Dementia
New Zealand

Our
Mind Matters

September 2023

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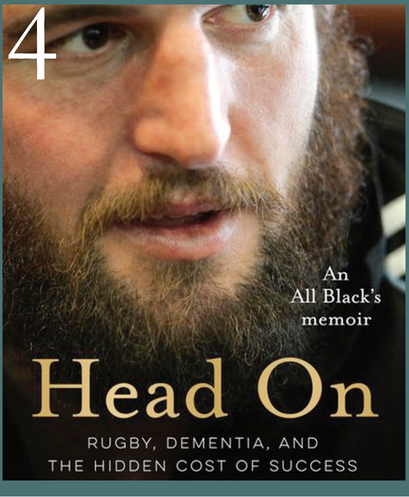

An
All Black's
memoir

Head On

RUGBY, DEMENTIA, AND
THE HIDDEN COST OF SUCCESS

THANK YOU

We truly appreciate all the amazing volunteers, sponsors, friends, donors, funders and supporters. Your kindness and generosity make it possible for us to make a real difference.

Thank you to the families, friends and generous donors

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COVER PHOTO: Eight volunteers living with dementia open a restaurant - Page 7

UPDATE
from Northern Regional Board Chair

Welcome to this edition of Mind Matters. It is a great pleasure to be able to introduce the interesting range of topics in this edition and to thank you for your support and encouragement of the work we do across our Dementia NZ network.

In this edition we feature the recently screened ***Restaurant that Makes Mistakes*** which was a very heartwarming and informative reality TV series. The show clearly demonstrated how important it is for those living with dementia to be actively involved and contributing members of their community. The series continues to be available on TVNZ+ and is definitely worth a watch. We appreciate the hard work of the production team and Rhonda Preston-Jones who worked on set to ensure the show was a success.

It reminds us that across the country our teams are committed to supporting people with a diagnosis and their carers, to be active and connected and living with purpose. Our vision is *Helping people live their best possible lives* and we are certainly proud of the work our staff are doing supporting people to live well in the community.

In the past eight months we have moved to a regional approach which sees our Dementia Waikato, Dementia Lakes and Dementia Auckland teams now working together for the benefit of those we support and for the professional development of our staff. We were particularly delighted in June to welcome the Dementia Advisor team based in Taupō and Turangi to the Dementia Lakes Rotorua team. We have already seen this regional approach enable the sharing of resources including Welcome Packs for new clients and the opportunity for carers and family members to participate in online learning and sharing sessions. We very much look forward to sharing stories from across all regions in future editions of Mind Matters.

We are also proud of the work happening jointly between Dementia New Zealand and Alzheimer's New Zealand on a suite of services that bring to life the commitment made by the Government in the Improving Dementia Mate Wareware Services in Aotearoa NZ Action Plan published in 2021. The plan describes the best combination of services that bring benefit to those living with dementia and their support people. The services have now been costed and will form the basis for a case to be put to Te Whatu Ora (Health New Zealand) by both our organisations with the goal of securing more sustainable future funding.

The Board join with me in acknowledging the work of our staff, and a big thank you to those who support us in practical ways such as being volunteers supporting our activity programmes, or through your generous donations and sponsorship. We greatly value your support as it enables us to continue to offer a range of community based active brain programmes and to provide opportunities for social connection, sharing and caring, and for people to have fun together.

Jocelyn Weatherall
Northern Regional Board Chair
Dementia New Zealand

In our April 2023 edition of Mind Matters we brought you the story of our Dementia Advisor, Janine Appleby, from Dementia Waikato - See ***On the roads less travelled***.

We are happy to update our Waikato Lakes community that Janine has recently been appointed to the newly created role of Senior Dementia Advisor, Waikato/Lakes Region.

The power of being FINANCIALLY PREPARED

By Jocelyn Weatherall

When a family member receives a diagnosis of dementia, it can be an emotionally overwhelming and challenging time for everyone involved. One aspect that often takes a back seat but is equally crucial is managing financial and associated affairs.
Having your 'financial house in order 'during such times can be incredibly empowering, providing a sense of control and security. Here are some tips for you to consider.

DOCUMENT ESSENTIAL FINANCIAL INFORMATION:
Start by creating a comprehensive record of all financial information (even if it's just a file box!) including assets, liabilities, and details of bank accounts and other accounts such as insurances, and other utilities. It is essential to keep these documents organised and easily accessible. We have added a check list to assist you.

REGULARLY UPDATE FINANCIAL RECORDS:
Life is ever-changing, and so are financial circumstances. Therefore, it is crucial to update financial records regularly. Inform designated persons with Power of Attorney about any changes to ensure smooth management of finances.

