

## Making a fresh start

Rosemary and John Parr tell us about the difference it made to their health and happiness

Stroke  
News  
is free!

### Healthy eating

Reducing stroke risk with diet changes

### In brief

Communication problems after stroke

### Money matters

Tips to help ease money worries

# Contents



## 14 Some simple diet changes we can all try



## 16 Why Patrick Daniels is helping others affected by stroke

Editor **Alex Bolton**  
Design **Rick Nicholls**

To subscribe to *Stroke News* or change your contact details, call **01604 687 721** or email **strokenews@stroke.org.uk**

*Stroke News* is published by the **Stroke Association**  
**Stroke Association House**  
**240 City Road**  
**London EC1V 2PR**

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

To advertise in *Stroke News*, call Redactive Media Group on 020 7880 6200.

Volume 32.1 Spring 2014

© Stroke Association 2014

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.

## Regulars

### 03 Volunteer spotlight

Meet Naunihal Punni

### 04 Over to you

We share your experiences

### 05 News

Catch up on the latest news about stroke

### 14 Supporting you

Six simple steps to improve your diet

### 18 Research

Support for vision problems

### 22 Money matters

Easing financial worries

### 24 Thank you!

A big thank you for your support

## Features

### 08 On the cover

The benefits of making simple lifestyle changes

### 11 Two of us

Stroke survivor Vickie Bulman and coordinator Jenny King share their story

### 16 Giving back

Patrick Daniels on helping others affected by stroke

### 19 In brief

A look at communication problems after stroke

### 26 Campaigning

Tackling the issues that matter to people affected by stroke

To receive your free copy of *Stroke News*, sign up at **stroke.org.uk/strokenews/subscribe** or call **01604 687 721**.



An audio version of this edition is also available at **stroke.org.uk/strokenews**



# Welcome...

After all the wind and rain this winter finally we've seen some spring sunshine! And what better way to welcome a new season than by making a fresh start?

Our cover story is about the positive impact that small lifestyle changes can make to reduce stroke and secondary stroke risk. We hear the difference that simple changes made to Rosemary

and John Parr's health and happiness. On page 14 we've got some diet changes we can all try.

We've also packed in the usual guidance articles and inspirational stories. Turn to page 11 to find out how Vickie Bulman's life was turned upside down by a stroke. With the support of our coordinator Jenny King, she's determined to bounce back.

Then there's Patrick Daniels, who, following an out of the blue stroke, is now volunteering for us. He wants to give something back to the service that helped him adjust to life after stroke. Find out more on page 16.

I hope you draw inspiration from the stories in this issue and have my fingers crossed for a sunny spring!

**Alex Bolton**  
**Editor**

## Volunteer spotlight

### Naunihal Punni

Someone has a stroke every three and a half minutes in the UK, but worryingly 31% of people don't know what a stroke is.

Making sure as many people as possible understand the causes, signs and impacts of stroke is a challenge – and one we can't achieve on our own.



Our volunteer Stroke Ambassadors play a vital in helping us meet that challenge. In Nottingham, Naunihal Punni is raising awareness by delivering talks in his local community.

Naunihal was a busy IT consultant until he had a stroke six years ago at the age of only 42.

"I didn't know anything about stroke and mistakenly thought it only affected older people," he recalls.

"After my stroke my memory was affected so I couldn't return to work. All the things I had worked so hard to achieve – a good job and financial stability – seemed to be slipping away.

"Volunteering for the Stroke Association has helped me refocus and made me feel better

about myself. I've learnt so much about stroke, the risk factors and how we can all make small changes to our lifestyles to minimise those risks.

"As an ambassador, I visit local community groups to provide key information about what the risks and signs are and tell people about my own experience. I hope to ensure other people are more knowledgeable about stroke than I was before mine."

4,200 volunteers help us take action on stroke. We couldn't do what we do without you!

To join our network of around 200 Stroke Ambassadors or volunteer for us in other ways visit [stroke.org.uk/involved/volunteer](http://stroke.org.uk/involved/volunteer)

# Over to you



We love hearing from you. Join the Stroke Association community and share your experience. You may help inspire others affected by stroke.

## The power of speech

I was totally ignorant about stroke and the consequences until my Mum had a life-changing one. Aphasia with dyspraxia is deeply frustrating both for Mum and all of us around, trying to understand her. She fights on physically and more so to try to speak. I had taken for granted the power of speech and how pivotal it is in our lives. It is so important that the Stroke Association continues its work to raise awareness and improve support. Speech therapy is so vital to people with this condition, and yet the resource seems so thin.



**Kate (Facebook)**

## Stay determined

One thing that stroke can't control is our determination to build a new life.

If you are at the beginning, don't give up. Keep going and you will find something that you are able to do. Once you can go to stroke groups, go. It helps your mind to accept what has happened and also lets you know that others

felt the way that you did. The Stroke Association is fantastic and helped me cope with having a stroke at 45. Good luck to you all recovering. Every bad day that you have, go and have two good days.



**Helen Woods (Facebook)**

## Mistaken for drunk

The article in the winter magazine relating to Eleanor McCallion being mistaken as drunk certainly brings back sad memories for me.

My stroke left me with left side weakness but I was able to gain strength after about seven months. I decided to take the train to my nearest city. I had forgotten however that the stroke had left me with balance issues. Feeling a sense of achievement at having made the journey I thought I would walk to the shops only to stagger along feeling 'wobbly.' It was at this point that a gentleman shouted "I'll have a pint of whatever he is on." I was devastated and did not emerge for another three months and then only with the help of Stroke Association staff.

Fortunately after input from a psychologist, 15 months later I am able to take journeys without suffering the guilt feelings I had before about appearing drunk.



**Tom Graham (email)**



## Hot topics

### What do you think of our information?

We're looking at how we can improve the information we produce for stroke survivors, their families and carers, and we want to hear from you. To tell us what you think contact Chloe on 020 7566 0333 or [feedback@stroke.org.uk](mailto:feedback@stroke.org.uk)

Find us on Facebook ([facebook.com/TheStrokeAssociation](https://facebook.com/TheStrokeAssociation)), Twitter (@TheStrokeAssoc), email us on [strokenews@stroke.org.uk](mailto:strokenews@stroke.org.uk) or write to us at Stroke News, Stroke Association House, 240 City Road, London, EC1V 2PR. Talk to others affected by stroke on our forum TalkStroke: [stroke.org.uk/talkstroke](https://stroke.org.uk/talkstroke)

# Recognising and

## Reduce your risk of stroke

It's important to remember that stroke is preventable and we can all take steps to reduce our risk. These simple steps are things that everyone can try:



### Know your blood pressure

High blood pressure is a contributing factor in more than 50% of strokes. Get yours tested at a *Know Your Blood Pressure* event or see your GP.

