

For everyone affected by stroke

# My Stroke Guide

Claire finds friendship and reassurance through our online stroke support tool

**App-solutely fabulous** 

Mobile and tablet apps for stroke survivors

Campaigning for change
The volunteers fighting for better stroke care

Helpline advice

Caring for a stroke survivor

stroke.org.uk



#### Rediscover the pleasure of eating, drinking and swallowing

After a stroke, many people experience swallowing difficulties, facial or throat paralysis, speech difficulties, snoring, apnoea, acidic reflux (LPR), or a sensation of a lump in the throat or chest. IQoro® addresses all these issues simply, effectively and without surgery.

IQoro® is a neuromuscular training device and regime that strengthens the affected muscles and activates the nerve system to and from the brain, thus allowing it to improve, rebuild and regain its control over functions to enable you to breathe, eat, smile and talk normally again.

The method is well-known in Sweden, and now available in the UK too. Training with IQoro® takes 1½ minutes per day, can be performed at home and can be used with an assistant for those currently lacking the necessary muscle function.

Visit www.igoro.com:

- Useful information on your symptoms
- Patient histories
- Training videos on 'How to use'

#### Start now - it's never too late

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.

#### Learn more, and order IQoro® at igoro.com

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











IQoro® is a CE marked Class 1 Medical Device produced by MYoroface AB, Sjötullsgatan 16, SE-824 50 Hudiksvall, Sweden.

### Contents

#### **Features**

- My Stroke Guide How our online support tool helped Claire's recovery
- 16 Aphasia cafés build confidence Heidi shares her experience of the Phoenix Project
- 20 Why I'm campaigning for change Julie's quest to raise stroke awareness
- 32 Friends, not just members Finding long-term support through clubs and groups
- 36 Support for the supporter Life After Stroke Grant helps football fan, John





#### **Guidance**

- 14 Apps to help with recovery
- 22 Getting up safely after a fall
- 28 Caring for a stroke survivor
- **42** Money matters



- Contact us on 01604 687 721 or visit stroke.org.uk/summer18 to:
- → subscribe to three editions of *Stroke News* per year for free (online, in print or audio)
- → change your preferences to online to help save the charity money
- → unsubscribe.

Editor Christine Webster

Design fullyfledgeddesign.com

Stroke News is published by the Stroke Association, 240 City Road, London EC1V 2PR.

stroke.org.uk

Helpline 0303 3033 100 / info@stroke.org.uk

To advertise in Stroke News, call Redactive Media Group on 020 7880 7668.

Volume 36.2 Summer 2018 © Stroke Association 2018

Every effort has been made to ensure that the information provided in this magazine is accurate, but we cannot guarantee accuracy and the information provided does not constitute legal or other professional advice. Opinions expressed in this magazine are not always to be taken as the opinions of the Stroke Association, Advertisements. products or services listed are not necessarily recommended by the Stroke Association.

Stroke News is printed on paper from sustainable sources. The Stroke Association is registered as a charity in England and

Wales (No 211015) and in Scotland (SC037789). Also registered in Northern Ireland (XT33805), Isle of Man (No 945) and Jersey (NPO 369).

### We come...

After a stroke, it's common for both stroke survivors and carers to feel anxious and isolated, so it is important to know where you can go and what you can do to help you take control of your recovery.

This issue, stroke survivors share with you the experiences that helped them to process these feelings and come to terms with life after stroke.

On page 8, Claire explains how having 24/7 access to information videos, and the ability to connect with other stroke survivors via forums on My Stroke Guide, helped her to realise she wasn't on her own. Then on page 16, we hear how attending her local aphasia café helped Heidi to feel confident enough to start volunteering.

We also find out how raising awareness of stroke locally can have a national impact (page 20), and share tips on getting up safely if you have a fall (page 22).

I hope you enjoy this issue.

**Christine Webster Editor** 



#### **Aphasia Voices**

Find out more about our consultation group for stroke survivors with aphasia.

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





Financial help through Life After Stroke Grants.

See stroke.org.uk/grantshelp

# Over to you



I used to play all sports, but after my stroke I had to give them up as my left hand and side are only partially operational. Instead, I maintain my love for sport, even when quite badly disabled, by attending major events.

Wheelchair facilities at sporting venues nowadays are so good, and while I need someone to push me, my companion goes free. I've been to Twickenham, The Oval, Wimbledon and Murrayfield.

I hope this might help others maintain their sporting interests after stroke. If anyone needs information, I may be able to help.



**Jeremy Coltart, Newbury** Stroke Care Group

lam 46 and 12 years ago I had a stroke. I haven't got all the feeling back in my left hand but I'm persevering.

For years I struggled with acceptance; I'm not working anymore which I find hard, but I'd like to let others know that you can live independently. I had to buy my own aids to help me, but I'm stronger and proud of myself for having learned things all over again.



**Deborah Moorhen** 

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 strokenews@stroke.org.uk



#### 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.



claimforpressuresores.co.uk

### From our Chief Executive

I'm always inspired by the huge amount of support you give us, and the last few months have been no exception. From taking part in Step out for Stroke, to hosting Make May Purple events, you've been vital in helping us to raise money and awareness of stroke.

I'd particularly like to thank our runners, supporters and volunteers across the UK for making our Resolution Runs such a huge success. I took part in our Swindon Resolution Run in April. Despite the looming rain clouds, spirits were high and we raised nearly £20,000!

The following week, I cheered on our amazing runners at the London Marathon, and was privileged to hear their reasons for supporting the Stroke Association. I've foolishly even decided to run the marathon myself next year for our wonderful charity!

Everything you do has an incredible impact, and enables us to support even more people affected by stroke through our services, including My Stroke Guide. By registering for free

at mystrokeguide.com you can access online information about all aspects of stroke, whenever you need it. You can also connect with others who've been through the same challenges as you via our online community.

