

# Speaking Up

Summer 2009

## New for 2009: Medical Passport

The 'Medical Passport' is a pocket-sized, 34-page conversation book comprising icons, pictures and words relating to health matters. The Passport aims to enable a person with Aphasia to discuss their medical needs with their doctor on an 'equal' basis.

With access to a medical communication tool, a person with Aphasia instantly regains control over a conversation about their health.

The idea for this tool came from people with Aphasia who have been frustrated about the difficulty in talking about their health issues with their doctor. People with Aphasia were involved in helping to develop the contents of the 'Medical Passport' to ensure that it fulfils all their needs as a patient.

- The 'Medical Passport' is Speakability's newest publication for 2009.
- It enables a person with Aphasia to discuss their medical needs with their doctor.
- The pocket-sized book includes icons, pictures and words relating to health matters.
- The idea for the book came from people with Aphasia and a small group helped to choose the book's contents to ensure it fulfilled all their needs as a patient.



### Dogs Make Tracks for Speakability

On Sunday 5th July 2009, brilliant sunshine with a cooling breeze saw a happy band of walkers, aged between 1 and 83 years, set off from the village of Sevenoaks Weald, across fields to the Greyhound Pub in Charcott, Kent. They were accompanied by 30 dogs, ranging in size from a Chihuahua to a Retriever. A great time was had by all – especially the dogs! Nearly £400 was raised to help start a new local Speakability Self-Help Group for people with Aphasia in the area local to Sevenoaks.

Speakability Chief Executive, Melanie Derbyshire, her son James and Scamper (English Springer Spaniel) were delighted to join the party for the 10 mile round trip. Speakability is particularly grateful to staff at the Greyhound for refreshments and lunch, to Ragna Tulloch for organising the event, and to everyone who gave their support – walkers and individuals who donated money or raffle prizes.

# Letter from Royal Street

Welcome to this new-look edition of 'Speaking Up'. Alongside our regular articles, we have included summary sections for those who prefer a quick read. At Speakability, we believe that communication is about building relationships, sharing information and supporting one another. So, please do let us have your news, examples of good practice, and what has worked for you either as a person with Aphasia or as someone who cares.

Throughout 2009/2010 Speakability will be marking its 30th Anniversary. Formed in 1979, under the inspirational leadership of the late Diana Law, Action for Dysphasic Adults was registered with the Charity Commission in 1980. The working name, 'Speakability', was adopted in 2000.

Diana experienced her Aphasia following a stroke. She wanted to offer people help and a sense of hope, believing that, with support and determination, it was possible to overcome the barriers to communication and to find ways of getting your message across. Diana only regained a handful of words, but people understood her passion for change and she was well respected by all who knew her.

Thirty years on, Speakability continues to campaign with, and on behalf of, more than 300,000 people in the UK who have difficulty speaking, reading and/or writing because of Aphasia – whether caused by stroke, head injury, brain tumour, or other neurological condition. The charity offers help and hope to people with Aphasia and their families through its dedicated Helpline, Information Service, low-cost publications and growing range of communication tools. The emphasis is on empowering people to rebuild their confidence and communication skills, and to help them to realise a better future. This philosophy is under-pinned by our network of Aphasia Self-Help Groups and a huge army



Speakability Chief Executive, Melanie Derbyshire with Speakability Group Member, Trevor Walker

of volunteers, right across the UK. I am very pleased to have this opportunity to thank publicly such a wonderfully resourceful and committed band of individuals for all their achievements.

Speakability relies on the goodwill and generosity of all those Charitable Trusts, Companies and individuals who understand the importance of speech and language and want to help others to have the opportunity to get practical help and free or low cost information quickly. At present, we receive no funding from the Department of Health in England, although we do in Scotland. The past two years have been challenging, but we have worked hard to create a lean administrative centre so that the bulk of our resources goes directly towards providing practical support for the people who need our help. I do hope that this snapshot of our activities encourages as many of you as possible to add your time, skills and donations to ensure that our work can continue.

We know that the people at the heart of Speakability have the passion and dedication required to achieve greater understanding about Aphasia as a communication disability. We now need a stronger commitment from those in Government to fund appropriate long-term support for people with Aphasia. Please help us in this fight by speaking up about Aphasia and working with us to raise funds. Together, we **can** make a positive difference.

