

Demelza Life

Autumn 2021

Inside this issue:

- Zak's parents share their experience of end of life care
- A private new garden for bereaved families
- Four marathon fundraiser in memory of baby Jade
- The positive impact volunteering has at Demelza



Demelza
Hospice Care for Children

Welcome

I am enormously proud that throughout the pandemic, Demelza has been able to provide specialist care to children and young people at the end of their lives and support to their families.



This has been achieved by our excellent specialist teams of Registered Nurses and Healthcare Assistants, and our Creative Arts Therapists and Family Liaison teams all of whom are assisted

every day by Demelza's volunteers. This is underpinned by other teams who all have the most important issue at the centre of their decision making; the children, young people and their families.

Our Registered Nurses are providing end of life care to a child in the community of West Kent. The family's choice is for the child to be at home. Registered Nursing teams are sharing resources and skills to make sure this can happen and that care is of the highest standard of quality and safety 24/7. We have supported many children with end of life care in their home environment, where they chose to be.

Of course, home care has been provided by Demelza since 2004 throughout East Sussex and Kent and more recently in South East London. Our aim is to offer choice of place of care and death, making sure children, young people and families can access services where they want them.

One of the #TeamDemelza values is Passion, Performance and Pride. Our values are lived; I see it every day and I feel it every day. I think our families feel it too; in fact I know they do because they tell us that the support we provide makes

a very real difference to them. As you will read in this issue, some families are cautious about the word "hospice" but they are always pleased they committed to seeking out how Demelza can help.

When I joined Demelza in 1999 I was blown away by the support shown by our donors and supporters, without you Demelza simply wouldn't be here. Your generosity of spirit and of deed has never waned, not once, and during the pandemic we have been so grateful that you have not forgotten our work and the children, young people and families we support now and those we want to reach.

As the world moves forward and many of us may have chosen to receive the "double jab" we must remember that this is not possible for many children with complex needs. Some may never be able to receive the vaccination. Their families will not be comforted by the assurance some of us may feel. Demelza wants to ensure there are more services available to support these families.

We know there are thousands of children with serious or terminal conditions in the areas we serve that we have yet to reach. We know we must do more and we want to do more. We will need your help and support more than ever in the coming years.

Thank you so much for your on-going support. With very best wishes.

Lavinia Jarrett, Demelza Acting CEO



Zak's story

"We knew the moment had come. It was the last time David and I would get to see our little boy. We walked into the bereavement suite where Zak lay peacefully, carefully dressed in the clothes we'd given to the Nurses, and kissed him goodbye.

"Something that should've been the hardest thing in the world, was made bearable. We walked out of Zak's final resting place; a beautiful bedroom so thoughtfully laid out, with Queen – his favourite band in the whole word – playing to him. We closed the door – which had his name and a picture of a guitar on it – and sat quietly in the adjoining family conservatory. We knew Zak had gone but he was still close by and being cared for by Demelza until the very end.

"Our lovely boy Zak was only two when he was diagnosed with rhabdomyosarcoma – a rare tumour in his liver. He was so ill that he spent 80 days on a ventilator and underwent intensive bouts of chemotherapy - the start of a gruelling four years of treatment.

"We were first told about Demelza by Sacha, a Senior Registered Nurse from the charity. Although Zak didn't access many Demelza services because of his prolonged hospital stays, Demelza ended up being there in our most critical time of need.

"In early 2021, Zak's surgeon told us that his tumour had returned. It was inoperable; nothing more could be done for our little boy. I asked how long Zak had – "six to 12 weeks," he replied. We only got three. Demelza Nurse Sacha visited us at home every morning to help control his pain and keep him comfortable. A special hand cast was also arranged with Zak's brother Tom.



• Zak with brother Tom

"Not long after our darling Zak died, the Demelza team arrived and removed all the medical paraphernalia – we needed Zak free from the equipment and medications that had consumed his short life. We didn't want his death to affect our memories of Zak at home so he laid at rest in Demelza's Hop Garden bereavement suite surrounded by all the things he loved. Sacha made sure all the thoughtful touches were in place and it was so calm and serene. The team also helped with funeral arrangements and support grants, which took an enormous weight off our shoulders. Demelza has since offered bereavement support, including a sibling group for Tom.

