Newborns to Adolescents:

A family centered approach to addressing the changing psychosocial needs of children with life-threatening diseases
Understanding Children and Death

Depends on the child’s:

- Developmental level
- Concept of death
- Life experiences
- Personality
Theories of Childhood Death

Nagy (1948)
- 3 developmental stages
  - Stage 1: Death is not final (<5yo)
  - Stage 2: Death is final but avoidable and not inevitable (5-9yo)
  - Stage 3: Death is final and inevitable (>12y)

Speece and Brent (1984)
- 4 concepts
  - Irreversibility, Finality, Universality, Causality
Child’s perception of death

American Academy of Pediatrics, Pediatrician and Childhood Bereavement; PEDIATRICS, volume 105, number 2, February 2000

- **0-2 years** - death perceived as separation and abandonment; no cognitive understanding of death

- **2-6 years** - death is reversible/temporary, may be seen as a punishment; Magical thinking that wishes can come true

- **6-11 years** – gradual understanding of irreversibility and finality. Specific death of self difficult to understand

- **>11 years** – death is irreversible, universal, inevitable. All people and self must die, although latter is far off. Abstract and philosophical reasoning
Child’s concept of death – ways to illicit conversation

- **Bluebond – Langner** “seriously ill children become aware of their mortality even in the event of deception”
  *The Private Worlds of Dying Children, 1978*

- Q & A: Listen for *unasked* questions
- Avoid confusing euphemisms
- Use nonverbal expressions – art, play & storytelling
- Allow children to see your sadness
- Teach parents to overcome reflex to shield their child from “*bad things*”
“Talking about death with children who have severe malignant disease”

- 449 of 561 eligible parents responded
- 147 of 429 reported speaking to their child about death
- None regretted having the conversation
- 69 (27%) of 258 parents who did not talk with their child about death regretted not having done so
- Parents who sensed that their child was aware of his/her imminent death were more likely to regret not having talked about it (47% vs. 13%)

*Kreicbergs U et al. NEJM, 2004*
What the literature says

- No prospective studies looking at effects of conversation and communication on patient, siblings, parents

- Some retrospective surveys indicating that parents value clear communication about what to expect at the end of life (*Troug et al, 2006, Mack et al, 2005*)

- Small case series indicating that siblings of children who die of cancer lack support and may benefit from more direct communication with the medical team (*Nolbris M J 2005; Finke LM 1992; Wilkins KL 2005*)
One study of Parents’ priorities and recommendations

- 56 parents of children who died in pediatric intensive care units in 3 Boston hospitals

- Parents identified 6 priorities for pediatric end of life care
  - Honest and complete information
  - Ready access to staff
  - Communication and care coordination
  - Emotional expression and support by staff
  - Preservation of the integrity of the parent child relationship
  - Faith

Meyer EC, Ritholtz MD, Burns JP Troug RD; *Pediatrics* March 2006
What defines a Family Centered Approach to Care?

- Acknowledges the role of the family in the child’s care
- Encourages collaboration between patient, family and health care team
- Honors patient and family strengths, cultures, traditions and expertise
- Supports and facilitates choice for child and family about approaches to care and support

AAP Policy Stmt 2003
Family Centered Care

- Can improve patient and family outcomes
- Increase patient and family satisfaction
- Increase professional satisfaction
- Decrease health care costs
- Is proactive not reactive
- Encourages a healthy environment
Incorporating family centered care

- How can this model of care be incorporated into the psychosocial care of children with life limiting diseases and their families?
  - Open effective communication
  - Addressing issues specific to child and parent
  - Specifically addressing sibling needs
  - Utilizing multidisciplinary team structure to individualize care plan
Communication

- Maintaining hope is essential
- Ability to reframe hope essential
When talking to children about death:

- Be mindful of their developmental level
- Choose medium most easily used by the child including:
  - non-verbal communication
  - symbolic language
  - art
- Lack or misinformation may lead to anxiety and/or fear
Communication

- Inherent desire to protect may result in constricted communication
- Children often know intuitively
  - Encourage parents to prepare child and sibs
- Maintain trust through honest communication
Communication to elicit spiritual & cultural context

