

Our Ref: FOI ID 38219

29 June 2017

southportandformbyccg.foi@nhs.net

NHS Southport & Formby CCG

5 Curzon Road

Southport

PR8 6PL

Tel : 01704 387028

Email: southportandformby.ccg@nhs.net

Re: Freedom of Information Request

Please find below the response to your recent Freedom of Information request regarding Palliative Care services within NHS Southport and Formby CCG.

Request/Response:

1. Do you commission palliative care for children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25? (yes/no) If yes, how much did you spend on children's palliative care in 2016/17?

Yes, NHS Southport and Formby CCG commission hospital based palliative care from Alder Hey Children's NHS Foundation Trust via their block contract, so we are unable to attribute a specific figure to this particular service line.

NHS Southport and Formby CCG commissions outreach palliative care for children and young people aged 0-23 via Claire House Children's Hospice. For those aged 24-25, they would receive care from within the hospital / community or hospice.

Value of spend for 2016/2017 was £14,000

2. Do you have a published strategy or care pathway for children with life-limiting and life-threatening conditions? If so, please provide a link or an attachment.

No

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

No.

4. Do you assess numbers and needs of children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25 among the population you serve (yes/no)? If yes, please tell us how. Please also tell us how many children and young people with life-limiting and life-threatening conditions there are in your area.

No, NHS Southport and Formby CCG does not hold this information. You may wish to redirect your query to NHS England

england.contactus@nhs.net

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)

Yes, if continuing care eligible. NHS Southport and Formby CCG also jointly funds overnight respite for children with disabilities.

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)

Yes

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)

Yes

8. Do you take steps to integrate assessments, plans and services for children and young people with life-limiting and life-threatening conditions between the ages of 0 and 25, including those without a special educational need and disability (yes/no)? If yes, please tell us how (For example, using education, health and care plans).

Yes, but at this time limited to those with education, health and care plans.

9. Do you offer personal budgets to children and young people with life-limiting and life-threatening conditions? If yes, how many children and young people with life-limiting and life-threatening conditions in your area have a personal budget?

Yes if in receipt of continuing care. There are 0 children and 0 young people who have a personal budget.

10. Do you take steps to make sure that 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, please tell us how.

NHS Southport and Formby CCG does not hold this information, you may wish to redirect your query to our provider Claire House Children's Hospice.

<http://www.clairehouse.org.uk/contact-claire-house>

11. Do you take steps 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)? If yes, please tell us how.

Yes, we expect all providers to deliver effective transition between services.

12. Do you commission any of the following services for children with life-limiting or life-threatening conditions? If yes, please state which outcomes you ask service providers to achieve and how much you spent on them in 2016/17:

- A level 4 paediatric palliative care consultant (yes/no)?

Please redirect your query to the providers:-

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

Southport & Ormskirk Hospital NHS Trust
soh-tr.foi@nhs.net

- Consistent with the NICE clinical guideline 'End of Life Care for Infants, Children and Young people', a multidisciplinary team that includes the following as a minimum (yes/no)?
 - a paediatric palliative care consultant
 - a nurse with expertise in paediatric palliative care
 - a pharmacist with expertise in specialist paediatric palliative care
 - experts in child and family support who have experience in end of life care (for example in providing social, practical, emotional, psychological and spiritual support)

Please redirect your query to the providers:-

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

Southport & Ormskirk Hospital NHS Trust
soh-tr.foi@nhs.net

- Acute children's palliative care nurses which provide children's palliative care (yes/no)?

Please redirect your query to the providers:-

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

Southport & Ormskirk Hospital NHS Trust
soh-tr.foi@nhs.net

- Community children's nurses which provide children's palliative care (yes/no)?

Yes – Alder Hey Children's NHS Foundation Trust. This is part of a larger community nursing service and costs regarding palliative care are not disaggregated.

- Voluntary sector children's palliative care services (including children's hospice services) (yes/no)? If yes, which voluntary sector services do you commission and how much did you spend on them in 2016/17?

Yes, NHS Southport and Formby CCG commissions Claire House Children's Hospice

Spend for 2016/2017 was £14,000

- Community paediatricians which provide children's palliative care (yes/no)?

Yes – Alder Hey Children's NHS Foundation Trust. This is part of a larger community paediatric service and costs regarding palliative care are not disaggregated.

