

**Cross Party Group on MS  
Minutes of meeting**

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**Date**                    Tuesday 7 October 2014

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**Time**                    18:00 – 19:30

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**Venue**                   Committee Room 5, Scottish Parliament

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**Agenda**

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Introduction and welcome from Lewis Macdonald MSP, Vice Convener

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Minutes of the last meeting

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AGM

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Financial security, welfare reform and MS-Alan Steven, Revive MS Support

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Financial security discussion

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AOCB and date of next meeting

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## Attendees

### MSP Members:

Lewis Macdonald MSP (Vice Convener)  
Neil Findlay MSP  
John Finnie MSP  
Nanette Milne MSP  
Mark McDonald MSP  
Rhoda Grant MSP

### Other attendees:

Iain Morrison	Chief Executive, MS Revive Support
Duane Patterson	MS Specialist Social Worker, Dundee Social Work Department
Merv Graham	Personal interest in MS
Judith MacSween	Speech & Language therapist, and interest in MS
Carole Macartney	Chair, MS Therapy Centre Lothian
Richard Lomas	
Becky Duff	Head of Policy and Communications, MS Society
Martine Douglas	Neurology Business Manager, Biogen Idec - ABPI rep
Karen Swan	Market Access and Government Affairs, Genzyme – EMIG rep
Fiona Burns	Personal interest in MS
Mairi O'Keefe	Chief Executive, Leuchie House
Steven Meldrum	Clinical Neuropsychologist, NHS GG&C
Alan Steven	MS Revive Support
Harry Travers	Chairman, MS Society Ayrshire & Arran branch
Christina Palmer	carer

### Apologies:

George Adam	MSP
Malcolm Chisholm	MSP
Elizabeth Quigley	Personal interest in MS
Anne Stewart	MS Specialist Nurse, NHS Highland
Andrew Johnston	Health Board Vice Chair, Dumfries and Galloway NHS
Moiria Flett	MS Specialist Nurse, NHS Orkney
Cat Johnson	Personal interest in MS
Jacqui Downs	MS Managed Clinical Network Manager, NHS Ayrshire

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## **1 Introduction and welcome from Lewis Macdonald MSP, Vice Convener**

Mr Macdonald welcomed members to the third meeting of the CPG on MS and welcomed our guest speaker Alan Steven from Revive MS Support. He passed on apologies for Convener George Adam.

## **2 Minutes of the last meeting**

The minutes of the meeting on 23/04/14 were agreed.

## **3 AGM**

George Adam MSP had indicated prior to the meeting that he'd be happy to stand for convener again. This was proposed by Nanette Milne MSP and seconded by Mark McDonald MSP. Lewis Macdonald MSP was agreed as Vice Convener by Mark McDonald MSP and Neil Findlay MSP. MS Society was nominated as secretariat by Lewis MacDonald MSP and Nannette Milne MSP.

## **4 Financial security, welfare reform and MS-Alan Steven, Revive MS Support**

The MS CPG welcomed guest speaker Alan Steven from Revive MS Support. Over the last 12 months Alan, who works one day per week, has had 192 encounters (82 different clients) in relation to benefits and welfare by people with MS.

Alan welcomed the MS Society's Voices for Change report, in particular the recommendation that "the UK and Scottish Governments should ensure that there is adequate provision and funding for advice and support services for benefits claimants."

Alan works with people with MS who are applying for benefits including Employment Support Allowance (ESA) and Personal Independence Payment (PIP). Overall Alan had a positive experience of working with DWP. He did acknowledge that Citizens Advice were overburdened, and didn't have the specialist knowledge for people with MS. There are many difficulties for people with MS in applying for benefits, not least the form filling (which typically takes over two hours to answer to 50 plus questions) and the challenges that come with the symptoms of MS, such as fatigue.

