

In this article...

- How teams worked together to provide a 24-hour end-of-life service for children
- The benefits of the service for paediatric patients and their families
- How the collaboration and further training have benefitted team members

End-of-life care for children: making it possible to die at home



This initiative won the **Children's Services nursing category** in the 2023 Nursing Times Awards. To find out more about the NT Awards go to [awards.nursingtimes.net](https://www.nursingtimes.net)

Key points

A children's community nursing team was unable to provide care out of hours and at weekends

The team collaborated with a palliative care urgent-response service to provide ad-hoc visits to paediatric patients' homes

The service made dying at home a realistic option for paediatric patients

Families appreciated the person-centred care, which reduced the need for hospital admissions

Teamwork, reflection and training have improved the knowledge, confidence and skills of staff

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Abstract A children's community nursing team collaborated with an adult palliative care urgent-response service to provide 24-hour end-of-life care for paediatric patients. This made dying at home a realistic option for these patients, which had not previously been the case. Parents reported that they appreciated having this choice, along with the support and person-centred care. Collaboration and reflection improved staff skills and knowledge, leading many adult-trained nurses to undertake additional training.

Citation Davies J (2024) End-of-life care for children: making it possible to die at home. *Nursing Times* [online]; 120: 2.

In 2021, Derbyshire Clinical Commissioning Group initiated a proof-of-concept pilot project to deliver end-of-life care that enables people to die comfortably, with dignity, in the setting of their choice. This palliative care urgent-response service (PCURS) is run by DHU Healthcare and cares for people who wish to remain at home, despite urgent palliative healthcare needs. Responding to crises, the service provides ad-hoc visits to patients' homes, providing care and prescription delivery, and making referrals to other teams for ongoing care needs provision. The PCURS was developed for adult patients and staffed by a community nurse and an advanced nurse practitioner.

Aims

Due to staffing issues, the children's community nursing team at University Hospitals of Derby and Burton NHS Foundation Trust was unable to provide support out of hours and at weekends to facilitate the option of dying at home for paediatric patients. To address this, the team, in collaboration with the paediatric oncology team at Nottingham Children's Hospital, asked the PCURS for support to extend care to children across Derbyshire.

The objective of this quality improvement initiative was to provide compassionate end-of-life care for paediatric patients who wish to remain at home. We aimed to provide a roaming service with the ability, equipment, medication and prescribing capability to deliver personal care to meet patients' urgent health needs without the need for hospital admission. This would support us to meet the following guidelines:

- Children can be cared for and die "at their preferred place" (National Institute for Health and Care Excellence, 2019);
- An urgent community response service can provide care for patients at home within two hours, from 8am until 8pm, seven days a week (NHS England and NHS Improvement, 2022).

Implementation

After reviewing the case for the collaboration, Derbyshire Community Health Services agreed that adult-trained staff from the PCURS could work collaboratively with the paediatric oncology outreach team and the children's community nursing team to provide out-of-hours care for children who wished to die at home. To

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monitor efficacy, we put in place comprehensive ongoing service evaluation and data collection. We agreed on key performance indicators and adopted a plan, do, study, act approach. We continue to undertake a case-by-case review of all paediatric cases and interventions, and learning and development are ongoing.

The PCURS sits within urgent care/out-of-hours services. Access to roaming vehicles was readily available, and licences to carry and prescribe drugs were already in place. Using community documentation enabled quick and easy directives to be completed. At the point of implementation, there were six PCURS nurses; due to the differences between paediatric and adult documentation and prescribing, we obtained example care plans and medication charts from the paediatric team to upskill them to care for children.

Many of the PCURS team were initially nervous about caring for dying children. However, thanks to the support and high-quality care planning of the children's oncology and community nursing teams, they now feel they are the next best-placed team to do this. To enable this to happen, the teams have worked together to establish safe and effective working relationships.

