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To whom it may concern:

**Response to Consultation on the Personal Independence Payment:
assessment thresholds**

Introduction

A stroke is the brain equivalent of a heart attack caused by an interruption of blood supply to the brain.

Stroke is third biggest killer and the largest single cause of severe adult disability in the UK. There are around 110,000 strokes and 20,000 Transient Ischaemic Attacks (TIA or “mini strokes”) in England a year and roughly 300,000 people are living with moderate to severe disability as a result of stroke.

The Stroke Association’s general concerns about PIP

The most recent figure from the DWP from 2010 revealed that 111,000 people who receive DLA are categorised as ‘stroke related’. Therefore there will be a huge number of stroke survivors affected by the change to PIP.

Whilst The Stroke Association agrees that Disability Living Allowance requires some reform, we have a number of concerns around the introduction of the Personal Independence Payment.

We are pleased that through our campaigning as part of the Hardest Hit campaign and the Disability Benefits Consortium the qualifying period will remain at three months. We do however have concerns about the need to show that your disability will continue for another nine months. Stroke is a complex condition and affects people in very different ways. Even very experienced stroke consultants find it difficult to predict a stroke survivor’s recovery.

We are concerned that the 20% cut in expenditure is an arbitrary target without a proper impact assessment. We understand that the DWP estimates that around 500,000 will lose their payment because of the changes being made. We are not aware of any statistic about which conditions will most lose out from this but would like to see as few stroke survivors being affected as possible.

Stroke survivors have experienced a multitude of problems with Employment Support Allowance's Work Capability Assessment. We would like to see lessons learnt from this experience to ensure that the PIP assessment works for stroke survivors. For example, the process itself must be accessible for people who have communication difficulties. The evidence of a stroke survivor's GP or Consultant must carry significant weighting. The descriptors need to take account of the hidden problems associated with stroke such as cognitive and communication difficulties. And the assessors themselves must be sensitive to issues around stroke and treat everyone as an individual.

We understand that reassessments will be more of the norm with PIP. Stroke survivors can often continue their recovery for a number of years so we support the fact that PIP will aim to get people who can work back into work. However we would not want stroke survivors to be over burdened with numerous re-assessments and would want to see vocational rehabilitation for stroke survivors to enable them to learn new skills.

We are also aware that DLA is currently the gateway for a number of other benefits – in particular Carers Allowance. We are not clear how the changes will affect this but we would want the new benefit to ensure that Carers of stroke survivors are supported for the time they give to help their loved ones.

Specific issues over the PIP assessment process and stroke

Many of the lessons learnt from WCA should be applicable to PIP. There have been many issues with this assessment and our latest figure shows that over 50% of appeals into ESA decisions are successful in stroke cases. This is clearly unacceptable and cannot be allowed to happen with PIP.

Taking account of the mental as well as physical

Stroke survivors have reported to us that there appears to be an emphasis on examining physical issues for the WCA. Stroke can have a significant physical effect but it also can have a severe impact on more hidden disabilities such as cognitive and communication disabilities. In particular, a condition called aphasia affects thousands of stroke survivors and results in some not being able to speak at all. Recovery from aphasia can take a long time with some stroke survivors continuing to

improve their speech over many years. It is imperative that the PIP assessment can take account of these difficulties

Knowledge and training of assessors in stroke

Another common complaint from stroke survivors with regards to the WCA, is that the professionals undertaking the assessment do not appear to understand some of the key issues about stroke. We recognise that not all assessors can be experts in all medical areas, however, it is essential that they have at least a basic knowledge of stroke and how it affects people.

To counteract this issue, the applicant's GP/Consultant's evidence must have a higher degree of weight than is currently the case with the ESA assessment process.

Taking account of an individual's circumstances

Related to the previous issue, it is very important that the assessment is sensitive to the fact that every stroke is unique in terms of the effect it has on the person. Stroke can lead to many complex issues including those of a neurological nature. However we have been told by some stroke survivors that their WCA lasted for around 40-45 minutes in which time they did not feel that any of their more complex issues were taken account of.

It is also important that the assessment is able to take account of the fact that stroke survivors will often not want to admit that they are failing to do certain things. It goes against their need to be positive after the stroke and they can be led by their pride. The assessment also needs to be sensitive to the fact that for some, particularly those with cognitive difficulties, some of their problems will not be apparent to the stroke survivor themselves.

However, we would still support any measure which would allow the claimants to describe their own conditions, as was the case with DLA.

Stroke as a fluctuating condition

We recognise that the DWP are working on how to take account of fluctuating conditions like stroke and are aware that there will be a further consultation looking into this.

The appeals process

Some stroke survivors have experienced a wait for over one year to hear the result of their ESA appeal. This is an unacceptable length of time particularly for someone who already has problems with stress. The PIP assessment process must have a much quicker appeals system. Waiting for over one year is unacceptable for stroke survivors who are already facing an uncertain future in terms of physical and mental health and financially. Stroke already can lead to family breakdowns. An uncertain financial future will only exacerbate these problems.

Support to complete process

The complexity of the WCA system has also been commented on. As stated previously, many stroke survivors will be left with cognitive difficulties which can make the comprehension of complex information very difficult.

There needs to be recognition of how much help some stroke survivors will need to go through the PIP assessment process. We would also like to know what help will be available to stroke survivors who could face both the PIP and ESA assessment process at the same time.

Conclusion

Our comments in this submission are generally around the PIP process and the more strategic issues. We have not looked specifically at the descriptors and carried out dummy assessments. Our main point on the descriptors is that the theory can be very different to the practice.

Our initial view is that the current descriptors and thresholds may allow stroke survivors with severe disabilities to still be eligible for the enhanced rates of PIP. However we have some concerns that those stroke survivors who have more moderate disabilities will be taken out of PIP altogether.

Thank you for giving us the opportunity to respond this important consultation. If you would like to discuss any of the points raised in this response please contact Patrick Olszowski, our Campaigns Manager on 020 7566 1548.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Joe Korner', written in a cursive style.

Joe Korner

Director of Communications