

Stroke News

Spring 2023

For everyone affected by stroke

Stroke
Association

"It took me three years
to say my own name."
**Kelly shares her
experiences of aphasia**

This issue:

- Supporting someone with communication difficulties
- Explore our new Online Stroke Activities Hub
- Getting into accessible cycling

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Editor's letter

Nearly two-thirds of stroke survivors have communication problems, such as aphasia, after stroke. Our cover star, Kelly, had severe aphasia, and couldn't say her name for three years. However, with support, Kelly has made great progress and is now helping us to raise awareness of the condition. On page 8, she shares her experiences and tips for tackling daily communication challenges.

Also in this issue, our Helpline Team has guidance for family and friends on supporting someone with communication difficulties. And researcher and speech and language therapist, Katie Monnelly, explains her work to

improve aphasia treatment, and offers advice on progressing your speech recovery (page 32).

Plus, find tips on eating well on a budget (page 42) and explore accessible cycling opportunities (page 24).

I hope you enjoy this issue, and keep sharing your stories with us.



Christine Webster, Editor

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Over to you

If I had a crystal ball when I was younger, would I have done anything differently? Possibly. Would it have changed what happened? Probably not.

I don't know why I developed a clot. All I can say for certain is, one evening, while watching TV with a cuppa and a biscuit, it happened.

Initially, I lost the use of my right arm and couldn't speak. My face had drooped, so classic FAST signs. I tried moving my arm and hand. Nothing, only strange tingling.

I've made quite a good physical recovery, but my emotional and mental health suffered. I'm not

the same as I was. I have my off days when I wish I could have prevented it from happening. But I'm here, still fighting.

I'm a work in progress. I've worked on my mental health. Fitness levels are lagging behind now I'm back at work, but it's something I'm trying to rectify.

I've realised it's no good dwelling on the "what ifs" - things happen that we have no control over. All we can do is the best we can to look after ourselves, our bodies.

Stay strong, keep fighting, keep pushing forward.

Mahoney

Shared on My Stroke Guide

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?

Email **strokenews@stroke.org.uk** or write to us at Stroke News, Stroke Association, 1 Sterling Business Park, Salthouse Road, Brackmills, Northampton, NN4 7EX.

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LIFE IN MOTION



From our Chief Executive

We understand how lonely and isolating the effects of stroke can be. Often meeting others who know what you're going through can help.

Our wonderful network of stroke support groups are a lifeline to many. And we now have a new Online Stroke Activities Hub (page 16), where you can chat to other stroke survivors and carers, share tips and experiences – and have fun.

You can also call our Stroke Helpline on **0303 3033 100** or visit **stroke.org.uk** if you need support.

We're working with organisations and businesses to support people affected by stroke to re-connect with their communities as well. In December, I was excited to join

stroke survivors, their families and Chris and Toby Tarrant (pictured), to celebrate our new partnership with Buzz Bingo. Together, we want to raise money, awareness and help tackle social isolation after stroke (see page 30).

Thanks to everyone who signed our open letter in the summer issue of Stroke News, calling on the UK Government to make thrombectomy available 24/7 to everyone. Along with stroke survivor Phil Woodford, who shares his story on page 20, I was delighted to deliver over 9,000 signatures to Downing Street.

By listening to and working with you, we are driving improvements in stroke treatment and care.

Juliet Bouverie OBE

Living with aphasia

"I'm a people person. Before my stroke I would talk to anyone. After my stroke, it took me three years to be able to say my own name."

In 2017, Kelly Fogarty, 54, had two strokes. They left her with aphasia – a condition that impacts speech and language.

Kelly has Crohn's disease and was in hospital for treatment when she had the first stroke. "When a nurse told me I'd had a stroke, I thought she was confused. I thought, 'I can't have had a stroke, I can walk'. I didn't realise stroke could cause aphasia.

"A speech and language therapist showed me pictures and asked me to say what things were. But I could tell by her face that the words I was saying were wrong. There was a picture of a teapot, but I was calling it an elephant."

At the time of her strokes, Kelly ran her own social care training and assessment business. "I was

always speaking with people, and needed to read and write to support learners.

"After my strokes, my speech and language wasn't functional. I felt like a child again. I couldn't do things like speak with the bank. On the phone, they would ask for my name, address and phone number but I couldn't say it. It makes you feel real anxiety."

Kelly had speech and language therapy after both strokes, but the support was limited. "It took six months to realise I would be living with aphasia for a long time," she says. "My speech and language therapist told me after my second block of sessions that I'd done all I could do but my speech would be the way it was forever. That wasn't true, but at the time I was so distressed and angry."

Do you
have **communication
difficulties?**



Listen to Kelly's story
at [stroke.org.uk/
strokenews](https://stroke.org.uk/strokenews)

Initially unable to read, process words or understand numbers, Kelly had to close her business. Lack of income also meant she had to sell her home. She felt powerless and depressed.

"When you have aphasia, your life becomes an open book. You need help with everything that is personal, like money. It opens you up to judgement from other people.

"It's not just me that is impacted. It's a learning curve for everyone. I remember having an argument with my son. He did the shopping as I couldn't drive. I wanted tartar sauce, but couldn't get the word out. He got tomato ketchup. I threw it across the kitchen. I'm not like that, but it was the straw that broke the camel's back. I couldn't drive, I couldn't write a shopping list and I couldn't check my phone because I couldn't process the words.