**Melanie Derbyshire**  
Chief Executive



Kendal Group Members, Janet Rockcliffe and Christine Adams (centre) with Dr Eva Cummins (left) and The Revd Dr Daphne Green (right)

# Speakability Group Members Attend Reception at Downing Street

Speakability Group Members joined Cherie Blair at 10 Downing Street, on 17th May 2007, in support of people with Aphasia. Around forty Speakability Group Members and supporters enjoyed a truly memorable evening reception. We were delighted that Lady Wilson, one of the charity's Vice-Presidents and former occupant of Number 10, was also able to attend.

Mrs Blair spoke about her own experience as a carer of someone who has Aphasia, since her husband's father

has had a number of strokes, resulting in this communication disability.

Chief Executive, Melanie Derbyshire, thanked Mrs Blair for her generous hospitality and reminded guests that each of them could influence the way in which Aphasia was viewed and how individuals with speech and language problems were treated. The most disabling feature of Aphasia is the way that people treat you! Aphasia does not make people stupid or less intellectually able. It merely makes it difficult for them to use the traditional channels of communication.

## Charity Flowers Direct

Everyone appreciates a beautiful gift of flowers. By ordering through Charity Flowers Direct, you can make the gift go twice as far.

When you place your order simply quote our special reference – **SPEAK** – and Charity Flowers Direct will donate **15%** of your total purchase to Speakability at no extra cost to yourself.

24/7 Order Hotline: **08705 300 600**

Order hotline [www.charityflowers.co.uk](http://www.charityflowers.co.uk)

# Speakability Launches New Website



We were delighted to launch our new Website in June 2008, funded through the kind generosity of the Garfield Weston Foundation.



The Internet has opened up a whole new world of opportunity for people seeking information and wanting to communicate with others. Speakability has recorded a huge increase in the number of email enquiries we receive each month, from health professionals, carers and people with Aphasia, who would like advice about living with this communication disability. Our

re-developed Website is a vital extension of our Helpline and Information Service, providing comprehensive Aphasia information that is quick to access, and in a simple format.

The Speakability Website offers a wider variety of information and services to users, and its simple design and menu bar make navigation more straightforward. It is possible to search online for local Speakability Self-Help Groups and download our Aphasia Fact Sheets and Publications List. In addition, the Website hosts an Aphasia Forum, which features a 'Discussion Board' and an 'Aphasia Software Testing Area' is under construction.

To date, the feedback we have received has been extremely positive. We are thrilled that our new Website is enabling our information and support to reach even more people with Aphasia and their carers.

By posting messages on the 'Discussion Board', users can share their experiences and advice with other people who are living with Aphasia. This Board also acts as an online support network for those who can access the Web but who do not yet have a local Speakability Group. The 'Aphasia Software Testing Area' will allow users to read reviews of various communication aids and, in most cases, to test out the software before deciding to make a purchase.

- The new Website provides information on Aphasia in an easy-to-read form.
- Fact sheets on Aphasia can be downloaded directly from the Website.
- Details of Speakability Self-Help Groups can also be found on the Website.
- The new Website hosts an Aphasia Forum, which includes an online 'Discussion Board' and an 'Aphasia Software Testing Area'.
- The 'Discussion Board' acts as an online support network for those who can access the Web, but who do not yet have a local Speakability Group.

# Communication Tools and Good Practice



- Combining pictures and words can make it easier for a person with Aphasia to communicate their needs.
- A personalised book about the person with Aphasia can aid conversation and interaction with others.
- The book should include basic information in the form of photos, pictures and words about the individual's family, hobbies, likes and dislikes, and so on.

## Personalised Communication – 'A Book About Me'

Personalised communication books act as ramps to conversation.

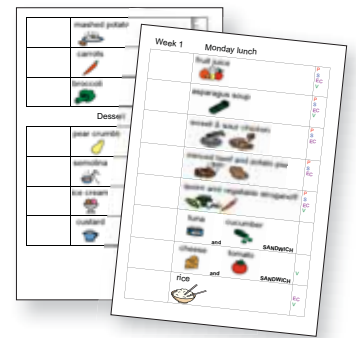
The combination of words and pictures makes it easier for a person with Aphasia to remember and communicate the words they want to. These tools can also benefit carers by helping them to understand and respond to the message. Ideally, these communication tools should be personalised and reflect the personality of the individual who will be using them.

