

Demelza Life

Spring 2020

**The life-changing impact
of volunteering**

**Simon Cowell says Hallie
has The X Factor**

**Volunteers grant special
Christmas wish for Demelza
family**



Demelza
Hospice Care for Children

Welcome

Dear all

Yesterday I watched a little home-made video of a young girl with complex health conditions in bed with her big sister who doesn't have serious health needs. It was the cutest thing in the world, both of them smiling and interacting with each other in their own private bubble.



It's a bond that I see a lot at Demelza. I think children are maybe more accepting of the world and what's in it sometimes. Quite often, toddlers form a relationship that to them is completely normal and which works for them; regardless of who might need tubes and equipment for their day to

day needs, and who might learn to verbally communicate and who might not. Giggling and happiness is good, pain and tears are bad – that's usually the basis, and when they grow older that bond can grow into something that provides immense mutual support.

It's why I think it's so important that Demelza provides care and support to siblings. Brothers and sisters have so much to gain from their relationships with their sibling, and so much

to carry too, practically and emotionally.

In December I attended one of our Candlelight remembrance services for bereaved families. The brothers and sisters who came with their parents and grandparents had just as many rich and happy memories as the parents, and of course just as much sadness.

So, in this issue I am reflecting on the fact that pretty much everything we offer is not restricted to children with health conditions. Everyone within the family is welcome and everyone is supported at Demelza. You'll see on page five with our Impact Report that this is how we judge ourselves. I hope that we can continue to help, and that you can continue to help us by letting us know what you need.

A handwritten signature in black ink.

Ryan Campbell CBE, Demelza CEO

You're invited to

Demelza's Legacy Afternoon Tea

Wednesday 20 May, Demelza South East London 2-4pm
Thursday 28 May, Demelza Kent 2-4pm

Leaving a gift in your Will is one of the most valuable and lasting ways you can support Demelza. Join us for afternoon tea and an opportunity to tour our hospices and hear the positive impact of our work.

The event is **free** but places are limited. To register your interest please contact Lisa Clark, Senior In-Memory and Legacy Fundraiser on 01 795 845275 or lisa.clark@demelza.org.uk

A stylized illustration of a teapot and two teacups. The teapot is on the left, and the teacups are on the right. They are all in shades of red and pink. The teapot has a heart logo on its side. The teacups have heart patterns on them.

Chloe's story



New parents Richard and Clare were overwhelmed with joy when their daughter Chloe was born.

But weeks later their excitement turned to devastation as she was diagnosed with epilepsy and polymicrogyria (PMG); a condition that affects the development of the brain.

The harsh reality of the diagnosis dashed their hopes and dreams for their first-born child – not only would her quality of life be severely impacted but so would her life expectancy. Richard, said: “She started having strange absences which developed into seizures. The diagnosis was devastating. We were living in a nightmare. Suddenly everything changed and it dawned on us that we would be looking after a three month old indefinitely.”

Chloe has been receiving care and support from Demelza since she was a toddler, which has been a ‘lifeline’ for the Chislehurst family. Now nine, Chloe suffers epileptic spasms all day and night which take a toll on the youngster’s health and cause great worry for her parents. She is also wheelchair-dependent, unable to speak and incontinent.

For Richard and Clare, it was difficult to hand over the responsibility of care when Chloe first stayed at Demelza South East London, but they were quickly reassured.

Richard, added: “At home we monitor Chloe overnight and take it in turns to put her in the recovery position when a seizure strikes. It’s a big thing to trust someone else to do it. The Demelza Nurses and Care Assistants are all fantastic; they are highly skilled and know Chloe well enough to spot the onset of a seizure and intervene.”

Chloe loves the sensory experiences on offer at the hospice and respite stays give her parents valuable one-on-one time with her little brother Joshua, four.

“A huge personal connection”

Keen to give something back to the charity that does so much for his family, Richard will be proudly sporting a Demelza t-shirt when he runs the London Marathon in April.

