



Quality Account 2025/26



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CEO statement of quality

I am delighted to report Demelza's Quality Account for the year 2025/26. Prepared by our Director of Clinical Services, with input from across the organisation, I can confirm this statement is approved and confirmed as accurate.

In the penultimate year of our current strategy, patient safety, clinical effectiveness and engaging with children, young people and families remain key priorities. We embrace diversity in our culture and values, as we recognise how differences enhance our decision making and help drive our compassionate care, led by learning.

Demelza has implemented a new model of clinical care delivery, Circles of Care, which utilises the most skilled resources when and where they are most needed, while ensuring there are a range of specialist services available for all children, young people and their families. We have learned, and will continue to learn from engagement with children, young people and families to iteratively inform development of our care and support. We have developed proactive communication plans for families, using all mediums to ensure families feel informed, involved and supported.

Collaboration is vital for the hospice sector to ensure all resources are employed to optimum effect and address the needs of the communities we serve. Demelza is actively aligned with hospice partners in the children's and adult sector, NHS partners, Integrated Care Boards and Local Authorities. Through collaboration, data sharing and partnership we work to provide sector-wide solutions for timely and equitable access to services. This is demonstrated by our open and transparent expertise sharing, formal alliances, in reach and honorary contracts, professional collaborations and ensuring we are advocating for the specific needs of children's palliative and end of life care, which is markedly different to those of adults.

Demelza has embraced digital solutions which support our strategic goals. We ensure systems are fit for purpose and share only relevant data safely, improving efficiency and patient

experience. This extends to our interactive, accessible new website for families, how we capture feedback and engagement from all our stakeholders, including partners and donors, how we implement learnings from feedback, how we record internal data and how this informs our decision making.

Capital investment, around half of which came from the government, has future-proofed the infrastructure of Demelza's buildings and vehicles to support our work in the communities we serve, enhancing safety, quality of care, patient experience and long-term sustainability.

I would like to pay tribute to the workforce of skilled and dedicated employees and volunteers across all Demelza services. They embrace lifelong learning and are responsive to change, acting in the best interest of children and families at all times.

In the absence of any fair funding programme for the hospice sector, Demelza supports Hospice UK's four-point plan for fair hospice funding. Any one of the points suggested would be transformational for the children, young people and families that Demelza supports, and for those we have not yet been able to reach.

L Jarrett

Lavinia Jarrett
Chief Executive
Officer





Review of quality performance in 2025/26

What we achieved

Circles of Care

We launched our innovative new care model, Circles of Care, designed to make access to our services more equitable for families with the highest needs.

Our services are now grouped within three Circles of Care, allowing us to offer a broad range of holistic services while our specialist nursing and care professionals provide personalised support to families when they need it the most.

- **Yellow Circle:** family services are offered to all families we support.
- **Blue Circle:** specialist short breaks are offered to children with the highest complex care needs.
- **Pink Circle:** specialist nursing care is provided when children need symptom management or end of life care.

Operating under this new model means we can be more responsive and allow our specialist teams to provide additional support during times of increased need.

Recruitment

Demelza's South East London hospice faced significant recruitment challenges, but a full staffing complement has now been achieved, leading to a complete 24/7 service offer. Despite the staffing challenges during this period, no child who could safely be admitted for end of life care was turned away.

Engagement

Family feedback and engagement

In order to use feedback from children, young people and families to enhance services, our Vantage system (incident, risk and compliance software) was developed to support the collection of family feedback and identifying key themes and trends. Family engagement is now also included in reporting to the Board of Trustees with improved data.

Widgets and sound buttons are now used at family events to support understanding, sensory participation and accessible feedback. Children and young people can show what they enjoyed and what they accessed by using widget-based feedback cards, enabling those who use alternative communication to share their views independently. This allows the engagement team to capture a wider range of voices.

These achievements ensure that children and young people with complex communication needs are not excluded from consultation and participation, strengthening Demelza's ability to reach, hear and act on all voices.



