

# theword



Aphasia New Zealand Charitable Trust  
mate ngaronga reo



Issue 55

Winter 2024

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## Emma Castle Award Winners for 2024

Stephen Gibbs being presented with his certificate by Jenny Buckley, CAA for the lower North Island.



Tony Petrasich receiving his certificate from Caroline James, Clinical Lead for Community SLT in Waitematā.

Congratulations to you both!

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PO Box 13435, Tauranga Central, Tauranga 3141

## From the Office

Thank you to everyone who helped us raise awareness in Aphasia Awareness Month (June). We were delighted with the response and we hope you enjoyed it. We will be asking for your feedback on the activities over the month. We would like to know what you liked the best. And what you felt was the most effective way to raise awareness and help people understand more about aphasia.

Congratulations to our Emma Castle Award winners this year – Stephen Gibbs and Tony Petrasich.

We had so many videos from people sharing the impact of aphasia on their lives that we were not able to feature all of these over June. Read more about this later in the newsletter.

We also have a couple of stories from people with aphasia to share with you.

And we have a prize on offer thanks to Stephen. We are going to run a competition for the most creative person with aphasia. More information about this will come next month.

There is an online workshop on making a Life History Book coming up in August. Don't forget to [register your interest](#).

Our Kōrero Clubs are getting competitive – we have been challenging each other to see who can do the best at some word-finding games. Read more later.

Until next time... Kate

## Community Aphasia Advisor News

We have said a sad farewell and thank you to Bidy Robb who has been working as our Community Aphasia Advisor in the Hauraki and Thames region.

The Trust is still looking for Speech Language Therapists to work as CAAs. There is a job advert on the NZSTA website. Please don't hesitate to [get in touch](#) if you are an SLT who is interested in supporting people affected by aphasia. It is a great role!

While we do not currently have CAAs in Auckland, we try to phone everyone referred for support in the region and we will support you to the best of our ability. We are being creative with how we can provide you with support. We will also link you in with other options where we can. Please do continue to reach out for support.

Did you know we have three online Kōrero Club meetings each week? We are now planning for a fourth Zoom Kōrero Club as our meetings are very nearly full! We also have our Young Persons online group, which also has a WhatsApp chat. And we have our Primary Progressive Aphasia support group which meets over Zoom, as well as a PPA support group for partners. [Contact us](#) if you would like to know more.



## AphasiaNZ's Community Aphasia Advisors (CAAs)

### Auckland Central and Franklin – Vacant

Email: [franklin@aphasia.org.nz](mailto:franklin@aphasia.org.nz)

### Auckland South – Vacant

Email: [aucklandcs@aphasia.org.nz](mailto:aucklandcs@aphasia.org.nz)

### Auckland North and West – Vacant

Email: [aucklandnw@aphasia.org.nz](mailto:aucklandnw@aphasia.org.nz)

### Waikato West Central – Christa Grbin

Email: [waikatowc@aphasia.org.nz](mailto:waikatowc@aphasia.org.nz)

### Hauraki plains – Vacant

Email: [hauraki@aphasia.org.nz](mailto:hauraki@aphasia.org.nz)

### Tauranga – Kate Milford

Email: [tauranga@aphasia.org.nz](mailto:tauranga@aphasia.org.nz)

### Eastern Bay of Plenty – Vacant

Email: [easternbop@aphasia.org.nz](mailto:easternbop@aphasia.org.nz)

### Rotorua – Milli Goodrich

Email: [rotorua@aphasia.org.nz](mailto:rotorua@aphasia.org.nz)

### Central North Island – Melinda Dakin

Email: [centralnorth@aphasia.org.nz](mailto:centralnorth@aphasia.org.nz)

### Hawke's Bay – Maxine Bevin

Email: [hawkesbay@aphasia.org.nz](mailto:hawkesbay@aphasia.org.nz)

### Wellington & lower North Island – Jennifer Buckley

Email: [wellington@aphasia.org.nz](mailto:wellington@aphasia.org.nz)

### Christchurch – Eleanor Maxwell

Email: [christchurch@aphasia.org.nz](mailto:christchurch@aphasia.org.nz)

### Central Otago – Alison Lunn

Email: [otago@aphasia.org.nz](mailto:otago@aphasia.org.nz)

