Pediatric Palliative Care

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June 29, 2017

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THE UNIVERSITY OF TEXAS
MD Anderson Cancer Center
Making Cancer History®

Project ECHO®

Infants to 2 years of age

2 to 6 years of age

7 to 12 years of age

Teenagers

Infants to 2 years of age

Basic Developmental Issues

- Do not have capacity to know something exists independently without seeing, touching, or even hearing it
- Attachment to parent or consistent other is basic for creating child's trust in universe

How to Engage

- Stranger anxiety peaks at 6-12 months of age
- Approach the child slowly, giving them time to warm up to you
- Have the caregiver hold the child if possible

Infants to 2 years of age

Experiences of pain, loss and suffering

- Most significant way children experience loss is through environment
- Prolonged separation from primary caregivers can lead to deeper levels of emotional and psychological stress with lasting impact
- **Concept of Death: do not have cognitive capacity to anticipate death**

Supportive Interventions

- Effective pain control empowers parents – they can now offer comfort to their child
- Effective pain control helps the child access security & comfort that familiar attachment provide
- Combined, it facilitates the essential nurturing that is crucial for healthy development

2 to 6 years of age

Basic Developmental Issues

- Children become more imaginative and can begin to use symbols
- Stories are real and everything has its place in the story of the child's life
- 2-3 years of age: developing more autonomy
- 4-6 years of age: become focused on initiative and guilt

How to Engage

- Get down to their eye level – literally
- Get down to their experiential level – ask them to play
- Most importantly, speak **to** them, not **at** them

2 to 6 years of age

Experiences of pain, loss and suffering

- Illness may be construed as punishment for bad behavior
- Likely to regress to infantile behaviors in effort to seek a more familiar and safe state
- Often experience "magical thinking" – hospitalization may be rejection or punishment
- **Concept of Death: reversible, "sleeping", do not personalize**

Supportive Interventions

- Support the child who wants to initiate rituals. The bedtime story or mealtime prayer may be something the child will initiate
- Children in palliative care need heroic stories, but they also need simple truths
- Euphemisms can do harm

7 to 12 years of age

Basic Developmental Issues

- Now has "work”’ – must be sustained for the child to feel successful
- School age child lives in two separate worlds:
  - Logical, "schooled" world of work, organized play, and peer involvement
  - Private world of imagination which is still largely mythical

How to Engage

- Be curious about their hobbies, sports, pets, friends or siblings
- Be prepared to listen to a child's worries and concerns
- Recognize that children are not comforted by being put off or given "nice" answers

7 to 12 years of age

Experiences of pain, loss and suffering

- Comprehend body's functions and processes, sensitive to body integrity
- May be insistent about knowing details of dying and death
- Intense curiosity about dying, seem overly morbid or psychologically hurt
- Children anticipate needs and take care of others, particularly parents and siblings
- They will worry about the future, how their parents will do without them
- **Concept of Death: final, personal, unpredictable**

Supportive Interventions

- Encourage children to stay connected with friends and outside groups as much as they want
- Help children to manage anxiety by drawing on their increased ability to comprehend their body's workings
- Explanations, illustrations, and demonstrations are helpful for enhancing coping

Teenagers

Basic Developmental Issues

- Initiation in abstract thinking and ability to engage in higher-order reasoning
- Teens make impulsive decisions, less likely to consider consequences, feelings of invulnerability
- Striving to locate themselves within the world, make sense out of their experiences
- Are developing a significant sense of the mysterious as available and full of potential

How to Engage

- Don’t try to act or be cool – they immediately recognize this as inauthentic
- Spend time talking with them without a parent present – get to know them as an individual
- Endorse feeling that what is inconsequential to adults may be central to their decision making process

Teenagers

Experiences of pain, loss and suffering

- "I'm fine" when asked how they are feeling
  - Truly believe on some plane that they are fine or
  - Are protecting themselves from awareness they are not fine
- Do not always understand importance of taking medication regularly
- 1st reaction to illness can be ask if it will be disfiguring and whether affects ability to be with friends
- **Concept of Death: final, universal, but distanced**

Supportive Interventions

- Allow for emotions and privacy, support independence
- Support friends who visit and take on the challenging role as confidant