### Have your pulse checked

Atrial fibrillation is the most common type of irregular heartbeat. It increases stroke risk by up to five times as it can create blood clots that lead to stroke.



### Stop smoking

You are twice as likely to have a stroke if you smoke. Smoking causes your arteries to fur up and increases your risk of a blood clot.

### Eat less salt

Eating a lot of salt can increase your blood pressure. There can be hidden salt in some processed and ready-made food, so check the labels carefully.



### Get regular exercise

Thirty minutes of moderate activity five days a week can reduce your risk of stroke by a quarter.

## Know your blood pressure

In 2013 our *Know Your Blood Pressure* campaign events gave free tests and advice to more than 40,000 people.

2014 is proving just as successful with events across the UK throughout the year. Find an event near you at [stroke.org.uk/kybp](http://stroke.org.uk/kybp)



One hundred and fifty Members of the Scottish Parliament had their blood pressure checked, including Cabinet Secretary for Health and Wellbeing Alex Neil, as part of our 2013 *Know Your Blood Pressure* campaign.

## New stroke charter in Scotland

In December the 'Charter for people living with stroke in Scotland' was launched to help stroke survivors and carers understand the support and services available to them after they leave hospital.

Find out more at [strokecharterscotland.org.uk](http://strokecharterscotland.org.uk)



# reducing stroke

## Act FAST

Did you spot the FAST adverts on television in March? We're working with Public Health England to make sure as many people as possible know to act FAST to save a life.

- F** **Facial weakness** – Can the person smile? Has their mouth or eye drooped?
- A** **Arm weakness** – Can the person raise both arms and keep them there?
- S** **Speech problems** – Can the person speak clearly and understand what you say?
- T** **Time** – If you see any one of these signs, it's time to call 999. Stroke is always a medical emergency.



### Did you know?

**19,000:** the number of enquiries made to our Stroke Helpline last year (via phone, email and Facebook).

**98,000:** the number of minutes our Helpline Information Officers spent supporting people affected by stroke last year.

**10:** the number of staff in our helpline team.

We're here for everyone affected by stroke. If you are a carer, family member or stroke survivor and need advice, call our helpline confidentially on **0303 3033 100** or visit [stroke.org.uk/support/helpline](http://stroke.org.uk/support/helpline)

### We hear success stories every day.

Our helpline worker, Tamara Eaton, took a call from a lady who rang to thank us for promoting the FAST test, which she believes saved her son's life.

"When her son had a stroke, her grandson immediately recognised the FAST symptoms, having seen them on TV. He knew to dial 999 straightaway and as a result his dad was in hospital within 20 minutes. The right hand side of his body was affected and he has some communication difficulties, but the effects of the stroke could have been far worse.

"The situation was even more poignant as the caller explained her grandson's mother had died 18 months earlier after fighting cancer. It is wonderful that something as simple as the FAST test can, and does, save lives," says Tamara.



# Action on Stroke Month is coming!

## We'll be talking about mini-stroke

We're planning lots of activities for Action on Stroke Month in May to raise awareness of mini-stroke (also known as transient ischaemic attack or TIA). Thanks to everyone who's taken part in our survey and shared their experiences of mini-stroke. Look out for the results at the beginning of May when we'll launch our report to kick off the month.

Action on Stroke Month is shaping up to be even bigger and better than ever and there are lots of opportunities to get involved and show your support for stroke survivors. Everyone can do their bit – whether it's wearing our Stroke Solidarity String, taking part in an event such as *Step out for Stroke* or offering to be a media volunteer to share your own experience.

Many thanks to Legal & General, sponsors of Action on Stroke Month.



It's not too late to get involved. To see what activities are in the pipeline, visit [stroke.org.uk/strokemonth](http://stroke.org.uk/strokemonth) or get in touch with us at [strokemonth@stroke.org.uk](mailto:strokemonth@stroke.org.uk) or call 020 7556 1500.

## Dates for your diary



**Volunteers' Week,  
1–7 June 2014**

In June we're celebrating and recognising the impact that volunteers have on our work. Whether you want to say thank you to a volunteer who has supported you, share what volunteering means to you or reflect on your own volunteering experience email us at [volunteering@stroke.org.uk](mailto:volunteering@stroke.org.uk)

**The UK Stroke Assembly,  
16–17 June 2014**

This is your chance to meet other stroke survivors, family members, carers and stroke professionals to talk about the issues that matter to you and learn new skills whilst having some fun. Visit [www.strokeassembly.org.uk](http://www.strokeassembly.org.uk) for more information and to book your place.

**UK Stroke Club Conference,  
10–11 October 2014**

Are you involved in running a stroke club or voluntary group? If so, then join us at the UK Stroke Club Conference to share experiences and celebrate your achievements. Visit [stroke.org.uk/club-conference](http://stroke.org.uk/club-conference) to find out more.



# Making a fresh start

"I can still picture the small Stroke Association poster on the wall of the GP waiting room. I read it over and over as I sat there – 'Are you somebody who's had a stroke or a TIA?' it said. The call I made later that day would help me turn my life around."

Rosemary knew she was a bit overweight and under enormous stress trying to keep the business she and her husband John owned afloat during the recession. However, she was unaware that her lifestyle was putting her at risk of stroke and that she had a number of underlying health problems.

When Rosemary had a stroke, she didn't display common FAST symptoms. For her, it was sudden onset of double vision, and it would go on to last three months. She realises now she should have gone straight to A&E.

"I didn't realise how bad it had got until John drove me to the opticians," she remembers. "I could see two of everything! I felt so ill and didn't know what was happening."

The optician sent her to an emergency eye clinic with a suspected bleed, but without a conclusive diagnosis,

Rosemary insisted her GP ran some tests. When the tests came back she was told that she had high blood pressure, high cholesterol and an underactive thyroid, and she'd probably had a stroke. It was a shock.

