January 2021 registered charity no. 294354 issue 52

north wiltshire group

newsletter

The Queen's Award for Voluntary Service

Welcome to the January issue of our Newsletter

This time last year we had no idea how difficult 2020 would turn out to be and how we would need to adapt to cope with a global pandemic. As the full impact of Covid-19 became clear, we knew we needed to develop tailored support for all our families affected by MND. Here are some of the things we tried:

- We called all families affected by MND in our area to ensure they had the most up to date guidance, were able to get shopping delivered and medications supplied
- From April to end of lockdown 1 - we sent electronic *Staying in Touch* newsletters with key messages about shielding, shopping, puzzles and lighthearted info about what we were doing to keep ourselves busy. It turns out that we have some very active and competitive gardeners, decorators and puzzle fiends
- Because we could no longer see each other face to face we introduced monthly Zoom Support Group meetings, inviting all those affected by MND in Wiltshire
- Together with colleagues in Gloucester, Bristol and Bath, we introduced a monthly Zoom Carers Support Group. Each meeting has a theme with guest speakers, therapy sessions and advice. We are lucky to have Natasha as our Group Carers' Champion
- Our monthly committee meetings have continued in the virtual world
- As a Group, we have been actively involved in the campaigns to have MND recognized in the Extremely Vulnerable category, lobbying local MPs and raising awareness with those who organize local services, and this will be remain a key focus for us in 2021

Best wishes and keep safe,

Alison Aviss
Group Chair

Group's Review of 2020

North Wiltshire Group – Our Impact in 2020

As a Group, we are very proud and committed to represent the Motor Neurone Disease Association and assist in delivering its aims in our local area. To help us to do this effectively, we develop our own action plan to help us focus our activities, assist in maximizing our resources and skills, and to provide a mechanism to identify and celebrate our successes. **The Covid 19 pandemic required us to revise our 2020 plan to reflect lockdown restrictions, the need for social distancing and the cancellation of all fundraising events. In July we introduced a revised plan.**

The revised 2020 action plan still focused on our 5 key areas:

- Support for people with Motor Neurone Disease
- Awareness Raising
- Fundraising
- Campaigning and Influencing
- Group Organisation

How did we do?

- The 2020 revised plan detailed 28 individual actions
- 27 actions have been successfully completed
- This result equates to a 96.4% achievement rate
- Collectively, our group volunteers quickly embraced a new way of working with enthusiasm

Here are some examples of our achievements:

⇒ We supported over 40 local families affected by MND with regular telephone and video calls, providing up to date advice on shielding, securing shopping deliveries and medical supplies

⇒ We worked closely with health and social care providers to ensure a coordinated approach to care

⇒ From April we introduced a fortnightly Staying in Touch newsletter with latest health and Government information, quizzes and puzzles and features on how our volunteers were keeping busy during lockdown

⇒ Stayed in touch with regular Zoom Support Groups and our Carer Champion, Natasha introduced dedicated Carer Support Group Meetings with colleagues from the South West region

⇒ We are proud that despite very low levels of fundraising opportunities we have provided nearly £6,000 in financial assistance to local families towards the cost of home adaptations, specialist equipment and quality of life improvement

⇒ Throughout the year we have continued to support the Association's campaigns programme lobbying local MPs to '**getMNDonthe list**' as clinically extremely vulnerable, **Scrap 6 Months** and **Act to Adapt** that calls on national and local government 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

All donations help us to assist local families with much needed support grants. Our very grateful thanks go to all who have raised money and awareness for our work during 2020 with special mention for:

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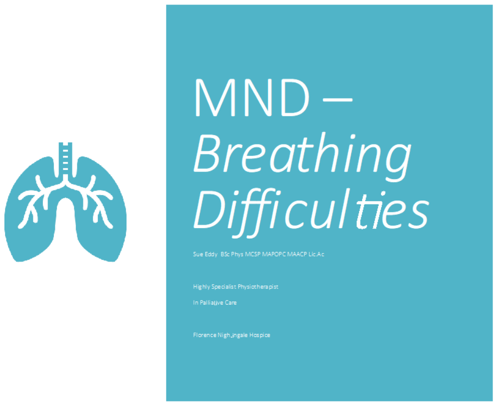
- Great Cheverell Soapbox Derby
- Waitrose Community Matters green token scheme
- South Cerney Ladies Golf
- Masonic Charitable Fund
- Gemini Outdoor

These achievements have only been possible due to the dedication and commitment of the volunteers that make up the North Wiltshire Group team, who share a common goal to make a real and positive difference to all those affected by MND in our area. Thank you all so much for your continued support.

If you would like to help us with this important work we would love to hear from you. Please contact us at info@mndnorthwiltshire.co.uk or call us on 08457 626262.

The benefits of a virtual world

Whilst meeting on a computer screen will never replace face-to-face contact, we have discovered a number of advantages! Our Association Visitors attend at least one development day each year to ensure that their knowledge and skills are kept up to date, particularly with the research advancements being made. They report that this year's event was 'one of the best' with presentations on latest research, Association directors, health and social care professionals, and record attendances from Visitors so great opportunities to hear from colleagues in the wider region.



