

Lived Experience of Stroke

Chapter 1 Hidden Effects of Stroke

Rebuilding lives after stroke





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Foreword

Paul Farmer, CEO of Mind

Around 10 years ago, my father had a stroke. When I brought him home from hospital, he was quite wobbly. The physical effects of the stroke were clear to see. As he settled in at home, I unpacked the huge box of medication that we had been given. I spotted the name of a well-known antidepressant. I asked my father why he had been prescribed this, but he just shrugged his shoulders.

This event has stayed with me, and is one of the reasons why I was delighted to be asked to write a foreword to this important report. On the one hand, the clinicians at the hospital had recognised that the impact of such a major change to my father's physical health was bound to have psychological implications, and had taken precautionary measures. On the other hand, there didn't seem to have been any explanation about why the medication had been prescribed, no discussion about possible side effects, and as far as I could see, no subsequent follow up or offer of therapy.

For too long, we have treated our physical health and mental health as parallel universes. Different systems, different providers, different funding approaches. The effect of that has been long term underfunding of mental health services for everyone, regardless of your physical health condition. This report highlights the disturbing truth that around one million people who have survived a stroke also have at least one mental health problem.



This imbalance is slowly beginning to change. The stigma around mental health is beginning to lift, and high profile campaigns have helped to improve public attitudes year on year. Society has begun to recognise the scale of the need and the opportunity to make a difference.

It should be obvious that if you experience a major life changing physical health condition, whether it's a stroke, cancer or a heart attack, then there will be consequences to your mental health. These consequences may pass briefly, but sometimes they are more profound, casting a double shadow over a life previously well lived, now just tolerable.

The 5 Year Forward View for Mental Health started a key programme, and extraordinarily was the first time that the health system recognised the essential interdependency between our physical and mental health. There was a promise of access to psychological therapies for people with long term conditions, and also a physical health check for people with severe mental illness. Both have seen progress being made, and the new NHS Long Term Plan promises an extension of both initiatives.

These are promising signs, but this report suggests that change can't come soon enough for many people who experience a stroke. Quite simply, anyone who has a stroke should be offered the chance to ask for help for their mental health. This may be support from a peer worker or a volunteer from Mind or the Stroke Association, an offer of an assessment to therapy, and yes, potentially a conversation about antidepressants.

This type of approach will help recovery, help people rebuild lost confidence and self-esteem, and to come to terms with a traumatic experience.

I very much hope that this report will shine a light on the importance of making access to support for our mental health as vital as the way that stroke care has changed, and will accelerate the much needed change for so many people.

Paul Farmer

Chief Executive, Mind

In summary

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

To better understand 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.

A stroke affects a person's brain impacting their physical, cognitive and emotional abilities. While some effects of a stroke may be obvious to others, many are hidden. And so stroke survivors do not always receive the help they need.



9 out of 10 stroke survivors

told us they had at least one cognitive impact, such as problems with memory or concentration.¹

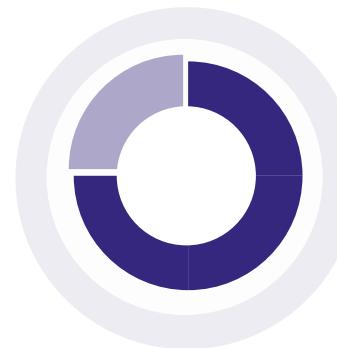


Around half of people feel anxious or frightened around the time of a stroke.³
A stroke can also change how they feel emotionally.

Hidden effects of stroke affect nearly everyone who has had a stroke. They include cognitive impacts, changes in mental health and changes in emotions.

With time, courage and the right support, stroke survivors told us that they start to feel like they are on the road to recovery.

We're here for stroke survivors. We provide support to help them cope with the hidden effects of stroke and we're working with governments and other partners to ensure that hidden effects are brought out into the open.



Three quarters of stroke survivors experienced a change in their mental health.² They may develop depression, anxiety or suicidal thoughts.





98%

of stroke survivors

told us their lives had been impacted by stroke.⁴ Many of these people felt this impact was significant.



¹Base: All respondents: 11,134 stroke survivors and carers.

²Base: All respondents: 11,134 stroke survivors and carers.

³Base: Nationally representative sample of 1880 stroke survivors and carers.

⁴Base: All respondents: 11,134 stroke survivors and carers.

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.⁵

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 a 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

