

Leading the way in Access to Work

Support is now available to people with aphasia who feel ready to return to work. Connect is leading the way by taking part in a government scheme that at last recognises aphasia as a disability.

The National Stroke Strategy says "We want people who have had a stroke ... to be able to do paid, supported or voluntary work, if they want to." The government's Access to Work initiative makes this possible. It helps anyone whose disability affects the way they do their job, giving support with extra costs arising from their needs. The long-established scheme has been made easier to use, but people with communication disability will need support with the application process.

Connect has first-hand experience of what the Access to Work scheme can offer. Alan Hewitt, our Communication Access and Involvement Project Lead, is a much-valued member of the team who has aphasia. Thanks to Access to Work, Connect

has recruited Jessica Doughty to support Alan with the communication side of his job. As she explains:

"I will be supporting Alan with tasks such as writing minutes and letters as well as helping him organise his diary. I feel privileged to be one of the first people to support someone with aphasia through this scheme. But I really feel it should be the norm rather than the exception."

Jessica works with Alan for 25 hours a week. This gives him more planning and preparation time. It's a win:win situation. Connect benefits as Alan is freed up to focus on the unique contribution his work makes, and as he says himself, "What a boon this has been!" ●

More information at www.direct.gov.uk/en/DisabledPeople/Employmentsupport and go to Work Schemes and Programmes, or ask the Disability Employment Adviser at your local Jobcentre about Access to Work.



Alan Hewitt with his 'Access to Work' supporter, Jessica Doughty

Inside pages

Your newsletter	2
Farewell to co-founder	2
What's new in your area	3
The power of Connect	4
Top tips for living with aphasia	5
Improving services after stroke	6
Meet Henrietta, Duchess of Bedford	7

Your newsletter

Since the first issue of *Get Connected* was published this spring, I'm delighted to say we've had lots of great letters and emails from you, our readers.

Many of you responded to our call to share your top tips on living with aphasia. You will find a selection of them on page 5. Your ideas certainly make it clear that little things can make a big difference.

Making a difference to services at a national level is the aim of the network of stroke improvement groups. Connect is already working with a number of these groups – and you can get involved too. Read more on page 6 and find out how.

It can be both comforting and inspiring to read others' experiences of aphasia. In this issue,

Margaret Hussey continues the story of what life is like for her and her husband Michael. And in a special interview for *Get Connected*, Henrietta, Duchess of Bedford reflects on her husband Robin's stroke and the impact aphasia had on their lives. It is a very thoughtful piece which I am sure many of you will enjoy reading.

Here at Connect we want to hear from you. Share with us your ideas and suggestions about living with aphasia – and of course about the newsletter. Help us make the most of this opportunity to spread the word about supporting people with aphasia. And enjoy this issue of *Get Connected*! ●

Phyllis Campbell-McRae
Chief Executive, Connect

Farewell to co-founder

Carole Pound, Director of Innovation at Connect, is moving on to Brunel University to undertake research in how people with communication disability can be more involved in everyday life.

Carole co-founded Connect with Sally Byng in 2000. She has worked with people with aphasia, staff and volunteers to pioneer new opportunities and innovative ways of working with people with communication disabilities. Her work began at the City Dysphasia Group in the 1990s, where therapies drew on the skills and stories of people with aphasia. More recently, Carole has exercised her natural ability to communicate to champion the involvement of people with aphasia in developing and delivering services for people with stroke and aphasia. The range of books she has co-authored or contributed to bears witness to her academic prowess. Carole has helped put aphasia on the disability map. She told us:

"I feel incredibly privileged to have been a part of Connect's development. It's been hard work, great fun and a fabulous opportunity to learn from

people with aphasia and their relatives. Thank you to everyone who has so generously shared their stories, expertise and friendship over the years."

