

theword



Aphasia New Zealand Charitable Trust
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Issue 56

Spring 2024

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Save the date!

The next online workshop for families on Supported Conversation will be held on Friday 19th November 2024 from 5pm-7pm.

For more details and to register, see page 6.



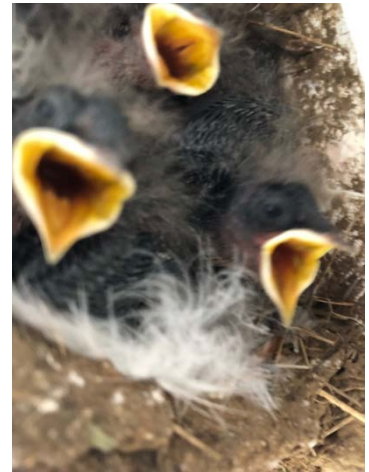
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From the Office

Spring is sprung! I have some baby swallows in a nest just by my front door... not the best place but the parents would not be put off.

This is a very quick photo of their hungry mouths...(trying not to disturb them too much!). There are four babies although this photo only shows three.



We are now planning for the Christmas and New Year period and looking towards 2025. The office will be closed from 20th December until 13th January. Any emails or phone messages will be answered when we return to work, but please do allow us some time to get back to you.

We have recently updated our Aphasia booklet in Te Reo, Chinese and Hindi – with reviewing of the translations. Thank you to Milestone Foundation for supporting us to achieve this. The NZ Stroke and Aphasia Handbook has also been revised and updated in the last couple of months. Read more about that below.

Would you be able to support our work with a testimonial? I understand that this is a difficult thing to do when you have aphasia, but if you or your family are able to give us some written feedback on our services, this is very useful information for us to use when we apply for funding. Many funders need several letters of support and testimonials in order to consider an application.

until next time... Kate



Community Aphasia Advisor News

Mikaela is our CAA for the Canterbury region while Eleanor is on parental leave. She introduces herself below. Welcome Mikaela!

We are also being joined by new team members in the new year. We have a new CAA who will be adding extra capacity in Tauranga (where the current Kōrero Club is full to the brim), and also in the Hauraki and Thames regions. Maxine is stepping down in the New Year, and we will be welcoming a new CAA in the Hawkes Bay region. They will introduce themselves to you in the Summer Newsletter.

The Trust is often looking for Speech Language Therapists to work as CAAs! 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.

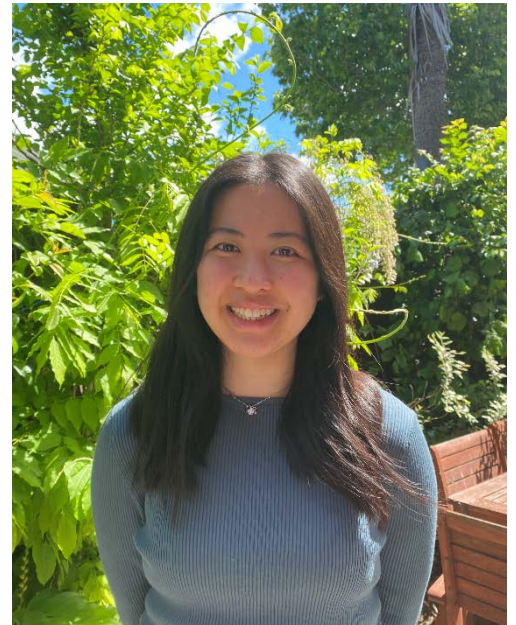
Christa has written about the advantages of contracting as a CAA in the most recent NZ Speech-Language Therapists Association magazine. We often have a chicken and egg situation with funding so if you are an SLT who doesn't have a CAA service in your region, but you are interested in the role, please reach out!

We now have four online Kōrero Club meetings each week. We also have our Young Persons online group, with a group 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.



