

Stroke News

Winter 2019

For everyone affected by stroke

Stroke
Association

"We want our experiences to help stroke survivors in the future."

Meet the stroke survivors shaping research

This issue:

- Driving after a stroke
- Resolution Runs
- Six month reviews: share your stories



A few hours a month can make a world of difference...

Work with us to rebuild lives after stroke. By supporting our stroke groups, you can share and learn new skills and get hands on experience of supporting people on their road to recovery.

Volunteer with your local stroke group.

Find out more at stroke.org.uk/volunteer

Rebuilding lives after stroke

Stroke
Association

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Contents

Features

8 Working together to shape stroke research

Researchers and stroke survivors collaborating on aphasia treatment

16 Rebuilding my identity

How Donna's facing the challenges of stroke

26 Sailing after stroke

Meet the stroke survivors seeking new adventures

32 Our legacy garden success

Raising awareness at Gardeners' World Live

Guidance

14 Driving after a stroke or TIA

24 Building movement into your daily routine

38 Money matters

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Editor **Christine Webster**
Design fullyfledgeddesign.com
Published by **Stroke Association**,
240 City Road, London EC1V 2PR.

Advertising **Redactive Media Group**. Contact **020 7880 7668**.
Volume 37.3 Winter 2019 © **Stroke Association 2019**



Editor's letter

Research is essential to developing new stroke treatments and therapies. But often the best way for researchers to ensure their work is practical and beneficial is to ask those with lived experience.

In our special research feature on page 8, we speak to researchers Madeline and Lucy, and stroke survivors Jan, Varinder, Lynn and Steve, about how they're working together to develop a new aphasia treatment, and what the collaboration means to them.

We also look at how stroke can affect relationships, work and finance. On page 16, Donna tells us about the impact this had on her confidence, and how she's been rebuilding her sense of

identity. And our Helpline Team share guidance on challenging a PIP decision on page 38.

In August, I had the pleasure of joining Pete, Judy and Thelma on a sailing trip for stroke survivors. Hear about how they've found friendship and fun on the high seas on page 26.



I hope you
enjoy this issue.

Christine Webster, Editor

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The Stroke Association is 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).

Over to you

Seven years ago, while working in the garden, I suddenly felt dizzy and a blue haze coloured my vision. I went to the GP but they said all seemed fine.

The haze stayed with me for a few days, so I went to my optician. He saw something at the back of my eye, and recommended I go to A&E, where doctors confirmed I'd had a stroke. In the following days, I had three more strokes – my chance of survival was 5%.

I beat the odds, but the trauma created huge emotional challenges including paranoia, OCD, panic attacks and

personality changes. It also affected my sight. However, with determination and practice, I was able to improve my vision.

I've come a long way and now work with a team of emotional coaches helping others with PTSD. I focus on recovery and being a survivor, never a victim. I want to share my story to help stroke survivors facing emotional challenges.

The stroke I had was very difficult to detect, so I'd also recommend an eye test as part of any health check.

Graham Hill

Stroke Helpline: **0303 3033 100**

Find your local services, clubs and groups: **stroke.org.uk/support**

Join our online community: **mystrokeguide.com**

Find information about stroke: **stroke.org.uk/publications**



Do you have something to share? Write to us:

Stroke News, 240 City Road, London, EC1V 2PR
or email **strokenews@stroke.org.uk**

We're here to rebuild lives affected by **stroke.**

Find out more:
stroke.org.uk/RebuildingLives

Stroke
Association

From our Chief Executive

Life changes instantly after a stroke. This can have a knock-on effect on your finances, health, independence and relationships. Overnight, a partner becomes a carer. A breadwinner becomes jobless.

Our recent 'Lived experience of stroke' report highlights the challenges that stroke survivors and carers have told us they face in their working and personal lives (stroke.org.uk/experience). We think it's vital to share these experiences to enable individuals, employers, governments and researchers to better understand the realities of living with stroke.

That's why we need your help with our new campaign to increase the number of people receiving six month post-stroke reviews. By sharing your story, you can help to improve the quality of life for others affected by stroke (see page 20).

It's also important to focus on the wider impacts of stroke to ensure people receive the right support. Thanks to you, our Rebuilding Lives campaign is starting to change public perceptions about stroke and reaching more people, letting them know that we can help.

Our charity provides information and support to help stroke survivors manage the wider impacts of stroke, from returning to work and seeking financial assistance, to finding peer support. If you're a stroke survivor or you know someone who has had a stroke, we're here for you. Call our Stroke Helpline (page 14), sign up to My Stroke Guide, or visit stroke.org.uk to find out more about stroke and our services.

Juliet Bouverie

Working together to shape stroke research

We want the research we fund to make a difference in people's lives. That's why we think it's important for researchers to involve stroke survivors in their projects. Stroke survivors' experiences can improve the quality of research, and help researchers to be more confident that their work will benefit people affected by stroke.

Researchers Dr Madeline Cruice and Dr Lucy Dipper from City, University of London, are collaborating with stroke survivors to develop a new type of aphasia treatment. They tell us how working with stroke survivors has shaped their project.

"Aphasia is a communication disability that affects a third of stroke survivors and can have a big impact on relationships, socialising, study and work. Speech and language therapy can help you to speak, read, understand and write again. However, many people still have trouble communicating in everyday life.

One reason for this is that many existing treatments improve your ability to say single words and short sentences, but don't improve everyday talking. For example, telling others what you've been doing during the week, or sharing memories about favourite holidays or special events.

