

Mind Matters April 202

April 2024

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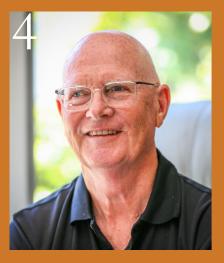
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THANK YOU

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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.



I am thrilled to share some exciting updates from the Dementia New Zealand - Northern region team, our dedicated staff, and Board as we anticipate a productive year of service to you.

To kickstart the year, we had the privilege of visiting Parliament to provide a comprehensive briefing to the Minister and her advisors. The discussions centred around the remarkable progress made in 2023 regarding the development of an international standard model of care and a corresponding costing model. The engagement was both enlightening and productive, setting a promising tone for our collaborative efforts.

On a local front, we are delighted to announce our participation in the award-winning second series of, "The Restaurant that Makes Mistakes," hosted by chef Ben Bayley. This series will feature some of our Dementia Auckland and Waikato clients, offering a first-hand look into the experiences of those affected by dementia. We believe this platform will significantly contribute to fostering a deeper understanding of the impacts of dementia, highlighting the amazing people we serve who have dementia and their whānau along with the support provided by their Dementia Advisors. We anticipate the series will be screened in mid-2024.

Additionally, we are pleased to be invited to collaborate with Auckland University, and their research colleagues, on two groundbreaking research trials. One is examining the prevalence of dementia in Aotearoa, and the other involves an innovative virtual Cognitive Stimulation Therapy program that holds the promise of reaching and benefiting people living with dementia in unprecedented ways. We are also working with Waikato University on a research project exploring the challenging issue of driving when experiencing declining cognition. In the coming months we will be supporting the Universities as they invite participants for the research studies.

In the latter part of 2023, our dedicated Auckland-based Board team enthusiastically applied and presented a compelling 'pitch' to be the charity of choice for the prestigious annual Grocers Ball. This grand event, which has been an integral part of the community for two decades, brings together grocers and their suppliers for a night of celebration and philanthropy. Following an application and a competitive shortlisting process, we are thrilled to announce that Dementia New Zealand is the charity of choice for the ball, scheduled to take place in September.

The theme for the night embraces an aspirational approach, promising to be "A Night to Remember," with a special emphasis on creating memorable experiences through the auction items. The event's primary focus is to generate revenue to target the first 90 days post-diagnosis, providing crucial resources and support during this critical period across New Zealand. Our heartfelt gratitude goes to the Grocers Ball Trustees and the dedicated events team, Type 40, for their unwavering enthusiasm and commitment to our essential services. We eagerly anticipate a remarkable night of collaboration and generosity that will significantly benefit those impacted by dementia.

During March, we were focussed on Brain Health Month, which presented opportunities for learning more about keeping our brains healthy and reducing risk factors.

As we navigate through the coming months, we remain committed to advancing our mission and making a meaningful impact on the lives of those affected by dementia. Thank you for your continued support, and we look forward to sharing more positive updates in the near future.

Jocelyn Weatherall

Northern Regional Board Chair Dementia New Zealand





THE RESIDENTIAL CARE SUBSIDY

By Jocelyn Weatherall

crucial component of planning for the cost of residential care is looking at whether you could qualify for a government subsidy.

For those aged over 65 years, eligibility is asset and income tested, however this may not be the case for under 65-year-olds who have a partner living in the community.

Subsidies are paid directly to the facility by Te Whatu Ora – Health New Zealand.

Most rest homes offer standard or premium rooms - which have additional features such as an ensuite, more space, or garden access. The funding is for a standard room only, and the additional charge for a premium room varies. Costs of general supplies, haircuts, medical appointments, and personal items are additional.

New Zealand Superannuation is redirected to fund care and is no longer available to the household.

Superannuation is adjusted for the partner in the community and typically alters to the living alone allowance.

Eligibility to enter care is dependent on a needs assessment concluding long term residential care is required. An application for a residential care subsidy can be supplied by the assessor.

You will be required to prove your assets and income are under a certain level. The criteria is available on the Work and Income website.

MSD will review any assets, including those held in a trust.

