Town Hall Forum

Making a Plan: The Smart Approach to Alzheimer's Care Needs

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Understanding the Progression of Alzheimer's and Related Dementias

And Planning for Future Changes

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Talk Outline

- Introduction including key points
- Defining dementia and Alzheimer's disease in various ways
- Preparing for progression: depression, sleep disturbance, wandering
- Obtaining appropriate treatment based on stage of illness
- Summary

Key Points

- Dementia is a general term for a deterioration of previously acquired intellectual abilities significant enough to impair function
- Alzheimer's disease is the most common cause of dementia
- Most dementias are progressive and problem behaviors tend to be stage specific
- Learning and preparing will help make the Alzheimer's journey as safe and as comfortable as possible
- Early recognition of critical changes in the disease progression is important and facilitates optimal intervention and adaptation.
- New or suddenly worsened problem behaviors require careful assessment
- Being aware of possible problematic family dynamics is a good idea

Defining Dementia

- **Dementia**: brain injury or malfunction from any of a large number of diseases that causes a deterioration of previously acquired intellectual abilities of sufficient severity to interfere with social or occupational functioning. Memory disturbance is often, but not necessarily, the most prominent symptom. In addition, there may be impairment of abstract thinking, judgment, impulse control, and/or personality change. Dementia may be progressive, static, or reversible, depending on the underlying cause and the availability of effective treatment.

Adapted from *A Psychiatric Glossary, Fifth Edition*,

American Psychiatric Association

Dementia: Epidemiology

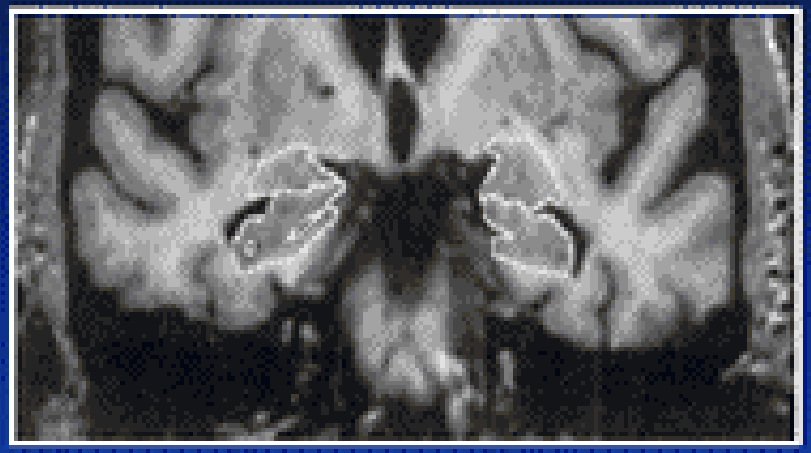
- Dementia of the Alzheimer's type (AD) is the most common form of dementia and accounts for approximately 55% of all cases.
- In 2017, approx. 5.5 million individuals in the U.S. are living with AD 5.3 million are 65 years-old or older
- The frequency of the next 4 most common dementias are listed below and coupled with Alzheimer's disease account for approximately 95% of all dementias:
  - Mixed (Alzheimer's and Vascular) 15%
  - Lewy Body Dementia 12 %
  - Frontotemporal Dementia 8%
  - Vascular Dementia 5%
- Other dementias which are relatively uncommon include: Parkinson's disease with dementia, Huntington's disease, corticobasilar degeneration, HIV-associated dementia, multiple sclerosis, chronic traumatic encephalopathy, other