### Dunedin – Meryl Jones

Email: [dunedin@aphasia.org.nz](mailto:dunedin@aphasia.org.nz)

### Invercargill – Megan Bell

Email: [invercargill@aphasia.org.nz](mailto:invercargill@aphasia.org.nz)

### Friends CAA – Nicole Lewis

Email: [admin@aphasia.org.nz](mailto:admin@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](mailto:info@aphasia.org.nz)



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## Aphasia Awareness - videos and stories

Thank you to the following people with aphasia who shared their stories:

- Stephen
- Debbie
- Drew
- Fiona
- Owen
- Ngaire
- Elaine
- Ron
- Heather
- Mike
- David
- Neville
- Paula
- Kevin
- Malcolm
- Jo
- Chris
- Marc
- Alana
- Bryan
- Jude
- Cathy
- Lee
- Eric
- Steve
- Hana and Peter
- Ray
- Suzie

Following our final email for June, there was an article in the Otago Daily Times. You can [find that here](#). There has also been a video about the Waikato Kōrero Club which you can [watch here](#).

Some people have also made TikTok videos. That makes me feel old as I would not know how to post a video to TikTok! But all these efforts reach people and raise awareness which is fantastic.

I hope I have not left anyone out – if I have, many apologies. We were extremely pleased that so many of you stepped up to take part. All the videos and stories (not the newspaper articles) are on our website under [Aphasia Stories](#). The videos are also on [our YouTube channel](#).





## Lee – my journey with aphasia

I had a severe stroke on the 14th of June 2021. I was 57 years old. It was early morning, 3:30 am, when the alarm went to go off to make my husband Roger's coffee. I was dizzy and unsure of what was happening. In the bathroom, my legs didn't work, and I fell. Roger thought I had hit my head and called for an ambulance. At the hospital, they knew it was a stroke I was young for a stroke. I thought I was just ill, but things quickly became overwhelming. Doctors, nurses, scans, needles, tubes, and a plane ride to Wellington and back. I was in Hastings Hospital, which was much quieter. I had a new understanding of what a stroke is, but the experience of having one was WOW overwhelming and scary.

Two days later whanau helped me to have a shower. My daughter Danielle bought me a big notebook and that was my buddy and my son Brad bought me crossword puzzles. I think this helped me with my aphasia. Into rehab where I had speech therapists and went to the gym twice daily. I loved walking around the hospital grounds and making my own coffee. I suffered from sleep deprivation, the doctor said I might sleep better once I got home.

Three weeks after my stroke, I went home, but sleeping didn't happen. I felt like I was losing my mind. I was frustrated, angry, crying, and having panic attacks. I hated everything and everyone. My family didn't understand me either. I went back to the hospital and felt like I had failed. They gave me sleeping tablets and rest, and I went to rehab again. This time, I had a big room with two beds, one for me and one for my husband.

He took sick leave from his work and stayed with me the whole time in rehab. I took all the help offered by the rehab teams, including the speech therapist, gym team, morning exercises, and coffee lady. Four months after my stroke, I felt much better. I listened to the hospital teams, and I think their patience with me was wonderful.

The second part of my journey involved getting my driver's license back and returning to my job at Hastings Countdown/Woolworths Supervising in customer service checkouts and lotto area. The speech therapist team at Hastings Hospital, helped with my money handling and numeracy skills. I continued to use the gym to improve my coordination and strength. Back home again, I kept my appointments with the rehab team. With the help of the speech therapist at the hospital, six months later I got my license back and a week later I got my job back.

Fatigue is a concern with my condition, as well as headaches and aphasia. I have had ups and downs, frustration, and stress, and I got help from the acupuncturist for headaches. The Woolworths team got counselling, all of which helps. The doctor told me that after 2 years I couldn't get any better, but I did.

Three years later, I still find myself working 30 hours a week. Hawkes Bay Kōrero with Maxine Bevin and online Zooming with Christa Grbin. I still meet with these lovely teachers. Every six months I talk with graduation nurses to learn with aphasia. I still have aphasia problems, but it's okay.

I believe I had a stroke. I felt it took my life, but now I feel I have taken my life back.

