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Alzheimer’s Disease and Advance Directives: A Primer for Primary Care Physicians

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Primary Care Physicians & Alzheimer’s Patients

- Assess early signs of mild to moderate dementia
- Window of opportunity for early discussions:
  - Diagnoses
  - Advance care planning, including advance directives

Alzheimer’s Disease Impact

- Neurodegenerative disease currently untreatable
  - Accounts for 60-80% of dementia cases
  - Terminal disease that eventually results in loss of capacity
- Comorbid conditions increase with age
- Median survival after diagnosis about 3-9 years
- Progresses differently for different patients
- Incidence and prevalence increase with age

Mild Cognitive Impairment (MCI)

- Measurable change in at least one cognitive sphere that does not interfere with occupational or social function
- Different types depending on domains affected
- Prevalence about 20% of those over 65 years old
- 10 to 20% with MCI progress to dementia annually
- Not all patients go on to develop dementia

Alzheimer’s Prevalence by Age

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The Growing Crisis

- Eldest Baby Boomers attained Medicare eligibility in 2011
- Alzheimer’s afflicts 1 in 9 older Americans, nearly 1 in 3 over age 85
- Fewer than 8% of Americans have long term care insurance
- Costs on health care system estimated at $214 billion
- Unpaid work by caregivers valued at $220 billion

A Leading Cause of Death

- # of Estimated Deaths/Year by Cause of Death:
  - Stroke: 128,978
  - Accidents: 130,557
  - Chronic Lower Respiratory Diseases: 149,205
  - Alzheimer’s Disease: 503,400
  - Cancer: 584,811
  - Heart Disease: 611,105

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Women are the Epicenter

By her 60’s, a woman’s estimated lifetime risk is 1 in 6

2.5x more women provide intensive “on duty” care, 24 hours a day

Almost 2/3 of Americans with Alzheimer’s are women

> 60% of ALZ/dementia caregivers are women

Dramatic Impact on Patients

- Depression
- Loss of capacity
- Fading self-awareness and engagement
- Eventually lives in a world of discrete moments
- Advanced stages require full time caregiver support

Dramatic Impact on Caregivers

Patient

- Physical
- Social
- Psychological

Physician ↔ Caregiver

Communication Topics

- Capacity Assessment
- Disclosing the Diagnosis
- Advance Care Planning
- Advance Directives
- Life Prolonging vs. Palliative

Barriers for PCP’s

- Time constraints
- Confusion over forms
- Concern about reimbursement
- Discomfort initiating the discussion
- Inadequate resources for patients and caregivers
- Patient hearing loss

End-of-Life Conversations

- Sometimes do not occur
- Lack of confidence, skills and knowledge
- Not systematically done
- Limited time for physicians
- Low reimbursement
Ethical and legal obligation of physician to disclose diagnosis during window of opportunity

- Speak directly to patient
- Disclose relevant natural course of this terminal disease

### Disclosing the Diagnosis

### Capacity Assessment

1. Understands treatment and care plan options
2. Appreciates how information applies to their situation
3. Reasons with information consistent with facts, values, and preferences
4. Communicates and expresses choices clearly

#### Capacity

### Patient Autonomy

- Patients with capacity are autonomous moral agents
- Patients have the right to receive appropriate medical treatments
- Patients have basic right to refuse unwanted medical treatments

### Physician-Patient Relationship

- Physician-patient relationship is grounded in the principle of respect for patient autonomy
- Medical care goals should be patient-centered when patients have capacity
- Physicians should engage patients in discussions about goals of care and respect patients right to self-determination

### Ensuring Self-Determination

- Right of patients with capacity (at present) to exercise their individual autonomy in relation to future health-care decisions (when one has lost decision making capacity)
- Legally grounded in the Patient Self-Determination Act (PSDA) of 1991
- Advance directives promote patient self-determination

### Case #1: Key Points

- Initiated discussion during window of opportunity
- Assessed capacity – patient met the four criteria
- Explored the patient’s goals of care
- Respected patient autonomy
- Documented patient’s wishes
Advance Care Planning

- Lessens financial and emotional burden on loved ones
- Avoids prolonged suffering
- Respects patient autonomy and guides decision making
- Increases chances patient’s wishes will be followed

Advance Directives

- Health Care Proxy
- Living Will
- Organ Donation
- Oral Advance Directive
  Important to document

Advance Medical Directives for Life Sustaining Treatment

- Antibiotics: Do not use/Limited use/Use if medically indicated
- Future Hospitalizations/Transfer: Do not send to hospital/Send to hospital only under certain conditions
- Cardiopulmonary Resuscitation: DNR Order, Full code
- Artificially Administered Fluids and Nutrition: No feeding tube or IV fluids/Trial period of feeding tube and IV fluids

Critical Questions & Goals

- What if the patient had respiratory failure, heart attack or renal failure?
- What if the patient is considered an ICD?
- What if the patient develops swallowing difficulties, or has a decline in nutritional status, or interest in eating?
- What if the patient develops pneumonia?

Critical Questions & Goals

- In general, does the patient want life prolonging treatment or maximum palliation?
- What are the goals of care at the end of life?
- How to balance quantity of life with quality of life
- Profoundly value laden decisions that only the patient can make
For More Complex Patients

- Aggressive medical measures may not be effective and could possibly be harmful
- Confused and erroneous understandings are common
- Listen to the patient’s and family members’ concerns, validate them, and provide compassionate, thoughtful responses
- Basic medical terms can be clarified

Case #2: Key Points

- Validated concerns of patient and family member
- Clarified misconceptions
- Disclosed likely diagnosis
- Provided realistic information
- Documented patient’s wishes

Cardiopulmonary Resuscitation

- Poor survival rates
- Survival decreases with increasing age
- Outcomes worse for dementia patients
- Near-zero survival in unwitnessed arrests
- In hospital setting, patient often taken to ICU after CPR - increases chance of death, confusion, delirium

Can Hospitalization Be Avoided?

- Patients with capacity or their proxies have a right to decline hospitalization
- Patients with advanced dementia can usually be kept comfortable at the end of life in the home or skilled nursing environment
- More likely to receive aggressive and unnecessary medical treatments in hospital

Artificial Hydration & Nutrition

- Patients’ desire to drink and eat wanes in advance stages
- Many caregivers feel obligation to hand feed the patient
- Patients have a right to refuse:
  - Hand feeding
  - Artificial nutrition and hydration via tube feeding
- Discomfort can be managed

Documentation

- Keep forms easily available for patients
- Become familiar with forms used in home states and hospitals
- Complete in the office when possible
- Do not procrastinate
- Advance directive on file increases chances of having patient’s wishes followed
Educating the Agent or Proxy

- Clarify agent’s role/responsibilities and comfort level with role
- Emphasize duty to follow patient’s wishes
- Relieve the agent of personal burden to decide
- Address caregivers’ concerns and needs
- Use team based approach for:
  - Education
  - Psychological support and counseling
  - Referral to community resources

Ongoing Process

- Ongoing support for patient and caregiver
- Best done with team approach
- Ongoing discussions, updates, monitoring of patient’s capacity
- Be sensitive to time when patient becomes incapacitated
- When this happens, clarify that the agent is now patient’s decision maker

Central Conclusions

Don’t Miss the Window of Opportunity!

- PCP’s should initiate discussions, assess capacity, and provide full disclosure
- Patients with capacity have right to self-determination
- Patients with capacity may refuse present or future interventions

Central Conclusions

- Early documentation of patient preferences is key
- Alzheimer’s is a family disease; caregivers should provide team support and assessment

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