Dementia
New Zealand

Our Mind Matters

April 2026

THIS ISSUE

YOUNG ONSET DEMENTIA

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UPDATE
from Dementia New Zealand

Kia ora and welcome to the April 2026 edition of Mind Matters.

Mind Matters is shaped by voices from across the Dementia New Zealand network. Each edition brings together stories from our Affiliates, reflecting the mahi taking place in communities throughout Aotearoa and the people at the centre of it.

The focus for this issue is young onset dementia – when symptoms appear before the age of 65. This often comes at a time when people are still working, raising families, and managing the practical demands of everyday life. The impact can be different, and the path to diagnosis is often longer and less clear.

What follows are first-hand accounts from people living with young onset dementia, alongside their care partners and whānau. These stories speak to how people adjust, what changes over time, and how they continue to stay connected to the things that matter.

I'd like to introduce you to Dementia Tai Tokerau, the newest organisation to join the Dementia New Zealand network. Based in Northland, the team is already supporting their community through local services, including their Active Brain Day programme in Whangārei, and connecting with whānau across the region.

We've recently launched Dementia Navigator - an online education hub designed to make it easier to find clear, reliable information about dementia | mate wareware. It brings together short learning modules and practical resources that people can work through in their own time, whether they're newly diagnosed, supporting someone, or working in the sector. It's designed to sit alongside the support people receive locally, providing information you can come back to at any time. For many people, knowing where to start can be one of the hardest parts. Dementia Navigator is one way we are helping to make that first step more straightforward.

In September 2025, the refreshed Dementia Mate Wareware Action Plan 2026-2031 was launched. This is an important foundational document for the sector, defining the priorities and shaping how services and support are organised and delivered across Aotearoa. You can find more information on our website.

This is the first edition of Mind Matters to be available in a fully digital format. Like many charitable organisations, we continue to balance rising costs with the need to ensure information and support remain accessible. We're grateful to everyone who contributes to making this work possible.

As always, thank you to our Affiliates, supporters, and wider community who stand alongside people living with dementia and their whānau across Aotearoa.

Cathy Cooney
Chief Executive, Dementia New Zealand

Ninety-Five Per Cent

It's Wednesday in Petone. Five people sit around a table. Coffee cups cool between sentences. Someone starts a story. Someone else finishes it.

The five range in age from 52 to 73. A retired GP. A former nurse. An IT specialist. A professional poker player. A teacher.

All five live with young onset dementia.

“People assume that when you've got dementia, you lose your intelligence,” GP Pat says. “They think you're stupid.”

He says it plainly. No self-pity. Just fact.

Three years ago, Pat noticed something was off during a game of Scrabble. Three spelling mistakes in one sitting. That had never happened before. Within days, he had organised his own neuropsychological testing.

He still plays bridge twice a week. Holds a trophy. Volunteers at the hospital. Walks two kilometres a day. He is the honorary president of the British Society of Clinical Hypnosis and will deliver a lecture in Scotland later this year.

“Oh, I was the Toastmasters champion of Wellington,” Pat says, almost as an afterthought.

Then he shrugs.

“I only spend about five per cent of my week thinking about dementia,” he says. “The other ninety-five per cent is the rest of my life.”

Above:

Pat with his Autumn team trophy.

Across the table, Jack leans back in his chair.

“People still come and ask me questions,” he says. For years, he was known as the ‘Godfather’ of New Zealand poker. Younger players still seek him out. “They think they can beat me,me." Then he adds with a grin, "they can't."

He has been a member of the same gym for 20 years. His grandchildren keep him anchored.

“I've got many things that motivate me,” he says. “Number one is my darling great-granddaughter.”

Leanne laughs at something Jack says, then shakes her head.

“There's no such word as can't,” she says.

She was a nurse and educator. At 59, she lives in a rest home. Some days she feels confined. Other days, she ‘escapes’ with an activities officer, heads to the library, then to a museum café for coffee and cake. She has taken up watercolour painting and is learning chess.

“Sometimes my words don't come,” she says. “Sometimes I forget what someone's told me. But that doesn't mean I'm stupid.”

Linda bowls. She swims. She goes to the cinema even if she forgets the plot before she reaches the car park.

“Hey,” she says with a shrug, “it's an outing.”

Recently she bought a book at a sale and read it in one night. She is reorganising her art supplies so she can see them. If they are out of sight, they disappear from her mind.

Fin is the youngest at 52.

Five months ago, he was working as an IT specialist. His days had shape. Meetings. Systems to fix. Problems to solve. Colleagues who relied on him.

At home, he and his wife were building a house while supporting two daughters through study. Two incomes. Church on Sundays. A calendar that filled itself.

Now, some mornings he stands in the kitchen and waits.

“What am I doing today?” he asks.

Work had given his days shape. Without it, the hours stretch.

“One day he was working,” Fin's wife explains. “Almost the very next day, he wasn't.”

The house build stopped. They secured a mortgage on an existing property while employment negotiations were still unfolding. Decisions that once felt steady suddenly felt urgent.

As a migrant family without extended whānau nearby, they are navigating this largely on their own.

They stopped going to church. The noise and conversations became too hard to manage. People began to wonder where they had gone.

For months, no one mentioned young onset support groups. No one suggested there were others in the same position.

Here, around this table, no one has to explain the pauses.

They forget things. Words. Plotlines. Appointments.

None of them have forgotten competition. Or curiosity. Or how to argue. Or how to laugh at themselves.

Jack finishes his coffee and pushes the cup aside.

“They think dementia is the end,” he says. “It's not.”

No one contradicts him.

The conversation moves on.

Listen to podcast

Katie Williams - Growing Up As My Dad's Young Carer

Katie was in just Year 8 when she first learned about her dad's condition - a moment that would quietly reshape her childhood. In the years that followed, she faced the often unseen challenges of being a young carer, watching her once vibrant and athletic father gradually fade as his illness progressed. Through her story, Katie opens up about the emotional weight she carried while still trying to navigate life as a teenager. She reflects on the deep bond she shared with her dad, the heartbreak of caring for him, and the isolation that came with her role.

‘Age-appropriate’ support in Young Onset Dementia: the difference between coping and crisis

By Paul Singh, husband of Jacki, who lives with young onset dementia, and an independent Young-onset Dementia advocate.

Most people still hear the word ‘dementia’ and picture old age. But for thousands of New Zealanders, dementia begins earlier, before 65. That is young onset dementia (YOD), and it arrives right in the middle of life.

