

This is what love looks like

And why change matters

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Kia ora koutou

I'm Jendi.

This is my family: Neil, Mike, Hamish, Kristy, and Audrey and Georgia — Mum and Dad's two very precious granddaughters.



Family, love, and the people walking beside Mum



Before there was dementia, there was Shirley

- Mum
- Wife
- Friend
- Grandmother
- Advocate
- A woman who made a difference

“She just believed people mattered.”



A life full of people

Friends. Family. Work. Travel.

A woman who turned up for people — usually without asking for any attention in return.

*A life does not start at diagnosis.
Support shouldn't either.*

The future was meant to look like this...

Travel. Friends. Family. More adventures. More time.



*This was meant to be retirement.
More places. More stories. More
memories.*



Then things started to change

- Not one dramatic moment
- Lots of little ones
- Muddled conversations
- Losing track of time
- A scan, a diagnosis
- A journey none of us really understood

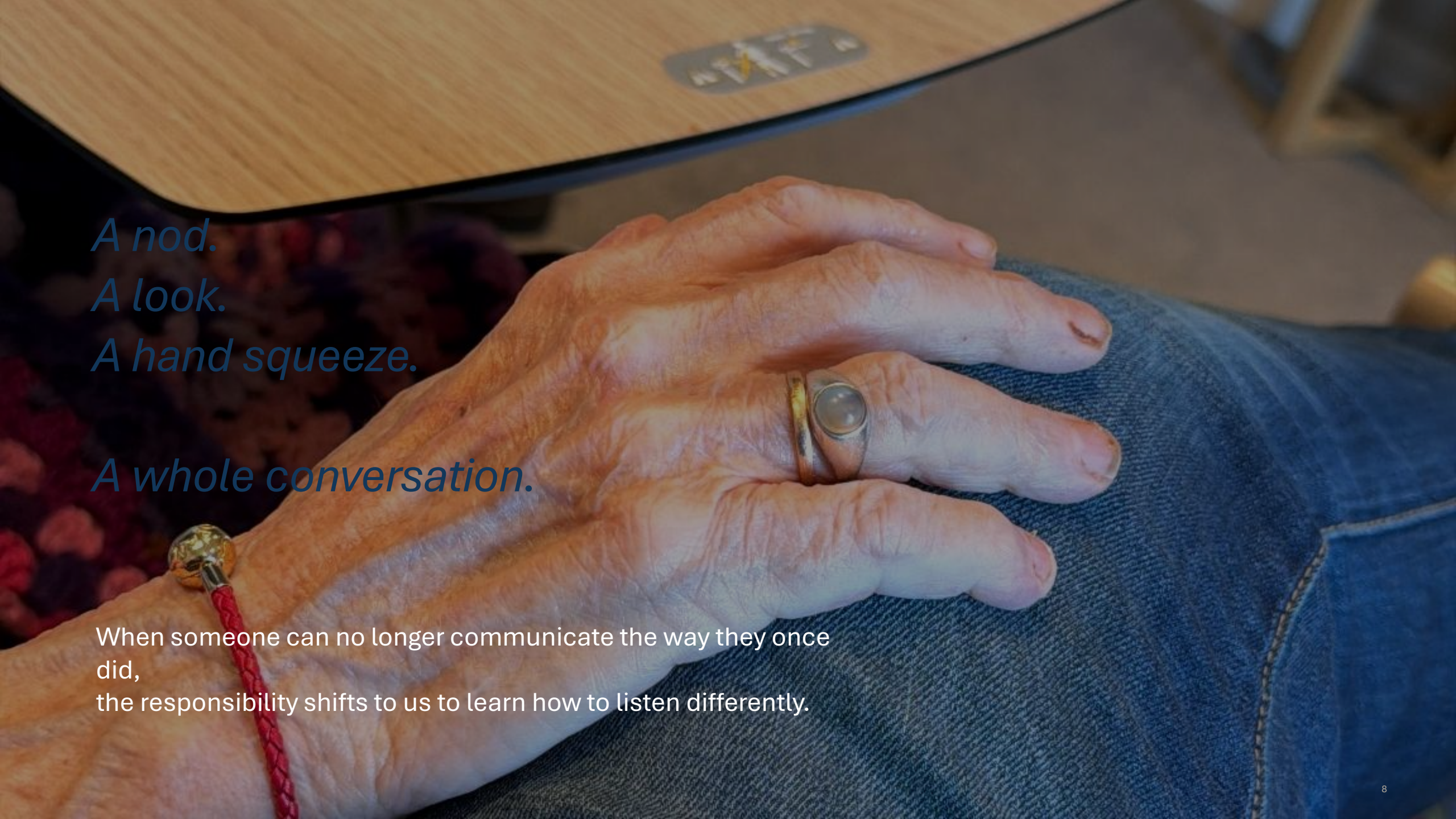
*We thought we would have more time.
We didn't.*



Today

- No longer independently mobile
- Largely non-verbal
- We get the odd word
- But mostly communication looks different now
- A head nod
- Knowing eye contact
- A hand squeeze

And she is still here.



A nod.

A look.

A hand squeeze.

A whole conversation.

When someone can no longer communicate the way they once did,
the responsibility shifts to us to learn how to listen differently.

The grief and the gratitude

- Dementia is a grieving process while the person you love is still beside you.
- You grieve conversations, independence and the future they should have had.
- But you also learn to grab the moments.
- To see what remains.

Mum is still Mum.



