

# Demelza Life

Spring 2018



**“The chance to be a parent, not a carer” - Will and Georgina share their story**

**Rugby legend Sam Warburton pledges support in testimonial year**

**South East London hospice gets incredible make over from Osborne**

**Bubble Rush is back with new venues for 2018!**



**Demelza**  
Hospice Care for Children

# Welcome

## Dear all

I'm starting this year with fire in my belly, **it's just not good enough**, that's what I think. I don't mean the support given by our donors, volunteers and staff of Demelza Hospice Care for Children – collectively, I think we do a great job and I hope you agree. I mean the wider help and choices available to all families with a child with a terminal condition.



At a recent event in Parliament, I listened to two mothers of children who had passed away. One of the children had died at home, which is where he and his family wanted him to be. But they had needed to arrange it themselves, and they hadn't heard of the local children's hospice until afterwards. The son of

the other mum died in hospital – they weren't aware anything else was possible. Very often families still do not have the option of dying at home.

There is a campaign underway led by a number of charities, including Together for Short Lives, to offer the choice of end of life care at home, and to better fund hospices so they can offer support to every family.

I'd like us to be able to do that. If we at Demelza can find just a fraction of the grit and courage shown by the young people and family members featured in this issue, then we'll get there one day.

Thank you for supporting Demelza and I hope you enjoy reading this latest edition of *Demelza Life*.

**Ryan Campbell**  
Demelza CEO

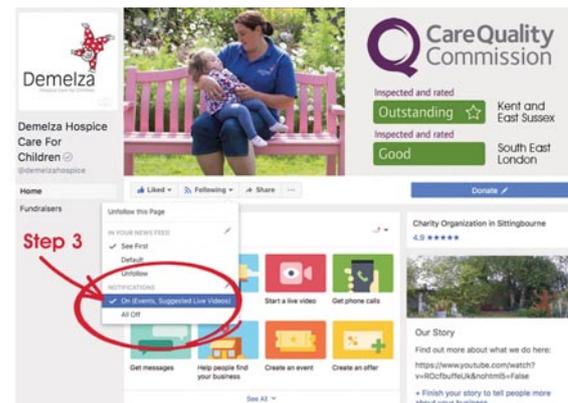
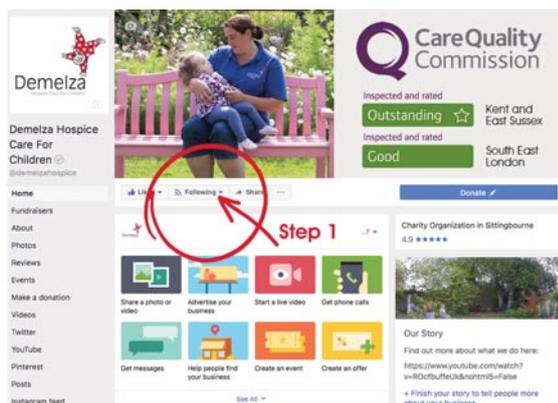
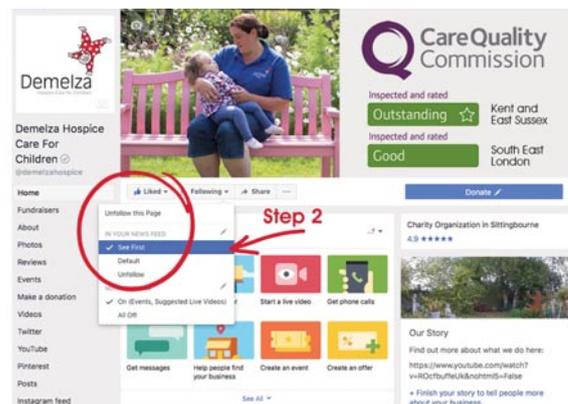
## How to stay up to date with Demelza on Facebook

Facebook have made changes to your newsfeed – we need your help to ensure you are kept up to date with news from Demelza.

**Step 1:** Go to the Demelza Facebook page. Just under the cover photo, click the “follow” button – you will see a pop up box with ‘in your news feed’.

**Step 2:** Click on ‘See First’ – make sure it shows a tick, and this will help to ensure that you see all of our Facebook posts.

**Step 3:** Make sure the ‘Notifications’ are turned on.



# The chance to be a parent, not a carer



For Will and Georgina, time at Demelza is time to just be mum and dad. “Demelza is somewhere to escape, it’s a comforting place to come,” explains Will. “I get to be a parent, not just a carer.”

