

Stroke News

Spring 2019

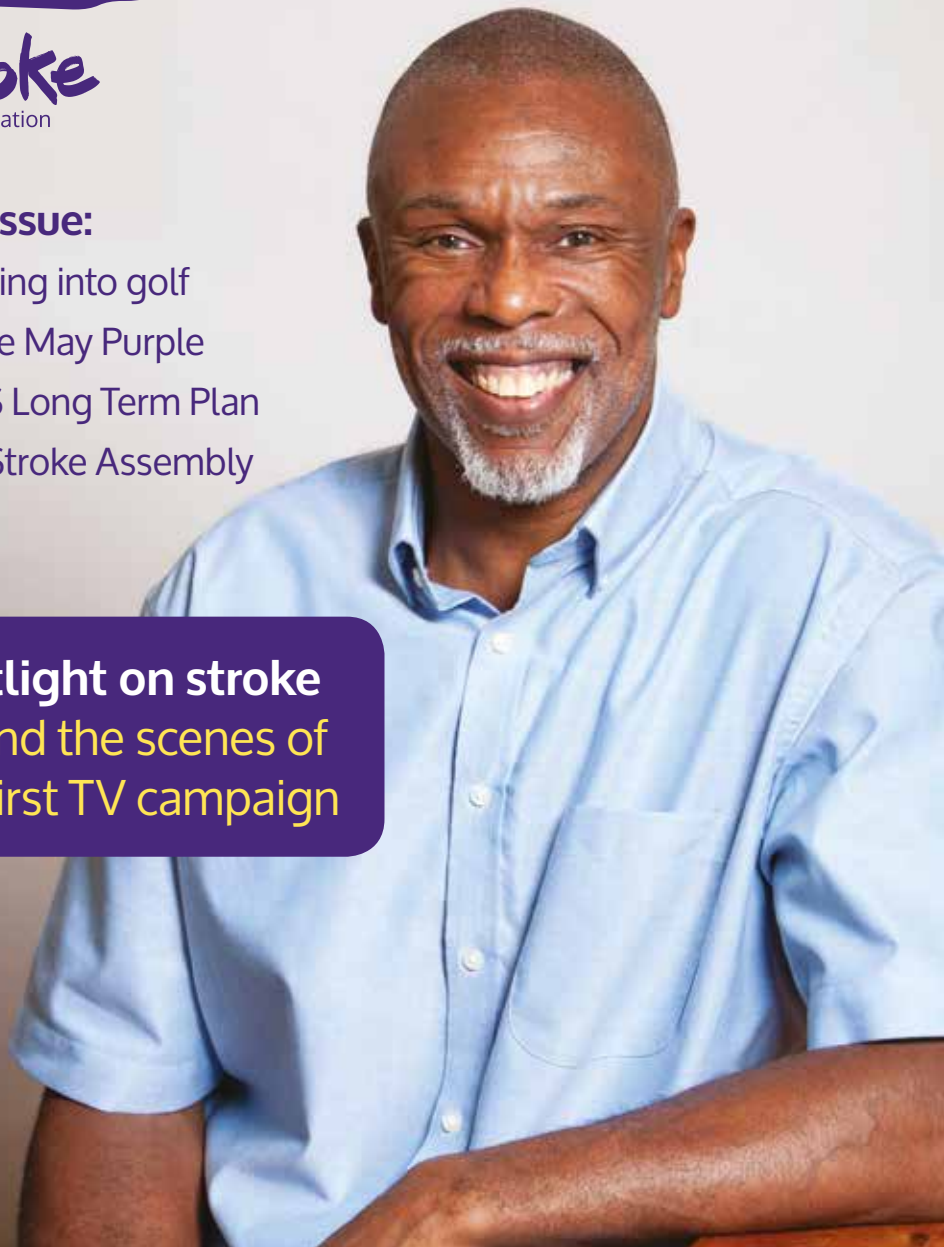
For everyone affected by stroke

Stroke
Association

This issue:

- Getting into golf
- Make May Purple
- NHS Long Term Plan
- UK Stroke Assembly

Spotlight on stroke
Behind the scenes of
our first TV campaign



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Editor's letter

Welcome to your spring edition of Stroke News!

What do you think of our new look? We want to put stroke on the map and transform the support we give and receive. So, as a charity, we've been working with the stroke community to refresh our brand – from our logo to our values.

It's great to be finally sharing it with you and we'd love to hear your thoughts. What works well? How can we improve? Get in touch and let us know.

Alongside our refresh, we're launching our first-ever TV campaign, Rebuilding Lives.

You can find out more about this on page 7. And meet one of its stars (pictured above), as well as our director, on pages 8 and 11.

Also, find out how golf is helping John with his recovery (page 24) and why Sarah is joining her local Step Out for Stroke (page 32).



I hope you enjoy this issue.

Christine Webster, Editor

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Over to you

I had my stroke three years ago, a brain bleed on my right side. It affected my left side, especially my leg from my hip down.

I recovered quickly thanks to prompt medical treatment, and was in hospital for 17 days. This all happened on the eve of my 60th birthday and meant the cancellation of two surprise parties!

My stroke was caused by high blood pressure, so I'm on medication now and receive regular checks from my supportive local GPs. I also play Walking Football once a week and thoroughly recommend it to anybody over 40, as it's great fun.