KEEP RECORDS OF SIGNIFICANT TRANSACTIONS:
Maintain records of significant financial transactions, such as gifting and large purchases or sales - like buying or selling a car.

UNDERSTAND YOUR INCOME AND EXPENDITURE:
Gain a clear understanding of income sources and monthly expenses. Budgeting and managing finances become more effective when you know where the money comes from and where it goes.

ENSURE LEGAL MATTERS ARE UP TO DATE:
Review and update legal documents such as Wills, Enduring Powers of Attorney, Trust Deed, and Memorandum of Wishes to reflect current wishes accurately.

ESTABLISH A FUNERAL FUND:
Preparing for future expenses, including funeral costs, can provide peace of mind. Establishing a recognised funeral fund ensures that the financial burden of such expenses is mitigated.

DESIGNATE AN AUTHORISED PERSON:
Choose a trusted individual who can act as an 'authorised person' (or this may be your Attorney under a Power of Attorney) to enquire on accounts such as utilities, insurance providers, medical providers, and other financial matters 'just in case' something happens to the primary carer.

INVOLVE FAMILY AND TRUSTED ADVISERS:
Engage your family and trusted financial advisers in planning your financial future. This collaborative approach can create a comprehensive 'game plan' tailored to your specific needs.

BE INFORMED ABOUT SUPPORT OPTIONS:
Familiarise yourself with government assistance programs that may aid in covering the cost of care. For example, in New Zealand, the Residential Care Subsidy helps with the cost of care and is paid directly to the hospital or rest home by the Ministry of Health.

COMMON PITFALLS TO AVOID

Caring for a family member with dementia comes with various challenges, including the complexities of managing their finances. To ensure a smoother journey, it's good to be aware of common pitfalls and how to avoid them.

- Neglecting to create and to review a Will and Enduring Power of Attorney (EPOA) to match with the current circumstances. Both are essential to avoid stress and cost.
- Selling your property and resizing, therefore releasing cash assets, can impact eligibility for the Residential Care Subsidy from the Ministry of Health.
- Not being aware of the Residential Care Subsidy policy rules ahead of time, especially the treatment of personal inheritances, trust treatment and the eligibility to gifts.
- Neglecting to establish a funeral fund: Not preparing for future funeral expenses can create financial strain on loved ones during a difficult time.
- Failing to plan for care options: Avoid rushed and expensive decisions by planning and exploring care options ahead of time.
- Not having the financial and legal framework properly mapped out ahead of time. When there is no clear plan or understanding of the individual's financial situation trusted advisers and attorneys may struggle to navigate the complexities effectively, resulting in potential financial repercussions and increased stress for all involved parties.
- Overlooking the benefits of respite care: Utilising respite care in a planned manner can provide much-needed breaks for caregivers and support overall well-being, possibly deferring the entry to longer term care.

By being aware of these common pitfalls and taking proactive steps to address them, families can navigate the financial challenges of dementia more effectively. Seeking advice from financial professionals and establishing a solid financial plan can offer peace of mind.

FINANCIAL AND LEGAL RECORD SYSTEM

A well-organised financial and legal record system is essential for managing your affairs effectively. The following key points outline what to include in this system:

1 **Personal Information:** Gather details of family members and beneficiaries, along with identification numbers such as bank accounts, IRD number, MSN reference and vital documents.

2 **Financial accounts:** Record information about bank accounts, investments, credit cards, and loans.

3 **Real estate documents:** Keep property documents, mortgage agreements, and rental documents (if applicable).

4 **Insurance policies:** Health, life, property, insurance policies.

5 **Estate planning documents:** Include your Will, Living Will, Advanced Care Plan, Power of Attorney, and trust documents, all deeds, and gifting statements (if applicable).

6 **Tax records:** Keep copies of previous tax returns and relevant tax-related documents.

7 **Retirement and pension information:** Record details of retirement accounts, and pension plans.

8 **Business documents:** Include business ownership papers and contracts (if relevant).

9 **Debts and liabilities:** Keep track of outstanding debts and repayment plans.

10 **Important contacts:** Compile contact information for financial advisers, attorneys, family, and friends.

11 **Healthcare information:** Maintain medical history, medications, and healthcare provider contacts.

12 **Funeral and burial instructions:** Include preferences for funeral arrangements.

13 **Safety deposit box information:** Keep details of the location and access to safety deposit boxes (if used).

14 **Legal correspondence:** Retain copies of legal documents and correspondence.