Their four-year-old son has a brain disorder so rare he is the only person in the UK to be diagnosed with it. Elliott has DNM1 gene mutation, causing epileptic encephalopathy, leaving him severely disabled and needing round-the-clock care.

The family, from Kent, relies on specialists in the UK, USA and Australia, working collaboratively on treatment options. Most recently, Elliott has undergone deep brain stimulation surgery in the hope they will be able to reduce the level of sedation needed to control his involuntary muscle movements.

“The aim is less medication, and less distress for him,” says Will. “We would love him to be awake more, and able to stay relaxed long enough to have a cuddle on the sofa before bedtime.”

The couple also have a toddler daughter, Grace, and the whole family enjoy short breaks at Demelza Kent, our hospice in Sittingbourne, as well as coming every Sunday to use the hydrotherapy pool – something Will particularly appreciates.

“We’re not able to do typical father and son things like kicking a ball around the park, so having that instead is really important.”

The family found out about Demelza through the continuing care team at Medway hospital. At first Georgina wasn’t too sure. “I thought Demelza must be all about end of life care. We came along and realised it wasn’t like that at all.

“I remember the first time Will and I left Elliott and went to Bluewater – it was the furthest I had ever been away from him. Now we have Grace and she loves the soft play and sensory room – she can use all the same facilities as Elliott. We can sit and have a cup of tea knowing Grace is happy pottering about and that Elliott is being looked after.”

# Thank you Osborne for giving us space to grow!



- Demelza CEO Ryan Campbell, Penny Lancaster and Andy Steele, Group CEO of Osborne with the Osborne supply chain who made this incredible project possible



**At the end of last year, Demelza received the most incredible gift from corporate supporter Osborne, in the shape of an impressive two-storey extension at Demelza SEL.**

In just 14 days the construction business and its suppliers worked tirelessly to complete the ambitious 'Space to Grow' project at our Eltham hospice, including a new reception, family suite, staff room, crucial storage space and a meeting and training area.

Loose Women star Penny Lancaster, who officially opened the renovation, said: "I have supported this incredible charity for a number of years, and this transformation is a fantastic gift that the children, families and the whole Demelza team truly deserve. This new space will make a real and lasting difference to everyone."

To see just how truly inspirational this project has been, check out the video of the build at [www.demelza.org.uk/sel](http://www.demelza.org.uk/sel)



## Exciting new business partnership with Swiss Re

The new year saw Demelza launch a new corporate partnership with Swiss Re – one of the world's largest reinsurance companies – with the aim of raising a whopping £200,000.

The #TakingCareHome initiative will enable Demelza to expand our vital community care service into Kent and South East London, taking tailored, individual care to homes, schools and other settings, giving families more choice as to when and where they receive care.

With Swiss Re's support Demelza can also fund expert care assistants, essential sensory, art and play materials and training for specialist nurses.

Please email [corporate@demelza.org.uk](mailto:corporate@demelza.org.uk) to find out how your company can make a lifetime of difference to families in desperate need of our support.



## 20th Anniversary special feature



• The Hall brothers on holiday at Disney World, Florida, for Wayne's 11th birthday



• Wayne with Martine McCutcheon at Demelza

## Demelza was here for the Hall family

– and they have certainly been here for us too

Jean and John Hall were tireless fundraisers for Demelza from the very start. Their involvement in the 1990s with Helen House in Oxfordshire – the nearest to their home in Medway – brought them together with the committed band of supporters campaigning with our founders, Derek and Jennifer Phillips, to establish a similar service in Kent.

The Halls' middle and youngest sons, Wayne and Ian, had Ataxia-Telangiectasia (A-T), a progressive genetic condition that causes severe disability. Sadly Ian did not live to see Demelza open and died in hospital in 1998, aged 18.

Wayne was able to make use of our services and enjoyed stays in our Sittingbourne hospice – especially when he was surprised by a visit from favourite actress, Martine McCutcheon! But for him and his family, the most important thing was the access to end of life care that Ian had not been able to have.

"He was in Medway hospital and we were all called in urgently," says Jean. "The doctor didn't want Wayne to go because he was afraid he would die in the ambulance. John asked Wayne if he still wanted to go to Demelza and he gave us the thumbs-up. That was all we needed to know."

