



north wiltshire group

newsletter



Welcome to the October issue of our Newsletter

This issue sees several important initiatives. On a national level, the MND Association is running the **Act to Adapt** campaign. Home adaptations to help people cope with MND can be expensive and slow. **Act to Adapt** aims to persuade government, both national and local, to **develop a faster and fairer system to ensure home adaptations happen in a timely, efficient manner with minimum impact on people with MND and their families.**

We asked 'who cares for the carers?' So we appointed a Carers' Champion, who is exploring ways to give support. Natasha reports on the August and September support sessions, and looks forward to October's (p.6).

This year Covid-19 means that we all have to do things differently in order to keep each other safe. This is equally true for fundraising. This issue highlights several events, and we are encouraging you to think of imaginative new ways to raise funds and awareness. This may include virtual sponsored activities (p.2). And use the Group's **JustGiving** page for donations.

Best wishes and keep safe,

Alison Ariss
Group Chair

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.

Fundraising

Fundraising and awareness-raising are as important as ever. Without your support the Group is limited in what it can achieve for local people. But in the present situation we all need to be imaginative. Virtual events are the way forward, and our **JustGiving** page allows you to donate safely.



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Virtual events to help support **North Wiltshire Group**

Autumn personal challenge—replacing our usual Walk to d’Feet.

If you or someone you know would like to help raise funds for our Group you might like to complete a sponsored personal challenge this Autumn. This might be distance walking the dog or a number of steps in the park, anything you choose.

Just use our **JustGiving** page and anything raised comes directly to our Group, helping us to continue our work in the local area.

Use our **JustGiving** page

<https://www.justgiving.com/fundraising/MNDA-North-Wiltshire>

Swindon Community Lottery

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



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 good 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>

Virtual Quiz and Raffle organised by Gemini Outdoor

Gemini Outdoor is a small outdoor fitness and adventure company based in our area at Malmesbury. Its activities include the Nordic walking group which our colleague Dawn belongs to. It is raising funds for the work of the MNDa North Wiltshire Group with an online quiz night on 28th October and a raffle draw on the 31st.

To join the Online Charity Quiz Night, you can donate using

<https://www.justgiving.com/fundraising/geminioutdoor-mnda>

(suggested donations of £6 per team), then please send an email to geminioutdoor@icloud.com with 'Online Charity Quiz Night' as the subject and the 'Team Quiz Name'.

To enter the Raffle, you can donate using [https://www.justgiving.com/](https://www.justgiving.com/fundraising/geminioutdoor-mnda)

[fundraising/geminioutdoor-mnda](https://www.justgiving.com/fundraising/geminioutdoor-mnda) (suggested donations £1 per strip of 5 tickets), then please send an email to geminioutdoor@icloud.com with 'Raffle Ticket Entry' as the subject, then a short email with your name and the number of strips of tickets you have donated please.

Local golfers raise funds

Two local golf clubs are raising funds for our Group in support of fellow members affected by MND. Stinchcombe Hill Gold Club men's team held an event for 48 players on 10th August, while South Cerney Golf Club ladies' team held a similar event on 23rd September. Our grateful thanks to both clubs for their support.

SOUTH CERNEY



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Amazon Smiles on the MND Association

At the moment many people are turning to online shopping. Amazon has launched an initiative which allows you to donate to the charity of your choice while shopping on line with them. AmazonSmile will donate 0.5% of the net purchase price (excluding VAT, returns and shipping fees) of your eligible AmazonSmile purchases at no cost to you. All you have to do is visit smile.amazon.co.uk and select the MND (the national Association not the North Wiltshire Group) to receive donations from eligible purchases before you begin shopping. Or there is a phone App if you prefer that sort of thing. After that, every eligible purchase you make through AmazonSmile will result in a donation. Since the initiative began, the Association has received a tidy £9,800 – well worth doing, I'm sure you'll agree.

Vacancies

The North Wiltshire Group has vacancies for volunteers, including:

- ◆ **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

If either of these might be you, email Alison for a chat at alisonaviss@mndnorthwiltshire.org.uk

Local support for local people

Act to Adapt — campaign

Through ACT TO ADAPT the MND Association, **calls on national and local governments to develop a faster and fairer system to ensure home adaptations happen in a timely, efficient manner with minimum impact on people with MND and their families.**



ACT TO ADAPT

Access to home adaptations for people with motor neurone disease

For people with MND, getting the home adaptations they need quickly and easily is vital to ensure they can live safely, independently, and with dignity in the time that remains to them. However, there are significant challenges many people face in adapting their home, including cost, length of time taken, and poor information about the process.

