Advanced Dementia Expert Panel
Summary and Key Recommendations

Objectives

• To convene experts to review current research, innovative practices, and health policy pertinent to the care of persons with advanced dementia and their families, and

• To make recommendations to HHS and the NAPA Advisory Council about priority initiatives to improve that care.
Rationale

- ~1,000,000 Americans with advanced dementia
- Pressing need to provide high quality care for these persons and families
- Special considerations

Advanced Dementia

- Vulnerable population with unique needs
- Severe functional and cognitive impairment
- Reliance on surrogate decision-making
- Cannot live alone
- Family/caregiver burden
Organization

- **Co-Chairs**: Susan Mitchell MD MPH, and Laurel Coleman MD
- **Facilitator**: Katie Maslow, IOM
- **Core Group**: Attend all meetings, formulate final recommendations
- **Experts**: Specific meetings
- **Observers**: public, professional and provider organizations, advocates, and staff from many federal agencies (AoA/ACL, AHRQ, ASPE, CDC, CMS, HRSA, NIA, NINR, SAMHSA, and VA)

Core Group +

- Co-Chairs: Coleman, Mitchell
- A. Bonner PhD: Northeastern, policy
- S. Brangman MD: SUNY, care delivery, education
- M. Ersek RN: UPenn, nursing, research, care delivery
- L. Hanson MD, MPH: UNC, clinical research
- R. Sean Morrison MD: Mount Sinai, research, policy

*Also participated in drafting final recommendations*

- D. Meier MD: Center to Advance Palliative Care, policy
- M. Gallagher DNP: Hospice of the Valley, care delivery
- G. Sachs MD: Indiana University, clinical research
- J. Teno MD: Brown University, clinical and policy research
- D. Hoffman: NY State Health Department, public policy
Meetings

1. Research
   • January 28, 2014

2. Clinical Practice
   • September 28, 2014

3. Policy
   • January 21, 2015

Research: Participants

• Core Group
• Invited Experts
  – Marilyn Albert, PhD
  – Ken Covinsky, MD
  – Joan Teno MD, MSc
  – Richard Schultz, PhD
  – Constantine Lyketsos, PhD
  – Greg Sachs, MD
• Observers
Research: Agenda

• Advanced Dementia Research Overview- Mitchell
• Patient Experience- Hanson
• Family Experience- Ersek
• Health Services Utilization- Teno
• Infrastructure and Funding- Morrison

Research: Main Conclusions

• 25 years of research
• Design: Descriptive >>> intervention
• Methodology: Database = primary
• Setting: nursing home> hospital> community
• Focus: Feeding tubes > infections > hospice > decision-making > prognosis > family > costs
• Knowledge: Delineated problems and main targets to improve care
Research: Main Conclusions

- Clinical Course
  - Terminal condition, prognostication difficult
- Sources of Distress
  - Treatable symptoms, measurement challenges
- Treatment of clinical complications
  - Feeding and infections most common
  - Tube-feeding has no benefit, overuse of antibiotics
- Health services
  - Hospice helps but under-utilized
  - Hospital: common, costly, burdensome, avoidable
  - Misuse of Skilled Nursing Facility (post acute care)
  - Disparities
- Strategies to improve care
  - Mostly observational: Advance care planning, hospice,
  - Two RCTs: decision support tools

Research: Main Conclusions

- Clearly delineated opportunities to improve care
- Current research priority: determine how to address opportunities
  - Design and test clinical interventions and models of care to improve advanced dementia care
  - Design and evaluate health policy initiatives that incentivize high quality goal-directed care
Clinical Practice: Participants

- Core Group
- Invited Experts
  - Margaret Noel MD – MemoryCare
  - Jody Comart PhD - Hebrew Senior Life
  - Jed Levine - NY Chapter of Alzheimer’s Association
  - Ashley Shreves MD – Mt. Sinai Hospital, NY
  - Maribeth Gallagher DNP – Hospice of the Valley
  - Dayna Cooper MSN – VA Geriatrics and Extended Care
  - Greg Sachs MD – Indiana University
  - Ann Wyatt MSW – Alzheimer’s Association consultant
  - Tena Alonzo MA – Beatitudes CCRC

Clinical Practice: Agenda

- Innovative practices in care for persons with advanced dementia in:
  - Nursing homes
  - At home and in the community
  - In hospice
  - In the hospital and emergency department
  - Support and training for families and other caregivers
Clinical Practice: Main Conclusions

• Nursing Home Program – Beatitudes
  – High family and staff satisfaction
  – Low medication use and reduced hospital and ER use.

