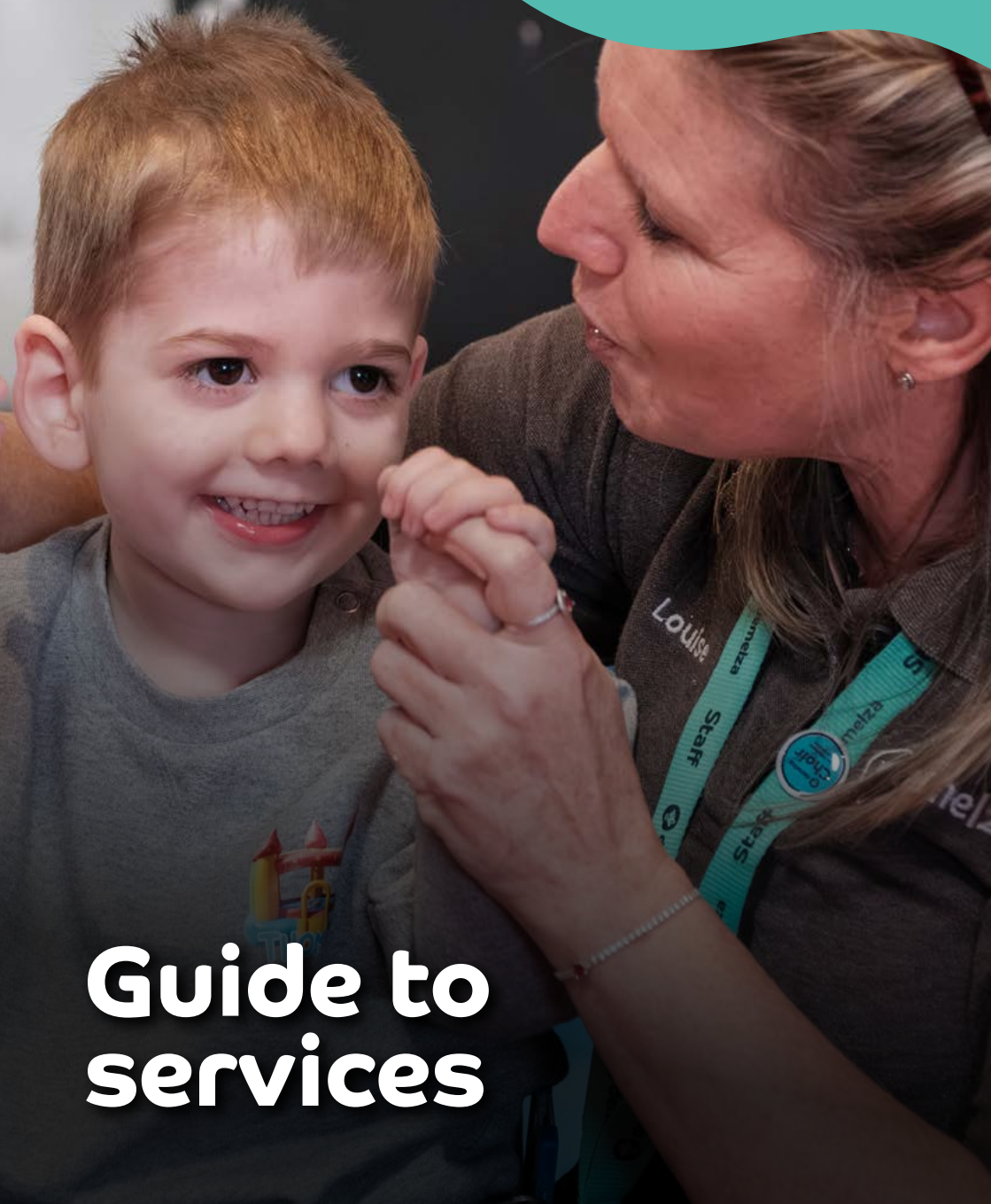




demelza



# Guide to services



## Contents

|                                   |           |
|-----------------------------------|-----------|
| Welcome to Demelza                | 5         |
| Being referred to Demelza         | 6         |
| Circles of Care                   | 8         |
| <b>Family Services</b>            | <b>10</b> |
| Practical support                 | 10        |
| Family events                     | 10        |
| Bookable facilities               | 11        |
| Groups and activities             | 12        |
| Transition into adult services    | 12        |
| Creative arts therapies           | 13        |
| Physical therapy                  | 14        |
| Sibling support                   | 15        |
| Family liaison                    | 15        |
| Counselling                       | 16        |
| <b>Specialist short breaks</b>    | <b>18</b> |
| In our hospices                   | 18        |
| In your home                      | 18        |
| Leaving hospital (step down care) | 20        |
| <b>Specialist nursing care</b>    | <b>22</b> |
| Symptom management                | 22        |
| Support during pregnancy          | 22        |
| Care towards the end of life      | 23        |
| Hospital in-reach                 | 24        |
| Bereavement support               | 25        |
| Safeguarding                      | 26        |
| Care Quality Commission           | 26        |
| Sharing your experiences          | 27        |
| Empowering and involving families | 27        |



# Welcome to Demelza

**Demelza is here to support you and your family – with care that doesn't back down.**

Demelza delivers extraordinary care to extraordinary children who are facing serious or life-limiting conditions, throughout Kent, South East London and East Sussex.

We support families when and where we're needed most – in our hospices, in your homes, in local communities and online.

With two residential hospices and community teams in Kent and South East London and a community hub in East Sussex, we go beyond providing outstanding clinical care and emotional support. We help children explore their creativity, have fun and make memories.

Our support is as unique as every child and family and is personalised to adapt to your specific circumstances. With over 25 years of experience, a range of services and a team of specialist nursing and care professionals, we do our best to meet the needs of your child and family.

To explore the services available, please review our directory on the back page. If you have any questions or would like to speak to someone, please contact our team on **01795 845270** or email **[enquiries@demelza.org.uk](mailto:enquiries@demelza.org.uk)**.



