Citizen Participation and Public Petitions Committee

2nd Meeting, 2022 (Session 6), Wednesday 2 February 2022

PE1913: Fast-track future Adult Disability Payment applications for people undergoing cancer treatment

Note by the Clerk

Petitioner Wendy Swain

PetitionCalling on the Scottish Parliament to urge the Scottish Government to
create a separate department within Social Security Scotland that will
fast track future Adult Disability Payment (ADP) applications for
people with a cancer diagnosis whilst they are undergoing treatment.

Webpage <u>https://petitions.parliament.scot/petitions/PE1913</u>

Introduction

- 1. This is a new petition that was lodged on 30 November 2021.
- 2. A SPICe briefing has been prepared to inform the Committee's consideration of the petition and can be found at **Annexe A**.
- 3. While not a formal requirement, petitioners have the option to collect signatures on their petition. On this occasion, the petitioner elected to collect this information. 314 signatures have been received.
- 4. The Committee seeks views from the Scottish Government on all new petitions before they are formally considered. A response has been received from the Scottish Government and is included at **Annexe B** of this paper.
- 5. A submission has been provided by the petitioner. This is included at Annexe C.

Background information

- 6. The Adult Disability Payment (ADP) will replace the Personal Independence Payment (PIP) in 2022.
- 7. The SPICe briefing notes that the Scottish Government's analysis of its consultation on ADP did not refer to anyone suggesting a fast-track payment for people undergoing cancer treatment.
- As highlighted in the petitioner's previous action, Martin Whitfield MSP lodged a PQ on this issue in 2021. <u>The Minister for Social Security and Local</u> <u>Government's response</u> highlighted changes to the fast-track system and definition of terminal illness.

Scottish Government submission

- 9. The Scottish Government's response to this petition outlines a specific change to the existing fast track application and payment process for people who are terminally ill. A fast-tracked application and payment process is currently delivered by the DWP. However, the Scottish Government have changed the definition of terminal illness to 'remove arbitrary time constraints and ensure decisions are better informed by clinical judgement.'
- 10. The submission states that research into the impact of this new definition has revealed that
 - the number of people with cancer accessing ADP using the fast tracked process will more than double, compared to DWP fast tracking;
 - it is estimated that the number of terminally ill ADP recipients who have cancer will increase from 2,800 to approximately 8,200, under the new definition;
 - it is projected that the majority of ADP recipients with cancer (62%) will be able to use fast tracked processes (compared with less than a third of PIP recipients);
- 11. A number of changes that are being delivered through the introduction of ADP outside of the fast-tracking for clients who are terminally ill are highlighted in the submission, including
 - the Scottish Government will aim to collect only one piece of supporting information from a formal source, such as from a GP or a support worker;
 - equal consideration will be given to all sources of information including insights from informal support networks such as family, friends and unpaid carers;

- functional examinations will not take place as part of a consultation.
 Instead, ADP consultation will consist of a discussion between the client and practitioner; and
- if the practitioner makes an informal observation, they will inform the client and allow them to respond to the observations.
- 12. The submission concludes by stating that the Scottish Government's approach is 'to provide a person-centred service and not prioritise any single condition or type of disability above any other' and that 'the Scottish Government does not support an additional fast track procedure specifically for people with cancer. Everyone deserves the best possible service that can be provided and that is what we intend to provide, no matter what their illness or condition.'

Petitioner submission

- 13. The petitioner shares the experience of her family member who has incurable blood cancer and has been on the highest dose of radiotherapy for his illness. The submission states that he has been told that his illness 'is not affecting his life enough' and is not in receipt of PIP.
- 14. It is possible that his future treatments may not be possible due to costs associated with travel and work absence.
- 15. The petitioner expresses that 'these people like my family member didn't ask for this and has worked hard all his life and they feel like their lives are worth nothing. We don't allow animals to suffer like this so why are we doing it to cancer patients.'

Action

16. The Committee is invited to consider what action it wishes to take on this petition.

Clerk to the Committee

PE1913: Fast-track future Adult Disability Payment applications for people undergoing cancer treatment

Petitioner

Wendy Swain

Date Lodged:

30/11/21

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to create a separate department within Social Security Scotland that will fast track future Adult Disability Payment (ADP) applications for people with a cancer diagnosis whilst they are undergoing treatment.

