

Macmillan briefing on Personal Independence Payments and terminally ill cancer patients

Briefing for: MPs and Peers

Purpose: To outline Macmillan's concerns with delays in processing Personal Independent Payments for terminally ill cancer patients

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1. Introduction

More than one in three of us will get cancerⁱ. For most of us it will be the toughest fight we ever face. Sadly, around 160,000 people will die from cancer each yearⁱⁱ.

Macmillan Cancer Support is very concerned that terminally ill cancer patients are currently waiting up to two months to receive their benefits under the 'special rules' claiming arrangements for Personal Independence Payment (PIP). Under Disability Living Allowance (DLA) a special rules claim was processed within 8 days.

Just over four in five (83%) people are, on average, £570 a month worse off as a result of a cancer diagnosisⁱⁱⁱ. For many income goes down and expenditure rises at a time when money worries should be the last thing on people's minds.

We are sure that the delays people are facing are an unintended consequence of the implementation of PIP, but the delays mean that terminally ill cancer patients are going without vital financial support at a time when they are most vulnerable. **Terminally ill cancer patients must receive their benefit in a timely manner, without undue stress.**

To resolve this issue Macmillan is calling on the Department of Work and Pensions (DWP) to:

- set out an official target of eight to ten days for processing special rules PIP cases and going forward, publish quarterly statistics on clearance times
- ensure transparency by publishing statistics on how long it is currently taking to process special rules PIP to reassure people affected by cancer
- work with Macmillan to develop a simplified application for terminal illness cases, such as a paper based application, that enables healthcare professionals to continue to support their patients through this process.

2. Delays to processing PIP claims

Macmillan has been monitoring the impact of PIP on people affected by cancer since the launch of pilots in April 2013. In June, Macmillan's benefit advice services began to report serious concerns about the processing of terminally ill^{iv} claimants in the pilot areas, with **some claims taking eight weeks to resolve**. We have been in dialogue with DWP officials since June.

These concerns have continued as PIP has been rolled out across the country and have been highlighted by the vast majority of Macmillan's 128 face-to-face services and the Macmillan Support Line.

3. Lack of targets

Under DLA, the DWP typically processed special rules claims within a target of 8 working days. In Macmillan's experience, they were often processed more quickly than this.

In August 2011, Lord Freud, Minister for Welfare Reform, stated in a written question "We intend to maintain the special rules provision in Personal Independence Payment ensuring that terminally ill people continue to receive valuable financial support through *automatic* and *immediate* payment of the enhanced rate of the daily living component."^{vi} Our emerging evidence indicates that this is not happening for a significant number of people.

People who are terminally ill deserve to receive a level of service equivalent to that under DLA, as committed to by this Government. We are, therefore, calling on the DWP to **set out an official target of eight to ten days for processing special rules PIP cases and going forward publish quarterly statistics on clearance times.**

Case Study: Keith, aged 55 from Cumbria.

Keith waited almost two months for his claim to be processed under special rules and was forced to rely on payday lenders.

He was diagnosed in May with bowel cancer, which had already spread to his liver. A part-time gardener before his diagnosis, his wife became the sole earner, working nights at the local petrol station on minimum wage. Keith made his original PIP claim on 13 June, which was updated on 11 July with a DS1500 claim to fast-track his benefits. Until Macmillan stepped in to help Keith on 2 September, no decision had been made on his claim.

The DWP did not link a PIP claim under normal rules with a DS1500 under special rules from the same person.

Keith, who has a mortgage, is not eligible for Employment and Support Allowance (ESA) as he does not meet contribution conditions, and his wife's earnings are over the applicable amount for a means tested ESA. As a result, Keith struggled to make ends meet, and had to borrow from payday lenders. He received support for his wider needs from the CAB. His palliative care nurse was extremely concerned about the effect Keith's loss of income was having on his health.

4. The financial impact on terminally ill cancer patients

People who apply for PIP via the 'special rules' process qualify for the enhanced rate of the daily living component, which is worth £79.15 a week. Sometimes people also qualify for a mobility component award and delays can mean people go without as much as £134 a week.

Delays processing claims can also impact on caring arrangements, as an award of PIP is required before Carer's Allowance can be paid. Furthermore, PIP has a number of other 'passported' benefits, including blue badges for parking and discounted council tax. As a result of delays, terminally ill cancer patients are therefore unable to access the support available to them.

From our survey of Macmillan benefits advisors, we know that the delays are causing multiple impacts; most people are experiencing emotional distress, a significant proportion have got into debt and are relying on food banks/vouchers.

Macmillan must be able to reassure patients, as well as healthcare professionals and benefits advisors that they will receive a level of service equivalent to that under DLA. We are, therefore, calling on the DWP to **ensure transparency and publish statistics on how long it is currently taking to process special rules PIP to reassure people affected by cancer.**

5. Introduction of telephone based claims

Since the introduction of PIP, healthcare professionals now, as standard, have to complete a telephone-based PIP1 claim on behalf of their patient. This means they now have to make a number of lengthy calls to register claims. This is far more time consuming, can depend on access to a phone and is an 'add on' to staff's core duties.

Under DLA, healthcare professionals used to complete a DS1500 and a paper claim form and often submit them together, which was easier, quicker and less cumbersome. The paper based process also reduced pressure on our benefits advisors who could focus on wider entitlements such as Carers Allowance, Employment & Support Allowance and Council Tax benefit. We would like the Department to work with Macmillan to **develop a simplified application for terminal illness cases, such as a paper based application, that enables healthcare professionals to continue to support their patients through this process.**

6. How can MPs and Peers help?

Over the last four months we have met with DWP officials to discuss the problems regarding the new process and delays and work on a solution. However, our key concerns have yet to be addressed.

We would be extremely grateful if you could:

- Raise our concerns with the Minister of State for Disabled People at the Work & Pensions evidence session on 11 December, specifically;
 - about the length of time it is currently taking to process special rules PIP and ask if he will publish statistics on this
 - ask if the Minister will set out an official target of eight to ten days for processing special rules PIP cases and going forward, publish quarterly statistics on clearance times
 - if the DWP will work with Macmillan to develop a simplified application for terminal illness cases, such as a paper based application, that enables healthcare professionals to continue to support their patients through this process.
- Ask Parliamentary Questions on the issues mentioned in this briefing. Naturally we can provide suggested wording.

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ⁱ Macmillan Cancer Support estimates that 44 per cent of people who died in the UK in 2010 had had a cancer diagnosis. For full details see [here](#)

ⁱⁱ 2011 cancer mortality data from Office for National Statistics (for England and Wales), General Registrar Office for Scotland, and Northern Ireland Statistics and Research Agency

ⁱⁱⁱ Macmillan Cancer Support (2013) *Cancer's Hidden Price Tag*. Published report available [here](#)

^{iv} The legal definition of terminally ill is someone who can be 'reasonably expected' to die within 6 months

^v Macmillan Cancer Support online survey of 138 Macmillan benefits advisors across the UK, out of a total of 260. Fieldwork conducted 13-28 November 2013

^{vi} Lords Hansard text for 11 Aug 2011 11 Aug 2011 (pt 0002).

http://www.publications.parliament.uk/pa/ld201011/ldhansrd/text/110811w0002.htm#wa_st_266 [Accessed 12/02/2013]