

Demelza Life

Autumn 2022

- Demelza launches five year strategy
- Henry's family share their story
- Read about our new Sevenoaks and Walderslade shops
- New bereavement photography service for families
- Fun in the sun at Little Warrior and Bubble Rush



Demelza
Hospice Care for Children

Welcome

Welcome to Demelza Life and our 2022-2027 Strategy! I am so excited to share our ambitious plans for the future, made possible by your support.



We know how precious life is, and we feel privileged to support families who trust us to care for those they love. We want to concentrate on the families who use Demelza now, making sure we are

meeting their needs and providing choice, but also those we are not yet reaching, and why, making sure any barriers are removed.

We want people to know what children's hospices are like. We provide care at the end of a child's life which is incredibly important, highly skilled and demanding work. Demelza also provides a great deal more. In one of our vibrant hospice buildings, full of colour and sounds of fun, or in the communities we serve, we are here to help families create special memories.

We have increased the support available in our local communities with activity sessions, more care at home, and an increased opportunity for families to go to the Sittingbourne and Eltham hospices to use the fantastic facilities you have helped to fund.

There are particular areas of need; we are supporting children into adult services. This is a time of worrying change for young people and their families and we will support them to navigate this, working with our partners in adult services. We also recognise that the prevalence of children

with a serious or terminal condition is highest amongst those under one year of age. We are working with local NHS partners to help those who refer and the parents, carers, and families of children who might need Demelza services to understand what a children's hospice can offer and have dramatically increased the number of children we have helped. However, there is always more to do.

Funding service developments will be incredibly important over the course of the five year strategy. With the newest additions of Sevenoaks and Walderslade, we now have a total of 30 high street and online retail outlets, which will inform people about our services and provide a great environmentally-friendly offer in the heart of the local communities we serve.

In this edition, you will see how our fundraising to support these vital services has extended to incorporate accessible family events, just for Demelza families. Did you know that you can play the Lotto and the Superdraw every week with multiple chances of winning, whilst supporting our work?

Whether you donate to our shops, volunteer, support our fundraising or just spread the word about Demelza's work; thank you for everything you do.

Warmest wishes

Lavinia Jarrett, Demelza CEO

A Celebration of Christmas

Demelza
Hospice Care for Children

Canterbury Cathedral
Monday 19 December 2022 at 7pm

Join us for an evening of joyful celebration. With a beautiful arrangement of carols, readings and musical performances the evening is set to be a truly uplifting occasion.

To purchase tickets please visit
www.demelza.org.uk/celebration-of-christmas-2022
Registered Charity No. 1039651

Demelza's Festive Wishes



• Henry and brother Edward

Henry's story

"We never imagined that our first visit to Demelza would be after Henry died; but what we gained from the following five days at Demelza, where we stayed and came to terms with our loss while Henry lay peacefully in their bereavement suite, is immeasurable.

Henry was a leader. When he was at nursery he would parade around at the head of a whole troupe of toddlers, and he took his little brother Edward under his wing instantly. He was always at the forefront, first in at everything; he never missed an opportunity. That's part of what made his diagnosis so devastating.

He was only six when he was diagnosed with acute myeloid leukaemia (AML), and despite receiving aggressive treatment and going into remission, he relapsed multiple times. In February 2022, his health rapidly deteriorated; he developed sepsis during a stay in hospital, and ended up in the intensive care ward at St George's Hospital. Sadly, he didn't respond to treatment and after only a few days we found ourselves saying goodbye to our little boy.

Henry was transferred to Demelza's hospice in Eltham, South East London, after he died. He stayed in his own special bedroom, where his favourite music played quietly in the background, and we had the time and space to begin to come to terms with our loss. Demelza staff were there for us in those first difficult days; giving us the opportunity to talk, as



• Henry with his family on holiday

well as guiding us through the practical arrangements when we had no idea where to start. The team also helped us make lasting and precious memories with Henry, and we now have plaster casts of his hands and jewellery with his fingerprints on so we can carry him with us. Despite everything we were going through, we felt an overwhelming sense of calm at Demelza.

