

Welcome

In this edition we focus on the invaluable work of staff members of the Motor Neurone Disease Association (MND). We introduce the four key members of staff who work within the North Wales Area on behalf of and in support of people living with MND. Actually they introduce themselves and though you may have met one or two of them each has their own story to tell and each plays a vital role in the Association.

The financial impact on those living with MND and their families is highlighted in a newly published report: MND costs. The extra costs are one off (eg. housing adaptations), regular (eg. extra assistance costs) and enhanced costs (eg. increased energy bills). The report suggests that, on average, spending on regular costs is £609 and enhanced costs £133 every four weeks which is equivalent to £9645 every year. For more information www.mndassociation.org/mndcosts

Inside you will also find details about the funds raised over the course of the year for the benefit of people living with MND and their carers across North Wales. This is apart from the enormous funds raised on our summer walk to d'feet MND in Llandudno.

Remember you can apply for extra financial support from your local branch or group.

Remember there are other avenues of support. Inside there are details of support meeting scheduled for the new year in our locality. You would be most welcome to attend as many of these as you feel able to do.

Best wishes

North Wales Forum

Useful Contacts

North West Wales Group Contact

Roger Sowersby
Tel: 01248 681 238
Email:
rogersowersby@gmail.com

Volunteer Team

Sioned Roberts Jones
Georgina Llewellyn
Howard Mence
June Watkins
John Williams

Clwyd Branch Contact

Chris Allen
Tel: 07908292621
Email:
eslessred@yahoo.co.uk

Volunteer Team

Helen Carey
Elin Roberts

Out of Hours GP

Tel: 0300 123 55 66

Out of Hours Social Services

Angelsey & Gwynedd
Tel: 01248 353551
Conwy
Tel: 01492515777
Wrexham County
Tel: 0345 0533116
Flintshire County
Tel: 01352 803444

Details of the MND Association staff can be found at the end of this newsletter.

Help at Hand

We invite you to come to any or all of our support meetings.

Our Support Meetings

Our Support Meetings offer an opportunity for you to come along and meet others living with MND and their carers in a relaxed and friendly setting to share experiences over a cup of tea or coffee.

We would love you to come and join us. Refreshments are provided free of charge for people living with MND and a family member or carer. Whether you are able to pop along for 10 minutes or stay for 2 hours it would be great to see you.

You are welcome to attend any meeting whichever one's are the most convenient for you.

North West Wales Group Support Meetings Contact Roger rogersowersby@gmail.com

These are held at Ty Golchi, Ffirdd Caernarfon, Bangor LL57 4BT in the afternoons from 2:30pm.

Dates for the next few meetings are:

10 January

14 February

14 March

18 April

Clwyd Branch Support Meetings Contact Chris eslessred@yahoo.co.uk

Clwyd branch support meetings have now moved to a new venue starting from 2018.

Cunliffe Arms Jeffreys Rd, Wrexham LL12 7PD . **NB VENUE CHANGE**

Dates for next few meetings are:

17 January

21 February

21 March

16 May

This is the third Wednesday of every month 7pm-9pm

Additional Support Meetings Contact Judith judith@northop567.plus.com

These are held at Tweedmill Shopping Outlet, Llannerch Park, St Asaph Road, St. Asaph LL17 0UY in the daytime from 10:45AM – 1PM. **NB TIME CHANGE**

Dates for the next few meetings are:

January 22nd

February 26th

March 19th

April 23

Support

We point you in the direction of support which is available locally.

May we introduce a number of dedicated staff who support people living with MND.

Kevin Thomas



Regional Care Development adviser (RCDA), North Wales, Mid Powys & Isle of Man

I have worked for the MND Association since 2006. I am a qualified and registered Social Worker (DipSW), have an MSc in Health & Social Care Leadership, a BA (Hons) in Social policy & Social Welfare, and a post graduate Diploma in Change Management. Before joining the MND Association I worked in the statutory sector as a Social Worker, Social Work Team Leader, and Service Operational Manager working in Child Protection, Learning Disabilities and Physical & Sensory Disabilities.

As an RCDA my main responsibilities are to influence Service Development; support our Association Visitors; facilitate and deliver education & training; and support people affected by MND directly with complex case issues.

