

## **Note of Joint Meeting of Cross Party Groups on MS & Epilepsy, 9<sup>th</sup> December 2020**

### **In Attendance:**

Alan Steven, Alasdair Allan MSP, Angela Feharty, Anna Telfer, Cassie Paterson, Carole McCartney, Chrissie Waters, Colleen Wilson, George Adam MSP, Gill Dickson, Helen MacDonald, Jacqui Downs, Jenny Sully, John Finnie MSP, John Thomson, Keith Robson, Keith Park, Mark Bevan, Linda Mason, Lorraine Mackenzie, Margaret Campbell, Michael McCulloch, Morna Simpkins, Nikola Plunkett, Phil Sully, Philip Robinson, Rebecca Marshall, Ian Morrison, Rona Johnson, Shirley-Anne Sommerville MSP, Stacey Adam, Stuart Milne, Tanith Muller.

### **Apologies**

Mary Douglas, Rachel Morrison

### **1 Welcome and Introductions**

George Adam MSP welcomed everyone and thanked the Cabinet Secretary for Social Security and Older People for attending the joint MS and Epilepsy CPG.

### **2 Joint meeting of CPGs on Epilepsy and MS on Social Security in Scotland**

The Cabinet Secretary thanked both CPGs for the invitation to speak and explained that she would attempt to answer all questions on Social Security Scotland and that she would give an update as to where things stood presently.

- There was an acknowledgement that people felt let down by the current system and have had poor experiences with the DWP.
- Social Security Scotland (SSS) should be a system that will support people and treat people with dignity and respect.
- COVID 19 has had an impact on the roll out of the devolved powers but SSS has continue to deliver changes.
- 3 new benefits were introduced during lockdown along with an increase in funds available for the welfare fund. There is also an additional coronavirus carers supplement which means that carers in Scotland received £690 more than elsewhere in the UK.

- There have been changes to the timetable of rolling out devolved benefits but these were unavoidable due to the impact of the pandemic.
- Still intend to have full transfer of all payments by 2025; however payments will not be put at risk by transferring them too quickly.
- New timetable for Child Disability Payment means that there will be a pilot launched in Summer 2021 with full roll out by Autumn 2021.
- New Timetable for Adult Disability Payment means that there will be a pilot launched in Spring 2022 with full roll out by Summer 2022.
- People with fluctuating conditions feel failed by the system but there is a commitment to ensure that people can access the best possible care and support.
- SSS staff delivering the system will be empowered to make quality person centred decisions. The process will be explained to clients beforehand so they understand what information is needed and why it is needed. They will also be supported to gather this information in the best way to support their application. This new approach will also support people that are struggling to get a diagnosis
- There will be no functional assessments; it will be a discussion between SSS practitioner and client, this will only happen in cases where necessary information cannot be obtained from the application form and the supporting documents and information
- It is important that people with lived experience have co-designed the system and are also being consulted on the application process, the forms, the consultations etc to ensure the process is clear and accessible.
- The duration of an award will increase for people whose condition will not improve and SSS will reduce the number of unnecessary reassessments.

## Q&A

GA: People transferring from PIP are very nervous is there anything that will allay those fears? Can you explain the issues with DWP.

Cab Sec: We'll minimise the effort for individuals in case transfer with onus / responsibility on Agency. For lots of people this will be their first experience with us, so we have to make it good. We're testing our processes so they're as seamless as possible with no forms to fill in. We don't always have the easiest relationship with DWP but devolution of benefits is only a tiny part of what they do and they are under a lot of pressure with Covid.

Political issues are also arising in terms of what impact any changes rolled out in Scotland may have for UK benefits.

LMcK: Why are women of pension age losing out on additional Coronavirus payment?

Cab Sec: There is a challenge on how to deliver additional payments to Carers as the quickest way to do this was with DWP data and this didn't identify these people. When we have all of our own data, we will be able to address issues like this. At present, the DWP pay Carers Allowance and SSS have paid the additional Carers payment based on who gets Carers allowance; SSS cannot change the eligibility for this. There will be consultation on Carers Allowance in future.

LMcK: Will this be backdated when Carers Allowance is devolved?

Cab Sec: The timetable for Carers Allowance consultation has not been announced and will be a joint programme of work with the DWP to transfer this benefit. Work on this will start again soon and at the appropriate time Parliament will be updated. It will be a number of years before it is transferred. We would like to go quicker but it takes time.

LM: If you are still receiving DLA will you need to transfer to PIP before you are eligible to transfer to Adult Disability Payment?

Cab Sec: We're thinking about the best way to do this. We've asked the DWP to stop transferring people from DLA to PIP (unless they want to or there's a change of circumstances) to reduce stress that may occur during reassessment process. We won't insist people move directly to ADP and want this to be a less stressful transition.

AS: Will the Scottish ADP payment be the same as PIP?

Fatigue and brain fog are daily occurrences for people living with MS and these are not recognised in current system will the new assessment address this?

Cab Sec: The first priority is a safe and secure transition and there will be no fundamental changes. If payments were increased, the DWP would need to agree to this due to the impact on passported benefits. The payment levels and benefit structures will be the same but the approach will change. The application form needs to be right so that all the necessary important information is gathered, so SSS can make their assessment. If a consultation is required it will be to gather further different information and will not be a functional assessment. The application forms will be tested repeatedly to ensure that SSS get them right. Not sure if MSS and Epilepsy Scotland will be involved in consultation but the involvement of the third sector and people living with both epilepsy and MS would be welcomed.

