

7 January 2025

Our Ref: FOI 437

Dear

**Freedom of Information Act 2000
Information in Relation to Palliative Care for Children and Young People.**

I am writing to confirm that the South Eastern Health & Social Care Trust (the Trust) has now completed its search for information relating to the above, which you requested on 18 December 2024.

A response to the questions you have raised has been provided by the Children's Services Directorate and is attached in Appendix A.

If you are unhappy as to how this request has been handled, you have the right to seek a review within the Trust in the first instance. You should write to the Information Governance Department, Lough House, Ards Community Hospital (informationgovernance@setrust.hscni.net) within two months of the date of this response and your complaint will be considered and a response provided, within 20 working days of receipt.

If, after receiving a response, you remain unhappy, you can refer your complaint to the Information Commissioner at The Information Commissioner's Office –Northern Ireland, 3rd Floor, 14 Cromac Place, Belfast, BT7 2JB. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's internal review procedure to try to resolve the matter with the Trust in the first instance.

If you have any queries about this letter, please do not hesitate to contact me. Please remember to quote the reference number above in any future communications.

Yours sincerely

Caroline Degans
Information Governance Officer

Q1. 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.

A1. In acute paediatrics, there are 4 hours of medical consultant time allocated per week to palliative care. For a child in their final illness, medical staff often provide significantly more support in their own time.

In Community, there is one Consultant Paediatrician who has a dedicated Personal Activity per week for palliative care. In addition, the Community Children's Nursing (CCN) team provide palliative care, as required to infants, children and young people on their caseload. As these children progress to the end of life stage, the CCN's would provide significantly more support outside of normal working hours; for example; on call service for the family, administration of end of life medication, contact with out of hours medical staff for symptom management and support for the family to have some rest within the home. There are a number of Community Paediatricians who provide care and support to children with palliative care needs.

Q2. 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.

A2. All children with life limiting conditions have a named Consultant. Often that person will give support over and above their job planned time during a final illness.

Q3. 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.

A3. Yes, those within maternity services can access psychology and bereavement support within maternity.

The Community Children's Nursing service provides parents or carers and their siblings with information about emotional and psychological support. This includes referral to clinical psychology within the Trust. Both acute and community paediatric services refer families to the Northern Ireland Children's Hospice for sibling support and signposting to charities for families to access support.

Q4. 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? (Yes/No). If yes, please specify the extent to which this service is dependent on good will.

A4. Yes. Children with complex health are known to many professionals and services within the Trust throughout their life. While we do not have a dedicated Specialist Paediatric Palliative Care Team, we do have a Complex Health Team. The service is needs led. As the complexity of need increases, the support a child and family requires increases. Staff often need to spend longer periods of time with the family which can extend outside of normal working hours. At end of life, where round the clock care is required; medical, nursing and AHP support is often provided on a good will basis.

Q5. 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.

A5. Families are usually directed to Northern Ireland Children's Hospice for bereavement support. Medical staff usually offer a one off bereavement appointment soon after death at which they signpost to other services. The Community Children's Nursing team would provide supportive visits after the child's death. These visits are also an integral part of the service.

Q6. 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.

- A6. Medical support is not routinely offered 24/7 but at Consultant discretion; some have made themselves available to families 24/7.

The Community Children's nursing service provide 24 hour on call service and nursing care to infants, children and young people approaching end of life, within their own homes; where possible. This service is based on good will of staff, and sometimes co-worked with other services such as Northern Ireland Children Hospice and MacMillan nurses.

- Q7. 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.**

- A7. Yes, referral is made for additional support through Northern Ireland Children's Hospice service

- Q8. How many whole-time equivalent community children's nurses does your Trust employ?**

- A8. There are 15.6 whole time equivalent Community Children's Nurses employed within the Trust.