

## Funding boost for aphasia services

**"The Connect Access to Life pilot in Cornwall really has changed lives", the Tavistock Trust for Aphasia and The Charles Wolfson Charitable Trust said as they gave their support for developing services for people with aphasia.**

The two organisations gave £430,000 to enable Connect to promote and develop Access to Life across the UK, starting with the south of England. The grant will also fund a system for monitoring and measuring the difference that Connect's Access to Life makes to people with aphasia.

Chairman Dr Jocelyn Cornwell expressed Connect's gratitude to The Tavistock Trust for Aphasia and The Charles Wolfson Charitable Trust. She said that "their funding will enable Connect to help thousands more people across the country."

### Tried and tested

The Access to Life pilot has been tested in Cornwall over three years, with tremendous success. Connect led a partnership in the county that included speech and language therapy departments, local health service trusts, social services and people with aphasia. They developed a unique range of services, led by people with aphasia, that help people to reconnect with life.

Both grant-giving bodies say that they now want "to see this ground-breaking model of support become available to people beyond Cornwall".

### Showing the difference

A new London "Demonstration" Centre – the first of its kind – will show people who make decisions about services how initiatives like conversation groups and befriending schemes can add to life for people with aphasia. Read more about this in future issues. ●



People with aphasia at the London Demonstration Centre

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## Connect's call to Parliament



**Connect works with Members of Parliament and decision-makers to ensure that they put in place policies and legislation which support people living with aphasia to reconnect with life. While we do not**

**endorse any specific political parties, we do support positive change for people living with aphasia, their family and friends.**

With a general election taking place this spring, we will be working hard to make sure that whichever political party forms a government in 2010 they continue to support and fund the implementation

To see the *Connect Manifesto*, visit [www.ukconnect.org](http://www.ukconnect.org)



of the National Stroke Strategy. This is one of the most important things they can do for people with aphasia.

Parliamentary candidates from the three major parties contesting seats in England will receive a copy of *Connect's Manifesto*. This states our primary purpose of working to support people with aphasia and to see their needs placed at the top of the government's agenda.

We will also give Parliamentary candidates your top tips for better communication, so that people with aphasia can be properly involved in the election. If you answer the door to a prospective Member of Parliament, please ask them to support people with aphasia by endorsing the National Stroke Strategy. And let us know what they say! ●

Phyllis Campbell-McRae  
Chief Executive, Connect

## People with aphasia and computers

**Thank you to everyone who answered our questionnaire about how people with aphasia use computers. Our survey showed some interesting results. We wanted to find out if Connect can help people with aphasia and relatives communicate and support each other using their computer.**

Of people with aphasia, 56% who responded to our survey say they do use a computer – a high proportion. The most frequent reasons given by respondents for not using a computer are difficulties with reading, writing, vision and memory. Almost a half of users use a computer for the internet, with 39% using email.

A computer can be a way to reduce isolation, and find hope, information and inspiration from others. Half of our respondents would like to keep in touch via the Connect website. We expect to have

a message board there soon. In the meantime, please sign up to our new Facebook page, which we hope you will enjoy. See the next page for more information. ●



Sonia Parsons tries out the computer at Connect

# Leading the way by raising awareness

**People with aphasia in Surrey are working with Connect to raise awareness of aphasia in the local community. Mike Cutler explains.**

Remember the old days of cinema? Every so often the film broke. The motion picture slowed right down, the sound track was distorted and finally the screen went blank. In my experience, that's what having a stroke is like. But when the film comes on again, everything is the wrong way round – the sound is back to front, high is low, no is yes, he has become she.

People may not even notice my aphasia. I can write, read and speak quite fluently – until I am out of my comfort zone or feel anxious. But in the early days, ten years ago, I struggled to get any words out. I never returned to work as a legal adviser.

## New skills

Recently I have regenerated the skills I once had, building up my confidence through a new Connect project. Working with people from Dyscover, an organisation for people with aphasia in Walton-on-the-Hill, we have delivered a presentation about living with aphasia to local community groups. We

try to help them understand what it's like, and many have said that they now know much more about aphasia.

Including group members with very little speech in the presentations has shown how much can be achieved with the right support and encouragement. The results are remarkable. We have all grown in confidence and learned so much from helping each other. It's so good to have a responsible role again! ●



Mike Cutler (left) with group member David Evans

## New from Connect

### Connect has a Facebook page



If you have aphasia, are a relative, or you are a supporter of Connect

and are interested in what we do, you can now sign up to be our "fan" on Facebook.

