

## Written evidence from Marie Curie (HAB0102)

Marie Curie is the leader in end of life experience in the UK. We work hard to provide a better life for people living with a terminal illness and their families. We offer expert care across the UK in people's own homes and in our nine hospices. Last year, we supported more than 50,000 people across the UK at the end of their lives.

Our free information and support services give expert care, guidance and support to families so they can have something that really matters to them – time to create special moments together.

We are the largest charitable funder of palliative and end of life care research in the UK and campaign inside and outside Parliament for the policy changes needed to deliver the best possible end of life experience for all.

### Summary

- For people living with a terminal illness, every moment matters. While the social security system can be a lifeline for people with a terminal condition, assessments for health-related benefits like PIP and ESA can be a significant burden for them.
- The process of applying for benefits can be time-consuming, with applicants having to fill in long forms, submit to health-related and work capability assessments, and face long waits at several stages in the process as well as delays before payments are made. For people with a limited time to live, this process is inappropriate.
- Marie Curie welcomes the DWP's decision to scrap the 'six-month rule' governing access to fast-track support under the Special Rules for Terminal Illness, allowing any claimant who may die within a year to access fast-track support from the benefits system.
- However, many terminally ill people will still be unable to claim under this new process and it is therefore critical that the DWP improves the process for claiming health-related benefits.
- In particular, reforming assessments so that they are less of a 'tick-box' exercise and take greater account of the complexities of how a person's condition affects them, making greater use of medical evidence from clinicians who know a person's case, and expanding the availability of remote or paper-based assessments will all help reduce the burden on applicants.
- Reducing the frequency of assessments, by increasing the length of awards under the Special Rules for Terminal Illness from three to ten years – in line with practice for claimants with severe conditions – as well as making it easier for terminally ill people who cannot claim under the Special Rules to claim under the Severe Conditions Criteria or Severe Disability Group, will help reduce this burden further.
- Improving the process of making a claim for health-related benefits, from moving to a single, integrated application for all relevant benefits, having a dedicated point-of-contact for claimants for support with their claim, and working with third parties to identify claimants who may benefit from additional support and advocacy with their applications, will also help make the process of claiming much-needed support from the benefits system a less stressful and challenging experience for terminally ill people and their families and carers.
- Marie Curie recommends:
  - The DWP must ensure that legislation and guidance make clear that its changes to the Special Rules for Terminal Illness apply to anybody who's condition means that they 'may' die within a year and that this is not an inflexible 'twelve-month rule.'

- Extending the Severe Conditions criteria – or the criteria for the Severe Disability Group proposed in the Health & Disability Green Paper – to make it easier for terminally ill people who cannot claim under the Special Rules for Terminal Illness to claim under these criteria.
- Framing the PIP activities and descriptors, and WCA criteria, against which claimants are assessed as asking what a person is ‘typically’ capable of doing, or what a person can easily or comfortably do.
- The DWP should offer people a choice between face-to-face and paper-based or remote assessments and consultations, to ensure their services are as accessible as possible in future.
- Medical evidence provided by clinicians and health professionals should be sought as standard to support decisions and reduce the burden of assessments on claimants.
- The DWP must therefore end the practice of its non-specialist assessors challenging and rejecting medical evidence provided by clinicians if it is to extend this principle to other parts of the benefits system.
- Developing a single application form or portal for all benefits to enable claimants to make one application and for this information to be used to assess their eligibility for all relevant support, and ensuring claimants have a single point-of-contact at the DWP for queries regarding their claim.
- The DWP should also ensure that it works with charities such as charitable hospices and community organisations that work directly with vulnerable people to identify clients who may benefit from greater support with their applications.
- The DWP should work to reduce the burden of assessments on claimants by reducing repeat assessments; in particular by adopting the same approach it has taken for severe conditions and adopt a light-touch review of benefit awards under the Special Rules for Terminal Illness only after 10 years.

