

Making sense of



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aphasia

Imagine you want to say something but the words just won't come. You keep trying and they're still not there. Then eventually you speak and it comes out all wrong. Even if you try to write, the words won't get from your brain to the paper – that's what it's like to have aphasia.

Aphasia happens when the communication centre of the brain is damaged. It is usually caused by stroke, but can be the result of brain haemorrhage, tumour or head injury.

Everyone experiences aphasia differently. Some people manage a few words, some cannot speak at all, others can't read, write or use numbers. All share similar feelings of frustration and isolation.

Connect is a national charity that works with people who have aphasia, their families and friends, and anyone who may meet someone with aphasia.

When the ability to communicate is taken away from you, it can destroy your life in an instant. This report explains how Connect is making sense of aphasia for thousands of people in the UK and supporting them to re-connect with life.

Every 15 minutes,
3 people in the UK
have a stroke.

Did you know...

One person in three
that has a stroke
will lose the ability
to communicate –
this is called aphasia.

There are more new
cases of aphasia each year
in the UK than breast
cancer and multiple
sclerosis combined.

Foreword: Dr Jocelyn Cornwell

Chairman of Connect

A winning year for Connect

2008-2009 was an outstanding year for Connect. We received three awards for our work with people with aphasia: from the BUPA Foundation, the Tavistock Trust for Aphasia and the Guardian.

Last year, we reported the success of the *Access to Life* project in Cornwall. This year, the future of these services looks secure, as the Primary Care Trust has taken over funding. One of our major goals over the next 3 years is to replicate the model across other parts of the country.

Despite the recent heightened awareness of stroke with the National Stroke Strategy in England, there is still too little awareness of aphasia. In an effort to turn this around, we will be increasing our investment in research, evaluation, and championing the rights of people with aphasia to policy makers.

I am always struck by the magnificent teamwork at Connect between staff, people with aphasia and volunteers. Without our volunteers we simply could not achieve as much as we do. I would like to thank the volunteers, my fellow trustees, Phyllis Campbell-McRae and all the staff for their hard work and creative effort.



As we face a difficult financial period, your support continues to be vital to Connect's work, enabling people with aphasia to have access to opportunity and fulfilment. Thank you for your continued support.

A handwritten signature in blue ink that reads "Jocelyn Cornwell".

Dr Jocelyn Cornwell
Chairman of the Board of Connect Trustees

My story: Beejal Mehta



"I had my stroke when I was 22. From then on my life changed. At first I couldn't speak at all, it was incredibly frustrating.

Connect has helped more than you can imagine. People at Connect understand because they're going through it themselves.

There is a huge gap between hospital and having the confidence to lead a 'normal' life again. This is where Connect came in. Being in the conversation group and working on 'Aphasia News' gave me the confidence to gradually return to my job as an optometrist. I couldn't have done it without Connect."

My story: Catriona Grant



“I first came to Connect five years ago – I couldn’t walk or talk.

Before my stroke – a deputy head teacher but aphasia meant I couldn’t work any more.

But now – Connect. I have a new role! Through ‘Training Together’ I train people how to communicate better with people like me. It helps improve services for people with aphasia, but it helps me too.

I still speak slowly. Finding words is difficult sometimes. But coming to Connect... I have a new confidence... new purpose – I’m a person again. It makes my job as a Mum better too!”

Catriona is one of Connect’s 176 ‘Training Together’ trainers working across the UK. At the 2008 Bupa Foundation Awards ceremony, she collected the Communication Award on behalf of Connect.



“Connect’s training has meant that Stroke Care Networks are now more easily able to involve and include people with aphasia in developing and improving services.”

Wendy Gray, National Improvement Lead, NHS Improvement

“Training in communication skills is essential – it tackles the general lack of understanding in society of what aphasia is and how to respond.”

Jeremy Shear-Hall whose wife Hilary has aphasia

Making sense of service delivery – training and consultancy for service providers

This year we extended the range and reach of our training and consultancy programme to ensure people with aphasia feel valued, listened to and more involved in services and society.

Through our partnership with health professionals, we now support 20,000 people with aphasia.

Using our Training Together module, people with aphasia have direct input into all of our communication skills training courses.

This year we have...

Trained more than 1000 health and social care workers.

Supported stroke service providers in addressing National Stroke Strategy requirements.

Championed equality and social inclusion for people with communication disability, through our conversation partner and communication access 'toolkit and training' resources.



Delivered on-site training in 18 sites across the UK and Ireland working with:

- 6 Primary Care Trusts
- 4 stroke networks
- 4 stroke improvement organisations
- 2 voluntary organisations
- 2 regulatory bodies.