For someone who has lost their speech, communicating with people around them, especially with those who do not know them well, can be an incredibly frustrating process.

'A Book About Me' is a simple but effective tool to aid a person's ability to communicate with others, by highlighting facts about their life and character in a creative and straight-forward manner. The book should include basic information in the form of photos, pictures and text about the person's family, hobbies, likes and dislikes, and so on.

## Picture menus

Speakability welcomes the creative initiative of Claire Harrison and Nicola Gilchrist, Speech and Language Therapists working for Berkshire West PCT.



Claire and Nicola put together a picture/photo menu for use at the Royal Berkshire Hospital, in order to increase the amount of accessible information available to patients with communication problems. The menu follows the Hospital's two week menu rotation.

As well as featuring symbols and pictures of each food choice, the menu includes photographs of every meal available to patients. The name of each food item is also written simply and in large print.

The symbols for the food items were provided by Boardmaker 6, a software programme that provides images for communication aids ([www.mayer-johnson.com](http://www.mayer-johnson.com)).

For further information, please email Claire Harrison at: [claire.harrison@royalberkshire.nhs.uk](mailto:claire.harrison@royalberkshire.nhs.uk)

- Two Speech and Language Therapists have created a picture/photo menu for patients with communication problems at the Royal Berkshire Hospital.
- The menu features symbols, photos and pictures of each food choice on the Hospital's menu.
- The name of each food item is also written simply and in large print.
- The symbols were provided by Boardmaker 6, a software programme that provides images for communication aids ([www.mayer-johnson.com](http://www.mayer-johnson.com)).

# Communication Software for People with Aphasia

In this issue, we are featuring two software programmes, **React 2 by Propeller**, and **StepByStep by Steps Consulting**.

These computer-based products include a variety of exercises and functions that are intended to help people with Aphasia to practice their communication skills in the comfort of their own home, and at their own pace. There are many more software programmes on the market, so it is important that you seek advice before making a purchase to ensure that you find one that best suits your particular needs and abilities.

It is essential that a specialist assessment is carried out before purchasing a piece of communication software. This can be done either by a Speech and Language Therapist who has experience in communication aids or by a Communication Aid Centre. AbilityNet (Helpline: 0800 269545) offers an assessment service and free open days for people with disabilities. You can also find information on their Website ([www.abilitynet.org.uk](http://www.abilitynet.org.uk)) about customising your current computer in a way that is more disability-friendly. This may be all that is needed to enable a person with Aphasia to use the computer.

It may also be possible to receive financial help for the purchase of software. Your public library should have names and addresses of local charities and charitable trusts. It may also be useful to refer to 'A Guide to Grants for Individuals in Need' publication by The Directory of Social Change, which should also be available from the library.

## Software Workshops

Speakability plans to run two specialist workshops during 2009/10. There will be opportunities for people with Aphasia to try out various programmes, with assistance from experienced Speech and Language Therapists.

If you are interested in attending one of these sessions (London or Manchester), please contact Lindsey Coleman on 020 7261 9572, visit our Website or email [lindsey@speakability.org.uk](mailto:lindsey@speakability.org.uk)



In March of 2009, Peter Garside and members of the Harrogate Speakability Group hosted a Computer Study Day in Yorkshire, organised by Gill Pearl, Chief Executive of the Bury based Charity, Speakeasy.

The Day was attended by 56 people, 31 of whom had Aphasia. The people were invited from Speakability Groups across Yorkshire. The presentation covered information about computers and how they can be useful for people with Aphasia. There was information about a range of software with more details about several of the systems, including React, StepByStep, Bungalow, Sword, and Penfriend. After discussion about each of these programmes, there was a chance to have a hands-on session using the laptops and specially devised worksheets. This opportunity was strictly for the people with Aphasia, although carers were invited to have their own discussion time.

Experience of using the Aphasia software shows that it works best when supported by a Speech and Language Therapist who has a high level of expertise in this area. Speakeasy has developed a way of allowing people to buy this support for some of the programmes

even for people living at a distance from Lancashire. Speakability and Speakeasy now plan to work in partnership to enable more people with Aphasia to have the opportunity to try this Aphasia software prior to purchase.

