

Our Mind Matters

April 2023

Small steps making a big difference

The story of a campaign
champion

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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: Murray, Tracie, Christy and granddaughter Starr with dogs Duke and Ruby. See the Steps for Dementia story, Page 2.

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Follow us on Facebook or sign up to our regular emails to keep informed about what is happening at Dementia Auckland – visit da.org.nz or our Facebook page

www.dementiaauckland.org.nz/sign-up

By your side

PO Box 5132, Victoria Street West, Auckland 1142

09 622 4230 | 0800 433 636

info@dementiaauckland.org.nz

www.da.org.nz

facebook.com/DementiaAKL

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Update from Dementia Auckland's Clinical Lead

This is the first Mind Matters for 2023. Normally at this time of the year we are farewelling a glorious Summer and beginning to adjust to the chillier mornings and clear skies of Autumn. Well, Mother Nature sure had other ideas.

January sunshine never really kicked in and by February Aucklanders were over the rain. Just when we were getting ready for a nice relaxing Anniversary weekend, Auckland was slammed by a weather event that few of us had ever seen in our lives. Flooded streets, swamped houses, cars floating or submerged. We heard from a few unfortunate families who had to move out of yellow-stickered homes. This experience is challenging enough for anyone, but extremely stressful for someone living with Dementia. Everything they know, the routines they trust, washed away overnight!

Our hearts go out to those affected by the floods, but especially to those in our community supporting someone with a disability, illness, or Dementia.

My basement was flooded with grey water, a minor inconvenience for the Dementia Auckland crew who work from there - and nothing like many have been through.

As if Mother Nature had not finished with us yet, along came cyclone Gabrielle. More calamities, loss of life and a whole nation grieving for the devastation in Northland, parts of Auckland, the Coromandel, Gisborne and Hawkes Bay. It will take some time for New Zealand to recover from all of this. In the meantime, we need to remain patient, be kind and keep hopeful.

Despite all the weather events, Dementia Auckland has been able to continue to offer services and to move forward and remain positive.

We have had quite a few staff comings and goings to update you on.

Farewells

Our CEO Martin Bremner has left us. We would like to thank Martin for his fine steering of the ship through the troubled waters of COVID and pushing us forward with boundless drive. We will miss his vision, his thinking 'outside the box' and his never-ending energy. We wish Martin well on his new endeavours. The CEO role is being managed by Cathy Cooney from Dementia New Zealand.

We are sorry to have lost Lesley Sowden, who retired at the end of last year. We wish Lesley well in her retirement, her garden, and her new home.

We have been joined by two new Key Workers who we will introduce on page four. We also have another new Keyworker, Brendan Hallam, who had not yet started at the time of print. He is replacing Lesley in South Auckland and we will introduce you to him in the next issue.

Our fabulous Educator, Winifred Henderson, has moved to sunny Wanaka, where she will continue to be our 'Zoom Queen' and run Carer Education Programmes and Masterclasses online. Winifred's first Masterclass in February, **What is Alzheimer's?** was well-received with over 90 people registered to attend.

Education Programmes

Our line-up of Masterclasses this year include:

- **What is Alzheimers?** which ran in February.
- **What is Frontotemporal Dementia?** which ran in March.
- **What is Lewy Body?** in April
- **What is Vascular Dementia?** in May.

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

In March we had a five day **All Things Dementia** refresher course for staff from Auckland, Waikato and Lakes, where a wide range of experts in their field imparted their valuable knowledge. We will be renaming our Key Workers 'Dementia Advisors' to align their title with the national and international trend.

Living Well Services

The Dementia Auckland Living Well groups for people with mild to moderate Dementia continue to evolve with gusto.

Our Young Onset Dementia Day Programme, featured in our last Mind Matters, is going from strength to strength. There are now 12 attendees ranging from 58 to 67 years of age. This group, like all our other Living Well groups, runs entirely on charitable donations. The Give-a-Little page for this group is still open.

If you live on the North Shore or Rodney area watch out for the two new book clubs starting up, offered by Sarah Dugdale in the Warkworth and Takapuna libraries. **Spending Time with Books** is a group for people living with mild to moderate Dementia, with or without their carers, who have always loved books, reading, libraries and literature.

Kelly Priest continues to run the **Mānawatia Pakeketanga** - celebrating our Elders group in Manurewa with amazing support from local Māori and the CMDHB Memory team.

Andrea Yates is about to start a new Petanque group in St Heliers and a women's craft group in Grey Lynn.

If any of these groups sound right up the alley of the person you support, please contact your Key Worker.

Futureproofing

The Dementia NZ network is increasing the way we work collaboratively. This sees Dementia Auckland, Dementia Waikato and Dementia Lakes working closely together as a team - an exciting journey which will provide great benefits.

