

Our  
**Mind Matters**

July 2022

**LiGHT** IN THE  
**DARKNESS**

**Shining a light on dementia  
with Carl Hayman**

**Page 2**

---

**Living Well with  
Creativity**

**Page 7**

---

**Silver Linings  
– a carers story**

**Page 9**

---

**HELP SAVE OUR SERVICES**



# Thank you

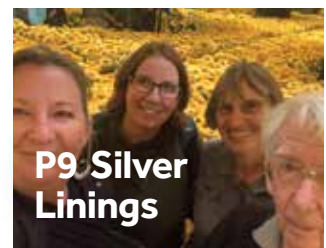
We truly appreciate all the amazing people, volunteers, sponsors, friends, donors, funders and supporters. Your kindness and generosity make it possible for us to make a real difference.

## Thank you to the families, friends and generous donors

- Ann Hayward
- Pushien Charitable Trust
- Graham Rhodes
- Oceanbridge Shipping Ltd
- N H Taylor Charitable Trust
- NZ Lottery Grants Board
- Charles Rupert Stead Trust
- The Trusts Community Foundation
- One Foundation
- Stephen Tindall
- The David & Genevieve Becroft Foundation
- Jim Barclay
- Dentons Kensington Swan
- RA Johnston
- Rob Nicoll
- Stanley Hoffman
- Catherine Hynes
- Room-Simmonds Charitable Trust
- Garth Barfoot
- Joan Mayes Charitable Trust
- Bronwyn Bryant
- Song Lam
- Anthony Quirk
- ARA Lodge No 348 I C Charitable Trust Board
- Four Winds Foundation Ltd
- Jim Feist
- Estate of Ernest Hyam Davis & The Ted and Mollie Carr Endowment Trust
- The Pukeko Charitable Trust
- The Miracle Tree Charity Foundation
- Duo Trust

# Inside

Longest Night -----	2
Dementia & Covid -----	4
Education Update -----	6
Living Well with Creativity-----	7
Technology -----	8
Silver Linings -----	9
Steps for Dementia -----	10



## Join our Community

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](http://da.org.nz) or our Facebook page

[www.dementiaauckland.org.nz/sign-up](http://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](mailto:info@dementiaauckland.org.nz)

[www.da.org.nz](http://www.da.org.nz)

[da.org.nz](http://da.org.nz)

[facebook.com/DementiaAKL](https://facebook.com/DementiaAKL)

[instagram.com/dementia.auckland](https://instagram.com/dementia.auckland)



Registered Charity: CC46885





# Board Update



Sadly we say farewell to Edgar Henson from the Dementia Auckland Board. Edgar, real estate agent, Justice of the Peace and farmer has long had an association with Dementia Auckland (formerly Alzheimers Auckland), becoming treasurer in 1987 and then vice president in 1991.

Edgar was instrumental in setting up the Dementia Auckland Foundation that exists to provide long term financial stability to Dementia Auckland. Edgars real estate expertise allowed the organisation to benefit from the purchase of our original offices which was later sold and formed part of the capital that seeded the foundation.

Edgar served on the Dementia Auckland board during 2021 and 2022 throughout COVID lockdowns and very challenging times for the not for profit sector. We sincerely thank Edgar for his dedication, commitment and wonderful contribution to the dementia community and to Dementia Auckland over the years.

We look forward to introducing you to the new members of the Dementia Auckland board in our next edition of Our Mind Matters.

## Why I Volunteer

Volunteering is my opportunity to give back and give thanks in a meaningful way to an organisation that supported Peter and I on our journey, navigating mixed dementia.

Peter and I loved our Tuesday mornings walk – actually when his mobility became more challenged it was the fellowship time after our walk, when we would enjoy a coffee and chat in the Café that was most special.

I was literally tapped on the shoulder by Living Well facilitator Kelly and asked to consider being a volunteer to support the Botanical Gardens walking group –it didn't take any arm twisting! After a very short consideration I knew this was what I wanted to do when my carer role came to an end. When Peter died in March last year, volunteering and eventually facilitating this walking group was a Tuesday morning blessing for me. A weekly calendar activity to look forward to as I started to rebuild my life. Every Tuesday I do my best to make this an activity for all to enjoy, and want to return to for as long as possible.

