Edge Hill University | EPA Unit for Evaluation & Policy Analysis

An Evaluation of the Kentown Children's Palliative Care Programme

Final Report
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We are also grateful to the Kentown Programme Board, whose clear direction and encouragement provided an important foundation for the evaluation and helped ensure that it remained aligned with the programme's wider vision and goals.

We would like to thank the professionals from other services for their time and insights into how the Kentown Programme has been implemented and collaborated with existing services.

Special thanks to the parents and children who kindly shared their time, experiences, and perspectives as part of this evaluation. Their contributions were central to our understanding of the impact of the programme and have provided invaluable insights that shaped the findings of this report.

We also thank and acknowledge Dr Chinebuli Uzondu for their contribution to data collection in year 2 of the evaluation.

Since these data were gathered and analysed, it has been announced that Kentown Support, a new charity established by the Kentown Wizard Foundation, will be taking forward the Kentown model so some comments regarding sustainability have been addressed prior to publication of this report.

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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 Nurses, Family Support Workers, and 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.

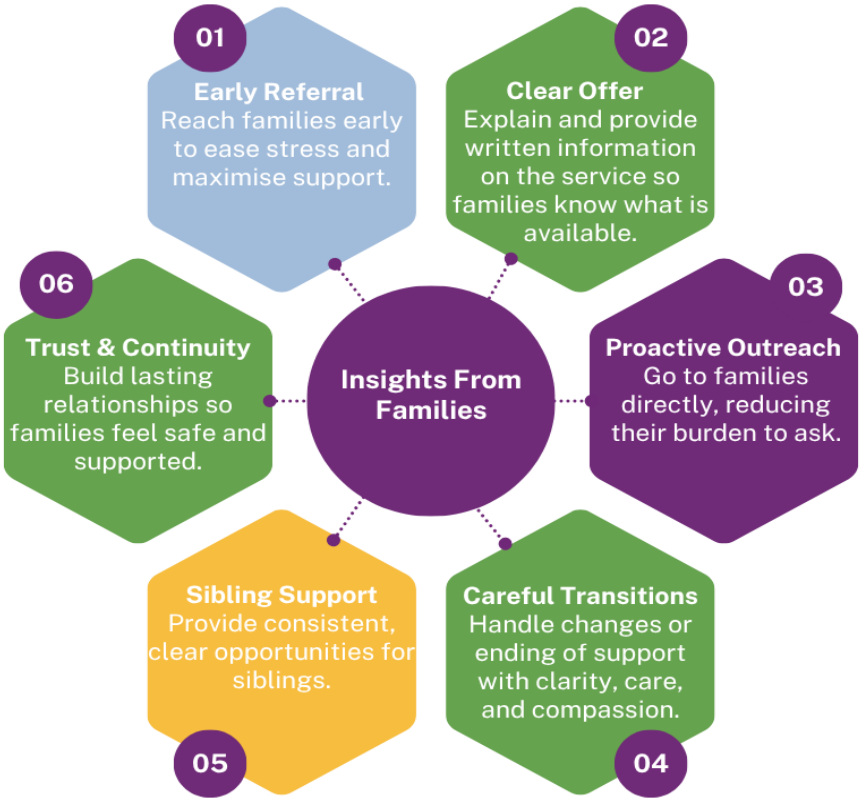
Key finding 1: Added value of the integrated Kentown model

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

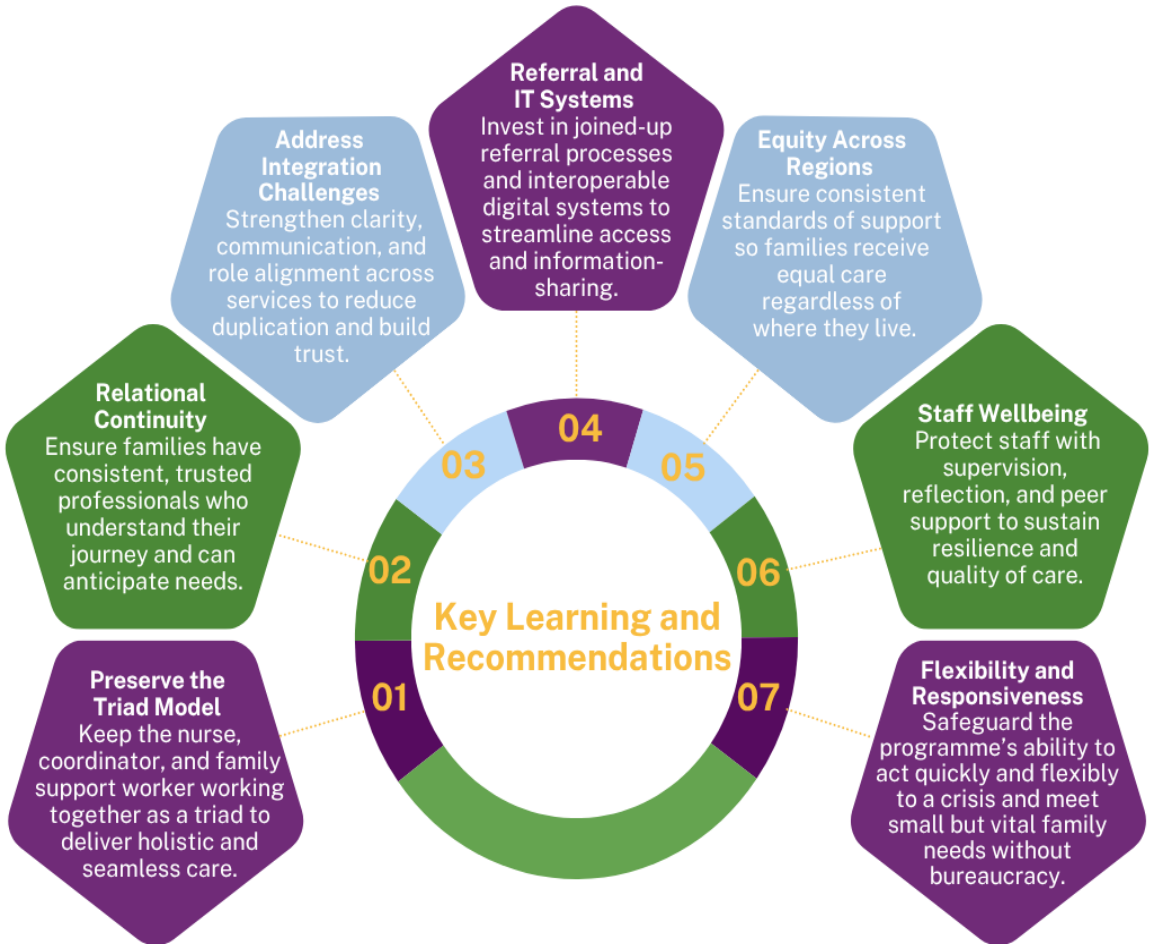
During the final year, there was increased reflection on the emotional toll of the programme work. Whilst the Family Support Workers received mandatory monthly supervision, other roles often relied on informal peer networks and mutual team check-ins which became critical mechanisms for maintaining resilience 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)

Background

In England, the prevalence of babies, children and young people with life-limiting conditions rose from 32,975 in 2001/2 to 86,625 in 2017/18.[1]. It is estimated that there will be between 67.0 and 84.2 per 10,000 children, and their families, living with such conditions in England by 2030. The importance of paediatric palliative and end-of-life care being provided in line with the wishes of children and families is a key component of national policy and guidance within the United Kingdom (UK).[2] There is also increasing international evidence highlighting that families wish to remain at home towards the end of their child's life, supported by specialist palliative care professionals.[3,4] Families have reported the key aspects for effective and valued end-of-life care at home include: flexible care embracing changes in preferred place of death; trusted relationships with care providers who were a presence when required in homes but never intrusive; child- and family-centred care informed by ongoing discussions of wishes; specialist support being available as needed; and compassionate death and bereavement care.[5,6] From a service perspective, key components for an effective home-based end-of-life care service include: an anticipatory approach to care planning and delivery; advance care planning; service responsiveness and flexibility; 24/7 availability of Nurse-led care with medical input as required; and partnership working.[7]

The development of the Kentown Children's Palliative Care Programme was rooted in a growing body of evidence highlighting service shortfalls, particularly for community-based, home-delivered palliative care with many families experiencing fragmented care and inconsistent access to palliative and end of life care, with a lack of clear pathways to support. Service mapping conducted by Together for Short Lives across England in 2021 identified that access to children's palliative care was variable and dependent on where they live.8 A key concern was the gap in access to 24/7 end of life care at home by professionals with access to the specialist advice needed to meet the complex needs of these children from experienced Nurses and senior consultants. Despite high prevalence of children with life-limiting conditions who are < 1 year, from minority ethnic groups and/or the most deprived areas, there was considerable inequity of access to services for these populations across the UK.

In the Northwest of England these issues were particularly acute. Lancashire and South Cumbria was identified as a priority area for action due to the high prevalence of children with life-limiting and life-threatening conditions, lack of reach to underrepresented groups, and lack of access to nursing and consultant support for 24/7 end of life care at home. These intersecting challenges called for a model of care that is responsive, equitable, and capable of bridging existing gaps. Following a series of mapping, consultation, and engagement events with commissioners, services and families in the Lancashire and South Cumbria region the Kentown Children's Palliative Care Programme was launched.

The Kentown Children's Palliative Care Programme

The Kentown Programme was a three-year pilot which ran from 1st September 2022 to 31st August 2025 to address significant gaps in the delivery of children's community palliative care services across Lancashire and South Cumbria. The programme was a collaboration between Together for Short Lives (TFSL), a leading UK charity for children's palliative care, Rainbow Trust Children's Charity, which specialises in providing emotional and practical support to families of seriously ill children, and NHS Lancashire and South Cumbria Integrated Care Board. The programme was funded by the Kentown Wizard Foundation whose mission is to have a positive and enduring impact on the lives of children and young adults with serious, life-limiting conditions and disabilities. The Kentown Programme represented an ambitious effort to reach every family caring for a child with a life-limiting condition by embedding a coordinated, family-centred model of care that responds to the complex needs of children with life-limiting and life-threatening illnesses, while also supporting their families.

Aim of the programme

The overarching aim of the Kentown Programme is to improve the quality, accessibility, and coordination of palliative care for children and their families. To achieve this aim, the pilot programme had several objectives.

Objectives of the programme

1. Ensure that children can be cared for at home, by professionals who know them well and who have the competencies to meet their complex needs.
2. To improve the timeliness of referrals, ensuring families are equipped with the information they need to make informed choices.
3. To give families more time to focus on what matters most, being together.

Programme outcomes

To meet these objectives the programme established outcomes in four main areas: (1) providing an integrated offer of nursing care, family support and coordination which has value and impact for families; (2) collaboration with service providers and commissioners to meet the needs of children and their families; (3) for the programme to have value to the Kentown staff through job satisfaction and opportunities for professional development; and (4) for the model to be sustainable and replicable in other areas.

Eligibility criteria for the programme

Eligibility for the Kentown Programme is based on clinical need and includes children and young people from birth to 19 years of age who are living with life-limiting or life-threatening conditions. The programme also extends its support to the wider family, recognising that caring for a seriously ill child or young person impacts parents, carers, and siblings. The programme is intentionally inclusive, with a particular focus on improving access for those who have historically been underrepresented in children's palliative care services.

The Kentown Programme is delivered through a comprehensive service model across five regional sites. The triad model integrates three core roles: a Kentown Nurse, a Family Support Worker, and a Service Coordinator (see Figure 1). Together, these professionals offer a complementary package of clinical, social, emotional and practical support that is delivered in the home and community, tailored to the unique needs of each child and family.

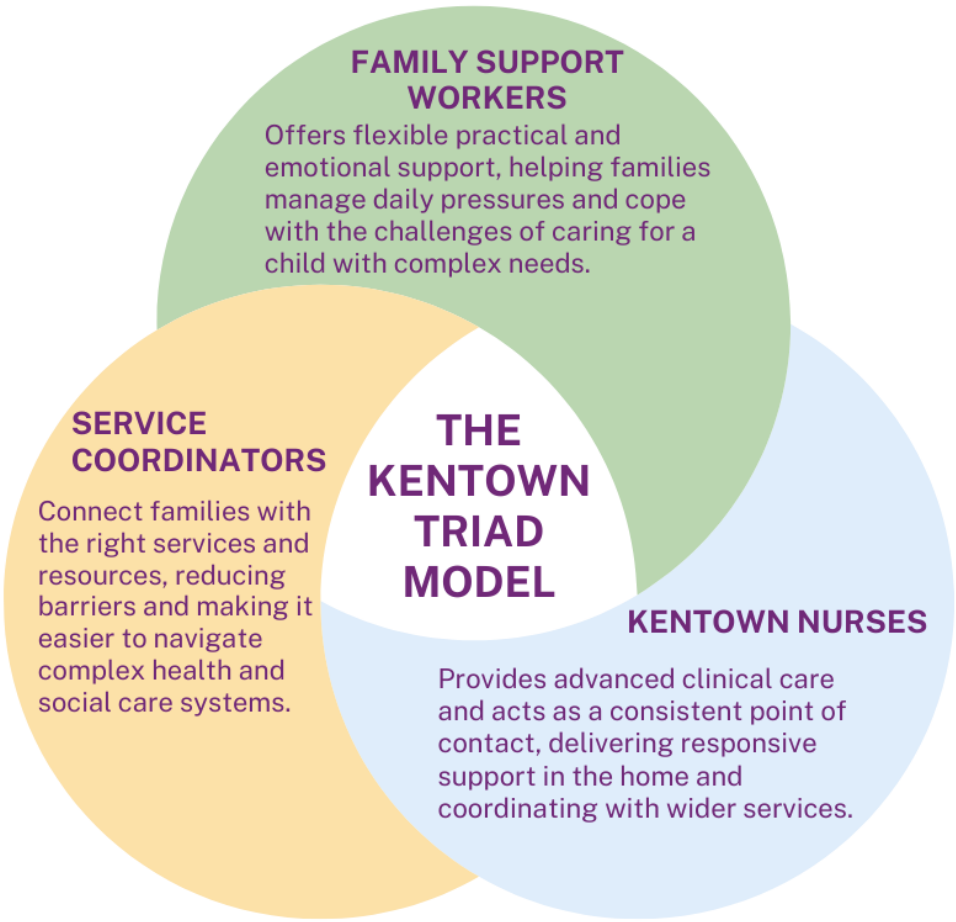


Figure 1. The Triad Model of Programme Delivery

The Kentown Nurses are Children's Palliative Care Community Nurse Specialists employed at Band 6 and 7 and are hosted by acute NHS Trusts across five areas: Blackpool, East Lancashire, Central Lancashire, North Lancashire, and South Cumbria. These Nurses provide advanced clinical care, including symptom management, anticipatory care planning, and emergency support. Importantly, they serve as a consistent point of contact for families and work alongside community Nurses, hospices, and other professionals to ensure coordinated care and provide palliative care guidance as needed. Their presence in family homes, hospitals, and the community enables the delivery of responsive, high-quality clinical interventions wherever needed, but with a focus on home and the community.

A second component of the programme is delivered by Family Support Workers, recruited and managed by Rainbow Trust Children's Charity. These workers provide a broad spectrum of practical and emotional support, from transporting families to appointments, offering respite and sibling support, to guiding families through bereavement. Their role is flexible and deeply relational, often embedded in the daily lives of the families they support. By relieving practical burdens and offering a stable source of emotional care, Family Support Workers help families cope with the day-to-day pressures of managing complex medical needs at home.

The third element of the programme is the Family Service Coordinator role. These Service Coordinators are responsible for mapping the landscape of services across the region, identifying local and national resources, and ensuring families are aware of, and connected to appropriate support (e.g., bereavement support, government aid etc.). Their work focuses particularly on families who may face additional barriers due to language, location, or socioeconomic disadvantage. By facilitating access and improving visibility of services and sources of support, the Service Coordinators help families to navigate a complicated health and social care system.

Evaluation of the Kentown Programme

The evaluation of the Kentown Programme was led by a team of researchers at Edge Hill University, with expertise in health and social care, multi-methods research, and policy analysis. The evaluation employed a longitudinal multi-method process and impact design which spanned the full three-year pilot implementation period from 1st September 2022 to 31st August 2025 incorporating a process and impact evaluation.

Aim of evaluation

The overarching aim of the evaluation was to understand the outcomes of the Kentown Programme and explore how those outcomes were achieved, for whom, and under what circumstances.

To meet this, the evaluation objectives were:

1. To evaluate the implementation and delivery of the Kentown Programme, including how various programme components interacted and contributed to implementation, and the consistency of implementation across different sites.
2. Identify the changes made by the Kentown Programme internally and externally; and
3. Demonstrate the experience and impact for children with life-limiting conditions and their families, Kentown operational and project staff, and stakeholder professionals.
4. The evaluation also explored the learning throughout the pilot and any lessons to inform the wider roll out of the Kentown Programme.

Evaluation design

The process evaluation examined how the Kentown Programme was implemented, the fidelity of the programme, and adaptations made. The impact evaluation assessed the effectiveness of the Kentown Programme in achieving the intended outcomes. The data gathered across the three years combined documentary analysis, individual and small group qualitative interviews, focus groups, observations, workshops, and service activity data (see Figure 5). Data were collected across several timepoints and participant groups to assess outputs of the service model, perceived value, integration, and sustainability within broader palliative care systems.

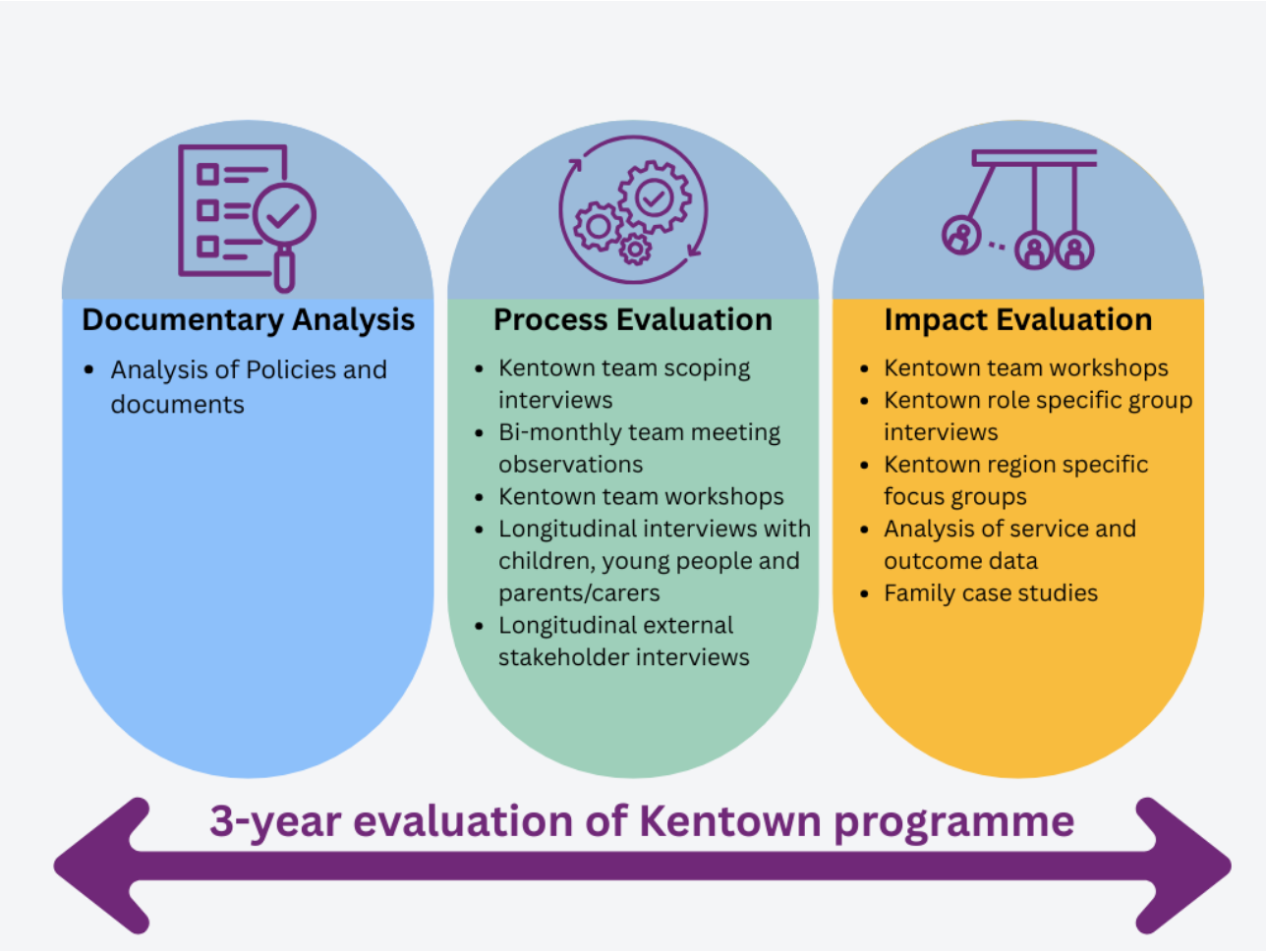


Figure 2. An overview of the Kentown Programme evaluation data collection

Sampling

A purposive sampling strategy was used to ensure diverse representation across professional, organisational, and regional boundaries. In addition to purposive sampling, snowball sampling (a sampling strategy where existing study participants suggest other potential study participants from among their peers) was used during the recruitment of stakeholder professionals to identify additional individuals who had substantial but less formalised contact with the Kentown Programme.

Participants and recruitment

There were three participant groups recruited during the evaluation:

1. Families comprised of children and young people aged 7–19 years receiving Kentown services, (referred child with a life-limiting condition or a sibling.) and their parents/caregivers.
2. Stakeholder professionals who collaborated with, or had some experience of, the Kentown Programme including those working in the NHS, hospices, other charitable organisations, and education.
3. Kentown Programme staff**,** including Nurses, Family Support Workers, Service Coordinators, Managers, and Operational Leads.