Rhonda Preston-Jones

Clinical Lead
Dementia Auckland



We have been amazed by the support for our Steps for Dementia campaign, where we asked people to take a step toward their brain health by completing a challenge for the month of March and seeking some sponsorship along the way.

Tracie Webb was one of our campaigners, spurred into action because of her husband Murray's experience with Young Onset Alzheimers. The Waikato resident says despite already having days where he didn't know who she was, his diagnosis at age 66 felt like "a hit in the stomach," as she had hoped there could be another explanation for the symptoms.

Tracie was overwhelmed with helplessness, so was thankful his specialist referred him to Dementia Waikato. She says she has been devastated to watch the disease progress very quickly for Murray.

"The first time they don't recognise you is something words really can't describe. It's heartbreaking to say the least, when you've been married for 30 years how can that be?"

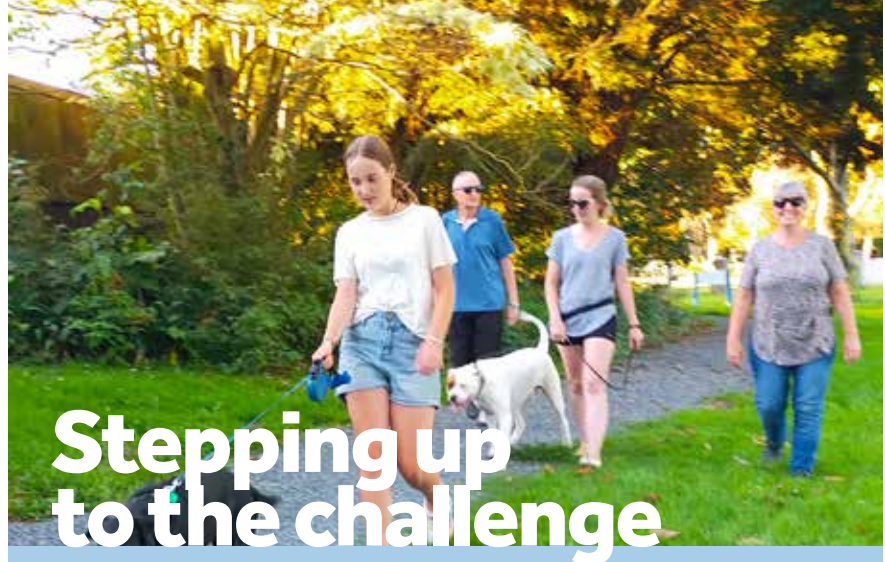
Tracie said when she saw the callout for support for the campaign, it was a small way she could show her thanks for the kindness, support and information she received from Dementia Waikato. She also hoped to raise awareness that younger people can get Dementia too.

She feels support is vital because "there are days where it feels like you're drowning".

Tracie, her daughter Christy and Murray's granddaughter Starr have each taken on a challenge, for Tracie and Starr it was to give up unhealthy snacks and for Christy, it was to walk everyday.

They were thrilled to make their fundraising targets within a few hours due to support from family and friends so extended their target further.

By Nicola Fletcher-Williams



Stepping up to the challenge



Left to - right: Tracie, Christy, Starr, Murray and daughter Michaela.

A week of Tracie's diary

Day 1:

Day one and I nearly blew it by the morning when I picked up a biscuit to have with my coffee at music group! Habit me thinks. Today is Murray's birthday. I couldn't not make him a birthday cake because we're not eating it! Our girls were here for Murray's birthday, so we all went for a walk to help Christy kick-start her goal for the month.

Day 2:

That banana cake is crying out to be eaten. Luckily Murray has a sweet tooth so it won't be around for too long. Isn't it funny when you're not allowed something you desperately want it even more! Had a testing time today with caregiving, so I'm glad it's summer fruit time because a nectarine tastes beautiful and sweet at least.

Day 3:

Had a friend drop by today. Both her and Murray eating sweets. Surprisingly I didn't feel like I was missing out too much.

Still parts of the day are very trying and by the end you just need something! Bought some outside games. This seemed to occupy Murray for a short time, pleased to have found something else that can help both of us!

Day 4:

Unfortunately, Murray isn't having a good day and wouldn't even get in the car. Very agitated and confused. It's times like this that some dark peppermint chocolate just seems to help lift your spirits. Oh well, a little dried fruit it is instead. Trying not to snack at all and only have two meals a day, lunch and tea.

Day 5:

Busy day today painting. Keeping the hands busy stops wanting to pick at food that's for sure. Physical things make you thirsty and drinking water makes you feel full. That's my theory anyway. I try to get him to help but it's not working today. When I finally clean up, I find furniture moved and things in strange places. Along with my car keys in the sink.

Day 6:

Is it really only day six? But our team has surpassed it's \$1000 goal today! Feeling the love and support!

Day 7:

For some reason I really feel like a snack today. A carrot it is, but it doesn't really cut it so I'll just have to drink more water and keep busy!



