Rebuilding lives after stroke

Our strategy from April 2019

Stroke Association
1. Our strategy

A stroke happens in the brain, the control centre for who we are and what we can do. Every five minutes, stroke destroys lives. Stroke can strike anyone – young, old and everyone in between, at any time. It is one of the leading causes of death and adult disability in the UK.

Stroke causes a wide range of physical and cognitive consequences that can have a sudden and massive effect on people’s lives. It can rob people of their movement, vision and ability to communicate, and cause fatigue, incontinence, memory problems, difficulties with problem-solving and depression. Every stroke is different, and many people are able to rebuild their lives in some way. But these consequences, often invisible, last a lifetime and frequently go unaddressed.

The condition also has a huge impact on the carers, families and friends of stroke survivors. Their lives are often turned upside down and they can struggle with the emotional and practical consequences of providing support. We estimate there are 7 million stroke survivors, carers and family members who are impacted by the consequences of stroke. We refer to these individuals and stroke survivors collectively as “people affected by stroke”.

There are over 1.2 million people living with the effects of stroke in the UK. And as our population ages, the number of strokes is projected to double over the next 20 years. So it’s vital that we act to ensure that stroke is better understood and stroke survivors and carers get the support they need now and in the future.

There are significant inequalities in treatment and support depending on where you live and between the four countries of the UK. Stroke is heavily associated with health and social inequalities. And the risk factors for stroke, most notably high blood pressure and irregular heartbeat, are greater among the poorest in society.

Stroke affects different people in different ways. But I would also like people to understand that it’s not their whole self. I’m still a person, still need to work, still have fun, still see my friends. It was just one thing that happened.”

Ruth, stroke survivor

Stroke is linked to a range of other complex conditions such as diabetes, vascular dementia, wider heart and circulation conditions and mental health problems. And half of the people who have a stroke also have four or more other long-term health conditions. This is why it’s crucial that post-stroke care considers the whole person, not just their stroke, and takes an integrated person-centred approach to their health, care and wellbeing.

We know that 80-90% of strokes are preventable. Rapid diagnosis and treatment are critical to survival and reducing disability. Rehabilitation and long-term support improve physical and emotional health and wellbeing. And an integrated, holistic approach to health and care delivers better outcomes.

Yet stroke outcomes in the UK compare badly to other developed countries around the world. The 2017 Commonwealth Fund rankings on health care outcomes place the UK 10th out of 11 developed countries, in large part due to our poor record on stroke and heart disease.

The economic case for tackling stroke as a priority is compelling. Stroke currently costs the UK economy £27 billion every year. Over half of these costs are borne by informal carers. Without improvements, these costs will treble by 2035. However, there are well-evidenced prevention, treatment and rehabilitation interventions that can significantly reduce the impact of stroke on people’s day-to-day lives, and the financial and social burden of stroke on our country.
Our vision is for there to be fewer strokes, and for people affected by stroke to get the help they need to live the best life they can.
4. Our core purpose

We want to be the trusted voice of stroke survivors and their families. We want to drive better outcomes in stroke prevention, treatment and lifelong support for everyone affected by stroke.

“We want to help stroke survivors and families, and to fund more stroke research. Anytime we do a challenge, we’ll try to turn it into a fundraising opportunity. We’re also keen to raise awareness about stroke and its risk factors as it’s not discussed as much as other diseases, despite having such a devastating impact on people’s lives. There are easy things to do to lower your risk, such as monitoring your blood pressure.”

Marcia, Fundraiser of the Year, Life After Stroke Awards 2018
5. Our three strategic goals

A. Make stroke the priority it needs to be

Stroke is the fourth leading cause of death in the UK. But it hasn’t received the public and political attention it needs – especially when compared to other conditions of equivalent scale and impact, such as cancer and dementia. This has had a considerable impact on stroke treatment and research.

Huge variations in the availability and delivery of stroke treatments across the UK are affecting people’s survival and recovery. For example, some stroke centres offer clot-busting thrombolysis to everyone who is eligible, while others aren’t able to offer it at all. This means that thousands of people who could benefit from this potentially life-saving treatment go without.

Similarly, up to 10,000 people a year could potentially benefit from thrombectomy, the game-changing clot retrieval procedure. Yet in 2016/17, fewer than 800 people in the UK received it. As a result, far too many stroke survivors live with avoidable disability.

Stroke research is also under-funded compared to other conditions. Currently the annual funding for stroke research equates to £48 for every stroke patient. This pales in comparison to £241 per person with cancer and £118 per person with dementia.

It’s imperative that we change this – stroke research is vital in creating the evidence, tools and techniques for future breakthroughs in treatment and care, in turn helping to reduce the personal and economic burden of stroke.

We want to see:

- Ambitious strategies and well-funded improvement plans which rival the best in the world.
- Closing inequality gaps in stroke treatment and outcomes.
- Increased investment in stroke research and capacity, that prioritises research that achieves the greatest impact for people rebuilding their lives after stroke.
- More people connected to stroke giving time, voice and money to rebuilding lives after stroke.

