

# Stroke News

Spring 2024

For everyone affected by stroke

**Stroke**

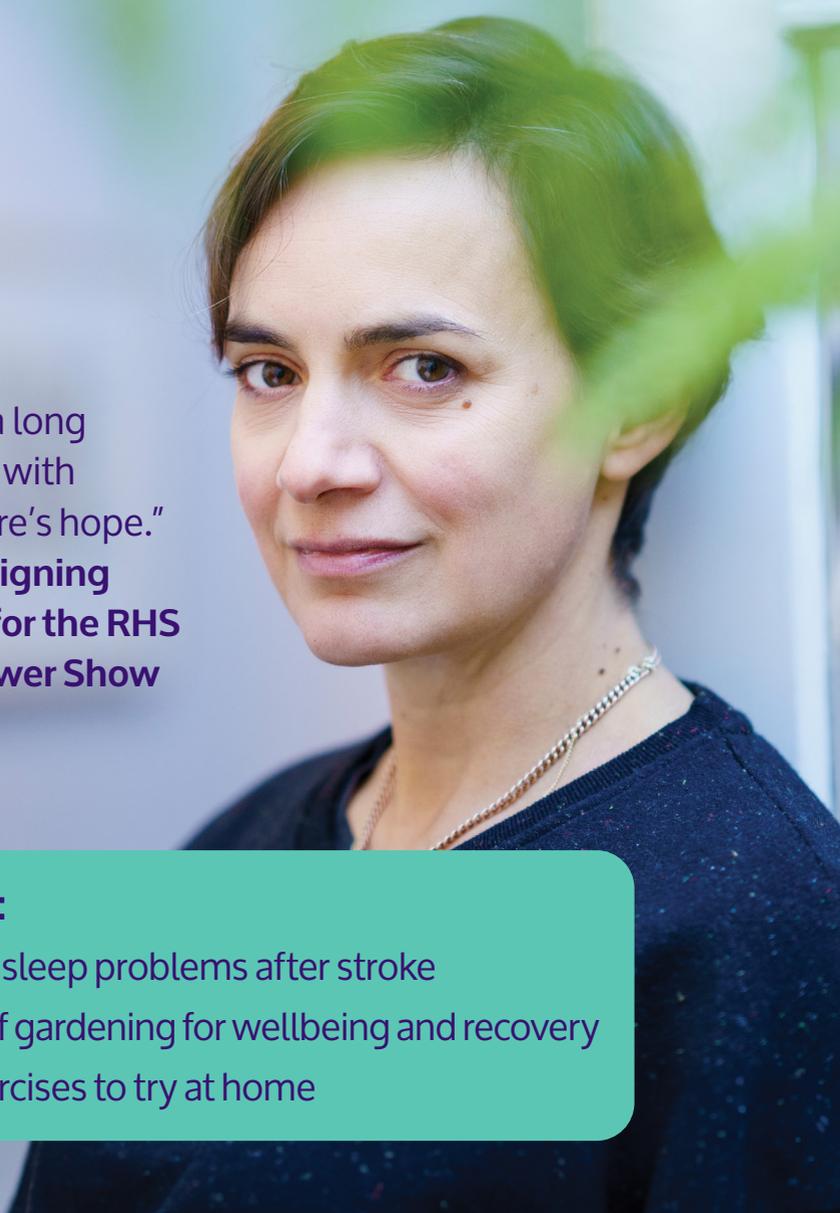
Association

“Recovery is a long process. But with support, there’s hope.”

**Miria on designing our garden for the RHS Chelsea Flower Show**

## **This issue:**

- Advice on sleep problems after stroke
- Benefits of gardening for wellbeing and recovery
- Tai chi exercises to try at home



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Editor **Christine Webster**

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# Editor's letter



Looking after your wellbeing is an important part of stroke recovery.

"Rebuilding connections with nature has been hugely important to my recovery," says our cover star Miria Harris, who is an acclaimed landscape designer and a stroke survivor. She's now using her experience to design a garden for the Stroke Association at the 2024 RHS Chelsea Flower Show (page 8).

We also hear how gardening has benefited Jonathan's mental health (page 24), and how getting back out in the community has rebuilt Annette's confidence (page 28).

And we have tips on improving sleep, managing bladder and bowel problems, and tai chi exercises to try at home.

I hope you enjoy this issue.

**Christine Webster, Editor**

## Correction:

In our winter 2023 issue, we published an article about medicines prescribed to reduce your risk of stroke, and why it's important to take them.

This article said that, over time, doctors usually move you from antiplatelets to anticoagulants

for long-term use. We should have clarified that you would only be given anticoagulants in the long-term if your stroke was caused by a heart condition, like atrial fibrillation.

The online article has been corrected and we apologise for any confusion caused.

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# Over to you

I had a stroke in 2021, when I was 19. I was at home when I began to feel nauseous. This was followed by a severe headache, loss of feeling in my right arm and the right side of my tongue. When I tried to ask my mum to help me, my speech was slurred. My mum called 999 immediately.

At hospital, the stroke team sent me for a CT scan. But when it came back clear, I was sent home and told, "You're too young to have a stroke. Go home and rest." Two days later, a stroke doctor called to ask me to go back for an MRI scan. This confirmed I'd had a stroke.

I have since had speech and language therapy and neuropsychology. I continue to have physiotherapy and to see a urologist. I still have slight weakness in my right arm/hand, slightly reduced cognitive function, fatigue and urinary incontinence, but I have made a recovery that I'm very proud of.

I now want to raise awareness about stroke, particularly in young people, with the aim of helping others.

**Georgia Hanson-Kay**

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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## From our Chief Executive

**Around 88,000 people survive a stroke every year in the UK. But this is just the start of a long and traumatic battle to find their way back to life.**

We are here to support every stroke survivor to achieve their best possible recovery. Right now, our charity can only reach one-third of the survivors who most need support. But we're working hard to change this.

This May, we're thrilled to be presenting a show garden at the RHS Chelsea Flower Show (see page 8). Our Garden for Recovery will raise awareness of our charity's work and will help us achieve our ambitious new goal – to reach every stroke survivor with the support they,

their families and their carers need as quickly as possible after a stroke.

We believe no stroke survivor should have to face life after stroke without stroke support. With a General Election on the horizon, we'll be doing all we can over the next few months to get this message across to political candidates.

On page 16, find out how you can support us in calling for political leadership on stroke to help improve access to vital treatments and services that can make a huge difference to millions of lives. With your help, we can make stroke the priority it needs to be.