STEPS FOR DEMENTIA
MATE AWAREWARE



Help raise funds for Kiwis living with dementia.

It's not too late to donate and support one of our fantastic fundraisers who have taken a step for dementia.

Visit www.stepsfordementia.nz





On the roads less travelled



Dementia Advisor Janine Appleby is an asset to the team at Dementia Waikato, with 28 years' experience as an Occupational Therapist – 12 of those specialising in Dementia care. She says creative problem solving is a key skill set when working with clients, and

in overcoming the challenges of covering her vast geographic area. She tells us a bit about what it's like to work in her rural patch.

I'm based at home in Paeroa and cover the area from the northern tip of the Coromandel Peninsula through the Hauraki Plains and down into the Piako district in the east, and am part of a small team here in the Waikato. Two of my colleagues are based across Hamilton and a third is based rurally in South Waikato, which extends as far as Taranui. We also rely on a small set of volunteers to support what we do, many of whom have previously been care partners.

Being rurally based has its challenges but there are also some great opportunities to network locally, develop a vast range of working relationships, and enjoy the cultural heritage that this locality brings. The thing that strikes me the most about working rurally is the level of resilience and community cooperation I come across each day.

During the recent flooding and Cyclone event, I was cut off from visiting many clients, so I called as many as I could - especially those that I knew lived alone or were particularly isolated. Many times I got the response "all good here, this is not our first rodeo, we are used to just hunkering down." I also heard frequently that local community members had already rallied around and checked in on each other.

My longest journeys are up the Coromandel Peninsula, both the east and west sides. There is a great big mountain range down the middle that I often traverse. These journeys can be between two to three hours one-way, so I have to plan them carefully.

I must be mindful of the weather and road conditions, often keeping a close eye on long range weather forecasts and Waka Kotahi (NZTA) daily road updates. I must be prepared to cancel, re-schedule or divert at the 11th hour. Recently weather events have challenged my confidence in driving over roads that remain in a poor state of repair.

Sometimes home visiting is just not feasible for many reasons, so I try to be as flexible as possible and meet with care partners and the person living with Dementia at a time and place that suits them. So much of my work can be conducted over phone or Zoom - where internet connection is available.

Most days this is a 9am to 5pm job, but not always. I am humbled by the 24/7 job care partners do, so I will go the extra mile on occasion. I like to educate care partners about how to support their person living with Dementia by maintaining activities and independence, especially when day services and support workers are limited or unavailable. This can be achieved by making adaptations to the environment or simplifying tasks.

I utilise my time out on the road by making connections with local health services, community trusts and support workers, it helps to build professional relationships with other healthcare providers. Also important is maintaining my professional connection to my colleagues, who are registered nurses and social workers.

Knowledge and skill sharing enables us to do our mahi with integrity and continue to add value to the lives of people living with Dementia, their care partners and their Whanau.



New Faces

It took quite some time to be able to re-hire Keyworkers due to our financial position, but we are delighted to report that Elin Staples and Julia Sodo have now hit the ground running, providing much-needed support in the Franklin and Rodney areas.



Elin Staples

Franklin Keyworker

Elin Staples moved to New Zealand 20 years ago from Sweden with her Kiwi husband and has always worked in aged care, including home-based support and Dementia units. Her interest in Dementia started when she was in high school and her best friend's Dad was diagnosed with Young Onset Dementia.

She comes with a wealth of professional knowledge, having studied behavioural psychology at the University of Auckland and worked as a clinician with the Memory Team. She is returning to work after taking some time out to raise her two young daughters.

Elin says that after working in a role involved with the diagnosis of Dementia, she is now excited to have the opportunity to help provide the support families need after diagnosis. As a behavioural psychologist, her main passion is supporting carers to try and understand and alleviate challenging behaviours.

Rodney Keyworker

Julia Sodo is relishing her new role as the Keyworker for the Orewa/Hibiscus Coast areas. She is a Registered Nurse and has been working for the past 11 years as a service coordinator for home-help agency Enliven. She is passionate about helping families to keep someone with Dementia at home for as long as possible.

Julia has gone through the Dementia journey with her Dad and brother. She didn't know about Dementia Auckland when caring for her Dad, but had a very positive experience of being involved with us when caring for her brother - initiating her interest in working for Dementia Auckland.

