

# StrokeNews

SUMMER 2013 Volume 31.2

## A dramatic return

Edward Petherbridge returns to the stage

## Life After Stroke Awards

Read our winners' inspiring stories

## Celebration funds

Our wedding gift to our dads

# Charlotte's victory

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**Stroke**  
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Editor **Jane Butler**  
Design **Rick Nicholls**

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# Welcome...



I hope you're enjoying the summer so far. Fingers crossed for more sunny weather! If you're gearing up for a trip away, you can get some top travel advice from other readers on page 4.

In this issue we're reflecting on our annual Life After Stroke Awards – a star-studded event that celebrates the achievements of stroke survivors and their carers. For a snapshot of the winners, see pages 11-14 and turn to page 8 to read 8-year-old

Charlotte Neve's incredible experience, our cover feature.

Like Charlotte, Stuart Hepburn and Leah Batchelor have found extraordinary strength to break through the barriers of locked-in syndrome. You can read their stories on pages 15 and 17. This issue also takes on a thespian feel with veteran actor Edward Petherbridge's return to the stage. Remembering every line of King Lear following his stroke, he returns with remarkable energy and charisma (see page 16).

And on page 21, Annabel Jones recalls how her stroke was initially dismissed as just a migraine. Now she's not only returned to work, but she's also a stroke ambassador. Annabel's determined to spread the word that anyone can have a stroke at any time. In this issue, we pay tribute to everyone who has overturned expectations to prove there's light at the end of the tunnel. I hope you enjoy reading this issue.

**Jane Butler**  
**Editor, *Stroke News***

## Volunteer spotlight

### Sophie Johnston

Sophie Johnston has been helping stroke survivors since her teens. 23-year-old Sophie, from Belfast in Northern Ireland, began volunteering for us six years ago. It was her interest in speech and language therapy that led her to work with the Stroke Association before taking up her studies at Manchester Metropolitan University.

On her return to Northern Ireland as a speech and language therapy graduate, Sophie once again contacted the Stroke Association and now regularly helps stroke survivors communicate, as part of speech and language

therapy programmes. As well as developing her practical skills and knowledge of speech and language therapy, Sophie enjoys helping people with aphasia. "I really look forward to meeting the members each week and supporting them to use different communication techniques to get their message across," says Sophie.

Sophie is also a keen fundraiser and helps out at many of our awareness-raising events. And if that's not enough, she also chairs the reference group of the Stroke Association's Northern Ireland committee. "Sophie has been a true asset to our services," says

Janice Kirkpatrick, Operations and Projects Officer. "Her commitment to supporting stroke survivors with aphasia has been outstanding."



# Dear Stroke News

## Great service

In March, my husband and I arrived at Gatwick for our Easy Jet flight to Montpellier. My husband is registered disabled and develops pain in his legs if he walks more than 20 metres. He has had a stroke and has an ongoing serious heart problem, but looks slim and well, so people don't see that he needs help and he is too proud to ask. I can only manage one suitcase when we travel, so we had struggled from the drop-off point up the lift to the entrance, when I saw one of Gatwick's assistants with a wheelchair. I stopped and asked him if he could help us.

Not only did he do so, but he took my case and looked after us right through all the queues in check-in and security. Then he took us to the departure pick up. Dave really cheered us up at the start of our holiday. The men on security were also friendly and smiling, something we have not seen before. I really cannot praise everyone enough because this cheery and helpful service continued right to the plane. Every kindness shown by airport staff and the airlines is very much appreciated by both of us.

**Carol Edgar**

## Backpacking adventures

Doing something and going somewhere completely different relaxes me. I had a stroke aged 21. It left me unable to do anything for myself, but I have since recovered full independence. A few years later, an acquaintance told me of her backpacking travels. These experiences excited me.

For over 10 years I have embraced this style of travelling, mainly through the developing countries of Latin America, Asia and Africa. I have seen amazing sights but it is the interactions with locals that I love. I met a man in Ghana and another in Indonesia who both had strokes and recovered well despite a lack of resources. For me, completely new experiences are exciting, satisfying and ultimately relaxing. I recognise my style of travelling is unlikely to suit many readers, but the idea of going somewhere different might.

**Elizabeth Heywood**

## Go for it!

I had my stroke in 2000 (aged 68). In 2001, I decided that I still had the urge to see more of the UK and many places worldwide. I have now reached the ripe old age of 81 (years young) and will continue travelling as long as I'm physically able. My advice is 'Go for it!' – there's a big, wide, interesting world out there. Plan your trips, accept the help and kindness of your fellow travellers and make sure you get wheelchair assistance at the airport if you need it.

**Michael Duffin**



## Hot topics

**Your experience of TIA/mini stroke**

Over the coming months, we'd like to find out more about how mini strokes have affected everyday lives, how you first knew you were having them, what action you took, the treatment and support you received and whether it met your needs.



Please write to us with your name, address and contact number at

Campaigns Team  
Stroke Association  
Stroke House  
240 City Road  
London, EC1V 2PR

or you can email us:  
**[campaigns@stroke.org.uk](mailto:campaigns@stroke.org.uk)**



## Gifted Jess finds freedom in art

38-year-old mum of two, Jess Thacker, from Exeter, is one of 50 stroke survivors who showcased her artistic talents in an exhibition called Stroke of Genius earlier

this year. Organised by the Stroke Association, it showed how it's possible to overcome disabilities caused by stroke and create stunning pieces of art.

Jess has constant pain in her hands, arms, legs, chronic fatigue and problems with balance when she is in a noisy or busy environment. When she wasn't at work as a teacher or looking after her family, she used to make films and enjoyed painting and sculpting prior to her stroke.

"I had to retire and my husband and mother had to look after me. My two daughters were scared and frustrated with me and we felt like we were being unpicked financially, socially and emotionally," explains Jess.

