

FOI 2738

20th November 2024

FREEDOM OF INFORMATION ACT 2000 – INFORMATION REQUEST

- 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.**

Response:

Within the Southern Trust we provide palliative care services to children 0-18 years old with life limiting conditions with support externally from the Northern Ireland Children's Hospice. This includes the development of advance care plans, this is done in partnership with the multi-disciplinary team and the child or young person's parent or carer. This is part of the role of the Consultant Paediatricians and Community Childrens Nurses with support from the Paediatric Consultant with specialist interest in Palliative Care.

Palliative Care should be part of all health and social care professionals' roles but there is a varying degree of expertise and training within the teams. There is no specialist team within the Trust specifically assigned to this and it is not consistently performed across the Trust.

- 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 coordinates their care? (Yes/No). If yes, please specify the extent to which this service is dependent on good will.**

Response:

All children and young people with a life limiting condition have a named Paediatrician. Dependant on condition the named medical specialist may be based in a tertiary centre rather than SHSCT, part of the Paediatrician's role would be to lead and coordinate the child or young person's care.

- 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? (No). If yes, please specify the extent to which this service is dependent on good will.**

Response:

The Paediatric Psychology Service is not commissioned to provide psychology support to children and families specifically in relation to palliative or end of life care needs. The Consultant Clinical Psychologist offers consultation and support for staff working with children and young people with palliative care needs.

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 multidisciplinary team that includes members of the [specialist paediatric palliative care team](#)? (No). If yes, please specify the extent to which this service is dependent on good will.**

Response:

Within the SHSCT there is no specific Specialist Paediatric Palliative Care Team, we have a Paediatrician with a specialist interest in Palliative Care and close links with the Community Children's Nursing Service who would provide palliative care. Out of hours support to children and families is often provided through the good will of Trust staff working beyond contracted hours and this is not a specifically funded service – meaning the team involved have many other duties.

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.**

Response:

Support before and after a child's death is provided by the named CCN and the wider team alongside the hospice team. In some cases, support is also provided by Paediatric Macmillan nurses. As part of the CCN role, there are bereavement visits arranged with the family, and contact maintained with families for up to two years following the child or young person's death. CCN's will provide and direct to appropriate resources for the families.

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.**

- a. **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.**

Response:

Within SHSCT there is no Specialist Palliative Care Nurse, however there is an on call rota put in place by the Community Children's Nurses for children and young people approaching end of life. The main purpose of the on-call rota is symptom management, as per the advanced care plan. This is agreed on an individual basis and in partnership with the family and local team. The CCN service is not funded for this 24-hour support, but staff work together to provide an on-call rota for end-of-life support. This is organised in each locality but at times other localities have to assist to provide the support to children and young people. This on call rota is operationalised on good will, this may have a direct impact on funded core CCN capacity.

There is no access to on call 24/7 medical cover (palliative care consultant) - there may be cover during 9-5 hours from the regional Paediatric Palliative Care consultant, but they are no longer in post. There is some cover from local paediatricians during the day which is additional to their funded role. Children with oncological disease will have telephone cover from the central regional children's hospital.

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 regular short breaks for respite? (Yes/No). If yes, please specify the extent to which this service is dependent on good will.

Response:

Children with life limiting conditions have access to short breaks for respite provided by the CCN Service, Children with Disability team and Hospice at Home. All consist of respite within the home setting and based on assessed need of the child and family. Families with children or young people with life limited conditions, have the opportunity to avail of short breaks within the Northern Ireland Children's Hospice, this consists of in-house overnight allocations in Horizon House for the child or young person, family can also be accommodated.

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

Response:

Below is a breakdown of Community Children's Nurse's WTE across 3 localities in SHSCT.

	WTE
Band 7 – Team Leader	3.0
Band 6 – CCN's	8.71
Band 5 – Staff Nurse's	7.68