Professional collaboration

We continued to prioritise and develop our collaborative working practices, including:

- Actively engaging as a collaborative partner with many regional children's hospice providers and NHS colleagues to address shared challenges and ensure consistency in service delivery.
- Working collectively toward a shared description of children's hospice services, helping families, referrers and clinicians clearly understand what hospices offer and who can be appropriately referred.
- Supporting the development of a single point of access referral form or centralised referral route, simplifying pathways for families and professionals and reducing duplication across the system.
- Contributing to the creation of streamlined, standardised data groups to improve the quality, comparability and clarity of information shared with external partners, including Integrated Care Boards (ICBs).

These initiatives demonstrate Demelza's commitment to improving efficiency, strengthening sector alignment and ensuring that children and families experience timely, equitable access to hospice care across the region.

Patient safety

Data safety and protection

To increase awareness of data protection and the Caldicott Guardian role, a poster and training video resource was created, with all clinical teams now undertaking this training either in person or via e-learning.

A new policy was developed and implemented to ensure Data Protection Impact Assessments (DPIAs) are completed for all new systems and processes.

Throughout 2025/26, the Clinical Governance Committee provided effective oversight across patient safety, safeguarding, medicines management, quality improvement, workforce assurance and service development.

The committee met quarterly with strong attendance and constructive discussion, supported by improved data quality, clearer reporting and the continued embedding of systems-based learning through the Patient Safety Incident Response Framework (PSIRF). Overall assurance confirms that services remain safe, effective, caring, responsive and well-led, with clear evidence of learning and improvement across all domains.

Clinical effectiveness

Clinical leadership

We recruited a consultant with a specialism in children's palliative care, strengthening Demelza's clinical leadership and medical expertise. This appointment has enabled Demelza to:

- Complete a focused three month period embedded within the Evelina London Palliative Care Team, strengthening partnership working, reviewing current practice and helping to shape a more effective collaborative model for the future.
- Support the design of training opportunities and clinical education resources, enhancing skills development across the nursing workforce.
- Contribute specialist guidance to preparations for the introduction of non medical prescribing (NMP) within the Clinical Nurse Specialist workforce.
- Begin shaping a strategy to become a research active organisation, identifying priority themes where Demelza's reach, data and expertise can improve outcomes for children and families.

Developing our in-reach offer

We have enhanced our hospital in-reach support, with key successes including:

- Setting in place honorary contracts for Demelza nurses across key NHS partners, including Maidstone and Tunbridge Wells NHS Trust, William Harvey Hospital, Queen Elizabeth the Queen Mother Hospital in Kent and The Conquest Hospital in East Sussex.

- Continuing strong collaboration with King's College Hospital and Medway Hospital through the established neonatal pathway, ensuring early identification and seamless support for babies and families.
- Through these partnerships, increasing Demelza's visibility within acute hospital settings, raising awareness of hospice services and improving understanding of referral criteria.
- Streamlining and strengthening referral pathways to allow earlier access to support for children with life-limiting and life-threatening conditions.
- Cross-team working to foster meaningful clinical relationships, supporting consistent communication, shared learning and a more coordinated approach to care across the region.
- The formation of a dedicated in-reach team, with family liaison in-reach practitioners and care colleagues coming together to support greater knowledge-sharing and ensure a more equitable offer across the region, extending our reach to children and families.



Patient experience

Digital accessibility

We launched our new website in autumn 2025, which was redeveloped to enhance accessibility and create a more user-friendly experience. The new website makes it easier for families to access the support and resources they need and for professionals to make timely referrals.

Skills growth

We have developed specialist skills within the care team, positioning Demelza to deliver safer, more efficient and more responsive care while aligning with our broader strategy to build a skilled Clinical Nurse Specialist (CNS) workforce across all sites.

Two nurses have successfully completed their Physical Assessment module, an essential foundation for progressing to Non-Medical Prescribing (NMP) training, while a further two senior nurses have been identified for development, ensuring cross-site consistency in the future CNS role and supporting a sustainable pipeline of advanced practitioners. Expanding the number of nurses progressing toward NMP will strengthen clinical decision-making capacity and enhance medicines management, acknowledged nationally as a high-risk area within hospice care.