**Juliet Bouverie OBE**

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# Our Garden for Recovery

This May, the Stroke Association is excited to present our first ever show garden at the RHS Chelsea Flower Show.

Sponsored by Project Giving Back, a charity that funds gardens for good causes, The Stroke Association's Garden for Recovery embodies the belief that there are paths to recovery for stroke survivors. It is designed by critically acclaimed landscape designer Miria Harris, herself a stroke survivor.

"Stroke can change your life profoundly. It did mine," says Miria.

In 2019, Miria was packing up her kitchen, ready for a renovation, when she suddenly started crying, then laughing hysterically. When she tried to speak, her words didn't make any sense. "I didn't know what was happening – I was scared and thought I was losing my mind."

Miria went to hospital, where she was diagnosed as having had a stroke. "My speech was affected. The fatigue was like nothing I'd experienced before. And I had headaches that went on for ages – like I'd bruised my brain.

"My voice came back to me relatively quickly, but the stroke led to a discovery that I had a hole in my heart and needed surgery to close it. Carrying the emotional trauma of both these events will always be with me. There's a whole new layer of vulnerability and anxiety in my life now that never existed before.

"In time I found my energy levels returned, but I still struggle with organising my thoughts. Sometimes my mind will go blank. It's like you're hitting a dark spot in the road. Then the lights are back on again, but you know for that second it was dark, there should have been a street lamp there."



"Stroke can change your life profoundly. It did mine."

Miria's garden design is inspired by her own experience and what she has learned from speaking to others affected by stroke – including survivors, carers, or people who've lost loved ones.

"Recovery is a long process. It's definitely not as simple as just getting better. There are many ups and downs and bumps in the road. But, with support, there's hope.

"The garden mirrors the Stroke Association's purpose, to support every stroke survivor to achieve their best possible recovery. I didn't know about the charity until quite late on in my recovery, and I wish someone had told me about them sooner. Part of the reason I want to do this garden is to raise more awareness of their work, so more people can get the support they need.

"With the Garden for Recovery, I wanted to design an immersive, calm and optimistic space to support stroke survivors and their loved ones. Somewhere for visitors to take time to stop, rest and reflect. A place for solitude or to connect with loved ones.

"After the disconnecting experience of stroke, rebuilding connections with the people and places I love and with nature has been hugely important to my recovery.

"I wanted to reflect that in the Garden for Recovery. You can feel the ground, hear the sound of water, see and smell the plants and feel connected, back on the ground after the out-of-body experience of stroke."

**Among the garden's carefully chosen flora are several tall, twisted pine trees, which were rescued from a forgotten nursery field and nursed back to health. "The pine trees are the most important plant that I've chosen for the garden," says Miria. "They're these incredible sculptural specimens, bent and twisted by the wind but still rooted firmly in the ground. To me, these trees are emblematic of the stroke recovery process - not straightforward or perfect. But possible.**





Illustration of our Garden for Recovery

“There’s no particular route round the garden. You decide which direction you want to take and when you’re going to pause and take a breath. This is your recovery – you get to own that process.”

After the RHS Chelsea Flower Show, the Garden for Recovery will be moved to its permanent home at the stroke unit at

Chapel Allerton Hospital in Leeds. “I hope the garden will give stroke survivors the opportunity to reconnect with family, friends and even pets, in a way that might not be possible inside the hospital, where there’s only room for two visitors at a bedside,” says Miria. “It’ll give people a bridge to nature and a space to be together, which is hugely beneficial for recovery.”



We’re here to support everyone affected by stroke. Contact us on **0303 3033 100**, **helpline@stroke.org.uk** or visit **stroke.org.uk/support** if you or someone you know needs our help.

You can also find out more about our garden and help raise awareness of stroke at **stroke.org.uk/chelsea-flower-show**.

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# Bladder and bowel problems after stroke

Stroke often causes problems with bladder and bowel control. This can be a sensitive issue, but with support, most of these problems can be improved.

Hema from our Stroke Helpline shares some guidance:

## Why has my bowel and bladder control been affected?

Continence issues can be caused by several things including the stroke itself, effects of medication and bladder infections. They can also happen if you have communication or mobility problems and can't ask for help or get to the toilet in time.

## Who can help me?

Your GP can refer you to your local continence service. Specialist nurses, known as continence advisers, will assess the causes of your problem and develop a plan to help you manage.

You might also be referred to a specialist consultant, such as a urologist or gastroenterologist, for further support.

If you care for a stroke survivor with continence problems you can get advice and support from specialists. Organisations such as Bladder and Bowel UK ([bbuk.org.uk](http://bbuk.org.uk), **0161 214 4591**) can also provide support and information.

## What can I do to manage my bladder and bowel problems?

- Know your own bladder and bowel patterns. Try to stick to your routine. Go to the toilet when you feel the need to, rather than 'just in case'.



For more support, download our 'Bladder and bowel problems after stroke' guide from [stroke.org.uk/continence](http://stroke.org.uk/continence) or call **0300 3300 740** for a printed copy.

Our Stroke Helpline Team are also here to help. Call us on **0303 3033 100** or email [helpline@stroke.org.uk](mailto:helpline@stroke.org.uk)

- Follow your continence adviser's training tips and exercises. It takes time for the effects to show, so persevere.
- Stay hydrated and eat plenty of fruit and vegetables to help avoid bladder infections and constipation.
- Keep as active as you can. This can help to reduce bladder leakage and stimulate your bowel.
- Get a 'Just Can't Wait' card or download the free app from [bladderandbowel.org](http://bladderandbowel.org). This gives you access to toilets anywhere, including those not usually available to the public.
- Get a RADAR key from [shop.disabilityrightsuk.org](http://shop.disabilityrightsuk.org). The scheme is for people with disabilities or health conditions seriously affecting their continence.
- Wear clothes that are quick to remove, such as trousers with elasticated waistbands.
- Take a change of clothing and hygiene kit when you go out.
- Take care of your skin. Clean with mild soap and dry thoroughly to prevent skin rashes and infection.

# Looking ahead to the General Election

Health and care services throughout the UK, including stroke services, are facing huge challenges.

Despite superhuman efforts by healthcare professionals, far too many people aren't getting the stroke support they need for their recovery. Ambulance waiting times have risen, and the number of people who have access to timely, specialist stroke treatment and follow-up care has fallen significantly.

The good news is that, with the right investment, stroke can be preventable, treatable, and recoverable. With strong leadership and sustainably funded programmes, the UK Government can save lives and prevent the long-lasting impact stroke has on millions of people and their loved ones.

