



demelza

Quality Account 2024/25

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CEO statement of quality

I am very happy to report Demelza's Quality Account for the year 2024/25. This report was prepared by our Director of Clinical Services with input and support from across the organisation and has been read and approved as accurate by me and by our Board of Trustees.

Midway through our five-year strategy, we're adapting our services to meet the growing number of unique children referred to us for end of life care and, equally importantly, their families.

In practical terms, that means the last 12 months have seen us extend and tailor our offer of services considerably. As an example, at each of our three locations, in Kent, East Sussex and South East London, our Family Support Teams are running a programme of events easily accessible for people in their local communities.

To complement this, our psychotherapeutic teams are providing bespoke and group support in a range of settings that work for children and their families.

Our multi-talented and willing workforce of volunteers also enable us to relieve families of some of the practical, everyday tasks, like garden maintenance or transport to appointments, that can be difficult to fulfil.

Just as the complexity of children and young people's needs has increased, so has the number who are living longer – often into adulthood. To meet this need we have further grown the size of our transition service, providing care and support for young people aged 14-25.

In pursuit of our commitment to ensure equitable provision, we ensure that families who are not resident in our hospice buildings can have independent access to many of the bespoke physical facilities our donors have so generously provided, offering activities and experiences that simply would not be possible in a public environment.

Fulfilment of this goal also sees us take our care and support out of the hospice and into various settings including people's homes, local

and tertiary hospitals, as well as our bespoke buildings, promoting choice and accessibility and ensuring healthcare professionals and families are aware of our services and the support we provide.

Sadly, there is no fair and sustainable source of funding, despite Demelza relieving pressures on primary care, paediatric wards, local authority social services, education and the children and families themselves. In collaboration with professional networks, we will continue to raise awareness and influence policy making and commissioning to ensure high quality end of life care is available for children and families in their place of choice.

Next year we will implement an adjustment to services to ensure they are allocated as equitably as possible to those most in need. Following a review of our service delivery model, this will ensure all families on our caseload have access to a range services whilst protecting core and specialist services for those most in need.

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 complements NHS services.

L Jarrett

Lavinia Jarrett
Chief Executive
Officer





Review of quality performance in 2024/25

2.1 What we achieved

Service delivery

The year 2024-25 has seen the development of a whole new service delivery model: Circles of Care. From August 2025, Demelza's services will be grouped in three Circles of Care – Family Services, Specialist Short Breaks, and Specialist Nursing Care. This new model is designed to ensure we offer a broad range of holistic services while allowing our specialist staff to provide personalised additional support to those families with the greatest need, when and where they need it most.

Workforce

Over the last 12 months we've continued to build on our firm foundations to create an inclusive workforce, recognised with the award of a Silver Award from Investors in Diversity. We have further developed and embedded FREDIE at Demelza and are in the process of launching internal FREDIE delivery groups to provide a focus on key areas within the programme, as well as wellbeing.

2.2 Engagement

With families

Increasing understanding of what we do is fundamental to our purpose, and in 2024/25 we've engaged in a number of ways to communicate our services and mission. We shared our good practice in engaging with services users at the Hospice UK conference in November 2024.

We established a new family communications focus group to help shape the services we deliver, the way in which we describe them, as well as the impact of any changes we make to service delivery.

The group also supported the organisation's understanding of terminology from the perspective of parents and carers and participated in the development of Demelza's new website to enhance their user journey. In response to requests for family information/open days, we collaborated with Families Voice, our parent/carers advisory group, on the development and delivery of our first Discovery Day.

The day brought to life Demelza's guide to services, providing visitors with information stands from internal and external providers, as well as workshops in popular topics like moving and handling, and travel. There was also a wellbeing hub, including a social café, which served to promote our deep commitment to enabling peer support.

With the media, politicians and fellow health organisations

Throughout 2024/25 we maintained our close focus on lobbying the 48 MPs who represent the constituencies we serve, ensuring they are acutely aware of the services we provide and their responsibility to increase awareness and support more widely.

