

## **APHASIA NOW CONFERENCE 2007**

### **'APHASIA, CONFIDENCE AND ME – WHAT HAS REALLY HELPED ME'**

**Monday 17 and Tuesday 18 September 2007**

**Royal Agricultural College, Cirencester, Gloucestershire**

## **NOTE OF TALKS AND DISCUSSION**

### **MONDAY 17 SEPTEMBER**

#### **1 WELCOME AND INTRODUCTION**

**Dr Jenny Dautlich, Chair of Aphasia Now**  
**Venue: Tithe Barn**

Jenny welcomed the delegates to the conference and especially thanked those who had made long journeys.

Jenny explained the 'birth' of the conference.

Aphasia Now was established in 2005 as a website with a forum. The website now has 2,000 visitors per month.

In June 2006 Aphasia Now attended the International Aphasia Conference and found that people with aphasia were not well represented there – only five people with aphasia attended.

Aphasia Now decided to organise their own conference – by and for people with aphasia.

The idea of the conference is that people with aphasia are the experts. The aim is to share experiences and learn from one another.

**Phil Nossek** covered general housekeeping points – fire alarm, emergency exits, directions for any health emergencies during the night, and so on. Phil also asked permission for photographs to be used on the website.

#### **2 'MY HOPES FOR THE CONFERENCE'**

**Dr Wouter Havinga, GP**  
**Venue: Tithe Barn**

Wouter asked the delegates to take part in an exercise to generate specialist knowledge.

The conference was divided into eight small groups for discussion about what delegates hoped to get out of the conference.

The delegates then reconvened and each group fed back one representative suggestion to the rest of the conference.

The following hopes for the conference were reported by delegates:

- To meet other people with aphasia
- To learn from each other
- To share ideas about how people with aphasia manage in day-to-day life
- To raise awareness of aphasia
- To share ideas and network (including use of computers)
- To learn new strategies for dealing with aphasia
- To have the chance to speak
- To find out what other people around the country are doing
- To gain knowledge and inspiration
- To educate non-aphasic people about aphasia and how to adapt or help people with aphasia
- To educate families of people with aphasia
- To have fun
- To stay happy

### **3      INSPIRATIONAL MUSIC**

#### **Ken Gareth and his euphonium**

##### **Venue: Tithe Barn**

**Pauline Turner** introduced Ken and provided communication support.

Ken has played the euphonium since he was 16 years old. He played in local bands in Swindon for 20 years then played for the prestigious Sunrise Insurance Company Band.

He has played at the Royal Albert Hall, competing against famous bands such as the Black Dyke Band.

After his stroke in 1993, Ken did not play for 6 years. He now plays a right-handed euphonium left-handed.

Ken played a number of familiar tunes, which the delegates named, such as 'Greensleeves', 'Danny Boy', 'The Skye Boat Song', 'Summertime' and 'Annie's Song'.

One delegate commented that he had hoped to meet inspiring people at the conference – and now he had met one.

### **4      INSPIRATIONAL TALK**

#### **'Thames and Severn Canal – Stroud to Kemble'**

**Brian Turfrey** (with communication support from **Pauline Turner**)  
**Venue: Tithe Barn**

Brian gave a Power Point presentation on this section of the Thames and Severn canal, explaining its importance to the commercial and transport history of the Cotswolds.

Brian researched the presentation, took all the photographs and produced the slides. He explained that he enjoys exploring the canal on foot.

Brian is also a hockey referee.

## **5      INSPIRATIONAL TALK**

**'What has really helped me'**

**Prof. Chris Code** (interviewer)  
**Dr Jenny Dautlich, Sue Gilpin, Tony Baldwin**  
**Venue: Tithe Barn**

**Wilfried Dautlich** introduced Prof. Chris Code to the delegates. Chris explained that the aim of this session was to ask the experts (people with aphasia) what had helped them, in the hope that this will inspire others.

### **a.      Sue Gilpin**

Sue talked about the speech and language therapy she received after her stroke 20 years ago. She had intensive therapy which lasted four and a half years. Sue spoke very highly of her speech and language therapist. She said that a speech and language therapist has to be 'saviour, teacher, counsellor and policeman'.

Sue began a self help group as part of Action for Dysphasic Adults (ADA – later known as Speakability). For one year the group was run by a speech and language therapist. After that Sue ran it herself.

Sue took part in a research project at City University London about living with the effects of aphasia. The research team interviewed 50 people with aphasia and their findings were published in the book *Talking About Aphasia* (Oxford University Press, 1997), which Sue co-authored.

Sue became a trustee of ADA. Two years later, ADA asked her to be the UK representative on the board of the International Aphasia Association in Brussels).

Chris asked Sue to explain why she has said that her stroke 'saved' her. Sue explained that before her stroke she was the head of a language faculty. Her job was very stressful and she was tired all the time. Her stroke had

given her a new philosophy of life. Sue described life since her stroke as 'brilliant – better than before'. She now enjoys what she does.

