

10 Year Review 2007-2017

giving a voice to people with aphasia



I have aphasia

Aphasia New Zealand Charitable Trust
mate ngaronga reo

))) i ahve ahapisa



10 Years of aphasia awareness and support

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a·pha·sia (ay-faze-yuh)

n. Partial or total loss of the ability to articulate ideas or comprehend spoken or written language, resulting from damage to the brain caused by injury or disease.

Cycling the Aphasia (Otago) Rail Trail (2017).
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About Us

AphasiaNZ has been helping people with aphasia and their whanau since 2007, having been formed in direct response to the expressed needs of New Zealanders living with aphasia. As of July 2012, and at the behest of our members, we completed the transition from an Incorporated Society to a Charitable Trust so as to assist all people affected by aphasia in Aotearoa New Zealand.

Aphasia affects not only the person who acquires it; the ripple effects spread to whanau, friends, and communities. The difficulties with communication that aphasia causes throw roles and relationships into disarray. The ability to work, manage finances, and access help in the community is also affected. Aphasia can affect anyone of any age, and the impact of aphasia when people are trying to support families can be devastating.

We know that at least 17,000 people are living with stroke-acquired aphasia in New Zealand right now, and that many thousands of others have aphasia acquired after a brain injury, brain tumour, or brain disease. Aphasia is more common than Parkinson's disease, Cerebral Palsy and Muscular Dystrophy and raising awareness and increasing knowledge of the nature and effects of aphasia will enable those with aphasia to reconnect and reintegrate, and live a successful life with a communication impairment.

Our mission is to empower people with aphasia to participate in their own communities.

AphasiaNZ's Wellington Conference (2013).
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What We Do

Through our support services and resources, we give a voice to people with aphasia and support partners, carers, and whanau who have a loved one with aphasia:

Community Aphasia Advisors (CAAs)

Expert field officers, who we call CAAs, facilitate local activities such as Aphasia Hubs and support groups, as well as provide support, resources and information to people with and affected by aphasia. AphasiaNZ currently has a CAA service in Auckland, Tauranga, Wellington, Christchurch and Dunedin.

Friends of AphasiaNZ

We invite individuals, families, community organisations and businesses to support us as a 'Friend of AphasiaNZ' and access loan devices and resource library items, as well as stay up-to-date with aphasia happenings around the country and overseas. All new 'Friends' receive a copy of the NZ Stroke and Aphasia handbook as part of a joining pack.

NZ Stroke and Aphasia Handbook

Designed for people whose lives are directly affected by aphasia, this useful resource is regularly reprinted and updated to contain New Zealand-specific information about living with stroke and aphasia, as well as information about how and where to access help.

Device Loaning

AphasiaNZ loans iPads and laptops to 'Friends of AphasiaNZ' for self-directed and SLT-supervised learning.

Resource Library

Our comprehensive loaning library offers 'Friends of AphasiaNZ' access to the latest and most useful books and resources about stroke, aphasia, recovery, communication and more.

Workshops and Education Events

We run 'Aphasia Days' and educational workshops for both people affected by aphasia and health professionals. As well as providing information and resources, these events serve as forums for those affected by aphasia to meet others for informal and peer support, and share strategies for living successfully with aphasia.

Aphasia Hubs, Support Groups and Field Trips

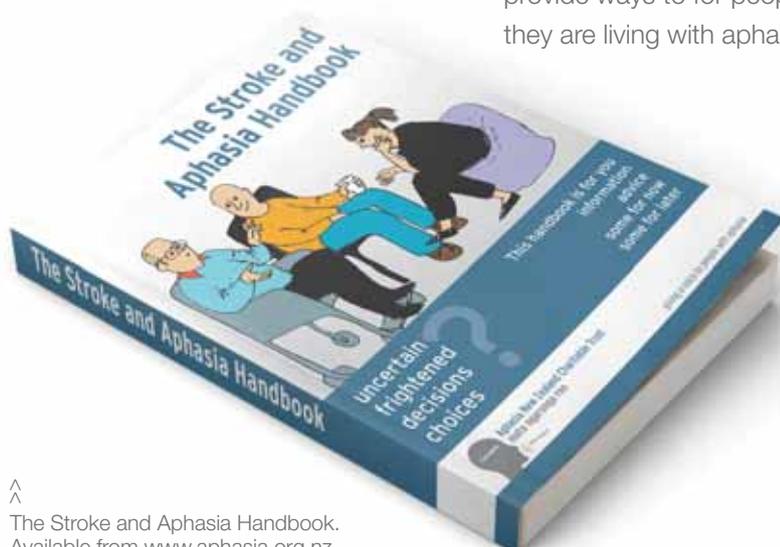
Usually facilitated by our CAAs, Hubs and support groups run throughout the country and include guest speakers, conversation groups and Gavel Clubs, aphasia-friendly field trips, and the opportunity to meet and speak to others in a friendly and relaxed environment.

