

### Alzheimers Manawatu Marion Kennedy Centre

## Autumn is a second Spring where every leaf is a flower - Albert Camus

Take some time out as the days become cooler to venture out and enjoy nature!

#### **BUTTERFLY COMPASSION COMMUNITY**



Butterfly Compassion Community (BCC) are a group of women and men drawn together to aid and assist communities and individuals near or far in their hour of need. BCC is filled with talented and amazing crafters, organisers, resources, donations and willing helpers. They offer their time and skills to all from babies to the elderly.

BCC align with NZ Police, FENZ, Social Workers, Women's Refuge, Teachers, Health Services and many other agencies to offer support to vulnerable people, from young to elderly. Their aim is to bring joy and smiles into peoples lives.

Recently Alzheimers Manawatu were very grateful to be on the receiving end of the amazing array of goodies for our members as featured in the photograph below.



Andrea Hodgetts, Dementia Advisor at Alzheimers Manawatu with a representative from Butterfly Compassion Community



#### **Don't miss out** SAVE THE DATE FOR OUR MOVIE FUNDRAISER...

**COMING UP!** 

QUARTERLY NEWSLETTER



(See page 6 for the details)





### good bitches

BAKING











**Good Bitches Baking** – Chapters in Palmerston North and Levin are delivering baking to MKC Clubs once a week, Monday in Palmerston North and Thursday in Levin.

**Good Bitches Baking** –'giving a moment of sweetness to people having a tough time ... We do this



by delivering baking made by our Good Bitches to organisations that support those people.



**Another SHOUT!** to Pat and the team at **WeedHunters Ltd** who are generously donating time each month to help keep Alzheimers Manawatu's Palmerston North MKC's garden in check. Thanks guys!!

SHOUT #3!! Glen and her team from Driving Miss Daisy West Palmerston North Franchise area. A delivery of Easter eggs gratefully received for distribution to MKC members. Thanks so much!!



**And finally a SHOUT!** to **Low Cost Bins** that provide services to Alzheimers Manawatu in Palmerston North at no cost. Your support is hugely appreciated!!

#### **NEW RELEASE**



This book has come together thanks to some wonderful people, each with their own connection to a person living with dementia. Our heartfelt thanks goes to the amazing author, Renata Hopkins, who has made our vision a reality. We would also like to thank Paul Beavis for his wonderful illustrations throughout the book. Our thanks go to Marcus Thomas for his book design, and Jane Parkin for her editing skills. A final massive thank you must go to Kate De Goldi who has been our valued mentor through this project.

Thank you to our amazing donors who have made this book into an incredible resource for families living with a new dementia diagnosis.

Catherine Hall, CE, Alzheimers NZ

### Kate De Goldi's story

Kate is a well-known and award winning short story writer, an author of young adult fiction, a children's book author and a writer of journalism pieces. She has won multiple awards for her writing. Her 2012 novel, The ACB with Honora Lee, explores the relationship between a young girl, Perry, and her cranky grandmother, who has dementia and lives in a rest home.

Kate's experience with dementia comes through her mother who started showing signs of memory loss in her early seventies. Through her association with Alzheimers NZ, Kate is looking to honour the experience she had with her Mum and Dad and help raise public awareness of dementia.

Our family's experience of Alzheimers began when our mother started showing signs of memory loss in her early seventies. As her dementia worsened over the next few years a heavy burden of care fell on our Dad, and on my sisters who both lived in Christchurch. It was a very difficult and sad time – and made even more so when we started to suspect that Dad, too, had dementia.

Interestingly, we had, in a sense, been made ready for our parents' dementia by our experience with our maternal grandmother years before when she had lived with us. In dealing with Mum and Dad my sisters and I called on our vivid memories of Mum's patience with her mother, her instinctive ability to play along with Nanny's confabulations and repetitions, her great sensitivity and patience. We felt that Mum had, in a way, taught us how to be with her in her own strange, altered reality.

