

4.6.01 End of Life - Specialist Paediatric Palliative Care

Context

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 not limited to the immediate period around the end of life. The definition most commonly used comes from the UK leading charity Together for Short Lives (togetherforshortlives.org.uk):

“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, social, 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.”

In Bradford District, there are a significant number of children with complex health needs and life limiting conditions (see section on special educational needs and disability), who will require the provision of high quality paediatric palliative care.

National and local targets

- NHS Outcomes Framework 4.6 'Improving the experience of care for people at the end of their lives'
- NHS Outcomes Framework 4.8 'Improving children and young people's experience of healthcare'

Relevant strategies and local documents

- Bradford Disabled Children and Young People's Needs Analysis 2010
- National Framework for Children and Young Peoples Continuing Care 2010
- Better Care: Better Lives – Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions (DOH 2008)
- Care Matters 2008, S3.73: Disabled children in long term residential placements
- Palliative Care Services for Children and Young People in England: An Independent Review for the Secretary Of State for Health 2007
- National Service Framework for Children 2004, Young People and Maternity Services: Standard 8
- Together from the start: Practical guidance for professionals working with disabled children (birth to third birthday) and their families 2003
- Supporting Children with Life Limiting Conditions and their families: a regional evaluation. Martin House Hospice, 2013
(<http://www.martinhouse.org.uk/MartinHouse/media/MartinHouse/Generic/Research-Full-Report.pdf>)
- Transition Care pathway: Together for short lives, 2014.
(http://www.togetherforshortlives.org.uk/professionals/care_provision/care_pathways/transition_care_pathway)

What do the data tell us?

Prevalence

A major epidemiological study carried out at the University of Leeds in 2011 (Fraser,2011) estimated the numbers of children in each local authority area with life limiting conditions.

Based on 2010/11 data, Bradford was estimated to have a prevalence rate of 42.4 per 10,000 population, much higher than any other local authority in the region. The next highest was Sheffield with a prevalence of 35.8/10,000 population. This figure will be affected both by the number of children with complex needs and by the youth of Bradford's population.

It was estimated that there were 595 children with life limiting conditions in Bradford, which again is much higher than any other local authority in the region.

Fraser also reported that the prevalence of life limiting conditions in children in Yorkshire and the Humber was much higher in the most deprived quintile of the population, and in children of South Asian ethnicity. This clearly suggests that the high levels of need for specialist paediatric palliative care in Bradford children are unlikely to change in the near future.

Services

Children with life limiting conditions receive a package of care which includes community nursing services, paediatrics, specialist input and respite care through local authority provision, Martin House Hospice, Wedgewood House (Bradford) and Clockhouse (Keighley).

In April 2015 it is proposed to introduce a national tariff for palliative care services. This will mean that Bradford families can access palliative care services for children and young people from any NHS commissioned provider, and may choose to use new providers based outside Bradford.

A paediatric palliative nurse specialist in Bradford provides a 7 day a week service to children between 0-18 years. While the original postholder has retired, the post is being filled on an acting basis and there are plans for permanent recruitment in September 2014. The Airedale outreach service provides a service 5 days a week. Children under the care of the Leeds oncology service can access a 24/7 specialist nursing service provided by the Macmillan team.

Martin House Hospice provides services to approximately 80 children from Bradford and Airedale. In 2012 the hospice undertook research mapping the services available to children with a life limiting condition. The research identified 388 services offering various forms of support to children and young people with life limiting conditions. 278 of these were located in the Y & H region (the remainder were national organisations) and in keeping with the high level of need in the District, 35 services were located in Bradford, more than in any area other than Leeds.

A summary of key recommendations from the Martin House research is given below.

- Specialist paediatric palliative care services must be made available to a greater number of children with life limiting conditions, and be available round the clock.
- There continues to be too much variation in the type, amount and quality of care available. ~ The review recommends better signposting and information about what is available; more consistent referrals criteria across organisations; and access to high quality training for staff working with families.
- Limited understanding and mixed opinions about what paediatric palliative care and life limiting conditions are can sometimes prevent families accessing key services. There is a need to raise awareness of paediatric palliative care and establish a shared language.

- 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.

Following on from this research, Martin House have commissioned a short review that will map the levels of specialist paediatric palliative care (SPPC) available to families in the region, and make recommendations on the optimum level and configuration of SPPC services required to secure access to specialist care 24/7.

The review is due to report in late autumn 2014 and will need to inform commissioning decisions in Bradford district.

What do our stakeholders tell us?

Families interviewed as part of the Martin House report (2013) identified difficulties in accessing specialist medical and nursing care, especially at weekends. Although Martin House provides 24/7 medical support remotely, families would benefit from a local service in Bradford which is able to visit at home out of hours (e.g. to change syringe drivers or to replace NG tubes). Both families and professionals locally have identified out of hours support as a significant gap.

The Martin House report described misunderstandings around the terms 'life limiting' and 'palliative care', leading to uncertainties about which children should be supported by whom, and at what stage in their lives. Families of children without a diagnosis, or whose complex health needs were difficult to define clearly as 'life limiting' tended to receive less support.

Issues of transition to adult services for young people with complex or life limiting conditions were identified as challenging by both families and local professionals. The new SEND Code of Practice which is designed to provide for children and young adults from 0-25 may address some of these concerns.

Future needs and gaps in provision

The need for specialist paediatric palliative care will remain high in Bradford, and following the publication of the service review, there may be a need to consider extending the existing services. It is important to work with families to offer access to specialist care throughout the life of a child with a complex or life limiting condition, not just around the end of life.

A new working group has been set up to consider neonatal palliative care and bereavement support at Bradford Teaching Hospital Foundation Trust (BTHFT). The group, led by two neonatologists, is undertaking a service evaluation of end of life care and bereavement support, and aims to set up a regional neonatal palliative care clinical network.

The BTHFT paediatric team plan to set up a similar working group across all areas of paediatrics, with links to Martin House, PICU and Embrace.

Summary of priorities

- Complete service review of specialist paediatric palliative care provision
- Maintain services appropriate to the particularly high level of need in Bradford

References

Supporting Children with Life Limiting Conditions and their families: a regional evaluation. Martin House Hospice, 2013 (<http://www.martinhouse.org.uk/MartinHouse/media/MartinHouse/Generic/Research-Full-Report.pdf>)

Fraser, Lorna et al, 2011. Life-limiting and life-threatening conditions in children and young people in the United Kingdom; national and regional prevalence in relation to socioeconomic status and ethnicity. Division of Epidemiology, University of Leeds, 2011.
(https://www.togetherforshortlives.org.uk/assets/0000/1100/Leeds_University_Children_s_Hospices_UK_-_Ethnicity_Report.pdf)