Symptom Management Beyond Pain

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Previous Courses

2/02 Foundation of Pediatric Palliative Care (Leilatul Ferdous)

9/02 Holistic and Specialized Pediatric Palliative Care (Pauline Uwa)

16/02 Pain in Pediatric Palliative Care (Janane Hanna)

Learning outcomes

At the end of this session, learners will be able to

1. List the most common symptoms in pediatric palliative care
2. Assess the severity of symptoms with the appropriate scales
3. Describe the best strategies known to reduce those symptoms
4. Propose non-pharmacological nursing interventions
5. Understand the impact of symptom management on well-being
6. Know where to find open-access resources to manage symptoms

Which are the predominant symptoms?

1. Anorexia
2. Nausea & Vomiting
3. Constipation
4. Dyspnoea
5. Fatigue
6. Seizures
7. Spasticity and Dystonia
8. Anxiety and Depression

1.Anorexia (=loss of appetite)

- **Assessment**:

Constipation, Pain, Dyspnoea, Depression, Nausea, Oropharyngeal problems, Medications, Radiotherapy

- **Lanksy Play- Performance Scale**
- **Management**:

! Food = Love (Parenting)

Treat the underlying causes

Encourage the child to eat for pleasure

Prepare small, tasty, (cold) portions

LANSKY PLAY-PERFORMANCE SCALE

Able to carry on normal activity; no special care is needed >16 y		Able to carry on normal activity; no special care is needed <16 y	
100	Normal, no complaints, no evidence of disease	100	Fully active
90	Able to carry on normal activity	90	Minor restriction in physically strenuous play
80	Normal activity with effort	80	Restricted in strenuous play, tires more easily, otherwise active
Unable to work, able to live at home cares for most personal needs, a varying amount of assistance is needed		**Mild to moderate restriction**	
70	Cares for self, unable to carry on normal activity or to do active work	70	Both greater restrictions of, and less time spent in active play
60	Requires occasional assistance but is able to care for most needs	60	Ambulatory up to 50% of time, limited active play with assistance/supervision
50	Requires considerable assistance and frequent medical care	50	Considerable assistance required for any active play, fully able to engage in quiet play
Unable to care for self, requires equivalent of institutional or hospital care, disease may be progressing rapidly		**Moderate to severe restriction**	
40	Disabled, requires special care and assistance	40	Able to initiate quite activities
30	Severely disabled, hospitalization indicated, although death not imminent	30	Needs considerable assistance for quiet activity
20	Very sick, hospitalization necessary	20	Limited to very passive activity initiated by others (e.g., TV)
10	Moribund, fatal process progressing rapidly	10	Completely disabled, not even passive play

Generally, the **Lanksy Play-Performance Scale** is used in children. This scale uses the parent's description of the child's activity to assess their activity level

Doherty, M. (2025) Global Handbook of Children's Palliative Care ; Appendix 7, p 222

2. Nausea & Vomiting

- **Assessment:**

Metabolic abnormalities, opioids, chemotherapy, radiotherapy, antibiotics, infection, constipation, high Intracranial pressure (brain tumour or metastases), anxiety

- **Management :**

Treat underlying conditions (e.g. for ICP: corticoids)

Diet (small portions) and eliminate strong odours & ensure fresh air

Remove non-essential medications

Provide emotional support and treat anxiety

Ensure good oral care

Aromatherapy (Peppermint, Ginger oil), acupressure, acupuncture

Pharmacological treatment: Metoclopramide (extrapyramidal reactions! Not to use if bowel obstruction!), cyclizine, haloperidol (extrapyramidal reaction!), ondansetron

3. Constipation

- **Assessment:**

Opioids, dehydration, immobility, stress, electrolyte imbalances (hypokaliaemie, hypercalcaemia), neuropathic conditions, nerve disorders, cystic fibrosis, inadequate fibre in tube feeding.

