

Our Ref: 67042

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NHS Southport & Formby CCG 5 Curzon Road Southport PR8 6PL

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Re: Freedom of Information Request

Please find below the response to your recent Freedom of Information request regarding end of life and palliative care for children and young people within NHS Southport and Formby CCG.

Request/Response:

I am writing to you under the Freedom of Information Act 2000 to request the following information from Southport and Formby CCG: services, funding and spend on end of life and palliative care for children and young people.

Please provide the information in the form attached

Please see attached appendix 1.



Appendix 1

 Do you commission palliative care for children and young people with life-limiting and lifethreatening conditions between the ages of 0 and 25? (Yes/No) If yes, how and with whom?

Yes: Alder Hey Children's Hospital and Claire House Hospice.

2. Do you have a published strategy or care pathway for children and young people (between the ages of 0 and 25) with life-limiting and life-threatening conditions? (Yes/No) If yes, please provide a link or an attachment.

No

3. Does your local sustainability and transformation plan include palliative care for children with life-limiting and life-threatening conditions? (Yes/No)

No

4. How many children and young people with life-limiting and life-threatening conditions are there in your area? If unsure, where do you access this information?

NHS Southport and Formby CCG does not hold this information.

5. Do you jointly commission palliative care for children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25 with your local authorities in a way which is consistent with the Children and Families Act 2014? (Yes/No) If yes, please tell us how and with whom.

Individual packages of care are commissioned locally by the CCG (and jointly in some cases) through Continuing Care for under 18s. Locally the CCG joint commissions overnight respite for disabled children with the local authority (which provides the service). Some children and young people with palliative care needs with life-limiting and life-threatening conditions will access this support.

Transitional arrangements are in place between children's and adult commissioners at the CCG liaising with children's complex commissioning support and adult continuing care practitioners to promote transition from child to adulthood.

6. Do you commission palliative care which enables a child or young person to receive end of life care at home if they wish to do so? (Yes/No) If yes, please tell us how and with whom.

Yes. Claire House Hospice

7. Do you commission a rapid transfer process for children and young people with life-limiting conditions to allow urgent transfer to the preferred place (for example from the intensive care unit to their home or to a children's hospice)? (Yes/No)



If yes, please tell us how and with whom.

No

8. Do you take steps to make sure that children and young people with life-limiting and life-threatening conditions can access palliative care services which are appropriate to their age and developmental stage? (Yes/No)

If yes, what steps do you take? How many children and young people fall into which category and

If yes, what steps do you take? How many children and young people fall into which category and what do they receive?

NHS Southport and Formby CCG does not hold this information. You may wish to forward your query to —

Alder Hey Children's NHS Foundation Trust info.gov@alderhey.nhs.uk

9. Do you commission transition services, to make sure that young people with life-limiting and life-threatening conditions experience smooth transitions from children's to adults' palliative care services? (Yes/No)

Yes.

10. If so, how and with whom?

Providers are required to work collaboratively to transition young people to adult services.

11. Do you commission any of the following services listed in the table for children with life-limiting or life-threatening conditions? If yes, please answer the questions below for each service.

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Alder Hey Children's NHS Foundation Trust info.gov@alderhey.nhs.uk



Services	Which outcomes do you	How much you spent on	Whether you commission
SCI VICCS	ask service providers to	them in 2019/20	them to provide care out
	achieve?		of hours and at weekends
	acineve:		for children with life-
			limiting or life-threatening conditions? We define 'out
			of hours and at weekends'
			as 6:30pm – 8am on
			weekdays and all day on
			Saturdays, Sundays and
			Bank Holidays.
A lovel 4 pandiatric			
A level 4 paediatric			
palliative care consultant			
Consistent with the NICE			
clinical guideline 'End of			
Life Care for Infants,			
Children and Young			
people', a multidisciplinary			
team			
Acute children's palliative			
care nurses which provide			
children's palliative care			
Community children's			
nurses which provide			
children's palliative care			
Voluntary sector children's			
palliative care services (including children's			
hospice services)			
,			
Community paediatricians			
which provide children's			
palliative care			
Emotional and			
psychological support for			
children and their families			
Bereavement care - to			
families before a child or			
young person aged 0-25			
has died			
Bereavement care - to			
families after a child or			
young person aged 0 – 25			
has died			
Equipment - including			
services which provide			
wheelchairs and services			
to maintain and repair			
equipment			
equipment			



12. If you commission voluntary sector services, who do you commission? Please provide us with names.

Claire House Hospice

13. Do you commission the following services to children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25? (Yes/No)

Yes

If so, who do you commission to do this? Please specify who for each service.

- Short breaks (respite) Claire House Hospice & Sefton Council
- Step-down care N/A
- End of life care N/A
- 14. Are you implementing the NICE clinical guideline 'End of Life Care for Infants, Children and Young People: Planning and Management'? (Yes/No)

 If yes, please tell us about the steps you are taking.

NHS Southport and Formby CCG does not hold this information. You may wish to forward your query to —

Alder Hey Children's NHS Foundation Trust info.gov@alderhey.nhs.uk

15. Are you implementing 'Our Commitment to you for end of life care: The Government Response to the Review of Choice' for children and young people with life-limiting and life-threatening condition? (Yes/No)

No

If yes, please tell us about the steps you are taking.

N/A