It's been lovely to hear how many stroke survivors and carers have benefited from My Stroke Guide since we made it universally available in January. Please carry on sharing your feedback as we develop it further to help you to take control of your life after stroke.

#### Juliet Bouverie



# My Stroke Guide

When nineteen year-old Claire collapsed on the underground in 2010, the doctors thought she was suffering from anxiety. They later found out she'd had two devastating strokes.

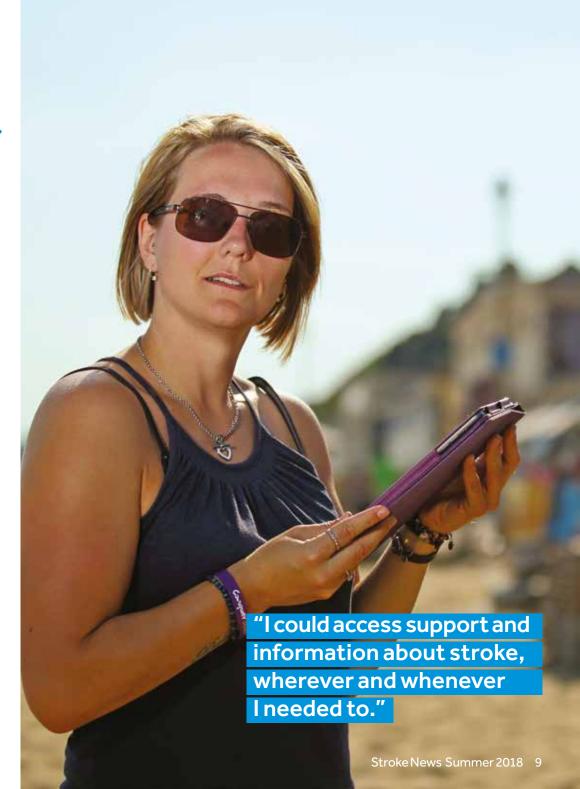
Claire's vision, hearing and speech were affected. She also experienced weakness on both sides of her body, as well as impaired balance. coordination and mobility, which meant she had to use a wheelchair.

"My life changed in an instant," remembered Claire. "I was scared that I was going to die. And all the things I loved, like playing football and plans of becoming a teacher, had been snatched from me. I felt like I was never going to have a purpose again."

She spent nine weeks in hospital and with intense physiotherapy, started to make a recovery. But when she was discharged home, the rehab stopped and she was left to cope with the devastating emotional impact of stroke as well as the physical disability.

"It was frightening. No-one contacted me from the hospital to explain what had happened. I lost a lot of friends who were scared by the change in me and didn't understand what had happened. I spent a long time trying to come to terms with things and worked hard to get my life back."

Three years after her stroke, Claire discovered My Stroke Guide, our online support tool. "I could access support and information about stroke, wherever and whenever I needed to. That gave me reassurance and a confidence boost to know that I could go out and if I felt  $overwhelmed \, and \, anxious, I \, could \,$ access My Stroke Guide on my phone and talk to someone via the My Social forum.



"Reading comments from other people who were feeling the same as me helped me to realise that I wasn't the only one. I would recommend it to carers too. I couldn't express how I was feeling to my mum, so I told her to go on the forum. She read the messages from stroke survivors and carers and that helped her to understand what I was going through."

Claire also used My Stroke Guide to access the information and advice to help her understand more about the effects of stroke. "I enjoyed the videos particularly, because they gave me an overview of the facts. For example, when I was extremely tired for no reason, I searched My Stroke Guide and found a video that explained that it was completely natural. This has helped me to move forwards. Now, when I have a blip in my recovery I don't get depressed about it. I know it's just a blip and that I'll carry on and I'll improve."



Claire now supports other stroke survivors and carers in her role as a Community Stroke Support Assistant. "My Stroke Guide has been a massive help to me as a coordinator too. I've gone out to help people to register and show them how it works, and you can already see the reassurance on their face that it's there for them. Having access to the information and videos gives them confidence and the forum allows them to talk to other people who're going through similar struggles, helping them to feel less isolated."

#### Log on to mystrokeguide.com today!

If you don't feel confident with technology or need help getting started, call our dedicated Enquiry Line on **0300 222 5707**. Lines are open Monday to Friday, 9am - 1pm.







**Drink** more with **Droplet**®

REMINDS you to drink regularly

**REDUCES** dehydration **PROVIDES** dignified

**ADAPTS** to individual DESIGNED for Stroke

RRP £45 for Stroke News readers www.droplet-hydration.com Promo code STROKE10





#### Are you drinking enough?

After a stroke you might find it difficult to drink unaided; heavy cups, tremors or having difficulty swallowing can all increase your risk of suffering from the effects of dehydration. Droplet® adapts to your hydration needs, reminding you to drink regularly in a dignified way to improve your overall health, recovery and wellbeing.

#### Droplet® benefits:

- Smart base plays friendly voice and visual reminders, encouraging you to stay hydrated
- On average people drink 500ml more a day\*\*
- Easy to grip and hold mug and tumbler
- The lid controls the flow of liquid and helps prevent spills for those who have tremors or trouble swallowing.



For more information visit www.droplet-hydration.com or contact us at sales@droplet-hydration.com

\*\*The average daily increase in fluid intake compared to pre-Droplet® consumption in care homes and control groups in hospital (8 weeks, 45 patients in care homes & 5 days, 43 patients in 4 hospital wards)



#### Replace your night storage heaters with dynamic Fischer elektrostore radiators



#### Request your FREE catalogue call us 0800 103 2708

#### Wireless temperature control



- ✓ Take control of your bills
- √ 24/7 programming
- ✓ Warmth when you need it
- ✓ Independently control room temperature

#### Removing heating uncertainty



If our radiator does not heat vour room to 21°C, we will replace it free of charge - no other heating manufacturer offers this

quarantee1.



