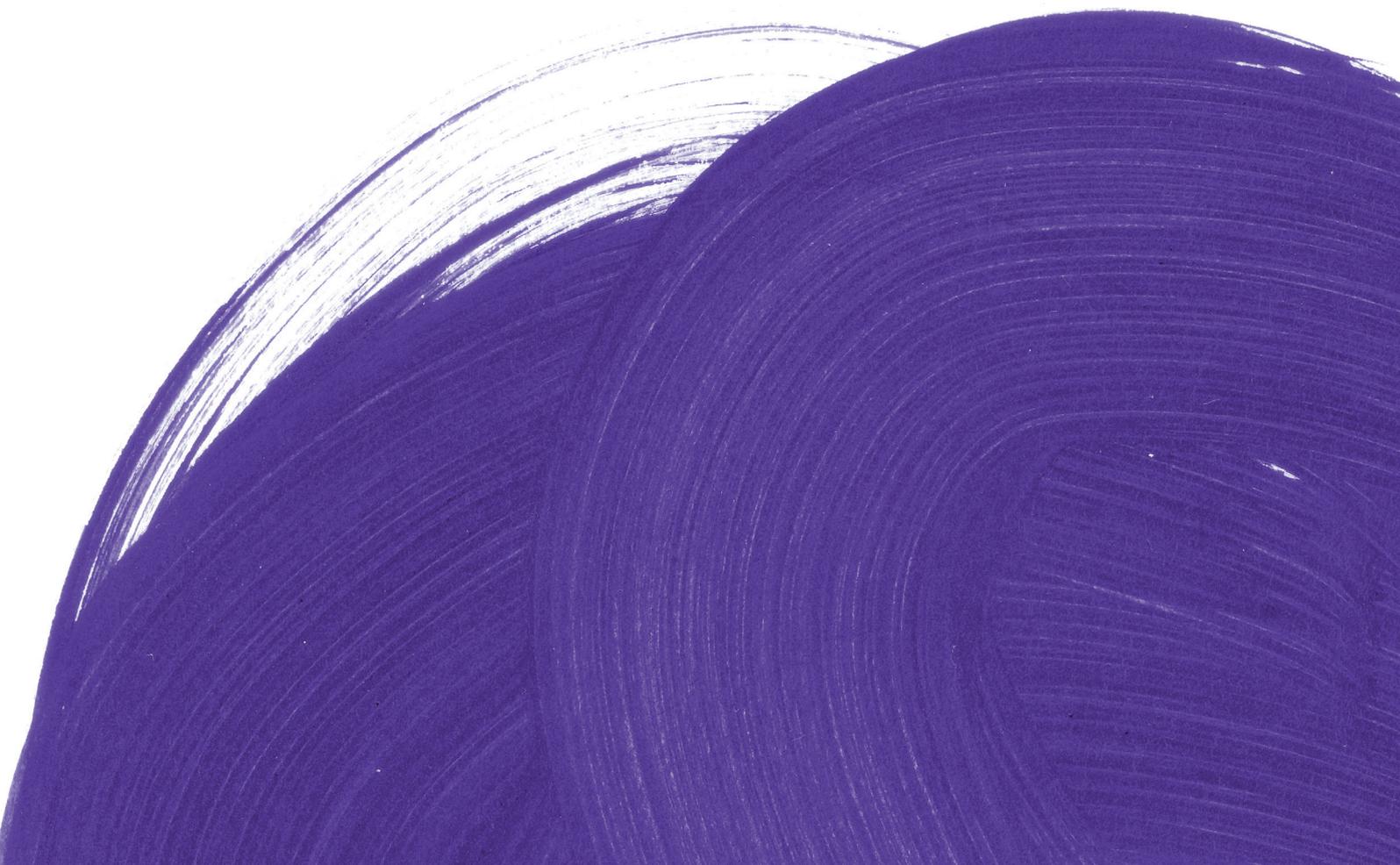


What we think about:

# Disability benefits



# Background

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

Stroke is a leading cause of disability in the UK, causing a greater range of disabilities than any other condition.<sup>1</sup> Over half a million people live with the disabling effect of stroke and many of them will have experience of the benefits system. This paper concentrates on the three specific benefits most relevant to stroke survivors: 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.