Families: The family recruitment process began with identification of the child or young person by a member of the Kentown team known to them. The team member provided verbal and written information about the evaluation to the parents, and the child or young person if appropriate. If any member of the family wished to participate, consent was gathered to pass their details to the evaluation team who then contacted the parent to discuss the evaluation and arrange data collection if they wanted to proceed.

Stakeholders: Professionals from a range of organisations were identified by the Kentown team and contacted by the evaluation team with written information. The participant list was reviewed and expanded for the second interviews to capture additional reach and collaborations.

Kentown Programme: All Kentown Programme staff representing the full range of roles and geographic coverage (regions) within the programme, along with the senior programme team from the partnership organisations provided informed consent for all elements of data collection in the evaluation.

Data collection methods

Data collection for the evaluation included a wide range of qualitative methods and observation with all participant groups across the three years.

Kentown Programme team (year 1-3)

The Kentown Programme staff were invited to share their experiences of delivering the programme, the challenges faced, and perceptions of impact through various data collections points. These included individual scoping interviews (year 1), facilitated impact and process workshops (Years 1-3), observations during the bi-monthly team meetings (Years 1-3), focus

groups or small group interview by role and region (year 3). These data collection points throughout the evaluation served as reflective opportunities to explore implementation experiences and challenges, regional variation, team development, and emergent strategic priorities.

Individual interviews with stakeholder professionals (year 1 and year 3)

Interviews were conducted with professionals across two data collection timepoints to capture external insight into service provision, system integration and inter-agency collaboration. The first timepoint of interviews was conducted after approximately one year of operational delivery and the second timepoint after approximately 2.5 years of delivery.

Interviews with parents, caregivers, children with a life-limiting condition, and siblings (year 2 and 3).

Children and parents were interviewed to capture their experiences of the service, including communication with staff, practical and emotional support received, and perceptions of continuity of care. They were interviewed separately, in person or remotely via telephone call or video call depending on the preference of the family. Interviews were conducted with families from across the five regions with a range of engagement experience with the programme. Longitudinal interviews were planned to capture change in engagement and impact, with the second interview occurring 3-6 months after the first one if the parent or child chose to continue their participation.

Data analysis

All qualitative data collected throughout the evaluation was initially analysed inductively using thematic analysis, following the steps outlined by Braun and Clarke (2022). This process involved familiarisation with the data through repeated readings, open coding to identify patterns, and iterative refinement of themes across transcripts. This inductive phase allowed for the emergence of contextually grounded themes without being constrained by predefined constructs.

To enhance the validity and robustness of the manual coding, AI-assisted qualitative analysis was conducted using ATLAS.ti. This software was used to independently scan and cluster coded transcripts, offering a machine-generated synthesis of recurring terms, co-occurrence patterns, and thematic themes. The AI-assisted process served as a confirmatory mechanism, ensuring that no important codes had been overlooked during manual coding. The AI data analysis supported the identification of latent links between themes. Discrepancies or additions flagged by the AI

data analysis process were reviewed by the research team and incorporated where appropriate (strengthening the overall rigour of interpretation).

NVivo software was used to support the data analysis with coding, and visualisation of thematic themes.

Ethical considerations and approvals

The evaluation entitled 'Evaluation of the Kentown Children's Palliative Care Programme' was reviewed and received approval from the Edge Hill University Health Research Ethics Committee (Reference number ETH2223-0287). The evaluation was also reviewed and registered at all NHS trusts where the Kentown Nurses were employed prior to any recruitment of families and stakeholder professionals.

All participants were informed of the purpose of the evaluation and provided informed consent prior to participation. Ethical practice was maintained throughout, including ensuring wellbeing of participants, and the protection of confidentiality and anonymisation of data.

Strengths and limitations of the evaluation

A key strength of the evaluation included the collection and synthesis of data using a range of qualitative methods over the three years of the pilot. This captured rich descriptions of process and impact experience from a diverse cross-section of participants.

The quasi-experimental economic impact analysis using a difference-in-differences approach was not implemented as initially intended due to the nature of the available data: service performance metrics were collected in aggregate form rather than at the individual level, and historical data from comparator sites were either unavailable or not comparable. These limitations precluded the possibility of identifying a robust counterfactual or attributing changes in outcomes directly to the Kentown model using statistical techniques. An additional limitation was the significant challenge in recruiting families of children with life-limiting conditions receiving support from the programme. This was often due to the unpredictability of health trajectories, and the considerable demands that families faced in their daily lives managing intensive caregiving routines, frequent hospital appointments, alongside financial and social challenges. These factors impacted on attrition between expression of interest to participation, and the breadth of family data in the evaluation. The referral and service data used to report demographics and support the case study narratives are based on data provided by the Kentown Programme to the evaluation team. This data has some gaps and inconsistencies within the dataset so some minor errors may exist.

Kentown Programme referrals and service data

Throughout the programme, referral and service activity data collected routinely by Kentown Programme staff was anonymised and shared with the evaluation team. The dataset captured basic referral data for each family, along with aggregated data on the frequency and nature of activities delivered across the programme by each role using pre-set categories for each role such as caseload meetings, signposting actions, advance care planning, and symptom management.

The final dataset received included data gathered from the 1st September 2022 to 13th August 2025. This section of the report will present a summary of the referrals and service data for key outcomes of the programme.

Pattern of referrals across the Kentown Programme

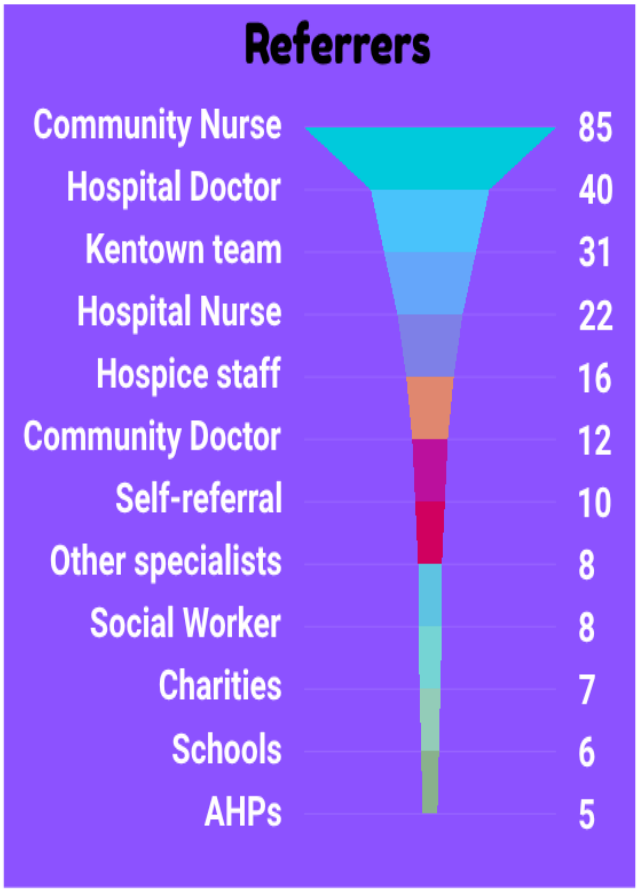


Figure 3. Referrals by profession

The dataset captured the professional who made each referral to the programme. The 250 referrals revealed a range of professionals made referrals with community and hospital-based professionals emerging as the leading sources.

Community Nurses accounted for 34% of referrals (n=85), highlighting the important role of frontline community nursing staff for the identification and onward referral of children with palliative care needs due to their contact with children in domiciliary and community health settings.

Collectively, hospital-based clinicians accounted for 49% of referrals, (Doctors n=40, Nurses n=22) highlighting the role of acute care services in recognising and initiating palliative care involvement. Other professionals based in the community made 10% of referrals (Hospice staff n=13, Community Doctors, n=12) indicating that both specialist palliative care and community care structures operated as meaningful gateways into the Kentown Programme. Notably, 12% of

referrals originated from the Kentown Programme staff or organisations. Kentown Family Support Workers (n=16), Kentown Nurses (n=9) and the TfSL Helpline (n=5) also made referrals from their contact with children and families, highlighting the multi-sectoral nature of referral pathways.

Self-referral from a parent/caregiver was recorded on 10 occasions. This pathway, while less frequent than professional referrals, and is significant as it reflects a level of public awareness and accessibility of the programme.

Social care professionals, particularly Social Workers (n=8), played a bridging role between health and social care, contributing to the referrals made into the programme. The remaining referral sources encompassed a broad range of roles, including educational professionals and allied health professionals (e.g., physiotherapists, occupational therapists). While individually contributing smaller numbers, these sources collectively demonstrated the breadth of professional engagement with the Kentown Programme.

There was no detail recorded for the organisation or service of the referrer in the dataset. To explore this, an email domain analysis was conducted of 207 identifiable email domains which were shared with the evaluation team. The dataset shows that 16 different organisations referred children into the Kentown Programme. The main referrers to the programme NHS trusts who made more than 60% of all referrals (n=135). Rainbow Trust made 18 referrals, and one children's hospice made 19 referrals to the Kentown Programme. In addition, two schools, a local authority, and other charitable organisations made 10 referrals into the Kentown Programme. This indicates a strong and stable partnerships across the pilot area; and areas where further awareness and collaboration could be sought.

Characteristics of the children referred

The gender distribution was 137 (55%) male and 113 (45%) female. Whilst the eligibility criteria for the Kentown Programme was 0-19 years, the age range reported in the dataset was from infancy through to 21 years, with a mean age of 7.9 years. Half of the children referred fell between the ages of 3 and 13, reflecting the concentration in early and middle childhood. Young children 1 to 5 years were the largest proportion of the cohort (39%), with numbers gradually tapering through adolescence and early adulthood.

In terms of ethnicity, the largest proportion of children referred were identified as White (66.5%). The rest of the children were Asian or Asian British (23.1%), other ethnic group (8%), and mixed or multiple ethnic groups (2%). A more detailed breakdown by ethnic subcategory provided found that the largest specific group consisted of participants identifying as 'English, Welsh, Scottish, Northern Irish or British' with 158 referrals representing 62.9% of the total. Within the

Asian or Asian British category, the Pakistani group was most represented (N=39, 15.5%). Other notable groups included those reporting 'Any other ethnic group' (7.6%), while smaller proportions were spread across categories such as 'Any other White background' (2.0%), 'Any other Asian background' (2.0%), and 'White and Asian' (1.2%). The Indian group also accounted for 1.2% of participants. Several categories such as 'White and Black African' and 'Any other Mixed or multiple ethnic background' were represented by a single individual each, making up less than half a percent. From this distribution, it was evident that while the dataset has a majority White demographic, there was diverse representation from Asian or Asian British participants, particularly of Pakistani background.

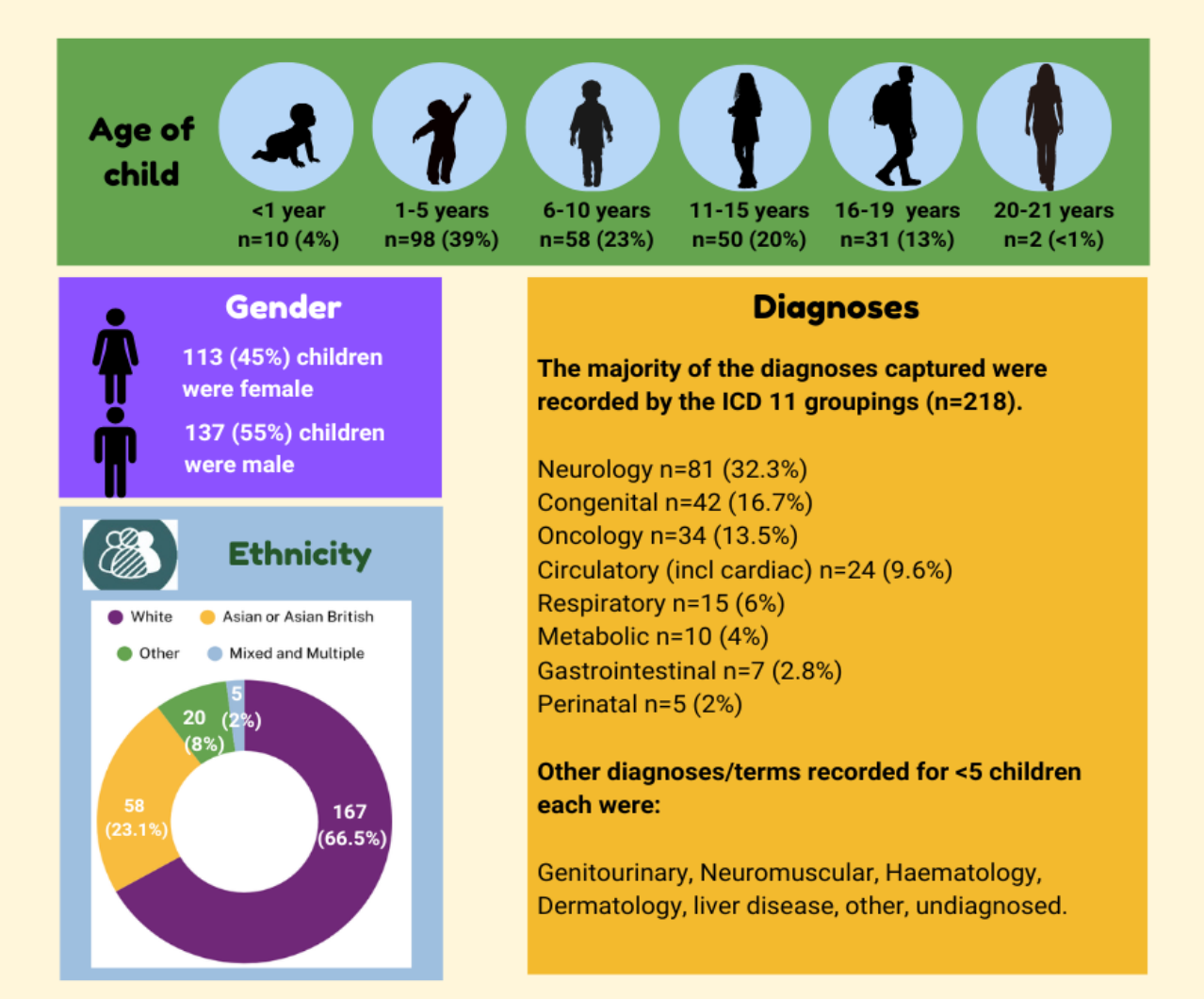


Figure 4. Characteristics of the children referred

The primary diagnosis was recorded in the medical history of the referral dataset, with 766 unique conditions across all referrals. Each child had a median average of 2 recorded conditions, and the maximum number for a single child was 22. The most frequently recorded condition was

epilepsy for 27 children (10.8%). Eleven children had cerebral palsy (4.4%), 7 had global developmental delay (2.8%), 7 had dystonia (2.8%), and 6 had chronic lung disease (2.4%). Other conditions recorded with moderate frequency included microcephaly (n=5, 2.0%), gastrostomy (n=5, 2.0%), scoliosis (n=5, 2.0%), VP shunt-related hydrocephalus (n=4, 1.6%), and low-grade glioma (n=, 1.6%). Less frequent but clinically important diagnoses included trisomy (n=3, 1.2%), acute lymphoblastic leukaemia (n=4, 1.6%), spina bifida (n=3, 1.2%), Rett syndrome and a variety of complex multi-system syndromes such as Dandy–Walker, congenital disorders of glycosylation, and VACTERL association.

The diagnosis category was reported also by the ICD11 groupings. Neurological diagnoses were recorded for 81 children, representing 32.3% of the total cohort. This was followed by congenital conditions (n=42, 16.7%), oncology (n=34, 13.5%) and circulatory and cardiac conditions (n=24, 9.2%). Respiratory diagnoses were recorded for 15 children (6.0%), followed by metabolic (n=10, 4.0%), gastrointestinal conditions (n=7, 2.8%) and perinatal diagnoses (n=5, 2.0%). Smaller groupings included liver disease (n=2, 0.8%) and single recordings (n=1, 0.4%) for genitourinary, neuromuscular, haematology, dermatology, and circulatory. There were several entries where other text was entered such as 'birth defect', 'secondary to group B streptococcal meningitis with sepsis.' In addition, 7 children (2.8%) were marked as undiagnosed, and 9 entries (3.6%) were left blank.

Time from referral to first contact

Of the 250 referrals recorded, 101 records include both the date of referral made and the date of first contact. For just over half of the cases, the first contact occurs on the same day as the referral or even earlier when the family is known to a member of the team. The average time from referral to first contact was approximately 5.93 days, although there were a small number of cases with long delays.

Role engagement with families

Many of the families who received support from the Kentown Programme had engagement with multiple roles of the triad model (n=172, 68%). Eighty-six (34%) families received support from all three components of the team: Service Coordinator, Family Support Worker and Nurse. A further 86 (34%) families received joint component support. Of those who received two components, the most common pairing was Nurse and Coordinator support (n=68, 27%). Followed by pairing of Coordinator and Family Support Worker without Nurse input (n=14, 5.6%). The combination of Nurse and Family Support Worker without Coordinator involvement was rare, provided to just 4 families (1.6%). Single-component support was provided to 47 (18.8%) families, with 37 of those families receiving Nurse-only support. Four families had support from

a Family Support Worker only, while Coordinator-only support was provided to six families. No data was available for 31 families, some of whom were the most recent referrals in the dataset.

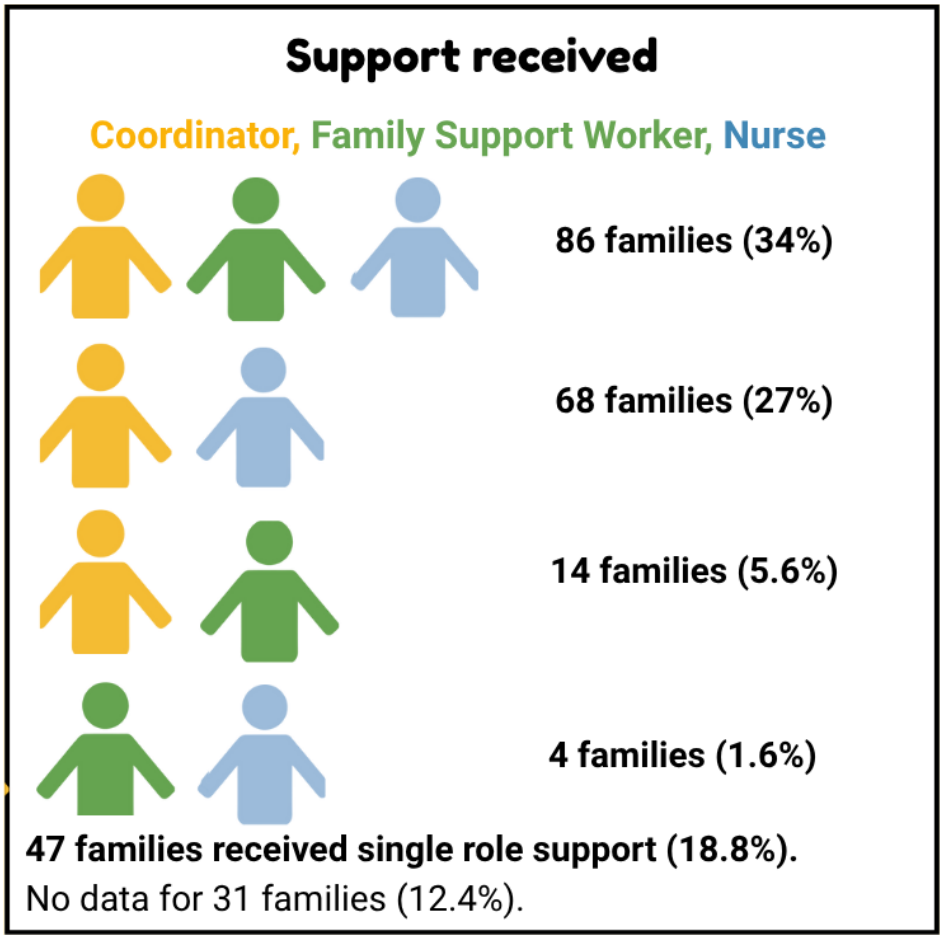


Figure 5. Role engagement with families

As described above the most common form of support provided was delivered either by the triad or joint roles (2 components). Looking at the delivery of each role component separately, Kentown Nurses were the most frequently used role providing support to 190 families, followed by Coordinator support to 174 families, and a Family Support Worker support to 113 families. The data demonstrates that the triad service model was providing multidisciplinary support as intended, with the flexibility to provide individual or wrap-around support as required by the individual needs of the child or family.

Advance care planning

Improving advance care planning was a key outcome for the programme related to objective 2. At the point of referral into the programme, the majority of children did not have an advance care plan in place. Data was available for 209 referred children, 42 (20%) had an advance care

plan at referral, while the remaining 167 did not. This indicates that referrals were being made to the Kentown Programme before formal discussions had taken place or documented plans were established.

The Kentown Nurses supported many conversations and preparation of advance care plans in collaboration with NHS partners. During the pilot phase, 58 advance care plans were completed which were led or supported by the Kentown Nurses. In addition to completed ACPs, a further 133 ACPs were in development by the end of the pilot, reflecting the programme's strong emphasis on ensuring families were equipped with the information they need to make informed choices. The distribution of ACPs in development varied across the participating NHS Trusts, highlighting both differences in local service capacity and the diverse needs of regional populations.

Case studies

As family level service data was not routinely captured (due in part to separate systems across organisations), the quasi-experimental economic impact analysis using a difference-in-differences approach was not feasible. To address this, it was agreed that additional family level data would be extracted from programme records, with consent from the families, for family case studies. This was to enable the case studies to develop a timeline of intervention and outcomes to supplement narrative analysis. These case studies are presented throughout the report to share examples of the experience and impact of the Kentown Programme for the families and the team.