Demelza has continued to play an active role with Integrated Care Board networks overseeing, planning and delivering palliative and end of life care in South East London, Kent and Medway, and East Sussex.

- In South East London Demelza established and now chairs the Children and Young People Palliative and End of Life Care Clinical Network Subgroup – dedicated to providing coordinated clinical leadership and the development of palliative and end of life care for children and young people in the area.
- Chaired the Kent and Medway Children and Young People Clinical and Strategic Managed Clinical Networks, and supported service mapping and future planning of services. Participated in the Ageing Well (All Age) Group to raise awareness of the needs of children and young people requiring palliative and end of life care.
- Participated in the Palliative and End of Life Care Oversight Group for Sussex and the Sussex Children and Young People Palliative and End of Life Care Stakeholder Group. As part of this, we supported completion of the Sussex ICB Palliative and End of Life Care Maturity Matrix for children and young people. This supports identification of good practice, areas for development, and development of prioritised plans for improvement in line with these priorities. The outcomes will inform a refresh of the current Sussex PEOLC Strategic Action Plan

With colleagues

We launched our Freedom to Speak Up platform in June 2024, which provides colleagues with an opportunity to raise their concerns or feedback anonymously, through an external guardian. In April 2025, we were pleased to launch a

new employee engagement platform, which provides managers and leadership with real time insights into how teams are feeling, against nine different categories.

Regular MyVoice Café sessions continue to ensure colleagues have the opportunity to provide feedback to the Senior Leadership Team.

2.3 Patient safety 2024/25

Demelza's ongoing commitment to the highest standards of patient safety is driven by the desire to provide the best possible outcomes for patients and their families. Over the course of the last year, we've taken a number of steps to increase our patient safety yet further. These include:

- Achieving approval of our Patient Safety Incident Response Framework (PSIRF) Plan and Policy from Kent and Medway Integrated Care Board.
- Increasing the status of our Medicines Assurance Meeting to a formal sub-Committee that meets quarterly, is chaired by a Pharmacist Trustee, includes representation from clinical teams at all sites and feeds into Clinical Governance Committee meetings. This has strengthened our ability to scrutinise processes and monitor performance. This leads directly to new and enhanced medicines' management and safety.
- Further enhancing our risk management policy and procedure, with clinical and non-clinical teams, including the introduction of recovery actions should a risk be realised.
- Developing a Strategic Risk Register with Board oversight, for business-critical risks and issues affecting Demelza's ability to operate.
- Reconfiguring services at our South East London hospice to focus on core end of life care and symptom management during a period of challenging nurse recruitment. This temporary measure has ensured we've met every referral for a core service where appropriate.

- Providing two Nursing Associates and one Health Care Assistant (HCA) with the opportunity to commence Nurse Degree Apprenticeships, giving Demelza a pipeline of suitably trained and committed nurses.
- Supporting two HCAs to complete their Nurse Associate training.

2.4 Clinical effectiveness

Improved data management, enhanced partnership working, the introduction of new therapeutic posts, and service audits have all combined to increase our clinical effectiveness. Some examples include:

- Playing a pivotal role in leading improvements to the Care Database, the care management software system for children and young people with life-limiting illness, thereby ensuring that we can capture the data needed to monitor, report and enhance our services.
- Using clinical data reporting to ensure service developments are in line with demand and capacity.
- Working closely with alliances and partners across the sector, including as a member of Children's Hospices across London and the South of England Collaborative Paediatric Palliative Care Education Networks.
- Increasing our support for those in transition from child to adult. As a specific example, we've extended use of some of our bookable spaces to young adults and their families, including the hydro pool and sensory room. We also now run monthly group hydro sessions for this group and offer swim sessions with peers at weekends.
- Providing a direct link between the hospice and neonatal and paediatric wards at Kings College Hospital.
- Introducing regular auditing of creative therapies, counselling and complementary therapies.
- Appointing a new complementary therapist, offering reflexology (with a specialism in oncology) and Indian head massage across all sites.
- Commencing weekly neonatal in-reach music therapy for Demelza babies and children in the Oliver Fischer Neonatal ward and paediatric wards at Medway Maritime Hospital.



