

Addressing the gaps: Evaluating an innovative 24/7 community nursing model for children and young people at end of life



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Background

Despite NICE guidance¹ stating that children and young people at end of life should have access to 24/7 face-to-face nursing provision, significant inequity continues to exist.^{2,3} A key barrier is the lack of children's community nurses who are critical to the delivery of palliative care in the home. An innovative model of care was developed and implemented with a children's hospice, addressing the gaps in out-of-hours provision and skills in community and acute settings. Evidence of service utilisation and successes can support shared learning to drive equitable care across the sector.

Aim

To assess the demand and utilisation of a unique 24/7 community nursing model to support children and young people at end of life.

Methodology

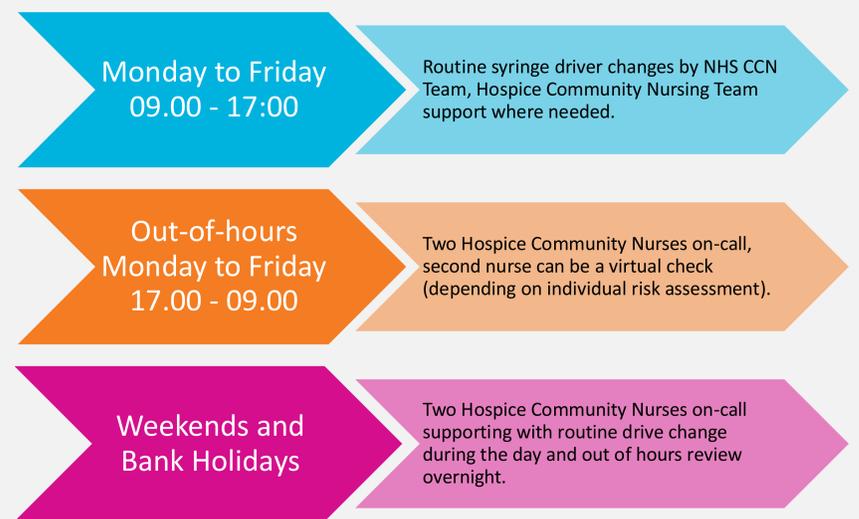
- Retrospective case note review of children and young people who accessed the children's hospice 24/7 Community Team on call service for symptom management and/or end-of-life care.
- Data collected between March 2023 and March 2025.

Service models

Service model 1



Service model 2



Results

Table 1. Demographics of children and young people

Children and Young People (n = 39)	
Age (years)	Mean: 9.9 (SD: 5.12) Median: 11 Range: <1 – 17
Gender	15 Female 24 Male
Diagnosis	18 Oncology 21 Non-Oncology
On-call service model	Service Model 1: 20 Service Model 2: 17 Other: 2

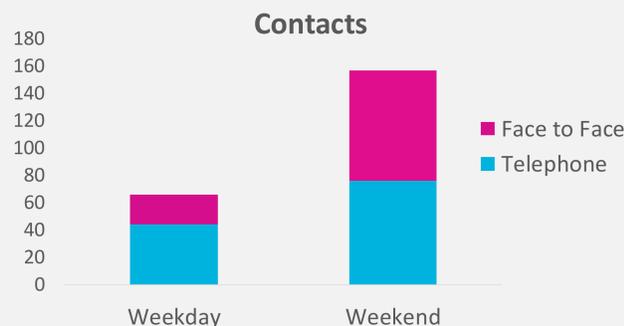


Figure 1. Out-of-hours service demand is highest at weekends for both telephone and face to face contacts.

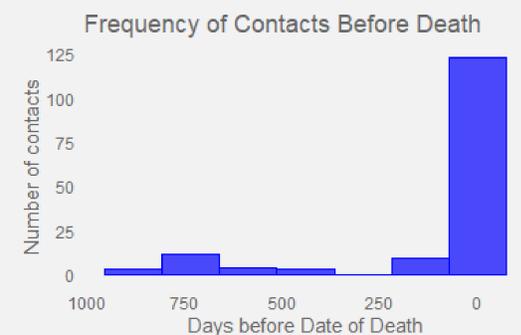


Figure 2. Frequency of contacts increased exponentially in the last months before death.

Table 2. Number of on-call contacts

On-call contacts	
No of days on-call service contacted	113
Total on-call contacts	223
Contacts per child (n = 39 children)	Mean: 5.72 (SD: 6.3) Median: 4 Range: 1-24
Total Telephone Contacts	120
Telephone contacts per child (n = 31 children)	Mean: 3.87 (SD: 3.33) Median: 3 Range: 1-13
Total Face to Face Visits	103
Face to face visits per child (n = 26 children)	Mean: 3.96 (SD: 5.5) Median: 1.5 Range: 1-24

Place of Death

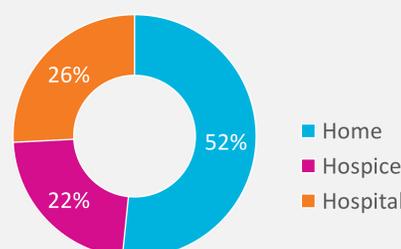


Figure 3. All children and young people who died (n = 31) were able to do so in their preferred place.

- Service usage demonstrates that a 24/7 community nursing models provided vital out-of-hours care, with a greater demand for support at weekends than weekday evenings.
- The service facilitated all children and young people to be cared for in their preferred place at end of life, most often at home.
- The distribution of contacts showed a clear clustering in the final month of life, with a sharp rise in the last days before death.

Conclusion

High quality 24/7 provision enables children and young people to be cared for in their preferred place during their end of life. High uptake and utilisation from families demonstrate a need for these equitable services nationally to deliver symptom management and end-of-life care to children and young people.

References

1. National Institute for Health and Care Excellence (NICE) (2016) *End-of-life care for infants, children and young people with life-limiting conditions: planning and management*. London: NICE.
2. Together for Short Lives (2024) *Short lives can't wait: the state of children's palliative care in 2024*. Bristol: Together for Short Lives.
3. Tatterton, M.J. (2019) Approaches to community-based palliative care provision by children's hospices in the UK. *Nursing Children and Young People*, 31(5), pp. 42–48.