



Multiple Sclerosis Society

## Personal Independence Payment consultation

A response from the MS Society  
April 2012

### Summary and general comments

Person with MS: "What does DLA mean to me? It's the difference between having a life and not having a life. I am disabled, not brain dead and quite capable of choosing how I spend my money."

1. **Fluctuating conditions** – the current proposal is difficult to apply, and doesn't fully take into account fluctuations – particularly short, severe fluctuations, which can lead to rapid escalation of costs and rapid onset of need (for which PIP should be ideal). We recommend that descriptors should not only increase along the scale of severity of the condition, but should also contain a time dimension. (See Q6 for further detail).
2. **Multiple impairment** – currently, individuals who face more than one impairment within an activity will only score for one – this does not always fully recognise the potentially cumulative impact of multiple impairments. (See Q6 for further detail).
3. **Thresholds** – 8 and 12 are reasonable thresholds on the whole, but some specific points allocations within activities need to be changed.
4. **Aids and appliances** - This category should be interpreted broadly, and should not exclude aids or appliances ordinarily used by people without a physical or mental condition.
5. **Assistance** – Those who do not currently receive support should not be automatically regarded as not needing it. Many people with MS restrict their activities due to the difficulties that they face, and because there is no support available. It should be considered whether support would increase their quality of life and ability to be independent.

#### Examples

- Cathy washes her hair every three days because she finds it too fatiguing to wash it more frequently. Will she therefore be treated as requiring support on the majority of days?
- Many people stated that they do not need support interacting and engaging socially with others, as they have simply stopped doing this as a result of the barriers they face. Would they be treated as requiring social support?
- Many people felt that they would be able to walk a short distance, and never used a wheelchair, but also commented that they rely on driving everywhere and would not go out unless they could use the car and park very close to their destination.

6. **Reliably, repeatedly and safely** - It is extremely important for assessors to ask not only *if* someone does an activity, but *how* they do it. The 'reliably, repeatedly, safely and in a timely manner' criteria must be a core part of the discussion around whether a person can complete an activity.
7. **Specific descriptors** – we have a number of concerns around specific descriptors, outlined below. Some are restrictive, or omit certain problems, and some set thresholds too high, points scores too low, or have gaps in points that we feel are too large.

We look forward to working with the DWP to ensure that the final assessment is as fair as possible, and we hope for continued engagement for continued refinement of the new benefit. This will ensure that PIP genuinely provides everyone with a disability or long-term condition with the support they need to live the same quality of life as everyone else.

## About MS

Multiple sclerosis (MS) is one of the most common disabling neurological conditions affecting young adults. Around 100,000 people in the UK have MS. For most 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.

## About the MS Society<sup>i</sup>

The MS Society is the UK's largest charity for people living with MS, with approximately 40,000 members and 300 local branches. We provide grants to individuals, for home adaptations for example, and to public sector organisations, to co-fund specialist nursing and other posts. The MS Society's information and support services are highly regarded by the MS community, and continue to be recognised by prestigious national awards. The MS Society is the UK's largest charitable funder of research into MS.

## How we gathered our evidence

### Testing the criteria

Over the last three months, the MS Society has used the latest draft of the assessment criteria and the regulations to conduct a series of 20 in depth interviews. Through these we talked to people with MS about the barriers and costs they face due to their MS. We also trialled the proposed assessment by talking through the proposed descriptors with the individuals to discuss what each individual might score, and what rates of PIP they may therefore be eligible for. We sought to interview people from a wide range of scenarios. All of the participants currently receive DLA at varying rates, have differing types of MS,

(relapsing remitting, primary progressive and secondary progressive<sup>1</sup>), were both in and out of work, and ranged in age from 29 to 63. We conducted interviews in Halifax, Essex, Coventry and Edinburgh. Please contact us if you would like more information, reports or case-studies of the individual interviews.

The results were extremely revealing. It became clear that the new assessment criteria could have a significant impact on the rates of DLA individuals with MS are currently receiving, and the rates of PIP they could receive in the future. We identified a number of points of contention throughout the criteria that were either problematic for people with MS, and failed to properly recognise their needs, or on which points could be inconsistently or inadequately applied across different groups. We welcome the opportunity to contribute to the development of the criteria and have set out our key concerns below.

### **Previous research**

In September 2010, the MS Society supported a survey, carried out by the Disability Benefits Consortium<sup>2</sup>, of over 6000 disabled people, asking about their experiences of the benefits system. 1449 people with MS who receive DLA answered questions about how they used this benefit. The top three things that people reported that their DLA was spent on were transport/ Motability car (90%), paying bills (49%), and support/ help from someone (38%).

In September 2009, the MS Society conducted a survey of 400 people with MS who receive DLA to ask them about the importance of this benefit, and their views on the (previous) Government's suggestion that the care component of DLA should be used to fund the social care system. 6 in 10 agreed that "disability benefits should not be used under any circumstances."

## **Q1 & Q2: Daily Living Activities**

### **Additional activity: Maintaining a safe and healthy living environment**

None of the current descriptors reflect the significant extra costs incurred by people with MS in maintaining a clean, safe and healthy living environment. In previous surveys carried out by the MS Society on how people use their DLA, large numbers of people with MS stated that they use the money to pay for a cleaner to help to keep their house clean, tidy and safe. Many people with conditions like MS, where fatigue is a major issue, state that they use so much energy in looking after themselves that all else – such as maintaining a safe and healthy home – is neglected.

This is particularly important to those who are still in employment, who find that they may not have the energy after work to clean their homes. Similarly, large numbers of respondents to MS Society surveys have stated that using DLA to pay for someone to do cleaning, gardening, ironing and other home maintenance allows a family carer to remain in work.

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<sup>1</sup> See [www.mssociety.org.uk/what-is-ms/types-of-ms](http://www.mssociety.org.uk/what-is-ms/types-of-ms) for further information on the different types of MS

<sup>2</sup> [www.disabilityalliance.org/dbc](http://www.disabilityalliance.org/dbc)

**Examples from survey respondents with MS**

"I am lucky that I can currently work albeit for 21 hours a week, but it comes at a cost. I suffer from fatigue, the care component of my DLA pays for my ironing/cleaning to be done. I am unable to carry out a weekly shop and need to use the internet. DLA is the only benefit I claim, if it were stopped in its current format, I would have to consider giving up work."

"I use my DLA towards the cost of help about the house - cleaning, ironing, shopping, childcare. I have had to give up my highly-paid career because of my disease. This extra bit of cash has helped us to maintain our home (although not our lifestyle) for our two children. It would be the "straw that broke the camel's back" if this small amount of cash were to be taken from me."