Ahead of the General Election, we'll be releasing our manifesto, setting out our expectations for

stroke care and stroke progress. We'll be talking to political parties and calling for political leadership on stroke to help improve access to vital services.

But we need your help to get this message out to political candidates. When stroke survivors speak out, decision makers listen – as your support

## Saving Brains campaign success

Thousands of you campaigned with us by signing our open letter to the UK Government, urging them to make 24/7 thrombectomy available to everyone.

Thrombectomy is a procedure to remove blood clots from the brain. It can significantly reduce disability and save lives, but many people who could have one miss out because of where they live or when they have their stroke.



Across the UK people will be voting for who they want to represent them in Westminster

of our 2022-2023 Saving Brains campaign showed (see below).

But there is still a long way to go to ensure that anyone in the UK who has a stroke can get the care they need.

Since the campaign, this treatment has become more widely available across England. This has resulted in more thrombectomy centres with longer opening hours and, crucially, more patients receiving this life-changing treatment. This shows that by combining targeted funding and resources, with the power of campaigning, it's possible for us to make a real difference.

As the election approaches, we'll be doing all we can to engage with political leaders. Helping them to understand the devastating effects of stroke will be crucial, particularly the impact that the lack of adequate stroke services has on individuals, wider health and care systems, and the broader economy. Join us, and with your help, we can make stroke the priority it needs to be.

## What can you do?

- Register to vote –  [gov.uk/register-to-vote](https://www.gov.uk/register-to-vote)
- Join our campaigns network –  [stroke.org.uk/campaigning](https://www.stroke.org.uk/campaigning)
- Tell us how you'd like to get involved by emailing [campaigns@stroke.org.uk](mailto:campaigns@stroke.org.uk)

# Introduction to tai chi

Looking to get moving again after your stroke? Tai chi is a low-impact activity that can be great for your health and wellbeing.

Tai chi and qigong are Chinese mind-body exercises rooted in ancient traditions including martial arts, traditional Chinese medicine, and philosophy. They are known for their slow, focused, intentional movements. Both tai chi and qigong can help to improve your balance, mobility, flexibility, and body awareness. They can also help you to relax, reduce stress and create a sense of wellbeing and calm.

They are usually practised standing, but many moves can be done while sitting too, making them adaptable for people with disabilities.

Howard Mitchell is an instructor with the Wutan School of Traditional Chinese Martial Arts, who often runs classes for our Frome Stroke Group. Here he introduces you to the seated versions of two simple exercises that you can try at home.

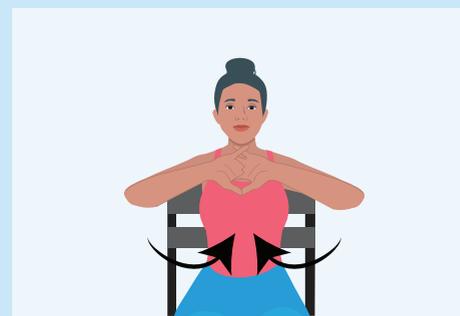
## Before you start:

- Perform these moves slowly and smoothly. Repeat each movement a few times.
- Stop if you feel any pain.
- If you have weakness on one side, ask a carer or family member to support you on your weaker side while you do the movements.

## Exercise 1: Holding the Hands High with Palms Up



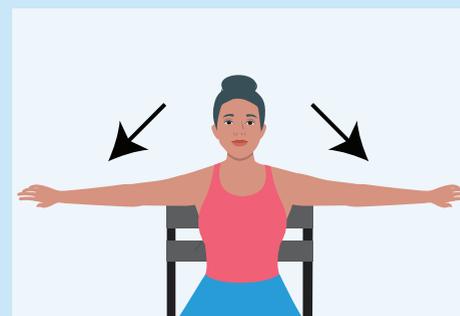
1. Start by holding your hands at your waist with your fingers interlinked and palms facing up.



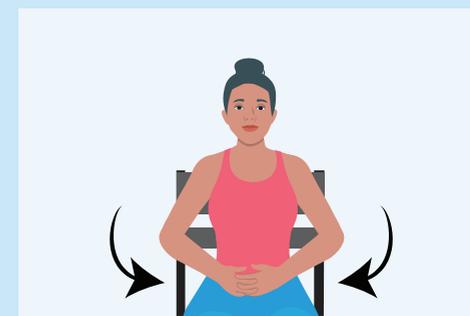
2. Raise your linked hands in front of your face and turn your palms away from you.



3. Raise your hands above and in front of your head. Look up at your hands.



4. Unlink your fingers and circle your arms out and down, looking ahead.



5. Continue to circle your arms down and back to the starting position.

## Exercise 2: Drawing the Bow



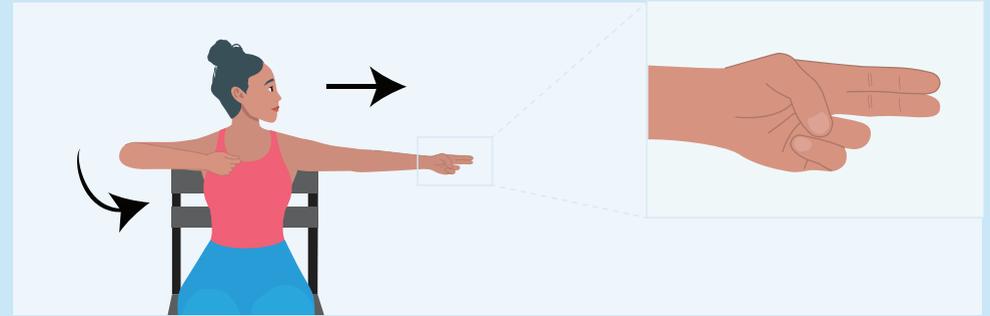
The Torbay and South Devon NHS Trust's website also has more information on the benefits of tai chi. And Worcestershire NHS Trust have an adapted tai chi exercise video you can follow at [youtu.be/ZbGvYXB08uk](https://youtu.be/ZbGvYXB08uk)



1. Start with your hands on your legs, palms upwards.



2. Raise your hands to chin height and close your fingers to make loose fists.

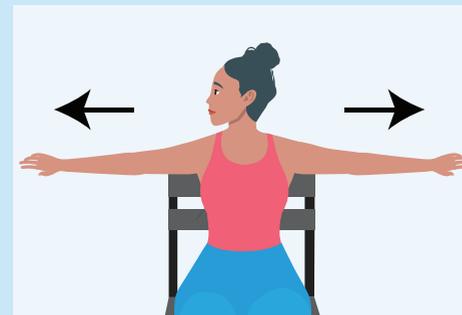


3. Push your left hand away to the left and point with the first and second fingers. Draw the right arm back as you do, as if you were drawing a bow.

