

Stroke News



WINTER 2014

For everyone affected by stroke

A stroke affects the whole family

Adam tells us how he stayed strong as a carer, a husband and a dad

The emotional impact of stroke

Where our befriending scheme can step in

Driving after a stroke

Are you ready to get back behind the wheel?

Back to business

Getting back to work after a stroke

stroke.org.uk

Stroke
association

Welcome...

With the festive season approaching, our thoughts often turn to family. Stroke can unexpectedly change family dynamics as half of all stroke survivors are left with a disability.

That's why, as the leading stroke charity in the UK, we provide support so families aren't alone.

On page seven of this edition, Adam Moy talks about coping as a carer when his wife had a stroke after child birth.

Colette Trainor, on page 19, didn't have family to turn to after a stroke, but she's found support from our befriending scheme. And on page 12 you can read how, with the support of a Life After Stroke Grant, Mark Ellis feels part of his family again. I hope these experiences offer you support and hope.

Sadly, the devastating reality of stroke means a life is taken every 10 and a half minutes

in the UK and many families lose loved ones. If you've been affected by the death of a loved one, our Stroke Helpline (**0303 3033 100**) is here to help.

Very best wishes for 2015.

Alex Bolton
Editor



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Regulars

3 Over to you

We share your views

5 Health note

Blood pressure explained

10 Guidance

Changes in social care across the UK

14 In brief

Helping hand mobility

18 Research

The emotional impact of stroke

24 Money matters

A look at Attendance Allowance

25 Thank you

How you're helping conquer stroke



Features

7 On the cover

A carer's perspective on staying strong for the family

12 Life After Stroke Grants

Helping stroke survivors achieve goals

15 Driving after stroke

Are you ready to get back behind the wheel?

19 Two of us

Could you benefit from befriending?

21 Clubbing together

Stroke clubs are there for you

22 Back to business

Bharat Patel's return to work



To receive three editions of *Stroke News* a year or hear an audio version, visit **stroke.org.uk/strokenews** or call **01604 687 721**.

If you no longer wish to receive *Stroke News*, or would be happy to read it online, please let us know on **strokenews@stroke.org.uk** or call **01604 687 721**.

Over to you



Your views matter. Your experiences may help inspire others affected by stroke.

Thank you

I receive *Stroke News* and find the reports interesting as I do not have the internet. The summer edition was so, so moving. The reports on Cheyenne and Angharad were so inspiring. It's so encouraging to read of people overcoming their problems. Thank you for producing such an excellent magazine.

 **Monica Broome (letter)**

Inspiration from others

I had two strokes in 2010. Although my recovery has been slow but sure, I have problems with balance showing no signs of improving. *Stroke News* has been an inspiration for me, reading how people overcome their disabilities. Never give up!

 **Richard Owen (letter)**

Supporting *Stroke News*

In response to *Can you help?* page 4 *Stroke News* summer 2014: I want a paper copy of *Stroke News* as I always give mine to a hospital waiting area or someone who has had a stroke. I shall increase my annual donation by £10 a year to help towards the costs. May I suggest this course of action to other people?

 **Elisabeth Traverse (email)**

Readers' tips

Thanks for a great magazine. I always enjoy reading it. How about a column called 'Readers' tips' for stroke survivors or their carers to share tips?



I am constantly looking for ways to improve my recovery and trying different things. Last year, I introduced breathing exercises and doing work outs in a pool. This year, I've been improving my diet.

One of my most helpful items has been an A4 homemade daily exercise sheet. You can tick off the boxes as you do things and get satisfaction from that. Alternatively, if you don't do any then there will be big blank spaces. It kind of nags you every day! It has worked for me brilliantly well.

 **Paul Foster (letter)**

Do you have a tip?

We'd love to hear from you.

Write to us at *Stroke News*,
Stroke Association House,
240 City Road, London, EC1V 2PR
or email strokenews@stroke.org.uk.

 Find us on Facebook
([facebook.com/TheStrokeAssociation](https://www.facebook.com/TheStrokeAssociation))

 and Twitter (@TheStrokeAssoc).



Hot topics

→ Keep healthy this winter

It's easy to catch a chill at this time of year. Cold weather can be dangerous and lead to health problems like pneumonia, especially if you're over 65 or have a long-term health condition. So it's important to keep healthy, eat well and keep warm.

→ Have you had your flu jab?

If you've had a stroke or mini-stroke, or you're over 65, contact your GP surgery or pharmacist for a free NHS flu jab. Don't qualify for a freebie? Many pharmacies offer flu jabs for a small fee.

→ Eat well and keep warm

- Stay active and, if possible, move around at least once an hour. If you're unable to move much, try chair-based exercises like moving your arms or wiggling your toes to get your circulation going.
- Wearing lots of thin layers will keep you warmer than one thick layer, as the layers trap warm air.
- Regular hot meals and hot drinks will help you keep warm and keep your energy up.



→ Could your bank understand you better?

Many people have financial worries after a stroke but don't get the help they need from their bank. We're working with the British Bankers Association to try to improve things. If you've had problems, get in touch campaigns@stroke.org.uk

→ How good is stroke care in your area of Scotland?