"The art helps to exorcise it from my system and enables me to start to move on."

Jess's art is something that broadens her world and helps her get in touch with other people again: "Art is one of the ways forward I can see for my future."

## Our wedding gift to our dads

### Sue's story

"When Steve and I were planning our wedding, the question of gifts came up in conversation. When you have all the toast racks and towels you need, there's not much else to ask for. If somebody could wave a magic wand and bring both our dads back, that would be our gift. But they can't. Steve's dad, Sid, died from a heart attack 30 years ago and my dad, Bill, died from a stroke seven years ago. Therefore, instead of asking for wedding presents, we decided to ask for donations to help others cope with the same conditions that cost them their lives.

The money raised might even prevent another bride walking up the aisle without her dad. Our family was devastated to lose someone so loved.

This fund, whether it's in celebration of an event or in somebody's memory, is about giving back to the people who are trying hard to beat this condition and supporting those who are living with it. That's why Steve and I decided to ask for donations rather than a gift. But in some ways it is a gift – one which is more useful than a toast rack."



Sue and Steve got married in May

To find out more about our Celebration Funds, visit [stroke.org.uk/fundraise/give-celebration](http://stroke.org.uk/fundraise/give-celebration), call Jackie Parnell on 01604 687783 or email [jackie.parnell@stroke.org.uk](mailto:jackie.parnell@stroke.org.uk)



# Life After Stroke Grants

## Stroke Association Life After Stroke Grants help stroke survivors experiencing financial hardship.

Stroke survivor Neil Kemp, who is from Sunderland, was granted a cooker and washing machine, as he didn't have any appliances in his new flat. "The grant was a big help. I didn't know these sorts of things were available until Ally from the Stroke Association told me," says 48-year-old Neil. "Having a cooker and washing machine has given me much more independence and I've gone from strength to strength."

The grant is a one-off payment, usually up to £300, and helps to pay towards what is most needed such as a fridge, a UK holiday, payment of gas or electricity bills, clothing, specialist



armchairs or even driving lessons following stroke. Although competitive, the process for applying is now quicker because decisions are made at a local level. Available throughout the UK, they are funded by donations to the Stroke Association and make a huge difference to people's lives.

For details of available grants, ask your health or social service professional to visit [stroke.org.uk/support/life-after](http://stroke.org.uk/support/life-after), or ask your local Stroke Association Co-ordinator.

## In brief

### Improving care

At the Stroke Association, we are delighted to announce our partnership with Balhousie Care Group. We'll be working with the care homes provider in Scotland to raise awareness of stroke, with accredited training on stroke for their staff. Balhousie staff will be working hard to raise funds to support our work in Scotland.

### Research

Are you interested in helping us choose the research we fund? To find out more about joining our research review panel, please visit [stroke.org.uk/research/get-involved](http://stroke.org.uk/research/get-involved) or email [research@stroke.org.uk](mailto:research@stroke.org.uk).

### Equip stroke

We've launched a colourful new self-help guide to help you assess how you can improve your life after stroke with aids and equipment. Take a look at [stroke.org.uk/dailyliving](http://stroke.org.uk/dailyliving)

## Could you be a Lay Reviewer?

Would you like the opportunity to influence stroke care? The UK Stroke Forum is offering stroke survivors and carers the chance to do just that.

We're looking for people who have been affected by stroke to help us with one of our projects, UK Stroke Forum Education and Training. We assess training and education against the Stroke-Specific

Education Framework (SSEF). The role involves advising applicants on how to include stroke survivors and carers in the design, development and delivery of training courses and events about stroke.

One of our Lay Reviewers says: "Stroke survivors want to be assured of the best attention from all the health professionals who contribute

to stroke care and therapy. Our critical evaluation of new education programmes is vital to ensuring continued high quality."

Why not join us and use your experience to improve stroke training and education in the future? For more information call the team on **01527 903904** or email [ukfst@stroke.org.uk](mailto:ukfst@stroke.org.uk)

# Feeling overwhelmed

Our latest report, *Feeling overwhelmed*, features the stories of nine people, who share their personal experiences of the emotional impact of stroke.

Many of us are aware of the physical impact of stroke, but the emotional difficulties that follow stroke can be just as hard-hitting. Last autumn, we surveyed people affected by stroke to find out how much they have suffered emotionally – the results reveal a shocking shortfall in emotional support across the UK.

Patricia Rodney (pictured) had a high-powered job and was temporarily signed off work due to a lung condition when she had her stroke. She had left-sided weakness and speech difficulties, but healthcare professionals didn't appreciate the emotional impact of her stroke. "I was expected to go it alone in a depressed and debilitated state," says Patricia. Back home she felt she had to "wear a mask" around her family as it was so difficult to talk about what had happened. She now writes poetry as a way of expressing her emotions, and she is being helped through counselling.

Sadly, we found her story is not unusual. The 2,700 responses to our survey highlighted that stroke survivors experience high levels of anxiety (67%) and feelings of depression (59%). For many people the reality of their stroke doesn't hit them until they are back home, sometimes months later. By this time, people don't know where to turn to get the information, advice or practical support they need to cope.

Carers of stroke survivors are also suffering. In our survey, 64% said that the emotional impact of stroke was the hardest thing to cope with. Levels of anxiety and depression are as high for carers as for stroke survivors.

We're now working to ensure that when stroke survivors and carers are assessed, they are asked about the physical and emotional effects of their stroke. We're working with healthcare professionals so that people know about all forms of available support such as Stroke Association services, the Stroke Helpline and our website, [stroke.org.uk](http://stroke.org.uk).

For a copy of *Feeling overwhelmed* call 020 7566 0300, or read it online at [stroke.org.uk/feeling-overwhelmed](http://stroke.org.uk/feeling-overwhelmed).



