

When the Time Comes: Collaborative Practices for End of Life Care



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Guardians, Advocates, Care givers and Family members:



We must consider

To be true friends and prevent suffering we must engage those for whom we hold responsibility with intimate concern.

Intimacy is prerequisite to discussing death. Intimacy takes both our time and skill. It is earned.

Death is an event best planned and prepared for among intimates before death arrives.

The law and the rules are there to protect. But only we, the caring human beings, can prevent unnecessary suffering.

objectives



- ❧ Review the hospice benefit, conditions of participation
- ❧ Review interdisciplinary functioning
 - ❧ General population
 - ❧ Persons with I-DD

Review unique needs and interface with care-givers, patients and families of persons with Developmental Disabilities

Why is Hospice so important for this population?

- ❧ Unique needs
- ❧ Unique, interdisciplinary model of care
- ❧ A service that reaches out to the “family” (care-giver team) as part of the unit of care

“Dying Well”



- ❧ Dignity
- ❧ In Control, Comfortable, Sense of Closure
- ❧ Affirmation/value of dying (redefinition of time, space, life and death.)
- ❧ Personhood recognized
- ❧ Trust in providers
- ❧ Recognition of impending death
- ❧ Beliefs and values honored
- ❧ Burden minimized, Relationships optimized
- ❧ Appropriateness of death
- ❧ Leaving a legacy, Family Care

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 care.....prior to hospice
- ❧ Increased need for advance care planning

Housing Trends



- ❧ Past decades
 - ❧ Decreased institutionalization
 - ❧ Mainstreaming of I-DD 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? Can they stay where they are known, and understood?

Further issues concerning medical and palliative care for I-DD



- ❧ Lack of full comprehension of their illness, symptoms or treatments
 - ❧ May interpret illness **or treatments** as punishment for wrongdoing
 - ❧ May not understand death and why their family/c/g's are sad
- ❧ Symptom assessment may be 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
 - ❧ Potential for inadequate death education, often excluded from funerals, memorial services

The Hospice Benefit



- ❧ The team and their roles
- ❧ Communication among the interdisciplinary team
- ❧ Patient/Family centered approach to care
- ❧ Hospice planning process

Supporting the life that is

- ☞ Data is beginning to show that palliative care extends life.....
 - ☞ Symptom management
 - ☞ Reduction in hospitalization
 - ☞ Support for spiritual, emotional, social :
whole person care
 - ☞ Support for care-giving team

The Hospice Planning Process

- ❧ IDT: a meeting of all disciplines
- ❧ Documentation: supporting collaboration
- ❧ Making a referral
- ❧ Communication strategies
 - ❧ Barriers to effective communication
 - ❧ Barrier-breaking: extending the team

Medicare's expectations



- ❧ Mandated appointment of hospice case management in the care and oversight of the dying person
- ❧ The role of the hospice team in providing support to other healthcare providers
- ❧ The role of the hospice in providing education for healthcare professionals during the dying process
- ❧ Who to approach when there are concerns about communication related to the care of a hospice pt.

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 or benefit be sustained long enough to warrant the duration of therapy, given the experience to the disabled person?

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

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
- ❧ Use of chocolate, aroma therapy, soft textures

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

Bringing it all together



- ❧ Palliative care and Hospice as a resource before dying
 - ❧ Hospice as a resource during the last phase of living
 - ❧ Teaming with existing resources
 - ❧ Hospice as a resource for the bereaved
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- ❧ Questions?