Brief Review

Infants to 2 years of age

Neonates and infants have special needs

Tailor support for families and siblings

Environment has a big impact

Separation from caregivers is significant

Pain control is essential at this age

2 to 6 years of age

Observe for imagination, initiative and guilt

Observe for signs that illness is a punishment

Find ways to assist expression

Support familiar rituals

Storytelling is an effective coping strategy

Brief Review

7 to 12 years of age

Observe for awareness of justice

Be prepared for intense curiosity about death

Listen to them, help them achieve wishes

Provide honest replies after ascertaining what the child wants to know

Teenagers

Observe for abstract thinking

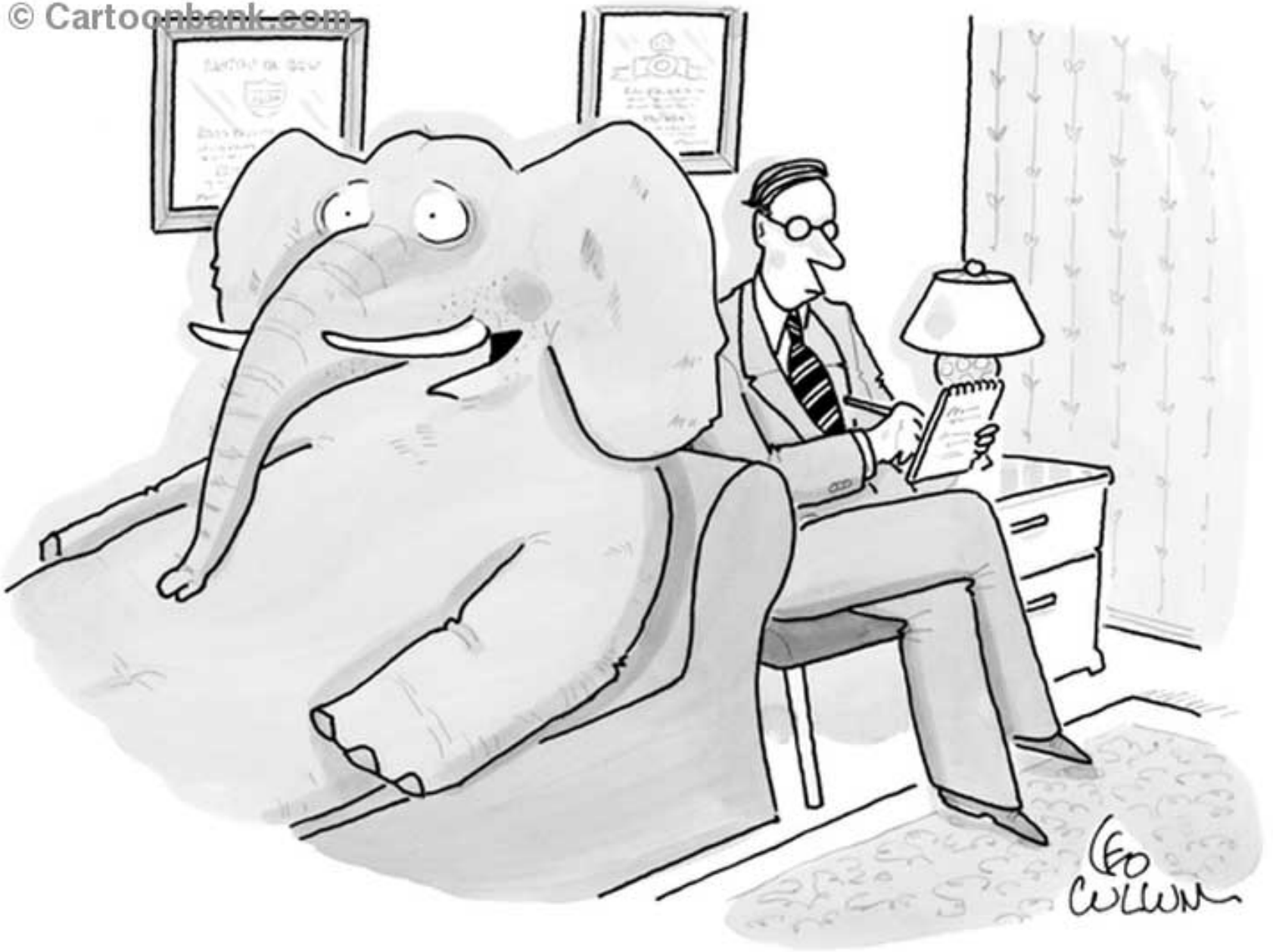
Observe for role confusion, emerging identity

Acknowledging the mysterious can help

Worried about disfigurement

Peers are very important, support them

Encourage to be as active & sociable as possible



"I'm right there in the room, and no one even acknowledges me."