The Scottish Stroke Care Audit Report looks at the quality of stroke care, like getting diagnosed and treated in the right place, by the right people at the right time. The 2014 results are out now: www.strokeaudit.scot.nhs.uk

World Stroke Day: Helping women know the score on stroke



In the UK:

- Three times more women die of stroke than breast cancer
- It's the third leading cause of death amongst women
- Around 30,000 women die of stroke each year

Reduce your risk of stroke and secondary stroke: see page six.

Reducing your risk of stroke or secondary stroke

Blood pressure explained

- High blood pressure is the biggest risk factor for stroke that we can control.
- It's a contributing factor to over 50% of strokes.
- The higher your blood pressure, the greater your risk of stroke or having a second stroke is.

High blood pressure puts a strain on your blood vessels, including arteries to the brain. The pressure can damage the lining of an artery, allowing blood clots to form which may block blood flow to the brain or cause blood vessels to burst and lead to bleeding in the brain.

Did you know?

Blood pressure tends to rise as we get older.

High blood pressure may be caused by an underlying health condition, such as certain kidney disorders. But it can also be due to lifestyle factors such as diet and smoking.

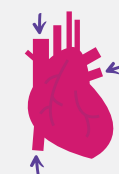
Blood pressure problems can run in families, and certain ethnic groups, such as South Asian people and African-Caribbean people are more at risk.

But what is blood pressure?

Blood pressure is the force exerted on the walls of the arteries by the blood as it circulates. It's recorded as two numbers.



The first number is the pressure created in the arteries when the heart beats and pumps blood out around your body (systolic pressure).



The second number is the pressure in your arteries when the heart relaxes between beats (diastolic pressure).

120/80

The ideal blood pressure for a healthy adult is less than 120/80mmHg.

140/90+

You are said to have high blood pressure if readings are consistently higher than 140/90mmHg on a number of separate occasions.

How do I know if I have high blood pressure?

High blood pressure often has no symptoms. There's no way of knowing your blood pressure unless you have it checked regularly. See your GP, a pharmacist or a trained professional.



You can reduce your stroke risk by controlling your blood pressure

Your doctor may give you medication to lower your blood pressure, but there are simple lifestyle changes which will also help:



Improve your diet

Too much of the wrong fat can raise cholesterol and stroke risk. Eating five portions of fruit and vegetables a day can reduce your risk by 30%.



Reduce alcohol intake

Drinking too much alcohol raises your blood pressure, increasing stroke risk. It can also raise cholesterol and make you gain weight.



Stop smoking

You are twice as likely to have a stroke if you smoke. Smoking causes your arteries to fur up and increases your risk of a blood clot.



Eat less salt

Eating a lot of salt can increase your blood pressure. There can be hidden salt in some processed and ready-made food, so check the labels carefully.



Get regular exercise

Thirty minutes of moderate activity five days a week can reduce your risk of stroke by a quarter.

Know Your Blood Pressure Day is coming

Saturday 18 April 2015 is *Know Your Blood Pressure Day*. It's the perfect excuse to encourage your friends, family and colleagues to have their blood pressure checked.

We'll be holding free *Know Your Blood Pressure* events across the UK on 18 April and throughout the whole of 2015. Find an event near you at stroke.org.uk/KYBP

So far this year we've held more than 1,200 *Know Your Blood Pressure* events in partnership with Rotary in Great Britain and Ireland. We've checked the blood pressure of nearly 50,000 people, helping to prevent stroke and save lives.

A stroke affects the whole family: A carer's story

When Mia Sarjeant had a stroke shortly after giving birth, shockwaves ran through the whole family. Her husband Adam tells us how he stayed strong as a carer, a husband and a dad.

Adam will always remember when the joy of meeting his second beautiful daughter shifted to fear for his wife's life. He says: "It was like an earthquake struck our family." But they pulled together and, just a year on, they're setting up a group to help others and, quite literally, climbing mountains.

Our world turned upside down

"Within an hour of giving birth, Mia became weak. Very quickly, she went dramatically downhill. She had a seizure in hospital and lost a lot of blood. I felt sick as she was rushed to intensive care for a blood transfusion.

"I stayed awake on the maternity ward with baby Esther while our first-born, Alice, was at home with family. I couldn't understand how the life of someone young, fit and healthy was on a knife edge. It was the next morning when she was in theatre having brain surgery that I was told Mia had had a massive stroke."

Staying strong as a family

Thankfully, Mia pulled through but she spent the next four months in hospital. Adam says "It was hugely intense but I found that being organised was a way of coping. I went into autopilot trying to join up the dots of the whole family's needs.

"I had to talk to Alice about how her mum might not make it. As an eight year old, it was important she understood what was happening. Working through her questions together about whether mum would ever come home, if she would have a wheelchair and her concerns about if she would still have feelings, brought us closer together."

Because a stroke can happen out of the blue, many people find themselves in a role they're not prepared for. It can be both physically and emotionally exhausting, but having somewhere to get some space away from everything can help.

