Introductory information about East Anglia's Children's Hospices (EACH)

Family information sheet 1

EACH supports families living with or bereaved of a child (aged 18 years or under) with a life-threatening or life-limiting condition and complex healthcare needs across Norfolk, Suffolk, Peterborough, Cambridgeshire and Northern areas of North, Mid and West Essex.

From diagnosis to end of life and throughout bereavement, EACH offers a range of services which can be delivered virtually, or in your own home, at hospital, in the community or at one of our three hospices: Milton near Cambridge, The Treehouse in Ipswich and The Nook in Norfolk. The hospice buildings are large and homely with a child-friendly and welcoming environment.

The word hospice can seem scary, but using EACH services doesn't mean a child's death is imminent, as care at end of life isn't the only service EACH provides. Many children and young people who use EACH services are extremely active and move on to adult services at 18. Some families may come to fun events and activities we provide, while others may need more focussed help and support with their wellbeing or their child's symptom management needs.

When a family is eligible for EACH services, a member of staff will contact you to arrange the best location to complete an holistic needs assessment, whether that is in person or on a virtual platform (Microsoft Teams). The purpose of the assessment is to learn about everyone in the family and what your priorities are. This assessment is also an opportunity for you to hear about EACH services so that together we can decide which of our services could best meet your family's unique needs.

Services EACH offers to families include:

- Specialist symptom management support and advice
- Care and support at the end of life
- Day and overnight short breaks
- Emotional and wellbeing support for individual family members and groups
- Family events and activities

You will be allocated a Family Co-ordinator who will review, with your family, what your current priorities are and how EACH could help you with these. EACH works in partnership with other professionals in health, social care and education and attends meetings with

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East Anglia's Children's Hospices (EACH) – www.each.org.uk – Royal Patron: HRH The Duchess of Cambridge EACH is a registered charity (no. 1069284) and relies on voluntary donations for the majority of its income. Leaflet available in other formats on request (including other languages, braille and Easy Read).

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them to ensure everyone is working together in the planning and co-ordination of care. This ensures continuity of care and support for your family.

Our multi-professional team includes qualified children's palliative care nurses, clinical nurse specialists, consultant nurse, care assistants, family therapists, counsellors, play specialists, music therapists, art therapists, physiotherapists, occupational therapists, chaplains, chefs and housekeeping staff. EACH regularly has students working with us under supervision.

EACH works with families from all faiths, cultures and ethnic backgrounds and fully respects the importance of religious customs and cultural needs that are essential to the daily lives of each family. Interpreters will be provided as needed.

EACH has an online family information service – <u>www.each.org.uk/informationservice</u>. This includes a section on specialist holidays for families and grant making organisations providing special trips and financial help.

To ensure the privacy and safety of all our service users, you must not take or share photos of, or information about, other children or young people on social media at any time.

The Care Quality Commission is the organisation responsible for ensuring our compliance with the required regulations and standards to ensure the quality and safety of our service delivery. The latest inspection reports are available at www.cqc.org.uk.

What families say:

Lucy's mum

"Children like Lucy don't get the opportunity to go to sleepovers or to their friends for tea, so the interaction she has at the hospice is priceless. The team know Lucy so well and they gear the activities and entertainment to what she likes. She's a typical teenager and loves watching music TV channels."

Jayden's mum

"When I first heard the word hospice I thought 'I don't want that for my son' but when I took the time to fully understand what they could offer I realised it could be a real benefit for us all. From

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the start we had support at the hospital so we didn't feel alone or isolated and there was always someone on the end of the phone whenever we needed help.

"The first time we came to the hospice to stay it was really difficult for me. We'd spent so much time by Jayden's side, that it was really difficult to leave him in the care of someone else. I had to try and keep myself busy to stop worrying, and as time has gone on I've been able to relax knowing he's being looked after. We can get a rest which is always needed!

"Because Jayden spent so much time in hospital he wasn't used to being held, and he really didn't like his hands or feet being touched which was heart-breaking for us as parents. We've done a lot of work with EACH play specialists and he's much better now – things like that have been invaluable."

Tallulah's mum

"We had such a short time with Tallulah which could so easily have passed in a state of confusion followed by regret, EACH guided us gently through that period ensuring we made the most of our time when we were unable to fully comprehend what we were facing."

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

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

EACH Symptom Management 0808 196 9495; each.each.smns@nhs.net

Nursing Service

www.each.org.uk/contact-us

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