

End of life care and support at EACH

We aim to make sure your child is as comfortable as possible during their end of life care; and for care to be well planned and co-ordinated (using the Advance Care Plan document as necessary). This will involve members of the EACH Team regularly assessing and responding to your child's symptoms, care and support needs. You are likely to be asked about your preferred place of death for your child. In most situations this can be at home, in hospital or at the hospice.

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. When your child moves towards "end of life", and taking into account your child and family's preferences, 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 receive is consistent and that everyone involved has the information they need.

A "lead" professional from this multidisciplinary team will be identified who 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.

There are legal processes which we must follow for children receiving end of life care. For example, we may ask a doctor (your GP, the hospice GP or your Consultant) to see your child regularly (fortnightly or monthly) to support with medical certification of cause 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 to review all child deaths by Medical Examiner and Child Death Review processes. The leaflet "When a child dies: a guide for parents and carers" explains this process and describes what you can expect from EACH and other services local to you.

After your child has died, you may want their body to stay at the hospice, come to the hospice from your home or stay at home, for a period of time before the funeral. We work closely with local funeral directors, seeking advice and guidance in order to ensure appropriate and safe care is delivered at this time.

Bereavement care

EACH is able to offer support and guidance in the immediate period after the death of the child and into bereavement. For more information please see our leaflet on Wellbeing Support.

Beatrice's mum *"As soon as we arrived we were made to feel at home and everything possible was done for us to allow us to just spend time in the most peaceful of surroundings, saying goodbye to our beautiful little girl. She arrived in a Moses basket and had her own room, with her name on the door and was cared for with such respect and dignity by everyone. As a parent we could not have asked for a better way to say goodbye in the worst of situations."*

Finley's mum *"While we were at the hospice we had nine precious days together. We were able to take lovely photos of Finley without all the tubes and wires, family and friends were able to come and visit at the same time and every night he slept in between us in bed – things we couldn't have done in hospital. "We worked with the EACH music therapist, and made a CD. You can hear Finley making sounds on the CD and it's so precious to us. The hospice didn't smell like a hospital, it was like a home, but somewhere that Finley could still get the nursing care he needed. While all this was going on EACH staff cooked us meals and did our washing for us – it meant we could spend every last moment there was with Finley. It was the hardest thing we've ever had to go through, but the time we spent at EACH made it easier. When Finley passed away, he stayed there for a while so we could go and visit him and EACH staff helped with all the funeral arrangements. I continue to go there now for counselling support and we always attend the memory days. EACH is amazing and I don't know what I'd do without them. It's always a warm friendly place to go to and Finley felt like ours for the first time when we got there."*

Tia's mum *"The week before Tia died we stayed in the hospice and didn't have to worry about anything. It meant I never had to leave her side. At hospital we were only allowed two visitors at a time which made family visits impossible. The hospice meant Tia didn't have to die in a hospital."*

How to contact our teams

EACH Milton (Cambridgeshire) 01223 815100; eachmiltonadmin@each.org.uk

EACH The Nook (Norfolk) 01603 967596; nook.admin@each.org.uk

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EACH Symptom Management Nursing Service 0808 1969495; each.each.smns@nhs.net
www.each.org.uk/contact-us