"Zak made a huge impact on the lives of everyone he met and we've been fundraising for Demelza. Please join us, in Zak's memory, to ensure other families can get the support they need www.demelza.org.uk/support-us. Thank you."

Caroline and David, Zak's mummy and daddy

Christmas Cards in store now

Christmas is just around the corner and one of the easiest ways to support Demelza is by buying some of our Christmas cards.

There's a whole range to choose from and every purchase will help us continue to provide care for the children and families who need us most.

Take a look at all card designs online here: www.demelza.org.uk/christmas-cards or call 01 795 503120 for more information.



The opportunity of a lifetime

Main photo: © Remember My Baby



Friendships, memories and life skills were made at Demelza's first ever residential trip for siblings.

In August brothers and sisters of children cared for by Demelza, were invited to an action-packed two-night stay at Kingswood adventure and activity park at Grosvenor Hall in Ashford.

The group of 10 and 11-year-olds faced their fears and supported each other as they tackled a number of exhilarating outdoor challenges including the high adrenaline 3G swing, trampolining sport Aeroball and a 10m pole climb. For many of the 13 children, the residential trip was their first time away from their homes in Kent, South East London and East Sussex since the start of the pandemic.

Emma Sweetlove, Demelza's Family Events Lead, said: "COVID-19 has put an enormous strain on the families we support; particularly for siblings who have had to shield alongside a brother or sister living with a serious or terminal condition.

"Many of the children are transitioning from primary to secondary school and the trip has undoubtedly helped to build their confidence and social skills. They were all so brave when doing the challenges and it was wonderful to see their confidence soar; especially amongst some of the quieter ones. One of the children described the trip as an opportunity of a lifetime. We can't wait to start planning our next one."

The stay at Kingswood also helped to forge strong bonds between the group, including new friends Darcie, 10, and 11-year-old Pearl who tackled 'Jacob's Ladder' together.



• Volunteer Sarah with Pearl and Oliver

Staff and volunteers from all corners of the organisation helped out and supported the children including Sarah Selley. The trainee children's Nurse, who is a housekeeping volunteer at Demelza's hospice in Eltham, jumped at the chance to attend the trip after hearing it was especially for siblings.

"My brother wasn't well when he was little and often spent a lot of time in hospital", says 25-year-old Sarah. "As a sibling, the experience was very challenging, isolating and I felt powerless to help. It was therefore an amazing opportunity to be able to support on the trip and help children that may be experiencing similar to what I did all of those years ago. They all had so much fun and made some lovely friendships."

Turn to pages six and seven to read about how other volunteers have been making a positive impact at Demelza.

Pearl said: "Jacob's Ladder was scary! But we are very good friends and a double act. I hope we stay in touch. Climbing has been the best and I want all of the equipment in my back garden. If I did, I would never go back to my devices!"



Running for baby Jade

The bereaved parents of a baby who died at Demelza are taking on a series of running challenges this year to raise £3,000 having already raised £30,000 for the charities that helped them.

Wayne will be running four marathons in three weeks, with partner Claire joining him for the final challenge, the Virgin Money London Marathon on Sunday 3 October.

Their second child Jade Peacock was just nine days old when she came to Demelza's hospice in Eltham, South East London, for end of life care in January this year.

It was the first time the couple, who were both COVID-19 positive at the time, could be together with their baby and four-year-old son Elijah since Jade was born.

Claire said: "Jade wasn't breathing and her heart wasn't beating when she was born which meant that her brain was without oxygen for a prolonged period of time. The care she received in hospital was phenomenal but COVID-19 restrictions meant that none of our family could meet Jade – not even her big brother. Going to Demelza meant our family could be together whilst being supported by their caring staff."

Demelza Nurses made it possible for extended relatives to visit and make memories with their 'Little Peacock' – a name lovingly given to Jade by her big brother. Jade's nan read her a book that had been gifted to her by her grandmother and her uncle played 'Somewhere Over the Rainbow' on his ukulele.

