

What are your views on the *Moving around* activity within the current PIP assessment criteria?

Briefing for: Department for Work and Pensions
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Date: 05 August 2013

Macmillan's response

Key points

- As of November 2012, there were 77,960 people with cancer in receipt of higher rate mobility under Disability Living Allowance. Macmillan is concerned that the introduction of a 20 metre measurement may be too high a threshold for many people with a variety of conditions who were previously considered the most in need of support.
- Cancer is expensive – the enhanced mobility rate is one way for cancer patients to offset the huge cost of travel to and from and parking at hospital appointments. If a claimant has high mobility-related costs but 'fails' the 20 metre threshold, it could be argued that PIP's policy intention has not been realised.
- Cancer and its treatment result in mobility needs, such as pain, fatigue and breathlessness, that can have long-term physical impacts, and which can impede someone's ability to move 'safely, reliably, repeatedly and in a reasonable time period'. The assessment criteria should take account of these factors, rather than focusing narrowly on a short 20 metre distance.
- Recognising the Department's intention to proceed with a distance-based assessment criteria as a proxy for mobility needs, rather than other factors such as incurring the greatest costs, **Macmillan calls on DWP to use a 50 metre qualifying distance as outlined in previous PIP draft assessment criteria and in other Government guidance.**

Introduction

Macmillan Cancer Support welcomes the opportunity to respond to the Department's consultation on the Personal Independence Payment (PIP) assessment criteria *Moving around* activity, as disability benefits are an important part of helping to alleviate the financial burden caused by cancer.

As of November 2012, there were 77,960 people with cancer¹ in receipt of the higher rate mobility component of Disability Living Allowance (DLA)². The number of people living with

¹ Those with 'Malignant Disease' as a main disabling condition. Approximately 90% of those who receive or are eligible for DLA with a main disabling condition of 'Terminal Illness' have a secondary disabling condition of 'Malignant Disease'

² Statistics provided by DWP, Freedom of Information ref: 2013-2060

cancer and requiring support continues to grow – there are two million people living with or beyond cancer in the UK, this figure is set to rise to four million by 2030.³

Cancer and its treatment can result in a sudden onset of daily living and/or mobility needs and can have long-term physical impacts. People living with cancer also face a huge financial burden as a result of their illness. It is vital that they receive the appropriate support as they live with and beyond cancer, including being able to access vital benefits at a time when they need them most. As the national roll out of new claims for PIP has commenced, and with reassessment due to start for some DLA claimants in October 2013, we are currently monitoring the wider impact on people living with cancer.

This response is based on previous research conducted by Macmillan⁴ and consultation with Macmillan's benefits advisers. These benefits advisers offer specialist advice to help ease these concerns about finances, including information on benefits, tax credits, grants and loans. In 2012, Macmillan's benefits advisers reached an estimated 112,820 people affected by cancer and Macmillan's Support Line benefits advice experts reached 26,803 people affected by cancer across the UK

General comments

We are concerned that the proposed introduction of a 20 metre qualifying criteria for Personal Independence Payment's enhanced rate mobility component may negatively impact on a number of people with cancer.

There are currently 77,960 people with cancer in receipt of higher rate mobility under DLA and, under these proposals, it is likely a number of people with serious mobility needs will find it much more difficult to access the support they need while undergoing and recovering from treatment. Those that no longer qualify will lose at least £34.25 a week,⁵ access to their Motability vehicle or may find qualifying for a blue (disabled) parking badge more difficult.

