



demelza



Quality Account

2023/24

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CEO statement of quality

I am happy to report Demelza's Quality Account for the year 2023/24. This report was prepared by our Director of Quality Improvement and Clinical Governance with input and support from across the organisation and has been read and approved as accurate by me and by our Board of Trustees.

Now in the second year of our five-year strategy, we can report significant, tangible progress against our key strategic objectives. Fundamental to meeting growing need and demand for our services is a dedicated and well-resourced workforce. I've reported previously on the serious nursing recruitment challenge all organisations are facing. I'm excited to report that our latest campaign – Be the Professional You've Dreamed of – has attracted the biggest response to date.

Retaining and developing our existing clinical teams to manage the increasing complexities involved with caring for children with serious and life-limiting conditions is equally important. We've now invested in developing Nursing Associates, integrating them into the workforce and offering some registered nurse apprenticeships providing a template for years to come.

Ensuring we're the most inclusive organisation we can possibly be is a major priority for us this year as we want everyone – be they children and their families or the valued members of our team – to feel welcome and comfortable at Demelza. We know we have work to do and are collaborating with a range of stakeholders to achieve this goal. Earning the Silver Investors in Diversity Accreditation this year is a great mark of the progress we've made and inspiration for us to achieve so much more.

Since launching our five-year strategy in 2022, we've seen our caseload increase by 40%. While it's wonderful that we are reaching more children and families, it means we are creating a virtuous circle. The success of our in reach nurses in signposting professionals and families in local hospitals to the full range of services at Demelza, means we're seeing many more children, particularly very premature and young babies and supporting them on a nine-month pathway.

As well as a skilled, caring and compassionate team we also need the finest facilities, maintained to the highest standards, ensuring they're not only safe but also inviting and welcoming.

We were very fortunate to be able to open Hill Farm in Sittingbourne this last year. As well as providing temporary accommodation for some of our new nurses, this state-of-the-art building – the land gifted by the Kemsley Family, the building funded by developer Esquire Developments and the fit out funded by loyal generous Demelza supporters – is the perfect place for young people transitioning out of children's services.

When I started at Demelza in 1999, this group made up a tiny part of our caseload. Now, young people aged 14-25 account for 25% of all those we support.

I believe that this Quality Account is an accurate synopsis of the quality of care provided by Demelza and am happy to be able to demonstrate how we, as a charity that also receives some limited statutory funding, delivers care that supports the wider health and social care economy.



Lavinia Jarrett
Chief Executive Officer





Review of quality performance in 2023/24

2.1 What we achieved

The year 2023-24 has witnessed Demelza expand in numerous ways. We've grown our teams in terms of both numbers and, importantly, the skills and confidence of our colleagues. We've increased knowledge of and access to our services and consequently grown the number of children, young people and their families able to receive care where they want it. We've also given more families the opportunity for a short break when they need it.

Workforce

In pursuit of the ambitions in our five-year strategy, we've successfully recruited new staff, inducted them as well as trained and developed existing members of the team. Specifically, we have two Healthcare Assistants, who are training to become Nursing Associates and will join two newly qualified Nursing Associates who will soon commence a nursing degree programme. This new and creative approach is helping us to meet the challenge of the ongoing nursing recruitment crisis. Meanwhile, three of our registered nurses have completed their Professional Nurse Advocate Level 7 qualification. We've also significantly expanded our non-clinical teams, including adding a counsellor, bereavement practitioner and both an additional music and art therapist to the psychotherapeutic team, in addition to new recruits to the family liaison and practical support teams.

The last year has witnessed significant progress on our long-term work to create an inclusive workplace and in recognition of that we were awarded the Silver Investors in Diversity Accreditation. Among the many successes in 2023/24, included:

- Monthly meetings of the FREDIE (Fairness, Respect, Equality, Diversity, Inclusion, Engagement) and Wellbeing Steering Group.

- Introduction of 'Curious Conversations' – a safe place for colleagues to explore and discuss FREDIE topics.
- Launch of FREDIE and wellbeing information and resource hubs on the Demelza intranet.
- Revision of Demelza's values and behaviours to reflect FREDIE.
- Translation of our Guide to Services into Punjabi and Somali.
- Appointment of a trustee as EDI lead.
- Agreed on a diversity calendar of celebrations using the nine protected characteristics.
- Installation of hearing loops.
- Introduction of pronoun badges for staff and visitors.
- Provision of several EDI training programmes: It's about race, Understanding LGBTQ+ and young people, and Equality Impact Assessments.

