



www.whyy.org/widerhorizons

150 N. Sixth St.
Philadelphia,
PA 19106
215-351-2095

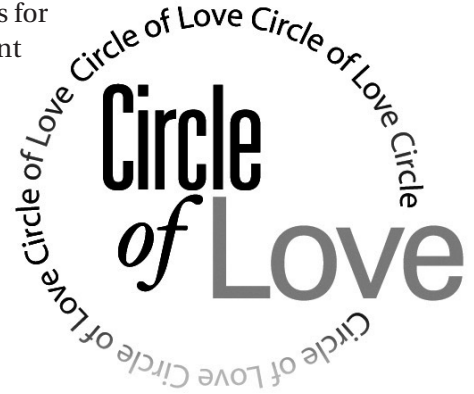
This Guide made possible by



Resources for Caregivers

This resource guide was compiled by members of Caring Community, WHYY's volunteer coalition of more than 100 non-profit organizations, universities, government agencies, faith-based organizations and health care systems in the Greater Philadelphia region. As a companion to CIRCLE OF LOVE, WHYY's series of first-person documentaries on caregiving and chronic illness, it offers resources for living with Alzheimer's, caring for an aging parent and caring for children with special needs. While not a comprehensive listing, this guide can be a starting point for anyone seeking to learn more about providing care to a loved one and supporting family caregivers you may know. We hope you will find it helpful.

For more information as well as archives of radio programming and webcasts, please visit www.widerhorizons.org.



LIVING WITH ALZHEIMER'S

Alzheimer's Association—Delaware Valley Chapter

Programs include a 24-hour toll free Helpline/Contact Center, Safe Return (wanderer's alert program), family caregiver training and conferences, newsletters, family assistance programs and support groups. The Alzheimer's Association also offers an extensive resource library, professional in-service training, public policy and advocacy.

100 N 17th Street, 2nd Floor
Philadelphia, PA 19103
(215) 561-2919
(800) 272-3900
www.alz-delawarevalley.org

Southern NJ Regional Office
3 Eves Drive
Suite 310
Marlton, NJ 08053
(856) 797-1212

Delaware Regional Office
2306 Kirkwood Highway
Wilmington, DE 19805
(302) 633-4420

Alzheimer's Disease Education and Referral Center

A service of the National Institute on Aging of the National Institutes of Health providing information about Alzheimer's disease and related disorders.

PO Box 8250
Silver Spring, MD 20907-8250
(800) 438-4380
www.alzheimers.org

ALZwell Caregiver Support

ALZwell is dedicated to helping dementia caregivers to find understanding, wisdom and support, offering information on dementia care and other aspects of eldercare, a network of support groups and links to other resources.

www.alzwell.com

The Association for Frontotemporal Dementias (AFTD)

AFTD is a new nationwide non-profit organization whose mission is to promote and fund research into finding the cause and cure for the frontotemporal dementias; to provide information, education, and support to persons diagnosed with FTD and their families and caregivers; and to educate physicians and allied health professionals about FTD.

For a brochure and newsletter:

P. O. Box 7191

St. David's, PA 19087-7191

www.ftd-picks.org

The Forgetting: A Portrait of Alzheimer's

This companion web site to the PBS documentary *The Forgetting: A Portrait of Alzheimer's* provides information and coping strategies and resources for caregivers and family members.

www.pbs.org/theforgetting

CARING FOR AN AGING PARENT OR PARTNER

& Thou Shalt Honor

PBS documentary and community outreach dedicated to increasing awareness in our communities about family caregiving. The web site for the series includes a resource listing which can be found at:

www.atsh.org/res

AARP

Offers extensive information on and support for caregiving, illness, grief, widowhood, funerals, wills, estate planning and advance directives. AARP's grief and loss services can be contacted at 202-434-2260.

601 E. Street NW

Washington DC 20049

www.aarp.org/life or

www.aarp.org/life/caregiving

The AIDS Library

The AIDS Library serves the community through delivery of information on HIV, including computer access to the library's online resource, Philadelphia Metropolitan Area Resources for Living with HIV. This web site offers an easily accessible and quite comprehensive source of HIV information and services to consumers, caregivers and the general public at no cost.

1233 Locust St., 2nd floor

Philadelphia, PA 19107

(215) 985-4851

E-mail: library@aidslibrary.org

ALS Association — Greater Philadelphia Chapter

Persons with ALS or their family members and caregivers register to participate in services which include local resource groups, education, respite and referrals.

(215) 643-5434

The Caregivers Marketplace

An online service providing rebates and discounts on the purchase of caregiving supplies and equipment.

