



Demelza
Hospice Care for Children



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Impact Report April 2020–March 2021





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A year of challenge, inspiration and achievement

2020/21 was a year like no other for the 575 children and young people with serious or terminal conditions, and their families, using Demelza's services. At a time of great uncertainty and fear, we had to ensure the needs of these families were at the very heart of every decision we made. This wasn't always easy, especially at the beginning of the pandemic when we had to find new ways of supporting clinically vulnerable children without putting them at risk. But we did it; we did it better than any of us could have predicted or imagined. We couldn't have gotten through this year without our amazing team or our incredible supporters, who stood by us during the most challenging of times, and for that, we cannot thank you enough.

During the pandemic, Demelza revolutionised services to continue offering a virtual lifeline and telephone communication to the vulnerable who were severely impacted, spending many months isolated and shielding. This programme of activities has been adapted and developed over time and continues each week. The Practical Support Volunteers were utilised to deliver therapy bags, Easter eggs, and Christmas presents; they also continued to support travel to hospital and other essential appointments.

Throughout the pandemic, Demelza implemented rigorous Infection Prevention and Control policies, procedures and training, and secured the essential equipment that enabled safe clinical care to continue for all emergency admissions, including end of life care, social care placements and symptom management.

Local NHS Trusts invited Demelza, as part of their vaccination programme, to receive early access to the vaccine to play our part in the pandemic recovery. Demelza rolled out rigorous testing regimes for all staff and volunteers who could not carry out work from home as early as possible to ensure we could safely restart our offer of respite care to children and families.

I am incredibly proud to report that Demelza was able to support the national efforts of the NHS and other colleagues during the pandemic by offering step down care to several children, as well as a young person not on our caseload, to relieve the pressures on London hospital resources. Demelza supported a specialist nurse to return to an adult ITU in the local general hospital and provided additional resource to local adult palliative care services. In return, Demelza received the valued help and support of local children's nurses from other NHS Trusts and from a recently retired Demelza Registered Nurse who immediately returned to regular duty.

Demelza's clinical services COVID-19 infection outbreak record is zero. We will continue to navigate our way with the same high levels of clinical safety at all times whilst offering the high standards of quality and care our children, young people and families deserve.

Demelza's staff and volunteers have shown exemplar commitment, and "Passion Performance and Pride" one of Demelza's organisational values, regardless of the role they hold or the part they have played in our journey this year. Demelza remains committed to providing development, support and training to all staff and volunteers to ensure we have the skills, expertise and knowledge to stay at the cutting edge of children's palliative care.

Our focus is very much on the future and how we continue to build on the services provided to babies, children, young people and their families. As we plan a new five year strategy that is strong, resilient and ambitious in an uncertain world, we look to the families who have used Demelza services for our inspiration and guidance. Families will form an essential strand of our consultation and planning that will take Demelza from strength to strength.

Lavinia Jarrett, Demelza CEO



Demelza
Hospice Care for Children

Our year in numbers

Between April 2020 and March 2021 we were able to carry out:



947
virtual wellbeing sessions



1,818
Virtual music, art and group therapy sessions



48
Day care sessions within the hospices



153,112
volunteer hours



262
days of expert nursing care provided to children at the end of their lives



1,529
Care at home hours



251
families attended Little Dots groups for pre school children



1,494
Overnight sessions within the hospices



108
new referrals



174
Hydro pool sessions

We provided **79 nights** of post bereavement care and support to all family members after their child had died



575
total number of children and young people who used Demelza's services

Kent:



South East London:



East Sussex:





Spring 2020

In the spring of 2020, a series of unprecedented events unfolded that would have an enormous impact on the way children's palliative care services operate – not just at Demelza – but across the UK.

On 23 March, households were plunged into a nationwide lockdown as prime minister Boris Johnson instructed people to 'stay at home, protect lives and save the NHS.'

Social distancing measures were put in place, schools closed, people entered bubbles, and many employees – including Demelza's non-care workforce – began working from home.

For families caring for a child with a serious or terminal condition, feelings of isolation and loneliness are already widespread, but the COVID-19 pandemic would only intensify this.

Therefore, it was imperative that Demelza adopted new ways of working throughout this extraordinary period to continue caring for the most vulnerable children in our communities and provide vital support to their loved ones.

Keeping everyone safe

Our first priority was implementing the most extensive system of infection control procedures we have ever known, with full PPE, deep cleaning, regular hand washing and social distancing to ensure families, staff and volunteers were all kept safe.

Outreach phone calls

Demelza's Family Support Team were instrumental in the early days of responding to the needs of our families with

outreach phone and video calls. They continued to be a vital point of contact for self-isolating families by providing helpful resources and lending a listening ear and creating a whole calendar of virtual activities.

Doorstop visits

In East Sussex, our Community Team would ordinarily be going into family homes, but this was not possible for those shielding vulnerable children. Instead, the team helped where they could; checking-in by phone, collecting medications (from specialist London hospitals where necessary) and dropping off activity packs for children to enjoy.

Collaborative working

Demelza was proud to support the NHS and other care settings with the invaluable skills of our clinical staff throughout this challenging period. The nursing and care teams at Kent and South East London increased provision of step-down care, as we supported the NHS with moving vulnerable children out of busy hospitals into our hospices. Our staff made families feel welcome by arranging treats, delicious meals and creating memories to treasure. We saw one nurse come out of retirement to bring valuable skills back to Demelza, whilst we were able to support another nurse to be seconded to a hospital ICU and a Health Care Assistant to be seconded to a local community care team. Demelza's community team in East Sussex worked closely with Children's Community Nursing and Chestnut Tree Children's Hospice to maximise resources available for end of life care at home.



