



north wiltshire group

newsletter

The Queen's Award
for Voluntary Service

Welcome to the Spring issue of our Newsletter

During these very difficult and challenging times, we like everyone else have had to suspend our normal activities and try to find other ways to support all those affected by MND and each other.

The Association has developed an action plan to ensure that everyone has the most up to date information, knows how to access help and to check if there are any particular issues that need to be flagged. Members of our Group are busy telephoning our local families to see how you are all doing and we look forward to speaking to you.

We have also launched *Staying in Touch*, a bi-weekly electronic newsletter with a lighthearted feel, and established *WhatsApp* groups for individuals to keep in regular contact. *If you would like to be considered for either of these please do let us know.*

Stay safe!

Alison Ariss

Group Chair

Self-registering with MND under COVID-19

Urgent! If you suffer from MND, have you self-registered on the government's website for extremely vulnerable persons?

The MND Association has received the advice that people living with MND should register themselves at www.gov.uk/coronavirus-extremely-vulnerable and follow the steps below:

- 1) After confirming you live in England, and indicating if you've received a letter from the NHS or not, enter your details as requested.
- 2) Tick "Yes I have one of the medical conditions on the list". It has been confirmed that, in this instance MND will be classed as a 'severe respiratory condition'.

URGENT APPEAL FROM THE MND ASSOCIATION

The Covid-19 crisis is an unprecedented situation for us all. We need your help to continue to be there for people with MND during this time.

We are urgently assessing where help is most needed and adapting our services quickly to ensure we can continue to be there for all those affected by MND.

We have committed to contacting every household that we know is affected by MND. These conversations will help us to understand the needs and challenges they are facing, so that we can provide a timely response and help wherever we can.

But, at a time when we need to do more, we are facing a devastating drop in income as a result of the crisis, with the loss of up to a third of our annual income.

We hope that you will understand why we need your help at this time. We are determined to continue to be there for people with MND, who need us now more than ever. Please, if you are able to, will you help us with an extra donation today?

Your support for this urgent appeal would mean so much. A gift of **£27** could pay for a trained advisor on our MND Connect helpline for one hour, helping to provide this vital service to people with MND when they need it most.

To make a donation, please go to the following page on the MND Association website:

<https://www.mndassociation.org/get-involved/donations/emergency-appeal/donate/>

Thank you.



Do not forget that the MND Association is here to help and support you at this time with advice, up to date information, or simply to listen and provide reassurance. Please phone **MND Connect** on **0808 802 6262**.

To keep up to date with the MND Association's **latest advice** for people affected by MND, please visit the following page on their website:

<https://www.mndassociation.org/mnd-and-coronavirus/>

Message from your local North Wiltshire Group of the MNDA:

We are thinking about you all and are still here to support you. For your AV's email contacts and other useful addresses see the final page of this Newsletter.

Other News

MND nurse breaks record to raise money

Two women have set a new world record, becoming the fastest people to circumnavigate the world on a tandem. Rachael Marsden, a Nurse Consultant for MND at the John Radcliffe Hospital, Oxford, and her fellow traveller Cat Dixon, cycled 18,263 miles (29,392 km) in just over 263 days.

The intrepid pair, who set out from Oxford on 29th June last year, raised almost £37,000 for the MND Association and Oxfam, smashing their target of £18,000. Rachael said it had been an amazing adventure, 'but we have returned to a different (Covid-19) world to the one we left, with very different priorities'.



Pulling together

Sadly, MND has touched the family of the landlord of the Blue Boar, Aldbourne, and regulars there have raised £2891.83 for the MNDA. In March our fundraiser, Theresa (left), was invited to receive the cheque on behalf of the Association.



Swindon Community Lottery

Don't forget, if you play the Lottery, the **Swindon Community Lottery** is an easy way to raise regular funds for the North Wiltshire Group.

This is a new weekly lottery that raises money for good causes in Swindon. The draw is every Saturday night when a 6 digit winning combination is picked. Tickets cost just £1 per week with a top prize of **£25,000**.

Players are able to choose which cause they wish to support. Nominating the Motor Neurone Disease Association North Wiltshire Group means that the Group will have more funds to invest in support for local people living with MND. So please do name the Group as your designated cause and you will be helping us to continue to fund adaptations for people with MND, assist with respite care for families and provide regular, invaluable support groups. It's simple to join; go to: <https://www.swindonlottery.co.uk/support/motor-neurone-disease-association>

Local support for local people

Things to Know

Useful Contacts

N Wilts Group website
www.mndnorthwiltshire.org.uk

N Wilts Group contact
info@mndnorthwiltshire.org.uk
or phone MND Connect

Facebook <http://www.facebook.com/MNDNorthWiltshire>

Twitter @MNDNorthWilts

Letters will be forwarded from:
**North Wiltshire Group, c/o MNDA,
PO Box 246, Northampton NN1 2PR**

MND Connect 0808 802 6262

MNDA national website
www.mndassociation.org

MNDA Volunteering Team
01604 611681

MND Benefits Advice Service
0808 8010620

Prospect Hospice 01793 813355

Campaigning news

The Policy and Campaigns team at the MND Association continues to support volunteer campaigners during the lockdown by transferring their planned London event to online sessions. Heather took part in two sessions focussing on how the central team works with campaign volunteers in a new way following changes to the Association team, and a very useful session with Art Conaghan, Parliamentary Researcher, to Andrew Lewer MP, Northampton South, and the Chair of the All Party Parliamentary Group for MND. Art gave some very helpful tips for getting your points noticed by MPs and how much demand there is on their time. There are more virtual sessions coming up to prepare the campaigners for getting back to driving forward the planned campaigns by the Association as soon as we are allowed.

Support Meetings

Sadly, our regular support meetings at The Lawns Community Centre, Swindon, and at Seend Community Centre have had to be suspended until the present health crisis is over.

Meanwhile, you can still **contact your AVs at**

alisonaviss@mndnorthwiltshire.org.uk

and

anitacreamer@mndnorthwiltshire.org.uk

Don't forget that you can still find information and advice at the numbers and addresses on the left.

We are thinking about you all and are here to support you.

New Head of Volunteering

Despite these testing times, the MND Association has welcomed a new Head of Volunteering, Matthew Cobble, following the retirement of Steve Gee.

Matthew started last month after working at the Riding for the Disabled Association and has been navigating his induction period during this challenging time. We look forward to hearing more from Matthew as he settles into post.

Contact the editor

The deadline for submission for the next issue of the newsletter will be **4th July 2020**.

The editor would love to receive your news, comment and photos for inclusion: please email him on *info@mndnorthwiltshire.org.uk*

To **unsubscribe** from this newsletter email your name and 'unsubscribe' to *secretary@mndnorthwiltshire.org.uk*