The stigma is still real

- It is getting better.
- But dementia still makes people uncomfortable.
- Sometimes people drift away.
- Sometimes the diagnosis replaces the person.
- Dementia needs its own version of the change we saw with mental health.

*Don't talk around her.
Don't talk over her.
She is still Shirley.*



What happened around Shirley

- When Mum's dementia was more manageable, there was support.
- When her needs increased, some support became harder to access.
- No real transition.
- No one clear next step.

*As need increased,
support decreased.*





What about the families who can't advocate?

- I understand government.
- I know how to find the right person.
- I know how to ask another question.
- I know how to escalate something.
- And even then, there were times I didn't know what we were meant to do next.

Access to care cannot depend on how good your family is at navigating bureaucracy.

We can do better

Other countries are doing parts of this better — coordinated pathways, case management, and stronger links between health and social care. None are perfect. But New Zealand does not need to invent all of this from scratch.

*The challenge now isn't knowing what to do.
It's doing it.*

Learn.
Adapt.
Fund.
Connect.
Act.

The numbers tell us we cannot afford to wait

83,000

New Zealanders living with
dementia in 2025

170,000

expected by 2050

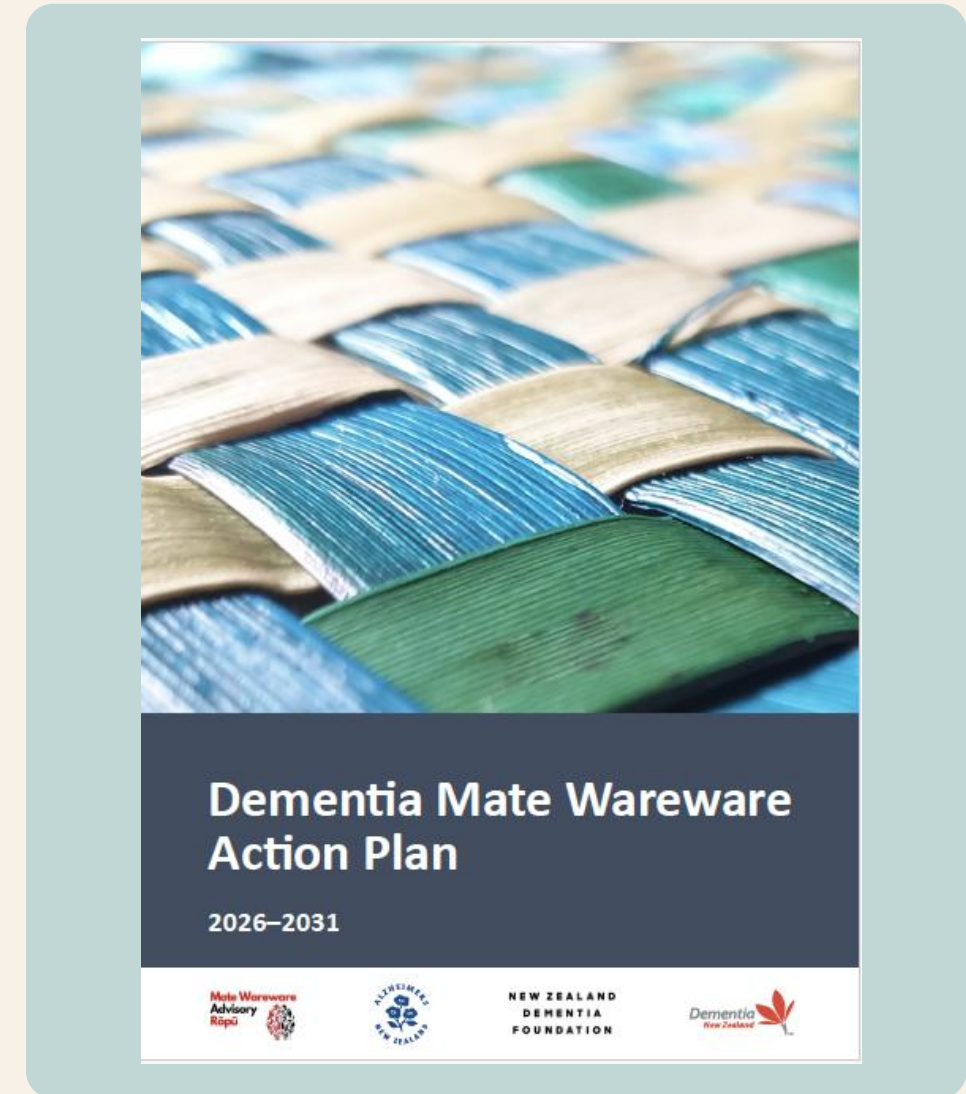
1 in 2

people living with dementia
may not have a diagnosis

*This is not a niche health issue.
And it is certainly not a future issue.
It is here.*

We know what needs to happen

- Timely diagnosis and planning
- Stronger community support
- A supported and skilled workforce
- Services that connect with each other
- Whānau treated as partners
- Governance and accountability



Every decision becomes somebody's Tuesday afternoon

- A phone call before a crisis.
- A support group that adapts.
- A GP who knows the pathway.
- A better experience in hospital or residential care.
- Someone noticing a nod.
- Someone holding a hand.

*Small moments.
Big meaning.*





For Shirley

She is my mum.

Neil's wife.

Mike and Hamish's mum.

Audrey and Georgia's grandmother.

A friend.

A woman who spent 28 years standing
up for other people.

*Although she can't stand up and speak for
herself now —
we can.*

Let's make the plan real

For Shirley.
For our families.
For the next 83,000.
For the 170,000 to come.

Ngā mihi
Jendi Paterson