Assets typically include bank deposits, Kiwi Saver, your home, rental home or secondary dwelling, beach house, your car, loans to others, boats, caravans, investments, and life policies with a value. When you are in a marriage or partnership your home is typically exempt.

ASSET THRESHOLDS:

THRESHOLD A

Able to be chosen by a single individual or a couple.

Entire assets are worth less than \$273,628. (Includes your home, car, gifted assets). This value is adjusted minimally each July.

THRESHOLD B

Only able to be chosen by a couple where one party remains in the community.

Combined assets of \$149,845 or less, PLUS the value of your home plus your everyday car. The threshold adjusts minimally each July.

If you have gifted assets, they will be added back in. There are some allowances such as gifts in recognition of care (\$37,500). Gifting in the 5 years before care can be \$7,500 per annum.

This is the typical option chosen by a couple with one partner in care and one partner in the community.

EXCLUDED ASSETS:

- Pre-paid funeral expenses for you and your partner of up to \$10,000 each, if they're held in a recognised funeral plan.
- Personal belongings such as clothing and jewellery
- Household furniture and effects
- Your home owned personally (not a trust) and car if you fall under threshold B

SOME KEY POINTS

- Selling a home and purchasing a lower-valued home or License to Occupy in a retirement village may impact on eligibility.
- If you're over 65 and don't qualify for the subsidy, you may be eligible for a Residential Care Loan. Details of this is on the MSD website.
- If you sold an asset in the last five years, you will be required to provide evidence of sale for a fair value.
- Inheritances will need to be documented, no matter how long ago.
- Any gifts to family or family Trusts will be reviewed and most likely included as an asset. If this is your circumstance, we recommend taking advice well ahead of time.

THE INCOME ASSESSMENT

Income must be below the threshold; this is a combined position if you are in a partnership.

What's included:

- New Zealand Superannuation, Veteran's Pension, or any other benefit for those in care (apart from a small personal allowance)
- 50% of private superannuation payments
- 50% of life insurance annuities
- Overseas government pensions
- Contributions from relatives
- Earnings from interest and bank accounts
- Investments, business, or employment
- Income or payments from a trust or estate

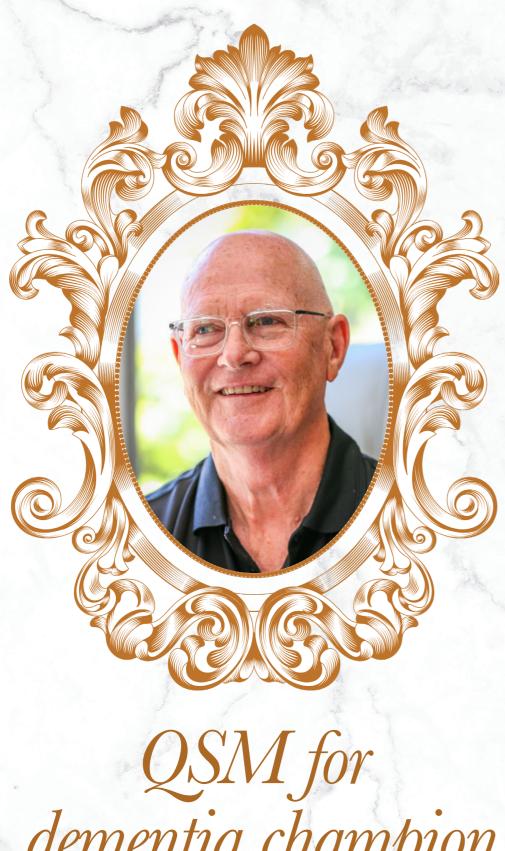
What's not included:

- Any money your partner has earned through work
- Income from assets when the income is under:
- \$1,188 a year for single people
- \$2,376 a year for a couple when both have been assessed as needing care
- \$3,564 a year for a couple where one partner has been assessed as needing care
- A War Disablement Pension from New Zealand or any other Commonwealth country

Consult with appropriate experts or relevant authorities to obtain personalised and accurate advice based on the current policy and regulations pertaining to residential aged care subsidy and individual circumstances.

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.



