

# Newsletter

Issue 45, Spring 2011

*different* Strokes

*Support for Younger Stroke Survivors*



Lisa Charlton accepting her MBE from HRH Prince Charles at Buckingham Palace in recognition of her voluntary work for Different Strokes in the North East



**Welcome** to Newsletter number **45!** Please feel free to contact us with your comments and views, Survivor Stories, Ask The Expert Questions, Lonely Hearts etc. If you have a book, CD, brain training game, or anything else that you'd like to review, or an issue that you'd like us to feature, please get in touch! We also love to share your recovery tips and useful ideas - see the back cover for our contact details.

Our **2011 conference** will be taking place on Saturday 15th October in Leeds with the theme of the **"Hidden Side of Stroke"** - see page 19. More details will follow in the next issue and we hope to see as many of you there as possible!

A big **thank you as always to our army of volunteers** who help in so many different ways from giving their time and energy; sharing their expertise, personal experiences and coping strategies to give hope and support to others; raising valuable funds for us; helping to raise awareness of stroke in younger people, etc. Massive congratulations to Lisa Charlton on receiving an MBE in recognition of her hard work setting up and fundraising for Different Strokes groups in the North East (see page 4 for more details).

**There are many ways that you can get involved:** if you are interested in becoming a trustee, see page 3 for more information. Our Chair of Trustees, Sarah Welsh, would be pleased to hear from you. Email your contact details to [info@differentstrokes.co.uk](mailto:info@differentstrokes.co.uk) and we will pass them on to Sarah for you. We'd also like to take this opportunity to say a big thank you to our departing trustees Mike Druce and Tim Wells for all their hard work, support and dedication over the years.

**Thank you to everyone who sent us their views on the government's proposed reforms to Disability Living Allowance (DLA).** Different Strokes strongly opposes the proposed changes and has urged the government to reconsider. Our response which was sent to the Department of Work and Pensions is available on our website at <http://www.differentstrokes.co.uk/DLA-response.pdf>. If you'd like us to send you a printed copy, please contact the office (see details on the back cover).

**Thank you also to our focus group volunteers who helped us with our Care After Stroke in Childhood information and with our yellow information leaflet.** We'll shortly be commencing work on improving other sections of our information pack - it's not too late to take part. You don't have to be based in Milton Keynes as we can send information to you by email or post. We'd particularly like to hear from you if you would be interested in helping us to reformat our information pack to make it aphasia-friendly. Please email [eileen@differentstrokes.co.uk](mailto:eileen@differentstrokes.co.uk) or contact the office for more details.

**Best wishes from Eileen Gambrell (Editor) and all the Different Strokes Team**

## Are you interested in helping Different Strokes in a new way?

I am the Chair of the Trustee Board and we are looking for some new Trustees to help guide Different Strokes in meeting the needs of younger stroke survivors.



### Q: What is a Trustee?

The Trustees help the organisation face risks, meet challenges and, above all, plan for the future. It's an important role as the Trustees are ultimately accountable for Different Strokes.

### Q: What are Trustees expected to do?

We meet once a quarter in London, usually on a Monday evening. In between meetings we are usually in email contact to discuss decisions that need to be made such as approving the budget or agreeing a staff policy.

Once a year we meet for a whole day, usually with the staff, and consider how successful Different Strokes is being in meeting its goals and how we can improve things.

Ideally trustees attend the Different Strokes annual conference (on a Saturday) to which over 100 stroke survivors, their carers and others come along.

### Q: How many trustees are there?

At the moment there are 7 trustees but we can have more.

### Q: Do Trustees need any special skills?

Trustees need:

- to be committed to Different Strokes aims.
- to have some time to give the organisation, not just coming to the Board meetings but taking an active role in helping to lead the organisation.
- specific skills such as financial, legal or fundraising are really helpful - but enthusiasm and a desire to help are more crucial.
- to be able to work as part of a team working to achieve the best for Different Strokes.

A majority of the Trustees need to be stroke survivors (I am one myself) and we would be very interested to recruit the parent of a child who has had a stroke.

### Q: What do trustees get out of it?

- You don't get paid but can claim travel expenses.
- Feeling that you are part of a team making a difference for a worthwhile cause.
- Useful experience that may help in the workplace.

### Q: How can I find out more?

Leave your contact details with Head Office and say you are interested finding out more about being a Trustee. I will contact you.

**Sarah Welsh, Chair of Trustees**

## Different Strokes North East

### Lisa Charlton MBE

"With a background in export marketing, I have extensive experience in marketing in the consumer, industrial and defence markets. I was the Export Manager at Ever Ready and then at Hawker Eternacell. When I lost my sight at the age of 29 through diabetic retinopathy, I continued with my work in export and travelled extensively.

However, 2 years later I suffered a major stroke which left me paralysed down the right side. I spent 7 months rehabilitating in hospital and then a further 6 months in a wheelchair. I have now regained a lot of movement and walk with a white walking stick.



Lisa receiving her medal from the Prince of Wales



Lisa and Anth McGhee - Chairman of her local Different Strokes exercise group

After taking a year off work it was time for a career change. I fell into fundraising by accident when I helped to set up Different Strokes in the North East. There was nothing available for younger people who had experienced stroke. Different Strokes in the North East had no funds so I got to work fundraising for start up costs. Fundraising is really a type of marketing, but promoting a charity is much more rewarding than selling batteries!

I then went on to help to set up Different Strokes South of Tyne and I now work on a part time basis as the Fundraiser at Gateshead Citizens Advice Bureau.

