

resources

and appendix

alzheimer's  association™

the compassion to care, the leadership to conquer

HOW TO FIND AND USE RESOURCES

Family, Friends and Neighbors

Make a list of the names and telephone numbers of important people in your life you could call in an emergency or if you needed a special favor (for example, a ride to the dentist, someone to bring groceries, etc.).

Community Resources

List names and telephone numbers of your community service providers, such as:

- Emergency numbers: police department, fire department, doctor
- Health care providers: health clinic or doctor, dentist, podiatrist, chiropractor, pharmacy that delivers
- Other helpful or important numbers: local senior center, grocery stores that deliver, taxi company or transportation system (bus, train, city or county special transportation services van for seniors or the handicapped), Alzheimer's Association Helpline at 1-800-272-3900.

To find these numbers, you can look up key words in your telephone book (start with the yellow pages): Senior Citizens' Services; Area Agency on Aging; Residential Care Information and Placement Bureaus; Elderly Care Consultants, Home Health Care, Handicapped Services; Assisted Living Services. Some services for the disabled may apply. When you see a service or organization that looks interesting, call to ask what services they offer and how you might use them. You never know unless you ask!

Organizations:

Alzheimer's Association 24/7 Helpline: 1-800-272-3900

Vermont Chapter Office: 802-316-3839

Adult Protective Services Program: 1-800-564-1612 (VT)

Area Agencies on Aging, Senior Helpline in Vermont: 1-800-642-5119

Senior Helpline 1-800-642-5119

Area Agency on Aging/Council on Aging www.cvaa.org/cvaa-info.html

Southeastern COA (Windham/Windsor) www.coasevt.org 1-802-885-2655

Southwestern COA (Bennington/Rutland) www.svcoa.org 1-802-442-5436

Champlain Valley Agency on Aging (Addison, Chittenden, Franklin, & Grand Isle) www.cvaa.org 1-802-865-0360

Area Agency on Aging for Northeastern Vermont (Caledonia, Essex, & Orleans) www.nevaaa.org 1-802-748-5182 St. Johnsbury, 1-802-334-2190 Newport

Central Vermont Council on Aging (services 54 towns, including all towns in Lamoille, Orange (except Thetford) and Washington counties, as well as the towns of Bethel, Granville, Hancock, Pittsfield, Rochester, Royalton, Sharon and Stockbridge) www.cvcoa.org 1-802-479-0531

An information and assistance resource for people age 60 and older, staffed by knowledgeable professionals. It is an information gateway to a wide range of programs and services available to seniors in Vermont. Welcomes calls from seniors, family members, health professionals or anyone concerned about a senior. They will answer questions, refer to agencies that can help, or connect with a case manager who can provide in depth assistance. To help seniors, over age 60, their families and caregivers understand and utilize the broad variety of programs and services available to them in their local area.

- Adult day programs
- Caregiver support
- Choices for Care
- Home health and in-home services
- Housing and transportation
- Legal services
- Long term care services
- Meals on Wheels
- Medicaid
- Medicare and other health insurance

- Mental health services
- Nursing and residential facilities
- Prescription assistance programs
- Senior centers and meals programs
- SSI and Social Security
- Support groups
- 3SquaresVT

For the Diagnosis and Treatment of Memory Loss

The Memory Center 1-800-358-1144, 1-802-847-1111 Dr. William Pendlebury www.med.uvm.edu/neurology/TB1+RL.asp?SiteAReaID=610
 Fanny Allen Campus
 Medical Office Building
 792 College Parkway, Suite 205
 Colchester, VT 05446

Upper Valley Memory Center 1-603-450-5000 Dr. Robert Santulli www.dhmc.org/webpage.cfm?site_id=2&org_id=754&gsec_id=0&sec_id=0&item_id=38733
 Dartmouth-Hitchcock Medical Center
 One Medical Drive
 Lebanon, NH 03756

Memory Clinic 1-866-MIND-DOC Dr. Paul Solomon www.memorydoc.org
 357 Shields Drive
 Bennington, VT 05201

Vermont Geriatric Medicine Doctors:
www.healthgrades.com/provider-search-directory/?d=w&state=vt&specialty=21