James' Story

My Family

Mum, partner, me, younger brother

Kentown Support

Referral: Self-referral June 2023
Time to first contact: Same day
First contact: Kentown Nurse
Region: 1

Coordinator, Family Support Worker, Nurse

James is 15 years old. His health issues were identified early, and he was diagnosed with a rare genetic condition. James' mother explained that James was currently stable but that providing care was becoming more challenging, partly due to his physical development as he entered his teenage years.

Previous support had been limited, mainly involving some social worker input to arrange respite at a centre, but the family withdrew as they did not find it helpful. His family were providing all his care required and his mother said it was challenging to think about arranging hospice respite or other memory making activities due to transport difficulties.

James' mother self-referred to the Kentown Programme after hearing about it and received a response on the same day from a Kentown Nurse in June 2023. From this point home visits and other contact via phone and email with the nurse was regular and has continued for more than two years.

"[Kentown Nurse] comes round every now and then, keeps up to date with his care plan ... She listens very carefully, she helps us out where she can, she's very friendly." (Mother)

The nurse visits include symptom management for pain, sleep and dystonia, reviews of his advance care plan, support with hospital admissions, and reviewing current concerns.

His nurse provides coordination of care, helping his family navigate all the professionals involved in James' care and providing support so they can access experiences and days out with Kentown.

The Coordinators discussed financial needs, and a cost-of-living grant was given along with a crisis pantry food delivery. The family also received an M&S Christmas voucher.

The persistence of the Coordinators meant James got his wish of meeting Mr Tumble

A Coordinator emailed a welcome information pack the same month, and made regular contact including inviting the family to attend memory making events.

Although short breaks and holidays were discussed, travel was challenging and delays in arranging a mobility car meant a holiday did not happen.

The Coordinators successfully supported James' mother to apply to Make a Wish for James to see Mr Tumble, although this did not cover travel costs or transport. Using the Turn2Us fund the Coordinators got funding to provide taxi travel for the whole family so James had his wish of meeting Mr Tumble.

"The shops that we got when we were struggling, one of them was at Christmas time and that just helped massively, and it made a huge difference,... We've also had some help with gas and electric because we were in a little bit of debt so that helped get us back up to speed as well, and obviously [the family trip], we wouldn't have been able to get down there if they hadn't helped us and then James wouldn't have got his wish." (Mother)

To help ease transport challenges, the Coordinators supported a second Turn2Us application to fund driving lessons for James' mother. She plans to take her driving test in December. Thanks to a mobility application, again supported by the Coordinators, the family now has an appropriate vehicle.

The Coordinators' support has included mobility, financial, and food support, as well as memory-making opportunities and a trip to remember

The Family Support Worker took James and his mother to an initial and positive visit to their closest hospice. However, a few months later James' parents declined the offer of respite or a holiday due to the distance and lack of transport.

The Family Support Worker also supported the family through two family bereavements.

During the evaluation, James' mother explained she did not want to start a new relationship at that point.

She did express interest in receiving written information about the practical support that could be made available so she was clear about what would be available to them if needed.

The Family Support Worker had been in regular contact including home visits every 2-4 weeks with the family prior to the Kentown Programme, with James' mother making additional contact as needed. Once part of the Kentown Programme, the Family Support Worker drew on the other elements of the programme to inform their support and meet family needs, such as discussing things with the Kentown Nurse who could provide informed support to the family.

Home visits continued with James and his mother, during which emotional and practical support was offered, along with indoor activities. Outings were arranged including a day out at a wheelchair accessible beach. James' younger brother was occasionally involved in these outings but did not receive regular support.

When the family were doing well, the Family Support Worker discussed stepping down her support but James' mother wanted support to continue. Another planned visit occurred a couple of months later than expected due to family illness, lack of contact from the family, and a change in the mother's phone number, which impacted communication. At that visit, the Family Support Worker explained they were leaving the Kentown team and a final visit from her was arranged.

An offer to meet the new Family Support Worker was agreed at the final visit but the family has not responded to any contact made by by the new team member so the family was marked as dormant on the Rainbow Trust system.

The added value of the Kentown Programme support for James' family

The support provided to the family was holistic and flexible responding to a range of health, financial and social needs which benefited the whole family.

The care was enhanced by the triad team approach of the Kentown Programme stemming from the Kentown Nurse relationship with James' mother which cascaded to other roles to enable specific areas of expertise and support to be offered. Good communication was maintained between team members through close working relationships and regular caseload team meetings.

James' family has received direct nursing support, as well as the Kentown Nurse providing support to other professionals involved in James's care.

Their Family Support Worker has provided direct practical and emotional support through a challenging time, including two family bereavements.

Their Coordinators were able to provide urgent financial and food support, and supported James' Mum to develop lifelong skills and overcome transport challenges.

The team facilitated memory-making opportunities and guided the family to other sources of support, such as respite care at their local hospice.

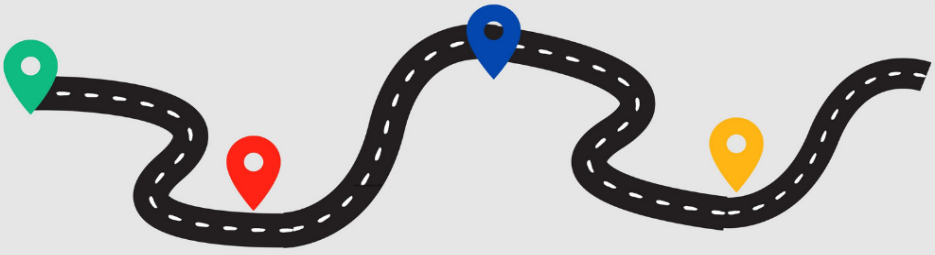
'I've been able to offer holistic/flexible support to this family and young person. I often review young person within the community and my support varies based on the needs of the family at the time. I hope I have helped to make [their health journey] feel smoother and more accessible by acting as a support for his key worker (Children's Community Nurse), offering advice and guidance to his care.' (Nurse).

'The family have been supported through a very difficult time and offered emotional and practical support which is priceless support.' (Family Support Worker).

'We have had a collaborative approach around this family. Mum has an excellent relationship the the Kentown nurse and this has helped with our relationship to mum. Kentown support has been life-changing to this family, enabling them to do so much more that wouldn't have been accessible otherwise.' (Coordinator).

JAMES' FAMILY JOURNEY

15 years old, rare genetic condition, White British



1 FAMILY SUPPORT WORKER
Regular visits started just prior to Kentown programme until FSW left programme **August 2022 - Nov 2023**

2 REFERRAL
Parent self-referral **June 2023**

3 KENTOWN NURSE
Same day response June 2023
Ongoing support as needed

4 SERVICE COORDINATOR
Contact within 2weeks of referral **June 2023**
Ongoing support as needed

SUPPORT RECEIVED

The Family Support Worker provided regular home visits and contact, emotional and practical support until they left the programme. The family declined further involvement.

The Kentown Nurse also provided home visits, symptom management, ACP reviews, and care coordination, supporting key workers.

The Service Coordinator provided financial and shopping support, opportunities for family days and outings, a Make a Wish experience

Support needs discussed at regular caseload team meetings.

Findings: Evaluation participants

Overall, 91 people took part in the evaluation across the participant groups (identified as key for the evaluation).

Figure 6. Evaluation Participants

Family Interviews (n=16)

Thirty families were identified by the Kentown team and consented to their details being passed to the evaluation team. Of those, adult family members and children representing 14 families took part. Participants included 10 mothers, three fathers, one grandmother, one referred child with a life-limiting condition, and one sibling. Families who did not participate despite their initial interest were unable to do so due to the changing condition of their child's health, sudden bereavement, lack of time or other ongoing challenges. The opportunity to include the views of children was further limited as many participating families had children who could not participate due to their condition or young age. The children of the participating families ranged in age from under 1 year to 15 years old at the time of the parent/caregiver interview; six of the children were female and eight were male.

The families were distributed across the five NHS Trust regions, reflecting geographical diversity and engagement with different members of the Kentown Programme team: Blackpool (n=4), East Lancashire (n=3), Morecambe Bay (n=2), North Cumbria (n=3), and Lancashire & South Cumbria (n=2).

Case study characteristics

Families who participated in the interviews were asked for consent to become a case study in the evaluation to share their experience and allow their engagement data that the Kentown team held to be shared.

Service data was extracted from the referral spreadsheet shared with the evaluation team, and the key staff involved were asked to provide more detailed information about their engagement with the family and their views on the experience of providing care to the family. The questions included their experience of any collaborations with other services, any training or development needs which emerged, and their view on what added value their role and the Kentown team involvement bought to the care the family received. The characteristics of the cases are provided below. Some details have not been specified such as the full diagnosis to protect the anonymity of the family. Each of the cases has been written narratively with supporting quotes.

Table 1. Case study characteristics

	James	Ahmed	Thomas	Habiba	Declan	Phoebe
Sex	Male	Male	Male	Female	Male	Female
Age (years)	15	3	16	1 (deceased)	1	12
Ethnicity	White British	Asian/Asian British	White British	Asian/Asian British	White British	White British
Diagnosis	Rare neurological genetic disorder	Rare neurological genetic disorder	Brain tumour	Rare neurological genetic disorder	Congenital condition	No diagnosis
***Index of Deprivation**	1	1	7	3	6	9
ACP in place on referral	Yes	No	No	No	No	No
Interviewee	Mother	Mother	Father	Mother	Father	Mother, Phoebe
Kentown Support	Nurse, FSW, Coordinator	Nurse, Coordinator	Nurse, FSW, Coordinator	Nurse, Coordinator	Nurse, FSW, Coordinator	Nurse, FSW, Coordinator

*Index of Multiple Deprivation 1 (most deprived) to 10 (least deprived); FSW (Family Support Worker)

Stakeholder professional interviews (n=40)

Professionals were recruited and interviewed at two timepoints throughout the project; 12-18 months and 30-34 months into the programme. At timepoint 1, 17 professionals were interviewed remotely through Microsoft Teams video call. Participants were nominated by the Kentown staff and represented a variety of roles from hospitals, integrated care boards, children's hospices, and community services, providing diverse professional perspectives.

At timepoint 2, 23 three professionals were interviewed. Participants were from an expanded range of healthcare (hospitals, integrated care boards, community services), education, and third-sector organisations (children's and adult hospices). Most participants had over 12 months' experience of collaborating with the Kentown team.

Table 2. Stakeholder professional participants at time 1 and 2

	Clinical and medical staff	Nursing staff	Leadership roles	Other roles	Support and Allied Health Roles
Time 1 (n=17)	3 Paediatric Palliative Care Consultants 2 Paediatricians Respiratory Consultant Clinical Director	5 Nurses Matron, representing hospital and hospice settings	Assistant Director Deputy Head of Community Service Clinical Team Lead Team Leader	NHS Integrated Care Board Strategic Representative	
Time 2 (N=23)	3 Paediatricians Paediatric Palliative Care Consultant Clinical Director	8 Nurses	2 Assistant Directors Clinical Team Lead Safeguarding Lead	2 Charity Grant Officers	Occupational Therapist Transition Coordinator Chaplain Teacher

Kentown Programme staff

The Kentown Programme staff took part in various data collection activities with the number and individuals changing as the programme developed and staffing moved in and out of the team. In total, 35 staff members participated across different data collection points and methods during the evaluation. The table below indicates the roles present and total number of team members at each data collection point.

Table 3. Kentown staff participants

	*Strategic Leadership roles	Nurses	Support Workers	Coordinators	Total
Scoping interviews (Year 1)	x	x	x	x	15
Impact workshop 1 (Jan 2023)	x	x	x	x	6
Impact workshop 2 (May 2023)	x	x	x	x	5
Process workshop 1 (Oct 2023)	x	x	x	x	13
Process workshop 2 (July 2024)	x	x	x	x	15
Process workshop 3 (April 2025)	x	x	x	x	17
Role specific interviews (April 2025)	x	x	x	x	17
Regional focus groups with frontline staff (April-June 2025)		x	x	x	12

*These roles include senior staff from both Rainbow Trust and TfSL partnership organisations including the programme director and programme managers.

Ahmed's Story

My Family

Mum, Dad, and me

Ahmed is 3 years old. Following a normal pregnancy, complications were discovered at the birth, and he was diagnosed with a rare genetic condition. The family felt there was limited information available about the condition but understood that it was life-limiting. The parents described how hard this was for them to come to terms with, particularly as he was their first and only child.

The hospital Consultant referred the family to the Kentown Programme in May 2023. The Family Service Coordinators made repeated attempts to contact the parents from January 2024 but received no response. Contact between the Service Coordinator and family happened once the Kentown Nurse had established contact 15 months later and established a relationship with the family.

The Kentown nurse had first contact with the family in August 2024 when Ahmed was 2 years old. Ahmed's mother did not respond to a previous attempt as the parents felt they were still coming to terms with the news and did not want to talk about it.

Kentown Support

Referral: Hospital Consultant May 2023
Time to first contact: 8 months
First contact: Kentown Nurse
Region: 2

Coordinator, Nurse

The nurse provided written information about the Kentown Programme and the different support available so the parents could read and discuss it together.

The nurse visits included providing written information, conversations about an advance care plan, signposting to other services and support, liaising with other professionals about the plan. They also support the mother with a family bereavement.

"...when you speak to someone it becomes very real, and you think, oh this is definitely going to happen, you're definitely going to lose your child. So I avoided the first call." (Mother)

The mother described how, in their first call, the Kentown Nurse focused on getting to know her and her family rather than talking about end-of-life care, which she had feared. The call made her feel at ease and able to speak about her concerns for Ahmed and herself.

"I felt like she understood, ... I felt like I was actually seen and heard. I felt she was actually there to support us as a family, come to terms with things, and take every step one step at a time." (Mother)

They had not received much support outside of Ahmed's medical care previously. With their extended family living in India, they had limited local support aside from a few friends. The mother described how her mental health had suffered and although she had sought counselling support, she found it unhelpful as it felt like bland reassurance without solid advice. She went through the GP for other talking therapies but soon realised that she preferred talking with the Kentown Nurse as they really understood the situation so she stopped the therapy sessions.

"I felt like they gave me a very clear picture, so they told me that if this happens you can do this, if this happens you can do that. But the thing I liked, it was all my decision, I didn't feel forced into doing anything, and when I made my decision, it didn't feel like a wrong decision." (Mother)

The nurse provided written information about the service and explained the Kentown offer, including how the Service Coordinators could also look at financial support. The nurse would visit every two weeks typically but the mother could contact her by phone or text as needed.

During subsequent visits, the nurse started a conversation about having an advance care plan for Ahmed. It took time for the mother to feel ready to have these conversations, as she had previously become upset when the consultant raised the topic during appointments. Over time they discussed together options for Ahmed's care with considering family and faith beliefs to write and finalise the plan, which took around nine months. The mother was grateful for the Kentown Nurse's approach and said she felt in control of what would happen.

The nurse discussed support available from the Kentown Programme. The mother agreed to talk with the Coordinator but did not take up any support offered, as they felt it was not right for them at that time.

The nurse also signposted the parents to other family support available, discussing sources such as local support groups and the local hospice. The family became more interested in hospice support through the nurse talking with them about what was available and the experience of other families.

In addition to home visits, the nurse liaised with other professionals including the Consultant to ensure all were aware of the advance care plan.

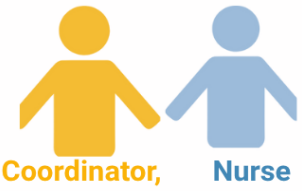
When there was a death in the wider family the mother appreciated the support she received from the nurse during this time, even though it was not directly related to the child's care.

The Coordinator explored opportunities that might interest the family, including the Make a Wish programme, the carers service, Together for Short Lives energy support, and available Children in Need grants. At the time the family did not take up these opportunities but are aware they can contact the Coordinator to discuss them as needed.

Support from the Family Support Worker was offered but declined.

The added value of the Kentown Programme support for Ahmed's family

The family were informed about all elements of the Kentown Programme's holistic support. They did not take up the Family Support Worker offer, as their needs were met through support from the Nurse and Service Coordinator.



The support required by this family was primarily met by the Kentown Nurse, as the main needs were for support around Ahmed's care and developing his advance care plan. The nurse also signposted the family to other relevant services, including the hospice. This support was viewed as invaluable by the family and had a significant impact on the wellbeing of the mother whose mental and physical health improved and ensured appropriate care planning for Ahmed.

'Mum explained that having the time and space to discuss her issues and concerns about her child's condition and the possibility of him dying in childhood, allowed her to process her issues. This enabled her to put strategies in place which reduced her anxiety and allowed her to concentrate on living and stop focusing on dying. ... Since completing the ACP she has taken him on walks out to many places... engaged with her extended family and community again, and is enjoying her child's life and celebrating his small progresses. She has stopped looking too forward, enabling her to focus on the present and enjoy every moment. As she expressed "I got my sparkle back".' (Nurse)

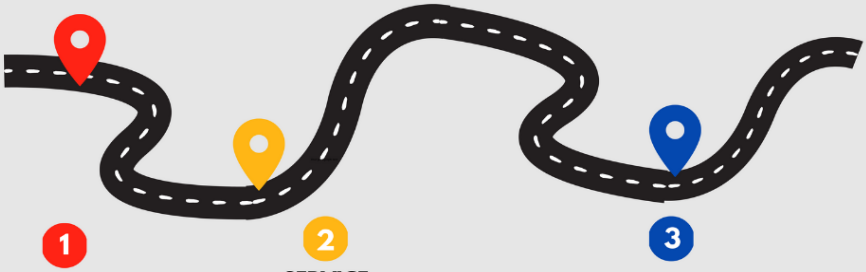
Following the establishment of a trusted relationship, the nurse was able to link the parents with the Service Coordinator who provided information on a range of opportunities and financial support that was available. At that time, the parents did not wish to take up any of these options, but they are aware of the types of support available and feel able to contact the Coordinator if needed.

'Our engagement has shown the family that there's support out there if this is something they would be open to. It took a while for Coordinators to contact the family but, after assessment, we were able to listen to their needs and offer solutions. The family didn't require our support at the time, but they are now aware of what we do.' (Coordinator)

Good communication was maintained between the team through close working relationships and regular caseload team meetings.

AHMED'S FAMILY JOURNEY

3 years old, rare genetic condition, Asian/Asian British



1 REFERRAL

Hospital Consultant
May 2023

2 SERVICE COORDINATOR

Contact attempted within 7 months of referral **Jan 2024,**
First engagement **Feb 2025.**
Support declined

3 KENTOWN NURSE

Contact at 15 months
August 2024
Ongoing support as needed

SUPPORT RECEIVED

The Service Coordinator provided information on grants, signposted to TfSL energy advisors, offered opportunities and a Make a Wish experience. Support was declined at this stage

The Kentown Nurse provided regular home visits and contact, signposting to support, and emotional support.

ACP development and coordination, emotional and practical support, signposting to other services.

The family declined the offer of Family Support Worker input.

Support needs discussed at regular caseload team meetings.

Findings - Process evaluation

This section of the report presents an overview of the development of the Kentown Programme approach, along with a summary of the key facilitators and challenges that shaped the implementation and delivery of the Kentown Programme.

Implementation and delivery of the Kentown Programme

Summary: Facilitated by appropriate processes, collaboration, and dedication on the ground, the Kentown programme's triad model approach to coordinated, holistic paediatric palliative care is achievable and impactful. However, sustaining it will require commitment from health systems, services, and policymakers

Development of the Kentown triad model approach

The Kentown team began the pilot with a shared purpose and sense of collective ownership and mutual respect, emphasising a genuine team ethos. From the outset, the integration of Kentown Nurses, Service Coordinators, and Family Support Workers into a cohesive triad model has been one of the programme's most valued features.

Staff described a strong sense of being "*one team*", with mutual trust between roles enabling smoother handovers, shared decision-making, and consistent information across services. Staff described being able to "*bounce off each other*," "*learn from each other*," and quickly "*respond to family needs without delay*." Early in the pilot, it was clear that joint visits played a pivotal role in building this cohesion. These visits allowed staff to observe and value each other's contributions. For example, Nurses spoke of how Family Support Workers helped to ease emotionally intense conversations, while Coordinators ensured that practical resources and system navigation were addressed. The division of labour was appropriate to their roles but not rigid; instead, it was characterised by flexibility and responsiveness, with team members stepping into gaps or offering support where needed.

The model operated without hierarchy between the Coordinator, Nurse and Family Support Worker roles and positioned staff to work flexibly across organisational boundaries if needed. Establishing regular caseload meetings, network calls, and shared referral pathways at key points in the pilot ensured that communication was continuous. These processes were also vital mechanisms for emotional support, peer learning, and workload management. This structure ensured families did not have to repeatedly explain their circumstances and supported proactive problem-solving by the team. It also created a culture in which team members felt safe to share challenges, ask for help, and learn from one another.

> *"It feels like one team. You know that you've got somebody else within the team who's got that knowledge and skills, that you can pass it over to, but you're not like just sending [families] off into the ether, thinking have they got the support that I think they should have? I actually know they've got it." (Kentown Service Coordinator)*

From the families' perspectives, the impact of this cohesion was substantial. Parents experienced this joined-up approach as leading to reduced duplication, fewer conflicting messages, and a clearer, more coordinated plan of care. The benefit of a team approach was particularly clear during moments of crisis, such as bereavement or hospital discharge, where the unified coordination between nursing, social, and emotional support ensured that families received care without duplication or delay.

All the roles evolved during the pilot while adapting to regional variability and need, with some expanding beyond the original remit to become increasingly multi-dimensional. For example, the nursing role extended beyond coordination and supporting care to include education, systems advocacy, emotional support, and mentoring for other professionals, including community Nurses, paediatricians, school staff, and coroners. These shifts within the team and external perception of the programme marked an evolution in the programme from service delivery towards service leadership and system influence.

The team received training from each other and external facilitators, in areas such as bereavement care, safeguarding, and symptom management, supporting them with the specialist and diverse capabilities required for the roles.

