



north wiltshire group  
**newsletter**



**Welcome to the Spring issue of our Newsletter**

**Welcome** to our first newsletter of 2024. We had a very busy year last year, celebrating our 35th anniversary in September, and welcoming Dorinda Moffatt as our MND Co-ordinator in Swindon. More about both of these events is included in this newsletter. We also had some successful Christmas events, fundraising to help provide support to local people living with MND.

Thank you so much for your support last year, we hope you enjoy reading what we have been up to. We have more events happening this month and we will report on those in our next newsletter.

Happy reading!

Heather Smith  
Group Chair

***Local support for local people***

On 26<sup>th</sup> September the Royal Wootton Bassett RFC provided an ideal venue as 45 people – local people living with MND and their carers, invited guests, Group supporters, medical professionals, representatives of partner organisations, staff from the national Association, and Group volunteers – all gathered to mark this significant milestone. **35 years of local support for local people in Swindon and North Wiltshire living with MND is a sign of our determination to challenge this cruel disease.**

The afternoon began with a welcome from our Chair, Heather, who also thanked those who had made the event happen. Brief speeches were then made before Dr Graham Lennox, former consultant at the GWH, proposed a toast.



Tanya Curry, CEO of the MNDA

The new CEO of the MND Association, Tanya Curry, expressed her sense of privilege at having this opportunity to meet volunteers and partners who pull together with a shared passion to make a massive difference locally. On a national scale, the Association is committed to promoting research into new treatments and to improving services to plwMND. But she emphasised it does not lose sight of individuals: it is about individual care and making things happen for each person and their family. She concluded by urging us to celebrate a real achievement, 35 years of support.

Jeremy Lune, CEO of Prospect Hospice, Swindon, echoed the extraordinary achievement of 35 years of seeking to make a difference in the face of tough challenges. He emphasised that MND must never define an individual. Both organisations, he believes, are about life, love and humanity – they share values of people-centredness. They both demonstrate the benefits of community-led health care, and the power and generosity of volunteering.

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Mr Angus Macpherson, Deputy Lieutenant of Wiltshire, knew of the good work done by the Group. He spoke of the importance of raising the profile of MND and of campaigning, as well as of the need for showing care to people in their darkest times. During conversations over tea, he was heartened to hear of research which could lead towards treatments offering alleviation or cures.

Two celebrity supporters of the MND Association had been happy to record short celebration video messages which were played. **Jeremy Vine** underlined the importance of the Association's work, and urged us not to be too busy to enjoy the friendships which volunteering together bring. **Charlotte Hawkins** commended the passion she has witnessed among volunteers for campaigning, fundraising and support – each of which makes a difference.

As the speeches ended, we moved on to tea! Sandwiches, scones and cream, and a celebration cake made of iced muffins which spelled out 'MND 35'. Thank you to everyone who has made the last 35 years so special.

Tanya Curry wrote in *MNDA Volunteer News*: 'I celebrated with the North Wiltshire Group at their 35th birthday party. It was great to see how the Group collaborate so successfully with the community, keeping people with MND at the heart of all they do.'

Special thank yous to the three wonderful Group members who worked hard to organise the event, Debbie, Mel and Susanne, and also to the lovely team at the Rugby Club.



*Group photo after the tea party*



*Birthday cake — 'MND 35' in muffins*

# Party Pics



*Left: Jeremy Lune speaking*

*Below: Heather welcoming our guests*



## **NEW CARE INITIATIVE** **Joined up care in Swindon**

On 2nd October we celebrated the launch of a new post which will enable people living with MND in Swindon and the surrounding areas to receive enhanced care thanks to a partnership between two local charities and the NHS. The three organisations will continue to work closely to support this essential work.

The MND Association and Prospect Hospice have teamed up to provide a new MND co-ordinator in Swindon to better support people and their families living with the illness. This new role means those living with MND will have access to a specialist clinical professional working with the wider community team who will ensure their care is well-coordinated and they are well-supported to the end of their life.

MND is a life-shortening illness which affects the nervous system. Although the disease will progress, symptoms can be managed to help achieve the best possible quality of life, and that's why it's essential people with the illness are supported by the right healthcare professionals to help them live well for as long as possible.

Jeremy Lune, chief executive at Prospect Hospice, said: 'For some time now, MND patients in this area have lacked the care that they deserve, and we've worked with the MND Association to ensure we can provide a support

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*Celebrations at the launch event at Prospect Hospice. Dorinda (centre) with knife!*

service to these patients to ensure they live well and are cared for by dedicated specialist professionals at the end of their life.'

'The reality of this new service is that those with MND and their carers will benefit from one point of specialist contact to oversee their care and care planning, helping to enable a smooth transition to hospice care if this is needed.'

'MND is extremely complex and requires several healthcare professionals to support a person as the disease progresses. This new role means people can spend time living their life and making memories with their families, rather than feeling the burden of organising a huge number of appointments. We're incredibly grateful to be working with Prospect Hospice and the NHS and we are delighted to welcome Dorinda into the role', said Chris Bennett, head of regional care partnerships at the MND Association.

