Results Patient and carer feedback was collated using satisfaction surveys. Feedback highlighted the lack of psychosocial support in community. For participants with communication issues, the Zoom format did not work. Participants reported that hour long sessions with SaLT, dietetics, physiotherapy was not necessary as they had access to these services in the community; what was beneficial was therapeutic services such as art and music therapy, complementary therapy and psychosocial services.

Conclusions As a result of feedback provided, the programme was adapted, adopting a holistic approach. A five-week face-to-face programme was developed with a focus on providing psychosocial and spiritual intervention, peer group support and familiarising the patient group with hospice care. This was in line with the hospice-wide approach, shifting to a rehabilitative palliative care model with focussed therapeutic intervention and individualised goal setting. Feedback continues to be collected to evolve the programme.

Background A new role, reaching into a neonatal ward, geographically close to a children’s hospice, was created to increase referrals, provide support to families and raise service profile. Data informed us that referrals were significantly low and services misunderstood, by parents and professionals.

Aims To be responsive to the needs of extremely premature babies and their families and grow our referrals of neonates. To bring a social care model into a medical setting and work in partnership to ensure families received the right support at the right time, specifically earlier than the current offer. Review of pilot, impact on criteria referral to children’s hospice and influence new post-death pathway, plus building positive awareness relationships with all stakeholders.

Methods Work in collaboration with organisational teams, such as Service Development and external stakeholders, specifically the Neonatal to Home Outreach team. Collate data comparisons, identify needs, especially for those without diagnosis, create pathways of rapid access to Family Support, redefine criteria and create dedicated pathways for post-death, bereavement support.

Results This work is now the second largest referrer into this children’s hospice following a tertiary centre. The development and implementation of two new pathways, neonatal and post death, which has resulted in the significant difference in the types of referrals, moving away from end of life and towards psychosocial care and bereavement. Better informed staff, rapid administrative processes and access to Music Therapy on the neonatal ward.

Conclusion Support to families starts at the earliest opportunities, which is consistent at such an uncertain time. The family are the focus, with opportunities for peer-to-peer support and access to creative arts therapies for brothers and sisters. Additional bespoke memory events delivered and an increase in resources in order to mirror this work within a different hospital trust.

Aims To educate and provide specialist palliative care in the acute hospital setting. Acute hospitals often have minimal understanding of the range of holistic palliative care services available to children, their families, and the wider professional network. To identify children who meet criteria for referral when they access acute services and support existing service users throughout acute admissions. Educate and support acute staff on the care of children with complex health needs to develop confidence and skills to improve the patient experience.

Methods Placement of a nurse within the acute paediatric ward one day a week, with an honorary contract and access to clinical utilities. Presence at core meetings to understand the needs of the acute staff and services. Deliver bespoke training to the acute team. Educate on referral criteria and services available to children and families. Provide respite for the caregivers during a child’s admission. Promote the hospice services on the wards. Be recognised as a member of the multidisciplinary team so that children and families are introduced to the concept of hospice services at the beginning of their journey, addressing myths and anxieties. Regular meetings with Matrons to continually review the service. Reciprocated education: Nurse to have opportunities to update acute clinical competencies.

Results Hospice care becoming embedded within the multidisciplinary team. Children and families being identified and referred earlier, improving their experience and journey. A change in the perception of what palliative care can offer. Increase in referrals, reaching more children who can benefit from the services. Collaborative working to provide seamless, holistic care to families. Breaking down barriers and addressing myths surrounding the word hospice. Supporting acute staff to provide quality care.

Conclusion Children being referred earlier. Established a strong link with one acute NHS trust, now developing this model with other NHS trusts that cover the hospice’s geographical areas.

Background Completing everyday tasks such as gardening, cleaning or painting may not be a focus for families who have a child with a life-limited or life-threatening condition. The hospice strategy (2016 – 2021) set out to provide much more supportive care in the child or young person’s own home. The outcome of this project was to place trained volunteers in families’ homes to support with everyday household tasks. A pilot project assessed participants’ perception, identified immediate and long-term impact and monitored activities undertaken.
Aims (1) To identify families’ needs and match with volunteer skills, within a limited region. (2) To examine processes and communicate learning and outcomes. (3) To identify improvements, ensuring sustainability and growth.

Methods Implement a volunteer recruitment programme and survey families on support required. Working cohesively with wider hospice teams, implementing a home assessment system with additional resources. Understand expectations and matching the right volunteer skills with the right family, within limited parameters. Collating feedback, reporting to Trustees and identifying future organisational opportunities including deliveries of seasonal gifts and memory boxes.

Results The pilot was a success and recognised as a crucial growing part of the children’s hospice service offer. The range of services developed included increased transport referrals, which ensures regular attendance and punctuality to appointments and removes challenges of comforting and supporting children whilst driving for families. Recognising some tasks were too large for volunteers to complete resulted in local Trades’ involvement.

Conclusion Impacted by the pandemic the service and support offered adapted, with improved responsive referral systems in place for families and professionals. “You are the first person to offer me support rather than just my child”, commented a parent following engagement with teams of multidisciplinary professionals involved in their child’s life. Increasing parent/carer wellbeing has positive effects on the child they are caring for.