## Cathy's experience of aphasia

In early 2024, I was diagnosed with Wernicke's aphasia by a speech and language therapist, although my written and verbal speech had been negatively impacted since the middle of 2020. This 2024 diagnosis was a positive intervention in my four year health saga to have my neurological symptoms be seen as a physical, not psychological, issue.

In the middle of 2020 I had an experience in my workplace where I didn't understand what my manager was saying to me. I understood the topic. I could hear her words, but there a big hole where understanding and language was - I just couldn't respond at all. I was taken home a few hours later as I didn't feel well either. Around the same time, I noticed my speech was off. I started saying the wrong words, or making up words by joining words together. I could pick up that my speech was off. However, it took me longer to realise that my written words were also jumbled. I was typing away, in my professional capacity, sending emails and material, that I thought was just fine, until I read them at a later date, and realised that my written work had become jumbled as well. The language changes sat alongside other neurological changes, that were at the time, pretty concerning.

During 2020/21, there were times when I found it very difficult to communicate. My brain was struggling so much. It was often overloaded and unable to cope with any additional environmental stimuli: it often felt like my brain was on fire, or that I was under water. I developed a stutter. Mostly, people were very kind and patient in social situations as I bumbled away trying to communicate. There was only one incident I felt treated





unkindly, as if was a nuisance, which is pretty good odds, all things considered.

Since 2024, there have been different chapters of improvement and possible decline in my communication. I am no longer able to work due to the wider neurological changes. I manage my brain energy, and certainly my reading and writing have improved. I manage my environment. When there is less happening, I am not too tired, one to one conversations, not too many emotions, not too much background noise, my brain and, therefore, my speech is a lot better. If I have to provide complicated or emotive material in a meeting, I have to type it and read it, otherwise I wander off topic, go a bit rogue, and generally end up just talking about whatever I like, whether that is on topic or not.

The diagnosis of aphasia, and then finding the AphasiaNZ Support Group, has been a real blessing. Jenny, our local facilitator, came to my home to meet me. It was the first time I had support that didn't come with being assessed. She was so kind and supportive. With Wernicke's aphasia, one has a tendency to ramble and roam in their speech. I am aware of it, but I can't seem to stop it. Listening to others is no longer my natural strong suit. I remember apologising to Jenny in our first meeting, as I probably had done a bit of a monologue. Jenny kindly replied, "You don't have to apologise for having an illness." It might not sound like a big statement, but was big to me.

I now attend our local aphasia support group. I find it humbling, kind, humorous, heart-warming, heart-breaking all in one. People with aphasia, are like all people, we have our strengths, weakness and quirks. Equally,

people with aphasia, like all people, can be amazingly funny, strong, resilient, kind, and smart, regardless of our presentation, sometimes others might just have to work a little harder and be a little bit more patient to still see that in us; our brains, and hearts, are working hard, persevering, to try and connect with those around us.

## Focus on Primary Progressive Aphasia

For families affected by PPA there are several groups around the country and online. These groups provide support and community as well as practical advice and resources.

The online PPA support group meets fortnightly over Zoom on Friday mornings. Anyone affected by PPA can attend, including individuals with a diagnosis of PPA as well as family members or loved ones of people with PPA.

At this meeting we cover many topics including:

- Current research on PPA
- Strategies to improve communication
- Strategies to preserve language skills for longer
- The use of alternative communication and visual support
- Non-language characteristics of PPA
- Advanced care planning
- Social connection
- Many more topics



The online care-partners support group is run by care-partners for care-partners. A care-partner is usually a husband/wife/partner of the person with PPA but could be a child or other family member. Individuals with PPA do not attend these meetings. This is a safe place for loved ones to speak of their own challenges, fears, and grief. It is also a place to share helpful ideas and resources.

This group runs monthly over Zoom on the last Tuesday of the month.

Families in the Waikato meet up once every second month at the Union Church in Cambridge to share lunch, chat and connect.

Families in Auckland meet up regularly for a coffee or meal. Usually at a café or members' homes.

[Contact AphasiaNZ](#) if you would like to find out more about these meetings.

[Here is a recent article](#) focusing on PPA.

There are a number of resources around supported decision making available through the NZ Dementia Foundation. [This page](#) has a range of best practice links and is a great resource for anyone who is thinking about issues such as enduring power of attorney, and capacity to make decisions. These issues often arise for people with aphasia due to any cause, not just progressive aphasia.

