Eligibility Criteria

Introduction

Demelza delivers extraordinary care to extraordinary children who are facing serious or life-limiting conditions, throughout Kent, East Sussex and South East London. We support families when and where we're needed most - in our hospices, in families' homes, in local communities and online.

With over 25 years of experience, Demelza's specialist nursing, care and support professionals are committed to meeting the needs of children and their families.

If you have any questions about Demelza's services, please call 01795 845280 or email demelza.referrals@demelza.org.uk

1.0 General criteria

1.1 Palliative care

Babies, children & young people with a serious or life-limiting condition who are unlikely to reach adulthood.

1.2 Location criteria

Babies, children & young people must live in the Demelza catchment area of Kent & Medway, East Sussex or South East London (specifically the boroughs of Bexley, Greenwich, Bromley, Southwark, Lambeth and Lewisham.)

1.3 Age criteria

Referrals can be made before birth up to the 16th birthday for non-urgent care and up to the 18th birthday for specialist nursing services such as end of life care.

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.

2.0 Antenatal referrals

2.1 Death of a baby during pregnancy

Referrals can be made for the death of an unborn baby past 24 weeks gestation where diagnosis meets Demelza's usual criteria, deaths between 22- 24 weeks gestation will be individually assessed.

2.2 Support during pregnancy

Referrals can be made for families expecting a baby who is likely to have palliative care needs or not survive long after birth.

3.0 Bereavement support

3.1 Children known to Demelza

Any baby, child or young person already on Demelza's caseload at the time of their death will be offered access to Demelza's bereavement support services, a new referral does not need to be made.

3.2 Sudden deaths

Demelza is unable to offer support to families of babies, children and young people who died due to a sudden or unexpected death such as an accident, suicide or homicide.

3.3 Bereavement support for family members

Referrals can be made for families of babies, children and young people who have died due to a serious or life-limiting condition that met our usual criteria, these referrals can be made up to 6 months after a child has died.

Demelza can offer support to those who had a significant emotional or caregiving relationship with the baby, child, or young person.

4.0 Assessing new referrals

New referrals will be reviewed and assessed by Demelza's referral panel after the assessment process is complete, this meeting is held regularly and consists of senior clinical staff. Demelza will seek proportionate clinical information to determine if a child meets criteria.

Clinical needs are to be evidenced through clinical letters so that any future changes to our service offer can be easily referenced.

Urgent referrals such as requests for an admission for end of life care, will be managed outside of referral panel via our urgent care pathway.

5.0 Service offer

5.1 Circles of Care

Demelza's circles of care are designed to ensure we offer a broad range of holistic services to all families on our caseload while allowing our specialist teams to provide additional support to families when they need it the most.

This means that not all children accepted on to Demelza's caseload will be offered specialist short breaks or specialist nursing care, an additional assessment will be completed to determine appropriate access to these services and these criteria are shown in this document in **blue**. This assessment will assess medical and social needs.

If babies, children and young people meet multiple components of the criteria which are not in written blue, Demelza's referral panel may decide that it is the child's best interest to offer access to specialist nursing care due to their clinical vulnerability.
The social factors considered may include, but are not limited to, the following;

- Children on a newly initiated child protection plan
- Families experiencing major life events such death of a parent/carer
- Safeguarding concerns that are known to the Local Authority which may mean that a short break will be beneficial to the child e.g. place of safety
- Families where there are multiple siblings on Demelza's caseload in the yellow circle of care leading to significant impact on parents/carers. Each case with be individually assessed.

6.0 Appeals

Families have the right to appeal a decision relating to a new referral, circle of care or decision to discharge from Demelza, a health or social care professional can also appeal on a family's behalf with their consent.

All appeals will be reviewed by our senior nursing team and can take up to 25 working days to be reviewed.

For further information about the appeals process, or to make an appeal, please contact **demelza.referrals@demelza.org.uk.**

7.0 Additional criteria

Babies, children and young people must meet one of the following criteria to access Demelza's services.

8.0 Oncology

- Any child who has a cancer diagnosis and currently undergoing treatment
  - Discharge will occur one year after successful treatment ending
  - Can be referred to community team for further assessment.
- **Palliative diagnosis, poor prognosis, relapse**

9.0 System failure

Each case will be reviewed on an individual basis and in discussion with the child's consultant or a consultant working with Demelza to ensure the best possible care plan.

Following successful treatment into remission or one-year post-transplant, children will be discharged.