I have a wide interest in the voluntary sector both at a regional level in the North East and nationally. I am the Treasurer of my local Different Strokes group, a Trustee of the Royal National Institute of Blind People (RNIB), and a Director of Newcastle Society for Blind People (NSBP). I have also been the Treasurer of Newcastle Disability



Lisa and her mum outside Buckingham Palace

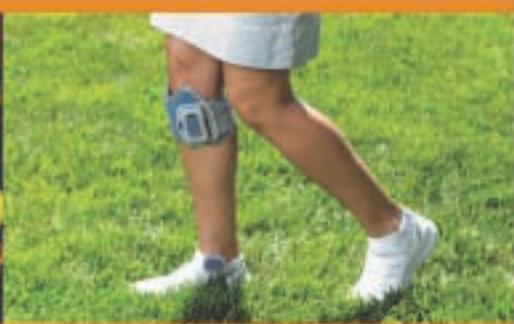
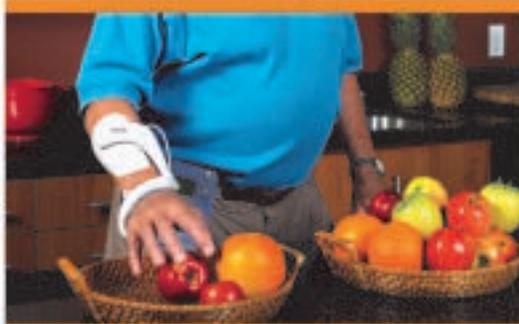
Forum, a Trustee of Tyneside Recreation Club for the Blind and a Director of the Community Foundation of Tyne and Wear and Northumberland. The majority of my voluntary involvement is with disability led organisations.



Last June to my great surprise I was on the Queen's Birthday honours list and was awarded a MBE for voluntary services to disabled people in Tyne and Wear. It was my work in helping to set up two successful Different Strokes groups that was instrumental in me being nominated for this award. It was a great honour to visit the palace in December and receive my medal from the Prince of Wales. He was absolutely charming and encouraged me to keep up the good work and inspire people to help me to do so!"

**Thank you to Lisa for sharing her inspirational story with us and many thanks also to all of our volunteers around the country who help us in so many varied ways. If you'd like to get involved, please contact the office - see back page for details.**

## STROKE CHANGES YOUR LIFE. CHANGE IT AGAIN FOR THE BETTER



### NESS H200™ HAND REHABILITATION SYSTEM

Designed to help you open and close your hand, perform daily activities and reeducate your muscles.

### NESS L300™ WIRELESS DROP FOOT SYSTEM

Designed to stimulate the muscles in your affected leg, thereby allowing you to lift your foot while walking.

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## Visual Problems After Stroke

One of the difficulties with visual impairment is that the person experiencing it can 'see' it but others around them often can't. It's then left to the person to report and describe their visual symptoms to others. This can be particularly difficult for those with communication or cognitive issues. It is therefore important to raise awareness of what sorts of visual impairments can occur following stroke and what to look for in the absence of obvious changes to how the eyes look.

### Loss of Visual Field

The most widely acknowledged visual problem after stroke is the loss of visual field (peripheral vision). The most common form is **homonymous hemianopia** – a complete loss of half of the field of vision in both eyes either to the right or left side and occasionally to both sides. There are many other types such as:

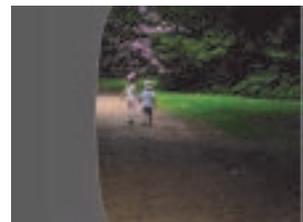
- quadrantanopia (loss of quarter of the field of vision in both eyes to one side)
- scotoma (a small patch of visual field loss)
- altitudinal (loss of complete upper or lower half of visual field)
- peripheral field loss (constriction of the field).



Normal vision



Complete right homonymous hemianopia



Incomplete left homonymous hemianopia

For further details and images use the following web link: <http://www.library.nhs.uk/Eyes/ViewResource.aspx?resID=300071&tabID=290>.

A sign that you may have impaired visual field is if you miss objects to one side, bump into objects, appear more clumsy than normal and move your eyes and head more to one side to compensate. Studies show that approximately half of stroke survivors with visual field loss show some recovery of this with most recovery occurring within the first 4 to 6 weeks post stroke. Approximately 10% have a full recovery of their visual field whereas the remainder have improvement but with residual permanent loss of field.

Nevertheless, improvement can result in better navigation skills and functional mobility. There are numerous treatment options, some of which aim to restore part of the visual field loss but most of which aim to compensate for the loss of vision. There are varying reports of effectiveness for the treatments but research is ongoing to find which options work best.

## Ocular Alignment and Movement Problems

Another form of visual impairment (more common than visual field loss) is ocular alignment and movement problems, which occur in up to 68% of stroke survivors. Ocular alignment is normal if both eyes are straight and point at the same object. If one eye isn't straight this is called a "squint" or "strabismus" and when it is acquired after stroke, it can cause double vision. A person with double vision is often seen to close one eye and move their head to one side to compensate for this.

Normal ocular movements occur when both eyes move in the same direction and at the same speed so there is symmetry of movement. Following a stroke, the brain control and nerve pathways for eye movement can be affected and different patterns of abnormal eye movements are seen dependent on which part of the brain is affected. In addition to double vision, individuals may complain of difficulty with reading, blurred vision or constant wobbling of their vision. Effective treatment for these problems is well established. Typically prisms or a patch are used to prevent double vision and where problems persist long term, botulinum toxin or surgery are alternative options.

