



demelza

extraordinary care for extraordinary children

Transforming Transition at Demelza

Anna Sillett, Family Liaison Lead

1. Introduction



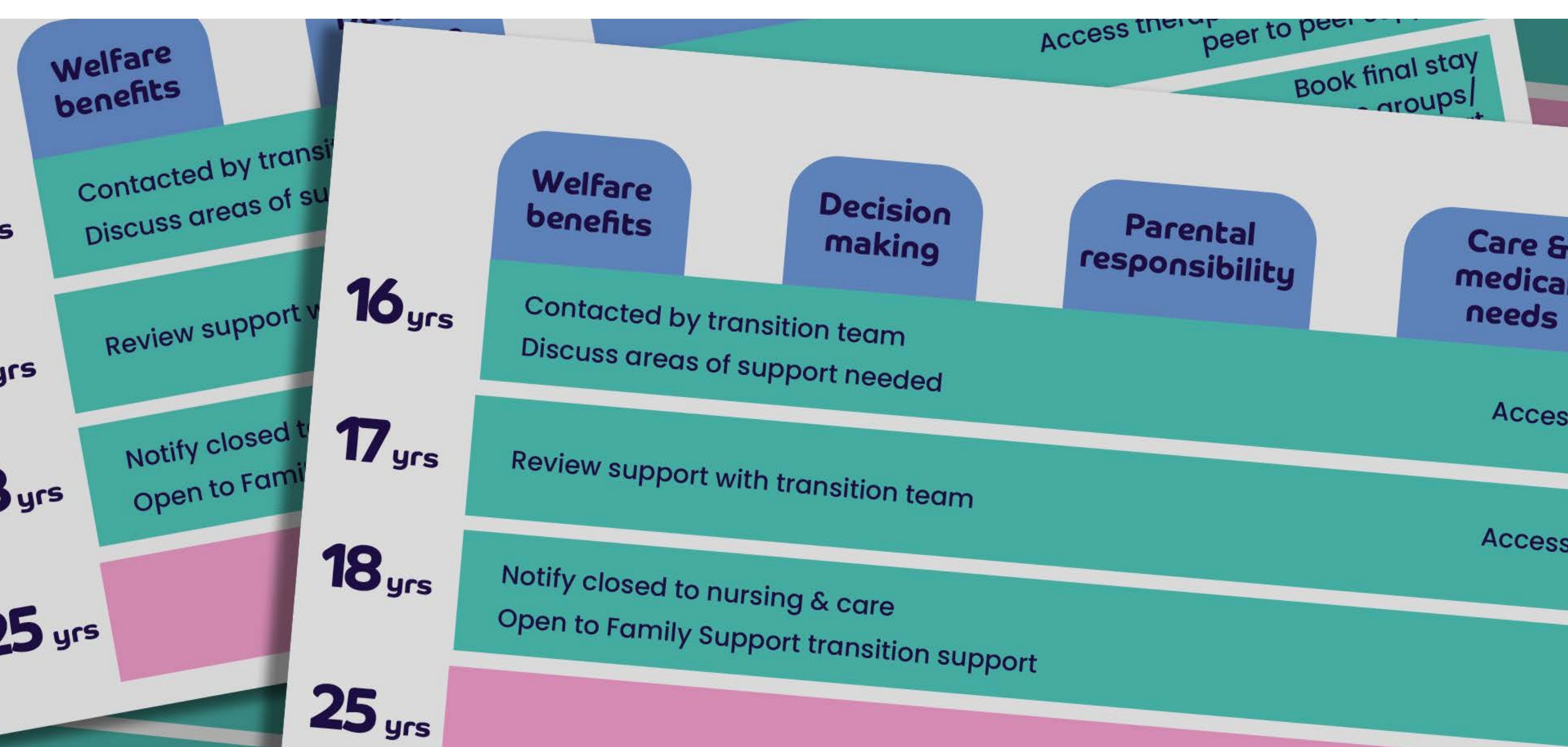
Demelza believe that transition from children to adult services isn't a single event but a gradual process of supporting a young person, and their family, through teenage years and into adulthood. There was a significant need to transform the support provided to families in transition, particularly in the absence of a national framework and differing offers across NHS trusts and local authorities. Transition is also a key priority within Demelza's current five-year strategy, recognising the many challenges this period presents for adolescents with complex needs and their families.

2. Steering group



Demelza created a steering group to provide strategic guidance and oversight, whilst ensuring that the service aligned with the organisational goals and importantly benefitted from the diverse expertise. In 2021, a transition steering group was formed made up of lead nurses, care team leaders, family support leads, family liaison practitioners, parents / carers and a representative from an adult hospice. It serves as a key mechanism for driving effective project management and stakeholder engagement.