15 **Miscellaneous documents:** Store any other relevant records related to your finances and legal matters.

Regularly update and secure this record system to ensure preparedness for any eventuality. Inform a trusted individual about the system's location and access for added security and peace of mind.

Note - Disclaimer:
The information provided in this article is intended for general understanding purposes only and should not be considered as professional financial or personal advice.

Head On

Once estimated to be the highest paid player in rugby, Carl Hayman was experiencing the dizzying heights of success. But the very vehicle that put him there – the sport he was passionate about – was slowly and cumulatively causing a spiralling descent.

The price he paid for every victory, accolade and pay cheque was profound, as now at age 43, he is grappling with Dementia.

Carl Hayman is doing what John Kirwan did for Depression – getting an often-stigmatised disease talked about with the help of their star power and willingness to be vulnerable and exposed, despite their lived experience being in a culture not about showing weakness.

His memoir Head On is a "living, breathing, suffering, cautionary tale" about the risks of contact sports. The known concussions were only the tip of the iceberg, as he estimates that throughout his 17 years as a professional rugby player, he took around 150,000 sub concussive blows. These do not meet the threshold to be classed as a concussion, the lack of symptoms makes the more minor damage go undetected, but each impact leaves it's fingerprint until collectively they paint a devastating picture on an MRI scan.

Few people will get to relate to the adrenaline of roaring crowds and celebrity Carl experienced, but when it comes to the emotional journey of dementia, it is something that vastly more people can feel connected to, and have their experience reflected by. In his strikingly honest account, he wrestles with all the same issues as a large percentage of our population – such as the conflict about pursuing a diagnosis. On the one hand providing the validation that his emotional lability was due to a force bigger than him, conversely if it was explained by a diagnosis of Dementia, he thought it was perhaps better to be oblivious to it.

When things started unravelling while he was coaching in France, it was a frustrating process to get answers. Being In his 30s, Dementia was not the obvious explanation, and not one that would be good PR for the rugby industry. It was many a time explained away as depression.

But depression doesn't turn a gentle giant into a man who would ever strike his wife, or account for his inability to remember conversations from five minutes ago and a raft of other cognitive deficits characteristic of Dementia. He painfully describes how he could remember each of his 45 test matches well, but not what he did yesterday. He was eventually diagnosed in London with Chronic Traumatic Encephalopathy (CTE) which he understood to be a type of brain injury. It was not until he read a New Zealand Herald article about himself that he realised it was a type of dementia.

"There was a really problematic line in that story. It was the first time I had been forced to confront the 'D' word. It might sound implausible, but after all the testing, and perhaps because I'd heard so much about what was happening in the US around the NFL, I was almost hyper-focused on the term CTE."

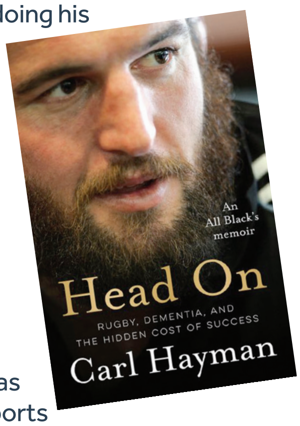
He rang his lawyer to find out if it were true that he had early onset dementia. What followed was a toxic cocktail of alcoholism mixed with a neurogenerative disease - each time he reached for alcohol to placate how he was feeling it only exacerbated his decreasing ability to regulate his emotions. This in turn lead to behaviour he regrets and the demise of his marriage.

When he relocated to New Zealand with a new partner, he struggled to get tangible support.

"I was beginning to feel the sort of rage you feel when you're impotent against the system. I wanted the Accident Compensation Corporation to recognise that the problems I was facing on a daily basis were due to my profession, to the sport I played and loved, but I just kept hearing that I was depressed because I was going through a bad divorce and once I was all clear of that, I'd bounce back and be fine. Try living inside my head and then see how that assessment looks."

He is part of a group of former rugby players taking legal action against World Rugby for failing to protect them from brain injuries. They take issue with the fact that World Rugby won't accept growing scientific research showing constant head knocks is causing CTE.

Carl, however, is doing his part to raise awareness of the issue through his book, media appearances and his work as an ambassador for Dementia New Zealand. His book is perhaps a confronting read for anyone who has played contact sports who may be thinking about their own risk of dementia. It may be comforting to those also experiencing early onset dementia, in that he is helping the public to understand what they are going through.



Carl is to be commended for his bravery in being able to share the details of his life he would probably rather emit. He is championing the cause Head On, and maintains that through everything, he is not without hope.

