

Demelza Life

Autumn 2018



Demelza launches Kent
Care@Home pilot

20th anniversary celebration

Find out about our exciting
new challenge events for 2019



Demelza
Hospice Care for Children

Welcome

Dear all

Twenty years ago Demelza sprang into life, accepting its first child for a visit. Some of you reading this will remember that and were a part of making it happen. We celebrated that occasion, and the 20 years since, at a little party in June.



But now here we are looking forward again. Celebrating 20 years of an organisation feels great, but when you're working with children and young people who may not, and usually will not, get to have that celebration in their own lives, that brings us straight back to today and the job we have to do.

and London. We are looking to expand our in-reach into hospitals, building on what we already do in London with the Evelina Children's Hospital, and we will be matching volunteers to families to provide a practical helping hand where it is needed. It's going to be a busy period.

I guess this is the time for me and all of you, as Demelza service-users, supporters, volunteers and staff, to make our mark on the organisation's history, as the current stewards of this marvellous cause. I personally think we've reached one of the really good chapters in the story and I can't wait to see what happens next.

Ryan Campbell CBE
Demelza CEO

Recently we launched a new community pilot service, Care@Home, which has seen us provide the first care visits in people's own homes in Kent – we know how important that is from our work in East Sussex, so more will follow in Kent

A CELEBRATION OF
CHRISTMAS

Canterbury Cathedral
Monday 17 December
7.30pm

To purchase tickets visit
[www.demelza.org.uk/
carol-concert](http://www.demelza.org.uk/carol-concert)

Demelza
Hospice Care for Children



Jacob's story

A bump, fall or even a common cold could result in an emergency hospital admission for three-year-old Jacob.

His vulnerability is a cause of constant worry for mum Frances, but a stay at Demelza offers much-needed reassurance. "When Jacob goes to Demelza this is the only break I get," she explains. "I still worry about him, but when he's at Demelza I worry less, knowing that he's in safe hands, with trained nurses and care assistants."

Jacob has adrenal insufficiency, a disorder where the adrenal glands do not produce enough of certain hormones, which play key roles in the functioning of the human body. His immune system is affected as well as his blood pressure and metabolism. He has to be given steroids four times a day and is at constant risk of an adrenal crisis which can cause death.

Frances said: "Some children who have an adrenal crisis do not pull through. I know what to do if this happens – and so do the staff at Demelza. They are experienced and have looked after other children with similar conditions."

Demelza provides short breaks for children with terminal conditions, giving families the choice to leave their child in a safe environment or to stay overnight too if they wish.

For Frances, having the support of Demelza means she can spend quality time with her other son five-year-old Jackson, while Jacob is having fun with the Care Team at Demelza's hospice in Eltham, South East London.

Frances added: "The first time I left Jacob I phoned three times, but the nurses told me to try to relax and as time has gone on I have found that a bit easier.



Did you know?

£840 could cover the cost of a child or young person's overnight stay at one of our specialist children's hospices



"Because of Jacob's condition friends and family are too scared to look after him. When he's at Demelza I can catch up on sleep, or spend time with Jackson, who does miss out. "Jacob loves it at Demelza. The staff are lovely and his favourite thing is the sensory room."

New Care@Home pilot project is launched



• Beth Helen (centre) with the Care@Home Team

Demelza has launched a new pilot project which will see children in Kent supported in the family home.

Care@Home was launched in August and involves four families, with children under five, who live close to Demelza's Kent hospice.

Children's Palliative Care Nurse Beth Helen, said: "We have found that not all families feel comfortable about coming to a hospice, but they would like our help. It can also be easier for families if we go to them rather than them having to pack lots of equipment and bring their child to us.

"Families have told us this is something they would like and we aim to give them a choice in the future. Some will still like to drop their children off and have a much needed break, others like to stay at our hospices as a family and others want support at home. In family homes we can provide a range of support, depending on the child and the family's individual needs.

"We can do a range of activities with children, looking after them while their parents have a break, or support a relative who might not have the confidence to look after the child on their own. We can offer the children new experiences such as art activities, story time, or whatever they enjoy."

The project has received significant funding from global reinsurance firm Swiss Re, but as with all Demelza services, it will require further and future funding to be rolled out to other families in need.

The pilot is due to end on 25 October, and there will be an on-going review to swiftly build on the programme.



Meet the East Sussex Community Team

Did you know Demelza has been providing a hospice at home service in East Sussex since 2004?

Pictured are members of the Demelza Community Team who are based at our offices in St Leonards on Sea. The team provide therapies, respite and end of life care in the comfort of a child's own home, which enables children with terminal conditions to have specialist care in familiar surroundings. Families also have use of the specialist facilities at our children's hospices in Kent and South East London.