Methods of Staging Alzheimer's Disease

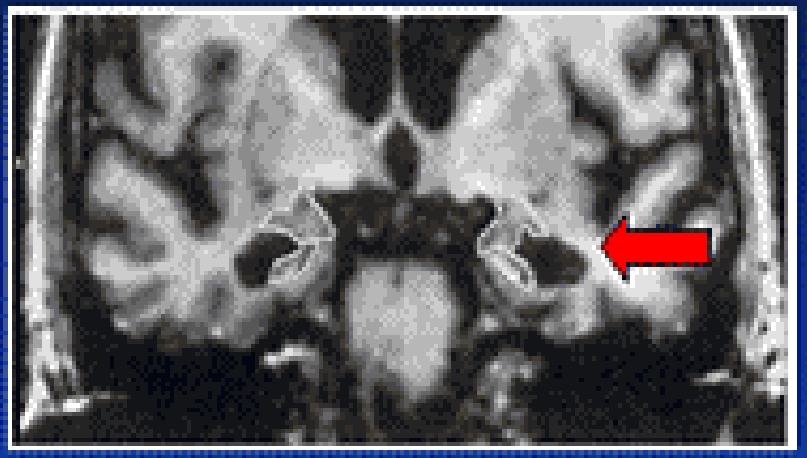
- There are a variety of approaches to staging Alzheimer's disease:
  - Assessments of brain anatomy or physiology
  - Clinical characteristics and functional losses
  - Care needs
  - Performance on cognitive tests
  - Behavioral issues

