

theword



Aphasia New Zealand Charitable Trust
mate ngaronga reo

10
2007 - 2017
Years

giving a voice to people with aphasia

Issue 36

Spring 2017

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Thank you to **Cecilia Reid** for putting much of this edition of **theword** together.

Even though we are nearing the end of 2017, there are lots of up-and-coming activities around the country for people with and affected by aphasia.



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From the Executive Director

Thank you to everyone who joined us earlier in the year for 10th Birthday celebrations around the country. It seems such a long time ago now, as 2017 continues to fly by at a rapid pace.



Some of the birthday cake (*to the right, you can see Kate cutting it*) even made it to Gisborne, where it was enjoyed by attendees at the **Gisborne Aphasia Day**.

There's more about the **Gisborne Aphasia Day** in this newsletter. It was such a worthwhile and enjoyable event; a special thank you to those who travelled many hours from places such as Fielding, Palmerston North and Napier to be involved, and share their strategies and tips for living successfully with aphasia.

We're in the early stages of organising a 2018 aphasia awareness and education event. We are planning to hold this in **Hamilton**. Your suggestions and ideas are welcome – so if you would like to be involved, or are keen for an Aphasia Day in your city or region, let us know by emailing info@aphasia.org.nz

AphasiaNZ is using social media more and more these days; please ['Like' AphasiaNZ on Facebook](#). Remember to keep an eye out for our e-updates and emails, which will keep you up-to-date on our activities, and useful information and resources for you and your family members, friends, and colleagues.

Ngā mihi - Emma

AphasiaNZ Community Aphasia Advisors

Get in touch with us!

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All Community Aphasia Advisors (CAAs) work part time hours, and may be unable to respond to you immediately.

You can contact our office in Auckland during business hours (Monday-Friday, 9am–5pm) by emailing info@aphasia.org.nz or calling 09 923 7781, or on our free phone number 0508 APHASIA (0508 274-274).

You may need to leave a message – But we will call you back as soon as we can ☺

Introducing our Christchurch CAA

Georgia Holibar

Annette Rotherham held the Christchurch CAA role from August 2015 until mid-last month. She has recently moved to the North Island and we wish her well, and thank her for the positive impact she has had on the lives of many with and affected by aphasia in the Christchurch area.

"Kia ora! Ko Georgia Holibar tōku ingoa. I am delighted to join AphasiaNZ as the new Christchurch Community Aphasia Advisor (CAA).

I am a final year Speech and Language Pathology student who comes from a small whanau in Christchurch. My passion began at the age of eleven when my Grandfather, Basil, had a stroke which led to communication being a challenge for him. This experience has been a major contributor to what I consider important; communication, support, empathy & understanding. I hold these values close to my heart, leading me to pursue a career in Speech & Language Pathology with the aim to work within our community & further increase accessibility.



I have a little dog who I love dearly & I enjoy volunteering at The Court Theatre, where I run *Communication Friendly Performances*. To the left is a picture of myself & other students with actors from *Hudson & Halls Live!*"

The Aphasia (Otago) Rail Trail - *Easter 2017*

Life Participation Approach to Aphasia - To the Max!

Words by Annette Rotherham

"Never ever, ever give up". This is the motto of the Christchurch Aphasia Hub so I should not have been surprised when Junelle Robinson suggested to our Aphasia Group that we all do the **Otago Rail Trail** together. She had completed it post-stroke on a tandem bike and had told us all about it in one of her Gavel Club prepared speeches; we were all very inspired. I felt pretty sure we wouldn't get enough takers and that it might be a bit of a pipe dream. However, we had quite a few people raise their hands and say they were keen to give it a go.

Our initial team consisted of Jill and Mark Steele, Junelle Robinson, Jo McAlister, Muriel and Graeme Poulsen, Judy and Peter Clarke, Virginia and Maurice Gibbens from Wellington, Suzanne and Tony Summerfield, and Wayne Wickstead.



We were doing this!