QSNI for dementia champion

Alister Robertson was awarded a Queen Service Medal in the 2024 New Year's Honours for services to people with dementia. The award is a remarkable feat, and exponentially more so because Alister himself has been living with dementia since he was 60.

n the nine years since he was diagnosed with Young Onset Alzheimer's he has dedicated himself to the advocacy and wellbeing of others sharing his journey.

Alister has been a member of the Alzheimer's New Zealand Lived Experience Advisory Group since 2017 and is currently chairman of Dementia Alliance International (DAI).

"My involvement with DAI helped me realise how important our voice is, and that our story needs to be told to not only help raise awareness of dementia but hopefully reduce the stigma associated with this disease," says Alister.

He plays a vital role with Dementia Hawke's Bay, running online tutorials, support groups, gym sessions and is utilised for speaking engagements.

Alister realised how invaluable peer support groups are for people living with dementia. It enables them to learn from others and take comfort in knowing that some experiences are not unique to the individual. It is a powerful outcome when people understand each other with no explanation required.

The thing he is both most proud of and hopes will make the most difference is his role in the development and release of the Dementia Declaration, setting out what people living with dementia want to enable them to live their best possible lives.

He's also working with the wider dementia sector to develop the first New Zealand Dementia Plan so more support networks can be available and funded in the

Alister's entrepreneurship is also going to leave a lasting legacy, as countless families will benefit from having the life story of a loved one documented on an app he spear-headed. After successfully applying for funding through MSD, Alister gathered an expert team of developers who brought to life his vision for an easy-touse app, now used worldwide. Alister recognised that it was also a great tool for the person documenting their memories, as a form of reminiscence therapy. The app provides prompts to write down memories with the option to upload photos and audio.

Despite his huge contributions, Alister says when he got an email informing him of his nomination for a QSM, he thought it must have been spam.

"The following day I thought I had better double check in case it was for real, not expecting anything like this to be bestowed on me. It was a complete surprise and not something I had ever contemplated may happen. I have done advocacy work because I deem it important that people living with dementia have a voice and can still contribute in many meaningful ways - I don't do it for personal recognition or award."

By Nicola Fletcher-Williams





Our online education seminars are to assist carers, families and health professionals to cope with the long journey through dementia.

UPCOMING MASTERCLASSES

31st May Caring for the Carer Presented by Winifred Henderson

19th July Safety at Home Presented by Winifred Henderson

23rd August **Transition into Care and Supporting** Someone in Care

Presented by Winifred Henderson





Fiona Faithful's mother Carol was diagnosed with Young Onset Alzheimer's disease at age 54. Symptoms were present for the four years prior, but because of her age they were put down to menopause and depression.

Carol passed away in 2022 at age 61. This is Fiona's story.

osing a mother is a profound loss, one that transcends age. Mine was my rock, a shoulder to lean on and a hand to pick me up. She was patient, caring, and without judgement. It was these virtues that I would then need in abundance when she became one of the approximately 600 people per year diagnosed with Young Onset dementia in New Zealand. Our journey, while unique to us, echoes the experiences of many families navigating this challenging terrain.

Growing up, I knew I would one day support my parents as they grew older. My upbringing, seeing my parents care for their parents in their later years, ingrained in me a sense of duty and familial responsibility. However, I never anticipated this responsibility would fall on my shoulders at the age of 29, just as I was embarking on my own journey into parenthood. In a whirlwind of events, my parents and my Nana (who Mum and Dad were supporting) moved in with my husband and me, coinciding with the arrival of our first child, Lachie. Four generations under one roof.

This convergence of life stages was both poignant and overwhelming. Despite Mum's declining cognitive abilities, the bond between her and Lachie and later our second son Max, remained palpable, a testament to the enduring power of maternal love. Yet, amidst the joys and tribulations of new motherhood, I grappled with the absence of being able to share this experience with my own mother - to seek her guidance, reminisce about my infancy, or simply revel in the newly shared understanding of motherhood's depths.

The path to diagnosis was fraught with uncertainty and missed opportunities. Initially dismissed as menopausal symptoms or depression, Mum's cognitive decline went undiagnosed for years, robbing us of the chance to intervene early and mitigate the disease's progression. The diagnosis, when it finally came, arrived too late for meaningful conversations or closure, leaving our family with unanswered questions and unspoken emotions.