Connect will miss Carole's unique humour and the special relationship she has with people with aphasia. The good news is that she will still be involved as an adviser and on special projects. ●



Carole Pound (centre) with Connect Chief Executive Phyllis Campbell-McRae (left) and Sharon Smith. One of Carole's farewell gifts was this special painting by Sharon, who has aphasia

What's new in your area

As Connect expands, so too are the number of areas where we can offer a service to people with aphasia or support others to do so. Here is a snapshot of our most recent work around the country.

Dorset

The Dorset Stroke Network commissioned Connect to train healthcare staff to improve "communication access". Examples include training reception staff in communication skills and improving the accessibility of written materials. This is to ensure that people with aphasia will feel more included and involved in services.

Gloucester and surrounding areas

Gloucester has asked Connect to run a new befriending scheme for people with aphasia in that crucial time after leaving hospital. Connect will recruit staff and run the service.

North-east London

We are helping the North East London Stroke Network to set up and run a befriending scheme for people with aphasia in the Bengali community, our first opportunity to work with a specific minority ethnic group.

North-west London

People with aphasia who rarely get visits or who are unable to leave their home will soon benefit from a new conversation-partner scheme. Connect is working with the North West London Stroke Network to train volunteers in Ealing, Brent, Harrow, Hammersmith, Kensington & Chelsea, Westminster, Hillingdon and Hounslow to support isolated people with aphasia.

North-west England and the Midlands

We have trained people with aphasia to be "communication trainers" in Cheshire, the East

Midlands, Liverpool, Manchester, Wakefield, Walsall and Wolverhampton. They are now equipped to train health and social care workers about the best way to communicate with people with aphasia.

North Tyneside

In collaboration with the Communication Hub for Aphasia in North Tyneside (CHANT), Connect is looking at ways of making it easier to get back to work after stroke and aphasia. We have talked to people with aphasia about their experiences, to benefits agencies and to JobCentre Plus. We are also working with charities who help people with disabilities find work or placements and with job providers to help them make their service more accessible.

Preston and Penrith

We have trained therapists in Preston and Penrith to run brand new conversation-partner schemes. Before volunteers visit isolated people in their own homes, they are trained by people with aphasia in the best way to communicate with them. Importantly, Connect trains these trainers to give honest feedback about the volunteers' communication skills. ●



The power of Connect

In the third part of her story about their experience of aphasia, Margaret Hussey writes of the impact on her husband Michael when he was invited to speak at an awareness-raising event for Connect.

We celebrated when Michael first read a page of a child's book unaided. He was downcast because he could still not read a page of *Hamlet*. For him, his achievements highlighted what he could still not do, and bouts of depression became more frequent.

From feeling worthless...

I woke to find him putting on his oldest clothes. "Me ... no knowing ... go way. Leave you free ... lone ... lone ... no wanting ... stupid, STUPID ... nothing there ... useless."



Michael Hussey at Connect

I thrust on trousers and jacket. "If you're going, I'm coming too." Looking disconcerted, he sat down and gradually the flow of words became undecipherable sounds. I led him back to bed. He slept within minutes while I lay awake, shivering with panic.

... to being valued

Nothing that I, his doctor, a psychiatrist, his family or friends could do really touched his deep sense of being worthless. The power of the way that Connect works has been that, in every activity, Michael was valued as someone who could make a worthwhile contribution. He has worked on tasks for Connect as seriously as he formerly worked on educational documents.

Reaching out to others

Michael's reading speed increased dramatically when helping as a volunteer at the Fire Brigade. When he was asked to speak at a Connect event, Michael practised reading his ten short sentences all day. Only before the audience did he finally get them right. Intense research and rehearsal went into learning German greetings to surprise a German-speaking member of his group. Most importantly, through Connect he has been given so many opportunities to reach out to other people with difficulties. He has found he can help in a very real way.

There is no room for depression. Michael has too much to do. ●

The fourth and final part of the Husseys' story will be published in the next issue.

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.

