

Demelza Life

Spring 2019

- Demelza's South East London hospice marks 10th Anniversary
- Volunteers offering a helping hand in family homes
- Meet our new Care Services Leads



Demelza
Hospice Care for Children

Welcome

Dear all

I am writing this at the end of February, when we are in the middle of a great amount of uncertainty about the future of the country. Perhaps by the time this is published everything will be clear, perhaps not, but it reminds me that all of us are at times subject to things happening, over which we are powerless. When you can't influence things that can have an impact on you, that's a bit scary.



control back to children and young people on how they live their lives and what they can get out of life, despite health

Sometimes the families we work with are in such a position, but to a huge extent because there is nothing that can have more impact than the health and wellbeing of your family. In this magazine we focus on some of the ways that we try to give choice and control back. We try to give

conditions, disabilities and other challenges. And we try to give choices on what type of support families need and would like, and where they receive it.

We aim to help bring joy, hope, fun and memories to life. And we hope that our support eases the pain when joy feels far away. Enjoy the magazine, and thank you as ever for being part of our family.

Ryan Campbell CBE
Demelza CEO



• Care Assistant Claire with Abigail

Abigail's story

Abigail was born a healthy baby girl; the third daughter to loving parents Funke and AJ.

Everything changed for the family when at 18 months old, Abigail convulsed suddenly, slipping into a coma. When she came around two weeks later, oxygen deprivation had tragically caused significant damage to Abigail's brain, leaving her unable to walk, talk, eat or breathe unassisted.

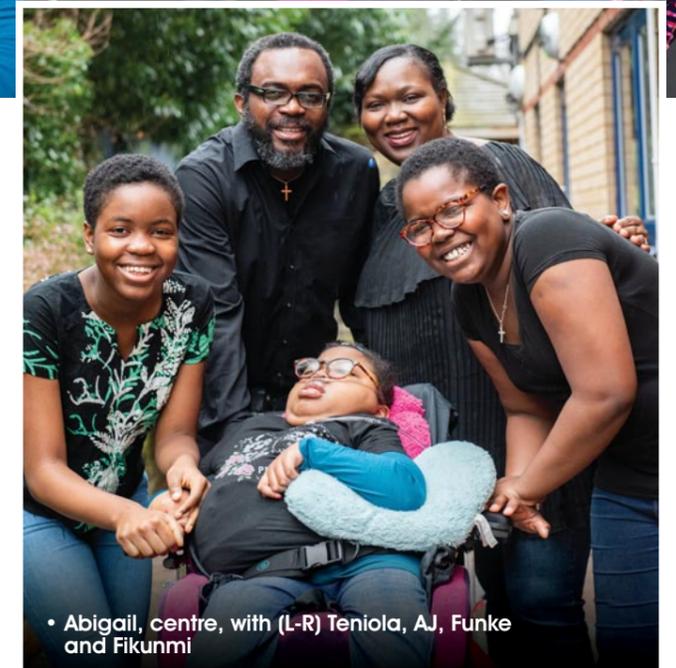
Mum Funke, said: "It was a very scary time for us all; we had no idea what was happening until we received Abigail's diagnosis. Abigail's Key Worker later on introduced us to Demelza, who welcomed her to the Eltham hospice for step-down care before we took her home."

Abigail, now 10 years old, has been able to depend on the support of Demelza over the years - not only during times of crisis, but for respite and rest with her whole family, including her two older sisters.

"Coming to Demelza is something for us to look forward to as a family. Abigail loves having a proper bubble bath," said 13-year-old Teniola.

Fikunmi, 11, added: "I like that everyone here is so friendly and welcoming - the staff at Demelza never hesitate to help you, and it takes the pressure off of Mum and Dad."

The family has been able to spend time together at Demelza South East London while adaptations are being made to their home to better accommodate Abigail's needs, as she also has cerebral palsy, scoliosis of the spine and a degenerative form of epilepsy. Explaining the positive impact it has had on the five



• Abigail, centre, with (L-R) Teniola, AJ, Funke and Fikunmi

Did you know?