"Despite the circumstances, we had the most precious time together as a family", added Claire. "The Demelza team did everything they could to help facilitate those special moments with our daughter and enabled us as a family to be able to grieve. When they removed Jade's life support, we heard her breathe without machines for

the first time. It was the most beautiful sound in the world. The Nurses passed Jade to us and we were able to hold our tiny baby girl, free of wires and tubes. We were free of our face masks to be able to give her a kiss. We spent 18 perfect hours together as a family of four."

Jade died the following morning in her daddy's arms, with her mummy and big brother by her side. In the days that followed Wayne and Claire and their extended family were able to spend time with Jade in one of Demelza's special bereavement suites, known as the Butterfly Suite.

For Wayne, running has been a way of channelling his grief, and he will be running four marathons in three weeks, taking part in the Brighton, Goodwood and London Marathons this autumn on consecutive weekends.

On 19 September, Wayne will be running 'The Little Peacock Marathon' – a 26.2 mile route that will take him on Jade's journey – passing Lewisham Hospital, Evelina London Children's Hospital and Demelza's hospice in Eltham. Wayne said: "We now want to pay it forward so that if anyone ever finds themselves facing their darkest hour, they are met with the same love, care and compassion that insulated our family.

Before all of this happened, we didn't know about Demelza or that it existed. Kindness sits quietly behind all things. Demelza is the epitome of that - it's location at the end of a quiet, unassuming South East London cul-de-sac - where kindness is found."

To sponsor Wayne and Claire, please visit <http://bit.ly/TheFlyingPeacocks>

How volunteering a little time can make a big difference

We are extremely fortunate to be supported by over **1,000 dedicated volunteers**. Our volunteers give their time and energy across all areas of the charity, in the community, at our hospices Demelza Kent, Demelza South East London, our community team in Demelza East Sussex, and in all of our charity shops. No matter what role they undertake, all our volunteers are helping us to continue the vital work we do.



Going the distance for Demelza families

For the parents of Zak, featured on page three, the thought of driving to weekly chemotherapy appointments was a big worry.

Following major surgery Zak was Type 1 diabetic, resulting in volatile blood sugars that required constant monitoring. A 45-minute drive to hospital was therefore incredibly daunting.

But Demelza's practical support volunteers stepped in to help.

"The incredible volunteers drove Zak and his daddy to every appointment and brought them home again", said mum Caroline.

"No longer did we have to worry about finding parking nearby, the money for petrol or making poor Zak walk to the entrance in the pouring rain. All he wanted was to hold his daddy's hand in the back of the car and thanks to the Demelza volunteer drivers he was able to."

David Fewkes, is one of a group of practical support volunteers, who helped to drive Zak to months of chemotherapy appointments.

He said: "Zak was a joyful, happy child. The last time I saw him his hair had grown back and I remember telling him he now had more hair than his daddy. Driving them to and from appointments took the stress away from them. I was always there on time and waiting for them when they came out. I never wanted them to have to worry."

Driving is just one of many services provided by Demelza's Practical Support Volunteers.

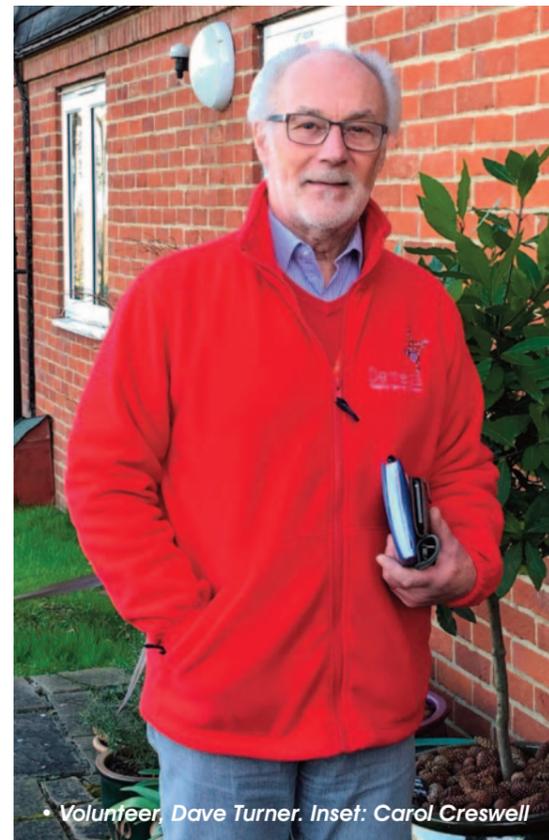
If you enjoy a spot of DIY, gardening, cooking and ironing and would like to make a positive difference to the lives of families supported by Demelza, please visit:

www.demelza.org.uk/support-us/volunteer

Join #Team Demelza

Whether you have just a couple of hours a week, or can devote more time, we would love to hear from you. Please visit www.demelza.org.uk/support-us/volunteer or call **01795 845170** to speak to someone in our friendly team about all of the exciting opportunities available

• Demelza's practical support volunteer, David Fewkes



• Volunteer, Dave Turner. Inset: Carol Creswell

A friendly ear for families during the hardest of times

At Demelza care does not stop after a baby, child or young person dies; we will continue to provide emotional support to the family. As part of this care, our fully trained volunteer befrienders are available to offer listening sessions and have a virtual tea or coffee with families to spend time to hear how they are feeling.

Dave Turner, who has been volunteering at Demelza for 23 years, said: "A family once told me that I am the glue holding their family together and this has always stuck with me, recognising how important listening and the support we can offer is to Demelza families."

Carol Creswell first heard about the befriending service from her son Mark who is also a Demelza volunteer.

She said: "I've wanted to volunteer for a while and was delighted to be offered an interview for the telephone

befriending service. I've been able to do all the training remotely during the pandemic and am really looking forward to when I can meet people face to face. Demelza has such a special place in our hearts. It's such a wonderful caring, happy place and I hope we can bring a little bit of happiness with what we contribute."

To find out more about our bereavement support services visit www.demelza.org.uk/how-we-help/services

Turn to page nine to read how Carol has also contributed to the new garden for bereaved families at our Kent hospice.



• JamJam with his family and volunteers

Strength in numbers

One person can make difference, but together our volunteers change lives. In July the family of three-year-old Jemiah, known as JamJam, reached out to Demelza's practical support team for help with their garden. JamJam has Patau Syndrome, also known as Trisomy 13; and the outdoor space at his Clapham home was not suitable for his additional needs. But in order to complete the project, some extra pair of hands were needed.

Mary Goodger, Demelza's practical support service manager, said: "When the family first got in touch I realised the work was bigger than our volunteers could deliver on their own and that we needed some expert skills and guidance as well as manpower." Mary called upon

Demelza's corporate partner Wilmott Dixon and together with GSE Group and Coblands Landscapes, volunteers from the firms helped to transform the space and breathe new life into the garden.

Mary added: "It is so good to be able to reach out to companies like Wilmott Dixon and their staff and enable positive changes to the lives of our Demelza families. This project was life changing for Jamjam and his family as they had never been able to be in the garden as a whole family before."

If your company would like to support Demelza with volunteering or fundraising, please visit www.demelza.org.uk/corporate-partnerships

New footie partnership promises to be a roaring success



• Millwall Football Club players Benik Afobe, George Saville and Jed Wallace

Exciting news for South London football fans! Millwall Football Club has teamed up with Demelza for a new charity partnership for 2021/2022.

Throughout the season, the Lions will assist with a wide range of Demelza's fundraising initiatives and events and is calling on the support of Millwall fans to help staff and volunteers continue our important work.

"Millwall fans are the most generous and thoughtful set of supporters in the country and I can think of few better causes than this," says Steve Kavanagh, Lions chief executive. "Hearing about the extent of Demelza's work and learning what they do for children and their families is incredibly moving and as a club we're committed to doing absolutely everything we can to help them this season, both in terms of spreading awareness of their efforts and also, crucially, with their fundraising.

Millwall's football stadium 'The Den', is just a few miles away from Demelza's hospice in Eltham, South East London, where we provide care and support to babies, children and young people with serious or terminal conditions.