Address:



#### Request your FREE catalogue today हैं Call us **FREE** on **0800 103 2708** Quote discount code \$N3018

Address the envelope to: FREEPOST FISCHER FUTURE HEAT (No stamp or address required)

Name:_		
; ¦Phone:_		
, 1 110116 I		

Postcode:

We like to listen to our customers - for this reason the Fischer Group of companies may contact you about exciting new products we are developing and offers or deals which may be of interest to you so that you don't miss out. To learn more about the Fischer Group of companies and how we look after your data please see our updated privacy policy at www.fischerfutureheat.com/privacy-cookie-policy/

"With a two year warranty on electronic controls (thermostat and receiver). Only applies where all rooms in the property are heated, there are no more than 2 air exchanges per hour within the room & heaters are used according to manufacturer's instructions. Will not apply where a room has an open chimney/vents. "Radiators use both ingish and day rate to control temperature. "Based on the purchase of 3-4 Fischer heaters. This offer is only available at point of purchase on new orders and does not apply retrospectively to heaters previously purchased. "Customer must become a subscriber to Fischer Energy." Free Heat Offer refers to a credit to a customer's electricity bill and is credited annually for two years. Dual-rate meter customers will receive a credit to the "economy" or "night" rate. Each heater purchased from Fischer Future Heat equates to 300kWho of credited electricity and is only available via a free no obligation survey. The more heaters you purchase, the more free electricity you receive. 'Free Heat Offer' is not to be used in conjunction with any other Fischer Energy discount or offer. Standard Fischer Energy Terms &

# App-solutely fabulous

Modern technology is a wonderful thing. If you have a tablet or smart phone there are now lots of apps (computer programmes designed for mobile devices) that can aid you with daily life and recovery after a stroke.

Here are a few recommendations to get you started:



• SmallTalk Oral Motor
Exercises – contains videos
showing exercises to help you to
strengthen the mouth, tongue,
and lip muscles that aid speech.
This is part of a series of apps
for people with communication
difficulties to help you practise
common speech activities.

**Price:** free

SmallTalk Aphasia – provides pictures and videos that talk in a natural human voice to support you with everyday communication.

Price: free



Development – activities and exercises to help you to re-build strength, control and coordination in your hands and fingers.

**Price:** IOS: £4.99; Android £8.99.





Lumosity – designed to help keep you to keep mentally active, with problem-solving games and brain training exercises to challenge cognitive skills such as memory and attention.

**Price:** free

Cozi Family Organiser – enables you to create and keep calendars, shopping lists and 'things to do' lists all in one place and share them with family members and carers. This can help you to keep track of your appointments. You can also set reminders.

Price: free

#### **⊙** Change4Life Smart Recipes –

has over 160 easy, calorie-counted recipes for breakfast, lunch and dinner, as well as desserts and snacks. It can also help you to plan meals and create a shopping list.

**Price:** free

All of these apps can be purchased from the iTunes App Store or Google Play. You can find more app recommendations on my-therappy.co.uk and mystrokeguide.com.

### Aphasia cafés build confidence

"After my stroke, I would sit down on my sofa and cry, looking out of the window and thinking - 'what do I do now?'"

Like many stroke survivors,
Heidi Matthews from Abergavenny
felt lost after her stroke at 47,
until she was invited to attend
the Phoenix Project by her stroke
support coordinator. The project
offers aphasia café meetings
to support Monmouthshire
survivors with communication
challenges after stroke. They use
a host of therapy apps to support
verbal communication, group
conversation, writing, spelling,
reading and comprehension.

"I was so nervous about going," said Heidi. "I was scared of going on the bus for the first time by myself and meeting new people. But I quickly realised what a positive experience it would be.

I learned to speak better, to improve my communication skills – it was amazing."

The first six weekly sessions are held in private in a small group, before moving on to meetings at a local café.

"To make an order is a big deal when you have aphasia," said Heidi. "There are lots of thumbs up and gesturing. But the people who run the café are lovely and patient."

Participants can take part in creative workshops using art therapy and singing to aid communication. The project also has monthly support meetings



for younger, working age stroke survivors to get together and discuss their experiences of work, driving, volunteering or finding new hobbies, and is not restricted to those with aphasia.

After she completed the sessions, Heidi was asked to be a volunteer, offering her support and experience to others.

"It's been brilliant and given meaning to my life," she added. "It's so rewarding to see how people begin to feel less isolated and improve their communication skills, just as I did.

"We do go and meet people at home before they start – many say they would never have come if we hadn't done that. I'm also part of an aphasia café for people who've finished the sessions too as we've all become friends. Phoenix is like a stepping stone to getting back into life."

For more information, contact chrissie.evans@stroke.org.uk, or visit stroke.org.uk/phoenix.

89

You can find communication advice and support groups on mystrokeguide.com.



### **GET A GRIP!**

Get the Saebo Glove & Saebo Aviva Stim combined at a reduced rate.

No Plateau in Sight

Available on a 14 day Money Back Guarantee Contact ukinfo@saebo.com for more information



Leaders in Stroke Rehabilitation

Call 01707 323 633 Email ukinfo@saebo.com or visit www.saebo.com for more information



#### **Feature**

Aphasia Voices

Aphasia Voices is our UK-wide consultation group for stroke survivors with aphasia, a communication disorder which affects around a third of people after stroke.

The group, supported by carers and volunteers, help us to design and improve the support that we offer to people with aphasia and other communication difficulties.

At their meetings they:

- discuss ways to help others to understand aphasia
- develop aphasia-friendly information, training courses and communication tools
- share the things that work well in clubs and groups.

