The Role of the Clinical Nurse Coordinator for Children with Life Limiting Conditions (CNC)

Sláinte Leanaí Éireann ag Cromghlinn

Children's Health Ireland at Crumlin

By Michelle Cunniffe and Louisa Hall (Crumlin CNCs)

What do CNCs do?

- Support the co-ordination of care for children with LLC alongside healthcare professionals in acute and community setting ensuring continued care
- Facilitate education and training for HCPs
 Δct as an informed resource for families &
- Act as an informed resource for families & other health care professionals
- Link with GP, PHN, community services and CDNTs, palliative care teams, schools, allied HCPs and voluntary organisations e.g. Jack and Jill, Lauralynn, etc.
- Support the collection of data related to children with LLC

Partnership in Care

Professionals:

- Primary care team
- Specialist palliative care
- Paediatric services
- CDNTs
- Schools
- Voluntary org.
- Hospice/respite
- Nursing agencies



Familes:

- Parents/carers
- Child
- Siblings

Who can be referred and how?

A child who meets the CNC referral criteria can be referred by any health care professional. The person making the referral must have discussed referral with:

- Parents & Child
- Consultant

Please note: Children are linked depending on geographical location, not their hospital.



Identification of CNC Referral Pathway

Informal contact with CNC

If approriate:

- 1.A form will be completed
- 2. Consultant approval
- 3. Referral accepted & CNC involvement commences

If not appropriate:

1. May be reviewed at a later date

Referral Criteria

A referral may be made to the clinical nurse co-ordinator for identified children (0-18 yrs) with a diagnosis of an ACT category life limiting condition and who are under the care of a paediatrician, particularly those with:

- Newly diagnosed life limiting condition with anticipated poor outcomes
- Deteriorating clinical condition
- Discussions of resuscitation status and advance care planning are being considered

Location and Catchment of Each Clinical Nurse Coordinator

Carlow/Kilkenny, South Tipperary, Waterford & Wexford - Laura Flaherty & Liane Murphy Cork - Tyrone Horne Donegal - Helen McDaid Galway - Nancy McCormack

Galway - Nancy McCormack Kerry - Karen Lovett

Laois, Offaly, Westmeath & Longford - Sinead Brennan & Fiona Corr

Limerick, Clare & North Tipperary
- Charlotte Evans

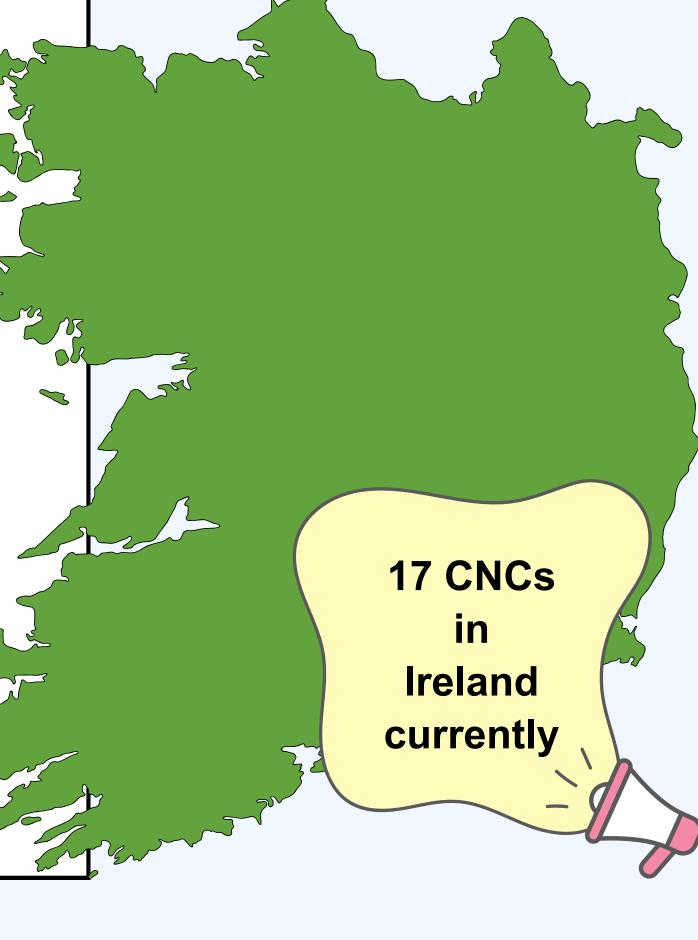
Louth, Meath, Cavan & Monaghan
- Irene O'Brien & Louise Hughes
Mayo & Roscommon - Tina Kenny
North Dublin - Alison Cashell &