2.5 Patient experience

When we talk about 'patient experience' at Demelza we mean the whole family and, in some cases, we mean providing our support to extended family members too. We also take seriously and listen carefully to what our service users have to say about the care and support we provide them. During 2024/25 we've doubled down on these commitments.

Here are some examples of ways in which we've done this:

- Through the What Matters to Me project Demelza's transition team has engaged directly with young people who have severe or profound learning difficulties to gather their experiences, preferences and views to help shape support services and to influence national policy.
- New initiatives like Facebook Live sessions connect families with specialists to enhance awareness of services.
- Our seasonal calendar of events delivers inclusive, family-focused occasions.
- We provide sibling-specific support in the form of residential stays, with creative play, pool parties, and peer connection, and regular bespoke support groups to address their unique emotional needs.
- Through Practical Support Services we provided essential help with transport, gardening, DIY, and cleaning, with an increase in transport requests to hospitals, day care and Demelza events. Volunteer driver recruitment and faster inductions have boosted support capacity and response times.
- We also offer dedicated support groups for grandparents, dads and male carers, as well as for families new to Demelza services.
- All of these groups create a welcoming space for individuals to share experiences, build meaningful connections and feel supported as they navigate their unique journey.
- Thanks to the generosity of our supporters, we're able to provide memorable moments for families through gifted experiences like immersive Santa visits.

- Vantage developments, including feedback. We now capture family feedback directly onto the Vantage system, enhancing data security. Additionally, this enables us to analyse this data, identify trends, make action plans and supply feedback to contributors.

Bereavement support developments

Demelza has significantly extended its support to people who have experienced a bereavement. We've provided bereavement support to 20% more people in the year to April 2025.

Among the ways we've achieved this has been the successful establishment of bereavement cafés now operating in all our locations, as well as a virtual evening café. Over the last year attendees have developed their own peer groups, and they are sharing ideas for future service development. We've also seen increased attendance at bereavement events.

Additionally, we've hosted our Together Exploring: Grief therapeutic groups at our Kent and South East London sites, and increased our collaboration with external bereavement networks, including other children's hospice teams and regional bereavement networks. To broaden engagement yet further, we hosted a professionals' exploration day for funeral directors and provided bereavement training to corporate partners.

June 2025 will see the launch of a café for parents who have experienced the loss of a child to cancer, in partnership with Young Lives vs Cancer and The Royal Marsden.



Priorities for improvement in 2025/26

3.1 Improvement priorities

Effective outcome measures, clear communication and effective stakeholder engagement sit at the heart of Demelza's priorities for improvement.

Here are some examples of our improvement plans for the year ahead:

- We will ensure we have meaningful performance indicators in place to measure success when our new-look service provision, Circles of Care, goes live in August 2025.
- We will build a clear communication plan to help all families understand the breadth of our services and streamline their access to them.
- We will engage more with, and create new materials for, healthcare professionals to enable them to refer patients appropriately and efficiently.
- We will create new communication tools designed for children and young people to better understand Demelza's services.
- We will explore how best we can record and monitor outcomes for children and their families to ensure our services are effective and meaningful.
- We will continue to use feedback from children, young people and families to adapt and enhance our family services, providing gaming sessions, bereavement cafes and online virtual therapy groups.

3.2 Patient safety

- We will have a clear statement on our website outlining our commitment to patient safety and provide links to our Patient Safety Incident Response Plan and Patient Safety Incident Response Policy.
- We will increase awareness of the importance

of the protection of patient data and provide training and posters on the role of the Caldicott Guardian.

- We will ensure data privacy impact assessments are completed for all new systems and processes where data and transfer of data is completed.