"I live alone and have no other income coming into the house. My DLA pays for a cleaner, extra heating bills in the winter, costs of repairs, redecoration which had I been able, would be carried out by myself but I am reliant on hiring at substantially increased cost. Cost of necessary equipment - stairlift - alteration of property - bathroom and kitchen to suit needs."

"I use my DLA for paying for others to help me to do things which I am unable to do myself, i.e. some housework, necessary for maintaining a clean and hygienic home so that extra medical care is not required."

"I use my DLA for the things social services will not provide for such as cleaning the house, washing, ironing and shopping. I am married and my husband works long shifts so he has very little spare time as he also cares for me in every aspect."

However, the current criteria mean that someone who is able to maintain their own cleanliness and health without aids and appliances or assistance can score zero points. Yet the reality may be that it is only the financial support to afford someone to help with domestic tasks, or to manage the high costs of utilities to keep the house at a healthy temperature, that enables the individual to maintain their own health. Without this support, the individual could be unable to afford the support they need, putting them and their family at risk (for example the house gets cluttered, the kitchen becomes unhygienic, and repairs can't be afforded).

A particular issue for many people with MS is problems with temperature. Temperature fluctuations can exacerbate symptoms. Keeping the house well heated or cooled (with air conditioning or fans) can mean considerably increased utility costs.

**Examples:**

"I feel cold even on a hot summer's day and DLA helps with extra heating costs, including purchasing a heater for my room so that the rest of the family don't swelter."

"I need to pay for extra heating throughout the year only needed because of my disability."

We support the recommendation from a number of organisations that a specific descriptor should be incorporated to address this issue. An activity based on this would also help bring in abilities that are so far not covered in full by the criteria, such as bending, kneeling, pushing, lifting and reaching – including addressing balance issues (for activities like ironing, hanging up washing, vacuuming and changing bedding).

We support the following suggestion, as recommended by RNIB. We encourage the DWP to work with a range of representative organisations to develop this activity further, particularly to discuss how to address the issue of additional heating and utility costs.

<b>Maintaining a safe and healthy living environment</b>	(a) Can maintain a safe home environment unaided <sup>3</sup>	0
	(b) Needs a complex aid or appliance to complete tasks essential for safe housekeeping <sup>4</sup>	1
	(c) Either: (i) Needs assistance to complete complex tasks <sup>5</sup> essential for safe housekeeping <sup>6</sup> ; or (ii) Needs prompting to complete complex tasks essential for safe housekeeping.	2
	(d) Either: (i) Needs assistance to complete basic tasks essential for safe housekeeping; or (ii) Needs prompting to complete basic tasks essential for safe housekeeping	4

## **Activity 1 - Preparing food and drink**

### ***Descriptors***

We welcome descriptor E which covers those who, ‘Need supervision to either prepare or cook a simple meal’, but the clarification point that follows the descriptor again places emphasis on the use of a microwave oven and should be removed. Individuals should not lose points because it is considered reasonable for them to use a microwave oven for every meal.

The concept of ‘aids or appliances’ in this section should cover pre-chopped vegetables and pre-prepared food, and this should be clear in the introductory note to the descriptors or underneath descriptor B itself. Many people with MS, particularly those who have problems with manual dexterity, rely heavily on aids

<sup>3</sup> This must be without risk of exacerbation of a health condition, and, as with other descriptors, reliably, repeatedly and safely without experiencing significant pain or fatigue.

<sup>4</sup> Complex aid to be defined in collaboration with DWP and representative organisations.

<sup>5</sup> To be discussed with the DWP but including vacuum, mop the floor and change a lightbulb. Basic tasks to include checking and cleaning spillages, checking and cleaning breakages, washing up, and turning the central heating on or off.

<sup>6</sup> To be discussed with DWP but provisionally defined to mean the tasks essential to keep the home hygienic, well lit and clear from obvious dangerous hazards and obstacles.

like pre-chopped vegetables, which attract a significant associated cost that should be adequately reflected in the assessment.

**Example: Cathy, 37, diagnosed with relapsing remitting MS in 2005**

Cathy is largely able to cook for herself. When she has a bad week with her MS, she relies on her mum to cook for her, or lives on takeaways. She isn't able to use a tin-opener, so has to use ring pulls, and uses a piece of cutlery to lever them open. She isn't confident using knives to chop and peel, so relies on pre-chopped vegetables. It's important for her to eat a fresh, healthy balanced diet to manage her condition; pre-chopped vegetables are a vital aid to help.

'Aids or appliances' should also include those aids and appliances needed to prepare food appropriate for the individual to be able to take nutrition. Many people with MS experience problems with swallowing, which requires them to have restrictive diets or rely heavily on soft or pureed goods. Items such as food processors should therefore be included under 'aids and appliances'. Some people rely heavily on this equipment in order to prepare every meal.

Similarly, this activity should also allocate at least some points to those who, due to a health condition, have special or very restrictive dietary requirements that lead to them incurring additional costs. For example, those who need to eat gluten-free products.

Further clarification is needed on whether the process of cooking a simple meal also includes cleaning up afterwards. Some people with MS, particularly those who suffer from severe fatigue, may 'manage' to prepare a meal with adequate aids and appliances, but then be unable to clean the kitchen, or wash up afterwards, requiring assistance from someone else or a dishwasher for this.

### ***Weightings***

We are concerned about descriptor C, 'Cannot cook a simple meal using a conventional cooker but can do so using a microwave'. While a 'simple meal' is defined in the introduction to this section as a, 'Cooked one course meal for one from fresh ingredients', the inference of this descriptor is that consistent reliance on a microwave is acceptable, as it only attracts a very low number of points. It is important to be aware that those without additional support would potentially have to rely on this method of cooking for all meals, despite the impact that this may have on their intake of nutrition and choice of food. People who have to follow a specific diet, or who can only eat certain types of food (as discussed in more detail below) may also find this method of cooking particularly restrictive. The points for this descriptor should be increased.

## **Activity 2 – Taking nutrition**

### ***Descriptors***

It is essential that a descriptor is added on 'supervision' in this activity, i.e. "Needs supervision to take nutrition safely." One of the most serious and consistent concerns for people with MS is the risk of choking. For many it is vital

that another person is present at meal times. The need for supervision has been recognised in activities 1 and 3, and should therefore factor here as well.

