

More on offer at Connect

Connect's London centre now showcases a wide range of tailor-made activities for people with aphasia.

The centre offers conversation groups, befriending, counselling, a music and photography group, volunteering and a conversation partner scheme. There is also a regular drop-in service – this is for people with aphasia who simply want to meet others over a cup of coffee.

Hope and inspiration

"Anyone with aphasia who can get to our London centre is welcome", says Sally McVicker, Director of Services. "People will have a chance to get involved, meet others and try something new. We have fully trained staff and volunteers who understand aphasia."

Showing the difference we make

We will be inviting people who make decisions about services for people with aphasia to visit the centre to see and hear for themselves what a difference Connect makes. In turn, this should help service providers to develop and deliver the best possible services. ●

How to get involved

People with aphasia can contact Connect direct or through their therapist or GP. Telephone 020 7367 0840 or email info@ukconnect.org for more details.

See our website for services in other areas. We look forward to welcoming you.



Peer-led conversation groups build confidence and reassurance. As one person with aphasia put it, "Wow, people the same as me – they know how I feel!"

Inside pages

Help us put an end to discrimination	2
Rewriting script ... cue applause	2
Addressing action on life after stroke	3
Skype – keep in touch without words	3
Back to work – why is it challenging?	4
Meet Tony who went back to work	4
Leaving a lifeline	5
Getting stronger, and thriving	6
My teenage daughter has aphasia	6
Get connected ... with Sarah	7
East meets West	8

Help us put an end to discrimination



The recent election was one of the most closely fought in decades. All political parties have worked hard to get our votes.

At Connect, we don't support any one political party – we support people with aphasia. With a new coalition government now in place, we want all politicians across the country to know exactly what aphasia is, and how it affects your lives. We want to tell them how they can help.

Tell us your stories about discrimination

Do you feel you have been discriminated against because of your aphasia? Or do you believe that you have not been supported to re-connect with

life? If so, let us know. We will make sure MPs know too.

No one can explain the impact of aphasia better than someone affected by it. So ... share your experiences – both good and bad – with us here at Connect. In turn, this will help bring to life the many problems and difficulties people with aphasia and their families face every day.

We want MPs to hear your stories. We particularly want them to know whether you have been affected by discrimination.

Contact us at Connect. See the back page for contact details. Together we can end the discrimination faced every day by people with aphasia. ●

Phyllis Campbell-McRae
Chief Executive, Connect

Rewriting script ... cue applause

How do you make theatres more inviting and accessible? Ask people with communication disability to rewrite the script!

Overture ... and loud round of applause

A group of people with stroke and aphasia met to see the play *Run for Your Wife* at Eden Court Theatre in Inverness. It was a great play, but the group noted challenges for people with aphasia.

They presented the theatre management with some solutions. These included positioning signs where wheelchair-users can see them easily and making it easy to identify theatre staff.

They also acted out scenarios on a DVD showing the kinds of challenges faced by people with aphasia when they go to the theatre. The finale? A theatre that is now in tune with the needs of people with communication disability. Cue applause. ●



People who find talking is a challenge after a stroke can enjoy taking an active role in Eden Court Theatre's new integrated performance group

Addressing action on life after stroke

Significant progress in delivering acute stroke care services is highlighted in *Progress in Improving Stroke Care*, published by the National Audit Office. However, the report argues that better support is needed for people with stroke and their carers once they leave hospital.

The report also highlighted the need for front-line staff to receive specific training to ensure they communicate and interact effectively with people with stroke and aphasia.

Access to Life is honoured

"Access to Life ... was clearly successful by hard outcomes and also by how patients and carers judged that", said Dr Damian Jenkinson, National

Clinical Lead for the Stroke improvement Programme. He was talking about Connect's work in Cornwall at the Public Accounts Hearing – where the report's findings were discussed.

Connect is working to make sure the *Access to Life* model is available across the country. We aim to reach many more people with aphasia, their carers and health professionals. ●



The consultation document used to develop the National Stroke Strategy

Skype – keep in touch without words

Sonia Timlett uses Skype to communicate with friends and family in the UK and all over the world. Sonia says, "Skype means we all communicate better. It's fantastic!"

When Sonia first had a stroke at the age of 28, she couldn't speak at all. Nine months later, she still struggles to find words, sometimes gets words mixed up, and finds using the telephone a challenge. But what makes a difference for her is communicating via Skype.

What is Skype?