It arrived for my wife, Jacki, when she was diagnosed at 58. The first changes showed up years earlier. By the time a family has a name for what is happening, they may already have lost work, income, friendships, and options.

That is why age-appropriate and life-stage-appropriate support is not a ‘nice to have’. It is the difference between coping and crisis.

In the YOD community, I keep hearing the same pattern. The details differ, but the themes repeat: lost income, patchy support, and a constant sense of being redirected. Before there is even a diagnosis, families can be left navigating multiple parts of the health and social support systems, trying to work out what help might exist and what they are entitled to.

Clinical pathways for YOD diagnosis do exist, but in New Zealand, they are largely regional, and they are not always applied consistently or followed in the same way everywhere. During that waiting period, families may also be trying to work out what social support they can access, what is means-tested or reduced through abatements, and how to keep going while income is already under pressure.

New Zealand research suggests people wait about 3.6 years from first symptoms to a formal YOD diagnosis, around 1.6 years longer than older-onset dementia. That is years of retelling the same story and hoping to find a ‘safety net’ that keeps crises at bay. Too often, the first decisive response comes only after an emergency, and the support offered assumes you are decades older, with assumptions that do not fit working-age life.

When dementia arrives in your thirties, forties, fifties, or early sixties, the life stage context changes. Many people are still working. Some are parenting or supporting young adult children. Many are paying rent or a mortgage. Caring for grandchildren may be part of whānau life. Whānau roles shift quickly. Partners become carers while still trying to keep the household afloat. Adult children of the person with YOD may be caring for their own children, while caring for a parent with YOD. Carer burnout is not a personal failure. It is a predictable outcome when support is late, unsuitable, or unavailable.

So what do we mean by ‘age-appropriate, life stage-appropriate’ support and services?

It means support that fits a working-age household, not a retirement-age template. It means recognising that YOD is not simply older-onset dementia happening earlier. It often presents differently, and it progresses while people are still expected to earn, parent, and provide leadership at work, in whānau, and in their communities, creating different pressures on identity, relationships, work, and income.

Age-appropriate support can be practical and very specific:

- A clearer and faster pathway to diagnosis, with consistent expectations across regions
- An automatic post-diagnosis offer (not ‘come back when it is worse’), including a key worker or navigator for the first months
- Respite and day support designed for working-age people, with flexible hours and activities that respect adult identity
- Support for whānau that acknowledges the financial shock and the long haul, including help to plan and coordinate across health and social supports
- Care options later on that do not force younger people into environments built for frail older age, because ‘somewhere’ is not the same as ‘appropriate’

None of this requires reinventing everything. It requires a national expectation, backed by funding, that people with YOD and their whānau will receive age-appropriate support wherever they live. Without that, crisis stays the default.

This is why the Dementia Mate Wareware Action Plan 2026–2031 matters. If it is to be implemented and funded, it needs durable bipartisan, cross-party support so it survives election cycles.

For YOD, the minimum expectation should be explicit: age-appropriate support and services, nationally consistent, and built around life-stage needs, not old-age-based assumptions. Without that, families will keep being treated as an ‘edge case’, and they will keep paying the price in lost income, lost health, and lost time.

The bottom line is simple. YOD arrives in the middle of life. Our support systems should meet people where they are, not where policy categories assume they ought to be.

Local YOD groups near you

Our Affiliate teams run dedicated young onset dementia groups in Auckland, Waikato, Hawke’s Bay, Wellington and Christchurch. These groups are safe, welcoming places where people can share experiences, enjoy activities together, and find personal connection through laughter and support.

Auckland:
Every Wednesday, 10am – 3pm
For more information, phone 0800 433 636

Waikato:
Every second Friday.
For more information, phone 0800 433 636

Hawke’s Bay:
On the third Wednesday of the month.
For more information, contact Katrina on 022 102 8211

Wellington:
First Wednesday of each month, 11am - 2pm
Second and fourth Wednesday of each month, 10am - 12pm
For more information, contact Mai

Christchurch:
Every Tuesday, 9:30 – 1:30pm.
For more information, contact
Erica or Diane

We could do this here

By Darral Campbell, Chief Executive, Dementia Canterbury

Darral Campbell is the CEO of Dementia Canterbury, which has a multi-modal established young onset dementia service. She is an experienced NGO leader and has spent her career working in social work and allied health-based services in community, Health New Zealand | Te Whatu Ora and university settings.

Above:

Saskia Leiwakabessy (Team Leader), and Jeffrey Slijfer (Case Manager/ Social Woker) at Florence Centre for Specialised Care in Early Onset Dementia, Mariahoeve Nursing Home.

When dementia is diagnosed before the age of 65, life doesn't slow down to match the system.

People are often still working. Many have children at home. There are mortgages, friendships, routines, and responsibilities that continue, even as memory, language, or judgement begins to change. Yet the services people encounter are largely designed for a different stage of life.

That mismatch has consequences.

I have worked alongside people living with younger onset dementia (YOD) and their care partners for many years. I have seen how long it can take to get a diagnosis, how often symptoms are misunderstood or minimised, and how hard it is to find support that truly reflects people's lives. Families adapt, fill gaps, and carry more than they should – not because better support isn't possible, but because it isn't organised with them in mind.

In Aotearoa, YOD services remain limited and inconsistent. Where they are available, they're often short-term, underfunded, or integrated into older persons' services that don't suit current needs. The result isn't just inconvenience; it's preventable stress, isolation, and wasted time for people who are still very much in the middle of life.

That gap – between what people need and what the system offers – was the starting point for my research.

In 2023, supported by a Winston Churchill Fellowship, I visited services in Canada, Scotland and the Netherlands to examine how other countries organise support for people living with YOD. I wasn't looking for idealised models. I wanted to understand, in practical terms, what works, what doesn't, and what could realistically work in Aotearoa.

What I found was clear: better support doesn't come from a single programme or intervention; it comes from how services are designed to work together over time.

Supporting the whole journey

Across the services I visited, the strongest examples shared one defining feature: they supported people across the dementia journey, not just at diagnosis or crisis points.

In the Netherlands, the Florence Centre for Specialised Care in Early Onset Dementia at Mariahoeve provides a connected pathway that includes community programmes, day support, respite and residential care. People move between these settings as their needs change, while remaining connected to the same specialist team.

That continuity isn't a luxury. It's fundamental.