In the face of such adversity, the importance of a strong support network cannot be overstated. From friends like Julia, who provided Mum with purpose and companionship through simple yet meaningful tasks, to the Dementia Auckland's Young

Ones group -a lifeline for caregivers navigating the unique challenges of Young Onset dementia, critical when typical diagnosis was often in people a whole generation older than my Dad (53 when mum was diagnosed) - these connections offered solace amidst the

Yet, beyond the emotional toll, the financial repercussions of Young Onset Dementia cast a long shadow. With my mother's inability to work and my father's subsequent caregiving responsibilities, our family's financial landscape underwent seismic shifts. The absence of pensions or benefits for caregivers compounded the strain, forcing my father to postpone retirement plans and recalibrate his financial future. He is still living with us and will be working hard (and saving hard) for the next few years to ensure he is in a position to retire come 65.

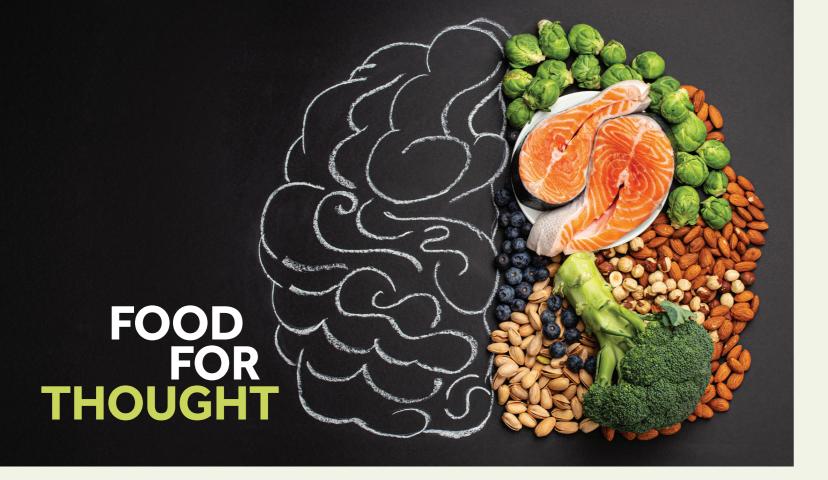
Driven by firsthand experience, I am able to provide subsidised legal assistance with Wills and Enduring Power of Attorney for those with Young Onset dementia, through my firm McVeagh Fleming.

For more information, visit www.mcveaghfleming.co.nz.



ne day you meet the love of your life. Her smile is as beautiful as her personality. There she sat, waiting to dance if asked. The dance floor beckoned as we walked. The moment you hold her the lights glow. Nobody else exists as you glide across the floor. She fills your thoughts from morn till dark. You work, but can't wait until you meet again. The room lights up when she walks in. You ask her to marry, a yes answer, your heart races. A new life has started, life is good, future assured. Honesty is as close to her heart as a glove to a hand. You walk on air whenever your thoughts go to her. The world is different, the sun shines new. She stands by your side through storm and calm. You and her walk with Jesus through baptism. Serving the Lord together comes naturally. The mission field calls, and you both answer. She is there in the decision to sell and walk on. I am down she is there, she is down I step in. Your love grows through the love of Messiah As the years pass, you become even closer You cannot bear to be apart, the days pass with love You look forward to your older years hand in hand. Many decades are straight out of the movies. You have the life you dreamed of when young. All is perfect, nothing will change, so you deem. One day you speak and there is no perception. She forgets her way, a simple thing, you think. As the months go by, there is more confusion. Next comes the driving, something of the past. Forgetting family names on visits comes as a shock. Your name, birthday and anniversaries are no longer At first the confusion is slow but speeds with time. Your heart begins to break at what may come. The months tick into years, names are of the past. She used to help with chores but tiredness takes over. The bond remains, you continue to hold hands. Sometimes you know it's so she won't stumble The questions come, over and over, but all is blank. She asks for a job, it gets half completed, and left. Showering and dressing come things of difficulty. You know as time slips away, so do the abilities. Early relationships can create lasting recognition. So enjoy the hand touch, grasp the memories. Enjoy the smile, remember it could mask a blankness. The hand hold lasts a moment, then turns into protection. Harness bonds when both are well, they mightn't last. Love without conditions, because the conditions change. One day you say I love you, the words mean nothing. You explain events, but there is no understanding. Toilet and hygiene are learnt young, but this is now lost. You lose track of events, mostly bad, so enjoy the good. Little tasks become large, moving is slow, thinking finished. She remains your love, you become, her safety blanket We have to accept one day, they will no longer smile. There will be no more touching when the day closes. You have memories of days of old, keep them near. For the day will come when that is all you will have. All this happens at the invitation of the silent destroyer.

ementia.