## Poor Central Vision



Approximately 25-30% of stroke survivors will have poor central vision and this is diagnosed by using a letter chart (or suitable alternative). Individuals can be seen 'screwing' up their eyes to try to see more clearly. About 50% of those with blurred vision after a stroke have this symptom directly due to the stroke and for these, improvement occurs in most cases by 3-4 weeks post stroke.

One third will have poor vision because of co-existent eye problems such as glaucoma, cataract and retinal degeneration. Importantly treatment for such eye problems should continue and if not being treated, requires referral for Ophthalmology assessment.

For many the cause of poor vision is because of a need for glasses. It has been found that up to 75% of stroke survivors require glasses and 25% don't have the correct glasses with them on admission to stroke or rehab units. A visit to an Optometrist or a home visit is essential to improve such glasses-related problems. If you have persistent poor vision, there are many treatment options including low vision aids and equipment, use of large print text and environmental modifications. The **RNIB** is an excellent source of such information: [www.rnib.org.uk](http://www.rnib.org.uk).

## Visual Inattention or Neglect

For many, intact visual information reaches the brain but can't be interpreted because of the damage caused by the stroke. Most commonly visual inattention or neglect occurs where one side of the visual world is ignored. Individuals ignore objects, people, etc to the affected side and may bump into things on the affected side. Other perceptual problems include visual hallucinations, failure to recognise objects or faces or find objects in cluttered surroundings, loss of colour vision, depth perception and visual motion.

## Visual Problems After Stroke (continued from page 7)

In order to diagnose these impairments, good questioning skills are required and there is no doubt that problems may go undetected because individuals haven't been asked the right questions or don't wish to report these problems. Visual hallucinations are a classic example and it is very important to reassure people that such problems are because of the stroke and not a sign of poor mental state. Various treatment strategies are available and are largely based on compensating for the visual impairment. Research continues to explore the effectiveness of such options to determine the most effective and beneficial.



### Referral to Eye Care Services

Referral to eye care services from stroke and rehab units remains inconsistent across the UK. This must change. Anybody with visual impairment must have an assessment by an appropriately trained professional for accurate diagnosis. Treatment in the acute stage can help with general rehabilitation.

For those discharged without assessment and with persistent visual impairment, it's never too late to seek an eye assessment to obtain an accurate diagnosis of the problem, receive explanation of what it is and discuss options to manage this. GPs and Optometrists can make referrals into the eye care service. Optometrists review the need for glasses and can screen for other eye problems ensuring appropriate onward referral is made. Orthoptists often act as the direct link between acute stroke services and the Ophthalmology unit but also are responsible for reviewing eye movement impairments.

### Registering Sight Impairment

Sight impairment (whether central or peripheral) can be registered. Certification of visual impairment can only be completed by an Ophthalmologist in the UK, hence referral to the eye care team is essential for this. This registration alerts social services and may help with adaptations at home and provide information about benefits.



### Driving

Anybody with visual impairment should be assessed to ensure s/he meets the DVLA requirements for driving. Individuals cannot drive within one month of the stroke. Some individuals make a good general recovery from their stroke but have persistent visual problems and return to driving without an assessment of these visual problems. Visual impairment is a notifiable issue and car insurance is invalid in these circumstances. In order to be sure of meeting the DVLA requirements, a formal assessment is needed. You should not drive if your vision (with both eyes open) is less than a certain level, if you have uncorrected double vision and if you have a restriction of visual field (<http://www.dft.gov.uk/dvla/medical/ataglance.aspx>).

**Dr Fiona Rowe, Senior Lecturer in Orthoptics, University of Liverpool**

## Do you have foot drop?

You may be interested to know more about the WalkAide system!

**WalkAide**<sup>®</sup>  
System



WalkAide is designed to improve the walking ability of people experiencing foot drop without the 'fuss' of setting up wires and a heel switch.

WalkAide uses advanced sensor technology to first analyse the movement of your leg and then sends impulses to activate the muscles to raise your foot at the appropriate time during the step cycle. The result is a smoother, more natural and safer stepping motion.

### Why WalkAide?

- Easy one-handed application and operation (no wires involved)
- Small, self-contained unit that attaches to the leg below the knee
- Does not require special shoes, may be worn barefoot or with slippers
- May improve circulation, reduce atrophy and increase joint range of motion

For further information please contact our customer service team on,  
Tel: 0114 2618 100 or Email: [info@trulife.co.uk](mailto:info@trulife.co.uk) (Quote Ref: TL/ DS\_0311)



## Families and Children

For the 100s of families whose child have a stroke in the UK each year, the effects ripple out to the whole family unit. There is help available:

- Please contact the Different Strokes office for a copy of our **Care After Stroke in Childhood** information. Thank you to the families who have recently taken part in our focus group to improve the content and style.
- Use the Different Strokes message board at [www.differentstrokes.co.uk](http://www.differentstrokes.co.uk) and Facebook group to make contact with other families and members who themselves had strokes as children to share experiences and coping tips.
- Use the Childhood Stroke Support message board on Facebook and at <http://www.strokesupport.com> - this has been specifically set up for parents and families by one of our members whose son had an AVM stroke at the age of 12. They know what you are going through as they are living it themselves.

### Young Carers

Sometimes adults think that children might be upset if they know about someone's health problem, but it's often more scary for a child not knowing what is happening. There are currently **175,000 young carers under the age of 18** in the UK so if you think you might be one or want to learn more, visit a special website just for young carers **[www.youngcarers.net](http://www.youngcarers.net)** which is run by the **Princess Royal Trust for Carers**. It has discussion boards, a chat forum, an agony aunt section and shared information about how it feels to look after a parent or brother and sister.