Vermont Neurologists:
www.healthgrades.com/provider-search-directory/?d=w&state=vt&specialty=28

Care Finder: interactive tool will give you recommended options and a list of questions to ask when screening a provider www.alz.org/carefinder

Long Term Care Facilities in VT

<http://www.dlp.vermont.gov/nursing-list>

Senior Housing Finder

http://www.alz.org/we_can_help_senior_housing_finder.asp?type=homepage

Wandering 1-800-272-3900

<http://www.alz.org/comfortzone/>

<http://www.alz.org/safetycenter/>

[we can help safety medicalert safereturn.asp](http://www.alz.org/we_can_help_safety_medicalert_safereturn.asp)

www.caretraknortheast.com, 802-467-3496

Adult Protective Services: if you suspect that an elderly or disabled adult may be a victim of abuse, neglect or exploitation

Vermont Adult Protective Services

1-800-564-1612

802-241-2345

Vermont Department of Aging & Disabilities 1-800-642-5119 1-802-241-2400

<http://dail.vermont.gov/>

103 South Main Street

Waterbury, VT 05671

Vermont Legal Assistance

Vermont Legal Aid 1-800-889-2047 www.vtlegalaid.org

Vermont Bar Association Lawyer Referral Service 1-800-639-7036

www.vtbar.org

Assistive Technology and Adaptive Equipment

www.getATstuff.com

Alzheimer's Store

1-800-752-3238

www.alzstore.com

Clinical Trials

TrialMatch 1-800-272-3900 www.alz.org/trialmatch

<http://Clinicaltrials.gov>

Publications

Many communities have local publications specifically designed for older readers. Often these are available at senior centers or in doctors' offices and contain informative articles and helpful listings of resources in your community. Or check with the Alzheimer's Association of Vermont.

National Resources and Referrals

Listed below are a few general resources, but you will want to create your own personal list based upon what is available in your community.

Keep an on-going list of resources that you can refer to when you need it.

American Association of Retired Persons (AARP) www.aarp.org

601 East St. NW

Washington, DC 20049

(202)434-2277, toll free (888) 687-2277

Alzheimer's Association National Office www.alz.org

225 North Michigan Ave.

Chicago, IL 60601

(800) 272-3900

Eldercare Locator: Nationwide service to identify local resources for seniors, especially agencies on aging www.eldercare.gov

(800) 677-1116

Family Caregiver Alliance: Information, education, services, research, and advocacy for caregivers www.caregiver.org

425 Bush St., Suite 500

San Francisco, CA 94019

(800)445-8106, (415) 434-3388

Family Resource Service www.ceridian.com

1400 Union Meeting Road, Suite 102

Blue Bell, PA 19422

(800) 847-5437

Grief Recovery Institute www.grief-recovery.com

PO Box 6061-302

Sherman Oaks, CA 91413

(818) 907-9600

National Association of Area Agencies on Aging www.n4a.org

1730 Rhode Island Ave, NW

Suite 1200

Washington, DC 20036

(202) 872-0888

National Association of Professional Geriatric Care Managers

www.caremanager.org

1604 N. Country Club Road

Tucson, AZ 85716

(520) 881-8008

National Council on the Aging, Inc. (NCOA) www.ncoa.org

409 Third Street, SW, Second Floor

Washington, DC 20024

(202) 479-1200

National Institute on Aging Information Center
www.nia.nih.gov

P.O. Box 8057

Gaithersburg, MD 20898-8057

(800)222-2225

National Institute on Health **www.nih.gov**

9000 Rockville Pike

Bethesda, MD 20892

(301) 496-4000

National Institute of Mental Health **www.nimh.nih.gov**

Depression Awareness, Recognition & Treatment Program

1-800-421-4211

Best Web sites for Family Caregivers

Description of the topic

Caregivers and their families are often looking for good Internet resources. Identified here is a selected list of Web sites for family members and others caring for persons with Alzheimer's. The list also contains links to resources on caring for the caregiver. Each site is unique and aimed at providing current, practical, and expert advice.

Alzheimer's Association National Office.

Comprehensive information for family caregivers is available through several links found at www.alz.org. The materials cover a robust selection of brochures, factsheets, and links to external Web sites on caregiving and caring for oneself.

Care Partners.