Welcome to Mikaela

Kia ora, my name is Mikaela Yung. I have joined the team as the Community Aphasia Advisor (CAA) for Canterbury. I'm originally from Wellington and made the move down south to complete my studies at the University of Canterbury where I completed a Bachelor of Speech and Language Pathology with Honours. I enjoyed living in Christchurch so much that I decided to stay here!



I have a real desire to help people overcome communication barriers so they can gain confidence and live a fulfilling life. As a CAA, I have enjoyed running the Kōrero Clubs - witnessing the wonderful connections made and seeing how they enhance quality of life. They are a joy to be a part of.

Outside of work, I enjoy baking, sewing, going on walks/hikes, being creative through arts and crafts and spending time with family and friends. When the sun is shining, you'll always see me out and about making the most of the day!

I look forward to continuing to connect and support people with aphasia and their whānau in Canterbury. It is a privilege to work with the aphasia community.



AphasiaNZ's Community Aphasia Advisors (CAAs)

Auckland Central and Franklin – Vacant

Email: franklin@aphasia.org.nz

Auckland South – Vacant

Email: aucklandcs@aphasia.org.nz

Auckland North and West – Vacant

Email: aucklandnw@aphasia.org.nz

Waikato West Central – Christa Grbin

Email: waikatowc@aphasia.org.nz

Hauraki plains – new CAA coming soon

Email: hauraki@aphasia.org.nz

Tauranga - Kate Milford

Email: tauranga@aphasia.org.nz

Eastern Bay of Plenty – Vacant

Email: easternbop@aphasia.org.nz

Rotorua – Milli Goodrich

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 – Mikaela Yung

Email: christchurch@aphasia.org.nz

Central Otago – Alison Lunn

Email: otago@aphasia.org.nz

Dunedin – Meryl Jones

Email: dunedin@aphasia.org.nz

Invercargill – Megan Bell

Email: invercargill@aphasia.org.nz

Friends CAA – Nicole Lewis

Email: 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



Online Event for Whānau

Supported Conversation
Education Event for Whānau



Supporting somebody with aphasia brings many challenges.



If you support a partner or family member with aphasia, you may be looking for more help and information.

When: Tuesday 19th Nov
Time: 5pm - 7pm
Where: Over ZOOM

For more information or to register please contact Christa
email: waikatowc@aphasia.org.nz
phone: 021 086 34362

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[Register to attend here.](#)

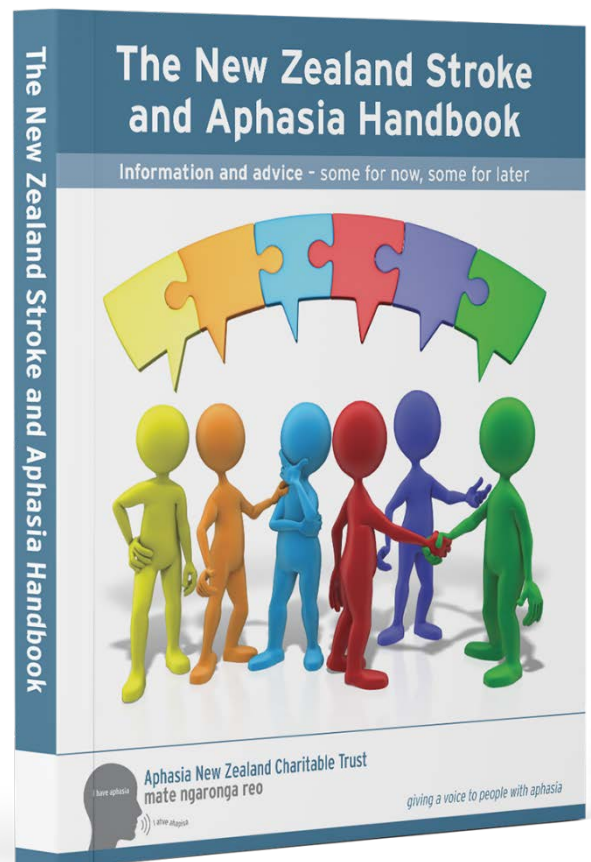
AphasiaNZ Resource Update

Version 7 of the **New Zealand Stroke and Aphasia Handbook** is being printed as we write!

