Chapter 3
Caring for a stroke survivor: what carers need
Rebuilding lives after stroke
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My mother had a major stroke in 1968. Back then, there was absolutely no support available to help either her or us. It was, without a doubt, the worst time of my life. If you have not lived through it, you just cannot understand the devastation of stroke, how horrifying it can be. My father and I became her instant carers and our family life completely ended. Daddy would do all of the caring during the week and as I had left home by then, I would return at weekends to help out and provide respite and support to both of them where I could.

Mummy had been the absolute the rock in my life. She was the most vivid person I have ever known. She was accomplished and brave and fearless. The stroke changed all of that instantly. From being this vibrant, alert, shrewd, funny lady she turned into someone who could barely talk and was unable to move - it was the most terrible, shocking transformation you could imagine. We had to do absolutely everything for her.

Over half a century has passed since my family’s life was transformed so terribly by stroke. I am thankful that stroke care has improved in that time. However, reading people’s stories in the Lived Experience of Stroke report, my heart breaks to learn that carers are still all too often being overlooked and under supported.

Most stroke survivors rely on a carer and while sometimes these are paid roles, it frequently falls to a family member or loved one to provide the majority of the physical and emotional heavy lifting. I know from experience that caring long term takes its toll.

Carers say they experience negative emotions such as stress or exhaustion and they don’t get the support or information they need to help them fulfil their caring role. On top of this, carers often have many other responsibilities in their lives which can be adversely affected. They may find that their careers suffer because of the stress they face at home or relationships with other family members and friends can become side-lined. The situation just isn’t good enough. Things can and must change.
The Stroke Association is working to change the picture for carers. The charity supports carers through their helpline, website and face to face, as well as providing information booklets full of practical tips and advice. They also fund stroke groups, which can give carers a couple of valuable hours off.

I support the Stroke Association in their belief that more needs to be done to support people caring for stroke survivors. All carers should be offered a carer’s assessment by their local authority and there should be enough services so that all carers can get the help they need. This help is vital to improve people’s knowledge of stroke, confidence in caring, awareness of support they are entitled to and connection to others who understand their situation. But most of all, it’s needed to make sure that the health and wellbeing of the carers themselves isn’t forgotten.

With the right support and a tonne of courage and determination, both stroke survivors and carers can rebuild their lives after stroke.

Miriam Margolyes
Actress
In summary

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

More than 6 in 10 stroke survivors rely on the help and support of a carer to help them with day-to-day living – activities like getting dressed, making meals or going out to the shops.

Sometimes people are paid to carry out these tasks. But often it falls to family members or friends, who become unpaid carers.

To better understand the challenges facing stroke survivors and the help they need, we ran a representative survey of stroke survivors and unpaid carers.

We found that:

• 85% of carers don’t get the support and information they need to help them in their caring role.

• 87% of carers feel at least one negative emotion, such as stress or exhaustion, when their loved one has a stroke.

• Whilst the emotional health and wellbeing of stroke survivors often improves over time, sadly, the same cannot be said for carers. Their health and wellbeing does not improve with time.

• Caring long-term can take its toll. People who have been caring for stroke survivors for over three years are more likely to feel stressed or anxious than people who have not been caring for as long.

It’s clear that people who take on a caring role are absolutely vital to stroke survivors rebuilding their lives after stroke. But caring can be incredibly demanding.

Together we can do much more to support carers in all they do for stroke survivors.
Introduction

Stroke strikes every five minutes in the UK. It can happen to anyone - young, old and everyone in between. There are over 1.2 million stroke survivors living in the UK.\(^1\)

Stroke isn’t like any other condition – it changes lives in an instant. And it’s not just the stroke survivor who is impacted but family and close friends too. You could be a husband or wife one day and need to take on a caring role the next.

It doesn’t come with a warning or a training manual or guidance notes but you’re in it because of the person you love. Many people might not think of themselves as carers, but simply as family members or friends doing the right thing for their loved one. They may only realise that they have been in a caring role many years later.

About the Stroke Association

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

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About the survey

In this report, we look at how carers feel their lives are affected by looking after their loved one, based on their responses to our survey.

Throughout the summer of 2018, 1,880 stroke survivors and carers from across the UK told us about their experience of stroke by completing an online or telephone survey. Most of these people hadn’t been in contact with us before. We made sure that this sample was representative of the UK population.

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

This report focuses on what the 681 carers who responded to our survey told us about their caring role – how it affects them emotionally and about the kind of support they need.

