# Symptom Management

Project ECHO Core Competency

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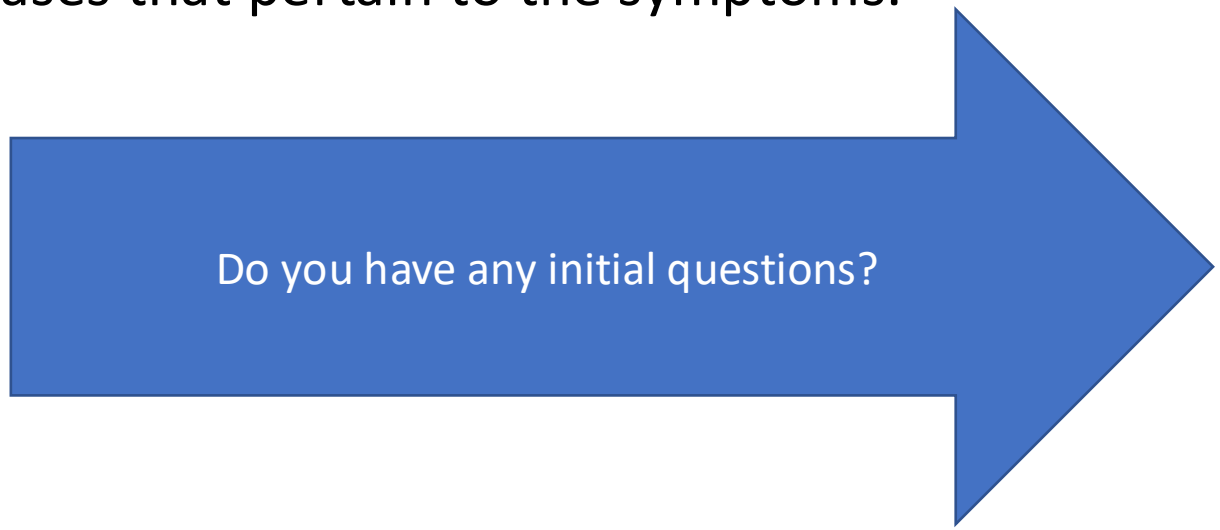
It’s nice to meet you...

# Disclosures

- Pain, anxiety and depression will be discussed further at other ECHO sessions.
  - Neuropathic pain will be included
- Our talk today relies on you - our amazing audience
  - Our case does pertain to a child with a neurological injury. But, we will discuss other cases that pertain to the symptoms.



# Objectives

At the end of this talk, the audience will be able to:

- Describe how goals of care impact symptom management strategies
- Explain symptom management strategies for:
  - Neurology: Seizures & neuro-irritability
  - GI:  Feeding intolerance & secretion management
  - Respiratory: Dyspnea
- Be able to access resources specific to symptom management in pediatric palliative care