It's now my turn to listen and support those who, like I did, bravely get up every day saying "I can do this". The banter, laughter and sometimes teasing is a healthy tonic. Sometimes it's challenging to keep a watchful eye on all, as there are varying degrees of mobility but we get through as others fall back to accompany those who are a little slower.

**■ ■ The most valuable gift of thanks to Dementia Auckland is my time, commitment & empathy to others on their journey. ■ ■**

Every Tuesday I leave the Botanical Gardens thinking to myself, how lucky am I to be part of this weekly gathering? And then I ponder – am I doing this for the group or for me? Obviously, a bit of both.

By Deb Taylor



### WE NEED YOU!

We are always looking for more volunteers and there are many ways in which you can help us, if you would like to find out more please email [winfredh@dementiauckland.org.nz](mailto:winfredh@dementiauckland.org.nz)



# LIGHT IN THE DARKNESS

## Longest Night

Tuesday 21st of June was the longest night of the year and we lit up the night sky to shine a light on the darkness of dementia.



**Former All Black Carl Hayman flicked the switch to send a pillar of teal light into the sky, creating a striking symbol of what our services can mean to those with a diagnosis of dementia, their carers and family.**

**"It's been incredibly tough... basically for a while I went to the bottom of the bottom that you can go... you can do things to improve your quality of life. There is hope."**

**- Carl Hayman**

This was the first time Carl has spoken publicly since an article came out last year announcing his dementia diagnosis, and after he has had time to come to terms with it.

Carl views his purpose now as using his profile to improve awareness, reduce fear and stigma so that people are not afraid to talk about dementia and know that it is possible to live well with the condition.

Carl talks about the strategies and tools he has gained which enable him to cope and about what a huge difference that has made to his wellbeing. He wants to ensure everyone has access to the same help and support he eventually found.

"It's been incredibly tough, but it's a matter of accepting that my brain energy is half full compared to other people, so I need to be careful about what I use that energy on. I need to plan my day, not take too much on and have little achievable goals for the day.

"Having that understanding and the tools to help deal with things, has really given me hope to move forward, in terms of having a productive future."

Our CEO Martin Bremner says "Our goal is to bring the same level of awareness and acceptance to dementia that John Kirwan has done for mental health in recent years, and Carl has taken a massive first step in helping us achieve that".

Our Light in the Darkness campaign focusses on sharing stories about moments or memories of joy and light in what can be one of the darkest time in people's lives. Our goal for the campaign is to ignite some conversation to create awareness and improve the understanding of dementia, while also raising funds for our support services.

Our services bring hope, joy, purpose and light to the dementia journey for so many people in the Auckland community. Sadly funding for our support services is at a critical level and we don't want to be in a situation of having to cut back on the support services we provide.

Thank you to everyone who shared their personal stories, memories and moments, it takes courage and it really makes a difference. A huge thanks to Carl for his incredibly selfless and brave move to help us bring light to the darkness.

After the longest, darkest nights come lighter days. What can YOU give to help bring light to the darkness and allow us to continue to deliver our support services to those in need?

**Visit [www.longestnight.nz](http://www.longestnight.nz) to make a donation today.**

Here are just a few of the amazing stories from our community about finding light in the darkness, about moments of joy in the dementia journey.



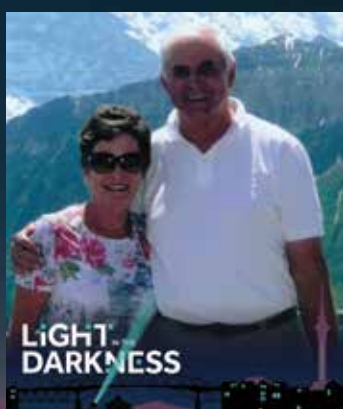
"Nana was a strong woman of faith. Whenever she hears church songs or prayers it brings her pure joy. It really warms my heart knowing her faith will always be in her no matter what" - **Jessica**



We still appreciate music together. Eileen spends hours watching her favourites in concert on You Tube. She remembers songs and we often sing together, 'Autumn Leaves' or 'Wouldn't it be lovely' from My Fair Lady, music remains when many other things have gone" – **Julianne**