MND –
Breathing Difficulties

Sue Eddy BSc Phys MCSP MAPOPC MAACP Lic.Ac

Highly Specialist Physiotherapist
In Palliative Care

Florence Nightingale Hospice

Impact of COVID-19 on MND Research

mnda
motor neurone disease association

AV Development Day
13th October 2020

Fundraising & Awareness

Tadpole Garden Village In Bloom

Pete Welsh writes: Tadpole Garden Village (TGV) In Bloom have decided to nominate MNDA as our chosen charity for the year. All our events will hold the MND charity pot for donations alongside any events we hold.

We are also hoping to plant cornflowers in the New Year at a location of your choice, preferably a hospice that your Group has an affiliation with. We think planting it in their garden would be something for the junior members of our group to work towards.

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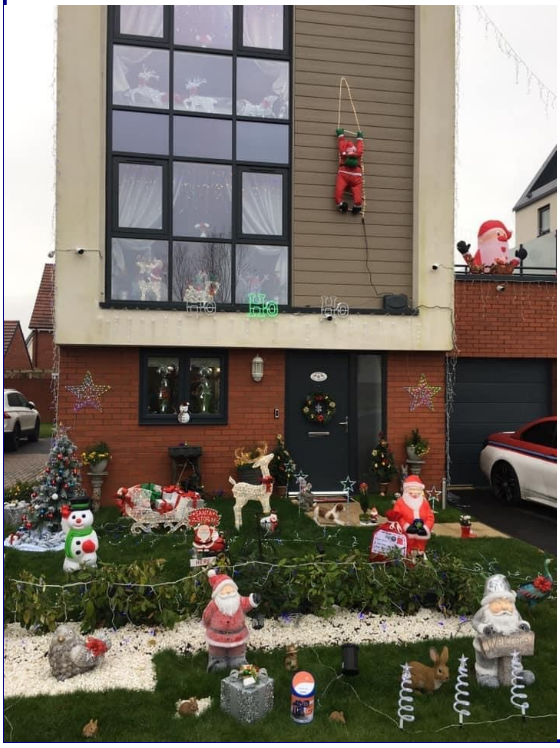
My son Joshua (right) lost his Grandpa earlier this year to MND. He helped plant seeds up at the TGV community allotment with the hope that we can gift them to MNDA. Any we have left over will be made available for our residents to purchase, with proceeds going to MNDA.



And on a more seasonal note: Thank you to Mirela & George Golea who raised an amazing £173.22 for the Group by collecting donations for their colourful Christmas light display

TADPOLE
GARDEN VILLAGE

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 good 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*

Local support for local people

For Carers

Carer Support Zoom sessions continue to run on the third Wednesday of each month, with a growing crowd of regular attendees. The reach has extended to include the MNDA Bristol Group, as well as Gloucestershire and Wiltshire, and we've even had people join from Portsmouth, which is the beauty of running them online. In November we had Lauren Wells, Gloucestershire MND Coordinator, talking about COVID and how this affected things such as hospital visits during the second lockdown. December was much more relaxing, with a lovely Mindfulness session and short guided visualisation, led by Suzanne Phillips, Family Support Practitioner at Sue Ryder Hospice Cheltenham. In January Dr John Ashworth, a psychologist with experience of working with people affected by MND, led a session on the Psychological Impact of Caring.

Coming up in February, we have Matthew Hollis and Richard Cave from the MNDA communications team joining us to share information on communication aids, APPs and devices. This will be on Wednesday 17th February at 8pm; look out for the Zoom link, which will be sent via email a few days beforehand. Our March session is with Respiratory Physio, Anita Sinclair. Contact Tash (Natasha) Flintoft on carersupport@mndnorthwiltshire.org.uk for more information.

MND Research

MND researcher makes new discovery

You may recently have seen a prominent news story indicating promising results from a study in Edinburgh by Dr Arpan Mehta into boosting energy to nerve cells. Dr Mehta’s research is jointly funded by the MND Association. The MNDA is aware that you or the people living with and affected by MND who you support may have questions about this study.

Whilst the indications from this study are good news, the MNDA would like to reiterate that this work is at a very early stage of development and the study is not currently at a clinical trial stage to test potential treatments.

Researchers are now conducting further laboratory studies including screening of potential compounds, which, if successful, could be recommended for a clinical trial platform and while we hope this will happen as soon as possible, this is a process that could take years. You can **read the blog on the journey of a drug - what it takes to be approved**.

MNDA has also published a blog where you can **read more about the science underpinning this study**

Anyone interested in opportunities to take part in research should first discuss this with their neurologist. The MNDA has several research opportunities advertised on its website.

source: MNDA Volunteer News Jan 2021

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

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.

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
- **Webmaster** to manage the Group's website

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

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*

Contact the editor
The deadline for submission for the next issue of the newsletter will be **3rd April 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*