– ADVERTISEMENT –

## Comments from users

"I found the StepByStep programme really easy to get around. It is good that you can select the right therapy and exercises at the right time for you, in the security of your own home." **Gill**

"I am helping a friend to use StepByStep Version 3. Since using it, she has gained much more confidence in her speech. She also finds it a great help when writing emails and can now write them without needing any assistance." **Pip**

"With Propeller, initially, I could only achieve 40% success in the word-finding exercises, but after only three sessions, I achieved a 70% success rate." **Ken**

"There are many levels to choose from so with Propeller you can progress at your own pace." **Lesley**

– ADVERTISEMENT –

## New hope for people with Aphasia

**For many people with Aphasia, speech and language therapy is withdrawn within months, leaving many people with the potential for further improvement without the professional help they need.**

StepByStep V4 is a new breakthrough product developed to provide guidance and structured exercises. There are exercises for speaking words, sentences and spelling. Each exercise is explained by a video of a Speech and Language Therapist, so that you can receive therapy at a time and place to suit you.

Ideal for therapy in a group, supported by volunteers, or independently at home, StepByStep V4 enables therapy to continue for as long as it is needed.



**For a free no obligation 30-day trial of StepByStep V4 contact: Dr Jane Mortley on 01454 218436**  
**Web: [www.aphasia-software.com](http://www.aphasia-software.com)**

# Speak About Aphasia Month

'Speak About Aphasia Month' is the annual awareness campaign co-ordinated by Speakability. It takes place during the month of June and has a different focus each year.

In 2009, the charity launched a national campaign to persuade cafés and coffee shops to offer hand-held illustrated Menu Cards so that people with communication problems can be confident about placing their order without relying on another person to do it for them. This simple solution will benefit both the customer and the shop owner. A campaign postcard was produced to ensure that the message could be communicated as widely as possible.

Speech and Language Therapy teams added their voice to the campaign mounted by Speakability's national network of Aphasia Self-Help Groups to create local media interest, arranging coffee mornings or fundraising activities and designing their own picture menus.

The Brentwood Gazette put its full weight behind the campaign and worked with local business, Café à Moore, to create a picture menu so that members of the Brentwood Aphasia Self-Help Group could order and enjoy their refreshments as easily as anyone else. Secretary of the Brentwood Group, Adele Ball, was thrilled to hear the news. Adele, who lives in Ingatestone, developed Aphasia after a stroke eleven years ago. She regards herself as fortunate because some of her speech has gradually returned. Owner of Café à Moore, Rich Delow, said he was just happy to help. "I've got a few people that come in here already that have had strokes, or can't communicate with me as easily as they would like, so it's a good idea," he said.

Café owners seeking advice on the creation of illustrated menus should contact Melanie Derbyshire on 020 7261 9572. If you would like to add your name to our campaign Petition please visit the Speakability Website: [www.speakability.org.uk](http://www.speakability.org.uk)





*Members of Brentwood Speakability Group outside Café à Moore*

Speech and Language Therapists at Addenbrooke's Hospital, Cambridge, have designed hand-held pictorial hot drink menus for Costa Coffee outlets in the hospital. The menus were launched during Speakability's 'Speak about Aphasia Month' Campaign in June 2009.

The team gathered feedback from the public and people with Aphasia. They hope to use the feedback to encourage the national Costa Coffee chain and other coffee shops to provide similar menus.

This June, the hospital began a new training programme, "Communicating Well – More than Words", to increase the skills of staff members who work with people with Aphasia (acquired language disorder) and Dysarthria (muscular speech difficulties). The team hopes that the changes will improve the hospital experience for patients on the unit. People with Aphasia have been helping with each training session.

The team has also been working towards a better environment for people with communication difficulties. Colour-coded rooms were introduced when the Lewin Stroke and Rehab Unit was renovated in 2007-2008. The environment is now brighter and less clinical and signs with symbols are now in use to help

people find their way around. The lounge area (day room) for patients and families has also been re-arranged to encourage conversation.

For further information regarding any of the projects at Addenbrooke's Hospital, contact the SLT team on 01223 217491 or you can email Helen Palmer at [helen.palmer@addenbrookes.nhs.uk](mailto:helen.palmer@addenbrookes.nhs.uk)



- Speech and Language Therapists at Addenbrooke's Hospital, Cambridge, have designed pictorial hot drink menus for Costa Coffee outlets in the hospital.
- This June, the hospital began a new training programme, "Communicating Well – More than Words", to increase the skills of staff members who work with people with speech and language difficulties.
- The hospital environment is now also more accessible to people with communication problems, with colour-coded rooms and the use of signs with symbols as well as words.