In previous reports we have shared more about the hidden effects of stroke and the practical and financial impacts of stroke. Later in the year we will publish a final report about the support stroke survivors receive, and bring all four reports together.
Charts on this page show the demographics of cares who answered our survey.
Who is a carer

Many stroke survivors rely on the help and support of a family member or friend to help them with day-to-day living – activities like getting dressed, making meals or going out to the shops.

Who has a carer?

- 62% of stroke survivors said they had an unpaid carer at some point since their stroke.\(^2\)
- This could equate to several hundred thousand people caring for stroke survivors at any one time.
- People whose stroke had had a more severe impact on their life were more likely to have a carer.

Often people become carers because of their relationship with the stroke survivor. Sometimes people don’t see themselves as carers but as family members or friends simply looking after their loved one.

Our survey found that, carers:

- Are more likely to be female (69%).
- Are of working age (60%).
  The average age of a carer was 57.
- Are looking after their partners (32%) or their parents (30%).
- Have been caring for an average of five and a half years.

\(^2\) Base: Nationally representative sample of 1880 stroke survivors and carers.
Stroke survivors highly value the support provided by carers. When asked about the support they received from family, friends, the NHS and other services, stroke survivors rated the support they received from family and friends the highest. Yet caring for a stroke survivor can take its toll on a carer, affecting them emotionally, physically and financially.
Ann Turner, 66, from Bedfordshire, now cares for her husband Les, 68, since he had two major strokes in 2010.

Les spent three months undergoing rehabilitation in hospital and since returning home Ann has taken on his care.

Ann said, “Our lives were turned upside down after Les had his two strokes. As well as major problems with speaking, Les has had to learn to do everything with his left hand so straight away he became reliant on me for everything he needed on a daily basis.”

“My main motivation has always been to keep Les in his own home rather than residential care, which we’ve been able to do. We have been married for 45 years, so of course I do everything I can for him - it’s just what you do for the person you love”.

“What I’ve learnt from the experience is that as a carer, it’s so important to take care of yourself physically and mentally too. I do exercise classes, walk to town and have coffee with a friend every other day and practice mindfulness. If you don’t look after yourself, how can you look after someone else?”

“It’s so important to take care of yourself physically and mentally too.”

Ann
Becoming a carer

A stroke is an unexpected event. This means family and friends are not prepared for their new role as carers. They’re thrown in at the deep end in an instant.

Carers take on tasks or roles they may never have done before. From managing medication to helping someone eat and drink safely. As they take on the role of carer, it’s important they are given information and support.

Yet nearly half of all carers said they could have been better informed about becoming a carer. A quarter said they felt extremely uninformed and that there were lots of surprises along the way.
Providing carers with more information as they begin their caring role might help them to manage better, both practically and emotionally.

Carers feel a range of difficult emotions around the time their friend or family member has a stroke. 87% of carers told us they’d felt one or more negative emotions, such as feeling frightened or nervous. About 4 in 10 felt stressed or anxious.

Some of the emotions carers feel come from concern about their loved one having a stroke. Anger that this has happened to them. Grief for a lost shared future. Fear that their loved one may be suffering.

Many feel a new weight of responsibility as they take on a caring role. They may be concerned about what the future holds for them or worried about whether they will be able to cope. Some may find the dynamics of their relationship with the stroke survivor changing, as they become a carer as well as a husband or wife or son or daughter.

How carers felt at the time they started caring: Top five emotions

- Exhausted - 23%
- Stressed - 40%
- Frustrated - 24%
- Sad - 29%
- Anxious - 41%
“My biggest concern as a carer initially was toileting, mainly down to the change it might have on the dynamic in our relationship, but you get used to it.”

Stuart
Stuart “There was no one I could turn to who could coordinate everything.”

Stuart Atkin, 75 from Bradford, found his life turned upside down, as he went from husband to full time carer overnight.

Pam had a life-changing stroke on New Year’s Day 2018. The stroke left her unable to walk, with left hand sided weakness and affected her cognitively.

To get Pam home from hospital, she needed two carers to visit four times a day and lots of equipment for the house including; a hoist, wheelchair, hospital bed. Even with paid carers visiting, Stuart had a full time job on his hands.

“I was so keen for her to get home but the reality was really hard. Nobody had talked to me and explained what being a full time carer involved. Organising all the medication, clothing, toileting, nurses visiting – it all just happened.