- How do you understand your child’s illness?
- What is the meaning of pain and/or suffering for your family?
- What is your child’s understanding of his/her illness?
- What have you told your other children about the illness?
Child Issues

- **Information**
  - Parent’s desire to protect may deny facing reality and meaning making
- **Social isolation from siblings & peers**
- **Feelings of loneliness and anxiety**
- **Grieve loss of normal life and experiences**
- **Facing pain, physical & emotional symptoms**
**Child Issues**

- **Facing mortality,**
- **Legacy building,**
- **Complications of adolescents & young adults**

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**Tayli’s List**

<table>
<thead>
<tr>
<th>Preference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tayli doesn’t want to be on a ventilator.</td>
</tr>
<tr>
<td>Tayli doesn’t want head gear (no halo)</td>
</tr>
<tr>
<td>Tayli wants an ambulance to the hospital and home (with sirens on!)</td>
</tr>
<tr>
<td>Tayli doesn’t want a walker</td>
</tr>
<tr>
<td>Tayli doesn’t want to worry</td>
</tr>
<tr>
<td>Tayli wants food</td>
</tr>
<tr>
<td>Tayli doesn’t want to be afraid</td>
</tr>
<tr>
<td>Tayli doesn’t want to be in pain</td>
</tr>
<tr>
<td>Tayli wants visitors on request by name only.</td>
</tr>
<tr>
<td>Tayli wants oxygen and an oxygen monitor</td>
</tr>
<tr>
<td>Tayli wants speech therapy when needed and when not needed</td>
</tr>
<tr>
<td>Tayli wants lots &amp; lots of cuddle time with Mom</td>
</tr>
<tr>
<td>Tayli wants to walk (by Christmas) independently</td>
</tr>
<tr>
<td>Tayli wants pink everything</td>
</tr>
<tr>
<td>Tayli wants a cure - even an experimental treatment.</td>
</tr>
<tr>
<td>Tayli doesn’t want the doctors to start her heart again if it stops.</td>
</tr>
<tr>
<td>Tayli wants to believe in God.</td>
</tr>
<tr>
<td>Tayli wants all conversations in front of her.</td>
</tr>
<tr>
<td>Tayli never wants to be lied to.</td>
</tr>
<tr>
<td>Tayli wants Mom to keep reminder her about her list and her goals and victories.</td>
</tr>
</tbody>
</table>

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# Range of Common Grief Manifestations in Children and Adolescents

### AAP February 2000

<table>
<thead>
<tr>
<th>Normal or Variant Behavior</th>
<th>Potential Symptoms of Complicated Grief</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shock or numbness</td>
<td>Long-term denial and avoidance of feelings</td>
</tr>
<tr>
<td>Crying</td>
<td>Repeated crying spells</td>
</tr>
<tr>
<td>Sadness</td>
<td>Disabling depression and suicidal ideation</td>
</tr>
<tr>
<td>Anger</td>
<td>Persistent anger</td>
</tr>
<tr>
<td>Feeling guilty</td>
<td>Believing guilty</td>
</tr>
<tr>
<td>Transient unhappiness</td>
<td>Persistent unhappiness</td>
</tr>
<tr>
<td>Keeping concerns inside</td>
<td>Social withdrawal</td>
</tr>
<tr>
<td>Increased clinging</td>
<td>Separation anxiety</td>
</tr>
<tr>
<td>Disobedience</td>
<td>Oppositional or conduct disorder</td>
</tr>
<tr>
<td>Lack of interest in school</td>
<td>Decline in school performance</td>
</tr>
<tr>
<td>Transient sleep disturbance</td>
<td>Persistent sleep problems</td>
</tr>
<tr>
<td>Physical complaints</td>
<td>Physical symptoms of deceased</td>
</tr>
<tr>
<td>Decreased appetite</td>
<td>Eating disorder</td>
</tr>
<tr>
<td>Temporary regression</td>
<td>Disabling or persistent regression</td>
</tr>
<tr>
<td>Believing deceased is still alive</td>
<td>Persistent belief that deceased is still alive</td>
</tr>
<tr>
<td>Adolescent relating better to friend than to family</td>
<td>Promiscuity or delinquent behavior</td>
</tr>
<tr>
<td>Behavior lasts days to weeks</td>
<td>Behavior lasts weeks to months</td>
</tr>
</tbody>
</table>
Siblings’ Needs and Issues When a Brother or Sister Dies of Cancer
Nobris et al. Journal of Oncology Nursing 2005; 22, 227