- **Management:**

Prevention is key (hydration, activity, laxatives if opioids)

Treat underlying causes

If NOT in EOL stage: increase fluids, fibres, activity, abdominal massage

Pharmacological treatment: laxatives (sennosides, lactulose, polyethylene glycol PEG, glycerin or bisacodyl suppository)

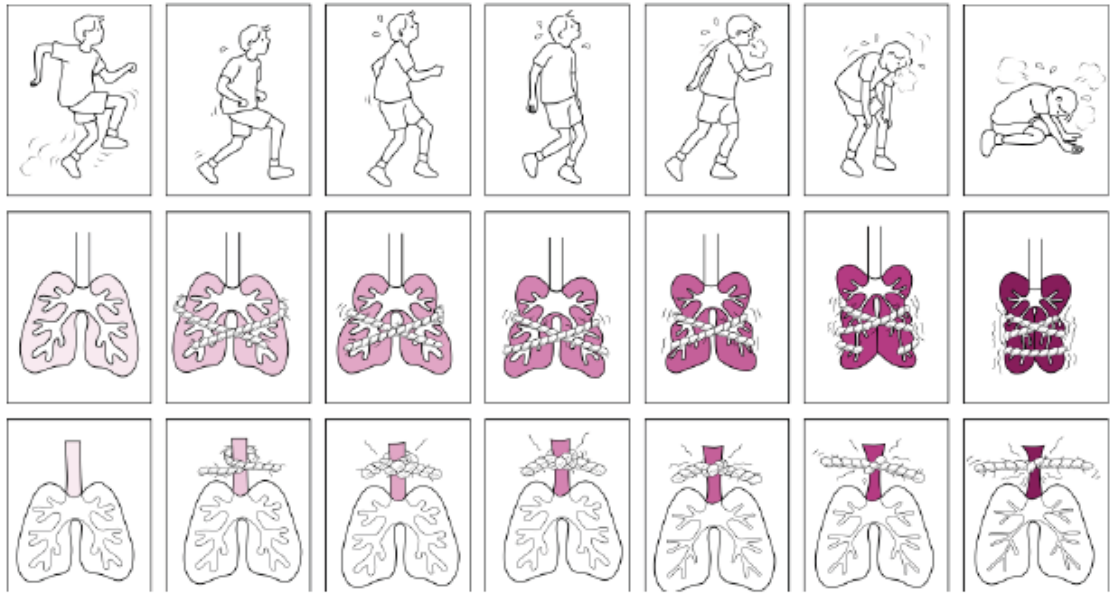
Attention: child with neutropenia/thrombocytopenia: NO suppository or enema

=> Risk of bleeding

4. Dyspnoea

Assessment: "Is your breathing troubling you?"

Figure 1. Dalhousie Dyspnea Scales (Pianosi PT, Huebner M, Zhang Z, McGrath PJ. Dalhousie Dyspnea and Perceived Exertion Scales: Psychophysical properties in children and adolescents. Respir Physiol & Neurobiol. *2014 Aug 1;199:34-40.*



In Doherty, M. (2025) GHCPC, p. 59

Management:

Treat underlying cause

Morphine subcut/IV 0,05 mg/kg/dose every 4 hours

peros 0,1 mg/kg/dose every 4 hours

Corticosteroids, diuretics, bronchodilatators (via nebulizers)

Position, handheld fan

Relaxation techniques, visualization

Oxygen ? Sat O2 not linked to subjective perception

Causes:

Pulmonary (lung metastasis), cardiac, haematologic (anaemia) or other (anxiety, obesity,...)

5. Fatigue

Is 1 of the 3 most commonly reported symptoms in EOL care in children

Holistic Assessment of fatigue:

Physical (pain, nausea, vomiting, seizures), **cognitive** (lack of concentration, irritability), sleep (somnolence, insomnia, non-restorative sleep), **emotional** (anxiety, depression, avoidance in play and social activities, apathy, lack of motivation)

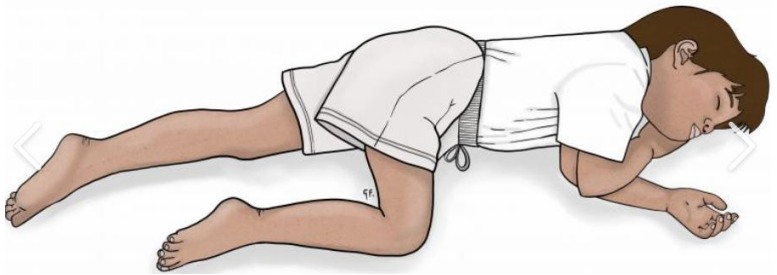
Management:

Patient-reported factors, including symptoms and underlying disease

Child factors, their age and developmental and cognition

Clinical factors, treatment regimes and side-effects of treatments

6. Seizures (focal or generalized)



Assessment:

Primary neurologic disease (e.g. epilepsy, brain tumour, brain injury, stroke,…)

Drug toxicity (e.g. pethidine/meperidine)

Metabolic/electrolyte abnormalities (Hypoglycaemia, Hyponatraemia, Hypercalcaemia)

Central nervous system infections

Management:

Position child on their side

If > 5 min seizures persist:

Pharmacological treatment

LORAZEPAM	0,1 mg/kg/dose	PO, SL, Buccal, subcutan, IV, IO, rectal
MIDAZOLAM Midazolam injectable solution can be given buccaly	0,1 mg/kg/dose 0,5 mg/kg/dose 0,2 mg/kg	IV, IO or subcutan Buccal intranasal
DIAZEPAM	0,3 mg/kg/dose 0,5 mg/kg/dose	IV, IO or subcutan rectal

7. Spasticity and Dystonia

Definitions:

- Spasticity: involuntary increase in muscle tone
- Dystonia: involuntary muscle contraction with abnormal movements and body positions

Assessment:

Cerebral palsy, brain injuries, demyelinating diseases,...

OBSERVATION + Ashworth Scale of Muscle tone

Management:

- **Multidisciplinary approach** (physiotherapy, occupational therapy, rehabilitation specialists)
- **Pharmacological** treatment

Spasticity: Diazepam, Baclofen, Clonidine, Tizanidine

Dystonia: Baclofen, Clonidine, Diazepam, Gabapentin

- **Surgical** treatment

Selective dorsal rhizotomy, intrathecal baclofen pump, orthopedic surgery to correct muscle shortening

Table 1. Ashworth Scale of Muscle Tone

1	No increase in tone
2	Slight increase in tone, "catch" when limb is moved
3	Marked increase in tone, passive movements difficult
4	Considerable increase in tone, passive movements difficult
5	Affected part is rigid in flexion or extension

8. Anxiety and Depression

! High risk of anxiety and depression in children with LLC
(Barker, M. M., Beresford, B., & Fraser, L. K. (2023). Incidence of anxiety and depression in children and young people with life-limiting conditions. Pediatric research)

Assessment:

Pain, Non-disclosure, Family conflicts, Parental distress, Spiritual/existential distress, Uncertainties, Anticipatory grief

Validated Scale for > 7 y old children: Screen for Child Anxiety Related Disorders (SCARED) to find here https://novopsych.com/wp-content/uploads/2025/08/child-anxiety-screening-tool.png

Management:

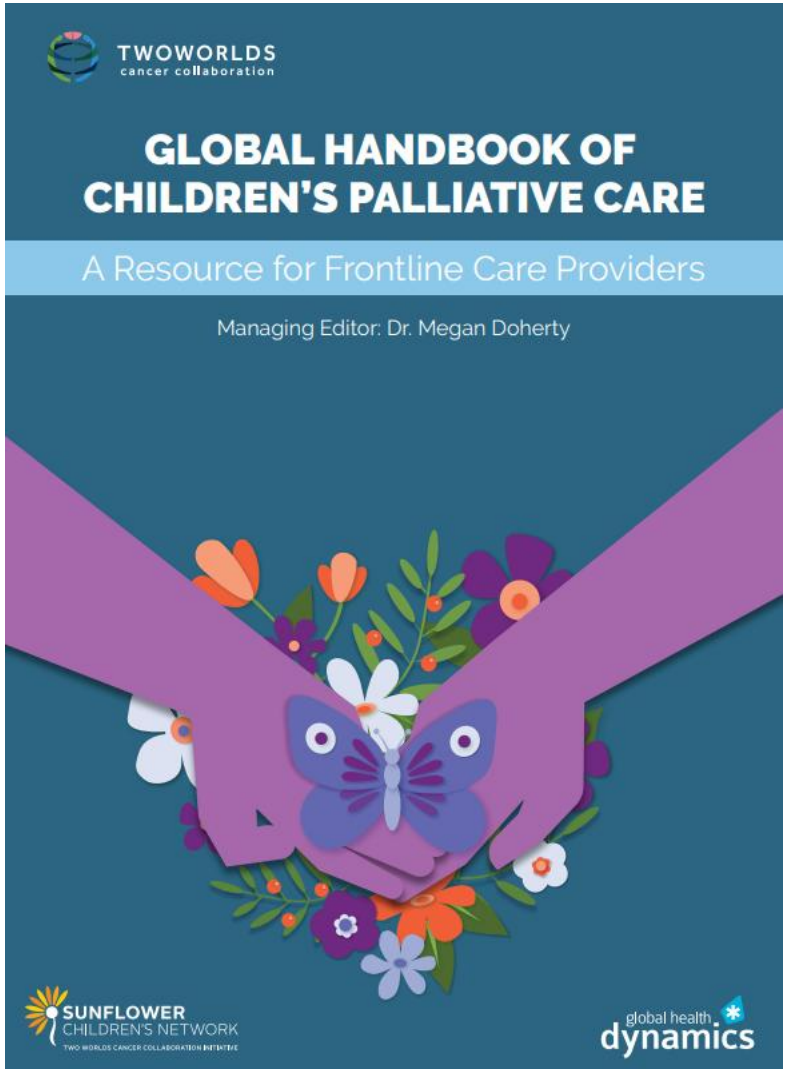
General measures: Use PROMS (e.g. Children palliative outcomes scale CPOS), effective communication, guided imagery, relaxation, mindfulness, breathing techniques

