

Reference: BW00709

Subject: Palliative Care

I can confirm that the CCG does hold some of the information requested; please see responses below:

QUESTION	Berkshire West CCG
	<p>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:</p> <p><i>Children's palliative care</i></p> <p>"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."</p> <p><i>Life-limiting and life-threatening conditions</i></p> <p>"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.</p> <p>Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancer."</p> <p><i>End of life care</i></p> <p>"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,</p>

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](#)

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/2oOUfj>

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>

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.

The CCG has been working with partners including the local CYP hospice to develop a CYP EoL offer. Finance has been agreed and we are working up the final operational details with the provider. A draft service specification is attached.

<p>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)</p>	<p>yes</p>
<p>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)</p>	<p>yes</p>
<p>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)</p>	<p>yes</p>
<p>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)</p>	<p>yes</p>

<p>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)</p>	<p>yes</p>
<p>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)</p>	<p>yes</p>
<p>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)</p>	<p>We are working with the local CYP hospice to develop the model. Short breaks are part of the core offer of the hospice.</p>

The information provided in this response is accurate as of 18th February 2021 and has been authorised for release by Rebecca Clegg, Chief Finance Officer Berkshire West CCG.



SIGNED: _____