**Example: Charlie, 60, diagnosed with primary progressive MS in 1998**

"I have a lot of problems with swallowing, so always need someone to be there with me. Sometimes I can't breathe when I'm trying to have a drink. It can be really frightening."

***Weightings***

The current difference between descriptors E and F of 4 points is too great, given that an individual who needs assistance to manage a therapeutic source to take nutrition would not be able to take any nutrition without this help. E should therefore be awarded at least 8 points.

A descriptor should be added that relates to supervision, and carries at least 6 points, given the significant amount of time requires of another person to be present during all meal times, and the high level risk involved if this supervision is not provided.

**Activity 3 – Managing therapy or monitoring a health condition**

***Descriptors***

This is the only activity that makes specific reference to an individual's health condition but the focus on monitoring and managing therapy is extremely restrictive. Re-focusing the activity on maintaining health and condition management would more accurately reflect the costs that people with MS incur to manage the condition on a daily basis.

People with MS rely on a broad range of activities to manage their condition and maintain general health that may not be recommended directly by a healthcare professional, such as exercise, accessing social support networks or complementary therapies. There are few licensed disease modifying drugs, so individuals are more likely to rely on complementary therapies and health management techniques.

**Example: survey respondent with MS**

"I also use DLA to get alternative treatments. These supplement my care package and make me feel more able to cope with the daily realities of life with MS. I use it for Reflexology and massage and other treatments that I believe have a positive effect on my MS. I have depression and chronic fatigue, so the occasional treat helps me cope.

The DLA also pays for my prescription drugs which are costing me on average £50 per month. On top of that are all the supplements I take to try and help with my MS. These cost a lot but in the absence of a cure, I continue to take them. I also use DLA for Yoga and Pilates classes both of which help a little with my symptoms. These classes cost me approx £20 per month."

In addition, people with MS do not qualify for free prescriptions and often use their DLA to help cover this cost. In the absence of the Government reconsidering its decision not to take forward the previous Government's promise of free prescriptions for people with long-term conditions<sup>7</sup>, PIP should take into account and support these costs.

More detail is necessary to ascertain the level of support an individual might require to qualify for descriptor B. For example, while an individual may only need support once a week to distribute their medication into a dosset box, this is essential for someone who is unable to remove pills from their packaging – a common problem for many people with MS. This assistance should be regarded as sufficient to qualify for points under descriptor B.

During our research a number of individuals made reference to using applications on their phones to remind them when and what medication to take. These applications should be included under 'prompting' in descriptor B.

**Example: Andy, 37, diagnosed with primary progressive MS in 2008**

Andy has to take a large number of pills to manage his MS. His 11 year-old daughter sometimes helps to sort his pills out into a dosset box for him, as he tends to drop or lose them. His wife used to remind him to take his medication daily, but their relationship broke down last year. He says that he regularly forgets what pills to take and when due to problems with short term memory caused by his MS. He therefore now relies heavily on his iPhone, through which he's set up a complex system of reminders to help him to manage his medication.

Andy should be treated as needing assistance and prompting to manage his medication.

Finally, we seek clarification as to why this activity does not take into account medication and monitoring requiring administration by a healthcare professional. For people with MS, treatments such as colonic irrigation or massage, usually administered by a healthcare professional, can be vital but can be extremely expensive – either in terms of the cost of treatment, the cost of transport to and from appointments, or requiring assistance around the time of treatment.

**Example: Cathy, 37, diagnosed with relapsing remitting MS in 2005**

Cathy has to go several times a week for colonic irrigation, taking around 4 hours, to help her to manage the continence issues associated with her MS. She was given a home colonic kit, but was unable to manage this by herself. She needs a friend or family member to drive her to and from the sessions, as she feels very fatigued and ill afterwards and would not be safe to travel alone at these times. Cathy would score at least 4 points under descriptor D if she were able to manage this therapy at home with assistance. It would be a bizarre outcome if Cathy was penalised for the fact that she is not able to manage this without professional assistance, given that this involves higher costs.

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<sup>7</sup> As announced in the Spending Review Autumn 2010:  
[www.dh.gov.uk/en/MediaCentre/Pressreleases/DH\\_120676](http://www.dh.gov.uk/en/MediaCentre/Pressreleases/DH_120676)



## ***Weightings***

We remain concerned that this is treated as a low-scoring activity, given how vital it may be to an individual's health that they are able to take their medication. Descriptors B and C are particularly low scoring given the potential importance of needing supervision, prompting or assistance to manage medication for up to 3.5 hours a week.

## **Activity 4 – Bathing and grooming**

### ***Descriptors***

We accept that it is very difficult and unnecessary to cover all activities associated with grooming in the current definition, and we welcome that the wording of this activity has improved significantly with the removal of 'above a standard of self neglect'. However, the scope of this activity remains too limited. There are a number of essential activities that have been omitted that would require support in addition to the assistance required to clean teeth, comb/brush and wash hair, as specified in the introduction to the activity. For example, shaving is extremely problematic for people with MS who have difficulties with manual dexterity, and is potentially dangerous, while cutting nails is very necessary but requires considerable hand strength and coordination. There are considerable costs associated with these activities, such as chiropody, paid assistance, or aids and appliances such as an electric razor.

We are also disappointed that the definition of grooming is so basic as to not include activities that are vital to enabling an individual to maintain dignity and self-esteem, and thereby participate in society in an equal and active way. Examples include the application of moisturiser, make-up, contact lenses and styling hair.

#### **Example: survey respondent with MS**

"Some of my DLA goes towards hair, nail, pedicure appointments, waxing. I know this sounds good, but believe me it isn't - I don't go every week-or even every month; I can no longer dry my hair, paint my nails or shave my legs, I wish I could. I can go for months before I can get my nails done or legs waxed – this often distresses me as I take care of my appearance, but I can no longer do it myself."

With regards to 'aids and appliances', items such as electric razors and toothbrushes are sometimes vital to allow people with MS to complete bathing and grooming activities independently, and should be included as an 'aid or appliance' as they carry significant additional costs.

The parts of the body referred to in this activity do not cover legs and feet, but looking down to clean these parts of the body can be very problematic for people with MS who struggle with balance, even when they are sitting down.

**Example: Fiona, 39, diagnosed in 2002 with relapsing remitting MS**

“There seems to be nowhere within the current assessment to say that I need to take care in the shower because of balance issues or the need to be extra careful washing my lower body.”

