

Dementia Canterbury



Noho ora pai ana I te korokeke – Living well with Dementia

Spring 2018

Volunteers and Staff at Walk for Dementia



(Left to right) – Lee Andrews, Diane Toothill, Shirley Starling, Val Dempsey, Graeme Dempsey, Julie Foster.

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From The Manager

Three months in at our new place and we are well settled here at Sir William Pickering Drive. Following an inhouse opening of the building we had a public open day at the end of June. It was great to see so many people come through and we are really pleased with the positive feedback. CBC (The Canterbury Brain Collective) is working hard behind the scenes on our longer-term plan to secure a site and develop a building.

We held our first Walk for Dementia at the end of March based at Avebury House and Gardens and incorporating two separate walking areas around the Otakaro Avon River Corridor. It was an enjoyable event with much valuable learning. Next year we will be looking for a space for a walk with good disability access. We hope to partner again with the wonderful Avebury House team for an alternative fundraising event.

A small team ably manned our stand at the Brain Day in late March. Great to see so many organisation in the industry together with a very steady flow of public attendees.

This year our annual appeal dates have changed. Together with other Dementia New Zealand affiliates we will be running a Remember December Appeal (see dates and information later in this newsletter).

With our Respite Activity Pilot Research complete, we were thrilled that a precis of our research and pilot program was published in the Australian Journal of Dementia Care in June. See some of the wonderful research findings later in our newsletter (pages 4 – 6).

Despite our growing service delivery arm, we are still struggling to get funding in to support our many programmes. If you, or someone you know, your organisation or group think you may be able to help us, we would love to hear from you.

Darral Campbell
Manager



CBC premises opened by (L to R) Jane Parfitt (President Dementia Canterbury), Malcolm Rickerby (President MS & Parkinsons) and Simon Challis (CBC)

Applauding our Patron

Six women who have worked tirelessly in the areas of nutrition, science education, science communication and the history of science, social sciences, dementia research and New Zealand history have been made Companions by Royal Society Te Apārangi.

They are Wendy Fleming, Dr Jennifer McMahon, Dame Claudia Orange, Associate Professor Robin Peace, Jennifer Pollock and Associate Professor Rebecca Priestley.

President of Royal Society Te Apārangi Professor Wendy Larner said the election as a Companion is an honour recognising outstanding leadership or sustained contributions to promoting and advancing science, technology, or the humanities in Aotearoa.

"The Society's Council is pleased to be able to recognise the significant impact and the sustained efforts each has made in their respective areas," she said.

"The honour of Companion is reserved for those who have made a contribution to society far above and beyond what might be expected of them from the roles they have held.

"While it is coincidental that we have elected all females in the year that New Zealand celebrates 125 years of women's suffrage, it's a fitting opportunity to reflect on the important contributions women have made and continue to make in many areas of our lives."

The award of Companion of the Royal Society of New Zealand Te Apārangi (CRSNZ) was introduced in 1999 and there are now 49 Companions.

Wendy Fleming has been elected as a Companion in recognition of her outstanding contributions to the promotion of dementia research in New Zealand. She has raised public awareness about the impact of Alzheimer's disease and dementia on quality of life and the necessity for world-class scientific research to help give hope to people with dementia.

Through her membership of national nursing, hospital and aged care committees in the 1970-1990s, she advocated that people with dementia have the right to expect the very best care and support through investment in research.

Over the last 20 years she has provided exceptional leadership in promoting scientific research in New Zealand through her community involvement as chair/vice-president of Alzheimer's NZ, Alzheimer's Disease International and as a member of boards providing primary health care for people with dementia.

Wendy Fleming, Christchurch — Giving people with dementia hope



Over the last 15 years she has been a passionate and successful advocate for scientific research on dementia through her establishment and chairing of the Alzheimer's New Zealand Charitable Trust. The Trust has attracted and provided close to \$1M from private and philanthropic sources to fund the establishment of a network of Dementia Prevention Research Clinics throughout New Zealand by the Brain Research New Zealand (BRNZ) Centre of Research Excellence.