By Nicola Fletcher-Williams

HEAD INJURY & DEMENTIA

Dr Helen Murray is a research fellow at the University of Auckland Centre for Brain Research and former captain of the New Zealand women's ice hockey team.

She completed her PhD in Anatomy at the University of Auckland in 2017 and conducted post-doctoral research at the National Institutes of Health in Washington D.C. from 2018, before returning to New Zealand in 2020. Her research examines the cellular anatomy of the human brain and how it changes in neurodegenerative diseases, with a particular focus on dementia in contact sport athletes.

Here she unpacks Chronic traumatic encephalopathy (CTE) for us.

Sport-related brain injuries account for up to 20% of all traumatic brain injuries in New Zealand. However, most impacts go unnoticed because they don't cause noticeable symptoms. We know that contact sport athletes may accumulate hundreds of these minor, asymptomatic impacts over their playing career, and the damage caused in the brain can accumulate over time.

Chronic traumatic encephalopathy (CTE) is a progressive brain disease seen in people exposed to hundreds of these small asymptomatic impacts over many years. Public awareness of CTE is growing as former professional contact sport athletes have shared their experiences of receiving a diagnosis of young-onset dementia.

Diagnosing CTE is a difficult task. The disease is defined by the accumulation of toxic clumps of the tau protein inside the brain. These clumps, called tangles, are also seen in other diseases such as Alzheimer's disease. However, in CTE, they form specifically around blood vessels deep in the folds of the brain. There are currently no reliable ways of identifying the tangles inside the brain, although researchers are working hard to identify new types of MRI scans or blood tests that can help detect it.

It is very difficult to diagnose CTE in the clinic because the symptoms that people commonly experience can be similar to those associated with other diseases, especially frontotemporal dementia. We don't yet know how the symptoms someone might experience relates to the amount of tau tangles in the brain. There is no magic number of head injuries known to cause tangle formation, and no magic amount of tau guarantees symptoms will develop.

What we really need is a set of biomarkers for CTE. Biomarkers are biological molecules that can be easily measured (for example, in blood) and indicate that disease-related changes are happening in the brain. It's important to develop biomarkers that can distinguish diseases like CTE and Alzheimer's disease, because the underlying brain changes may require different treatments. My research team at the University of Auckland Centre for Brain Research are searching for potential biomarkers by examining brain tissue donated to the Neurological Foundation Human Brain Bank.

The best way to understand a disease is to study the brain of someone who had that disease.

In our research, we use a novel tissue labelling method called multiplexing to see 50 different proteins on the same piece of brain tissue. This allows us to efficiently explore the disease from many different angles, all at once, while making the most of the precious gift of a loved one's brain.

We are looking at many different markers that could be involved in the tau tangles forming after head injury. We are particularly interested in markers of blood vessel damage and neuroinflammation as this process occurs directly after a head injury and can linger for a long time.

By comparing brain tissue from people with CTE, Alzheimer's disease and normal aging we hope to identify a signature of brain changes unique to CTE that could be measured in blood or with an MRI scan.

Support:
https://www.auckland.ac.nz/en/giving/donate/a-z-list-of-funds/dementia-in-contact-sport-athletes.html

Brain bank information:
https://www.brainbank.ac.nz/

DAD, YOU'VE GOT DEMENTIA

One of our own has become a published author with the release of "*Dad, you've got dementia.*"

"Lyrical, honest, unfailingly loving: a portrait of the power of connection, even when there are no more words"

- Charity Norman, author of Remember Me

Dementia Wellington office manager Kristen Phillips chronicled her father Don's journey, with a focus on the connections he and his whānau made despite his dementia. It is told in short lyrical pieces that convey snapshots in time.

Kristen says it was a cathartic experience to write and a way of processing her grief. She felt that many books about dementia were written with much more focus on the carer, but she feels this book has her Dad's voice throughout it.

She found that Don had some interesting insight and ways of articulating his dementia, with comments such as "I need to tidy my mind" or "I'm not where other people's memories are".

As things progressed, he could still show love and care even without verbal communication.

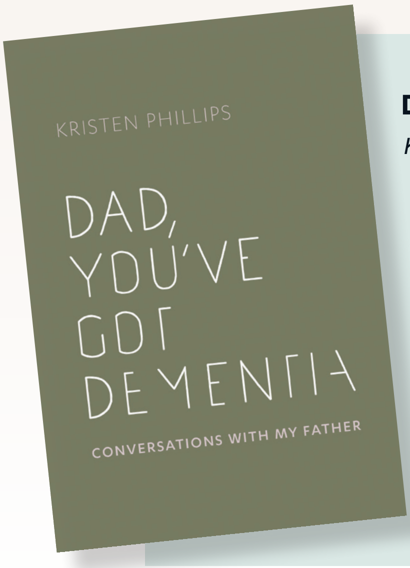
Kirsten says every experience of dementia is different and she hopes it will provoke thought about the reader's own journey.

