

# Lived Experience of Stroke

## Chapter 2

### The wider impact of stroke

Rebuilding lives after stroke

**Stroke**  
Association





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# Martin Lewis

Nick Cann used to be the boss of the Institute of Financial Planning, a great communicator who'd also dabbled in stand up. I too, am in the financial world, a communicator by trade, and once dabbled in stand up. Yet I met Nick, to give him an award for fundraising, after he'd had his serious 'brain attack' and lost most of his ability to talk.

His acceptance speech, using the limited words he has left, was perhaps the most moving, passionate and determined I've ever seen. Even now I can recall some of the short phrases he fought hard to get out. I stood there with mixed feelings of admiration for his steadfastness, and trepidation at the visceral display of the forced change a stroke can bring.

It's the impact that speech had, and imagining myself in Nick's shoes, that led to me writing the foreword to this important report. Understanding how stroke can effect a stroke survivors working and personal life means we can start to learn how best to support stroke survivors, their families and friends and their carers to improve the quality of their lives.

We can't ignore the fact that after a stroke life changes for some. Adaption is necessary, at home and in work.

Work is a cornerstone of most people's lives, for many losing it sucks. Work pays the bills, gives us a purpose, independence, challenge, and possibly a sense of achievement. It also defines who we are, providing an internal CapGen (the little caption at the bottom of the screen which says who someone is when they appear on TV) – a sense of who we are and what we do.

More than a third of working age stroke survivors must give up work after their strokes. This affects income and self.

Over half of stroke survivors said their relationships had been affected by stroke. The two will often be linked. When someone loses their job suddenly, their confidence and sense of purpose can disappear, freedom turns into reliance.

Then there's the more prosaic matter of lost income, which adds a further burden. Losing a job affects relationships too, and a sense of esteem. And no longer bringing in an income can create stress and anxiety over a diminished lifestyle, meeting the bills, and providing for a family.

Even for those who aren't struggling financially, stepping back to watch others take on what were their responsibilities can be tough to take.

As this report shows, sadly the knock-on consequences don't finish there.

A stroke's impact on people's confidence can change how some relate to everyone they know. Meeting friends or going to social events, can be really daunting for them. And, avoiding socialising can result in loneliness, or being a prisoner in your own home. Those who know stroke survivors should reach out.

Work, even if it's not the same as before can provide a lifeline and improve recovery. Employers need help to understand what strokes are and what can be done to support stroke survivors return to work – after all 'legally' it's their responsibility, not the stroke survivors.

For those who can't return to work, access to disability benefits should try to incorporate the greater difficulty some stroke survivors will have both in navigating the system, and in surviving.

We need to give survivors opportunities to improve their lives, regain happiness and purpose, whether through hobbies, friends, volunteering or owt else.

We need to want to get out of bed in the morning, and we often want to need to.

**Martin Lewis**

Founder of Money Saving Expert



## In summary

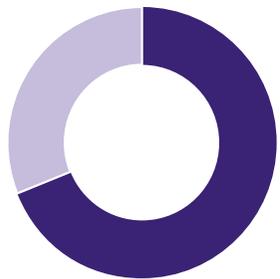
### The Stroke Association is here to support people to rebuild their lives after stroke.

To understand better the challenges facing stroke survivors and the help they need, we conducted the biggest ever survey of stroke survivors. Over 10,000 people closely affected by stroke shared their experiences with us.

The physical, emotional and cognitive changes caused by a stroke can affect every part of a person's life. They can impact on their important relationships. They can prevent them from working. They can inhibit their social life.

It is important that we all recognise these wider impacts of stroke, and that the right support is provided. Stroke survivors must be made aware of what help is available and where they can find it.

We're here for people affected by stroke. We provide information and support to help stroke survivors manage the wider impacts of a stroke.



**For 69% of people stroke**

had impacted their independence.



More than a **third** of working age stroke survivors gave up work following their stroke.



**One in two** people said stroke had impacted their relationships.



A further **16%** of stroke survivors of working age reduced their working hours.



# Introduction

## What is a stroke?

A stroke strikes a person every five minutes in the UK. Stroke can strike anyone - young, old and everyone in between. There are over 1.2 million stroke survivors living in the UK.<sup>1</sup>

A stroke happens in the brain, the control centre for who we are and what we can do. When a stroke happens, part of the brain loses its blood supply. This may be caused by a clot or bleed and it damages the brain. The impact of a stroke varies depending on which part of the brain is affected and how much the brain was damaged.

## About the Stroke Association

Everyone deserves to live the best life they can after stroke. We provide specialist information and support, fund critical research and campaign to make sure people affected by stroke get the very best care and support to rebuild their lives.

