

The Stages of Alzheimer's Disease

Watching loved ones gradually lose their ability to function will always be difficult. That's why families affected by Alzheimer's disease need information, support and assistance. The Alzheimer's Association is committed to funding research and providing assistance to families in communities across the country. Social and behavioral research is an important means to developing new programs and interventions to better assist families and caregivers in coping with the emotional, physical, and financial burdens that often accompany Alzheimer's disease.

This article focuses on research that is being done to improve the lives of individuals currently living with the disease, and to help caregivers cope with behavioral and personality changes that often result from Alzheimer's.

UNDERSTANDING THE STAGES OF ALZHEIMER'S DISEASE

Over the years, several different assessment scales have been used by physicians in an attempt to identify the stages of Alzheimer's disease more precisely. "Information about how the disease progresses help families and professionals better understand a person's care needs," says Barry Reisberg, MD, of the New York University Medical Center's Aging and Dementia Research Center. "It also helps them prepare for what's ahead."

As more is learned about the various stages of Alzheimer's disease, assessment scales — used by some professionals to track disease progression — have become more detailed. For example, *The Functional Assessment Staging (FAST)* scale, developed by Dr. Reisberg and colleagues, divides the progression of Alzheimer's disease into 16 successive functional stages and assesses the loss of functional abilities — such as dressing, toileting, eating, walking — within each stage (see Table 1).

According to Dr. Reisberg, caregivers can more easily meet the needs of their loved ones by knowing what activities they can still manage, and what activities become increasingly difficult. Structuring activities of daily living based on functional capabilities can enhance quality of life for someone with Alzheimer's, and in turn,

| FAST Stage (plus clinical diagnosis) | Characteristics |
|---|--|
| 1 (normal adult) | No decline in function |
| 2 (normal adult) | Personal awareness of functional decline |
| 3 (early AD) | Deficits noticed in demanding employment situations |
| 4 (mild AD) | Requires assistance in complicated tasks, such as handling finances, planning dinner party |
| 5 (moderate AD) | Requires assistance in choosing proper attire |
| 6 (moderately severe AD) | |
| 6a | Requires assistance dressing |
| 6b | Requires assistance bathing properly |
| 6c | Requires assistance with mechanics of toileting |
| 6d | Urinary incontinence |
| 6e | Fecal incontinence |
| 7 (severe AD) | |
| 7a | Speech ability limited to about a half-dozen intelligible words |
| 7b | Intelligible vocabulary limited to a single word |
| 7c | Ambulatory ability lost |
| 7d | Ability to sit up lost |
| 7e | Ability to smile lost |
| 7f | Ability to hold up head lost |

Table 1. The functional stages of Alzheimer's disease and their incorporation into the Functional Assessment Staging (FAST) scale. © 1984 by Barry Reisberg, MD. All rights reserved.

reduce stress associated with caregiving. Anticipating that a loved one with Alzheimer's may have difficulties with various activities — such as handling money or managing personal finances — alerts caregivers about a challenging task before the activity becomes overly frustrating to the affected individual.

While working with the FAST scale, Dr. Reisberg and colleagues also have found a correlation between functional decline in Alzheimer's disease and functional development in early childhood. This correlation suggests that Alzheimer's disease sets into motion a reversal of the abilities humans acquire during early childhood (see Table 2). "The care needs in the middle stages are often similar to those of a young child," says Dr. Reisberg. Using these findings, researchers hope to learn more about how to care for individuals with Alzheimer's disease by further investigating functional losses and studying how abilities are acquired in young children.

DESIGNING INTERVENTIONS FOR THOSE AFFECTED

As individuals suffering from Alzheimer's progress through the various stages of the disease, their needs change, as do the needs of those who provide care. To improve the quality of life for those with the disease and to help caregivers cope with the feelings that sometimes

accompany caregiving (e.g., frustration, anxiety, stress, and depression), the Alzheimer's Association has recently funded several important research projects.

Throughout the early stages of the disease, individuals diagnosed with Alzheimer's, along with their family members, may not know what to expect, understand changes that take place, or be able to provide needed support and assistance. Because many families don't know about or take advantage of available services, researchers continue to work on improving access to information and support services for families living with Alzheimer's.

