From the Chair

Justin Tomlinson MP
Minister for Disabled People, Health and Work
Department for Work and Pensions

Dear Justin

Re: Universal Credit for claimants with terminal illness

Thank you for your response dated 8 April on the Department’s Special Rules for Terminal Illness. In the light of the amended guidance published this morning, I would be grateful if you could answer some further questions.

As you know, the Committee has recommended the Department adopt a more flexible approach to help terminally ill claimants access benefits via the SRTI more easily. We recommended that the Department should remove from legislation the requirement for claimants to provide a completed DS1500 form stating that they are expected to die within six months.

Your letter reiterated that the six month timeframe is “not an absolute” and that clinicians should always consider whether there is a “reasonable” expectation of a person dying within six months. You referred to the Department’s consultation on reform to Disability Living Allowance, carried out in 2010/11, in which the majority of respondents felt that the process was working well. The letter says it “is of note that the Special Rules clause passed without amendment or debate during its Parliamentary passage in 2011 to 2012”.

On 25 April 2019 the Department issued revised guidance to clinicians on how it would like them to interpret the SRTI/DS1500 requirements. The guidance now advises:

You should complete the form promptly if you believe that your patient meets the special rules criteria, namely:

- they have a progressive disease and, as a consequence of that disease
- you would not be surprised if your patient were to die within 6 months

The special rules criteria do not just apply to patients with cancer.

As an example, they may also apply to severe, life limiting cardiorespiratory and neurological conditions (this is not an exhaustive list).

This is helpful. I would suggest, however, that the relevance of responses to the DLA reform consultation may have declined in the intervening eight years—especially coinciding as they do with a period of substantial change in disability/incapacity benefits and the welfare state more widely. The Committee continues to hear concerns about the impact of the rules. I have attached, for example, further case studies from the National Association of Welfare Rights Advisors. These set out in detail the “fallout” of the six month rule for terminally ill people and the organisations that support them.
You declined in your letter to give details of the “senior clinicians” who attended Professor Gina Radford’s review group, on the basis that this was an informal meeting of which “no report” was produced. Your letter makes clear that the outcomes of this meeting, and subsequent work with stakeholders, have influenced policy. The lack of transparency is therefore worrying. The Committee has previously emphasised that transparency is vital to improving trust in DWP policy, especially among disabled people.¹

Given that and the concerns we have heard, I would be grateful if you please tell us:

1. **How the findings from Professor Radford’s group were used to inform this wording change;**

2. **Whether the Department:**
   a. consulted with claimants and stakeholder groups on the guidance change;
   b. what the findings of those discussions were; and
   c. how findings fed into the wording change.

3. **How the Department will monitor whether the rule change is leading to a more flexible approach to the SRTI amongst clinicians.**

With best wishes and I look forward to hearing from you,

Rt Hon Frank Field MP  
Chair, Work and Pensions Committee  
Cc. Madeleine Moon MP

¹ PIP and ESA Assessments