## Introduction

The survival rates of children and young people (CYP) with cancer has improved over the past decades, however, CYP still die from cancer (Sawin et al., 2019). The nurses role is critical to ensure the patient is comfortable and quality of life is maintained as much as possible to assess the patient, provide pain relief and monitor the CYP response to pain management. During this time the wellbeing of the entire family is affected and the support from nurses with daily tasks and routines can alleviate some distress during the last phase of the child's life (Hammer et al., 2022).

### Background

Nurses can provide end-of-life care in a variety of settings including the family home, a hospice, acute wards and specialist units and comprises of emotional, physical, social and spiritual elements (Royal College of Nursing, 2023). The pain for a CYP is one of the most distressing aspects of oncology practice (Moody et al., 2021), and controlling the pain during end of life is a central part of nursing care (British Medical Association, 2017). According to the British Medical Association (BMA) (2017), controlling pain is the most frequently reported barrier. It is essential that 24/7 access to services is provided, as distress of uncontrolled pain and symptoms should not wait for opening hours (National Palliative And End of Life Care Partnership, 2021).

# Advantages

- $\circ$  Cancer pain at end-of-life is responsive to opioid therapy allowing family to focus on other aspects of the process (Moody et al., 2021).
- Giving adequate pain relief can significantly reduce physical and emotional suffering (Royal College of Nursing, 2023).
- Pain relief can improve family relationships, as there is reduced stress levels and they can support the CYP during their difficult time (Together for Short Lives, 2018).
- Improved comfort by relieving symptoms such as nausea and fatigue contributing to their overall well-being (Together for Short Lives, 2019).
- End-of-life training is provided so high quality care can be delivered by confident and competent staff (NHS England, n.d.).
- Close communications with the multidisciplinary team to include a personalised approach to planning and care (NHS England, 2023).

# Delivering Good Pain Relief for Children and Young People With Cancer at End-of-Life By Lucie Jenks (Together For Short Lives, n.d.)

Challenges

O The child or young person may have communication barriers and unable to indicate their level of pain (Van der Geest et al., 2016). • Some families may have cultural or religious beliefs that prevent them from accepting certain types of pain relief (National Institute for Health and Care Excellence, 2016).

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 Side effects can make families hesitant to use due to concerns such as fatigue and shallow breathing (Van der Geest et al., 2016).

• Ethical dilemmas can arise over

treatment choices (Akdeniz et al., 2021).

## Key Points

• Each person should be treated as an individual. Cultural, spiritual, social and emotional needs should be considered and respected.

- Nurses should work closely with the multidisciplinary team to develop a comprehensive plan and update when required.
- o It is important for the nurse to know their patient well to be able to recognise what is causing them distress.
- person and alleviate pain or distress when necessary. validated pain assessment tools.

Score Zero 🔻	Score One 🔻	Score Two 🔻
No particular expression or smile	Ocasional grimace or frown, withdrawn, disinterested	Frequent to constant quivering chin, clenched jaw
Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up
Lying quietly, normal position moves easily	Squirming, shifting back and forth, tense	Arched, rigid or jerking
No crying (awake or asleep)	Moans or whimpers, occasional complaint	Crying steadily, screams or sobs, frequent complaints
Content, relaxed	Reassured by occasional touching, hugging or being talked to, distactable	Difficult to console or comfort
al., 2021).	(Cerebra, 2019)	

Ensure comfort measures by regularly monitoring and assessing the child or young

o It is vital for the nurse to carry out thorough routine symptom assessments using

#### O Nurses can make a difference between a child who suffers and one that is comfortable and pain free when dying, EOL training for nurses will support this.

# References

• Akdeniz, M., Yardimci, B., & Kavukcu, E. (2021). Ethical considerations at the end-of-life care. SAGE Open Medicine, 9(1). https://doi.org/10.1177/20503121211000918

- British Medical Association. (2017). Improving analgesic use to support pain management at the end of life. https://www.bma.org.uk/media/2102/analgesics-end-of-life-1.pdf
- Hammer, N., Hansson, H., Pedersen, L., Abitz, M., Sjogren, P., Schmiegelow, K., Bidstrup, P., Larsen, H., & Olsen, M. (2023). Intersectoral collaboration in home-based end-of-life pediatric cancer care: a qualitative multiple-case study integrating families' and professionals' experiences. Palliaive Medicine, 37(1), 149-162. https://doiorg.ezproxy.herts.ac.uk/10.1177/02692163221135350
- Mahfudah, S. (2011). Nurse's role in controlling cancer pain. Journal of pediatric hematology/oncology, 33(2), 146-148. https://doi.org/10.1097/MPH.0b013e318230dfd8
- Moody, K., Baig, M., & Carullo, V. (2021). Alleviating terminal pediatric cancer pain. Children (Basel), 8(3), 239. https://doi.org/10.3390/children8030239
- National Institute for Health and Care Excellence. (2016). End of life care for infants, children and young people with life-limiting conditions: planning and management. Retrieved March 14, 2023, from
- https://www.nice.org.uk/guidance/ng61/resources/end-of-life-care-for-infants-children-and-young-people-withlifelimiting- conditions-planning-and-management-pdf-1837568722885
- National Palliative and End of Life Care Partnership. (2021). Ambitions for palliative and end of life care: a national framework for local action 2021-2026. Retrieved March 14, 2023, from https://www.england.nhs.uk/wp
  - content/uploads/2022/02/ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf
- NHS England. (n.d.) About the end-of-life care for all programme. Retrieved April 20, 2023, from https://www.elfh.org.uk/programmes/end-of-life-care/
- NHS England. (2023). Specialist palliative and end of life care services. Retrieved April 20, 2023, from https://www.england.nhs.uk/wp-content/uploads/2023/01/B1675-specialist-palliative-and-end-of-life-care-services-cypservice-spec.pdf.pdf
- Royal College of Nursing. (2023). Palliative and end of life care. RCN. Retrieved March 21, 2023 from
  - https://www.rcn.org.uk/clinical-topics/Children-and-young-people/Palliative-and-End-of-Life-Care-Nursing
- Sawin, K., Montgomery, K., Dupree, C., Haase, J., Phillips, C., & Hendricks-Ferguson, V. (2019). Oncology nurse managers' perceptions of palliative care and end-of-life communication. *Journal of Pediatic Oncology Nursing, 36*(3), 178-190. https://doi-org.ezproxy.herts.ac.uk/10.1177/1043454219835448
- Together for Short Lives. (2018). A guide to children's palliative care. Retrieved March 15, 2023, from https://www.togetherforshortlives.org.uk/resource/a-guide-to-childrens-palliative-care/
- Together for Short Lives. (2019). Caring for a child at end of life. Retrieved March 15, 2023, from
  - https://www.togetherforshortlives.org.uk/resource/guide-end-life-care/
- Van der Geest, I., Bindels, P., Michiels, E., Van de Heide, A., Pieters, R., Darlington, A., & Van den Heuvel-Eibrink, M. (2016). Palliative care in children with cancer: implications for general practice. British Journal of General Practice, 66(653), 599-600. https://doi.org/10.3399/bjgp16X688009