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| Tel No: 01709 428722  Our ref: F.O.I. Response/CCG 1890  E-mail: [roccg.foi@nhs.net](mailto:roccg.foi@nhs.net)  Date: 12 March 2021 | Oak House  Moorhead Way  Bramley  Rotherham  S66 1YY  <http://www.rotherhamccg.nhs.uk/> |

Emailed to: [Dan.Steer@togetherforshortlives.org.uk](mailto:Dan.Steer@togetherforshortlives.org.uk)

Dear Mr Steer

**Re: Freedom of Information Request – request from the All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care and Together for Short Lives**

I am writing to confirm that the NHS Rotherham Clinical Commissioning Group (CCG) has now completed its search for the information you requested on 15 February 2021 and can now provide the relevant information as follows:

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| The questions below which we would like you to answer are designed to help me understand how you commission children’s palliative care for children and young people with life-limiting and life-threatening conditions in your local area. In order to help you meet my request, I provide definitions to the terms I use in my questions below:  ***Children’s palliative care***  “An active and total approach to care, from the point of diagnosis or recognition, throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the family. It includes the management of symptoms, provision of short breaks and care through death and bereavement.”  ***Life-limiting and life-threatening conditions***  “Life-limiting conditions are those for which there is no reasonable hope of cure and from which children will die. Some of these conditions cause slow deterioration over time rendering the child increasingly dependent on parents and carers.  Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancer.”  ***End of life care***  “Care that helps all those with advanced, progressive, incurable illness, to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition. This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both child/young person and the family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family into bereavement.”  Contd/…  Please note that NHS England and NHS Improvement has created a draft Children’s and Young People’s Palliative and End of Life Care Service Specification. This is available for CCGs to access from the [FutureNHS Collaboration Platform](https://future.nhs.uk/)  The following national standards apply to palliative and end of life care for children and young people in England:  **NICE Guidance NG 61:** End of life care for infants, children and young people with life-limiting conditions: planning and management  <https://www.nice.org.uk/guidance/ng61>  **NICE Quality Standard QS 160:** 2017. End of life care for infants, children and young people – NICE quality standard [QS160].  <https://www.nice.org.uk/guidance/qs160>  **Department of Health.** 2016. ‘Our Commitment to you for end of life care: The Government Response to the Review of Choice’.  <http://bit.ly/2oOUsfj>  **NICE guideline NG43:** 2016. Transition from children to adults’ services for young people using health or social care services  <https://www.nice.org.uk/guidance/ng43>  **NICE Quality standard QS140:** 2016. Transition from children to adults’ services <https://www.nice.org.uk/guidance/qs140> | |
| Request 1 | Do you have a children’s palliative care service specification? (Yes/No). If so, please attach a copy to your response to this request. |
| Response 1 | No, NHS Rotherham CCG does not have a Children’s Palliative Care service specification.  The commissioned Children’s Community Nursing Service provides palliative, and end of life care, as an element of their service.  Rotherham is actively engaged with work across the Integrated Care System to develop a specification for palliative care for South Yorkshire and Bassetlaw. |
| Request 2 | Do you have a children’s palliative care service specification which states that  infants, children and young people with a life-limiting condition and their parents  or carers should have opportunities to be involved in developing an advance  care plan? (Yes/No) |
| Response 2 | Please see Response 1. |
| Request 3 | Do you have a children’s palliative care service specification which states that  infants, children and young people with a life-limiting condition should have a  named medical specialist who leads and coordinates their care? (Yes/No) |
| Response 3 | Please see Response 1. |
| Request 4 | Do you have a children’s palliative care service specification which states that  infants, children and young people with a life-limiting condition and their parents  or carers should be given information about emotional and psychological  support, including how to access it? (Yes/No) |
| Response 4 | NHS Rotherham CCG does not have a Children’s Palliative Care service specification.  Contd/…  The Children’s Community Nursing service specification states that the service will provide psychological support (for the child or young person, or family including siblings).  Rotherham is actively engaged with work across the Integrated Care System to develop a specification for palliative care for South Yorkshire and Bassetlaw. |
| Request 5 | Do you have a children’s palliative care service specification which states that  infants, children and young people with a life-limiting condition should be cared  for by a multidisciplinary team that includes members of the specialist  paediatric palliative care team? (Yes/No) |
| Response 5 | NHS Rotherham CCG does not have a Children’s Palliative Care service specification.  The Children’s Community Nursing service specification states that the service will provide care co-ordination and have access to nurses with additional skills in palliative care management. |
| Request 6 | Do you have a children’s palliative care service specification which states that  parents or carers of infants, children and young people approaching the end of  life should be offered support for grief and loss when their child is nearing the  end of their life and after their death? (Yes/No) |
| Response 6 | NHS Rotherham CCG does not have a Children’s Palliative Care service specification.  The Children’s Community Nursing service specification states that the service will provide end of life and bereavement support (for child and family including siblings).  Rotherham is actively engaged with work across the Integrated Care System to develop a specification for palliative care for South Yorkshire and Bassetlaw. |
| Request 7 | Do you have a children’s palliative care service specification which states that  infants, children and young people approaching the end of life and being cared  for at home should have 24-hour access to both children's nursing care and  advice from a consultant in paediatric palliative care? (Yes/No) |
| Response 7 | NHS Rotherham CCG does not have a Children’s Palliative Care service specification.  The Children’s Community Nursing service specification states that the service will provide end of life care including provision of a 24 hours a day, 7 days a week, on call service. |
| Request 8 | Do you have a children’s palliative care service specification which states that  infants, children and young people with a life-limiting condition and their  families should have access regular short breaks for respite? (Yes/No) |
| Response 8 | NHS Rotherham CCG does not have a Children’s Palliative Care service specification.  The Children’s Community Nursing service specification states that children and young people with life-limiting conditions and their families will have short break care away from home and/or short break care at home, or other community setting. The CCG supports Bluebell Wood Hospice via a grant arrangement.  Contd/… |

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 NHS Rotherham CCG 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 [roccg.complaints@nhs.net](mailto:roccg.complaints@nhs.net)

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**