By the end of Year 3, the Kentown Programme had combined care, leadership, and education while adapting flexibly to local contexts, creating a trusted and responsive service valued by both families and professionals. The triad of Kentown Programme staff became crucial 'connectors' in a fragmented system, often acting as the only professionals consistently present for families across hospital, home, school, and hospice settings. Whilst there were challenges throughout the pilot, through establishing operational processes, clear communication, shared responsibility, joint visits, flexibility, and mutual respect, this model of team dynamics became a catalyst for effective implementation and service impact.

An overview of the development and changes in delivery of the Kentown model is presented in Figure 7.

Figure 7. Journey map of programme development and delivery

Facilitators of the programme

Summary: The flexibility and responsiveness of the team was a key facilitator for the programme. This was fundamental to the relational continuity with families and professionals, and collaborative working which positioned the programme as a catalyst for culture change in children's palliative care in the region.

Programme flexibility, responsiveness, and joint working

The flexibility of the programme, both in terms of location (hospital, hospice, home, or community) and professional boundaries, was frequently highlighted as a strength. As the programme developed during the first year the team developed joined up ways of working which brought together previously siloed roles to respond to complex family needs. Through regular meetings, clear communication, and joint visits, the team shared knowledge and skills, drawing upon each other's roles to provide the coordinated, wrap-around care required by families. The

staff reported feeling less siloed and described how the integrated model resulted in clear benefits for families, such as timely support, assistance with basic needs and how joint visits reduced the burden on families navigating multiple services. The Service Coordinators and Family Support Workers described how the model enabled them to become involved quickly and act on the 'small things' that could have a disproportionate impact on family wellbeing, such as helping replace a broken washing machine or assist with transport to a medical appointment.

Stakeholder professionals underscored the value of a model that placed family wellbeing at the heart of service delivery. Kentown Programme support was widely perceived as empowering families and enabling them to focus on living well through both emotional support and practical interventions that reduced stress and enriched family experiences.

> *"Well, from the feedback that we get from the families, the main one, is the support that the whole team gives the family and the child. So that includes the grants that can be looked into for these families and there's some Center Parcs breaks that our families have received." (NHS Manager)*

The speed of response was a recurring theme in both professional and parent accounts. Families spoke about urgent needs such as essential equipment and financial grants through to emotional support being met "*now, not in two weeks time*". Staff credited the flexibility of the model and direct access to discretionary or grant funding for that enabled rapid intervention. Coordinators and Support Workers often initiated contact rather than waiting for requests, which was particularly important for parents who were too overwhelmed to seek help.

The programme was designed with minimal bureaucracy for decision-making and a focus on empowering front-line staff to act quickly. Having a single point of contact for each family meant requests were handled without unnecessary delays and strong relationships with external agencies allowed for swift referrals and joint visits.

A major factor in the programme's success has been its ability to reduce the exhausting task of navigating fragmented systems by parents. Coordinators acted as "trusted connectors" handling complex paperwork, liaising with multiple agencies, and securing resources that families often did not know existed. This advocacy and practical help reduced stress, freed up emotional capacity for caregiving, and ensured more equitable access to support. This enabled the programme to address both clinical and support needs in an integrated way.

Another key strength of the programme has been its ability to adapt to the specific needs and contexts of different regions. Rather than delivering a fixed model, the Kentown team made deliberate adjustments to roles, processes, and priorities in response to variations in local

infrastructure, referral patterns, and family circumstances. This adaptability meant the service could remain relevant and effective even in areas where resources, relationships, or system structures differed significantly between areas.

> *"I think the value of this programme is that we went in to meet a need in this region and we have adapted the programme to meet the needs in the region." (Kentown Lead)*

In summary, the development of the Kentown model has been shaped by its commitment to joint working, rapid and flexible responses, relationship-based practice, and a clear focus on reducing the burden on families. By embedding skilled Kentown staff into integrated teams, investing in workforce development, and adapting to the specific needs of each locality, the programme has created a service that is both effective and trusted. Parents, staff, and professionals consistently described it as a model that "*makes things happen*", not only by meeting immediate needs but by building lasting networks of support. This blend of structural coordination, human connection, and adaptability has been central to its success and provides a strong foundation for sustaining and replicating the approach in other regions.

Relational continuity and empowerment

The Kentown model provides benefit to families through a multifaceted interplay of relationship-centred practice, specialist knowledge, proactive coordination, and empowerment. For many families, particularly those who encountered fragmented, delayed, or confusing support before Kentown, establishing a trusted, consistent point of contact was transformative. The time taken in early encounters to build rapport, to understand the family's world beyond medical notes, and to distinguish their own approach created an early sense of emotional security that underpinned later engagement and was particularly valued in moments of crisis or coping with a change in their child's health status. For Kentown Nurses and Family Support Workers, this relationship building was the gateway to greater impact. A recurrent theme was empowerment, helping parents find their voice with medical teams, enabling them to manage aspects of care themselves, and building their confidence in making decisions about their child's quality of life and end-of-life care.

Coordination was another mechanism by which the model produced benefit. Kentown staff acted as '*connectors*' across the NHS, hospices, community nursing, education settings, and voluntary services. This mitigated the burden on families of repeating their story and ensured that plans, especially advance care plans, were understood and operationalised by everyone involved. Professionals highlighted how Kentown's style was to "*do with" rather than "do to,"* ensuring that care planning and daily management remained anchored in the family's own values and capabilities.

Kentown as a catalyst for culture change in children's palliative care

As the programme went on, professionals consistently described a shift in attitudes and practices regarding early palliative care intervention, noting that the programme helped reframe palliative care from being associated solely with end-of-life to being understood as an ongoing process of support. The programme supported new innovative collaborations that filled service gaps.

> *"The collaboration between Together for Short Lives and Rainbow Trust is just amazing. I just think it's like the icing on the cake for me". (NHS Community Nurse)*

This cultural shift was facilitated through education and training, modelling of practice, and joined-up working. Kentown Nurses were described as agents of change, acting as "*ambassadors for doing the right thing.*" Nurses provided specialist input into advance care planning, symptom management, sensitive communication, and facilitated earlier and more open conversations about palliative care needs, while upskilling colleagues in acute and community teams to engage in advance care planning, have difficult conversations, and use resources to guide decision-making. Their presence was described not merely as an additional clinical resource, but as a strategic force for transformation and cultural shift.

> *"I feel like [Kentown Nurse]'s role has made that a possibility as well. There's a whole culture now in our team of getting better, trying new things, being brave" (NHS Nurse)*

Embedding Kentown Nurses into existing teams allowed for day-to-day knowledge exchange. When supported by NHS trust expectations, protected time for education, peer learning, joint visits, and reflective practice ensured that expertise was shared rather than siloed.

> *"The other hurdles I think have been helped by Kentown are things like education and awareness, so [Kentown Nurse] has managed to help upskill us massively by seeking out educational opportunities for us, she's done training, we've had advance care planning awareness training […] that's definitely not something that I had an opportunity to access before Kentown was in post, so that's been really good" (NHS Nurse)*

The theme of empowerment also extended to professionals, particularly community nurses, teachers, and paediatricians, with Kentown staff modelling holistic, anticipatory care and encouraging others to "*look outside the box*" in their own practice. Professionals described how Kentown Nurses brought cohesion and strategic clarity to previously disjointed pathways. By reframing palliative care as an everyday, integrated consideration rather than a conversation of last resort, Kentown Nurses normalised open dialogue about prognosis, care preferences, and advance care planning. Hospice colleagues noted that Kentown staff reached into the community

meaning conversations began earlier, were more consistent, and were shared with all relevant agencies, reducing the likelihood of families being unprepared if their child's health deteriorated.

Challenges faced by the programme

Summary: During the pilot a range of challenges arose for the team to address. In the first year, key challenges included IT infrastructure and information sharing between organisations, staffing and equity of provision across regions, and resistance to integration. As the pilot progressed, different challenges around caseload management, gaps in existing services, staff wellbeing, and sustainability of the programme were present. Whilst many of these issues were resolved or improved, some persisted.

Referral process and information sharing

A key internal challenge during the first year of the pilot was the lack of alignment between the IT systems of the programme partners which reduced efficiency, limited information sharing and created bottlenecks in referral and documentation processes. As a result, considerable time was spent navigating parallel documentation systems. Efforts to address this issue included the development of new referral procedures and the implementation of shared spreadsheets. These processes improved programme management but did not resolve the structural issue of fragmented digital systems, which remain a risk to integrated practice, a known endemic issue across all NHS and social care settings.

This challenge was also recognised externally during the first year of the evaluation. Multiple professionals from other services described fragmented referral systems as a persistent barrier, with duplication of effort or missed referrals occurring due to lack of clarity and integration between the three programme partners. Professionals expressed a desire for more joined-up approaches, where communication between services would be smoother and more collaborative, particularly when families were navigating complex decisions.

> *"That was just a [communication] challenge, I guess hindsight's a great thing isn't it? But maybe a more joined up approach, to be a part of that conversation a little bit more, particularly if families are exploring whether they'd want end of life care to be in a hospice setting." (Hospice Manager)*

Staffing and equity of provision across regions

Staff recruitment and retention challenges during the pilot resulted in disruption to continuity of care in some areas, an outcome experienced by both families and professionals. Professionals described how turnover and staff absences undermined the relational continuity with the

Kentown team with a lack of clarity about whether the role was being covered and what the programme could offer during staff absences, and concern that families needed to "start again" with building relationships with new staff.

> *"I think we've had the opposite effect with [Kentown staff] going off and I don't know if there's any chance of them coming back or whether it'll be someone new … I think they will then almost have to start again because it's been such a long period of time and start to build up that relationship again" (NHS staff)*

Gaps in staffing capacity led to increased workloads for those remaining, sometimes delaying planned interventions and placing strain on the model's responsiveness, along with reduced time for the relational elements of the work valued by families. When it occurred, staffing instability reduced capacity, fragmented continuity, eroded inter-professional trust, and increased the potential for staff burnout. While individual staff members demonstrated resilience, compassion, and adaptability, the cumulative impact of workforce instability fundamentally altered the programme's ability to deliver consistent, responsive, and holistic care at times.

As with many services, caseload management was a challenge at points in the pilot. When the programme began, it was known from previous mapping that there were a high number of families in the region who would benefit from support, and low resources of support available, so this context, along with awareness of the programme growing, lead to referrals increasing steadily from early on. At times, the ability to respond to referrals in the planned way was also impacted by staffing gaps in some regions. The Kentown team adapted their processes to step up or step down the support offered, depending on the needs of the families, with some families moving to a dormant status if current support was not required. This approach ensured resources were used where most needed and supported the team in maintaining some capacity for a rapid response in urgent situations.

Integrated working

Integration of the Kentown Programme into existing services across Lancashire and South Cumbria was met with both opportunity and complexity. The degree to which the programme was able to embed itself into local systems varied by region, organisation, and professional relationships. In some regions, partnerships with hospices, community nursing teams, hospital teams, and the voluntary sector providers grew stronger over time, in others the process was slower and occasionally met with resistance, particularly where historical ways of working or entrenched service boundaries were slow to shift.

The most frequent challenge reported by both Kentown staff and professionals early in the programme was a lack of clarity around roles and responsibilities. Professionals were uncertain

about where Kentown staff fitted within the broader system. In practice, this sometimes meant that Kentown professionals had to repeatedly explain their remit and purpose, while also working to reassure others that their role was intended to complement, not replace, existing provision.

> *"We have had issues where external staff don't truly understand what our role is and how we are not threatening, and we are not taking over their job."* (Kentown Nurse)

Challenges of information-sharing and consistent referral pathways were made more acute by Kentown staff sometimes being excluded from multi-disciplinary team (MDT) meetings, and communication with schools, CAMHS, and hospices could be inconsistent. During the first year of the pilot, Kentown staff relied on personal contacts and informal arrangements to remain connected to wider care planning due to a lack of formalised processes. Where integration was successful, it was driven not by systems, but by strong relationships and trust. Kentown staff who were known locally, embedded in co-located teams, or had built credibility through consistent presence were more likely to be welcomed into planning and delivery structures. This was particularly evident where staff had pre-existing relationships in the area or were physically based alongside other services, allowing for day-to-day interaction and informal problem-solving.

For the Kentown Nurses, expectations from NHS employers did not always align with the demands of delivering the Kentown model, particularly in relation to the time and flexibility required. There were regional differences in how the role of the Kentown Nurse was interpreted and their role in training. Some Kentown Nurses were embedded in Trusts that supported expansive training and gave them autonomy to lead it. In contrast, other regions limited the Kentown Nurse to more traditional roles and diverted them into bereavement-specific or non-palliative responsibilities. This limited their ability to share learning or build consistent training models. This not only affected the consistency of service delivery but also had implications for how local teams understood and engaged with the Kentown model.

Initial tensions were present in how the specialist nursing role was perceived externally by some professionals. In one tertiary setting, the designation of 'specialist Nurse' was seen as contentious, triggering resistance to collaboration and raising questions about supervision. This highlighted early on the need for clearer role definitions and a need for stronger system-wide advocacy around the Kentown nursing function. There were also calls for a paediatric palliative care consultant to be linked or embedded in the programme to provide clinical leadership and enhance credibility with some external services.

An unintended consequence of Kentown's presence was statutory services withdrawing because Kentown was now "involved." While this was not frequent, it highlights the importance of clear communication and shared expectations with other services to ensure families do not lose access to other valuable support.

Over the three years, the programme naturally evolved and addressed some of the above challenges through collaborative problem-solving and strategic adaptations. In addition, the Kentown Programme also helped to build bridges between acute and community services, facilitating smoother transitions and better understanding of shared responsibilities. One professional noted:

> *"Having the Kentown Nurse there has improved our relationships across the board, community, hospice, hospital. We talk more now. There's trust". (NHS Consultant)*

The evaluation revealed critical challenges in inter-agency coordination, service boundaries, and infrastructure limitations, but also showed that innovation flourishes when professionals are allowed to lead with values and relational depth**.**

Gaps in existing services

As the programme progressed, the pre-existing gaps in services continued to be a challenge to implementing wrap-around care when needed for families, highlighting the difficulty of sustaining a transformative model within the constraints of current health and social care systems. While the Kentown team was highly responsive during working hours, an urgent concern expressed by the team and stakeholder professionals was the lack of a 24/7 provision, particularly for families providing end-of-life care at home. Although Kentown Nurses worked creatively to mitigate this with anticipatory planning such as preparing GPs, hospices, and schools in advance, the absence of 24/7 support placed emotional strain on families.

Staff wellbeing

During the final year, there was increased reflection on the emotional toll of this work. While Rainbow Trust staff received regular mandatory monthly supervision and benefited from established systems of support, this was not the same for other team roles. Kentown Nurses did not consistently take up or have access to equivalent clinical supervision despite this being anticipated as part of their position in the trusts. The lack of dedicated, mandatory professional or clinical supervision placed a significant burden on the team at times. Informal peer networks and mutual team check-ins became critical mechanisms for maintaining resilience and sustaining the quality of care. The Kentown team emphasised that the emotionally and ethically complex nature of the work, often involving trauma, death, and family grief, made such support essential moving forward.

Sustainability

Stakeholder professionals raised concerns about the longevity of the Kentown model without ongoing funding or formal integration into statutory services, raising fears that, in the absence of clear governance structures, the momentum and innovation introduced by the pilot programme could be lost. Whilst professionals praised the pilot as a progressive and compassionate initiative that shifted the culture of paediatric palliative care and empowered families, operational challenges, including fragmented communication, regional inconsistencies, and uncertainty about sustainability, posed real threats to its long-term impact. These insights highlight the importance of both maintaining the value driven strengths of the programme while investing in structural supports that ensure coherence, continuity, and equity across regions moving forward.

Summary of learning points from the process evaluation

1. **Triad model approach is effective and impactful**
   The integrated Kentown team structure, has proven highly effective in providing coordinated, wrap-around care to families while facilitating shared learning, responsibility, and support across the team. Retaining the non-hierarchical culture and integrated key roles will be integral to future implementation.
2. **Rapid and flexible response capacity has been invaluable to families in crisis**
   The ability to respond quickly to urgent family needs is a defining feature of the programme. To maintain this rapid and flexible approach of frontline staff, it will be key to ensure process-related constraints do not undermine the proactive ethos and team capacity is retained to respond promptly when needed.
3. **Role modelling, mentoring and training provide cultural change**
   Kentown staff have acted as catalysts for cultural change, particularly by promoting early palliative conversations and reframing palliative care as a continuous process. Modelling of holistic, anticipatory practice for other professionals has been a standout feature of embedded Nurse roles. Continuing this and offering region-wide training opportunities for all staff will ensure that mentoring and learning opportunities are available internally and for other professionals.
4. **Flexible implementation ensures regional needs are met**
   A key strength of the Kentown model has been its ability to adapt to regional service landscapes while preserving the core, family-centred values and mechanisms. This flexibility has enabled the model to align with varying regional infrastructures, referral patterns, and community needs. Continuing this and strengthening communication between regions and services will support the sharing of best practice.
5. **Referral and data systems alignment remains a challenge**
   Programme management experienced challenges due to IT and data system challenges. The development of a single referral process and shared data system has the potential to eliminate duplication, burden for staff, and streamline operations by enabling seamless information sharing.
6. **Clear service offer and role boundaries support integration**
   The establishment of a clear service specification and well-defined role boundaries for Kentown staff has been critical in reducing misunderstandings and strengthening trust with hospices and tertiary teams, facilitating collaboration. Continuing to provide clear communication regarding how Kentown complements, rather than replaces, existing services in all regions as the programme spreads would further clarify its unique position and strengthen partnerships.
7. **Workforce challenges impacted offer and relational consistency**
   Challenges of staff recruitment and retention were managed within the team but left gaps in provision at times during the pilot. Plans for cover when needed and clear communication with collaborating services remain key to ensuring consistency of the offer in different regions and maintaining relational continuity with families and professionals.
8. **Staff wellbeing**
   Supervision is mandatory for family support workers but was not routinely taken up or available for all the Kentown team. Introducing proactive wellbeing frameworks and supervision for all team members will be crucial in managing the emotional demands of the role, preventing burnout, and ensuring long-term resilience within the team.
9. **Out-of-hours provision gap impacts on families and creates challenges for team**
   While the current Kentown model has been highly effective during standard hours, the absence of out-of-hours provision in the region remains a gap, which causes challenges, especially for families opting for home-based end-of-life care. The Kentown Nurses have supported families with anticipatory planning but there is a need for 24/7 or overnight nursing 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.

Thomas' Story

My Family

Mum, Dad, 2 sisters and me

Kentown Support

Referral: Kentown Family Support Worker, April 2023
First contact: Family Support Worker
Time to first contact: Same day, April 2023
Region: 3

Coordinator, Family Support Worker, Nurse

Thomas was diagnosed with a brain tumour in 2022 when he was 13 years old. He underwent several operations and procedures, developing complications along the way. Although he was improving, he was still in hospital at the time of the evaluation interview in November 2024. The long period of hospitalisation was a stressful and challenging time for the family, as they worried about their son's health while trying to maintain a sense of normality for their other children, who also had their own needs.

Previous support offered to the family had been limited, despite appearing promising on paper. The father expressed that it felt as though professionals had given up on them during their long hospital stay.

The hospital oncology nurse told the parents about a new service called the Kentown Programme and contacted a Kentown Family Support Worker to learn more and refer the family. At the point of referral, the family did not have any expectations of the Kentown team.

"...the support we've been offered has on paper been fantastic, so if you were to read it and not know what that actually means, you would go, that's amazing, but in reality, it means nothing. There is no help on the ground ...and you're left to flounder. What Kentown did in that first year was actually try and make a way through the trees and really help you, when unfortunately, you have no support." (Father)

"...when you're thrown into this washing machine of disaster, you can't help but think, well, what can they do for me? You just hope that people are going to help you." (Father)

The Family Support Worker referred the family to the Kentown Programme and provided practical and emotional support to Thomas and his mother in hospital. This included respite so the mother could take a break to do chores such as laundry or have some personal time.

They also provided hospital transport for family members and bereavement support.

Two key areas were identified for Kentown input: support for Thomas and his mother in hospital, and emotional support during the family's bereavement. The Family Support Worker met the family in hospital prior to the referral and made regular weekly or fortnightly visits, providing practical and emotional support, including respite breaks so the mother could do laundry or take a walk. They also provided hospital transport for a grandparent and siblings to visit Thomas, offering emotional support throughout the journey. The family experienced an adult bereavement during this period, which was supported by the Kentown team. The Family Support Worker left the team in October 2023, and another team member continued providing support until April 2024.

When it became clear that Thomas would survive, planning began for his discharge from hospital, which involved making home adaptations to meet his care needs. At this point in June 2023, the Family Support Worker contacted the Kentown Nurse who became involved to support discussion on discharge planning, attend multidisciplinary team meetings, and liaise with the hospice. They met Thomas and the family on the ward in early 2025 and supported planning meetings until July 2025.

The Kentown Nurse was involved in the family support for a year, supporting professional meetings, discharge planning and liaising with the hospice. They met the family on the ward once amongst these other engagements to support the family. The parent did not recollect meeting the nurse or their engagement aside from a couple of online meetings. This case is an example of how the Kentown Nurse role can be 'behind the scenes' and unseen in some cases.

The Coordinator provided a wide range of support over an extended period, including a crisis pantry shop, access to legal advice and an energy advisor, support with applications for mobility and charitable grants, and liaison with health and social care professionals and the council about home adaptations.

The Coordinator also supported a REACT application to provide audio books for Thomas.

'the Coordinator was excellent... His involvement was incredibly important to us. It was pivotal in so many things...that sort of input for that year, or just over a year was absolutely invaluable. He invested himself in that job and gave everything he could to make a difference. If you don't get that sort of individual in these roles, you won't deliver what you really want to deliver. What we got for a year was somebody who was highly invested, very empathetic and caring and did what they could, and did more than all the other support services rolled into one." (Father)

After exploring various options and costs, the family decided to move house to make this possible. The costs of moving to a more suitable home and completing the necessary adaptations were very high and exceeded available statutory funding. The family carried out fundraising activities as the available funding was not enough to cover costs and had an overwhelming number of applications and paperwork to complete.