# Symptom Management

Health History

- OPQRST

Physical Exam

- Inspection
- Auscultation
- Percussion
- Palpation

Investigations

- Location

Treatment

- Pharmacological
- Non-pharmacological

# Pediatric palliative care

## **Who?**

Advance care planning

Symptom management

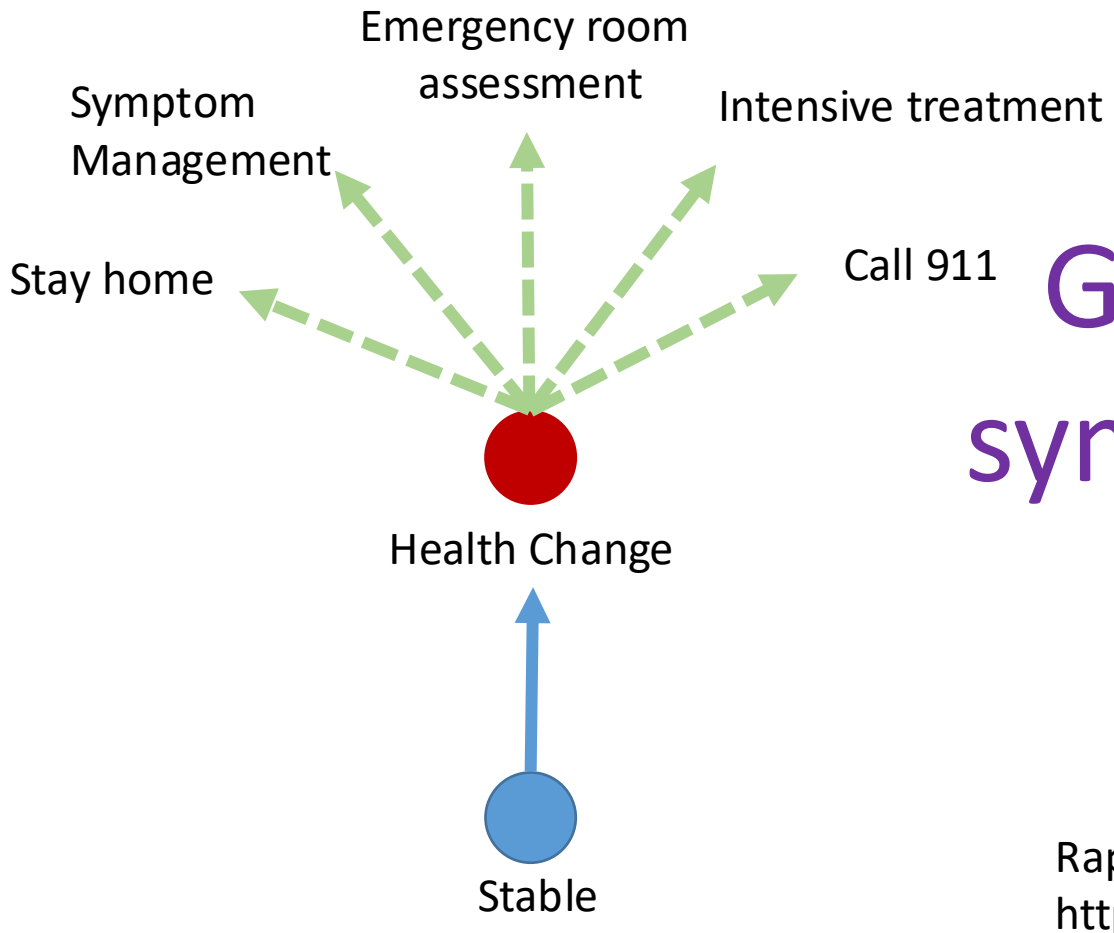
Where do you start when discussing symptom management?

...with a family's goals of care

Prolong life

Comfort

# Treatment pathway




## Goals of care inform symptom management and treatment

Rapoport, A. Pediatric Child Health, 29(6).
https://cps.ca/documents/position/advance-care-planning

# Case Study – Maria

Maria is a 6 day old, term baby girl with severe hypoxic ischemic encephalopathy.
Her breathing is stable on room air.
She has intermittent seizures on maintenance phenobarbital.
She has an uncoordinated suck and is deemed unsafe to orally feed.

You have been consulted for palliative care support.
You are following her after discharge home.

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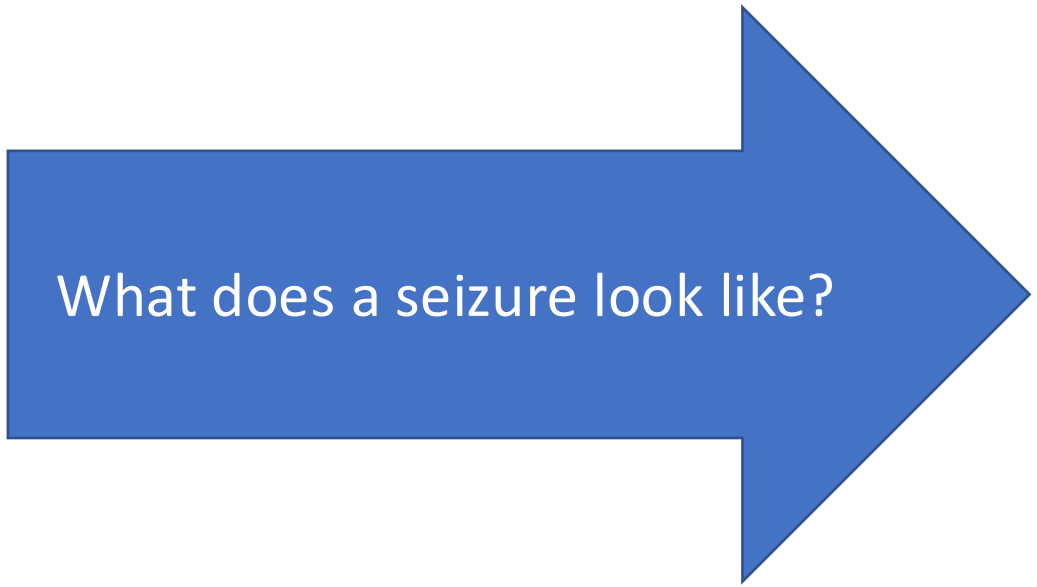
# Neurology: Seizure