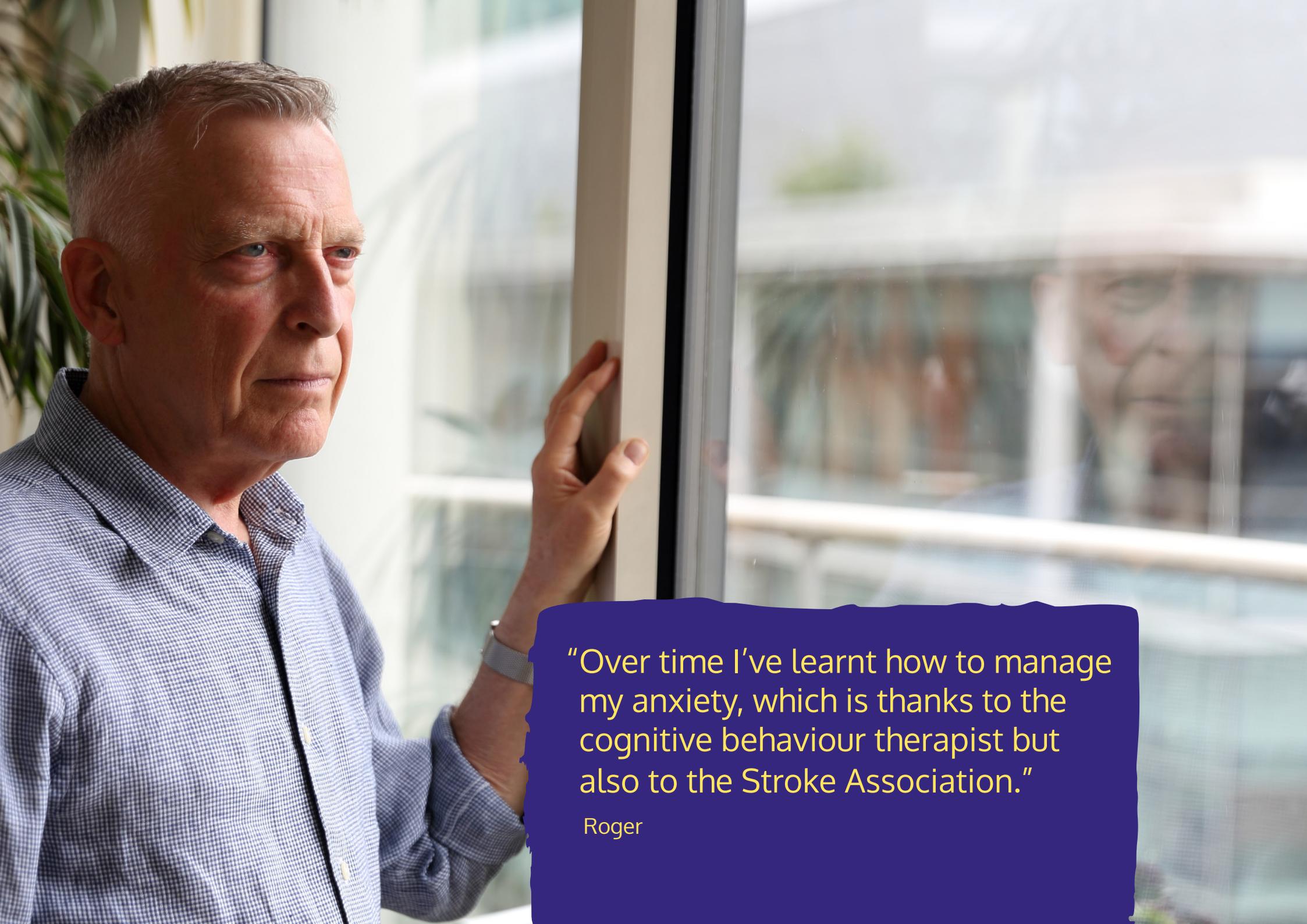
Everyone deserves to live the best life they can after stroke. We provide specialist support, fund critical research and campaign to make sure people affected by stroke get the very best care and support to rebuild their lives.

About this report

This report examines what stroke survivors told us about the hidden effects of a stroke. Effects like depression, memory loss and extreme tiredness. Later in the year we will share what people told us about how stroke impacts other aspects of their lives.

⁵Stroke Association, State of the Nation: Stroke statistics, 2018,
https://www.stroke.org.uk/system/files/sotn_2018.pdf





"Over time I've learnt how to manage my anxiety, which is thanks to the cognitive behaviour therapist but also to the Stroke Association."

Roger

About the survey

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.

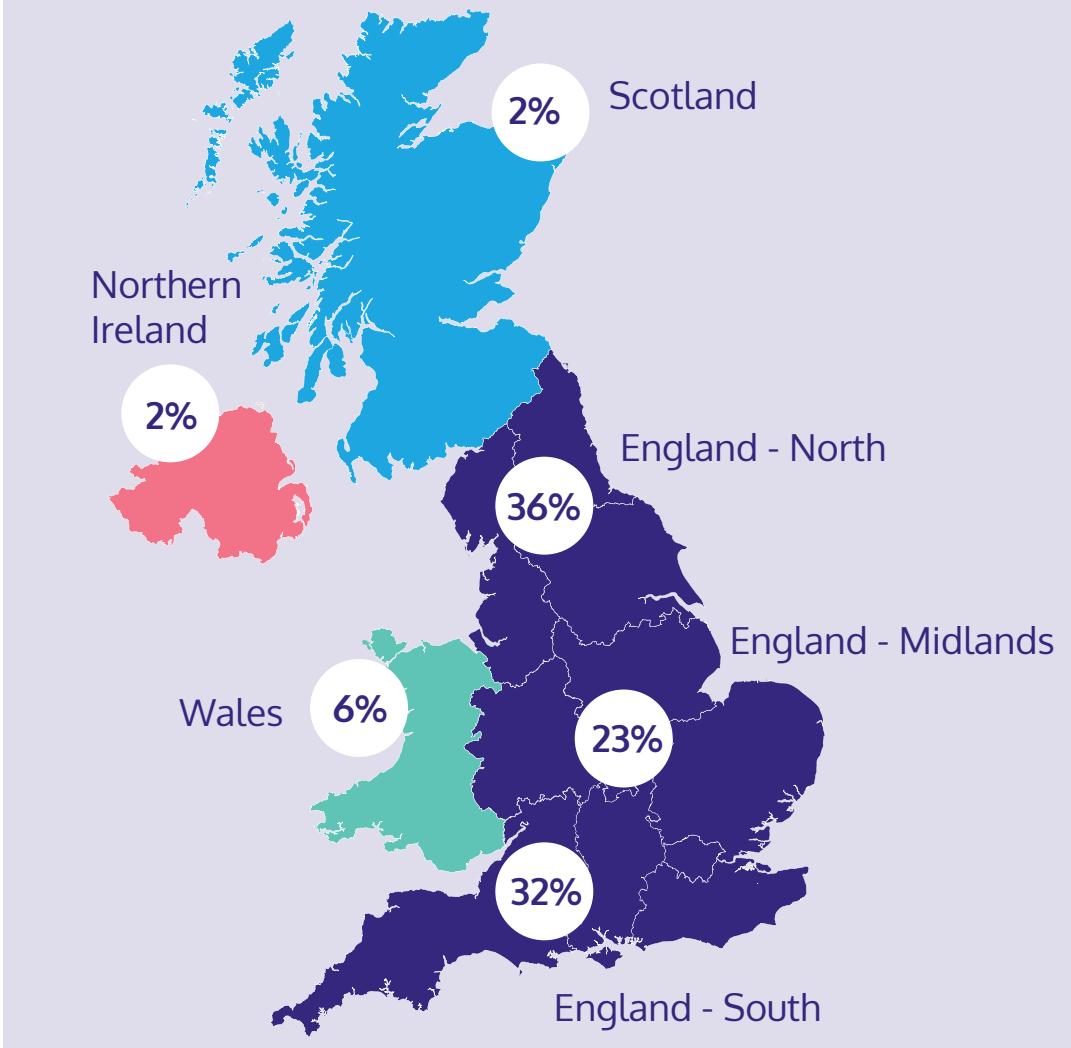
We ran the survey so that stroke survivors and carers could tell us in more detail about how their lives are most affected and where they need more support.

