


**Caring for Persons with
Developmental Disabilities at
the
End of Life**
A mandate for planning and Dignity

Jan Jahner, RN, CHPN
Pain and Palliative Care Specialist
St. Peter's Hospital
April 3, 2008
Special Thanks to: Neil Ellison, MD and Robert Shabanowitz,
PhD



Objectives

- Discuss the emerging issues for persons with intellectual disabilities as they near the end of life.
- Discuss decision making and advance care planning
 - Review ethical and legal issues related to this population

Discuss Hospice and Palliative Care, and the educational needs of persons with Intellectual Disabilities and their families.

Case presentation

- 62 yo man with severe DD admitted from group home: resident for 10 years
- Lived with mother, then sister, 30 yrs
- Sister's visiting reduced lately; CA DX: turned guardianship over to State with her health decline
- Pt. non-communicative and no interaction with anyone for past 6 months. Stopped eating 4 days PTA
- DX: CVA and status epilepticus-multiple consults predict no recovery to baseline level of function
- Sister has strong interest in comfort measures
- Guardian hasn't been involved that long, has contacted MAP, they encourage/demand feeding tube, continued treatment

Adults with Developmental Disabilities: definition

- Decreased ability
 - Comprehend new or complex information
 - Learn new skills
- Impaired social functioning
- Issues are established before adulthood and affect future development
- Examples:
 - Autism, Downs syndrome cerebral palsy associated mental retardation

Patients with DD: demographics

- Life expectancy within 5 yrs of the general population
- Increased frequency of death from age related illnesses
 - Cancer, Heart Disease, Chronic lung disease
- Increased need for palliative and hospice
- Increased need for advance care planning

Housing Trends

- Past decades
 - Decreased institutionalization
 - Mainstreaming of ADD to the community
- Home care often provided by elderly parents...what happens when parents die or become disabled?
- Group Homes, Community housing, what level of familiarity, continuity?

Primary Issues

- Life style with potential adverse health effects
 - suboptimal nutrition
 - Limited exercise
 - decreased utilization of health screening
- Communication barriers leader to advanced illness presentation
- Possible lack of clarity of goals of care
- Poorly defined decision-makers

Further issues concerning medical and palliative care for ADD

- Lack of comprehension of their illness, symptoms or treatments
 - Interpret illness **or treatments** as punishment for wrong-doing
 - Not understand death and why their family/c/g's are sad
- Symptom assessment compromised by an inability to communicate well
 - Wide range of behaviors indicating discomfort
 - Signals may be only apparent to people that know them well
 - Unclear what is causing distress: pain, anxiety, fear, sadness?
- Not allowed appropriate bereavement
 - Inadequate death education, often excluded from funerals, memorial services (Snow Cake)

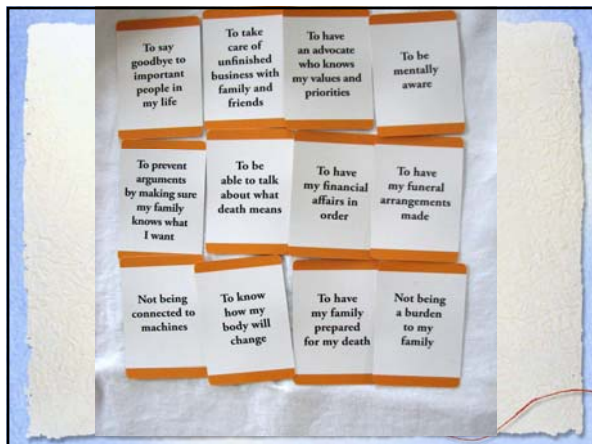
Providing Effective Palliative and Supportive Care

- Education for persons with DD, their families, care-givers
 - Person centered approach involves exploration of understanding
 - Values, past experiences, what comforts, what frightens,
 - Time: Interview, observation, "normal" activities and expression
- Maximize time in familiar surroundings
 - Familiar people and objects, smells,
 - Routines and activities enjoyable to the patient, emotional reassurance, presence
 - Communication across settings vital

Advance Care Planning

- Elicit preferences regarding end of life care
 - Directly from ADD, if possible
 - Guardians, family, caregivers
 - Early in the course of the disease Early and clear understanding of the efficacy of CPR, appropriateness of either Comfort One or attempt resuscitation, benefits and burdens of Life-sustaining treatment
- Early discussions of a disease's likely course, and risks of possible complications as illness progresses
- Explore spiritual values, place and circumstances of death.





