



When the Diagnosis Is Dementia- What You Can Do?

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Visibility of Disease

- **Only 19 percent of people with Alzheimer's and other dementias actually have the diagnosis recorded in their medical records**
- **Seventy (70) percent of people with Alzheimer's and other dementias live at home- cared for by family and friends**

Alzheimer's In Facility Care

- **Seventy (70) percent of nursing home residents have some degree of cognitive impairment; 47 percent of all nursing home residents have a diagnosis of Alzheimer's or another form of dementia in their medical records- more cases are likely not documented**

Mortality

- **Alzheimer's disease is the sixth leading cause of death for people in the United States; and the fifth leading cause of death for those over the age of 65**

Mortality

- **From 2000 to 2004:**
 - **Deaths from Alzheimer's disease increased by 32.8 percent**
 - **breast cancer deaths decreased by 2.6 percent,**
 - **Deaths from heart disease decreased by 8 percent**
 - **prostate cancer deaths decreased by 6.3 percent, and**
 - **stroke deaths decreased by 10.4 percent**

Risk Factors

- **Age is the greatest risk factor for Alzheimer's. A small percentage of Alzheimer cases is caused by rare, genetic variations found in a few hundred families worldwide**
- **One out of eight people age 65 and older has Alzheimer's and nearly one out of two over age 85 has it**

Causes/Risks of Alzheimer's

- **Inflammation**
- **Head Injury**
- **Heart disease**
- **Diabetes (Type II)**
- **Hypertension**

Causes/Risks of Alzheimer's

- **Hispanic/ African American greater risk than anglo**
- **High Fat Diets, Obesity**
- **High Cholesterol**
- **Lifestyle- less physically and mentally active**

Prevalence As of 2009

- **More than 5.3 million people living with Alzheimer's disease in the United States**
- **Most persons over the age of 65**
- **200,000 and 500,000 people under age 65 with early onset Alzheimer's disease and other dementias**

What Is Dementia?

A Syndrome characterized by the following symptoms:

- **Memory Loss**
- **Loss of Ability to Think & Reason**
- **Loss of Ability to Make Judgments**
- **Loss of Ability to Solve Problems**
- **Agnosia, Apraxia, Aphasia**

Is It Alzheimer's or Dementia?

- **Hearing Someone Has Dementia Probably Means the Diagnosis Is Alzheimer's**
- **You can have dementia without it being caused by Alzheimer's Disease but not have Alzheimer's without it being a dementia**
- **Alzheimer's Disease Is the Most Common Dementia**

ADVANTAGES OF SCREENING & EARLY DIAGNOSIS

- **Avoiding the crisis.**
- **Financial savings.**
- **Participating in care planning.**
- **Continuing to work longer.**
- **Managing resources for future for PWD and family.**
- **Implementing treatment strategies.**
- **Resolving uncertainty (Peace of mind).**

Causes of Dementia

- **Alzheimer's- >60%**
- **Vascular Dementia- 10-20%**
- **Dementia with Lewy Bodies- 10-20%**
- **Frontotemporal Dementia- 5-10%**

Types of Alzheimer's

- **Genetic and Familial- Early Onset (before age 65)**
 - **Autosomal Dominant Form of Transmission**
 - **5-10%**
- **Sporadic and Late onset (after age 65)**
 - **90-95%**

What Is Disease and What Is Person?

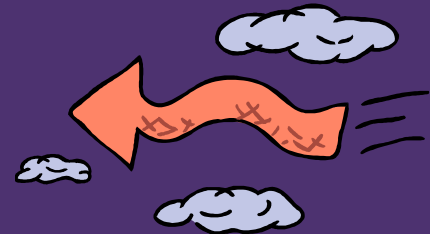
- **Distinction can be helpful in understanding problems and responding to needs of the person**
- **Persons with the symptoms are usually aware of changes for a time**
- **Families may initially attribute changes to person rather than disease**
- **Attributing symptoms of dementia to something else can continue for a long time.**

What Is Disease and What Is Person?