I think being a very positive-minded person has helped me enormously, in both my recovery period and in my post-stroke life.

I know I'm not 100% who I was, I still have some balance issues. But I've been fortunate enough to recover to the extent that people are surprised when I tell them.

Of course, I dread that it may happen again, but I won't live my life in fear either. Down with stroke I say, and keep positive people.

Mike McLoughlin

Stroke Helpline: **0303 3033 100**

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

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

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



Do you have something to share? Write to us:

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From our Chief Executive

It's an exciting time for our charity and the wider stroke community. We started 2019 with the launch of NHS England's Long Term Plan, which formally recognised stroke as a priority condition. This is fantastic news and the result of a lot of hard work by thousands of people, including our Stroke News readers.

The plan focuses as much on improving rehabilitation and long-term support as prevention and treatment. This is an important step as after-care is something we know is a priority for people affected by stroke.

We're now supporting regional health leaders to prioritise stroke locally (see page 16). And we're actively shaping the national stroke programme. We will give you more information about this in the next issue.

We're also really excited to be shining a spotlight on stroke through our new Rebuilding Lives campaign (see page 8). By raising awareness of the impact of stroke through stroke survivors' own voices, we hope to inspire more people to take action and join our growing community. Visit **stroke.org.uk** to find out how you can help.

Juliet Bouverie

Spotlight on stroke

"Everyone needs to be aware that stroke can hit anybody at any time - believe me."

Baz Kelly has come far since a stroke 27 years ago took away his speech, part of his vision and his mobility. Now 54 years old and a proud father of two, Baz is one of the stars of our new Rebuilding Lives campaign to change the way people think about stroke.

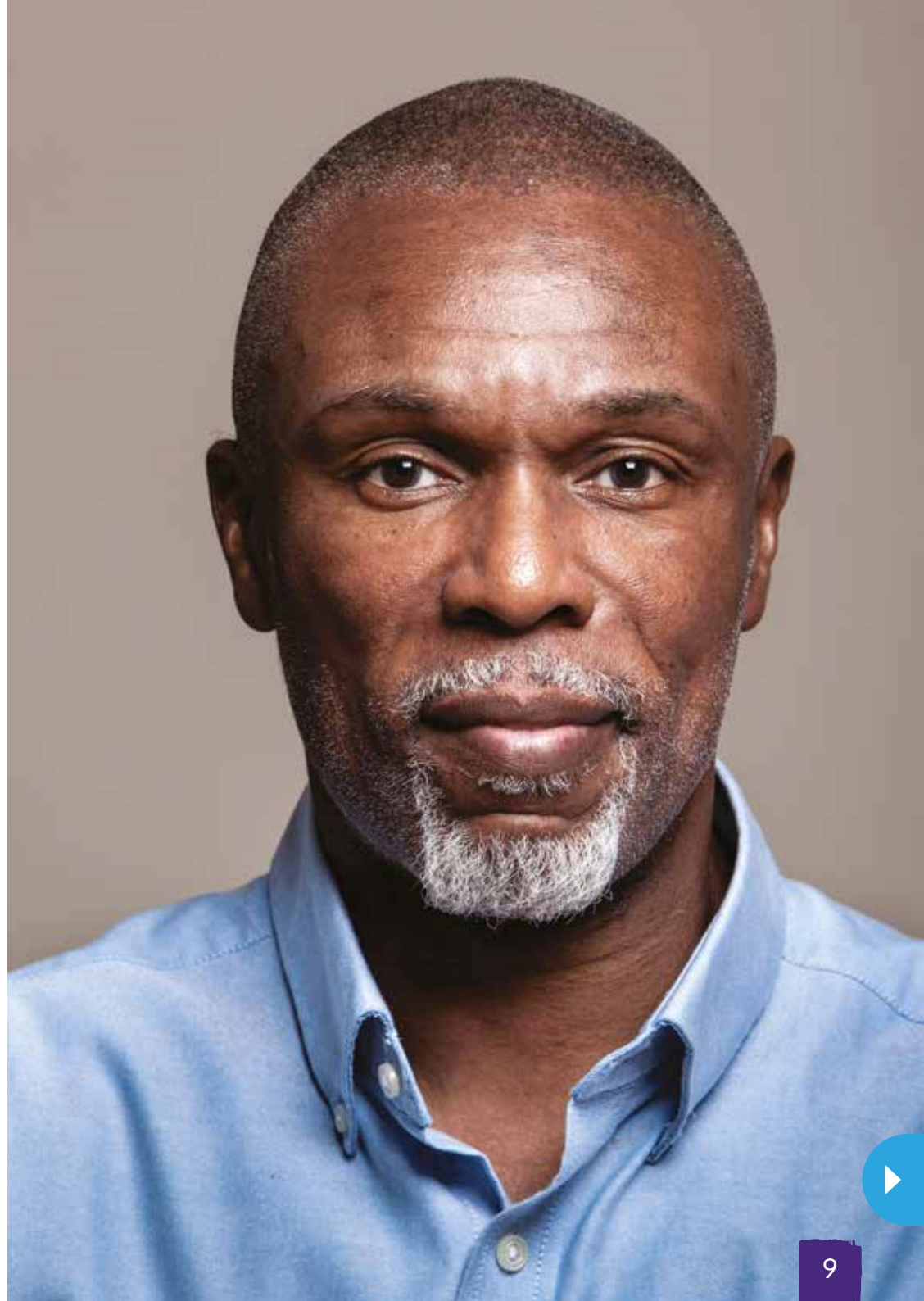
In our first-ever TV campaign, Baz and fellow stroke survivors Alisha, Max, Paul, Luna and Erin all tell their stories in their own words. Unscripted and unfiltered, they show how stroke changes lives in an instant. Shutting down part of the brain. And part of you.