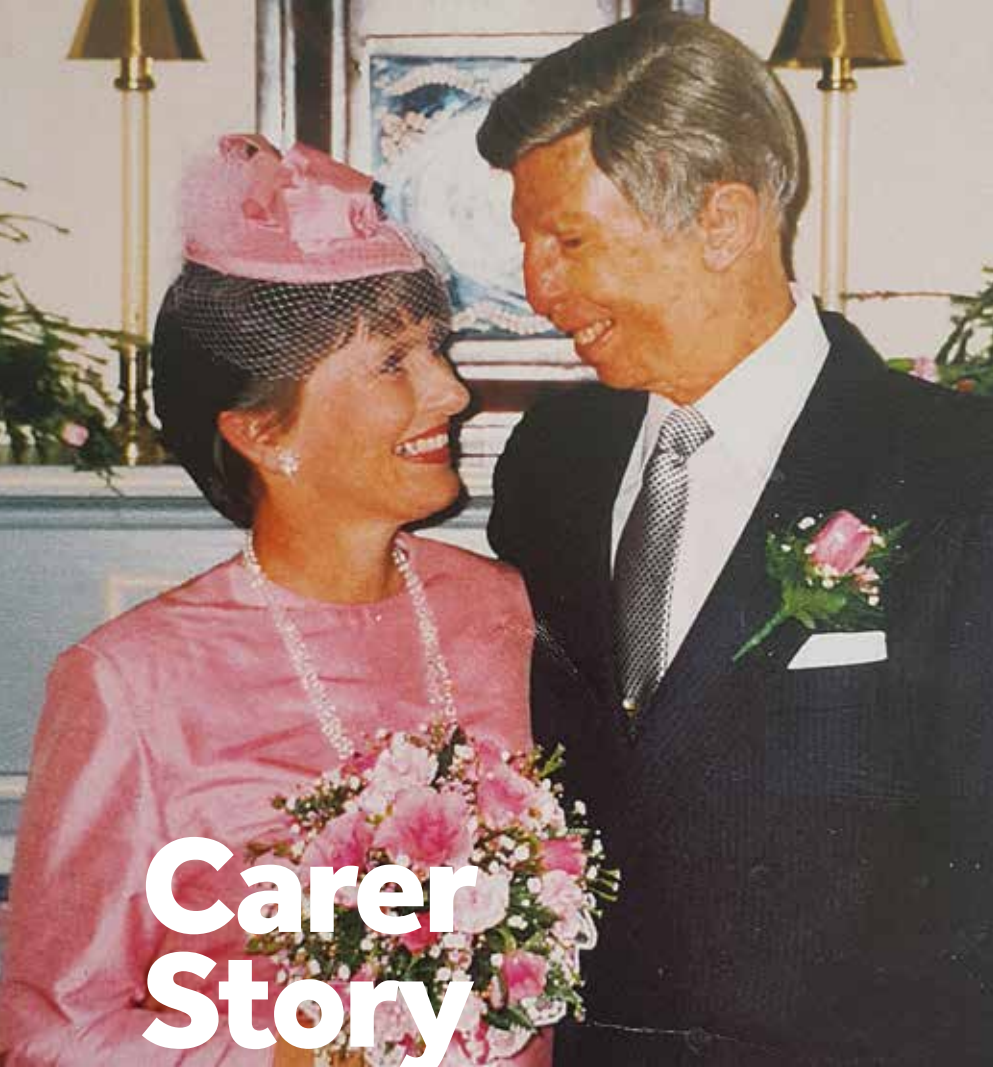
She and other family members took turns in the live-in carer role for her Dad, so she can relate to all aspects of what her carers are going through with an abundance of empathy. She has particular insight into the complexities of navigating Dementia when other family members have different ideas and opinions on what is best for their loved ones, and of going through the ambiguous grief process. Julia is looking forward to meeting all her new clients and providing the support that made such a difference in her second experience of caregiving.

Through her personal and professional experiences of working with older people, she says she has a good understanding of what is important to families.

Julia lives with her husband Alfredo in Titirangi, and has five amazing children and their partners in her life. She has 3 beautiful grandsons who she spends a lot of time with. Her role with Dementia Auckland is 4 days a week, her 5th day of the week is "Nana day." Julia enjoys tramping and getting out in nature when she can.



Julia Sodo



Carer Story

Caring for Alan - a man who inspired so many

My husband Alan was diagnosed with mild Dementia at the age of 90. Up until this time, he had been pretty much fully engaged in all that was going on around him.

After triumphantly emerging from a serious medical trauma at the age of 47, nothing ever phased him. This was just something to accept and move on through. Whatever it took, you just deal with it. Dementia was just another challenge to accept and work through as best he could.

As a chemical engineer, he was on a business trip when he was severely burned in a plane crash in New York in 1963, suffering full thickness burns to 40% of his body. He lost the top of his head, an eye, an ear, nose, a thumb and several fingers. He actually died twice, was hospitalised for 5 years and eventually underwent over 80 surgeries in total.

At the time of his discharge, he discovered that although there were support organisations for almost every medical affliction known to mankind,

there was nothing to help the burned and disfigured, so he founded and established a world-wide organisation, The Phoenix Society for Burn Survivors, which was at that time based in Philadelphia and is still flourishing today.

