MND Association ~ Oxfordshire Branch

Summer 2026 Newsletter

New Year Branch Event

Changes, priorities and developments in the Oxford MND Care Team

As always, our New Year events are open to all of our members, fundraisers and supporters, allowing time to socialise, eat an array of delicious, freshly-baked cakes and ask questions.

On Saturday 31st January, we were delighted to welcome the Oxford MND Care Team, an integral part of the Oxford MNDA Care & Research Centre, based at the John Radcliffe Hospital.

The team gave an engaging and inspirational talk, sharing the changes, priorities and developments in the Care Team. We had updates from Phillipa Sharpe, Occupational Therapist, Jessica Newman, Specialist Nurse and Rachel Woolrich, Clinical Psychologist. We also heard from Taniya Esmail about some very important research.

The session kicked off with hearing about what's changing. Firstly, the team said a fond farewell to Consultant Nurse, Rachael Marsden (more about that later in this newsletter). They welcomed Consultant Neurologist, Jakub Scaber, to the team for one day per week to support the MND FU and NP clinics and the EXPERTS-ALS study. Jakub is well known to the team, having previously completed an MND research PhD with Professor Kevin Talbot. Last but not least, we heard the exciting news of the confirmation of a permanent role for Rachel Woolrich, Clinical Psychologist.

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Changes, priorities and developments in the Oxford MND Care Team

Phillippa Sharpe started by reminding us of the current work under the Occupational Therapy umbrella. She outlined a number of new developments, which included increased joint-working, an Orthotics joint clinic, trialling an Equipment Library and supporting the TONIC (Trajectories of Outcomes in Neurological Conditions) project, one of the largest UK studies aimed at understanding and improving the quality of life for people living with neurological conditions.

We then went on to hear from Jessica Newman, who talked through the process for when people see the Specialist Nurse, starting with the initial meeting at the New Patient Clinic. Jessica went on to outline the range of areas a patient can talk about with a Specialist Nurse and how this is managed, in conjunction with the Multi-Disciplinary Team (MDT).

Rachel then talked about her role in more detail, which totals three days per week as part of MND team, comprising one day at the John Radcliffe Hospital with the team and working remotely for the other days, offering video appointments. She delivers psychological support to patients, partners and families, using a model called ACT (Acceptance and Commitment Therapy), plus integrating CBT and compassion-focused approaches. Rachel also facilitates reflective peer supervision for the team and community professionals. The New Patient Clinic, among many things, critically supports emotional self-care in first few weeks, covering areas such as information processing about the diagnosis, managing stress, sharing the news and focusing on the day-to-day.

And last but certainly not least, we heard from Taniya Esmail, Clinical Research Fellow, who outlined her fascinating research project, focusing on iron in ALS.

We are extremely grateful to the team for giving up their valuable time to meet with us. A huge thank you from us all.

Farewell to Rachael Marsden

In January, the team said a fond farewell and huge thank you to Rachael on her retirement as Care Centre Coordinator, better known to clinic patients as the Specialist MND Nurse, then MND Consultant Nurse. When the Oxford MND Care and Research Centre was established 25 years ago, under the direction of Professor Kevin Talbot, he appointed Rachael who worked with him to develop the Care Team which has expanded hugely over the years, as you will have read along with more neurologists to care for people with MND.

Rachael has been a key driver in ambitious ideas for projects like the nutrition and respiratory clinics and for psychological support, among her own various valuable research projects. She has been a great supporter of the Oxfordshire Branch over the years, giving talks, joining the Branch Walk and supporting our AVs. Her memorable epic round the world cycle ride, just before the pandemic, raised over £67,000 for the Association and she has been highly respected for her expertise as a consultant by the staff of the MNDA.
Her knowledge, experience and positive support has been greatly appreciated by both her patients and her colleagues, who will all miss her dedication and fun-loving, can-do attitude.
A comment on her retirement by a former carer said, ”*Rachael always made you feel as if she was interested in you and your family. Her care and compassion during that time is a lasting memory*”.
A current patient has said, “*She has been a remarkable source of support over the years and I will miss her knowledge and kindness*”.

Does your garden need a bit of TLC?

GoodGym is a community of people that combines getting fit with doing good. They run, walk and cycle, to do practical tasks for community projects and to support older people and people living with disabilities.
If you could do with a one-off visit from the GoodGym volunteers, whether it's to give your garden a bit of a spring clean or tidy up, or you have some small jobs around the house that you just can't do yourself, please do send us an email or call and we can refer the task into the GoodGym team.

For more information, please contact: tagreed.ismail@mndassociation.org

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Tell Us Your Stories

Let us know what’s happening......we’d love to hear your stories, fundraising activities and achievements to include in the next newsletter. Please email details and attach photographs, if you have them, to:

cathy.burch@mndassociation.org

Living with MND - Mike Staples shares his journey

In January 2024, I was diagnosed with MND after various tests of nerve conduction in my legs. Getting to the diagnosis was complicated by my having had a ruptured Achilles tendon in 2020. I had felt that I'd been less able to run about the tennis court for a while and had developed a dropped foot which may or may not be linked to the MND. In a way, the final diagnosis was less unexpected than I thought, as the tests I was having did seem to point in that direction; however, it was still a shock.