In the Government's *Consultation on PIP assessment criteria and regulations*, a 50 metre measure was used.⁶ In the notes to the second draft of the PIP criteria, dated November 2011, DWP noted on page 61:

"50 metres is considered to be the distance that an individual is required to be able to walk in order to achieve a basic level of independence..."⁷

However, for many people, the threshold for qualifying for the enhanced mobility rate was subsequently lowered to being unable to move more than 20 metres.⁸ A 50 metre benchmark is also used elsewhere in Government – the Department for Transport's 'Inclusive mobility' guide uses 50 metres as its benchmark as part of its recommendations on how to create an accessible public transport infrastructure and barrier-free pedestrian environment for disabled people.⁹

This change to 20 metres may be too high a threshold for people with a variety of conditions who were, under both DLA and in previous PIP consultation documents, considered the

³ Maddams J, Utley M, Møller H. (2012) Projections of cancer prevalence in the United Kingdom, 2010-2040. Br J Cancer; 107: 1195-1202. (Projections scenario 1 presented here)

⁴ Macmillan (2011) Disability Living Allowance Reform: Macmillan's Response

⁵ If they are awarded the Standard Rate Mobility Component, instead of the Enhanced Rate

⁶ DWP (2012) Personal Independence Payment: assessment thresholds and consultation

⁷ DWP (2011) Personal Independence Payment: second draft of assessment criteria

⁸ DWP (2012) PIP: assessment thresholds and consultation - government response

⁹ Citizens Advice Bureau (2013) Personal Independence Payment: is it fit for purpose?

most in need of support. 20 metres is a particularly short distance and narrowing the eligibility criteria for the enhanced rate mobility component may result in many people with severe support needs losing out. It is currently unclear how the measure of 20 metres has been arrived at. We would be concerned if any decision on measurement was a result of cost implications, at the expense of realising the policy intention of PIP – supporting those with the greatest needs to meet the additional costs arising from disability or illness.

Mobility-related costs

Not only is cancer the toughest fight many of us will ever face, it's expensive and its impact lasts long after treatment has finished. New research, set out in *Cancer's Hidden Price Tag*, reveals the sheer scale of the financial burden faced by people living with cancer – four in five (83%) people are, on average, £570 a month worse off as a result of a cancer diagnosis.¹⁰ This is comprised of reduced income and increased costs.

Many cancer patients now receive their treatment as outpatients, and need to make regular trips to hospital. As cancer treatment often puts people at greater risk of fatigue and infection, public and hospital transport is often not suitable for them. Cancer patients are forced to rely on travelling by car or taxi, and often find themselves out of pocket for fares, petrol and car parking charges.

Subsequently, getting to and from outpatient and inpatient appointments is the most common cost that people living with cancer face, with trips back and forth adding up:

- The cost of travel to and from outpatient appointments affects 69% of people with cancer and costs them, on average, £170 a month
- Parking for outpatient appointments affects 38% of people with cancer and costs them, on average, £37 a month
- Over a quarter (28%) of people with cancer incur costs for inpatient appointments and, on average, this amounts to £20 a month for those affected.¹¹

PIP has been designed to contribute to the extra costs arising from a disability or health condition; however, if a claimant has high mobility-related costs but 'fails' the 20 metre threshold, it could reasonably be argued that its policy intention has not been realised. The support received from the mobility component of PIP, and previously DLA, is one way of offsetting these huge costs. Without the additional financial support of the enhanced mobility rate, it is possible that a significant number of people affected by cancer will be pushed further into financial hardship. This can cause unnecessary stress and worry at a time when people should be focusing on their treatment and recovery.

Barriers

Cancer itself can result in a sudden onset of mobility problems, while people may also have long-term problems sometimes resulting from treatment, such as nerve damage and peripheral neuropathy that can lead to pain and numbness in the feet and make walking very difficult. There are a number of symptoms that are common to many people living with cancer. With particular regards to the mobility criteria, these include pain and fatigue which can impede someone's ability to move 'safely, reliably, repeatedly and in a reasonable time period'. It is vital that the assessment criteria adequately takes account of these factors which impact on mobility; in their current iteration, the criteria appear to give undue prominence to a particularly short measure of distance.