(866) 327-8340

www.caregiversmarketplace.com

CARIE (Center for Advocacy for the Rights and Interests of the Elderly)

Provides free telephone consultation, which includes options counseling and problem resolution services to the older person, their caregivers and professionals.

(215) 545-5728

www.carie.org

Children of Aging Parents (CAPS)

A non-profit organization which establishes and facilitates caregiver support groups, provides educational outreach and information on available services to assist caregivers.

(800) 227-7294

www.CAPS4caregivers.org

Counseling for Caregivers, Madlyn and Leonard

Abramson Center for Jewish Life

(formerly Philadelphia Geriatric Center)

Helps caregivers through information, referral, education and counseling find the skills and services they need to balance caring for their older relative with taking care of themselves.

(215) 371-1800

www.abramsoncenter.org

Family Caregiver Alliance, National Center on Caregiving

Works to advance the development of high-quality cost-effective policies and programs for caregivers in every state of the country. The Family Caregiver Alliance site has specialized information on Alzheimer's disease, stroke, traumatic brain injury, Parkinson's disease, ALS and other disorders. Some materials are available in Spanish and Chinese.

(800) 445-8106

www.caregiver.org

Geriatric Assessment

Geriatric assessment differs from a standard medical evaluation and involves a team of health care professionals who evaluate the older person's functional abilities (ability to get around and do everyday activities), physical health, memory abilities and mental health, as well as their social and environmental situation. The potential benefits of having this type of assessment include greater diagnostic accuracy, improved function and mental status, decreased use of hospitals and nursing homes and overall quality of life.

Contact your local hospital to find a geriatric assessment program.

National Alliance for Caregiving

Supports family caregivers through resource guides and information available online or in print. Web site is home

of the AXA Foundation Family Resource Connection, a searchable database of books, videos, web sites, etc. for caregivers.

4720 Montgomery Lane, Suite 642
Bethesda, MD 20814
www.caregiving.org

National Association for Home Care and Hospice

Provides information on what home care is and how to select a provider. The web site includes a consumer section.
(202) 547-7424

www.nahc.org/Consumer/coninfo.html

National Association of Geriatric Care Managers

Provides a searchable database of geriatric care managers who are committed to maximizing the independence and autonomy of elders while striving to ensure that the highest quality and most cost-effective health and human services are used when and where appropriate. A comprehensive list of organizations serving the needs of elderly and their caregivers can be found via the home page by clicking on "Care Management Resources."

www.caremanager.org

National Family Caregivers Association

A grassroots organization created to educate, support, empower and speak up for the common needs and concerns of all family caregivers.

(800) 896-3650

www.nfcacares.org

The National Hospice and Palliative Care Organization

NHPCO is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones. Provides information to better your understanding about hospice and palliative care and a national database for services near you.

1700 Diagonal Road, Suite 625

Alexandria, Virginia 22314

(703) 837-1500

(703) 837-1233 (Fax)

www.nhpco.org

Philly Health Info

Philly Health Info is a major new initiative offering a free, comprehensive and objective health information service for all residents of Greater Philadelphia, sponsored by the College of Physicians of Philadelphia. The Web portal provides access to the latest quality health and medical information, with an emphasis on regional resources and services and tools to expand the user's knowledge of health issues and help them make informed decisions about their medical care. Online help in using the database is available.

www.phillyhealthinfo.org

Today's Caregiver Magazine

Published on a monthly basis, this magazine and companion web site provides helpful information and resources for caregivers.

(800) 829-2734

www.caregiver.com

Well Spouse Foundation

An association of spousal caregivers which provides peer support groups for longterm caregivers. Participants form friendships with other caregivers in similar situations.

(800) 838-0879

www.wellspouse.org

U.S. GOVERNMENT RESOURCES

Administration on Aging Elderpage: Information for Older Persons and Families and

Because We Care: A Guide for people who Care

These guides provide information and a range of suggestions to make caregiving easier and more successful—whether you are a caregiver or the person who ensures that your family member or friend receives the best possible care from others.

www.aoa.dhhs.gov/elderpage.html

www.aoa.dhhs.gov/wecare/default.html

Eldercare Locator

A nationwide service available toll free or on the Web which helps older adults and their caregivers find local services for seniors. The toll free Eldercare Locator service operates Monday through Friday, 9:00AM to 8:00PM, Eastern Time and can be reached at (800) 677-1116 or the Eldercare Locator can be accessed via the internet at

www.eldercare.gov

Aging Parents and Adult Children Together (A/PACT)

A series of 10 articles produced by the Federal Trade Commission in partnership with AARP. The series will introduce you to eldercare issues you may confront and help investigate options and make decisions.

www.ftc.gov/bcp/online/pubs/services/apact

National Institute on Aging — Resource Guide for Older Persons

A comprehensive directory of services and organizations compiled by the NIA and the Administration on Aging. It contains listings of more than 250 public and private organizations.

www.nia.nih.gov/resource

REGIONAL RESOURCES—PA

Area Agencies on Aging

Every county has an "area agency on aging" which offers information and referral to hospice and support groups,

mental health care, community-based long term care, home delivered meals, caregiver support programs and other services.