"Day after day, I paced the wards with Esther in the pram, dividing my time between Mia, the baby and talking to the doctors," says Adam. "What helped was finding a haven in a Ronald McDonald Charities home around the corner from the hospital. I'd take Esther there, get a break from the hospital and organise the next few days. Having that breathing space was absolutely priceless."

"We were also enormously lucky that friends and family pulled together and Alice was well looked after in her normal routines. Getting this help was essential to stay strong and remain physically and emotionally stable. I learned you mustn't be shy to reach out to everyone and everything."

Also vital to Mia's recovery was her determination. It took four months in hospital to learn to walk again but she didn't give up. She gradually got out of bed and built up the strength and balance to walk further and further along the corridor. ▶

"I learned you mustn't be shy to reach out to everyone and everything."





"When she came home she was very frail and walked with a stick," says Adam. "But we took the girls to the common near our house every day to build up Mia's strength. She remained motivated for the girls. Bending down and picking up the children and keeping busy with them was probably the best kind of therapy. A maternity nurse was also a huge support, coming every day and helping out in the evenings."



Moving mountains

"Throughout Mia's recovery, we desperately felt we needed to be in touch with young families affected by stroke. There are a lot of groups available for older people but we couldn't find anything for younger people

with children. Social services weren't able to help and it wasn't until we met Jane Turner from the Stroke Association, that suddenly we found half a dozen families locally who could share their experiences and advice.

"We became determined to help others in the same position and with the Stroke Association's help we've set up a New Parents Stroke Group. We're trying to raise awareness and engage with political and medical communities to ensure support is available to young families affected by stroke."

To help fundraise for the group, and as a goal in Mia's recovery, the whole family came together to climb the 1,000m tall Lochnagar munro in Scotland. "It was a nine hour round trip. I carried Esther, and Mia and Alice walked the whole way. It's a mark of how far Mia has come and I'm extremely proud of how much she's achieved just a year on from her stroke."

Adam's advice for carers

1. Accept help from friends. Have a list ready of ways people can help, like taking the children to school or going to the supermarket.
2. Make time for yourself. It's vital to have a break and space away from everything to keep up your energy.
3. Hear from other carers and families in the same position about how they've coped. The Stroke Association can help you connect.
4. Be open with friends and family about what's going on. There are books which help explain stroke to children, like Medikidz. Doctors can also help.
5. Talk to your employer. You have the right to request flexible working and time off to care for dependants in an emergency.

Talk to your GP if you're a carer – you're legally entitled to a carer's assessment to identify your needs.



To donate to Mia's climb and help fund the New Parents Stroke Group, visit: justgiving.com/Mia-Sarjeant



To attend the group, which meets regularly in Clapham, London, contact info@stroke.org.uk.

A picture of social

After a stroke, people don't always get the support they need to live independently, which can put pressure on stroke survivors and their families. The care system is complex and differs across the UK. Over the last year, some changes have been announced across England, Wales and Scotland which should make things simpler.

England

In England, a new law known as the Care Act will come into effect in April 2015. It should make the system fairer and help people get better care.

There are five major changes:

- 1 An assessment of carers' needs regardless of income**
Even though carers have always had a right to an assessment of their needs, people told us they often found they couldn't get one until the local authority had looked at their financial resources.

Thanks to pressure from carers' charities and the Stroke Association, the new Act is now clear that all carers must be offered an assessment. And it means that all carers can access the things that are often the most important, like free information and signposting to support.
- 2 Advocacy support will be available to anyone who needs care**
People who may struggle to understand what's being offered to them or who may find it hard to come to terms with what their needs may be must be offered an independent advocate by the local authority so their needs can be properly represented.
- 3 Better recognition of related problems**
Visual problems often accompany a stroke or mini-stroke. The Act means local authorities must now maintain a register of people with visual impairments, and may choose to maintain a register for people with learning difficulties to know who is living in their area and what services are needed.
- 4 Continuity of care**
When an adult who is receiving care in one area of England moves home, the new Act will mean they'll continue to receive care on the day of their arrival in their new area. The local authority in the new area must meet the needs that were being met by the previous authority.
- 5 Capping the cost of care**
For the first time, the Act will put a limit on the amount anyone will have to pay towards the costs of their care. This is due to come into effect in April 2016.

Read the full details about the Care Act here:
tinyurl.com/kpuwjuu

care in the UK

Self Directed Support in Scotland

Since April 2014, everyone in Scotland who receives care and support from their local authority has the right to Self Directed Support (SDS). SDS puts a person in charge of what sort of support they receive and how they receive it. This could be support at home with daily tasks such as washing, eating or housework, or may be things outside of the home, like shopping or visiting friends and family.

For more information see:
stroke.org.uk/selfdirected

A new Social Services and Wellbeing Act in Wales

The new Act aims to:

- Give people who use social services, including carers, a strong voice and control over the services they receive.
- Enable earlier intervention to sustain and improve people's well-being.

What does this mean in practice?