Being able to connect with other families taking part in music therapy has been a lifeline. During lockdown, the music therapy sessions with Demelza helped tackle the feeling of isolation as we were connected as a group. As a family, we were told by doctors to shield our daughter for the first seven months, and we had no respite, no therapy and no school. We did this whilst juggling home learning and having to continue working from home as neither of our jobs qualified for furlough.

Moments like the music therapy sessions offered much-needed relief and focus points to look forward to. Demelza has always been there to help families like ours in times of need, and lockdown was no exception. Moving therapy services to online, meant that families could still access their fun but in the safety of their own homes. I can't tell you how vital this was for all of us, as it felt like society had forgotten families like ours, whereas Demelza staff celebrated them.

We feel privileged to be part of this group and so lucky to be members of Victoria's Saturday music club!"

Sam, Lucy's mum



Full PPE in place



Daily phone & video calls



Doorstep drop-offs



In the first virtual music group of May 2020, children excitedly recognised each other in a Zoom session and spent several minutes laughing and pulling faces on screen, having not seen each other for several weeks because of lockdown, allowing connections to be made that had been absent for many. It's a wonderful opportunity for families who access Demelza's services to enjoy something together, and see that they are not alone.

The groups have explored the Wild West, the jungle, travelled to space and all around the world. We've celebrated Christmas, Easter, Bonfire Night and Diwali together. We always have at least one song that we sign using Makaton to support children and their families to learn to communicate using Makaton in an accessible and fun way."

Demelza Senior Music Therapist, Victoria Swan

Virtual support

Even before the country went into lockdown, our fantastic teams were putting in place flexible, innovative and far-reaching virtual programmes of support for families to access from home. What we thought would be a short-term offering has turned out to be one of the great successes of our pandemic response, with much of it continuing in a hybrid form for the foreseeable future. This support helped with the feelings of isolation and fear and gave the whole family some daily structure, a chance to socialise with others and have some fun. The virtual timetable includes:

- **Little Dots:**

Health Care Assistants Nicola and Clare took this stay and play group online, with singalongs, arts and crafts and story time with **251 families** attending over the year.

- **Wellbeing sessions:**

Mindful Mondays, Together Tuesdays, Wellness Wednesdays and Family Support Wednesdays – a weekly timetable for children, siblings and parents created a community for families ensuring they never felt alone.

- **Social activities:**

In response to the changing needs of families, the team introduced reading sessions during school closures, parties, discos and cream teas – we wanted to ensure families were spending quality time together as well as meeting and having fun with other families.

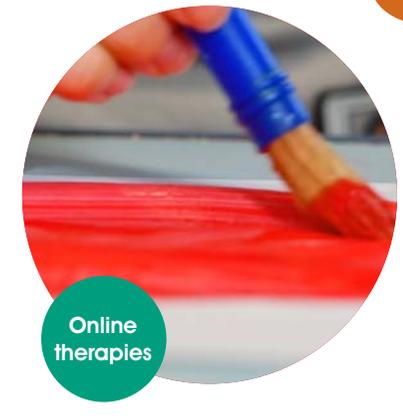
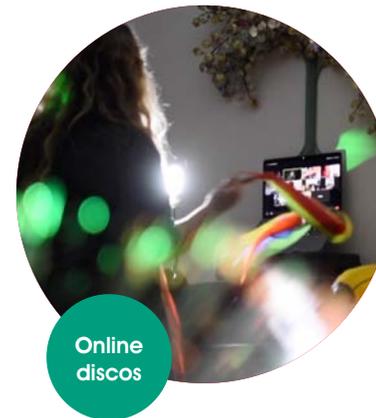
Virtual therapies

Despite the Prime Minister declaring the UK was 'past the peak' in April, isolation became all too familiar for vulnerable children supported by Demelza. The Demelza team worked tirelessly to adapt rapidly and continue working closely with families in the chaos and uncertainty of lockdowns.

One silver lining to be found in the nation's self-isolation was the increase in accessible therapies for families shielding with a child with complex care needs. Until last year, the creative services at Demelza were delivered primarily within the hospice setting or in the family home. COVID-19 changed all that, with a Facebook page for families and information email with a weekly virtual support timetable that ran throughout the year.

The team incorporated everyday household objects and materials to provide stimulating, creative, fun and inclusive experiences and secured funding for families that did not have access to iPads so they too could enjoy virtual therapy sessions.

Throughout the period, we were able to facilitate **210 art therapy sessions and groups**, allowing families to use creativity as a way to explore and express emotions. Our Saturday morning music sessions were a big hit with families from all areas and soon became a permanent addition to our therapy offering. Thanks to the generosity of our supporters, we were able to hold **1,608 virtual music therapy sessions** and groups throughout the year.





During the first lockdown a family contacted us in a panic as their transport to a hospital appointment had been cancelled at the last minute and they had no way of getting there. Their child was ventilated, so public transport was not an option.

Practical Support Volunteer Mick Cranfield immediately stopped what he was doing, rushed over to the hospice in Kent to be fit tested for the IP3 masks, as protocol for transporting ventilated children during the pandemic, and safely transported the family to their appointment."