People are not repeatedly assessed by new services or required to re-explain their situation. Relationships, knowledge and trust carry through. Care partners are supported alongside the person with dementia, and children are recognised as part of the picture, not an afterthought.

I met people who attended the community programme several days a week while their partners continued working. Some used overnight respite regularly, which allowed them to remain at home for longer without crisis. Others eventually moved into supported living or residential care on the same site, supported by staff they already knew.

One man told me that without the programme, he would spend most days at home watching television, isolated, while everyone else was at work. Instead, he travelled independently, exercised, socialised, and took part in activities that reflected his age, interests and sense of self.

That difference isn't marginal; it changes how people experience dementia, day by day.

Where systems fall short

The services I visited in Scotland and Canada also demonstrated good practice, particularly in early post-diagnostic support. Funded link workers, counselling and structured programmes made a meaningful difference for many families in the first year after diagnosis.

What was harder to sustain was continuity over time.

Access often depended on postcode, transport, or personal finances. Once initial support ended, families described uncertainty about what came next. Residential options designed specifically for younger people were limited or unavailable, leaving families to choose between settings that didn't fit or managing alone for longer than was safe.

Across all three countries, the pattern was consistent. When services are designed for older people by default, younger people and their families are expected to adapt – and many struggle to do so.

That pattern is familiar in Aotearoa.

YOD affects people in the middle of life. It disrupts employment, parenting, relationships and financial security. Care partners often balance paid work with increasing care responsibilities. Children and young people absorb changes that are rarely acknowledged by the system around them.

These realities are well known. What's missing is a coordinated service response that takes them seriously.

What could – and should – work here

I don't believe we can simply import overseas models into Aotearoa. Our funding systems, legislation and geography are different. But the principles that underpin effective support are transferable, and the evidence is strong.

International research and current practice support the development of specialist YOD services that remain alongside people and families throughout the dementia journey. A recognised best-practice model exists, and the opportunity now is to adapt this into an Aotearoa context – including the needs of tāngata whenua, Pasifika and other cultures – rather than continuing with ad-hoc or short-term solutions.

From the research, several elements stand out as both necessary and achievable:

- Specialist, interdisciplinary teams with expertise in YOD
- Clear pathways linking diagnosis, community support, respite and residential care
- Continuity of relationships, rather than time-limited interventions
- Age-appropriate environments and activities
- Structured support for care partners and children.

There is a persistent assumption that our population is too small to sustain specialist YOD services. I don't agree. In major urban centres, there is sufficient population to support designated services if they are intentionally organised and delivered in partnership.

The question is not scale. It's design.

In the Netherlands, the workforce was predominantly registered and specialist, inclusive of allied health professionals, who remained involved even when people moved into residential care. That approach reduced disruption, improved continuity, and supported families to plan ahead rather than respond to crisis.

It also created respite options that allowed people to remain at home longer, improving the quality of life for both the person with dementia and their care partner.

Elements of this already exist across Aotearoa, within parts of the Dementia New Zealand affiliate network and among other dementia service providers. We're not starting from zero. What's lacking is consistency and connection across the wider system, and the confidence to organise services differently where current models no longer fit.

Leadership through collaboration

While a fully co-located model such as Mariahoeve may be difficult to replicate immediately in New Zealand, the findings highlight the importance of engaging early with both Health New Zealand | Te Whatu Ora commissioners and community residential care providers to better integrate specialist YOD services across settings over time.

There is a clear role for Dementia New Zealand and our Affiliate network in promoting this discussion alongside the broader dementia community. Some regions have established YOD programmes. Others are eager to do so but encounter challenges. All struggle with with funding, workforce, or infrastructure.

This isn't about competition between regions or providers. It's a chance to work together – to define what good support looks like, to share expertise, and to enhance services that are locally delivered and nationally connected.

It also requires collaboration beyond the dementia sector:

- Diagnosis pathways matter. Evidence from the research suggests that diagnosis through neurologists specialising in cognitive disorders can lead to earlier, more age-appropriate diagnosis for people with YOD, and a clearer pathway into specialist support than services designed primarily for older adults. Community involvement/integration in such clinics is pivotal to engagement.
- Residential care providers influence later options. Their role in providing age-appropriate respite and residential care determines whether continuity can be maintained as needs change.
- Funders and policymakers set the conditions. Their decisions determine whether services remain fragmented and short-term or can be organised into more integrated pathways across the dementia journey.

Where services operate effectively overseas, responsibility is collaborative. No single organisation handles the entire task, but progress relies on organisations being willing to work together and lead discussions in their respective roles.

Testing our readiness

I'm realistic about the challenges. Residential care legislation, huge community funding pressures and workforce shortages all influence what's achievable. Change will require time and needs to be implemented gradually.

At present, designated funding for younger onset dementia services in Aotearoa is limited or absent. Without funding that recognises the distinct nature of YOD, services remain reliant on short-term arrangements or are absorbed into older-person models that cannot deliver continuity across the journey.

However, realism should not turn into inertia.

People living with YOD deserve services that meet their needs now; age should not limit what people are entitled to. Their care partners and whānau deserve support that acknowledges the long, complex journey they are undertaking.

We already know what better support can look like. We have seen it working elsewhere, and we are beginning to build elements of it here.

The question is no longer whether this could be done in Aotearoa. It's whether we are prepared to organise our services – and our thinking – differently enough to make it happen.

To read Darral's full research paper, visit www.dementia.nz/we-could-do-this-here/.

My People

By Anita Shaw

Through adversity I have made special friends
With them there is no stigma - we are who we are
Together we share a journey that I could not have imagined
Doing on my own

Each one has a special place in my heart
When we get together we are stimulated
By our interaction and activities
That fill our cups

This day is my favourite day of the week
Singing, Sharing,
Trivia and laughter

I went places I never expected to go

Alister Robertson QSM

I didn't expect dementia to take me anywhere new.

Like most people, I assumed a diagnosis meant things would slowly narrow – fewer choices, fewer opportunities, a smaller world. What surprised me was that the opposite happened. Over time, I found myself doing things I would never have imagined, not because I planned to, but because life shifted direction.

Before my diagnosis, I was practical. I worked in banking. I ran businesses. I wasn't someone who stood up in front of rooms full of people, and I certainly wasn't someone who spoke publicly about my personal life. If you'd told me then that I'd one day be speaking to ministers, sitting in disability forums, or playing drums with a group of people living with dementia, I would have said that didn't sound like me.

