U.S. Department of Health and Human Services
Administration on Aging

Alzheimer's Disease Demonstration Grants to States Program &
National Family Caregiver Support Program Resources

FACT SHEET

For the Caregiver for the Person with Intellectual/Developmental Disability and Alzheimer's Disease: Information and Resources

Introduction

You may be an expert in providing care for your loved one with an intellectual or developmental disability (I/DD). But if your loved one also has Alzheimer's disease or a related dementia, you are now experiencing a new and different type of challenge.

There are around 9,000 people in the United States with I/DD and dementia. This number will only increase as those with I/DD age. Additionally, approximately 75% of individuals with I/DD live with family members. This means that more and more caregivers like you will be providing care for a person with both I/DD and Alzheimer's disease.

This fact sheet will provide an overview of:

1. Alzheimer's disease and dementia
2. How your role as a caregiver is changing
3. Important steps in planning for the future
4. Resources for caregivers of people with I/DD and Alzheimer's disease.

What is Dementia?
What is Alzheimer's Disease?

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 of dementia among older people.

> Alzheimer's disease and other types of dementia are not a normal part of aging.

Dementia and intellectual disabilities are very different. In I/DD, intellectual abilities may not develop or are under-

developed, but in dementia there is a gradual loss of the existing abilities and this loss continues to worsen over time.

Symptoms of Alzheimer's will depend on your loved one's prior level of functioning. However, some common symptoms in persons with I/DD include:

- Loss of memory and logical thinking
- Personality change
- More emotional ups-and-downs; irritability
- Increased apathy or withdrawal
- Decreased ability to take care of themselves
- Seizures may begin to occur
- Changes in coordination and way of walking
- Loss of control in bladder and bowel habits

Who is at Risk?

Most people with I/DD do not have an increased risk of Alzheimer's disease. Like the general population, approximately 10% of people over the age 65 and 50% of people over age 85 have Alzheimer's disease. In most people with I/DD, the disease follows the same course as the general population and can last as long as 20 years.

There are three groups of individuals with a higher risk of developing Alzheimer's disease:

1. individuals over 40 with Down syndrome
2. individuals with a family history of Alzheimer's disease
3. individuals who have experienced head injury, especially if the injury was severe or if there were multiple injuries over a lifetime.

Meeting one or more of these categories does not mean that Alzheimer's disease will definitely occur. However, if someone meets one of these categories and is experiencing one or more of the symptoms mentioned above, a thorough evaluation is needed.

Alzheimer's disease typically begins around age 50 in people with Down syndrome but can occur in individuals who are much younger.

People with Down syndrome are thought to be at greater risk because of the extra genetic material associated with chromosome 21. In fact, most individuals with Down Syndrome who are over age 50 develop Alzheimer's disease. The course of Alzheimer's disease, typically 2 to 8 years, is more rapid in people with Down syndrome.

Diagnosis

When changes in memory or behavior occur, a diagnosis is important. An early diagnosis will help you understand what kind of care your loved one may need now and in the future. Additionally, some illnesses, such as depression, thyroid disease, or urinary tract infections, produce symptoms of dementia. With treatment, dementia caused by those illnesses may be reversed.

There is no single test for Alzheimer's disease or related dementias. Instead, a thorough evaluation 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.

Some tests may be difficult to complete with a person with I/DD, depending on your loved one's level of functioning. However, several tests have been designed for people with I/DD and possible dementia. Increasingly, clinics that specialize in the care of persons with I/DD have staff able to complete these tests.

Those at greater risk of developing Alzheimer's disease should have a baseline assessment of their functioning completed at age 30. Some experts suggest creating a video recording of your loved one at this age. Like a formal baseline assessment, a video recording will show the normal level of behaviors and skills for your loved one. If symptoms appear, the baseline will provide a comparison or benchmark.

If possible, visit a Memory Diagnostic Center, Alzheimer's Disease Center, or a doctor with dementia expertise. They are more likely to have the specialized tools for people with I/DD. Contact your local Alzheimer's Association or developmental disabilities services agency for information on these centers and doctors.

Treatment

For symptoms of Alzheimer's disease and other irreversible dementias, prescription medications are available. These medications will not cure Alzheimer's disease, but they may delay the progression of symptoms.

If your loved one experiences behavior changes or sleep disturbances, adjustments to the home environment or daily schedule should be tried first. Experts recommend analyzing the behavior to see if the behavior may be caused by pain or other discomforts such too much light, noise, or heat that can be easily modified.

Medications may be a necessary additional support for some individuals and can help manage certain behaviors, such as agitation or sleep disturbances. A physician will be able to advise on these medication options. It is important to remember that medications also have side effects, and people with dementia should be monitored by regularly.

A Changing Caregiver Role

Caring for your loved one with dementia is different from caring for someone with I/DD without dementia. For example, when caring for someone with I/DD, you probably tried to increase your loved one's independence as much as possible. Now that your loved one also has dementia, a continued increase in their capacities will not be possible. Over time, you will experience an increase in their need for supervision and assistance along with decreases in their skills and ability to care for themselves. Additionally, you may become concerned about your own ability to care as you also age and experience your own health changes.