*Please note that not all of the questions in the Committee’s call for evidence are relevant to Marie Curie’s work. Our response to the Committee covers those areas which are relevant to our work only.*

## **Suitability of assessments**

### **1. How could DWP improve the quality of assessments for health-related benefits? a. Have you seen any specific improvements in the process since the Committee last reported on PIP and ESA assessments, in 2018?**

For people living with a terminal illness, every moment matters. The All-Party Parliamentary Group’s 2019 report<sup>1</sup> found that for people with a limited time to live, the process of applying for benefits was extremely burdensome and time-consuming, with assessments in particular being inappropriate given their condition.

Marie Curie welcomes the DWP’s decision to scrap the ‘six-month rule’ governing access to fast-track support under the Special Rules for Terminal Illness and introduce a new definition of terminal illness, that will allow anybody who may die within a year to access fast-track support. However, while this is a significant step forward it will not be enough on its own to address the challenges terminally ill people face when claiming benefits.

***The DWP must ensure both when it legislates to enact the changes it announced in July, and in its guidance to both clinicians and its own assessors, that it is made clear that the new definition of terminal illness applies to anybody who’s condition means that they ‘may’ die within a year and that this is not an inflexible ‘twelve-month rule.’***

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<sup>1</sup> APPG for Terminal Illness (2019). Six months to live? Report of the All-Party Parliamentary Group for Terminal Illness inquiry into the legal definition of terminal illness.

The APPG for Terminal Illness's report into the six-month rule in 2019 found considerable confusion both among clinicians and DWP assessors on this point, with reports of claimants being denied a DS1500 by clinicians or their claim under the Special Rules for Terminal Illness being rejected on the basis that they were not certain to die within six months<sup>2</sup>.

Secondly, to help ensure that terminally ill people who are unable to claim under the Special Rules for Terminal Illness, but whose condition will not change, do not have to claim again after three years, the DWP must make it easier for them to claim the support they need. The Severe Conditions criteria recognises that it is burdensome and unnecessary for people with lifelong conditions that are unlikely to improve to have to submit a new claim every three years; this is also the case for people with terminal illness, even if their condition means that they might live longer than a year. However, the criteria as designed now are not sufficiently flexible to allow these claimants to claim under the Severe Conditions criteria.

Marie Curie proposes ***extending the Severe Conditions criteria – or building into the criteria for the Severe Disability Group proposed in the Health & Disability Green Paper – to include two additional criteria***. These would capture a) conditions where symptoms are progressive or will lead to a decline in health or function over time, and b) conditions that can be reasonably expected to cause a person's death (even if this may be over a longer timescale than required for a claim under the Special Rules for Terminal Illness).

This would enable terminally ill people who are likely to live longer than a year, but whose condition is nevertheless terminal and likely to deteriorate over time, to benefit from a "light-touch" review after 10 years and avoid inappropriate, repeat assessments for benefits. As not all Severe Conditions or Severe Disabilities will necessarily be terminal or progressive, these additional criteria should be inclusive, not exclusive, i.e. claimants who do not satisfy them but satisfy the existing criteria should continue to be able to benefit from the Severe Conditions or Severe Disability Group criteria.

### **3. Do the descriptors for PIP accurately assess functional impairment? If not, how should they be changed?**

At present, many terminally ill people are unable to claim under the Special Rules for Terminal Illness because they do not meet the six-month (soon to change to twelve-month) criteria for access to the Special Rules. They have told us that they find assessments unsuitable for their conditions. The nature of disability benefits assessments, with points lost where capability is demonstrated, can lead to people being denied benefits – or awarded lower levels of benefits – if they demonstrate they are capable of, for example, a short walk or preparing a meal. While many terminally ill people are capable of these things on a limited basis, they often struggle to do so or find that their capability changes day to day as the symptoms of their illness fluctuate.

