Implementation of the

Clinical governance and operational arrangements for supporting a model of care for children with life limiting conditions towards the end of life in the community in Ireland

Report – An Update

Ní neart go cur le chéile

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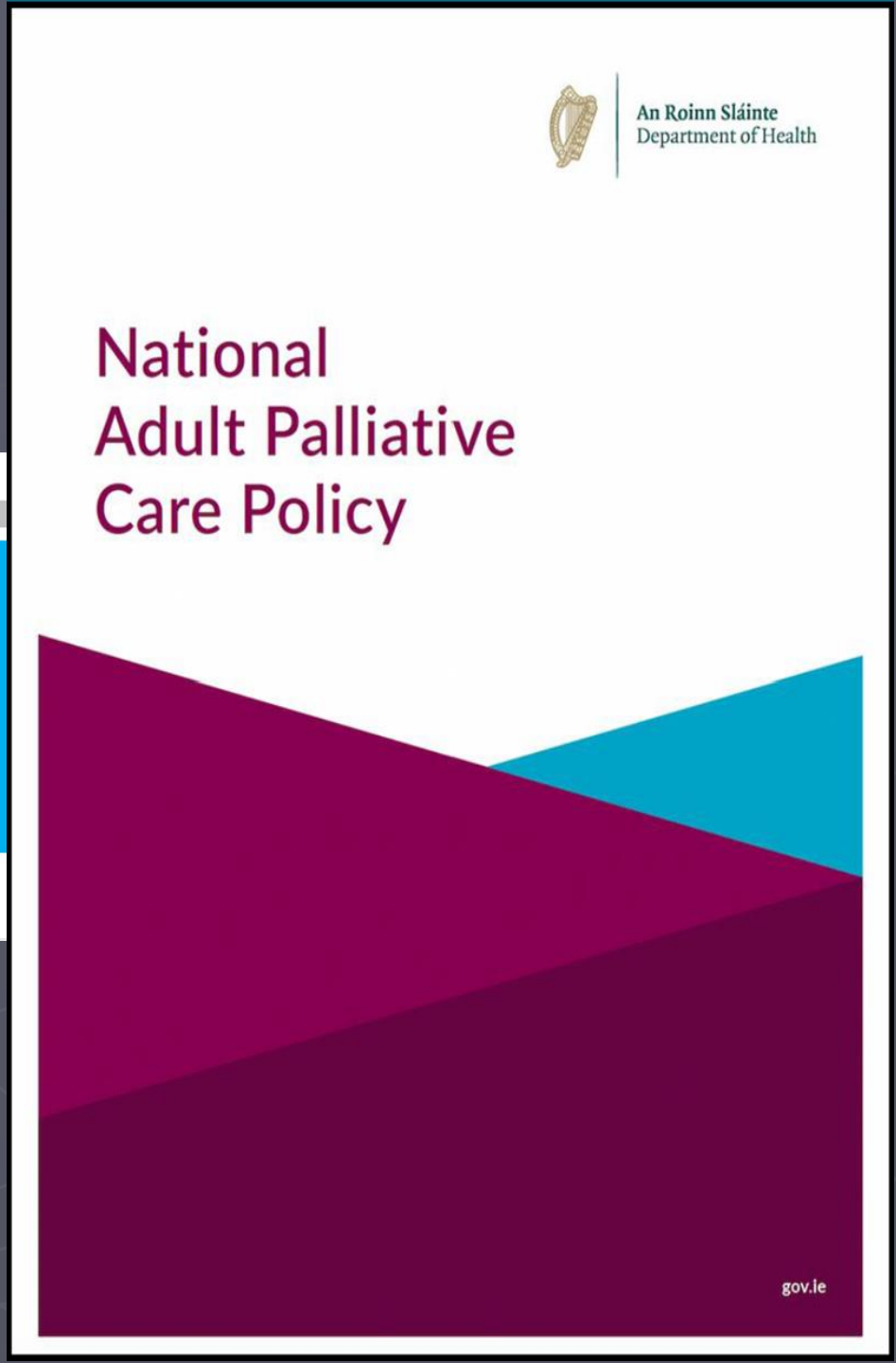
Context

ADULT PALLIATIVE CARE SERVICES
MODEL OF CARE FOR IRELAND
The National Clinical Programme for Palliative Care
National Clinical
& Integrated Care Programmes
Person-centred, co-ordinated care
PALLIATIVE
ROYAL
COLLEGE OF
PHYSICIANS


An Roinn Sláinte
Department of Health
National
Adult Palliative
Care Policy
gov.ie

Recommendation 1. Every person with a life-limiting or life-threatening condition will receive care that respects their dignity and autonomy and meets their physical, psychosocial, and spiritual palliative care needs.

