

Cross Party Group on Multiple Sclerosis (MS)

Minutes

**Tuesday 19 September 2017
6 pm – 8 pm
Scottish Parliament – TG20.21**

Attendees: Stacey Adam, Yasmin Fraser, Nigel Graham, Iain Morrison, Greg Stevenson, Becky Duff, Morna Simpkins, Niall Sommerville, Nicola Sinclair, Jacquie Downs, Helen Walsh, Bill Scott, Mairi O'Keefe, Angela McCormack, Steven McAvoy, Pat McAuley

MSP Attendees: George Adam MSP, John Finnie MSP, Jeane Freeman MSP (by invite)

Apologies: Donald Cameron MSP, Annie Wells MSP, Neil Findlay MSP, Ruth Sumpter, Judith MacSween, Mervyn Graham, Claire Cairns, Belinda Weller, Marion Butchart, Elizabeth Quigley, Elinor Jayne

1. Welcome

George Adam MSP welcomed guests to the CPG. It was agreed that we would move straight into agenda item 3 on social security.

2. Social Security – Jeane Freeman MSP – Minister for Social Security

The CPG invited the Minister for Social Security, Jeane Freeman MSP, to attend the meeting and answer questions on the creation of the new social security system for Scotland. The changes will have a big impact on people with MS and it is hoped will create a fairer and more accessible disability benefits system.

The session opened with scene setting from Niall Sommerville, MS Society Scotland, Bill Scott, Inclusion Scotland, and Stephen McAvoy, Enable Scotland. They talked through their organisations points of agreement with the bill and potential areas for improvement. These included welcoming the principles and human rights approach; the reintroduction of long term awards; reduction of face to face assessments; as well as calling for more to be on the face of the bill; clarity around advice and advocacy provision; and further information on the mechanisms for reconsidering awards.

The Minister responded to the comments and talked through various aspects of the proposed new system. She mentioned the plans for the original application and eligibility process, the need for evidence to come from the most relevant source, support for a reduction in face to face assessments and the need for specialist assessors where a face to face assessment is absolutely necessary. The Minister also addressed the issues of uprating, advocacy, and the potential for more

elements to be added to the face of the Bill. On redeterminations, the intention is to ensure the decision is right first time, however, where this may not have been done a second decision maker would run the whole process again and seek their own evidence. Finally, on the issue of scrutiny she felt it was for the Parliament to decide how the legislation and future agency should be scrutinised, not for the Government to decide this.

Mairi O'Keefe asked how the subjectivity of assessors would be ensured and mentioned the potential role of organisations such as Leuchie House in providing evidence to the new system. The Minister said that applicants would be able to point towards organisations like Leuchie House for evidence. Subjectivity of assessors/assessments will be ensured through performance measures and duties on Ministers.

Morna Simpkins noted previous comments from the Minister about there being less focus on the prescription list in determining awards. The Minister agreed and noted MS as an example of a condition where people may not take treatments they are eligible for due to side effects, etc.

Bill Scott discussed the difference between advice and advocacy noting that regardless of how good the system is there will always be a need for advocacy support for some people. Angela McCormack added about her experience as an independent advocate and how the advocate can help decision makers get the relevant information. The Minister agreed that the Govt has perhaps been too narrow in its thinking about advocacy and they will relook at this. Steven McAvoy felt that judicial review should also be relooked at in terms of how money is recovered.

Becky Duff asked how we can ensure health professionals have the capacity to provide evidence and how do we get systems from the third sector to 'talk' to the public sector. The Minister noted there is currently a lot of protectionism of data. She said the intention is that the new agency can cut through a lot of this to make evidence gathering easier. Currently getting all parties around the table to discuss how the different IT systems can work together.

George Adam MSP asked the Minister to address the point of how we ensure the system works on the day of transfer. The Minister explained there are 11 benefits affecting around 1.4million people and they need to work seamlessly with other UK benefits. One of the biggest challenges is unpicking the complex systems and structures the DWP currently has for each of these benefits, they all operate on different systems and data is stored very differently and not very coherently. That's why the Scottish Govt is taking an incremental approach to taking on new benefits, they will build it up piece by piece to minimise disruption and to learn and adapt as they go.

Iain Morrison spoke about the changing mindset amongst people – saying that people understand the need to get things right from the start and that in order to deliver the rhetoric around a fairer society it will take time to set up a new system.

The CPG thanked the Minister for her time and offered to provide any further evidence to the Government that she felt would be helpful.

3. Election of Office Bearers

The following were elected as office bearers for the upcoming year –

Convenor: George Adam MSP – Proposed by Donald Cameron MSP, seconded by John Finnie MSP

Vice Convenors: John Finnie MSP – Proposed by George Adam MSP, seconded by Donald Cameron MSP

Neil Findlay MSP – Proposed by George Adam MSP, seconded by John Finnie MSP

Donald Cameron MSP – Proposed by George Adam MSP, seconded by John Finnie MSP

Secretariat: MS Society Scotland – Proposed by George Adam MSP, seconded by John Finnie MSP

4. Update on Cladribine

Nigel Graham, Merck Group, noted where the current status of the treatment Cladribine and updated the CPG on progress to date.

5. AOCB

Rebecca Duff gave an update on the nursing situation in Lanarkshire and noted the proposed increase in MS nurse provision from 1 FTE to 2.6 FTE. This has been welcomed by the campaigners and politicians involved. Iain Morrison noted that one of the big issues in Lanarkshire was data about the number of people with MS in the area. Rebecca Duff noted that the NACNC will be undertaking a big piece of work on prevalence data in the near future to try and address this.

Meeting closed at 19:35