Yet that's what happened.

When I was diagnosed, the advice I was given was straightforward: keep doing the things you can still do and enjoy, reduce stress as much as possible, and stay socially connected. At the time, I didn't realise how much that advice would shape the years that followed.

Reducing stress meant stepping back from parts of life that were no longer a good fit for me. My role in our business changed, and that happened earlier than it otherwise might have. Staying socially connected meant saying yes to things I might once have avoided, even when I wasn't sure where they would lead.

That's how I became involved in peer support groups and, later, in advocacy work. At first, it wasn't about speaking out or leading anything. It was about listening – sitting with other people living with dementia and learning from their experiences. I began to see how much understanding already existed among people with lived experience.

Gradually, I found myself doing things I wouldn't have attempted before. Speaking to groups. Taking part in discussions where my perspective was useful. Dementia didn't suddenly make me confident, but it did remove some of the internal barriers I'd carried for years.

One of the most unexpected parts of this journey has been learning through activity. Through Dementia Hawkes Bay, we began drumming sessions as part of a group programme. I wasn't musical, and I didn't think I had rhythm. Drumming turned out to be challenging – keeping time, coordinating hands, listening to others, and carrying on even when it didn't quite come together.

It didn't really matter whether we got it right. Some people could play but not sing. Others could sing but couldn't keep the beat. We worked around that.

Music uses different parts of the brain, and you notice it. There are moments when words are hard to find, but rhythm still makes sense. Moments when concentration slips, but the beat carries you through. Ability doesn't disappear all at once – it just changes.

The same has been true in other parts of my life. I still cycle regularly. I take part in community disability groups, raising practical issues like transport access and mobility. I go to programmes where we play pool or snooker – not because it's therapy, but because it's normal. It's social. It's familiar.

I've also found myself in conversations I never expected to have - with organisations, with officials, and with people who want to better understand what it's like to live with dementia. I don't speak as an expert. I speak from experience.

A diagnosis doesn't end your ability to contribute. It changes how you do it. Some things fall away, but others appear in their place – things you might not have chosen, but are glad you discovered.

I didn't plan this path. I didn't expect it. But dementia led me to places I never thought I'd go, and along the way, life continued to surprise me.

A Daughter’s Experience of Young Onset Dementia

Fiona Faithfull remembers her mum, Carol, as intelligent, a community leader, and the most patient, unjudgmental mother. But when Carol developed young onset dementia, everything changed.

“Mum had a successful career starting at what was then DSIR [Plant and Food Research, a Crown Research Institute]. Later, she set up a business with Dad, introducing New Zealanders to dwarf citrus trees, supplying nurseries and orchards throughout Aotearoa,” said Fiona.

Carol was one of those hands-on mums, heavily involved at school and in the community. At one point, she was president of Plunket in the Far North, chair of the PTA at Kerikeri Primary School (where her four children attended) and was always active on school camps and sports.

Fiona remembers: “She was so patient and level-headed – I never heard her yell. I think the worst thing she ever said to me as a teenager was that she was ‘really brassed off’ following me smashing a window with a football!”

The first signs of dementia

In her late 40s, Carol began to struggle with what doctors described as a mix of anxiety, depression and that ‘cover-all ailment’, menopause.

“Something clearly wasn’t right – our normally vivacious, outgoing mum was lacking confidence and was withdrawn,” said Fiona.

After searching for answers, Carol was eventually diagnosed with Alzheimer’s disease at the age of 53, a diagnosis she was never capable of accepting or understanding.

“Mum was unable to acknowledge or believe her diagnosis, and in many ways, that robbed us of the opportunity to have those conversations you would ordinarily have with those you love before you lose them.

“When we lost my mother-in-law to cancer, we were all able to say our goodbyes. We were able to talk to her about how much we loved her – and in turn, she told us how much she loved us all. In many ways, it made it easier to get closure.

“While Mum became stubborn and determined, I believe that this was due to her cognitive decline rather than a reluctance to accept the diagnosis. We hadn’t come across anyone in support networks who had similar experiences with the inability to discuss the elephant in the room.”

Because it had taken so long to get an accurate diagnosis, primarily due to her age, none of the therapies that would ordinarily be available to people in an early stage of dementia were suitable.

It was clear to the family that Carol’s illness was progressing rapidly and that Fiona’s father would need help caring for her. The decision was made that both Fiona’s parents and her nana (who had been living with them) would move in with Fiona and her husband so they could care for Carol together.

Caring for mum while starting a family

Shortly after, Fiona became pregnant with their first son.

“When my friends had their babies, their mums were there to help and support – but when I had Lachie, I also had to look after mum. My beautiful, patient mum would have moments where she became a whole different person – someone none of us even recognised at times.

“I’d make her a cup of tea, and she’d look at it in suspicion, demanding to know what it was that I had put in it. She used to say some terrible things – often telling my siblings or Dad about imagined mistreatment or neglect. It was frustrating and heartbreaking to be constantly painted as the villain, especially when I was doing all I could to help her. I remember feeling so overwhelmed and exhausted.”

Living with increasing needs

Carol also began to have micro-seizures – presenting most commonly as jerk-reflex movements, which caused her to suddenly throw things or fall over, further complicating her care needs.

Eventually, it became clear to everyone that she needed more help than the family could provide. “Everything became a battle – she became combative and aggressive about everyday tasks, from getting dressed to personal hygiene.”

It was after one more significant seizure that Carol ended up in the hospital, and the decision was made within the wider family that it was time for her to have around-the-clock care.

“It was a decision that I knew I would never be able to make and something I had asked my sister to take on; she did a great job of stepping in at the right time. As Mum was moved to a home straight from the hospital, we weren’t able to take our time to place her in a care home near our home, as they had no space – simply because we had ignored the probability that an event such as this would dictate the move to care. We had planned which home we wanted her to go to, but we didn’t plan the timing well.

“It’s not something you want to think about, but I feel we cared for her as long as we could, and in the end, she needed more than we were able to provide. As Mum’s daily needs increased slowly over time, how much weight we were carrying really only became evident to us when she was admitted to hospital and we had a real break from her 24-hour care.

“Another difficulty in placing her into care was that mum was still so young and physically capable, and this had always been a roadblock for us. In the end, her illness had progressed so far that by the time she moved into care, her age didn’t carry the weight we thought it would.”