Top tips for living with aphasia

In our last issue, we asked readers for their suggestions to help people living with aphasia. Many thanks to everyone who wrote to us.

Some of the most effective tips are the simplest: Try not to get frustrated when things go wrong. If you can laugh at your 'silly' mistakes, it's easier to try again. Take things SLOWLY – one thing at a time. And if things get difficult, don't be afraid to ask for help. Here are some more readers' tips:

Tell people about your aphasia

"I use the 'I have aphasia' card from Connect. It is a lifeline when I get stuck for words, in the bank or post office. It is also useful to have a note of your name and address on you – in case you get lost!"

Jane Clarke, who has aphasia



Do your own "therapy"

"Make a picture book – family pictures, drawings, photographs. Try finding reminders of fun days out – tickets, programmes – to help you have a conversation."

Michael Davidson, relative of a person with aphasia

Use a communication tool

"When out and about, I use *Point it: Travellers' Language Kit* by Dieter Graf. It's a small book of pictures of things to help you ask for what you want: food, clothes, items that are difficult to explain. It's light to carry around."

Gerald Hartup, who has aphasia

Take your time

"I never allow Jane to give up on the end of a conversation. I always say to her, just take your time and it will come back. If she gets flustered, I take her to one side and encourage her to take five minutes and come back to the situation."

Chris Newman, whose wife Jane has aphasia

No need to rush!

"Relax! Be comfortable in your surroundings or situation – it will help release tension."

John Humfries, who has aphasia

Help with computers

Colin Green can use a computer but finds it hard to read large blocks of text. So he uses some software called Read Please. It helps him read an email or information on a website.

Read Please will read anything you can see on the screen. All you do is copy and paste the text into a special box. Press play and the words are read out to you. You choose the voice you like and you control the speed of reading. Read Please can be downloaded free at www.readplease.com.

Other well-known text-to-voice software packages:

- TextAloud: <http://textaloud.en.softonic.com>
- SpeakOut: www.inclusive.co.uk/catalogue/acatalog/speakout.html
- Browse Aloud: www.browsealoud.com.

The five readers who were chosen at random to receive a copy of *Falling and Laughing* by Grace Maxwell are Michael Davidson, Bob Jones, Gerald Hartup, Chris Newman and Henrietta Search.

Have you used software that helps you? Can you share it with us? Please let us know – contact details on the back page.



Improving services after stroke

The National Stroke Strategy was launched in December 2007. It is good news for people with aphasia in England as it's a chance to think about how people can get better services after a stroke – not just in the early days but after hospital and life-long.

A system of 28 stroke improvement networks covering all areas of England is one way of making sure the strategy moves things along. Based on the successful model used to improve cardiac and cancer services, the networks aim "to improve the way that services are planned and delivered for both individuals with stroke and staff".

I got involved with my local stroke network because I want to make new services better for people with aphasia. Plus it's given me confidence and a mission!"

Basia Grzybowska, who has aphasia

The networks are at different stages of development. Recently, Connect has worked with those in Dorset, Cheshire, Liverpool, Manchester, Preston, the Black Country, Warwickshire and London. With people with aphasia and our Connect trainers, we work with local teams to think about creative ideas to change services and ways to develop better communication and better involvement.

Contact your network

People with aphasia following a stroke and their relatives can get involved in improving local services. To find out more about your local network, call 07824 407932 or contact Anne Coleman at anne.coleman@improvement.nhs.uk.

