

StrokeNews



SUMMER 2014

For everyone affected by stroke

A stroke can happen at any age

Since her sister was born severely disabled following a stroke, Cheyenne has been there for her

Childhood stroke

What does the research say?

Action on Stroke Month

We've been talking TIA

Mobility issues after stroke

Physiotherapists tell us about drop foot

stroke.org.uk

Stroke
association

Welcome...

It's worrying to think that nearly a third of people in the UK don't know what a stroke is. I imagine that of those that do, a huge proportion think strokes only happen to older people.

But a stroke can happen at any age. In fact, the rate of people having strokes under the age of 55 doubled in the UK from 1995 to 2010. Children and babies can have strokes too, and babies can even have strokes before

they are born (see our cover story on page seven).

We've had lots of calls to our Stroke Helpline recently from people affected by stroke at a young age. While there is no doubt that stroke can be devastating at any age, in this edition of *Stroke News*, we're focusing on some people of working age and younger who've had life-changing strokes.

Like Angharad who was 20, and is now volunteering for us (page 21) and Kevin and Alan who had to stop work in their early 50s (page 22) but are fighting back.

I hope you enjoy this summer edition.

Alex Bolton
Editor



Editor **Alex Bolton**
Design **Rick Nicholls**

Stroke News is published by the **Stroke Association**
Stroke Association House
240 City Road
London EC1V 2PR

stroke.org.uk
info@stroke.org.uk
Helpline **0303 3033 100**

To advertise in *Stroke News*, call Redactive Media Group on 020 7880 6200.

Volume 32.2 Summer 2014
© Stroke Association 2014

Every effort has been made to ensure that the information provided in this magazine is accurate, but we cannot guarantee accuracy and the information provided does not constitute legal or other professional advice. Opinions expressed in this magazine are not always to be taken as the opinions of the Stroke Association. Advertisements, products or services listed are not necessarily recommended by the Stroke Association.

Stroke News is printed on paper from sustainable sources.

The Stroke Association is a company limited by guarantee, registered in England and Wales (No 61274). Registered office: Stroke Association House, 240 City Road, London EC1V 2PR. Registered as a charity in England and Wales (No 211015) and in Scotland (SC037789). Also registered in Northern Ireland (XT33805) Isle of Man (No 945) and Jersey (NPO 369).



18

Regulars

03 Over to you

We share your experiences

06 News

Talking TIA during *Action on Stroke Month*

10 Guidance

Childhood stroke Q&A

12 Money matters

We look at Personal Independence Payments

16 In brief

A focus on drop foot

18 Research

We're investing in research to understand childhood stroke

25 Thank you

A big thank you for your support



13

Features

07 On the cover

Fourteen-year-old Cheyenne is the eyes and voice of her little sister

11 A carer's perspective

Anna McCartney shares her story of becoming a carer

13 Life After Stroke Awards

We recognise our amazing winners

19 The UK Stroke Assembly

Learning skills, supporting each other and influencing stroke campaigns

22 Two of us

Stroke survivor Kevin Allum and coordinator Alan Kerby share their story



To sign up to receive three editions of *Stroke News* per year or to listen to an audio version, visit stroke.org.uk/strokenews or call **01604 687 721**.

Over to you



We love hearing from you. Join the Stroke Association community and share your experience. You may help inspire others affected by stroke.

Fighting back

I had two strokes aged 42. Now 48 and back at work caring for disabled children. Glad I fought a good fight to get my life back.

 **Sharon Simpson (Facebook)**

Find us on Facebook (facebook.com/TheStrokeAssociation), Twitter (@TheStrokeAssoc), email strokenews@stroke.org.uk or write to us at Stroke News, Stroke Association House, 240 City Road, London, EC1V 2PR.

Can you help?

We're facing increasing costs to produce and send *Stroke News* to you for free.

Stroke News is a lifeline for thousands of people who've been affected by stroke, offering guidance to cope after a stroke and inspirational stories showing you there is life after stroke.

We'd like to continue to make *Stroke News* available for everyone who would like to receive it.

If you're able to help us, please make a donation at stroke.org.uk/strokenews-donate or call 01604 687 777.

As a charity we rely on your support.

If you'd like to unsubscribe or would be happy to read *Stroke News* online, please email strokenews@stroke.org.uk or call 01604 687 721.

Thank you for your support.

We're the leading stroke charity in the UK. We're here for you.

We can answer your questions about stroke and help you get the support you need.



Stroke Helpline

If you need advice call our helpline confidentially on **0303 3033 100**. We'll arrange interpreters to help if English isn't your first language.



TalkStroke

Find out what has worked for other stroke survivors and carers and provide each other with support at stroke.org.uk/talkstroke



Factsheets and leaflets

We produce information on issues from driving after stroke to depression and exercise. See stroke.org.uk/shop to order printed copies or download them for free.



Clubs and groups

Whether you need communication support or you're a carer who needs a break, we have clubs and groups across England, Wales and Northern Ireland. Find what's near you at stroke.org.uk/support/search

Hot topics

A quick round up of what's hit the headlines and what new support is available for you.