'Jack 'sees' our mothers around the house lately and asks me where they have gone. I asked him once "my mother Jo, or your mother Guert or both?". His answer? "Oh yes, YOGHURT" and we both laughed. When the subject comes up again he says straight away "Haha youghurt", he does have a great sense of humour". – **Lisa**



Several generations of our family sat watching a movie together and a big shaggy dog appeared full face on the TV screen. "What an ugly fish", she said. Our granddaughter hooted with laughter at the thought of a dog becoming a fish. Days later Granddaughter was still smiling, not at her Granny but rather at the funny things that 'pop out'. – **Jim**





# Dementia and the COVID-19 Pandemic



**Whilst the COVID19 Pandemic has been devastating for the whole world, people living with dementia have suffered at a far higher rate than the general population.**

The reality is a disproportionate number of people living with dementia have caught COVID and a disproportionate number have died. Whilst many may think the loss of an older adult is not so tragic, every one of these older adults was someone's mother, father, grandmother, grandfather, dearly loved relative or friend. Every one of those people had lived a full and productive life, worked, played, laughed, loved and been loved. The whole world needs to acknowledge and mourn their loss.

## A Summary of what the Experts are saying:

**The National Institute on Aging of the US Department of Health & Human Services reports:**

*People with dementia have a higher risk of getting COVID-19, are more likely to require hospitalization, and are more likely to have severe or fatal cases of this disease compared with people without dementia.*

*A new study, from Case Western Reserve University, which used information from the electronic health records of about 61.9 million U.S. adults, found that people with dementia were twice as likely to get COVID-19, even after adjusting for age, sex, living in a nursing home, and having similar pre-existing conditions. The research suggests that the memory problems associated with dementia might make it difficult for patients to stick to safety measures such as wearing masks, washing hands frequently and social distancing.*

*Patients with dementia were almost four times more likely to die from COVID-19. Researchers also found that vascular dementia, which is caused by damage to the vessels that supply blood to the brain, led to the highest risk of COVID-19, suggesting that damaged blood vessels might make it easier for disease-causing bacteria and viruses to get from a person's blood into the brain.*

**Alzheimer's UK writes:**

*People with dementia in a care home are at higher risk of getting coronavirus. This is partly because frailer older people have weaker immune systems that are less able to fight off infections – unless they are vaccinated against coronavirus. It's also because people in care homes live very closely together, making it easier for the virus to spread.*

*If a person with dementia does catch coronavirus, they are at higher risk of getting worse COVID-19 symptoms.*

*They asked the question -*

**Does COVID-19 make dementia worse?**

*There is evidence that infections such as coronavirus can cause a person's dementia to worsen. With rehabilitation, it's possible to regain some abilities, but some deterioration will be permanent.*

*When COVID-19 does worsen dementia, this is probably caused in several ways:*

- *the virus gets into the brain and damages more cells there*
- *delirium is a symptom of COVID-19 in people with dementia and can lead to worse symptoms such as confusion or loss of ability*
- *long COVID can cause problems with memory or concentration ('brain fog')*
- *invasive ventilation (use of tubes to help the person breathe) or intensive care worsen confusion.*

## So what of the Future?

Alzheimer's Disease International (ADI) is urging the World Health Organization and governments around the world to "urgently fast track research on the potential impact of COVID-19 on increasing dementia rates", stating that the pandemic could cause a significant rise in the number of dementia patients in the long term.

The group's Medical and Scientific Advisory Panel are particularly concerned about the effects of so-called long COVID. That includes symptoms such as loss of taste and smell, "brain fog" or a loss of mental clarity, as well as difficulties with concentration, memory and thinking. That can give "easier access to things that can harm your brain" and cause symptoms of neurological disorders — such as dementia — to show up earlier.



## So where does that leave people living with dementia and people who have had COVID?

Recently you may have heard a lot about preventing cognitive decline and the onset of dementia through the concept of Brain Health.

In 2020 the Lancet Commission Report on dementia prevention identified 12 modifiable, risk factors for dementia-education, heart health, hearing impairment, smoking and drinking, weight, mental health, physical activity, diabetes, social stimulation, air pollution and brain injury, that could account for 40% of dementia diagnoses worldwide. Making changes in some of these areas could delay or prevent the onset of dementia.