Coronal MRI: Hippocampal Atrophy in AD

Control

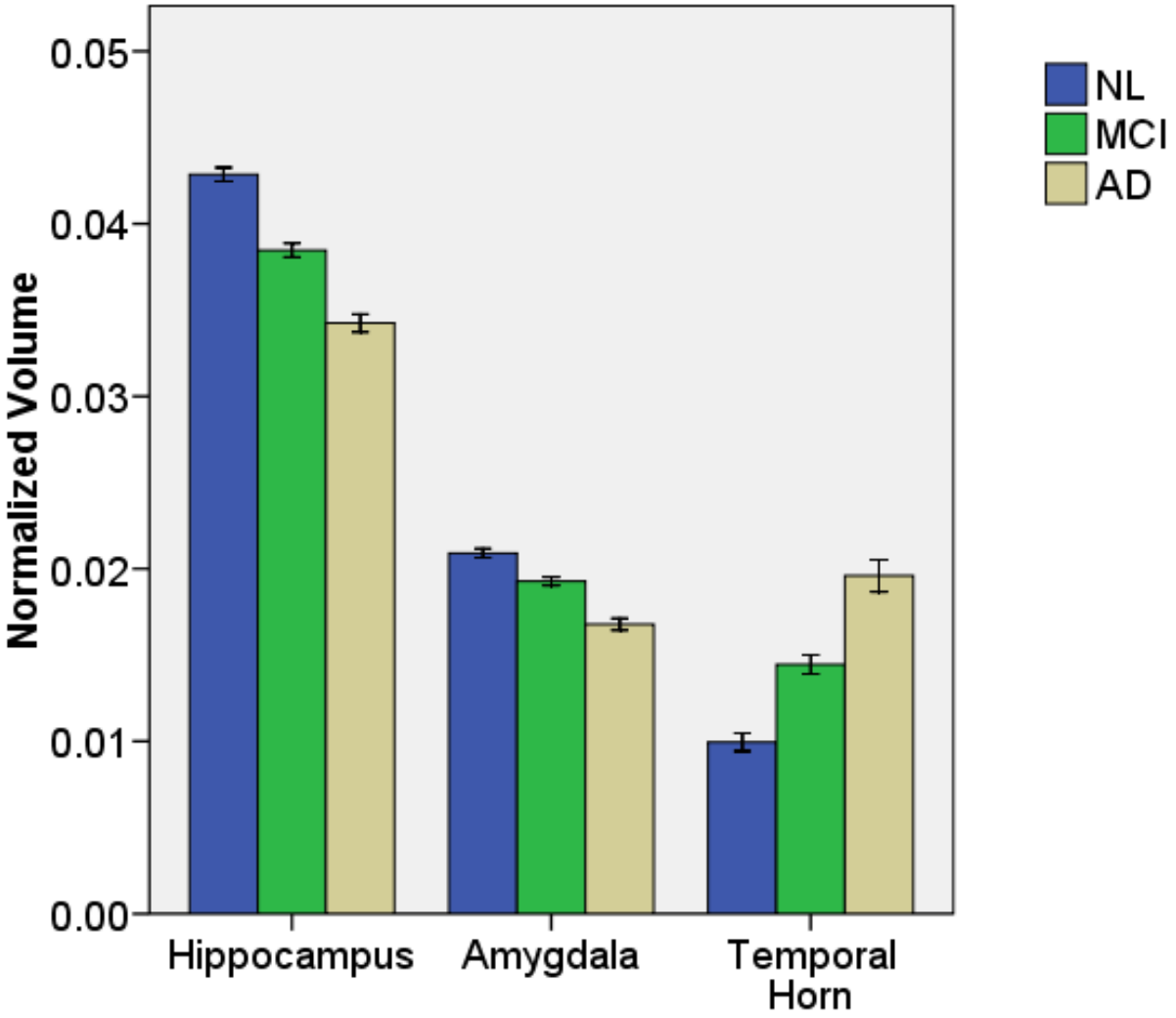


AD



Jack et al. *Neurology*, 1997.

ADNI Preliminary Analysis



Methods of Staging Alzheimer's Disease Based on Function

- Rating systems sometimes used by clinicians and researches include:
  - Clinical Dementia Rating (CDR)
    - Consists of 7 stages
  - The Global Deterioration Scale (GDS)
    - Consists of 5 Stages
  - Functional Assessment Staging (FAST)
    - Consists of 7 stages

Functional Assessment Staging (FAST)

Functional (Fast) Stage	Clinical Characteristics	Level of Functional Incapacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
1	No difficulty either subjectively or objectively	No deficit	Normal adult	50 years

Functional Assessment Staging (FAST)

Functional (Fast) Stage	Clinical Characteristics	Level of Functional Incapacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
2	Complains of forgetting location of objects. Subjective work difficulties.	Subjective forgetting	Age-associated memory impairment	15 years

Functional Assessment Staging (FAST)

Functional (Fast) Stage	Clinical Characteristics	Level of Functional Incapacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
3	Decreased job functioning evident to coworkers. Difficulty traveling to new locations. Decreased organizational capacity.	Complex occupational performance	Mild cognitive impairment	7 years

Functional Assessment Staging (FAST)

Functional (Fast) Stage	Clinical Characteristics	Level of Functional Capacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
4	Decreased ability to perform complex tasks (e.g. planning dinner for guests), handling personal finances (e.g. forgetting to pay bills), difficulty marketing	Instrumental activities of daily life (IADLs)	Mild AD	2 years

Functional Assessment Staging (FAST)

Functional (Fast) Stage	Clinical Characteristics	Level of Functional Capacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
5	Requires assistance in choosing proper clothing to wear for the day, season, or occasion (e.g. wears the same clothing repeatedly, unless assisted)	Activities of daily living (ADLs)	Moderate AD	18 months

Functional Assessment Staging (FAST)

Functional (Fast) Stage	Clinical Characteristics	Level of Functional Capacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
6	a) Improperly puts on clothes (e.g. may put on street clothes at bedtime or put shoes on wrong feet or difficulty with buttons) b) Unable to bathe properly	Deficient ADLs Deficient ADLs	Moderately severe AD Moderately severe AD	5 months 5 months

Functional Assessment Staging (FAST)

Functional (Fast) Stage	Clinical Characteristics	Level of Functional Capacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
6	c) Inability to handle the mechanics of toileting (e.g. forgets to flush, does not wipe properly or properly dispose of toilet tissue)	Deficient ADLs	Moderately severe AD	5 months

Functional Assessment Staging (FAST)

Functional (Fast) Stage	Clinical Characteristics	Level of Functional Capacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
6	d) Urinary incontinence e) Fecal incontinence	Incipient incontinence Incipient incontinence	Moderately severe AD	4 months 10 months

Functional Assessment Staging (FAST)