"My confidence went completely, my eyesight disrupted day-to-day life and I sometimes had difficulty finding words. I was terrified it would happen again. Because I hadn't gone through the usual stroke channels I felt very isolated."

## Getting the right support

"I called the number on the poster and spoke to Carmel Austin, a Stroke Prevention Service Coordinator at the Stroke Association in Norfolk. She was the first person to address John's and my diet and weight. She signed us up to a Stroke Association healthy lifestyle programme which has helped us to turn our lives around."



"We learned about different food groups, portion sizes and how to change habits. We also set achievable targets and made things part of our everyday routines, like getting out in the fresh air and walking short distances. I used a stability ball when I was checking my emails every morning and got into the habit of standing at an adjustable table to help strengthen my core."





**“Having a stroke made me realise I needed to act. It was a wakeup call; a warning – to both me and John.”**

“We’d tried to lose weight in the past but this time we really wanted something that would stick. Having a stroke made me realise I needed to act. It was a wakeup call; a warning – to both me and John,” says Rosemary.

With determination, the help of the Stroke Association programme and a dietician, they began to manage the lifestyle factors which were

putting them at risk of stroke and secondary stroke. John lost three and a half stones and Rosemary lost two and a half stones.

“Dealing with stress was a lot harder but Carmel introduced me to Tai Chi sessions which she runs for the Stroke Association,” says Rosemary. “These are for stroke survivors but also their carers and are geared towards those that are less mobile.

It’s one form of relaxation I can actually work with.”

When a stroke happens, it’s not just the stroke survivor who is affected. When someone you love is unwell it can be very difficult but it helps to pull together and get the support you need. For John, that support was essential. Not only did he worry about Rosemary but it gave him the motivation to address his own lifestyle too. ▶



**"In some little ways there's still scope out there to do things that just make you feel a bit better."**

"I remember a lot of panic and worry and not being able to sleep. The love of my life had an incident and I felt totally helpless. It's difficult, but if you pull together anything is possible," says John.

"I would not have done half of the things I've done around healthy attitudes if Rosemary hadn't had the stroke. We've done everything together. We have our own support team between the two of us but also the external support telling you there is life after stroke helps enormously – that's where Carmel and her team helped a lot."

Pulling together, Rosemary and John have found change doesn't have to be frightening.

"We've realised change can be a lot of fun. I've started playing the guitar again and borrowed a drum set which is something I've wanted for years. Many years ago, before I knew him, John played Sweet Georgia Brown on the electric double bass. He wants to be able to do that again. Throwing rhythms around is something we've found very therapeutic and a fun way to de-stress."

Rosemary and John have gone a long way to improve their lifestyles. Not everybody is in a position to make the changes that they have, but even small changes can make a big difference to your health, happiness and outlook.

Rosemary says "There are people who have been affected by stroke more severely than me but in some little ways there's still scope out there to do things that just make you feel a bit better."

As Rosemary's experience shows, the warning signs of a stroke aren't always the same. Symptoms can include vision problems, sudden unsteadiness, pins and needles on one side of the body and severe headaches.

It's essential to be alert to the warning signs of stroke and treat them as a medical emergency.

Our new campaign briefing, *'Not just a funny turn,'* launches in May and aims to highlight the need for vigilance. The campaign is about mini-stroke (sometimes called transient ischaemic attack or TIA) which is the same as a stroke, except the symptoms get better within 24 hours.

The message of the campaign is that unexpected symptoms,

however brief, must not be ignored. They need urgent medical attention as they could be a warning sign of a full stroke in the future.

You can help us. Sign up to our Supporters' Network to help us get stroke the attention it deserves. Find out more at [stroke.org.uk/campaigns/signup](https://stroke.org.uk/campaigns/signup)

# Two of us

"I remember leaving the hospital was the worst feeling. Once the support from the early discharge team stopped, I had no support whatsoever. If it wasn't for Jenny, my Family and Carer Support Coordinator, I wouldn't have known how to go about anything. It would have been so hard."



**"If I'm really down, I can ring Jenny and she'll make me smile."**

## Vickie Bulman

Vickie's life changed completely after she had a haemorrhagic stroke at the age of just 48. "I can't walk very well. The right hand side of my face suffers from facial palsy. I can't move my left hand side well – which is difficult because I'm left handed. I now have ataxia so my left arm moves of its own accord and I have a head tremor," says Vickie.

"I have my down days. I lost my mum last year and was diagnosed with breast cancer, but you get what's thrown at you and you just have to get on with it. I can still think things – the little grey cells still work, but my body doesn't.

"My husband Paul has to do everything in the house; I can't even put clothes on. I can find it frustrating – but I'm not the sort of person who will lie down and take it. I get on with it.

"I remember the day I first met Jenny. She gave us lots of

information about stroke and what we might expect. Since then she has helped me to get a wheelchair and arranged for a shower chair to be fitted. She also got Social Services involved to get a stairlift fitted, as it's getting harder and harder to get up the stairs. Jenny helped with all the paperwork. It has made a huge difference.

"Jenny has a good sense of humour and we make each other laugh. She's always warning me about speeding tickets on my scooter and we laugh about how my friends call me Churchill the dog because of the tremor in my head.

"If I'm really down, I can ring Jenny and she'll make me smile. She is very caring and passionate about what she does. Anything she can do for you, Jenny will try and she'll be there if it's stroke related or not. More than that, it helps just knowing she's there."



## Did you know?

Our Life After Stroke Services helped more than **67,000 people** last year.

We have **350 services** helping stroke survivors, their families and carers.

We have nearly **400 coordinators**, including Family and Carer Support Coordinators, Speech and Language Therapists and Information, Advice and Support Coordinators.

To find out what support is in your area visit **[stroke.org.uk/support/search](http://stroke.org.uk/support/search)** or call our Stroke Helpline on 0303 3033 100.



## Jenny King

"In my role as a Stroke Association Family and Carer Support Coordinator I provide practical and emotional advice to stroke survivors and their families.

"My first impression of Vickie was what an incredibly positive person she is – that's what shone. She was determined to get back to work and she had an amazing sense of humour, even about her problems and disability.

"I remember she told me: 'There's no point sitting in a corner. I have to push forward.' That was what I took away that day. When I sat in the car afterwards, I thought: wow, there are very few people like that. That impression has stayed with me and, if anything, grown the more I have got to know her. She has had one thing after another thrown at her – but she bounces back thanks to her determined attitude.

