Symptom Management

Project ECHO Core Competency

June 7, 2023

Drs. Kevin Weingarten & Natalie Jewitt

it’s nice to meet you...

Disclosures

- We will not be discussing pain
- Our talk today relies on you - our amazing audience
- Many medications used in pediatric palliative care are off-label

Objectives

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

- Explain how goals of care impact symptom management strategies
- Describe symptom management strategies for:
  - Seizures
  - Feeding intolerance
  - Sialorrhea
  - Neuroirritability
  - Dyspnea
- Access resources specific to symptom management in pediatric palliative care

Where do you start when discussing symptom management?

…with a family’s goals of care

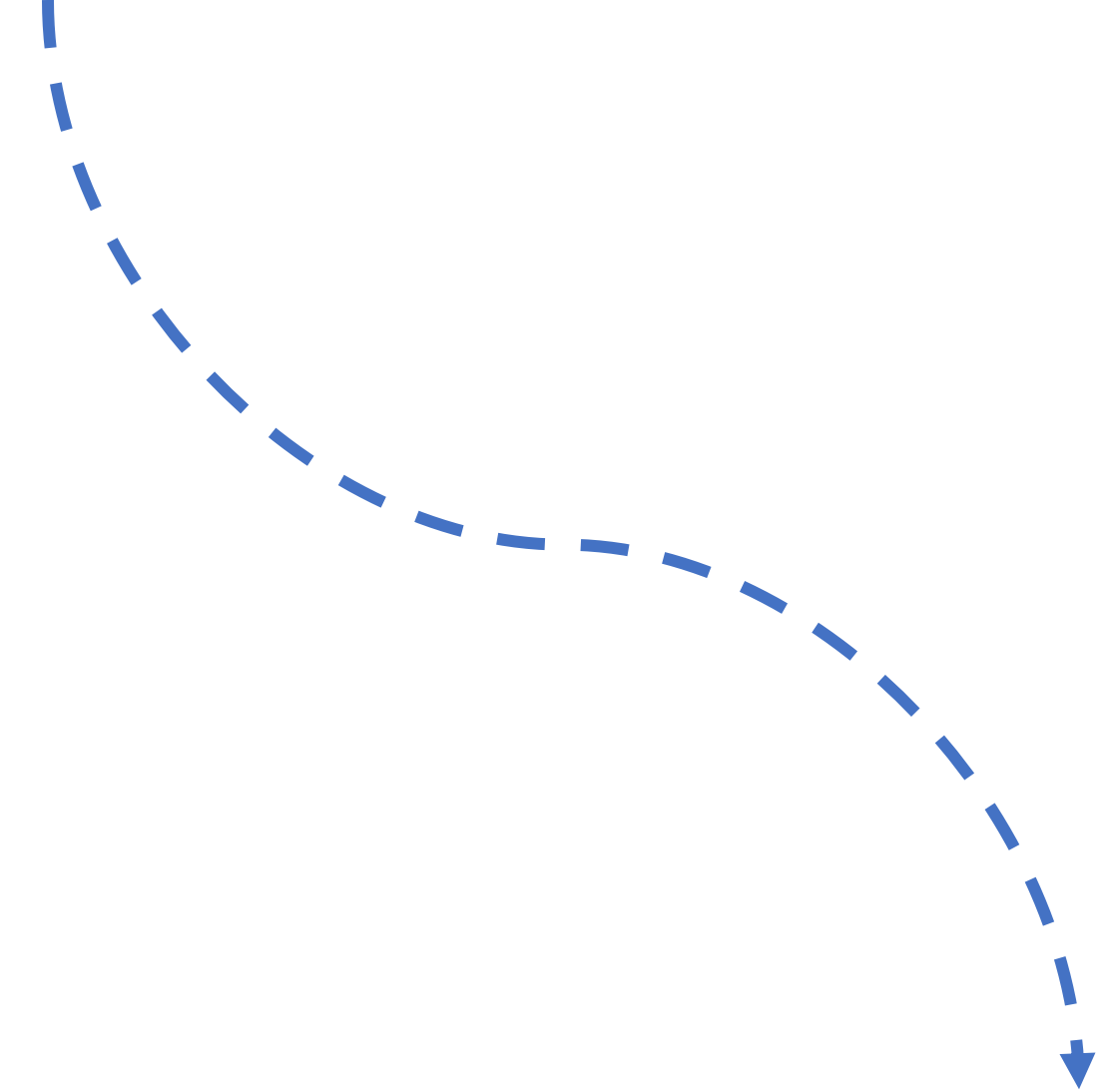
Prolong life

Comfort

Arevia 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.