Aphasia Voices members meet through workshops but we are also keen to encourage anyone who wishes to get involved – via email or phone, Skype or face-to-face where we can. "It's great to see people gaining confidence by coming along," said the group's leader, Janet Rockliffe. "If you would like to share your views on aphasia-friendly resources and the way we campaign about aphasia matters, then this is the group for you."



If you have aphasia and would like to join us, please email aphasiavoices@stroke.org.uk or call Melanie on 0207 566 1516.

# Why I'm campaigning for change



Campaigner Julie Payton shares her experiences of campaigning locally for A New Era for Stroke.

#### Why did you first get involved with campaigning?

When my husband had a stroke in 2013, they said he wouldn't work again. We got support from the Warrington Stroke Association which made a huge difference to us. That's why we both now volunteer for the Stroke Association, and why I wanted to get more involved with campaigning. I felt it was important for stroke survivors and carers to have a voice and to be included in the decisions about the new stroke strategy for England.

We were invited to a meeting to discuss starting a local campaign group and there was a group of us who wanted to take it forward. It was all very new to us, so we got advice from the Stroke Association, but mainly drove the campaigning ourselves.

#### What activities have your group organised?

During the 2017 general election, we invited the three MPs standing in our constituency, Warrington South, to a meeting to discuss the stroke strategy, which was due to expire in December 2017, but unfortunately had to cancel the event as it was the same day as the Manchester bombings.

After the election, we invited our new MP, Mr Faisal Rashid again. He came to the meeting and listened to stroke survivors and carers' experiences. He took it all on board, and did everything he said he was going to do. This included writing a letter to Jeremy Hunt within two weeks of our meeting, asking what he was going to do



about the stroke plan. A local newspaper was there taking pictures too, and put a small piece in the paper and online.

"We need to start
more conversations
about stroke locally
and nationally."

#### Q

#### Why is campaigning important?

We need to start more conversations about stroke locally and nationally. I didn't really know about stroke until it happened to my husband. Taking the time to tell people why it's important to get their blood pressure checked, or making sure they know the FAST test makes such a difference.

"We need it to help stroke survivors to get better support and care so we need to get the word out."

It's incredibly important that the new national plan for stroke in England is implemented. We need it to help stroke survivors to get better support and care, so we need to get the word out.

### What advice would you give to others who want to get involved?

Talk to the Stroke Association. They can put you in touch with local groups or help you to set up a campaign group. If we don't speak up, no one will.

For regular campaign updates and to find out how you can get involved, join our Campaigns Network: stroke.org.uk/campaigners.

### Getting up safely after a fall

Bex Townley, Exercise Specialist and Director of Later Life Training, shares her advice for getting up from the floor safely.

It can happen in a moment: one quick turn, an uneven surface or an unsuspecting cat, and you find yourself on the floor! Balance problems after a stroke can also increase the risk of having a fall. Knowing how to get up from the floor can increase your confidence and help you to feel less concerned about what happens if you do take a tumble.

Stroke affects people in lots of different ways, so get advice from a physio or occupational therapist for a method more tailored to your needs. However, there are some basic steps you can use as a starting point. These steps can also be helpful for family, friends and carers if they need to talk someone through getting up off the floor.

If you fall, try not to panic. Breathe deeply to help you to relax if you are shaken up or in shock. If you think you may be hurt, call for help and don't attempt to get up.

Roll onto your weaker side, or the side most affected by your stroke.



Use your stronger arm to push yourself up into a sitting position.



Move along on your bottom to a sturdy piece of furniture that you can use to help you up, such as a chair or bed.



Position yourself sitting sideways with your stronger side closest to the furniture.



#### Guidance



Use your stronger arm to position yourself so you are kneeling with both knees on the floor. Put your arms on the furniture to support you as you kneel up.





Lean your weight over your arms. Step your strongest leg forward so your foot is flat on the floor. Then push your hip up onto the furniture. Sit down and rest.



#### How to work towards this skill:

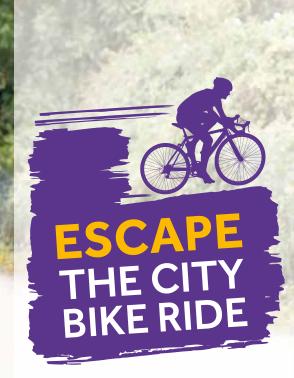
- If you know you can already rise from the floor without concern, keep practising on a regular basis; it's not a skill you want to lose!
- If you're not sure about your ability to rise from the floor you can try to improve your mobility with simple shoulder, trunk and hip exercises. Think about how you transfer, roll and get out of bed – these are similar movements.

For more information, visit laterlifetraining.co.uk/ llt-home-exercise-booklets.

Visit **stroke.org.uk/balance** to read our *Balance problems after stroke* guide.



Find tips and advice on how to avoid falls on **mystrokeguide.com**.



Sunday 30 September 2018 King's House Sports Ground, Chiswick, W4 2SH

Choose your distance 30-mile, 60-mile or 80-mile

escapethecity@stroke.org.uk 0300 330 0740 #escapethecity

Enter online: stroke.org.uk/Escapethecity

Together we can conquer stroke

© Stroke Association 2018

The Stroke Association is registered as a charity in England and Wales (No 211015) and in Scotland (SC0377)





### medimotion

GET MOVING EVERYDAY...





Parkinson's



Children's



**Bed Model** 









Wide range of arm and leg adaptations

tel: 01559 384097

#### www.medicotech.co.uk

ADVANCED TECHNOLOGY TO KEEP YOU ON THE MOVE



Choose the right exercise bike to suit both your needs and budget from our range of THERA-Trainers





Regular exercise at home is encouraged to help maintain and improve muscle tone, improve circulation and flexibility, decrease fluid retention and increase stamina levels - all vital for anyone with limited mobility

**EDICOTECH** 







Attachments for weak hands

FOR A FREE NO-OBLIGATION **DEMONSTRATION IN YOUR OWN HOME** OR REQUEST A BROCHURE CALL US ON 01908 - 564100

Email us at: info@medicotech.co.uk







## Caring for a stroke survivor

Stroke never just affects one person. It has a far reaching impact on families, friends and loved ones as well. A carer is anyone who gives support to someone who couldn't manage otherwise.