3.3 Clinical effectiveness

- We will endeavour to secure access to South East London Care records, having already done so with Kent and Medway Shared Care Records. That access has resulted in improved care.
- We will advertise for a consultant with a special interest in children's palliative care to complement our multi-disciplinary team and further our ability to deliver extraordinary, safe and effective care to more children.
- We will scope the appropriateness of enhancing our hospital in-reach work, to further our support for non-specialist colleagues with children's palliative and end of life care, as well as to raise awareness and accelerate referrals.
- We will strengthen the integration between nursing and care and family support teams to ensure a holistic approach to care planning.

3.4 Patient experience

- We will build on the roll out of Circles of Care and create a clear and obvious 'contact me' button on the website and our Facebook page to ensure families can reach out to us whenever they need and we will take responsibility for following up with them. This is in response to feedback from families and recognises that at times of increased stress, families may find it hard to reach out.
- We will launch our newly enhanced website in autumn 2025 to improve user experience

by ensuring content is accessible, friendly, engaging and easy to navigate. These changes will raise awareness of Demelza and support engagement with families, prospective families and healthcare professionals.

- We will grow a hub of resources that are child friendly, helping children to understand what Demelza is and what they can expect from us.
- We will include more children and young people in our service user engagement, proactively seeking their views and involvement in shaping services.

- We will strengthen our nursing teams by creating Clinical Nurse Specialist roles at each site, thereby ensuring we have the skills and experience to complement and support our colleagues across the sector in providing safe, effective and timely services to children and families in their setting of choice.





The Board of Trustees' commitment to quality

The Board of Trustees maintains active oversight and scrutiny to ensure that Demelza delivers the highest quality and safest services in alignment with the Statement of Purpose.

The governance structure remains under review and has been strengthened with the recruitment of additional Board members, including two paediatricians and a second pharmacist to join established nursing and allied health professionals on the Board. These appointments underscore the importance of clinical scrutiny and ensure that, as Trustee tenures conclude, we retain essential expertise.

Additionally, we have convened a sub-committee on Medicines Assurance, chaired by a Pharmacist Trustee and reporting to the Clinical Governance Committee. This recognises this as a high-risk area for clinical services, allows complete review of all medication

incidents, ensures system benefit with external reporting, and provides the maximum opportunity to learn and improve.

Trustees are pleased to report that there is an external Board Effectiveness review planned for 2025, recognising the maturity of the Board structure and the opportunity to formally review the current structure and reporting framework.

The Board has remained well-informed about the work undertaken to review the clinical service delivery model. This collaborative, data-driven, and child- and family-informed project demonstrates Demelza's ongoing work towards strategic objectives: 1) to be effective, and 2) to be responsive. Transitioning from an equal access model to an equitable access model ensures responsiveness to need, capacity to meet rising demand, and a transparent and sustainable model fit for the future. The Clinical Services team are closely monitoring the effect of this change on Family Support and Therapeutic services and keeping the Board fully

informed. The team's efforts to communicate the new Circles of Care ahead of the August 2025 launch, assured Trustees that children and families remain central to all service developments.

Safeguarding has appropriately remained high on the agenda, with the Safeguarding Assurance Committee continuing to report to the Clinical Governance Committee and subsequently the Board of Trustees. Trustees are pleased that the Safeguarding team has grown and an Adult Safeguarding Lead identified and trained. This recognises the 'everyone's business' aspect of safeguarding and our commitment to colleagues, volunteers, service users, and their families alike.

Reflecting the national trend, nurse recruitment at the South East London hospice has been particularly challenging in 2024/25. While a significant recruitment drive is underway, the team temporarily realigned service delivery to ensure that the most unwell children, or those

requiring end of life care, have their needs met promptly. The Board is pleased to report that no end of life care referrals have been declined due to staffing issues at any site.

The Board of Trustees continues to advocate the development of an inclusive culture within the organisation, recently recognised by the National Centre for Diversity as Demelza was granted its Investors in Diversity Silver Award.

At Board level, recruitment has also improved the diversity of the Board of Trustees such that it has become more reflective of the communities served by the charity. Demelza maintains a Trustee appointed with specific responsibility for EDI.

