

STROKE news

Life after stroke

Why Christmas
is so important to
Daniella Gonzalez

New series

Money Matters

Latest research

Improving mobility after stroke

Health note

Occupational therapy –
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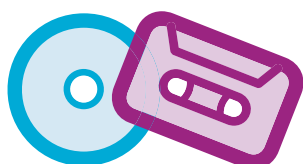
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Welcome...

to the winter issue of *Stroke News*

Our cover star Daniella Gonzalez was in her early thirties when she had a stroke, which left her with speech and mobility difficulties. She proves that rehabilitation really is possible and that seemingly small steps can make a huge difference in helping to rebuild confidence. This Christmas, she's celebrating writing her

own Christmas cards. Who knows what this time next year will bring?

As the leading UK-wide stroke charity, we understand the needs of people affected by stroke. That's why we're re-branding our services to make them easier to access, and to commission by local

healthcare authorities (see page 16). We hope that by next Christmas, more people than ever will have access to our services, giving them the confidence and independence to enjoy life after stroke.

Zoë Beer,
Editor *Stroke News*

Volunteer spotlight

Keith Emmerson



Keith has been volunteering since April, when he spotted a call-out for help on the website www.facebook.com. He spends three days a week helping The Stroke Association to build up its social networking presence on websites such as Facebook, Twitter, My Space, Bebo and more. 'What I do isn't volunteering in a traditional sense' he says.

Keith works to help stroke survivors to connect with each other and share information online. He responds to any questions visitors may have and signs up new members. It's a great way to link together stroke

survivors, families and carers,' he says. 'A lot of people join because someone they know has had a stroke and they want to show their support or ask questions,' explains Keith. 'Sometimes they just want to talk. People can share some really touching stories and everyone else always rallies round, which is brilliant.'

Keith also helps with The Stroke Association website, www.stroke.org.uk. 'I really enjoy the website – you see what you've created and that it makes a difference.' Keith proves that there are many ways to help by volunteering – as he puts it, 'everyone has something to give'.



Dear Stroke News...



Life after stroke

I would like to share Peter's story. I am sure you will find him an inspiration and positive role model to all. Peter Walton had a stroke 18 months ago resulting in aphasia. His wife Pat has been extremely supportive of his recovery to independence. Peter organised a local golf event at Ashton-on-Mersey Golf Club. He arranged golf matches and an evening reception. It was a huge success, raising £600 for The Stroke Association and valuable awareness in his local community.

Peter has shown great strength and courage overcoming the 'hidden disability' aphasia. I am so proud of the progress he has made. He proves that there is life after stroke!

Lorraine Longmore, Trafford

Editor: Congratulations Peter for proving aphasia can be overcome to achieve great things.

Beating my pain

I too was suffering severe pain three years ago after my stroke (autumn *Stroke News* letters) but with a lot of trial and error from my neurologist and GP I have found a drug that helped to keep the pain under control.

Valerie Allen, Romford

Editor: We can't publish details of Valerie's medication but if you're suffering from pain after stroke, we urge you to continue seeking help from your doctors, as Valerie has done.

Wheelchair debate

TV period dramas show wheelchairs with their small trolley-type wheels conveniently at the back. I don't have a luxury of a live-in pusher (who has?). Would it really cost too much to return to this better design?

Lesley Boyde, Isle of Man

Editor: You might find our article about new research into wheelchair designs (page 28) of interest.

Raising awareness

In your Dementia health note (autumn *Stroke News*), you mention multi infarct dementia. The symptoms for this appear similar to those for Cadasil, a systemic vascular disease, which also causes stroke.

My wife and two daughters all have this condition. Only a few hundred cases have been confirmed in the UK, although

I'm sure there are a great many more who have not been diagnosed. If more people were confirmed as having Cadasil, this may influence the amount of research being done into it.

Mr R G Pritchard, Worcester

Editor: Does anyone else have experiences of Cadasil? If so write into Stroke News and share your story.



If you would like to write to *Stroke News*, send your letters to: **Stroke News, The Stroke Association, Stroke House, 240 City Rd, London EC1V 2PR** or email: **strokenews@stroke.org.uk**

Letters may be edited and unfortunately we are unable to respond to or publish every letter we receive.

Stroke helpline

If you have a specific question about stroke, call our helpline: **0845 3033 100** or email **info@stroke.org.uk**



Community Voices

Do you volunteer as a patient or carer representative for stroke, attend NHS meetings or reply to surveys sent out by your local hospital? If so the new *Community Voices* project should interest you. It aims to empower stroke survivors and carers to positively influence local stroke services across England.

Why is this project needed?

Many volunteers give up their time to advise health services on how they can improve stroke services. Patient and carer representatives provide vital information and without them stroke services would not reflect the real problems people face.

