Muscular Dystrophy Campaign – Response to the Personal Independence Payment Assessment: Independent Review: Call for Evidence

Introduction

1. The Muscular Dystrophy Campaign welcomes the opportunity to submit written evidence to the Department of Work and Pensions’ inquiry into Personal Independence Payments (PIP), and wishes to draw particular attention to the way in which the assessment procedure has affected individuals with muscular dystrophy and related neuromuscular conditions. We would also welcome the opportunity to discuss this with officials from the Department of Work and Pensions.

2. ‘Muscular Dystrophy and related neuromuscular conditions’ is an umbrella term used to describe 60, mostly genetic conditions that cause the weakening and wasting of the muscles. These conditions are serious and progressive, with effects that range from mild to severe disability and premature death, most typically in childhood or early adulthood. Approximately 70,000 people in the UK are affected by one of these conditions.

3. At the Muscular Dystrophy Campaign we help to support people affected by muscle-wasting conditions through the charity’s advocacy service, Information days and Muscle Group Meetings (information and support group meetings). Our advocacy service in particular, has helped to support a number of individuals through the Disability Living Allowance (DLA) and PIP process. We also attend Engagement Forums with ATOS and CAPITA.

Previous Involvement

4. The Muscular Dystrophy Campaign has previously worked closely with Baroness Thomas of Winchester to secure legal changes in regards to the assessment process and, in particular, the terminology used.

5. We have worked to ensure that individuals will be assessed on what they can do safely, reliably, repeatedly and in a reasonable time period.

Observations of Issues with the implementation of PIP

6. We submit below points on difficulties observed in the rollout of the PIP process, which have prevented individuals from receiving the necessary level of support to protect their health and safety, with case studies to illustrate.

Delays

7. One of the primary obstacles to a smooth delivery of PIP around the country appears to be the severe delays throughout the process - in the initial application (the sending out of PIP2 forms), assessment, award and appeal of PIP decisions.

8. In some instances, we have seen the process taking up to 9 months for a decision to be made. For example, two separate individuals in the West Midlands made applications in July 2013 and were still just waiting for an assessment in November. We have also observed a particularly significant amount of these cases in the East of England, particularly Norfolk and Suffolk (observed by neuromuscular care advisors
who we work closely with), and in the North East we have been informed that lead times ranged from anywhere between 10 weeks and six months. However, these problems have been seen all over England, Wales and Scotland. One young man, with an undiagnosed form of Muscular Dystrophy, got in touch with us after he submitted his application in the Spring of last year and was only contacted for further information in September.

9. When speaking with staff at the Department of Work and Pensions earlier this year, the delay has appeared to lie with the assessment providers (ATOS and Capita), mostly due to understaffing issues. Even once the assessment has taken place, we have been informed that, on average, it has been taking the assessment providers a minimum of 4 weeks for them to return the report. We are aware that ATOS have been increasing recruitment of health professionals in order to help to rectify this situation.

10. The Muscular Dystrophy Campaign is particularly concerned that some applications have been waiting significant periods of time to enter the system and receive any form of disability benefit. These individuals have not been in receipt of a DLA and are left without the vital support that they need to address their complex and often costly care and mobility needs.

11. A clear example of this, Laura, a 16 year old girl with Emery-Dreifuss and a very serious heart condition, could not get through to the PIP phoneline to complete the first stage of the application for a few days. She was sent the forms in October of last year, but was still waiting for an assessment in the beginning of the new year. She lives with her elderly grandparents who were struggling to help meet her care and mobility needs. As a result of these delays, it is clear that Laura’s quality of life and her health were being put at risk.

12. This means that some families and individuals will have to go significant periods of time without receiving adequate levels of care and are putting not only their physical health, but mental and emotional well-being at risk. Others, awaiting receipt of the mobility component – especially those who would qualify for the high rate and qualify for a Motability vehicle – have suffered significant restraints on their independence and ability to leave the house to go shopping to feed themselves and attend vital hospital appointments (many forms of muscular dystrophy have respiratory and cardiac complications as well, which need to be regularly monitored).

13. Sally, from Bradford, is a woman in her thirties with a form of Muscular Dystrophy. She was initially refused PIP. After our advocacy service helped her lodge a request for a mandatory reconsideration, she was then awarded the standard rate for the care and mobility components. However, Sally is virtually housebound without access to an adapted vehicle, which she would only be able to procure through the Motability scheme. She is unable to transport a mobility scooter or wheelchair in her current vehicle, which means she cannot travel independently to carry out daily activities such as shopping for food, or to pursue an active social life. This has had a significant impact on her mental health and she believes she is becoming depressed and has resorted to sleeping most of the day.

