

Feeling overwhelmed

The emotional impact of stroke

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Foreword

Stroke is life-changing and the emotional impact can be far-reaching for both the stroke survivor and their carer. But it doesn't seem to be much talked about. We'd like to change that.

There are approximately 1.1 million stroke survivors living in the UK.¹ *Feeling overwhelmed*, the third report in our Life After Stroke campaign series, highlights the emotional impact of stroke on survivors, their carers and families. We call on those who plan and provide health and social care to work with us to address this serious and underappreciated problem.

Stroke is a sudden, life-changing event. Stroke survivors grieve for the life and identity they have lost so suddenly and unexpectedly. They often feel intensely frustrated and angry at being unable to carry out the simple, everyday tasks they used to take for granted. Anxiety and depression can also result from the damage caused by the stroke itself. Carers are suffering too and are often left to cope alone.

In this report you will hear how only two in ten stroke survivors and one in ten carers received the support they needed to cope with the emotional aspects of stroke. The Stroke Association's services offer emotional support but currently we are only commissioned to see around 40% of stroke survivors in the UK.² We support many more through our UK-wide helpline, information leaflets, stroke.org.uk and stroke clubs. But we want to reach everyone affected by stroke. To do this we need your help.

Our report shows that improving emotional support for people affected by stroke is not necessarily about spending more money. Signposting and referrals to existing services (including free sources of information), combined with duplicating best practice examples, can deliver support that puts the needs of stroke survivors and carers at the centre of stroke care. Underpinning this report you will see mention of the *Stroke Survivors' Declaration*, written by 120 stroke survivors across the UK it sets out the level of support people affected by stroke expect.³

If you are involved in planning or providing health and social care your role is crucial in helping stroke survivors and carers deal with the emotional impact of stroke. We can help you to signpost stroke survivors and carers to the information, practical advice and emotional support they need. We are building a community of people who care about stroke and want to see people make their best recoveries. Please see our calls to action on page seven and sign up online to show your support, hear about best practice and access free sources of information.

Show your support at stroke.org.uk/campaigns/signup or by scanning this code using a smart-phone.

Jon Barrick
Chief Executive
Stroke Association



Key findings of this report

The emotional impact of stroke can be just as devastating as the physical effects.

During the autumn of 2012 we surveyed people affected by stroke to find out about the emotional impact that stroke has had on their lives and whether they had received the support they needed to help them cope. We received over 2,700 responses and this report is based on what they told us.

Please note that all data presented is UK-wide, however breakdown by nations can be found online at stroke.org.uk/campaigns/feeling-overwhelmed

What stroke survivors told us

- Only two in ten were given information, advice and support on coping with the emotional aspects of stroke.
- Almost two-thirds agreed or strongly agreed that their emotional needs were not looked after as well as their physical needs.
- Although 67% had experienced anxiety and 59% felt depressed, over half of those who responded to our survey did not receive any information, advice or support to help with anxiety or depression.
- Nearly half said their relationships or contact with friends and families had been put under strain.

What carers told us

- Two-thirds had experienced difficulties in their personal relationships with a husband, wife or partner as a result of stroke. Of these, one in ten had broken up with their partner, or considered doing so.
- Caring gets harder as time goes by. For those who have been caring for up to three years 48% said they were stressed by caring, but when they had been caring for seven years or more 69% of carers said this was the case.
- Three-quarters agreed or strongly agreed that they put the needs of the stroke survivor above their own needs.
- Although 79% had experienced anxiety and 56% felt depressed, two-thirds did not receive any information, advice or support to help with anxiety or depression.

Everyone reading this report can improve the emotional wellbeing of stroke survivors and carers by recognising the serious emotional impact of stroke and by being confident in signposting people to further help.

Why focus on the emotional impact of stroke?

Both stroke survivors and their carers can feel overwhelmed by worries, fears and emotions as they struggle to cope with the aftermath of a stroke. If these feelings are not recognised and addressed at an early stage they can lead to more complex and costly health and social care interventions.

Previous research has shown that:

- Healthcare costs for patients with long-term conditions who also have depression are typically 45% higher than for those without.⁴
- Depression also increases the risk of cardiovascular disease (including stroke) by one and a half times as compared with the general population, so stroke survivors presenting with depression are more likely to have another stroke.⁵
- Over half of carers for someone who has had a stroke have experienced mental health problems.⁶
- However, over half of stroke units in England, Wales and Northern Ireland still have no access to psychology services at all.⁷ In Scotland only a third of stroke units have access to clinical psychology services.⁸
- Work by the Stroke Improvement Programme (in England) indicates that an investment of around £69,000 in psychological care through a clinical psychologist-led service, with clinical psychology assistant support and an appropriately trained multi-disciplinary team, may deliver a benefit of around £108,000 to the NHS and social care in around two years.⁹

Each of the four UK national governments has also put a strong focus on emotional wellbeing:

- In England, the Department of Health's new *Cardiovascular Disease Outcomes Strategy* (2013) calls on commissioners and providers to pay particular attention to the emotional and psychological support of stroke survivors and carers.¹⁰
- In Northern Ireland, *Transforming Your Care* (2011) includes recommendations around promoting mental health and wellbeing.¹¹
- In Scotland, the *Better Heart Disease and Stroke Care Action Plan* (2009) recognises the emotional impact of stroke and the need for better access to psychological support in hospital and the community.¹²
- The Welsh Government's *Together for health – Stroke Delivery Plan* (2012) states that Local Health Boards should provide robust psychological support in hospital.¹³

Our calls to action

All stroke survivors, their carers and families deserve the best possible support to help them cope with the emotional impact of stroke. Together with them, we call on those who plan and provide health and social care to:

- 1 Recognise that emotional support is just as crucial for recovery as physical rehabilitation after stroke, and make sure that services are in place to support this.
- 2 Ensure all stroke survivors, their carers and families are given accurate, timely, and accessible information at all stages of their stroke journey to help them adjust to the emotional impact of stroke.
- 3 Ensure that all stroke survivors receive a regular review of their health and social care needs that should include an assessment of their emotional and psychological wellbeing. Survivors' emotional wellbeing should also be a key part of their health and social care plans.
- 4 Recognise carers as "partners in care" and include them in the stroke survivor's ongoing stroke journey towards recovery, whatever their individual goals.
- 5 Ensure all carers are aware of, and receive, a carer's assessment. This assessment should include a review of their emotional wellbeing and result in them getting the help they need.
- 6 Ensure stroke survivors who are affected by aphasia can easily access support, from community based services, other people with aphasia, or from stroke clubs.
- 7 Increase investment in the provision of clinical psychologists, who should ideally be part of the multi-disciplinary stroke team, both in hospital and in the community.
- 8 Support children and younger stroke survivors from diagnosis, through sign-posting to peer support groups and ensuring a seamless transition to adult services. This must include more effective assessment and treatment of the emotional and psychological impact of stroke on children and younger stroke survivors and their families.
- 9 Ensure the monitoring and publishing of data on the long-term emotional experiences of survivors, carers and families to show if and how they are accessing emotional support, for how long, and whether their needs are met. This should look at people's experiences beyond the stroke pathway and focus on the stroke journey taken by survivors and carers.
- 10 Ensure that health and social care providers share best practice. If you're particularly proud of your service or the work that you're doing to help people affected by stroke please get in touch with us at campaigns@stroke.org.uk so we can share your best practice with others.

Patricia's story

Patricia worked in London in a high-powered job. Already signed off temporarily due to a lung condition and in hospital being treated for an aneurysm, it was a triple blow when she had a stroke. Patricia still can't quite believe it happened to her.

She was rushed to a specialist stroke unit where she received life-saving, clot-busting drugs. She spent one month in hospital and her treatment was good. Despite this, she was left paralysed down one side, and the stroke also affected her speech.

Patricia received occupational therapy and physiotherapy in hospital, but once discharged there was a two-month gap without therapy, support or information. During this period, "I was expected to go it alone in a depressed and debilitated state," says Patricia.

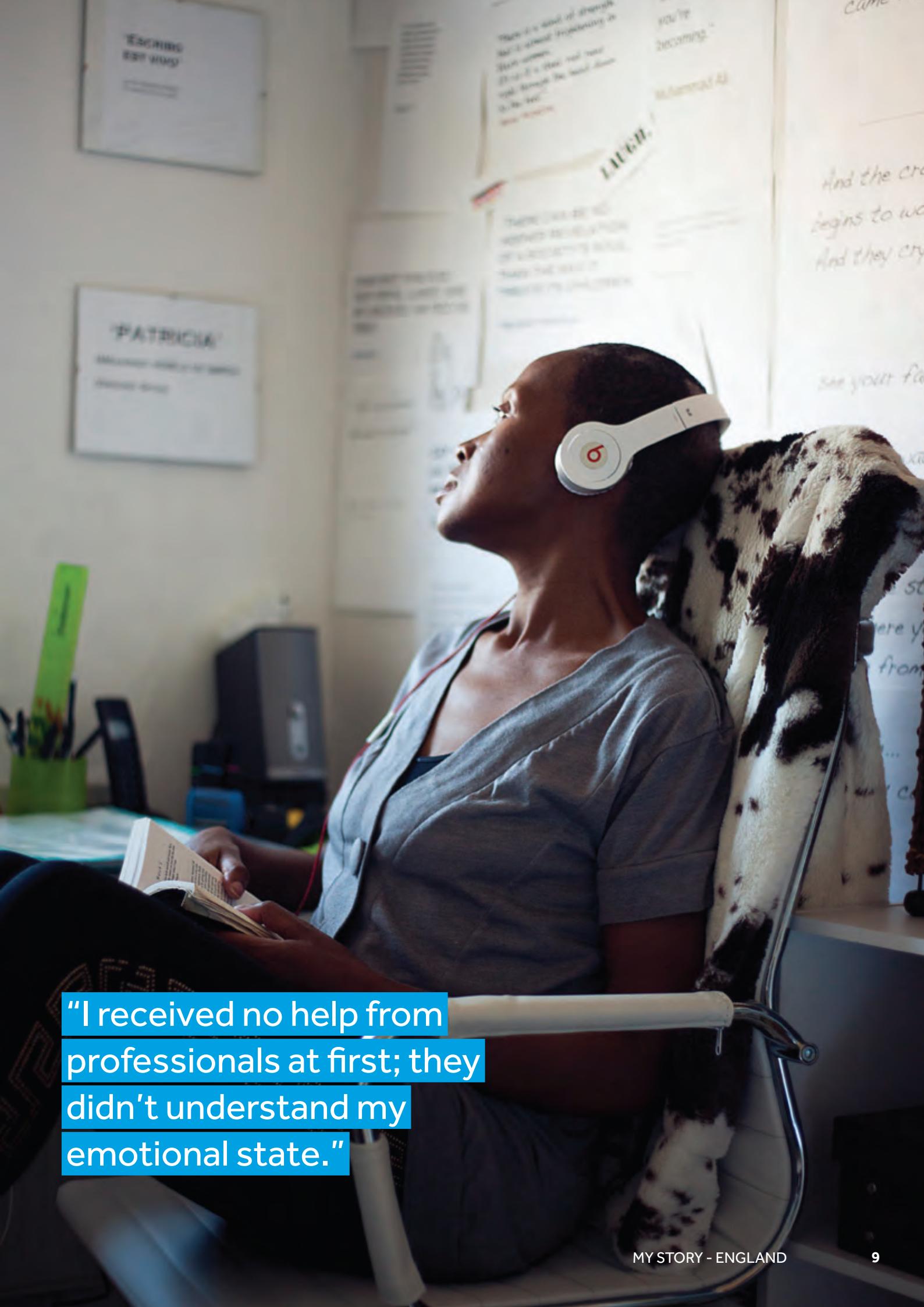
"I received no help from professionals at first; they didn't understand my emotional state. When I cried, they didn't know what to do; despite the fact that I had been told by them that a right-sided stroke would directly affect my emotions."