Wendy has also served on the advisory and governance boards of BRNZ and the Centre for Brain Research and has provided input into the Ageing Well National Science Challenge, advocating for and promoting the advancement of research on the ageing brain.

(Taken from: <https://royalsociety.org.nz/news/six-women-recognised-for-leadership-and-sustained-contributions-to-science-and-the-humanities-in-aotearoa/>)

Respite Activity Pilot Research

"I feel alive": An evaluation of Dementia Canterbury's community-based activity respite programme

at a glance | **100%** of care-partners noticed a difference in the person with dementia

A range of activity groups

appreciating art at the gallery	discussing literary extracts at a local library	gardening at the botanic and community gardens
water activities at a local pool	getting involved with the arts	creating a life story book at the library
walking with community organisations	baking for families with children receiving medical treatment	making something DIY at a hardware store

Initial needs assessment



% of people with dementia who wanted to do something but couldn't over the last week



% of care-partners who felt stressed trying to meet other responsibilities

For care-partners



For people with dementia

Enjoyment and feeling normal

*I feel alive.
Can we do this
every week?*

Getting out in the community

*If I wasn't doing this
I'd be at home
climbing the walls*

Social connection

*It's been very good
because of the people
...have a good laugh*

Respite Activity Pilot Research



"I feel alive": An evaluation of Dementia Canterbury's community based activity respite programme

Impacts for the individuals with dementia

Engagement in meaningful activity can provide in the moment pleasure that can be seen in behaviours like laughter and smiling, engagement, alertness or leaning forward to listen, sharing conversation and offering opinions. These in the moment experiences can be a reprieve from the stress and frustration of the challenges of living with dementia [6].

Across 15 short structured observations in two activity groups there was support for the groups providing positive in the moment experiences. After an initial opening period which primarily involved passive engagement (e.g. paying attention but just watching or listening), the participants in every observation were actively engaged and showed in the moment pleasure.

The structured observation of activity groups found that each participant observed:

- were involved in constructive engagement for the majority of the time
- showed sustained attention
- were content or showed positive pleasure
- were observed to smile

The participants, care-partners, and coordinators all talked about the enjoyment and laughter of the groups and loving the experience.



Initial needs assessment:
% of people with dementia
experiencing issue at least
sometimes over the last week

Did the carers think the participants enjoyed the groups?