The Board remains confident in the high-quality, safe, and cost-effective care and support provided to children and families facing serious and life-limiting conditions across our geographical areas.



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 is 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.

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 2024/25. 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 2024/25, 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.

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 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 MHRA and patient safety alerts, keeping an accurate spreadsheet and actioning those affecting the children and families at Demelza. During 2024/2025 we received 96 alerts, 32 of which were shared with our teams and actioned to maintain the safety of the employees, volunteers, children, and families.

External research requests 2024/25

Demelza supported King's College Hospitals NHS Foundation Trust to complete recruitment onto the Children's Palliative care Outcome Scale Validation Study C-POS.

Demelza's Creative Therapies Lead contributed a chapter titled: **The Power of Connection: Family-Centred Virtual Music Therapy Groups** to a book celebrating music therapy in children's palliative care.



What others say about us

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

"Demelza has shown a clear and consistent commitment to the shared goals of the Managed Clinical Network. Their leadership and collaborative approach have been key in moving forward important areas of work. As co-chair, they played a vital role in helping to shape a joined-up, integrated approach, ensuring that progress continued across the many organisations involved in the network. Their proactive involvement and support have been vital to the co-production of key policies and guidelines, helping to turn shared ideas into practical outcomes."

**Teresa Boffa, Project Manager – Acute & Community Paediatrics
NHS Kent and Medway.**

"The Challenging Behaviour Foundation has been leading on a project called What Matters to Me, seeking the experiences, preferences and views of young people with severe or profound and multiple learning disabilities through direct engagement, to influence policy and shape support and services.

"We have been really lucky to have had the opportunity to partner with Demelza on this and have been really grateful for the support from the transition team in making it such a success not only for the CBF but also more importantly for the young people and families who participated. It is clear how valued the team are to the families they support and what a fantastic relationship they have been able to build up with them. This has provided a platform to empower families to raise awareness of the importance of engaging with people with severe/PMLD. This has only happened because of the partnership with Demelza and the transition team."

Taylor Anderson, Project Officer – Engaging Young People / Forward Together



Finance and sustainability

The financial plan for year three of the current five-year strategy was a planned deficit budget, as Demelza continues to implement the five-year strategy drawing from the strong levels of reserves. The in-year results were more favourable than originally planned with income overachieving and expenditure being underspent.

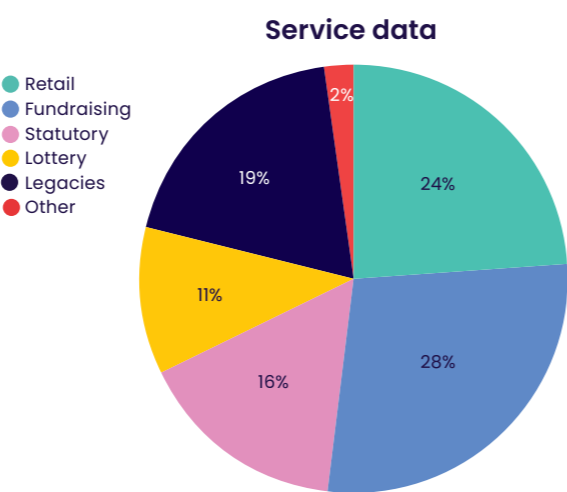
Another strong year for fundraising offset lower than budgeted profits in retail. Legacy income, both received in-year and the pipeline, remain strong. Lottery income dipped slightly in 2024-25 but picked up towards the end of the year and the plans for 2025-26 are on track.

The diversified nature of the income streams reduces risk to Demelza with the top five income streams all providing over 10% of our total income.

