Striking back for mum

Fundraisers Bethany, Marvin and Marcia share their story

Life After Stroke Awards
Meet this year’s inspiring winners

Shaping stroke research
How you can get involved

Money Matters
Caring for a stroke survivor

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Evidence-based studies show that 97% of stroke survivors with dysphagia (swallowing difficulties) show improvement after 5 -13 weeks training with IQoro® and that 71% are able to swallow completely normally again.* Other studies show that the training is equally effective no matter how long after the stroke the IQoro® treatment is started – from a few weeks, to many years.*

*Visit our website for details of these studies.

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Contact us at info@iqoro.com, or tel. 07518 511 620

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Welcome...

In this edition, we talk to families and survivors about how they’re moving beyond the loss and devastation caused by stroke, and using their experiences to help others.

We start by celebrating the achievements of our Life After Stroke Award winners, including our Fundraisers of the Year, Bethany, Marvin and Marcia. Read their story on page 8 and find out how they’ve been striking back against stroke in memory of their mum.

16-year-old Harry also tells us about his experience of going back to school after a stroke (page 20). And stroke survivor Marney talks about how she’s helping to shape the future of stroke research (page 36).

If you want to get active after a stroke but aren’t sure where to start, we have some top tips for you (page 34), as well as important advice on coping with depression (page 16).

I hope you enjoy this issue.

Christine Webster
Editor

Over to you

Christmas card competition 2019
Would you like to see your design on our 2019 Christmas cards? Find out how to enter on page 50.

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

- **Stroke Helpline**
  Call confidentially on 0303 3033 100.

- **Life After Stroke Services**
  Find support near you at stroke.org.uk/local-support.

- **Clubs and groups**
  Provide a lifeline.
  See stroke.org.uk/strokeclubs.

- **Free factsheets**
  Guide you through all aspects of stroke. See stroke.org.uk/shop.

- **Financial help**
  Through Life After Stroke Grants.
  See stroke.org.uk/grants.

I’d just been appointed Managing Director of a large company when I had a brain haemorrhage in 2005. I went back to work after only three months. I had double vision and fatigue, but tried to hide it. I felt the world was dependent on me and I’d failed it. I didn’t recognise that I had depression until two years later. But I didn’t seek help because I didn’t want people to think I was weak.

Luckily, I had the support of my wife, but regret that I didn’t accept that I needed help sooner. Being able to share experiences makes recovery easier in the long-run for you and those around you. I hope my story can bring support to others.

Richard Dobson

I am a stroke survivor and volunteer. I recently came across this free travel mentoring service in London: tfl.gov.uk/transport-accessibility/learn-to-use-public-transport. I wanted to share it, as it’s a useful tool to get stroke survivors out and about around the capital.

Shani Shamah

Thanks very much Shani. If readers know of similar schemes around the UK, please get in touch. Editor.

Do you have a tip or something to share?

Write to us at Stroke News, Stroke Association House, 240 City Road, London, EC1V 2PR or email stokenews@stroke.org.uk
ENJOY
WHAT REALLY MATTERS

In a single moment, stroke can snatch away life as you knew it. But the human spirit is powerful. I’m privileged to work with stroke survivors, carers and their families whose determination and resilience to overcome the worst that stroke throws at them is truly inspiring.

At the Life After Stroke Awards in November, I had the pleasure of meeting our remarkable winners, and celebrating their achievements. It’s important to share these successes to raise awareness of stroke, change how people think about the condition and challenge the myths surrounding it. If you’d like to nominate someone for our 2019 awards, visit stroke.org.uk.

As a charity, we think it’s vital that we listen to and work with people affected by stroke to drive forward improvements in stroke care.

From influencing our research (page 36) to testing our My Stroke Guide aphasia resources (page 26), there are lots of ways you can make your voice heard.

For the last year or so, we’ve been working with NHS England and others to develop a new national plan for stroke. It’s thanks to you that we’ve come this far, but we need your help to make sure the plan is implemented locally after its launch (see page 18). By working together and engaging the whole stroke community, we can help everyone affected by stroke to get the support they need.

Juliet Bouverie

85 DELICIOUS DISHES
PROUD SUPPLIERS TO THE NHS
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WILTSHIRE
EST. FARM 1991
FOODS
Striking back for mum

Stroke strikes at any time - and when it does the consequences are devastating. On 25 June 2017, Marvin, Marcia and Bethany lost their mum, Jean Fray, to a stroke. Less than 24 hours earlier, the family had been celebrating together at Marcia’s wedding. Since then, they’ve dedicated themselves to helping us support people affected and at risk of stroke.