Terminally ill people have told us that they feel punished if they are assessed on a 'good day,' or for being honest about their capability – if, for example, they confirm that they are able to walk unaided for short distances, but this is painful or difficult – and so lose out on benefits support. Assessments, and those carrying them out, must recognise that the symptoms of many disabilities or conditions are changeable and what they see in front of them at the assessment is a 'snapshot' of the claimant's condition.

Wherever possible, we believe that the ***PIP activities and descriptors against which claimants are assessed should be framed as asking what a person is 'typically'***

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<sup>2</sup> *Ibid.*

**capable of doing, or what a person can easily or comfortably do**, to be as accurate as possible a reflection of their capability.

**4. Do the descriptors for ESA accurately assess claimants' ability to work? If not, how should they be changed?**

While claimants of Employment & Support Allowance under the Special Rules for Terminal Illness are not required to undergo work capability assessments (WCAs) as part of their claim, as outlined above many claimants who have been told their condition is terminal cannot claim under the Special Rules, are therefore required to undergo these assessments.

We believe all people with a terminal illness should be exempt from work capability assessments because it should be for them to choose how much of the limited time remaining to them is spent working, and how much is spent with their loved ones. We are also concerned that WCAs offer a snapshot of one moment in time that will often become rapidly out of date and inaccurate for people with a terminal illness that is progressive in nature.

If, however, the DWP does decide to continue requiring people with a terminal illness, but who cannot claim under the Special Rules, to undergo WCAs, as outlined above we believe that **WCA activities and descriptors should be framed as asking what a person is 'typically' capable of doing, or what a person can easily or comfortably do**, to be as accurate as possible a reflection of their capability.

**5. DLA (for children under the age of 16) and Attendance Allowance usually use paper-based rather than face-to-face assessments. How well is this working?**

**a. Before PIP replaced DLA for adults, DLA was also assessed using a paper-based system. What were the benefits and drawbacks of this approach?**

The symptoms of and treatments for many terminal illnesses leave people with limited mobility or make travelling difficult and burdensome. This can make attending assessments in person very challenging. For these claimants, a paper-based assessment, or an assessment conducted remotely – for example over the telephone or via video-call – may be more convenient and more appropriate for their circumstances.

As a minimum, **the DWP should offer people a choice between face-to-face and paper-based or remote assessments and consultations, to ensure their services are as accessible as possible in future.**

**6. How practical would it be for DWP's decision makers to rely on clinician input, without a separate assessment, to make decisions on benefit entitlement? What are the benefits and the drawbacks of such an approach?**

**Medical evidence provided by clinicians and health professionals should be sought as standard to support decisions and reduce the burden of assessments on claimants.** In particular, evidence from a person's clinician which confirms the condition they have, their symptoms, and how it affects them would help to establish a person's capability under the PIP or WCA activities and descriptors, reducing the need for the claimant to be assessed against these criteria for a decision to be made.

For example, knowing that a person is receiving treatment for, for example, motor neurone disease (MND) from a specialist clinician should not only be regarded as adequate evidence that they have MND, but information provided by that person's clinician about how the condition affects their day-to-day life and the level of debility the condition causes them

would enable the DWP to assess this against the activities and descriptors without the need for an in-person or remote assessment.

However, Marie Curie has concerns with how the DWP currently makes use of evidence from clinicians in the one area of the benefits system that is already reliant on this – the Special Rules for Terminal Illness. In order to access the Special Rules claimants must obtain a DS1500 from a clinician or other health professional certifying that they may have fewer than six months (soon to change to twelve months) to live.

The All-Party Parliamentary Group for Terminal Illness found in 2019 that DWP assessors have been found to challenge the decision to provide a DS1500 for a claimant even where their application and terminal diagnosis is supported by their doctors. Witnesses to the APPG's inquiry showed that clinicians often find their decision to sign a DS1500 queried or challenged by assessors, with the form even being rejected in some cases and claimants unable to claim under the Special Rules. In some cases, the APPG was told that the DWP did not contact the doctor who signed the DS1500 in such cases, instead simply notifying the claimant and leaving them to contact their doctor should they wish to challenge the decision and need more evidence.