Doug Youngson from our Stroke Helpline answers some commonly asked questions.

#### I'm thinking of becoming a carer for my parent. What should I consider?

Think about your emotional and practical needs. Many carers tell us that caring is exhausting. It might also change your relationships with your loved ones.

If the person you care for needs special equipment, ask the hospital or local council who will provide this and when. You may need training in moving and handling, so that you don't injure yourself. Try keeping a diary. You may find this helps you identify where you need extra help.



#### lam a carer. What support is there for me?

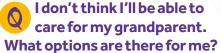
The first step is to get a carers' assessment from the local council where the person you care for lives. In England and Wales you can get an assessment whether you care full time, occasionally or will do in the future (ask your local council if you live in Scotland or Northern Ireland).

Generally, if your caring role is likely to have a significant impact on your wellbeing, you will be eligible for support. Most councils don't charge for carers' services, although some do. Support might include help with transport costs, help with



#### Call our Stroke Helpline on 0303 3033 100.

housework or a respite break for you and the person you care for.



Sometimes family members can't provide care. Perhaps you live far away or have other commitments, such as work or children. Perhaps caring is just not for you. It's not selfish to be realistic about how much you can do. The local council can put together a package of support which takes into account your loved one's needs. This could include equipment, such as grab rails or a personal alarm, or carers to come in and help throughout the day. If someone needs a lot of support the local council may suggest



Contact our helpline for more information about carers' services or visit stroke.org.uk/carers.



residential care.

On You can also find lots of advice for family and friends, as well as carer support forums on mystrokequide.com.

# Going from strength to strength

Last summer, we expanded our trained Stroke Helpline team. We also opened for longer on Tuesdays and Wednesdays and began opening on Saturday mornings.

This has proved to be a big success, enabling us to respond to more enquiries and help more people with the challenges of living with stroke.

Stroke can leave survivors and their families suddenly stranded. The Stroke Helpline was a lifeline for Rhodri when his dad had a TIA, then his mum had a stroke. "The helpline was there when I was panicking and needed someone to talk to," said Rhodri.

"Stroke changes everything so fast. Being able to speak to someone on the helpline who can talk you through it and help you to find support and information is reassuring at a time when so much is uncertain."

We'll be increasing our helpline team again this year so we can answer even more of your enquiries. We know there are

over 1.2 million stroke survivors in the UK and everyone's stroke is different. People often have questions long after a stroke has happened. If you have questions or, like Rhodri, need someone to talk to, you can call **0303 3033 100** or email helpline@stroke.org.uk



Our opening times are:

Monday, Thursday, Friday - 9am-5pm

Tuesday, Wednesday -8am-6pm

Saturday - 10am-1pm.

You can also send us enquiries by Facebook and Twitter.

### Stroke Helpline facts

18,000

Last year our helpline answered over 18,000 enquiries for help, support and advice.

#### How do people get in touch?











Phone

**Email** 

Facebook

**Twitter** 

and other channels

#### Who gets in touch?



Family members / family carers



Stroke

survivors



Stroke Association supporters



**Professionals** 

#### What do people contact us about?



26%

Life after stroke



Association

Stroke or the Stroke

Therapy and recovery



10% **Physical** 



effects

Health and social care

# Friends, not

When Trudy had her stroke in November 2014 she thought that would be the end of life as she knew it. Affecting her mobility and communication, and worsening her arthritis, she was forced to give up a job she loved.

"I remember sitting in a chair with a blanket over my knees thinking my life was over," said Trudy.

After attending her local communication support group, Trudy and a friend were inspired to help others. Together, they set up the Mackem Life After Stroke Group in 2016. That same year, Trudy attended the UK Stroke Club Conference for the first time to learn about running a group, meet other people and get ideas for her new group.

"Setting up the group is the best thing I've ever done and has given me a purpose. Without them, I wouldn't be here today. "It's great to watch people get better and see them get the help they need. They come in, feeling helpless like I was, and six months or a year down the line they're feeling so much better.

"We meet every two weeks and have speakers, sports activities, fundraising events, and quizzes - we get very competitive. We also go out for meals as a group. We are all friends, not just members."

A long-term stroke support club or group can offer lots to its members including friendship, shared experiences of stroke and confidence.

# usimembers











Do you volunteer at a stroke club or group? Why not join other group representatives and share your ideas and tips at the UK Stroke Club Conference 2018 on Friday 28 - Saturday 29 September at the East Midlands Conference Centre in Nottingham.

Invitations will be sent to the main club or group contact in July. Places are limited so hold the date and make sure you book your place by the end of August. Visit stroke.org.uk/ukscc18.



There are hundreds of stroke groups across the UK, run by volunteers like Trudy. To find your local group visit **stroke.org.uk/groups** or call **0303 3033 100**.



You can also find groups and talk to other stroke survivors around the UK via the online forum on **mystrokeguide.com**.

# Research is key

Every year, the Stroke Association hosts a Keynote Lecture in London, to bring together experts from all areas of stroke research and to showcase the latest advancements being made.

This year, the lecture was given by Professor Marion Walker MBE, Professor of Stroke Rehabilitation at the University of Nottingham.

In her talk on 'Living life well: Rehabilitation matters', Professor Walker spoke about the importance of rehabilitation in restoring quality of life, for both stroke survivors and those close to them. She also highlighted the importance of investing in stroke rehabilitation research.

