

**Understanding End of Life
Decision-Making with and for people with significant
Intellectual Disabilities
Collaboration among people with disabilities, their
support network and community health organizations**

Presented by:

Marisa C. Brown, MSN, RN

Director

DDA Health Initiative

**Georgetown University Center for Excellence in
Developmental Disabilities**

Washington, DC

Advance Care Planning for People with Intellectual Disabilities

- the need for advance care planning and advance directives among intellectually disabled persons has been recognized for over a decade
- only a tiny fraction of intellectually disabled persons had completed advance directives
- end-of-life care issues are seldom raised
- substantial barriers exist to integrating such discussions with other services

VALUE

- **V**aluing and appreciating what the family members communicate
- **A**cknowledging their emotions by using reflective summary statements
- **L**istening to family members
- **U**nderstanding who the patient is as a person by asking open-ended questions and listening carefully to the responses
- **E**liciting questions from the family more effectively than by simply asking, "Any questions?"

Definition of Terminal Illness

January 2008

The presence of a fatal condition, the chance of death with the next exacerbation of disease and the patient's acknowledgment of the seriousness of the situation.

Most Common Causes of Death

Centers for Disease Control

2013 data

Heart disease

Cancer

Chronic lower respiratory disease

Accidents (unintentional injury)

Stroke (cerebral vascular disease)

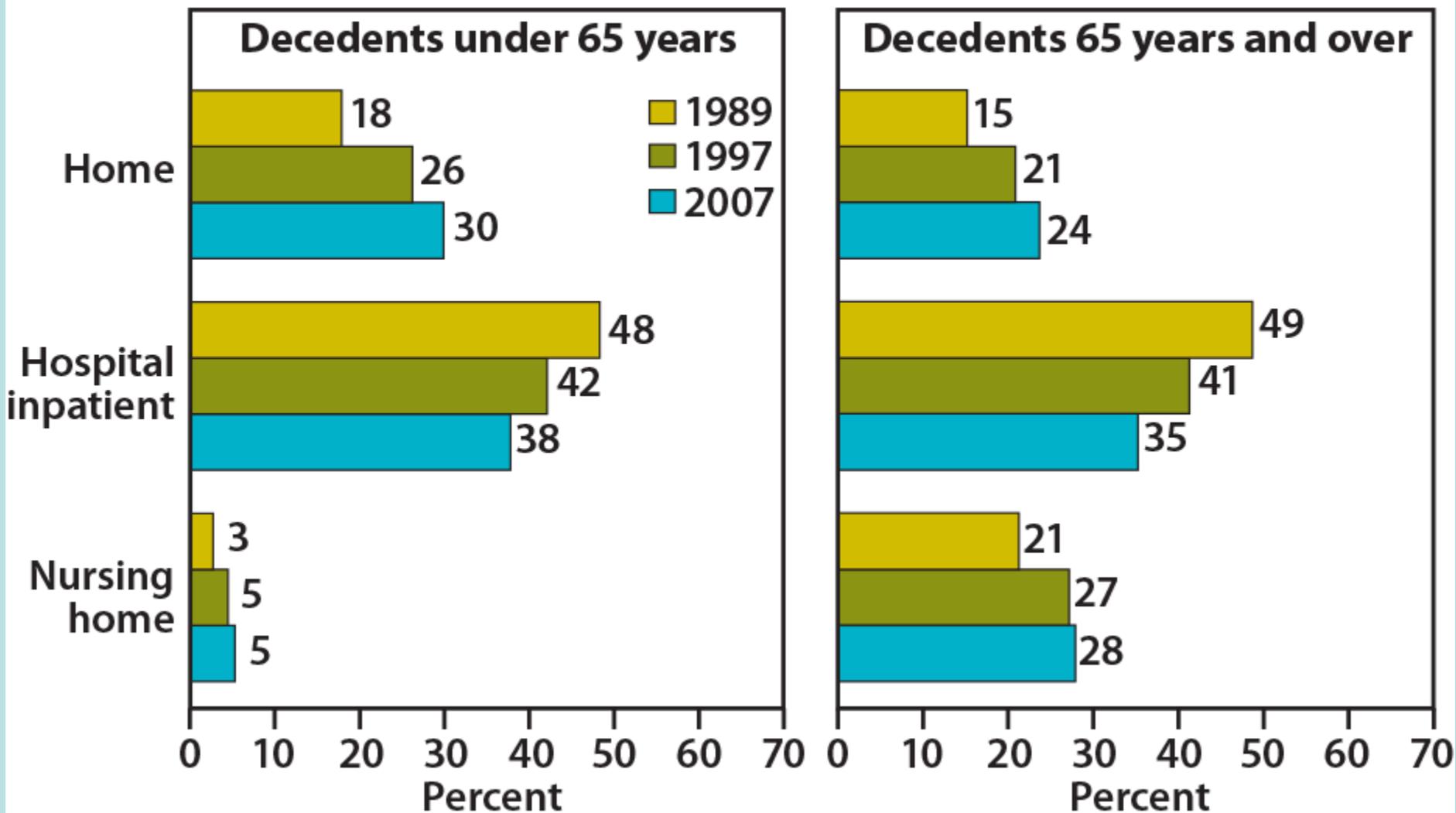
Alzheimer's disease

Death in People with ID

DISABILITY AND REHABILITATION. 1999; VOL. 21.so.5/6.284-294

- Bronchopneumonia or other respiratory infections
 - Carcinomas
 - Seizures
-
- Asphyxia due to aspiration
 - Pulmonary embolisms
 - GI diseases

Place of death, over time



SOURCE: CDC/NCHS, *Health, United States, 2010*, Figure 33. Data from the National Vital Statistics System.