"The Stroke Association came to my house to talk to me about support. This was a lifeline. I also received support for my mental health."

Five years on, Kelly has made huge progress. She still mixes up pronouns and words, and struggles with some processing. But with determination and support from her partner, friends and family, Kelly is learning to live life well with aphasia.

She has a new job at Birmingham City University, supporting students by sharing her professional experience, as well as her lived experience of aphasia. "I'm different from the person I was. But working with the students at the university has just been the best thing. I am passionate about aphasia. I need to talk about it, so more people understand. It's part of my life now."

"I am passionate about aphasia. I need to talk about it, so more people understand."

Kelly's top tips:

✓ **Tell people you have aphasia** – "I used to be embarrassed. Now when I meet people, I say I've got aphasia. People in shops or banks are happy to listen when they know."

✓ **Carry a Stroke Association communication card** – "It stops my anxiety when I show it to people as they know I'm preparing to speak and don't keep asking me what I want."

✓ **Try to meet others with aphasia** – "We have an aphasia group at the university. They understand. There's no judgement."

✓ **Have a pen and paper handy** – "Even when I couldn't write, using a pen and paper helped me to process words."

✓ **Keep going** – "It can be a long journey, but speech can improve a lot over time, so keep a sense of humour and keep going!"



➡ ☎ Find out more about communication difficulties after stroke. Visit stroke.org.uk/aphasia or call **0303 3033 100**. You can also order communication cards and new aphasia resources (available from May), from stroke.org.uk/shop

Scotland Online Stroke Support Cafes

Stroke changes lives in an instant. Local volunteers host bi-weekly, friendly online cafes to connect and chat about stroke. They are a safe place to talk about what matters to you and meet other people affected by stroke in Scotland.

Contact us for more information.

Email: engagementteamsotland@stoke.org.uk

Stroke Helpline: 0303 303 3100 Website: stroke.org.uk

Rebuilding lives after stroke

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Supporting someone with communication difficulties

When a family member or friend has communication problems after stroke, it can be difficult to know how to help them. Maintaining social interactions can be a huge factor in someone's recovery so it's important to offer support.

Liz Jenkins from our Stroke Helpline shares some guidance:

How can I support with speech and language therapy?

Talk to the speech and language therapist (SALT)

– Ask the SALT for information on the stroke survivor's communication skills and progress, so you can support them to meet their goals.

The SALT can also help you learn how to have successful conversations with the stroke survivor and find alternative ways to communicate.

Encourage them to practise

– Show an interest in what they're doing and make time to practise with them, whether

that's supporting with exercises or prompting conversations. But don't force them into practising if they're not feeling up to it.

Take breaks –

Communicating can be exhausting, especially to begin with. Suggest a time limit on exercises or encourage them to rest if they're getting tired.



Keep it light-hearted –

Try to make it fun and introduce a bit of humour. Having a laugh about it can help you both to relax and ease the pressure.


Be patient if they get frustrated or don't want to practise

– They may be struggling with other effects of stroke such as pain, fatigue or depression, which can impact their motivation and outlook.



  Visit stroke.org.uk/communication-problems, call our Stroke Helpline on **0303 3033 100** or email helpline@stroke.org.uk for more support.

If you feel they need help with these, ask the GP for medical advice.

 **Keep track of their progress** – Seeing how far they've come and the improvements they've made can be a real boost.

How can I support them in conversation?

Talk about things you're both interested in, but stick to one topic at a time. Keep sentences short and ask one question at a time to avoid bombarding them with information.

Choose times to chat when you both have the energy and patience to concentrate. Remove distractions, such as turning off the TV, so you each have the other's full attention.

Listen carefully and don't rush. It can take 30 seconds or more for someone to respond, so give them the time they need to find the words. Try not to finish sentences or guess what they're trying to say. Be honest and tell them if you haven't understood.

Online Stroke Activities Hub

We've launched a new Online Stroke Activities Hub, which can help support you in your recovery no matter how long you've been living with stroke.

From support groups to social quizzes, our online activities are a great way to meet new people, feel more supported and increase your confidence.

Graham had a TIA (transient ischaemic attack or mini-stroke) and a stroke in April 2020, a few weeks into the first Covid-19 lockdown.

"I was taken to hospital quickly," says Graham, "But my CT scan showed that I had spider veins, so they couldn't give me the clot busting drugs because I was likely to bleed out. And I couldn't have a thrombectomy.

"I lost the use of my right side. I couldn't swallow properly, I couldn't move my fingers, arm, legs or toes. The consultant said I should have been having physio in hospital for three months. But because of Covid, I was released after eight days."

The stroke had a huge impact on Graham's wife, Kay, too. "Initially he couldn't do anything for himself," remembers Kay. "It was an exhausting time. But the community stroke rehabilitation team were amazing. I learned a lot from them about Graham's care, and with their help he progressed quite quickly and became more mobile."

Lockdown and the stroke left Graham and Kay feeling quite isolated, so their Stroke Association Support Coordinator suggested they try some of our online activities. These included



Graham and Kay enjoy the online quizzes at home

weekly quizzes and Me and My Stroke – sessions to help participants to understand stroke and learn more about living well with the effects of stroke.