March 2019 marks the **10th anniversary** since our Eltham hospice opened. Turn to pages six and seven to find out how it has supported other South East London families over the past decade.

of them, mum Funke added: "Abigail, to the glory of God, loves it at Demelza - she is full of smiles when she is here. Our faith gets us through, but Demelza gives us peace of mind that she is being so well taken care of. Staying here is our only respite so we have a chance to rest and sleep soundly, which is a rarity at home.

"We can't thank the team here enough for being so helpful and kind through challenging times."

Demelza
Hospice Care for Children

Demelza is coming to Petts Wood

New charity shop opening in spring.

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

Meet our new **Care Services Leads** for East Sussex and South East London



Melissa Mungovan, Care Services Lead for Demelza's Community Team in East Sussex

My career started at Chailey Heritage and I worked there for eight years as a Care Assistant, Speech Therapy Assistant and Classroom Assistant. I have been a qualified Paediatric Nurse since 2006 and since then I have Qualified as a Health Visitor (Specialist Community Public Health Nurse) and Practice Teacher. As part of my Practice Teacher role I supported Student Nurses/Health Visitors and regularly taught at the University of Brighton, for the local council and for Sussex Police.

In 2013 I was successful in my application for a grant through the Queen's Nursing Institute which allowed me to complete a project to improve the health of the Gypsy and Traveller community in East Sussex. Following this I was awarded the title of 'Queen's Nurse' in 2014.

I hope to provide families with an improved and increased service and to raise the profile of Demelza within East Sussex. Community working is challenging but extremely rewarding and is a real asset to our local area.

Did you know?

Our Community Team has been delivering care and support to families in East Sussex for 15 years, bringing care to the child's home.



Mirelle Cassidy, Care Services Lead for South East London

I first became aware of Demelza when I moved to South East London around the time of the fundraising drive for the new hospice in Eltham. I cannot believe it is now 10 years since the doors were officially opened, and I feel very privileged to be a part of #TeamDemelza.

I am a paediatric nurse with over 20 years of experience, having trained at Great Ormond Street Hospital, spending my early career at the haematology/oncology unit before moving to the Paediatric Intensive Care Unit. In 2009 I left GOSH and the NHS to take up the post as a nurse co-ordinator for a private provider. Over the last 10 years I have had the good fortune to work in a variety of roles that have all centred around complex health care, including both direct clinical care and managerial roles.

Professionally, I have cared for children and young people that have benefited from the incredible service that Demelza provides and often thought how much I would like to be a part of such a fantastic team. I am passionate about teamwork and all services that a child accesses providing a joined up approach to their overall care - it really does make such a difference to the lives of the families and children we care for.

Support for **bereaved grandparents**

Coping with the loss of a child is an unimaginable hardship for any parent, but there is often a hidden layer of grief for grandparents who also suffer the complex impact of supporting their children whilst coping with their own bereavement.

Our Family Support Team in Kent has formed a support group especially for grandparents. Zoe Workman, who organises gatherings for the group, said: "Many grandparents feel like the 'forgotten mourners' after the loss of a grandchild, as they also suffer a huge loss, but have to see their own children go through losing their child. The group was created so grandparents can share their worries and feelings in a safe and welcoming environment and meet others who understand."

At the first group meeting in February, bereaved grandmothers Christine and Iris chatted over tea and cake, and shared photos of their grandsons with each other. Iris, who lost grandson Harley whilst at Demelza's Kent hospice three years ago, said: "You think there's nothing worse than losing a child, but never in your wildest dreams do you expect to face losing a grandchild."

Christine welcomed the chance to be amongst others who understood her situation, saying: "It's nice to be able to talk about Alfie still with other grandparents who've experienced loss. Our grandchildren will always be with us, and we want to remember them. Demelza will always be part of our lives."