➔ Atrial fibrillation (AF)

New guidelines issued by the National Institute for Health and Care Excellence (NICE) in June highlight the need to make sure people who have AF are offered the right treatments to help avoid stroke. If you have AF, speak to your doctor and check the guidelines at nice.org.uk/guidance/CG180



➔ Good news for carers in Wales

The Social Services and Well-Being (Wales) Act 2014 became law on 1 May laying the basis for a shake up of how adult and children's social services operate in Wales.

The Act will help carers get the equivalent rights to those they look after. Find out more at <http://tinyurl.com/mfn45cp>

➔ Raising concerns about care

In June, the Nursing and Midwifery Council (NMC) produced a new leaflet for patients, carers and the public which explains the role of a nurse and midwife and what you should do if you have any concerns about the care you or a loved one has received.

Find *Raising concerns about nurses or midwives* at <http://tinyurl.com/l75vg9p>



➔ Update on Alteplase

We wrote a joint letter in June in response to a *Sunday Times* article suggesting thousands of deaths could be blamed on clot-busting drug Alteplase. We feel the article misrepresents the evidence base for its use in treating acute stroke and dangerously contradicts current guidelines. It may result in patients inappropriately declining treatment which can reduce the impact of their stroke. See the full response at stroke.org.uk/news/letter



Not just a funny turn

The real impact of TIA

Most people don't know that a TIA or transient ischaemic attack (also known as mini-stroke) is a warning sign that a major stroke could be on its way.

Every year 46,000 people in the UK have a mini-stroke for the first time. More than one in 12 will go on to have a major stroke within a week. Thousands of people a year could avoid the serious consequences of stroke by spotting the symptoms early and having swift access to specialist services.

Our latest campaign report, *Not just a funny turn*, based on the feedback of 670 people across the UK who have had a TIA, found:

- more than a third of people having a mini-stroke thought it was a 'funny turn'
- only one in five people experiencing symptoms rang 999
- a quarter of people said that healthcare professionals had not recognised the symptoms
- a fifth of people went on to have a major stroke
- fortunately, some people saw mini-stroke as a wake-up call to reduce their stroke risk through lifestyle changes such as improving diet.

What are the signs of a mini-stroke?

They're the exact same as a major stroke but they last less than 24 hours.

The FAST test can help you recognise the most common symptoms but other symptoms include sudden weakness or numbness on one side, sudden loss of vision or blurred vision, memory loss or confusion, dizziness or unsteadiness.

- F** Facial weakness – can the person smile? Has their mouth or eye drooped?
- A** Arm weakness – can the person raise both arms and keep them there?
- S** Speech – can they speak clearly and understand what you say?
- T** Time – if you see any of these signs, it's time to call 999.

Don't dismiss the signs, even if they pass quickly – it is a medical emergency.

What should you do if you think you've had a mini-stroke?

If you've not sought medical attention, see your GP urgently. Investigation and treatment could reduce your risk of having a major stroke.

We are now working with other organisations and government bodies to tell people how to recognise a mini-stroke, not to dismiss it as a 'funny turn' but treat it as a medical emergency.

To read the report and get involved in the campaign, visit stroke.org.uk/tia

An action-packed Month

Thousands of people across the UK came together in May to celebrate our biggest and best *Action on Stroke Month* yet and spread the word that a mini-stroke is not just a funny turn.

Thanks to each and every one of you who got involved to help change the way people think about mini-stroke. Whether you sent out our mini-stroke awareness booklets, held a community fair or helped raise vital funds through a *Step out for Stroke* event – your support is invaluable.

People hit the streets to spread the message and nearly 40,000 mini-stroke awareness booklets were sent out to health professionals and the public. More people will now get urgent medical attention if someone is showing any of the signs of stroke, even if their symptoms don't last very long.



More than 2,000 of you took part in *Step out for Stroke* events aiming to raise £250,000 to prevent stroke and improve the lives of people affected by stroke.

Special thanks go to Legal & General for supporting *Action on Stroke Month*.



Fourteen-year-old Cheyenne wins carer's award

"I remember when the doctors told me that my baby sister might never walk, talk or see. I thought 'she's my little sister and I'll be here for her no matter what'."



The moment Cheyenne McLaughlin's little sister was born, she was rushed into intensive care. She was having seizures and the doctors could see she was weak on one side. An MRI confirmed their suspicions; Caitlin had had a devastating stroke before she was born.

Hearing their baby girl may never lead a normal life was devastating for Caitlin's family. They didn't know it was possible to have a stroke before birth. They were in shock.

The majority of children with brain damage receive damage to one part of their brain, but for Caitlin, the entire rear of her brain was damaged on both sides. The damage it caused was so devastating that most adults would not have survived.

For Cheyenne, who was eight years old, her life took a dramatic turn as she chose to help care for Caitlin, supporting her parents and the doctors in her baby sister's life after stroke.