# Neurology: Seizure Management

If focus is to prolong life…

- call Neurology
- 911/EMS

If focus is on comfort, consider…

- helpful investigations
- route for pharmacological treatment
  - maintenance
  - breakthrough

# Pediatric Palliative Care Approach to Pain & Symptom Management

Dana Farber Cancer Institute/Boston Children's Hospital
Pediatric Advanced Care Team

| | |
|---|---|
| **LORazepam**<br>2mg/mL; 0.5mg, 1mg, 2mg tabs | 0.1 mg/kg (4–6 mg) PO/SL/PR/IV q15 min x 2 |
| **Midazolam**<br>2mg/mL, 5mg/mL | 0.2 mg/kg SL, intranasal, or IV (10 mg) x 2;<br>5mg/mL with mucosal atomization device (MAD) for intranasal |
| **DiazePAM**<br>2.5mg, 5mg, 10mg rectal gel | 2–5 years: 0.5 mg/kg q15 minutes x 3<br>6–11 years: 0.3 mg/kg q15 minutes x 3<br>> 12 years: 0.2 mg/kg q15 minutes x 3 |

POGO
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FOR KIDS WITH CANCER FOR NOW, FOR LIFE.

Provincial Council for Maternal and Child Health
building a brighter future

Symptom Management for Children Near/At End-of-Life

EXPERT OPINION GUIDANCE FROM THE ONTARIO PEDIATRIC PALLIATIVE CARE STEERING COMMITTEE: 2023 UPDATE

# Seizure Management

## Symptom management plan

SEIZURES

Step 1: Position on side (recovery position)

Step 2: For seizures greater than 3-5 minutes, take Lorazepam 0.5mg sublingual.

Step 3: If seizures are continues for 5 minutes, repeat Lorazepam 0.5mg sublingual.

Step 4: If seizures continues for 5 minutes, call 911

## Sudden unexpected death from epilepsy - SUDEP

- Counselling
- DNR-C
- Support
- Discuss what death associated with seizures could look like

# Case Study – Maria

Maria's parents chose to pursue a G-Tube.

Maria, now 3, has had ongoing difficulty with feeding intolerance, constipation, vomiting and excess secretions.

You receive a page that Maria is back in the ED with vomiting.

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# Gastrointestinal – Feeding

If focus is to prolong life…

- Insert feeding tube
- Feeding tube management

If focus is on comfort, consider…

- TFI management
- Oral care
- Skin care

# Gastrointestinal: Feeding intolerance

# Gastrointestinal: Feeding intolerance

- Treat constipation
- Consider formula alternatives or changes to feeding schedule
- Assess for and treat reflux
- Assess candidacy post-pyloric feeds
- Decrease total feed volume
- Treat visceral hyperalgesia

# Gastrointestinal: Constipation

‘Start big and then titrate down’

Consider softeners +/- stimulants

Start with PEG 3350

Ensure adequate hydration

Use the underlying diagnosis and using your imagination:

- Methylnaltrexone (opioid induced constipation)

# Gastrointestinal: GERD

**Decrease Acid**

- Check pH
- Proton pump inhibitor
  - Start, optimize, or rotate

**Keep things moving**

- Treat constipation
- Use prokinetic
  - Start, optimize, or rotate.

# Nausea and vomiting

## Assessment

What can cause nausea and vomiting in a child with life-limiting illness?

## Treatment

- Targeting the receptor/mechanism to target
- Consider the underlying cause.