Dorinda Moffatt, Prospect Hospice's dedicated MND and neurorespiratory specialist practitioner, will lead this new team and brings with her a wealth of respiratory practitioner experience to the role, having worked in this area for over 13 years.

*One of those who has already benefitted is Clare, whose husband Dale sadly died recently. Clare said: 'When Dale was first diagnosed, we had no one who understood or had good knowledge about MND. A lot of other health care professionals did not really understand the disease. It is so reassuring to have someone to go to. Dorinda was our first point of contact to go to for any problems. She brought everything together, answered any questions and we had confidence in her and her ongoing support.'*

Dorinda said; 'I am delighted to be taking on this role supporting people and their families living with MND. I am looking forward to the challenge of developing the service and working in partnership with my colleagues across the Swindon area. My father died from MND so I understand on both a personal and professional level the importance of helping people live well with MND, and I look forward to working with patients and their families so they can make every day count.'

*Part of the team that brought the new support to Swindon*

source: [www.prospect-hospice.net](http://www.prospect-hospice.net)  
photos: Prospect Hospice





Anita, Debbie, Jill & Susanne selling MND Christmas cards

## Christmas Past

Chippenham Golf Club held a Christmas Fayre on Nov-ember 25th. This year's captain of the ladies section - Jill Tinson - has chosen the North Wiltshire Group of the MNDA as her charity of the year. Sadly, Jill lost her sister to MND a couple of years ago.

The Fayre raised about £1200, which is a wonderful sum to start off her year (and ours!).

Very many thanks to the Golf Club.

## Regional Roadshows:

**Share — learn — connect — be inspired**

The MND Association is now taking bookings for its **Regional Roadshows 2024** (formerly called the Regional Conference). It is a chance to celebrate the important work of members and volunteers; to meet with other members, volunteers and staff; and to learn about the work and future priorities of the Association.

Four locations are planned. 10.30am to 4pm at York (14th May), London (20th May), Exeter (24th May) and Northampton (18th June). **Booking is free.**

To register visit [www.mndassociation.org/events/regional-roadshows](http://www.mndassociation.org/events/regional-roadshows) or email [conference@mndassociation.org](mailto:conference@mndassociation.org) or phone 01604 611844.

*Local support for local people*

## Mrs Scrump's Christmas Market



Once again the Group was excited to be the nominated beneficiary of Mrs Scrump's Christmas Market, held on Tuesday 28<sup>th</sup> November at the beautiful Dauntsey Park House, near Malmesbury.

It was a very cold wintery day, but the beautiful Dauntsey Park House generated an amazing Christmas atmosphere, just the perfect setting.

*Susanne prepares the MND stall in the grand surroundings of Dauntsey Park House*

*The day is going well!*

Entry to the Market and refreshments were paid by donations to the MND. An exciting and original selection of stalls offered high quality merchandise from local craft retailers while home-made cakes and hot drinks were available in the large manor kitchen.

Donations and sales on the MND stall raised a fantastic £2,352. Thanks to all those who donated so generously. Our most sincere thanks once again go to long-term supporter Susannah Dibben for organising the event, and to Emma Amiti.



## Things to Know

### Useful Contacts

N Wilts Group website  
[www.mndassociation.org/northwiltshire](http://www.mndassociation.org/northwiltshire)

N Wilts Group contact  
[info@mndnorthwiltshire.org.uk](mailto: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](http://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 **Swindon Support Group meetings** at Lawns Community Centre, Guildford Avenue, Swindon:  
2pm-4pm on **14th May 2024**  
2pm-4pm on **11th June 2024**

There will be **Wiltshire Support Group meetings** at Riverside Centre, Bath Road, Melksham SN12 6LP at  
2pm-4pm on **18th May 2024**  
2pm-4pm on **29th June 2024**

All are welcome to join us for a friendly chat, a catch up with friends, and to see your Visitor.

You can **contact your AVs** at  
[anita.creamer@mndassociation.org](mailto:anita.creamer@mndassociation.org)  
[sally.smith@mndassociation.org](mailto:sally.smith@mndassociation.org)  
[karen.maisey@mndassociation.org](mailto:karen.maisey@mndassociation.org)

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

The **Carers Support Group Zoom** meeting is usually at 7pm on the third Tuesday of the month. The next meeting will be at 7pm on 16th April. For details contact Tash at  
[natasha.flintoft@mndassociation.org](mailto:natasha.flintoft@mndassociation.org)

### Living with MND guide

The national Association has published a helpful guide on its website. If you have been diagnosed with MND or are caring for someone, this guide provides an overview of the disease and ways to achieve the best possible quality of life from diagnosis onwards.

<https://www.mndassociation.org/support-and-information/information-resources/information-for-people-with-or-affected-by-mnd/living-with-mnd-guide>

*If you are planning an event or have taken part in one, why not let the editor know. He would be delighted to include a short item or a photo.*



### Contact the editor

The deadline for submission for the next issue of the newsletter will be **23rd June 2024**. Email the editor on  
[andrew.sargent@mndassociation.org](mailto:andrew.sargent@mndassociation.org)  
To **unsubscribe** from this newsletter email your name and 'unsubscribe' to the editor.