A new process for assessing staff pay progression was implemented this year. The process was enhanced to recognise children's hospice-specific knowledge and skills, supporting progression, strengthening recognition of expertise and improving staff retention. Demelza continues to benchmark with NHS Agenda for Change and other children's hospices pay scales for clinical employees.

Access to bereavement suites

We have been working to ensure children and families have maximum access to Demelza's bereavement suites, making full use of our existing resources, including:

- Establishing a new Service Level Agreement (SLA) enabling Ellenor hospice to access Demelza's bereavement suites for children on their caseload, even where the child or family is not otherwise known to Demelza.

- Extending access for young people over 18 who were previously known to Demelza, ensuring continuity of compassionate post-death support for families when a young person dies after transition.

These developments enhance regional capacity, reduce inequalities in access and demonstrate our commitment to collaborative, compassionate, system-wide support for bereaved families.

Development of family support

We have continued to evolve our family support offer, including:

- Increased capacity in our counselling service through engaging student counsellors.
- Expanded access to bereavement support, including a new bereavement café in East Sussex.
- New immersive and inclusive family experiences, including hosting our first sibling residential at Hill Farm (Demelza Kent) for ages five to six.
- Increased access to our bookable spaces for young adults.
- Extending bereavement suite use to include our transition caseload.
- Dedicated teen weekends and all-age sibling activity days.
- Increased choice of personalised memory items for bereaved families.
- The launch of new engagement models, including 'Together Exploring' group sessions and a collaborative Gold Ribbon bereavement café.
- Development of our Butterfly Project with volunteer-led installations at each site, providing a special place for families to remember and honour each child.

We worked with local cultural and community leaders on an innovative arts project during Dying Matters Awareness Week, exploring death and grief through creativity. The project helped us to reach deeper into communities, build lasting connections and raise greater local awareness of our offer.

We partnered with Medway Interfaith Action and Dialogue Society, strengthening our understanding of faith-based practices and diverse approaches to death and bereavement, creating a more inclusive experience for children and families.



Priorities for 2026/27

In the year ahead, we will continue to develop our services to ensure we are providing the highest quality care to the children and families that need us most.

Clinical effectiveness

We will:

- Become research ready by training staff in Good Clinical Practice (GCP) courses, contributing to large scale research studies by registering as a Principle Investigator Pipeline (PIP) site, supporting staff and families to take part in research studies and working towards running qualitative studies at Demelza.
- After specialist short break visits, send discharge letters to keep the child's GP and consultant teams aware of our involvement and any clinically relevant information we can share. This is especially important following the implementation of our new Circles of Care model, reflecting the high acuity of those we are supporting.
- Set up regular structured skills and drills training at each site to ensure clinical skills remain up to date.
- Work with Children's Hospices across London (CHaL) to develop consistent competency documentation and establish the ability to benchmark medication errors, supporting shared learning, comparison of trends and continuous improvement across children's hospice services.
- Develop safeguarding training into a scenario-based approach to improve staff understanding, practical application and learning from real-life situations.
- Refine and evaluate the Oncology Pathway pilot, focusing on early engagement with children and families following a cancer diagnosis. The pathway aims to reduce barriers to understanding hospice services and provide tailored support based on level of need, in line with Circles of Care. In partnership with NHS oncology teams, we will work towards establishing automatic introduction to hospice support alongside standard multidisciplinary referrals.

Patient experience

We will:

- Support completion of a Non-Medical Prescribing course and embed this capability within a Clinical Nurse Specialist (CNS) role, strengthening advanced practice and medicines safety.
- Enhance how we record and measure outcomes for children and their families. This will enable us to better understand the impact of our care, support continuous improvement and demonstrate the difference Demelza makes in a meaningful and consistent way.
- Support two nurse associates to complete their nursing degree programmes and progress into preceptorship programmes, while one nurse associate will continue their degree training.
- Work with hospitals and child development centres to strengthen bonds and multi-disciplinary working around the child.
- Strengthen our engagement with professionals across health, education and social care sectors to ensure timely and appropriate referrals into Demelza. While this work is already underway, we will build on existing relationships, improve awareness of our offer and streamline referral pathways to make access as straightforward as possible.
- Develop approaches to ensure effective annual reviews and regular wellbeing check-ins for families, promoting proactive, consistent and meaningful contact rather than reactive support alone.