We've further grown the links we established in 2022/3 with the acute hospitals in the area in pursuit of our objective to increase knowledge of and access to our services, notably at Oliver Fisher Neonatal Unit at Medway Maritime Hospital. This in reach programme that sees Demelza nurses and allied health professionals, including music therapists, collaborate on-site with our hospital colleagues, has successfully raised awareness of the support we offer via our neonatal pathway. Building on this, we have started developing relationships with all South East London hospitals as we look to emulate the in reach nursing model across the region.

Our South East London community team has increased the number of children it supports to 39 – ensuring families preferred place of care is prioritised. Such has been the success of the team there is now a waiting list for this community service. Working closely with nursing colleagues in the community and with the expansion of our own community team in Kent, we've supported more children and families across Kent, South East London and East Sussex in the last year.

When it comes to supporting families, we are constantly listening, learning and adapting.

2.2 Patient safety

Fostering a spirit of openness and transparency, providing specific, relevant training and encouraging and enabling continuous learning have been the three key behaviours at the heart of our successful efforts to enhance further patient safety which in turn will improve patient outcomes.

Successes include:

- Completion of Health Services Safety Investigations Body training by two Lead Nurses.
- Completion of thematic review of medicine incidents.
- Use of System Engineering Initiative for Patient Safety (SEIPS) framework approach for two investigations.
- Implementation of 'Just Culture' training for clinical teams.
- Installation of Vantage – a new incident report portal – including the Learning from Patient Safety module.
- Establishment of good working relationship with Lead at the Integrated Care Board.

To ensure optimal levels of continuity, efficiency and timely care, Demelza has been engaged in several collaborative digital transformation projects with our health and social care partner providers.

Successes include:

- Engaging with NHS to access clinical records for Kent, ensuring we have key medical information for babies, children and young people in the county.
- A review of Demelza's document management to ensure information is accessible and secure.
- Maintaining Demelza's place at the forefront of the system-wide developments to the Clinical Database, thereby ensuring enhanced functionality and engagement and, as part of phase two of the payroll system development, we place a special focus on rostering processes to reduce manual interventions for payment of overtime.

2.3 Clinical effectiveness

Demelza has, through strategic recruitment, service enhancement, additional training, new partnership working and digital switch-over, further increased clinical effectiveness.

Successes include:

- Switch to a new online recruitment system (Recruitment+) thereby streamlining applications.
- Recruitment of a speech & language therapist – helping Demelza embed feeding and communication best practice.
- Recruitment of a bank physiotherapist to extend availability of aquatic therapy to three mornings a week.
- Appointment of a behaviour liaison nurse to provide families and staff with expert support and guidance.
- Introduction of new referral system for physical therapies to ensure equitable access across all sites.
- Implementation of action plan following review of all recommendations in mock Care Quality Commission report.

Transition support

We have made significant progress building on our strategic priority to improve our model of care for teenagers and young adults.

Successes include:

- Implementation of a transition pathway for young people aged 14-25, including regular events, bespoke advice and activities.
- Provision of increased support for 18-24 year-olds including activity days at the new Hill Farm building at the Kent site.
- Publication of twice-yearly dedicated newsletter.
- Extension of links with adult services and hospices
- Facilitation of peer-to-peer support, a monthly network and in-person meetings as well as teen weekends.

Bereavement support

Communication, training and events are just some of the means with which we have further improved our bereavement offering for families.

Successes include:

- Publication of a six-weekly newsletter for bereaved families.
- Increase in social and memory events, including a specific baby loss event.
- Introduction of specialist groups – including Together: Exploring Grief and in-person cafés at all sites.
- Establishment of check-in call system to enable contact with all bereaved families.
- Increase in bereavement training – making it available for all staff and volunteers.