She also found it hard to talk about the stroke with friends and family. "I still don't like to burden them with it." She says she "wears a mask", even with her brother who lives close and comes round to help her when she can't cope. Instead, Patricia talks about her feelings through poetry. "This was how my family found out about how I really feel."

Patricia still feels intense frustration and depression. "The stroke was such a shock at my young age, I'm still struggling to accept it." But the counselling she now receives helps; as does performing her poetry and talking to nurses and companies about her stroke journey.

But her stroke journey isn't over yet. "People say things like 'oh, you're almost there, you're almost recovered', but they don't understand that the last 5% of recovery is the hardest. Each time I've taken a step forward, something has knocked me several steps back, and the last 5% of my recovery feels more like 50%."

"I don't like to burden my friends and family with my stroke. Around them I wear a mask."



"I received no help from professionals at first; they didn't understand my emotional state."

The emotional strain on stroke survivors

The emotional impact of stroke can be just as profound as the physical effects.

"The emotional side of stroke is a wasteland. Many of the emotional issues arrive not at the time of the stroke, when all you are doing is trying to get well again physically, but it's months later when the reality hits that you will never be the person you once were."

A stroke survivor

Throughout this report people recount the daily problems, worries and fears they have experienced, and how support and understanding is at best patchy and at the worst absent as they struggle to recover.

The full extent of the emotional impact is not always obvious until the stroke survivor returns home and the reality of the situation sinks in.

Stroke can leave a long-term emotional legacy, which survivors and carers are usually totally unprepared for. The journey to recovery taken by survivors and carers continues even when the formal help from health and social care tails off.

While seven in ten survivors agreed or strongly agreed that they felt well looked after and cared for when in hospital, more than four in ten felt abandoned after leaving.

The day to day emotional effects of stroke

Almost three-quarters of stroke survivors said they felt less confident after their stroke. They grieve for the life they've lost and feel intense frustration at not being able to complete simple, everyday tasks that others take for granted. These hidden, but very real, worries can change relationships with partners and friends, leading to further social isolation.

To make matters worse, many stroke survivors in our survey (63%) said their greatest fear is having another stroke. They also have other concerns: for example, 48% of survivors reported a lack of motivation or feeling angry. Three-quarters of all strokes happen to people over the age of 65, who may also be suffering from a range of other health conditions which can also affect their emotional wellbeing.¹⁴

However, in our survey, the emotional impact of stroke was particularly evident for those aged 30-59 years who reported high levels of anxiety (76%), depression (69%) and fear (55%).

Many survivors are acutely aware of the impact of the stroke on their partner and family, and feel that they have become a burden. Yet, despite this, 69% said they still felt they "had to stay strong for their family". This report calls for searching discussions by all involved in stroke about the often harrowing emotional impacts of the condition, to help everyone touched by stroke adjust to their new reality.

Stroke, anxiety and depression

"I would not wish what I've been through on my worst enemy. I've battled with depression and fatigue but I no longer consider suicide on a daily basis. I can talk and I make myself do things. Life is a constant daily struggle."

A stroke survivor

When the part of the brain that normally controls emotions becomes damaged by a stroke, the result can be a change in how people think, feel or behave.

Stroke survivors can experience a range of emotions following a stroke, such as anxiety, depression, anger and frustration. They may become more emotional than usual or have difficulty controlling emotions ("emotionalism"). Moreover, a stroke can cause changes to personality so that to others the survivor seems like a different person.

Given the scale of the problems reported by respondents to our survey, it is clear that a lot more needs to be done to support the emotional wellbeing of stroke survivors and their carers. If emotional problems are not identified and addressed early, they can lead to more serious psychological problems, such as anxiety, phobia and depression. At worst they can result in a suicide.¹⁵

The regular assessments that should form part of the stroke pathway can pick up emotional issues if the right questions are asked. It is then key to ensure that people get access to the appropriate level of emotional support, or more serious emotional problems can result.

In our survey 67% of stroke survivors reported suffering anxiety and 59% felt depressed. Our findings reinforce other studies which found high rates of depression in stroke survivors.¹⁶

Stroke can be a traumatic and frightening event and stroke survivors can experience Post-Traumatic Stress Disorder (PTSD). One study found that up to one-third of stroke survivors experience the symptoms of PTSD.¹⁷ Again early identification is critical.

Stroke Survivors' Declaration point seven:
My mental health and physical needs will be recognised and I will be able to access the relevant support.¹⁸

The wider healthcare cost implications

Healthcare costs for patients with long-term conditions who also have depression are typically 45% higher than for those patients not presenting with depression.¹⁹

When a physical illness like stroke is accompanied by mental illness it worsens outcomes such as life expectancy.²⁰

Stroke survivors who are depressed are four times more likely to die within six months as those who are not.²¹

Depression also increases the risk of stroke by one and a half times, so stroke survivors with depression are more likely to have another stroke.²² But current provision to treat stroke survivors with depression can be inadequate.

There is also a strong economic case for investment in psychological support.

Work by the NHS Stroke Improvement Programme indicates that an investment of around £69,000 in psychological care through a clinical psychologist-led service, with clinical psychology assistant support and an appropriately trained multi-disciplinary team, may deliver a benefit of around £108,000 to the NHS and social care in around two years.²³

Psychological support is lacking across the UK despite each of the four national governments putting a strong focus on emotional wellbeing. Over half of stroke units in England, Wales and Northern Ireland still have no access to psychology services at all.²⁴ In Scotland only a third of stroke units have access to clinical psychology services.²⁵

The importance of information

"I was offered tablets for depression, when I wanted therapy and verbal support to deal with the changes in my role."

A stroke survivor

Information empowers people; it helps them to understand what has happened, plan for the future and better manage their situation. Despite this, half (52%) of stroke survivors participating in our survey did not receive any information, advice or support with anxiety and (56%) reported a similar lack of help with depression.

These findings chime with those of our 2010 research, where four in ten (39%) survivors reported their need for help with emotional problems was unmet.²⁶ (See pages 38-39 for further information).

Call to action for those who plan and provide health and social care

Ensure that all stroke survivors receive a regular review of their health and social care needs that should include an assessment of their emotional and psychological wellbeing. Survivors' emotional wellbeing should also be a key part of their health and social care plans.

Ann's story

Neil was a fit, active man so it was a total shock when he had a stroke; and then another. His second stroke, the most severe, left him with slow and slurred speech, and he had to get around the house on his hands and knees.

But this story isn't about Neil. It is about Ann, his wife.

Ann feels as if she has a different husband now. His personality has changed and, for a year, Ann grieved for the man she had lost, the man he used to be.

Finances became a worry. They had a mortgage to pay and Ann wasn't sure if Neil ever would be able to return to work. Neil went back to work six months after his stroke, part time. But their entire relationship had changed. They argued a lot and the worry and grief began to make Ann physically ill.

Neil didn't realise he'd changed at first, but once he did he told Ann he wouldn't blame her if she left him. She was just thankful that he was still alive and she slowly felt more able to accept the "new him".

Neil was beginning to sink into depression and Ann, realising, sought help from a local mental health team which helped get him back on track. But Ann, who herself felt incredibly isolated, worried and low, wasn't offered any support at all, other than from their family.

After reading an article in the local paper, Ann was put in touch with a local stroke club. It was through the club she realised they weren't alone, that other people were going through a similar experience and that personality change could accompany a stroke. The Stroke Association also put Ann on a course about how to cope after stroke, which helped her enormously.

Neil still struggles with the fatigue, and gets frustrated because he used to be so active. "Neil's still not the man I married but he's slowly coming back; he's becoming 'him' again.

"Things are beginning to get easier, but it's been a long, hard journey and it's not over yet."

Her husband's personality changed and, for a year, Ann grieved for the man she had lost, the man he used to be.



"Things are beginning to get easier, but it's been a long, hard journey and it's not over yet."

The emotional impact of stroke on carers

Carers play a vital and very demanding role. Without them many stroke survivors would be unable to live independently.

Currently less than a quarter of carers feel supported after the stroke survivor they care for leaves hospital. Recovering from stroke is not just about providing support along the stroke pathway – it is about supporting stroke survivors and their carers along their whole personal stroke journey, however long that takes.

Perhaps the worst news is that being a carer doesn't seem to get any easier. In our survey we asked people if they were stressed by caring. For those who had been a carer for up to three years 48% said they were stressed by caring, but when they had been caring for seven years or more 69% of carers said this was the case. Two-thirds of all carers who responded to our survey had experienced difficulties in their personal relationships with a husband, wife or partner as a result of stroke. Of these, one in ten had broken up with their partner, or considered doing so.

We also need to acknowledge that many stroke survivors and carers will have multiple health problems and these issues are likely to increase with an ageing population and the increase in diseases like diabetes, which is a known risk factor for stroke. The need to support carers properly will therefore become an even larger issue.

"My husband's stroke has been the most devastating experience of my, and his, life. First you have to rebuild the survivor and their life. Then your joint lives together and, if you have any energy left, you can have a go at remembering who you are."

A carer



The challenges faced by carers

Carers of stroke survivors face many challenges. Many carers are not getting the support they need, and their own health is suffering. They care out of duty and love but usually without any training, information or support, and they learn their caring role as they go along. Carers have told us how they feel guilty or selfish for finding it hard to cope or wanting time for themselves.

Too many carers are not receiving the information or support they need to help them adjust to life after stroke. Carers are also exhausted – eight in ten tell us they don't have enough time to themselves and six in ten are not getting enough sleep.

Caring can be physically demanding as it involves helping stroke survivors with tasks like washing, dressing and lifting. As a result, carers can experience a range of physical problems, which may include tiredness, back strain from lifting and illness. Over half of the carers in our survey also told us they have difficulty communicating with their partner because they have cognitive and/or speech deficits following their stroke.²⁷

"No one really realises how I am suffering, my husband comes across to people that don't know him as fine and healthy, but they don't realise he looks like my husband but the stroke took his personality away. I am suffering as he now hates me and because of his cognitive problems he doesn't realise I am here to help him."