On 24 June, Jean watched with pride as her daughter Marcia got married. After the ceremony, she began to feel unwell, and it soon became clear that something was very wrong. She began losing consciousness and was rushed to hospital in Bristol, where doctors confirmed she’d had a brain haemorrhage.

Marvin, Marcia, Bethany and their dad, Les, were given the devastating news that she may never wake up. Still in their wedding outfits, the family stayed by her side until she sadly passed away.

Jean, a 60-year-old primary school teacher, was fit and healthy, and seemed fine on the morning of the wedding. “We have so many unanswered questions about how our mum, who always took great pride in her health, could become very ill so quickly and with few warning signs,” said Marcia. “But we’ve since learned that strokes can impact anybody at any time. They are life-changing for the survivors and their families, as well as those that are left behind.”

Three weeks later, on the day of Jean’s funeral, Marvin, Marcia and Bethany’s maternal grandmother, Audrey, sadly also passed away from a stroke.

Despite everything they’d been through, the family were determined to do something positive to remember Jean.

“We have so many unanswered questions about how our mum, who always took great pride in her health, could become very ill so quickly...”
We’re delighted to introduce this year’s wonderful winners, who received their awards at a ceremony hosted by Anna Richardson at The Landmark Hotel, London in November.

Children and Young People’s Courage Award
Elizabeth Kiss
Elizabeth was 13 when she had a severe stroke. She worked hard to overcome physical and emotional challenges during her recovery, and now volunteers in her community. She recently organised a fun day, raising awareness of childhood stroke and £1,500.

Adult Courage Award
(18–64 years old)
Emma Raven
Emma had a stroke five days after discovering she was pregnant. Tragically, her unborn baby died and Emma was left with severe aphasia. Despite this, Emma is an avid campaigner and ambassador, committed to raising awareness of stroke.

Our mother was the kindest person,” said Marcia. “We wanted to do something in her honour to prevent others from experiencing our pain.

“Our uncle ran the Great South Run every year. I’d spoken to Mama about running it as a challenge, and she encouraged me to do it. After the wedding, I decided to take part and the rest of the family jumped at the challenge - we knew we’d do it to raise money for the Stroke Association.”

The siblings also set up a Strike Back Fund in Jean’s memory. With the support of family, friends and colleagues, they’ve raised over £30,000.

“We want to help stroke survivors and families, and to fund more stroke research. Anytime we do a challenge, we’ll try to turn it into a fundraising opportunity. We’re thinking about taking part in the Devil’s Mud Run in 2019. We’re also keen to raise awareness about stroke and its risk factors as it’s not discussed as much as other diseases, despite having such a devastating impact on people’s lives. There are easy things to do to lower your risk, such as monitoring your blood pressure.”

In recognition of their achievements, Marvin, Marcia and Bethany have won the Fundraiser of the Year Award at our Life After Stroke Awards 2018. “We’re proud to have won for our fundraising. We channelled our inner-Mama and tried to make something positive out of our heart-breaking situation. It’s also an opportunity to celebrate the brave people who’ve been impacted by stroke, as well as celebrating our wonderful mother.”

Visit stroke.org.uk/awards to find out more about our wonderful winners or to nominate someone for the 2019 awards.
Life After Stroke Awards

Carer’s Award  
Grace Matthews  
When her mum, Heidi, had a stroke, 13-year-old Grace became her full-time carer. As well as taking on all of the household tasks, Grace was a vital part of Heidi’s recovery, helping her with speech therapy and supporting her in rebuilding her confidence and independence.

Adult Courage Award (65+)  
Kate Aitken  
Kate has severe aphasia following a stroke in 2017. Sadly, while she was recovering, her husband passed away. With great courage and determination, Kate set out to regain her independence and improve her speech. She now supports and encourages others at her local communication support and singing groups.

Award for Volunteering  
Liz Topliss  
Liz has been a volunteer for over 40 years. She started the Sutton Coldfield Stroke Support Group, helping stroke survivors and carers locally. Liz is on the UK Stroke Forum Scientific Conference Committee, and ensures that the views of those affected by stroke are heard by professionals.

Stroke Group Award  
North West Community Stroke Choir  
The North West Community Stroke Choir welcomes anyone with a connection to stroke and a desire to sing. They’ve represented the Stroke Association at events all over the North West. Their choir nights are a lot of fun and a great source of support.

Award for Creative Arts  
Rebecca Morrow  
Rebecca was 18 when she had two strokes, caused by an undiagnosed hole in her heart. Rebecca used her talent for art in her recovery, and explored the concept of becoming “more than my stroke” in her art A-Level. She’s now doing a Foundation Art and Design course at Ulster University Belfast Campus.