"Working with someone like Vickie confirms why I enjoy doing what I do. I'm based on the rehab ward at Leicester General Hospital and see patients who have had a stroke and offer them support. When they go home I make contact and assess their needs. We identify goals to

work towards and put together a plan establishing problems and working out solutions.

"Everybody I work with has the common thread of stroke but a stroke affects everyone differently. Someone who has had a stroke or a TIA (mini-stroke) could make a very good physical recovery, but can be very anxious; worrying that a full stroke may happen – it can be very disabling.

"Emotional support is a big part of my job. People tell me that my help is invaluable and I find that extremely rewarding.

Often hospital wards are busy but I'm there to ask people about their concerns and I'm there for them after hospital and when all other services have ended.

"You meet people in life who you have a connection with. I maintain a professional, supportive role in my job and know I can't get too involved but every once in a while you meet someone that makes an impression on you. Vickie is one of those people."



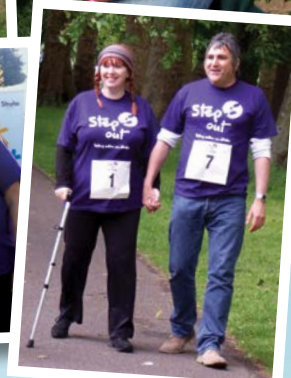
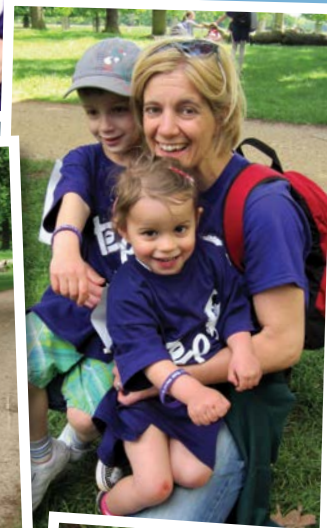
# Step Out for Stroke

*Step out for Stroke* is back and this year is set to be even bigger and better.

*Step out for Stroke* is a sponsored walking event for the whole family. Each event is especially planned with a short course suitable for all ages and walking abilities and with wheelchair access too.

We are running more than 50 events across the UK, mostly throughout May to celebrate *Action on Stroke Month*. Why not set yourself a challenge and get the whole family involved to help us raise more than £250,000 in vital funds to support stroke survivors?

To find your local *Step out for Stroke* event, visit [stroke.org.uk/stepout](http://stroke.org.uk/stepout)



"After my stroke, I set myself a goal to walk again. I wanted to do *Step out for Stroke* to raise money for the Stroke Association but also to challenge myself. On the day I walked half a mile. It took me a really long time but I did it! The sun shone, we all wore our purple t-shirts, there were dogs and children and grandparents and we had such a happy time."

Rachel Inglefield, *Step out for Stroke* 2013 participant



# Six simple steps to

A healthy balanced diet, low in salt and saturated fat and containing plenty of fruit and vegetables can reduce your risk of stroke, lower your blood pressure and help you lose weight and control diabetes.

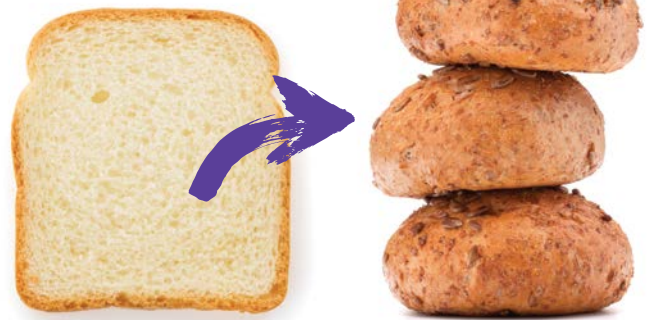
Banishing the biscuits and side-lining the salt needn't be as hard as you think. Here are six simple changes we can all make:



1

## Reduce salt intake

Keep your food flavoursome using lemon juice, garlic and spices instead of salt which can increase your blood pressure and risk of stroke. You should have no more than a teaspoon (or 6g) a day. Check labels carefully for hidden salt.



2

## Switch to wholegrain

Wholegrain equivalents of carbohydrates like bread, cereal and rice generally contain more vitamins and minerals. They're also a good source of fibre which can help lower cholesterol and your risk of stroke.



4

## Go for 'good fats'

We need some fat in our diet but eating too much of the wrong type of fat can raise your cholesterol and risk of stroke. Cut down on food high in saturated fat like full-fat dairy products, pastries and takeaways. Unsaturated fats, found in nuts and seeds and oily fish like salmon, mackerel and tuna, are 'good fats' and are better for you.



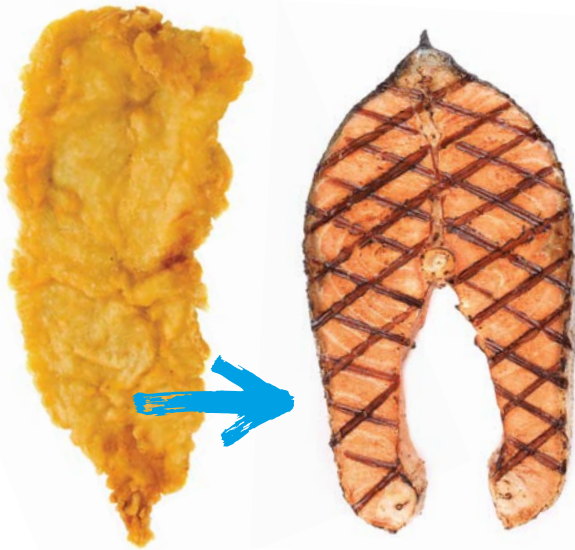
5

## Replace red meat with leaner types

Red meat such as beef, pork, lamb and goat contain saturated fats which can increase your cholesterol. Go for leaner cuts and leaner varieties like chicken, turkey and game. Cut off visible fat and remove chicken and turkey skins.



