Overview of the Palliative Care Service at Our Lady’s Children’s Hospital Crumlin
April 2015

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…where children’s health comes first
Outline of Presentation

1. Background of CPC
2. Specialist PC team & CON service
3. Focus on neonatal PC
4. Neonatal discharge planning
5. Community Team
6. Care of baby at home
7. References and Websites
“Palliative care for children & young people with a life-limiting conditions is an active and total approach to care, embracing physical, emotional, social, and spiritual elements. It focuses on quality of life for the child & support for the family, and includes the management of distressing symptoms, provision of respite, and care through death and bereavement.”

Irish Figures 2005

- Difficulty assessing prevalence rates - probably underestimated
- Estimated 1,369 children are living with Life-Limiting Conditions
- Approx 350 deaths per year
- 57% occurred in children under 1 year of age
- 53% of *infant deaths* occurred in the first week of life
- Only 11% died in a domiciliary setting (but 67% of children with cancer)

*(Palliative care Needs Assessment for Children, DHC and IHF, 2005)*

‘Fast rising need ‘ for Palliative Care in Europe (Irish Times, April 2015)
CPC National Policy

Blueprint for development of children’s palliative care services in Ireland (2010)

A key challenge for children’s palliative care (CPC) is establishing services for a small number of children with a very highly complex level of need (Downing et al., 2012)
Neonatal Palliative Care

Neonates and infants have the highest death rates in the paediatric population and approximately 53% of deaths are from life-limiting conditions which occur in 1st week of life.

ACT (2009) A Palliative Pathway for babies with Palliative Care Needs
http://www.act.org.uk/

Together for Short Lives (formally ACT)
Levels of Palliative Care

■ Level one - Palliative Approach
Palliative care principles, Foundation & Communication skills for all staff

■ Level two - General Palliative Care
Professionals with some additional training and experience
More contact with children who have life-threatening conditions e.g. NICU, Oncology

■ Level 3 - Specialist Palliative Care
Core activity is palliative care

http://www.hse.ie/eng/about/Who/clinical/natclinprog/palliativecareprogramme/Resources/competencyframework.pdf
Specialist Palliative Care Team OLCHC

- Consultant Paediatric Palliative care: Dr Mary Devins (sessions in Coombe Women & Infants University Hospital)
- Dr. Marie Twomey & Dr. Maeve O’Reilly J/S sessions in OLCHC Monday & Thursday
- SpR & SHO (GP in training) based in St. Luke’s
- CNS Palliative Care (1.5 WTE)
- Children’s Outreach Nurse
Role of CNSs CPC

- Hospital based specialist service
- Advisory & consultancy role: Symptom Management / Provide information
- Support family (hospital & home)
- Support colleagues
- Education
- When chosen to assist / advise re transfer of child from hospital to home
- Liaise with community teams / CON
8 Children’s Outreach Nurses
Regional Locations

Colette Goonan
Galway

Hilary Noonan
Limerick

Tyrone Horne
Cork

Liane Murphy
Waterford

Deirdre Murphy
Mullingar

Irene O’Brien
Drogheda.

Gail Mc Grath
Temple Street Hospital

Laura Flaherty
Our Lady’s Children’s Hospital
Role of Children’s Outreach Nurse (CON)

➢ Co-ordinate care for children with LLC in collaboration with HCP in acute and community settings thus ensuring continuity in care
➢ Link with GP, PHN, Acute/Community Paediatric Services, Adult Palliative Care teams, Voluntary organisations
➢ Act as informed resource for family and HCP
➢ Facilitate education and training for HCP
➢ Support the collection of data related to children with LLC

Palliative Care for Children with Life Limiting Conditions in Ireland (DoHC 2010)
Life Limiting Categories (1-4)

1. Children with life threatening conditions for which curative treatment may be feasible but can fail. E.g. cancer, irreversible organ failure of heart, liver kidney

2. Children with conditions where there may be long periods of intensive treatment aimed at prolonging life but premature death is still possible or inevitable. E.g. cystic fibrosis

3. Children with progressive conditions without curative treatment options E.g. Metabolic disorders – Batten’s Disease, I Cell Disease

4. Children with severe neurological disability which may cause weakness and susceptibility to health complications. Deterioration may be unpredictable and not usually progressive. Severe multiple disabilities – following brain or spinal cord injuries, including some children with cerebral palsy.
Survey neonatal palliative care practice in Ireland.