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<sup>1</sup> Stroke Association, State of the Nation: Stroke statistics, 2018  
[https://www.stroke.org.uk/system/files/sotn\\_2018.pdf](https://www.stroke.org.uk/system/files/sotn_2018.pdf)

## About our survey of stroke survivors

Throughout the summer of 2018, over 10,000 stroke survivors and carers from across the UK told us about their experience of stroke. They shared their thoughts and feelings by completing a survey that asked them about how their stroke had affected them, the length of time since their stroke, the things they have found challenging to adapt to, the support they have received and the areas in which they wish they had been better supported.

We ran the survey so that stroke survivors and carers could tell us in more detail about how their lives are most affected and where they need more support.

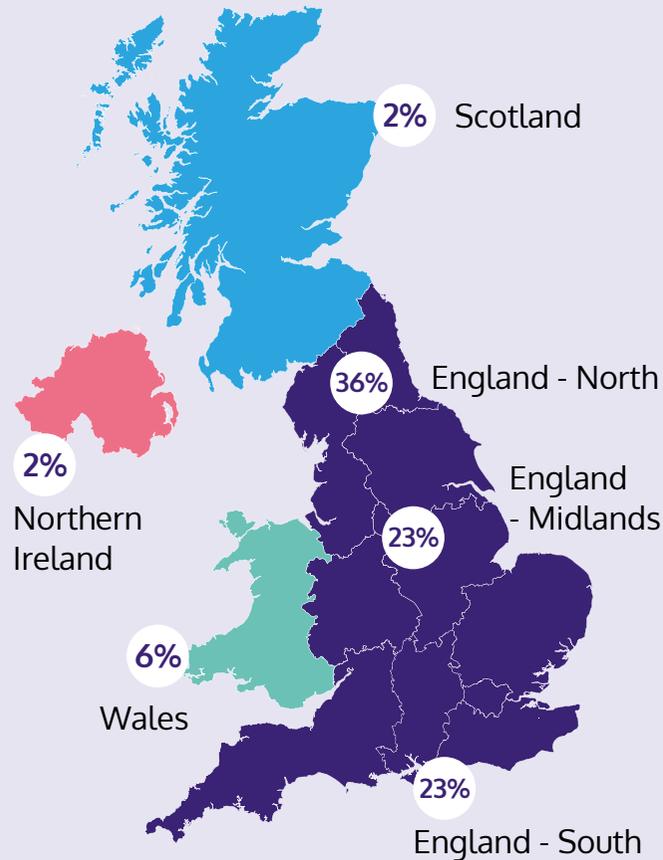
1,880 stroke survivors and carers completed an online survey. We ensured that this sample was representative of the UK population. Most of these people had not been in contact with the Stroke Association before.

9,254 stroke survivors, who we have supported in recent years, completed a survey. Mostly these respondents took a paper based survey, although a few completed the survey online.

In total 11,134 stroke survivors and carers told us about their experience of stroke, making it the largest survey ever conducted.



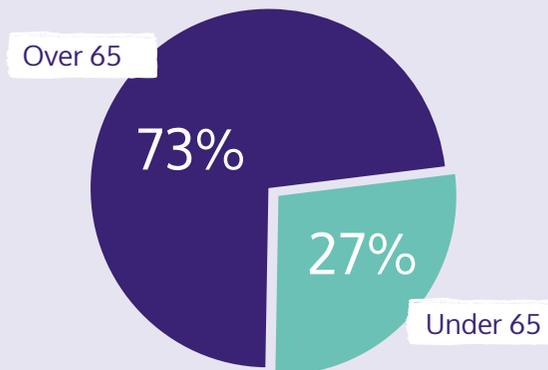
## Who we spoke to



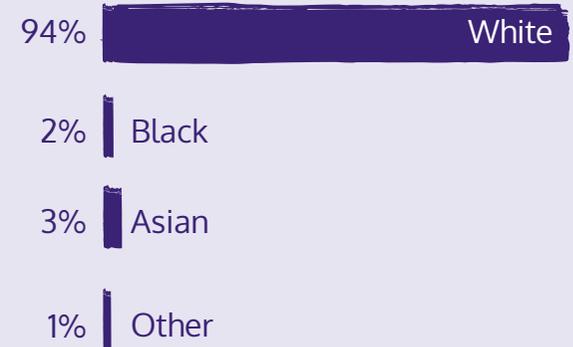
## Gender



## Age



## Ethnicity



## About this report

This second chapter (of a four part report) examines what stroke survivors told us in the survey about the wider impacts of a stroke on their lives, from relationships to hobbies to work and finances.

In June 2019, we published the first chapter which looked at the hidden effects of a stroke. Later in the year, we will share what people told us about the impact of being a carer for a stroke survivor and about the support that survivors wanted and received.

# How a stroke affects relationships

The impact of a stroke can extend to all parts of a person's life. From how someone feels about themselves to how they feel about their families and friends.