*Demelza Practical Support Service Manager,
Mary Goodger*

Thank you to each and every volunteer

Our amazing volunteers donated 153,112 hours, throughout the year, saving £1.3million – money we were able to direct to where it is needed most, to our children and families.

Over 1,000 volunteers supported us across all areas of the organisation, including practical support - with many kind-hearted people stepping up to drive children to essential hospital appointments or delivering vital medications.

Continuing vital care for the most vulnerable

COVID-19 affected everyone; even more so for children with serious or terminal conditions, like Albie, who spent his first months of life at Demelza's South East London hospice. Adjusting to life as a parent is hard for anyone; but for new mum Katie the prospect of caring for her gravely ill baby amidst a global pandemic was terrifying. Albie came to Demelza as a newborn with a heart condition that was believed to be incompatible with life; he could die at any moment. Our specialist registered nurses could manage Albie's symptoms, make him comfortable and support his mum emotionally should the worst happen.



Being a mum to Albie means I have to take life day by day. Doctors have said he won't make it to his teenage years. If I focus on that too much, I will fall apart, but Demelza have reassured me that they will be there if and when the time comes. Albie is going to have a short life, but with the help of Demelza, he will definitely have a good life."

Katie, Albie's mum





Summer 2020

Demelza shops are back in business! Deserted streets and shops with their shutters down – it’s a bleak image we all became familiar with at the start of the pandemic. The months of closure resulted in a substantial loss in income, which is essential to fund our care.

But the summer months were to prove busy for Demelza’s retail teams after non-essential shops were given the go-ahead by the government to reopen in June. This wouldn’t have been possible without the support and dedication of Demelza’s volunteer workforce. Some familiar faces were sadly unable to return due to shielding, but others – like Lucy – stepped in to lend a helping hand.



At the start of the pandemic I was furloughed and unable to continue with my volunteering role on the care corridor at Demelza’s hospice in Eltham due to safety protocols. I then heard that the Demelza shop in Eltham needed volunteers so I moved across to retail. I was keen to get back out there and show my support.

“It was a hands-on role which involved sorting through all of the clothes – and I absolutely loved it. We were inundated with donations; so much so that we had to limit it to one bag a day per customer. It was amazing how so many people came forward to support us by dropping off donations and spending in the shop. I was also impressed to see all the safety measures that were put in place to protect the staff, volunteers and customers.”

Lucy McInerney, Demelza Volunteer

Bookable experiences

We created a new booking system for families looking to access our hydro pool, cinema space, sensory room (in Kent and East Sussex) and gardens, when government guidance allowed. This offered families the opportunity to enjoy time out of the house together in a space they knew they were safe. For some, it was the first time they had left their home for months.



Because of knee surgery, Aimee had already been off school for six weeks before the lockdown started, so finding out about the Demelza sensory room was a real lifeline. We booked a session every Friday morning, which gave us something to look forward to. We felt completely safe and it was good to have a break from being at home all the time."

Marie, Aimee's mum



Marie & Aimee

Fundraising superheroes join #TeamDemelza

The summer months would usually see Demelza's events team at its busiest, with our own jam-packed events calendar and supporting people with their fundraising activities. But social distancing restrictions and other safety measures, resulted in events being cancelled or postponed.

During this extraordinary period, Demelza continued to provide end of life care and essential clinical support for those that needed us. But with income dropping rapidly, we needed our supporters more than ever.

So, we called on our communities to join #TeamDemelza and continue supporting us through the challenging period – and we were overwhelmed by everyone's support and generosity.

The following are just some of the ways our amazing supporters stood by Demelza when we needed them the most:



• **Five-year-old James** challenged himself to read as many books as he could in just one week. He read an incredible 60 books and raised £610.

