Short-changed by stroke

The financial impact of stroke on people of working age

LIFE AFTER STROKE CAMPAIGN BRIEFING

Get involved at:
stroke.org.uk/short-changed
#shortchanged
or #lifeafterstroke
We believe in Life After Stroke. We believe that stroke survivors should be supported to make their best possible recovery.

We believe that a stroke should not leave families in financial difficulties and that the benefits system must support stroke survivors who are unable to work because of illness or disability.

Urgent action is needed to tackle the financial impact of stroke on stroke survivors and their families and carers.

The benefits system should provide support during recovery and rehabilitation to help people regain control and independence. It should provide support in the long-term for people who are unable to work, to give them the means of living a dignified and fulfilling life.

A word about the data

The findings which form the basis of this briefing come from two sources:

- **Daily Life Survey:** In late 2011, over 2,200 stroke survivors and carers across the UK responded to a survey that asked them about their daily lives. 520 respondents were between the ages of 25 and 59 years.
- **Employment and Support Allowance (ESA) questionnaire and interviews:** In early 2012, 120 stroke survivors filled in our online questionnaire about their experience of applying for ESA. Ten of those responding to the questionnaire were then interviewed in more depth about their experiences.

This campaign briefing is informed by the personal stories of these survivors and carers. It provides a valuable and timely insight into the experiences of stroke survivors and their families, and the financial impact of stroke.

We would like to thank everyone who took part.

Briefing written by Alison Clarke and Danielle de Bruin

With support from Patrick Olszowski, Chris Randell, Emma Nye, Nikki Hill, Morwenna Kirke, Anne Pollock, Anil Ranchod, Meredith Molony, Jamie Whear, Kam Cheema, Sue Blackmore, BCD Associates and many other colleagues – thank you!
Most of us will experience ill health at some point. If this is just for a few days, we then get back on with our lives and think no more of it.

If, however, the illness lasts longer or results in a disability it could affect our ability to work or fulfil other commitments.

Stroke is the leading cause of severe adult disability and can leave people with visible impairments as well as hidden disabilities. These include extreme tiredness, aphasia (which makes communication hard) and cognitive difficulties affecting memory, attention and perception. These changes are often accompanied by emotional distress. Taken together these can make everyday tasks, including work, extremely difficult, if not impossible.

Such major life changes can quickly impact on people’s income and expenses. Financial commitments do not stop just because of illness and people are soon forced to make difficult decisions on how to economise. Over the last year, hundreds of stroke survivors and their families have told us that they are increasingly worried about, and in many cases are being adversely affected by, the changes being made to the benefits system which should be helping those most in need.

This briefing, Short-changed by stroke, looks at some of the financial consequences of stroke on people aged between 25 and 59. Our research told us that it is this group, at the peak of their working lives, who take the heaviest and hardest financial hit. These are people who have often been working for many years, paying National Insurance and planning for their futures. They may have some savings, but these don’t last long when a stroke happens. Home adaptations are expensive. More time at home means higher utility bills and many people are also faced with high social care costs.

These changes also affect carers and families. Carers may be forced to work longer hours to support their families, or to reduce their hours because of caring responsibilities.

The consequences of stroke can be shattering both for the survivor and for the rest of the family. Too often it results in severe financial hardship and when hard times hit people look to the state for help. We believe there must be an adequate financial safety net for stroke survivors who are in need as they face their daily battle to adjust to a life after stroke. It is a mark of a civilised society. And yet survivors tell us that too often this support is hard to access or is denied to them completely. They tell us that the way they are treated by the system that should support them leaves them feeling demeaned and humiliated. This is unacceptable and must change.

We can all play our part in bringing about a more just and tolerant system and a society that supports stroke survivors to get back to their best possible quality of life after a stroke.

You can help us to campaign for a better life after stroke and to make the benefits system fairer for stroke survivors. Join the Life After Stroke campaign at stroke.org.uk/campaigns

See our calls to action on page 12 of this briefing. Together we can help more people make better recoveries after stroke.