1.6 Fully implement and embed in practice the recommendations of the report on 'Clinical governance and operational arrangements for supporting a model of care for children with life-limiting conditions towards the end of life in the community in Ireland.'

1.7 Design and implement models of transition from children's to adult palliative care services.

1.8 Develop prescribing guidance to support services providing palliative care to children.

16.2 Review the curricula of postgraduate degrees or Higher Specialist Training in palliative care to incorporate content relating to the end-of-life care of children and young people in the home setting by specialist palliative care teams.

Prior to 2020

- Relative rarity of end of life care in childhood
  - Staff in all settings unfamiliar with the management of a child or young adult's palliative care needs
- No standardisation of clinical governance or operational practice across the country
- The workforce was underdeveloped, e.g., most regions had one Clinical Nurse Coordinator, ergo no cross-cover
- The CHI specialist team had two Consultants who provided out of hours advice on grace and favour basis.

Fourteen Recommendations

Four Themes:

1. Governance and Professional Practice
2. Strategy
3. Education & Training
4. Workforce

- Implementation Group established by the CCO
  - Chaired by Dr Ellen Crushell

Governance and Strategy

- Core team & roles described. Shared care model implemented nationally
- Development of clinical guideline – *Integrated Discharge and Guidance for Children and Young People with Life-Limiting Illness Transitioning to a Community Setting for End-Of-Life*
- Structured out of hours summary developed to communicate essential information and enable rapid, effective out of hour's decision-making
- The Association of Paediatric Palliative Medicine formulary adopted
- CNC Governance Framework being updated to reflect the *Bee Wee* report and development in the role of CNC

Workforce

- Expansion of CHI Paediatric Palliative Care Team since 2022
  - Two WTE additional Consultants in Paediatric Palliative Medicine
  - Two WTE additional CNS posts
  - One WTE additional SpR in Paediatrics
  - One WTE admin staff
- Four Consultant Paediatricans s.i. in Paediatric Palliative Medicine
  - Two permanently recruited
  - One locum in place, one recurrently advertised
- Separately, in keeping with National Policy, the first Consultant in Adolescent and Young Adult Palliative Medicine has recently taken up her role between CHI and St James's Hospital, Dublin.

Workforce – 2

Clinical Nurse Coordinators

- Increase from 12 to 19.5 WTE
- Means at least two CNCs in each region for cross-cover
- Capacity to provide education, conduct after death reflections

Specialist Palliative Care Services – since 2022

- Fourteen new Consultant posts in Palliative Medicine
- Almost 40 additional CNS for community SPC Services

Education and Training

- Children's palliative care requirements incorporated into the RCPI HST curriculums for Palliative Medicine and for Paediatrics
- Education and training resources for children's palliative care have been collated and published on both Clinical Programme microsites

- Centre of Children's Nurse Education at CHI
  a. Level A: 1-day introduction for healthcare professionals working caring for children with life-limiting conditions requiring palliative care
  b. Level B: an advanced course specialising in particular education for healthcare professionals who are frequently confronted by palliative care situations
- UCG and UCD: Postgrad Dip/MSc in Children's Palliative Care/Complex Care (Level 8) Grant funding provided by IHF/HSE for Clinical Nurse Specialists from SPC teams interested in this course.

Education and Training – 2

- End of life care for children and young people – 2025
  - Curriculum design group led by Mairéad Loftus, Mayo CNME
  - Mixed method course with six hours online on HSELanD and one day in person. CNCs as lead facilitators
  - Five courses in Q3/4 2025 to 120 people from three Health Regions
  - Attendees expressed challenges in clinical practice
    - Medication management and calculations
    - Active dying in children
    - Family dynamics
    - Communication
  - 95% said the programme met their learning needs & 98% would recommend the programme to a colleague

Not all heroines wear capes

- Áine Ní Laoire
  - Mairead Bluett
    - Suzanne Ryan
      - Stephanie O'Keeffe
        - Mairéad Loftus
          - Lucy Balding
            - Ellen Crushell
              - Mary Devins
                - Fiona McElligott
- Maurice Dillon