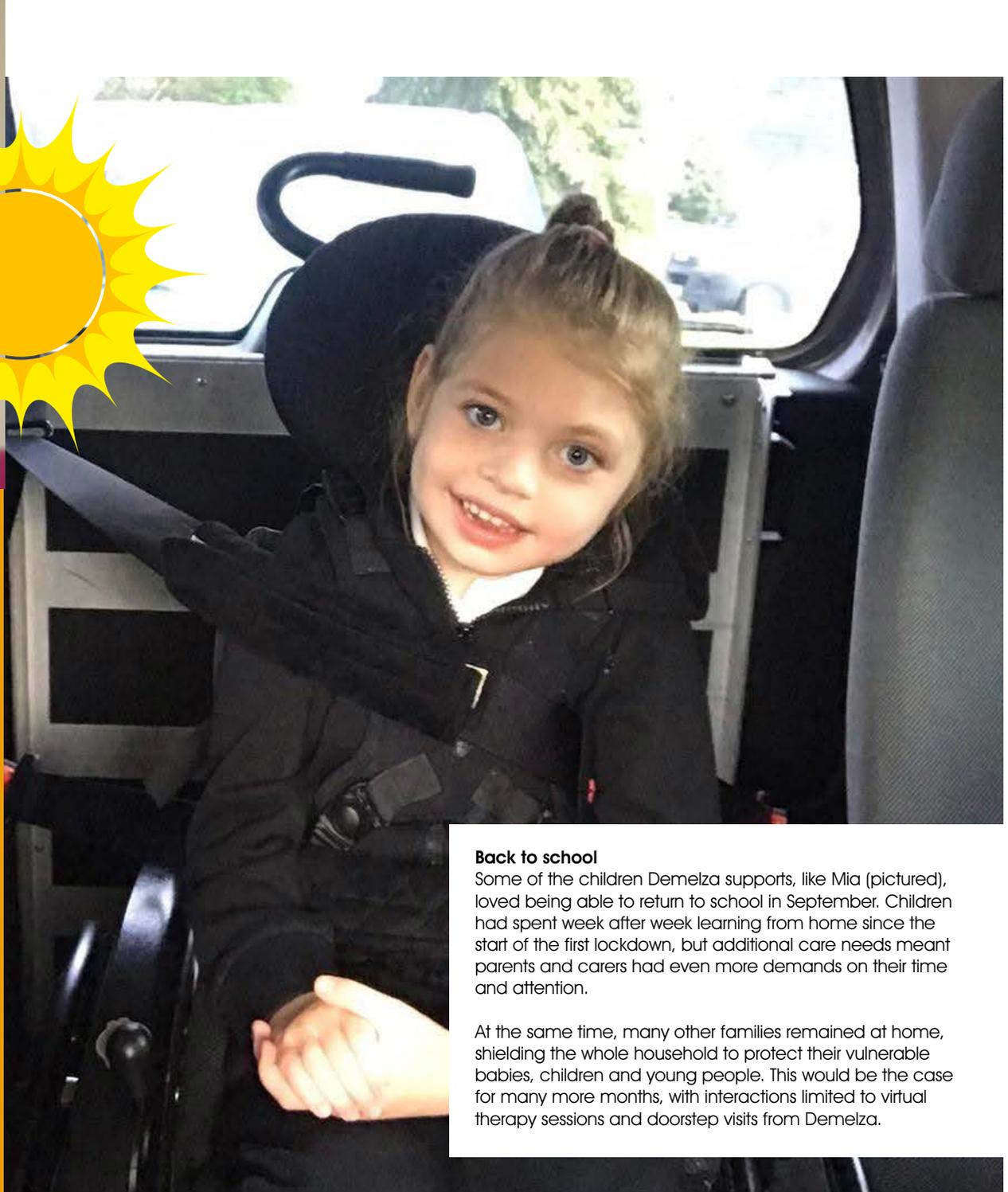
• **Oly** set himself an intense Ultimate Fitness 60k challenge to complete in one day - with a little help from **Sir Rod Stewart and Penny Lancaster**, Oly's proud sister! Oly ran, swam, rowed, cycled, did press-ups and more to the tune of £11,420 – with a generous donation from Sir Rod and Penny.

• **Kevin** enlisted the help of family and friends to take part in The 100 Challenge – 100 people raising £100 for Demelza on the same day. Over £15,000 was raised in memory of Kevin's nephew Sonny, who was cared for by Demelza South East London at the end of his short life.

• **Terence** started posing these cuddly characters in fun scenarios to cheer up his neighbours and raise funds for Demelza. The residents of Shirley Way, Croydon, have now donated over £2,100, which is bear-y nice of them indeed.

• Youngsters like **Niamh**, three, scooted, cycled and roller-skated for our first ever sponsored Scootathon. Together, these fun-sized fundraisers raised £4,073 for their local children's hospice. We're wheely impressed!





As the rest of the UK returns to life as we knew it before lockdown, many of the families supported by Demelza have had to make difficult decisions about returning to school. Much like Mia's, some families feel reassured by the safety and sanctuary of their children's schools, who understand their child's needs and have put in every measure possible to protect them. For others, mixing with people again is simply not an option as their child is too at risk.

Many siblings are also affected because they share the same household. There's a lot for families to consider and juggle, because it can be exhausting for parents and carers who have to work, care for their child, and now home school. That's why we offer many different kinds of support, from dedicated hours to call us for a listening ear to a whole range of virtual sessions to take the strain off of caring for children, and even sibling groups for children to socialise with others their age who know exactly how they feel.

There is also a worry hanging over many families that the pandemic infection rates will go up again and how they might cope with a second lockdown, which is why we've set up parent pop-ins for families to come together, share their concerns and experiences with their peers and with us."

Anna Sillett, Family Liaison Lead

Back to school

Some of the children Demelza supports, like Mia (pictured), loved being able to return to school in September. Children had spent week after week learning from home since the start of the first lockdown, but additional care needs meant parents and carers had even more demands on their time and attention.

At the same time, many other families remained at home, shielding the whole household to protect their vulnerable babies, children and young people. This would be the case for many more months, with interactions limited to virtual therapy sessions and doorstep visits from Demelza.

Care at home

For parents and carers of a child with a serious or terminal condition, a lot of the focus becomes on treatment, managing symptoms, appointments and medications – and it can all get exhausting. That's why Demelza offers Care at Home. Our registered nurses and health care assistants go directly into the family home to provide care, crisis intervention, an on-call service and respite.

Going from lockdown to strangers coming in took some adjusting but everyone was so patient and understanding; they wanted to help. Within a few months, we'd built great relationships with the nurses and health care assistants and they would all bring something different to the table. For the first time ever, Ethan was given the opportunity to have independence away from his parents."

Harriet, mum to Ethan



When social distancing measures meant Sarah couldn't go in to work at a care home and Charlie and his siblings had to stay home from school, life changed dramatically for the family. Charlie, affectionately described as 'a Duracell bunny', has no awareness of danger. This means he needs constant supervision to keep him safe. When Demelza received the call from Sarah, the Kent Care at Home Team stepped in with some support for the family, which has been a relief for Sarah and a delight for Charlie.

