



demelza
extraordinary care for extraordinary children

**Impact Report
2023-2024**



Welcome from Lavinia Jarrett, Demelza CEO

Twenty five years after starting work for Demelza, it's with a sense of great pride that I'm able to report that the last year has seen us care for and support more families than ever before and, thanks to the exceptional generosity of our funders, raise record sums.

When I started at Demelza in 1999, young people aged 14-18 made up a tiny part of our caseload. Now they account for 25% of all those we support. As we strive to meet this patient group's specific needs, the opening of Hill Farm at our Sittingbourne site was a huge boost. One of these young people, announced he wanted to cook lunch for his family. He wrote a menu, we took him shopping and, in the specially adapted kitchen in Hill Farm he was able to fulfil his wish and, in doing so, felt a sense of independence and self-worth.

As well as being the perfect place for young people transitioning out of children's hospice care, it also provides us with much needed temporary accommodation for some of our new nurses.

In previous years I've reported on the serious nursing recruitment challenge facing the whole hospice movement. I'm excited to report that our latest campaign – **Be the professional you've dreamed of** – has attracted the biggest response to date.

Not only do we have an exceptionally dedicated and skilled paid workforce, but we're also reliant on the extraordinary commitment and willingness of our team of volunteers who make our work possible.

While it's wonderful that we are reaching more children and families, it means we are creating a virtuous circle. The success of our in-reach nurses in signposting professionals and families in local hospitals to the full range of services and joyful atmosphere at Demelza, means we're seeing many more children. That means, that with your continuing support, I fully expect to report record-breaking caseloads and fundraising again next year.

All that's left is for me to say a huge thank you. To the fantastic children and families who inspire us every single day. To our dedicated Demelza colleagues and volunteers who use that inspiration to provide extraordinary care and support and to our donors and supporters whose enormous and sustained generosity make it all possible, helping Team Demelza to look back with pride and ahead with hope.





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 support families when and where we're needed most: at our three core sites, in their 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 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 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.

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.



Over the last year we have...

Supported 705 children with serious or life limiting conditions and their families

705

Facilitated 492 visits to the hydro pool

492

Welcomed 216 new families into our care

216

We provided:

- 254 day care sessions
- 533 overnight short breaks
- 3,489 short break sessions within our community
- 114 specialist clinical end of life, step down and symptom management sessions
- 59 siblings with support, activities and events
- Family events for 1,604 children and family members
- 2,797 volunteer driving hours, including taking families to hospital appointments
- 454 counselling sessions to 54 children and family members

Yet again we've raised a record amount – an incredible

£6,209,264

Trusts: £317,442
Regional: £643,331
Corporate: £898,286
Events: £541,404
Special Events: £303,890
Philanthropy: £676,187
Individual Giving: £585,645
Central: £36,752

In 2023/24

83p in every £1

donated to Demelza was spent providing care

Our retail shops and outlet served **648,298 customers**

and we received

£14,415 additional income

via rounding up transactions at the till

Have you signed up to our Lottery?

25,600

Lottery players raised

£1.866 million

Strategic objectives

Two years after publishing our five-year strategy in 2022, we're delighted to be able to share a further update on our progress with the five objectives.

Strategic objective:

Be effective

For Dying Matters Awareness Week, we explored how we communicate with families who have experienced a bereavement at Demelza, and why it's so important to get it right.

At Demelza, Dying Matters Awareness Week gives us an opportunity to start and continue the conversations about death, dying, and grief which are all part of the care we provide. This year's theme, "The way we talk about Dying Matters" focuses on the language we use and the conversations we have about these sensitive subjects.

We recognise that when a family we support loses a child, they are changed forever by that experience – and the way we communicate with those families must change with them.

From this came the idea for the In Touch newsletter, specifically for families who have been bereaved. The idea was to give those families a way to keep in touch with Demelza, to know what support, events and resources are available to them, and to give them opportunities to engage as much or as little as they feel comfortable with. It needed to be quite



different from what's on offer for other families, from the language we use to the tone we communicate with.

The newsletter has marked a clear shift in how Demelza communicates with bereaved families, as Jo, our Psychotherapeutic Services Lead, shares: "From the start, it's been about the newsletter becoming a constant and reliable form of support, that shares how we remain present and what form our support can take. This gentle approach then allows families to connect with us when they are ready to engage, at a time that's right for them and to choose the level of direct contact that feels appropriate. In Touch also role models growth and changes shape through the year, something that mirrors the nature of grief."



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Strategic objective:

We are Demelza

We would not be here without our supporters and volunteers. This is why we were so delighted when Jim and Liz, who have been supporting Demelza since 2008, asked if they could use their skills and knowledge to also support Demelza through volunteering.

Prior to retiring, Jim had a career in finance and Liz was a teacher supporting children with additional needs. So naturally, Jim soon started volunteering within our finance department and Liz at our Dots sessions.

