NW London Branch Newsletter - Autumn 2022



Message from Co-Chairs

Dear Readers

Welcome to the autumn edition of our newsletter. As the nights are drawing in, our focus is turning to the festive season. We are delighted to announce that we are planning a Christmas Open meeting on 4 December at St John's Hospice. Further details are overleaf. We very much hope you will join us.

Support MND Carers Campaign

The Association is launching a Support MND Carers campaign which is calling on the Government to review carers' assessments. The campaign will launch on Tuesday 29 November during the All-Party Parliamentary Group on MND meeting. Carers of people with MND will share what life is like for them to an audience that will include MPs. We will also focus on what MPs can do to ensure carers are better supported and encourage them to join our call for a government review into carers' assessments. It is vital that we get as many MPs as possible to attend and show their support. Please invite your MP to take part: https://ecampaigns.mndassociation.org/page/109974/action/1?ea.tracking.id=staffcomms

Carer Support Services study

We are calling on all carers to take part in the FACTOR-MND research study. This study investigates how the experience of being a family carer impacts the carer's own wellbeing. Our results will help inform current MND services, and future carer support services. Interested carers are invited to complete this online survey. If you prefer a pen and paper version of the survey, please contact Polly Trucco (mnd.research@uea.ac.uk)

We are also inviting current carers to participate in an interview about their experiences and how they are coping with everyday changes. If you wish to take part in this study, please contact Polly Trucco for further information. Contact details: Polly Trucco mnd.research@uea.ac.uk / Tel: 07825 863389 @FactorMND

Interested in volunteering? We are always looking for committed volunteers to join our branch. There are various roles available subject to your availability and skills. Do let us know if you're interested. cherylstroud@hotmail.com

If we don't see you at our open meeting on 4 December (and we very much hope to), may we wish you and your family a peaceful Christmas.

With best wishes

Cheryl & Sarah November 2022

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MND CONNECT HELPLINE

MND Connect helpline is available to anyone seeking information and support about motor neurone disease, linking you to a trained team within the MNDA. The hotline is live between 9am-5pm & 7pm-10.30pm and calls are free from landlines/mobile phones.

Contact: mndconnect@mndassociation.org I Tel: 0808 802 6262

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Support Meetings



Recently Diagnosed Support Group

Friday, 18 November at 2pm

Online Group for people living with MND in NW London. If you or a loved one have recently been diagnosed with MND, you are invited to join this online support group. These small group meetings are facilitated by staff from the MND Care Centres and the MND Association. Future dates: 16 December at 2pm. Please contact ahmed.abdeldayem@mndassociation.org for further information and zoom link.



Carers' Support Meetings

Next morning session - Tuesday, 6 December at 11am Next evening session - Wednesday, 30 November at 6.30pm

Online Group for carers of people living with MND in NW London. Are you caring for someone living with MND? If so, you may wish to join this online meeting for a friendly supportive chat with other carers. For further information and zoom link, please contact alli.anthony@mndassociation.org



NW London Support Meeting

Wednesday, 16 November at 11am
Online Group for people living with MND in NW London

Our virtual meetings give you the opportunity to meet online other people living with MND in your area. These small group online meetings take place regularly and are run by our branch's Area Support Coordinators. For further information and zoom link, please contact alli.anthony@mndassociation.org. Future dates: Wednesday, 19 December



PMA-PLS Support Group Monday, 12 December at 5pm

Meet up online with other people living with or affected by PLS or PMA. For further information and zoom link, please contact alli.anthony@mndassociation.org





NW London Branch Open Meeting Sunday, 4 December 3-5pm

Come and meet your branch members! We would like to invite you, your family and carers to our Christmas get-together in the afternoon of 4 December. We hope you will join us for a chat over festive afternoon tea. There will also be a short Christmas quiz and raffle. The event will take place in the Day Room of the St John & Elizabeth Hospice in St Johns Wood. The venue is wheelchair friendly (inc toilets) and there is parking on site. Please contact Cheryl for further information: cherylstroud@hotmail.com

Location: St John's Hospice. 60 Grove End Road, London NW8 9NH



PAST EVENTS

Wheels & Walkies, 21 August 2022

Sarah and Cheryl led our first ever Wheels & Walkies fundraising event this summer, which brought together about 20 people and two dogs. Cockerpoo Sully and Labrador Sebastian were in charge of stick fetching as the group took a gentle stroll around Hendon Park in memory of loved ones and helping raise awareness. Our walk raised £545, an amount we would hope to beat next year. There was talk of a picnic (rather than just bunking off to the pub, led again by Sarah) after next year's walk.

Canal trip, 16 October 2022

Mo would like to thank all of you who joined her on the canal trip. She says that everyone had a lovely day leisurely cruising through the countryside. Thanks to Mo for organising and providing the delicious onboard refreshments.