In the period before Mum went into care we sought and were given great help by Alzheimers Canterbury. It was enormously reassuring to know that here was a group of people who had seen it all before, who could acknowledge our difficulties and sadness but give practical advice as to every stage of the dementia trajectory. We were also greatly supported and uplifted by the loving care and attention Mum received when she was in care. Her new home became a new home for us, too – and her fellow residents, their families and the extraordinary caregivers were a new community that touched our lives in marvelous ways. It was just like this, too, when we went down the same road all over again with Dad a year of so later.

Both our parents have died now. It is good to know that their struggle is over, though we miss them very much. But the legacy of their experience with Alzheimers is profound for myself and my sisters. We learned so much amidst all the sorrow. The big takeaway for me is this: though I may have felt that Mum and Dad were lost to me it does not mean they were not there. Though they may not have known who I was, or indeed who they were, they existed still, they were themselves. Though their lives were different and difficult by our measure it did not mean that they had no quality of life. It was incumbent on us to think more imaginatively about what their lives and selves had become and to see their humanity beneath the altered body and personality.

I feel very lucky to have the opportunity to work with Alzheimers New Zealand, to honour in a way the priceless experience I had with Mum and Dad. I look forward very much to helping raise public awareness of dementia and the work of this excellent organisation.

### Protect Yourself from Scams

An online scam is any scheme designed to trick people out of money or steal their personal information. Scams are becoming more sophisticated so here are a few tell-tale signs from Netsafe (https://netsafe.org. nz/) to alert you that you might be being scammed:

- Contact that is out of the blue even if the person says they're from a legitimate organisation like the bank, an embassy or your internet provider
- Getting told there's a problem with your phone, laptop or internet connections often they will offer to fix your device or say they are from your phone or internet company
- Being asked for passwords legitimate organisations will never ask for the passwords to your online
  accounts
- Needing to verify your account or details don't respond or click on any links in the communication even if it looks like it's from a real organisation
- Trying to get you to move outside of an online trading or booking website or app (like Air BnB) don't pay outside of the normal website or app processes
- Offering money or a prize in exchange for something up front they might say that it's a "processing" fee or something similar
- Being asked for money by friends/partners you've met online this is a very common tactic, do not pay the money
- Unusual ways to pay for something scammers try to use payments that can't be traced such as preloaded debit cards, gift cards, bitcoins, iTunes cards or money transfer systems
- Asking for remote access to your device never do this unless you have actively sought out the service they are providing
- Pressuring you to make a decision quickly this could be to avoid something bad (e.g. account being closed, trouble with the IRD) or to take advantage of something good (a deal or investment).

**Remember** to keep your personal information secure and be sure to think carefully before entering your details online, or giving them to someone. Protect information that can be used to access your accounts, build a fake online presence or impersonate you including:

• Login details and passwords to any online account including banking,

email, social media and trading sites • Bank account and credit card details

Address • Phone number • Birthdate • Personal information linked to the

security questions on your online accounts • Driver's licence • Passport details.



This is a great **FREE** booklet full of information about scams and how to avoid being scammed.

It is published by the Commission for Financial Capability. It includes information about Romance Scams; Door to Door Scams; Purchase of Merchandise Scams; Health and Medical Scams; Investment Scams; Identity Theft; Tax Scams; Business Email Compromise Scams; Phishing and Smishing Scams; and Subscription Scams.

#### "Forewarned is forearmed!"

We have copies available for collection from our office – 642 Featherston Street, Palmerston North





### DONATIONS MADE TO ALZHEIMERS MANAWATU

Our sincere gratitude to all who have made donations to Alzheimers Manawatu during this past year. Your donations assist us to provide advice, support and information to an ever-increasing number of families living with dementia in the Manawatu, Tararua, Horowhenua and Otaki areas.

Remember you can claim a tax credit from Inland Revenue (using form IR526) at the end of a tax year if during that year you

- Made a donation of \$5.00 or more to Alzheimers Manawatu
- are a NZ tax resident
- received taxable income.
- provide a valid receipt (which we will send to you if you make a donation)

The total claim in any year cannot exceed an individual's taxable income. The claim is limited to the lesser of 33.3% of an individual's taxable income or total donations made Thank you to all those who support us!

