

# Stroke News

Spring 2020

For everyone affected by stroke

**Stroke**  
Association

"I had to adapt, accept  
and build on the new  
version of me."

**Read Hannah's story**

## This issue:

- Rick's guide to My Stroke Guide
- Meet your Patient  
Voice Representative
- Research around the UK
- Walk Your Way



# 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](https://stroke.org.uk/volunteer)

Rebuilding lives after stroke

**Stroke**  
Association



A photograph of a man and a woman in conversation. The man, on the left, is wearing a black cap and glasses, looking towards the woman. The woman, on the right, is wearing a white hijab and a purple top, looking back at him. A purple banner with the word 'Contents' is overlaid on the bottom left of the image.

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Contact us on **01604 687 721**, email **[strokenews@stroke.org.uk](mailto:strokenews@stroke.org.uk)** or visit **[stroke.org.uk/strokenews](https://stroke.org.uk/strokenews)** to:

- Subscribe to three editions of Stroke News per year for free (online, in print or audio).
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# Editor's letter

Few people truly understand what life after stroke is like, unless they've experienced it themselves. Speaking to others who can relate to you can make a big difference to your wellbeing.

This issue, we explore how stroke survivors and communities around the UK support each other to rebuild their lives after stroke.

Our cover star, Hannah, had a stroke at 23. Hear how meeting other young stroke survivors online helped her to move forward, and what she's learned about managing anxiety (page 8).

Rick regularly supports others in our online community, My Stroke Guide. On page 20, he gives you a

tour of the website and introduces some of its new features.

We also speak to Chris (page 14) and Dawn (page 32) about why their stroke groups are so important to them. And our Helpline Team share advice about finding support if you're struggling with isolation and loneliness (page 12).



I hope you enjoy this issue.  
**Christine Webster, Editor**

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# Over to you

I had my stroke on a sunny Saturday in 2009. I'd been getting ready to go on holiday and was in high spirits. On the bus home, I remember having a thumping headache. I managed to get off at my stop, but could barely walk - it took me half an hour to go the three hundred yards to my flat.

I woke on Sunday with another headache, but carried on as usual and took my clothes to the launderette. Peggy, who worked there, took one look at me, used the FAST checklist and called an ambulance. She saved my life.

My right side was paralysed, my speech disappeared and my brain felt enveloped in fog. I was released from the hospital a few weeks later, but it took me 18 months to get the minimum six physiotherapy sessions that stroke survivors should get.

Over ten years, I've gradually regained control over my right side and learnt to speak again. I'm now a stroke club leader and I use my experiences to help others on their journey towards recovery. I'm proud to call myself a survivor.

**Clive Baulch**

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Stroke Helpline: **0303 3033 100**

Find your local services, clubs and groups: **[stroke.org.uk/support](https://stroke.org.uk/support)**

Join our online community: **[mystrokeguide.com](https://mystrokeguide.com)**

Find information about stroke: **[stroke.org.uk/publications](https://stroke.org.uk/publications)**



## Do you have something to share?

Write to us at Stroke News, 240 City Road, London, EC1V 2PR or email **[strokenews@stroke.org.uk](mailto:strokenews@stroke.org.uk)**.

# This candle helps to rebuild lives after stroke

Our spiced fig candles make a great gift for friends and family, or a well-deserved treat for yourself. Every candle sold will help to fund stroke prevention, research and support.

**Candles cost £11.95 inc. P&P.** They have a burn time of 40 hours. Please always follow safety instructions.

Buy your candle at  
[stroke.org.uk/candle](https://stroke.org.uk/candle)

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# From our Chief Executive

As our Rebuilding Lives campaign continues, it's great to see people reaching out through our clubs, groups and services to ask for and offer advice and support to fellow stroke survivors and carers.

We now have an online community of 15,000 stroke survivors, carers and stroke professionals on **mystrokeguide.com**. Guided by your user feedback, we're continuing to make improvements to enable as many people as possible to give and get support. Find out more on page 20.

We want to ensure that policy makers and opinion formers are listening to people affected by

stroke too. We've appointed stroke survivors Nisba Ahmed and James Redgate as your new Patient Voice Representatives on the Stroke Delivery Board for NHS England. We want to make sure that plans to improve stroke treatment and care focus on what matters most to people affected by stroke. Nisba explains more about her role on page 24 and we'll catch up with James in a future issue.

We're also calling on you to tell us what you want stroke research to change in the future. There are lots of exciting ways to get involved - visit **stroke.org.uk/jla** to have your say.

**Juliet Bouverie**

# "This is me now"

Hannah McGrath, 28 from Manchester, was working night shifts as a nurse in 2015, when she found herself needing medical care after having two strokes.

Fortunately, Hannah hasn't had lasting physical issues. But the emotional effects have had a huge impact on her life. "I really struggled with anxiety and fatigue," she says. "I was 23 at the time and I felt like I'd lost all control over my life. I moved back in with my mum. I didn't know if I'd be able to go back to nursing and thought everything I'd worked for had gone.