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It’s time to take hydration seriously

We know what you’re made of

Are your patients drinking enough?
We all know that water is essential for life. Unfortunately, not everyone finds it easy to drink enough to stay hydrated. Dysphagia sufferers, estimated at 8% of the population often struggle to take in enough liquids, even developing a fear of swallowing.

Dysphagia

We all know that water is essential for life. Unfortunately, not everyone finds it easy to drink enough to stay hydrated. Dysphagia sufferers, estimated at 8% of the population often struggle to take in enough liquids, even developing a fear of swallowing.

It’s time to take hydration seriously

Thick & Easy™ Clear
Thick & Easy Clear is prescribed to modify the consistency of drinks, helping people with dysphagia to swallow safely.

Thick & Easy Clear:
• Encourages fluid intake, therefore reducing the risk of dehydration
• Is a gum-based thickener
• Doesn’t alter the natural appearance, taste or texture of drinks
• Retains a consistent thickness over time
• Lessens the fear of swallowing

Helping patients to stay hydrated
Fresenius Kabi are sponsors of Hydration Angels. Together we’re helping to hydrate the nation.
To find out more, visit www.whatwearemadeof.org

Find out more about dysphagia
For expert information, advice, case studies and the latest developments in clinical dysphagia research call Fresenius Kabi on 01928 533 516 or email scientific.affairsUK@fresenius-kabi.com

References

Date of preparation: January 2018. Job code: EN446.
Thick & Easy is a trademark of Hormel Health Labs. Fresenius Kabi is an authorised user.
Coping with depression after stroke

Stroke is sudden, shocking and affects every part of your life. This can have a huge emotional impact, causing you to feel angry, anxious and depressed.

For more information, visit stroke.org.uk/emotions.

Is it normal to feel depressed?
Everyone’s experience of stroke is different, but it can often feel like you’ve lost the life you had before. Adjusting to life after stroke can feel overwhelming, and it’s normal to feel down or sad. But depression is when feelings of hopelessness and sadness don’t go away.

Depression is very common after stroke. It can make you feel low, lacking in energy and uninterested in things you usually enjoy.

You may find that depression doesn’t start straight away, but comes months or even years after a stroke. It’s important to know the signs of depression and understand how you’re feeling so you can get support.

Will it get better?
Although it might not feel like it at the time, it does get better. There is help and support available — you don’t have to cope alone. You might find you have good and bad days, but this is normal. Try different strategies and find what works for you.

What help is available?
Asking for help can be hard and it’s often difficult to know where to turn. Start by speaking to your GP about the support available.

People, including health professionals, can forget that there are effects of stroke that you can’t see. Don’t wait to be asked about them and keep trying to get support. Contact our Stroke Helpline if you don’t think you’re getting the right help.

Call our Stroke Helpline on 0303 3033 100.

Tips for coping with depression:

1. Talk to someone about how you’re feeling. Reach out to a friend, family member or therapist — whoever you’re comfortable approaching.

2. Join a support group and meet others who have been through similar experiences. Find your local stroke group at stroke.org.uk/clubs.

3. Take it easy on yourself and ask for help if you’re struggling. Don’t be embarrassed about the way you are feeling.

4. Be proud of the steps you are taking - the smallest successes deserve celebration.

For more information, visit stroke.org.uk/emotions.

Hema Patel from our Stroke Helpline answers some commonly asked questions.
Making the national plan a local success

Following our successful A New Era for Stroke campaign, we’re now working with NHS England to write a new national plan to improve stroke care across England.

Once the plan is launched, we want to work with stroke groups and supporters all over the country to help them ensure the national plan is being implemented in their local area.

To help us find the best way of doing this, we’ve set up a Campaign Input Group, which includes stroke survivors, carers, volunteers and staff with a mix of backgrounds and campaigning experience. They’ve been helping us to develop ways to support local groups to take action to make sure the plan is benefiting stroke survivors, carers and their families in their communities.

Carer and volunteer Tony Goodger is a member of our Campaign Input Group and attended their most recent meeting in Leicester. “One of the Stroke Association’s strengths is that it engages with those whose lives have been affected by stroke and uses their experiences to shape current and future campaigns,” said Tony. “With this in mind, our group wanted to come up with ways to effectively communicate the national plan and to monitor progress at a local level.

“One of the main ideas we discussed was an online database whereby volunteers, carers, stroke survivors and staff can access information about stroke and the national plan where they are.

