About MS and the MS Society

Multiple sclerosis (MS) is one of the most common disabling neurological conditions affecting young adults in the UK. Around 100,000 people in the UK have MS. For some people, MS is characterised by relapses followed by periods of remission while for others it follows a progressive pattern. The causes of MS are unknown, there is no cure and the treatments that are available are effective in only certain cases and for some of the time. MS symptoms include loss of mobility, pain, fatigue, visual impairment, numbness, loss of balance, depression and cognitive problems. MS can lead to severe and permanent disability.

The MS Society is the UK’s largest charity for people living with MS, with almost 40,000 members and over 320 local branches. We provide grants to individuals, for home adaptations for example, and to public sector organisations to co-fund specialist nursing posts. The MS Society is the UK’s largest funder of research into MS.

How we gathered our evidence

- Major survey with Disability Benefits Consortium (around 1500 MS responses to date, of around 2770 responses in total)
- Gathering anecdotal evidence through the MS Society helpline, online discussion forums, and e-mails, letters and phone-calls to the policy and campaigns team.
- Gathering evidence from specialist healthcare professionals through a survey of fifty MS nurses, physiotherapists, occupational therapists and others.
- Discussions with local and regional volunteers and advocacy workers.

Summary – MS Society recommendations

The MS Society has gathered a large amount of evidence to indicate that the current WCA is not working. People with a complex and fluctuating long-term condition like MS are particularly disadvantaged by the current WCA, because both in design and in practice, recognition of fluctuation; symptoms like pain, fatigue, and cognitive problems; and of the impact of multiple impairments is poor.

To address these problems, we have the following set of recommendations, which are set out in detail in our responses to the specific review questions.

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1 Disability Benefits Consortium survey, initial results as of 9.09.10. Over 200 people with MS who have responded have gone through the ESA application process to date. Full results will be released after the survey closes on 20th October. For more information, visit http://www.disabilityalliance.org/dbc5.htm
1. The internal review of the WCA should not be implemented, and the proposed changes should be reconsidered in the light of findings from this independent review.

2. Training of the ATOS medical professionals carrying out the assessments must be improved, particularly in understanding the impact of fluctuation, pain, fatigue and multiple impairments.

3. An improved review process must also be brought in to ensure that problems of inaccuracies in reports are combated.

4. People with MS should be allocated to the support group without going through a WCA where information from a healthcare professional supports the evidence in their application form that they would be eligible.

5. Specific questions to reference fatigue and pain should be added both to the application form and to the WCA.

6. The MS Society supports the Citizens Advice Bureau\(^2\) recommendation that a further ‘real-world’ test should be brought into the WCA, based on the social model of disability.

7. Healthcare professionals carrying out the assessment should be given the discretion to allocate additional points where multiple conditions or impairments are present, and the reintroduction of a 3-point descriptor should be considered.

8. ESA113 forms should more routinely be used to gather information from specialist healthcare professionals when someone with a complex condition like MS applies for ESA.

9. Information should be shared across the DWP from DLA application forms and supplementary evidence, such as reports from MS nurses.

Answers to specific questions

Question 1a: How effectively does the WCA correctly identify those claimants whose condition is such that they are unable to undertake any form of work related activity (the support group?)

Question 1b: How effectively does the WCA correctly identify those claimants whose condition is such that they are currently unable to work due to illness or disability (the limited capability for work group?)

The MS Society has a number of reasons to believe that the current WCA does not correctly identify those claimants whose condition is such that they have limited capacity for work and/or limited capacity for work related activity. There are serious concerns among claimants, organisations, and indeed among the DWP’s own staff\(^3\) that the WCA is proving too stringent.