Katherine Cordrey, Senior Community and Events Manager at Demelza, added: "We are really looking forward to working with everyone at Millwall Football Club over the next 12 months. As a charity, we're almost entirely dependent on the generosity of our supporters to provide the funds that keep our services going. Huge thank you to Millwall for their commitment and we can't wait to get started!"

To make a donation please visit www.justgiving.com/campaign/millwallfootballclub Keep an eye out on our website and social media for updates!



Demelza is coming to Hempstead Valley – new charity shop opening in autumn

Staff and volunteers needed! To apply visit www.demelza.org.uk/work-with-us

Opening soon



New garden for bereaved families at Demelza Kent

A beautiful new garden has opened up at Demelza's Kent hospice for bereaved families.

Adorned with pretty roses, flowering shrubs and a wisteria archway, the intimate space offers privacy for those wishing to reflect and remember their child.

The garden is situated outside the hospice conservatory; a room used by parents and carers if their child is in one of our bereavement suites – a special bedroom known as the Hop Garden.

Senior Healthcare Assistant Louise Cairney said: "This beautiful new garden forms an important part of our bereavement support service and is available for families of children of all ages. For parents grieving their baby, we can support them to take a walk with them in a pram, in a space which is tranquil and private.

"Earlier this year we were able to provide end of life care for a child in the garden. This space will play an important part in helping family wishes to be realised."

Work on the garden started before the pandemic struck and although progress was slowed, staff and volunteers pulled together to bring the concept to fruition.

For head gardener Sam O'Brien, seeing the garden in bloom



Demelza volunteer Carol Creswell is one of many kind-hearted people who contributed to the development of the garden. Carol, whose daughter Debbie died at the age of 15, donated £1,400 from the auction of a beautiful Silver Cross pram and a rare Hamley's doll. Her generous donation has helped to buy flowers and shrubs for the garden, which Carol looks forward to visiting.

She said: "Everything was so different when we lost Debbie. I so wish there had been a Demelza to support us through such a terrible time. You never ever get over that loss, but to have the support that Demelza provides for bereaved families is very special. When lockdown restrictions lift, my son Mark and I can visit the garden when its not in use and sit and remember Debbie."

after years of hard work has been worth the wait. He said: "Bringing the garden to life has been a real community effort. So many people have donated flowers, plants and trees. One volunteer, who has been at Demelza for 22 years, even donated 22 roses. Our vision for the space was to create a calm and gentle garden with a woodland feel and soft colours. It's still in its infancy but in a few years, it will flourish.

"We are now making plans to make further improvements to the garden, with the addition of gates, which will provide even more privacy."

If you would like to help our garden grow, please donate at www.demelza.org.uk/donate

The garden at Demelza East Sussex has had a spruce up!

Children visiting can now enjoy the beautiful safe space at our St Leonard's site under the watchful eye of our fantastic home care team. The new sensory planters look and smell fantastic too!



Challenges and Events

These are just some of our challenges, events and activities.

For a complete list or to book any featured on this page please visit

www.demelza.org.uk, call **0300 365 3653** or email eventbookings@demelza.org.uk

Celebration of Christmas

20 December 2021

Join Demelza and special guests for a truly magical evening of Christmas carols and festive readings at Canterbury Cathedral.

Tickets from £8 available at www.demelza.org.uk/celebration-of-christmas



Mount Kilimanjaro 2022

22 September 2022 - 1 October 2022 (New date!!)

Join #TeamDemelza for the experience of a lifetime. See the stunning scenery of Africa from the world's best vantage point. Reach the summit knowing you have just completed one of the most iconic treks to support the children and families at Demelza. Registration from £195 and £3,328 minimum sponsorship (not including Gift Aid).

Visit www.demelza.org.uk/mount-kilimanjaro



Christmas Tree-Cycle

Friday 7- Sunday 9 January 2022

Let Demelza collect and recycle your real Christmas tree, in exchange for a donation. Following the success of last year, Demelza are now collecting in more postcodes.

