

## WELFARE REFORM COMMITTEE

### THE FUTURE DELIVERY OF SOCIAL SECURITY IN SCOTLAND

#### WRITTEN SUBMISSION FROM ACTION FOR M.E.

M.E. (Myalgic Encephalomyelitis) affects an estimated 21,000 adults and children in Scotland. Symptoms include post-exertional malaise (a period of intense exhaustion following exertion) and chronic pain. M.E. affects different people in different ways and symptoms can fluctuate and change over time. M.E. is defined by the World Health Organisation as a neurological condition. It may be diagnosed as Chronic Fatigue Syndrome (CFS). This should not be confused with chronic fatigue, which is a common symptom of many illnesses.

Action for M.E. ([www.actionforme.org.uk](http://www.actionforme.org.uk)) is the UK's largest charity for people affected by M.E. Our mission is empowering people with M.E. to fulfil their potential and secure the care and support they need, while working towards a greater understanding of the illness and ultimately a cure.

Our response to this call for evidence is based upon our experience as a primary provider of information – including a dedicated Welfare Advice and Support Service – to people affected by M.E. across Scotland and the UK. Additional evidence has been drawn from our qualitative study (April-August 2015) of people with M.E. in Scotland and their experiences of claiming PIP and from 2014 UK-wide survey data (more than 2,000 respondents).

#### **Key points and recommendations on welfare**

**The welfare system is extremely stressful to navigate** and this has been exacerbated by the welfare reform process. In our 2014 survey, 77% of respondents said they were worried about the impact of welfare benefit reforms. The stress of claiming benefits is undermining claimant health and capacity for recovery or stabilisation of symptoms. Where people believe they are eligible for a benefit and are turned down, we are finding this contributes to feelings of desperation and helplessness and individuals' sense that their illness is not 'believed'.

With an illness such as M.E. where stress can worsen the severity of symptoms, people are being pushed even further into ill-health and away from active work and other roles by the system. People have reported experiencing relapses as a direct result of benefits related stress. Descriptions from our PIP study include: "*It made me feel a lot less of a person*", "*a dehumanising experience*", felt "*sheer terror*", "*I broke down completely [during assessment]... it's really difficult emotionally*".

**The welfare system as a whole could potentially be more efficient and less of a burden on claimants if it was more joined-up.** At present claimants have to make separate applications for different benefits providing essentially the same information (eg. PIP and ESA). However, safeguards need to be in place to ensure that the information recorded is accurate, complete and fairly applied without placing an additional burden upon claimants. Claimants also need to be confident that they will not unfairly lose access

to multiple benefits because of poor decision-making with one. Should Universal Credit be devolved to Scotland these considerations should be factored in.

**The welfare system could potentially be improved by sensitive integration of aspects of the welfare system with health and social care provision.** This could help to resolve the following issues:

Lottery of supporting medical evidence. At the moment, claimant ability to provide supporting medical evidence varies hugely, depending upon the goodwill of, and their access to, individual practitioners. There is widespread confusion amongst claimants and practitioners about the extent to which any supporting medical evidence provided influences claim outcomes. A recent survey of GP practices in Fife found that claimants were being charged between £5 and £100 per letter requested. Patients in Dumfries have reported being asked to give a donation of their choice to their practice in return for medical evidence. Where evidence is required for welfare claimants it should be mandatory that this information is provided free as part of the health service.

Few people with M.E. are accessing social care support. This includes those who are long-term house- or bed bound as a result of their condition. The situation is placing a considerable burden upon family members, and sometimes friends, and can lead to crises when carers become unable to sustain their support. Our 2014 survey found that 84% of respondents with M.E. who were receiving care from a family member or friend said that their carer had not received an assessment. This included carers under 18 years. 81% of respondents with M.E. had not had a social care assessment themselves in the past five years, including 60% of those with severe M.E. (ie. house or bedbound). One patient in Fife told us: *"I was given a social worker just as the social care cuts were made. It took a year for them to tell me that there was no money for people like me."*

There is currently no systematic monitoring of the ongoing health and wellbeing of people with M.E. or their carers. This leads to future health and care problems that could be addressed more effectively if identified earlier. Our 2014 survey found that 73% of respondents with M.E. had had no contact with an M.E. specialist in the past five years and 31% had not seen their GP in the past year. This situation exacerbates the difficulties faced by people with M.E. attempting to provide supporting medical evidence.

## **Response to inquiry workstream a) PIP, DLA and Carer's Allowance**

**PIP assessments and decision-making need to be improved to provide fairer and more accurate results.** PIP claims are the area of welfare about which we are currently being asked most often for advice. Claimant testimony as well as the level of successful appeals of PIP (and also ESA) claim decisions indicates that there is considerable need for improvement of the following aspects of assessment processes:

The timescale for completing and returning paperwork is too short, bearing in mind the cognitive and physical impairments that limit many people with M.E.'s capacity. People described taking several weeks to complete the form. This is exacerbated by lengthy waiting lists for support from advisors and delays in acquiring supporting medical evidence. Inaccuracy in assessment reports. As well as factual inaccuracy, claimants report that assessors are failing to record or take into account pertinent information.

The PIP assessment is not suitable for people with fluctuating and cumulative M.E. symptoms despite changes that were supposed to address this failing. Although claimants should only be deemed capable of completing an activity if they can do so “repeatedly, reliably and safely,” in practice people with M.E. have difficulty communicating the impact of M.E. in written forms and in assessments due to the way the questions are phrased.