## How people feel about themselves

A stroke affects what a person can do, how they think and how they feel. It can also cause physical changes. This can alter how someone looks. More than half of stroke survivors surveyed said their physical appearance had changed as a result of their stroke. And it can alter what a person can do, making once simple activities like talking, eating, drinking and dressing difficult.

These changes can affect a stroke survivor's self-esteem. Seven in ten people told us that their self-esteem had been impacted. Younger people (those under 45) were more likely to find their self-esteem affected.

## Loss of independence

Stroke survivors told us they lost independence because of their stroke. They need help to do the things they used to do for themselves. 69% of stroke survivors said their independence had been impacted and for 42% this impact was moderate to severe.

Loss of independence is felt more strongly by stroke survivors who aren't in a relationship. People who are divorced or separated, widowed, or single, were significantly more likely to say a stroke had a severe impact on their independence compared to people who are cohabiting, living with a partner or married.



Seven in ten people told us  
that their self-esteem had  
been impacted.





**Paul** "I think people need to find a reason to fight for. Mine is my little girl."

After his stroke, 33 year old father of one, Paul, battled with depression, which affected his relationship.

He said: "I felt so down because I couldn't do things with my daughter Lily any more. Even just playing on her scooter and running around, she could outrun me. She doesn't understand what I've been through but she helps me so much and nurses me better.

"It was hard on the relationship between myself and my ex-partner, Lily's mum. I couldn't work and she struggled to keep up with hours at her work place. She lost her job and the impact on our finances was very stressful. I couldn't cook, clean or change Lily's nappies and my partner had to do everything. She was left to pick up all the pieces. It all got too much for her. From there my relationship broke down and I moved into Holly House hostel.

"At first, I did think 'Why did I even bother surviving this, what life have I got?' I didn't think I was going to improve and would be bed bound. But as I progressed with my physiotherapy I realised I could get stronger. Now I'm overcoming my depression and feel much better. I think people need to find that reason to fight for. Mine is my little girl.

"I have a support worker at the hostel, so there is always someone I can talk to. I'm just grateful to wake up each morning and take each day as it comes. I'm in a lot better place now than I was six months ago. I'm surrounded by a lot of good people and they keep me going. The Stroke Association has supported me all the way through my recovery and even helped me to be mobile with a grant to get my wheelchair. They've been amazing.

"I want to be able to play in the park and take her to the beach, do the sort of things a dad should do."

**Paul**

## Emotional Relationships

An individual's many different relationships are impacted when a stroke hits: relationships with partners, family and friends. Over half of people said their relationships had been affected by their stroke.

The dynamics of a relationship may shift when a person has a stroke. Stroke survivors may worry that they are a burden due to the increased support and help they need. A husband, wife or child may find they are suddenly required to take on the role of a carer. Friendships may wane because people stay away or do not know how to help. Plus a stroke survivor may be unable to do the things they once shared with family and friends. For example, reading bedtime stories with children, going out with a partner or playing sports with friends.



**Over half** of people said their relationships had been affected by their stroke.

## Sexual relationships

Half of stroke survivors told us their stroke had affected their sexual relationships. People may struggle to maintain sexual relationships due to the physical changes they have experienced. Problems like pain or muscle weakness may make sexual intercourse more difficult.

The emotional impact of a stroke and the emotional changes that can occur may change the way they feel about themselves or their partner. A stroke survivor may feel less sexually attractive or too low to want to initiate intimacy.

Starting new relationships can be daunting but is particularly challenging for stroke survivors. Their stroke may have impacted how they feel about themselves and their body, they may be concerned about the impact on their ability to be sexually intimate and they may worry that new partners could find their medical history concerning. A stroke can also physically restrict a person's ability to go out and meet new partners.



**Half of stroke survivors** told us their stroke had affected their sexual relationships.

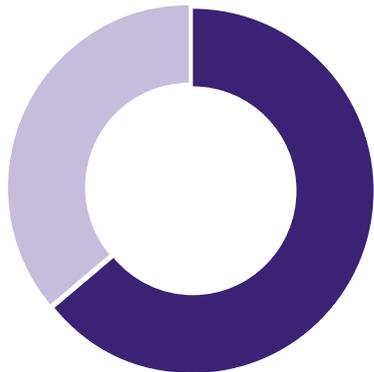


## Social lives

An active social life helps people feel connected within their neighbourhood and communities.

Hobbies can make up a large part of a person's self-identity. 64% of stroke survivors told us their hobbies had been impacted by their stroke. This can lead to a loss of sense of self and isolation from friends and family who shared these hobbies.

But a stroke can also present new opportunities. Stroke survivors often form new friendships through peer support groups. Some stroke survivors go on to volunteer, helping others affected by stroke. Therapeutic activities provide the chance to discover new hobbies and interests.



**64%** of stroke survivors told us their hobbies had been impacted by their stroke.



"I felt I met so many inspirational people at the group who helped me so much."