Wayne was transferred to Demelza that afternoon and died later that evening, surrounded by friends and family in a place he loved. Asked to describe what Demelza means to families like hers, Jean says simply: "It's a lifesaver. We would encourage anyone who can help to do so because it means so much to the families who need help."

**We are grateful to everyone who has supported us over the last 20 years. With your continued generosity, we will be able to provide specialist care and support for children with terminal conditions and their loved ones for years to come.**

## Do you have a Will or need one updated?

Write a free Will **during May** for a donation to Demelza. For your nearest participating solicitor visit [www.demelza.org.uk/willwriting](http://www.demelza.org.uk/willwriting)

For more information contact Lisa Clark on 01795 845175 or email [lisa.clark@demelza.org.uk](mailto:lisa.clark@demelza.org.uk)



# A good meal makes a big difference

The kitchen is often described as the heart of a home, and that's certainly the case at Demelza. One of the first things families see when they come into Demelza Kent, our hospice in Sittingbourne, is the huge communal dining table - a welcome vision of normality, a home from home feel.



• Pancake Day fun at Demelza

• Chef Pie (right) with kitchen volunteers, Chris Bistram and Rosemary Small

The kitchen itself is a hive of activity with staff and volunteers working together on a rota basis to prepare and serve, breakfast, lunch and dinner seven days a week.

Chef Philip Martin – universally known as Pie – has worked in the kitchen in Sittingbourne for the past 10 years.

"We want to make sure that families don't have to worry about anything to do with meals while they are here," Pie explains.

"Before coming to Demelza, families might have spent months in hospital living on canteen food and sandwiches, or their child may have very specific nutritional requirements. When they want to give all their attention to their child, being able to put a good meal on the table makes a big difference."

While there is always a healthy option on the menu, comfort food like cottage pie and toad in the hole are always a popular choice. With a rueful grin, Pie admits that the children's favourite is chicken nuggets.

Some of our kitchen volunteers are trained chefs themselves and are invaluable for helping with the menu planning and preparation. Paul Brown brings 48 years' experience in the catering industry to Demelza, and now loves working with his fellow volunteers.

**Will you give £25 to Demelza to feed a family for one day? We are also grateful for donations of tea, coffee and sugar, as well as Sainsbury's vouchers. Please visit our website to read more about Pie and the kitchen team at [www.demelza.org.uk/kitchen](http://www.demelza.org.uk/kitchen)**

# Rugby legend supports Demelza in exciting testimonial

We're very excited to announce that rugby legend, Sam Warburton OBE, has chosen to support Demelza as one of his charities during his testimonial year.

The two-times Lions skipper will be raising vital funds throughout the season in recognition of his long and outstanding service to the game. Father-of-one Sam, says: "It's an absolute privilege to be able to support Demelza Hospice Care for Children.

"I came across the charity and instantly fell in love with the amazing care and support they provide, and I can see the invaluable, life changing differences they make to families' lives. Being a relatively new father to my two-year-old daughter has helped me appreciate how wonderful Demelza is for families in need.

"To be able to try and help contribute to Demelza is an honour, and I'm really looking forward to helping raise money and awareness for this brilliant charity. Thank you Demelza for accepting, and here's to another successful year!"



## Meet our apprentices

Demelza's new apprenticeship programme is going from strength to strength following a recruitment drive last summer. We caught up with our new apprentices to find out what they've been up to in their new roles.

Events administration apprentice, Bethany Murrell tells us: "I've been involved in lots of event planning already such as The Monster Dash, Candlelight Walk, the Carolathons and our fantastic Carol Concerts."

Emily Ingram is Demelza's fundraising apprentice and says she's been made to feel part of the team from day one and is enjoying learning about all the different areas of fundraising. Whilst Care administrator apprentice, Jennifer Davies, loves working with all our Demelza families and is particularly looking forward to learning about the

care events that take place throughout the year.

Finally, Sandra Wozna has been in the role of resources administration apprentice for over six months now and says: "My time here has really helped me to develop both people skills and administration knowledge. I feel that the confidence this role has given me will be invaluable for my future career."

Once the apprentices finish their training they will have gained a City and Guilds Level 3 qualification in Business Administration.



• Our fantastic apprentices: Emily, Bethany, Jennifer and Sandra

**Working together to make a difference**

Visit [www.demelza.org.uk/work-with-us](http://www.demelza.org.uk/work-with-us) for job opportunities at Demelza

# New year brings lucky £25,000 win for Demelza Superdraw player

When Demelza Lottery player Sarah signed up as a member several years ago, she never imagined she would be a winner.