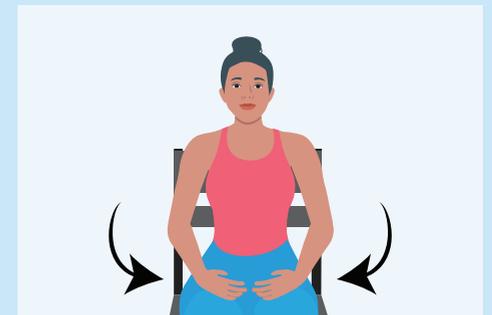


Visit [stroke.org.uk/active](https://stroke.org.uk/active) to download our 'Getting active after a stroke' guide or call **0300 3300 740** to order a printed copy.

If you want to know more, talk to your GP, stroke therapists, local community centre or library to find out if there are classes in your area suitable for you.



4. Open both hands and extend your right arm to the side, so you are holding both of your arms out to the side, looking at the right hand.



5. Circle both arms down to the starting position.  
6. Repeat this exercise with your right arm.

# Sleep problems after stroke



**Sleep is important for stroke recovery. However, many stroke survivors struggle with sleep problems, which can have an impact on physical and mental health.**

Stroke researcher and sleep specialist, Melanie Fleming, shares some advice.

## Common sleep problems

### Insomnia

About a third of stroke survivors experience insomnia. This is when you can't get enough sleep because you find it difficult to fall asleep, or you wake up in the night and can't get back to sleep.

### Sleep-disordered breathing (sleep apnoea)

Sleep apnoea is when your breathing stops and starts during sleep. It can be hard to tell if you have sleep apnoea, so ask someone to help you identify the symptoms including loud snoring, breathing stopping and starting, making gasping or choking noises. See your GP if you have symptoms.

### Sleep cycle disruption

Some people find their sleep patterns change after a stroke, meaning they are unable to follow a set pattern for when to sleep and when to wake. It may feel like constant jetlag.

## Tips for getting a good night's rest

- ✓ Keep a regular sleep-wake schedule. Even after a poor night's sleep, try to wake at your normal time as sleeping in can make it harder to fall asleep the next night. Try setting an alarm, or keeping a sleep diary to find a sleep pattern that works for you.
- ✓ If you have difficulties falling asleep at night and waking in the morning, then exposure to bright light in the morning might help. If you fall asleep earlier at night and wake too early in the morning, then light exposure in the evening may help.
- ✓ Get regular exercise.
- ✓ Try to relax before going to bed. Making a list of things you want to remember the next day can help 'put them to bed'.
- ✓ Practice relaxation techniques during the day, such as breathing exercises. Try them at night if you're struggling to sleep.
- ✓ Create a comfortable sleeping environment (dark, comfortable temperature).

- ✓ Try not to nap during the day as this reduces your body's instinct to sleep properly at night. If you do need to nap, avoid napping late in the day and set an alarm to shorten the nap.
- ✓ Avoid television or devices (like smartphones) before bed because bright lights affect your ability to fall asleep.

## I still need help

If you've tried these tips and you're still struggling, talk to your GP. They may:

- Refer you for cognitive behavioural therapy (CBT) to help with insomnia.
- Give you a CPAP machine if you have sleep apnoea, which gently pumps air into a mask you wear while sleeping.
- Check your medication, offer other treatment options, or refer you to another health professional.



For more information, contact our Stroke Helpline on **0303 3033 100**.

# Getting into gardening



Jonathan was lucky to be alive after a severe stroke in 1999. Here, he shares his story, and explains how gardening has helped his recovery:

"Like many stroke survivors, I felt that everything I'd worked for or enjoyed had been taken away by the bleed in my brain.

Those feelings of loss have influenced my wellbeing - I often feel low. Sometimes, the only way out of the darkness is to remember how far I've come.

"The stroke badly affected my right side. I had to learn to walk and talk again. It was a long, hard journey, spending months in the hospital trying to get back to normal life.

"I'd never been a keen gardener, but my wife, Joanne, and I saw an advert for an allotment and thought it would be a good way for me to get some exercise and fresh air. It was also something we could do as a family with our daughter Megan, who was only three when I had my stroke.

"My mood was low, and I was very negative. I didn't know how I'd manage an allotment, or even if I could.

"Slowly, the garden took shape. As it did, I felt my mood improving. The fantastic views from the allotment, across to the Gateshead Angel and the County Durham coast, made me feel better.

"I adapted the garden to suit me. I have smaller, raised beds, so they're less work to look after and I don't need to stand and dig all the time. I use a kneeler and dig crops out of the soil with a trowel, which I find easier. We also have a summer house, where I can take breaks or shelter from the rain.

"Seeing the first shoots appearing from the soil made me feel good.

I'd planted potatoes and cabbages, never expecting them to actually grow. I'd always thought gardening was a 'dark art' that only experienced gardeners could do. But here I was, growing food to put on the table!

"I'd felt guilty that I wasn't able to do my full-time job as a journalist anymore. But digging potatoes, cabbages, beetroot and lettuces out the ground, and picking apples, gooseberries, raspberries and blackcurrants from the fruit bushes we planted, made me feel a success again.

"As well as saving us money on food, it also helps us to eat healthily, which is important for stroke recovery. Although over the years, we've learnt that it is possible to have too many potatoes!"



Interested in using gardening to help your recovery? Find more information, watch 'how to' videos and chat to other stroke survivors on our online forum at [stroke.org.uk/garden-blog](https://stroke.org.uk/garden-blog)

# Supporting plans for a smoke-free generation

"I knew smoking was a risk factor for stroke and other things, but as a smoker, nothing puts you off."

Before his stroke in 2019, Stephen D'Arcy, 41, smoked 20 cigarettes a day. He started as a teenager. "It was a habit I'd kicked in the past, but found myself getting back into," says Stephen. "Before I knew it, smoking was part of everyday life."

Smoking 20 a day makes you six times more likely to have a stroke than someone who doesn't smoke. "I wish I'd never started smoking," says Stephen. "After the stroke, giving up was easy – I've not thought twice about smoking because of how scary it all was."

Before the 2007 smoking ban (2006 in Scotland), more than one in five people were smokers.