His little personal credos and philosophies were what helped me through what I knew could be some challenging times ahead. Particularly when, despite every piece of equipment given to me by the health system - including a hospital bed, a bathing machine and hoist, the decision was made that private hospital care became necessary.

The day the ambulance came to transfer him was one of the worst days of my life, because although I knew he would never be returning home, he didn't know this - and there was no way I could bring myself to tell him. Throughout our 32 years together, we never ever kept anything from each other, and I felt consumed with guilt that I was letting him down, even though I had been caring for him while he was totally immobile and bedridden for almost a year. To watch him being carried out of our home tore my heart out.

He very reluctantly settled into the hospital routine, and to try and assist with his adjustment I took in his electronic keyboard. Although his mental acuity was far from what it used to be, he never lost his keyboard skills and could still belt out rag time and honky tunes at the drop of a hat. Although his repertoire was now reduced to just a handful of songs from the 200 he used to play without any music, it never ceased to amaze me how the brain seems to still be 'wired' to be able to function where music is concerned.

“The amazing gift of music with which he had been blessed, proved to be a wonderful comfort to us both, because when he wasn't playing, we would listen to all our favourite music which I had downloaded on my phone.**”**

I always knew about the therapeutic value of touch. On many visits I had no hesitation in closing his door and hopping up on the bed so we could at least lie in each other's arms again. The lockdowns were emotionally brutal but eventually, strictly controlled visiting was allowed if one wore a mask and stayed one metre apart. At this stage of his gradual decline, he was eating and speaking very little, if at all. This didn't really matter because having been together for so long, our bond was so close that we always knew what the other was thinking anyway! All we wanted to do now was hold hands to communicate our love, which was prohibited due to Covid restrictions. A charge nurse who recognised this innate need took my hand and discretely guided it under the blanket on top of his. Allowing me to break the rules on compassionate grounds is something I am forever grateful for. I will never forget the squeeze Alan gave my hand, confirming his need and appreciation for being able to physically connect again.

Alan passed peacefully from this life at age 94 on the 26th of November 2022.

By Delwyn Breslau

If you would like to share your story, please email : nicolaf@dementiaauckland.org.nz



Travel Tips

Travelling with a person living with Dementia requires more planning and care, but is still possible for a long time after diagnosis. To be enjoyable, a trip needs to be well thought-through to avoid situations that might heighten confusion or agitation.

Be realistic and consider what will work for them now rather than what did work in the past. This may involve modifying and adapting the way you travel, where you travel to and whom you travel with. Everybody's journey through Dementia is different and how some will cope with travel will be unique to them.

When planning the holiday:

- 1** It is not advisable for a person living with Dementia to travel alone.
- 2** Take someone else. It is not much of a holiday for the Carer if they are always watching out for the person living with Dementia. Travel with someone else who understands the challenges associated with Dementia.
- 3** Make sure connections between flights allow for unexpected delays and hiccups. Avoid the stress of rushing. Arrange transport at the end of the flight so your arrival is hassle free.
- 4** Before planning an expensive holiday overseas do many smaller practice holidays. Try all day outings, overnight and 2-3 day breaks to local places. That way you can always come home if things are not going so well. This will detect any problems that could arise on the more ambitious trip.
- 5** Keep it simple. Choose time zones which cause the least disruption, English speaking destinations, familiar foods. Shorter, closer, simpler, holidays with less risk are more likely to be successful.

- 6** Consider what will work best for the person living with Dementia - Is it best to stay in one place or will they cope with multiple changes? Would they cope with extensive tours? Will they be able to keep up with a group? A person living with Dementia may take some time to become orientated to an unfamiliar place. At a familiar place, the person may settle into the holiday routine reasonably quickly.
- 7** Do not overfill your holiday. Always plan rest times and recuperation times into your schedule.
- 8** Consider what is the best time to start a trip with a person living with Dementia. Starting in the morning when the person with Dementia is fresh or travelling at night so they sleep on the plane. If you have had to travel to a main centre for the international flight spend the preceding night at an airport hotel.
- 9** If the person living with Dementia has a poor sense of direction, get a GPS tracker.
- 10** Check out if the insurance company will cover something that was directly linked to the person's Dementia ie: a person living with Dementia getting lost at the airport and missing a flight.
- 11** Be realistic and have an exit plan if the holiday is not working well. It may be better to come home early than stay the full length of the planned holiday and come home an emotional wreck.
- 12** Inform the airline beforehand. The airlines do not preclude travel for people with cognitive impairment, though some might ask for a GP's letter saying that they are fit to travel. The cabin crew are very helpful if they are made aware of the situation.
- 13** Travel Premium Economy or Business Class if feasible. This gives more space, easier access to the toilets, more cabin staff and boarding is quicker and easier.
- 14** Short flights with frequent stops might work better than a long-haul flight. It is better to stop frequently, get a good night's sleep, adjust to the time zone and then start out again in a day or so.
- 15** Discuss the trip with your GP who may prescribe some medication for agitation on the plane or for sleep. Try it out first at home to make sure there are no adverse effects. Ask your GP practice nurse to help with a management plan for everyday medications if you are doing long-haul with time zone changes.
- 16** Get the PWLD to wear a brightly coloured hat or jacket, they will be easier to spot if you are separated.
- 17** When booking a hotel consider complexity - is it a 1-2 story hotel or a high-rise hotel with lifts and the capacity to get lost easily? Think about how many exits a place may have, and if it is on a main road or a quiet side road.
- 18** If booking on a cruise, consider issues of orientation, dining room manners, risk of not being able to go home should the wheels fall off.
- 19** Around New Zealand, you should avoid prolonged car trips and have frequent breaks.
- 20** Leave the toilet light on or take a night light as this may help the person living with Dementia find the toilet at night.
- 21** Plan you return home with equal focus as you will both be tired and eager to get home.