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

9,254 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.

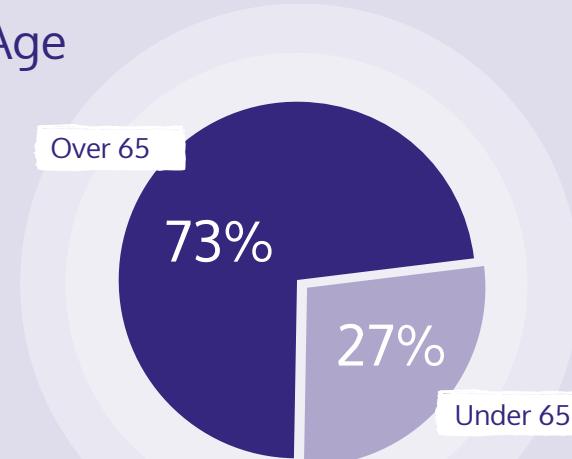
Who we spoke to



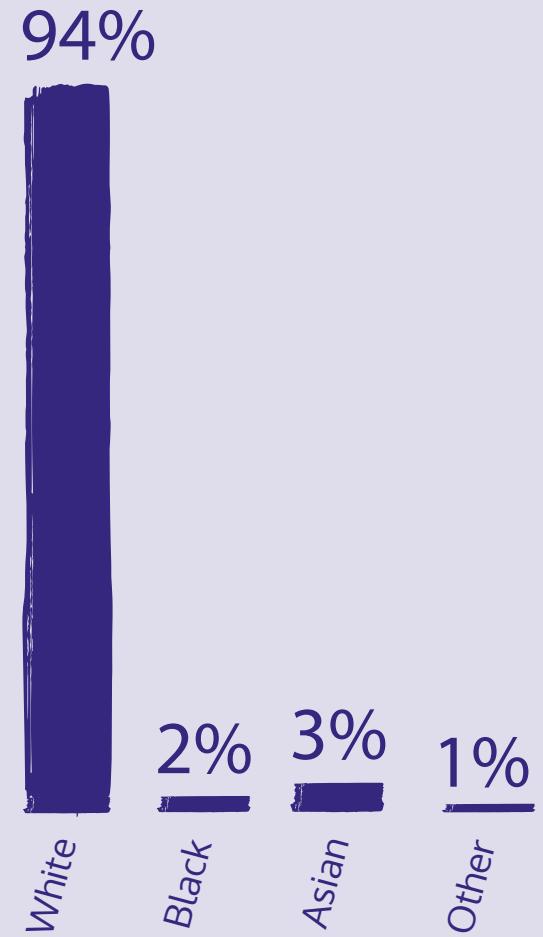
Gender



Age

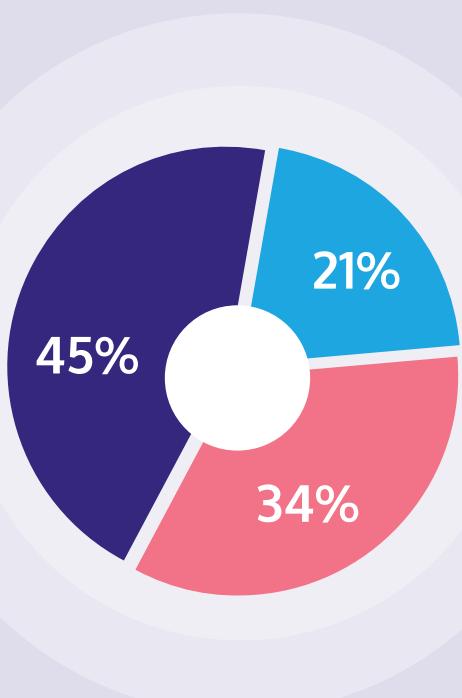


Ethnicity



Types of stroke

Ischaemic stroke
A stroke caused by a blood clot or other blockage, cutting off the blood supply to the brain



Haemorrhagic stroke
A stroke caused by a bleed in or around the brain

Transient ischaemic attack (TIA) - Also known as a mini-stroke, where the effects are often resolved within 24 hours



Hidden effects of stroke

When a person has a stroke, it can devastate their life in an instant. It can affect their physical health and abilities, their mental health, their emotions and how they function cognitively.

Some people lose the ability to speak. Others lose their ability to process information. And some lose the feeling of who they are. These effects may not be obvious to people living with or supporting a stroke survivor, or to health professionals and the wider public.



Cognitive effects are issues with the way the brain understands, organises and records information.

Examples of cognitive effects:

- Memory problems
- Difficulty concentrating
- Fatigue



People's mental health can be affected by a stroke. Examples of mental health impact:

- Anxiety
- Depression
- Lack of confidence



The feelings and emotions that people regularly experience can change as a result of a stroke.

Examples of emotional impact:

- Feeling frustrated
- Feeling lonely
- Feeling nervous



Often people experience difficulties in all of these areas. While the physical effects of a stroke may be easier to spot and better understood by family, friends and health professionals, other kinds of effects may be hidden to others. These can be even more difficult for the stroke survivor to live with.

People told us about the wide range of hidden effects that they experience. These hidden effects can arise at the time of a stroke or develop as a person recovers. People desperately need support for them, both during hospital care, and afterwards as they recover wherever they live.

It is important that families, friends, health professionals and the public understand what it means to live with these hidden effects so that they are not overlooked or neglected. If hidden effects are better understood, then stroke survivors are more likely to receive the right support.



