Parent Knowledge Network
Session summary: Isolation and connection

This session of the Parent Knowledge Network featured **Elijah, whose daughter Hannah has UBTF Neuroregression Syndrome (UNS)**, who shared reflections on the topic of 'Isolation and connection'. As part of the session, Elijah and the group explored specific layers of isolation that parents can experience while caring for a child with dementia: from the necessity of building intentional, diverse support networks, to the personal risks involved in sharing a diagnosis. Below is a summary of the key themes and reflections from the session.

Finding companions along this shared road

Elijah reflected on the childhood dementia experience as a journey families travel together and how, despite being at different stages, he has found connection with families 'further along' the road. It was discussed that a sense of community helps alleviate the deep isolation that often comes with navigating a complex reality that the wider world struggles to understand. Having progressed further along his journey since his family first connected with Childhood Dementia Initiative, Elijah highlighted the significance of transitioning from feeling like he was receiving support to offering it to others and how this can be a potential dual-role for other parents over time as well.

With strong roots, you can weather the storms

A central theme of Elijah's reflection was that intentional outreach to build a network of support is necessary for long-term well-being. Elijah drew on the metaphor of a specific type of tree, the Moreton Bay Fig, to speak about the need for a healthy support system. The Moreton Bay Fig is supported by a network of strong buttress roots, which offer stability in the elements. He cautioned against the mistake of expecting one person or group to fill multiple roles, which can leave the 'tree' unstable and vulnerable to collapse. Instead, he advocated for a network where support is matched to specific needs: 'mates' for normalcy, health professionals for medical needs, and therapists for emotional processing, which helps maintain a healthy sense of balance.

Care vs expertise

The group discussed that while medical and therapeutic expertise is essential, the human element of care is equally vital. Some shared that they often feel helpless when experts lack answers; however, when a

professional shows genuine care – such as taking the time to research the condition before an appointment – it can play a significant role in reducing a sense of isolation.

Connections will evolve along the way

A self-described introvert, Elijah stressed that support does not appear on its own; it must be nurtured and grown. He emphasised that proactively building a 'crew' of people who understand your specific situation is a necessary step in ensuring a family remains supported along their journey. Participants observed that relationships are seasonal. As a child's condition changes, so too do the needs of a family. People may enter and exit a family's support network at different phases, and although these kinds of transitions may be natural, some parents shared that this can be difficult as it requires an ongoing, adaptive approach to finding the right community for different 'seasons'.

Telling people 'more' is not a guarantee of more support

There was sensitive reflection about the unexpected isolation which can emerge from unexpected places – such as the decision to share your family's personal story with the wider world. One parent spoke about how sharing the diagnosis of a family member - in the hope it would lead to more community support - left them with much less connection than they had expected. When friends or community members respond in unhelpful ways, such as avoiding your family, or by making it about their own (unfiltered) reaction to the news, it can bring unexpected emotional challenges and the choice to share (or not) is an individual family decision.

Doing the best you can with what you know at the time

It was discussed that there is no universal roadmap for when or how to share a diagnosis. There are a multitude of factors that determine what choices families make when navigating the challenges of isolation and connection. The discussion concluded with a series of reflections on the individual nature of who and how much you choose to share about your life as you seek to build networks of support:

- It is never really possible to know the full picture of another family's life or give advice on these matters
- Connecting with the experiences of other families in the childhood dementia community can bring clarity to your own unique questions and difficult choices, including deciding what aspects of your journey you feel comfortable sharing

- It is okay to change your mind on decisions you make over time. For example, not choosing to be as open or vulnerable initially in what you share with others doesn't necessarily equate to avoidance. It could be that you are working through a process in your own way
- Often as a parent, 'you just have to do the best you can with the information you have at the time'
- Whether you choose to engage in public advocacy or keep your experiences private, both approaches are valid personal choices. You know your needs and preferences best

Helpful resources discussed in the session

- The Childhood Dementia Online Community: A private Facebook group, co-designed with parents, where families affected by childhood dementia can connect with one another

To view the recording from this session, please register to become a member of the Parent Knowledge Network. Presentation recordings will be shared with members during the monthly reminder emails. Here is a reminder of the Parent Knowledge Network Community Guidelines.

Date: June 2026. This written summary reflects the transcript from the parent lead presentation and group discussion.