Edge Hill University | EPA Unit for Evaluation & Policy Analysis

Executive Summary

An Evaluation of the Kentown Children's Palliative Care Programme

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Executive Summary

The Kentown Children's Palliative Care Programme was a three-year pilot initiative designed to address longstanding gaps in children's palliative care across Lancashire and South Cumbria from 1st September 2022 to 31st August 2025. Funded by the Kentown Wizard Foundation and delivered in partnership by Together for Short Lives (TfSL), Rainbow Trust Children's Charity, and NHS Lancashire and South Cumbria Integrated Care Board, the programme offered a coordinated, family-centred triad model of care that combined the expertise of Kentown Children's Palliative Care Community Nurse Specialists (hereafter referred to as Kentown Nurses), Family Support Workers, and Family Service Coordinators. This triad model enabled the delivery of advanced clinical support alongside practical and emotional care, tailored to the needs of children with life-limiting conditions and their families.

The evaluation, conducted by Edge Hill University, followed a longitudinal multi-methods design incorporating process and impact phases across the three years of the programme. Data were collected from 91 participants including 16 interviews with parents, children and siblings, 35 Kentown staff, and 40 professional stakeholders, supplemented by service activity records, family case studies, and workshops. This design allowed the evaluation team to capture both the outcomes achieved by the programme and the mechanisms that generated impact, paying attention to differences across regions and contexts.

The evaluation findings revealed that the Kentown model filled a critical gap in statutory provision by offering holistic support, relational continuity, and earlier access to palliative care than families had previously experienced. Service data reported over 250 referrals during the programme, with more than a third of families accessing support from all three components of the model consisting of a Kentown Nurse, Service Coordinator, and Family Support Worker. The average time from referral to first contact was under a week, with more than half of families receiving contact the same day. Advance care planning was noticeably improved, with conversations becoming more normalised and embedded across the whole region. Professionals noted that Kentown staff also enhanced the wider system, providing training, role modelling, and supporting confidence while acting as a catalyst for cultural change in how paediatric palliative care was understood and delivered.

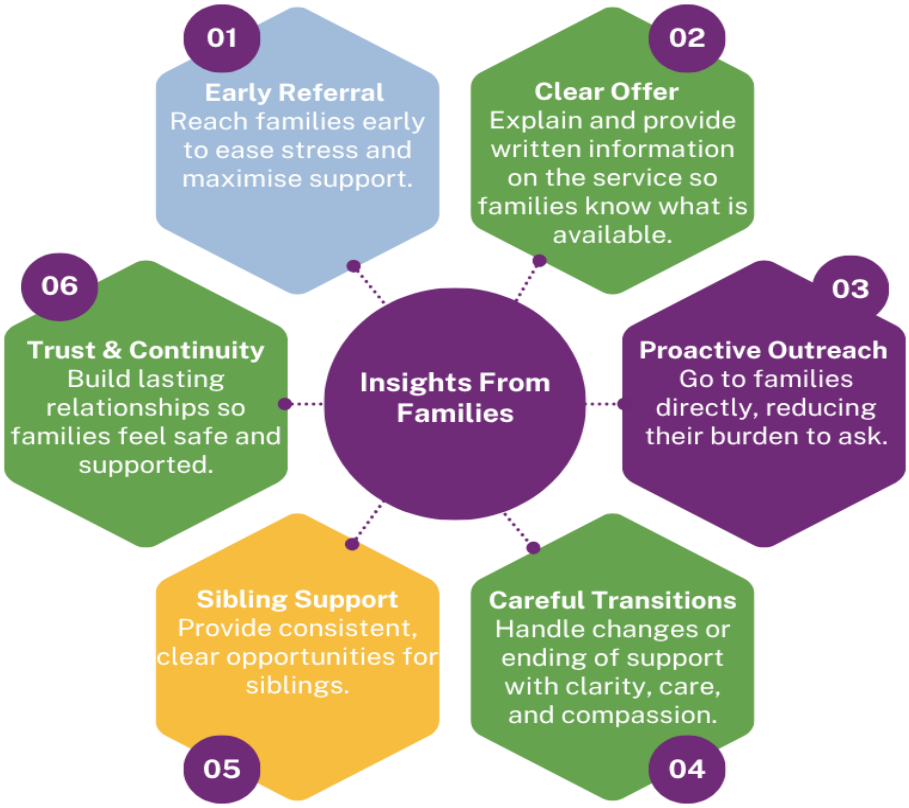
Key finding 1: Added value of the integrated Kentown model