"You get to meet other people who've had a stroke and realise you're not the only one in this situation," says Graham. "Hearing their perspectives and recovery hints and tips gives you something else you can look into to help with your recovery."

"The stroke couldn't have happened at a worse time, but the online activities have helped us see the light at the end of the tunnel. You get support from people who know what you're going through."



The online activities have supported Kay too. "The stroke couldn't have happened at a worse time," says Kay. "But the online activities have helped us see the light at the end of the tunnel. You get support from people who know what you're going through. And have a laugh with them. If we were closer, we'd go and meet them."

"There are activities on every day," she continues. "I did some of the genealogy sessions and we both did the Me and My Stroke sessions, which were really informative. The way they're delivered worked for us because they're light-hearted. Although it's a serious subject, you can also have a joke - you can take more in when you're relaxed."

"We enjoy the Friday quizzes the most – they're always a laugh," says Graham. "We do the quizzes in different rooms. We started off doing it together, but between us we get most of it right, which is a bit unfair as there's two of us! Also, I find it easier to concentrate on my own, so we split ourselves up. Kay still stays with me for the music quizzes though because I'm better at them!"

"I'd say to other stroke survivors and carers to join in!" he adds. "They've got a session for young people and an exercise group too now. You get a lot of understanding of where you are in your recovery journey. People will listen and help with a lot of information. They're a very friendly bunch, very accepting and welcoming."

What's on?



Me and My Stroke

Whether your stroke was recently or a while ago, these sessions over four weeks can help you come to terms with what's happened and support you to rebuild your life.



Young People Connect

For stroke survivors aged 18-45. Meet others of a similar age who understand what you're going through, and talk about the things that matter to you in a supportive environment.



Genealogy

Want to try something new? Our six-week course exploring the basics of genealogy gives you the tools to discover your ancestry and learn how to create your family tree.



Stroke-specific exercise

Get active and support your recovery with our six-week exercise programme. Choose exercises for your level of mobility to help improve your stability, stamina, flexibility and motor skills.



Social activities

Have fun and meet new people at our quizzes and games. These can also support recovery by building confidence and are a great way to help improve your memory and concentration.



Find out more about online activities and sign up at stroke.org.uk/online-activities.

Delivering your signatures to Downing Street

Thrombectomy is a stroke treatment that can significantly reduce disability and save lives. However, many people who could have it miss out because of where they live or when they have their stroke.

Last summer, Stroke News readers joined our Saving Brains campaign by signing our open letter to the UK Government, urging them to make 24/7 thrombectomy available to everyone.

In October 2022, campaigner and stroke survivor, Phil Woodford, helped deliver your signatures to Downing Street. He shares his experiences and what's next for the campaign:

"I'm 52 now, but I was 45 when I had a TIA and a stroke. I was thrombolysed (given clot-busting medication) but was unable to have a thrombectomy because

it was a Sunday and the service wasn't provided over the weekend.

My life changed overnight. It took six months' rehabilitation in hospital and then another four months till I could return to work.

My stroke has caused musculoskeletal problems, permanent pain and weight gain because I'm less mobile. I walk with a limp and my left arm has a mind of its own. But it's the psychological effect that I find really hard. My confidence levels dropped dramatically. Physical adjustments at work can be made with a little bit of money.

"I was thrombolysed but was unable to have a thrombectomy because it was a Sunday and the service wasn't provided over the weekend."



But trying to explain to people why I cry every day is almost impossible.

Unfortunately, when back in work, I was bullied and discriminated against. I found this really hard and it spurred me on to use my experience to help others.

I got involved in the Saving Brains campaign to improve access to thrombectomy because I didn't want anyone else missing out.

A thrombectomy mechanically removes blood clots in the brain. For many, this procedure prevents life-long disability. This has a huge knock-on effect – savings in rehab, care and emotional savings for the individual and family post-stroke.

But access to this life-changing treatment is poor. There isn't a 24/7 service across the country and we don't have enough doctors trained to do it.

In October, I was proud to be asked to help deliver 9,000 signatures in the Saving Brains open letter to Number 10, Downing Street.



Dr Sanjeev Nayak, Phil Woodford and Juliet Bouverie deliver our open letter to Downing Street

The political changes to the UK Government have affected the campaign, but I think we've capitalised on it. At Rishi Sunak's first Prime Minister's Questions, we saw Members of Parliament wearing Stroke Association badges, which was brilliant. We have to continue the campaign, never mind changes in government. It's not just saving a life – with thrombectomy people can return to work and to their hobbies, which positively impacts society.

Since we launched the campaign in July 2022, two thrombectomy services have committed to 24/7

access. The UK Government have also announced they'll be launching a stroke workforce plan and a new thrombectomy training credential, which we recommended in our Saving Brains report for England. This is fantastic, it will help so many people.

Health inequalities are unnecessary. The treatment you receive shouldn't be determined by where you live and what time you have a stroke. I hope that the workforce plan uses

our recommendations and governments across the UK provide what's needed to improve access to thrombectomy.

We're continuing the campaign this year and I will get involved with every opportunity that arises. I encourage you to write to your MP and get them to ask why this life-changing treatment is postcode and time dependent. We can use our lived experience to ensure stroke survivors have the best treatment available."



You can help us to drive improvements in stroke care. Visit stroke.org.uk/campaigns to find out more and get involved in our campaign, or call **020 7566 0341**.

