

DWP Ministerial Meeting – 18th June 2019 (WC = 1937)

**Meeting at the House of Commons on Tuesday 18th June 2019 with Justin Tomlinson MP, Minister of State for Disabled People, Health and Work to discuss problems faced by people with ME/CFS when claiming Employment and Support Allowance (ESA) and Personal Independent Payment (PIP)**

**Report prepared by Dr Charles Shepherd with additional input from Ann Innes**

**Present:**

Justin Tomlinson MP - Minister of State for Disabled People, Health and Work  
DWP civil servants responsible for ESA and PIP

Carol Monaghan MP

Katherine Ladd (Researcher for Carol Monaghan)

Countess of Mar

Dr Charles Shepherd - Hon Medical Adviser, MEA

Ann Innes - Welfare Rights Adviser, MEA

**Background to the meeting**

This meeting was arranged to take forward points and concerns about DWP benefits that were raised during the House of Commons debate on ME/CFS that took place in January 2019 and was led by Carol Monaghan MP.

As part of the information gathering process for the meeting people were asked on social media to contact either Carol Monaghan or the MEA with problems they are facing with claims for ESA or PIP. Over 500 emails and social media comments were received. Key points were then summarised by the MEA and by Katherine Ladd, Carol Monaghan's research assistant, for use at this meeting.

Thank you to everyone who responded to this request for information. And to Carol Monaghan MP for securing this meeting, and to the Countess of Mar for all her continuing work in the House of Lords on DWP benefit issues as they affect people with ME/CFS.

As previously noted, there was not enough time to raise the often complex

individual problems that people are facing during the meeting. However, we did manage to cover a lot of ground during the meeting - which went on for longer than expected.

We also quoted from the section on Prognosis in the Chief Medical Officer's (2002) report on ME/CFS and from Professor Malcolm Harrington's first (2010) Independent Review of the Work Capability Assessment.

### **General information on ME/CFS in relation to DWP benefit applications**

During the course of the meeting we emphasised a number of important points relating to the symptoms and resulting disability that occurs in ME/CFS, many of which are not being taken into account during medical assessments for ESA and PIP. In particular:

1 The core symptoms of ME/CFS - activity-induced muscle fatigue and pain, cognitive dysfunction/brain fog, the inability to sustain physical and mental activity, and the resulting post-exertional malaise/symptom exacerbation if people go beyond their physical and cognitive limitations. The latter being important because claimants should be able to carry out descriptor tasks without any significant after effects.

2 The way in which ME/CFS symptoms often fluctuate throughout the day and from day to day - so 'snapshot' conclusions as to what someone can do once, or on a good day, are both inappropriate and inaccurate.

3 Many of the descriptors used in medical assessments for ESA and PIP do not measure or reflect the impact that the core symptoms of ME/CFS have on a person's capacity to carry out meaningful employment.

4 The need to ensure that people are asked by the medical assessors if they can carry out descriptor tasks reliably, repeatedly, safely and in a timely manner. If they cannot do so they cannot be scored as being able to do so.

5 Case law states that if someone cannot carry out a descriptor task for a significant period of time (ie more than an hour) within a day they should be considered as being unable to do that descriptor task for the entire day.

## **Specific points that were raised during the meeting**

We were able to raise a number of specific issues covering the whole claimant journey from filling in the application forms to going through reconsiderations and challenging a DWP decision through an appeal.

1 People with cognitive dysfunction often require help and extra time to fill in the long and complex paperwork when applying for ESA (ie the ESA50 form) and PIP. In particular, we asked for a two week extension period on request to the original return deadline limit for the ESA50 - in the same way that this applies for PIP. The DWP agreed to consider this relatively straightforward request. However, this is something that would have to be requested, if the DWP do decide to adopt our suggestion. The DWP pointed out that it should be possible to arrange a home visit from one of their staff to help to fill in forms such as the PIP and ESA medical questionnaires if this is requested.

2 People should be able to have a medical assessment at home if this is supported by their GP. Just because someone may be able to cope with a visit to a nearby GP surgery does not mean that they can cope with travel to and from a medical assessment centre for a detailed interview and physical examination that could last for up to two hours. More use of paper-based assessments should be made in cases where a GP can confirm that the person is severely affected and housebound as a result. We were asked to submit any cases where home visits or paper based assessments are refused without good cause.

3 It was pointed out that the medical assessors have a duty to make reasonable adjustments in assessment procedures (ie arranging a home assessment or terminating an interview/assessment when the person was clearly unwell or not able to properly answer questions). Failure to do so could be a contravention of the Equality Act.

4 Assessment centres must be suitable and accessible for people with mobility problems and/or are having to travel a long distance.

5 People with ME/CFS are often under no regular medical supervision - so it can be very difficult, or even impossible, to obtain supportive medical information in the time required.