However, patient and carer engagement around England is patchy. Some health services may be weak at recruiting representatives or not using them effectively. We want to ensure methods are used to

recruit different types of people with different experiences.

By the end of the project more NHS organisations should be using stroke survivors and carers effectively.

How will it work?

Firstly we'll conduct a survey of existing and potential patient and carer representatives. Then next year we'll arrange a series of three regional events and an online forum for people to share their experiences. Finally, we will produce a guide for patient and carer representatives. We want

to show that this kind of work can be fulfilling, empowering and influence important decisions. It can also be undertaken by stroke survivors of any age or their carers and by those with aphasia.

How can I get involved?

We are undertaking a survey to find out more. If you attend NHS meetings about stroke and would like to tell us about your experiences, please email campaigns@stroke.org.uk with your name, phone number and contact details.

Britain's **KINDEST KID**



© Five News



Congratulations to 11-year-old Harry Elson, who reached the finalists for this year's Britain's Kindest Kid competition last month. Harry cares for his mum, Andrea, after she had a major stroke. He also volunteers at his local Communication

Support Group and has even raised awareness of stroke at his school. Here he is meeting the Prime Minister at No.10 Downing Street. Although he didn't win the competition, he's certainly won our hearts.

FASHION FUN

Good news for fashion fans. Stroke Awareness fashion shows are continuing to sweep the country, with the latest show going down a storm in Knaresborough, Harrogate. Among the 20 stroke survivors that took to the catwalk was Janet Stuart, a keen seamstress before her stroke who has since learnt to sew using one hand. Janet made her own outfit for the show, and 150 supporters came along to spur on the budding models. All were members of The Stroke Association's Communication Support Service. Jenny Jones from The Stroke Association says, 'The show gave people



the chance to take to the limelight, build confidence and enjoy themselves.'



Shouting from the rooftops

Deborah Blythe, from Birmingham, has reached new heights in spreading the word about stroke. She topped a plinth in Trafalgar Square as part of a living art project by artist Antony Gormley. Hundreds of people took it in turns to top the plinth for one hour each. Deborah used her time on the plinth to support The Stroke Association by showing a collection of images of stroke survivors. 'I lost both my grandmothers to stroke so this charity is very near to my heart,' says Deborah.

Fancy a new year's resolution?

Why not take up our rowing challenge for *Stroke for Stroke* week? We're looking for people to get rowing this January to raise money for The Stroke Association. You can row on your own or in a crew, on water or even dry land. Visit www.strokeforstroke.co.uk.

Coming together

This month, over 1,000 health professionals will attend the 4th UK Stroke Forum Conference – we find out what's in store

What's the conference all about?

Hosted by The Stroke Association, it's the largest UK multidisciplinary stroke conference of the year.

Who's it for?

Anyone who works with stroke – doctors, nurses, occupational therapists, speech and language therapists, geriatricians, physiotherapists, stroke physicians, clinical psychologists and more!

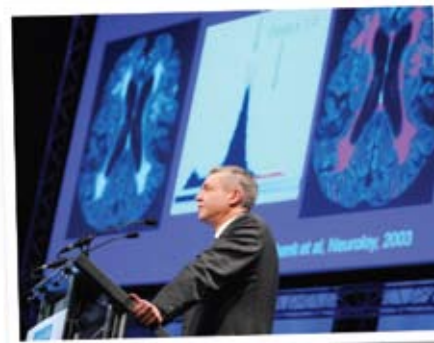
Where and when?

1–3 December at the Scottish Exhibition and Conference Centre, Glasgow.

So what happens?

People who work in the field of stroke come along to share ideas and continue their professional development. It's an opportunity to hear about the latest developments in stroke care, research, service development and delivery.

'This is our fourth year of running the UK Stroke Forum Conference and it looks like it's going to be our biggest yet,' says Sally Atkinson, Forum Co-ordinator, 'It's always good to see so many stroke experts come together in one place to share ideas and experiences and make a real difference for the lives of people and their families who live every day with stroke.'



UK
STROKE FORUM

Hosted by



How can I find out more? Visit www.ukstrokeforum.org or call 0845 521 2505.

Can you help?

We are looking for people affected by stroke to help us review our publications. If you are interested in taking part, send your name, address, telephone number and email address to: **Stroke Information Service, Stroke House, 240 City Road, London EC1V 2PR** or email: info@stroke.org.uk and we'll be in touch.



Know Your Blood Pressure 2010

Did you know that 40 per cent of strokes could be avoided by controlling high blood pressure?