A carer

But 64% of carers said that the emotional impact of stroke was by far the hardest thing to cope with. Our survey shows that levels of anxiety and depression are as high for carers as for stroke survivors. Over half of carers for someone who has had a stroke have experienced mental health problems.²⁸

Carers are entitled to an assessment of their needs, but many don't know how to go about getting one. Only a quarter told us they would know where to get an assessment.²⁹ When they do find out how to, many are told that they are ineligible.

Stroke Survivors' Declaration point ten:

The impact of my stroke on my carers will be recognised. They will have access to appropriate information and services to help them understand and make adjustments.³⁰

How stroke affects carers emotionally

"He is like Jekyll and Hyde, going from a loving husband to someone constantly belittling and criticising, which is very difficult to deal with. I am now on anti-depressants and have been for the last year."

A carer

Caring for a stroke survivor can be emotionally demanding. Survivors can find it difficult to understand, or communicate what they would like or how they are feeling. They may also feel depressed, have mood swings and vent their anger on carers. Carers responding to our survey also had a range of emotions as a result of stroke occurring in their families, including frustration (84%) and anxiety (79%).

They were also more likely than stroke survivors to feel angry, with over six in ten carers reporting this compared to half of stroke survivors. A number of respondents told us that they needed time to grieve for the person they had lost and the plans they had for the future, but there is often no recognition of this.

"After 18 years of looking after my husband I seem to be going through another stage of depression and frustration having to still ask for financial assistance for respite. I feel it is an uphill struggle even now."

A carer

Six in ten carers did not receive any information, advice or support to help with anxiety and seven in ten said the same for help around depression.

Fewer than two in ten carers were given information on coping with the emotional aspects of stroke. By delaying asking carers about these issues and how they are coping we are storing up future problems that will affect both the carer and the stroke survivor.

Enquiring after the emotional wellbeing of carers makes good sense and should be a priority, particularly as so much of what can be provided, in terms of support, costs very little.

What happens after discharge from hospital?

"We were initially strongly supported by the Early Discharge Team. A little way down the line the support is tailing off and I have to go and look for it myself as my husband has become severely depressed and attempted suicide."

A carer

Only one in five carers was asked if they would take on caring responsibilities. Many carers told us that there was an expectation from health and social care professionals that they would be the carer, and they felt ill-prepared to take on the role.

According to one study, one month after the stroke survivor was discharged from hospital 33% of carers reported feeling ill-prepared to take on their caring role. After nine months this had risen to 72%.³¹

We believe that there is an important role for training here. Providing carers with training has been shown to improve their psychological outcomes and reduces the total health and social care costs.³² The Stroke Association can provide this kind of training.

Not only do carers feel unsupported and stressed, but fewer than four in ten felt their knowledge of the stroke survivor was respected or valued. This is despite guidelines stating that carers should be viewed as an additional source of important information about the patient, both clinically and socially.³³

Many carers told us that they feel they have to fight tooth and nail to get services they or their loved one needs.

"I wish hospital and healthcare staff would listen to information about the patient and where possible and practical act upon it, instead of ignoring it. Most carers know more about the stroke survivor's physical and emotional problems than someone who has only just met them."

Call to action for those who plan and provide health and social care

Ensure all carers are aware of, and receive, a carer's assessment. This assessment should include a review of their emotional wellbeing and result in them getting the help they need.

Inger's story

Holding down a high-powered job at London's Royal Academy, responsible for a budget of millions, Inger was in the prime of her working life and watching her two children blossom into young women. But one day, home alone, she had a stroke.

"I felt a rushing in my ears. At first I thought it was food poisoning, but I was so violently ill that I knew something was terribly wrong." Inger called an ambulance, begging them to stay on the line, fearing she would die.

She was taken to hospital, scanned quickly and a stroke was diagnosed – a bleed in the brain. But Inger had to leave hospital earlier than planned due to MRSA on the ward. Then it was down to her husband.

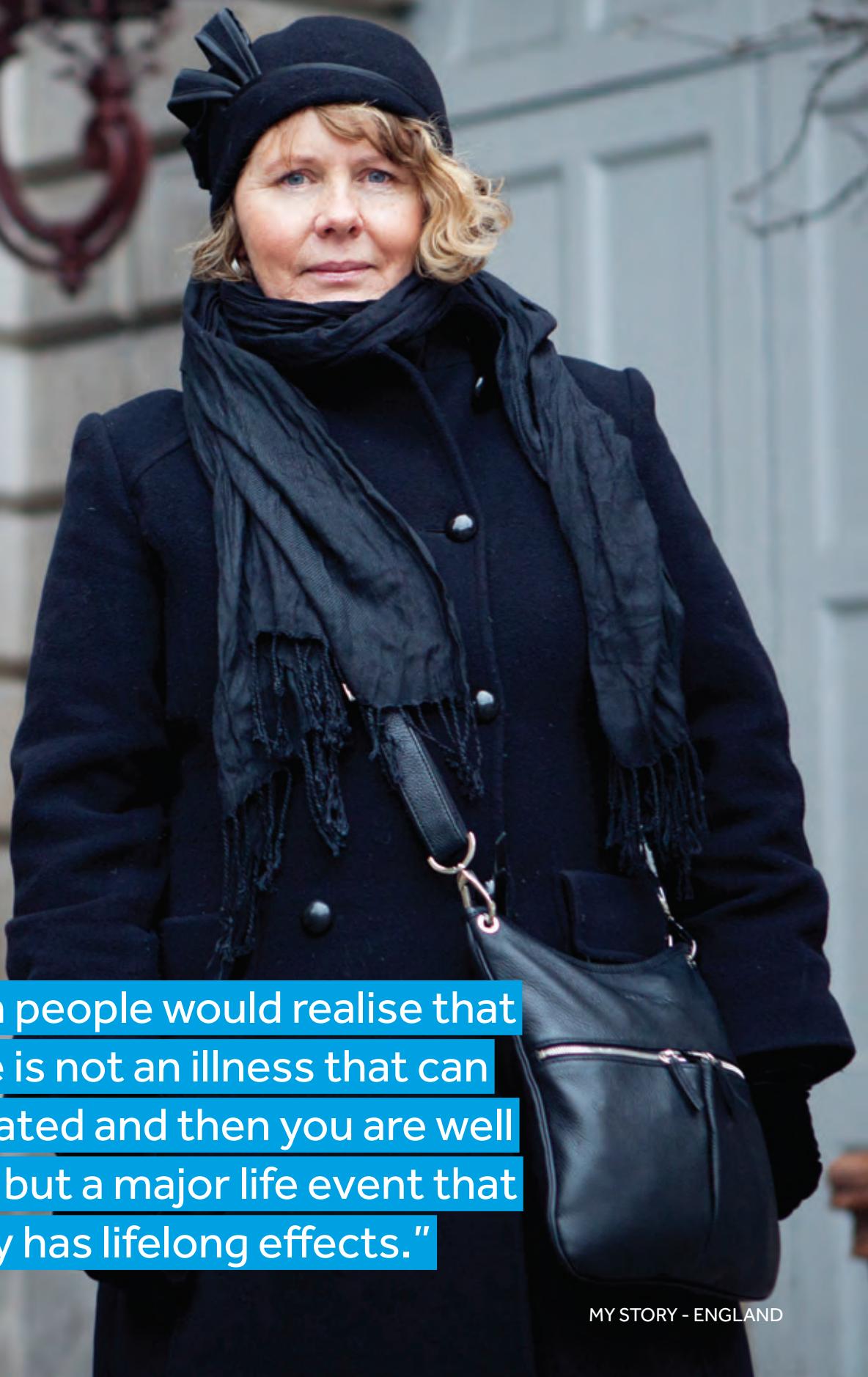
For six months Inger felt drained, slow and detached. "It was almost like being drunk, not having full control. The ramifications are horrendous. I still can't even relax with a book; reading is challenging. I wish people would realise that stroke is not an illness that can be treated and then you are well again, but a major life event that usually has lifelong effects."

Inger's now back at the Academy, but in a different role and only part time. "My job used to be part of my identity. I used to be a gold-standard multi-tasker, but the part of my brain that made me so good is damaged."

Since then, Inger's been diagnosed with Post-Traumatic Stress Disorder. Her partner became depressed. Intimacy became a big issue, both fearing a stroke could happen again. Inger worried he viewed her "as an invalid rather than a partner" but there wasn't any specialist counselling available.

Inger became involved in campaigning on stroke issues, and this has brought new and valuable friendships. But has she recovered? "My family sometimes talk about the road to recovery, but it's not a choice, or a lack of effort. It's a road to adjustment. Adjustment is the best hope for me."

"I used to be a gold-standard multi-tasker, but the part of my brain that made me so good is damaged."



"I wish people would realise that stroke is not an illness that can be treated and then you are well again, but a major life event that usually has lifelong effects."

How relationships, families and friendships feel the pressure

The impact of stroke is not restricted to individuals; it also throws families into crisis. The majority of stroke survivors and carers are emotionally affected by stroke but too many feel that they are facing its consequences on their own.

"I never ever realised how difficult it would be looking after someone who has had a stroke, it has nearly destroyed our relationship, and has left me feeling angry, bitter and resentful."

A carer

The emotional impact ripples through families. Nearly seven in ten stroke survivors told us they "try to stay strong for the family" while at the same time three-quarters of carers said they "put the needs of the stroke survivor above their own". With both parties not feeling comfortable or able to express how they really feel following a stroke, there can be a negative impact on partnerships and the entire family.

How the whole family cope following a loved one having a stroke is a largely unexplored area in research terms. Dr Caroline Kinney an NHS Stroke Clinical Psychologist says: "the impact on family systems is complex and therefore all members of the family need support in understanding what has happened."

The importance of maintaining friendships after stroke

Friendship is not the same as family support or social support, but both can be invaluable to the stroke survivor and carer in that they represent the "real" world. However, in our survey over half of the stroke survivors who responded told us they were being treated differently by friends after their stroke.

"I lost a lot of so-called friends who promised to come and see me but never did."

A stroke survivor

"I feel judged by friends and colleagues because although I appear fairly normal I still don't drive and find a lot of things exhausting. My husband is immensely supportive but I think friends think I am a pain."

A stroke survivor

Some stroke survivors in our survey told us that friends seem uncomfortable or awkward around them and are unsure how to act. Keeping friendships was also mentioned as an issue by a number of stroke survivors, as some friends stop seeing them altogether, leaving them further socially isolated.

Research has highlighted that friendships are an untapped resource in supporting rehabilitation, self-management, participation and wellbeing following stroke.³⁴ Different friends can play different roles in helping to support stroke survivors in re-establishing their identity.

How couples are affected

"After my stroke, during recovery, my wife left me, and I now feel my world is falling apart around me. I feel totally depressed and unable to move on."

A stroke survivor

Partners, friends and families are under strain and the build-up of frustration, anger, anxiety and exhaustion exact a particular toll on relationships. The emotional impact of stroke can lead to family breakdown.

