



What we think about:

Claiming disability benefits

Rebuilding lives after stroke

Stroke
Association

Background

People claim benefits for a range of reasons, from helping with the costs of raising children to support with funeral costs. Some are available to everyone, like the State Pension, while others are based on personal circumstances, such as benefits for those who are out of work or have a disability.

Stroke is a leading cause of disability in the UK, with over a million people living with the devastating effects of stroke. That means many stroke survivors are likely to be entitled to disability benefits such as Personal Independence Payment (PIP), Employment and Support Allowance (ESA) and Attendance Allowance (AA). More information on these benefits can be found in the Q&A section below. Carers are also eligible for benefits to support them in their caring role.

Most disability-related benefits are controlled by the UK Government but responsibility for some has been devolved. For example, the Scottish Parliament has been given significant new powers over some disability benefits including the Personal Independence Payment.¹



More information on these types of benefits can be found in the Q&A section.

What we think

Stroke causes a greater range of disabilities than any other condition. The benefits system should be fair, quick and accessible for stroke survivors. However, we know that this is often not the case.

Stroke survivors and carers tell us that claiming benefits can often be a difficult and complicated process. Application forms are challenging or impossible to complete for anyone who has difficulties with reading or writing. Assessors, who decide on the outcome of someone's benefits application, often don't know enough about the complex effects of stroke and how much of an impact they can have on people's lives. This is particularly the case for the hidden effects of stroke, such as fatigue and difficulties with memory, concentration and problem solving, which are not easy to explain or

recognise. Too many people also wait too long for decisions to be made about their applications, which leaves them without vital financial support, sometimes for long periods of time.

These problems are unacceptable and the Government has a responsibility to improve things through working closely with those most affected, as well as charities and other experts.

We want applying for and claiming disability benefits to be a simple, swift and respectful process which involves assessors who have a good knowledge and understanding of how stroke affects people.

Why do we think this?

Stroke is a major cause of disability, affecting people's ability to work and increasing their living costs, so many stroke survivors are entitled to benefits

Stroke is a leading cause of disability in the UK. Almost two thirds of survivors leave hospital with a disability in England, Northern Ireland and Wales.² People of working age who have had a stroke are two to three times more likely to be unemployed eight years after their stroke³ and almost a third of stroke survivors say they have to spend more on daily living costs.⁴

No two people are affected by stroke in the same way. Stroke causes a greater range of disabilities than any other condition.⁵ It can impact everything from eyesight to mood to swallowing. Around a third of stroke survivors have aphasia, affecting their ability to speak, read, write or understand language.⁶ Unlike many other conditions, stroke strikes

suddenly, often leaving the survivor with immediate, unexpected and life-changing disabilities. One stroke survivor told us:

"I had to retire from work. I do not drive. I require a caretaker. I was a healthy, employed, very independent person before my stroke. The disabilities and change in lifestyle have been devastating"⁷

Applying for benefits is too challenging

Stroke survivors and carers have told us that the disability benefits applications process is too long and complex, particularly when dealing with the effects of a stroke.

Just under half of those who responded to our survey on disability benefits described the application process for PIP as 'poor' or 'very poor', with 61% saying they needed help filling in application forms.⁸ Feedback was similarly negative in relation to ESA, with 46% telling us that they felt the assessment didn't take the unseen effects of stroke like difficulties in



controlling emotions into account. Over a third of respondents rated the application process for Attendance Allowance as 'poor' or 'very poor', with 47% saying they needed help filling in the form.

Recent research with stroke survivors in Northern Ireland also highlighted that the benefits system is confusing and complicated, and that forms can be difficult, or impossible for people experiencing the effects of stroke to complete.⁹ The stroke survivors we spoke to were also often unaware of sources of help available to them such as Citizens Advice.

Between September 2017 and August 2018, our Stroke Helpline received

over 1000 enquiries about benefits from people affected by stroke. Most of the queries were around finding out what benefits stroke survivors are entitled to, people losing money when being switched from Disability Living Allowance to PIP, being declined a benefit, and help with filling in forms, either for an initial claim or for an appeal process.

Many of our stroke support coordinators have also told us that application forms can be lengthy and confusing for all stroke survivors and particularly for those with communication difficulties.

There is not enough understanding of stroke in the benefits system

The effects of stroke can be complex and not always obvious. Around a third of stroke survivors experience some level of aphasia, which affects their ability to speak, write, read or understand what others say.¹⁰ 87% of those who responded to our survey about benefits said they struggle with fatigue or difficulty in understanding.¹¹ Stroke survivors also can have severe problems with memory, problem solving and concentration. These hidden effects of stroke can be difficult for people to clearly describe and difficult for assessors who do not sufficiently understand stroke to diagnose:

“I knew I was different but couldn’t totally explain why or understand it, I didn’t know what I was experiencing was common after a stroke. I found it very hard to tell people I was struggling to comprehend what was going on around me or why I was forgetting so much. It was very frustrating.”

