




Support for your family

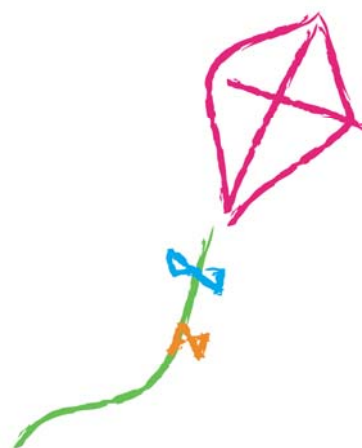
East Anglia's Children's Hospices (EACH)

WHEN YOUR FAMILY NEEDS SUPPORT

When a family has a child with a life-threatening condition, there are often stresses and strains upon all family members. Relationships can become difficult when there is someone who needs a lot more care than everyone else. Brothers and sisters sometimes have a particular need for support. It is sometimes hard to make decisions about your child's care, and you may feel you do not have all the information you need to make those decisions. There are times when it might seem that there is nowhere to turn and no one to talk to.

We can help you consider the choices that are open to you and support you where possible to achieve what your family needs. This leaflet on Family Support at EACH contains:

-  Supporting your family
-  Planning the support for your family
-  Community care agreements
-  Dates and times for support sessions
-  Cancellations
-  Telephone advice and support
-  Professional boundaries
-  Endings





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SUPPORTING YOUR FAMILY

EACH services can be accessed individually or in any combination. This means if you don't want to receive nursing care for your child, you can still access Family Support.

All three EACH hospice sites have a Family Support Team of professionally trained and experienced workers. Their job is to offer support to all family members - they are known as Family Support Practitioners.

Every family situation is unique so we aim to support your family according to your individual circumstances. This support can be offered in a variety of ways:

- support for your child
- individual support for parents or guardians, brothers and sisters and significant others
- support for family members together
- group support with other parents, children and carers
- information about practical issues, such as benefits and support groups
- helping you to liaise with other services
- helping you to create memories

The process of bereavement can start at the moment of diagnosis. We believe that having support available when you need it, both during your child's life and afterwards, helps families to cope during the more difficult times. The Family Support Team is available to you at any time from your family's acceptance for EACH services up to three years after the death of your child.

Support can be provided in the family home, the community or your local hospice depending on your preference.

PLANNING SUPPORT FOR YOUR FAMILY

The support EACH provides is individual to your family's needs. For this reason, we need to ask a range of questions and collect some quite detailed information about your family.

Before support can start, a Family Support Practitioner will meet you to discuss you and your family's needs and agree a support plan with you. The meeting may last up to two hours.

The Family Support Practitioners will liaise with others involved in supporting your family. By working together, we aim to ensure the psycho-social needs of families are met by the most appropriate person and without duplication. If it is felt that your family's needs would be better met by an external professional for alternative or additional support, then this will be discussed with you.



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HOME CARE AGREEMENT

When nursing care and/or family support is required in the home, the staff will discuss the home care agreement with you. The agreement ensures that family members and EACH staff have shared understanding of the care plan and what is expected by both parties.

A responsible adult will be expected to remain in the home during family support sessions for children up to the age of 16.

DATES AND TIMES FOR SUPPORT SESSIONS

Whenever possible, the Family Support Practitioner will try to meet your family's preferences for dates and times for support sessions. They normally only work weekdays but are able to offer evening appointments.

CANCELLATIONS

On occasions it may be necessary for us to cancel a support session at short notice, e.g. staff required to provide end of life care or staff sickness. In these circumstances we will advise you as soon as we can. If you wish to cancel a support session, you should telephone the Family Support Practitioner directly or if they are not available, telephone your local hospice.

TELEPHONE ADVICE AND SUPPORT

This is available from the Family Support Practitioners, Monday to Friday, during normal office hours. If you need support out of these hours then it can be accessed by telephoning your local hospice:

Ipswich (Suffolk)	Tel. 01473 714194
Milton (Cambridge)	Tel. 01223 815115
Quidenham (Norfolk)	Tel. 01953 888603

When the hospice buildings are closed, an answer phone message will give the contact telephone number for the on-call Palliative Care Manager.

PROFESSIONAL BOUNDARIES

EACH care staff are required to maintain professional relationships with the children and their families at all times and are therefore unable to discuss other children and families with you, accept personal invitations to family events, give families their personal telephone numbers or accept gifts from families.



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ENDINGS

A family may end their involvement with EACH for various reasons, including:

- your child's illness or condition improves and they no longer meet criteria for EACH services
- your child requires transitional care to adult services
- your family moves from the area
- at any time up to three years after the death of your child

Following the death of a child, the Family Support Practitioner will facilitate the ending of regular support from the other EACH staff as part of an agreed bereavement plan.

