



demelza

extraordinary care for extraordinary children



Trustee Recruitment Pack



Thank you for your interest in becoming a Demelza Trustee.

We are looking for exceptional people who can help drive Demelza services forward and help implement our exciting 5-year strategy. We particularly welcome applications from people from black and ethnic minority communities. We are striving for a more diverse Board membership to better reflect the communities we serve. We understand that celebrating and embracing the unique differences people bring will engender a creative, forward thinking organisation.

Day to day supervisory management of the organisation is delegated to me as Demelza's CEO, an honour I hold very dear, and to the Senior Leadership Team. I have been at Demelza for 25 years and have been privileged to be part of the organisation's history and am hugely excited by future opportunities.

Demelza is in a good financial position, after the Covid-19 pandemic we have tailored services to become more agile and offer choice of how, and where, our care is offered. We want to build on everything we have learnt and put this to good use to achieve our strategic aims.

We regularly consult with our stakeholders, and work on the development of our current strategy. The future will be both challenging and rewarding and we seek inspiring strategic leaders who will support the team at Demelza to deliver our goals.

Lavinia Jarrett
Demelza Chief Executive

Welcome to Demelza

Demelza delivers extraordinary care to extraordinary children who are facing serious or life-limiting conditions, throughout Kent, South East London and East Sussex.

Demelza is here to support children and their families at every step – from first diagnosis and for as long as we’re needed. And when we’re needed most, Demelza is here with care that doesn’t back down. By their side when they feel isolated, helping to celebrate the joy in family life and making precious memories during challenging times.

We were founded over 25 years ago and are named after Demelza Phillips, who inspired the creation of our first hospice and our charity. Since we began, Demelza continues to be dedicated to reaching more children and families who need our support.

There are currently almost 90,000 children and young people in England living with a condition that means they are likely to die young. This number has tripled over the last 20 years, and with advancements in research and medical interventions, this number will continue to rise.

With more babies being born with serious or terminal conditions and children living longer with increasingly complex medical and social needs. Demelza is needed now more than ever.

Many children need care and support 24 hours a day, seven days a week and providing this care puts families under enormous emotional, practical and financial pressure. The constant run of hospital appointments, gruelling medication and caring regimes and the unpredictability of their child’s condition (around 15% will not even have an official diagnosis) can make it challenging to maintain healthy relationships and stable family life.

At Demelza, we provide expert clinical and emotional support to help families live the best life they can. We can help keep children out of hospital or leave hospital sooner, and our specialist clinical care and advice enable parents to meet the complex medical needs of their children with confidence.

Our support can assist parents in improving their well-being, independence, knowledge and resilience whilst empowering them to do their very best during the most difficult of times. We can help them to smile, laugh and offer the rare opportunity to relax.

Most importantly, we can help them all to be families; enjoying their time together and creating memories that will last a lifetime.



Our five year strategy 2022-2027

We are excited to present Demelza’s five year strategy.

Our strategy will focus more than ever before on Demelza’s history of actively seeking the views and feedback from those who are the real experts; the children, young people and their families themselves. We will strive to involve those who use or might need Demelza’s services in our decision making and how we develop our services. This will ensure services are accessible to all those that need support, particularly those from diverse and minority backgrounds.

Find out more by visiting:
demelza.org.uk/strategy-2022



Be effective



Be responsive



Extend our reach



“We are Demelza”



Strengthen and sustain

Care

We support families when and where we're needed most: in our hospices, in their homes, in local communities and online. Our support is as unique as every child and family, and personalised to adapt around their specific circumstances: from creative therapies and short breaks, to practical and emotional support for families and siblings, alongside expert clinical and end of life care. Our specialist teams are on hand when we are needed most.



Specialist clinical care

Our specialist nursing and care team supports parents/carers of children who are ready to leave hospital but need some additional advice and training to confidently look after their child's needs. For children with complex symptoms and medication regimes, the team have the experience and knowledge to help manage their condition effectively.

Short breaks

Daycare and overnight breaks within our Kent site and our day care in our South East London site. We also deliver care within the family home giving children a break in an environment tailored to their needs.

