



north wiltshire group

newsletter

The Queen's Award
for Voluntary Service

Welcome to the July issue of our Newsletter

The last few months have been a difficult time for everyone, but particularly for plwMND. During this period the North Wiltshire Group has had to find new ways of supporting plwMND. Life has become 'virtual' and new opportunities have been opened up. We convened our regular Group meetings on Zoom; we experimented successfully with online support group meetings; we tried a WhatsApp group; we issued a fortnightly 'Staying in Touch' bulletin online; the regular Multi-Disciplinary Team Meeting (of medical professionals) was held on Microsoft Teams.

Things now seem to be beginning to find a new normality, but the world is not yet 'safe'. The Group will seek to protect plwMND (and themselves) while still offering support, by continuing to operate online where that is possible. For example, we propose to continue to host support meetings on Zoom for the foreseeable future.

Fundraising now requires even more imagination to come up with a 'safe' event — but examples of virtual challenges and online quizzes are often in the news, so it CAN be done.

Ironically, new ideas and new ways of working which improve all our lives may be a legacy of Covid-19.

Stay safe! Be kind! Think big!

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.

New Roles

A New MND Specialist Practitioner Role at the RUH

Congratulations to Dawn Beckett on her appointment to the new MND specialist practitioner role at the RUH Bath. This specialist role was introduced at the RUH following the publication of the NICE guidelines in 2016. It highlighted the need for patients to have a single point of contact to support and co-ordinate their care due to the numerous health professionals that can be involved. Since its inception, the role has evolved and the post has been increased from 3 – 4 days a week, so is able to offer on-going support for patients with MND, their families and carers, from diagnosis through to end of life.



The MND specialist practitioner works within the RUH, Dorothy House Hospice and the community, and visits patients on the wards or in their own homes, across three counties. It provides a link between the consultants and in-patient services, with the community, and provides expertise and training to those less familiar with the disease, particularly in care homes.

The MND specialist practitioner can offer:

- ⇒ Information about MND, onward referrals, benefit advice, advance care planning, training and development with other professionals and help with developing protocols and pathways.

In light of the recent pandemic, the role and the MND service as a whole at the RUH is evolving again to provide a safe yet effective service for all our patients. They are no longer required to attend any face to face consultations (unless absolutely necessary) and have virtual video calls with the relevant consultants and allied health professionals. Overnight oximetry is now achieved by the delivery and collection of the equipment to and from the patients' homes, reducing the risks of infection and minimising fatigue and travel costs. The results are then analysed and the outcome is given via video link.

This is a difficult journey for our patients and their families, so providing support during this time is an honour and a privilege! MND has been a passion and specialist interest of mine for many years, so being a part of this team and developing this role further is exciting and I am so grateful for the opportunity.

Experts talk about Coronavirus

The MND Association has posted a series of video interviews with experts who answer questions about the impact of Coronavirus. Watch these helpful podcasts at www.mndassociation.org/video/ask-the-experts/



New: Carers' Champion with the North Wiltshire Group

The Group is piloting this much needed new role on behalf of the Association. Natasha, our new Carers' Champion, writes:

I decided to look for a volunteering role last year when I was working in a rather unfulfilling job, and when I saw the Carers' Champion post advertised for the MNDA, it seemed like a perfect match for me.

I became very aware of MND a few years ago when my mum's close friend was diagnosed and then sadly passed away. I saw how tough it can be on the person themselves but also the impact that it has on their family and friends. If I am able to help make someone's life slightly easier in some small way then I will be happy. I feel that I am suited to the role as I am very personable and enjoy communicating with all types of people. Though I may not always have the answer to queries straight away, I am not shy of hassling people until I get the answer! My 'day job' is as a Welfare Support Officer and so this gives me a good basis for signposting to agencies that are available to support Carers.



Natasha (left) taking part in our Walk to d'Feet MND at Coate Water on 6th October 2019

I attended the virtual support meeting on 23rd June and found it to be very worthwhile; and I am keen to set up a separate virtual meeting specifically for Carers if there is interest. I am most looking forward to being able to arrange gatherings in person and to offer respite opportunities once Covid-19 is over.

Please do not hesitate to get in touch if you have any questions or need support with anything; I am available on 07961 821097 or email carersupport@mndnorthwiltshire.org.uk

Measures of success

At this time of year the Group would normally report on progress against our year's action plan targets, but the plan has been superseded by Covid-19. Even so, of the 45 actions listed, 26 have been achieved while 19 are now out of our control. A new plan is being drawn up to address the changed circumstances, but by being realistic and dedicated we are hopeful that we can have another fruitful year.

Local support for local people



- £25,000 jackpot!
- Sign up from £1 per week
- Support our good cause today
- Your support makes a real difference to our local community

To start supporting, visit:

www.swindonlottery.co.uk

and search for: **Motor Neurone**

Supporters must be 16 years of age or older. Offer ends 29th August 2020. See website for terms and conditions.

Swindon Community Lottery

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

This new weekly lottery raises money for good causes in Swindon. 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>

Caring by any other name ... What do you think?

Following the recent Carers' Week, the Group want to review our use of the term 'carer'. The Association is also reviewing its use of the word. We understand why many people reject the word: it sounds like an impersonal paid job! In reality it is about a relationship with a loved one, and every relationship is unique. People who are helping a loved one with everyday tasks are husbands and wives, partners, sons and daughters, friends and companions, and a host of other things.

The Government groups these varied relationships together under the term 'carer' for administrative ease. But we need a better term to use in general communications which does not cause irritation – of course, in one to one contact with individuals we would always use your name.

We are looking for a word or a simple phrase to express this personal relationship aspect which could be used in place of the word 'carer', for example in this newsletter or in a general letter or email. A descriptive phrase like 'a person who ...' would be too cumbersome, while a single word like 'partner' is not always appropriate. We know of one charity which uses the phrase 'essential companion'.

So we are asking for your input. If you can think of a word or simple phrase which might cover this range of relationships, we would love to hear from you. Please email suggestions to info@mndnorthwiltshire.org.uk

Thank you.

New look workbook for young children

Do you need help to talk about MND to a child or young person? The MND Association has developed materials and advice specially suited for children and young people with a family member living with MND. Visit:

<https://www.mndassociation.org/support-and-information/children-and-young-people/>

The MND Association's workbook for children aged 4-10, *When someone close has MND*, has been refreshed using characters from their storybook, *Why are things changing?*

Following the gentle introduction in the storybook, the new workbook, which includes drawing activities, covers more about MND to help a child and trusted adult continue communicating about the disease. The workbook is only available in print.



To order a copy from Care Admin; tel. 01604 611812 or email careadmin@mndassociation.org

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.

North Wiltshire Group members attend a virtual meeting on Zoom

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 **19th September 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