¹⁰ Macmillan (2013) [Cancer's Hidden Price Tag: Revealing the costs behind the illness](#)

¹¹ Macmillan (2013) [Cancer's Hidden Price Tag: Revealing the costs behind the illness](#)

Pain is the first symptom of cancer in 20 - 50 per cent of all cancer patients. 75 - 90 per cent of advanced or terminal cancer patients experience chronic pain syndromes related to chemotherapy, failed treatment, and/or tumour progression.¹² The most commonly diagnosed cancers, lung, prostate, and breast cancers, often move to the bone, and in advanced states, they are associated with bone destruction and eventual bone fracture causing incapacitating pain and limited or total loss of daily activity.¹³ Pain from bone destruction is very difficult to control, and it represents one of the most serious and highly debilitating cancer related events.¹⁴

Recent Macmillan research shows that at least 200,000 cancer survivors are estimated to be left with pain, often with nerve changes after surgery, radiotherapy or chemotherapy.¹⁵ In particular around one in five diagnosed with breast, colorectal or prostate cancer report moderate or extreme pain or discomfort up to five years after initial cancer diagnosis.¹⁶ Pain can persist after the end of cancer treatment for many reasons. For example, radiotherapy and chemotherapy can cause nerve damage that leads to neuropathic pain,¹⁷ while surgery or radiotherapy in the pelvic area can lead to parts of the bowel sticking together.¹⁸

Cancer-related fatigue is one of the most common side effects of cancer and its treatment.¹⁹ Fatigue is not merely passing tiredness, but is experienced as a chronic and debilitating consequence of the treatment of cancer.. where a person living with cancer experiences physical fatigue, they feel weak and lack energy which can subsequently impact on their ability to walk reliably.

Fatigue is not predictable by tumour type, treatment, or stage of illness. Usually, it comes on suddenly, does not result from activity or exertion, and is not relieved by rest or sleep. It is often described as 'paralysing' and can continue even after treatment is complete.²⁰ Fatigue affects between 70 - 90 per cent of people with cancer. Many people with cancer say that it is the most disruptive side effect of all and over 90 per cent of people with cancer who experience fatigue said it stopped them leading a normal life.²¹

Variability or fluctuation of conditions across a day may also mean that someone may meet the 20 metres later in the day, but not in the morning due to fatigue or being unable to eat properly as a result of surgery or treatment. Macmillan would be extremely concerned if the narrowing of the eligibility criteria resulted in people affected by cancer with severe mobility needs being denied adequate support.

¹² Ballantyne J et al (2010) Opioids in cancer pain: New Consideration. International association for the study of pain

¹³ Ballantyne J et al (2010) Opioids in cancer pain: New Consideration. International association for the study of pain

¹⁴ Ballantyne J et al (2010) Opioids in cancer pain: New Consideration. International association for the study of pain

¹⁵ Macmillan (2013) Cured – but at what cost?

¹⁶ Macmillan (2013) Cured – but at what cost?

¹⁷ Macmillan Cancer Support. Causes of pain.

<http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Symptomssideeffects/Pain/Causesofpain.aspx>

¹⁸ Macmillan Cancer Support. Possible changes caused by surgery to your bowel.

<http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Lifeaftercancer/Lateeffectsbowel/Possiblelateeffects/Possiblechangescausedbysurgery.aspx>

¹⁹ www.medicinenet.com/cancer_fatigue/article.htm

²⁰ www.medicinenet.com/cancer_fatigue/article.htm

²¹ www.cancerhelp.org.uk/coping-with-cancer/coping-physically/fatigue/what-is-cancer-fatigue

Recommendation

Whether someone can walk the distance safely, reliably, repeatedly and in a reasonable time period is essential to the PIP mobility assessment and we welcome the recent steps taken by the Government to enshrine this principle in law. Recognising the Department's intention to proceed with a distance-based assessment criteria as a proxy for mobility needs, rather than other factors such as incurring the greatest costs, Macmillan calls on DWP to use a 50 metre qualifying distance for the enhanced rate of the mobility component of PIP as outlined in previous PIP draft assessment criteria and in other Government guidance. With reassessment of some DLA claims due to begin in October 2013, it is vital that the Department gets the balance right and ensures that those most in need of support and facing high mobility-related costs do not lose out.