Accessible cycling after stroke

Cycling is a great activity to try after stroke. As well as having lots of physical, mental health and social benefits that can help your recovery, cycling can be adapted for almost every type of disability.

Whether you want to get some exercise, rebuild your confidence or just enjoy nice days out, there are inclusive cycling organisations around the UK helping stroke survivors of all abilities to enjoy the adventure and freedom of cycling.

Adapted cycles

Cycling instructor, Scott, recommends getting professional assistance, often free through the council, when returning to riding after stroke. "Lots of people come to me because they're struggling with physical effects, such as their balance," he says. "We start

off by going right back to the basics and building up from there, practising techniques and finding adaptations to help them progress.

"You can adapt your bike to make it work for you – from putting your brakes on your good side for one-handed braking, or changing pedals, chain and cranks to make cycling better for your gait and leg strength.

"For people with limited or no use of their arms or legs, limited stamina or balance issues, there are also tricycles, recumbent, hand pedal, tandem and electric bikes available that help to make cycling accessible to everyone.

"Local cycling groups and charities like Wheels for All can support you to try accessible cycling. All good bike shops will allow you to take a test ride and lots of parks offer recumbent and tricycle rental if you'd like to give it a go."



Visit cyclingwithoutage.org.uk to find a group near you. And find out more about inclusive cycling at bikeability.org.uk/go-cycling/inclusive-cycling.

Cycling for everyone

International charity, Cycling Without Age (CWA), supports people who aren't able to cycle by themselves to enjoy the social and emotional benefits of a cycle ride.

Martin couldn't walk or stand independently after his stroke in 2020. After lockdown, he was keen to get out, so his Stroke Association Support Coordinator, Venita, put him in contact with his local CWA group in Portsmouth. Their rides are on trishaws, which have their own pilot who pedals for you. "Once on the trike you wear a seat belt and off you go!" says Martin. "The seat is on the front of the trishaw so at first

you feel vulnerable, but you soon get used to the freedom and people waving at you!"

"The pilots are all volunteers. We travel locally, which is lovely as I live on the coast." The rides are free and give less mobile people the chance to explore where they live and have a chat with their pilot.

"I can't speak highly enough about Cycling Without Age, as without them I would rarely, if ever, get out. Do it if you get the chance. It will make a difference."

Photo courtesy of The YOU Trust, who run the CWA Chapter in Portsmouth and Southsea: theyoutrust.org.uk/cycling-without-age

Recognising the signs of stroke

Stroke is a medical emergency. The quicker people receive treatment, the better their chance of survival and recovery, so it's vital to know how to spot the signs of a stroke in yourself or someone else.

The FAST test is a very effective way to spot the three most common symptoms of stroke or TIA (transient ischaemic attack or mini-stroke). But there are other signs that you should also take seriously, including sudden weakness or numbness, vision problems, or a severe headache (see page 29).

When Tabitha, 50, had a stroke in August 2022, the symptoms were very subtle. "My vision suddenly whited out," says Tabitha. "Then there was a

sparkling white noise in my peripheral vision that made me feel slightly vertiginous and sick. There was no pain. I assumed it was a perimenopausal migraine."

But a week later, Tabitha still had a headache and had started noticing other symptoms too. "Typing had become very difficult. I found it almost impossible to hit the right keys on my phone.

"And there were other weird things happening. I suddenly couldn't work out how the strap of my cross-body bag was supposed to loop round my neck and where my arm was supposed to go. I put my jeans on backwards and couldn't work out what I was doing wrong.

"I could do things - there was nothing wrong with my strength - but I couldn't work out how to do them."



Worried, Tabitha went to see her GP, who checked her for signs of a stroke. Everything seemed normal, apart from her coordination, so the GP recommended that she go to the hospital as a precaution. "The A&E doctor ran through the same tests as my GP, but couldn't see any neurological abnormalities, so I went home," says Tabitha.

Tabitha's symptoms continued to get worse, so she went back to hospital. This time she brought a sample of her typing as evidence of what was happening to her. "I showed it to the nurse. She said, 'You need a brain scan now.'"

A CT scan revealed Tabitha had had a stroke. "I was in total shock. I had no idea that the odd, vague symptoms I was experiencing were symptoms of a stroke. I thought they happened to much older people.

"My symptoms were subtle, but the stroke itself was not small. It has been a long process towards accepting my new reality. That's an emotional journey as much as a physical one: accepting

"The FAST test is a useful tool but it's important to recognise other indicators of stroke as not all neurological symptoms are obvious."

that you are disabled forces you to confront all kinds of hidden assumptions about how you and the world work.

"I returned to work as a teacher in January 2023, five months after the stroke. It was much harder than I thought it would be, but my school has been excellent at adapting my timetable.

"As a woman, I have spent all my life being trained to ignore pain and brain fog and discomfort, to put it all down to hormones and difficult female bodies. But headaches that last for days need medical attention.

"The FAST test is a useful tool but it's important to recognise other indicators of stroke as not all neurological symptoms are obvious."

FAST test



Face: Can the person smile? Has their mouth or eye drooped?



Arms: Can they raise both arms?



Speech: Can they speak clearly and understand what you say?



Time: If you see any of these signs, it's time to call 999.

Other symptoms of stroke

There are other signs that you should always take seriously. These include:



Sudden weakness or numbness on one side of the body, including legs, hands or feet.