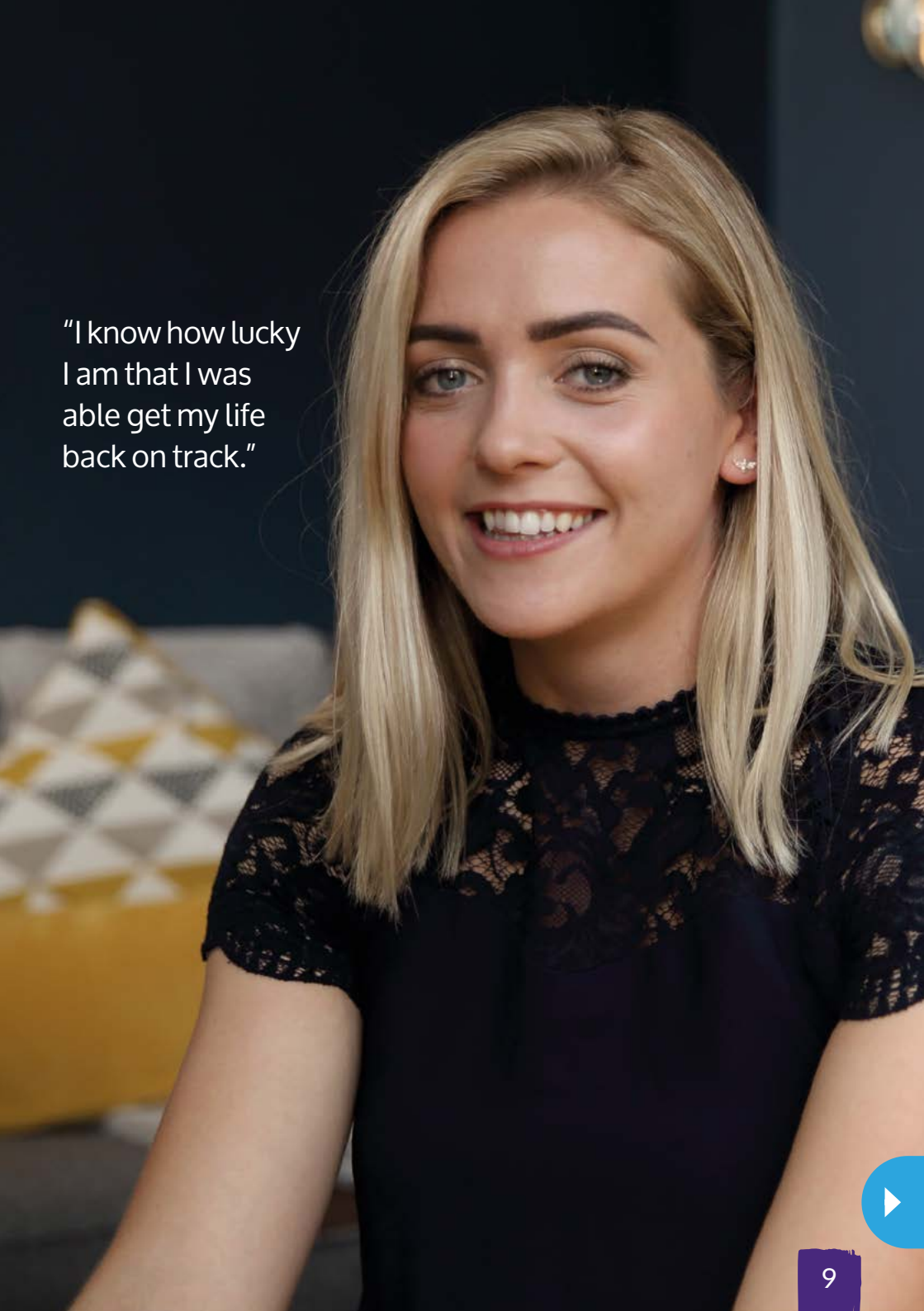
"I had such bad anxiety about having another, far worse, stroke that I wasn't sleeping. I was exhausted during the day and had no interest in doing anything.

"Breaking out of that vicious cycle was a gradual process. To be honest, if it wasn't for my mum, I'd probably still be in bed. She gently encouraged me to come downstairs or get a shower.

"I just took it day-by-day and built up from there. I started working in my local pub's kitchen for a couple of hours a week, and volunteering with the Stroke Association. I supported other working-age stroke survivors, which gave me purpose, much-needed social interaction and helped me to begin to rebuild my life."

Hannah was able to return to nursing less than a year after her strokes. "I know how lucky I am that I was able to get my life back on track. I've learnt that progress isn't quick, it builds over time. I don't know if I'll ever be fully there emotionally, but I'm a lot better than I was five years ago.





"I know how lucky  
I am that I was  
able get my life  
back on track."



"I've thought about the things that helped me to work through my anxiety and depression. I hope they'll help you too:

### **Start with the basics**

"Set short-term achievable goals. For example, 'Today I'm going to get out of bed and get washed' - you always feel better after a shower. Even if you don't achieve anything else that day, you've taken a step forward and can build from there."

### **Find a positive focus**

"When you're feeling a bit more confident, pick a longer-term goal to aim for. Having something to work towards keeps you going and helps control the anxiety. To give me something positive to focus on during my recovery, I decided to raise £2,016 for the Stroke Association in 2016. I did a fundraising activity every month and ended up getting over £4,500."

### **Talk to people who know what you're going through**

"Meeting other people who'd had a stroke, whether it was in person or online, gave me confidence and helped me to realise I wasn't alone.

I spent a lot of time on Stroke Association forums and on young stroke survivor Facebook groups. It was comforting to know that others, often in worse situations, were rebuilding their lives.