• Community programs –
  – Focus on palliative care - support for family/caregivers
  – Advance care planning is common theme.
  – Persons with dementia are less likely to die in the hospital and have lower levels of pain and distress.

Clinical Practice: Main Conclusions

• Hospice Program
  – Published results with lower use of restraints, feeding tubes, lower rates of hospitalizations.
  – Works cooperatively with long term care facilities
  – Excellent symptom management and family satisfaction.

• New strategies and programs –
  – All show promising results: training family caregivers, ER consultations, printed guides for advance care planning/education.

• Very POSITIVE and encouraging day for all.
Clinical Practice: Main Conclusions

- Challenges
  - Promising programs are slow to “scale up” and replicate
  - Programs merit broader evaluation
  - Successful programs need good leaders and culture change
  - Are there policy incentives/and regulatory “levers” that could hasten implementation of these models?

Policy: Participants

- Core Group - and David Hoffman

- Invited Experts:
  - Diane Meier MD: Mt. Sinai Hospital, CAPC
  - Joan Teno MD: Brown University
  - Susan Miller PhD: Brown University
  - David Grabowski PhD: Harvard University
  - Greg Sachs MD: Indiana University
Policy: Agenda

- Transforming care for persons with advanced dementia – what will it take?
- How do we measure quality for this population?
- Policy barriers and opportunities for providing good care in various settings:
  - Home and community
  - Nursing home
  - Hospice
  - Hospital and care transitions

Policy: Main Conclusions

- Very complex policy issues with high risk for unintended consequences
- Lack of access to palliative care
- Long-term care: complex fiscal and regulatory policies create misaligned incentives that promote poor care
- Hospice: problems with access for persons with dementia, documentation of dementia diagnosis, and coordination with the Medicare SNF benefit
- Home and community care: Large number of persons with advanced dementia but little information about specific needs
- Acute and sub-acute care settings and services: High use but care is often not beneficial
- Quality metrics: many unique issues for advanced dementia
Final Recommendations

- Formulated by Core Group
- Principles
  - Focus on advanced dementia
  - Build from and fill gaps in the existing National Plan
  - Not iterative of other federal initiatives
  - Focus on priorities
  - Feasible

Over-Arching Goal

- To ensure the quality of life and quality of care for persons living with advanced dementia and their families across care settings
Strategy 1

- To ensure access to high quality palliative care for persons with advanced dementia and their families across all settings
  - Primary palliative care
  - Palliative care consultation
  - Hospice
    - Beneficial but ...
    - Major access concerns

What is Palliative Care?

- Specialized medical care for persons with serious illnesses.
- Relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis.
- Improves quality of life for the person and family.
- Team of doctors, nurses, and other specialists who work with a person’s other doctors to provide an extra layer of support.
- Appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatments.
Strategy 2

- Prepare a workforce that is competent to deliver care to persons with advanced dementia and their families
  - Healthcare workers (nurses, physicians, direct care workers, social workers) and long-term services and supports (e.g., transportation, meals)
  - Culturally competent
  - Across all settings
  - New and existing workers

Strategy 3

- Incentivize documentation and tracking of level of functional and cognitive status to identify people with advanced dementia
  - Harmonize documentation across settings
  - Critical to care, research, program evaluation, and policy
Strategy 4

• Support research, evaluation and dissemination of models of care to meet the needs of persons with advanced dementia and their families
  – Across care settings
  – Align payment and delivery
  – Unique considerations that merit focus on advanced dementia

Strategy 5

• Leverage existing mechanisms to ensure access to high quality care for persons with advanced dementia and their families

• Examples: payment, regulatory, and public reporting
  – Consider existing infrastructure, e.g. state coalitions to improve dementia care, QIOs (Quality Improvement Organizations), HHS Partnership for Patients
Strategy 6

- Support quality metrics that ensure transparency and accountability for the care of persons with advanced dementia and their families
  - Must include proxy reporting (e.g., family, nurse)
  - Examples of unique metrics
    - Effective symptom assessment and management
    - Burdensome, non-beneficial treatments (e.g., tube feeding, transitions)
    - Care concordant with values and preferences
  - Critical for clinical care accountability and research and policy evaluation