Respite Activity Pilot Research

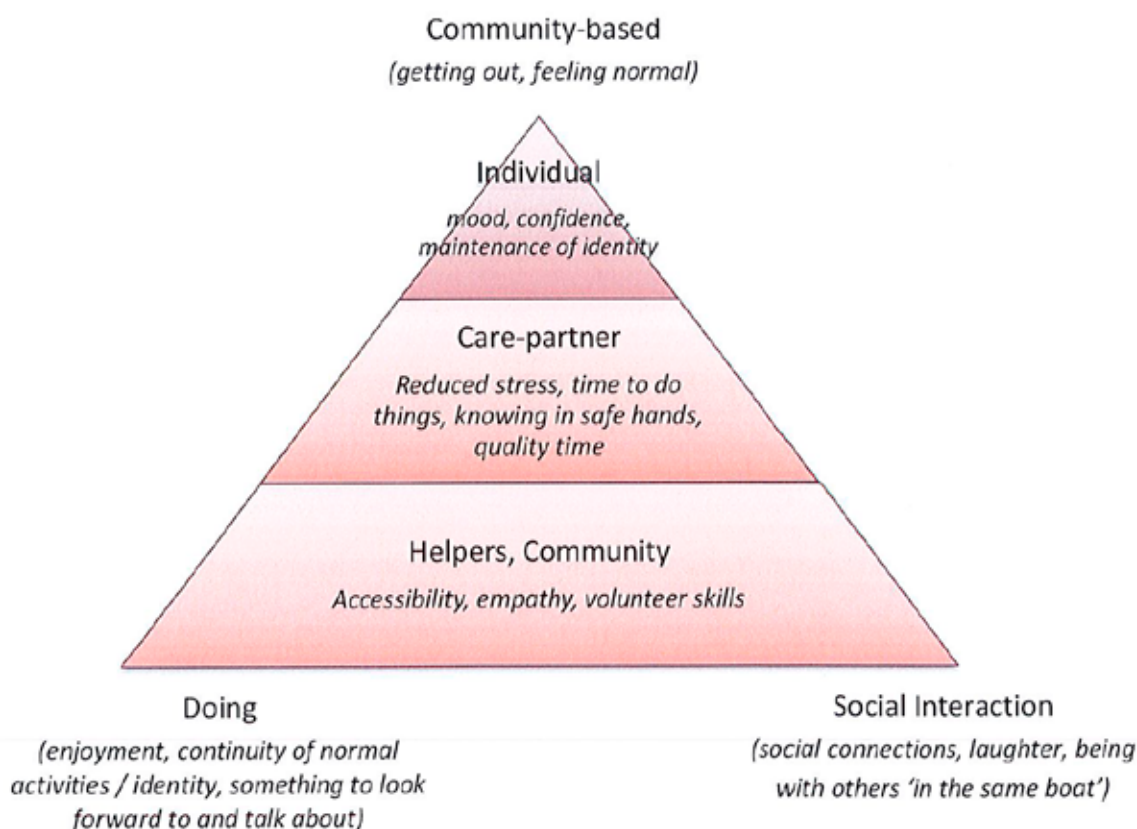


"I feel alive": An evaluation of Dementia Canterbury's community based activity respite programme

Conclusions

This evaluation found that the pilot activity programme offered by Dementia Canterbury was received enthusiastically and consistently seen as beneficial. The activity groups were seen as meaningful and having a positive impact including providing enjoyment, social connection and opportunities to continue aspects of identity and build confidence [17]. Being located in the community helped to normalize the activities and provided opportunities to get out of the house. These components benefited not only the individual but also the volunteers and community partners.

Positive impacts of the community-based activity respite programme



A Daughter's Perspective

My grandmother had dementia, so when we first noticed Mum having a few difficulties with names and relationships within the family (she would call her son her brother for example), we started to wonder if perhaps she had dementia too. She had been a great cook but I noticed she stopped doing much cooking and I would try and encourage her by saying "what can we make?". Around this time too we were caring for my father who had terminal cancer. It was a stressful time for Mum. She needed to renew her driver's licence and I went with her to her Doctor's appointment. There when she did the memory test it became very apparent that she just couldn't do a lot of it, that there was a significant short-term memory issue – it was just so sad to see this. Needless to say, she didn't get her licence and it was the start of the process of being diagnosed with dementia. I asked that we be referred to a support agency which turned out to be Dementia Canterbury.

Early on we introduced a large whiteboard which I write up every month with all the days on it plus appointments and activities for the month. (Unlike a diary or piece of paper it does not get lost or misplaced.) It's been really helpful for her and helps keep her focused on what she has on each day.

Mum is managing in her own home where everything is familiar. She is happy doing her garden which she loves, and keeping the house tidy. She still works hard on both and it used to worry me that she was working too hard, but I have realised that these are the things that make her happy.

I have made sure that Mum maintains social contact which she always enjoys but she had become quite isolated. Many friends had died, and not being able to drive means I need to take her places more. I actually really enjoy hanging out with her, and doing stuff together like we have done for years. Saturday we go grocery shopping and have often visited her grandson.

Sunday we go to Riccarton Market and she comes for Sunday dinner at home. I visit four days a week. I've learnt to give her plenty of time, not rush her if we are going out, or tell her things that are too far away from the here and now. Sometimes I get frustrated, but then I think "what must it be

like for her?" and I say to myself "pull your head in!".

It's hard to see her sometimes not managing her grooming as she used to but I'll say something like, "why don't you put your beautiful coat on and brush your hair?" to prompt her and that's all she needs. When she looks great I tell her how gorgeous she looks.

I often think there must be sadness for her about what she can't do, and how much of a struggle it must be for someone who has always been independent to accept help.