Therapeutic support

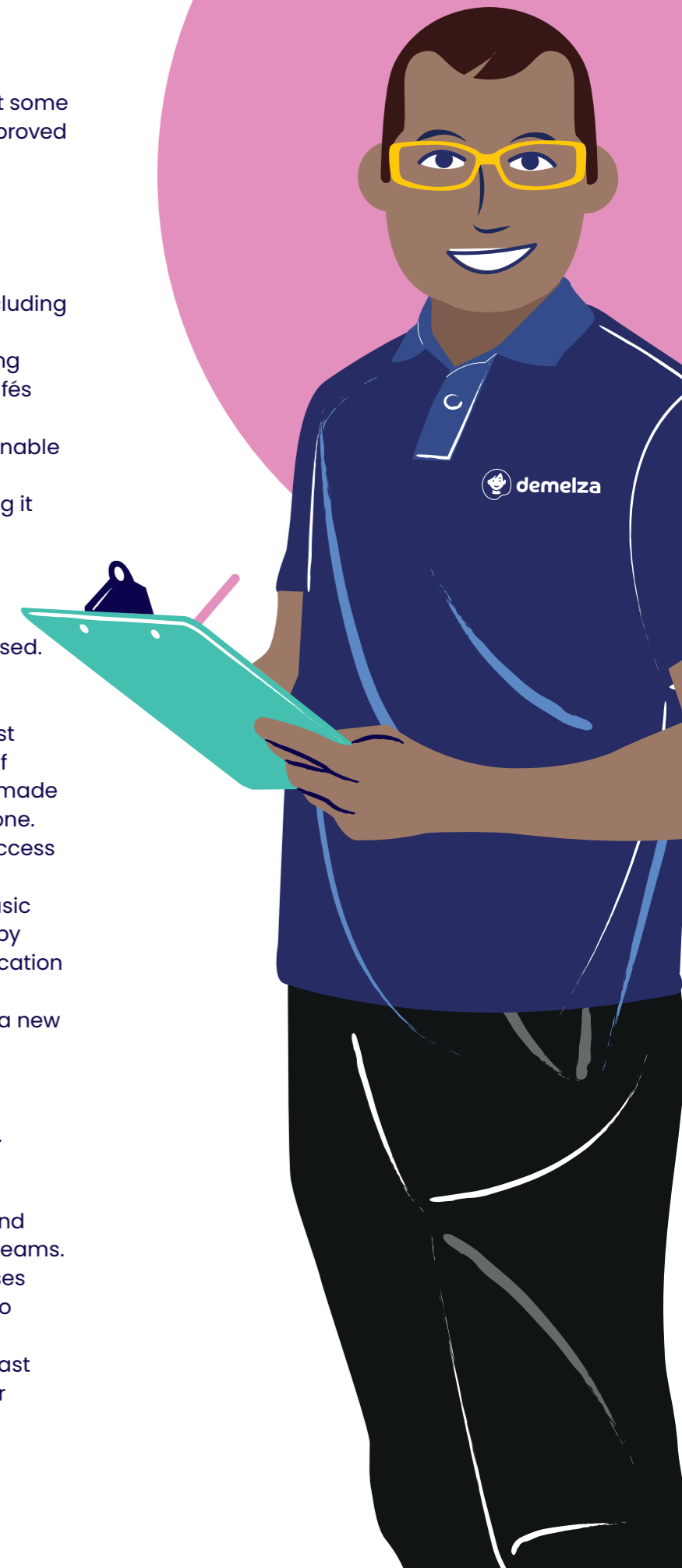
The availability, accessibility and range of therapeutic support was successfully increased.

Successes include:

- Embedding of counselling within South East London and Kent sites plus appointment of affiliate counsellor in East Sussex. Service made available in person, online and via telephone.
- Development of new system to improve access to therapies across all sites.
- Introduction of placements for art and music therapy, and counselling students – thereby reducing waiting lists and supporting education in these critical specialisms.
- Recruitment of an additional new art and a new music therapist.

Nursing support

- Prioritisation of urgent and end of life care.
- Increase in day care provision.
- Growth of Demelza Dots – a stay and play event to encourage family peer support and strengthen relationships with the nursing teams.
- Increase in reviews conducted by our nurses in hospital to enable quicker discharge into our care.
- Expansion of community teams in South East London helping more families choose their place of care.



2.4 Patient experience

Involving service users

At Demelza we strive to develop all our services based on feedback following events or groups, and we actively seek the voice of the family (Strategic Objective 3.5, 5.1). We elicit that feedback in many different ways, including online, in-person, one-to-one and in group settings and then look to identify trends that could inform future service provision.

Notable successes:

- In Summer 2023 we sent families an extensive survey. The findings of which resulted in some significant changes to services.
- We have made changes to the family events programme based on feedback gathered in our quarterly parent carer group meetings, Families' Voice.
- Families' requested the chance to meet up after a teens weekend. We provided this opportunity. Take-up was high and the response was overwhelmingly positive.

Digital Transformation

Busy families with caring responsibilities want and need to be able to access information that's relevant to them quickly and easily. We've responded to this need.

