

MAKING A DIFFERENCE



Water Memories Group

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From The Manager

It has been another busy few months for Alzheimers Canterbury. In May we took part in our local "Good in the Hood" promotion, and were thrilled to be chosen to make an advertisement for national television. Blink and you may miss us but watch out for the advert or check the full advert out on "Z" or our Facebook pages. Thanks "Z". It was an amazing experience.

In July we held our AGM and fare-welled long standing Patron Gaynor Reid (Duff). Gaynor has had a long and illustrious association with our organisation from its inception. Her skilled, calm, professional and knowledgeable input has been significant in shaping this organisation. We are in your debt Gaynor and acknowledge your unfailing commitment to making life better for people affected by dementia. Alongside this, Gaynor and her family have had and are having a very personal journey with dementia. We are humbled and grateful that their story is shared with us later in this newsletter.

Moving into the role as our new Patron, we welcome Wendy Fleming. Wendy is very well known in dementia circles having worked at both national and international levels. She has recently stepped down as Vice Chair of Alzheimers Disease International but remains an Honorary Vice Chair. We are privileged to have her as our Patron and look forward to working with her. July was also "Cuppa for a Cause" month. Thank you for all the wonderful people who organised events and to those who attended.

We are delighted to be launching our two year pilot Respite/Activity Program. Read on for more information.

As we approach our biggest event of the year (our Annual Appeal) we again seek your support to help us collect and to raise awareness about dementia.

Darral Campbell
Manager



(from left to right) Gaynor Reid (past Patron), Paul Tunley (President), Wendy Fleming (Patron)

Genetic Reality: When Professional & Personal Worlds Collide - Gaynor's family story

My interest in dementia is both professional and personal.

In his mid-50's my father and mother were visiting me in London when I noticed changes in Dad's behaviour which were quite perplexing. He was having difficulty managing currency exchanges and seemed to show little interest in the many new experiences Mum and he were sharing on their travels or much interest in his little grandchildren. That was strange as Dad had previously loved small children and been excited about seeing them and about their travel.

When they returned to New Zealand their GPs didn't believe the changes my mother reported were happening. This was in the late 1970s when there wasn't the knowledge and awareness there is today, especially for someone of his age. I suspected he might be developing dementia but it wasn't until he was 57 that a diagnosis of dementia and depression was finally made. Dad was still working at that time but soon after he had to give that up. There were many small 'dings' in the car which he couldn't account for, often blaming someone for denting it whilst parked in the supermarket carpark. Not that he ever shopped at the supermarket himself! Finally, he was persuaded that, because of the medications he was on, he should not drive anymore and he fortunately accepted this.

In 2001 at the ADI conference here in Christchurch Dr Chris Collins mentioned the link between fronto-temporal dementia and motor neurone disease and, as I sat in

the audience listening, my blood ran cold. I made the connection for our family as I knew two first cousins had died in their 40s from motor neurone disease and by now I suspected that Dad's diagnosis, if it had been possible to fully test him back then, would probably have been fronto-temporal dementia.

Since then I've traced Dad's family history, as far as I was able, and noted that his father, at least three of his brothers and one sister all died in their fifties in psychiatric hospitals with various diagnoses, but dementia or psychosis seemed to be the problem common to all. Dad also died in Sunnyside psychiatric hospital, after living there for two and a half years. No suitable rest home care was available. My brother developed a psychosis in his late 40's and he also required some time in a psychiatric unit and has not been able to work since. Recently I have learned that at least two first cousins have also developed dementia. So, a picture of something passed down through the family was emerging.

Almost two years ago my younger sister, Tui, noticed she was choking frequently, for no apparent reason, and then her speech became slurred. A full neurological assessment resulted in a diagnosis of bulbar motor neurone disease which was rapidly progressive. Tui died earlier this year age 67 years. It was suggested, because of our family history, that she have a genetic test and when the result showed a mutant gene, C9orf72 caused her illness, my elder sister, Wilma, and I decided to also have this test.



Gaynor's family story continued

After several months of anxious waiting our results came back from USA – mine negative, but sadly my Wilma's test showed that she also carried this same mutant gene. These genetic changes are on chromosome 9 and, instead of multiplying about 30 times, the mistake in the gene repeats hundreds of times. This genetic flaw can cause three illnesses: fronto temporal dementia, motor neurone disease, and some psychiatric illnesses, all three of which have affected so many relatives in Dad's family. It might also explain my brother's psychosis, although he is not having the genetic test as he has no children and therefore will not be passing on the mutant gene. Where a parent tests positive any of their children has a 50% chance of also carrying the mutant gene too.

