



For the Person with Early Onset Dementia: Information and Resources

Introduction

Dementia is a brain disease that seriously affects a person's memory, thinking, and reasoning skills. People with dementia often have trouble speaking clearly, remembering recent events, and learning new things. There are many causes of dementia, but Alzheimer's disease is the most common cause among older people.

Alzheimer's disease is usually divided into two types: early onset or late onset, depending on the age at diagnosis. Late onset AD is the more common form and it is usually diagnosed after age 65. The other type, early onset AD, occurs before age 65. A small portion of people with early onset disease have an inherited form of the disease, which tends to develop between ages 30 and 60. More recently, doctors have begun diagnosing more people who are younger than 65 who have AD but do not have the identified genetic mutations.

A diagnosis of AD is challenging at any age, but there are special problems that people with dementia and families are likely to encounter when the diagnosis occurs prior to age 65. This fact sheet is designed to help you navigate the programs and services that you may need during this time. It describes tips, action steps, and community resources.

In 2006, the Alzheimer's Association estimated that between 220,000 and 640,000 individuals have early onset dementia.¹

Diagnosis

A diagnosis is critical—it can help you find support that can help you live successfully with dementia. Additionally, while there is not a cure for Alzheimer's disease, there are prescription medications that can slow the progression of the symptoms. If you think you have early onset dementia but do not have a diagnosis, be an advocate

¹Alzheimer's Association. (2006, June). *Early Onset Dementia: A National Challenge, A Future Crisis*. Retrieved from: <http://www.alz.org/>

for yourself. You may want to ask a trusted friend or family member to help you through this process.

- Write down symptoms so that you feel prepared when going to the doctor. Consider having a family member or friend write down changes they have noticed.
- If possible, visit a Memory Diagnostic Center, Alzheimer's Disease Center, or a doctor who is an expert in dementia. Ask your local Alzheimer's Association for information on these centers and doctors.
- Ask questions and tell your concerns to physicians and nurses.
- Most evaluations will include a detailed medical history, physical and neurological examination, laboratory tests including blood and urine samples, a mental status test, and a psychiatric assessment to rule out a mental illness such as depression.

Employment

Many people with early onset dementia are working when symptoms develop, affecting job performance.

You might choose to continue work-

ing. People in the early stages of dementia have many abilities. However, in certain positions this choice may be dangerous without increased supervision or changes in your job responsibilities.

- Consider whether shifting job responsibilities and/or reducing work hours are necessary. Brainstorm and discuss options with trusted family members and friends.
- Do background research. For example, know the ADA and employment conditions such as sick leave and disability benefits.
- You will want to decide if and when to tell your employer of your diagnosis. Carefully plan and consider role-playing that conversation.
- You may want to target one or two other trusted people in the organization to tell of your diagnosis and discuss how they can help.

You may have been asked or forced to leave a job because of the changes you are experiencing. If you leave a job before a diagnosis, you may not have the chance to receive the assistance provided to people with disabilities, such as workplace accommodations and disability referrals. This may result in your family's medical cover-

age being put at risk and your overall family income being drastically reduced, especially if you are your family's primary "breadwinner."

- If you are employed, the Americans with Disabilities Act (ADA) requires employers with more than 15 staff members to make "reasonable" accommodations. If you're unsure how to proceed, call the Equal Opportunity Commission at 1-800-669-4000 or Job Accommodation Network at 1-800-526-7234.
- You may also want to consider whether early retirement is a viable option for you and your family.

Financial Planning

Financial planning is very important when considering your future care. While planning for the future can be a challenge, it will help make sure you receive the care you deserve.

- Speak to a qualified advisor such as a financial planner or elder-law attorney to help you plan for your long-term care. You may want to involve a trusted family member or friend in this process.
- Look into programs such as Social

Security Disability Insurance, Supplemental Security Income, Veterans Benefits, Medicare, and Medicaid. Medicaid is particularly important. Of the programs mentioned, only Medicaid covers long-term care and to qualify for Medicaid you must have limited resources

- If you have long-term care insurance, check your coverage.
- If you're unsure what benefits you may qualify for, call your local Area Agency on Aging (AAA) for Information and Referral. Many states also have Aging and Disability Resource Centers (ADRCs) that can help link you with resources. For contact information for AAAs and ADRCs please see page 6.

