

theword



Aphasia New Zealand Charitable Trust
mate ngaronga reo

ahve ahapisa

Issue 50

Summer 2023

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15 YEARS
OF APHASIANZ

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From the Office

This newsletter is a little later than we had planned. The last month has been a very difficult time for many. Our thoughts are with everyone whose lives have been affected by the flooding and the strong winds. Some of our services will be impacted but we will keep you as informed as possible.

Thank you for your many messages of condolence and your memories of Emma. We will treasure these and I am collating them together to give to her family so they know how much we all valued her in the world of aphasia.

With his permission, I share a few words from Stephen Gibbs:

"I loved her dry sense of humour and her compassion. She was unflappable, organised and did everything with 100% effort. And I know she was



instrumental at raising the awareness of Aphasia in Aotearoa New Zealand and our place in the Worldwide Aphasia Community.

Life is eternal, and love is immortal, and death is only a horizon; and a horizon is nothing save the limit of our sight.

I will raise a glass to Emma tonight. Bless her. She made a difference."



In other news:

Nicole, our Friends CAA, is starting a new chapter in her life with a Masters course at Canterbury University. Although we have lost her as our Rotorua CAA, we are delighted that she will continue to support new Friends with information and administer our iPad loaning scheme (among lots of other things!). Nicole has a desk alongside Eleanor, our Christchurch CAA, at the Braintree Wellness Centre in Christchurch.

There have been quite a few changes to the Community Aphasia Advisor team. We have a number of vacancies – this is frustrating for everyone affected. If you are a Speech Language Therapist looking for an opportunity to make a difference in a very enjoyable role with a great team, please get in touch!

As we are currently short-staffed, and I am going overseas in mid-March to visit my family (a long overdue trip), we may take a little longer than usual to respond to queries. Please bear with us, and if you are worried, please email again... We will always do our best to support you.

Our support options for people affected by aphasia who live in a region without a CAA position are outlined later in the newsletter (page 5).

Keep safe and be kind to yourselves and each other. Connecting with each other – with family and friends – is important in stressful times. Take time for yourself – to eat healthily, to get enough sleep. Know your limits and focus on addressing one problem at a time. Let us know if we can help...

Until next time... Kate



AphasiaNZ's Community Aphasia Advisors (CAAs)

Auckland Central and Franklin – Linda Mains-Barnett

Email: franklin@aphasia.org.nz

Auckland South – Vacant

Email: aucklandcs@aphasia.org.nz

Auckland North and West – Vacant

Email: aucklandnw@aphasia.org.nz

Auckland Hibiscus Coast – Vacant

Email: hibiscus@aphasia.org.nz

Waikato West Central – Christa Grbin

Email: waikatowc@aphasia.org.nz

Hauraki plains– Biddy Robb

Email: hauraki@aphasia.org.nz

Tauranga - Kate Milford

Email: tauranga@aphasia.org.nz

Eastern Bay of Plenty – Vacant

Email: easternbop@aphasia.org.nz

Rotorua – Vacant

Email: rotorua@aphasia.org.nz

Central North Island – Melinda Dakin

Email: centralnorth@aphasia.org.nz

Hawke's Bay – Maxine Bevin

Email: hawkesbay@aphasia.org.nz

Wellington & lower North Island – Jennifer Buckley

Email: wellington@aphasia.org.nz

Christchurch – Eleanor Maxwell

Email: christchurch@aphasia.org.nz

Central Otago– Emma Burnip

Email: otago@aphasia.org.nz

Dunedin – Meryl Jones

Email: dunedin@aphasia.org.nz

Invercargill – Vacant

Email: invercargill@aphasia.org.nz



Most CAAs work part-time hours and may not be able to respond to you immediately.

The best way to contact the office is by emailing info@aphasia.org.nz



If you can't see a CAA -

- We will send resources and information to anywhere in the country.
- We try to talk with everyone who is referred for support on the phone. If you would like to talk with us, [email us here](#) or phone us on 0508 APHASIA (0508 274 274)
- We have a number of **online support groups** which are run via Zoom. [Contact us](#) if you want to know more.
 - Online Kōrero Club meetings for people with aphasia – held every week
 - Online Progressive Aphasia Support group for people with PPA and their whanau – held every fortnight
 - Young Aphasia Group – held once a month
- We also have **online workshops** to help – for example, with supported conversation, or putting together a Life History Book
- If you join as a Friend of AphasiaNZ (individual or family joining), you can access our **iPad loaning scheme and borrow books from our resource library**. Your SLT will be able to advise if therapy support using apps on an iPad might be helpful for you.
- We might be able to connect you with someone else who has aphasia who lives in your area. Connecting with other people who know what aphasia feels like can be very helpful and a big support.
- The Stroke Foundation also runs groups which might suit your needs. Talk with your SLT or Community Stroke Advisor.
- There is lots of information on our [website](#) and on our Facebook page