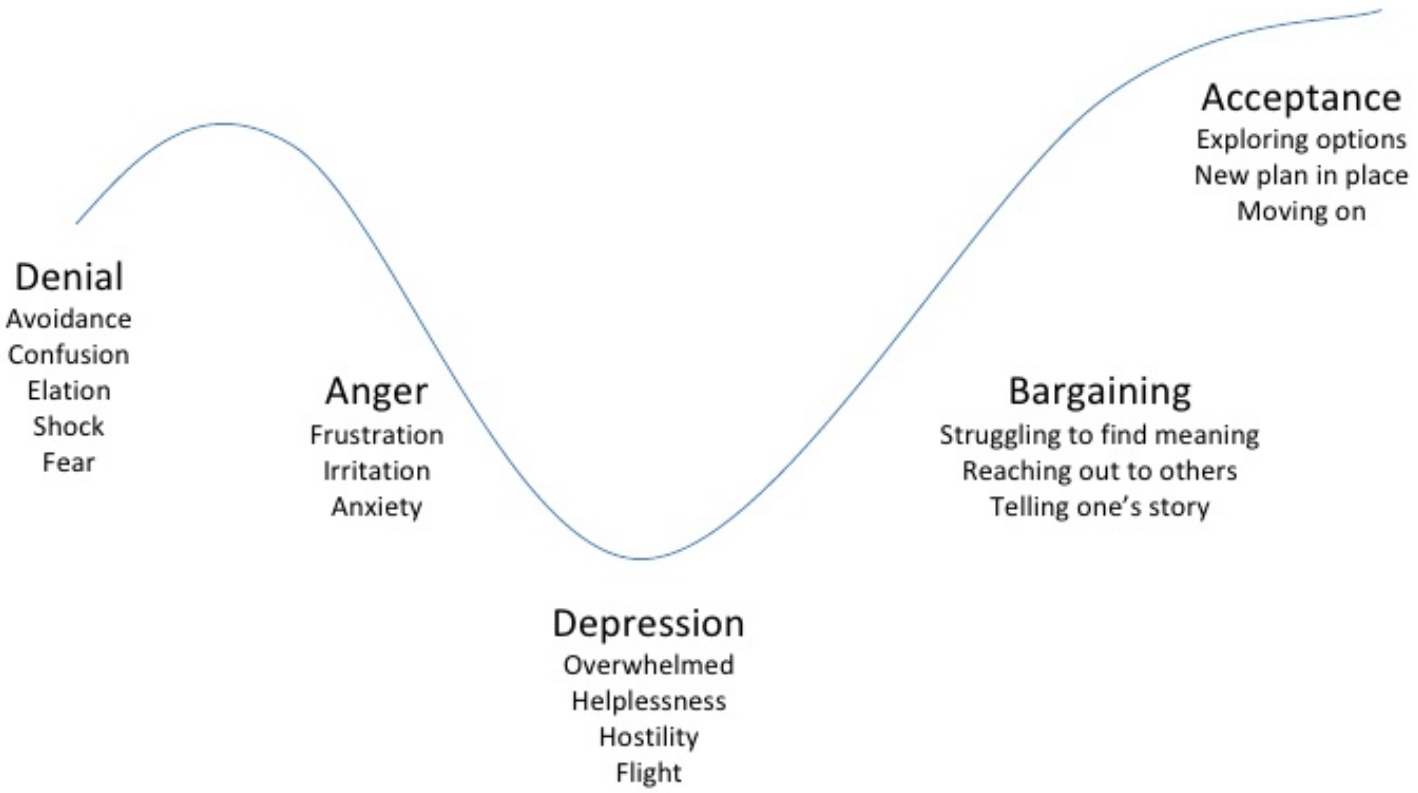
How Do We Talk About Death and Dying with Parents and Children?