Patient safety

We will:

- Utilise the Vantage database more effectively to support integrated governance by capturing Care Quality Commission (CQC) evidence, contract oversight, risk assessments and a centralised audit database, improving visibility, assurance and reporting.
- Continue our commitment to patient safety, following the Patient Safety Incident Response Framework (PSIRF), a national approach

that supports a culture of fair responsibility, recognising the role of systems, processes and environments while supporting staff to learn and improve the care we provide.

- Further develop a Clinical Governance (CG) hub which will provide a central, accessible source of policies, guidance and learning resources to support safe practice. It will promote continuous professional development by enabling role-relevant, self-directed learning and support the organisation's aim to be a learning organisation, improving care for children and families.

Engagement

We will:

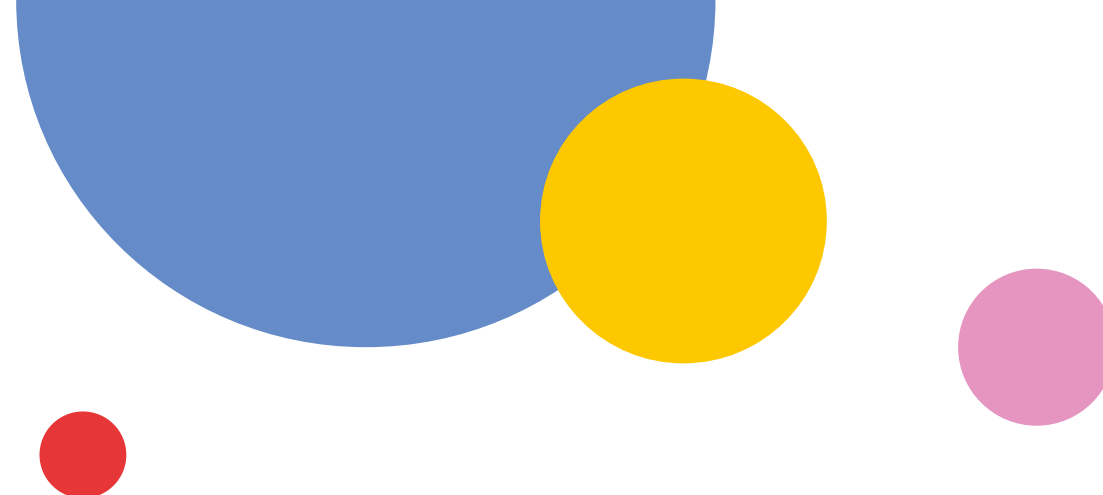
- Explore digital solutions to gather feedback from families more effectively, making it easier for them to share their experiences and views in real time. This will help us remain responsive and shape services around what matters most to those we support.
- Develop a structured communications plan for families to ensure timely, clear and compassionate information sharing at every stage of their journey with Demelza. This will include digital updates, printed materials

and direct conversations to suit different preferences and needs. Our approach will focus on proactive communication, ensuring families feel informed, involved and supported.

- Further our work alongside health and social care partners to support delivery of the CYP PEoLC Service Specification, Ambitions Framework and the priorities of the NHS 10-Year Plan, including contributing to the developing Neighbourhoods model of care and the Modern Service Framework. This will enable improved system integration, easier access for partner organisations and better outcomes for children and families through improved access to and sharing of specialist expertise, cohort insight and data, in line with GDPR requirements.

Our commitment to FREDIE (Fairness, Respect, Equality, Diversity, Inclusion and Engagement) will underpin all this work, ensuring that our services are inclusive, equitable and responsive to the diverse needs of the communities we serve.





The Board of Trustees' commitment to quality

The Board of Trustees is proud to present Demelza's Quality Account for 2025/2026.

This year has been one of continued commitment to exceptional care, strengthened governance and strategic development across all areas of our clinical services. We have seen strong performance, meaningful innovation and an organisation-wide dedication to delivering safe, effective, equitable and compassionate care to every child, young person and family who needs us.

Quality, performance and service development

Over the past year, our clinical teams have undertaken detailed and thoughtful service reviews, ensuring that our care delivery remains both evidence-based and responsive to the increasingly complex needs of children with serious and life-limiting conditions.

