



TOP TIPS CARING FOR THE SERIOUSLY ILL CHILD

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No Disclosures

- Objective 1: Describe the unique challenges parents and professionals experience when caring for a seriously ill child.
- Objective 2: Identify the difference between hospice, concurrent care for children and pediatric palliative care.
- Objective 3: Describe the importance of interdisciplinary team approach when caring for pediatric families.



OBJECTIVES

Why we do what we do?

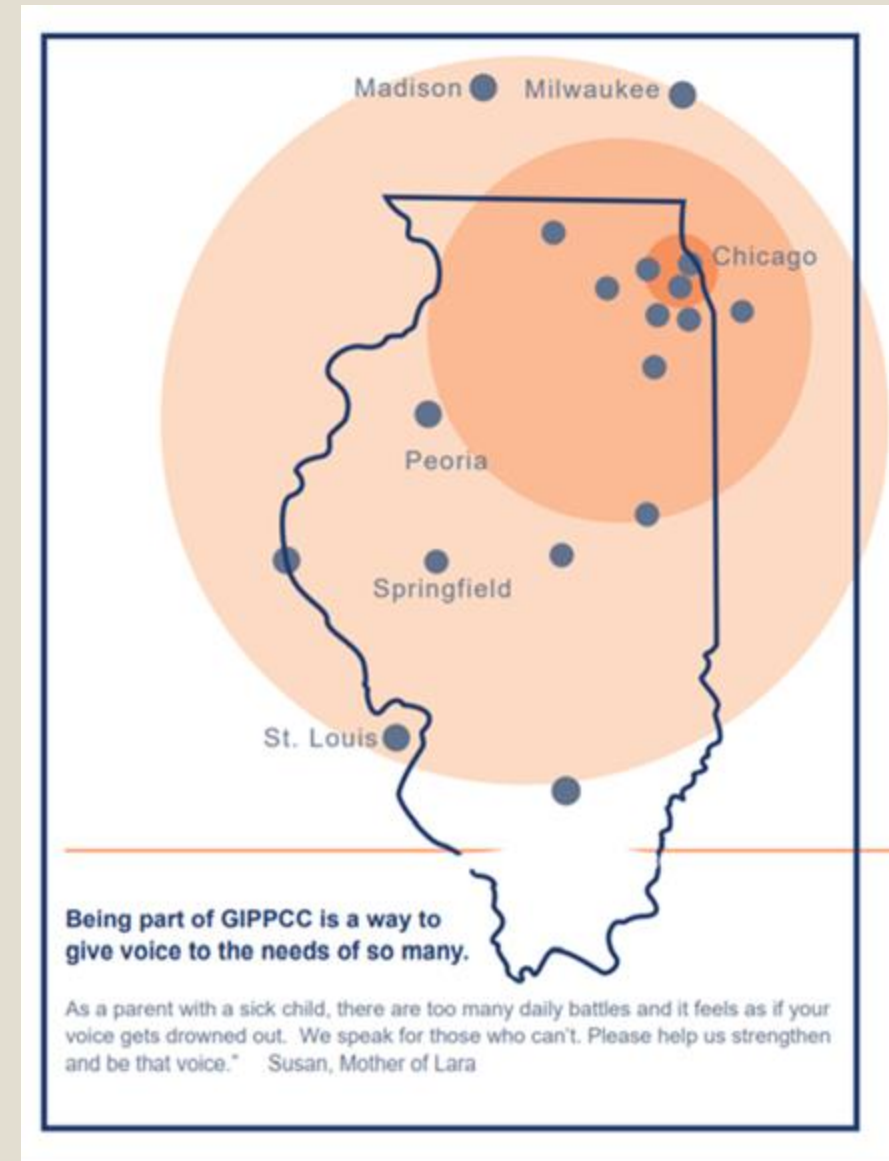
The Journey

Helping Children Find
their Voice

Helping Families
Feel Heard

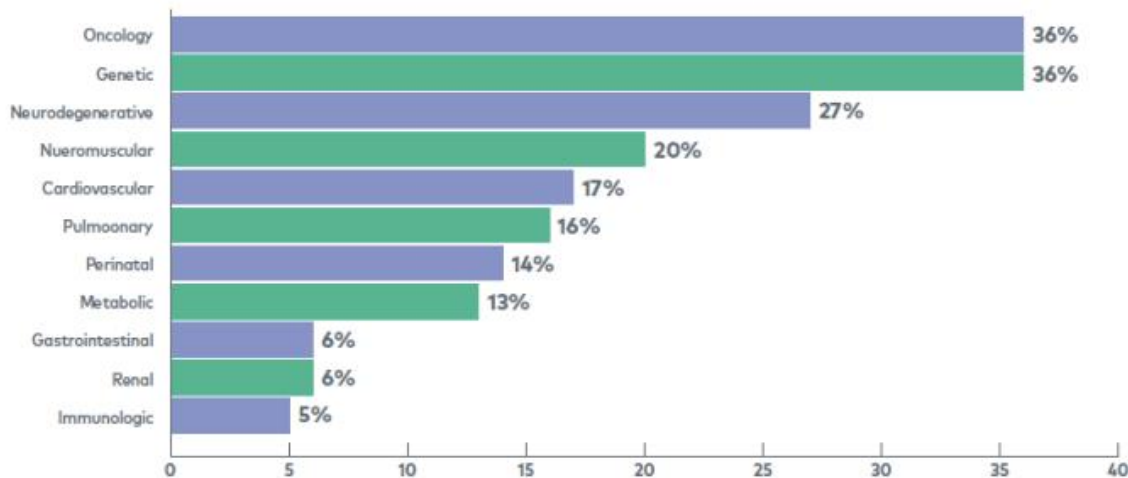
Illinois Landscape

- 37% of national hospices have a pediatric program- less than 18% in Illinois
- Only 1 in 10 dying children receive Hospice/Palliative Care
- 89% of parents reported that their children suffered at the end of life
- 50% of children died inpatient even though family's preference is home



Pediatric Facts and Figures

Figure 2: Pediatric conditions commonly referred to pediatric hospice and palliative care.



