

Parent Knowledge Network Session summary: Working with support workers

This session of the Parent Knowledge Network **featured Felicity (Orla's mum) and Alicia (Kiana's mum)** discussing the topic of 'Working with support workers'. Together, they reflected on the realities of recruiting, employing and managing support workers as part of everyday family life – from building flexible rosters and navigating the private versus agency decision, to finding the right fit for the whole family, creating systems for day-to-day care, and navigating the grief that comes when a valued worker moves on. Here we capture the experiences and insights shared during the session.

Flexibility and compromise in finding the right support

A central theme from both parents was that flexibility is a necessity. Schedules change, workers move on, and the needs of a child with a childhood dementia condition evolve in ways that are often unpredictable. This means that finding someone available at exactly the right times, with exactly the right skill set, is a common challenge. Felicity reflected that she has at times needed to employ two people to cover what one person might ideally do, and that as her child's needs have changed over time, so too has the profile of the support worker she is looking for. Therefore, the role is not static and this is something to be managed.

Private vs agency: finding a model that works

Alicia has navigated virtually every model of support over the 15 years she has been engaging support workers – from agency-based support to self-managed arrangements, and eventually to running a 'service-for-one', directly employing workers through a not-for-profit structure. This places the family in the driver's seat, with full control over who is employed and how care is delivered. However, a boutique team means there is no pool of backup workers to draw on if a support worker is unwell or takes leave. To address this, Alicia now uses a mixed model, supplementing her core team with a separate agency for specific shifts. For families earlier in their journey, her advice is to build a clear structure before bringing workers in – identifying what is and is not acceptable in the home, documenting it, and being clear with workers from the outset.

Communication and building a connected team

Alicia described the evolution of her record-keeping systems – from a handwritten communication book, to a daily tracking sheet, and eventually a fully digital, integrated system. She currently uses a combination of rostering (Deputy), team messaging (Whatsapp), and shift reporting tools (Maslow). She has plans to consolidate these into a single platform (Connecteam) with conditional forms, voice notes and automated sharing with health professionals. For example, a ‘yes’ response to a question about swallowing concerns opens a sub-form that can be shared directly with a speech therapist.

Impact on the whole family

Both parents spoke to the reality that support workers are not entering a clinical setting, they are entering a family home. Felicity reflected that finding workers who are a good fit for the whole family, including siblings, has been one of the most important and most challenging aspects of the process. She described a worker who was part of the family for six years, and whose ability to step in so completely meant Felicity’s other children gained something invaluable: their mum’s full attention. Because this worker could step in so confidently, Felicity was able to genuinely switch off in a way that is not always possible even when support is present.

When a support worker leaves

Both parents acknowledged that the end of a close support worker relationship can carry a weight that people outside the experience may not fully appreciate. Felicity spoke openly about the grief her family experienced when their long-term worker left – a departure that, despite significant notice, brought anticipatory grief alongside the logistical pressure of finding a replacement. The gap left, she reflected, is both practical and personal, and an additional challenge to navigate.

Where to advertise and what to look for

Alicia shared that in her experience, Facebook has consistently been the most effective channel for finding support workers, through community, National Disability Insurance Scheme (NDIS)-related and local groups. She noted that platforms like Seek and Indeed suit more formal employment advertising and attract a different type of applicant. Her approach is to write ads that include specific instructions and use responses as an early filter – candidates who read carefully and respond thoughtfully stand out quickly. She’s also found that ads that feel personal and give a genuine sense of the family tend to attract more engaged responses than a list of tasks.

Learning from others

It was acknowledged that while you cannot fully know what lies ahead until you are in it, there is real value in looking to others who have walked the path before. Learning from their experiences, their systems and even their mistakes can make a meaningful difference. Importantly, it was expressed that when the right person is found, the benefits are significant and extend to the whole family.

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](#).

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