

Palliative Care Opportunities

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Poll

Palliative care is consulted when doctor's give up hope for a cure.

Objectives

- Define pediatric palliative care (PPC) as a set of tasks
- Identify predictable opportunities for palliative care intervention at different stages of disease
- Evaluate myths and assumptions about PPC

What is Pediatric Palliative Care?

Pediatric Palliative Care prevents, identifies and treats suffering in children with serious illnesses, their families, and the teams that care for them. It is appropriate at any stage of the illness, and can be provided together with disease-directed treatment.

What are the tasks involved . . .

Suffering requiring communication:

- Identifying problems and challenges
- Understanding illness
- Exploring hopes/Setting goals
- Advanced care planning
- Making decisions

. . . What are the tasks involved . . .

Suffering requiring care coordination:

- Collaborating with other providers/specialists
- Facilitating logistics of medical and social needs
- Partnering with community programs
- Identifying community resources

... What are the tasks involved

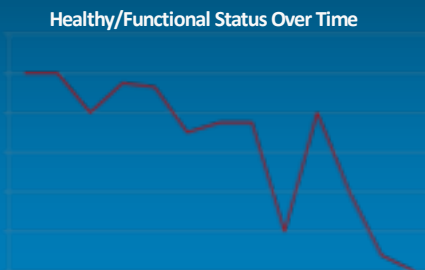
Suffering requiring interventions:

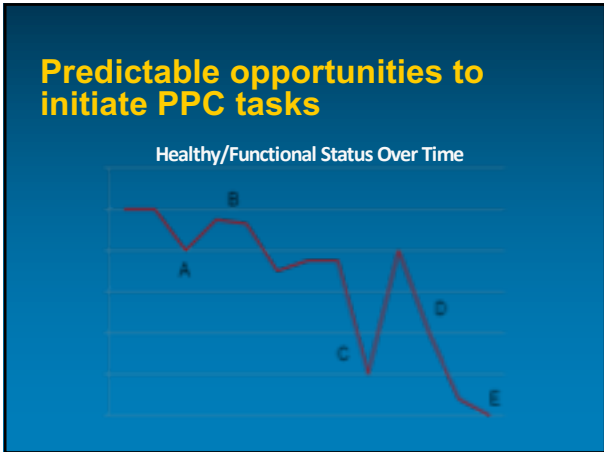
- Physical suffering
- Psychosocial suffering
- Spiritual suffering
- Bereavement
- Family support
- Team support
- Community support

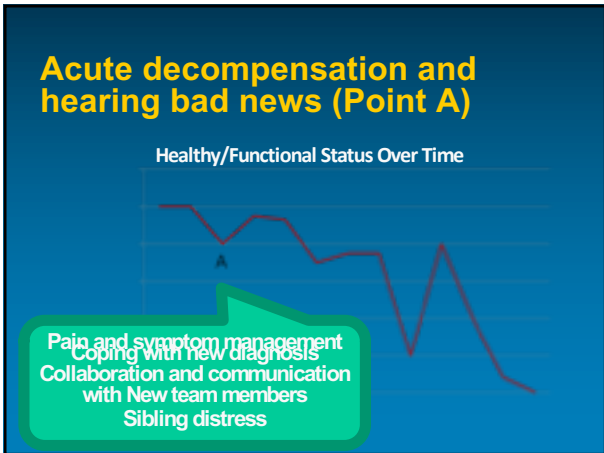
Meet Jake and His Family

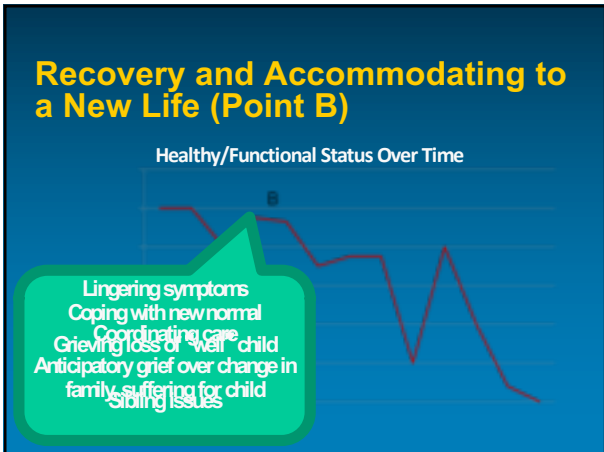
Jake is a 15 yo male with a several month history of leg pain that he and his family thought was related to the year round soccer that he has been playing. He was seen by his pediatrician several times but his parents became worried when it prevented his participation in soccer. They went to Ortho Now where x-rays showed a mass in his femur. Jake was admitted to the general pediatrics service and oncology was consulted.

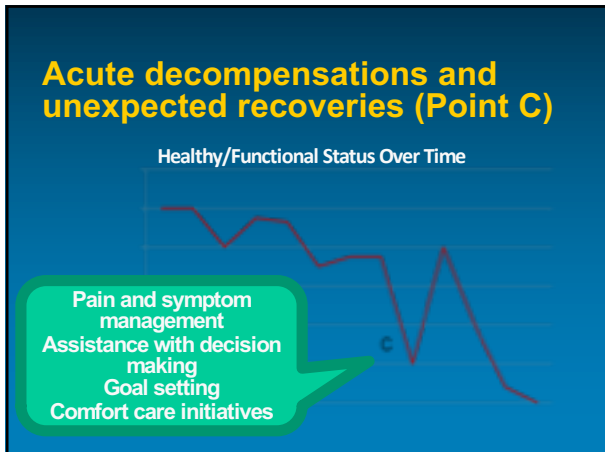
A child's suffering:

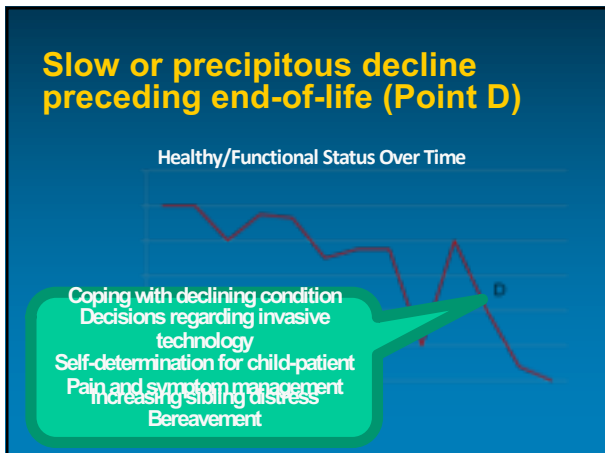


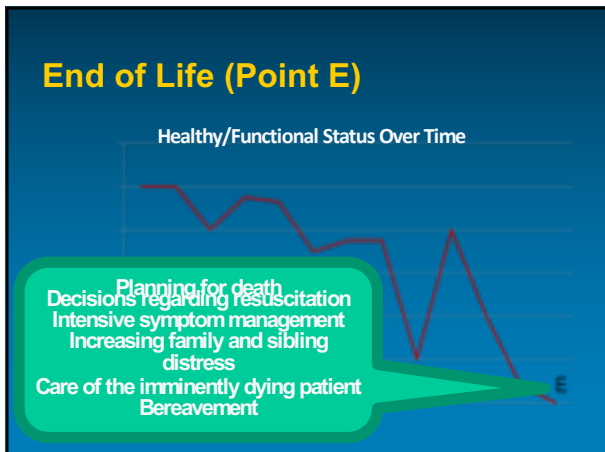


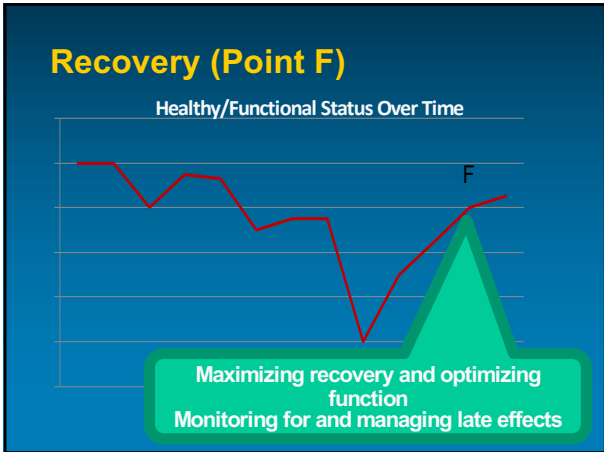








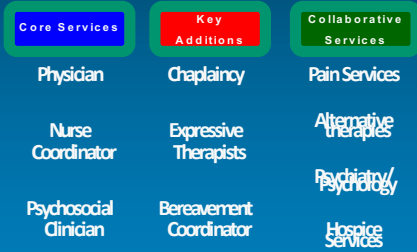




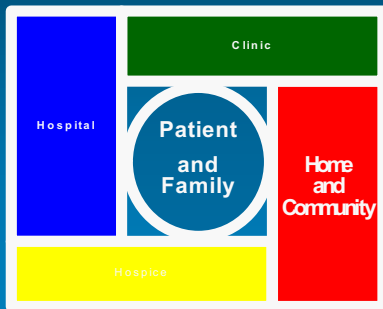
- ### The family experience as context
- Stress and anxiety
 - Multiple demands
 - High degrees of uncertainty
 - Balancing hopes for a good outcome with fears of a bad one: death
 - Pressures last months to years and can erode resilience

- ### Impact of pediatric palliative care
- Children with serious illnesses and their families benefit from PPC
 - Earlier initiation of PPC improves symptom management & quality of life
 - May lead to prolonged life

Who provides PPC services?



Where are PPC services offered?



Myths in palliative care and hospice . . .

1. Palliative care = hospice = giving up hope
2. Child must be terminally ill or at the end of life
3. Only for children with cancer
4. Must abandon all disease-directed treatment

. . . Myths in palliative care and hospice

- 6. Must abandon primary treatment team
- 7. Child will die sooner/lose hope if PC introduced
- 8. Administering opioids causes respiratory depression and quickens death

**Changing attitudes:
Early integration of palliative care . . .**

- Care should be integrated at diagnosis
 - Provides focus of disease and suffering in all stages
 - Provides necessary supports to help families cope
 - Prevents perception of transition in care or abandonment

Introducing palliative care to families

- Introduce as close to diagnosis as possible
- “The part of care for kids with serious illness that focuses on:”
 - Helping patients and families manage the symptoms and stress of serious illness
 - Providing an extra layer of psychosocial support
 - Spending the time with patients and families necessary to help them understand disease and treatment

The language of PPC . . .

- Interdisciplinary
- Life-threatening, not just life-limiting
- Children range in age from prenatal to young adult
- Family (biological, adoptive, foster, etc) core to decisions

. . . The language of PPC

- Surrogate decision making
- Benefits/Burdens
- Goals of care
- AVOID: Withdrawal of support/care/treatment
- Transition to focus on quality and comfort

Summary

- Think about appropriate times to integrate the palliative care team
 - Bad news/overwhelmed at diagnosis
 - Phase I enrollment
 - Relapse/recurrence
 - Serious complications
 - ICU admissions/transfers
 - Change in technology (new trach)
 - Listing for transplant

EPEC - Pediatrics

**The Education in Palliative and End of Life Care:
EPEC-Pediatrics**

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