<http://www.alz.org/Care/overview.asp>

Daily Care.

<http://www.alz.org/Resources/TopicIndex/DailyCare.asp>

Residential Care: A Guide for Choosing a New Home.

<http://search.alz.org/Resources/FactSheets/guidenewhome.pdf>

Respite Guide: How to Find What's Right for You.

<http://www.alz.org/Resources/FactSheets/RespiteCareGuide.pdf>

Alzheimer's Disease Education and Referral Center (ADEAR).

Caregiver Guide: Tips for Caregivers of People with Alzheimer's Disease from the National Institute on Aging.

This online booklet provides solid advice on a comprehensive array of caregiving topics. Noteworthy is the easy to read, bullet-point format. Free copies are available at 800-438-4380.

<http://www.alzheimers.org/careguide.htm>

Alzheimer's Disease Research Center, Washington University, St. Louis.

Dementia and Driving.

Contains driving and dementia Web links, including the popular guide from Hartford Insurance.

<http://alzheimer.wustl.edu/adrc2/Education/SpecialTopics/dementiaanddriving.htm>

American Medical Association.

Caregiver Self Assessment Tool.

A checklist to help caregivers take stock of their own well being and minimize risks to their health.

<http://www.ama-assn.org/ama/pub/category/5037.html>

Elder Care Online.

Alzheimer's and Dementia Care Channel.

Guest authors provide unique solutions to challenging behaviors and offer advice to caregivers on coping and taking care of oneself.

<http://www.ec-online.net/alzchannel.htm>

Family Caregiver Alliance.

For those caring for family members with chronic health conditions of all kinds, this Web site offers factsheets, monographs, policy and statistical documents, and consumer and training materials on caregiving and caring for oneself.
<http://www.caregiver.org>

Geriatric Research, Education and Clinical Center (GRECC).

Caring for a Patient with Dementia.

Offers detailed brochures containing practical information not easily found elsewhere. Notable are such topics as dealing with declining abilities, how to work with service agencies and healthcare providers, and holding family meetings.

<http://james.psych.umn.edu/~grecc/caring.htm>

Massachusetts General Hospital-Harvard University.

Caregiver Support Forum.

An electronic forum for caregivers of people with neurological disorders to find support from other caregivers.

<http://neuro-www.mgh.harvard.edu/neurowebforum/CaregiverSupportMenu.html>

Mayo Clinic.

Practical Tips for Alzheimer's Caregivers.

Recommends techniques to assist with behavior, such as promoting independence in the person, minimizing distractions, and adjusting expectations. The site also covers care for the caregiver.

<http://www.mayoclinic.com/invoke.cfm?id=HO00125>

MedlinePlus.

Home Care Services.

Provides links to numerous agencies and organizations that have prepared resources on identifying, evaluating, and hiring home health care staff.

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

Rush Alzheimer's Disease Center.

The Rush Manual for Caregivers.

A comprehensive treatment of caregiver issues in 30 chapters. Coverage includes: stages, communication, intimacy, coping, spiritual needs, legal matters, traveling, driving, hygiene, nutrition, and more.

http://www.rush.edu/cms_docs/rushdoc_26.pdf

Wisconsin Department of Health and Family Services.

Guidelines for Initiating Meaningful, Quality, Home Visits with People Who Have Alzheimer's Disease and Related Dementia.

Detailed information by stages of the disease on creating a successful environment for visiting. Includes tips on listening and speaking.

<http://dhfs.wisconsin.gov/aging/dementia/visits.pdf>

Best Web sites on Alzheimer's disease

Description of the topic

Families, caregivers, students, and trainers are often looking for good Internet resources on the general topic of Alzheimer's disease. Identified here are the best Web sites on the science of Alzheimer's: what it is and how it progresses. Each site is slightly different. Aimed at promoting an environment of trust for persons with Alzheimer's and those who care for them, the information is current, authoritative, and easy-to-understand.

Alzheimer's Association National Office.

<http://www.alz.org>

Information on Alzheimer's disease is available through several links found on the home page. Information is geared toward researchers, healthcare professionals, and families. General information is located under *About Alzheimer's*. Scientific theories on the causes of AD are under *Research*. *Media* carries the most recent findings reported in the medical literature. The *Resources* section has the most in-depth information: association fact sheets and brochures, library resource lists, glossary, and a topic index of internal and external resources.