People with MS also report that the heat of a bath or shower can affect feeling and stability in the legs, so washing this part of the body is very different from activities such as putting on shoes or socks. Jean, who has secondary progressive MS, told us “I have a seat in the shower but as soon as I lean my head down I get dizzy and I’ve fallen over and hurt myself a few times. Sometimes in the bath my legs just turn to jelly completely.” The need to keep all parts of the body clean and hygienic is vital and should be covered here. We also seek reassurance that ‘torso’ includes genitalia, which is particularly important for people with continence problems and women who are menstruating: UTIs are a common cause of hospital admission for people with MS and proper hygiene is extremely important to avoid this.

**Example: Alison, 56, diagnosed in 1999, has secondary progressive MS**

Alison has carers who come in to help her to shower every other day, and is only able to wash the top half of her body (face and underarms) without this assistance. She has had problems with vaginal and urinary infections, and believes that this is as a result of not being able to wash thoroughly enough on a daily basis.

Alison should certainly be treated as needing assistance to bathe.

### ***Weightings***

Supervision and prompting should be separated, as prompting involves somewhat less input from a third party than supervision. Needing supervision should score 4 points, as it entails the presence of a third party throughout the activity – and the activity cannot be completed safely without this presence.

The difference of 4 points between descriptor G and descriptor H is too great given that, without assistance, a person qualifying for G would not be able to bathe and groom reliably and safely. We recommend that G should therefore score at least 6 points.

### **Activity 5 – Managing toilet needs or incontinence**

Menstruation is not covered in this section but is a significant concern for many women with MS, and can be particularly difficult to manage. Women who are menstruating may require additional assistance to that which they normally require. For example, those who also suffer from incontinence may require significantly more pads than normal, and potentially a much greater degree of assistance. In addition, under the current wording of this activity, women who can manage their toilet needs unaided and are not incontinent will score zero points under descriptor A, although they may require assistance with menstruation, such as opening packets, applying sanitary towels and/or using tampons due to difficulties with mobility or manual dexterity. We believe that an additional

descriptor should be added, which carries a weighting of 3 points and sits between current descriptors C and D. It should read, 'Needs assistance to manage menstruation'. Descriptor A should be reworded to "Can manage toilet needs or incontinence and menstruation unaided". Not addressing this issue would be a serious failing of the assessment, causing a significant gender inequality issue.

We seek reassurance that adapted toilets are classed as an aid or appliance in this section. Many people with MS can manage their needs, but only in a toilet that has been modified accordingly – such as having grab rails. It should be made clear that claimants can only satisfy descriptor A if they could manage toilet needs, incontinence and menstruation in an un-adapted public toilet.

It is also vital that incontinence pads are included as an aid or appliance, which can be extremely expensive. In previous surveys by the MS Society on how people with MS use their DLA, buying incontinence pads has come up repeatedly in responses. People with MS who use them daily can spend hundreds of pounds per year, with one research participant spending in excess of £600 per year on incontinence pads. While incontinence pads can be provided by the NHS, people with the condition tell us that the number provided is often insufficient, and in some cases individuals have been told they should restrict use to as few as 4 pads a day, when in order to stay comfortable and hygienic, they have previously used at least double this number. This is a particular issue for those with double incontinence and given the high risk of UTIs for people with MS, as previously mentioned. Members of the MS Society also tell us that there are often restrictions on the type of incontinence pad that PCTs will provide. They tell us that the type supplied can be uncomfortable and undignified, and severely restrict their self esteem and ability to participate in society. It is important that PIP continues to offer people the financial support to make the choice to buy more comfortable and appropriate continence aids.

**Example: survey respondent with MS**

"I pay for continence products with my DLA, those provided by the NHS are not user friendly!!"

It is unclear what the difference between Descriptors F and G would be in reality. More clarity needs to be given as to how 'managing incontinence' would be defined. Many people with MS face difficulties with frequency and urgency which can result in occasional episodes of incontinence if they are not able to reach a toilet quickly. Managing this risk can be extremely restrictive to people's participation, independence and dignity. In particular, it often means that people feel unable to use public transport, increasing their transport costs. It is unclear how these additional costs and barriers would be reflected in the current wording of this activity. We are particularly concerned at how the '50% of days' rule would be applied, as this could leave those who experience episodes of incontinence on less than 50% of days without any support to manage this – although it is the *risk* of incontinence that is the barrier.

We are also concerned that this descriptor does not take into account any difficulties experienced in getting to a toilet while inside or outside the home. In

particular, getting to a toilet can be more difficult during the night time. The need for assistance throughout the night should be addressed. We believe that this issue can most appropriately be tackled by extending the mobility descriptors to include the issue of movement around the home – see comments below.

### **Activity 6 – Dressing and undressing**

We are concerned that descriptors D and E could be interpreted very narrowly unless it is clearly stated that individuals should be able to wear *appropriate* clothing – not only culturally appropriate, but also contextually appropriate. This should be defined subjectively according to the individual. For example, claimants who require support to wear specific clothes that they need to wear for work, such as a uniform or an outfit that is smart but more difficult to put on, should also be able to score under descriptors D and E, although they may not need assistance with all clothes. Also, women who are unable to put on a bra without assistance should be treated as needing assistance to dress.

As explained above in comments on Q5, ‘aids and appliances’ should be interpreted broadly to support individuals’ personal choice. Specifically, individuals are unable to manage fiddly buttons or zips, but choose to simply avoid clothes with these, rather than buying specially adapted clothes, should still score under descriptor B.

#### **Example: Guy, 29, diagnosed with primary progressive MS in 2009**

Guy lives alone and gets no support with dressing, so has to wear clothes without fiddly buttons or zips (he was offended by the suggestion that he might be expected to buy clothes with adapted buttons), and has to sit or lie down to get dressed. However, he’s actively job-hunting, and if he wanted to wear a shirt with buttons for a job interview he’d need to get someone to help me to put it on. In addition, during relapses, he needs friends to help him.

Although Guy doesn’t wear clothes with adapted buttons, he should be treated as needing assistance, or aids and appliances, since he is unable to dress unaided in clothes with fiddly buttons – such as a shirt, which would be appropriate for someone wants to look smart for job interviews.

The extra washing costs incurred by people with MS are not currently reflected. Points should be awarded to those who experience additional costs through the need to buy additional clothes due to wear and tear, or who may experience high utility costs for washing clothes. This may apply particularly to those with continence problems who may need to do additional washing. This should be reflected in this descriptor.

### **Activity 7 – Communicating**

This activity needs to extend to cover those who need assistance to communicate through written communication, rather than just those who need assistance to access such communication. Many people with MS can read and communicate verbally, but are unable to fill in forms or express themselves on

paper or through typing, largely due to problems with manual dexterity, and will therefore need assistance in this regard.

