Caring for a Family Member with Alzheimer’s Disease

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September 3, 2015

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“As a parent begins the slow descent into illness and incapacity, the adult child begins the process of mourning. You mourn mommy, mom, mother, the good and the bad, what you had from your parents and what you didn’t have. You mourn the loss of a vital, able grandparent for your children”

*Caring for Yourself While Caring for Your Aging Parents*
*Claire Berman*
Dementia

The loss of intellectual functions (such as thinking, remembering and reasoning.)

It is NOT a disease in itself, but rather a group of symptoms which may accompany certain diseases or physical conditions.
Alzheimer’s is the most common form of dementia, a general term for memory loss and other intellectual abilities serious enough to interfere with daily life. Alzheimer’s disease accounts for 50-80% of dementia cases.
Other Types of Dementia

- Vascular Dementia
- Mixed Dementia
- Dementia with Lewy Bodies
- Parkinson’s Dementia
- Frontotemporal Dementia
- Creutzfeldt-Jacob Disease
- Normal Pressure Hydrocephalus (NPH)
- Huntington’s Disease
- Wernicke-Korsakoff Syndrome
- Mild Cognitive Impairment (MCI)
10 Warning Signs of Alzheimer’s
Alzheimer’s Association

- Memory loss that disrupts daily life
- Challenges in planning or solving problems
- Difficulty completing familiar tasks at home, at work or at leisure
- Confusion with time or place
- Trouble understanding visual images and spatial relationships
- New problems with words in speaking or writing
- Misplacing things and losing the ability to retrace steps
- Decreased or poor judgment
- Withdrawal from work or social activities
- Changes in mood and personality

Source: Alzheimer’s Association
What’s the Difference Between **Typical** Age-Related Changes and Signs of **Alzheimer’s**/Dementia

**A:** Poor judgment and decision making  
**T:** Making a bad decision once in awhile

**A:** Inability to manage a budget  
**T:** Missing a monthly payment

**A:** Losing track of the date or the season  
**T:** Forgetting which day it is and remembering later
A: Difficulty having a conversation
T: Sometimes forgetting which word to use

A: Misplacing things and being unable to retrace steps to find them. Thinking things have been stolen.
T: Losing things from time to time

Alzheimer’s Association
Other Causes of Alzheimer-like Signs

- Depression
- Reaction to medications: polypharmacy
- Poor Nutrition
- Vitamin/mineral disorder: Too little/too much
- Brain tumor
- Blood vessel Disease
- Thyroid Problems
- Infection
- NPH: Normal Pressure Hydrocephalus
- DELIRIUM
In early and middle stages of dementia
Individual looks the same...

*But is disappearing*
Understanding/Misunderstanding Behaviors

- Pt deliberately trying to provoke
- Pt manipulating caregiver
- Pt not trying hard enough
- Pt not listening
- Pt not concentrating

- Pt is selfish; not appreciating my sacrifices

- Pt accusatory, paranoid. Accusing family of stealing and conspiring to control life
“Many’s the time I find myself instinctively reaching for the phone, wanting to talk to my mother about a concern, but then I stop myself because I realize that mother’s no longer able to support me in this way. I have found myself of late feeling a mixture of love and irritation towards my mother. She’s eighty-four now, losing her grip on reality, and I have to be there for her instead of the other way around.......... 

The fact is I want the mother I always had.”

-Claire Berman
“The only thing worse than having aging parents is not having aging parents. The old-old die by inches. At first, father can no longer jog, then he can no longer take walks or do heavy lifting. Later, he gives up foreign travel and flying, with all its stresses. Finally he can’t drive the car. At first, mother is no longer the best cook in the country, then the children worry she will poison herself with spoiled food or burn down the house. *Families must adjust to each new lost inch.*”

-Mary Pipher
Caregiving
Spouses and Adult Children

- Renegotiation of roles in couple
- Caregiver may be frail/ill
- Complex marital history; possible domestic violence
- Children lose real or idealized parents, or ones never had...and never will have
- Sandwich Generation: Stressors of marriage, parenting, professional life, caregiving
- Unresolved issues between siblings emerge at time of parent need
Stages of Alzheimer’s Disease

**Mild**

- Problems coming up with the right word or name
- Trouble remembering names when introduced to new people
- Having greater difficulty performing tasks in social or work settings
- Forgetting material that one has just read
- Losing or misplacing a valuable object
- Increasing trouble with planning or organizing
Moderate