This work has culminated in the development and adoption of our Circles of Care model, an equitable approach that places each family at the centre of coordinated, multidisciplinary support. The Board fully endorses this model and recognises the outstanding work undertaken across all sites to embed it into practice.

This year also marks a significant milestone in strengthening our clinical leadership. We successfully recruited a Consultant Paediatrician, bringing advanced medical expertise to complement our long-established nurse-led environment. This appointment positions us strongly ahead of next year's creation of Clinical Nurse Specialist (CNS) posts at every Demelza site, further enhancing specialist capability, professional development pathways and consistency in care delivery.

Safeguarding and a whole Demelza approach

Safeguarding continues to be a fundamental and non-negotiable priority for the organisation. We have maintained a rigorous, organisation-wide approach supported by robust training, highly engaged clinical teams and transparent escalation processes. The Board is confident that safeguarding governance remains strong, reflective of a culture where safety is deeply embedded and where concerns are raised openly, promptly and collaboratively.

Governance and board effectiveness

This year, we welcomed an external and independent board effectiveness review. The review identified Demelza as having a highly effective Board with clear governance

structures, strong strategic oversight and a well-established focus on quality and safety. Importantly, the review also provided constructive recommendations to move us from good to great. The Board, working closely with the senior leadership team, has embraced these recommendations, and we are already seeing strengthened committees, improved clarity of reporting lines and enhanced assurance processes.

In line with the review, the Medicines Management and Safeguarding Assurance Committees will be transitioning to advisory groups in the coming year. This change will ensure that all clinical trustees are directly and consistently engaged in scrutinising these critical areas through strengthened reporting to the Clinical Governance Committee. This development not only streamlines governance but ensures appropriate expertise is applied with the right level of oversight.

Regulation, transparency and culture

We were delighted to receive an Outstanding rating from the Care Quality Commission (CQC) at our Kent hospice. This reflects the commitment, skill and compassion of our teams and the culture of learning and openness that permeates the organisation. We look forward to

welcoming the CQC to our East Sussex and South East London sites and we remain fully committed to transparency and continuous improvement across all areas of practice.

The Board continues to be impressed by the quality of clinical reporting into the Clinical Governance, Safeguarding Assurance and Medicines Management Committees. These submissions reflect a mature culture of honesty, professional curiosity and shared responsibility for safe care. The insight and assurance we receive from these processes remain vital in guiding our decisions and ensuring that quality and safety remain at the forefront of our work. The Board of Trustees extends its sincere gratitude to all Demelza staff, volunteers and supporters. Their unwavering commitment ensures children and families continue to receive exceptional care characterised by compassion, dignity and expertise.

We look forward to building on this year's achievements and continuing our journey of excellence in 2026 and beyond.



Statements of assurance

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 support.

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 community nursing and therapy teams, NHS England, ICBs, local authorities and Holding On Letting Go, to collaborate and focus support where it is most beneficial.

Additionally, Demelza worked collaboratively with other agencies nationally, including Hospice UK, Together for Short Lives, the Children's Hospices Business Development Group, Children's Hospices across London (CHaL),

and various networking groups to share best practice and work towards shared objectives. Demelza works closely with our health and social care partners, both at a strategic level and operationally, to provide joined-up services for babies, children, young people and their families, and to influence service planning.

Participation in national audits

There were no national audits concerning children's palliative care during 2025/26. However, we continue to receive and review information from the Healthcare Quality Improvement Partnership Ltd (HQIP). Following the Fuller Inquiry, Demelza has implemented stricter access to bereavement suites and ensured all recommendations from the report are followed.

Local clinical audits

Demelza's annual audit plan is shaped by significant events and practice changes. Collaborating with the Good Governance Network and CHaL, we continue to benchmark palliative care audit activities. Results are disseminated through the 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 2025/26, there was one potential clinical outbreak of illness at Demelza. Public Health England was consulted and reassured by our interventions. No medical intervention was required for the children. No further cases were identified.