Skype is special software. It's like the telephone except you can hear *and* see the person you are speaking to on your computer screen. And they can see you too. "If I don't know the word ... I use writing or a gesture", explains Sonia. "Because they see me, they can see when I am stuck ... and they slow down." ●



Sonia uses Skype to speak to her mum in Chile

Skype is completely FREE! You just need a computer, a telephone line and a webcam. To find out more, visit www.skype.com. !

Visit the Connect website to download your aphasia-friendly instructions on how to get started with Skype.

Back to work – why is it challenging?

Why do so few people return to paid employment after a stroke, when nearly 25% of them are of working age?* Connect explored the challenges in North Tyneside.

Connect was one of the partners in a North Tyneside project called CHANT (Communication Hub for Aphasia in North Tyneside). The project links the local authority, the NHS and the Stroke Association to support people with aphasia to explore and engage in a range of opportunities. As well as talking to people with aphasia, Connect talked to Jobcentre Plus staff, council officers and voluntary organisations that help people with disabilities get back to work.

Lack of confidence, difficulty with numbers, getting tired easily, problems when explaining things, all mean returning to work is difficult. People with aphasia often find they don't get time to explain their needs. In North Tyneside, the CHANT project is addressing this by offering individual and group activities to help people overcome the barriers they face when trying to return to work.

**National Stroke Strategy, 2007, page 11.*

Training in communication skills

Connect has developed a new training resource full of examples of good and bad communication. It will inform and support employers and job-finding services on how to communicate better with people with aphasia and to understand their needs. The CHANT project helped to test out the resource, and it is now being used locally. ●



Lively discussion at a Back to Work event – a joint project between Connect and CHANT

Meet Tony who went back to work



Tony D'Souza was a police officer for 31 years until he had a stroke nine years ago.

His aphasia meant he couldn't return to his work on the beat. However, he was offered a different police job – working in a stolen

property office. He preferred his outdoor job – “outside is much better” – and gestures “boring” about his new job. “Half is bad but some is quite good”, he says.

Can't beat it!

Tony can read and copy words but can't produce written words freely. After his stroke, Tony and his wife Reshma were keen for him to continue working. The police force was fair and supportive, he says. “My colleagues understand my aphasia.” They didn't just ask him to retire but came to an agreement for Tony to return to work. This keeps him busy and active. ●

Are you living and working with aphasia? Did you find going back to work a challenge? Tell us your story.



Leaving a lifeline

Connect has joined the Remember A Charity consortium. More than 140 charities are working in partnership to raise awareness about wills and legacies. The aim is to encourage people to support their charities of choice – and support causes close to their hearts.

What do you want to happen after you've died? For most of us, the answer is quite simple. We want to know that we've taken care of everything that's important to us. The first priority is looking after those closest to us.

Why should I make a will?

Making a will is the only way we can be sure that our wishes will be followed after we've died.

If we don't make a will, we will have no control over who benefits from part or all of our estate. To make matters worse, inheritance tax laws mean that if we don't prepare properly, a large part of what we leave behind may go to the state as tax.

Making sure ... making sense

Making a will makes sure ... and makes sense. It makes sure that you choose how to provide for your family. It also allows you to make a lasting impact on other things that you care about – such as leaving a gift (known as a legacy) to your preferred charities.

Why remember a charity?

Gifts left in wills are vital. Many charities would not survive without this source of income.

Luckily, 74% of the UK population support charities. When asked, 35% said they would happily leave a gift in their will once they had provided for their family and friends.

The problem is that *only 7% actually do*.

The gift that keeps on giving

Later this year, the Remember A Charity consortium will be running a campaign to help



Leaving a legacy to a charity means that everyone can leave the world a better place

more people make sure their wishes are carried out. One aim is to make legacy-giving become a normal thing for everyone, rather than just the few.

We don't have to be rich

The word "estate" can sound like someone who has a stately home and rolling fields. But the majority of gifts come from ordinary people, whose gifts make a real impact.

Many people choose to donate a small percentage of their estate (the amount that is left once they've looked after their family and friends). These donations soon mount up. Charities really depend on legacies, and it's no exaggeration to say that we simply couldn't continue all our activities without them.

We can all make a real difference to the future by thinking about our will and our legacy. ●

Find out more

Visit www.ukconnect.org to read Connect's publication *Your Guide to Making a Will*. Or telephone Rose Grissell (020 7367 0865).



Getting stronger, and thriving

Craig Grant was just 11 when his mother, Catriona, had a massive stroke. Catriona was later told she had aphasia.

I heard a loud thud upstairs. It was mum hitting the floor. We were told later she'd had a stroke. Mum all of a sudden had to be very dependent on other people ... the physical struggles were really challenging but her communication had also gone.