Icycle electric bikes in Christchurch were really helpful at looking at ways to get people with physical disabilities onto bikes again. We were all amazed to see Jo ride a bike for the first time since her stroke, and look like a pro. She could get her balance and with a little bit of electric boost, take off with ease.

The challenge for people with a hemiparesis on a bike is that the affected side may not have sensation or awareness of where the foot is on the pedal. They are also at risk of a bit of injury from the pedal as it comes around and hits the back of their calf. The other challenge is balancing at the level of the handle bars. Initially Junelle was putting her right arm in a sling and biking one armed, but this was also risky for stopping in a hurry.

Once solutions had been found for these issues, training began. We trained on the **Little River Rail Trail** one day in January in a blustery nor'wester and we met up on a few Saturdays at Hagley Park. Aphasia-friendly gear lists, schedules, and itineraries were prepared and we planned to spread the word about aphasia in the Otago region.



Our itinerary for the **Otago Rail Trail** experience was prepared by

Shebikeshebikes starting in Clyde and finishing in Middlemarch 4 days and 152km later.

Sadly, our starting team did change pre-event. We had 2 group members pass away suddenly in the later part of 2016; Graeme and Tony. But I was so pleased and proud of Muriel and Suzanne for sticking to the plan and coming along anyway. It turned out to be a very therapeutic and happy time for them.

Team Aphasia ended up with 13 cyclists and 3 support crew which was perfect. 1 on a recumbent bike, 1 tandem, 4 electric bikes and the hard-core on mountain bikes.

The weather couldn't have been more golden. Otago was a bit colder than Christchurch over the Easter weekend, but we had very little wind, no rain and plenty of sunshine to make the journey a spectacular experience for everyone.

I'm blown away by what this group of stroke survivors and their friends and family achieved. I also had one of the best holidays with this awesome group of people. We must all remember to never set the bar too low in our rehabilitation as anything is possible!



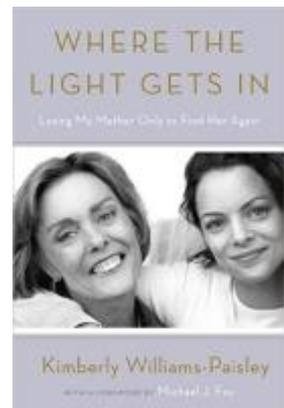
AphasiaNZ Resource Library - Book Reviews

From Kate Milford, AphasiaNZ Trustee and Tauranga CAA:

Where the Light Gets In: Losing My Mother Only to Find Her Again - by Kimberly Williams-Paisley

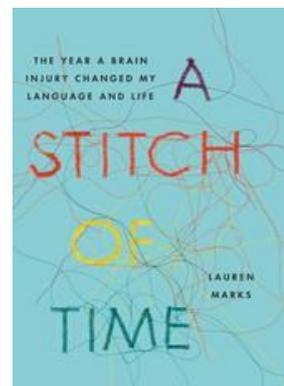
This book tells the story of one family's experience of PPA (Primary Progressive Aphasia).

I would be hesitant to recommend it for anyone dealing with a recent diagnosis of dementia, but it does cover the challenging aspects of behavioural change that can occur. The author's mother seems to have been a difficult woman in many ways throughout the author's life, and this book details Kim's journey to finding acceptance.



A Stitch of Time – by Lauren Marks

You can listen to a podcast of the author being interviewed at www.theillusionist.org

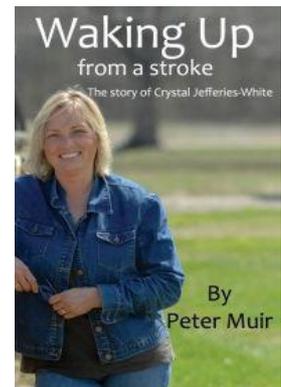


Lauren Marks suffered an aneurysm aged 27, and developed severe aphasia. This memoir focuses on the year that followed as Lauren gradually recovered much of her language.