Notable successes:

- Developed family and young voices sections of the website. These provide families and young people with a dedicated area providing information and news about services and events relevant to them. They also provide a space where they can feed back.
- Created a wellbeing section and events calendar, too.
- Helped busy families access their own dedicated part of the website sending each one a fridge magnet with a QR code that takes them directly to it.

Transition

Recognising the specific needs of 16-25-year-olds, we participated in the 'What Matters to Me' project with the Challenging Behaviour Foundation, giving young people in our care the chance to support a multi-media manifesto, raising awareness of those in this age group who have profound and multiple learning disabilities.

Young people and their families also contributed to an extensive evaluation report to inform future service provision that was submitted to and funded by South East London Integrated Care Board.



At last! Thank you for including the over 18s. This day together has been so important to help reconnect and share our experiences and future plans."



Thank you for organising this weekend for teenagers, I don't think this has ever been done before as teenagers always get forgotten. Thanks!"



Priorities for improvement in 2024/25

3.1 Improvement priorities

Demelza will increase its advocacy for children and families requiring palliative care and support through an intensified focus on:

- Raising awareness of their needs through media campaigns.
- Establishing relationships with all MPs across our area – enlisting their support for a sustainable funding model for children's palliative and end of life care services.
- Working collaboratively with Integrated Care Boards and the Integrated Care Systems. This will involve providing them with the data to support them with their obligation to ensure provision of the palliative and end of life care services children and young people want and require.

To help us provide meaningful, individualised care in line with children and families' needs and preferences, we will review how we capture and act upon their preferred outcomes from our services.

In pursuance of a Demelza Nursing and Care Career Progression Pathway we will build upon our workforce initiatives.

To ensure all stakeholders best understand our clinical services – how they are structured and accessed – we will review and categorise them in a clear matrix.

We will continue to develop and embed Fairness, Respect, Equality, Diversity, Inclusion and Engagement (FREDIE) initiatives. We will repeat FREDIE surveys for employees, volunteers, families, and external stakeholders. We aim to pass final assessment to obtain accreditation with Investors in Diversity.

3.2 Patient safety

- Document our Patient Safety Investigation Framework (PSIRF) plan, achieve sign-off from our lead at the Integrated Care Board and implement training on its principles across the organisation.
- Produce the risk management policy and procedure with input from clinical and non-clinical teams.
- Continue to enhance our support for patients with timely access to key information for babies, children and young people through ongoing engagement with NHS to extend access to clinical records for South East London.
- Maintain Demelza's place at the forefront of system-wide developments by the supplier of the Clinical Database by continuing to focus on its enhanced functionality and engagement.
- Implement a new 'Raising Concerns' policy which will include a new Freedom to Speak Up platform and Freedom to Speak Up Guardian.
- Create and communicate to professionals a clear referral pathway.
- Scope and implement an 'alert' system, allowing Demelza to respond both swiftly and safely to urgent care requests.

3.3 Clinical effectiveness

- Utilise demand, capacity and complexity data to enhance our ability to provide a reliable and equitable short break service.
- Enhance Demelza's ability to meet demands of increasingly complex clinical conditions by recruiting more clinical team members.
- Work with Acorns Academy to consider a shared competency framework in collaboration with Children's Hospices across London (ChAL).
- Work closely with and support the South of England Collaborative Paediatric Palliative Care Education Network to develop an education and training platform for paediatric palliative care.

- Ensure yet more children and families have access to appropriate support sooner by continuing to increase and enhance nursing in reach into hospitals across our regions, sharing knowledge and skills with colleagues across organisations.
- Explore methods to enhance communication with families by exploring family data being migrated onto the CRM, Raisers Edge. This will give us the ability to track and manage family journeys, create personalised communications and evidence the longer-term impact of our work.
- Continue to invest in workforce initiatives and training opportunities across clinical services teams such as Nursing Associate and Nurse Degree opportunities.

3.4 Patient experience

- Increase our co-production work with families through the Families' Voice Group.
- Improve our response to recurrent themes by moving feedback onto the Vantage system.
- Focused feedback opportunities – where we notice trends in feedback/questions from families or colleagues, our engagement team have, and will continue to, explore additional feedback on these themes.
- Improve families' welcome experience at all Demelza sites using the 15 Steps Challenge.
- Create a seasonal calendar of events for families in each of our areas.
- Provide additional opportunities for Demelza professionals to meet families' need for information, advice and discussion on specific subjects as well as enhance opportunities for peer support by building on the Together Exploring programme.





The Board of Trustees' commitment to quality

The Board are fully committed to ensuring Demelza provides a high-quality service to children, young people, and their families. Robust clinical governance structures and reporting are in place and are continually reviewed, ensuring that appropriate reporting arrangements and accountability are in place.