National Average Daily Census:

Pediatric Hospice: *4 patients*

with annual average of 16

Pediatric Palliative Care: *13 patients*

with annual average of 36

- More children with medical complexity living longer, often in rural areas and far from subspecialty medical homes
- increasing rates of death at home
- Pediatric Palliative Care (PPC) resources are often limited outside of academic medical centers
- Demand for specialty PPC is greater than the supply

FUNDING MECHANISMS vs PHILOSOPHY

Traditional Hospice

2010: ACA Concurrent Care for Children

2021: SB 2384: Pediatric Palliative Care Program -Medicaid

2022: SB 3819 Insurance-Pediatric Palliative Care

LANDSCAPE BEFORE 2010

Very few families enrolled into hospice care



If elected to enroll in hospice, often very late
in disease process

Pain &
symptoms
poorly
managed

Introduced
new
caregivers
late in
prognosis

Emergency
enrollments

AFFORDABLE CARE ACT 2010

Concurrent Care for Children



Families no longer need to decide
between CURATIVE & HOSPICE

Hard to
discern
billing

Only
Medicaid

The "H" word
Still have to
elect hospice



New Illinois Legislation:

Home-Based Pediatric Palliative Care Program

Anticipated Implementation: 2024

January 2024: State Regulated Private Insurance

What we do know:

- Eligibility Criteria
- Reimbursable Services
- Provider Qualifications

*****priority to enroll children currently in PPC programs***

Eligibility:

- Under 21 years old
- Diagnosed by the child's primary physician or specialist as suffering from a serious illness, life limiting, life threatening condition
- Covered by Medicaid or State-Regulated Insurance
- *And one functional need*





Provider Qualifications

- Hospice
 - Home Health
 - Home Nursing
 - FQHC/Federally Qualified Health Centers
 - Rural Health Clinics
 - Public Health Departments
-
- Medicaid certified
-
- Visits Structure
 - Minimally once every 3 months with monthly monitoring
 - Yearly Re-evaluation

Provider Qualifications

Minimally:

- Physician- Board Certified in Pediatrics and/or Hospice & Palliative Medicine
- Registered Nurse
- Social Worker
- All demonstrating ongoing proficiency in principles of end of life care, successful completion of training in communication with children & families, bereavement process



Reimbursable Services:

- Pain & Symptom Management
- Expressive Therapies (art, music, play, massage)
- Therapeutic Serious Illness & Bereavement
- Respite- Home & Inpatient
- **And allowed to continue disease directed, curative treatments**



REFRAMING HOPE: PEDIATRIC PALLIATIVE CARE



https://www.youtube.com/watch?v=IsAuOEwxy_c

Leads to Opportunity

- Community-based hospice and palliative medicine (HPM) providers may be asked to help with home care for a child
- Adult HPM providers may “inherit” care of young adults as transitioning to adult services



What makes kids different?

MEDICATION LIST		
Medication	Dose/kg	Form
Defibrillation (biphasic)	2j/kg, 4j/kg, 4j/kg	Round joules up to available setting
Cardioversion (Initial)	1j/kg, 2j/kg, 2j/kg	3mg/1mL
Adenosine IV (Initial)	0.1 mg/kg	3mg/1mL
Adenosine IV (Repeat)	0.2 mg/kg	50mg/1mL
Amiodarone IV	5 mg/kg	0.1mg/1mL
Atropine IV	0.02 mg/kg	100mg/1mL
Calcium Chloride Slow IV	20 mg/kg	0.1mg/1mL
Epinephrine 1:10,000 IV	0.01 mg/kg	20mg/1mL
Lidocaine IV	1 mg/kg	500mg/1mL
Magnesium Sulfate IV (torsades)	50 mg/kg	1mEq/1mL
Sodium Bicarbonate IV	1 mEq/kg	
Acetaminophen PO	15 mg/kg	160mg/5mL
Activated Charcoal PO	1 g/kg	50g/240mL
Dexamethasone IV/IM/PO (croup)	0.6 mg/kg	10mg/1mL
Dextrose 10% IV	0.5 g/kg	25g/250mL
Dextrose 25% IV	0.5 g/kg	12.5g/50mL
Diphenhydramine IV/IM/PO	1 mg/kg	50mg/1mL
Epinephrine 1:1,000 IM	0.01 mg/kg	1mg/1mL
Fentanyl IV/IM/IN	1 mcg/kg	50mcg/1mL
Fluid Bolus IV	20 mL/kg	1mg/1mL
Glucagon IM/IN		
Ibuprofen PO (Infant's)		
Ibuprofen PO (Children's)		
Magnesium Sulfate IV (resp fail)		
Midazolam/Diazepam IV (x2 for)		
Morphine Sulfate IV/IM		
Naloxone IV/IM/IN		
Ondansetron IV/PO		

