

Demelza Strategy 2022-27



demelza
extraordinary care for extraordinary children



This is Demelza

Demelza delivers extraordinary care to extraordinary children who are facing serious or life-limiting conditions, throughout Kent, South East London and East Sussex. Demelza is here to support them and their families at every step – from first diagnosis and for as long as we're needed.

It's now over 25 years since Demelza was founded, and this strategy outlines our five key objectives to help us continue to support families and children, to adapt our care and services to meet their needs and to extend our reach in the years to come.



A strategy for the future, and for families





We're excited to present Demelza's new strategy for the future. Our strategy focuses more than ever on actively seeking input and feedback from the real experts: children, young people and their families. We will strive to involve families in our decision making and in how we develop our services and ensure accessibility to all those who need our support, particularly people from minoritised ethnicities.

The objectives outlined in the strategy are based on the findings of six consultation workshops with trustees, volunteers, operational and leadership team members, and families from across all three of our regions. In total we consulted with 70 participants: 13 family members, 6 trustees, 41 staff and 10 volunteers. All participants shared that they felt their involvement was welcomed and valued.

The pandemic has been a time of extraordinary hardship. Many children with serious or life-limiting conditions, and their families, have been disproportionately negatively affected. As we begin to emerge from this challenging time, we will embrace the progress made in how we deliver our services and will continue to seek out and embed how digital technology can support Demelza to be effective and responsive to families who may need our care services now and in the future.


We will collaborate across the health and social care sectors, with private, corporate, statutory and not-for-profit colleagues, to provide seamless services to babies, children, young people and families. Working together will strengthen and sustain services that will remain fit for purpose and best meet the aims and aspirations of those who need them.

Of course, we can't do any of this without the right people. Our staff, volunteers, donors, customers, partners and funders all form an essential chain of expertise and support that we will continue to nurture and develop, to ensure we can meet all the objectives set out in this ambitious strategy.

A handwritten signature in black ink that reads "L Jarrett".

Lavinia Jarrett, CEO, Demelza

We're here to support family life



At Demelza, we want life to be the best it can be for children who have serious or life-limiting conditions – and for their families, and all those who love them.

There are currently almost 90,000 children and young people in England with a life-limiting condition. This number has tripled over the last 20 years and with advancements in research and medical interventions, it will continue to rise.

(Fraser et al, 2020).



Demelza supports over 2,500 children and family members. But we want to go even further.

Since we began, over 25 years ago, Demelza continues to be dedicated to reaching more children and families who need our support. With more babies being born with serious and life-limiting conditions and children living longer with increasingly complex medical and social needs, we want to ensure children and families can access Demelza's individualised, expert care. We want to explore every opportunity to ensure our services are accessible to all, including expectant mothers, children under one, and young people as they move towards adulthood.

Our support is as unique as every family, and personalised to adapt around their specific circumstances: from creative therapies and short breaks, to practical and emotional support for families and siblings, alongside expert clinical and end of life care. Our specialist teams are on hand day and night, all year round.

Demelza offers a different type of care.

Our specialist clinical nursing and care teams provide advice that enables parents to meet their children's complex medical and social requirements with confidence. We also help children to leave hospital, so they can be where they want to be – with their family.

When we're needed most, Demelza is here, with care that doesn't back down. By their side when they feel isolated, and helping to celebrate the joy in family life, making precious memories during challenging times.

1



Our objectives

Be effective



We will provide services that best meet the needs of expectant mothers, children under one, young people and their families. We will constantly work to understand our sector and our families. We will reach out to those who do not access our services, to explore every opportunity to ensure our services are accessible to all.