Millions of people across the UK have a connection to stroke, but most don’t see it as a cause that needs their involvement. We want these people to understand the scale and impact of stroke. To engage with stroke as a condition, take action to reduce their own stroke risk and benefit from support. And to inspire them to give time, voice and money to the cause.

It’s clear that stroke is playing catch-up. But we aim to drive it forward. We want governments, funders and providers in each country of the UK to make stroke the priority it needs to be.

“...It’s very easy when you have had a huge life-changing event to become lost, bitter and demotivated. That’s why it’s so important that stroke care is top of the agenda for survivors so they can see they will not just be left, but actually supported, helped and motivated to make a new path for themselves. Everyone, wherever they live, deserves the opportunity to live the best life they can.”
Karen, stroke survivor and campaigner
B. Ensure that everyone affected by stroke has access to the rehabilitation and lifelong support they need

45% of stroke survivors feel abandoned when they leave hospital. Many don’t have adequate access to quality therapies and rehabilitation, and only one third have a follow-up review. Consequently, stroke survivors and their carers often report high levels of unmet emotional and psychological need.

Stroke survivors are caught in a postcode lottery - where they live determines whether or not they’ll receive adequate rehabilitation and support. This could include physiotherapy, occupational therapy, and speech and language therapy, as well as help and advice to get back into education or work, peer support and social activities.

The quality, intensity and promptness of rehabilitation is directly linked to improved outcomes and reduced long-term costs. People supported to make a good recovery are less likely to require welfare support and social care, and less likely to re-enter the health and care system at its most expensive point – in hospital. Inadequate rehabilitation undermines improvements in acute treatments.

We want to see:

- Funders and providers increase investment in research and services for rehabilitation and lifelong support.
- Everyone affected by stroke has the information they need to make informed choices about treatment, care and support which help them to take more control of their ongoing recovery and rebuild their lives.
- A range of emotional, practical and social support offers available in the community for stroke survivors and carers wherever they live.
- More people benefit from our own support offerings.

“My Stroke Guide helped me to improve my reading, writing and confidence.”

Heidi, stroke survivor

“I had wonderful care from the hospital, rehabilitation, the Stroke Association and more. But some are not as fortunate. By involving stroke survivors and sharing different experiences, we’re making a real difference!”

Amber, stroke survivor
C. Partner with people and communities to help them take action on stroke

The health, social and political system is struggling to deal with the scale and impact of stroke.

Even if that were not the case there are many aspects of stroke support and care that are not best delivered by professionals or services. Compassionate communities are able to offer a constant and close-by presence, helping hand and companionship that are particularly effective in supporting people through loneliness, grieving, lack of confidence, stigma, or caregiver fatigue.

We also know that other stroke-related groups, such as the clinical and research communities, struggle to get their voices heard or influence policy and funding decisions nationally and locally.

We want to see:

• Communities - local and national, professional and social - advocating for and influencing action on stroke.
• Stroke survivors and carers bring their insight and empathy to improve stroke outcomes for themselves and others – and in doing so rebuild their own confidence and self-esteem.
• Stroke survivors benefit from and contribute to the human kindness found in all communities.
• An increase in the number of people within communities who are inspired to give time, voice or money to stroke.

“The group helped me get back to my old self. You feel like you’re part of something; you help people and they help you. We’re all there for each other.”

Ian, stroke survivor
6. How we behave

We’ve worked with our staff and volunteers to develop a set of values to guide our behaviour and interactions with each other. Our values are:

- **We are human.** We spend time getting to know people and recognise everyone’s individuality with kindness, putting ourselves in the shoes of the people we support.

- **We believe in better.** We want the best for people affected by stroke. We’re driven by a desire for improvement. We learn from mistakes and focus on the possibilities for a better future.

- **We say it how it is.** We listen to everyone’s needs, never over-promising, but focusing on what matters. We’re not afraid to challenge ourselves or others.

- **We give our all.** Our resolve to make a difference motivates everyone we work with. With one eye on the bigger picture, we harness our passion and expertise to inspire others to give their all.
7. How we work

Our staff developed a set of **principles** through conversations with stroke survivors, carers, volunteers, colleagues and other organisations. These principles inform and shape our decisions as we implement our strategy.

**We are stroke to the core.**
We focus on all aspects of stroke. We ensure that everything we do is informed by those with lived experience of stroke. We strive for genuine co-creation of ideas and actions with people affected by stroke. We want to ensure that we’re listening carefully to stroke survivors and carers, and that they’re heard by key policy makers and opinion formers. We want people affected by stroke to feel genuinely involved so that they can see the difference they make, including in our decision-making.

**We are in the conversation.**
Our expertise makes us the ‘go to’ organisation when it comes to stroke. We’re bold, brave and confident as we make sure that the voice of stroke survivors is always heard. We are credible and equal partners with health, social and political organisations, nationally and locally. We make sure that teams have the time, knowledge and skills to develop relationships and form alliances with a wider range of partners in the private, public and voluntary sectors. We add value through our leadership, expertise, independence, and trusted relationships. Making sure that the UK works better for stroke survivors.