Erikson's Stages of Psychosocial Development

Approximate Age	Psychosocial Crisis/Task	Virtue Developed
Infant - 18 months	Trust vs Mistrust	Hope
18 months - 3 years	Autonomy vs Shame/Doubt	Will
3 - 5 years	Initiative vs Guilt	Purpose
5 -13 years	Industry vs Inferiority	Competency
13 -21 years	Identity vs Confusion	Fidelity

Pediatric Vital Signs			
Age	Heart Rate	BP/ Systolic	Respirations
Infants	100-160	>60	30-60
Toddler	90-150	>70	24-40
Preschool	80-140	>75	22-34
School Aged	70-120	>80	18-30
Adolescent	60-100	>90	12-16

Author intends this reference to be accurate and free of errors, but no guarantees can be made. Author assumes no responsibility for outcomes from use of this reference.

Vaccine	Birth	1 mo	2 mos	4 mos	6 mos	9 mos	12 mos	15 mos	18 mos	19-23 mos	3-5 yrs	4-6 yrs	7-10 yrs	11-12 yrs	13-15 yrs	16-18 yrs
Hepatitis B (HepB)	1 st dose	2 nd dose	3 rd dose													
Rotavirus (RV) (2-dose series) (2-dose series)		1 st dose	2 nd dose	See footnote 1												
Diphtheria, tetanus, & acellular pertussis (DTaP) (<7 yrs)		1 st dose	2 nd dose	3 rd dose	4 th dose											
Tetanus, diphtheria, & acellular pertussis (Tdap) (>7 yrs)																
Hemophilus influenzae type b (Hib)		1 st dose	2 nd dose	3 rd dose	4 th dose											
Annual vaccination (RV only) 1 or 2 doses																
Annual vaccination (DTaP) 1 or 2 doses																
See footnote 9																
See footnote 11																
See footnote 13																

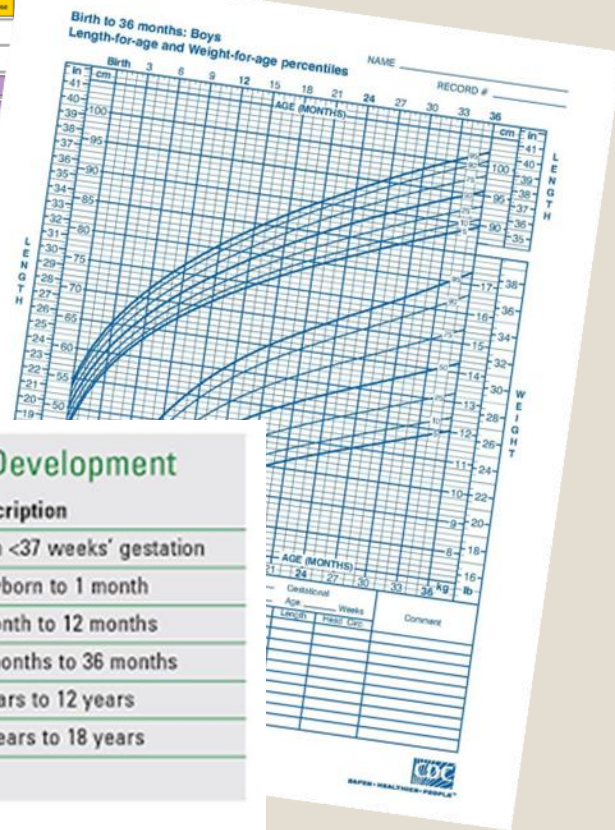


Table 2 Pediatric Stages of Development	
Stage	Description
Preterm	Birth <37 weeks' gestation
Neonate	Newborn to 1 month
Infant	1 month to 12 months
Toddler	12 months to 36 months
Child	3 years to 12 years
Adolescent	12 years to 18 years

Source: Reference 4.

Similarities

- Start at the beginning of an illness and be given along side treatment
- Improve quality of life by relieving distressing symptoms
- Decision making and goals of care
- Multidisciplinary team – physicians, nurses, social workers, chaplains, expressive therapies, etc.



Differences

- Diagnosis: complex chronic illness
(neurological, neurodegenerative, metabolic/genetic, oncology)
- Prognostication ???
- Live for over a year beyond the referral
- Not “normal”
- Care Coordination
- Moral Distress



Table 1. Synthesis of Recommendations for Communication

Assessment of QoL	Ask family about child's narrative	"Tell me about Leo"
		"What has life been like since his diagnosis?"
	Ask family about child's QoL	"Describe to us a typical day for Leo when he is well"
		"What things bring Leo comfort/joy?"
Assessment of symptoms	Ask parents/patients about symptoms and response to prior treatments	"What does it look like when he is in pain?" "When he has been in pain before, what has helped him?"
Goals of care conversations	Ask family how they make decisions for their child	"Who is involved when you have difficult decisions to make in your family?"
		"How are decisions made in your family?"
	Ask family how they want to receive information	"What is most important when you are receiving information from the medical team?"
		Involve providers who have long-standing relationship with child/family
	Ask parents/patients their hopes and worries	
		Ask parents/patient their source of strength
	Ask parents/patient their source of strength	
		Ask parents/patient their source of strength
Ask parents/patient their source of strength	"How well is that working for you right now"	
	Talking with child	A child's developmental state and family preference determine communication with the child
Ask parents, "What does Leo know about his illness?"		
"How can we partner with you in talking to Leo about his illness?"		

