



# Assessment Criteria

## General criteria:

- Babies, children and young people with a serious or life-limiting condition who are unlikely to reach adulthood.
- Referrals must be made with the knowledge and consent of an adult that holds parental responsibility.

## Location criteria:

- Live in the Demelza catchment area of Kent & Medway, East Sussex and South East London.

## Age criteria:

- Referrals can be made before birth up to the 18th birthday for specialist end of life care.
- Referrals can be made antenatally up to the 16th birthday for non-urgent care.
- Referrals can be made for the death of an unborn baby above 24 weeks' gestation where diagnosis meets the usual criteria. Deaths between 22–24 weeks' gestation will be assessed on a case-by-case basis.
- Nursing services will stop when the young person reaches their 18th birthday, however young people who are on Demelza's caseload on their 18th birthday can continue to receive support from Demelza's transition team until their 25th birthday.

## Bereavement support criteria:

- Referrals can be made for families of babies, children and young people who have died due to a serious or life-limiting condition and would have met our usual criteria.
- These referrals can be made up to six months after a child has died.

## Additional criteria:

- **Our services are grouped within three Circles of Care, allowing us to offer a broad range of holistic services while our specialist nursing and care professionals provide personalised support to families when they need it the most.**
- **All babies, children and young people must meet the following criteria.**

## Family services

- An oncology diagnosis and currently going through treatment.
- System failure (heart, renal, liver, gut, skin) or genetic disorders – with conditions deemed life-limiting.
- Progressive conditions (without curative treatment options) where death before 18 is possible, however condition is currently stable.
- Extreme prematurity between 22- 24 weeks and currently under neonatal team on Oliver Fisher or Kings neonatal intensive care unit (will be reviewed after six months).
- Non-invasive ventilation level 1.
- Artificial airway (could manage for short time without compromise)
- Medications and feeds administered via jejunostomy
- Epilepsy disorder which has required rescue medication within last 6 months. This includes vagus nerve stimulation where regular magnet stimulation is required. Those with drug resistant epilepsy but not febrile seizures.
- Baby under one year old with an acquired neurological condition – please see eligibility criteria for further information.
- Baby who remains on neonatal intensive care unit with an uncertain future.
- On paediatric palliative care team caseload (annual reviews, no access to on call service required).
- Generalised or multifactorial dystonia which significantly affects feeding, sleep, breathing, and requires frequent additional medication (e.g. weekly).

## Specialist short breaks

- Oncology diagnosis with a palliative, poor prognosis or relapse.
- On transplant list or not suitable for transplant. Palliative or poor prognosis. Unstable or compromised health needs. Example: requiring long term oxygen.
- Severe scoliosis that compromises respiratory function.
- Repeated prolonged and severe chest infections requiring hospital intervention or Intravenous antibiotics.
- Non-invasive ventilation level 2 or long-term ventilation 3.
- Neurogenic gut failure.
- Unstable airway if artificial airway fell out.
- Vulnerable unsupported airway e.g. Stridor, apnoea's requiring intervention.
- Long-term oxygen therapy – continuous use of oxygen to maintain oxygen saturations above 92%.
- Parenteral nutrition, gut failure (pain or distress associated with feeding necessitating progressive feeding reduction), severe bulbar involvement (worsening swallow, cough, gag reflex).
- Poorly controlled seizures requiring frequent hospital admissions / frequent use of seizure rescue intervention (weekly).
- Central shut down (instability of brainstem function – temperature, circulation or breathing).
- Severe dystonia despite regular medication, severe hyper or hypotonia or deep brain stimulation / baclofen pump.
- Past year's health has been unstable with significant deterioration requiring escalating medical interventions.
- On active paediatric palliative care team caseload (regularly engaging / access to on-call service / ceilings of care / advance care plan in place / active symptom management).

## ○ Specialist nursing care

- Acute symptom management, introduction or adjustments to medications.
- Antenatal or postnatal diagnosis condition which may not be compatible with long-term survival.
- Antenatal or postnatal diagnosis of a condition which carries a high risk of significant morbidity or death, however babies may live months or years into childhood.
- Babies born at the margins of viability, where intensive care has been deemed inappropriate. Example: severe bilateral hydronephrosis and impaired renal function, SMA type 0.
- Postnatal conditions which result in the baby experiencing 'unbearable suffering' in the course of their illness or treatment, e.g. severe necrotising enterocolitis, where palliative care is in the baby's best interests.
- Compassionate extubation, end of life care.



**To speak to the team about making a referral please contact:**

**Referrals Team**

**Call:** 01795 845253

**Email:** [demelza.referrals@demelza.org.uk](mailto:demelza.referrals@demelza.org.uk) or [demelza.referrals@nhs.net](mailto:demelza.referrals@nhs.net)

**[demelza.org.uk](https://www.demelza.org.uk)**

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