To get in touch with the Demelza East Sussex Community Team please phone 01323 446461.

Did you know?

£60 could pay for a visit in the comfort of a child's home by the Community Team in East Sussex

Support for siblings

Having a brother or sister with a terminal condition can often be lonely and having fun can seem difficult, or almost impossible at times.

Demelza organises fun days out, art therapy and other support to ensure brothers and sisters do not get forgotten and can enjoy some time out or have the chance to talk about their emotions.

Over the summer, siblings in South East London enjoyed learning basic sailing skills on the Thames after taking part in a two day Royal Yachting Association Course at the Ahoy Centre in Deptford. Meanwhile in Eastbourne, East Sussex, brothers and sisters were treated to a Mad Hatters Tea Party and in Kent, siblings got to meet some cute, cuddly and creepy creatures!

Sam, pictured below with the bearded dragon, recently wrote to tell us about his 11-year-old brother Louie, who uses the services offered at Demelza.

The nine-year-old said: "I am going to tell you about a person who is very close to me. He is short with blond hair. When he was born he was very sick and his mum and dad were very worried about him. They were told he would never be able to sit up on his own nor would he speak. There are only 16 children in the world with his problems. He is a unique little boy.

"He is fed through a tube by a button in his tummy, but he does love eating Milky Bar yoghurts. He can eat as many as five or six a day and this helps him to grow as he is tiny.

"The person that I am talking about is Louie, my big brother. Louie, I am your biggest fan!"

To read Sam's letter in full visit www.demelza.org.uk/sams-letter.

"A privilege to be a part of the day"

Demelza staff can do 'Work in Their Shoes' to experience the roles of colleagues. Senior Community Fundraising Manager Nicola Irvine joined the Family Support Team at an older sibling's games day.

Commenting on her experience, Nicola said: "It felt like a little family. It was emotional to see this group of young people come together, knowing that each of them were either bereaved or had a sibling with a terminal condition and that was the main thing they each had in common. Not that I heard them talking about it much - I mostly heard conversations about school or the strategy to win the next game and the occasional mention about a hospital appointment. It was a privilege to be a part of the day."

To find out more about Nicola's role at Demelza and to meet the Community Fundraising Team, see page 11.



Twenty years of Demelza

In the summer Demelza marked 20 years since the opening of our first hospice with a special afternoon tea.



• Demelza Phillips

Those invited to the anniversary gathering at our Sittingbourne hospice included Derek Phillips, Founder President and father of Demelza, the charity's namesake, trustees past and present whose fundraising efforts made Demelza possible, long serving volunteers, corporate sponsors, fundraisers and others.

Derek Phillips thanked all present for their help and support over the years. He said: "My daughter would have been thrilled to see how much has been achieved."

Chief Executive, Ryan Campbell CBE, also thanked those attending for the

contribution they had made. He said: "We are thrilled to be celebrating 20 years of Demelza Hospice Care for Children. Since opening we have helped thousands of families and every single one of our supporters has played a part in helping us to do that and to reach this special anniversary."

Volunteers received a special thank you from Vice President, Lady Kingsdown OBE, who presented long service awards and told them: "We wouldn't be where we are today without you."

Lavinia Jarrett, Demelza's Deputy Chief Executive, has worked with the charity for more than 18 years. She said: "Over the years Demelza has

changed and grown but still at the heart of all we do are the children and families that we care for and support.

"We rely on our local communities to support us and we'd like to thank everyone who has contributed over the years. Without them we could not continue. Their support is vital, whether this is volunteering for us, donating goods to our charity shops, supporting the Demelza Lottery or raising funds.

"Here's to the next 20 years of striving to meet the needs of the children, young people and families we serve."



• Demelza's Kent Care Team enjoying the celebrations

• Founder President and father of Demelza, Derek Phillips, making a TV appearance

• Two-year-old Ava-Lily cuts the celebration cake

Welcome to our new Chair

Demelza has welcomed a new Chair – and said a fond farewell to Sarah Phillips who previously held the post for six years.



• A fond farewell to Sarah Phillips at the 20th anniversary celebration



• Demelza's new Chair, David Highton

David Highton took up the position at the end of June, taking over from Sarah who had served as Chair for two terms.

Sarah was thanked for her hard work and dedication at Demelza's 20th anniversary celebrations, which was her last official engagement.

David is also Chair of the Trust Board at Maidstone and Tunbridge Wells NHS Trust, a position he has held since May 2017. He previously worked in Qatar as a Ministerial Advisor to the Minister of Public Health and also as Executive

Director of Corporate Development at Hamad Medical Corporation, the main public hospital provider in Qatar.