# Secretion management

- Medications
  - Ophthalmic atropine 0.5-1%, 1-2 drops SL q4-6h
  - Glycopyrrolate 40-100mcg/kg/dose tid-qid

  - Anti-cholinergic side effects (tachycardia, urinary retention, constipation, flushing)

- Salivary duct ligation
- Botox
- Decrease fluid intake

# Gastrointestinal: Visceral Hyperalgesia

- Tissue inflammation or injury results in sensitization of the internal organs.
  - GERD
  - Constipation
  - GI Surgery (G-tube)
  - Infection

- **Normal** stimuli (distension or pressure) in the GI tract results in pain

Pause

# Case Study – Maria

Maria is now 7 years old.

Family reports increasing episodes of irritability they cannot explain.

They worry about her quality of life.

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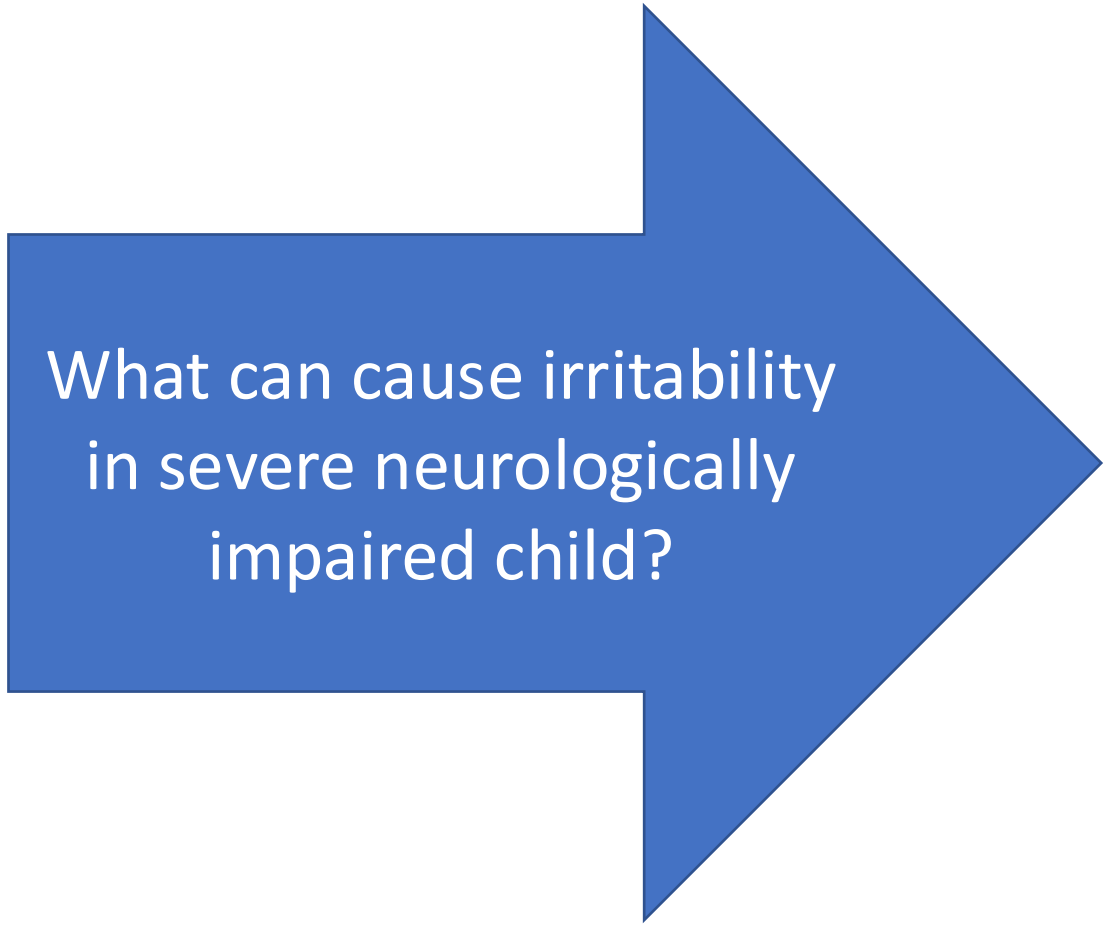
# Neurology - Irritability



# Neurology - Irritability

If focus is to prolong life…

- Balance of sedation
- Need for investigations
- Threshold for side effects

If focus is on comfort, consider…

- Start medications (no investigations)
- More aggressive titration
- Quicker progression to second line