Having volunteers who want to share their existing experience and skills, or those who want to learn new ones, is the backbone to any charity and we are thrilled that Liz and Jim, along with hundreds of other volunteers, have chosen to support Demelza in so many ways.



Jim explains, "Volunteering at Demelza has given us a new lease of life. We feel enriched and stimulated by the experience of working with the children, their parents and the wonderful staff. Being such new volunteers, we are aware of the number of unsung heroes you have".



Strategic objective:

Be responsive

Every young person and their family respond differently to their diagnosis and we at Demelza have to respond accordingly and appropriately. Sometimes, it's easiest to illustrate this by recounting the experience of one of our families. Here, Steph shares her experience of the care and support we provided her, her daughter Isla and their family, both before and after Isla died.

"Isla was diagnosed with an aggressive brain tumour called DIPG... within nine months of that diagnosis, Isla was gone.

When we were referred to Demelza, Sacha, a Demelza nurse, told us some of the services we could access but I just thought 'we don't need a hospice, leave us alone!' Thankfully she kept trying, and eventually we said yes to a home visit so she could do some activities with Isla. I really wish I could turn back time and say yes sooner because Isla absolutely loved it.

The fun was important, but we also felt like we could talk about the worst case stuff with Sacha – like what would happen if Isla needed

a nasogastric tube to eat, or what would happen after she died. Demelza were the only people we felt we could trust to speak openly and have those conversations with us.

When Isla's health deteriorated, it happened quickly. We went to bed at about 10pm on Saturday, and when I woke up at 1am Isla had gone. It was that quick. It was the worst moment of our lives, but I'm so grateful we had Demelza there to support us – it wasn't a stranger who came out to see us, it was Sacha. That bond made it easier.

We took Isla to Demelza after she passed, and we spent five days with her there. 'Amazing' isn't the right word for the time we spent there because it was such an awful thing – we'd lost our little girl – but I'm so grateful for it. There was a night during that time that was, to me, more important than Isla's actual funeral. Isla loved our pizza and prosecco nights – we would order in pizza, the grownups would have prosecco and Isla would have her own glass with lemonade in it! That night at Demelza we invited all of our closest family, ordered takeaway pizza, and opened a bottle of prosecco for one more pizza and prosecco night with Isla – it was



so special to have everyone all together, doing what Isla would have wanted.

They still support us now, more than a year on; we attend their bereavement events which give us a chance to remember Isla, and also to connect with other families who 'get it'. I do actually want to talk about Isla, and I want to hear other people talk about her and say her name, but it can be awkward – so going to Demelza for these events is really special.

I don't like to imagine what things would have been like without Demelza; some of Isla's favourite memories were made there, and some of ours too. I'm so grateful for all of the support we've had."

Steph, mum to Isla



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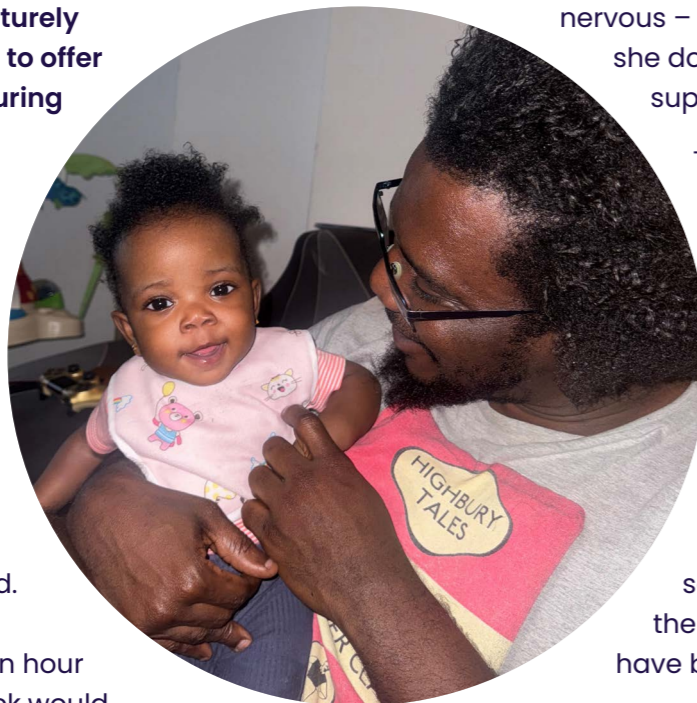
Strategic objective:

Extend our reach

Demelza has developed a neonatal pathway that supports local families of babies born extremely prematurely between 22-24 weeks. This pathway allows us to offer emotional and practical support to families during this uncertain time, and ongoing support for those that need it. We spoke to Mo, mum to Teniola, to find out how this support made a difference to her.

