How to make a referral to EACH

If you are a social or health care professional and have permission from the family to make a referral to EACH, you can do so in the following ways:

- **Download** the referral form from our website at www.each.org.uk/refer and return via:
  - email to: each.referrals@nhs.net or
  - post to: Referrals to EACH, Church Lane, Milton CB24 6AB
- **Email** each.referrals@nhs.net and request a referral form
- **Telephone** 01223 800 800 to request a referral form
- **Ask** for a referral form **in person** from an EACH member of staff

Please note:
The referrer is responsible for ensuring that relevant clinical information is provided to ensure prompt decision making. If this is not included, the process will be delayed whilst clarification is sought

All referrals are managed through our weekly multi-professional panel, which determines eligibility for our services. Once eligibility has been established a member of EACH staff will visit the family to make a Holistic Needs Assessment (HNA) which takes into account the needs of the whole family. This helps us to establish how we can best meet their needs, involving the whole family and using a person-centred approach.

Urgent referrals for end of life care or for care of a deceased child or young person are dealt with immediately. Please telephone 01223 800800 and your information will be passed to the relevant locality leadership team to action.

If you are making a referral for your own child or young person we require the name and contact details of a professional involved in the care of your child so that we can fully understand your child's or young person's needs.

For more information about your referral to EACH please look at the introductory information leaflet called: about how a referral to EACH is managed.

Eligibility for EACH services

A baby, child, young person (CYP), their family and those significant to them are eligible to access services from EACH, if the following criteria are met:

The baby or CYP has a life-threatening or life-limiting condition and may benefit from palliative care input, which is tailored to their needs. This includes:

Life-threatening conditions

- In these conditions curative treatment is possible but may fail. Palliative care services are generally not involved during active treatment unless there are very specific needs e.g. for emotional support or short breaks, which cannot be met by other services
- Palliative care services are usually needed if curative treatment fails and may be given alongside experimental therapies
- Cancer and leukaemia are the most obvious examples, but children with congenital heart disease or renal or liver failure may follow this pattern.

Life-limiting conditions where premature death is inevitable, but where there may be long periods of intensive treatment aimed at prolonging life and facilitating participation in normal activities

- Examples include conditions such as Cystic Fibrosis and Duchene Muscular Dystrophy
- Children with these conditions usually live well into adulthood and rarely require palliative care input during childhood
- A few children, whose disease progresses unusually quickly e.g. CF with progressive respiratory failure during adolescence, may benefit from access to symptom management and palliative care planning. This may include parallel planning during transplant assessment

Life-limiting conditions which are progressive and without curative treatment options, treatment is exclusively palliative and may extend over many years

- Examples include Mucopolysaccharidoses, metachromatic leucodystrophy, Krabbe's disease, SMA type I and many very rare genetic and metabolic conditions. Children with a progressive clinical picture but no definitive diagnosis may also fit this pattern.
- Children with these conditions often need a wide variety of palliative care services at different times.

Life-limiting conditions which are irreversible but non-progressive associated with severe disability leading to susceptibility to health complications and the possibility of premature death

- Examples include severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury
- These children may have long periods of stability but may have chronic symptoms and pain syndromes and may also be at risk of acute deterioration
- Families may benefit from access to short breaks and emotional support plus symptom management and anticipatory planning

Children who have not responded to maximal intensive therapy (PICU or NICU) for a variety of conditions may be referred for palliative care support for withdrawal of intensive treatment

- These children may need careful symptom management and transfer to home or hospice
- Families will benefit from access to emotional support
- A significant number of children survive withdrawal of intensive treatment: they and their families will need on-going symptom management and support

Examples of conditions for perinatal palliative care:

- Category 1. An antenatal or postnatal diagnosis of a condition which is not compatible with long term survival, e.g. bilateral renal agenesis or anencephaly.

- Category 2. An antenatal or postnatal diagnosis of a condition which carries a high risk of significant morbidity or death, e.g. severe bilateral hydronephrosis and impaired renal function.

- Category 3. Babies born at the margins of viability, where intensive care has been deemed inappropriate.

- Category 4. Postnatal clinical conditions with a high risk of severe impairment of quality of life and when the baby is receiving life support or may at some point require life support, e.g. severe hypoxic ischemic encephalopathy.

- Category 5. Postnatal conditions which result in the baby experiencing "unbearable suffering" in the course of their illness or treatment, e.g. severe necrotizing enterocolitis, where palliative care is in the baby's best interests.

AND the CYP or family live in Norfolk, Suffolk, Peterborough, Cambridgeshire and Northern areas of North, Mid and West Essex.

In exceptional circumstances EACH may offer a service to CYPs and their families who live outside these areas if it is deemed 'safe' to deliver the care required and there is no other service available to meet CYP and family need.

AND the CYP is less than 18 years of age. The needs and goals of young people referred aged 16 years and over are considered on an individual basis. They are eligible for a service if they are entering the final phase of their life and there are no alternative services available.

Families bereaved of baby, child or young person who died as a result of a life threatening / life limiting condition, not previously known to EACH before their death, are eligible for bereavement support from EACH.