Donna



## Donna "I felt vulnerable and didn't know how to fit in anymore."

Just days before her 51st birthday, Donna had two strokes caused by a hole in her heart.

Donna said: "I was babysitting my grandchildren with my husband Alan, when I felt a strange sense of impending doom. For me, the feeling was instant; it was like my body had been sliced in half. I could see my family looking terrified and I was petrified I might die in front of my grandchildren."

She added: "After my stroke I felt like I lost my independence and was so much more reliant on others. I needed help washing and dressing and I could no longer do the things I used to with the grandchildren. I never had confidence issues before my stroke, but now my life seemed to centre around endless hospital appointments. I felt vulnerable and didn't know how to fit in anymore."

Donna met with Jane, a Stroke Association Coordinator, who encouraged her to go along to several groups run by the charity, where Donna could meet others affected by stroke as well as taking part in art workshops to help with her recovery.

Donna adds: "Even though I hadn't done it since school, it turns out I love art. I felt I met so many inspirational people at the group who helped me so much."

Having worked in the beauty industry for brands such as Benefit and Clarins, Donna has now worked with Jane to develop a beauty workshop to help stroke survivors who also lost the use of movement in one side.

"A lot of stroke survivors suffer from a loss of identity and disability, and fatigue often means a beauty routine is out of the question. I wanted to give something back."

## Support

Feeling positive about ourselves, engaging in an active social life and relationships with friends and family are vitally important.

Stroke survivors need the opportunity to talk about how they feel. They need support to overcome the barriers that prevent them getting out and taking part.

But only a third of stroke survivors accessed relationship support. Stroke survivors need to be encouraged to seek help.

## Stroke Association Clubs and Groups

Stroke Association Clubs and Groups offer peer support to stroke survivors, carers, family and friends. Many are run or supported by volunteers and can help stroke survivors on the way to recovery. They provide the opportunity to take part in social activities from outings and meals, to art and crafts and exercise classes.

## Vanessa 'Singing helped my memory and my confidence'



Vanessa, a nursing home matron, had three strokes in her mid-40s.

Vanessa said: "I loved my job and it was so hard to accept that I wouldn't be able to go back to nursing. It really affected my social life too, my former colleagues would visit once and never come back. I learned that even if you've nursed people who've had a stroke, you can't fully understand what it's like until you've had one yourself.

"I looked to find anyone else who would understand the anxiety I was feeling, and came across the Cwmbran Stroke Support Group. The other survivors and volunteers there helped me regain my confidence and soon I began to sing with the Strike a Chord choir.

"Language is based in the left side of the brain, where I had my strokes, so finding words can be difficult for me. However I've been told that singing comes from the right side of the brain, and it's so amazing to be able to let go and just sing. At Christmas I even sang a solo at our concert!

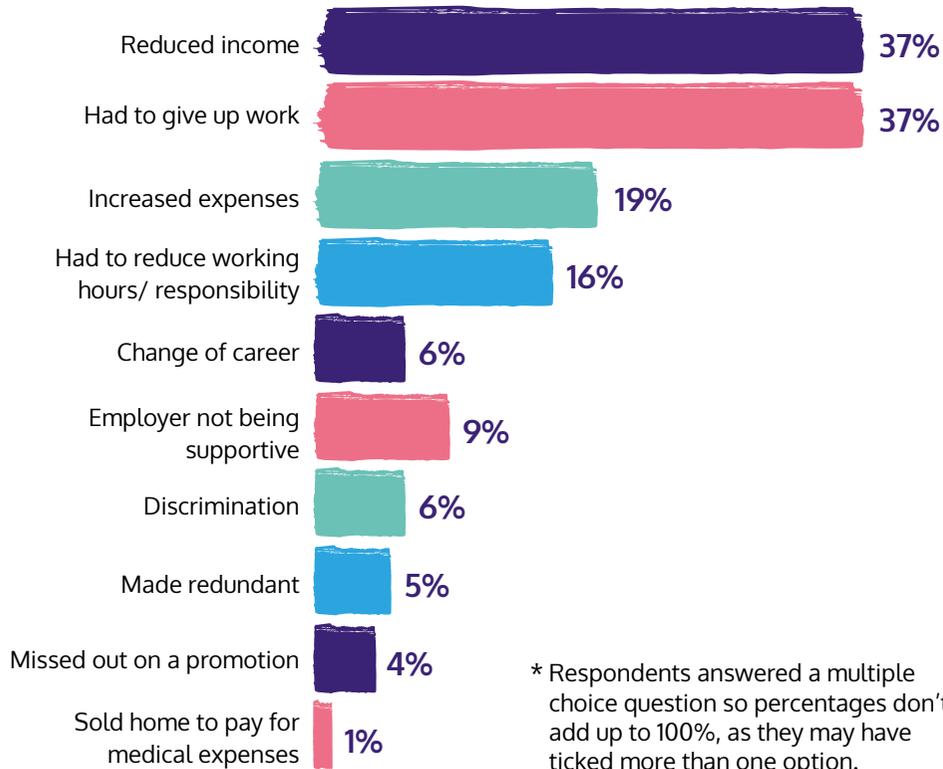
"Singing has helped my memory and my confidence and I'd recommend it to anyone who is struggling to adjust after having a stroke."