Family support

Bespoke emotional and practical support for the whole family. This includes support during pregnancy should a complex medical condition be diagnosed, one to one advice and support from trained Family Liaison Practitioners, family events and group work and sibling support.

Therapies

Physiotherapy, Music and Art Therapy sessions for the child or young person and the wider family giving the opportunity to use creativity to explore and express emotions and deal with difficult experiences.

Practical support

Specially trained volunteers who help with a range of short-term activities including driving to specialist hospital appointments, decorating and walking the dog if a family is in hospital.

Transition

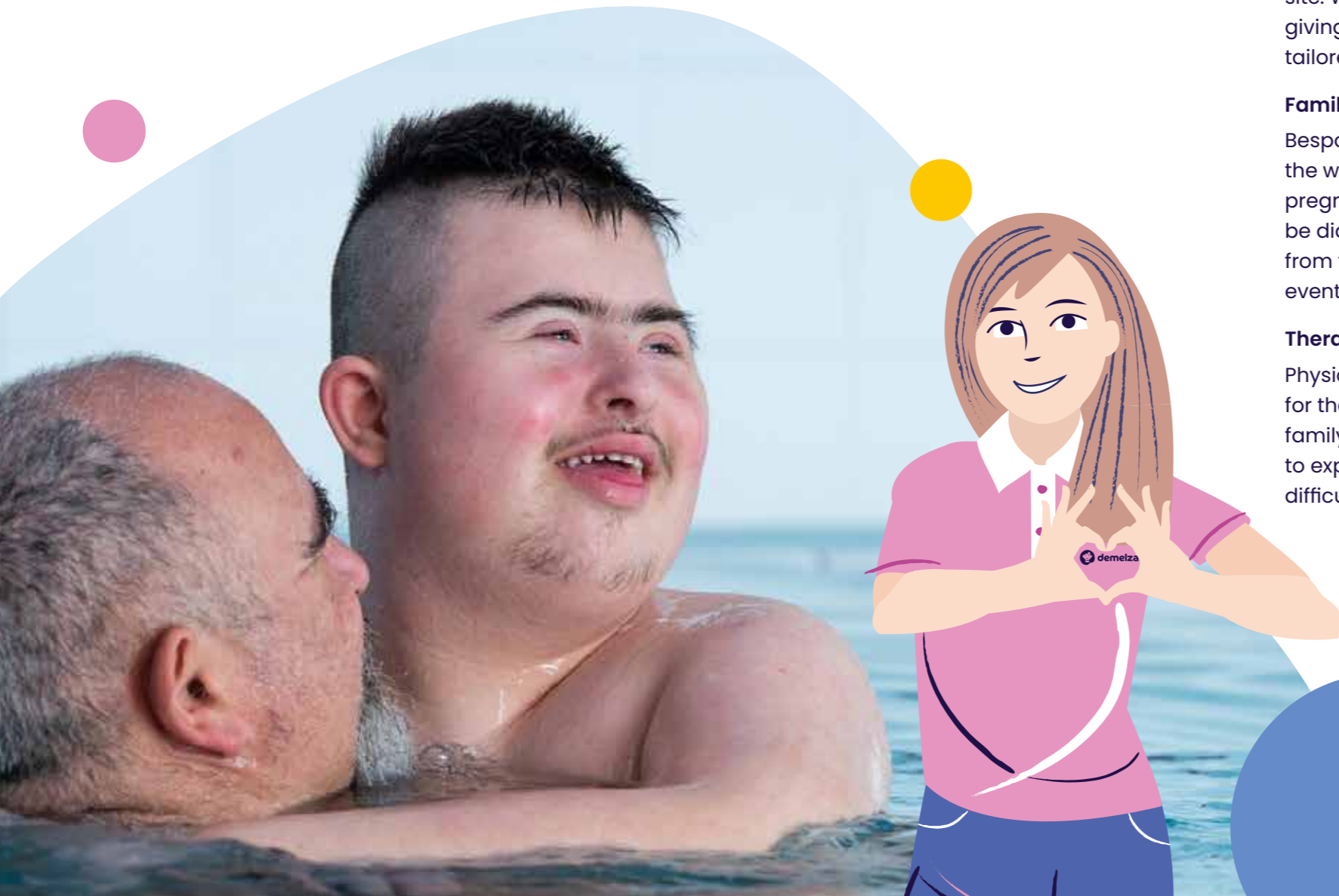
As a young person nears 18, they need to prepare for the move from children to adult services. We have created a transition framework and pathway to help guide parents/carers through this challenging time and set up links with adult hospices around the area to ensure joined-up care.