- To care for PWD in family setting changing basis for understanding behavior means changing perspective of person
- Having a frame of reference suggested by diagnosis is very helpful since it leads to learning about what to do to help and how- the disease model

What Is Disease and What Is Person?

- **Diagnosis gives direction to planning and addressing present and future needs of person with disease and family caregiver**



Changes in Executive Functions

- Organizing
- Planning
- Abstracting
- Sequencing
- Reasoning

**Behavioral and Psychological
Symptoms of Dementia (BPSD)
Are Very
Common and Are Significant
Symptoms that accompany AD**

Among the Most Intrusive and Difficult BPSD to Cope With Are:

**Psychological Symptoms of Delusions,
Hallucinations, Depression,
Sleeplessness and Anxiety**

Common Delusions

- 1. People are stealing things**
- 2. House is not one's home – may also be classified as misidentification**

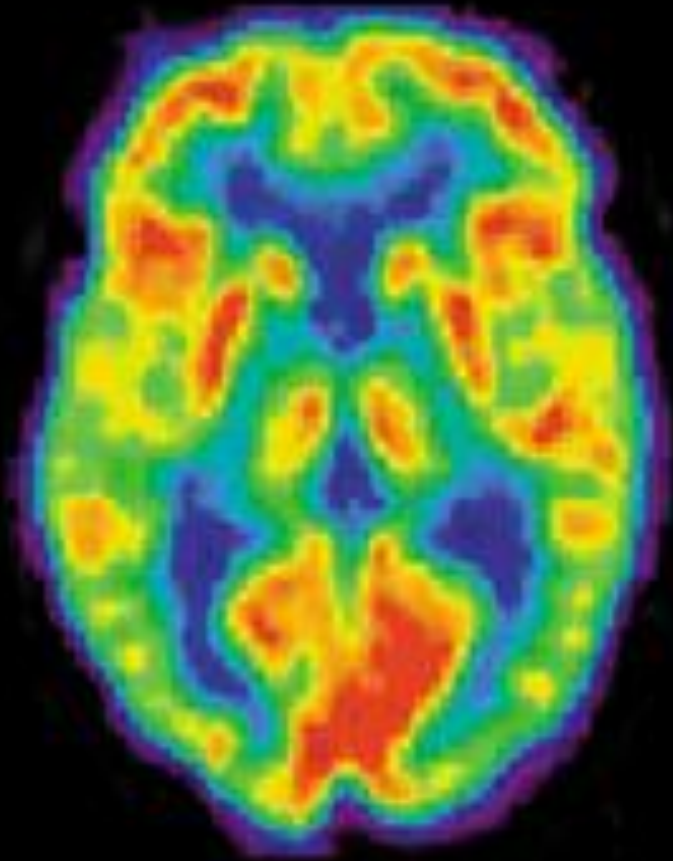
Common Delusions

3. Spouse (or other caregiver) is an impostor – may also be classified as misidentification
4. Abandonment
5. Infidelity

Depression and PWD

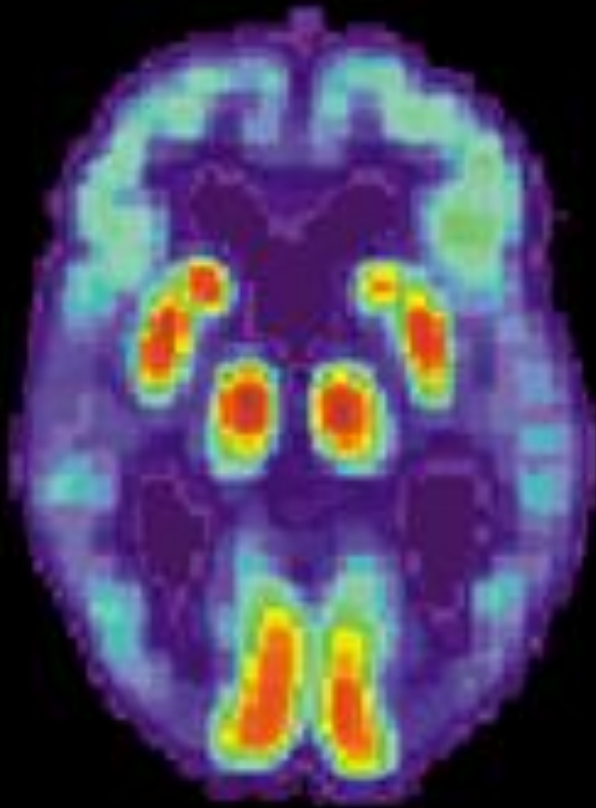
- ❑ Estimates of the prevalence of depression among patients with Alzheimer's disease have ranged from 0% to 86%, with most values clustering in the range of 30% to 50%
- ❑ Between 40% and 50% of persons with Alzheimer's have depressive symptoms