Leading causes of death in individuals with intellectual disabilities (U.K.)

Respiratory disease

Cardiovascular disease related to congenital heart disease

Cancer

Location

The rapidly changing location of death in Canada., 1994-2004.
Wilson, D.M. et.al. Social Science and Medicine, 68:2, May 2009,
1752-1728.

Category	1994	2004	% change
Rural provinces and territories	71.7%	58.3%	-12.4%
Urban provinces	78.9%	61.0%	-17.9%
Nursing home	3.0%	9.9%	
Private residences	19.3%	29.5%	

Chronic Illness in the Elderly Typically Follows Three Trajectories

Short period of evident decline - typical of cancer. Most patients with malignancies maintain comfort and functioning for a substantial period. However, once the illness becomes overwhelming, the patient's status usually declines quite rapidly in the final weeks and days preceding death. Hospice is an important part of the care for this trajectory.

Chronic Illness in the Elderly Typically Follows Three Trajectories (cont'd)

Long-term limitations with intermittent exacerbations and sudden dying - typical of organ system failure. Patients in this category often live for a relatively long time and may have only minor limitations in everyday life. From time to time, some physiological stress overwhelms the body's reserves and leads to a worsening of serious symptoms. Patients survive a few such episodes but then die from a complication or exacerbation, often rather suddenly. Ongoing disease management, advance-care planning, and mobilizing services to the home are key to optimal care.

Chronic Illness in the Elderly Typically Follows Three Trajectories (cont'd)

Prolonged dwindling - typical of dementia, disabling stroke, and frailty. Those who escape cancer and organ system failure are likely to die at older ages of either neurological failure (such as Alzheimer's or other dementia) or generalized frailty of multiple body systems. Supportive services at home, like Meals on Wheels and home health aides, then institutional long-term care facilities are central to good care for this trajectory.

Tailoring Services to Needs

It is possible to live comfortably, even with serious chronic illness. But living with such illness requires planning for the ongoing course so that services match the course of the illness.

Serious chronic illnesses require continuity and comprehensiveness of care. Care needs generated by symptoms or disabilities are urgent priorities. Flexibility is also important - adjusting care to family and patient resources, to varying needs, and to patient and family preferences.

Tailoring Services to Needs (cont'd)

The timing of death remains unpredictable until late in the course of serious chronic illness. Therefore, special arrangements for care near the end of life must be triggered by severity of symptoms, rather than waiting for a reliable prediction that death is near.

The major causes of death are all progressive, degenerative illnesses that leave people in fragile health for a long period of time before death. Programs and policies to improve care for chronic conditions need to accommodate the fact that death is the eventual outcome.

Tailoring Services to Needs (cont'd)

Designing reliable care systems might best build upon the time, course and nature of the service needs of a small number of populations, differentiated by trajectory of disability and symptoms over time, rather than conventional differentiation by care setting (e.g., hospital or home) or diagnosis.

A highly reliable care system for the usual "cancer" trajectory would accomplish the following:

- Build advance-care planning into early treatment, using a patient-centered approach & adapting the plan as the disease progresses.
- Provide palliation for symptoms and rehabilitation for disabilities throughout the course of illness.
- Provide some costly "aggressive" treatments even very late in the illness, because they still work to enhance lives.
- Smooth the transition across settings - from hospital or office to home care (mostly hospice) as the patient becomes more ill.
- Attend to family and support staff needs and spiritual/emotional issues throughout.

A highly reliable care system for an advanced chronic organ-system-failure trajectory would include the following:

- Teach the chronically ill elderly and their families and staff the essentials of disease management, especially how to recognize symptoms and prevent worsening of illness.
- Ensure constant availability of key medications.
- Include planning that provides advance directives for sudden death.
- Provide early intervention for signs of exacerbation, including mobilizing care to the patient's home.
- Offer in-home adaptations and equipment (e.g., oxygen) to ensure comfort.
- Tailor the care plan to the patient and family.

The dementia and frailty trajectory requires further adaptation of services:

Provide realistic training, financial support, benefits, and respite for family caregivers.

Ensure quality care in long-term care facilities.

Ensure availability of competent home health aides.

How to assess “futility”?

