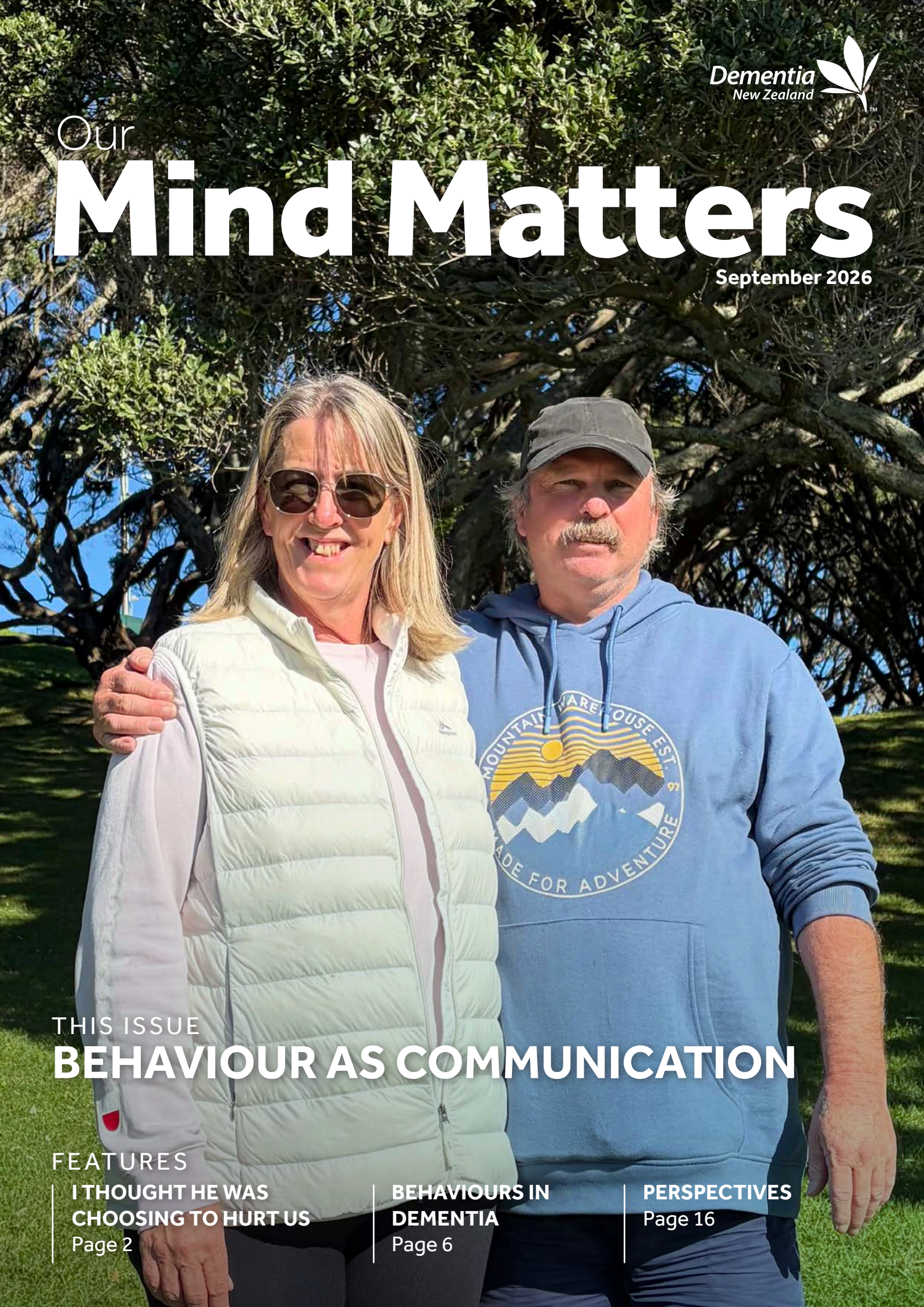
Dementia New Zealand

Our Mind Matters

September 2026



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BEHAVIOUR AS COMMUNICATION

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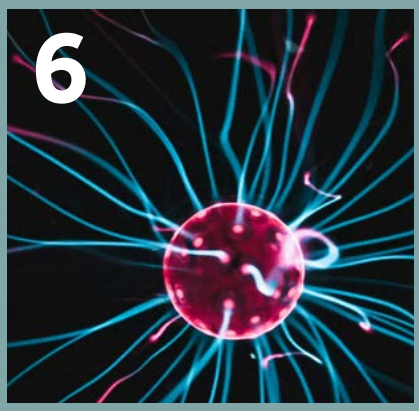

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With special thanks to the Pelorus Trust whose generosity has helped to produce this publication.

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A Message

From our chairperson, Frances Blyth

When dementia | mate wareware is discussed publicly, new tests and drug treatments often dominate the headlines. These developments offer hope, but they can also draw attention away from the reality faced by people and whānau now.

In June, the New Zealand *Listener* published an article by Sarah Catherall titled 'Getting Ahead of Dementia', which examined advances in assessing dementia risk and in providing treatment. I wrote in response, and my letter was published the following week:

I hope your cover article (Dementia, 6 June) on advances in medical dementia | mate wareware research helps put the true situation in perspective for readers: by far the most important consideration for all people with dementia is their ongoing support and care. This role largely falls to whānau and friends, supported by community dementia support services.

Early support can make the difference. People who are diagnosed early and have access to consistent guidance and support are more likely to live well at home for longer, experience fewer health crises, and feel less isolated. Whānau and friends who understand what to expect are better equipped to respond.

The therapeutics companies need to continue to do their work, of course. They know full well that what they might offer for the future will not change the reality of home-based care for people with dementia | mate wareware. The need for community support services will grow as the population ages and as we live much longer lives.

The new drugs aren't the solution for most people any time soon. We all need hope, yes, but the best hope still lies in making early contact with the community dementia support experts.

This edition of *Mind Matters* brings that reality into focus.

Its theme, Behaviour as Communication, asks us to consider what may sit behind changes in behaviour and how greater understanding might lead to a better response. It also recognises the pressure placed on care partners and whānau, who are often trying to make sense of and respond to situations for which there is no simple answer.

