



SayAphasia
Easy For You To Say

ISSUE NO 4
JUNE 2018



SayAphasia Chichester



SayAphasia Crawley

**We have two
NEW drop-in
groups!**

- 20 people in Say**Aphasia** Chichester
- 10 people in Say**Aphasia** Crawley.

Plus we now have **40 people** joining us in Brighton and the Sheffield Aphasia Group's drop-in is thriving.

Thankfully, people are **truly appreciating** everything that we are doing at Say**Aphasia**.

The people who go there **enjoy** having a drop-in group to go to and to **meet like-minded people**.

This is wonderful and more progress is being made ... more groups to come!



***Don't forget - June is
National Aphasia Awareness Month.
Make it count!***

SayAphasia newsletter's Co-editor



Alan

About a year and a half ago I met Colin Lyall, over tea in a South Downs café, and we ‘hatched’ a plan to have a SayAphasia newsletter which would go to all the aphasia self-help groups we knew of, and to those who knew of them.

Now the fourth issue of SayAphasia newsletter is in your hands, and the group which I’m a peer-leader of, Sheffield Aphasia Group, is one of the SayAphasia groups (along with Chichester and Crawley).

It’s been 26 years since I had a brain haemorrhage and aphasia... a lot to look back on. I worked my way up, starting with the first **Gateshead Speakability Group**. Then I went to **Aphasia Nottingham** for six years. Then in 2000, **Connect the communication disability charity, London**, (a great, in the first instance, organisation) appointed me as a trustee. Then for 13 years, I was a **Project Leader** - ending up as **Senior Team Management member** and **London Groups Co-ordinator** – conversation, art galleries, music, women’s’ group etc. I was secretary to the **Central London aphasia group**. I, among other things, started and co-ordinated, with the help of people with aphasia and communication supporters -

- the **first Connect Drop-in group**. I designed it so it could be taken (in a box) to any of the **aphasia self-help groups**. Some of you may know it!
- the **first Connect newsletter for people with aphasia, Aphasia News**.

It was at **Connect** that I first met **Colin**. In 2015 I retired from **Connect** and moved to Sheffield. I was “drafted in” to the **Sheffield Connect Outreach** group. **Connect** went bust. Then the group went from the Outreach Group to the **Sheffield Aphasia Group**. Which is where I am now.

*I know how hard it is to keep an aphasia self-help group going – I’ve been secretary and peer-leader to **four** of them. With Colin’s **expertise and hard work** he has set up a charity which has at the heart of it **real people with aphasia**. Long may it thrive!*

Andy's walking – in the Canaries ...



Andy Ibbott is taking part in the Half Marathon Des Sable in September... in the Canaries!

He is doing this for the SayAphasia charity - Andy had a stroke and aphasia in Northampton.

He now walks with support of a walking stick.

Even with the paralysis in his **right side** of his body does not stop him! He's on Facebook.

Let's wish him luck while he ventures unassisted in the Canary Islands!

So please keep an eye out for the update on his progress in the next SayAphasia newsletter.



Colin's "Adventures" ...



I visited a lovely sailing group in Shoreham called Sailability, which is for anyone with disabilities.

A couple of Say **Aphasia** members are regulars and **spoke very highly** of this club, so I thought I had better check it out! **It was a great day** and I will definitely be doing it again!



They have a website - 

www.sussexsailability.org.uk

I did the **BRIGHTON MARATHON** in April... again! It took 6 hours...again! The second half was **VERY slow**. The crowd was great and there was lots of spectators! I would love to do this next year, **if my legs will let me!**

It is a very **tough challenge** as some may know, but it is all worthwhile in the end. I have been running for the charity and hope to continue doing so, **so as always please donate**, any way you can, as this is hugely appreciated!



www.justgiving.com/campaigns/charity/say-aphasia/fundraising

Speech & Language Therapist runs Aphasia Befriending Scheme



I have worked for the Sussex Community NHS Foundation Trust Community Neuro Rehabilitation Team (Brighton and Hove) since 2003, as a Speech and Language Therapist.

We are a multi-disciplinary team who provide intensive rehabilitation for adults with acquired brain injury, including stroke and aphasia.

We provide an **early supported discharge service**. This enables people to continue their rehabilitation **at home**. Everyone who has a stroke is offered a **6 month review**, so that unmet needs can be identified and can be referred back into **stroke specialist services**.

*By Kirsty
Maguire*

In 2010, I got funding to set up an **Aphasia Befriending scheme**. This is a **peer led scheme** where **people with aphasia** provide **support and friendship** to others with aphasia. I rely heavily on **volunteer support** to keep this scheme running. **I am incredibly grateful** to my loyal and dedicated **aphasia befrienders**, who make such a difference to the lives of people affected by aphasia who are **socially isolated**.