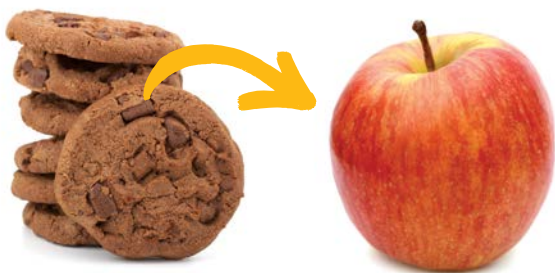
# improve your diet



3

## Steam, grill, bake or poach

Frying your food can add fat and calories which can cause you to put on weight. Being overweight raises your risk of health problems including type 2 diabetes, high blood pressure, heart disease and stroke. Try to grill, steam, boil, stew, microwave or bake food to keep it healthier.



6

## Snack on fruit and veg

You should have less than 60g of sugar a day (12 teaspoons).<sup>\*</sup> Many snacks contain a lot of sugar, like fizzy drinks which can have up to eight teaspoons. Try snacking on fruit and vegetables instead. Eating five or more portions a day can reduce your risk of stroke by 30%.

<sup>\*</sup>Under review as at March 2014.  
Check [www.nhs.uk](http://www.nhs.uk) for up to date guidance.

## What do our experts say?



**Douglas Youngson,**  
Stroke Association Helpline  
Information Officer

"A healthy diet should form part of a healthy lifestyle.

We should all do 30 minutes of exercise a day, five to six times a week. It doesn't need to be about hitting the gym – walking to the shops and choosing the stairs can make a difference. If you haven't been active for some time, start slowly and build up.

"There are lots of services and resources to help quit smoking and cut down on alcohol, which are important for your health. Drinking large amounts of alcohol quickly can raise your blood pressure and smoking tobacco doubles your risk of stroke."

Our *Healthy eating and stroke* factsheet has more information. See [stroke.org.uk/healthy-eating](http://stroke.org.uk/healthy-eating)

**Dr Madina Kara,**  
Neuroscientist at the Stroke Association



"Some types of medication can be affected by the foods you eat. If you take statins (which lower cholesterol), avoid drinking grapefruit

juice. If you take warfarin (a blood-thinning medication), you need to be careful what you eat and avoid making sudden changes to your diet. Foods high in vitamin K, such as spinach and broccoli, can interfere with the effects of warfarin if eaten in large amounts. If you have any concerns about your medication and diet speak to your GP or pharmacist."

Our factsheet *Atrial fibrillation (AF) and stroke* has information about managing your diet on AF medication. See [stroke.org.uk/AF](http://stroke.org.uk/AF)

# Giving back

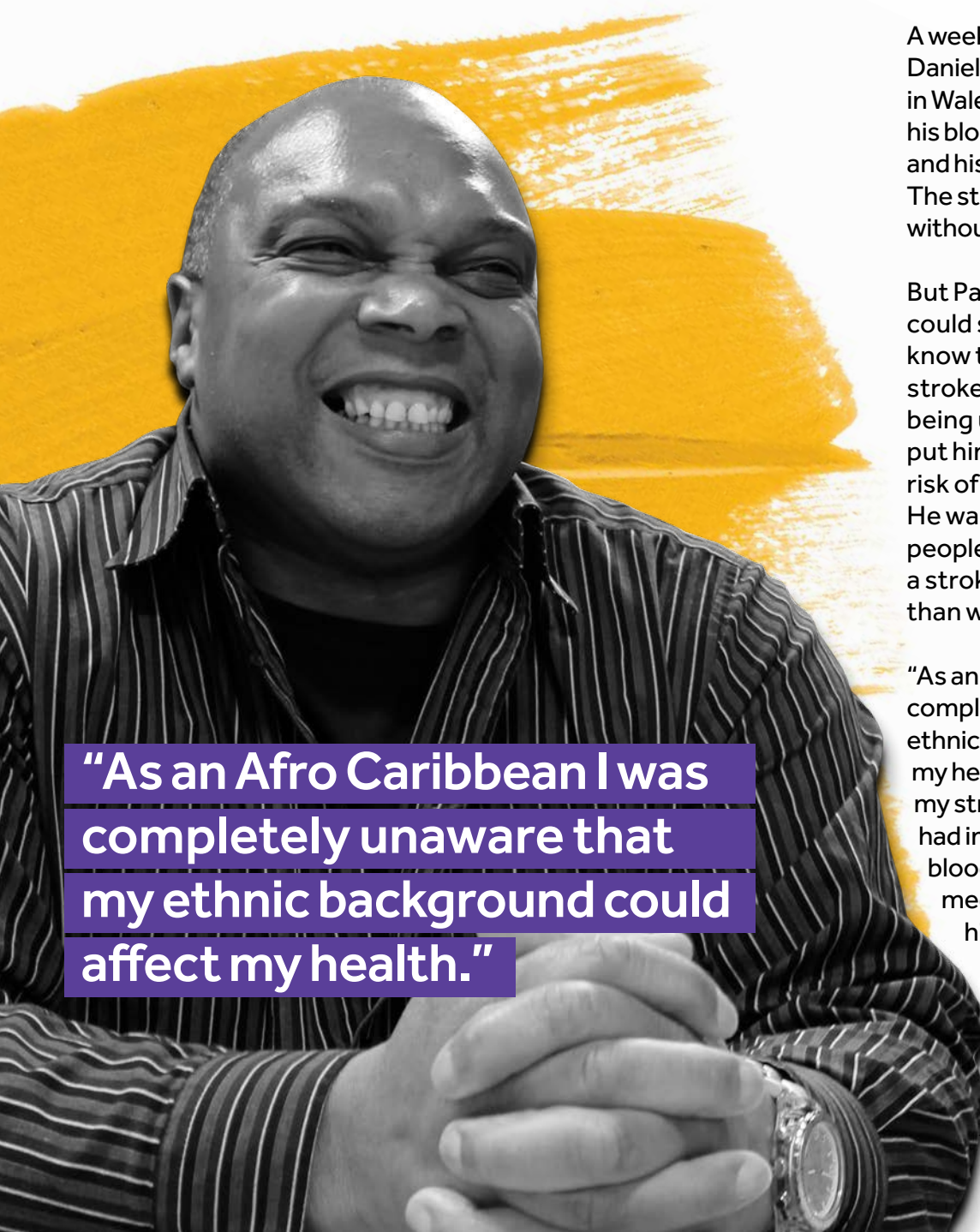
When Patrick Daniels had a stroke two years ago he didn't allow any obstacle to stand in his way of trying to lead a normal life. Although his career was cut short, Patrick is now volunteering to give something back to the Stroke Association service that helped him adapt to life after stroke.

