Royal Manchester Children's Hospital

NHS Manchester University NHS Foundation Trust

# End of Life Care on the Paediatric High Dependency Unit

**C. Burrows[1] D. Pask[1] G. Mason[1] L. Ellison[1]**

**1. Paediatric Critical Care, Royal Manchester Children's Hospital**

## Background

- NICE guidance on end of life care recommends "**agree preferred place of care** and place of death with young people and their carers, taking into account their wishes and values, the views of relevant healthcare professionals, safety and practicality" (1).
- When the preference is the hospital setting then traditionally RMCH critical care patients have received their end of life care (ELC) on PICU. Recently an **increased number of patients have received ELC on** PHDU. As a tertiary referral centre the evolution of ELC from PICU to PHDU is beneficial for bed capacity, and with the nursing staff not differentiating between the departments then there is no impact on continuity of care.
- This group of patients include those that have a ventilatory requirement not provided outside of critical care (high flow or NIV) but intensive care treatment is either not required or, due to limitations of care, inappropriate.
- In the twelve month period of 1st June 2021 to 31st May 2022 there have been 43 patient deaths on PCC. Five of these patients (12% of PCC deaths) received their ELC on PHDU.

## Managing End Of Life Care on PHDU

- Following exploration of alternative places of ELC (hospice, home, hospital ward) families have requested to remain on PHDU due to the support and services available. The patient cases provide **examples of clinical excellence** of ELC.
- The emerging themes include; **one to one** nursing care, **twenty-four-hour** medical cover, **pharmacist** support for prescription of anticipatory medicines, support from the **family liaison team** to meet holistic needs, **faith** representative involvement if desired, **dynamic parallel planning** by the MDT (PHDU medical and nursing staff, speciality team, family liaison team and PCC psychology team as a minimum) and clear and sensitive communication with consideration of need for interpretation services.

## Conclusions

- The core components to facilitate delivery on quality ELC on a tertiary PHDU are:
- ✓ **One to one nursing care.**
- ✓ **Twenty-four-hour medical cover.**
- ✓ **Support from pharmacist and family liaison team.**
- ✓ **Dynamic parallel planning.**

## References

(1)National Institute for Health and Care Excellence. End of life care for infants, children and young people with life-limiting conditions: planning and management [Internet]. [London]: NICE; 2016 [updated 2019 July; cited 2022 June 22]. (NICE guideline [NG61]). Available from: https://www.nice.org.uk/guidance/ng61

(2) Longden V. Parental perceptions of end-of-life care on paediatric intensive care units: a literature review. BACCN Nursing in Critical Care[Internet]. 2011 [cited 2011]; 16(3):131-9. Available from: https://onlinelibrary.wiley.com/doi/epdf/10.1111/j.1478-5153.2011.00457.x

## Patient Case Examples

**PHDU patient cases demonstrate excellent ELC**

- The families chose PHDU because they wanted the confidence of being in the critical care environment whilst receiving the high level of holistic care that RMCH PHDU provides. Patients were able to be nursed in a cubicle for privacy and comfort, whilst having twenty-four hour on-site care from tertiary level healthcare professionals and support from the PCC family liaison and psychology team. This resulted in the high standard of ELC for each patient.
- Meeting parental needs is identified as being fundamental to the provision of quality ELC (2). Below are examples of individualised care reflecting the families needs.

**Communication and comfort**

- One patient required high doses of sedation and analgesia to reduce their agitation, pain and withdrawal symptoms. Daily MDT discussions (with the pharmacist, PHDU team, palliative care team, haemato-oncology team, paediatric pain team and Macmillan nursing team) helped professionals navigate complex anticipatory medication management to successfully alleviate their symptoms. This would have been much more difficult to achieve in the community.
- The patient had the potential to have a major haemorrhage and the MDT members formulated a management plan in anticipation of this event occurring. Every possible way of providing comfort and reducing patient distress was explored and actioned.

**Supporting parents in their role of caregiver**

- When memory making was discussed with the family of one patient the parents explained that their child really enjoyed being outdoors and they wished for their final memories to include experiencing time outside. This was facilitated by a collaborative approach between the PCC play specialist team and the community palliative care nursing team.
- They also expressed that with their child's birthday coming soon it was important to them that there could be a family celebration on the day. The staff worked together to ensure that a family party was achieved, with photographs to capture the special moments.

**Spirituality/holistic approach**

- The RMCH PCC holistic round identified ways for the team to support each family as early as possible.
- The family liaison team led on the provision of holistic care and bereavement support and had extensive input with each of the families throughout their ELC. The wealth of experience and devotion of the members of this team, is reflected in their care.
- PCC psychology team offer support to all the PCC families and their level of involvement is guided by the family.
- The spiritual needs of the families are addressed by the healthcare staff during their daily cares in addition to specific wishes. The administration of holy water via the gastrostomy tube is one example of this. Families have benefited from the support provided by the RMCH Chaplaincy service regarding their ELC choices, especially during the decision making process about withdrawing of life sustaining treatment. The strong relationship between PHDU and the Chaplains is evident through the case examples.
- In some of the cases, due to faith reasons, rapid discharge of the patient was required to facilitate an early burial. This was achieved due to the commitment of the team in the ongoing care of families after death, another aspect of the deliverance of high quality ELC.