

theword



Aphasia New Zealand Charitable Trust
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I have aphasia

Issue 17

Spring 2012

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giving a voice to people with aphasia

AphasiaNZ is on **Facebook**

Have a look at our page today...

www.facebook.com/AphasiaNZ

...for regular **updates** and **news**

If you have any interesting stories to include in the next issue, or feedback about the newsletter, please contact us!

Notice Board



For information about **Aphasia Hub / coffee mornings** in both **Christchurch** and **Auckland**, go to our website www.aphasia.org.nz and look for the **support meetings tab** (under services)

Ph: 09 373 7599 ext 87781
Toll free: 0508 APHASIA (0508 274 274)
info@aphasia.org.nz www.aphasia.org.nz

Aphasia New Zealand (AphasiaNZ) Charitable Trust
Building 731, 261 Morrin Road, St. Johns, Auckland 1072
Private Bag 92019, Victoria St West, Auckland Mail Centre 1142

From the Executive Officer

Emma Castle

So much has **happened** in the **last few months** – far too much to be able to condense it all into a **short update** for our spring newsletter!

As you may know, the **Aphasia Association Inc.** has now become the **AphasiaNZ Charitable Trust**. All Association **members** - individuals, friends, and organisations - will have **received** a **letter** from me to confirm that the Trust's **registration** with the **Charities Commission** was formally accepted in **July**. All **Society members** are now **'Friends of AphasiaNZ'** (FoANZ) and in the **coming months** I will be talking more about FoANZ and how the Trust wants to **better support all people** whose lives have been **affected by aphasia**.

I am also excited to **announce** that the **2013 AphasiaNZ conference** will be held in **Wellington** from the **13th-15th of November**, at the **CQ Conference and Function Centre**. More **information** is available on **page 14** of this newsletter. I am interested in any **ideas** that 'Friends' have for the conference to make it the **best yet** and I **invite** you all to get in touch with me with your **suggestions** for **conference workshops** and **presentations**.

Another fantastic **development** is that **Aphasia Hub / coffee morning** meetings now run **fortnightly** in **Auckland**, and **monthly** in



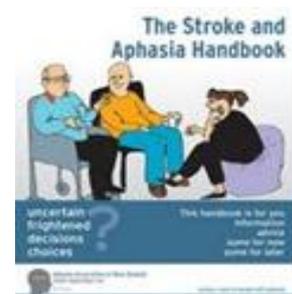
Christchurch. Meetings have a number of **purposes** but serve as a place for people with aphasia, caregivers, family and whanau, and friends to meet in a relaxed environment to **seek help, information,** and **support:** both from others who face **similar challenges** while living with the **effects** of aphasia **after stroke or head injury,** and from **professionals** who are qualified and experienced and who **work** with **people with aphasia** in New Zealand and overseas.

It is my hope that **Hub meetings** will soon be available in **other places** in New Zealand and that **everyone** with aphasia will be able to easily access **support** and **information.** If you think you can **help** this to happen, **get in touch** with me by email or phone.

In the last month I have done a lot of **updating** to our **website** www.aphasia.org.nz so if you **use the internet** please have a look at both the **public** and **aphasia friendly pages.** I welcome your **feedback** and **suggestions** to make our information more **accessible** for people with aphasia and those supporting people with aphasia.

Volunteers are still needed for a number of tasks so again; **please get in touch** if you are able to help.

Emma Castle
Executive Officer



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Aphasia events in New Zealand...

Waikato Health and Disability Expo



This year the **Waikato Health and Disability Expo** is being held on **Friday the 14th** and **Saturday the 15th of September 2012** at the **Claudlands Events Centre**. AphasiaNZ will be **sharing** a stand at the **Expo** with the **Hamilton Stroke Foundation**.

To help **raise awareness** of **aphasia**, **AphasiaNZ** will be asking people who visit our stand to **complete** a **short questionnaire** and go into the draw to win a fantastic **gift basket**. The **gift basket** will contain a copy of the **NZ Stroke and Aphasia handbook**, as well as a number of other items.

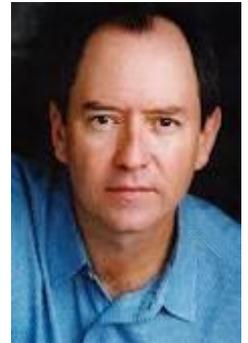
Thank you to the **Mt Wellington Foundation** who has enabled **AphasiaNZ** to get **new banners** designed and printed. We display our banners at **events** such as the **Waikato Health and Disability Expo** in order to **tell others** in a clear and simple way about **aphasia** and **inform** the general public about **AphasiaNZ**.