- Forgetfulness of events or about one’s own personal history
- Feeling moody or withdrawn, especially in socially or mentally challenging situations
- Being unable to recall their own address or telephone number or the high school or college from which they graduated
- Confusion about where they are or what day it is
- The need for help choosing proper clothing for the season or the occasion
- Trouble controlling bladder and bowels in some individuals (UTI)
- Changes in sleep patterns, such as sleeping during the day and becoming restless at night
- Increased risk of wandering and becoming lost
- Personality and behavior changes, including suspiciousness and delusions or compulsive, repetitive behavior like hand-wringing
Late Stage

- Individuals may require full-time care with daily needs
- May lose awareness of recent experiences as well as of their surroundings
- Require high levels of assistance with daily activities and personal care
- Experience changes in physical abilities, including the ability to walk, sit and, eventually, swallow
- Have increasing difficulty communicating (may not be able to communicate pain; may see increased agitation as expression of pain)
- Become vulnerable to infections, especially pneumonia
“Alzheimer’s family care is intense, personal, and unrelenting. It has been compared to running a marathon without ever seeing the finish line.”

“......the wear and tear and prolonged strain of constant supervision have been shown to have negative consequences on health, family relationships, and future financial security of surviving family members”

Lisa Gwyther, MSW, LCSW
Duke Aging Center’s Family Support Program.
“Family Care and Alzheimer’s Disease What Do we Know? What Can We Do?”
MC Med J Jan/Feb 2005, Volume 66, Number 1
Immediate Needs of Patient and Family

**Ongoing**

- Accurate diagnosis: never assume
- Patient and family meeting with healthcare provider
- Communication with all family members
- Education regarding disease: stages, functional capacity and incapacity: Challenges over time for all.
- Discussion of legal, financial and insurance issues
- Recommendation of Elder Law Attorney as specialist
- Advance Directive: Having the Conversation
  [http://theconversationproject.org/](http://theconversationproject.org/)
- Support groups for patient and family
- Community resources
Key Decision Points: Transitions

- Diagnosis (reluctance to seek or accept early diagnosis by the person with dementia or family).

- Changes in driving (getting lost), handling money, taking medications, alcohol use

- Decisions about the safety of living alone (fraud, neglect, exploitation)

- Decisions about hospitalization, surgery, diagnosis, and treatment of co-morbid conditions
- Decisions about the use of antipsychotics, antidepressants, sedative hypnotics and other psychiatric meds
- Changes in primary caregiver
- Need for constant supervision (respite options, in-home help, or day services)
- Residential/assisted living care
- Skilled nursing facility care
- Palliative care and/or hospice care options
Nine Strategies for Alzheimer’s Families- Mid-late stage

- Being reasonable, rational, and logical will just get you into trouble
- People with dementia do not need to be grounded in reality
- You cannot be a perfect caregiver
- Making agreements with the person with dementia doesn’t work
- Doctors need your input on what’s really going on and what works
You can’t do it all. It’s okay to get help before you are desperate

It is easy to both overestimate and underestimate what your relative can do

Tell, don’t ask

It is perfectly normal to wonder about the diagnosis when the person has moments of lucidity, insight and good judgment.

Adapted from Family Caregiver Alliance Update 2004 Gwyther Article
10 Ways to be a Healthier Caregiver: Alzheimer’s Association

1. Understand what’s going on as early as possible
2. Know what community resources are available
3. Become an educated caregiver
4. Get help
5. Take care of yourself ???!!!???
6. Manage your level of stress
7. Accept changes as they occur
8. Make legal and financial plans
9. Give yourself credit, not guilt!
10. Visit your doctor regularly
10 Symptoms of Caregiver Stress
Alzheimer’s Association

1. Denial about the disease and it’s effect on the person diagnosed
2. Anger at the person with Alzheimer’s or others
3. Social withdrawal
4. Anxiety about facing another day and what the future holds
5. Depression that begins to break your spirit and affects your ability to cope
6. Exaustion that makes it nearly impossible to complete necessary daily tasks
7. Sleeplessness caused by a never-ending list of concerns
8. Irritability that leads to moodiness and triggers negative responses
9. Lack of concentration
10. Health Problems that begin to take their toll, both mentally and physically
“There are only four kinds of people in this world—those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who need caregivers.”

-Former First Lady Rosalynn Carter
Alzheimer’s Association
www.Alz.org/MANH
800-272-3900

Massachusetts Resources
http://www.elderinfo.org/
617-292-6211

Elder Locator (national resources)
www.eldercare.gov/