• Superdraw winner Sarah (left) with Lindsey Farrington from the Lottery team

So when Sarah found out she'd won the £25,000 Superdraw Jackpot in January, she was 'stunned'. Sarah said: "When I heard the news my jaw-dropped. I just couldn't believe it. I'm treating my son to a Nintendo Switch and I'd like to get my bathroom done, which is wonderful."

Our Lottery is one of the most simple, yet most sustainable ways you can support Demelza. Collectively, our members make a huge difference, because the money raised by our lottery provides vital, regular income that helps us to reach more children and families. From as little as £1 a week you get the chance to win £1,000 with our Lotto, and for an additional £1 a week you could win up to £25,000 with our Superdraw.

Sarah added: "I would encourage anyone to sign up. You know your money is going to help local children and families in their time of need."

**To be in with a chance of winning, sign up today at [www.demelza.org.uk/lottery](http://www.demelza.org.uk/lottery) or call 01795 845224 to speak to our Lottery team.**

## Shops pull out the stops for 20th Anniversary

We'll be celebrating 20 years of Demelza across all our retail outlets this year, with lots of special events planned. Look out for in-store raffles, street parties, a volunteer drive and the big '£20k day' where we will be aiming to raise £20,000 across all our shops in just one day.



Demelza's Head of Retail, Ashley Henson said: "We've got some great activities planned to run across the summer to celebrate Demelza's 20th Anniversary. We'll also be taking this opportunity to celebrate our volunteers and encourage more people to join our fantastic team. Do keep an eye out in your local Demelza shop or on our shops' Facebook pages to find out what's going on near you."

**For locations of our shops and how to become a volunteer, visit [www.demelza.org.uk/shop-with-us](http://www.demelza.org.uk/shop-with-us)**

## Siblings day a success

The stakes were high at the first siblings social day in Hastings, for brothers and sisters of children supported by the Demelza Community team in East Sussex. The youngsters were challenged to make the tallest giraffe, using only newspaper, cello tape and scissors, followed by a fast-paced game of bench-ball and an arts and crafts session.

The day was a success, with parents reporting their children had "an absolutely brilliant day" and the opportunity to "just play and be themselves."

Demelza family support worker, Toni Goodall, said: "Having a brother or sister with a serious or terminal condition can often be lonely, and having fun can seem difficult or almost impossible at times, but this snapshot really highlights the value of Demelza's siblings groups. We can't wait for the next one."



# Tuning in to the power of music



Everyone knows that hearing a certain song can instantly lift their mood, while another tune will bring a tear to their eye – we all respond to music.

At Demelza, we use the power of music to comfort babies, children and young people in our care, and give them and their families an outlet for their emotions.

Music Therapist Victoria Swan, who works at our hospices in Kent and South East London, explains: "Music therapy is based on the belief that we can all respond to and appreciate music, regardless of age, disability or illness."

Victoria uses her voice, a wide range of instruments, and – particularly popular in sessions with older children – digital music technology in individual and group sessions.

"Every session is completely different. If I am working with bereaved siblings, for instance, they might want to write a song about how much they miss their brother or sister. They may be dealing with emotions they struggle to talk about, like guilt at feeling glad to have their mum and dad back to themselves, and music is an outlet for expressing them."

As well as an emotional response, music also has a physiological effect. "Music has an extraordinary capacity to offer a distraction during painful and invasive procedures or muscle spasms," explains Victoria. "It has been shown to reduce pain levels by influencing the levels of endorphins."

Music therapy is just one of the ways Demelza helps families to build precious memories. When a child is receiving end of life care, Victoria offers to sing and play for everyone.

"Music can bring families together during extraordinarily difficult times. Families can bond over music because it offers a shared experience which is not about the next medical procedure. For the child, music aids relaxation and helps with their breathing, and brings an acoustic source of comfort, reassuring them of their family's presence."

Music can also help address cultural and spiritual needs when a child dies. Through working with a Nigerian mother whose newborn son was receiving end of life care, Victoria discovered that in her culture musicians sang when people died to guide their spirit into the next life. Victoria was able to sing and play for the baby boy, bringing the mother great comfort.

"I am very proud to work for Demelza," she says. "I love that my job is different every day, and feeling that I make a difference."