\(^3\) DWP research report 631
a) DWP statistical releases have shown that a much higher number than originally predicted are being found ineligible for ESA through the WCA – a figure of about 70% compared to the predicted 51%.

b) The high number of appeals is cause for concern. DWP statistics show that a third of people found fit for work have had an appeal heard to date. However, it is clear that there are serious delays and backlogs in the current appeals process, so many more appeals could be going through the system. Of the appeals that have been heard, a worrying four out of ten decisions are overturned. There is no data available on appeals where someone has been placed in the work related activity group and feels that they should be in the support group – these figures could significantly add to the number of appeals being heard.

c) A report by the DWP themselves highlighted some serious problems with the WCA, including an information deficit, significant delays and IT issues, poor training of staff and concerns with customers being put into inappropriate groups.

d) The MS Society and other organisations such as the Citizens Advice Bureau (the CAB) have gathered large amounts of anecdotal evidence from individuals with MS who have been wrongly refused ESA or put into the work-related activity group (WRAG), many of whom have had decisions overturned on appeal or are currently going through an appeal.

e) Initial findings from a major Disability Benefits Consortium survey suggest that more than half of people with MS who have had an assessment for ESA so far do not agree with the decision; fewer than 40% of people stated that all of their symptoms that affect their ability to work were taken into account; seven out of ten said that the assessment did not take into account how their symptoms fluctuate or are affected by repeated activity.

Question 1c: What are the main characteristics that should identify claimants for each group, where these may differ from the current assessment?

We support the DWP’s position that the WCA should focus on an individual’s functional capability to work, rather than on their condition. We also recognise, as stated in the DWP’s recent internal review of the WCA, that the WCA should take into account aids and adaptations which an individual may successfully and reasonably use to mitigate the disabling impact of their condition.

However, we believe that the WCA must also take into account the broader picture to the full barriers to work presented by an individual’s condition – including skills, experience, age, extent of adaptations needed and distance from job market. All factors and symptoms that can limit someone’s ability to work, including symptoms like fatigue, pain (see below for more information on fatigue and pain) and cognitive problems should be taken into account. Fatigue and pain are two very common symptoms of MS which can provide major barriers to work. The difficulty of managing these symptoms while working, and the way in which the stress and exertion of work can exacerbate these symptoms is often cited as significant reasons for people with MS to give up work.

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4 Transformation of the Personal Capability Assessment, DWP, November 2007
The cumulative effect of a number of lower-level problems should also be recognised by the WCA.

The following symptoms of MS are characteristics which can present a barrier to work which we feel should be acknowledged in the WCA:
- Fatigue
- Musculoskeletal and neuropathic pain
- Muscle weakness, stiffness and spasms
- Problems with walking, bending and kneeling
- Problems with use of hands and arms
- Problems with eyesight, including blurring of vision and double vision
- Loss of balance, coordination and dizziness
- Problems with memory and concentration
- Problems with speech, including slurring and ‘word blindness’
- Difficulty swallowing
- Bladder and bowel problems, including incontinence
- Depression

The MS Society believes that a number of these, particularly fatigue, cognitive problems and pain, are not given adequate weight in the current WCA.

We are very concerned that the WCA proposed by the DWP’s internal review makes the assessment harsher still and takes away adequate recognition of problems with speech, eyesight, memory and concentration, bending and kneeling and use of hands, and urge the DWP to reconsider these changes to ensure that even more very ill and disabled people will not be wrongly found to be ‘fit to work’ in future.⁷

**Recommendation 1:** The internal review of the WCA should not be implemented, and the proposed changes should be reconsidered in the light of findings from this independent review to ensure that the full spectrum of characteristics that can present a barrier to work are reflected in the descriptors.

**Question 2:** What evidence is there to suggest that any issues with the operation of the WCA are as a result of the policy design, and what evidence is there to suggest that they are as a result of the delivery?

It is clear that the problems with the operation of the WCA are the result of a mixture of policy design and delivery.

a) Delivery
In terms of delivery, evidence gathered by the MS Society suggest that the following problems are prevalent in assessments being carried out across the country:

ATOS healthcare professionals often fail to understand the fluctuating and/or degenerative nature of MS, and how this affects an individual’s ability to work. They fail to ask probing questions to discover whether activities could be carried out reliably and repeatedly, and to find out how the condition affects an individual on good and bad days.