With Stroke Association funding, we're developing a new language treatment called LUNA (which stands for Linguistic Underpinnings of Narrative in Aphasia) to support people with aphasia to share personal stories. Currently, we're developing the evidence for this new treatment and testing it with stroke survivors with aphasia.

We're developing a new language treatment called LUNA (which stands for Linguistic Underpinnings of Narrative in Aphasia) to support people with aphasia to share personal stories.



In the future, we want speech and language therapists to deliver LUNA to people with aphasia during their hospital or community rehabilitation.

Involving stroke survivors in developing this new treatment is essential. It ensures that the treatment makes sense and will motivate stroke survivors to engage with their aphasia rehabilitation. This is important because if people understand how their rehabilitation will make a difference to their life, they'll feel more in control and are more likely to benefit from it.

In the past year, we've worked with stroke survivors with aphasia, including Steve, Lynn, Jan and Varinder on page 11. As members of our project advisory group, they've guided the direction of the project and jointly co-designed the LUNA programme at monthly meetings.

At these meetings, we made sure the stroke survivors felt comfortable and supported to share their honest opinions and ask questions. Then together, we explored their previous therapy experiences, practised and



discussed story-telling therapy activities, brainstormed ideas and shared feedback on prototypes.

Their input has been invaluable. Our stroke survivors have helped us to choose specific therapy activities and given us the words to explain what LUNA is to future patients – translating researcher-speak into instructions that make sense! They've also helped us to understand how and when stroke survivors might independently practise the treatment in their everyday lives, and how the speech therapist should support patients to get the most out of their rehabilitation."

"Our experiences can help others"

Stroke survivors Lynn, Steve, Varinder and Jan share their perspectives on taking part in the LUNA research.



Why did you get involved in the LUNA research?

Lynn: I love to learn and I want to help so I put my name down for stroke research at City University. That's how I found out about LUNA.

Steve: I was a Sales Director. I was always communicating. Then I had a stroke and couldn't say anything. I wanted to say "pyjamas" and I was saying "kettle". I'm not working now, but I want to do something else if I can. I'd like to help with aphasia.

Varinder: It's inspiring to work on a project about telling personal stories. It helps you accept who you are – a person with aphasia, who does things and has stories to tell about it.



What did you do in the LUNA co-design sessions?

Steve: We tried different therapies to do with telling stories. Everyone's aphasia is different. It was interesting to see how they did the tasks.

Lynn: The researchers showed us ways to think through a story. One was what they called a "spider" [diagram], to help us think about where a story started from, and where it goes. It's well worth taking time to put the story in the right order.

Varinder: We shared our opinions, and stroke and aphasia experiences. The researchers made the sessions easy for us. They made notes as we talked.

How has taking part in the LUNA sessions helped you?

Varinder: Everyone has stories to tell. So do stroke survivors. Being able to tell stories makes us feel more like part of society, rather than apart from it.

Jan: I like that LUNA is about "my stories". They've helped us think about the beginning, middle and end. I mixed them up before.

Lynn: I learnt more from them in three months than in eight years going to college! I feel like I've improved my speech and my writing.

Steve: It's helped me to be more confident and will help others to move forward.

Would you recommend taking part in research to other stroke survivors?

Varinder: Yes. The researchers, professors and students I've worked with have been supportive and compassionate and I've learnt a lot. I feel proud to be part of research that will help people in the future.

Jan: Research is always on the cusp of new things. Together we can make better language research. Community is better than one-by-one.

Lynn: Put your name down and try it. If you've had a stroke, you can help make it better for someone else.



If you'd like to find out more about getting involved in stroke research, contact Laura Piercy on research@stroke.org.uk or **020 7566 0300**. Learn more about LUNA and our other research projects, at stroke.org.uk/research.

Driving after a stroke

You might be keen to get back behind the wheel after a stroke or TIA (transient ischaemic attack or mini-stroke). But it's important to follow the right procedures to make sure you're able, safe and ready to drive again.



Lucy Sherman from our Stroke Helpline shares some advice.

Q What are the rules for driving after a stroke?

The Driver and Vehicle Licensing Agency (DVLA), and the Driver and Vehicle Agency (DVA) in Northern Ireland state that you must stop driving immediately after a stroke or TIA.

If you have a car or motorcycle licence, you may be able to start driving again after one calendar month. But it depends on how many strokes you've had and the type of stroke. So, it's important to get individual advice about how any medical conditions and treatments would affect your ability to drive.

If you have a large goods vehicle (LGV) or a passenger carrying vehicle (PCV) licence, you aren't allowed to drive this kind of vehicle for a minimum of one year after your stroke. If you drive a taxi, your local authority (or the Public Carriage Office in London) decides on the medical standards you need to meet to continue driving.

Drivers' medical enquiries:

DVLA (England, Wales and Scotland) – **0300 790 6806**

DVA (Northern Ireland)
– **0300 200 7861**



Q Do I need to let my insurance company know I've had a stroke or TIA?

Yes. If you don't, your insurer might not honour future claims, even if you're safe to drive after a stroke or TIA. Talk to your insurer and check your policy carefully.

Q Stroke has knocked my confidence. How can I make sure I'm safe to drive?

You might find having refresher lessons with an instructor helpful, or perhaps ask someone you trust to accompany you on quiet, familiar roads.

If you have ongoing physical disabilities, it may still be possible for you to drive again with adaptations. Specialist mobility centres across the UK can carry

out assessments and make individual recommendations.

Q What if I can't get back to driving?