# How stroke affects work and finances

A stroke can make working more challenging. At the same time a stroke survivor may face additional expenses. The consequences mean stroke survivors and their families have less money. Some struggle to make ends meet.

The financial impact of stroke on people of working age (under 65):



## Staying in work

Altogether, nearly half of working age stroke survivors could not return to the job they once did, either reducing their hours or giving up work.

A stroke can impact a person's ability to work. Of working age stroke survivors, 37% gave up work following their stroke. For some people the physical changes they've experienced means they can no longer undertake the tasks required of their job. Or the cognitive and mental effects can make working difficult or impossible. The long period of time needed for recuperation after a stroke can be challenging for those who are self employed or on fixed-term contracts.

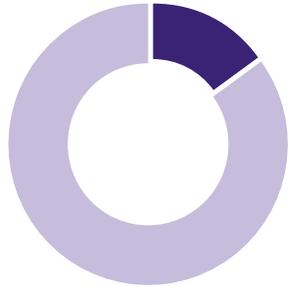
Stroke survivors may no longer cope with longer working hours. In addition to those who gave up work, a further 16% of working age people reduced their working hours or responsibilities.

Some stroke survivors may need to find alternative careers. Among working age stroke survivors, 6% changed their career following their stroke.



Of working age stroke survivors, **37%** gave up work following their stroke.

## Discrimination at work

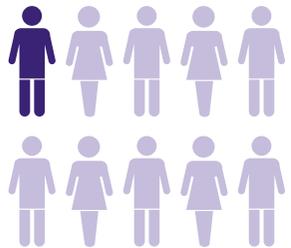


A significant minority **(15%)** of stroke survivors experienced some form of discrimination at work following their stroke.



**1 in 20 people**

of working age said they experienced discrimination, were made redundant or missed out on a promotion.



Even more, **1 in 10**, told us their employer was not supportive.

Employers have a legal obligation to support employees affected by stroke. They must make reasonable adjustments to allow them to do their job and ensure survivors have the same access to opportunities as others.

**Sean** "I couldn't cope with work now."

Just 8 months after being made redundant, 54 year old Sean Barr from Northern Ireland, had a stroke.

Sean said: "I was looking forward to retirement and then all of a sudden the stroke happened. It was a big shock.

"I've worked all my life and after the redundancy I planned to get a part time job to tide me over until I could retire. My wife Sharon and I had always planned to retire together when we were 57 but the stroke has changed all that. She's still out at work but I'm at home. My wife had to take a month off work after my stroke to help me recover. She worries about me doing too much and the kids are always calling to check I'm not doing things I shouldn't be. My daughter, Toni, won't even let me cut the grass and she's very protective.

"I worked for 40 years as a security manager. It was a demanding job but I always coped fine. But since the stroke, I've struggled with anxiety and I'm just so tired all the time. I couldn't cope with work now so we have to tighten our belts financially. It's not how I planned our retirement and the fear and worry of me having another stroke affects all the family. But I'm grateful that my recovery is going well. The doctors told my family that I had a 50-50 chance when I got to hospital so it's a miracle I'm here. Your health is your wealth but stroke definitely has an impact on your life, career and finances".





"And the kids are always calling to check I'm not doing things I shouldn't be."

Sean

## Household income

Giving up work or reducing working hours impacts a stroke survivor's household income. 43% of stroke survivors of working age have been financially impacted by their stroke. Income had gone down as a result of their stroke for 37% of these stroke survivors.

At the same time, 16% of stroke survivors of all ages faced increased costs as a result of their stroke. Additional expenses such as paying for adaptations to the home or support from a carer. And increased bills because the person is at home more often or because insurance premiums have gone up. The likelihood of a stroke survivor facing additional costs increases with the severity of their stroke.

**43%**  of stroke survivors of working age have been financially impacted by their stroke.

**37%**  of stroke survivors had seen their income go down as a result of their stroke.

**16%**  of stroke survivors of all ages faced increased costs as a result of their stroke.

## Coping financially

A small minority resorted to drastic measures to manage finances. Of the people who answered our survey, 1% said they had to sell their home to pay for medical expenses. Thinking of this in terms of the whole stroke population, this could mean there are as many as 12,000 people facing this situation across the UK.

People living in households with low incomes were more likely to find their financial situation severely impacted by a stroke, compared to those with higher incomes. Low income households have less of a financial cushion when a stroke strikes and may have little or no savings to fall back on.