During 2025/26 there were ongoing water hygiene issues at the South East London site. Our processes ensured that these issues were safely managed at all times. Following targeted modifications to the water and circulation systems, water quality levels are now within normal safe limits. Routine water hygiene testing continues across all three sites to ensure ongoing compliance and safety.

We have a mandatory training programme for all staff, which includes infection prevention and control. This training 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 90% compliance.

Hand hygiene audits were carried out monthly, and the annual Infection Prevention and Control (IPC) audit, 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 Medicines and Healthcare products Regulatory Agency (MHRA) and patient safety alerts, keeping an accurate spreadsheet and actioning those affecting the children and families at Demelza. During 2025/2026 we received 99 alerts, 36 of which were shared with our teams and actioned to maintain the safety of the employees, volunteers, children and families.

External research requests 2025/26

During 2025/26, Demelza staff and families participated in the following external research projects:

- **CHES:** Led by King's College London, this study aims to enable delivery of high-quality child-centred care through assessment of complexity and outcomes by health, social care and education providers care for children and young people with life-limiting conditions.
- **EMBRACE:** Led by King's College London, this national study focuses on the experiences and support needs of parents caring for children with life-limiting and life-threatening conditions, with a particular emphasis on ethnic minority parent-carers, who are currently underrepresented in research.



What others say about us

"Demelza staff are highly approachable and consistently receive excellent feedback from families, many of whom describe them as an essential part of their care team. Families particularly value the sense of community support and the assistance provided when attending appointments, especially during periods when large amounts of information can feel overwhelming.

"We are able to commission Demelza to deliver daytime support in the home, as well as overnight care within the hospice setting. From our perspective, we would welcome increased capacity to commission additional support, as Demelza offers specialist skills and expertise that other providers do not, particularly through their advanced training in palliative care"

Angela Little, WellChild Clinical Manager, NHS Surrey and Sussex

"This year the Demelza team have always tried to accommodate requests for transfers and community support for complex or end of life patients. They have attended our MDT regularly and the two-way communication is really enhancing patient care."

Ella Aidoo, Paediatric Palliative Care Consultant, Evelina Hospital

"As a unit we feel extremely lucky to have Pete visiting regularly from Demelza to use music therapy to support both the emotional and physiological development of the babies he supports, but also in helping to foster parent-child attachments. His presence is a positive experience for the families as a great introduction to the wider services of Demelza through their family support, showing a lighter side of the service. Pete provides a professional and individualised personal service to each baby he sees. Music therapy can be a good outlet for parents, encouraging engagement with their babies outside of Pete's visits which fosters stronger parent-child bonds. Staff have seen how music therapy decreases stress and crying from discomfort and overstimulation, improves babies' heart and breathing rates and oxygen saturations, as well as increasing the ability to suck and feed, promoting healthy weight gain. It is an extremely useful developmental activity that the unit and families really appreciate."

Neonatal Community and Outreach Lead Nurse, Medway NHS Trust.



Finance and sustainability

The financial plan for the fourth year of the current five-year strategy was a deficit budget. The in-year results were more favourable than originally planned with an underachievement of income being offset by an underspend on expenditure.

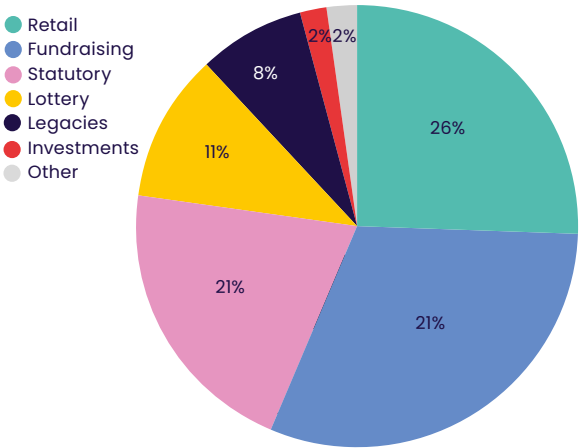
Despite it being a challenging year, fundraising finished ahead of plan. We have seen a decline in retail profitability which is in line with reports from across the charity retail sector. Legacy income was low in the year, however the pipeline remains strong. Lottery income finished behind

plan due to slower than planned recruitment, however we did experience some year-on-year growth.