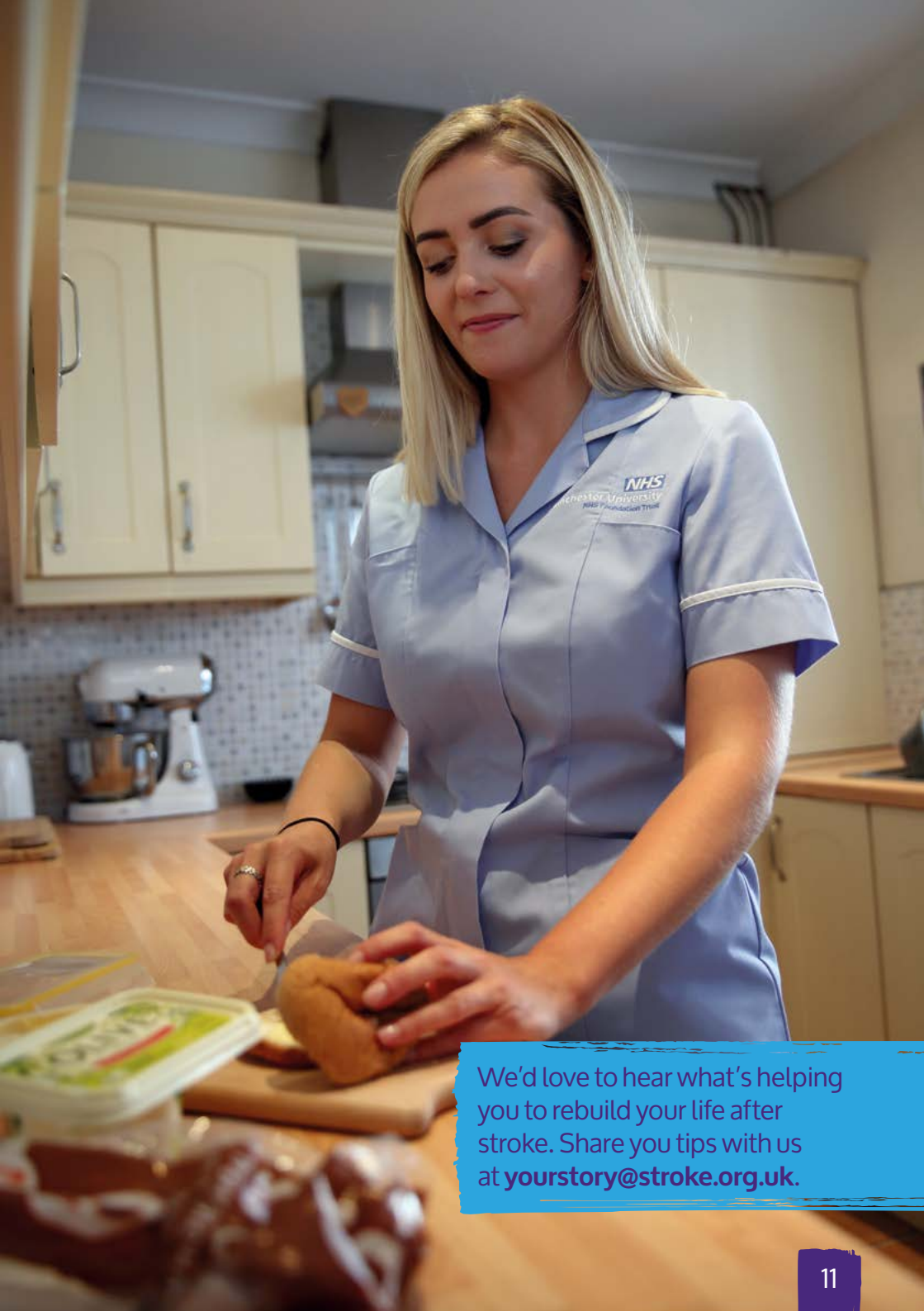
I'd definitely recommend online forums to carers or stroke survivors who are struggling. Particularly if you don't have a friend or family network, or can't or don't want to go to meetings. You can just read the comments or you can vent and people can reply and relate. It made me stronger and gave me courage."

### **Go outside**

"Being outside is good for mental health. I try to go for a walk or a run at least once a week. But you don't have to do a physical activity - just sitting out in the fresh air helps. Volunteering also got me out of the house, helped me to socialise and distracted me from worrying."

### **Accept yourself**

"A real turning point for me was realising that I had to stop comparing myself to how I was before. This is me now. I'm adapting to this new version of me, and accepting and building on who I am."



We'd love to hear what's helping you to rebuild your life after stroke. Share your tips with us at [yourstory@stroke.org.uk](mailto:yourstory@stroke.org.uk).

# Managing loneliness and isolation

Stroke can be life changing. Coming to terms with the after effects can leave you feeling lonely, isolated, and like no one understands what you're going through. This can have a big impact on your emotional wellbeing and mental health, so it's important to get some support.

Vicki from our Stroke Helpline shares some help and advice:

## How can I reduce my feelings of loneliness following my stroke?

- It's important to remember that you're not alone. You can call our Helpline and speak to someone who understands the effects of stroke. We're here to listen and can help you to find out what support is available to you.
- Some people find it helps to talk to others affected by stroke. Go to **stroke.org.uk/clubs** to find a stroke group in your area where you can meet other stroke survivors.
- Talk to your friends, family, GP or stroke professionals too. Let them know what you're going through and how you feel so they can give you the support you need.

## I'm housebound, what can I do to reduce my isolation?

- Join our online community on My Stroke Guide. You can connect with stroke survivors and carers around the UK on the forums, and find advice, information and support to help manage your recovery: **mystrokeguide.com**.
- If you are happy using social media, you can connect with other stroke survivors through our Facebook groups too.
- If you prefer to use the phone, SupportLine (**01708 765 200**) also offer confidential emotional support to anyone of any age. The Silver Line Helpline (**0800 4 70 80 90**) also offer friendship and advice to older people.



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



For more information about finding  
support, go to **stroke.org.uk/**  
**support** or **mystrokeguide.com**.



### **How can I support my friend or family member who is feeling isolated after a stroke.**

- Be patient and remember that not all stroke effects are visible. They might feel depressed, anxious or have other issues such as incontinence, which might be why they don't feel ready yet to leave the house.
- Call or visit them as much as you can, even just a weekly phone call to check on their wellbeing will make a difference.
- Help them by searching for stroke groups or clubs in their area, where they can meet other stroke survivors.
- Encourage them, or help them to sign up to My Stroke Guide so they can join an online stroke community.
- Also, if your family member or friend has had a stroke, you might also be feeling lonely. Remember the Stroke Helpline is there for you too.



# Supporting other stroke survivors

"To be able to share your experience of life after stroke, and to have others who know what you're going through offer help and advice, or maybe just say that they understand, is very important to recovery and rebuilding your life after stroke."

Chris Mahood, 37, from Annalong, Northern Ireland speaks from experience. He had a stroke when he was 24, a week after the birth of his son. "I couldn't speak or move anything on my left side," said Chris. "I spent three months in a wheelchair until I learnt how to walk again."

