NAPA Advisory Council Ethics Subcommittee

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Role of ethics in health policy for Alzheimer’s Disease

• Support autonomy
• Protect vulnerability
• Balance rights/needs of AD patients and those of family, community
• Promote research
  – For all phases of AD
  – Protect research subjects
Goals of the Subcommittee

- Identify key ethics issues around Alzheimer’s Disease and Related Dementias
- Determine which issues have highest priority
- Determine their scale and impact
- Determine which might be actionable

Facilitator Role

- Promote discussion
- Identify members’ concerns
- Inform policy recommendations with ethics perspective
Subcommittee Members

- Laurel Coleman
- David Hoffman
- Jennifer Manly

- With input from Nina Silverberg and others from the Dementias of Aging Branch in the Division of Neuroscience at NIA

Subcommittee Process

- Monthly calls to identify key AD ethics issues
- Presentation on findings at July Advisory Council meeting
- Final document, with subcommittee member input
Topics to Consider

• Health Privacy and Disclosure of AD Diagnosis: Educational Proposal

• Feeding Tubes and Severe Dementia

• Promoting AD Research

• Research on Later Stage AD

Health Privacy and Disclosure of AD Diagnosis: Educational Proposal

• Patients may request clinician NOT disclose AD to family
• What does HIPAA require? Forbid?
• What is responsibility of clinician?
• When do families have right to know?
• Assessment of Decisional Capacity
• Case Specific Recommendations
Feeding Tubes and Severe Dementia

- NAPA Severe Dementia IOM Workshop
- Feeding Tubes in severe dementia
  - No benefit on duration or quality of life
  - Increase in pressure sores
- Geographic variation
- Health policies as perverse incentive?
- Promote best practices
  - Staffing
  - Oral nutrition programs

Promoting AD Research

- Research on “pre-clinical” AD
- Large numbers of currently healthy volunteers
  - 1/3 over 65 show plaques/tangles
  - 11% over 65 have AD symptoms
- Inclusion of research medical data in EMR?
- Lack of protections for:
  - Long term care insurance
  - Life insurance
Research on Later Stage AD

- Safely staying at home
  - Built environment
  - Support without intrusion
  - Support for caregivers
- Better institutional care
- Non-pharmacological interventions

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Sample References