Jordan, M., Keefer, P.M., Lee, Y.A., Meade, K., Snamen, J., Wolfe, J., Kamal, A., Rosenberg, A. (2018). Top Ten Tips Palliative Care Clinicians Should Know About Caring for Children. *Journal of Palliative Medicine*, 21 (12).

Assessment Quality of Life

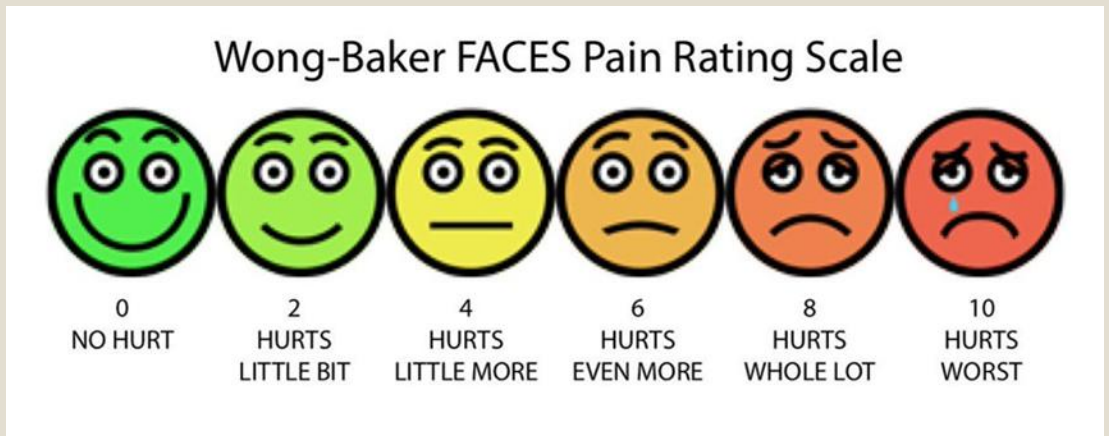
- **Ask the family about the child's narrative and quality of life**
 - Tell me about Leo
 - What has life been like since his diagnosis
 - Describe a typical day for Leo
 - What things bring Leo comfort/joy

The logo for Make-A-Wish, featuring the text "Make-A-Wish" in a blue serif font. A blue arc with a star at its end is positioned above the letter "A".

Jordan, et al. (2018). Top 10 Tips Palliative Care Clinicians Should Know About Caring for Children. Journal of Palliative Medicine, 21 (2).

Assessment of Symptoms

- **Caregivers are the experts**
 - What does it look like when he is in pain?
 - What has helped him?
- **Peds Pearls**
 - Weight based
 - Route – Oral liquid
 - Methadone long-acting
 - Developmental Level
 - Feeding intolerance/Constipation



Medication Management

Table 2. Symptom Management Pearls

Generic pearls for medications in all pediatric patients	Weight based dosing is used until adult dosing is reached The preferred route for medications is liquid administered orally or through feeding tube Intranasal fentanyl and midazolam can be used to avoid PIV placement
Age specific issues for medications	Metabolism changes rapidly in the first two years of life PCA use by children is affected by developmental ability, however often used with assistance of parents and/or nurses Delirium medications are often off-label for use in pediatrics
Opioid specific issues	Given typical need for liquid medications, methadone is the only long-acting option for opioid therapy
Pearls for patients with SNI	Ask caregivers about sources of pain and typical pain behavior Symptoms include seizures, spasticity, neurostorming, and neuroirritability Consider use of gabapentin
Feeding issues and intolerance	Neonates and infants have higher rates of reflux Feeding intolerance may present as abdominal pain, anorexia, retching, and vomiting Constipation is a common problem Management may include adjusting feeding route or regimen, use of motility agents, or considering various feeding tube options

Assessment of Goals of Care

- What are you hoping for Leo?
- What are you most worried about?
- What/who is your support? Gives you strength?

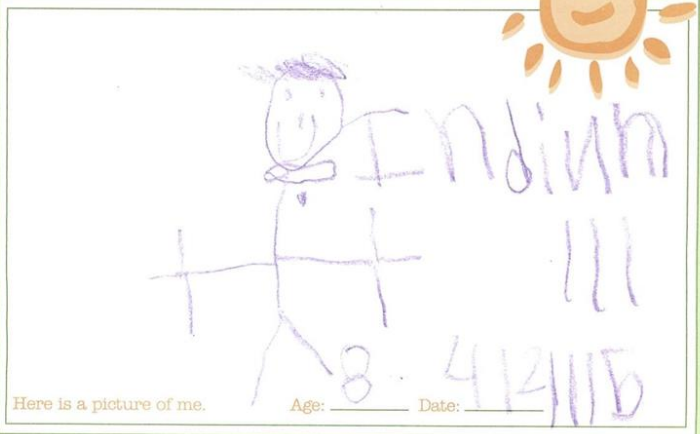


Assessment of Decision Making

- Determine legal decision maker
- Inclusion of children in care and decisions
- Obligation from medical team
- Resources