Demelza's Trustees are proud of the high quality, nurse-led services at Demelza. The nursing and care team's work has increased in complexity to meet the needs of children and their families, and the team have dealt with this with commendable aptitude and focus on clinical safety. Open and transparent reporting allows Trustees to provide meaningful scrutiny and support for the clinical team.

The growth of holistic family support and psychotherapeutic services in the last 12 months has been an area of focus. In line with our 2022-2027 Strategy, the team has grown considerably, allowing Demelza to expand services, which includes the formalisation of both psychotherapeutic and transition pathways, meaning a family will know what to expect, and when, from these services. Family engagement are also using qualitative and quantitative feedback from families to support decision making and Trustees are pleased to see both areas grow this year.

Throughout this period of growth in delivery and complexity of services, Trustees have highlighted the importance of consideration for staff wellbeing. Demelza's commitment to wellbeing with the development of a wellbeing team, resources, and staff feedback is pleasing to see.

Demelza is an inclusive organisation where we value the differences in our colleagues and the children and families we serve. Trustees play an active part in supporting and guiding the work to achieve and sustain equality, diversity, and inclusion (EDI) in all areas of the charity's business. To help achieve this, the Board of Trustees has appointed a trustee with specific responsibility for EDI. The Trustee Board is therefore represented on the Steering Group created to work with the National Centre for Diversity, to provide evidence that embedded in the culture of Demelza are the pillars of Fairness, Respect, Equality, Diversity, Inclusion, and Engagement (FREDIE). The conditional award of the Investors in Diversity Silver Award confirms Demelza has an inclusive culture.

Demelza's commitment to safeguarding children, young people, employees, and volunteers remains absolute. Quarterly

Safeguarding Assurance Committee meetings continue, chaired by a Trustee who is a retired paediatrician and is well supported by a Lead Nurse for Safeguarding. Both bring extensive insight and experience in the field. These meetings are well attended by teams from all departments across Demelza in recognition of safeguarding being everyone's business.

As Demelza Trustees, our commitment to the voice of the children and families is critical, strengthened by the work of the Demelza team and a Parent Trustee who is a key part of the Trustee Board. We recognise and thank all the employees and volunteers for their dedication and commitment to the delivery of high quality services, provided in support of our children and families.

Statements of assurance

These statements are ones set out within Quality Accounts Regulations that providers must include.

Review of Services

Demelza delivers extraordinary care to extraordinary children who are facing serious or life-limiting conditions throughout Kent, South East London and East Sussex. We are here to support them and their families at every step – from first diagnosis and for as long as we're needed.

Demelza supports over 2,500 children and their families every year. When we're needed most, Demelza is here. By their side when they feel isolated, helping to celebrate the joy in family life and making precious memories during challenging times.

Our support is as unique as every family, providing creative therapies, short breaks, practical and emotional support for families and siblings, end of life care and post death.

Our specialist nursing and care teams provide expert advice on complex symptoms and medication regimes and are here every day and every night, all year round.

Collaborating with providers

Demelza continued to work closely with partners, including NHS Tertiary Centres, District General Hospitals, local adult hospices and other charitable organisations, including Holding on Letting Go, community nursing and therapy teams, NHS England, ICBs and local authorities, to collaborate and focus support where it would be most beneficial.

Additionally, Demelza worked collaboratively with other agencies nationally, including Hospice UK, Together for Short Lives, Business Development Group, comparable children's hospices, Children's Hospices across London (CHaL), and various networking groups to share best practice and work towards shared objectives.

Participation in national audits

Although there were no national audits or enquires relating to children's palliative care during 2023/24, we continue to receive and review information from Healthcare Quality Improvement Partnership Ltd (HQIP).

Local clinical audits

Demelza has an annual audit plan which is influenced by significant events and changes to practice. Working with the Good Governance Network and CHaL (Children's Hospices across London) we are continuing to benchmark audit activity specific to palliative care. Result dissemination continues through Clinical Governance Committee, team meetings and clinical governance newsletters.

Infection prevention and control

Infection prevention and control procedures have been constantly reviewed and updated in line with guidance.

During 2023/24 there were no clinical outbreaks of illnesses at Demelza.

There were ongoing issues with water safety at our South East London site, specifically with the risk of pseudomonas. This has been very closely monitored and safely managed.

We have a mandatory training programme for all staff which includes infection prevention and control. This is delivered face-to-face for all clinical staff and electronically for all other staff and volunteers every year. During the reporting period we achieved an average of 87% compliance.