"Teni, my beautiful, strong-willed daughter, was born prematurely after an emergency C-section in Tunbridge Wells. She was almost immediately transferred to the Oliver Fisher Baby Care unit in the Medway Maritime Hospital.

It was such a painful time, and I really struggled. I wanted to spend as much time with her as possible, but the bus ride to the hospital took an hour and a half each way, while a taxi there and back would be £120. It's just my husband Tito and me, and we couldn't manage that.



Demelza's practical support drivers were amazing. Nothing was too much trouble."

Thankfully, Demelza was there for us. When we were referred, I was nervous – I thought, 'Teni is premature, but she's healthy; she doesn't need a hospice!' I had no idea the kind of support they could offer.

Their practical support drivers were amazing, providing me with free transport to and from the hospital; nothing was too much trouble. They were so respectful of me as a person, whether I was struggling one day and needed to keep to myself or having a better day and wanted a chat.

Teni was discharged from the intensive care unit with no health complications; we won't need Demelza's support going forward, but we're so grateful that they were there when we needed them in those first weeks. I don't know where we'd have been without them."

Strategic objective:

Strengthen and sustain

Caring for and supporting young people with complex needs is challenging even for the most experienced practitioners. That's why it's so important for us to support all of our colleagues to feel confident in their role.

"I came to music therapy later than some, after working for many years in advertising and project management.

I first heard of music therapy when my mum became ill and spent the final week of her life being cared for by a hospice. I was so interested that I enrolled in the training programme which included a foundation course and masters degree.

I'd always known I wanted to work with children and, after the experience with my mum, I felt connected to hospice work. As such, I requested a placement with Demelza. I was nervous as I wasn't sure if I would be emotionally robust enough. However, about three weeks in, I knew that Demelza was where I wanted to work, and I am thrilled to now be one of Demelza's Music Therapists.

I have had some deeply poignant learning experiences, such as end of life support for families. When a family is amidst waves of medical staff, constant medications and often pain or distress, being able to



What I really love about working here is the variety Demelza feels like where I'm meant to be."

provide a little oasis of musical calm, of empathy, humanness, and kindness is such a privilege.

What I really love about working here is the variety; one day you could be supporting premature babies with a music therapy session in a local hospital, the next you're working with a child whose sibling has a complex condition, and the next you could be delivering a group session to several young adults.

Demelza feels like where I'm meant to be."



Hill Farm opening

In Autumn 2023 Demelza officially opened Hill Farm, our new facility opposite Demelza Kent in Sittingbourne.

The building, which has been flexibly designed to ensure it has longevity to meet the changing needs of families, contains two self-contained flats, as well as a huge kitchen area, event space and parking.



The space can be used for families whose children may require longer term care in the hospice, sibling activities, nurse accommodation and the specially adapted kitchen areas will allow young adults to not only socialise with their peers, but also learn valuable life skills before leaving children's services. The space can also be used for families as holiday accommodation, allowing them much-needed breaks.

The official opening took place on 1 November with contractors, supporters and funders gathering for the unveiling. Following the reveal, Lavinia Jarrett, Demelza's CEO said, "I have been at Demelza for over 20 years now and the children's palliative care sector has changed dramatically over that time. Children with complex conditions are living longer and our services need to adapt to flex and meet the changing needs of local families. This state-of-the-art building will give us the flexibility to adapt to families' specific circumstances and to support family life to be the best it can be".

The building was made possible by the generous gift of the land from the Kemsley Family, the build itself was funded by Kent-based developer Esquire Developments and their contractors and the adaptations were funded by generous Demelza supporters: Catalent, CMS Cameron McKenna Nabarro Olswang LLP, Garfield Weston Foundation, Mr. Christopher Hawkins, Royal Bank of Canada, South East Consortium, The Edward Gostling Foundation and The Sir Peter O'Sullivan Charitable Trust. Thank you to everyone involved.

Wildlife garden opening

Outdoor space is incredibly important at Demelza as it can fulfil a variety of functions – whether that's a space for fun and play, a place for quiet reflection and remembrance or adventure and making memories.

We were delighted this year when Greenfingers Charity returned to Demelza to help us transform an underused space at Demelza Kent, creating a wildlife garden for children and families to enjoy for many years to come.

Having supported Demelza 25 years ago with their very first garden, Greenfingers Charity returned with a design for a space that is inclusive, interesting and will grow and evolve every year.

Hayley Richardson, Demelza's Deputy Chief Executive, said, "outside space is incredibly important at Demelza. Throughout the grounds, we have different spaces for different things, from fun and play to reflection and remembrance to adventure and making memories. A huge thanks to the team at Greenfingers Charity and their supporters for funding this beautiful wildlife garden which will be enjoyed by children, families, volunteers and staff for many years to come."



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

THANK YOU!

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