It can be difficult to come to terms with not driving again. Talk to your friends, family and healthcare professionals, especially if you're feeling low, and ask for help with finding alternatives, such as community transport schemes. If you work, you may be able to get help from Access to Work to cover transport costs.



Call our Stroke Helpline on **0303 3033 100** or email **helpline@stroke.org.uk**.

For more information visit **stroke.org.uk/driving**.

Rebuilding my identity

"One minute you think you're healthy.
Then in a moment, everything's changed."

A few days before her 51st birthday in May 2016, Donna Mackenzie-Smyth had two strokes. "I was with my three grandchildren and my husband," said Donna. "Suddenly, it felt like I'd been sliced in half. I was terrified that I might die in front of them."

The effects of stroke – left-sided weakness, fatigue and cognitive problems – had a huge impact on Donna's life. "I couldn't go back to work and had to rely a lot on my husband and family for help with washing, getting dressed – most things really."

"I'd always loved dressing in bright clothes and putting on make-up, but the fatigue meant

I had no energy to make myself feel nice. When my friends visited, I saw in their faces how much stroke had impacted my world."

With encouragement from her Stroke Association Support Coordinator, Donna started attending peer support groups. "The first time I went was out of curiosity really. Now I try not to miss any of them. To me, the value of peer support is immense. I don't think I'd be mentally where I am now if it wasn't for my group."

Having worked in the beauty industry throughout her career and keen to give something back, Donna decided to set up beauty workshops to support stroke survivors and carers in her groups.



"To me, the value of peer support is immense. I don't think I'd be mentally where I am now if it wasn't for my group."

We're here to support you to rebuild your life after stroke. Find out more: stroke.org.uk/RebuildingLives.



"After my stroke, I felt like I'd lost my identity. I decided I needed to feel better about myself. I've always believed that if you put on a bright lipstick, then no one looks at the rest of your face because they're looking at your lipstick! I found my lipsticks, put them on and it made me feel a bit better.

"I spoke to others who also had issues with how they felt. They didn't want to look in the mirror because they had facial drooping, or if they were caring for someone, they felt guilty about spending time on themselves.

"So I set up a session and asked everybody to bring their make-up. I did a demonstration and we talked

about how to feel good by putting on a small amount of make-up. It was wonderful. Sometimes, something like putting make-up back on can make you feel empowered, and help you to start addressing your issues."

Donna is now a Stroke Ambassador and shares her story to raise awareness and help others to rebuild their lives after stroke. "Physically, life is still a real challenge, but mentally, I'm in a good place. I set myself daily goals. Ultimately, I'd like to go back to work. But sometimes just getting up is a good achievement. Recovery is slow but it does happen. You must keep going. You have more strength than you realise."

Donna's top beauty tips

Keep it simple

- My favourite product is a tinted moisturiser, as it gives you a bit of colour in your skin so you don't need to worry about applying moisturiser and foundation.
- A bit of eyebrow pencil and lipstick or lip gloss also helps me to feel more confident and cheerful.

Try before you buy

- Go into stores and ask for free samples to take home. Or test them in-store to see if they're right for you – for example, can you undo the lid?
- If you're struggling, let the cosmetic consultant know that you're a stroke survivor so they can help you to find products to suit you.

Make feeling good part of your recovery

- I have a weakness in my left hand, so I make a point of squeezing make-up onto the back of my hand or arranging my make-up brushes in it, because it makes my brain aware that my left arm is still a part of my body.



- When my friends came to visit after my stroke, I asked them to bring their favourite colour nail polish and paint one of my toenails. Looking at the different colours reminded me of them and encouraged me to try to move my foot!

Shape stroke care by sharing your story

Over the past year, we've made great progress in influencing UK health and social care leaders' plans to improve stroke prevention, treatment and care. We're also working with stroke survivors and carers to make sure these plans reflect your needs and experiences. Here's an update on what we're doing and how you can get involved.

England

Since stroke was recognised as a priority in NHS England's Long Term Plan, we've been involved in developing the National Stroke Programme to make the promised improvements a reality.

As part of this, we're encouraging local health providers to increase the number of stroke survivors who receive a six month post-stroke review. Currently only a third of stroke survivors who need a six month review receive one.



Currently only a third of stroke survivors who need a six month review receive one.

These reviews are important as they help to monitor a stroke survivor's recovery and identify any extra support they may need, preventing unnecessary readmissions to hospital and care homes.

"As stroke survivors, we know what it's like to live daily with the life-changing physical, emotional and mental effects of this condition. Our voices matter so much.

"It's important that we campaign for things to be improved and changed to make life better for ourselves, our family members and carers."

Julie Monk,
stroke survivor
and campaigner



We need your help:

If you've received a six-month review, or wish you had, we'd love to hear from you. What was your experience? How did it help you? Or how do you feel you could have benefited if you'd had one? You can share your stories with us by emailing campaigns@stroke.org.uk.

Northern Ireland

We've been working with stroke survivors and carers on our response to the Department of Health's public consultation on reshaping stroke care. We submitted our consultation response in August 2019.

We'll be keeping a close eye on developments in the coming months. To find out more, visit stroke.org.uk/NIconultation.



Scotland

Our campaigning and influencing work in Scotland focuses on the first few hours of treatment after stroke. There's lots of evidence to show that reshaping stroke care by creating hyper-acute stroke units, with the best experts and equipment all in one place, can save lives, improve recovery and reduce disability.