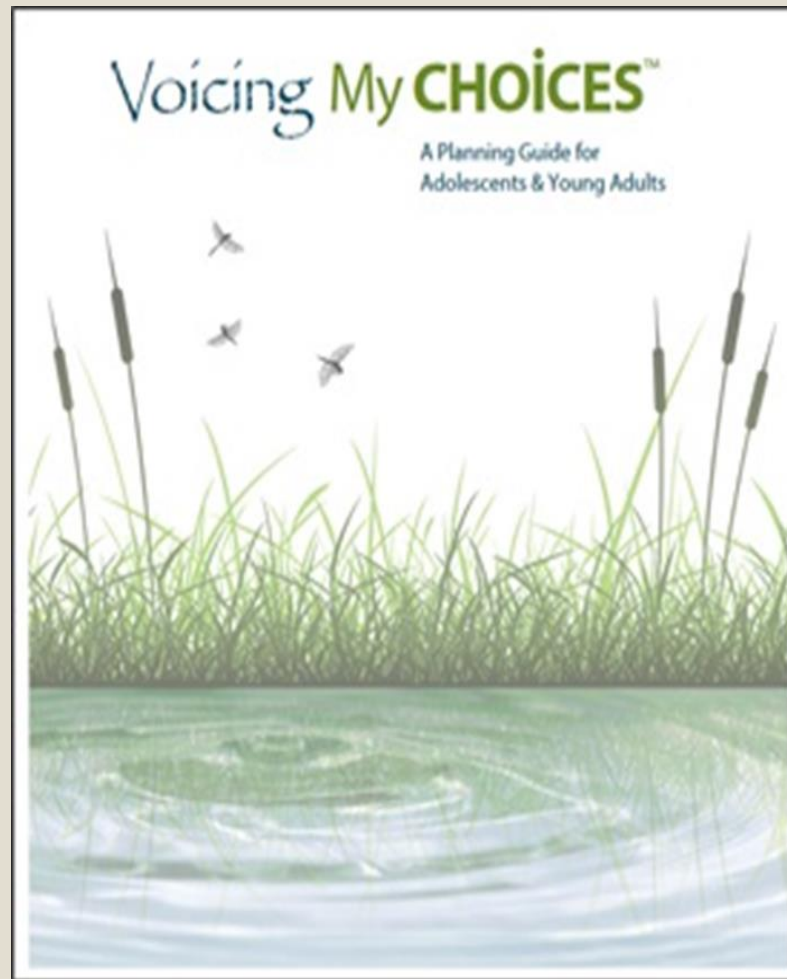
My Wishes SM



Here is a picture of me. Age: 8 Date: 4/11/15

My wishes for:

- How I want people to treat me.
- How comfortable I want to be.
- What I want my loved ones to know.
- What I want my doctors and nurses to know.



FIVE WISHES®

MY WISH FOR:

THE PERSON I WANT TO MAKE CARE DECISIONS FOR ME WHEN I CAN'T:

THE KIND OF MEDICAL TREATMENT I WANT OR DON'T WANT

HOW COMFORTABLE I WANT TO BE

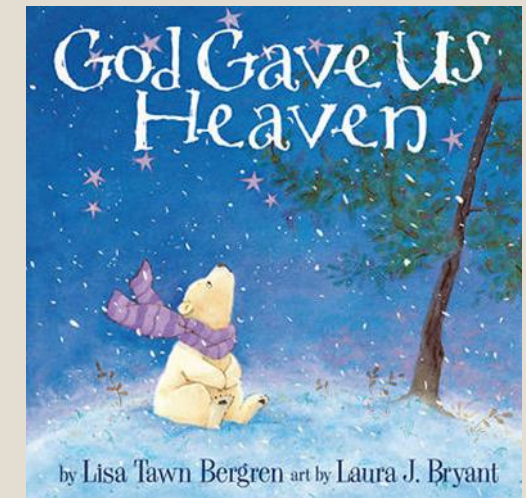
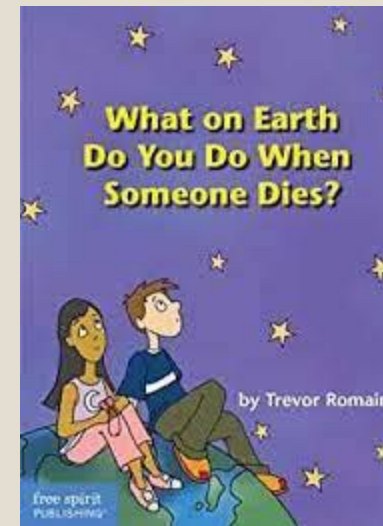
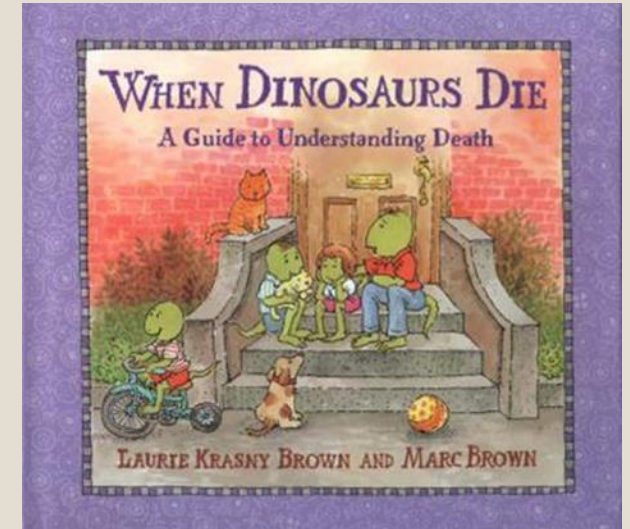
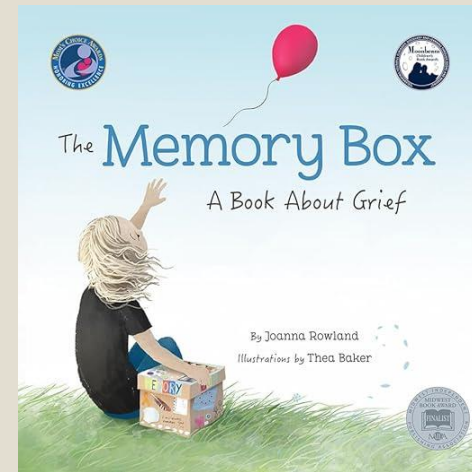
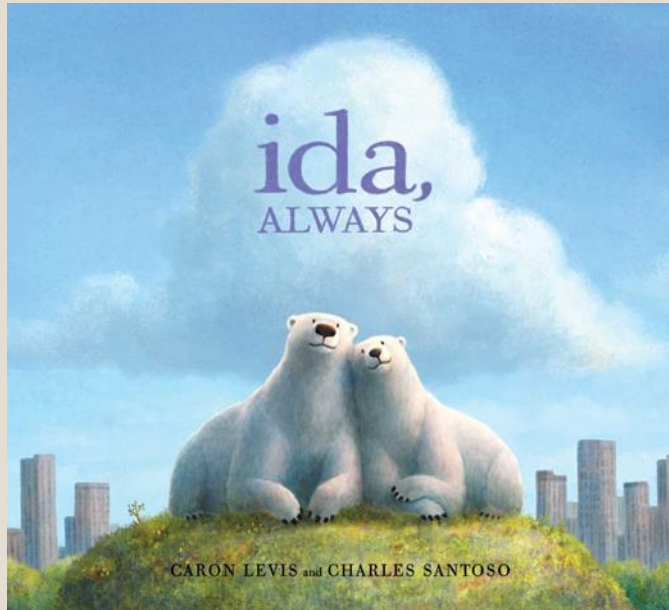
HOW I WANT PEOPLE TO TREAT ME