➢ Only 1 unit had a palliative care guideline
➢ Majority of units reported inadequate facilities
➢ The majority of care was provided by neonatal nurses, neonatologists, chaplains and social workers.
➢ There was no in-house teaching and little bereavement support.
➢ Morphine was the medication of choice for symptom-relief in 12 units however 9 units surveyed use paracetamol only.
➢ Only 2 units had formal family bereavement follow-up.

Helen Walsh, E Molloy  Irish Medical Journal (2009)
Survey neonatal palliative care practice in Ireland.

Conclusion:
There is an urgent need for appropriate guidelines, specialist paediatric palliative care posts, improved community support and the establishment of continuing education.

Helen Walsh, E Molloy  Irish Medical Journal (2009)
Practical guidance for the management of palliative care on neonatal units (RCPCH 2014)

- Management once a decision has been made to withdraw or withhold life-sustaining treatment
- Management of conflicts about end-of-life decisions
- Support offered to parents and families (bereavement support)
- Support for staff to help them manage an infant receiving palliative care
- Post mortem examinations and organ donation
- Medications and dosages
- Quick reference guide addressing key principles
Nursing assessment of baby’s actual or potential care needs

➢ Diagnosis / Actual medical condition
➢ Clinical presentation of baby
➢ Likely problems to be encountered
➢ Parents ability to provide care/cope
➢ Previous pri-natal, early infancy death
➢ Additional demands to be considered (i.e siblings, work commitments, etc).
Introducing the palliative care model to parents

➢ Requires excellent communication skills
➢ Palliative Care does not mean no care
➢ Explore potential treatments, benefit/burden for the infant and family
➢ Less invasive measures, availability in the home
➢ Memory care
➢ Prepare parents for dying process
Working with families

Educate parents about goals of palliative care
- relief of symptoms (e.g. pain)
- improving quality of life
- providing a peaceful death

There will be a move from an emphasis on prolonging life to comfort and quality.
Common symptoms in Neonates?

- Pain
- Respiratory distress
- Secretions
- Seizures
- Gastro-Oesophageal Reflux
- Constipation
- Feeding issues
Location of care

- Many deaths occur in the hospital setting

- Approximately 98% neonatal deaths occur in hospital setting with most a result of lethal anomaly, prematurity or birth related incidents.

Location of Care

- Anecdotal evidence has shown that the quality of life for families is greatly improved when babies can be cared for at home (ACT, 2009).

Community Team

- GP
- Children’s Outreach Nurse
- PHN
- Specialist Palliative Care Team (HCT)
- Jack & Jill Nurses
- HSE Nurses
- ICS Nurses
- Laura Lynn House (Hospice@Home)
- Chemist
- Paediatrician
Home Management of dying NICU patient

- Evidence suggests bereavement may be easier for parents when child dies at home
- Infants receiving PC may live months > stress
- There is no medical reason that should prevent a family taking their dying baby home.
- Parents should be given information and choice

Craig F, Goldman A Seminars in neonatology 2003 (8), 177-83
Advantages of being cared for at home

- Greatly diminish feelings of fear, isolation & helplessness.
- Allow care of child be shared among family members
- Allows child the chance to participate in family routines
- Offer many more opportunity for communication
- Enables parents to be satisfied that they have done all they possibly could for their child
Neonatal discharge planning

Objectives:
- To discharge neonates home who are nearing their end of life.
- To discharge neonates who require on going care from a maternity hospital cot safely, effectively and timely
- To support the effective and safe discharge of a neonate home with community care support
Co-ordination of discharge planning

Effective discharge planning requires a multidisciplinary team approach that includes the family & makes use of available community resources.

