

Note of Meeting – Joint Cross- Party Group on Epilepsy and MS, 09 December 2020
Held virtually via Zoom

In Attendance:

Alan Steven	Alasdair Allan MSP
Angela Feharty	Anna Telfer, Epilepsy Scotland
Carol Wilson, Epilepsy Connections	Carole Macarthey
Cassie Paterson	Chrissie Watters, Scottish MS Register
Colleen Wilson, Epilepsy Connections	George Adam MSP
Gill Dickson, PSPA	Helen MacDonald
Jacqui Downs, NHS Ayrshire and Arran	Jenny Sully
John Finnie MSP	John Thomson, Eisai Ltd
Keith Robson, MS Society Scotland	Keith Park, MS Society Scotland
Mark Bevan, Leuchie House	Linda Mason
Lorraine MacKenzie	Margaret Campbell
Michael McCulloch	Morna Simpkins, MS Society Scotland
Nikola Plunkett	Phil Sully, Coloplast
Philip Robinson, Lanarkshire Epilepsy	Rebecca Marshall, Mindroom
Ian Morrison, Revive MS Support	Rona Johnson, Epilepsy Scotland
Shirley-Anne Somerville, Cabinet Secretary for Social Security and Older People	Stacey Adam
Stuart Milne, MS Society Scotland	Tanith Muller, Neurological Alliance of Scotland

Apologies:

Kenneth Gibson MSP	Jo Campbell
Ailsa McClellan	Sylvia Lawrie
Mary Antczak	Chris Jeans
Celia Brand	Hilary Mounfield
John Bruce	

1. Convener George Adam MSP welcomed attendees and introduced the Cabinet Secretary for Social Security and Older People.
2. The Cabinet Secretary for Social Security and Older People, Shirley-Anne Somerville MSP, discussed the latest developments in devolution of benefits.

Shirley-Anne Somerville MSP, Cabinet Secretary for Social Security and Older People:

During Covid-19, the Scottish Government introduced three new funds and increased funds for the Welfare Fund. Moreover, the Scottish Government introduced an additional coronavirus carers supplement which amounted to £690 more for carers in Scotland than elsewhere in the UK.

The impact of Covid-19 was too great to stick to the devolution of social security schedule that had been planned – up until Covid-19, the agency was on schedule. They are still on track to fully complete transfer of benefits by 2025.

The Adult Disability Payment (replacing Personal Independence Payment (PIP)) is due to be piloted in Spring 2022, with the plan for it to be fully rolled out by Summer 2022. Once rolled out, people who are in the existing system will begin to transfer over to Social Security Scotland.

The Cabinet Secretary acknowledges that people with fluctuating conditions feel failed by the Department for Work and Pensions (DWP). Social Security Scotland staff will be empowered to fully consider the needs of individuals. Robust training will be rolled out to provide a quality service, with an emphasis person-centred decisions. They have an understanding of what works, and what doesn't.

The new system will ensure people understand how and when applications will be dealt with. Clients will receive support during the application process by people who know what, why and the best way to fill in application form to get maximum entitlement they are due.

In contrast with the current system, the length of award will change – the duration of an award will increase where it is unlikely an individual's condition will change or improve. Face to face consultation discussions will be carried out only as a last resort, by social security practitioners. These will only be carried out when information cannot be obtained in another way. The process will be explained to clients beforehand. Functional assessments are a poor way to make decisions about people, and so there will be none of those in the new Social Security Scotland consultations. Scottish Government and Social Security Scotland are still currently working with people with lived experience to redesign the system and make improvements.

The Child Disability Payment will commence with a pilot in Summer 2021, full rollout by Autumn 2021.

One of the Scottish Government's key considerations is how they move people over safely and securely, so they don't have to do this themselves. Clients should not have to jump through hoops, this is the responsibility of the agency and the Government.

3. George Adam MSP thanked the Cabinet Secretary for her update on the devolution of social security and opened the meeting to questions from members.

George Adam MSP: Question regarding the relationship between DWP and Social Security Scotland (SSS)

Cabinet Secretary, Shirley-Anne Somerville MSP: DWP have different political views of social security and how it should be delivered.

Lorraine MacKenzie: Question regarding Carers Allowance, eligibility and questioning why pensioners are missing out on the Covid supplements. Noted those over 65 are still carers and need support. Asked if the money certain people have missed out on will be backdated, and when is the system likely to change?

Cabinet Secretary: When it comes to the Carers Allowance, SSS cannot change the eligibility for that. They deemed the easiest way to support carers was through the Corona payment. With the system we have at the moment, there isn't a way to pay carers who are pensioners.

The timeline for Carers Allowance was inevitably affected by Covid, and they are yet to announce a revised date for this. The agency are currently delivering 9 benefits.

Linda Mason: If you are not on PIP yet, and still on DLA, will you go straight to Adult Disability Payment directly or will you have to go via PIP?

Cabinet Secretary: They are keen to ask the DWP to stop transferring people onto PIP and hold them on DLA. They aim to prevent stress of going onto PIP for a short period of time. They are currently looking carefully at people on DLA, and are trying to avoid making them go through a protracted process.