"I was scared when Caitlin was born," she remembers. "I'd heard the word 'stroke' but I had no idea what it meant. I can remember when the doctor sat me and my brothers down and showed us a picture of what a brain looks like. He said that before she was born, Caitlin didn't have enough blood going to her brain and she might not ever walk, talk or see."

With the support of Cheyenne, her parents and a team of medical experts, Caitlin has made a remarkable recovery.

She has severely impaired vision, cerebral palsy and epilepsy due to the brain damage caused by the stroke. She has a speech delay and learning difficulties, but when she said her first word 'daddy' and then at the age of three started to walk, her family and the whole medical community were stunned. ▶

Cheyenne became Caitlin's eyes, her voice and her carer.





“Don’t always believe what you’re told – you can achieve anything.”

Taking on the role of carer

From the moment Cheyenne met her little sister in intensive care, it was clear they would have a special bond. As soon as Caitlin was home, Cheyenne took on a very special role in Caitlin’s life; she became her eyes, her voice and her carer.

Cheyenne is the first to support Caitlin with everyday tasks. She wakes her up and helps her get ready for school in the morning and she’s there to pick her up from the bus at the end of the school day.

She plays and reads with her in the evenings.

She also supports her parents and the doctors with her rehabilitation and constantly helps to stimulate Caitlin’s brain, helping encourage it to take over the parts she lost. She jumps in and helps with physiotherapy sessions and she’s the first person to help when Caitlin has seizures. She even chose to share a bed with Caitlin, so she knows if she has a seizure during the night and can be there to comfort her if she is distressed.

Getting the recognition a carer deserves

Now 14, Cheyenne has been recognised with the Stroke Association’s Carer’s award at the *Life After Stroke Awards*.

The award is for a person who continues to demonstrate their commitment to caring by providing personal, practical and emotional support for a stroke survivor – qualities which Cheyenne shows in abundance. As actress Tamsin Greig said as she presented Cheyenne the award, “Those caring for stroke survivors are often unsung heroes. I can’t think of a more deserving recipient than the truly inspiring, Cheyenne.”

Supporting you

A stroke can happen at any age, but childhood stroke in particular can come as a huge shock. If you need support, see our factsheet at stroke.org.uk/shop/childhood-stroke and our Q&A on page 10.

The role of a carer can be vital but it can be physically and emotionally challenging. Our factsheet, *Stroke: A carer’s guide*, contains a lot of useful information. See stroke.org.uk/shop/carers-guide and our guidance article on page 11.



Guidance

Q&A on childhood stroke

About 400 childhood strokes happen every year in the UK – that’s more than one a day. Yet many people think strokes only happen to older people, so a stroke in a baby or child can come as a big shock and families often don’t know where to turn for support.

Our Child Stroke Project Manager, Anna Panton (right), answers some common questions families ask.



Our Child Stroke Project, in collaboration with Evelina London Children’s Hospital, is here for you. Contact Anna on 07715 065 925 or visit stroke.org.uk/about/childhood-stroke

Q

What are the signs of childhood stroke and secondary stroke?

A

Seizures are a common symptom in babies up to 28 days old. Between 28 days and 18 years, the symptoms are the same as adults and may include weakness or paralysis on one side, facial drooping, speech problems, headaches and vomiting.

Q

What can be done to reduce my child’s risk of another stroke?

A

Childhood strokes are caused by very different factors to adult strokes. They can be linked to an infection, underlying heart condition or a problem with the way blood clots or is supplied to the brain. Each child who’s had a stroke will be assessed to identify their risk factors. If there’s a risk of further stroke, doctors will aim to minimise this, perhaps through medication, scans monitoring blood flow to the brain, or surgery.

Q

What services can help?

A

After a stroke your child should be under the care of a paediatrician. They can help refer you to local therapy teams and support. If this hasn’t happened, ensure you get a GP referral.

If your child is at school, the school will have Special Educational Needs (SEN) Coordinators (or Additional Support Needs (ASN) in Scotland) to discuss learning concerns. They may put you in touch with an educational psychologist to assess your child’s needs.

Q

How can I help my child’s recovery?

A

Sit down with the team working with your child. You may find it helpful to talk through test results, hear about different treatment options and how you can help deliver therapy at home.

It’s important to be able to re-access services as children get older, as other issues may arise. This might include seeing clinical psychologists about mood and behaviour, or occupational therapists about everyday independence. Your paediatrician or GP can make appropriate referrals.



A carer's perspective

It was just two days before one daughter turned 18 and the other graduated that David McCartney had a devastating stroke at 47. His brain swelled so much that the doctors presented his wife Anna with a choice; operate to remove half of his skull, or do nothing, and risk losing David.

It was an easy decision but taking on a carer's role has been a huge challenge.

"David came home after more than four months in hospital," remembers Anna. "His memory and speech were affected; he needed help with everything. To begin with, he wasn't David and our relationship changed as I went from wife to carer.

"I went into autopilot. I stopped work, got involved in every aspect of David's physical and emotional support and looked after the girls. It was hard but we had to carry on as usual.