"When I heard about Rebuilding Lives, I was keen to get involved," says Baz. "I had a stroke in 1992, 11 days after my 32nd birthday. I rolled over in bed and felt a sharp pain in my head. Everything went

topsy-turvy. My leg shot up in the air. I was being sick. My room-mates came flying in, but I could hardly see them. They threw me in a taxi and took me straight to hospital.

"I woke up on the ward with everything spinning. A clot in my brain had destroyed the right side of my body. My vision was bad and my speech was gone. I couldn't get out of the wheelchair. I remember the doctor saying, 'If I was you, I'd learn to write with your left hand'. I was devastated.

"For months afterwards I felt horrible. I wanted to die. I still get upset when I think about it. Stroke is awful, I wouldn't wish it on my worst enemy."



Baz with his family



But crucially, while Baz and his co-stars know only too well the impact stroke can have on who you are, they're also living proof that life after stroke is possible. Recovery is tough but with support, courage and determination, the brain can adapt.

"The work it took me to get to the position I'm in now is unbelievable," says Baz. "Recovery was slow and single-minded. I'd bounce a ball against a wall for ages to rebuild strength in my arm. I took up Japanese

and Spanish - articulating words in different languages was good physio for my mouth and tongue.

"I'm one of the lucky ones to recover the way I have. A person from the outside looking in would think, 'No chance this guy's had a stroke'. But when I explain it to them, they get it.

"I think a campaign like this with a wide range of people, from youngsters to old age, is really important. People need to understand more about this condition. And that there is hope."



We want everyone to know that we're here to support people to rebuild their lives after stroke. Look out for our campaign on Channel 4's network from 26 April. Find out more on stroke.org.uk.



Meet our director

Film-maker Lotje Sodderland ('My Beautiful Broken Brain'; 'Can You Rebuild My Brain?') tells us what the Rebuilding Lives campaign means to her.



Q Why did you want to get involved?

As a stroke survivor with residual, hidden disabilities, I am thrilled to direct this film. I've wanted to get involved with the Stroke Association ever since I first heard about their work following my brain haemorrhage. Working on this TV campaign is beyond exciting because the message we're putting out will reach a very broad audience.

Q Why do you think a campaign about stroke is important?

There is a lot of mystery

surrounding both the causes and the effects of stroke, including the fact that it can happen to anyone at any age, and the results are often devastating. There are many stroke survivors struggling, but you can't see what they are going through as the residual conditions are often invisible.

My goal is to increase a sense of compassion and patience among the public. And to educate people about the experience of surviving a stroke and what it is to live with brain damage.

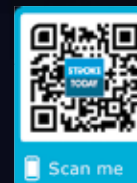
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Coping with anger

After a stroke, you might find you feel angry more often about things that wouldn't usually make you feel that way. Or you might have less control of your temper.

Anger and aggression can have a big impact on your health, recovery and those around you, so it's important to process your feelings.

Laura Read from our Stroke Helpline shares some advice.

Q How can I manage my anger?

Don't be too hard on yourself. Anger is a normal part of recovery – a sign you recognise things have changed and are trying to work through them.

If you're struggling with anger, here are some ways to help you regain control:

- Learn your triggers. Talk to friends and family to work out what makes you angry so you can act before things get too heated.
- Write down your thoughts. This can help you to process how you're feeling and why.
- Find a safe way to let out your anger. Do something physical, like walking or a chair-based exercise, or find a relaxation technique that works for you.

Q How can family and friends help?

Anger and aggression is often directed at carers and loved ones. It's easy to be hurt by words or actions, but remember that the anger they're feeling is a side-effect of stroke, and isn't personal.

Here are some tips to help you:

- Listen. People often lash out when they feel ignored or out of control. Involve them in decisions and let them know you're there to help.
- Be patient. Allow time for them to carry out tasks or to respond to you.
- Look after yourself. Having a stroke doesn't give anyone the right to hurt you. If you feel drawn into an angry encounter, walk away or explain that you feel frightened or upset.

Getting help from a professional

Whether you're a stroke survivor or carer, speak to your GP if you need more support. They can refer you to a therapist to help you to develop ways of coping with your thoughts and feelings.



 For more advice, visit stroke.org.uk/emotions or visit mystrokeguide.com.

 **Telephone**
Call our Stroke Helpline on **0303 3033 100**.



Making a change

In January, NHS England produced its new Long Term Plan, outlining its priorities for the next 10 years. And the great news is that stroke is now named as a national priority.

The plan sets out key aims for improving stroke treatment and care including:

- Making thrombectomy (game-changing clot removal surgery) available to ten times more patients by 2022.
- Improving stroke rehabilitation so people receive better after-care when they leave hospital.

"We campaigned. We ensured the stroke community was given a voice. And together we achieved the Long Term Plan," said carer and campaigner Julie Payton. "This means a new generation of stroke care, better support for families and carers, and increased research to improve the lives of stroke survivors."