Stephen in hospital after his stroke

Smoking in the UK has declined a lot since then, but the rate of decline is slowing and one in eight people still smoke. Surprisingly, it's younger people that are more likely to smoke.

The health risks of smoking – including the increased risk of stroke – are well known, which is why the government introduced ambitions for England to be smoke-free (where fewer than 5% of adults are smokers) by 2030. Last year, the government, backed by all parties, made its biggest commitment to a smoke-free Britain yet.



Stephen and his daughter



If nobody smoked, over **13,000** lives could be saved in England and Wales every year.

The plan is to raise the smoking age every year, so that people born after 1 January 2009 can't legally buy tobacco and cigarettes; effectively, banning smoking for a whole generation.

"Stopping a generation from getting addicted to cigarettes is one of the most effective public health actions a country can take," says Emily Heard, Stroke Association Campaigns Manager. "We're pleased that current plans include a commitment to fund

services to help people quit smoking, which will be vital for current smokers.

"It's important that members of this and any future government support the Tobacco and Vapes Bill. We'll promote the Bill through our parliamentary supporters and networks. We know the tobacco industry will oppose the Bill, but it's clear that this legislation will massively reduce pressures on the NHS and improve people's lives."



Roughly half of smokers want to quit. If you'd like support to help you to cut down or quit smoking altogether, search for your local stop smoking service on [nhs.uk/live-well/quit-smoking](https://www.nhs.uk/live-well/quit-smoking) or call our Stroke Helpline on **0303 3033 100**.

# Reconnecting with my community

Annette Gillies, 60, has aphasia following a stroke in December 2020. Her aphasia means she struggles to speak and recall words. It can make spontaneous conversation difficult and tiring for her.

Devastatingly, her communication difficulties took away her much-loved career as a primary school teacher after 36 years of working with children.

"I couldn't speak at all when I came out of hospital," says Annette. "It was awful. I felt like I wasn't me anymore."

With the support of Diane, her Stroke Association Support Coordinator, Annette began pushing herself to improve her speech by reconnecting with her community.

As well as volunteering in a friendly community shop, Annette started attending a local stroke support group, where she met Julia, another stroke survivor with aphasia. The pair formed an instant friendship and have been helping each other in their recovery – from challenging themselves to take on journeys navigating public transport, to being a listening ear and support for each other.

"After a long time, I can now say, 'I have had a stroke'," says Annette. "Then people can help me. When people know, they are usually very nice."

Keen to meet other stroke survivors her age, Annette also decided to give the Stroke Association's Here For You service a try. Here For You offers an eight-week block of telephone calls with a Stroke Association volunteer who has lived experience of stroke, either

Annette and her husband Colin, with their dog Willow



For more information or to sign up to weekly volunteer calls, visit [stroke.org.uk/here-for-you](https://stroke.org.uk/here-for-you). You can also find your local stroke group at [stroke.org.uk/groups](https://stroke.org.uk/groups). Or contact our Stroke Helpline on **0303 3033 100**.

as a stroke survivor themselves or as the carer of a stroke survivor.

"With my aphasia, any situation that forces me into trying to talk to another person is good," she says. "It is very stressful, but very necessary. I think the calls have helped with my recovery and coming to terms with my stroke. The lady who rang me was so lovely. We immediately clicked and made a connection."

"It is vitally important to be able to talk to other stroke survivors.

Otherwise, it is easy to sink into a dark place where you think it is only you who has suffered this terrible bad luck.

"These calls offered the genuine warmth and understanding that you can only get from another person in the same situation as yourself. I can't recommend this service highly enough."

"All the people who have helped me are just amazing. They help me to think that I can do it. I know I will get there."

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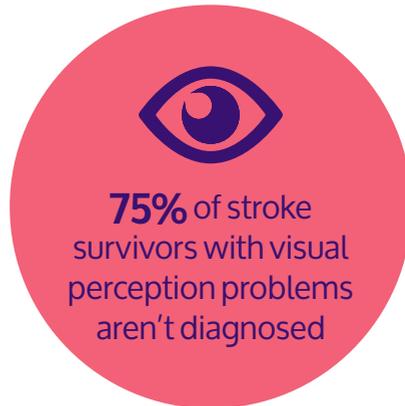


HANDCRAFTED IN GREAT BRITAIN



# Improving the diagnosis of visual perception problems after stroke

After a stroke, people can struggle with visual perception problems like recognising objects or faces, or seeing colours or motion. This can make everyday tasks more difficult, impacting their wellbeing.



Visual perception problems often go undiagnosed as they're difficult to detect. But stroke researcher, Dr Kathleen Vancleef, and her team have been developing a new tool to change this.

"My research is about improving the diagnosis of visual perception problems after stroke," says Kathleen. "Visual perception is how the brain processes information coming from the

eyes. For example, when I look at a flower, it's the brain that recognises it's a flower, works out what type of flower I'm looking at and where the flower is in relation to a tree that is standing behind it.

"But someone with visual perception issues might look at the flower but not be able to find it because their brain doesn't recognise it as a flower.

Kathleen presents her research



"This can make daily life a struggle. For example, they might not be able to find the things they need when they go shopping. They can't cross the road as they can't judge the traffic. Or they find it hard to recognise faces, which can be distressing for them and their loved ones.

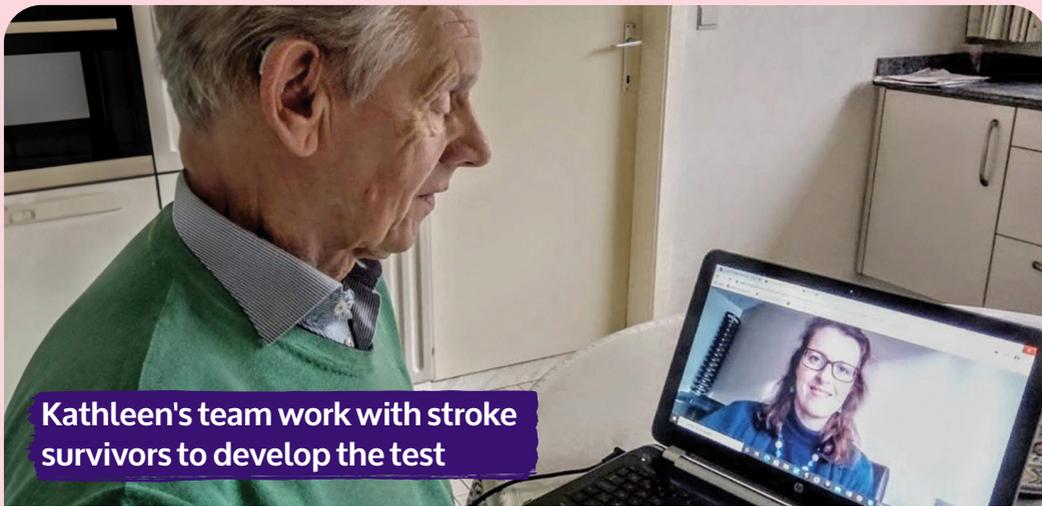
"We estimate that about 75% of stroke survivors with visual perception problems aren't diagnosed and don't get the support they need. Our research showed that this is because existing screening assessments aren't fit for purpose.