**1%** of stroke survivors said they had to sell their home to pay for medical expenses.

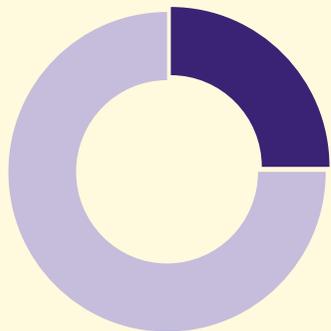


## Support

Stroke survivors may need to claim financial assistance from the benefits system to cope in the short or longer term. The benefit system can be confusing, complicated and slow for many stroke survivors. This can cause additional financial pressures.

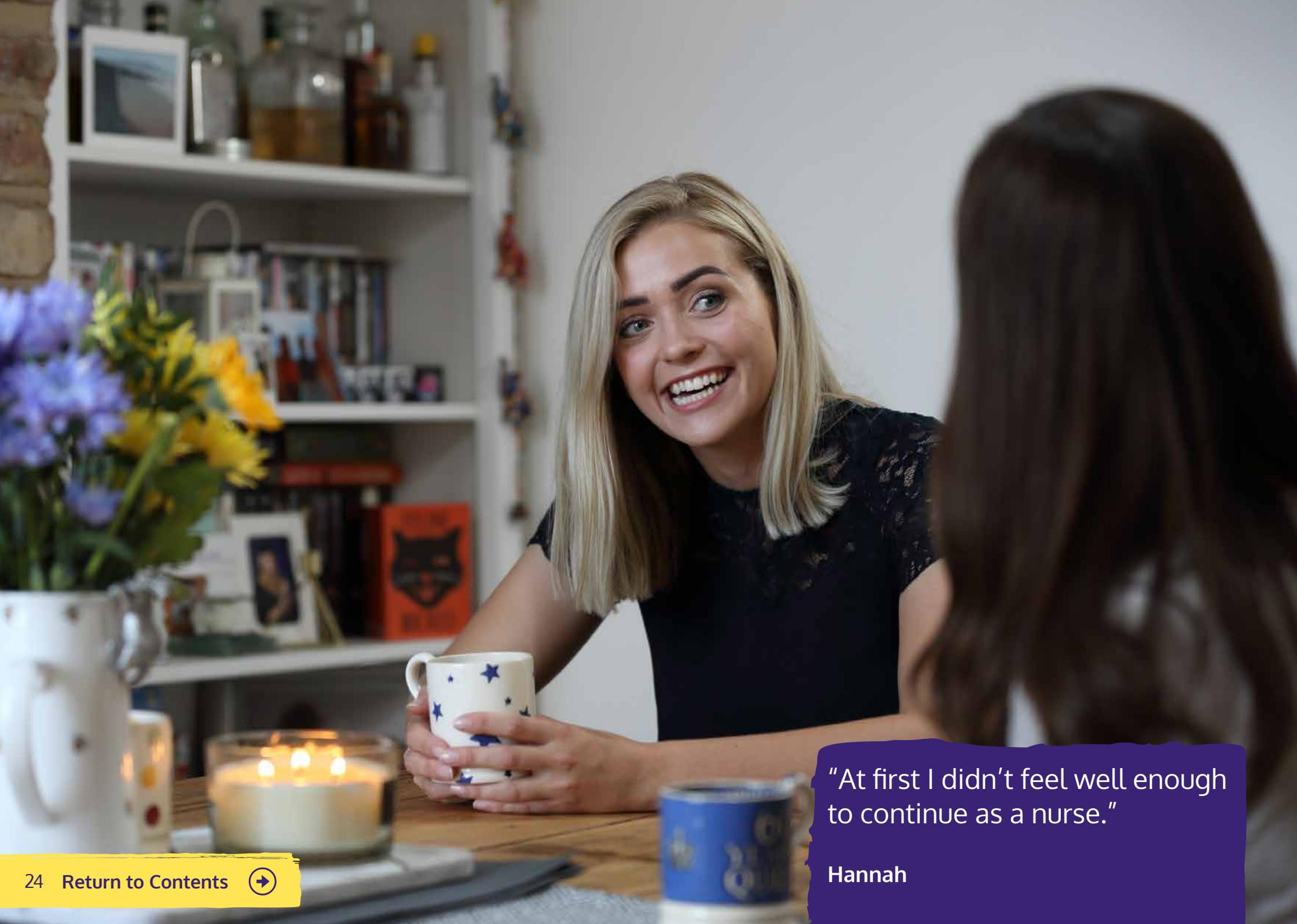
Only 10% of stroke survivors had used a benefits or financial advice service. Some respondents said they didn't need this service, but 18% were not aware these services existed and 8% said that benefits services were not available.

Those who did use such services did not always find them helpful. A quarter rated financial support services as poor and 19% needed to access these services for longer than they were available.



**A quarter of stroke survivors**  
rated financial support  
services as poor.





"At first I didn't feel well enough to continue as a nurse."