Jon Barrick
CEO, Stroke Association
Peter was 39 when he had a stroke.

“I’m far worse off after my stroke. I had a good job before. You work hard for 20 years to achieve a comfortable standard of living, but it’s taken away through no fault of your own. My wife works full-time and has to look after our young children.”

Peter applied for Employment and Support Allowance and had a Work Capability Assessment. He explained:

“I don’t have many physical disabilities but I suffer with lots of things you can’t see, like migraines, motion sickness, seeing flashing lights, poor concentration and problems with my memory. The assessors just don’t get it.”

Peter recalls what the assessor said to him:

“He said that I was a bit young for a stroke. It felt like he was saying I had managed to secure a diagnosis that was not accurate or truthful.”

Peter spent 12 months fighting for support from the benefits system.

“It wasn’t just about money, though I mustn’t make it seem like that was unimportant. It was about ‘my status’ – I am currently unable to work and I don’t want to be thought of as some kind of scrounger.”

---

1 stroke.org.uk/involved/life-after-stroke-campaign
2 stroke.org.uk/get-involved/stroke-survivors-declarations
Stroke can have a sudden and unexpected effect on working people’s finances

Stroke is the leading cause of severe adult disability in the UK. Every year approximately 150,000 people have a stroke and one in every four of these is under 65. With the right support, care and advice many can get back to work, but for a large number the disabilities caused by stroke mean they are unable to work.

Income goes down, and not just for stroke survivors

In the Stroke Association’s 2011 Daily Life Survey, over 65 percent of stroke survivors between the ages of 25 and 59 told us that their household income fell after their stroke.

69 percent of those who answered this question told us that the main reason for this was because they were unable to work.

Stroke can have a major impact on a family’s income beyond affecting the survivor’s ability to work. In our survey a quarter of respondents reported that their partner or relative had to reduce their hours or give up work completely because of their caring responsibilities.

Expenses go up, for the whole family

When someone has a stroke, mortgages, rent and bills still need to be paid and the family needs to be clothed and fed.

The majority of survivors found their household income went down while at the same time over 65 percent of survivors reported that their bills and other expenses went up.

Those who said their household expenses had increased were asked to identify the cause of this. The majority (93%) had higher gas and electricity bills because they were at home more or needed to keep their houses warmer because of the difficulty they have in moving around. Their problem is made worse by rising fuel costs. Almost a half (47%) had increased transport costs because they had difficulty walking or using public transport.

Difficult decisions

“We eat less; turn off the lights and heating more. Use less of everything.”

These increases in expenses can have a drastic effect on stroke survivors and their families. Stroke survivors need to regain their confidence and independence yet 64 percent reported cutting back on going outside their house.

53 percent said that they tried not to turn on their heating unless absolutely necessary. By definition, living in fuel poverty occurs when a household spends more that 10 percent of its income on fuel. On this basis, 63 percent of stroke survivors between the ages of 25 and 59 in our survey are living in fuel poverty.

Nearly 40 percent of respondents reported that they have had to cut back on food.

---

Len’s Story

Len’s wife Carol was 57 when she had a stroke last year.

“My wife spent seven weeks in hospital where I was told she was the sickest person on the ward. I had to take two weeks off work from my factory job to be with her.”

“After she left hospital I took more time off to be there for her and was called into the office for a meeting about my timekeeping. I was angry about that. I felt under pressure and thought, do I struggle back and forth from home to work to look after her, or do I leave? So I handed in my notice and gave up my job to care for her.”

“My wife didn’t ask to have a stroke. Why can’t carers in my position have a year off with the guarantee we’ll get our jobs back?”

Impact on carers

For respondents whose carer or family member was working, nearly 60 percent said that caring had an impact on their work. They are under pressure both to work longer hours in order to financially support the family, and at the same time to reduce their hours in order to care for their loved ones. This leads to some very difficult decisions.

This is what survivors told us:

“My wife has to provide more care for me as funding was cut and I could not have carers to put me to bed each evening.”