## Being referred to Demelza

### To access Demelza's services your child must:

- Be between 0-25 years old (and not older than 16 when referred except for specialist nursing care).
- Have a serious or life-limiting condition.
- Live in Kent, South East London or East Sussex.
- Have a parent or carer with parental responsibility who consents to the referral.

Our nursing care is available to babies, children and young people up to the age of 18. We also accept referrals during pregnancy (details can be found later in this guide).

### Bereavement support referrals

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.



## Who can refer to Demelza?

Anyone can make a referral with parental consent, such as a health and social work professional, family liaison officer or teacher at your child's school. You can also refer your child directly to Demelza.



## Circles of Care

### How we help

Demelza's services are grouped within three **Circles of Care**. These are designed to ensure we offer a broad range of holistic services while allowing our specialist nursing and care professionals to provide personalised additional support to families when they need it the most. We help children and their families explore their creativity, have fun and make memories.



### How does it work?

#### Family services

All families supported by Demelza have access to our yellow Circle of Care, receiving a holistic offer of wraparound support.

#### Specialist short breaks

Demelza can provide specialist short breaks for children with the highest complex care needs. Our experienced team of nurses and healthcare assistants provide these short breaks in our hospices or in the family home for a few hours.

Our specialist short breaks are offered to families in our blue Circle of Care. These families can also access the services in our yellow Circle of Care.

#### Specialist nursing care

Providing specialist nursing care for children experiencing complex and distressing symptoms, including those requiring support at the end of life, will always be our priority. We work in partnership with healthcare teams to provide the highest quality care and to support families when and where we are needed most.

Specialist nursing care is provided to families in our pink Circle of Care. These families can also access the full range of services in both our blue Circle of Care and yellow Circle of Care.

### Annual reviews

We want to make sure the services we offer your family are aligned with your child's changing clinical needs. That's why we carry out annual reviews of all children supported by us, including a review of their Circle of Care.