NHS Tayside is the first Scottish health board to make this change. Their new hyper-acute stroke unit opens in Dundee in November. Actor Brian Cox, who is originally from Dundee, is supporting our campaign to draw attention to this positive move and encourage other health boards to take action to improve stroke care.

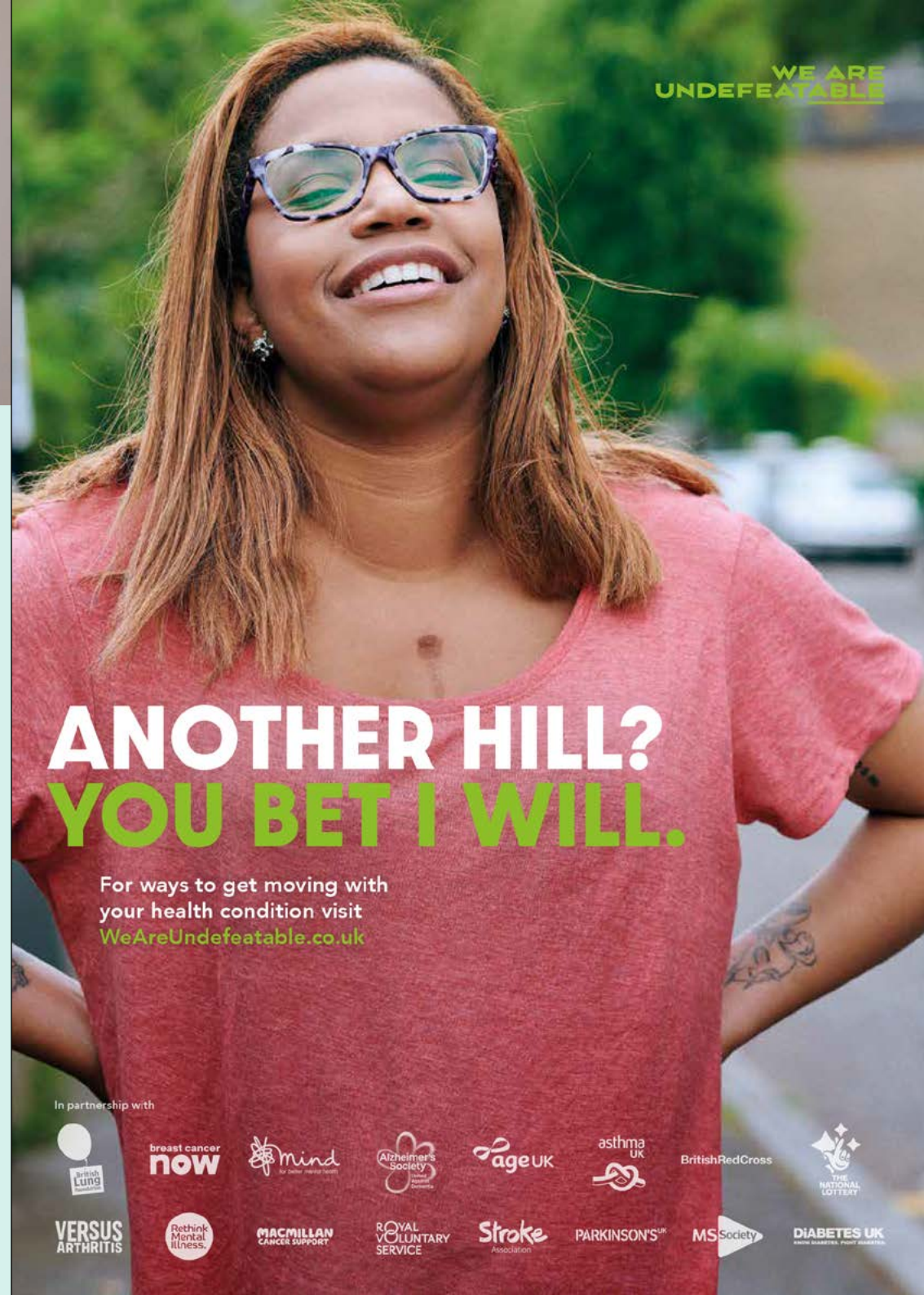
To find out more, please contact campaigns@stroke.org.uk.

Wales

We're working with a cross-party group of politicians in Wales on an inquiry to examine whether the Welsh Government's Stroke Delivery Plan has improved services for stroke patients and survivors. They want to survey stroke survivors to inform their work. If you'd like to share your experiences, please email cpgcymru@stroke.org.uk.



We'd love to have as many of you on board with our campaigns as possible. For updates and information about how you can get involved, sign up to our Campaigns Network at stroke.org.uk/campaigning.



**WE ARE
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ANOTHER HILL? YOU BET I WILL.

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your health condition visit
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Stroke
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PARKINSON'S

MS Society

DIABETES UK



Everyday activity

You can find more advice about getting active on stroke.org.uk/moving and weareundefeatable.co.uk.

Tristan Maynard, 71, had a stroke in March 2018, which left him in constant pain and paralysed on his right side.

Supported by his physiotherapists and Moving Forward After Stroke group, Tristan looked for ways to build movement into his daily routine to help him get active again. Here he shares his top tips:

Set yourself goals

"I set myself short, medium and long-term goals. My immediate goal was to be able to walk to the toilet. The pain was indescribable, but I kept at it.

As I improved, I aimed to walk to the corner shop to get the newspaper. The day I did it,



I was so chuffed. It took me a while as I had to keep pausing, but it felt incredible.