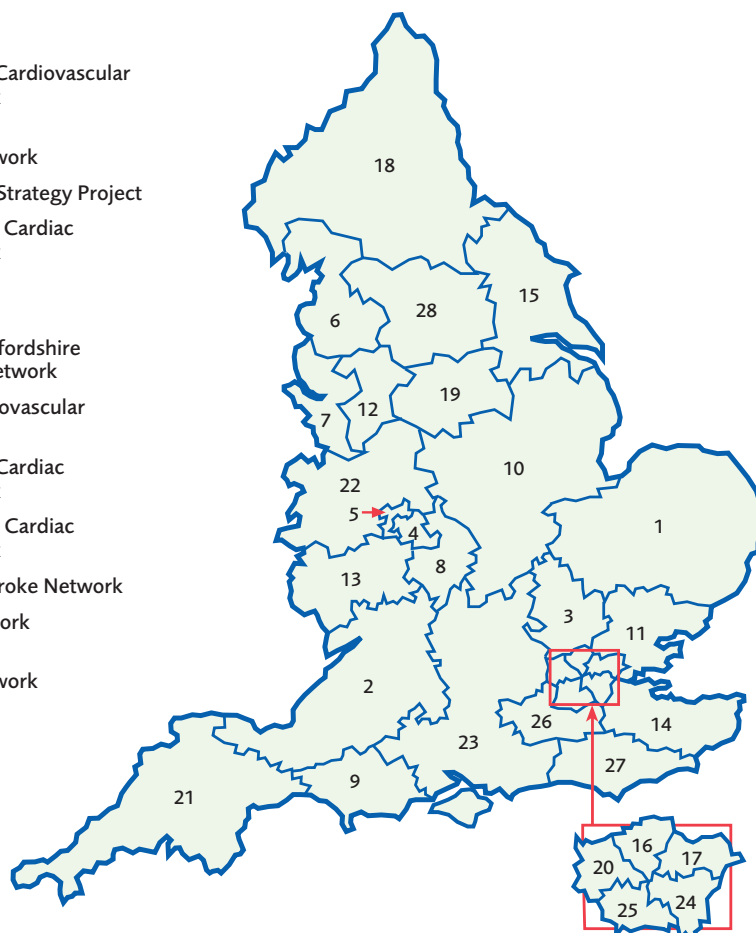
For more, go to www.improvement.nhs.uk/stroke. ●

Been involved already? Tell us about it.
Call Alan Hewitt on 020 7367 0845.



Stroke Networks in England

- | | |
|----------------------------------------------------------------------------------|----------------------------------------------------------|
| 1 Anglia Stroke and Cardiac Network | 17 North East London Cardiovascular and Stroke Network |
| 2 Avon, Gloucestershire, Wiltshire and Somerset Cardiac and Stroke Network | 18 North of England Cardiovascular Network |
| 3 Bedfordshire and Hertfordshire Heart and Stroke Network | 19 North Trent Stroke Strategy Project |
| 4 Birmingham, Sandwell and Solihull Cardiac and Stroke Network | 20 North West London Cardiac and Stroke Network |
| 5 Black Country Cardiovascular Network | 21 Peninsula Heart and Stroke Network |
| 6 Cardiac and Stroke Networks in Cumbria and Lancashire | 22 Shropshire and Staffordshire Heart and Stroke Network |
| 7 Cheshire and Merseyside Cardiac Network working with the stroke community | 23 South Central Cardiovascular Network |
| 8 Coventry and Warwickshire Cardiovascular Network | 24 South East London Cardiac and Stroke Network |
| 9 Dorset Heart and Stroke Network | 25 South West London Cardiac and Stroke Network |
| 10 East Midlands Cardiac and Stroke Network | 26 Surrey Heart and Stroke Network |
| 11 Essex Cardiac and Stroke Network | 27 Sussex Stroke Network |
| 12 Greater Manchester and Cheshire Cardiac and Stroke Network | 28 West Yorkshire Cardiovascular Network |
| 13 Herefordshire and Worcestershire Cardiac and Stroke Network | |
| 14 Kent Cardiovascular Network | |
| 15 North and East Yorkshire and Northern Lincolnshire Cardiac and Stroke Network | |
| 16 North Central London Cardiac and Stroke Network | |



Meet Henrietta, Duchess of Bedford

After a brain haemorrhage in 1988, Robin Tavistock, 14th Duke of Bedford, then aged 48, could say only "yes" and "no" and had no access to other language. With the support of family and therapists he began to recover, and in 1992 set up The Tavistock Trust for Aphasia, which provides grants to support people with aphasia and those who work with them, including Connect.