Hannah

## Hannah "After nearly a year of feeling sorry for myself I started to get my life back on track"

Hannah McGrath, 27 from Manchester, was working night shifts as a nurse, when she had a life changing stroke and found herself on the receiving end of hospital care.

She said: "The biggest impact of the stroke was how it affected me emotionally. Something I can't even comprehend now, was that I was 23 years old, fit and healthy. I'd just booked a one way ticket to travel the world with my friend, Fran. This wasn't in my plan.

"I really struggled with anxiety and fatigue and didn't feel well enough to continue as a nurse, so I moved back in with my mum. Initially when I was discharged from hospital my fatigue meant I was just constantly napping through the day.

"I'd never experienced fatigue before and with such an intense job I'm used to running on empty. But this was just a different type of tiredness. I didn't have a clear diagnosis of the exact cause of the stroke, which made me fearful it would happen again. I had such anxiety about having another stroke in my sleep that would leave me paralysed, or worse, that I wouldn't wake up.

"This went on for some months. It got to a point where I was in a very low mood, and I was stuck in a rut of doing nothing at home, being in bed, not leaving the house, not seeing anyone. I didn't know how to get out of it.

"Eventually I started to work a couple of hours a week in a pub kitchen peeling potatoes and helping to prep the food. I needed a reason to get out of the house and a bit of a distraction, otherwise I'd have been worrying at home. It helped with social interaction too."

Hannah returned to nursing a year after her stroke. She moved to Manchester and started a post in Manchester Royal A&E.

Hannah said: "I just went fully back into nursing, which was probably too much really but I stuck it out. I was exhausted to begin with. My fatigue has definitely improved but I am still aware of it. I can't do more than two days in a row with shift work.

"After nearly a year of feeling sorry for myself, I started to get my life back on track and I feel so fortunate to be here."

# Supporting stroke survivors

Stroke survivors deserve access to support that meets all their needs across all parts of their lives. Help with practical day-to-day tasks to retain independence, support to manage their important relationships and advice to help them remain in work or access benefits.

## How we can help

- We offer hands on support to stroke survivors and their loved ones. In many places, our teams visit stroke survivors and their family members in hospital and at home.
- We listen and support people affected by stroke through our helpline (**0303 3033 100**) and website (**[www.stroke.org.uk](http://www.stroke.org.uk)**), including family and friends.
- Our online community, accessed through My Stroke Guide, and our many stroke clubs and groups bring people together. These groups offer social support, promote independence and reduce the risk of isolation. Most groups offer activities, such as art and exercise sessions, as well as outings.
- We provide information for employers to help them understand stroke better. We also have information for stroke survivors on returning to work, changing career, retirement and volunteering.
- We support stroke survivors to understand the financial support they may be entitled to, via our helpline and website.
- We offer means-tested grants to support recovery. For example, these can contribute towards respite breaks, tablets to help with communication or gym memberships.