To begin with, I could only walk by swinging my right leg out in a semi-circle. I wanted to be able to walk in a straight line to take my daughter down the aisle at her wedding, so I practised at the

exercise classes, and at home by walking along a join in the tarmac on our cul-de-sac. The neighbours thought I was mad, but I could soon do 30-40 yards!"

Start slowly and build up

"You don't spring out of bed and start doing star jumps! You build up slowly. I did physiotherapy exercises every day for nine months. For example, there's an exercise where you take macaroni pieces out of a cup and line them up on the table. To begin with, it was agony. But it got me using my fingers and helped me to write again.

I still do half sit-ups, leg and arm raises for 10-15 minutes every day, but I have fatigue so I take breaks when I need to."

Build activities into your daily routine

"Treat ordinary activities as exercises, for example making a cup of tea or picking stuff up off the floor. Look at lifting the Hoover as the same as lifting a dumbbell! Doing the washing up or loading and unloading the dishwasher can help with dexterity and strength. Some days, you do three cups and that's enough. But you've tried. It's important to get a sense of achievement from the little things."

Do what you enjoy

"I love woodwork and DIY, which are good for arm strength. Gardening was fundamental to my recovery. It gets you moving and gives you something to look forward to. Even if you don't have a garden, some plant pots on a windowsill can give you a lot of satisfaction. I also go swimming every week, which helps with the pain and is a good resistance exercise."

Try activities with others

"Group exercise sessions are good because you can see your progress. It's also helpful to get tips from other stroke survivors and to know you're not alone."

Sailing after stroke



Sailing is a great way to get active, support your mental health and connect with people. Whether you're seeking an adventure or a tranquil cruise, there are many sailing initiatives around the UK offering disabled and able-bodied people the chance to enjoy the freedom of the open water together.

Pete and Stephanie Nash started sailing after Pete had a bleed in his brain in 2005. "Pete was very active but that all changed overnight," says Stephanie. "His therapists helped him to walk and talk again, but his mobility is limited, so we started looking for new things to do together."

The couple got in contact with the Gwennili Sailing Trust. "We partner with other organisations on the south coast of England

to run day-sailing, cruising and race programmes for individuals, families and organisations," says Skipper, John Douglas. "We're completely volunteer-based meaning we keep it as affordable as possible.

"We often charter a 35-foot catamaran, which is fully wheelchair-accessible. People get as involved as they want. Some just want to relax or chat and enjoy the experience. Others are quite active in sailing, so they'll help with slipping lines, helming the boat, adjusting the sails, keeping watch, and we give them some informal teaching at the same time."

"The social scene is good," explains Pete. "There's always a group. It's fun and keeps me active." It's benefited Stephanie as a carer too. "It's changed my life," she says. "I trained to be a skipper and now organise all the day sails for Gwennili. I love bringing people out on the water. They open up when they realise there's something else out there they can do. Everyone goes away with a smile."

Stephanie and Pete recommended the experience to fellow stroke survivors Thelma Keleher and Judy Brinkman. "I attend the Stroke Association's New Milton Group with Pete," says Thelma. "When he suggested I come sailing, I said 'Yes, please!' It's just wonderful. The boat is easy to get around. I get to talk to others, which helps my aphasia, and even have a go at helping on-board if I want." Judy agrees. "This was my third trip and it was lovely. I enjoy everything about it. I love my experiences on the high seas!"



Visit stroke.org.uk/leisure for advice about hobbies and leisure activities after stroke.

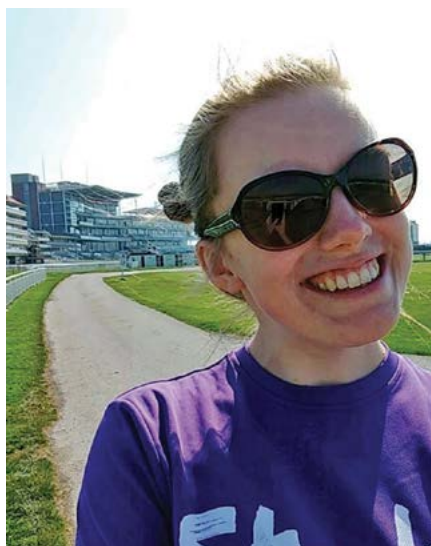
For more information about the Gwennili Trust go to www.gwennili.org.uk. They're part of the Royal Yacht Association's (RYA) Sailability programme, which supports and encourages people with disabilities to take up sailing. You can find opportunities near you by visiting rya.org.uk/programmes/rya-sailability.

A volunteering victory

From work experience to recovery goal, Bryony Dansey, 25, tells us why volunteering for the Stroke Association means so much to her.

Bryony first started volunteering with the Stroke Association in 2016, while she was studying Sports Science and Injury Rehabilitation at York St John University. "I saw on Twitter that the Stroke Association were looking for massage therapists to help at the Yorkshire Marathon," remembers Bryony. "I was qualified, so I jumped at the opportunity.

"We had so much fun! Dressing up, cheering on, massaging and listening to people's stories. After that day, I wanted to support the Stroke Association again, so I signed up to steward runners at a Resolution Run and then did massaging again at the Yorkshire Marathon in 2017."



Then, on Christmas Eve 2017, everything changed. "I couldn't talk; I started having seizures and was in and out of consciousness. My housemate rang the paramedics as we realised what was happening – I was having a stroke at 24. My right side was paralysed and I had to learn to walk and talk again.

"When I returned to my parents' home in Kent to recover, I got in contact with the Stroke Association in Medway. The stroke team got me out to



socialise with people of the same age and people who could empathise with me.