Delivered 12 practical resources to transform stroke services.

Next year we will increase the number of areas we visit and extend the breadth of our consultancy programme.

Making sense of aphasia through Connect's *Access to Life* project

Connect enables people with aphasia to find a purpose, not just a voice.

This year we developed a ground-breaking pathway of support, called *Access to Life*. In both London and Cornwall there are many activities – developed and led by people with aphasia. These include conversation and music groups, informal drop-in sessions and 'Hubs' – where they can help develop services they need and want. People with aphasia also take the lead in strategy planning, campaign speaking, advocacy, networking and recruitment initiatives.

“Access to Life makes all the difference to people with aphasia at our hospital. It should be available throughout the UK.”

Katya Adie, Stroke Consultant,
Royal Treliiske Hospital, Cornwall

The impact of *Access to Life* has been exceptional.

People with aphasia tell us that before the project:

- 86% felt frustrated
- 60% felt isolated
- 38% felt helpless

After the project:

- Only 8% felt frustrated
- No one felt isolated
- No one felt helpless

Connect *Access to Life* survey 2008



“People often think we should accept aphasia and not have ambitions and dreams anymore. No way! We have expertise and skills to offer to others with aphasia (and those without aphasia too!).”

Cressida Laywood, who has aphasia

Next year: *Access to Life* will become a commissioned service throughout Cornwall and a blueprint for services across the country.

My story: Nigel Stephens



“I am convinced *Access to Life’s* success is down to Connect’s willingness to put people with aphasia in the driving seat.”

“I had my stroke in January 2004. It was lunchtime and I was walking back to my office when I felt as though I’d been hit in the neck by a cricket bat.

Two weeks later I had a second stroke. In hospital I wasn’t able to speak, read, write or even understand what a number was. Suddenly everything was thrown into confusion. It wasn’t just my life that had changed.

My wife Rose didn’t know what to expect and my children didn’t recognise their incompetent father who suddenly couldn’t spell his own name. We were full of questions. What was aphasia? Would there be more strokes? Would I be like this forever?

Life was so frustrating. I couldn’t get money from the cash machine or understand prices or bus timetables. But what really hurt was

when people I knew looked the other way rather than try to talk with me.

My speech and language therapist introduced me to Connect. I remember thinking “here are people who realise that a stroke is something you have to live with for the rest of your life”.

I became involved in the *Access to Life* project in Cornwall as a steering group member and campaign speaker. I also joined the ‘Hub’, working with providers to develop services which people with aphasia need and want. I am convinced *Access to Life’s* success is down to Connect’s willingness to put people with aphasia in the driving seat. The project for me, became a life-line.”

“Connect has helped me to find my voice and given me a purpose – it’s been a life-line. We have moved from being victims, to people who have regained control over our lives.”

Nigel Stephens, who has aphasia

This year, Connect has put aphasia on the political agenda



Out of 2000 people surveyed, more people thought aphasia was a fruit than a disability.*

In the UK, there is a desperate need to raise the profile of aphasia. In a national survey*, 90% of people said they had never heard of aphasia. And 54% of people surveyed with aphasia, said they hadn't been told they had aphasia†.

This year we held a reception at the House of Lords to put aphasia on the political agenda. We explained that communication access has to gain the same profile as physical access, and that policy needs to support people with aphasia at the highest level.

In another big step forward, our Chief Executive, Phyllis Campbell-McRae, was appointed Chair of the Adult Communication Coalition England (ACCE). This group of almost 30 organisations works together to raise the profile of aphasia and other communication disabilities.

* 2008 GFK NoP survey

† Connect Access to Life survey 2008



“Connect helps people with aphasia, but... much more to be done for raising awareness – how it affects people, the isolation, the impact on work and relationships.”

Jasvinder Khosa, Connect Trustee, who has lived with aphasia for 17 years

Next year: We will continue to raise awareness of aphasia with policy makers, the media and the general public. We will also establish a research programme with people living with aphasia, to identify their needs and aspirations.