Newsletters and E-Updates

Our quarterly newsletter and regular e-updates inform 'Friends of AphasiaNZ' and supporters about local, national and international aphasia activities and events, as well as provide links to resources and information for carers and those with a loved one with aphasia.

Wallet Cards and Communication Tips

Our aphasia and communication resources, free for those with aphasia, explain aphasia in an uncomplicated way, offer tips on communication for and with people with aphasia, and provide ways to for people to identify they are living with aphasia.



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The Stroke and Aphasia Handbook.
Available from www.aphasia.org.nz

From the Chairman

At such times, it is traditional to acknowledge the many people whose individual efforts have contributed to an organisation's success, and in AphasianZ's case, there are many. But I would like to concentrate here on the remarkable group efforts of those who have together taken us from very small and local beginnings to the national body, with Community Aphasia Advisors and Aphasia Hubs in almost every region of New Zealand, that we are today.

We owe a great deal of thanks to those who first came together – people with aphasia, their family members, Speech-language Therapists and others – and a decade ago constituted themselves as an Incorporated Society; their initial vision and drive are the catalyst which still fuels our work today.

The first Board of Directors, the founding committee, proved themselves to be insightful and adaptable, quickly evolving and developing the organisation to meet and overcome the challenges faced by all young charities, first re-writing and developing a Constitution exactly suited to New Zealand needs, and more recently transitioning the organisation to become a Charitable Trust.

And then there are the many people throughout New Zealand, who, first as members of the Society and latterly Friends of the Trust, have contributed time and treasure to ensure our services have developed and responded to the actual needs of people across the nation.

Not least important in the story of our successes, of course, are our funders, large, small, and individuals. They have understood and shared our aim to provide first-rate services, and have put their money where our mouth is. I think they can be greatly pleased with what their support has achieved.

And so, there are many, many people responsible for the continuing success of the Aphasia Trust (AphasianZ) of New Zealand. They know who they are and they know they have the thanks of all of us.

However, it would be invidious of me not to mention two by name; Emma Castle and Kate Milford. Emma took on the role of Executive Officer, despite having at the time arguably better and certainly more lucrative offers, having initially been Treasurer to the Society. Her enthusiasm and energy are known to all of you, but are in an incalculable way directly responsible for the expansion and success of our organisation.

Kate is now the longest-serving Director of AphasianZ, having been central to defining the initial concept; a founding signatory of and Secretary to the Society; drafter of two Constitutions and the Trust deed; planner, with Emma of all of our conferences; and a continuing Trustee of the Trust. Emma and Kate keep this Chairman in line and make the job much less difficult than it otherwise might be. Emma and Kate, you have my personal thanks and appreciation and those of all who benefit from your considerable efforts.

And so; as we reflect on our first ten years, and look forward to the next, I invite us all, howsoever we have been involved, to congratulate ourselves on having played a part in the success of the Aphasia New Zealand (AphasianZ) Charitable Trust and all who sail in her.



Justin Combe
Chairman





From the Executive Director

It is a privilege to have been involved with AphasiaNZ for over 8 years; initially in a voluntary capacity and more recently as the Executive Director. I have had the opportunity to meet many inspirational and hard-working people throughout New Zealand and across the world; those working in their communities with and for people with aphasia, as well as build relationships with professionals in both government and not-for-profit organisations.

Wearing a multitude of hats – those of a fundraiser, financial controller, educator and awareness-raiser, supervisor and event organiser – has not been without its challenges but the diversity and pace of the role has helped equip me with the skills needed to lead AphasiaNZ through periods of change and immense growth.

Funding for our activities – sourcing and securing it – remains one of AphasiaNZ's biggest and most complex challenges. While New Zealand is ranked the second most charitable country in the world, we have an increasing number of charitable organisations competing for a decreasing pool of funds.

Demonstrating the positive impact our work is having on the lives of people affected by aphasia, and the need to support AphasiaNZ ahead of other deserving groups working in our communities, remains critical to ensuring we can continue to deliver services.