"I've had something I wanted to say and have said it through this book".

She wants people to know it is possible to have a meaningful connection no matter how advanced the dementia journey is.

"My Dad gave me a lot despite having a terminal illness."

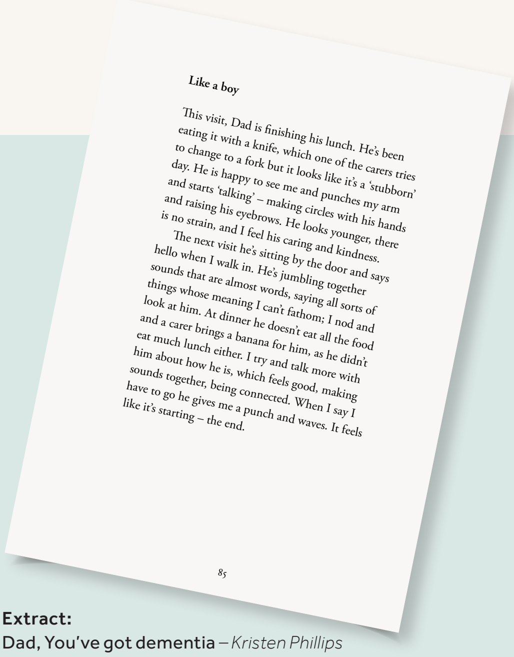
Kristen and her dad at Bob Scott Retirement Village.
Credit: Mia Farlane



Dad, you've got dementia

Kristen Phillips

Dad, you've got dementia is not about what is being lost on a daily basis but what there is still to find. It shows people living with dementia and their whānau that it's possible to stay connected with those they love.



Like a boy

This visit, Dad is finishing his lunch. He's been eating it with a knife, which one of the carers tries to change to a fork but it looks like it's a 'stubborn' day. He is happy to see me and punches my arm and starts 'talking' – making circles with his hands and raising his eyebrows. He looks younger, there is no strain, and I feel his caring and kindness.

The next visit he's sitting by the door and says hello when I walk in. He's jumbling together sounds that are almost words, saying all sorts of things whose meaning I can't fathom; I nod and look at him. At dinner he doesn't eat all the food and a carer brings a banana for him, as he didn't eat much lunch either. I try and talk more with him about how he is, which feels good, making sounds together, being connected. When I say I have to go he gives me a punch and waves. It feels like it's starting – the end.

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Extract:
Dad, You've got dementia – *Kristen Phillips*

THE RESTAURANT THAT MAKES MISTAKES

A charming, educational and uplifting TV series has taken great strides towards challenging people's perception of dementia.

The series The Restaurant That Makes Mistakes featured eight people living with various forms of dementia running a restaurant alongside renowned chef Ben Bayley, with the idea that people with dementia still have much to offer the world.

Dementia Auckland Clinical Lead Rhonda Preston-Jones helped recruit the participants and acted as an advisor during filming, ensuring the wellbeing of the participants through the process. The decision to be involved was not made lightly, as the merits of the concept were debated alongside the fear that the show could be seen as exploitative.

But with the commitment to produce a show with dignity at its core and the chance to challenge stereotypes and get the condition better understood, Rhonda agreed to be involved.

Families too, had some hesitancy. As there can be a lot of stigma around the disease, they were concerned about around how their loved one would be perceived and were protective of the judgement that could come from others towards the people they support.

How the participants would cope was a great unknown - the task at hand involved doing many things that people with dementia would find especially challenging. Restaurant work is busy, noisy, fast-paced, physically demanding, requires multitasking skills and the ability to learn the task at hand and retain information. It can be sensory overload for someone with dementia, they could tire easily, and could have less resilience when facing these challenges. It could be setting them up for failure if they weren't so well supported. Ben and his team provided an abundance of encouragement and understanding the whole way through, so it became more about what the participants could do rather than what they couldn't.

Rhonda says over the five weeks of filming, the participants showed blossoming confidence and belief in themselves, and the show became a lesson in what people with dementia are capable of - given the right support to thrive.

It enabled viewers to get to know the participants through their backstories and see the person, not the disease.

A daughter of one of the participants said "I'm just waiting for the whole of New Zealand to fall in love with our dad because we love him so much – he's amazing".