Stroke survivor and ambassador Amber Garland added: "I'm so proud of what we've achieved. By involving stroke survivors and sharing experiences, we're making a real difference!"

But this isn't the end of the story.

Our next step is to make sure that the Long Term Plan is implemented locally.

We're looking for people affected by stroke to work with our staff campaigners and others in their stroke community to push local decision-makers to ensure that the plan becomes a reality. This could include organising petitions, meeting your local councillors or talking to clinical staff. How you campaign is up to you and your fellow campaigners.

Take action to improve the lives of stroke survivors and their families in your area. Email campaigns@stroke.org.uk to find out more.

Karen Pritchard has been involved in the campaign for a new national stroke plan from the start. "Being part of something that means so much to me has been incredible," she said. "It's easy when you have had a life-changing event to become lost and demotivated. That's why it's so important that stroke care is top of the agenda."

"Everyone, wherever they live, deserves the opportunity to live the best life they can and I believe this Long Term Plan will give survivors exactly that."



Have your say

What three things would you change about stroke care in your area?

Wherever you are in the UK, we would love to hear your views. Email our Campaigns Team at campaigns@stroke.org.uk or write to

Jess Rich, Stroke Association House, 240 City Road, London, EC1 2PR.

Campaigning across the UK

Scotland

Volunteers and Stroke Ambassadors are vital in helping us to campaign on behalf of stroke survivors and raise awareness about stroke in Scotland. They've run blood pressure checking events at the Scottish Parliament. And been involved in the Cross Party Group on Heart Disease and Stroke's inquiries into high blood pressure and atrial fibrillation – two of the biggest risk factors for stroke.

We recently put out a call to all those interested in campaigning (see Ruth's story on page 30). The more campaigners we have, the stronger we will be. Join us and help to improve stroke treatment and care.

Northern Ireland

We've been working with the stroke community on proposals to improve stroke services in Northern Ireland. And our recent 'Struggling to Recover' report gained a commitment from statutory services to improve long-term support.

A public consultation on reshaping stroke services is currently underway – please get involved in this significant opportunity to change stroke services for the better.

Wales

Local campaigners have been essential in challenging and changing decisions to cut important local services. If you're keen to get involved but not sure where to start, we've developed toolkits and training to help. Visit stroke.org.uk/speakout.

Our Community Steps programme (see page 24) also supports stroke survivors and local volunteers to get involved in campaigning, so please get in touch.

Become a campaigner and make change happen in your nation: email campaigns@stroke.org.uk or visit stroke.org.uk/campaigning.



Sharing ideas and experiences

As the Chair of the North East Worcestershire Stroke Group, stroke survivor Dennis Hill had heard a lot about our UK Stroke Assemblies over the years. So in 2018, he and his wife, Lesley, decided to attend the event in Manchester to see for themselves.

"I've been a volunteer and a Stroke Ambassador for many years now, but I'd never been to a Stroke Assembly before," said Dennis. "I wanted to know what went on. Others from our stroke group had been and said how great it was, so I was keen to attend. I was particularly interested in finding out more about new developments in stroke after-care, both for myself and to share with our group."

Our Stroke Assemblies are the largest gathering of stroke survivors in the UK. They're an excellent opportunity for everyone affected by stroke, including carers and family members, to understand more about stroke, have your say on stroke care and find out about organisations and services that can help with recovery. You can also find out how you can get involved with campaigns and research.

To find out more and book your place visit stroke.org.uk/uksa19.

Stroke Ambassador, Dennis Hill, shares his experiences



"It was great to meet other stroke survivors and to share ideas," said Dennis. "I also had the opportunity to learn more about My Stroke Guide and how to use it."

While he was there, Dennis also met people who were looking for a stroke group to join in Worcester. Afterwards, he invited them to visit the North Worcestershire Stroke Group. For many that attend an Assembly event, meeting others and sharing experiences and achievements is a great benefit and inspires them in their own long-term recovery.



Join us this year at a UK Stroke Assembly near you:

UK Stroke Assembly Central
Monday 1 - Tuesday 2 July
Radisson Blu Hotel,
East Midlands Airport

UK Stroke Assembly Wales
Autumn 2019
Venue TBC

Making May purple for Harry

After a dramatic childbirth, Emma Winwood's worst fears were realised when her new-born son, Harry, stopped breathing and had to be revived several times. Doctors later discovered that Harry had had a stroke.

"It was all such a whirlwind," said Emma. "We were in shock – how can a baby have a stroke? It's unheard of, or so we thought. It was the best day and the worst day of our lives."

Despite his early struggles, Harry, now two, has made a good recovery and attends regular physiotherapy sessions to aid his mobility.

"The doctors can't believe how well he is. He has a weakness on his right side. His leg's not too badly affected, but because he can't use his right arm he has adapted to using his left side. He's such a determined little boy and figures out everything for himself."



A year after Harry was born, Emma's best friend, Amelia, also had a transient ischaemic attack or TIA (sometimes called a mini-stroke), aged 26.

"Amelia realised she was having a stroke because of Harry. I'd been investigating stroke and telling her about it. So when she felt her face droop, she knew to call an ambulance."