The DWP has confirmed that its policy is that it is possible for claims made under the Special Rules to be rejected as a Special Rules case by the assessment provider for not satisfying the terminally ill definition<sup>3</sup>, even where the claim is supported by a DS1500 issued by their clinician. This means that non-specialist assessment provider staff are overruling the clinical judgment of clinicians who have first-hand knowledge of the claimant and their condition and who may have specialist clinical knowledge of the condition, excluding those claimants from the Special Rules process.

Unless a clinician has misunderstood the eligibility requirements for the Special Rules or incorrectly certified the form, it is wholly inappropriate for the judgment of a clinician to issue a DS1500 to be overturned by a DWP assessor with no first-hand knowledge of the claimant's case, based on the assessor's understanding of the typical prognosis for a claimant's condition, often a generalised figure from a prognostic table, especially in conditions where prognostic certainty is difficult to obtain.

Marie Curie supports the principle of greater reliance on evidence from health professionals and other support organisations with first-hand knowledge of a claimant's circumstances and condition. However, this must be based upon the principle that a person's health professionals are best-placed to know the details of their case. ***The DWP must therefore end the practice of its non-specialist assessors challenging and rejecting medical evidence provided by clinicians if it is to extend this principle to other parts of the benefits system.***

## **7. Appeals data shows that, for some health-related benefits, up to 76% of tribunals find in favour of the claimant. Why is that?**

### **a. What could DWP change earlier in the process to ensure that fewer cases go to appeal?**

As outlined above, Marie Curie has significant concerns with the current process of disability benefits assessment and the impact this has on claimants. In particular, the inflexibility of activities and descriptors used for PIP and WCA assessments has created a 'tick-box' process that in practice often fails to capture the complexity of a person's condition and how it affects them. In some cases this significantly misrepresents the true nature of a person's condition. Similarly, reported cases of DWP assessors rejecting or overturning a clinician's

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<sup>3</sup> HC Deb 30 April 2019, vol 659, WA 245707

decision to sign a DS1500 form in respect of a claimant living with terminal illness have a similar effect.

It is therefore unsurprising that a significant proportion of both Mandatory Reconsideration and Tribunal decisions overturn the initial decision made by the DWP; when a claimant's case is considered in more detail than is allowed for in the initial assessment, it is often very clear that the initial decision was flawed. Marie Curie is aware of cases where Tribunals have concluded very quickly as the severity of the claimant's condition was immediately apparent to the panel despite not being reflected in the initial assessment.

The DWP's inability to reliably ensure that it gets these decisions correct the first time has a particular impact on terminally ill claimants who have a limited time to live, and for whom the length of the appeals process is particularly challenging. Marie Curie's analysis of DWP statistics shows that around 100 people each month die within six months of being rejected for PIP<sup>4</sup>. Not only does the fact that these people died within six months of their claim mean that many should have been eligible to claim under the Special Rules for Terminal Illness, but the length of the appeals process also means that if these people wished to challenge the DWP's initial decision, they would likely have died before reaching a Tribunal.

The proposals outlined above, including changing the nature of assessments to reduce the extent to which they are a 'tick-box' process and making greater use of medical evidence from clinicians, would support the DWP to more reliably make the correct decision on applications at the initial application stage.

#### **8. Is there a case for combining the assessment processes for different benefits? If not, how else could the Department streamline the application processes for people claiming more than one benefit (eg. PIP and ESA)?**

Moving to a single, simplified application for all relevant benefits and support would significantly reduce the amount of time that people with terminal illnesses, who are often eligible for multiple health and disability related benefits as well as income-based benefits and other support, have to spend making applications.

DWP forms can be long, complex and difficult for many people with terminal illness to complete, especially if their condition leaves them prone to tiredness and fatigue, or with limited use of their limbs. Terminally ill people should not have to make multiple, separate applications to the DWP and other government departments for different support or benefits, especially where much of the information requested is identical between forms.