“In the first few weeks, everything went wrong. District nurses were getting mixed up and bringing equipment Pam didn’t need. Medication was being provided, but when it arrived, it only had half the medication needed in it. It was a nightmare.

“As a former architect and company director, I’ve always been in charge, but this was out of my control. There was no one I could turn to who could coordinate everything. I was always having to ring different people and being pointed in different directions.

“It was getting me down, I felt stressed and couldn’t sleep. Things were getting on top of me. I was prescribed medication, which didn’t help initially. I was looking at Pam, thinking we can’t go on like this. It was completely out of character for me. I just couldn’t see an end to it all.”

Realising he couldn’t cope, Stuart and Pam’s son and daughter took over and made preparations for Pam to go into Park House Nursing Home. Pam spent about 5 weeks in the nursing home. Stuart received psychiatric support while Pam was in the nursing home, afterwards he was in a better place to adapt to their new normal.

“My experiences of everything going wrong the first time helped me to get everything sorted. I knew what to expect. I had the experience to organise it.

“I’m still on some medication which I’m sure helps. But I’m in control now. The professional carers come just once each morning, which I pay for. We’ve just had a stair lift fitted which Pam uses easily. She’s much more confident now. I’m enjoying preparing meals and I’m looking to get a vehicle so we can go out and about. I’ve been through a bad caring experience, and now a positive one.”
Long term emotional impact of caring for a stroke survivor

Being a carer can be very demanding. The role can involve round the clock care and some stroke survivors may be completely reliant on their carer to function. This pressure can lead to emotional problems such as stress and depression.

The negative emotions carers experience when they become a carer increase over time. Carers who have been caring for longer than three years are more likely to feel exhausted or anxious than those who have been caring for less than three years.

These emotional changes may arise from a sense of being trapped in their role, or frustrated that they have little support. Carers who have been caring for many years may feel exhausted and need a break from their responsibilities. They may have had to change their working pattern or leave work altogether. And that can leave them worried about finances.

This is in contrast to stroke survivors themselves. The emotional health of stroke survivors improves somewhat with time. About 49% of stroke survivors whose stroke occurred one to three years ago told us they feel positive emotions, rising to 66% for people whose stroke was over ten years ago. Yet 53% of carers who have been caring for between one and three years felt positive emotions, compared to only 41% of carers who have been caring for over three years.

While the situation for stroke survivors may improve a little over time with support and rehabilitation, for carers, their situation remains somewhat the same. The issues causing them to feel negative emotions are not being addressed. Carers need more ongoing support to help them cope with caring.
Grace Farquharson, 29, was newly married and looking forward to her future with her husband Finn, when he had a stroke in July 2017.

He was just 43 and at work as a vascular radiologist at Manchester Royal Infirmary. Finn’s stroke left him with severe aphasia, which means he struggles to find his words, structure sentences and understand what is being said to him. Finn also had a second stroke two years later but now he is recovering well.

A service manager for the NHS, Grace was juggling the pressure of a demanding job with caring for Finn after his stroke.

Grace said: “For a long time I was in denial about my role as Finn’s carer. He was able to do most things on his own such as washing, dressing, and eating. The kinds of things you typically associate with caring. I convinced myself that the increased burden I had taken on dealing with our finances, and acting as his personal assistant creating, rescheduling and taking him to appointments was merely me acting as his wife. I took him wherever he needed to go. I helped him to say what he needed to when words failed him or helped him to prepare what he wanted to say in advance. I provided a listening ear or a shoulder to cry on while he questioned why him, why now? I learned to remain calm when he snapped at me in frustration.

“Trying to balance all of that with a full time, high pressured job took its toll on me. Eventually I was failing at my caring duties because I was throwing myself into work to escape. With the daily commute I was away from the house from 7am until 7pm most days. By the time I got home I was exhausted and collapsed on the sofa. If Finn tried to talk to me I did my best to hold the conversation but most of the time I just couldn’t face it. The result of this? Feelings of failure, isolation, loneliness, frustration, guilt and anxiety for both of us.

“Although I might not look like a carer when you see me out and about with Finn, that doesn’t mean that I’m not one. Of course I am acting in my capacity as Finn’s wife and I have vowed to be there for him in sickness and in health. Yet if you remove me from the equation Finn would still need the support that I offer him. For that reason I shouldn’t be belittling the effort I put in to help him keep as close to a normal life as possible.”

