



Cynghrair Niwrolegol Cymru
Wales Neurological Alliance

WNA Annual Review 2018

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Foreword by WNA Chair

A warm welcome to WNA's 2018 Annual Report. One of our main areas of work this year has been to continue bringing key issues of importance for people affected by neurological conditions to the attention of Welsh Government and the wider political establishment.

Of relevance is the work we did on behalf of the National Assembly's Cross Party Group on Neurological Conditions (CPG). Member organisations engaged with their respective members and audiences to gather the evidence about whether and how the Social Services and Wellbeing Wales Act had improved the services people need from social care. The evidence submitted highlighted that many people in need of services are not necessarily receiving information, assessments or the needed services. This formed the focus of CPG meeting in the winter and WNA will continue to raise the issues highlighted with Welsh Government and to implement the survey in 2019 to assess how things improve.



Earlier in the year, WNA members from across Wales were brought together again, under the auspices of the CPG, to a round table discussion to start mapping the priorities for the Awareness Raising Project being funded by the Neurological Conditions Implementation Group.

We completed the initial element of the project with the production of the Patient Reported Experience Measures (PREMs) questionnaire that people with a neurological condition contributed to develop by testing it. Once all the modifications are complete it will be available to be used by NHS services.

Having completed this first part, we commenced this second element of the project.



It was truly encouraging to have such a high level of participation on the day and to reach consensus on what matters most. There was consensus that one key priority must be raising awareness and education amongst NHS services used by people with neurological conditions in order to improve understanding and therefore quality of services. This will form the basis of the project's objectives once the Project Officer is appointed in early 2019. We are grateful to NCIG for this funding.

We attended the Party Political Conferences where we were able to engage in dialogue with many politicians across the parties through our key issues paper.

During 2018 we also collaborated with the Royal College of Nursing Cymru in highlighting the importance of specialist nurses and the positive impact this function makes to people living with a neurological condition.

We continued to represent WNA members at the National Neurological Conditions Implementation Group meetings and attended the Neurology Services day organised by Welsh Government where WNA was able to present evidence from members that highlighted patients' experience of neurology services.

Clearly, 2018 has been a very busy year for WNA. The detail of this and other activity is contained within the report which I hope the readers find of interest.

My sincere thanks to all the members and in particular those who are active in the Executive committee and its subcommittees ensuring that the work taking place 'behind the scenes' is delivered.

A handwritten signature in cursive script, reading "Ana Palazón".

Ana Palazón
Chair, Wales Neurological Alliance.
May 2019

Influencing

Cross Party Group (CPG) on Neurological Conditions

During 2018 WNA continued to provide the secretariat for the Cross Party Group on Neurological Conditions which met on three occasions. The themes of the meetings were as follows:

March 2018

A meeting was planned for 20th March 2018 to discuss working in partnership with Pharmaceutical Industry in improving neurological services in Wales, unfortunately the speakers had to pull out of the meeting with little notice, so the meeting was cancelled.

July 2018

This was a special meeting of the Cross Party Group which invited people living with neurological conditions across Wales to discuss their experiences.

The Welsh Government's Neurological Delivery Plan says that all staff involved in managing care for people with neurological conditions should have an appropriate understanding of the condition and its impact on the individual and their family.

These basic principles are needed to make sure that people with neurological conditions have confidence their condition is understood by which ever health or social care service they access.

Participants were asked to consider the following key questions.

Q1. Share your experiences where your neurological condition was well/ poorly understood and the difference that made to your care?

Q2. Which professionals do you think need to be our priority?

Q3 What are the key things that they need to understand about your neurological condition/ or neurological conditions generally?

Q4. What do you think are the best methods for raising awareness?

A summary of the responses was produced and will be used to inform the next stages of the Wales Neurological Alliance Raising Awareness project.

The meeting also heard from the Cabinet Secretary for Health and Social Services about the Welsh Government's commitment to raising awareness of neurological conditions.

December 2018

The Cross Party Group received the Annual report 2017 which had been delayed in coming to a meeting due to the cancelled meeting in March and the special meeting in July. The report was accepted unanimously.

Mark Isherwood AM was elected as Chair for a further term, and Diane Gleeson, in her role as WNA Co-ordinator was nominated as Secretary. Both accepted for a further term.

The meeting then received a report on the Social Services and Wellbeing Wales Act and the experiences of people living with a neurological condition survey

In summary 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.

An open discussion followed with various other examples given of people living with neurological conditions having very little knowledge 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.

Professor Anne Rosser gave the WNA Member Presentation on the South Wales Huntington's Disease Service and asked the CPG for help taking the recommendations forward.