The Coordinator became involved from the point of referral, initially speaking with both parents before moving to regular contact with the father, providing support around decisions and arrangements for the home adaptations. This included providing a crisis pantry shop, access to legal advice and an energy advisor through Together for Short lives, Motability application and other charitable grant applications, liaising with health professionals, social workers, and the council about the adaptations including a home visit, and social care package. A REACT application for audio books for Thomas was also supported to provide some entertainment in hospital. During this period, emotional support was given to the father as it was a very challenging time for the family, with lots of decisions and applications.

'Well, you've got a seriously ill child in hospital for months, if you can imagine having to live your life around that and go to work and run a house and be away from your partner and all those things, having that support [from Kentown] to help you through was just, well, amazing. But there was a change in Kentown earlier this year, which basically destroyed the support for us. Until then was incredibly beneficial and worked really well.' (Father)

In the summer of 2025, a charity agreed to help with the required adaptations, which was a great relief for the family. At this stage, Coordinator support was stepped down due to the change in situation for the family. Dad expressed gratitude for the Kentown support that had helped them reach this point over the two years, but also disappointment at losing such excellent support and navigation from the Coordinator which they found challenging with many things still to organise. This case highlighted the challenge of meeting family expectations while maintaining capacity for the Kentown team to reach out to other families in need.

The added value of the Kentown Programme support for Thomas' family

The support provided to the family was holistic and flexible, responding to a range of health, financial, emotional, and social needs that benefited the whole family. The care was enhanced by the triad team approach of the Kentown Programme stemming from the Family Support Worker's relationship with Thomas' mother which cascaded to other roles enabling specific areas of expertise and support to be offered by the Service Coordinator and Kentown Nurse.

Thomas' family received support from the Kentown Nurse, who contributed to discussions and arrangements regarding Thomas' discharge and liaised with the hospice. This activity was key to ensuring holist planning but was not always visible to the family.

The Family Support Worker provided direct practical and emotional support during a challenging time, including a family bereavement and an extended hospital stay for Thomas and his mother. Transport was provided for a grandparent and siblings to visit the hospital, helping maintain family contact and support for both the mother and Thomas. This support was vital for Thomas' mother who remained at the hospital throughout his stay.

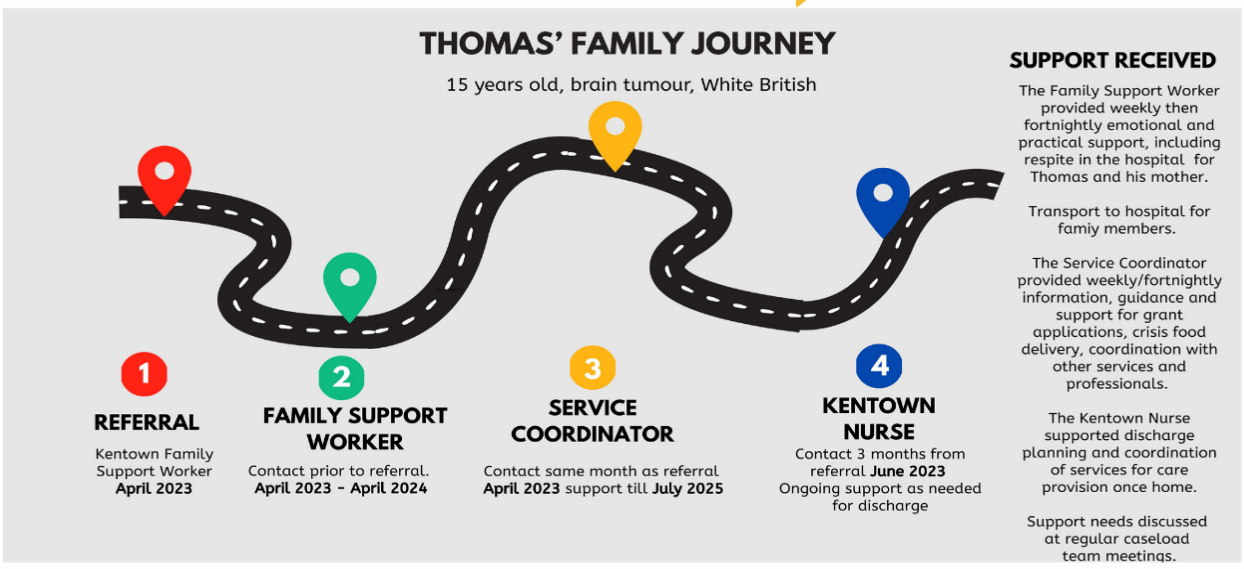
The Coordinator was able to provide much-needed expert guidance and support, helping the family navigate a complex system involving multiple professionals and organisations to arrange the home adaptations required for Thomas' discharge. Once the final support was in place for the adaptions, the support was withdrawn following discussion.

Good communication was maintained within the Kentown team through close working relationships and regular caseload team meetings.

My role has been limited due to the young man being an inpatient for over 3 years. I have attended meetings to begin discharge planning and looking at how support would look in the community. I have contributed towards the health needs assessment. (Nurse)

'All aspects of the Kentown team were involved to try and meet the needs of the family appropriately. We provided essential support in the hospital.' (Family Support Worker)

'It enabled a family who were severely affected by their son having major complications following brain surgery to have support tailored around their needs. We arranged out of hours home visits, and provided support through counselling, support with mobility and helping an overwhelmed dad with applications and transcription. Nurses were present and the Family Support Worker help was immeasurable supporting them, taking the grandparent to the hospital and providing mum with a few minutes to come away from her son's bedside.' (Coordinator)



Findings - Impact evaluation

The impact evaluation captured the views and experience of families, stakeholder professionals and the Kentown programme team to understand their perspectives on the key impacts had been for families.

Impact and added value of the programme for families

Summary: The Kentown Programme had a range of impacts for families through the holistic, wrap-around support offered, tailored to individual family needs. The experience for families was shaped by the consistent relationships, service coordination, practical and emotional support, and the perceived quality of support offered. While many experiences were overwhelmingly positive, with families highlighting the depth of care received, there were a small number of occasions where expectations were not met due to gaps in continuity or changes in support.

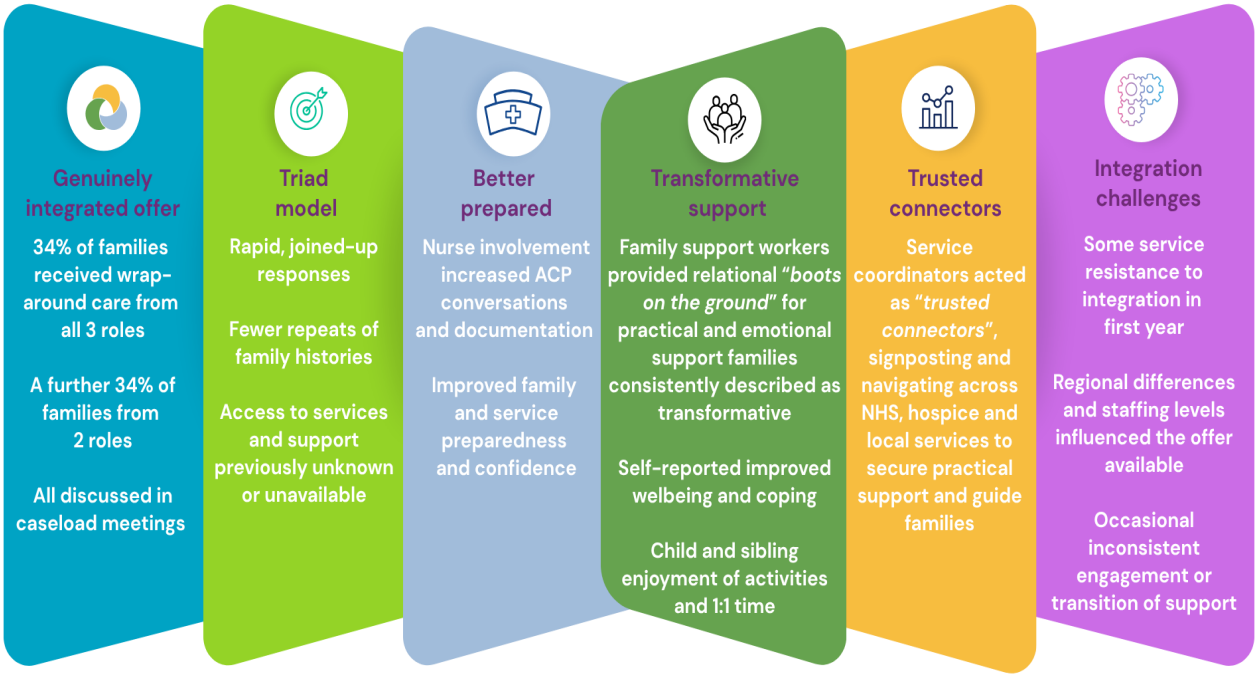


Figure 8. Impact of the Kentown Programme for families

Introduction to the Kentown Programme

For most families, the Kentown team was introduced with care and clarity. This included named professionals taking time to explain the service, parents emphasised that being "introduced properly" mattered, particularly in emotionally charged situations. Other families were referred to Kentown later in their journey after long periods of struggle during which they had little or no

emotional, financial, or respite support. The contrast of support available was significant and reduced feelings of being overlooked or isolated.

> *"I think we were only referred to the Kentown service as we were thinking about being discharged from hospital, so that's nearing three months after [Child's] birth. So contact with Kentown could have come in a bit sooner, because we were still enduring the same stresses and financial strain then." (Parent 5)*

Several parents said they were initially unsure what Kentown was, what it offered, or how it differed from other services. Some said they did not recall ever seeing a leaflet or guide to explain what the offer included.

> *I don't believe I've ever seen a leaflet or anything like that so I don't fully know what they cover or help with, I think a leaflet would be probably helpful to families." (Parent 14)*

In some cases, the word 'palliative' triggered alarm or confusion, leading parents to question whether something had not been explained to them about their child's condition. Others assumed the service was only for children in the end-of-life stage or associated it with hospice care.

> *"I remember being quite shocked that it was a palliative care nurse. I remember thinking has somebody not told me something? [laughs] But actually, [Kentown Nurse] was lovely with that." (Parent 5)*

Most families began their engagement with Kentown without clear expectations. For some, this was because they were too overwhelmed by medical and emotional strain to anticipate what support might be helpful. Others had been repeatedly let down by previous services and entered cautiously, expecting little.

> *"I didn't really have any expectations at that point because I felt so let down by the system… because we had a lot of healthcare professionals involved that have just not been consistent or done what they say they're going to do something, but it was just completely different to what I've experienced before. [Kentown Nurse] actually did do things and she actually did everything that she said she would do, she did." (Parent 9)*

Holistic support

One of the key impacts of the Kentown Programme for families was the emotional support it provided through deeply human, relationship-based care. Parents described feeling "seen," and "heard," by Kentown professionals who connected not just clinically, but personally. This support was particularly evident in the role of the Kentown Nurses, whose presence helped parents process overwhelming

experiences like anticipatory grief and difficult decision-making, whilst feeling advocated for in complex systems.

> *"She just understood that bit more about what it's like to have children with special needs, she's got this extra understanding of the complexity. I didn't really know what to expect, but it's been nice to know that [Kentown Nurse] is there really. I felt like she was actually there to support us as a family." (Parent 3)*

The emotional resonance of Kentown's support was not always about formal counselling or structured interventions, but about how staff showed up, with empathy, authenticity, and time. Their presence alone often created the conditions for parents to offload long-held fears or talk through grief. This emotional dimension of support, the sense of being genuinely known, cared for, and not alone, emerged as a defining feature of the Kentown model. It helped families move from states of emotional crisis toward stability and enabled them to face difficult decisions with greater support.

The programme's support extended beyond the individual referred child to the wider family, particularly parents and siblings. Families described feeling "held" by a team that recognised the emotional and practical toll of complex care and actively worked to relieve it. Family Support Workers were particularly praised for providing consistent emotional presence, peer-like parenting insight, and tangible respite from overwhelming responsibilities.

> *" [Family Support Worker's] been amazing because suddenly I was, or I'm now, parenting three children on my own and trying to support them through the grief and understanding the actions or whatever they may be doing. It was really helpful to have somebody to talk it out with, that wasn't a family member, you know, it was a lot more, easy. It was just easier because you're not having to hide what you're saying or protect that person." (Parent 4)*

Others described how Family Support Workers provided critical hands-on support, such as transport, childcare, or advocacy during appointments, often stepping in where no other help was available.

> *"since [the Family Support Worker]'s came along, she's there every two weeks to see him, she takes him out, she picks him up from school, absolutely fabulous lady, she's really there to support me, and she always wants to be at meetings, if I've got an MDT meeting, or if I think that I can't put things the way that I want to put it." (Parent 1, Interview 2)*

The two children who shared their experiences spoke of how much they enjoyed the time spent with their Family Support Workers. The sibling had enjoyed outings on a one-to-one with the support worker as well as attending some group events organised by the Kentown team. For him, it was fun time where he was the focus. When he heard that the Support Worker would not be able to come anymore as they were leaving the programme, he was very upset and expressed how he still wanted someone to come and visit with him.

"So, we went to somewhere and it had green water instead of blue. Then, we hopped over the stones and we went to go and get some ice cream and we went down to the beach…. I do want somebody to come and see me!" (Sibling 1)

The child with a life-limiting condition shared how she enjoyed playing games with the support worker, such as computer games or Lego, going on outings, and talking with her. These outings often included a friend who was also being supported by a Family Support Worker, enabling peer social time.

"So we've been outside and we've also been to the maize maze, and bowling. We've also done a couple of trips McDonald's… we played on the game on my switch. It's all very fun." (Child 1)

Her mother spoke of how the child had opened up to the support worker after the death of her father and how this provided another source of support when the child may have been worried about upsetting her mum.

"I think at times [Child] has opened up to [Support Worker]. When [Child's] been on her own with her, if that makes sense, because she probably gets really upset because she thinks she's going to upset me, so she'll bottle things up and not say anything, so it's quite nice that option is there." (Parent 4)

Families emphasised that sibling support, whether through trips, one-on-one time, or simply being acknowledged, had meaningful benefits. It gave siblings a sense of normalcy, visibility, and connection during otherwise stressful times.

"I want him to just be a normal kid. So, that was great when they came on board. […] it's hard for siblings, it's really difficult for them, like I say they do get pushed aside and they do spend lots of time without their mum and dad because their sister or their brother is in hospital and you split up from your family and they get passed here there and everywhere, it's not an ideal situation but they're part of the family too and I just think there needs to be more support for the siblings."(Parent 1)

For families where a sibling has regular support from a Family Support Worker, they spoke about its value not just for the children, but for parents as well, offering rare moments of relief, reassurance, and shared happiness.

> *"At first, when [Child] came out of hospital, the [Family Support Worker] stays and played with [Child] so that I could get a shower, so that mum could go out if she needed to, and I wasn't left sort of on my own with him because of his complexities and then as he grew more, as his capabilities grew, we go out once a week, we go to the park, to the beach. We've taken [Sibling], who is the eldest along with us in the school holidays, we go to soft play. Nothing is off limits with [Family Support Worker], nothing." (Parent 12)*

Relational Continuity

For many families, the most powerful aspect of Kentown's impact was not a single intervention, but the continuity of support over time. Knowing that someone who understood their story created emotional safety and reduced the pressure of constantly re-explaining their situation. Consistent relationships with Coordinators, Nurses, and Family Support Workers were seen as the foundation for trust, confidence, and forward planning.

> *"There's a real kind of consistency with having [Coordinator] for the last year at the end of the phone […] what I really appreciated about the Kentown project was that there was [Coordinator], and he was, it felt like he was the hub on a cartwheel." (Parent 5)*

Where consistency was maintained with roles, families described their Family Support Worker or Nurse as "part of the family." This trust gave parents space to focus on their child's needs rather than chasing professionals or services.

> *"I didn't feel like I had a timeframe to make a decision, she was like, 'It's completely up to you, even once we draft this care plan, you can tear it up, you can make another decision,' everything, it was my decision, I wasn't forced to do anything, and I felt like that was really nice of her, and like the support, it was really good." (Parent 13)*

Coordination and navigation of services

In addition to emotional support, families described the Kentown Programme as transformational in its ability to ease the daily burden of navigating complex systems. Coordinators and support workers played a central role in helping families access funding, manage paperwork, and understand what resources were available, often stepping in where statutory services had failed to offer timely or meaningful support. Families did not need to chase information or fill out daunting forms alone. Instead, Kentown staff offered hands-on assistance, removing barriers at a time when parents were

overwhelmed. Coordinators were seen as trusted connectors, helping reduce the burden of navigating fragmented services and preventing parents from having to repeat distressing or complex information to multiple professionals.

> *"[Kentown Service Coordinator] actually helped, he came out to the house and filled in the mobility form for [child] because I was just like, '[Coordinator] I've got no idea what to write in this" (Parent 1)*

The service extended beyond administrative support, especially during moments of acute hardship. Several families said the funding or other goods they received was essential, allowing them to meet basic needs or provide opportunities they could never have afforded otherwise.

> *"Oh, that's right, in January time, they'd got some money from Morrisons as well and we've got a week shopping which was just like, honestly, I cried because January is an awful time for anybody, isn't it? Quite often and it was like, 'Oh my goodness, we've got food, you know'." (Parent 4)*

Kentown also provided strategic advice and connections across multiple systems (e.g., legal, educational, charitable) providing support and reducing the mental load on parents trying to manage everything alone. Even where families were aware of support that existed, they highlighted how the hands-on involvement made a practical difference.

> *"Also that bank of knowledge, so you can Google charitable support for a disabled child, and there's millions of results, and you don't know where to start, whereas [Coordinator] was able to kind of point us in the right direction with what was on offer." (Parent 5)*

Unmet expectations

There were three occasions where families spoke about unwelcome changes in the support they received, or the support not meeting expectations. These involved loss of support due to a member of the team leaving, the available support not quite aligning with what the family needed at that point, and withdrawal of coordinator support due to an improvement in the family circumstances indicating intensive support was no longer needed. For families navigating complex emotional and practical challenges, the reduction or loss of a trusted source of support was deeply felt and had an emotional impact. There were learning points in these experiences for the Kentown team processes regarding communication and handling of transitions of support which were addressed internally and with the families.

Continuing presence

Many parents expressed a desire for long-term involvement with the Kentown team, with support that could adapt over time and could be called upon when circumstances changed. The idea of a "light touch but lasting presence" was echoed across interviews. For families managing uncertainty, knowing someone was still there, made all the difference.

Perceived impact for families by stakeholder professionals

Summary: Professionals identified key impacts for families including provision of holistic support helping to bridge gaps or inequity in available provision, follow up support for families following difficult news, initiating advance care planning conversations, and creating a culture shift by normalising conversations about palliative and end of life care. Concerns were raised about the sustainability of the programme and future work was needed to address inequity experienced by families outside the coverage area, particularly in northern regions.

Professionals described the Kentown Programme as a key support mechanism for families during a challenging period of their lives. Many families encountered the programme following some difficult news relating to their child. In these moments, the presence of a dedicated Kentown Nurse offered comfort, guidance, continuity, and access to further resources.

The perceived impact on families centred around how the programme softened the isolation that often accompanies life-limiting conditions. Several professionals highlighted that, in contrast to traditional models of care, where families can be left to process difficult information in a vacuum, the Kentown Programme provided a follow-up structure that offered consistent support.

> *"Helping families cope at a really difficult time, I think is key. I've got at least a couple of cases that families feel like they've been left. They've had either a new diagnosis or a change in prognosis that's been shared by a consultant in a clinic and then they've gone away and they're trying to get their head around that and they're really struggling and actually the signposting and just knowing that there's someone who they can contact has been hugely valuable. For the child themselves that means if everyone around them is coping better, the child is going to be picking up on that and hopefully better supported too. I think that's probably the biggest benefit." (NHS Consultant)*

Professionals felt strongly that the model of care was right for families and that it provided a key support.

> *"The support available for families and also for us as clinicians, particularly for children or families who are at a very difficult point in their journey, whether that be shortly after a diagnosis or a change in prognosis or actually planning ahead for something like an admission for someone who's got really severe needs. So yeah, the support is the biggest thing." (NHS Consultant)*

A core area of impact perceived by professionals was the Kentown Programme's role in initiating and sustaining timely conversations around advance care planning. Where such discussions were previously avoided or delayed until a child was actively dying, Kentown Nurses enabled families to engage in these discussions earlier, more gradually, and on their own terms.

> *"Families are getting the opportunity to have these discussions, and that is fabulous, because we're really trying to advocate advance care planning and having those conversations, and I think Kentown has been amazing at that." (Hospice Staff)*

This proactive approach helped families emotionally prepare for what lay ahead, make informed decisions, and convey their wishes regarding end-of-life care which was perceived as extremely valuable.

> *"[Kentown Nurse] has made it an everyday discussion, rather than, ooh, I don't know how to broach this conversation and that to me is worth its weight in gold."(NHS Community Nurse)*

Professionals observed a cultural shift in that previously difficult conversations became more normalised, and families became more confident and empowered in participating in decision-making. In many cases, the groundwork laid by Kentown staff made interactions with other services smoother and more productive.

> *"Prior to the Kentown project I was very aware of things like advance care plans but I didn't have any in place for any of my patients, I now have two in place […] and I couldn't have done that beforehand because I don't have enough regular contact with these families to have these kinds of conversations." (NHS Consultant)*

Families' ability to trust healthcare providers, particularly around life-limiting illness was perceived to improve when a Kentown Nurse was involved. Professionals described how families developed deep, trusting relationships with their allocated Kentown Nurse, which fostered emotional security, openness, and stability in times of challenge.

> *"The Kentown Nurse brings something really unique, she makes sure the family is okay, not just medically but emotionally. That's often the bit that gets missed." (NHS Nurse)*

This continuity was considered particularly vital in communities where external involvement was viewed with suspicion or reluctance.

