

## Adult Disability Payment: Review of the Mobility Component

### Scottish Government

April 2023

This is a submission prepared by About Dementia, Age Scotland's Dementia Policy and Practice Forum on the Scottish Government's consultation on the review of the mobility component within Adult Disability Payment regulation. About Dementia have not consulted on section 4 of the review, however, we echo the views within Age Scotland's response on the matters held within section 4.

#### **Section 1: the moving around activity**

##### **1. Do you agree or disagree that the moving around activity criteria for Adult Disability Payment are easy to understand?**

Agree/Disagree/Don't Know

##### **1(a). Please give reasons for your answer, outlining which parts you think are easy or difficult to understand and why.**

Whilst we understand the need for a somewhat objective and means tested criteria, the test fails to account for fluctuations in a person's ability to walk 20, 50 or 200 metres from one day, to the next. Additionally, mobility needs a person may have in daily life are often not comparable with these tests. For example, those living with vascular dementia may find great difficulty in getting up from sitting to stand, but once up may be able to walk somewhat steadily. Similar variation in an individual's mobility can be found in Lewy body Dementia, which often impacts co-ordination, causes shaky hands, and stiff muscles. We do not believe that the current moving around criteria reflects a person's full daily movement. Before being able to access an individual's ability to walk 20 metres, consideration around the individual's ability to arrive at the 'test sight' location should be studied. The individual will have had to navigate getting up, leaving the house, locking the door and potentially navigating stairs or pavements before being able to walk the distance. Every step and potential barrier up to the point of the 20 metre assessment space must be considered to provide a representative overview of an individual's ability to move around.

Furthermore, and as highlighted within the consultation document itself, assessors will often see people on their best days or, at the assessment, people feel the need to try their best to carry out tasks well. Due to dementia's fluctuating nature an individual, especially someone

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living with vascular dementia, may experience days of severe imbalance and weakness or tremors within their limb. If this is not captured on the day of assessment a person may miss out on eligibility. We would urge that the guidance considered inserting a question around whether an individual would be able to carry out this test well on any given day. If the answer is no, the individual should be given an opportunity to explain what their ability would be on a 'bad day'.

### **3. How effective do you think the moving around section of the application form is at helping us understand a person's mobility needs? Please give reasons for your answer**

Very effective/effective/**somewhat effective**/not very effective/not effective at all

As alluded to above, the current criteria does not factor in a person's changing ability depending on the day of assessment. A metre measuring system is also not an accurate representative indicator of a person's daily life. Additionally, points systems to measure ability, as well as the imagery included in the application form are subjective measures which could be clearer. There must be careful consideration between objective and subjective guidance for assessors. It would be unfortunate for an individual to lose their allowance based on the subjective opinion of the assessor, who may not consider fluctuating day to day ability or who may score more harshly than a fellow assessor. That said, we are acutely aware that PIP has previously been criticised for being too rigid and not providing enough flexibility for assessors. The guidance needs to better define and give scope for assessing fluctuating impairment, this should consider an individual's mental wellbeing as a fluctuating factor as well as their physical ability to move.

### **4. What impact do you think the changes to how we make decisions on the moving around activity have on understanding a person's mobility needs?**

We support the positive shift in guidance around the collection of further supporting information on an individual before a decision is made. Information from a GP or a support worker may work to provide a more well-rounded view of an individual's needs. Additionally, the inclusion of equal consideration given to information from a person's family, carers, or friends weighing into the application decision is a positive move to recognise the knowledge unpaid carers and family members may have about a person's needs.

### **5. If there was an opportunity to change the moving around activity criteria, what changes would you make (if any)?**

In conjunction with Age Scotland, About Dementia continues to support calls from the MS Society, Inclusion Scotland, and other disability organisations for the removal of the 20 metre rule within the moving around activity criteria.

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Though it exists due to its ‘objective’ nature, measuring a person’s overall mobility based on the distance they can walk is often not a good indicator of ability. It fails to consider a person’s strength or ability in other areas of life. Additionally, the ability to walk 20 metres is not a direct indicator of independence, as the criteria does not factor in an individual’s geographical location. Those living centrally at the top of a hill with a bus stop 10 metres from their door may be far more able and independent than someone who lives at the bottom of the hill with the bus stop 50 metres away. The lack of consideration for terrain or any unexpected changes to the environment limit the effectiveness of this criteria.

Whilst a primary focus for ADP must be to ensure a safe and secure transition of PIP and DLA claimants to the new system, we urge the removal of this eligibility measurement. A more flexible criteria which considers a person’s ability to move around their own home, local area, and other places they may need to go is encouraged.

**5(a). If you proposed changes, what positive impacts could these have, and for who?**

Considering an individual’s fluctuating needs, by reshaping the current criteria, would make a real difference to the health and wellbeing of many disabled people, particularly those living with fluctuating conditions.

**Section 2: the planning and following journeys activity**

**6. Do you agree or disagree that the planning and following journeys activity eligibility criteria is easy to understand?**

Agree/Disagree/Don’t Know

**6(b). How could we make the planning and following journeys activity eligibility criteria easier to understand?**

While we would agree that the current criteria is easy to understand on a very basic level, lack of clarity around language is where confusion may lie. In line with Age Scotland, we would suggest the phrase “overwhelming psychological distress” would benefit from a clearer definition. Given ‘prompting’, ‘supervision’ and ‘assistance dog’ all have clear further definitions within the application, it seems out of place that ‘overwhelming psychological distress’ has not been defined.