# Charlotte's miraculous recovery

With her family in the audience and her teachers on standby to help, 7-year-old Charlotte Neve took to the stage to narrate her school's Christmas nativity play. It's almost impossible to believe that eight months earlier, Charlotte was lying in a coma after having a series of massive strokes.

**C**harlotte performed her lines perfectly – marking a huge step forward in her recovery following her ordeal.

One night while sleeping, she suffered a large brain aneurysm which led to a series of massive strokes. After being in a coma for two days, she was rushed into surgery. The surgeon explained to Leila, Charlotte's mother, that there wasn't any specific treatment for childhood strokes. He would have to do everything he could using adult treatment and medication in smaller doses. Charlotte then had two life-

saving operations. When she woke up afterwards she was completely locked-in. She had no reactions and couldn't move or blink and the doctors told Leila they didn't expect Charlotte to ever recognise her again. The outlook was very bleak and Charlotte's family was told to expect the worst.

Having been told to say her final goodbyes, Leila climbed into her daughter's hospital bed to cuddle her for the last time. Adele's Rolling in the Deep started playing on the radio, their favourite song, and she started singing it to her daughter. ▶









**"Charlotte will never be told she is incapable of achieving anything."**

Miraculously, Charlotte began to smile. "Doctors told me to say goodbye and I thought I was going to lose my little girl... she was wired up to machines and unresponsive," says Leila. The nurses felt that this was the moment her mother 'unlocked her'. "The nurses were astounded and told me to keep singing – and she smiled again."

From this point on Charlotte's recovery has been incredible. From being unable to blink, swallow or even produce saliva, within a few days Charlotte started to sit, speak and laugh. "I could see she needed to be stimulated," Leila explains. "I needed her to hear things, I needed her to see things, I needed her to feel things as much and intensely as possible and, bit by bit, she came back."

Charlotte had to relearn every single thing she had spent seven years learning: speaking, eating, walking and even recognising

people, including her own mother. "The doctors have stopped telling us what she should be able to do – because she has amazed them so much," says Leila. "She sat relentlessly repeating sounds to relearn her reading and writing and is determined to be at the top of her class again."

Twelve months on, Charlotte has also regained partial sight and has returned to school and dance classes, which she loves. "She went back to school for one hour a day and still has occupational therapy and speech therapy, which is helping," says Leila. "Music is a big part of her life. She loves singing and dancing along to Adele, Katy Perry and Pink." She is also progressing well in class, learning to read and write again with exceptional determination. Leila explains how she manages to stay

strong. "People ask 'How can I not be upset? How can I not be devastated?' Charlotte has never once complained. She has never said 'why me?' She has never said she can't. If she's not like that, then I have no right to be at all."

Charlotte always finds a way to tell other children like her, 'not to be scared' and uses her experience to raise awareness and funds so that other families can be helped. "She talks candidly of nearly dying twice and of her fear of nearly leaving me," says Leila. "Charlotte will never be told she is incapable of achieving anything and I firmly believe nobody will stop her." If she comes up against anything that will stop her doing something due to her stroke, she will always ask how she can do it. There is no way to say no to Charlotte and no such word as can't.

**Charlotte is the winner of our Life After Stroke Children and Young People's Courage Award. See page 13 for more details.**



# Life After Stroke Awards 2013

## Introducing this year's winners...

The Stroke Association's Life After Stroke Awards celebrate the outstanding achievements of stroke survivors, their families, carers, and support services. Our Life After Stroke Awards Patron Karren Brady and legendary British television and radio journalist John Sergeant led the proceedings at a star-studded ceremony at The Dorchester in London.







### **Corporate Supporter of the Year Award**

Presented by Lord Julian Fellowes

**ICAP**

Few people realise that teenagers, children and even babies in the womb can experience stroke. ICAP is funding a three-year project to develop the UK's first dedicated service for child stroke survivors and their families. The Stroke Association is working with the Evelina Children's Hospital to develop a service to ensure childhood stroke survivors and their families get all the support they need, every step of the way.



### **Special Recognition Award**

Presented by Jon Barrick, our Chief Executive

**The Daily Mail Health Team**

The Daily Mail Health Team received this award in recognition of their commitment to raising awareness of stroke, covering its symptoms, new treatments and inspiring life after stroke stories in the newspaper and on Mail Online. Over the last year, the Daily Mail has published more than 70 articles on stroke and its website has received over eight million visits every day. The paper has nearly six million readers.



### **Fundraiser of the Year Award**

Presented by Andy McMenemy

Sponsored by Toni & Guy

**Rachel Inglefield, aged 39, London**

Rachel had a stroke 12 days after she gave birth to her son, James, in March 2012. The stroke had a huge impact on Rachel's life; her balance was affected meaning that she was unable to walk or sit up and she lost all feeling down her left side.

Following the stroke, Rachel set herself a target to walk half a mile by hosting her own Stroke Association Step out for Stroke event in May 2012, just two months after her stroke. With the help and support of her family and friends Rachel raised an incredible £16,350. Her fundraising didn't stop there; she then went on to walk 7.5 miles at another event and raised a further £7,700.



### **Professional Excellence Award**

Presented by Louise Minchin

In association with Pulse Magazine

**Redditch and Bromsgrove Clinical Commissioning Group (CCG)**

Redditch and Bromsgrove CCG received this award in recognition of their dedication and commitment to raising awareness of stroke and its risk factors in the local area.

Redditch is in the top 2% of the most deprived populations of England and blood pressure readings in the Redditch and Bromsgrove area are, on average, 5% higher than the national average. High blood pressure is the single highest risk factor for stroke. In 2012 the CCG embarked on an awareness-raising initiative, in partnership with the Stroke Association, in order to tackle local blood pressure and make more people recognise the signs of stroke.