WHAT I WANT MY LOVED ONES TO KNOW

print your name

signature

Children's Books



CHILDREN'S UNDERSTANDING OF DEATH

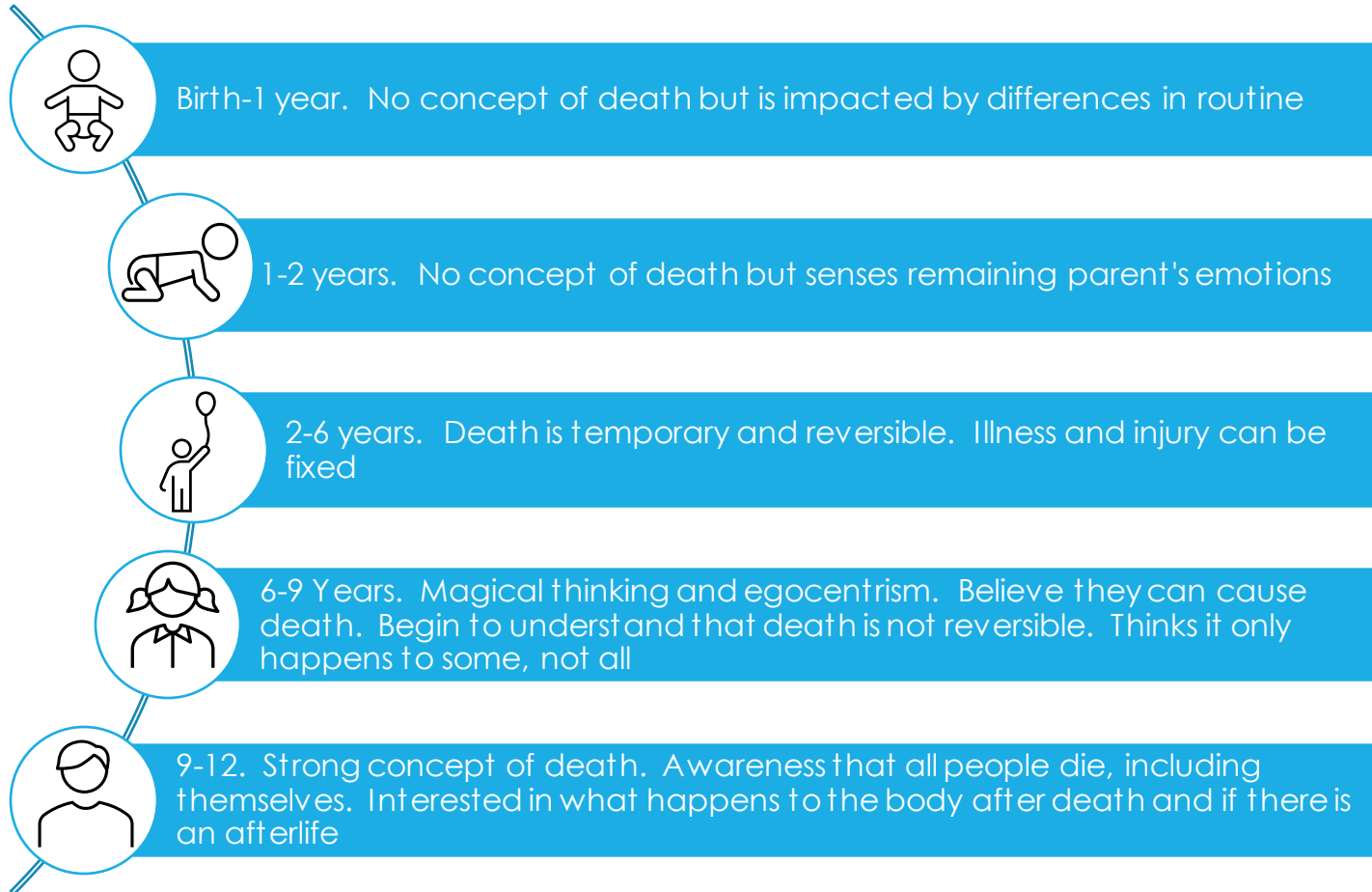


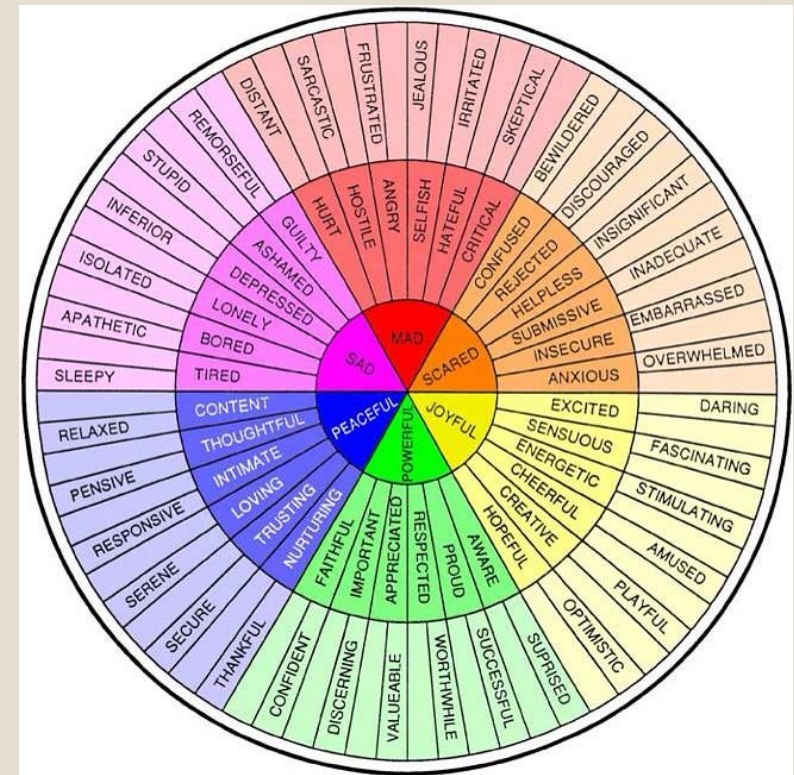
TABLE 3. DEVELOPMENTAL STAGES AND CONCEPT OF ILLNESS AND DEATH

<i>Age (years)</i>	<i>Characteristics</i>	<i>How child understands illness</i>	<i>How child understands death</i>	<i>Clinical practice implications</i>
2–6	Developing language skills, magical thinking, egocentric, symbolic play	See illness as a form of punishment or attributed to magic/supernatural. They have difficulty differentiating between contagious illnesses and noncontagious illnesses (e.g., cancer)	Temporary or reversible, form of separation, can be caused by thoughts, form of punishment	Minimize separation, correct perceptions of illness/death as punishment, use precise language (dead, dying)
7–12	Concrete thinking	Understand that contagious illnesses occur through physical contact and are capable of differentiating between different illnesses	Gradual awareness that death is irreversible and permanent	Provide concrete details if asked, allow participation in decision making
13–18	Abstract thinking, self-reflection	Understand cause and development of an illness, that exposure to illness may not necessarily result in illness, and aware of psychological forms of illness	Irreversible, universal, and inevitable. May have sense of invincibility.	Allow expression of strong feelings, privacy, access to peers, and participation in decision making

Jordan, M., Keefer, P.M., Lee, Y.A., Meade, K., Snamen, J., Wolfe, J., Kamal, A., Rosenberg, A. (2018). Top Ten Tips Palliative Care Clinicians Should Know About Caring for Children. *Journal of Palliative Medicine*, 21(12).

What Does Grief Look Like?

- Grief is characterized by any internal thoughts, emotions, or physical symptoms that are present as a result of a death or loss
- A normal and natural response to loss
- Often a combination of feelings:
 - Sadness
 - Shock
 - Confusion
 - Anger
 - Regret
 - Relief



Supporting Parents and Siblings

- Be a good observer. A bereaved child's behavior can be very telling in regard to their emotions.
- Listen. Let each child teach you what grief is like for him/her.
- Be patient. Children's grief is not typically obvious and immediate.



Supporting Parents and Siblings



- Be honest. Don't lie to children about death. They need to know that it's permanent and irreversible. Avoid using euphemisms. Use simple and direct language.
- Be available. Bereaved children need to know they can count on the adults in their lives to listen, support, and love them.