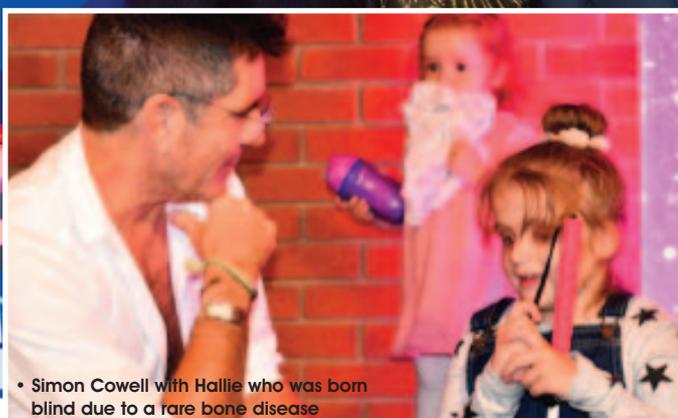
To sponsor Richard please visit bit.ly/3szzxk

Richard, said: “When Chloe is at Demelza we’re able to get a decent night’s sleep. My wife and I also get the opportunity to have an evening out together, which is a huge thing. We’re also able to do things with our son Joshua that sadly we couldn’t possibly do when Chloe is with us.”

With an uncertain future ahead, the family is focussed on making precious moments together with the help of Demelza. Richard added: “We know the seizures will shorten her life and we try not to look too far ahead. We’re just so grateful to Demelza for all the support which has enabled us to do so much.”

Celebrities show their support for Demelza

• James Jordan on his winning edition of *Celebrity Catchphrase*, with Louis Walsh, Fiona Wade and host, Stephen Mulhern.



• Simon Cowell with Hallie who was born blind due to a rare bone disease

Music mogul Simon Cowell brought smiles to little faces when he visited Demelza Kent at the end of last year.

Simon, who is a Patron of Together for Short Lives, came to the hospice in Sittingbourne and spent the afternoon chatting with children, siblings and families and posing for photos and selfies.

Among them was nine-year-old Hallie, who treated The X Factor judge to an impromptu performance of 'A Million Dreams' from The Greatest Showman.

Simon was so impressed that he asked her to sing on The X factor celebrity charity single; a cover version of Snow Patrol's 'Run', which was a "dream come true", says Hallie's mum Megan.

She added: "We can't thank Simon enough. Times like this can never be underestimated and it's a day we will never forget."

To see Hallie perform with all 13 of The X Factor celebrity finalists visit www.demelza.org.uk/xfactor

Dancing legend James Jordan donated £29,700 to Demelza after winning ITV's *Catchphrase*.

The *Strictly Come Dancing* star from Kent appeared on the TV game show in January.

James is no stranger to waltzing his way to the top, as he also won *Dancing on Ice* in 2019 – a show created by Olympic Champion ice skater and Demelza Vice President, Jayne Torvill.

James, who lives with his wife Ola in Maidstone, said: "I felt quite emotional when I won actually. I've supported Demelza for a number of years – it's a local charity so it's very close to my heart. Lots of my friends support it too."

Did you know?

The generous gift donated by James could fund *Demelza's Care at Home* service in Kent for two months. Turn to page eight to read more about this vital service.

Impact Report 2018-2019

Demelza is proud to share our first Impact Report which demonstrates how all donations, volunteered time and overall support has directly benefited children with terminal conditions and their families.

It also highlights the breadth of our services and that we are so much more than our hospice buildings. Demelza provides expert care, family support, music and art therapy, care in the home, bereavement events and more.