Hand hygiene audits were carried out monthly and the annual Infection Prevention and Control (IPC), which covers clinical practice and physical environments across all our sites, achieved consistently high compliance.

MHRA and patient safety alerts

Our Clinical Governance team subscribe to the MHRA and patient safety alerts, keeping an accurate spreadsheet and actioning those affecting the children and families at Demelza.

During 2023/2024 we received 89 alerts, 20 of which were shared with our teams and actioned to maintain the safety of the employees, volunteers, children, and families.

In August 2023 a Prevention of Future Deaths Report and MHRA alert were released. The alert was on medical beds, trolleys, bed rails, bed grab handles and lateral turning devices and the risk of death from entrapment or falls. All cots, beds, cot beds, trolleys and shower trolleys were reviewed to ensure they were safe and compliant with current standards.

External research requests 2023/2024

The nursing team have supported external requests for employee feedback on dissertation subjects including; communicating with families during verification of expected death and safe staffing levels.

We continue to support King's College Hospitals NHS Foundation Trust in recruiting for the Children's Palliative Care Outcome Scale Validation Study C-POS. It is the largest primary data paediatric palliative care study ever.

The project aims to help test a questionnaire developed for children and young people who are unwell and their parent carers. The questionnaire assesses their concerns and is intended to ensure that health professionals ask about and address the things that matter most to children and young people and their families.



What others say about us

We continue to receive strong positive feedback from referrers and commissions across Kent, South East London and East Sussex.



Listening to professionals giving praise comes as no surprise to me as this is the calibre we have become used to from you and the Demelza hospice community team.



It is a credit to you personally and the team that this mother opted for end of life care at home. Your unseen expertise and efficiency in facilitating the transfer from hospital so quickly was remarkable.



When we both visited the mother, it was obvious that you were held in high regard, the family felt they were in safe hands. You made yourself available to the family in the very early hours of the morning and in that calm efficient way that you have.*

Child Death Review Specialist Nurse following a multi-professional review meeting.



Since Demelza staff have been working alongside our acute paediatric oncology team we have been able to discuss and refer patients more readily. It has also given us the opportunity to introduce their service to patients early on in treatment. This inevitably has lessened the patient and family anxiety at end of life, but more importantly it has allowed those patients not at the end of life to access more supportive services than before. Professionally we have been able to share expertise which is invaluable.*

Paediatric Oncology Nurse Specialist referencing our one day a week nursing In Reach support.

*Name/title not provided



Our South East London hospice was inspected by CQC in February 2024. The report and findings have not yet been received.

Finance and sustainability

2023-24 sees Demelza completing the second year of the current five-year strategy. Despite planned in-year deficits, reserves remain strong due to the two large legacies received in 2018 and 2020.

Income continues to grow across the most income streams with an overall growth of £2m on 2022-23 levels. Gains from investments continue to fluctuate, but finished the year strongly.

Income sources at Demelza remain well diversified with the top five income sources (making up 93% of the income) each

contributing a minimum of 12%, reducing risk to the financial sustainability of the strategy. Costs continue to rise, both planned and in response to inflation, and operational break-even isn't forecast until the end of the strategy.