This is where accessible, community-based support has such an important role. Information, education and guidance can help whānau understand what they're seeing, consider what the person may be communicating and respond in a way that protects dignity and wellbeing.

For Dementia New Zealand, strengthening these services is central to helping people live their best possible lives with dementia | mate wareware. It reflects our commitment to Ki kōna tāua hui ai – meeting people where they are – and to supporting a connected network that can respond to the needs of people and whānau in their own communities.

Medical advances may change what's possible in years to come. Alongside them, we must continue to invest in the knowledge, services and human support people need today.

Frances Blyth
Chair, Dementia New Zealand

LIVED EXPERIENCE – JACQUI SAWFORD

I Thought He Was Choosing to Hurt Us

For years, Jacqui Sawford thought her husband Kevin was choosing to turn away from their family, lying, stealing and drinking heavily.

His diagnosis with behavioural variant frontotemporal dementia changed how she understood the behaviour – but it didn't erase what it had cost them. This is Jacqui's story.

My phone buzzes with a text from Kevin.

"The washing's folded and the animals are fed."

Kevin spends most of his time in his room now. Folding the washing and feeding the animals are among the few familiar tasks he can still do. When he finishes something, he sends me a message to let me know.

For a long time, I didn't know whether our marriage would survive.

Kevin had always been dependable. He stayed in jobs for 15 or 20 years. He was a hands-on father to our seven children and a man who worked hard for his family.

Then his behaviour began to change.

He moved from job to job. He drank heavily. He lied.

He tried to have affairs and sent messages to other women. Later, he began stealing from a former workplace.

Nothing added up.

I thought it might be depression, grief, burnout, COVID or a midlife crisis. We had recently lost several close family members, so there were explanations for why he might be struggling. But it just got worse. He was becoming someone none of us recognised.

I ping-ponged between feeling hurt, confused, shocked and angry at his behaviour. Our children were angry. Some of them wanted me to leave him.

I came very close.

The moment I knew something was seriously wrong came when Kevin drove me to hospital to have a stent inserted. He dropped me outside and simply said, "See you later. Good luck."

I stood there thinking: Who does that?

This was my husband. I was about to have a heart procedure, yet he showed no concern and seemed unable to understand that I might need him. It wasn't just thoughtlessness. The empathy I would once have expected from Kevin simply wasn't there.

When I confronted Kevin about his behaviour, his answer was often the same: "I don't know."

At the time, it felt like another lie. I would push harder because I wanted him to explain how he could do these things to us. Now I understand that he genuinely didn't know.

In April 2025, after I told Kevin I couldn't keep living this way, he drove north to stay with his mother. He arrived, said he was going to get petrol and disappeared. The police eventually found him disorientated and took his licence.

I wrote a detailed letter to his doctor describing everything we had seen. After cognitive testing, blood tests and brain scans, Kevin was diagnosed in August 2025 with behavioural variant frontotemporal dementia, or bvFTD. He was 55.

Unlike forms of dementia that may first become apparent through memory loss, bvFTD can affect judgement, self-control, empathy and socially appropriate behaviour. In Kevin's case, those changes had been unfolding for years.

The diagnosis was devastating, but it also brought relief.

Not happy relief. It was the relief of finally understanding that Kevin hadn't chosen to become this person. The disease had changed how his brain worked.

The diagnosis gave Kevin his dignity back within our family. Our children could look at him and see their dad again – not simply the man whose behaviour had caused so much hurt.

Understanding the reason didn't make those painful years disappear. The attempted affairs still broke my heart. The lies still happened. Our family still carries that pain. Both things can be true: Kevin wasn't responsible for having dementia, and living with his behaviour was extraordinarily hard.

Today, my focus is keeping him comfortable and safe.

Alcohol had become an obsession, but arguing or simply refusing him could create more distress. So I found alcohol-free versions of drinks he already enjoyed: hazy beer, ginger beer and even a chocolate stout.

He doesn't feel he's being punished or deprived. He gets a drink he likes, and I can protect the distance we've created between him and alcohol. A small success – meeting his needs while protecting myself.

I don't yell anymore. The anger and bitterness went after the diagnosis because I stopped expecting Kevin to explain behaviour he couldn't understand himself.

That doesn't mean I always get it right.

On a family holiday, one of our daughters noticed I was becoming snappy with him. I realised I was expecting Kevin to respond as my husband always had – to see what needed doing and step in without being asked.

He still looked like Kevin, but his brain could no longer make all those connections.

I often ask myself: what hat am I wearing today? Am I Kevin's wife, or am I his care partner? The answer can change from one moment to the next.

I miss my husband. I miss the intimacy we had and the life we expected to share. But love hasn't disappeared. It just looks different now.

Sometimes it looks like a meal prepared before I leave for work. Sometimes it's an alcohol-free beer passed across the room without an argument.

And sometimes it's a message on my phone telling me the washing is folded and the animals are fed.

As told to Meg Jones, editor.

BY SHEENA FARQUHAR
Clinical Lead/Educator, Dementia Wellington

Sheena is a registered nurse, bringing clinical knowledge and frontline experience to her work with people living with dementia, whānau and care partners. She is committed to practical education, connection and helping people navigate the dementia journey. This article was written with the support of the Health Improvement Practitioners at Tu Ora Compass Health.

What is Anosognosia, or Lack of Insight?

Anosognosia is a symptom in which a person is unaware that they have the symptoms of dementia | mate wareware.

This happens because of changes thought to occur in a part of the brain called the right frontal lobe.

Normally, the brain keeps an up-to-date picture of the body, which helps us know when something is wrong, like an injury or illness. But with anosognosia, the brain cannot update this picture. For people with dementia, this means they don't realise anything has changed, even when it's clear to others.

It's not a deliberate act. They are not in denial; their brain simply cannot recognise the changes.

This can look like:

- Avoiding or refusing to talk about memory or thinking problems (may seem like denial or covering things up)
- Not wanting to see a GP or get assessed
- Becoming angry with family or health professionals who suggest an assessment, give a diagnosis, or take away their driver's license
- Refusing support or services offered (such as a referral to a dementia support service)
- Taking risks, such as continuing to drive even after their license has been taken away
- Strain or breakdown in relationships with family or carers.