How does this story unfold?

Seizure management

If focus is to prolong life…

call neurology.

If focus is on comfort, consider…

your route

your location of care

your maintenance

your breakthrough

Pediatric Palliative Care Approach to Pain & Symptom Management

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

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

Feeding

If focus is to prolong life…

insert a feeding tube.

If focus is on comfort, consider…

oral care

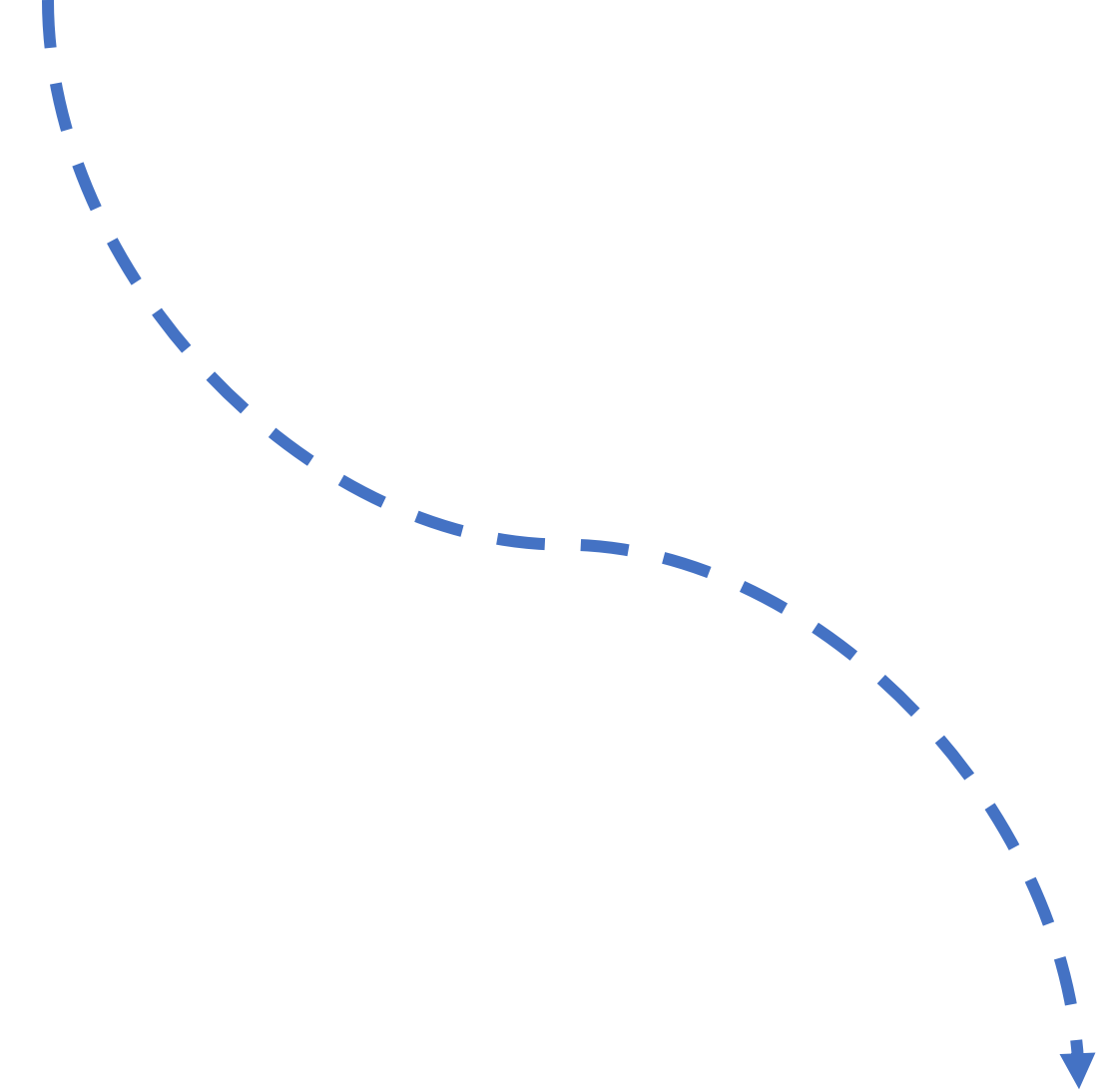
skin care

counselling

Arevia’s parents chose to pursue a G-Tube and a few years have passed.

Arevia has had ongoing difficulty with feeding intolerance and secretions. She has had multiple admissions to hospital with aspiration pneumonias.

You receive a page that Arevia is back in the ED with fever and respiratory distress.



How does this story unfold?

Secretion management

- Medications
  - Ophthalmic atropine 0.5-1%, 1-2 drops SL q4-6h
  - Glycopyrrolate 40-100mcg/kg/dose tid-qid
  - Scopolamine patch (1mg) behind ear q72h
- Salivary duct ligation
- Botox
- Decrease fluid intake

Feeding intolerance

…or constipation?

‘start big and then titrate down’

consider softeners +/- stimulants

PEG 3350

February 2020 | Form P5593E | www.cheo.on.ca

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WHAT YOU NEED TO KNOW: CONSTIPATION

Slowing of the bowels causes stool to become hard, dry, and difficult to pass. This sometimes causes a large mass of impacted stool in the rectum (the part of the bowel that holds stool). Stool builds up behind the impaction and may leak liquid stool out of the anus, soiling a child's underwear.