An alternative measure of individual functional capacity is cardiopulmonary exercise testing (see [Van Ness et al, 2007](#), [Snell et al, 2013](#)). This would have a much wider purpose of aiding in accurate diagnosis and supporting self-management. Test data could also provide a solid foundation for much needed research into M.E. Such testing would need to be developed and delivered by fully trained, specialist NHS staff as an integrated part of overall health and social care provision – not benefits assessors. A cautious approach would be required to ensure individuals are not subjected to overly strenuous tests that could cause harm and that realistic thresholds are established to identify support needs.

Lack of assessor understanding of M.E. Assessors often appear to be systematically applying unsound assumptions about claimants’ capacity based on snap shot appearances on the day and conjecture ie. that if an individual is able to do ‘X’ once, they must be capable of ‘Y’. Describing the muscle strength testing and assumptions made during an assessment about cognitive function and ability to travel, one claimant said: *“This fails to take into account... the very limited amounts of activity I can undertake without suffering exhaustion and debilitating symptoms and after-effects. It had to be a better day for me to be able to attend but I am still feeling unwell during it and was exhausted afterwards for several days”.*

In some cases claimants report that assessors appear to be ignoring M.E. altogether and choosing to focus on a comorbid condition (eg. depression). However, claimants whose individual assessor appeared to have a good understanding of M.E. and its impact find the process a much more positive and fair experience. It is vital that assessor training is expanded to include fluctuating conditions such as M.E. and the impact it has on claimants’ ability to function.

The weighting of supporting evidence in decision making needs to be clarified, and the circumstances in which supporting evidence should be requested (and paid for) directly by the assessing organisation. Health professionals are less motivated to engage when they feel their input is being ignored in decision-making as is currently the case. Placing the onus on claimants to provide supporting evidence is undermining patient-practitioner relations and, in some cases (as noted above) resulting in a considerable financial burden.

Lengthy and stressful appeals process. Anecdotally, people who are in need of benefits are foregoing their right to appeal decisions due to the physical and emotional toll of the extensive appeals process. Those who appeal successfully tend to do so with substantial support. The mandatory reconsideration phase appears to rarely result in decisions being overturned in practice and is a substantial barrier to ill people with limited capacity proceeding with appeals, even where they have been advised that they would be likely to have a successful outcome.

**Claimants are unsure of the differences between DLA and PIP** and the implications for their claim. There is high demand (and need) for third-sector advice and support. People

awarded DLA who must make a new PIP claim find the process particularly stressful and demeaning.

**Loss of Motability vehicles as a result of being transferred from DLA to PIP** (and not being awarded the enhanced mobility component) is a substantial source of stress and hardship for some claimants. Where Motability support is reinstated on appeal, claimants still face losing their vehicle for several months in the interim.

**Driving capacity is a difficult issue for some claimants.** On the one hand, they feel that being able to drive short distances is equated with having too high a functional capacity to qualify for PIP. On the other hand, people who rely on driving to retain some independence are reluctant to disclose difficulties they experience for fear of losing their license.

**Some claimants feel that the fact they are working has been used unfairly against them** as evidence that they do not meet the PIP criteria. For example, a young woman with M.E. who moved back in with her parents as a result of her ill-health and relies heavily upon their support with cooking meals etc. to enable her to remain in work was turned down for PIP.

**The current negative focus of PIP on claimants having to evidence what are unable to do is detrimental.** Several PIP claimants said they would like a system with a more positive focus on how they could be enabled to live as independently as possible. M.E. patients require a system that facilitates self-management and support during set-backs. One asked, *“Shouldn’t they [Assessors] be using their skill to get the full story out of somebody, rather than just letting people who are genuinely ill provide inadequate answers?”*

**Current ‘Daily living components’ of PIP don’t cover common real life needs** of people with M.E. eg. support with shopping and housework, eating healthily with dietary restrictions. Some people we interviewed told us they were relying on PIP money to pay off debts and household bills accumulated through being unable to work.

**Assessing Carers Allowance is relatively unproblematic.** The main issues we encounter are when people have not been awarded a qualifying benefit (ie. PIP or DLA).

## **Response to inquiry workstream b) Universal Credit and DHPs**

The overlap between ESA and PIP claims and assessment is substantial and it would be in the interests of developing a coherent and more person-centred system for the Scottish Government to take control of both benefits.

## **Response to inquiry workstream c) Work Programme and Work Choice**

We have come across examples of people who have been told, incorrectly, that they must look for and apply for jobs whilst in the work-related activity group. This type of pressure is unhelpful and counter-productive.

We detect a need for more tailored, individual support from professionals who have an understanding of the impacts of M.E. and its fluctuating symptoms. Action for M.E. is currently piloting an employment support programme for people with M.E. in Bristol. We would be happy to share the results of this pilot following a review.

Suggested ways of helping people with M.E. to remain in, or access, employment include: greater support (including mentoring) for people managing illness in the workplace; transitional support for people moving between education, training and work; greater access to flexible working arrangements; adaptations to increase effectiveness of working from home; removal of punitive sickness absence policies; health sabbaticals; more gradual/longer phased return to work arrangements.

In our 2014 survey, 33% of respondents with M.E. were in full or part time paid work, education or training. 40% said they did not receive any specialist support at work, school or college. Many people with M.E. actively want to work, and health practitioners as well as people with M.E. tell us about pushing themselves very hard, whilst giving up social and other activities in attempting to remain in work.

People often say the current system puts unhelpful stress on them, making recovery even harder. There is a feeling that benefit income security would help people to focus on their health with the aim of – where possible – returning to work within an appropriate timeframe. The threat of losing benefits and stress of the current system is undermining instead of supporting recovery.