Overwhelmed with anxiety at leaving Finn to go to work, Grace found it too much to cope with, and took a career break to help Finn with his recovery.
She adds: “I can see the benefits from my increased presence at home. His mood has improved, his expressive speech has shown great improvements and he has been able to start new activities to help with his fitness and rehabilitation. More personally I have managed to regain control of my anxiety and depression. It was exhausting to just exist back then. I didn’t realise how badly I had been suffering for the past 19 months until I took some time to look after myself and finally feel more ‘normal’. I haven’t felt this positive or happy in a long time.

The stroke has brought us more love. They say absence makes the heart grow fonder but in our situation I think that spending so much time together has made my heart grow fonder. My heart swells with pride every time I see improvements in his speech or watch him try and do something independently.”

“For a long time I was in denial about my role as Finn’s carer.”

Grace
Getting enough support

Carers take on a range of demanding and difficult caring tasks, on top of their daily lives. It is vital that they have all the support and information they need. Yet 85% of carers said they don’t have enough support or information.

Carers want more support at all stages of the stroke journey – from when a stroke first happens to time in hospital and during ongoing recovery. The needs of a stroke survivor change over time. Carers need information about all the different stages of stroke recovery – from how best to support them in hospital to caring for them at home.

When stroke survivors would like more support

29% at all points
27% when they first had a stroke
24% during time in the hospital
19% once they had recovered
9% quite some time after
15% none - I had all the support and information I needed

Carers are more likely to want ongoing support if the stroke survivor they care for experienced a more severe stroke or if they have been caring for a long time.

Carers may need to help stroke survivors with a range of physical, emotional and cognitive issues. From help moving them around the house to supporting them with depression or anxiety.

All of this can affect carers heavily. They need more support on a range of different issues:

<table>
<thead>
<tr>
<th>Support Area</th>
<th>% Who Didn’t Receive Enough</th>
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<tbody>
<tr>
<td>I didn’t receive enough support on changes needed for my home</td>
<td>37%</td>
</tr>
<tr>
<td>I didn’t receive enough emotional support</td>
<td>35%</td>
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<tr>
<td>I didn’t receive enough physical support</td>
<td>35%</td>
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<tr>
<td>I didn’t receive enough face to face support</td>
<td>30%</td>
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<tr>
<td>There were not enough support groups for me</td>
<td>27%</td>
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<tr>
<td>I didn’t receive enough support on going back to work / managing work and being a carer</td>
<td>27%</td>
</tr>
<tr>
<td>I didn’t receive enough support on carers allowance / benefits</td>
<td>27%</td>
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</tbody>
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John Milnes, 72, from Cardiff, has been caring for his wife Anne since her stroke in 2015, despite being diagnosed with Parkinson’s disease himself.

He said: “Anne’s stroke left her unable to use her right side and with speech and language difficulties. Anne was an English teacher and her mind is as sharp as ever, but she can’t get her words out, which is so frustrating for both of us.

“Only a few months after Anne’s stroke, I was diagnosed with Parkinson’s, which affects my energy levels and thoughts. I attend voice training and exercise classes each week to help.

“My wife does have carers come to the house for an hour or so each morning and evening, which is very helpful. But otherwise, I’m her carer, 24/7. I also need to make sure that any new care staff that come to the house understand what Anne needs, which can be very draining and means I have very little free time for myself.

“It’s never been clear at which point I could get any help for me. As soon as I tell people my wife is being supported, the doors which could offer me support seem to close.

“One thing which has made life easier are the golfing sessions for carers, organised by the Stroke Association. It’s good to spend time with others who understand, while my wife enjoys some respite at the local stroke group.

“One benefit of golf is the chance to meet for a coffee and chat afterwards. So even if our golf pro isn’t available, we’re going to organise some get together for the group of carers.”
Sources of support

Many carers (64%) rely on a partner, friends or relatives for help and support. Others use their GP or practice nurse (56%). However, nearly a fifth (19%) of carers haven’t used any form of help.

Carers who didn’t use any sources of support told us it was because:

- Friends/Relative/Partner: 64%
- GP/practice nurse: 56%
- Counsellor/therapist/psychotherapist: 26%
- Support group/independent advice service: 22%
- Financial/employment benefits advice: 19%
- Charities: 19%
- None: 19%

- They were more focused on day-to-day practicalities: 30%
- They weren’t offered any: 25%
- There was too much going on: 23%
- They didn’t know where to start: 22%
Sometimes carers don’t access support because they don’t know about it.