- Emotional and psychological support for children and their families (yes/no)?–

Yes – Alder Hey Children's NHS Foundation Trust. This is part of a larger community paediatric service and costs regarding palliative care are not disaggregated.

- Bereavement care - to families *before* a child under the age of 1 has died (yes/no)?

Not routinely commissioned but available on a case by case base.

- Bereavement care - to families *after* a child under the age of 1 has died (yes/no)?

Not routinely commissioned but available on a case by case base.

- Bereavement care - to families *before* a child or young person aged 1 – 25 has died (yes/no)?

Not routinely commissioned but available on a case by case base.

- Bereavement care - to families *after* a child or young person aged 1 – 25 has died (yes/no)?

Not routinely commissioned but available on a case by case base.

- Equipment - including services which provide wheelchairs and services to maintain and repair equipment (yes/no)?

Please refer this to specialist commissioning at NHS England

england.contactus@nhs.net

13. Do you commission any of the following services to provide care out of hours and at weekends 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 level 4 paediatric palliative care consultant (yes/no)?

NHS Southport and Formby CCG does not hold this information, you may wish to redirect your query to the providers:-

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

Southport & Ormskirk Hospital NHS Trust
soh-tr.foi@nhs.net

- Consistent with the NICE clinical guideline 'End of Life Care for Infants, Children and Young people', a multidisciplinary team that includes the following as a minimum (yes/no)?
 - a paediatric palliative care consultant
 - a nurse with expertise in paediatric palliative care
 - a pharmacist with expertise in specialist paediatric palliative care
 - experts in child and family support who have experience in end of life care (for example in providing social, practical, emotional, psychological and spiritual support)

Please redirect your query to the providers:-

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

Southport & Ormskirk Hospital NHS Trust
soh-tr.foi@nhs.net

- Acute children's palliative care nurses which provide children's palliative care (yes/no)?

Please redirect your query to the providers:-

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

Southport & Ormskirk Hospital NHS Trust
soh-tr.foi@nhs.net

- Community children's nurses which provide children's palliative care (yes/no)?

Yes, Alder Hey Children's NHS Foundation Trust

- Voluntary sector children's palliative care services (including children's hospice services) (yes/no)? If yes, which voluntary sector services do you commission and how much did you spend on them in 2016/17?

Yes, Claire House Children's Hospice
Value of spend for 2016/2017 was £14,000

- Community paediatricians which provide children's palliative care (yes/no)?

Yes, Alder Hey Children's NHS Foundation Trust.

- Emotional and psychological support for children and their families (yes/no)?
[Yes, Paediatric psychology service within Alder Hey Children's NHS Foundation Trust](#)
- Bereavement care - to families *before* a child under the age of 1 has died (yes/no)?
[Not routinely commissioned but available on a case by case base.](#)
- Bereavement care - to families *after* a child under the age of 1 has died (yes/no)?
[Not routinely commissioned but available on a case by case base.](#)
- Bereavement care - to families *before* a child or young person aged 1 – 25 has died (yes/no)?
[Not routinely commissioned but available on a case by case base.](#)
- Bereavement care - to families *after* a child or young person aged 1 – 25 has died (yes/no)?
[Not routinely commissioned but available on a case by case base.](#)
- Equipment - including services which provide wheelchairs and services to maintain and repair equipment (yes/no)?
[Please refer this to specialist commissioning at NHS England](#)
england.contactus@nhs.net

14. 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)? If yes, please state how much you spent on them in 2016/17:

- short breaks (respite)

[Yes, £75,400 p/a](#)

- step-down care

[Please redirect your query to the providers:-](#)

[Alder Hey Children's NHS Foundation Trust](#)
Info.gov@alderhey.nhs.uk

[Southport & Ormskirk Hospital NHS Trust](#)
soh-tr.foi@nhs.net

- end of life care.

Yes but NHS Southport and Formby CCG cannot identify these costs as they are part of a block contract.

15. 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.

Please redirect your query to the providers:-

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

Southport & Ormskirk Hospital NHS Trust
soh-tr.foi@nhs.net

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

Please redirect your query to the providers:-

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

Southport & Ormskirk Hospital NHS Trust
soh-tr.foi@nhs.net