In our survey, about a third have broken up with their partner or have considered doing so. 56% say their intimate relationship with their partner has suffered, and 34% feel they have no one to talk to. That's why well-coordinated support in the community is so important. Relationship difficulties were especially high for the 30-59 age group (61%), of whom 44% had broken up or considered doing so.

Couples can have different reactions to stroke depending on how the relationship was formed, what each person's expectations are, what their roles were, and what each partner feels they contribute towards their relationship. Some people feel rejected by their partner even though they have not been. Others feel that their partner should reject them. Conflict can also occur where a partner is trying to support a stroke survivor but is inadvertently causing them stress.

Clinical psychologists or stroke staff who have received psychological training, can provide counselling to couples to help them understand what is happening and support them to adjust to changes in their relationship. Other organisations, such as the Stroke Association and RELATE can also offer support to families.

"Straight after my stroke I actually wanted to divorce my wife in order to leave her in a good financial position and without me as a burden."

A stroke survivor

Stroke Survivors' Declaration point ten:

The impact of my stroke on my family will be recognised. They will have access to appropriate information and services to help them understand and make adjustments.³⁵

Call to action for those who plan and provide health and social care

Recognise carers as "partners in care" and include them in the stroke survivor's ongoing stroke journey towards recovery, whatever their individual goals.

Marie and Paul's story

Paul was in his fifties, the finance director of a large company and into sport. Then like "a thunderbolt from the blue" Paul had a stroke.

In hospital Paul had problems communicating his needs. His wife Marie takes up the story. "He would say 'yes' to a cup of tea, but couldn't say what he'd normally say after that, such as 'are there any biscuits?' We had months of speech therapy."

It wasn't until they started speech therapy that aphasia was mentioned. "I'd never heard of the word; neither had some of the nurses; but we learnt what it meant very quickly." ³⁶

Back home, Paul didn't seem particularly distressed, but Marie was "terrified". Paul was on an emotional high. He started doing strange things such as eating soup with a fork and laughing at inappropriate times. "I don't think he understood what had happened. It was like being with a silly child."

Six months after his stroke, Paul went back to work, but lasted only three months because he couldn't concentrate and process information quickly enough. And the fatigue was "phenomenal".

There were days when Marie didn't feel she was in a relationship. "He's not the man I married. I would never have chosen to marry someone like this. People say I came off the rails and my anger was enormous." But the speech therapist was wonderful. "I could lean on her and cry and she understood."

"Paul's biggest problem after the stroke was lack of confidence and he still prefers me to answer the phone. But if I take the calls I'm doing him no favours."

Five years on, Marie and Paul are closer than ever, Marie is back at work and Paul's rehearsing speeches for two of his daughters' weddings!

"I cannot believe how lucky we've been, and that Paul is still improving. It's quite amazing. I'm so proud of him, and I wish I could help more people with aphasia because I've learned so much from this experience."

Paul went back to work, but lasted only three months because he couldn't concentrate and process information quickly enough.



"I cannot believe how lucky we've been, and that Paul is still improving. It's quite amazing."

The devastating impact of aphasia

Aphasia is a common side effect of stroke. As many as one in three survivors will experience it.³⁷ Aphasia (also known as dysphasia) does not damage intelligence but does affect how someone speaks, understands, reads or writes.

"I get frustrated when people can't understand me."

A stroke survivor

Aphasia can be mild, and sometimes only affects one form of communication, such as reading. However, it is more common for several aspects of communication to be affected at the same time.

Aphasia can also sometimes cause subtle changes to emotional aspects of speech. For example, the stroke survivor's tone of voice may sound "flat" or their facial expressions may not vary. Stroke survivors with aphasia may also have difficulty in understanding humour or when to take turns in conversation. They may, or may not, be aware of these effects.

What support do people with aphasia need?

"I was discharged from hospital after 7 days of having my stroke, unable to speak, write, no letter recognition, barely able to walk. My children were 16 and 14 and they provided all of my care."

A stroke survivor

Survivors with aphasia need specialist support from professionals who understand the challenges and emotional impact stroke and aphasia bring, as too often health and social care professionals haven't even heard of it. The Stroke Association has developed skills and experience to help people with aphasia.

"Because I looked and still look physically well, I had hardly any help in dealing with inability to read, write, and understand speech, lack of confidence or emotional problems. My GP supplied medication and I had 3 sessions with a speech therapist and that is all."

A stroke survivor

Frustration and stress in people with aphasia

Many stroke survivors with aphasia reported the frustration they felt at trying and failing to communicate. They faced the same difficulties as other survivors in finding the right information at the right time but with the added difficulties caused by aphasia.

"The treatment I received in hospital was awful. The small advice I received after leaving hospital was too soon and too in-depth as I suffered from aphasia."

A stroke survivor

Survivors with aphasia suffer higher levels of stress than other stroke survivors.³⁸ Aphasia is an important cause of low mood among stroke survivors but depression among people with aphasia is often under-diagnosed and untreated.³⁹

Trying to communicate when important parts of your brain have been damaged needs a lot of effort. Not being able to express yourself clearly is very isolating.

"It's a journey that feels like it will never end, still to this day 2.5 years after, I suffer from cognitive and emotional issues. I feel I'm not there for my family anymore, it's just so difficult. It's a rollercoaster I can't get off."

A stroke survivor

Stroke Survivors' Declaration point two:

I will be involved in decisions about my own care and have personal choices about, and control over, the support I receive. Services will be designed around my need to live as well as possible for as long as possible. If I have difficulties with speaking, writing or thinking, I will be able to appoint someone to advocate on my behalf.⁴⁰

Communication, carers and frustration

In our survey, many carers told us they know that the stroke survivor wants to express their feelings about changes following a stroke, but simply can't. Carers and partners also experience feelings of isolation and frustration and relationships can come under stress.

Carers are key. We know that carers need information and practical advice to better understand aphasia. They act as supporter and interpreter and may have to explain to professionals what the survivor needs.

Each survivor and carer needs tailored support depending on the extent of the disability the aphasia causes.

"While his speech is now reasonable he can't take things in quickly. We find NHS staff ignore me as a carer and speak to my husband as though he can understand and make decisions immediately. Consequently we don't get the correct information after hospital appointments."

A carer

"We continually struggle to get medical professionals to recognise that he is not stupid when he gets treatment. He is ignored when he tries to communicate."

A carer

Survivors reported that aphasia leaves them feeling isolated and alone. In turn, feelings of loneliness and low self-esteem can lead to long-term psychological distress.

Keeping in touch with friends and peers, feeling part of society and feeling "useful", are all important in helping stroke survivors make the best recovery they can.⁴¹

"One of the worst effects on my son is loss of friends and workmates and his freedom. He cannot converse with his friends now. He cannot do things when he wants to, it always has to be when we, his parents, can do things with him; except for a few hours a week at a class which he pays for it is just home."

A parent of a stroke survivor with aphasia

Supporting people with aphasia

"On discharge from hospital, I was left with a very confused and angry individual who did not really understand what had happened to him or the consequences. Help was very slow coming for his aphasia and there was absolutely no support for me."

A carer

There is professional help available with some exceptional work going on. Specialist speech and language therapists (SLTs) assess communication difficulties and occupational therapists (OTs) can give practical help and advice on returning to work or participating in leisure activities. We are also aware of a pilot involving an individual SLT trained as a counsellor.⁴² However, these are not available to all who might benefit.

Practising communication skills can also help. We heard from survivors who practise with friends or family, face to face or over the phone. In some areas communication groups and stroke clubs offer help to relearn communication skills, or simply offer conversation.

Some people with aphasia find singing can be a good form of expression, though this doesn't work for everyone. The part of the brain that we use for lyrics and music is different to the part we use for spoken language.

"The public should be made aware of aphasia and the hidden problems of being unable to read and write. We were not told about this for about six weeks by any medical staff - we thought he understood but could not speak."

A carer

However, relearning to communicate is only one of the issues faced by stroke survivors with aphasia. While the best already do this, we need to get to a situation where all professionals recognise that the serious emotional strain of stroke can be exacerbated by aphasia, and services need to be in place to support those affected.

Call to action for those who plan and provide health and social care

Ensure stroke survivors who are affected by aphasia can easily access support, from community based services, other people with aphasia, or from stroke clubs.

Eoin's story

Eoin was an independent 19 year old, a year through a business degree, when his world was turned upside down by a stroke.

His dad took him to a hospital. Eoin can't fault the hospital care but outpatient care was a different story. Arriving at the Occupational Therapist's office, Eoin could see chairs and a desk, and a children's book. "I remember thinking, please don't let that be for me, but it was. It was humiliating. I tried to complete an exercise but couldn't. That destroyed me and I didn't want to know after that."

"I was still in contact with my friends; they listened, they were there. But I was so aware of the gap from the life that I knew and the one that my friends were still in."

Eoin tried to go back to his degree – "in an attempt to get back to my old way of life" – and then worked with his dad. This was probably when the depression started. "When you're in employment and find you're not able to meet expectations purely because of your stroke, it's difficult to keep a positive attitude."

His family were very supportive, but Eoin experienced feelings of guilt for being the person who "brought issues into the family".

Eoin went into denial. "I needed someone to make a connection, to break through the shield I'd put up, but no one ever did." He was given an assessment for depression at his GPs. "But I didn't answer truthfully because I knew intervention might come and I didn't want any."

Eoin's now in the third year of an Occupational Therapy degree, something he feels passionately about.

Finally, he feels comfortable starting a relationship, self-esteem used to be a problem before. But his journey could've been easier. "I needed someone, not necessarily a health professional, just someone, to knock down the wall I'd put up to protect myself. The wall did protect me; but it also stopped me dealing with things."

"But there comes a point when you've just got to stop looking back. If you want to move on with your life, you've just got to let it go."

His family were very supportive, but Eoin experienced feelings of guilt for being the person who "brought issues into the family".



"When you're in employment and find you're not able to meet expectations purely because of your stroke, it's difficult to keep positive."

The impact of stroke on children and younger people

Stroke is an even more unexpected illness when it happens to children or younger people and everyone affected can feel emotionally devastated by the diagnosis.

"Stroke services and support need to be improved for younger survivors. The whole NHS infrastructure and community care is only equipped to look after the older survivor."

A young stroke survivor

Around 400 children a year have a stroke in the UK.⁴³ The lack of awareness among many professionals of stroke in younger people, means that it is often left to the family to pursue treatment, rehabilitation and appropriate support.⁴⁴

The emotional impact on younger stroke survivors

Dr Vijeya Ganesan, a paediatric neurologist who specialises in childhood stroke at Great Ormond Street Hospital, explains: "When a stroke first happens it can be very frightening to a child and hard for parents to explain what has happened to them. The effects of stroke on children are often long-term, invisible impacts."

Lots of people say that children recover better than older people but there is very little attention given to the "hidden" emotional or psychological impacts. As with adults mood disturbances are common but children are often not assessed for depression or anxiety, although many display symptoms. Behavioural issues are also common as, for example, a child might find it hard to readjust to school and so their behaviour will deteriorate.