To read about the positive impact Demelza is making because of your support please visit www.demelza.org.uk/impact-report

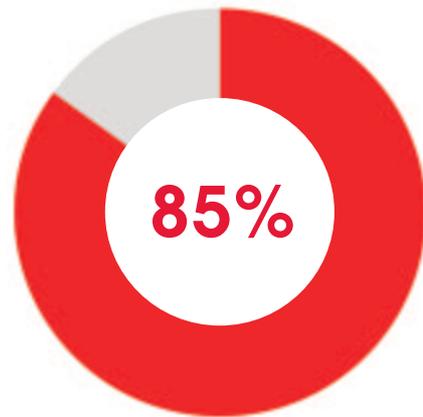


“The difference you make is the reason we exist”

Ryan Campbell CBE



Overall, **94%** of families were satisfied with the service received from Demelza. The aspects of the service which received the highest ratings centred around the quality of the staff.



85% of families said their expectations were met or exceeded, mainly due to the quality of the staff, the **24/7** support and the support provided to the other members of the family.

Spring has sprung at Demelza

Families visiting Demelza are able to enjoy more than six acres of stunning gardens that surround our hospice in Kent. Throughout winter, staff and volunteer gardeners planted over 5,000 bulbs to provide early nectar for pollinating insects and a beautiful floral display for the warmer months ahead. *Blooming marvellous!*



Our unique, dedicated

We owe so much to our incredible team of volunteers who
Each volunteer is one in a million; quite literally. Last year it was
of our 1,000 volunteers who cooked, cleaned, packed, u
way to **148,000 hours** of



For **Karen Russell**, volunteering at Demelza has been 'life-changing'.

In 2006 Karen was diagnosed with a chronic pain condition from failed spinal surgery which also caused her to suffer with crippling anxiety and confidence issues.

After seven years of unemployment, a friend of Karen's who worked at Demelza suggested she try out volunteering.

The 37-year-old from Minster on Sea, said: "I wanted to get back into work but because of my anxiety I couldn't get out of the house. My friend said I should try volunteering at Demelza for a couple of hours a week as a way of easing me back in gently and I'm so glad I did."

As a trained chef, Karen began volunteering in the kitchen at Demelza Kent but sadly the role worsened her pain condition. With the help of Demelza's Voluntary Services Team, Karen was able to help out in other departments for three years before interviewing for a paid role in IT.

Karen, who is now employed at Demelza as an IT & Risk Management Executive and volunteers at fundraising events, said: "After my time in the kitchen I volunteered in the Care and Fundraising teams. Volunteering boosted my confidence enormously and gave me back a purpose in life. I am extremely passionate about the work Demelza does and I am glad that I have been able to do my bit to help families in need."

“Volunteering at Demelza for a couple of hours a week gave me my confidence back”

**“It's been a h
experience”**

Patrick, 23, from Lewisham, loves working at the hospice in Eltham since completing his training in J

Working alongside the Care and an extra pair of hands, assisting t as well as playing with the childre medical school in September th
“Volunteering at Demelza has he my career. I was able to include application which really helped competition was really tough.”

and brilliant volunteers

who donate their time and vast range of skills to Demelza. It would have cost at least **£1.2million** to provide the services unpacked, sold, drove, answered phones and DIYed their **of life-changing support.**



“ I became a volunteer just before Christmas and I really love it. Everyone is so kind and it is a really happy place to volunteer ”

Teenager Cat Birmingham spotted an opportunity to learn new skills by becoming a Demelza volunteer. The 19-year-old from Gravesend, who currently works in retail but has an ambition to work in PR, helps out in Demelza's Marketing and Communications department one day a week. For Cat, the position has been of mutual benefit to both her and the charity, with her gaining useful experience while indirectly helping the families Demelza cares for. She said: "I became a volunteer just before Christmas and I really love it. I know that my contribution to the marketing and communications arm of the charity is helping to raise vital awareness of Demelza. Everyone is so kind and it is a really happy place to volunteer."

“ You will get far more out of it than you could ever imagine ”

Retirement brought an exciting opportunity for Linda Chapman to try out volunteering. At the time Demelza was opening a new shop in Parkwood and Linda was keen to lend a hand. Eight years later, Linda is still there and continues to enjoy every aspect of her volunteering role. Linda said: "The best thing about volunteering for Demelza is knowing the difference it makes to the families that Demelza helps." Encouraging others to join #TeamDemelza, she added: "To anyone thinking of becoming a volunteer; you will get far more out of it than you could ever imagine. You will make many new friends and feel you are really making a difference to children who have to face many challenges in their lives."



ambling

the variety and flexibility of and has been a volunteer one last year.