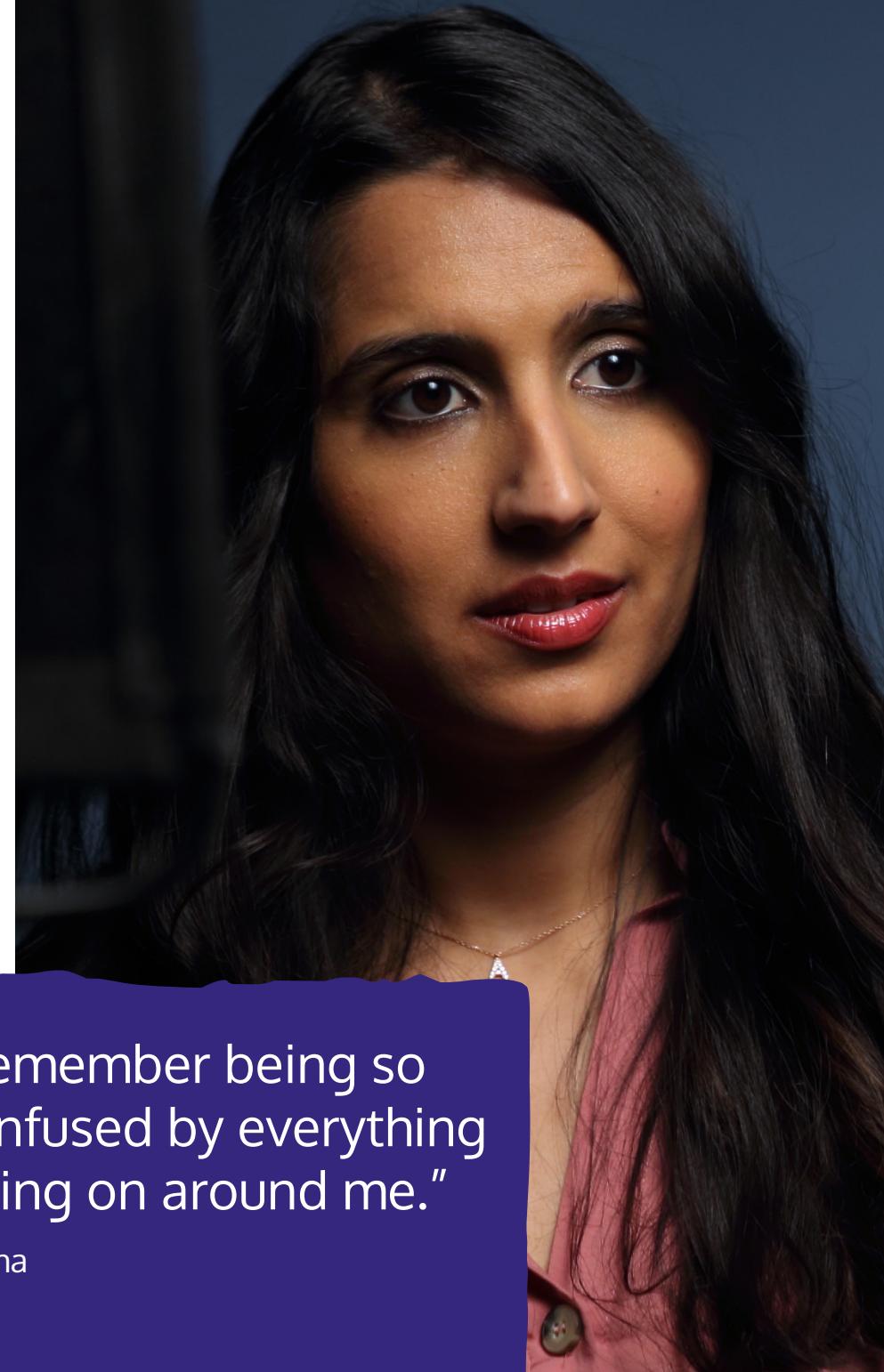
Cognitive effects of stroke

Most people tend to associate a stroke with physical effects and as a consequence, the cognitive effects of stroke are perhaps less well understood. Yet cognitive effects are as common as physical effects and can be just as challenging to live with.



**9 out of 10 stroke survivors
experience at least one cognitive effect**

This is the same number as those who experience at least one physical effect.⁶ Types of cognitive problems stroke survivors experience include fatigue, difficulties with concentration, decision-making, problem-solving, multitasking, reading, writing and poorer memory.

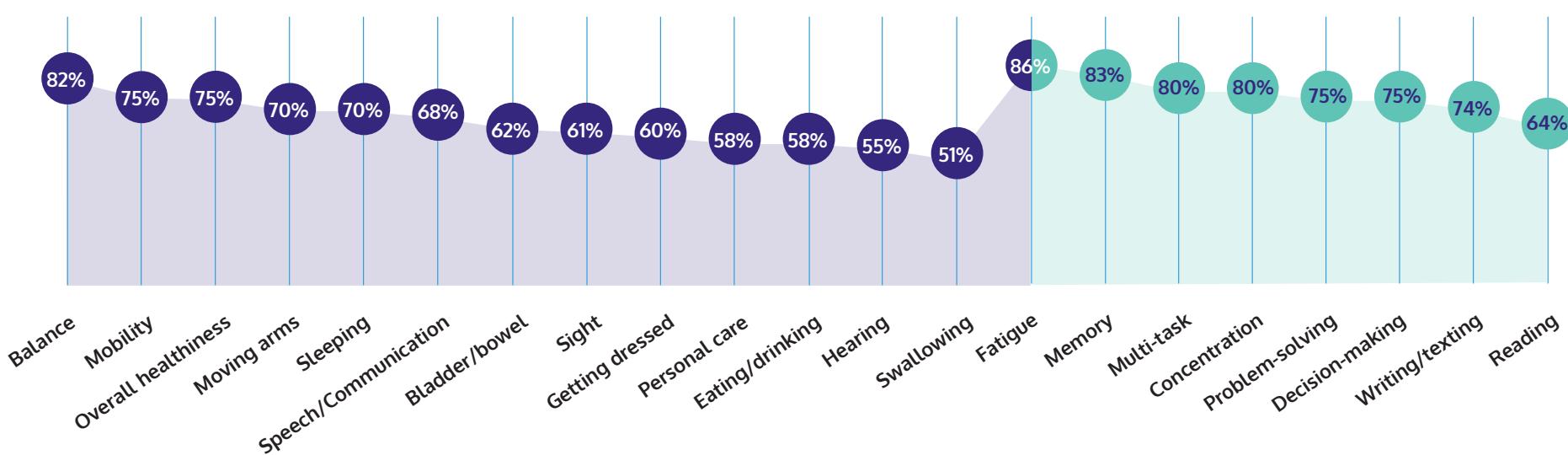


"I remember being so confused by everything going on around me."