Alan gave six examples of people who he has worked with. They had required assistance with a range of issues, including;

- Being put in the wrong group for ESA
- Being awarded a lower rate mobility or caring competent for DLA/PIP
- Appealing decisions
- Debt management due to length of time for payment to be awarded
- Carers allowance
- Long timescales for processing Personal Independence Payment (PIP) claims

## **5 Financial Security discussion**

Mairi O'Keefe commended the work of Alan and Revive. From her experiences she acknowledged that people with MS and other long term conditions cannot always fight for their own rights and get what they're entitled to. She was also aware of the issues around debt many people can face. Mairi went on to ask the MS Society if they would be responding to the Smith commission, MS Society responded that they would be.

Neil Findlay MSP raised the issue of local authorities and their role in supporting people through welfare reform. Mr Findlay commented that, due to large resource cuts in some areas in Scotland, local authorities were not set up in a way that was conducive to supporting people to access benefits. We should be looking at improvements that can be made in this area, such as improved telecoms systems.

Mark McDonald MSP questioned what the MS Society's Voices for Change report had been used for. He also compelled the group to make individual submissions to the Smith commission, as well as as a collective. In particular, Mr McDonald highlighted the important of the MS CPG pressing the issue of the change in criteria for the mobility component, which has negatively impacted people across Scotland.

John Finnie MSP praised the Citizen's Advice Scotland's latest report, "Voices from the Frontline". Mr Finnie also praised the work of SCVO and encouraged other members to work with them on the issues of welfare.

Duane Patterson highlighted the need to make people aware of the help that's out there, in a more accessible and streamlined way.

Rhoda Grant MSP questioned the role of hardship grants in supporting people to stay out of or reduce their debt while their benefits claim goes through. She also flagged the availability of project funding for organisations, and that this may be an avenue to increase the support for people who need help accessing benefits. Ms Grant also raised the issue that people who are terminally ill are sometimes waiting so long for a condition they are no longer alive when the award is finally made.

Iain Morrison highlighted the issues for the Citizen's Advice Bureaux, which include being completely inundated. Also, they do not have the specialist knowledge of MS, long term or fluctuating conditions. MS Revive Support's benefits advisor post is funded through trusts, and this funding is due to end soon. Iain highlighted how important it was that funding criteria be diversified to allow the continued running of vital welfare support services.

Nannette Milne MSP questioned the communication around welfare support, and suggested that the MS annual health review could be used as an opportunity to highlight the support available for people with MS.

Mairi O'Keefe compelled the group to identify opportunities for partnership working, with other long term conditions, Neurological Alliance of Scotland, Health and Social care Alliance and the Scottish Partnership for Palliative Care.

Carole Macartney shared the Lothian Therapy Centre's experience. They are referring people to other agencies such as LCIL and social work departments. Carole highlighted the importance of pathways and effective signposting.

Mark McDonald MSP questioned if there were other CPGs who we could do some joint working with around welfare reform.

Judith MacSween explained that people don't know where to access services. She questioned if health and social care integration presented an opportunity to bring together the health and the day to day realities and requirements of living with a condition. Judith also explained that often pathways are reactive to crisis rather than preventative. Anticipating that next step can be very difficult. She also questioned the role of health care professionals in signposting to other support.

Merv Graham praised the Lanfine unit (NHS Lothian) who offer support with filling in benefits forms. He explained that they can look at what you need compared to what you are getting, and help people to bridge that gap.

Henry Traverse explained that his branch is offering support to people to complete benefits forms. He also highlighted that with a fluctuating condition like MS, you have to be thinking of your worst day to ensure you get the support you need.

## **6 AOCB and date of next meeting**

Becky Duff, MS Society, indicated that she will not be at the next two MS CPG meeting as she is going off on maternity leave. MS Society Scotland Director, Mark O'Donnell will be in attendance and the Policy, Press & Campaigns Manager will be secretariat. In Becky's absence any queries regarding the CPG should be sent to [scotlandcampaigns@mssociety.org.uk](mailto:scotlandcampaigns@mssociety.org.uk)

The next meeting will take place on **Wednesday 14 January** at **6 pm**. The 2014 CPG evaluation and 2015 workplan for the CPG will be discussed and agreed.