Family Support teams, Patrick is the Nurses with their daily tasks, en. Taking up a place at is year, Patrick said: helped me in the next stage of my experience on my university as places were limited and



Volunteer Practical Support service

Last year saw the launch of a new volunteering service aimed at giving Demelza families a helping hand.

Turn to page nine to hear how our Practical Support volunteers helped to bring some decorative Christmas cheer to six-year-old Jessie and his family.

Care at Home this CHRISTMAS



Care at Home Christmas Appeal

Thank you to everyone who supported Demelza's 2019 Christmas Appeal and helped to raise over £28,600 to support the expansion of Care at Home.

This vital service enables children with a terminal condition to access support and help in the comfort of their own home.

Our two-and-a-half-hour tailored sessions can be a lifeline to the families who benefit from our visits. Care at Home aims to reduce isolation for parents and carers and gives them time to do everyday things - like the food shopping or seeing friends - all in the confidence and knowledge that one of our Health Care Assistants is looking after their child.

The service has grown from strength to strength since our pilot in Kent first began in summer 2018 and now thanks to the Christmas Appeal we are in a position to reach out to more families and begin a pilot in South East London.

Our gratitude also extends to Demelza families for their ongoing feedback and for helping us to shape and improve upon the delivery of this care.

To view the campaign film, visit www.demelza.org.uk/christmas

Christmas grotto returns

For the second year running children and families were able to meet Santa at a festive grotto at Demelza Kent.

Once again, the grotto was an incredible team effort with staff and volunteers from all over the organisation chipping in with whatever they could to turn the cinema room into a magical winter wonderland with handmade decorations.

With special thanks to Santa Visits Kent and Wish Upon a Pony for helping to make the occasion truly magical for all.



A Christmas cracker... Jessie's story

Little Jessie has been through a lot in a short life. At the age of three, he was diagnosed with chronic liver failure and is now waiting for a liver and bowel transplant.

So, when the six-year-old from Kent, was admitted to hospital just before Christmas, Demelza's Practical Support volunteers made it their festive mission to bring happiness to his family home.

Jessie's guardian, Lucy, 21, said they were living in her mother's house and needed to make it more personal: "We wanted him to say this was his house; like it was his new home."

While Jessie was away receiving specialist treatment for his Short Bowel Syndrome, Rodney and Jane Watts and Joe Mueller, set about secretly redecorating the dining room, much to Lucy's surprise.

Armed with paint, brushes and bundles of enthusiasm, the three musketeers transformed the space and brought smiles to the whole family on their return.

"We came home the week before Christmas," explained Lucy. "I came in and said 'Oh My God!' I was in shock! It was such a kind thing to do at Christmas time. It did feel like a magical moment."

"It's difficult for us," admits English graduate Lucy, who has given up work to care full time for Jessie. "We are constantly in and out of hospital. This took a massive job off me. The Demelza volunteers certainly have big hearts and they did a fantastic job."

She added: "It is just an amazing charity. No one realises how they go above and beyond. People don't realise how Demelza is so much more than a hospice."

For information about Demelza's volunteer Practical Support service please email mary.goodger@demelza.org.uk or call 01795 845283

With special thanks to volunteer Tony Clark for interviewing Lucy on behalf of Demelza Life



• Some of the Practical Support volunteers, Joe, Rodney and Jane - making a house a home



Did you know?

Throughout 2019, a total of 38 dedicated volunteers stepped up to assist with tasks, trips and odd jobs to ease pressure and make life a little easier. Thanks to the service, the team of volunteers gave over 1,000 hours of time and helped 69 families across Kent, South East London and East Sussex with DIY, dog walking, cleaning, gardening, driving to appointments and even help with homework.