We will:

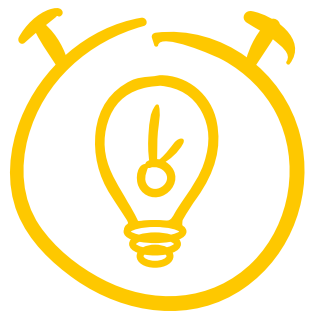
1. Undertake a detailed analysis of the areas where we work: their geography, diversity, deprivation, economics and other relevant factors.
2. Determine the spectrum of need amongst our children and their families, for example, family dynamics, trigger points, crisis triggers, and additional services used.
3. Examine the known prevalence data and look at those we don't reach, and why, with particular emphasis on people from minoritised ethnicities.
4. Continually evaluate the effectiveness of each of our services by analysing who accesses them and the outcomes achieved.
5. Review and benchmark other national and international services.
6. Involve our service users in decision making.
7. Establish outcomes defined by families and verify who can access services from a family group (cousins, aunties, great uncles).
8. Clarify, refine, and develop our service offer to reflect demand.
9. Communicate our service offer effectively to all audiences, both internal and external.



Success means:

- We can map a family journey in our service.
- We can evidence outcomes achieved.
- We interact at a mutually agreed level (a minimum of twice a year) with our families.
- We can evidence the longer-term impact of our work and interventions.
- We can demonstrate the changes put in place thanks to the feedback and involvement of our families.
- We can offer pre-emptive service interventions that offer additional support to families in times of potential crisis or additional need – reducing or removing additional anxiety, stress and crisis points.

2



Our objectives

**Be responsive
(do more)**



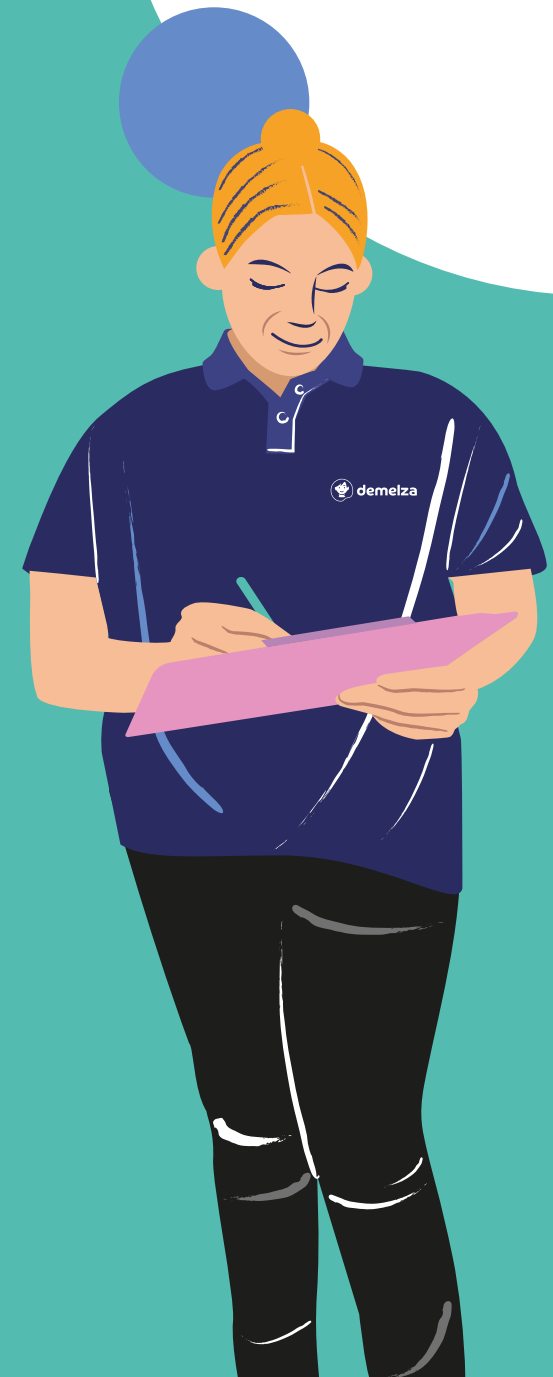
We know that the prevalence of families of children living with a serious or life-limiting condition in the UK has almost tripled, reaching nearly 90,000 in just 18 years, and will continue to rise. We want to ensure more children and families can access our individualised, expert care.