Most disability 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 Disability Living Allowance and the Personal Independence Payment.<sup>2</sup>

# What we think

## **Stroke is one of the biggest causes of disability, meaning many stroke survivors are likely to be entitled to disability benefits.**

It is important that the benefits system works for stroke survivors, but we know that too often this isn't the case. Our survey of stroke survivors and carers has highlighted that claiming benefits is a difficult and complicated process.

The forms are difficult to complete for anyone who has difficulties with reading or writing. The assessors, who decide on the outcome of someone's benefits application, often don't know enough about the effects of stroke and how much of an impact they can have. This is particularly the case for the hidden effects of stroke, including severe fatigue and difficulties with memory, concentration and problem solving, which are not easy to explain or diagnose. Too many people are waiting too long for decisions to be made about their applications, which can mean a long time without vital financial support.

These problems are unacceptable and the Government has a responsibility to improve things. We want applying for and claiming disability benefits to be a simple, swift and respectful process. It should also involve assessors who have knowledge of how stroke affects people.

### **That's why we are calling for:**

- all disability benefits assessors and advisors to be trained to recognise and understand the impact of stroke and aphasia
- the Government's Accessible Information Standard to be applied to the benefits system to ensure information is available in an accessible format
- assessments and decisions to be made much sooner after someone applies and within a reasonable timeframe.

### **We will be:**

- working with like-minded charities to pressure the Government into improving the system
- writing to the Secretary of State for Work and Pensions to call for the Accessible Information Standard to apply to the benefits system
- offering to support the Government with training benefits assessors and advisors in stroke
- continuing to support stroke survivors through the benefits applications process, including continuing to signpost to local services such as Citizens Advice Bureau.

# Why do we think this?

## Stroke is a major cause of disability 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.<sup>3</sup> People of working age who have had a stroke are two to three times more likely to be unemployed eight years after their stroke<sup>4</sup> and almost a third of stroke survivors say they have to spend more on daily living costs.<sup>5</sup>

No two people are affected by stroke in the same way. Stroke causes a greater range of disabilities than any other condition.<sup>6</sup> It can impact everything from eyesight to mood to the ability to read, write or swallow. Around a third of stroke survivors have aphasia, affecting their ability to speak, read, write or understand language.<sup>7</sup> Often, stroke will cause a range of disabilities in a survivor. Unlike many other conditions, stroke strikes suddenly, often leaving the survivor with immediate, unexpected and life-changing disabilities. One stroke survivor told us<sup>8</sup>:

*"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."*

## There is not enough understanding of stroke in the benefits system

The effects of stroke can be complex and not always obvious. It is not just the physical effects of stroke that many survivors have to deal with. 87% of those who responded to our survey struggle with fatigue or difficulty in understanding. Stroke survivors also have severe problems with memory, problem solving and concentration. These hidden effects of stroke are difficult for people to describe clearly, and difficult to diagnose for assessors who do not understand stroke:

*"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 the hidden effects of stroke, in particular, 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.

In response to our survey, one stroke survivor suggested that the 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, in particular mental health problems which come and go, something that affects so many stroke survivors.<sup>9</sup> The MPs 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."*

## 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. 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 emotionalism 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.

Many of our Stroke Association co-ordinators support stroke survivors and carers throughout the benefits process. They have told us that application forms can be lengthy and confusing for all stroke survivors, not just those with communication difficulties.

## The performance of many benefits assessors isn't good enough

Our coordinators have also reported that assessors can be impersonal, and the appeals process can be very distressing.