"We wanted to take part in Make May Purple to make people aware that stroke can happen to younger people and babies, so if they see someone having a stroke, they know what to do. We did a raffle at our work. We dressed up in purple and put purple accessories on. It was really good therapy for both of us. Just talking about our experiences really helped."

With the support their friends and family, Emma and Amelia raised £1,395. Emma's husband, Luke, also raised £2,500 by climbing Mount Snowdon.

Emma's advice to anyone thinking of taking part this year? "Do it! We thought it was great dressing up and just being silly for the whole month. I would encourage anyone

to do it, have fun with it and most importantly raise awareness. It's really important for people to know more about the signs and symptoms of stroke."



Have fun and raise awareness of stroke by making May purple in your community. Get started by downloading your fundraising pack: stroke.org.uk/may19.

Back in the swing of things

After the shock of a stroke, rebuilding your life again is challenging. So last year, we launched Community Steps in Wales to support stroke survivors and carers to get back out into their communities.

This four-year project, sponsored by the Big Lottery Fund, aims to help people feel less isolated and boost their wellbeing by helping them to access local facilities and activities including golf, painting, sailing and bowls.

John Manning, 66, from Abergele, recently joined one of our Return to Golf sessions at his local course. John was a busy



electrician and keen golfer until a stroke affected his speech and mobility in 2017.

"After his stroke, John couldn't return to work and didn't feel like he could ever play golf again," said his wife, Anne.

"It's not just about hitting the ball - John felt self-conscious about going to the club to meet friends because of his speech difficulties.

"Since he joined the Community Steps golfing sessions, his confidence has improved so much. His consultant is astonished at how well John has recovered. His brain scan showed huge amounts of damage and he wasn't expected to be able to walk again, or regain so much speech."

John added: "Going to the golf sessions is fantastic. I didn't think I would ever play again, but the pro has been great and now I go back to my old club.



"Also it's about being with other people who understand. When I meet with people who are finding things hard after a stroke, I want to see what I can do to help them."

Dylan Williams, PGA Director of Golf at Pyle and Kenfig Golf Club in Bridgend, is one of the golfing professionals involved in delivering the sessions for stroke survivors.

"I've learned so much working with this group," said Dylan. "Everyone who attends is dealing with different issues due to their stroke. Some struggle with vision and many with balance, so we've worked hard on building up a golf swing that people are comfortable with."

"Everyone has found a way - it's been so rewarding for all of us to see the progress, and the determination in the group. Other players could learn a lot from them."

Dylan's top tips for golfing after stroke:

- Try clubs of different lengths and weights.
- Use thicker club grips for a more secure hold.
- Get a brightly coloured ball if you're vision impaired.
- Wear a grip glove on your weaker hand and strap it onto the club to help your swing.
- Attach a ball picker to the putter to lift the ball out of the hole.



Learn more about Stroke Community Steps: stroke.org.uk/communitysteps. Find out about local clubs and groups in your area by visiting stroke.org.uk/clubs.

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Combating loneliness

Coping with the effects of stroke can be a lonely experience. Perhaps you don't see or talk to people as often as you'd like because you feel less confident since your stroke? Or maybe you have people around you, but feel like they don't understand what you're going through?

There are lots of things you can do to help tackle loneliness. Here are some ideas to get you started:

Join a peer support group –

Talking to others who understand what you're going through can help you to feel less alone. We have lots of supportive, friendly clubs, groups and befriending services. Visit stroke.org.uk/clubs to find one near you. You can also chat to people affected by stroke online at mystrokeguide.com.

Phone a friend – Sometimes people will assume that you're not up for visitors unless you tell them otherwise. If you'd like company, don't be afraid to phone up a friend or family member for a chat. Or invite them over for a cuppa. Often people are just waiting to be asked.



Take up a hobby – Hobbies and interests are an important part of life after stroke and can help to improve your confidence. You could return to, or adapt, an activity you enjoyed before. Or why not try something new?

If you find new people or situations daunting, work up to it slowly. For example, try an activity-focused class, where you can build up to talking to



people in your own time. Or you could try a quietly communal activity, like going to the cinema, theatre or library.

Contact your library, council or leisure centre to find out about activities near you. Your GP or nurse can also refer you to local community groups, befrienders, events or learning opportunities.

Volunteer – Meet new people, build your confidence, develop existing skills and learn new ones. If you'd like to volunteer for us, visit stroke.org.uk/volunteering.

If you need more information or support, contact our Stroke Helpline on **0303 3033 100** or email helpline@stroke.org.uk.

Ruth's recovery

Like many stroke survivors, 33-year-old Ruth Hector from Stirling struggled with her mental health without much support.

After a life-long heart condition caused a blood clot in her brain, Ruth was given a thrombectomy - a procedure that can greatly reduce the effects of stroke. She made a speedy recovery and returned home a few weeks later. "But that's when my mental health started to decline," she said. "I turned from the bubbly person I'd always been, to wanting to kill myself. At the time, I thought it was for no reason, but it was caused by my stroke."

"I realised I desperately needed help and dialled 111 for NHS support. They told me to go to Forth Valley Hospital mental health unit. It took them a few days to put me on the right anti-

depressant, but it was a lifeline. I felt a lot better in a couple of days. "If you're feeling the same way, get help. See your GP, go to your hospital's mental health unit or ring 111. Do what you can to survive. Don't give up - it does get better. Think: 'This is the way I feel, but it's not forever. It's the stroke affecting my emotions'."