Edward accessed art and music therapy over those five days as well, and the care hasn't stopped just because we left Demelza – he has continued his art therapy sessions, helping him process his loss in the setting that's best for him.

Our close friend Francesca, a children's nurse herself, was able to visit us at Demelza during that time; now she's taken on a challenge to cycle to each of the 54 children's hospices in the UK, aiming to raise £500k for their vital services. We were humbled that, after Henry died, she chose to dedicate the challenge to him – read her inspirational story on page 8."

Henry and Edward's mum and dad, Sam and Hua

A new service for bereaved families



Recently, four of Demelza's Healthcare Assistants had the opportunity to take part in a photography course focused on creating memories for bereaved parents.

The course was funded by 4louis; both UK-based registered charities which offer the gift of remembrance to bereaved parents.

"We offer parents the chance to make memories at Demelza, and it is primarily about choice," said Louise, one of Demelza's Senior Healthcare Assistants specialising in bereavement.

Creating memories with their child can be a powerful tool in helping families process the grief they're experiencing, as well as giving them something tangible they can look back on should they ever want to. It can be incredibly difficult to face activities that feel so normal in the face of something so terrible – and what works for one family certainly won't work for another.

That's why I'm so glad we're growing our offering to include photography – it's another way we empower families to make the choices that are right for them at the most difficult time in their lives."



Demelza's Little Dots

Little Dots has always been a place for families to come together; that's why we're excited that alongside our return to in-person Little Dots sessions at our Kent hospice, we've also launched Little Dots Tunbridge Wells and Dover Dots this year! We're thrilled to be further extending our reach to our East and West Kent communities, offering families choice so they can attend the sessions that have the most positive impact on them.

"Before Little Dots, Jack was a totally different child. He didn't walk, he barely signed, and he hated messy play; but weekly sessions at Little Dots have turned him into a hugely confident little boy. It's been great for us as parents too. Every other parent there knows to some degree what you're going through; rare conditions aren't that rare at Demelza, they're often the norm. That shared understanding makes it much easier to relate to other parents, and to make friends."

Josh and Hannah, parents to Jack.



Isabella opened our Walderslade store

Demelza VP Cheryl Baker opened our Sevenoaks store

Two new Demelza charity shops open for business

In the past six months we've opened two new charity shops – one on the busy high street of Sevenoaks, and another nestled in the heart of Walderslade!

In its fantastic central location, our Sevenoaks store will be pivotal in raising our profile further, as we aim to reach more families that need our support. Our celebrity Vice President, Cheryl Baker, came along to the grand opening, even cutting the ribbon to make it official! "It's an honour and a privilege for me to support Demelza and I'm delighted to open the shop," she said.

Our spacious new Walderslade store is one of only a few Demelza superstores, offering a huge selection of pre-

loved bargains! Its position in bustling Walderslade puts it right at the centre of our Kent community, accessible to many of the families who use our services at the nearby hospice – like Isabella and her family, who came along on the big day. "Demelza have supported us since Isabella was only two years old. This new shop is right in the heart of our little community, and the money made with each purchase will make such a difference to families like ours," said Isabella's mum, Nicola.

Demelza Lottery

"I've been playing the Demelza Lotto and Superdraw for years, and I never expected to win – I don't even know what to do with the money! I'd 100% recommend anyone to sign up. You'll easily make back the few pounds you spend on it, but knowing you're supporting Demelza's mission makes it more than worth your while. Plus, you never know when your luck might come in!"

Anthony, who pocketed over £11,500 in Demelza's Superdraw.

From just £1 a week, you could win the Demelza Lottery. For more information please visit www.demelza.org.uk/lottery



We are excited to present Demelza's new five-year strategy!

