

Repositioning Dementia: What's next?

Follow-up questions for speakers which weren't answered on the day

Catherine Hall – Alzheimers NZ

Q. More a comment than a question: With around 7,000 of the approximately 70,000 today with dementia under 65 years old, we are feeling very marginalised given we are not 'aged'. So can we please keep this in mind. For example, can each speaker today include please keep us with YOD and their care givers in mind please? Therefore, my question for each speaker is 'how does what you say include those with YOD, their family and supporters, and how will those with YOD benefit?

A. Thank you, that's an important point. People with young onset dementia and their whānau are often forgotten or overlooked and yet have a number of specific issues that are not experienced by older people living with dementia. One of the issues that makes it complicated is that the health funding for all dementia, including for people with young onset dementia, sits within the health of older people budgets so it's essential we make do everything we can to sure that services are flexible and able to be tailored to individual and whānau needs.

Q. Excellent presentation Catherine. You stressed the importance of the integrated continuum and the interface with PHOs/primary care. Have you got thoughts on the two or three key ways we can advance the relationship with primary care?

A. It's certainly not easy given how many pressures there are on primary care given their funding and workforce issues. Some successes I have heard about though have come from personal contacts and relationships within local communities; offering education, resources and support to the wider primary care team including the practice nurses and health improvement practitioners who both have such important roles, and initiatives such as joint projects to test new ways of working.

Peni Hillman – Te Puna Ora a Mataatua

Q. Any programme like this happening in Australia? If so, where?

A. I'm not sure if there are existing pilots, but I was aware that in 2023 they did have pilot studies on Younger Onset Dementia detection, but not sure if there are programmes similar to what we have in New Zealand.

Q. Have you guys done an evaluation with whānau and funders? How was the results?

A. Not yet, but it is on list to do before the end of the year as it will be our one year anniversary coming up in November, so we will be able to get feedback then. If we have further opportunity next year, we will be happy to share our results.

Sheena Farquhar – Dementia NZ

Q. Could lived experiences help carers to understand this aspect of dementia?

A. Yes, lived experience could be helpful in managing this aspect of dementia. As with dementia, anosognosia will be different for each person. As long as the carer is able to adjust their actions and reactions to stand alongside the person living with dementia, they will be able to manage. It is also important to note that 'living in two realities' can be very tiring for the carer, and nobody gets it correct 100 per cent of the time. It essential that the carer takes time out for themselves to rest and recuperate.

Dr Emma Eason – Ryman

Q. How often do dementia nurses and care staff undertake training modules on the latest care standards for dementia residents

A. We have a comprehensive learning programme that meets the diverse needs of our workforce and we are in the process of developing this and are committed to developing our teams as well.