Previous action

I initially raised this issue with my Local Councillor Shamin Akhtar who helped me progress this further. I asked Martin Whitfield MSP to ask the Scottish Government about this issue, which he did via a written question (answered on 3rd September).

I have also been in contact with Macmillan Cancer Support about this issue and they confirmed that many others have had similar experiences with delays in receiving PIP.

Background information

One in two people in the UK will be diagnosed with cancer in their lifetime around 33 million individuals. The most difficult and challenging time for a family is when you undergo treatment and are unable to work. From 2022 PIP will be devolved. There have been many examples under the current system when people undergoing treatment do not receive their PIP at a time they need it the most. This is forcing people into hardship or back to work while undergoing treatment. I believe that the devolution of PIP and change to Adult Disability Payment offers an opportunity to change the system to make it fairer for people undergoing cancer treatment.

I want to ensure that the principles of being treated with dignity, fairness and respect are applied to people and that they are able to access ADP during their treatment when they most need support.

SPICe The Information Centre An t-Ionad Fiosrachaidh

Briefing for the Citizen Participation and Public Petitions Committee on petition PE1913: Fast-track future Adult Disability Payment applications for people undergoing cancer treatment, lodged by Wendy Swan

Brief overview of issues raised by the petition <u>Petition PE1913</u> asks for 'fast-track' payments of Adult Disability Payment for those undergoing cancer treatment.

- <u>ADP is replacing Personal Independence Payment</u> (PIP) in Scotland in 2022.
- Initially ADP will have much the same legal rules as PIP. This is to ensure 'safe and secure transfer' from the DWP benefit to Social Security Scotland.
- Like PIP, ADP will 'fast track' claims if a person is terminally ill – albeit there is a wider definition of 'terminal illness' in ADP.
- A consultation on ADP was held in early 2021. The <u>consultation analysis</u> did not refer to anyone making the same suggestion as the Petitioner.
- Regulations setting out the rules for ADP are due to be introduced shortly by the Scottish Government. These will be considered by the Social Justice and Social Security Committee in due course.
- <u>PQ S6W-02362</u>, referred to by the petitioner, answered on 3rd September, referred to the new rules on terminal illness,

but did not make any statement about whether cancer treatment ought to trigger fast-track payments.

 There will be an independent review of ADP 2023, and this will be an opportunity to consider possible changes to the rules. (<u>Review announced in ADP consultation paper</u> <u>December 2020</u>)

Camilla Kidner Senior Researcher 09/11/2021

The purpose of this briefing is to provide a brief overview of issues raised by the petition. SPICe research specialists are not able to discuss the content of petition briefings with petitioners or other members of the public. However, if you have any comments on any petition briefing you can email us at spice@parliament.scot

Every effort is made to ensure that the information contained in petition briefings is correct at the time of publication. Readers should be aware however that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.

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Scottish Government submission of 1 December 2021 PE1913/A – Fast track future Adult Disability Payment applications for people undergoing cancer treatment

Throughout the development of the new social security system the overriding commitment of the Scottish Government is to the safe and secure transfer of disability benefits from the Department for Work and Pensions (DWP) to Social Security Scotland. It is essential that people continue to receive the current payments they rely on with no interruptions.

Improvements to ADP (Adult Disability Payment) Decision Making Process

Whilst prioritising safe and secure transition, the Scottish Government is making significant changes in order to provide a social security system that treats people with dignity and respect, therefore improving how decisions are made and meeting our aim to get decisions right first time. These changes will have a positive impact on all clients and it is likely that a significant proportion of people with a cancer diagnosis will experience direct positive benefits as a result of the changes the Scottish Government is making.

The Scottish Government is providing a fast tracked application and payment process for people who are terminally ill. The DWP already do this but we have changed the definition of terminal illness from that used by the UK Government, to remove arbitrary time constraints and ensure decisions are better informed by clinical judgement.