Difficulty finding words or speaking in clear sentences.



Sudden blurred vision or loss of sight in one or both eyes.



Sudden memory loss or confusion, and dizziness or a sudden fall.



A sudden, severe headache.

If you spot any of these signs of a stroke, don't wait. Call 999 straight away.

For more information about the symptoms of stroke, visit stroke.org.uk/actFAST or call 0303 3033 100.

Overcoming loneliness after stroke

Socialising can be daunting after a stroke. Struggling with confidence, physical challenges, mental health or fatigue, many stroke survivors stop seeing family and friends or are forced to give up their hobbies, leaving them feeling isolated and lonely.

For Tracy, 52, having a stroke meant giving up her active social lifestyle. "I used to go to British Military Fitness (BMF) four times a week," says Tracy. "I was really fit and healthy. I was at a BMF event in Leeds, when my whole left side went weak and I started slurring my speech."

Tracy received thrombolysis, and was discharged from hospital after six days. Despite feeling lucky in her recovery, the lasting effects of stroke have affected her social life and mental health. "I've become more anxious, I've got fibromyalgia and fatigue. I don't go out like I used to. It's hard to plan anything because I never know what I'm going to be like on the day."

"I made a load of friends at BMF, and doing exercise made me feel so good. But the pace is too much for me now. In my mind I can do anything, but my body lets me down – it makes me feel really low."

While Tracy's recovery is ongoing, she has found new activities that help her to feel better about herself and meet new people.

"I go to bingo with my daughter once a week - it's our thing. We really enjoy it. There's a good atmosphere and you can have a laugh with the staff. It gets me out of the house and gives me some "me time".

"I also now have a personal trainer who knows what I can and can't do. Some days I struggle but I'm persevering. We do classes or exercise outdoors. It gets me out, and I always feel better after."

"I've taken up more hobbies since my stroke. I'm really into ancestry and go on the

genealogy sessions on the Online Stroke Activities Hub (see page 16). It's my chill out thing, it takes my mind off everything else.

"When you have a stroke, you have to take every day as it comes. But doing things like bingo, or joining groups online or in person, is a good way of connecting with people."



We've partnered with Buzz Bingo, to help tackle loneliness and social isolation after stroke. We're working together to ensure Buzz Bingo's clubs are accessible and supportive places, where anyone impacted by stroke can meet others, rebuild confidence and have fun.



If you're feeling isolated after a stroke, we can help. Visit stroke.org.uk/support or call our Stroke Helpline on **0303 3033 100**. You can find out more about our partnership with Buzz Bingo at stroke.org.uk/BuzzBingo or call **0300 3300 740**.



Researching aphasia rehabilitation

Aphasia happens when a stroke damages the parts of the brain responsible for language. Losing the ability to communicate makes it difficult to maintain friendships, and families may find it hard to cope. But many stroke survivors with aphasia and their families don't get the support they need.

Katie Monnelly, at City University London, is a stroke researcher and speech and language therapist (SALT). She's using her experience to develop an aphasia treatment that includes family members and focuses on recovery of communication skills, life adaptations, and regaining independence. She tells us about her work:

Q What inspired you to go into research?

I've been a speech and language therapist since I qualified in 2010. I love clinical work but found I had questions about the aphasia therapy I provided, so decided to pursue a PhD to look for the answers.

Q What's your research about?

My research is on aphasia. People with aphasia know what they want to say but have difficulty saying the words. This can be incredibly frustrating for them and their loved ones.

I want to improve treatment for stroke survivors with aphasia. Intensive speech and language therapy has been shown to help, but most people in the UK do not receive this type of therapy after a stroke. I am exploring one approach called an Intensive Comprehensive Aphasia Programme (ICAP) to see what happens in the therapy, what the outcomes are for people with aphasia and their families, and whether it could be adapted for a mainstream UK NHS service.

Q How has being an SALT helped your research?

It's hugely beneficial as I can map what I read onto my clinical experiences, keeping real life people in mind when I'm studying. The lack of public awareness of aphasia is a major issue, so raising the profile of aphasia is an important aim.

Q How do you hope your research will help people?

I hope my research will be able to give a clear evaluation of the pros and cons of an ICAP to stroke survivors. I plan to involve stroke survivors in designing and testing an ICAP, so it's an exciting road ahead.



What advice would you give someone who wants to do something extra to progress their recovery?



Practise – It is best to **practise words** or **short phrases** that are important and **meaningful to you**, rather than repeating names of generic pictures.



Connect with others – A huge impact of aphasia is loss of friendships. This can affect your mental wellbeing. Find local **stroke support groups** or **online aphasia groups**. These are an opportunity to make new **friends** with aphasia who **understand** what you are experiencing.



Keep going – It's **not true** that your **recovery plateaus** after a year. Evidence shows good quality and adequate amounts of speech and language therapy can produce improvements even years post stroke. **There is hope.**



Ask for more therapy – You can request **re-referral** for **NHS speech and language therapy**, especially if there are **specific goals** you wish to work on. Each service will have different policies but it is worth exploring.



Use digital tools – You can continue to work on your language with **aphasia resources**, such as mobile apps and computer software (free versions can be found on aphasiasoftwarefinder.org). The BBC has some good resources for English-learners that can be adapted (bbc.co.uk/learningenglish).



