

End of life care and support at EACH

End of life care is planned and co-ordinated to try to make sure your child is as comfortable as possible. The team will regularly assess and respond to distressing symptoms and ensure treatments are appropriate and changed when needed.

Planning of care at end of life is guided by the hopes and wishes of your child and family alongside the expertise of the professionals involved. We work closely with external professionals to provide care and support that is appropriate and meets the individual needs of your child and family.

When the "end of life" phase is recognised, professionals involved in the care of your child and family will meet to discuss and plan care, taking into account family hopes and wishes and all the needs of your child and family. A "lead" professional will be identified who will keep in regular contact with you to make sure you know of the choices available to you, and for your child and family to be able to discuss your care.

End of life care is always a priority and this will sometimes mean that planned care may be cancelled. Advanced care planning and family hopes, wishes and choices are recorded and regularly reviewed with you by EACH staff.

After a child has died, a family may want their child's body to stay at the hospice or the family home, for a period of time before the funeral. At EACH, we work closely with local funeral directors, seeking advice and guidance in order to ensure appropriate and safe care.

To try to improve end of life care for other children and support for bereaved families, there is a statutory requirement when a child dies to review the care and support around the time of death. This is undertaken by local specialist child death review panels which EACH staff attend. The Lullaby Trust has produced a leaflet for parents and carers of any child under 18 who has died, which explains what happens in the Child Death Review. The leaflet can be downloaded from the Lullaby Trust website - www.lullabytrust.org.uk/child-death-review.

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."

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."

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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."

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 leaflets FIS 3 – Wellbeing Support and FIS 7 – Practical information for when your child has died.

How to contact our teams

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

EACH Quidenham (Norfolk) 01953 888603; eachquidenhamadmin@each.org.uk

EACH The Treehouse (Suffolk and Essex) 01473 271334; ipswichadmin@each.org.uk

EACH Symptom Management
Nursing Service 08454 501053; each.smt@nhs.net

www.each.org.uk/contact-us