Provision of Specialist Paediatric Palliative Care in Yorkshire and the Humber

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On behalf of the
Yorkshire and Humber Children and Young People’s Palliative Care Network
Work force changes in region was the impetus for a children’s palliative care network conference entitled “Specialist Children’s Palliative care Services in Yorkshire. How should they be organised?”

- strong support for collaborative
- lack of formal 24 hour cover for families with a non-oncological diagnosis.
- The present provision is not sustainable.

....A report detailing the current service provision for children’s palliative care in Yorkshire and Humber and the future model of care should be commissioned.
Background

- 40,000 LLC in England
- Although diagnosis are rare the group is large (c.f. diabetes)
- Increasing survival, in time and numbers (i.e. ICU/Home ventilation)
- 1.2 million C&YP in Y & H less than 19 years
- Prevalence 29.7 per 10000 (n=3741) in 2009/10 Y&H

definitions.

The service specification for highly specialist paediatric palliative care has been defined by NHS England as “This service specification will provide a consultant-led multi-professional specialist palliative care team, providing a clinical leadership role in planning delivery and evaluation of children’s palliative care services across a managed clinical network. It will be led by a medical consultant working at Paediatric Palliative Care Competency Level 4.”

Method

- Steering group
- Telephone survey to all Heads of CCN teams and Clinical Directors
- Propose new model of care
- Next steps
Areas covered by Children’s Hospice Providers
Medical provision:

Consultant (Level 4)

- One based at Martin House Children’s Hospice (6 PAs)
- One based in Sheffield Children’s Hospital and Bluebell Wood Hospice (6 PAs)

There are also four consultants/GPs working at Level 3 in the region:

- One based at Martin House Children’s Hospice (6 PAs)
- One based in York/Scarborough (2 PAs)
- Two based at Forget Me Not Children’s Hospice (1 PA each)

Specialist oncology services and PC at 2 tertiary hospitals
Grid trainee (F/T)
Named/Lead Clinician for Children’s Palliative Care

50% Lead Clinician (n=12)

- Level 3/4 Funded
- None
- Named

[Map showing distribution of Named/Lead Clinicians]
63% Lead Nurse (n=15)
Wide variation in skills

Lead Nurse for CPC
- Red: No
- Green: Yes
Routine On Call Provision

25% Routine (n=6)
• 75% (n=18) Full on call cover 24/7
• Two of these were Hospice only
• Most community services were non commissioned

- Planned short breaks (home/hospice)
- Emergency short breaks
- End of Life care
- Tracheostomy Care
- Care of the ventilated child
- Symptom Management
- Home administration of IV drugs
- Family Support

- Central Line care
- Oxygen therapy and monitoring
- Gastrostomy Care
- Bereavement Services
- Sibling Support
- Physiotherapy/Occupational Therapy
- Spiritual and Pastoral support
Conclusions

- Large gaps in the provision of 24/7 services across the region
- Especially home based care
- Incomplete provision of medical cover in children’s hospices
- Lack of formal arrangements for provision of EOLC in the majority of the region
- Lack of formal commissioning of these services
- Vast majority of SPPC in Yorkshire & Humber is provided by charity funded organisations.
BUT....

- We are uniquely placed to develop SPPCS in Yorkshire and Humber
- Clinical (medical and nursing) expertise across the region
- Needs to be sustainably funded
PROVISION OF SPECIALIST PAEDIATRIC PALLIATIVE CARE IN YORKSHIRE AND THE HUMBER

**LEVEL 1:** Building Local Capacity

**LEVEL 2 & 3:** Specialist Paediatric Palliative Care

**LEVEL 4:** Highly Specialist Paediatric Palliative Care

- **LEVEL 1**
  - Martin House
  - District General Hospitals, Community Nursing Teams, GPs

- **LEVEL 2 & 3**
  - Forget me Not
  - Bluebell Wood
  - St Andrews

- **LEVEL 4**
  - 24/7
  - CLINICAL GUIDELINES
  - INFORMATION SHARING

**Children’s Hospice Providers**

**District General Hospitals,**
Community Nursing Teams,
GPs
Recommendations

- Establish a managed clinical network for children’s palliative care in Yorkshire & Humber and to develop a strategy for delivering this 24/7 service (12 months).

- To develop a hub and spoke model of delivering children’s palliative care (12 months).

- Establish a clinical lead for PPC in areas covered by the 16 DGH’s and 2 tertiary children’s hospitals in Yorkshire & Humber (12 months)

- Establish a lead nurse PPC in areas covered by the 16 District General Hospitals and 2 tertiary children’s hospitals in Yorkshire & Humber (12 months)

- To develop a regional Children’s Palliative Care Register (36 months).
Next Steps

• Recruit a network coordinator

• Engage with commissioners

• Work towards recommendations