



Frank Field
Work and Pensions Committee
House of Commons
London
SW1A 0AA

23 April 2019

Dear Frank

Special Rules for Terminal Illness

Further to your email asking about NAWRA members' experiences of accessing benefits via the Special Rules for Terminal Illness, I am sending you some case studies provided by Macmillan advisers from across the UK which highlight some of the issues within the process as it works currently.

Below I also set out some comments that were made by a Macmillan Welfare Rights Advisor and Project Lead who has been in her role for 11 years and has a wealth of experience –

In my roles as a Macmillan welfare rights advisor /Hospice welfare rights advisor (and the project manager) I have to deal with the 'fallout' of the 6 months rule around DS1500s and spend many hours discussing with clinicians as to whether they should issue a DS1500 or not.

I have multiple examples of clients having to claim PIP under 'normal rules' when they are palliative and have a very limited prognosis but a clinician won't do a DS1500 (but invariably ends up doing one part way through the claims process) so rather than give you specific examples thought I would try to give you my view of the bigger picture .

Specialist nurses are the most open to issuing, most consultants are very resistant as are GPs.

There are many reasons I feel for this reluctance to issue a DS1500 from a fear that they will be held accountable if the client lives for longer than 6 months to a lack of understanding of how the DWP looks at DS1500's and sadly a rigid approach to the 6 month rule combined with no understanding of the impact of going through a normal rules claim as opposed to a SR claim.

Coincidentally I did a talk about my role to a large GP practice in Wiltshire today and discussed D1500s and showed them the Committee's recommendation and government response as detailed below-

We recommend the Department adopt the approach taken in the Social Security Act (Scotland) 2018 in determining who can use the SRTI. This would permit claimants to use the SRTI if: "It is the clinical judgement of a registered medical practitioner that the individual has a progressive disease that can reasonably be expected to cause the individual's death"

- but the government rejected this saying it expects clinicians to take a flexible approach.

This prompted an interesting discussion and it was clear that most of the GPs have a lack of understanding of the appropriateness of issuing a DS1500 and I think the government saying it expects clinicians to take a flexible approach is a non starter.

I have been in my current role for 11 years and when I first started it was much clearer when someone was DS1500 whereas with advances in cancer treatments there is a large and increasing number of people living with advanced and non curative cancer and it is this group where the discussion around issuing a DS1500 is a difficult issue. The DWP guidelines are out of date - there is no middle ground - a claimant is either special rules or normal rules but it is not appropriate to have the same claims process for PIP for someone who might have a debilitating condition in terms of care and mobility issues (e.g. MS) and someone who has a prognosis of perhaps 2 years if treatment works . We either need to adopt the Scotland approach or at least have a 'softer' claims process for those who are palliative but don't qualify for a DS1500.

I think the above highlights the lack of understanding by some in the medical profession of the terminal illness rules and the inconsistency in practice.

Another Macmillan adviser wrote –

I have been told by nurses before (and I get a lot of DS1500s from them), that the DWP are keen to check the DS1500s and if they don't put on enough information then they are sometimes rejected. I also get the impression that when they state a client is having treatment such as chemotherapy, they often see this as the client's life will be prolonged and unless it clearly states that treatment is palliative only and will not alter disease progression, again this can be rejected.

The difficulties that my clients who claim UC seem to have is that it can take a while for a DS1500 to filter through to UC, especially if it's been sent to PIP. I send the DS1500 to the Disability Employment Adviser at our local Jobcentre and ask them to forward this on to UC but I have had a case of a UC client ringing me today to say he's still on basic rate UC with no support element when I sent the DS1500 to the DEA around 3 weeks ago. This is something I will now have to chase up.

I personally feel that the current 6 month rule for DS1500s is a sticking point for many medical professionals and as a result many clients are being denied benefit under the special rules because of this.

As the above information and the case studies at the end of this letter show, the current process for terminal illness is not operating as well as it should for a number of reasons –

- Medical professionals not fully understanding the phrase ‘death could reasonably be expected within six months’ and deciding that a DS1500 is not appropriate
- Rigidity of specifying six months which is difficult to align with current treatments which may offer the opportunity of giving a few extra months to someone with a terminal illness
- Disagreement between professionals about whether a DS1500 should be provided
- Refusal to accept DS1500s by the DWP
- Delays in the process, particularly within universal credit

NAWRA strongly believes that the government should follow the Scottish approach thereby ensuring that people in the last stages of their lives receive the benefit they need as quickly and easily as possible.