"We spoke to occupational therapists (OTs) and orthoptists who work with stroke survivors

and found that the existing tests take a long time to do – between 45 mins and an hour and a half. This makes it difficult for busy OTs to use and isn't suitable for stroke survivors so soon after their stroke.

"To solve this problem, we've created a new tool, called the Oxford Visual Perception Screen, or OxVPS, that is quicker, easier to use and more accessible.

"We've involved stroke survivors and carers throughout our research. They've helped us with everything from telling us how to make the test clear and readable, to designing the studies we're doing in hospitals



**Kathleen's team work with stroke survivors to develop the test**

to check OxVPS works as it should. Their feedback is very valuable as they know things that I can't know because I don't have that lived experience.

"Even the illustrations used in the test were drawn by the carer of a stroke survivor, and photographs were taken by a professional photographer who'd had a stroke.

"This has helped us make the test more accessible to stroke survivors, including people with communication difficulties, spatial neglect, as well as common eye conditions, like cataracts.

"We recently launched OxVPS at the UK Stroke Forum in December 2023, and have made it freely available for NHS

staff. We hope that healthcare professionals caring for stroke survivors will use it to help them diagnose visual perception problems more easily, and make sure patients get the support they need sooner. We also hope our research will help stroke survivors to understand more about their condition, so they know what rehabilitation or adjustments they need to make life easier.

"We're now working with other researchers across the UK, many of whom I met through the Stroke Association, to improve treatments for visual perception problems."



Visit [stroke.org.uk/research](https://stroke.org.uk/research) to learn more about the research we fund.

## Supporting stroke research

We're committed to funding research to build our understanding of stroke and to improve treatment, care and quality of life for everyone affected.

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

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Funds raised will go towards vital services and pioneering research to help rebuild the lives of people affected by stroke.

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### Return your form

Please detach this form and return it to us using the envelope enclosed, or post it to:  
**Stroke Association, Bumpers Way, Bumpers Farm, Chippenham SN14 6NG**



# 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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Email  Text  Phone

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Please enter your phone number  or email:

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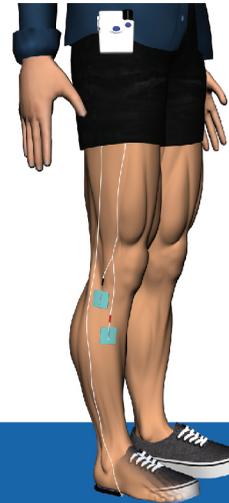
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# My experience of epilepsy after stroke

Four years on from his stroke in 2018, Duncan was “just about accepting” the physical and mental impacts of the stroke he had while celebrating his 56th birthday.

Although he couldn't return to work or drive and his left arm remained mostly paralysed, he was proud of the steady recovery he'd made.

“As well as receiving support from my family, rehab team and the Stroke Association, I also saw a psychologist, who helped me to cope with the emotional impact of the stroke,” says Duncan. “They recognised that I was mourning my previous happy life and introduced me to ‘the seven stages of grief’. I found this helpful in processing how I was feeling.”

Like many stroke survivors, during his initial recovery he had experienced a few episodes of “twitching” in his left arm and hand but these always subsided quickly.



Duncan on holiday in Italy in 2023

“Then in August 2022, I had mouth and face spasms for several hours,” says Duncan. “After a 13-hour wait in A&E, a neurologist diagnosed me with epilepsy as a result of my stroke.

“This made me feel depressed and I worried that more significant seizures could follow. Unfortunately, I've since had four intense seizures resulting in hospital admissions, which were distressing for me and my wife and adult son, who thankfully were with me.

“The onset of epilepsy is really ‘kicking a man when he's down’! It impacted my stroke recovery as I can't do as much walking now. I dare not go too far from home, for fear of a seizure. It effectively re-started the seven stages of grief.

“There is no ‘cure’ for epilepsy, it's just managed with medication,

so I'm learning to live with it. I've found that getting too tired can trigger my seizures, so I'm now careful to rest regularly.”

Despite everything he's been through, Duncan is looking to the future and celebrating proud milestones such as completing a walk on a rough country path with friends.

“We covered 3.5 miles and a total ascent of 500 feet! I thought, ‘Wow! I've come a long way since being lifted out of bed by a hoist!’”

Five years after his stroke, he is still working on regaining movement in his left hand.

“I try to use my left hand to do anything I can manage. My wife and I had a meal, which included fresh fruit and grapes. I managed to grasp a grape and lift it to my mouth without dropping it.

“It was a lovely, sweet grape, and I thought, ‘I will take that as another win!’”



Find out more about seizures and epilepsy after stroke at [stroke.org.uk/seizures-and-epilepsy](https://stroke.org.uk/seizures-and-epilepsy) or call our Stroke Helpline on **0303 3033 100**.

# Wheelchair accessible vehicle adaptations

Wheelchair accessible vehicles (WAVs) are specially adapted cars or vans that enable people who use wheelchairs or have mobility difficulties to drive or travel comfortably and safely.

If you're thinking of getting a WAV after a stroke, they can be modified to suit your needs, as our partners, WavMob, explain:

## Driving adaptations

If you have mobility problems but are otherwise able to drive safely after your stroke, there are lots of adaptations to enable you to stay behind the wheel. For example, if you're unable to use foot pedals, you could have a push/pull lever fitted, so you can operate the brake and accelerator by hand instead.

If you have arm or hand weaknesses, you could opt for an easy release handbrake

and gearshift. You can also get steering aids such as easy-to-grip steering balls and keypads so you can steer and control functions like indicators and lights one-handed.

## Getting in and out of the car

If you prefer to travel in your wheelchair, powered ramps or tail lifts help you to get you and your wheelchair into and out of the car. You can then secure your wheelchair with robust restraints to ensure stability and safety while you're moving.