This strategy will focus more than ever before on actively seeking the views and feedback from those who are the real experts; the children, young people and their families themselves. With passion, performance and pride at our core, we will work to develop our services according to this feedback, and ensure that they are accessible to all those that need support. Read on to find out more about each of the five objectives we have set out in this ambitious strategy, and how your support will make these aspirations possible.



Be effective

We will continue to provide services that best meet the needs of our families, working to understand the geographical, social and economic challenges and trends across our area as well as families who are, and are not, accessing our services. We will explore every opportunity to ensure our services are accessible to all. We will incorporate the voices of children and their families into decision-making, allowing us to refine and develop our service offer to reflect what they need most. We will also work to communicate this service offer more effectively, both internally and externally, and combat prevalent myths about children's hospice care.

Be responsive

We know that the number of children living with a serious or terminal condition in the UK has almost tripled, reaching nearly 90,000 in just 18 years. This number is only set to grow - with expectations of it rising over the next decade and beyond. That is why it is important for us to be responsive to families' needs, ensuring our services are accessible to all who need them and adaptable to changing circumstances. We will offer families choice, both in the type of care services that can be accessed, and in the places where those services will be delivered.

Extend our reach

Children in the UK with a serious or terminal condition is highest in the under-1s. Meanwhile, an increasing number of young people are surviving to 19 (and beyond), an increase of over three-fold. To fulfil the growing need in these areas, we will extend our reach by developing our comprehensive range of clinical and non-clinical services. We will support young people age 14-25 as they transition out of children's hospice care, offering them clear pathways; we will develop and embed our bereavement support, becoming a lead provider for this service; we will extend our family support services, based on the evidence from families about their needs; and we will support more expectant parents, neonates, and babies under one year old.

"We are Demelza"

At Demelza, we understand we are our people. With the right people in our various stakeholder groups, we will enable our organisation to be well-led, in all respects, and representative of the communities in which we work. We will ensure we meet the ambitions and aspirations in supporting babies, children, young people, and their families. To do this, we will invest in our staff; encouraging them to embrace learning opportunities as we provide formal training and career pathways for nursing and other staff - like the bereavement photography course offered to our Healthcare Assistants. We are also committed to excellent stewardship of our donors and supporters, like you, and aim to increase our supporter base by 40% over the next five years.

Strengthen and sustain

We will strive to reduce our carbon footprint, collaborate with others and embrace digital means to provide consistent, safe and equitable services - services that are sustainable beyond the life of this strategy. We will increase our presence on the high street - as you may have read, we have already opened two new charity shops this year. We will also seek to collaborate with other organisations; offering training in our areas of expertise and seeking out training from others, so the sector as a whole is more equipped to support the families who need our services. Building on the digital progress we made during the pandemic, we will offer more services digitally and streamline processes to enable us to achieve our other objectives. Finally, Demelza will be carbon neutral by 2030.



This strategy is our most ambitious ever; we cannot do any of this without the right people. Our staff, volunteers, donors, customers, partners and funders will all form an essential chain of expertise and support that we will nurture and develop to ensure we can meet all the objectives set out in this ambitious strategy.

Thank you for your support as we embark on this exciting new chapter in Demelza's history.

Nurse Francesca's epic cycling adventure



Francesca and Hua at the Demelza Kent leg of the cycle

Kicking off at the beginning of Children's Hospice Week in June, children's nurse Francesca took on an epic 3200-mile cycle to visit each one of the 54 children's hospices across the UK.



Francesca with Edward and Henry

Read Henry's story on page 3

She hoped to raise awareness about children's hospice care, as well as £500k in funds for their valuable services – and after Henry's death, the son of her good friends Hua and Sam, she dedicated the challenge to him.

"As a children's nurse I've seen first-hand what these children and families go through every day, and then I was on the other side of that journey with Henry," said Francesca. "I saw the difference children's hospice care makes; it's life-changing. It means the world to know Demelza have a whole troupe of supporters out there, helping us make sure they can do the specialist work that they do."