A lady from Hertfordshire who was recently diagnosed with MS and chronic fatigue syndrome was found fit for work in her assessment. She told us:

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⁷ The MS Society supports the Disability Benefits Consortium’s comments on the revised WCA. Please see Annex 1 for the full list of DBC concerns about the proposed new WCA.
“Essentially on a bad day I’m house-bound as I can’t walk anywhere without experiencing fatigue, dizziness etc. But none of this was reflected in the report. The tick boxes they go through don’t seem to be at all related to whether I can realistically sustain any sort of work. The stressful situation is starting to badly affect my physical condition.”

They fail to fully understand and take into account the effect of symptoms like fatigue on an individual’s ability to work.

Language is often cited as a barrier with ATOS healthcare professionals, particularly when discussing a complex condition.

“The person who assessed me wasn’t British... there were certain points in the assessment where he didn’t seem to understand what I was saying, especially since it’s such a complex condition.” Lady with MS, Hertfordshire

A man from Coventry with MS who was found fit for work remarked that he had “massive communication problems” with the ATOS doctor. When he mentioned that he used to run restaurants, the doctor noted down that he goes running. When asked about what sports and social activities he liked, he said he used to play pool, and the doctor noted down that he plays regularly. Given the chance to elaborate, he would have explained that this would be impossible given his tremors and spasticity.

Sweeping assumptions and simple inaccuracies are made. The CAB report,¹ launched earlier this year and endorsed by the MS Society, highlights a number of examples of inaccuracies, distortions and assumptions. Evidence gathered by the MS Society supports these examples.

One lady from Coventry has shocked to discover that the ATOS assessors had made the inaccurate assumption that with rehabilitation her MS would be improved within 6 months:

“I noted it took the Dr 9 minutes to complete the report! I was stunned at the amount of discrepancies, repetition, things left out etc. One comment about my eye problems being ‘mild’ was disproven when in January this year DVLA revoked my driving licence due to my eye problems. I questioned how a prognosis could be made for someone with progressive MS that in 6 months time, with the right treatment and rehabilitation, I would be able to return to work. After a lot of phone calls and about 3 or 4 letters to ATOS I eventually received a reply with a profuse apology stating that a senior manager had looked at my case and decided that the prognosis was totally inappropriate for someone with my condition and that rehab had proven successful for stroke patients but had never proven useful for people with MS. The whole process was incredibly stressful.”

One lady with MS from County Durham was awarded 0 points initially and is awaiting a tribunal date. She highlighted that the report from her medical assessment even contradicted itself:

“The ATOS report was full of inaccuracies and contradictions. On one page it stated that there were no needles involved in my treatment, on the next, it mentions the Tysabri infusions! Large areas of my symptoms went ignored – particularly the fatigue. Because I’d managed to get to the medical, they
assumed there couldn’t have been any fatigue. Obviously, they didn’t see me curled up on the sofa for the next 2 days…There was also no mention of my problems with speech, cognition, fine motor control, swallowing, dizziness, joint pain etc.”

“The errors included, passing me on a test which had not been completed and passed me on another test which I failed at the time. She had suggested I cook ready meals each day but cooking was not discussed. The report also states I practice my mobility on stairs every 2 weeks but I lived on a ground floor level. Various problems I have with MS were ignored fully.” Lady with MS, Birmingham

Questions asked by the healthcare professionals in the assessment can be unclear or misleading, preventing the applicant from revealing and explaining the full extent of their problems. For example, people with MS regularly cite problems with questions about how they got to the assessment centre being used to make assumptions about their level of mobility.

One applicant told the ATOS medical professional that they had arrived by car, and their report said that they had walked 100m from the car park, although in fact the claimant had been dropped at the door of the assessment centre by her husband.

