



demelza
extraordinary care for extraordinary children



Impact Report 2022-2023



Welcome from Lavinia Jarrett, Demelza CEO

Looking back on what's been my first full year as Chief Executive, it's been a fabulous whirlwind.

Since publishing our five-year strategy in 2022 we've spent the last 12 months laying the foundations. It's an ambitious strategy that really does require us all to reach for the stars, but that's because the children and families we support deserve nothing less. I am so proud of the way everyone connected with Demelza has responded, getting us to a point where we now have the stones on which to build. I've been incredibly impressed with the tenacity and dedication shown by the whole team – it's been palpable every single day.

Like me, all our people have embraced the changes we're making because they can see the benefits they'll bring for children and families. We've added more than 40 new people to our team and they've brought with them new ideas and fresh perspectives, complementing the huge skills and competencies of the existing team.

Honestly, we've exceeded even my expectations for the year. And that's down to the passion, performance and pride demonstrated across the whole organisation.

People sometimes ask me how I know that we make a positive difference to people's lives. Sometimes, it's as simple as hearing the shrieks of laughter coming from the playground outside my office window.

Those standout moments also happen at more formal events. One that really resonated for me was at the fabulous evening we hosted at the Victoria and Albert Museum, when 12-year-old Hallie enchanted our 100 guests, with a beautiful rendition of a Taylor Swift song. We had created a moment for Hallie and her family, a moment for her to shine and for them to remember.

There's a third way in which we can witness the impact we're making and that's in demand for new services. Nowhere is that more evident than with the neonatal caseload; those young babies in the first 28 days of life and those who have sometimes been born early. The data told us that this is a growing group with unmet needs. Now, with a nine-month pathway and a growing team, we're helping to meet that previously unmet need.

The year hasn't passed without its challenges. The cost-of-living crisis has affected us all. We've responded as best we can and we shall continue to adopt that flexible and responsive approach – something everyone connected with Demelza demonstrated brilliantly during the pandemic.

The ongoing national nursing shortage continues to test us too, but we've responded positively in two ways. Firstly, by launching our 'be the nurse you dreamt of' recruitment campaign. We've also seen this as an

opportunity to ensure we're using all the other members of Team Demelza, like our brilliant occupational therapists, physios, creative art therapists and healthcare assistants as effectively as we can to enhance our range of services.

All that's left is for me to say a huge thank you to three incredible groups of people; the fantastic children and families who motivate us to do what we do every single day, the dedicated Demelza colleagues who use that motivation to provide extraordinary care and support and our donors and supporters whose enormous and sustained generosity make it all possible, helping Team Demelza to look ahead with hope.

A handwritten signature in black ink that reads "L Jarrett". The signature is written in a cursive, flowing style.



Why are we here

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.

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

We were founded over 25 years ago and are named after Demelza Phillips, who inspired the creation of our first hospice and our charity. Since we began, Demelza continues to be dedicated to reaching more children and families who need our support.

Our mission, vision and 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 the best lives they can.

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.



Demelza looks and sounds different!

We engaged with internal and external stakeholders, including families, health professionals, colleagues, and donors to tell us what they thought of our branding – the look, feel, logo, how we talk about our services and the general understanding of what we offer.

The big message we heard was that we needed a new look that more clearly communicates the full range of our expert clinical care, compassion and commitment to families, so that even more people recognise who we are, what we stand for and how we can help.

The research also showed that the word 'hospice', for many, had an association with something negative or something to avoid. The misconceptions coming from the word 'hospice' also presented barriers, particularly to families and volunteers.

This research has led to us adopting a look that's adaptable for the digital age, inclusive, and welcoming. We have removed the word 'hospice' from our logo and branding as we believe the description of **'extraordinary care for extraordinary children'** succinctly conveys what we offer and who we're offering it to.

Success of the rebrand will increase:

- Brand awareness
- The number of families being referred to Demelza
- The number of volunteers
- Professional recruitment
- Income, retention of supporters and retail income
- Digital engagement

And develop and evolve:

- Our messaging to change the perception of children's hospices
- Targeted media
- Thought leadership
- PR and healthcare strategies

Our impact

In 2022 we published a five-year strategy with five objectives which, together, will help us continue to support families and children, to adapt our care and services to meet their needs and to extend our reach further. We wanted to share an update on the progress we've made in the first year.