"In the first couple of years after the stroke, I was very angry at the world. I wasn't able to return to work, as I couldn't manage the physical demands of my job as a landscape gardener. Eventually it dawned on me that I had a son and I had to wise up for his sake."



Chris and Juliet, our CEO, at the Northern Ireland Life After Stroke Awards 2017.

Chris first found out about the South Down Stroke Association Voluntary Group through his neighbour. "He was already a member and convinced me to come along to give it a go - and I've been going ever since."



"After a stroke, you can get very down and feel cut off or alone. But that's where peer support comes in – the power of sharing how you feel or what you're going through with others. I can honestly say that groups like this help your mental health."

Six years on, Chris now organises and runs activities and day trips for the Newcastle based group. "I volunteered as leader because I had time to give and wanted to help the group thrive. I get a lot of satisfaction knowing that the activities we do make our members happy. Our group also thrives because of our terrific volunteers. They're the backbone of the group."

"I'd say to anyone who has been affected by stroke and hasn't been to a peer support group like

ours, give it a go. You won't regret it. Stroke recovery takes time and there are plenty of us going through it too. I was fit and healthy when I had my stroke and my family found it tough at the start. But now, I don't let it worry me. I know you just have to get on with life. It's about accepting where you are and going forward."

We have Stroke Association Voluntary Groups across the UK, run by amazing volunteers like Chris. Go to [stroke.org.uk/clubs](https://stroke.org.uk/clubs) or [mystrokeguide.com](https://mystrokeguide.com) to find a group near you.

If you'd like to volunteer to support stroke survivors in your area or learn more about starting a group of your own, visit [stroke.org.uk/volunteer](https://stroke.org.uk/volunteer).

# Walking my way to recovery

Twenty years ago, Lisa Ogun, 47, had a stroke that left her with chronic pain. Since then, she's continued to find new ways to manage her condition, including taking part in our Walk Your Way challenge. She tells us how walking a marathon distance in her own time, at her own pace, has helped her recovery and reignited her love of walking:

"I was getting ready to celebrate my birthday with my children when I had my stroke. I developed dystonia, which means I have uncontrollable and often painful muscle spasms in both of my left limbs and my spinal column.

I was 28 at the time and quickly realised our lives would never be the same - I would never be the same. The pain is the most intrusive and debilitating in my left foot. It causes my foot to curl underneath me when I walk. It can be excruciating. I wear in-shoe walking aids to try to minimise its effects, and I thank Lily Allen for making wearing trainers cool. Even in a ball gown!

I had always wanted to do a marathon but thought my chances were over because of my disability. So, when I read that Walk Your Way was a marathon I could do in my own time, taking it bit by bit, I applied there and then. After my stroke, the Stroke Association was there for me straight away and helped me to find support groups, so it was good to be able to raise some money too.

Ordinary day-to-day walking is challenging for me, so I surprised myself with my determination. Walking instead of taking public transport, or even just getting off the bus one stop earlier, enabled me to discover beautiful areas



# association

Take part in Walk Your Way and challenge yourself to get active, and build up to 26.2 miles at your own pace. Sign up at [stroke.org.uk/walk](https://stroke.org.uk/walk).

Rebuilding lives  
after stroke

of my neighbourhood that I'd not been able to see before. It reinstated my love of walking and helped me be healthier - I was even told I'd visibly lost weight!

When I finished Walk Your Way, I missed it but had realistically reached my walking limit for a while. However, I've bought an

exercise bike to help me carry on building the muscles I'd developed while walking.

Although it was hard at times, it reminded me that as long as I can smile and have the support and encouragement of the people around me, I can always manage."



## Lisa's tips for managing pain and getting active after stroke:

- **Don't struggle by yourself** – Get support, be it from family, friends, your GP or therapists, or charities like the Stroke Association.
- **Set yourself achievable goals** – Be truthful with yourself about your limitations and challenges, but don't wallow in them. Focus on what you can do so you don't get frustrated.
- **Keep active** – Gentle exercise can help with chronic pain, so keep moving and try not to neglect the affected muscles.
- **Listen to your body** – We are stronger and more resilient than we sometimes think. Do as much as you can, but rest when you need to.
- **Remember** – we're all amazing. Being positive goes a long way.

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You can find more information and advice about pain after stroke on [stroke.org.uk/pain](https://stroke.org.uk/pain) and [mystrokeguide.com](https://mystrokeguide.com).







## Say **thank you** to your wedding guests in a meaningful way with our new **wedding favours**

Whether you're acknowledging a recovery, remembering someone important in your life or simply celebrating the start of married life – our wedding favours are the perfect finishing touch to your special day.

Every wedding favour sold will help us raise the vital funds needed to rebuild more lives after stroke.

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Buy your wedding favours from  
[stroke.org.uk/weddings](https://stroke.org.uk/weddings)

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# Rick's guide to My Stroke Guide

**Rick Hein is a My Stroke Guide veteran. The former IT teacher used his "techie background" to help us test and develop our online support tool.**

Rick now visits My Stroke Guide regularly, welcoming new members and helping them to use the website. He talks us through his favourite features:



## My social

"My social' is a marvellous tool to help with communication. I use it to practise my written conversation and I've improved a lot by answering questions and supporting other users.

The forums give you a chance to 'pick the brains' of stroke survivors, carers, and health professionals that have experienced stroke first-hand. I'm always amazed by the ability of carers and survivors to overcome what seems like long odds to get back to the new normal."



## Video library

"I like the videos – they're short and answer specific questions. There are over 200 videos about stroke, prevention and improving your health. I recommend the 'Back to work' videos. And I think the 'Looking after yourself' and 'Exercise' videos are also crucial. You can be at a low point after a stroke, so taking care of yourself is not always a priority. The videos help you think about how to get active and to start doing things for yourself again."