Meeting with Cabinet Secretary for Health and Social Services

Members of the Executive Group met with the Cabinet Secretary for Health and Social services on two occasions in 2018, topics discussed included: The effectiveness of the Neurological Conditions Implementation Group in bringing about meaningful change across Wales; the role of the Neurological National Scientific Advisory Group and a Clinical Lead role; Healthier Wales, Transformation funding and third sector involvement; and condition specific issues e.g. Botox Clinics for people with dystonia, access to HSCT in Wales for people living with MS, and Lyme Disease.

Meeting with Welsh Government Officials led by Deputy Chief Medical Officer

Welsh Government Officials held a one off meeting with representatives of LHBs, WHSSC and WNA to discuss the sustainability of neurological services in Wales. WNA submitted evidence to the meeting highlighting the following concerns:

Workforce Planning

There must be urgent planning and investment in a neurological workforce that is fit for the future. Public Health Wales undertook a Neurological Conditions Needs Assessment in 2015. The report identified that there was a significant shortage of consultant neurologists in Wales in comparison to recommendations made by the Royal College of Physicians and the Association of British Neurologists. This lack of expertise is further exacerbated by significant shortages of neurology clinical nurse specialists.

There are currently no disease registers for neurological conditions in Wales (with the exception of epilepsy), so planning is based on estimates of the number of people living with these conditions rather than an accurate measure of need. It is vital that a whole system strategic approach is taken to planning across all tiers of care so that people with neurological conditions in Wales have access to the right care, at the right time, in the right place by the right health, social care or third sector professional.

Compliance against NICE guidelines

Some neurological conditions have disease specific NICE guidelines, including MS, Epilepsy and MNDA. WNA would question whether there are measures in place across to determine if the Local Health Boards are meeting these.

Horizon Scanning, Planning for New Medicines and Implementation delays

This is an urgent issue for services for people with MS. The treatment landscape is changing rapidly,

There a real concern about the lack of infrastructure that is currently in place to cope with existing treatments. Future approval of new and more effective treatments is likely to lead to additional assessment and monitoring requirements which will inevitably place further demand on a service which is already working at capacity. Timely follow up of people living with MS is becoming more and more difficult resulting in less time to assess people effectively, discuss treatment options and manage risks.

Lack of joint working across specialities.

When condition specific expertise lies outside of the neurology service, as exemplified by Parkinson's patients being seen in care of the elderly services, if/when the individual care of the elderly consultant retires/ moves on the expertise is lost from the service and a cohort of patients is left without the specialised care they require for their neurological condition.

We also have concerns about the linkages between different delivery plans for example how well the Neurological Delivery Plan and the End of Life Delivery Plan

Access to Therapies

For most neurological conditions, pathways of care are not fully integrated with the wider multi-disciplinary workforce that are essential to the promoting the wellbeing of people with neurological conditions ensuring that they can live their lives as independently as possible.

Of particular concern is access to psychology and psychiatry. Neurophysiotherapy and rehabilitation can also struggle to achieve parity in investment to acute physiotherapy services. We have seen some improvements as a result of the targeted investment from the Stroke and Neurological Conditions Delivery Plan at individual health board level, there is little to suggest that wider strategic change is yet to take place.

Report on the Posture & Mobility Group

There have been numerous difficulties over the past year which have had an adverse effect on the Posture & Mobility Stakeholder Group. The Stakeholder Group is intended to be the voice of representation at the Technical Group (dealing with the Posture & Mobility Service operations) and the Partnership Board (dealing with the strategic and monitoring of the Posture & Mobility Service).

Due to sickness, there has been no Chair since March 2018, which has resulted in several actions being deferred and meetings cancelled whilst awaiting the Chair's return.

Planned work for the Group was:

- Role & remit of a Vice Chair
- Review effectiveness of representation
- Establish Stakeholder group representation from South Wales
- Reviewing the current 'Treat Me Fairly' NHS mandatory training against the needs of Disability Equality Training.
- Responding to the question raised by WHSSC (Welsh Health Specialised Services Committee) 'Which quality standards would we like P&MS to report on'?

The Group met in February 2018 to review the mandatory training module used by NHS Wales (4). The Group had long discussions with the Posture & Mobility Service about the appropriateness of their Disability Equality Training. Members of both the Partnership Board and the Stakeholder Group have increased responsibility under governance requirements to have a good understanding of equality issues due to their roles and actions in making recommendations and decisions for the Service.

The outcome of the review was:

- The 'Treat Me Fairly' mandatory training was not suitable as Disability Equality Training. The content was too generic, the software has access issues, and there were questions of good practice.
- The 'Treat Me Fairly' package was not suitable because the workforce of the Posture and Mobility Service, by definition, need a more targeted approach and one which focusses on the Social Model of Disability.
- The 'Treat Me Fairly' package was not suitable as the original stated aim for the training was 'for the Posture & Mobility Service Board, and Stakeholder Reference group members to have an increased understanding of disability equality, specifically the social model of disability'.

