



Cynghrair Niwrolegol Cymru
Wales Neurological Alliance

Minutes of Cross-Party Group Neurological Conditions meeting on

Tuesday 22 September 2015

Committee Room 4, Tŷ Hywel, National Assembly for Wales

Via VC to Wrexham Maelor Hospital

Present

Cardiff

Mark Isherwood AM (Chair)
Pip Ford, Chartered Society of Physiotherapy
Lynne Hughes, MS Society Cymru
Ana Palazon, Stroke Association
David Murray, Cure Parkinson's Trust
Rachel Williams, Parkinson's UK
Megan Evans, WNA Coordinator
Ann Sivapatham, Epilepsy Action Cymru
Nathan Sivapatham, Epilepsy Action Cymru
Kelly Bevan, Children's Brain Injury Trust
Sat Sandhu, ABPI Neurology Group
Dilwyn Jones, Brain Injury Rehabilitation Trust BIRT
Catherine Clenaghan, HD Nurse Specialist, Cardiff University
Kay Holmes, Huntington's disease Association
Carol Smith, MDNA
Manel Tippet, Royal College of Psychiatrists
Gwen Philips, Welsh Neuropsychiatry Service
Seth Mensah, Welsh Neuropsychiatry Service
Jennifer Thomas, Cardiff & Vale UHB
Margaret Ware, Myotonic Support Group
Miriam Wood, MESIG ME Support
Christella Bailey, MESIG ME Support
Jean Francis, Ataxia a Fi
Gareth Power, BASW Cymru
Fiona McDonald, MS Society
Samantha Fisher, Psychologist, Cardiff and Vale NHS Trust
Darren Millar, AM
John Meredith, Dystonia Society Support

Wrexham link

Annette Morris, Betsi Cadwaladr UHB
Urtha Felda, MS Society Cymru
Sylvia Prankard, Parkinson's UK
Craig Roberts, Clinical Psychologist Betsi Cadwaladr UHB
Elenud Plack, Wrexham Neurological Alliance
Jane Johnston-Cree, Neuro Therapy Centre

Apologies

Barbara Locke, Parkinson's UK
Michelle Herbert, Brain Tumour Charity
Carl Cooper, PAVO
Dafydd Williams, Myotonic Dystrophy
Janet Finch Saunders AM
Marcus Longley, Cardiff & Vale UHB
Kevin Thomas, MNDA
Ruth Crowder, Wales College of Occupation Therapists
Matthew Makin Betsi Cadwaladr UHB
Jane Stein, PSP Association
Carol McCuddon, Ataxia UK
Simon Thomas AM
Leigh Campbell, BCUHB
Angela Collett, Brain and Spine Foundation
Carol Ross, Fibromyalgia Wales
Aled Roberts, AM
Janet Haworth, AM
Bethan Jenkins, AM
Karen Bonham, AM
Helen Owen, ABMU
Sue Mullock, ABMU
Bernie Conway, ABMU
Kate Steele, SHINE
David Maggs, Headway

A minutes silence was held to remember Harry Prankard, Parkinson's UK who sadly passed away in the weeks after giving a presentation at the last WNA CPG. Mark Isherwood expressed his sincere condolences to his wife Sylvia on behalf of the group.

Minutes of the last meeting and matters arising

Minutes of the meetings held on 9 June 2015 recorded as true and accurate account.

Lynne Hughes explained that the committee was still waiting for Ian Langfield to get back with further information to ensure that the letters that we need to send accurately reflect the issues.

The provision of neuropsychology and neuropsychiatry services in Wales

Lynne explained that the WNA had held a meeting in West Wales in 2013 on this issue. The focus of the presentations highlighted the many diseases that cause neurological cognitive dysfunction and the resulting impact on employment and family as well as psychiatric issues such as depression and anxiety. However services in Wales are still worse than in the rest of the UK and Lynne explained that the presentations and discussions at this meeting may highlight the need for the WNA to campaign for improved services.

The importance of neuropsychiatry services for those with functional and other neurological disorders – David Linden (Professor of Translational Neuroscience, Cardiff University, Honorary Consultant Psychiatrist, CVUHB Chair, Neuropsychiatry Faculty, Royal College of Psychiatrists in Wales.

David explained that he wanted to raise awareness of neuropsychiatry and neuropsychology. Although he is based in Whitchurch Hospital, Cardiff, his role is national. He takes referrals from South West and South East Wales. Services in North Wales are provided by the North Wales Brain Injury Service and the Walton Centre, Liverpool.