It should also cover those who struggle with speech. Individuals with MS often struggle with pronunciation and slurring as well as finding the right words to express themselves. Some struggle to use the phone so are forced to communicate face to face or via the internet despite the additional costs such as travel, or appropriate technology, that this may entail. Similarly, those who struggle to express themselves due to speech or cognitive difficulties may find it difficult to engage socially without social support from a friend or family member. Currently, however, people facing these difficulties may struggle to score points under either activity 7 or activity 8.

### **Examples**

**Guy:** “I have to keep phonecalls to less than five minutes, or I get tired and confused.”

**Mary:** “At some point most days, I’m just too tired to communicate. I can’t think of or form the right words.”

**Andy:** “I can’t stand being in big groups. The brain fog comes on and I have to think so much more about what I want to say, then I always need someone to prompt me. My speech slows right down and slurs. It’s so frustrating.”

A more comprehensive definition of written information is needed, including, for example, the font size and length of text that individuals are reasonably expected to be able to access. Written information should not be defined as single words or signs, but a length of text likely to be encountered on a daily basis, such as a story in a newspaper or an official letter in Size 12 font. ‘Accessing’ written information must be interpreted to include not just reading, but being able to understand and retain information: individuals must be able read and comprehend important correspondence without assistance, such as an official letter from the DWP.

### **Example: Mark, 30, diagnosed with relapsing remitting MS in 2009**

Mark is able to read short, simple pieces of text (such as an ‘Exit’ sign or a single sentence), but needs to use a ruler to read paragraphs of text, as difficulties with eyesight means that the “words blur together”. He also struggles to process and understand complex or lengthy pieces of written communication, particularly when he is fatigued, which happens most afternoons and evenings. He therefore always asks his wife to read and explain anything of importance, such as official letters.

We believe Mark should score at least 4 points under descriptor D for needing assistance to access written communication.

## **Activity 8 – Engaging socially**

We are concerned that the introduction to this activity only refers to those who have an, ‘inability to engage socially’ and that this definition does not adequately

cover individuals who suffer from conditions like depression, which is a common side effect of MS. People who are affected in this way will often need prompting to engage socially and should score points under descriptor B.

Many people with MS also have difficulty engaging socially in group situations due to cognitive difficulties such as concentration, processing large amounts of information, and fatigue. For this reason they rely on a third party for additional support. We propose that an additional descriptor is added prior to B, which states, 'Needs prompting or social support to engage socially in large groups', for which 1 point should be awarded.

#### **Examples**

##### **Guy, 29, diagnosed with primary progressive MS in 2009:**

Guy used to be nicknamed 'united nation' because he was so actively engaged in his area with a wide range of people and communities. Since his diagnosis, he now feels extremely uncomfortable and finds it difficult to cope in large groups, unless he has a friend or family member to support him and help to build his confidence. He has restricted his social life enormously, and rarely goes out.

The definition of social support should be re-worded to include friends and family members who may provide informal support, not just those who are specifically trained to do so. The current definition is very restrictive and appears designed to meet the needs of those with very specific mental health conditions or learning disabilities, as opposed to people who need for additional social support as a result of other conditions, like MS.

#### **Examples:**

**Mark:** "At the moment I wouldn't go anywhere without my wife really. If she's there it's ok – I just tend to shadow her at parties or social things."

**Mary:** "I have no social life. It's a bit crap. I have to really restrict how much I go out as I just get so fatigued by the effort of interacting with people. I'd be too overwhelmed by a big crowd to be there alone, and would get stressed."

**Fiona:** "I just don't engage socially in the afternoon and this is very restricting on my life."

As mentioned below (Q8), the definition of 'social support' in the regulations should be changed to mirror the wording for 'communication support', which includes the phrase, 'Support from someone experienced in communicating with the claimant'.

### **Activity 9 – Making financial decisions**

The basis of this activity is confusing, and the phrasing is problematic. Many of the participants involved in our research found it difficult to understand what is meant by the descriptors and how this would apply to them. Participants often felt that they had the mental capacity to make financial decisions, and were offended by the inference that they did not, but stated that they may need support to

manage their financial affairs - either due to confusion or memory problems, or simply on 'bad days' due to fatigue or physical ill health.

We seek clarification as to whether this activity is designed to be a proxy to assess capacity to make decisions as a cognitive process, or whether it looks at ability to manage financial affairs. The latter is a much wider issue, and should consider physical as well as mental or cognitive problems, such as manual dexterity using money or card machines, or fatigue.

The word 'support' should be added to the descriptors that currently focus solely on prompting. 'Prompting' is defined as 'reminding or encouraging', which is too narrow to capture the full range of barriers in this activity. Many people with MS are aware that financial decisions must be taken, so do not need 'prompting', but need additional support in order to make them.

**Example: Mark, 30, diagnosed with relapsing remitting MS in 2009**

When asked if he felt able to make complex financial decisions, like calculating the household budget, Mark told us:

"I don't really know how to answer that. I want to say yes. Maths isn't a problem. If it was all written down for me – everything that's coming in and going out at different times. But there's so many different individual things to deal with, it's hard to take it all in. I don't think I'd manage it without [my wife]."

Ian: "Of course I am able to make financial decisions. But I suppose having said that, if I am going through a relapse I am not physically able to. I'm just not well enough. My wife has to make relevant decisions if this is the case."

### **Q3 & Q4: Mobility Activities**

#### **Activity 10 – Planning and following a journey**

There is an overemphasis on mental distress in this activity, which does not recognise the wider range of barriers that people can face to planning and following a journey. The definition of 'overwhelming psychological distress' needs to be revised – it does not recognise anxiety or panic attacks that could arise from a wider range of issues. People with MS can become easily disorientated, which can make the prospect of planning and following a journey significantly more complex, and potentially too daunting to manage. We also seek greater clarity on how physical barriers such as fatigue and problems with continence may factor in this activity, as the descriptors currently focus on mental, cognitive and sensory impairment. For example, people with MS will often be forced to avoid using public transport as they are unable to stand for indefinite periods of time. This can be particularly problematic while waiting for a bus or train. We would like reassurance that those who are unable to undertake a journey on public transport as a result of physical impairments will qualify for descriptor C.