Stroke in people of a younger age can also result in ongoing emotional issues which surface over time. New situations demand new expectations of younger people. For example, starting a new school, socialising, dating and work can all be triggers for emotional anxiety or even depression. Yet there has been little long-term research into the emotional impact on young stroke survivors.

We believe there needs to be greater recognition of the short and long-term emotional impacts on both the young person and family, both of whom should be supported by professionals who understand the range of difficulties stroke can cause.⁴⁵

"Because I had my stroke when I was a young child my parents were left to get on with it. After my parents died, people assumed I was able to do everything for myself, even though for over 40 years I heavily depended on them."

A young stroke survivor, now middle-aged

Emotions experienced by parents and families

"It's like a form of grief - you go through all the stages – coping, denial, anger."

Parent of a childhood stroke survivor

Parents describe various stages of emotional distress resulting from a child or younger person having a stroke. Initial shock and panic caused by the stroke itself is heightened by the general lack of awareness that strokes can occur at any age. Many parents find they pour all their energy into ensuring their child receives the best treatment and care. Anxiety and depression can hit later when longer term effects of the stroke become apparent.

"Was it our fault, was it genetic, was it because of an accident we didn't prevent? There was an internal struggle of guilt. Was there something we could have done?"

Parent of a young stroke survivor

Many parents blame themselves for their child having a stroke, and are anxious that they will have another one.

There is often a tension between wanting to protect their child and at the same time allowing them to become more independent. Parents can also have concerns about their child's future and how they will deal with any ongoing effects of a stroke as they progress into adulthood.

"I am terrified about if they go out drinking, or try smoking like teenagers can do – there are just so many extra risks. When they are older will they be able to get life assurance or loans; will it have an impact on job prospects?"

Parent of a young stroke survivor

"Other people didn't really understand or believe that my child had had a stroke, especially as they look 'normal'. They're very sporty; people say they look fine."

Parent of a young stroke survivor

Parents experience frustration when others do not understand the "hidden" effects of the stroke, such as the emotional consequences. Some parents report a low level of professional understanding of stroke in children and younger people and issues with awareness of the impact of stroke in schools. There are some excellent professionals out there, but we would like to see all younger people who need specialist support being able to access it.

Siblings are also affected. They can feel neglected while parents are focused on the stroke survivor, or confused about what has happened and what changes they may see in their brother or sister.

What help is available to support younger stroke survivors and their families?

Parents report a lack of information and advice about stroke in children and younger people. Others comment on the lack of stroke support services specifically tailored for younger stroke survivors and their families.

"Just knowing there is a place you can go, where people know what you have been through and where you can get advice, is so important."

Parent of a young stroke survivor

Many parents emphasise the importance of peer support. One parent we spoke to created the *My Child had a Stroke* Facebook group to help parents connect with each other and share information and experiences of stroke in children and younger people.

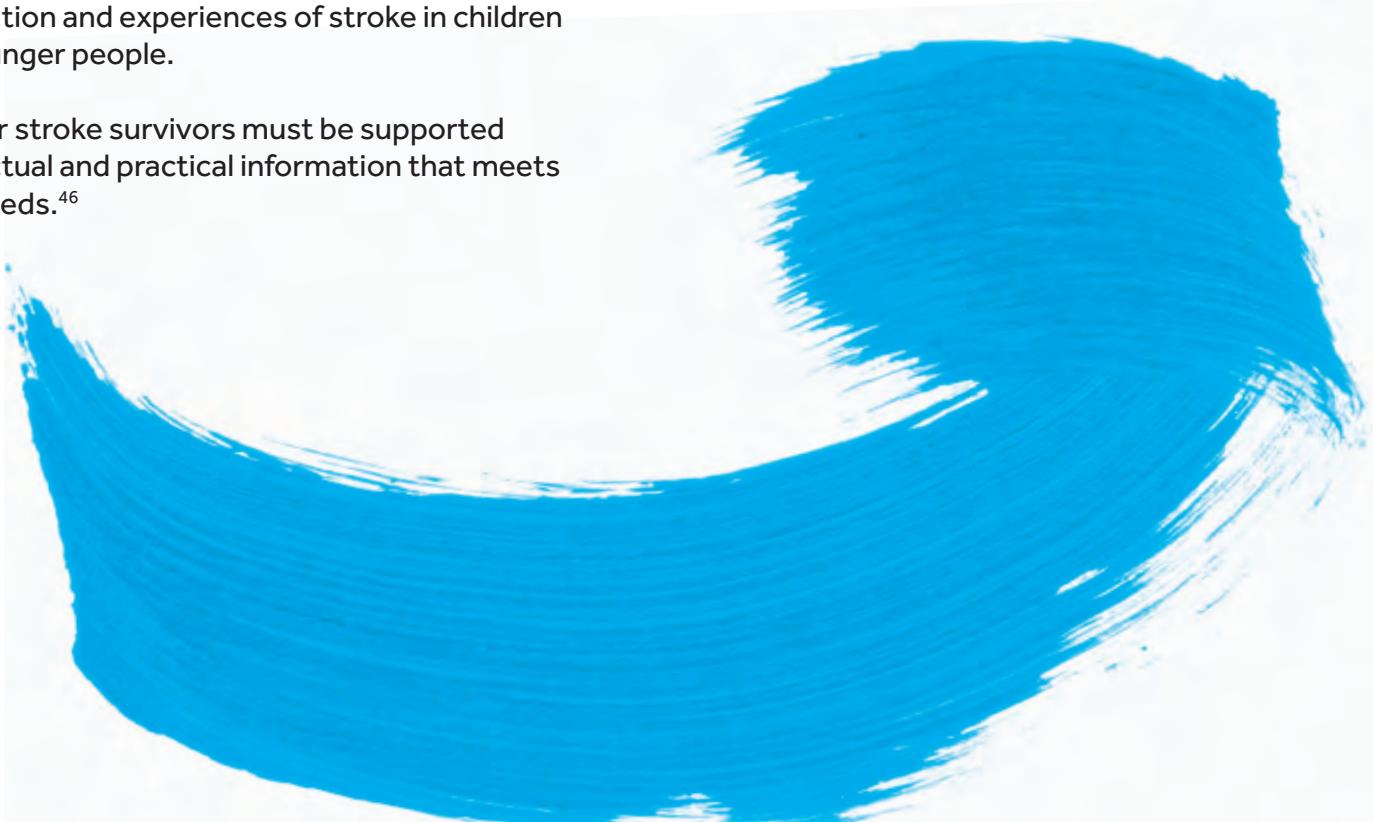
Younger stroke survivors must be supported with factual and practical information that meets their needs.⁴⁶

"I am a young stroke survivor and feel that there is not much available for me in terms of support. It has taken a year to be referred to a wellbeing counsellor about my fear of having another stroke."

A young stroke survivor

Stroke Survivors' Declaration point three:

When I go home from hospital I will have specialist support.⁴⁷



The Stroke Association and The Evelina Children's Hospital Childhood Stroke Project

Working with the Evelina Children's Hospital in London, the Stroke Association is developing the UK's first dedicated childhood stroke community support service as part of a three year project. This will give children and their families in London, and the South East of England the long-term support they need after a child has had a stroke.⁴⁸

The childhood stroke coordinator will work with health professionals to raise awareness of childhood stroke and produce new information materials.

The service also aims to create a network for families affected by childhood stroke, enabling them to meet, forge bonds and create friendships with one another so that they can reach out and support each other, something that many parents of young stroke survivors have reported would have been useful to them.

We are hopeful that the learning from this project may provide a template for helping younger stroke survivors across the UK and will establish cost effectiveness of investing in these vitally needed services.

Call to action for those who plan and provide health and social care

Support children and younger stroke survivors from diagnosis, through sign-posting to peer support groups and ensuring a seamless transition to adult services. This must include more effective assessment and treatment of the emotional and psychological impact of stroke on children and younger stroke survivors and their families.

Joanne's story

Joanne led a full and busy life, working with vulnerable adults as well as being mum to two boys. But one day she felt her sight "go funny" and went to her optician. It was only seven months later she learned she'd had a stroke. Two and a half years after that, she had a second stroke.

Then her life started to crumble. Joanne had to give up work. And the dynamic in the house changed. "I'm sure that because I looked fine, and there was no diagnosis, family and friends just couldn't believe I was ill. It was hard to explain and hard for them to adjust." Her relationship with her husband became strained and they split up for three months.

Joanne felt so emotional all the time, often crying, and if she had a bad day she'd find it hard to bounce back. "There was no in-between; it was all extremes. With the damage to my brain if something upsets me there's no cut off point."

Joanne's second stroke was diagnosed immediately and she was in hospital for ten days. Once she'd left the hospital, the only support she had was from her occupational therapist, but this had to end after a year, even though that's when Joanne really needed someone.

"I kept going into the kitchen and leaving the gas on. It only made sense once I knew what a stroke meant and what damage had happened to my brain."

"I do now get counselling to help me cope with my depression though. Everything needs to be written down for me or I forget. And I'm only recently learning to say no to things, to cancel appointments if I haven't got the energy. I do hate to let people down but sometimes I just don't have the stamina and not many people understand that."

The Stroke Association also helped. "They explained why I was tired all the time, why I kept going into the kitchen and leaving the gas on. It only made sense once I knew what a stroke meant and what damage had happened to my brain. They also met with my husband, and that helped a lot.

"Having information about stroke earlier would definitely have prevented the split from my husband; and it's only because of my Stroke Association worker that we are all now back together as a family."



"I'm sure that because I looked fine, and there was no diagnosis, family and friends just couldn't believe I was ill. It was hard to explain and hard for them to adjust."

Timely information, practical advice and support is essential

Stroke survivors, their carers and families need support in understanding what has happened to them.

"I am a new, inexperienced carer just trying to do what I can. I haven't had much time to think about what help there may be or what questions to ask."

A carer

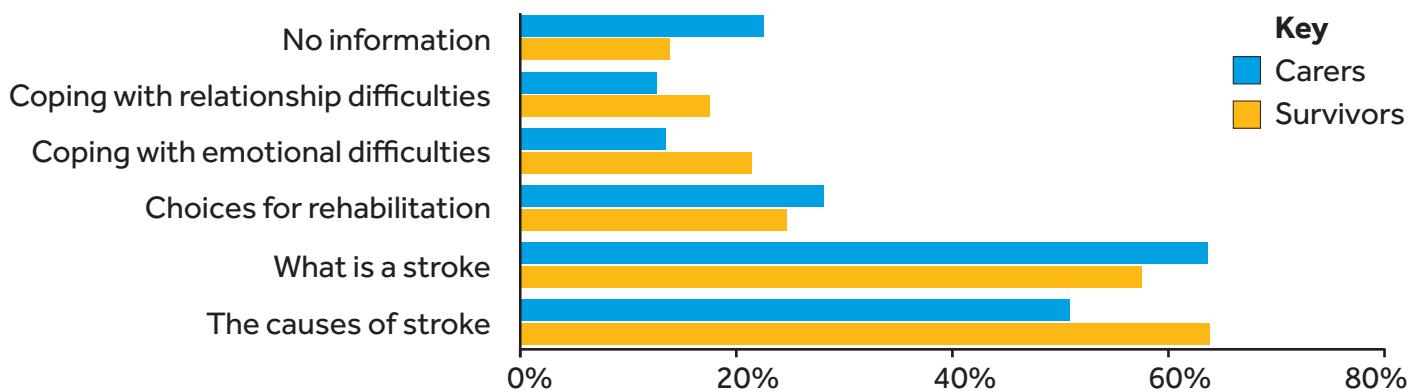
A stroke can change everything, however with help families can better manage the situation and plan for the future with realistic expectations. Many people tell us they are relieved to hear that the after effects they are experiencing are normal, and indeed to be expected.

