

# Richmond & Kingston



## M.E. Group

Serving Richmond & Kingston Boroughs & the surrounding areas

### **Response to PIP (Personal Independence Payment) Consultation**

Richmond and Kingston ME (Myalgic Encephalomyelitis) Group is a self help group supporting around 140 members with ME in the boroughs of Richmond and Kingston and the surrounding areas. We are already familiar with stress and relapses amongst our members as a consequence of the constant reassessments involved in ESA. One of our members writes, *"The stress levels of my receiving zero points at my second medical, was high, knowing that I will have to face the whole process all over again - I would go as far as to say Post Traumatic Stress - having to re-live a needless exercise of appealing which drags on for months. The Appeal was submitted in March and I've been told it could be September to October perhaps longer for my Appeal"*

ME is a long term chronic disabling condition – sadly people who have been housebound for years are unlikely to recover sufficiently to go back to work over a period of 3-6 months. We are responding to this consultation despite our very limited energy levels in the hope that the proposed PIP scheme will prove better at assessing the levels of disability amongst our members.

### **Questions 1 and 2 Daily Living Activities**

The descriptors listed for Daily Living Activities do not at present reflect the difficulties people with ME have in completing activities because of fatigue and pain. For example, in Activity 1 preparing food and drink , sometimes if I prepare a meal I will be so tired because of the physical effort involved, that I may not have the energy to sit up and eat it afterwards. Fatigue has a knock on effect therefore from activity to activity. Another example: if I wash my hair I would not be able to also cook a meal the same afternoon. Physical effort can result in mental fatigue. For example, if I do too much physically carrying out Activities 1 and 2, I will suffer from cognitive difficulties (brain fog) and may forget to take medication or forget to lock the door or switch off appliances.

Fatigue and pain mean therefore that we cannot carry out the particular activity repeatedly or safely.

We suggest therefore that an additional descriptor is added to each activity saying "*Cannot [carry out activity] without severe fatigue/and or pain.*"

We would suggest that such a descriptor should carry 4 points for each activity.

### **Questions 3 and 4 Mobility Activities**

Again it is important to realise that physical *and* mental fatigue can follow from physical exertion so there is an overlap between the two mobility activities for someone with ME. For example, one of our members is unable to leave the house unaccompanied because cognitive difficulties mean he is unable to remember where he was going or how to get home. Another member says " { I } *become exhausted quickly, and also the neurological problems e.g. high sensitivity to sensory input (noise, light) and memory loss and confusion means I can't go out of the house alone.*"

For Activity 11 again a descriptors which say *Cannot move at least [200/50/up to 50/at all] without severe fatigue and pain* should be added and awarded similar points as descriptors BCD or G depending on the distance pain and fatigue set in.

Because I am unable to walk more than 50 metres repeatedly, safely, and reliably without using a wheelchair propelled by another person or a motorised wheelchair I think the weighting of 15 points for this descriptor is correct. People with ME cannot use manual wheelchairs propelled by themselves as our arm muscles are as weak as our leg muscles. The cost of buying, and maintaining a powered wheelchair which is essential if I am to lead an independent life is currently met by my DLA mobility component and this needs to be continued in future or I will be housebound.

### **Question 6 Fluctuating conditions**

ME is a fluctuating condition which can vary unpredictably from hour to hour, day to day month to month or year to year. While we recognise that the PIP proposals are trying to take account of fluctuating

conditions we foresee a number of problems in the way this is being applied:

1. Asking claimants to measure their condition over the period of a year is very difficult because of the unpredictability (relapses can follow viruses, family emergencies, unforeseen stressors and so on) Also the cognitive difficulties facing people with ME for example short term memory loss, mean keeping such records would be a herculean task and totally absorb our very limited energy supply.
2. Even if on average a person with ME only needs money to provide for care or, for example, taxis because of limited mobility for less than half the year this help still needs to be paid for. Providing support during relapses can prevent the condition spiralling downwards so that less and less can be done by the person themselves which in the long term is self defeating and will cost the benefit system more.

**Question 7 What are your views on the definitions of ‘safely’, ‘timely’, ‘repeatedly’ and ‘ in a timely’ manner?**

These definitions are vital if the problems encountered by people with ME are to be fairly assessed under PIP. People with ME can often do an activity once, for example I may be able to iron one shirt or I walk around the house on a good day but be unable to do the activity repeatedly without severe post exertional fatigue and pain. We would argue therefore that these terms should be included in the regulations preferably as part of the descriptors for each activity so that they are legally binding. Again this will save money long term. If assessors are constantly aware that the claimant needs to be able to carry out each activity safely, reliably, repeatedly and in a timely manner there will be less need for expensive and time consuming appeals.