• Zoe, right, with grandparents



Work in their shoes

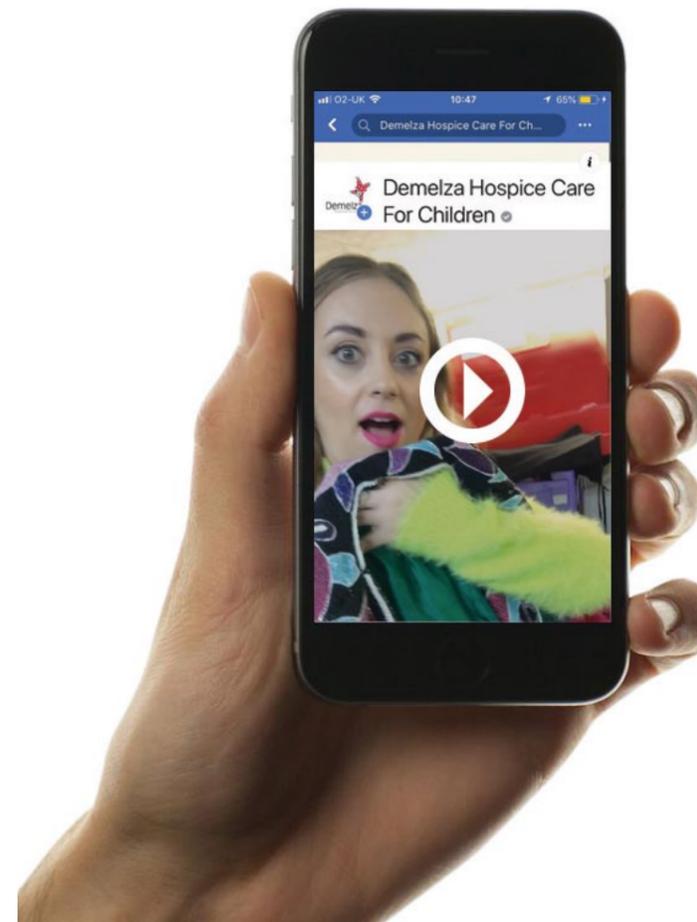
Staff at Demelza are encouraged to discover first-hand what it's like to spend a day in the life of their colleagues, by participating in a programme called **Work in Their Shoes**.

The scheme brings colleagues closer and allows for greater understanding of the myriad facets it takes to run an organisation of Demelza's size. Chief Executive Ryan Campbell CBE leads by example, regularly joining teams like the one at Maidstone's Retail Distribution Centre.

Now, you can see what it's like to work in their shoes too, with a new blog from Sophie Batchelor, who works in our Marketing and Communications Team. Senior Content Executive Sophie, said: "This year I set myself a challenge to spend a day every month with one of the many teams that make up our organisation and record it in a blog. I find it a real privilege to get to know the people of #TeamDemelza, as everyone comes with a unique story."

Sophie has already discovered vintage treasures in our Rochester Boutique, and witnessed the impact our Family Support Team has on siblings of children with terminal conditions.

Sophie's blog is available to read at www.demelza.org.uk/work-in-their-shoes, and you can watch her vlog at www.facebook.com/demelzahospice.



10 years of Demelza South East London

This March, Demelza marks 10 years since the opening of our second hospice. The facility in Eltham offers the very best care and emotional support for families living in South East London. **Phoebe and Jake are just two of the thousands of children Demelza South East London has supported since opening in 2009.**



Phoebe with dad, John

Phoebe's story

For parents Pippa and John, the elation of seeing their daughter born was short lived when they witnessed their baby turning blue and put onto ventilation.

Tests revealed baby Phoebe had a rare disorder called Congenital Hypoventilation Syndrome (CCHS), meaning her tiny body was unable to safely expel carbon dioxide when she slept. Phoebe received a tracheostomy – a tube inserted into an opening in her neck and connected to a ventilator - and remained in hospital until she was nine months old.

The family of seven were put in touch with Demelza for step-down care but were initially reluctant to access the services on offer at the newly opened hospice in Eltham. John from Bromley, said: "We were a bit wary about visiting because of the word 'hospice'. We didn't know what to expect but once we were given a tour, we knew it would be perfect for Phoebe. The staff made us feel so welcome. Phoebe was lucky to be one of the first children to use the new services at Eltham just after it opened. For us as a family, it was a lifeline."

