East Anglia’s Children’s Hospices (EACH)

Symptom Management Nursing Service (SMNS)

End of Life Care

What does end of life care look like?

- We aim to ensure your child or young person is as comfortable as possible during their end of life care, and for care to be well planned and co-ordinated, often using the Advance Care Plan document as necessary.

- It will involve the team regularly assessing and responding to your child’s symptoms and care needs holistically.

- You are likely to be asked about your preferred place of death for your child. In most situations this will be at home, in hospital or at the hospice. We aim to support your preferred place of death where possible.

- Planning for care at end of life is guided by your child and family preferences alongside the expertise of professionals involved in your child’s care.

- Some families find it helpful to talk about specific cultural or spiritual needs. We can work closely with you and your team of professionals to provide care and support that aims to meet the individual needs of your child and family.

- When your child moves towards the end of their life, the team of professionals involved in your child’s care will meet to discuss and make a plan for care and support. These multidisciplinary meetings help to ensure the care you and your child receives is consistent and that everyone involved, including you, has the information they need.

- A ‘lead’ professional from the wider multidisciplinary palliative care team will be identified and will keep in regular contact with you.

- The role of the lead professional is to provide support, and make sure you have all the information you and your child need to contribute to discussions and decisions about your child’s care.

- When we support end of life care at home, we often arrange for a nurse to be available locally in case an urgent visit is required outside of office hours. We will discuss these arrangements with you at the time if this is necessary.

- There are legal processes which we must follow for children receiving end of life care. For example, we may ask a doctor (a GP or your consultant) to see your child regularly (fortnightly or monthly) to support with medical certification of death.

- If your child dies suddenly or sooner than expected, it may be necessary for there to be urgent discussions with the coroner. Usually this is done by one of the doctors involved in your child’s care.

- There is a statutory requirement in England to review all child deaths. The leaflet ‘When a child dies: a guide for parents and carers’ explains this process and describes what you can expect from local services. This leaflet can be found in your SMNS Family Folder and will be discussed with you by a member of the team.

What care can you expect after your child dies?

Some parents find it helpful to make decisions about funeral arrangements before their child dies, others wait until after their child’s death. This is a personal matter, but support can be provided whenever the timing is most suitable for your family.

- The process for care after death may vary depending on whether your child dies in the hospice, at home or in hospital. If your child dies with you at home, you can contact the team on the freephone number when you are ready (0808 196 9495).

- Verification and certification of death are legal requirements but do not usually need to take place immediately after your child has died. Verification of death is often carried out by an EACH nurse. The most appropriate doctor to complete the medical certificate of cause of death is usually identified before your child dies following conversation with the local medical examiner office. Once the death certificate has been issued, you will be able to register your child’s death.

- Your child can be cared for at your home, hospice or funeral directors with the use of specialist cooling equipment. Sometimes we may advise that it is more appropriate to receive this care at the funeral home based on assessment of your child’s body. The hospice team can provide you with information and guidance about the role and practices of Funeral Director Services in your local area, if you would like us to.

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Call 0808 196 9495 anytime (freephone)

- During office hours your call will be answered by the SMNS administrator who will direct your call to a nurse, or please leave a message and one of the team will contact you as soon as possible.

- Outside of office times, when you have access to the on-call service, telephone calls are answered by a call handling service:

    - Please ask to speak to the on-call Symptom Management Clinical Nurse Specialist.
    - You will be asked for basic information about your child, including name, date of birth and a brief reason for calling.
    - This information will be given to the SMNS Clinical Nurse Specialist who will return your call as soon as possible.

- In the unlikely event you are unable to reach us via this number, please call the EACH central number 01223 800 800 (calls charged at local rate).

- If you need urgent attention, please call 999.