



We are demelza

Autumn 2023



**I don't know
where we'd
be without
Demelza**

Read the full story on
pages 8 and 9

Extraordinary care for extraordinary children

Hello and welcome to the autumn edition of our magazine, We Are Demelza.

In this issue we mark the 25th anniversary of our first hospice opening its doors; we touched on it in our spring edition, but so much has happened and so many events have taken place since then to celebrate 25 years of providing extraordinary care to extraordinary children.

In these pages, you'll find photos of those early days – from when we built the first hospice in Kent, to building and opening a second brand new hospice in South East London, to the care and support we're offering right now in the community in East Sussex.

You'll read how our charity shops, supported by shoppers like you, have grown from a single store in Herne Bay to a whopping 29 stores across Kent, East Sussex, and South East London – and about their successes these past six months.

We have updates on our fundraising efforts (emphasis on the fun!), as we've welcomed thousands of supporters back to our most popular summer events

and challenges and raised hundreds of thousands of pounds in the process.

And most importantly of all, you'll read the stories of the families we support, and how our care has enabled them to go on living their best lives. We'll hear from Sharon, mum to Fenton, as she shares how Demelza's support helped her switch off from being a carer for the first time in nearly 16 years. We'll also hear about Lara, who received music therapy during an 18-month admission in the London Evelina Children's Hospital, and what that support meant to her and her family.

Every story you'll read has been made possible by your incredible ongoing support, and we hope you see the impact of that as you read on and explore the work we've done, the work we're doing, and the work still to come. Thank you.

Oliver
Storytelling Officer



Demelza on the high street

Demelza's 29 charity shops, as well as our online offerings, bring in important funds all year round for our services – and this year they're doing better than ever! Here are the highlights from the wonderful world of retail.

New location, same great value

Our Hythe books and media shop has a new home on the high street! The team moved into a larger shop on 31 July – meaning we can sell more donated items, attract more customers and raise those all-important funds.

Second-hand September

It's the month for second-hand, sustainable shopping! For a limited time only, visit Demelza's Depop pop-up shop at our Maidstone Shopping Outlet (from 29 September–2 October) and grab some bargains in our huge online 50% sale (from 23 September–1 October).

A strong start to the summer

We started this summer with a bang, serving more than 160,000 customers in just three months! This resulted in over 315,000 pre-loved items finding new homes with our happy shoppers, instead of going to landfill.

Going further with Gift Aid

Did you know you can sign up for Retail Gift Aid and help us claim an additional 25p on every £1 we make selling your donated goods? Demelza are hitting record-breaking Gift Aid numbers this year, with more than 130 signups each week – could you be our next signup?

Explore retail volunteering opportunities near you





Cracking construction: Demelza Kent looks unrecognisable from when ground was broken 25 years ago – now we have over six acres of beautiful buildings, accessible playgrounds, and gorgeous gardens.

How times have changed

We look back at 25 years of Demelza, and how things have changed from then to now.



A fresh lick of paint: Our charity shops have always been at home on their local high streets – but with the new signs and paint job, they're even more eye catching than before!



The right car for the job: We've always been lucky to have specially kitted-out vans and mobility vehicles, so we can take children with the most complex needs, and their families, where they need to go.



Still going strong: Demelza South East London opened in 2009 – with an opening ceremony attended by Jayne Torville (top left), and children like Ryan (bottom left) are still enjoying the facilities today.

A summer of FUNdraising

From clown rallies and motorcycle club visits to fun runs and matched funding campaigns; the ways we fundraise might have changed over the years, but the unerring generosity of our supporters certainly hasn't!

Miles in May

The Demelza Miles in May challenge, which tasked participants with racking up 37 miles of walking, running, biking, scooting, skipping or jumping in May, was a hit – with a huge £25,000 raised overall. One star fundraiser, Jayden took on the challenge in honour of his brother Thomas, who has a condition called lissencephaly and is supported here at Demelza; Jayden ended up smashing his target, travelling more than 200 miles and raising over £350 all by himself.



We use Demelza as a family to make memories, and I would like to help them make some money for all they do to say thank you and to raise awareness for my brother as well."

Jayden, Thomas' brother

Jayden



London Marathon 2023

Our London Marathon runners did amazingly too. Despite some rainy weather, our team of 30 runners weren't put off – they raised £78,000 overall and achieved an incredible milestone for themselves in the process. One of Demelza's own Lead Nurses, Melissa, took part and said that it was an "amazing experience, can't recommend it enough!"



Melissa



Bubble Rush 2023

Racing through frothy walls of multicoloured bubbles, 6000 amazing supporters cumulatively helped us raise over £120,000 at Bubble Rush 2023! An impressive 120 staff members and volunteers kindly offered up their weekends in Kent, East Sussex and South East London to make these trademark Demelza events into a sudsy success.

care that doesn't back down

Care That Doesn't Back Down

This ambitious matched funding campaign, supported by Mr. Andrew Cooper at Forstal Properties Ltd, and our corporate partners Axis Europe, Canary Wharf Contractors and LGT Wealth Management, saw all donations to Demelza doubled for 36 hours! Demelza colleagues, our VPs and Trustees, businesses and supporters pulled together and reached out to as many people as possible across their networks to make the most of this opportunity and we were thrilled to raise an astonishing £266,000 by the end of the campaign.