It is a useful tool to support people with stroke and aphasia, which you can refer to again and again. The 2024 edition contains updated New Zealand-specific information about healthcare, support services, and more.

Order your copy by [emailing us](#). The cost of a copy of the Handbook is \$50 plus GST. Or you can [join as a Friend](#) and we will send you a copy.

You may feel that this is an expensive resource – and you would be right! But it is expensive to produce. The Handbook is designed to be easily read by someone with the use of only one hand, and easily navigated by people with aphasia. We believe that it represents excellent value.

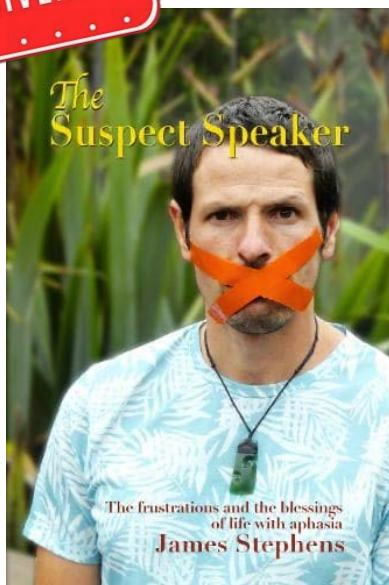


Arts Competition

James Stephens has very kindly donated a copy of each of his excellent books for a prize. This prize is for an artistic or creative endeavour by someone with aphasia.

Enter our Arts Competition by **drawing, painting, singing, writing a short story or poem, knitting, sewing, or making something out of clay, wood or metal.** Anything creative! All entries will have a chance to **win a prize – The Suspect Speaker book series by James Stephens.**

The competition will close on 20th December and the winner will be announced in early 2025.



[Email us](#) with your creation – a photo with a description. If you would like to donate your entry to help us raise funds in a raffle, we would be delighted.



Primary Progressive Aphasia: Through the Eyes of Partners

THE POWER OF PEER SUPPORT

Introduction:

Primary Progressive Aphasia (PPA) is a neurodegenerative condition that originates in the language part of the brain. PPA affects an individual's language skills. Symptoms start small, like momentarily forgetting occasional words or mispronouncing longer words. Overtime language skills worsen, making conversation more and more difficult for people with PPA. As communication always involves at least 2 people, PPA affects everyone in the family, not just the individual with the diagnosis.

Life for the partners of people with PPA changes dramatically. As well as dealing with the grief of their partners' diagnosis, they are left managing the practical side of living in a PPA household. Whilst information and resources for managing these practicalities can be helpful, emotional support is essential.

Aotearoa New Zealand is lucky to have an online support group for the partners of people with PPA. Gary Sutcliffe and Robyn Commins, both partners of people with PPA, started this monthly support group over two years ago. Gary shares with us his and his wife, Janell's, journey so far as well as why he co-facilitates this group.



Gary's Story:

My wife was diagnosed with PPA in December 2021, two years after retiring from a busy administrative role in a growing accountancy practice. Janell started working in the practice in the mid-1990's. At this time there were just 4 people working there. By the time she retired in December 2019, there were 14.

Janell had an extraordinary memory, remembering all her clients (up to 2,000) and often their partners too. I remember doing an IQ exercise several decades ago. Janell was at the higher end of the scale whereas I was barely average!

We married in 1974 and in 1976 headed off on our OE to the UK and Europe. Although we did the planning together, Janell was the primary organiser. After 18 months away we returned home to settle and have our two children. We now have five granddaughters.

It would be fair to say that Janell was the quintessential working mother who handled everything. She organised the kids, prepared virtually all the meals, did most of the housework and worked a 40-to-45-hour week. Everything inside the house was her domain; everything outside was mine (probably many men reading this can relate to that).