Central to all of this is good communication.
Our Lady’s Children’s Hospital, Crumlin, Dublin 12

Palliative Care

Multi-disciplinary Discharge plan

<table>
<thead>
<tr>
<th>No.</th>
<th>Activity</th>
<th>Yes / No</th>
<th>Comment</th>
<th>Signature &amp; Grade</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td><strong>HOSPITAL STAFF / TEAMS</strong></td>
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<td></td>
<td>Medical team (primary)</td>
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<td>Discharge letter &amp; prescription</td>
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<td>Nursing Team</td>
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<td>Discharge letter</td>
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<td>Follow up call to parents 24hrs post D/C</td>
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<td>Social Worker</td>
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<td>Informed of discharge</td>
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<td>Chaplaincy (if applicable)</td>
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<td>Informed of D/C</td>
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<td></td>
<td>Physiotherapist (if applicable)</td>
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<td></td>
<td>Information given to parents</td>
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<td></td>
<td>Occupational Therapist (if applicable)</td>
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<td></td>
<td>Information given to parents</td>
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<td></td>
<td>Dietician (if applicable)</td>
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<td></td>
<td>Equipment ordered / provided</td>
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<td></td>
<td>Information given to parents</td>
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<td></td>
<td>Pharmacy (OLCHC)</td>
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<td></td>
<td>Written information/education given to parent</td>
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<td>Personalised Medication Chart given</td>
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<td></td>
<td>Other (OLCHC)</td>
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...where children's health comes first
<table>
<thead>
<tr>
<th>2</th>
<th>COMMUNITY SERVICES</th>
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<tbody>
<tr>
<td></td>
<td><strong>GP</strong></td>
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<tr>
<td></td>
<td>Phoned and medical summary faxed</td>
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<td></td>
<td>Hours of duty/visit of child</td>
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<td></td>
<td><strong>PHN</strong></td>
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<td></td>
<td>Phoned &amp; summary of child faxed</td>
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<td></td>
<td><strong>Home care Team (If applicable)</strong></td>
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<td></td>
<td>Phone &amp; medical summary faxed</td>
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<td></td>
<td><strong>Jack &amp; Jill Referral (if applicable)</strong></td>
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<td></td>
<td>Phoned &amp; referral form faxed</td>
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<tr>
<td></td>
<td><strong>Night nurse (Irish Cancer Society)</strong></td>
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<td></td>
<td>Phoned &amp; referral form faxed</td>
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<td></td>
<td><strong>Local Pharmacy</strong></td>
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<td></td>
<td>Obtain contact details/hours of opening</td>
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<td></td>
<td>Order supply of medication</td>
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<td>Fax discharge prescription</td>
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<tr>
<td>No.</td>
<td>Activity</td>
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<td>3</td>
<td><strong>PARENTS</strong></td>
</tr>
<tr>
<td></td>
<td>Give contact details &amp; hours of duty of all healthcare professionals in their child’s care</td>
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<td></td>
<td>Discuss symptom management plan</td>
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<td></td>
<td>With support from the Pharmacy Department, provide limited take home supply of morphine +/- Midazolam if appropriate</td>
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<td>4</td>
<td><strong>TRANSPORT</strong></td>
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<td></td>
<td>Own transport</td>
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<td></td>
<td>Ambulance</td>
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<td></td>
<td>Other</td>
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<td></td>
<td>Garda escort required</td>
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<tr>
<td>5</td>
<td><strong>ADDITIONAL INFORMATION</strong></td>
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Contact numbers for parents

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<tr>
<th>Service</th>
<th>Personnel</th>
<th>Contact details</th>
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<tbody>
<tr>
<td>Our Lady’s Children’s Hospital, Crumlin</td>
<td></td>
<td>01 4096100</td>
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<tr>
<td>Teams</td>
<td></td>
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<tr>
<td>Palliative Care</td>
<td>Dr. Mary Devins, Valerie Jennings, Liz O’Donoghue</td>
<td>01 4096100 Nurses Bleep 8301</td>
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<tr>
<td>Community</td>
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<tr>
<td>Family Doctor</td>
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<td>Public Health Nurse</td>
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<td>Pharmacy</td>
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<tr>
<td>Community Palliative Care</td>
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<td>Homecare Team</td>
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<tr>
<td>Jack &amp; Jill Nurse</td>
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</table>
### Sample Medication Advice Sheet