“We thought it was important to have up-to-date data, tools and a contact at the Stroke Association to encourage people to set up and get involved in local campaign groups. We agreed on suggestions for templates for emails and letters, and looked into options to enable people to see how neighbouring areas were progressing.

“We also felt it was essential to come up with a careful plan focusing on how to engage with stroke clubs, groups, associated organisations, pharmacists and medical professionals across the country. This will be vital in raising awareness of the national plan.

“It’s now everyone’s task to unify and inspire all within the stroke community to make the new stroke plan a success locally as well as nationally.”

Interested in getting involved with campaigning in your area? Email campaigns@stroke.org.uk for more information.
Top of the class

Stroke can happen to anyone at any age, including babies, children and young people. For many, returning to school is an important part of their recovery. Harry Baker had just turned 16 when he had a stroke in January 2017. He shares his experiences.

“I collapsed on the train on my way back from school. I had the worst headache of my life, face weakness, and no feeling in my left leg and arm. My friends called an ambulance and I was rushed to the hyper acute stroke unit at King’s College Hospital.

Initially I was unable to walk, shower, focus on anything, and life felt hopeless and ruined by the changes. But I realised that if I stayed positive, focused on getting better and put 100% into my therapy, life would get better. And it did.

Getting back to school
Throughout my recovery, my main aim was to get back to school and be with my friends. I was excited to be going back, though I worried about how I would cope with the physical and academic demands as I found it so hard to focus, and got very tired. My closest friends had visited me in hospital and also attended a peer support day with the therapists, so knew a lot about my stroke, but most friends at school knew nothing at all.

My school set up meetings to help me to settle back and staff came to see me in hospital, even my headmaster, to plan for my return. They suggested a three year sixth form, so I could come back on a half timetable for the first year, allowing me to manage my fatigue and the new academic challenges.

“... I realised that if I stayed positive, focused on getting better and put 100% into my therapy, life would get better.”
With the support of the Stroke Association, my teachers learnt about stroke. The school’s special educational needs coordinator was amazing, making time for me to talk to her, and giving me a space to go to when everything was too much.

**Secrets to success**
My teachers asked me how I wanted to be supported, and what helped me to learn. By changing the way they delivered their lessons they enabled me to succeed. I learnt not to give up because my brain found it too hard, but to focus on ways to get round the problems, sharing my thinking with those supporting me.

**Looking forward**
I don’t think too far ahead now, as my life changes so quickly. At the moment, I’m focusing on doing as well as I can in my sixth form courses, and hope to study languages and economics at university. I also want to support other young people who’ve had a stroke by raising awareness and encouraging optimism about a successful future after a stroke.

Together with the Evelina London Children’s Hospital, we’ve developed a new toolkit to help teachers and childcare professionals supporting children and young people affected by stroke with their education. You can download this along with our other childhood stroke resources from stroke.org.uk/childhood.
My Stroke Guide: supporting others

Maureen Hunter understands only too well the devastating impact stroke can have. As well as working with people affected by stroke throughout her career, she supported her own family in the aftermath of stroke.

“I managed a respite service for carers for 16 years and witnessed the effect stroke had on both stroke survivors and their families. I also experienced it first-hand when my uncle had a stroke and was in hospital for three months. Then my brother-in-law had a haemorrhagic stroke and sadly died aged 39-years-old. I also cared for my mum after she had a really bad stroke, which initially left her with locked-in syndrome.”

Maureen knew how difficult it could be for people to access stroke information when they most needed it, and felt passionately about finding new and innovative ways to support people in their stroke recovery. She first came across My Stroke Guide when she joined the Stroke Association as a Support Coordinator three years ago. Our online support tool provides free, 24/7 access to trusted advice and information. This includes practical tools and over 200 videos to help stroke survivors, carers, family and friends to understand stroke and manage its effects. It also offers online peer support so people can connect with others who’ve been affected by stroke and share stories, tips and advice.

“I could have done with My Stroke Guide four years ago,” said Maureen. “It could have helped myself, my mum and my uncle. It’s got loads of information which does help people to understand what’s happened to them.

“When someone suddenly has a stroke, their life is turned upside down. But with My Stroke Guide, they can ask questions that they would not necessarily be confident enough to ask before, and it gives them more confidence knowing that they’re not on their own.”

Today, Maureen organises and attends stroke cafés in Glasgow and Renfrewshire, where she often demonstrates My Stroke Guide. “I now have some stroke survivors who have come through the recovery journey and are now volunteering at the stroke cafés,” she said. “Three years ago, they would never have imagined they would be doing what they can do now. They’ve gained that confidence and information from My Stroke Guide and now want to share their experience to let people know things do get better.”