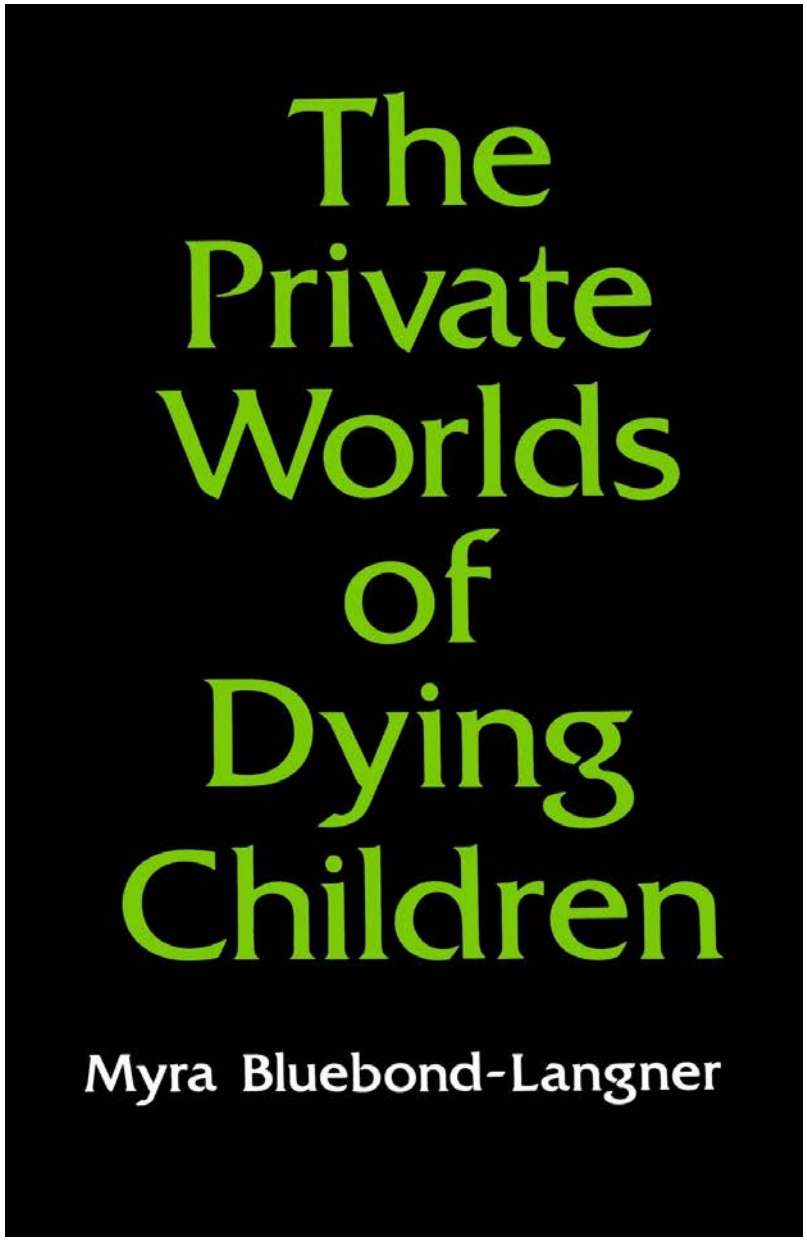
- Strict social rules about dying
- Children quickly learn that death is an inappropriate topic of conversation with adults
  - Evidenced by adults' reactions when children try to discuss it

How Do We Talk About Death and Dying with Parents and Children?

- Children are eager to share information about it ***with each other***
- Terminally ill kids learn to safely discuss their prognosis where adults cannot hear them
- Children are socialized to act secretively around adults and openly around their peers

Kübler-Ross Grief Cycle




The Private Worlds of Dying Children
Myra Bluebond-Langner

1. I am seriously ill
2. I am seriously ill but will get better
3. I am always ill but will get better
4. I am always ill and will not get better
5. I am dying

“Mutual Pretense”

- Unspoken agreement to follow certain specific rules to avoid talking about the child’s prognosis

Parents are not meant to bury their children

“Mutual Pretense”