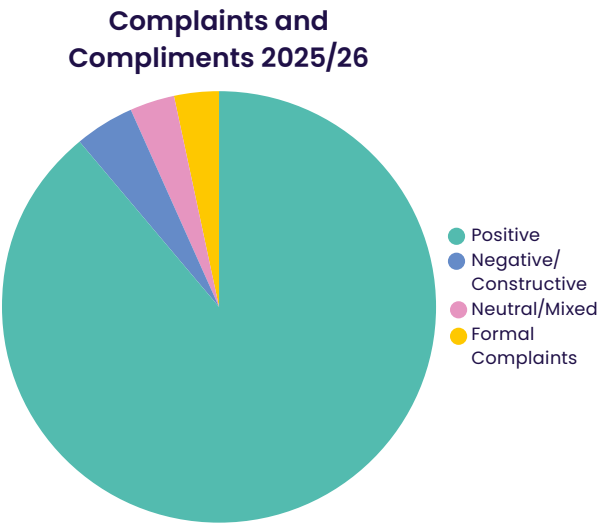
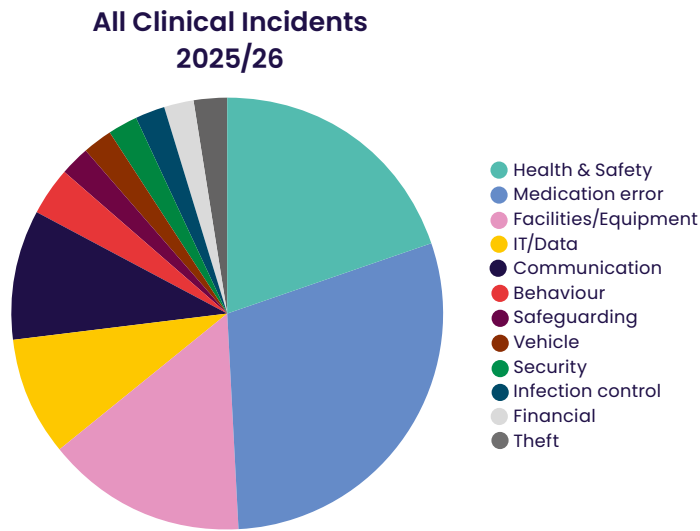
The diversified nature of the income streams reduces risk to Demelza.

Expenditure was below plan, which contributed to the in-year position which was more favourable than planned. It should be noted that this was primarily due to staffing vacancies. Every year Demelza develops a three-year financial plan to ensure the financial stability for the organisation whilst ensuring that reserves remain within the defined range.

Income 2025-26	%	£
Retail	26%	£4,346,000
Fundraising	31%	£5,167,000
Statutory	21%	£3,493,000
Lottery	11%	£1,912,000
Legacies	8%	£1,300,000
Investments	2%	£280,000
Other	2%	£320,000
100%		£16,818,000



Incidents, accidents, complaints and compliments



Activity report

Community care hours (excludes end of life on call)	East Sussex 5757.02	Kent 2559.93	South East London 2473.59	
Kent site visits (Number of family led bookings at Kent)	Kent Sensory room 74 bookings	Kent Hydro Pool 238 bookings (family splash & transition family splash)	Kent Cinema 43 bookings	Kent Soft Play 44 bookings

Hospice usage

Residential nights Departure after 01.04.2024 and arrival before 01.04.2025	Kent 1482	South East London 497
Day Care bookings	171	296

Family Support attendance figures

	Child	Family Members including siblings
Family events FE	291	861
Creative & Bereavement events	637	1294
Family Liaison and Transition events	100	312
Hospital in-reach visit events	51 unique visits/events	
FSD bookings/sessions	2723 bookings	

Nursing and Care training compliance % March 2026

	Kent	South East London*	East Sussex	Average
Fire	95.00%	95.00%	100.00%	93.75%
Safeguarding children (L3, 3 yearly)	96.00%	-	100.00%	98.67%
Safeguarding children (L3, 1 yearly)	87.00%	97.00%	100.00%	96.00%
Safeguarding adults	100.00%	97.00%	100.00%	99.00%
Moving & handling	100.00%	90.00%	100.00%	92.75%
Data protection GDPR	93.00%	97.00%	93.00%	93.25%
Infection control	93.00%	100.00%	100.00%	94.75%
MCA & DOLS	99.00%	100.00%	100.00%	96.75%
BLS	91.00%	95.00%	100.00%	96.50%

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 guide and lead Demelza with Diversity, Equality and Inclusion and 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' accreditation 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

There have been no serious safeguarding incidents in the 2025/26 period.