**Three in ten carers**
weren’t aware they could access support from charities.

**Three in ten carers**
weren’t aware they could access support from support groups or independent advice.

**3 in 10**
carers weren’t aware they could access financial, employment or benefits advice.

**3 in 10**
carers weren’t aware they could access support from a counsellor, therapist or psychotherapist.

**Two in ten carers**
weren’t aware they could access support from a counsellor, therapist or psychotherapist.

All carers should be offered an assessment of their needs, carried out by their local authority. This assessment is the first step in working out who qualifies for support from the local authority. Only 27% of carers had an assessment in England, according to a recent Carers UK survey.3

Sometimes carers want to use a service but it doesn’t exist. One in ten carers told us they’d wanted to use a counsellor or psychotherapist and 8% wanted to use financial, employment or benefits advice. But they weren’t able to because they were not available. Benefits advice services are important for carers as they are sometimes entitled to receive Carer’s Allowance and may need help with making a claim.

Local health and social services are responsible for making sure services exist to meet the needs of carers. Carers UK has found that carers have reported cuts to services in recent years.3 It is important that there are sufficient services for carers, especially as their support is so highly valued by stroke survivors.

The Stroke Association offers support online, over the phone and face to face. We understand how important support for carers can be, not only for their own wellbeing, but to ensure they are best able to help their loved ones. We’re here for everyone affected by stroke. More information can be found in the **How we are helping** section.

People caring for stroke survivors deserve high quality support, to help them manage their caring responsibilities as well as their own lives. Carers are entitled to have an assessment of their needs, carried out by their local authority. But not every carer gets one.

What we believe needs to happen:

- Everyone looking after a loved one affected by stroke should recognise that they are carrying out a caring role and that support is available for carers.

- All carers should be offered a carer’s assessment (England, Wales and Northern Ireland) or an adult carer support plan (Scotland).

- There should be enough services so that all carers can get the help they need.

- All carers should be given support to take regular breaks and maintain their wellbeing.

- All carers should be given reliable information and advice to understand stroke and their caring role.

- All carers should be given access to emotional support if they need it to adjust to their caring role, and peer support to reduce the impact of loneliness and social isolation.
How we are helping

- Our Stroke Helpline (0303 3033 100) supports approximately 5,500 formal and informal carers a year. This includes people who define themselves as carers and others who are family members caring for someone after a stroke. The majority were family members.

- Where available, our support coordinators and counsellors offer practical and emotional support to carers face to face, working with 1,500 in the last year. We also offer support groups for carers.

- In some areas, our five week educational programme, ‘Caring and you’, helps carers learn more about stroke, offers practical tips on caring with confidence and signposts where to go for support and advice.

- We have information available online, through our website and downloadable guides including, ‘Supporting a stroke survivor’, ‘Stroke: a carer’s guide’ and ‘You’re not alone’. There are tips for how to cope in these guides.

- My Stroke Guide features videos about caring for someone who has had a stroke. It also provides a way to connect with other people caring for stroke survivors through our online community.

- We also provide information and support about how to request a carer’s assessment.

- We’re working with carers to explore how we can better help to address the challenges they face.

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4 Based on 2018/19 Stroke Helpline data.

There are other organisations that can help:

**NHS: Your guide to care and support**  
Website: [www.nhs.uk/care-and-support](http://www.nhs.uk/care-and-support)

**Carers Direct (England only):**  
Tel: 0300 123 1053

**Carers UK**  
Website: [www.carersuk.org](http://www.carersuk.org)  
Tel: 0808 808 7777 (England, Scotland and Wales)  
Tel: 0289 043 9843 (Northern Ireland)

**Carers Trust**  
Website: [www.carers.org](http://www.carers.org)  
Tel: 0844 800 4361

**Crossroads Care NI**  
Website: [www.crossroadscare.co.uk](http://www.crossroadscare.co.uk)  
Tel: 028 9181 4455

**Crossroads Caring Scotland**  
Website: [www.crossroads-scotland.co.uk](http://www.crossroads-scotland.co.uk)  
Tel: 0141 226 3793
Appendix: Further information about the survey

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

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

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

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

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

People most severely impacted by stroke, or people with aphasia, significant cognitive impairments and/or vision problems are less likely to be able to complete a survey, so are possibly under-represented in the results.
When stroke strikes, part of your brain shuts down. And so does a part of you. Life changes instantly and recovery is tough. But the brain can adapt. Our specialist support, research and campaigning are only possible with the courage and determination of the stroke community. With more donations and support from you, we can rebuild even more lives.

Donate or find out more at stroke.org.uk

Rebuilding lives after stroke

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