Functional (Fast) Stage	Clinical Characteristics	Level of Functional Capacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
7	Over an average day:			
	a) Speech limited to approx. 6 intelligible words or fewer	Semi-verbal	Severe AD	12 months
	b) Speech limited to a single intelligible word	Semi-verbal	Severe AD	18 months

Functional Assessment Staging (FAST)

Functional (Fast) Stage	Clinical Characteristics	Level of Functional Capacity	Clinical Diagnosis	Estimated Duration of FAST Stage or Substage in Alzheimer's dementia
7	c) Cannot walk without help	Nonambulatory	Severe AD	12 months
	d) Cannot sit up without help	Immobile	Severe AD	12 months
	e) Loss of ability to smile	Immobile	Severe AD	18 months
	f) Loss of ability to hold up head	Immobile	Severe AD	12 months

Methods of Staging Alzheimer's Disease: Performance on Cognitive Tests

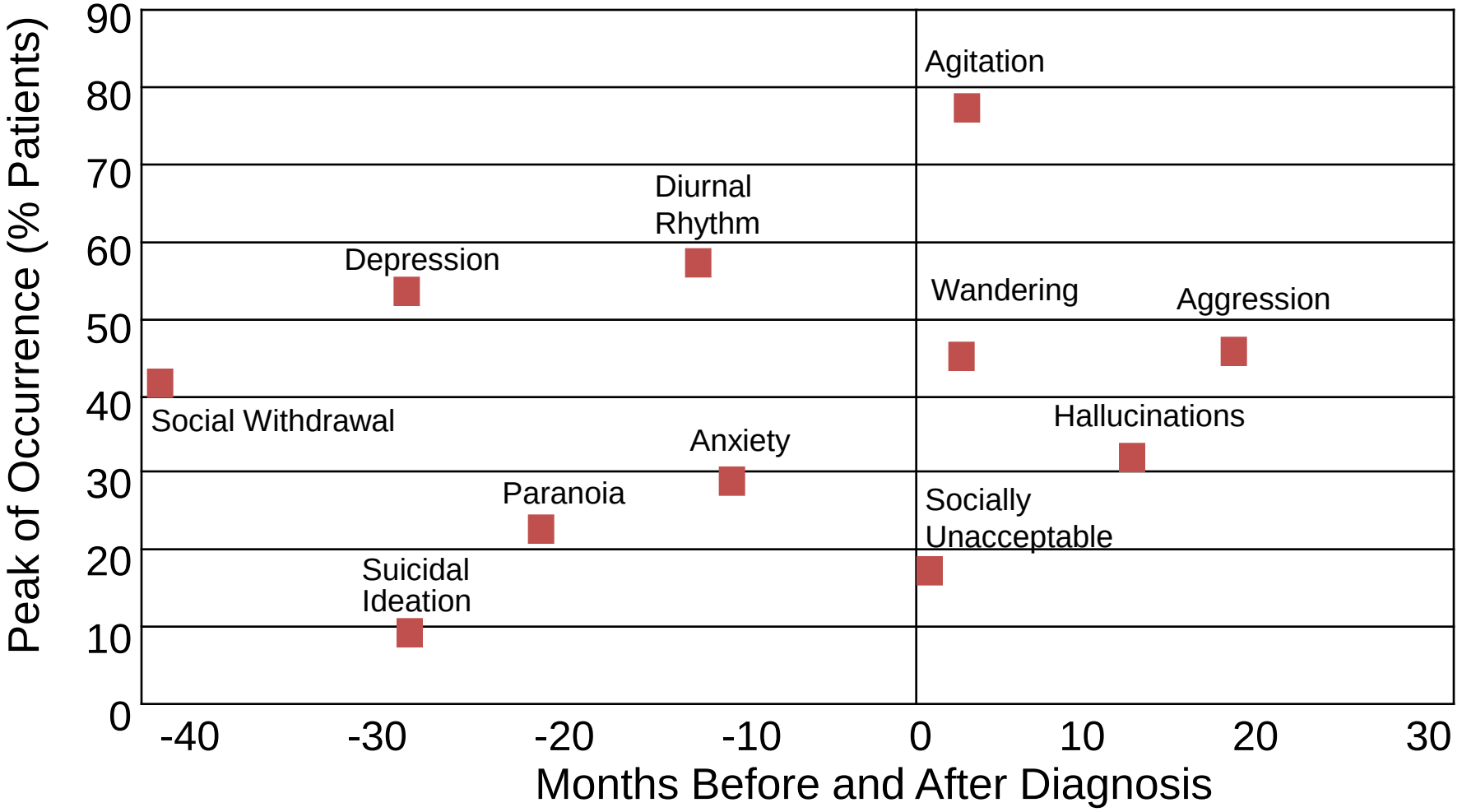
- Commonly used bedside cognitive screening tests
  - MMSE
  - SLUMS
  - MOCA
  - RUDAS
- All based on 30 maximum points
  - Mild Dementia 21-30 points
  - Moderate dementia 11-20 points
  - Severe Dementia 0-10 points