Sadly, Robin Tavistock died in 2003. His wife Henrietta, Duchess of Bedford here reflects on living with aphasia.

What were the greatest difficulties facing Robin at the beginning?

Not being able to access language must be one of the most frightening things. I always ask people who know nothing of aphasia to imagine they are in a foreign country and know perhaps just four or five words in that particular language. Not being able to get their meaning across and using the few words they have inappropriately does not mean that their brain is impaired – just that they lack the words they need to express themselves.

Sadly, because "normal" people do not understand what aphasia is, many people with aphasia are treated as if they are stupid: not "like us". This my husband found to be incredibly frustrating and extremely hurtful. And often when people do try to talk to people with aphasia they shout or talk very slowly in pidgin English, which again was a great frustration.

What was the effect on you at the time?

First I had to try to understand what aphasia was. I had never heard of it. I realised that Robin could not speak, but he seemed to understand what I was saying. I think we were really lucky that we had known each other since we were three, since before we could talk. We probably had subconscious communication skills.

Did Robin get the support he needed?

There was virtually no support for aphasia in 1988. A great problem regarding speech therapy arises

Photograph courtesy Derek Tamea



Robin and Henrietta in 2001

from the fact that the same therapist is responsible for both swallowing function and speech therapy. Because very many problems call for swallowing to be monitored, there are not enough therapists to go round. We were very lucky because we fell into the catchment area of one of the very best speech therapists in Great Britain, and I was able to drive him there.

At the start, one doesn't really know what support one needs nor how much nor what is on offer. When aphasia happened to us, I had absolutely no idea whom to talk to nor what to ask. I just did the best I could. I believe too that my lifelong involvement with horses has taught me to communicate without language and has made me more aware.

How would Robin have felt about the achievements of The Tavistock Trust for Aphasia?

I know he would have been absolutely thrilled with how the trust has developed. We held a two-day symposium at Woburn on the first anniversary of his death, aiming to get together the many organisations involved with aphasia to form an alliance. That has happened, and I believe it has made a difference. Organisations that had never met now exchange ideas. Also Robin would be amazed to know that we are the only grant-giving trust in the world dealing solely with aphasia.

Continued ►

What are the most positive elements in your life now?

Knowing that I am not letting Robin down even though I am not with him. Having three wonderful sons who are all good human beings. And being with my horses – alone-time is not possible when looking after a loved one with aphasia.

What are your top tips for living with aphasia?

Patience and understanding are the most important factors for relatives of people with aphasia.

Be patient; make time and make sure you include your aphasic companion in everything. Stimulation and being taken out and about is vital. As is rest, little naps. People with aphasia find communicating even harder when tired.

I found doing jigsaw puzzles made a big difference to language access. Maybe there is an affinity between language and the structure and shape of the pieces.



Henrietta, Duchess of Bedford (centre) presenting The Robin Tavistock Award 2008 to Connect's co-founder Sally Byng (left) and Phyllis Campbell-McRae. The award was presented in recognition of Connect's achievements in the field of aphasia

Above all, don't believe it when medical people tell you at the end of the first year "this is all the improvement you can hope for". It is not true. Robin continued to improve right until the end, 15 years after his first stroke. ●

If you haven't received this through the post, you can request your own copy, delivered to your door. It's free! Just complete the form below.

Please send a free copy of *Get Connected* to the address below.

Mr/Mrs/Miss/Ms First name Last name

Address

..... Postcode

Telephone number Email

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

My job title is

How to contact us

The Editorial Team

Connect

16-18 Marshalsea Road

London SE1 1HL

Tel 020 7367 0840 • Email newsletter@ukconnect.org

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