International travel:

This is easier if the person living with Dementia is used to air travel, the trip is not too long, and the person goes regularly to the same place. Longer trips are more fraught because of the hours on the plane and time zone changes. The oxygen level in planes is lower than that at ground level and this could contribute to increased confusion. There is an increased risk of dehydration, constipation or deep vein thrombosis on long haul flights.

Airports:

These are noisy, busy stressful places at the best of times. For a person living with Dementia they can be overwhelming.

- ▶ If suitable, pre-book a wheelchair with assistance for the person living with Dementia. This means less walking, another pair of hands, and it allows you to go through Immigration together. At Auckland Airport book in with the Concierge Service for extra help navigating the airport.
- ▶ Ensure the person living with Dementia has identification on them, including the Carers details and contact. At Auckland Airport ask for a Hidden Disability lanyard which will alert ground staff to be extra helpful. Carry a Dementia friendly card explaining that your companion has Dementia and needs extra support.
- ▶ Use the quiet spaces at the airport while waiting or have headphones to reduce the noise.
- ▶ Go with minimal hand luggage. Wear a small travel wallet around your neck to hold passports and GP letters so you can go through Customs and Immigration with minimum fuss.
- ▶ If possible, the Carer should carry the passports. Also carry a photocopy of your passports.
- ▶ When collecting the luggage at the baggage carousel ask for airport staff to help you.

On the Plane:

- ▶ Pre purchase food and fluids to prevent distress through hunger or dehydration if there is any delay. Avoid alcohol, this can contribute to dehydration and cause unwanted behaviour changes.
- ▶ Aeroplane toilets cannot accommodate two people, so it is not advisable to travel with people who cannot manage their own needs. Airline staff are not able to assist with toileting. Ask the staff how to open the locked toilet door from outside if your person gets in a pickle.
- ▶ Put a bright familiar item of clothing on the back of your seat so the person living with Dementia can find their seat after going to the toilet.
- ▶ Walk frequently up and down the plane together for exercise, prevent blood clots and relieve restlessness. Take suitable distractions and activities on the plane to keep the person living with Dementia occupied.

General:

While travel and holidays are part of most people's lives, this becomes increasingly difficult as the Dementia progresses. At some point, a decision needs to be made as to whether it is worth going away together. There is no point in holidays or travel if neither person enjoys it and they end up more exhausted than when they started. There will be a point at which travelling is no longer a viable option for the person living with Dementia.

While a carer might feel guilty about going away alone, it is probably kinder than taking the person living with Dementia into situations that distress them. By using family, in-home or residential respite care, the support partner can have a break and return refreshed to continue the carer role.

By Rhonda Preston-Jones



Use this checklist to determine how your person living with Dementia will cope:

On a day-to-day basis does your person living with Dementia cope with:

		Yes	No
1	Noise	<input type="checkbox"/>	<input type="checkbox"/>
2	Crowds	<input type="checkbox"/>	<input type="checkbox"/>
3	Changes in routine	<input type="checkbox"/>	<input type="checkbox"/>
4	Being tired or stressed	<input type="checkbox"/>	<input type="checkbox"/>
5	Frequent changes	<input type="checkbox"/>	<input type="checkbox"/>
6	Orientation in an unfamiliar place or at night	<input type="checkbox"/>	<input type="checkbox"/>
7	You becoming incapacitated (ie: if you had an accident or became unwell)	<input type="checkbox"/>	<input type="checkbox"/>
8	If they became accidentally separated from you	<input type="checkbox"/>	<input type="checkbox"/>
9	Toileting independently	<input type="checkbox"/>	<input type="checkbox"/>
10	Requests of others to obey the rules (ie: stay seated with seatbelt on)	<input type="checkbox"/>	<input type="checkbox"/>
11	Behaving in a socially acceptable manner	<input type="checkbox"/>	<input type="checkbox"/>
12	Waiting patiently	<input type="checkbox"/>	<input type="checkbox"/>
13	Long car, bus, train, or plane journeys	<input type="checkbox"/>	<input type="checkbox"/>
14	Outings and adventures	<input type="checkbox"/>	<input type="checkbox"/>
15	Are they aware of their surroundings and able to appreciate them	<input type="checkbox"/>	<input type="checkbox"/>
	Score	<input type="checkbox"/>	<input type="checkbox"/>