Since receiving her test results my elder sister, age 73, has been assessed by the psychogeriatric service and a diagnosis of behavioural variant fronto-temporal dementia confirmed. Rather like Dad, the symptoms of this illness are seen at first in behavioural changes before any memory loss develops. These symptoms include such things as loss of empathy, disinhibition, loss of social manners, fixed ideas and routines, and eating or drinking too much, to name a few.

As with all forms of dementia there is a great deal of grief associated with the loss of the person as they used to be and an inability to relate to the person as one used to. It makes little difference to this awful sense of loss I experience with my siblings' illnesses that I have been involved with the Alzheimers Society since its inception and that my work for more than 25 years was with people affected by dementia. What does make a difference is that I have a good understanding of dementia and know its progression and what to expect and can support other family members as they come to terms with the inevitable changes. It also means that I recognise the importance of seeking professional support and services for the person with dementia, their family and carers.

Services offered by Alzheimers Canterbury, such as the education course and support groups for carers, the café, and social work support plus many other supports, will be increasingly necessary as time goes by.

I know that Alzheimers Canterbury will continue to play an important part in my life in the years ahead!

Gaynor Reid

Next Chapters Book Group

This Group is a collaboration between Alzheimer's Canterbury and Christchurch City Libraries. The focus is on gathering together people at a similar stage of Alzheimer's or dementia, presenting them with library and digital resources, and involving them in a stress-free learning environment that promotes discussion, memories and humour.

The theme for our last meeting was 'At home during the War' – rather than focus on the soldiers fighting in the World Wars, we talked about the women and children at home, food rationing, the home guard etc. Video clips from Youtube were used to promote conversation, photographs were handed around. This prompted a lot of animated conversation – one participant was born on Guernsey Island, on the day WWII broke out.

To get into the spirit of the discussion, Catherine (a librarian) wore a genuine vintage 1940's dress – this was very popular, with the group also wanting to know what sort of car she drives (a white 1957 Morris Minor called Audrey) and the conversation segued into Morris Minors

that most of the group had owned or learned to drive in at some stage ("I had a green Morris Minor called Priscilla" declared Pat – who also told us that she was born in 1937, in the bush, in Tuatapere) ...

The Next Chapters group meet monthly at South and Fendalton Libraries.

Kim Slack

Christchurch City Libraries



Launch of Respite/Activity 2 year Pilot Program

We have been working behind the scenes for some time to secure funding to pilot the above. Our proposal concentrates on providing meaningful community based activities for people living with dementia in normal social settings. Research increasingly endorses the benefits of maintaining and enriching social and physical environments and opportunities for people living with dementia. The program also provides another respite option for carers whilst encouraging social involvement and connections. It increases opportunities to challenge stigma and raise awareness in our community about living with dementia.

Thanks to the wonderful support of Canterbury Trust we have the first year's funding for this 2 year pilot program. Alongside the groups themselves (all of which will be based in existing community environments and delivered in partnership with other community providers), we will be researching the benefits for those involved – both people with dementia and carers.

We are very pleased to have employed Maria Scott-Multani (Occupational Therapist) one day per week to

be the Project Leader of our program. Many will know Maria from her work within CDHB/SI. She developed the “Walking in Another’s Shoes” education program and continues to deliver this as well as supporting trainers throughout the South Island. Maria has a particular passion and commitment to promoting a person centered approach when caring for people living with dementia.

Working alongside Maria as Activities Co-ordinator Shelley Wright also joins our team, as an experienced Diversional Therapist and Occupational Therapy Assistant. And finally Dr Susan Gee (Lead Researcher, Psychiatry of Old Age Academic Unit, CDHB) and Masters Student Julia Bergman, will be involved in researching the outcomes of our Respite/Activity Program.

It is a great line up that has us very excited. We have many ideas in mind and plan to start with our Water Memories (aquatic activity) groups in October. Watch this space for more detail as we develop many activities in our pilot program.



Our ‘trial’ Water Memories Group for the “Good in the Hood” advertisement.