End of life care

We aim to be there for every child and family who need us, as they approach the end of their life with clinical care, emotional support and memory making.

Bereavement support

We understand that everyone's experience of loss is personal and there is no one way, or right way, to manage grief. Because of this, our bereavement support threads throughout the service and is about supporting family's unique journey, whether this is from the point of diagnosis, or later.



Retail

Charity Retail is more than a face of a charity or a simple income stream. Retail locations provide considerable benefits for a charity, the local community, and beyond.

The primary role of a charity shop is to raise funds. However, our shops are also the face of our charity. On your way out for a coffee, we're who you say hi to. We're part of your shopping trip. We're there to answer your questions, take care of your collection pot, and be a signpost locally for all things Demelza.

At Demelza, we currently have 30 retail stores across our geographical areas which support our income generation.

Find out more by visiting:
demelza.org.uk/shop



Lottery

Demelza Lottery, is a society lottery run entirely for Demelza in accordance with the Gambling Commission rules and guidelines.

Currently there are approximately 24,000 Lottery players and 11,000 Super Draw players. .

Lottery can be found at many outdoor and indoor events throughout the year either singularly or in support of a Demelza event such as Bubble Rush and is essentially our mobile shop front, detailing how to support Demelza in many ways.

Demelza Lottery provides approximately £1.3m of income each year.

Find out more by visiting:
demelza.org.uk/support-us/lottery



Fundraising

Fundraising is a vital part of what we do as an organisation, the majority of our funds coming through the generosity of our local community. From making a regular donation each month to attending an event, there are many ways in which someone could support Demelza through fundraising.

The fundraising team is broken down into sub teams:

Our team of regional fundraisers help other people to fundraise. This could be going to a local school across the patch to speak to them about what Demelza does, or visiting a small business as they may have chosen us as their charity of the year. The team also attend things such as Rotary dinners, Women's Institutes and other community groups. They also support our generous community in their own events, they may be organising a fête, a ball or a bucket collection and the team will ensure that they have everything they need to be able to do this activity.

We have larger Corporate Partnerships with companies such as LGT Wealth Management, Axis and Berkeley Homes as well as larger local companies such as Kent Reliance. We work with these companies who typically raise over £10,000 by visiting them in their offices and ensuring that they have everything that they need to support Demelza.

We engage their staff by offering them events to take part in, volunteering opportunities and when possible, the chance to visit our hospices. We also often pitch to organisations about why they should choose Demelza over another charitable organisation.

We hold many events throughout the year, these can be for 5 people up to 4000 people. We have runners in events such as the London Marathon and Royal Parks Half Marathon. Thrill seekers jumping out of aeroplanes, and fitness fanatics taking on trekking and cycling challenges.

We also hold many family fun events such as our fully accessible Bubble Rush which can have up to 4000 participants. The events we hold are not only about income but also raising awareness in a local area.

People often give to Demelza as individuals, this may be through a regular monthly gift or through a one-off donation via one of our appeals such as our annual Christmas Appeal. Within this area, we also have in memory giving where people give gifts in memory of a loved one in lieu of flowers. This will come directly from families or it may come through a funeral director. Legacies are a vital part of Demelza's fundraising, this is when someone leaves a gift in their will to Demelza. It may be that someone has only encountered Demelza once in their lifetime and they kindly choose to support us in this way.

We have Philanthropists who donate to us often once a year, they may donate to something in particular such as funding our solar panels or it may be an unrestricted gift. We also hold special events for these donors such as golf day or a magical winter ball raising in excess of £200,000.

We receive great support from Trust and Grant organisations, the team put together a significant number of applications each year which are submitted to trust and foundations. These applications are for particular projects or work that needs funding or for general running costs of the organisation.