Here are a few examples of the impact we've made so far:



Objective 1

Be effective

Families Voice

To be confident we're providing the care and support young people and their families need and want, we've taken a further step to include them in the decision-making process. In Families Voice, we've created a forum to ensure that the people who matter most have a say in what our services look like, influencing and improving them. Additionally, we've expanded our family engagement team and it includes a dedicated young people engagement officer whose job is to gather feedback directly from the children and young people we support.

Kirsty, advocating for her daughter, Ava-Lily

After four years of care and support from Demelza, Kirsty was keen to join our family feedback forum, Families Voice. She shared why advocating for her daughter Ava-Lily and other families is important.

"It's been great attending the sessions as I feel our opinions as a group are being heard and acted on; it gives me, as a parent, an opportunity to talk directly to decision-makers and help them understand what it's like from my perspective."

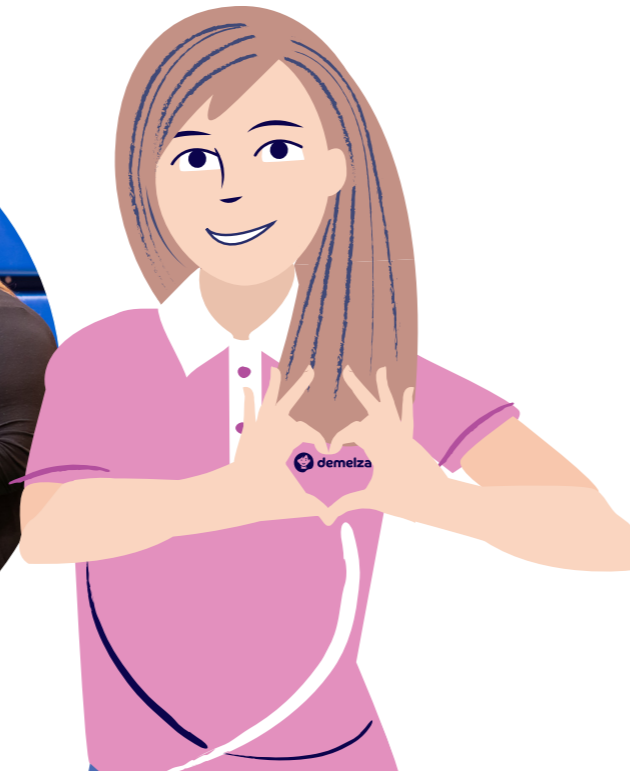
"We recently had a chance to talk to Demelza's CEO, Vin, to discuss the five-year strategy and the aspects we think are most important. I think it's so valuable that we had that chance to talk to the person at the very top and feel like we've been heard."



Objective 2

Be responsive

Understanding the challenge many families have faced as their children have grown up, we've established a transition service. It's enabling us to help parents and carers obtain the right information at the right time – from the age of 14 to 25 – relieving anxieties and providing a smoother pathway to adult services. There are currently 225 families with children at this age who access Demelza's services; our range of transition support is available to every one of those families if they need it.



Support for Lily and her mum

As 17-year-old Lily approaches adulthood, our Transition Navigator, Paul has ensured she will still have access to the services that benefit her most.

"Using the hydro pool at Demelza lets Lily relax and get some exercise without being in pain," says Lily's mum, Michelle. "She turns 18 next year and will transition out of Demelza's nursing and clinical care – until recently, that included the pool. Every time I saw him, I would talk to Paul about how much this worried us."

When Paul told me that he'd managed to secure two Demelza hydro sessions a week – not just for Lily, but for any family using Demelza with a child between 18-25 – I just couldn't believe it. It's so amazing knowing I have somewhere I can bring Lily that's safe and familiar, where she can still get all the benefits of using the hydro pool. I can't thank Paul and Demelza enough for making this happen for us."



Objective 3

Extend our reach

Increased referrals

As we strive to reach the families that need our help the most, we've taken proactive steps to go out and find them. We've increased referrals by raising awareness of what we offer through our new work within hospitals, where we've placed expert staff in three local NHS trusts.

Demelza Community Team

Sophie and Jay have three children, Oscar, Sofia and Luca, all of whom have Dravet syndrome, a rare and severe neurological condition. They now receive welcome support from Demelza Community Team Lead, Beth, on their visits to Tunbridge Wells Hospital at Pembury, where she now works regularly.