That's why each year The Stroke Association runs the *Know Your Blood Pressure* campaign, to raise awareness and offer free blood pressure tests. We're calling on individuals, clubs, groups and organisations to arrange blood pressure testing events in their local area. By joining in, you can help us to spread the word that strokes can be prevented.

Planning is already underway for next year's campaign. Why not help to prevent stroke and raise

awareness by organising your own blood pressure testing event? *Know Your Blood Pressure Day* events will be taking place across the country on or around Saturday 17 April 2010. You can register to hold an event by visiting www.stroke.org.uk/kybp or calling **01604 687 720**. We'll provide you with advice and guidelines for your event, plus promotional materials to help you spread the word.



Learning from the experiences of stroke survivors

'Nothing tells a story more powerfully than people themselves'



Stroke survivors in Scotland may soon have more of a say in the care that they receive. The Stroke Association in Scotland is working with NHS Forth Valley Health Board to gather people's personal stories of

stroke. They're hoping to build a better understanding of the needs and concerns of stroke survivors in the area.

We think it is vital to listen to people's experiences of the hospital care they receive, and what life is like after being discharged and returning home. Already many people have talked about the importance of emergency care, their fear of having another stroke and the anger and frustration they have felt.




Charlotte Lee, from the The Stroke Association Scotland, says 'The information we collect will help work out what's working well and not so well. Nothing tells the story more powerfully than people themselves.'

If you are from Scotland and would like to tell us your story, call **0131 555 7244** or email Scotland@stroke.org.uk

Life after stroke

For stroke survivor Daniella Gonzalez, Christmas isn't just about the gifts or carols. Every year she charts her recovery and this year will bring some very special milestones.

Written by – **Richard Mountford**

 Christmas is an important time of the year for most people, but for 36-year-old stroke survivor Daniella Gonzalez, it will forever be a key landmark in her life 'I was with my partner in my flat in London. I was packing to go to Madrid to see my family for Christmas. My partner went to the bedroom and found me lying on the floor. He tried to talk to me but I did not respond, and that was when he called 999. The ambulance came within five minutes and I was taken to hospital.'

Daniella's stroke was three years ago this Christmas and she sees each 'anniversary' as a measure of the fantastic progress that has been made in her recovery. 'This will be the first year that I have written Christmas cards. My handwriting has been slowly getting better and even though I find it very tiring to write, I am determined to put a few short messages in cards for those special friends and family'. Daniella describes intently how she, and partner Chris, notice small improvements in her speech and mobility in comparison to the previous festive period. →





'This will be the first year that I have written Christmas cards. I am determined to put a few short messages for special friends and family'

'I found after my stroke that I was able to sing old songs that I'd learned as a child more easily than I found speaking'



'The first Christmas after my stroke was when we noticed the most improvement, but every year Chris always points out how my speech is getting better and better'.

Daniella has even been able to resume her interest in music and singing over the last 12

months, having joined her local Bath Chorus back in January. 'From a young age I have always been in choirs as I come from a very musical family. I found that after my stroke I was able to sing old songs that I'd learned as a child more easily than I found speaking.'

This Christmas sees a particularly special occasion for Daniella and the Bath Chorus as they are performing a concert with world-famous soprano Hayley Westenra. Impressively, Daniella doesn't seem worried about performing with one of the world's most famous opera singers, 'I'm very excited about singing with such a beautiful voice as Hayley's but I'm not nervous, no. For me, singing with my friends in the choir is always exciting and we will all have done lots of practice for the concert.'

Daniella's interview this issue is not her first dealing with the media.

She has appeared on *Five News* to talk about the incidence of stroke amongst young women as well as being interviewed for *Good Housekeeping* magazine.

Since participating in an Exercise and Lifestyle Group in Bath, Daniella has gone on to become a regular volunteer within the *Life After Stroke Services* network. 'Volunteering was for me the next step. I am involved with a really great group where I have made lots of friends and I understand the frustration they sometimes suffer. But you have to keep going and stay positive'.

Daniella's stroke was due to a blood disorder called hughes syndrome (commonly known as sticky blood syndrome). According to the Hughes Syndrome Foundation, the condition accounts for approximately one in five deep vein thrombosis (DVTs), one in five strokes in people under 45 and one in five recurrent miscarriages. 'Not too many people have heard of hughes syndrome even though lots of people carry the gene,' says Daniella, who is keen to raise awareness of the syndrome.

Christmas is of course a time for meeting up with family and friends, and this year will be no different for Daniella. 'Where as maybe a few years ago I was running round making Christmas dinner and mince pies, now it's not so easy, but it is important to stay positive and still have fun with everybody,' says Daniella with a smile.

Hughes Syndrome

If you'd like to find out more about this condition, visit www.hughes-syndrome.org or call 020 7188 8217.