- Assessments will focus on the outcomes that people want to achieve.
- A portable assessment will be introduced so that when people move from one local authority to another, their assessment will go with them.
- Social services and the NHS will have a duty to collaborate and deliver more integrated services so there will be better follow-up with patients once they've left hospital and they're back in the community.

To find out more, see
tinyurl.com/mfn45cp

A glimpse at stroke and care in the UK:

Stroke strikes every **3 ½ minutes** in the UK



Britain has at least **1.16m** stroke survivors. Half have been left with a disability



1 in 5 dependant stroke survivors in the UK is cared for by family and friends



64% said the emotional impact of stroke was the hardest thing to deal with



2/3 of stroke carers experienced difficulty in their relationship with the stroke survivor



Finding a care home

Finding a care home for yourself or a loved one can be difficult.



Our factsheet *Accommodation after stroke* has lots of helpful information and checklists to work through. See stroke.org.uk/accommodation or call the Stroke Helpline confidentially on **0303 3033 100**.

Refusing to give up on goals

Mark Ellis had everything to fight for. Aged 22, he'd been married two months and his daughter was just two weeks old. So when he had a devastating stroke which left him with locked-in syndrome, he certainly wasn't going to give up. He fought back, and now, with the help of a Life After Stroke Grant, he's achieved his goal of picking up his daughter from school.

Mark had been complaining of a migraine just days before his stroke. When the pain persisted, he went to A&E but was sent home with some paracetamol. His concerned wife, Amy, insisted he went back and while Mark was in A&E his health rapidly deteriorated and he went into a coma. Amy learnt the devastating news that he'd had a brain-stem stroke. She was told he might not survive.

Thankfully, Mark came round. But the stroke left him with locked-in syndrome, a condition that meant his brain was alert but his body was paralysed. He could only

communicate by rolling his eyes. Mark astonished medical staff by breaking out of locked-in syndrome and after eight months of intensive physiotherapy and speech therapy, he was able to walk short distances with a frame and talk with a speak text device on his mobile phone. Refusing to let up on his recovery, Mark set himself some goals.

"I wanted to be able to do more with my wife and daughter, Lola, who is now four," says Mark. "They have been so brilliant from day one when I was in hospital. The major thing I missed out on was picking my daughter up from

nursery. It was something I was desperate to do so I set myself the long-term goal of collecting her from school.

"We looked in our local mobility shop for a scooter but couldn't afford one so we spoke to our Information, Advice & Support Coordinator at the Stroke Association in Derbyshire, Sophie Dawson. She told us about Life After Stroke Grants and helped us apply for a grant to put towards the cost of the scooter. When Sophie told us the application had been approved, I couldn't believe it – I was excited!



"The day I was able to pick up Lola from school was a dream come true."

"The day I was able to pick up Lola from school was a dream come true. I went with Amy and we felt like a family.

"The scooter has been amazing for me as an individual and for my family. I've got a massive

part of my life back which I never thought would happen. I can watch Lola play in our local park and we have races outside our bungalow, with Lola on her bike against me on my scooter. We can also go to the shop together.

"The grant from the Stroke Association has been amazing for me; it has helped me feel like part of the family, which is what I always wanted. Thank you so much to the Stroke Association for making this possible and making my goal achievable."

Life After Stroke Grants

Life After Stroke Grants provide a vital lifeline to stroke survivors and their families. Grants can be for up to £300. So they're able to help those most in need, grants are means tested.

Recovery grants help fund household appliances such as cookers and washing machines but also home and equipment modifications such as handrails, specialist kitchen appliances and adapted wheelchairs – the sort of things that will help to improve your quality of life.

Activity grants help stroke survivors back into their local communities by funding activities linked to their recovery plan, such as training courses to get back into work.

Hardship grants help towards critical living costs such as food and fuel.

For more information or to apply, see stroke.org.uk/support/life-after or call the Stroke Helpline on 0303 3033 100.

First class news

Royal Mail Group has chosen the Stroke Association as its Charity of the Year, after receiving almost 40,000 staff votes.

Over the next two years Royal Mail aims to raise at least £2 million to fund our Life After Stroke recovery and activity grants. It's thanks to their amazing fundraising efforts that we'll be able to provide these vital grants to up to 10,000 people affected by stroke.



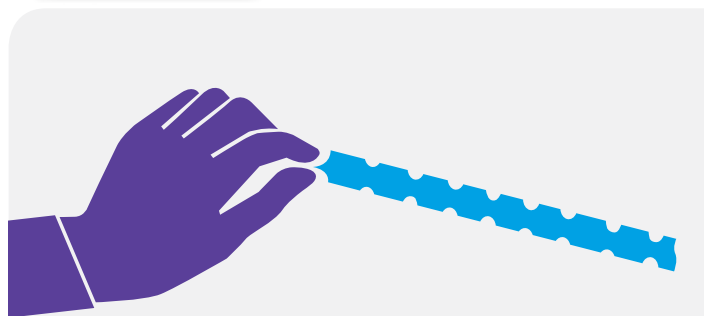
In brief: Helping hand weakness



After leaving hospital, someone with a long-term condition spends on average just three hours a year in contact with a healthcare professional. You can help your recovery by doing exercises at home every day.