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Within 'Dementia and the Outdoors Guidance Note' designed by Paths for All, in partnership with dementia friendly walking, there are several principles to be considered, which will influence a person living with dementia's ability to plan and follow journeys. Familiarity of environment, legibility of environment and distinctiveness of environment to the individual being assessed will impact on their ability to navigate the surroundings (Paths for All, 2019). We urge that guidance is provided within the criteria to make assessors aware of this. A person living with dementia may be able to positively score on this part of the criteria if they are tested in an area which they feel they are familiar with, but that ability to plan and navigate journeys may be limited to a very set route. Assessors must be made aware of these factors in order to fairly assess the person living with dementia.

Further consideration should be given to whether or not the area of assessment is rich in signage and symbols. A person living with dementia may feel comfortable for example making their way to the supermarket because signage to that location is clear, frequent, and legible. However, they may not be able to independently navigate their way to the GP surgery, for example, because there is a lack of signage. Providing assessors with more guidance in relation to what may impact a person living with dementia's ability to navigate routes not only in relation to familiarity, but to signage should be considered.

While the guidance does contain the option 'cannot follow the route of an unfamiliar journey without another person, we would advise greater clarity on the definition of an 'unfamiliar route'. We also recommend that the criteria considers including the following question:

- Can the individual follow a route (familiar or unfamiliar) without signage?

## **7. Are there any other issues with the planning and following journeys activity that we have not captured above?**

Yes/No/Don't Know

### **7(a). If you said yes, what other issues with the planning and following journeys activity do you think need to be considered?**

Consideration for changes to the built environment should be given. Uneven pavements, temporary bus stops, road maintenance work or dropped kerbs, can also impact people's ability to plan or follow a journey. For those living with dementia, planning alternate routes, or encountering obstacles may be obstacles in an individual ability to navigate and follow journeys. Additionally, a person living with dementia may be able to follow a specific familiar journey once en route, however, when asked to describe or articulate said journey the individual may be unable to. The criteria should consider these variables and further consider

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the challenges people living with dementia, or cognitive impairment may face when relaying information.

We may suggest the following question be added to the criteria:

- Can the individual communicate and consider an alternative route to their destination, should an obstacle arise while following the intended route?

## **10. If there was an opportunity to change any specific aspects of the planning and following journeys activity, what changes would you make (if any)?**

Descriptors within the eligibility criteria continue to read as more relevant to an individual with physical disabilities. Wording or descriptors which better reflect the needs and challenges of individuals with mental health conditions and other impairments including dementia are encouraged. As alluded to, providing a clearer definition of “overwhelming psychological distress” could help with this.

## **Section 3: support for people with fluctuating conditions**

### **14. Thinking about the changes we have made to how we make decisions about fluctuating conditions, what impact do you think this is having on understanding the impact of a person’s fluctuating conditions?**

**Significant positive impact/a positive impact/neither positive nor negative/a negative impact/significant negative impact**

About Dementia continues to advocate for a person centred approach to social care. We support a move towards a more individual approach when considering fluctuating conditions. We are particularly encouraged by the following: *‘people are not asked unnecessary or repeated questions, nor are they rushed into giving an account... practitioners take the time necessary to fully understand the impact of a disability/or health condition’.*

Those living with dementia, as outlined above, may have good days and bad days, but may also find answering questions challenging. Guiding assessors to allow an individual a good amount of time to process the question being asked is a positive addition to the application process, which we welcome. The difficulty comes in ensuring these elements are followed through to become a norm and a reality.

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**15. If there was an opportunity to change any specific aspects of the fluctuating conditions criteria, what changes would you make (if any)?**

In line with Age Scotland's response, we believe that criteria and questions should focus more heavily on a person's symptoms on a bad day, rather than symptoms on a good day. If people have more than one condition, how their different conditions impact each other should also be considered.

The impact of this change may encourage individuals to be more forthcoming about the reality of their condition, if the questions directly ask about symptoms of a bad day individuals may be more willing to disclose difficulty, whereas if questions only point to good days, individuals with a stoic nature may downplay the challenges they face in order to fit the questions.

**Section 4: other considerations.**

We echo the views of Age Scotland within this section. Please look to their response for opinion.

**References**

Paths for All, Dementia Friendly Walking (2019) 'Dementia and the Outdoors Guidance Note'  
<https://www.pathsforall.org.uk/resources/resource/dementia-and-the-outdoors-guidance-note> (Accessed: 20/04/2023)

## Want to find out more?

As Scotland's national charity supporting people over the age of 50, Age Scotland works to improve older people's lives and promote their rights and interests. We aim to help people love later life, whatever their circumstances. We want Scotland to be the best place in the world to grow older.

Our Policy, Communications and Campaigns team research, analyse and comment on a wide range of public policy issues affecting older people in Scotland.

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About Dementia: Shaping Our Worlds Together, launched in April 2019 and is Scotland's forum for improving lives. It is hosted by Age Scotland and funded by the Life Changes Trust.

We bring together people affected by dementia, and organisations who are interested in working for change, to look at how we can improve policy and practice across many different areas of life.

About Dementia believes that people affected by dementia, including people living with dementia, and unpaid carers, are in the best position to say what is and isn't working and how to do it better.

### Further information

Contact the Age Scotland Policy, Communications and Campaigns team:

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