A week before his stroke, Patrick Daniels, then 54, from Ceredigion in Wales, was in excellent health; his blood pressure was normal and his cholesterol healthy. The stroke came completely without warning.

But Patrick was unaware he could still be at risk. He didn't know that his father had had a stroke when he was a child and being under the age of 65, this put him at three times greater risk of certain types of stroke. He was also unaware that black people are twice as likely to have a stroke and at a younger age than white people.

"As an Afro Caribbean I was completely unaware that my ethnic background could affect my health," he says. "Following my stroke, my brother found he had inherited my mother's high blood pressure. He's now on medication and has changed his diet."

The stroke happened when he was about to drive home from his brother-in-law's house.



**"As an Afro Caribbean I was completely unaware that my ethnic background could affect my health."**



Stroke can happen to anyone at any time, but if you are black and of African or Caribbean origin you may have a higher risk of stroke than other people in the UK. Our factsheet explains key risk factors and steps you can take to reduce your risk. See [stroke.org.uk/african-caribbean-people](http://stroke.org.uk/african-caribbean-people)

Very suddenly, he felt unwell and collapsed. An ambulance took him straight to the stroke unit where he was immediately scanned and treated with the clot-busting treatment, thrombolysis.

### Staying strong

Patrick had had an ischaemic stroke. He was in hospital for a week before returning home. He refused the use of a wheelchair and walked out of the hospital. To begin with he stayed upstairs in bed for days as the house had not been assessed or modified for him.

"I was too strong-minded to let any obstacles stop me from trying to lead a normal life. After a few days I was out of bed and finding new ways to adapt to everyday tasks. It was a struggle but I'm a stubborn person."

Determined to get his strength and movement back, when he wasn't working with the reablement team he was practising catching and throwing with his friends' children.

"I joined a gym and kept busy to keep my mind off the pain but it also built my confidence and strength, when I saw my progress."

### Helping others

Although Patrick would love to return to his job in building restoration he is realistic about his recovery and for now wants to concentrate on helping others affected by stroke.

The Stroke Association was awarded a grant from the Big Lottery Fund which made it possible for us to have a presence in Ceredigion. Previously there had been no information or advice services for people affected by stroke in the area.

The funding meant our coordinators could visit stroke patients in hospital, GP surgeries could hold stroke clinics and clinic reviews, and a Peer Support Network could be set up. It also meant stroke survivors in Ceredigion could meet as a group and take part in workshops and go on trips.

Patrick and his wife Julie were visited by one of the project's coordinators after Julie called our Stroke Helpline. They attended the group together, recognising how important it was for both of them to feel supported.

As part of the Peer Support Network, Patrick and Julie volunteered at a monthly coffee morning open to stroke survivors in the local area. Along with other volunteers, Patrick and Julie now run the group.

"Before the support of the Stroke Association we didn't know where to turn, how to cope or where to get answers," says Patrick.

"We want to give something back and help new stroke survivors who have no knowledge of adapting to life after stroke and may feel alone and terrified, like I did. People don't know about the Stroke Association in Ceredigion so we're spreading the word that information and advice is available."



# Tackling gaps in support for vision problems



Over half of stroke survivors experience sight problems but how they are assessed and treated differs greatly across the UK. We're working to ensure every stroke survivor gets the right support.

Visual problems can have a huge practical and emotional impact – difficulties with things like reading or getting around increases your dependence on others and can affect your confidence. However, vision problems can often be treated or managed with aids and training.

Thanks to voluntary donations to the Stroke Association and support from the Thomas Pocklington Trust, we commissioned Dr Fiona Rowe from the University of Liverpool to investigate gaps in vision support.

Her research found assessments and treatments vary significantly. Only 41% of the professionals

surveyed carried out vision assessments within one week of a stroke and only 21% of these used screening tools in their assessments. Stroke units with eye care specialists as part of their team and those with established systems in place to refer people to local eye services had better outcomes for patients.

The research highlights the importance of early vision assessments and information for stroke survivors with vision problems and their carers. Early advice allows stroke survivors to adapt to their impaired vision quicker and leads to a better quality of life.



In the last 20 years, the Stroke Association has invested more than **£40 million** in vital stroke research.

Research prevents strokes, saves lives and helps stroke survivors make the best recovery they can.

But more needs to be done. For every cancer patient living in the UK, **£295** is spent each year on medical research, compared with just **£22** a year for every stroke patient.

Our research programme is totally funded by voluntary donations. To find out more about the research we're supporting visit [stroke.org.uk/research](http://stroke.org.uk/research)



**Dr Fiona Rowe,**  
**Researcher**

"Some positive outcomes from the research are the existence of vision tests and care pathways that are available for widespread use. It's vital that these are now routinely employed to support stroke survivors in every part of the UK."



**Dr Dale Webb,**  
**Director of Research and Information  
at the Stroke Association**

"The disparity in vision care for stroke survivors is unacceptable. We need to work with the British and Irish Orthoptic Society and others to ensure that high quality vision services are available to every stroke survivor."

# In brief: Communication

Around one in three stroke survivors has difficulty speaking or understanding what others say and many have trouble reading or writing. Understanding why this happens and how you can support someone with communication difficulties can help carers and loved ones.

A stroke is an injury to the brain and our brain controls everything we do, including everything we interpret and understand. A stroke can cause problems with communicating if there is damage to the parts of the brain responsible for language. The range of communication problems depends on where in the brain a stroke happens and how large an area is damaged.



## The main conditions in brief

### Aphasia

Sometimes called dysphasia, this is the name for the most common language disorder caused by stroke. It can affect speech, the ability to understand what is being said, and reading or writing skills. It does not affect intelligence.

### Dysarthria

This happens when a stroke causes weakness of the muscles we use to speak. It does not affect the ability to find the right words or understand others.

People affected by dysarthria may sound different and may have difficulty speaking clearly. They may sound slurred, strained, quiet or slow.

### Dyspraxia

This affects movement and coordination. Muscles cannot be moved in the correct order and sequence to make the sounds needed for clear speech.

Those affected may not be able to pronounce words clearly, especially when asked to. At times, they may be unable to make any sound at all.