There has also been much research on what helps people living with a diagnosis of dementia stay as able as they can, for as long as they can. It will come as no surprise that these include physical exercise, not smoking, drinking alcohol in moderation, eating well, managing weight and diabetes, stimulating your brain and keeping socially active, which challenges the old concept of 'getting a diagnosis of dementia, giving up, sitting on the couch waiting to die.'

People with a diagnosis of dementia should be encouraged to keep engaging with their normal hobbies, activities and social networks for as long as they can. However, as dementia takes its toll many find it harder to keep pretending that they are the same. They often describe feeling judged by others, struggling to keep up and appear on top of things. Some drop out of their clubs and groups and this disengagement and withdrawal can often lead to a decline in confidence, mood and even a dip in cognition.

## Living Well with Dementia

When people join Dementia Auckland's Living Well groups, where they feel welcome and supported, we often see an improvement in people's confidence and mood and for some an improvement in their cognition. We do not need research to know that finding a group of people, who totally get you and understand you, because they are standing in the same place as you, is so good for your well-being. We see people blossom in these groups.



Having structure to your week, getting out, going somewhere you enjoy, interacting with others, having a laugh and finding purpose are all things that make human beings happier. This need does not change with a diagnosis of dementia. Even more so, people living with dementia need a predictable life structure, places to go and people to interact with.

We run 24 Living Well groups per week to help people living with mild to moderate dementia stay socially connected and keep their brain stimulated. Exercise groups, art groups, Cognitive Stimulation Therapy groups (CST), dancing groups, singing groups, walking groups etc. These groups are full of people with dementia trying to live the best life they can, despite their diagnosis.

In 2020, along came COVID bringing uncertainty, fear, anxiety, lockdowns and disruption to normal life. People stopped going out, they stopped interacting with others and people with dementia declined. Families and carers at all stages of the dementia journey describe how COVID has had a detrimental effect on their person's cognition. From people with mild and moderate dementia, who could no longer go out and enjoy conversations with others, to people in care, who could not receive visitors and went months without a touch, a hug or a real connection with someone they loved.

Throughout COVID many of our group participants tried to keep connected and stimulated by joining in our virtual CST groups, virtual Travel groups, virtual Singing group and our coffee chat groups on Zoom.

Slowly we are beginning to return to something that used to be called "normal". People are beginning to return to having a structure to their week, getting out, going somewhere they enjoy, interacting with others, having a laugh, finding purpose and doing the things that make them happy.

This revitalisation is shining through with some of our well-established groups reopening and some new groups starting. We now have seven walking groups, 4 new Cognitive Stimulation Therapy groups, a new art group and a Young Woman's group.

For most people in residential care facilities families are now able to visit again, they can hug, talk face to face, connect through shared memories and laugh together again. It almost feels like spring in the middle of winter!

**By Rhonda Preston-Jones**







# Education Update

Dementia Auckland's Education Programme has once again been disrupted by COVID in 2022. To date all of our Carer Education Programmes (CEP), Masterclasses and Dementia Talks have had to be converted and presented via Zoom only.



## Carer Education Programme

In December last year, Dementia Auckland decided to increase the time allotted to our Carer Education Programme – expanding it from 4 weeks to 6 weeks long. This gave more time to cover topics in-depth, have discussions and Q&A time. It also gives more time to focus on Caring for the Carer. Our amazing Educator Winifred Henderson has skilfully converted the Carer Education Programmes from face to face to morning and evening zoom sessions. This has allowed a lot more families members who work to attend at night. As the COVID Pandemic slows and people feel saver to return to face-to-face contact we will restore our CEP Programmes in venues across the city.

***“While I can't fix my wife's Dementia, and while at times I have struggled to know what to do and where to turn, I am now comforted to know there is light. Your excellent series of four Zoom session has comforted me and shone the light on where I can bridge the gaps in my knowledge and care”***

– Carer



## Masterclasses

Our ever-popular Masterclasses were also converted to online only for the first part of 2022. We have run two successful sessions, What is Alzheimer's? and Safety to Continue Driving. We hope to deliver the rest of our 2022 Masterclasses both face-to-face and online, so please keep an eye out for our regular updates in our In Touch email newsletter and on our Facebook page.

