

# **Cross Party Group on Multiple Sclerosis (MS)**

## **Minutes**

**Tuesday 29<sup>th</sup> November 2016**

**6 pm – 8 pm**

**Scottish Parliament – TG20.21**

### **Attendees:**

Niall Sommerville, MS Society  
Victoria Holloway, MS Society  
Rebecca Duff, MS Society  
Morna Simpkins, MS Society  
Judith Macsween, NHS Lothian  
Stacey Adam,  
Iain Morrison, Revive MS  
Carole Mccartney, Lothians MS Therapy Centre  
Mairi O'Keefe, Leuchie House  
Matt Lancashire, Remploy Scotland (invited speaker)  
Marion Butchart, Novartis  
Dr Niall MacDougall, NHS Lanarkshire (invited speaker)  
Sam Graham, Biogen  
Merv Graham,  
Jaquie Downs, NHS Ayrshire + Arran

**MSP Attendees:** George Adam MSP, John Finnie MSP, Neil Findlay MSP, Donald Cameron MSP, Claire Adamson MSP

### **1. Welcome and introductions**

George Adam MSP welcomed members to the CPG and noted apologies. Minutes were approved by acclaim

### **2. Employment and MS**

Victoria Holloway from the MS Society gave a presentation on a recent report published by the APPG on MS at Westminster. The report, entitled 'Employment that works – Supporting people with MS in the workplace', was the culmination of a year-long review into whether people with MS have the support they need to stay in, or get back into, work. The report included information garnered from APPG sessions and surveys of the MS community. The report makes a number of recommendations to the UK Government, employers and service providers.

Findings include:

- Almost a third of people who've told their employer about their MS haven't had reasonable adjustments put in place

- A third of employers only offered support to their staff member when their symptoms got worse, despite knowing about their MS
- Almost a third of people with MS in work say they have experienced MS-related stigma or discrimination by colleagues or managers in the past five years.

#### Recommendations include:

- Improve the provision of employment retention support, for example through the Work and Health Programme and Disability Confident.
- Work with employers and progressive condition charities – such as the MS Society – to establish best practice for transitions out of employment for disabled people.
- Consistently recognise that some people cannot work due to their health, and follow through on this understanding in policy and practice. This must include the provision of adequate support for people who cannot work.
- Employment support service providers should ensure their employment programmes engage with employers wherever possible, to facilitate their active involvement in the support of people with MS.
- Employers should adopt policies and practices which promote inclusion and opportunity for disabled employees, and deal quickly and effectively with instances of bullying, harassment or discrimination in the workplace. Wherever possible, employers should adopt a disability absence policy.

#### Discussion:

- Stacey Adam asked what are the chances of seeing these recommendations implemented? Victoria Holloway responded that the Green Paper on Work, Health and Disability, is a real opportunity to push the UK Govt on these asks.
- Iain Morrison said there is a need to move beyond having employers purely meeting legislation; this doesn't fully meet people's needs. The biggest worry for newly diagnosed people is how it will impact their work; we need to drill down to real life examples on this.
- Carol McCartney asked whether there were differences in terms of the way people were treated depending on what level they of seniority at when diagnosed? Victoria Holloway replied that this wasn't captured in the data and that it was more the type of work that was looked at.
- Mairi O'Keefe asked how the MS Society plans to take this forward? Victoria Holloway said that this is the start of the journey on employment work and there is more stats and influencing work to come. Niall Sommerville added the MS Society is looking at opportunities to have these discussions, such as at the CPG, and raising awareness. Employment devolution is a big opportunity in this regard.
- Judith MacSween said that in her experience vocational rehab would have helped and that there remain big gaps – Access to Work scheme very

important. Victoria Holloway noted that one of the issues faced in gathering the evidence was that employers wouldn't admit to issues in the way they treat a person with a disability. Private discussions and awareness raising is still very important.

Matt Lancashire from Remploy provided a background on the work of Remploy and how they support people with a disability into employment. He talked about the devolution of powers on employment and the opportunity this gives Scotland to create improved support for people with a disability. He went on to talk about the recently announced Work First Scotland programme which is one of the first examples of devolved employment support. Remploy will be a key agent in delivering this piece of work. Finally, Matt noted there is a need to build capacity within organisations to better support people with a disability, create champions, and to use the transition of powers to Scotland as an opportunity to try something new.