Stroke survivors tell us that these hidden effects of stroke are either not recognised or not seen as important by benefits assessors. This means

survivors, their families and carers worry that the full extent of their disability is not going to be taken into account when the assessor decides whether or not to grant benefits applications. It can also mean that stroke survivors are deemed fit for work when in reality they are not.

One stroke survivor told us that they weren’t deemed eligible for PIP “as the effects of my stroke were hidden”. In response to our benefits survey, another stroke survivor suggested that assessors “aren’t educated enough on the different effects a stroke has from one person to the next”.

This view is supported by a parliamentary report which found that disability benefit claimants were not receiving an “acceptable level of service” from the contractors the Government pays to assess people. They found that assessors don’t understand the full range of disability associated with having a stroke, in particular mental health problems which often affect so many stroke survivors.¹² The report recommended that the Department of Work and Pensions and its contractors should employ “well-trained, knowledgeable assessors who are sensitive to the complex issues that claimants are dealing with.”



The Department accepted this recommendation and committed to working with contractors to improve their training plans and materials for assessors to ensure that they are equipped with the relevant skills and knowledge to deal sensitively with claimants and the various issues presented by their conditions.¹³

Stroke isn't well enough understood by assessors

Our stroke support co-ordinators have told us that assessors can often lack understanding of the ways stroke can affect people. This is supported by a parliamentary committee who found serious problems with the performance of assessors used by the Government to deal with applications. The committee found that there are "unacceptable local and regional

variations in the performance" of the Government assessors and that those trying to claim benefits are not receiving an acceptable level of service.¹⁴

Claimants are waiting too long for a decision to be made

According to the latest statistics, people who are claiming PIP for the first time have to wait an average of 14 weeks between submitting a claim and a decision being made.¹⁵ Stroke can have a devastating financial impact on the lives of survivors and their families. Stroke survivors often can't return to work and home adaptations can be costly. Long waiting times for a decision to be made about a benefits claim can leave those affected by stroke without vital financial support when it is most needed.

What do we want to see happen?

We want the disability benefits application process to be simpler, fairer and quicker, with more consideration given to the unique nature of stroke as a long-term condition.

That's why we are calling for:

- The **Accessible Information Standard to be applied to the benefits system** to ensure information is available in an accessible format and that stroke survivors have the support they need when completing application forms. Organisations that provide NHS or adult social care services must follow the Accessible Information Standard. This makes sure that people who have a disability, impairment or sensory loss get the information they need about these services in an accessible format and also any support they may need with communication.¹⁶ This is

particularly important for stroke survivors, many of whom have communication difficulties as a result of their stroke;

- All **disability benefits assessors and advisors to be trained** to recognise and understand the full range of impacts of stroke and aphasia;
- **Benefits assessments and decisions about claims to be made much sooner** after someone applies so people are not left without vital financial support for long periods of time; and
- **Sources of support for people claiming benefits** such as Citizens Advice and Make the Call in Northern Ireland to be more widely promoted and advertised.

We also **endorse and support the Disability Benefits Consortium's calls for action around PIP**

specifically, which include:

- Reviewing the PIP assessment criteria to ensure these are fair and reflect the extra costs that people face;
- Ensuring indefinite PIP awards for people with severe and complex conditions that will not improve over time;
- Simplifying the claims process and making the applications form available in accessible formats;
- Improving staff training and guidance for PIP assessors; and
- Exploring ways to improve the evidence gathering process for making a claim.¹⁷

We would also like to see the **recommendations of an independent review of the PIP assessment process in Northern Ireland to be implemented**. In 2018 the Department for Communities in Northern Ireland commissioned an independent review to look at how the PIP assessment is working there.

The reviewer spoke to people who have experience of claiming PIP as well as organisations who support those individuals and disability assessors. 14 recommendations were made in June 2018 about what should change in the assessment process including making information more accessible and training the assessors in specific health problems and disabilities.¹⁸ We welcome these recommendations and want to see them put into practice as soon as possible in Northern Ireland.

A decision in April 2018 means that benefits for Scottish residents will now be the responsibility of the Scottish Parliament.¹⁹ It is vital that this change does not negatively affect stroke survivors claiming benefits and that the system and processes for claiming are also make fairer, quicker and more accessible.

What are we doing?

The Stroke Association is a member of the Disability Benefits Consortium, a coalition of over 80 charities and other organisations who are working towards a fairer benefits system. Through the consortium, we are putting pressure on the UK and Scottish governments to make the benefits system fairer and simpler so that it meets the needs of disabled people, including stroke survivors with disabilities.