**We know how to make an impact.**
We measure ourselves by the difference we make, rather than the work that we do. We believe that large impacts can sometimes be achieved with relatively small resources. We use evidence to inform decisions and actions, working together towards a shared set of outcomes. We’re transparent in what we do, holding ourselves and others to account. We’ll develop our capabilities to use data and evidence to inform our decision-making, service design and delivery. We’re a learning organisation that questions, tests, learns, adapts and shares, to improve.

**We unleash potential** in people affected by stroke, ourselves and others, harnessing the value and diversity that everyone brings to help deliver our goals. We invest in the culture, skills and knowledge of our people (volunteers and employees), strengthening our ability to deliver our goals. We focus on expertise over position – driving more collaboration, creating more cross-functional teams and embedding ownership and accountability at all levels of our charity. We recruit, keep and develop the best people to deliver our goals.

**We care for ourselves as for others.** Together we foster a culture of mutual respect and empowerment. We want to do more than practice kindness – we want to be an organisation that excels in it. This isn’t about making allowances and tolerating mediocrity. It’s about creating and protecting time and space for the kindness, wellbeing and authenticity that benefits us all. Whether that’s through small, everyday actions. Or through bigger programmes of support and change when we need it.

“Setting up the group is the best thing I’ve ever done and has given me a purpose. Without them, I wouldn’t be here today.”

Trudy, stroke survivor and volunteer
Underpinning everything we do is a focus on our internal productivity and efficiency. For us as a charity working in the health and social care space the financial climate is particularly challenging at the moment. Alongside our strategy to grow our income we need to do all we can to ensure expenditure is focused where it will have the most impact.

We’ll work across the board to ensure that as much money as possible goes to delivering our charitable objectives. We’ll drive organisational economy, efficiency and effectiveness across all of our teams and functions.
8. Our priority areas for action

Our strategic goals give us a long-term focus. We expect our priorities and activities to flex over time as we adapt to seize opportunities in the changing external environment and gain a deeper understanding of the needs of people affected by stroke. From April 2019, we’ll focus on:

- **Increasing our influencing nationally and locally.** We want to get political and health systems to commit to delivering comprehensive improvement programmes and increased funding for stroke across all areas. We’ll partner with commissioners and providers to transform services so they focus on outcomes that matter to people affected by stroke. In this work we’ll flag the importance of prevention at the population level for stroke and other conditions. We’ll also highlight the importance of investing in treatments and ongoing support for life after stroke.

- **Strengthening our leadership and impact in research** in order to leverage more funding into stroke research that’s equal to its prevalence and impact. We’ll build capacity to grow stroke research leaders across multiple disciplines. And we’ll ensure that our own investment goes into the areas of research that have the potential to have the greatest impact on people with stroke and life after stroke.

- **Targeting support** in order to reach more people and help communities most at risk of stroke and most in need of support. This will include developing our own universally accessible support offerings such as the helpline, website, My Stroke Guide, and information leaflets. And we’ll explore working with partners on further specialised and local opportunities.

- **Engaging and mobilising communities** in order to support them to take action on stroke as ambassadors and activists. We’re at the beginning of this journey and first need to understand how best we can support them either directly or through our partnerships and networks. This will involve us gathering insight, exploring and testing different approaches in collaboration with people affected by stroke and other partners. From there we can evaluate and learn what is most effective.

- **Increasing and improving public awareness and engagement** to dramatically change public attitudes about stroke and make it a public priority. We’ll continue to provide everyone with a positive experience of our charity, taking a more joined up approach to engaging our beneficiaries and supporters so that more people get and give support. This will enable us to fulfil our purpose, grow and make the transformational impact that people affected by stroke need and deserve.

9. The difference we want to see

We’ll only realise this vision and these goals by working collaboratively across the whole health and care system. We’ve identified a set of long-term objectives, referred to as system impacts. These can’t be delivered by us - or any other single organisation - alone, but we can achieve them together.

We’ll consult with our partners about our proposed system impact measures. But as a starting point, these are the impacts that we want to collectively track across the UK and within each nation:

- Reduce the incidence of stroke, taking account of changes in population
- Reduce the proportion of strokes which are fatal or result in institutionalisation
- Increase the proportion of people who are able to access appropriate treatment
- Reduce the self-reported physical, cognitive and emotional impacts of stroke
- Increase proportion of people helped by the support they receive after a stroke
- Improve the position of the UK in international rankings for stroke outcomes

We’ll use evidence from insight and research to develop a balanced and sustainable approach to our universal, local and more personalised support.
When stroke strikes, part of your brain shuts down. And so does a part of you. That’s because a stroke happens in the brain, the control centre for who we are and what we can do. It happens every five minutes in the UK and changes lives instantly. Recovery is tough, but with the right specialist support and a ton of courage and determination, 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

Contact us
We’re here for you. Contact us for expert information and support by phone, email and online.
Stroke Helpline: 0303 3033 100
From a textphone: 18001 0303 3033 100
Email: helpline@stroke.org.uk
Website: stroke.org.uk

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