Phoebe was the first child with a tracheostomy to be cared

for by Demelza South East London, and with the help and support of the Care Team, John and Pippa could get some much needed rest after months of long journeys and hospital visits. Phoebe stayed at the hospice for three months and the family has continued to receive support ever since. John added: "Once Phoebe moved to Demelza her brothers and sister were able to come and play with her, and we were able to spend time together as a family. With the support of the Care Team, my wife and I were also able to learn more about managing her condition before we took her home just after her first birthday. We know Phoebe loves every minute of her time at Demelza."

On her favourite activities at Demelza, nine-year-old Phoebe, said: "I like being able to do my own things. I like drawing pictures to take home in the art room, making slime or playing video games. I love baking and we're going to make cupcakes next time I visit."



One-year-old Phoebe



Phoebe with Care Assistant, Victoria



Jake with dad, Darren



Jake's story

Born with brain damage and cerebral palsy quadriplegia, after being starved of oxygen at birth, Jake was not expected to survive beyond three months. But he continues to defy the odds and last year celebrated his 18th birthday.

Demelza has supported Jake and his family since he was a baby – through the good times and the bad, as Jake has battled serious illness several times. His mum Mandy was initially reluctant to access services, but after her first visit several years ago, she hasn't looked back.

She said: "When I first went to the hospice I didn't know what to expect. But I soon realised it was a wonderful place which was not about death and dying, but about fun and living."

The family initially used Demelza's hospice in Sittingbourne, Kent and were then instrumental in helping with fundraising efforts to get our Eltham hospice up and running. They have since used both facilities for overnight stays and Jake's two brothers and three sisters also accessed Demelza's sibling support service when they were younger.

Mandy, who is local to Demelza's Eltham hospice, said: "I know he's safe and well looked after at Demelza, as there are trained nurses there 24/7 and they know Jake and his needs. They have the expertise. Jake doesn't like travelling, so to have something right on our doorstep has been great. He also loves using the hydrotherapy pool when he visits the Kent hospice."

Now that he is 18, Jake and his family are being supported by Demelza's transition service as he moves from our child services to adulthood.

Mandy added: "Demelza has been like part of the family for more than 17 years and we've made some great friends. There's always a friendly face there and someone to talk to."

Did you know?

Our Eltham hospice provides support for families in seven South East London boroughs: **Bexley, Bromley, Croydon, Greenwich, Lambeth, Lewisham and Southwark.**



Jake celebrating his 18th birthday with staff at Demelza South East London

A helping hand at home

It's hard enough for any family to keep on top of odd jobs, but throw in round-the-clock care and hospital visits to the mix of daily life and it feels impossible to tackle even simple tasks like ironing or walking the dog.



• The Care@Home Team taking children out and about

To give Demelza families a helping hand, we've introduced a special team of volunteers to help out with tasks, trips and odd jobs that will ease the pressure and make life a little easier, thanks to our Practical Support Project.

During our trial, which began in Kent and expanded to South East London and East Sussex, our volunteers gave over 95 hours of practical help and 29 hours of driving services. Thanks to this project, we've decorated rooms, walked dogs, cleaned houses, taken families to appointments, repaired doors, helped with homework, strung up Christmas lights and tidied gardens.

We've had some really positive feedback from the families who took part, with one parent saying: "Having a volunteer who is able to drive our child and a parent to hospital appointments will have a great impact as it means that we would not have to use so much of our holiday allowance, giving us back quality time to spend with the children."

To continue this great work and to help support more families, we are looking for new volunteers.

If you are able to give some of your time to help support families in their own homes with some practical everyday jobs and tasks, please contact Demelza's Voluntary Services Department for further information on 01795 845170.



