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15 March 2021

PRIVATE AND CONFIDENTIAL

Mr James Cooper

Via email to: Dan.Steer@togetherforshortlives.org.uk

Dear Mr Cooper

Freedom of Information Request

Thank you for your email dated 15 February 2021 addressed to the Leicester, Leicestershire and Rutland Clinical Commissioning Groups (LLR CCGs) in respect of your request for information under the Freedom of Information Act 2000. The LLR CCGs confirm our response below (your request is set out in italics for ease of reference).

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: yes, the LLR CCGs use the Diana Service, which has a Standard Operating Procedure in place and is updated when required. Please see attached document.

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: the LLR CCGs have a specific procedure in place for end of life planning, which states that staff must initiate, a Children's and Young People Advance Care Plan (CYPACP) if one has not been written, or update if one already exists, this should be done both on system1 and patient held copy. On system1 this is found in Communications and Letters section. From 01.01.20 the CYPACP will be implemented which incorporates the ReSPECT document (Recommended Summary Plan for Emergency Care and Treatment)). Previous

Chief Executive: Andy Williams

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www.leicestercityccg.nhs.uk

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www.westleicestershireccg.nhs.uk

Glenfield office: Leicestershire County Council, Room G30, Pen Lloyd Building, County Hall, Glenfield, Leicester, LE3 8TB. Tel: 0116 295 7572. www.eastleicestershireandrutlandccg.nhs.uk

EHCP/PRP's will remain valid but there is an expectation that Consultants update onto the new paperwork when reviewing the child/Young Person.

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: The child whose condition has deteriorated unexpectedly must be assessed by a doctor to judge whether the person's change in condition is potentially reversible or they are thought to be in EOL.

Children discharged from UHL for end of life care should have their CYPACP completed by a UHL doctor. The UHL doctor may request for a Diana nurse to be present during the completion of this document. If staff are available this would occur to facilitate in completion of the document and to meet the family.

If the child is not in hospital then the process below should be followed:

- Children known to a community paediatrician should be identified by reviewing SYS1 notes for City children or a medical secretary checking HISS for a county child. If a child is known to a community paediatrician and needs an CYPACP then that clinician would be contacted via the medical secretariat explaining that this is an urgent end of life request for medical assistance.
- If the clinician involved is unable to respond within a timely manner (or away) then the Diana coordinator would contact the medical secretaries and ask to speak to the lead doctor for palliative care or (if unavailable) any of the doctors who are available.

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: If the appropriately trained and competent clinician and doctor judge the child is likely to die soon, s/he must clearly and sensitively communicate this to the child or young person if appropriate and with their family. This should include explaining when and how death might be expected to occur and the basis for that judgement, acknowledging and accepting any uncertainties and giving the opportunity for those involved to ask questions.

Support is provided as outlined below;

- During the assessment process the key nurse needs to identify the appropriate level of support and ensure any referrals are made in a timely manner.
- Ensure timely referrals are made to Diana Child and Family Support Services (CAFSS) and/or Rainbow's Hospice to ensure the family have support of their emotional needs.
- The family must be supported to care for the dying child and ensure their feelings and wishes are explored and clearly documented.
- When death is close, family, should be given information and explanation about what to expect and preference for support established and documented using the end of life care plan on S1 (Appendix 1b 'Setting up 24/7 End of Life On-Call' and Appendix 1c 'End of Life Care Plan')
- When the child has died, the wellbeing of the bereaved family must be considered and support for their immediate needs be made available. The key nurse involved in the care will follow the relevant care plan (Appendix 1d 'After your child has died/family support').

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: No, the LLR CCGs do not have this in the specification, please see attached SOP for EOL FYPC

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: yes, support is provided as outlined below.

- During the assessment process the key nurse needs to identify the appropriate level of support and ensure any referrals are made in a timely manner.
- Ensure timely referrals are made to Diana Child and Family Support Services (CAFSS) and/or Rainbow's Hospice to ensure the family have support of their emotional needs.
- The family must be supported to care for the dying child and ensure their feelings and wishes are explored and clearly documented.
- When death is close, family, should be given information and explanation about what to expect and preference for support established and documented using the end of life care plan on S1 (Appendix 1b 'Setting up 24/7 End of Life On-Call' and Appendix 1c 'End of Life Care Plan')
- When the child has died, the wellbeing of the bereaved family must be considered and support for their immediate needs be made available. The key nurse involved in the care will follow the relevant care plan (Appendix 1d 'After your child has died/family support').

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: yes, the specification states that;

- The dying child and family must be given the name of the general practitioner/ consultant and nurse who has overall responsibility and is leading on their care. Clearly explain who will cover in the event of absence and ensure a plan for change in care arrangements/care settings is in place. This must be clearly documented and accessible to all those involved in the person's care. See Care Plans (Appendix 1b,c,d) and Diana Palliative Care Update Sheet (Appendix 4)
- The dying child and family should be supported to make informed decisions as much as possible and to the extent they wish.

Once a child has been identified as being at end of life then if needed the Diana on call will be activated that gives the family access to a CCN 24 hrs a day.

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: No, this is not in the specification.

Please note that some documents that we provide may be copyrighted to East Leicestershire and Rutland Clinical Commissioning Group and, under the Re-use of Public Sector Information Regulations, may incur a licence agreement and fee should you wish to re-use them. If you do wish to re-use copyrighted material, you must ask our specific permission in all cases, which we may or may not give. Should you wish to apply for a licence, please write to the Corporate Governance Team at the above address.

If you are unable to open this or any other documents related to this request, please contact a member of the Corporate Governance Team in order to agree a new format.

If you are unhappy with the service you have received in relation to your request, please contact the Head of Corporate Governance in writing at the following address:

Head of Corporate Governance
Leicester, Leicestershire and Rutland Clinical Commissioning Groups
(i.e. East Leicestershire and Rutland CCG, Leicester City CCG and West Leicestershire CCG)
Leicestershire County Council
Room G30, Pen Lloyd Building
County Hall, Glenfield
Leicester
LE3 8TB

If you are still not satisfied following this, you can make an appeal to the Information Commissioner (ICO) who is the statutory regulator. Generally, the ICO cannot make a decision unless you have exhausted ELR CCG's complaints procedure. The Information Commissioner can be contacted at:

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

T: 0303 123 1113 or 01625 545745

E: casework@ico.org.uk.

Yours sincerely

**Corporate Affairs Senior Assistant
Corporate Affairs Team**

Encs SOP For EOL FYPC