs-oaa/programs-oaa-default-page>

Virginia

<http://www.easyaccess.virginia.gov/caregiversupport.shtml>

<http://www.virgininavigator.org/vaprovider/consumer/indexVnNavigator.do>

Washington State

<http://www.aasa.dshs.wa.gov/caregiving/>

West Virginia

http://www.state.wv.us/seniorservices/wvboss_article.cfm?mnhd=ACE1FD08-D1FE-11D5-8DA00002A52CB920&atl=ACE1FD0A-D1FE-11D5-8DA00002A52CB920

Wisconsin

<http://www.dhfs.state.wi.us/Aging/caregiver.htm>

Wyoming

<http://wdh.state.wy.us/aging/services/nfcp.html>

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