We have met with the Minister for Disabled People and other officials from the Department for Work and Pensions to talk about the effects of stroke and the difficulties stroke survivors' experience when claiming disability benefits. As a result of this meeting we have been invited to join a group of national stakeholders that meet with the Minister every few months to review and improve the PIP assessment guidelines.

Q&A

Q. How many stroke survivors claim benefits?

A. As of July 2018 around 43,800 stroke survivors were claiming for PIP, however this is only those who put down stroke or TIA as their main cause of disability and does not include those claiming other benefits such as ESA or Attendance allowance.

Q. Does the Stroke Association agree with the Government's welfare reform programme?

A. There have been huge changes over the past few years across a wide range of benefits from Child Benefit to the State Pension. It would not be appropriate for us to have a single position on all aspects of welfare reform and that's why we have concentrating on specific disability benefits, which are the greatest impact on stroke survivors.

Q. Who is responsible for disability benefits?

A. Responsibility for most disability benefits sits with the UK Government in the Department for Work and Pensions. However, in 2016 the Scottish Parliament were given greater powers over some disability benefits including Disability Living Allowance, Personal Independence Payment and Attendance Allowance.²⁰

Q. What support does the Stroke Association provide for stroke survivors applying for benefits?

A. Our Life After Stroke Services in many parts of the country provide stroke survivors and their families with information and advice on benefits as well as signposting to other services.

Our Stroke Helpline provides information and support to anyone affected by stroke who has a query about benefits.

We also have a factsheet on the benefits and financial support that is available to those affected by stroke.

Q. Which benefits are you talking about here and why?

A. For the purposes of this policy position we are focusing on those benefits which stroke survivors and carers are most likely to be eligible for. These are:

Personal Independence Payment (PIP) – a benefit that helps with some of the extra-costs caused by long-term ill health or disability. It replaces a benefit called Disability Living Allowance (DLA). To qualify for PIP you must be aged between 16 and 64 and have a long-term illness or disability. We have included this benefit in this paper because so many stroke survivors of working age live with the long-term effects of stroke.

Employment and Support Allowance (ESA) – if you can't work because of an illness or disability you may be able to claim ESA. You must be under State Pension age and not be receiving Statutory Sick Pay. There are two types of ESA – contribution-based (if you have paid enough National Insurance contributions) or income-related (if you have a low income). If deemed eligible for ESA, you will be put into one of two groups:

- Work-related activity group – for people who are assessed as being able to return to work in the future. You will be expected to take part in work-related activities and go to regular interviews with an adviser, which will help you prepare for work; or
- Support group – if your illness or disability has a severe effect on your ability to work, you will be put into this group and not be expected to look for work or go to interviews.

We have included this benefit in this paper because people can and do recover after their stroke and return to work.

Attendance Allowance – if you are over 65 and need help with your personal care because you have a disability, you may be able to claim Attendance Allowance. In most cases, you must have needed help for at least six months before you can receive this benefit. It is paid at two different weekly rates and the rate you receive will depend on the level of care you need. We have covered this benefit in this paper because three quarters of strokes happen to people over the age of 65.

Q. What other benefits are available and what other help is out there?

A. As well as the benefits listed above, some stroke survivors may receive **Universal Credit**, which is being introduced across the UK in stages and replaces benefits such as Jobseeker's Allowance, Housing Benefit and income-related ESA. You may be able to claim Universal Credit if you are out of work or on a low income, as is the case for many stroke survivors who are unable to return to work.

If you care for someone who has had a stroke you may be eligible for **Carer's Allowance**. You must be aged 16 or over and spend at least 35 hours a week caring for a disabled person who receives a disability benefit to meet the criteria for this benefit.

To find out more about Universal Credit, Carer's Allowance and other benefits paid by the Government, visit: www.gov.uk/browse/benefits.

Citizens Advice also provide information on benefits at: www.citizensadvice.org.uk/benefits.

Q. What is Make the Call?

A. This is a free helpline in Northern Ireland for people who are claiming benefits. People can call the helpline if they are unsure whether they are getting all the money and support they are entitled to. The helpline is open Monday to Friday 9am – 5pm and can be reached on 0800 232 1271.

You can find more information about Make the Call here.

Q. Does this policy apply across the UK?

A. Yes.

Q. When will this policy be reviewed?

A. This policy will be reviewed in October 2021.

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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

Contact us

We're here for you. Contact us for expert information and support by phone, email and online.

Stroke Helpline: **0303 3033 100**

From a textphone: **18001 0303 3033 100**

Email: helpline@stroke.org.uk

Website: stroke.org.uk

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