# Family Services

## Practical support

Sometimes it's the little things that make the biggest difference. At Demelza, we have specially trained volunteers that can help families by providing driving support, making life easier when you're caring for a child with a serious or life-limiting condition.

Whether it's getting to your child's next hospital appointment, support getting to a Demelza event or travelling to one of our hospices, we can help make the journey a little easier.

## Family events

Throughout the year we organise a series of planned, specialist events for Demelza families. Events are held across our region and include parties and a seasonal programme of activities. Family events are all about making precious memories together, having fun and providing the opportunity to connect with other children and families.



## Bookable facilities

We understand that access, parking and facilities can sometimes make taking your child out challenging. Demelza has fully accessible facilities for you to enjoy as a family.

At Demelza Kent we have a sensory room, soft play, cinema room, hydro pool and fully accessible outside play area. At Demelza South East London and Demelza East Sussex we have sensory rooms.

Our facilities are for all families who access our support no matter where you live. If you want to book some time at one of our sites but would have trouble getting there, why not contact our practical support team to see if they can arrange transport for you.



## Groups and activities

### Demelza Dots

At each Dots session there's a range of toys and fun activities for children to enjoy. Led by Demelza's healthcare assistants, these sessions often include interactive storytelling, singing and messy play, as well as being a space for parents and carers to connect over a coffee.

### Music and art

We run art-making groups during school holidays and offer seasonal music sensory bags, which are sent out to families at their request as part of our seasonal programmes. We also hold a choir in Kent with an option to join virtually.

## Counselling

When life presents challenges, it can be hard to find the space and opportunity to explore your feelings.

Counselling aims to offer safe and confidential space for you to talk and process your emotions with a member of the Demelza team. Following a referral, the team will contact you for a screening call to talk through where and when counselling will be most helpful. Please be aware that there might be a waiting list.



## Creative arts therapies

### Art therapy

Art therapy offers individuals and families the opportunity to use creativity through art-making to explore and express emotions and deal with difficult experiences.

### Music therapy

Music therapy offers a space to explore feelings through play, songwriting, listening, vocalisation and leading music through body language and facial expressions. Sessions can be tailored to your needs, to be exciting or calming, joyful or poignant. In addition to musical instruments, music therapists use sensory props and technology to enhance the musical experience.



Both music and art therapy can be offered individually and to siblings or to family groups. We offer blocks of up to 10 sessions, which can be assessed virtually or face-to-face. Please be aware there is likely to be a waiting list.

### Dance movement therapy

Dance movement therapy involves sensory play to stimulate the imagination and awareness, and music, songs and colourful props to inspire movement. It helps children express their vitality and joy as well as process more difficult feelings and emotions. Dance movement therapy is best suited to children who have some level of intentional movement.

Up to 10 sessions are offered to each child on a weekly basis and can take place within our East Sussex Hub, at your child's school or in your home if it's within a 45-minute drive of Hastings. Please be aware that there might be a waiting list.



## Physical therapy

Using a child's strengths and abilities, we aim to promote independence and wellbeing. Our therapists work closely with you and other professionals to support the implementation of therapeutic plans. We can offer advice and support in the following areas:

### Occupational therapy and physiotherapy

- Positioning.
- Moving and handling.
- Equipment needs.
- Physical development.
- Daily living skills.
- Respiratory physiotherapy.

### Aquatic therapy

The team can provide one-off sessions in the water to offer guidance and support on handling your child and suggest activities that may be beneficial during your family splash sessions. These sessions can be accessed following an assessment by our team.

### Complementary therapy

We provide reflexology for children, young people and adults. Benefits include a deep sense of relaxation, release of tension, better quality of sleep and mood improvement. We also offer Indian head massage.



## Sibling support

Our sibling support programme aims to nurture personal and emotional development while helping siblings understand and accept the challenges they may face. We also offer the opportunity for them to be young, have fun and build friendships with others who have similar experiences to them.

Through a combination of virtual and face-to-face, group and one-to-one sessions, activities and events, we provide a safe space for siblings. We also run a residential trip for a targeted age range during the summer holidays, where siblings can have fun, make memories and create truly wonderful friendships.