Let those who care about you and your loved one know about the changes you both are experiencing. This will be a time when you need increased support from friends, family, and/or professionals. While it can be difficult to seek outside help, this will be an important source of support as you adjust to the changes you and your loved one are experiencing.

You may want to consider respite care—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.

> When other family members, friends or an agency case manager say "What can I do to help?" think about asking for respite assistance.

Planning for the Future

Planning for the future is essential. Most people with I/DD, particularly people with Down syndrome, are considered independent adults when they reach 18 years of age. Dementia changes independence. Even as individuals continue to have many capacities, Alzheimer's disease will increase care needs. When possible, planning for the future is best when it is done early. This allows the person with dementia to be involved as much as possible and appropriate. Here are some key elements you also can consider:

- Look into advance directives, living will, and power of attorney documents
- Discuss future housing arrangements for your loved one (in-home vs. long-term care setting)
- Consider writing a "Letter of Intent." If your loved one is able, talk with them about their living preferences and other life style choices. Include their desires in the letter of intent.
- Research and enroll (if eligible) your loved in government programs such as: Supplemental Security Income, Social Security, Medicaid, Medicare, Social Security Disability Income, and Food Stamps.
- Consult with an elder law or disability attorney. This is especially important if you may leave your loved one an inheritance, are considering guardianship, or if you are interested in setting up an OBRA 93 Payback Trust or Special Needs Trust.

Community agencies including your local area agency on aging offer a wealth of resources. They can help you find information and make decisions when planning for the future. They can also help you navigate the social service system, determine financial supports and eligibility for services, offer support, and plan for end-of life care of your loved one. See page 4 for a list of organizations and resources.

Resources

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ORGANIZATIONS

Administration on Development Disabilities
http://www.acf.hhs.gov/programs/add/states/ddcs.html

Aging and Disability Resource Centers (ADRCs)
http://www.aoa.gov/prof/aging_dis/aging_dis.asp
http://www.adrc-tae.org/tiki-download_file.php?fileId=2410—States with ADRCs

Alzheimer's Association
1-800-272-3900
http://www.alz.org
http://www.alz.org/findchapter.asp—Find your Chapter
http://www.alz.org/carefinder/index.asp—CareFinder

Alzheimer's Disease Education and Referral Center
1-800-438-4380
http://www.nia.nih.gov/Alzheimers/

The ARC
http://www.thearc.org
http://thearclink.org/—ARCLink to resources

Area Agency on Aging/ ElderCare Locator
1-800-677-1116
http://www.eldercare.gov/

National Down Syndrome Society
1-800-221-4602
http://www.ndss.org/
http://www.ndss.org/index.php?option=com_wrapper&Itemid=244—local offices

National Family Caregivers Association
1-800-896-3650
http://www.thefamilycaregiver.org/index.cfm

Alzheimer's Disease Overviews

Alzheimer's Disease and Related Dementias
http://www.alz.org/AboutAD/RelatedDiseases.asp

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Resources, Cont.

Alzheimer's Disease
http://nihseniorhealth.gov/alzheimersdisease/toc.html

Understanding Alzheimer's Disease
http://www.nia.nih.gov/Alzheimers/Publications/UnderstandingAD

I/DD AND ALZHEIMER'S DISEASE

Alzheimer's Disease and Down Syndrome
http://www.ndss.org/index.php?
option=com_content&task=view&id=33&Itemid=119

Frequently Asked Questions
http://www.thearc.org/faqs/almr.html

Dual Diagnoses
http://www.alz.org/grtrcinc/aaRelDownSyndrome.htm

Aging with a Developmental Disability: Transition Guide for Caregivers
http://www.opadd.on.ca/Documents/transitionguide-final-sept0105.pdf

Developmental Disabilities and Alzheimer's Disease...What You Should Know
http://www.thearc.org/misc/alzbk.html

Down 's Syndrome and Alzheimer's Disease: A Guide for Parents and Carers
http://www.downs-syndrome.org.uk/pdfs/DS%20&%20Alzheimers.pdf

RISK FACTORS, DIAGNOSIS, & TREATMENT

Alzheimer's: Getting a Diagnosis
http://www.alz.org/AboutAD/Diagnosis.asp

Alzheimer's Treatment Options
http://www.alz.org/AboutAD/Treatments.asp

Working with Your Doctor When You Suspect Memory Loss
http://www.alzla.org/education/HKEnglishBooklet.pdf

Alzheimer's Disease Centers
http://www.nia.nih.gov/Alzheimers/ResearchInformation/ResearchCenters
1-800-438-4380

Resources, Cont.

FACT SHEET

CAREGIVING

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

Dementia, Caregiving and Controlling Frustration
http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=891

ARCH – National Respite Network
http://www.respitelocator.org/index.htm

Dementia and I/DD Discussion Group
http://groups.yahoo.com/group/Dementia-IDlistserv

PLANNING FOR THE FUTURE

Advance Planning: Legal, Medical & Administrative
http://www.albany.edu/aging/lastpassages/manual-02.htm

A Family Handbook on Future Planning
http://www.thearc.org/publications/futureplanninghandbook.doc

Future Planning: Guardianship and People with Mental Retardation
http://www.thearc.org/faqs/guard.html

Future Planning: Making Financial Arrangements with a Trust
http://www.thearc.org/faqs/futureplanning.doc

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).

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