



# PEDIATRIC PEARLS:

Working in Pediatric Hospice and Palliative Care with Confidence

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# Objectives

- To learn at least three concrete tools for increasing comfort in working with children with life-threatening and life-limiting illness and their families.
- To learn memory-making resources and activities for children with life-threatening and life-limiting illness.
- To learn 2-3 methods of self-care while working with children with life-threatening and life-limiting illness and their families.



# Who we are and what we do



# Hospice By the Bay Offers

- Palliative Care and Hospice Services
- Bereavement Counseling for youth and adults
- By the Bay Camp for grieving children and teens

**By the Bay Kids** is the pediatric program at Hospice By the Bay



# Who is on our Team

- Physician
- Nurse
- Social Worker
- Expressive Therapists: Massage, Music, Art, and Child Life Specialist
- Spiritual Support Counselor
- Home Health Aide





# What makes pediatric palliative care unique?

- Concurrent care (hospice)
- Involvement of family/caregivers
- Involvement of providers
- Qualifying diagnoses (palliative)
- Life expectancy



# The sad reality



# Mortality Rates and Causes for Children (ages 0-19 years) in the US

41,881 deaths in 2015

## **Under age 1 – 23,215 deaths**

- Congenital malformations / Genetic abnormalities
- Short gestation/low birth weight
- Maternal complications

## **1-4 years – 3,840 deaths**

- Accidents
- Congenital malformations / Genetic abnormalities
- Homicide





# Mortality Rates and Causes for Children (ages 0-19 years) in the US

41,881 deaths in 2015

## 5-14 years – 5,250 deaths

- Accidents
- Cancer
- Suicide

## 15-19 years – 9,586 deaths

- Accidents
- Suicide
- Homicide



# What are some challenges to providing pediatric palliative care?



# Potential Challenges

- Provider apprehension
- Provider lack of knowledge/understanding
- Perception of “giving up”
- Misunderstanding of concurrent care
- Limited access to programs



# Working with Children

## Age-Appropriate Assessment



When you think of working with children,  
what feelings come to mind?





# Sources of information about the patient

- Chart review
- Consult with colleagues
- PARENTS (a critical source of information)
- The child
- Additional family and friends



# Skills adult and pediatric providers share

- Observational skills
- Assessment skills
- Communication skills
- Compassion
- Experience
- Education
- Working with multi-disciplinary team



# Differences in Pediatric vs Adult Patients

- Anatomy
  - Size
- Physiology
  - Metabolism
  - Resiliency
  - Variations in development
  - Unique childhood illnesses
- Self/world perceptions
- Meaning of death
- Supportive networks/family
- Decision-making
- Insurance/
- Access to care
- Autonomy



# Physiology

## Child

- Faster rate of metabolism
- Pristine-system functioning
- Developmental immaturity

## Adult

- Slower rate of metabolism
- Age-altered system functioning
- Development complete



Normal Heart Rate by Age  
(Beats/Minute)

**By comparison -**

**Adult average range:**

**60 - 100**

Age	Awake Rate	Sleeping Rate
Neonate (<28 d)	100 - 205	90 - 160
Infant (1 mo-1 y)	100 - 190	90 - 160
Toddler (1-2y)	98 - 140	80 - 120
Preschool (3-5 y)	80 - 120	65 - 100
School-age (6-11 y)	75 - 118	58 - 90
Adolescent (12-15 y)	60 - 100	50 - 90



## Normal Respiratory Rate by Age (Breaths/Minute)

**By comparison -  
Adult average range: 12-20**

Age	Normal Rate
Infant (<1 y)	30 - 53
Toddler (1-2y)	22 - 37
Preschool (3-5 y)	20 - 28
School-age (6-11 y)	18 - 25
Adolescent (12-15 y)	12 - 20



## Normal Blood Pressure by Age

**By comparison -**

**Adult average normal:  
Systolic <120  
Diastolic <80 (120/80)**

Age	Systolic Blood Pressure	Diastolic Blood Pressure
Birth (12 h)	60-76	31-45
Neonate (96 h)	67-84	35-53
Infant (1-12 mo)	72-104	37-56
Toddler (1-2 y)	86-106	42-63
Preschool (3-5 y)	89-112	46-72
School-age (6-9 y)	97-115	57-76
Preadolescent (10-11 y)	102-120	61-80
Adolescent (12-15 y)	110-131	64-83



# Symptom Management

- Diagnosis
- Specific patient history
- Current assessment
- Anticipatory concerns