Before moving to Qatar he worked in the independent healthcare sector and was an NHS Chief Executive from 1991 to 2003 during which time he was instrumental in setting up a dedicated children's hospital.

David, 64, who is married and has a grown up family, has strong links with Kent, having spent his childhood in Meopham and Sittingbourne. He currently lives in Whitstable.



Imagine what **you** could achieve in your spare time.

Do something amazing.

Become a **Demelza shop volunteer today.**

- Meet new people**
- Learn new skills**
- Enhance your CV**

And more importantly see the difference you can make to children with terminal conditions and their families by becoming a Demelza volunteer.

Call **01795 845170**
 Visit www.demelza.org.uk/volunteer-vacancies
 Email volunteering@demelza.org.uk

**NEW
Tonbridge
shop now
open!**

**Petts
Wood
shop coming
soon!**

Housekeepers tackle hidden dangers

Everyone at Demelza has a vital role to play – some less visible than others.

The staff and volunteers who make up the Housekeeping Teams at our hospices in Kent and South East London are on the front line of infection control. They know that failing to clean a surface properly could see germs spread quickly – and in an environment housing children with terminal conditions with low immunity that must be avoided at all costs.

Therefore, it's not surprising that housekeeping is organised with military precision. Everywhere in the hospice buildings – from the communal spaces and therapy rooms, to bedrooms and bathrooms – are regularly cleaned, with each and every surface wiped down with antibacterial alcohol wipes.

Every eight to 12 weeks, children's rooms and clinical areas are scrupulously disinfected during a deep clean. Every item that can, goes in the washing machine, and those that can't – some toys and treasured artwork for instance – are purified using an ozone generator that kills airborne bacteria when there is an increased risk of infection.

In Kent the popular hydrotherapy pool presents an additional challenge – the cleaners regularly have to don their swimsuits to scour the tiles!

Both hospices also offer family accommodation and the Housekeeping Team strive to offer an experience that families would enjoy in a hotel – such as crisply laundered sheets and piles of fluffy towels.

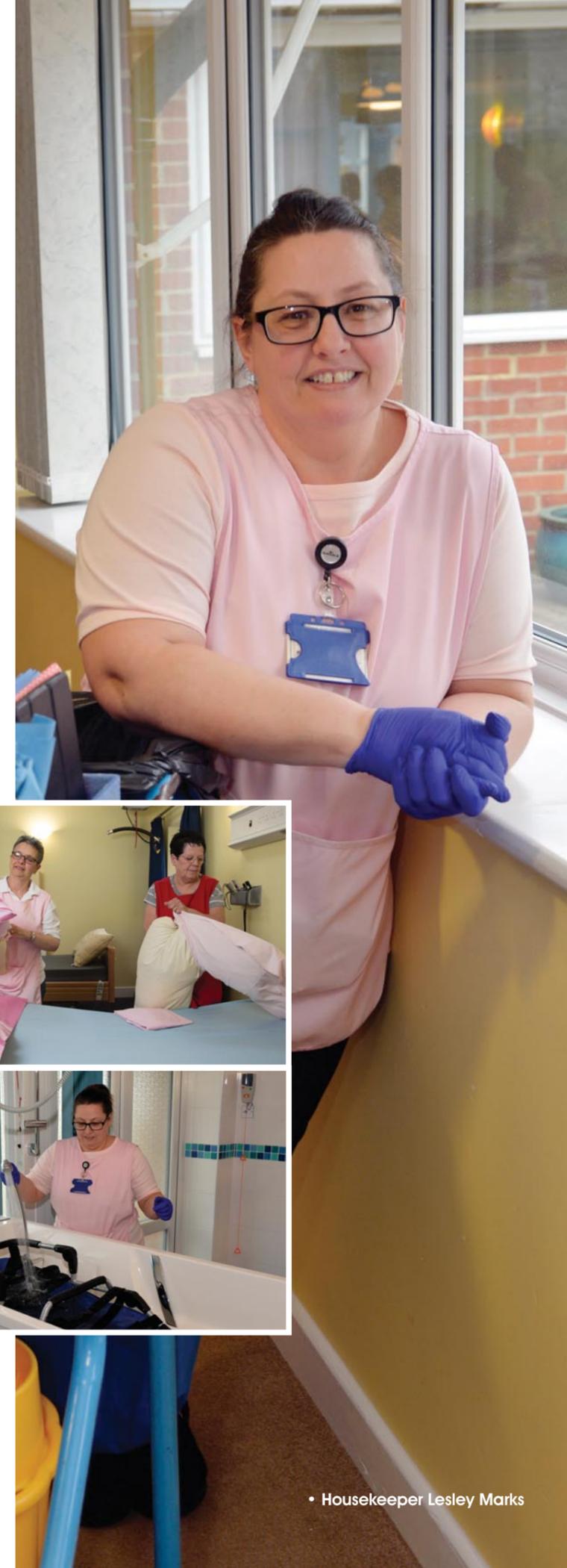
Lesley Marks, Housekeeper at our Kent hospice for 10 years, explains: "When parents walk through the door you can see them thinking, 'I can have a break'. A large part of our job is about making mums and dads happy. Knowing I made their stay that little bit more comfortable is really rewarding."