***Developing a single application form or portal for all benefits would enable claimants to make one application and for this information to be used to assess their eligibility for all relevant support.***

Similarly, ***ensuring that claimants have a single point of contact for their claim***, especially for claimants who are terminally ill, would greatly simplify the application process. Having to deal with multiple different departments or points of contact can be confusing for claimants and lead to communication failures. Providing a single point of contact for terminally ill people, who is trained in and sensitive to the issues people face at the end of life and the support they are entitled to, will ensure a more sensitive and streamlined experience for claimants.

### **The impact of the pandemic**

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<sup>4</sup> Marie Curie. [DWP failures mean dying people are rejected for vital support](#). June 2021.

**10. What lessons should the Department learn from the way that it handled claims for health-related benefit claims during the pandemic: for example, relying to a greater extent on paper-based assessments, or using remote/telephone assessments?**

**a. Is there a case for making some of the changes permanent?**

Marie Curie welcomes the DWP's move to introduce remote consultations and assessments by telephone or video call during the Covid-19 pandemic. The symptoms of and treatments for many terminal illnesses leave people with limited mobility or make travelling difficult and burdensome. This can make attending assessments in person very challenging and the DWP should offer people a choice between face-to-face and remote assessments and consultations to ensure their services are as accessible as possible in future.

**12. DWP believes that applications for some benefits dropped sharply at the start of the pandemic because claimants weren't able to access support (for example, from third sector organisations) to complete their applications. What are the implications of this for how the Department ensures people are able to access health-related benefits consistently?**

**a. How can the Department best help the third sector to support claimants in their applications?**

The DWP should ensure that it works with charitable hospice providers and NHS providers, GPs, and specialist clinicians – for example oncologists or specialists in conditions like motor neurone disease (MND) – to make people with terminal illnesses aware of their entitlement to fast-track support under the Special Rules for Terminal Illness. Many people with a terminal illness are not aware of their entitlement to claim support on a fast-track basis and ensuring that health professionals who are likely to come into contact with terminally ill patients are empowered to signpost them to this support will ensure that everybody who is entitled to claim under the Special Rules can do so. Similarly, the DWP should ensure that it is signposting to other services and other support that people with terminal illness may be entitled to claim from in addition to disability benefits.

***The DWP should also ensure that it works with charities such as charitable hospices and community organisations that work directly with vulnerable people to identify clients who may benefit from greater support with their applications.*** The DWP should also encourage NHS providers, GPs, and specialist clinicians – for example oncologists or specialists in conditions like motor neurone disease (MND) – to identify people who could benefit from this support to access their benefit entitlement. This support should range from support completing applications through to support during either paper-based, remote or face-to-face assessments.

## **The impact of assessment/application on claimants**

**13. DWP recently published research on the impact of applying for PIP or ESA on claimants' mental and physical health. What would be the best way of addressing this?**

As outlined above, the application and assessment process for disability benefits is often a significant burden for terminally ill people with a limited time left to live. In addition to the proposals outlined above to move to a single application for all relevant benefits, improve the flexibility of assessments and make greater use of medical assessments, ***the DWP should work to reduce the burden of assessments on claimants by reducing repeat assessments.***

Most people diagnosed with a terminal illness live for a matter of months or a small number of years. Only 39% of patients live for longer than a year with a brain tumour, for example, while more than half of people with MND within two years<sup>5</sup>.

A very small number of people are lucky enough to live for more than three years after they have been diagnosed as terminally ill. However, as benefit awards under the Special Rules for Terminal Illness are only made for three years, if a claimant is fortunate enough to reach this milestone, they must make an entirely new application or risk losing their benefits.

Even though a minority of terminally ill people live for three years with their condition, their underlying need for financial support will not change; and indeed, in many cases, such as with progressive conditions like MND or dementia, a person's needs will actually increase over time due to increasing debility, despite living longer than the six months (soon to change to twelve) required to obtain a DS1500 and claim under the Special Rules for Terminal Illness.

