

SUPPORTING CHILDREN WITH LIFE-LIMITING CONDITIONS AND THEIR FAMILIES – A REGIONAL EVALUATION

PROJECT SUMMARY – APRIL 2014



INTRODUCTION

Between 2011 and 2013, Martin House Children's Hospice undertook comprehensive research into paediatric palliative care and support in Yorkshire and the Humber. The research collected information about the range of services available to children and young people with life-limiting conditions and their families living in the region. The work also explored the views of professionals and families about the care and support available, and the strategies and resources families draw upon in order to access the support they need. This summary presents the key messages and findings from this work, and concludes with implications and recommendations for paediatric palliative care policy and practice.

KEY MESSAGES

With the right resources and support to draw upon, the quality of life for children and young people with life-limiting conditions, and that of their parents and other family members can be enhanced.

While there are gaps in provision and barriers to access, there is a wide range of both regional and national services available to families, many of which are well regarded by families and professionals alike.

Services are provided by both universal and specialist statutory, voluntary and private sector organisations across health and social care, and also through education, leisure and information provision.

Specialist providers, such as children's hospices, play a central role in supporting children throughout their lives. However, families are not always able to access this at the times they need it, and there is a lack of understanding among some families and professionals about what palliative care involves and when to access it.

Despite policy and practice developments in paediatric palliative care, and increased knowledge from research and practice about families' needs, many families are subject to poor assessments and experience little co-ordination of care.



"You can still have a good life. You're not stuck doing less things... except from flying and things like that, but apart from that, I mean you can travel round the country in vehicles easy. I need a carer there nearly all the time but that's OK. We have a laugh anyway so it's fine."

(Paul, age 23)

Consequently, whilst some families are able to access a range of resources to help them establish a sustainable home life and achieve a good quality of life, other families continue to fall through the gaps and will reach 'breaking point' before the process of building effective care around them can begin.

Improving awareness, access and availability of services, and developing effective care co-ordination that can respond to the changing needs of families are therefore essential if we are to better enhance the quality of life for ALL children with life-limiting conditions from the point of diagnosis and throughout their lives.

MORE ABOUT THE PROJECT

This project builds on the findings of a recent service evaluation of Martin House, which found that whilst families highly valued the support provided by their children's hospice, they experienced uncertainty about the role of different service providers in supporting them; limited information about the range of support available in their local area; and difficulties in accessing the support they needed.

Taking Yorkshire and the Humber as the focus for this work, the project aimed to:

- **Further understanding of the barriers to and facilitators for providing effective and appropriate paediatric palliative care and support to children and their families**
- **provide a better understanding of regional provision, therefore enabling organisations involved in supporting children with life-limiting conditions to work together in ensuring provision is accessible and equitable, and to develop services not currently available.**

The project involved three overlapping phases – understanding paediatric palliative care; mapping regional provision; and exploring families' needs for support. The methods are summarised in the following table. In total, 28 parents, 12 young people, 53 key informants and frontline staff, and 181 organisations took part in the research.

Phase One <i>Understanding Paediatric Palliative Care</i>	Phase Two <i>Mapping Regional Provision</i>	Phase 3 <i>Exploring Families' Needs for Support</i>
Interviews with 25 key informants in paediatric palliative care Focus group with 8 young people to discuss project and service provision Project advisory group consultations (13 members) Narrative review of paediatric palliative care literature	Mapping of service providers (388 organisations identified) Survey of organisations (181 out of 274 returned questionnaires) Analysis of survey data to examine service provision, funding, access & availability	Semi-structured interviews with 24 parents and 4 young people (families = 24, including 4 bereaved); 19 frontline staff (2 GPs, 6 paediatricians, 7 nurses, 4 social workers) Transcription and thematic qualitative analysis of interview data, young person's focus group data, and key informant notes

KEY FINDINGS

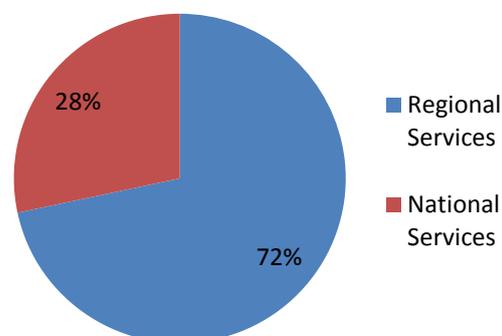
1. Staff, parents and young people found the process of identifying what services are available an on-going challenge and a key barrier to securing care and support that is needed. This was borne out by the research, which found the process of mapping services in the region to be an arduous and time-consuming task.