Last month's brain health symposium featured Professor Yoram Barak from Otago's Department of Psychological Medicine who presented on a new diet - appropriately known by the acronym MIND. The diet could significantly lower a person's risk of developing Alzheimer's disease, according to a study funded by the National Institute of Aging in the United States.

he study concluded The Mediterranean-DASH Intervention for Neurodegenerative Delay (MIND) diet lowered the risk of Alzheimer's disease by as much as 53% in participants who adhered to the diet rigorously, and by 35% in those with moderate compliance.

It is a hybrid of the Mediterranean and DASH (Dietary Approaches to Stop Hypertension) diets, with modifications based on the science of nutrition and the brain.

The MIND diet places particular emphasis on eating "brain-healthy" foods including leafy greens, nuts, berries, dried beans, whole grains, fish, poultry, olive oil and a moderate intake of red wine.

A diet rich in these foods is high in fibre, antioxidants, vitamins and healthy fats – essential nutrients that encourage good blood flow to the brain and help fuel and detoxify brain tissue. Blueberries and strawberries were identified as especially powerful in protecting the brain.

The detrimental foods to avoid are red and processed meats, fried and fast foods, butter

and margarine, cheese, pastries and sweets as these promote excess calorie intake and high consumption of saturated and trans fats. This clogs brain cells and impairs blood flow to the brain due to their harmful effect on vascular (blood vessel) health. As a result, the brain is affected by reduced nutrient availability and reduced toxin removal.

With diet in MIND:

• Eat at least 3 servings of **whole grains** each day as they are high in fibre, magnesium, folate and B6. This regulates blood pressure, blood glucose, cholesterol, lowers homocysteine (linked to heart disease and dementia) and helps develop blood cells

One serving equates to: Half a cup of cooked grains - brown, red or black rice, quinoa, millet or wholemeal pasta, One slice of wholegrain bread - grains visible, dark in colour, dense, heavy. Try pumpernickel, wholemeal or sourdough. Check the ingredients for use of wholegrains (eg bran, kibbled wheat, kibbled rye).

Half a cup of whole grain breakfast cereal homemade bircher, toasted muesli or porridge. Use whole oats, millet, quinoa or Weetbix. - Two wholegrain crackers

Swap couscous or white rice for buckwheat, quinoa, brown rice, millet or barley. Use for salads or with casseroles/curries. Add barley or brown rice to soups, sprinkle toasted buckwheat onto salad.

- Eat at least 3 servings of **vegetables** each day as they are loaded with antioxidants and fibre. Snack on vege sticks, load up a wrap with salad, take a salad to work. Make an extra-large pot of vege soup, portion and freeze.
- Eat **legumes** (lentils, chickpeas, dried beans, split peas) in at least 2 meals per week as they are high in fibre and protein but low in fat.

Add adzuki, blue peas, mung beans, alfalfa, chickpeas, lentils to salads or eat as a snack, add edamame beans to salads or stir fry, substitute meat for legumes to make vegetarian meals. Add beans to soups, casseroles and curries, Use kidney beans/black beans to make Mexican chilli, minestrone soup, bean dip, black bean brownie. Use cannellini beans for Tuscan bean soup, homemade baked beans. Use lentils in Dhal curry, lentil cottage pie, lentil loaf. Use chickpeas in curries, soups, salads, falafel, patties or hummus.

• Snack on a handful of **nuts** (30g) on most days, as they are full of heart-healthy oils and high in antioxidant vitamin E.