9.1 Cardiac

All cardiac conditions are lifelong and require ongoing follow-up and potential treatment, including medical, catheter, or surgical interventions. This list is not exhaustive, and clinical expertise may identify additional conditions that require palliative care input:

- Functional Single Ventricle (FSV): Treatment is individualised and usually requires open-heart surgery, such as the Norwood, Glenn, and Fontan procedures
- **Baby/ child will be eligible for specialist nursing care until completed all surgeries**
- **Pulmonary Atresia with MAPCAs**
- **Children referred for cardiac transplantation**
- **Cardiomyopathy (<10kg) with no improvement**
- **Critical aortic stenosis**
- **Pulmonary Hypertension requiring input from national pulmonary hypertension service**
- **Pulmonary vein stenosis affecting ≥2 veins**
- **Ebstein's anomaly/tricuspid atresia with significant cardiomegaly and functional pulmonary atresia in utero**

Complex Cases

- **Children with complex co-morbidities or atypical progression (e.g., inoperable tetralogy with additional health issues)**
- **Life-threatened children with initial palliative operations but potentially curable with subsequent surgeries (e.g., tetralogy with an arterial shunt)**

9.2 Liver disease

The liver can recover quickly despite significant injury, and sometimes a full recovery is possible without need for transplant. Most children receiving a liver transplant will make a full recovery and, although they will require lifelong medication, the majority will be able to lead a normal life.

- Acute Liver Failure: When liver cells suddenly die or stop functioning normally
- Alagille Syndrome: A rare genetic condition affecting the liver, heart, kidneys, eyes, face, and bones. There is no cure, but treatments manage symptoms, including vitamin supplements, medications, nutritional assessment, and, in rare cases, liver transplantation or other surgery
- Alpha-1 Antitrypsin Deficiency: This condition affects children differently. Some may require a liver transplant, while others lead almost

normal lives with annual check-ups. Post-transplant outcomes are excellent
- Autoimmune Liver Disease: Treatment usually continues for years. Stopping treatment is considered only after at least two years of normal blood tests and a liver biopsy showing no inflammation. Remission is the aim
- **Children waiting for a liver transplant or with a poor prognosis, and those not eligible for transplant**.

9.3 Kidney disease
- The following is a list (not exhaustive) of conditions that would meet criteria:
- Acute Kidney Injury (AKI): Severe cases where the kidneys suddenly stop working, leading to life-threatening complications
- Chronic Kidney Disease (CKD): Advanced stages where the kidneys have lost most of their function and the child is experiencing significant symptoms and complications.
- Congenital Kidney Disorders: Conditions present from birth that severely affect kidney function and overall health
- Polycystic Kidney Disease (PKD): A genetic disorder causing numerous cysts in the kidneys, leading to kidney failure
- Nephrotic Syndrome: Severe cases where the kidneys leak large amounts of protein into the urine, leading to significant health issues
- Glomerulonephritis: Severe inflammation of the kidney's filtering units, leading to kidney failure
- **Children waiting for a kidney transplant, on dialysis or with a poor prognosis, and those not eligible for transplant**

9.4 Gut failure
The following is a list (not exhaustive) of conditions that would meet criteria:
- **Short Bowel Syndrome (SBS): Severe cases where the child has lost a significant portion of the small intestine, leading to malabsorption and dependence on parenteral nutrition**
- **Intestinal Failure: When the intestines cannot digest food and absorb nutrients adequately, often requiring long-term parenteral nutrition**
- **Chronic Intestinal Pseudo-Obstruction (CIPO): A condition where the intestines have severe motility issues, mimicking a blockage without an actual physical obstruction**
- **Severe Gastrointestinal Motility Disorders: Conditions that significantly impair the movement of food through the digestive tract, leading to severe nutritional and growth issues**
- **Children Awaiting Intestinal Transplant: Those on the transplant list or with a poor prognosis and not eligible for transplant**

9.5 Skin disease
Epidermolysis bullosa (EB) is the most common skin condition that is life limiting. The outlook for children with epidermolysis bullosa (EB) depends very much on the disease type they inherited. Some forms are mild and may even improve with age these include:
- Epidermolysis simplex, EBS
- Dystrophic epidermolysis bullosa (DEB)
- Kindler syndrome

Others are so severe that a child is unlikely to live into adulthood.
- **Junctional epidermolysis bullosa (JEB) - The life expectancy of children with JEB is poor, and about half do not survive past the first year of life, and many die before they are 5 years old.**

10.0 Progressive conditions without curative treatment options

These may include metabolic, genetic / chromosomal diagnoses where it is unlikely they will reach their 18th birthday. Examples include, Edwards syndrome, Patau syndrome, early on-set Metachromatic leukodystrophy (MLD), Canavan disease, Tay-Sachs disease, Battens disease, Duchenne Muscular dystrophy (DMD), Spinal Muscular Atrophy (SMA)
- Children who have a diagnosis but are currently stable
- **Children who are palliative (this could be from diagnosis) and unlikely to reach 18th birthday**
- **Children whose health is very unstable and meet one of the other criteria in the blue**

10.1 Duchenne muscular dystrophy
Whilst it is recognised that a diagnosis of Duchenne Muscular Dystrophy can be devastating, due to medical advances children are living into adulthood with this condition.
- Children at stages 1,2,3 (without cardiac involvement) as confirmed by their neurologist
- **Children at stage 3 with additional cardiac involvement or level 2/3 NIV support and stage 4**

Stages:
1: Early Ambulatory: Getting up from the floor or from lying down may be difficult. Calf muscles may appear to be enlarged or swollen. Learning or behavioural difficulties may appear at this stage.