2. A significant proportion of services are provided by the voluntary sector, offering a wide variety of services, some very small and local, whilst others are national with an online presence. Families and staff were not always aware of the support available from national charities, despite them being identified as a key resource for some parents and young people.

3. The research identified a range of barriers to accessing services. These included differing referral criteria (e.g., age, condition, geography); short opening hours; limited transport and translation arrangements; service charges; difficulties supporting children with complex care needs; waiting lists; short-term funding and continuous changes in both the statutory and voluntary sector.

SERVICE MAPPING

In July 2012, 388 organisations were identified from the process of mapping services available to families living in the region. 51% were from the voluntary sector. 278 organisations were located within Yorkshire and the Humber.



In December 2013, the database of services was updated. A small number of existing services were no longer available. New services were located, in part due to better information from Local Authorities. In total, 465 services were identified this time. 77% of these were located within the region.

Main Types of Provision Identified from Service Mapping

NHS Children's Community Nursing Teams	Disabled Children's Social Work Teams
Specialist NHS Palliative Care Providers	NHS Continuing Care Teams
Bereavement Services and Charities	NHS and Other Specialist Therapy Services
Family Information and Signposting Services	Portage Services
Parent Partnership Services	Youth Clubs / Play Schemes / Holiday Clubs
Grant and Equipment Providers	Family Support Groups and Forums
Condition Specific Charities	Short Break and Respite Providers
Wish Making Organisations	Children's Hospices
Providers of Social and Leisure Activities	Providers of Special Trips and Family Holidays

4. Specialist end of life and bereavement care is only provided by a minority of organisations taking part in the research (20% and 24% respectively). Children's hospices were identified as the main provider in the region, described by parents as invaluable, and by some staff as a facilitator of a 'good death' experience.

5. Families and staff identified the difficulties of accessing specialist medical and nursing care, particularly on evenings and weekends, as a barrier to effectively supporting children. This was confirmed in the survey, which found that only 16% of organisations taking part offered a 24hr service.

6. The importance of being able to access flexible and high quality personal and nursing care was identified, both for the home and in other settings, establishing trust through continuity of care. However, in reality quality and continuity were variable, with many families sharing their experiences of both poor and excellent care; challenges of finding appropriate carers and service providers; and anxieties about losing valued and trusted support.

"You almost need people who know you well enough, they see what is going on with Anna ... so you get that consistency, you get those relationships and you get that trust as well." (Mother of Anna age 19)

Acknowledging the dearth in provision, some families drew attention to the invaluable advice and on-going care available from their children's hospice.

7. Variation in the care and support offered to different families was reported, even among those whose child had the same condition or similar needs.

Contributing factors included: differences in local provision; variation in needs assessments; assumptions made by professionals and families; parents' reservations about accepting help or accessing services, (e.g. children's hospices or social workers); and variations between families with and without access to

a children's hospice or special school, both of which were identified as key providers of care.

"I know other people that have got really good packages. Saw one girl ... who went to the same school. And his mum introduced us to the carer ... At that time we didn't have anything... I had to ring to find out what to do to get a social worker involved." (Mother of Andrew age 16)

8. Families described their own unique package of care and support, provided mainly by public and voluntary sector organisations. Care arrangements ranged from Local Authority or care agency provision to some using their local contacts to identify potential carers known to the child; and others with the financial resources to do so, using their own money to pay for additional support. For some families, extended family members and well siblings also played an important caring role.

9. Families and staff identified the needs assessment carried out by a social worker as both a barrier and facilitator to securing support. While some parents identified their social worker as an important resource and gatekeeper to care, others were less positive, describing constant battles with their local authority in to secure increased hours of care, or funding for adaptations or equipment. Many families felt their social worker lacked experience of paediatric palliative care; and some social workers expressed a desire to learn more about how to effectively support families.