**Find out more about the therapies on offer at Demelza by visiting [www.demelza.org.uk/therapies](http://www.demelza.org.uk/therapies)**

## DID YOU KNOW?

**£60 could pay towards an hour of music therapy for a child or sibling in our care**

# Challenges and Events

Our calendar is jam-packed with UK and overseas fundraising events for the whole family.

These are just a handful of our challenges and events. For a complete list or to book any featured on this page please visit [www.demelza.org.uk/challenges-and-events](http://www.demelza.org.uk/challenges-and-events) or call **01795 845191**

## Demelza 101



**2 - 6 May**

Take on this challenge from our Kent hospice to the Eiffel Tower. Registration £100 with minimum sponsorship £1,750

## Wing Walk



**Saturday 2 June and 18 August**

Join #TeamDemelza for this exciting adrenaline filled challenge! £99 registration with minimum sponsorship £600

## Pedal for a Purpose



**Sunday 3 June**

Pedal for a Purpose is back! With three exciting routes to choose from and prices starting from £5, there is something for everyone

## Solstice Swim



**NEW  
for 2018**

**Saturday 23 June**

Take a plunge and swim against the sun at the Olympic-sized outdoor Charlton Lido pool. Prices start from £10

## British London 10k Run



**Sunday 15 July**

10k route past the landmarks of London. Registration fee £25, minimum fundraising target £200

## Prudential Ride London



**Sunday 29 July**

Secure yourself a guaranteed place, plus a free cycling jersey. £50 registration with £500 minimum sponsorship

## Community Fun Days



**Demelza Kent Sunday 23 Sept**

**Demelza South East London Sunday 7 Oct**

We're opening the doors to our hospices – we hope you can join us for a day of free family fun!

## Royal Half Parks Marathon



**Sunday 14 October**

Take in some of the capital's world-famous landmarks on closed roads. Registration is £25 and minimum sponsorship £500.



# BL OOMING GOOD GARDENS

This year, open your garden to raise vital funds for Demelza Hospice Care for Children

Take a look at our Blooming Good Garden resources on our website for ideas on supporting Demelza using your garden. Find out more, call **01795 845288**

# Fantastic Friends

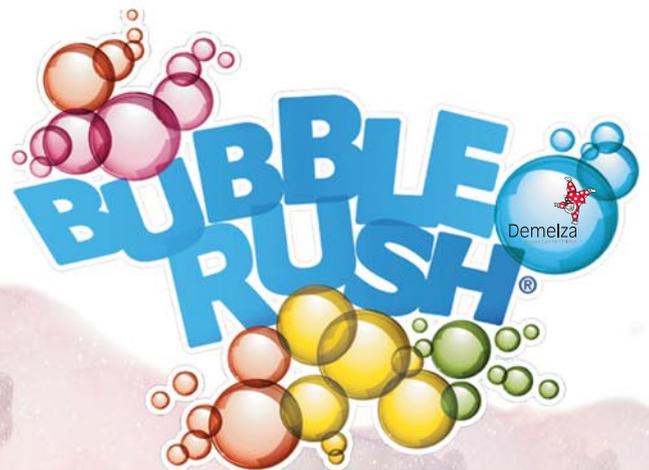


**Our Friends' Groups raise awareness and funds for Demelza in their local communities and are also a great way of meeting new people.**

We have groups in Lewisham, Chislehurst and Orpington, Erith, Sidcup, Bromley, Shirley, Heathfield, Uckfield, Hailsham and Eastbourne. We're also looking for members for new groups in Ashford, Hastings and St Leonards, Thanet, Sittingbourne, Eltham and Dulwich. If you'd like to find out more, please call our Community Fundraising Manager, Nicola Irvine on **01795 845288** or email [nicola.irvine@demelza.org.uk](mailto:nicola.irvine@demelza.org.uk)

Places  
going fast!

Sign up at  
[www.demelza.org.uk/  
bubble-rush](http://www.demelza.org.uk/bubble-rush)



**Sunday 20 May:  
Hove Park, Brighton**

**Sunday 15 July:  
Avery Hill Park,  
Greenwich**

**Sunday 12 August:  
Mote Park, Maidstone**

All venues pushchair and wheelchair accessible.  
Suitable for all ages and abilities.

# Enhancing experiences for seriously and terminally ill children

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A serious birth defect means Isabella has limited mobility and cannot speak.

Thanks to your generosity, Isabella can express her emotions in our sensory room.

To make a donation, please visit [www.demelza.org.uk/donate](http://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](http://www.demelza.org.uk)  
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