

DWP consultation on the PIP assessment 'moving around' activity

From: Chartered Society of Physiotherapy

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1. About the CSP

- 1.1 The Chartered Society of Physiotherapy (CSP) is the professional, educational and trade union body for the UK's 51,000 qualified physiotherapists, physiotherapy students and support workers. 97% of physiotherapists working in the UK are CSP members.
- 1.2 Physiotherapy enables people with disabilities to move and function as independently as possible, optimising quality of life, physical and mental health plus well-being and social participation. With a focus on quality and productivity, physiotherapy puts meeting patient and population needs, selection of appropriate clinical outcomes and enhancement of the patient experience at the centre of all it does.
- 1.3 Physiotherapy has a key role to play in care for people who live with disability resulting from a range of conditions including stroke; multiple sclerosis (MS) and other inflammatory diseases; Parkinsonisms and other neurodegenerative conditions; chronic obstructive pulmonary disease; arthritis; musculoskeletal disorders; lymphoedema; asthma; mental health; and chronic pain.
- 1.4 CSP's membership includes clinical specialists working with patients with these conditions and their carers. The evidence we submit draws on this expertise and the CSP is particularly indebted to members of the two CSP professional networks; the Association of Chartered Physiotherapists working with Older People and those with Long Term Conditions (LTC) living in the community (AGILE) and the Chartered Physiotherapists Interested in Neurology (ACPIN). We would be pleased to supply additional information on any of the points raised in our evidence at a later stage.

2. Summary of CSP response

- 2.1 The CSP welcomes the recruitment of healthcare professionals into the PIP disability assessor role and the enhanced quality of assessments that this should produce.
- 2.2 The profession has considerable experience in working with people of all ages and across a spectrum of diagnoses, observing and contributing to how they manage lifestyle changes in order to retain independence, social status, family and community engagement and workability where possible.
- 2.3 The main points that we wish to make in response to this consultation are:
- The CSP calls for the 50 metre distance criterion to be reinstated for the enhanced mobility component;
 - The CSP believes that disability claims should protect those who have mobility limitations but strive to maintain their walking ability;
 - The reduction of the test distance 50 to 20 metres will force more to
 - adopt wheelchair use and will increase the rate of their progressive disability.
 - incur secondary effects of immobility sooner, such as contractures, pressure sores and respiratory tract infections
 - increase the need for full time carers
 - increase social isolation and dependence.

3. Reducing payment entitlement to only those technically non-ambulatory

- 3.1 The CSP acknowledges the requirement to develop some method of category for mobility and that a mobility limit of 20 metres identifies an individual as functionally non ambulatory (as described by Kurtzke JF(1983) *Rating neurological impairment in multiple sclerosis. An expanded disability status scale (edss)* Neurology, vol 33 no 11 pp. 1444 – 52).
- 3.2 However, the reduction of enhanced payment entitlement to only those who are technically non-ambulatory is detrimental to all those struggling to achieve 50 metres to meet national ambulatory guidance standards such as those followed by the Department of Transport and Blue Badge Scheme.

- 3.3 The CSP believes that disability claims should protect those who have mobility limitations but strive to maintain their bipedal (on their feet) mobility despite their limitations: we know that those who remain on their feet as much as they can will maintain fitness and often in turn reduce the rate of progression of disability.
- 3.4 Those who are able to receive disability assistance including a blue badge to reduce the daily demands on mobility tend to opt to use a wheelchair only intermittently compared with those who are forced to adopt full time wheelchair use. For many, the line between maintaining mobility and managing fatigue is a delicate balance. If the test distance is decreased from 50 to 20 metres many people face the slide to reduced independence as they:
- will be excluded from obtaining assistance in their efforts to remain ambulatory;
 - will be forced to adopt wheelchair use sooner;
 - will inevitably increase the rate of their progressive disability;
 - will incur the secondary effects of immobility sooner, such as contractures, pressure sores and respiratory tract infections;
 - will need increasing time from carers.
- 3.5 At least 50 metres gives the ability to cross a road, get from parking spaces to scooters, and for some access public transport. Without this distance, independence and the ability to maintain a working life is put at risk.
- 3.6 The CSP welcomes the recognition of those with lower limb amputation as automatically qualifying for the enhanced mobility component based on their inability to place two biological feet on the ground.

4. Impact of changes on people with long term conditions

- 4.1 A further consideration for people with LTC is the impact on their deteriorating health on their mood and motivation, depression being diagnosed in at least 20% (often as high as 50% of people with a LTC). For a person prone to low mood and apathy as a consequence of their medical condition, a further barrier imposed on mobility may lead to both decline in physical and mental state, either of which have financial and resource implications to the Government.
- 4.2 Ensuring the promotion of independence and retention in work, preferred lifestyle and social interaction for people living with disability is the philosophy behind personal independence payments. All these positive impacts of PIP support serve to

retain social status and inclusion and prevent the decline of mental resilience described in 4.1.