Our supporters are at the heart of what we do in fundraising, we want to ensure that they have the best experience with us and that they understand what Demelza does as an organisation. We hope that they may come back to do something else in the future. Every interaction with our supporters is important and is vital to the sustainability of our fundraising.

Find out more by visiting:
demelza.org.uk/support-us/fundraise-for-us



Our mission, vision and values

Our vision

To see a world where children and young people with serious or life-limiting conditions, and their families, have access to personalised, expert care – enabling them to live their best lives.

Our mission

To deliver care that doesn't back down to children and young people with serious or life-limiting conditions, and their families, across Kent, South East London and East Sussex – from first diagnosis and for as long as we're needed.

Our values...



What we need

Demelza employs over 360 staff and relies on thousands of volunteer hours to deliver our services and raise over £16 million. Our Chief Executive Officer reports to the Board of Trustees. We are currently seeking experienced individuals to join our board.

As a Trustee you will help to shape the future of our services and ensure we have income streams to enable us to plan and meet demand.

Demelza greatly values the benefits of a diverse team and embraces diversity, equality and inclusion in all areas of its work. We are committed to building a diverse and authentic workplace, ensuring that our team reflects the diversity of the children and families we support.

Our leadership team is under-represented by those from ethnic minority groups. We encourage candidates from all backgrounds and celebrate the value of difference.

Do you have medical expertise to strengthen the clinical strategy delivery and support a multidisciplinary approach. Your expertise might come from a relevant medical discipline – e.g. paediatrician, consultant, critical care, GP or an area of acute medicine.

Are you a senior experienced retailer, familiar with all aspects of maximising profitability and positive customer experience. You will help us to maximise the financial, reputational and PR opportunities of our suite of retail outlets and optimise the model to support growth.

We also seek professionals with experience in technology or data. Your experience might be in IT, applications and systems, cyber security, artificial intelligence, networks and infrastructure. Alternatively you may be experienced in data protection, data analytics, data governance or digital transformation.



Being a Trustee

Time commitment

Our Trustees serve on at least one Board Sub Committee and the main Board, both meet quarterly. Each meeting lasts 2-2.5 hours, with agendas and papers to read in advance. We seek regular involvement in relevant Directors, perhaps bi monthly, and attendance at organisational events which would be approximately 6 times per year, ranging from family events, to celebration and fundraising events. We hold an annual Trustee/Senior Leadership Team Away Day to strategically plan.

Approximate time commitment – a total of three days per quarter minimum.

Location

Demelza services extend across Kent and East Sussex and into the London boroughs of Bromley, Bexley, Croydon, Greenwich, Lambeth, Lewisham and Southwark.

Interaction with our two residential hospice sites in Sittingbourne, Kent and Eltham, South East London are required and also with our Community Nursing Team in East Sussex. Meetings can be joined digitally. However, some meetings, for example, the annual Away Day would be required in person.

Remuneration

The role is unremunerated, however we will:

- Reimburse reasonable out of pocket expenses.
- A tablet will be provided to access paper and use for Demelza work.

Role description

Key responsibilities as a member of the Board of Trustees:

- Ensure that the Charity and its trading subsidiaries are governed effectively.
- Work in partnership with the Chief Executive to ensure that the organisation has a clear vision, mission and strategic direction and that the organisation, the Trustees and the Chief Executive are focused on achieving these.
- Work within the Board to ensure future sustainability, in terms of the impact of activities against assessed need, and financial sustainability.
- Ensure that the Board is monitoring performance through reports provided by the Chief Executive and senior staff.
- Take a particular interest or, by agreement, a lead role in any areas of specialist expert knowledge.

Specific responsibilities:

- Within the Board, to contribute to the Board's undertaking of its fiduciary duties in all required areas of governance, including:
 - Financial management
 - Clinical governance
 - Corporate governance
 - Information governance
 - Fundraising good practice
- To participate in a framework of scrutiny and audit so that this assurance is verified and demonstrated.



