

# MND Association

## Oxfordshire Branch Newsletter

Autumn 2024



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# Our 2024 Summer Event



Thanks to those who managed to attend our Summer Event in Abingdon on Saturday 22 June, hosted by **Martin McLeman, Chair of the Oxfordshire MND Association Committee**. We had around 40 attendees who had the opportunity to hear about the branch's activities over the past year. A delicious lunch with an array of cakes, baked by our branch volunteers was served and amongst others, we heard from MND Association's Research Director, Brian Dickie and Chair of Trustees, Usman Khan who outlined positive and inspiring progress on both the research programme and MNDA's strategy for the future.

One of the highlights of the event was a moving speech by Dave Taylor a former carer who regularly fundraises for our Branch Walk.

## News about Lesley Ogden - Oxfordshire Branch Secretary

At the event, we also took the opportunity to thank **Lesley Ogden for everything she's done**. After her brother was diagnosed with MND, Lesley started getting involved with other people with MND then there was very little knowledge about the disease and a lack of support for those diagnosed. Along with her mother and father, Lesley was one of the founding members of the MND Association which started in 1979 in order to provide vital support for people with MND. Over the years she has volunteered for the Association in various roles in the London and Manchester branches as well as a member of the MNDA's National Executive Committee before becoming a member of the newly formed Oxfordshire branch many years ago.

Lesley will be stepping back from her Branch Secretary role but will continue her activity supporting people as an Association Visitor.

We marked the occasion with flowers and a lovely stone bench for her beautiful cottage garden. A huge thank you, Lesley, for all you've done for the MND Association and community over so many years.



# Miles for Mark Smith - bike ride meet & greet



Earlier in the year, we were at the John Radcliffe Hospital to welcome the amazing Miles for Mark Smith cyclists as they made a stop on their 11-day fundraising challenge. Many of the Oxford clinical team joined the group to cycle with them on the 8th day of their 1000km ride down the country through their own "M-N-D route" (Morpeh - Norfolk - Dorset) which started on Monday 29 April 2024 and finished on Saturday 11 May.

Miles for Mark Smith was a bike ride to raise funds for MND research and to celebrate the incredible life of Mark Smith. Their aim was to raise £20,000 for two charities: MND Association and The Oxford Motor Neurone Disease Centre. All funds will support critical research to find a cure for MND. They smashed their target of £20,000 by around 250% raising more than £50,000!

Well done to everyone involved, what an amazing achievement!

# The Oxfordshire Branch Walk is just around the corner! Are you registered?



It's nearly that time of year again, when the bunting comes out, balloons are blown up, and flags are flown. Of course I'm talking about the MND Association Oxfordshire Walk to D'Feet 2024.

Blenheim Palace have once again kindly provided the glorious setting and the date is set for Saturday 5th October 2024, so please do dig out the previous year's MND Association T-Shirt, grab your walking boots and hopefully slap on some sunscreen - either that or an umbrella and thermals! As I write, it is nearly a year ago today that we held a beautiful funeral for my father who sadly passed away from MND. We were fortunate, in a way, that he was able to battle through for over 13 years from diagnosis and he still came on the walks with my mother and thoroughly appreciated all the support from the Oxfordshire branch. It was his strength and support that drove me to want to help in any small way I could with raising funds and awareness for the MND Association. I have the pleasure of working with the MND Association Oxfordshire Committee in organising this walk. Every year the volunteers come out to help and we all spend the day thinking about our loved ones in the company of those who understand and appreciate the challenges, twists and turns this illness can present. I am truly looking forward to seeing everyone again this year and regardless of the weather, it will be another wonderful day. Please feel free to get in touch if you would like any further information about the walk or other fundraising events. My email address is [jill.garner@outlook.com](mailto:jill.garner@outlook.com).

*Jill Garner*

## Fundraising & Awareness Let us know what's happening!

We'd love to hear about your fundraising or awareness activities and include your stories in the next newsletter.

Please email details and attach photographs, if you have them, to:  
Keith Bird, Oxfordshire Newsletter Editor [keith.bird@mndassociation.org](mailto:keith.bird@mndassociation.org)

MND Connect is available 9am to 5pm and  
7pm to 10.30pm Mondays to Fridays.

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# Regional MND Association Roadshow - Midlands



**Oxfordshire MND Association Branch committee members, Cathy Burch and Keith Bird, attended the Regional Roadshow in Northampton.** The series of roadshows were well-received by people with MND and their carers, volunteers, Association members and staff who welcomed the opportunity to learn more about our future strategy and to have the chance to engage with others in the MND community.