## How can you help a stroke survivor with communication problems?

### Ask

- Face the person when you speak.
- Ask them what helps.
- Speak slowly and clearly, using short sentences.

### Wait

- Wait for a response without interrupting.
- If you don't get a response, repeat or reword the sentence.

### Listen

- Check that Yes/No responses are reliable.
- Use gestures to confirm, like thumbs up or down.

# problems after stroke

The rate and level of recovery from communication problems is different for everyone, depending on the severity of the stroke and on the individual's general health at the time. Many people may be left with some degree of long-term difficulties but therapy can help. 83% of stroke survivors who use our communication support services tell us they feel more able to go out into the world again.

## Q&A

We meet Stroke Association Speech and Language Therapist, Sharon Millar, in Northern Ireland.



**Q** What does your role as a Speech and Language Therapist involve?

**A** I run two communication support groups for stroke survivors and their carers. I try to equip people with a variety of strategies to communicate in all situations using activities like word retrieval, gestures, reading, spelling, writing and drawing.

When I'm not planning new group activities or running sessions I'm visiting stroke survivors at home to assess their suitability to attend a group and offer communication advice to their family.

**Q** What do you enjoy most about your job?

**A** I love meeting so many lovely people affected by stroke. Suddenly not being able to communicate can be exasperating but I enjoy helping people find ways to adapt and it's wonderful to see people grow in confidence.

**Q** What's something most people don't know about you?

**A** I was picked to play for the Northern Ireland ladies football team in my younger years!

**"Sharon is brilliant! She has really encouraged Ivan and going to the group has really improved his speech. When he had his stroke he didn't feel confident going out on his own so it's given him more independence."** Kathy Maybin, carer

Find support in your area at [stroke.org.uk/support/search](https://stroke.org.uk/support/search) or call our Stroke Helpline on **0303 3033 100**.

We've also developed a visual communication aid for people with aphasia with illustrated sections covering "How I am feeling" and "Can I have" as well as letters and numbers. Find out more at [stroke.org.uk/aphasia-visual-aid](https://stroke.org.uk/aphasia-visual-aid)



# Please will you help to fund ground-breaking stroke research?

Tragically, someone will have a stroke every three and a half minutes in the UK. Please will you join the fight against stroke by becoming a Research Partner today?

Research Partners are scientists, stroke survivors and people like you – who are all playing an important role in powering the Stroke Association's research programme. As a Research Partner, every penny of your monthly gift will help fund vital medical research.

Scientific research is intensive and meticulous. In order to accurately measure the effects of certain treatments or drug therapies, individual research projects can last for many years. This means that life-saving stroke research is expensive, which is why your support is so urgently needed.



Research Partners help to save people's lives and prevent stroke

The Stroke Association's research programme is entirely funded by voluntary donations. As a Research Partner, your £3 a month will help to fund new research to save lives and ensure more people make the best recovery they can.

Please join as a Research Partner today by completing the below form, or by calling 0300 330 0740. Thank you.



To set up a direct debit, please fill in your details below and return the form to: Freepost RRZA-KCEU-UKSB, Research Partners, Stroke Association, 1 Sterling Business Park, Salthouse Road, Northampton, NN4 7EX. Thank you.

I wish to make a monthly gift of £3 ☐

Or my own choice of £

I would like the payments to start being taken from my account from the 1st ☐ or 15th ☐ day of  (month).  
(Please make sure the start date is at least one month from today)

Please provide your full address below, so we can process your details properly.

Name:

Address:

Postcode:

Telephone number:

If you would be happy to receive information about the Stroke Association by email, please enter your email address here:

Email:

**If you would prefer to set up your Direct Debit or make a donation by phone, call 0300 330 0740.**

**You can also give online: [stroke.org.uk/donate](http://stroke.org.uk/donate)**

*giftaid it*

To enable us to claim back the tax already paid on your donations, and add 25p to every £1 you donate, please complete the Gift Aid declaration below. (This will help us to carry out more research and provide information and support for more people affected by stroke who desperately need our help).

☐ I am a UK taxpayer and would like the Stroke Association to treat all donations I have made in the last four years, and all donations I make hereafter, as Gift Aid donations. I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify.

☐ Sorry, I am not a UK taxpayer, and therefore cannot take part in Gift Aid.

## Instruction to your Bank or Building Society to pay by Direct Debit

Service User Number 676605

**Please fill in the form in CAPITALS using a ball point pen**

Name and full address of your Bank/Building Society

To: The Manager  Bank/Building Society

Address:

Postcode:

Name(s) of account holder(s)

Bank/Building Society account number:

Branch sort code:  /  /

Reference No.  (for internal use only)

**Instruction to your Bank or Building Society:** Please pay the Stroke Association Direct Debits from the account detailed in the Instruction, subject to the safeguards assured by the Direct Debit Guarantee. I understand that this Instruction may remain with the Stroke Association and, if so, details will be passed electronically to my Bank/Building Society.

Signature(s):

Date:

Banks and Building Societies may not accept Direct Debit Instructions for some types of account.



# Money matters

Recent increases to the cost of living put extra strain on household budgets. If you and your family are already struggling with the impact of stroke, rises to the cost of food, travel and fuel could make things really tough. It's important that you get the help and advice available.

In our report, *Short-changed by stroke*, stroke survivors told us about the extra costs they face because of disabilities caused by stroke. Many stroke survivors of working age find they can't go back to work and carers may have to cut their hours or give up work altogether because of their new responsibilities. They also noticed that bills went up as they were home more and used more energy to keep warm.

One stroke survivor told us "We eat less, turn off the lights and heating more – use less of everything."

If you are struggling with money it's important that you get the help and advice that's available. Here are three tips that might help:

## 1. Check your benefits

Make sure you are getting all of your entitlements including sick pay and disability benefits.

## 2. Think about what you owe

If you owe money on credit or store cards, get advice on switching to a low cost alternative.

## 3. Managing your debt

Get advice on prioritising and reducing your debt and budgeting to avoid debt in the future.



## Where to turn to for advice

For advice on budgeting, benefits or dealing with debt contact the Money Advice Service. This is a free, independent service set up by the government. Phone **0300 500 5000** or visit **[moneyadviceservice.org.uk](http://moneyadviceservice.org.uk)**

We believe that a stroke should not leave families in financial difficulties and that the benefits system must support stroke survivors who are unable to work because of illness or disability. To find out more about our campaign work in this area visit **[stroke.org.uk/short-changed](http://stroke.org.uk/short-changed)**

# The people you need at your finger tips

We're pleased to announce a new partnership with OwnFone to offer a simple, easy to use mobile phone.