Finally, the Kentown Programme was seen to directly address long-standing inequities in access to children's palliative and end of life care. Whilst palliative and end of life care has been provided as part of commissioned services and hospices in the region; there were considerable gaps and some professionals felt that end of life care provision across the region was very limited and inequitable. Professionals expressed that families in the programme received a level of holistic support that was otherwise unavailable.

> *"What they've [Kentown Programme] done is they've filled in a gap in practice. There was nobody doing the palliative care role, there was nobody doing end of life care. Other people were supporting. So they are now complementing other services and they're filling a gap." (NHS Assistant Director of Nursing)*

Some professionals raised concerns about the sustainability of this support beyond the life of the programme, and the inequity experienced by families outside the coverage area, particularly in northern regions.

Overall, the Kentown Programme was widely perceived by professionals to have delivered substantial benefits to families and children living with life-limiting conditions. Its approach offered a holistic support framework that enhanced emotional wellbeing, enabled informed planning, and addressed service gaps.

Perceived impact for families by programme staff

Summary: Kentown staff identified key impacts for families which, reached beyond the boundaries of clinical care. Staff accounts emphasised how the programme supported emotional wellbeing, strengthened family bonds, and opened access to meaningful memory-making experiences. Families were able to take a break from caregiving in moments of reconnection, joy, and empowerment which supported how families perceived themselves, and the navigation of challenges associated with their child's condition.

One of the most prominent impacts was the way in which the programme enabled parents to rediscover their identity beyond the role of caregiver. For some, family life had been narrowed to medical tasks and appointments. For families where there had been limited previous support, the Kentown Programme created opportunities for moments of normalcy and emotional reconnection,

allowing parents to reclaim aspects of parenthood that had been lost under the weight of their child's illness.

> *"The parents said they felt like parents again, not just carers. That was very powerful." (Kentown Nurse)*

These experiences were often described as transformative, helping parents to re-centre their relationships and experience joy together as a family unit.

> *"One family told me it saved their marriage. They were both at breaking point, and this gave them time to reconnect." (Kentown Nurse)*

Staff described how the Kentown Programme provided a validating and empowering presence for families, often in stark contrast to previous experiences of being treated primarily as service users.

> *"I visited a family and they were just saying how it's been amazing to have [Family Support Worker] there, but then to also know that there's other people that they can contact if it wasn't a support worker role that they needed. When you speak to the families, you can hear and see how relieved they are to know that they don't have to worry about every individual thing because there's a team behind them now that can support them with everything that they need." (Kentown Service Coordinator)*

The integrated team approach was felt to be key in how families perceived the programme.

> *"I think for families seeing that sort of unified approach that everyone's on the same team… and we're all here for the same reason, that's really important, and they've already seen the benefits of that." (Kentown Family Support Worker)*

The support was deeply personal, offering a non-judgemental space for parents and other family members to express their feelings, process grief, and feel genuinely heard. This emotional support helped families to feel less isolated, and more resilient during periods of uncertainty.

> *"One mum said, 'No one's ever asked us what we want before.' That really stuck with me." (Kentown Nurse)*

Staff also highlighted the programme's role in opening doors to new possibilities and normalised family experiences. Many families gained access to resources, such as financial grants, short breaks, and National Trust passes that would otherwise have been inaccessible. These opportunities not only brought immediate enjoyment but also helped families feel more connected to wider systems of support.

"We've managed to help them get a grant, … they've now booked onto a Centre Parcs break, so they can go on holiday together and then the Support Worker's obviously been in to check in and they've said that they just feel a lot of support from everyone." (Kentown Service Coordinator)

In addition, the programme opened opportunities for families to experience moments that might otherwise have been inaccessible due to financial strain, or the complexity of care needs.

"The mum just sobbed. She said, 'We've not had a break in years. Just to be somewhere where someone else thinks about things, it's amazing […] It made them feel like a family again, not just people dealing with illness.'" (Kentown Nurse)

"There's one mum who said, 'We've never been anywhere like that, we've never had the money.' And now she says her daughter has seen the sea for the first time. That's massive." (Kentown Nurse)

An emotionally charged impact described by staff was the programme's role in creating a legacy of positive memories. In the context of serious or life-limiting illness, these experiences became deeply meaningful, offering families something to hold onto during times of crisis or grief.

"Mum said, 'If the worst happens, I know we gave her the best week of her life […] The memories gave them strength. It's something they'll carry forever.'" (Kentown Nurse)

The creation of joyful shared memories allowed parents to balance the harsh realities of illness with moments of profound connection and happiness.

"One dad told me he'll always remember his son's face when they saw the dolphins. He said he'd never seen him so happy" (Kentown Nurse)

Overall, Kentown staff perceived the programme as transformative in the lives of families, echoing many of the family stories heard through the evaluation. It was not only a means of supporting them through the medical complexities of their child's condition, but also a way of restoring their sense of identity beyond caregiving, validating their emotional experiences, expanding their access to opportunities, and enabling the creation of enduring positive memories. In doing so, the programme helped families to reclaim moments of meaning, connection, and joy in the midst of immense challenge.

Habiba's Story

My Family

Mum, Dad, and me

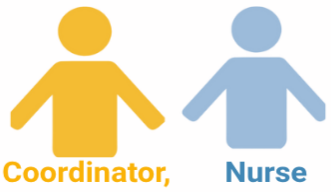
Habiba was born in January 2024. Soon after birth, she was diagnosed with a rare neurological genetic condition and admitted to the neonatal intensive care unit for further assessment and care. The clinical team supported the parents on the ward and made them aware of available support groups. The mother explained that they did not access any groups, as they already had a supportive family, which was enough for them while coming to terms with the news.

The clinical team explained to the parents that it was a life-limiting condition and that Habiba would experience multiple symptoms, including seizures. She also required oxygen and experienced pain, with body stiffness that left her very unsettled. The consultant worked with the parents to develop a care plan and put medications in place to help manage Habiba's symptoms at home.

When the family went home, they continued to receive support and home visits from the neonatal nurses and consultant, until Habiba was discharged with a referral to the local hospital nursing team and the Kentown team in May 2024.

Kentown Support

Referral: Hospital Consultant, May 2024
First contact: Kentown Nurse
Time to first contact: Same day, May 2024
Region: 2



"So we weren't really getting much in the hospital. It was just from the doctors and the nurses. I was offered other support and emotional support groups and stuff, but I didn't take it. I have quite a supportive family, so I didn't feel I needed it at that time." (Mother)

"...the Kentown nurses that used to come out quite regularly, and I had their number as well so if there were any concerns or anything, they were really good in getting back to me and giving me advice and just kind of helping me to come up with a plan of how to work, of how to just make her a bit more relaxed. I think that was the main concern for us, she was really, really unsettled all the time. " (Mother)

The Kentown Nurse had regular contact with the family, providing emotional and practical support, symptom management, and advance care plan discussions, and liaising with many professionals to implement the parents' end-of-life wishes for Habiba.

The nurse also attended hospital appointments with the parents, providing reassurance and supporting understanding of complex information.

Throughout May to December 2024, the Kentown Nurse provided a range of support to the family. Contact with the family varied depending on need during this period, ranging from two to seven visits a month, either at home or in hospital, and sometimes involved multiple contacts a day with the family or professionals.

The nurse was pivotal in discussions for Habiba's advance care plan, providing symptom management support, and contributing to the family's wellbeing with emotional and practical support.

In addition to home visits, the nurse attended all hospital appointments with the parents, which they found very helpful, as she was able to reiterate what was said and explain it further, improving their understanding and providing reassurance.

The nurse also liaised with many professionals and services regarding the advance care plan and making arrangements for end-of-life care, in line with the family's wishes. This coordination of care ensured that all professionals were kept up to date, multiple times a day if required. As Kentown Nurses are based within the same trust organisation, they were able to support ambulance crews, paramedics, accident and emergency staff, and acute ward teams. During an admission, they helped assess and enable safe and appropriate discharge for end-of-life care when it became evident that Habiba had reached that stage.

There were some challenges accessing 24/7 on-call support from services, including the hospice, while end-of-life care was being provided at home. The Kentown Nurse worked with all relevant professionals and services to support the family's wishes.

"... I spoke to her, after my baby passed away. I've spoken to her a few times, and even now, she still says that even if you want to ring me for a chat or anything, then you're more than welcome. So even now, she's still really supportive." (Mother)

The Service Coordinator became involved with the family in June 2024, following a request from the nurse. They contacted the family and, following an assessment of needs, signposted them to the Newlife charity and Caudwell Children's Trust for sensory toys, as well as their local carers' centre. A REACT application for help with transport and essential items was discussed. It was identified in the Kentown caseload meeting that the family would like a professional photoshoot to take family portraits. At the end of Nov 2024, the coordinator organised a family photo shoot for following week, which the parents were looking forward to. In early December, the nurse informed the coordinators that Habiba died so the photo shoot was cancelled.

"Every appointment that we had with the consultant, she was always there. So if there was something that maybe I didn't understand, she would like later help me out with that, or kind of repeat it, because sometimes consultants can just kind of talk really fast and say all about the medical side, and it was sometimes a bit hard to understand. ... it was nice to see her at the appointments as well." (Mother)

The Kentown Nurse had regular meetings with upskill acute teams so they could recognise when a child may be approaching end of life. This enhanced staff confidence to have discussions with the family and when to contact the Kentown Nurse for discharge planning support. This highlights an impact the Kentown Nurse role can have for wider services through case based learning which will benefit other families in the future.

When Habiba died, the nurse continued to provide bereavement support to the family and ensured all relevant professionals, including the Kentown Coordinators, were informed.

The Coorindator signposted the parents to charity organisations for sensory toys for Habiba and their local carers centre. Supported an application to help with transport and essential item.

They also arrange a professional photoshoot to take family portraits. Unfortunately, this was cancelled as Habiba died just before the booked date.

"...they organised a day for family pictures and for them to come out to our house and take like professional pictures. It was all booked and everything, but she just didn't, we just didn't get a chance to do it." (Mother)

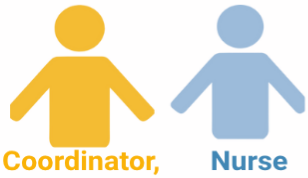
The added value of the Kentown Programme support for Habiba's family

The support provided to the family was holistic and flexible, responding to a range of health, financial, emotional, and social needs that benefited the whole family. The needs of the family were met by the Nurse and Service Coordinator support. Once they had established a relationship with the parents, the Nurse was able to bring in the Coordinator to assess other needs and support that could be offered.

Habiba's family received significant Kentown Nurse support during the nine months from referral to Habiba's death. They supported preparation of the advance care plan, attended hospital appointments, and coordinated services and professionals to ensure that end-of-life care took place at home, as the family wished, despite challenges in the region's out-of-hours provision. The nurse also provided upskilling to other staff who provided care for Habiba and her family, an often hidden impact of the role.

The Coordinators were able to provide support and information on charities that could offer resources such as sensory toys and financial help. They also met the family request for a photoshoot, although this did not go ahead.

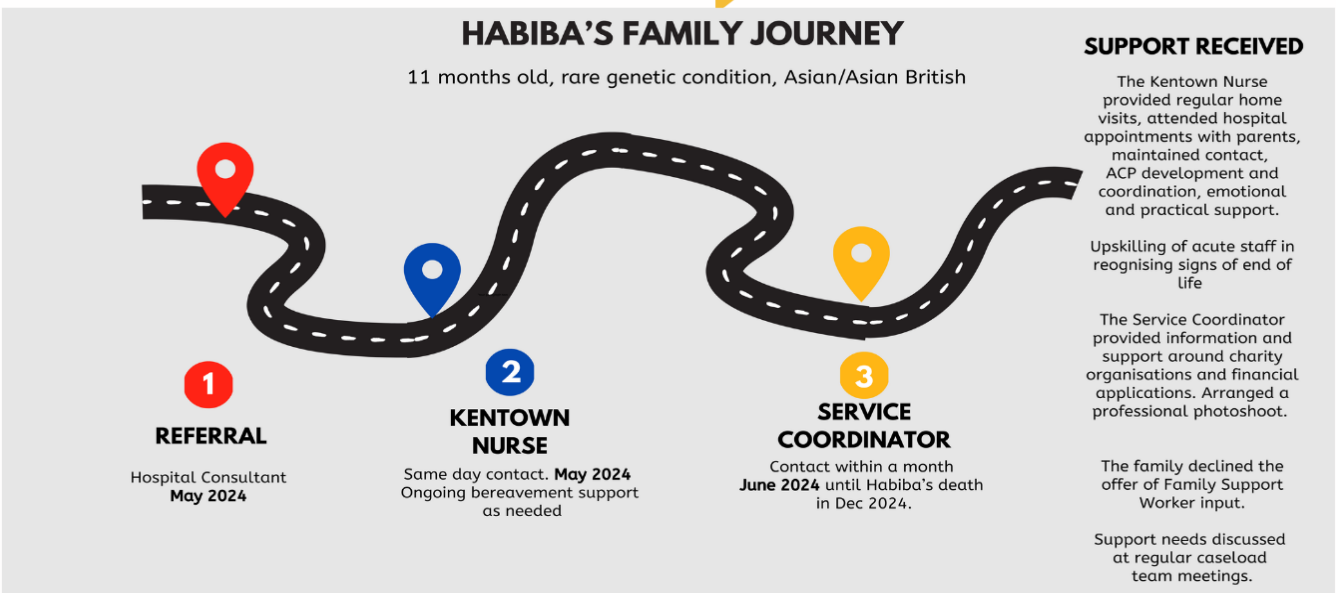
Good communication was maintained between the Kentown team via close working relationships and and regular caseload team meetings.



'Early involvement helped the family accept and process the child's diagnosis and develop confidence to complete an advance care plan to document the wishes for their child's shortened life and death which included to care for their child at home at the end of her life. The child was able to be surrounded by her entire family in a place of peace and familiarity at the end of her life. The availability of a Kentown nurse meant that the family were able to be physically, emotionally and psychologically supported during a very frightening experience. We were able to provide them with support and guidance in the last moments of her life that they were doing the right thing.

Close liaison with the family doctor (GP) by the Kentown Nurses meant that the GP service were able to verify and certify the Habiba's death at home and allow for rapid burial. Without the availability of a 24/7 advice service in the region, significant preparation of the family GP was required in order to support them to prepare their out of hours service to have full knowledge of the families situation and provide rapid and sensitive care of the child after death in order to facilitate rapid burial.' (Nurse)

'Our involvement enabled the family to have awareness of what support was available to them and removed any hassle of them identifying and applying for a photoshoot.' (Coordinator)



The added value of the Kentown Programme in the region

Stakeholder professionals frequently described a service landscape pre-Kentown that was marked by longstanding gaps in palliative care provision. In some regions, there was no dedicated specialist paediatric palliative care service at all. Even where services did exist, they were often stretched, inconsistent, or inaccessible to many families. Provision was particularly limited in geographically dispersed areas, where long travel times, low staffing levels, and limited commissioning made it impossible to deliver equitable support. This left children and parents without adequate specialist input, particularly outside of hospice settings or in rural and isolated communities.

> *"Greater Manchester hasn't really got a specialist palliative care service at all. It's very, very limited and then Lancashire and South Cumbria, it's got even less… It's really important to recognise this gaping hole in Lancashire and South Cumbria" (NHS Manager)*

Similarly, families who did not wish to engage with existing hospice care models were often left without any equivalent community-based alternative. Kentown was viewed as bridging this divide, particularly through the integration of nursing roles with family support from Rainbow Trust and service coordination from Together for Short Lives. By offering a different route into specialist care, the programme reached families who otherwise would have remained outside the system.

> *"That support that is invaluable for some of those families, and ongoing support in their home. You worry because there is no services that would pick that up to that level of support. So then it would be the impact of those children and families in crisis again, where would they get the support from? because children's social care isn't providing that layer of support for these specific families." (NHS Matron, Children's Nursing)*

Staff who provide palliative and end of life care through the hospice model appreciated the additional value of the integrated Kentown team which offered the broader family support components to families.

> *"The most valuable part of that project is the Rainbow Trust and Together for Short Lives part of it, because that is the family support, because with the greatest respects to the [Kentown] Nurses, we do the same thing." (Hospice Nurse)*

Many professionals also reflected on their own limitations before Kentown. Without the dedicated time or continuity of contact, they could not initiate or sustain the kinds of sensitive, ongoing conversations required for effective palliative care planning. Families might be seen only once a year, making it impossible to build trust or address difficult topics in a meaningful way. Kentown's dedicated posts created the space and continuity needed to address these gaps.

"Prior to the Kentown project I was very aware of things like advance care plans but I didn't have any in place for any of my patients, I now have two in place for which I am the lead obviously but have completed those documents with support from one of the Kentown Nurses. I couldn't have done that beforehand because I don't have enough regular contact with these families to have these kinds of conversations. So most of the young people that I see unfortunately I can only see about once a year clinically and for these types of conversations you just can't start and then put it on hold for a year and come back and have another conversation. The input there has been invaluable." (NHS Nurse)

Another area where Kentown had a significant input was discharge planning.

"His discharge was just so good. It was really well planned, there were things in place before they even came home that never normally would be, like social care and financial support" (NHS Clinical Lead)

Although there had been concern about whether Kentown duplicated roles and support early on in the pilot, these were not new issues across services. The wider system before Kentown was described by some professionals as disjointed, with role confusion and duplication between services. In some cases, families were visited by multiple professionals covering similar topics, while in other cases important tasks fell between service boundaries and were not done at all. There was little consistency in coordination across organisational boundaries. Professionals suggested that Kentown's model helped to bridge these divides, though they acknowledged that building relationships and clarifying roles took time.

"Me and the Kentown Nurse worked together, and her skill and the time that she had to be able to coordinate the discharge, the planning, the way that she could communicate across different trust boundaries… she had that, to be able to orchestrate and coordinate a really good transition from an out of area hospital back into locality and then home, and then supported the child right up until she died and after she died." (NHS Community Nurse)

Another example of collaborative working was between Kentown and the hospice to support a family struggling while trying to care for their child in intensive care.

"The [Kentown Service Coordinator] has massively helped them, like I can't even tell you how amazed I was when we did what we did for that family that I mentioned …. They had a child in intensive care that was extremely poorly. We did a food shop for them and the Kentown project managed to get them fridges, freezers, sibling support and hospital support. That's what's needed. That's like, really important but I haven't got a Family Support Worker I can just go and send out, so that's why it's important… for us all to come together, we're so, so good and very positive." (Hospice Nurse)

In addition to direct family care, the programme was credited with bringing new training opportunities and specialist expertise into local teams that had not been available before. Staff reported improved confidence, clinical skills, and awareness of best practice changes they attributed directly to Kentown's investment in education. This upskilling was seen as a lasting benefit, strengthening the system beyond the families directly supported by the programme.

> *"The other hurdles I think which have been helped by Kentown are things like education and awareness, so [Kentown Nurse] has managed to help upskill us massively by seeking out educational opportunities for us, she's done training, we've had advance care planning awareness training which [Kentown Nurse] is now a facilitator of so she can do that training herself, she's sought out specialist hospices from children's and adults to provide education in how to provide good quality end of life care to children, and I think that's definitely not something I had an opportunity to access before Kentown was in post, so that's been really good."(NHS Nurse)*

In summary, professionals agreed that Kentown had brought much-needed specialist capacity, continuity, and coordination into a system where families had previously fallen through the cracks. While integration into existing services sometimes posed challenges, there was a strong consensus that the programme was addressing longstanding gaps, improving the timeliness of care, and widening access to high-quality, family-centred palliative support.

Perspectives of the Kentown Programme team

The team reflected that the programme filled significant service gaps that existed across many regions in the Northwest of England. Prior to Kentown, data and service mapping had identified that children and families were often referred late, were not identified at all, or were left to navigate a fragmented system with little coordination between providers. Staff noted that without early identification, many children had missed out on the opportunity for timely intervention and joined-up planning at a stage when it could have made the most difference.

> *"The identification of the children and families that would benefit from support, and they might be families that wouldn't normally be identified if they're having palliative care needs because early identification is not really recognised as a concept." (Kentown Nurse)*

In some regions, it was perceived that there was simply no equivalent coordinated provision. Whilst Rainbow Trust had a presence in the region before the pilot providing support to families, strategic leaders reflected on the scale of change, describing how the programme had moved from a starting point of an uncoordinated community-based offer to a situation where families across the region had access to specialist coordinated support.

> *"You will see benefit from this service because we can bridge that gap…the gap between generalist to specialist is quite big. Often, in that generalist area, families don't get referred to the top until end of life and that's too late." (Kentown Programme Manager, TfSL)*

Before Kentown, existing services often operated in silos. Nursing, coordination, and family support were delivered separately, with little communication between roles or services.

> *"I know from my ten years at Together for Short Lives, services are very siloed, and we know that navigators, Coordinators, are really welcome - just someone to be alongside the family to introduce them to the service, to different services. That works well, particularly as at the moment Together for Short Lives is able to offer families who come into contact through Kentown additional support, whether it's through grants, short breaks, or referrals to the Rainbow Trust, and again, we know that the support workers who work really closely often become part of the family." (Kentown Operation Manager, TfSL)*

This meant there was no guarantee that all parts of a families' needs would be met, and families could be passed from one service to another without continuity. Staff described how this created avoidable gaps with no single service taking overall responsibility for a family's care. The Kentown model, by contrast, integrated these functions into one team, allowing for shared accountability and consistent follow-up.

> *"It feels like one team. You know that you've got somebody else within the team whose got that knowledge and skills, that you can pass it over to but you're not like just sending them off into the ether, thinking have they got the support that I think they should have? I actually know they've got it." (Kentown Nurse)*

Operationally, the programme has moved the available support from what could be a slow response to one that was rapid and proactive. Before Kentown, it could take weeks for families to access grants, equipment, or other urgent support, if they could access it at all. The introduction of streamlined processes and clearer boundaries allowed staff to respond quickly to immediate needs, ensuring that support was timely and relevant.