Communication

- Communication about symptoms: high potential for extensive tests due to poor communication
 - Information understandable
 - Not about abstract diseases, ideas
 - Touch, teaching, reassurance
- Understand the burdens, as well as possible within the persons world
- Will remission of benefit be sustained long enough to warrant the duration of therapy, given the experience to the disabled person?

Symptom assessment

- Individualized
- Based on the experience of the patient's closest caregivers
- DisDAT: Distress may be hidden, but it is never silent!
- Focus on careful examination of patterns of distress
- Thorough physical examination
- Judicious use of diagnostic testing

DisDAT

- 1) Identified distress, rather than pain
- 2) Documented signs and behaviors when a person was content and when they were distressed
- 3) Helped to put the distress into context by providing a checklist that suggested possible causes of distress
- 4) Summarized the signs and behaviors for easy reference by other carers and teams
- 5) Monitored changes in distress as an intervention was tried.

Symptom Management

- Empiric use of comfort medications: trial and error
- Strong need for non-drug measures: what soothes? What frightens: recognize the roll of taste, touch and hearing, all the senses that may be impacted

Communication

- Avoid the use of the term "futility" (HO)
- Avoid language that otherwise seems to undervalue the pt.'s life
- Recognize that trust may need to be built with families or institutions
 - Past history "your baby will never live to be an adult"
 - "they will never have a meaningful life"

Making decisions for incompetent patients

- Patients themselves
 - Decisional directives
 - Proxy directives
 - Combined directives
- Family members
 - Hierarchy: spouse, adult children, parents..
- Courts: guardian *ad litem*
 - "guardian at law": *The person appointed by the court to look out for another's best interests*

Making decisions for Incompetent Patients

- Extreme vulnerability of this population
- Pt-centered theory of decision making
- Procedural safeguards
 - State has compelling interest in preservation of human life
 - Clinicians should be aware of local regulations
 - Mt. law: defines surrogate hierarchy, with holding and withdrawing if guardian appointed Early and clear understanding of the efficacy of CPR, appropriateness of either Comfort One or attempt resuscitation, benefits and burdens of Life-sustaining treatment
- Early discussions of a disease's likely course, and risks of possible complications as illness progresses
- Explore spiritual values, place and circumstances of death.

Standards for Surrogate Decision-Making

- Principles
 - Respect for individual self determination and bodily integrity
 - Patient's treatment preferences: Approximate, as closely as possible, the decision about treatment the patient would make if able to do so.
- 14th amendments "liberty interests" vs compelling state's interests
 - Procedural safeguards
 - Clear and convincing evidence



Pause for poetry

- Patrick Clary
- Five Things I Learned from Hospice Nurses

- We can think of this poem going both directions

Making decisions for incompetent patients: How?

- Subjective standard: explicit pt choice
- Substituted judgment: through discussion
- Best interest of the patient
 - Guided not by patient's preferences but by his/her interests
- AMA Code of Medical Ethics
- "if there is no reasonable basis on which to interpret how a patient would have decided, the decision should be based on the best interests of the pt, or the outcome that would best promote the pt's well-being. include the pain and suffering associated with treatment. Any quality of life considerations should be measured as the worth to the individual...and not as a measure of social worth."

Typical story: hospitalized 104 days prior to death

- Pt. is not in a persistent vegetative state, has no fatal disease such as terminal cancer, conditional waxes and wanes, and whose end of life preferences are unknown.
- Care of non verbal persons with severe chronic, developmental, neurologic, and orthopedic disabilities requires vigilance
- Serious complications can supervene for a seemingly curable condition

Clear and convincing evidence

- Supreme court ruling curbing conservator's right to remove life support
- Medical opinion is what counts the most to determine the patient's best interests
- Tools to assist: Go Wish cards?
- Solid teamwork, incorporating persons that know the individual well.