I love to take her for a visit to her old home town, Ashburton. There she knows the place, the name of all the streets and who lived there. We visit old haunts and enjoy catching up with friends and family. We always have a great chinwag in the car.

Dementia Canterbury has been fantastic for Mum. She attends Artzheimers, Art Therapy, Gardening and Walking groups, as well as a social café group. We loved doing her Life Story together in the group some time back. She is so proud of it.

I have learnt to be a bit more observant about what's going on for Mum. When she is a little grumpy I try and think about what might be behind it. This was the case recently and then I realised that weeks of wet weather had kept her away from her happy place in the garden. It was wonderful to have her show me the exercises they had been doing inside on the day of her gardening group at Avebury House because of wet weather. She had had fun and social contact and stimulation.

Sometimes It's hard for me to keep the balance between my own life and friends, and being supportive of Mum, but she has always been incredibly supportive of me, and although it does affect our lives, we are not living with it daily like she is.

It's really important to keep 'doing'! Mum has a wonderful saying that she learnt from an elderly lady she supported many years ago "Hands remember to do things that they have always done".



Matisse Art at Art Therapy Group).

Book Review

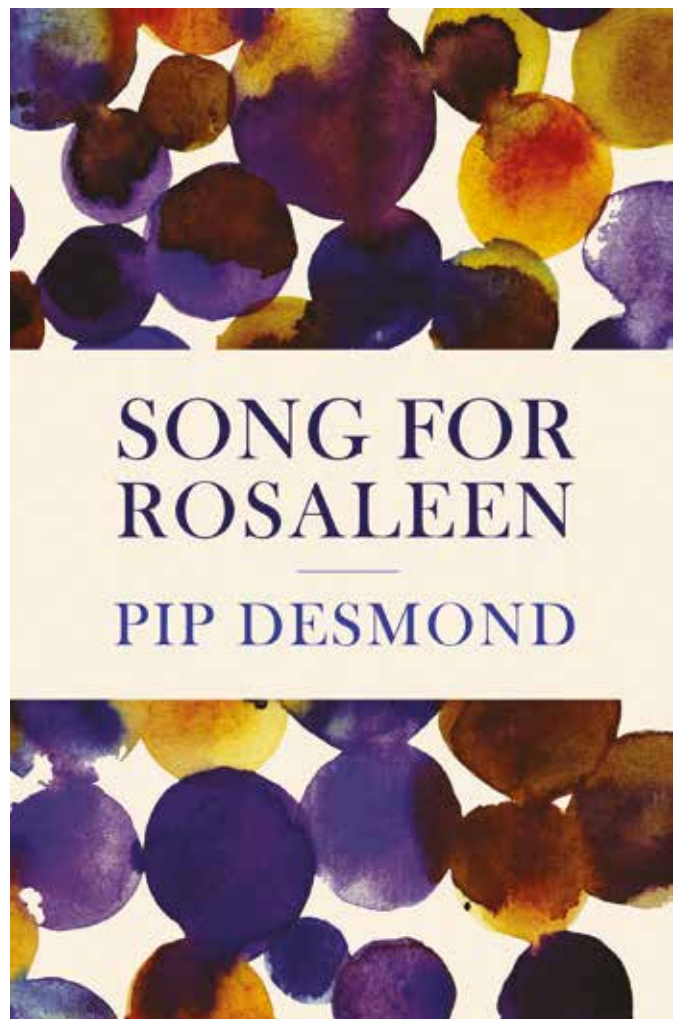
"Song for Rosaleen" by Pip Desmond Massey University Press 2018

It is always good to add another New Zealand memoir of life with dementia to our Dementia Canterbury library. The majority of memoirs we house are by American, English or Australian writers and while expressing the universal themes of supporting a family member with dementia, or of living with dementia, they also inevitably focus on the particularities of navigating their own health care systems.

"Song for Rosaleen" is a deeply honest portrayal of a daughter (one of six siblings) supporting her mother through the journey of dementia, from the long and protracted effort to get a diagnosis through to her death in a hospital level care facility in Wellington in 2009. Like all good dementia memoirs it is a story of relationships, history, family, love, struggle, self-discovery and other-discovery. For all that we hear of dementia as a condition that robs, it is also one that reveals. For Desmond what is revealed is both deeply painful and ultimately cathartic as she comes to understand and appreciate a mother beyond the "good and quiet" one she has always known.