Trying to chase after Charlie all day and keep him occupied meant I had less time to sit down and teach his brother and sister. I was getting emotionally and physically drained. I had to ring Demelza when I was crying every day from finding it so hard to cope. I was struggling to give Charlie the care and attention he needed. If we didn't have Demelza, we wouldn't have any support at all. Having Demelza come in and look after Charlie, even for a couple of hours a week, has helped us so much. I don't know what we'd do without them."

Sarah, Charlie's mum

Autumn 2020

Shoppers show their support!

Once again, our supporters showed their loyalty to Demelza as they flocked to grab a bargain from our charity shops before a second national lockdown came into force. We saw a drastic increase in footfall and profits doubling on 4 November – the day before our all non-essential businesses in the UK closed. We were delighted to welcome customers, volunteers and retail staff back four weeks later, on 2 December, after receiving the green light to reopen.




SORRY, WE'RE CLOSED

Following Government Coronavirus guidelines, all our high street shops are now regrettably closed



Stock donations:
While we are closed, please do not leave any donations outside the shop. This will be classified as fly tipping and will be dealt with accordingly and treated as such.



Online shopping:
We remain online, so you can still support Demelza by shopping on e-Bay, Depop and our main website:

- www.demelza.org.uk/ebay
- www.depop.com/demelzahospice
- www.demelza.org.uk/shop-with-us/online-shop

Fun for families

After a tough start to the year, it was time to ramp up the festive fun with Demelza providing:



from October to December including Christmas music and disco sessions, parent and carer festive crafts and a party, especially for siblings.



including 24 children and young people, 13 siblings and 33 other family members. Fa-boo-less!

Demelza's most successful Christmas appeal

Demelza's 2020 Christmas appeal raised £89,000 – our most successful festive campaign to date - and showed how everyone came together to ensure we could give the *#BestPossibleChristmas* to the children using our services. The support shown by our communities continued to humble the team at Demelza. It made us even more determined to be there for families in what could be another challenging year ahead.

Christmas presents

As we couldn't hold our traditional grotto, our amazing volunteers stepped up once again. They dug out their elf outfits and hand-delivered **473 gifts to children and siblings from 250 families across our whole area**. As an extra special treat, vulnerable children and their siblings were also sent a personalised video message from Father Christmas for being on his 'nice list.'

We couldn't change the COVID-19 restrictions that prevented many families from enjoying Christmas in the way they wanted to, but we could put a smile on their faces and bring a little Demelza festive cheer to their homes.



Demelza
Elves



Christmas
Appeal
2020



Father
Christmas
Video
Message



I enjoyed dropping off the Christmas presents to families. My wife knocked on the majority of the doors as I was driving, but I did do the families I knew - including Zak's family, so I could wish him and his family a merry Christmas and check-in with them. It was a nice opportunity to touch base with Zak's mum and dad. Zak was over the moon with his present."

Demelza practical support volunteer and part-time elf, Mick Cranfield



Finley was hospitalised with pneumonia. We don't have a support network around us so Demelza is crucial; it is our lifeline. We were at breaking point and desperately needed help so Demelza agreed for him to stay for four nights to recuperate.

When we pulled up to the hospice in November, Finley's body went tense, and I could see the pure excitement on his face. He hadn't been in a long time because of the pandemic, but he knew straight away where he was. I also felt a huge sense of relief knowing he would be receiving the best possible care.

A few days later, Finley's dad, sister and I all tested positive for COVID-19. It was agreed the hospice would be the safest place for Finley, where the care team could nurse him to health and lift his spirits. During his extended stay, Demelza nurses brought fun to Finley's room and ensured he had plenty of video calls with us.

I was fraught with worry. I felt so poorly and all I wanted was to be with Finley. But he couldn't have been in a better place. He isolated in his room but he didn't go without; the nurses brought amazing projectors and floor mats in and he spent time in the garden.

The nurses put themselves at risk to ensure Finley got the care he needed and I will forever be thankful to them. It made a very difficult time in our lives- bearable."

Sarah, Finley's mum

Vital care continues

Demelza continued to provide end of life and other urgent care, in our hospices and in the comfort and familiarity of a child's own home. The fundraising efforts and generous donations from supporters made it possible for Demelza's team to come home with Darcey last Christmas Eve – and enabled Demelza Registered Nurse Lottie to continue giving care throughout 2021. *Read Darcey's story (right).*

We were also able to offer residential stays at our hospices for children who were unable to be safely cared for at home, and for those being treated in tertiary NHS hospitals to free up beds, and reduce infection risk for those children. *Read Finley's story (left).*



Adapting our bereavement support

A wrap-around framework in the form of virtual bereavement groups, cafes, helplines, online forums and a befriending scheme was established and now empowers Demelza bereaved families to choose when and how to engage at a time that is right for them.



With a team of bereavement volunteers in place to support the new changes, we are ready to embrace a positive future; one that continues to grow and reach more families.

Thankfully the changes made to accommodate COVID-19 have never been perceived as temporary.

The creation of a virtual presence is now firmly established, and our team will continue to offer this alongside face to face sessions – when safe to do."

Demelza Therapeutic and Bereavement Lead Jo Burton



Our first virtual bereavement event

Bereaved families were invited to attend Demelza's first-ever virtual Candlelight Remembrance event. The pre-recorded memorial service was dedicated to all the children and young people known to Demelza who sadly died. Families were able to light a candle at home in their children's memory while listening to music, poems, readings and contributions from Demelza's staff and volunteers.



