



## For the Caregiver 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.<sup>1</sup>

### Diagnosis

A diagnosis is critical—it can help you find help so that you can support your loved one. 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 your loved one has early onset dementia but has no diag-

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

nosis, try to support them. You can:

- Write down symptoms so that you feel prepared when going to the doctor. Have you loved one participate in writing down symptoms, if appropriate.
- If possible, visit a Memory Diagnostic Center, Alzheimer's Disease Center, or a doctor with dementia expertise. 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.

Some individuals may choose to continue working. This is appropriate in some circumstances; 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 their job responsibilities.

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

It is possible that your loved one may be asked or forced to leave their jobs because of the changes they are experiencing. Those who leave their jobs before a diagnosis may never 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 the person with dementia was the primary “breadwinner.”

- If the person you are caring for is 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 the person with dementia.

### Financial Planning

Financial planning is very important when considering care for your loved one. While planning for the future can be a challenge, it will help you provide the best care possible for your loved one.

- Speak to a qualified advisor such as a financial planner or elder-law attorney to help you plan for the long-term care of the person with dementia.

- 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 your loved one has long-term care insurance, check their 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 and your loved one. Seek help navigating the system from social workers and other professionals in social service organizations.

### Legal Planning

If the person you are caring for is in the early stages of their disease, initiate a discussion with them regarding

Durable Power of Attorney for Healthcare, Living Wills, and their end-of-life care wishes.

Remember that you cannot be designated a Power of Attorney when the person with dementia is no longer capable of making decisions – **start this process early**. This will allow the person with dementia to have a say in their future and relieve you of the burden of making certain important decisions without their input. If your loved one can no longer designate you Power of Attorney, you may be forced to consider a court-appointed guardian.

Make a habit of periodically reviewing legal documents, particularly 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 the person with demen-

tia, 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 a related dementia.

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 loved one are experiencing.

### Children

In addition to providing care for the person with dementia, you may be providing care for your children. Children will have different needs depending on their age and relationship to the person with dementia. 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 the child about how he or she is feeling.
- Notify important people in the 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 the child or visits to their school social worker.
- Call your local Alzheimer's Associa-

tion 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.

### Take Care of Yourself

As a caregiver for a person with early onset dementia, you have a responsibility that you and the person you're caring for certainly never wanted and probably never expected. Caring for yourself is part of responsible caregiving and will help reinforce your ability to do the caregiving tasks that you now have.

Consider respite care, which is simply taking time off from caregiving to do something important for yourself, such as running personal errands, resting, or seeing friends. Respite can be provided formally, such as through adult day services or in-home help, or less formally through friends and family.

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

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## Resources

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### **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

Alzheimer's Disease Education and Referral Center (ADEAR)

1-800-438-4380

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

Aging and Disability Resource Centers

[http://www.aoa.gov/prof/aging\\_dis/aging\\_dis.asp](http://www.aoa.gov/prof/aging_dis/aging_dis.asp)

[http://www.adrc-tae.org/tiki-download\\_file.php?fileId=2410](http://www.adrc-tae.org/tiki-download_file.php?fileId=2410)—List of States

Area Agency on Aging (AAA)/ElderCare Locator

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

<http://www.eldercare.gov>

National Family Caregivers Association

1-800-896-3650

<http://www.thefamilycaregiver.org>

### **EARLY ONSET**

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>

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## Resources

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### **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).

Money Matters

[http://www.alz.org/Resources/FactSheets/moneymatters10\\_5.pdf](http://www.alz.org/Resources/FactSheets/moneymatters10_5.pdf)

Planning Ahead

[http://www.alz.org/Resources/FactSheets/FS\\_planahead.pdf](http://www.alz.org/Resources/FactSheets/FS_planahead.pdf)

Medicare

[www.medicare.gov](http://www.medicare.gov)

Social Security

[www.ssa.gov](http://www.ssa.gov)

Social Security Disability Documentation Guide

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

### **LEGAL PLANNING**

LawInfo.com

<http://resources.lawinfo.com/>

Legal Plans

[http://www.alz.org/Resources/factsheets/legalplans10\\_5.pdf](http://www.alz.org/Resources/factsheets/legalplans10_5.pdf)

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## Resources

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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>

Sexuality  
<http://www.alz.org/Resources/FactSheets/FSsexuality3.pdf>

### **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>

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**

Alzheimer's Family Relief Program  
<http://www.ahaf.org/afrp/afrp.htm>

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

Caregiver Stress  
[http://www.alz.org/Resources/FactSheets/CaregiverSt\\_Eng.pdf](http://www.alz.org/Resources/FactSheets/CaregiverSt_Eng.pdf)

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.

#### **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](mailto:aoainfo@aoa.gov); or contact our website at: [www.aoa.gov](http://www.aoa.gov)