Challenges and Events

The Grate Descent

Friday 15 May

Abseil down the Cheesegrater - one of London's tallest skyscrapers! Experience the most spectacular views of the capital whilst dangling an incredible 730ft above the ground. Registration fee £50, minimum sponsorship £550 (not including Gift Aid), group fundraising target £500 per person (for groups of four or more and not including Gift Aid).

www.demelza.org.uk/abseil



London to Brighton Challenge

Saturday 23 May

Walk, jog or run an epic 25km, 50km or 100km from capital to coast, setting out from Richmond to the finish line in Brighton. Registration fees starting from £4.50.

www.demelza.org.uk/london2brighton



Bubble Rush – Family Fun Run

Sunday 14 June, Mote Park, Maidstone

Sunday 28 June, Avery Hill Park, Eltham

Bubble Rush is a fun run like no other! Join us for a day of smiles and laughter as you walk, jog or run through lots and lots of coloured bubbles. The course is pushchair and wheelchair friendly, and there's no minimum age limit, so the whole family can take part.

www.demelza.org.uk/bubblerrush2020



Pedal for a Purpose

Sunday 19 July

Starting and finishing at Demelza's Kent hospice, saddle up for a 52 or 80 mile cycle ride through the surrounding picturesque countryside. Whether you are a novice or avid cyclist, this event is perfect for all.

Registration 52mile, £25 and 80 mile, £35.

www.demelza.org.uk/pedal



Your Run, Your Way

1 May – 30 May

Don your trainers or walking boots and join the virtual #TeamDemelza this May. Your run, your way – choose your distance and timeframe and if you're feeling competitive, join our Strava group for your chance to make it onto our challenge leaderboard. All distances require just a £10 registration free, with different incentives for total sponsorship raised.

www.demelza.org.uk/your-run



Demelza's Corporate Partners

Demelza is fortunate to have relationships with many businesses that go far beyond simply donating money. Here's a snapshot of how our corporate partners showed their support for Demelza last year.

Active International donated over £20,000 worth of beds to be sold at Demelza shops across Kent.

Employees from **Avast** – one of our newest corporate partners and donors – have given their time, energy and skills through volunteering in our hospice gardens and retail warehouse.

Axis Europe PLC held an annual Golf Day and Christmas Ball in aid of Demelza raising £60,000.

CLS Group gift Demelza regular monthly donations alongside sponsorship and an annual golf day for clients.

Gravity Active Entertainment gave complimentary tickets to its Bluewater and Maidstone parks to Demelza children and families and donated raffle prizes.

Kent Invicta Chamber of Commerce donated stand space at the Kent Construction Expo and have provided further invaluable networking opportunities.

Kent Reliance raised £6,000 by offering customers a special children's savings account in support of Demelza.

For information about how to volunteer or support Demelza at your workplace contact corporate@demelza.org.uk or 01795 845260



• Demelza's Tonbridge shop is a boutique store specialising in womenswear, men's fashion and children's essentials.

Spring clean your closet for Demelza

If your wardrobe is bursting at the seams, then there is no better time than the present to have a fashion detox. You can cleanse your closet this spring and feel good at the same time by donating your unwanted clothing to Demelza.

"We are particularly in need of ladies' tops and high quality garments," explains Director of Retail, Ashley Henson. "We gratefully receive so many donations but it is those special ones that really make a difference and boost the money raised."

Donations can be dropped to individual shops directly, to our Distribution Centre in Maidstone or at the donation station at Demelza Kent in Sittingbourne. To find your nearest Demelza shop, visit www.demelza.org.uk/local-shops



• The Avast team volunteering in the Demelza Kent gardens

Having two children with complex health conditions has been hugely challenging for the Debruins.

The support given by Demelza has been a lifeline for the whole family.



Demelza
Hospice Care for Children



Please help children with terminal conditions and their loved ones by making a donation at www.demelza.org.uk/donate

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