

## 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

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## Facilitator Role

- Promote discussion
- Identify members' concerns
- Inform policy recommendations with ethics perspective

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## 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

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## 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

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## 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

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## 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

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## 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

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- 6. Mitchell SL et al, Clinical and Organizational Factors Associated with Feeding Tube Use, *JAMA*, 2003.