Saying goodbye too soon

Carol passed away in 2022 at the age of 61. She is deeply missed by all of her family, and her memory is kept alive with photographs, stories, and a special bench seat along the Waipu River.

“Mum’s favourite tree is a Tibouchina – it has huge bright purple flowers. Dad found a miniature version of it that’s just been released – it’s called ‘Carol Lyn’, just like mum – so the bench seat is now surrounded by beautiful flowers and her own Carol Lyn.”

Fiona is telling her story as a way of sharing with others that dementia, and in particular, young onset dementia, can look very different to what people might expect, and that it is often misunderstood. She also wants other care partners to know they are not alone in the challenges they face, and that support and understanding are available.

“If there’s one thing I’d say to others, it’s that you’re doing a good job. You might not feel it at the time, but the love and effort you put in may not feel appreciated, but it matters more than you know.”

• • •

Fiona is a lawyer at McVeagh Fleming. Her experience has shaped not only her family life but also her professional one. She is providing subsidised legal support (wills and Enduring Powers of Attorney) for people living with dementia and their whānau. Find out more here.

Support where you are

Young onset dementia (YOD) doesn't wait for retirement. It arrives when someone is still working. When children may still be at school. When the mortgage still needs paying. It interrupts a life that is still in full motion.

Too often, the services available were never built for that stage of life.

More than a decade ago, a small group of Wellington clinicians and people who had experience of YOD in their families saw this clearly. Younger people with dementia were being directed into environments designed for those twenty or thirty years older – lounges and programmes built around retirement, not midlife. The fit was wrong. The distress was real. There was no dedicated national source of information for families trying to make sense of it.

So, they built one.

The Young Onset Dementia Aotearoa Trust (YODAT) was established to address the absence of age-appropriate services and to provide guidance for people living with YOD and their whānau. Its goal remains clear: people with YOD should retain belonging, autonomy, and meaningful activity for as long as possible.

A place built for midlife

In Wellington City, YODAT runs a two-day-a-week programme for people living with YOD. Cognitive stimulation therapy sits alongside structured activities that reflect mid-life adult interests and abilities. A cooked lunch is shared. Conversation is part of the day. Twelve people currently attend, aged 54 to 80. The youngest person to have attended the programme was only 39.

The programme exists because younger people do not stop needing purpose when they develop dementia. Research shows that unfamiliar, institutional settings can heighten distress for this group. Age-appropriate services are not optional. They are necessary.

YODAT has never intended this work to remain in a single city. They freely share what they have learned with others seeking to develop similar responses in their own communities, including Dementia Auckland, providing advice to set up their own day programme.

When you live outside the main centres

Not every family can attend a weekday programme. Some live hours from a major centre. Some are still in full-time employment. Some are still waiting for a diagnosis, unsure how to move forward.

Through its website, families can submit questions and receive guidance. Many enquiries relate to diagnosis and referral pathways – it's all too common for younger people to encounter delays in primary care or uncertainty about how to access specialist assessment. Early, clear advice can prevent months of delay and uncertainty

YODAT also runs national online support groups.

There is a group for people living with YOD, facilitated by Alister Robertson QSM, who has lived with YOD since 2014. There is an online group for whānau supporting someone at home, and there is a separate group for whānau whose loved one is living in residential care.

They meet at weekends. The timing is deliberate. It recognises that many care partners are still in paid work. It removes geography as a barrier.

Emma Fromings, YODAT trustee, says the decision to separate the two whānau groups came from listening closely.

"We realised very quickly that families at different stages were carrying different questions," she says. "If your partner is still at home, you're managing safety, routines, finances, and work. Once someone moves into care, you're dealing with a completely different set of decisions.

"When someone moves into care, the enduring power of attorney is usually activated. You become the decision-maker. That can feel enormous. You're trying to advocate well. You're trying to get it right. And you're holding grief at the same time."

She has also seen what happens to social networks during the final stretch of intensive caring.

"By the time someone goes into care, families often realise their own world has narrowed. Friends have drifted. Life has shrunk to the essentials. The online group gives people a place where they do not have to start from scratch. Others already understand."

These groups offer more than conversation. They offer practical information about progression, communication with care facilities and navigating legal responsibilities. They provide clarity as well as companionship.

Part of a wider response

YODAT works within the broader dementia community, focusing specifically on younger people and their families. Its national model complements regionally delivered services and helps address the uneven access that families can experience depending on where they live.

For some, especially outside the main centres, the online option may be the only specialised support available.

Emma is clear about what she wants people to hear.

"I want people with young onset dementia and their families to know that wherever they are in Aotearoa, support is there," she says. "You might not have a group down the road. But you can reach out. You can ask the question. You don't have to struggle alone."

For the partner who is still working, still parenting, still trying to hold a household together, that can be a lifeline.

Families can find information or ask a question at https://www.yodat.org.nz/.