Alzheimer Research Forum.

<http://www.alzforum.org/dis/abo/default.asp>

About Alzheimer's Disease offers a brief description of the disease, including prevalence and prognosis data, areas in the brain affected, and the changes that characterize AD. Linked to

this page is an Alzheimer FAQ (frequently asked questions) and an extensive section on disease management. Notable are the Tests and Drugs and Therapies sections. Information is geared primarily toward healthcare professionals and researchers, but family caregivers will also benefit.

eMedicine.com.

<http://www.emedicinehealth.com/articles/39500-1.asp>

In easy-to-read language and format, *Alzheimer's Disease Overview* highlights the biological characteristics of Alzheimer's, demographic data, the general course of the disease, and the costs to society. Additional sections link to two and four-page articles on causes, symptoms, advice on when to seek medical attention, tests, treatments, steps to take after the diagnosis, and synonyms and keywords.

Fisher Center for Alzheimer's Research.

<http://www.alzinfo.org/understanding>

Understanding Alzheimer's is divided into five sections: what is Alzheimer's, warning signs and symptoms, getting a diagnosis, where to go for medical help, and fact sheets. With the exception of the fact sheets, each section provides answers to typical questions asked by families about the disease and its management. Selected vocabulary is hyperlinked to glossary terms. In general, the information is geared toward the public and would be excellent for someone wanting a brief but thorough introduction to Alzheimer's.

Mayo Clinic.

<http://www.mayoclinic.com/findinformation/conditioncenters/subcenters.cfm?objectid=00061A7C-89B7-1B37-8D7E80C8D77A0000>

Understanding Alzheimer's links to a brief overview of the disease, which further divides into an array of subtopics including cause, diagnosis, management, coping, prevention, and the Alzheimer's Center. The Center contains additional information on treatments, caregiving, and taking control. Each section provides cross-references and links to more articles. The quality of information on this Web site is excellent and the content is core. Plan to explore more than one page, however, to find all the information on Alzheimer's. The Web site is geared primarily toward the general public.

National Library of Medicine.

<http://www.nlm.nih.gov/medlineplus/alzheimersdisease.html>

Alzheimer's Disease links to numerous government agencies and nonprofit

organizations that have prepared overviews of the disease. Additionally, it carries resources on symptoms and diagnosis, disease management, coping, research, genetics, and statistics. The Web page also links to Reuters and United Press International (UPI) for recent news on Alzheimer's and has materials specifically geared toward women, men, children, and teens. A sidebar links to Web pages dedicated to caregivers, memory, the brain, and senior health. The Alzheimer's Association, National Institute on Aging, Area Agencies on Aging, Fisher Center, Family Caregiver Alliance, American College of Physicians, and other source agencies are represented.

Neuropathology - Dementia.

<http://www.uvm.edu/~jkessler/NP/neudemmen.htm>

The University of Vermont, College of Medicine has assembled a two-part teaching module on Alzheimer's. "Alzheimer's: Overview of Dementia and Alzheimer's Disease" and "Detailed Review of Alzheimer's Disease" are primarily for the healthcare professional.

NIH Senior Health – Alzheimer's Disease.

<http://nihseniorhealth.gov/alzheimersdisease/toc.html>

The National Institutes of Health has put together a Web page for seniors who are computer saavy. The content is divided into small portions of one or two ideas per page; at the same time, the presentation is sophisticated. Viewing options such as font resize, contrast, speech capability, and printer friendly versions are available. The main sections include a definition of AD, causes and risks, symptoms and diagnosis, treatments and research, and frequently asked questions.

Unraveling the Mystery.

<http://www.alzheimers.org/unraveling/index.htm>

Revised in 2002, this comprehensive online booklet by the National Institute on Aging is an authoritative resource that includes both basic and technical data. Numerous illustrations and sidebars illuminate information on the science and social aspects of Alzheimer's. Included are the disease impact, how the brain works, known causes and disease theories, techniques for diagnosing, the search for new treatments, and improving support for families and other caregivers. The resource also contains a glossary, list of supportive organizations, and recommended readings. The walk through the brain is neat. Print copies are available from the Alzheimer Disease Education & Referral Center, 800.438.4380.