Best wishes,

Daphne

Daphne Hall

Vice Chair - National Association of Welfare Rights Advisers

Case studies

Case study 1 – claimant unable to claim PIP as consultant thought claimant may live a little longer than six months

Client was married, husband in full time work and regularly travelled abroad with his work. As she was not working and dependant on him, she would travel with him. Their home base was UK – bank accounts, house etc all here. She was diagnosed with a brain tumour, Glioblastoma grade 4, with a limited life expectancy but the consultant felt she had a bit longer than six months so refused to issue a DS1500. The only way this woman would be entitled to PIP would be under the special rules as she had not been in the country for sufficient time in the previous three years to meet the past presence rules. Due to the inflexibility of the consultant she was unable to claim PIP.

Case study 2 – DWP refusing to accept evidence of DS1500

Client with ovarian cancer which had spread to lungs and peritoneal. Had an award for Disability Living Allowance (middle rate care and higher rate mobility). Due to the client's health condition a request for a DS1500 was made to the Gynaecology Department by Support Worker on 27/11/2018. A reply to this request stated that as they had not seen the patient they would be unable to issue a DS1500. Subsequently, a further request was made on 30/11/2018 to the doctor's secretary. After several enquires, a DS1500 was eventually completed by the Clinical Nurse Specialist (CNS) on 30/01/2019 which was then immediately forwarded to the DWP with a cover letter. This DS1500 made it very clear the client had Stage 4 intra-abdominal metastatic adenocarcinoma and high-grade serious adenocarcinoma. This was followed up by a telephone enquiry to Personal Independence Payment as, due to a change of circumstances, she was now being assessed under this benefit. During this call, I was informed that this DS1500 was not to be accepted as it showed no progression of her disease and neither did it show that the client was likely to pass away within 6 months. As a result, the CNS was emailed and provided with Personal Independence Payment enquiry number to clarify this to the DWP. However, as she was on annual leave the Special Rules Team for Personal Independence Payment were emailed. No response was ever received. During this time the DWP had received a further DS1500 from the client's GP. However, the decision remained unchanged. The client then reported she had received a PIP2 to complete as she was being assessed for Personal Independence Payment under normal rules as neither DS1500 had been accepted. At this point, the Macmillan Welfare Rights Service Manager was contacted and informed of the situation. She subsequently spoke with the CNS who in turn spoke with the Consultant in charge. As a result of this, a further DS1500 was issued stating the client had Stage 4 cancer and was receiving palliative care. This DS1500 has now been forwarded to the DWP for which we are currently awaiting a decision almost four months after the original DS1500 sent.

Case study 3 – cancer nurse specialist saying DS1500 not appropriate

83 year old with multiple co-morbidities including heart condition and cancer. Living in housing association rented accommodation with elderly brother. Requested DS1500 from Cancer Nurse Specialist on 30/1/19 and told it was not appropriate. Attended home visit with client on 19/2/19 and found medical letter stating he was not expected to survive 12 months. Re-requested DS1500, which was then completed on 27/2.

Case study 4 – delays getting DS1500 and difficulty with length of prognosis

Client has grade IV glioblastoma which means that death is reasonably expected within a year – that is the standard prognosis with Grade IV. Awaiting confirmation from the CNS, who is on leave until Tuesday, whether they will issue him with a DS1500 or not. Claimant likely to be denied PIP under normal rules, at least at the assessment, because he presents as capable (he's actually not).

Case study 5 – disagreement amongst professionals as to whether DS1500 should be issued

Client referred for benefits advice by a nurse from local hospice. She stated on the referral that a DS1500 was appropriate and yet the Palliative Care Consultant at the Hospice who usually issues these, disagreed. An intent to claim PIP under the Special Rules had already been lodged and the client advised that he would hear from PIP about his award within 3 weeks. This client was self-employed and relieved to hear that he could qualify for PIP and decided to run down his business on the strength of this information. After explaining to the client what had happened he rang his Oncologist who said it was appropriate to issue one but to ask his GP to do this and get back to her if they couldn't. In the end his GP rang PIP and sorted it over the phone and his PIP will now be assessed under the special rules.

Case study 6 - delays getting DS1500 issued and uncertainty about whether appropriate

Client has metastatic breast cancer so rang the Breast Care Team who said a DS1500 applied and they would issue one. Unfortunately, they changed their mind but an intent to claim PIP under the special rules had already been lodged. Contacted local hospice regarding whether they can issue one as they are now dealing with her. This client is currently in hospital and still waiting for hospice to respond. There is a month to follow up a PIP SRTI form with a DS1500 and this has now passed. Case if then passed to the assessment provider to decide. Excessive delay for the client in getting benefit sorted at a time when they have a lot of expenditure in relation to their condition.