Research has been undertaken into how this new definition of terminal illness may impact on people receiving ADP, including those with cancer. The research, detailed in *"Estimating the Impact of the New Definition of Terminal Illness for Disability Assistance in Scotland*", indicates that the number of people with cancer accessing ADP using the fast tracked process will more than double, compared to DWP fast tracking to Personal Independence Payment (PIP). It is estimated that

the number of terminally ill ADP recipients who have cancer will increase from 2,800 to approximately 8,200, under the new ADP definition of terminal illness. In practice, it is projected that the majority of ADP recipients with cancer (62%) will be able to use fast tracked processes due to our new definition of terminal illness. This compares with less than a third of PIP recipients with cancer who are regarded as terminally ill and have been fast tracked for payment through PIP by DWP.

The Scottish Government appreciates that the revised fast tracking process will not be available to everyone with a cancer diagnosis. For people with cancer who are not regarded as terminally ill, they will benefit from a range of other changes that will significantly improve how decisions are made. For example, the Scottish Government will aim to collect only one piece of supporting information from a formal source, such as from a GP or a support worker. This information only needs to determine, on the balance of probabilities, that the individual's condition is consistent with the needs detailed on their application. Useful insights can be provided by a client's informal support network including family, friends, or unpaid carers, and under the Scottish Government's approach equal consideration will be given to all sources of information. This is a departure from the current DWP system which requires formal supporting information to evidence each and every difficulty reported.

Additionally, the Scottish Government will not conduct any functional examinations as part of a consultation, as is done by DWP. The Scottish Government does not believe that functional examinations meet our values of fairness, dignity and respect. Instead an ADP consultation will be a discussion between a client and a practitioner employed by Social Security Scotland, and will be based on a position of trust.

If a practitioner makes an informal observation during a consultation, they will inform the client of this and any inferences. The client, or person accompanying them, will be given the opportunity to respond to the observations. This is a significant change to the current DWP system where an assessor can make assumptions about the client without telling them, and can do so before or after the assessment has taken place.

Cancer Treatment Support

The Scottish Government has initiated a number of programmes which help to support cancer patients as they are navigating their cancer pathway and are actively receiving treatment. These include the flagship single point of contact initiative, which seeks to provide a single, easy to access point of contact to help navigate the clinical pathway. In addition, the *Transforming Cancer Care* programme with Macmillan Cancer Support aims to ensure all cancer patients have a key support worker to aid with their mental, emotional, and financial wellbeing.

Separate Fast Tracking for People with Cancer

The Scottish Government's approach is to provide a person-centred service and not prioritise any single condition or type of disability above any other. This is the fairest way to provide our social security service and ensure that individual access to benefits is managed equitably. The enhanced procedures the Scottish Government is putting in place will significantly broaden fast tracked payments to people with cancer. Therefore the Scottish Government does not support an additional fast track procedure specifically for people with cancer. Everyone deserves the best possible service that can be provided and that is what we intend to provide, no matter what their illness or condition.

Petitioner submission of 26 January 2022 PE1913/B - Fast-track future Adult Disability Payment applications for people undergoing cancer treatment

I have had around thirty people tell me their horror stories of people to have tubes inserted to feed them and told they not entitled to PIP as it is not affecting their lives enough or they have not received their PIP until treatment finished around 20 weeks after.

I can only give details of what my family member is going through. He was told last February that he has uncurable blood cancer and he had the highest dose of radiotherapy for the cytoma on his back. He has not been able to give up work for this and has only had 2 weeks off. He is now going for a by-op on his left kidney as he has a growth there which is probably due to his treatment.

He was told that although he has this, it is not affecting his life enough. He is at the moment getting no PIP and his future treatments may not happen as we can't afford the travel cost or for me to take time of work. The result of patients not getting financial help is 3 times as much stress and they don't recover quickly, it takes longer. My family member also has PVD in both legs and can't walk down street and he suffers from fibre myalgia syndrome which means he is pain 24/7. These people like my family member didn't ask for this and has worked hard all his life and they feel like their lives are worth nothing. We don't allow animals to suffer like this so why are we doing it to cancer patients.