Central to the programme's success was the triad delivery model, which integrated Nurses, Service Coordinators, and Family Support Workers. This model provided a holistic approach to addressing the complex needs of families, combining clinical expertise, and logistical coordination, along with practical and emotional support. Families consistently highlighted how this combined expertise created a seamless and family-centred experience. All roles in the model

made a unique and combined contribution to the success of the programme. Families and professionals also highly valued the flexibility and responsiveness of the Kentown model which enabled the team to provide support in any setting where needed (i.e. home, community, hospital, hospice, school) and a rapid response to families in crisis, often on the same day as receiving the referral. The model has also facilitated Kentown and stakeholder team development in the region through role modelling, shared learning, and joint working which created a culture shift in practice and supported professional progression in teams through increased knowledge, confidence, and autonomy. Preserving the Kentown model with these vital aspects is viewed as fundamental to the integrity and success of future delivery.

Key finding 2: Importance of relational continuity and family-centred approach

Families and professionals highly valued the continuity of relationships with Kentown staff. Families often entered the programme with low expectations based on previous support experiences, and so the deep emotional connection and follow-through of support they experienced with the Kentown team was viewed as transformative. Once engaged, families consistently valued the wrap-around support they received, expressing a sense of safety and emotional reassurance, along with appreciation for practical support and reduced administrative burden. Kentown staff were seen as trusted *anchors* and *connectors* within a fragmented care landscape. There was strong support for the programme to continue, and several key insights were shared by families to support continuation of the family-centred approach.



Key finding 3: Clear communication and building credibility effectively addressed many integration challenges

Initial challenges due to role ambiguity and communication issues created tensions with some existing providers, who perceived overlap or encroachment. The programme made notable progress in strengthening collaborations and integration with services during the pilot, by raising awareness of their roles and remit, along with building trust and credibility with professionals. Enhancing clinical leadership with a paediatric palliative care consultant linked or embedded in the programme was identified as a future development for consideration.

Key finding 4: Essential support structures for team wellbeing is key to fostering a thriving and highly resilient workforce

