Paediatric Palliative Medicine  
Past, Present & Future

Paediatric Oncology Update  
Dr Mike Miller: 11th March 2015
Why do you want to be a doctor?

Want to get people better.

Learning how the human body works.

Fancied exploring Africa.
History

1989   Young consultant -
       “Children should have good local care and be managed at home”

1995   Jealousy!

2003   Helping Martin House draw up job description
History

2004  Consultant in Paediatric Palliative Medicine at Martin House

2005  Links with Children’s Oncology

2015  Replacement of Consultant
Organisational

- Ann Golding Consultant in PPM GOS 1990s.
- Children’s Hospices
- RCPCH report 1997
- Big Lottery Funding 2003
- Better Care, Better Lives 2006
- Networks, PCT’s & SHA’s
- Child Death Review Process
- Advanced Care Planning (LOTA)
ACT categories (1997)

1. Life-threatening conditions for which curative treatment may be feasible but can fail. *oncology*

2. Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. *Cystic fibrosis*

3. Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. *Metabolic disease*

4. Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. *Cerebral palsy*
Paediatric Palliative Medicine comes of Age

Palliative Care is now a recognised sub-speciality
Increasing Complexity

Gastrostomy Feeds
Jejunal tubes
Total Parenteral Nutrition
Kidney dialysis
Tracheostomies
Non invasive ventilation
Invasive ventilation
Enzyme Replacement Therapy
Bone marrow transplants
Palliative Oncology

Where does palliative care begin?
Better Care, Better Lives

Some clarity of roles SHA & PCT
Some confusion between Specialist and general Palliative Care
1. Improved data
2. Equality of access to universal services
3. Responsible and accountable leadership
4. Choice in preferred place of care and expansion of community services
5. Better end-of-life care
6. Stronger commissioning and value for money
7. Successful transition between children’s and adult services
8. Planning and developing an effective and responsive workforce
Networks

Call the helpline
0808 8088 100

If you taught a child with a life-limiting condition, do you know what to do? Our new interactive resource can help your school. #SEND & make sure your child gets the palliative care education they need.
Yorkshire and Humber Children & Young People’s Palliative Care Network
(YHCPPCN)

4 Hospices
- Bluebell Wood, Sheffield
- Forget me Not, Huddersfield
- St Andrew’s, Grimsby
- Martin House, Boston Spa

Children’s Community Nursing services
Macmillan nurses
Links to adult palliative care
Neonatal network
Networks

The mark of a good network is that, where wanted, end of life care at home can be organised within the patient’s time scale.
Child Death Overview Panel

Anonymized review of all childhood deaths.

0-19th birthday.

Under auspices of Safeguarding Board – local authority based.
Child Death Overview Panel

Leeds
182,000 children 0-18
Approx 70 deaths.
40% neonatal
30% expected
30% unexpected
Advanced Care Planning

1. Not strictly a legal document
2. Signed by the responsible Consultant
3. Name of child on each page
4. List of Contacts
5. All contacts to have a copy
6. Copy to ambulance service
7. LOTA (Limitation of Treatment Agreement)

Possibly the value is in the discussion involved rather than the document
Palliative Care in Oncology

Centered on child and family
Continuity from Macmillan Outreach Nurses and oncology team
Seamless link with Hospices
- symptom management wherever
- respite stay
- emergency stays
- terminal care
- bereavement support
Palliative Care in Oncology

Services working together – recognising other’s expertise

Giving families choice

Communication

Flexible choice over place of care (Freedom of palliative care)
Children’s Hospices

- Care becoming more complex
- Need for outreach/community care
- Links with acute services incl. PICU
- Acceptance criteria
Future of Palliative Care

Symptom Control is the easy bit
But it is the bit that doctors definitely take the lead on.
Palliative Medicine – maturing nicely
Paediatric Palliative Medicine

Managing suffering and uncertainty.
Being there.