**connexions direct**

See also **[www.connexions-direct.com](http://www.connexions-direct.com)** for info on being a young carer, or call 080 800 13219.

**Sibs**

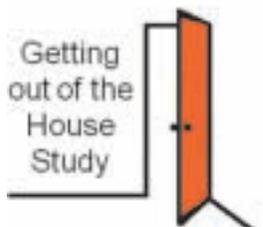
**UK charity that provides support for brothers and sisters**

Sibs is the UK charity for people who grow up with a disabled brother or sister. There are **over half a million young siblings** and **over a million adult siblings** in the UK.

Siblings growing up in a family where the majority of family resources, parental attention, and professional services are often directed towards another child (i.e. the disabled child) have specific needs that require attention at different stages of their lives, including relief of isolation, information, and strategies for coping with the situations they find themselves in. Sibs aims to enhance the lives of these brothers and sisters by providing them with information and support, and by influencing service provision.

For more information go to <http://www.sibs.org.uk> or call 01535 645453.

## Research



### Would you like to get out of the house more often?



The University of  
Nottingham

We are looking for people who have had a stroke and who'd like to get out of the house more often. The team needs volunteers who could help with this important research aimed at improving rehabilitation following stroke – there are about 10 study sites across the UK taking part.

Getting out of the house after a stroke is important and we are trying to help people get out more often. As a volunteer you'll be offered information about travel and transport in your area and the team will collect information about how you have managed after a stroke. Some participants will also have targeted rehabilitation from therapists to help them get out the house more often.

The information collected will be entirely confidential and only used for research purposes.

**If you are interested and would like further information then please contact:**

Nottingham Clinical Trials Unit  
B39 Medical School,  
University of Nottingham  
Nottingham NG7 2UH

**E-mail:** [pat.morris@nottingham.ac.uk](mailto:pat.morris@nottingham.ac.uk)

**Phone:** 0115 823 0516

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## Prospective Memory Research Study

### Teenagers with brain injury wanted for memory study

Difficulties remembering to do things in the future are common after brain injury and can lead to many problems in daily life for people who are affected. This study aims to evaluate a strategy that may help improve these memory problems. The strategy involves training participants to 'stop and think' about things they need to remember to do, and then sending several text messages to people's phones reminding them to do this.



#### Who are the researchers looking for?

The researchers are looking for people aged **12 to 17** years old, who have had an acquired brain injury and are medically stable enough to participate in research. They are looking for people who have prospective memory problems in their daily life as noticed by themselves or others (e.g. often forgetting things they had planned to do). People also must be willing to use a mobile phone for the study, and living in England.

**Find out more:** For further information please contact Rebecca Rous: Email: [R.Rous@uea.ac.uk](mailto:R.Rous@uea.ac.uk) Phone: 01603 591507 (leave a message on Dr Adlam's voicemail)



**Pankaj Sharma**  
Neurologist/Stroke Expert

**“In January I suffered a stroke in my Thalamus. Following an MRA scan of my neck, my vertebral artery was found to be “thready” and fragile looking with signs of dissection therefore the probable cause of my stroke. I don’t have any motor deficit at all but am suffering overwhelming fatigue and memory-gaps, particularly the names of people I have known for quite a long time and general knowledge questions that I am sure I knew before.**

**My questions are:**

- **How common is this type of stroke?**
- **My GP has commenced me on Aspirin 75mgs and Simvastatin 40mgs. My Cholesterol level was 5.7. Is this the appropriate treatment or should more be done to prevent a further stroke?**
- **Will my memory return to normal or am I likely to suffer this loss permanently?**
- **Also I am a road cyclist, which I do to keep fit, am I putting myself at risk by following this hobby? Thanks.”**

Thank you for your question and I am sorry you have suffered a stroke. The cause for your stroke seems to be a vertebral artery dissection which essentially is a rip in the lining of one of the arteries that supplies blood to the brain. The cause for this rip would have no doubt have been investigated by your doctors, although it should be said that a cause is often not found. Dissections are frequently seen by stroke physicians but are not as common as 'usual' strokes.

Fatigue is a very common complaint following any stroke. However, the area of the brain that has been affected in you is involved in memory and may explain your memory gaps. These symptoms are likely to improve as time goes on but the exact level of improvement is of course difficult to predict.

Your cholesterol level does seem to be high but it is not clear whether this level was taken after starting simvastatin. If the level does not drop to around 4mM/l then I would approach your GP for alternative and more powerful drugs.

Undertaking exercise like cycling is an excellent idea and to be encouraged. It is unwise to cycle soon after a stroke but if your memory has improved enough to allow you to cycle and your physical condition does not impair your cycling, then you should go out cycling and enjoy yourself!

**Ask the Expert**



Jon Graham  
Physiotherapist

**“I had a CVA in 2000, aged 28. I now find I have lost confidence with walking, even short distances. When I recovered I was a very determined person, walking everywhere. I have a limp and left sided weakness. Now I get what I presume is anxiety - where my legs shake and the tone gets tight and I cannot envisage going out on my own in case I get stuck. I have visited anxiety nurses which has helped a bit.**

**My questions are:**

- **Is it normal for stroke survivors to lose confidence?**
- **Would you recommend getting medication to make things a little easier to deal with? Thanks.”**

Stroke survivors can lose confidence following a trip or fall whether whilst still in hospital or several years after they have left hospital. Other causes for losing confidence can be muscle tightness in the weaker leg or gradual loss of strength in either leg. This often happens if the total distances that the individual walks are much less than they were walking previously – or less than someone of their age who has not had a stroke would be walking. Loss of confidence can then lead to the symptoms of anxiety that you describe. With regards to medication, this is a discussion that is best had with your GP.

