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

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/65551427C5999B6010EBA4B82675F09.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
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
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
Arkansas
http://www.choicesinliving.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

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

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

Maine
http://www.maine.gov/dhs/beas/caregivers.htm

Maryland
http://www.mdoa.state.md.us/caregiver.html

Massachusetts
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

Virginia
http://www.easyaccess.virginia.gov/caregiversupport.shtml
http://www.virginianavigator.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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