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| **NHS Bolton Clinical Commissioning Group**  **Freedom of Information Response** | |
| **Reference Number: 2020-116** | |
| **Date received: 15/02/21** | |
| **Internal deadline: 23/02/21** | |
| **20 day response deadline: 15/03/21** | |
| 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.”  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>  **My questions** | |
| **Question:** | **Response:** |
| 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. | No – Children’s palliative care provision forms part of Bolton’s wider Integrated Community Paediatric Service. |
| 1. 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) | Please see Q1 |
| 1. 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) | Please see Q1 |
| 1. 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) | Please see Q1 |
| 1. 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) | Please see Q1 |
| 1. 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) | Please see Q1 |
| 1. 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) | Please see Q1 |
| 1. 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) | Please see Q1 |
| **Queries:**  It is hoped you will find these details helpful to your enquiries. However, if you are unhappy with this response please let us know, giving your reasons for believing we have not satisfied the requirements of the Freedom of Information Act.  The matter will then be considered by NHS Bolton CCG who will respond in writing. This correspondence will include details of the Information Commissioner who you can contact if you remain dissatisfied with our response.  Governance & Safety Team  NHS Bolton CCG, 3rd Floor, Lever Chambers, 27 Ashburner Street, Bolton, BL1 1SQ  Email: [bolccg.foi@nhs.net](mailto:bolccg.foi@nhs.net)  Telephone: 01204 462022 | |