Alisha

Percentage of people experiencing different physical or cognitive effects

Physical impact



Cognitive impact

Cognitive problems following a stroke can affect anyone, regardless of age, gender, ethnicity or where they live. A stroke causes a burden of cognition problems for stroke survivors to deal with. On average people have approximately 6 different problems with cognition.⁷ The more strokes people experience, the more likely they are to have difficulties with cognition.

⁶ Base: All respondents: 11,134 stroke survivors and carers.

⁷ Base: All respondents: 11,134 stroke survivors and carers.

⁸ Base: All respondents: 11,134 stroke survivors and carers.

Fatigue

Fatigue, or extreme tiredness, is the most common effect of a stroke. 86% of survey respondents told us they experienced fatigue.⁸ Fatigue affects almost all stroke survivors and can be far more debilitating than others imagine. It affects people both physically and cognitively. Unlike normal tiredness it doesn't get better with rest. People find it difficult to find the mental energy required to think or the strength to take part in everyday activities.



Nicola "I was completely wiped out"

Just two weeks after giving birth to her third child, 33 year-old Nicola, from Alloa in Scotland, experienced a devastating stroke.

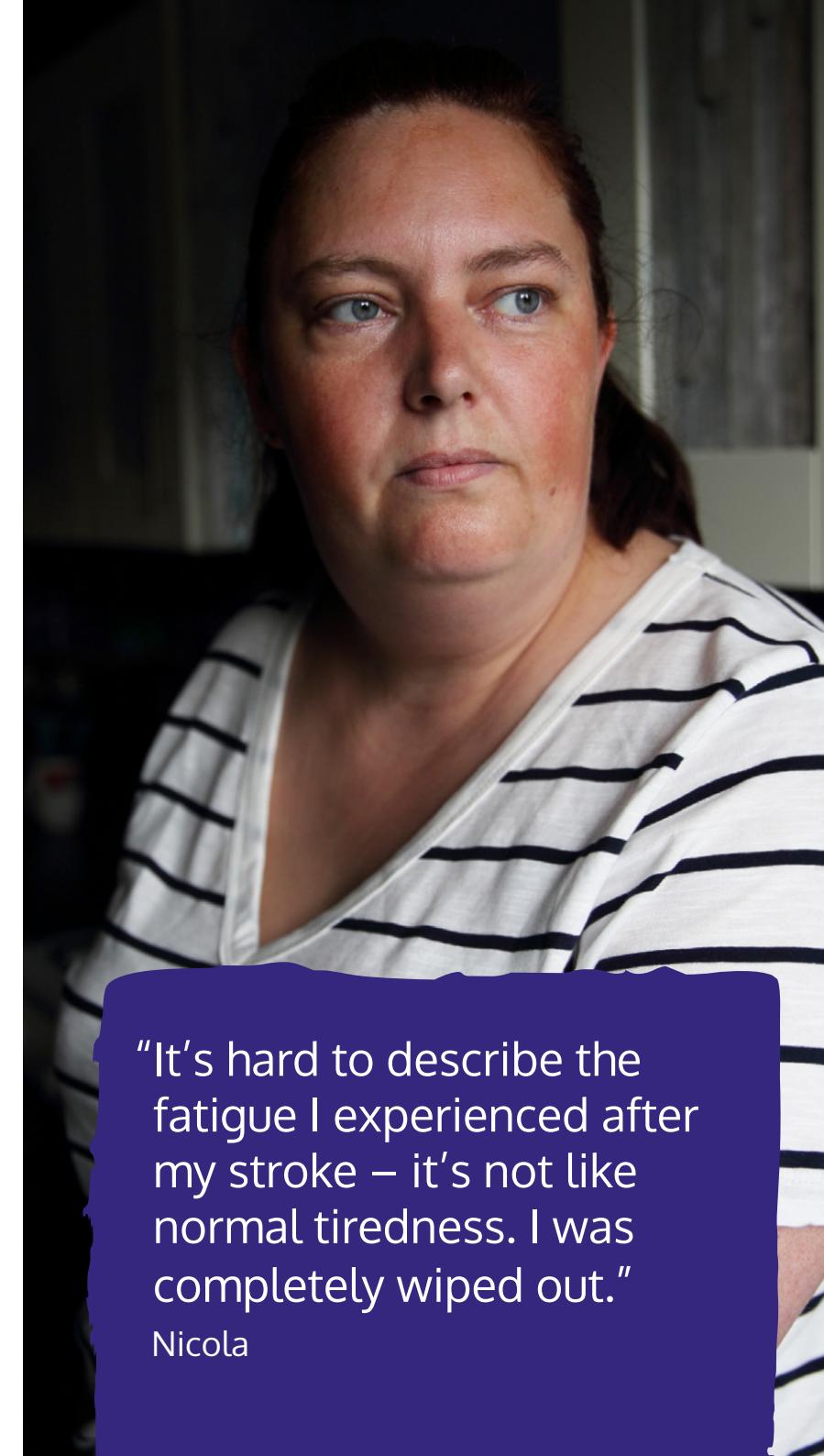
Nicola said: "It's hard to describe the fatigue I experienced after my stroke – it's not like normal tiredness. It's different. I was completely wiped out. Filling the washing machine or doing the dishes was exhausting and making the bed or going for a short walk was impossible at first.

"Even now, going to a restaurant where there is a lot of noise and a lot of things for my brain to process. It is so exhausting and that's incredibly frustrating."

"It really gets you down emotionally and you wonder if your life is going to be the same again. The whole situation is devastating. I felt so guilty leaving my husband to do the things I found so easy to do before.