One lady with MS from Essex told us: “I have right sided weakness and my right foot has spasms and I also have a brace on my right foot to keep my foot upright and have talepes; I asked him whether he wanted me to take my boots off but he said "No that isn’t necessary". He didn’t ask me about my memory or cognitive skills. I had a letter from my consultant about a cognitive test that I had had a couple of weeks before this interview, which he read but I still got "0" points.”

Recommendation 2: Training of the medical professionals carrying out the assessments must be improved to address these problems.

Recommendation 3: A more thorough review process must also be brought in to ensure that improvements are being made and that reports are thorough and accurate, including if possible ‘mystery shopping’ assessments, spot checks to ask individuals whether they agree with the content of their report, independent surveys of applicants who have gone through the assessment, and allowing applicants to record their assessments if necessary to allow for verification of reports.

b) Policy design
The MS Society believes that there are a number of underlying problems in the policy design:

Too many people put through WCA
Too many people who are seriously affected by a disability or health condition are being put through the WCA in the first place. This causes huge amounts of unnecessary stress to applicants as well as wasted expenditure for the DWP, and such unnecessary costs are set to increase dramatically when migration from Incapacity Benefit to ESA begins in 2011.

On receipt of an application form, a decision is made as to whether an individual should be invited for a WCA. If someone appears on the strength of their form and available
medical evidence to be eligible, they can be allocated directly to the support group. However, this decision is currently being made by ATOS, and it seems that very few people are currently excused from the WCA. Firstly, we believe that it is inappropriate for this decision is made by the organisation contracted to carry out the assessments. Secondly, we believe that far too few people, particularly those with degenerative long-term conditions like MS, are allocated directly to the support group without having to go through a WCA.

**Recommendation 4:** People who are severely affected by a long-term condition like MS should not have to go through the assessment. Information on an application form which indicates that someone is seriously affected by a long-term condition like MS (particularly if they have a progressive form of the condition) should automatically trigger the gathering of further information from a specialist medical professional, such as an MS nurse, via an ESA 113. If this evidence indicates that someone should be in the support group, this should exempt the individual from going through the stress of a WCA.

**Poor recognition of fluctuating conditions**
The questionnaire, descriptors and guidance are poorly worded to recognise the impact of fluctuating conditions on an individual’s capacity for work. (See response to Question 3.)

**Poor recognition of ‘hidden’ symptoms**
Symptoms such as, cognitive problems (such as memory and concentration) and pain are not given adequate weight and recognised as discrete symptoms that affect an individual’s ability to work.

Fatigue is one of the most common symptoms experienced by people with MS and, for some, it is the symptom that affects them the most. In MS, fatigue is not just an ordinary tiredness that people might experience after a hard day’s work or strenuous exercise. Many describe it as an overwhelming sense of tiredness with no apparent reason. Some people become tired after very little or no activity, or rarely wake up feeling refreshed in the morning. Yet fatigue is omitted from the WCA descriptors.

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Problems with fatigue are regular topics of phonecalls to our helpline, and discussions on our online discussion forums:

“\[I\ am suffering really badly with fatigue. I need a couple of hours sleep in the afternoon and then I don’t really gain enough energy to do much of the night time. I just feel trapped and miserable and this isn’t really any kind of life - everything seems covered in a grey haze. My MS nurse said I could look at the things I do that may be tiring me but in honesty I really don’t do much because I’m tired.\]”

“\[Fatigue is my worst symptom. Like having flu all of the time...and also what I call 'meltdowns' which is like having plug pulled out. Very sudden and just have to sit or lie till it passes. Cannot even talk.\]”

“\[Fatigue for me is finding every day I think I can do more than I can, being very frustrated, getting shouty at the kids because I can’t function after doing the school run, being unable to remember what day it is, what a persons name is because I am so drained, being angry with family/friends because they have no clue what I am talking about, feeling like I have lost all brain matter because I cant spell or talk properly or even think how to get things done. Becoming\]”
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hysterical because I suddenly find I can’t cope and don’t know what to do when I am in the middle of town or in the playground. It is without question the worst of my MS symptoms, I can manage the pain, loss of sensation, bladder problems etc but there does not seem to be any way to manage the fatigue without giving up some part of your day to day life.”