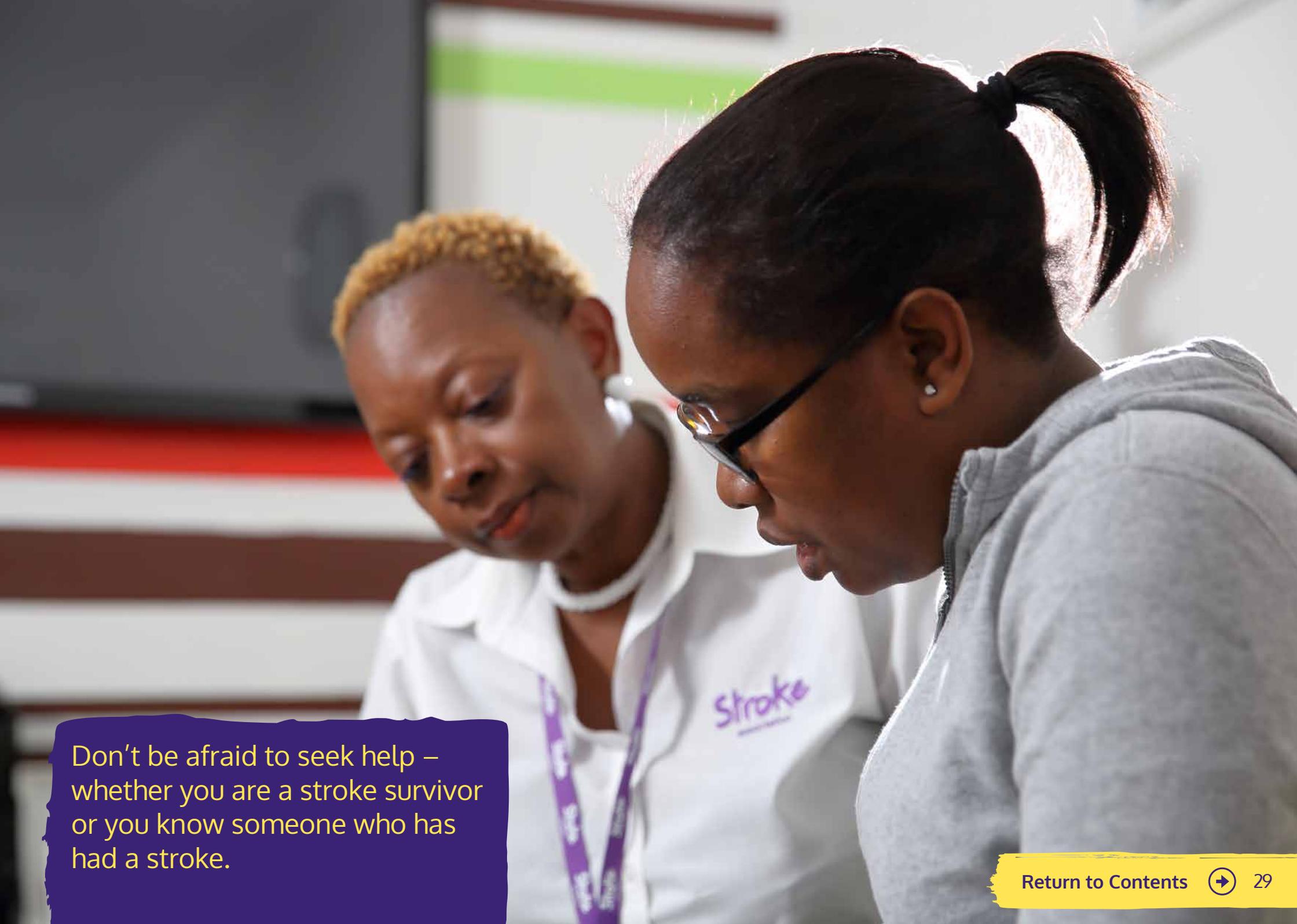


We listen and support people affected by stroke through our helpline (0303 3033 100) and website.

## Stroke survivor recommendations

We spoke to stroke survivors, who offered advice for anyone who has found their relationships, work or finances impacted by stroke. This is what they told us.

- Don't be afraid to seek help – whether you are a stroke survivor or you know someone who has had a stroke.
- If you are a stroke survivor, take part in stroke rehabilitation such as talking therapy, join stroke groups and sign up to the Stroke Association's 'My Stroke Guide'. This guide connects you to thousands of others, so you can share stories, advice and tips.
- If someone you know has had a stroke, be conscious that everybody's needs and recovery vary. Let your loved one know that you are there for them and let them reach out to you in their own time.
- If you are returning to work after a stroke, talk to your employer and agree reasonable adjustments to help you in the work place. Things that may help include a phased return, part-time and/or adjusted hours, and moving to lighter duties.
- If your employee has had a stroke, learn about the condition to understand how it may affect them. Ask your employee what they need so you can support them in the best way.
- Employers can also contact the Stroke Association if they would like more information about what they should be doing to support stroke survivors.
- Those supporting stroke survivors and their families can signpost to services or charities that offer relationship support and financial support and advice.
- Those unaffected by stroke can take action to protect themselves financially in case a stroke strikes in the future. They may wish to consider income protection insurance, critical illness cover or life insurance.



Stroke

Don't be afraid to seek help – whether you are a stroke survivor or you know someone who has had a stroke.

## Appendix: Further information about the survey

People took the survey in one of two ways. **1,880 stroke survivors and carers** completed an online survey. We ensured that this sample was representative of the UK stroke population. Most of these people had not been in contact with the Stroke Association before.

**9,048 stroke survivors** who we have supported in recent years completed a paper based survey. A further 206 people we have helped took the survey online. In total, **11,134 stroke survivors** and carers told us about their experience of stroke, making it the largest survey we have ever conducted.

2CV, a market research company, ran the survey for us. To help develop the survey, 2CV first conducted qualitative research by interviewing 27 stroke survivors and 16 carers. They then wrote the surveys, which were completed between June 2018 and September 2018.

Though the survey results we have shared in this report are representative of stroke survivors and their carers, the following groups were not included:

- Children who have had a stroke.
- People not able to complete the survey in English or Welsh.
- Wider family and friends, other than the main carer.

People most severely impacted by stroke, or people with aphasia, significant cognitive impairments and/or vision problems are less likely to be able to complete a survey, so are possibly under-represented in the results.



When stroke strikes, part of your brain shuts down. And so does a part of you. Life changes instantly and recovery is tough. But the brain can adapt. Our specialist support, research and campaigning are only possible with the courage and determination of the stroke community. With more donations and support from you, we can rebuild even more lives.

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Donate or find out more at [stroke.org.uk](https://stroke.org.uk)

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Rebuilding lives after stroke

**Stroke**  
Association