I am confident in the Governing Board's ability to continue to steer AphasiaNZ in the right direction, enabling the Trust to continue to grow and evolve into an adaptable organisation which is equipped to meet the needs of anyone affected by aphasia in Aotearoa New Zealand. Let us congratulate ourselves on this 10-year milestone and all who have contributed to the organisation AphasiaNZ is today.



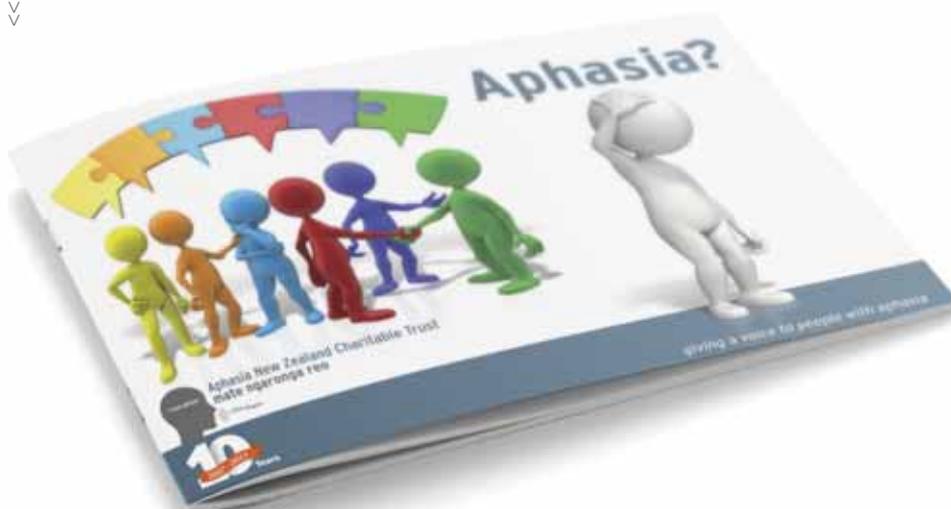
Nga mihi maioha

Emma Castle

Executive Director

AphasiaNZ informational booklet.
Available from www.aphasia.org.nz

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Financial Snapshot

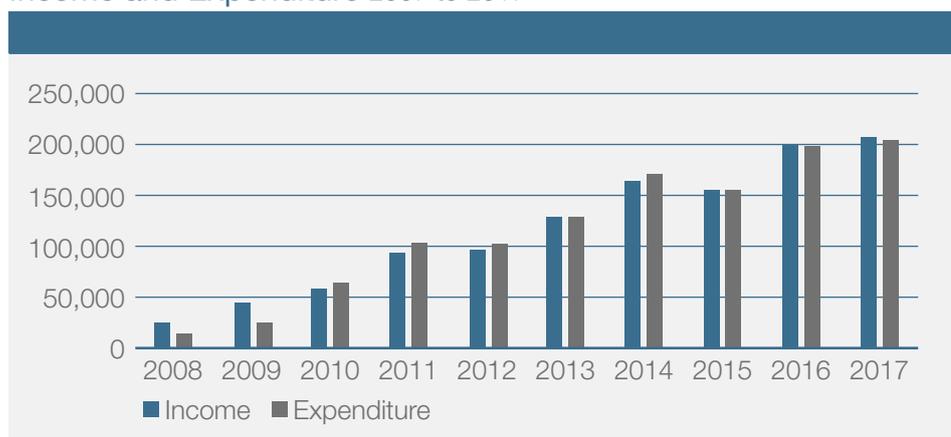
Statement of Financial Performance for the year ended 31 March

	2017	2016
Total Income	205,203	197,525
Total Expenditure	202,411	196,757
Operating Surplus	2,792	768

Statement of Financial Position as of 31 March

	2017	2016
Total assets	107,116	58,707
Total liabilities	104,304	58,687
Net assets	2,812	20

Income and Expenditure 2007 to 2017



Note: The Trust receives grants as well as income in the form of interest and donations. Income is recognised when received, although where income is related to specific activities, income is recognised as income in advance and matched to the related expense when obligations have been met. The unused portion of these specified grants is recorded in the Statement of Financial Position as a current liability.



AphasiaNZ wishes to thank our Auditor Dave Mackay, from NZ Small Audit, for completing the Trust's FY16 and FY17 financial audits in a timely and highly efficient manner.

Community Aphasia Advisors (CAAs)

The CAA service was officially rolled out in August 2015 in Christchurch, and has since expanded to many of New Zealand’s main centres. As well as being a source of information for those new to aphasia, CAAs facilitate local support and group services, educate health professionals about supportive communication strategies, and provide people with encouragement and support to reconnect with and meet others with and affected by aphasia, and reengage in activities in their local community, after acquiring aphasia.