Hua, Henry's dad joined her on the Demelza leg of her cycle – from Demelza's Kent hospice in Sittingbourne to our South East London hospice in Eltham – to support her and her inspiring mission. "It's impossible not to be inspired by Francesca; after five minutes with her, you'll want to be involved because she's so passionate. We're honoured that after so many years of friendship she's dedicated this challenge to Henry, and the support he received at Demelza. Henry would be so proud," he said.

She also dedicated her cycle to children she helped care for as a children's nurse; like little Joshua, who she met during her time working at Evelina London Children's Hospital. Joshua also came to Demelza for end-of-life care, at just five months old. "There is no doubt that losing Joshua has been the most traumatic part of our lives," said Joshua's mum, Vicky, "but having the support of Demelza, Francesca and nurses like her has really pulled us through. I don't think we would be in the position we are today without them."

So far Francesca's journey has received donations from over 800 generous supporters; if you'd like to learn more about her mission and how you can help, visit www.chatukproject.com

"The 54 children's hospices around the UK support families during their darkest times. But with over 90,000 seriously ill children, hospices are struggling to raise the funds they need to continue the vital work they do"

– Francesca



How gaming at Demelza helps young people connect

Paul, a Healthcare Assistant and avid gamer who's been with Demelza for eight years, sat down with us to share his experiences leading on all things gaming at the Kent hospice – and why he thinks it's more than just a hobby.

"Gaming levels the playing field for our Demelza teenagers. For a boy with a condition like Duchenne's (Duchenne Muscular Dystrophy, or DMD), picking up a controller and playing Call of Duty with his friends is about more than just having fun. When he tops the scoreboard for the fourth time in a row he stops being 'the guy in the wheelchair', and he becomes 'the guy who's really good at Call Of Duty'. Letting our young people shed those preconceptions, even for the brief time they're with us in the hospice, is why gaming is so important to me.

It's an icebreaker too. If a teenager came in for their first short break and I just bombarded them with questions – 'do you like football, who do you support, have you ever been to a game'

What our young people think:

"I like gaming at Demelza because I can play for as long as I want!"

"Paul makes sure Demelza has the same games and consoles I'm playing at home, which makes it easy to sit down and play."

"Gaming makes it easier to get to know new people. I didn't know the other boys before coming to Demelza, but we ended up gaming together all day."

"I'd like it if Demelza was able to get surround sound speakers so it felt more like you were in the game."

"I think having a dedicated gaming room would be really cool, so we had our own space to play together."

Photo above (left to right): Draven 12 years old, Dylan 13 years old, Liam 13 years old

– their reaction would likely be to clam up, because that's what you do as a teenager when an adult is trying to get to know you. But if I sit down next to them with a controller and say 'Do you fancy a game of FIFA', suddenly I have a way in.

You make comments about the game, you start laughing and joking about what's happening, and before you know it you're having a full-blown conversation and you're not even trying. Now a teenager who might have been shy or withdrawn when they arrived is actively engaging with me, and they'll be excited about future opportunities to visit the hospice because they know it's not the dreary hospital setting they were expecting – it's somewhere they can come to have fun."

Challenges and Events

For our full list of events, please visit www.demelza.org.uk/events or call **0300 365 3653**

Christmas Tree-cycling

Bookings open November 2022

Our popular Christmas Tree-cycling scheme is making a return from 6-9 January 2023! Have your droopy Christmas Tree collected and recycled, and support your local children's hospice at the same time. Now in more postcodes than ever before.