Desmond makes clear that the story she is writing and the mother that she is describing are her own, that each of her siblings will have a different story and a different mother to describe. In laying out the dangers and pitfalls of writing memoir she does not shy from delving into the sometimes fraught dynamics and complexities of family relationships while never blaming or abnegating her own responsibilities. The memoir is punctuated by emails between the six siblings that span the length of Rosaleen's illness and provide a wider point of view to the unfolding events. Those readers who are navigating this journey without five caring siblings may feel a pang of envy at the level of support they are able to provide their mother and each other.

The failings of the health care system are described in detail, from the G.P. and geriatrician who refuse to give a diagnosis of dementia, to the psycho-geriatrician who does but with complete tactlessly, right through to the frail Rosaleen being over-prescribed Clonazepam by a GP without seeing her. The family's dealings with the village where Rosaleen purchases a license to occupy studio also falls well below the mark, "Most staff did their best but they seemed bemused by her obstruction, too stretched to provide more than basic care and react to crises. Management seemed invisible. Real estate not health care".



However, the real strength of the memoir is Desmond's ability to describe her own journey of grief and learning, her coping and at times barely coping; "To thrive, we need positive emotions like love and joy in our lives. Gritting our teeth, soldering on, doesn't work indefinitely". "Song for Rosaleen" illustrates powerfully that the story of who someone is does not end when dementia begins, but that the whole messy glorious complexities of relationships and life continue and that despite the heartache and suffering there is also the possibility for growth and discovery.

Reviewed by Philippa Cosgrove, Educator, Dementia Canterbury

Activity Groups Update

It is our goal in the Activity Programme, to support people to remain active, to be engaged in a welcoming community, to feel productive and most importantly to enjoy themselves in the company of others. We love hearing the feedback and suggestions, it helps us to adapt, and aspire to provide the right activity, at the right time for as many people as we can. We see that after each group (even if people are not able to put it into words) people look brighter, stand taller and smile more, when they have been out doors, keeping busy and sharing laughs with likeminded people. Hence, we are excited to report that the activity group programme continues to grow and develop.

Opawa Community Garden

Over this cold wet winter, we have only had to be indoors on one occasion. Thankfully Jenny from the Garden and the Opawa Church opened their doors and came to our rescue. We made bird feeders with pine cones, lard and peanut butter. Which were delightfully messy, smelt delicious and were a huge hit with our feathered friends. Then we devoured Jenny's delicious vege soup. All in all it couldn't have been better, sitting warm and cosy, looking at the weather outdoors, with lots of laughter and mess making, a perfect day.

Bunnings DIY

Our industrious DIY'ers are doing a sterling job at Shirley Bunnings. The DIY men put together over 90 tool boxes, far exceeding the plan (it was meant to take us three sessions, not one!). This was a bonus, the next week we were able to make gum boot stands. Perfect for this wet winter, dry gum boots for all, and happy DIY'ers.

Museum

We are absolutely thrilled to announce the start of a new partnership. The Museum, a Christchurch treasure, nestled beside the Botanic Garden has so much to offer. Our guide Marissa is going to lead us on a trail of discovery, one department at a time. There is sure to be something for everyone, from Mrs Popes haberdashery shop, to Moa bones and Penny Farthings. It will be a chance for us to learn something new and to reminisce and share what we know with the others in our group.

McBakers

We continue to do our little bit for the families staying at Ronald McDonald House. This month we filled the communal kitchen with laughter and the smell of home baked apples pies, and cheesy bacon puffs. It's feels good, to brighten, just a little, the difficult days for the children and the families staying at the House.

Swimming

Huge respect to our hardy bunch who brave the pools and swim year-round. Of course, the pools are heated, but still,

Making Bird Feeders at Opawa Church.