10. Nearly all parents described having been in crisis at varying points in their child's life, and the vital need of securing appropriate care and support to able to recover from this, or better still, avoid it happening.

"For a good year we were surviving on I don't know three hours sleep each...And you are not doing anything or saying anything to him but your mind is just God will you go to sleep... so there is never any respite there, the sleep was a huge killer." (Father of Shane age 3)

Many parents reported that their package of care was just right, providing them with the emotional support and resources to effectively care for their child and maintain a 'normal' family life. For some parents, this took many years to achieve. Other parents identified unmet needs, whilst a few parents described being close to 'breaking point' and expressed uncertainty about how to access support and who to ask for help.

"I think when you have got a child with such complex needs you are just treading over...you are juggling, you don't realise what a tightrope you are walking really sometimes and it is the slightest thing to tip it."
(Mother of Lucy age 12)

11. Parents need a break from daily life and from providing around the clock care for their child. Respite at home and away from home were equally important. For families who accessed a children's hospice, planned stays were an essential part of their care package, providing parents with time to recoup while their children engaged in fun activities they sometimes missed out on; and enabling them to live more independently.



Help at home was equally valued by parents, and viewed as essential in helping families maintain a supportive and sustainable home life.

"It does make a huge difference because you feel that people are looking out for you and the rest of the time I am holding it together for everybody else."
(Mum of Anna age 19)

12. Families have different needs for support depending on their own circumstances and environment, as well as their child's condition and associated symptoms; and these may shift over time. Influencing factors for parents included being in paid work; being able to drive; household income; housing tenure; adequacy of the home; their own physical and emotional well-being; the relationship with their spouse or partner; changing circumstances such as divorce or pregnancy; and having extended family support or other children.

13. Information was identified as one of the key resources parents draw upon to help them cope with

their child's diagnosis; to learn more about how to effectively care for their child; and to access support they need. Young people also identified the important role of information. Services that were able to signpost families when a problem occurred, or when a new need became apparent, were highly valued. However, many families and staff identified this as a gap in provision and expressed disappointment at finding out about services after they were really needed.

"I know we hadn't heard of it [service] before and we didn't really know ... that there was somewhere to go like that around here or that it actually existed to be honest." (Tracey, age 19)

14. There were misunderstandings about the terms 'life-limiting' and 'palliative care' among families and service providers. This caused uncertainties about which children should be supported by whom, and at what stage in their life. Families of children without a diagnosis and those with complex healthcare needs that were difficult to define as 'life-limiting' were reported to receive less care and support.

15. The transition to adult services was identified as a time during which young people and parents could lose vital care and support. Reported barriers included the lack of equivalent adult services (also identified in the survey); limited opportunities for young people to engage in social and leisure activities; the different funding and transport arrangements; and the limited knowledge in adult health and social care about childhood life-limiting conditions.

"He's just gone into adult services and the respite centre that he's going to he's the first one with a gastrostomy. So they're struggling with that and he's not settling." (Mother of Robert age 19)

16. The involvement of one service or professional who acted as an effective co-ordinator of care was the single most important factor that helped families secure the care and support required; and help predict future needs to prevent reaching breaking point. This was sometimes a child's paediatrician, community nurse or social worker, but it could also be an allied healthcare professional, a child's special school, a service manager, or a children's hospice. This role was often not formalised and instead provided above and beyond an individual's normal duties.

"It was the first time any help had been offered. But it was only because of this particular person. She was the sort of person that was interested and that's why...It wasn't offered to us through the health services."
(Mother of Debbie age 21)

"I think just having somebody that knows what doors to unlock is a big thing."
(Father of Rachel age 2)

IMPLICATIONS AND RECOMMENDATIONS

A. Specialist paediatric palliative care providers, which include children's hospices and specialist clinicians and nursing teams, are highly valued by families and other service providers, offering a total approach to care from diagnosis through end of life, and specialist medical, nursing and psycho-social care.

These specialist services must be made available to a greater number of children with life-limiting conditions and their families, and be available around the clock.