Find out if your area is covered and register your tree at www.demelza.org.uk/christmas-treecycle

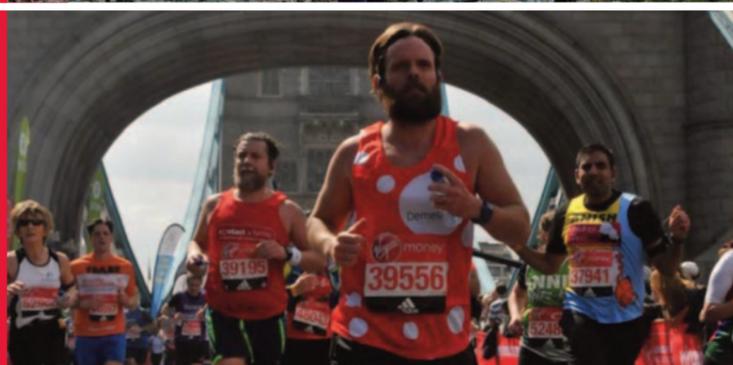


London Marathon 2022

2 October 2022

Apply now for your place to join #TeamDemelza in next year's Virgin Money London Marathon. Applications close late January 2022. Successful runners will be required to pay a £50 registration fee and raise a minimum of £2,000 (not including Gift Aid).

To apply visit www.demelza.org.uk/london-marathon-2022



Immerse yourself into Demelza with video tours of our Kent, South East London and East Sussex sites.

Available to watch now on the new Demelza website:

www.demelza.org.uk/about-us



Photo taken pre-COVID-19

• Thank you to all the children at Kingswood Primary School and Pre School including (left to right) Jacob, Bertie, Nate, Lillie, Tom, Scarlet and Harry



Putting the fun back into fundraising

Thank you to everyone who took part in this year's **Shorts 4 Short Lives** day, helping to raise over £10,000 for Demelza.

Supporters – including local schools and corporate partners – as well as some of Demelza's celebrity ambassadors, wore their funkiest shorts on 25 June and donated to help keep our vital services going. Demelza Vice Presidents Jayne Torvill, Robin Cousins and Len Goodman all bared their knees, alongside James Lock from reality show TOWIE and staff from corporate supporters Stagecoach, Pfizer and law firm CMS. Tom Hammond, along with friends from Kingswood Primary School and Pre School wore customised shorts and collectively raised £366.20 in memory of younger brother Zak who was cared for by Demelza.



Andrew's ultra-running challenge for Demelza

Well done Andrew Ferguson for raising over £23,000 for Demelza by running a whopping 48 miles. Andrew, 36, was joined by runners in Essex, Kent, Surrey, London, Hertfordshire and Toronto in Canada, for his epic 4x4x48 challenge in August, which saw him run four miles, every four hours, for 48 hours. The RBC Capital Markets employee, said: "My motivation began at the 2021 RBC Charity Day for the Kids and getting to learn about this incredible charity. I have been amazed by the support of clients, colleagues and friends alike with their incredible generosity in terms of donations and willingness to run individual legs with me."

To sponsor Andrew, visit <https://givepenny.com/4-x-4-x-48-fergs>

Miles in May raises over £28,000

An incredible 170 people walked, jogged, ran, cycled and rollerbladed 37 miles throughout May, raising sponsorship to help fund a Demelza Nurse. Our top fundraiser was six-year-old Freddie who raised an amazing £1,661. Freddie cycled the challenge as a thank you to all the Demelza Nurses who help care for his little brother Ralph. If you feel inspired to fundraise for Demelza, visit www.demelza.org.uk/support-us/fundraise-for-us or email fundraising@demelza.org.uk



run, walk or scooter 37 miles to help raise £37k to fund a Demelza nurse



The Nursing Appeal



Providing unique, professional and expert clinical care for children with serious or terminal conditions

Thank you to everyone who has supported **The Nursing Appeal** so far. We want to be able to support more families in your local community, but we need your help to do this.

To donate please visit
[www.demelza.org.uk/
the-nursing-appeal](http://www.demelza.org.uk/the-nursing-appeal)

Photo taken pre-COVID-19

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Registered Charity Number: 1039651

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 [demelza-hospice-care-for-children](https://www.linkedin.com/company/demelza-hospice-care-for-children)