Feeling inspired?

To find out what fundraising opportunities and events are happening near you, visit [page 16](https://www.demelza.org.uk)

Fenton's story



Fenton is 15 years old and fully quadriplegic with cerebral palsy, which means he can't move his body independently from the neck down. He can't eat, feed, or bathe himself; he can't even lift a hand to scratch his nose. He also has severe epilepsy which cannot be controlled and is severely sight impaired. He has had these conditions since birth.

Despite his severe disability, he's got a huge personality; when he was little, he was very cheeky and comical, and now he's your typical moody teenager. He loves to give me a bit of side-eye and a bit of cheek, and as any of the ladies will tell you he's also a massive flirt!

His care is a full-time job and can be exhausting, but it's our 'normal'. Our house is filled with medical equipment, and I rarely have days to myself – everything revolves around Fenton.

I can't even take a long shower in case Fenton has a seizure, so I wash in just a few minutes and then just try and make the

most of the warm water until I need to get out and carry on his care.

When we had our first respite stay at Demelza, I was terrified – worrying it was going to be the wrong thing, or too much like a hospital. The second we pulled up to Demelza those worries melted away. The nurses came out to greet us from the car, and they knew Fenton by name and spoke directly to him – not at him. It was like a lead coat had been lifted off my shoulders and I could breathe for the first time in years.

During one of these respite stays I had my first bath in nearly 16 years. It's the

Fenton



Sharon and Fenton

first time I can remember feeling totally unhurried; I was in there for half an hour, then got straight into bed and read a book, then slept for 15 hours! It just let me be me for a while, just 'Sharon'. It sounds silly but I never would have done that without Demelza.

I'm never worried about handing Fenton's clinical care over either; they are so

attentive I just know he will be looked after. He gets so much out of it socially too – he does arts and crafts, or other times he might use the pool (another thing that's near-impossible in day-to-day life). Demelza is a blessing for both of us, a real lifeline – I don't know where we'd be without them."

Fenton's mum, Sharon.



Demelza nurses came out to greet us from the car, and they knew Fenton by name and spoke directly to him – not at him. It was like a lead coat had been lifted off my shoulders and I could breathe for the first time in years."

Care where it's needed most

Demelza's creative therapies team, which has long provided the children and families we support with a safe space to explore their emotional, cognitive and social needs, are always looking at innovative ways to deliver this service to more families.

For Claire, Demelza's music therapist in South East London, this has recently taken the form of regular sessions with young person Lara who has been resident in The London Evelina Children's Hospital for more than 18 months.

The family was already being supported with visits from Demelza nurse and team lead Lottie and her colleagues and, in order to relieve some of the social isolation Lara might be feeling, Lottie made a referral for her to receive music therapy.

Normally one-to-one music therapy sessions are offered on-site at Demelza, at the family home, or at a child's school – but Claire worked hard to figure out the logistics of delivering sessions in the Evelina for the first time, to meet Lara's unique needs.

"It required some problem-solving," said Claire. "Normally I can travel by car and bring a whole range of instruments and equipment to support my sessions, but using public transport to get to the hospital meant I was limited to whatever I could carry. I'm so pleased that my efforts are paying off."

The sessions Claire delivers on the ward give Lara a chance to socialise and relax – she is non-verbal, but her mum, Umesh shares that she can see a positive change in her during the sessions and that she responds in her own way.

It's also a form of short-term respite for Umesh; she spends hours on the ward every day, but while Lara is enjoying her music therapy, Umesh can take a break from the constant care. She tends to use this time to step out of the room, grab a coffee and refresh herself, knowing that Lara is in safe hands and enjoying herself.



Len Goodman: a tribute

In April this year, we learned of the sad death of Len Goodman, Vice President of Demelza for nearly 20 years.

Len, a professional ballroom dancer and former head judge of BBC's ever popular "Strictly Come Dancing" was a passionate supporter, devoted to fundraising, as well as singing the praises of all who work at Demelza whenever given the opportunity.

He never missed the chance to take on a TV quiz show for Demelza, taking home the money on "Tipping Point: Lucky Stars", "The Weakest Link" and "Celebrity Chase". And keeping the audience on the edge of their seats while he banked the money!

Len was always delighted to lend us his distinctive voice whether as a question master for one of our lockdown quizzes, recording a heartfelt message of thanks to Demelza volunteers, a voiceover for our 2019 Christmas campaign

or reading his favourite Christmas poem – "The Twelve Days of Christmas" – at our celebration of Christmas at Canterbury Cathedral last year.

Kind, charming, generous and a true gentleman – he will be greatly missed by all whose lives he touched at Demelza.





Care through the years

We've been providing extraordinary care for 25 years – unsurprisingly, a lot has changed! Demelza Kent Lead Nurse Helen shares more on how we've developed our services to meet families' needs.

