

Understanding Down Syndrome and Alzheimer's Disease

What is Alzheimer's disease?

Alzheimer's disease is a progressive, incurable brain disease that causes memory loss, behavioral changes and confusion. The disease is characterized by neurological changes in the brain: plaques and tangles form, which makes communication between brain cells difficult. Alzheimer's disease is not a normal part of aging. In the general population, Alzheimer's disease affects roughly 10% of people 65 and older, and nearly 50% of people 85 and older.

How does Alzheimer's disease affect persons with Down syndrome?

The tangles and plaques of Alzheimer's are present in the brains of all adults with Down syndrome by the age of 40 years, which suggests a shared genetic susceptibility to Down syndrome and Alzheimer's disease. It is well documented that the prevalence of dementia increases with age in persons with Down syndrome. Depending on the study that one reads, it is estimated that clinical and behavioral symptoms of Alzheimer's are present in approximately 50 to 70 percent of those with Down syndrome by the time they reach 60 years of age.

What will the warning signs be?

In persons without Down syndrome, one of the first signs of Alzheimer's disease is progressive short term memory loss. In a person with Down syndrome, however, memory loss may not be one of the first symptoms noticed. Instead, family, friends and caregivers may notice changes in the individual's behaviors or adaptive abilities. For instance, the individual may experience disorientation to time and place, personality or productivity changes and increased apathy or inactivity. In addition, there may be a decline in the person's ability to perform activities of daily living (e.g. dressing, bathing, eating). New seizures may develop. It is important to note, however, that these changes in abilities may be caused

by conditions other than Alzheimer's disease, some of which are reversible.

What should caregivers do?

Caregivers should monitor changes in the behaviors of persons with Down syndrome. A baseline of behaviors should be created at age 25 and reassessed annually. When a decline in abilities is noted, the person with Down syndrome should see his or her primary physician, a neurologist, or a geriatrician for an evaluation. If the diagnosis is Alzheimer's disease, caregiver expectations and philosophy of care should shift from a focus on requiring self-directions and work plan accomplishment to a focus on complimenting remaining strengths and abilities.

It is critical that all caregivers develop a care plan that is realistic and will meet the needs of both the individual, family and care providers. As in the general Alzheimer's population, this involves:

- Planning for the legal and financial future of the individual
- Preparing advance directives
- Planning for the future long-term supportive housing needs
- Learning how to continue to care for the individual throughout the course of the disease

Dementia Care Specialist Contact Information

Heart of America Chapter Dementia Care Specialists Amy Yeager and Brenda Gregg have expertise in assisting individuals with intellectual disabilities and Alzheimer's disease.

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The Heart of America Chapter provides programs and services in 66 counties in Kansas and Missouri. These programs and services are made possible thanks to generous donations from individuals, corporations, and foundations. Contributions and donations allow the Chapter to provide supportive services, including care consultations, free of charge to individuals and families.