Suggested donation £15

www.demelza.org.uk/treecycling



TCS London Marathon

Sunday 23 April 2023

Apply now to join #TeamDemelza and run the TCS London Marathon for charity! Challenge yourself and join the ranks of heroic Demelza fundraisers as you support your local children's hospice. Already booked your own place in the marathon? Get in touch to find out how you can still fundraise for Demelza as you run!

www.demelza.org.uk/london-marathon-2023



Bubble Rush 2023

Get messy and join thousands of Demelza supporters in the bubbliest fun run around! Make your way through a sea of frothy bubbles and raise vital funds for our services in the process. Courses are pram- and wheelchair-friendly and there's no age limits – so bring the whole family along for a day of colourful fun! **Join us in Deal, Eltham, Maidstone and a brand new location for 2023!**

Adults from £12.50, child (under 16s) from £10, under 3s £3

www.demelza.org.uk/bubblerrush



Paris to Sittingbourne Cycle

September 2023

Experienced and beginner cyclists alike can join this mega cycling challenge. Pedal an epic route surrounded by beautiful scenery, that will take you all the way from Paris to our Sittingbourne hospice. When you arrive, you will be welcomed into our hospice which will be open to the public for the first time since the pandemic. A once in a lifetime challenge, not to be missed!

www.demelza.org.uk/paris-to-sittingbourne



Open Day

Saturday 16 September 2023

Save the date! We hope you'll join us as we open the doors of our Kent hospice to the public for the first time since before COVID-19, to celebrate Demelza's 25th anniversary.

To apply visit www.demelza.org.uk/openday



Bubble Rush back in full swing

We've had a hugely successful few months of events this summer, with all three of our Bubble Rush events making a triumphant return to form in Deal, Maidstone, and Eltham.

Among the 1800 participants at Bubble Rush Eltham were dozens of children who access Demelza's services and their loved ones, as we proudly launched our first ever family wave. We were charmed by little fundraisers like Kai, a two-year-old from Greenwich with a complex brain condition, who came along and managed to raise over £100 with his Aunty Em – and had a great time!

His mum, Leanne, said: "We had an absolutely fantastic, fun-filled day, raising money to help children like Kai who are supported by Demelza. It's so important to us to make memories as a family – and Demelza help us to do that."

Our inaugural Little Warrior event

We were also delighted to debut Little Warrior, our new accessible challenge event, in Tunbridge Wells in June. The sun was shining as participants charged through several zones, each representing a service that Demelza offers, including:

- A hydro zone representing the hydro pool
- A musical instrument lucky dip representing music therapy
- A Demelza art board representing art therapy
- A family space hopper race with photographer for memory making services
- A ball pool representing our sensory play

Each zone also had an accessible option for wheelchair and pushchair users, much to the delight of families who came along on the day.

Demelza service user Harry took part in the event alongside his eight-year-old twin brother Thomas, big brother James, 12, mum Juanita and dad Gary.

Juanita, said: "It was great fun; the boys loved getting mummy wet! It's so lovely to have something inclusive and to see other Demelza families here. Harry has raised over £300."



In total, these four events raised over £140,000 for Demelza's services and saw more than 6100 participants attend. We're looking forward to bringing these events back in 2023 to even bigger crowds of smiley faces (including a new fourth location for Bubble Rush), so keep your eyes peeled for details!





Demelza
Hospice Care for Children



Our five-year strategy will see us extend our reach to support more families, whilst doing more for those already accessing our services, but we need your help to do this.

A regular gift to Demelza provides a sustainable source of income which is crucial when planning ahead. It will help support children with serious or terminal conditions and their whole family with our expert clinical care, as well as providing experiences and creating memories that will last a lifetime.

If you are able to help with a regular gift today, please visit www.demelza.org.uk/donate or scan the QR code.



Demelza Kent

Demelza House, Rook Lane
Bobbing, Sittingbourne
Kent ME9 8DZ

Telephone: 01795 845200

Demelza South East London

5 Wensley Close
Eltham, London
SE9 5AB

Telephone: 020 8859 9800

Demelza East Sussex

150a Bexhill Road,
St Leonards On Sea,
East Sussex, TN38 8BL

Telephone: 01323 446461

www.demelza.org.uk

Registered Charity Number: 1039651