## Dementia Talks

During International Brain Health Awareness month we hosted another online Dementia Talk – Your Brain Health. The focus was on neuroplasticity, the brains remarkable ability to grow, modify and adapt. Our wonderful guest speakers presented to our 65 attendees on a wide range of topics from Brain Health and Dementia Prevention, Cardiovascular and Auditory Health to Meditation and Neurology.

A highlight was Billie Jordan, the inspirational founder of Hip Op-eration Crew who talked to us about Dance for a Healthy Brain and the journey she went on to get her elderly dance troupe to the World Hip Hop Championship Finals in Las Vegas.

***“This has been an enormous wealth of information, has given me plenty to think about and tools I can use”.*** – Dementia Talks Attendee



## Farewell to our long time Educator Maria

Many Dementia Auckland carers and families will know the familiar face and gentle voice of our long time Educator Maria Co. Maria, who came to New Zealand from the Philippines with an extensive nursing background in dementia care, started working for Dementia Auckland in 2013 as a Key Worker in the South Auckland area. In 2017 Maria became our fulltime Educator – offering wisdom and kindness through our Carer Education Programmes, Community Talks and Professional Talks all over the Greater Auckland area. Maria was pivotal in the formation of the now legendary Masterclasses and Dementia Talks.

In 2022, Maria resigned to move onto new pastures and to expand her wings in other areas of health care.

We were very sad to see her go and on behalf of all our carers and community, we would like to thank Maria for her amazing energy, warmth and contribution.

*The Dementia Auckland Team*





# Living well with creativity

*"It is so rewarding for everyone involved to see their weekly contributions come together into a colourful detailed image, and to be part of this collaborative project."*

Facilitated by Creative Arts Therapist Mary McGeever)

**Every week for almost two years, a group of dedicated creative artists living with dementia and their carers come together to create beautiful art and to enjoy each other's company at the Lake House Art Centre in Takapuna.**

Over this time, we have made some great artworks together including a Garden Arbour work and a wonderfully vibrant peacock, with individually coloured and cut feathers with stunningly intricate displays.

The most recent artwork is finally finished. We started working on the 'Underwater' themed artwork the almost a year ago, in July 2021. After numerous

delays due to Covid-19 and the need to be extra cautious about meeting in groups, our fabulous new mural is now completed and installed in HR Studio 4, at the Lake House Art Centre, Takapuna. We are very proud of it.

The months of creative sessions and some home-based projects have culminated in the installation of this stunning underwater scene. A variety of materials and techniques were used, including acrylic paint printing, stencilling, watercolour sketching and textural collage.

Everyone contributed to the end product. Each artist can see their own work on display in the installation and the end product is colourful, vibrant and inclusive in a very appealing way.

The Lake House Art Group is a Dementia Auckland Living Well group and meets weekly on a Thursday afternoon. Members are supported by a professional tutor, volunteers and carers. Currently, new members are welcome to join this wonderful group, and numbers will be limited to ensure a safe and well supported environment is provided to our members. For more interest, please feel free to contact the Living Well team facilitator, Sarah Dugdale on [sarahd@dementiauckland.org.nz](mailto:sarahd@dementiauckland.org.nz)

The Lake House Art Group is supported in 2022 with a grant from the Becroft Foundation.





# New Technology supports independent living

When Rob Willcox and his family found out that their Mum had early-stage dementia last year, they wanted to help her fulfil her wish to stay living independently for as long as possible. Concerned for her well-being, but wanting to support and encourage her desire to keep living in her own home, they had a look around at the options available. Traditional medical alarms were effectively just an emergency call button. As the Director of the Auckland-based technology company Smartlife, Rob knew it was possible to do more; it was a case of assessing the problems and working out the best solutions.

Smartlife Care already has a technology solution which assists older adults to stay living independently for longer. Rob fine-tuned this technology to help his Mum. In collaboration with Auckland University and AUT, we have been developing a feature set specific to people with dementia, blind and low vision, the elderly and others requiring extra assistance."