## Family liaison

We have a team of experienced family liaison practitioners who support with advice and information, signposting and personalised one-to-one support. The team runs regular groups and events for siblings, parents and carers and families with children who are transitioning to adult services, as well as for children under two years old. A private families' Facebook group provides a space to share experiences and seek advice while hearing about upcoming events and news.



## Transition into adult services

We believe that transition from child to adult services isn't a single event but a gradual process of supporting a young person, and their family, through their teenage years and into adulthood. From the age of 14 and up to 25, we help you to navigate the many changes in finances, care and decision making, with support from our transition navigators. They provide emotional and practical support with a focus on early planning, to help prepare young people and their families to move on from Demelza and access relevant care and support within adult services.





# Specialist short breaks

## In our hospices

Specialist short breaks can be provided up to the age of 18. Day care and overnight breaks for your child are offered at our Kent or South East London hospices where they will be looked after by our specialist nursing and care teams.

Our experienced teams provide individualised support for the whole of your child's stay, giving them the opportunity to enjoy new experiences and take part in activities tailored to their needs.

## In your home

Our community nursing teams provide support in the family home. You can request sessions lasting two to four hours and we personalise each session with fun activities and sensory aids, centred around your child's specific needs.

Our specialist nurses also work with other healthcare professionals to provide clinical care at home, which we can discuss with you.





## Leaving hospital (step down care)

Step down care is for children who are ready to leave hospital but cannot – or are not ready to – go straight home.

If your child has been in hospital, has had an operation or their condition has changed, our nursing and care teams can help you learn how to manage new daily routines and medications.

For new parents, if your baby has been born with complex health needs, you may need additional support when leaving hospital for the first time. The nursing and care team can provide training and support, helping you learn to administer medications and care for your baby, supporting your plans to take them home.





## Specialist nursing care

### Symptom management

If your child has complex symptoms and medication regimes, the nursing and care team have the training, experience and knowledge to help manage their condition effectively. We will work in partnership with your child's healthcare professionals and liaise directly with hospital staff or social workers to arrange a stay at one of our hospices to manage your child's symptoms.

If your child is currently in hospital awaiting an operation and you need support afterwards – or you feel you could benefit from some additional support around your child's medication or symptoms – please contact our referrals team.

### Support during pregnancy

During your pregnancy, your baby may have been diagnosed with a complex medical condition. To support with the questions, concerns and worry this may cause, our family liaison practitioners, specialist nurses and healthcare assistants can offer:

- Emotional support including counselling.
- Special memory making when your baby arrives.
- Advice on any ongoing support you, your baby and family may need.
- Advocacy, financial and grant applications.
- Benefits advice, sibling support and signposting.

Please speak to your medical team about including Demelza in your pregnancy planning or contact the referrals team.



### Care towards the end of life

At Demelza we aim to be there for every child and family who need us, as they approach the end of their life.

Demelza's nursing and care teams will work closely with your child's medical team to manage any symptoms your child may have in the best way possible while supporting the spiritual, cultural and emotional needs of the whole family

This care can be provided in either of our hospices and in the family home.

Demelza will work with hospital staff to support the removal of assisted ventilation, and our bereavement suites and specialist equipment are available to support you to be close to your child for up to five days after they have died.

Our trained team will support you with memory making, such as hand and footprints, hand and footcasts, photographs, pieces of music or art and memory boxes.

If your child is not already known to Demelza when they approach the end of their life, the referral will usually come from your child's medical team. However, you can still contact us to self-refer. We will liaise with your medical team and offer all appropriate support to you, your child and your family.

## Hospital in-reach

Demelza is committed to building strong partnerships with hospitals through our family support and nursing in-reach roles.

By attending multi-disciplinary team meetings and ward rounds, we aim to identify children who may benefit from our services, while also raising awareness of children's hospices and the value of paediatric palliative care.

We want families that have been admitted to hospital to feel informed and supported. Being notified when a child is admitted to hospital allows us to work together to ensure continuity of care – supporting both the child and their family throughout their journey.