### DONATIONS IN LIEU OF FLOWERS

Thank you to all the families who have requested donations to Alzheimers Manawatu be made in lieu of flowers in memory of a loved one's passing. These donations help us to continue giving support, information and education to those families who are caring for someone living with dementia.



### A gift in your Will is a very special way to continue to support the work we do.

There are two types of bequests you may like to make:

- Leaving a specific amount
- Leaving a percentage of your estate

We recommend that whether you are thinking of making a new Will, or updating an existing one, you consult a professional legal adviser. They will make sure your will is valid and that your intentions are clearly and legally stated.

If you have already included Alzheimers Manawatu in your Will, or if you intend to do so, we would be grateful if you would contact us to let us know. This information will be treated in confidence and is not binding in any way, but we would like to have the opportunity to thank you personally for your generosity.

Even the smallest amount will make a big difference.

Any bequest, large or small, will bring hope to those living with dementia, and enable us to continue our work within your community. Every dollar helps in our efforts to:

- Provide practical support services and information
- Reduce the risk of dementia through health promotion and education.

Should you prefer to make your bequest for a specific location (Palmerston North, Feilding, Dannevirke, Levin) or have more questions regarding this process, please call Tracy Lynn on 021 258 5941 or email <u>manawatu@alz-man.org.nz</u>

## ALZHEIMERS SOCIETY MANAWATU FUNDRAISER FOCAL POINT CINEMAS \$ 30 NCLUDES DRINK

## THE GREAT ESCAPER

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TRUE LOVE STORY

In the summer of 2014, Bernard Jordan (Michael Caine) made global headlines. He had staged a "great escape" from his care home to join fellow war veterans on a beach in Normandy, commemorating their fallen comrades at the D-Day Landings 70th anniversary. It was a story that captured the imagination of the world as Bernie embodied the defiant, "can-do" spirit of a generation that was fast disappearing. But of course, it wasn't the whole story. It was an inspirational but sanitised retelling of one man's need to come to terms with the lasting trauma of war. Bernie's adventure, spanning a mere 48 hours, also marked the culmination of his 60-year marriage to Rene (Glenda Jackson) – THE GREAT ESCAPER celebrates their enduring love but always with an eye to the lessons we might learn from the Greatest Generation.

FEILDING 2 PM TUESDAY, 23 APRIL 2024 PALMERSTON NORTH 6 PM THURSDAY, 18 APRIL 2024 LEVIN 6 PM TUESDAY, 23 APRIL 2024 TO PURCHASE YOUR TICKETS PLEASE CONTACT PHIL BURT projects@alz-man.org.nz or 021 284 2322

# What's On

#### **CARER SUPPORT GROUPS**

A chance for you to connect with others in a similar situation to you with the opportunity to share ideas and strategies that work for you.

#### **Palmerston North**

First Wednesday of each month Contact Andrea or Liam on 027 357 9560 (Andrea) or 027 600 4408 (Liam)

#### Palmerston North Men's Carer Support Group

First Friday of each month Contact Liam on 027 600 4408

#### Feilding

First Monday of each month Contact Andrea on 027 357 9560

#### Dannevirke

First Thursday of each month Contact Andrea on 027 357 9560

#### Levin

First Wednesday of each month Contact Anne at 027 357 9543

If you are unwell or isolating, we may be able to offer Zoom for our Carer Support Groups. Please enquire with the Dementia Advisor

#### Memory Cafés

Memory Cafés are an option for carers/families and loved ones to continue to enjoy the ongoing support of others after their loved one has gone into residential care or passed away or you would just like to meet socially.

#### Levin

Third Friday of each month

**Dannevirke** Third Wednesday of each month

#### Woodville

Second Wednesday of each month

#### Feilding

Third Thursday of each month

Please note the Palmerston North Memory Café is currently on hold. If you are interested, please give us a call.