Debbie's story

Hi I am Debbie one face of many with aphasia

I am no less intelligent than when this all started, my intelligence is intact, my words are trapped



Short version of my story

- I have a rare disorder
- I have had aphasia since 2020
- It is very frustrating
- I want to raise awareness of aphasia
- Life is for living – keeping positive is important
- Writing my story took me 2 months.
- I love hearing other people's stories – it helps us to connect.

oh jeeppers If you reading my story I apologize in advance if seems not making sense in parts to paragraphs, its the joys of aphasia...

I have 22 perineural cysts right through my whole spine, and I now have low pressure in the brain. In May 2020 I had my first episode Cerebral Venous Sinus Thrombosis in my brain. in May 2020 I was only a spring chicky 50 years old, to then a year later having a Recurrent Cerebral Venous Sinus Thrombosis again May 2021. Cerebral venous sinus thrombosis is in a category a rare form of stroke. This is very rare blood clots in the veins in the brain, not in the arteries.



I have been left with numerous disabilities/challenges - aphasia, right hand side weakness, hearing loss and balance problems - my second thrombosis made things a whole lot harder in symptoms. To date I still have residue clots. More surgery is on the horizon.

After my first clots I was diagnosed with aphasia, trying to express myself in speaking and writing became enormous feat, I didnt know what aphasia was till suddenly living it, I remember May 2020 at hospital speaking with consultant neurosurgeon and regristrars as I couldn't recognize/read the words on paper I thought I was going bonkers, I look at a word blankly not being able to read, literally just staring at the word for ages I was becoming very frustrated, couldn't grasp why this was happening, trapped in my own brain cells, and then trying to speak to get words out is on another level of chaos, because i also suffer from dysarthria meaning I slur my words as my muscles have been damaged also with the low pressure in the brain certainly dont help things.

How I explain aphasia I loss the ability to find my words it's like a box of scrabble without the points of a winning combination

In other words my filing cabinet in my brain fell over and now trying to place the files back in the right order that's one explanation that was explained to me by speech therapist it so resonated what exactly was happening.

with my volcubary I would use the same words all the time as this was easier for me to communicate, I didn't realize that's what I was doing but I had adapted to the situation I was in, my family and friends would still



agree to this to this day I say the same words over and over, and have now learnt to syphone what I say if I get it wrong. They are laughing with me not at me I have found my new normal how to deal with my speech thanks to this experience out in the community.

Bringing awareness to aphasia is a goal of mine if I am stuck with it so is everyone else!

One other comment thank you to aphasianz for the aphasia card this comes in handy to get me out of some sticky situations. I have always been a chatterbox, though aphasia has made this challenging, when you fatigue fast, you get brain drain

Frustrating is the word, actually this the word that ended up with my diagnosis, I couldn't find any other word to describe why I couldn't access my words from my nogging.

When you have been very sharp and very witty all your life in conversations suddenly losing the ability of making a conversation that is really so stuffed up, we use words to communicate and when you lose that ability big or small it impacts daily living, aphasia it's on another level of new chaos

But I guess in the end of the day all said and done I can still make people laugh, I haven't lost the ability altogether, let me share a snip bit how my aphasia can play its part anytime of the day



A guy asked me do I dance my response of a well known quote "I have 2 left ears" he cracked up laughing, I was confused, he proceeded to tell me its "2 left feet.... not 2 left ears" - Yip that ended up being a boo boo moment and I tend to make many of those every single day, I can be a joy to live with

So Life with disabilities/illness has its challenges I won't lie, In my circumstances i have to have a lot of time laying down due to headaches when I am upright, and to get the pressure off my lower spine as still have complications, when i am able to get I will go speeding around in the neighborhood on my disability scooter all of 6kph watch out I am speedy gonsous

How I cope with all this is keeping positive I don't let negative creep in, I have survived two major life significant events of thrombosis that now celebrate I made it, life is for living not living for the what ifs, I can't change the situation I can only live for the now, my life has changed in a different direction and that's okay

How are I progressing with my aphasia/dysarthia, I learning every day to practice my writing, my reading, my speaking, if I don't know something I get stuck on which is very regularly I go to the world of Google

Online ordering for me can have its disadvantages I have been caught out many times ordering online a incorrect item. My hubby shakes his head when things arrive but he has had a stroke as well so we are a right pair when it comes to these things.