Contact your health-care provider if your child or youth:

- has severe pain or pain lasting longer than 30 minutes
- gets a fever
- has vomiting
- loses weight
- wakes up from sleep to pass stool
- keeps crying and you can't soothe them
- develops cracks in the skin around the anus (anal fissure)
- has intestine drooping out the anus (rectal prolapse)
- is still having problems with constipation after following the above plan for two weeks
- has lots of blood in the stool

How is constipation treated?

Children and youth usually need medication for a few months, along with some other steps to resolve constipation. They can take medication by mouth or through the rectum (bum). We usually suggest medications by mouth. You won't need a prescription, but you may have to ask the pharmacist for these medications.

Step 1: PEG3350 bowel clean out

The first step is to clean out the bowels using an oral laxative that has polyethylene glycol 3350 (PEG3350). Not all laxatives have this key ingredient, so read the label carefully. Some common brands that have PEG3350 are Lax-a-Day®, Restoralax®, Relaxa® and Clearlax®.

Weight	Dose of PEG3350	Frequency
7-10 kg	2 tsp in 100 mL fluid	Twice a day for 3 days
11–13 kg	3 tsp in 150 mL fluid	Twice a day for 3 days
14–19 kg	4 tsp in 200 mL fluid	Twice a day for 3 days
20–34 kg	5 tsp in 250 mL fluid	Twice a day for 3 days
35-50 kg	5 tsp in 250 mL fluid	3 times a day for 3 days
50+ kg	10 tsp in 500 mL fluid	3 times a day for 3 days

Bowel clean out routine for children older than six months.