At least a third of all people with MS will feel some level of pain at some time. If pain continues, it can be exhausting, affect their mood, and make it harder to continue with everyday activities. People with neurological conditions like MS can experience different types of pain: ‘musculoskeletal pain’ results from damage to muscles, tendons, ligaments and soft tissue, while ‘neuropathic pain’ is caused by nerve damage in the brain and spinal cord. Often people with MS describe neuropathic pain as shooting pain, or like walking on shards of glass. Neuropathic pain is not related to level of activity or exertion, and traditional painkillers are much less effective for neuropathic pain.

**Recommendation 5:** Fatigue and pain should be taken into account and given sufficient weight when considering an individual’s functional capability. Specific questions to reference fatigue and pain should be added both to the application form and to the WCA.

**Lack of recognition of multiple conditions/impairments**

As highlighted by the CAB report, the WCA fails to look at the combined effect of low level problems, or at problems which are serious, but where each one is a problem for only a minority of the time. (Please see answer to question 4).

**Lack of recognition of ‘real-world’ barriers to work**

The WCA takes no account of the additional considerations that may mean that their disability presents a greater barrier to work, including:

- age and experience:

  One man in his fifties with MS who has spent his life driving trucks has recently reluctantly accepted that he is no longer able to do so because of his problems with vision, movement in his hands and fatigue. While his MS prevents him from taking on any physical work, his low literacy levels and lack of experience in an office-based role mean that he may find it almost impossible to find other work.

  Conversely, another man of a similar age told us: “I am an experienced and very capable manufacturing manager / external sales manager but I can no longer do this work, with the long hours and driving required. My experience is extensive but in a limited sector, my abilities similar but my capability diminished. Very few private sector companies will employ somebody who on paper should be fully employed with a salary of over £30k and a company car when the job on offer remunerates at a much lower level.”

- willingness of an employer to adapt a workplace and employers’ prejudices: despite the Disability Discrimination Act, many disabled people still face barriers to work through employers’ prejudices, and someone who requires significant adjustments to a workplace to be able to work will find it much harder to get a job, particularly if their skills or impairments mean that the jobs they are capable of are unskilled roles.

- barriers in getting to work or to the Job Centre:
"I was told to attend a work related interview at the Job centre plus at Kettering. If I did not attend money would be stopped. This Job centre plus has NO disabled parking. So parked at the back of the mobility shop. So I would be able to use a scooter. I asked if there were disabled toilets I would be able to use as I have a bladder problem. I was informed to use toilets at Morrisons which is 5 min away. DOWN the hill. Was directed to the desk and I was sideways to as my legs would not go under the table."

Recommendation 6: The MS Society supports the CAB recommendation that a further ‘real-world’ test should be brought into the WCA, based on the social model of disability. Applicants should be given the opportunity when applying for ESA to explain if they feel there are any additional factors which will provide a barrier to them working, and decision-makers should be given the discretion to take these factors into account when considering whether an individual has a limited capacity for work.

Unnecessary or too regular re-assessments
People with long-term conditions are being asked to return for assessments sometimes as regularly as every year, every six months, or even every three months. This creates unnecessary costs and administration for the DWP, as well as being stressful for the individuals going through the assessment. Seven out of ten people with MS surveyed told us that they found the assessment stressful, and 64% felt that the stress of the application process made their condition worse.

One man with MS from Coventry scored just six points in his initial assessment. After waiting six months for an appeal, he was put into the support group for ESA. However, just three months after his appeal, he was invited to go through the whole assessment process again. He found the whole process extremely distressing, and suffered significant relapses while waiting for an appeal: "It took so long to come to terms with the fact that I'm ill, and then I had to go through all of this."

Although people can recover from the worst of their relapses, the disease progression of MS is degenerative.