Just as she was starting to feel like herself again, Ruth had another stroke. "This time I couldn't get a thrombectomy. My recovery was a lot slower. I had to have more speech and language therapy and physio for drop foot."

It was Ruth's physiotherapist who referred her to the Forth Valley



Moving Forward After Stroke programme. "We did exercises, then talked about healthy living. This wasn't the reason I had the strokes. But it's why a lot of people do, so it's useful. I used it as an opportunity to chat to other stroke survivors and got a lot out of it."

"On the whole, I've done well at getting better. I go for long walks every day as part of my recovery and I'm off the anti-depressants now. I volunteered to become a Stroke Ambassador at the 2018 UK Stroke Assembly

in Scotland as it's something I'm passionate about.

"I want to talk to people about preventing strokes and continue campaigning about thrombectomy. We don't have it at the moment in Scotland and I know how much it can help people to recover. Mental health is also a big thing for me. People need to know who they can speak to if things go wrong after their stroke."



For information about emotional changes after stroke call our Helpline or visit stroke.org.uk/emotion. Find out how you can become a Stroke Ambassador at stroke.org.uk/ambassador.

One step at a time

Sarah Harbron was 29 when she was paralysed by a stroke. Three years on, she's celebrating her progress by taking on her third Step Out for Stroke.

One Sunday in December 2015, Sarah felt so ill she couldn't get out of bed.

"I was really tired and didn't feel like myself," she recalled. "My mum saw my face had dropped and called 999. My limbs were lifeless and I couldn't speak."

But half an hour later, Sarah's symptoms had vanished, and after a few tests, she was sent home. A few days later, she was getting ready to go out when she collapsed.

"I couldn't move. I had to drag myself along the floor to call an ambulance. By the time it arrived, my symptoms had gone. Three hours later my face drooped again. I deteriorated in hospital and was told I'd had a brain stem stroke."

Sarah was put into an induced coma. When she woke, she was paralysed and unable to speak. She spent eight months in hospital re-learning how to do everything for herself.

"When I was discharged, I was using my wheelchair. Now I can walk with a stick. The Stroke Association visited me and their support was invaluable. I lost my job as a civil servant as a result of my stroke, and they supported me with advice about finance."

Keen to challenge herself, Sarah took part in her local Step Out for Stroke in 2017 and every year since. "Walking the one mile route was a challenge but worth it to prove how far I've come with my recovery," said Sarah. "I want to raise awareness and vital funds to help others affected by stroke to get the support they need."



Join your local Step Out for Stroke this spring. Our routes are accessible and suitable for all ages and fitness levels. So whether you're walking or wheeling, going as a group or setting yourself a challenge, you'll be supporting others affected by stroke.



Visit stroke.org.uk/step, email stepout@stroke.org.uk or call **0300 330 0740** to find a walk near you.

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Marathon motivation

Before a stroke changed his life in 2016, Dale Biggerstaff from Belfast was a local marathon-running legend. He's now working hard to rebuild his fitness, while encouraging fellow runners to fundraise for people affected by stroke.

Dale's stroke was caused by a bleed in his brain. "I felt off-balance and had a banging headache," he said. "Then I lost power in my left hand and was slurring my words. My wife, Kathy, got help quickly and probably saved my life.

"The impact of the stroke has been huge – both physically and emotionally. I went from being a super-fit, busy dad with my own business, to re-learning how to walk.

"At 42, it was a huge shock. But the Stroke Association has been there whenever we needed them. They've supported our family to believe there can be life after stroke."

When the Stroke Association became a charity partner of the 2019 Belfast City Marathon, Dale, who'd completed the race six times, got involved by mentoring and motivating members of his running club to join #TeamStroke.

"There's no denying I miss running. But meeting up with my running mates and motivating them to run for the Stroke Association has been great. It's helped me to focus on getting ready to run again in a relay team - something I thought I wouldn't be able to do after my stroke but I'm determined to try.

"Throughout my running, and now more than ever since the stroke, my motto has always been never, ever give up."



From races to bake sales, find out how you can join #TeamStroke at stroke.org.uk/get-involved.



Dale's top running tips:

- **Pacing** – It's important to get your pacing right so you can keep going. If you're taking part in a longer race, run beside an official pacer.
- **Hydration** – Drink plenty in the lead up to and during your run.
- **Vaseline** – Apply generously to areas that might chafe, including thighs and soles of feet.
- **Nutrition** – Eat plenty of carbohydrates to give you plenty of energy.



- **Kit** – Make sure everything you wear has been tried and tested on your training runs.
- **Most of all** - Enjoy becoming a running legend like me!

Fit-to-fly certificates

If you've had a stroke or have any other medical conditions, it's important to talk to your GP to make sure you're fit to travel.


We work with AllClear to offer people affected by stroke specialist medical travel insurance. Here they share some advice about fit-to-fly certificates:


Q When do I need one?
Airlines might need a fit-to-fly certificate if you've recently been discharged from hospital or are recovering from an ongoing medical condition. Certificates can be needed for a wide range of conditions, so it's best to check with your airline in advance.

Q When will my fit-to-fly certificate expire?
Your certificate indicates that you're fit to fly at the time of your trip. If you have a long-term condition, your certificate may need updating each time you travel. Check with your airline before your next trip to make sure.