Some of this year's achievements and key milestones

We received 'The Robin Tavistock Award' from the Tavistock Trust for Aphasia (bottom left)

The first issue of 'Aphasia News' was published

People with aphasia led the first *Access to Life* Forum conference in Cornwall (top right)

We worked with Healthcare for London to develop commissioning guidelines for 'Life after Stroke'

David Robins walked 340 miles from Boston to Barnstaple – his third mega-walk, raising a grand total of over £100,000 for Connect (middle left)

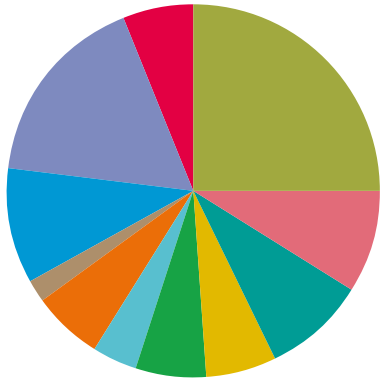
We won the award for 'Care of Older People' at the Guardian Public Services Awards 2008 (top left)

We distributed nearly 5000 publications and resources (bottom right)

Access to Life was shortlisted at the NHS Impact to Involvement Awards 2008

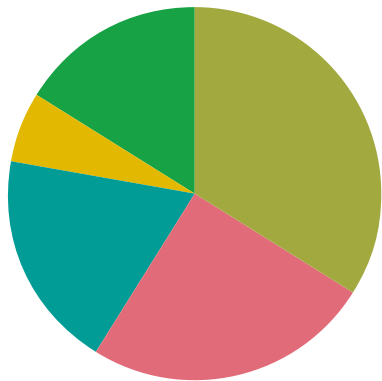


Finances



Money in: total £1,208,000

- 25%** The Dunhill Medical Trust
- 9%** The Charles Wolfson Charitable Trust
- 9%** The Tavistock Trust for Aphasia
- 6%** The Henry Smith Charity
- 6%** The Duchy Health Charity
- 4%** Other trust grants and donations
- 6%** Department of Health
- 2%** Big Lottery Fund
- 10%** Individual and corporate donations
- 17%** Consultancy, training and publications
- 6%** Bank interest and other money in



Money out: total £1,110,000

- 34%** Changing services
- 25%** Promoting active citizenship
- 19%** Influencing policy and legislation
- 6%** Governance
- 16%** Cost of generating funds

Summary financial information – year ended 31 March 2009

	2008/09	2007/08
Money in	£'000	£'000
Grants and donations	939	911
Consultancy, training and publications	201	206
Bank interest and other money in	68	58
Total money in	1,208	1,175
Money out		
Cost of generating funds	181	150
Charitable activities:		
Changing services	376	501
Promoting active citizenship	272	326
Influencing policy and legislation	216	195
Governance	65	73
Total money out	1,110	1,245
Total assets	675	577

The above information gives an overview of our money in and money out. We have taken the information from our full audited annual accounts. You can receive a copy of our full annual accounts, trustees' report and independent auditor's report by writing to us at: 16-18 Marshalsea Road, London, SE1 1HL or by e-mailing us at info@ukconnect.org

Connect would like to extend a huge thank you to our funders and donors in 2008/9. In particular, we are indebted to The Dunhill Medical Trust, The Charles Wolfson Charitable Trust, the Tavistock Trust for Aphasia, The Henry Smith Charity, The Duchy Health Charity, The Lanvern Foundation, the Department of Health, the Big Lottery Fund and David Robins. We couldn't continue our work without you.

My story: George Snell



When George first had aphasia he almost lost hope, but joining the Connect Hub and becoming a befriender turned him around.

"After having a stroke and being in hospital for 6 months, I felt so low I wanted to kill myself. Three times I drove up to the cliffs in my electric buggy and thought about going over. But, I didn't. Connect has changed my life! I've met so many great people and made some really good new friends. I first joined the hub group in the West and then became a conversation group member. We are all like a family and help each other.

My confidence grew so much that I was able to give awareness-raising speeches about aphasia and trained to be a befriender. There are so

many more people with aphasia who are not getting help. I want to get to them, to help them to have fun. I can get another person with aphasia talking, that's what I really want.

Since Connect, there's nothing I can't do. Life doesn't just stop when you've had a stroke. I'm just so confident now. I've even gone back to stained glass teaching and am setting up a workshop for anyone who has a brain injury to learn stained glass and woodwork. None of this would have happened without Connect. I'm so different now and it's great!"

Now that we have helped George get his life back, he no longer needs to attend our activities. Ultimately this is what Connect is all about.



When people with aphasia come to us they can begin an amazing journey. With Connect, there is life after stroke.



Our vision

A world where people living with aphasia and communication disability find opportunity and fulfilment.

Our mission

To improve the lives of people living with aphasia and communication disability, equipping them to reconnect with life.

We will continue to:

- Support people with aphasia to develop and deliver services that they need and want
- Provide training and consultancy to a wide range of service providers
- Provide information and support to help everyone understand aphasia and its impact
- Champion the rights of people with aphasia and communication disability.



Need help making sense of aphasia?

Contact: Connect, 16-18 Marshalsea Road, London SE1 1HL

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