



north wiltshire group newsletter



Welcome to the April issue of our Newsletter

Welcome to our Spring Newsletter. In this issue we are focussing on the launch of the Association strategy for 2022 and beyond with 5 promises, each with 5 clear ambitions to ensure clarity and focus for our work.

You will also see the feature on a research programme into Carer Support, looking at a 12 week peer to peer support programme. If you have experience of caring for someone with MND, this may be of interest to you and you can register via the links in the article.

Hope you enjoy reading our news.

With very best wishes,

Alison Aviss
Group Chair

Don't forget, the North Wiltshire Group can now accept donations by text.

**Text MNDWILTS to
70085
to donate £5**

to support MND North Wiltshire Group
helping local people with MND

Texts cost £5 plus one standard rate message



Registered Charity no. 294354



Local support for local people

Beating MND Together: 5 Promises – what we are doing locally

In 2022 the **MND Association** set out its vision for future priorities in **5 promises** to people living with MND and their carers. Each promise is underlined by 4 or 5 more **detailed** 'ambitions'. If you are a member of the Association you will have received a personal copy. The full document is also available on the MND Association website.

The North Wiltshire Group is proud to endorse these promises and to work towards their fulfilment in our local area. Each year the Group agrees its action plan. The 2021 action plan was reported on in the January 2022 Newsletter. We are now making sure that our plan addresses these 5 big promises in order to deliver the best outcomes we can for **local people**.

We promise we won't rest ...

Promise 1. until MND is treatable and ultimately curable

This is mostly about medical research, which is organised at the national level. Last year the Group contributed £6,000 from the funds you raised towards specific projects sponsored by the Association.

Promise 2. until everyone gets the care they need when they need it

This is about diagnosis and quality of care delivered in a timely way, involving all people living with MND in decisions which relate to them. Last year the Group continued to work closely with all health and social care providers to ensure a coordinated approach to care, and our Visitors are actively involved in Multi-Disciplinary Team meetings throughout the area.

Promise 3. until every day with MND counts

This is about supporting people's quality of life. Last year the Group supported over 40 local families affected by MND, switching to telephone and video during lockdown periods. We held regular Zoom Support Groups for all those affected by MND and continued with Carer Support Group Meetings. We are proud to have provided £8,100 in financial assistance for local families towards the cost of home adaptations, specialist equipment and quality of life improvement grants.



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Promise 4. until you are heard

This is about listening to your concerns, involving you, and finding ways to speak to power. The Group is actively involved in campaigns and initiatives organised by the Association, and we seek to influence local policy.

Promise 5. until no-one faces MND alone

This is about responding to the needs of all communities, and involving people living with MND earlier in planning. The Group seeks to provide good quality, efficient and up to date two-way communication via a range of channels. Support groups and AV visits allow personal discussion.

If you have ideas or want to discuss these promises, just speak to your Visitor, email info@mndnorthwiltshire.org.uk or phone Alison on 07976 155635

Research into Support for Carers — could you help?

ARE YOU INTERESTED in supporting someone who is caring for someone living with MND? We all know the carer's role is tough. By taking part in this study, you could make a huge difference to people living with MND and their carers.

THE STUDY: This research study aims to find out the usefulness of a 12-week virtual support programme for people caring for someone with MND. We will look at the impact caring has on wellbeing and try to understand how user friendly and acceptable the online peer support programme is to family carers in the study. This is an exciting opportunity for you to become a peer supporter.

WHAT'S INVOLVED? You must have lived experience as a carer for someone with MND. As a peer supporter, the research team will link you via an app with a family carer of someone with MND. This app is a bit like WhatsApp but more secure and can be used on your smartphone, tablet, or computer. These family carers are part of the research study and you'll be helping them.

MY COMMITMENT? The role is a **12-week commitment**. During this time, you will need to check-in (contact) with your allocated family carer a minimum of once a week for each of the 12 weeks. This will be done via the app called **aTouchAway**. You will also need to reply to texts or calls from your allocated family carer. You will share your carer experiences and knowledge via a weekly discussion forum on Zoom.

THE ROLE? In your role, you can share your personal experiences and your knowledge of resources or tips on useful carer strategies you have learnt. However, you are not expected to provide specific advice related to medical treatment or medical technologies.