Carer's Comments

“When my father was diagnosed with Alzheimers years ago and I attended a course, over a series of weeks with a small group.

The reason for my email is during that course I met three other women who I have maintained contact with through this long hard journey.

We have all been a real support for each other and I wanted to let you know that this community support and the groups you offer – really does make a difference.

Thank you !

Volunteer Award



Congratulations to Don Giblin on receiving a Canterbury Volunteers Award. Don's volunteer work with Alzheimers Canterbury is very much appreciated. - Alzheimers Canterbury

New Staff



We welcome Julie Foster as Accounts/Administrator Co-ordinator to the staff



We welcome Maria Scott-Multani (Occupational Therapist) one day per week as the Project Leader for the Respite/Activity Pilot Programme



LIVING WELL WITH DEMENTIA

seminar 23RD SEPTEMBER 2015

To register for this seminar go to: www.livingwellwithdementia.co.nz

Living Well With Dementia Programme - 23 September 2015

8.45am to 9am	Welcome & Opening (Darral Campbell, Alzheimers Canterbury)
Theme: Setting the Scene for Living Well	
9am to 10am	Dr Matthew Croucher, Specialist Psychiatrist of Old Age Helping people to live well with dementia: medical models of care are not enough
10am to 11am	Professor John Dalrymple-Alford, University of Canterbury Lifestyle and other factors to combat dementia
11am to 11.20am	Tea break
Theme: The Inside Story	
11.20am to 12.05pm	Consumer Perspectives Different accounts: People with dementia; care partners; when personal and professional worlds collide
12.05pm to 12.45pm	Philippa Cosgrove & Letitia Meadows, Alzheimers Canterbury Sexuality, Intimacy and Dementia (Sharing insights from the 'Let's talk about sex' Conference 2015)
12.45pm to 1.30pm	Lunch
1.30pm to 2pm	TBC Challenging Stigma
Theme: Activities – Interactive Sessions	
2pm to 3.50pm	Maria-Scott-Multani, Occupational Therapist I do therefore I am: the value of activity in supporting a person-centered approach Lana Coles, Christchurch Art Gallery Artzheimers: An Art Appreciation Group Kim Slack, Christchurch City Library Next Chapter Book Group Therapy Professionals: Music for Life Music Therapy
3.50pm to 4pm	Darral Campbell, Alzheimers Canterbury Thank you and Closing Speech
4pm Finish	

Cuppa for a Cause



Sincere thanks to the many people/groups who held a Cuppa for a Cause during July and raised much needed funds for our groups. Your efforts are very much appreciated.



Alzheimers *Canterbury*

COLLECTORS NEEDED

18 & 19 September 2015



to support people affected by dementia

WILL YOU HELP?

Do good in the community by collecting for a few hours for Alzheimers Canterbury.

Have you got someone in your family affected? Or perhaps you'd like to help in memory of?

Our Annual Appeal is the most important fundraiser of the year. Call Annelies on **3792590** or email annelies@alzcanty.co.nz if you can help raise much-needed funds.

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<http://www.manchesterunity.org.nz>



<http://z.co.nz/about-z/how-we-invest-in-our-neighbourhoods/good-in-the-hood>

Donation Slip

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

As a not-for-profit agency, Alzheimers 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

PHONEEMAIL

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

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

Internet Banking Details: ASB 123240:0097861:00 Alzheimers 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 Alzheimers Canterbury in your Will.

Contact us for more information. Email annelies@alzcanty.co.nz or call 3792590.

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District Health Board

Te Poari Hauora o Waitaha

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<http://www.pubcharity.org.nz/index.php/contact>

Christchurch
City Council



<http://www.ccc.govt.nz/thecouncil/contactus.aspx>



<http://www.dia.govt.nz/lotterygrantsboard>



<http://www.dia.govt.nz/>



[http://www.dia.govt.nz/Services-Community-Funding-Community-Organisation-Grants-Scheme-\(COGS\)](http://www.dia.govt.nz/Services-Community-Funding-Community-Organisation-Grants-Scheme-(COGS))



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<http://www.advanceashburton.co.nz/>



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Four Winds
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<http://www.ashburtondc.govt.nz/>

United Way
New Zealand

<http://www.unitedway.org.nz/>



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New Zealand Permit No. 185322	
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