

palliative and hospice care for children and young people

Clair Holdsworth

Director of Clinical Services



Aims

- What is children's palliative care
- Consider agencies involved
- The needs of the child
- Impacts on family
- What is good End of Life care



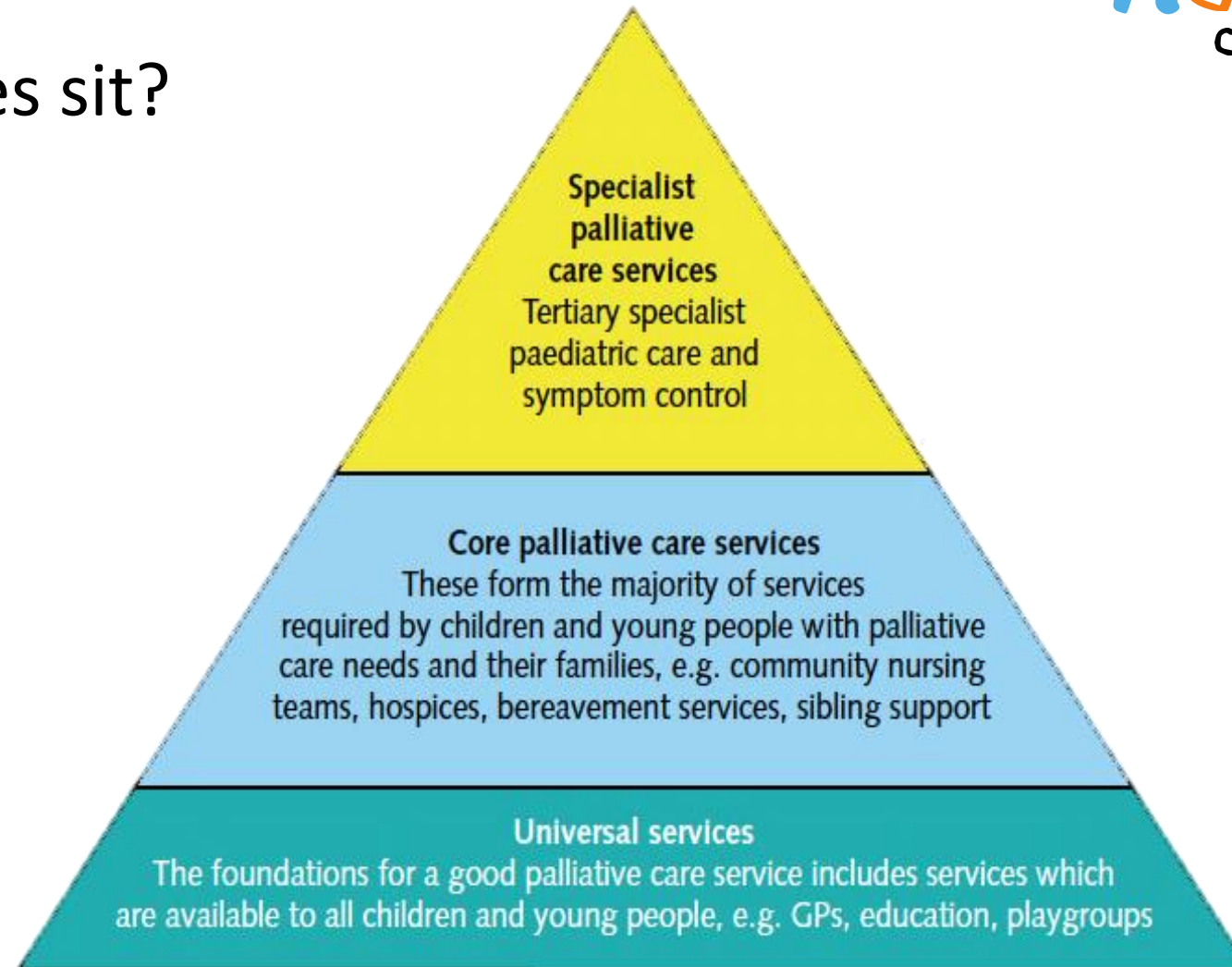
Scope of palliative care

“Palliative care for children and young people with life-limiting conditions is an active and total approach to care, **from the point of diagnosis or recognition**, embracing physical, emotional, social and spiritual elements through to death and beyond.”

ACT(2008)

