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Registered Charity No. 1039651



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**Guide to
services**



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Welcome to Demelza

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

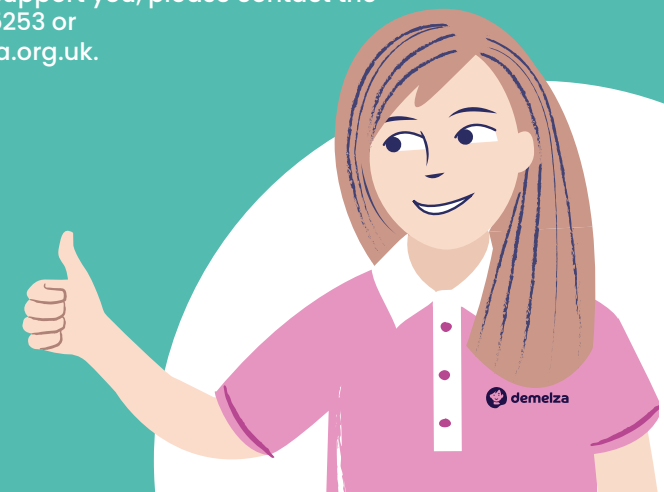
Demelza delivers extraordinary care to extraordinary children who are facing serious or life-limiting conditions, throughout Kent, South East London and East Sussex.

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 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 will be 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 will do our best to meet the needs of your child and family.

If you have any questions or would like to speak to someone to find out how Demelza can support you, please contact the referrals team on 01795 845253 or demelza.referrals@demelza.org.uk.



Being referred to Demelza

All services mentioned in this guide are for babies, children, young people and families who have been accepted to receive Demelza's services.

To access Demelza's services your child must:

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

We also accept referrals during pregnancy (details can be found later in this guide).

Once referred, our nursing care is available to babies, children and young people up to the age of 18. All other services are accessible up to 25 years of age.

Who can refer to Demelza?

Anyone can make a referral with parental consent, such as a health and social work professional, family liaison officers or a teacher at your child's school. As a parent or carer you can also refer your child directly to Demelza or the young person themselves can self refer.

If you would like to find out whether your family could access Demelza's services, please contact our referrals team on 01795 845253, demelza.referrals@demelza.org.uk or go to www.demelza.org.uk/refer.



Practical support

We have specially trained volunteers who can help you with a range of one-off or short-term activities in a way that works for you. These can be small projects such as decorating a room or putting together furniture, or general help such as mowing the lawn or cleaning.

If transport is a challenge, we can also drive you, your child and family to hospital appointments or to Demelza events or activities.

Please contact us on 01795 845299 or practicalsupport@demelza.org.uk and we can have a chat about what you need and how we can help.



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. If you would like to find out more about upcoming events you can opt in to our regular updates at familysupportdepartment@demelza.org.uk



Bookable experiences

We understand that access, parking and facilities can sometimes make taking your child out challenging. This is why we have created a booking process for some of our fully accessible facilities, for you to enjoy as a family.

At Demelza East Sussex we have a sensory room – contact 01323 446461 or eastsussex@demelza.org.uk to book.

At Demelza Kent we have a sensory room, soft play, cinema room, hydro pool and fully accessible outside play area – please contact 01795 845270 or careadministration@demelza.org.uk to book.

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



Jaxson loves the sensory room – with the heated waterbed that keeps him cosy despite his poor blood flow – and we've just gone for our first swim in the hydro pool at Demelza Kent, as Jaxson may never be well enough to use a public pool. We had so much fun.

Laura, mum to Jaxson-James



Groups and activities

Demelza Dots

Stay and play groups for messy and sensory play, story times and social interaction whilst parents and carers can chat to each other. Currently offered within the Kent and South East London hospices, East Sussex hub, in our East and West Kent communities and there are plans to expand into other areas.

Music and art

We have a weekly schedule of online activities such as inclusive art making experiences and music groups and our in-person summer creative therapies programme, which runs over the summer holidays.

Music sensory bags are sent out to families joining the online groups to add a sensory experience to the activities.

Contact us on 01795 845270 or careadministration@demelza.org.uk if you would like more information about these groups.



Transition into adult services

We believe that transition from children 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 16 and up to 25, we will help you to navigate the many changes in finances, care and decision making, with support from our transition navigators. Providing support emotionally and practically with a focus on early planning to help prepare young people and their families to move on from Demelza and be in contact with relevant care and support within adult services. We will also support the young people themselves with advice and activities.

