

Short break care for your child

EACH offers a holistic family-centred, needs-led approach to care ensuring all your child's needs are met, whether psychological, physical, emotional, social or spiritual. Care delivery can take place in a variety of settings including at home and in the hospice.

Care and support is provided by qualified nurses, clinical nurse specialists, counsellors, care assistants, play specialists, music therapists, art therapists, physiotherapists, occupational therapists, a family therapist, a psychologist, spiritual care advisors, chaplains, chefs and housekeeping staff, and a consultant nurse. EACH provides educational placements to students studying on relevant health and social care courses such as nursing, occupational therapy, music therapy and art therapy. Students may participate in your child's care under the supervision of EACH staff.

Medical services at home continue to be provided by your GP and at the hospice by our local GP service. The care team liaise with other professionals involved in supporting your family, such as your child's medical consultant, community physiotherapist or school.

Jayden's dad:

"Jayden's care is very complicated and he needs supervision 24/7 as he is unable to breathe for long by himself. This means it's stressful for us as parents and it means we very rarely get a decent nights' sleep which is why the time we spend at EACH is invaluable."

"Because Jayden's condition is undiagnosed and his needs are so complex, there's a complicated routine for his care. He has so much medical equipment; ventilators, nebulisers, oxygen cylinders, emergency resuscitation kits and suction machines, which means it takes a long time to get ready to go anywhere. The equipment is also complicated to use and we as parents, as well as EACH staff, need lots of training to use it."

Tyler's mum:

"Tyler loves to be outside in the fresh air so the woodland area is perfect. He particularly loves the row of chimes which play a song and the wheelchair swing. Music is very important to Tyler and he really enjoys playing with the wind chimes."

Bobby's mum:

Short break care for your child

"I can't take Bobby to playgroups outside of the hospice as they are not geared up for his needs. He loves sensory rooms with the lights, sounds and tactile objects. He smiles, makes sounds and moves his legs about helping him to communicate."

Planning for your child's care

We are guided by your expertise, hopes and wishes in providing the right care for your child. For this reason, we need to ask a range of different questions and collect some quite detailed information about your child and family.

Before EACH can provide care we will arrange to meet you to complete a number of documents, which include a care assessment and care plan. The meeting may last up to two hours depending on the amount and type of information that we need to care safely for your child/family.

Our care records are held electronically and can be shared with other care providers if you wish – but only with your consent.

Care plans

Our staff will work with you to complete a set of plans to ensure the safe delivery of your child's care at home or in the hospice. These plans cover a wide range of care, e.g. eating, drinking, sleeping, mobility, elimination, breathing and respiration, care of the gastrostomy tube and feeding regime, seizure management, pain management, moving and handling your child safely, and emotional and spiritual support needs.

They are designed to ensure our care is tailored to your child and their normal routines.

The plans will be reviewed with you before each care session, and are used by staff to keep up-to-date with your child's needs and ensure safe and consistent care.

Personal resuscitation plan

We are required to have a plan that describes what we do if your child becomes unwell or requires resuscitation while in our care. The plan has to be agreed with you and your child (if appropriate) and signed by your child's lead consultant.

Consent for activities

Short break care for your child

As part of the care plan, you will be asked if you would like your child to take part in activities such as outings away from the hospice. Occasionally, we may also seek your consent for using photographs in our marketing activities.

Care of your child in your home

Care and support in your home

We can provide care and support for your child at home. The amount of care will depend on your assessed needs and the agreed allocation of services.

We offer care during the daytime or evening, weekdays or weekends, according to your preferences, assessed need and the availability of staff.

Care of your child in the hospice

Care in the hospice

Our hospices are designed to create a homely environment suitable to care for children with a diverse range of needs. We provide overnight short stay breaks and day care in the hospice. The type and amount of care will depend on your assessed need and agreed allocation of services.

If you wish for your child to receive care in the hospice, your family can choose whether to stay at the hospice with them and how much of your child's care you wish to provide.

Staff will follow the care plan to continue your child's normal daily routine including administration of medicines, as discussed and agreed with you. They will give your child the opportunity to take part in a range of activities such as arts and crafts, sensory activities, computer games, music, board games, cinema, hydrotherapy (if applicable), shopping – all appropriate to their age, ability and preference.

What you need to bring

There is a list on the website of what you will need to bring for the stay, at www.each.org.uk/thingstobring.

Short break care for your child

Please ensure all equipment your child brings is clean and fit for purpose, and make sure its service is up to date, to ensure infection control and safety. Feel free to discuss with us if your child uses other equipment such as special seating, a standing frame or sleep system, so we can decide together whether it would be useful or possible for this to be brought in as well. We may also have the same equipment that your child can use during their stay.

