1. **Demographics of Childhood Deaths**
   - Age 0-1: 30,000 annual deaths
     - Congenital abnormalities, prematurity, perinatal events, SIDS
   - Age 1-14: 14,000 annual deaths
     - Trauma, cancer, congenital conditions
   - Age 15-21: 16,000 annual deaths
     - Trauma, cancer, heart disease

2. **Differences from Adults**
   - Relative rarity
   - Epidemiology/etiology
   - Interpersonal dynamics
   - Developmental/communication issues
   - Legal/non-autonomy issues
   - Symptom measurement tools
   - Symptom management tools
   - School/community issues
   - Acuteness/suddenness
   - Bereavement issues

3. **Goals of Palliative Care**
   - Optimal living in the face of life challenge/limitation
   - Child- and family-focused service
   - Care at home, limiting hospitalization
   - Balance between sustaining life/attempts at cure and relieving suffering
   - Consistency of care by the same interdisciplinary team
   - Holistic education of professional and lay caregivers
   - Enhancing comfort of professional and lay caregivers

4. **Tasks of Palliative Care Team**
   - Establishing a child and family care plan
   - Minimizing symptoms
   - Assisting in child’s and family’s grief work
   - Facilitating conflict resolution
   - Optimizing the child’s quality of life
   - Supporting the parents, siblings and friends
   - Educating the child, family and caregivers
   - Minimizing hospital time as far as possible
   - Bereavement counseling
   - Facilitating closure for professional caregivers

5. **Reimbursement Issues**
   - Reimbursement mechanisms very limited
   - Time-intensive counseling, education, advocacy, family support, communication: either limited or no reimbursement
   - Federal and state initiatives (eg, Florida’s Partners in Care) are under development
6. Ways to Support a Seriously Ill Child
~ Take time to listen empathetically to child and family individually and together
~ Acknowledge the child’s understanding and decision-making ability
~ Let the child control the conversation and set the pace
~ Give detailed explanations when asked about the illness, prognosis, dying process, etc
~ Be truthful; use simple concrete language
~ Acknowledge one’s own feelings
~ Use art, music, stories, play
~ Verify a child’s understanding
~ Be ready for strong emotion strongly expressed

7. Language
~ The concept of hospice care may be rejected, and especially “terminally ill” label
~ “Palliative”, “supportive”, “advanced”, or even “home care” may be preferred

8. Approaching the Concept of Palliative Care
~ Acceptance of a final illness and failure of life-sustaining measures is especially hard in pediatrics
~ Therefore this is likely to involve a gradual process with repeated conversations
~ The palliative care team is best introduced early, often at diagnosis, to children and families facing the probability of incurability
~ The transition from the intensive care team to the palliative care team should be as gradual and smooth as possible
~ The traditional “less than 6 months prognosis” is not relevant to pediatric palliative care
~ The extent of palliative care team involvement can vary widely and is dictated entirely by the child’s and family’s needs and wishes
~ The child’s involvement, as developmentally appropriate, in planning and decision-making is essential
~ The palliative care option should never be seen as “doing nothing” or “giving up hope”
~ It is quite possible for a child and family to be discharged from palliative care services if the outcome proves unexpectedly favorable

9. Ethical and Legal Issues
~ “Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.”
~ Legalities, practicalities and realities will often seem in conflict
~ Development of the child’s sense of autonomy varies broadly, especially in the teenage years
~ The child’s decision-making capacity can be assessed by offering developmentally appropriate explanations and choices, then asking the child to restate the information in their own words; chronically ill children often have understanding and decision-making abilities well beyond that of age-matched peers
~ Factual information, good communication, and caregiver availability to the child and family are key
~ Relief of suffering and provision of physical, psychological and spiritual comfort are of overriding importance
~ NIH mandates that children aged 7 or older must provide assent to participate in experimental treatments
~ In obtaining informed consent/assent physicians must be completely prepared to accept refusal to participate and must avoid at all times all forms of coercion
~ Baby Doe: Federal regulations require continuing life-sustaining measures to infants less than 1 year, regardless of the projected quality of life, unless the infant is permanently comatose or imminently dying. However, if the condition is irreversible, life-sustaining treatment is not required, and palliative care is an appropriate alternative.
References:


Liben S: Pediatric Palliative Medicine, Journal of Palliative Care 12, 24-28, 1996.