Scoring:

0-4 No's: *May be OK to travel*

4-8 No's: *Marginal to travel*

8-15 No's: *Don't travel*



Ambiguous Grief

THE LONG GOODBYE



The emotional toll Dementia can have on family members is profound. Like grains of sand in an hourglass, aspects of who a person is are gradually depleting, often over a long period of time.

It may not seem obvious then, that those close to someone with a diagnosis will grieve for them for years before they are gone. We often think of grief as our biological response to death. While it is something no one wishes to go through, we understand it. The person is no longer with us, so grief is the expected response. People rally to support those grieving after death.

But what about when no one around you understands how different your spouse or parent is at home, therefore couldn't possibly identify the type of pain you're in?

We hear time and time again that family who do not live with the person with Dementia think things seem fine when they come for a short visit, but do not get to see what is going on behind closed doors over a more sustained period. It adds another layer to the pain of grief when those around you don't recognise what is going on, so you don't have a support system to act as your pillar.

Dementia grief is a specific type of anticipatory grief in response to ongoing losses of varying degrees of severity and is marked by ambiguity. Ambiguous loss is characterised by a lack of clarity and resolution. It derives from the manner of losses that fluctuate through the disease trajectory.

Ambiguity emerges from increasingly profound changes in cognition and states of consciousness in the person with Dementia. Losses of identifying personality characteristics and the ability to access personal memories lead to experiences of ambiguity in family members: the person with Dementia may not appear to be the same person or may be psychologically inaccessible.

Grief can be a constant companion during the caregiving journey, one which we need to grow around. Due to the long timeframe involved, it can be particularly challenging to process feelings related to loss, grief and burden because a final resolution cannot typically occur until after death.

As with stress and burnout, grief can take a toll on physical health. Caregivers who experience higher levels of pre-death grief have a higher risk of health complications post-death.

Allowing yourself to grieve and maintaining usual activities is important, otherwise coping may be harder as the disease progresses. Ambiguous loss also confuses relationships and can prevent moving on. You may feel as if you are no longer in a marital relationship if your spouse doesn't know who you are anymore. Despite this, your spouse is still a whole person who can be reached at all stages of the disease. Recognising these feelings and understanding the concept of ambiguous loss can help to ease the effects. With guidance and support, you can work through these feelings, begin to grieve the losses and stay connected to the person with Dementia while also building your own strength and resilience.

By Nicola Fletcher-Williams

TIPS FOR COPING WITH GRIEF

- Allow yourself to feel pain. Sit alongside it. When you don't let it in, it only intensifies and prolongs the pain.
- Crying is a therapeutic tool, it serves a purpose to cleanse and release pain, so allow the flood gates to open. Relieve tension through shouting or punching a cushion, if the person with Dementia is not around you.
- Talk to others even if it is hard to do so, it is the most vital time to share with others. Sharing grief helps reduce the burden of it. Talk to family, but also talk to someone outside the family such a counsellor, friend or with a Dementia support group.
- Writing in a journal helps to express feelings, particularly those you struggle to share with others. Explore your thoughts and feelings in this private space as another cleansing tool.
- Remember to think of your own wellbeing so you are not all-consumed with the needs of the person you care for. Use respite options to take breaks and keep you in touch with what is going out outside your household. When you can't get out of the house, make time to do things for yourself at home that fill your emotional tank.
- Use prayer, meditation, or any other sources of personal comfort.
- Avoid making any big decisions in times of heightened emotion.
- Be kind and patient with yourself, the way you would be to a friend.
- Find opportunities to laugh. Finding joy is a way to honour the happy times you used to share with the person with Dementia.

Special care for a special person



Caring for a loved one with Dementia often comes with a lot of work and worry.

Stewart had been caring for wife Margaret at home for several years with the help of daughter Delwyn, who moved back in, and support from their son Glenn. But, when Margaret's Dementia progressed and she needed specialist care 24/7, her family started to look at residential care options in their community. Driving by Summerset's Memory Care Centre at Rototuna prompted them to call in and have a look. After that first visit, they knew they had found a very special place, one that was right for Margaret and them.

"What really stood out for us was the caring nature of the people. When we visited, everyone was just so lovely, and the centre had such a warm and welcoming feel," Stewart says. "The gardens were beautiful, just like ours. We saw a room looking out onto the garden, and it was beautiful too. I thought Margaret would love this."