Q Where do I get the certificate from?
Your GP surgery should be able to help you with this. Contact them directly or check their website.

Q How much do certificates cost?
Fees are determined by your GP surgery, but they usually range from £20-£40.

 For more information about AllClear's travel insurance visit stroke.org.uk/allclear or call **0808 168 8733**.

 AllClear will contribute up to 20% of your premium to the Stroke Association when you purchase a policy (see stroke.org.uk/allclear).



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

Making medication more manageable

Stroke survivors are often given lots of medicines to reduce their risk of having another stroke. Although this medication is important, many find it difficult to manage the amount they're prescribed, and to keep taking it in the long-term.

Since 2016, the Stroke Association has funded the KeMIST study (Kent Medicine Support in Stroke and TIA). This aims to find out what issues prevent stroke survivors from taking their medication, what support they need, and how this should be offered.



Dr Sarah Corlett who leads the KeMIST research team tells us about their work:

Q What did the study find?
Our researchers asked stroke survivors and healthcare professionals about their experiences. We found that there are points during their recovery when stroke survivors are more likely to have problems managing their medicine. For example, ordering their first repeat prescription, or adjusting to a new medicine routine when they get home from hospital.

Stroke survivors also said they'd experienced a mixture of practical issues and worries about taking their medicines. They were unsure how to get and take their medicines, had concerns about side effects or didn't understand why they were taking the medicine in the first place. Age and living situation also affected how likely they were to have problems with medication.

It's clear that people often need support with their medication after stroke. This needs to be available in the long-term so people can access it at different points in their recovery.

Q How have you used your research?
We're developing two tools to help with medication management. The first is to help healthcare professionals to identify stroke survivors who're likely to have problems with taking medicines. They can then pass this information on to the stroke survivor's pharmacist and GP so they can get support.

The second is a short questionnaire to help stroke survivors to recognise their own issues with medication. They could fill this in and take it to their pharmacist to help them discuss any issues they're having.

Q What's next for the KeMIST study?
We're now applying for funding to test the tools we've developed, so we can make sure they're easy to use and able to identify the people who need support.



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



You can support stroke research by donating what you can at stroke.org.uk/donating or calling **0300 330 0740**.



Money Matters

Did you know that you can get VAT relief on certain services and equipment if you have a long-term disability or health condition? Our Stroke Helpline Team tell us more:

What is VAT relief?

VAT or Value Added Tax is a tax paid on goods and services, and is usually included in the price. Most things are taxed at the current standard rate of 20%. But if you're chronically ill or disabled, you can buy certain goods or services without having to pay VAT.

Who can get VAT relief?

If you have a permanent disability or health condition, including dementia or diabetes, you don't have to pay VAT on things to support your personal and domestic living. VAT relief isn't means-tested so doesn't depend on your financial situation.

What items are eligible?

Practical products designed to help you because of your illness or disability are often available without VAT. These include wheel-chairs, specialist chairs and beds, low vision aids, lifting equipment and emergency alarm call systems. Some building works, such as installing lifts, can also be VAT-free.

How do I get it?

The retailer or supplier is responsible for checking if goods can be sold VAT-free. You then need to sign a declaration to confirm your disability or health condition. If you're unsure if this applies to you, speak to your GP.

VAT isn't refundable by HMRC, but rather doesn't get charged in the first place. If you think you've paid too much VAT, contact your supplier for a refund.

What if I'm not eligible?

If you have a temporary disability, for example a broken leg, you don't qualify for VAT relief. However, if you're over 60, you can get a reduced VAT rate of 5% on certain mobility aids, including grab rails, ramps, stair lifts and adapted bathrooms supplied and fitted in your home. Ask your supplier about reduced VAT.



Where can I find out more?

Call HMRC's VAT Disabled Relief Helpline on **0300 123 1073**.



Visit **gov.uk** and search "VAT relief".



Write to: **Charities, Savings and International 2, HM Revenue and Customs, BX9 1BU.**

Puzzles

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

Word search

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

NATIONAL
PRIORITY
REFRESH
TEAM
COMMUNITY

GOLF
WALK
TALK
INVOLVE
AIMS

Across

- 1 One paying a brief visit (6)
5 Unlucky accident (6)
8 Surrounded by (4)
9 Grand Canyon river (8)
10 Not uttered (6)
12 European mountains (4)
15 Process killing bacteria (13)
16 Genuine (4)
17 Island in Bay of Naples (6)
19 This clue's number (8)
21 French cheese (4)
22 Something paid for hire (6)
23 (Actors) leave the stage (6)