# Developmental Stages



# Infants (0-1 year)

- Trust v. mistrust (Erikson)
- Major fears:
  - Separation from parents
  - Strangers (6 mo – 2 years approx)
- View of death: none
- Psychosocial
  - Recognize familiar faces
  - Use crying, facial expression and body language to convey wants and needs
  - Get pleasure from being held, rocked, feeding and tactile stimulation
  - No understanding of death, may be more fussy or clingy





# Tips and Techniques for Infants

- Minimize separation from parents
- Provide consistent caretakers
- Control parent / guardian anxiety, as possible
- Minimize stressors: loud noises, bright lights, sudden environmental changes
- Talk to them during your assessment in calm, quiet tones



# Toddlers (1-3 years)

- Autonomy v. shame and doubt (Erikson)
- Major fears:
  - Separation from caregivers
  - Loss of control
- View of death: not permanent
- Psychosocial:
  - Increasing independence, frequent use of 'No'
  - Egocentric, magical thinking
  - Poor concept of body integrity
  - Short attention span, one direction at a time
  - Expect exaggerated response to pain, frustration or changes in the environment
  - No understanding of death, may be more fussy or clingy



# Tips and Techniques for Toddlers

- Minimize separation from caregivers
- Prepare child immediately before procedure, not too far in advance
- DO NOT make promises you can't keep (“this won't hurt”, “this is the last time”...)
- Keep explanations simple, use play to explain and prepare
- Children will have a wide range of verbal skills



## Toddler tips continued...

- Loss of control and restriction of movement are threatening
- Use the least intrusive approach possible
  - Axillary temps
  - Oral medications
- Moods change quickly



# Pre-Schoolers (3-5 years)

- Initiative v guilt (Erikson)
- Major fears:
  - Bodily injury and mutilation
  - The unknown (the dark, being alone, etc)
- View of death: not permanent
- Psychosocial:
  - Highly literal interpretations; choose words carefully
  - Limited logical or abstract thought
  - Egocentric, magical thinking (jealousy, wishing for parents' full attention)
  - Increasingly social; initiates dramatic and imaginative play
  - Understand time, past and future
  - Think death is temporary / reversible
  - May regress during periods of illness or grief (aggressive, temper tantrums, nightmares)





# Tips and Techniques for Pre-Schoolers

- Keep explanations simple and concise
- Allow longer advanced preparation (hours to days)
- Continue to re-explain things every time they happen
- Reassure the child that he/she has done nothing wrong to ‘deserve’ pain or discomfort
- Assure them they will be cared for



## Pre-Schooler tips continued...

- Provide realistic explanation for what the child will experience during a procedure or assessment (don't underestimate discomfort if it will be present)
- Teach simple coping skills as possible
  - Distraction
  - Comforting self-talk
  - Imagery
- Allow time at the end of the interaction to allow the child to understand and integrate the experience



# School-Age (6-8 years)

- Industry v Interiority (Erikson)
- Major Fears:
  - Loss of control
  - Bodily injury and mutilation, disability
  - Failure to live up to the expectations of others
  - Concern for being 'different'
- View of death: magical thinking
- Psychosocial:
  - Concrete, literal and specific thinking
  - Beginnings of logical and deductive reasoning
  - May be unwilling to ask questions or to ask for help
  - Peer group increasingly important
  - Begin to understand death as permanent
  - May believe illness or death under their control (caused illness, failed to prevent...)
  - Interested in how the body works, may ask questions about body or death
  - May have more fears, nightmares, bodily complaints



# Tips and Techniques for School-Age

- Allow child to participate in care as much as possible
- Ask the child to describe their symptoms, pain and concerns
- Give permission to display fear or pain
- Offer support in potentially fearful situations



## School-Age tips continued...

- Assure that information is understood by asking for repeat back
- Use the least invasive approach possible
- Respect the need for privacy and normalcy of routine
- Support relationships with peers





# Late School-Age (9-12 years)

- Industry v Inferiority (Erikson) to Concrete Operational Thinking
- Major fears:
  - Mutilation / disfigurement
  - Separation from family or peers
- View of death: death is final
- Psychosocial:
  - Understand own mortality
  - Question concrete details, not emotional aspects
  - Difficulty expressing feelings (joking, acting “strong”, not crying)
  - Try to be good, “get it right”
  - Embarrassed to show emotion in front of their friends
  - Understand that death is part of life, begin to see how others are affected by death



# Tips and Techniques for Late School-Age

- Provide clear, unambiguous information
- Provide opportunities to express feelings, self expression
- Allow as many choices and as much control as possible
- Maintain contact with peer group as possible
- Teach coping techniques as appropriate
  - Relation
  - Deep breathing
  - imagery