I'd use letter cards to communicate with her, and she'd make sounds and point. You realise there are other ways you can get your message across without talking. During her rehabilitation I felt so proud of mum and how hard she tried, every day.

Nothing is a barrier for mum! At first, of course, her confidence was badly knocked, but she has adapted to her disability, as we have. Mum's involvement with Connect has restored her sense of self-worth. There really are ways to find your life again. I've seen it first-hand. ●



Craig says, "Despite such an enormous event you realise that you can find a way of surviving and being stronger than before." Visit www.ukconnect.org to see Craig and Catriona together on the Connect DVD

Catriona Grant continues to be involved at Connect. She is a befriender, and trains service providers in communication skills.

My teenage daughter has aphasia

Teenage years bring many challenges, but no parent expects their child to have a stroke. Joanie Scott says how it was for their family.



Joanie (left) with her daughter Sarah – read more about Sarah opposite

In May 2009, our daughter Sarah was in her sixth form class, reading aloud in an English lesson. Suddenly, she found she could no longer speak and became paralysed on her right-hand side. She'd had a stroke.

It's hard to put into words how we felt as parents, seeing our daughter in hospital unable to swallow, speak or walk.

It slowly dawned on us that Sarah's speech problems would be the hardest thing to overcome. She was assessed as having severe expressive aphasia. She couldn't read, write or understand money. Sarah has regained some speech, and she is determined to communicate using whatever means she can.

We've always been very close, but the relationship we have now means that we tune into each other differently. We use gestures, drawing, single words and humour to understand each other. ●

Get connected ... with Sarah



Sarah Scott, who has aphasia

Sarah Scott was reading out loud in an English lesson when she had a stroke. She was 18 years old. Her aphasia means she has just a few words of speech.

In this conversation with Jessica Doughty, a support worker, she communicates with a few words of speech, pointing, pen and paper, gesture and facial expression.

How did you feel during the first few weeks after your stroke?

I can't remember. I was in hospital for quite a while.

How do you feel now?

Fine and quite positive. I find my difficulties with speaking and reading annoying.

What do you enjoy about coming to Connect?

Just speaking with other people with aphasia. Other people know what having aphasia is like.

How has Connect made a difference to you?

Meeting other young people who have aphasia and talking to them makes a real difference. I think that speaking to all the people at Connect now will help me in the future.

How do you spend your time now?

Gym, riding horse, swimming, speech and language therapy, cinema, coming to Connect, talking books. Horse riding is the best.

What is the most positive thing you have done since you first had aphasia?

Interview soon [with a newspaper*]. I want to tell people that young people and old people have stroke and aphasia.

What is your most prized possession?

My iPod. Reading is difficult now so I listen to a lot of music.

How would you spend a lottery jackpot win?

Buy my own horse.

Which living person do you most admire?

My mum. She has been there a lot through everything.

Do you have any tips for other people who have just acquired aphasia?

Write words down if you can't think of the word. Don't just sit there, it's not good at all. Keep busy and active and do things you like doing. ●



Jessica Doughty, support worker, who talked to Sarah

*Sarah was featured in an article about stroke in the *Daily Express* in May 2010. Visit our website to see a video of Sarah.

East meets West

East met West in London earlier this year. Two groups – one from Connect, another from Japan – came together to share stories of living with stroke and aphasia.

This meeting was organised by Endo Takashi, a speech and language therapist from Japan. Over the past ten years he has set up a number of groups for people living with stroke. Each year, various members are offered the chance to travel with Mr Takashi. Together, they meet others living with stroke and aphasia – and learn about what is happening in the stroke world globally.

Both groups had people with aphasia, relatives and therapists. Translators were on hand, but at times were not needed – ideas and feelings were shared through gesture and recognising common situations.

The party shared stories of their work and glimpses of their culture. There were short introductions

and reports, as well as songs in English and Japanese, and an exchange of gifts. The day ended with invitations for Connect members to return the gesture, with a trip to Japan – an idea met with great enthusiasm! ●



People with aphasia from Connect greet our Japanese visitors

Aphasia – what is it?

Aphasia is a communication disability that occurs when the communication centres of the brain are damaged. It is usually caused by stroke. Some people cannot speak at all. Others have just a few words. Because aphasia affects communication, suddenly all aspects of life can become a huge challenge.

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Please tick: I have aphasia I am a relative I work with people with aphasia

My job title is

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Connect – the communication disability network is a national charity for people living with aphasia (communication disability), which is often caused by stroke.

The views expressed in this newsletter are personal and not necessarily those of Connect.

www.ukconnect.org