Join thousands of others affected by stroke. Log on to mystrokeguide.com today.
Help us test our aphasia resources

About a third of stroke survivors experience aphasia after a stroke, which can cause difficulties with speaking, understanding, reading and writing.

Our Aphasia Team works with stroke survivors to make sure that the services and resources that we offer to people with aphasia meet their needs.

One of the projects the team is involved in is the development of an aphasia suite on My Stroke Guide, our online support tool (see page 24). The aphasia suite will be a collection of resources specifically designed to support people with communication needs.

Over the past few months we have run focus groups around the UK to ask people with aphasia:

- which devices and software they have found helpful since their stroke
- what else they would like to see on My Stroke Guide to help with their aphasia
- what would help them to use online resources more easily.

Lin Cheveau recently attended a focus group and also helped to support other people at the session. “I’ve had two strokes so I know how it feels to lose confidence and struggle to manage,” said Lin. “It’s important to me to try to help and share my experiences.

Julia Burge also attended a session to share her experience of aphasia. She said: “The group was really friendly and I enjoyed meeting and talking to other people with aphasia. It was good to get involved and I think that other people would enjoy it too.”

The next stage of the project will be to develop some resources and ask people with aphasia to test them and tell us whether they are helpful.

If you are interested in the project and would like to get involved in testing the resources as we develop them, please contact Judith in our Aphasia Team on Judith.moreland@stroke.org.uk or 0161 742 7487.
If you have fatigue, mobility or memory problems after a stroke, getting back into the kitchen can be a challenge. But cooking and baking can be great ways to support your recovery, regain independence, make sure you’re getting a well-balanced diet and have fun.

So we’ve put together some ideas to help you get back into it:

- **Plan.** Write down the steps you need to follow. If you have memory difficulties, this can help you to keep track of where you’re up to and what you have to do next. If you’re following a recipe, it might be helpful to break down each step into individual actions.

- **Prepare.** Make sure all your ingredients are ready before you start cooking. Or buy pre-chopped or grated items instead. Gather up all the equipment you’ll need, so you don’t have to search for things while you’re cooking.

- **Keep it simple.** Start with easy recipes that don’t need a lot of preparation and aren’t too time-pressured, like one-pot recipes or oven meals. Don’t worry if it doesn’t go to plan. Have a back-up in mind in case you have any problems – for example, cheese on toast!

- **Set a timer** to remind you how long your food has been in the oven or on the hob, and to prompt you when it’s done.

- **Organise your kitchen.** Make sure the items you use most regularly are easy to find and access.

- **Get the right tools.** There are lots of adaptive kitchen tools available such as one-handed chopping boards, can and jar openers and pan stabilisers. Non-slip mats and kitchen processors can also make tasks like stirring and chopping easier.

- **Keep yourself safe.** Don’t over-do it and ask for help when you need it. Keep a stool nearby in case you need to sit down. Be careful with hot things, especially if you have sensation problems - make sure you have good oven gloves, or delegate this task to others. If you can’t manage food shopping, get a home delivery instead.

- **Talk to your occupational therapist.** They can give you specific tailored advice if you need more support.

You can find more practical advice on life after stroke on mystrokeguide.com. For information about daily living aids visit stroke.org.uk/dailyliving.
At Stannah we have been helping people travel effortlessly between floors for over 150 years. And whilst our product offering has expanded over the years, we still hold true to the same values and ethics that have guided us from the beginning.

Depending on your needs and budget, we offer a great range of solutions for your home in the shape of our stairlifts and homelifts. Whether you simply need a helping hand on the stairs, or require a lift to transport you and your wheelchair between floors, our range of products will provide you with a smooth and safe journey.

All our products are extremely practical and intuitive to use and can be customised with options and extras to complement your home. They are also quick and easy to install. So why consider moving from the home you love? Contact Stannah today to find out how much easier life at home could be.

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0800 289 788
stannahstairlifts.co.uk
Running for families like mine

Lydia Redfern had never been interested in running, or exercise really, until stroke struck her family in October 2017.

She and her husband, Joe, were on holiday in Corfu with their two young children, Reggie and Stanley, when Joe had a life-threatening stroke. “We were at the hotel when Joe started to try to speak, but couldn’t get his words out and struggled to lift his right arm,” remembered Lydia. “We were both so frightened. I screamed for help and fortunately, a kind-hearted family helped us with the children as Joe was taken to hospital.”

Joe was rushed to hospital in Corfu then transferred to mainland Greece, before being flown back to the UK to begin his recovery. Doctors confirmed that his stroke was caused by a previously undiagnosed hole in his heart.