Recommendation: If someone with MS (and particularly with primary or secondary progressive MS) has been placed into the support group following their first medical, they should be exempt from any further assessment. If someone with relapsing-remitting MS has been placed in the support group, medical evidence should be sought before determining whether they should be put through a re-assessment: if their condition has not changed significantly, there should be no need to re-assess these individuals.

Question 3: What is the best way to ensure that the effect of fluctuating conditions is reflected in the recommendation of the WCA?

Improved guidance and training on fluctuation
Much of the guidance and training concerning fluctuation is very general, with a large number of examples dealing with back pain or mental health problems. There needs to be a clear distinction made between the variability of something like back pain, and complex neurological conditions like relapsing-remitting MS.

While fluctuations in back pain which can be affected/managed (to some extent at least) with pain relief, exercise, physiotherapy and massage (and this is repeatedly
relapses in MS are very different: they are unpredictable, can vary enormously in severity and frequency, and there is little symptom relief or treatment available. An MS relapse is an episode of neurological symptoms which arrive unexpectedly. This usually lasts for around four to six weeks, but this can vary from only a few days to a few months. Common symptoms include weakness, unsteadiness, bladder disturbance or double vision. However, symptoms can be as extreme as losing vision or mobility entirely, or suffering debilitating fatigue and neuropathic pain.

Major conditions in which relapses or fluctuations are particularly common should be clearly listed for healthcare professionals who are carrying out the WCA. They should also be encouraged to seek further evidence in such cases, for example from a GP or specialist such as an MS nurse, neurologist or Occupational Therapist (OT).

Improved guidance and support for applicants with fluctuating conditions
The ESA50 should contain clear directions at the start of the form to individuals whose condition fluctuates to explain in detail how their condition affects them on good and bad days, and to state how often good or bad days occur on average (if possible). People with complex and fluctuating conditions should also be expressly encouraged to give details of specialist healthcare professionals who can give information on their behalf.

Longer assessments for people with fluctuating conditions
The MS Society has anecdotal evidence that WCA assessments can be as short as half an hour. This is not enough time to fully understand the complexities of a condition like MS and its affect on an individual’s ability to work. We are concerned that the huge burden of reassessing the thousands of people currently on IB will put even more pressure on ATOS assessors to conduct assessments even more quickly. Assessments for complex conditions like MS must be allocated more time for the correct decisions to be made.

Gathering further information from specialist healthcare professionals
As explained in the CAB report, ESA 113s are used far less regularly under the ESA system. MS Society evidence appears to confirm this. The MS Society surveyed fifty specialist healthcare professionals who work with people with MS, including MS nurses, occupational therapists, physiotherapists. More than half have been asked by an individual to provide a report to support their application for ESA or appeal, and many stated that this was often at the appeal stage. However, just one in five had ever been contacted by the DWP to provide evidence.

Where an individual states in their application form that they have a complex and fluctuating condition like MS, we feel that this should trigger far more regularly the use of an ESA 113 to gather evidence from and individual’s specialist healthcare professionals. The healthcare professionals surveyed by the MS Society unanimously stated that they would be happy to more routinely give evidence regarding someone’s application for ESA, through a short report or ESA 113.

“Most definitely yes, I’d be happy to give evidence more routinely - we are often asked for ‘evidence’ or info for DLA forms.” MS nurse

An MS nurse in Epsom is currently helping two patients who are going through an ESA appeal, but feels that her evidence has not been fully taken into account. She told us:
“It would save an awful lot of time by being contacted in the first instance at the beginning. We regularly fill out DLA forms – they’re relatively easy, it doesn’t take too much time and it’s not really a problem. It’s much better to get the correct information to make the correct decision at first than to end up going to an appeal.”

**Question 4: What is the best way to ensure that the effect of multiple conditions is reflected in the recommendation of the WCA? Are there specific conditions that should be regarded as contributing to or adding additional weight to others, where both are present?**

Many people with MS will have a broad range of symptoms, which will affect them differently at different times. Symptoms can include problems with memory and concentration, tingling and numbness, mental health problems, dizziness, clumsiness, intense fatigue, bladder problems, pain, problems with eyesight, insomnia, problems with speech, mobility problems, spasticity and tremor.

