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# We are Demelza

Bringing you news from Demelza



demelza

## Meet Demelza Music Therapist - Pete

### A tribute to Demelza's founder president

**Derek Phillips, Demelza's founder president, has sadly died, aged 83.**

Along with his late wife Jennifer, Derek established the charity in memory of their daughter Demelza, who tragically died of a brain tumour aged 24. The charity has been dedicated to supporting care for local children with complex conditions ever since, helping families to make precious memories during challenging times.

#### **Demelza's Legacy**

After a mammoth four-year fundraising effort which amassed £4 million, the couple opened Demelza's first hospice in 1998 in Sittingbourne, Kent – a beautiful building with its iconic oast house which Derek, an architect, had designed himself.

Derek's wife, Jennifer, sadly died three years later. She is remembered in the Kent hospice's Garden of Tranquility, along with many of the children and young people who have benefited from Demelza's care and support.

Paying tribute to the founder, Demelza CEO Lavinia Jarrett, who joined Demelza in 1999, said, "We owe a great deal to the insight, dedication and fortitude of Derek Phillips. He had great vision and belief that the people of the South East would support the needs of a hospice for the children in our area.



Our supporters have never disappointed and have never failed to ensure Derek's vision lives on, providing specialist care and support to children and their families."

Derek, who was living in Southampton at the time of his death, stepped down as chairman of the Board of Trustees in 2001, taking on the role of Demelza's founder president.

In May 2022, Derek received a Prime Minister's daily Points of Light award, which recognises outstanding individuals who are making a change in their community and inspiring others.

If you would like to share your condolences and memories, please visit: [derek-phillips-2024.muchloved.com](http://derek-phillips-2024.muchloved.com)

**"I came to music therapy later than some, after working for many years in advertising and project management.**

I first heard of music therapy when my mum became ill and spent the final week of her life being cared for by a hospice. I was so interested that I enrolled in the training programme which included a foundation course and masters degree.

I'd always known I wanted to work with children and, after the experience with my mum, I felt connected to hospice work. As such, I requested a placement with Demelza. I was nervous as I wasn't sure if I would be emotionally robust enough. However, about three weeks in, I knew that Demelza was where I wanted to work, and I am thrilled to now be one of Demelza's Music Therapists.

I have had some deeply poignant learning experiences, including end-of-life support for families. When a family is amidst waves of medical staff, constant medications and often pain or distress, being able to provide a little oasis of musical calm, of empathy, humanness, and kindness is such a privilege.

What I really love about working here is the variety; one day you could be

supporting premature babies with a music therapy session in a local hospital, the next you're working with a child whose sibling has a complex condition, and the next you could be delivering a group session to several young adults."



**Demelza feels like where I'm meant to be."**



**Through your support**

### Music therapy sessions

**Last year Demelza delivered 447 music therapy sessions to 159 children and their family members.**



## “Henry was born on Christmas Day in 2021, when we were catapulted into a completely different world to what we had expected.

Henry spent a month in the Neonatal Intensive Care Unit (NICU), during which time doctors ran every test possible to work out what was going on with our son.

Henry was eventually diagnosed with an exceptionally rare genetic condition called CASK gene mutation, which causes seizures, global development delays and difficulties swallowing and feeding, among other challenges.

We were told there were only eight living boys with the condition and that the life

expectancy of our son would be very short.

It was soon after this that we were referred to Demelza. At the time, hospice care to us meant that our son needed end of life care. It wasn't until we visited that we learnt the range of support on offer.

Overnight respite and care at home have enabled us to enjoy some of the pleasures that we simply cannot have with a disabled child. Hiking, long cycle rides, the theatre, a meal out and going

to the gym together. These are all things that have brought us joy, thanks to Demelza.

My partner Matt and I have been able to enjoy 'being us' rather than being exhausted parent carers. We spent three nights at Demelza Kent last year, where we enjoyed swimming with Henry, film nights in the cinema room, long morning bike rides and afternoon naps. It felt like a holiday.

The hydro pool is just amazing. We have spent many an afternoon watching Henry floating in the warm waters, whilst Matt and I relax in the jacuzzi. We also love the beautiful tranquil gardens there. Sitting with an early morning coffee, listening to the birds, without having to worry about whether Henry needs us, is a memory that I still think back to.

The community nursing team are equally amazing. When we have care at home, we can do little things – go for a coffee together, have a lie in, or even get odd jobs done that are otherwise difficult to do. The time always flies by as Henry is making music or crafting and having a happy time.”



**At the moment, Demelza is the only support that we get and they have been a lifesaver for us as a family.”**

### Short breaks

Last year we provided 533 overnight short breaks and 3,489 community nursing sessions.

Through your support

Watch the case study film here



# News in brief...

## Trail with a Tale - coming soon!

A free family-friendly art trail is coming to Tunbridge Wells next Summer. Partnering with leading producer of art trails, Wild in Art, this beautiful sculpture trail will help Demelza reach more children and families in the area. Find out how you can get involved at [trailwithatale.co.uk](http://trailwithatale.co.uk) and please follow our Trail with a Tale social channels @trailwithatale  



## Happy Birthday Demelza East Sussex

Demelza East Sussex is 20 years old this year! Thank you to the volunteers, supporters and colleagues who have been part of this journey - helping us to provide extraordinary care to extraordinary children in the area.



## Record breaking London Marathon

We saw record income from this year's London Marathon with 48 runners raising an amazing £150,000 - thank you to everyone for your support, and if you have a place for 2025, please consider joining the Demelza team. Email [events@demelza.org.uk](mailto:events@demelza.org.uk)



## New warehouse!

Following our departure from Sandling Road, we are opening a new distribution centre and shop in Larkfield. Please get in touch if you are interested in volunteering at [volunteering@demelza.org.uk](mailto:volunteering@demelza.org.uk)



## Bubble Rush

Four Bubble Rushes, 6,000 people and £150,000 raised - thank you to everyone who came along and we hope to see you all next year!



## Wildlife garden opening

Greenfingers Charity transformed an underused space at Demelza Kent, creating a wildlife garden for children and families to enjoy for many years to come.

## Family Exploration Day

This Spring we held our very first family exploration day at Demelza Kent where families had the opportunity to learn new skills, find out about Demelza, meet other families and learn about other service providers in the area - it was a great day and we will build on this success and feedback for next year's event!



## Sensory room revamp

We have officially opened our new sensory space at Demelza Kent! A huge thank you to Lee Lougheed Builders and the Madden Family for making this possible.





# How you can get involved...



## Celebration of Christmas

Celebration of Christmas returns to the Old Royal Naval College, Greenwich on 4 December and Canterbury Cathedral on 16 December. We would be delighted for you to join us for these truly magical events. To book visit: [demelza.org.uk/celebrationofchristmas](https://demelza.org.uk/celebrationofchristmas)



## Open Days

Join us for our annual Open Day at Sittingbourne on 15 September and Eltham on 20 October. Learn more about the work we do, meet the teams behind our extraordinary care, discover our grounds through a guided tour and enjoy our various stalls and activities. To book your free guided tour visit: [demelza.org.uk/penday](https://demelza.org.uk/penday)



## Join our Lottery

The Demelza Lottery gives you the chance to win big whilst also having an impact on the children and families we support. From as little as just £1 a week, you could win £1,000 and 52 other fantastic cash prizes! You can also enter our Superdraw, for the chance of winning our rollover jackpot of up to £25,000! Sign up today: [demelza.org.uk/lottery](https://demelza.org.uk/lottery)

Sign up to  
an event



Sign up to  
the Lottery



To find out more  
[demelza.org.uk](https://demelza.org.uk)

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