Around 80% of stroke survivors have movement problems, usually on one side, because the part of the brain that controls movement has been damaged. Hand weakness can make everyday tasks, like preparing food and getting dressed, difficult and frustrating. Anna Lavelle, a physiotherapist at Virgin Care in Surrey, explains some simple exercises to help mild to moderate weakness in the hand which you can practice at home.



1. Stretching and strengthening fingers

Rolling out plasticine or playdough into a long sausage can help strengthen and straighten your fingers. Carefully judging how much pressure to apply stimulates the skin and helps regain feeling. For further practice, try coiling the sausage into a spiral or pinch with your thumb and fingertip at intervals along the length.

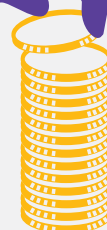
2. Increasing feeling

Touching different textures may help improve feeling in your hand. Fill a large container with dried beans, lentils or rice and push your hand through the beans, allowing them to cover the back of your hand. Stir them with your hand. Try grasping a handful and then let them fall through your fingers. Progress this exercise by feeling for and picking out small household objects hidden in the beans or rice, for example, a clothes peg or teaspoon.



3. Improving dexterity

Practising picking up small objects can help improve your ability to make precise movements with your hands and fingers.



First, try to pick up coins and turn them over. You may need to slide them to the edge of a table. Gradually try to pick them up without sliding. Then build stacks of coins, placing them accurately on top of each other. Use larger coins to start - £1 or £2, and then progress to smaller, thinner coins.

Driving after a stroke

After a stroke your ability to drive safely can be affected. You may experience vision problems, weakness or paralysis, difficulty concentrating or making quick decisions and fatigue. But when the time is right, many stroke survivors get back behind the wheel.

Q

Can I drive after a stroke or mini-stroke?

A

If you've had a stroke or mini-stroke (also known as a transient ischaemic attack or TIA) you're not legally allowed to drive for one month, even if your symptoms have fully stopped. After a month, your doctor will need to agree you're fit to drive. If you've had a number of strokes or TIAs, you'll have to wait three months.

Different regulations apply to drivers of Large Goods Vehicles or Passenger Carrying Vehicles so speak to your doctor for advice.

Q

Who do I have to notify?

A

If, after a month, your doctor agrees you can drive again, you can do so without informing the DVLA (DVA in Northern Ireland). If you've had multiple strokes or TIAs or your doctor or you feel that you're not fit enough to drive, you have to tell the DVLA/DVA. Before you start driving again, you must tell your insurance company, even if you've been passed by a doctor to resume driving, otherwise your insurance could be void.

Q

What if the doctor says I'm not fit to drive?

A

The DVLA/DVA will assess your circumstances with you and your GP. You may be required to undergo an assessment. Your local mobility centre can do this. Find yours at mobility-centres.org.uk or call **0800 559 3636**. The DVLA/DVA will use this information to decide whether or not it's safe for you to resume driving.

Tips for driving after a stroke

1

Always speak to your GP about your personal circumstances and take your return to driving slowly.

2

Always check if it's necessary to send your driving licence back to the DVLA/DVA before doing so.

3

If you get your car adapted you must inform the DVLA/DVA and your insurance company. Consider having lessons using the adaptations you've chosen.

4

You don't have to pay VAT on adaptations, their installation, repairs or maintenance.

5

Speak to your local mobility centre (mobility-centres.org.uk) and shop around for the best price on adaptations.

6

If you can't afford car adaptations, see if you're eligible for a Stroke Association Life After Stroke Grant. Find out more on page 12.

7

Under the Disability Discrimination Act, insurers cannot refuse disabled drivers insurance or charge extra without justifying evidence.

8

Stroke Association Insurance Services might be able to help. See stroke.org.uk/get-support/motor-insurance or call **0800 519 0759**.



Getting back behind the wheel

Last year, at the age of 63, Colin suffered a stroke which left him with paralysis down his right side. But he was determined to get back behind the wheel. When he left the rehabilitation hospital five weeks after his stroke, he was walking with the aid of a stick, and he started planning how to get back to driving.

Three weeks after leaving hospital, his occupational therapist applied for his assessment and test for him.

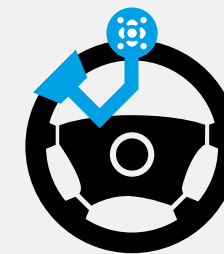
Colin said "It took two months to get an appointment and I was assessed at my local mobility centre in an adapted car because I'm unable to use my right arm properly and don't have much strength in my right leg. It took a while to get the pressure right on the accelerator and brake with my left foot, but it went well. The assessor was happy but wanted me to have some lessons to become more familiar with the adaptations before my test.

"Passing the test and getting my car adapted has made a huge difference to my independence. I can go and play bowls every week and do the shopping so my wife no longer has to do it all."