David Scott, whose wife Suz was on the show, said she loved the teamwork environment and got a lot of satisfaction and enjoyment out of the experience.

"She got a positive kick out of doing something worthwhile, It took her a long time to come down from the high of it, "I was so proud of her and pleased that she had the opportunity to do something meaningful."

Rhonda says there is a powerful message behind the show.

"If you provide people with the right scaffolding to support them, they can still be themselves, and still function. "Yes they'll make mistakes, but that's OK."

Participants were scored on their level of wellbeing at the start and end of filming, and a significant increase was noted. The confidence boost, pride, enjoyment and sense of achievement they got out of it made the show well-worth doing, says Rhonda.

By Nicola Fletcher-Williams

THE ART OF ENABLEMENT

The Restaurant That Makes Mistakes showed what 8 volunteers living with a dementia were able to achieve.

The ability to resurrect old skills, learn new skills, work under pressure, make mistakes but quickly recover and try again was beautiful to watch. The humour, the laughter and the amazing respect shown by everyone made the show a success. What the programme did not show was the support in the background enabling the volunteers to succeed.

A whole crew of people were dedicated to getting the volunteers there, warming them up, reinforcing, encouraging, guiding, and rewarding success. The use of visual cues, repetition, and timely interventions allowed the volunteers to function at their best. The allowance for mistakes took the pressure off the volunteers, who knew they did not have to be perfect. The efforts made by everyone involved at The Restaurant That Makes Mistakes is the embodiment of Enabling.

Enabling someone with dementia to succeed involves focussing on what someone can do, not what they can't.

All adults spend their lives developing skills, abilities, interests, values, likes and dislikes. All people with dementia have lived a full, competent, and rich life. As dementia begins to take away the person's cognitive abilities and they can't recall recent events, remember new instructions, or manage their reactions to challenges as well, the people surrounding them need to step in to support them. This does not involve taking over and doing everything for the person with dementia. It means helping them to do what they can. When we take over all the tasks, roles and activities someone used to do, we are in essence disabling them. When we enable, we help people to do these things to the best of their ability.

A person without activities is at the very least bored, frustrated and irritable, and at worst just existing in a void. This is particularly evident in care facilities where everyday tasks such as preparing food, washing the dishes, doing the clothes washing and attending to the garden is done by others. Residents rely on entertainment to replace the normal everyday activities they have done all their lives.

Every person with dementia is different – some will be able to do activities independently if someone initiates it for them, others do better if someone is doing the task alongside them. As the dementia advances, carers need to help simplify the task, break down the steps and modify the task in a way that works for the person. We need to let go of perfection and focus on the engagement in the task, not the outcome.

The tasks themselves do not need to be elaborate. There is simple pleasure in folding a pile of washing, raking some leaves, wiping a bench, sweeping the driveway, washing the lettuce, setting a table or cleaning the car.

Take a task that the person used to love doing, break it down into the steps required, work out what they are still able to do safely and set them up to do that part.

By Rhonda Preston-Jones

If you want to learn more about Enabling, you can request our two hour Enabling Masterclass online. (Carers or family members $20, health professional or facility or paid care givers $50)

Please contact Dementia Auckland at info@dementiaauckland.org.nz and we will send you the link.

Tailoring activities for people with dementia for an active lifestyle

Dementia doesn't need to stop us from doing things - we just need to find ways to adapt and modify activity so that it's suitable for the person living with dementia.

Our Tailoring Activities for People with Dementia Resources will be up on the Dementia Auckland website for families to access easily. Please feel free to download what is useful for you.

STEP 01	STEP 02	STEP 03	STEP 04
IDENTIFY	**STRENGTHS**	**MODIFY**	**EMPOWER**
Identify what is meaningful to the person Use old skills rather than new skills Involve past interests	Identify the person's current strenths and abilities	Modify Adapt Simplify the task or activity One step at a time Use repetition	Set up the task Support and supevise Guide Do it with them Help Demonstrate Role Model Prompt Praise Encourage

Individually tailored activities for people with dementia

10 USEFUL TIPS FOR DOING

1. Always use adapted adult activities, people living with dementia are adults with a neurological disease, not children.
2. Be the initiator if the person struggles to get started.
3. Work on tasks and activities together.
4. Work at the pace of the person living with dementia, stop if it causes agitation.
5. Do things within the person's concentration span, little and often.
6. Have periods of activity followed by periods of rest.
7. Focus on the process of doing and enjoying, not what the finished product looks like.
8. Let go of unrealistic expectations.
9. Let go of the rules and doing it right, just do it for fun.
10. Let go of competition if it is not useful - keep it if it is.