Summerset's industry-leading memory care centres enable people living with Dementia to lead active lives in a safe and homely environment. They combine apartment-style living with outdoor courtyards and gardens to connect residents to the natural environment, sensory spaces, and trained Dementia care staff.

Homely and familiar

"Making the transition and settling in was surprisingly easy for Mum and us. The staff were just so helpful," says Delwyn. "Before Mum moved in, we set up her room and filled it with the things she was familiar with and loved, including her own furniture, special ornaments and our family scrapbooks she had made. The finishing touch was her wedding photo above the bed, just like it was in her bedroom at home. Being able to personalise her room made it feel comfortable, homely and familiar."

"Mum's happy, safe and well cared for. That means so much to us."

"Mum's room and the centre are now like an extension of our family home. We can visit anytime, stay as long as we like and even take Dad's Labrador Oscar along, who Mum adores," says Glenn. "The staff treat Mum and us like family. It's a really special place."

"Although it was hard coming to the realisation that Mum would be better off being cared for outside of home, and quite emotional and overwhelming, especially for Dad, we knew it was the right decision.

Mum is a very special lady. We wanted her to have the best because she deserved the best," says Delwyn.

For Margaret and her family, moving to Summerset's Memory Care Centre has positively impacted all of their lives. "We've found a place where Mum is treated with the care and dignity she deserves. So, we've been able to step back, worry less and take a break that we desperately needed. Knowing Mum is happy and being taken care of has meant Dad can go back to being her husband, not the caregiver. That's wonderful for both of them."

Love the life you choose.

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

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

Summerset
RETIREMENT VILLAGES



Inspiration Corner

Creative projects are an effective way to put some maintenance into the brain's neural highways.

The cognitive stimulation helps to slow down the decline in those with Dementia and can help prevent it in others. Creativity is also a vehicle for self-expression and provides a sense of achievement that sends out a beautiful cascade of feel-good endorphins. It's equally a great therapeutic outlet for carers. So if you are stuck for an idea, this inexpensive one is both fun and practical.

You will need:

- Two larger pots and four smaller ones, mine were 13cm high and 6cm high. I got all 6 for \$10 from Mitre 10.
- Cord rope, \$1.50 for 1 metre, from Mitre 10
- Acrylic paint, about \$7 per colour, or whatever you have at home
- I decided to dress my lady in pearls, these were \$3 from a bargain store
- A plant. I chose a fern because it created the look of amazing hair. This was \$20 from Kings Plant barn.
- A drill. However, if you want a simpler option, you don't need to attach "arms and legs" and she still looks great without them.



Method:

Use a large pot the right way up to paint a face and the other large pot, upside down, to paint the body. I created a lady in a leopard-print outfit, but dress her however you want! Your character is only limited by your imagination.

To add the arms and legs, drill two small holes on the sides of the body and two at the base. I found the drainage holes in the small pots were not quite big enough to feed the cord through, so I used the drill to make them a bit bigger. You can tie a knot to secure the cord on both the inside of the small pot and the large pot.

I secured my pearls with twisty ties. You could glue the two main pots together with ceramic glue but if it is staying inside, you don't need to.

Not all projects work out how you would like all the time, but don't get disheartened! Enjoy the process as much as the result. A few failed attempts at a creative project are part of the process and can make it all the more satisfying when your next attempt is successful.

If you get together to do projects with others, you are simultaneously reaping the benefits of the social contact, and you can get ideas from each other.

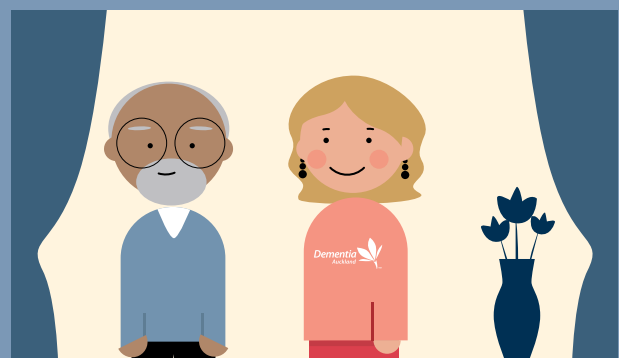
Doing projects with the children in your family is a great inter-generational bonding activity, and you can share skill sets. We hope this may inspire the creative in you!

By Nicola Fletcher-Williams

We're here to help improve the quality of life for those affected by Dementia through support for those living with Dementia, their caregivers, whānau and support networks for the journey ahead.

We can help with:

- How to recognize signs of Dementia
- Information and resources
- 1:1 keyworker support
- Living Well services
- Navigation through the health system
- Education courses and support groups for carers and families
- Phone consultations, advice and support



Learn more at www.da.org.nz or talk to one of our friendly team today on 0800 433 636.