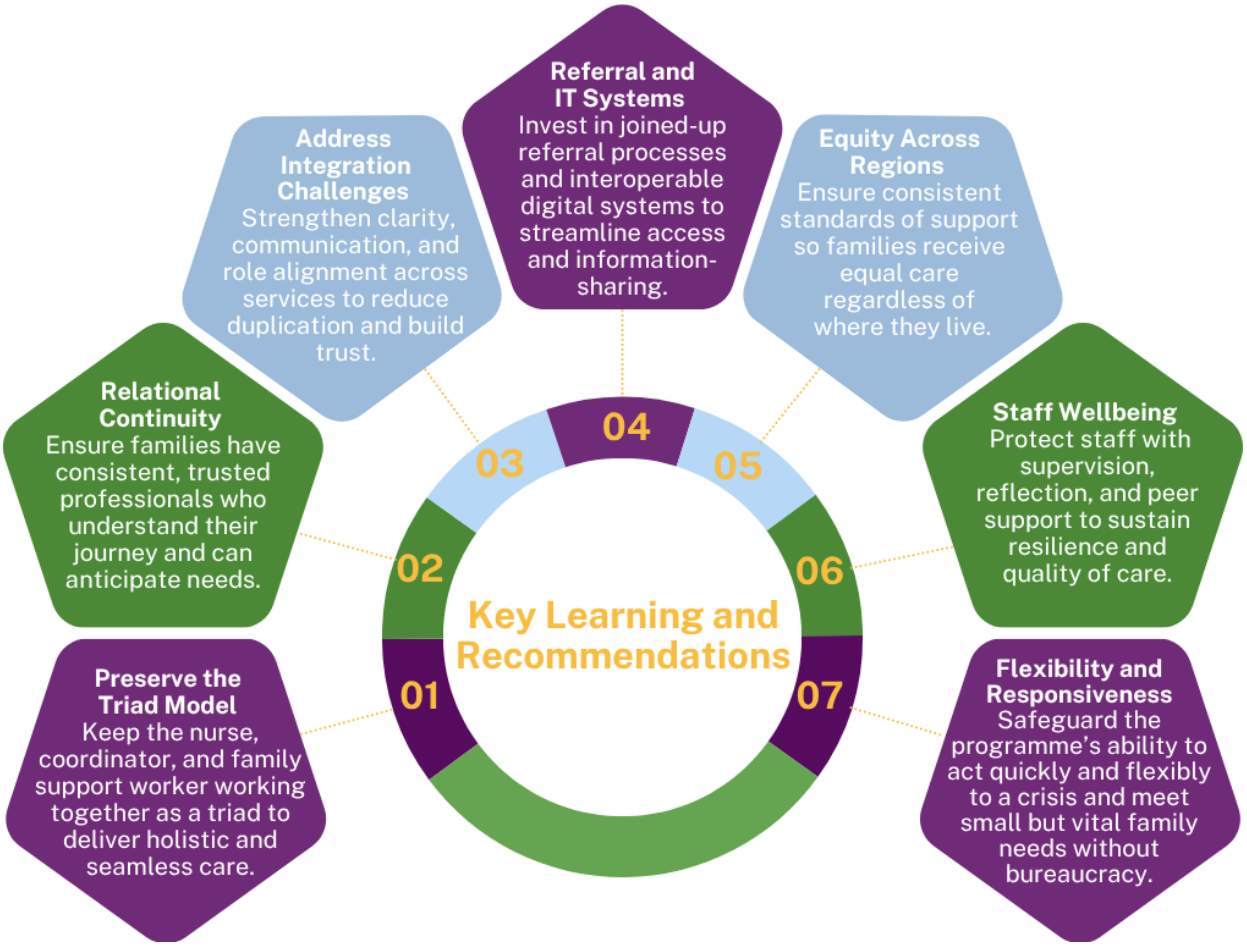
During the final year, there was increased reflection on the emotional toll of the programme work. Whilst the Family Support Workers received mandatory monthly supervision, other roles often relied on informal peer networks and mutual team check-ins which became critical mechanisms for maintaining resilience and sustaining the quality of care (across the team). The need for mandatory professional or clinical supervision across all roles in the team was identified to prevent burnout and promote long-term resilience.

Key finding 5: Addressing challenges of IT systems and staffing will support programme management and consistency of provision

The lack of a universal IT system for the programme created challenges for sharing of information and referrals across the partner organisations, reducing efficiency and resulting in some delays or duplications of referrals and assessments. Processes were further developed during the pilot to improve this including a new referral process and shared spreadsheets which improved programme management; further exploration of interoperable digital solutions will further support integrated practice across partners. Staff recruitment and retention challenges during the pilot resulted in some disruption to the offer or continuity of care in some areas, with implications for families and professionals, and at times increasing workloads for the other Kentown staff.

Recommendations

The key learning and recommendations captured during the evaluation are summarised in the figure below. Throughout the pilot, the Kentown team's approach and commitment to continuous learning allowed these areas to evolve dynamically so they have not remained static. The following points celebrate the learning journey and provide considerations to support future implementation and success of the Kentown model.



The evaluation has demonstrated that the Kentown model has filled a critical gap in the care and support for seriously ill children and their families in the region. It has added clear value by complementing existing provision and offers important lessons for future integration and scaling of children's palliative care services nationally. The model also facilitated Kentown and stakeholder team development through role modelling, shared learning, and joint working which has seen professional progression and a culture shift in the region through increased confidence, knowledge, and autonomy. The absence of out-of-hours provision in the region remains a challenge. The Kentown Programme has supported families with anticipatory planning but there remains a need for 24/7 support in the region to provide a more comprehensive and responsive service to meet the needs of these families at critical times. The Kentown programme is well positioned to lend valuable insights and expertise to inform regional planning for the commissioning of 24/7 children's palliative and end of life care.