Discussion:

- Marion Butchart asked what support do people get when diagnosed? Matt Lancashire responded that there is currently a lack of support and lag to when people receive it. He added that Work First Scotland is a positive step change.
- Victoria Holloway added that in England there is a push to have employment regarded as a health outcome, could be a useful approach to consider.
- Mairi O'Keefe raised the issue that often people with MS don't want to tell their employer. She also asked where does the role of the third sector come in? Matt Lancashire replied that there is a real need for employers to be open and to demonstrate to individuals their potential career progression to help keep them in employment. More broadly the third sector certainly has a big role to play, as it currently does in other areas of delivery.

It was agreed by the CPG that due to the devolution of powers around employment and employability to Scotland, the CPG should write to the Scottish Government highlighting the report and asking them to provide a response, stating their vision on supporting disability and employment.

### **3. NHS Lanarkshire and MS**

Dr. Niall MacDougall, Consultant Neurologist NHS Lanarkshire, gave a presentation on the issue of MS nurse provision in Lanarkshire and the impact it was having. He noted:

- MS affects approximately 1 in 421 people in Lanarkshire with an estimated total number of approximately 1554

- There is one MS nurse with a caseload of 1206 patients over a wide geographical area
- Approximately 400 patients in the region are on treatment for RRMS with effective drugs that require close monitoring by the nurse
- The MS nurse has the most patients in Scotland and is vastly over stretched
- The MS Trust has offered to partially fund a new MS nurse in Lanarkshire having identified a critical need. Neurology managers in Lanarkshire are working to try to find additional money to do this
- If the single nurse has an accident, becomes unwell or leaves there will be no service and a lot of patients will be seriously impacted.
- There is no cross cover for the nurse while she is on holiday
- There is inadequate administrative support for the nurse
- The appointment of a consultant with an interest in MS in the region may have improved things a bit but more needs to be done.

Neil Findlay MSP noted that in Health Committee the issue of staffing and resources is one that is constantly raised by health professionals. He asked how we can hold the NHS and Scottish Government to account on this. Further discussion included issues raised around similar resource issues in Lothian and the need for investment in the Scottish MS Register.

It was agreed that following the decision by NHS Lanarkshire and the MS Trust that the CPG would write to the Scottish Government and NHS Lanarkshire, highlighting the issues and seeking answers on what can be done to solve this problem.

#### **4. Fampyra**

Sam Graham from Biogen updated the CPG on the recent decision by the SMC not to recommend Fampyra for use on the NHS. It was noted that it would still be available under IPTRs as previously.

Issues around the submission included challenges around capturing quality of life data using the preferred elicitation instruments and this therefore not meeting the quantitative evidence needs of the SMC. Although the proposed patient access scheme was deemed acceptable, the uncertainty in the underlying clinical benefit rendered fampridine not cost-effective. Sam Graham stated that Biogen remain committed to Fampyra and believe the benefits of it can be shown, it is hoped that a larger study reporting in Q1 2017 will provide good quantitative data and that they are considering a possible resubmission in 2017.

Becky Duff noted that at the SMC meeting it was clear that the Patient Group Submission was well regarded and highly considered as useful evidence to support a submission, particularly in capturing non-quantitative evidence. Sam Graham

noted that Biogen need to re-examine how they can utilise real world evidence in any re-submission. Marion Butchart noted that the findings of the Montgomery Review will be very interesting in relation to how recommendations are made.

## **5. Neurological Alliance of Scotland**

Becky Duff from the MS Society has been appointed as the Chair of the Neurological Society of Scotland. She will keep the CPG updated on any important developments.

## **6. A.O.C.B**

MS Week is set for the week beginning 24<sup>th</sup> April and there will be events in Parliament.

The next meeting of the CPG is scheduled for Tues 7 Feb, 6-8pm, TG 20.21.

George Adam MSP thanked members for attending and closed the meeting at 8pm