"From there, I set myself the goal of massaging at the marathon again. And in October 2018, I did it. It was exhausting, but I did it. No one believed that I'd had a stroke. I put that down to my sheer determination and stubbornness!"

Inspired by her achievements, Bryony's fiancé and friends recently ran the Leeds Half Marathon on her behalf and raised £4,000 for the Stroke Association.

"I don't run, so I drummed up fundraising instead," says Bryony. "I know how important the money is for the charity and how it supports others. It's helped me get a Life After Stroke Grant for taxi and train vouchers, which helps me when I'm exhausted."

Bryony's next goal is to volunteer again at her local Resolution Run in 2020. "If you're thinking of signing up as a runner or as a volunteer, my advice would be just do it! It's fun, you meet some humble people, hear some amazing stories and learn a lot too."

Join the Resolution and walk, run or volunteer at one of our UK-wide Resolution Runs in spring 2020. Visit resolutionrun.org.uk to sign up to an event near you.

Making my wife proud

Bhav Gohil lost his wife Sheetal to a stroke when she was just 37. He tells us how he's using his experience to help others and honour her memory.

"Sheetal was generous and fun. When people met her as my girlfriend, they said, 'Of course you're going to marry her – she's perfect for you!'

She had her first stroke at night. I was coming back from the bathroom and noticed her arm was waving in the air. I tried to wake her but she couldn't talk or move, so I called the paramedics.

Ten days later, she had a second stroke in hospital. She passed away on the 7 November 2016.

After her funeral, I questioned my faith; I questioned everything. But I knew Sheetal wouldn't want that. My best mate

recommended I take up jogging. It was tough at first, but getting out helped me cope.

I worked my way up – first 5k, 10k, then a half-marathon. I used each new challenge to raise money for the Stroke Association. With their help, I set up a Tribute Fund for Sheetal and link all my fundraising events to it so people can donate, share photos and leave memories. So far, I've raised £13,000. It's a privilege to keep Sheetal's memory and build her legacy in this way. I want her to be proud of me.

2019 would've been our 10th wedding anniversary and Sheetal's 40th birthday, so I decided to do the London Marathon as a present to her. I trained hard, but it was tough. By mile 23, I was in a lot of pain. I stopped, put our favourite band, Queen, on my headphones, and took out the photo of Sheetal that I always carry when I run. She kept me going.



Crossing the finish line with 'We Are The Champions' playing in my ears was amazing. It felt like we'd done it together.

I'm now a volunteer and work with stroke survivors at the Life After Stroke Centre in Bromsgrove. When I took the medal in, they tried it on and took pictures like they'd run the race. It was great to know it meant so much to them."

Families like Bhav's often find comfort in creating tribute funds in memory of their loved ones. If you'd like to create a Tribute Fund, visit tributefunds.stroke.org.uk or email tributefunds@stroke.org.uk.

You can find information about grief and bereavement on stroke.org.uk/bereavement. Our Stroke Helpline is also here for you. Call **0303 3033 100**, or email helpline@stroke.org.uk.

Our legacy garden success



Today, Phil Pooley works in our Legacy Team, helping to spread the word about the huge benefit of leaving a gift in your Will. But he's also an experienced landscape gardener. When he discovered that the BBC Gardeners' World Live exhibition offered spaces for charity gardens, he realised it was a huge opportunity to develop our first-ever legacy garden.

Phil worked with award-winning garden designer Alex Daley, to plan a stunning and evocative outdoor space depicting the devastation of stroke and the recovery journey.

When he was creating the garden, Phil was able to draw on his own experiences. "I had a stroke in 1978, a few months before my sixth birthday," remembers Phil. "I was admitted to hospital as a suspected meningitis case. I don't think

anyone would have suspected a boy of five could have a stroke."

At the time, understanding of stroke was not as good as it is today, and Phil struggled with his recovery. "At first, I couldn't speak and my movements were reduced, but with my Mum's encouragement, I regained my voice and learnt to walk again."

Growing up, Phil developed a passion for gardening, and it's been an important part of his



life ever since. "Gardening has been a great friend of my wellbeing throughout my life. It's really helped me to increase my strength, dexterity and general fitness and has helped me mentally as well."

Phil's concept for the legacy garden begins with an area of shattered paving stones and spiky plants to represent the devastation of a stroke. As visitors walk along a winding path, the surroundings

gradually become softer and more complete, showing the rebuilding of a life after stroke.

The garden was made possible by donations of materials and design time, along with some hard labour from our amazing volunteers. "Ours was the only garden in the show created solely by volunteers," says Phil. "They worked all through the appalling early-June British summer, and I can't thank them enough for their amazing commitment!"



Phil shows actress and supporter Victoria Yeates our award-winning garden

Over the four days of the show, our garden received a fabulous reception from everyone who saw it. We also won a Bronze Award. "I was gob-smacked when we were announced as winners," says Phil. "Not only was this fantastic recognition of the passion and dedication at the heart of the project, but also heightened the

garden's profile, attracting lots of visitors and raising even more awareness of stroke." After the show the garden was donated to St Margaret's Community Hospital, Epping, and re-assembled in the grounds near their stroke unit for patients, their families, staff and visitors to enjoy.



Thanks to everyone who helped make our garden a success. You can see more photos and videos at stroke.org.uk/GWL. To find out about leaving a gift in your Will, visit stroke.org.uk/legacy.

My Stroke Guide

Online stroke support

Stroke can change your life in an instant, but recovery is possible. As well as free access to trusted advice, information and support 24/7, My Stroke Guide connects you to our online community, to find out how others manage their recovery.



