

Cross Party Group on Muscular Dystrophy meeting minutes

31st October 2012, 5.30pm to 7pm, Committee Room 5

1. Jackie Baillie MSP, Chair of the Group, introduces the session and welcomes MSP colleagues and guests
2. Jonathan Kingsley, Muscular Dystrophy Campaign, Secretariat for the Cross Party Group, updates the group on recent campaigning activity in Scotland
3. Self Directed Support discussion

Key points:

- Emphasis that PAs are undertaking complex tasks; PA regulation – PVG checks, health and safety training
 - A lack of clarity surrounds the funding process
 - Usage of Direct Payments to further independence has made a positive impact overall after initial resistance
 - Welcoming hands-off approach and empowering people to do things themselves
 - Importance of the review process to ensure patients' needs are met
 - Challenge of securing adequate equipment provision highlighted and the different ways of purchasing equipment
4. The group discusses the provision of neuromuscular care advisor support across Scotland, including the transfer of existing posts into the NHS and the gap in care advisor support in the North of Scotland
 5. Closing remarks – the group decides to focus on the integration of health and social care for the next session.