# Celebrating Personal Achievements



*Claire Fowler (right) with fellow runner*

Below we celebrate the achievements of Claire Fowler and Ian Cragg. For these two individuals, living with Aphasia has made them even more determined to go that extra mile!

Four years ago, Claire Fowler suffered a brain haemorrhage and was given only 2 hours to live. Six operations later and Claire is now fitter than ever, with a remarkable courage and determination that impelled her to run the 2007 Glasgow Women's 10k run on behalf of Speakability.

Although Claire received the all-clear after her final operation, she was left with Aphasia and was unable to return to work. Claire filled her new-found time by setting herself an intense exercise routine. Claire and her husband, Hugh, also contacted Speakability for advice and support about coping with Aphasia and they were inspired by stories from people who attended our Speakability Self-Help Groups.

We were amazed when Claire decided to take part in the Glasgow run, through which she aimed to raise funds for Speakability as a thank you for the help she received after leaving hospital.

Claire has since completed the 10k run again, completing it in only 49 minutes! Claire's success is incredible when you consider the physical and mental challenge it must have presented. The £500 raised by Claire has been invaluable in helping us to maintain our Helpline and Information Service and to continue the development of our UK-wide network of Aphasia Self-Help Groups.

## Calling all runners...!

**Are you thinking of running the London Marathon 2009 or another official run?**

**If so, why not consider running on behalf of Speakability in support of people with Aphasia?**

**We can provide you with a fundraising pack and a T-shirt featuring our logo.**

**For more information, phone Speakability on 020 7261 9572 or email [speakability@speakability.org.uk](mailto:speakability@speakability.org.uk)**

Ian Cragg had a stroke in 2006 and, only a year later, he was running the Reading Half Marathon, completing the run in just two and a half hours! Speakability was honoured to be awarded £638 in sponsorship from Ian's run. This gift has enabled us to continue our work in support of people with Aphasia and their carers. Ian hopes that his success, only a year after his stroke, will encourage other people with Aphasia to regain control of their life, rather than live a life that is dictated by it.



*Ian Cragg*

# Campaigning

## Speakability Group Members Speak Up at Scottish Parliament Reception

Speakability co-hosted a Reception at the Scottish Parliament, November '08. The Reception was organised to present the findings of a survey of stroke survivors, who had experienced Aphasia, to Members of the Scottish Parliament. The survey – “Back to Life after Stroke” – was jointly run by Speakability, The Royal College of Speech and Language Therapists, Chest, Heart and Stroke Scotland and The Stroke Association in Scotland. Records show that every year in Scotland, more than 4,000 new people will experience Aphasia following a stroke.

The survey took place across Scotland in September 2008. Nearly 300 stroke survivors with Aphasia following their stroke responded to the survey and described how speech and language therapy and voluntary Aphasia support services had improved their lives.

90% of people said speech and language therapy was important both in hospital and the community. However, more than one in four of those responding to the survey said that they did not receive speech and language therapy after leaving hospital following their stroke. Of those that did, one third said they had to wait for their therapy to begin. On average, one third said they did not receive speech therapy after leaving hospital and in some parts of Scotland, this rose to nearly two thirds.

More than three-quarters said that the voluntary sector support services they have received are important, have allowed them to remain independent and have had a positive impact on their confidence and relationships with family and friends. Nearly two-thirds of those who received voluntary Aphasia support services said that they would like more of these services to be provided. One respondent wrote, “It is difficult to become part of anything when you cannot communicate and in the end you become isolated”.

At the Reception, sponsored by Richard Simpson MSP, Deputy Labour Spokesperson on Health, two Speakability Self-Help Group Members, Lindsay Richard-

son and Helen Gowland, gave excellent presentations about their individual experiences of Aphasia. Other Scottish Group Members also attended the event along with Melanie Derbyshire, Chief Executive of Speakability.

### The four campaign partners are calling on the Scottish Government to:

- improve provision of both speech and language therapy and voluntary Aphasia support services in hospital and in the community
- raise healthcare professionals' awareness of the impact that stroke can have on communication and how to support people with Aphasia
- improve the communication accessibility of all public services and the information they provide
- collate local incidence and prevalence figures of people with post-stroke Aphasia as well as data on their needs and the current provision of Aphasia support services. This data should be used to inform service development and planning.