It is vital that a wider range of barriers are recognised in order to properly account for the additional costs that people with MS incur when planning and following a journey. For example, the cost of taking a companion on a journey, relying on expensive taxis due to inaccessible public transport, or the additional

fuel and wear and tear on a personal car. People with MS may also have to undertake more journeys to and from hospital or other healthcare appointments.

### **Examples**

**Andy:** “If I’m somewhere I don’t know where I am and it’s busy, the brain fog starts, I get stressed and I start to panic. Then I end up going around in circles. I know it’s because of my MS - I used to have a pretty good sense of direction.”

**Kiran:** “It’s quite sad to admit, but I can’t remember the last time I went somewhere. I can’t use public transport on my own, and wouldn’t go to a new place without support – it’s a combination of problems with confidence, mobility and cognition. I can get confused and anxious.”

This activity should focus on routes, rather than destinations. For someone with MS, what determines whether a journey is achievable or not may not be familiarity of the journey. For some, the important issue is how busy the route is and the number of distractions faced, such as busy, noisy streets or heavy traffic. For others, low light or unexpected weather conditions can be particularly problematic.

### **Examples**

**Cathy:** “If it’s windy, rainy or snowy, I can’t go out. If my hair blows into my face, it knocks out my balance completely.”

**Linda:** “I can’t see properly to cross a road safely, because if I look left then right quickly, my balance goes. I also lose my bearings really easily. I need someone with me all the time as I never know how much help I might need”

Individuals could face these barriers whether a journey is known to them or not. We seek reassurance that people facing these barriers will qualify for points under descriptor E, as they are unable to plan and follow a journey to a familiar destination reliably, repeatedly, safely and in a timely manner due to these additional factors. If this is not the case, the DWP should consider whether the use of the distinction between familiar and unfamiliar journeys is appropriate, or if it should be replaced with consideration of ‘simple’ or ‘complex’ journeys.

We recommend the inclusion of an extra descriptor to allocate at least 2 points to those who would need assistance to deal with unexpected changes to a journey. For example, those who may encounter anxiety or confusion upon unexpected changes to a familiar journey (e.g. a diversion due to roadworks, or a change to public transport routes and times), or those who would need assistance due to a sensory impairment (such as being unable to hear an announcement in a train station, or to read diversion signs).

We recommend the inclusion of a descriptor which allocates at least 2 points for those who need to use an aid or appliance (including the use of sat navs and smart phones) to plan and follow a journey. As described above, many people with MS suffer from disorientation and would not consider a journey without using these devices (and without these devices, would require assistance from another



person to plan and follow a journey). They do, however, represent a considerable cost.

### **Examples**

**Mary:** “Following a route is extremely tiring. I always use a sat nave and drive everywhere. I’d find it really stressful and get really fatigued finding my way around a big city on my own”.

**Cathy:** “Travelling is quite a drama. I have to plan toilet stops wherever I go and I never use public transport. I can’t get on and off trains and buses. I won’t leave home without a sat nav”.

**June:** “I have a car with a sat nav and go everywhere with it, because going somewhere new scares me.”

**Shona:** “I’d have to think twice about doing a journey without a sat nav. If I get lost, I get stressed and fatigued and then I really am in a sticky wicket! I can’t use public transport because of the uncertainty – I once had to wait for a bus for nearly an hour and felt really ill afterwards because it made me so tired.”

### **Activity 11 – Moving around**

Activity 11 sets a high threshold: only the use of a wheelchair qualifies people for the higher rate of the benefit, and those who can mobilise just 100m but no further will only score 4 points, and potentially not qualify for any mobility payments.

Those with walking difficulties but not using a wheelchair (such as those with conditions who experience severe pain or fatigue walking further than 100m) experience significant barriers to participation and high costs – often needing to use taxis or a car to get around: this should be reflected in the scoring.

It’s particularly vital that ‘reliably, repeatedly, safely and in a timely manner’ are applied to this activity. Clear guidance is needed as to what is meant by ‘reliably’ and ‘safely’ in this descriptor. The large majority of people with MS currently qualify for the mobility rate of DLA because their walking ability is so poor that they are treated as ‘virtually unable to walk’. Yet Activity 11 sets a high threshold: it appears that only the use of a wheelchair qualifies people for the higher rate of the benefit. Those who can mobilise just 100m but no further will only score 4 points, and potentially not qualify for any mobility payments. Those with walking difficulties but not using a wheelchair (such as those with conditions who experience severe fatigue, pain or breathlessness walking further than 100m, or those whose walking is slow and hesitant, who are at risk of stumbling due to balance problems) experience significant barriers to participation and high costs – often needing to use taxis or a car to get around. This should be reflected in the scoring - it is currently unclear whether someone who is unable to move around safely would be treated as if they need to use a wheelchair (even if they don’t actually do so). It should be clarified that those who choose to continue to try to walk, rather than use a wheelchair, but cannot do so reliably and safely, should be eligible for Descriptor F.

In addition, activity 11 needs to make clear expressly that pain, fatigue and breathlessness should be considered (as the 'planning and following a journey' descriptor does with psychological distress).

#### **Examples**

**Kiran:** "The level of concentration I need to put one foot in front of the other and concentrate on everything going on around me to be safe means walking is absolutely draining. I've got a basic NHS manual wheelchair that I use infrequently but even that's quite a struggle. As for cobbles – even in flat shoes, I may as well be in stilettos – they're impossible."

This activity is restricted to considering claimants' ability to mobilise 'on the flat' in relation to outdoor surfaces. Although it is welcome that kerbs are specifically mentioned, it does not consider individuals' ability to move around inside the home (or workplace) – such as navigating steps, nor does it consider uneven surfaces, such as cobbles, countryside or hills – which can be particularly problematic for people with balance problems.

#### **Examples**

**Shona:** "I really struggle on uneven ground – I get unsteady and fall. My left leg drags a bit so I always need someone with me in case I trip."

This is one of the areas in which the most extreme fluctuations for people with MS occur. Many people can get around walking with a stick much of the time, but when fatigued, going through a relapse, or in order to spend a full day out of their home, a mobility scooter or powered wheelchair is absolutely essential. Some may need a powered wheelchair for many weeks or months of the year, yet may fall short of needing it on 50% of days. The 50% of days rule should not prevent people from getting the support they need to manage these severe (and regular) fluctuations. (See Q8 for more comments on this issue).

### **Q5: What are your views regarding how the regulations work regarding benefit entitlement?**

#### **Aids and appliances:**

We strongly believe that 'aids and appliances' should not be restricted solely to aids and appliances specifically adapted or solely designed for and used by disabled people. 'Aids and appliances' should be interpreted broadly to include increased reliance upon or use of widely available un-adapted appliances, as well as restricted choice of everyday items, such as clothes, shoes, ingredients or cutlery.