## Online Workshop

# Workshop on making a Life History Book

Date: Wednesday 14<sup>th</sup> August

Time: 10.00am – 11.00am

Where: On Zoom

What we will cover:

- What is a Life History Book?
- How they can help someone with Aphasia.
- Ideas on making your own Life History Book.

**To Register:**  
contact Christa Grbin at  
[waikatowc@aphasia.org.nz](mailto:waikatowc@aphasia.org.nz)  
or on 021 086 34362





## Would you like to take part in research?

### Communicating After Stroke

#### Research study



**Kia ora.** Can **you** help us understand **what changes** should be made **in hospitals** to **improve communication** for people who have **communication difficulties after stroke**?

We are looking for **people**:

- who had **a stroke** within the last **12 months** and had **communication difficulties** after their stroke, or
- **whānau** and **family members**, or
- **healthcare professionals** working with stroke survivors.



This study is led by Clare McCann, Karen Brewer and Felicity Bright

We would like to interview you about your **experiences** of **communication** in **stroke services in hospitals**.



**To find out more** please contact us via **phone** or **email**:

Maia Watling (Ngāti Kuri, Ngāpuhi): **0272340810**

Gabby Francis: **0272214113**

**email:** [communicationaccess@auckland.ac.nz](mailto:communicationaccess@auckland.ac.nz)

**Watch videos** about the **study** via this **QR code**







## Communicating After Stroke: Experiences of People with Aphasia

### Seeking Participants

#### What is this research about?

This research project collects information on the lived experiences of people with aphasia communicating in the hospital after having a stroke. We aim to collect information about the facilitators and barriers to communicating in the hospital directly from people with aphasia.

#### Who can participate?

You are welcome to participate if you are:

- 16 years and older
- Have had a stroke in the last 6 months
- Can communicate in English

#### What do you have to do?

You will participate in one informal semi structured interview either face to face or over Zoom. This will take approximately 30 minutes to 1 hour. All the information you provide will be kept confidential.

#### A gift of appreciation:

As a thank you and a compensation of your time, you will be gifted with a \$30 countdown voucher upon completion of the interview.

### If you are interested in participating in this research project, please contact:

Sarah Waters

Student researcher

Email: [swat862@aucklanduni.ac.nz](mailto:swat862@aucklanduni.ac.nz)

Supervisor: Dr Clare McCann

*Approved by the University of Auckland Human Participants Ethics Committee for 3 years on 21/05/24. Reference Number UAHPEC27397.*



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# Technology Corner

## Talking Photo Album Apps



**Little Story Creator**



**Pictello**



**Our Story 2**



**Story Creator**

These apps use **personal photos**, **written text** and **audio recordings** to create **talking photo albums**, **task planners**, and **stories** to tell others.



All apps, except for the 'Pictello' app are free.

All apps can be downloaded from the **App Store**, and only 'Our Story 2' can be downloaded from the **Google Play Store**.

## Winter Word Game

Our Kōrero Clubs have been holding a competition to see which group can make the most words from the name of one of our locations! We started with 'Invercargill'.

The rules are:

- You can make words with any number of letters, including 1.
- You can only use each letter once.
- Words can be in English or Te Reo.
- No cheating by asking artificial intelligence!

How many words can you make?

The Tauranga group members found 84 words;

Hawkes Bay group members found 89 words;

The online group found 71 words;

The Rotorua group found an amazing 121 words!

*I have not checked all these words in the dictionary...*

We are going to have another competition soon!

## 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](mailto:info@aphasia.org.nz)

### **Through our website:**

[www.aphasia.org.nz](http://www.aphasia.org.nz)



### **On our Facebook page:**

[www.facebook.com/AphasiaNZ](http://www.facebook.com/AphasiaNZ)

**We look forward to hearing from you**

*E tatari ana matou ki te whakarongo ki a koe*

*If you have prior governance experience and an interest in serving as a Trustee for AphasiaNZ, please do get in touch with us at the office.*



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## 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 information, resources and 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. The easiest way to donate is to visit our website.

As AphasiaNZ is an approved donee organisation, you can claim a tax credit for all donations over \$5.00 if you earn income. [\*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?? [Email us](#) to tell us where it is!