However, I have found the following ideas have helped others. Fear of falling is often made worse by worries about how you would get up from the ground. So practising getting up from the ground in the comfort of home can help reduce the anxiety about going out. If you haven't been shown how to do this, or have forgotten, then I would recommend that you seek a Physiotherapy referral.

Practical ways of dealing with the anxiety of “*getting stuck*” are: building your confidence again with short walks around your immediate neighbourhood and gradually increasing the distance day-by-day, “*lamppost-by-lamppost*”; and also to always take a mobile phone with you with numbers of people who'd be able and happy to assist you stored on it. “Shooting sticks” can be helpful – these are walking sticks with foldable seats as handles.

Fear of “*running out of steam*” can reduce confidence. Knowing that with such an aid you could take a rest at any point can help. Be sure that you are SAFE using this device as a rest before considering purchasing, and again practice using one. Perhaps best of all is regularly attending your local Different Strokes exercise class and even practising some of the exercises at home.

# Ask the Expert

Please note that while our panel endeavours to give the best advice based on information provided, it is always advisable to have a face-to-face consultation with a practitioner about any health issue that concerns you. Comments expressed are general in nature and are not intended to provide specific advice.



Yash Bedekar  
Clinical Specialist OT  
Vocational Rehab

**“What proportion of young stroke survivors change job after their strokes? It never occurred to me that I would but, 4 months post stroke and less than a month back into work and that’s the consideration. Am I alone or very common?”**

It’s difficult to answer this one because research findings really vary on work outcomes post stroke! One article I found useful is by Treger et al, (2007) called ‘Return to work in stroke patients’.

This is a review of studies of work and stroke, and it describes the following:

- one study in the USA found that 58% of respondents who did manage to return to work acknowledged that their jobs required modification;
- one study in Taiwan found that 12.9% of respondents had returned to work on a limited basis, 17.3% had partially returned, and 27.4% had returned to full time work;

Studies suggest that being in a ‘white collar job’ indicates more success at returning to work - possibly because of less physically demanding roles.

I think that if someone has managed to return in some capacity then that is a good outcome and adjustments made initially may not need to be permanent, depending on the nature of the work and the nature of the difficulties they experience post-stroke. For example, initially returning on shorter hours and then increasing the hours, getting transport assistance initially and then managing on your own as your mobility changes. If there are good management and HR structures in place then these things should be modifiable/negotiable as needed, and changed as needed.

People should make sure they’ve got access to all the resources they need, for example **Access to Work**, which can fund things such as specialist equipment, transport and even support workers. Info on Access to Work is available at [http://www.direct.gov.uk/en/DisabledPeople/Employmentsupport/WorkSchemesAndProgrammes/DG\\_4000347](http://www.direct.gov.uk/en/DisabledPeople/Employmentsupport/WorkSchemesAndProgrammes/DG_4000347) or via your local JobCentre Plus office.

You also state that you have returned to work 4 months post-stroke. Four months is a relatively short time in terms of rehabilitation post-stroke, so potentially there is still scope for change that will influence what you can do at work in the future.

Please note that comments expressed are based on the information provided and are necessarily general in nature and therefore not intended to provide specific advice.

Ask the Expert

**Different Strokes carried out a survey of its members in 2000 to see what they felt about work after stroke. The results were:**

- 239 (48%) stated you would like to work but do not feel fit enough
- 135 (27%) returned to the same or modified job
- 11 (2%) became self-employed
- 31 (6%) obtained a different job than before their stroke
- 61 (12%) became students and/or did voluntary work
- 16 (3%) were unemployed
- 10 (2%) were not working before your stroke but are working now

If you are thinking about returning to work after stroke, or are considering options for retraining or volunteering, contact us for a copy of our **Work After Stroke** pack.

If you're currently on sick leave, one of the best tips is for you or a family member to keep in contact with your employer so you can plan a stepped return together once you are ready to do so. If you need modifications to your role, working hours, environment etc, these are "reasonable adjustments" and you are entitled to these under the Equality Act.

Our Work After Stroke pack also has separate sections for family and friends; employers; and health and social care professionals. Email [info@differentstrokes.co.uk](mailto:info@differentstrokes.co.uk) or call us.

## Do you have Neurological Questions?

The **Brain & Spine Foundation Online** at <http://www.brainandspine.org.uk/> has an A to Z of Neurological Topics and information sheets that will help answer your questions.

If you don't have access to the internet, call the **Brain & Spine Helpline on 0808 808 1000**. It's a service run by neuroscience nurses and other health professionals.



## Looking for local information and advice?

**DIAL UK** is a national organisation of 120 local disability information and advice lines run by and for disabled people. To find your local branch, go to <http://www.dialuk.info/> or call 01302 310 123. Or try your local branch of Different Strokes!

## Stem cell research and nutrition - research into how diet could play a role in stroke recovery

Until the early nineties it was believed that once development in the adult human brain had come to an end, no newborn neurons (nerve cells) could be generated after that point. It was even assumed by one of the greatest neuroscientists that *“Everything may die, nothing may be regenerated”* (Cajal, 1914).

But in the last 20 years there has been more and more evidence that the birth of new neurons is occurring in specific areas of the brain. These newborn neurons are obtained from neural stem cells, which are located in a few restricted areas. One of these areas is the “hippocampus”, which is involved in learning and mood. An increase of newborn neurons in this area of the brain is associated with improved memory and learning abilities as well as with a better mood, whereas a decrease is associated with poor learning performances and depression.