“Joe’s stroke left him unable to speak and he couldn’t move his right arm,” said Lydia. “He was a self-employed stonemason and had just set up his own business, which was doing really well before his stroke. Fortunately the Stroke Association was there to help us with information and advice about benefits and support, as well as providing a Life After Stroke Grant for a hoover to help at home.

“In the months since his stroke Joe has done really well with his recovery and continues to do so. He is able to say quite a few words and has gained the use of his leg and arm. He’s very determined and always positive.”

Inspired by Joe’s determination and the support they’d received, Lydia and Joe challenged themselves to take on our 5km Resolution Run in Derby to raise vital funds for stroke survivors, like Joe, all over the UK.

“...I wanted to raise as much as I could to help other families affected by stroke...”

“Until January 2018, I had never done any exercise and didn’t have a great diet, but then I joined a running club, Solemates, and trained twice a week. We’ve had a lot of support from the Stroke Association, so I wanted to raise as much as I could to help other families affected by stroke to get the support they need.”

Join us at our UK-wide Resolution Runs in spring 2019. Challenge yourself to run, jog or walk the 5, 10 or 15km routes, volunteer to help us on the day, or come along and cheer everyone on. Visit stroke.org.uk/yourresolution to sign up to an event near you.
Being active after a stroke

Getting active after having a stroke can be daunting, especially if you haven’t done much exercise in the past. However, doing purposeful activities throughout the day can help to strengthen muscles and increase your energy levels.

Here are some tips to get you warmed up:

- **Pace yourself.** Fatigue is common after a stroke and resuming your day-to-day activities may feel like an uphill struggle. Take it easy and rest when you need to.

- **Make rehabilitation and recovery part of your daily routine.** Small actions like standing up correctly and using the affected parts of your body to do tasks such as housework will have more impact than just doing your exercises once a day.

- **Exercise in your local pool.** Activities such as walking, squats, marching and side-stepping, as well as swimming, improve your cardio and are low impact on your joints.

- **Are you sitting comfortably?** If you’re spending most of the day sitting down, make sure you’re sitting upright and engaging your core muscles. Having good posture is vital for your arms and legs to work efficiently. Small movements like bending and straightening your knees or marching your legs up and down can be vital to keep your joints in good working condition and help to prevent pain.

- **Look to rebuild the strength in your muscles.** Joining a gym can be a good way to access resistance machines or weights to help you to achieve this. If you’re at home, there are bodyweight exercises you can do, for example a seated push-up:
  - Sit on the floor with your knees bent and your palms on the floor.
  - Keep your fingers pointing forward.
  - Push through your hands to lift your bottom off the floor slightly.
  - Always speak to your physiotherapist first about which exercises are best for you.

- **Don’t give up.** Recovery takes time, so stay positive and remember how far you’ve come rather than focusing on what you haven’t achieved yet. Set yourself small goals and focus on your ‘wins’.

Daily tasks will have more impact than just doing your exercises.

For more advice, explore the Chartered Society of Physiotherapy’s ‘Love activity, hate exercise?’ campaign. Visit csp.org.uk/activity.

You can also find information and advice on stroke.org.uk and mystrokeguide.com.
Decide the future of our research

We think that listening to the experiences of people affected by stroke should be a key part of the research process. That’s why Patient and Public Involvement in research (PPI) is so important. PPI gives you the chance to have your say on the research we fund.

Being ‘involved’ in research is different from being the ‘subject’ of a research trial. You are an active partner in the research, helping to make decisions that influence how the research is developed.

Marney Williams has been involved in multiple research projects since her stroke in 2009. Currently, she’s advising on a study we’re jointly funding with the British Heart Foundation, known as TASMIN5S. This is trialling a new system to enable stroke survivors to monitor their blood pressure at home. It’s hoped that the system will help people to control their blood pressure and reduce their risk of another stroke or TIA.

How did you get involved in research?
When I first had the stroke, I found it difficult to find groups and life after stroke support, so a friend recommended that I join a communication disability network. It was through this network that I found out about the opportunity to become a Service User Representative on the UK Stroke Forum (UKSF) conference committee, ensuring the voices of stroke survivors were heard by professionals and researchers.

At my first UKSF conference in 2011, I saw a presentation by the Stroke Research Network (SRN) about what people with experience of stroke could bring to research. This made a big impact on me – I rushed to the front and asked how I could get involved. They were recruiting, so I applied and was successful. Through the SRN, I’ve met lots of stroke researchers and others affected by stroke, who I still see now.
How did you get involved with the TASMIN5S study?
I met Professor Richard McManus, the Chief Investigator of TASMIN5S, through the SRN, and helped with his research funding application. I’m a co-applicant on the funding application, so I’m a full member of the research team.