MĀNAWATIA PAKEKETANGA

Celebrating Eldership

When Frank Solomon was diagnosed with Mate Wareware, (dementia), he and his wife Judy pioneered a new program to help others access culturally appropriate support.

“We had been educators for 50 years and when Frank was diagnosed, we decided to get educated,” says Judy.

Frank says there are many barriers to Maori engaging in services and existing groups were not reflective of his world lens. Frank says the stigma of Mate Wareware is even more pronounced in the Maori community and people become isolated because it is not talked about.

As a way of giving back to the community, the couple wanted to help bridge the divide and tailored a program with mana at its core.

“We decided to create a Maori Kaupapa programme for Maori and their whanau living with dementia, and that we would fund this ourselves because we did not want to be limited by the present processes of current providers,” says Judy.

A group was born where people participated in karakia, (prayer) whakawhanaungatanga, (connecting and sharing) waiata (song) and poi, in sessions running once a week for five weeks. The aim is to whakamana (empower) and enable pakeke and their whānau to understand and live well with Mate Wareware.

Staff from Middlemore hospital, Dementia Auckland and Auckland University’s Brain Research Centre helped to promote the program and provided onsite support and relationship building with participants, also working to establish the trust of the whanau.

Combining the benefits of connection and the power of music lead to glowing reviews from both participants and health providers.

“There was a huge sense of wellbeing and togetherness, it gave me goosebumps,” says Frank.

Frank and Judy’s vision was to identify people within the group to keep it running while they went on to set groups up in other locations.

“We felt that It is important for this to be led by the community in partnership with providers, “says Judy.

They have taken the model they created in South Auckland to set up a Northland group, with intention to start further groups wherever there is interest.

Government funding has been applied for, but Frank and Judy will continue to lend financial support until then.

“Our vision is that all Maori communities in New Zealand will have access to these programmes,” says Judy. Although the group is set up with a focus on Maori culture, it is not exclusive to Maori.

Judy says that an insight she gained was that until people are diagnosed, they are not able to access the support gateway, so helping people to get formally diagnosed is crucial for much-needed support.

Kelly Priest from Dementia Auckland says the Solomon’s initiative has been a catalyst for Maori whanau to access support early.

“Seeing the wairua enhanced and strengthened is truly amazing. There is so much aroha within the group, it’s been a pleasure be able to tautoko this program.”

Judy says it has been a privilege for her and her husband to put their time and expertise into the initiative.

Frank and Judy were inducted onto the King’s Honors list in June, becoming Members of the New Zealand order of Merit (MNZM) for services to education, particularly Māori and Pacific education.

By Nicola Fletcher-Williams

Leading the way in memory care

Building for the future

Since 2017, Summerset have been leading the New Zealand retirement industry with 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 into several of our new village centres across the country.

It's Summerset's aim to provide New Zealander's and their families the opportunity to move their loved one into a safe and secure environment with all the touches of home, without the worry that they'll be 'locked off' from the world.

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. Our qualified diversional therapists offer a range of activities to help build both a sense of community and ongoing personal development for our residents.

What sets us apart?

When we decided to undertake the commitment of building a fit for purpose environment for people living with dementia. We had specialists from across the business study how dementia friendly design was being implemented globally.

We wanted to start from a platform created by professionals who live and breathe improving 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 planned and 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.

Sensory room: this room houses a digital interactive table which encourages residents to engage all their senses. The sensory room looks onto a garden with a range of plants and other sensory experiences.

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.

Care your loved ones deserve.

Summerset's memory care centres are currently located in 6 villages across the country in: Hamilton, Poirura, Richmond, Levin and Christchurch.

There are new memory care centres being planned. Find out more here: summerset.co.nz/memorycare

Summerset
RETIREMENT VILLAGES

KNITTING MATTERS

If there was ever any doubt that someone with advancing dementia could still do something meaningful, look no further than Phil Dunlop for the evidence they can.

He is one about 15 contributors to the Cuddle Kids knitting club in Tokoroa, who knit clothing for premature babies. The club regularly supply Hamilton, Tokoroa, Rotorua and Middlemore hospitals with garments to help parents unprepared for their baby's early arrival.

Phil's wife Tina, a keen contributor to the club, encountered a knitting loom enabling Phil to get in on the act too. All that is required of Phil is to turn the handle of the device, which produces knitting for Tina to sew together. Doing such a meaningful task has given him back a sense of purpose, a universally intrinsic human need.