B. A wide range of public, private and voluntary sector organisations are involved in supporting families in daily life. However, there continues to be too much variation in the type, amount, and quality of care available.

Better signposting and information about what is available; more consistent referral criteria across organisations; and access to high quality training for staff working with families is required to ensure that provision is distributed more equitably and to improve the standards of care.

C. Limited understanding and mixed opinions about what paediatric palliative care and life-limiting conditions are can sometimes prevent families accessing key services.

To ensure that more families receive the right combination of specialist and generic support, there is a need to raise awareness of paediatric palliative care and establish a shared language that encompasses the wider range of organisations involved in supporting families.

D. There is little formal provision currently for the role of co-ordinator across the region, and many parents have no single professional with responsibility for their overall care, despite this being a statutory requirement. **An effective co-ordinator of care who has experience of working with children who have a life-limiting condition and can support families over time as their needs change, is an essential component of the care families need.**

Establishing specialist paediatric palliative care co-ordinators who can build relationships with families and work across organisational boundaries and transitions could help to ensure that more children, young people and families are effectively supported in the future.

The recommendations from this project should be considered alongside wider developments in paediatric palliative care and emerging national policy developments affecting children and young people, such as:-

- the establishment of paediatric palliative care as a distinct specialism;
- a multi-disciplinary team approach to care, which involves many professionals working together;
- transforming the quality of care, and ensuring that the right support is available regardless of who commissions or provides it;
- personal budgets, aimed at giving families more control over the support they need;
- better integration of health and social care; and



- the Children and Families Act (2014), which aims to better support children with special educational needs and disabilities, and includes the establishment of integrated Education, Health and Care plans.

ABOUT PAEDIATRIC PALLIATIVE CARE

Paediatric palliative care services aim to enhance a child's life expectancy and their quality of life, adopting a holistic approach to care and providing support for the whole family. Palliative care planning should begin around the stage of diagnosis and continue for a number of years in order to meet the continually changing needs of the child and family.



Paediatric palliative care is provided by a range of organisations across the public, private and voluntary sectors, and support will often continue through death and bereavement. In recent years, paediatric palliative care has developed as a sub-speciality in medicine. There has also been an increasing interest among policy makers to develop services that better meet the care needs of seriously ill children and their families.

The definition most commonly used to describe palliative care comes from Together for Short Lives (www.togetherforshortlives.org.uk), the UK leading charity committed to supporting the lives of children with life-threatening and life-limiting conditions:

“An active and total approach to care, from the point of diagnosis or recognition, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.”

Life-Limiting Conditions

The term 'life-limiting' was poorly understood by some families and professionals involved in the project. Together for Short Lives offer the following useful definition:

“Life-limiting conditions, sometimes known as life-shortening conditions, are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers.”

Due to the wide spectrum of diseases, children are unique and will follow their own distinctive illness trajectory. Some children will live for only a few weeks or months whereas others will live for years and even decades.

Some children may not receive a formal diagnosis because of the complexity of their symptoms or the rarity of their condition. However, if it is agreed that there is no reasonable hope of cure and that their life will be shortened because of their symptoms, they will still be classified as having a life-limiting condition.

ABOUT MARTIN HOUSE

Martin House Children's Hospice was identified as a key provider of care for families in the region and an exemplar for what excellent paediatric palliative care looks like. However, the lack of clarity about what a children's hospice is and who it can support continues to act as a barrier to access.

“I thought that they were just there for children with either cancer or end of life sort of children. Totally oblivious that they'd be able to help us.”
(Mum of Andrew age 16)

Although Martin House can support children throughout their lives, it is not expected to provide the full range of support that a child with a life-

limiting condition might need, and families very much view Martin House as one among many services they access, albeit a central one.

Martin House has been supporting families in the region for over 25 years, and the organisation is in a good position to help identify the wider palliative care needs of children and young people and their families. Martin House intends to utilise the findings from this, and other research they are involved in, to help improve the care available in the region, and work more collaboratively with other organisations involved in supporting children and their families.

Please visit www.martinhouse.org.uk for further details about the services provided by Martin House, or contact Sheila O'Leary on 01937 845045.