**Adult Courage Award (18 to 64 years old)**

**Presented by Sian Lloyd**

**Sponsored by QVC**

**Eileen Matthews, aged 62, Vale of Glamorgan**

Eileen had her first stroke at the age of 47. Her stroke left her unable to walk and she became very frustrated that she was unable to return to her previous active lifestyle.

Over time Eileen began to recover; she returned to work and learned to drive a car again. However, eleven years later she was struck down by another stroke. This time Eileen was unable to return to work and her social life suffered enormously.

With the support of her family, Eileen was eventually persuaded to attend the Stroke Association's Positive Action for Stroke group and she has slowly rebuilt her life. Eileen is now at the heart of the group providing support and comfort to other stroke survivors and motivating them to keep going.



**Adult Courage Award (65 years and over)**

**Presented by Ronnie Corbett**

**In association with Yours magazine**

**Peter Farrow, aged 79, Northumberland**

Before his stroke in 2005, Peter enjoyed a number of hobbies including golf and singing with a highly accomplished choral group. However, the stroke left him with right-sided paralysis, communication difficulties and confusion, which meant he was unable to continue his hobbies.

Despite losing his speech, Peter was determined to try and get as much of his old life back as possible. With help from his singing teacher, Peter found that despite not being able to speak, he was not only able to sing but was also pitch perfect. He persisted with the singing and through this eventually recovered his ability to frame sentences and speak clearly. Since then, he has sung major pieces of classical music to audiences of several hundred people.

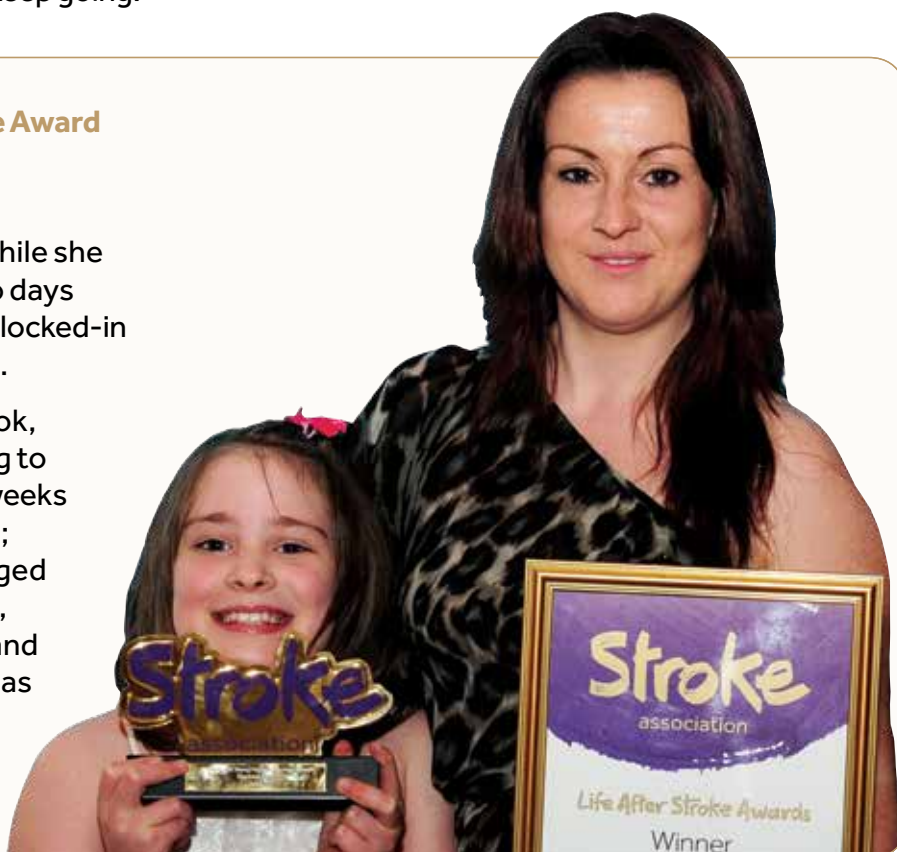
**Children and Young People's Courage Award**

**Sponsored by NEXT**

**Charlotte Neve, aged 8, Lancashire**

Charlotte had a stroke in April 2012 while she was asleep. She was in a coma for two days and when she came round she was in a locked-in state, unable to speak, move, or blink.

However, despite the worrying outlook, one day Charlotte's mother Leila sang to her and Charlotte smiled. Within two weeks Charlotte had started speaking again; she could focus on colours and managed to get up from her bed. Just a year on, she is learning to walk and talk again and has regained some of her sight. She has returned to school and her favourite hobby, dancing. You can read Charlotte's story on page 8.







### Stroke Group Award

#### Western Active Stroke Group, Weston Super Mare

Western Active Stroke Group was founded ten years ago by stroke survivor Jim Brown, who sadly died last year. The group started meeting in a local church hall and the membership grew quickly. Western Active regularly organises activities and outings, from skittles matches and quizzes, to talks by guest speakers. During the summer months, they plan one outing a month and have even arranged two holidays in Babbacombe.



### Carer's Award

#### Sponsored by Co-operative Pharmacy

#### Paula Coates (right), aged 51, Northumberland

Paula and Ann met in 1992. Two months later, Ann had a stroke which left her severely disabled. She was unable to communicate and spent a year in hospital. Paula asked Ann to move into her own home and gave up her job so that she could care for her full time. At the time, Paula was living in a first floor flat which was not suitable for Ann's wheelchair, so she found a new home that they could both move into.

Since Paula first started caring for Ann, Paula has married and has become a foster parent to six children. Despite her many commitments and busy lifestyle, Paula has continued to care for Ann full time and they remain wonderful friends.