Melanie Derbyshire said, “Community based Aphasia Self-Help Groups play a vital role in enabling people to re-build communication and re-kindle their zest for life. As an empowering charity, Speakability is delighted to acknowledge the excellent contribution to this survey by Members of our Aphasia Self-Help Groups in Scotland. Our Members know what it is like to live with Aphasia – it is absolutely essential, if future services are to meet the true needs, that their views are heard.”



# Communication Forum (Scotland) Launch Web Based Toolkit

Speakability is a key member of Communication Forum (Scotland). This is an informal alliance of organisations representing people of all ages with varied communication support needs. Members of Communication Forum (Scotland) recently launched a web-based communication toolkit for people with Aphasia.

Aims for the Communication Forum (Scotland) are to:

1. highlight the diverse range of communication support needs
2. promote ways of meeting these needs.

Melanie Derbyshire, Speakability's Chief Executive, was very pleased to join members of the charity's Self-Help Groups in Scotland for the public launch of the web based Communication Toolkit, which has been put together by the charities that form the Communication Forum (Scotland).

The Communication Toolkit was commissioned by the Scottish Government Equality Unit. It is designed to give decision-makers and service providers in public and voluntary organisations advice and examples of the best way to engage with people who have communication support needs. Along with practical advice, it includes templates of accessible written materials and sources of further information and support. For more information visit [www.communicationforumscotland.org.uk](http://www.communicationforumscotland.org.uk)

Speakability Group members in Scotland have been very involved in making this project a huge success and we are grateful to them for all their hard work.

- Speakability is a member of Communication Forum (Scotland). This is an alliance of organisations representing people with communication support needs.
- The Forum has launched a web-based communication toolkit for people with Aphasia.
- Speakability Group members were involved in consultation for the project.



From left to right:  
Graham McGuire  
(Edinburgh  
Group), Lindsay  
Richardson (Forth  
Valley Group),  
Melanie  
Derbyshire, and  
Helen Gowland (Tayside Speakeasy Group)

## The Aphasia Alliance Campaign



Speakability is a key member of the Aphasia Alliance. An initiative of the Tavistock Trust for Aphasia, this is a UK-wide coalition of 11 organisations working with people who have this communication disability. Their vision is a world where everyone with Aphasia receives the support and understanding they need.

The Aphasia Alliance launched its campaign, 'Aphasia – the Hidden Disability', on 14th April 2008, to raise public awareness of this widespread disability. As part of their campaign, the Aphasia Alliance commissioned a UK-wide survey to measure levels of awareness of Aphasia among the general public. The survey revealed widespread ignorance and public misconception about what constitutes a disability. Physical indicators such as 'using a wheelchair' and 'using a walking stick' are widely recognised, but a worrying 72% of people did not mention those affecting communication as something that would suggest a disability.

For further information about the Aphasia Alliance, visit [www.aphasiaalliance.org](http://www.aphasiaalliance.org)

# Fundraising

## Speakability Chief Executive Successfully Completes Greenwich Santa Run in Support of Speakability

Melanie Derbyshire stunned herself and her staff team (as well as her dog!) by taking part in this 5km Fun-Run on Sunday 7th December 2008. It is fair to say that the idea of running anywhere was a totally new concept for Melanie. Walking the dog is one of her favourite ways to relax, but dressing up in an oversized Santa costume, complete with a beard (!) was, until quite recently, not her idea of a good weekend activity.

The Speakability running team comprised Melanie, fellow staff member Lindsey ("It will be great fun") Coleman, some of Lindsey's equally enthusiastic friends, a couple of generous Speakability supporters and Amanda Darby from AG Thames.

Thank you to everyone who so kindly sponsored the team.

## St Mary's Support for Speakability

Speakability was thrilled to be accepted as the Spring 2008 Focus Charity at St Mary's Parish Church in Battersea.

St Mary's supports local, national and international charities covering issues including the elderly and the young, justice, and mental and physical health. On Mission Giving Sundays the Church invites a speaker from their focus charity to give a presentation about their organisation as part of the service.

The Church welcomed Melanie Derbyshire to speak on behalf of Speakability at their Sunday service on 27th January. Melanie greatly appreciated the opportunity to show the Speakability video (presented by the BBC's Andrew Marr) and talk about the important work carried out by the charity. Speakability Vice Chair, Diana Moir, spoke eloquently at the evening service on that day.