"From the outset, when we met on the ward, Jane, a Family and Carer Support Coordinator at the Stroke Association, has been

a big support. She made sure I had a carer's assessment so someone comes every morning and evening to help David in and out of bed and shower him.

"The biggest problem I faced was finding groups for young stroke survivors. But I refused to give up. Eventually we found a painting and a gardening group. It means I've been able to go back to work two mornings a week, catch up with the girls and concentrate on something different – it's a huge relief.

"It's taken two years but David is back. He's got stronger and his speech and memory have improved. It's been a tough journey but as a carer it's about making sure you get the right support."

If you're a carer, you're not alone.

Consider these steps:

- 1 Think about your emotional support and register as a carer with your GP. If you're going to provide substantial care, you're entitled to a carer's assessment of your needs. Speak to your GP about how to access this in your local area. They can also advise about respite care.
- 2 Talk to your employer – you have the right to request flexible working and time off to look after dependants in an emergency.
- 3 Visit our online forum (stroke.org.uk/talkstroke/carers) to speak to people in a similar position.

Money matters

Almost a third of strokes happen in people under 65. As the leading cause of complex adult disability it can make everyday tasks, including work, extremely difficult, if not impossible. Many people find they're unable to work, which quickly impacts their income and expenses.

The benefits system is complex and changes frequently. Your first step should be to speak to your local Citizens Advice Bureau for personalised advice.

Focus on PIP

In this *Money matters*, we look at Personal Independence Payments (PIP), a relatively new benefit which is replacing Disability Living Allowance (DLA).

We've heard some people have had to wait a long time for their claim for PIP to be decided. An independent review of PIP is looking at ways it can be improved. You can contribute to the review, which will be taken to Parliament before the end of the year.

Complete the survey online before 5 September at <http://tiny.cc/w3fsix> or call our Stroke Helpline on **0303 3033 100** for information of other ways to respond.

Who is entitled to claim PIP?

To qualify, you must be between 16 and 64 and have

a long term illness or disability that affects your ability to get around or complete daily tasks such as preparing food or managing your medication.

What are the benefits?

You can claim PIP whether you are in work or not and regardless of your income or savings. PIP recognises cognitive and communication difficulties more than DLA.

I claim DLA, will this affect me?

Most people on DLA will be reassessed for PIP starting from next year. If your condition changes or your award of DLA comes to an end you will need to make a new claim for PIP. Find out more at www.gov.uk/pip-checker or call the PIP helpline on **0845 850 3322**.



Did you know?

The Stroke Association is part of the Disability Benefits Consortium (DBC), a coalition of more than 50 charities. We are committed to working towards a fair benefits system and we are calling on the government to provide support for those in severe financial hardship as a result of the delays.

Life After Stroke Awards 2014

Emotion and celebration ran high at this year's *Life After Stroke Awards* as we recognised the outstanding achievements of stroke survivors, carers, volunteers, stroke clubs and health professionals – all of whom have shown incredible determination and spirit in their journey with stroke.



They came together for a very special day hosted by our award's patron Karren Brady CBE and much-loved actor Christopher Biggins. And the winners were...

Special thanks to Toni&Guy, our *Life After Stroke Awards* 2014 sponsor.



Corporate supporter of the year award
Presented by Michael Lynagh, Nick Hewer and Lord Sugar
Herbert Smith Freehills LLP

Herbert Smith Freehills chose us as their charity of the year in 2013. Their staff were completely committed to changing the lives of people affected by stroke, raising an incredible £105,000 through bake sales, quizzes, marathons and a zip wire challenge.

Fundraiser of the year
Presented by Hilary Devey, sponsored by QVC
Amanda Morris

When Amanda's friend Paul had a stroke just before she turned 39, she found a unique way to raise money for us. 'Forty challenges b4 40' included 40 challenges with a '40' theme. She's so far raised an amazing £11,500 by running, rowing and cycling 40kms and making 40 cups of tea in a day.

Stroke group award
Presented by Kim Woodburn and Kate Haywood
Burton and District Stroke Club

More than 50 members of Burton and District Stroke Club meet every fortnight. Over the last 39 years, the group, staffed by volunteers, has offered valuable community-based support. It has organised trips which stroke survivors thought were no longer possible, from the London Eye to Scotland.

Special recognition award
Presented by Phyllida Law and Dr James Logan
Rotary Great Britain and Ireland

Rotary won this award for its outstanding contribution to our *Know Your Blood Pressure* campaign. Organising 426 events in 2013, they checked the blood pressure of thousands of people to help prevent stroke and save lives.

Professional excellence award
Presented by Andrew Marr, sponsored by Gemini Search
Melissa Peters

Physiotherapist Melissa, was nominated by a patient, Andy. He says: "My life fell apart when I suffered a stroke. But if I had known I was going to meet the world's best physio I wouldn't have been half as worried. She helped me stand up by myself and taught me to walk again. She is my hero."