# Neuro-irritability

Unexplained irritability in neurologically impaired children

Diagnosed after somatic pain sources are ruled-out

Consider potential triggers

Neuro-journey, Courageous parents network

# An Approach to irritability

1. Focused History
2. Physical Exam
3. Generate Differential Diagnosis
4. Consider appropriate investigations
5. Treat symptoms appropriately – Non-pharm and pharm
6. Consider a trial of Gabapentin or pregabalin
7. Manage triggers
8. Have PRN medication available: symptom management plan for acute symptoms

**TABLE 1**
**Approach to agitation/irritability**

| Thought-provoking questions | Elements to consider |
|---|---|
| Is this agitation/irritability? | • Completing a detailed history and physical examination is essential to:<br>○ Differentiate between agitation/irritability versus changes in functioning resulting from primary psychiatric illness, encephalopathy and delirium (7) |
| What are the provoking factors? | • Pain is of key consideration; nociceptive pain (somatic and/or visceral) and neuropathic pain must be considered (Figure 1)<br>• Systemic symptoms can lead to agitation/irritability especially in children with neurological impairment. Dyspnea, nausea and dysautonomia should be considered<br>• Psychological distress should also be considered |
| Are medications contributing? | • Drug toxicity should be considered and trial discontinuation of specific medications may be indicated |

# Sources of nociceptive pain in children with SNI

| Common | Less Common |
| --- | --- |
| Musculoskeletal (osteopenia, scoliosis, hip subluxation, pathological fractures) | Dental caries |
| Hypertonia (spasticity, dystonia) | Non-specific back pain |
| Muscle fatigue and immobility | Renal stones and urinary tract infections (UTI) |
| Constipation | Pancreatitis |
| Gastro-oesophageal reflux disease (GORD) | Cholecystitis (tube feeding) |
| Gastrointestinal dysmotility (autonomic and post-surgical e.g., fundoplication) | Ventricular shunt blockage, infection |
| Iatrogenic | Headache |
| Sources common to all children (e.g., Otitis media, dysmenorrhoea, appendicitis) | |