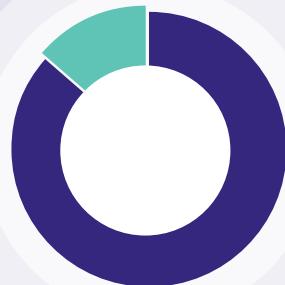
"Things are getting better. I can drive again and am able to take my youngest to the park and do the shopping. My fatigue has improved to the extent that I was able to take part in the Stroke Association's Moving Forward After Stroke programme, which helped with my mobility and confidence. I am also now on a phased return to work, to build up to two days a week.

"At the moment I am exhausted after work and need to rest for a while before the kids come home. But I love work and look forward to it every week. I really hope that despite the stroke and the life changing fatigue that comes with it, I can manage it. I think I can."



"It's hard to describe the fatigue I experienced after my stroke – it's not like normal tiredness. I was completely wiped out."

Nicola



Memory

83% of stroke survivors told us they have problems with their memory.⁹

Memory problems can affect short-term and/or long-term memory. Stroke survivors can forget what someone has said to them or fail to recall important dates.

Concentration



**8 out of 10 stroke survivors
Reported problems with concentration.¹⁰**

Problems with concentration can include not being able to do more than one thing at a time, such as making a cup of tea while chatting to someone. Or it may mean people are not able to follow a television programme or read a book.

⁹Base: All respondents: 11,134 stroke survivors and carers.

¹⁰Base: All respondents: 11,134 stroke survivors and carers.

How stroke survivors cope

Stroke survivors have to develop techniques and new ways of doing things to compensate for their poorer cognition. For example, writing things down or doing one thing at a time.

People find that the cognitive effects of stroke continue to get worse for the first year before starting to report some improvement. Cognitive effects including reading and problem solving improve the most, whereas stroke survivors do not report as much improvement for fatigue, concentration and memory.

Fatigue continues to be a real problem for people three years after their stroke (81%), affecting a similar number of people as those who had their stroke six months ago (88%).¹¹

Cognitive effects do not tend to go away completely. Even if their stroke was five years ago, 88% of stroke survivors still report having at least one problem with cognition.¹²

How stroke affects mental health

A stroke has a profound effect on stroke survivors' mental health. Around three quarters of stroke survivors experience at least one mental health problem following a stroke.¹³

47% of people experience a lack of confidence

44% of people experience anxiety

44% of people experience depression

42% of people experience mood swings

16% of people experience suicidal thoughts.¹⁴

Stroke survivors with mental health conditions feel frightened, anxious, confused and shocked after a stroke. They worry about having another stroke and do not know who or where to turn to for help.

Over time there is a slight decrease in the number of stroke survivors experiencing depression and a lack of confidence. This is not the case for the number of stroke survivors experiencing anxiety and suicidal thoughts.

With three-quarters of stroke survivors struggling with their mental health, it is clear that every stroke survivor is at high risk of developing a mental health condition.

¹³Base: Nationally representative sample of 1880 stroke survivors and carers.

¹⁴Base: Nationally representative sample of 1880 stroke survivors and carers.



Roger "I felt so nervous about going anywhere"

Arts journalist Roger, 73 from Manchester, had been experiencing severe headaches and peculiar visual distortions for around a year before he had a stroke in September 2017.

One day he woke up and couldn't see to his left side. The GP initially referred Roger to the eye hospital, where a CT scan showed he'd had a stroke.

He said: "It was almost a relief, because it answered so many of my questions. Deep down, it was what I had anticipated."

Roger was transferred to Salford Royal Hospital where he had further scans and spent around a week before being discharged home with advice to keep an eye on his blood pressure.

Roger said: "While I was in hospital I didn't cope very well; I was scared of going to sleep, scared of walking about, always thinking that I'd have another stroke. I got myself into such a state that I had a terrible panic attack.

When I was discharged I still felt so nervous about going anywhere or doing anything. A visit from the outreach team within a day of me leaving hospital assessed my needs and they recognised that I was experiencing severe anxiety and was completely worn out. I was referred to a cognitive behaviour therapist.

"I was also contacted by the Stroke Association who gave me lots of information which I found really reassuring, if a little overwhelming at how much there was to take in. Over time I've learnt how to manage my anxiety which is thanks to the cognitive behaviour therapist but also to the Stroke Association, for suggesting things like meditation. It's been a life changer."



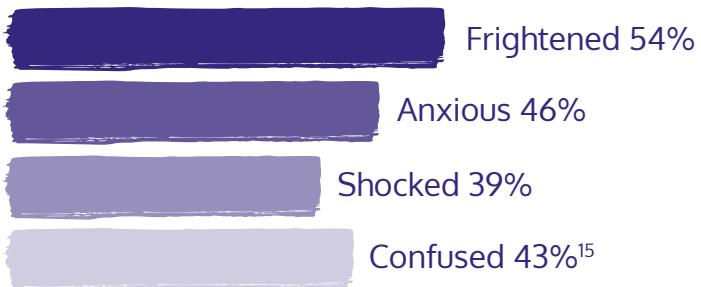
"While I was in hospital I didn't cope very well; I was scared of going to sleep, scared of walking about, always thinking that I'd have another stroke."

Roger

Emotional changes as a result of stroke

A stroke is a life-altering event. It can severely impact a person's emotions.

