

Parent Knowledge Network Session summary: Siblings

This session of the Parent Knowledge Network featured Nicole (Toby's mum) and Alicia (Kiaana's mum) discussing the topic of 'Siblings'. Both parents reflected on what growing up alongside a child with a childhood dementia condition means for their brothers and sisters – from having honest conversations at different ages, to finding support that exists for siblings alone, to living with divided attention, and the belonging that can come from connecting with other families. Here we capture the experiences and insights shared during the session.

For siblings, this is their *normal*

A theme from both parents was that siblings tend to experience family life as ordinary in some sense, because it is the only life they know. Asked what it is like to have a brother or sister with a childhood dementia condition, one parent shared that her children often turn the question around and ask "Well, what would it be like not to?". Both parents reflected that the emotional weight often sits more heavily with them as parents, than with their child, and how this can be something to seek support (as parent) for specifically. The session also highlighted how siblings often cultivate more compassion, demonstrated by how siblings may notice and respond to peers with extra health or disability needs much more quickly and attentively than other children their age.

Answering difficult questions with honesty

It was discussed that parents have found being honest with siblings (about diagnosis, and prognosis for example) matters more than finding exactly the right words. Questions tend to arrive unplanned, and parents rarely feel ready for them. The approach shared was to adjust the language to the child rather than adjust the truth: a simple analogy can be enough for a young child, while an older child may ask directly how long their brother or sister will live, and can accept a direct answer without the need for extended discussion immediately after. A related insight was that children who are not informed or provided information about their siblings' condition at home will look elsewhere and assemble this themselves. This could range from conversations they overhear at school, or from searching online, where they are most likely to find worst-case scenarios. Working through information sharing together as a family was described as more useful than trying to 'protect' children from it.

The most helpful support may not be formal therapy

Both parents reflected on an assumption that siblings of children with a childhood dementia should (by default) be seeing a psychologist, and that this is not the only or always the right form of support. What was described as more central is keeping conversation open at home, so children can raise things when they choose to, with people they already know and trust. Sharing information with school was raised as a practical and low-cost way to increase avenues of support for siblings.. When school staff understand a family's circumstances, a late arrival or an unfinished task can be met with understanding rather than questions, and children can be given an 'opt in' background support in the form of a nominated staff member they can go to as or when they feel they need to.

School and peer group challenges

The school peer environments were raised as an area with less practical guidance available. Siblings can be singled out or bullied over comments about their brother or sister, particularly at the ages when children are establishing social identities. It was noted that raising this with a school carries its own risk of drawing further attention to the child, which is often the last thing a pre-teen or teenager wants. Whole-school approaches, such as an assembly marking Rare Disease Day, were discussed as a way to normalise differences without focusing too intensely on an individual sibling.

Support that exists for siblings alone

Support designed specifically for siblings was one of the most practical suggestions to emerge during the session. The Young Carers Bursary, run by Carers Australia, offers annual rounds of financial support for young carers who are studying. State and territory carers organisations also run young carer programs with camps, school holiday activities and funding for siblings to have time out. It was noted that these programs often ask the child directly what they would like, rather than asking the parent, and that this matters in itself: it gives siblings something that is about them. Parents also reflected that this information is rarely offered by services, and is most often found through other parents or online networks.

Divided attention, and the value of small moments

Parents openly discussed the ongoing guilt and reality of finite capacity when balancing attention between children. This imbalance persists over time, though parents who were siblings themselves noted making conscious efforts to celebrate each child's milestones, informed by their own lived experiences while growing up..

Simple, regular one-on-one routines, like park visits or hugs, matter more than elaborate plans. These moments create natural opportunities for children to talk when something is on their mind.

Belonging through connection with other families

Both parents described condition-specific and childhood dementia community gatherings as valuable for siblings, in ways they had not anticipated. While parents connect over shared experience, much of the benefit for children is being able to be children together, without the reason for the gathering being the focus. Friendships formed at these events can last for years, including across countries.

It was acknowledged that joining these communities can feel daunting, because it exposes children to seeing other children and families who are further along in disease progression - and this was ultimately something the group felt brought benefits with it.. Reflecting on many years of seeing siblings be aware of the deaths of many children they knew over the years reaching end of life care and dying. The view shared by one lead parent was that this approach had not caused harm, but rather had made the realities of life and death possible to talk about more openly in family life. .

Helpful resources discussed in the session

- [Young Carer Bursary Program](#): Financial support from Carers Australia for young carers aged 12 to 25 who are studying
- [Carers WA Young Carer program](#): Support, activities and school holiday programs for young carers in WA. Each state and territory has an equivalent carers organisation
- [Siblings Australia](#): A national organisation offering support, counselling and resources for siblings of people with disability or chronic illness, and their parents
- [The Childhood Dementia Online Community](#): A private Facebook group, co-designed with parents, where families affected by childhood dementia can connect with one another

- [Having Difficult Conversations](#) : A Childhood Dementia Initiative resource with a section on speaking to siblings about diagnosis.

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](#).

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