# Citizen Participation and Public Petitions Committee

9th Meeting, 2022 (Session 6), Wednesday 18 May 2022

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

# Note by the Clerk

Lodged on 30 November 2021

Petitioner Wendy Swain

**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.

 Webpage
 https://petitions.parliament.scot/petitions/PE1913

#### Introduction

- 1. The Committee last considered this petition at its meeting on <u>2 February 2022</u>. At that meeting, the Committee agreed to write to Macmillan Cancer Support and Cancer Research UK.
- 2. The petition summary is included in **Annexe A** and the Official Report of the Committee's last consideration of this petition is at **Annexe B**.
- 3. The Committee has received new responses from Cancer Research UK and Macmillan Cancer Support Scotland which are set out in **Annexe C**.
- 4. Written submissions received prior to the Committee's last consideration can be found on the <u>petition's webpage</u>.

- 5. Further background information about this petition can be found in the <u>SPICe</u> <u>briefing</u> for this petition.
- 6. The Scottish Government's initial position on this petition can be found on the <u>petition's webpage</u>.

#### Action

The Committee is invited to consider what action it wishes to take.

#### Clerk to the Committee

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

Petitioner Wendy Swain

Date lodged 30/11/2021

#### 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

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.

### **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.

# Annexe B

# Extract from Official Report of last consideration of PE1913 on 2 February 2022

**The Convener:** Under item 3, we have just one new petition to consider. As I say to any petitioner tuning in for the first time, in advance of our consideration of a new petition we send it to the Scottish Government to seek its views so that our discussion is just a little bit better informed before we launch into consideration of it.

PE1913 has been lodged by Wendy Swain and it calls on the Scottish Parliament to urge the Scottish Government to create a separate department in Social Security Scotland that will fast-track future adult disability payment applications for people with a cancer diagnosis while they are undergoing treatment.

I am delighted to welcome Martin Whitfield, who is joining the committee on his first visit to the public petitions process, I think. We will hear from him in a moment, but first I will provide some further background on the petition.

Adult disability payment will replace personal independence payment in 2022. The Scottish Government's submission states that the definition of terminal illness will be changed under ADP to remove arbitrary time constraints and ensure that decisions are better informed by clinical judgment. Research into the impact of the new definition has revealed that the number of people with cancer accessing ADP using the fast-track process will more than double compared to Department for Work and Pensions 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—a whopping increase—and it is projected that a majority of ADP recipients with cancer, 62 per cent, will be able to use fast-tracked processes, compared with less than a third who were able to do so under PIP. Further changes to the delivery of disability benefits through ADP are detailed in the clerk's note. The Scottish Government has stated that it does not support an additional fast-track route specifically for people with cancer and that its approach will not prioritise any single condition over another.

The petitioner shares the experience of her family member who has incurable blood cancer and who has been told that his illness is not affecting his life enough for him to receive PIP.

Before the committee considers the petition, I welcome Martin Whitfield and invite him to speak in support of it.

**Martin Whitfield (South Scotland) (Lab):** Thank you very much, convener, and good morning to you and the committee. A very educational morning it has been too, listening to your debates.

I thank Wendy Swain for lodging the petition. She has shared family circumstances that are incredibly trying. This Friday is of course world cancer awareness day, so it is perhaps apt, if only coincidental, that this petition should come before your committee this week.

We are at the moment of transition from PIP, which ia Westminster-controlled benefit, to ADP here in Scotland, where one of the great promises of devolution is the ability to do things differently. I welcome the additional submissions that the petitioner has made, which very eloquently express the circumstances of her family. I thank the Scottish Parliament information centre and your clerks for the accompanying notes.

I understand why the substantive part of the Government's response of 1 December relates to the changes for this benefit in respect of terminal illness, but not all cancers are terminal, thankfully. Nevertheless, cancers affect every individual and their family when they receive that diagnosis. The petitioner's intention was to raise awareness of the circumstances where cancer is not identified as terminal early on in the diagnosis but the effects are still enormous and substantial. I can do no more than highlight the original background information that the petitioner gave, which was that she lodged the petition 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."

That treatment needs to begin very swiftly and it is at that point that the financial impact of cancer hits families—and hits them very hard.

I know that the Government has said that it does not want to prioritise how it deals with applications by condition but merely wants to base it on the terminality of the condition. It has said—I think that we are all in agreement with this—that it hopes that the voyage of any claimant is far better under ADP than ever it was under PIP. That is both applauded and welcome.