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'Aphasia the Movie'

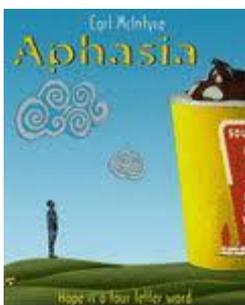
The New Zealand Speech Language Therapists' Association (NZSTA) has organised a **screening** of '**Aphasia the Movie**' at the University of Auckland Tamaki Campus on **Friday the 21st of September at 7pm.**



A seasoned **American actor** with impressive notoriety, **Carl McIntyre** was also a very successful salesman and a beloved teacher when he was felled by a **massive stroke** in **September 2005**. The stroke left him with **aphasia**.

After his stroke, Carl was given a **deadline** of **18 months for recovery**. After that, he was told, there would be **little** or **no more improvement**. Carl met this **challenge** head on and **defied the expectations** of most experts.

In **2010**, Carl starred as himself in the **celebrated short film, Aphasia**. He received rave reviews for his **powerful** and **nuanced performance** and is the driving force of the film. Although his **speech** is still **affected**, Carl is a **shining example** of perseverance, determination, and personal motivation. He shows humour, strength of heart, and an **amazing spirit** in the face of staggering obstacles and **inspires**



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audiences to do the same in their lives.

For more **information** about the **movie screening**, go to our website:

<http://www.aphasia.org.nz/news/11/85/Aphasia-the-Movie/>

'Focus on Aphasia 2012'

A '**Focus on Aphasia 2012**' day was held in Taradale, **Napier** on **Wednesday the 5th September 2012**. The day was organised by Maxine Bevin from the **Stewart Centre @EIT**, an organisation providing **brain injury rehabilitation** for people in the **Hawkes Bay**.



The day included **presentations** from **people with aphasia**, the **Stroke Foundation**, and the **District Health Board (DHB)**. Approximately **60 people** gathered at the '**Focus on Aphasia 2012**'

day to **share** their stories and **learn** from others; and to **support** and talk to each other.

The **amazing cake to the left** was made by **Maea**, a person with aphasia who was involved in surveying students



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and staff at the EIT campus to find out what they **knew** about aphasia. It was a **delicious cake** and it, along with the day, was **enjoyed** by all!

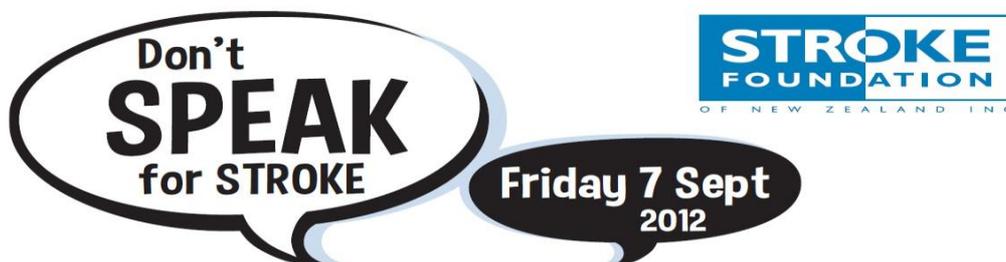
Stroke Awareness Week: 3rd-9th September 2012

Don't Speak for Stroke: Friday the 7th of September 2012

Stroke affects thousands of people in New Zealand every year, and it affects them all in **different ways**. **Stroke** is the **leading cause** of **severe adult disability**, and one of its most common after effects is **aphasia**.

To **raise awareness** and highlight the impact stroke has on people's lives **AphasiaNZ** and the **Stroke Foundation** asked people **NOT TO SPEAK** for **one hour** of their day on **Friday 7 September**.

Did you do anything for Stroke Awareness Week? Let Emma know by emailing info@aphasia.org.nz



New Zealand News

Stroke patients may soon be able to **rehabilitate themselves** from home thanks to the **invention** of a Wellington engineering student.

Victoria University Masters student Abigail Rajendran has **designed** a **stroke rehabilitation device** and has a company working to patent and sell it. Her device **straps** on to a **person's hand** to **exercise** it in an opening and closing motion, while a **connected computer game activates** and keeps **both sides** of the brain **engaged**.

Once the person **regains the strength** to do the motion themselves, they can **increase** the **resistance** from a special liquid in the device also used in Audi car suspensions.