Around the time of their stroke, people report feeling:

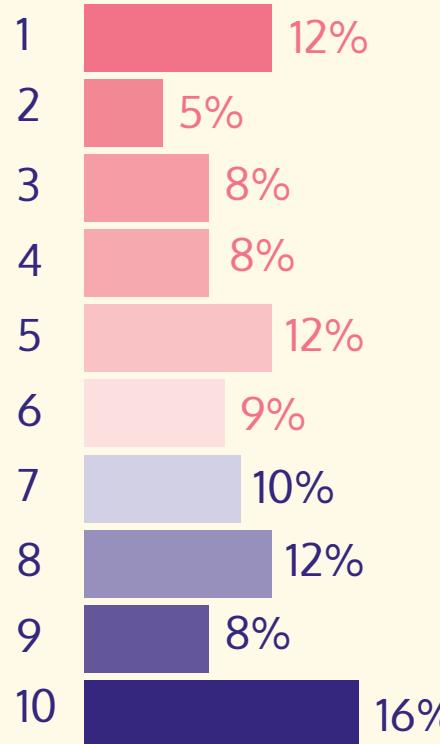


Stroke survivors continue to feel these difficult emotions during the six months following their stroke. Over time these negative feelings can diminish and are replaced by more positive emotions for some people. 49% of stroke survivors whose stroke occurred one to three years ago told us they now feel positive emotions, rising to 66% for people whose stroke was over ten years ago.¹⁶

The emotional impact of a stroke changes stroke survivors. Their emotions may be a reaction to what has happened to them. Or the stroke itself may change the brain causing someone to experience more intense emotional reactions than they used to. Stroke survivors told us they feel different emotionally as a result of their stroke. They are not the same as before.

We asked how different people feel in relation to their emotional health compared to before their stroke (on a scale of 1-10):

No different



Completely different

¹⁵Base: Nationally representative sample of 1880 stroke survivors and carers.

¹⁶Base: Nationally representative sample of 1880 stroke survivors and carers.



Dave "Emotionally I'm very different now"

Dave, 54 from Gateshead, was on a caravanning holiday with his wife when he had a stroke in September 2017.

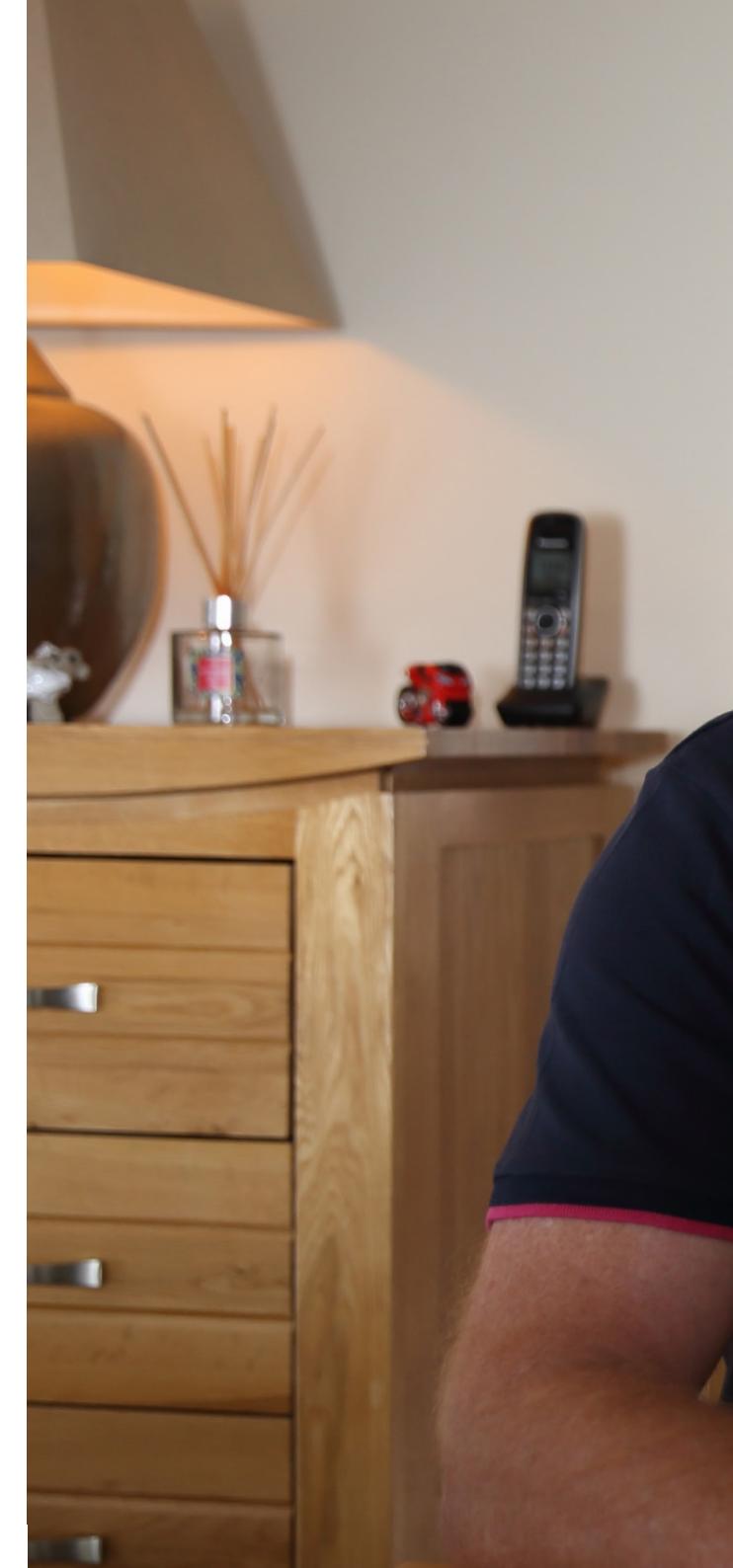
Dave said: "Every stroke is different. When I got home from hospital I was lucky in that I could walk, talk and use my hands, arms and legs, although not to the same extent as I could before my stroke. I know not everyone is lucky as me in that way."

"As a result, I started to change my life. I changed everything from diet to exercise, the whole lot. The lifestyle aspects are all the bits I had an influence over – I could change those. What goes on in your head is a different story."

"Emotionally I'm very different now since my stroke. I'm more likely to get upset, or breakdown; I would have never done that before my stroke. Before I was very practical and didn't really show any emotion."

"I'm trying to come to terms with being much more emotional, it's a strange feeling. It's difficult to avoid things that just happen and it makes me feel upset. The slightest little thing can get my blood pumping, which wouldn't have happened before the stroke."

"I'm also a lot more grumpy in my relationship with my wife. I try to be as calm as I used to be and still have a good laugh. Sometimes it's the little things that irritate me. Occasionally I'm not as polite. I obviously don't want to upset her, but sometimes it's just the way it goes."