Navigating the system can be difficult and time-consuming, but it will benefit you to check all your options. Seek help navigating the system from social workers and other professionals in social service organizations.

Legal Planning

You will want to make sure that all your legal documents are in order, including your: Durable Power of Attorney for Healthcare, Living Wills, and your end-of-life care wishes. Honest,

open, and frank discussions with your family or loved ones are very important and will help ensure that you receive the care you want and deserve.

Remember that you can not designate a Power of Attorney when you are no longer capable of making decisions – **start this process early**. This will allow you to have a say in your future and will relieve your family or loved ones of the burden of making important decisions without your input. If at some point, you have not designated your Power of Attorney, your family or loved ones may be forced to consider a court-appointed guardian.

Make a habit of periodically reviewing, or having a trusted family member or friend review, legal documents. This is most particularly important if there have been changes in location, a death in the family, divorce, or any other large changes in family status.

Laws governing financial and legal planning vary from state to state. Be aware that someone's experience in another state may differ from yours because of this.

Relationship Changes

Regardless of the type of relationship (e.g. spouse, parent/child, or sibling)

and strength of the relationship between you and your family or loved ones, relationship dynamics will change. Relationship changes can be particularly difficult for spouses - sexuality, intimacy, and a sense of partnership can each be affected.

Feelings of grief and loss are normal as you face these changes.

- If you have access to a counselor or Employee-Assistance Program (EAP), consider taking advantage of it.
- Attend a support group. Some organizations have special support groups for people with early onset dementia and their caregivers. Call your local Alzheimer's Association for details.
- Online chat rooms and message boards are also a great way to communicate with others. Try this one: <http://alzheimers.infopop.cc/eve/forums/a/frm/f/2711002361>
- The Alzheimer's Association offers a telephone Helpline (1-800-272-3900) staffed by professionals. They have many resources and can provide information on counselors in your area specializing in issues related to Alzheimer's disease or related dementias.

Realizing that you need outside support is difficult, but it can result in one more source of support as you begin to adjust to the changes you and your family and loved ones are experiencing.

Children

In addition to changes you are experiencing, if you have children, they are experiencing dramatic changes as well. Children will have different needs depending on their age and relationship to you. And, just like adults, each child will react differently to the disease. Anger, withdrawal, sadness, resentment, apathy, and many other emotions are all normal reactions.

- Have age-appropriate conversations about the changes they see.
- Be honest and keep the lines of communication open. Check-in with your child about how he or she is feeling.
- Notify important people in your child's life (e.g. teacher, mentor, or best friend's parent) and provide them with information on early onset dementia.
- Consider counseling sessions for your child or visits to their school social worker.
- Call your local Alzheimer's Association chapter to see if they have programs, such as support groups, for children. Some children may simply prefer to talk to others their own age.

Taking Care of Yourself

As person with early onset dementia, you are experiencing something that you and your family and loved ones certainly never wanted and probably never expected. Caring for yourself physically, socially, emotionally, and spiritually will be vital as you live with early-onset dementia. For example, many people with dementia develop new hobbies, skills, and joys after a diagnosis of dementia such as becoming advocates for yourself and others with early-onset dementia. Many people gain comfort from joining the online community. For more information, refer to our list of "Resources" starting on page 6.

Your friends and family are valuable resources , and they can help you. Most people are willing to help. They just need to know when and where.

Resources

ORGANIZATIONS

Alzheimer's Association

1-800-272-3900

<http://www.alz.org>

<http://www.alz.org/findchapter>—Find Chapter

<http://www.alz.org/carefinder>—CareFinder Tool

<http://alzheimers.infopop.cc/eve/forums/a/frm/f/2711002361>—Message Boards

Aging and Disability Resource Centers

http://www.aoa.gov/prof/aging_dis/aging_dis.asp

http://www.adrc-tae.org/tiki-download_file.php?fileId=2410—List of States

Alzheimer's Disease Education and Referral Center (ADEAR)