- Philadelphia Corporation for Aging Senior Helpline
(215) 765-9040
(215) 765-9041 (TDD)
www.pcaphl.org
- Bucks County Area Agency on Aging
(215) 348-0510
- Chester County Department of Aging Services
(610) 344-6353
- Delaware County Office of Services for the Aging
(610) 490-1300
(800) 416-4504
- Montgomery County Office of Aging and Adult Services
(610) 278-3601
- Berks County Office of Aging
(610) 478-6500

CaregiverPA

CaregiverPA is a web site providing resources for older adults and their families. The site helps you to answer caregiving questions, find descriptions of available resources by county.

caregiverpa.psu.edu

National PACE (Programs for All-inclusive Care for the Elderly) Association

Programs for All-inclusive Care for the Elderly provide and coordinate all needed preventive, primary, acute and long term care services so that an older individual can continue living in the community. To be eligible for PACE a person must be 55 or older, be certified by the state to need nursing home care and live in an area served by a PACE program. In Pennsylvania, this program is called LIFE (Living Independently for Elders), due to the pre-existing pharmacy benefit program administered by the state also called PACE. Further information on PACE and LIFE programs can be found at the national web site:

www.npaonline.org

LIFE University of Pennsylvania School of Nursing
4101 Woodland Avenue
Philadelphia, PA 19104
(215) 573-7200

LIFE Saint Agnes
1500 S. Columbus Boulevard
Philadelphia, PA 19147
(215) 339-4447

REGIONAL RESOURCES—DE

Cancer Care Connection

A free statewide service providing information, guidance and referrals to help you find local services and Internet resources.

(302) 266-8050

(866) 266-7008

www.cancercareconnection.org

CARE Delaware

Assistance for caregivers is provided by Delaware Division of Services for Aging and Adults with Physical Disabilities (DSAAPD), including needs assessment and care planning, support groups and caregiver training, respite care and community-based caregiver resource centers.

(800) 223-9074

(302) 453-3837 (TTY)

(302) 255-4445 (Fax)

www.state.de.us/dhss/dsaapd/care.html

Contact Delaware

24-hour, 7 day/week crisis helpline for all problems, staffed by trained volunteers who provide telephone support and referrals, including bereavement support groups and grief counseling throughout the state.

(800) 262-9800

REGIONAL RESOURCES—NJ

NJ EASE (New Jersey Easy Access, Single Entry)

Department of Health and Senior Services initiative in partnership with county governments to provide a new and easy way for senior citizens and their families to learn about and obtain needed services.

(877) 222-3737

www.state.nj.us/health/senior/sanjease.shtml

Caregiver NJ

An online guide to information on a variety of caregiving situations, resources and services available in New Jersey to assist caregivers and searches for resources by county.

www.state.nj.us/caregivernj

Community Choice Promoting Dignity, Independence and Choice

Community Choice is a statewide program of the New Jersey Department of Health and Senior Services created to assure that senior citizens, persons with disabilities and their families are aware of choices they have when it comes to long term care. The 'Useful Links' section of the web site contains a comprehensive list of national and state organizations, organizations related to specific diseases, advocacy groups, and associations for those in different cultures.

www.state.nj.us/health/consumer/choice



CHILDREN WITH SPECIAL NEEDS



[www.whyy.org/
widerhorizons](http://www.whyy.org/widerhorizons)

150 N. Sixth St.
Philadelphia,
PA 19106
215-351-2095

This Guide made
possible by

Farber Institute for Neurosciences
of Thomas Jefferson University



Thomas
Jefferson
University

Autism

Autism Society of America (ASA)

Nationwide support network that promotes lifelong access and opportunities for persons with autism. Information about local chapters and resources can link consumers and families to key services such as special education departments, parent training information centers, technical assistance about insurance and protection of the rights of persons with disabilities as well as early intervention, health, mental health and mental retardation resources.

7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814-3067
(301) 657-0881 or (800) 3AU-TISM
www.autism-society.org

Autism — PDD Resources Network

The purpose of this web site is to guide you to the key issues associated with autism spectrum disorders. There is a growing awareness of the nature of autism and the kinds of approaches to diagnosis, treatment and care that are likely to be effective in meeting the needs of autistic individuals and their families.

www.autism-pdd.net

Cure Autism Now Foundation

Read the latest news about autism; browse answers to frequently asked questions; discover support resources for parents; find out about ongoing initiatives to fund research; and link to the organization's Delaware Valley chapter.