I’ve made suggestions about how we can work with people affected by stroke during the consultation phase, which is happening now, and involve them in designing the system. I’ve been involved in making sure the system is accessible for people with aphasia, and that they can take part in the research. I also suggested that the UK Stroke Assembly would be a good place to talk to people affected by stroke about the study, and to get their opinions on the system.

Why is it important that people affected by stroke are involved in research?
For researchers, working with stroke survivors helps to put a human face to the problem they’re trying to solve, giving them a viewpoint that comes from lived experience.

If involvement is done well, the study and its outcomes tend to be better, and more relevant.

What advice would you give to someone wanting to get involved in research?
Get in touch with the Stroke Association; they can point you in the right direction!

To find out more about getting involved in stroke research, contact Laura Piercy on research@stroke.org.uk or 0207 3873 5717.
Guidance

Checking your blood pressure

High blood pressure plays a part in half of all strokes so it’s one of the biggest risk factors for stroke. You can reduce your chance of a stroke or another stroke by getting your blood pressure checked regularly.

What is it?
Your heart pumps blood through your blood vessels. When the blood presses too hard against the blood vessel walls, this is known as high blood pressure (or hypertension).

Why is it a risk?
High blood pressure can lead to clots forming, or cause bleeding in the brain. It can also increase the risk of heart attacks, dementia and kidney disease.

How do I know I have it?
It usually has no symptoms, so get your blood pressure checked regularly. Having your blood pressure measured is simple, quick and painless. You can get this done at your GP surgery or pharmacy.

Blood pressure monitors are also available to buy. To find a local Stroke Association Know Your Blood Pressure event for a free and easy blood pressure check, visit stroke.org.uk/kybp.

What can I do about it?
If you are diagnosed with high blood pressure, making some healthy lifestyle changes can help, and you may need medication. If you are advised to take tablets it is very important to take them regularly.

Thank you to OMRON Healthcare, who donated 50 blood pressure monitors to enable us to run more Know Your Blood Pressure events.

Visit stroke.org.uk/bloodpressure for more information and to download our ‘High blood pressure and stroke’ guide.
Money matters

Are you a carer for someone who has had a stroke? A carer is anyone who gives unpaid support to a family member, partner or friend who couldn’t manage without this support. Taking on caring responsibilities can have an impact on your finances, so it’s vital that you have the right information and support to help you both.

What support is available?
The benefits system is complex so it’s a good idea to get expert advice and information. Speak to your local Citizens Advice about your situation either face-to-face or by phone. They can sometimes arrange home visits too. You can find your nearest Citizens Advice office on citizensadvice.org.uk.

You can call Citizens Advice on:
- England: 03444 111 444
- Wales: 03444 77 20 20
- Scotland: 0808 800 9060
- Northern Ireland: 0300 1 233 233

Online benefits calculators such as turn2us.org.uk can also help you to check which benefits you may be entitled to.

What is Carer’s Allowance?
If you provide regular care for someone with a disability for at least 35 hours per week, you could be entitled to claim Carer’s Allowance. You don’t need to be related to the person, or live in the same property. It’s not means tested, and you can qualify if you’re in or out of work. If you’re eligible, you could currently get £64.60 a week.

Good to know
Carer’s Allowance is a taxable benefit. It can also affect any other benefits you or the person you care for are receiving, so make sure that you check this with the person you’re caring for before you make a claim.

Are you eligible?
To qualify, the person you are caring for must be getting a benefit because of their disability. If you’re in paid work, you can only claim if you earn less than £120 per week take home pay. You can’t claim if you’re in full-time education.

How to apply
If you live in England, Scotland or Wales, visit gov.uk/carers-allowance or call the Carer’s Allowance Unit on 0800 731 0297. If you live in Northern Ireland, visit nidirect.gov.uk/articles/carers-allowance or call the Disability and Carers Service on 0800 587 0912.
Puzzles can be a fun way to exercise your mind and improve concentration, understanding and memory.