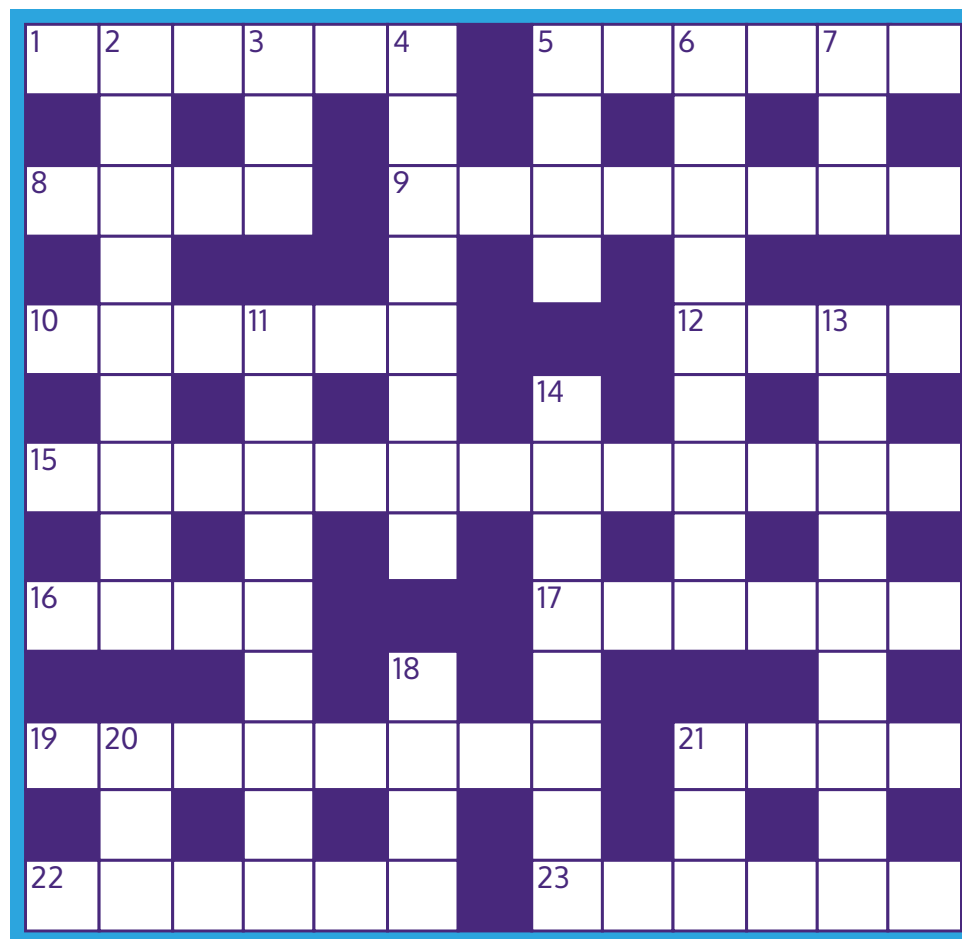
Lottery

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

Solutions
see page 50

Down

- 2 Type of carpet (9)
3 Top crust of a pie (3)
4 Town NE of Manchester (8)
5 Think (over); island (4)
6 Using biting irony (9)
7 Help, support (3)
11 Harmony in opinion (9)
13 Something supplied (9)
14 One to whom legal right is transferred (8)
18 Source; in good health (4)
20 Frozen water (3)
21 Stinging insect (3)



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

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



BHTA September challenge

Congratulations to everyone who completed the British Healthcare Trades Association's Steptember challenge. They clocked up over 10,000 steps a day during September and raised over £3,500 for us – thank you very much!



Unipart Dorman

Thanks to Nena Green and her colleagues at Unipart Dorman for choosing us as their charity of the year. From taking part in our Resolution Runs to organising bike rides, they raised £2,050.

How does your donation help?



£5 could provide 15 people with crucial factsheets, to help them to come to terms with stroke.



£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.



Volunteer spotlight

Gill Farley is a volunteer with our Oxfordshire Communication Support Service. For five years, she's helped stroke survivors with aphasia to find ways to communicate.

"I've had some very memorable moments and met some truly remarkable individuals. One man wanted to become confident writing short Facebook messages to keep in touch with friends and family. But his stroke had affected his ability to spell and write.

"Together we worked on a message to explain his aphasia. It took him a long time to write, but he did it. It reads like a poem as short sentences work best."



Give a Hand and Bake

In October, bakers UK-wide whisked up some amazing treats for Give a Hand and Bake. Thanks to everyone who took the opportunity to enjoy some cake and a cuppa while raising money for a great cause!

Find out more about our different volunteering opportunities by visiting stroke.org.uk/volunteer.

Dates for your diary



Make May Purple 1-31 May

Sign up for a Make May Purple pack (see page 22):
stroke.org.uk/may19.

London 2 Brighton Challenge 25-26 May

Walk, jog or run from city to seaside for #TeamStroke. Contact **LondonFundraising** @stroke.org.uk.



Life After Stroke Awards 2019: nomination closing date 24 May

Give someone the recognition they deserve: stroke.org.uk/lasa2019.

The Kiltwalk June – September

Walk for us at events in Aberdeen, Dundee and Edinburgh this summer: stroke.org.uk/kiltwalk.

Robin Hood Half Marathon 29 September

Sign up for one of our charity places by contacting joanne.drake@stroke.org.uk.

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

Crossword solution

Across:

1 Caller, 5 Mishap, 8 Amid, 9 Colorado, 10 Unsaid, 12 Alps, 15 Sterilisation, 16 True, 17 Ischia, 19 Nineteen, 21 Brie, 22 Rental, 23 Exeunt

Down:

2 Axminster, 3 Lid, 4 Rochdale, 5 Mull, 6 Sarcastic, 7 Aid, 11 Agreement, 13 Provision, 14 Assignee, 18 Well, 20 Ice, 21 Bee

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

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Head of the Health and Community Care Team

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