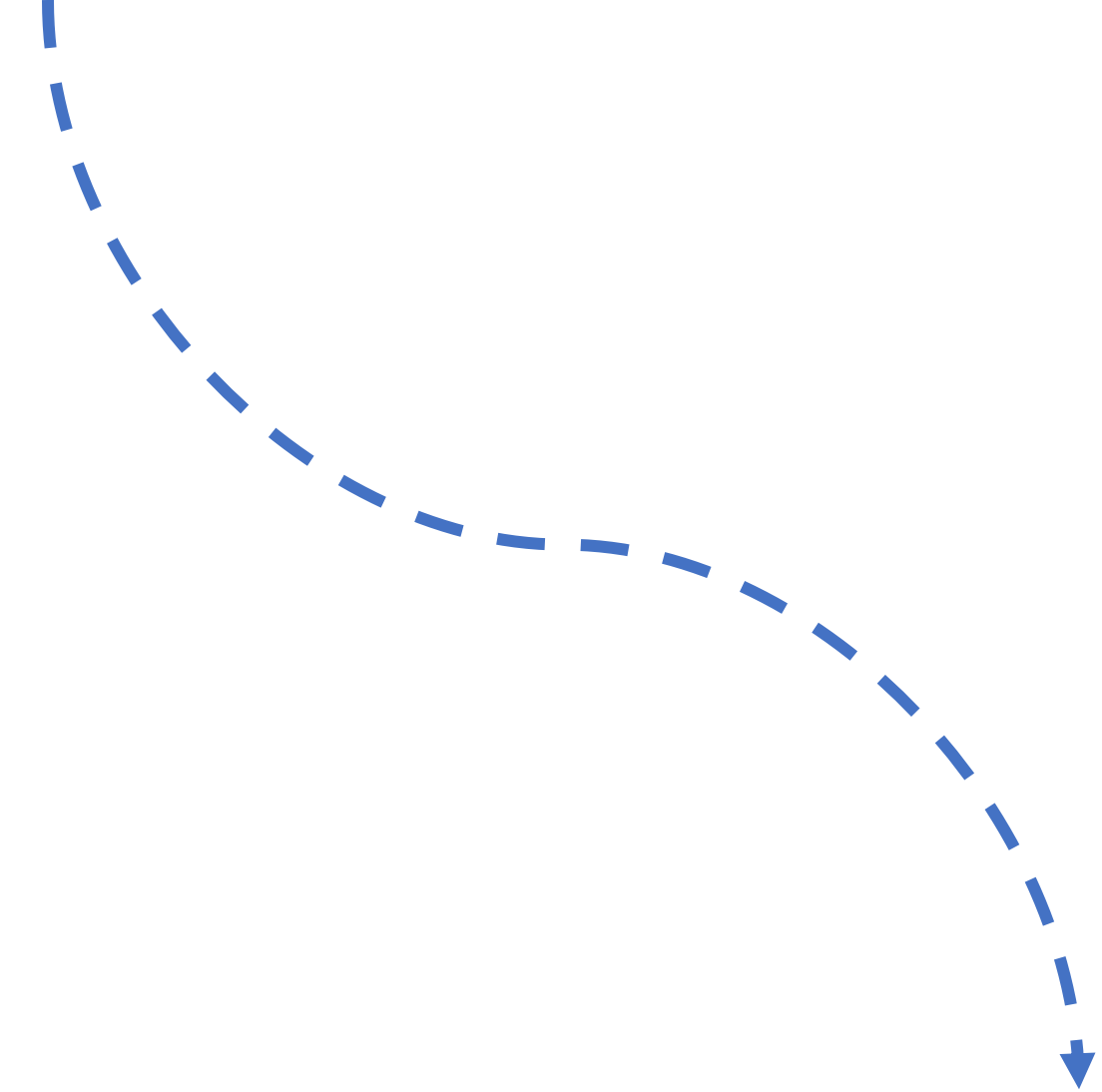
Feeding intolerance

- Consider formula alternatives or changes to feeding schedule
- Assess for and treat reflux
  - Test gastric pH
  - Start or optimize a proton pump inhibitor
  - Start or optimize a motility agent
- Assess candidacy for fundoplication or post-pyloric feeds
- Decrease total feed volume

Arevia is now 7 years old.

Family reports increasing episodes of irritability they cannot explain.

They worry about her quality of life.

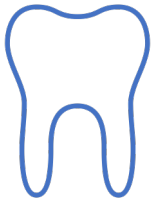


How does this story unfold?