MND Association's Chief Executive, Tanya Curry kicked off the session and attendees heard presentations from the volunteering community. Mark O'Brien, who is living with MND, also gave an inspirational talk on his successful Guinness World Record challenge for the longest distance swimming non-stop in open water with motor neurone disease. Roadshow attendees took part in breakout sessions to discuss how the MND Association shapes its future strategy.

## Building a small equipment demonstration kit and loan library. Can you help?

Do you have any small items of equipment that you purchased that were useful, but are no longer used? Would you be willing to donate them to a small equipment demonstration / loan library?

Phill Sharpe, Occupational Therapist at the MND Oxford Care Centre is keen to build up a small demonstration kit and if possible, a loan library for items such as button openers / cutlery or other small aids that might be helpful for people with MND

Please do email Phill if you have anything you think might be of benefit to others that you are willing to donate. (NB – Small items only due to space and storage issues).  
[phillippa.sharpe@ouh.nhs.uk](mailto:phillippa.sharpe@ouh.nhs.uk)



# May Family and Friends Support Group



**For the Friends and Family Support Group meeting in May, we met up at Yarnton Garden Centre.** Despite the awful weather, fifteen of us made it to the Garden Centre, shepherded in by poor Lesley waiting at the door, in the torrential rain! We welcomed two family members of two of our regular members, as well as new attendees who we hope will come again. Five volunteers came, including Ginny who is a new volunteer for the Banbury group. We enjoyed delicious cakes and hot drinks and there was lively chat and discussion on all manner of topics, MND and non MND-related. We look forward to meeting again soon.

On Tuesday 17th September 2-4pm Wytham House, Farmoor, Oxford will welcome us once again to this pleasant venue for a get together. Contact [lesley.ogden@mndassociation.org](mailto:lesley.ogden@mndassociation.org) for details.

A meeting of the Banbury group who met on August 27th will be held again in October. Contact: [matthew.hollis@mndassociation.org](mailto:matthew.hollis@mndassociation.org) for details.

## My life with MND

Until 2019 I had been unusually strong, fit and active for my age. I worked as a visual artist, using many media, including sculpture, drawing, painting, textiles, collage, photography and more. Before that, I had a 30-year long career as a classically trained pianist and piano teacher. I also wrote hundreds of poems, many of which I made into books with the help of my partner of 30 years, Graham. I also wrote one volume of prose. I loved to go for long walks and cycle rides in the countryside, both alone and with Graham.

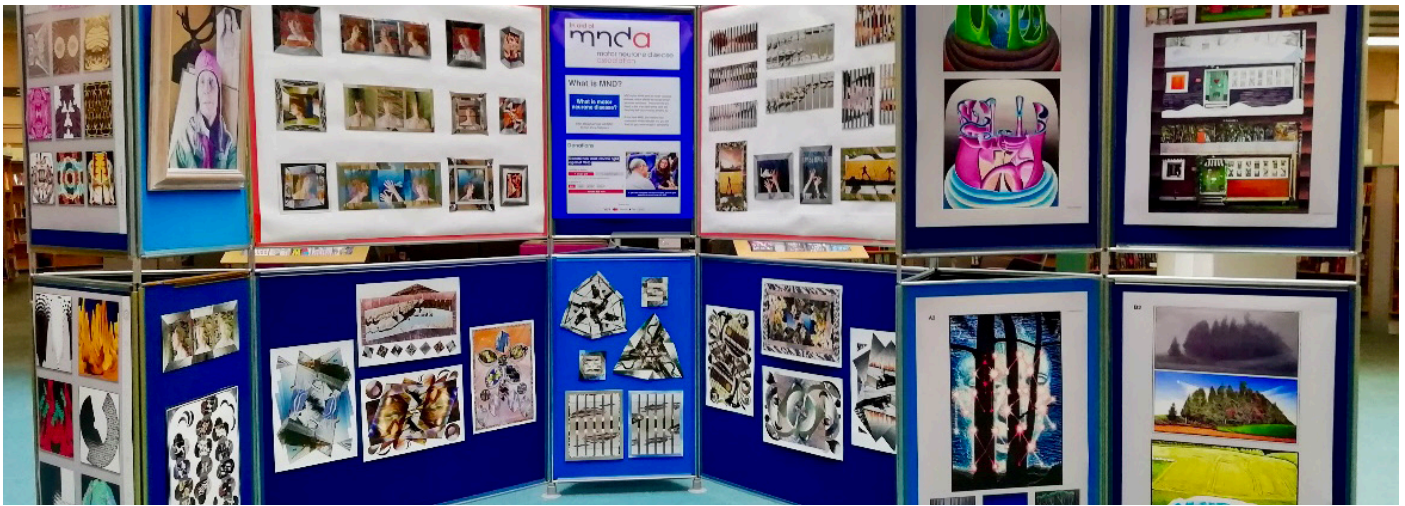
All that came to an end when I began to develop strange symptoms. I lost strength and dexterity in my fingers, hands and arms, which made the activities impossible. From one week to the next I could no longer cycle, as my thighs lost strength, and my balance became poor.

