childhood
dementia
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Parent Knowledge Network
Session summary - After the diagnosis

This session of the Parent Knowledge Network **featured Sarah (Charlotte's mum) and Renee (Austin's mum)** discussing the topic of 'After the diagnosis'. Together, they reflected on the days, weeks and months that follow a childhood dementia diagnosis – from giving yourself permission to slow down, to sharing the news with family and friends, to gradually building a support and care system, and to letting go of the expectation that you need to feel strong or have everything figured out. Here we capture the experiences and insights shared during the session.

Giving yourself permission to slow down

In the immediate hours and days following a childhood dementia diagnosis, families often find themselves overwhelmed by a rush of clinical information, allied health appointments and practical decisions – all without being given any type of guiding roadmap. A central insight shared was the importance of giving yourself permission to slow that pace down, to say "not right now" to health professionals, to step away from your phone, and to take time to absorb the news before trying to act on it. The diagnosis can feel surreal and impossible to accept at first, but reminding yourself that this is still your child, and that nothing needs to be solved in the first 24 hours is important.

Sharing the news with family, friends and community

It was discussed that telling family, friends and the wider community is one of the first major challenges, and there is no single right way to approach it. Sharing the news in stages – for example, immediate family first, then siblings, then the broader community – and nominating one trusted person to manage incoming messages, can protect the parent(s) from fielding questions during the rawest moments. Saying the diagnosis out loud can sometimes make it feel more real, so moving at your own pace is important. Once others do know, accepting offers of help, whether meals, childcare for siblings or practical errands, was mentioned as something to lean into rather than shy away from. It was also acknowledged that support sometimes comes from unexpected places, while others who seemed close may step back; this is common and not a reflection on the family.

Building a support and care system

It was discussed that building a support and care system takes time, and the early months can feel like survival mode. Connecting with Childhood Dementia Initiative (CDI), condition-specific groups and other parents – including families overseas, where peers at a similar stage may be easier to find – can be a vital source of practical knowledge on treatments, equipment, therapies and system navigation. The National Disability Insurance Scheme (NDIS) in particular was mentioned. It has its own language and processes that benefit from a guide or experienced parent walking you through it. Establishing relationships with a hospital nurse navigator, consistent therapists and/or trusted carers, and making sure the wider hospital team knows your child, can gradually transform appointments from overwhelming events into part of a manageable routine.

You don't need to have it all figured out

Finally, both parents wanted families newer to this experience to hear that you do not need to feel strong, share your child's story publicly, or have everything figured out – particularly within the first year. Comments such as "you're so strong" are usually well-meant but can feel isolating; the reality is that ordinary parents are simply meeting what is in front of them, learning on their feet and doing their best. Grief, exhaustion and bad days continue to surface, and that is expected. With time, a rhythm emerges, the diagnosis becomes one part of life rather than its whole definition, and the capacity to connect with and support other families often grows alongside it.

Helpful resources discussed in the session:

- Understanding your child's condition - A guide for parents
- Finding Hope - A message of support from a parent who has walked in your shoes
- Having Difficult Conversations - Practical Strategies for navigating challenging discussions about your child's condition

To view the parent presentation 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: April 2026. This written summary reflects the transcript from the parent lead presentation.