To ensure that Demelza plans strategically by:

- Contributing towards the development, appraisal and updating of strategic plans and the monitoring of performance against such plans as are adopted by the Board.
- (Through the Chief Executive) ensuring that management effort is effectively directed within a framework of clearly stated strategies and key tasks.

To participate in a governance and financial policy framework to ensure that:

- A governance and financial policy framework is established within which the Senior Leadership Team shall manage the charity.
- The Chief Executive is clear about the key performance indicators by which they and their colleagues will be held accountable.
- The particular risk factors inherent in Demelza's activities are analysed.

Other:

- Maintain effective networks with supporters and stakeholders.
- Seek opportunities to expand and promote the role of the organisation.
- Promote Demelza to its public audience and represent it at appropriate events.

Person specification

- Proven leadership skills
- Strategic vision
- Commitment to the organisation and ability to demonstrate organisational values
- Ability and willingness to devote the necessary time commitment and effort
- Good, independent judgement
- Understanding and acceptance of the legal duties, responsibilities and liabilities of trusteeship
- Financial literacy and the ability to read and understand accounts
- Ability to lead and work effectively as a member of a team
- Tact, diplomacy and confidentiality
- Excellent communication and interpersonal skills
- An enhanced DBS Disclosure will be required for the successful applicant
- A Fit and Proper Person Declaration to demonstrate good character and suitability will be required

Previous trustee experience is NOT required





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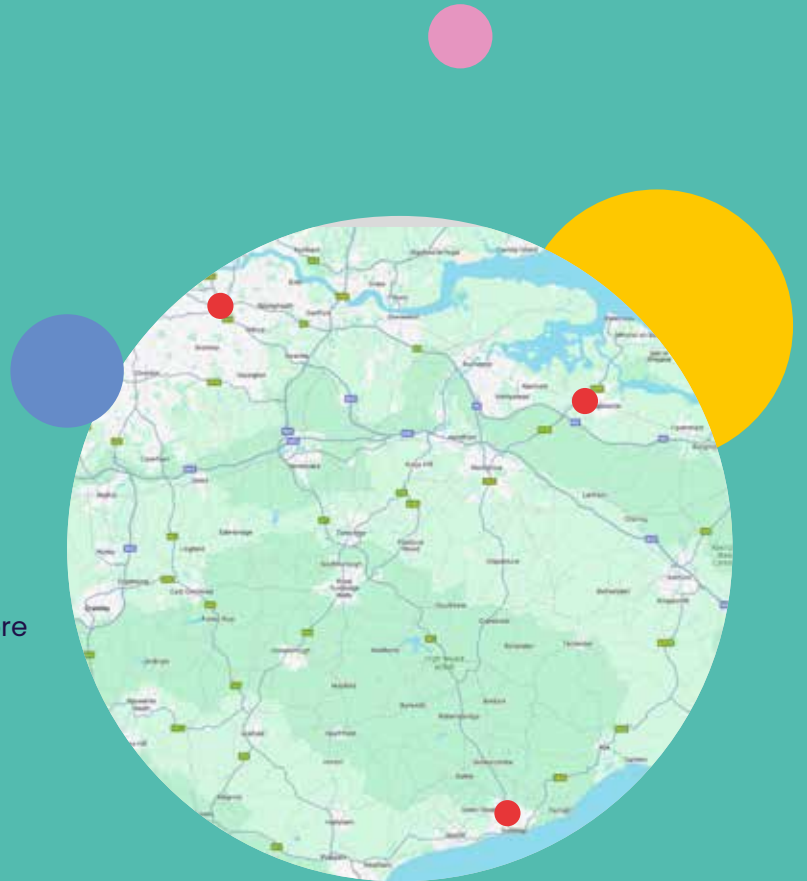
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To apply:

Please supply a supporting statement of no more than 500 words plus your up-to-date CV to:

Nikki Dunncliffe, EA to Board of Trustees
nikki.dunncliffe@demelza.org.uk

All applications will be treated in confidence.
Informal conversations and visits are welcome.



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For more information about us,
please visit our website:

demelza.org.uk

Registered Charity No. 1039651

[@demelzacharity](https://www.instagram.com/demelzacharity)     



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