Until now, stroke patients relied on **expensive** and **large rehabilitation equipment** available only in **hospitals**. But this new device would be something they could use **regularly at home**.

There are few, if any, **home rehabilitation instruments** available for **people recovering from strokes**. The full **article** about the home kit to help stroke patients is **available** on the www.stuff.co.nz website:

<http://www.stuff.co.nz/waikato-times/news/national-news/7458365/Home-kit-to-help-stroke-patients>

Aphasia around the World

www.strokesurvivor.com

At the age of 36, Paul Berger **suffered** a **stroke** from a ruptured brain aneurism resulting in **severe aphasia** and **paralysis** on his right side. Paul and his wife Stephanie Mensch have put together **tips** for stroke survivors and caregivers to **maximize rehabilitation and therapy**, **regain control** of their lives, and **achieve goals and dreams**.

The website has lots of **interesting information** for people with aphasia, caregivers, and family members.

Here is something from Paul and Stephanie's August newsletter:

Stephanie's Tips for Caregivers: Decision-Making

*...Making **decisions** as part of a family is always a **give-and-take proposition**. This **doesn't change** when a family member has a stroke, except when you consider the **change in roles** that often results, particularly when you have the primary bread-winner **losing** his job, **losing** his leading role in the family, and **becoming dependent** on the spouse or other family members. Suddenly, the **"power" shifts** in the relationship and someone else has **"the final word."***

*The shift seems to start with healthcare professionals who **turn** to the **caregiver** for decisions, sometimes **talking "over"** the survivor who is*

right there in the bed or chair. They **expect** the **caregiver** to take on all **responsibility** for the survivor's care, **irrespective** of their ability to do so or the **wishes** of the survivor.

With both the survivor and caregiver **in shock** from the stroke, it is easy to fall into a **pattern** where the caregiver **follows** what the healthcare professionals advise, **making decisions** without **consulting** the survivor, and often **without thinking** through the **impact** on the survivor or herself. **Imagine** if this had happened **before** the stroke when you were **deciding** what color to paint the living room, what car to buy, where to go on vacation, or what to have for dinner.

While the **stroke survivor** might **feel** resentful, angry, and demoralized by having someone else **make all the decisions** for them, I think that the **caregiver** is **equally troubled** by the **burden** of having so much **responsibility**, by the **anxiety** of having to **weigh the choices**, and by the **guilt** when the **result** is less than perfect. Also, typical of caregivers like me, I try so hard to do "**the right thing**" for the survivor, that I often **short-change my own needs**. Then I **feel resentful, unappreciated, and stressed-out**.

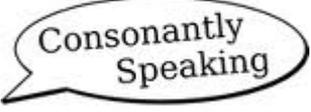
Communicating is the key to **sharing responsibility and decisions**, no matter how **difficult** it is to **communicate**. While the **survivor's needs** can be **overwhelming and all-consuming**, the caregiver should not always **give in and give up** her own needs. **Take time** to



understand each other's perspective, to **balance the decisions**, and to try for a **win-win approach**...

National Aphasia Awareness Month

June was **National Aphasia Awareness Month** in the **US**. Have a look at <http://consonantlyspeaking.com/about> specifically under the **June 2012** monthly archive. There is a page '**ABCs 4 SLPs: A is for Aphasia – Resources for Aphasia Awareness Month**' which contains lots of interesting **information** for people with aphasia, caregivers and family members, and professionals.



Consonantly Speaking

I like **Understand Aphasia's** blog and the list of **films** and **documentaries** relating to **aphasia** which **Consonantly Speaking** have compiled.

While some of the information is **US specific**, there is a lot of information that is **relevant** and **useful** for us in **New Zealand too**. If

you **don't use the internet** and would **like to know more** about the site, let Emma know.

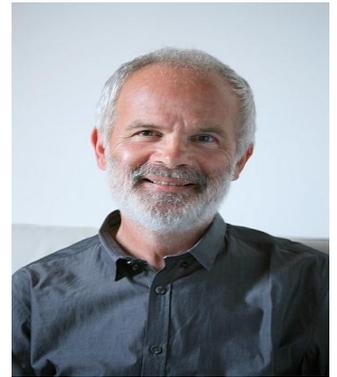


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"Life as a bilingual"

The reality of living with two (or more) languages

By François Grosjean, Ph.D.



François Grosjean, Ph.D., is Emeritus Professor of psycholinguistics, Neuchâtel University, Switzerland. His **domains of interest** are the perception, comprehension, and production of language, be it speech or sign language, in monolinguals and bilinguals. He also has interests in biculturalism, applied linguistics, **aphasia**, sign language, and natural language processing.

