Myasthenia Gravis Association
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MGA Response to DWP Consultation on the PIP assessment *Moving around* activity

About Myasthenia and MGA

There are three main types of myasthenia, all characterised by fluctuating muscle weakness. **Myasthenia Gravis (MG)**, the commonest, is an auto immune disease, where the body's immune system, in the form of antibodies, attacks and damages the nerve signal reception areas on muscle, causing a breakdown in communication between the nerve and muscle. **Lambert Eaton Myasthenic Syndrome (LEMS)** results from a similar autoimmune attack directed at the nerve endings in both voluntary and 'automatic' muscles. **Congenital Myasthenic Syndromes (CMS)** are genetic disorders affecting transmission of messages from nerves to muscles, usually with symptoms from the first years of life.

The myasthenias are associated with varied disability, ranging from mild to severe muscle weakness, which in some cases may involve the breathing muscles. For some patients effects are limited to droopy eyes, double vision and blurred speech, but others suffer more general weakness significantly limiting their ability to reliably stand, walk and get around. If untreated MG is dangerous or even life threatening. When breathing and eating are affected the result can be a medical emergency and hospital admission.

Myasthenia Gravis Association (MGA) is a registered charity established in 1976 with three objectives: care; research and education. Membership of the association for people with myasthenia and their families brings peer support, friendship and information. A network of local and special interest branches are supported by Regional Organisers to reduce the isolation and fear often associated with this debilitating and rare disease. In some areas MGA funds specialist nurses. The Association provides financial support for medical research and runs education programmes to increase awareness of myasthenia amongst medical professionals and the general public. We employ a benefits advisor who provides telephone, on-line and face to face advice to our members.

Response to the Consultation

- We understand that the criteria includes *'no more than twice as long as the maximum period that a person without a physical or mental condition which limits that person's ability to carry out the activity would normally take to complete that activity'*. Have standards been set for *'a reasonable time period'* for regular activities such as walking over the given distances of 20, 50, 200 and over 200 metres and will these be published? Alternatively, what is considered to be a normal walking speed? We would also welcome clarification if the assessment is over a smooth and level surface and if so, will difficulties walking on gradients or rough ground be taken into consideration?
- As myasthenia is a condition characterised by extreme fatigue the assessment of *'Repeatedly – as often as the activity being assessed is reasonably required to be completed'* is of particular interest to our members. Will the assessment will be able to consider for example, that a person with myasthenia may be able to stand satisfactorily and unaided for only a limited period of time without falling? Will a time be stated in the assessment criteria for how long someone should be able to stand in a full upright position without assistance or the use of an aid?

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- As myasthenia is a variable condition, we are interested in the assessment criteria in this area. We understand that the criteria may consider a % of time that a person is able to reliably compete the moving around activities. Will this % be set and if so, will it be shown as part of an average day, week, month or year? A typical person with myasthenia may be able to meet some of the moving around criteria some of the time. For example, some are better in the morning than in the evening; others experience reduced symptoms following medication – this could be on a daily basis or it the person is being treated with IvIg or Plasma Exchange on a monthly or quarterly basis. Extremes of weather also have a significant effect on whether or not many people with myasthenia are able to move around or not.