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THE ROLE WILL SUIT YOU IF YOU:

- ⇒ have lived experience as a carer for someone with MND
- ⇒ are a good communicator
- ⇒ are happy to use the app (like WhatsApp) for communication and have access to your own device suitable for this
- ⇒ can develop and maintain supportive relationships
- ⇒ are non-judgmental and respectful of diverse lifestyles
- ⇒ understand the need for confidentiality and the importance of data protection
- ⇒ can assess when extra support is needed

The research team will give you training (via Zoom) on how to use the app and on peer support. The research team will be there to support you throughout the 12 weeks, including check in/debrief sessions at 6 and 12 weeks.

HOW CAN I TAKE PART?

Please contact Rebecca Rogers at rebecca.e.rogers@kcl.ac.uk or Thilipan Thaventhiran at thilipan.thaventhiran@kcl.ac.uk if you would like to take part or if you have any queries and need more information.

Fundraising

Waitrose 'Give a Little Love'

Our friends at Waitrose Malmesbury have presented us with a cheque for £333 from their 'Give a Little Love' funds.

Anita Creamer, Association Visitor for the North Wiltshire Group, visited the store to collect the cheque from Deborah Barnes, who was very interested to hear how the Group supports local people affected by MND.



Gemini Outdoor 10s Challenge

We are so pleased to have been supported again by Steve Ellis and members of Team Go from Gemini Outdoor as part of their 10 year celebration. Team members pledged to walk 10K for 10 days from 1st to 10th February inclusive, raising donations for the MND North Wiltshire Group.

Alison and Anita went along to The Wild Carrot Cafe at Chavenage to welcome them back after completing their last walk in the 10s Charity Challenge with a very well deserved coffee and cake!



Together they raised an amazing £825 (excluding gift aid) via the **JustGiving** page. This is an amazing sum and Alison and Anita were able to share how the money will be used to help local families affected by MND.

We salute and thank you all, and wish Steve and Michelle the very best of luck for their new life in New Zealand.

Easy money

Here is a painless way to raise money for the Motor Neurone Disease Association. The National Association recently received a quarterly donation of £4,012.73 from AmazonSmile, thanks to customers shopping at smile.amazon.co.uk or with the AmazonSmile app turned on. To date, Amazon has donated a total of over £21,860 to the MNDA. Why not give it a go? It seems a waste not to!

Westlecot Bowls Club Ladies

We are delighted to have been chosen as Charity of the Year by the ladies of Westlecot Bowls Club in honour of one of the founding members who is currently living with MND and supported by our Group.



Alison and Barbara went along to the coffee morning on Thursday 3rd March to meet members, speak about MND and our work, explain how we use funds raised for us and the difference that these make to those affected by MND.



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
Dorothy House 01225 722988

Support Meetings

The next Support Meetings will be face-to-face (Covid permitting):
New Support Meeting for West Wiltshire, see below.
2pm-4pm on **17th May** at The Lawns Community Centre, Guildford Avenue, Swindon.
2pm-4pm on **26th July** at The Lawns, Swindon.
All are welcome to join us for a friendly chat, a catch up with friends, and to see your Visitor.
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.
For the Carer Support Group see the separate notice in this issue.

Trialling a New Support Group for West Wiltshire

We have arranged a Support Group Meeting for the afternoon of Tuesday **10th May at Stanton Saint Quintin Village Hall**, just north of Chippenham and off Junction 17 of the M4. The hall is very well equipped and has good wheelchair access and facilities.

More details will come out nearer to the time, and we have arranged this as a one off to see if the location works for those on the west side of the county.

NB. This is in addition to the Swindon Meeting at The Lawns on 17th May.

Vacancies for Volunteers

 Might one of these roles be for you?

- ♦ **Social Media Officer** to take responsibility for our Twitter and Facebook presence
- ♦ **Fundraiser** to encourage local organisations to raise funds in aid of the Group

Email Alison for a chat at alisonaviss@mndnorthwiltshire.org.uk

Contact the editor

The deadline for submission for the next issue of the newsletter will be **18th June 2022**. Email the editor on info@mndnorthwiltshire.org.uk
To **unsubscribe** from this newsletter email your name and 'unsubscribe' to secretary@mndnorthwiltshire.org.uk