- 4.3 To reduce access to the enhanced mobility component, by lowering the 'moving around activity' criterion from 50 metres to 20 metres however will risk increased demand on services. For example, additional resources will be required through health and social service shared equipment stores that provide adaptive aids or mobility devices such as walkers, wheelchairs, scooters.
- 4.4 There will be an impact on the informal services of carers required to give more of themselves to maintain the independence of the individual, especially with the possibility of the increasing difficulty to qualify for motability eligibility and carers benefits.
- 4.5 This could have a negative impact on the individual's health and well-being in terms of their ability to conduct activities necessary to an independent lifestyle e.g. occupation-related needs; daily living activities such as being able to shop and carry groceries for themselves; restriction of attendance at meetings, such as Parkinson's UK Branch meetings where they gain education and support, plus the stress of a challenging situation in addition to the challenges they are already coping with as a consequence of a disability-causing diagnosis.
- 4.6 In short, the DWPs attempt to reduce costs related to disability claims will have a catastrophic impact on those with long term progressive conditions, such as those with ataxia, and that this will result in higher NHS, societal and productivity costs incurred in the longer term.

5. Disruption will have financial and personal implications for people with disabilities, their families and their carers

- 5.1 The changes proposed to the PIP assessment will disrupt many people's established lifestyles and preferred methods of transport, communication and work. This can have financial and personal implications for people with disabilities, and for their families, carers and even employers.

6. Neurological conditions

- 6.1 For people with a degenerative neurological or inflammatory condition such as Parkinson's or MS, the issue is not about the ability to manage a set distance, but the summative effect of functional or recreational use of that distance. For example, a

person on optimal dose of Parkinson's medication, or after a period of rest with MS may be able to manage 20 metres on assessment thus disqualifying them for the proposed PIP, however, once they have completed the shopping, the hospital clinic appointment (notorious places for poor parking availability), their situation due to elements of fatigue or body response to utilising medication can severely impact on mobility.

- 6.2 Should people post stroke be penalised for persevering to walk greater distances than 20 metres, then it may disincentivise community ambulation- which it could be argued will impact Quality of life and mood.

7. Cardio-respiratory conditions

- 7.1 With reference to the assessment and scoring of the mobility component; many people find that their limited ability to walk is not always aided by the use of an aid or appliance, for example those with claudication, chronic obstructive airway disease, asthma and other associated conditions. These people can score a maximum 8 points whilst those in the same position but using an aid can score 10 points. Shortening the walking distance for these people will again put them at risk of social isolation and a possible slide into immobility.

8. Definition of timely

- 8.1 The PIP process allows disability assessors to consider an individual's ability to undertake everyday activities when preparing their report, which is then used by the DWP to determine entitlement to benefit. However, the way in which the descriptors are presented means that an individual who agrees when asked if they can walk more than 20 metres but less than 50 metres unaided will now only achieve 8 points, putting them at high risk of not qualifying for enhanced disability status.
- 8.2 Many people post-stroke recover independent walking but most at speeds in the community with substantial limitations. So 50 metres may be possible but for most it will be at a significantly reduced speed. The experience of community walking has been shown to substantially improve quality of life and function at whatever distance and speed.
- 8.3 The definition 'timely' should therefore be supported by guidance on timeliness. A measure of time or physiological cost needs to be considered in the assessment to take account of fatigue levels following a walk, on the ability to undertake the planned activity on arrival at the chosen destination.

- 8.4 There are functional ambulatory measures with good evidence showing validity and reliability which may be considered for PIP assessment tools.

10. The test distance – key factors

- 9.1 Observation of an individual's mobility in a home or clinic environment cannot replicate typical outdoor public environments that people with disability have to contend with; uneven ground, slopes and different textured surfaces without the availability of hand holds. For this reason, the proposal to assess physical mobility in a different way altogether for this category of conditions would be more ideal. If not, clearer guidance for assessors to achieve a more consistent measurement of mobility regards disability.
- 9.2 The test distance should represent the mean distance that people with a blue badge need to mobilise to get from their form of transport to the intended destination (for example from current designated blue badge parking spaces to a post office counter, hospital parking to clinics, medical and dental centre access) in order to ensure participation in society, to maintain societal roles and to avoid ostracising those with disability.
- 9.3 The current advice from the Department for Transport that public area seating be 'provided at intervals of no more than 50 metres' is clear indication that the 50 metre mark is recognised as the maximum distance an individual with a mobility disability can be expected to walk (Department for Transport (2002) *Inclusive Mobility: A Guide to Best Practice on Access to Pedestrian and Transport Infrastructure*, DfT 2002 pp. 13).
- 9.4 50 metres remains a fairer test of a person's ability to meet these required distances but in reality even this is a gross underestimate of the demands on mobility to maintain participation.
- 9.5 The revised activity criteria mean that a person who has previously managed to maintain a limited level of independence including walking up to 50 metres may now be penalised and lose the benefits dependent on the enhanced mobility component. Loss of the enhanced mobility component will have implications for community access and social engagement, which should be given high priority consideration in this review.

The following factors should be taken into account:

- A patient who can only walk 20–40 metres is unlikely to be able to reach a local bus stop.
- The enhanced rate means that people have independence and choice and reducing the distance to 20 meters means many won't be able to keep their motability cars and may mean this is no longer viable as an option
- Such individuals without access to a car or mobility scooter may be effectively housebound.
- Similarly, an individual unable to achieve 50 metres on a regular basis may find it difficult to walk from a bus stop to social environments such as supermarkets and clubs.

9.6 The risk of knock-on effects on carers' entitlements and Motability eligibility through the 'demotion' from the enhanced to the standard mobility component will also have drastic impacts on social interaction.

10. CSP proposals

- 10.1 The CSP therefore calls for the 50 metre distance criterion to be reinstated for the enhanced mobility component.
- 10.2 Should the 20 metre limitation be retained, the CSP calls for clearer guidance to be developed in order to enable true and consistent reflection of mobility, leading to correct assessment of need and entitlement to PIP.

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