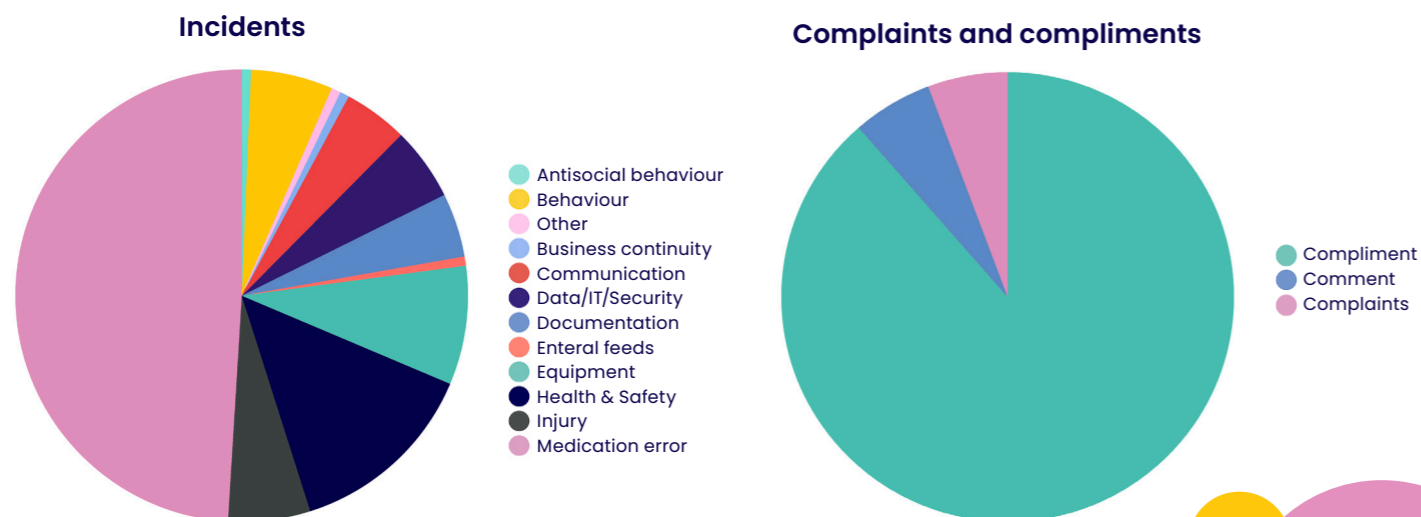
Underspends, mainly due to vacancies resulting from the challenges with recruitment (particularly nurses at the SEL Hospice) have reduced the in-year deficit by £800k.

Demelza has a robust financial plan for the remaining three years of the strategy to maximise income, achieve a break-even position and ensure appropriate resources are in place to fulfil the aims of the strategy, whilst also maintaining an appropriate level of reserves.

2023-24 Income	£	%
Retail	4,650,000	28%
Fundraising	4,000,000	24%
Statutory	2,550,000	15%
Legacies	2,200,000	13%
Lottery	1,900,000	12%
Investments	600,000	4%
Other	600,000	4%
	16,500,000	100%

Service data

Incidents, accidents, complaints and compliments



Activity report 01.04.2023 to 31.03.2024

	East Sussex	Kent	South East London		
Community care hours <small>(Excludes end of life on call shift hours and sensory/garden/cooking.)</small>	6,311	2,416	1,966		
Site visits <small>(Number of family led bookings.)</small>	3	1	Kent Hydropool 267	Kent Cinema 6	Kent Soft Play 21
	<small>(Garden/Sensory/cooking)</small>	<small>(Garden/Sensory/cooking)</small>	<small>(Family Splash & Transition)</small>		

Hospice usage

	Kent	South East London
Residential nights <small>(All reasons for visit. Includes post death clinical care.)</small>	1185	724
Day care bookings <small>*arrival and discharge times for overnight stays may be extended to include a day care session and this would not be reflected in figures above.</small>	187	67

Family Support attendance figures

	Child	Sibling	Family Member
FSD event attendance	328	426	854
Psychotherapeutic Services group attendance	525	58	736
Family Liaison and Transition groups/days	80	63	108
Family Liaison hospital in-reach visits	19		
FSD bookings/sessions <small>(Bookings delivered by Psychotherapeutic Services, Family Liaison, and Transition Support).</small>	1599		

Nursing and Care training compliance %

	Kent	East Sussex	South East London	Average
Fire	92	83	95	90
Safeguarding children	95	91	91	92
Safeguarding adults	96	96	99	97
Moving & handling	84	80	90	85
Data protection	90	84	95	90
Infection control	85	77	100	87
MCA & DOLS	97	96	97	97

(% includes flexi Nursing and Care staff, Family Support, and Leadership).

Best Practice

Duty of Candour

Demelza continue to follow duty of candour processes for all incidents involving children, young people and family members.

EDI (FREDIE – Fairness, Respect, Equality, Diversity, Inclusion, Engagement)

We are continually striving to improve our approach to equality, diversity, and inclusion at Demelza.

The FREDIE and Wellbeing Steering Group will guide and lead Demelza with Diversity, Equality and Inclusion and will support initiatives to ensure that Demelza creates an inclusive and engaged culture. This is to ensure that:

- All people feel welcome and comfortable when receiving care or support from Demelza or when working or volunteering as a member of the Demelza team.
- We have a diverse staff and volunteer workforce that benefits from the innovation and richness that diversity brings.
- We are playing our part in making a fairer society by tackling prejudice and privilege. FREDIE is recognised within the 'Investors in Diversity' as a way of implementing and embedding change and buy-in from employees and volunteers to create a natural environment for an inclusive culture to flourish.

To create an inclusive culture, organisations must build on the solid values of FREDIE.