- Questionnaire/ interviews
- Sibling age ranged 10-30 years
- 6 common themes emerged
  - Dissatisfaction with information and support
  - Loneliness
  - Expressions of anxiety>anger>jealousy
  - Need to find place of refuge
  - Mourning not continuous. Needed “time out” periods from grief
  - Positive memories of dead sibling
    - Bond between siblings remained
    - Needed other places than grave to remember sibling
Sibling care

- Encourage siblings to ask questions
- Provide age appropriate honest information
- Create safe place to talk about feelings and worries
- Share your own feelings and worries
- Involve siblings in decision making whenever possible
- Let siblings help out
- Encourage normal activity
- Keep things consistent

- American Society of Clinical Oncology
Issues for Parents

- Intense & complex emotions-
  - pre-morbid mental health issues relevant
- Anticipatory grief
- Need to provide emotional support and information
  - for siblings, grandparents, cousins
  - Community, school, church, groups
- Intense & complex decision-making needs complicated by
  - Relationship of parents/guardians
  - Deciding for child
- Increased demand to negotiate
  - With medical system
  - Social service system
- Uncertain path of life-limiting illness-often chronic
- Death = ultimate failure of parent
Maintaining parental roles

- **Helping parent remain present**
  - Providing emotional care in face of physical care giving needs
  - Focus on whole child, not just illness

- **Maintain family integrity**
  - Nurture the playfulness/joy of child
  - Encourage “routines” i.e. Wednesday night dinners, school, church
  - Maintain family celebrations, rituals
  - Encourage sibling involvement
Memory Making

- Infant
  - Encourage normal parent roles – bathing, holding, feeding
  - Consider creative memory making – trips to garden/museum
  - Tangible memories – hair/hand-foot prints/
  - Encourage photos/videos/creating a scrap book
  - Involve siblings
Memory Making - School aged children

- Finding ways to continue the “work” of school – adapt as needed
- Keeping social networks active
- Provide honest/developmentally appropriate information to create opportunity
- Normalize routines/celebrate holidays/create special events
- Use multiple media to help children acknowledge who they are and how they want to be remembered
- “I don’t want to be forgotten”
- Involve siblings
Adolescents

- Find ways to maintain relationships/peer importance
- Keep connections with school
- Find ways to support independence in context of increasing dependence
- Encourage writing/journaling – create lists of “what I want” or “How I want to be remembered”
- Maintaining physical appearance and normal teenage activities (make-up, trip to the mall, trip to school, sporting events)
Examples of child specific therapies

- Play therapy can be a useful tool in assisting children and adolescents in expressing their feelings associated with hospitalization, illness, death.

- Child life specialists develop a therapeutic relationship where patients feel safe expressing their fears.
Even very young children can express their feelings through art

A 4 year old with refractory leukemia painted the picture on the left on a day he was feeling particularly badly. After he was finished he told the therapist he wanted a picture of something that looked better than he felt and had her draw a picture of his house. He told her what to draw and what colors to use.
School aged children can express their negative feelings about their illness in appropriate ways.

This was done by a child with cancer who drew a picture of planes bombing the hospital. The child in the middle was done so people knew he only wanted the building destroyed and that all the children were safe.
Play and Art can be used as tools to help siblings connect and communicate.

These were done by sisters the older of which had refractory AML. She was 9 and her sister was 5. They were separated during a long hospitalization and these were done on a day they could spend together.

The child with cancer soon after drew a picture for her school of a girl going to heaven in a hot air balloon.
Examples of child specific therapies - Music

- Considered an important part of a child life program
- Some nonrandomized studies indicate benefit to child’s comfort during hospitalization for pediatric cancer (Barrera, 2002)
Summary

- Using a family centered approach is essential in caring for children with life limiting illnesses.
- It’s important to consider a child’s developmental level in communicating with children and families about illness and death.
- Parents need guidance in maintaining their parental roles.
- Specific tasks can be used to help families and children communicate.
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