



MS Society policy position statement

Employment and Support Allowance

October 2017

Issue

MS is a neurological condition that affects more than 100,000 people in the UK. Due to the fluctuating and progressive nature of the condition, people are affected differently by symptoms that include fatigue, pain, loss of mobility, visual impairment and cognitive problems.

Many people with MS can and want to work. People with MS who are no longer able to work as their symptoms have become too severe can apply for Employment and Support Allowance (ESA), an out-of-work benefit for disabled people and people with long-term health conditions. As of November 2016, 23,350 people with MS were in receipt of ESA, and a further 1,100 were in the process of being assessed for eligibility for the benefit¹. Eligibility for the benefit is determined through a Work Capability Assessment (WCA).

The average employment rate of people with MS is 55%, although this varies depending on the type of MS and the severity of symptoms. The employment rate for people with relapsing remitting MS is 69%, whereas only 28% of people with secondary progressive are in employment². Other research suggests much lower employment rates – 37% for people with mild MS, and only 4% for people with severe MS³. Out of work support is therefore very important for people with MS, and it should be available to people with MS who are no longer able to work, without needless repeated assessments.

These employment rates are reflected in WCA decisions. The majority (92%) of people with MS who claim ESA are placed in the Support Group, and are not currently required to take any work-related activity. A smaller proportion (6%) of people with MS are placed in the Work Related Activity Group (WRAG), and are required to take some work-related activity, and prepare to return to employment. However, for people with MS, committing to work-related activity could be

¹ FOI 2590 – response from DWP to request by MS Society (2017)

² APPG for MS – Employment that works: Supporting people with MS in the workplace, (2016), p. 11

³ Bajorek et al – The impact of long term conditions on employment and the wider UK economy (2016)

impossible due to the fluctuating nature of the condition, and the severity of the symptoms. People with MS in both groups require the right support to achieve the work goals that are right for them, without the risk of losing financial security.

In April 2017 the benefit rate for new claimants who are placed in the WRAG was cut to by £30.00 per week. The level of payment in the Support Group has not changed. Disability benefits provide a safety net that enables people with MS to live independent lives and participate in society. The cut to the benefit rate can therefore cause significant financial hardship for people with MS and their families. The government rationalised the cut to the benefit as an incentive to find work. However, this ignores the multiple barriers to employment that people with MS face.

Evidence/Findings

1. Awareness of ESA and social attitudes

Eight out of 10 people who are entitled to ESA (or income support) claim the benefit, meaning that 1 in 5 people could be losing out on an average of £4500 per year⁴. Lack of awareness of eligibility for the benefit could contribute to the low number of people with MS who are not working but are not claiming ESA. However, social attitudes towards benefit claimants may also contribute to decisions not to claim ESA. 25% of respondents to the MS Enough survey said they don't claim all the benefits they need because of the associated stigma⁵. However, if an individual does not claim ESA when they are eligible for it means they are also losing out on National Insurance credits which build up eligibility for the State Pension, meaning that the amount they receive when they reach state retirement age can be reduced⁶.

2. Assessment quality

People with MS report that assessments for ESA do not always accurately capture their condition and how it affects them. Nearly half (49%) of respondents to our MS Enough survey who had had a WCA disagreed that the assessor understood their MS and 48% disagreed it accurately assessed their capability for work⁷. Assessments should consider whether a person is able to do activities repeatedly, reliably and safely. Of respondents who have had a WCA for ESA 46% disagreed that it took into account whether they could do activities reliably. Also, 45% disagreed that the assessment took into account how their symptoms fluctuate⁸. The lacking assessment quality is borne out by the fact that nearly two thirds (65%) of all WCA decisions

⁴ [Department for Work and Pensions – Income-related benefits: estimates of take-up, data for financial year 2015/2015](#) (June, 2016)

⁵ MS Society – MS Enough: Make welfare make sense (2015), p. 8

⁶ [UK Government – National Insurance credits – eligibility](#) (accessed online October 2017)

⁷ MS Society - MS Enough: Make welfare make sense (2015), p.18

⁸ MS Society – [MS Enough: Make welfare make sense](#) (2015), p. 20-21

that are challenged are overturned at appeal⁹, and the proportion of successful appeals has been rising year on year.