In addition, the Church's Mission Giving Committee generously donated £1,250 to Speakability. This kind gift will enable us to continue the help and support that we offer to people with Aphasia, their families and carers.



- Melanie Derbyshire, Speakability Chief Executive, took part in the 5km Fun Run in December 2008, dressed as Santa no less!
- The Speakability running team comprised Melanie, colleague Lindsey Coleman, as well as some supporters and friends of the charity.
- The team raised over £1000 – thank you so much to everyone who so kindly sponsored the team.



## Leaving a Legacy

We receive funds from many individuals during their lifetime for which we are most grateful, but we also have the opportunity to make a difference to other people's lives after our death.

A bequest to Speakability would enable us to plan our future work – which in turn could make all the difference. It would help us to tell more people about our Helpline, Information Service and network of Self-Help Groups. It would help us to influence change and secure better services for people with Aphasia.

Don't put off making your Will – it is your opportunity to choose what happens to your treasured possessions and estate. For a copy of our 'Making a Will' information sheet, please call Speakability on 020 7261 9572 or email [speakability@speakability.org.uk](mailto:speakability@speakability.org.uk)

# Aphasia experience voiced at UK Stroke Forum

Speakability is a member of the Steering Group and Committee which organises the UK Stroke Forum each year. Hosted by the Stroke Association, this year's event takes place on 1-3 December at the SECC, Glasgow. For more details visit: [www.ukstrokeforum.org](http://www.ukstrokeforum.org)

We are now delighted to report that Speakability Development Worker, Janet Rockliffe, has secured a place as a Service User Representative on the UK Stroke Forum Committee. Janet will be contributing to two sessions at the Conference. She will be helping to ensure that the voice of people with post-stroke Aphasia is heard by the full range of professionals working in the field of stroke care.

## Rugby Legend Speaks at UK Stroke Forum

The third UK Stroke Forum Conference was held in Harrogate in early December 2008. Rosemary Cunningham, a Speech and Language Therapist from Derbyshire, gave a presentation about 'Communicating after Stroke'. Ken Rollin, Chairman of Speakability Wakefield, was invited to be her co-presenter.

In the 1960s, Ken played Rugby League for Wakefield Trinity. He is famous for scoring the fastest try in a Cup Final at Wembley. After a stroke in 1999, Ken was left with Aphasia and could say only a few words. In 2002 he became Chairman of the new Wakefield Speakability Group.

At the Stroke Forum, Ken spoke to an audience of more than 200 people. The audience included many doctors, consultants, nurses and therapists. Ken spoke

about his battle to overcome his Aphasia and how he had been helped by Speech and Language Therapists. Ken also spoke about being a member of the Wakefield Speakability Group and how much this had helped him on his long road to recovery. Now he helps other people with Aphasia in the Wakefield area.

- The third UK Stroke Forum Conference was held in Harrogate in December 2008.
- Ken Rollin, Chairman of Wakefield Speakability, spoke about his battle to overcome his Aphasia.
- Ken played Rugby League for Wakefield Trinity in the 1960's. He had his stroke in 1999.
- Ken also talked about being a member of Wakefield Speakability Group and how much it had helped him on his road to recovery.



*Ken Rollin (left) with Graham Johnson (right) on the Speakability stand at the UK Stroke Forum*

## Corporate Supporters can you help?

**Speakability is delighted to have the support of Global Marketing Network**

Do you know a company that will offer its support to Speakability in 2009/10 when we celebrate our 30th Anniversary? If you can help, please do get in touch either by calling us on 020 7261 9572 or emailing [melanie@speakability.org.uk](mailto:melanie@speakability.org.uk)



**Global Marketing Network**  
When we talk marketing, we really mean business

# Self-Help Groups

## Scottish Aphasia Self-Help Groups – Network Meeting

On 15th October 2008, members of Forth Valley Speakability Group hosted a very successful Network Meeting for Scottish Groups and supporters at the Rugby Club in Stirling. We are grateful to all those who contributed to the day's programme, especially our guest speakers from Headway, the Stroke Association and Connect. All of the six active Scottish Groups were represented and members shared information about their activities. For the sixty or more participants, there was also time to talk about hopes for the future for new Speakability Groups in Scotland and the challenge of raising funds to sustain this work.