• Volunteer David Fewkes

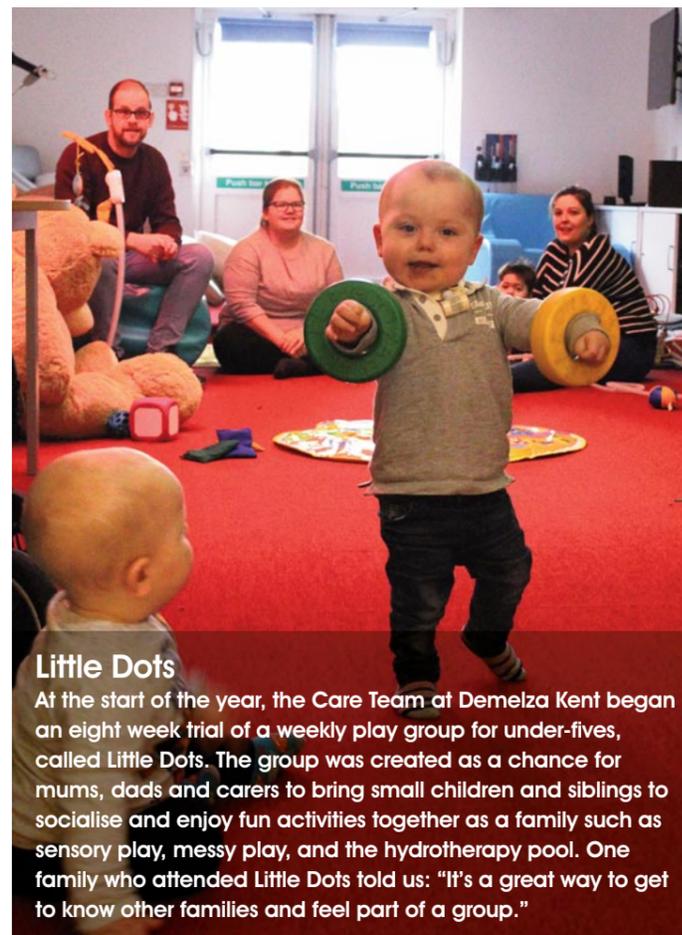
Care@Home Project update

We are delighted to be continuing with the delivery of our new Care@Home service in Kent and building upon the success of the pilot programme last year. The team visited families in their own home to provide care and support, which included responding to crisis situations. We are currently working with around 10 families, and looking to increase the service from three to five days a week from March so that we can reach even more.

Care@Home Team Leader Beth Helen, said: "It might not seem important, but our visits allowed one mum to have more time to put her washing away – an everyday task that is easy for most of us to manage but made a big difference to her."

New initiatives at Kent hospice

We're determined to help families in more ways; learning from them to provide better services, like these...



Little Dots

At the start of the year, the Care Team at Demelza Kent began an eight week trial of a weekly play group for under-fives, called Little Dots. The group was created as a chance for mums, dads and carers to bring small children and siblings to socialise and enjoy fun activities together as a family such as sensory play, messy play, and the hydrotherapy pool. One family who attended Little Dots told us: "It's a great way to get to know other families and feel part of a group."