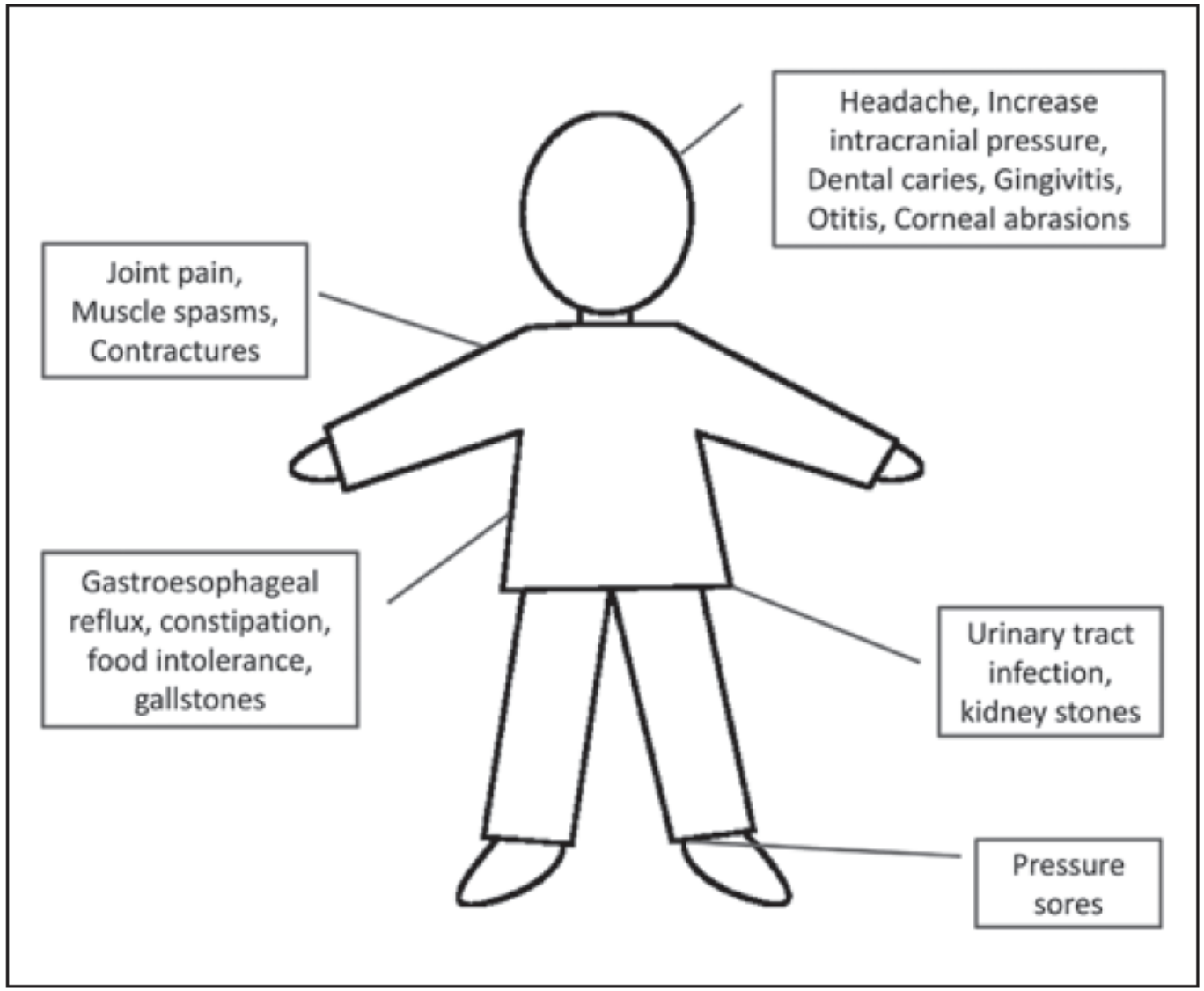



**Figure 1)** *Sources of hidden pain in children with neurological impairment.*

# neuro-irritability versus neuropathic pain versus visceral hyperalgesia

# Gabapentin and Pregabalin

**TABLE 8** Analgesic Dosing Guidelines and Suggested Titration Schedules

Gabapentin

- Days 1–3: 2 mg/kg (100 mg maximum), enterally, 3 times daily
- Days 4–6: 4 mg/kg, enterally, 3 times daily
- Increase every 2–4 days by 5–6 mg/kg per day until the following[92]:
  1. Effective analgesia reached (may be noted at 30–45 mg/kg per day)
  2. Side effects experienced (nystagmus, sedation, tremor, ataxia, swelling)
  3. Maximum total dose of 50–72 mg/kg per day reached (2400–3600 mg/day)
  4. Younger children (<5 years) may require a 30% higher mg/kg per day dosing, such as a total dose of 45–60 mg/kg per day[13,103,104]
  5. Half of the total daily dose may be given as the evening dose if symptoms occur mostly in the evening and overnight
  6. Titrate more rapidly for severe pain or as tolerated, titrate more gradually if sedation noted