Log on to **[mystrokeguide.com](https://mystrokeguide.com)** to access information, advice and support 24/7, and to join our online community. For help using My Stroke Guide, email: **[mystrokeguide@stroke.org.uk](mailto:mystrokeguide@stroke.org.uk)**.



### Goals and journal

"I try to signpost to the goals and journal, because goal-setting helped me a lot after my stroke. It's important to break down your goals into achievable little steps. When I woke up after my stroke, I was mute. But I was grateful to be alive, and worked hard at recovering. I wrote in my journal that I wanted to speak in a full sentence, then to speak in two full sentences without stopping. I worked my way up like that and over time, my confidence improved greatly."



### Advice and information

"This is my 'go-to' section because you can find almost everything you want to know about stroke, stroke care and therapies. Having this easy-to-read information in one place can help you feel less isolated and uncertain, especially when you leave hospital and the appointments for physio and speech move to once a week or less. This section is also helpful to carers, as it explains the physical, practical and emotional sides of stroke."

# Make your mobile or tablet

Mobile devices, such as smart phones and tablet computers, can be great tools for supporting recovery and daily living.

Most devices have accessibility features to enable you to adapt them to your needs. Here are a few ways you can make your device easier to use:



Look for accessibility options in your device's 'Settings' app.



## Set up voice controls

You can control your device with your voice instead of typing. Most onscreen keyboards have a microphone icon. To use voice control, tap the microphone. Then you can speak your messages or web searches and the words appear on the screen.



## Enable your device to talk to you

Most devices now have a built-in text-to-speech app that reads out the text on your screen. This can be particularly useful if you have reading difficulties, sight problems, or fatigue.

You can change the speed and pitch of the screen reader's voice to suit your needs. You can sometimes change the way it pronounces words to make it easier to understand.

You can also get your phone to describe your actions when you touch the screen. This enables you to navigate your device without having to see it. Look in the 'Settings' app for TalkBack (on Android devices) and VoiceOver (on IOS/Apple devices).

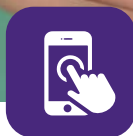
# easier to use



## Make websites and applications easier to see

Change the text size and font type to make words clearer, or adjust the colour settings to improve contrast.

You can also set up your device so you can zoom in and out by pinching or tapping the screen. Or turn on the magnification settings to see the whole, or part of the screen in more detail.



## Adapt your phone for one-handed use

Go into your device's keyboard settings to change the on-screen keyboard to one-handed mode. You can also choose whether you use your left hand or right hand.

Some devices also have a 'one-handed', or 'reachability' mode, that makes the screen smaller, so that it's easier for your thumb to reach.

We've partnered with AbilityNet, a charity helping people with disabilities to use technology. Their online guide, My Computer My Way, gives you information on how to set up your technology to suit your needs, including step-by-step instructions for the features mentioned here.



Visit [abilitynet.org.uk](https://abilitynet.org.uk) or call their technology advice helpline on **0800 269 545**.

You can also find guidance on [mystrokeguide.com](https://mystrokeguide.com).



# Representing stroke survivors

Meet Nisba Ahmed, your new Patient Voice Representative. Nisba had a stroke in 2011, and together with fellow stroke survivor James Redgate, is now working alongside health care leaders and experts to oversee and help deliver the improvements in stroke care set out in their the NHS Long Term Plan for England. She tells us more about her experiences:

## **What is a Patient Voice Representative (PVR)?**


As Patient Voice Representatives, James and I use our lived experience of stroke to inform and influence the work of NHS England services in a national context.

We attend the Stroke Delivery Board meetings, chaired by Juliet, the Stroke Association's Chief Executive, and the Cardiovascular and Respiratory Programme Board meetings.

We hear about projects to improve stroke care and services, and have the opportunity to voice our thoughts. For example, the NHS are piloting a new rehabilitation programme across England, so we plan to share stroke survivor experiences to help them develop this.

## **Why did you want to become a PVR?**

I had a stroke when I was 37 weeks pregnant. I now have half vision in each eye and no

A photograph of a woman with dark hair and glasses, wearing a dark scarf and a purple top, smiling and speaking to a group of people. The background is slightly blurred, showing other attendees.

Nisba talking about her experiences at the City Lit Mental Wealth Festival 2019.

Credit: Philip Hardman

peripheral vision on the left side (hemianopia). This means I often bump into things or don't see things that are there on the left side, unless I swivel that way. My left side is also weaker and I've had emotional and cognitive problems.

I didn't get any stroke rehabilitation or mental health support and relied on my mum to help me look after my son, who was born a few days after my stroke.

I've adapted to my situation but I've had to work hard to get to this stage and don't want other people to have to go through the same experience I did. I was looking out for opportunities to use my lived experience to benefit others and saw the Patient Voice Representative advert on the Stroke Association's website. I wanted to get involved on a national scale to influence and improve services and to make a difference.

## **Q Have you done any campaigning before?**

I do talks and raise awareness of stroke and the FAST signs, particularly in black, Asian and minority ethnic communities in Bristol, my local area, as well as with young people in Lancashire where I'm originally from.

I'm also a Commissioning Officer for the local authority – I commission services based on the community's needs and have supported local stroke groups in the past.

## **Q Why is it important for people affected by stroke to be on these boards?**

We've had experience of stroke so we know how debilitating it can be and how it can affect you physically and psychologically.

It's really important to have those experiences reflected on a national scale and I hope our involvement will help to influence and improve the quality of care for stroke survivors, carers and their families.



## **NHS terms explained:**

### **NHS Long Term Plan –**

Sets out NHS England's priorities for healthcare, including stroke, over the next 10 years.

### **Stroke Delivery Board –**

Oversees the improvements to stroke treatment and care in England promised in the Long Term Plan.

### **Cardiovascular (CVD) and Respiratory Programme Board –**

Oversees all the improvements promised in the Long Term Plan for stroke, cardiac and respiratory conditions.

"I hope our involvement will help to influence and improve the quality of stroke care."



To find out how you can get involved in campaigning around the UK, go to [stroke.org.uk/campaigning](https://stroke.org.uk/campaigning).