Mix with seeds and add to breakfast cereals and salads, make your own pesto with walnuts or

pinenuts, add crunch to roasted vegetables, top quiches and bakes. Add walnuts to lentil or zucchini loaf. Substitute flour for ground nuts in baking. Add to bran muffins, make your own dukkah – sprinkle on salad, use to crumb fish or use as a dip for wholegrain bread or veggies (cauliflower works well). Make bliss balls with cashews, almonds or walnuts.

• Eat **fish** twice a week for extra heart benefits as it is lean protein low in saturated fat. Fish is high in heart-healthy omega-3s

Put tuna on wholegrain crackers or in a wholemeal pasta bake with leeks, tomato and goats' cheese. Make a fish pie – try smoked fish and kumara mash. Put smoked salmon on a rye bread sandwich. Make a tinfoil parcel with Asian veggies, ginger, lemongrass, chilli, lemon and bake. Make Thai salmon fish cakes, brown rice salmon sushi, white fish with chilli and lime salsa, Dukkah crumbed fish or Cajun spiced fish pieces.

• Eat **fruit** every day in a variety of colours. Eat berries at least twice per week – especially blueberries and strawberries as they are high in antioxidants and polyphenols.

Add berries to smoothies, put on breakfast cereal, mix through plain low-fat unsweetened yoghurt, make a berry crumble for dessert. Replace sugar in baking with frozen berries, pour over buckwheat pancakes.

Try this salad in a jar for when you are on the go

- 1. Put dressing in the bottom.
- 2. Add a layer of hard, robust vegetables that will benefit from marinating eg root veg, fennel or cabbage.
- 3. Next rice, barley, buckwheat noodles or legumes.
- 4. Then fairly firm veg that can withstand some weight, followed by green beans, peas, capsicum or corn.
- 5. Add another layer of more delicate vegetables such as roasted aubergine or pumpkin
- 6. Add a layer of protein such as tofu, chicken or fish, then dry protein such as seeds, buckwheat and nuts.
- 7. Top with salad leaves and herbs.
- 8. Shake and serve in a bowl.



THE IMPORTANCE OF SLEEP

Dr Rosie Gibson has a background in psychology, aged care, and clinical sleep practice. She is based at Massey University's School of Psychology and is affiliated with the Health and Ageing Research Team and Sleep/Wake Research Centre. She is currently Vice President of the New Zealand Association of Gerontology. Her research focuses on sleep across the lifespan, with a special focus on the sleep-related changes among people with dementia and their carer's.

Her presentation on sleep highlighted the extent to which quality and quantity of sleep impacts on our overall health and wellbeing.

uring sleep, the brain consolidates and stores memories, helping to solidify learning and improve recall. Sleep helps cognitive function - a deficit can impair attention, decision-making, and reaction time, leading to decreased productivity and increased risk of accidents. It has a role in regulating our mood and emotional processing. Inadequate sleep has been associated with feeling more irritable int he day as well as increased likelihood of anxiety and depression.

Sleep supports brain plasticity - the brain's ability to change and adapt in response to experiences. This is important for cognition as well as recovery from brain injury.

The different stages and depths of sleep work together to consolidate and strengthen useful neural connections (and weakens unusual ones). Sleep enriches the glymphatic system - the neural 'waste clearance system' that removes harmful products like protein beta-amyloid, associated with Alzheimer's disease.

It also regulates sleep neuro transmitters - the chemicals transmitting signals between neurons in the brain - including dopamine, serotonin, and norepinephrine, responsible for mood, motivation and attention.

Sleep protects the immune system, essential for safeguarding the brain and body from infection and disease. It balances several hormones including cortisol, which regulates stress, growth hormone, important for tissue

repair and regeneration; and leptin and ghrelin, which regulate appetite and metabolism.

Because of its profound functions, sleep is recognised as a 'pillar of health'. Research finds that over a quarter of over 65-year-olds report sleep problems, which are associated with poorer physical and mental health, falls, hospital admissions, higher care needs and mortality. This highlights the importance of supporting sleep health for ageing well.

Dementia-relates sleep problems are common. These include irregular sleep patterns, increased symptoms of insomnia, increased likelihood of sleep-disordered breathing, and confused awakenings at night. Such sleep disturbances have been related to neurophysiological degeneration associated with dementia, other health issues, as well as psychosocial changes and the situational environment.