Now for gratitude

I am grateful for my hubby, daughter, family and my friends

I am grateful to aphasianz, especially Kate and Eleanor speech therapist, nz stroke foundation especially Jane, thank you for all the support that you all give, I am grateful to my wonderful GP and urologist and all the medical teams involved in my care and most of all my neurosurgeons that have kept me safe while going through these rocky periods of life with a rare disease patient.

Disclaimer

To write my story Has taken alot, I can't write like I use to it has taken me two months to write this so if sounds like it all over the place it probably is, but I done it and hopefully it will inspire others to share their journey as we all are in different stages of our story, sometimes we hold back because the fear of been scrutinized or judged for maybe it not sounding correct but trust me I love hearing others experiences because it all helps knowing we are all connected in the aphasia way.

To family, friends, acquaintances I do make sense, just in a different way that you may not be familiar with, it's called the aphasia way

Signing off

the limited edition

Debbie Malloch



Online Groups

Online Kōrero Club

- Chat with other people with aphasia
- Support from others who understand
- Have a go at new challenges

Three groups are running each week – two on Monday and one on Friday.

Young people with aphasia group

This is an opportunity to meet with other young people and support each other, while making new friendships.

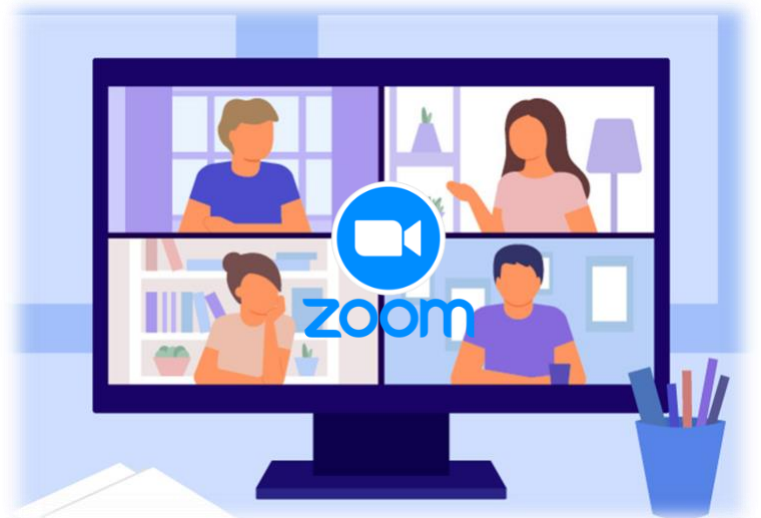
Tuesday mornings once a month

Online progressive aphasia support group

This is a group for people with PPA and their whanau. Support each other and share information.

Fortnightly on a Friday morning

Please contact Christa to register your interest.

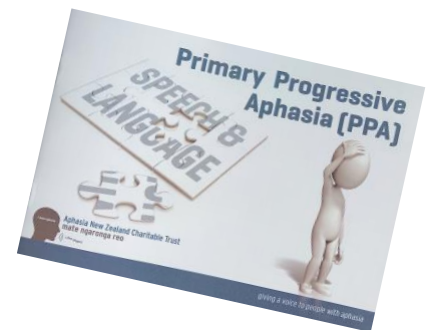


Primary Progressive Aphasia (PPA)

There have been lots of news stories about progressive aphasia recently following the announcement by Bruce Willis's family that he has been diagnosed with frontotemporal dementia. The letter that they wrote can be [read here](#).

At AphasiaNZ, we have noticed an increasing awareness of progressive aphasia across the country, and our CAAs report receiving more referrals for support. We are gradually increasing the support groups we have available for people affected by PPA – and our booklet on PPA has proved very popular.

If you would like a copy of our booklet on PPA, please contact the office.



Research opportunity

Hello. I am Annabel Grant, a researcher at Massey University.

We are asking people with early-stage dementia to take part in interviews about their friendships and their communication with friends.

I am a speech and language therapist who works to support people with dementia to live well in the community. Learning about the views of people with dementia will help us develop better supports and services in the future. Interviews can be face to face or over zoom with individuals, or jointly with a friend.

If you would like to hear more or want to take part in this research, please contact me Annabel.Grant.2@uni.massey.ac.nz , phone **09 213 6522**, or read more on [Massey's website here](#).

Technology Corner

There are lots of apps available on the app store that can be good fun and also a good way to practice finding words or improving your spelling.

Here are a few games that we have looked at:

4 Pics 1 Word



Words with Friends



Wordscapes



Word Search Pro



Wordle!



Pictoword



Do you use Facebook?

