



Cynghrair Niwrolegol Cymru
Wales Neurological Alliance

Minutes of Cross-Party Group Neurological Conditions meeting on

Tuesday 4th December 2018

National Assembly for Wales, Ty Hywel, Pierhead Street, Cardiff Bay, Cardiff

Present Mark Isherwood, AM (Chair)
Lynne Hughes, MS Society Cymru, (WNA Vice Chair)
Annette Morris vc
Bernadette Conway, ABM ULHB – Neuro Inflammatory Team
Cassy Ashman, Cardiff University
Catherine Clenaghan, Huntington's Disease Nurse Specialist
Dave Maggs, Headway
Diane Gleeson, WNA Co-ordinator
Ed Bridges, Cardiff University
Emily Wooster, MND Association
Fiona McDonald, MS Society Cymru
Helen Allen, Shine Cymru
Irena Erchova,
John Meredith, Dystonia Association
Mark Morgan, MESiG
Matthew O'Grady, Stroke Association
Miriam Wood, MESiG
Phillipa Ford, CSP Public Affairs & Policy Manager for Wales
Prof. Anne Rosser, Cardiff University
Rachel Williams, Parkinson's UK

Apologies Alison Shakeshaft, ABUHB
Ann Sivapatham, Epilepsy Action Cymru
Ana Palazon, Stroke Association & Chair of WNA
Astrid Burrell, BRAIN Involve, Cardiff University
Bill Fawcett
Carol McCudden, Ataxia UK
Carol Shillabeer, Powys Teaching Health board – Chief Executive
Catherine Evans O'Brien, Older People's Commissioner for Wales
Eluned Pack
Gareth Llewelyn, ABUHB
Helen Mary Jones, AM
Jane Johnston-Cree, Neurotherapy Centre

Jim Wilson
Karen Shepherd
Kate Steele, Shine
Kevin Thomas, MNDA
Kirsty Williams, AM
Kym Troman, HDUHB
Llyr Gruffydd, AM
Nia Williams, BCUHB - North Wales Brain Injury Service
Peter Carr, ABUHB
Ruth Glew, ABM ULHB – Regional Services
Stephen Davies, ABUHB
Sylvia Prankard
Vaughan Gething, AM

Introduction

Mark Isherwood, Chair, introduced the meeting and those attending introduced themselves. Lynne apologised that it had not been possible to confirm the availability of a VC link in North Wales prior to today.

Minutes of the last meeting and matters arising

Minutes of the last meeting were recorded as a true and accurate account..
There were no matters arising.

Annual Meeting of Cross Party Group, Annual Report and election of Chair and Secretary

Lynne Hughes, Vice Chair of WNA, summarised the Annual Report and invited questions. The report was accepted unanimously.

Fiona McDonald, MS Society Cymru, nominated Mark Isherwood as Chair for a further term, seconded by Rachel Williams, Parkinson's UK. Diane Gleeson, in her role as WNA Co-ordinator was nominated as Secretary by Emily Wooster, MND Association, seconded by Phillipa Ford, CSP Public Affairs & Policy Manager for Wales. Both accepted for a further term.

Social Services and Wellbeing Wales Act – experiences of people living with a neurological condition & Survey Results

Lynne introduced this item, explaining that Wales Neurological Alliance (WNA) were asked by the Cross Party Group on Neurological Conditions to conduct a survey to track the differences that the Act has made so far to people with a neurological condition since its introduction in April 2016.

The results are reported in Briefing paper No. 1 (attached) which outlines a summary of the results, conclusions and recommendations.

A total of 415 people living with a neurological condition responded: MS – 25.74%, Parkinson's – 23.28%, Dystonia – 16.19%, Epilepsy – 5.39%, MND – 3.68%, Acquired brain injury – 2.94%, Ataxia – 2.94%, Other – 19.85%.

22% of respondents had been diagnosed for more than five years and 49% for more than ten years.

56% of respondents were aged 36-64, 30% were aged 65 or older, 9% 18-35 and 4% 0-17.

73% of respondents had not been offered or requested a formal assessment indicating that people's rights to a formal assessment are not being promoted, or that people are not aware of their rights.

80% of respondents did not receive any services from a local council as a result of a care plan, indicating that a care plan does not necessarily lead to social care support.

64% of respondents did not see any information that would help them with a social care or support need and only 37% were given advice from a professional that would help with a social care need.

46% of respondents have paid out of their own money for additional support which is completely unacceptable when they should receive this from statutory services.

Fiona McDonald then read out a number of free text comments from the survey that expanded on the above statistics.

An open discussion followed with various other examples given of people living with neurological conditions having very little knowledge of the Act. Helen Allen, Shine, said that they had conducted a similar survey and 80% of their beneficiaries had not heard of the Act. A general consensus from the meeting was that people living with a neurological condition in Wales are being failed by the Act and are missing out on vital support and services.

Actions:

- Letter to be sent to the Minister/Cabinet Secretary & also to Regional Partnership Boards with the summary, conclusion & recommendations of the survey report asking for action.
- Mark to invite the new Minister responsible for Social Services to the next CPG meeting in 2019 to respond to the survey results

WNA Member Presentation – South Wales Huntington's Disease Service

Professor Anne Rosser presented a briefing to the meeting (copy attached) and asked the CPG for help taking the recommendations forward.

Actions:

- A letter to be sent to the Chair of the Health & Social Care Committee asking for the recommendations to be considered.
- WNA have recently met with the Chair to consider an enquiry into the progress of the neurological delivery plan & they will ask for the recommendations from this briefing to also be included
- A letter to be sent to the Health Secretary asking them to consider the Scottish Framework model.

Future Meeting Dates

TBC

AOB

Matthew O'Grady, Stroke Association, reminded the meeting that the next Cross Party Group Meeting for Stroke is due to be held on Tues 11th December 12.30.

Mark Morgan, MESiG, informed the meeting that a lot of progress had been made regarding Lyme Disease since he presented to the group at a previous meeting & thanked the WNA for the opportunity.

Close

Mark closed the meeting at 8.00pm wishing everyone a Merry Christmas.