## Bereavement support

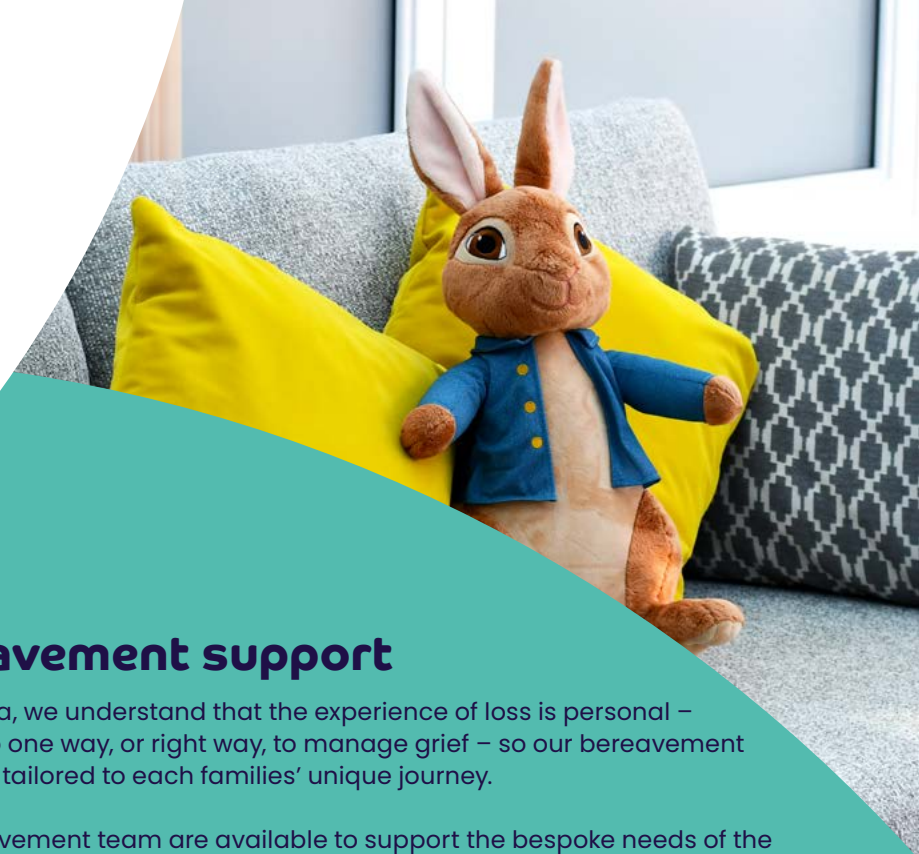
At Demelza, we understand that the experience of loss is personal – there is no one way, or right way, to manage grief – so our bereavement support is tailored to each families' unique journey.

Our bereavement team are available to support the bespoke needs of the whole family through listening and remembering. This may be in person, virtually or over the phone.

Our team will support you with memory making, such as hand and footprints, photographs, pieces of music or art and memory boxes.

We hold bereavement events throughout the year, giving time to reflect, reminisce and meet other families who have experienced the loss of a child. Bereaved families can also access a private Facebook group offering understanding, support and information.

Our bereavement support is available for as long as a family needs us.





## Safeguarding

Safeguarding is the action taken to promote the welfare of children, young people and adults and protect them from harm. At Demelza, safeguarding is paramount at every level of care to keep everyone safe and protected.

Training is provided to Demelza colleagues across the organisation and our designated safeguarding leads are always available for advice and support. If you see or hear anything that makes you worry about a child, young person or vulnerable adult, even if it doesn't seem important, please contact a member of Demelza's safeguarding team – posters with contact details are displayed throughout the hospices and on our website.

## Care Quality Commission

Demelza is regulated by the Care Quality Commission (CQC) who monitor, inspect and regulate health and social care services to make sure they meet fundamental standards of quality and safety.