Life after stroke services are often inadequate. Aphasia is a life-long condition, and those living with it, and their families, **face many hard challenges**. We are very lucky in Brighton & Hove to have Say **Aphasia**. Along with the **Aphasia Befriending Service**, we try to provide **ongoing support** for people with aphasia. In the future, it would be wonderful to see long term support for people with aphasia **offered to everyone who would benefit from it**. I feel very strongly that it is our role as Speech and Language Therapists **to support charities** such as Say **Aphasia**.

I like to keep fit and recently took up **triathlons**. Last year I took part in the **Brighton Triathlon**, and raised money for Say **Aphasia**.



Alan

Sheffield Aphasia Group and Sheffield NHS Speech & Language Therapists



We're starting to build a 'bridge' between Sheffield Aphasia Group and the Sheffield NHS Speech & Language Therapists.

Jane Pawley and myself (both peer leaders for **Sheffield Aphasia Group - SAG**) met with **Speech & Language Therapists Dr Caroline Haw** and **Jenni Crisp**, and discussed ways **we could work together**. It was a very good meeting and **we came away with a plan...**

- We would put on a joint display for the NHS and Sheffield Aphasia Group (SAG) for Aphasia Awareness month – June. Jenni came to one of our three-times-a-year meetings at the Millhouses Park Café and we booked a table for Tuesday 19 June with the owner of the café. We'll load the table with information and balloons about the NHS and SAG ...*
- At the community SLTs meeting in September we will give a PowerPoint slideshow on Sheffield Aphasia Group and how we can help each other ...*
- Jane and myself will go the new stroke rehabilitative centre at Beech Hill to see what ways we can help, with, for example, befriending ...*
- Jenni to take forward the idea of the Conversation Partner Scheme volunteers to supporting the Sheffield Aphasia Group ...*

I realise that this is, compared to Say**Aphasia's**, and other aphasia self-help groups, "ventures", a start. But with **the commitment** of Jenni and Caroline and **the impetus** of **SAG** who knows what will come of it!



Caroline is the SLT Lead Clinician at the Beech Hill Stroke Rehabilitation Unit in Sheffield. She is employed by Sheffield Teaching Hospitals NHS Foundation Trust.



Jenni is employed as a specialist SLT by Sheffield Teaching Hospitals NHS Foundation Trust. She also runs the Sheffield Conversation Partner Scheme.



Wives, husbands and carers of people with aphasia

Not enough is said about those who care for the people with aphasia. It could do with more research, and better care.

Sheffield Aphasia Group is acutely aware of this. Not only do they have to **cope with the shock** of having their partner **not speaking** to them, or saying very little, and **coping** with their disabilities - but they have to take on the burden of carrying out the tasks they thought **they were never meant** to do.

These are the some of the people in Sheffield we want to introduce you to, who come to our group, and who play an **important part** in it ...

Ian and Traudel



"Traudel has aphasia for the past eight years. The difficulties of not being able to communicate is frustrating for her and sometimes results in tears. It is then that patience and understanding is essential from me as trying to understand her wishes can be equally frustrating."

Ian

Malcolm and Erica



"Erica had aphasia, from a stroke, in 2013. Her aphasia is very severe and she is unable to say more than a few words. In spite of intensive self-funded speech and language therapy – both person-to-person and using various computer based programs - her speech has not improved over the past years. Erica communicates by writing words/names or by drawing pictures, maps and diagrams. Undoubtedly, having been together for over 40 years our memories have much in common. This is the key to helping me understand what she is trying to communicate."

Malcolm

“Person to Person” in Sheffield

Jane Pawley is nothing if not tenacious!

Jane is the co-peer leader of the Sheffield Aphasia Group. You may have seen her in the last newsletter trying out the walking system.



She is **passionate** about getting her **right side** to perform **the best it can be**. Of course she realises it will never be the same ... **but that doesn't stop her**.

Last month she went to the **Princess Royal Spinal Injuries & Neurorehabilitation Centre at Sheffield Northern General Hospital**. She had surgery on her **right hand** to **loosen the tendons** to allow her to relax a **little bit more**. This was part of a year's **straightening** the tendons in the **foot and the hand**. She had **three surgical operations** ... two on the foot and one on the hand. She went to the unit to get stitches taken out of a **seven-inch cut below** the right hand wrist. Phew ...

She used to have **Botox** to ease the tension - but this is much better. Before the **hand and foot were “clawed” up**. In the pictures below you can see how the **hand is relaxed**, and fitted **with a new splint** ... this has to be worn at night.



“This is great. Before the hand and foot were very tight and balled-up. Now I can just about relax the tendons.”

Jane



In this issue we have put a picture like this - it means that the article has a link to other organisations. Look out for it in the future!

Meanwhile, if you want to send us articles & photographs – tell us and we'll print it.



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Colin Lyall



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Alan Hewitt

SayAphasia's aim is to help people get better. Our primary group, the **Brighton & Hove group**, and our groups **Chichester, Crawley & Sheffield Aphasia Group**, are **FRIENDLY** and **SUPPORTIVE**