# Adolescents (13-18 years)

- Identity formation v Identity confusion (Erikson)
- Formal operational thinking
- Major fears:
  - Change in appearance
  - Dependency
  - Loss of control
  - Separation from peers
- View of death: death is final
- Psychosocial:
  - Understand death as permanent, but conflicts with developmental stage
  - Beginning to understand concepts outside their own experience
  - Quest for independence from parents
  - May view illness in terms of change in appearance and abilities
  - Peers very important for support and social development
  - Tendency toward hyper-responsiveness to discomfort
  - Explosive emotions with or without trigger



# Tips and Techniques for Adolescents

- Allow adolescents to be involved in decision-making as possible
- Advance preparation (days to weeks) vital to their ability to cope
- Allow as many choices and as much control as possible
- Allow space for independence and reassurance of backup



## Adolescent tips continued...

- Maintain contact with peer group as possible
- Assess for depression, suicidal ideation
- Teach coping techniques as appropriate
  - Relaxation
  - Deep breathing
  - Imagery





# Helpful Strategies Engaging with Children



- Contact the child in you and proceed from there. That's the key to empathy with kids.
- Be genuine
- Build trust and rapport; this can take time (which we know you don't always have). How do you do this if you have only 1-2 visits vs several weeks or months?



- Get to the child's level
- Introduce yourself and your role in the age-appropriate language
- Be sure you understand what the child is really asking
- Give choices **ONLY** when they are real
- It's OK to say "I don't know"
- Do not make promises that you cannot keep



- Use descriptive and age-appropriate words: short, simple, concise
- Explain what you are doing and keep an eye on the child's response
- Do not use the following words: “Be a big girl / boy”, “Big girls/boys don't cry”, “sick” / “sleeping” / “gone away” when talking about death



- Keep cultural and spiritual beliefs/practices of family in mind. What have the parents/guardians given you permission to share? What if they don't want you to acknowledge what is happening?
- Try to find out what the child knows and what concerns them. They likely know more than the adults around them think they know. Make space for difficult feelings.





# WENDY



# Providing Support to Children and Families



# Supporting Parents/Guardians

- Conduct life review – even if a newborn
- Allow for silence
- Honor where they are
- Don't try to fix things – be someone who can tolerate their pain, fear, grief, etc.
- Challenge myth of divorce rate
- Make tissues available ahead of time – don't grab for them once crying
- Use their child's name after the death



# Helping parents/guardians support their child(ren)

- Provide information on child development, including magical thinking.
- Suggest questions they can ask and phrases to use or avoid using.
- Clarify that children process through play and a child's grief will look different than an adult's.
- Explain that children often protect the adults in their lives just as the adults are trying to protect them.