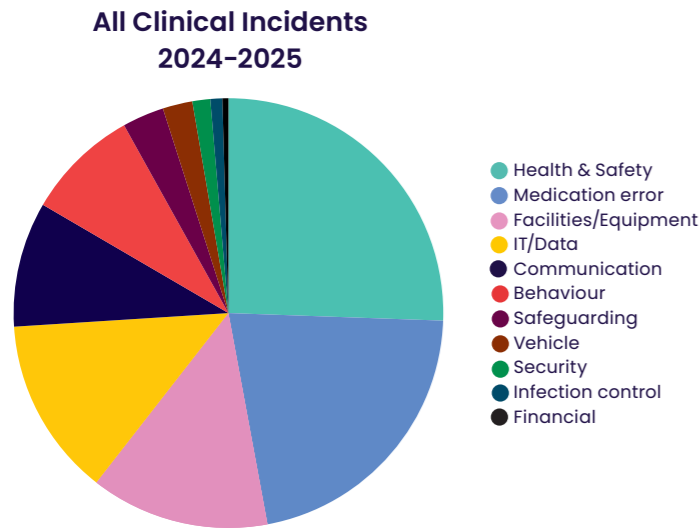
2023-24 Income	%	£
Retail	24%	£4,186,000
Fundraising	28%	£4,780,000
Statutory	16%	£2,816,000
Lottery	11%	£1,868,000
Legacies	19%	£3,194,000
Investments	1%	£204,000
Other	1%	£208,000
100%		£ 17,256,000

Expenditure was below plan contributing to the more favourable than planned in year position. It should be noted that this was primarily due to staffing vacancies, which the organisation is working hard to fill. The main challenge is the recruitment of nurses at our South East London hospice – there is a shortage of children’s palliative care nurses across London, and we are working hard to resolve the situation through targeted recruitment campaigns and by raising the profile of nursing with Demelza through recruitment open days and our online social media platforms. We remain at full complement of nursing staff in Kent and East Sussex.

Every year Demelza develops a three-year financial plan to ensure the financial stability for the organisation. The aim is to deliver a break-even financial plan at the end of the three-year period whilst ensuring that reserves remain within the defined range.



Incidents, accidents, complaints and compliments



Activity report

Community care hours (Excludes end of life on call shift hours and sensory/garden/cooking)	East Sussex 5183.08	Kent 2537.49	South East London 1847.76	
Kent site visits (Number of family led bookings – cinema, family splash, sensory, soft play, garden, cooking – currently only recorded at Kent)	Kent Sensory room 26 bookings	Kent Hydro Pool 209 Bookings (family splash & transition family splash)	Kent Cinema 105 Bookings	Kent Soft Play 33 bookings

Hospice usage

Residential nights (All reasons for visit including post death clinical care) Departure after 01.04.2024 and arrival before 01.04.2025	Kent 1415	South East London 296
Day Care bookings (Arrival and discharge times for overnight stays may be extended to include a day care session and this would not be reflected in the figures above) RFV is day care offer or day care short break	163	407

Family Support attendance figures

	Child	Family Members including siblings
FSD event attendance – Family events FE	260	662
Psychotherapeutic Services group attendance CR and BR	645	1186
Family Liaison and Transition groups/days FL and TR excluding	645	1186
Ward/hospital visits	-	-
Family Liaison hospital in-reach visits	-	90 unique visits/events
FSD bookings/sessions (Bookings delivered by Psychotherapeutic Services, Family Liaison, and Transition Support, Practical support)	-	3064 bookings

Nursing and Care training compliance % March 2025

	Kent	East Sussex	South East London*	Average
Fire	93.22%	100.00%	73.53%	88.92%
Safeguarding children (L3 F:F)	94.83%	93.33%	88.24%	92.13%
Safeguarding adults	98.33%	100.00%	94.12%	97.48%
Moving & handling	85.96%	100.00%	73.53%	86.50%
Data protection GDPR	93.33%	100.00%	94.12%	95.82%
Infection control	91.53%	100.00%	70.59%	87.37%
MCA & DOLS	93.33%	100.00%	91.18%	94.84%
BLS	93.22	100.00%	75.53%	88.92%

(% includes flexi Nursing and Care staff, Family Support, and Leadership).
*When care staff are prioritised for delivering core services and miss mandatory training, they undertake on-line training to remain up to date and are placed on the next face to face course within three months.