Jean Fitzsimons

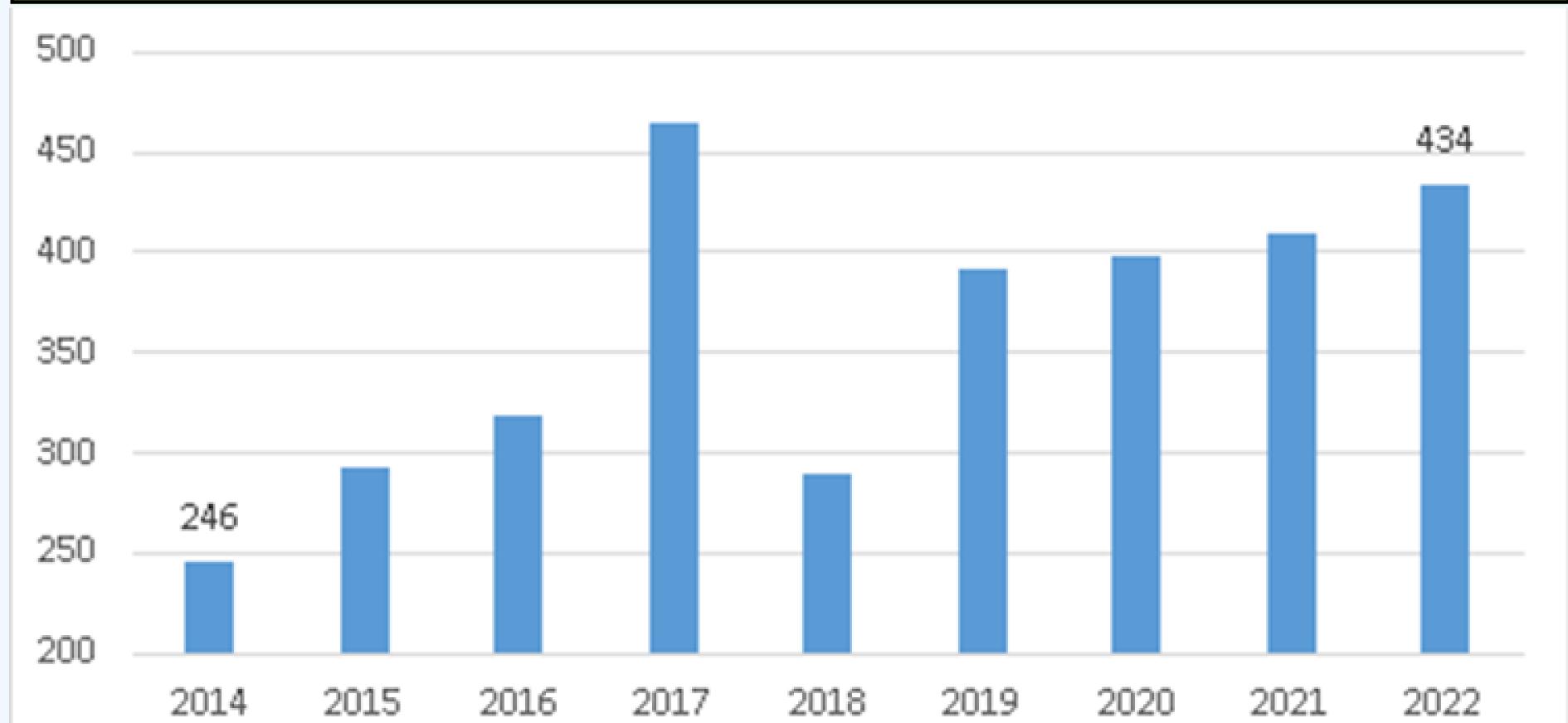
Sligo & Leitrim - Caroline McGarry

South Dublin, Kildare and

Wicklow - Michelle Cunniffe, Louisa



Number of individual children who received services from CNCs



References

- A Palliative Care Needs Assessment for Children (2005)
- Palliative Care Needs Assessment for Children (2003)
 Palliative Care for Children with Life Limiting Conditions in Ireland A National Policy (2009)
- Education and Governance Framework for Outreach Nurses for Children with Life Limiting Conditions (2012)
 Respite Services for Children with Life-Limiting Conditions and their Families in Ireland A National Needs Assessment (2013)
- Evaluation of the Children's Palliative Care Programme (CPCP) (2016)
- 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 (2020) (Bee Wee Report)

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Hall and Regina Dolan

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.



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