

# The Aphasia United Conference Warwick UK 5-6 March 2017

## What is Aphasia United?

Aphasia United started 2011 for

- an integrated international strategy uniting the global aphasia community
- the advancement of aphasia science and services.

## The Conference

### Organisation

North and South steering groups made up from 2 aphasia support services  
Gill Pearl Speakeasy in Bury, Manchester  
Gill Jackson Dyscover Surrey  
Sponsored by Tavistock Trust for Aphasia

### Content

Watch a video of conference memories from Dyscover - <https://youtu.be/DHj6pkoHe-o>

#### 1. Aphasia round the world

**Spain** - Seville house Spain - role play in real life situations

**Japan** - Aphasia Fellowship - PWA international travel to meet aphasia “circles” around the world

**Canada** - Sea to Sky Aphasia Camp Aphasia Summer Camp with students..

**Florida** - Intensive therapy 5 hours a day for 6 weeks using crowd funding £20,000. We already have similar in the Tavistock Aphasia Clinic.

**New Zealand** Reported study of friends and aphasia.

Many people had to make new friends

Importance of friends rather than own family

- treating you as an equal

- encouraging you to take more risks - have a go
- finding new ways of spending time together if talking difficult.

### “friends make me feel myself”

Maori concept of extended family. Think of having Personal Assistants within family circle rather than “carers”

## 2. Living with aphasia

### i) Travel

Airports, stations -useful to have **visible indication disability** - stick/ wheelchair (or aphasia card)

**Aphasia Recovery Connection** <http://www.aphasiarc.org/> **Cruises for PWA**

**Revitalise Holidays** [www.revitalise.org.uk](http://www.revitalise.org.uk) - respite holidays for disabled people and carers. They put on **Aphasia Weeks**

### ii) Communication Access

Working towards **universal symbol for communication impairments** like the deaf and wheelchair symbols



Training local businesses=> need for Specsavers for example

possible choice for all Communication disability



double appointments in

### iii) Telling my story

People with aphasia talking about how aphasia changed their lives and how they have continued recovering and regaining independence and contentment

**“You be in charge of your life with aphasia; don’t let it be in charge of you”**

Use of **Social media and aphasia** - regular YouTubes; linking with others across the world; raising awareness; connecting groups together sharing ideas etc

### iv) Sports

<http://www.sportability.org.uk/>

provide **sport and challenging pursuits** for people with paralysis - typically people who have had a spinal cord injury, **stroke** or have M.S. It is about **putting the buzz** back into a life.

<http://disabledgolf.org.uk/>

### 3. Technology Jane Marshall

GeST tool to train use gesture - very early development stage. Not reliable yet

Communicate - **assorted technologies** used with 90 PWA including **Dragon text to speech** and vice versa; **Kindle** for reading group

EVA Park **virtual reality** conversation practice in **different scenarios** (make a GP appointment; give a talk; go to the hairdresser; order a drink), fun to use. Needs 2 set-ups in different locations. Aim **free software available once ready**.

### 4. Connecting groups together

Discussed setting up **closed Facebook groups** to share ideas; **twinning** with other groups; multiple **Skyping**

### 5. Raising awareness Linda Worrall

**Awareness of the word aphasia:**

UK phone survey 90% never heard of aphasia

World wide 40% knew word, only 9% knew meaning

Push stroke organisations to use term **Aphasia**

**How common** is aphasia?

Not certain due to **differences in counting** e.g. stroke only or head injury and cancer as well? Is this **new aphasia** at admission to hospital or **pre-existing**?

In Australia approx. 80,000 PWA. In UK 300,000+

Resources for **aphasia awareness raising** from designing a talk to use of video

<http://www.aphasiapathway.com.au/?name=community-awareness>

Importance of **making videos and uploading** to YouTube reaching millions, plus positive **feedback at a global level** e.g. Sarah Scott tracking her progress via regular videos. **Reaches 1.5 million people**.

Use **Facebook and Twitter** to tell about Aphasia

#### 4. Carers Joanie Scott

Joanie Scott mother of Sarah awarded **Tavistock Trust for Aphasia prize**

Mentioned **blogs from carers** promoted by Katarina Hilari

Also reported from **acute period**: not told anything; told aphasia but not what it is; told would never speak again.

**Speech and Language therapy very variable between areas and between therapists. Reasons for having/not having further therapy not always made clear**

**National stroke strategy ends soon (10 years).**

**The Stroke Association campaigning to get it replaced with focus on longer term needs**

**Carer assessment. Use direct payment to recruit personal assistant. Leonard Cheshire help with managing employment personal assistant such as tax and insurance payments (age limit ?)**