Alternatively, aids like electric person hoists will physically lift you from your wheelchair into the vehicle seat. You can also



To find out more about WAVs, visit [wavmob.co.uk](http://wavmob.co.uk) or call the WavMob team on **0239 2245 570**.

For guidance on driving after stroke, visit [stroke.org.uk/driving](http://stroke.org.uk/driving) or call our Stroke Helpline on **0303 3033 100**.

get swivel seats that rotate and lower out of the vehicle to make it easier for you to get in and out. Or transfer plates that bridge the gap between your wheelchair and the car seat so you can slide from one to the other.

## Storing wheelchairs and scooters

Lifts and hoists can help you get heavy mobility equipment in and out of the car. If you use

a wheelchair and want to be able to drive independently, you can also get devices that automatically load and retrieve your wheelchair from the boot or a roof box.

If you need space inside the car for luggage or passengers, you can also store your mobility equipment using tow bar mounted wheelchair or scooter carriers or specialist roof racks and trailers.

# Help with travel costs if you have disabilities

Getting out and about after your stroke is important for your wellbeing and independence. If you have disabilities after a stroke, you might be able to get help with your travel costs to make it easier for you to use public transport or to drive.

## Car schemes

If you receive a disability benefit, such as the higher-rate mobility component of Personal Independence Payments (PIP), you might be able to use some or all of your benefit to lease a new car, powered wheelchair or scooter through the Motability Scheme ([motability.co.uk](http://motability.co.uk)).

You can still get a Motability vehicle, even if you can't drive. A Motability car can be driven by other people to drive you around, or for journeys without you to support you, such as doing your shopping.

## Driving lesson grants

Motability also offer driving lesson grants for people with disabilities

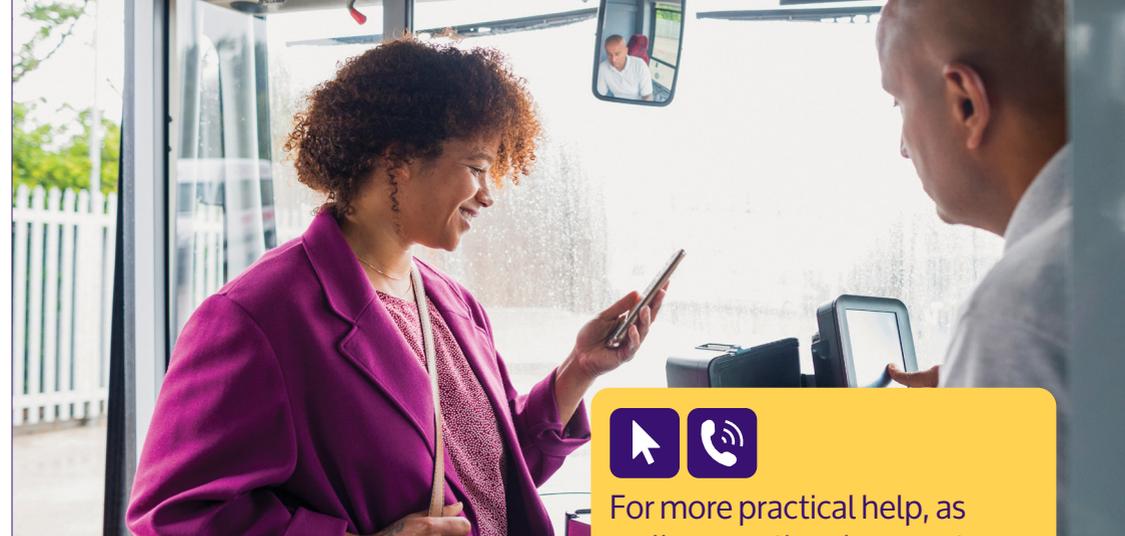
([motabilityfoundation.org.uk](http://motabilityfoundation.org.uk)

or call **0800 500 3186**). This includes familiarisation lessons to teach you how to drive an adapted vehicle. You can learn to drive in a Motability car or another vehicle. To apply, you need to be eligible to use Motability (see 'Car schemes'), or on a means-tested benefit such as Universal Credit.

If you need to learn to drive to care for a stroke survivor, ask your local social services for a Carer's Assessment. Depending on the outcome, you might be eligible for funding for driving lessons through the disabled person's direct payments.

## Blue Badge scheme

With a Blue Badge, you can park conveniently for free



For more practical help, as well as emotional support, visit [stroke.org.uk/driving-alternatives](http://stroke.org.uk/driving-alternatives) or call our Stroke Helpline on **0303 3033 100**.

around the UK. The scheme is run by local councils. Visit [gov.uk/blue-badge-scheme-information-council](http://gov.uk/blue-badge-scheme-information-council).

## Train discounts

You may be able to buy a Disabled Person's Railcard. This entitles you to a third off the cost of most rail fares in England, Scotland and Wales, including Transport for London train and underground services. Visit [disabledpersons-railcard.co.uk](http://disabledpersons-railcard.co.uk) or call **0345 605 0525**.

If you live in Northern Ireland, you could be entitled to a half fare SmartPass, which can be used for bus and rail travel ([nidirect.gov.uk/information-and-services/people-disabilities](http://nidirect.gov.uk/information-and-services/people-disabilities)).

## Free bus travel

If you are over 60, have sight or mobility problems or have been refused a driving licence because of your health, you might be eligible for a free bus pass.

Contact your local council if you live in England and Scotland, or local authorities in Wales. For Northern Ireland, you may be entitled to the SmartPass, which gives you half-price travel, if you receive the mobility component of Personal Independence Payments (PIP) or Disability Living Allowance (DLA). Visit [gov.uk/apply-for-disabled-bus-pass](http://gov.uk/apply-for-disabled-bus-pass) for more information.