We will:

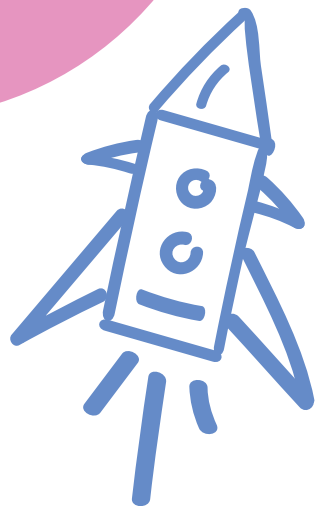
1. Offer choice of the type of care service that families can access.
2. Offer choice of place where our services are delivered.
3. Understand what would make families feel more supported to use our services.
4. Ensure services are accessible, flexible and responsive to changing needs.
5. Create and facilitate interactions that are self-supporting: families supporting each other and communities supporting their families.

Success means:

- We have a clear matrix of services for families to access.
- We offer a choice of place to receive end of life care.
- We offer pre-emptive interventions to reduce stress and anxiety.



3



Our objectives

**Extend
our reach**



Children under one in the UK are the largest group with a serious or life-limiting condition, but an increasing number of young people are surviving in adulthood. We want to ensure our services are accessible to all.

We will:

1. Define who we are not reaching, particularly people from minoritised ethnicities, and why, and plan to fill this gap.
2. Develop our non-clinical service offer and clarify what that this will look like for young people as they move towards adulthood (14–25 years).
3. Grow our referrals to expectant parents, neonates and babies under one.
4. Embed our bereavement service offer, becoming a recognised lead service provider in this sector.
5. Increase our service offer to families, based on the evidence from families themselves about their specific needs.

Success means:

- Our caseload reflects the demographic of the areas we serve, particularly diverse and minority groups.

Increasing caseload:

- We have supported 500 new families, children, and young people.
- We have supported 250 new expectant parents, neonates, and babies under one.



4



Our objectives

**We are
Demelza**



It's our people who make Demelza what it is. With the right people across all areas of our organisation and partnerships, from expert clinicians and therapists to fundraisers and volunteers, we will enable our organisation to be well-led. We will ensure we meet our ambitions and aspirations to more support babies, children, young people, and their families.

We will:

1. Involve children, young people and their families in decision making.
2. Be a learning organisation, seeking evolution and continually embracing learning opportunities.
3. Provide a palliative care career pathway and formal training opportunities for nursing and other team members.
4. Utilise the wealth of skills available from our corporate partners, donors and supporters.
5. Promote holistic wellbeing for all our people.
6. Provide excellent stewardship of our donors and grow our supporter base, ensuring they understand the impact of their generosity.

Success means:

- We can measure improved and increased communication and engagement with families that feeds into our service improvements and development.
- We have grown the diversity of our team and volunteers, particularly in the representation of people from minoritised ethnicities, celebrating the positive impact of difference.
- We have employed 10% more nurses by the end of this strategy.
- Our supporter base has increased by 40%, adding 90,000 new supporters in five years.



5



Our objectives

**Strengthen
and sustain**



We will continually strive to reduce our carbon footprint, collaborate with others and embrace digital technology to provide consistent, safe and equitable services that are sustainable beyond the life of our strategy.

We will:

1. Continue to recognise that babies, children, young people and families will mould our services, in this strategy and beyond it.
2. Increase our presence on the high street, in healthcare settings and in the communities we serve.
3. Increase the use of digital technology to deliver services and improve efficiency to enable us to 'do more' and 'extend our reach'.
4. Offer training in our areas of expertise to other professionals from all sectors.
5. Seek training and development from others in their area of expertise to upskill and develop our careers for our people.
6. Work collaboratively with other organisations to deliver services when and where they are needed.
7. Merge with others, where we can, to increase the breadth and/or depth of services we offer.