These behaviours aren't intentional. They happen because the person's brain is unable to recognise the changes in themselves.

WHAT YOU CAN DO TO HELP - HUGS

H Honour the person's perspective

- Seek to understand what the person believes or understands about themselves and their situation. Even if their beliefs seem inaccurate to others, they are real and valid to the person.
- Involve the person in decisions wherever possible to promote dignity and autonomy.

U Use empathy

- Remember the person isn't being deliberately difficult – they're unwell. The part of the brain responsible for self-awareness and insight is damaged.
- Avoid confrontation or trying to convince the person of their condition. Instead, listen attentively and validate their feelings.
- Have compassion for yourself. Supporting someone with anosognosia can be emotionally demanding. Recognise that it's normal to feel frustration, sadness, or grief – reach out for support when you need it.

G Get alongside

- Avoid using potentially triggering words like "memory loss" or "dementia" if they lead to distress or resistance.
- Identify a family member, friend, or health professional who the person trusts and who can help guide, support, or manage more difficult conversations (e.g., around driving or safety).
- Work together rather than "taking over" – this supports the person's dignity and may help reduce resistance.

S Strategise interactions and support

- Only ask questions the person can answer or assign tasks that are achievable. Simplify or modify tasks if needed.
- Continue offering choices in daily life to help the person retain control and dignity.
- Manage safety risks calmly and respectfully – where necessary, make adjustments in the background that protect the person while preserving their sense of autonomy.
- Set up third-party consent at medical practice so whānau can share relevant information.
- Seek legal advice early to ensure Enduring Power of Attorney (EPOA) is in place.
- Connect with your local Dementia New Zealand Affiliate or support organisation for guidance, resources, and emotional support.

Example

- *Person living with dementia: "There* is no reason why I can't drive. I have been driving safely for many years."
- *Supporter:* "Yes you have been driving safely for many years and you feel you are still safe. "Knowing that I can understand how upset/angry/ frustrated you must feel."
- *Supporter:* "You have always trusted your GP in the past, maybe I should drive today until we can clear this up."

The HUGS approach has been developed by the Health Improvement Practitioners at Tu Ora Compass Health, with input from Dementia Wellington, an outreach nurse at Tawa Medical Centre, and family supporters.

VIEW THE BROCHURE FOR MORE INFO

BY CHANTELL BRAMLEY
Communication Manager, Dementia Canterbury

Mackenzie Ebbett, Clinical Nurse Specialist, Older Person's Health, regularly presents on Behaviours in Dementia as part of Dementia Canterbury's Specialist Dementia Education Series. This article by Chantell is a summary of Mackenzie's most recent presentation.

Behaviours in Dementia

As dementia | mate wareware progresses, many people experience behavioural and psychological changes.

These changes may be caused by the condition itself, changes within the brain, physical health, medication, daily routines, or the surrounding environment. Understanding why these changes occur can help both the person living with dementia and those supporting them to respond with greater confidence and understanding.

Understanding the Brain

Different parts of the brain are responsible for different functions:

- **Frontal lobe** – thinking, initiation, memory, behaviour, and movements
- **Parietal lobe** – language and touch
- **Temporal lobe** – hearing, learning and feelings
- **Occipital lobe** – vision
- **Cerebellum** – coordination and balance
- **Brain stem** – breathing, heart rate and temperature regulation.

Different types of dementia affect different areas of the brain. Alzheimer's affects all areas but particularly the parietal and frontal lobes in the early stages. Parkinson's dementia and Dementia with Lewy bodies primarily affect the frontal, parietal and occipital lobes. Vascular dementia mainly affects the frontal lobe, while frontotemporal dementia primarily affects the frontal lobe.

Five Guidelines to Live By

When responding to behavioural changes, Mackenzie encourages carers to keep five key principles in mind:

- Think of behaviour as a form of communication
- Try to identify the cause of a behaviour change
- Consider whether a behaviour is genuinely risky or hazardous, rather than simply frustrating or annoying
- Maintain a structured and predictable routine wherever possible
- Create an attitude of acceptance.

Behaviours We May Encounter

Anxiety, apathy and disrupted sleep are all common changes experienced by people living with dementia.

As dementia progresses, people often have less ability to cope with stress and become more dependent on those around them to help manage their emotions.

Apathy, or a lack of interest and enthusiasm, is also common. The person living with dementia is often unaware of it or bothered by it, although it can be very noticeable for whānau/family members and carers, particularly if they were previously highly motivated. Importantly, apathy doesn't necessarily mean the person is depressed, even though it may appear that way.

People living with dementia may need help getting started with activities or support to complete them. Many carers worry that reduced

engagement may contribute to further decline, and this is a valid concern. Sometimes it can help to simply begin an activity rather than asking if they would like to do it. For example, putting on shoes and heading out for a walk together without a lengthy discussion.

Changes in sleep patterns can occur as part of the normal ageing process, but they're also common in dementia. Sleep disruption can be linked with apathy and reduced physical activity.

Depression is also common, particularly in the early stages of dementia when people are often more aware of their diagnosis and what the future may hold. Many grieve for the future they had imagined and worry about becoming a burden on those they love. These feelings can lead to despair.

Delirium, Delusions and Hallucinations

Delirium is an acute state of confusion caused by an underlying physical problem, such as dehydration or a urinary tract infection. It can cause a person to become much more confused suddenly or unwell and requires urgent medical assessment.

Delusions involve believing things that aren't true, such as believing someone is trying to harm them or that events are happening when they're not.

Hallucinations involve seeing, hearing or sensing things that aren't there. Strong emotional memories from the past may also feel as though they're being relived or experienced again.

Understanding Behaviours of Concern

Some behaviours can be frustrating for carers and those around the person living with dementia. However, it can be helpful to remember that these behaviours often reflect an underlying need that the person is unable to express in another way.

Sometimes repetitive behaviours are soothing or comforting. Compulsive or perseverative behaviours may include folding pieces of paper repeatedly, holding onto objects or continually cleaning. These behaviours generally become a concern when they begin to affect the person's normal daily activities or health.

Impulsive or disinhibited behaviours can be particularly challenging in public settings. There are cards available that people can carry or display to help explain dementia-related behaviours to others and encourage understanding and empathy.