APPENDIX: OTHER DEMENTIA-RELATED CONDITIONS AND DISEASES

Following is a brief list of dementia-related diseases that may cause symptoms similar to those of Alzheimer's disease. As you can see from the illustration below, Alzheimer's disease is the source of nearly two-thirds of all dementia, making it the most likely (but not the only) source of dementia symptoms.

Mild cognitive impairment (MCI)

In MCI, a person has problems with memory or one of the other core functions affected by dementia. These problems are severe enough to be noticeable to other people and to show up on tests of mental function, but not serious enough to interfere with daily life. When symptoms do not disrupt daily activities, a person does not meet criteria for being diagnosed with dementia. The best-studied type of MCI involves a memory problem.

Individuals with MCI have an increased risk of developing Alzheimer's disease over the next few years, especially when their main problem involves memory. However, not everyone diagnosed with MCI progresses to Alzheimer's or another kind of dementia.

Vascular dementia (VaD)

Many experts consider vascular dementia the second most common type, after Alzheimer's disease. It occurs when clots block blood flow to parts of the brain, depriving nerve cells of

food and oxygen. If it develops soon after a single major stroke blocks a large blood vessel, it is sometimes called "post-stroke dementia."

It can also occur when a series of very small strokes, or infarcts, clog tiny blood vessels. Individually, these strokes do not cause major symptoms, but over time their combined effect is damaging. This type used to be

called “multi-infarct dementia.”

Symptoms of vascular dementia can vary, depending on the brain regions involved. Forgetfulness may or may not be a prominent symptom, depending on whether memory areas are affected. Other common symptoms include difficulty focusing attention and confusion. Decline may occur in “steps,” where there is a fairly sudden change in function.

People who develop vascular dementia may have a history of heart attacks. High blood pressure or cholesterol, diabetes or other risk factors for heart disease are often present.

Mixed dementia

In mixed dementia, Alzheimer’s disease and vascular dementia occur at the same time. Many experts believe mixed dementia develops more often than was previously realized and that it may become increasingly common as people age. This belief is based on autopsies showing that the brains of up to 45 percent of people with dementia have signs of both Alzheimer’s and vascular disease.

Decline may follow a pattern similar to either Alzheimer’s or vascular dementia or a combination of the two. Some experts recommend suspecting mixed dementia whenever a person has both (1) evidence of cardiovascular disease and (2) dementia symptoms that get worse slowly.

Dementia with Lewy bodies (DLB)

In DLB, abnormal deposits of a protein called alpha-synuclein form inside the brain’s nerve cells. These deposits are called “Lewy bodies” after the scientist who first described them. Lewy bodies have been found in several brain disorders, including dementia with Lewy bodies, Parkinson’s disease and some cases of Alzheimer’s.

Symptoms of DLB include:

- Memory problems, poor judgment, confusion and other symptoms that can overlap with Alzheimer’s disease

- Movement symptoms are also common, including stiffness, shuffling walk, shakiness, lack of facial expression, problems with balance and falls
- Excessive daytime drowsiness
- Visual hallucinations
- Mental symptoms and level of alertness may get better or worse (fluctuate) during the day or from one day to another
- In about 50 percent of cases, DLB is associated with a condition called rapid eye movement (REM) sleep disorder. REM sleep is the stage where people usually dream. During normal REM sleep, body movement is blocked and people do not “act out” their dreams. In REM sleep disorder, movements are not blocked and people act out their dreams, sometimes vividly and violently.

Parkinson’s disease (PD)

Parkinson’s is another disease involving Lewy bodies. The cells that are damaged and destroyed are chiefly in a brain area important in controlling movement. Symptoms

include tremors and shakiness; stiffness; difficulty with walking, muscle control, and balance; lack of facial expression; and impaired speech. Many individuals with Parkinson’s develop dementia in later stages of the disease.

Frontotemporal dementia (FTD)

FTD is a rare disorder chiefly affecting the front and sides of the brain. Because these regions often, but not always, shrink, brain imaging can help in diagnosis. There is no specific abnormality found in the brain in FTD. In one type called Pick’s disease, there are sometimes (but not always) abnormal microscopic deposits called Pick bodies.

