

RESOURCES FOR HUNTINGTON'S DISEASE

Huntington's Disease Associations & Support Networks

Huntington's Disease Society of America

Information about HD. The Northwest chapter is located in Seattle, WA.

contact: 1-800-345-HDSA <http://www.hdsa.org> or Seattle: www.geocities.com/nwhdsa/

The HD Lighthouse

Current research, treatment, and HD community information Features a chat option.

contact: <http://www.hdlighthouse.org/>

Huntington's Disease Advocacy Center (HDAC)

Message Board. Political Advocacy Links. Reviews of HD books. Articles on Caregiving, recipes, etc.

contact: <http://www.hdac.org/>

Huntington's Outreach Project for Education, Stanford (HOPES)

Focuses on scientific side of HD. Designed to complement the HDAC's website (above).

contact: <http://www.stanford.edu/group/hopes/>

The Huntington's Disease Association (United Kingdom)

Printable booklets on HD, choosing adaptive equipment, speech, and more

contact: International: 020 7223 7000 <http://www.hda.org.uk/>

Huntington Society of Canada

Printable booklets and brochures on a variety of topics: Estate planning, caregiver handbooks, etc.

contact: <http://www.hsc-ca.org>

The Movement Disorders Center at OHSU

Specializes in the diagnosis, treatment, and clinical care of Huntington's disease.

contact: (503) 494-7231 <http://www.ohsu.edu/pco/>

The Parkinson's Disease Research, Education and Clinical Center (PADRECC) at the Portland VA

Specializes in the diagnosis, treatment, and clinical care of Huntington's disease.

contact: (503) 721-1091 <http://www.va.gov/portland/padrecc/>

Caregiver Support and Education

Caregiving online

Online support group for caregivers, tips to caregiving

contact: <http://www.caregiving.com>

Family Caregiver Alliance

Email forum for HD and other movement disorders.

contact: www.caregiver.org

Legacy Caregiver Education – Powerful Tools

Offers a 6-week program to help caregivers take care of themselves. **No charge** – donation asked, but not required

contact: (503) 413-7706



Family Caregiver Support Program

Information about available services, access to support services, individual counseling, advice on organizing support groups and caregiver training, respite care , supplement services to complement the care provided by caregivers. There are two groups of eligible clients that can receive services under the FCSP: Adult, non-paid family member, or other individual, who is an informal provider of in-home and community care to an individual 60 years of age and older. Grandparent or older individual who is a relative caregiver (grandparent or step-grandparent, or a relative by blood or marriage) who is 60 years of age or older who lives with a child and is the primary caregiver to the child. The child has to be 17 years of age or younger.

contact: 1-800-282-8096

National Family Caregiver Association

The mission of this organization is to empower and educate caregivers of those with chronic illness.

contact: (800) 687-2277 <http://www.nfcacares.org/>

Home Care Services / Assistance Resources

Private Organizations

Caregiver Connection

Caregiver Connection offers a unique registry of 40-60 caregivers that clients hire directly for a referral fee. Services range from companionship to hospice level care.

contact: 503-246-4672 <http://www.caregiverconnection.pdx.com/>

National Association for Homecare

Listings of home health agencies. Search by city or state for services, payment info, and accreditation

contact: <http://www.nahc.org>

Home Instead Senior Care

Agency with certified & bonded caregivers. Multiple location throughout state – check web site.

contact: (503) 335-0626 www.homeinstead.com

Homewatch Caregivers

Caregiver agency - Locations in Portland and SW Washington

contact: (503) 254-8343 www.homewatchcaregivers.com

Generations Home Care

Two locations in the Portland area

contact: SE - (503) 652-0753 SW - (503) 297-0114

Legacy Health System Caregiver Listings

All caregivers on this list have completed a Legacy training program. The listing has details about the caregiver's skills.

contact: 503-413-7706 <http://www.legacyhealth.org/body.cfm?id=767>

Metropolitan Family Service

Portland Metro Area: Senior companion services provide respite services, in-home services (assist with meal preparation, transportation to the grocery store). Project Linkage: Help for transportation, shopping, yard work, home repair, bookkeeping and companionship.

contact: 503-249-8215 ext. 22 www.metfamily.org

National Association of Professional Geriatric Care Managers

Search site for database of members (GCM).