Success means:

- Our income levels across our group portfolio return to pre-COVID-19 levels by 2025.
- Our income growth can sustain a balanced budget by the end of this strategy (2027).
- Our services are provided to families through collaborative health and social care networks, e.g. Managed Clinical Networks and Integrated Care Systems and/or are self-supporting.
- By 2030 Demelza will be carbon neutral.



Our values

Our Vision:

To see a world where children and young people with serious or life-limiting conditions, and their families, have access to personalised, expert care – enabling them to live their best lives.

Our Mission:

To deliver care that doesn't back down to children and young people with serious or life-limiting conditions, and their families, across Kent, South East London and East Sussex – from first diagnosis and for as long as we're needed.





Passion, performance and pride – it's how we get the best from each other and deliver exceptional care and support.

We love what we do. It's the most rewarding job in the world. We feel privileged to care and support children and their families. We are proud to be part of an inclusive team Demelza.



The families and children we help, and our supporters, deserve nothing but excellence.

Each one of us has a vital role to play in providing unique care and support, and we always strive to deliver outstanding service. By working together, we can give even more families a chance to enjoy their time making precious memories. We recognise everyone brings a different perspective and we celebrate all forms of diversity.



We see every person as a unique individual. We give every child and family member a service that suits their individual needs.

We're all human beings, and through empathy and understanding, we can provide essential care as unique as the person who receives it. All our differences are respected and valued and makes us stronger. We value and respect everyone who is part of our story.



Each member of team demelza is driven to do better.

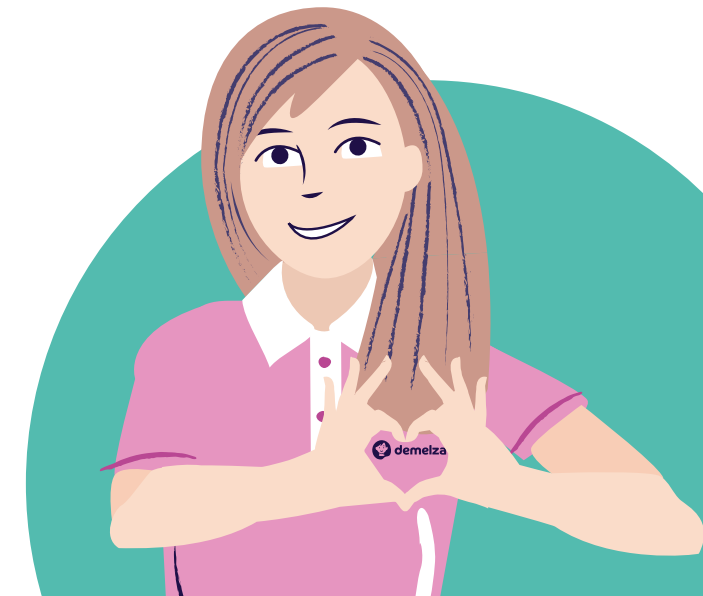
Through evidence, insight and experience, we strive to develop and improve to give children and families outstanding care and support. We always look for ways to transform change into opportunity and growth. We actively seek and welcome representation from all diverse and minority groups.



Always honest, always authentic

We are clear, open, and honest because we value everyone and their unique insight.

We always look for the best solution. We exist to give outstanding care and support to children and their families.





@demelzacharity



info@demelza.org.uk

**Demelza Kent
(Registered Office)**

Rook Lane, Bobbing,
Sittingbourne, Kent,
ME9 8DZ
T: 01795 845200

**Demelza
South East London**

5 Wensley Close,
Eltham, London,
SE9 5AB
T: 020 8859 9800

**Demelza
East Sussex**

150a Bexhill Road,
St Leonards-on-Sea,
East Sussex, TN38 8BL
T: 01323 446461

Find out more at:

demelza.org.uk

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