Requiring this small number of patients to go through the stress and burden of another benefits application after three years is inappropriate and insensitive, and leaves families at risk of losing their benefits, despite their conditions not having changed. Elsewhere in the benefits system, the DWP has moved away from frequent reassessments for people with severe conditions that are unlikely to improve, replacing them with a "light touch" review only every 10 years, at which point the Department will contact the claimant's doctor to confirm their condition remains the same. ***We recommend the DWP should adopt the same approach it has taken for severe conditions and adopt a light-touch review of benefit awards under the Special Rules for Terminal Illness only after 10 years.***

## **Waits for assessments**

### **14. What could the Department do to shorten waits for health-related benefit assessments—especially for ESA/UC?**

#### **a. How effectively does the "assessment rate" for ESA cover disabled peoples' living costs while they wait for an assessment? Is there a case for introducing an assessment rate for other health-related benefits?**

The APPG for Terminal Illness's 2019 report found that delays in assessment after an application has been made, as well as long delays before a decision is made on their claim and waiting periods before payments are eventually made, were wholly inappropriate for terminally ill people with a limited time left to live<sup>6</sup>.

While widening access to the Special Rules for Terminal Illness by allowing anybody who may die within a year to access fast-track support will reduce the impact of delays on terminally ill people, many people diagnosed with terminal conditions will still be unable to claim under the Special Rules and subject to long waiting periods.

In addition to offering people paper-based or remote assessments, the DWP should make greater use of evidence from health professionals or other organisations that work with terminally ill and other claimants, to reduce its reliance on formal assessments to determine a person's condition or capability. This will reduce the assessment burden not only on claimants, but also on DWP assessors, allowing those assessments which do need to be conducted to take place more quickly.

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<sup>5</sup> APPG for Terminal Illness (2019). Six months to live? Report of the All-Party Parliamentary Group for Terminal Illness inquiry into the legal definition of terminal illness.

<sup>6</sup> *Ibid.*



## **Health assessments in the devolved administrations**

**15. The Scottish Government intends to introduce its own assessment process for the Adult Disability Payment, which will replace PIP in Scotland from 2022. What could DWP learn from the approach of the Scottish Government?**

**a. PIP started rolling out in Northern Ireland in 2016. Is there evidence that the Department learned from the experience of rolling out PIP in the rest of the UK?**

There are examples of good practice in the devolved administrations which the DWP could learn from in its own approach to assessments. In particular, in Northern Ireland Capita – the contractor for PIP assessments in Northern Ireland – agreed to receive training from the Multiple Sclerosis Society on assessing claimants with multiple sclerosis. This included educating assessors on the condition, its symptoms and how these affect people, the impact that the condition can have on a person's capabilities and how this relates to the activities and descriptors in PIP assessments.

The training was primarily delivered by people living with multiple sclerosis who had been through the PIP assessment process themselves and were therefore experts through experience. This is an innovative example of good practice in how government can work with people who have lived experience of the benefits system to improve the assessment process. A similar approach by the DWP in England and Wales, working with organisations and people with lived experience of conditions for which PIP is claimed – including terminal illnesses – would support the Department to better understand the lived experience of claimants and improve assessors' understanding of the conditions that people claiming PIP are living with.

## **Policy development**

**16. How effectively does DWP work with stakeholders—including disabled people—to develop policy and monitor operational concerns about health-related benefits?**

**a. What steps could the Department take to improve its engagement with stakeholders?**

Marie Curie has had extensive engagement with the DWP over the past several years in relation to our #Scrap6Months campaign to improve access to the Special Rules for Terminal Illness, as well as around the Health & Disability Green Paper and on other issues. The Department consults widely on developing policy and actively seeks views from stakeholders, including people with lived experience of the benefits system. Marie Curie has organised two virtual events over the last year for terminally ill people with lived experience of the benefits system to share their experiences with DWP officials and the Minister for Disabled People, Welfare & Work.

***December 2021***