“I have to depend on close friends to care for me, whilst my carer has a part time job so we can pay the mortgage.”

Increasing financial worries also lead to strains on relationships:

“She shouldn’t have to work at her age to keep the household going. It affects my self-esteem. I’m not ‘macho’ but it is very undermining.”

“My carer had to reduce his hours, but still needs to work as we have a mortgage.”

“My wife has had to take time off and had to make it up which is affecting her health due to stress.”
Short-changed by stroke

When Janet’s husband Christopher had a stroke in 2007, she carried on working but found it very difficult. Stress-related illness made her give up her career as a lecturer to care for Christopher full-time, swapping her £37,000 a year salary for a carer’s allowance of about £58 a week.

“I felt isolated (and still do), like I had lost my husband… It’s like bereavement, but the person is still alive. I am constantly tired and as time moves on he gets more demanding and dependent on me. However, that does not mean I will give up on him EVER!”

“I can cope with the role of being a carer, it is all the other stuff that surrounds my husband’s needs and the constant fighting I have to go through to get him what he is entitled to or needs. The authorities see ‘support’ for a stroke survivor as a ‘privilege’ whereas it should be seen as a ‘right’.”

An ongoing problem

For many stroke survivors the financial impact of stroke will last for the rest of their lives. In our Daily Life Survey, 80 percent of stroke survivors between the ages of 25 and 59 told us they are worried about their financial future – worried that they are facing a future of poverty in old age.

“We have to try to manage on what we have; life is very hard and just getting harder.”
How the benefits system is failing stroke survivors

In 2012 the Stroke Association asked stroke survivors to tell us what it is like to claim Employment and Support Allowance (ESA) and have a Work Capability Assessment (WCA).

120 people filled in our survey and in addition we carried out ten in-depth interviews through an external company (BCD Care Associates).

None of the stroke survivors we interviewed had claimed benefits before. They told us that they found the system very confusing and difficult to navigate.

“We didn’t know anything about benefits – and nobody told us. I know a lot more now and have grown weary going through the same routines over and over again for the past seven or eight years.”

Another said:

“A week or two after they withdrew my ESA the lady I spoke to suggested I apply for Jobseeker’s Allowance (JSA). I was speechless. I explained to her that I am not a 17 year old school leaver living at home with my parents and I cannot, with the best effort, live on Job Seeker’s Allowance of £60 per week. More importantly I am NOT seeking a job. I’ve paid thousands of pounds in income tax and national insurance and am treated like a criminal.”

Rob’s Story

Rob was 49 when he had a stroke. Almost four years on, and after a significant relapse, getting back to work remains his intention and hope.

“If I carry on making good progress I believe I can get back to work in another 12 months or so. That will be five years after my first stroke. It’s been a slow process.”

The first thing Rob said when talking about his experience of Employment Support Allowance was:

“That’s a sore point – they’ve cancelled mine. I’ve had my 365 days and now I’m expected to be supported by my wife as she works more than 24 hours.”

“I’ve paid National Insurance all my life – more than 30 years of contributing. I thought I would be able to rely on the benefits system if I ran into difficulties. This hasn’t been the case at all.”

4 See appendix on page 13 for more information about ESA and WCA.
**The Work Capability Assessment (WCA)**

In the questionnaire, the survivors gave graphic accounts of their experiences of undergoing the WCA. They used words like unfair, humiliating, frustrating, degrading and offensive to describe how they felt.

The Stroke Association believes this treatment is unacceptable and must change.

**A survivor told us:**

“It was a scruffy place. The assessor called me in, then sat behind a desk, put his feet up, put a computer keyboard on his lap and then proceeded to ask me a series of questions. It seemed like he was trying to catch me out.”

Most of the interviewees felt the assessors who carried out the WCA did not understand the effects of stroke and in particular didn’t take into account the cognitive impact stroke can have.

Other hidden effects of stroke that can have a big impact on people’s ability to work include depression, anxiety, communication difficulties and loss of self-esteem. Stroke survivors said these were also not recognised by assessors.

