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Date: 3 July 2017

Emailed to: [Patrick.McKenna@togeytherforshortlives.org.uk](mailto:Patrick.McKenna@togeytherforshortlives.org.uk)

Dear Mr McKenna

**Re: Freedom of Information Request – Plan and fund palliative care for children and young people aged 0-25.**

I am writing to confirm that the Rotherham CCG has now completed its search for the information you requested on 2 June 2017 and can now provide the relevant information as follows:

Request 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?
Response 1	Yes. The funding is part of a block contract.
Request 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.
Response 2	No
Request 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).
Response 3	No
Request 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.
Response 4	RCCG do not hold this information
Request 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)
Response 5	No
Request 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)
Response 6	Yes
Request 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)
Response 7	Yes
Request 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).
Response 8	This is the role of the Provider Trust who is The Rotherham NHS Foundation Trust please contact them via <a href="mailto:freedomofinformation@rothgen.nhs.uk">freedomofinformation@rothgen.nhs.uk</a>
Request 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?
Response 9	Yes through children and young peoples' NHS continuing healthcare service
Request 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.
Response 10	See response 8
Request 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.
Response 11	Transition to adulthood included in service specification
Request 12	<p>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:</p> <ul style="list-style-type: none"> <li>• A level 4 paediatric palliative care consultant (yes/no)?</li> <li>• 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)? <ul style="list-style-type: none"> <li>○ a paediatric palliative care consultant</li> <li>○ a nurse with expertise in paediatric palliative care</li> <li>○ a pharmacist with expertise in specialist paediatric palliative care</li> <li>○ 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)</li> </ul> </li> <li>• Acute children's palliative care nurses which provide children's palliative care (yes/no)?</li> <li>• Community children's nurses which provide children's palliative care (yes/no)?</li> <li>• 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? Bluebell Wood Hospice on an ad hoc basis as required.</li> </ul>

	<ul style="list-style-type: none"> <li>• Community paediatricians which provide children's palliative care (yes/no)?</li> <li>• Emotional and psychological support for children and their families (yes/no)?</li> <li>• Bereavement care - to families <i>before</i> a child under the age of 1 has died (yes/no)?</li> <li>• Bereavement care - to families <i>after</i> a child under the age of 1 has died (yes/no)?</li> <li>• Bereavement care - to families <i>before</i> a child or young person aged 1 – 25 has died (yes/no)? community nursing team cover age 0-18</li> <li>• Bereavement care - to families <i>after</i> a child or young person aged 1 – 25 has died (yes/no)? community nursing team cover age 0-18</li> <li>• Equipment - including services which provide wheelchairs and services to maintain and repair equipment (yes/no)?</li> </ul>
Response 12	Please see response 8.
Request 13	<p>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.</p> <ul style="list-style-type: none"> <li>• A level 4 paediatric palliative care consultant (yes/no)?</li> <li>• Consistent with the NICE clinical guideline 'End of Life Care for Infants, Children and Young people', a multidisciplinary team that includes as a minimum: <ul style="list-style-type: none"> <li>○ a paediatric palliative care consultant</li> <li>○ a nurse with expertise in paediatric palliative care</li> <li>○ a pharmacist with expertise in specialist paediatric palliative care</li> <li>○ 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)</li> </ul> </li> <li>• Acute children's palliative care nurses which provide children's palliative care (yes/no)?</li> <li>• Community children's nurses which provide children's palliative care (yes/no)?</li> <li>• 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?</li> <li>• Community paediatricians which provide children's palliative care (yes/no)?</li> <li>• Emotional and psychological support for children and their families (yes/no)?</li> <li>• Bereavement care - to families <i>before</i> a child under the age of 1 has died (yes/no)?</li> <li>• Bereavement care - to families <i>after</i> a child under the age of 1 has died (yes/no)?</li> <li>• Bereavement care - to families <i>before</i> a child or young person aged 1 – 25 has died (yes/no)?</li> </ul>

	<ul style="list-style-type: none"> <li>Bereavement care - to families <i>after</i> a child or young person aged 1 – 25 has died (yes/no)?</li> <li>Equipment - including services which provide wheelchairs and services to maintain and repair equipment (yes/no)?</li> </ul>
Response 13	Please see response 8.
Request 14	<p>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:</p> <ul style="list-style-type: none"> <li>short breaks (respite)</li> <li>step-down care</li> <li>end of life care.</li> </ul>
Response 14	Yes
Request 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.
Response 15	Please see response 8.
Request 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.
Response 16	Not yet.

If you have any queries about our response to your request please contact our FOI Officer using the contact details shown above. It would also be helpful if you could quote our reference number in any communication.

If you are unhappy with the decisions made in relation to your request from Rotherham Clinical Commissioning Group you may ask for an internal review. If you wish to complain you should contact our Governance & Complaints Officer at the above address or by email [complaints@rotherhamccg.nhs.uk](mailto:complaints@rotherhamccg.nhs.uk)

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at:

Information Commissioner's Office  
Wycliffe House  
Water Lane  
Wilmslow  
Cheshire  
SK9 5AF

Yours sincerely

Ruth Nutbrown

**Assistant Chief Officer**