Alan Steven: Will the Scottish version of PIP be paid at the same level or better than the current system? Also, changes in assessments, can fatigue accompanied with brain fog be given greater recognition than at present?

Cabinet Secretary: Their first priority is a safe and secure transition. Not to make fundamental changes to existing benefits and rules (e.g. changing amount to payment/ extend eligibility) DWP would have concerns and opinions as this could affect levels paid in passported benefits. Payments and benefit structure will be the same – but system will be very different. We need the application form to be right so people don't need to go near a consultation, and to make sure people can get the information across that they need. Decision can be made and consultation done in a different way when needed: eg, information we gather (a person who knows someone well: family member, carer etc.). If we get the design right at the start we know with confidence that it will work for you. The MS Society and Epilepsy Scotland will have the opportunity to test the form and feed back in the consultation in the new year.

Leuchie house: For those passing 65, re-assessment almost always disadvantages older people receiving care e.g. respite and by extension, Carers.

Cabinet Secretary: This particular issue seems more about health and social care rather than social security. But it is something they need to look at - people's transitions throughout their life, child to adult, adult to pensioner etc.

Question: Respite services during the pandemic - access to respite has been a real challenge. Frustration that in some areas, respite isn't opening and happening.

Cabinet Secretary: Flagged the additional funding in the short breaks fund and the guidance to help respite to continue.

Colleen Wilson: Can you expand on the robust guidance and training that Social Security Scotland staff will receive?

Cabinet Secretary: Organisations involved: inclusion Scotland, Glasgow disability alliance. Conversation on how we're broadening out net further in the New Year to get more people involved in the user research. When it comes to guidance, very keen to get feedback on guidance. Equally important is the guidance in front of people when making the decisions. Want feedback on this too. Hopefully, this will help us ensure the guidance is fit for purpose.

Lorraine MacKenzie: Said her son lives in supported accommodation and is paying an ever-increasing amount out of his benefits to the local authority for housing support.

Cabinet Secretary: Said this was out with her area of expertise and will take this away and feedback information through the CPG.

Rona Johnson: What will the transfer from DWP to SSS look like? Can we expect everyone in Scotland to be receiving Adult Disability Payment by Autumn 2022? Or will people be transferred when their PIP review comes through?

Cabinet Secretary: The case transfer process will start once we've launched the adult disability payment. Want to get to the place where we've finished case transfer by 2025. Case transfer is one of the most complicated areas because the DWP isn't one system – it is lots of systems patched together. Some parts of the system haven't been updated in decades. It is hard to pull this information - case transfer is the biggest technical challenge so far. It will be the responsibility of SSS to identify people who are up for PIP reassessment, and transfer people over – these will be priority cases. They recognise that people will be cautious/reluctant due to negative experiences in the past.

Gill Dickson: In rarer forms of neurological conditions, even the health & social care practitioners are unfamiliar with the features of the conditions - will the training of the assessors formally involve third sector orgs who have a lot of expert knowledge?

Cabinet Secretary: There will be a case manager that will look at each case: if it's simple, they can make a decision. If it is not simple, then they can go to a practitioner that works at SSS. It isn't going to be the practitioner for everything – they will know where expertise lie and how we can pull that in. How can we get in house service as good as it can, but then if that has gone as far as it can go, consider how they can pull in external expertise. We want people to have confidence to pick up the phone to agency and have a discussion and be supported to get the maximum entitlement.

Looking forward: The consultation on social security is imminent, potentially due out before Christmas.

4. George Adam MSP thanked the Cabinet Secretary for her attendance at the meeting and moved onto CPG business.

CPG on Epilepsy, Alasdair Allan MSP

- The minutes of the previous meeting in October 2020 were approved.
- Updates since the last meeting:
 - o Following recommendations in the Cumberlege Review, the Cabinet Secretary for Health, Jeane Freeman, committed to implementing a Patient Safety Commissioner in Scotland. The Scottish Government have begun work to map out what this role will look like by engaging with appropriate groups representing Primodos, pelvic mesh and sodium valproate.
 - o Round one of funding to support the implementation of Scotland's Neurological Care and Support Framework has been allocated. £492,535 was dispersed to various third sector organisations and health boards. Round two of funding is expected to open in 2021.
 - o A new study published in the British Medical Journal has found that people with epilepsy who catch COVID-19 are slightly more likely to suffer from more severe symptoms like hospitalisation. In light of this, people with epilepsy have been considered a priority by the Joint Committee on Vaccination and Immunisation to receive the COVID-19 vaccine. In the meantime, prior to getting vaccinated, all people with epilepsy should be extra mindful of the public health advice.

- The next CPG meeting on epilepsy will be held virtually 26th February 2021, 1-2pm. The meeting will focus on the video sharing platform VCreateNeuro.

CPG on MS, George Adam MSP

- Minutes of the previous three meetings were approved and AOBC were discussed.

George Adam MSP thanked all for their attendance and closed the meeting.