Our safeguarding practice has continued to evolve and improve during this time. We've reviewed and updated our adult safeguarding e-learning and our Level 2 training now includes a wider adult safeguarding element, reflecting the nature of the work of those attending. We have improved our system of recording non-clinical concerns to allow for more effective audit and thematic reviews.

The mandatory training content is reviewed and updated annually to reflect on learning from national serious case reviews, internal

cases, experiences and staff evaluations. An external company fulfils the Level 3, 4 and 5 training requirements every three years, with the Named Nurse for Safeguarding providing the Level 3 annual updates and the Level 2 training updates every three years. All training meets the requirements of the RCN Intercollegiate document (Safeguarding children and young people: roles and competencies for healthcare staff, 2019). The Safeguarding Assurance Advisory Group (previously the Safeguarding Assurance Committee) meeting is held quarterly and chaired by the Safeguarding Trustee and continues to have representation across teams.





Family stories

Zoya's story

"Zoya was born at 23 weeks old. The whole first year of her life was spent in hospital.

"When she was born, she was intubated and ventilated, and for a long time she couldn't be taken off the oxygen support. At one point, her lungs collapsed and the doctors told me she wasn't going to make it. But she was still trying, so I wasn't going to give up on her. I looked at this child and I saw someone so full of life, smiling, playing with toys. I wasn't calling it quits.

"When we finally came out of hospital, my husband had returned to work and I was so lonely – I felt stuck all the time. I couldn't just take Zoya to a children's centre and meet other mums. But going to the Little Dots sessions at Demelza was the best thing ever. I met lovely parents there – I think I learned more from the other parents than I have from doctors and nurses!

"It took me two years to build up the courage to let Zoya go for day care at Demelza, but it's amazing. As soon as you arrive they greet you, they greet your child, they don't care that she's got tubes stuck to her neck and her belly, it's just normal. Every single person has a big smile on their face and they're not just thinking about Zoya, they're thinking about me as well. They'll just give you the warmest hug and tell you everything's OK.

"Demelza has helped us with so much. Sometimes as a mum you wonder what would happen if I'm not there – who's going to look after her the way I can? Now, there isn't anywhere else I would leave Zoya."

Tahira, Zoya's mum

Joshua's story

"In April 2022, out of the blue, cancer broke into our lives. Joshua, who was 10 at the time, was diagnosed with a rare form of bone and soft tissue cancer called Ewing Sarcoma. We were thrown into an alien world of scans, tests, biopsies and medication.

"After 10 months of frontline treatment, against all the odds, in January 2023 we got the news that he had no evidence of disease. We embraced life and made up for lost time. We became experts in living for the now – living life with no regrets. Heartbreakingly, just six months later Joshua's cancer returned aggressively, and despite every effort, we lost him just four days before his 13th birthday.

"In the last week of Joshua's life, we met some of their wonderful staff at our home where we did some memory making with Joshua. We did handprints together and now have an amazing cast of our hands holding his – it is such a special

and personal keepsake and means we still get to touch his hand, even though he's not here anymore.

"After we lost Joshua, we were given the chance to make use of the bereavement suite – a place of calm, care and kindness, where we and our family and friends could say goodbye in our own time, surrounded and supported by people who truly understood.

"We were able to spend a few extra days with him, which gave us time to be with our thoughts, with Joshua and without having to make any decisions. We were wrapped up in care by the team. Being there also meant we got to spend time with him on his birthday, which meant the world to us. The bereavement suite is a place that shouldn't be needed, but we are incredibly grateful that it was there for us as a family at the worst time."

Donna and Duncan, Joshua's parents