Chris asked Sue what makes her feel most proud. Sue talked about being asked to chair a Special Interest Group of speech and language therapists in Cambridge who work with people with aphasia. She felt proud that the speech and language therapists were asking for her views about treatment.

## **b. Dr Jenny Dautlich**

Chris introduced Jenny to the delegates. Jenny had her stroke 8 years ago, when she was 42 years old. She had trained as a doctor and worked in the field of public health in Yorkshire for 4 years.

Jenny talked about the speech and language therapy she received after her stroke. She said that the amount of therapy available differed in different places.

When Jenny was in New York for 3 months she saw a speech and language therapist every day. When she returned to Yorkshire she had no therapy for months. She felt abandoned. When she moved to Stroud she immediately had speech and language therapy at least once a week. This lasted for 4 years.

Jenny spoke about her involvement with GlosSpeak and Aphasia Now. She attended a self help group in Leeds. This helped because 'the people spoke the same language as me'.

When she arrived in Gloucester there were no self help groups there. It took 2 years to form GlosSpeak, a group affiliated to Speakability.

Chris asked Jenny about complementary and alternative therapies and how they had helped.

Jenny said that while she was in hospital in New York her stepson had given her a set of paintbrushes. When she returned to Yorkshire she started to see an art therapist. This had helped her to use her right hand.

She also uses movement therapy – eurhythmmy. This helps when she is tired.

Jenny spoke about returning to work after her stroke.

She was not help to return to her previous job in public health. She has recently got a job working part-time on the Expert Patient Programme for chronic illness.

On the bad side, Jenny said that her colleagues do not know how to communicate with a person with aphasia. She suggested that health professionals need to be trained in this.

In summary, Jenny recommended that people with aphasia should get involved with activities and should persevere. She added: 'Laughter is the best medicine'.

### **c. Tony Baldwin**

Chris introduced Tony to the delegates.

Tony had his stroke 7 years ago. Before his stroke he was the director of a large company.

Tony described how he was determined to start a new life after his stroke. When he first received speech and language therapy, the therapist helped him to use drawing and writing to communicate.

Now, at the start of a conversation, Tony tells people: 'I have a speech problem. You can either wait or go.' He said that a lot of people choose to wait.

Chris asked Tony what has helped him to start his new life.

Tony talked about how he started painting after his stroke. Headway in Gloucester helped Tony to start painting scenery for a local theatre.

Two months ago, Tony started volunteering for a furniture recycling organisation as a van driver. He collects furniture and takes it to the warehouse. Then it is restored and sold.

Tony explained how a lot of people in Evesham lost furniture after the recent floods. He was working at Evesham College to help these people.

Tony spoke about how his life has been better since his stroke.

His job as a company director was very stressful and he never had time to talk to his children or meet his friends. After the stroke he said to himself: 'Change everything. No stress.'

Tony goes dancing 3 nights per week, which he described as 'fantastic'. He does line dancing and has just started ballroom dancing. He explained that the music and dance steps help him with movement.

## **6 ART AND CRAFT EXHIBITION**

### **Venue: Tithe Barn**

**Wilfried Dautlich** encouraged the delegates to examine the art and craft exhibition at the back of the Barn.

This featured work by members of GlosSpeak and Dyscover, including word carvings, marquetry, paintings, needlework and handbags.

## **TUESDAY 18 SEPTEMBER**

### **1 INSPIRATIONAL TALKS**

**Phil Nossek, Alison Anderson**  
**Janet Rockliffe** (chair)

## **Venue: Bathurst Wing**

### **a. 'How I climbed out of the black hole' Phil Nossek (Oxford)**

Phil talked about his reaction to having a stroke 4 years ago. At first he was in shock, then denial. He was also confused in the beginning. Phil described how he was determined to solve his difficulties himself. He decided to work on improving his communication skills and mathematics.

Phil talked about the adult education courses he has done at the University of Oxford.

The first course he took was 'The Neuroscience of Human Senses'. He learned about the structure and function of the brain and nervous system – and what can go wrong. He also learned about different kinds of aphasia. At the end of the course he submitted an essay according to the university's guidelines.

Phil said that the tutor on this course was supportive. Through dialogue with the tutor and the other students, Phil developed his communication abilities. Phil explained how he has also taken courses in architecture, English folk songs, astronomy and astrophysics.

Phil also described a local authority computer course which he has attended. In less than a year, he developed skills in word processing, spreadsheets (to help with mental arithmetic) and use of the web.

In summary, Phil said that he has met a lot of people, enjoyed himself and made friends that he still keeps in touch with. Above all, he has improved his conversation skills.

His message is that you have to keep working at it.

A delegate asked Phil if he explained his speech and communication problems in advance.