Safety is paramount, but they also wanted a way for the family to be directly involved in her care. The family group has access to the platform via the App, which includes a chat feature so that everyone is included and informed and notifications go to all family and carer group members. It's reassuring to know that if the family does not respond to an alert, optionally, the system can notify a call centre who will try to get in touch with the resident or family members, or failing that, emergency services.

Research shows that panic buttons are often not used or cannot be used when needed. The family wanted something that would give them peace of mind, knowing that if there is no movement, say in her kitchen during key times, they will get an alert. "It is reassuring, without it being intrusive. She has complete privacy in her own space while knowing there is a backup system in place should she need it." The system doesn't have cameras, just security PIRs and motion sensors. "With Smartlife Care, we can make sure Mum's doing okay without having to bother her."

Rob found that his Mums biggest frustrations were having difficulty doing the little things she had always done. He wanted to be able to help to solve issues



quickly, without her having to ask for help, feeling like she was "being a bother". TVs today can be complex, and it's easy to press the wrong button. With the Smartlife Care solution, she can now use voice control with Alexa or push a button on a very simplified remote for TV control. Things can also be adjusted remotely, such as turning on her TV or adjusting her air-con. "This adds to her quality of life. She is so relieved when we can help easily from wherever we are," says Rob.

When we can't be there, we use video communication via the portal, where the camera view comes up on her TV and ours so that we can have a lovely catch up over video. This provides a much more "lifelike" remote visiting experience, and Smartlife Connect takes the complexity out of it.

Smartlife Care offers various packages starting with simple passive monitoring to a customised solution to suit the individual needs and the unique living environment.

## Features of the Care solution at Rob's Mums place

- Occupancy sensors in the kitchen and the lounge
- Panic pendant on a lanyard and a panic button in the bathroom
- Temperature sensor and Heat Pump remote control
- Smoke sensors
- Flood sensor
- Alexa- voice control enables calling for help and controlling the TV. "Alexa, Turn on TV1"
- Video conferencing Portal on the TV
- TV Control - voice control with Alexa or via a very simplified remote, and remotely controlling the TV

More information <https://www.smartlife.nz/care>



# Silver Linings

**Mum knew something was wrong well before we came to the realisation that there was something going on. I remember her telling me years ago: “My memory is not right, and when I tell people about it they say “oh – I’m the same, always forgetting things, it’s nothing to worry about” and being dismissive, which really upsets me because I know it’s more than that”.**

We are all guilty of that kindness, downplaying and normalising as a knee-jerk response to make others feel better when there’s no obvious illness or cause for concern.

Mum was in her early 60’s – fit, healthy, running, cycling, swimming, so dementia wasn’t even on the radar and many years passed before her specialists settled on a diagnosis of early onset Alzheimer’s and Dementia. When the letter with the diagnosis was received, it was destroyed and denied, and it was several years later before we found out at a GP appointment. By then Mum was very obviously suffering from short-term memory loss and had forgotten the diagnosis altogether, telling everyone (repeatedly) she was “having a few memory problems”. Her world had gotten much smaller over those years – the physical activity had dropped away, she got lost when she drove places and called Dad in a panic to get him to guide her home with visual landmarks.

Dad is 10 years older and was diagnosed later in life with high functioning Asperger’s. He knew something was not right with Mum, but was really struggling to understand it, and while he cared for her greatly, caregiving was not something he was wired for. Tasks were fine – making a cup of tea, sorting out medications, grocery shopping. But the aspects of care where intuition and foresight are needed were beyond him. So if Mum announced she was going for a walk to see her friend on the other side of Auckland, it didn’t occur to him that she didn’t have a wallet, mobile, ID, money or any memory of how to navigate there, he just waved her off up the road! The amazing neighbours became our eyes and ears, and Mum was quickly located and returned.

I am one of 3 siblings, fortunately we have a great relationship and work cohesively, which I have discovered is quite rare. But we are scattered – I am in Auckland not far from the family home, my sister is in Wellington and flies up frequently to help out, and our brother lives in Denmark. The arrival of Covid added extra pressure. My brother was on a visit staying with our parents when the first lockdown hit which gave us our first good insight into some of the cracks that were appearing in their home life. There was a lot of confusion, forgetting and Dad really struggled with the total upheaval to his shopping routine in particular.