Sometimes the effects of stroke can seem frightening and embarrassing, such as problems with intimacy, sex and incontinence.⁴⁹ We believe all stroke survivors and carers must have access to quality information and advice, in a format they understand and at a time that works for them, in order to enable them to make their best recovery.

While the majority of the stroke survivors who participated in our survey had received information about stroke, few had received information, practical advice or support about coping with emotional and relationship difficulties following stroke.

Our latest findings chime with those of our previous surveys, where over a quarter of stroke survivors were not aware of sources of free information and support.⁵⁰

What information and advice people say they received after stroke



"Being given lists of useful links and phone numbers is no use when we are not able to take in the information, can't summon up courage to phone, don't know where to start. Don't wait for us to phone up."

A stroke survivor

Stroke survivors told us if they did receive information, it was often during the early stages of recovery, at a time when they had difficulties understanding it because of the enormity of what had happened to them.

Too often the information given did not mention the emotional impact of stroke and where they could seek help. Some mentioned they received good support from GPs, but others said that they were offered little help.

"When I was discharged I was left to research my stroke myself. GPs were only concerned with feeding me tablets. No one discussed my weight or diet. I now pay for a private doctor and I'm very happy."

A stroke survivor

Carers feel overlooked and unappreciated

When asked to tell us about their experience many carers said they were never asked if they wanted to be the carer, it was simply assumed they would take this role on. Too often their wishes were not taken into consideration, and their knowledge of the survivor was not respected.

Most carers would have appreciated information, practical advice and support about the emotional effects of stroke. Many carers felt they lacked training and peer support which would have been really useful. They often had their own, different questions that they needed answering.

Call to action for those who plan and provide health and social care

Ensure all stroke survivors, their carers and families are given accurate, timely, and accessible information at all stages of their stroke journey to help them adjust to the emotional impact of stroke.

Stroke Survivors' Declaration point six:
I will be given the information and advice I need, in the format I need.⁵¹

Eleanor's story

Eleanor was driving when all of a sudden she felt as if she was drunk, so she stopped and got out of the car. Moments later she fell to the ground. Eleven hours and two hospitals later, Eleanor was diagnosed with a stroke. Doctors told her family she had six hours to live.

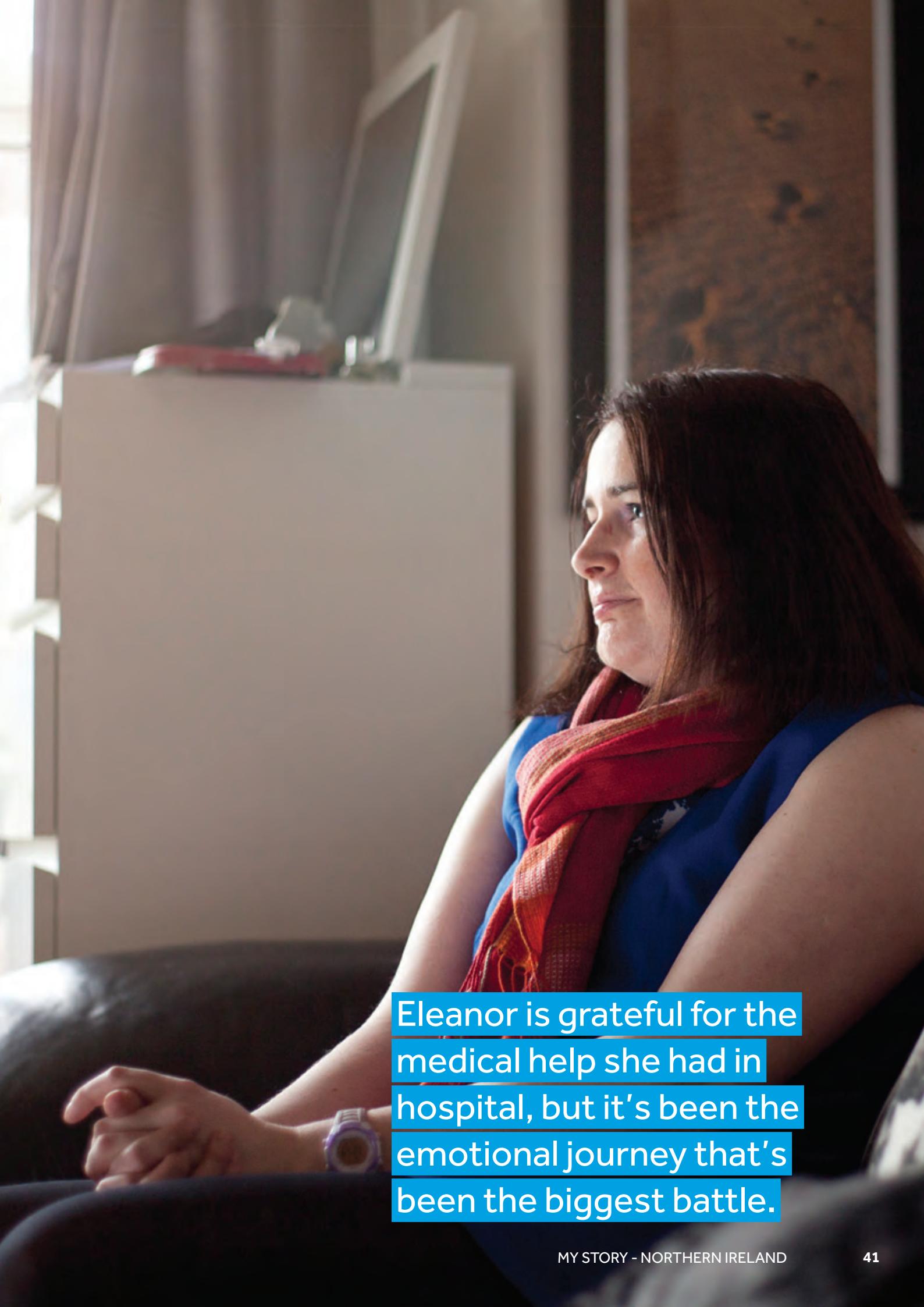
Eleanor was in intensive care for seven weeks, during which time she could do nothing but move her eyes. It was a terrifying experience. And yet, she felt safe in the hospital, being cared for.

The "nightmare" began after she left hospital and had to rely on community services. "The stroke meant that I couldn't work. It took weeks before I received any help applying for benefits."

Eleanor's parents didn't know what to do to help. It was only when they got in touch with the Stroke Association, who listened and gave advice, that they felt more confident supporting their daughter.

"My balance was all wrong; I always felt so tired, and I couldn't eat or drink, so just having a coffee and catching up with friends was hard." Eleanor's parents didn't know what to do to help. It was only when they got in touch with the Stroke Association, who listened and gave advice, that they felt more confident supporting their daughter. "Even now we still have to work at keeping ourselves together, because the stroke changed everything."

Eleanor is grateful for the medical help she had in hospital, but it's been the emotional journey that's been the biggest battle. "The team in the hospital saved my life. But it was the rehabilitation team that made my life worth living."



Eleanor is grateful for the medical help she had in hospital, but it's been the emotional journey that's been the biggest battle.

What stroke survivors and carers need

Regular assessments and reviews are vital for stroke survivors and carers.

"If I am to be assessed I want it to be someone who understands stroke and all the after effects if you are lucky enough to survive in the first place."

A stroke survivor

Emotional and physical health assessments

While the format differs across the UK, stroke survivors should be offered regular reviews of their health and social care needs. However, studies have shown that too many stroke survivors and carers are not receiving these reviews.⁵² Reviews are vital as they are an opportunity for emotional and physical issues to be identified before they develop into something more serious. This is particularly important for people whose strokes occurred a number of years ago and may no longer be on the stroke pathway.

It is important that stroke survivors are supported by professionals and care staff who are knowledgeable about stroke and fully understand its impacts.⁵³ More than eight in ten stroke survivors say people they came into contact with after their stroke did not understand stroke and its impact.⁵⁴

Feedback from people who use Stroke Association services demonstrates how much stroke survivors and carers appreciate working with people who understand stroke and the complexity of its effects.

We know that survivors treated by stroke specialists and other professionals with relevant stroke knowledge and skills are more likely to survive stroke, return home and become independent.⁵⁵

As well as national plans and strategies for stroke, best practice recommends that all health and social care staff in direct contact with survivors and carers should have a broad understanding of stroke.⁵⁶ Those responsible for developing services should consider the additional needs of those living with aphasia, and professionals should support survivors with aphasia to access services.

Clinical psychologists are a vital part of the team

"The Acute Stroke Unit gave excellent 'physical' care, but no one seemed able to offer emotional help or was aware that it may be needed. All people in the ward were frightened. The nursing staff knew how we felt, but didn't openly acknowledge that fear."

A stroke survivor

Multi-disciplinary teams (MDTs) and those who plan and provide services should already consider emotional support as being as crucial to recovery as physical rehabilitation.⁵⁷ We believe increased investment in clinical psychology is vital.

Work by the NHS Stroke Improvement Programme (in England) indicates that an investment of around £69,000 in psychological care through a clinical psychologist-led service, with clinical psychology assistant support and an appropriately trained multi-disciplinary team, may deliver a benefit of around £108,000 to the NHS and social care in around two years.⁵⁸

The Stepped Care Model⁵⁹ is one way of supporting stroke survivors to deal with the emotional impact of stroke:

- Level 1 involves providing stroke survivors with education about the natural process of psychological adjustment following stroke and education regarding cognitive problems.
- Level 2 is a more intensive level of intervention to manage mild to moderate psychological needs but can be carried out by non-psychology staff, by stroke-specialist staff who have had training from a clinical neuropsychologist and have access to supervision from them.
- Level 3 is designed for individuals who have more severe and complex psychological and cognitive problems.

In the North West of England, Stroke Association Information, Advice and Support Coordinators attend meetings with clinical psychologists. Our staff will work with people at the lower level of the Stepped Care Model, some of whom are on a waiting list to see the psychology team. By the time some of them reach the front of the waiting list their issues have been resolved by our staff, saving clinical psychologists unnecessary work.

"I finally am seeing a psychologist to help with my problems, but the amount of time taken to get rehab has left me in a state that cannot easily be gotten out of."