Wandering can present a significant safety risk. It may be triggered by something in the person's environment, a desire to complete a task somewhere else, or an unmet need or impulse. Even during a familiar walk, a person living with dementia may become disoriented.

Seeking Support

If you need help, speak with your GP, your local Dementia New Zealand Network Affiliate, or trusted friends and whānau/family.

Mackenzie also recommends using the DICE approach, a framework commonly used by clinicians:

- **Describe** what is happening
- **Investigate** possible causes
- **Create** a plan to address the behaviour
- **Evaluate** whether the plan has been effective.

It can also be helpful to explain the person's changing needs to others. Dementia symptoms aren't always obvious, and behaviours may vary considerably throughout the day. It's perfectly acceptable to explain what support the person needs at that particular time.

If behaviours such as physical aggression or verbal abuse develop, it's important to seek help and ensure your own safety. Speak with your GP or your Dementia Affiliate team. You are not alone.

Looking After Yourself

Mackenzie reminds carers that supporting someone living with dementia is a journey, not a sprint.

Laugh when you need to laugh, and cry when you need to cry. Remember that you are not alone. It is natural for the person carrying the greatest responsibility – the 'anchor' person – to find themselves in the hardest position.

Mackenzie Ebbett's Behaviours presentation was delivered in March 2026 as part of Dementia Canterbury's Specialist Dementia Education Series.

YOU CAN WATCH IT HERE

BY JACQUI SAWFORD, CARER FOR HER HUSBAND KEVIN

What Hat

Today
I was reminded to be gentle.
Not to snap, not to let
frustration spill out sideways.

Today I saw myself
through other eyes.
And I asked
What hat today?

In this moment,
who do you need me to be?
Am I your carer right now,
or am I your wife?

I can't always tell.
It's all blended, edges bleeding
into one another.
Everything feels blurred
different, difficult,
impossible to name.

I want it to be the wife.
The one who loves without
instruction, who offers
compassion without
reminders.
Care, kindness, patience
I give you all of this.

And then the carer takes over.

Guidance.
Prompting.
Reminding you to change,
to brush your teeth,
to do the things
you once did without thought.

A hat I never imagined wearing.
Not this young.
Not like this.

I snap.
I grieve what I no longer have.
I get frustrated, of course I do.
Words fall away.
I fumble.
I grow sad.

And maybe this, too,
is part of the wife hat.

I don't want a carer's hat.
We don't deserve that one.
We were never meant
to wear it at all.

So I'll aim for gentleness.
I'll notice when I'm snapping,
when frustration creeps in.
I'll do what I can to be both,
without needing to name it,
without swapping hats at all.

Podcast

Dementia care specialist Teepa Snow shares practical ways to connect, communicate and respond to changes in the brain.

She explains why recognising retained abilities, adjusting our own approach and leading with empathy can make everyday interactions more positive and meaningful for people living with dementia and their care partners alike.

WATCH ON YouTube

Living well with dementia

Building for the future

Since 2017, Summerset have been building state-of-the-art memory care centres designed to enable residents living with dementia to continue to lead active, positive lives in a safe and homely environment.

We know that the number of people living with dementia is only going to increase, so we're building memory care centres in a number of villages across the country.

It's Summerset's aim to provide New Zealanders and their families the opportunity to move their loved one into a safe and secure environment with all the touches of home.

What sets us apart?

Our memory care centres offer specialist dementia care delivered by trained and dedicated professionals with knowledge, expertise and passion for caring for people living with dementia.

As residents can sometimes get confused or anxious, our staff focus on understanding the resident's world and therefore how to best support them. A range of activities help to build both a sense of community and ongoing personal development for our residents.

Our memory care centres are designed using international research and best practices to enhance residents' well-being and provide the best quality of life for those living with dementia.

We had specialists from across the business study how dementia friendly design is being implemented globally to improve the lives of people living with dementia. One of those learnings was the need to design differently.

Specialist building design

Our memory care centre design creates a connection with nature, providing places to enhance wellbeing and in keeping with the latest biophilic principles.

This design has many proven health benefits including stress reduction, improved cognitive performance and enhanced moods. Every facet of our memory care centre has been carefully considered to enhance the well-being of all residents.

Unique design features such as wall murals help residents find their way around. The ability to personalise the entrance of each residents front door also assists with wayfinding.

Throughout the centre, calming colours and consistent flooring materials, along with easily recognisable signs, are used to help residents avoid feeling disorientated, while guiding lights are used to assist during the night.

Activity room: every memory care centre has an interactive table with games which are designed to be effective at engaging with residents on physical, cognitive and sensory levels.

Courtyard and Garden: this is a beautiful, secure area which enables residents to move freely between indoors and outdoors, relax in the garden or engage in gardening activities.

Summerset's memory care centres are currently located in 14 villages across the country, with several new memory care centres being planned.

To find a Summerset village with memory care near you, visit summerset.co.nz/memorycare

Summerset
RETIREMENT VILLAGES

BY TINA CARTER
Dementia Advisor at Dementia Wellington

Tina Carter is a registered social worker and enjoys connecting with people living with dementia | mate wareware and their whānau to share information and support as needed. Tina describes her mahi as challenging, stimulating and extremely rewarding. In her spare time, Tina enjoys raranga/weaving, learning Te Reo, singing and time with whānau.

Name Tags, Scones and Stayin' Alive

What do I do in a week? Lots of rewarding mahi! It's always varied.

Let's start with Cog Café [cognition café for social connection]. At our last one, 17 people came into our usual hangout in Wellington. Husbands and wives. Adult children with parents. Some solo – by bus or on the train. Someone ducked out of work to drop off his wife.

I arrive with the name tags in a little kete and soon everyone has a scone and a cup of tea. Then we talk. Not about dementia | mate wareware.

Topics vary. What's happening in Wellington? Local festivals and concerts. What's in the news? And the Wellington weather, obviously. There had been snow the day before.

From the outside, we're just a bunch of people having morning tea. Laughing, talking, enjoying each other's company. And that's the point. It's an ordinary café visit where everyone understands dementia and responds in a mana-enhancing, accepting way.