Auckland – Melinda Dakin

Tauranga – Kate Milford

Wellington – Stephen Gibbs

Christchurch – Annette Rotherham (until September 2017) and Georgia Holibar (from October 2017)

Dunedin – Alison Zani

AphasiaNZ CAAs
(Left to right) Alison Zani, Georgia Holibar, Stephen Gibbs, Kate Milford and Melinda Dakin.



Community Aphasia Advisors in Aotearoa: A framework for a 'Virtual' Aphasia Centre

Emma Castle and Annette Rotherham of Aphasia New Zealand (AphasiaNZ) Charitable Trust

Background

Aphasia is for many a lifelong communication condition that affects over 16,000 New Zealanders. (AphasiaNZ, 2011). Social networks can be reduced (Hilari & Northcote, 2006) and third party disability has been identified for family members of those with aphasia (Grawburg, Howe, Worrall & Scarinci, 2013). Depression rates post stroke for those with

aphasia can be as high as 60% (Code & Herrmann, 2003).

Howe (2017) suggests "Lack of communicatively supportive opportunities for social participation is a critical barrier for many people with aphasia. Speech-language pathologists need to address this barrier by playing a key role in ensuring that adults with aphasia

have appropriate social participation choices in their communities. Speech-language pathologists may provide these services themselves or may draw on their unique expertise in communication and aphasia to work with people with aphasia, family, friends, other health care professionals, and disability support organizations to advocate for and/or develop opportunities".



Development of New Roles



In New Zealand, The Aphasia New Zealand (AphasiaNZ) Charitable Trust has 5 Community Aphasia Advisors (CAAs) providing supported services to people with and affected by aphasia across the whole country in approximately 1 FTE.

The roles are filled by 4 Speech-language Therapists (although SLT services are not contracted) and 1 person with aphasia.

This unique model has shown to be a sustainable and cost effective way to provide vital, long term support to families and people living with aphasia.

The role of Community Aphasia Advisors (CAAs) in New Zealand



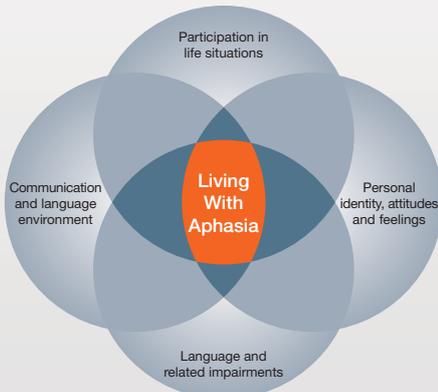
The key focus of the CAA role is around supporting all those affected by aphasia; the person post stroke or brain injury, and their family and friends. Ideally this support is offered as soon as possible post stroke or brain injury and extends to the longer term.

Understanding the important complexities of living with aphasia, and the subsequent psychosocial implications, makes this an important new role that cannot easily be fulfilled by other stroke agencies. Crucial components of the role include:

- Connecting people with others with aphasia,
- Provision of education, information and resources,
- Communication strategy training,
- Key knowledge of the stroke pathway and navigation of the health system.

Advantages of SLT Training in non-SLT Role:

- In depth understanding of psychosocial consequences of aphasia,
- Skilled in communicating effectively with PWA (users of supported conversation strategies and ability to train others in effective communication strategies),
- Skilled in facilitating groups.



The Living with Aphasia: Framework for outcome measurement or A-FROM (Kagan, 2011) is a model that incorporates the World Health Organisation's International Classification of Function (ICF). The development of a role that can meet the ongoing support and participation needs for people with aphasia and their families was the driving force in creating a "virtual" aphasia centre.

Key Aims and Activities of Aphasia Hubs



Groups (Rotherham et al, 2015)

- Reconnection
- Social network building
- Participation / LPAA
- Activities and enjoyment
- Making friends
- Building on communication skills / opportunities
- Confidence
- Mentors

Connection and Reconnection

- Acting as a bridge for communication
- Providing resources, tools and strategies to improve communication opportunities
- Ensuring people are still actively involved in discussions and decisions about their lives

Education and Information About Aphasia

- Resources – AphasiaNZ loaning library
- Workshops / conferences
- Conversation training



Regions

Auckland: Melinda Dakin (CAA)

- Aphasia Hubs
- Korero Club
- West Drop-in and Sing-along
- 1:1 support
- Early intervention
- PPA (Primary Progressive Aphasia)



Tauranga: Kate Milford (CAA)