Cancellation/Rescheduling of Assessments
14. Unfortunately, in several cases across the UK, we have observed last-minute unexplained cancellations from assessors who come out to perform home assessments – inevitably leading to further delays in the process.

Dawn is a 44 year old woman with Facioscapulohumeral Muscular Dystrophy (FSH) from the North East of England. As with many people who we support, Dawn also has complex mental health and wellbeing needs. Dawn suffers from depression and anxiety to the point of which she cannot leave her home. Her condition has rendered the muscles in her legs weak and wasted and she cannot go outside for significant fear of falls. She is also coming to terms with her diagnosis and the progression of her condition, which makes it difficult for her to speak about her condition. It took Dawn great courage to be able to fill out the form, let alone agree to an assessment.

Jeremy, a young man with Limb Girdle Muscular Dystrophy (LGMD) from the West Midlands, contacted us after he had been waiting nearly six months to have an assessment. Jeremy had been contacted to arrange an assessment twice – both of which were cancelled at the last minute by the health professionals. Unfortunately, after the second cancellation, the assessors were unable to provide Jeremy with another date for an assessment and he was forced to wait several months more till they could finally carry one out.

Negligence (loss of files)

15. Heather, a woman from Wales in her early fifties with a severe form of Muscular Dystrophy, made an application in Spring of last year. She had an assessment in June, after which she regularly called to ask for an update on her application. Despite this, it was only in September that she was informed that her files had been lost and she would have to carry out another assessment. Heather, has various health complications, including suffering from heart complications to incontinence. She, like many others with muscular dystrophy, fatigue quickly, and the first assessment had already taken quite a toll. However, with no other choice, she underwent another assessment in the Autumn of last year. Nearly a year later, she is still waiting for an outcome. However, Heather is not alone – we have heard of several other cases in which the records appear to have been lost.

Inaccurate Assessments and Impact on Motability

16. As mentioned above, we have more recently observed cases in which first-time applicants with high mobility needs who would require a mobility scooter or adapted vehicle have been inaccurately assessed and refused the enhanced rate of PIP. However, we are also now observing cases in which individuals who formerly received the high rate of DLA have been awarded a lower rate of PIP, meaning that their Motability vehicles have been taken away.

17. For example, Emily, from Berkshire, is a young lady in her twenties with Minicore Myopathy, an extremely rare condition that she was diagnosed with from birth. Emily had been receiving DLA for most of her life. She received a letter asking her to be reassessed under the new PIP guidance last year. However, in August of last year, the decision was made to award Emily the standard rate of mobility under PIP, which meant that her Motability scheme would be stopped and she would have to return her adapted vehicle. Motability gives individuals a period of seven weeks to return the
vehicle or buy it if they so choose after such a decision is made. This is to allow time to request a mandatory reconsideration and appeal the outcome if it is still unfavourable. Unfortunately, Emily has been trying to appeal the decision with no luck since last August and so has had to return her car to Motability. This has put very strict limitations on her independence as she relied greatly on her car for mobility. She is unable to leave the house to pay bills, go to the bank, do her shopping and/or visit friends and family without this.

**Assessments: Inappropriate Conduct and Inaccessibility**

18. There have been complaints over staff not knowing anything about the conditions and therefore treating patients inappropriately. This has included inappropriate requests and handling such as attempting to force people to stand and inappropriate comments.

19. We received one complaint about an assessment centre not being accessible. A young lady with Muscular Dystrophy was invited to a face-to-face assessment in Basildon and was sent home because she could not access the assessment centre. Her assessment was then rescheduled as a home visit. However, as a result, the whole process was pushed back another 3 months.

**Issues with Further Medical Evidence**

20. In 98% of cases in which ATOS assessors have tried to contact GPs etc. to get further medical evidence they have been unsuccessful and a face to face assessment has been made necessary.

21. For those listing multiple conditions, further medical evidence must be submitted for each condition – this is even if they would easily qualify for just one condition. This has caused difficulties and delays in processing the application for people who require a very high level of support.

22. This inability to secure the information/medical evidence needed has led to calls for face-to-face assessments where it is inappropriate/highly stressful for the patient. It has also exacerbated the problem with delays.

**Key Points**

23. To conclude, the key concerns which we have observed with the delivery of PIP have been in:

   a. Delays, caused by several factors, such as understaffing, negligent handling of documentation, and the cancelling and/or rescheduling of assessments

   b. Difficulty in obtaining further medical evidence

   c. Inappropriate attitudes towards claimants

   d. Inaccurate assessments having an impact on other benefits and Motability