### Stroke Association Award for Volunteering

#### Presented by Christopher Biggins

#### Sponsored by Boehringer Ingelheim

#### Lynn Scarth, aged 52, Surrey

When Lynn had a stroke in 2006 at the age of 45, she was left with communication difficulties and paralysis down her right side. She was unable to return to work as a receptionist and a hairdresser. However now Lynn spends 75% of her time volunteering and supporting other stroke survivors. As well as volunteering at two Stroke Association groups, she also volunteers with the Wolfson Stroke Unit at St George's Hospital and at another stroke charity.



### Award for Creative Arts

#### Presented by Stephanie Beacham and Phyllida Law

#### Maggie Turbitt (left), aged 51, Cumbria

Maggie had a stroke at the age of 45. She was left severely disabled. Prior to her stroke she was a full time nurse and worked as a ward sister on a stroke ward. She had never painted before and didn't have a great interest in art. Maggie was then introduced to art three years ago when her sister, Sonjie, booked her onto an art course. Maggie has been painting every week ever since and believes it is essential therapy for her. Having sold some of her work at craft fairs, Maggie has now set up two art workshops in the local area, enabling 20 stroke survivors to benefit from art therapy.

Nominations for next year's awards will open in December – find out more in the next issue of *Stroke News*.



# Confounding expectations

Defying all the odds against her Leah Batchelor, from Belfast, found the spirit and strength to come back from the brink. Her story was televised earlier this year on the BBC's *Story of a Lifetime* series.

21-year-old Leah was in a supermarket when she suddenly felt sick and dizzy and collapsed to the ground. She was left paralysed and, within an hour, she was put on life support in hospital, having had a massive stroke. The diagnosis from the doctors was devastating as they explained to her family that if she survived, she would be locked into her body with locked-in syndrome for the rest of her life. The only part of her body that she would be able to move would be her eyes – to blink. "It was hard for us to take in, so even harder for Leah," recalls Alison, Leah's mother.

But Leah fought back. She willed every part of her body to move until eventually she managed to move her finger. And nine months later, Leah confounded everyone's expectations by stepping out of hospital. Today Leah is continuing therapy and is able to take a few steps with a stick. She has also recovered some speech, with the unwavering help and support of her family. As a lifelong member of St Michael's Church in Belfast, Leah has also gained much

support from her faith. "It was never believed that Leah would walk again, but she is now walking with support," says the Ven Barry Dodds, Archdeacon of Belfast and rector of her church. "Leah has been a wonderful inspiration to many people. She has a can-do spirit."

Before her stroke, Leah had already battled severe dyslexia and achieved As in her A-levels. She was studying visual communications at the University of Ulster and is now determined to go back in September to finish her degree: "Tell me I can't do it. Just watch me."

In recognition of Leah's extraordinary resilience, she has been awarded our Northern Ireland Stroke Association Life After Stroke Award for Courage.



**"Leah has been a wonderful inspiration to many people."**



# The return of King Lear

Acclaimed veteran actor Edward Petherbridge was rehearsing the role of King Lear two years ago. He had just arrived in New Zealand and was two days into rehearsals for the part every actor dreams of. Then a major stroke left him barely able to move.

It was terrible timing. Edward's home and loved ones were on the other side of the world, when he had two strokes in two consecutive days.

While in hospital Edward tried to keep his mind stimulated. "I couldn't write or read but still my mind was being fed all the time." Music was particularly important. "One of the things that saved me was getting a radio brought in," recalls Edward. "I used to listen to the world service, which was full of current programmes and world music." He noticed small improvements every day with the help of a therapist who spent ten minutes with him each day. And because he had spent months committing his Lear role to memory, rehearsing lines under the lilac

tree in his garden, he could still remember Shakespeare's words.

Not one to dwell on regrets, Edward's priority was to get better. "Whenever I passed a doorknob, I made myself turn it or I'd take a clothes peg and squeeze it." Back home, in England, his family encouraged him. "One day my daughter said to me, 'Can you catch this lemon with your right hand?' I caught it and then she said 'Now can you throw it back to me?' This seemed quite unthinkable but I managed to do it."

Along with continued therapy, Edward set himself creative goals. "I drew a poor picture of myself and about three weeks later, I went over it and found I could draw so much better."

He also trained himself to write again – the slow progress meant he was able to think up poems and rhymes. "That was exercising my brain and hand at the same time, which was important," explains Edward.

Remarkably, 76-year-old Edward has now returned to the stage. He recently co-wrote and starred in a play called *My Perfect Mind* based on his experiences and wonders how successful his King Lear production in New Zealand would have been. "My old friend and colleague Sir Ian McKellen was doing a world tour of Lear, too, and I was rather looking forward to the comparisons. This little spin-off of mine could be seen as a booby prize but I don't see it at all like that. We've had such kind and positive reviews."





**"If you find yourself in a shell of a body, it's still possible to find meaning if you want it."** Stuart Hepburn

# A Most Curious Detour

Stuart Hepburn broke through the communication barriers of locked-in syndrome to write a book about his experiences, which have been brought to life in a play called *A Most Curious Detour*, performed in both Glasgow and Edinburgh.

Stuart, who is 61 and from Edinburgh, was a business consultant and trainer before he had a massive stroke eight years ago. This left him with locked-in syndrome. He was almost completely paralysed, unable to walk or talk.

Stuart has now recovered the ability to move two fingers and can type to communicate, with his words displayed on a small screen. He has written an account of what it's like to be locked inside your body on a busy hospital ward and his own story has been turned into a play. *A Most Curious Detour* covers Stuart's life before his stroke –

especially his time in India where he lived the life of a yogic monk – through to the stroke itself, his time in hospital and his life after stroke.