Dexterity aids

Losing dexterity in your hands and fingers after a stroke can make everyday tasks more difficult. But there are adaptations and tools available to help you at home and to assist your recovery.

We work with **Essential Aids**, who provide a range of products to make life easier. Here are some of their recommendations:



If you're having trouble with gripping and turning, aids like tap turners can really help. They slot over or clamp onto your existing taps, making them easier to turn on and off properly. You can also get grips that fit onto door handles and keys too.



Therapeutic hand putty is great for rebuilding strength in your hands. Squeezing and manipulating it with your palms and fingers can gradually help to improve dexterity. You can get putty in varying degrees of firmness so you can increase the resistance as your strength returns.



Dressing aids, like button hooks and zip pullers, can be very useful if you have limited movement in your fingers and can assist you in fastening your clothing independently.



For more information, visit stroke.org.uk/essential-aids or call **01273 719 889**.



If you're a stroke survivor, or buying something for a stroke survivor, tick the box at the checkout and Essential Aids will donate 5% of the item price to the Stroke Association.

Money matters

Personal Independence Payment (PIP) is a benefit to help people with the extra cost of living with a long-term condition or disability. But what happens if your PIP application is rejected or you think you're receiving the wrong amount? Our Helpline Team explain how you can challenge the decision.

Challenging a PIP decision

After your PIP assessment, you'll receive a letter from the Department for Work and Pensions (DWP) explaining their decision about your claim. If you're unhappy with the outcome, you can ask them to review the decision. This is known as a mandatory reconsideration. Information about how to ask for this and who to contact is included in the decision letter.

You need to ask for a mandatory reconsideration within one month of the date on your decision letter.

Your PIP might increase, decrease, stop or stay the same following the mandatory reconsideration. For advice about checking a PIP decision before you challenge it, visit turn2us.org.uk and search "appeal PIP".

Did you know?

74% of PIP appeals are successful at the tribunal stage.

Mandatory reconsideration

When you ask for a mandatory reconsideration, it's important to explain what part of the decision you disagree with and why. It's helpful to include evidence to support your points, such a letter from a GP or specialist involved in your care. The DWP will then send you a letter to tell you whether or not they've changed their decision and why.

Tribunal

If you still disagree, you can take your appeal to a tribunal, which is independent from the DWP. The tribunal includes a judge, a doctor and a disability adviser. They'll ask you questions about how your disability affects you and look at written evidence.

You don't have to attend this tribunal in person, but doing so allows you to explain your case directly to the panel. You can take an advocate, family member or friend to support you. After the tribunal, the panel will write to you to let you know the outcome of the appeal, which is likely to be legally binding.

Where can I find out more?

Contact the benefits appeal helpline:

England and Wales – **0300 123 1142**

Scotland – **0300 790 6234**

Northern Ireland PIP Centre – **0800 587 0932**

Visit gov.uk and search "appeal a benefit decision".

Or go to citizensadvice.org.uk/PIP.



Puzzles

Puzzles can be a fun way to exercise your mind and improve concentration, understanding and memory.

Word search

S R D R A W R O F
P E A P D E F M T
E B B C W G F L S
E M J O H A R U I
C E P T T I I G S
H M F I T N E S S
E E M Z T O N V A
X R T S U J D A E
G N I L I A S X K

Speech
Empower
Fitness
Friends
Sailing

Adjust
Forward
Remember
Assist
Achieve

Across

- 1 Source of aid in troubles (8)
- 5 Ancient western Europe (4)
- 8 Type of punch (8)
- 9 South African native (4)
- 11 Cars (5)
- 12 Yearly allowance (7)
- 13 Completely swamp (6)
- 15 Lump (of gold) (6)
- 18 Hug; bridge tactic (7)
- 19 Up to (a time) (5)
- 21 Illegal ticket seller (4)
- 22 Animal (8)
- 23 Small, weak (4)
- 24 Disturb, make anxious (8)