Detailed notes, with recommendations for further Stakeholder Group involvement, were passed to the NHS Centre for Equality & Human Rights for information and further action. Nothing has been received by the Group since.

The other four areas of work remain outstanding. In December 2018, Claire Nelson (Acting Assistant Director of Planning/Specialised Planner, Neurosciences and Complex Conditions, WHSSC) informed the Technical Group that she was awaiting guidance from the recently appointed Director of Planning where the role of the Stakeholder Group and the frequency of meetings during this period would be discussed. There has been no information following this announcement despite e-mails from the Stakeholder Group requesting an update.

Going forward, the key concern for the Stakeholder Group is the communication between it, the Posture and Mobility Service and WHSSC and the effectiveness of its representation.

Neurological Conditions Delivery Plan

The Neurological Conditions Implementation Group (NCIG) oversees progress of Local Health Boards against the Neurological Delivery Plan. WNA has three representatives on the NCIG which has ensured WNA representation at all meetings and several task and finish groups and subgroup meetings.

In WNA's work as members of NCIG we have constructively critiqued the delivery of the plan and the focus on monitoring of the funded projects as opposed to the broader issues and actions raised in the plan.

Awareness Raising & PREMs

As stated in last year's report the WNA secured funding from Welsh Government through the Neurological Conditions Implementation Group (NCIG) to deliver a programme of Awareness Raising. This programme will focus on raising awareness of living with a neurological condition, the impacts that this can cause and the barriers that people with neurological conditions face daily, both as patients but also as citizens in their everyday lives.

The draft Patient Reported Experience Measures tool (PREMs) was presented to the NCIG in December 2017. Further work was then carried out co-productively with people with neurological conditions to refine this down to a

more meaningful and user friendly tool. This has been tested by a group of clinicians in the latter part of 2018 and will be finalised in early 2019.

As highlighted in the Cross Party Group Section of this report a special meeting was held in July 2018 to define the parameters for the raising awareness element of this work. The previous Project Officer left in early 2018 but we have recruited a replacement to take this forward in 2019.

Augmentative and Alternative Communication (AAC) Project Board

Purpose of group:

The ACC Project Oversight Board oversees:

- The development of a Policy and Service Specification for the service.
- The development of a contractual mechanism, which links activity and cost and includes arrangements for performance management.
- The review of the Business Case to provide assurance to the WHSSC Joint Committee and Welsh Government.

The Project Oversight Board will also:

- Agree and implement formal communication arrangements for the Board.
- Agree evaluation of the Project and make recommendations to the WHSSC Joint Committee and Welsh Government regarding long term funding arrangements.

WNA was represented at this national board, we attended two meetings during 2018.

However, we were unable to join the last meeting of 2018 as our representative left WNA. This affected our capacity to connect with developments.

At the June meeting:

- It was confirmed that WHSSC had proposed to provide £480k of funding in total over a 2 year period, up to 2020, as recommended by the evaluation report.

- This was superseded by the funding provided by Welsh Government, which is up to £750k for one year, with a further £50k available to help deliver the spoke services (as in a hub and spoke model).

Most of the September meeting looked at waiting times for the service Key points were:

- 12 people waiting greater than 52 weeks.
- Large percentage of people coming through were urgent referrals.
- Different scenarios for reducing the waiting list were discussed, however with a question on whether the service would remain by March 2019 when the funding was due to end
- There was also a discussion around the need to demonstrate impact and of the evaluation.
- There was no clarity on whether or how the recommendations made by MNDA and WNA would be implemented.
- It was agreed to gather information now for the next funding bid for post March 2019.

Unfortunately, WNA was unable to send a representative to the November meeting. However, we will be contacting the relevant NHS colleagues to re-establish contact and get the relevant updates.

BRAIN Unit

WNA has a key relationship with the BRAIN Unit. Three representatives of the WNA sit on their Executive board and input significantly into the workings of the BRAIN Unit.

Mission of the Brain Unit

To be a Welsh and UK national centre of excellence for;

- Delivering novel cell/drug/growth factor and other complex therapies to human brain
- Supporting translational research underpinning disease modification and brain repair in patients with neurological and neurodegenerative conditions.

Their mission is to make the BRAIN Unit a pre-eminent centre of international leadership that is unique in the UK and in the top-5 worldwide.

Aims and Goals

Their aim is to take novel intracranial therapeutics and other complex interventions for disorders of the nervous system through to clinical application and to provide a robust evidence base supporting their future implementation. Many of the most promising new and emerging therapies (including cell and novel gene therapies) are complex and will require direct delivery to the CNS, and this is a principal focus for the Unit.