Dementia New Zealand

DEMENTIA TALKS

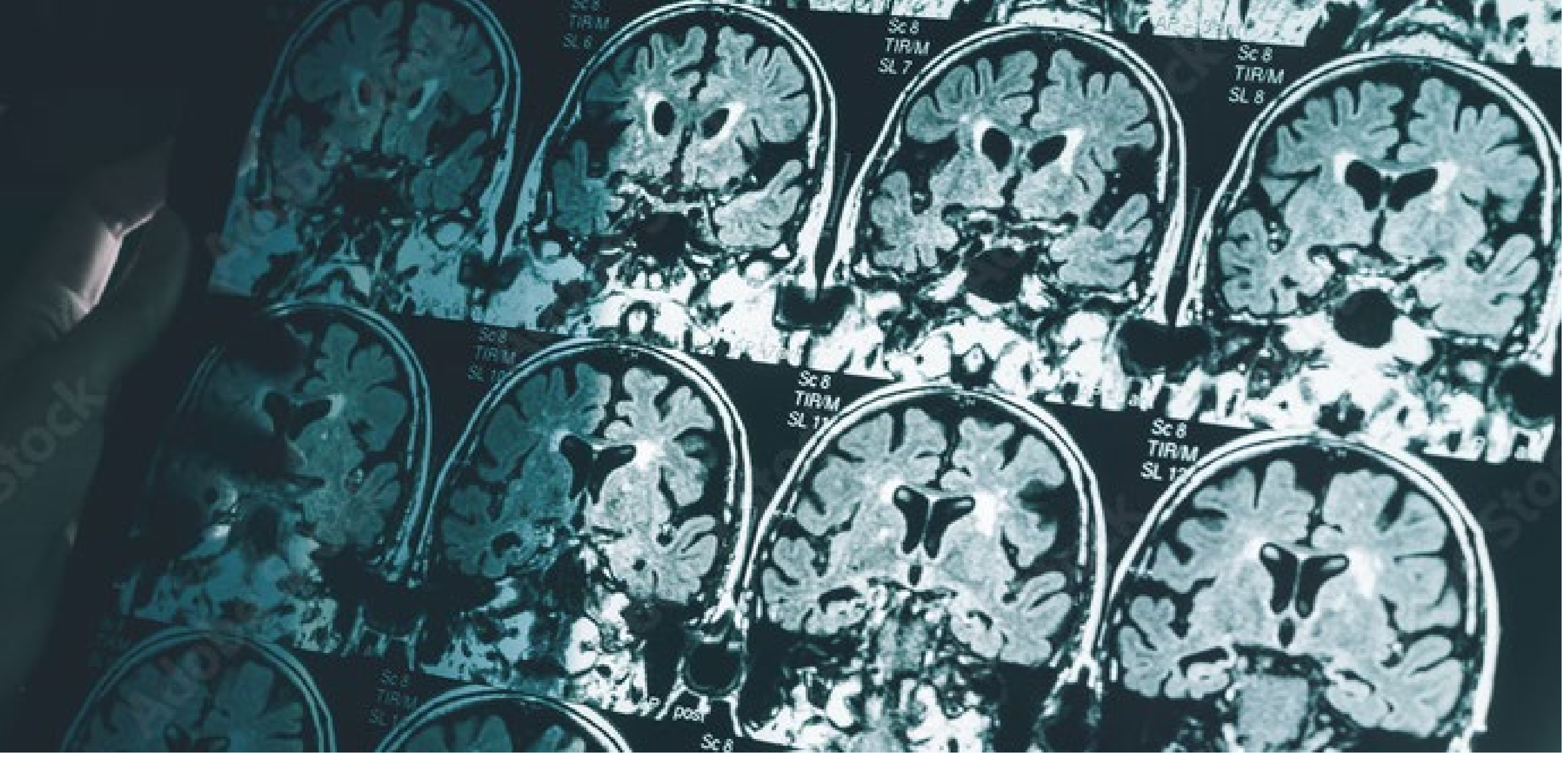
BOOK NOW

Upcoming Dementia Talks

Friday, 17th April
Depression and Anxiety

Friday, 15th May
How to stop worrying

Friday, 26th June - *Technology series*
Staying Connected: Apps that support life with dementia | mate wareware



Understanding Alzheimer’s disease: diagnosis, timing and what it means for families

Dr Campbell Le Heron MBChB, FRACP, DPhil, is a Consultant Neurologist at Te Whatu Ora Waitaha Canterbury and a Senior Lecturer and Neuroscientist at the University of Otago (Christchurch) and New Zealand Brain Research Institute. He runs a young onset dementia clinic, is Principal Investigator for the NZ Dominantly Inherited Alzheimer’s Network site, and leads research investigating the causes of behavioural disturbance in neurodegenerative disorders, as well as broader issues around diagnosis of neurodegenerative disorders such as Alzheimer’s disease.

The word dementia is often used as if it were a diagnosis. In fact, dementia describes a situation in which changes in thinking, memory, language, or behaviour affect daily life and independence. Therefore, it describes the consequences of a disease affecting brain function, rather than the disease itself.

Alzheimer’s disease is one of many diseases that can cause dementia.

This difference is important because understanding what’s causing someone’s symptoms can make a real difference, not just medically, but emotionally, for people and their whānau. In clinic, this distinction comes up all the time. People have often been told they have “dementia” without being given a clear explanation of what’s causing it, or what that means for the future.

Dementia and Alzheimer’s disease are not the same thing

Dementia isn’t a disease in itself. It’s a description of what’s happening when cognitive changes start to interfere with everyday life.

Alzheimer’s disease is the most common cause of dementia, both in older people and in those diagnosed at a younger age. It’s associated with specific changes in the brain, including the build-up of abnormal proteins called amyloid and tau, which interfere with brain function over time.

One of the challenges with Alzheimer’s is that it doesn’t always look the same in everyone. While many people think of memory loss first, Alzheimer’s can also initially affect language, visual processing, or problem-solving, and can cause subtle changes in behaviour, such as loss of motivation. That variability can make diagnosis harder and, at times, slower than people would like.

Why early and accurate diagnosis matters

People come for assessment for different reasons. Some notice memory or concentration problems and wonder whether stress, anxiety or depression might be the cause. Others experience changes that slowly worsen over months or years, but it isn’t yet clear what’s behind them. Less commonly, people present with unusual or confusing symptoms that don’t fit a familiar pattern.

In all of these situations, uncertainty can be deeply unsettling. Many people describe a period of self-doubt and anxiety, particularly when difficulties begin to affect work or relationships. This, in turn, can further affect their function in a negative spiral, whatever the cause turns out to be. For many, having a clear diagnosis lifts a heavy burden of self-blame and worry, even when the news itself is difficult.

Knowing what’s happening helps people stop questioning themselves, plan ahead, and access the right support. It can also reduce the need for repeated testing and investigations, which, in themselves, can be exhausting and distressing.

Everybody experiences minor slips in their thinking – like forgetting a word or someone’s name – from time to time. We suggest seeking a medical review, which usually begins with an appointment with your GP, if you’re experiencing more persistent symptoms that are interfering with your daily function.

What assessment involves

Assessment for cognitive change isn’t based on a single test or scan. It involves listening, observing, and gathering information over time. The cornerstone of assessment remains the clinical history – what changes has a person noticed, how have they progressed across time, and how is their everyday life going. It’s also important to find out about other things that can also affect thinking, such as changes in mood or sleep.

Input from whānau members, friends or others who know the person well is also crucial, as changes aren’t always obvious to the person experiencing them. This is usually accompanied by a physical examination to look for evidence of processes that might be affecting the nervous system (this is often fairly normal in people with Alzheimer’s disease, but can provide important clues in conditions such as dementia with Lewy bodies or frontotemporal dementias).

Cognitive tests we use in the clinical setting provide screening assessments of different areas of thinking, such as memory, language, and attention. But how someone approaches tasks is often just as important as the score itself.

