



demelza

extraordinary care for extraordinary children

"I'm not alone"

The importance of residential trips for brothers and sisters

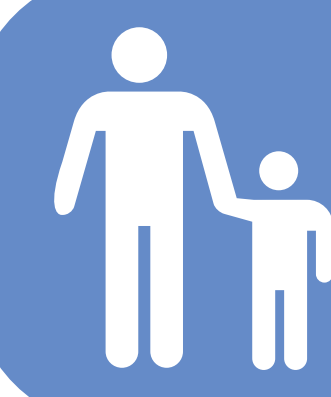
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Imbalance of parental attention

Siblings of children with serious or life-limiting conditions may have unmet needs as a result of parental attention being focused on the affected child. Siblings may face unspoken challenges, internalise issues rather than seek parental guidance, engage less in an educational setting and struggle in social situations and personal relationships. Siblings are also more likely to experience, anxiety, depression, withdrawal, anger and behavioural problems, affecting childhood development.

In a 2010 TEDx talk, speaker Alicia Arena drew attention to this phenomenon – Glass Children Syndrome. Glass children take on caretaker responsibilities and are conditioned not to have problems: "Parents are so consumed with the needs of brothers and sisters that when they look at us [sic] they look right through us as though we're made of glass."



Family Support

Family Support proactively deliver compassionate and practical services to support families. Comprising of four different teams within the department, we operate in synergy with other Clinical Services (Nursing and Care and Service Demelza) within Demelza.

Family Events: Throughout the year this team organise a series of planned, specialised events for families and children. Events are held across the Demelza region and include parties and a seasonal programme of activities ensuring all safeguarding, risk assessment and inclusion policies are prioritised.

Family Liaison: Offer guidance and information across a range of important areas, including assisting with benefit related matters, directing individuals to local services and facilitating charity applications. Additionally, the team includes specialised practitioners dedicated to Neonatal Services and Transition Support.

Psychotherapeutic Services: This service provide Creative Arts Therapies and counselling. This space provides a confidential and supportive time to explore thoughts and feelings and is available to individuals, groups and families. This team also offer a complimentary therapy service to promote physical and emotional wellbeing. We offer specialist bereavement support, bespoke remembrance events and also create physical memory items through unique methods such as casting.

Practical support: A volunteer-centred service that carries out everyday tasks for families such as gardening, deep cleaning or painting. This service also provides essential transportation for children and their parents/carers for hospital treatment and appointments.



Challenges

Transition from primary to secondary education is a significant time of change for young people. They can often feel a lack of belonging.

At this already challenging time, socialisation in primary education has been affected by the COVID-19 pandemic, as well as recent industrial action. This has further limited opportunities for young people to develop key skills needed to build more relationships with peers in secondary school, impacting siblings of children with a life-limiting condition, who may already feel isolated.



Objectives

To deliver an annual sibling residential to Year 6 students, offsite over two nights and three days, bringing siblings together to provide:

- An opportunity for peer-to-peer support.
- A safe space for open, age-appropriate discussions.
- Space for personal interests.
- Activities designed to develop social skills that would also help equip them in their transition to their final year of primary or first year of secondary education.



Methods

The residential spaces used are activity centres providing a range of activities. These can include abseiling, low and high ropes and pedal karting. With opportunities to spend time outdoors with peers, children are encouraged to take part in physical activities with a focus on increasing confidence, building resilience and developing life skills. These opportunities are delivered through a carefully designed mix of challenge, play and reflection. Each residential has included singing and marshmallow toasting around a campfire. It is also a tech free camp, allowing children a rare opportunity to engage away from digital devices. As this event has developed over the years, so has the opportunity to improve the service. To lessen anxiety and worry about meeting new people for the first time at a residential, Demelza now offers pre-residential meetings, such as the sibling sleepover at the hospice. Children are given the opportunity to camp out in a large meeting room, have pizza and watch a film in the cinema space until late. For others, it might be about spending time with the creative arts therapists or crafting in their new scrapbooks or designing their new pillowcases.

Financial challenges are exacerbated with a family that has a child with a serious or life-limiting condition. Research reveals these families disproportionately struggle to access appropriate financial advice and credit. It is estimated to cost up to three times as much to raise a disabled child than raise one without a disability. Demelza proactively sought to break down any financial hardship barriers by providing transport and kit list items to those families and children who needed them. Demelza's retail arm donated clothing, footwear and additional items for children, that they were able to keep after the trip. Location of the residential could also be a barrier to attending. Therefore, Demelza's Practical Support team provided transport for children in the South East.



Collaboration

The residential brought teams of staff and volunteers from across the organisation and their specialist skills together to deliver a safe and supportive experience for siblings. Additional responsibilities aside from their day-to-day roles were required by those assisting with the trip, such as, promoting professional development, and increasing experience working closely with young people. Both staff and volunteers reported positive experiences of being involved.

"Best.Trip.Ever." *Sibling August 2023*

"It was so fulfilling to participate in the residential trip – supporting young people and watching them grow in confidence over the three days and make memories that will stay with them – I can't wait for the next one!" *Volunteer, August 2023.*

"I had the opportunity to work with colleagues and volunteers I wouldn't usually, which provided a deeper understanding of what they do and how they support family members within the hospice." *Staff member, August 2023.*



Results and Outcomes:

The residential effect

The residential experiences impacted socialisation, maturation, pro-active decision making and positive behaviours. The challenging, collaborative and enjoyable outdoor tasks allowed relationship building with peers, reducing isolation and finding safe ways to express a range of emotions. Social interaction is seen as one of the most significant benefits whilst also affording the family opportunities to have additional space during this time. The relationship with Family Liaison Practitioners and trained volunteers built confidence with future service engagement and there are planned post-residential opportunities such as a reunion. Siblings' independence increases, attitudes change and there is huge pride in their accomplishments, improved physical skills and resilience. The children leave this residential knowing that they are part of a sibling community.



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Demelza's Guide to Services

