



north wiltshire group newsletter



Welcome to the July issue of our Newsletter

Welcome to our Summer newsletter.

Our Group is made up of some amazing volunteers who give their time, enthusiasm and professionalism to support all those affected by MND in our area and also campaign for improved services. We would love to have new members to join us and continue this vital work. Do read the article about the positives of volunteering and please get in touch if you are interested in being part of our team.

Hope you enjoy the lovely weather and 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
mnda motor neurone disease association
Registered Charity no. 294354

The graphic features a dark blue background with white and orange text. On the right side, there is a photograph of a hand holding a smartphone with various app icons on the screen. The text is arranged in a clear, hierarchical manner, starting with the call to action and ending with the organization's name and registration number.

Volunteering

Volunteering: a win-win opportunity

We are always keen to further develop the service we offer to local people affected by MND and build upon our legacy. **To achieve this we need motivated people!**

Over the years, with hard work and dedication, we have moved from being solely a fundraising group to one that offers a wide range of services and support, strong campaigning and awareness raising and accepted as a 'respected partner' within the health and social care professional team, resulting in us being awarded the **Queen's Award for Voluntary Service** in 2019.

This has only been possible because of the vision, dedication and commitment of our team members. And in order to continue developing, we are looking for people to bring **new ideas and skills**.

Our group is dynamic, and over the years several people have worked with us to build their own confidence, develop skills that contribute to career progression and achieve a real sense of self worth. After they leave us they say how **valuable** their time with us has been.

As the poster (previous page) shows, we know we need help with fundraising, social media, administration and direct support for people with MND but we can and do create roles around individuals, taking account of their skills and wishes.

Volunteering with us is a two way street – you will get so much out of it too!

If you think this is you or someone you know, we would love to hear from you. Please email us at info@mndnorthwiltshire.org.uk or call Alison for a chat on 07976 155635.

It's a Lottery

Your fun on the Swindon Community Lottery helps to give the Group a regular income which we can invest in local people lwMND. Just go to www.swindonlottery.co.uk and select Motor Neurone as your good cause. Thank you.

Local support for local people

Fundraising

Marlborough Mayor's charitable donation

Alison and Barbara were delighted to be invited to the Marlborough Mayoral Ceremony where they witnessed the election of new mayor, Councillor Lisa Farrell. Lisa has taken over from Councillor Mark Cooper who supported the North Wilts Group together with two other charities during his time in office. Mark presented us with a cheque for £653.56.



Above: Cllr. Mark Cooper at his appointment in 2021



Left: The new mayor, Cllr. Lisa Farrell, at her installation.

Funds well spent

The Group raises money to help fund home adaptations, specialist equipment and quality of life improvements for people lwMND. A local family writes:

"My family and I were able to go away for a weekend to the Forest of Dean and could take part in activities I would not normally be able to do without payment for the extra facilities. The forest lodge we stayed in was for disabled people, meaning access was on a level (no stairs) with a wet room and easy to reach appliances. There was a hot tub which had a hoist, that meant I could get into it and join my daughters for a wallow! Realise how thin my top half is now after seeing photos... However, I most enjoyed the hire of the tramper which meant I could go on forest walks with the family. We did a lovely walk to Symonds Yat which gave me a sense of getting outside in nature, fresh air and enjoying the wood. The view was fantastic at Symond's Yat too. Thank you very much. (My husband has pancreatic cancer so it was a break for him too.)"

We are absolutely delighted that this break was such a success.

Heart of Cabi supports women affected by MND

On Wednesday 11th May, Cabi Clothing stylists from around the UK joined together in Failand, Somerset, to host an uplifting treat for women affected

by MND. Forty women from around the South West who have been affected by MND received a complimentary shopping and personal styling experience with help from a Cabi Stylist.

Cabi Clothing was established to offer specially designed high end clothing to women in their own homes, guided by specially trained Cabi Stylists. The company was created by women for women. A big part of the organisation is the charitable Heart of Cabi Foundation which seeks to empower women around the globe, and gives small business loans to women entrepreneurs in the developing world.



the heart of
cabi foundation

Penny Gunter, whose husband was diagnosed with MND and subsequently died, understands the devastating impact of MND on families. A Cabi Stylist herself, she organised the event to help support other carers and those affected by MND. The invited women were able to try on various items of Cabi clothing, generously donated by the fashion brand, and with help from the stylists decide what they loved the most. The day was also made possible with the support of the Malcolm Gunter Foundation which funded the hire of the venue and baked home-made cakes for everyone to enjoy.