Helen



Whatever happens, I know we'll be here supporting families for another 25 years."

Clinical needs

"The complexity of children's medical needs has increased significantly in my time here. Due to advances in medical science, children with serious or life-limiting conditions are living longer, and care that used to be delivered only in hospitals can now be provided in the community and at our three core sites.

That means our training has also changed; we have responded by creating a robust training schedule to make sure our nurses are ready to deliver the safest, highest-quality care."

Facilities

"18 years ago, we had a single bathroom in the care area at Demelza Kent – we had to queue the children up and take them through one by one. It took forever! Now, all our bedrooms have ensuite bathrooms with specialised baths, lowered sinks and wide doors for wheelchair access. This is only one example; our facilities have improved from top to bottom, from overhead hoists in every room to a fully equipped hydro pool and sensory room."

Services

"When I started, we only really offered respite stays and end of life care; they were important services, but limited and mostly clinical. Now, the number of services we have is so vast and impressive it can be a little mind-boggling! We're well-equipped to provide care in the community now, for example, which was a direct result of family feedback.

We also have our family support services, which are comprehensive; we offer support for siblings, grandparents, parents and carers through regular online and in-person groups, residential trips, social events and more. Our bereavement support is just as robust, and constantly developing."

Looking to the future

"I have a lot of hopes. It would be great to see a future in which families have more statutory support, and Demelza's services can be in addition to that – making sure children and families get more of the care and support they so desperately need. Whatever happens, I know we'll be here supporting families for another 25 years."

A flaming feat!

What better way to celebrate 25 years of providing extraordinary care to extraordinary children than walking across hot coals?

That's the question Senior Healthcare Assistant Vicky is asking herself as she prepares to take on the Firewalk for Demelza on 3 November this year!

It's an extra special anniversary for Vicky as she joined Demelza when we opened the doors of our first hospice, so she has personally been supporting children and families for that whole 25 years.

"It's a privilege to work for Demelza," said Vicky. "Giving the parents a break from their day-to-day routine is really rewarding, and if I can prompt the odd smile or little bit of movement from the child I'm working with then it always makes my day. I just love it – I can't imagine being anywhere else."

The Firewalk will see Vicky and her son Matt – who has volunteered in the Demelza kitchens and at several of our open days – walk barefoot across sizzling, red-hot coals that burn at a scorching 550°C! The event takes place in the grounds at Demelza Kent, bringing things full circle for Vicky who was there when we opened the doors for the first time in 1998.

To join Vicky and Matt on this adrenaline-fuelled experience, visit demelza.org.uk/ events or scan the QR code for your area

Vicky



Firewalk Kent



Firewalk East Sussex



Fun at Family Fest

Every day our nursing and care team goes above and beyond to make families feel welcome, at what can be a very uncertain and anxious time.

Demelza was thrilled to welcome families from Kent, East Sussex, and South East London to our Family Fest 25th anniversary celebrations this summer! 136 families signed up for the events – that's 585 mums, dads, grandparents, siblings and of course the children and young people we support.

These mini festivals had everything families needed to celebrate 25 years of Demelza. For many, this was a rare opportunity to mix and socialise with other families without stress; knowing their children's needs were catered for and they were in safe hands, they could relax and enjoy the sunshine and activities on offer.

Chloe, Family Events Coordinator, said: "Being new to the family events team this summer it has been fantastic to see so many families celebrating such a special year for Demelza. There have been bouncy castles, discos, face painting and even our newly created 'Juice Pong,' which has been a hit in our Teen Chill Out Zone!"

Paige, Family Events Lead, added: "It has been amazing to organise three regional events to celebrate Demelza's 25th anniversary with families, in their local areas. These events would not have

been possible without the enthusiastic collaborative working across multiple teams at Demelza and it has been really special witnessing families come together, make connections and have fun as a family."



Happy 25th birthday Demelza! Thank you for organising such an amazing event... It's only rarely our child can have fun and enjoy in a party! Well done and thank you."

Feedback from a family



Mark your calendars – these fundraising events are on the horizon!

November 2023



Put your mind and body to the test with the Firewalk for Demelza in Kent and East Sussex. Make your way barefoot across sizzling coals, with temperatures up to a scorching 550°C!

December 2023



Get in the Christmas spirit with carols, readings and the most beautiful setting as we come together in the stunning Canterbury Cathedral for our annual Celebration of Christmas.

May/June/July 2024



Get ready to get messy! Join us in our Bubble Rush 5k fun runs as they return to Deal, Maidstone and Eltham – or, lead the charge as we introduce an exciting new fourth location in East Sussex.

September 2024



Do you love to travel? Are you looking for a challenge unlike any other? Then take on a once-in-a-lifetime four-day trek to the lost city of the Inca, Machu Picchu.

To learn more about Demelza's upcoming events or sign up, visit demelza.org.uk/events.

You can also pop us an email at eventbookings@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

info@demelza.org.uk
[@demelzacharity](https://www.demelzacharity.org.uk)



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

Registered Charity No. 1039651