Professional **Psychotherapeutic** interventions: Cognitive behavorial therapy, Dignity therapy, Meaning-centred psychotherapy

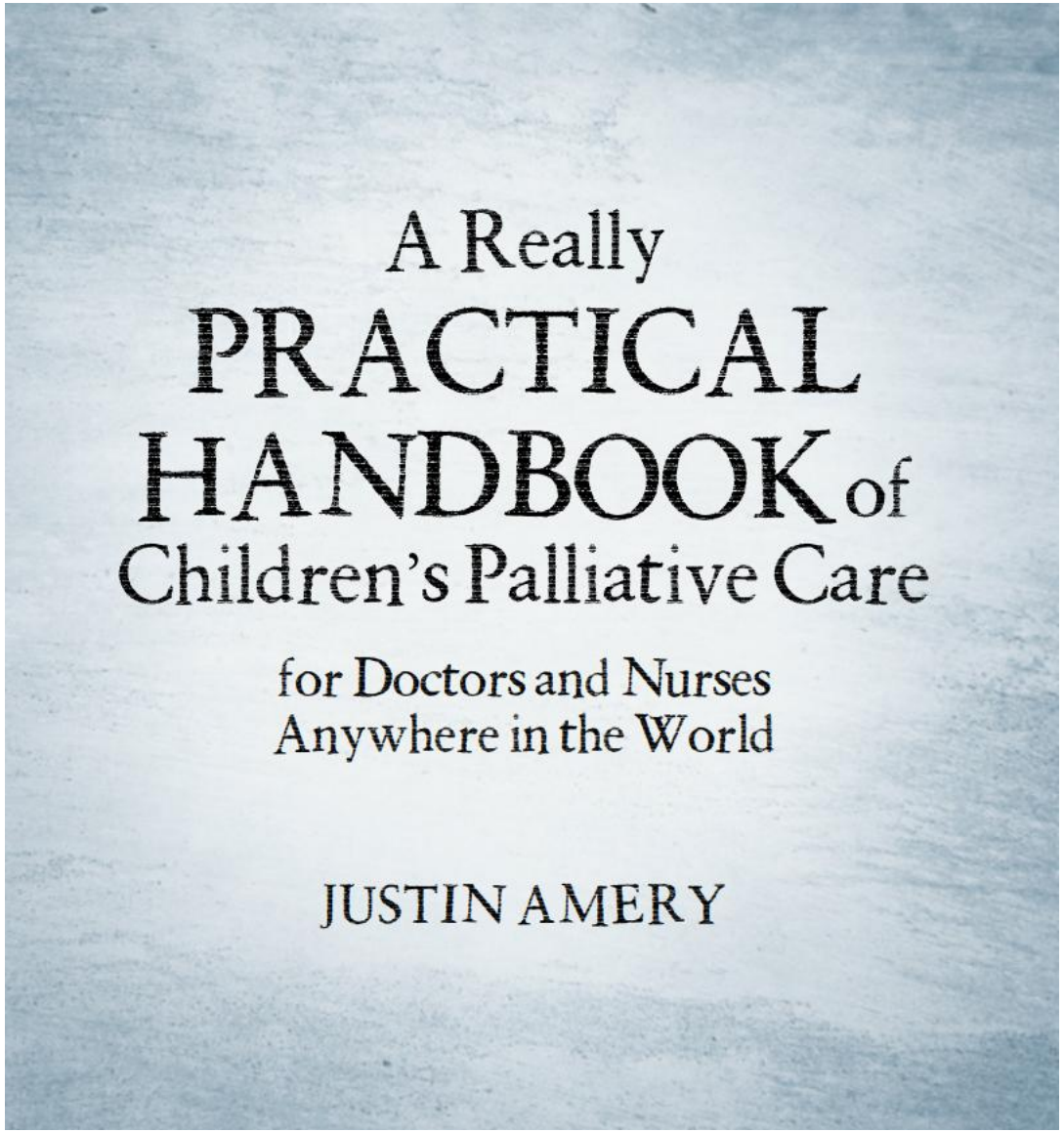
Pharmacological treatment: antidepressant (e.g. Fluoxetine), stimulant (e.g. Methylphenidate, anxiolytics (e.g. Lorazepam, Midazolam), mood stabilizers (e.g. Valproic acid, Carbamazepine), alpha-agonist medications (e.g. Clonidine)