A parliamentary committee found serious problems with the performance of the assessors used by the Government to deal with applications. It found that while the overall number of health and disability assessments has fallen, there are "*unacceptable local and regional variations in the performance*" of the Government assessors. It also found that those trying to claim benefits are not receiving an acceptable level of service.<sup>10</sup>

# 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.**

The Department for Work and Pensions, which is responsible for the benefits system, needs to do more to reduce the delays in decision-making which are having such a negative impact on stroke survivors, families and carers.

The Government also needs to do more to make sure that those employed to assess and advise disability benefits applicants are better trained so that there is more understanding of the range of issues stroke survivors can experience.

Organisations providing 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 in an accessible format and any support they may need with communication.<sup>11</sup> This is obviously particularly important for stroke survivors, many of whom have communication difficulties as a result of their stroke.

# What are we doing?

The Stroke Association is a member of the Disability Benefits Consortium, a coalition of over 70 charities and other organisations who are working towards a fairer benefits system. Through the consortium, we are putting pressure on the Government to make the benefits system fairer and simpler so that it meets the needs of disabled people, including stroke survivors with disabilities.

We will be writing to the Secretary of State for Work and Pensions to ask that the Accessible Information Standard is applied to the benefits system to make assessments and form-filling more understandable.

We will also be standing ready to offer our stroke expertise and training to the Government in an effort to improve the knowledge that benefits assessors and advisers have of this unique condition.

Our service co-ordinators in some parts of the country and helpline regularly support stroke survivors and their carers to find their way through the benefits system. We will continue to do this, and will continue to signpost stroke survivors to other local sources of help, including to the Citizens' Advice Bureau.

# Q&A

## How many stroke survivors claim benefits?

There are no exact figures on how many stroke survivors claim benefits. We do know that almost two thirds of the 1.2 million stroke survivors in the UK have a disability as a result of their stroke. We can assume that many thousands will be claiming or applying for disability benefits.

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

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

## Does this policy apply across the UK and what about the new powers over benefits given to the Scottish Parliament?

Yes, although some disability benefits are to be transferred to the Scottish Parliament shortly, including Disability Living Allowance, Personal Independence Payment and Attendance Allowance.<sup>12</sup>

Powers over some other benefits, not directly related to disability, have already been transferred from the UK Parliament. In September 2016, the Scottish Parliament was given new power to change employment support, Universal Credit, Tax Credits and Child Benefit. In April 2017, it gained the power to make discretionary housing payments.<sup>13</sup>

We will engage with Scottish politicians as appropriate to highlight issues affecting stroke survivors as the new social security system in Scotland takes effect.

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

Our Life After Stroke Services in many parts of the country support stroke survivors and their families with a range of support, including information and advice. In 2016, we supported 3,750 people with queries about a range of benefits or finances.

Our helpline provides information and support, and we have a **factsheet** on the benefits and financial support available to those affected by stroke.

### Which benefits are you talking about here and why?

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 it is agreed that your illness or disability limits your ability to work, you will be able to receive 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.
- 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 Attendance Allowance. It is paid at two different weekly rates and the rate you receive will depend on the level of care you need. We have included this benefit in this paper because three quarters of strokes happen to people over the age of 65.

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

A full list of the benefits paid by the Government can be found at [www.gov.uk/browse/benefits](http://www.gov.uk/browse/benefits).

Citizens Advice also provides information on benefits at [www.citizensadvice.org.uk/benefits](http://www.citizensadvice.org.uk/benefits).

### When will this policy be reviewed?

July 2018

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## **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 to develop new treatments and ways of preventing stroke.

**We're here for you. Together we can conquer stroke. If you'd like to know more please get in touch.**

**Stroke Helpline:** 0303 3033 100

**Website:** [stroke.org.uk](http://stroke.org.uk)

**Email:** [info@stroke.org.uk](mailto:info@stroke.org.uk)

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

We are a charity and we rely on your support to change the lives of people affected by stroke and reduce the number of people who are struck down by this devastating condition.

**Please help us to make a difference today.**



**Facebook** - Stroke Association  
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*Together we can conquer stroke*