FTD progresses more quickly than Alzheimer’s disease and tends to occur

at a younger age. The first symptoms often involve changes in personality, judgment, planning and social skills. Individuals may make rude or off-color remarks to family or strangers, or make unwise decisions about finances or personal matters. They may show feelings disconnected from the situation, such as indifference or excessive excitement. They may have an unusually strong urge to eat and gain weight as a result.

Creutzfeldt-Jakob disease (CJD)

Creutzfeldt-Jakob disease (pronounced CROYZ-felt YAH-cob) is a rare, rapidly fatal disorder affecting about 1 in a million people per year worldwide. It usually affects individuals older than 60. CJD is one of the prion (PREE-awn) diseases. These disorders occur when prion protein, a protein normally present in the brain, begins to fold into an abnormal three-dimensional shape. This shape gradually triggers the protein throughout the brain to fold into the same abnormal shape, leading to increasing damage and destruction of brain cells.

Recently, “variant Creutzfeldt-Jakob disease” (vCJD) was identified as the human disorder believed to be caused by eating meat from cattle affected by “mad cow disease.” It tends to occur in much younger individuals, in some cases as early as their teens.

The first symptoms of CJD may involve impairment in memory, thinking and reasoning or changes in personality and behavior. Depression or agitation also tend to occur early. Problems with movement may be present from the beginning or appear shortly after the other symptoms. CJD progresses rapidly and is usually fatal within a year.

Normal pressure hydrocephalus (NPH)

Normal pressure hydrocephalus (high-droh-CEFF-a-luss) is another rare disorder in which fluid surrounding the brain and spinal cord is unable to drain normally. The fluid builds up, enlarging the ventricles (fluid-filled chambers) inside the brain. As the chambers expand, they can compress and damage nearby tissue. “Normal pressure” refers to the fact that the

Spinal fluid pressure often, although not always, falls within the normal range on a spinal tap.

The three chief symptoms of NPH are (1) difficulty walking, (2) loss of bladder control and (3) mental decline, usually involving an overall slowing in understanding and reacting to information. A person's responses are delayed, but they tend to be accurate and appropriate to the situation when they finally come.

NPH can occasionally be treated by surgically inserting a long thin tube called a shunt to drain fluid from the brain to the abdomen. Certain television broadcasts and commercials have portrayed NPH as a highly treatable condition that is often misdiagnosed as Alzheimer's or Parkinson's disease. However, most experts believe it is unlikely that the significant number of people diagnosed with Alzheimer's or Parkinson's actually have NPH that could be corrected with surgery. NPH is rare, and it looks different from Alzheimer's or Parkinson's to a physician with experience in assessing brain disorders. When shunting surgery is successful, it tends to help more with walking and bladder control than with mental decline.

Huntington's disease (HD)

HD is a fatal brain disorder caused by inherited changes in a single gene. These changes lead to destruction of nerve cells in certain brain regions. Anyone with a parent with Huntington's has a 50 percent chance of inheriting the gene, and everyone who inherits it will eventually develop the disorder. In about 1 to 3 percent of cases, no history of the disease can be found in other family members. The age when symptoms develop and the rate of progression vary.

Symptoms of Huntington's disease include twitches, spasms, and other involuntary movements; problems with balance and coordination; personality changes; and trouble with memory, concentration or making decisions.

Wernicke-Korsakoff syndrome

Wernicke-Korsakoff syndrome is a two-stage disorder caused by a deficiency of thiamine (vitamin B-1) . Thiamine helps brain cells produce energy from sugar. When levels of the vitamin fall too low, cells are unable to generate enough energy to function properly. Wernicke encephalopathy is the first, acute phase, and Korsakoff psychosis is the long-lasting, chronic stage.

The most common cause is alcoholism. Symptoms of Wernicke-Korsakoff syndrome include:

- Confusion, permanent gaps in memory and problems with learning new information
- Individuals may have a tendency to "confabulate", or make up information they can't remember
- Unsteadiness, weakness and lack of coordination

If the condition is caught early and drinking stops, treatment with high-dose thiamine may reverse some, but usually not all, of the damage. In later stages, damage is more severe and does not respond to treatment.