I found this book fascinating as the author also lost her 'inner voice'

and the resulting 'quiet' in her head was something that she treasured. Lauren also lost many of her memories. She describes the disconnection between how she was feeling - peaceful, calm and happy much of the time - and how her family and friends were feeling, and how she struggled to appreciate their feelings in her altered state of being. A great read for anyone interested in aphasia!

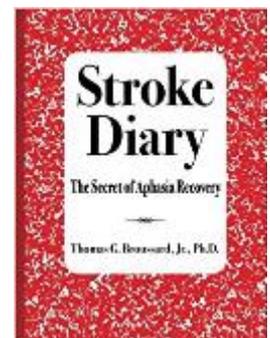
Waking up from a Stroke: The story of Crystal Jefferies-White – by Peter Muir



This is Crystal's story told through her friend Peter. It is an engaging read - and has lots of tips and advice throughout. Crystal has severe aphasia, and initially she believed that she was dying of cancer. It took many weeks before her understanding of language was recovered enough for her to understand what had happened and that she was not dying! I admired Crystal's perseverance, her good humour, and her determination to do things independently despite her very limited speech.

From Cathy Marshall, Wife of Ian who has aphasia:

Stroke Diary: The Secret of Aphasia Recovery - by Thomas G Broussard, Jr, Ph.D.



An insight into one man's recovery of his speech. It provides key messages - motivation and practice - and that Speech Language Therapy on its own is not enough. His excerpts from his diary as he

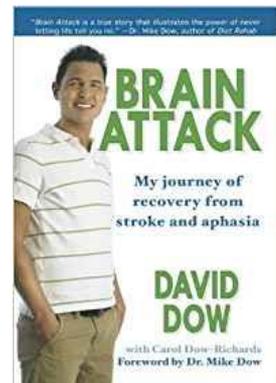
was recovering highlight how aphasia affects the written language also - good for carers to see this.

An easy read for those of us with full language, but good for aphasia people to try to read key parts.

From Judy Elliott, AphasiaNZ Trustee and Mother of a Man with aphasia:

Brain Attack – by David Dow

This book is written by stroke survivor David Dow with input from his mother, Carol Dow-Richards. The foreword is written by David's brother Dr. Mike Dow.

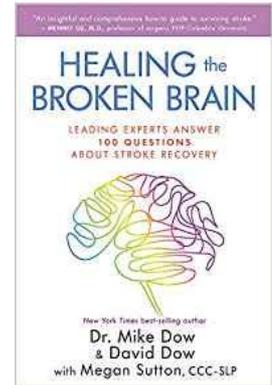


David suffered a severe stroke when he was ten years old and his life changed in so many ways. He was paralysed on the right side and was left with aphasia, unable to speak, read, or write. David shares his story in *Brain Attack*.

He is frank, open and honest about his road to recovery, but his main message in the book is that of hope. He has never given up hope that he can continue to recover and he has done just that! This story is a time-line of David's recovery and it reflects his positive approach, with family support being of the utmost importance. David's story is applicable to all stroke survivors, their families, caregivers and friends.

Healing the Broken Brain - by Dr. Mike Dow and David Dow

Healing the Broken Brain is full of information for stroke survivors, caregivers and families and is written in a straight forward, easy to understand manner. It provides information, inspiration, advice and support as you read your way through it. The book consists of the top one hundred questions that survivors and their families ask, with answers from the top medical specialists and therapists in the U.S.A. The questions start out basic but then get more specific to address different areas of recovery. There are *takeaway points* at the end of each chapter to help simplify everything. The book also includes answers to frequently asked questions you may have.



There is an excellent chapter in the book on *Recovering your Communication* which deals with aphasia and other communication issues. It discusses various types of therapy that families can do to help. There is a section on how technology can help people with aphasia.

It's important to note though that this book was written and published in The United States of America, therefore some of the information included in the book pertains to stroke survivors who live there. However you will still find *Healing the Broken Brain* full of very useful information and it can be used as a guide to provide lots of ideas for recovery.