5455 Wilshire Boulevard, Suite 715
Los Angeles, CA 90036 – 4234
(888) 8-AUTISM
(323) 549-0500
(323) 549-0547 (Fax)
www.canfoundation.org

Disability Resources, Inc.

Searchable by state and topic, the site includes a wealth of links to resources designed to help people with various physical and mental disabilities live, learn, love, work and play independently.

www.disabilityresources.org

Down Syndrome

National Association for Down Syndrome

The mission of the National Down Syndrome Society is to benefit people with Down syndrome and their families through national leadership in education, research and advocacy.

National Association for
Down Syndrome
National Down Syndrome Society
(800) 221-4602
(212) 460-9330
E-mail: info@ndss.org
www.ndss.org

Elwyn

Non-profit organization serving children and adults with all types of challenges, including developmental, physical and emotional disabilities, as well as those with disadvantages. A resource for families, caregivers and local communities.

111 Elwyn Road
Elwyn, PA 19063
(610) 891-2000

Delaware Elwyn
321 E. 11th Street
Wilmington, DE 19801
(302) 658-8860 (Voice/TTD)
(302) 654-5815 (Fax)

Learning Disabilities

PBS "Struggling to Learn"

Learn more about how to recognize and understand a variety of learning problems; read the advice of several learning disability experts; discover strategies for helping a struggling child; and print out a list of resources pertaining to reading, writing, math, attention and general learning difficulties.

www.pbs.org/parents/issuesadvice/strugglingtolearn

Other Resources

Easter Seals

Provides services to children and adults with disabilities and other special needs, and support to their families.

www.easterseals.com

Easter Seals Eastern Pennsylvania
1503 North Cedar Crest Boulevard, Suite 317
Allentown, Pennsylvania 18104-2130
(610) 289-0114
(610) 289-4282 (Fax)

Southeastern Pennsylvania
3975 Conshohocken Avenue
Philadelphia, PA 19131
(215) 879-1000
(215) 879-8424 (Fax)

Delaware and Maryland's Eastern Shore
61 Corporate Circle
New Castle, DE 19720
(302) 324-4444
(800) 677-3800
(302) 324-4441 (Fax)

New Jersey
1 Kimberly Road
East Brunswick, New Jersey 08816
(732) 257-6662
(732) 257-4442 (TDD)
(732) 257-7373 (Fax)

March of Dimes

March of Dimes researchers, volunteers, educators, outreach workers and advocates work together to give all babies a fighting chance against the threats to their health: prematurity, birth defects, low birthweight.

1019 West 9th Street
King of Prussia, PA 19406
(610) 945-6050
www.marchofdimes.com

MyCityMyPlace

A Web-based resource directory, sponsored by Philadelphia's Mental Retardation Services, that links users to a wide array of services and supports in the Philadelphia

area, including information about assistive technology, education, jobs, recreation, housing, health, transportation and income resources, as well as volunteer activities and networking. Referral and consultation are also provided.

Philadelphia Mental Retardation Services
1441 Sansom St., 2nd Floor
Phila., PA 19102
(215) 686-0297
www.mycitymyplace.com

National Dissemination Center for Children with Disabilities (NICHCY)

NICHCY compiles disability-related resources for each state to help in locating organizations and agencies that address disability-related issues, including: state agencies and organizations serving children and youth with disabilities; disabilities-specific organizations; organizations specifically for parents and other disabilities-relevant organizations. NICHCY provides referral and consultation on a cost-free basis in Spanish as well as English.

P.O. Box 1492
Washington, DC 20013
(800) 695-0285 (Voice/TTY)
(202) 884-8200 (Voice/TTY)
(202) 884-8441 (Fax)
E-mail: nichcy@aed.org
www.nichcy.org

United Cerebral Palsy (UCP)

UCP has long been recognized for the timely information it provides to parents and families of individuals with disabilities. This information assists parents and families in obtaining the necessary support and services in child care, supported living, education, health, employment, health and recreational activities for their family members. Information is available in Spanish.

www.ucp.org

UCP of Philadelphia & Vicinity
102 East Mermaid Lane
Philadelphia, PA 19118
(215) 242-4200
(215) 247-4229 (Fax)
E-mail: ucpkravitz@aol.com
www.ucpphila.org

UCP of Delaware
700A River Road
Wilmington, DE 19809-2746
(302) 764-2400
(302) 764-8713 (Fax)
E-mail: williammccool@ucpde.org

UCP of Morris-Somerset
245 Main Street, Suite 113
Chester, NJ 07930
(908) 879-2243
(908) 879-8363 (Fax)
E-mail: info@ucpmsnj.com