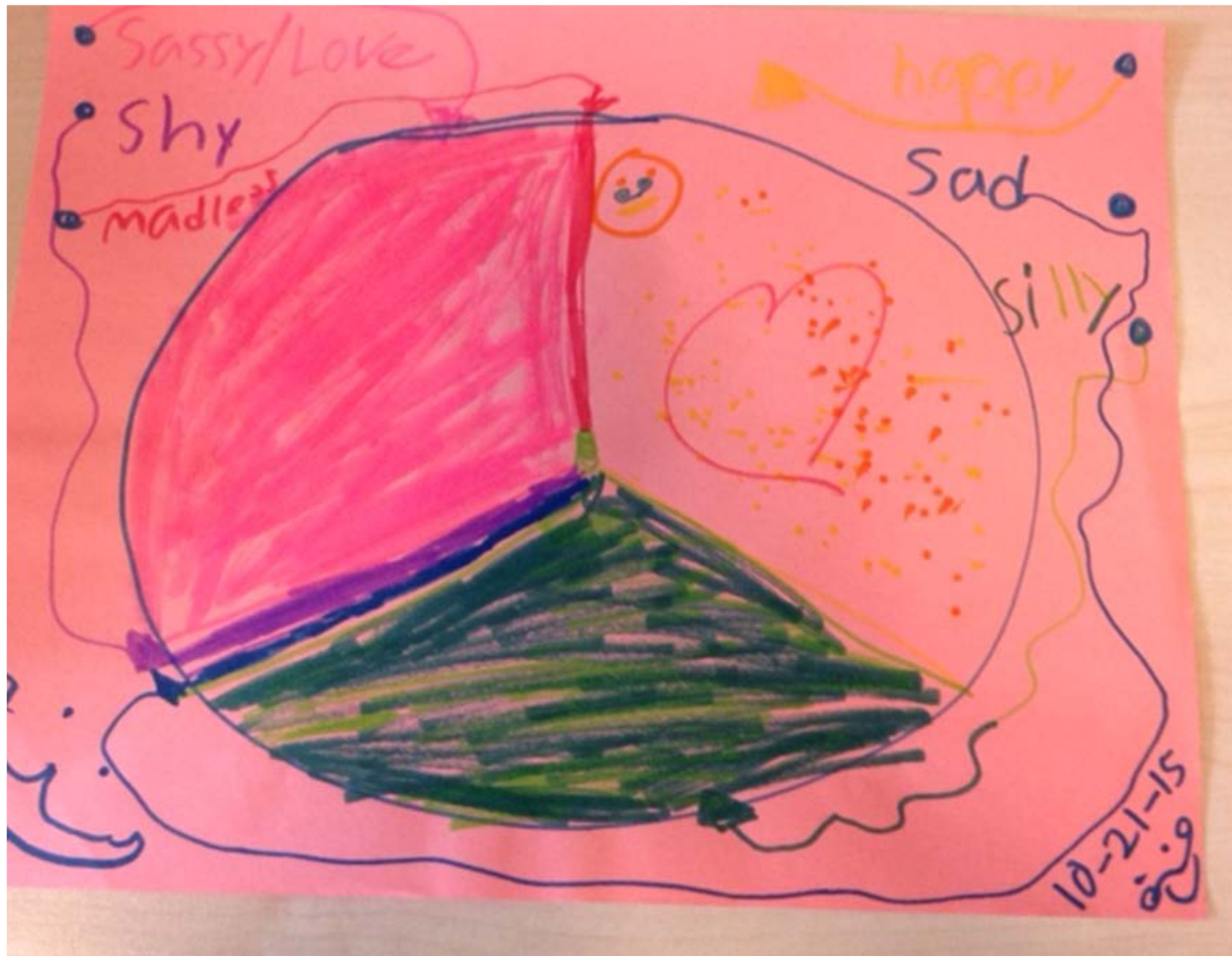
# Art Activities

- Feeling Mandala
- Collages
- General artwork: drawing, coloring, stickers
- Memory boxes
- Story telling, song writing
- Let them guide you





Feeling Mandala #1 – 3/9/2015



Feeling Mandala #2 – 10/21/2015



Feeling Mandala #3 – 11/24/2015





# Play Therapy

- “Adventure Park”
- “Shop Talk”
- Board games/card games
- Let them have choices and control



# Supporting Siblings

- When possible, keep siblings informed and involved
- Acknowledge impact of illness on their lives; SibShops
- Encourage siblings to visit the hospital, send photos or pictures to ill sibling
- Birthday cards and pillowcases for siblings
- Include them in visits, when appropriate





# Supporting Dying Children and Young Adults

- Don't be afraid to talk to them about their death – they are thinking about it
- Explore beliefs about what happens after death
- Explore legacy ideas
- Life review
- Let them set the pace- brief can still be meaningful
- Ask how they want to be remembered



# Memory Making



# Memory Making

- Children's Wish Foundation- Young Minds Program
- Songs of Love
- Peach's Neet Feet
- Make-A-Wish
- Do it For the Love Foundation
- Cases 4 Smiles
- Sons of Baseball



# Memory Making

- Now I Lay Me Down to Sleep/Moment by Moment-photographs
- Celebration of Life – while child still alive
- “Graduation” parties
- 3-D Handprint
- Oncology specific referrals: Julia’s Grace, Jessie Rees Foundation-Breakaway Adventure, Sunshine Kids





## Rituals after the Death



Comfort Bears, Photo Necklaces, Memory Tree, Memory Stones, Memory Notecards





Dear Everyone,

Thank you for everything – for spending your time with me, for making good memories with me – for making me strong and helping me feel like there was always a tomorrow.

Be happy for what you have, be happy for what you can do. Do not focus on what you don't have or can't do because someone out there has it worse than you.

Don't get lost in sorrow, be happy you'll wake up tomorrow. I might not be there but the memories of me are here to stay. Be happy.

I love you all, that love will always stay. Always be calm and pray. I love you all for making what left I had of life a joy. Thank you.

Love, ...



# Self-Care



# Helpful Ways to Cope

- Hold joint visits
- Maintain clear and consistent personal and professional boundaries
- Attend memorial services
- Talk, talk, talk... tell their stories
- Use humor
- Be fearless
- Meditation and/or Mindfulness



- Take breaks/vacations
- Offer support to/seek support from colleagues
- Appreciate the difference you make
- Notice and celebrate the gains made by patients and families
- Learn from the children and families; let them inspire you



# QUESTIONS?





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