Celebrating 10 Years of AphasiaNZ – June 2017



On Wednesday 10th June, we held a morning tea with guest speakers in **Auckland** as part of our **10th Birthday celebrations.**

Kate Milford, our Tauranga CAA (who is also a Trustee, and founder of the Aphasia Association of NZ Inc. in 2007) provided a history of AphasiaNZ since its inception, and some highlights and achievements along the way.

Dr. Clare McCann, Senior Lecturer from the University of Auckland, spoke about some of the things which help people live successfully with aphasia, and reiterated the importance of therapists and health professionals listening to people with and affected by aphasia, so that services are what people want and need.



Emma Castle,
Executive Director,
thanked some key

people who have made AphasiaNZ what it is today, in particular AphasiaNZ's Chairman Justin Strugnell-Combe, who has put in many hundreds of hours of his own time and energy over the last 10 years.

In **Wellington**, CAA Stephen Gibbs coordinated a 10th Birthday celebration at the Lighthouse Cinema in Petone, featuring the Spanish film *El olivio* (*The Olive Tree*).



The movie and delicious cake (baked by Stephen himself!) were enjoyed by all.

It's not very common for not-for-profits and charitable organisations in New Zealand, and around

the world, to celebrate success. We think however that it is important to acknowledge the hard work of many individuals who have contributed to the organisation which AphasiaNZ has transitioned into today. It's also valuable to look back and reflect on how the past has shaped AphasiaNZ, and contributed to our success.

We know that there will always be challenges – sustainable and regular funding is a thread which runs through both the past and present – but we are confident that AphasiaNZ will continue to grow and evolve into an organisation which can meet the needs of those affected by aphasia in Aotearoa.

Can you help AphasiaNZ reach a 20-year milestone? Your ideas about sustainable funding could make this happen. Get in touch with us if you can help.

Gisborne Aphasia Day: July 2017

Earlier in the year we held an event for people with and affected by aphasia, and those working with people with aphasia, in **Gisborne** at the [Emerald Hotel](#).

Over 30 people came together to hear from Melinda and Emma (AphasiaNZ), Dr. Maxine Bevin (The Stewart Centre @EIT), Caroline Callow (Gisborne Stroke Support Coordinator), and Leanne Thomas SLT.



Maxine's presentation was supported by a panel of experts – people living with aphasia who are part of the **Stewart Centre's Aphasia Project Group**.

Girlie Ngawharau from Gisborne shared her story and experience of stroke and aphasia, and was an inspiration to all of us.

Some of the feedback from the day included:

- *"Speakers were knowledgeable, relevant, brief, interesting and had*

diverse skills”

- *“Having people who have aphasia get up and speak is the best ever introduction to what aphasia is, at face value”*
- *“It’s great to hear of and speak with other organisations that support people with unique needs – thank you”*

Up until recently, AphasiaNZ ran conferences every second year, over 2 or 3 days. The last conference was held in Auckland in November 2015. We are now focusing on smaller, regional events which are more cost-effective for AphasiaNZ, and those who benefit from attending and participating – anyone with and affected by aphasia, including those working in our communities with people with aphasia.

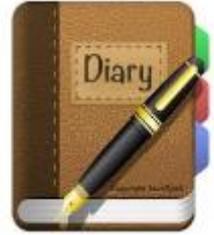
If you think an Aphasia Day is something which would benefit your area or community – [email us](#) with your suggestions.

We are working hard to offer professional development opportunities, as well as forums for people with and affected by aphasia to receive support and connect with others, around New Zealand.



*Keep your eye on your inbox and on our Facebook page for information about the planned **Hamilton Aphasia Day** in early 2018.*

Dates for your Diary – What's Coming Up?