While people connect, I scan the table. Has someone gone quiet? Does a care partner need a private word? I might arrange a call about respite

Tina Carter, Dementia Advisor at Dementia Wellington, on a home visit

care, organise a one-on-one meeting at the Kilbirnie or Karori community centres, or a quiet café catch-up. I don't get into private details at the table. Then, the name tags go back into the kete and off I go.

Home Visits

A home visit looks like a conversation. We just talk.

At the same time, I'm ticking things off in my head. Meals, shopping, showering, dressing. Is there whānau nearby? Friends? Neighbours? What changes has the person noticed, and what would help?

Sometimes a person has anosognosia. Changes in the brain make it hard for them to recognise changes in their abilities. They may say they're eating well when there's no food in the fridge, or insist they're managing their medication when the tablets haven't been taken. To them, both things may feel true. They're not denying what's happening; their brain can no longer give them an accurate picture of what has changed.

Every person living with dementia is unique. Each has different support needs specific to them, so I look to see what strategies, services and approaches will work in each person's or whānau situation. I might say, "Would it be easier if I called you again in three months?" If they'd like more support, and they agree, I can speak with their whānau or connect them with another service. The person with dementia remains at the centre of every conversation and every decision.

One-to-ones also happen at local community centres, online, or in the whānau room at our Hub in Petone. I've had eight family members join a video call from different places on their lunch breaks, trying to support Mum and Dad at home. I keep bringing the conversation back to the person with dementia while listening to the whānau trying to make things work. People talk about balance between maintaining independence while mitigating risks. How do you achieve it? That's the tricky question.

Support Groups

The Active Brain Connection Group is great fun. We begin with karakia and mindfulness, then break into smaller groups and see where the conversation takes us. Recently, everyone brought a taonga – photographs, family heirlooms and other treasures. We filled a whiteboard with what those taonga meant to people: a story, a memory, an achievement, a gift. I loved hearing that.

People living with dementia often find that others stop asking what they think. The questions go to the person with them, even though they're standing right there. But it's very different in this room. Our clients choose what we talk about. They share their stories. Everybody listens. And we have a good laugh. This week, we put on 'Stayin' Alive', stood in a circle and passed a dance move from person to person. You copy whatever comes your way. This dips into creativity, movement and the joy of music. Everyone has a smile as they leave.

Then there's the Supporter Groups. Partners and adult children arrive at different points in their lives – some are still working, some retired. Someone may come with three questions on a Post-it note: "I've come to ask the experts." I tell them they're the experts. I'm there to learn from the people doing this every day.

We talk about changing relationships, care fatigue, grief, guilt and the things that can be hard to say anywhere else. We talk about funny moments too – there's actually a lot of laughter in our Supporter Groups. People can see the funny side, even on difficult days. I find that part of the job very rewarding.

Quite often, somebody from a seniors' group, church, Rotary club, kaumātua group at a marae, or matua group in a Pasifika community will ask, "Can you come and talk to us?" And off I go. We might talk about brain health, living well with dementia or signs that it's time to speak with a GP. If somebody in the room needs support later, Dementia Wellington won't be a name they've never heard before. They've met me. They know what we do. That can make the first phone call a little easier.

That's my calendar. Cuppas, home visits, family calls, Post-it notes, taonga and the occasional round of Stayin' Alive. A lot of listening. A lot of laughter. And always the people we're here for, right in the middle.

BY STEPH HARLAN
Volunteer and Community Engagement Coordinator, Dementia Tauranga

As well as looking after Dementia Tauranga's volunteers, Steph coordinates fundraising and community engagement and leads the annual Artful Mind exhibition.

Outside of work, Steph is an artist herself and spends her time either with her children, painting, or quite often, doing both. Steph holds a Bachelor of Applied Science, majoring in Psychology.

When Words Are Gone, Behaviour Speaks

For years, dementia | mate wareware care has talked about "behaviours" almost like a symptom to suppress.

The terms still sit in care plans everywhere: "wandering", "resistive to care", "aggression", "sundowning". They're tidy, clinical labels, but they describe behaviour rather than help us understand the person.

What if every one of those behaviours is actually a message?

It's a simple shift in thinking, but it changes everything about how we respond. A behaviour stops being something to stop and becomes something to understand.

This is the heart of what's known as the unmet needs model, encouraging us to look beyond the behaviour itself and ask what need the person is trying to express; it's shaped good dementia care for a generation now. Tom Kitwood, a British psychologist widely regarded as one of the pioneers of person-centred dementia care, argued that what looks like disruptive behaviour is almost always communication once language has gone. The person calling out, pacing, refusing a shower, or pulling at their clothing isn't being difficult. They're telling you something the only way they have left.

Picture an iceberg. The behaviour you see is the small visible tip. Underneath sits the real message: pain, fear, boredom, loneliness, too much noise, too little to do, the need to feel useful, or confusion about what's happening to their own body in that moment. Our job isn't to manage the tip. It's to go looking for what's underneath.

I see this constantly in our volunteer groups.

A volunteer once told me about a member who kept trying to leave the room during craft sessions, over and over, never settling. The easy read was "wandering," and some days that's exactly what gets written down. But when our volunteer slowed down and watched more closely, she noticed it always happened around morning tea, the same time this woman had once walked her own children home from school for twenty years. That wasn't restlessness. That was muscle memory, purpose, identity. Once we gave her a basket to carry and a job handing round the cups, the leaving stopped. The need underneath the behaviour had been met.

This is the shift volunteers need most: from managing behaviour to reading it. It asks for curiosity instead of correction and patience instead of a quick fix.

A few questions help every time.

What changed right before this happened? A new face, a missed meal, a louder room, a change of seat. Could this be pain talking?

Dementia often takes away the words for "my hip hurts," but agitation, grimacing, or shouting can carry that message instead.

Is there an unmet emotional need underneath it?

Loneliness and fear often show up as clinging, repeated questions, or distress whenever someone leaves the room.

And the question that does more work than any checklist:

What would I be feeling if I couldn't explain myself and nobody understood me?

That last one is the empathy reframe good volunteer training is built on, and it's the same lens a background in psychology brings to this work. Behaviour always has a function, even when we can't see it straight away.