Carole, who attended on the day, said 'I want to give my heartfelt thanks to the Heart of



Cabi and Malcom Gunter Foundation for a really lovely afternoon. The people there were so welcoming and helpful and the new clothes are such a treat.'

Thank you so much to all who gave their time.



Association News

MND Awareness Day — view the virtual gallery

21st June was Global MND Awareness Day. To help increase awareness, the National Association worked with award-winning celebrity photographer **Richard Cannon** who kindly captured powerful portraits of people living with MND. The **virtual gallery** can be viewed via the MND Association website by going to About us → Who we are → Global Awareness Day 2022 → Virtual Exhibition. Over 3,600 people have visited so far.

MND Matters podcasts: friendship and Pride

Don't forget the series of podcasts launched earlier this year by the National Association. They explore a wide range of subjects alongside people living with and affected by MND. They are an extra information source for the MND community, and also raise awareness more widely.

Episode 15 was around the theme of how **friendship** can support people affected by MND. In this heartfelt episode three ladies discuss the impact of their good friend Jennie's MND diagnosis. Jennie shares how she broke the news of her diagnosis with her friends and how their friendships have strengthened from it. She talks openly about the different reactions she received and how her friends have been a much needed space to allow her to just be herself.

Listen to episodes of using the link below or your usual podcast provider.

https://www.mndassociation.org/media/mnd-matters/?dm_i=40VS,1A0YA,2S9FAE,4M2N8,1

The latest podcast, Episode 16, looks at the issue of inclusivity. It marks **LGBTQ** and Pride Month by considering matters of sensitivity and equal access to health care. The Association stresses its own commitment to inclusivity.



Sally Light stepping down

Sally Light, CEO of the MND Association since 2012, will be stepping down at the end of the year. Under her guidance the Association has come a long way. We are now able to invest much more in research to end MND and in the care of plwMND. In collaboration with health-care professionals and other charities, we present a much more effective voice to government.

We wish her well in her next venture.



Sally Light, CEO

Solution to Government's £50 million to MND research conundrum

Our concerted *United to End MND* campaign achieved a **huge success** in November 2021 when the Government announced a commitment of **£50million** to invest in targeted **MND research**. But it hit a huge snag when it became clear researchers would have to make between 100 and 300 time-consuming grant applications. This could have delayed research 'by decades'.

Thanks to the tenacity of the *United to End MND* coalition, a compromise has now been reached which would see the researchers submit around three or four applications a year for funding.

Speaking to the *Sunday Express*, leading neurologist Professor Ammar Al-Chalabi from King's College London, said: 'It is not our preferred method but it is a compromise we can work with. This is the best way forward and we are optimistic.'

Sally Light, Chief Executive of the MND Association, said:

'We have been striving to show the government that the current system – applying hundreds of times for small pots of money – will not accelerate progress in MND research in the way we hope, and we are pleased they have finally listened to our concerns. It is important to recognise the relentless dedication of our MND community and the impact they have had to make this happen. They have emailed Ministers in their thousands, used social media to keep MND on the agenda of those in power, and shared their stories to highlight what progress in MND research would mean to them. **Thank you.**'

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

Support Meetings are now face-to-face (Covid permitting):

The next **Swindon Support Meetings** at Lawns Community Centre, Guildford Avenue, Swindon are:

2pm-4pm on **26th July** and
2pm-4pm on **27th September**

There will be a **Wiltshire Support Group meeting** at Riverside Centre, Bath Road, Melksham SN12 6LP at 2pm-4pm on **28th July**

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
anitacreamer@mndnorthwiltshire.org.uk
helenbox@mndnorthwiltshire.org.uk
and
sallysmith@mndnorthwiltshire.org.uk

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

The next **Carers Support Group** will be an informal cuppa & chat on Zoom at 7pm on 14th July. Contact Tash at carersupport@mndnorthwiltshire.org.uk

Old money

Did you know the Bank of England's last paper banknotes (£20s and £50s) must be spent or deposited by the 30th September 2022? You can still swap your paper £20 and £50 notes at the bank before 30th September.

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 **17th September 2022**. Email the editor on info@mndnorthwiltshire.org.uk
To **unsubscribe** from this newsletter email your name and 'unsubscribe' to secretary@mndnorthwiltshire.org.uk