### To view our reports please visit:

Kent: <https://www.cqc.org.uk/location/1-119107818>

South East London: <https://www.cqc.org.uk/location/1-119107844>

East Sussex: <https://www.cqc.org.uk/location/1-9220478498>

## Empowering and involving families

Demelza's family engagement team leads a wide range of activities designed to amplify the voices of families, children and young people. These events create meaningful opportunities for families to share their experiences, influence service development and connect with others.

### Get involved

Join one of our feedback groups for young people or parent carers – make your views heard, connect, and have fun.

- **Families Voice** is Demelza's network of parents, carers and family members who help shape our services by sharing feedback and meeting regularly with senior leaders.
- **Young Voices** brings together children and young people through groups, activities and one-to-one sessions.

### We're listening

We are always looking for ways to collaborate with families to hear your perspectives. We do this through in-person consultations, attending Demelza events and conducting surveys. Each year, we hold Extraordinary Conversations events, where families, Demelza colleagues, external service providers and others discuss specific topics.



# Who to contact

## All general enquiries

01795 845270

[enquiries@demelza.org.uk](mailto:enquiries@demelza.org.uk)

## Bereavement support

01795 845280

[familysupport@demelza.org.uk](mailto:familysupport@demelza.org.uk)

## Bookable facilities

01795 845270

[enquiries@demelza.org.uk](mailto:enquiries@demelza.org.uk)

## Care towards the end of life

Demelza East Sussex

01323 446461

[eastsussexcare.demelza@nhs.net](mailto:eastsussexcare.demelza@nhs.net)

## Demelza Kent

01795 845201

[kentcare.demelza@nhs.net](mailto:kentcare.demelza@nhs.net)

## Demeza South East London

0208 859 9801

[selcare.demelza@nhs.net](mailto:selcare.demelza@nhs.net)

## Counselling

01795 845280

[familysupport@demelza.org.uk](mailto:familysupport@demelza.org.uk)

## Creative arts therapies

01795 845280

[familysupport@demelza.org.uk](mailto:familysupport@demelza.org.uk)

## Family engagement

01795 845293

[familyengagement@demelza.org.uk](mailto:familyengagement@demelza.org.uk)

## Family events

01795 845280

[familysupport@demelza.org.uk](mailto:familysupport@demelza.org.uk)

## Family liaison

01795 845280

[familysupport@demelza.org.uk](mailto:familysupport@demelza.org.uk)

## Groups and activities

01795 845270

[enquiries@demelza.org.uk](mailto:enquiries@demelza.org.uk)

## Physical therapy

01795 845270

[physicaltherapies@demelza.org.uk](mailto:physicaltherapies@demelza.org.uk)

## Practical support

01795 845299

[practicalsupport@demelza.org.uk](mailto:practicalsupport@demelza.org.uk)

## Referrals

01795 845253

[demelza.referrals@demelza.org.uk](mailto:demelza.referrals@demelza.org.uk)

[demelza.referrals@nhs.net](mailto:demelza.referrals@nhs.net)

## Safeguarding

01795 845270

[safeguardinggroup@demelza.org.uk](mailto:safeguardinggroup@demelza.org.uk)

## Share feedback

01795 845293

[familyengagement@demelza.org.uk](mailto:familyengagement@demelza.org.uk)

## Sibling support

01795 845280

[familysupport@demelza.org.uk](mailto:familysupport@demelza.org.uk)

## Specialist short breaks

01795 845270

[enquiries@demelza.org.uk](mailto:enquiries@demelza.org.uk)

## Symptom management

Demelza East Sussex

01323 446461

[eastsussexcare.demelza@nhs.net](mailto:eastsussexcare.demelza@nhs.net)

## Demelza Kent

01795 845201

[kentcare.demelza@nhs.net](mailto:kentcare.demelza@nhs.net)

## Demeza South East London

0208 859 9801

[selcare.demelza@nhs.net](mailto:selcare.demelza@nhs.net)

## Transition into adult services

01795 845280

[transition@demelza.org.uk](mailto:transition@demelza.org.uk)

Find out more at:

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

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