Award for volunteering
Presented by Jermain Jackman and Ping Coombes
Sarah Scott

Sarah had a stroke when she was just 18 that caused severe communication difficulties. She's shown remarkable bravery in her recovery and determination to help others with aphasia through a communication group she set up. She's also raised awareness of stroke at events and in local schools.



Check out our short videos of all of the winners' stories at stroke.org.uk/lasa

Award for creative arts

Presented by Tim Vine and Stephen K Amos
Pieter Egriega



Pieter had a massive stroke in 2013 which left him unable to move his right arm or leg. His biggest fear was that it would be the end of his music, painting and writing – the talents he cherished most. With immense determination, five months later he was performing at the Manchester Town Hall and has gone on to write two books.

Children and young people's award

Presented by Sian Lloyd and Amanda Lamb, sponsored by The Entertainer
Hannah Garrity



Hannah was eight when she had a stroke which she was not expected to survive. She couldn't move or speak for weeks. With inspirational courage, after six months of intensive rehabilitation, she returned to school in an electric wheelchair before regaining her ability to walk. She's now a champion swimmer.

Adult courage award (18-64 years)

Presented by Russell Howard, sponsored by Herbert Smith Freehills LLP
Angharad Lloyd-Thomas



Angharad had a stroke at the age of 20. She had to quit her job and couldn't consider going back to university. But, just six weeks later, her courage paid off as she returned to her studies. She went on to graduate with a 2.1 and has now become an inspirational volunteer for the Stroke Association.

Adult courage award (65 years +)

Presented by Lynda Bellingham, sponsored by Hospital of St John and St Elizabeth
James Cho



After his stroke at 62, James suffered further strokes for three consecutive days in hospital. He was unable to walk or talk and lost mobility on one side. He's shown huge courage to regain his strength and get back on his beloved motorbike.


Carer's award


Presented by Tamsin Greig, sponsored by Delta Global Source
Cheyenne McLaughlin




Fourteen-year-old Cheyenne's little sister had a stroke before she was born. Cheyenne took on a very special role in Caitlin's life; becoming her eyes, voice and her carer. She's shown huge commitment to help care for Caitlin, who has extensive brain damage, cerebral palsy, epilepsy and visual problems due to the stroke.

Top tweets from the #StrokeAwards

 **@jazzbhogal_DH** #StrokeAwards In the company of the most inspirational and strong people - see prevention, early diagnosis and treatment in action!

 **@Dr_JamesLogan** I've never met so many brave and inspirational people in one day! #StrokeAwards @TheStrokeAssoc

 **@CharlotteAugst** Feeling humbled yet energised after the fabulous, moving #StrokeAwards. Amazing what people can achieve through effort of hearts and minds.

Follow us on Twitter @TheStrokeAssoc

Nominations for next year's awards open in November – see your next edition of *Stroke News* to find out more.

In brief: Drop foot

Around 80% of stroke survivors experience mobility problems. Needing help with everyday tasks can be frustrating; you may feel you've lost your confidence or independence. But, with time and hard work, many people are able to relearn normal patterns of movement.

Drop foot is when the muscles that lift your toes and/or ankle are weak or aren't working correctly. Your toes catch the ground and you are more likely to trip and fall. It affects nearly a third of stroke survivors.

Physiotherapists Dawn Hicklin and Clair Finnemore, from Sandwell and West Birmingham Hospitals NHS Trust, explain three common treatments.



"Every stroke is different. A multidisciplinary stroke team will assess what treatment is right for you."

1

Functional Electrical Stimulation (FES)

What is it? FES uses small electrical signals to directly stimulate the weak muscles to work. The signals replace the nerve impulses that have been interrupted by damage to the brain.

Usually, electrodes are applied directly to the skin by self-adhesive patches and are connected to a battery-powered stimulator. When your heel leaves the ground, a sensor in your shoe activates the electrodes to stimulate the nerves and shorten the affected muscles to help you lift your foot.

Is it right for me? FES is not for everybody. It must be assessed on an individual basis by a registered and qualified professional. You cannot use it if the nerves controlling your muscle movement have been damaged. Also, you may be hypersensitive to the pads or dislike the sensation of the electrical impulse.

How do I find out more? Your GP might refer you to your local service if FES is right for you.

2



Ankle-foot orthosis (AFO)

What is it? It's a brace worn on the lower leg that holds the foot and ankle in the correct position to prevent drop foot. The brace supports your ankle so you can support your weight safely. It can help to improve walking speed, stability and balance.

Is it right for me? An AFO must be assessed on an individual basis by a registered and qualified professional such as a physiotherapist. People who have diabetes, peripheral vascular disease, reduced sensation or excessive swelling of the legs may not benefit from this device.

The AFO may be bulky, affecting the style and size of the shoe you can wear. It can cause redness or irritation, which you should speak to your healthcare professional about. Wearing a thin sock between the skin and device can help. The AFO needs to be regularly checked to ensure it fits correctly at all times.

How do I find out more? Speak to your GP for a referral to a specialist physiotherapist and orthotist.