A stroke survivor

Promoting better understanding of stroke

In writing this report we spoke to many health and social care professionals and heard of lots of innovative work delivering better outcomes. However despite pockets of good, some healthcare staff have reported avoiding talking to a visibly upset stroke survivor to avoid opening a can of worms. To help with this we have produced a leaflet called *You're not alone: coping with the emotional effects of stroke - a practical guide for stroke survivors and carers*, which we hope may provide a useful support and starting point for conversation.⁶⁰

Over the past five years, much of the improvement in the hospital treatment of stroke has been made possible by sharing evidence and best practice. We will work with any person in health and social care who can help make this a reality.

This report shows that 40% of stroke survivors feel abandoned after leaving hospital. We now believe it is vital to collect data about what happens weeks, months or even years later to support people to get on with their lives.

If you're particularly proud of your service or the work that you're doing to help people affected by stroke please get in touch with us at campaigns@stroke.org.uk so we can help share your best practice with others.

Stroke Survivors' Declaration point five:

I know my needs will be reassessed after 6 weeks, 6 months and/or 12 months, and as they change.⁶¹

Calls to action for those who plan and provide health and social care

- Ensure all stroke survivors, their carers and families are given accurate, timely, and accessible information at all stages of their stroke journey to help them adjust to the emotional impact of stroke.
- Ensure that all stroke survivors receive a regular review of their health and social care needs that should include an assessment of their emotional and psychological wellbeing. Survivors' emotional wellbeing should also be a key part of their health and social care plans.
- Ensure all carers are aware of, and receive, a carer's assessment. This assessment should include a review of their emotional wellbeing and result in them getting the help they need.
- Ensure the monitoring and publishing of data on the long-term emotional experiences of survivors, carers and families to show if and how they are accessing emotional support, for how long, and whether their needs are met. This should look at people's experiences beyond the stroke pathway and focus on the stroke journey taken by survivors and carers.

Abdul's story

Dad to a ten-year-old little girl, and busy working for London's Labour Party, Abdul was busy but happy. Then one day at work he felt unwell, his words stopped coming out, and a colleague drove him to hospital. Abdul had had a stroke.

In hospital for two weeks, Abdul felt that doctors talked about him rather than to him. "But I kept going because my family came in and gave me support."

It was only after leaving hospital that the full impact of his stroke hit him. "I couldn't walk or talk. I didn't know anything about stroke, and there wasn't much information. I relied on Stroke Association leaflets to educate me about my condition."

In some ways the stroke brought him and his daughter closer together, but he still feels guilty he was a burden at a time when he should have been supporting his family.

"My young daughter gave up things to help my recovery, to the point that I felt she'd lost years. It still kills me when I think about it."

It's taken Abdul two years to get back to any sort of normality. "I look and sound like a healthy man, and to anyone who didn't know me before, it'd be hard to imagine how bad my stroke was."

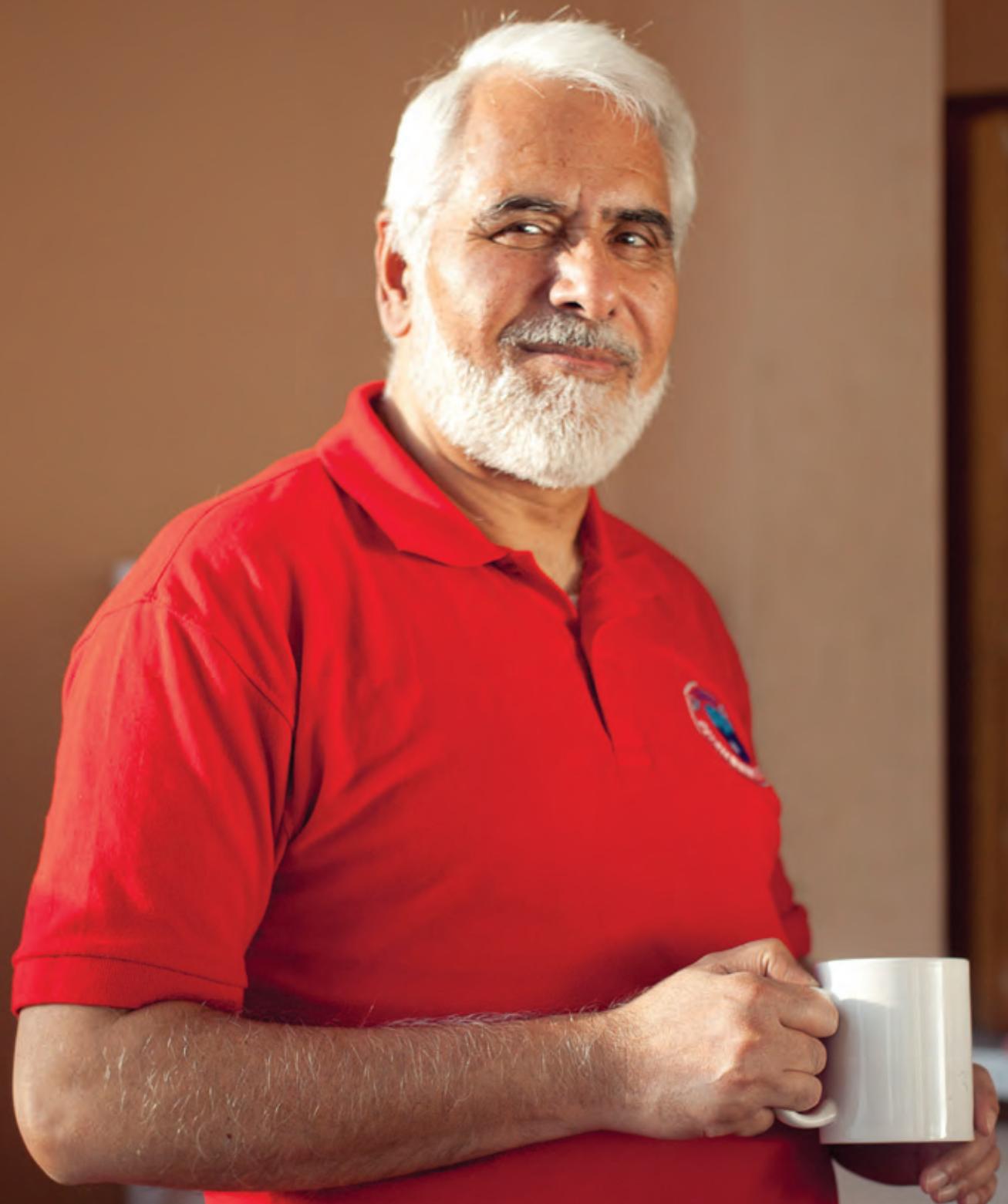
But Abdul was "very stubborn" and worked hard to regain control over his mind and body. It was this same drive that helped Abdul set up a stroke club in Newham, London. "You can't always speak to your family about how you feel; you need to know that there are others who've gone through a similar experience."

At first 11 people met once a month. But there are now two meetings a week and about 40 people attend each meeting. "People would like to go twice a week, but they cut our dial-a-cab funding."

Abdul watches members make friends and, as they become stronger and more independent, sometimes come back to support new survivors. "You can see people grow from week to week."

"People need stroke clubs for the practical and emotional support. There is only so much that medicine can do."

It was only after leaving hospital that the full impact of his stroke hit him.



"People need stroke clubs for the practical and emotional support. There is only so much that medicine can do."

Support from other stroke survivors and carers

Clubs and groups offer stroke survivors and carers the opportunity to meet others and help them to make better recoveries.

"The only ray of sunlight is that we belong to a self-help group of stroke survivors in a weekly exercise session."

A carer

Stroke survivors and carers have told us that friendships change following a stroke and many feel alone and isolated with no one to talk to.⁶² Clubs and groups offer the opportunity to meet others who have gone through a similar experience and make new friendships. Through regular meetings and a programme of activities, they invite people to come together, share experiences, regain confidence, relearn skills, and try out new things.

What are the different types of groups and clubs?

There are over 600 stroke clubs and groups supporting people affected by stroke across the UK. Most are independent stroke charities with many choosing to affiliate to the Stroke Association. There are also approximately 90 Stroke Association voluntary groups, which are run by our volunteers as part of the Stroke Association's Life After Stroke model. There are also many more groups that are not stroke specific.

Once people have joined a club or group they can remain members for as long as they need to on their stroke journey. In addition, there are other types of support available.

Befriending – when someone, who is usually a volunteer and often a stroke survivor, goes to visit a stroke survivor and/or their carer to offer support.

Peer support – where a stroke survivor supports another survivor, or a carer supports another carer.

Group support – a mix of befriending and peer support, but taking place in a group setting.

Why are stroke clubs and groups important to recovery?

Once stroke survivors have left hospital and all other interventions have ended, stroke clubs are a way for people to continue receiving support.

For some people, it's the only time they get the opportunity to socialise. Particularly for those living with aphasia, it's an opportunity to build confidence by practising their communication skills in a supportive environment. Stroke survivors and carers get hope from seeing other people recover.

Clubs and groups allow people to "normalise" their experience, and hearing from people who have been through the same experience can be much more powerful than hearing from a professional.

There are opportunities to get involved in pursuits that can be therapeutic and helpful to recovery, such as art, music and exercise. Many people consider belonging to a stroke group as a way of giving back to their community, making use of skills they had when they were employed and allowing them to move on with their life.

"Joining a stroke club gives interaction with other stroke survivors and professionals and get ideas on matters that would be of concern to you, and you can get advice."

A stroke survivor

What commissioners can do to support clubs and groups

Support for stroke clubs and groups by those who plan and provide health and social care is critical to the survival of this kind of community-based help.

To be considered an effective source of support and part of the stroke pathway, stroke clubs should provide high quality, and high impact long-term social and peer support. Promoting the work of clubs and groups, signposting and referring survivors and carers costs very little but can be very beneficial for the individuals concerned.

Some commissioners have made small grants available to people or organisations to allow them to set up a group or club which then becomes self-sufficient. This can result in good outcomes for survivors and carers, whilst being cost effective for service planners and providers.

"We attend a stroke club. This used to be every Wednesday. Due to lack of funding, this is now once a fortnight, which my husband misses. We are now losing touch with friends made."

A carer

As an example, one stroke group was given a grant of £3,100, allowing an exercise group to be created for stroke survivors. The money paid for exercise equipment, group outings to build confidence and invited guests such as neuro-physiotherapists who work with members. The group has gone on to identify the need for carer support and has secured funding from a charitable source to enable a monthly carers group to be set up.

Call to action for those who plan and provide health and social care

Ensure that you are promoting the work of clubs and groups and signposting and referring survivors and carers.

Stroke Survivors' Declaration point fourteen:

I can expect to participate in my community, either through employment or volunteering, and be supported in doing so.⁶³

Christine's story

Christine was in her forties, working part time to finance a new business, caring for her ill father and volunteering with disabled children. "Probably doing too much, really." Then in May 2011, her world changed forever.

Christine had a stroke caused by a blood clot in the brain.