**Stroke survivors told us:**

“At no time did he (the assessor) address my mental state - a key issue in the problems I had been facing since my stroke.”

“I was not asked a single question with regard to my everyday problems.”

“Did they understand I had aphasia? No. They just seemed to think I was thick.”

Our interviewees told us that the WCA seemed too focussed on physical ability and that only those with the most severe disabilities would qualify for Employment and Support Allowance.

One stroke survivor said:

“If you are not going to soil yourself at your desk, then you are fit for work.”

Another said:

“You lose points for dressing nicely and not rocking in the chair. Their terms of reference are to take money off you.”

The lack of sympathy shown by some of the assessors frustrated other interviewees:

“When the ESA report arrived by post I was really upset – I don’t mind telling you that I cried. I thought they were calling me a liar.”

---

1 Problems with memory, attention and perception, among others, which are common to many stroke survivors.

2 A problem with communication common to many stroke survivors.
Simon is in his 50s, and lives alone. He had a stroke in 2009 and was in intensive care for six months followed by another six months in a rehabilitation unit. Simon suffers from memory loss and fatigue. He can’t write easily and struggles to deal with all the paperwork that comes from being out of work.

Following his stroke, Simon was told by his employer he could not go back to his old job as he wouldn’t be reliable or safe. He misses work and can sometimes go five or six days without seeing anyone.

“If you talk to me I suppose I might sound cheerful. In fact, I often feel very down. I love being with people and I miss that.”

In 2011 Simon started receiving Employment and Support Allowance (ESA) but after a year it stopped suddenly. He described to us what happened:

“Because my ESA stopped, the council stopped my council tax and housing benefit. They thought I was back at work. I also lost free dental care and prescriptions. I have no money and no real savings. I now have to make a new claim for means-tested ESA.”

Simon found going through the process of applying for benefits very difficult.

“It’s not as if I lay down on my bed and had a brain haemorrhage so as to avoid going to work.”

Our concerns about Employment and Support Allowance and welfare reform

At the Stroke Association we have had long standing concerns about Employment and Support Allowance and the Work Capability Assessment that people must undergo as part of the process for claiming benefits.

In general there have been many successful appeals against the original decision on whether to award benefit or which group the claimant is placed into.

Stroke survivors have reported that their WCA focussed on the physical difficulties they had and did not take into account other effects of stroke such as cognitive and communication problems, depression and fatigue which also affects the ability of stroke survivors to work.

Related concerns are that the assessors often do not appear to have even a basic understanding of stroke or that every stroke is unique in terms of the effect it has and that stroke survivors can have good and bad days. All of these must be recognised by the system. The assessment also needs to be sensitive to the fact that for some, particularly those with cognitive difficulties, their problems may not be apparent to the stroke survivor themselves.

For people in the work related activity group their entitlement to contributions based ESA lasts for one year. After this year they can claim means-tested ESA. However if they have a working partner or some savings they will not be entitled to any help. We are concerned that this unfair limiting of support puts added strain on stroke survivors and their families.

See Appendix on page 13 for an explanation of the different groups claimants are placed into.
Harrington Review

When Employment and Support Allowance was introduced (2008) provision was made for an annual independent review of the benefit. The Harrington Review is now in its third year. The Stroke Association has submitted evidence to the review about our concerns about ESA and the WCA. In addition we raised the issue that information on stroke in the guidance that assessors use in the WCA is incorrect and misleading and potentially threatens the chances of a fair outcome for stroke survivors.

Disability Living Allowance (DLA)

DLA is paid to people who need care or support due to ill-health or disability. It is to cover the extra costs associated with disability which is why it is not means-tested and is paid to anyone who qualifies regardless of their income or capital. This benefit will be phased out over the next few years and replaced with the Personal Independence Payment (PIP).