He was motivated to write his book not only to help others, but also to educate them. "On one occasion, two nurses came to make my bed then proceeded to discuss their birth control measures as though I was not present," says Stuart. The stroke hadn't affected him intellectually and mentally but he was 'locked-in'. When he lay in his hospital bed he was fully aware of everything happening around him, but couldn't interact.

In the early days, Stuart would blink to make himself understood as Pam, his wife, recited the alphabet. She asked him one day to name the man-of-the-match in a recent rugby match. When he blinked out 'Sean Lamont', Pam rushed to the doctors thrilled that his brain was functioning. It is such wisdom he hopes to share through his book, which has been adapted for the stage by the scriptwriter, Alistair Rutherford.

The spiritualism and meditation Stuart discovered in India in his 20s has helped him cope. Stuart says "I've learned that the secret of sanity is to be accepting." He is striving not "to do, but to be".



# An action-packed month to remember!

Following our first Action on Stroke Month last year, in May 2013 many people got together again to spread the word about stroke.

Whether you took part in a Step out for Stroke walk, got on your bike for a cycling event, organised a community fair, had your blood pressure checked, shook a collection tin, or did something completely different, you've made a difference. Together we've helped raise awareness of stroke and reached out to many more stroke survivors and their families. As we reflect on all that we've achieved together, we'd like to say a big thank you to everyone who took action across the UK.

Here's a selection of photos that capture the spirit of Action on Stroke Month, and the fantastic stroke survivors, supporters, volunteers, fundraisers, family and friends that made it possible.



Step out for Stroke at Glamis Castle, Scotland



Check out this great photo of comedian Russell Kane sporting our Stroke Solidarity Strings!



Thames Bridges Bike Ride, London





## And the winner is...



Action on Stroke Month would not be possible without the hard work and dedication of our thousands of amazing volunteers.

We're pleased to announce that the winner of our volunteers' photo competition is Kieran Boswell from Sandbach in Cheshire. Kieran attended our Step out for Stroke event in Knowsley on 13 May. Here's his winning photo:



We love the way he captured participants and volunteers in his photo, and used his artistic eye and digital skills to focus the viewer on the purple Step out for Stroke banner. The sun is shining through the trees and it looks like everyone had a great day!

**500 mile cycle and climbing 7 mountain peaks over 5 days, Northern Ireland**



Stroke pop-up shop, Wales



Ellie McCallion prepares for the Belfast marathon

Bob Bryant took part in Step out for Stroke in Victoria Park in Widnes in May. Bob founded Let's Go, Britain's biggest stroke club, 17 years ago and has campaigned tirelessly for patients and the disabled ever since. Despite suffering ill health including five strokes – the first when he was only 31 – Bob says "You don't want to sit at home and vegetate. I'm like a bull in a china shop."

In recognition of his work, he has received a top accolade in the Queen's Birthday Honours this year – the British Empire Medal.



Bob Bryant with players from Widnes Vikings

Many congratulations to Bob, who believes the secret to his club's success is fun, laughter and support.



# A night of fashion, fine food and fun

In March, Shamsul Arafen and his volunteer, Nagheena Haroon, held a glamorous stroke awareness evening for ladies at the Anams Restaurant in Bradford.

Shamsul runs our Stroke Health Awareness service in Calderdale, offering support to people, particularly from South Asian communities, to reduce their chances of having a stroke.



The night was jam packed with entertainment: over 140 people watched the fashion show and partook in Mehndi Art, crossed their fingers for the raffle and enjoyed a special performance by singer Hussnain, whilst tucking into a delicious healthy buffet.

Aside from the fun, Shamsul had a serious message to convey. "South Asians have a higher risk of stroke than the rest of the population," he explains. "One quarter of South Asian adults in England have high blood pressure, the biggest cause of strokes." You can reduce your risk by eating healthily and being regularly active.

The Stroke Association and Wiltshire Farm Foods are working together to promote the importance of healthy eating. To find out how certain foods can help protect you against stroke, you may be interested in reading our factsheet 'Healthy eating and stroke'.

You can request a copy by calling **0303 3033 100** or download a free copy from our website: [stroke.org.uk/information/resource-library](http://stroke.org.uk/information/resource-library)

## Taking part in research – Tess's view



If you have aphasia, you may not realise that you can play a key role in ground-breaking stroke research. We talked to Tess about her experiences of participating in the PLORAS study at the University College London.

PLORAS stands for 'Predicting Language Outcome and Recovery after Stroke'. The research aims to help future stroke survivors by making predictions about the recovery of their language skills.

Tess decided to take part in PLORAS after researchers visited her stroke club.

"Taking part involved having an MRI brain scan and doing some language tests. The atmosphere was

relaxed so I wasn't even worried about the MRI scan. I enjoyed talking to the researchers.

"My advice to other people with aphasia who are interested in research is to make sure you understand what it's all about before you take part. I think it's good to get involved as it helps you stay up-to-date with what's happening in the field of stroke research and will hopefully help other people with aphasia in the future."

If you would like to take part in the PLORAS study, please contact the research team by calling **0207 813 1538** or email: [ploras@ucl.ac.uk](mailto:ploras@ucl.ac.uk)  
Website: [www.ucl.ac.uk/ploras](http://www.ucl.ac.uk/ploras)

For more information about taking part in stroke research, please visit our website: [stroke.org.uk/research/get-involved](http://stroke.org.uk/research/get-involved).





# Anyone can have a stroke

23-year-old Annabel Jones, from Cardiff, had just started her career when she had a stroke in November 2011.

"When it happened I was finishing my lunch with my co-workers. Suddenly, I lost part of my sight in each eye and the pain in my head was excruciating. My GP took my blood pressure, which was incredibly high, and using his stethoscope and a reflex hammer, he told me I was having a stroke."

Annabel knows all too well how important it is that people understand that a stroke can happen to anyone at any age. When she arrived at the hospital, the junior doctor she saw mistook her stroke initially for a severe migraine.