None of this makes the moment easier in the room. Sitting with someone who is distressed, confused, or repeating the same question for the fortieth time still asks a great deal of a volunteer. But naming behaviour as communication changes the tone of the whole interaction. It stops being something to survive and starts being something to listen to.

It also protects the volunteer. When behaviour is understood as language rather than defiance, it stops feeling personal. Nobody is trying to be difficult. Someone is doing their best to tell you something important, in the only way still available to them.

The same applies at home, where the stakes feel even higher because it's someone you love. Family carers tell us the hardest part isn't the physical work; it's the not knowing why. Why has Mum started hiding her handbag? Why does Dad refuse the same shower he had no trouble with last week? The questions above work just as well around a kitchen table as they do in a group setting. They won't solve everything, but they turn guesswork into something closer to a conversation, even when the words themselves are gone.

As our network grows under Dementia New Zealand, this reframe is one of the most valuable things we can carry between regions. Whether a volunteer is sitting with someone in Tauranga or anywhere else in the country, the same truth holds: behind every behaviour is a need, and behind every need is a person still very much there, still trying to be understood.

Our work, simply, is to keep listening.

Behaviour is Communication

What we see is only the tip of the iceberg. When we look deeper with empathy, we can understand the message behind the behaviour

WHAT WE SEE (the behaviour)

- Aggression
- Yelling
- Hitting
- Refusal
- Pacing
- Withdrawal

These behaviours are communications, not choices. They are a persons way of telling us something.

Empathy turns frustation into connection. Understanding changes everything.

WHAT MIGHT BE BENEATH THE SURFACE (the message)

- Pain or physical discomfort
- Emotional distress
- Unmet needs
- Environment
- Need for connection
- Loss and change

Our role is to look deeper, respond with empathy, address the need, build trust, offer connection and to make a difference.

HOW CAN WE RESPOND

Pause and notice
Take a breath. What is the person trying to tell me?

Look beyond the behaviour
Consider what might be going on.

Meet the need
Respond with kindness and understanding.

Connect
Connection heals and empathy builds trust.

See the person
Rember the person. they are still who they have always been.

BY WINIFRED HENDERSON
Senior Educator, Dementia New Zealand

Winifred delivers online dementia education, and hosts the popular monthly Dementia Talks. She holds a Master of Dementia with distinction and postgraduate Psychology qualifications. Drawing on eight years supporting her mother, she brings valuable lived experience, research expertise and passion for increasing awareness and reducing stigma.

Beyond the Behaviour: Being a Detective, Not a Judge

Once we understand that behaviour is a form of communication, the next question is: How do we respond?

Our instinct is often to correct, explain or reason with someone living with dementia. We want to reassure them with the facts. Unfortunately, because dementia changes the brain's ability to process information and reasoning, facts rarely reduce distress. In fact, they often make it worse.

Instead, one of the most powerful tools we have is **validation**.

Validation means acknowledging the person's feelings without arguing about whether the facts are correct. The facts may belong to today, but the emotions are very real.

When someone repeatedly says, "I need to go home," the need is often not about a physical house. Home may represent safety, familiarity, belonging or the people they love. Rather than saying, "But you are home," we might respond, "It sounds as though you're really missing home. Tell me what you loved about it." Once the emotion has been acknowledged, it becomes much easier to gently redirect the conversation or introduce a comforting activity.

Validation creates trust. Only then do redirection and distraction have the best chance of succeeding.

Successful responses also depend on something equally important: **knowing the person really, really well.**

Think like a detective rather than a judge. Behaviour rarely appears without a reason. Our role is to gather clues.

Ask yourself:

- What does this person enjoy?
- What do they like or dislike?
- What are their values?
- Are there cultural beliefs or traditions that influence how they respond?
- What routines have shaped their life?
- What hobbies, skills or occupations gave them purpose?
- What situations seem to trigger distress?
- What usually helps them settle again?

Every answer helps explain what the behaviour may be communicating.

Imagine a retired teacher who becomes anxious every morning, insisting they must get to work. Rather than repeatedly reminding them they retired years ago, we might acknowledge their sense of responsibility: "Your students were lucky to have such a dedicated teacher." We can then redirect that purpose by inviting them to help organise papers, check a clipboard or assist with another meaningful task. The need to contribute has been recognised, even though the circumstances have changed.

Or consider someone who repeatedly asks for their mother. Correcting them by saying their mother died many years ago often creates fresh grief each time. Validation might sound like, "You really miss your mum. What was she like?" After listening, we might offer a warm drink, a favourite blanket or look through old family photographs. The person's need for comfort has been met, even if the original request cannot be fulfilled.

Even resistance to showering often has an explanation. It may not be stubbornness at all. The person may feel cold, frightened, rushed, embarrassed or overwhelmed. Slowing down, acknowledging those feelings and breaking the task into smaller, respectful steps often achieves far more than insisting they must cooperate.

There is no single solution that works for everyone. What calms one person may distress another. A hug may reassure one individual but feel intrusive to someone else. Music may soothe one person yet overwhelm another. This is why personalised care matters so much.

Families hold an incredible amount of knowledge that can help. They know favourite songs, treasured routines, lifelong occupations, comforting phrases, foods, celebrations and the small details that make someone feel safe. Sharing this information with everyone involved in the person's care creates a much richer picture of who they are.

Some days one approach will work beautifully. The next day it may not. Dementia changes from day to day, and flexibility is part of good dementia care. Keep observing, keep learning and keep adding to your collection of "keys" that help unlock successful interactions.

Above all, remember that behaviour is not the problem. It is often the person's best attempt to communicate a need they can no longer express in words.

When we pause, become curious instead of judgemental, validate emotions before correcting facts, and truly know the individual behind the diagnosis, we replace conflict with connection.

And sometimes, that simple change in approach makes all the difference.

WHEN BEHAVIOUR IS COMMUNICATING SOMETHING

PAUSE
Before correcting

VALIDATE
Acknowledge the feeling

CLUES
Consider the person and context

RESPOND
Choose a personal approach

LEARN
Notice what helps

Think, what might this be communicating?

Look beyond what is said or done to the feeling or need beneath.

Perspectives

Changing behaviour in someone with dementia | mate wareware can come with enormous challenges that can feel like a test of endurance for those caring for them.