In stroke and traumatic brain injuries that have caused cells to die, more new neurons are generated from the patient’s own stem cells and some will travel toward the site of damaged areas. It is clear that the generation of these new cells migrating to sites of damage or injury represents an attempt by the adult brain to self-repair. If these new neurons are purposeful and their formation can be stimulated, a new treatment strategy might be developed for stroke in humans.

The use of the patient’s own sources for cell replacement offers several potential advantages. For example, the ethical concerns that have been raised regarding the use and manipulation of foetal tissue and embryonic stem cells wouldn’t apply. But there are problems with the use of patients’ own cells:

- the number of new neurons generated may be too low to compensate for the loss of the old ones
- the new cells that are produced may not develop into fully mature neurons, or may not develop into the right type of neurons, or may be incapable of integrating into the surviving brain circuitry
- the severity of damage at the individual sites of the brain injury may limit the regeneration process.

We therefore need a better understanding of neural stem cells biology to try to improve the effectiveness of brain self-repair. We also need to understand more about the processes that are specific to stroke. Once we understand these, we need to develop new tools that allow the easy and safe manipulation of the injured brain.

## Neurogenesis (birth of new neuron cells)

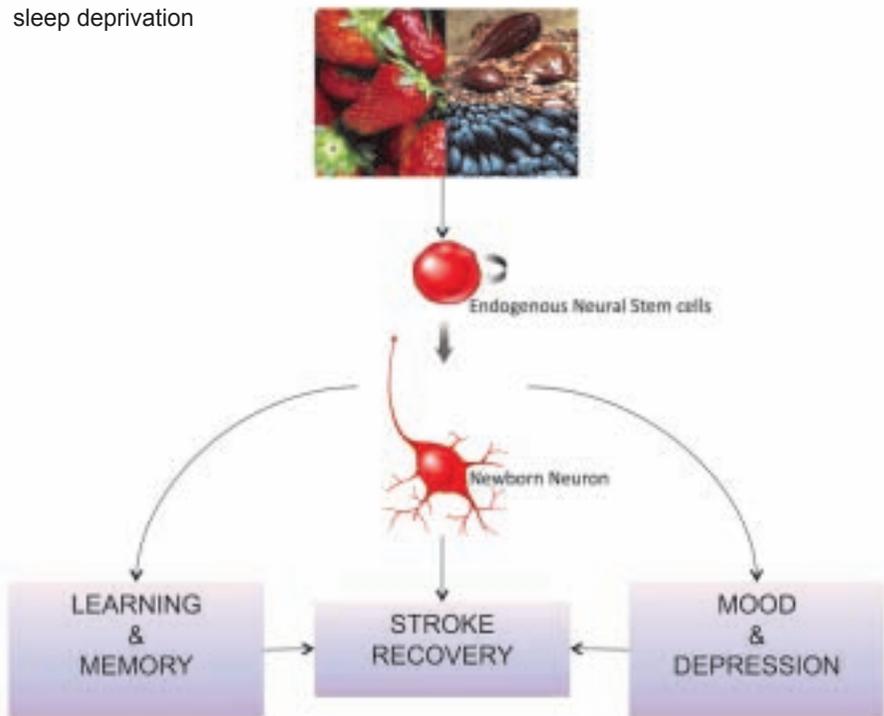
Several laboratories are working on stem cells, with only a few on stroke (Imperial College London being one of those few). Researchers at Kings College London have discovered that the environment can greatly affect the level of production of new neural stem cells.

For example, new cells being can be made to develop:

- in physical activity
- in the context of an enriched environment
- upon learning a new task
- in appropriate diet, e.g. it has been shown in laboratory animals that consumption of blueberries or omega-3 fatty acids extracted from fish will increase adult neurogenesis in the hippocampus area of the brain. It has also been demonstrated that a 30% reduction in calorie intake will lead to increased neurogenesis, whereas a high fat diet will lead to a decrease of neurogenesis.

In contrast, new neuronal cell development will decrease with:

- ageing
- stress
- sleep deprivation



## Stem cell research and nutrition - research into how diet could play a role in stroke recovery (continued from page 17)

There is some early evidence that diet could offer protection against stroke-related brain degeneration, but we have no evidence yet that changes would have a direct therapeutic effect if made after a stroke has already occurred.

However, it is particularly interesting and promising to note that zinc deficiency was linked with a low level of neurogenesis in laboratory animals, whereas a recent study has shown that a regular intake of 10 mg of zinc per day enhances the neurological retrieval of patients suffering from ischemic strokes.

We don't yet understand the processes by which diet can influence neurogenesis. Once we understand the neurobiological mechanisms that link nutrition with the generation of newborn neurons in the adult brain, we'll be able to recommend a specific diet to stimulate the formation of newborn neurons through nutrition to promote increased memory and mood as well as promote stroke recovery. However, it's too early to make any such recommendations yet.

Dr Sandrine Thuret, Kings College London

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## Do you have problems reading words on a computer screen? Text to Speech Software could help you ...

If you have **aphasia** and experience difficulty reading words on a computer screen, you may find that a Text to Speech software programme can help. Some programmes like BrowseAloud, Natural Readers, Read Please and Word Talk are available free of charge.



