



Hospice, Palliative Care, and the Journey of Huntington's Disease

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Objectives

- Review potential routine and urgent indications prompting a discussion about end of life
- Recognize feelings of loss and grief as integral to the conversation
- Introduce the possibility of a different model of care
- Offer the potential guidelines relative to a palliative approach and hospice care for Huntington's disease

- Youth -oriented society
- High expectations of health and life
- Dying is not promoted as having significant social value
- Dying is often an isolated aspect of the daily world
- Death is excluded from most people's experience of growing up.
- Death within the construct of home is infrequent

- Model of care is primarily curative/restorative
- 80% of deaths occur in hospitals or extended care facilities
- Only 20% have completed an advance directive
- < 10% have hospice care
- Palliative/end of life care is not readily discussed

- Treatment complications
- Treatment fails
- Unmanageable side effects
- Significant change in functioning
- Life threatening event
- Individual decides to discontinue treatment

- Palliative approach
- Healing, body mind and spirit
- Opportunity for growth and closure
- Find meaning and maintaining connection
- Commit to face the unknown together
- Death as a natural end of the life cycle

Palliative care is the comprehensive, interdisciplinary care, focusing primarily on promoting quality of life for patients living with a terminal illness and for their families. Key elements for helping the patient and family live as well as possible in the face of life-threatening illness include assuring physical comfort, psychosocial and spiritual support, and a provision of coordinated services across various sites of care.”

J.A.Billings, MD

“Less attention.....is paid to caregiver grief, that relentless, ongoing process that is brought about, not by a loved one’s death, but by the changed aspects of their life, and inevitability of our own.”

Caregiver quote



Palliative and hospice care philosophy

- Support and care across settings
- Promotes “living until you die”
- Focus on quality of life
- Patient choice is the focal point
- Patient and loved ones are unit of care
- Bereavement after care for those surviving the death

General Goals of Patients

- Control over treatment and choices
- Emotional and spiritual support
- Maintaining quality of life, relative to course of disease
- Effective pain and symptom management
- Safety net for loved ones

Considerations for a palliative approach

- Goals and values of treatment:
 - Prolonging life
 - Quality of life
- Potential Interventions:
 - Advance Directive
 - Life sustaining therapies
 - Palliative care
 - Code status

Curative

- Diagnosis of disease & related symptoms
- Restorative focus
- Treatment
- Alleviation of symptoms

Palliative

- Patient/family identify their end-of-life goals
- Address how symptoms, issues are helping/hindering attainment of goals
- Interdisciplinary plan of care
- End-of-life goals.



When does the conversation begin:

Urgent Indicators

- Imminent death
- Patient talks about wanting to die
- Inquiry about hospice
- Re-admissions for severe progressive illness
- Severe suffering and poor prognosis

Routine Indicators:

- Discussing prognosis
- Treatment success low
- Addressing hopes and fears
- Physician/team would not be surprised if death occurred < 6-12 months

Process that requires:

- Understanding
- Reflecting
- Discussing
- Formulating a plan

And takes into account,

- individual's current health status
- values and goals



How to begin the conversation

“What are you hoping for”

“ What do we need to prepare for?”



“Hospice care has been one of the great counter cultural revolutions of the modern world. What hospice has brought to the medical community is nothing less than a re-awakening of our too long dormant humanity in the face of anonymous technology. Hospice insists that death is a natural phenomenon that must be respected when it cannot be reasonably forestalled. This vision has saved thousands of patients’ and their families the indignity of a painful technological, institutional death.”

Walter Hunter, MD



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Huntington's Disease General Guidelines/Criteria for the Hospice Benefit

- Physician's exam within 3 months
- Disease progression within the past 12 months includes:
 1. Transition from independent ambulation to w/chair, or bed
 2. Transition from independence in all or most ADL's to requiring assistance in all ADL's
 3. Critical nutritional impairment
 4. Life-threatening complications
 5. Karnofsky Performance Status <50 % in the following areas:
 - Ambulation
 - Activity
 - Self-care
 - Intake
 - Level of consciousness

- Choices differ based on information
- Individuals and their loved ones are able to make informed decisions
- Clinicians must obtain informed consent
- Hospice is an entitlement
- It's the right thing to do

- Right to know the truth
- Right to consent to or refuse treatment
- Right to expert care
- Right to confidentiality and privacy
- Right to control environment and setting
- Right to determine plan after death

- To take joy in simple pleasures
- To heal and mend relationships
- To share time with those you cherish
- To leave a legacy of your choosing
- To be in touch with one's spiritual self
- To plan a memorial /funeral of your choice

- The circle of life includes death
- The human experience at the end of life is enormously valuable
- Hope is vital, changes as circumstances change
- Each person has the capacity of acceptance, forgiveness and love
- Life perspective that embraces the beginning and the departure

“Hope is frequently defined as the expectancy of good in the future. When a patient’s future is defined in months or even hours, physicians who equate hope with cure, must acknowledge the dynamic and changing nature of hope and how it changes during the dying process. Physicians are urged to face the challenge of balancing honest communication with maintaining hope.”

Paul Rosseau, MD

- National Hospice and Palliative Care Organization
www.nhpco.org
- Pennsylvania Hospice Network
www.phn.pahospice.org
- Promoting Excellence in End of Life Care
www.promotingexcellence.org
- Center to Advance Palliative Care
www.capc.org
- Family Hospice and Palliative Care
www.familyhospice.com