"We can't be everywhere at once and it can be a massive strain to worry about what's going on at home, or in another hospital room – so getting that on-the-spot respite from Beth, who can sit with Oscar or Sofia while I grab a coffee and recharge for twenty minutes, is fantastic. I think what's different about Demelza is how personal it is."





Objective 4

We are Demelza

Ongoing investment

To provide families with the very best and most appropriate care we need a team that's competent, confident and motivated. That requires us to invest in our teams financially and emotionally. And we're doing just that; training up two more of our healthcare assistants to be nursing associates. As part of our progressive workforce strategy, we've also invested heavily in digital transformation to efficiently support data, decisions, equipment and training across Demelza.

Training and support

Amy Jones joined us as a healthcare assistant in 2012. Amy and the families she works with are feeling the benefit of the support we've given her to progress to a Band 6 nurse.



"For me, the time and skills that Demelza offers lead to some truly satisfying professional experiences. Although the support we offer can be at the worst time of a family's life, the expertise and reassurance that the Demelza team provides mean the world to them and that's what means the world to me".

"When I progressed to a Band 6 nursing role, I was again a bit worried. It can be daunting initially to take on a leadership role, but actually, the team is so incredibly supportive of one another that I have really enjoyed the step up."

Objective 5

Strengthen and sustain

Prioritising collaboration

By collaborating more closely with partners in local hospitals and other healthcare settings, we're increasing awareness about the care we offer and helping our clinical colleagues there feel better supported when they're caring for children and young people with complex needs.

Demelza family liaison

Ruth Woodhouse a nurse at the Oliver Fisher Baby Care Unit at Medway Maritime Hospital says the presence of Lauren, a Demelza family liaison practitioner, has made a huge difference to her colleagues and the families they care for.

"Whether it be counselling, benefits or help with travel – especially if they have babies in other hospitals – it's been an invaluable service to support those families.

"We also feel very supported as a team on the ward. We know Lauren is at the end of the phone if we have any questions, but we've gained a lot of confidence in knowing for ourselves the babies that we can refer directly to Demelza."



Facts and stats...

663

Children with serious
or life-limiting
conditions supported

240

day care sessions
provided

187

new families referred to
access our service

1601

overnight stays – over
491 bookings within
our hospices

3010

sessions provided by the
community care team

290

visits to our
hydro pool

Together we raised...
more than we ever have before.

Total fundraising:

£5,584,000

Community: £552,027

Corporates: £846,568

Individuals: £506,629

Events: £735,000

Legacies: £1.82m

Trusts: £396,748

Central fundraising: £633,250

Major donors: £362,498

In 2022/23

82p in every £1

donated to Demelza was
spent providing care

669,324 retail customers
1,283,825 items sold!

Have you signed
up to gift aid?

6,984 supporters

signed up to Retail Gift Aid, raising an additional...

£187,000!

We can only do what we do because of our incredible community, so thank you to every supporter, sponsor and donor for your fantastic support; to those listed below and to those who are not,

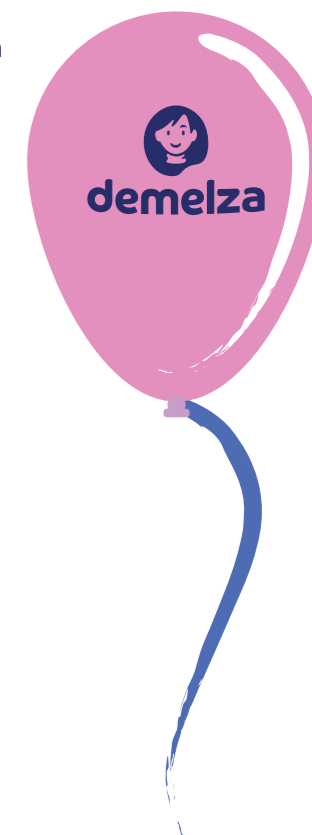
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The Freddie Green & Family Charitable Foundation
The Lawson Trust
The Madden family
The Pack Foundation
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The Sir Peter O'Sullivan Charitable Trust
The Thompson6 Charitable Trust
Thomson Snell & Passmore
Vistry Kent





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