Visit stroke.org.uk/research to find out more about our research.

Support stroke research

40% of stroke survivors have aphasia due to a stroke. We're funding research to explore new treatments to support their recovery.

If you can, please support others whose lives have been changed by stroke. You can make a donation by visiting stroke.org.uk/donating, by calling us on **0300 3300 740** or by completing the form below.

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Return your form

Please detach this form and return it to us using the envelop enclosed, or post it to:
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Keeping in touch

We would love to send you information about the difference you can make to families affected by stroke through campaigning, volunteering, donating and through your own fundraising. Please tell us how you'd like us to stay in touch by filling in your details below.

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Please enter your phone number or email:

Address

Postcode

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Supportive stroke communities

Mark, 56, loved mountain biking and long walks with his wife prior to his stroke in June 2021. Although he quickly regained the ability to walk and made great progress in his rehabilitation physically, Mark struggled with anxiety attacks.

"In the months after my stroke, I was panicking about lots of things, like my son going out to the gym or with his mates, and just getting through the day. My wife was having to write lists for daily tasks to help me. Worrying about everything was affecting me so badly – it was debilitating.

"I was linked in with the Stroke Association during my time in hospital. When I got home I received a call from one of the Stroke Association's Support Coordinators. She was absolutely

incredible. In the first few calls I had a lot of questions about stroke and wanted to get advice on things, such as acupuncture. She told me about My Stroke Guide and sent me some information about some things I'd been asking about.

"My coordinator also asked me if I would be interested in the online Stroke Cafes. She said I was more than welcome to come along and listen, or chat, and there was no pressure to join if I didn't want to.

"The Stroke Cafes really helped my recovery because I was getting acknowledgement from other stroke survivors that they were going through similar things to me.

"Within two or three sessions I felt comfortable with it. I felt quite encouraged by speaking to the group. Over time, others who didn't talk started to talk too, and it felt nice to have helped people with that.



It gave me a good feeling for returning to work, because it showed I could talk to and understand others.

"I started reading the My Stroke Guide online forums, but it took me three or four months before I plucked up the courage to join in and post my story on there. Everyone really welcomed me and from then on I've been on the forums every day. I really value the people on there as friends now. It's incredible – so reassuring and useful."

Mark has now returned to work with the same employer. They have supported him to work from home and allow him recovery time after a day in the office.

"If you have the opportunity to join an online Stroke Cafe, give it a go. You don't have to talk, you can just listen. Join the My Stroke Guide forums too. You find out so much from people who have experienced stroke as well."



Visit mystrokeguide.com to access 24/7 information, advice and support from our online community. From local services and groups, to telephone befrienders, we're here to support you. Go to stroke.org.uk/support or call **0303 3033 100**.

Returning to work: reasonable adjustments

Going back to work after a stroke can be a big change. If you feel ready to return, your employer should work with you to identify what your needs are and what adjustments they can make to help you.

Our partners, Posturite, are specialists in workplace health and well-being. Their Enablement Lead, Andy Rigby, explains your legal rights and what you should expect from your employer:

What does the law say?

The Equality Act requires employers to make “reasonable adjustments” for people recovering from a stroke and returning to the workplace. It’s important that individuals and families are aware of the support that is available.

i Reasonable adjustments are changes to your workplace or the way you do your job to enable you to work without disadvantage if you have a disability.

How can your employer help you?

Your employer can arrange a Workplace Needs Assessment for you. These are one-to-one appointments with an enablement expert – paid for by your employer – to establish your needs and find solutions to both physical and/or cognitive challenges you may have at work.

The assessor will explore your job role, what you want to achieve, what your employer requires and the barriers you may face. They’ll then produce a report with recommended changes.



Find out more about Posturite, their Workplace Needs Assessments and products to help people returning to work after a stroke at Posturite.co.uk

What adjustments can help after a stroke?

✓ **Ergonomic equipment** – Ergonomic and adjustable office chairs, keyboards and mice can help with physical challenges, such as one-sided weaknesses. Screen magnifiers can sometimes help with visual difficulties.

✓ **Changes to working arrangements** – Changing your contracted hours or enabling you to work from home can help, especially if you have fatigue.

✓ **Assistive Technology** – You can get digital tools and software to support with reading aloud, writing and grammar.

✓ **One-to-one coaching sessions** – These are a great way to help you focus on your strengths and re-build your confidence. You could also do co-coaching sessions with your line manager, so you can work together to achieve your objectives.



For guidance on returning to work visit stroke.org.uk/work. Or call our Helpline on **0303 3033 100**.

Making your money go further: eating well on a budget

Rising food prices and energy bills are making it harder for people to afford regular, nutritious meals. However, eating a healthy diet is an important part of your recovery, and can help to reduce your risk of further strokes or TIAs.

If you're struggling to afford food, you can get support:

1 Financial assistance – You may be eligible for government benefits or a grant or loan from your local authority. Go to gov.uk/benefits-calculators to work out if and how much you could claim. You can also get information on the different types of financial support available at stroke.org.uk/financial-support.

2 Food banks – Food banks provide free food to people who are struggling financially. You usually need to be referred to a food bank by a professional such as Citizens Advice service

(citizensadvice.org.uk), your GP or a social worker. Your council can also give information about food banks and other crisis support in your local area.