*Contd.*



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All kinds of daily activities became difficult or impossible, and I became increasingly dependent on Graham for shopping, cooking, housework and some personal care. I debated with myself whether to see my GP, and finally I did. He gave me a thorough neurological examination of the upper limbs, and immediately referred me to the MND Clinic at the John Radcliffe Hospital in Oxford, where we live.

When I first set foot in the Clinic, I was met by Lesley Ogden from the MND Association. She made me feel welcome, which helped me greatly. I was examined and diagnosed by Professor Martin Turner. He told me I had MND. I had some tests which confirmed the diagnosis. He assured me that I would be supported by the clinic, and was introduced to the rest of the team, who were without exception caring, very competent and kind. I also decided I wanted to take part in research, as that made things seem more meaningful.

Like everybody who gets this diagnosis, I went into a state of shock and two years of deep depression. This coincided with the COVID pandemic, which didn't help. All I could do was to lie on my bed listening to the radio. I didn't really find life worth living with what I saw as a bleak future.

I did get help, though. I saw a doctor at the clinic every 3 months, and I had some marvellous sessions with the clinical psychologist, Rachel Woolrich.

In February 2022 something new happened: I developed a fierce pain in the abdomen, which took me to A&E 3 times in quick succession. I was given morphine for the pain and several tests. MRI showed that I had Chronic Pancreatitis. It took a while to get the pain under control with morphine and to get my diet and gut under control.

Then an apparent miracle happened: My depression disappeared; it just melted away! This seemed totally paradoxical! Everybody was pleased for me, but also surprised. It took me a long time to work out the cause of this complete change. My conclusion was that there were several causes, some of them buried in the distant past and rather complex. But the main thing was that I was now, by some miracle, able to focus on all the things I still CAN do, rather than on all the abilities I had lost. I can still talk, I can eat, I can walk short distances. I have started reading avidly again, something I have always loved. I look forward to every day, rather than dreading it. What a change! A great thing for me has been to go to MND Association meetings. It's so healing to meet other people in my situation, their carers, and the marvellous committee members.

Graham and I had an art exhibition in the Oxford Central Library in May, which had a great response, and we may well do it again some time. Graham did all the logistics, and my work was, by necessity, older work, whereas his was right up to date.

Another thing I have done recently which seems very positive, is that I have changed my will. The previous one was an executor's nightmare, with lots of beneficiaries receiving small things. The present one is greatly simplified. There are two beneficiaries, one, as before, Graham, the other is the MND Association who will receive a very large gift of money, to go towards research into MND. This feels very meaningful to me.

I just want to add that I have gained so much by becoming a member of the MND Community, which is a Beautiful Community!!

*Ellen Wang*

# The Oxfordshire Branch Walk in Blenheim Palace Park Saturday 5th October – 1pm Start

**Register now!**



Our popular annual fundraising and awareness event for families, friends and supporters, to join together to walk a 2 mile or a 5 mile route on wheelchair accessible paths in these famous attractive grounds.

More details and registration contact:  
[jill.garner@outlook.com](mailto:jill.garner@outlook.com)



## Branch Committee Members

<b>Chair</b>	Martin McLeman	<a href="mailto:martin.mcleman@mndassociation.com">martin.mcleman@mndassociation.com</a>
<b>Treasurer</b>	Roger Payne	<a href="mailto:roger.payne@mndassociation.org">roger.payne@mndassociation.org</a>
<b>Branch Secretary</b>	Lesley Ogden	<a href="mailto:lesley.ogden@mndassociation.org">lesley.ogden@mndassociation.org</a>
<b>Committee member</b>	Sue Butler	<a href="mailto:david.butler212@aol.com">david.butler212@aol.com</a>
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<b>Committee member</b>	Cathy Burch	<a href="mailto:cathy.burch@mndassociation.org">cathy.burch@mndassociation.org</a>

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