Phil said that he explained to the tutor, but not to the other students. He said that they 'probably thought I was a bit funny'.

A delegate asked Phil what he meant when he said he had been determined to get better.

Phil said that his aim was to get back to his pre-stroke state. He believes that he can only speak now because he tried.

Another delegate said that what Phil had achieved was fantastic, but that some aphasic people cannot regain their speech, no matter how much they try.

### **b. Alison Anderson (Glasgow)**

Alison explained that she is 44 years old and has had kidney problems since the age of 19. She needs daily dialysis at home. Two and a half years ago, Alison had 2 strokes and 1 TIA (transient ischaemic attack = 'mini-stroke'). She was in hospital for 5 weeks.

Alison described how she was frightened after her stroke but that her family and speech and language therapist calmed her down. She spoke of how she was angry for 3 months after leaving hospital, because she had no speech and language therapy.

In October 2005, Alison attended a consultation event for people with aphasia and their carers, run by the local speech and language therapy service. This event produced the following messages:

- Information provided to people in hospital after a stroke needed to be improved, made clear and easy to understand.
- Training and education about aphasia is needed for key people such as: nurses, doctors, banks, public transport and further education providers.
- People with aphasia should have a link person on their transfer from hospital to the community.

In 2006 Alison was involved in setting up a new group in Glasgow with 5 people with aphasia and 5 carers. The group decided to produce their own information. First they attended a Connect training session on making information easy to understand for people with aphasia. The group has produced a range of information, for example an appointment card with a map and a clock to indicate the time of the appointment.

Alison spoke about her experience of joining a speech and language group. She said that it made her feel good about herself, gave her support and hope for the future.

The group helps members to communicate their thoughts, makes aphasia friendly minutes and ensures the meetings suit the needs of members.

Alison described some of her group's ideas for the future:

- Raise awareness of aphasia
- Set up training for ward staff in communicating with people with aphasia
- Introduce a menu with pictures onto the wards
- Produce a DVD for families of people with aphasia
- Set up training for people with aphasia to visit other people with aphasia to provide support at home
- People with aphasia to be involved in training nurses, doctors and so on.
- Improve links with social services.

She explained that some of these plans can be achieved quickly while others will take a long time. People with aphasia and the speech and language therapy service need to work together to improve services. Training is needed for people to take on new roles. In summary, partnership working is the way forward.

**Cressida Laywood** agreed with Alison's point about partnership working. She explained that her group has been trying to achieve the same thing in Nottingham.

## 2      **INSPIRATIONAL TALK**

### **'Work, Confidence and Me'**

**Tim Wells** (Saltaire)

**Cressida Laywood** (chair)

**Venue: Bathurst Wing**

Tim described his life before his stroke.

Tim graduated from Cambridge University in 1997. He joined the Civil Service, working as a Design Engineer for GCHQ in Cheltenham.

Tim had his stroke after having a brain tumour removed from his pituitary at Frenchay Hospital in Bristol. He then moved to the Rivermead Centre in Oxford for rehabilitation.

Tim talked about his return to work.

After his stroke Tim was still employed by GCHQ. He was allowed to return part-time and gradually returned to full-time work. He was lead designer for a module on a satellite (Skynet 5) which was launched recently.

Outside work, Tim met Wilfried and Jenny Dautlich and joined GlosSpeak.

In 2002, 2 years after his stroke, Tim toured Australia.

He then returned to Cambridge to study for a Master's degree. While there he had a great time, did aikido and gliding, but did not get his Master's.

Tim talked about his change of career.

When he returned to work, GCHQ had contracted private industry to do design work. Tim had only wanted to do design, so he felt uninspired. This led to depression.

Tim left GCHQ in March 2007 and spent 2 months looking for work. He then got some contract work for Pace, a firm in Saltaire, West Yorkshire who make set-top boxes. He was made permanent and full-time at Pace, starting on 24 September.

A delegate asked Tim how he works with one hand.

Tim explained that most of his work is done on a computer, so he can type with one hand.

A delegate asked if Tim received the support he needed on the Master's degree.

He replied that he did to a certain extent. Cambridge University has a disability centre, but it is mainly geared towards dyslexia.

Another delegate asked how much support Tim had from his employer when he returned to work.

He replied; 'Not much'. Health and Safety had supplied a chair and sorted out an appropriate computer screen. Tim commented that the attitude of GCHQ was that he was lucky to have a job at all.

His main motivation for leaving was his own confidence, and his belief in his right to expect more.

### **3      INSPIRATIONAL TALK**

#### **‘The Way Forward’ – Power Point presentation**

**Members of Dyscover** (Walton on the Hill): **Rex Pearson, Trish Henson, Dave Newnham and Roger Lewis**

**Cressida Laywood** (chair)

**Venue: Bathurst Wing**

Rex gave the delegates an overview of Dyscover.