"I didn't have any expectations at all, because you can't help but think, well, what can they do for me? You just hope that people are going to help you.... What Kentown did in that first year was actually try and make a way through the trees and really help" (Parent)

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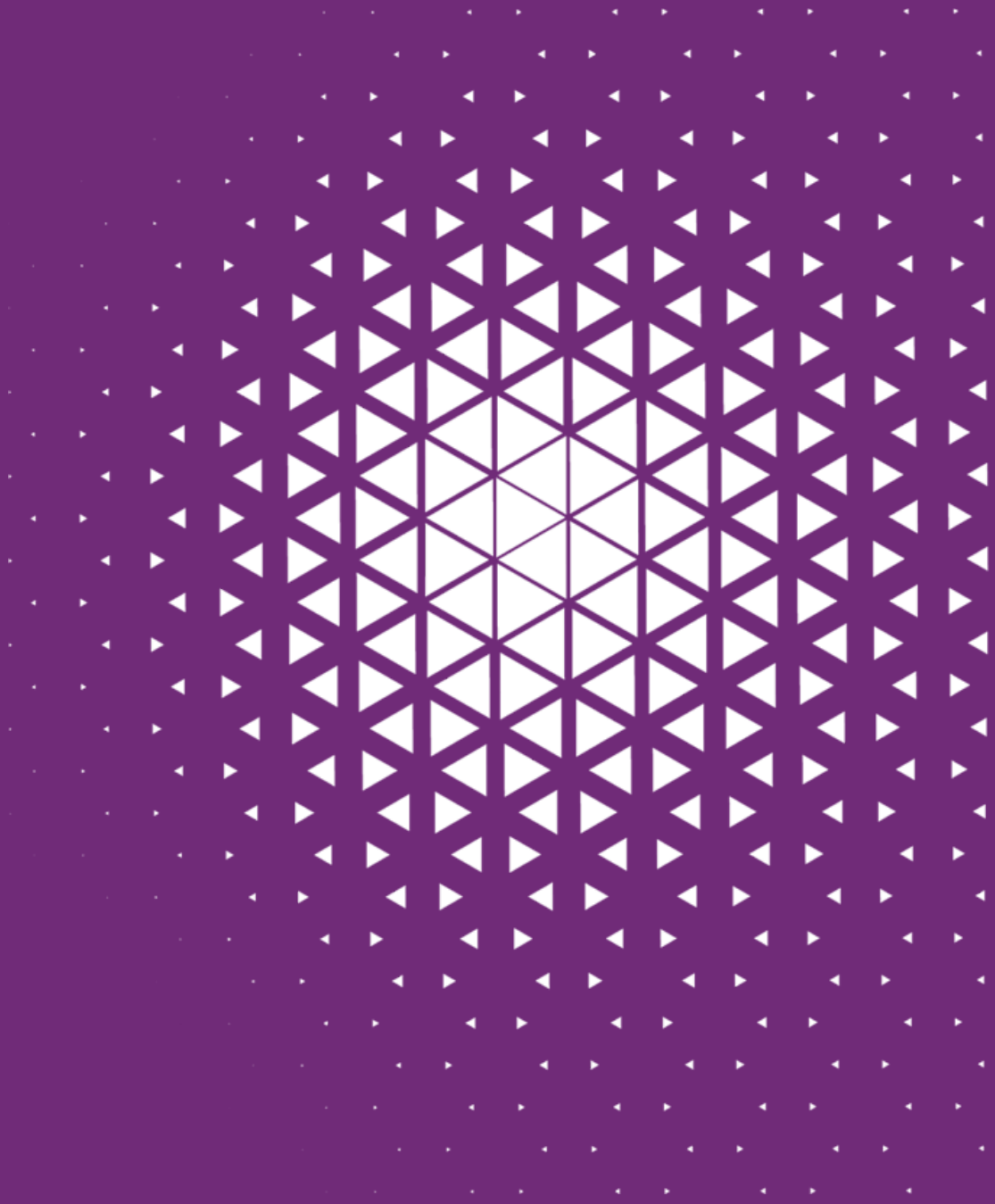

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