

The Impact of Alzheimer's Disease on the Capacity to Work

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**Compassionate Allowance Hearing on Early Onset
Alzheimer's Disease and Related Dementias**

Social Security Administration July 29, 2009

Disclosures

- Medivation, Inc. Alzheimer's Disease Advisory Board

Background

- Neuropsychologist
- Alzheimer's disease researcher
- Focus area: loss in AD of medical-legal capacities such as medical decision-making, financial capacity, capacity to make a will

- Attorney
- Corporate law and litigation
- 1987-1989 Assistant Regional Attorney (part time)
Office of the General Counsel/Region V-- Chicago, Illinois
Briefing SSA disability appeals in federal district court

Outline

- Dementia
- Alzheimer's disease (AD)
- Early onset AD
- **Impact of AD on capacity to work**
- Questions

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Dementia

“a condition of deteriorated mentality”

Webster's New Collegiate Dictionary (1981)

Dementia

“a usually progressive condition (as Alzheimer's disease) marked by development of multiple cognitive deficits (as memory impairment, aphasia, and inability to plan and initiate complex behavior)”

Webster's On-Line Medical Dictionary (2009)

DSM-IV-TR (2000): Diagnostic Criteria for Dementia of the AD Type

- A. Development of multiple **cognitive** deficits manifested by both
- (1) **memory** impairment (impaired ability to learn new information or to recall previously learned information), and
 - (2) one (or more) of the following cognitive disturbances:
 - (a) **aphasia** (language disturbance)
 - (b) **apraxia** (impaired ability to carry out motor activities despite intact motor function)
 - (c) **agnosia** (failure to recognize or identify objects despite intact sensory function)
 - (d) disturbance in **executive functioning** (i.e., planning, organizing, sequencing, abstracting)

Dementia and Functional Change

B. The cognitive deficits in Criteria A1 and A2 each:

- ◆ Cause **significant impairment in social or occupational functioning**

“going to school, shopping, dressing, bathing, handling finances, ...”

- ◆ and represent a **significant decline** from a **previous level of functioning**.

Like cognitive change, change in everyday functional abilities is a critical aspect of dementia

Dementia and Disability

Progressive dementias like Alzheimer's disease involve both cognitive and functional decline, and early on cause substantial disability

Alzheimer's Disease

- Disease causing degeneration of brain cells (neurons)
- Chronic and progressive (~8 years from diagnosis to death)
- Causes dementia
- AD is the leading cause of dementia (60-70% of dementia cases)

Alzheimer's Disease

- Early stage symptoms of AD:
 - ◆ Short term memory loss (verbal and visual)
 - ◆ Language problems and loss of knowledge
 - ◆ Executive dysfunction (impairments in planning, organization, self-monitoring)
 - ◆ Decision making impairment
 - ◆ Anxiety and depression

- AD is already vocationally disabling at time of diagnosis

Early Onset Alzheimer's Disease

- Defined as AD occurring before the age of 65 (@ age 35 to 64)
- < 10% of cases of AD
- Half of early cases directly genetic in origin- “familial AD” (chr. 1, 14, 21)
- Other early cases do not have clear origin- “sporadic AD”

- **Aggressive**—may have more rapid progression than later onset AD
- **Global**—early on affects more cognitive areas than later onset AD
- **Misdiagnosed**—because person is so young, clinicians often do not consider AD as possible diagnosis (eg., “conversion disorder”)

Early Onset Alzheimer's Disease

- Devastating event--dementia in the prime of life
- Destroys a person's work life and family life:
 - ◆ Cannot work
 - ◆ Loss of career
 - ◆ Premature retirement--loss of full retirement benefits
 - ◆ Can no longer parent their children
 - ◆ Loss of other family leadership responsibilities
 - ◆ Marriage dramatically altered--spouse now a caregiver in mid-life

Impact of AD on Capacity to Work

- How do cognitive and personality changes in mild AD impact capacity to work?
- Key areas affected in mild AD:
 1. Short term verbal and visual memory
 2. Knowledge of words and concepts
 3. Executive function and organization
 4. Mood, personality, and motivation
 5. Judgment and decision-making

Impairment of Short Term Memory (STM)

- STM--vitally important cognitive function for vocational capacity
- Severe STM loss (amnesia)—hallmark sign of mild AD
- “rapid forgetting” of new information (not historical knowledge/information)
- Example of story recall:
 - ◆ Immediately after listening to two new stories, mild AD patients recalled only **32%** of the story details normal older adults recalled
 - ◆ 30 minutes later, mild AD patients recalled only **10%** of what the normal adult group recalled 30 minutes later
 - ◆ After 30 minutes, mild AD patients retained only **20%** of details they originally recalled...in contrast, the normal older adult group retained **86%**

Impairment of Short Term Verbal Memory

■ Vocational implications:

Cannot not recall new verbal information in work setting

- ◆ Cannot not recall daily instructions—forget to do work tasks
- ◆ Cannot learn new work protocols, procedures, routines
- ◆ Lose train of thought—“go blank” frequently
- ◆ Miss appointments—STM loss + disorientation to time
- ◆ Make errors by recalling work information incorrectly:
 - ☞ *confuse* different sources of information—source memory problems
 - ☞ *confabulate* information—“recall” false memories

Impairment of Short Term Visual Memory

■ Vocational implications:

Cannot not recall new visual info and events in work setting

- ◆ *Office*: constantly losing keys, papers, get lost in new settings
- ◆ *Sales*: forget the customer route, where car is parked
- ◆ *Design*: blueprints/designs remain “new”, have to be reviewed again and again
- ◆ *Assembly line*: cannot recall new warning sign
- ◆ *Computers*: forget location of computer files
- ◆ **Additional supervision, oversight, reminding will not help**

Impairment of Word and Concept Knowledge

- Loss of semantic knowledge: meaning of words and concepts
- Word finding problems
- Word substitution errors: “accordion” said instead of ‘harmonica’
- Increasing confusion about meaning of previously familiar words and concepts: eg., mortgage, loan, work terms/acronyms

Impairment of Word and Concept Knowledge

■ Vocational implications:

Difficulty with communication and comprehension in the workplace

- ◆ Word finding problems--more difficulty expressing thoughts, particularly complex ideas
- ◆ More difficulty understanding complex material—new and old
- ◆ Harder to follow workplace conversations (STM issue also)

Executive Dysfunction and Disorganization

- Executive dysfunction/disorganization—second hallmark of mild AD
- New impairments in carrying out goal oriented activities:
 - ◆ Planning, sequencing, monitoring, revising/modifying plans, mental flexibility
 - ◆ Cannot multi-task anymore
 - ◆ Difficulties working with numbers or solving problems
- New impairments in organizational abilities:
 - ◆ Documents missing, in disarray, misfiled
 - ◆ Can no longer adequately pack suitcase for trip, or pull off large family dinner

Executive Dysfunction and Disorganization

■ Vocational implications:

Cannot successfully complete new or familiar work tasks

- ◆ *Office:* cannot fully understand and implement new procedures
- ◆ *Assembly line:* confusion about new routines, how to proceed
- ◆ *Sales:* cannot manage client information, details, appointments
- ◆ *Design:* spatial relationships confusing, cannot solve problems
- ◆ *Computer:* can no longer write program code--too complex
- ◆ *Law:* cannot integrate case facts, miss key legal arguments, miss filing deadlines due to disorganization

Changes in Mood, Personality, Motivation

- Anxiety and depression common psychiatric symptoms in mild AD
- Personality changes include social withdrawal
- Symptoms linked to AD as a brain disease
- Symptoms also reactive to challenges to sense of self, self-esteem
- Patient with AD has marked existential anxiety--caused by a mental world that is increasingly uncertain, unpredictable, incoherent
- Loss of confidence and independence; dependency on others

Changes in Mood, Personality, Motivation

■ Vocational implications:

Loss of confidence and independence in work setting

- ◆ Anxiety/depression causes withdrawal from public presentations
- ◆ No longer able emotionally to sustain leadership roles
- ◆ Less effective interpersonal interactions in work setting
- ◆ Decline in motivation
- ◆ Dependence on co-workers to help carry out work duties

Impaired Judgment and Decision-Making

- Combination of cognitive and psychiatric changes in mild AD significantly impair judgment and decision-making
- Decisions founded on limited information due to STM deficits
- Declining comprehension of complex concepts
- Difficult to organize information effectively to identify key issues
- Judgment and discrimination/flexibility re alternatives impaired
- Lack of confidence and deferral of decision-making to others

Impaired Judgment and Decision-Making

■ Vocational implications:

Impaired business and other decisions in work setting

- ◆ Impulsive decisions not based on all the facts
- ◆ Cannot recall facts needed to make a decision
- ◆ Inability to reason through alternatives, come to closure, and make a decision
- ◆ Deferral of decisions, procrastination
- ◆ Inappropriate delegation of decision-making

Summary

- Dementia involves cognitive + functional change, causes disability
- **AD causes a dementia which is disabling by the time of diagnosis**
- Cognitive changes in mild AD affecting vocational capacity include impairments in STM, semantic knowledge, executive function, and decisional capacity.
- Mood/personality changes in mild AD affecting vocational capacity include anxiety, depression, loss of independence and motivation.
- Early onset AD is devastating for patients and their families

Support

NIA P50 AG16582 Alzheimer's Disease Research Center

NIMH R01 MH55247 Studies of Financial Capacity in AD

NIA R01 AG021927 Functional Change in MCI