Rhonda Montgomery, PhD, of the University of Kansas in Lawrence, Kansas, is conducting research that assesses the value of educating caregivers about the disease and how to access community services. Using the Individualized Family Education Intervention (IFEI) method to provide information about Alzheimer's, instructors help family members learn how to cope with changes in their loved ones, and teach them about resources and services available locally. The support and education provided is tailored to meet the specific needs of each participating family. More informed caregivers are expected to experience less anxiety and are better able to cope with stressful situations.

| Age of acquisition during development | Ability | Alzheimer's stage at which ability is lost |
|---------------------------------------|------------------------|--|
| 12+ years | Hold a job | 3 – earliest symptoms of AD |
| 8 – 12 years | Handle simple finances | 4 – mild AD |
| 5 – 7 years | Select proper clothing | 5 – moderate AD |
| 5 years | Put on clothes unaided | 6 – moderately severe AD |
| 4 years | Shower unaided | |
| 4 years | Toilet unaided | |
| 3 – 4.5 years | Control urine | |
| 2 – 3 years | Control bowels | |
| 15 months | Speak 5 –6 words | 7 – severe AD |
| 1 year | Speak 1 word | |
| 1 year | Walk | |
| 6 – 10 months | Sit up | |
| 2 – 4 months | Smile | |
| 1 – 3 months | Hold up head | |

Table 2. Relationship between Alzheimer's disease progression and child development. ©1984 by Barry Reisberg, MD. All rights reserved.

Similarly, Richard Fortinsky, PhD, of the University Hospitals of Cleveland in Cleveland, Ohio, will implement a Physician Partnership Program (PPP), to help connect individuals with Alzheimer's disease and their caregivers to their primary care physicians and local chapters of the Alzheimer's Association. This program will educate physicians about the services and programs offered by the local chapter so they can refer families for more information, resources, and ongoing support.

Because Alzheimer's affects people in different ways, finding activities and tasks suitable for individuals at all stages of the disease can be difficult. Activities that are enjoyable and relaxing for some may be frustrating, confusing, and problematic for others.

Cameron Camp, PhD, of the Menorah Park Center for the Aging in Beachwood, Ohio, is examining the use of the Montessori educational method – currently used to teach preschool children practical activities of daily living – to design more effective activities for individuals in the middle stages of Alzheimer's. This teaching method uses familiar materials taken from the everyday environment to enhance learning.

In this study, individuals with Alzheimer's disease are given an opportunity to teach children (from a local day care center) in daily lessons, such as counting and phonics, with assistance from professional instructors. Both "teachers" and students seem to benefit from this exercise. Dr. Camp has noticed increased levels of confidence in the individuals with Alzheimer's as they become more familiar with the activities they are teaching. "Participants have maintained their internal capability for improvisation and creativity," Dr. Camp reports. "Not only are the participants working on designated activities with the children, but they're also teaching with ideas of their own, some based on personal experiences."

In the future, Dr. Camp will develop activity and lesson plans for caregivers to use with persons who have Alzheimer's, aimed at increasing independence, interaction, and cognitive and functional abilities.

To help individuals with Alzheimer's who currently reside in nursing homes, Kimberly Van Haitsma, PhD, of the Polisher Research Institute in Philadelphia,

Pennsylvania, is working with nursing assistants to implement an Individual Positive Psychosocial Intervention. This intervention is designed to enhance the quality of life for nursing home residents with Alzheimer's disease through a one-on-one caregiving approach. Activities are tailored to individuals based upon past preferences and current abilities, rather than what can be done easily with a group. Objectives of the study include increasing positive emotions in persons suffering from Alzheimer's disease, while decreasing negative feelings such as isolation, agitation, and depression.

Many researchers are also investigating the use of current services and social support in various caregiving populations. Two studies recently funded by the Alzheimer's Association focus on caregiver access to local programs and services.

Ronald Toseland, PhD, of the State University of New York at Albany, is analyzing what types of services are most used by caregivers and who those caregivers are. This information will then be used to create a service model that will enable caregivers to receive support in the most appropriate ways, and encourage them to turn to their local chapter of the Alzheimer's Association for information and referral services within their communities.

Brian Lakey, PhD, of Wayne State University, and colleagues will focus on the use of social support provided through support groups, therapy, and other means, as a way to decrease caregiver stress. Dr. Lakey's team is specifically looking at the difference between caring for individuals with Alzheimer's disease and caring for older adults without memory impairments. Because not all caregivers seek social support and may not be aware of the help that is available to them, this study also examines the role ethnic and educational backgrounds play in requests for assistance.

"Care, as much as cure, must be an urgent priority for the future," says Dr. Reisberg. The Alzheimer's Association continues its commitment to support research and provide assistance to those with Alzheimer's, their families, and their caregivers.

This is an edited version of the article "Research Seeks to Improve Quality of Life" that first appeared in the Alzheimer's Association newsletter, *Advances in Alzheimer Research* (Winter 1996) Vol. 6, #4. The information contained in this article was current at the time of its initial publication.