HERE WE EXPLORE THREE PERSPECTIVES ON THE ISSUE.

Diane Eason

CARER TO HER HUSBAND

What's one thing you wish more people understood about behaviour in dementia?

That people with dementia aren't being deliberately aggressive or difficult and are unaware they have been.

What's the biggest misconception you encounter?

Comments from friends who say to me "He looks really well and seems fine"

They only see him for a short time and assume you are coping well with this amicable man. They don't see the issues you deal with 24/7.

Can you share one moment that changed the way you think about behaviour?

One day my husband fought tooth and nail with his care person and refused to get in the shower. The shower had to be abandoned, and I was very angry because I put so much energy into organising a pleasant experience for him - heated the bathroom, heated the towel and made sure the water was the correct temperature.

We just dressed him and I took him to his day programme, I was still seething and didn't speak to him, just dropped him off. My daughter-in-law picked him up and he told her in the car that I was angry with him. My daughter-in-law asked why; he just shrugged.

She remembered it was shower day and asked him, "Did you shower today?"

He replied "No! I flatly refused". She told him that would be the reason why I was angry. He came inside and after about an hour he placed his hand on my shoulder and said,

"I don't know what I did, but I am sorry".

I felt so small and terrible that I had seethed all day and he had no recollection of the shower at all or his behaviour. I realised I had to learn to let things go and he wasn't deliberately trying to cause problems. He had his reasons and they seemed very valid to him at the time. I have to learn to look for the reason he is not confident or feeling safe going into a shower now. I have to think now, that behind every behaviour that he exhibits there is a reason and it makes sense to him, and I have to learn to accept that. He isn't trying to attack me personally.

What's one practical thing families can try?

When it gets tough, introduce something new, something to redirect them. Give them a challenge that you know they can achieve. We open up the family tree book and ask him to pick out certain relatives; he loves doing this. We always then get the story that goes with the relative.

What gives you hope?

I hope that the more professionals learn about this terrible condition and we get further information about how to cope with the changes that will be ahead of us. The more information we get, the more it will help the person with dementia.

Paula Greenstreet
MEN'S GROUP VOLUNTEER

What's the one thing you wish more people understood about behaviour in dementia?

That people with Dementia are not deliberately doing odd things on purpose to frustrate you, they are doing their best to make sense of things. Their brains are working harder which causes tiredness, so they are not being lazy and neglecting the tasks they used to do. Let them rest!

What's the biggest misconception you encounter?

They can't always help themselves – they are not being difficult, they're just not able to process information as they once did.

Can you share one moment that changed the way you think about behaviour?

You notice gradual changes, so you change your expectations and learn to cope with it. Your behaviour needs to change as they can't.

What is one practical thing that families can try?

Have patience, don't argue the point and keep your tones level – they pick up on tone rather than words. Keep up with social activities. If someone is doing something you are aware is different and maybe unacceptable, try to distract them by doing or suggesting something else.

What gives you hope?

That more people become aware of dementia and how they can help both the person with dementia and their families.

Nicola Williams
DEMENTIA ADVISOR

What's the one thing you wish more people understood about behaviour in dementia?

That past life experiences can influence current behaviour, so it's really important for a care team to know a person's history to understand why the behaviour could be occurring and to formulate strategies around it. For example, when a client went into residential care he was constantly shifting furniture, which annoyed the people around him. When you look at his life history, there was a time he used to work as a furniture mover, so for him, he was just getting to work. By providing some moving boxes, he was able to shift these around instead of the furniture making it less disruptive to the people around him.

If the person has had a traumatic experience with authority in the past, perhaps uniforms could be triggering. The care team could try covering uniform for this person.

What's the biggest misconception you encounter?

That people with dementia are deliberately trying to be difficult, that they remember some things and not others so they must be "putting it on," that they are unkind or unappreciative – personality is affected by dementia too and these changes are due to the condition, not the person.

Can you share one moment that changed the way you think about behaviour?

Leaning more about how behaviours of concern can be a response to unmet needs that can't be expressed. Trying to problem-solve what the needs are/what the problem is can alleviate many issues. Also addressing underlying anxiety as a cause of the behaviour.

What is one practical thing that families can try?

People with dementia will have false beliefs about things - validate how they feel about what they think has happened even if you don't validate the belief. It can make them feel heard and can de-escalate heightened emotion. If they are accusing you of having an affair, try "It sounds like you are worried I might leave, that must be concerning for you. I am not going anywhere." Or if they think there is someone in the house "That would have given you a terrible fright, let me make sure there is no one there now."

What gives you hope?

Dementia is gradually becoming less stigmatised than it used to be, so more people are talking about it and adding to collective wisdom - which is important as it takes a village to support someone with dementia.

ONE SHARED UNDERSTANDING IS The behaviour isn't deliberate. Look for what may be happening underneath.

Beyond the Pilot: Lessons from Wairoa

When people think about dementia | mate wareware support, they often picture services based in larger towns and cities.

For many New Zealanders living with dementia and their whānau, however, where they live can make accessing support just as challenging as the diagnosis itself.

Wairoa is a rural community with a high proportion of Māori residents, where distance, limited health services and an ageing population create additional barriers to specialist dementia support. In recent years, those challenges have been compounded by severe weather events, including Cyclone Gabrielle, which had a lasting impact on the community. The loss of local aged residential care has placed even greater pressure on whānau, with many families now supporting loved ones with increasingly complex needs at home.

Recognising these challenges, Dementia Hawkes Bay and Kahungunu Executive joined forces to establish a four-year pilot programme designed specifically for the Wairoa community. The partnership combines Dementia Hawkes Bay's expertise in dementia education and support with Kahungunu Executive's trusted local relationships.

From the outset, the focus has been on bringing support to Wairoa, rather than expecting people to travel to Napier or Hastings. Working alongside local organisations, the programme has been shaped by the community itself, with whakawhanaungatanga, cultural understanding and trusted local relationships guiding its design.

The programme is steadily building awareness and trust within the community. More people are reaching out for information, families are finding support, and conversations about dementia are becoming more open.