3. Framework of support



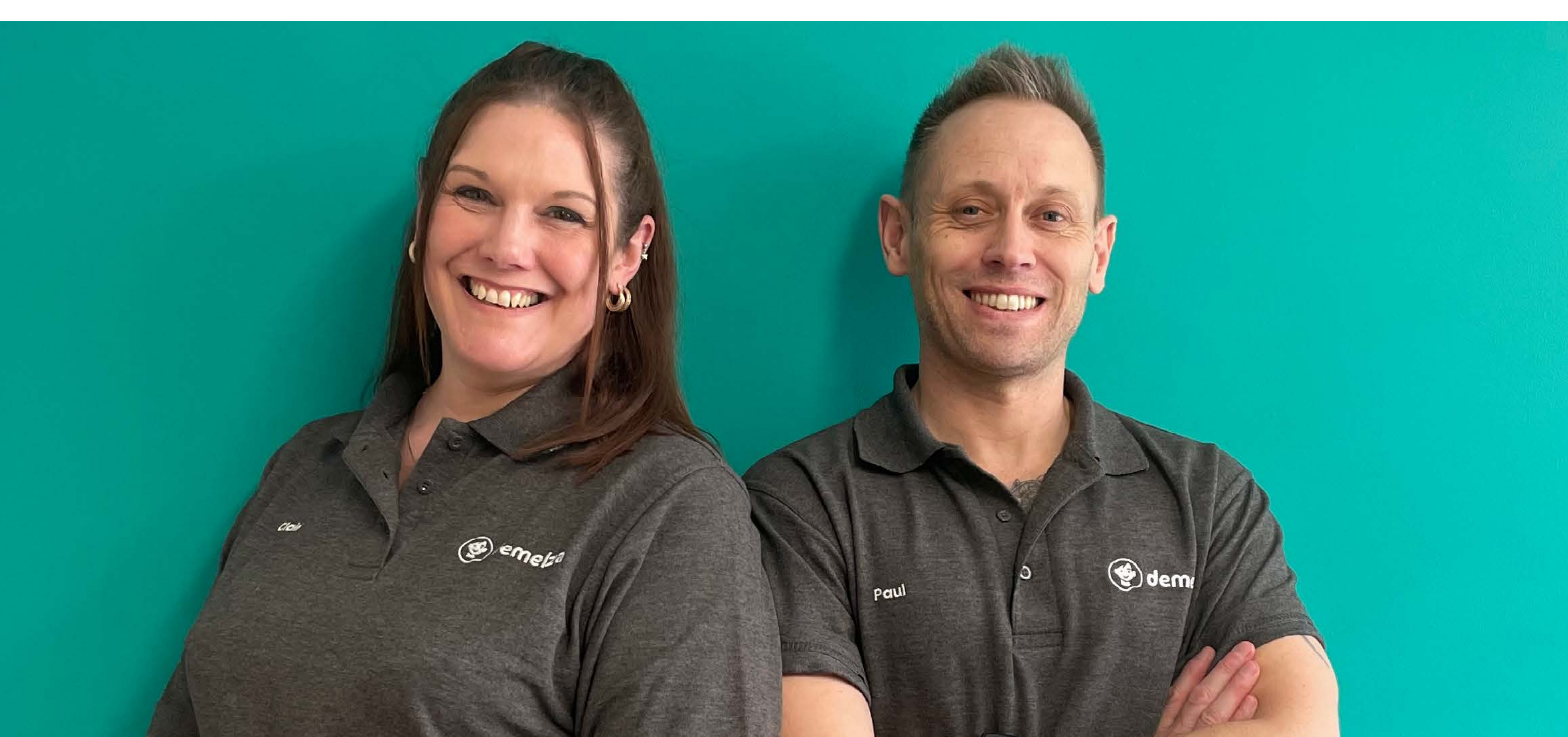
Our first transition framework of support was created in February 2022. This was based on the lived experiences of families that Demelza has worked with and using information from the steering group. The framework also took research from sources such as the National Institute of Clinical Excellence Guidelines (NICE), Hospice UK & Together for Short Lives (TFLS)

4. Whose shoes?



Whose shoes? (created by Gill Phillips) Is an innovative approach to improving user experience in health and social care settings, centring efforts on actively listening to the voices of young individuals and their families. Demelza initiated collaborative consultations involving families who utilise the service, Demelza colleagues, and external providers, including adult hospices, to collectively envision the future of the Transition Service. This feedback played a pivotal role in maintaining the young person as the focal point of the service offer and simultaneously facilitated the emergence of new opportunities for peer support.

5. Transition team



In November 2022, Demelza recruited two transition navigators. Claire joined our team, following two decades of work in the Department of Work and Pensions. This expertise has greatly contributed to our ability to assist families with benefits and provides valuable guidance on appointeeship and deputyship. Paul, who has worked for Demelza since 2012 as a Health Care Assistant, brought a wealth of expertise regarding digital and holistic engagement.

6. Family Transition Support and Peer Connections



Engaging families directly played a pivotal role in comprehending their unique requirements. We've reached out to more than 50 families through calls, virtual meetings, in-person interactions, community outreach and home visits. Our teams is well-equipped to offer guidance and advice on finances and decision making. Additionally, we've found great value in fostering connections among families and facilitating peer-to-peer support. To facilitate this, our team held events to encourage such support. We extended invitations to young individuals to participate in a teen day, where they could socialize with peers of similar age groups. Families were also warmly welcomed to join our creative coffee mornings, where they could engage in craft activities, connect with other families, and catch up with our transition team.

7. Collaborative Initiatives and Participation



We have engaged in collaborative efforts with adult hospices and services throughout the southeastern region to establish cooperative prospects and investigate upcoming service developments. We are actively involved in the 'What Matters to Me' project in partnership with *Challenging Behaviour Foundation*. This project is geared towards working with young individuals aged 16 - 25 who have severe or profound multiple learning disabilities with the aim of creatively capturing their experiences, preferences and perspectives. The ultimate goal is to influence both local and national policy.

8. What's next



We look forward to the expansion of our services in the future! Our upcoming plans include enhancing our peer-to-peer support network to facilitate mutual assistance among families, enhancing our communication and engagement with families and fostering greater collaboration with external partners throughout the South East to establish a more comprehensive *Pathway for Practice*.

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Demelza's support to transition into adulthood