3



Gait re-education

What is it? Gait re-education can be an important physical therapy intervention for patients following stroke. A therapist, orthotics or gait specialist may observe your walking pattern and help you re-learn to walk through a variety of interventions. These can include muscle strengthening, muscle stretches, assisted devices (such as an external brace), treadmill work, hydrotherapy or a home exercise programme.

Is it right for me? It depends on each individual; how much your walking has been affected and how long ago you had your stroke. The ultimate aim is for a good walking pattern but this has to be balanced against how much movement and the quality of movement you have regained since your stroke.

How do I find out more? If you think your walking pattern has altered recently, discuss referral options with your GP.

You can find products to help with mobility issues, including aids and adaptations to your home on our website at stroke.org.uk/dailyliving

Research **to** understand childhood stroke

Strokes probably cause 10% of all deaths in childhood and many childhood stroke survivors will be left with severe physical and mental problems. However, not enough research is being carried out to understand childhood stroke.

Strokes happen in children for very different reasons than adults. Strokes in adults tend to happen because arteries 'fur up' and block blood from flowing to the brain. The risk of this can be increased due to certain lifestyle factors, including poor diet and smoking.

However, childhood strokes usually happen because a child already has an existing condition that makes them vulnerable to stroke. The two most common are being born with a heart that isn't formed properly, which is called congenital heart disease (CHD), or being born with blood that isn't formed properly, called sickle cell anaemia (SCA).

We funded Dr Finbar O'Callaghan, from the Institute of Child Health, to find out at how often a type of childhood stroke called AIS (arterial ischaemic stroke) occurs in children of different age, gender and ethnic background.

AIS is caused by a blocked artery in the brain. There are lots of different reasons why it can happen, and we still find it difficult to know what the cause is.

The findings

His team found that black and Asian children were at a higher risk of AIS when compared to white children and the highest risk was found in children under the age of one. He also found that gender did not make a difference to the risk of this type of stroke.

Dr Shamim Quadir, Research Communications Manager at the Stroke Association, said "We now need further investigation into what causes the increased risk of AIS in these children, and how we can use that knowledge to reduce the impact of childhood stroke."



Stroke remains one of the biggest health challenges today, yet it is still not getting the attention or funding it deserves.

Our research helps prevent strokes, save lives and helps stroke survivors make the best recovery they can. It is totally funded by voluntary donations. To find out more see stroke.org.uk/research

Talking about the issues that matter to you

The UK Stroke Assembly brought together more than 200 people affected by stroke to learn new skills, support each other and help influence stroke campaigns.

The annual two-day event had a packed programme with leading stroke experts presenting the latest developments in stroke healthcare, research and campaigns.

Presentations, which were influenced by people affected by stroke at last year's event, focused on vision problems after stroke, research into predicting language outcomes and recovery after stroke and the Stroke Association's most recent campaign about the real impact of mini-stroke.

Professor Tony Rudd, National Clinical Director for Stroke with NHS England, talked about the future of long-term stroke support services and how the most recent NHS England Business Plan will impact the availability of support for stroke survivors and their carers.

"We need to recognise that the NHS will not be pouring massive amounts of money into stroke care over the next five to 10 years," he warned. But he added that if resources are used effectively and efficiently more strokes can be prevented and people can access the right support to make their best recovery.

He stressed the need to make stroke services more coordinated and standardised, so that everyone has immediate access to the highest quality of specialised acute care to minimise the effects of stroke. He also talked about the need for enough therapy of the right sort to be available for as long as it continues to be of benefit.

In addition, Professor Rudd expressed the importance of recognising the psychological impact of stroke and its impact on quality of life. He described how there is an opportunity within the NHS England Business Plan for stroke survivors to get better access to psychological services of a high quality under the structure of services called Increasing Access to Psychological Therapies (IAPT).

Professor Rudd encouraged the Stroke Association to continue our collaborative work with Public Health England to increase awareness of the signs of stroke through the 'FAST test' (Face, Arms, Speech, Time) and also to ensure the right decisions are made by policy makers so that people lead healthier lifestyles by increasing knowledge of salt content in foods and ensuring better recognition and treatment of atrial fibrillation.



"We need to recognise that the NHS will not be pouring massive amounts of money into stroke care over the next five to 10 years."

Sharing experiences

People affected by stroke shared their concerns and hopes for stroke care. Some of the key themes raised included the need for more support for carers and for more information about how to support aphasia in the long-term.

We will use this feedback to help support future campaigns to bring about positive change for people affected by stroke across the whole of the UK. Some of the key messages from the assembly will also be discussed with stroke care professionals at the UK Stroke Forum in December to help shape services and standards of stroke care.

Rehabilitation workshops

The UK Stroke Assembly also offered practical sessions and workshops for stroke survivors' more immediate rehabilitation, many run by stroke survivors themselves. Workshops explored issues from pain management and fatigue, to more hands-on sessions about horticultural therapy, dance and music rehabilitation.



To find out more about next year's event, visit strokeassembly.org.uk or call 01527 903 930.