For people living with dementia, the programme provides a safe and welcoming place to stay socially connected, take part in meaningful activities and keep both mind and body active. Just as importantly, it gives whānau and care partners something that is often in short supply in rural communities – time. Knowing their loved one is safe, engaged and supported allows carers to attend appointments, run errands, catch up with friends or simply take a well-earned break. That respite can make the difference between feeling overwhelmed and being able to continue caring at home.

Yet we know many families are still facing dementia without support, often simply because they don't know help is available.

With a district population of 8,940, including 795 people aged 65 years and over, it is estimated that between 140 and 151 people are living with dementia in the Wairoa District. Local health advocates and the mayor also estimate that around 50 families are currently providing hospital-level care for loved ones in their own homes.

As Aroha Clair, who cares for her mother, shared on an episode of *The Hui*:

"We got to be their guide, we got to be sometimes their voice, and we got to make sure that they're OK where they are."

The programme isn't simply about providing activities; it's about walking alongside people living with dementia and their whānau, helping them remain connected, supported and valued within their own community.

Tracey Lanigan, Chief Executive of Dementia Hawkes Bay, often encourages people to look at dementia differently.

"Come and exercise your brain, just get it going."

She believes reducing stigma is just as important as providing support.

"The stigma will naturally start to decline as people realise actually it's not so much the dementia that we focus on – it's actually being well and living as well as we possibly can."

The Wairoa programme has shown that rural dementia services can't simply mirror those offered in larger centres. Its success has come from genuine partnership, local leadership and designing services around the people who use them.

This approach aligns closely with the Government's Dementia Mate Wareware Action Plan, which identifies Māori and rural communities as priority populations because they experience greater inequities in accessing dementia support. The Wairoa pilot shows what can be achieved when those priorities are supported through practical, community-led action.

As the four-year pilot approaches its conclusion in 2027, demand for the service continues to grow. The programme has built trust, raised awareness and established a model that works for the Wairoa community. The challenge now is ensuring that momentum is not lost.

As Aotearoa looks ahead to another election, there is an opportunity to think differently about how dementia support is delivered. Rural communities like Wairoa have shown that locally designed, culturally responsive services can make a real difference. Sustaining successful models like this would help ensure that where someone lives does not determine whether they can access the support they need to live well with dementia.

The Wairoa pilot shows what's possible when organisations work together and communities help shape the services they receive. The hope is that the lessons from Wairoa will help inform future investment, so more people living with dementia and their whānau can access support close to home, no matter where they live.

DEMENTIA TALKS

Dementia New Zealand

Upcoming Dementia New Zealand Talks

Understanding Behaviours of Concern
Friday, 11 September 2026 @ 10.00am – 12.00pm

Tech Series: Staying Safe with GPS and Tracking Technology
Friday, 9 October 2026 @ 10am - 11am

Upcoming Dementia Canterbury Events

For Adult Children and Family Members of a Person Living with Dementia
Wednesday, 21 October @ 7pm - 8pm

Dementia Canterbury

Legal Matters
Wednesday, 18 November @ 7pm - 8pm

We Need Your Help

Your donation enables people living with dementia | mate wareware and their whānau across Aotearoa to access the support, education and guidance they need – when they need it most.

Please note for your own protection, we no longer take postal or over the phone donations.

To make an online donation to support your local Dementia New Zealand Affiliate, simply visit:

DEMENTIA.NZ

Bringing Banking to a Community Near You

While many Westpac customers now prefer to do their banking through digital online channels, there will always be times when people want to chat to someone face-to-face.

That's why we've launched our community banking services, enabling us to connect in person with customers in smaller centres.

We now have three community banking vans regularly visiting locations throughout Southland, Canterbury and Northland. The vans park in places that are easy for people to access and that they're familiar with – from the Riverton RSA through to Lyttelton's Te Ana Marina and the Paihia Baptist Church.

Specially trained bankers travel with the vans, providing customers with non-cash services including opening accounts, loan applications, support with using online channels and a range of other enquiries.

We also provide support through our community banking services in public spaces such as libraries and community centres throughout the country.

We now serve 20 locations through our community banking initiatives, complementing our extensive branch network, which is the joint-largest of the country's four major banks.

If you're interested in learning more about these services, including locations and times, you can visit our community banking website page at **www.westpac.co.nz/community**.

And learn more about our commitment to accessibility and inclusion, as well as some of the services we provide to enable that, at **www.westpac.co.nz/about-us/accessible-banking**.

DEMENTIA NAVIGATOR

Dementia New Zealand™

Understanding dementia | mate wareware can feel overwhelming, especially in the early stages.

Dementia Navigator brings together trusted information to help build knowledge and confidence - at your own pace.

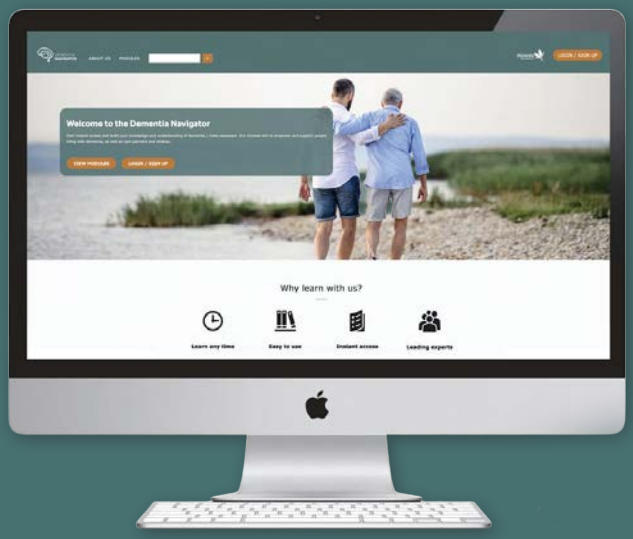
Dementia Navigator is an online education hub with short learning modules covering topics such as what dementia is, getting a diagnosis, early planning, and different types of dementia. It also explores changes that can occur, including behaviour, hallucinations, and disinhibition.

Each module includes practical resources such as information sheets, videos, and links to further support.

Designed for people living with dementia, care partners, whānau, and health professionals.

Learn anytime, in any order. Once registered, you'll have 12 months' access.

Free for people living with dementia, care partners, and whānau.



EXPLORE DEMENTIA NAVIGATOR