- Unspoken agreement to follow certain specific rules to avoid talking about the child’s prognosis
- Children are responsive to this pattern of social order, and join to ensure their social acceptance and worth
- Enables all parties to continue doing what society expects of them: to fulfill certain social roles and responsibilities

Social Roles and Responsibilities

Child	Parent	Doctor
• The primary role of the child is to maintain their parents' presence • By reinforcing adults' rules of hope, children guarantee their continued presence ➢ **They will not be abandoned**	• The primary role of the parent is to raise a child ➢ **In order to raise a child, parents need to perceive a future for the child**	• The primary role of the physician is to "treat" the child ➢ **The doctor needs to view the child as "treatable"**

Talking about Death with Children

The NEW ENGLAND JOURNAL of MEDICINE

ESTABLISHED IN 1812 SEPTEMBER 16, 2004 VOL. 351 NO. 12

Talking about Death with Children Who Have Severe Malignant Disease

Ulrika Kreicbergs, R.N., Unnur Valdimarsdóttir, Ph.D., Erik Onelöv, M.Sc., Jan-Inge Henter, M.D., Ph.D., and Gunnar Steineck, M.D., Ph.D.

Did you talk about death with your child at any time?

n = 147 (34 %) — ***Yes*** → Do you regret having done so? → ***No parents regretted having talked with their children about dying***

No (**n = 282 (66 %)**) → Do you regret *not* having done so?

	Yes	*No*
Overall:	**27%**	**73%**
Sensed Child Aware Of Dying:	**47%**	**53%**
Did Not Sense Child Aware:	**13%**	**87%**

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1. No parents regretted having talked with their children about dying.

2. Overall the majority of parents (73%) who chose ***not*** to talk to their dying child about death ***did not regret it***.

3. BUT about 50% of those who sensed their child was aware of dying and did not to talk to their child about death regretted it.

Titrating Opioids In Treating Pain Children

Look Up Recommended Dose

↓

Start conservatively, usually with lower end of recommended range unless severity of distress dictates otherwise

↓

Observe/assess response, titrate accordingly

Titrating Truth In Communicating With Children

"Look Up Recommended Dose":

- Consider developmental understanding of issue
- Ask parents & health care team what child understands
- Check with parents if/how they would like information shared

↓

Start Conservatively:

- I'm wondering what made you ask this today?
- Can you tell me what you understand is going on?

↓

Observe/assess response, titrate accordingly

Tell them only what they want to know, what they are asking about, and on their own terms.

Nociceptive Pain – Opioids

Opioid	Initial Dose – Oral	Initial Dose – IV (Intermittent)	Initial Dose – IV (Continuous)
Morphine	0.2-0.3 mg/kg (15 mg max)	0.05-0.1 mg/kg (5 mg max)	0.01-0.02 mg/kg/hr (1 mg/hr max)
Methadone	0.1 mg/kg (5 mg max)	0.1 mg/kg (5 mg max)	NA
Oxycodone	0.1-0.2 mg/kg (10 mg max)	NA	NA
Hydromorphone	0.04-0.06 mg/kg (2 mg max)	0.015 mg/kg (0.6 mg max)	0.002-0.004 mg/kg/hr (0.5 mg/hr max)

Neuropathic Pain – Gabapentin*

Day	Dose
Day 1-3	2 mg/kg (100 mg max) PO TID **OR** 5 mg/kg/dose (250 mg max) PO qhs
Day 4-6	4 mg/kg TID **OR** 2.5 mg/kg/dose am and midday and 5 mg/kg qhs
Day 7-9	6 mg/kg TID **OR** 2.5 mg/kg/dose am and midday and 10 mg/kg qhs
Day 10-12	8 mg/kg TID **OR** 5 mg/kg/dose am and midday and 10 mg/kg qhs

Increase every 2-4 days by 5-6 mg/kg/***day*** until:

- Effective analgesia reached (often noted at 30-45 mg/kg/day)
- Side effects experienced (nystagmus, sedation, tremor, ataxia, swelling)
- Maximum total dose of 50-72 mg/kg/day reached (2400-3600 mg/day)
- Younger children (<5 years) may require a 30% higher mg/kg/day dosing, such as a total dose of 40-60 mg/kg/day
- Half of the total daily dose may be given as the evening dose if symptoms occur mostly in the evening and overnight
- Titrate more rapidly for severe pain or as tolerated

* = Available as a liquid preparation

DSM-5 diagnostic criteria for delirium

1. Disturbance in attention and awareness.
2. Change in cognition that is not better accounted for by a preexisting, established, or evolving dementia.
3. The disturbance develops over a short period (usually hours to days) and tends to fluctuate during the course of the day.
4. There is evidence from the history, physical examination, or laboratory findings that the disturbance is caused by a direct physiologic consequence of a general medical condition, an intoxicating substance, medication use, or more than one cause.