Will the quality of life resulting from a medical intervention be so poor that the intervention does not actually benefit the person?”

```
graph LR; A[Will the quality of life resulting from a medical intervention be so poor that the intervention does not actually benefit the person?"] --> B[Will that person's life be worth living?]; B --> C[Assessments must be objective.]
```

Will that person's life be worth living?

Assessments must be objective.

Communication Processes

Proactive, multidisciplinary sessions that provide patients (when they are able to communicate) and family members with the opportunity to ask questions, articulate the patient's values, express painful emotions, discuss concerns, and obtain help with managing feelings of guilt.

Quill TE. Perspectives on care at the close of life -- initiating end-of-life discussions with seriously ill patients: addressing the "elephant in the room." JAMA 2000;284:2502-2507.

What you can do to improve the quality of life?

- Review what is really important to the person. What are favorite activities? Who are their favorite people?
- Should you plan a visit to friends and family they have not seen in a while?
- What are vacation plans for this year? Does the date need to be moved up?
- Review dietary orders and liberalize diet.
- How well do you understand how the person reports pain/discomfort?

End-of-Life Decisions for Adults with Significant Intellectual Disabilities

- Think - a framework for applying ethical decision-making about health care treatment on another's behalf.
- Act - A guided interview to assist decision-makers who care for a person with significant intellectual disabilities before they meet with healthcare professionals.
- Plan – Assess medical intervention impact on quality of life

An Ethics Workup

What are
the facts?



What is the
issue?



Frame the
issue.



Weigh
alternative
courses.



Critique.

Mary Johns

- The facts:
 - CVA not likely to recover previous functioning
 - You have known her for 4 years and she requires extensive, 24 hour supports
 - Placed on ventilator
 - One week later, still on ventilator, no progress, requires gastric tube
 - Staff from residence believe she needs time to recover

Mary Johns

- What is the issue?
 - Should you consent to a “do not resuscitate” order in the event her heart stops or she stops breathing?
 - Should you consent to a gastric tube to provide her with nutrition?

Mary Johns

- **Frame the issue.**
 - **Identify the appropriate decision-maker.**
 - **Apply the criteria to be used in reaching clinical decisions.**
 - The specific biomedical good of the patient
 - The broader goods and interests of the patient
 - The goods and interests of other parties
 - **Establish the health care professionals' and guardian's moral/professional obligations.**

Mary Johns

- **Identify and Weigh Alternative Courses of Action and Then Decide.**
 - Balancing benefits and harms in the care of patients
 - Disclosure, informed consent, and shared decision making
 - The norms of family life
 - The relationships between clinicians and patients
 - The professional integrity of clinicians
 - Cost-effectiveness and allocation
 - Issues of cultural and religious variation
 - Considerations of power

Mary Johns

- Critique
 - Once implemented, carefully follow the outcomes to see what can be learned that would be helpful in a similar situation in the future.

Think: A Guided Interview to Healthcare Decision-Making for People with Significant Intellectual Disability

- Prior to meeting with health care professionals to talk about medical treatment and care, reflect on what you know about the person, how they make decisions, the adequacy of supports
- Find out the medical facts.
- Find out the options.
- Determine best course of action.
- What is the overarching goal of the plan of care: 1) restoration and cure, 2) stabilization of functioning, or 3) preparation for a comfortable and dignified death? To what degree do the proposed interventions/plan of care support this goal?

Considerations for Quality of Life

- What treatments are in the person's best interest if there is **no chance** that the treatment would **reverse** or **improve** their condition?

Definitely want treatment



Definitely do not want treatment

- No longer can recognize or interact with family or friends.
- No longer can think or talk clearly.
- No longer can respond to commands or requests.
- No longer can walk but gets around in a wheel chair.
- No longer can get outside and must spend all day at home.
- Is in severe untreatable pain most of the time.
- Is in severe discomfort most of the time (such as nausea, diarrhea).
- Is on a feeding tube to be kept alive.
- Is on a kidney dialysis machine to be kept alive.
- Is on a breathing machine to be kept alive.
- Needs someone to take care of them 24 hours/day.
- No longer can control their bladder.
- No longer can control their bowels.
- Lives permanently in a nursing home.
- Other:

Resources

- **Complex moral issues: End of life decisions for adults with significant intellectual disabilities**
 - <http://gucchdgeorgetown.net/UCEDD/complex/index.html>
- **A caregivers guide to the dying process.**
 - <http://store.hospicefoundation.org/home.php?cat=15>
- **End of Life Care for Children and Adults with Intellectual and Developmental Disabilities**
 - <http://bookstore.aaid.org/BookDetail.aspx?bid=98>
- **End-of-Life Care: A guide for supporting older people with intellectual disabilities and their families.**
 - <http://www.albany.edu/aging/lastpassages/manual-entire.htm>
- **People Planning Ahead**
 - <http://bookstore.aaid.org/BookDetail.aspx?bid=94>
- **Thinking Ahead**
 - <http://www.dds.ca.gov/ConsumerCorner/ThinkingAhead.cfm>