Stay and Play

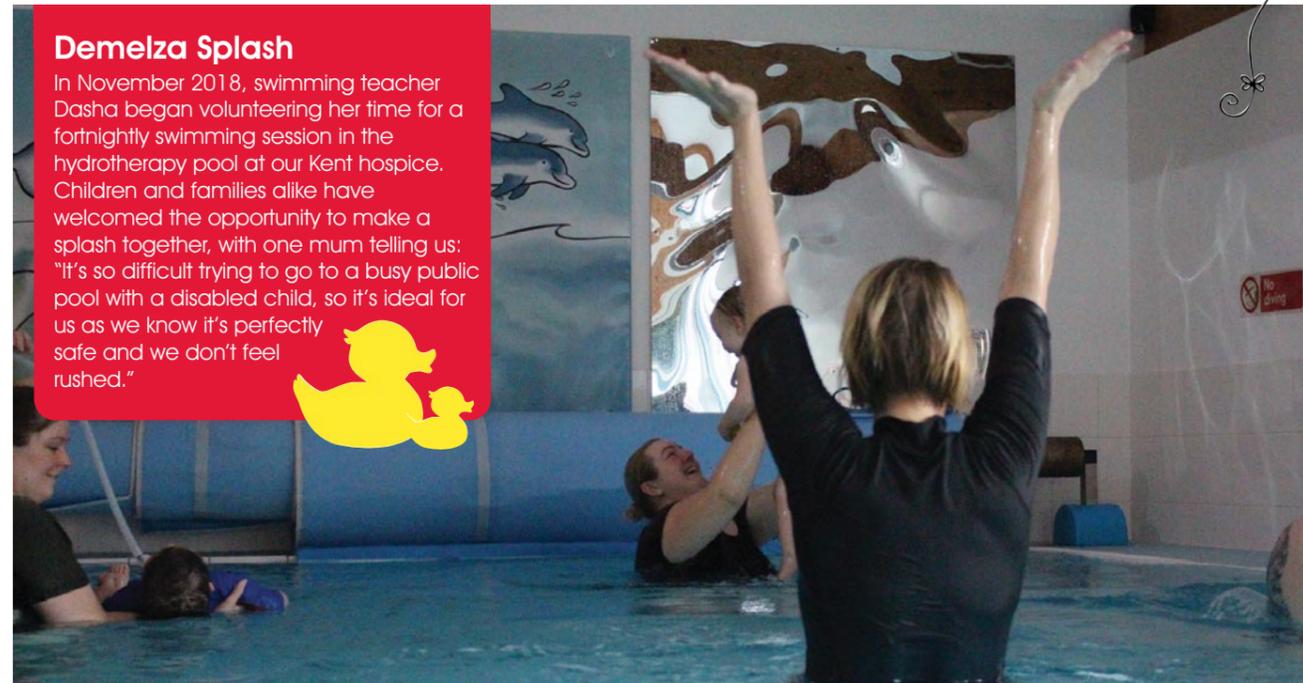
Last year we tried something new during school holidays by facilitating Stay and Play two hour sessions with families, allowing them to use our playground and soft play. This proved to be so popular that we'll be running the sessions again during Easter. The families who participated loved being able to take their child somewhere safe to play, where they can enjoy activities alongside their siblings.

Coming Soon: Parties!

We hope to soon be offering the use of our Kent hospice to Demelza families for parties. Children will be able to celebrate occasions in the safety of our adapted facilities, including the art room, soft play and sensory room, and enjoy food from our kitchen. Watch this space!

Demelza Splash

In November 2018, swimming teacher Dasha began volunteering her time for a fortnightly swimming session in the hydrotherapy pool at our Kent hospice. Children and families alike have welcomed the opportunity to make a splash together, with one mum telling us: "It's so difficult trying to go to a busy public pool with a disabled child, so it's ideal for us as we know it's perfectly safe and we don't feel rushed."



Challenges and Events

Bubble Rush - Family Fun Run

Sunday 23 June, Mote Park, Maidstone
Sunday 7 July, 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/bubblerush



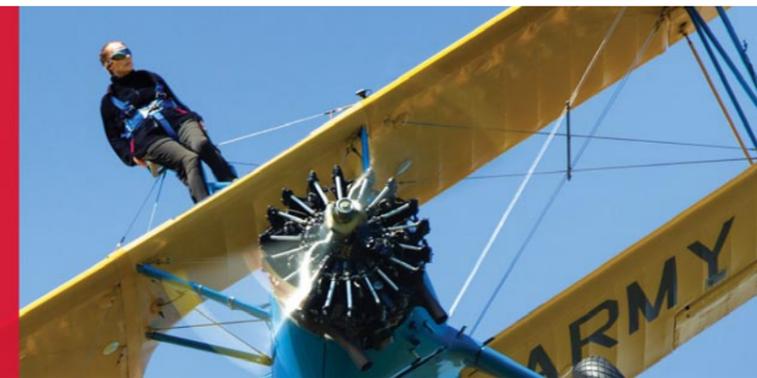
Wing Walk

Saturday 17 August

Feel the freedom of flying with this exciting challenge. Work up your adrenaline with zooms and climbs at speeds of up to 130mph, whizzing by your friends and family who are welcome to come and watch.