Next Chapter in Shirley – School Days



Stan's Gumboot Holder at Bunnings



Eric and Graeme at Avebury Gardening Group

it takes extra effort to brave the outdoors, "togs in hand" on these winter days.

It's made easier by the wonderful staff and life guards at the pool who are so welcoming. We have lots of laughs, and after a brisk swim, an aqua jog and a soak in the spa, all head home rosy cheeked, blood pumping, full of life, all set for a good sleep that night.

Life Stories

We have a life stories group running at the moment. Each of our 10 story tellers, is paired with an experienced volunteer, at the South library technology suite. Over the six sessions our group gather up their special photographs, remember the lives they've lived and document their stories, in the form of a pictorial autobiography. Family and friends are often involved too, either in the gathering of the stories or in the presentation at the end, which is always a celebration of "each and every" story teller. We hold this group 3 times per year with the next one due to start in October.

Art Making at the Gallery

Our partnership with the Art Gallery continues to forge ahead, it is such a privilege to be able to work in such a great venue and alongside this committed staff team. This month we had to say fond farewells to Bianca, from the art gallery, who worked tirelessly with us to initiate the art making group. As we ate cake we reminisced about the painting, the printing and the collage projects which worked so well. We then met Susie, who is taking over, and have already planned wonderful new projects, with pottery, screen printing and photo/collage, for our enthusiastic group of creators. I know they sound "quite ambitious" but as always, no prior skill or talent is necessary, just a "give it a go" attitude is all that is required.

Ashburton DIY Group

We are delighted that we have been able to start a monthly DIY group in Ashburton. The MenzShed in Ashburton have kindly allowed us to use their fabulous space, plus offer their time and expertise, and Bunnings Ashburton are generously supplying materials for our projects. At our first group we put together a tool box and a toy car, and at our next group we plan to make a birdhouse and planter box. It was great to see the enthusiasm, enjoyment, and comradery of our group members, with some reconnecting with past skills and experience, and others learning something new. We are looking forward to working with Bunnings and the MenzShed over the coming months, and seeing this group grow and develop.



David and Hec together with Lindsay from the MenzShed, busy working at the DIY Ashburton Group

Kaikoura Update

A small team has been visiting Kaikoura each month (18 times since April 2017), to offer Social work support, education and to assist the staff at Kaikoura Hospital to develop an Activity Programme for people in their community who have been diagnosed with dementia, and/or people who are socially isolated.

In April, it was timely to start recruiting volunteers from the local community. To this end, during the May and June visits Dementia Canterbury staff formally interviewed a range of skilled and energetic people, and as a result now have 10 great volunteers ready to donate their time to supporting the Activity Programme. This was followed up in July by an education session on dementia for our own 10 enthusiastic people, together with others who volunteer for a range of organisations locally, (for example the Kaikoura Community Vehicle Trust).

The long-term goal has been to partner with existing organisations in Kaikoura in order to convene four different activities each month for our client group, and it is exciting to report that we are very nearly there! With three established activities on Tuesday mornings: "The Next Chapter Club" at the Library/Museum; "Activate" at the Croquet Club; and "Sowing the Seeds" at Fyffe House (although this has been relocated over the winter months while Fyffe House is closed), we have a cooking group planned for the first Monday afternoon of the month. Having negotiated the hire of the Croquet Club for this activity, we are keenly awaiting the installation of an oven into their kitchen.

The Cooking Group plans to donate its tasty bounty to the Kaikoura Community Meal, which is coordinated by the Vineyard Church and takes place at the Scout Hall on Monday evenings. They have negotiated with us to provide something sweet for dessert each time. We look forward to the inaugural Cooking Group in early Spring!



Volunteer Activities

Volunteering Canterbury 2018 Volunteer Recognition Awards

On Monday 18th June, 27 individual and 5 group Awards were presented by Volunteering Canterbury in recognition of an outstanding voluntary contribution to the community. One of these awards went to a very deserving Dementia Canterbury volunteer, Jillian Crossen. Jillian has been a highly valued volunteer with us since 2006. She initially became involved through speaking at our support meetings about her own experience of her mother having dementia. She is a caring, thoughtful woman who cheerfully uses her time and skills for the good of others. Jillian is an excellent gardener and has put these skills to great use both in maintaining and beautifying the garden at our old premises on Worcester Street and in volunteering with our monthly group in the Botanical Gardens. She has also regularly transported clients with dementia to and from the Gardening Group and formed great relationships with them. Her contribution to Dementia Canterbury is invaluable, and we are very grateful for all she does to support people to 'Live Well with Dementia'.