# Research around the UK

We recently began funding a new study in Northern Ireland, so right now, we're funding stroke research in every nation of the UK. Come with us on a trip around Britain, to explore some of the projects aiming to improve people's lives after stroke.



## Northern Ireland

**Project:** Could a medication used to treat gout help to stop stroke and TIA survivors having further strokes?

**Background:** We've partnered with research funders in Ireland to support a trial that looks at whether a medication called colchicine, usually used to treat gout, can stop stroke and TIA (mini-stroke) survivors from having further strokes.

This clinical trial, called CONVINCE, is taking place in nine countries across Europe.

Our funding has enabled them to extend the trial to give 200 stroke and TIA survivors living in Northern Ireland the opportunity to participate.

**Aims:** Previous trials found that heart attack survivors treated with colchicine had fewer heart attacks and strokes, compared to those who didn't receive it. So now the CONVINCE trial is hoping to find out if colchicine has the same effect in stroke and TIA survivors.

If it does, then colchicine could be offered to stroke and TIA survivors to prevent further devastating strokes, allowing them to focus on rebuilding their lives.






## Wales

We spoke to Alexander Smith at Cardiff University about his work to ensure that stroke survivors are able to give their views on their treatment:

### **Tell us a bit about your research.**

Patient-reported outcome measures (PROMs) are questionnaires that aim to measure patients' opinions about their health after an illness or during treatment. I want to understand the circumstances that influence whether or not someone is able to complete the questionnaire after a stroke so I can develop and test an adapted version that's easier for stroke survivors to complete.

 **Why is this important to you?** I'm an occupational therapist by background.

Occupational therapy can have a big impact on stroke survivor's day-to-day lives, but it can be difficult to measure the effect it has. Using PROMs could enable us to identify and measure its impact from a stroke survivor's perspective.

### **How are stroke survivors involved in your study?**

I've set up a lived experiences group and they're advising me on all aspects of the study. They help me to understand a bit about their world, and tell me what does and doesn't work for them, so I can make the best possible adaptations and adjustments.

### **What benefits do you hope your research will have in the future?**

I want to use PROMs to give stroke survivors a voice. I think it's important to allow stroke survivors to reflect and identify their priorities for rehabilitation as it puts them back in control of their recovery.



## Scotland

Dr Lisa Kidd from Glasgow University is researching supported self-management. This is the type of help offered by community rehabilitation services when stroke survivors leave hospital. It can include groups and programmes, or one-to-one support from health care professionals.

Lisa tells us about her work: "We're exploring what supported self-management in stroke looks like in different areas of Scotland, what makes it work and why. Our aim is to help ensure that everyone is offered high quality supported self-management, regardless of where they live.

We've researched and developed a set of ideas about what we think helps supported self-management to work. We're now asking stroke survivors and people working in community rehabilitation to tell us what they think of these ideas and if they think they'd work in their area. We'll be sharing the data we gather to see how our findings could apply around the UK.

Stroke survivors have been involved throughout our project. Our Patient and Public Involvement Group are fantastic – they've helped to shape our methods and showed us how to approach research in a more meaningful way that will make a difference to people's lives."

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### What do the stroke survivors think?

"The researchers really listen to the genuine needs of stroke survivors and aim to make self-management work in the real world.

The project will ultimately help health care professionals and stroke survivors to better understand the importance of supported self-management in helping stroke survivors to move forward with their recovery. It's an honour to be part of this research."

**- Patient and Public Involvement Group**



## England

### How can singing support people after stroke?

About a third of stroke survivors have difficulties with communication, which can have a big impact on their mental health.

They've told us that singing with others at stroke groups or choirs helps their recovery. But for singing to be offered as a stroke therapy, we need research to find out how singing groups can help people, what makes them successful, and who benefits the most from taking part.

Since 2017, we've funded Dr Mark Tarrant at Exeter University to test out a new group-based singing programme.

"We think that group singing can help people with communication difficulties after stroke by creating a safe space and strong bonds between people," said Mark. "This is important for people to rebuild social connections and confidence that can be devastated by stroke."

We're continuing to work with researchers like Mark, and our Stroke Support groups to find out how activities, like group singing, can improve people's wellbeing.



We want to support UK-wide stroke research that makes a difference to people's lives. If you've had a stroke, or support someone that has, as a family member, friend or health professional, we want to hear from you.

What do you think are the most important questions stroke research should answer? Have you say and find out more at [stroke.org.uk/jla](https://stroke.org.uk/jla).

# "No one should struggle alone"

Understanding how stroke has affected you is an important part of making sure you can get the rehabilitation and support you need. But what if you didn't know you'd had a stroke?

Visit [stroke.org.uk/peersupport](https://stroke.org.uk/peersupport) to find out more about our peer support for stroke survivors and carers.

Dawn Minker, 69, from Sandown, Isle of Wight, had a stroke when she was a baby. The stroke partially paralysed her tongue, causing speech and language difficulties. But thinking she wouldn't understand, her family decided not to tell her.

"I grew up not having any idea I'd had a stroke," says Dawn. "As a baby I struggled to feed and when I eventually learnt to talk, I found it difficult to form words. But I just thought I'd been born different."

When she was eight, her parents moved her to a residential special needs school. Although she loved helping her fellow pupils, she struggled to understand why she'd been sent away from her family.

Dawn was 50 when she discovered the truth from her sister. "I was so upset," she remembers. "Back then, nobody talked about babies and children having strokes. I spent too many years thinking that my mum



didn't want me, as no one explained what had happened. But it was also a relief to finally know the reason for my communication problems."

Wanting to know more about stroke, Dawn and her husband, Trevor, joined the Stroke Association's Isle of Wight Stroke Club. "We have a big laugh," says Trevor. "If somebody new comes in, Dawn will sit next to them and they relax."

Dawn is now a full-time volunteer, supporting stroke survivors with severe communication difficulties at groups and workshops.