If you're not eligible for benefits, but are finding it difficult to make your budget stretch, here are some practical tips:

✓ **Food waste apps** – You can buy unsold food at a discount from cafes, restaurants and shops through apps such as Too Good To Go (toogoodtogo.com) and Karma (old.karma.life). You can also claim surplus food in your area through food sharing apps like Olio (olioex.com).



✓ **Community Fridges** – These are public spaces that collect surplus fresh food (mainly fruit and vegetables) from local businesses and households so it can be shared in the local community. Unlike food banks, you don't need a referral so anyone can use it at any time. Visit hubbub.org.uk/the-community-fridge to find one near you.

✓ **Batch cook** – Buying food in bulk, batch cooking and freezing portions for later, can save you time and money. This is particularly worthwhile if you need to use an oven, which can be surprisingly expensive to run,

unless you're getting the most out of it by filling it up.

✓ **Energy efficient cooking** – You can reduce energy costs in the kitchen by using a microwave, pressure cooker, air fryer or slow cooker to prepare a meal. They're more energy efficient and cheaper than an oven. Keeping lids on pots when boiling food also reduces costs by speeding up cooking time.

✓ **Opt for frozen fruit and veg** – This is usually cheaper than fresh and is just as nutritious. It can help you to avoid waste as you only use what you need when you need it.

For more information, visit stroke.org.uk/financial-support, or call our Stroke Helpline on 0303 3033 100 or helpline@stroke.org.uk

Puzzles

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

Word search

P R E H T A E H S
V R C T N M T Y N
I S I M Z N P S O
O M G M I C U N W
L Z N C R R T A D
E W A O H O I P R
T Y C Q V N S S O
H U T U L I P E P
S L I D O F F A D

PRIMROSE TULIP
SNOWDROP IRIS
CROCUS HEATHER
DAFFODIL PANSY
HYACINTH VIOLET

Across

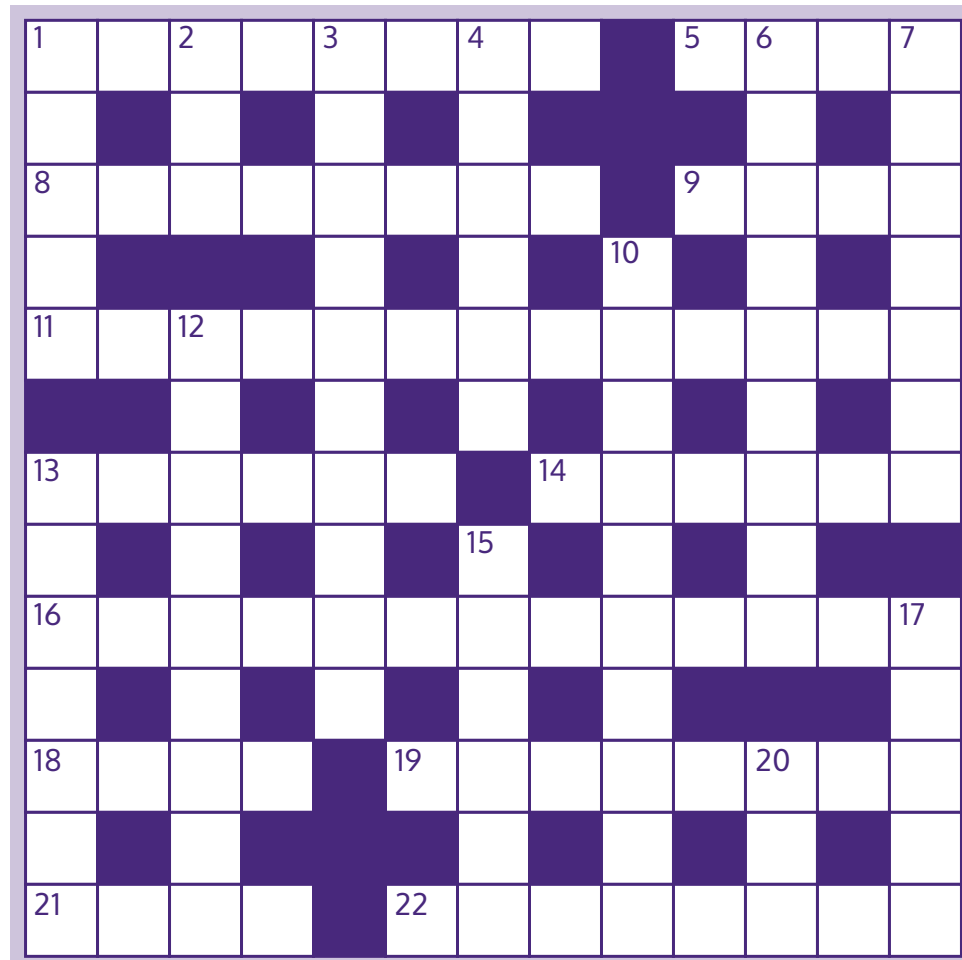
- 1 Wavy line (8)
- 5 Absorbent pad (4)
- 8 Start shooting (4,4)
- 9 Remain (4)
- 11 Grilling (13)
- 13 Protrude (6)
- 14 Creative person (6)
- 16 Fuddy-duddy (5-2-3-3)
- 18 Waterless (4)
- 19 Covetousness (8)
- 21 Book after II Chronicles (4)
- 22 Make light of (4,4)

Lottery

For your chance to win £1,000 every week, play the Stroke Association Charity Lottery. Go to lottery.stroke.org.uk to find out more.