Some common car adaptations

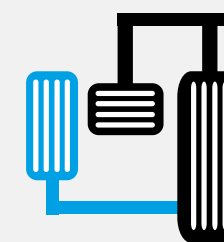
Steering wheel hand control/lollipop grip

This can be connected to your dashboard controls, so you can operate the indicators and windscreen wipers without removing your hand from the wheel.



A second accelerator

A left foot accelerator can be added to automatic cars. It can be flipped up so that other drivers can still drive the car.



Handbrake extension

This helps if you can't reach across your body to the handbrake as it raises it higher, making it easier to reach.



Life After Stroke Awards 2015

Do you know someone affected by stroke that has been truly inspirational?

They could be a stroke survivor, a healthcare professional, a carer or someone who's gone the extra mile to raise money to help conquer stroke. Whoever they are, nominate them now for a Life After Stroke Award and help them get the recognition they deserve.

Nominate before 30 January 2015 at stroke.org.uk/lasa

A courageous winner

James Cho won the 2014 Adult courage award (65+ years). After his stroke, James suffered further strokes for three consecutive days in hospital. He couldn't walk or talk. But, he fought back and he's shown incredible courage to regain his strength to be able to play with his grandchildren and get back on his beloved motorbike.

At the award ceremony James said: "It was an honour to receive the Stroke Association's award. It means a lot to me to be able to show people that there is life after stroke. I think others should get involved in the future to share achievements and recognise their efforts."



Travel insurance at any age

The team at Stroke Association Insurance Services are always looking at ways in which we can offer improvements to the service that has already helped so many. We're pleased to say that we have now removed the upper age limits on our annual policies. Of course, every policy is individually assessed and subject to terms and conditions and dependent on what medical conditions are declared and the destination. However, for those who may have been turned down for annual cover before on age alone, this may now be a different story.

Call us today **0800 519 0759** or visit stroke.org.uk/insurance to find out more and for no obligation quotations.

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The emotional impact of stroke

Most people know that a stroke can affect you physically. But stroke can also cause difficulties that are harder to see. These more hidden effects, such as emotional changes, can be just as devastating.

Uncontrollable, unprovoked crying after having a stroke is known as Post-Stroke Emotionalism or PSE for short. It affects a lot of stroke survivors but very little is known about the cause of PSE, with previous studies being small, and short term. Almost nothing is known about why and how PSE continues for a long time after having a stroke.

So the Stroke Association has funded a much needed study to learn more about PSE, including how it can continue long after a stroke has happened.

The research, starting early next year, will involve taking brain scans of stroke patients when they've first been admitted to hospital. This will allow the researchers to understand which part of the brain has been affected by their stroke. The patients will then be followed up regularly for a year after the stroke, to have their PSE symptoms assessed.

The goal of this study is to reveal how common PSE is, and what the connections are between PSE, the areas of the brain affected by stroke, symptoms such as depression and anxiety and overall quality of life.



Dr Niall Broomfield, NRS Career Fellow at University of Glasgow and Consultant Psychologist/ Head of Stroke Neuropsychology at NHS, Greater Glasgow and Clyde, is leading the research.

He said "The findings of this study could help develop new psychological treatments for PSE in the future and help more stroke survivors overcome the emotional impact of stroke."

Stroke is one of the biggest health challenges today. The Stroke Association funds research that is the driving force behind improvements in stroke treatment and support.

Our research programme relies on voluntary donations. We need your support to continue this vital work. To find out more see stroke.org.uk/research or to donate, visit stroke.org.uk/donation

Two of us

Only one in five stroke survivors receive the support they need to cope with the emotional impact of stroke. That's why our volunteer befriending scheme is so vital, particularly for people who don't have family support. But, befriending isn't all one way. Colette and Bernie have become the best of friends.

Colette Trainor

"I felt as if my body shut down when I had a brain stem stroke in 2007 at 43. My hand is still paralysed and I've lost the power down one side. I have chronic vertigo so struggle to balance and I suffer from incontinence.

"But the biggest problem my stroke caused was something you can't see; it was the anxiety I suffered which made every day a struggle. I felt paralysed with fear; I couldn't move, eat, or go outside. All I could do was sit in a chair. I thought I'd lost the life I once had and I didn't have family to support me, but then I met Bernie."

"Bernie must've thought I was mad when Janet Thompson from the Stroke Association in Belfast introduced us; I was shaking all over. But I knew I could trust her because the Stroke Association put us in touch.

"I thought I'd lost the life I once had but then I met Bernie."

"We clicked right away. We like the same things – popping out for a cup of tea, going to the shops and having a chat. But Bernie can also relate to my stroke. She's had two brain haemorrhages so when I heard about her health problems and how far she'd come, she gave me the confidence to think, 'If Bernie can do it, I can do it.'"

"For 18 months, we've been meeting for two or three hours a week. We call ourselves 'the talking twins' because we never shut up! It makes such a difference to talk to someone who's been through something similar to me. I can discuss my fears with her and she gives me confidence.

"If I hadn't met Bernie I'd still be sitting on the sofa. But she's given me hope, enjoyment and some fun. I've got a quality of life back. I feel awake."

"My role is to help Colette, but she's helping me."