According to a government impact assessment, the changes will result in £2.24 billion less paid out annually in benefits and lead to 500,000 fewer claimants. The Stroke Association believes that DLA is a vital benefit that helps stroke survivors deal with the many added costs of disability. The Department for Work and Pensions must make sure that the administration of this new benefit is fair and that stroke survivors get the support they need to make their best possible recovery.

8 dwp.gov.uk/docs/dla-reform-wr2011-ia.pdf
At the Stroke Association we believe that a stroke should not leave families facing financial hardship. For stroke survivors and their families, access to benefits and financial support is vital. Point 8 of the Stroke Survivors’ Declaration\(^8\) says ‘I will be given advice on the financial benefits I can claim’. We believe the benefits system must support stroke survivors who are unable to work because of illness or disability.

- The benefits system should provide support during recovery and rehabilitation to help people regain control and independence.
- It should provide support in the long-term for people who are unable to work, to give them the means of living a dignified and fulfilling life.

Urgent action is needed to tackle the financial impact of stroke so that stroke survivors are able to make their best possible recovery and live a dignified life.

**What you can do**

Short-changed by stroke demonstrates the huge financial pressures that stroke survivors are under. Too often the system that should give them the support they need fails them. Any further cuts to benefits, care and services will make this situation much worse.

**We are calling on everyone that cares about the financial impact of stroke to support the Life After Stroke campaign.**

- Write to, or visit your MP and tell them how stroke has affected your finances. Demand ‘No More Cuts’ to the vital benefits disabled people rely on
- Share this report at [stroke.org.uk/short-changed](http://stroke.org.uk/short-changed)
- Follow the story on Twitter [#shortchanged](http://shortchanged) and [#lifeafterstroke](http://lifeafterstroke)
- Get involved in Hardest Hit campaign [thehardestdit.wordpress.com](http://thehardestdit.wordpress.com)
- ‘Like’ our campaign on Facebook
- Share your story at [stroke.org.uk/talkstroke](http://stroke.org.uk/talkstroke)
- Join the campaigner’s network [stroke.org.uk/campaigns](http://stroke.org.uk/campaigns)

Short-changed by stroke is the second phase in the Life After Stroke campaign.

---

\(^8\) stroke.org.uk/get-involved/stroke-survivors-declarations
Appendix: Employment and Support Allowance and the Work Capability Assessment

Employment and Support Allowance (ESA) is a benefit for people of working age who have limited capacity for work because of ill-health or disability.

Claiming Employment and Support Allowance

When someone makes a claim for ESA, they usually have a Work Capability Assessment (WCA) that looks at how their ability to work, or prepare themselves for work, is affected by their illness or disability.

After the assessment, the Department for Work and Pensions (DWP) makes a decision on whether the claimant is entitled to ESA and, if so, which of the following groups they will be placed into:

**Work-Related Activity Group** – This group is for people the DWP think are able to return to or start work at some point in the future. To receive all of their benefit they must take part in work-related activity to help them prepare for suitable work.

**Support Group** – This group is for those who are considered unable to work due to their illness or disability and who will not be expected to take part in work-related activity.

**ESA is made up of two kinds of benefit:**

**Contribution-Based ESA (ESA(C))** This is a non means-tested benefit (i.e. it is paid irrespective of income or capital) paid on the basis of having made enough National Insurance contributions.

For those in the Work Related Activity Group the ESA(C) will end after one year. They are then entitled to claim Income Related ESA (ESA(IR)) but this is means tested and depends on any income or savings they or their partner have.

For those in the Support Group the ESA(C) is not time limited and can continue indefinitely (up to retirement age).

**Income-Related ESA (ESA(IR))** This is a means-tested benefit paid to those who have not made enough National Insurance contributions or whose entitlement to ESA(C) has ended after a year.
We are the Stroke Association

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

The Stroke Association is a charity. We rely on your support to change lives and prevent 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

Short-changed by stroke
The second phase in the Life After Stroke campaign
Helping more survivors achieve a better life after stroke

September 2012

Get involved at:
stroke.org.uk/short-changed
#shortchanged
or #lifeafterstroke