**Name:** xxxxxxxxx  
**D.O.B:** xxxxxxxx

<table>
<thead>
<tr>
<th>What for</th>
<th>Medicine</th>
<th>Instructions</th>
<th>Mon</th>
<th>Tue</th>
<th>Wed</th>
<th>Thurs</th>
<th>Fri</th>
<th>Sat</th>
<th>Sun</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevention of seizures</td>
<td>Phenytoin Oral Suspension</td>
<td>Give 0.83ml (5mg) twice a day (am pm am am am am am am)</td>
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<tr>
<td>Treatment of seizures</td>
<td>Midazolam (Epistatus®)</td>
<td>Give 0.15ml (1.5mg) into the space between the gum and cheek for seizures that last longer than 5 mins every two hours as needed (am pm am pm am pm am pm am)</td>
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<tr>
<td>Pain or discomfort</td>
<td>Oramorph (Morphine Sulphate)</td>
<td>Give 0.3ml (600microgram) every two hours as needed (am pm am pm am pm am pm am)</td>
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<tr>
<td>Reduction of secretions</td>
<td>Hyoscine patch (Scopoderm®)</td>
<td>A half patch every 72 hours</td>
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Pharmacy Department, Our Lady’s Children’s Hospital, Crumlin (Chart prepared 20/7/06 based on Dr. XXX’s prescription 20/7/06)
Care of the baby in the community

Baby under the care of the

- GP
- Public Health Nurse
- Paediatrician (NICU or local hospital)
- Specialist palliative care Team
- +/- paediatric palliative care team, community paediatrician, community physiotherapist, OT etc
Care of the baby in the community

➢ Requires on-going assessment and evaluation of care needs
➢ Prior to discharge identification of roles and responsibility of various members of team
➢ Including hours available to family (delivered by whom)
➢ Equipment
Sustainable support

End of life is difficult to predict in all babies with complex needs: teams need to be available to sustain many weeks of care, and have contingencies for support if the end of life phase is prolonged.

(ACT, 2009)
The role of Specialist Palliative Care in Symptom management

- To anticipate symptoms and discuss their management with parents
- To organize availability of drug, dose, frequency, and route of administration
- Oral route easiest (option rectal, NG, s/c)
- Effective symptom control essential for future bereavement
When the child dies

- Care of the infant
- Whom to contact
- Post mortem/biopsy
- Involving siblings
- How to arrange a funeral
- Registering their infants birth and death
- Bereavement support
Additional Services

In recent times much work has been accomplished to promote the needs for services for children & young people with life limiting or life threatening conditions

- Palliative Care Service OLCHC
- Children's outreach nurse’s
- Irish Hospice Foundation funding educational programmes
- IHF/ Irish Cancer Society
Additional Services

➢ The Children’s Sunshine Home, Laura Lynn House
➢ Jack and Jill Foundation
➢ Community Palliative Care teams
➢ Early intervention services
➢ ISANDS
➢ All Ireland Institute of Hospice & Palliative Care
Conclusion

- Palliative care does not mean “no care”

- Palliative care for children aims to accompany the whole family from the child's diagnosis right through to the end of life care & bereavement.

- For the child whose life is limited, life is about living, and about a peaceful death.

- For the people left behind, life is about living too, & support necessary to give strength at the time of diagnosis, throughout the illness & following the child's death (Pfund, 2006).
As professionals the difference that we can make is not in the outcome but in the process of how the child and family live, often for many years, how the child dies and how the family continue to live. (Pfund, 2006).
Caring for a dying child is one of the most difficult responsibilities a health care professional will ever encounter because of its intensive management of the physical, psychosocial, and spiritual issues facing both the child & the family.
References & websites

- [http://www.act.org.uk](http://www.act.org.uk) (last accessed 04/05/14).
- A neonatal Pathway for Babies with Palliative Care Needs (2009), ACT.
- A Mancini, S Uthaya, C Beardsley, D Wood and N Modi (2014) Practical guidance for the management of palliative care on neonatal units, RCPCH
Some Helpful Websites:

- http://www.act.org.uk/ - the ACT main website
- http://www.togetherforshortlives.org.uk/
- www.lauralynnhospice.com
- www.jackandjill.ie
- www.cancer.ie/
- www.childhoodbereavement.ie/
- http://www.tyhafan.org/ - Ty Hafan Hospice, Wales
- http://www.iapc.ie/ - Irish Association of Palliative Care
- http://www.hospice-foundation.ie - Irish Hospice Foundation
- www.anamcara.ie - supporting parents after bereavement
- www.feileacain.ie - Stillbirth/neonatal death support group
- www.isands.ie - Stillbirth and neonatal death society
- www.isida.ie - Irish Sudden Infant death Association
- www.rainbowsireland.com - bereavement support for children