"The psychological support has definitely helped me to come to terms with things. Both the NHS and the Stroke Association have been great.

"If I see people that I haven't seen for a while, they wouldn't know I had had a stroke. But they don't know what's happening in my mind."

"I'm trying to come to terms with being much more emotional, it's a strange feeling."

Dave

Road to recovery

Hidden effects do not just disappear. Stroke survivors have to adapt and alter the way they do things to cope.

Though a significant majority of stroke survivors continue to experience hidden effects, many stroke survivors begin to feel better. Seven out of ten people told us they feel close to full recovery.¹⁷

Given time, courage and support, stroke survivors learn to live with their hidden effects as they recover from stroke.

¹⁷Base: Nationally representative sample of 1880 stroke survivors and carers



"They didn't realise just how much I was hiding behind my smile"
Alisha

Alisha "My frustration led to me being angry."

Alisha, 29 from London, had a severe stroke in 2016 which left her unable to read, write, speak or walk. Alisha, who was a primary school teacher when she had her stroke, spent five months in hospital recovering.

She said: "Within an instant, I'd lost everything. I didn't know any words; hello, goodbye, mum, dad – they'd all gone.

"I had no idea what had happened to me, and I don't think I realised in hospital just how serious it was. I smiled and nodded to nurses and doctors, and everyone would tell me how well I looked. They didn't realise just how much I was hiding behind my smile; I remember being so confused by everything going on around me.

"Once I was home, I received regular speech therapy, physiotherapy and had an occupational therapist teaching me daily living skills. My days were full but I started feeling frustrated and fed up. I didn't understand why I couldn't do things as before. It started to get me down.

"My frustration led to me being angry. I wished I was in another place, but with help from my family and professionals I learnt to control these anxiety attacks. I wanted to be positive and motivated the way I used to be. I did not want to become an angry depressed soul. I persevered and I was determined to get through this and do more and more."

Alisha now attends the Stroke Association's support group at Harrow Arts Centre, and still has speech and language therapy.

"Speech and language therapy has been a huge help to my recovery, but it's really hard work. I've had to completely start from scratch. The Stroke Association's local support group has helped me to meet other stroke survivors who are in a similar position to me, which has been really helpful.

"It's not easy and life is never the same but giving up should not be an option because improvement, however small, does keep happening. Very few people understand the mental effects of stroke because you may look fine on the outside but they don't realise the internal struggle."

Securing better support for stroke survivors with hidden effects

Stroke is devastating. It changes people's lives.

At the Stroke Association, we influence across the UK to make sure that national stroke policies include support for the hidden effects of stroke.

We want decision-makers in all four UK nations to prioritise stroke. Stroke survivors deserve access to long-term psychological, cognitive and emotional support when they need it.

This kind of support is vital for stroke survivors to help them cope with hidden effects.

What we are doing in England

Developing a new National Stroke Programme with NHS England.

The Programme aims to improve many aspects of stroke care, including better psychological support for stroke survivors.

What we are doing in Northern Ireland

Working with the Department of Health to reshape stroke services. This aims to improve all aspects of stroke care, including more long term and psychological support for stroke survivors.

We are also launching a new Emotional Support Service.

What we are doing in Scotland

Working to influence the Scottish Government to reconfigure acute stroke services.

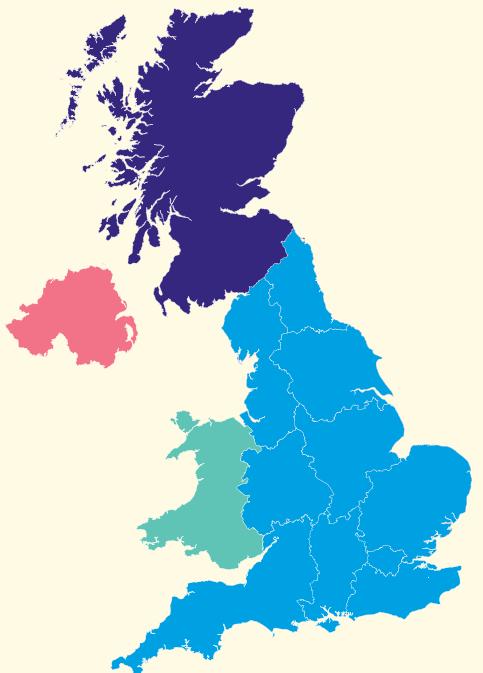
We believe reconfiguring acute services will be a catalyst for improvements across the stroke pathway

What we are doing in Wales

Working with the National Assembly for Wales's Cross Party Group on Stroke to scrutinise delivery of the Stroke Delivery Plan, to ensure it meets the needs of stroke survivors and their carers in Wales.

Life after stroke, including hidden effects, will be a key focus of this work.





We are here for stroke survivors too.

We know that the hidden effects of stroke can turn people's lives upside down. We are dedicated to helping stroke survivors and their families lead the best life possible.

We work across the UK to make sure that people affected by stroke can access support to help their recovery. We also partner with others to ensure they can help people affected by stroke.

Valuable emotional support is available through our helpline, who support thousands of people affected by stroke across the UK. Peer groups and colleagues who visit stroke survivors in their own homes also provide emotional support, which helps people to cope with the impact of stroke on their lives.

Advice and tips to help people to manage effects such as fatigue, poor memory or problems with concentration, are available as online resources and information leaflets. My Stroke Guide is available online 24/7 and features practical tools and videos to help people understand stroke and manage its effects.

We bring people affected by stroke together through our online community or at one of our many stroke groups that meets socially. Being connected to others who have had a similar experience helps people affected by stroke to gain confidence and to feel less alone.

For more information on the support we offer visit: stroke.org.uk/finding-support

We now know even more about the major impact of stroke on people's lives, including the hidden effects of stroke. Often these do not disappear with time.

Using the results of this survey, we will continue our efforts to make sure that stroke survivors are better supported with the damaging hidden effects of stroke. It is vital that we do so.



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.

Donate or find out more at stroke.org.uk.

Rebuilding lives after stroke