However, the petition talks about the effect of a cancer diagnosis and how that was exacerbated by the experience that the petitioner had with a family member trying to obtain PIP and the stress and almost mental harassment that occurred because of events that were outwith the individual's control. We need to have a fast-tracked system for people with cancer. It is certainly one of the few conditions where the mere name of it sends a shudder of fear through people who have not experienced it. People who receive a cancer diagnosis are often in difficult circumstances and to then have the financial barriers that loom so quickly afterwards is enormously challenging.

Because of the week that we are in but also because we are currently designing what this benefit will look like in Scotland, there is an opportunity to understand

through the charity and third sector organisations that deal with cancer how widespread this problem is and why dealing with it quickly is of huge benefit to those who are going through the system. Thank you, convener.

**The Convener:** Thank you for that contribution, Mr Whitfield, and particularly on behalf of the petitioner. Notwithstanding how this is subsequently resolved, when someone is told that their illness is not affecting their life enough, I wonder how that definition is arrived at and whether the person imparting that sage advice would feel much the same way if it was being imparted back to them in return. It seems to me remarkably unsympathetic.

Colleagues, are there any suggestions how we might proceed?

**David Torrance:** I would like to keep the petition open. We should write to the charities Macmillan Cancer Support and Cancer Research UK to seek their views on what the petitioner is calling for but also to seek their views on how improvements by the Scottish Government will affect payments for people.

Alexander Stewart: As Mark Whitfield indicated in his presentation, we have an opportunity here to engage with the third sector. We talk about dignity, fairness and respect, and I think that it fits those criteria for us to at least investigate this matter for those individuals going through the horrific experience of being given such news and having to cope. The third sector organisations have a wealth of knowledge and experience of what takes place with individuals who are suffering, so it would be very beneficial to have their input as well as to find out from the Scottish Government how it wants to progress this. We should keep the petition going so that we can clarify that and take further information and evidence.

The Convener: Are we content with those proposals? We will keep the petition open and we will write to the organisations as summarised. I thank Mr Whitfield for joining us this morning. We will hear and consider the petition further when we have received responses to those inquiries.

That concludes the open part of this morning's meeting. I thank those people who have been following our proceedings and we will now move into private session.

# Annexe C

# Cancer Research UK submission of 17 February 2022

PE1913/C – Fast-track future Adult Disability Payment applications for people undergoing cancer treatment

Thank you for giving Cancer Research UK (CRUK) the opportunity to respond to the above public petition.

CRUK provides people with general advice on coping with cancer, including practical matters such as money. But the specific issue raised in the petition is something which lies outside of CRUK's policy expertise. We regret, therefore, that we are unable to offer any substantive views on the petition.

We understand, however, that Macmillan Cancer Support have also been contacted and we hope they will be better placed to provide insights to the committee. I am also arranging for the petition to be drawn to the attention of the members of the Scottish Cancer Coalition, some of whom provide people with support on matters such as benefits. I hope Coalition members will be able to offer the committee some assistance.

I am sorry that we are unable to supply a detailed response, but I hope this letter is helpful nonetheless.

# Macmillan Cancer Support Scotland submission of 8 March 2022 PE1913/D - Fast-track future Adult Disability Payment applications for people undergoing cancer treatment

Thank you very much for offering Macmillan Cancer Support the opportunity to contribute to your Committee's assessment of this newly devolved social security matter and the very real issues raised by the Petitioner Wendy Swain.

As a brief background, Macmillan Cancer Support has long experience of dealing with the welfare system across the UK on a practical level. Macmillan employ staff across the UK as Benefits Advisers to support cancer patients through the social security system – and we have thousands of nurses and support staff who sign-post patients to our benefits advisers and those of Citizens Advice and other organisations.

On a policy level, we regularly engage with UK Ministers and the DWP – and since the beginning of devolution of welfare powers to Holyrood we have worked with the civil service, Scottish Government Ministers, MSPs and the new Scottish Social Security Agency (SSSA) to help them with our understanding of the cancer patient journey through the benefits system, and to lobby for faster benefit application times.

On the back of this petition, Macmillan would like the Committee to urge the Scottish Government to ensure the new system of Adult Disability Payment in Scotland has the following principles:

- Processing times for benefits applications are published regularly by the new SSSA so that we can all clearly monitor any delays – broken down by condition to help understand the situation raised by the Petitioner
- 2. Processing times for special rules cases (those with a Terminal Illness) are kept to the bare minimum of around a few days that we currently see from the DWP
- 3. The processing times for applications for normal rules (nonterminal patients) are far too long as the Petitioner

explains. Clear targets should be set to reduce these to 11 weeks or less.

4. Where possible, the system should maximise the use of paperbased assessments and make greater use of evidence from medical professionals, in order to avoid unnecessary face to face assessments. We welcome SSSA's emphasis on limiting face to face assessments.