Another key difference from the pre-Kentown landscape has been the programme's flexibility in adapting to local priorities and gaps. Senior staff from partner organisations compared this with previous systems, which were often rigid and unable to respond to new needs without lengthy processes or formal restructuring.

> *"The value of this programme is that we went in to meet a need in this region and we have adapted the programme to meet the needs in the region." (Kentown Programme Leader, Rainbow Trust)*

> *"We were contacted by [NHS Trust], and they asked could they keep [Kentown Nurse] on one day a week, and we've all agreed to that really quickly. I think that needs to be celebrated, the responsiveness of the board and funder to this project has been a huge success." (Kentown Programme Lead, TfSL)*

For Kentown staff themselves, the approach has filled a professional training and development gap as well as a service gap. Previously, there were few opportunities to learn from colleagues across regions or to develop skills through joint problem-solving. The integrated team model has enabled cross-role learning and shared experience, as well as accessing external learning opportunities, which has built professional confidence and leadership. This was in parallel to the impact for stakeholder teams who also experienced progression and a culture change, as discussed earlier.

> *They're growing and adapting as a team as well, seeing the needs and the gaps… What they're bringing to the table now, they're problem solving themselves, we're not leading in the way we had to at the very early stages". (Kentown Programme Lead, TfSL)*

Senior programme leads observed a transformative cultural shift in the team with staff transitioning from reliance on management directives to proactively taking initiative, engaging in constructive collaboration, and solving problems autonomously. This growth in autonomy and mutual respect has yielded positive outcomes for staff and service delivery, strengthening the team's resilience and adaptability.

> *"They're recognising gaps in provision, they're not bringing as much to me, they're leading the charge" (Kentown Programme Manager, Rainbow Trust)*

In summary, programme staff described Kentown filled gaps with earlier identification, provided a faster and more coordinated responses, and a holistic model that combined clinical, practical, and emotional support. The programme has also facilitated internal team development through shared learning, joint working, and accessing external opportunities which has seen professional progression in team through increased confidence and autonomy, leading to enhanced resilience and leadership.

Summary of learning points from the impact evaluation

1. **Relationships with staff were central to impact**
   Families described Kentown Nurses and Family Support Workers as becoming "part of the family," offering emotional safety and consistent support that statutory services did not provide. This relational trust was identified as one of the most valued aspects of the programme.
2. **Practical navigation reduced stress and enabled access**
   Coordinators' hands-on support with complex forms (e.g., Disability Living Allowance) and advocacy with statutory services was described as transformative. Families contrasted this with being "left to flounder" prior to Kentown, and professionals noted that Kentown enabled access to resources that would otherwise have been missed.
3. **Holistic family and sibling support promoted resilience**
   Where delivered consistently, sibling trips, activities, and emotional recognition provided substantial benefit. Parents reported that siblings felt included and visible, which strengthened overall family wellbeing. However, the evaluation also recorded a few inconsistencies in such support due to staffing issues which did not meet family expectations.
4. **Continuity of care underpinned trust and preparedness**
   Data showed that continuity of staff contact was crucial: families valued not having to "re-tell their story", while transition in the support offered could cause distress, particularly for children. Families expressed a preference for "light-touch but lasting" support they could call on when needs changed.
5. **Advance Care Planning was normalised**
   At referral only 20% of families had an advance care plan in place. By the end of the programme, 58 advance care plans had been completed and 133 were in progress, with Kentown's support, demonstrating a significant cultural shift. Families and professionals both noted that Kentown's time and continuity enabled earlier and more constructive advance care plan conversations.
6. **Kentown model addressed critical gaps through integrated working and collaboration with services**
   Professionals viewed Kentown as bridging gaps in existing services and organisational boundaries to provide a level of consistency, timely support and holistic care previously not available. While building relationships and clarifying roles took time, services and families experienced added benefit, including new training and upskilling opportunities for community teams.
7. **Multidisciplinary working enhanced effectiveness**
   Service data showed that 34% of families received all three support components (Nurse, Service Coordinator, Family Support Worker), while another 34% received two components. The most common pairing was Nurse and Coordinator. Families and professionals described this joined-up model as a major strength, ensuring clinical, practical, and emotional needs were addressed together. This shared learning and working also had significant development impact for the team who grew in confidence and leadership.
8. **Responsiveness was valued but sometimes delayed**
   Evaluation data highlighted that just over half of families were contacted on the same day as referral, with the average wait time being 5 days. However, occasionally families waited significantly longer indicating a need to continue close monitoring of response time.
9. **Referral pathways were effective but concentrated**
   Referrals came from 15 organisations, with four NHS trusts accounted for over 60% of all referrals. Community Nurses (n=83) and hospital doctors (n=37) were the largest referrers. This demonstrates strong partnerships overtime but also reveals opportunity for raising awareness of the programme to encourage referrals from broader services.

Declan's Story

My Family

Mum, Dad, brother, sister and me

Declan is one year old. At birth, he presented with profound limb deformity and was unable to move his joints or limbs. He was diagnosed with a congenital condition characterised by joint contractures (stiff, fixed joints) caused by a lack of muscle formation and replacement with fatty and fibrous tissue. Declan uses a ventilator at night and is PEG fed by a tube going directly into his stomach through the skin. The parents view it positively that there is no sign of mental impairment and that he appears to be a happy boy.

Coming to terms with and managing Declan's needs has been challenging for both parents, who have also been supporting their other children, working, and managing without local family support. They have been grateful for the kindness of friends and neighbours since returning home after Declan's birth, and to charities who have provided some financial support.

Due to Declan's posture and lack of body control, the family have an increasing amount of disability equipment, which the father described as a reminder of the challenges and life-changing events they are still processing.

The Kentown Nurse supported the family for a year. Their role included discharge and care coordination, before moving to provide support to the Children's Community Nursing team, as well as making requests for additional input from other members of the Kentown Programme.

Kentown Support

Referral: Children's Community Nurse, December 2023
First contact: Kentown Nurse
Time to first contact: 2 months, February 2024
Region: 1

Coordinator, Family Support Worker, Nurse

"Our kitchen is increasingly filling with disabled equipment, which gets in the way and is a daily reminder of how hard it is." (Father)

"We have received a lot of kindness, there was a little rota of people cooking meals across the [community] for a few months after Declan was born, which was helpful. A local charity gave us a cheque for £600 for travel costs to the hospital which is two and a half hours from here, and to help with extra childcare for the children." (Father)

Declan was referred to the Kentown Programme by a Children's Community Nurse in December 2023, when he was two months old. The Kentown Nurse was the first to have contact with the family in February 2024, when they met Declan and his mother in hospital. Initially, due to the number of professionals involved, the parents were unsure how the Kentown Programme fitted in, but this became clearer over time.

The nurse's role consisted of checking in with the family, supporting discharge planning, and providing ongoing support to the Children's Community Nurse and wider team for just over a year.

"I wasn't really sure what Kentown was. I mean, they're all absolutely, undeniably lovely, and so helpful, I cannot sing their praises enough, but I was never clear at the beginning. I remember being quite shocked that it was a 'palliative' care nurse. I remember thinking has somebody not told me something? [laughs] But actually, the Kentown Nurse was lovely about it." (Father)

The Service Coordinator contacted the family in February 2024, after the Kentown Nurse requested their involvement. The coordinator organised a supermarket crisis pantry delivery and discussed grants and other sources of support such as the Together for Short Lives family support Facebook group.

The Coordinator provided a wide range of support, including a crisis pantry delivery, support with grant and holiday applications, signposting to other sources of help, and an M&S shopping voucher.

The Family Support Worker identified to the Coordinator that a specialist pushchair was needed for Declan. The Coordinator supported a Turn2Us grant application to help with extended hospital stay costs and to fund the pushchair, which was successful. In May 2024, the family were supported to submit an application via REACT for an iPad and sensory equipment, but this was declined.

In the summer, the family were offered the opportunity of a holiday at Center Parcs, and were supported with the application process. In November, they were given a £100 M&S voucher to support their holiday in December.

"...there's a real consistency with having a Coordinator for the last year at the end of the phone, which I've appreciated. He is someone that I've come to know, you get the impression he thinks of us quite frequently and is in touch which is very good, and the single point of contact is helpful. ...with Declan's care, there's just so many different people at the end of the phone, all great, but what I really appreciated about the Kentown project was that there was the Coordinator, it felt like he was the hub on a cartwheel." (Father)

"...a very nice person came, for three or four sessions. My wife and I were both very excited but it didn't quite offer us what we needed at that time." (Father)

The Family Support Worker and their manager visited the family at home in March 2024. They outlined the emotional and practical support that could be offered. The mother was keen to receive support and spoke of still processing and accepting the situation. The support worker liaised with the coordinators on several occasions to request support for equipment grant applications.

The Support Worker helped with transport to a hospital appointment and arranged a supermarket shop on the way home. On several visits they discussed being able to support outings or look after the children so the parents could have a break which the family responded positively to but this did not seem to happen.

The Family Support Worker provided practical and emotional support to the family in the home over a few visits. They also provided hospital transport and support for a supermarket shop.

The father spoke of how it has been a struggle to juggle the children and come to terms with their new life. They were pleased that they would be receiving continuing care support for Declan from May 2024 which would help.

The father shared that whilst they were initially excited at the potential support on offer, they did not feel that it offered quite what they needed at the time. As they had other support coming on board, they withdraw contact. The father expressed disappointment that the planned male support group had not started at the time of the evaluation interview. and hoped it would start soon.

"..there were quite a few promises of days out and there was definitely going to be a male peer support group. In my position, I would love to meet other fathers who are going through similar things, but nothing has materialised yet." (Father)

The added value of the Kentown Programme support for Declan's family

The support provided to the family was holistic and flexible, responding to a range of health, financial, emotional, and social needs that focused on Declan but benefited the whole family. The care was enhanced by the triad team approach of the Kentown Programme with the Kentown Nurse liaising with the Service Coordinator and Family Support Worker to engage their specific expertise and support for identified needs.

The Kentown Nurse supported Declan's discharge from hospital, and later supported the wider team who were caring for Declan and the family as needed. This was key to ensuring holistic planning but was not always visible to the family.

The Family Support Worker provided direct practical and emotional support through a challenging time, including offering transport to the hospital and supermarket. The engagement was short as other preferred services began providing other support for the family.

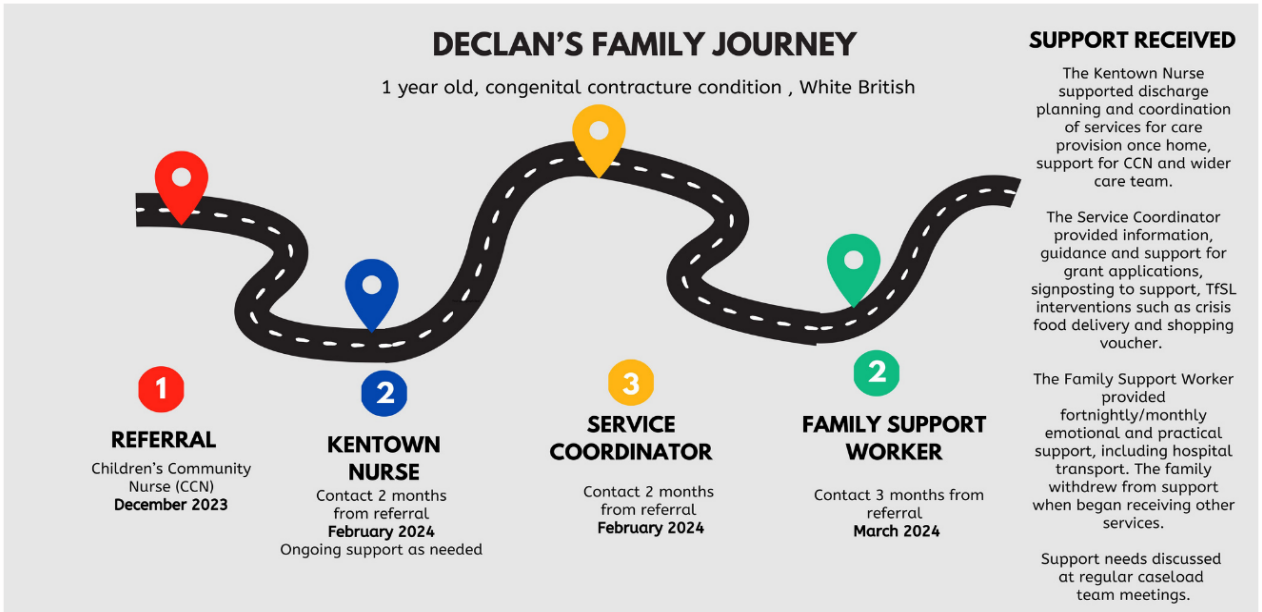
The Coordinator was able to provide expert support for equipment grants and a holiday application while organising interventions such as shopping and vouchers. The family appreciated his role as a single point of contact with a wealth of knowledge to draw on.

Good communication was maintained between the Kentown team through close working relationships and regular caseload team meetings.

'I was able to support the initial discharge planning from tertiary hospital. The family live in a very isolated area so we liaised with all the relevant teams, ensuring care plans were in place and shared with the right teams such as the ambulance service.

I have been able to provide support to the Children's Community Nurse as the family's key worker and the wider multidisciplinary team (MDT). I have been present within the MDT considering other avenues of support for family such as a referral to hospice and continuing health care package. Although not always the main key worker I am available for advice and support to hopefully ensure an equitable service, and the holistic support that palliative care adds.' (Nurse)

'My support for the family was only short. After a while they did not engage and leaned more towards the Kentown Nurse and Coordinator and other agencies who began providing support.'
(Family Support Worker)



Key learning and recommendations

The following section outlines the key takeaways and recommendations emerging from the evaluation of the Kentown Programme. These findings reflect learning from across the full duration of the programme; however, it is important to note that a continuous cycle of reflection and adaptation was embedded throughout its implementation. This meant that many of the challenges and insights identified were actively addressed as the programme evolved, resulting in improvements over time. Therefore, the recommendations should be viewed not as static outcomes, but as part of an ongoing process of learning and refinement that characterised the programme's development and delivery.

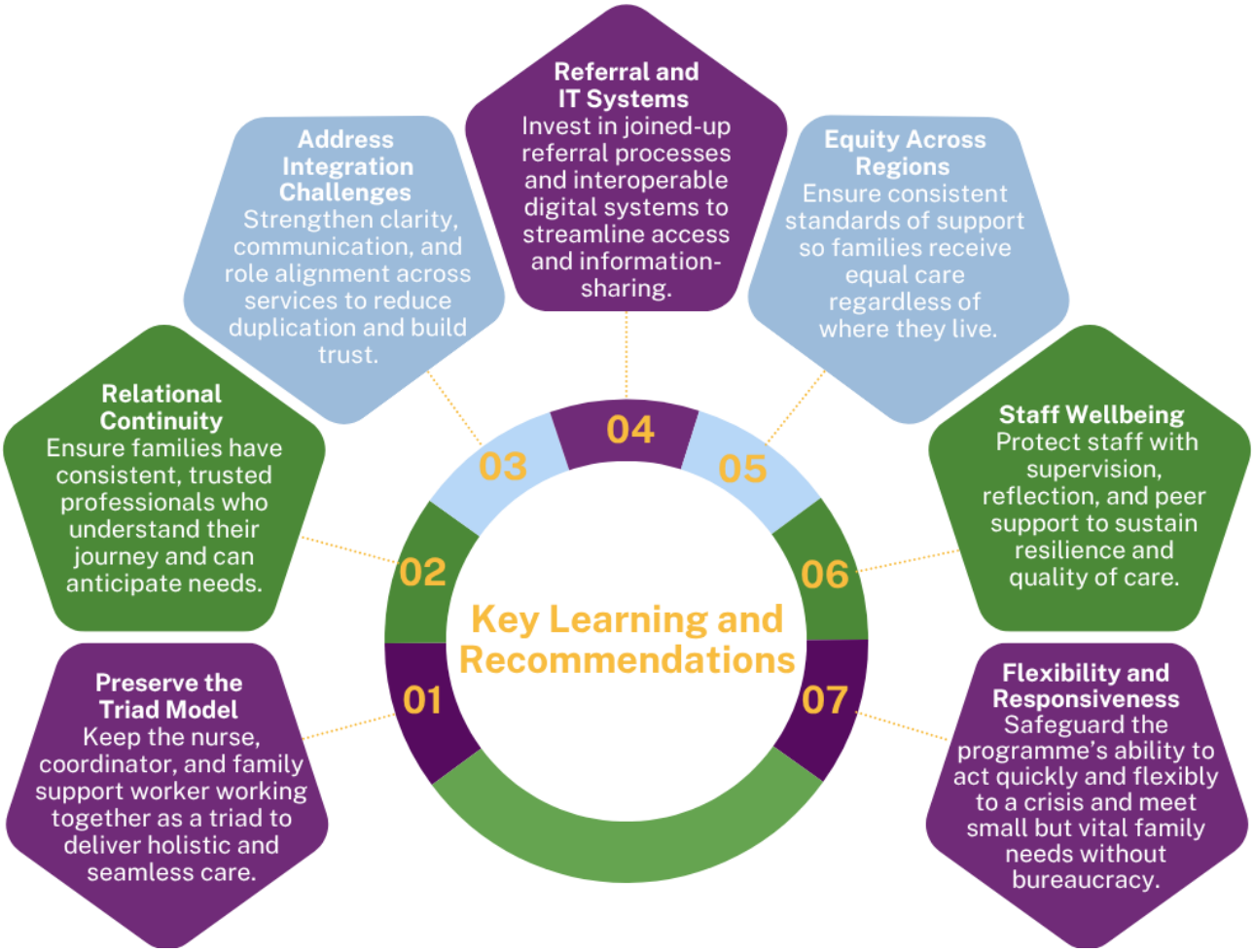


Figure 9. Key Takeaways and Recommendations

1. Preserve the Triad Model

A unique feature of the programme was the integration of three professional roles: the Nurse, Coordinator, and Family Support Worker. This Triad Model created a holistic approach that balanced clinical expertise, practical coordination, and emotional support. The evaluation found that this blend of skills was crucial to addressing the multi-dimensional needs of families, particularly those navigating complex and often distressing care pathways. Each professional component reinforced the others; for instance, the Nurse's clinical oversight gave families confidence in medical decision-making, while the Coordinator ensured access to wider services and practical arrangements, and the Family Support Worker provided relational and emotional continuity. Families consistently highlighted how this combined expertise created a seamless and family-centred experience that could not be replicated by a single role in isolation. Preserving this model is therefore fundamental to the integrity and success of future delivery.

2. Importance of Relational Continuity

A central lesson from the evaluation relates to the value of continuity in relationships with families and professionals. Families reported significant benefits when they had a consistent key contact who understood their circumstances and could anticipate needs over time. This relational continuity fostered trust, reduced the emotional burden of retelling their story to multiple practitioners, and provided a sense of stability at times of profound uncertainty. Where staff turnover occurred for whatever reason, families described a loss of trust and disruption to support, which in some cases delayed engagement with services. The findings highlight the need for workforce strategies that promote staff retention and stability, recognising continuity as not only a matter of efficiency but also a critical mechanism for building therapeutic and supportive relationships.

3. Address Integration Challenges

The programme made notable progress in strengthening collaboration across hospices, statutory services, and third-sector partners. However, the evaluation also highlighted some persistent integration challenges. In some areas, a lack of role clarity led to duplication of effort or, conversely, hesitation among professionals unsure of Kentown's remit. This occasionally created tensions with existing providers, who perceived overlap or encroachment. Families also reported confusion when responsibilities were not clearly outlined. The evaluation highlights the need for clearer role definitions, structured communication pathways, and formalised agreements with partner organisations. Strengthening alignment with existing systems should not only reduce duplication but also build trust and credibility with professionals in the wider care ecosystem. This will promote a whole systems approach that may lead to more efficient working.

4. Improve Referral and IT Systems

Operational systems were found to be a significant source of inefficiency during the first year of the programme. Fragmented referral processes and disconnected digital systems resulted in delays, duplication of assessments, and additional burden for programme staff. In some cases, referrals were lost or required repeated follow-up before services were accessed. The lack of a universal IT system meant that information could not easily be shared across organisations, increasing the likelihood of miscommunication and inconsistent records. While the programme team put new processes in place to address this within the pilot, it was raised by the team and other professionals that smoother referral pathways and more integrated digital infrastructure would substantially improve efficiency, reduce frustration, and free staff capacity for direct support. The evaluation findings suggest that investment in interoperable systems is a central requirement for sustainable scaling, although it is acknowledged that this is persistent issues across health and social care.

5. Ensure Equity Across Regions

While the programme's overall model was highly valued, the evaluation found that service delivery varied across regions. Factors such as local workforce capacity, the maturity of partnerships, and the presence of hospices, shaped the level and quality of provision. As a result, some families accessed comprehensive, timely, and coordinated support, while others experienced delayed services. This inconsistency risks creating geographical inequalities in access and outcomes, which runs counter to the programme's ethos. Future development must therefore include mechanisms to promote greater consistency across regions, such as minimum service standards, targeted workforce support, and active partnership-building in areas of lower capacity.

6. Support Staff Wellbeing

The evaluation highlights the emotional intensity of this work and the potential pressures it can place on staff. Providing support to families navigating end-of-life care and bereavement requires deep emotional engagement. Staff frequently reported feeling the weight of these responsibilities, which, if left unsupported, risked leading to stress, compassion fatigue, and burnout. Structured clinical supervision, reflective practice sessions, and opportunities for peer support emerged as critical enablers of resilience and sustained quality which need to be available for all team members. The findings suggest that investing in staff wellbeing is not optional but integral to safeguarding both the workforce and the families they support.