Neuroirritability (neuropain)

Unexplained irritability in neurologically impaired children

Only diagnosed after somatic pain sources have been ruled-out

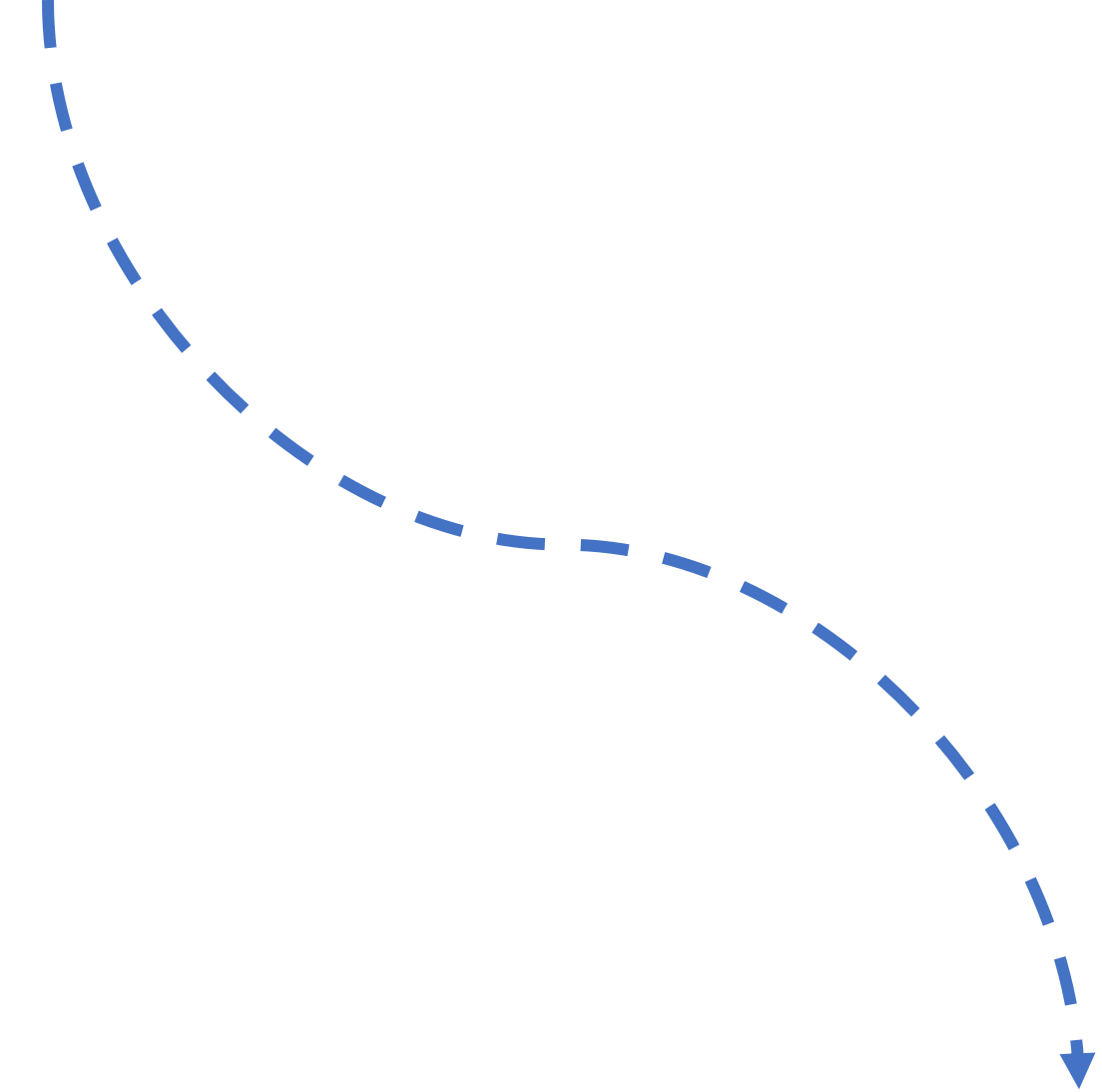


Consider potential triggers

Neuroirritability (neuropain)

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

Family asks to see you.