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 an Adult Safeguarding Lead role was established in response to a diverse Demelza team and recognising it is often adult safeguarding concerns that are raised by teams outside of the clinical directorate.

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 Committee meeting is held quarterly and chaired by the Safeguarding Trustee and continues to have representation across teams.





Family stories

Daisy's story

Demelza provides support for the whole family, helping them make the most of every day.

"When Daisy was diagnosed, she was just four months old. She has very rare, complex medical conditions – she's ventilated via a tracheostomy 24/7, and has a feeding peg. She also has epilepsy and global development delay.

Daisy's complex needs mean she needs one-to-one care, she needs a safe environment, and someone who knows what they're doing.

The first time we left Daisy was nerve wracking. I had full trust and faith in the nurse and the carer that we left her with, but that's our baby, that's our very complex, very changeable baby, who we're walking away from.

But that was the turning point for us. Becoming comfortable leaving Daisy with Demelza nurses

came from knowing that they actually do the same kind of checks you would expect in intensive care in hospital, but in your own home. Once you know that's taking place and you can see your child smiling when you're walking away, there's no turning back from there.

Daisy loves coming to Demelza, because there is nothing that's off limits. She can paint, she can get covered, she can go in the garden safely, she can have as many slices of toast as she wants. She can run up and down the corridors and she can watch whatever she wants on TV, on repeat.

Demelza has helped us in ways I didn't even think they could help us, from taking us up to London for hospital appointments and coming back the next day to bring us home, to entertaining Freya on the most fantastic sibling events, to making sure that Daisy is well cared for. They have supported us every step of the way."

Fiona, mum to Daisy

Jude's story

Demelza's facilities provide families with the specialist support they need to keep doing the things they love.

"Cycling was always mine and Jude's thing – we'd go out riding together for hours and hours. He was a strong swimmer too. On holiday he used to snorkel all the time. From what we've learned now it was that strength and fitness that kept him going. But really, we should have lost him.

Jude was about to turn 10 when everything changed. His decline wasn't sudden, it had been slow – he choked randomly on holiday, his voice started to get weaker, he lost his confidence swimming, his muscles were weaker, and he was struggling to eat – sometimes even too frightened to eat.

Through all this he'd been in and out of hospital for testing. We went to a specialist who detected some trembling in Jude's throat they were concerned about, so Jude was kept in overnight. And it was staying in overnight that saved his life, because the next morning he went into respiratory arrest. If he was at home, we'd never have known – we'd have gone into his bedroom in the morning, and he'd have been gone.

Jude went into a coma and woke up a week later on his 10th birthday. After all the tests imaginable and doctors all over the world working on his case, we still don't know what is wrong with our son. And they couldn't stop him from regressing. That was awful to see – it was whole year of watching him get to the point where he couldn't move anymore.

Today, Jude's condition is still unknown – we're in the position of always hoping for the best and trying not to expect the worst.

It's tough some days. We made this wonderful child and then 10 years down the line, he's no longer walking or talking, and no one knows why. It's still such a shock. We've blamed ourselves, we've argued, we've cried about it so many times, because we don't understand it. But we're finding ways to do all the things Jude loves.

The hydro pool at Demelza is the best thing ever. The team here are amazing – they notice all the little changes in him – sometimes things move more, sometimes they move less – but they try all kinds of different things to support his movement. The access to Demelza's changing space is phenomenal. We can't convert our bathroom to a wet room, and although his nurses can wash him fully in his bed, it's still so nice for him to have a proper shower and wash his hair – coming here just gives him that extra bit where everything is clean from tip to toe.

And it's brilliant when the Demelza nurses come for play therapy – I can nip into the other room to get bits done while he's still safely being watched over, but also getting care and attention.

You'd rather Jude not be ill, we don't want to be going through this, but being able to come somewhere like Demelza – it's like a sigh of relief. We've got people who understand us, who understand Jude. It's somewhere he feels confident, he feels safe, and he's got good people around him."

Peter, dad to Jude





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