"Research funding from the Stroke Association has provided a lifeline of support for researchers like me," said Professor Walker. "In recent years, we have seen dramatic improvements in stroke care and more people than ever are surviving a stroke. However, the importance of continuing vital rehabilitation therapy once a patient has been discharged from hospital is still not being recognised and as a result many stroke survivors are missing out on their best chance of recovery.

"We have robust evidence that shows stroke rehabilitation therapy can help people to regain the skills of daily life. Stroke is a recovering condition, so rehabilitation is absolutely worth investing in."

After the Keynote Lecture, we presented our latest Priority Programme Awards. These awards fund areas of stroke research where there are still significant gaps in our knowledge, or where progress is limited:



Watch Professor Walker's
Keynote Lecture on
stroke.org.uk/keynote18, or
visit stroke.org.uk/projects
to find out more about all our
current research projects.

- Professor Rustam Al-Shahi
   Salman's research investigates
   the swelling that occurs around
   a bleed on the brain. One aim
   is to understand the effect of
   blood on brain cells in order
   to find treatments.
- Professor Colin Smith's
   project is jointly funded with the
   Medical Research Council. His
   aim is to build a human brain
   bank to help researchers to
   better study how and why small
   vessel disease, a key cause
   of both stroke and dementia,
   damages the human brain.

We also presented two lectureship awards. Our lectureship

- programme is helping to build the next generation of stroke research leaders:
- Dr Emily Sena's work looks at increasing the reliability of laboratory stroke research, so researchers can design more effective human clinical trials with a higher chance of success.
- Dr Grant Mair's research aims to better understand how CT scans, which provide images of the brain, can be used to improve treatment for people who have ischaemic strokes, and if they can also be used to accurately estimate the time since the stroke began.

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

Support for the supporter

When a stroke left Middlesbrough FC supporter John Quinn with life-changing mobility difficulties, he was determined to get back to normality however he could.

"I had a haemorrhagic stroke (a brain bleed) during a back operation in October 2016," recalled John. "I was 60 at the time." The stroke affected all his limbs, particularly his left side, making him reliant on a wheelchair.

When he first left hospital, John had to go to a care home as he needed a hoist to transfer in and out of his wheelchair. But this just made him all the more motivated to get home to his wife as quickly as possible. He worked hard in his therapy and with the help of his early supported discharge team and a comprehensive care plan, he soon achieved his goal.

Stroke Association Coordinator Marie visited John regularly to provide advice, reassurance and information on stroke, including our Life After Stroke Grants. These are one-off payments of up to £300 to help those who need some extra financial assistance after stroke to afford equipment or opportunities to support their recovery.

"I've been a Middlesbrough supporter for years, most of my life," said John. "Before my stroke, I used to go to their matches as often as I could. I missed going to the games, so I asked Marie about the possibility of getting a grant for a 2016-17 season ticket."

Marie said: "Season tickets are expensive and John has additional costs associated with his situation, so I helped him to apply for an activity grant to put towards the cost. We were even able to make sure that John would not be sat near the drums in the stadium and was in the appropriate place for his electric wheelchair."



Being able to go to Middlesbrough's matches again really helped John's wellbeing and confidence, giving him an opportunity to get out of the house, spend time with his son who took him to the games, and make new friends.

"It felt good to watch the games from the terraces again," said John. "It was nice to meet other supporters, and I enjoyed seeing the footballers and supporting my team. It's easy for me to attend the matches in my wheelchair and I've found the stadium is wheelchair-friendly. My son and I sit in the lower block, which is great - unless it's raining and the wind blows it into your face!



For more information, visit stroke.org.uk/grantshelp, email Grants.External@ stroke.org.uk or call our helpline on 0303 3033 100. (Please note that our grants are for goods and support—we're unable to offer cash grants.)

# Walking in a winter wonderland

Congratulations to our 2018 Christmas card competition winner, Steven Ferrari for his beautiful *Snowy Winter Walk* design.



Steven was 45 when he had a stroke at work in 2015. He could no longer use his right hand and had restricted movement in his right leg as well as severe communication difficulties.

Unable to say many words, Steven found socialising very difficult. On the recommendation of his Stroke Association coordinator, he joined his local Brush Strokes art therapy group to help with his recovery.

A number of our Stroke Association groups across the UK offer creative art therapy sessions to help people learn or re-learn to paint and draw following a stroke. Art therapy groups give stroke survivors the opportunity to find new ways to express themselves, re-build their confidence and feel less isolated, improving self-esteem, well-being and happiness.

Steven now attends Brush Strokes on a regular basis and enjoys learning new art techniques. He is able to paint and draw at his own pace, which he finds very relaxing, and gives him a great sense of achievement. Steven also attends the West Kent Stroke Group regularly where he enjoys socialising and exercise sessions with other stroke survivors.

It was while he was at Brush
Strokes art group that he
learned of our Christmas card
competition and started working
on his winning design, a beautiful
watercolour that perfectly
captures the feeling of walking
through fresh white snow on a
tranquil winter morning.



Steven's father Michael said:
"Winning the competition means
a lot to Steven, knowing that his
design will be used to raise money
for the Stroke Association. Being
part of the art group has helped
him to regain the confidence
to try art again, something he
used to very much enjoy before
his stroke."

Steven's Snowy Winter Walk design can be ordered from our Christmas shop, along with our lovely range of cards and gifts. Visit stroke.org.uk/christmas or call 01233 214 320 to order.

For details on how to enter the 2019 Christmas card competition, visit stroke.org.uk/cardcomp19 or email cardcompetition@stroke.org.uk.

# All Clears air travel tips

Medical costs abroad can be expensive so make sure you have comprehensive travel insurance to give you peace of mind.

To get a quote or purchase specialist medical travel insurance with AllClear 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. For details see stroke.org.uk/allclear.

We work with AllClear to offer stroke survivors, family and friends specialist medical travel insurance. Here are their tips to make you feel more confident and comfortable when travelling by air.