£99 registration fee, £600 minimum fundraising target.

www.demelza.org.uk/wing-walk



The Italian Job

4 - 8 September

A three day cycling challenge that has it all - starting and finishing in and around Milan, with a breathtaking backdrop of seven stunning lakes. Those wanting an extra challenge can also tick off the famous Madonna climb.

£100 registration fee, £1,650* minimum sponsorship.

www.demelza.org.uk/italian-job

Flights not included



Thames Path Challenge

Saturday 7 September

Take on the Thames Path Challenge following England's greatest river and taking in the wonderful scenery along the route. With 50km and 100km distance options - there's a challenge for everyone.

50km Challenge:

£9 registration fee, £395* minimum sponsorship.

100km Challenge:

£13.50 registration fee, £595* minimum sponsorship.

www.demelza.org.uk/thames-path



Thames Bridges Trek

Saturday 7 September

Join other trekkers as we venture 25km across the Capital, from Putney Bridge, past many landmarks including iconic Tower Bridge and finishing in Southwark.

£4.50 registration fee, £245* minimum sponsorship.

www.demelza.org.uk/thames-bridges



**Gift Aid is not included in any sponsorship target*

Festivities for families at Kent

A trip to see Santa is no easy feat during the busiest shopping period of the year, especially for families who have to think about accessibility for their children, as many of those we support do.



Last December, for the first time, we brought Santa and his grotto to Demelza Kent - and it was an absolute hit with families, with parents and carers telling us: "The grotto was beyond beautiful" and "Santa was so good with my child; very calming."

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.

• Jamie, 16, with his family at the grotto

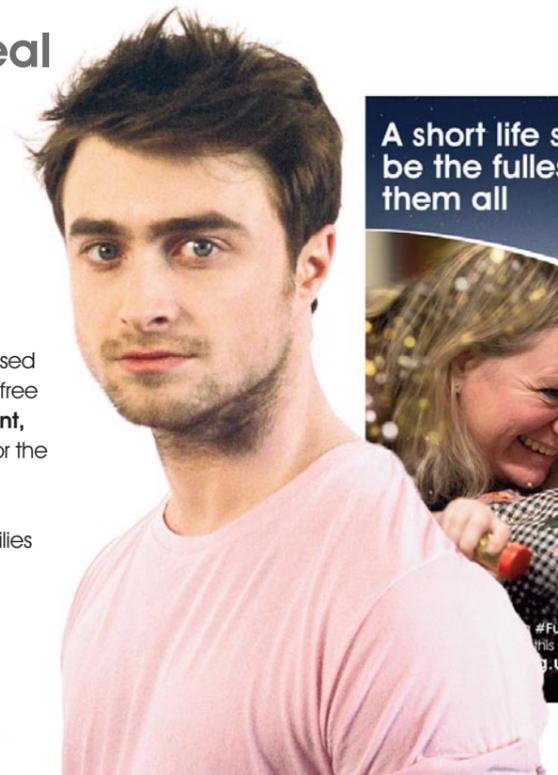
#FullLife Christmas Appeal

Thank you to everyone who supported Demelza's #FullLife Christmas Appeal 2018 and helped to raise **£27,000!**

We were fortunate to partner with Tunbridge Wells-based creative agency Southpaw, who gifted their time for free and to receive the support of **Demelza Vice President, actor Daniel Radcliffe**, who provided a voiceover for the appeal video.

Our special thanks also goes to all the Demelza families who appeared in the film and showed what it really means to live a #FullLife.

• To view the campaign film visit:
www.demelza.org.uk/full-life-video



#FullLife for children
this Christmas
www.demelza.org.uk/christmas Demelza



Demelza
Hospice Care for Children

Our volunteers strive to bring joy to the lives of the children we meet.

No matter what role they undertake, they're vital to the work we do.



See the difference you can make to children with terminal conditions and their families by becoming a Demelza volunteer.

www.demelza.org.uk/volunteer-vacancies

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