Please call 06 357 9539 or email manawatu@alz-man.org.nz for more details

## GLOBAL ATTITUDES TO DEMENTIA

Alzheimer's Disease International has launched the 2024 Attitudes Towards Dementia global survey giving you the opportunity to join thousands of others and help build the world's largest international survey on prevailing attitudes and stigma towards dementia mate wareware. A survey of this scale helps gain a truly global perspective on attitudes to dementia mate wareware. This survey is open to everyone, so please share it with your friends and whanau, and don't forget to take part yourself – it only takes 10 to 15 minutes!

https://www.alzint.org/get-involved/ attitudes-to-dementia-world-alzheimerreport-2024-survey/



## NEW REPORT HIGHLIGHTS DEMENTIA MATE WAREWARE AS CRITICAL ISSUE FOR AGEING KINTS

Aotearoa New Zealand can expect a 240 per cent jump in dementia mate wareware cases in coming years, which makes the recommendations in the just released report by the Aged Care Commissioner critically important.

That's the message from Alzheimers NZ chief executive, Catherine Hall, who says the lack of systemwide planning for Aotearoa New Zealand's ageing population, including the looming 'dementia mate wareware crisis', is difficult to understand.

"Given older people are the biggest users of the health systems and ageing is the most significant risk factor for dementia mate wareware, you'd think health policymakers would be very focused on addressing this issue, but they're not.

"The health system is not planning for New Zealand's ageing population in any meaningful way," she says.

The Aged Care Commissioner's report 'Amplifying the voices of older people across Aotearoa New Zealand' highlights the lack of support and care for older people and whānau living with dementia mate wareware.

That's one of three critical issues listed in the report in which commissioner, Carolyn Cooper, says there is a lack of a dedicated strategy and planning for the health needs of an ageing population.

Hall was also pleased to support the Commissioner's call to reduce the number of people living with dementia mate wareware in future by investing in public health measures, including hearing aids.

She also backs the call for a coordinated strategy and action plan for older people, both to address the growing unmet need and prepare for increased need as Aotearoa New Zealand's population continues to age.

"Our ageing population is not a new phenomenon. We've known it was happening, and our policymakers and politicians should know and be planning for, the impact, especially on the health system."

Hall says it is important to help older people navigate the health system, and improve the transitions of care across hospital, the community and residential care.

"The <u>Dementia Mate Wareware Action Plan</u>, that the dementia mate wareware sector drafted as a national response plan for Government, holds the key to addressing many of the issues raised in the Commissioner's report," Hall says.

Read the report on the Health and Disability Commissioner website

## RECIPE ANZAC BISCUITS

#### INGREDIENTS

1 cup Edmonds Standard Grade Flour (150g)
 1½ tsp ground cinnamon
 1¾ cups rolled oats (210g)
 1 cup desiccated coconut (100g)
 ½ cup Chelsea White Sugar or Chelsea Raw Sugar (113g)
 ¼ cup (firmly packed) Chelsea Soft Brown Sugar (50g)
 125g Tararua Butter, cubed
 ¼ cup Chelsea Golden Syrup (tin) (90g)
 2 Tbsp water
 1 tsp Edmonds Baking Soda



#### METHOD

Preheat oven to 150°C bake. Line 2 large baking trays with baking paper.

In a medium-sized bowl, sift together the flour and cinnamon. Add the rolled oats, coconut and sugars; mix well. Place butter, Chelsea Golden Syrup and water in a small saucepan and stir over low-medium heat until the butter melts and the mixture is well combined (ensure the mixture does not simmer or boil).

Remove from heat and stir in the baking soda. Add immediately to the dry ingredients and use a wooden spoon to stir until well combined.

Roll 1-2 tablespoons of mixture into balls and place on trays about 5cm apart. Use your fingers to flatten each slightly (until they are about 1cm thick). Bake for 16 minutes (for a chewy biscuit) or 20 minutes for a crunchier biscuit.

Allow to cool on trays for 5 minutes before transferring to a wire rack to cool completely. Store in an airtight container for up to a week.



### THE RESTAURANT THAT MAKES MISTAKES

SEASON

#### The award-winning local television series The Restaurant That Makes Mistakes is back!

The award winning local television series The Restaurant That Makes Mistakes is back and currently being filmed at Origine in the heart of Downtown Auckland and will be screened on TV One later this year.