On retiring at the age of 69, there was no evidence as to what was to follow a few years later. In hindsight, there were some signs around mid-late 2020 that not all was well with Janell's confidence in speaking. However, over the next 12 months, her speech and language started to deteriorate, and it seemed obvious to some that something was not right. After family encouragement/insistence, we sought professional help.



Janell had a neurology assessment and was given a diagnosis of Primary Progressive Aphasia. It was recommended by a dementia specialist that we contact Aphasia NZ. We discovered the lovely Christa (a Speech Language Therapist based in the Waikato) who was running online education sessions and had just started an online support group for people with PPA. We joined the group around March/April of 2022. And, to the purpose of this paper. In late 2022, Christa spoke to Robyn, whose husband John has had PPA, and I about the prospect of having a support group for the partners of people with PPA.

My work background included peer support within the mental health sector. I understood the power of peer support and in sharing your experiences with those on a similar journey. Members of peer support groups learn from each other while receiving comfort and an understanding that they are not alone on this journey.

So, in September 2022, with support and encouragement from Christa, Robyn and I started the online support group for partners of people with PPA. From small beginnings, the partners support group now has over 20 members from across Aotearoa. Our monthly meetings regularly have between eight and twelve participants.

Here is what some people have said about the group:

- *I appreciate the group very much and I'll attend when I can. Thanks for your help and support*
- *I have made friends in this group, and it is lovely to be able to stay connected with everyone*



- *This group is really helpful in getting a realistic perspective on the journey by gathering others' experiences.*
- *I am lucky to be a confident operator, but I find day/night caring for my dear characterful husband greatly challenges my composure and patience ... my own sanity! The opportunity to share with others who are tussling with the same ordeals is surprisingly comforting. Like a warm blanket.*
- *This Group gives me a sense of camaraderie. It connects me to kindred spirits that are at different stages of the journey and, as such, helps me along the way. On a practical level, this Group is a forum for shared experiences and challenges. I learn from my colleagues' different approaches to similar challenges.*
- *I gain a lot of strength and confidence from my association with the other people in the groups who all share very similar difficulties to my own.*
- *The benefit of the Partners Group is that the focus is on the Partner. There is lots of help, although not always easily accessible, for the person with PPA, but there is not much out there for carers. Sure, you can get respite, but that's not easy. Leaving your loved one, whom you have been in a relationship with for some 40-50 years for many of us, is not easy. People will say 'you need a break' and assume that you can just leave your dear loved one with complete strangers. Even in the first instance, for a few hours a day, let alone overnight or several nights, is not easy. We often have to get desperate to take that difficult step.*



But having the Partners Group we support each other, and sometimes gain the strength to take those hard steps along the way and accept that 'your long-time mate' is no longer the person they were and that you have to move on. As others have done this before you, as evident in the group, I find it very rewarding helping others that have come after me and are now very sad, bewildered, and often struggling to accept what their life has become, in a relatively short space in time. Furthermore, what their life will be like in the future, on their own.

And from a daughter who often joins her Mum at group sessions:

- *My Mum who is supporting my Dad day to day has found the PPA partners group great. Just to know that there are others out there managing the same issues, and to get a glimpse of what might be to come is very helpful. This insight gives us time to process the possible future and to also be grateful for the present. The pooling of real information and ideas is invaluable.*

Inevitably, at some point during the PPA journey, the spouse's role changes from that of a partner to that of a carer. Nobody signs up for this change and the transition can be confusing and painful. Knowing that there is a community of people also making this painful transition can be empowering for the partners of people with PPA. Connecting with others in this community can ease some of the pain. If you would like to know more about joining the Partners of People with PPA Support Group, please contact AphasiaNZ.



Online rehabilitation and aphasia support

Aphasia resources available online are increasing rapidly. Here is a round-up of some recent developments and supports that might be of interest to both families affected by aphasia and Speech Language Therapists.