What to do if you can't bring or collect your child

If you can't bring or collect your child from us, or you won't be at home, you can nominate someone else instead, such as a relative, friend or carer. The person should be competent to care for your child's needs. You need to tell staff prior to the care session and give contact details for the alternative person. You'll need to make other arrangements with the staff for checking your child's medicines and reviewing care.

Communicating with us when your child stays

When you arrive, our staff will spend time with you reviewing your child's care plan and checking in their medicines.

During their stay, you are welcome to phone us as often as you wish to speak with your child or enquire about them. With your permission, family and friends are welcome to visit your child while they are staying.

When you collect your child, staff will spend time talking to you about their stay. You need to allow sufficient time for handover at the start and end of each care session or stay.

Allocation of dates and requests

Families that are eligible to receive short break care have the opportunity to request specific dates for some of their allocation. Families may choose to request day care sessions or overnight sessions in the hospice or to have care delivered in their home during the day. Families may decide not to request dates, but to be allocated short breaks by the bed booking team. This increases the flexibility of the allocation process and allows us to book around dates that may have been requested by other families. Similarly some families will choose to inform us of dates that they definitely cannot do, we then know what dates not to offer them.

On occasions it may be necessary for us to cancel our services at short notice, e.g. if staff are required to provide end of life care or because of staff sickness. If this happens, we'll advise you as soon as possible. If you wish to cancel care, please call us as soon as possible.

Page 4 of 7

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).

V8. Oct. 2021

Short break care for your child

Medicines

When your child comes to stay at the hospice, our nurses and care assistants need the following to be able to give your child's medication safely.

1. All boxes/bottles must be clearly labelled with the correct name, correct date and correct frequency for the medication to be given (please check expiry dates and write on liquid medication the date it was opened).
2. Evidence of prescription- this may be a green repeat prescription slip or a recent clinic letter
(this can be photocopied at admission so you can take it home again).
3. Enough of each medicine to last for the duration of the stay.
4. The medicine must not expire during the child's stay with us.
5. If your child /young person uses buccal midazolam medication (prefilled syringes), the container the syringe is kept in, needs to be sealed on admission (the plastic seal should be intact).
6. Enough syringes to administer all of your child's medication for the length of your stay.

If the prescription label information on the container has the wrong dosage (for example due to the dosage having recently changed or is unlabelled), please can you:

- Bring a recent clinic letter or a recent prescription (green paper) with the correct medication and dosage prescribed or
- Call the hospice and ask for a copy of the EACH Verification of Prescription form which you can take to clinic for the consultant to sign to confirm the change
- Food supplements, vitamins and prescribed creams should also be verified by a clinic letter or a prescription.

As part of the admission process the nurse or care assistant will need to;

Short break care for your child

- Complete the Medicines Administration Record (MAR) recording all the medicines which your child/young person is currently receiving
- Confirm which medicines are required and which have already been given
- Clarify any difference or concerns about the dose, route, strength or type of medicine
- Record in your child or young person's record the discussion and confirm the administration instructions.

If you are worried that you may not have this information, please can you phone the hospice before the admission to discuss with the Nurse in Charge or Deputy Service Manager, so that a safe plan can be put in place before you arrive. Failure to do this may result in our staff not being able to admit your child/ young person and regrettably the stay may be cancelled.

Transfer to hospital

If your child needs admission to hospital while in our care either at home or in the hospice, they will be transferred to the local hospital by emergency services. Once the staff have handed over to the paramedic team, the paramedics then assume responsibility for the ongoing delivery of care. It may not be possible for the staff to escort your child to hospital. We'll advise you of the situation as soon as possible.

In the event of an emergency

You will be asked to complete an emergency contact sheet and these details must be confirmed before each care session. If you won't be available for contact, you can nominate someone else who we can contact on your behalf.

Occasionally the hospice may need to close or cancel short break care at short notice. If you are not available to collect your child then you must provide us with details of a nominated individual who is competent to care for your child, and who can collect them.

In the event of an unforeseen emergency, which prevents you from returning home or collecting your child at the agreed time, please contact our staff immediately. If you haven't returned by the agreed time or made contact, staff will use the emergency details provided. If we can't make contact with you, we'll inform the social care emergency duty team to ensure your child continues to be cared for safely until your return.

Short break care for your child

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
Nursing Service 0808 196 9495; each.each.smns@nhs.net

www.each.org.uk/contact-us