The MND Association's report **Act to Adapt** sets out a range of recommendations to improve the current situation and includes examples of good practice from across the country demonstrating what can be achieved

What can we do? Two easy online actions will allow us all to get involved in the campaign. These are:

1. *'Have Your Say'* – People living with and affected by MND are encouraged to share their experiences of housing adaptations, and other supporters/stakeholders are asked to share a message about their vision for accessible housing for people with MND and why this matters to them. The power of sharing stories is crucial to the campaign; it will help raise awareness, influence and inspire support.
2. *'Email your councillor'* – A simple ask from supporters to councillors to read the published report, share it with colleagues, and then link to the *'Have Your Say'* action where they can read the stories and leave a message of support.

Note:

The North Wiltshire Group invests a proportion of its fundraising in home adaptations such as stair lifts and useable wet rooms to allow people lwmnd to manage in their own homes. We believe this is an important use of our funds, though as a small local charity there is a limit to what we can do alone. The national Association also helps fund adaptations, but has other important calls on its funds, such as research into treatment and cure.

MND Corona Virus Hub

For advice, FAQs and links to organisations providing up-to-date information visit

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

For Carers

Carers' Support Zoom Meetings

MNDA North Wiltshire and Gloucestershire branches have teamed up to deliver a monthly Zoom session aimed specifically at carers. The sessions began in August, with a bit of a false start as we realised halfway through the pamper session that most of the participants had not had their pamper packs delivered yet; though we all enjoyed one of the ladies doing a fabulous demo for us! The rescheduled session ran much more smoothly where everyone did a relaxing facemask with Neals Yard Remedies products. September's session was very informative with a representative from Gloucester Carers Hub offering advice on the Carers Emergency Scheme, the Carers Assessment and other topics.

The sessions are run monthly on a Wednesday evening (usually the third Wednesday of the month) at 8pm. The next one is 14th October, with the topic of 'Thinking Ahead'. Anyone who would like to attend and has not already received the email invite, or if you would like any other support then please contact Tash at carersupport@mndnorthwiltshire.org.uk or tel. 07961821097. Suggestions/requests for future topics are also welcome.

Wednesday 14th October - 8pm - Carers only Thinking Ahead

Our commitment to carers: Opportunity to relieve isolation & to improve well-being & resilience

We hope you can join us for the next session, 'Thinking Ahead', led by Dr Emma Husbands, Consultant in palliative medicine.

Often carers are hoping for the best but understandably have worries for the future. Emma will gently address concerns in this area and will explain ways of communicating so that people can express their wishes and make plans for their future care and treatment. There will be opportunities to ask questions and for support from MNDA after the session, if wanted.

Contact us and we will send you the Zoom meeting link nearer the time.

Liz Attwood lizattwoodmnd@outlook.com 07753 346799
Natasha Flintoff carersupport@mndnorthwiltshire.org.uk

 MND Association Carer Support Glos

*For details of this event
or an invitation, contact
Tash (Natasha) or Liz*

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 MND, 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

In place of our regular Support Meetings at The Lawns Community Centre, Swindon, and at Seend Community Centre, which have had to be suspended until the present health crisis is over, we are hosting a 'virtual' Support Meeting on Zoom. Watch your emails for dates and passwords.

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.

MND Association AGM online

As I am sure you will know, the National AGM had been due to take place in July, but, in light of the coronavirus pandemic, the Association made the difficult decision to postpone it.

The safety and wellbeing of our members, volunteers and staff is always of the utmost importance and, having considered all the options available, the **Association's 35th AGM** will now take place as a live, online event on **Tuesday 13th October at 4.30pm** (and last approximately 90 minutes).

Members of the Association are invited to register for this important event and to vote on the resolutions put forward. If preferred, you may appoint a proxy to vote at the online event. You also have the option to submit a question in advance for the directors and Board of Trustees, or to ask one on the day.

Please ensure you complete your voting online by noon on **Friday 9th October 2020**. Information and instructions on all of the above can be found by visiting the AGM page on the Association's website.

Contact the editor

The deadline for submission for the next issue of the newsletter will be **10th January 2021**. 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