People with MS can have some or all of these symptoms at any one time. Many of these symptoms are ‘hidden’ and not easily picked up in a short assessment. Someone may have no one symptom which can attract 6 or more points on the WCA descriptors, but the combined effect of a number of these symptoms can very easily provide a significant barrier to work. We have encountered numerous cases where an individual with a large number of unpredictable symptoms has scored no points under the WCA.

“I have IBS, leg spasticity, optical neurosis in my right eye, cognitive difficulties, heat intolerance and an intermittent tremor in my right hand. In April I had an MS relapse which: severely impaired my balance (making walking very difficult), left half my tongue without taste, caused bladder problems, further affected my eyesight, caused tremor in my right arm and leg, increased my fatigue so that I was virtually useless after 2pm and further exacerbated the spasticity in my legs. My assessment was at 8:30am so my apparent MS symptoms were at their lowest. I was given 0 in the points.” Man with MS, Staffordshire

**Recommendation 7:** Healthcare professionals carrying out the assessment should be given the discretion to allocate additional points where multiple conditions or impairments are present. This is particularly important where no single impairment is sufficient to attract points alone, but where the sum of a number of lower-level impairments provides a barrier to work and/or work-related activity. The reintroduction of a 3-point descriptor should also be considered for this reason.

The guidance and training should also be improved to highlight how the combined effect of multiple impairments can be greater than the sum of the factors. Examples should include in particular examples of people who have a combination of physical and mental health problems – a feature which is common for many people with MS.

**Question 5: What is the best way to give adequate weighting to additional (or initial) evidence outside of that gathered through the WCA? How can any changes be achieved without placing a burden on GPs and health care professionals, and without compromising their relationship with their patients?**

The healthcare professionals surveyed by the MS Society unanimously stated that they would be happy to routinely give evidence to a WCA application through the use of a simple form such as the ESA113.
One occupational therapist stated: “I would be more than happy to provide information even through a phonecall from assessors to myself, rather than seeing clients be put through this horror.”

Occupational therapists were cited as particularly good source of evidence where possible, given their knowledge of the individual, their condition, and their ability to work. However, many specialist nurses commented that they are not sure whether their evidence is taken into account or ‘really appreciated’.

They also highlighted that information should be better shared throughout the DWP – where someone already receives mobility and care components of Disability Living Allowance, their application form and any medical evidence gathered to support this claim should be taken into account in determining their eligibility for ESA.

One key improvement that was regularly recommended by healthcare professionals was better training of ATOS medical professionals to help them to understand MS, and particularly the impact of fatigue, problems with cognition and variability. Only 20% of people with MS surveyed who have gone through an ESA assessment felt that the person who carried out their assessment understood their condition.

“I found the assessment completely unsuited to my condition and it took no account of the ‘hidden’ symptoms of MS: fatigue, balance, loss of fine motor functions, bladder and bowel management problems, which frequently prevent me from leaving home, cognition problems that worsen as the day advances, and depression. The report was inconsistent and in parts simply inaccurate. I was insulted and wounded by the opinion expressed that ‘with time and appropriate treatment’ my condition could improve and I could return to work in 18 months.” Lady with MS, Surrey

**Recommendation 8:** ESA113 forms should more routinely be used to gather information from specialist healthcare professionals when someone with a complex condition like MS applies for ESA, and ATOS medical professionals should be better trained to understand complex and fluctuating conditions like MS.

**Recommendation 9:** Information should be shared across the DWP from DLA application forms and supplementary evidence.

**Contact**

We look forward to working with you on this important matter. If you would like any further information about the points raised in this response, please do not hesitate to contact Hayley Jordan, Policy and Campaigns Researcher; hjordan@mssociety.org.uk, 020 8438 0753.

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