3. Collection and use of further evidence

The collection of high-quality detailed medical evidence from health care professionals is crucial to ensuring that assessors have the right information on the condition and how it affects the functionality of a person with MS. MS specialist health care professionals have told the Society that they struggle with providing evidence as this sometimes requires long appointments (particularly for people with progressive MS who have less access to specialist care than those more recently diagnosed¹⁰) and working out of hours due to the strain evidence provision puts on their caseload. The Society is currently conducting further research with health care professionals on evidence provision.

Furthermore, some people with MS tell us that they do not believe medical evidence is adequately collected or considered. Of respondents to the MS Enough survey, 39% disagreed that the assessment took into account additional evidence about their condition¹¹.

4. Conditionality

People with MS in the WRAG are required to take on work-related activities by the Work Coaches, including skills training and preparation for return to work. Failure to take part can result in sanctions and reductions in benefits until the activity is done. This is concerning, as 51% of respondents to the MS Enough survey who are in the WRGA of ESA said they were unable to do the actions which were asked of them to take steps towards employment¹².

Work Coaches are not sufficiently trained to recognise hidden symptoms such as fatigue, pain and cognitive difficulties, as they are not disability specialists. Work Coaches are therefore unable to provide effective tailored support for people with MS, that takes into account how their condition affects them, including the consideration of hidden and fluctuating symptoms. Correspondingly, the majority of people with MS who are in the WRAG (66%) told the Society they received no support to help them get back to work and 61% disagreed that the support they received from the Jobcentre would help them find a job¹³

⁹ Ministry of Justice – Tribunals and gender recognition certificates statistics quarterly: January to March 2017 and 2016 to 2017, main tables January to March 2017, table SSCS.3 social security and child support

¹⁰ MS Society – My MS My Needs 2016: access to treatment and health care, technical report (2016) p.45 – the survey showed that people with MS who have been diagnosed within the previous 12 months are the most likely to have seen a specialist nurse (88%) compared with those diagnosed 10 years ago or more (62%) ([green paper response page 31](#))

¹¹ MS Society – MS Enough: Make Welfare Make Sense, p.24 (2015)

¹² MS Society – MS Enough: Make welfare make sense (2015), p.

¹³ MS Society – MS Enough: Make welfare make sense (2015), p.17

There is currently no requirement for people in the Support Group to take any work-related activities, and therefore conditionality does not apply at the moment. However, recently the government proposed to extend conditionality to the Support Group as part of new measures to ensure individuals in this group do not miss out on support from the Jobcentre¹⁴.

5. Repeat Assessments

Too many people with MS have had to undergo repeated Work Capability Assessments. Almost half (47%) of those with MS in the Support Group are currently given a prognosis of being unlikely to be able to return to work in the longer term and an additional 18% were not expected to return to work within two years¹⁵. In a survey conducted by the MS Society in 2016, 80% of respondents who are no longer working said they left work due to the impact of their MS symptoms, and of those placed in the Support Group, 82% agreed or strongly agreed their MS meant they are unable to work, while only 9% agreed they are able to return to work¹⁶. Continued unnecessary reassessments cause stress and anxiety for people with MS who have a life-long condition and little chance of recovery.