Down

- 1 Japanese papered wall (5)
- 2 Exploit (3)
- 3 Risk everything (2,3,5)
- 4 Bacon cube (6)
- 6 Quip (9)
- 7 Muzzle blade (7)
- 10 Mild white cheese (10)
- 12 Witness (9)
- 13 Subjugate (7)
- 15 Introduce publicly (6)
- 17 Senior member (5)
- 20 (Possibly) alien craft (3)



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

Solutions
see page 50

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Keep on being you



Rebuilding lives after stroke

Our charity supports people to live the best life they can after stroke. But rebuilding lives is a team effort and we need your help. A huge thank you to everyone who's gone the extra mile to fundraise, volunteer and campaign with us. Your support means we can reach even more people who need us.



Bethany Sharpe

Amazing Bethany Sharpe, 10, raised over £900 by cycling all 26 miles of Marriott's Way in Norfolk. "My great Nanna died from a stroke and four of my other great grandparents have been affected," says Bethany. "I want to help other families who are impacted by strokes and raise money to support stroke survivors."

Wing Lee Chan

Congratulations to Wing Lee Chan, who succeeded in her mission to run 12 half marathons at events in London and around the South East throughout 2022. She raised over £2,000 in memory of her dad.



Find out what events we've got coming up on page 50 or make a donation at stroke.org.uk/donating

How does your donation help?



£10 supports our Helpline to answer a call from someone who urgently needs support after a life-changing stroke.



£25 could be part of a hardship grant for a stroke survivor who is struggling to pay for basics like food and clothing.



£50 could help us be there for children and families through our Childhood Stroke Support.



Southport Dramatic Club

Thank you to the Southport Dramatic Club, who kindly fundraised for us during performances of *Sleeping Beauty* at the Little Theatre and raised over £2,100.



Volunteer spotlight

Sue Schofield volunteers with stroke groups in Burnley and Bolton.

"I've been a volunteer for 12 years, firstly starting a carers group to support people like me, who felt isolated when their lives were affected by stroke.

"In 2015, I started the Fun 4 Strokes Group for stroke survivors. I love seeing people enjoying the activities I organise, including seated yoga, crafts, online bingo and outings.

I recently did a talk on salt and its effect on blood pressure, which led to a good conversation about healthy eating and made the group more aware of the salt in their food. I've shared my talk with the Stroke Group Network so other groups can use it too."

Find out how you can volunteer at stroke.org.uk/yoursupport

Join Team Stroke

Get involved and fundraise at home, or join us at exciting events around the UK:

Spin for Stroke April-May

Get on your bike and raise money for the 1.3 million stroke survivors in the UK. Choose your distance, where you want to cycle and go to stroke.org.uk/spin to sign up.

Great Birmingham Run 7 May

Looking for a challenge? Join Team Stroke for Birmingham's biggest 10km and half marathon running event. Sign up at stroke.org.uk/Birmingham23



Edinburgh Marathon Festival 27 - 28 May

From 5km to full marathon, this flat course in Edinburgh is great for beginners and seasoned pros: stroke.org.uk/EdinburghMarathon23

Parallel Windsor 2 July

Push, walk or run this fully accessible challenge in Windsor. From 100m to 10km, these fully accessible events welcome all ages, health conditions and abilities. Sign up at stroke.org.uk/ParallelWindsor

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

Crossword solution

Across: 1 Squiggle, 5 Swab, 8 Open fire, 9 Stay, 11 Interrogation, 13 Exsert, 14 Artist, 16 Stick-in-the-mud, 18 Arid, 19 Jealousy, 21 Ezra, 22 Play down

Down: 1 Shoji, 2 Use, 3 Go for broke, 4 Lardon, 6 Witticism, 7 Bayonet, 10 Caerphilly, 12 Testifier, 13 Enslave, 15 Unveil, 17 Doyen, 20 UFO.



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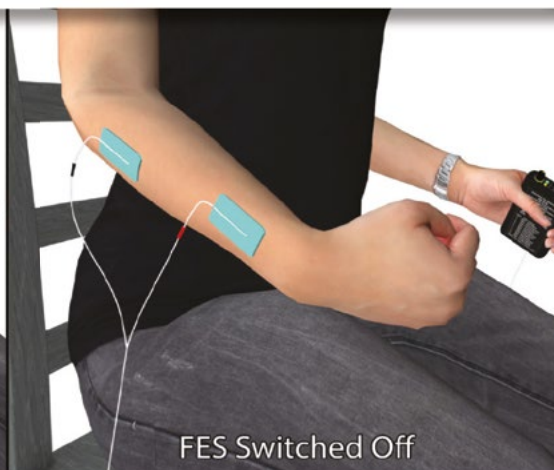


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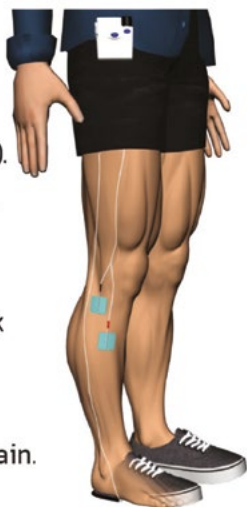
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