Normal PET/Glucose Utilization



**More colors
indicate more
brain activity**

Alzheimer's Brain



**Note the
decreased brain
activity in most
areas**



Beta Amyloid Plaques

A light micrograph of a brain section stained for tau protein. The image shows several dark, irregularly shaped neurofibrillary tangles (NFTs) of varying sizes. The background is a lighter, yellowish-tan color, representing the surrounding brain tissue. The tangles are most prominent in the center and lower right. The text "Neurofibrillary Tangles" is overlaid in the upper middle, and "Tau Protein" is overlaid in the lower right.

Neurofibrillary Tangles

Tau Protein

**It's Important to Know What
Disease a Person Has, But It's
More Important to Know What
Person the Disease Has.**

---- Dr William Osler

Personhood Defined

The parts of self that extend beyond memory have been called “personhood,” and include feelings, emotions, and reactions of the persons with dementia (Kitwood 1993).

Personhood Concerns of People with Dementia

- ❑ **Fear of being out of control**
- ❑ **Fear of being seen by others as out of control**
- ❑ **Feelings of being lost**
- ❑ **Feeling the meaning of things slipping away**

Personhood Concerns of People with Dementia

- ❑ **Concerned about being a burden**
- ❑ **Desire to be useful**
- ❑ **Anger with dementia itself**
- ❑ **Resentment that life has been marred by dementia's presence**
- ❑ **Feeling rejected and left out**

Caregiving Dilemma

ALL THINGS MAY BE ENDURABLE IF THE DEMANDS ARE FINITE IN DEPTH AND TIME. BUT A FUTURE THAT OFFERS NO EXIT AT ALL, EVEN IF THE BURDEN ON A DAILY BASIS IS NOT UTTERLY OVERWHELMING, CAN BE AN OBVIOUS SOURCE OF SADNESS AND DEPRESSION...

NO BURDEN CAN BE GREATER THAN TRYING TO IMAGINE HOW ONE CAN COPE WITH A FUTURE THAT PROMISES NO RELIEF.

----- CALLAHAN, 1988

Caregiver Risks

- ❑ **50% suffer clinical depression**
- ❑ **Risk for depression greatest for spousal caregivers**
- ❑ **Immune system breakdown due to chronic stress**

Caregiver Risks

- ❑ Risk type II diabetes, hypertension and heart conditions greater
- ❑ High probability of social isolation
- ❑ Risk for depression greatest for spousal caregivers
- ❑ Depression and health problems of caregivers put aside by caregivers

Caregiver Services

- Counseling**
- Coping skills**
- Support groups**
- Education about AD**
- Health monitoring and medical care- caregiver's plan of care for self**
- Maintain community connections**

Caregiver Services

- ❑ **Treatment depression**
- ❑ **Respite services**
- ❑ **Adult Day Care**
- ❑ **Grief support**
- ❑ **Time to oneself/Privacy**
- ❑ **ALZHEIMER'S ASSOCIATION**



Reality: Disease & Person

There Is a Need for Us to Hold Together in a Kind of Creative Tension the Reality of the Illness, As It Inexorably Progresses, With the Reality of the Person Whom We Know and Love.

--- Malcolm Goldsmith

Hearing the Voice of People With Dementia