Disabled people often use aids and appliances that are available to, and used by the general public, rather than specifically adapted for disability. Examples may include electric toothbrushes or razors, kitchen gadgets such as food processors or microwaves, cooking ingredients such as or pre-chopped vegetables, or dry shampoo. However, while using such aids and appliances is a choice for those without a disability or impairment, it may be a necessity for someone with a disability.

### **Examples**

"I have used my DLA for buying such things as large nail-clippers I could use with a disabled right hand, dry shampoo to make my hygiene easier to manage, an automatic vacuum cleaner because I could no longer use a normal one.... etc etc. The list goes on."

"I use an electric toothbrush and an electric razor as I don't have the strength or energy to use conventional ones. I need a computer and broadband connection to shop online for clothes, food and equipment because I struggle to go to the shops."

"My DLA pays for good quality bedding (because it's washed so often); more washing powder, the tumble dryer and the cost of use (I cannot peg out washing and daily have to wash clothes and bedding due to continence issues)."

Similarly, disabled people may rely on un-adapted aids and appliances more heavily, which may cause increased wear and tear, increasing costs in terms of utility bills and replacement. For example, someone with continence issues, mobility problems and/or a visual impairment (not an uncommon set of symptoms for people with MS) that means clothes are soiled more regularly may face increased costs related to the use of washing machines and tumble dryers, as well as more regularly needing to replace clothes; someone with mobility problems may wear down shoes more quickly.

Finally, disabled people may be restricted to a smaller range of everyday items that they are able to use, which can increase costs by limiting choice. In needing to buy clothes that are easy to put on, or food that is pre-prepared, disabled people often miss out on bargains and deals available to other members of the public. They do not have the choice to opt for cheaper items because their requirements are so specific.

For example, some people with MS are only able to wear particular kinds of shoes or clothing due to difficulties dressing – they may avoid buttons and zips, rather than buying specially adapted clothing or using some kind of button-fastening aid; or avoiding wearing socks as getting them on was too difficult. None of the people with MS that we have consulted stated that they would buy disability-adapted clothing, and were offended by the suggestion that they should be expected to. Yet most faced difficulties dressing which, had they not restricted the type of clothing they bought and wore, would mean that they would require aids or assistance to dress.

### **Q.6: What are your views on how we deal with fluctuating conditions?**

It is vital that PIP continues to play the important preventative function of DLA, to allow people with unpredictable and fluctuating conditions to afford the support they need. The social care system will never be responsive enough to support people to manage the unpredictable nature of their condition, and it's vital that a

benefit like PIP allows people the financial support to prepare for and to manage relapses, to prevent unnecessary hospital admissions.

**Examples:**

Survey respondent with MS: “My needs change not just weekly or daily but often hourly. I may be able to feed myself in the morning but unable to do so in the evening for example or vice versa. DLA allows me the control to adapt to an ever changing situation and affords me a little dignity, which is a rare commodity when battling a condition like MS. DLA gives me the freedom to pay for help as and when I need it. It is such a small amount of money in the overall scheme of things but for a person like me, it means the difference between surviving and living. That is something you can not put a price on.”

Person with MS: “You don’t count it, you live it.”

We welcome the continued efforts to improve the way that the assessment will work to identify and support people with fluctuating conditions, but we remain concerned that it will not fully meet the needs of people with MS.

For people with a complex, unpredictable and fluctuating condition like MS, assessing whether someone fits in to a particular descriptor on at least 50% of days will be an extremely complicated and difficult task. When testing the descriptors on people with MS, many were very confused by this approach and how it would apply to them, and how this would be assessed. People found it extremely difficult to quantify how many days in the previous year they have had been able to complete an activity.

The approach proposed fails in particular to recognise the additional barriers and costs faced by the following people in three common situations:

1. Those who have short but severe fluctuations – these people often scored zero points despite facing severe barriers to daily living and mobility for a significant period of time, as they were unable to satisfy the ‘50% of days’ rule. The Government stated in the second draft of the criteria that they do not believe that support needs arising from short, acute periods of impairment should be met by the benefit, as it is targeted at long-term impairments. However, this neglects the fact that unexpected and severe fluctuations can be a regular feature of a long-term condition like MS. The nature of the fluctuating condition itself means that the impact of preparing for and dealing with sudden and unpredictable relapses (involving exacerbations of both needs and costs) is long-term, if not continuous.

**Examples**

**Shana** has issues with double vision quite frequently, but for the majority of the time feels able to get around safely unaided. However, during some relapses she has lost her vision completely. This can last for a few weeks, and happens two or three times a year. When this happens, she requires 24 hour support for all daily activities. Under the current descriptors she will score no additional points to recognise this, although it leads to enormous exacerbations of cost on a reasonably regular basis.

**June** is able to get up and dress herself most days. However, ‘one or two days per week’, the depression that she experiences as a symptom of her MS means that she feels unable to get out of bed at all, as she doesn’t feel that she has the energy or motivation to dress herself. June has been actively job-seeking for several years, and feels this is a hindrance to her search for work. Although this is a regular and serious problem that occurs for a significant minority of the time, she is unlikely to score any points on this activity.

**Anne** states that most days she is able to walk, albeit hesitantly, at least 200m with a stick on level ground outdoors. On bad days, a few days a month, this can be extremely fatiguing, and causes some pain in her legs. If she is going for a day out with her family, or feeling particularly fatigued, she requires a scooter. Similarly, in order to walk her dog on the countryside near to her home in rural Scotland – an important part of her daily routine – she requires a mobility scooter. Her wheelchair service will not provide her with a scooter, as she does not require a scooter for over 50% of days – yet she is unlikely to score more than 4 points on the mobility activities so may not qualify for the PIP mobility component.

2. Those who meet the requirements of two descriptors in the same activity but for less than 100% of the time - While satisfying the ‘50% of days’ rule, the descriptor that impacts these people for the largest part of the time is applied and, crucially, this could be the barrier that carries the lowest amount of points. This means that individuals will not be compensated for the additional, and potentially higher costs of the other barrier(s) they face.