Pregabalin

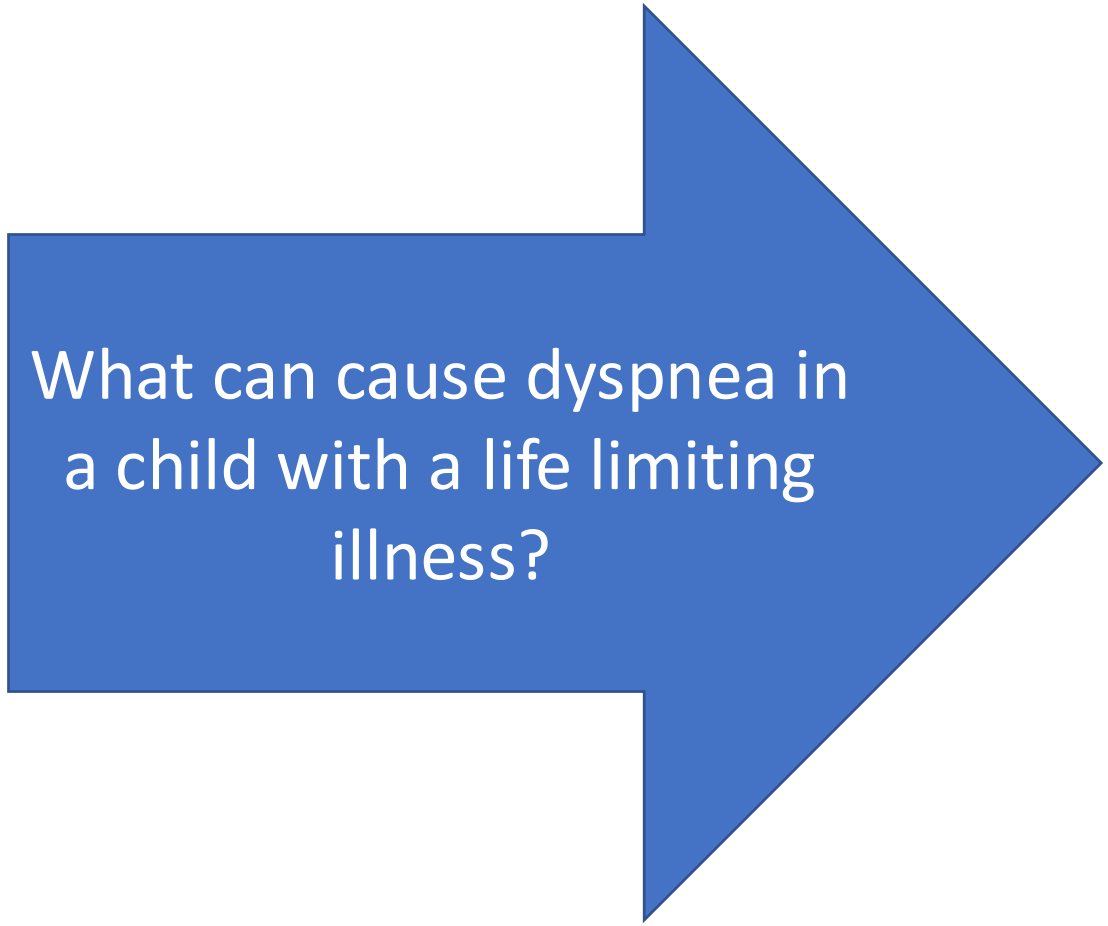
- Days 1–3: 1 mg/kg (50 mg maximum), enterally, every night
- Days 4–6: 1 mg/kg, enterally, twice daily
- Increase every 2–4 days up to 3 mg/kg per dose, enterally, given 2 or 3 times daily (maximum 6 mg/kg per dose)

# Case Study – Maria

Less than 1 year later, Maria is back in the ED with increased work of breathing.

Family asks to see you.

# Respiratory – Dyspnea



# Respiratory symptoms

If focus is to prolong life…

- Focus on treating underlying cause
- Use of ventilation

If focus is on comfort, consider…

- Faster initiation of medications
- Less reliance on invasive assessments and interventions