There's information about Connect and useful links. You can also use it to keep in touch with other people with aphasia and to support others.

Joining Facebook is easy, and it's free! Look up Facebook. Complete the form on the home page. Type "Connect communication" in the Search box. Or visit our website for "aphasia-friendly" instructions.

### Launch of Connect DVD

Connect have launched a new DVD. People with aphasia explain what having aphasia is like and how Connect has helped them. ●



**Facebook:** [www.facebook.com](http://www.facebook.com).

**Connect DVD:** available to view on our website, [www.ukconnect.org](http://www.ukconnect.org).

# Connect – making a difference

**People with aphasia say that it is vital that all public places are easy for people with communication disability to use. Here are two examples of how Connect has helped make this happen.**

## Communication champion

**In Dorset, health service staff across the county are learning what people with aphasia need to make health services easier to navigate.**

For someone with aphasia, a hospital ward can be a confusing place. They may be in a state of shock and find it hard to make sense of words, or to read or write. So, it's important that everyone – from the canteen staff to the stroke consultant – understands that person's anxiety and knows how to respond.

### Communication champions

Deborah Slate leads an innovative scheme for the Dorset Cardiac and Stroke Network called the Communication Inclusion Project (CIP). Nine "communication champions" from health service



*(Left to right) Peter Ridley and Mary and John Yeats – people with aphasia and relatives involved in service development in Dorset*

settings across the county have been trained by Connect on the benefits of better communication. In four months they have cascaded the training to 126 staff working with people with aphasia who have each pledged to make at least one change in their workplace.

### Over a hundred changes

"The project has inspired over a hundred changes", Deborah told us, "some very simple, some more technological. For example, a community matron in Poole is developing a rescue device which will operate outside the home. It will enable people with communication disability to be located if they become stranded."

### Picture menu

In Bournemouth, a nurse in the rehabilitation unit has produced a picture menu for the drinks trolley, so that people can identify what they want without using words.

### Quiet room

Staff at Westhaven Community Hospital are designing a quiet room so that people with communication disability can have a peaceful space in which to share information.

### Positive feedback

The people taking part in the training come from diverse professional backgrounds. All their ideas are presented to groups of patients with communication disability so that their comments can be taken into account. It's good to know that all of the changes met with positive feedback.

There are more changes to come thanks to CIP.

For more information, contact Deborah Slate on 01305 361543 or [deborah.slate@bp-pct.nhs.uk](mailto:deborah.slate@bp-pct.nhs.uk).





*Lucie White (seated) with her husband John and Michèle Fuirer*

## Drawing on Speech

**Getting involved in new activities is one way for people with aphasia to reconnect with life. Connect is working with Tate Modern to open up modern art to people with aphasia.**

Lucie White has severe aphasia – she has only very few words of speech. She also has a lifelong interest in art. She can pursue that interest thanks to Art into Life sessions, tailor-made for people with aphasia as part of Tate Modern's Community and Adult Learning programme. She and her husband John regularly join a group to learn about modern art at the gallery.

### Confidence and knowledge

"Art into Life is a free introduction to Tate Modern for adult groups from informal education, social and health settings", explains Artist Educator Michèle Fuirer. "Over the years, many people with aphasia attending the workshops have clearly

grown in confidence and knowledge. The partnership between Connect and Tate is very important to us. Learning from each other helps us to improve what we do."

### Opening up the world

"Michèle gives an enormous amount of thought to preparing us for the works of art we are going to see", John told us. "The sessions have helped to open up the world for Lucie and her animated expression shows just how much she enjoys them." Connect volunteer John Lewis helps communication by writing, in large type, any key words used during the session. "Another plus is that for Blue Badge holders it's easy to park at Tate Modern!" John added.

"Drawing on Speech" is an exciting new research project run by Tate Modern, with the aim of finding ways for people with aphasia to give their ideas about modern art to others. "It is time to build on the experience of the Art into Life sessions", Michèle told us, "and this group will take the lead, creating their own communication tools". ●

To find out more about Tate Modern's Community Programme, visit [www.tate.org.uk/modern/eventseducation/community](http://www.tate.org.uk/modern/eventseducation/community).



*Learning about modern art together*

# The beginning of a new life

## Reflections on life, love and living together

**In the final part of her reflections, Margaret Hussey, whose husband Michael has aphasia, describes the impact of aphasia on their relationship.**

We all live with unspoken expectations of how our close relationships will be tonight, next week, next year – “One day we’ll have time to ...”, “If she could understand that ...”, “I must try to ...”.