I am pleased to have been involved in the development of several areas of service improvement over the years. A major piece of work over the past few years has been making the business case for two part-time MND Care Coordinators for North Wales funded by the MND association and employed by the Health Board. These posts are funded for a time limited period by the MND Association with a commitment from the Health Board to continue funding if clear outcomes are demonstrated. A key focus over the next year will be to secure this Health Board funding.

Another key area of my work is supporting our Association Visitors who have an invaluable role to play in supporting people affected by MND. We have increased the number of Association Visitors to six across North Wales. It is my job to support these AVs and keep them up to date with relevant information in supporting people affected by MND.

Facilitating and delivering education and training for professionals ensures best practice in MND is promoted across the workforce. This ranges from an annual pan North Wales Study Day for professionals, awareness training to domiciliary care agencies, residential and nursing care homes and working with partners such as the hospices to deliver training sessions together.

Jo Cunnah



Volunteer Development Coordinator Wales, Northern Ireland and Isle of Man

I have worked in Volunteer Management within the Health Charity Sector for over 14 years following a career change from Financial Services in 2003. My role involves recruiting and supporting Volunteers in a number of roles and in particular Volunteers within our Branch and Group networks.

I have been with the Association for almost three years and in that time I have been lucky enough to be part of a fantastic team who have helped to develop our reach across North Wales. Together, we have strengthened the number of Volunteers within the Clwyd Branch, the North West Wales Group and increased the numbers of Association Visitors from one to six. This means we have not only been able to significantly increase the level of much needed support we provide to People with MND and their families but also offer that support in a variety of ways.

A particular highlight for me has been the development of the North Wales Forum. The Forum has enabled staff and Volunteers to come together to discuss, shape and develop our work across North Wales and in just a year this has grown into something very special indeed.

Working with Volunteers is my passion and I am extremely lucky to be able to work with such an amazing team of Volunteers across North Wales. Without their hard work, commitment and support we simply couldn't do what we do so I hope this passion shines through when people meet me.

On a personal note, I live in North Wales with my family. I enjoy cooking, anything to do with musical theatre and after quite a few years I am still persevering with trying to learn how to play the piano!

Richard Shackelford



Regional Fundraiser for Wales & Northern Ireland

I live near Hay on Wye in Mid Wales and work from a shared office space in the town. I started work with the Association in 2013 and although I have not had personal involvement with MND, my work has brought me into contact with people affected by the disease and this experience has confirmed my determination to do what I can to help.

My first fundraising post was with the British Red Cross back in the late 1980's, subsequently I have gained experience with Macmillan, the Kidney Research Fund, a small UN based Human Rights NGO and Hereford's St Michael's Hospice.

As a fundraiser for the Association I am here to support the work of our Branches and Groups in my region and those individuals who register with the Association to raise in excess of £1000. This can involve attending Branch meetings, events and supporting fundraising initiatives such as our sponsored walk programme *Walk to D'feet* and our sponsored silence event *Silence Speaks*. With individuals the work is varied involves simple encouragement, planning PR and social media strategies up to attending events, giving presentations and receiving those all-important giant cheques!

I work closely with my Regional colleagues to deliver our Regional plan and strategy and to ensure continuity of service to people affected by MND across the Region.

Tim Atkinson



Campaigns Manager

Hi, I'm Tim, and I have been the Campaigns Manager for Wales (I also cover Northern Ireland and parts of England).

My role has been to help our supporters raise awareness of MND among politicians and decision makers and improve services for people with MND and their families. I have worked to deliver our big campaigns (like *Champion The Charter* or *MND Costs*) and to campaign on health and social care issues we have identified with branches, groups and colleagues.

Campaigning is something everyone can help with, even if you only have a little time in front of your computer: please do join our Campaign Network (www.mndassociation.org/campaignnetwork) to hear about opportunities to e-mail your local politicians about MND issues.

Editor's Note : Tim has recently moved to another role. We thank him for all his efforts on behalf of people living with MND in North Wales and being a lively and insightful colleague. We wish him well.