That year I started attending Mum’s GP appointments to “take notes”, we got her diagnosis, arranged EPOA’s and continued to strongly encourage a move to a more manageable home, but were met with fluctuating enthusiasm, (mostly zero!). We muddled our way through that year and Covid as best we could, keeping them safe, getting tasks done, but with no clear pathway for the future.

In early 2021 an A & E visit went badly when Mum decided she was leaving and went missing from the hospital with police being involved. Soon after that we had our first “hallelujah” moment when we discovered Dementia Auckland and were allocated a Keyworker. Jemma unravelled the whole process for us in terms of getting a diagnosis, involving NASC for an assessment, and some of the activities they offered, like walking groups. My sister and I



completed the Carer Education Programme (CEP) via Zoom and what a revelation that was! We finally understood what Dementia was all about, the science, the symptoms, and things all fell in to place - our experiences suddenly made sense. This is the point where we realised we needed to have strategies, and change the way we had been approaching our care and support. Don’t challenge, question, argue, or try to rationalise with Mum, just do your level best to smooth over the memory gaps and keep her happy in the moment.

Just as we felt we were making some headway with Mum, we realised that Dad was really not coping. We again got the wheels

in motion for his own diagnosis, but the July lockdown disrupted that, and he took a deep dive into delusion. An emergency house visit from his amazing geriatrician confirmed Dad also had Dementia and the

recommendation was that they needed some emergency respite care for their safety and wellbeing.

We were supported through this whole process by Veronica at Dementia Auckland, and came to realise that having a married couple committed to care together was quite an unusual scenario, let alone with this combination of Alzheimer’s/Asperger’s and dementia. We had done our research and visited a couple of dementia units earlier in the year as an option for ‘worst case scenarios’ if needed which paid off in spades when we found ourselves suddenly in one of those scenarios. We chose one of the many great villages we had visited with Mum and Dad (the one they had hated the LEAST!) so it felt like their wishes were taken into account as best we could.

It’s been really difficult for all of us dealing with this over lockdowns, with the limitations on visiting, but in some ways Covid was also a blessing, as it gave Mum and Dad an all-encompassing reason why these really confusing things were happening to them. We have also had to adjust and deal with the grief that this loss of capacity brings, but we know they are safe, and aside from the initial upheaval, they are now enjoying lots of new experiences. Mum made pasta last week from scratch! Her years as a registered nurse have all fallen back into place too like it was yesterday, and she is most happy when she is helping the caregivers with their duties and assisting other residents.

My sister and I have also joined a “Daughters of Dementia” support group run by Dementia Auckland on Zoom and this has been an amazing space to go for connection, support, advice, strategies, a few laughs and some tears. It’s also been cathartic for us to pass on some of our experiences and tips for the new joiners who are all in different stages of a different but same journey as us. Silver linings.

**By Pamela Shaw**

# STEPS FOR DEMENTIA

During February and March our Steps for Dementia campaign was aimed at increasing awareness of how we can all improve our brain health, as well as fundraising for our wonderful Living Well groups.

As March was Brain Health Awareness month, we asked Aucklanders to sign up to take a step for their brain health, such as aiming to get an optimum amount of sleep each night, to stop drinking, to read 10 pages of a book each day or to take a diet or fitness step for the month.

We had 39 teams and individuals sign up and their friends, family and colleagues sponsored and supported them on their brain health journey.

It's becoming a common refrain, but unfortunately Covid had other ideas as daily case numbers surged in Auckland throughout March. Even members of the Dementia Auckland team who had great plans to run 30km or walk 500,000 steps were affected by isolation and testing positive for Covid.

Even so, together we raised **\$69,928**. This allows for **2797** people living with dementia to attend a Living Well session.

It costs **\$489,000** each year to run our Living Well groups which enable those living with dementia to participate in meaningful activities with those that are on the same journey, providing them with purpose, improved wellbeing and joy. Unfortunately this part of our service is not currently funded by outside sources and so we rely on fundraising and donations to keep these groups running.

Thank you so much to everyone that supported Steps for Dementia, whether you took a step for your brain health, donated or helped to spread the word – thank you!

