Children’s Palliative Care in Ireland – past, present and future

Julie Ling  
LauraLynn Children’s Hospice

Dr Maeve O’Reilly  
Our Lady’s Children’s Hospital, Crumlin
Palliative care for children...

...an active and total approach to care embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes management of distressing symptoms, provision of respite and care through death and bereavement.
Four groups of children who are most likely to have palliative care needs...

Group 1
• Life-threatening conditions for which curative treatment may be feasible, but can fail. Where access to palliative care services may be necessary when treatment fails children in long term remission or following successful curative treatment are not included.
(Examples: cancer, irreversible organ failures of heart, liver, kidney.)

Group 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.
(Example: cystic fibrosis)
Group 3
• Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years.
(Examples: Batten disease, muscular dystrophy.)

Group 4
• Irreversible, but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death.
(Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord insult.)

ACT, 2009
Disease trajectory by ACT group
The Past
Then...

• No children’s palliative care team in Ireland (PPC not yet recognized as a specialty anywhere)
• Children with Life-limiting conditions cared for by paediatricians, primary care team
• Adult community palliative care teams (cancer only)
• No hospice
• Variable respite
• Voluntary organizations
Children...

- Three levels of palliative care
- Palliative care for children is different to adult palliative care.
- Palliative care for children is best provided in the home, with family supported by the GP, PHN and Specialist Palliative Care team where available
- Medical and nursing care of children should be the responsibility of those trained in paediatrics' with support from Specialist Palliative Care
- Services, include respite should be locally-based
- A Children’s Palliative Care Needs Assessment should be performed
Palliative Care Needs Assessment for Children (2005)

“To provide a referenced report on existing services in PC for children up to 18 years of age and to identify the projected needs over the next ten years”
Mortality

- Mortality 370 (range 354-398) with average death rate 3.6/10,000 (excl ICD 800-999)
- Many deaths in first year of life, majority from congenital anomalies
- 53% infant deaths occur in first wk
- Of all childhood deaths, 57% <1 year, 32% in first week
- For all childhood deaths 66% from Life-limiting conditions
Prevalence

• Data inaccurate
• Using estimates of 12 / 10,000 (UK) national prevalence 1,369
• Nb Estimates and likely to be significantly higher
Key findings

• Comprehensive data not available on children with Life-limiting conditions
• Services inequitable, differing significantly according to diagnosis and geography
• Development of services in the community including respite care
• Need to improve coordination of care, communication and linking of services
• Urgent need for education at all levels
• Urgent need to develop specialist children’s palliative care posts, initially medical and nursing
A National Policy (2010)

31 recommendations
Achievements???
Consultant Paediatrician

- Appointed 2011
- Funded voluntary sector
- OLCHC and Coombe Hospital
- Clinical leadership, education, research
- 70% increase in referrals
Outreach nurses

- Key worker
- 8 nurses now in post: appointed between 2007 and 2013
Healthcare Professional Educational initiatives

• Level A - 2067 healthcare professionals
• Level B – 262 RGN’s
• Funding – 2007-2011
  Irish Hospice Foundation
  2013
  HSE Funded
• LauraLynn (since January 2013) provides a range of education programmes
• NUIG children’s module at level 9 since 2008 & since 2011 stand alone module
• General Bereavement Masters RCSI National
National Development Committee

- Acute hospitals
- Regional lead on palliative care
- Clinical care programme
- Paediatric care programme
- Service user
- Adult palliative care consultant
- Children’s outreach nurse
- Consultant paediatrician
- Paediatric director of nursing
National Development committee

- Forum for information sharing and for key stakeholders to influence policy
- Annual work plan to progress the implementation of the national policy
- Prepare an annual commentary on children’s palliative care

- Sub-groups:
  - Hospice at home
  - Clinical governance
  - Minimum data set and database
  - Communications
Health Committee to resume hearings on end of life care

The Joint Oireachtas Committee on Health and Children will continue its hearings on end of life care tomorrow, Tuesday, 5th November 2013.

Tomorrow the Committee will hear from Primary Palliative Care Initiative, Nursing Homes Ireland, Institute of Community Health Nursing, the Alzheimer Society of Ireland and Professor Declan Walsh, Professor of Palliative Medicine, Trinity College Dublin & University College Dublin.

Committee Chairman, Jerry Buttimer TD said: "Tomorrow we will resume our hearings on end of life care when we will hear from groups and organisations involved in providing end of life and palliative care. It is important that those approaching end of life and their families, friends and loved ones are treated with dignity and respect and are given proper care and support. Death is a fact of life, 22,000 people died in Ireland during 2012 and up to 250,000 people were coming to terms with their loss. Our series of meetings will allow us to consider how we currently care for those who are dying and how our health services are organised from an end of life perspective."

The meeting will start at 5pm in Committee Room 1, Leinster House tomorrow, Tuesday, 5th November 2013.

Committee proceedings can be followed live [here](#).

Media Enquiries to:

Ciaran Brennan,
Houses of the Oireachtas,
Communications Unit,
Leinster House,
Dublin 2

Committee Membership:

Deputies: Jerry Buttimer (Chair), Catherine Byrne, Clara Conway (Vice-Chair), Regina Dolerty, Robert Dowds, Peter Fitzpatrick, Seamus Healy, Billy Lawless, Éamon Ó Cuív, Kathleen Moloney, Mattie McGrath, Sandra McLellan, Dan Neville, Mary Mitchell-O'Connor, Caoimhghín Ó Caoláin and Robert Troy

Senators: Joan Collins, John Crown, John Cilleroys, Imelda Howley, Marc Mac Sharry and Joan Van Turnhout
The Future
Outstanding recommendations

• Development of hospice at home
• 24 hour nursing at EOL when necessary
• Access to therapy services
• Parents should be actively involved in the decision making and planning of location of care for their child
• SCPC team in National children’s hospital and providing support to maternity hospitals and neonatologists
• Database
Outstanding recommendations ...

- Development of a range of respite services
- Bereavement supports to be developed
- Children should have continuing access to education
- Supply and demand for staff should be examined
- Education and research opportunities for healthcare professionals (e.g. Masters)
- Closer working between HSE and voluntary providers of care
Challenges

• Minimum of one consultant and 8 outreach nurses
• Workforce
• Funding
• Integration between voluntary and state sectors
• Figures
• Education (not big numbers)