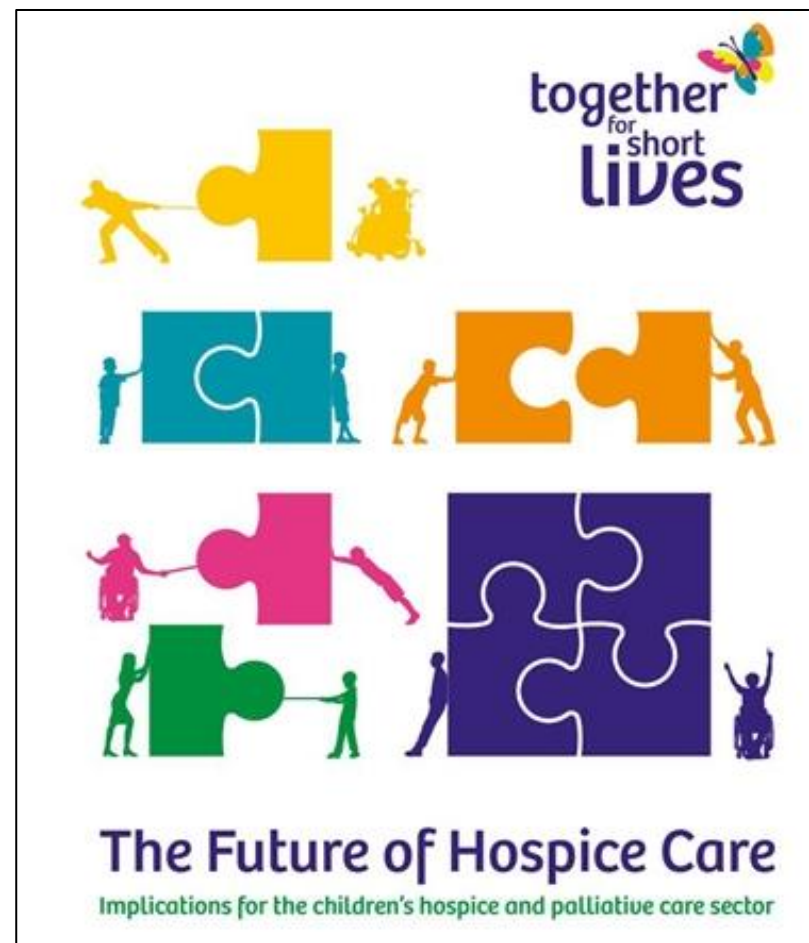


Where services sit?





Martin House
children's hospice



Children's hospices

- Offer specialist palliative care throughout the child and family's journey
- Short breaks, symptom control, end of life care and bereavement



children's vs. adult palliative care

- Palliative care focus
- Hospice services provision
- Prevalence of hospices
- Conditions
- Transition
- Community support
- Funding
- Environment



Martin House

children's hospice



category 1



As the illness progresses, the emphasis gradually shifts from curative to palliative care



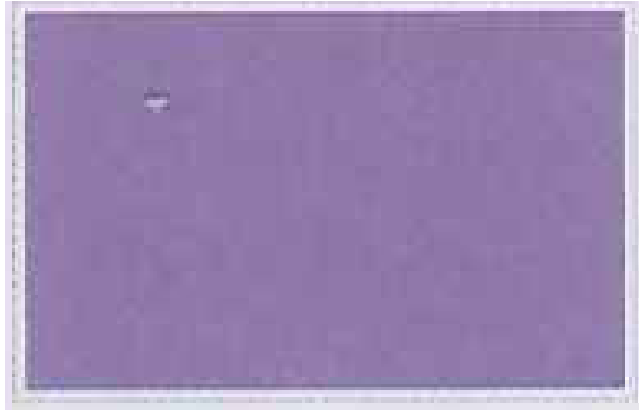
category 2



Highly technical, invasive treatments may be used to both prolong life and improve quality alongside palliative care, each becoming more dominant at different stages of the disease.



category 3



*no cure is possible and care is palliative from the
time of diagnosis*



category 4



At first it may not be apparent that this will be a terminal illness and palliative care starts suddenly once the realisation dawns.



so, how many children?

It's estimated that:

- In England there are **more than 40,000 children** with life limiting and life threatening conditions.
- **5,800 children and neonates die** each year in England. Of these...
 - **3,900** will have required palliative care
 - **2,100** are neonates.
- **Most children will die in hospital.**
- **Approximately two-thirds of children with palliative care needs will also have a recognised disability.**



so, how many children in North Yorkshire?

- North Yorkshire (Fraser et al 2010) – identified 398 children
- Recent studies suggest this will have increased considerably in the last 6 years (+40% more = +160 children, 558 in total)
- Currently (Jul-Sep 2016) Martin House is caring for 56 children and 20 bereaved families

Providing 106 nights for Children, 60 nights for parents & 31 nights for siblings



child and family needs

- Choices in all aspects of their care.
- Coordination of services at home, where this is their choice. This should include specialist equipment and access to **24 specialist advice, care and support when needed.**
- Care and services that is right for their age – from neonates to young adults.
- Care and services that are culturally sensitive.
- Expert symptom management.
- Emotional, spiritual and practical support for all family members
- Short breaks, with nursing and medical support when required



- Parents and carers need practical support, including clinical equipment, financial grants, suitable housing and domestic help.
- Transport and mobility assistance.
- A simple system for accessing benefits, allowances and other financial assistance.
- Planned transition from children's to adult services
- To continue with their education and take part in extended school opportunities and other appropriate childhood activities.
- The opportunity to participate in social activities and be with their friends
- Good end of life care. Children should be allowed to die at home if this is what they need.
- Specialist support for siblings.
- Bereavement support.



End of life care plans

A good plan should contain...

- Wants and wishes of the child and family
 - Wish granting
 - Complimentary therapies
 - Fears
 - Religious and cultural needs
- Anticipatory symptom management
- Limitation of Treatment Agreement (LOTA)
- Up to date emergency contacts
- Plans for death



Parallel planning

Potential benefits:

- A combination of a palliative and rehabilitative approach will result in improved quality of life.
- A commitment to parallel planning will facilitate improved care at all stages.
- Enhanced quality of life offered by long-term palliative care is valued by families.
- Improved symptom control
- Better recognition of dynamic condition

The Children's Trust 2011



our approach

Our philosophy is one of **well coordinated services** that enable, support and inform families so that they can exercise **true choice** relating to:

- Choice of place of care.
- Choice of social opportunities.
- Choice of place of death.
- Choice of emotional, psychological and bereavement support.



“having the courage to walk into a room where there are no answers, and having the strength to stay there.”



Questions?

choldsworth@martinhouse.org.uk

01937 845045