- Gavel Club
- 1:1 support
- Community education
- Community networking



Wellington: Stephen Gibbs (CAA with aphasia)

- Support group meetings
- Communication Club
- Outings and field trips
- 1:1 support
- Community education
- SoundsWell Singers



Christchurch: Annette Rotherham (CAA)

- Gavel Club
- Aphasia Hubs
- Hospital drop in / education
- 1:1 support
- Early intervention
- Biking group



Dunedin: Alison Zani (CAA)

- Support group meetings
- 1:1 support
- Community education
- Community networking



References

- AphasiaNZ. (2011). Aphasia [Pamphlet]. Auckland, NZ: Aphasia New Zealand (AphasiaNZ) Charitable Trust.
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- Hilari, K. & Northcott, S. (2006). Social support in people with chronic aphasia. *Aphasiology*, 20(1): 17-36
- Howe, T. (2017) Found Opportunities for social participation: Facilitating inclusion of adults with aphasia. *Topics in Language Disorders*, 37(1): 38-51.
- Kagan, A. (2011) A-From in Action at the Aphasia Institute. *Seminars in Speech Language Therapy* 32(2): 216-28
- Rotherham, A., Howe, T., & Tillard, G. (2015). "We just thought that this was Christmas": perceived benefits of participating in aphasia, stroke and other groups. *Aphasiology*, 29(8): 965-982.



Aphasia New Zealand Charitable Trust
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Feedback from around Aotearoa

Until 2015, AphasiaNZ held biennial international conferences for both people with and affected by aphasia and SLTs (Speech-language Therapists) and health professionals working in acute, sub-acute and community settings with people with aphasia. Our focus has moved to delivering smaller, more frequent local events which are more financially accessible for both those affected by aphasia and the Trust.

<< Poster presented by AphasiaNZ at the 27th Annual Scientific Meeting of the Stroke Society of Australasia 2017 in Queenstown.

Over the years we have received lots of positive feedback about our events and activities:

- Speakers (at an AphasiaNZ workshop) were knowledgeable, relevant, brief, interesting and had diverse skills
- It's great to hear of and speak with other organisations that support people with unique needs – thank you
- Awesome organisation, so glad it exists! Keep up the awesome work!
- This is the first AphasiaNZ conference that I have had the opportunity to attend. I enjoyed it and learnt a lot. Thank you for organising a great conference! I look forward to the next conference. Congratulations!

- Thank you for arranging events which are important for learning, improving, and feeling successful and fulfilled
- AphasiaNZ is doing an incredible job to provide professional development opportunities for SLTs, health professionals and people with aphasia and their families
- Thanks for stimulating me to rethink my practice with clients. You've provided me with a great resource to take back to my allied health team



Our Funders

AphasiaNZ receives no government or regular funding and is only able to provide support services and resources because of financial assistance from the following organisations and Trusts:

- JM Thompson Charitable Trust
- Lottery National
- COGS (Community Organisation Grants Scheme)
- Pub Charity Ltd
- Mt. Wellington Foundation
- Milestone Foundation
- Four Winds Foundation
- Southern Victorian Charitable Trust
- TECT (Tauranga Energy Consumer Trust)
- Otago Community Trust
- Dragon Community Trust
- Blue Waters Community Trust
- Lion Foundation
- Trillian Trust
- Pelorus Trust
- Foundation North
- The Tavistock Trust for Aphasia
- BlueSky Community Trust
- Southern Trust
- Z Good in the Good: Z Glen Innes
- First Sovereign Trust
- Perpetual Guardian
- Eastern & Central Community Trust
- Mainland Foundation
- Auckland Council
- Dunedin City Council
- Christchurch City Council
- Rata Foundation
- Constellation Communities Trust
- Rehabilitation Welfare Trust
- The Sargood Bequest
- Central Lakes Trust

AphasiaNZ also wishes to thank our 'Friends' and supporters for donations which have been instrumental in enabling the delivery of support services and provision of aphasia information and resources.

Grants and donations enable us to provide activities for people with aphasia, such as field trips and outings. Some of the Wellington Aphasia Hub visited parliament for an aphasia-friendly tour (2016).

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Aphasia New Zealand (AphasiaNZ) Charitable Trust
Private Bag 92019
Victoria Street West
Auckland 1142

Phone: 09 373 7599 ext. 87781
DDI: 09 923 7781
Freephone: 0508 APHASIA (0508 274 274)
Email: info@aphasia.org.nz
Web: www.aphasia.org.nz
Facebook: www.facebook.com/AphasiaNZ

Charities Services registration CC47907