7. Protect Flexibility and Responsiveness

Finally, the evaluation highlights the value families placed on the programme's flexibility and responsiveness. Staff were often able to act quickly and address "small but significant" needs, whether arranging urgent equipment, navigating a sudden change in care, or providing emotional reassurance at short notice. Families described these moments as disproportionately important, with relatively minor interventions making a profound difference to their sense of security and wellbeing. This responsiveness was possible because staff were empowered to act without being constrained by excessive bureaucracy or rigid protocols. However, as the programme scales, there is a risk that such flexibility could be eroded by standardisation and administrative requirements. Protecting capacity for rapid response must therefore be a guiding principle in future models, as it represents a defining strength of the service.

Actionable insights from families as the programme recipients

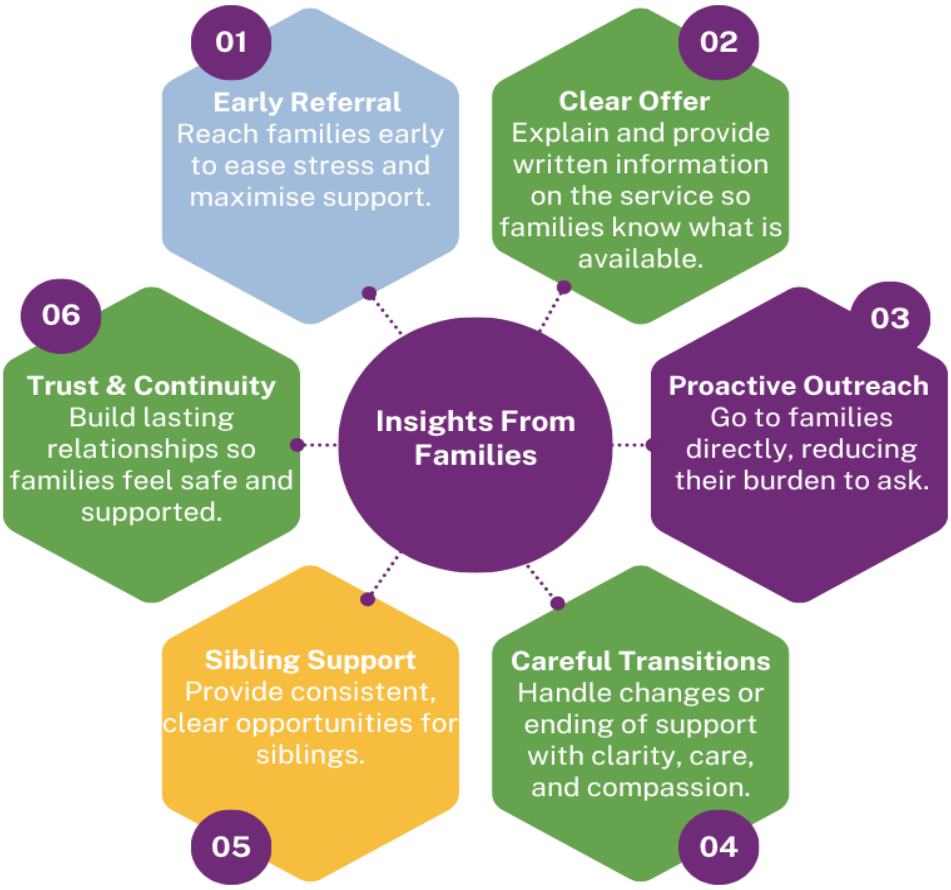


Figure 10. Insights From Families

1. The Importance of Early Referral

Timely access to Kentown support emerged as a central issue for parents. Several families described how they wished Kentown had been available earlier in their journey meaning they did not receive the help they needed as early as they have liked. Parents emphasised that much of the stress, exhaustion, and feelings of isolation they endured could have been mitigated if support had been introduced earlier. The findings suggests that the value of the service is maximised when families are reached early, before their coping mechanisms are overwhelmed.

2. Communicating the Offer Clearly

A recurring theme was an uncertainty about what Kentown actually provides. While families highly valued the contact they had, a few reported that they were unclear on the breadth and limits of the service offer and were unsure if they could ask for specific support. This lack of clarity

sometimes resulted in parents not fully accessing the available support, instead relying on what was immediately visible or offered. For Kentown, this suggests that setting out the scope of services in plain, family-friendly terms (i.e., through a brochure or booklet) could increase both uptake of the full-service offer and build greater trust.

3. Proactive Outreach as a Gateway to Support

Families were transparent about the pressures they face in daily life, which often limited their ability to seek out help. Several parents indicated that they might not have accessed Kentown at all without a proactive approach from staff. Direct, relational offers of support, (made at the right time in a non-intrusive way) were described as critical to families' engagement. This approach not only increased access but also reduced the emotional labour required of families to self-advocate in an already complex and exhausting system. The findings highlight that proactive outreach should remain a cornerstone of Kentown's operating model.

4. Careful Transition

In a service designed to support families facing complex challenges, even a single instance of poor communication can undermine the trust that has been carefully built over time. The manner in which a family's involvement with the Kentown Programme comes to an end, or is stepped down, could have a lasting emotional impact, particularly if families experience this as sudden or insufficiently explained. The learning from two occasions where this occurred suggests that the way support is transitioned is as significant as how it begins, and must be managed with clarity, empathy, and thoughtful communication. These reflections point to the need for clear protocols to ensure that families are fully informed about the reasons for transition, the process itself, and other support that may be available to them.

5. Sibling Support Requires Clarity and Consistency

Siblings were often described as the "hidden" members of the family who needed recognition and support. Families valued opportunities for siblings to receive dedicated attention, time away, or peer connection. However, in two cases expectations were raised but not followed through, leading to disappointment or confusion. Where sibling support worked well, it was seen as transformative in helping children feel less isolated. To ensure consistency, families suggested the need for clearer communication about what sibling services are available, how to access them, and what children can expect.

6. Building Trust Through Consistent Relationships

Families repeatedly described how their willingness to engage with Kentown depended on the trust they developed with individual staff. Many parents entered the service with low expectations, citing previous disappointments with other parts of the health and social care system. In this context, the reliability, authenticity, and follow-through of Kentown staff were particularly powerful. Once trust in an individual was established, families became more open to engaging with the wider service. This highlights the relational, rather than transactional, nature of effective support and the importance of staff training in building these connections.

Continuity of relationships was seen as a major strength of Kentown where it was achieved. Having a stable, trusted point of contact provided families with a sense of safety and reduced the burden of repeatedly explaining their circumstances. Parents likened Coordinators to the central hub of a wheel, holding together the different spokes of services and professionals involved in their child's care. This consistency not only fostered practical support but also emotional reassurance, reinforcing the idea that someone knew their story and was actively thinking of them.

Conclusion

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.

Phoebe's Story

My Family

Mum, brother, sister, and me

Kentown Support

Referral: Community Nurse October 2023
Time to first contact: 2 days
First contact: Kentown Nurse
Region: 1

Coordinator, Family Support Worker, Nurse

Phoebe is 12 years old. She was born premature and spent the first two months of her life in hospital. When she was discharged home, Phoebe had a range of health conditions which needed care including lung disease and a cardiac condition requiring oxygen. There was no clear diagnosis. At 5 months old, it was discovered Phoebe was blind due to very dense cataracts. Her sight was saved through surgery. She is visually impaired.

Phoebe did not gain weight as expected or reach typical developmental milestone such as walking and talking. The family were told that she had global development delay. When young, Phoebe was frequently unwell with infections in hospital. The family have many memories of spending holidays such as Christmas in hospital.

At 7 years old, a routine scan of her lungs identified multiple holes in her heart and valves not working properly. Phoebe had surgery to close the holes in her heart but due to her age would require more surgeries. Her mother described how Phoebe is small for her age due to a lack of growth hormones. While no diagnosis has been made, Phoebe's DNA is part of a genetic study which the mother hopes will provide some answers. Due to her range of conditions Phoebe was receiving clinical care from three hospitals and had 4 personal assistant hours a week.

The Kentown Nurse did a joint visit with the Children's Community Nurse two days after the referral to explore support needs. The Nurse opened the referral for Family Support Worker and Coordinator input.

"[Family Support Worker] has been amazing, suddenly I'm now parenting three children on my own and trying to support them through the grief ... it was quite awful to suddenly find myself very much alone in that respect. It was really helpful to have somebody to talk it out with, that wasn't a family member because you're not having to hide what you're saying or protect that person. She's amazing." (Mother)

The Family Support Worker made a home visit to meet the family and discuss the support available. Fortnightly visits were arranged.

Within a week, Phoebe's father died. Contact was maintained during the initial bereavement period. Weekly visits started soon after.

Phoebe was referred to the Kentown Programme in early October 2023 by the Community Nurse who felt the family would benefit from additional support at a challenging time as the father had terminal cancer. The Family Support Worker was in touch the same day. Two days after the referral, the Kentown Nurse did a joint visit with the Children's Community Nurse to explore avenues of support and completed a hospital passport. A referral was opened for Family Support Worker and Coordinator input.
Following assessment, the Family Support Worker visited in late October 2023 to meet the family. Fortnightly support was planned, but Phoebe's father died a week after this visit in early November, support was increased to weekly. Contact was maintained during the initial bereavement period and funeral by messages until the family were ready for visits in early December.

"[Coordinator] accessed a grant which helped amazingly. ... they'd got some money from Morrisons as well and we got a week of shopping which was just like, honestly, I cried because January is an awful time for anybody, isn't it and it was like, Oh my goodness, we've got food, you know." (Mother)

The Family Support Worker planned visits to arrive before Phoebe was home from school to offer individual support to the mother so they could talk freely about their feelings and concerns. They also discussed the possibility of applying to Make a Wish and what Phoebe may like.

Phoebe was supported with 1:1 time to talk, in addition to spending time playing games and enjoying outings such as bowling, soft play and meals out. The outings were often with a friend who was receiving support from their own Family Support Worker, supporting peer social time. The Family Support Worker provided some occasional support for the older siblings when they were around during visits and wanted to talk.

The Kentown Nurse contacted the mother in January but there was no identified need for Kentown nursing input at that time so after ensuring they knew how to get in touch if this changed, nursing support was stepped down.

The Family Support Worker arranged visits to spend 1:1 time with the mother supporting her with life after the loss of her husband before Phoebe was home from school.

They spent 1:1 time with Phoebe playing games and providing space to talk. They also arranged outings, sometimes jointly with Phoebe's friend who also had a support worker.

"You go to an endless amount of hospital appointments. ... it's all very much about what needs fixing? What medication? Whereas Kentown, it's like a big hug. ... [they] come along and say 'it's OK', ... people are here for you and Phoebe." (Mother)

Service Coordinators became involved early in 2024. They organised a Morrisons crisis pantry food delivery and spent time discussing what support could be offered. In August 2024, the Coordinator completed a grant application for Turn2US to pay for roof repairs and a broken appliance which was successful. They also identified and signposted the family to sources of support including charities where the family would meet the eligibility criteria for support and a carers centre.

The Coordinator support included food and financial support, as well as memory-making opportunities and a Make a Wish trip. They also signposted the mother to charities and local services which could provide additional support.

In May 2024 another heart operation was being planned for Phoebe but she had to gain weight first which was challenging. Hospital visits were required to discuss care and plan for the surgery. The Family Support Worker provided transport and support during discussions at the hospital. The mother spoke of how being driven had reduced stress about parking and the risk of being late, along with how valuable the support had been in the discussions with clinical staff and being able to talk about the options afterwards. The Family Support Worker continued regular contact through messages and home visits.

The Family Support Worker provided transport and support for hospital a ppointments.

"I went to the Paddington Bear experience. We also went to TGI Friday's and ABBA Voyage, it was very good and on the Tuesday I went to the World Observatory which was very fun and there were astronomers there!" (Phoebe)

The whole family enjoyed a wonderful Make a Wish trip to London in October 2024, making memories visiting exhibitions and a show. In November the Coordinator sent an M&S voucher for Christmas shopping and food. In early 2025 they supported a second Turn2Us grant application due to ongoing financial issues which was successful.

In January 2025 the Family Support Worker informed the mother they were leaving the Kentown team and asked if they would like another worker to provide support which they agreed to. This support began a few months after the interviews with Phoebe and her mother.

The added value of the Kentown Programme support for Phoebe's family

The support provided to the family was holistic and flexible, responding to a range of health, financial, emotional, and social needs that benefited the whole family. Support was provided initially by the triad team approach of the Kentown Programme starting from a joint visit by the Kentown Nurse and the Children's Community Nurse who made the referral. Following the visit, the Nurse involved the Family Support Worker and Service Coordinator to address emotional, practical and financial needs. The Kentown Nurse support was stepped down as it was not required at that point.

"My involvement has mainly been identification of child and signposting whilst keeping good communication between teams, child has been stable from a health perspective however I am a point of contact should she have any difficulties or need some support with care planning ." (Nurse)

The Family Support Worker provided direct practical and emotional support during a challenging time, including the death of Phoebe's father, and support for hospital visits. This support was vital for Phoebe's mother who was now caring for three children on her own whilst grieving herself.

"I have been able to provide emotional and practical support to the family during many difficult times, and been seen as a friend being there at times of need. (Family Support Worker)

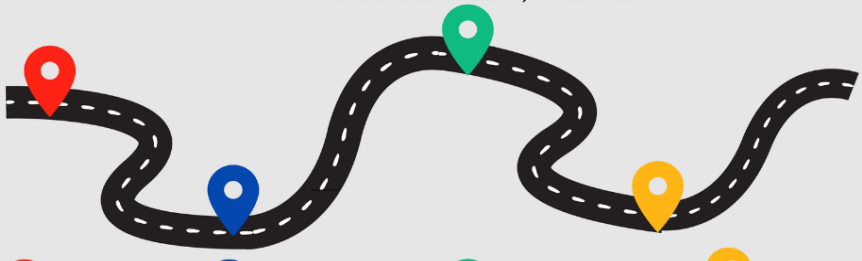
The Coordinator was able to provide much-needed expert guidance and practical support, helping the mother with two grant applications to fund urgent home repairs and replace an appliance. They also arrange a voucher and food delivery, along with a memory-making Make a Wish trip for the whole family.

Good communication was maintained within the Kentown team through close working relationships and regular caseload team meetings.

"The family have faced multiple challenges. We've supported mum with the lost of her husband around the time of referral. She had 3 children to support, one of whom has a life limiting condition. Her finances were uncertain and the support we've been able to offer through food shops, M&S voucher at Christmas and 2 x Turn2Us grants has been invaluable to supporting this mum during these difficult times when she's not had other support to turn to." (Coordinator)

PHOEBE'S FAMILY JOURNEY

12 years old, No formal diagnosis, multiple conditions including lung disease and a cardiac condition, White British



1 REFERRAL
Children's Community Nurse (CCN)
October 2023

2 KENTOWN NURSE
Home visit 2 days from referral
October 2023 - January 2024
Support stepped down but available as needed

3 FAMILY SUPPORT WORKER
Home visit 3 weeks from referral
October 2023 - ongoing
FSW left the team, Jan 2025. New person took over role shortly after

4 SERVICE COORDINATOR
Contact 4 months from referral
February 2024 - January 2025
Support stepped down but available as needed

SUPPORT RECEIVED

The Kentown Nurse supported initial home visit and assessment. Engaged other members of the Kentown team.

The Service Coordinator provided information, guidance and support for grant applications, signposting to support, TfSL interventions such as crisis food delivery and shopping voucher.

The Family Support Worker provided weekly emotional and practical support, including bereavement support and hospital transport.

Support needs discussed at regular caseload team meetings.

Lessons learned for future evaluations

From this evaluation, some key learning was identified which may help guide future evaluations of the programme.

As mentioned earlier, the original evaluation plan included a quasi-experimental economic impact analysis using a difference-in-differences approach. This component was not implemented as initially intended because of the nature of the available data: service performance metrics were collected in aggregate form rather than at the individual level, and historical data from comparator sites were either unavailable or not comparable. These limitations precluded the possibility of identifying a robust counterfactual or attributing changes in outcomes directly to the Kentown model using statistical techniques. However, this presented a valuable learning opportunity. The evaluation team worked closely with the programme team to explore what data were being captured in which data systems, formats, and definitions across settings. These insights highlighted the importance of developing consistent, person-level data collection protocols at the outset of new service models if robust impact and economic analyses are intended downstream. Our work reiterated the need to co-develop a more standardised outcome framework, which could support both operational improvement and future evaluation ambitions, including economic modelling. For evaluations to provide a robust measurement of impact and value for money, it is recommended that future iterations of the Kentown model prioritise the development of a shared data infrastructure and build in appropriate data collection and measures from an early stage. This would include:

- Standardised outcome measures collected at the individual (child/family) level across all sites.
- Consistent definitions and data collection protocols for service activities and outcomes.
- Agreed minimum datasets co-designed with delivery staff, commissioners, and evaluators.
- The ability to track changes over time and link data to relevant service milestones.

In addition to challenges relating to data, identifying and recruiting families into the evaluation was also a key challenge (particularly throughout both year two and three). Whilst a strong contributing factor was how families were experiencing life at that point and time constraints; it is also helpful to reflect on the processes and how this could be integrated further into the programme moving forward. Whilst the plan for this evaluation was to use qualitative methods to capture depth of experience, other approaches such as use of standardised measures and online surveys may support capture of simple numerical data and higher engagement. Some of the Kentown team reported uncertainty about the timing and how to introduce the evaluation to families, along with lack of time to discuss it during visits or calls. The evaluation team

supported the Kentown team through ongoing discussions in the bi-monthly Kentown Programme meetings and clear documentation to guide family selection, along with attending a family event. Incorporating other methods such as sending out of the information for the evaluation more frequently, may support higher engagement.

A small number of families shared with the evaluation team aspects of the support that did not fully meet their expectations. Whilst they remained broadly positive about their experiences overall, they expressed some disappointment at the sudden withdrawal of support. It is recognised that families receiving free support may be less inclined to make formal complaints, and that evaluative interviews can therefore provide an important space for sharing such reflections. While the Kentown team identified and addressed these issues during the pilot phase, they are included here to provide a balanced and transparent account of family experiences. Importantly, this feedback offers valuable learning for refining communication, continuity, and transition planning within the programme. Given the limited number of families represented in the current data, further engagement, particularly with children and young people Is vital to ensure the service continues to evolve in response to families' needs and expectations.

The Kentown Nurses delivered structured training on a range of topics during the programme including administering medication and advance care planning. Gathering robust data about the scale, reach and impact of training sessions would also contribute to future evaluations.

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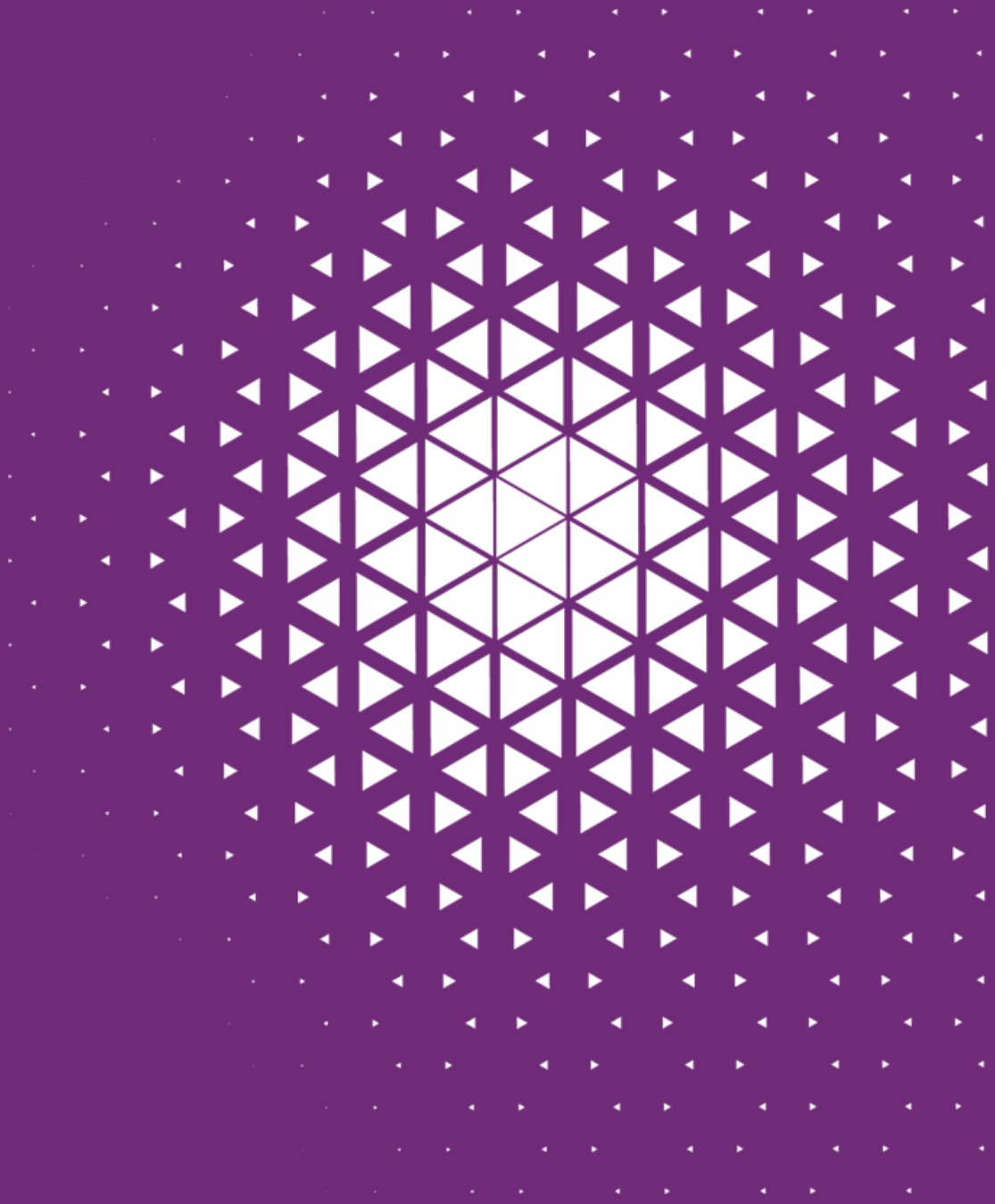

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