In hospital, professionals seemed to talk about her, not to her, although Christine's still not sure if it was the after effects of the stroke that made her feel this way. All she knows is that she will be forever grateful to the nurse who comforted her when she had her breakdown.

After leaving the hospital, Christine had no support – until she found the Stroke Association. Before that, her husband, Steve, had to take time off work to care for her. He was made redundant, "probably because of the time he'd had to take off to look after me". But although this has caused other pressures, Christine's glad they're together now.

In hospital, professionals seemed to talk about her, not to her, although Christine's still not sure if it was the after effects of the stroke that made her feel this way.

"Our relationship is even stronger now. Steve refused to leave me, even at my lowest point."

Since the stroke, Christine feels changed as person. "It's like I haven't fully come back. I've not had too much damage to my mobility, and I think that's why friends say they can't see any change; but I know I'm a different person."

She has to take things easy – dirty pots and pans have to wait. But she can't cope with the noise of the TV, the car radio or the sound of her grandchildren. Everything feels so intense. And she still has anxiety attacks and is being treated for depression.

"I can see the wood for the trees now. But if it wasn't for the Stroke Association I wouldn't have received any support at all."



"I've not had too much damage to my mobility, and I think that's why friends say they can't see any change; but I know I'm a different person."

Ways in which the Stroke Association can help

At the Stroke Association we understand the devastating emotional impact of stroke. As you have seen in this report, the stroke journey is different for each stroke survivor and their family.

Every year nearly 40,000 stroke survivors and their families are helped by our Life After Stroke services. Stroke survivors and carers have told us of the crucial difference our services have made to their lives, even after they have left the stroke pathway and are trying to regain their best possible life. However there is still much to be done if we are to help all people affected by stroke make better recoveries.

"I feel after stroke the home care and help dwindles away and you are left to fend for yourself. Physiotherapy stops, speech therapy stops. What happens with the long-term care?"

A carer

We need your help to enable us to ensure that everyone affected by stroke across the UK is supported in making their best possible recovery.

"The only support I have had since having my stroke has been from the Stroke Association. When I was in hospital the only suggestion made was to get in touch with them. I think that it is often so hard for someone who has had a stroke to access information as people are often confused or unable to go out and get information themselves."

A stroke survivor

Services we provide across England, Wales and Northern Ireland

The difference our services make

Our dedicated service staff and volunteers help people to understand how to manage their stroke, we equip carers to support their love ones whilst caring for themselves, and we prevent thousands of people from having further strokes by helping them change their lifestyles.

Our services have assisted people in avoiding being unnecessarily readmitted to hospital by alerting other professionals of crises or problems that need assessing, and we continue to support thousands of stroke survivors in making their best possible recovery and regaining their lives after stroke.

"Thank goodness for the Stroke Association. In my experience they filled the gap in information. They played a vital role."

A stroke survivor

Information, Advice and Support

We offer high quality evidence-based information, a listening ear, emotional support, and practical advice, all of which make a huge difference in helping stroke survivors and their families better understand what has happened.

We work alongside other health and social care professionals to make sure that stroke survivors and their families understand what their options may be, and work with others to see that the support that is needed is in place. Stroke Association coordinators will often continue to provide support through the transition from hospital to home and will stay in touch for many months, supporting carers as they adjust to their caring role and helping the stroke survivor access the support they need. When people are ready to start thinking about the future we can help them determine what they want to achieve and start to self-manage their situation.

A key part of this support is the emotional help we can offer. Our coordinators are linked into their communities and can provide timely advice and information about what is available from the wider health, social services and other voluntary organisations. We can provide information on finance and benefits along with opportunities to access support groups and peer support activities.

If you are responsible for planning health or social care services and want to help stroke survivors and carers we would love to talk to you. Please email us at campaigns@stroke.org.uk. We have a range of paid for services as well as free support that can help improve outcomes and save money.

Communication Support

Stroke survivors who are affected by aphasia have an even bigger hill to climb. Our services enable people to continue to relearn new skills of communication and to rebuild their confidence, which can be badly affected by the loss of their previous communication skills.

Our Communication Support Services complement any formal speech therapy the stroke survivor may have received. We run communication workshops to help the person living with aphasia and their carer/families to understand their condition, and offer possible solutions to the challenges they face. We cannot help people regain their speech but we can help them adjust.

Aphasia is a very isolating condition and it is critical that people are supported to engage with normal activities. So, as well as running group workshops, we work with individuals to establish what they want to be able to achieve, and we have a team of experienced volunteers who can support people to undertake those activities. For some, this may be expressing their feelings through art or gardening, learning how to shop independently, or travelling on public transport with confidence in spite of the disability. It could be we help the person's employers understand their challenges so they can return to their employment.

Where need is identified, we can create peer support groups which help people adjust and rebuild their self-worth and confidence. Our approach is one of integration across services and communities.

Carer Support

Carer support is a key element of our services. Being a carer can be difficult and relationships are often affected. Our services help carers to identify their needs and try to ensure that these are met. It is critical that carers feel supported and have opportunities to talk or seek respite, so they can continue caring without their own health suffering adversely.

Our initial home/hospital visit is often with the families as the stroke survivor's needs are addressed by the stroke team. We can focus on helping the families understand what is happening or will happen next, and also help them be clear about decisions they may need to take together, before the stroke survivor leaves hospital.

Adjusting to life back home can be as traumatic for the carer as it is for the stroke survivor they care for. Knowing we can be on hand to offer a listening ear, emotional support, practical advice and information can help carers to cope where otherwise they may feel isolated and overwhelmed.

Stroke Prevention

All of our service users are provided with stroke prevention support and advice as part of the package we offer. We can also provide bespoke services, where we work with people identified as at high risk of primary or secondary stroke. We offer group and one to one activities which enable people to understand their personal risk factors and take positive steps to adjust their lifestyles to reduce their stroke risk.

People tell us that these specialist prevention services make a big difference to their lives and the lives of those close to them.

Other support we provide

You're not alone is a practical guide for stroke survivors and carers which offers advice on how to cope with the emotional impact of stroke. You can download this from stroke.org.uk/feeling-overwhelmed

High quality information is essential in the aftermath of a stroke. We have a range of information leaflets covering everything from what a stroke is to what's likely to happen in the future and how to live with the changes. All of our leaflets are available at stroke.org.uk/information/resource-library.

Our Stroke Helpline (0303 3033 100) is open Monday to Friday, from 9am to 5pm. Each year we support over 20,000 people. We also have a language line to translate for people who don't speak English as a first language.

Our Stroke Information Service is also available by email on info@stroke.org.uk. We ask people to include their postcode so we can direct them to local support where it's available.

Stroke clubs and groups are a fantastic way for stroke survivors and carers to get help and support from others who have had similar experiences. To see if there are stroke clubs or groups in a particular area please call our Stroke Helpline on **0303 3033 100** or search on our website at stroke.org.uk/support/search.

We offer volunteering opportunities for those who would like to help support stroke survivors, their families and their carers in these clubs, groups and services. We can help people to set up stroke clubs in their local area and can also offer speakers to come and talk to your group.

Our Talkstroke online community is a place for people to meet, share stories and experiences and support others affected by stroke. Go to stroke.org.uk/talkstroke. If you are online you may also want to look us up on Facebook and Twitter for more information and support.

The Campaigners' Network supporters receive regular email newsletters with interesting news, personal stories and small things they can do to improve the lives of all those touched by stroke. You can sign up at stroke.org.uk/campaigns/signup.

Other sources of help

If you are experiencing relationship problems you can contact RELATE on 0300 100 1234

If you want more information about childhood stroke you can refer to our website stroke.org.uk/involved/childhood-stroke. You can also contact hemihelp.org.uk, differentstrokes.co.uk and scyss.org. There is also a Facebook group for parents of childhood stroke survivors called *My child had a Stroke*

If you want more information about aphasia you can refer to stroke.org.uk/aphasia

Endnotes

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- ²⁴ Sentinel Stroke National Audit Programme (SSNAP) (2012) *Acute organisational audit report*.
- ²⁵ The Scottish Government (2009) *Better Heart Disease and Stroke Care Action Plan*
- ²⁶ Stroke Association (2012) *Struggling to recover*
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- ³⁶ Stroke survivors with aphasia have trouble communicating and may be unable able to speak, understand, read or write.

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- ⁴⁸ This project has been made possible by funding from city trading firm, ICAP, whose Charity Day in December 2012 raised over £11 million for good causes.
- ⁴⁹ We have leaflets available on all of these topics that are free to download at stroke.org.uk/information/resource-library
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- ⁵² Department of Health (2007). National Stroke Strategy. (Though this differs across each of the 4 UK Nations). Studies include - Stroke Association (2012) *Struggling to recover*
- ⁵³ Those responsible for developing a stroke skilled workforce can make use of resources available from the UK Forum for Stroke Training (UKFST), which has a database of UKFST endorsed courses for health and social care professionals.
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- ⁶⁰ Available at stroke.org.uk/feeling-overwhelmed
- ⁶¹ stroke.org.uk/get-involved/stroke-survivors-declarations
- ⁶² For more information about how relationships, families and friendships are affected by stroke please see pages 22 and 23.
- ⁶³ stroke.org.uk/get-involved/stroke-survivors-declarations
- ⁶⁴ stroke.org.uk/feeling-overwhelmed



About the data in this report

We are presenting this data as a snapshot, it's not representative but it is a large sample size which we believe gives a useful insight into the real-life experience of stroke survivors and their carers. All data referred to in the report is UK-wide, national breakdowns can be found on our website.⁶⁴ Quotes used throughout the report from stroke survivors and carers are taken from the "In Your Own Words" section that was part of this survey.

Purpose

In 2012 we ran a survey to understand the emotional impact of stroke on survivors, carers and their families.

Methods

The UK-wide impact of stroke survey ran from October to December 2012 and was aimed at stroke survivors and their carers who each had a separate section to answer. The survey was both online (via Survey Monkey) and paper-based. The survey questions covered questions about the physical, cognitive, emotional and practical impact of stroke.

Sample

The total sample size is 2,711, of which 1,765 people completed the paper-based version and 946 completed it online. A total of 1,774 stroke survivors responded to their section of the survey and 937 carers completed the section designed for them.

Find out more at **stroke.org.uk/feeling-overwhelmed**

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Throughout this briefing, data is mentioned
from the impact of stroke survey; data tables are
available online at
stroke.org.uk/feeling-overwhelmed.

You will also find national policy calls for the four
UK nations and a detailed bibliography here.

We are the Stroke Association

We believe in life after stroke. That's why we support stroke survivors to make the best recovery they can. It's why we campaign for better stroke care. And it's why we fund research into finding new treatments and ways of preventing stroke.

We're here for you. If you'd like to know more please get in touch.

Stroke Helpline: 0303 3033 100

Website: stroke.org.uk

Email: info@stroke.org.uk

From a textphone: 18001 0303 3033 100

The Life After Stroke Campaign

Helping more stroke survivors and carers achieve a better life after stroke

Help make this happen, get involved at:
stroke.org.uk/campaigns/signup or **#lifeafterstroke**



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