


Principles of Children's Palliative Care / End of Life Care Planning & Collaborative Practice

16th January 2020




CHILDREN'S PALLIATIVE CARE
Professional Education Programmes
2019 – 2020

Housekeeping



What to expect today?

AIM: To explore the principles and practices that underpin children's palliative care and the process of care planning in the context of a changing and deteriorating disease trajectory

INTRODUCTIONS

Who's in the room?

Palliative Care Competence Framework

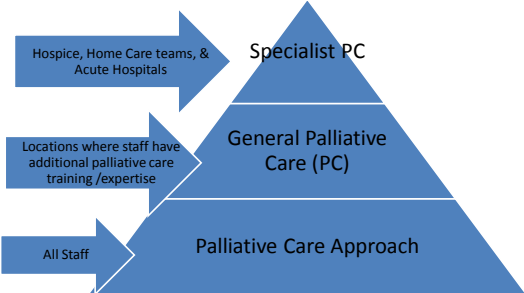


MEDICINE | NURSING
MIDWIFERY | HEALTH CARE ASSISTANTS | SOCIAL WORK
SPEECH AND LANGUAGE THERAPY DIETETICS / CLINICAL NUTRITION | OCCUPATIONAL THERAPY | PHYSIOTHERAPY
PHARMACY | PSYCHOLOGY
CHAPLAINCY/PASTORAL CARE

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Levels of Palliative Care



Hospice, Home Care teams, & Acute Hospitals → Specialist PC

Locations where staff have additional palliative care training/expertise → General Palliative Care (PC)

All Staff → Palliative Care Approach

(IHF Website)

Palliative Care Competence Framework

- **Domain of Competence 1 - Principles of palliative care**
- Domain of Competence 2 - Communication
- Domain of Competence 3 - Optimising comfort and quality of life
- **Domain of Competence 4 - Care planning and collaborative practice**
- Domain of Competence 5 - Loss, grief and bereavement
- Domain of Competence 6 - Professional and ethical practice in the context of palliative care

Learning Outcomes

On completion of the Professional Education Programme 'Principles of CPC /Care Planning and Collaborative Practice', the learner will be able to:

- Take cognisance of national and international policies and directives in children's palliative care
- Demonstrate an understanding of the principles and philosophy of palliative care as applied to children and young people with life-limiting conditions and their families Understand the essential role of the family in the child's or young person's care
- Take cognisance of the potential role of specialist palliative care services in supporting staff in other agencies to provide a palliative care approach to persons with a life-limiting condition
- Work in collaboration with the team in providing care and support to the child or young person and family from the point of diagnosis/suspicion of diagnosis throughout the illness trajectory
- Be able to anticipate, recognise and respond effectively to signs and symptoms of imminent death (from Domain3 Opt Comfort & QoL).

Principles of Children's Palliative Care / End of Life Care Planning & Collaborative Practice

Principles of CPC in a Childrens Hospice

Fiona Woods
Head of Clinical Education
16th January 2020

Language in CPC

"Similar to scalpels for surgeons, words are palliative care clinician's (professional's) greatest tools"

Dr Eric Cassell



Define CPC (1)

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.

- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.



(WHO; 1998a)

Definition of CPC (2)

Palliative care for children and young people with life-limiting or life-threatening conditions is an active and total approach to care, from the point of diagnosis or recognition throughout the child's life and death. It embraces physical, emotional, social, and spiritual elements, and focuses on enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and **care through death and bereavement**.



ACT/RCPC, UK 2003

Palliative Care

Palliare, to cloak (*Latin*)

Balfour Mount (1939 -)

[pallio, palliare, palliavi, palliatus](#)

verb

conjugation: 1st conjugation

Definitions:

cloak

disguise

palliate

Age: Medieval (11th-15th centuries)

Area: All or none

Geography: All or none

Frequency: Having only single citation in Oxford Latin Dictionary or Lewis + Short

Source: Latham, "Revised Medieval Word List", 1980

Latin Dictionary



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ACT/RCPCH, UK 2003



The journey so far.....

- Dame Cicely Saunders (1918-2005)
- St Christopher's London (Adult Hospice, 1967)
- Dr Balfour Mount (1939 -)
- Helen House UK - 1982
- Palliative Care for children (OLCHC) - early 1990's - CNS
- Palliative Care Needs Assessment - 1995
- First Consultant in CPC (Ireland) - 2011 - Dr Mary Devins
- LauraLynn Children's Hospice – 2011
- Dr Fiona McElligott - 2019



Domains of Palliative Care



Other terminology.....

- Life-Limiting
- Life-Shortening
- Life-Threatening
- End-of-life care



Video

- <https://www.youtube.com/watch?v=6qwndXMfms0>



Life-Limiting Conditions

- Any illness in a child where there is no reasonable hope of cure and from which the child or young adult will die. (ACT)

NOTE: Life-shortening (LSC) is used by some and is interchangeable with Life-Limiting Conditions.

(Goldman et al. 2012)



Life-Threatening Conditions

- Life-threatening conditions (LTC) are those for which curative treatment may be feasible but can fail for example in cancer treatments.



End-of-Life Care

- 'End-of-Life care... is the care provided for patients who are actively dying, in the minutes, hours or perhaps days that precede death'.
- 'End-of-Life care may or may not be palliative care, and much of paediatric palliative care is provided prior to the end-of-life period'



Who needs Palliative Care?



Categories of LLC

- Four broad categories (ACT, 2003)
- Not all will require active palliative care at all times
- Each group has a different illness/ palliative care trajectory



Categories of life-limiting illness

- Group 1: Conditions where treatment may be feasible but can fail**
 - (cancer, organ failure)
- Group 2: Premature death inevitable but may have long periods of treatment**
 - (cystic fibrosis, muscular dystrophy, cardiac anomalies)
- Group 3: Progressive conditions with no curative options, treatment is palliative and may extend over many years**
 - (metabolic disorders, neurodegenerative disorders)
- Group 4: Irreversible but non-progressive conditions with likelihood of premature death**
 - (severe cerebral palsy, congenital malformations)

(ACT & RCPCH 2008)

Some Irish Statistics....

1.2million¹ - Children in Ireland (0-17)

3,840² - Living with a Life-Limiting Condition

320-350³ – Deaths/year from a Life-Limiting Condition

1 (CSO)

2 (Ling et al. 2015)

3 (Department of Health & Children, 2009)

Group exercise

- What do children want at end-of-life?
- What do parents want at end-of-life?
- What do professionals want for the child and family at end of life?



What children & their families want from palliative care services

- Flexible, responsive service
- Individual needs assessment
- Information – appropriate and timely
- Access to medical, nursing & social supports
- Good symptom management
- Access to respite
- End-of-life care choice, home, hospice or hospital



References

Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT), The Royal College of Paediatrics and Child Health (RCPCH). (2003) A Guide to the Development of Children's Palliative Care Services. (2nd Ed.), Bristol: ACT and London: RCPCH, UK.

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