- Auckland **PPA (Primary Progressive Aphasia) workshop** at the University of Auckland (Tamaki Campus)
 - Enhancing Communication: For those with a spouse, family member or loved one with PPA
 - No cost
 - **Wednesday October 25th** – [click here for more information](#)
 - RSVP to info@aphasia.org.nz

- Napier **Focus on Aphasia 2017** at the Stewart Centre @EIT
 - Guest speakers and personal stories
 - \$20 per person (**no charge for people with aphasia**)
 - **Friday November 3rd** – [click here for more information](#)
 - RSVP to maxinebevin@xtra.co.nz

- Auckland **Shore Talk** and **Korero Club**
 - Come along to one of our new Auckland communication groups for people with aphasia
 - **Shore Talk** is held **monthly** in Takapuna, and **Korero Club** **fortnightly** in Manurewa
 - Email Melinda at aphasianzauckland@gmail.com for more information, or [click here](#)



Six Ways to Engage your Brain

How do you engage your brain? Here are lots of suggestions!

1. **Nurture your inner artist.** To do this, you could re-connect with a musical instrument that you used to play, or learn how to play a new one. Join a choir. Learn how to paint, draw, or sculpt. Write a poem or essay, or start a journal.



2. **Take up a new hobby.** Are there activities that you always thought would be fun to learn? You could build model airplanes and learn how to fly them. Join a knitting group.

Buy a scrapbook-making kit and organise your photos. Learn how to make your own wine or beer. Join up with a friend to play board or card games that require strategic thinking or memory, such as chess, bridge, scrabble, or backgammon.

3. **Explore cultural activities.** These may be right outside your door, or half a world away. Depending on your budget and ability to travel, you may want to explore new places and expose yourself to unfamiliar languages, customs, and people. Or, you could travel closer to home and discover local tourist attractions. You could go to the theatre, symphony, ballet, or opera. You could visit a museum.

4. **Do old activities in new ways.** If you already have some favourite activities, think about how you could “shake them up” and make



them into novel, challenging activities. If you like to cook, buy a new cookbook or search the internet for new recipes. If you like to explore, look at a map and figure out alternate routes to get to familiar places, using back roads or streets you rarely use. Then walk or drive these different routes from time to time.

5. **Learn something new, just for the fun of it.** Learn how to play logic games like Sudoku. If regular Sudoku puzzles seem intimidating, start with simpler versions. Once you master the basic puzzle, move on to variations like Kakuro, Killer Sudoku, and Hypersudoku. If you are more athletically inclined, think about playing a sport that you have never played before. Or, read up on the rules of a sport that is new to you, then attend a game or match and see what you learn.
6. **Take the ultimate learning challenge.** Take advantage of formal learning or volunteer opportunities. You could sign up for a course at your local library, community centre, or college. You might learn how to speak a new language, or brush up on a language you used to know. Volunteer in a new organisation (such as AphasiaNZ), doing something you have never done before.



Source:

<https://www.psychologytoday.com/blog/living-mild-cognitive-impairment/201408/6-ways-engage-your-brain>

Can you help us? Consider a donation...

As AphasiaNZ does not receive any government or regular funding, we are only able to do what we do with your support – and the support of Trusts, gaming grants, and individual donors.

A \$25 donation will enable us to update one of our loaning iPads, and send it to a person with aphasia to borrow to trial as a communication device, or to help with therapy and recovery. ***Bronze donation.***

A \$50 donation will enable us to print a copy of the NZ Stroke and Aphasia handbook, and send it to a person affected by aphasia and their partner, family members, and friends. ***Silver donation.***

A \$100 donation will enable us purchase a therapy app for someone with aphasia to use on an iPad – enabling them to better communicate with family and friends. ***Gold donation.***

A \$200 donation will enable us to provide a years' supply of brochures, pamphlets, wallet cards and aphasia education material to your community group, medical centre, or health professional, so that more people are educated about the nature and effects of aphasia.

Platinum donation.

If you can help with a **bronze**, **silver**, **gold**, or **platinum** donation, or a donation of another amount, please get in touch. You can **donate online** by clicking the link below:

[Yes, I'd like to donate!](#)