Jillian receiving her Volunteer Award with Dementia Canterbury's Volunteer Co-ordinator, Jasmine Salam.

Library Tidy Up

On Saturday 9th June a fantastic group of volunteers from Your Volunteers Christchurch came along to help Dawn (Volunteer) and Jasmine (Volunteer Coordinator) re-sticker and tidy up our library. With great enthusiasm and attention to detail, they methodically worked their way through every section, completing the books faster than we could get them back on the shelves! We sincerely appreciated their support with this task, which would have taken many hours otherwise. Your Volunteers Christchurch volunteer for a different organisation each month, so if you'd like their support, contact us and we'll put you in touch.



Volunteers working in our Library.



Vests worn by Volunteers and Staff at the Walk.

Brain Day Canterbury

Colleagues from around the neurological community joined forces at Brain Day to share information with the public. Some exciting public seminars ensured good community engagement on the day.



Stamps for Library

Trevor Hayes, our amazing Philatelist, has a target to make \$20,000 by the end of this year through the sale of stamps donated to Dementia Canterbury to fund our Library collection. Please help Trevor reach this wonderful target by donating any stamps/ stamp albums for him to sell on our behalf. Thank you Trevor for your valued support.



Events

Walk for Dementia

Our first Walk for Dementia was held on a very warm and sunny Sunday on the 25th March 2018 based at Avebury House and gardens and incorporated two separate walking areas around the Otakaro Avon River Corridor (Red Zone).



Enjoying the entertainment at Avebury House on the day of Walk for Dementia.

Kell's Ride For The Future, a Cure

Greg Kelly will be riding the length and breadth of New Zealand this September and October, raising awareness for Younger Onset and Frontotemporal Dementia. This time a filmmaker will be accompanying him, Elizabeth McLeish, to film a full-length feature documentary.

Greg and his wife Janet, are in a caravan travelling through outback Queensland, and hope when he visits New Zealand Greg can speak about his reason for doing "Kell's Ride for The Future, a cure". During his Australian Ride, he spoke to a variety of organisations – Dementia Australia teams, carers meetings, professionals working in the Dementia field, medical research teams and other community groups. He attracted a lot of media attention along the way and is excited about doing the same in NZ this year.

Keep an eye on our Website and Facebook page for more updates:

<https://www.dementiacanterbury.org.nz>

<https://www.facebook.com/DementiaCanterburyNZ>



Dementia Canterbury Annual Appeal

**Friday 7th and Saturday
8th December 2018**

Help us make this the best year ever!

If you can collect, please contact admin@dementiacanterbury.org.nz
or phone 03 379 2590



Donation slip

YES, I'd like to support people living with dementia

As a not-for-profit agency, Dementia Canterbury needs the support of the community to continue to deliver services that really make a difference to the quality of life for all affected by dementia.

NAME _____

ADDRESS _____

PHONE _____ EMAIL _____

☐ I would like to receive regular email updates from Dementia Canterbury

Please accept my donation of: ☐ \$10 ☐ \$25 ☐ \$50 ☐ Other \$_____ or:

Internet Banking Details: ASB 123240:0097861:00 Dementia Canterbury

(Please use your Surname as a 'Reference') or: Cheque is enclosed ☐

Credit Card Details: Please charge my credit card with \$_____ Visa ☐ Mastercard ☐

Card number _____ Expiry Date _____

Name on Card _____ Cardholder's Signature: _____

Invest in your future – remember Dementia Canterbury in your Will.

Contact us for more information. Email admin@dementiacanterbury.org.nz or call 03 379 2590.

Canterbury

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Te Poari Hauora o Waitaha



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