I never knew a stroke could happen to someone so young

Life couldn't have felt brighter for Angharad Lloyd-Thomas; she was at university with dreams of becoming a teacher and living away from home for the first time. But it all seemed to be snatched in an instant when she woke feeling numb down her left side one morning. She couldn't balance or speak clearly. She was having a TIA.

"I ran unsteadily into my housemate's bedroom and said 'I think I'm having a stroke,'" Angharad remembers. When her housemate heard things crashing to the bathroom floor moments later, she jokingly called; "you're not having another stroke are you?" Neither of the girls was aware a stroke could happen to someone who was only 20.

After a series of TIAs, or transient ischaemic attacks (also known as mini-stroke), it was in the waiting room of A&E that Angharad had a major stroke. It left her unable to move for days. Her speech was muddled and her vision blurred.

When she left hospital, she had to move back to her mum's home, quit her job and abandon university. Suddenly, everything she'd hoped for seemed to come crashing down.

Turning things around

But Angharad was determined that nothing would stand in her way of graduating. She focused on exercising her weak side and started swimming which she found made her stronger.

Just six weeks later Angharad returned to university and, more driven than before the stroke, she went on to graduate with a 2.1.

Now 22, Angharad still suffers chronic post stroke pain in her left side and gets tired easily, but she is living life to the full. She's working as a Learning Support Assistant and starts teacher training next month.

Volunteering for the Stroke Association

Angharad is determined to increase young people's awareness of stroke. She's become a Stroke Association Stroke Ambassador and Media Volunteer giving talks to young people in her community and raising awareness of stroke through the media. But she hasn't stopped there. She's spoken to decision makers from the Welsh Assembly about her experiences and volunteered at *Step out for Stroke* in Cardiff.

Volunteers, like Angharad, are vital to our work. Your skills, time and passion will make a huge difference. See what you can do at stroke.org.uk/involved/volunteer



Two of us

"Alan helped me reorganise every aspect of my life – from managing my finances after having to stop work, to coping with the frustrations of learning to walk again. But more than that – as a stroke survivor himself, he's shown me what can be achieved. I don't know where I'd be without him."

Kevin Allum

"When I first met Alan, an Information, Advice and Support Coordinator at the Stroke Association, I was at a total loss. I'd just left hospital after my stroke. I didn't know where to go or what to do. My life seemed over at 52."

"I'd always been active and spent the last 28 years in the army, but all of a sudden I could no longer walk, I'd lost the use of my left side, which was tough as I was left handed, my memory was affected and sometimes I picked the wrong words."

"One of the biggest fears was imagining I'd never go back to work. I couldn't stand the idea of people thinking of me as a 'freeloader'."

"Alan was so outgoing and positive and because he's a stroke survivor too, he was such an inspiration. Just hearing him say 'I remember that' made me determined. All of sudden it didn't feel like the end of the world."

"I was stuck in a financial black hole and he helped me access benefits. It meant all the difference to be able to get by, pay bills and put food on the table. Hearing his journey back to work was a huge inspiration. It's a goal I continue to focus on."

"He put me in touch with a speech and language therapist and motivated me to get back into exercise. I worked really hard at the gym and with the physiotherapist. After five months I was able to start walking with a stick."

"Alan's been there through thick and thin. I got easily frustrated

at first; it would bring me to tears trying to do something that I'd taken for granted before – something as simple as making a cup of tea. It was so tedious having to do something not once or twice, but 300 times as I re-learned it, but I was determined to get there."

"Now, life is looking up. My walking and speech have improved dramatically and I'm able to write better with my right hand now than I ever could with my left. I'm focused on the future and getting married at the end of August, and of course Alan is invited. He's not just helped me enormously; he's become a friend."

"Hearing Alan say 'I remember that' made me determined. All of sudden it didn't feel like the end of the world."

Did you know?

Almost a **third** of strokes happen to people of working age; many are unable to work and face financial hardship.

Help is available. Call our Stroke Helpline on **0303 3033 100** for support in your area.

If you're in London, our 'Back to work' scheme can help with workshops on anything from interview techniques to confidence building. For information, contact Kate Pieroudis on **020 7940 1353**.

In North East England we work in partnership with Momentum Skills. To find out how we can help with your journey back to work contact Alistair Miller on **0191 4879 988**.



Alan Kerby

"Kevin was very poorly when we first met and finding himself not in control was a real blow. But I quickly realised he had a tremendous fighting spirit and was determined to take on challenges one by one – and that's half the battle."

"I remember how frustrating it was when I had my stroke, not knowing there were things out there that could help. Through my job I help people like Kevin access the support that gives them a route through their problems."

"Kevin was living in inaccessible housing so we sorted that and applied for benefits."

Administration can be confusing when you've had a stroke because your cognitive abilities are impaired so I helped with filling out forms to access support. He's grabbed all the help available, which is important."

"I was a similar age to Kevin when I had my stroke. At first I couldn't walk or do anything. I had to stop work and I know how hard that is. My whole family was affected. My youngest daughter was five – she woke up one morning and I wasn't there. But I spent six months with occupational therapists and a physio and didn't give up hope. That sense of determination is something Kevin and I share."