**Example: Kiran, 52, diagnosed with primary progressive MS 2009**

Kiran struggles with using knives and forks much of the time. She often drops them and regularly spills food on herself when eating. She has to use a particular knife and fork set (although not specifically adapted) which are lightweight and small with thick handles, and occasionally needs someone to cut her food up for her, if she is having a bad day. She also states that when her partner is not around to prompt her, she occasionally forgets to eat, or lacks the motivation, as “the thought of having to prepare and eat something can be overwhelming”. She has suffered from anorexia in the past, so the cumulative impact of the lack of motivation to eat alongside physical difficulties eating could cause serious problems. However, as she only needs prompting some of the time, she is likely to only score 2 points under descriptor B, which applies for most of the time. We believe that it would be more appropriate to award Kiran more points than this.

3. Those who satisfy two or more descriptors in the same activity for 100% of the time – the current assessment criteria assume that the highest scoring descriptors subsume the lowest scoring descriptors in each activity, but this is often not the case. For example, an individual who needs prompting could score the same as someone who needs prompting *and* an aid or appliance, but the latter individual will face additional costs.

It would be helpful for some activities, particularly the mobility activities, to bring in an additional descriptor with a time dimension, which recognised those who

may have shorter (i.e. less than 50% of days) but regular and severe fluctuations in a long-term condition. For example, those who need to use a powered wheelchair for at least 20% of the time.

We recognise that this is an extremely complex issue, and that it requires detailed consideration. We therefore encourage the DWP to host a workshop with a number of representative organisations to discuss in detail how this issue of fluctuating conditions could be better addressed.

### **Q7: Reliably, repeatedly, safely and in a timely manner**

We believe that this is an extremely important part of the assessment. We support the definitions suggested. However, ‘reasonable standard’ within the definition of ‘reliably’ needs to be further clarified: this should be interpreted to mean to a similar standard that a non-disabled individual would expect, according to the activity.

In the Work Capability Assessment (WCA) for Employment and Support Allowance (ESA), these terms are only contained in guidance, and as a result, they are not applied to the descriptors in assessments as consistently as they should be. We strongly feel that it is important that these terms are included within the regulations. This would give the strongest force of law to the implementation of these terms within assessments, and would give claimants enforceable rights to ensure that these terms are considered. This is particularly important for complex cases involving people with fluctuating conditions like MS.

We recommend that this should be included as a general provision within the regulations, perhaps within the ‘Interpretation’ section of the Schedule to the regulations, to specify that each descriptor should be interpreted as if each activity is followed by the words ‘repeatedly, reliably, safely and in a timely manner’, along with a definition of these terms.

### **Q8: What are your views on the definitions in the regulations?**

We have the concerns and comments about the following definitions:

“aid or appliance” – the current definition is far too narrow. Please see comments above (Q5).

“bathe” – please see above comments on the ‘bathing and grooming’ activity. This should be extended to state ‘clean one’s torso, face, hands, underarms, legs and feet’.

“groom” – please see above comments on the ‘bathing and grooming’ activity. It should be made clear that this is not an exclusive list, but it should also include on the face of the regulations:

- (d) cut one’s fingernails and toenails;
- (e) shave one’s face, underarms and/or legs (as appropriate)

“prompt” – ‘and references to prompting are to prompting by another person’ should be removed (see above comments on the ‘managing medication’ activity).

“social support” – should be extended to include:

or b) support from someone experienced in communicating with the claimant

### **Q9: Do you have any other comments on the draft regulations?**

In Part 2, s.4(d), it is important that in determining what aids and appliances the claimant could ‘reasonably be expected to wear or use’, the cost of the item is considered, and that the claimant’s personal choice and dignity is not ignored. For example, someone who needs assistance to manage toilet needs (particularly during the night) due to issues such as urgency and mobility problems should not be expected to simply use incontinence pads and treated as needing an aid or appliance, rather than treated as needing assistance.

We would welcome the insertion of a clause under Part 2, s.7, to ensure that no-one will be called for an unnecessary face-to-face consultation, where there is enough evidence that a claimant should qualify for the benefit without the need for a face-to-face assessment.

We suggest the following clause:

7.(1A) Claimants will be exempt from the requirement to attend a consultation where sufficient medical and other expert evidence from a relevant care professional is available to determine whether the claimant has limited or severely limited ability to carry out activities.

Evidence from the MS Society indicates that face-to-face assessments for benefits can be extremely stressful. In a 2010 survey by the Disability Benefits Consortium (DBC), more than half of those who had been through an assessment for ESA found it stressful and more than four in ten said it made their condition worse because of the stress and anxiety caused. Stress has been shown to exacerbate MS, and in some cases even to bring on serious relapses. Putting PIP claimants with MS (and particularly the progressive form of the condition) through repeated and stressful reviews is therefore not only unnecessary expense for a system which is supposed to be designed to save the DWP money, it risks unintended and serious negative consequences for the health and wellbeing of the individuals at stake.

In addition, in the current ESA system, Atos, (the contractor paid to undertake assessments), takes the decision as to whether a claimant can be admitted to the benefit on the basis of paper evidence, or whether to bring a claimant in for a face-to-face assessment. This risks a perverse incentive to bring people in for an unnecessary face-to-face assessment. We urge the DWP to ensure that such a conflict of interest does not exist for PIP assessment providers.

**People with MS have told us:**

“Face to face assessments are abysmal. It is just not possible for one person who does not know me, in one brief meeting, to assess my cognition, my mobility my fluctuating needs. Of course they can't. Unless I ham it up, which is against my character, they won't see me fall, they won't see me shut a door on myself because my co-ordination doesn't work, where are they when pain stops me sleeping or I can't get off the floor myself.”

“I have an incurable progressive condition. Life will only get harder for me. Being awarded DLA ‘indefinitely’ gave me peace of mind. This current review is causing stress through uncertainty which makes my condition worse.”

“MS is a condition which can fluctuate from one extreme to another. If I were to be assessed on a good day my leg would not drag, my balance might not cause problems and I would probably speak quite clearly AND I would 'look really well'. The stress of such an interview would have an adverse effect on my MS - examining my medical records would be sufficient - MS is a chronic condition - an 'objective face -to-face assessment' for someone with a diagnosis of MS is a waste of time & money ..... AND the stress could cause a major relapse ..... requiring more money to pay for medication, nursing, doctors to right the wrong!”

## Further information

If you would like any further information about the points raised in this response, please contact Hayley Jordan, Senior Policy and Campaigns Officer, MS Society, 020 8438 0753, [hjordan@mssociety.org.uk](mailto:hjordan@mssociety.org.uk); or Claire Nurden, Policy and Campaigns Researcher, 020 8438 0970, [cnurden@mssociety.org.uk](mailto:cnurden@mssociety.org.uk).

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