Alzheimer's Disease and People with Mental Retardation

What is Alzheimer's disease?

Alzheimer's disease is age-associated, that is, it affects primarily older adults and its prevalence increases with advancing age. It is a slow and progressive, degenerative disorder of the brain that eventually results in diminished brain function and death. Clinically, Alzheimer's disease is expressed through dementia, or the impairment of cognitive and adaptive skills necessary for successful personal, community and occupational functioning. Dementia also involves memory loss, personality changes, and diminished self-care abilities.

Initial symptoms often appear gradually. There may be some minimum memory loss, particularly of recent events. The individual may experience difficulty in finding the right words to use during casual conversations. Work performance may begin to deteriorate, and changes in behavior may become obvious.

As the disease progresses, memory losses become even more pronounced. There may be specific problems with language abilities. Persons affected may have difficulty naming objects or with maintaining a logical conversation. They may have difficulty understanding directions or instructions and become disoriented as to time of day, where they are and with whom they are. They may also begin to experience loss of self-care skills, including eating and using the toilet. Severe changes in personality may become obvious, and social behavior may be marked by suspiciousness and delusions.

Finally, the disease will progress to the point where all abilities to function normally are lost, and affected individuals need total care. Such deterioration may occur over different time periods in different individuals, ranging from 18 months to 20 years.

How many people are affected by Alzheimer's disease?

The Alzheimer's Association notes that Alzheimer's disease accounts for more than 50 percent of the dementias seen in the general adult population (others include vascular, Pick's, Lewy-body, AIDS, etc). About five percent of people over the age of 60, and some 35 percent of people over 85, will have Alzheimer's disease. Currently some four million Americans are affected and this number will increase to 12 million over the next 30 years.

How many people with mental retardation are affected by Alzheimer's disease?

Excluding adults with Down syndrome, adults with mental retardation are at the same risk for Alzheimer's disease as are other adults in the general population. Generally, adults are at greater risk of developing the disease if they:

- Are more than 60 years old.
- Have Down syndrome.
- Have had some form of severe or multiple head injury.
- Have a history of Alzheimer's disease in their family.

Large population studies show that the rate of occurrence of Alzheimer's disease among persons with mental retardation and related developmental disabilities appears to be about the same as in the general population (or about 6% of persons age 60 and older). The rate among adults with Down syndrome is much higher - about 25% for adults age 40 and older and about 65% for adults age 60 and older. It is estimated that there are some 9,000 adults with mental retardation affected by dementia and that this number will grow threefold over the next 20 years.

How are people with Down syndrome affected differently by Alzheimer's disease?

People with Down syndrome have higher rates of Alzheimer's disease. A growing body of research suggests that people with Down syndrome also experience premature aging, perhaps as many as 20 years earlier than would be expected in normal aging. They are often in their mid to late 40s or early 50s when symptoms of Alzheimer's disease first appear, compared to the late 60s for the general population.

Although about 20 to 40 percent of adults with Down syndrome show the behavioral symptoms of dementia, upon autopsy nearly all older adults with Down syndrome show the brain changes associated with Alzheimer's disease. Men and women seem to be equally susceptible. The progression of the disease takes, on the average, about eight years – somewhat less time than among persons in the general population. The disease course generally mirrors that of other people, but is compressed due to the shorter longevity of adults with Down syndrome. A small group of adults with Down syndrome will progress more rapidly.
syndrome are dramatically affected, such that following the appearance of initial symptoms, the person experiences a precipitous decline, loss of all skills, and death within 2 to 3 years.

The symptoms of the disease may be expressed differently among adults with Down syndrome. For example, at the early stage of the disease, memory loss is not always noted, and not all symptoms ordinarily associated with Alzheimer's disease will occur. Generally, changes in activities of daily living skills are noted, and seizures may occur when there had been none in the past. Cognitive changes may also be present, but they are often not readily apparent, or they may be ignored because of limitations in the individual's general functional level.

What are some signs that an older person with mental retardation may be developing Alzheimer's disease?

Behavioral symptoms of Alzheimer's dementia may include, but are not limited to: the development of seizures in previously unaffected individuals, changes in personality, long periods of inactivity or apathy, hyperactive reflexes, loss of activity of daily living skills, visual retention deficits, loss of speech, disorientation, increase in stereotyped behavior, and abnormal neurological signs.

How is Alzheimer's disease diagnosed in people with mental retardation?

There is no single diagnostic test for Alzheimer's disease. If the presence of Alzheimer's disease is suspected, a complete physical examination and more frequent medical, neurological and psychological evaluations are strongly recommended to establish the progressive nature of the symptoms. A definitive diagnosis can only be made at the time of autopsy. The numerous test and evaluation procedures currently employed result only in a possible or probable diagnosis of Alzheimer's disease.

A probable diagnosis of Alzheimer's disease, it is necessary to observe a well-documented progression of symptoms. Complete evaluations must be performed periodically using the person’s previous performance as the comparison measure. Such evaluations or tests are necessary to rule out conditions other than Alzheimer's disease, particularly reversible forms of dementia.

The AAMR/IASSID* guidelines for the diagnosis and care management of dementias offer guidance on how screening and diagnosis can be carried out.

Where can someone go to be evaluated for possible Alzheimer's disease?

A good place to start is the person's physician. A neurologist, geriatrician or an internist can also be a valuable resource. States may have specialized centers for the evaluation and treatment of people with memory disorders, or Alzheimer's disease. These centers may provide geriatric evaluations and assessment procedures, in addition to other services. States may also have specialized services for people with mental retardation who are aging. These may include special clinics of local mental retardation, mental health or aging agencies, and university developmental disabilities programs.

What actions after diagnosis can help an individual affected by dementia?

Studies show that persons affected by dementias can continue to live in the community, if the right supports and assistance are provided. Some agencies have redesigned or developed group homes to accommodate adults with dementia. Agencies have also set up specialty teams that can provide advice and guidance to staff and families confronting care challenges. Since persons affected by dementia may not be able to continue to live on their own, “dementia capable” housing and supports need to be provided. If such services are in place, admission to nursing facilities in older age can be prevented or deferred.

Tips on care and supports are contained in the booklet, Developmental Disabilities and Alzheimer’s Disease: What You Should Know, available from The Arc.

Resources - Publications

Resources - Internet
Disability-related resources and technical information are available at the University of Illinois at Chicago’s web site at http://www.uic.edu/orgs/rrtcamr/dementia.htm

General information on Alzheimer’s disease and local resources is available at www.alz.org.

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