Being inactive for a period of time on a long flight can make you more likely to develop deep vein thrombosis (DVT). DVT is a blood clot in a vein, often in the leg. You can reduce your risk by:

- wearing compression socks to improve blood circulation
- booking an aisle seat to enable you to stretch out your legs
- exercising by walking around and/or stretching while seated
- drinking lots of water, and avoiding alcohol, to prevent dehydration.

The Stroke Association is an Introducer Appointed Representative of All Clear Insurance Services Limited, All Clear Insurance Services Limited, registered in England No. 4255112. Registered Office: All Clear House, 1 Redwing Court, Ashton Road, Romford, RM3 8QQ. Authorised and regulated by the Financial Conduct Authority firm reference number 311244. All Clear is a registered trademark.



## Money matters

The availability of NHS rehabilitation therapies such as physiotherapy, occupational therapy and speech and language therapy can vary a great deal across the UK. As a result, many stroke survivors find themselves wondering whether private therapy is the answer. There are costs associated with 'going private', so it's important to weigh up the options carefully.

#### Talk to your GP

A sensible first step is to speak to your GP. While they can't advertise private practitioners, they will talk you through which therapies may benefit you. They can also explore the availability of NHS services in your area, so you can make an informed decision.

#### **Financial considerations**

Paying a private therapist can be a big financial commitment for many people - a significant number of stroke survivors rely on welfare benefits or the state pension as their main source of income.

This usually means that there's very little left over after shopping, bills and other costs are covered.

If you decide that you need private treatment, but would struggle to afford it, the following tips may be helpful:

Check that you are receiving all of the income you are entitled to – billions of pounds of welfare benefits, tax credits and pension credits go unclaimed every year. Online benefits calculators such as entitledto.co.uk and turn2us.org.uk, can help you to work out what you can claim.



If you prefer to see or speak to someone, Citizens Advice can help. You can search for your local bureau on citizensadvice. org.uk. National charity Turn2Us also offer financial advice and support. You can call their helpline on 0808 802 2000.

• In some cases, you may be able to get financial help towards the cost of treatment from a charitable grant or trust fund. The criteria to qualify for funding can vary greatly. For example, there may be trust funds related to a particular job or industry, or area of the country. Turn2Us can help you to search for charitable support via their online grant search or helpline. You can also search for disability grants on disability-grants.org.

For more advice, contact our Stroke Helpline on 0303 3033 100 or info@stroke.org.uk. You can also read our *Private treatment* guide on stroke.org.uk/privatetreatment.



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

#### Word search

E F S S H A S NUKOYDRN GQCVEFE PIIRUOT DCAVPRW RMECLPVUO YLWNMMR GUIDERAK FRIENDSC

**FRIENDS INFORM** CAMPAIGN **FORUM NETWORK CARERS GUIDE** SOCIAL **ADVICE AWARENESS** 

#### **Across**

- 7 Pureed vegetable (6,6)
- 9 Eight-armed mollusc (7)
- **10** Conifer (5)
- 11 Engrave (metal/glass) (4)
- 12 Very heavy defeat (8)
- 15 Excessive amount (8)
- 17 Hindu queen (4)
- 19 Simile, metaphor (5)
- 21 Main railway stations (7)
- 22 Periodic visitor to Earth's skies (7.5)

#### Lottery

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











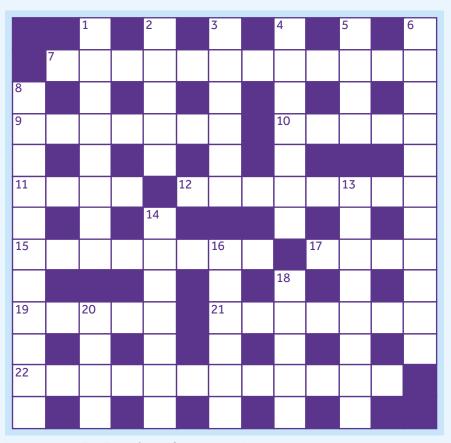


Solutions See page 50

#### Down

- 1 Minute piece of matter (8)
- Gambling counters (5)
- Ukrainian Black Sea port (6)
- Using few words (7)
- Worker; pointer (4)
- The middle class (11)
- Be revealed (4.2.5)

- 13 Woodwindinstrument (8)
- **14** Changed (7)
- 16 Declare (that something is the case) (6)
- **18** Mistake (5)
- 20 One co-operating with another (4)



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

### Getajab, notflu

**Our partners Well Pharmacy offer** their expert guidance on why it's important to get a flu jab:

- Flu occurs every winter. The most common symptoms are fever, chills. headache, aches and pains in the joints and muscles, and extreme tiredness.
- If you've had a stroke. getting the flu can put you at an increased risk of developing more serious illnesses which could result in a stay in hospital. This is because your heart has to work much harder to combat the flu virus and is under increased stress.
- The flu jab provides the best protection available against the flu virus. If you are a carer, family member or friend of a stroke survivor, it is also important for you to have the jab too, so that you avoid catching and spreading flu.



Get your flu jab this winter at Well Pharmacy, no appointment necessary. To find the one nearest you, visit finder.well.co.uk.

#### Classifieds

Please contact Gemma Davies at gemma.davies@redactive.co.uk or call 020 7880 7668 to book

Sea - Sun - Sand Pembrokeshire

#### **Homeleigh Country Cottages**

Very close to all beaches



Offer a warm welcome to guests who need a little help to make their holiday perfect. We are a wheelchair friendly complex with careful planning for ease of access. Situated in the peaceful Pembrokeshire countryside yet only a few minutes drive to Pendine, Amroth, Saundersfoot, Tenby and much more.