There are regular meetings between the teams to discuss cases, due to patients' changing needs. This level of planning ensures care plans and key information are available to all, which aids the delivery of seamless, safe and effective care. During periods of active involvement, there is often daily contact and handover of care. This includes meetings before the dying phase to discuss and prevent issues.

Care planning is person-centred, and personal resuscitation, medication and care plans are comprehensive. Communication is vital, and we meet parents via Microsoft Teams to introduce the service and explain the support we can provide. This increases confidence in both directions. We also put in place 24-hour support for staff and debriefing opportunities following a death.

***“This initiative was a clear example of how nurses go the extra mile to ensure vulnerable children and their families are given the basic human right to choose where they die”
Judges' comments***

Learning from experience is shared with the team, as well as with Joined Up Care Derbyshire, a health and social care partnership for the region. This is used to improve comprehensive healthcare provision, staff training and development. In addition, following an intervention, we frequently work with other providers to meet patients' and families' ongoing support needs. This collaboration:

- Increases patient choice;
- Reduces hospital admissions;
- Promotes patient satisfaction.

Outcomes

By working together, we have created a unique, 24-hour service that is helping more children and young people to be cared for, and to die, in the place of their choice. Although it is a temporary fix, until a longer-term solution is sourced, this collaboration is meeting an urgent need. It has extended the option to die at home to >300 paediatric patients in Derbyshire, which was not previously possible.

So far, the PCURS has been actively involved in the care of nine children, enabling four to die at home in their preferred place of care. The PCURS has supported the paediatric team with syringe driver management, anticipatory medication administration, personal care and parental support. In two cases, we also performed verification of death.

Being able to offer a choice other than in-patient care has been greeted positively by both children and families, especially where there are siblings. This arrangement

allows families to stay together and maintain some 'normality'. All parents who experienced the death of their child at home reported their gratitude that this was possible. Feedback received from them during bereavement follow-up has also highlighted the value of the person-centred care provided. Parents have reported appreciating 24-hour support being available, both for routine tasks and when they were not coping or were in crisis. Without it, they reported they would have contacted a hospice (if available) or phoned 999. They thought it was likely that their child would have been transferred to an acute hospital ward, which was not where they wanted to receive care or to die.

Internally, we have held after-death reflection meetings and identified learning. As a result, several adult-trained staff have accessed paediatric courses and study days to improve their knowledge, confidence and skills. The PCURS is now a team of >12 nurses. We have also established links with key staff across the county and the wider East Midlands region. The PCURS lead is working with paediatric oncology, community nursing and hospice advanced nurse practitioners to develop further guidance and links for adult staff, and the PCURS is now part of the East Midlands Children's and Young People's Palliative Care Network.

Conclusion and future plans

The collaboration between the children's community nursing teams and the PCURS has allowed us to provide 24-hour end-of-life care for children. Families have reported appreciating the person-centred care and assistance, and the collaboration has also facilitated learning and development among staff.

The concept of the PCURS is readily transferable and easy to adopt by other organisations. We have received interest from children's community services in other regions that are struggling to provide weekend and out-of-hours coverage. Adopting the PCURS model could help them meet targets for both paediatric and adult end-of-life care. **NT**

References

- National Institute for Health and Care Excellence (2019) *End of Life Care for Infants, Children and Young People with Life-limiting Conditions: Planning and Management*. NICE.
- NHS England, NHS Improvement (2022) *Community Health Services Two-hour Urgent Community Response Standard: Guidance for Providers of Care, Integrated Care Systems and Clinical Commissioning Groups*. NHS.

Box 1. Advice for similar projects

- Focus on what you want to achieve by considering the pros and cons of your quality improvement initiative
- Be prepared to be flexible with your approach and to go out of your comfort zone
- Be imaginative - think of the challenges you may face and ways to get around them
- Be persistent - you are likely to face setbacks, so consider ways to prove that what you are doing is worthwhile
- If you are passionate about something, go for it - quality improvement can return huge rewards