- **Fairness.** Being reasonable, right and just.
- **Respect.** Having due regard for the feelings and wishes of others.
- **Equality.** Where every person has equal rights and every person has a fair chance.
- **Diversity.** Diverse means different so diversity includes everyone. The concept of diversity encompasses understanding, acceptance and respect.
- **Inclusion.** Where every person feels respected, valued and that they fit in with the organisational culture.
- **Engagement.** Two-way commitment and communication between an organisation and its employees, volunteers and service users.



Safeguarding

Our Safeguarding practice has continued to evolve and improve. One example of this is the Safeguarding Assurance Committee. Attendance remains high at the quarterly meetings. The agenda has developed to include a stronger and more structured 'voice of the child' and an increased focus on adult safeguarding. A trustee chairs the meetings, and three other trustees attended the April meeting.

The mandatory training content has been reviewed and updated to reflect on learning from national serious case reviews, internal cases and experiences and staff feedback. The Level 1 and 2 e-learning programmes for volunteers have been re-designed to make them more accessible in printed and digital form. The volunteer training matrix was also reviewed, and small amendments made to ensure all volunteers are receiving the appropriate level of training.

An external company is fulfilling the Level 3 training requirement every three years, with three of the Safeguarding Leads providing the annual updates and induction session. The same external company also provides the Level 4 and 5 training required for Demelza's safeguarding team. All training meets the requirements of the RCN Intercollegiate document (Safeguarding children and young people: roles and competencies for healthcare staff, 2019).





Family stories

Neo-Natal

Demelza has developed a neonatal pathway that supports local families of babies born extremely prematurely – between 22-24 weeks. This pathway allows us to offer emotional and practical support during this uncertain time, and ongoing support for those that need it.

We spoke to Mo, mum to Teniola, to find out how this support made a difference to her.

“Teni, my beautiful, strong-willed daughter, was born prematurely after an emergency C-section in Tunbridge Wells. She was almost immediately transferred to the Oliver Fisher Baby Care unit in the Medway Maritime Hospital.

It was such a painful time, and I really struggled. I wanted to spend as much time with her as possible, but the bus ride to the hospital took an

hour and a half each way, while a taxi there and back would be £120. It’s just my husband Tito and me, and we couldn’t manage that.

Thankfully, Demelza was there for us. When we were referred, I was nervous – I thought, ‘Teni is premature, but she’s healthy; she doesn’t need a hospice!’ I had no idea the kind of support they could offer.

Their practical support drivers were amazing, providing me with free transport to and from the hospital; nothing was too much trouble. They were so respectful of me as a person, whether I was struggling one day and needed to keep to myself, or having a better day and wanted a chat.

Teni was discharged from the intensive care unit with no health complications; we won’t need Demelza’s support going forward, but we’re so grateful that they were there when we needed them in those first weeks. I don’t know where we’d have been without them.”

Transition

Demelza helps create pathways that support a whole family as their child moves through their teenage years into adulthood.

We spoke to Michelle, who feared her daughter Lily would lose her access to our hydro pool when she became an adult.

“Lily, our 17-year-old, has Sanfilippo syndrome which is a life-limiting illness for which there isn’t a cure; the best way I’ve found to describe it is that it’s similar to dementia. She got to a certain point of development and then, sadly, she started to lose her skills again – her speech and mobility in particular.

Using the hydro pool at Demelza lets Lily relax and actually get some exercise without being in pain. She isn’t bearing any weight, she’s able to take things at her own pace and we can help to move her arms and legs to slowly feel less ‘tight’. She loves it while she’s in there, you can tell how relaxed she is by how dozy she gets, but you also see the benefits in the days after a hydro session; the way she moves more freely and clearly feels happier in herself.



Lily will be 18 next year and won’t be able to access Demelza’s nursing and clinical care anymore – until recently, that included the hydro pool. Every time we would go for a hydro session with Lily I would talk to Paul, one of Demelza’s transition navigators, about how much this worried us.

Paul said he would try and find a way for us to access the Demelza hydro pool after Lily turned 18. He wasn’t sure if it would even be possible, but he wanted to try.

When he eventually told me that he’d managed to secure two sessions a week – not just for Lily, but for any family using Demelza with a child between 18-25 – I just couldn’t believe it. It’s just so amazing knowing I have somewhere I can bring Lily that’s safe and familiar, where she can still get all the benefits of using the hydro pool. I can’t thank Paul and Demelza enough for making this happen for us.”





demelza

extraordinary care for extraordinary children

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