Some people think that mobile phones are getting more and more complicated to use. If you do too, we'd like to tell you about the OwnFone – a brand new design of phone that connects you instantly with the people you need to talk to.

To make a call all you need to do is press the name or image of the person you want to call – it's that simple. You can have up to 12 contacts on your OwnFone. There's no text or Internet function, it simply allows you to easily make and receive calls.

A personalised OwnFone costs from £40 and is available on pay monthly.



Call **0800 669 6699** or visit **stroke.mymownfone.com** for more information or to order now.

## Travel insurance to suit your needs

Having a stroke can affect your chances of getting comprehensive insurance cover, or the cost of your premiums could be much higher than average. So for stroke survivors, finding suitable insurance protection at affordable prices isn't always easy.

Stroke Association Insurance Services has been specifically developed for stroke survivors, their families and carers too. Mr Riley from Shropshire contacted Stroke Association Insurance Services for travel insurance after being given information by his consultant.

"Prices overall have increased since I had a stroke – that cannot be avoided, but I was really happy with the service I received with Stroke Association Insurance Services. I was going to purchase online to get the discount initially, but then decided to pay a little more because your people are excellent and it was worth it to discuss everything..."

Many people, like Mr Riley, are finding what they need with our service. Call us today **0800 519 0759** or visit **stroke.org.uk/insurance** to find out more.



Stroke Association is an Introducer Appointed Representative of Heath Lambert Limited. Heath Lambert Limited is authorised and regulated by the Financial Conduct Authority. Registered Office: The Walbrook Building, 25 Walbrook, London EC4N 8AW. Registered No: 1199129 England and Wales. [www.gallagherheath.com](http://www.gallagherheath.com)



# Thank you!

The Stroke Association is a charity. We rely on your support to prevent stroke and change lives. We'd like to say a huge thank you to everyone who's gone the extra mile to support us since the last edition of *Stroke News*. Here's a handful of our wonderful supporters.

Remarkable Celia Barlow tackled the 56 mile Kennet and Avon Canal Race and raised nearly £700



In his spare time on active service, Andy Carlyle rode the equivalent of Afghanistan to Worcester hospital (5,800km), where his dad was supported after his stroke and raised nearly £1,400



Our amazing London to Paris cycle team helped raise more than £30,000



200 Santa's and Santa's Little Helpers brought some festive cheer to Richmond Park, raising £7,000



Dare-devil Jo Davies took to the skies in a wing walk in Gloucestershire following her dad's stroke and raised more than £900





A group of our wonderful volunteers in the North West, led by stroke survivor Nick Clarke, held a collection and raised close to £1,300

Aiden Tolley braved the mud in a Tough Mudder event in memory of his gran and raised £185



## How does your money help?



**£5** could help 15 people begin to come to terms with the effects of stroke with crucial factsheets like *Communication problems after stroke*.

**£20** could support our helpline team to give life-changing advice to people struggling to cope with life after stroke.

**£50** could help us continue to invest in vital research to help save lives and improve the lives of stroke survivors.



## Feel inspired?

Run, walk, ride, bake – there's something for everyone. Visit [stroke.org.uk/fundraise/find-an-event](http://stroke.org.uk/fundraise/find-an-event) to see what's on in your area or visit [stroke.org.uk/donation](http://stroke.org.uk/donation) to donate.

## Stroke stars

When Ruby Smith was just four years old her mum had a stroke during the birth of her little sister Amber. Nine years on, her mum still has difficulties speaking and is unable to use the right hand side of her body. Since the age of four, Ruby has helped to care for her.

If that wasn't courage enough, Ruby, now 13, decided to brave hot coals in a sponsored fire-walk to support the Stroke Association. Smashing her £100 target, Ruby raised over £1,500 towards our work.

"My mum is a very strong lady and has learned how to do many things with just her left hand," said Ruby. "Since I was four years old I have been my mum's carer, and I believe this has allowed me to grow into a kind and caring young lady, as well as being more respectful and understanding towards people that are disabled."

On behalf of the Stroke Association, a huge thank you goes to Ruby for her bravery and support.



# Improving stroke care



In December, the UK Stroke Forum conference brought together more than 1,250 stroke care professionals and survivors to share their experiences and help shape services and standards of care.

Our Deputy Director of External Affairs, Nikki Hill, led a talk on 'Survivorship'; the importance of listening to those affected by stroke and removing the barriers they encounter so that they can lead a full and active life for as long as possible.

Inger Wallis who had a stroke aged 48 gave a moving insight into the emotional impact of stroke and her experiences and the impact it had on her and her family.

"Stroke survivors are treated like cars, whose wheels or doors are not working properly," Inger said. "The doors and wheels are repaired but barely any petrol put in the car – the 'petrol', is the emotional support that enables the person to have the will, energy, strategy, to move themselves along their journey of recovery or adjustment."

Nikki highlighted Stroke Association surveys that found widespread anxiety, depression and stress amongst stroke survivors and carers, a lack of support for people once they're home and the alarming cost of stroke that sees large numbers of families having to cut back on heating and eating just to make ends meet.

We have been pressing home these concerns with politicians and policy makers to ensure stroke survivor's needs are heard.

But more work is needed. You can share your views and team up with others taking action on stroke by joining our Supporters' Network: [stroke.org.uk/campaigns/signup](http://stroke.org.uk/campaigns/signup)

## UK Stroke Forum top tweets



@Joe\_Korner

Nikki Hill reminds us that shockingly over 60% of stroke survivors are in fuel poverty and 40% cut back on food. Eat or heat? #UKSF13



@bill\_russell3 #uksf13

Stroke survivors & carers live their condition 24/7, 365 days a year. Support must be seamless from their point of view.



@Lisa\_A\_Kidd

Only by seeing things from #strokesurvivors perspectives will we enable change on the ground that meets needs #UKSF13

Keep up to date with Stroke Association news on Twitter @TheStrokeAssoc

Our factsheet *Emotional changes after stroke* provides advice and information. See [stroke.org.uk/emotional-changes](http://stroke.org.uk/emotional-changes)