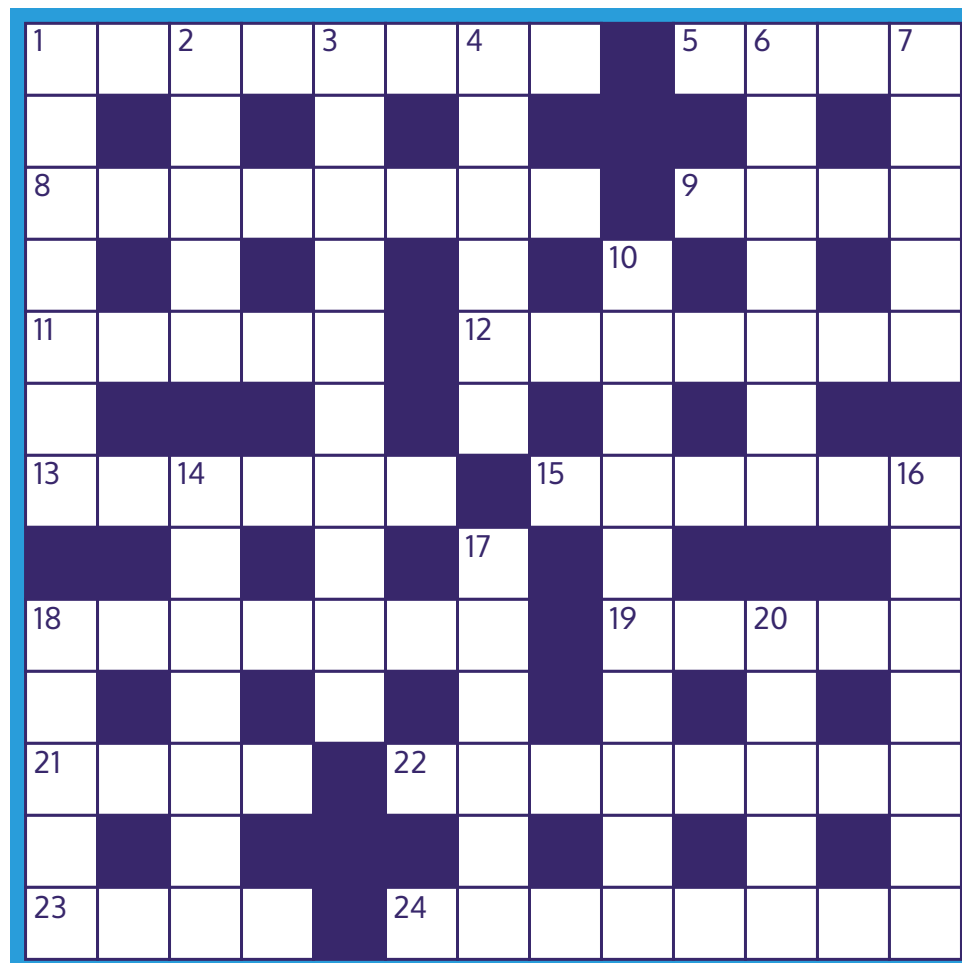
Lottery

For your chance to win £25,000 every week, play the Stroke Association Charity Lottery. Find out more at stroke.zaffo.com.

Down

- 1 Rolled-up dish (7)
- 2 Head (anatomy) (5)
- 3 Not settled (10)
- 4 Mouse's cry (6)
- 6 Giving entertainment (7)
- 7 Very bad (5)
- 10 Introduce (a new system, etc) (10)
- 14 Paul —, French artist who worked in the Pacific (7)
- 16 Hydrocarbon present in petroleum (7)
- 17 Nerve cell (6)
- 18 Arrangement (3-2)
- 20 Firm belief (in a thing) (5)

Solutions
see page 44



With thanks to The Times/News Syndication who granted us rights to this crossword.

Rebuilding lives after stroke

Our charity supports people to live the best life they can after stroke. But it's a team effort and we need your help. A huge thank you to everyone who's fundraised, volunteered and campaigned with us. Your support means we can reach even more people who need us.



Libby's challenge

Well done to Libby Watt who ran the BHGE 10km in Aberdeen and raised £4,240.57 to help stroke survivors like her dad.



Cycling success

Congratulations to Barry Smith who cycled from Land's End to John O'Groats in just two weeks, raising over £2,500.



Dale Biggerstaff

In the spring 2019 issue, we chatted to Dale Biggerstaff about preparing for the Belfast City Marathon Relay. We're delighted to say that he achieved his goal and with help from his friends, raised over £7,000! You can now register for the 2020 Belfast Marathon, and challenges like it around the UK by visiting stroke.org.uk/fundraising.

How does your donation help?



£8 could enable a stroke survivor to access vital peer support.



£10 could help us provide crucial information guides about stroke to 25 people.



£50 could help us fund research to find new ways to help stroke survivors with communication difficulties.



Ray's Rovers

Thank you to Katie Judge and Dean Johnson, who held a charity football match in memory of their dad, Ray Johnson. With the support of their friends, family and local community, they raised a wonderful £4,111.



Find out more on page 44 or make a donation at stroke.org.uk/supportus.



Volunteer spotlight

Stewart Anderson has been a Stroke Ambassador for over six years. "As an enthusiastic supporter of the FAST campaign, which almost certainly saved my life, I'm keen to raise awareness to help others," he said.

"I run regular blood pressure checking events in my community, and recently set up a new fundraising event called the Baldoon RUNway. It's a fun run at an old WWII airfield near my home in Wigtownshire. We've raised over £6,800 so far, and are already looking forward to the next one in October 2020."

To find out how you can get involved in fundraising and volunteering, visit stroke.org.uk/yoursupport.

Dates for your diary



**Last chance to order
Christmas cards
16 December 2019**

Visit stroke.org.uk/Christmas19, to order your Christmas cards and gifts.

**2020 Christmas card
competition deadline
31 January 2020**

Visit stroke.org.uk/cardcomp20 for details or send in your entries by emailing cardcompetition@stroke.org.uk or calling **01604 687 775**.

**Resolution Runs
February – May 2020**

Join the Resolution near you and chose your distance at 34 events around the UK. See page 28 or visit resolutionrun.org.uk.



**Walk Your Way
Throughout 2020**

How do you complete a marathon? One step at a time! Find out more about our year-round Walk Your Way fundraising challenge at stroke.org.uk/walk.

For more events and ways to get involved in our work, see stroke.org.uk.

Crossword solution

Across:

1 Recourse, 5 Gaul, 8 Uppercut, 9 Zulu, 11 Autos, 12 Annuity, 13 Engulf, 15 Nugget, 18 Squeeze, 19 Until, 21 Tout, 22 Creature, 23 Puny, 24 Unsettle

Down:

1 Roulade, 2 Caput, 3 Unresolved, 4 Squeak, 6 Amusing, 7 Lousy, 10 Inaugurate, 14 Gauguin, 16 Toluene, 17 Neuron, 18 Set-up, 20 Trust