Recently in North Wales he also been supporting the Clwyd branch and their campaigns volunteer Vincent Ryan to meet local MP's to build relationships and highlight the financial burden of MND. If this sort of action interests you, please do get in touch to find out more.

We hope to have news of his replacement in our next Newsletter.

Carer's Corner

We have pleasure in introducing a new part to the support section. We recognise the vital role that carers play in supporting members living with MND. We hope this section will, in a small way, help and support you.

Have you ever thought about what might happen if you as the Carer was unable to provide care or support because you are unwell or have to be away from home at short-notice?

Planning for the unexpected

Sometimes, no matter how well we plan, or how much support you have in place, something unexpected might happen. Below are a list of emergency numbers that can help. It is important to identify out-of-hours support and emergency services, so that you feel prepared.

As a Carer you are entitled to a Carers Assessment. If you have one ask about emergency care services. If you have not had a Carers assessment, contact your local Social Services department. Check with your GP that the person with MND has been added to an electronic end of life register which can help professionals remain aware of particular needs in emergency situations.

But, remember these are services that can help in an emergency only. Whilst it may be impossible to plan for every eventuality, it is possible to plan for many different types of situations that may arise if we are helped to think about them. The MND Association have a new Carers Hub on the website <https://www.mndassociation.org/for-carers/> Here you will find a range of resources to help you think about how to look after yourself as a Carer and how to plan ahead if you were unable to care. For example, the *Motor neurone disease checklist* and the *Understanding My Needs* booklet are helpful tools to think about what others would need to know about the person living with MND if you as the Carer could not. If you do not have access to the Carers Hub on the internet you can request a copy of 'Caring and MND' by phoning MND Connect on 0808 8026262. If you have an Association Visitor, ask him or her if they can help you use these tools to think about planning ahead.

Finally, If you have thought about planning ahead it is important that you write these plans down, keep them somewhere easily and quickly accessed if you are not around, and let your health or social care professionals know about them and where to find them.

Raising Funds

We raise money locally that goes to support our efforts in helping people living with MND and their carers.

North West Wales Group

The North West Wales group has been active across the region this year raising funds for people affected by MND in our local area.

Supermarkets collections are held most months and this year we have raised over £3600.

Ysbty Gwynedd Hospital stall is also held most months and we have collected over £1300.

Through a street collection and two day event in Pwllheli we also raised over £1800 due to the generosity and support of local people.

Clwyd Branch

Our fundraising events this year have included a 50-mile cycle ride, a half marathon and supermarket bucket collections raising over £4000. In May and October, we had a jewellery stall at the Kenyon Hall in Holt and at the Cilcain show all raising awareness and funds for our branch.

A warm welcome to our new fundraising co-ordinator, Rachel Ritchie, who joins our team of volunteers.

The Clwyd branch now have a just giving page:

https://www.justgiving.com/fundraising/Clwyd_MND_Branch

Donations can be also made by text: Send message "CMND70 £5" to 70070.

Forthcoming events

A [charity night](#) is planned at Brymbo cricket club on Saturday 24th February.

If you would like a ticket or further details contact Elin on 07545 047768 or

Elin.m.roberts@gmail.com.

Awareness Raising

We try hard to raise public awareness of MND and celebrate the success and support given by individuals and organisations.

MPs October Reception

Despite a really busy week in Parliament, we're really pleased that over 50 MPs attended and met with over 130 MND Association branch and group representatives, including 39 people living with MND attended – the largest ever gathering of people with MND at an Association event ! A number of people from North Wales attended. We were delighted by the overrepresentation of MPs from North Wales attending the event and would like to thank each and every one of those Members of Parliament for sparing the time to attend and support our event.



MND Connect

The MND Connect team offers information and support on all aspects of **motor neurone disease** (MND), including symptom control, practical management, improving quality of life, clinical research and signposting to other organisations.