Clinicians aim to determine whether symptoms are linked to mood, stress, neurological disease, or a combination of factors. Spending time with a person, hearing their story, and understanding their day-to-day life is a crucial starting point for interpreting any further tests that may be ordered next.

Alzheimer’s disease begins long before symptoms appear

Over recent decades, research has changed how we understand Alzheimer’s disease. We now know that the biological changes linked to Alzheimer’s begin many years, often decades, before noticeable symptoms appear.

Studies show that amyloid changes in the brain can start 15 to 20 years before memory or thinking problems are detected. Changes in tau tend to follow, along with many other things, with cognitive changes appearing later. Importantly, though, this doesn’t mean that everyone with Alzheimer’s pathology will develop dementia. Many factors influence whether and how symptoms emerge, and understanding and predicting this course is a crucial task that researchers in Aotearoa New Zealand and around the world are engaged with.

Importantly, this means a person can have Alzheimer’s disease pathology in their brain without yet having dementia – or even any noticeable problems. Although we’re not at this stage yet, in the future, it may be that a goal of Alzheimer’s treatment – at least for some people – is to prevent the development of dementia at all.

New diagnostic tools – what they can and can’t tell us

In people who have developed problems with their thinking, new tools now allow clinicians to diagnose Alzheimer’s disease with more confidence, although they must be interpreted alongside symptoms and patient history.

Up to this point, these tests have included spinal fluid tests (requiring a lumbar puncture) and amyloid PET scans. These tests are designed to answer a specific question: Is Alzheimer’s disease pathology present? Unfortunately, though, access is limited and not straightforward. Some tests aren’t publicly funded in Aotearoa, and specialist expertise is needed to use them well. Importantly, though, blood tests that can answer the same question – is Alzheimer’s pathology present? – are emerging and, hopefully, will become available in Aotearoa in the near future.

It is important to emphasise that these tests don’t replace clinical assessment. They also can’t yet tell us exactly how quickly an individual’s symptoms will progress or what their future will look like. Results still need to be interpreted alongside a person’s symptoms, history and overall health. They work best when used to support careful diagnosis, rather than as stand-alone answers.

Emerging treatments – progress with limits

Recently, two different medications (Lecanemab and Donanemab) have been approved in many countries for use in early Alzheimer's disease. This is based on good-quality clinical trial data showing that these agents, which clear amyloid plaques from the brain via the body's immune system, modestly slow the rate of cognitive decline. These medications are not currently available in Aotearoa.

It's important to be clear about what these treatments can and can't do. They don't restore lost memory or thinking abilities, and they're not a cure. They do aim to modify the course of Alzheimer's, and their benefit may be greatest when used early, before significant brain damage has occurred, although there is still much we need to understand about this.

These therapies also come with risks, including brain inflammation. They're also expensive, and most governments worldwide (including Australia and the United Kingdom) aren't currently paying for them. Research continues to explore whether treating earlier, even before symptoms appear, could have a greater long-term effect. Broadly, though, the emergence of these new therapies further emphasises the importance of improving pathways for diagnosis and care for all people with cognitive symptoms and Alzheimer's disease.

What this means for people and whānau now

This evolving research landscape shouldn't distract from the point that early clarity matters.

A clear diagnosis can help people make informed decisions about work, driving, finances and living arrangements. It can open access to support services and allow time for planning and conversations that may become more difficult as options narrow.

But a diagnosis is also just one point along a person's journey. What follows – practical support, good information, and ongoing connection – is crucial and relies on collaboration between clinicians, dementia services, primary care and local supports. Diagnosis should open doors to support, not close them.

Looking ahead

Understanding of Alzheimer's disease is moving quickly. New tools are improving diagnostic accuracy, and treatments that once seemed out of reach are now being tested and implemented in clinical settings.

No single service can do this alone. Good care depends on coordination among specialist services, primary care, and community organisations. Access to specialist care isn't the same everywhere, and closing those gaps remains important. Collaboration across groups will be crucial as overall management of Alzheimer's disease undergoes a paradigm shift over the coming years.

For now, the key message is simple: clarity helps. Being listened to matters. And planning, support and compassion remain just as important as any test or treatment.

DEMENTIA TALKS

Dementia New Zealand

How Will I Ever Get Through This? Finding Meaning, Connection and Strength while Living With Dementia.

Wednesday, 3rd June 2026
10am - 11am
Online via Zoom

Limited tickets - book now

With leading expert

Dr Lucy Hone
Resilience Researcher
and Grief Educator

"It's just so lovely being a daughter again."

As families grow, dynamics change. Parents age quickly and at times, their little habits become concerns, and those concerns raise the need for change. In some cases, it means that adult children become their parents' caregivers.

Heather Taylor and her husband, John, cared for Heather's mum, Ann in her home for almost two years before the Doctor advised that Ann needed full-time care. "Every time I went to mums, I'd come home grumpy or crying and things were changing, she couldn't remember how to use her remote anymore and she would hide her pills. When we cleaned out her house, we found so many pills. said Heather. "John and I visited Summerset before mum moved in. We had a look around the village and decided this was the place, I just felt good about everything. It feels homely."

Like any big change, it took time for Ann, Heather and John to adjust to their new way of living. But once Ann was settled into her care apartment, knowing that her mum is safe and cared for has allowed Heather to be a daughter again. "It took around four or five months for mum to fully settle in, it was a bit of a roller coaster. But I knew we had done the right thing. And suddenly, everything seemed to come right. I came in one day to visit, and she was sitting on the lounge with a couple of ladies. She wasn't really interested in me, I thought this is fabulous." said Heather. "I found it hard handing the care responsibility over to other people, but you could see the benefits almost straight away. Mum started looking better. She was having her pills, three meals a day, she was hydrated."

"When people ask how it's going, I say it's just so lovely being a daughter again. We now have a stronger relationship than we've ever had, even before dementia. Recently mum told me she loved me before I told her I loved her, and that was huge, because she always tells my daughters she loves them. When I say, 'I love you,' mum doesn't normally say it back. But just recently she put her arms around me and said, "I love you."

If you'd like to know more about the Summerset life, or find a village near you, visit summerset.co.nz

Summerset
RETIREMENT VILLAGES

Nanny Raiha

The soft click of knitting needles and the sound of her mum's favourite playlist are memories Bev Cassidy-MacKenzie treasures.

"When Mum and I sat knitting together, it was peaceful," she says. "Even when her memory began to fade – mum was diagnosed with vascular dementia in 2021 – her hands always knew what to do. It became her purpose - to get up, get ready for the day and then do some knitting."