Core Areas of Activity

The BRAIN Unit's remit will span preclinical laboratory and imaging validation, through to first-in-man clinical trials and onward into clinical practice.

WNA Main Role

WNA has supported discussions, particularly around patient involvement for BRAIN. Involve so that the work of the BRAIN Unit is strongly based upon principles of involvement and coproduction.

In addition, this year one of the WNA member organisations (Parkinson's UK Cymru) held a research day in partnership with Cardiff University where the BRAIN Unit also played a key part. It was aimed at people affected by the condition who have an interest in research. As a result, the BRAIN Unit will be proposing similar days for other conditions as part of its next funding bid. Clearly, WNA will continue to be a partner and support the next funding bid as a collaborator.

Management & Governance Sub-committee Report

The Executive Committee undertook an audit of skills and knowledge framed around good governance. This has enabled us to focus on recruitment and elections of new members.

In 2018 we welcomed John Meredith from Dystonia UK as a co-opted member of the Executive Committee.

Sadly, we said goodbye to Emily Wooster from MND Association as she left her position with the Executive committee to commence her maternity leave. Our gratitude to Emily for her work and dedication and many congratulations on the birth of her baby.

Jonathan Canty from The Brain Tumour Charity also left the Executive committee due to changes in his role within his organisation. Again, our sincere thanks to Jon who made a very valuable contribution to the work of WNA.

Income Generation Sub-Committee Report

As I am sure members will remember, this year we concentrated on finding new income to ensure the long term sustainability of WNA. As part of work undertaken, we consulted on increasing the membership fees. As a result of what members told us we introduced a sliding scale based on criteria around organisational size / income. During 2018 many of our members have contributed an increased amount.

Whilst this change contributed to the income solution, in itself was not enough so we also investigated other possible sources of funding.

We produced a report highlighting a workable process for seeking corporate sponsorship. Unfortunately, the meeting planned with representatives from the pharmaceutical industry had to be cancelled for reasons beyond WNA's control. This remains a commitment for 2019

he Subcommittee also undertook a funding advice application to WCVA who provided us with a breakdown of appropriate trusts and foundations for WNA to approach.

The subcommittee developed some of the background and information for this, coupled with a survey of members to understand what additional benefits the membership would want if new income could be secured. The subcommittee recommended to the Executive committee to engage the services of an independent consultant in order to add capacity to this important area. This work will be undertaken during 2019.

Treasurer's Report

WNA accounts from 01.01.18-31.12.18		
Opening bank balances 01.01.18		
	BMM account	£0.25
	Community account	£16,650.77
	Total	£16,651.02
Income for the year		
	Membership fees	£4,000.00
	Parkinsons UK donation for 2017	£1,950.00
	Total	£5,950.00
Expenditure for the year		
	Diane Gleeson Co-ordinator fees	£5,400.80
	Catering Welsh Assembly CPG meeting	£59.40
	AGM room hire and buffet	£340.20
	Web hosting	£90.00
	Total	£5,890.40
	Bank balance	
	BMM account	£0.25
	Community account	£16,710.37
	Total	£16,710.62

WNA Executive Committee Members 2018

Name	Organisation	Position
Ana Palazon	Parkinson's UK	Chair
Lynne Hughes	MS Society	Co-Vice Chair
Carol McCudden	Ataxia UK	Co-Vice Chair
Ann Sivapatham	Epilepsy Action	Treasurer
Dave Maggs	Headway	Member
David Murray	The Cure Parkinson's Trust	Member
Emily Wooster	MDNA	Member
John Meredith	Dystonia Association	Co-opted
Kate Steele	Shine	Co-opted
WNA Coordinator		
Diane Gleeson	WNA Coordinator	wnacoordinator@gmail.com

WNA Membership 2018

Member name	Type
Ataxia UK	Full
Brain Injury Rehabilitation Trust	Full
British Polio	Full
Chartered Society of Physiotherapy	Associate
Child Brain Injury Trust	Full
College of Occupational Therapists	Associate
Different Strokes	Full
Dystonia Society	Full
Epilepsy Action Cymru	Full
Epilepsy Wales	Full
Headway Wales	Full
Huntington's Disease Association	Full
Migraine Action	Full
Motor Neurone Disease Association	Full
Multiple Sclerosis Society Cymru	Full
Muscular Dystrophy UK	Full
Myotonic Dystrophy Support Group	Full
Neuro Therapy Centre	Full
Parkinson's UK Cymru	Full
Shine Cymru	Full
Stroke Association	Full
The Brain Tumour Charity	Full
The Cure Parkinson's Trust	Full
The Neurological Alliance	Full
Welsh Association of ME & CFS Support (WAMES)	Full

Further information regarding membership of the WNA is available from the WNA Coordinator wnacoordinator@gmail.com