David highlighted the incidence of depression amongst stroke patients and despite core pathways he questioned the ease of access. Epilepsy patients has found their condition had a profound effect on the quality of their life. In Wales, specialist input is provided by Prof Michael Kerr, Cardiff University. Rates of Parkinson's disease are increasing as the population increases and ages with a quarter to a half of patients suffering serious psychiatric disorders. However these are often managed by the GP rather than hospitals or CMHT's and so patients lacked a more specialist opinion. Functional neurological syndromes are medically unexplained conditions and have no specific service in Wales.

The need for neuropsychology services – Dr Tanya Edmonds, Lead Consultant Clinical Neuropsychologist, Department of Neuropsychology, Morriston Hospital.

Tanya explained that access to a neuropsychologist was fragmented and patchy in Wales although effective services are an indicator of long term well-being both for patients and their families.

She outlined the large gap in neuropsychology services for stroke management with many people in Wales having no access at all to services, despite the impact of strokes on cognitive functioning including behaviour and the corresponding impact on the family and carers. She explained that early assessment is vital but Wales is lagging behind the UK even though the long term costs of no intervention are huge. Overall there are very few resources for people with neuropsychological issues in Wales as they are often deemed not appropriate for local CMHT's.

Tanya had gathered patient experiences and looked at methods of peer support and its impact on well-being. She had instigated community neuro-rehab projects using a coproduction approach involving patients to deliver training to medical students and other professionals. She felt that although resources should be increased there also needs to be a rethink on how services are delivered and how health services work together with the third sector.

Questions and debate

Mark Isherwood then opened up questions from the floor.

Jenny Thomas stated she was pleased to see the added value that psychology services bring and that there was a need for LHB's to see the importance and value for money of such a service. The needs of those with functional problems must be taken seriously and psychology must be embedded in all services. All present agreed with this point.

Ana Palazon explained that although these issues had been discussed in 2013, the challenges were still there and there has to now be a change as less than 25% of stroke survivors are currently getting the help they need. She asked the CPG for their views so that the WNA can put questions to the minister explaining that investments need a clear direction.

Mark Isherwood suggested writing to individual political parties in the near future to inform manifestos and future policy. Ana explained that individual organisations are doing their own manifestos and the WNA are looking at developing pan organisations asks.

Jenny Thomas identified that the delivery plans bids are soon to be considered it would be helpful if the successful bids included a neuropsychology focus.

David Linden explained that any action that could synchronise the voices of psychiatrists, the Royal College of Psychology, the Psychology Society and the WNA would be helpful.

David Murray explained that from the patient perspective, the psychological impact is huge. Although he has Parkinson's, all neurological conditions have similarities and should work collaboratively. He explained that the issues for carers and families of people with neurological conditions must not be forgotten.

David Linden agreed that there are commonalities and in Wales, services that are trans-diagnostic are the most likely way forward, i.e. services designed according to need rather than diagnosis.

Craig Roberts explained in North Wales they are piloting small scale trans-diagnostic services using the skills they have but there is still a great need for services in North Wales.

Margaret Ware described how she was the carer for her son with Myotonic Dystrophy and was only recently asked if she, herself had any questions thus greatly helping understanding. She felt it was so important that services are expanded.

Mark Isherwood asked if patients were actually involved in the designing of services. Tanya explained it was the case with adult services but not with children as there is no child psychology service for those with neurological conditions in Wales. Mark gave details of a Barnardo's scheme run by young carers.

Miriam Wood gave details of GP's making referrals for patients with ME to neurological services but they could not access the service. Jenny Thomas explained that there were no resources to provide such services for those with ME as the service would be overwhelmed. In individual cases, Mark suggested people go to their individual AM's.

Closing remarks

The Group agreed a number of actions to be taken forward from the meeting as follows:

- Write to the Ministers and party policy directors to highlight gaps in neuropsychiatry and neuropsychology services and ask how they will be addressed.
- Mark Isherwood explained he is going to write to minister on behalf of the MS Society regarding MS nurse ratios in North Wales. NICE recommend 1:300 while in reality in Wales it is 1:1100.

John Meredith explained there are no dystonia specialists in Wales and asked if the Cross Party Group could write to the minister asking to help address this.

Ana Palazon stated that the conclusion was that neuropsychiatry and neuropsychology services are not a luxury and trans-diagnostic services are the way forward, taking into account the needs of the family.

Darren Millar suggested organisations put a price tag on any suggestion for services and requests for manifesto commitments.

Tanya Edmonds explained that there is a need to spend more to save as early intervention improves long term outcomes.

Eluned Plack explained that in North Wales there is great need for specialists and a reduction in the time taken to access primary care.

Dates of future meetings:

The dates of the next meeting is 9 February 2016 at 6.30pm in Committee Room 4, Ty Hywel, Cardiff Bay. There will be a VC link to Wrexham Maelor Hospital.