**Jerry: "I use BrowseAloud every day to help me with Word documents, pdf documents and websites. I move my cursor over the words and it reads them aloud to me. This makes it clearer for me and easier for me to do my work."**

**Jerry Johnson: [jerry@differentstrokes.co.uk](mailto:jerry@differentstrokes.co.uk)**

For more information on the free programmes that are available, go to:

- [http://www.browsealoud.com/page.asp?pg\\_id=80002&tile=UK](http://www.browsealoud.com/page.asp?pg_id=80002&tile=UK)
- <http://www.naturalreaders.com/index.htm>
- <http://www.readplease.com/>
- <http://www.wordtalk.org.uk/Home/>

Other programmes that are not free:

- <http://www.expressivo.com/>
- <http://www.nextup.com/TextAloud/>
- <http://www.readspeaker.com/>
- <http://www.texthelp.com/page.asp>

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## 2011 Different Strokes Conference Details

Date: **Saturday 15th October**

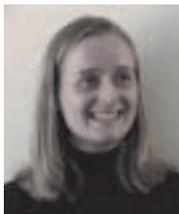
**"The Hidden Side of Stroke"**

### Keynote Speaker:

The Moira Lister lecture will be given by: **Professor Allan House**,  
Director Leeds Inst. of Health Science  
Prof of Liaison Psychiatry Leeds Univ

**Woodkirk Valley Country Club**  
**Leeds Rd**  
**Leeds WF12 7JL**

More details to follow



## Fundraising

A big thank you to everyone who raised money for Different Strokes in 2010. We already have some keen fundraisers who are in training for this year.

If you'd like to do some fundraising for us you can take part in a sponsored 5km event where you can run, walk or use a wheelchair. There are locations all around the country - contact me to find out more. There are also places still available for the London 10K run.

I can help you to organise an event such as a cake sale or a quiz or even a parachute jump if you are feeling brave! And there are many free ways that you can help Different Strokes. You can recycle your old mobile phones and printer cartridges - get in touch at the office and we can send you a freepost recycling envelope. You can also raise money every time you search the internet by registering with [www.everyclick.com](http://www.everyclick.com).

**Jo Lewis: [jo@differentstrokes.co.uk](mailto:jo@differentstrokes.co.uk), 0845 130 7172 or 01908 317618**



## **Beejal's Story - Living with aphasia**

Two years ago I had a stroke. I was on holiday in India, visiting for a wedding. I couldn't speak at all and I couldn't move my arm. It was devastating and so unexpected. I was 22 years old. Fit and healthy and just starting on my career as a trained optometrist – I just couldn't believe it.

I had three weeks in hospital in India. Then, there was another week in hospital in England. With the help of physiotherapists and occupational therapists my physical disability gradually improved. And thank goodness I had the support of my family who were there for me throughout.

### **My words had gone missing**

But in spite of this support, I still had aphasia. My words had gone missing! I found it hard to remember the right words, I found reading and writing a challenge. And I had lost my confidence. I went back to my job but it didn't work out – it was too early. I was very concerned about how I would ever return to a normal life. I had no support and people didn't understand what I needed to help me. That's where **Connect** came in.

### **Support and understanding**

My speech and language therapist suggested I go to 'Drop-In' at Connect's London centre. Here I met, for the first time, other people with aphasia. It was a huge comfort to meet other people just like me who have aphasia. Some people have quite severe aphasia and can only say a few words. Others have more fluent speech but have totally lost their confidence. Here I found support and understanding and it was somewhere I could relax and be myself.

### **Joining in**

Soon I joined in other things and began to help with the newsletter 'Aphasia News' which is written and designed by people with aphasia. It was something to focus on and became a stepping stone to getting back to work. It was fun working with the team and thinking of articles people with aphasia would be interested in.

## More confidence

Last year Connect asked me to get involved with training health professionals. I spoke at a big conference called the UK Stroke Forum conference. I talked about my experience of having 'goals' set to help me get better. It was to help people see how services can be improved by listening carefully to what people with aphasia want. I was very nervous but Connect helped me prepare and we practised so I felt comfortable. I was so pleased I did it and it gave me more confidence.



Beejal Mehta (right) and Ken Cording at Drop-In

I am thrilled that I am now back working part-time in optometry. It is not the same job as before and it is still quite a challenge. But it is a start. I am also starting on a course to help me do a degree in Psychology. I still come to Connect to help and to keep in touch with my friends there. I receive the free newsletter and I get regular updates through Facebook. Connect have helped me to fill that gap after leaving hospital and help me to reconnect. I would recommend Connect to anyone with aphasia!

**Beejal Mehta, who has aphasia**

**Connect is a charity for people living with aphasia. We welcome all ages.**

**Information**

**Conversation groups**

**Counselling**

**Support**

**Befriending**

**Art workshops**

**Drop-in**

**Conversation-partner schemes**

**Aphasia Hubs**

### Contact details for Connect:

16-18 Marshalsea Road, London SE1 1HL

Tel. 020 7367 0840

[www.ukconnect.org](http://www.ukconnect.org)

[www.facebook.com/connectaphasia](http://www.facebook.com/connectaphasia)

[www.twitter.com/connectaphasia](http://www.twitter.com/connectaphasia)



**Ranj Parmar**

## Meet Our Volunteers ...

### Ranj and Andi

“My name is Ranj Parmar. I suffered a subarachnoid haemorrhage in September 2009. When I left hospital, I felt very isolated and alone, almost left to get on with my rehabilitation. This struck me as being very odd, and thanks to a colleague of mine from work, I discovered Different Strokes.



**Andi Clay**

Now, in conjunction with a friend of mine, Andi Clay, we have started up a group in Southampton. With the support of Different Strokes, we now have bi weekly meetings at **Semal House** where members can come and discuss their issues, get support and help us to move the group to the next level.