COMPLICATED!

Delirium – Assessment

RASS Score ____ (if -4 or -5 do not proceed)

Please answer the following questions based on your interactions with the patient over the course of your shift:

	Never 4	Rarely 3	Sometimes 2	Often 1	Always 0	Score
1. Does the child make eye contact with the caregiver?						
2. Are the child's actions purposeful?						
3. Is the child aware of his/her surroundings?						
4. Does the child communicate needs and wants?						
	Never 0	**Rarely 1**	**Sometimes 2**	**Often 3**	**Always 4**	
5. Is the child restless?						
6. Is the child inconsolable?						
7. Is the child underactive—very little movement while awake?						
8. Does it take the child a long time to respond to interactions?						
					TOTAL	

EASY!

Figure 1. Cornell Assessment of Pediatric Delirium revised. RASS = Richmond Agitation and Sedation Scale.

Delirium – Assessment

TABLE 1. Selected Cornell Assessment of Pediatric Delirium Developmental Anchor Points and Diagnostic and Statistical Manual IV Delirium Domain Correlates

Cornell Assessment of Pediatric Delirium Item	Diagnostic and Statistical Manual Delirium Domains	Selected Normal Developmental Anchor Points[a]	
		Age (8 wk)	Age (1 yr)
1. Does the child make eye contact with the caregiver?	Consciousness	Follows moving object past midline, regards hand holding object, focused attention	Holds gaze. Prefers primary parent. Looks at speaker
2. Are the child's actions purposeful?	Cognition	Symmetric movements, will passively grasp handed object	Reaches and manipulates objects, tries to change position, if mobile may try to get up
3. Is the child aware of his/her surroundings?	Consciousness Orientation	Facial brightening or smile in response to nodding head, frown to bell, coos	Prefers primary parent, upset when separated from preferred caregivers. Comforted by familiar objects (i.e., blanket or stuffed animal)
4. Does the child communicate needs and wants?	Consciousness Psychomotor activity	Cries when hungry or uncomfortable	Uses single words or signs
5. Is the child restless?	Cognition Psychomotor activity Affect/distress	No sustained awake alert state	No sustained calm state
6. Is the child inconsolable?	Orientation Cognition Affect/distress	Not soothed by usual comforting actions, for example, rocking and singing	Not soothed by usual comforting actions, for example, singing, holding, talking, and reading
7. Is the child underactive—very little movement while awake?	Orientation Affect/distress	Little if any purposive grasping, control of head and arm movements, such as pushing things that are noxious away	Little if any play, efforts to sit up, pull up, and if mobile crawl or walk around
8. Does it take the child a long time to respond to interactions?	Consciousness Psychomotor activity	Not cooing, smiling, or focusing gaze in response to interactions	Not following simple directions. If verbal, not engaging in simple dialogue with words or jargon

CAPD – Assessment

- Score > 9:
  - Sensitivity 94.1%
  - Specificity 79.2%
- Children with Developmental Delay
  - Sensitivity 96.2%
  - Specificity 51.2%
- Works well with 0 – 13 years of age

Delirium – Antipsychotics

Drug	Sedating Effect	Dose
Haloperidol	↑	0.01-0.02 mg/kg PO/IV q 8 h prn (0.5 – 1 mg max)
Olanzapine*	↑↑	< 3 years of age: 0.625-1.25 mg PO up to q6 hours 3-10 years of age: 1.25-2.5 mg PO up to q6 hours > 10 years of age: 2.5-5 mg PO up to q6 hours
Quetiapine	↑↑↑	25 mg PO daily; may increase to BID. Increase daily by 25 mg/dose

* = Available as an oral dissolving tablet