Our Facebook feed has lots of information and advice. Mel Dakin is our Social Media Lead, assisted by Nicole.

This year, we are hoping to have a regular feature called 'Ask the researcher' where we will feature an aphasia researcher. They will explain a little about their research and you can ask them questions. This is also an opportunity for you to tell them what you think is important.

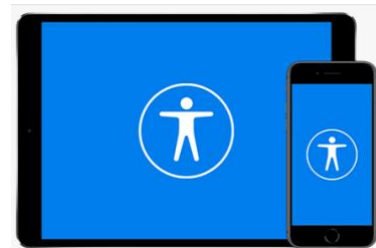
Do you use Instagram?

You can follow [AphasiaNZ @aphasia_nz](#) – let us know what you like to see!



Accessibility Features for iPad/iPhone

If you have an iPad or iPhone but find it difficult to use, here are some features that were designed to help people who have physical, visual, or hearing difficulties. These features can also be used to assist with language difficulties such as reading.



To access this feature, open the settings app and click on the 'Accessibility' button where you will find the different features available. Some of the options include:



- **VoiceOver** – can describe text or objects on the screen.
- **Spoken Content:**
 - **Speak Selection** – allows you to select text to be read aloud.
 - **Speak Screen** – can read text aloud on the screen. The speaking rate can also be adjusted.
 - **Typing Feedback** – can read and correct your typing as you go.
- **Display & Text size** – allows you to increase the font size for larger and bolder text.
- **Audio descriptions** – when available, the iPad will automatically play the audio version.
- **Subtitles & Captioning** – allows you to change the style and size of captions offered in video or other media.
- **Voice Control** – allows you to use your voice to control your iPad.

Click on the following links for more information:

- <https://www.apple.com/nz/accessibility/>
- <https://www.youtube.com/watch?v=kKyYyTv4hDQ>

Trustee Talk with Judy Elliott

I have been a Trustee of AphasiaNZ Charitable Trust for a number of years. My motivation for volunteering to become a trustee was having my son acquire severe aphasia after suffering a stroke and the many pathways his recovery took. There were appointments with neurologists, doctors, neuro-physiotherapists, occupational therapists and other rehabilitation specialists and especially, with speech language therapists. I accompanied my son to these appointments. I also did a lot of research and accessed information about aphasia and the treatment available at the time.

Along the way I became aware of AphasiaNZ and I was impressed with the support it offered to me and especially my son. Knowing AphasiaNZ did such wonderful work, I wanted to be able to give back and help in any way I could to promote the Trust and make its services easily available and accessible to people like my son and their families and caregivers.

Since becoming a trustee, I have enjoyed being part of a team which is so committed and enthusiastic about helping people affected by aphasia. As a trustee, I know I play a significant role in the governance of the trust by utilizing my life skills (I am retired, so have a few of these essential skills by now!) and the professional skills and experience I gained as an Educator and in Education management and leadership roles. I have also learned new skills which has been good for me.

I would reach out to anyone who would like to become a trustee and to share the responsibility of governing on the board of AphasiaNZ Charitable Trust, to make contact. You will find the commitment to be so rewarding and fulfilling and, sometimes, a lot of fun!



Our Contact Details



You can get in touch with us in the following ways:

By writing to us:

AphasiaNZ, PO Box 13435, Tauranga Central, Tauranga 3141

By making an appointment and visiting us:

At 36 Cameron Road, Tauranga 3110

By calling us:

In the office on (07) 220 9973, OR

On our free phone number **0508 APHASIA** (0508 274 274)

By emailing us:

info@aphasia.org.nz



Through our website:

www.aphasia.org.nz

On our Facebook page:

www.facebook.com/AphasiaNZ

We look forward to hearing from you

E tatari ana matou ki te whakarongo ki a koe



Can you Help with a Donation?



As a Charitable Trust which does not have members, we do not ask for a yearly 'membership' fee or payment.

But as you may know, we do not receive government funding - grants and donations enable us to provide all services and resources.

It is only with your help and support that we can continue to provide vital and much-used services and resources in our communities.

Can you help us by making a donation?

Your donations enable us to provide Community Aphasia Advisor (CAA) services across New Zealand.

Donations can be made online into the AphasiaNZ bank account, or by credit card via PayPal online.

As AphasiaNZ is an approved donee organisation, you can claim a 33.33% tax credit for all donations over \$5.00. [Information about tax credits from the IRD is available here.](#)

Please click here to donate online today!

And lastly.....before you go... People with aphasia!
Can you spot the spelling mistake??
Spelling mistakes in Debbie's story don't count...
[Email us](#) to tell us where it is and win a prize!