At the time when your nearest and dearest had a stroke, where was *your* relationship?

### Unreal expectations

Michael and I loved each other and we loved our life together, but discussions could turn into exchanges of criticism and blame. If you want the other person to change in some way, compassion can be slow, “Why didn’t he listen to me?”, “I knew that would happen if she ...”. We were some way from accepting each other fully, and I,



*Margaret and Michael Hussey*

certainly, had unreal expectations that Michael was responsible for my happiness and I for his.

A stroke arrives like a sudden death – of your way of life together and your expectations of how that will continue. It is so irreversible.

### Acceptance and getting better

The amazing gift is that the more you can accept the way life is, the freer you are to enjoy each other. We love and accept each other for the way we are. Life between us is better than before.

### Learning from Connect

In meeting people at Connect, I have been able to see my own problems in proportion, and feel privileged to have met so many people who demonstrate such courage and wisdom. Through Connect we have both learned more about our own humanity – what more can one ask?

### Optimism and hope

I am about to have a fairly major operation. Michael will be my carer for some time afterwards, and I know that he has the inner resources to be optimistic and cheerful for me. I am so very proud of him. ●

Get Connected is privileged to have been able to share with readers the experiences of aphasia that Margaret Hussey has written about so openly in these pages. Our thanks and very best wishes go to Margaret and Michael.

### 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.

# Connect with ... Carole Headley-Barton

**Connect volunteer Lucy Maran meets Carole Headley-Barton, who has aphasia. Carole and Lucy used speech and gesture to communicate.**

## What caused your aphasia?

A car accident which led to a stroke.

## What did you do before you had your stroke?

I was an admin officer for a printer in Nottingham.

## What do you most enjoy doing now?

Holidays! Especially Barbados and The Maldives.

## What is the biggest challenge with living with aphasia?

Writing. And other people not knowing what aphasia is.

## What do you do at Connect?

I'm the co-chairperson of the women's group. I help with peer support – to motivate people at



*Carole Headley-Barton at Connect*

hospital and at home. I also help train people who work in the health service about the best way to communicate with people with aphasia.

## How has coming to Connect made a difference for you?

I thought I had dyslexia before I came to Connect. Connect told me I had aphasia. I met others with communication disability who were young, like me and that helped me so much.

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

All the roles I have taken on at Connect. I have got much more confident.

## What makes you smile?

Going on holiday and succeeding at something difficult.

## What are you most proud of in your life?

Perseverance and getting so far.

## Which living person do you most admire?

Stephen Hawking. He has a degenerative disease yet still communicates, with a computer, and he is a famous disabled person.

## What is your most valued possession?

My husband!

## What are your three top tips for someone who has just acquired aphasia?

Grieve.

Remember that when you get upset, speech is more difficult.

Persevere – do whatever you can to communicate.

## Can you sum up Connect in one word or gesture?

AMAZING! ●

## Connect gets support from the City

**Since their first fund-raising dinner in October 1987, a group of City executives have raised over £6.5 million for 21 charities. Known as The October Club, they chose to support Connect as their charity of the year in 2009.**

The October Club asks charities who apply for support to show how the funding will help transform the charity's effectiveness. Chairman Nigel Gliksten told us that "the committee was unanimous in deciding to support Connect's vision of changing the landscape for people with aphasia across the UK". A dinner & auction and a Race Day raised £400,000 for Connect.

Catriona Grant, who has aphasia, gave a presentation on behalf of Connect at the dinner at the Park Lane Hotel in October 2009. Her family was told that she would never walk or talk again, but with moving eloquence she explained how Connect's model of support had made all the difference. "It was one of the proudest moments of my life", she said, after receiving an unprecedented standing ovation from the 400 guests.

Catriona describes herself as one of the lucky few. The October Club's funding will enable Connect to reach many more people like her, through its strategy of extending the Access to Life model of services across the UK.

Nigel Gliksten says, "Connect has an excellent vision of a brighter future for the people they help. It is a benchmark charity." ●



*Connect Chair Dr Jocelyn Cornwell (left) with Nigel Gliksten*

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### How to contact us

The Editorial Team

Connect

16-18 Marshalsea Road

London SE1 1HL

Tel 020 7367 0840 • Email [newsletter@ukconnect.org](mailto: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](http://www.ukconnect.org)