contact: (520) 881-8008 – Phone <http://www.caremanger.org>



State agencies

Oregon Department of Human Services/Lifespan Respite Care Program

Listings of assisted living sites in Oregon. The respite program offers resources, support groups, and financial information. Each county has its own location.

contact: 503-945-5811 or 800-282-8096 <http://www.oregon.gov/DHS>

Clackamas County, 18600 SE McLoughlin Blvd., Milwaukie, 503-794-8008

Multnomah County Protective Services, 4610 SE Belmont St., Portland, 503-988-4450

Washington County, 133 SE 2nd, Hillsboro, 503-640-3489

Long Term Care Ombudsman

The role of this office is to assure quality of long-term care homes. Also offers consultations on how to navigate the system.

contact: (800) 522-2602 or (503) 378-6533 <http://www.oregon.gov/LTCO/index.shtml>

Washington State Aging and Disability Services

Has information for caregiving, in home care, and residential care. Also a community resource locator. Also offers a long term care ombudsman.

contact: 1-800-422-3263 www.aasa.dshs.wa.gov Ombudsman: 1-800-562-6028

Home Health Care specific (these services may also provide general caregiving)

Adventist Home Health Care and Personal Care Services

Provides nursing, OT and PT, Speech Therapy, and general household and personal assistance

contact: (503) 251-6301 www.adventisthealthnw.com

Providence Home Health

Provides nursing, OT and PT, Speech Therapy, and general household and personal assistance. Locations around state.

contact: (503) 215-4646 or (800) 531-9754 www.providence.org/oregon

Legacy Visiting Nurse Association

Provides Nursing, Hospice, PT and OT, Speech Therapy, Psychiatric Care

contact: (503) 220-1000 or (800) 896-6287 www.legacyhealth.org

Housecall Providers, Inc.

Provides in-home medical care.

contact: (503) 249-7941

Adult Day Programs

Adult Day Care Listing

Listings of Adult Day Care centers in the Portland area

contact: www.thecityofportland.org/adultdaycare

Centers

Lambert House East Day Program

Service provided includes: social activities, medication supervision, and entertainment.

contact: 503-760-2075

Velma Joy Burnie Center

Service provided includes: social activities, medication supervision, and entertainment .

contact: 503-232-4117



Marie Smith Center

Adult day care facility serving adults, primarily seniors, needing supervision and personal care, medication management, recreation, outings and restorative therapy.

contact: 503-335-9980

Cedar Sinai Park/Robinson Health Center

contact: (503) 535-4300

Living Alternatives/Placement Assistance Services

Adult Care Providers of Oregon

Adult Care Providers Of Oregon is a volunteer organization promoting and assisting adult foster care homes, while providing a complete resource guide to those who are looking for adult foster care for someone they love.

contact: (866) 823-2276 or 541-345-8223 www.acpoforegon.com/index.cfm

Adult Living Alternatives

Referrals for extended stay care/housing and in home care. Serves Multnomah and Washington counties in Oregon and the Seattle area in Washington

contact: (503) 288-0686 or 1-877-952-7636 <http://www.a-la.com/>

Adult Placement Network

Provides listings, walk-throughs, and support for families looking for long-term care.

contact: (503) 892-2661 www.adultplacementnetwork.com

Northwest Senior Care Management Services

Provide geriatric assessment, care management, geriatric consultation, trained caregivers and alternative living environments services in Oregon.

contact: (503) 282-9926 <http://www.nwelder.com/>

Oregon Health Care Association

Under the "Consumers" section of their site is a listing of various living alternatives, nation wide.

contact: <http://www.ohca.com>

Standing By You: Eldercare consultants

Assist families in finding and screening long term care facilities. Portland and SW Washington area.

contact: 503-659-2029

Safety

Telephone Reassurance Service

A brief in-coming phone call, every 5-7 days at a pre-set time. Conducted through Portland Police Bureau.

contact: (503) 823-0291

Lifeline Services

Provides a personal help button for use in emergencies when you are unable to make it to the phone.

contact: (800) 380-8111 <http://www.lifelinesys.com>



Transportation Assistance

Ride Connection

Provides transportation, personalized Trip Planning, and Travel Training Assistance to seniors and people with disabilities in Clackamas, Clark, Multnomah, and Washington counties. No charge, but \$1.50 donation asked. Works with multiple agencies, such as the Red Cross.

contact: 503.528.1720 <http://www.rideconnection.org/>

Tri-Met

Transportation for seniors and those unable to use buses or trains (LIFT service). Also specialized medical transport.