"Getting back to work meant everything to me – and I know Kevin will get there too. I began volunteering at a Stroke Association Communication Support Group before I accepted a full time job with the charity. It was such a big thing to feel useful again."

"I feel I have a unique insight into people's problems as a stroke survivor myself. People tell me they really appreciate that I know what they've experienced. It's extremely rewarding to hear that and to see improvements people make because of the support I've given them."



Congratulations to this year's competition winner



Congratulations to our 2014 Christmas card competition winner, Sally Johnson, with her card, *Knitvity*.

Sally, 67, had a stroke four years ago which caused communication difficulties and reduced mobility in her left side. She suffered severe anxiety and low self-esteem which left her practically housebound for 18 months.

Then she met Lucy, a Communication Support Coordinator at the Stroke Association. Sally says, "When Lucy came into my life, she helped me take up my old hobbies – her encouragement brought back confidence and self-belief."

With determination, Sally taught herself to knit again. It took three months but she knitted the figures on the card to show other stroke survivors what could be achieved following a stroke.

Sally's winning card is available to buy, alongside a range of other fantastic cards and gifts in this year's Christmas catalogue. You'll also find out how to enter the 2015 Christmas card competition.

Find your Christmas catalogue inside this issue of *Stroke News*.

Could you benefit from a Stannah stairlift?

After a stroke, you may find day-to-day tasks more difficult than before, including climbing the stairs. To help you stay as independent as possible, Stannah and the Stroke Association have come together to offer you a 10% discount on any Stannah stairlift purchase. Stannah will also make a donation to the Stroke Association on any rental or purchase.

How it works

1. For a free no obligation quote, contact **0800 715 346** quoting 'shop ref 217' to ensure the Stroke Association receives the donation.

2. Stannah will arrange a technical sales consultant to visit you to assess your requirements and provide a full written quote with no hidden costs.

Benefits include:

- quick and easy installation
- available new, reconditioned and to rent
- choice of straight or curved stairlifts
- local engineers available 24 hours a day, 365 days a year, in the event of an emergency
- two year warranty and two free services with all new stairlifts*
- 14 day money back satisfaction guarantee.*



*Terms and conditions apply

Thank you!

Our Life After Stroke services helped more than 67,000 people across the UK last year and we invested more than £2 million in research to prevent strokes and help stroke survivors. We couldn't do it without our supporters. Together we can change the world for people affected by stroke.

... to our amazing volunteers

4,000 of you help us do the work we do. From raising awareness of stroke through our Stroke Ambassador programme to peer support to reduce isolation and improve the self-esteem of stroke survivors; your skills and time are vital.

See how you can help at: stroke.org.uk/involved/volunteering

Thanks to all our volunteers who entered our *Action on Stroke Month* volunteer photo competition and congratulations to our winner Rachael Dinsmore.

Rachael became a volunteer for us in honour of her Dad who died suddenly of a stroke earlier this year aged 61.



Rachael's winning shot in this year's volunteer photo competition.

... to our wonderful campaigners

You handed out 40,000 mini-stroke awareness booklets to health professionals and the public containing vital information to help prevent stroke. If all mini-strokes were treated urgently, 10,000 full strokes could be prevented each year in the UK.

You can still help. Order copies to take to your GP surgery at stroke.org.uk/involved/mini-stroke-booklet



... to our fantastic fundraisers



More than 2,000 of you took part in the Thames Bridges Bike Ride in May. Thanks to your support we're looking set to have raised in excess of £250,000.



Around 850 runners took part in five Resolution Runs in Scotland during spring, raising close to £40,000.

How does your money 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 Stroke 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

When 15-year-old family friend Joseph Lockington had a spinal stroke last year and was left paralysed from the neck down and in need of 24 hour care, Sue and Dai Phillips wanted to do something to help both him and the Stroke Association.

They've been amazing. They completed a 400 mile cycle challenge through France and held a fundraising garden party on their return, which combined raised more than £12,000 – a huge achievement.

Knowing that music is a huge passion of Joseph's, with the money they've raised they are funding for some adapted musical equipment to be fitted into Joseph's home.

As a long term supporter of the Stroke Association, Sue also wanted to donate



a portion of their fundraising efforts to support our work to help prevent more people like Joseph from having a stroke and improving the lives of stroke survivors. Thank you for your support.

Dates for your diary

UK Stroke Club Conference, 10–11 October 2014

Share your experiences and celebrate your achievements of running a stroke club or voluntary group. See stroke.org.uk/club-conference for all the details.

Christmas card design competition, 23 January 2015 (closing date)

Calling all budding artists! Check your Christmas catalogue inside this edition of *Stroke News* to enter or email cardcompetition@stroke.org.uk



Feel inspired?

Run, walk, ride, bake – there's something for everyone. Visit stroke.org.uk/fundraise/find-an-event to see what's on in your area or visit stroke.org.uk/donation to donate.