Our Ref: 224-2021 Civic Centre

Freedom of Information Officer West St E-mail:[oldccg.foi.oldham@nhs.net](mailto:oldccg.foi.oldham@nhs.net) Oldham

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**W:** [www.oldhamccg.nhs.uk](http://www.oldhamccg.nhs.uk) Date: 03/03/2021

Reply sent by email to: [Dan.Steer@togetherforshortlives.org.uk](mailto:Dan.Steer@togetherforshortlives.org.uk)

Dear Dan

**Re: Request for information under the Freedom of Information Act 2000**

Thank you for your email dated 18/01/2021, making a request under the Freedom of Information Act 2000 for access to information which may be held by NHS Oldham Clinical Commissioning Group (CCG).

Please find detailed below NHS Oldham CCG’s response to your request, which is formatted as follows:-

1. A schedule of all the records covered by your request
2. A statement concerning copyright and re-use of public sector information
3. Details of how you can appeal this decision should you wish to do so

**1. A schedule of all the records covered by your request - this letter addresses each of these parts in turn**

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>

**Question:** 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:** No

However, palliative care is provided as part of the wider Community Paediatric services (Childrens Community Nursing Team, community medical & Long Term Vent Team), and delivered by Salford Royal Foundation Trust. We have also recently commissioned respite care through a Hospice At Home service with Derian House Childrens Hospice.

**Question:** 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:** We do not have a specific childrens’ palliative care service specification, however, within the community paediatrics services, parents and carers do have the opportunity to be involved in developing advance care plans.

**Question:** 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:** We do not have a specific childrens’ palliative care service specification, however, within the community paediatrics services children requiring palliative care are assigned a lead healthcare professional to take ownership of the care plan and co-ordinate care.

**Question:** 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:** We do not have a specific childrens’ palliative care service specification, however, within the community paediatrics services CYP and parents/carers are given appropriate information on emotional and psychological support and how they can access it.

**Question:** 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:** We do not have a specific childrens’ palliative care service specification, however, within the community paediatrics services there is an MDT approach for care planning, symptom management and collaborative working to deliver patient centred care.

**Question:** 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:** We do not have a specific children’s’ palliative care service specification, however, within the community paediatrics services, CYP and parents/carers are given appropriate information regarding grief, loss and psychological support and how they can access it from locality & regional colleagues and online resources.

**Question:** 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:** We do not have a specific childrens’ palliative care service specification, however, the Community Paediatric service offers out of hours consultant support when needed, however this is additional to their job plan and is currently under review.

**Question:** 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:** We do not have a specific childrens’ palliative care service specification, however, we have recently commissioned a Hospice at Home service which provides respite at home for approximately 3 hours every fortnight.

**2. A statement concerning copyright and re-use of public sector information**

Most of the information provided by NHS Oldham CCG in response to Freedom of Information Act 2000 requests will be subject to copyright protection. In the majority of cases the information will be owned by NHS Oldham CCG. The copyright for other information may be owned by another person or organisation, as indicated in the information itself: in this case you must apply to the copyright owner to obtain their permission.

You are free to use any information supplied for your own use, including for non-commercial research purposes. It may also be used for the purposes of news reporting. However, any other type of re-use, for example, by publishing the information or issuing copies to the public will require the permission of the copyright owner.

**3. Details of how you can appeal this decision should you wish to do so**

If you are dissatisfied with the service you have received in relation to your request and wish to make a complaint or request a review of our decision, you are entitled to complain in the following way:

Initially you should complain in writing to the freedom of information officer, either by email to [oldccg.foi.oldham@nhs.net](mailto:oldccg.foi.oldham@nhs.net) or post to The Freedom of Information Lead, NHS Oldham CCG, Ellen House, Waddington Street, Oldham, OL9 6EE specifying why you feel you have been wrongly denied access to the information requested. The freedom of information officer will ensure your complaint is investigated under NHS Oldham’s CCG’s internal processes and provide you with a written response within 20 working days.

If you are not content with the outcome of your complaint, you may apply directly to the Information Commissioner’s Office (ICO) for a decision. Generally, the ICO cannot make a decision unless you have exhausted the complaints procedure provided by NHS Oldham CCG.

Yours sincerely,

**Freedom of Information Officer**

**Oldham CCG**