"Phil has taken a real keen liking to it. I thread it up for him and he sits winding the handle until the length is achieved. It has been so rewarding for him and so great for his confidence," says Tina.

The Cuddle Kids knitting club was started about five years ago by Sharyn Newman, who saw a need for the garments. She also recognised that the knitting would benefit the knitter as much as the recipient. She says there are many older people who would like to knit but the cost is prohibitive, especially since pure wool is required for the job, with another barrier being the inability to go out to source it. So a Facebook page was started to enable people who have wool to donate to contact Sharyn, who picks it up and distributes it to willing knitters. She then makes deliveries of the knitted items to hospitals.

"It's helping the little ones and the bigger ones too," she says.

Sharyn says it's heartwarming to see the pleasure Phil gets out of being involved.

"You can see he is quite proud by the smile on his face, everyone needs a sense of purpose."

To help the club, search Cuddle Kids Tokoroa on Facebook or email sharyn@windowslive.com

By Nicola Fletcher-Williams

A Carer's Poem

Journey so far...

By Paula Greenstreet

Diagnosed with dementia,
Why all the fuss?
Situations like this doesn't happen to us

At first life was quiet - almost same as before
But it didn't take long when it was noticeably more!
Gradually things that were easy became harder to tackle
The ideas and concepts seemed harder to grapple

Over the years things slowly got worse
We felt this disease life sent us a bit of a curse

However, we managed,
Things aren't always bad
A reasonable life is still to be had
Help has been offered,
A real Godsend
We can live with support
Right to the end.

Humorous moments are often to be
Like the time he scooped breadcrumbs into my tea

And the time he saw wedding photos with both of us there
For ages he just looked with a blank sort of stare
He recognised himself but the bride he did not
So I said have another look, give it a shot
I tried once again saying "Give it a go"
With that he replied "I'm dammed if I know"!!

It's important to have a sense of humour
And if you sometimes lose patience
Well that's only a rumour

We all try our best to do what we're able
To keep our lives normal
And hopefully stable!!

MEET OUR NEW DEMENTIA Advisor/Educator

London-born Brendan Hallam has studied psychology, clinical mental health and is completing his PhD this year with a research project about the risk factors and characteristics of people with subjective memory concern and mild cognitive impairment.

He has worked in the field of dementia for the past 10 years across hospitals and charities, as well as in university-based research.

Brendan moved to New Zealand earlier this year with his fiancé Grace, who is half South-African and half Kiwi. They are looking forward to their wedding in South Africa next year, and wanted to spend a few years experiencing a different culture and a few adventures in New Zealand, such as our great walks. He likes all kinds of sports - in particular football, although now in New Zealand his preference may have to lean toward rugby.

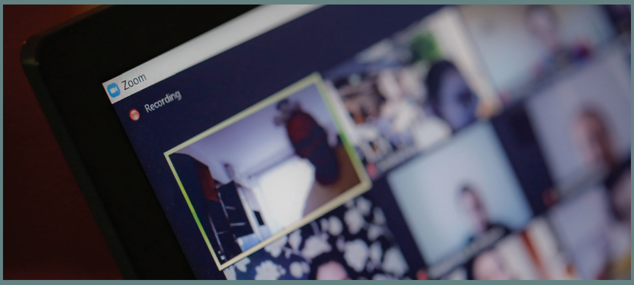
Brendan is passionate about supporting people living with dementia and their family members by providing them with the tools, knowledge and support to be able to live as well as possible with dementia. He splits his time between the role of Dementia Advisor for South Auckland and as an Auckland-wide Educator.

What's coming up

DEMENTIA TALKS

EDUCATION PROGRAMMES

We have four more Carer Education Programmes scheduled before the end of the year.
If you wish to register for one of these please contact you local Dementia Advisor.



ZOOM MORNINGS
12 Oct- 16 Nov

ZOOM EVENINGS
4 Oct- 8 Nov

FACE TO FACE
RED BEACH
19 Sept- 17 Oct

FACE TO FACE
PUKEKOHE
31 Oct- 28 Nov

OUR LINE UP OF MASTERCLASSES UNTIL THE END OF THE YEAR

MASTERCLASS
15th September
Understanding Anxiety and Depression – presented by Rhonda Preston-Jones

MASTERCLASS
13th October
Giving Up Worrying – presented by Rhonda Preston-Jones

MASTERCLASS
17th November
Sleep Matters – presented by Winifred Henderson

If you miss any of our Masterclasses you can request to have the link sent to you at a later point. Contact kahu@dementiaauckland.org.nz (We do ask for a $20 donation for these to help cover our costs)