Functional Assessment Staging Test

FAST STAGE	CHARACTERISTICS	APPROXIMATE DURATION	TYPICAL MMSE SCORE
1	No objective findings. Subjective and evolving preclinical changes only	50 years	30
2	Forgets location of objects, subjective work difficulties	15 years	30
3	Decreased functioning in demanding settings, difficulty traveling to unfamiliar locations	7 years	27
4	Cannot plan complex tasks (e.g. shopping)	2 years	24

Reisberg B. Functional assessment staging (FAST). Psychopharm Bulletin 24(4): 653-59, 1984

Peak Frequencies of Behavioral Symptoms in Alzheimer's Disease



Jost BC, et al. *J Am Geriatr Soc*. 1996;44:1078-1081.

Preparing for Changes

- Learn as much as possible about the disease including indications of disease progression
- Educate you family members and other members of your social support network about the disease

Preparing for Changes

- Take steps now to make the future better:
  - Learn and document the wishes and priorities of your loved one (e.g. Advance directives, DPOAs)
  - Learn about potentially helpful resources and programs (e.g. Medicare benefits, The Glenner Centers, the Alzheimer's Association, residential facilities)
  - Select and hire a team of professionals to help you (e.g. a geriatrician, an elder law expert, others)
  - Form a comfortable working partnership with your loved one's clinicians
  - Join a support group
  - Enroll your loved one is the Safe Return Program
  - Renovate your home (e.g. special locks)

Protecting Yourself and Your Loved One from Harm

- **Recognizing Disease Progression**
  - Psychological factors (e.g. denial) may blind a loved one to indications of disease progression.
  - Living in another city or state may also interfere with recognition of disease progression.
  - Nonetheless, there are many reasons why recognizing disease progression is important.

Recognizing Disease Progression

- Recognizing disease progression in important because:
  - It helps you to protect yourself and your loved one from harm.
  - It allows you to adapt activities and communication so that you and your loved one who is living with dementia be as healthy and happy as possible.

Some Guidelines for Dealing with Problem Behaviors

- A careful investigation may reveal triggers such as:
  - Noise
  - Changes in environment
  - Unfamiliar caregivers or visitors
  - Hunger
  - Fatigue
  - Need to toilet
  - Pain
  - Time of day (sundowning)
  - Uncorrected sensory deficits
  - Suboptimal communication patterns

Are Communication Problems from Hearing Loss Involved?

Remember to Look for Environmental Triggers

When to Seek Outside Help for Problem Behaviors

- If the behaviors do not improve with simple interventions
- If the behaviors are disruptive or dangerous
- If brand new problem behaviors emerge or pre-existing behaviors suddenly worsen
- Discuss the behavior with members of your Alzheimer's caregivers support group

A Careful Medical Examination is Essential

Could the Behavioral Symptoms be Due to Depression?