Beautiful. Such thought and care. Knowing that Demelza were thinking of me and my boy. I really liked that it was delivered by someone from Demelza. So very kind. Great idea to have everything you needed to make the snowdrop, even the glue! The tile is very special and already framed. The heart keepsake is simple and beautiful. I will always know that it is for my boy, without necessarily having his name on it and others asking who it is for."



Candlelight helped to open the window for me to begin talking"

Demelza parents on the Candlelight Event



On Christmas Eve last year, it was our festive wish to bring our daughter home so she could be surrounded by family and love.

When I was 20 weeks pregnant, we were told that our baby would need heart surgery – but would hopefully go on to lead a normal life. Darcey was born in October 2020 – and at two months old, our little girl had already been through two major operations. It was such a difficult time and the added complications and restrictions of COVID-19 prevented us from being with her as a family as we so desperately wanted to. Sadly, and very unexpectedly, just before Christmas she started to struggle. We were given the devastating news from doctors that Darcey's heart could not be fixed.

Darcey was very fragile and we were told she could pass away at any moment. With a tube helping her to breathe, she just looked so poorly. Very quickly our thoughts turned to Archie, Darcey's four-year-old brother. How could we possibly break the news to him? Having only met his little sister once, he longed for her to come home whilst, of course, being very excited about Christmas! We desperately wanted to give Archie a happy memory of his sister and his new family and didn't want this Christmas and those that followed to be focused on sadness. And so, we decided we would bring Darcey home on Christmas Eve. Being together as a family at home for the first time would make Christmas Eve our special day to celebrate for years to come.

On Christmas Eve I travelled with Darcey and two wonderful intensive care nurses in a specialist ambulance. At home, we were introduced to more nurses including Lottie, our Demelza nurse. That day, Lottie helped us make all sorts of precious memories. She took clay impressions of Darcey's feet so we could remember how delicate they were. I remember that she laughed when she realised I had bought 10 kits! It was so comforting to have Darcey home for Christmas, with the chance to take lots of photos and have cuddles. After just a few hours, it was time for the nurses to remove Darcey's Lottie is still our Demelza nurse. She is so wonderful, calm and knowledgeable and we can hand Darcey over to her without worry, knowing that she will care for our little girl as if she was her own. A home visit from Lottie means she takes over all of Darcey's care for a few short hours, enabling us to spend some quality time with Archie or get some much-needed rest."

Zoe, Darcey's mum



Winter 2020

A safe place for families

The national COVID-19 vaccine rollout for frontline healthcare workers began, in the midst of the third national lockdown and Demelza hospices continued to offer a safe and comforting space for vulnerable families to be together.

For Wayne and Claire, Demelza was the place where their two children met for the first time, following the birth of their daughter Jade in January 2020. This is their story...





We are a family of four and this is one of only two pictures you'll ever see of us all together. Jade is nine days old in this picture. It was the first time Jade and her big brother Elijah got to meet. They met at Demelza. From the moment Elijah found out he was going to be a big brother he fell in love with his sister, giving her the nickname Little Peacock which he still fondly calls her.

Due to complications during Jade's birth, her heart stopped immediately after she was born. The midwives, doctors and nurses worked furiously to save our little girl's life and managed to get her heart going again. However, due to the prolonged period of time without oxygen to her brain, Jade suffered irreversible brain damage. There were no signs of improvement in her condition and the knowledge that keeping her on a ventilator would cause her more pain meant we had to make the heartbreaking decision to take Jade off life support.

Due to restrictions on visitors in hospitals because of COVID-19, only Wayne and I had been able to make precious memories with our Little Peacock. It meant everything to us that Jade and Elijah could meet, and Jade could also be introduced to her grandparents, aunts and uncles that had been eagerly awaiting her arrival. That's when we found out about Demelza, and that's where this precious photo was taken.

We were blissfully unaware of children's hospices before having Jade. We admit to not being able to contemplate what happens at hospices such as Demelza but now realise they are places of love and support and we are exceptionally grateful that Demelza was there in our darkest hours. It's at Demelza that we got to be the family of four we'd always imagined, that we are.

Not only that, Jade was serenaded by her Uncle Steve, who played her Somewhere Over the Rainbow on his ukulele and Jade's Nanny Nash read her a special book she'd been given by her nan when she was little. Memories our family will hold so fondly from their short time with Jade.

At just after 4pm on the 18th of January, Jade's ventilator was removed and for 18 hours our little girl laid peacefully on our chests. We got to take in all her beauty. It was the first time we'd been able to see her without her tubes and wires and we were free of our face masks. We got to kiss Jade. Elijah got to kiss her, stroke her and show her his favourite cars and teddy.

We laid lazily in bed in the room that had been set up for us and plied with tea and biscuits. Most importantly, the care team tended not only to our little girls every need, but ours too. It felt as close to being at home as possible.

We would especially like to recognise the hard work and tenderness shown by care team members Lottie, Laura and Hilary. They were at our every beck and call and were incredibly sensitive in giving us space.

As Wayne wasn't able to be at Jade's birth due to COVID-19 we agreed that Wayne would hold Jade in her final moments. At 09:58 on the 19th January of this year, lying peacefully on Wayne's chest, Jade took her last faint breath.