Leuchie House and our guests:

Many people and their carers' in receipt of health and social care services face distress and harm as a result of being arbitrarily moved from Adult to Older People's services. This can lead to an immediate reduction in funding for short breaks and respite, despite no change in the person's need for them. Will the Scottish Government review this with an aim to ensure that funding for respite care follows the need of the person and their carer(s) and not their age?"

Cab Sec: This touches outside my portfolio but transitions are an area that need to be looked at whether it is children to adult or adult to older people services. Decisions need to be person-centred and the Scottish Government (SG) has overall responsibility but it is generally delivered by NHS boards and local authorities. SG has a role to review and address this and there is an overall responsibility to assess the individual and not their age.

MD: Would be interested to know what, if any additional support, will be offered to carers, including respite funding.

Cab Sec: Everyone knows access to respite has been a challenge during the pandemic with services closed but they can reopen albeit with a reduced capacity. They can operate in areas in tiers 0-3 and guidance is in place to safely facilitate this. There is a frustration that this is not necessarily happening at present. Additional funding has been made available within the short breaks fund.

CW: Can you expand on the training and guidance that will be given to SSS staff?

Cab Sec: Most important way to get this right is to co-design with people who have lived experience. The engagement process was paused due to COVID but has started again. A number of sessions will take place to review the assessment form and SSS will be broadening the net to get more people involved in this.

In terms of guidance it is as important that we get stakeholder feedback while drafting the guidance that people receive.

RJ: What will the transfer from DWP to SSS look like?

Cab Sec: Case transfer process will start when the new payments are launched with the intention for this to be complete by 2025. This is a joint programme with the DWP so could be slowed as a result. Transfer is complicated as the DWP is not just one system and requires information to be transferred from a really complex system that may not actually

contain all the necessary information. As more information is being transferred it is becoming more apparent how complicated this is.

It will be up to SSS to identify when people are due for reassessment for PIP and will transfer these cases first.

GD: Once the system is in place and assessments are working well, will SSS engage with the third sector in relation to rarer neurological conditions?

Cab Sec: the system needs to work for all and there is never going to be one person who is an expert in everything. There will be case managers who in most cases will make the decisions. They can then approach clinical practitioners for advice and guidance on more complex cases but there needs to be an ability to realise when people are not experts and bring in expert knowledge to support decision making when required.

GD: At present people with progressive conditions need more than reassurance but an ability to advocate for themselves.

Cab Sec: There is a fear of telling DWP that they have progressed in case their award gets taken off them and they lose their benefit. If people deteriorate they need to have the confidence to engage and start discussions about getting their benefits increased as appropriate.

LMcK: My son is in supported accommodation and is paying an ever increasing amount out of his benefits to local authority for housing support.

Cab Sec: This is out with my area of expertise and I will take this away and feedback information through the CPG.

KR: Can you share with us the Disability Assistance consultation timeline?

Cab Sec: This is currently sitting with Cabinet Secretary and it is hoped that it will be launched before Christmas. .

The question and answer session came to a close and George Adam MSP thanked the Cabinet Secretary for taking the time to attend the meeting.

### **3 Matters Arising from previous meeting**

#### **CPG on Epilepsy**

Alisdair Allan MSP conducted the business of the meeting.

There were no matters arising from the meeting on the 1<sup>st</sup> of October and there were no corrections to be made to the draft minutes that were circulated.

The minutes were proposed by Rona Johnson and seconded by Anna Telfer

## **Update**

The Cabinet Secretary for health will appoint a Patient Safety Commissioner who will be responsible for the implementing the recommendations in the Cumberland report. This will address the issues around sodium valproate and the people that suffered avoidable harm. RJ will circulate more information about this.

Round 1 of funding from the Neurological Framework has allocated £500,000.

A study has been published that explored the impact of COVID 19 on people living with Epilepsy. This shows that people with epilepsy are more likely to experience symptoms than the general public and that these symptoms are generally worse than normal. It is therefore really important to follow the public health advice.

## **CPG on MS**

George Adam MSP conducted the business for the meeting.

The minutes for the meeting on 3<sup>rd</sup> of February were proposed by Ian Morrison and seconded by Keith Robson. There were no matters arising.

The minutes for the meeting on the 9<sup>th</sup> of September were proposed by John Finnie MSP and seconded by Keith Robson.

The minutes for the meeting on the 30<sup>th</sup> of September were proposed by George Adam MSP and seconded by Keith Robson.

At this meeting it was agreed that the CPG should make a submission to the inquiry on the impact of the Covid-19 pandemic on Equalities and Human Rights. This submission was shared with the elected officials for sign off and then forwarded to the inquiry.

John Finnie MSP thanked Keith Robson for collating the submission.

## **4 Update on Treatments and Research (CPG on MS)**

A briefing was circulated prior to the meeting to the members.

## **5 AOCB**

Morna Simpkins highlighted that it was Keith Robson's last CPG as an MS Society employee. She thanked him for all his efforts and work during the time he worked at the Society.

George Adam MSP as convenor also took the opportunity to mark Keith's last meeting and thank him for all the work and support he has given during the past three years. GA wished Keith all the best for the future.

Ian Morrison asked about the COVID vaccination priority list and where 3<sup>rd</sup> Sector clinical staff would be on this list.

GA will try to get an answer and get back to IM.

**i. Future Dates of CPG on epilepsy meeting:**

- February 2021, exact date TBC, virtual

**ii. Future Dates of CPG on MS meeting:**

- 3 February 2021, Room TG20.21 or virtual TBC

George Adam MSP thanked everyone for attending and closed the meeting.