Common Family Dynamics and Possible Remedies

The Martyrdom Syndrome

- Many factors may trigger or perpetuate the martyrdom syndrome. These factors include:
  - A desire to express love and devotion
  - Guilt regarding past actions or situations
  - Survivor guilt
  - Fear of being judged by others (this may be more likely in blended families)
  - Sublimation of painful feelings
  - Avoidance
- The major risk of the martyrdom syndrome is that the caregiver who has slipped into this pattern is actually jeopardizing the safety and well-being of the patient AND themselves.

The Martyrdom Syndrome: A Potential Remedy

- Perhaps the most consistently helpful remedy for this pattern of behavior in a caregiver is to explain to the caregiver how essential he or she is to the well-being of the individual who is living with dementia.
- In essence, the caregiver needs to be reminded that, although their devotion may arise from the most noble of motives, it is, ultimately a strategy that is likely to backfire and to cause more harm than good.
- Specifically, the caregiver, especially caregiving spouses, need to be reminded that no one knows the patient better and no one is more qualified to provide care or supervise care. If martyrdom causes the spousal caregiver to become ill or to die, then the spouse with dementia will be placed in a potentially very precarious situation.

The Out-of-Town Family Member

- One fairly common challenge is keeping out-of-town family members accurately informed of the patient's status
- Out-of-town family members are often unaware of the level of impairment of the person living with Alzheimer's disease
- Often this lack of understanding is the result of
  - The family member with Alzheimer's having preserved social skills
  - The style and content of communication between the out-of-town family members and the family member living with Alzheimer's
  - No recent, or only very minimal recent, contact between the patient and the out-of-town family member
  - The common tendency for patients and family members to experience denial in the face of tragic life threatening illnesses like Alzheimer's
  - Pre-existing trust or communication issues between family members

The Out-of-Town Family Member: Remedies

- Invite out-of-town family members to visit as often as possible
- When out-of-town family members do visit, engage them actively in caregiving
- Consider letting the out-of-town family member provide respite care when the primary caregiver is on vacation
- Request that a neutral third-person explain to the out-of-town family member the nature and extent of the cognitive losses that the person with dementia is experiencing
- Look for opportunities to explore with the out-of-town family member what it means to him or her that his or her family member is living with dementia
- Encourage the out-of-town family member to attend a Alzheimer's caregiver support group

The Parent who Refuses Help from Adult Children

- Once a parent, always a parent
- For most parents, regardless of their age and the age of their children, it feels wrong to “lean on” or “burden” their children
- Many patients living with Alzheimer’s and many spousal caregivers of patient’s with Alzheimer’s
  - Minimize the symptoms of the patient
  - Minimize the challenges of care for the patient
  - Refuse offers of help from adult children

The Parent who Refuses Help from Adult Children: A Potential Remedy

- Every stage of life has important psychological developmental tasks.
- An important developmental task for individuals who are middle aged is to adequately thank their parents for all that their parents did to help the child grow up and become a reasonably healthy, successful adult.
- Although this gratitude can be expressed verbally and this is helpful, it is generally not as helpful as actually having opportunities to express gratitude through helpful actions or behaviors.
- If a parent is able to allow for their adult child or adult children to provide help then this parent is doing the adult child or children a favor and helping the child or children accomplish an age appropriate developmental task.

The Adult Child with Unrealistic Expectations

- Watch out for the adult child who, perhaps due to denial, has unrealistic expectations of what the patient with dementia can accomplish
- Another important developmental task of mid-life is to resolve residual conflicts with one's parents
- If the parent who was party to these unresolved or enduring conflicts has dementia then it may no longer be possible for the parent and child to achieve resolution of the conflict and repeatedly attempting to do this will only make matters worse
- Each time the adult child attempts to resolve the conflict the adult child may end up feeling re-injured or re-traumatized

The Adult Child with Unrealistic Expectations: Potential Remedies

- Work to help the adult child understand that their goal may be healthy and reasonable but their method is no longer realistic
- Encourage the adult child to find some other pathway to achieve resolution of the conflict:
  - Individual psychotherapy
  - Group psychotherapy
  - An Alzheimer's support group

Key Points

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