The days that followed Jade's death were so unbelievably difficult but Lottie, Laura, Hilary and the rest of the care team made it just that bit more bearable. Not only did they help with the formalities of registering Jade's death and arranging her funeral but they continued to tender to her with such love.

They helped me bathe her, settled her into the Butterfly Suite and made her a Peacock sign for her bedroom door. They were also there for Elijah in the moments we couldn't be, playing games, drawing and building dens.

Nothing beats kindness... it sits quietly behind all things. To us, Demelza is the epitome of that. Its location at the end of an unassuming South East London cul-de-sac.

Claire and Wayne, Jade's mum and dad

Support for the whole family

At Demelza, we believe every child and young person who has a serious or terminal condition should receive the care and attention they need to live the most fulfilling life they can, and that they and their families have the opportunity to build memories- for however long they have together. For grandparents Julie and Liam, Demelza enabled them precious time with their baby granddaughter Jade – to say hello, and goodbye. This is their story...



I spent 10 minutes with my baby granddaughter Jade when she was alive. In those precious moments I introduced myself as 'Nanny Nash', I held her tiny hand through the incubator, and then, I said goodbye. At just nine days old Jade had been transferred from hospital to Demelza for end of life care in the thick of a COVID-19 lockdown. The hospice and all of the Nursing and Care team were amazing; they ensured that Jade could be with the people who loved her. I wish I could've held her. I wish I could've had longer. But I feel so incredibly grateful every day for the 10 minutes I had with her. When Jade died, our world fell apart. I grieved for my loss but also for the pain that my daughter Claire and son-in-law Wayne were feeling. There was nothing I could do to alleviate it; I felt completely helpless. But thanks to Demelza, our family were given more time with Jade to make precious memories. I visited her in a special bereavement bedroom at the hospice called The Butterfly Suite. It was here that I read Frisky and Her Friends by Mary Brooks to her; a special book that my Nana had given to me in 1971. I also read 'Guess How Much I Love You' – a beautiful story about two hares who share a special bond and the boundlessness of their love. In those moments together, I felt Jade could hear the sound of Nanny's voice reading to her and just how much I love her."

Julie Nash, Jade's Nanny



Without Demelza, I wouldn't have had the chance to say hello – and goodbye - to my baby granddaughter. Without Demelza, we wouldn't have the memories that we have of Jade. Without Demelza, it would have been a different and even more tragic experience.

Jade was born in the middle of a COVID-19 lockdown, and the situation was so isolating. The amazing team of Demelza nurses enabled the wider family to visit Jade at the hospice; where we could also be a support to my son Wayne, his wife Claire and my grandson Elijah.

When the time came for us to meet Jade for the first time, my other son – Jade's uncle Stephen - played 'Somewhere Over the Rainbow' on his ukulele. I held her hand and told her stories. After Jade passed, Wayne and Claire always wanted one of us to always be with her; they couldn't bear the thought of her being on her own. So, Jade's nanny Cathy mainly and the rest of the family, took it in turns to spend time with her in the Butterfly Suite.

When we were at Demelza, the nurses were always there in the background. Now and again, they would appear with a coffee in hand and a smile on their face. They were amazing with Jade's brother Elijah and would whisk him away to do fun activities. He never had to worry about a thing."

Liam Flanagan, Jade's 'Grandowd'

An award-winning team

The Markel 3rd Sector Care Awards took place on 12 February to celebrate the excellence, innovation and creativity in the voluntary care and support sector. At the virtual awards ceremony Demelza claimed the prize for incorporating creative arts into the very bones of our service delivery. Judges shared praise for our authenticity, passion and willingness to share methods and learning outcomes with other sector organisations.



Creative arts at Demelza give space for laughter and tears. It's about being in that moment. Creative sessions have enabled families to hear their child sing for the first time or become relaxed after a traumatic seizure or give direct eye contact and engage. The improvised music in sessions follows breathing patterns and tiny body movements. In this way, the creative sessions are empowering and focus on what children can do rather than what they are unable to do.

We will continue to use the arts in our hospice care to provide a beacon of hope in what can be, at times, a deeply sad setting. Creative arts are embedded into the everyday care, and support Demelza gives to families who have a child with a serious or terminal condition. We will continue to use the flexibility and power of the creative arts to hold and acknowledge difficult feelings, to facilitate positive change and develop emotional growth."

*Demelza Senior Music Therapist,
Victoria Swan*



Demelza
Hospice Care for Children

Family Feedback

We are continually seeking feedback from our families to ensure we meet their needs and identify new opportunities within our work.

A family survey at the end of the year revealed that by accessing Demelza's services:



81%

benefited from improved physical or emotional wellbeing



81%

had a chance to make memories



72%

felt less isolated



77%

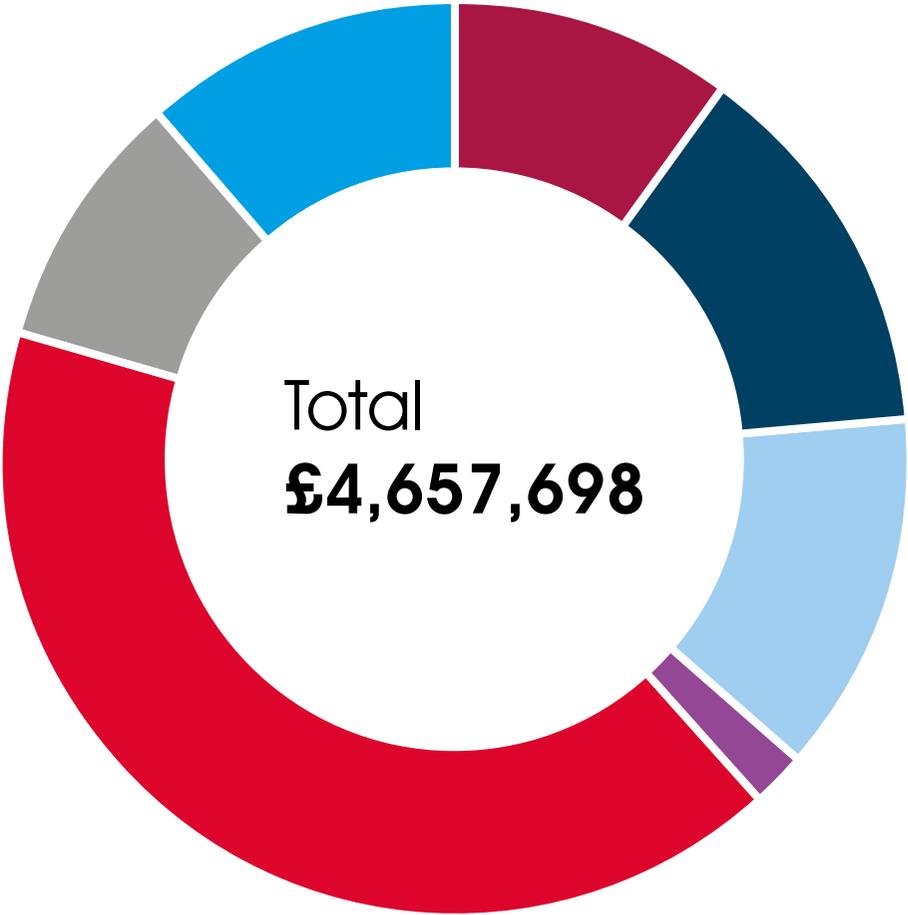
had a meaningful break from caring for their child



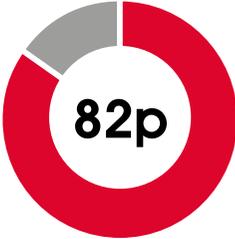
63%

felt more confident or better able to care for their child

How we raised **our money**



● Community	£472,374
● Corporates	£630,531
● Individuals	£592,232
● Events	£90,820
● Legacies	£1,916,281
● Trusts	£427,451
● Major Donors	£528,010



For **every £1** donated to Demelza, **82p** was spent providing care services in 2020/21

To read Demelza's Annual Report and Financial Statements for 2020/21 please visit www.demelza.org.uk/impact-report

We couldn't do it **without you...**

Demelza has been providing care since 1998 and, through the generosity of others, we can continue to be there for families for years to come. To every individual, business, trust, group and volunteer that supported us through our most challenging year – we salute you.

Thank you for helping us to raise a fantastic **£7,606,227**

We would like to thank

Our current Trustee Board:

David Highton (Chairman)
Bob Alexander
Darren Anstee
Pippa Barber
Paul Smith
Kate Stephens
Susan Lawson
Dr Yvonne Parks
Matt Kepple
Debbie Kemp
Pedro Avery
Dr Nicola Tyers
Charlotte Parry-Jones

Our previous Trustee

Rhiannedd Brooke

Our former CEO

Ryan Campbell, CBE

Founder President

Derek Phillips

President

Richard Oldfield, OBE DL

Vice Presidents

The Most Reverend and Right Honourable
Justin Welby, Archbishop of Canterbury
Daniel Radcliffe
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James Kelly
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Trusts and Foundations

The Wolfson Foundation, The Childwick Trust, John Swire 1989 Charitable Trust, The Fairstead Trust, JMCMRJ Sorrell Foundation, The Thomas J Horne Memorial Trust, W H & A Hawkins Charitable Trust, Balcombe Charitable Trust, BBC Children in Need, The National Lottery Community Fund, The Morrisons Foundation, The Lawson Trust

Community

- Stephanie England for raising £3,419 with the Shirley Scarecrow hunt.
- Terry Turner for establishing Shirley Way Bears and raising nearly £6,000.
- Paul Green for his campervan expedition and camp outs, raising £2,000.
- LPT Holly Cole and a crew of eight from HMS Kent for kayaking 145 miles, raising £3,361.
- Kevin Robbins and friends for raising £15,000 with the 100 Challenge in memory of his nephew Sonny.

Corporate

Axis and The Axis Foundation, Active International, Berkeley Homes, Cabot Financial, Catalent, Cenkos Securities, Countryside, Kent Reliance, The Range, Royal Bank of Canada, Stagecoach

Philanthropists

PHAT Dads
The Frank Brake Trust
Neil Chapman

Friends Groups and Committees

Hailsham Friends, Heathfield Friends, Uckfield Friends, Sunshine Girls, Friends of Bromley and Shortlands, Shirley Friends, Lewisham Shopping Team

Statutory

NHS England

We would love to thank everyone individually, but this document just doesn't have enough room to allow us to! We are very grateful to each and every one of you who has raised funds during the last year for Demelza – you know who you are, and we thank you all!



Demelza
Hospice Care for Children

Demelza Kent

Rook Lane,
Bobbing,
Sittingbourne,
Kent, ME9 8DZ
Telephone: 01795 845 200

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 446 461

www.demelza.org.uk

Registered Charity Number: 1039651



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