Word search

Across
1 Government report (5)
4 Blooms (7)
8 Goods of fired clay (7)
9 Greek island (5)
10 — Mountains; — owl (5)
11 Make tidy (6)
13 A Connecticut — in King Arthur’s Court (Twain) (6)
15 Clever, skilful (6)
18 Accept without proof (6)
20 Fine white ceramic (5)
22 Lively dance (5)
23 Where animals come to breathe through ice (7)
24 Exceptional (7)
25 Very great suffering (5)

Down
1 Edible sheep’s gland (5,3)
2 Humiliating remark (3-4)
3 (Of voice) high/thin (5)
4 Moving quickly (6)
5 Land with fruit trees (7)
6 Strange, frightening (5)
7 Dirt on surface (4)
12 Long-term plan (8)
14 Match by imitation (7)
16 Venezuelan river (7)
17 Calm, unhurried (6)
19 Break, fissure (5)
20 Approximately (5)
21 Duelling sword (4)

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

With thanks to The Times/News Syndication who granted us rights to this crossword.
You could be entitled to compensation for the pain and suffering caused

For anyone in hospital or nursing care, pressure sores are an ever-present danger. They are incredibly painful and can take a long time to heal, and in many cases could have been avoided with proper nursing care.

Significant awards of damages have already been made to pressure sore victims. Those awards have even extended to the families of loved ones who have died. If you or a loved one has suffered from pressure sores in the last 30 months, we urge you to seek legal advice as soon as possible.

Contact us for confidential help and advice on 0800 214 216, absolutely free. We are specialists in this field, there is no obligation.

Example settlement:

£55,000 compensation for an elderly lady who developed a pressure sore to her leg whilst in hospital.

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Classifieds

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Book a 4, 7 or 11 night break in January or February 2019 and your carer or partner can join you for free.

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www.treworgans.co.uk

If you or a loved one has suffered from pressure sores, you need to read this…
Together we can conquer stroke

As a charity, we rely on your support to prevent stroke and change lives. A huge thank you to everyone who’s gone the extra mile to fundraise, volunteer and campaign with us.

Thanks to martial artists who organised and attended the Joint Aikido Council’s annual training seminar in Durham and raised £652.

We welcomed The Lord Mayor of Nottingham, Councillor Liaqat Ali, to a Know Your Blood Pressure event at the Nottingham Council House. Thank you to the Lord Mayor, who has chosen us as one of his charities of the year.

Well done to Jade, Neil, Nicola, Mirabela and Tom from Source BioScience, who skydived 13,000 feet and raised over £4,000 for us as their charity of the year.

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

How does your donation help?

- **£5** could help 15 people begin to come to terms with stroke with crucial factsheets.
- **£20** could support our Stroke Helpline in giving advice to people struggling to cope.
- **£50** could help us to invest in life-saving stroke research.

To make us your charity of the year, contact supportercare@stroke.org.uk.

Adam Kerry and his family were devastated when his dad, Tony, had a stroke in 2001.

Tony was well-known for doing challenges for charity, including pulling heavy items around their village in Kent. When he passed away, Adam continued his dad’s fundraising tradition.

Since 2012, Adam and his team have pulled a two-tonne boat, a tractor and a helicopter, raising over £39,000.

In August, they pulled a four tonne lorry for 21 miles and are aiming to raise £16,000. “My dad will always be my hero,” said Adam. “I’m joined by friends and family, who help me to remember dad while raising money for charity.”

Thank you to the Ritchie family who raised £17,500 by completing a 17-mile coastal challenge, Tough Mudder, the Fraserburgh Half Marathon, and the London Marathon, in memory of their wife and mum, Jane.

Visit stroke.org.uk/fundraising for fundraising ideas and events.
Supporting us

Dates for your diary

Last chance to order Christmas cards
19 December 2018
Get your Christmas cards from stroke.org.uk/Christmas19, including the design by Steven Ferrari, our competition winner.

2019 Christmas card competition deadline
29 January 2019
It’s time to get creative for our stroke survivors’ Christmas card competition. Visit stroke.org.uk/cardcomp19 for details or send in your entries by emailing cardcompetition@stroke.org.uk.

Resolution Runs
Challenge yourself to run 5, 10 or 15k or volunteer at one of our events around the UK. See page 32 or visit stroke.org.uk/resruns19.

UK Stroke Assemblies spring and summer 2019
Sign up to our emails for details about UKSA Northern Ireland in the spring and UKSA central zone in the summer: stroke.org.uk/SAsignup.

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

Crossword
Across:
1 PAPER, 4 FLOWERS, 8 POTTERY, 9 CORFU, 10 SNOWY, 11 NEATEN, 13 YANKEE, 15 ADROIT, 18 ASSUME, 20 CHINA, 22 POLKA, 23 AIRHOLE, 24 EXTREME, 25 AGONY

Down:
1 POPEYE, 2 PUTDOWN, 3 REEDY, 4 FLYING, 5 ORCHARD, 6 EERIE, 7 SCUM, 12 STRATEGY, 14 EMULATE, 16 ORINOCO, 17 SEDATE, 19 SPLIT, 20 CIRCA, 21 EPEE

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