# Puzzles



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

## Word search

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

DIG WEED  
 GROW ROOT  
 PRUNE MULCH  
 WATER SOW  
 MOW PLANT

## Across

- 1 Easy to talk to (7)
- 5 Frolic (4)
- 7 Unlawful (12)
- 8 Reject (4)
- 9 Song of lamentation (8)
- 11 Rank (6)
- 13 Performer's routine (6)
- 15 Salacious (8)
- 18 Competent (4)
- 19 Credulous (12)
- 20 Fable (4)
- 21 Entourage (7)

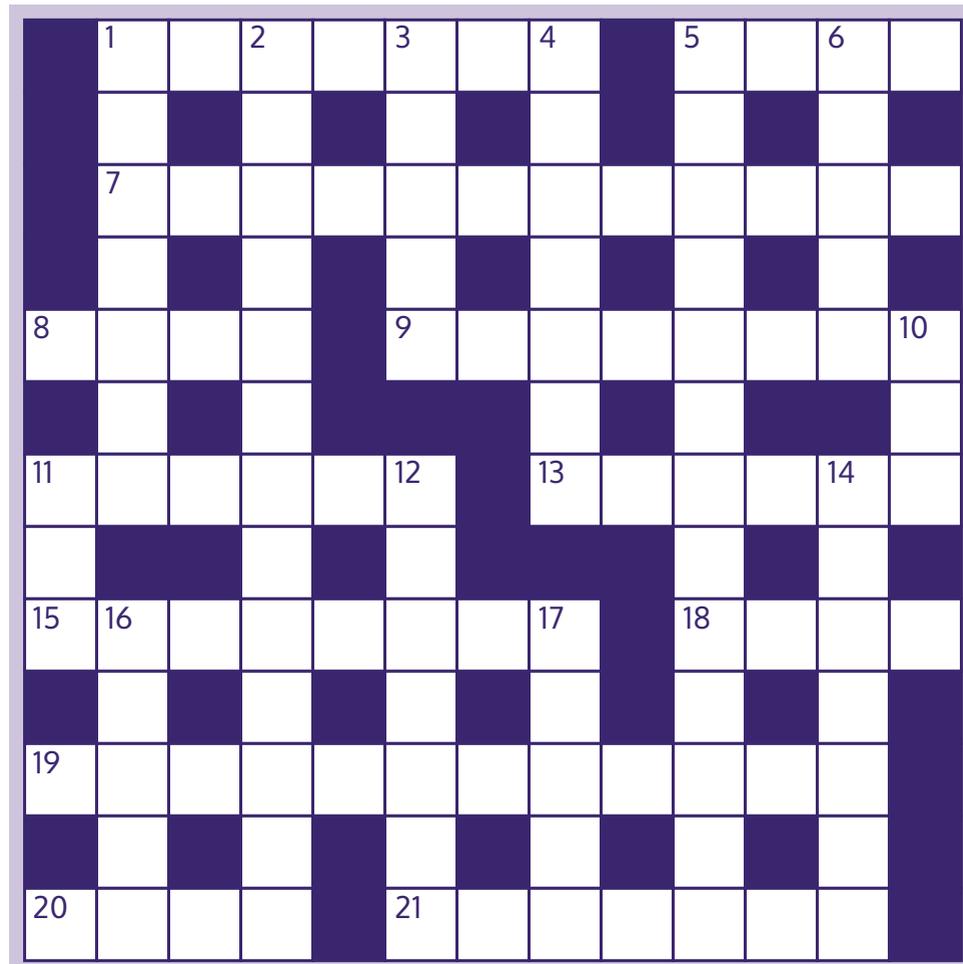
## Lottery

For your chance to win £1,000 every week, play the Stroke Association Charity Lottery. Find out more at [lottery.stroke.org.uk](http://lottery.stroke.org.uk)

Solutions  
see page 50

## Down

- 1 Food (7)
- 2 Carry to conclusion (6,7)
- 3 Prejudiced person (5)
- 4 Gains by force (7)
- 5 Disapproval (13)
- 6 Quiet (5)
- 10 Tibetan ox (3)
- 11 Enfeeble (3)
- 12 Defensive footballer (7)
- 14 Scent (7)
- 16 Long-legged (5)
- 17 Unspoken (5)



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# 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 has gone the extra mile to fundraise, volunteer and campaign with us. Your support means we can reach even more people who need us.



## Glynn Hoyle

Glynn Hoyle, 79, organised a sponsored hair dye at his local pub, The Wooldale Arms in Holmfirth as a thank you for the support he received after his strokes. The landlord, Dusty, also organised a harvest auction. Together they raised a fantastic £1,600. A big thank you to Glynn, Dusty and all the pub's patrons.

## Viva Acapella

Thank you to harmony group, Viva Acappella, whose special charity performance at The Glades shopping centre in Bromley in December raised £500 for people affected by stroke. The group were inspired to support us after one of their members had a stroke,



which left her with language communication disorder, aphasia.

## 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.



## Andrew and Alasdair Smith

Congratulations to Andrew (pictured) and Alasdair Smith from Scotland, and their friends Roddy and Terry, who raised £4,234, by shaving their heads. They were inspired to lose their long locks after Andrew and Alasdair's mum had a stroke in 2022.



## Volunteer spotlight

Karen Cousins volunteers with the Cuckfield Communication Stroke Group.

"I started volunteering when I retired. I was a social work assistant and I missed helping people.

"Our group is very social and lively. I enjoy seeing people gaining confidence and making friends.

"We do lots of activities and sometimes you'll see people at the start of the session thinking, 'This isn't my cup of tea'. But once they see others having a go, they'll try and often surprise themselves.

"Volunteering helps you see things from a different point of view. I enjoy the social aspect of attending the group and meeting others who want to help."

Find out how you can volunteer at [stroke.org.uk/yoursupport](https://stroke.org.uk/yoursupport)



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

# Join Team Stroke

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



## London to Brighton Bike Ride 16 June

Join Team Stroke and pedal your way through the idyllic English countryside towards the beautiful seafront finish line. Sign up at [events.stroke.org.uk/L2B24](https://events.stroke.org.uk/L2B24)

## Parallel Windsor 7 July

Push, walk or run this fully accessible challenge in Windsor. From 100m to 10km, these events welcome all ages, health conditions and abilities. Visit [events.stroke.org.uk/Parallel24](https://events.stroke.org.uk/Parallel24) to sign up.

## 31 minutes of exercise challenge Throughout May

Fundraise to support stroke survivors by choosing your exercise and completing 31 minutes every day in May. Join our Facebook group to chat to other participants. Visit [stroke.org.uk/31mins](https://stroke.org.uk/31mins) to sign up to get your free t-shirt!

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

## Crossword solution

**Across:** 1 Affable, 5 Romp, 7 Illegitimate, 8 Veto, 9 Threnody, 11 Status, 13 Shtick, 15 Prurient, 18 Able, 19 Unsuspecting, 20 Myth, 21 Retinue

**Down:** 1 Aliment, 2 Follow through, 3 Bigot, 4 Extorts, 5 Remonstrations, 6 Muted, 10 Yak, 11 Sap, 12 Sweeper, 14 Cologne, 16 Rangy, 17 Tacit

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

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