Bernie Toner

"The first time we went out, Colette was a nervous wreck. I told her 'nobody's going to hurt you'. I saw how hard she found it but I also saw how determined she was to get out and about, no matter what. Every week I've seen an improvement in her anxiety.

"I told Colette about my two brain haemorrhages at 13 and 19 which left me paralysed down my right hand side and affected my speech. I was in a wheelchair and know what it's like to want to walk again. I had to learn how to do everything over so we can really relate to each other.

"How Colette's coped is astonishing. Her partner is brilliant, but she has no family. Her parents both died of cancer and her brother died due to alcoholism. So before we met she was isolated and just needed to get out. And I needed to get out as well.

"When I decided to volunteer, I'd hoped to make a difference to someone's life but I can't get over the difference it's made to my life. My role is to help Colette, but she's helping me. She totally inspires me and we've become the best of friends. She's made a huge difference to my life."



Interested in becoming a volunteer befriender?

You can help reduce isolation and improve the confidence of someone affected by stroke. To find out more, see stroke.org.uk/volunteer and email volunteering@stroke.org.uk



Need help to cope with the emotional impact of stroke?

Call our Stroke Helpline on **0303 3033 100** to find out about access to a befriender or other local support.



Clubbing Together

Whether you've had a stroke or you're a carer, stroke can leave you feeling very alone. That's why we support voluntary groups and stroke clubs that provide long-term peer and social support to thousands of stroke survivors and carers across the UK.



Almost three quarters of stroke survivors leave hospital feeling isolated. Once stroke survivors have left hospital and all other interventions have ended, stroke clubs and groups are a great way to continue receiving support.

They can act as a lifeline to people who need further support, but they're also there for family and carers too – either to attend with their loved ones or as an opportunity for a break for themselves.

You can socialise and get involved in therapeutic activities, such as art, music and exercise.

"You think that you're the only person in the world that it's ever happened to until you speak to people that have gone through it."

Find a club or group near you  stroke.org.uk/support/search  Stroke Helpline on **0303 3033 100**.

UK Stroke Club Conference

This year's UK Stroke Club Conference took place over two days in October. It brought together 152 representatives from 76 clubs and groups and was a fantastic opportunity to share ideas about running a stroke club or group. Workshops included fundraising for, and being a voice for, your local club or group, how to use twitter and understanding the hidden effects of stroke. To find out more see stroke.org.uk/club-conference



Back to business

When Bharat Patel had a stroke nearly three years ago, he worried he'd never go back to work and the business he worked so hard to grow would collapse. But thanks to his determination and a little help from the Stroke Association's Back to Work Service, Bharat is now celebrating his return to work.

"I was 53 when I had a stroke which left me with paralysis on one side and reading difficulties. I'd spent the last seven years running a dry cleaning business in North London and my biggest fear was that I wouldn't be able to return to work.

"Work was everything to me - it meant I could be there for my family and it was a social lifeline too since I was well known in the local community and loved getting to know my customers. I was used to being there every day, looking after the books and handling the cleaning - both physical and mental tasks I worried I was no longer capable of. I felt my stroke was a barrier to my past self and I lost my confidence.

"After my stroke, returning to work seemed almost impossible but I refused to let it prevent me from working and became resolved to get back to my business and my day-to-day life."

"I only work a couple of hours a day while I ease back into work."

Overcoming barriers

Around a quarter of strokes happen to people of working age. Some people find they're unable to return to work but with time and the right support, many people work again.

Bharat approached the Stroke Association's Back to Work Service which supports stroke survivors in London to return to employment or access volunteering and training opportunities, as well as helping employers to understand stroke.

The Back to Work Service helped Bharat set work-related goals and take small actions to reach them, such as rebuilding his confidence by attending a confidence building workshop. The project also supported Bharat to access a Life After Stroke Grant to adapt his car so he could get to and from work.

After a lot of hard work, last month, Bharat felt ready to go back to work.

"To be back in my business with a warm welcome from my regular customers meant the world to me. My staff have been extremely encouraging, and really understanding about my stroke."

Taking things slowly

Many stroke survivors experience fatigue. It can help to stagger your return and adapt your workplace.

"I now have a small chair for when I get tired and make sure I'm supported to use the dry cleaning equipment due to my mobility problems. I only work a couple of hours a day while I ease back into work but I'm hoping to increase this in time. It's a huge sense of achievement to be back and I owe a lot of thanks to the Stroke Association for helping."

Back to work tips

- 1 You may find you're not ready to go back to work, but there are still lots of options to explore so don't write yourself off too soon. You could try volunteering. Find out about roles at the Stroke Association at stroke.org.uk/involved/volunteer
- 2 Talk to your employer. They have a legal responsibility to do all they can to ensure you keep your job. They may be able to adjust your role, install equipment or let you work reduced hours. Put them in touch with your occupational therapist for advice or suggest they call the Stroke Helpline on **0303 3033 100**.
- 3 If, like Bharat, you're self-employed, find out what financial support you may be entitled to. Start by talking to your local Citizens Advice Bureau.
- 4 You may be entitled to financial support for practical assistance such as help with transport costs or a support worker to help you at work. See gov.uk/access-to-work
- 5 Talk to your occupational therapist about how you can make small adaptations to your workplace.
- 6 If you're in London, you and your employer can access our Back to Work Service. Find out more at stroke.org.uk/back-to-work



Money matters

Attendance Allowance – a vital benefit for older stroke survivors

- Q Are you 65 or over and living with a long-term disability?
- Q Do you find it difficult to look after yourself?

