

## **CROSS PARTY GROUP ON MULTIPLE SCLEROSIS (MS)**

Notes of Meeting on Tuesday 5 December 2017, held at Scottish Parliament

### **In Attendance:**

George Adam, MSP  
Clare Adamson, MSP  
Audrey Birt, Alliance  
Jacqui Downs, NHS Ayrshire & Arran  
Becky Duff, MS Society Scotland  
John Finnie, MSP  
Yasmin Fraser, Biogen  
Elinor Jayne, Sue Ryder  
Angela McCormack, IA  
Mairi O'Keefe, Leuchie House  
Niall Sommerville, MS Society Scotland  
Greg Stevenson, Roche  
Janice Thomson, MS Therapy Centre

### **Apologies:**

Marion Butchart, Novartis  
Merv Graham,  
Claire Cairns, Coalition of Carers in  
Scotland  
Morna Simpkins, MS Society Scotland  
Elizabeth Quigley,  
Judith MacSween,

### **MEETING**

George Adam MSP welcomed attendees and minutes of the previous meeting were agreed.

#### **Sue Ryder – Rewrite the Future report**

Elinor Jayne from Sue Ryder talked through their recent Rewrite the Future 2 document. This report tries to consider neurological care from the perspective of integration. Key findings included:

- 9 out of the 14 health boards have no neurological services plan and only one had started to develop a plan with local integration authorities. 6 had no intention of developing a joint plan.

- 5 health boards said they had specialist neuro community rehab teams, a further 5 provided some support eg, for some conditions, in some areas, 4 didn't have a team of any description
- Support to care homes from these teams is very limited so if you are in a care home chances are you don't get any specialist input

Elinor noted that many of the recommendations were progressing and that it was particularly pleasing to see the Scottish Government commit to a Neurological Action Plan.

The group discussed the report and asked whether there was an update on the neurological standards. It was noted that there were concerns about the neuro standards not protecting specialisms. The group agreed to invite the Minister for Public Health and Sport to a future meeting to discuss this area of work.

It was noted that if there are to be impactful standards then there needs to be some form of oversight group looking at the reporting on these standards.

### **Lived Experience Discussion**

Audrey Birt of the Health and Social Care Alliance outlined the work she is leading with the Neurological Alliance of Scotland to shape the Scottish Government's National Action Plan for Neurological Conditions. Audrey highlighted the importance of getting the voice of people with lived experience into this area of work and how it is shaping the themes of the work.

The themes that Audrey and the CPG explored were: Community support, carers, communication, care coordination, diagnosis and access to acute services, specialists and education, information and self-management support. Loneliness and social isolation were also seen as developing themes.

George Adam MSP noted these themes looked along the right lines but raised concerns about Integrated Joint Boards approach and whether or not they were truly embracing opportunities. Niall Sommerville noted that this is beyond just IJBs, there is a need to look at the whole system including for example how carers can be supported via the new Social Security system.

John Finnie MSP talked about the importance of culture and 'attitude' to engage with the system. It was also noted about the lack of current advocacy support for people to engage with the system.

The CPG agreed to stay involved in this piece of work and feed in where it would be helpful.

### **Treatments Update**

Niall Sommerville and Greg Stevenson both talked about treatments currently being considered by the SMC and what may be in the pipeline over the coming year.

The group were made aware of the range of potential treatments including Cladribine which it hoped would be passed in early 2019, providing another treatment option for people living with Relapsing Remitting MS in Scotland.

### **AOCB**

Janice Thomson noted that the MS Trust run an annual AHP national conference and that once again there was no one from Scotland in attendance. She raised concerns that MS nurses don't get time and space for CPD training.

Becky Duff agreed that this is an important point as it is so important that people continue their professional development and are given the time and space to do so.

It was agreed that the CPG would try to increase the involvement of MS nurses in the CPG meetings including a dedicated session on MS nurses within the next year.

The meeting closed at 19:50