2: Late Ambulatory: Children at this stage will still be able to move around by themselves, but it will become increasingly difficult, walking becomes harder. Balance may be affected, which may lead to a change in posture. They may walk on the balls of their feet or their toes more than other children.

3: Early non-Ambulatory: Will lose the ability to walk independently and will start using a wheelchair on a more regular basis. They will still be able to use their arms to propel themselves around, but increased weakness will start spreading to the arms and neck. Lungs will weaken, which may lead to difficulties with breathing. Breaths may become shallower, and the ability to cough lessens. This may lead to more chest infections because it's harder to clear mucus and germs from the chest. The heart muscles may also be affected, cardiomyopathy,

4: Late non-Ambulatory: Dysphagia, requiring gastrostomy/ jejunostomy. Breathing weakens, oxygen levels in the blood may fall, leading to tiredness, irritability, headaches on waking, inability to sleep and vivid dreams. Breathing respirators, and cough assist technologies can help with this. Breathing support may be needed, first overnight and then during the daytime.

10.2 SMA

There are several types of SMA and due to medical advances life expectancy has increased. The following stages of condition as confirmed by their neurologist:

- **SMA 0**
- **SMA 1 & 2 (service offer subject to eligibility assessment)**

SMA Type 0 and 1

The symptoms and effects of SMA Type 0 is evident antenatally and Type 1 usually begins from birth or within the first few weeks or months of life.

- Breathing muscle weakness, which can cause a weak cry and difficulties with breathing and coughing
- An increased chance of chest infections, which can be life-threatening
- Difficulty swallowing their saliva and other secretions, which may make them sound chesty or make them cough
- Difficulties feeding and gaining weight
- An increased risk of fluids or food passing into their lungs (aspiration), which can cause choking and, sometimes, chest infections or pneumonia

SMA Type 2

The symptoms and effects of SMA Type 2 usually begin between 6 and 18 months of age. Generally, the earlier the onset of symptoms, the more severe the condition.

- Each child is affected differently; however, they are likely to experience:
- Muscle weakness on both sides of their body
- Muscle weakness closest to the centre of their body as these muscles are more severely affected than muscles furthest away
- Difficulties moving their arms, but their hands and fingers less so
- Difficulties lifting their legs – legs that are weaker than their arms

11.0 Respiratory

- Any child requiring Non-Invasive Ventilation (NIV 1) or having an artificial airway which is stable and would survive accidental tracheostomy disconnection
- **Child requiring level 2 or 3 ventilation**
- **Unstable airway if artificial airway fell out**
- **Vulnerable unsupported airway e.g. Stridor, apnoea's requiring intervention**
- **Long term oxygen therapy – continual use of oxygen to maintain saturation above 92%**
- **Severe scoliosis that compromises respiratory function (frequent infections or breathlessness or oxygen therapy or frequent hospital admissions/interventions for difficulty in breathing)**
- **Repeated, prolonged and severe chest infections requiring intervention or IV antibiotics**
- **Central shut down (unable to control temperature, circulation or breathing)**

11.1 Definitions of Ventilation:

Level 1: Able to breath unaided but needs to go onto a ventilator for supportive ventilation. The ventilation can be discontinued for up to 24 hours without clinical harm.

Level 2: Requires ventilation at night for poor respiratory function: has respiratory drive and would survive accidental disconnection but would be unwell and may require hospital support.

Level 3: Individuals is unable to breathe independently and requires permanent mechanical ventilation or has no respiratory drive when asleep or unconscious and requires ventilation and 0ne to one support while asleep (as disconnection would be fatal).

12.0 Nutrition

- Medications and feeds administered via jejunostomy
- **Neurogenic gut failure as diagnosed by consultant**
- **PN, gut failure, severe bulbar involvement**

13.0 Seizures

- Epilepsy disorder which has required rescue medication within last 6 months (this includes VNS where regular magnet stimulation is required). Those with drug resistant epilepsy.
- **Complex and poorly controlled requiring frequent hospital admissions or frequent use of seizure rescue intervention (weekly).**

14.0 Dystonia

- Dystonia is a neurological condition causing uncontrollable muscle spasms. While it is usually lifelong but not life-limiting, in some children it can severely affect feeding, sleep, breathing, and additional medication (weekly basis).
- **Those with frequent or severe symptoms may require advanced treatments like deep brain stimulation or a baclofen pump, especially if there is significant respiratory compromise or poor nutrition and weight gain.**

15.0 Neonates/ Babies under 1 that do not fall into any above criteria

- Extreme prematurity (babies born between 22-24 weeks gestation) and currently under NICU team in Oliver Fisher or Kings College Hospital
- Babies under 1 with acquired neurological condition with one of the following:
  - Vulnerable unsupported airway, e.g. laryngomalacia, stridor, apnoea, requiring airway repositioning or jaw thrust
  - Severe scoliosis that compromises respiratory function
  - Ongoing need for oxygen therapy or ventilatory support
  - Escalating medical interventions
  - Neuro-genic gut failure
  - Central shut down
- Babies that remain on NICU with an uncertain future

16.0 References

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To speak to the team about these changes please contact:

Referrals Team

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