Chris Martin, Ben Bayly & Mike Shatura alongside Great Southern TV are again guiding a team of 10 new volunteers, each impacted by some form of dementia, as they prepare and serve a Five Course lunch of premium seasonal dishes at Origine in Commercial Bay.





#### Calling all volunteers!

Would you like to volunteer at Alzheimers Manawatu day programs at the Marion Kennedy Centre (MKC)? MKC's are located in Palmerston North, Feilding, Levin and Dannevirke. For information please contact Tracy at manawatu@alz-man.org.nz or ph. 06 3579539 ext 202.



## **Brain Disease in New Zealand**

A breakthrough study of New Zealand rugby players has, for the first time, concluded a link between the national sport and neurodegenerative disorders.

The retrospective statistical study dubbed Kumanu Tāngata - The Aftermatch Project – is the largest of its kind.

Alongside projecting a higher risk for rugby players of brain disease the report, led by the University of Auckland and funded by World Rugby and the New Zealand Rugby Foundation, has a surprising revelation as to which positions pose greater threat of Alzheimer's and other dementias.

The study compared 12,861 males who played high-level rugby between 1950 and 2000 with 2,385,543 men from the general population matched by age, ethnicity and birthplace. Female players were not included because of the low number during the period studied.

The Herald has obtained a yet-to-be-peer-reviewed preprint of the 29-page report that provisionally concludes playing high-level rugby is associated with a "slight to moderate" increase in neurodegenerative diseases such as Alzheimer's and dementia.



The extensive report found a higher percentage of rugby players (4.7 per cent) than the general population (3.9 per cent) developed neurodegenerative diseases. It also states three of the 20 players who developed a neurodegenerative disease each year would not have been expected to if they had not played rugby.

While reports abroad previously purported ties between rugby and brain disease, this study is the first in a New Zealand context.

The report compared health outcomes of first-class players from historian Clive Akers' New Zealand Rugby Register - featuring 729 former international and professional players and

12,129 who played at provincial or first-class amateur level - with the general population by using Statistics New Zealand's integrated data.

"We found that former rugby union players were at increased risk of neurodegenerative disease diagnosis compared to males in the general population," the report states.

This increased risk was observed for Alzheimer's disease and other dementias but not for Parkinson's disease or motor neurone disease. Across all neurodegenerative diseases, players who played for six or more years had the greatest risk of disease.

"There was no difference in the rate of neurodegenerative diseases between those who played at a higher level and those who played at a lower level only (provincial/first-class amateur). The magnitude of association between playing rugby and neurodegenerative disease found in this study tended to be smaller than most previous investigations of the association between exposure to contact and collision sports and neurodegenerative disease."

Surprisingly, given the combative nature of rugby forwards, players in back positions (6066) had greater risks of Alzheimer's and other dementias than those in the forwards (5253).

The provisional report found the rate of risk onset for Alzheimer's was 42 per cent higher for rugby players than the general population – and 17 per cent higher for any neurodegenerative disease.

Rugby players were also deemed 28 per cent more at risk to die from a neurodegenerative disease. Other causes of death such as cancer and heart disease were, however, more prevalent among players – and lower than the general population.

"We observed that out of every 1000 men in the general population, 39 died from or were diagnosed with a neurodegenerative disease over the follow-up period," the report says. "Among former rugby players, the number was 47 per 1000; an extra eight cases per 1000 people over the study period, or approximately three extra

neurodegenerative disease cases per year given the size of the player cohort."

Of the 4.7 per cent of rugby players found to have suffered from neurodegenerative disorders, 30 per cent would not have been expected to have had Alzheimer's had they not been exposed to high-level rugby. That equates to 48 former players.

The equivalent statistic for diagnoses of other dementias was 14 per cent or 59 players.