"My symptoms were not the common signs of a stroke and because I was young, they felt there was no sense of urgency.

The only contributing factor the doctors agreed on was that the contraceptive pill I was taking played a part, as it led to a spike in my blood pressure," says Annabel.

Annabel's stroke has left her about 40% blind, but she has managed to return to work for Barclays, initially part-time and then in June she returned to a full-time post. "Barclays has been really great and supportive," says Annabel. "The RNIB came in to assess my working environment and I was provided with a desk lamp. I now use a wide screen monitor, a large print keyboard and special software, which magnifies everything."

After returning to work, Annabel was keen to get involved with

volunteering, raising funds and awareness to ensure that what she went through doesn't happen to other young people.

"I'm thrilled to be a Stroke Ambassador with the Stroke Association and recently, despite my nerves, really enjoyed speaking to the WPSA (Welsh Pharmaceutical Students Association) at Cardiff University." Inspired by her story, 30 students signed up for the Cardiff Half Marathon and there was a great response on Twitter.

"I'm looking forward to doing more work with the Stroke Association as it's really helped me to regain my confidence and if I can improve the recovery and life of even one stroke survivor, then I will be thrilled!"

# Money matters

## Five tips to help you save money on prescription charges

Knowing that paying for prescriptions is a financial burden many of us could do without, The Royal Pharmaceutical Society has issued five top tips to help you save money and get the best advice on buying medicines.

### Five top tips

1

#### Prepay and save money

Opting for a Prescription Prepayment Certificate can save you money if you need to take a number of medications over three or more months. To find out more call **0300 330 1341** or visit **www.rpharms.com**

2

#### It may be cheaper to use over-the-counter alternatives

This may be a cheaper option for one-off types of medication including painkillers, allergy tablets and dermatology creams. Talk to your pharmacist for advice. For longer periods, it may be cheaper to get a single prescription from your doctor.

3

#### Check out the NHS Low Income Scheme for help with health costs

Anyone who is on a low income may be able to gain financial assistance through the NHS Low Income Scheme. You can apply by completing an HC1 form available at Jobcentre Plus or by calling **0845 610 1112**. Phone **0300 330 1343** for the Low Income Scheme helpline.

4

#### You may be eligible for free prescriptions

- If your medicine is both prescribed and dispensed in Scotland, Wales or Northern Ireland
- If you are under 16 or over 60
- If you are in full time education and are aged between 16 and 18
- If you are pregnant or have had a baby in the last 12 months
- If you or your partner receive Income Support, Income-based Jobseeker's Allowance, Income-related Employment & Support Allowance, or Pension Credit Guarantee Credit
- If you have a war pension exemption certificate
- If you have a valid **Medical Exemption Certificate** (given for a range of illnesses, e.g. epilepsy, cancer, severe disability).

Proof of exemption may be required when you have your prescription dispensed at the pharmacy.

5

#### Talk to your pharmacist

You can talk to your pharmacist about any aspect of your medication and you don't need to make an appointment in advance. Most high street pharmacies also have a private consultation area where you won't be overheard.





# Help stroke survivors make their best recovery possible this Christmas



We know it's a bit soon to mention Christmas so early on in the year. It's because we're delighted to announce that stroke survivor John Lea's entry to our Christmas Card Design Competition not only won our hearts, but also won the contest.

His limited edition card, entitled *Waiting For Santa*, is available to buy, alongside a range of festive cards and gifts, in your Christmas catalogue. [You'll find your catalogue in this issue of Stroke News.](#)

John had a stroke five years ago. He was left with aphasia (a communication disability) and weakness in his right side, but his stroke couldn't take away his passion for art. In fact, 81-year-old John has since learnt how to paint and draw just as beautifully with his left hand. Following his stroke, John joined a Stroke Association Voluntary Art Group and has been a member for five years. He says he wouldn't miss the weekly meet up for anything.

These art groups, organised by the Stroke Association, use art therapy to provide support and rehabilitation, and can help stroke survivors to build on their confidence by expressing themselves in new ways.

We believe everyone should have the right to make their best possible recovery after stroke. If you make a purchase from the Christmas catalogue, you will be helping us to be there for more people like John. Your support could help to fund potentially life-saving stroke research, provide practical and emotional support for those who need it, and enable campaigners to fight for better care for stroke survivors.

## Christmas card design competition, 2014

Are you a stroke survivor? Do you share John's passion for art? Whether you enjoy drawing, painting or photography, we would love to hear from you. To enter the competition, please send your festive and original artwork to: Christmas Card Competition, Stroke Association, 1 Sterling Business Park, Salhouse Road, Brackmills, Northampton, NN4 7EX – along with some information about yourself and when your art was produced. The closing date for submissions is **24 January 2014** and all artwork will be returned so please include your contact details. For more information, please email [cardcompetition@stroke.org.uk](mailto:cardcompetition@stroke.org.uk)



# What's on ac

Have fun and take action on stroke – there's something for everyone!