"I do what I do because I love it," says Dawn. "I've met some lovely people who've had strokes, and speaking to them has made me feel differently about my own."

If you, or someone you know, has difficulty speaking or with other issues, there is support available. No-one should have to struggle alone."



# Travelling with medication

Planning your next holiday or trip abroad? Don't forget about your medication.

Our partners AllClear Travel Insurance share some top tips to help you plan ahead:

**Check your medication is permitted in the country you're visiting** – Different countries have different rules about the type and amount of prescription and non-prescription medications you can bring with you. Check with your destination's embassy before you travel to avoid any issues.

**Get a copy of your prescription and a letter from your GP** – to explain your health condition and prove the medication is yours. This is particularly important if you need to take injectable medicines

or liquids over 100ml in your hand luggage – you'll need to contact the airline in advance to check with them too.

**Make sure you have enough medication to last the whole trip** – plus some extras in case of delays, loss or damage. Check your supplies a month before you travel to avoid the stress of having to get a last-minute GP appointment.

**Keep your medication safe** – Carry essential medication in your hand luggage, or split it between bags, so you still have a supply if your suitcase is lost or delayed. Keep your medicine in its original packaging to avoid problems at customs. Use an insulated bag or thermos flask for medicines that need to be kept at a certain temperature.



AllClear will give up to 20% of your premium to the Stroke Association when you purchase a policy (see [stroke.org.uk/allclear](https://stroke.org.uk/allclear)). To find out more about their travel insurance policies, go to [stroke.org.uk/allclear](https://stroke.org.uk/allclear) or call 0808 168 8733.

The Stroke Association is an Introducer Appointed Representative of AllClear Insurance Services Limited which is authorised and regulated by the Financial Conduct Authority. AllClear Travel Insurance is arranged by AllClear Limited, which is registered in Gibraltar company number 117274. Registered Office: 1st Floor, Portland House, Glacis Road, Gibraltar, GX11 1AA. AllClear Limited is licensed and regulated by the Gibraltar Financial Services Commission number FSC1329B and trades into the UK on a freedom of services basis, FCA FRN 824283.

# Money matters



Attendance Allowance is a benefit for people aged 65 or over who need help with their care because of an illness or disability. Stroke survivors are often eligible for this support but many don't know enough about it to apply. Our Stroke Helpline Team tell us more:

## Am I eligible?

You can claim Attendance Allowance if you have:

- Reached state pension age.
- A physical or mental health disability or illness that means you need help caring for yourself. For example, you need help with getting dressed, communicating your needs or supervision to keep you safe at home. It doesn't cover mobility needs.

You can get this benefit even if you don't actually have someone helping with your care. You just need to show that you have needed help for at least six months - unless you're terminally ill, then you can claim straight away.

However, you can't get Attendance Allowance if you already get Personal Independent Payment (PIP) or if you get Disability Living Allowance (DLA).

## How much will I get?

There are two rates for Attendance Allowance. Whether you get the lower or the higher rate will depend on how much care you need because of your disability.

- If you need help or supervision during either the day or night, you'll receive the lower rate, currently £59.70.
- If you need help or supervision during both the day and night, you'll receive the higher rate, currently £89.15.

Attendance Allowance isn't means-tested, so what you earn, receive from your pension, or have in your savings won't affect your claim.

## What can I spend it on?

You can spend Attendance Allowance as you wish - you don't have to spend it on someone looking after you. Although, people often choose to use it to make life a bit easier, for example, paying for a cleaner or gardener.

## How can I get help with completing the forms?

- Contact your nearest Citizens Advice ([citizensadvice.org.uk](https://citizensadvice.org.uk)) and ask if they can help you with your form.
- Talk to a friend, relative or carer if you'd prefer to go through the form with someone you know.
- In some areas, your local Age UK can also help with completing the form.

## Where can I find out more or request a claim form?

### England, Scotland or Wales

Go to [gov.uk/attendance-allowance](https://gov.uk/attendance-allowance)  
Call the Attendance Allowance helpline:  
**0800 731 0122** (Textphone: **0800 731 0317**)

### Northern Ireland

Go to [nidirect.gov.uk/attendance-allowance](https://nidirect.gov.uk/attendance-allowance)  
Call the Disability and Carers Service:  
**0800 587 0912** (Textphone: **0800 012 1574**)





# Puzzles

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

## Word search

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

Community  
Advocate  
Voice  
Guide  
Forum

Involve  
Share  
Helpline  
Positive  
Change

## Across

- 5 Search for hidden objects (8,4)
- 8 Military signal/display (6)
- 9 Refuse to be associated with (something/someone) (6)
- 10 A quarrel (4)
- 12 Temple of Jupiter at Rome; Washington building (7)
- 14 Distraught with fear (7)
- 15 Gas used in fluorescent signs (4)
- 17 Small plant; colour (6)
- 18 Seldom (6)
- 20 Sweat (12)