Tel: 01834 831765





01726 883240 / 07762 173860 www.treworgans.co.uk

Treworgans

Two specially converted and detached

cottages - both level access with wheel in

shower. We can provide free use of

electric profiling beds, air mattresses,

hoists, shower chairs, riser recliner chairs

plus a wide range of extra equipment to

make your stay easier and more

comfortable. Care is available locally. We

are only 15 mins from Truro and 30 mins

from the Eden Project, making Treworgans

the ideal place to explore the beautiful

county of Cornwall.





**Quality Used** Wheelchair Accessible Vehicles Supplied Throughout The UK



View our large range of vehicles www.mobilitynationwide.co.uk

#### Holiday cottage Peak District

www.croftbungalow.co.uk 01629 650979



Fully adapted wheelchair friendly. Level access. Country views, private level garden great location. Electric profile bed, riserrecliner chair, free wifi, freesat tv. 100m to food pub. 10mins to Bakewell/Chatsworth enquiries@croftbungalow.co.uk

### 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







Thank you to everyone who walked, ran, volunteered at or came to support our Resolution Runs around the UK this spring. A whopping 11,000 of you challenged yourselves to take on our 5, 10 and 15km routes and together you have so far raised an incredible £628,000.



Jim Clark was inspired to raise funds and awareness for us in memory of his brother-in-law. He and his colleagues at the Babcock site in Rosyth raised £1,162 by taking part in our Glasgow Resolution Run and fundraising at work.



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

How does your donation help?



£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.



Well done to Sharon McIntosh from Hamilton who challenged herself to run 100km in February and raised over £1,000.

### Volunteer spotlight

Kim started volunteering about three years ago for 4ward Strokes. Leicester.

For the past year she has also been a My Stroke Guide (MSG) Buddy and helps people log in and navigate around the system.

Kim says: "I really enjoy helping people use My Stroke Guide. The films are really popular with the group. For some people, who may have lost a lot of confidence after their stroke, being able to talk and share using My Stroke Guide, is sometimes easier than having to do that in person."



48 Stroke News Summer 2018

### Dates for your diary

#### Christmas shop opens 10 August - 19 December

Buy Christmas cards, including the design by Steven, our competition winner (page 38) from stroke.org.uk/Christmas18.

#### Escape the City 30 September

Cycle our 30, 60 or 80 mile routes. Visit **stroke.org.uk/escape** to book.

#### Great South Run 2018 21 October

Join #TeamStroke for the UK's leading 10-mile flat course running event through Portsmouth. Sign up on stroke.org.uk/greatsouthrun18.



#### Supercar Saturday 27 October

Join us for an adrenaline-fuelled day of fast-speed car rides around Castle Combe race track: stroke.org.uk/supercar18.

#### World Stroke Day 29 October

Get involved in Give a Hand and Bake to raise awareness of stroke and funds to support those it affects: **stroke.org.uk/GAH18.** 



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

#### Crossword

Across: 7 MASHED POTATO, 9 OCTOPUS, 10 CEDAR, 11 ETCH, 12 MASSACRE, 15 OVERLOAD, 17 RANI, 19 IMAGE, 21 TERMINI, 22 HALLEYS COMET

**Down:** 1 PARTICLE, 2 CHIPS, 3 ODESSA, 4 CONCISE, 5 HAND, 6 BOURGEOISIE, 8 COME TO LIGHT, 13 CLARINET, 14 ALTERED, 16 ATTEST, 18 ERROR, 20 ALLY

S	1	Ε	F	S	S	Н	Â	S
S	N	U	Κ	0	Υ	D	R	N
Ε	F	G	Q	C	٧	Ε	F	Ε
Ν	0	Р	1	1	R	U	0	Т
Ε	R	D	C	A	٧	Р	R	W
R	M	E	C	L	P	٧	U	0
Α	В	Υ	Ĺ	W	N	М	М	R
W	G	U	1	D	Ε	R	Α	K
Α	F	R	ı	Ε	Ν	D	S	C

### ENJOY

#### WHAT REALLY MATTERS



Expertly prepared for people with swallowing difficulties, our delicious frozen Softer Foods range delivers safe, easy to prepare, nutritious meals nationwide, direct to your door. Just one part of our range of over 300 delicious dishes.



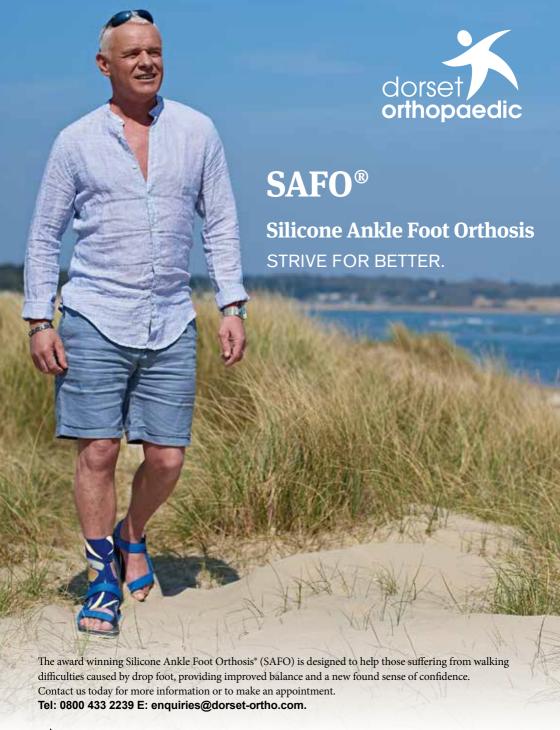
To request a brochure or place an order, visit wiltshirefarmfoods.com or call 0800 524 4987

**85 DELICIOUS DISHES** 

PROUD SUPPLIERS TO THE NHS

**FREE FRIENDLY DELIVERY** 

WILTSHIRE
EST. FARM 1991
FOODS



Nationwide Clinics

Partner of Clinical Services Network

ottobock.