What Do Children Need?

- **Honesty**
 - They need honest information
- **Safety**
 - They need to feel safe
- **Inclusion**
 - They need to be included
- **Expression**
 - They need to express their grief/emotions



Things to Keep in Mind

- Children need to be thoroughly prepared for what they will see and experience
 - Hospice, palliative care, complex medical needs
- Encourage children to express themselves through art, notes, photos, etc.
- Provide opportunities for choice and remember every child will respond differently- this is normal



What Matters Most to the Child?

- What makes the child uncomfortable? Or confused? Or angry? Or scared?
- What does the child want the doctors and nurses to know?
- What can you do to make sure your child feels safe? And comfortable?
- If your child is in the hospital, does he want to have his favorite stuffed animal? Or a favorite piece of clothing? Or a picture of a favorite place? Or playing favorite music?



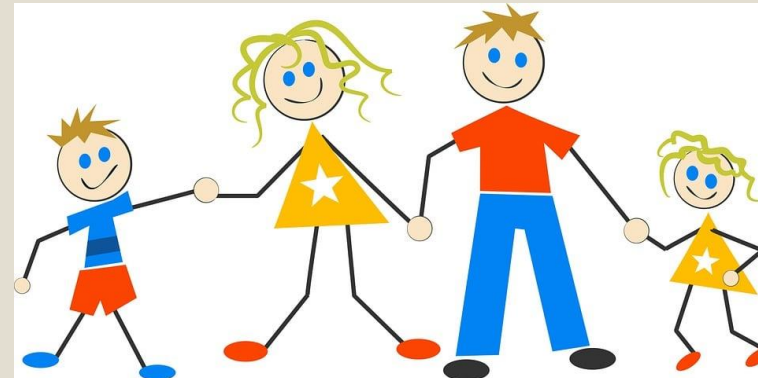
Concerns

- Will having the conversation upset my child?
- Will having the conversation frighten my child?
- Will having the conversation make a difficult situation even worse?
- Is it better for my child not to know how sick he or she is?
- Will talking about death and dying make it come true?



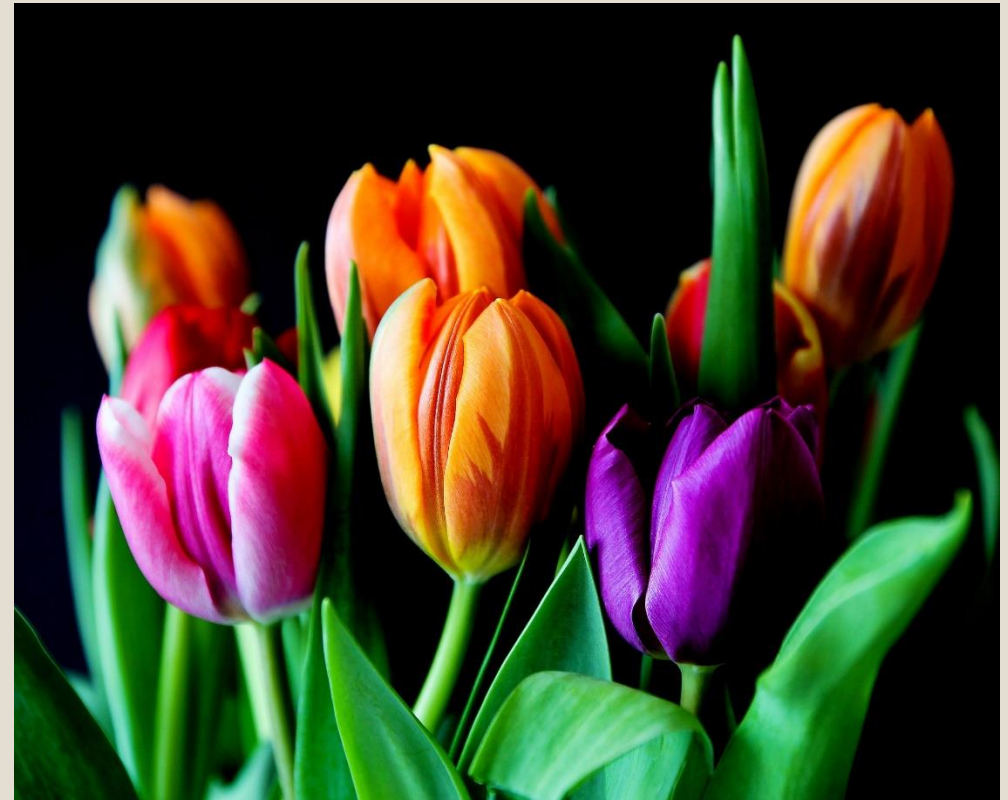
Follow the Child's Lead

- It's okay to "go there"
 - Open the door for conversation
- Many children do not talk about dying because they want to protect their parents
 - A child may need the parents' permission to "go there"
- Parents who talk about death with their children do not regret it
 - Parents who talk to their children about death often report coping better after their child dies



Follow the Child's Lead

- Important to note:
 - Do not force the child to talk about or view anything they are uncomfortable with
 - Children often sense that they are dying even if nobody is talking about it



Takeaways



“We cannot protect children from tragedy, but we can let them teach us how they feel about it”

- Wolfelt

Questions