6. Financial support

From April 2017, levels of support for new ESA claimants placed in the WRAG have been cut by £30 per week. Reducing the level of support to people in the WRAG to the same level as Jobseekers' Allowance was explained by the government as an incentive to re-enter work. However, this rationale ignores the fact that people in the WRAG are further away from employment, and spend longer claiming an out-of-work benefit, than people claiming JSA. It also ignores the findings of the Extra Cost Commission that people with a neurological condition such as MS spend on average an extra £200 a week on costs associated with their condition. Even before the cut to financial support, people with MS have been telling us that they struggle to afford essentials such as food, gas and electricity¹⁷. People with MS in the WRAG, as well as those in the Support Group, require adequate financial support when they are no longer able to work, which recognises the multiple barriers to employment they face, as well as the extra costs imposed by their condition. The current level of financial support is arguably too low even in the Support Group, considering that the payment rate is far lower than the average weekly

¹⁴ Department for Work and Pensions – Work, Health and Disability: Improving Lives Green Paper (2016)

¹⁵ Department for Work and Pensions, Freedom of Information request

¹⁶ Ms Society, Response to Improving Lives: The Health and Work Green Paper Consultation, February 2017, p. 18

¹⁷ MS Society – MS Enough: Make welfare make sense 2015, p. 7 – 41% of ESA claimants have told us that benefit changes have forced them to reduce spending on food and 33% had reduced spending on gas or electricity

earnings, while people with MS also face extra costs associated with their condition.

Recommendations for government

- The Department for Work and Pensions (DWP) and disability organisations should undertake an awareness raising campaign of Employment and Support Allowance (ESA) to make sure those entitled are receiving it. Particular focus should be placed on ensuring people with MS continue to accrue pension credits once work is no longer possible.
- Statutory and employer provided occupational health support should signpost disabled or long-term sick people to ESA.
- The UK Government should undertake a review of the descriptors used in the WCA. The descriptors should be simplified so that they are easy to understand by both assessors and claimants. Descriptors should be designed in a way that captures the reality of a fluctuating condition such as MS.
- The role of pain and fatigue should be embedded explicitly in the wording of all Work Capability Assessment (WCA) descriptors.
- Additional descriptors should be added to cover cognitive dysfunction in both physical and mental conditions and the impact of generalised pain and/or fatigue.
- People with MS should only be assessed by neuro specialist assessors who have received training approved by neurological condition charities.
- The Department for Work and Pensions should make available the Key Performance Indicators (KPIs) included in the WCA contract and routinely publish data on assessment providers' performance against these.
- Department for Work and Pensions should always seek consent from ESA claimants to consider any PIP or DLA evidence they may hold.
- The Department for Work and Pensions should engage with the MS Society and MS specialist professionals including MS Specialist nurses, Occupational Therapists and Physiotherapists to review evidence collection mechanisms to ensure they are easy to use and well understood.
- People with MS placed into the Support Group should continue to be exempt from conditionality. Support must only be offered to people with MS and other disabled people in the Support Group on a voluntary basis.
- The DWP should review the effectiveness of current back-to-work conditionality on return-to-work rates for disabled people with a view to removing conditionality mechanisms which are not proved to be effective.
- Work related requirements placed on people with MS in the Work Related Activity Group (WRAG) should be signed off by a specialist professional such as a Disability Employment Advisor or a member of the individual's clinical care team.
- The Government should ensure that people with MS in the Support Group who face very little prospect of recovery are exempted from future reassessments by a simple process based on reasonable expectations of the supporting evidence clinicians and others can provide to inform this.

- The Government should reinstate the WRAG of ESA to ensure it addresses the additional barriers and costs faced by people with MS who are struggling or currently unable to work.
- The Support Group, or equivalent in terms of financial support, should be maintained.

Recommendations for assessors

- An evaluation should be carried out by assessment provider Maximus of the Semi Structured Interview tool to prompt assessors to better consider fluctuation.
- Assessors should be required to demonstrate that they have sought further evidence from the professionals a person with MS lists on the ESA50 form and explicitly set out how this has been used in their decision.
- The assessors should be able to accept telephone reports as evidence. Health care professionals are sometimes too busy to provide written evidence, but this should not work against the claimant if the professional is willing to provide a telephone report.
- As a default, a list of further evidence received by the assessment provider and/or DWP should be provided to the claimant both at the face to face assessment and on notification of a decision.
- Assessors should be legally bound to provide a copy of the assessment and any medical evidence they obtained at the decision stage, so that claimants are fully aware how a decision was made, and provided with all the information they require should they decide to appeal.