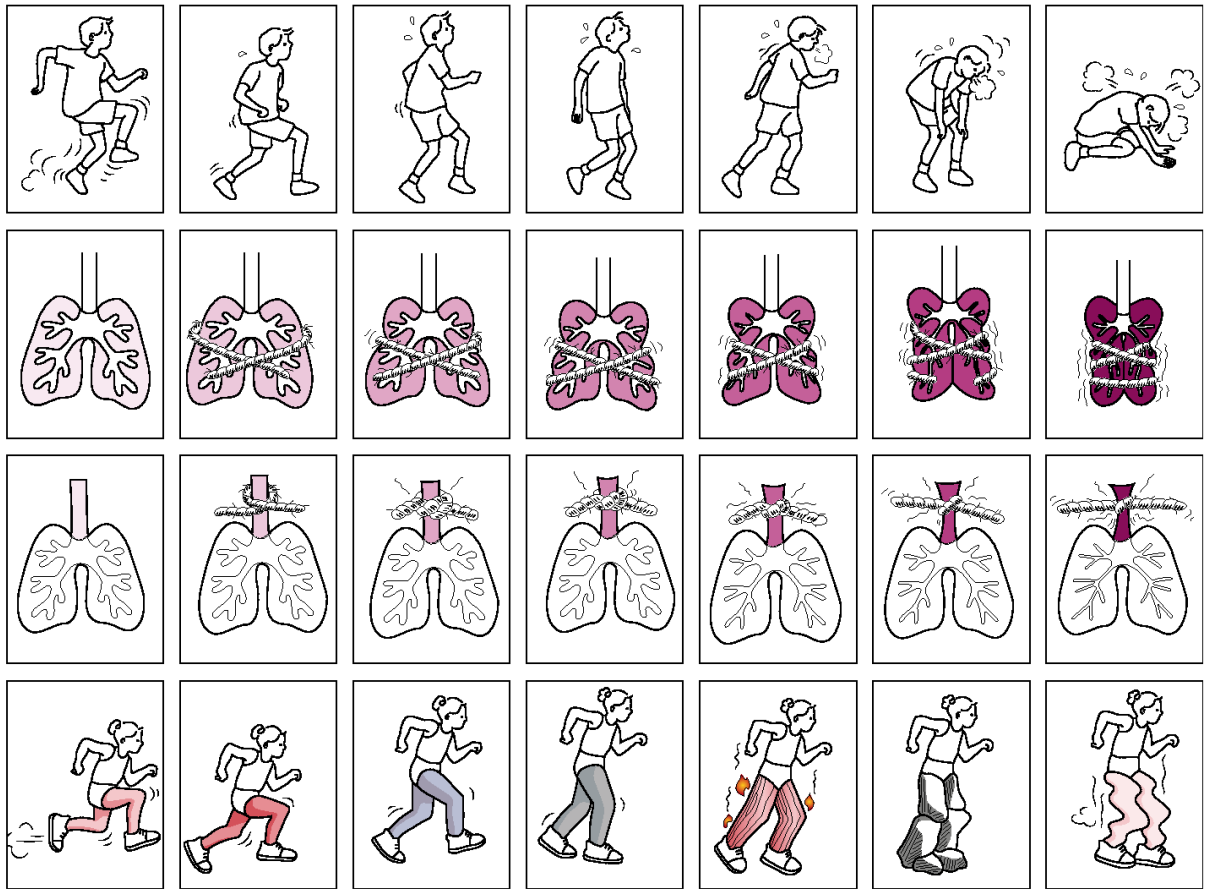
# Dyspnea

Subjective sensation of being unable to breathe adequately

Usually accompanied by anxiety

Does NOT correlate with RR, SPO2, blood gases

# Dalhousie Dyspnea Scale



# Dyspnea (non-pharmacological)

| |
|---|
| Treat underlying cause based on goals of care |
| Resist the urge to crowd |
| Keep the room light |
| Position, position, position |
| Open a window or use a fan |
| Distraction and guided imagery |

# Dyspnea (pharmacological)

| Opioids | Benzodiazepines |
| --- | --- |
| 25-50% of analgesic doses | Correlation between dyspnea and anxiety |
| | |
| **Oxygen** | **Other Considerations** |
| Use controversial | Non-invasive ventilation |
| Oxygen vs room air | Radiation/steroids |
| Seems to be helpful when both dyspnea and hypoxia present | |
| | |

Where do you start when discussing symptom management?

...with a family's goals of care

# Create a Symptom Management Plan

**Irritability/Pain**
Step 1: Give Tylenol
If not effective in 15 minutes,
Step 2: Give Clonidine
If not effective in 15 minutes,
Step 3: Give Morphine
If not effective in 15 minutes,
Step 4: Call QoLA Care

**Seizures**
If they last longer than 5 minutes:
Step 1: Midazolam intranasal and call QoLA care
If seizures continue for another 5 minutes:
Step 2: Midazolam intranasal

**Constipation:**
Dulcolax half suppository every 2 days rectally
If no bowel movement in 24hrs,
Step 1: Dulcolax half suppository daily
Then, if no bowel movement in another 24hrs
Step 2: Fleet Enema rectally
Then, if no bowel movement in another 24 hrs
Step 3: Call QoLA Care

**Vomiting**
Step 1: Ondansetron
If no response after an hour
Step 2: Call QoLA Care

# Resources

**Pediatric Palliative Care Approach to Pain & Symptom Management**

Dana Farber Cancer Institute/Boston Children's Hospital
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together for short lives

**Basic Symptom Control in Paediatric Palliative Care – new edition May 2022**

# Reflections

1. What is your key takeaway from today's session?

2. What is something new that you plan to apply to your clinical practice?

3. What challenges do you face in your practice when it comes to symptom management? What have others found helpful?

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THANK
YOU