MND Connect is available Monday to Friday between 9am to 5pm and 7pm to 10:30pm. You can call direct on **0808 802 6262** or e-mail at: mndconnect@mndassociation.org

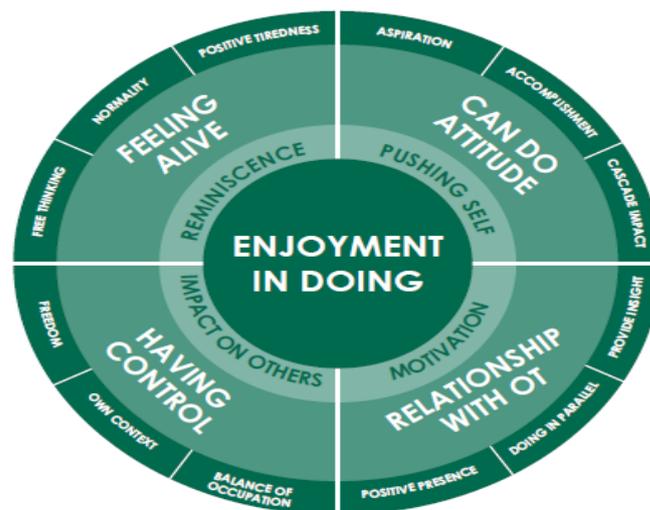
Research

In December 2014, this newsletter invited people who had MND and lived in North Wales to be part of a research study which looked at whether exercise in the form of doing everyday activities affected symptoms of motor neurone disease. The research needed six people who were willing to receive a six week period of rehabilitation. Very quickly, six people responded to the invitation and our journey began!

The research is now complete. The research found that mild to moderate rate of exercise can have the potential to alleviate the experience of symptoms of motor neurone disease in people who experience mild to moderate functional difficulties from having MND. The research found that the effect is more positive when people are involved in “doing” rather than simply carrying out repetitive exercise.

The research study also produced a model which is named the Model of Doing for People with MND and its purpose is to provide a framework for the delivery of occupational therapy. Glyndwr University and the MND Association recently partnered to establish a North Wales Occupational Therapist Best Practice Group. This group is considering the recommendations from the research as part of its work.

Model of Doing for MND



A huge thank you to those of you who participated in this study. It was a privilege to work with you and your families. The research is being presented at the International Symposium in MND, Boston, USA and am waiting to hear if it can be presented at the Royal College of Occupational Therapists Conference, Belfast in June. If anybody wants to hear more about the research please do contact me and I am happy to talk your through aspects of it.

Many thanks again for the support of the MND Association in North Wales for supporting this study to happen and giving us the opportunity to develop occupational therapy knowledge in North Wales.

Dr Helen Carey

Professional Lead in Occupational Therapy

Glyndwr University

Would you like to share your story?

We are looking for Welsh and non Welsh speakers living with MND or caring for someone with MND to come forward and support us with our media work. This could involve sharing your story on local radio or TV, being featured in press articles or on social media. Your support will help us to ensure that people with MND in Wales have a voice and enable us to raise the profile of all aspects of our work within the Welsh media. If you, or someone you know, would like to find out more, please contact **Jo Cunnah**, Volunteering Development Co-ordinator, 03453 751856 , or **Tim Atkinson**, Campaigns Manager , 01543 415121

Future Editions of our Newsletter

We hope that you have enjoyed reading this edition of our newsletter which is available by post and by email. Below are a list of staff members and details of how to contact them directly should you have any questions for them.

We would be pleased to receive feedback and any contributions to the newsletter. (See below)

NAME	PHONE	EMAIL
Regional Care and Development Advisor Kevin Thomas	012488 53428	kevin.thomas@mndassociation.org
Care Coordinator Kathryn Lancelotte Angela Mitchell	01745 448720 extension 2772.	
Volunteering Development Coordinator Jo Cunnah	03453 751856	jo.cunnah@mndassociation.org
Regional Fundraiser Richard Shackelford	01497821247	richard.shackelford@mndassociation.org
Newsletter Editor Howard Mence	01492548649	mence1@hotmail.co.uk

Are you on Social Media?

In the North West of Wales

Why not follow us on Twitter @northwestwales or join us on Facebook

<https://m.facebook.com/North-West-Wales-MND-Support-Group-Grwp-MND-Gogledd-Orllewin-Cymru-174854996057613/>

In the Clwyd area

Why not follow us on Twitter @ clwydmnda, or join us on Facebook

www.facebook.com/clwydmnda or visit our website www.mndclwyd.org.