Open access-resources

- https://www.rallyforacause.org.au/wp-content/uploads/2025/11/GHCPC_2025DigitalHandbook.pdf



- https://icpcn.org/wp-content/uploads/2023/01/A-REALLY-PRACTICAL-Handbook-of-CPC.pdf



https://www.togetherforshortlives.org.uk/resource/basic-symptom-control-paediatric-palliative-care/

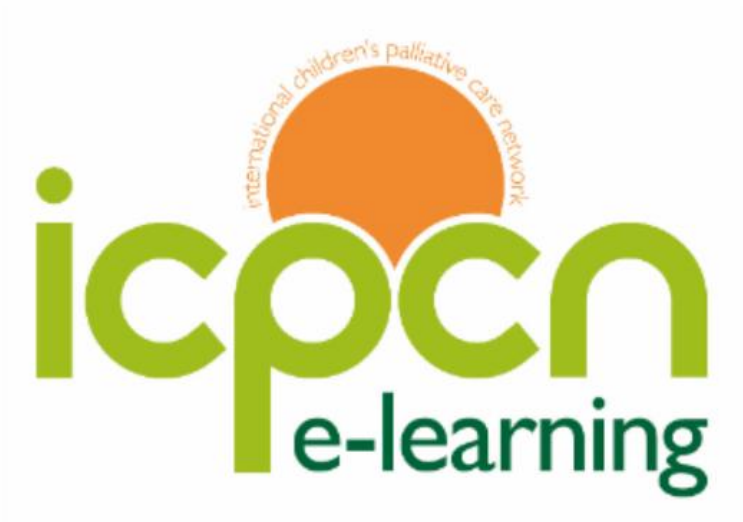
2024

6th Edition of the Formulary of the Association of Pediatric Palliative Medicine 2024

- https://www.appm.org.uk/formulary/

E-learning course on symptom management

- https://icpcn.org/resources/icpcns-e-learning-programme/



References

Amery, J. (2016). A really practical handbook of children's Palliative Care for doctors and nurses anywhere in the world. England. Lulu Publishing Services. 423 p.

Doherty, M. (2025) Global Handbook of Children's Palliative Care. Sunflower children's Network. 256 p.

Randall, D., Neilson, S., Downing, J. (2025) Children's Palliative Nursing Care. Routledge. 378 p.

Together for short lives (2024) Basic symptom control in Pediatric Palliative Care. 10th Edition. 469 p.

Wolfe, J., Hinds, P., Sourkes, B. Eds.(2022) Interdisciplinary Pediatric Palliative Care. 2nd Edition, Oxford Press. 598 p.

Acknowledgements

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