

19 November 2024

Palliative Care for Children and Young People with Life-Limiting and Life-Threatening Conditions

- 1. Does your Trust provide children's palliative care services that involve infants, children, and young people with life-limiting conditions, along with their parents or carers, in the development of advance care plans? (Yes/No). If yes, please specify the extent to which this service is dependent on good will.**

Community Children's Nurses (CCN) contribute to the development of advance care plans for children with palliative care needs, in conjunction with the child's parents / carers and their Community Paediatrician or Lead Consultant. This care is undertaken as part of the CCN role. There are members of the Community Children's Nursing Team who have a background in palliative care and palliative care training, which is beneficial to their CCN practice.

- 2. Does your Trust provide children's palliative care services that ensure infants, children and young people with a life-limiting condition have a [named medical specialist](#) who leads and co-ordinates their care? (Yes/No). If yes, please specify the extent to which this service is dependent on good will.**

CCN would rely on the support of our Community Paediatrician colleagues or the child's Lead Paediatrician who would not generally have a community remit. In our most recent case, the extensive input from a Community Paediatrician was invaluable and the majority of her input was provided on good will.

- 3. Does your Trust provide children's palliative care services that ensure infants, children and young people with a life-limiting condition, their parents or carers and their siblings are given information about emotional and psychological support, including how to access it? (Yes/No). If yes, please specify the extent to which this service is dependent on good will.**

Referral to psychology would be progressed by a Consultant Paediatrician.

Referral to Children's Hospice can be made by CCN for emotional support, sibling support and pre and post bereavement support.

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4. **Does your Trust provide children's palliative care services that ensure infants, children and young people with a life-limiting condition are cared for by a multi-disciplinary team that includes members of the [specialist paediatric palliative care team](#)? (Yes/No). If yes, please specify the extent to which this service is dependent on good will.**

There is no funded Specialist Palliative Care Nurse within Belfast Health and Social Care CCN Team.

5. **Does your Trust provide children's palliative care services that ensure siblings and parents or carers of infants, children and young people approaching the end of life are offered support for grief and loss when their child is nearing the end of their life and after their death? (Yes/No). If yes, please specify the extent to which this service is dependent on good will.**

The Belfast Trust offer grief and loss support with a Clinical Nurse Specialist for Palliative and Life Limited Services to siblings, parents or carers of infants, children and young people approaching the end of life. This service is available in the Children's Hospital and Royal Jubilee Maternity Hospital.

In the circumstances where an infant, child or young person dies suddenly or unexpectedly in the Belfast Trust, the family are referred for Bereavement Counselling through the NI Children's Hospice Horizon Family Support Team. Currently, two years of Bereavement Counselling is offered. Families of children previously known to the Northern Ireland's Children's Hospice, are also able to receive bereavement support from the Horizon Family Support Team.

In the Belfast Trust's Paediatric Intensive Care Unit, parents and the infants siblings can be supported in grief and loss conversations by the unit's Clinical Psychologist. A Family Liaison Nurse supports parents and siblings with communication, memory making activities and resources and offers ongoing support to the family at the end of the child's life. The family receive a sympathy card six weeks after the child has died and this is followed up with a bereavement support call from the Family Liaison Nurse.

The Childbirth and Loss Midwives offer support to parents and siblings at the time of the diagnosis of the loss of a baby and then at the time of delivery. In some cases, support for grief and loss is offered when a Mother has experienced early pregnancy loss. The Fetal Medicine Unit offer support for grief and loss to patients and their families with the Childbirth and Loss Midwives.

6. **Does your Trust provide children's palliative care services that ensure infants, children and young people approaching the end of life and being cared for at home have [24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care](#)? (Yes/No). If yes, please specify the extent to which this service is dependent on good will.**

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Note: We would like to capture those areas where registered nurses can provide both core and specialist children's palliative care to children with a range of medical complexity. We acknowledge that, where this is provided, it is done so by nurses with different roles, employed by the Health and Social Care Trusts and/or the voluntary sector. This will include specialist children's palliative care nurses providing care directly or providing advice to other nurses providing direct care.

The core working hours for the Community Children's Nursing Service are 9am to 5pm, Monday to Friday. There is not a dedicated 24-hour commissioned CCN Service. In the event of a child / children requiring 24-hour End of Life care in their own home, the service is dependent on additional hours provided on good will by team members. This provision is provided on an ad hoc basis, in conjunction with multi-disciplinary support from staff within hospital specialities. However, the expectation and a large bulk of the provision is undertaken by the CCN Service.

7. Does your Trust provide children's palliative care services that ensure infants, children and young people with a life-limiting condition and their families have access to regular short breaks for respite? (Yes/No). If yes, please specify the extent to which this service is dependent on good will.

The CCN Team provide overnight respite care for those children assessed using the Northern Ireland Paediatric Nursing Assessment (NIPNA) Tool as having most complex needs. This care is provided by Band 3 Senior Healthcare Assistants, with child specific training, to afford parents / carers the opportunity for undisturbed sleep.

Nurses from the CCN Team provide overnight support and on-call support for End of Life care. This provision is additional to core funded nursing care and based on good will, provided as additional hours.

The Trust has a Respite Care Unit, Forest Lodge, which provides nurse-led respite support for children with complex needs and disabilities.

The Northern Ireland Children's Hospice accept respite referrals for children with palliative care needs.

Children with palliative care needs can also access Direct Payment supports, which their parents can use to fund respite care.

8. How many whole-time equivalent community children's nurses does your Trust employ?

Funded Staffing Level (FSL) of registered nurses employed by Belfast Trust:

1 WTE Band 8a Clinical Co-Ordinator / Assistant Service Manager
1 WTE Band 7 CCN Team Leader

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1 WTE Band 7 Community Paediatric Epilepsy Nurse Specialist

1 WTE Band 7 Clinical Educator

1 WTE Band 7 Paediatric Continence Nurse Advisor

10.98 WTE Band 6 CCN Sisters

10.45 WTE Band 5 CCN Staff Nurses

14.4 WTE Senior Healthcare Assistants

Within Belfast Trust, the CCN Team provide direct nursing support into 5 Special Schools across the Trust, Monday to Friday, 8.30am to 3.30pm.