1-800-438-4380

<http://www.nia.nih.gov/Alzheimers>

Area Agency on Aging (AAA)/ ElderCare Locator

Find your state & local aging office: 1-800-677-1116

<http://www.eldercare.gov>

EARLY ONSET

Early-Onset Alzheimer's Disease: I'm Too Young to Have Alzheimer's Disease

http://www.alz.org/Resources/FactSheets/EarlyOnSet10_5.pdf

Early Onset Alzheimer's Disease:

<http://www.asmt.org/earlyonsetAD.htm>

Early-Onset Alzheimer's: An Interview with a Mayo Clinic Specialist

<http://www.mayoclinic.com/health/alzheimers/AZ00009>

DIAGNOSIS

Alzheimer's Disease Centers

<http://www.nia.nih.gov/Alzheimers/ResearchInformation/ResearchCenters>

How is AD Diagnosed?

<http://www.nia.nih.gov/Alzheimers/AlzheimersInformation/Diagnosis>

Working with Your Doctor When You Suspect Memory Loss

<http://www.alzla.org/education/HKEnglishBooklet.pdf>

Resources, Cont.

EMPLOYMENT

Equal Employment Opportunity Commission

<http://www.eeoc.gov/facts/fs-ada.html>

1-800-669-4000

Employment and Early-Onset Alzheimer's Disease: A Guide for Employees

Available from the OK/AR Chapter of the Alzheimer's Association. Contact Tulsa@alzkoar.org or call 1-800-272-3900 and ask for the Tulsa chapter.

FINANCIAL PLANNING

Advance Directives by State

<http://www.caringinfo.org/i4a/pages/Index.cfm?pageid=3425>

Early-onset Alzheimer's: Financial Challenges

<http://www.mayoclinic.com/health/early-onset-alzheimers/AZ00010>

Legal and Financial Planning for Alzheimer's Disease

<http://www.nia.nih.gov/Alzheimers/ResearchInformation/Newsletter/CurrentIssue.htm> (NIA Connections Newsletter v. 15 #1-2).

Medicare

www.medicare.gov

Money Matters

http://www.alz.org/Resources/FactSheets/moneymatters10_5.pdf

Planning Ahead

http://www.alz.org/Resources/FactSheets/FS_planahead.pdf

Social Security

www.ssa.gov

Social Security Disability Documentation Guide

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

LEGAL PLANNING

Legal Plans

http://www.alz.org/Resources/factsheets/legalplans10_5.pdf

Resources, Cont.

National Academy of Elder Law Attorneys

<http://www.naela.com/public/index.htm>

RELATIONSHIP CHANGES

Relationship Changes

<http://www.alz.org/care/coping/changes.asp>

CHILDREN AND DEMENTIA

Just For Children

<http://www.alz.org/Resources/FactSheets/FSjust4children.pdf>

Just For Teens

<http://www.alz.org/Resources/FactSheets/FSjust4teens.pdf>

Alzheimer's Foundation of America – Teens

<http://www.afateens.org/index.shtml>

Helping Children & Teens Understand Alzheimer's Disease

<http://www.alzmigreatlakes.org/files/resources/articles/Helping%20Children%20and%20Teens%20Understand%20Alzheimer's.pdf>

TAKING CARE OF YOURSELF

Early-Onset Newsletter

<http://www.alzokar.org/ok-newsletters.asp>

Available from the OK/AR Chapter of the Alzheimer's Association. Contact Tulsa@alzkoar.org or call 1-800-272-3900 and ask for the Tulsa chapter.

Alzheimer's Forum: A Website Produced By and For People with Dementia:

<http://www.alzheimers.org.uk/AlzheimersForum/home.htm>

Alzheimer's Spoken Here:

<http://www.alzsh.net>

Living with Alzheimer's:

<http://www.alz.org/People/Manage.asp>

FOR MORE INFORMATION

AoA recognizes the importance of making information readily available to consumers, professionals, researchers, and students. Our website provides information for and about older persons, their families, and professionals involved in aging programs and services. For more information about AoA, please contact: US Dept of Health and Human Services, Administration on Aging, Washington, DC 20201; phone: (202) 401-4541; fax (202) 357-3555; Email: aoainfo@aoa.gov; or contact our website at: www.aoa.gov