Such sleep disruptions have been found to exacerbate the waking symptoms of dementia as well as affect the sleep and wellbeing of carers.

The brain has a central body clock which helps regulate the timing of sleep and wake. Activity within the body clock is informed by the hormone melatonin as well as well as exposure to external cues like bright light and physical activity.

A reduction in size and activity of the central body clock is seen in healthy ageing but degeneration to this area

is exacerbated with dementia. It can be further influenced by conditions such as glaucoma, because the pathways from the eye are impaired, thereby disrupting the reception and processing of daylight, which is essential for regulating the body clock.

It is also important to consider that the changing situation with ageing, dementia, and caregiving can influence sleep. For example changed waking responsibilities, stress, and living arrangements can all influence timing and quality of sleep.

Steps to improving sleep:

- Keep a regular routine for supporting sleep - try to go to bed and get up at the same time each day
- Maintain enough light to get to the bathroom safely but not too much that it impacts on sleep
- Avoid eating or drinking too much that it makes you feel too alert before bed.
- Avoid alcohol and caffeine before bed.
- Use relaxation techniques to help fall asleep, such as mindfulness.
- If you don't fall asleep in about 30 minutes, get out of bed and do something for a little while then return to bed. The bed should be only associated with intimacy or sleep. Time spent doing other things in bed like being on devices disassociates the bed with sleep.

Sleeping medications should be used with caution; they can cause daytime drowsiness and impaired balance.
See your GP for a discussion about whether medication is appropriate.





Above: John and Nkki Bennett

Features

4G LTE - VoLTE

Two-way Voice Calling

Heart rate detection

SOS Alarm

Fall Alert

Waikato carer has forged his own path to meeting the needs of other carers by providing a tracking and communication device option that sets itself apart from others on the market.

John Bennett became a carer to his wife Nikki when at age 60, she was diagnosed with a rare form of dementia. At this stage he was still working full time and concerned about her safety.

The idea that she could go missing was stressful, so it was a priority for him to have a product that gave him piece-of-mind.

John had a background in procurement, so he set about sourcing overseas products.

"I went through a lot that didn't work in New Zealand or Nikki wouldn't wear."

He wanted to be able to track her himself, as opposed to phoning a contact center for information. The ones that made the grade are now available through his

The LifeGuard watch is designed specifically for the elderly and loan workers. The watch combines a variety of intelligent functions, two way calling, SOS, alarms, heart rate, blood oxygen, lockable clasp, IPX7 rated and indoor location technologies. Simple to use with a lightweight elegant design.



non-profit organisation Guardian Support Services.

John and a few other volunteers work to provide a pre-programmed watch, pendant or vehicle GPS to help whanau stay connected. When family make a call, the device will automatically answer allowing communication with the wearer.

Multiple numbers are able to be programmed into the device so that when the SOS is pressed, the device will start calling through the list. If there is no answer from the first contact, the next contact is called. If no one answers after the first round of numbers, the sequence will be repeated until a contact is reached.

Watches have a lockable strap and are waterproof for up to an hour. All products come with round the clock technical support.

John says because his venture is non-profit, the products are able to be offered at around half the cost of others on the market.

The recent changes to the Te Whatu Ora Support Subsidy mean carers can now use some of the allocated respite days to purchase an annual subscription for one of the LifeGuard devices. The current guidelines would use 8 to 9 of the respite days on an annual basis.

John says he is thrilled with the feedback received so far.

"We are dedicated to doing everything possible to simplify life for both the caregiver and their loved one."

For details, please visit www.guardiansupportservices.co.nz/collections/all or call 027 4894 380.





THE GUILTY **CAREGIVER**

Understanding and coping with guilt when supporting someone with dementia

Julia Sherwood has provided counselling support to Dementia Auckland clients for two years. She has also supported her own family members with dementia.

aring for loved ones with dementia often includes times of emotional strain. One prevalent and often overwhelming emotion experienced by caregivers is guilt. Whilst the experience and causes of guilt are unique to everyone, this article cites common scenarios that can elicit caregiver guilt and explores the possible causes of these uncomfortable feelings. Strategies are suggested to help carers head off or respond to

Guilt can occur as part of a cycle: Stress > Resentment > Emotional outburst > Guilt > Stress ...