"I'd put a video on, or a playlist with all her favourite music, like Dolly Parton and Freddy Fender. Sometimes she'd just start singing the words – songs she hadn't sung for a good three or four years.

"All of a sudden, a memory would come back - of her and my dad who had passed 30 years ago. So we'd see all these little spikes, and I'd think, gosh, this whole knitting thing is just so positive."

Bev and her mother Lisa Cassidy - affectionately known to many as Nanny Raiha - knitted baby blankets for local hospitals, up to 20 a month. When her mother passed, Bev wanted that quiet rhythm to live on - and to share it with others.

Drawing on her corporate background, Bev and her whānau set out to make the experience of knitting - and the sense of purpose it brought - accessible to others. With support from their wider whānau, they reached out to friends and connections to create the first knitting packs.

From that collective effort, the Nanny Raiha Charitable Trust was born - a tribute to Raiha and to the kindness that grows when communities work together. The Trust now provides free knitting packs across Aotearoa, complete with wool, needles, patterns, and links to online tutorials for those who need a little guidance. For those who aren't able to knit, colouring-in packs can be ordered.

Each completed baby blanket is donated to local maternity units and hospitals, continuing the circle of care.

"It's about whanaungatanga," Bev says. "People of all ages coming together, creating with their hands, and giving back to others – just because you have dementia, it doesn't mean that you're not able to contribute to society.

"Some of these babies are leaving the hospital with very little, but having something precious and made just for them is something their parents treasure."

Since then, many packs have been shared nationwide, supported through donations and partnerships. For many, the familiar rhythm of knitting brings focus and comfort - supporting memory, fine-motor skills, and emotional wellbeing.

"What I love about Nanny Raiha is that it reminds us how everyday activities can help people stay connected and feel valued," says Dementia New Zealand Chief Executive Cathy Cooney. "It's a wonderful expression of Ki kōna tāua hui ai (meeting you where you are) and Manaakitanga (showing care, inclusion, respect, support, trust and kindness)."

You can learn more, or request a free knitting pack at www.nannyraihacharitabletrust.com.

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 21 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

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.

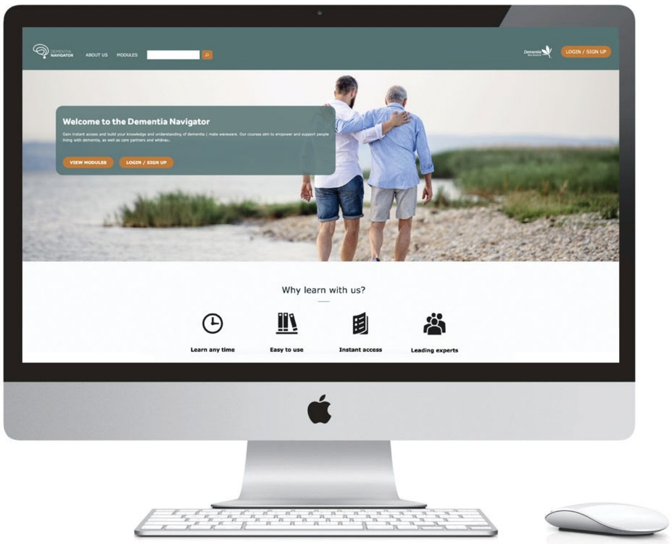
Each module includes practical resources such as information sheets, videos, and links to further support.

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.

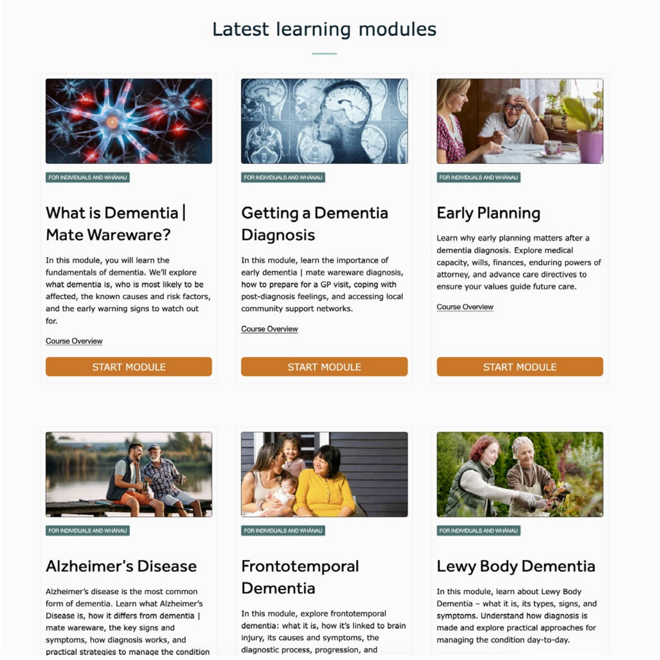
Explore Dementia Navigator



Welcome to the Dementia Navigator

Gain instant access and build your knowledge and understanding of dementia | mate wareware. Our courses aim to empower and support people living with dementia, as well as care partners and whānau.

Why learn with us?


Latest learning modules

What is Dementia | Mate Wareware?

In this module, you will learn the fundamentals of dementia. We'll explore what dementia is, who is most likely to be affected, the known causes and risk factors, and the early warning signs to watch out for.

Getting a Dementia Diagnosis

In this module, learn the importance of early dementia | mate wareware diagnosis, how to prepare for a GP visit, coping with post-diagnosis feelings, and accessing local community support networks.

Early Planning

Learn why early planning matters after a dementia diagnosis. Explore medical capacity, wills, finances, enduring powers of attorney, and advance care directives to ensure your values guide future care.

Alzheimer's Disease

Alzheimer's disease is the most common form of dementia. Learn what Alzheimer's Disease is, how it differs from dementia | mate wareware, the key signs and symptoms, how diagnosis works, and practical strategies to manage the condition

Frontotemporal Dementia

In this module, explore frontotemporal dementia: what it is, how it's linked to brain injury, its causes and symptoms, the diagnostic process, progression, and

Lewy Body Dementia

In this module, learn about Lewy Body Dementia – what it is, its types, signs, and symptoms. Understand how diagnosis is made and explore practical approaches for managing the condition day-to-day.

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.

To make an online donation to support your local Dementia New Zealand Affiliate, simply visit **www.dementia.nz/**.

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

SCAN TO DONATE