Dyscover was set up as a charity 13 years ago by Bill Johnson, a speech and language therapist. The name combines the words ‘dysphasia’ and ‘recover’. The main centre is in Walton on the Hill (Surrey) with a satellite in Richmond. Dyscover provides support for around 80 members aged 30 to 90+.

Dyscover offers:

- Regular sessions 4 mornings a week
- Outside activities
- A group for younger members
- Family support meetings
- Training for volunteers
- Special courses (such as creative writing, conversation partners, and so on).

Dyscover is run by 3 speech and language therapists with 13 trained volunteers, an admin worker, fundraiser and a board of trustees.

Dave explained more about the activities of Dyscover.

The morning sessions are used for small conversation groups. Conversation topics include the news, hobbies and holidays. These sessions are also used for talks, word games, creative activities, quizzes and cooking. For example, Dave and Rex recently gave a talk about the tall ships.

Outside activities include sailing, outward bound courses and day trips (such as an organic farm or a trip down the Thames).

Dave also produces the Dyscover newsletter 4 times per year.

Trish told the delegates what members say about Dyscover.

Members were quoted as saying the following things:

- It provides comradeship and friendship
- It makes them feel less isolated
- It is a home from home
- They feel respected as a person
- They are not self conscious about their disability
- ‘People laugh with me, not at me’.

Trish said that Dyscover had changed her life. It had given her the confidence to return to driving, which gave her a feeling of freedom.

A delegate asked how far people travel to meetings.

Dave replied that members come from a large area, as far away as Sussex. They travel by Dial-a-Ride, by car or on foot.

A delegate asked if members can attend on any day they want. The speakers replied that sessions are run 4 mornings a week, but the building is open more often than that. Members book into a particular session, which is tailored to their needs. They can attend more than one session per week. Members can attend a group for as long as they wish.

#### **4 TIME FOR ANYONE TO HAVE A SAY**

**Alan Hewitt** (chair)

**Prof. Chris Code** (communication support)

**Venue: Bathurst Wing**

Alan introduced himself to the delegates.

He is Secretary of the Central London Dysphasia Group and works for Connect as a Project Lead.

Alan invited the delegates to comment on the conference:

##### **Monday afternoon:**

- Several delegates said that the reception on arrival was good.
- Delegates liked the choice of venue.
- More tables for the tea break would be helpful.
- The acoustics in the Tithe Barn made it difficult to hear what speakers were saying.
- Delegates enjoyed the small group discussion. Some said they would like more of this in a future conference. Others found it difficult to hear or concentrate when there were many people speaking in the same room. Using separate rooms for small group discussion would be better.
- Delegates said Ken Gareth provided a good example of someone continuing to recover long after his stroke.
- Delegates said they enjoyed Brian Turfrey's talk. They felt that Pauline Turner worked well with him as a communication helper.
- Delegates commented on the use of the computer with projector for communication support. This was a good idea, because it meant there was no problem with reading handwriting. However, some delegates felt that it did not work very well, as they found it distracting. Opening a new screen to type into would be better than deleting the text to clear the screen.
- Delegates enjoyed the interviews with Chris Code.

##### **Monday evening:**

- Delegates said the dinner was very good.

- Staff were very helpful. Delegates appreciated that staff in the bar turned down the music when asked so people could talk.
- Delegates enjoyed the music and sing-along session. More songsheets would have been helpful.

### **Monday night:**

- Delegates who stayed the night said that the rooms were cold. The heater instructions were difficult to understand and delegates had not been told that there was a blanket in the wardrobe.

### **Tuesday morning:**

- Delegates commented on the use of parallel sessions. Some were sorry to have missed sessions which were running at the same time.
- Wilfried Dautlich explained to delegates the reason for having parallel sessions. Aphasia Now carried out research with 50 people with aphasia, asking them what they would like to do at the conference. As a result they planned to cater for people with a range of severity of aphasia.
- Some delegates found the programme for Tuesday a little confusing.

### **The next conference:**

- Delegates would like to have a list of attendees with contact details in the conference pack.
- Transcripts of talks and Power Point slides could be made available afterwards.

## **5 CLOSING SESSION**

### **Dr Wouter Havinga**

#### **Venue: Boutflour Hall**

The delegates divided into small groups around the tables.

Wouter asked delegates to decide on one thing that they could start doing as a result of the conference. Delegates were asked to use the 'GROW' model to guide their discussions: Goal, Reality, Opportunities, Way Forward.

After the small group discussion, several delegates fed back to the conference about what they planned to do. The following examples were raised:

- Use the computer more
- Return to doing things that they used to do, such as life coaching.
- Meeting more people of the opposite sex
- Painting
- Pottery
- Reflexology
- Start doing a newsletter

Wilfried and Jenny thanked all delegates for coming.