This pattern is often a sign of caregiver stress, where frustration and resentment may escalate in response to challenging situations with the person with dementia, leading to an emotional outburst. If you notice your emotions rising in the moment, try to pause, then: walk around the block, count to ten, hide in the bathroom, call a trusted friend or relative, or switch on the TV as a distraction. Then congratulate yourself on keeping your cool and avoiding the guilty aftermath. Follow this up by working on a plan to reduce your stress by enlisting more support. If you don't know how to get help, ask your Dementia Advisor or support group for ideas.

Guilt can serve as a useful signal. The uneasy feeling of quilt can prompt us to apologise or adjust our behaviour. If we feel we've behaved unfairly to our person with dementia, apologising, even when they no longer remember the incident, can be cathartic. Expressing regret communicates the care and concern we feel for them.

requests. For instance, if plans to meet a friend for coffee are met with a plea not to go, consider that what lies beneath this is likely anxiety about being alone without their emotional 'anchor'. Depending on the stage of dementia, offering reassurance, and writing the plan on a whiteboard can help. Reminding ourselves of the importance of our separate personal time to our overall health and ability to cope, can help counteract quilt in this situation (i.e. constructive self-talk).

External criticism from friends and relatives can contribute to caregiver quilt. Those who are not regular caregivers of the person with dementia may not comprehend the challenges. Educating others about the complexities of caregiving can be empowering, along with requesting specific help. An alternative strategy to shield ourselves from critique is to decide to ignore it, while mentally noting that others can rarely understand what it is like unless they have walked in our (sometimes uncomfortable) shoes. This is another example of constructive self-talk.

Conflicting wishes and decision-making guilt.

This can arise when caregivers act against their person's apparent wishes, such as encouraging them to join an activity, or attend a Dementia Day Centre when the person is reluctant. Effectively communicating the potential benefits from this outing in terms of stimulation or friendly company, can sometimes be persuasive and help assuage quilt. However some carers can feel they have overruled the autonomy of the person with dementia, which induces quilt, especially when autonomy is a strongly held value. In this situation, assess how your person with dementia seems directly after the activity; if they enjoyed it, then the reluctance was likely rooted in apprehension. Next time they seem reticent about going somewhere, remind them of their previous positive experience. Realistically, they may have forgotten the experience, and this may not work. In this situation, we may need to accept that we do know better! To continue to be a helpful, supportive caregiver, we also need this time-out, because when

we don't, frustration and resentment may increase (Stress > Resentment > Emotional escalation > Guilt > Stress...).

Guilt when transitioning to full-time care.

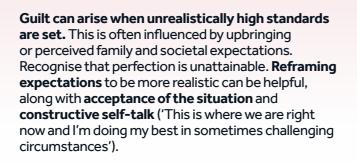
The decision to transition a person with dementia from home to full-time care can provoke profound guilt. Research suggests the decision is less guilt-inducing if a medical professional has made the recommendation. Consulting with the GP or a geriatrician may help. Meeting with other family members to discuss what is best for the person with dementia and the caregiver can also help with decision-making and reduce guilt. Some caregivers find it helpful to create a list of the disadvantages and advantages of full-time care to provide more clarity and moderate guilt. Finally, we can remind ourselves that regardless of where our person with dementia lives, we are still their advocate and will remain a loving contributor to their life.

Caregiver guilt is a natural and common emotion which everyone experiences differently. If you are worried about excessive feelings of quilt, reach out for support. Share your feelings with a trusted friend or family member, your caregiver support group, your Dementia Advisor, or a counsellor. This can help you uncover what lies beneath the guilt in your specific situation and explore ways to alleviate it.

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Julia Sherwood

STC Counselling www.stccounselling.net.nz



The person with dementia can make guilt-inducing







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 looking at the 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. Summerset's proud to have dementia-friendly accreditation from Alzheimer's New Zealand.

Homely and familar

"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 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 oth of them."

Summerset's memory care centres are currently located in 9 villages across the country, with several new memory care centres being planned.

Love the life you choose.

summerset.co.nz/ memorycare