The event received excellent coverage in the local press and Speakability Chief Executive, Melanie Derbyshire, was delighted to have the chance to meet so many of the charity's Scottish Group Members. We are particularly grateful to Lindsay and Allan Richardson and Alex and Rena Frederick for their help and support with this event. Plans are now in hand for the next Scottish Network Meeting due to take place in Dundee on Thursday 19th November 2009. For more details please contact Melanie on 020 7261 9572.



Photo © Scottish & Universal



## Ilford Group Open Day

Melanie Derbyshire (Speakability Chief Executive) and Edward Hodgkins (Speakability Chairman) were among those who dropped into the Ilford Open Day 2008, arranged by Speakability Ilford Group Members for 'Speak About Aphasia Month'. Members enjoyed a wonderful buffet lunch and were kept busy with the various stalls and activities throughout the day. The Ilford Group was also presented with a cheque for £1,325 raised by Carly Williams, who had taken part in a sponsored run in support of the Group and Speakability.

## Interested in Speakability Aphasia Self-Help Groups?

Speakability has a growing UK-wide network of Aphasia Self-Help Groups – currently around 90 Groups at various stages of development.

- To find out more details about Groups in your local area, please phone the Helpline on 080 8808 9572.
- If you would like to work with us to start a Self-Help Group in your area, please contact Melanie Derbyshire on 020 7261 9572 or email [melanie@speakability.org.uk](mailto:melanie@speakability.org.uk)
- For details about volunteering opportunities with Speakability, please contact Lindsey Coleman on 020 7261 9572 or email [lindsey@speakability.org.uk](mailto:lindsey@speakability.org.uk)

### The newsletter of Speakability

(Action for Dysphasic Adults)

Registered Charity No. 295094

1 Royal Street London SE1 7LL

Tel: 020 7261 9572

[speakability@speakability.org.uk](mailto:speakability@speakability.org.uk)

**Helpline: 080 8808 9572**

Calls to the Helpline may be monitored.

Opinions expressed in this newsletter do not necessarily reflect the policy of Speakability and any products/services mentioned are not necessarily endorsed or recommended by the charity.

# My Experience of Living with Aphasia



*Sue Burnell (left) with her Speech Therapist, Jane Mortley*

Managing our banking needs online is considered to be a quick and easy process in a world where the Internet is fast becoming the primary communication channel. However, for those living with Aphasia, Internet banking is often far from simple.

Sue Burnell, Treasurer of the Newbury Speakability Self-Help Group, tells us how she has overcome some of the barriers faced by Aphasia.

"I had my stroke in October 2001. It left me unable to read and write (recognising letters), no cognisance of the right side of my body, reduced peripheral vision on my right side and so on. I have severe problems saying proper nouns – names of people and places being the most difficult – but I can get by in one-to-one conversation. I am able to recognise some writing by identifying blocks of information and as such can browse a newspaper (The Times is difficult but the Mail

is easier due to heavier type and smaller paragraphs) and I can understand numbers.

I would like to be able to look at my Internet banking accounts but cannot get past the security procedures required by the banks and financial companies. My partner, Norman, has to get me in through the security checks and then I can negotiate through the account details myself.

As Norman used to be a computer consultant he is always looking for ways to make life easier for me and has found me a device, the size of a mouse, which will recognise fingerprints. I wrote to the bank but they have their own projects in hand are not really interested, even though the interface could be used together with the bank's own software without a great deal of modification.

One way we have found to get round the first, third and sixth character check is to make the memorable information all "A"s and if the bank needs a numeric character then we stick a 1 as the last required character. For Sky programs on our television, we also use a PIN of 1111 on the remote control handset."

**Sue Burnell**

**Dictated to Norman Sinclair-Baines  
(communicative partner)**

## Speakability Welcomes Royal Visitor

Speakability was delighted to welcome HRH The Countess of Wessex to a special Self-Help Group meeting on Wednesday 21st March 2007.

The meeting was hosted by members of the Farnborough Speakability Group and they invited friends from the Basingstoke Speakability Group to join them for the day.



The highlight of the day was the opportunity for Group members, carers and volunteers to speak to HRH The Countess of Wessex (Sophie Wessex), the Lord Lieutenant of Hampshire and the Mayor and Mayoress of Rushmoor. In attendance also were Edward Hodgkins (Speakability Chairman), Roy Matthewson (Speakability Trustee and Group Member, *pictured above*) and Melanie Derbyshire (Chief Executive).