If you would like to speak to us about your child's transition journey, please contact us on 01795 845280 or familysupportdepartment@demelza.org.uk.

Creative arts therapies

Art therapy

Art therapy offers individuals and family groups the opportunity to use creativity through art-making as a way to explore and express your emotions, and support children, young people and adults to deal with difficult experiences.

Music therapy

Music therapy offers a space for exploring feelings through musical play, song-writing, 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 at Demelza is given in blocks of six sessions and can be accessed virtually or face-to-face.

Dance 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 to express their vitality and joy as well as to process more difficult feelings and emotions. Dance movement therapy is best suited to children who have some level of intentional movement. Up to 12 sessions are offered to each child on a weekly basis and can take place within our East Sussex Hub, within your child's school if it is in St. Leonards or your home if it is within a 45 minute drive from Hastings.

If you think you would benefit from art, music or dance therapy, please contact us on 01795 845280 or familysupportdepartment@demelza.org.uk.



Physical therapy

The team will work closely with you and other professionals to develop physical therapy support including positioning, moving and handling, equipment needs, physical development, daily living skills and respiratory physiotherapy. We aim to promote independence, using the child's strengths and abilities.

Aquatic therapy

The team can provide one-off sessions in the water for guidance and support on handling your child and to suggest activities that may be of benefit during your family splash sessions. The aquatic therapy service is currently being developed for children with particular health conditions but the service will be expanded over time.

If you would like to speak to someone about a referral to physiotherapy or aquatic therapy, please contact us on 01795 845270 or careadministration@demelza.org.uk.





Sibling support

Our sibling support programme aims to nurture personal and emotional development whilst helping them to 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 some truly wonderful friendships.

If your child wants to hear more, please contact us on 01795 845280 or familysupportdepartment@demelza.org.uk.

Family liaison

Offering emotional and practical support to your family, we have a team of experienced family liaison practitioners who support with advice and information, signposting and personalised one to one support.

We have a private families Facebook group, which provides a space to share experiences and seek advice whilst hearing about upcoming events and news.

If you would like to contact the family liaison team, join our Facebook pages or email distribution list please contact us on 01795 845280 or familysupportdepartment@demelza.org.uk.



Counselling

When life presents challenges, it can be hard to find the space and opportunity to explore feelings around this. Following an assessment, the team will talk with you about how and when counselling may be most helpful. Counselling is available to those who are not accessing any other therapeutic intervention. Please be aware there is likely to be a waiting list.

If you would like to speak to someone about counselling, please contact us on 01795 845280 or familysupportdepartment@demelza.org.uk.



Support during pregnancy

During your pregnancy, your baby may have been diagnosed with a complex medical condition.

With the questions, concerns and worry this may cause, our family liaison practitioners, registered 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 us on 01795 845253, demelza.referrals@demelza.org.uk or demelza.referrals@nhs.net and we can contact your medical team directly with your consent.



Short breaks

In our hospices

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 will 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 2 to 4 hours and we will personalise each session with fun activities and sensory aids, centred around your child's specific needs.

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



Specialist clinical care

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, 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.

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 the referrals team on 01795 845253, demelza.referrals@demelza.org.uk or demelza.referrals@nhs.net.



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 possible way whilst 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 foot prints, photographs, pieces of music or art and memory boxes.

If it is your first time at Demelza, the referral will usually come from your child's medical team. Otherwise, we can be part of the discussions and support for your family around end of life care. If you have any questions, please contact 01795 845253.



Bereavement support

At Demelza, we understand that the experience of loss is personal; there is no one way, or right way, to manage grief. Our bereavement support threads throughout our service and is about supporting 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.

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

Our bereavement support is available for as long as a family need us. For further information about Demelza's bereavement services please contact the Family Support team via our helpline on 01795 845280 or familysupportdepartment@demelza.org.uk.





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 in 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 visible 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>



Sharing your experiences

Our family engagement team ensures the services we offer at Demelza have the maximum impact by engaging with and supporting families who use them.

Empowering and involving families

Families Voice is Demelza's parent carer group. Their goal is to share their experiences to help enhance Demelza's services. They organise informal cafes, meetings and socials for parents / carers to connect and share experiences. There is also a Young Voices group which aims to give children and young people a chance to share their views, meet others and have fun.

We're listening

We are always looking for ways to collaborate with families to hear your perspectives and experiences. 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.

To contact us please email family.engagement@demelza.org.uk or call 01795 845293. You can also pick up a feedback card on-site.