As the data for the Kumanu Tāngata report stopped in the year 2000, no accurate judgements can be made about rugby's post-professionalisation era. It is, however, accepted that athletes have grown increasingly larger and stronger and that collisions are more frequent in the modern New Zealand game that also embraces a vastly greater number of powerful Pasifika players.

University of Auckland researchers declined to comment on the study until it is peer- reviewed but in a statement to the Herald, New Zealand Rugby said player welfare remained one of its highest priorities.

"We are absolutely focused on doing everything we can to keep players as safe as possible from the risks of concussion," NZ Rugby said.

"We are particularly proud to be involved in world-leading research like Kumanu Tāngata. The project is the largest of its kind ever undertaken and is vital to the future understanding of brain health in rugby. In time, the study will also publish papers which look at other aspects of playing rugby, including the health benefits of playing.

"The Kumanu Tāngata research is currently undergoing an independent peer review process with an international scientific journal that will impact the final published version. It would be improper to comment on the study's findings until this is complete."

Compared to previous studies of head impacts in rugby such as that completed by Glasgow University last October, Kumanu Tāngata's 0.8 per cent increased risk for brain diseases is significantly less. The common theme, though, contributes to a consistent picture of rugby collisions impacting brain health which will strengthen the spotlight on whether the game needs to change.

Last year the Glasgow University paper showed elite rugby players were at 2.7 times more risk of brain disease than the general population. The study revealed rugby players' risk factor for motor neuron disease was 15 times higher than the general population's - and suggested the risk of developing Parkinson's disease was at three times higher.

Researchers found 47 (11.4 per cent) of the former rugby players and 67 (5.4 per cent) of the general population comparison group had an incident-related neurodegenerative disease diagnosis, based on death certification, hospital admission or prescribing information.

That study, however, compiled a much smaller sample size of 412 players resulting in wide confidence intervals around effect estimates for some neurodegenerative diseases.

"NZR is at the forefront of concussion initiatives in both professional and community rugby," NZ Rugby said. "This includes the blue card, mandatory stand down periods for community players, reducing the tackle height across community rugby, compulsory education for community coaches, head injury assessment protocols and the use of smart mouthguard technology in the professional game, and the 20-year RugbySmart programme with ACC which has seen a significant reduction in playing injuries."

Rugby is not alone in confronting mounting evidence that strongly suggests its players are at greater risk of neurodegenerative disease than the general population, with other studies abroad indicating the rate of mortality from brain disease increases three or fourfold in former football and American football players.

A study of Swedish football, published last April, found 537 (8.9 per cent) of 6007 male football players and 3485 (6.2 per cent) of 56168 from the general population were diagnosed with neurodegenerative disease.

The New Zealand report comes as a lawsuit is being prepared overseas covering former rugby players left with cognitive issues from post-concussion syndrome to suspected chronic traumatic encephalopathy (CTE). Former All Blacks prop Carl Hayman, who claims rugby exploited him since being diagnosed with dementia, is among that group.

Ongoing debate about links between concussions and CTE, a progressive brain condition, in collision sports can only be proven through autopsy.

Get in touch



642 Featherston Street, Palmerston North

06 357 9539

manawatu@alz-man.org.nz

www.alzheimersmanawatu.org

/alzheimersmanawatu

alzheimersmanawatu

### **Membership & Donation Form**

Mr / Mrs / Miss / Ms

Name(s): Address: \_

Telephone: \_\_\_\_

Email:

Membership Fees

Individual \$35 Organisation/Corporate \$100

Lifetime Membership \$200

Become a Champion by making a regular monthly donation Champion Donation: \$\_\_\_\_\_

#### How to pay:

Internet Banking - You can pay the membership fee directly into our bank account. Account number 03 1521 0013792 01 (Alzheimers Society Manawatu Inc). Please add 'membership' as reference and email your details to us at manawatu@alz-man.org.nz or call us on 06 357 9539.

Please accept our sincere thanks for your support.

Alzheimers Manawatu "Marion Kennedy Centres" will be closed on the following upcoming public holidays Friday 29th March (Good Friday), Monday 1st April (Easter Monday) and Thursday 25th April (ANZAC Day)

### HAPPY EASTER