## Runs

### Resolution 5,10 and 15k

**Finsbury Park  
London**

**1 September**

☎ 020 7655 0311

@events@stroke.org.uk

### Run to the Beat

**London**

**8 September**

☎ 020 7566 0311

@events@stroke.org.uk

### Great North Run

**Newcastle**

**15 September**

☎ 0161 742 7469

@greatnorthrun@stroke.org.uk

### Resolution Run 5k/ 10k/ 15k

**Mote Park**

**Kent**

**21 September**

☎ 02380 720431

@southeastfundraising@stroke.org.uk

### 10k Beach Run

**Hunstanton**

**22 September**

☎ 01284 749650

@eastenglandfundraising@stroke.org.uk

### Berlin Marathon

**29 September**

☎ 020 7566 0311

@events@stroke.org.uk

### Loch Ness Festival of Running

**Inverness**

**29 September**

☎ 0131 555 7252

@scotlandfundraising@stroke.org.uk



### Great Scottish Run

**Glasgow**

**6 October**

☎ 0131 555 7252

@scotlandfundraising@stroke.org.uk

### Royal Parks Half Marathon

**London**

**6 October**

☎ 020 7940 1344

@sarah.maling@stroke.org.uk

### Resolution Run

**Stoke on Trent**

**6 October**

☎ 01527 903 903

@westmidsfundraising@stroke.org.uk

### Dublin City Marathon

**8 October**

☎ 028 9050 8053

@eventsni@stroke.org.uk

### Resolution 5,10 and 15k

**Hyde Park**

**London**

**13 October**

☎ 020 7566 0311

@events@stroke.org.uk

### Yorkshire Marathon

**York**

**20 October**

☎ 0161 742 7469

@FRYorkshire@stroke.org.uk

### Birmingham Run

**Birmingham**

**20 October**

☎ 01527 903 903

@westmidsfundraising@stroke.org.uk

### Great South Run

**Portsmouth**

**27 October**

☎ 023 80 720 431

@gsr@stroke.org.uk

### Resolution Run

**Warwick Castle**

**2 March 2014**

☎ 01527 903 903

@westmidsfundraising@stroke.org.uk

## Walks

### Thames Path Challenge

**London**

**14 and 15 September**

☎ 020 7940 1344

@sarah.maling@stroke.org.uk

### Step out for Stroke events

**Throughout the UK**

☎ 029 2052 4426

@stepout@stroke.org.uk

## Rides



### Stroke London to Paris Bike Ride

**5-8 September**

☎ 01527 903 903

@nancy.lillington@stroke.org.uk

## Swims

### Great Scottish Swim

**Loch Lomond**

**24 August**

☎ 0131 555 7252

@scotlandfundraising@stroke.org.uk

### Great London Swim

**31 August**

☎ 01527 903 903

@westmidsfundraising@stroke.org.uk



# ross the UK

## Something different

### Headingley Carnegie Stadium Zip Slide

Leeds

12 October

☎ 0161 742 7469

@FRYorkshire@stroke.org.uk

### Firewalk Challenge Stonelees Golf Club

Ramsgate

19 October

☎ 02380 720431

@southeastfundraising@stroke.org.uk



### Santa Run 5k and Santa's Little Helpers 2k

London

7 December

☎ 020 7566 0311

@events@stroke.org.uk

## Christmas Carol Service

London

13 December

☎ 020 7940 1347

@charlotte.wahlich@stroke.org.uk

## Jumps & abseils

### The Europa Abseil

Belfast

Dates throughout 2013

☎ 028 9050 8053

@eventsni@stroke.org.uk

### The Ultimate Skydive

Northern Ireland

Dates throughout  
2013

☎ 028 9050 8053

@eventsni@stroke.org.uk



## Sip for Stroke



Why not get together with friends and organise a Sip for Stroke party?

Call **0207 566 1525**, or visit us at [stroke.org.uk/news/sip-stroke](http://stroke.org.uk/news/sip-stroke), email [sipforstroke@stroke.org.uk](mailto:sipforstroke@stroke.org.uk) to find out about events in your area.



The Stroke Association is a charity. We rely on your support

Text **STROKE 5** to **70300** to donate £5. 100% of your donation goes to the Stroke Association. Find out how your support helps at [stroke.org.uk/savelives](http://stroke.org.uk/savelives)

## Stroke stars

Sue Belfield pulled together with her family and friends following her mother's stroke. Her family's world was turned upside down 18 months ago, when her mother had a stroke. She was left severely disabled and in need of 24 hour nursing care. One of the most difficult things, Sue says, was arranging her move into a care home. "In January, this year, I decided I needed to help and raise awareness of stroke. So with the help of my husband, Ivan, my two sons, Jamie and Luke, my sister's family and



lots of friends – 17 of us in total – we all ran or walked the 5km Resolution run at Escot Park in Devon." They raised over £1,500 and spurred on by this success, on 25 May, they also took part

in the Step out for Stroke day in their home town of Teignmouth. Sue says "My mum is very proud of us. She is aware of all her family and I believe our love and strength helps her every day."

# Getting on with day-to-day life

Do you suffer from limb pain or need help with tasks around the home?

In partnership with Homecare from The Consortium, the Stroke Association offers a range of products that can make day-to-day tasks easier.

Among our most popular products are our rehabilitation tools such as the Mirror Therapy Box. It is designed to improve the motor functions in your affected limb to help you to recover more quickly.

You place your affected limb inside the box and the unaffected limb in front of the mirror. While you're looking at the reflected image and doing gentle symmetrical exercises, it appears the affected limb is moving normally. People with no limb movement can visualise and attempt to move the limb whilst moving the unaffected limb in the same way.



For other ideas to help with everything from dressing to getting out and about, visit [strokeshop.org.uk](http://strokeshop.org.uk) or call **0843 487 8740**.

## Onwards and upwards

Thinking of buying a stairlift?

Stannah and the Stroke Association have come together to offer you a 10% discount on any purchase of a Stannah stairlift. As a thank you, Stannah will also make a donation to the Stroke Association on any purchase or rental agreement.\*

**Why choose Stannah?**

- Quick and easy installation on straight and curved staircases
- Stairlifts for every budget – new, reconditioned or rental
- Emergency call outs available night and day
- Nationwide, locally-based Stannah engineers
- Two year warranty and two free services with all new stairlifts\*
- 14 day money-back satisfaction guarantee\*



To find out more about how you can regain your independence and help the Stroke Association, please call **0800 715346**. Please quote '**Shop Ref 217**' to receive your discount and ensure the Stroke Association receives the donation.

\*Terms and conditions apply