6 People should not have to pay a GP to provide supportive medical evidence - evidence collected for the meeting indicates that this is quite

common and the charge can be up to £40. Medical evidence is also often ignored and the decision is based solely on the assessment report. In evidence collected for the meeting, it was clear that some reports bore little resemblance to what the person had said during the assessment.

7 Evidence from private healthcare professionals, other health professionals, and carers should also be considered.

8 Some medical assessors do not have an accurate or sufficient knowledge of ME/CFS. Training on symptoms, fluctuation and severity in ME/CFS is clearly required along with how this affects mobility, intellectual capacity, self-care and the ability to take on meaningful work. It was pointed out that members of the Forward ME group are involved with the preparation of professional development modules and other training initiatives

9 Cognitive dysfunction (ie problems with memory, concentration, attention span, information processing) can be a very disabling aspect of ME/CFS. However, most people find that they are awarded low or no points for descriptor tasks that involve some form of assessment of cognitive function.

10 Training on ME/CFS for DWP decision makers and members of tribunal panels was also raised. NB: Administration and training of tribunal members come under the Ministry of Justice

11 Medical reports still contain inaccurate or guesswork conclusions, or even dishonest information, especially for descriptor tasks that require specific information (eg walking distances). Note: This has also been brought to the attention of the DWP by the House of Commons Committee on Work and Pensions.

12 All claimants should be able to have their medical assessment audio recorded and facilities for doing so should be readily available - which is not the case at present

13 Re-assessments, which form part of the on-going review process, should be reduced in frequency where a person can supply medical evidence to show that their condition has stabilised for a period of years and that all appropriate approaches to management have been tried. Information on 5 year prognosis in ME/CFS from the CMO report was referred to here.

14 Some people with ME/CFS are now having to wait for a long period of time (in some cases over six months) between making an appeal and the appeal being heard.

14 The whole procedure can be very stressful, especially when a decision is being challenged, so some people just give up trying to obtain a benefit that they should be entitled to as a result.

## **Conclusion**

Both sides agreed that this had been constructive and useful meeting. The points we made were listened to very carefully and we felt that the Minister had been well briefed and was genuinely interested and concerned by what we had to say.

The DWP ministerial group requested that we forward any cases to them with names and national insurance numbers where the law around being able to carry out a descriptor “reliably” was not being taken into account.

A further meeting, this time involving representatives from the three organisations - Atos, Capita and Maximus - that carry out medical assessments for the DWP is now being arranged.

## **LINKS AND FURTHER INFORMATION**

### **1 House of Commons debate:**

<https://www.meassociation.org.uk/2019/01/parliamentary-debate-kids-being-taken-into-care-by-medics-who-refuse-to-believe-me-is-real-25-january-2019/>

**2 Pro forma PIP letter that has been written by Ann Innes. This can be used as an aid by health professionals in relation to the provision of supportive medical evidence:**

**Attach to email: (See note above from Ann giving permission to use and to add the MEA logo)**

### 3 Tribunal service stats on appeal rate success

Source: Benefits and Work website

Claimants are winning PIP and ESA appeals at the highest rate ever recorded, according to the latest Tribunals Service statistics.

Overall, 70% of social security appeals are successful, with the claimant getting a better award than they originally received from the DWP.

The success rates for benefits include:

- ∞ ESA 74%
- ∞ PIP 73%
- ∞ DLA 66%
- ∞ UC 58%

The success rate for PIP is up 4% on a year ago, whilst the success rate for ESA has risen 5%.

The number of appeals is down, however.

ESA appeals are down by 42% compared to a year ago, although much of this is due to the introduction of universal credit.

PIP appeals are also down, this time by 14% compared to a year ago. This may, in part, be due to a slow down in the transfer of claimants from DLA to PIP.

Overall, social security and child support appeals are down 19% on a year ago.

The time it takes for appeals to be dealt with is rising, however, in spite of a diminishing caseload.

The mean length of time for a case to be dealt with has risen to 30 weeks, up from 24 weeks a year ago.

#### **CS note:**

This high success rate on appeal for both ESA and PIP benefits indicates that it is well worth appealing against an unfavourable DWP decision if you believe you have a good case.

The success rate on appeal can be significantly improved by providing up to date and supportive medical attendance that is relevant to the claim and attending the tribunal in person.

Please seek advice from a welfare rights adviser to assess the strength of

your case as your whole award is looked at again at the tribunal, not just the bits you disagree with. So if your evidence / case isn't strong enough there is a risk to your existing award. If you have not been given an award, however, it is certainly worth appealing.

#### **4 Justin Tomlinson MP CV:**

**<https://www.gov.uk/government/people/justin-tomlinson>**

**Dr Charles Shepherd  
Hon Medical Adviser, MEA  
June 25th 2019**