The group is aimed at people that have suffered a stroke. We also welcome carers, and anyone that wants to know more about strokes. We are currently deciding what services we will be able to offer, how frequently and in what capacity - so if you have any thoughts or recommendations please contact us.

Our main goal is to provide support services for stroke survivors in the Southampton area. We want to work with local groups and communities in order to better support these folks. In addition to our regular bi weekly meetings, we will be hosting outings and events for stroke survivors - enabling them to have a better quality of life.

We look forward to seeing you at the regular meetings at Semal House Resource Centre, Handel Terrace, Southampton SO15 2FH.

Contact us on: **Ranj Parmar - 07703 503252** or **Andi Clay - 07817 874440**

Email: [southampton@differentstrokes.co.uk](mailto:southampton@differentstrokes.co.uk)

**There are lots of volunteering opportunities around the country. If you'd like to get involved, email [volunteering@differentstrokes.co.uk](mailto:volunteering@differentstrokes.co.uk) or call us (see back cover)**

## Tips from other members ...

Check out <http://www.mumswithdisability.co.uk/> - a site for Mums to share experiences and offer advice. Anna bought a Rotato Express from the Gadgets section - a potato/fruit peeler that can be used with one hand. “I'm so excited I can now eat oranges as the gadget peels them for me!”

Pat: “If gardening was your hobby and you want to get back try this excellent place: Thrive”  
<http://www.thrive.org.uk/>

If you have any tips to share, please email [newsletter@differentstrokes.co.uk](mailto:newsletter@differentstrokes.co.uk) - thanks!



## Group Development - Regional Update

Well, 2011 is well and truly here and thank you to everyone who helped us to achieve such a great deal in 2010! We opened a further 8 groups with the help of some wonderful volunteers, which means we now have a total of 50 Different Strokes groups throughout the UK.

Naturally, with your help, I'd like to achieve the same if not more for this coming year! The existing exercise and support groups provide valuable and vital support systems for stroke survivors and carers once they are discharged home from hospital, together with ongoing rehabilitation in the form of exercise. In some instances groups also offer communication support and a range of other therapies.

Currently I am working with some enthusiastic, lovely volunteers to get exercise groups up and running in **Hemel Hempstead**, **Luton** and **Watford**, so watch this space.

It would be fantastic if we could extend our reach even further throughout the UK to provide more exercise and support groups for stroke survivors and carers where currently there are none. Examples of locations where groups are needed include: **Blackpool, Cardiff, Derby, Doncaster, Dundee, Edinburgh, Exeter, Kent, Liverpool, Nottingham, Sheffield, Stafford, Taunton, and York** and I'm sure there are many other places that I haven't mentioned. So if you live in any of these towns or cities, or anywhere else where we currently don't have a group and you are interested in volunteering your time to give something back to stroke survivors and carers, please get in touch. During the process of setting up a group, and also when you're up and running you'll be given as much or as little support as you need. I'll help you with a range of tasks including looking for a venue, a suitable exercise instructor, and the promotion of the group to stroke survivors and the healthcare sector. Together, we'll look to identify other volunteers to help you with setting up and running the group. You won't be required to take the exercise class itself, as your role will be to act as a point of contact.

We also have volunteering opportunities for stroke survivors based in the **Coventry** area who would like to help represent Different Strokes and the patient's view to health and social care professionals at local level. If you're interested, get in touch for more info.

Volunteering for Different Strokes is fun, rewarding, and fulfilling, and by giving something back and being compassionate this not only improves self esteem, but also increases levels of confidence, and general feelings of wellbeing.

**Lorraine Ayres: [lorraine@differentstrokes.co.uk](mailto:lorraine@differentstrokes.co.uk), 0845 130 7172 / 01908 317618**



Why not receive your newsletter by email? This not only saves Different Strokes the cost of printing and postage but saves the environment too! Just email [newsletter@differentstrokes.co.uk](mailto:newsletter@differentstrokes.co.uk) and ask to be added to the email mailing list.

**Different Strokes** was established in 1996 **by** younger stroke survivors **for** younger stroke survivors.

**Different Strokes** aims to enable younger stroke survivors to optimise their physical and psychological recovery, take control of their own lives, regain as much independence as possible and move on to live a full, active and fulfilled life.

### Contact us:



Different Strokes, 9 Canon Harnett Court, Wolverton Mill, Milton Keynes MK12 5NF



01908 317618 or 0845 130 7172



info@differentstrokes.co.uk



**Website:** [www.differentstrokes.co.uk](http://www.differentstrokes.co.uk)—visit our **message board** to make contact with other members, offer advice and share tips and strategies for coping and maximising recovery. Also visit the website to download copies of our info pack



join the Different Strokes group on <http://www.facebook.com> to make online friends and share experiences

**Exercise Classes:** to find your nearest Different Strokes exercise class please contact us or visit [www.differentstrokes.co.uk](http://www.differentstrokes.co.uk) and see Regional Information

**Different Strokes has become one of the first organisations to have obtained the Information Standard accreditation. The scheme set up by the Department of Health helps the public identify trustworthy health and social care information easily.**

**We have gained the quality mark for our information pack and are now in the process of reformatting it to ensure that it is:**

- **Accurate, impartial, balanced, evidence-based, accessible, well-written**

**If you'd like to help with the process by providing feedback as part of a focus group, email [eileen@differentstrokes.co.uk](mailto:eileen@differentstrokes.co.uk) or call and ask to speak to Eileen.**