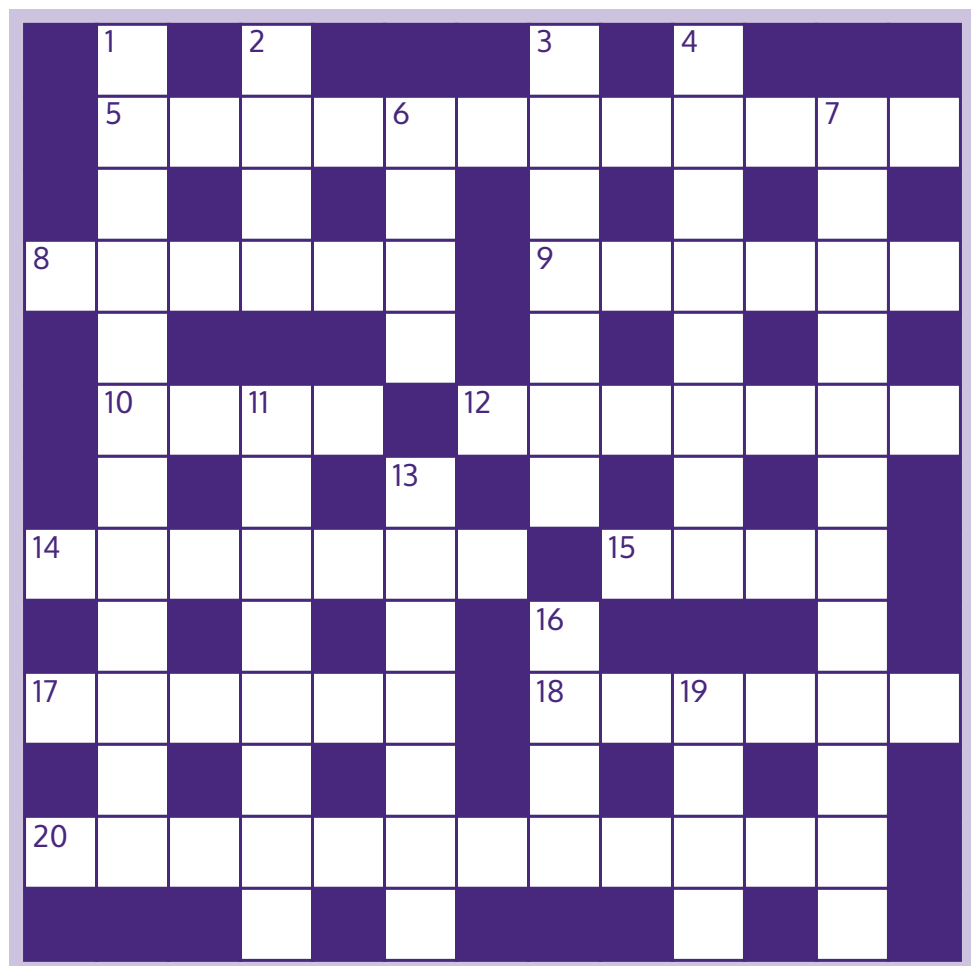
## Lottery

For your chance to win £25,000 every week, play the Stroke Association Charity Lottery. Find out more at [stroke.zaffo.com](http://stroke.zaffo.com).



## Down

- 1** Power generator (5,7)
- 2** Portable shelter (4)
- 3** (Of slope) not steep (7)
- 4** Severely reprimand (8)
- 6** Pollution haze/fog (4)
- 7** Canadian province;  
breed of dog (12)
- 11** Agree on definitive  
version of (something) (8)
- 13** Plaited hair (7)
- 16** Region; space (4)
- 19** Waterside bird;  
part of track (4)



# 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.

## Woodford House Dentist

Thank you to the lovely staff and patients of the Improve Your Smile Dental Practice in Woodford Green, who've so far raised over £3,490 for us at their annual cake and coffee mornings.



## Celebration of Christmas

A huge thank you to the committee of volunteers, chaired by stroke survivor Rachel Inglefield, who organised A Celebration of Christmas at Marlborough College Chapel in December. Over 600 people attended the carol service and enjoyed readings by celebrities, including Chris



Tarrant, and beautiful music. Together they raised an incredible £53,000.



Find out what events we've got coming up on page 42 or make a donation at [stroke.org.uk/donation](https://stroke.org.uk/donation).

## How does your donation help?



£10 could enable a stroke survivor to attend an art therapy group to help with their recovery.



£25 could help run our communication support sessions, helping stroke survivors find their voice again.



£50 can help us to invest in research into new stroke treatments.



## Volunteer spotlight

Sarah Alculumbre started volunteering in 2019. "The Stroke Association were my guiding star after my stroke," she says. "They gave me the confidence to ask for help and get back on my feet. I wanted to give back and connect with people, so I volunteered at fundraising collections around London. I also read to stroke survivors in hospital and see the difference it makes to them.

"I'm proud to be a part of the team talking to people about stroke and the Stroke Association's work. People often don't know how devastating stroke can be, so I'll continue to do as much fundraising and promoting as I can!"



## Arvind and Shirley

Arvind Seewoosungkur and Shirley Chamberlaine completed the Richmond Run Fest 10k for, and in memory of, their loved ones affected by stroke. They raised £605 – thank you!

To find out more about fundraising and volunteering opportunities, visit [stroke.org.uk/yoursupport](https://stroke.org.uk/yoursupport).

# Dates for your diary



## Kiltwalks April - September

Join #TeamStroke at Kiltwalks in Glasgow, Aberdeen, Dundee and Edinburgh throughout 2020. Visit [stroke.org.uk/kiltwalk20](https://stroke.org.uk/kiltwalk20) to sign up.

## Stroke Prevention Day 15 May

Visit [stroke.org.uk/prevent](https://stroke.org.uk/prevent) to find out more about our campaign to help people to understand and reduce their risk of having a stroke. And look out for stroke prevention events near you.

## Richmond Run Fest 12-13 September

Enjoy the scenic 10k route around the Royal Botanic Gardens, Kew or challenge yourself to the Richmond Half Marathon and Marathon: [stroke.org.uk/runfest20](https://stroke.org.uk/runfest20).



## Vélo Birmingham and Midlands Sunday 21 June

Get #TeamStroke places for this thrilling 100-mile ride on closed roads through the West Midlands. Riders of all abilities welcome. Visit [stroke.org.uk/velo](https://stroke.org.uk/velo) to find out more.

For more events and ways to get involved in our work, see [stroke.org.uk](https://stroke.org.uk).

## Crossword solution

### Across:

5 Treasure hunt; 8 Tattoo; 9 Disown; 10 Tiff; 12 Capitol; 14 Frantic; 15 Neon; 17 Violet; 18 Rarely; 20 Perspiration

### Down:

1 Steam turbine; 2 Tent; 3 Gradual; 4 Chastise; 6 Smog; 7 Newfoundland; 11 Finalise; 13 Pigtail; 16 Area; 19 Rail