The contribution of volunteers within housekeeping is invaluable, but finding people to lend a helping hand is increasingly difficult.

Could you spare a few hours to join our volunteers in housekeeping? Please visit www.demelza.org.uk/volunteer-vacancies to find out more.

Did you know?

Every year our Kent hospice gets through **4,600** toilet rolls, **300** tubs of hard surface wipes and over **2,000** packs of paper towels



• Housekeeper Lesley Marks

Challenges and Events

Pumpkin Hunt

25 and 26 October 2018

A ghoulish adventure hunting pumpkins and collecting sweets and treats through a town near you.

Entry £5 per child. For dates and locations visit www.demelza.org.uk/pumpkin-hunt



Photo: Warren King Photography

The Big Half

10 March 2019

Join 20,000 runners in this iconic new challenge through the streets of London, starting at Tower Bridge and finishing at the Cutty Sark.

£25 registration fee, £300 minimum sponsorship. Secure your spot at www.demelza.org.uk/big-half



Brighton Marathon

14 April 2019

Soak up the sea air as you run 26.2 miles in one of the country's most vibrant cities.

£30 registration fee, £500 minimum sponsorship. www.demelza.org.uk/brighton-marathon



The Italian Job Cycle Challenge

4 – 8 September 2019

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

Registration fee £100, minimum sponsorship £1,650 (flights not included). www.demelza.org.uk/italian-job

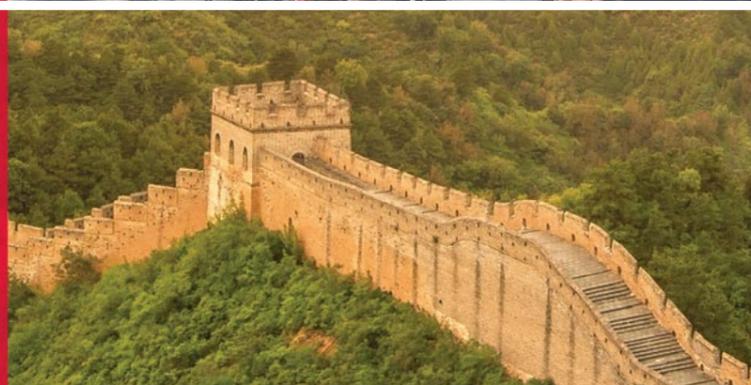


China Trek

5 – 13 October 2019

An adventure awaits as you trek and experience thousands of years of history on the Great Wall of China. A challenge not to be missed.

£295 registration fee, £3,010 minimum sponsorship. www.demelza.org.uk/china



Sponsored bake, summer fete?

Demelza's Community Fundraising Team want to hear from you!

This cheery bunch have a big job to do and it's one that's made a whole lot easier thanks to the incredible support of the local community.

Every year the Community Fundraising Team raise around £1 million, working with individuals, groups, clubs, businesses and schools who do their own events and fundraising for Demelza.

Nicola Irvine, Senior Community Fundraising Manager at Demelza, said: "We're here to guide, support and encourage people at each stage of their fundraising journey."

"We're always so inspired by the passion they demonstrate and are so grateful to them for making a difference to the lives of so many children through their fundraising for Demelza."

If you're organising an event, need tips on how to raise money or would simply like us to come and tell you and your friends more about Demelza – the Community Fundraising Team is here to help. Contact Nicola on 01795 845176 or nicola.irvine@demelza.org.uk and she will put you in touch with your local Community Fundraiser.

Well done Cameron!

Cameron Harbird from Sittingbourne is hoping to raise £2,000 for Demelza throughout 2018. The inspirational 10-year-old has already completed a 56 mile static bike ride and is due to do the National Three Peaks Challenge. Good luck Cameron!



Did you know?

Demelza must raise over **£10.5 million every year** to be able to provide care and support to children and their loved ones in Kent, South East London and East Sussex



#TeamDemelza

Despite being a healthy toddler, Jenissa is now unable to walk, stand or speak.

Some of her happiest moments are spent at Demelza with her little brother Astin.



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

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Telephone: 01323 446461



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Registered Charity Number: 1039651