Tactus Therapy introduced a web-based treatment platform earlier this year. They have launched an Online Virtual Rehab Center where SLTs can manage their caseload, make treatment plans, set goals, deliver treatments, generate notes and assign home programmes. I have not tried this out, but SLTs can try the Virtual Rehab Center for 21 days for free. After that time, there are monthly or yearly plan payment options. Want to know more? [Here is the link](#). As an aside, I think all SLTs working with people who have aphasia should subscribe to receive the Tactus emails- they have lots of useful information.

Aphasia Recovery Connection has produced printable PDFs called Talk Tools to help people with aphasia to navigate common situations in their lives. You can [find the link here](#). The PDFs cover situations such as going to the doctor, pharmacy, post office and bank.

Don't forget that you can use www.aphasiasoftwarefinder.org to find out what apps and software might be most useful. You can also use the free [aphasia therapy online](#) website for therapy tasks.



Research round-up

A couple of articles have caught our attention recently. The first has some pilot results for a new conversation-level intervention for people with moderate to severe aphasia. [The summary is here](#). Although there were only 4 people with aphasia in this study, the results look promising.

Info for SLTS! - The intervention used a least-to-most hierarchy to maximise people with aphasia's independence in self-repair within unstructured, participant-led conversation. Generalisation occurred to tests, functional communication, spontaneous conversation and structured monologue tasks.

What might this tell us? That having conversations where people with aphasia can practice strategies and work out how to repair the conversation when it goes wrong is perhaps more useful than telling people with aphasia what they should have said, asking lots of questions or providing cues.

The second article is an open-access article from Aphasiology by Wallace et al, published in September 2024 called "*It's the car, that is the wor, that is worst.*" [The link is here](#). This article recognizes the difficulties that many people with aphasia have in returning to driving and recommends that clinicians should initiate conversations about return to driving post-stroke and prioritise support to achieve these goals. If people with aphasia are not able to return to driving, effective supports must be provided to help them navigate alternative transport options.



Technology Corner

Can ChatGPT help people with aphasia?

ChatGPT is an artificial intelligence computer program that can understand and write text like a person. It responds to questions and prompts you give it. You will need to check the information it gives you.

ChatGPT can:

- make words and sentences easier to understand
- help you find simple words
- check your writing
- help you engage in a conversation

You can ask ChatGPT to help explain things, write messages, make a story, write a birthday card, write an email, and more. Here are two examples to show how ChatGPT could help you to write a birthday card message and an email:

You ask: "birthday card friend?"

ChatGPT suggests:

"Happy Birthday, [Friend's Name]! Wishing you a wonderful day filled with joy and laughter. Hope this year brings you all the happiness you deserve. You're an amazing friend, and I'm so lucky to have you in my life. Enjoy your special day!"



You ask: "email friend catch up?"

ChatGPT suggests:

Subject: Hi [Friend's Name]! Just Checking In

Hi [Friend's Name],

I hope you're doing well! It's been a while since we last caught up, and I wanted to see how things are going with you. How have you been?

Things have been pretty good on my end. I'd love to hear what you've been up to lately—let's try to catch up soon!

Take care,

[Your Name]

If you need help with using ChatGPT, [email us](#).



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

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.



Aphasia New Zealand Charitable Trust
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giving a voice to people with aphasia

Can you Help with a Donation?

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



\$10 will cover the cost of one person attending an online Kōrero Club meeting.

\$20 will send a resource pack to a family affected by aphasia.

\$50 will print a copy of the NZ Stroke and Aphasia handbook.

\$300 will fund one Kōrero Club meeting.

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. If you are interested in [payroll giving](#), please get in touch. This is an easy way to give us a regular donation, and you receive the tax credit instantly.

[Please click here to donate online today!](#)

And lastly.....before you go... People with aphasia- can you spot our deliberate spelling mistake?? [Email us](#) to tell us where it is!