Best interest standard

- Determination of greatest net benefit
- Focuses primarily upon the current and future interests
- Heavy focus on quality of life
- Favorable balance of simple pleasure or contentment over pain/discomfort, minimizing pain and suffering
- Prolonging life can effect burdens that are often disproportionate to any benefits that person receives
- Goals: Restorative, supportive, palliative

QOL Judgments

- Social worth or interpersonal judgments
 - Makes comparative value to the life of an individual
 - Ranks worth of individual relative to worth of others
- Intrapersonal or con-comparative judgments
 - According to value or quality of an individual's life to that individual
 - Regardless of how society or other calculators of social utility evaluate it.

Intrapersonal QOL

- Very Well circumscribed
 - Not whether QOL is below average
 - Not whether QOL is worse than it used to be
- Only whether quality of patient's life will be so poor as to be not worth living or worse than no further life at all

AMA Code of Medical Ethics

E-2.17 Quality of Life

- "In the making of decisions for the treatment of seriously disabled...persons...the primary consideration should be what is best for the individual patient and not the avoidance of a burden to the family or to society. Quality of life, as defined by the patient's interests and values, is a factor to be considered in determining what is best for the individual. **It is permissible to consider Quality of Life when deciding about life-sustaining treatment.**"

Looking back at the original case

- 62 yo man with severe DD admitted from group home: resident for 10 years
- Lived with mother, then sister, 30 yrs
- Sister's visiting reduced lately; CA DX: turned guardianship over to State with her health decline
- Pt. non-communicative and no interaction with anyone for past 6 months. Stopped eating 4 days PTA
- DX: CVA and status epilepticus-multiple consults predict no recovery to baseline level of function
- Sister has strong interest in comfort measures
- Guardian hasn't been involved that long, has contacted MAP, they demand feeding tube, continued treatment

New York: model in collaboration

- NYSARC: grant provided by the New York State Developmental Disabilities Planning Council
- in collaboration with the Hospice and Palliative Care Association of New York State, NYSARC Inc., the Center for Excellence in Aging Services at the State University of New York at Albany, and the Office of Mental Retardation and Disabilities of New York State (OMRDD)

Steps they have taken

- Recognize the role of collaboration
- Grant secured
- Organized approach to education
- Community networking
- Final steps were statute change
- They have presented nationally

Montana's Needs

- Recognize the role of collaboration
- Prioritize the needs, Identify the stakeholders,
- Secure funding (grants, private)
- Organized approach to education and
- Community networking
- Statute change
- Other??

Quality of Life and Death

- Decisions are made with person, their Family, possibly care-providers
- The transition from curative to palliative is well managed
- Death occurs at home or in a homey, familiar setting
- Relationships are maintained right up until death
- Physical and psychological distress is well managed through the disclosure of the prognosis and the involvement of the person and their family, medication management is tailored to the individual.
- Everyone works together from the same guiding principles.

Resources

- Montana Code Annotated: 75-5-321,
 - MCA 50-9-106
 - Fast Facts# 192 and 193
 - End of Life Care for a Man with Developmental Disabilities: Journal AM Board Fam Pract. 16 (1) 58-62 2003
 - New York Code NY CLS SCPA 1750 (2007)
- Draft of Thomas Dooling's White Paper, MAP
- "Palliative Care and people with learning disabilities" Learning Disability Practice 6,7, 30-37
- Deciding for Others" The Ethics of Surrogate Decision Making
A. Buchanan and Dan Brock 1989

A true leader in the Field

- **Developmental Disabilities: The New York Policies Larry Faulkner**
- *Lawrence R. Faulkner is the General Counsel and Director of Quality Assurance at Westchester ARC. Prior to this position, he was the Deputy General Counsel for the New York State Office of Mental Retardation and Developmental Disabilities.*
- *NYSARC office: Nan Cannon, Erica Berman*