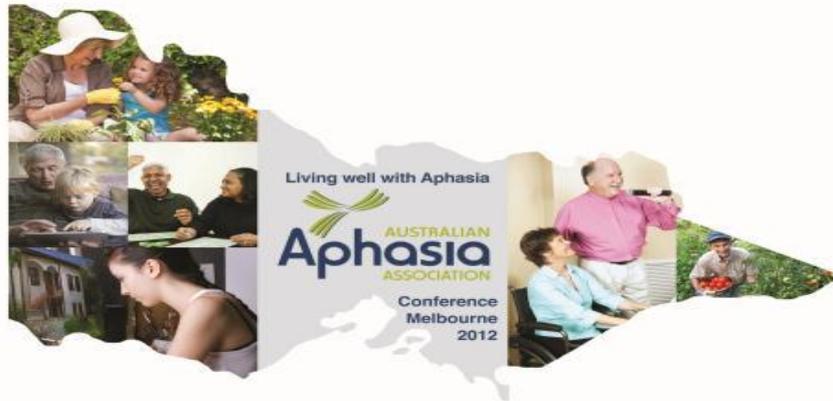
He has a **Psychology Today blog** entitled "**Life as a bilingual**" and has recently posted on **multilingual aphasics**. Have a look at the blog here:

<http://www.psychologytoday.com/blog/life-bilingual/201209/the-man-who-could-no-longer-speak-his-wife-part-ii>



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Dates to Remember



The Australian Aphasia Association's **Conference 'Living Well with Aphasia'** is being held in **Melbourne next month!**

Dates: Friday 12th & Saturday 13th October 2012

Location: Darebin Arts and Entertainment Centre
387 Bell Street, Preston 3072, Victoria

Details on: www.aphasia.org.au

Enquiries: aaaconference@aphasia.org.au



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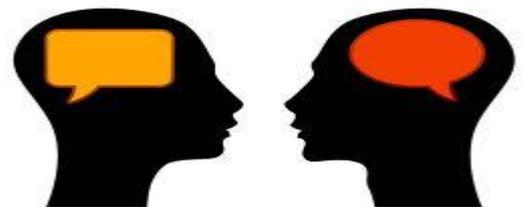
2013 AphasiaNZ Conference

Update! Add to your diary or schedule now!

AphasiaNZ is pleased to announce the following:

- Venue:** CQ Conference and Function Centre
Cuba Street, Wellington
<http://www.hotelwellington.co.nz/cqfunctions.html>
- Dates:** 13th – 15th November 2013
- Conference Title:** **'Aphasia: Putting the Puzzle Together'**
- Theme:** How the lives of people with aphasia are interconnected to and affected by families, friends, health professionals, and the wider community.

More information will be available on our website soon, and in our November update to AphasiaNZ 'Friends'



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Aphasia United



Aphasia United

Aphasia United is a newly formed **umbrella organisation** for the **global aphasia community**.

The idea for *Aphasia United* grew from the realisation that there was a need for an **integrated international strategy** for the advancement of **aphasia science and services**. *Aphasia United* seeks to **foster collaboration** between consumer, professional and research organisations throughout the world through a **strategic plan** and **shared vision**.

'*Creating a united voice for aphasia*' - a publication about the globalization of health care and the development of *Aphasia United* - is now available on *Aphasia United's website* at www.aphasiaunited.org

Aphasia consumer, professional, and research organisations can register as **members** of *Aphasia United* by emailing contact@aphasiaunited.org



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t4c Therapy 4 Children and Adults



t4c is a private practice based in **Buckland's Beach** that has been seeing children for over 15 years. They have recently **expanded** their services by bringing on an American speech-language therapist who specialises in **adult rehabilitation**.

Tally Smith, M.A., CCC-SLP, MNZSTA, has practiced at Mayo Clinic as a clinical fellow and at Sister Kenny Rehabilitation Institute as full time staff. t4c now offers **adult services** to meet any rehabilitation need. They can tailor a programme to your **specific goals** whether to **increase** your **complex language skills** to get back to professional work, or work on **functional goals** such as ordering your own meal at a restaurant.

Please contact Tally if you are **interested** in an assessment or to get more information about **services offered**. Book **before October 1st** to receive a discounted rate.

Email: Tally@t4c.co.nz **Website:** www.t4c.co.nz **Phone:** 09 535 1690

Facebook: <http://www.facebook.com/pages/T4C-Therapy-4-Children-and-Adults/408556715847841>



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