contact: Medical transportation – (503) 802-8700 LIFT program – (503) 802 –8200 www.tri-met.org

American Medical Response: Medical transport and ambulance services

contact: In Portland: (503) 228-7601

In Vancouver: (360) 737-2525

Disabled Parking Permit

Parking permits through state. Must have physician signature and completed paperwork.

contact: Oregon: (503) 299-9999 www.oregondmv.com/DriverLicensing/disabled.htm

Washington: (360) 902-3770 Option 5 <http://www.dol.wa.gov/vs/dpfaq.htm>

Durable Medical Equipment

Apria

contact: Portland: (503) 255-5864

Care Medical

Locations throughout the state of Oregon and Washington.

contact: 1877 NE 7th Ave, Portland, OR 97212, (503) 288-8174, 1-800-952-9566

1944 Mc Gilchrist SE, Salem, OR 97302, (503) 378-1756, 1-800-785-7756

1280 Charnelton St., Eugene, OR 97401, (541) 343-0304

564 NE Greenwood Ave, Bend, OR 97701, (541) 388-2414

1900 NE Andresen Rd, Vancouver, WA 98661, (360) 693-4777, 1-800-767-7181

946 Washington Way, Longview, WA 98632, (360) 636-3120, 1-800-927-9339

Choice Medical

contact: Portland: (503) 233-2201 <http://www.choice-med.com>

DZ Discount Medical

contact: Beaverton: (503) 642-0155 or (877) 642-0155 www.dzdiscountmedical.com

Shamrock Medical

contact: Portland: (503) 654-4333

Legal Support

Legal Aid Services of Oregon

Free legal aid for non-criminal matters. Locations around the state, check website.

contact: Portland: (503) 224-4094, (503) 417-0147 www.oregonlawhelp.org

Lawyer Referral Services/Oregon State Bar Association

contact: (800) 452-7636 <http://www.osbar.org/index.html>



Mental Health Wellbeing

Oregon Office of Mental Health Services Mental Health and Addiction Services

contact: Phone: 503-945-5763 http://www.oregon.gov/DHS/mentalhealth/contact_us.shtml

Clackamas County Mental Health

contact: Main Line: (503) 742-5300

Multnomah County Behavioral Health Division

contact: Main Line: (503) 988-5464

Washington County Health & Human Services

contact: Main Line: (503) 846-8881

Washington State Mental Health Division

contact: (360) 902-8070

Clark County Mental Health Crisis Line

contact: (800) 626-8137

Food

Loaves and Fishes Meals on Wheels

Delivered meals for those over age 60 or younger, if enrolled in disability services

contact: 503-736-6325 www.mowaa.org

Store to Door

Shopping and delivery service for those who are unable to get their own groceries for a delivery fee.

contact: 503-413-8223 www.storetodooforegon.org

Medical Benefits and Social Security

Oregon Department of Human Service: Seniors & People With Disabilities

Helping seniors and people with disabilities live as independently as possible, through in-home services, licensing of facilities that provide care, and administration of the Lifespan Respite program.

contact: 503-945-5811 or 1-800-282-8096 www.dhs.state.or.us/index.html

Social Security

contact: 800-772-1213 www.ssa.gov/SSA_Home.html

Medicare

contact: 800-633-4227 www.medicare.gov

Kaiser Family Foundation – Navigating Medicare and Medicaid

Guides related to 2005.



Senior Health Insurance Benefits Assistance (SHIBA)

Statewide network of trained volunteers who educate, assist, and serve as advocates for people with Medicare. SHIBA volunteers assist Medicare beneficiaries with Medicare problems and questions and help beneficiaries make better health-insurance decisions.

contact: (800) 722-4134 or (503) 947-7984 <http://www.cbs.state.or.us/external/shiba/contactus.html>

Miscellaneous

Independent Living Resources

Resource Center for persons with disabilities, Portland

contact: 503-232-7411 www.ilr.org

Caresource Healthcare Communications, Inc.

Advance directives, checklists for hiring in-home help and for facilities evaluation

contact: 800-448-5213 www.seniorclix.htm

Unlimited Choices Adapt-A-Home Program

Modifications to homes or apartments in Multnomah and Clackamas counties. Retrofitting and renovation services up to \$2,000 per household.

contact: 503-234-6167 or http://www.co.multnomah.or.us/dscp/hps_adapt_mend_house.shtml