If so, you might be eligible for Attendance Allowance.

Many older stroke survivors may not know they're eligible for Attendance Allowance. This is a benefit paid to people aged 65 or over who have difficulty staying safe or looking after themselves because of a physical or mental disability.

How much can you claim?

You could get £54.45 or £81.30 a week, depending on the level of care you need.

Attendance Allowance is not means tested which means that your income or savings don't affect how much you can get.

How to claim

You can download the claim form AA1A from gov.uk/attendance-allowance

You can also get claim packs from the Attendance Allowance helpline. Ring **0345 605 6055** (Textphone: **0345 604 5312**) and you will receive a pack in the post. If you complete and return the form within six weeks, and you are successful, your claim will be paid from the date of the phone call.

The form comes with notes telling you how to fill it in and where to send it. It is a good idea to get help from an advice centre on how to fill the form in. Our Stroke Helpline will be able to suggest local sources of help and advice. You can call on **0303 3033 100**.



For younger stroke survivors

If you are under 65 and need help because of a long-term condition, you can claim Personal Independence Payment. For more information see gov.uk/pip/how-to-claim. We know some people have had difficulties claiming PIP and there have been delays in processing claims. Let us know if you've had problems by contacting our Campaigns and Policy Team at campaigns@stroke.org.uk or **020 7566 1510**.

Together we can conquer stroke

It's thanks to you that our Life After Stroke Services helped more than 67,000 people last year and we invested more than £2 million in stroke research to help prevent stroke and support stroke survivors. Here's a huge thank you and a look at what you've been up to.

You've been volunteering

You helped deliver 18 Resolution Runs across the UK between February and April, raising more than £136,000! If it wasn't for you marshalling, handing out water, registering runners and cheering them on, this wouldn't have been possible. The next series is kicking off soon. If you can volunteer, please contact resolution@stroke.org.uk to find your nearest run.



And taking on fundraising challenges



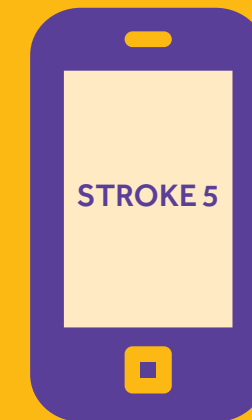
A huge thank you to the 2,000 of you who took part in **Step out for Stroke 2014** aiming to raise an incredible £250,000 to help conquer stroke. To take part in 2015, see stroke.org.uk/stepout



Steve and Russell Fagan raised more than £5,000 cycling 600 miles from Montrose in Scotland to Croydon in England in 10 days. Is cycling your thing? Register now for the Thames Bridges Bike Ride. Find out more at stroke.org.uk/TBRR



After Jake and Jade Wilson's mum had a stroke they got their friends together to do a sponsored walk up Snowdon raising more than £2,000.



Text STROKE 5 to 70300 to donate £5. 100% of your donation goes to the Stroke Association.

How does your donation help? (£)

£5 could help 15 people begin to come to terms with the effects of stroke with crucial factsheets like *Communication problems after stroke*.

£20 could support our helpline team to give life-changing advice to people struggling to cope with life after stroke.

£50 could help us continue to invest in vital research to help save lives and improve the lives of stroke survivors.

Stroke stars

Six-year-old Lily Dewbery had a stroke when she was just four. She has made an amazing recovery but still has mild weakness on her left side which affects her balance and sometimes her walking, and she can't move her hand very well. She has to take medication and undergo physiotherapy every day.

But this didn't stop her wanting to join her mum, Amanda, in the Lowestoft Scores Race in September. Race organisers arranged a mini route for Lily and her eight year old brother



Max and not only did they whip round the course on race day, but they helped to raise an amazing £500 for the Stroke Association to help other families affected by stroke.

Dates for your diary

17 December 2014

Last chance to buy! Stroke Association Christmas cards are available for orders received by 17 December. Order at shop.stroke.org.uk

23 January 2015

Got a creative flair? Entries close for the Stroke Association Christmas card design competition soon. Email cardcompetition@stroke.org.uk

May 2015

Action on Stroke Month is coming. Help Make May Purple for stroke. Order your information pack now at stroke.org.uk/strokemonth

10 May 2015

Registration is now open for the Thames Bridges Bike Ride. Three routes suiting families through to keen cyclists take in London's best landmarks. Sign up at stroke.org.uk/TBRR



Feel inspired?

There's something for everyone. Find an event near you at stroke.org.uk/find-an-event or to make a donation visit stroke.org.uk/donate or call us on 0300 330 0740.