How does this story unfold?

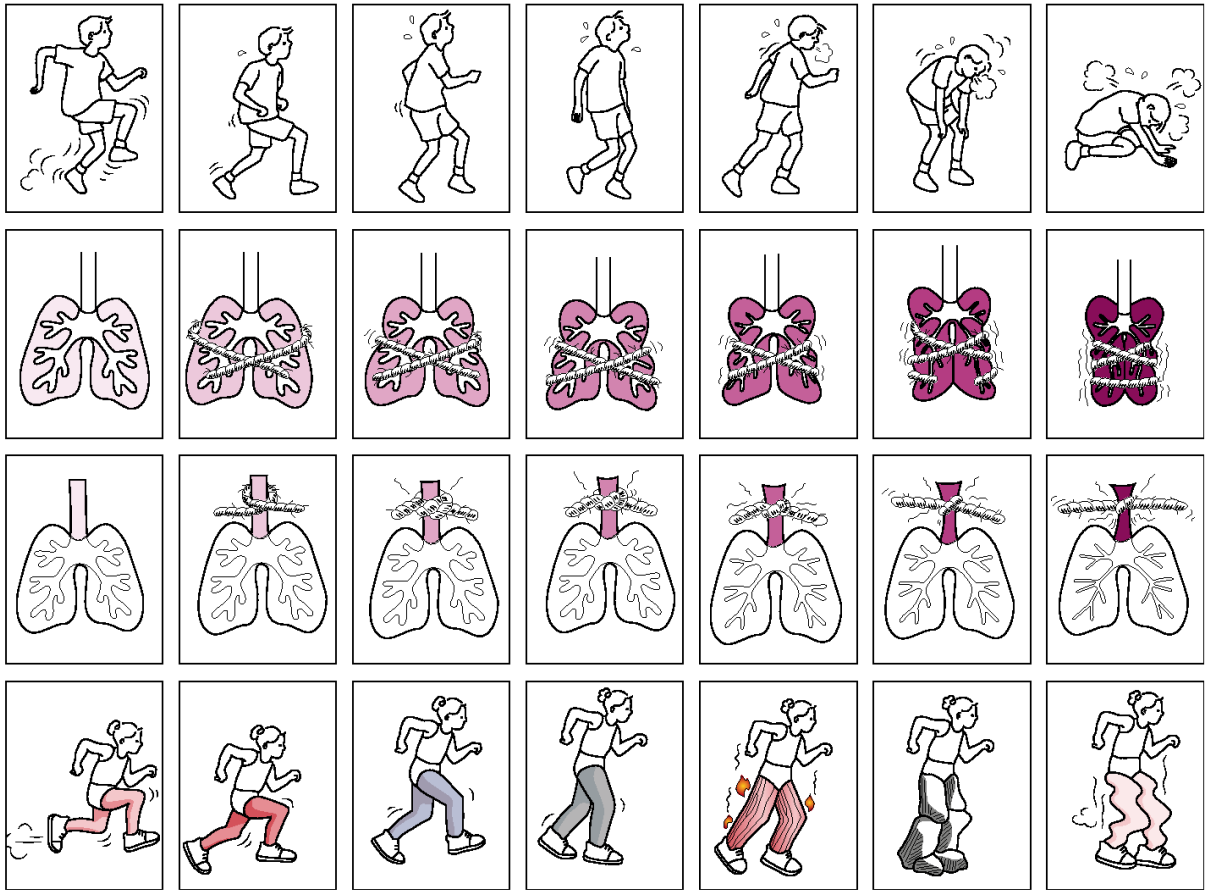
Dyspnea

Subjective sensation of being unable to breathe adequately

Usually accompanied by anxiety

Does NOT correlate with RR, SPO2, blood gases

Dalhousie Dyspnea Scale



Dyspnea

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

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	

Resources

COURAGEOUS PARENTS NETWORK

Pediatric Palliative Care Approach to Pain & Symptom Management

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

together for short lives

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

SickKids® | Paediatric Advanced Care Team (PACT)

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?

4. What have others found helpful?

References

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Thank you!