One thing that lessened this was that the neurologists at the John Radcliffe said that they thought my MND had been active for about three years and therefore was progressing slowly; that being the case, it would not speed up in the future. This at least gave me the view that I had several years to go before I was severely affected. One thing that helped was an article written by someone who had a more severe form of the disease who, having been very active before her diagnosis, was devastated to find that there were quite a few things that she could no longer do. This led to severe depression. However, one day she decided that she would concentrate on those things that she could still do and not on those that she couldn't. She found that this attitude improved her mental well-being dramatically; her words are always in the back of my mind.

I still play tennis once a week, having practised yelling "yours" at my partner if it looks like running is going to be involved. As a lot of the people who I play tennis with are my age, it is sometimes difficult to determine whether my tennis is going downhill through MND or just advancing years. Walking is one of my favourite hobbies and last year finished The Chiltern Way, took me 300 miles to do. In 2002 I walked the Thames Path from source to the Thames Barrier and since then have continued around Kent and all along the South Coast. Last year, I reached Ilfracombe in north Devon. I still have 40 miles of The South West Coast Path to do between Ilfracombe and Minehead, a big chunk of which I intend to do this year. I have reduced the average length of walks a bit and plan a slower speed but still manage to do it.

I also ride my bike – I can still get up Watlington Hill but when I can no longer manage it, I shall probably get an electric bike. We have booked to go skiing again in March but will probably ski only in the mornings as we have to look after our granddaughter in the afternoons. Swimming is fine but I retired from windsurfing several years ago as it got too tiring – probably nothing to do with MND.

My MND has made me consider the future and we have made a certain effort to declutter our lives whilst we can, but the current plan is to carry on doing what we have always done, including taking the ferry to northern Spain each autumn and visiting various locations there by bus and train. I don't intend to climb Everest, although Ben Nevis and Snowden would be nice, having already climbed Scafell Pike in the third year of secondary school.

I very much appreciate the work of MNDA, in particular the Oxfordshire Branch; I have raised some money through two Blenheim Palace walks and also contributed to some research into the disease. I would like to do more of both of these things. I don't expect a cure to appear in time to help me but more than happy to help those in the future. I also appreciate the support that my wife, Sabine and family and friends have given me including coming with me on the Blenheim walks– it makes all the difference.

Claire’s amazing bike ride to the Arctic

Claire McCombe is cycling the full 11,000 km (6,835 mile) Atlantic Coast Cycle Route (EuroVelo 1), from Portugal all the way to 300 miles north of the Arctic Circle in Norway. She says, “I’m doing it as a solo woman in my late 60s, travelling with my bicycle, Margaret”. At the time of writing, Claire and Margaret had completed Portugal, Spain, France, England, Wales, Scotland and half of Ireland, 7,761 km (4,823 miles).
The final stretch- 2,980 km (1,851 miles), is in honour of her father, who gave Claire her adventurous spirit.

She said “He died of MND, and this ride is my way of doing something positive in his memory”. As Claire is doing this solo and self-supported, every decision - navigation, safety, logistics, carrying kit and managing risk, rests with me.

Half of the funds raised will support research into Motor Neurone Disease, helping the scientific community deepen its understanding and move closer to effective treatments. The other half will go to the Oxfordshire Branch of the MND Association, enabling them to continue supporting people living with MND, along with their families and carers – thank you!

Read more of Claire’s story here:

https://www.justgiving.com/page/claire-poulton-3?utm_medium=FR&utm_source=CL

Summer Branch Event

13 June 2026

12:00 The Barn at Christ Church, Abingdon

We are Listening: strengthening how we work in partnership with people who have lived experience of MND.
Sophie is looking forward to meeting our Oxfordshire members, to hear their perspectives, and begin gathering insights into what matters most, what needs to change, and what we can do together to strengthen involvement.

Speaker: Sophie Cordwell James
MND Association’s Involment Manager

For more information please contact:
cathy.burch@mndassociation.org

Please support our branch

Donate to our branch

Oxfordshire Branch’s ongoing support which makes such a difference for local people, has increased considerably recently and the branch would welcome both large and small donations, as well as contacts from those who might possibly raise funds for the branch. Information and help is available from Roger Payne Branch Treasurer - roger.payne@mndassociation.org and Luke Robson MND Association Relationship Fundraiser, South and West area - luke.robson@mndassociation.org

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Our Regular Update from Rachel Woolrich

It's wonderful to be writing this update to you all as a fully substantive member of the Oxford MND Care & Research Centre, rather than being on a fixed term contract. As I reflected on in my update at the New Year event, it really is a privilege to be part of the team, supporting people living with MND in Oxfordshire and further afield. I appreciate the warmth of response from you all.

Over the past few months, alongside my usual clinical activity, I've benefited from taking part in some training, which has evolved from the COMMEND trial (a research trial which demonstrated the benefit of Acceptance & Commitment Therapy for people living with MND), sharpening my skills in this psychological approach.

I've also been contributing to a book chapter on working psychologically with MND, with other clinical and research psychologists across the UK. My colleague Dr. Audrey Daisley, Consultant Clinical Neuropsychologist at the Oxford Centre for Enablement (some of you will know her) and I are collaborating to deliver a brief talk at this year's Dying Matters Symposium for staff at OUH in May, co-ordinated by our palliative care colleagues. We are focusing our talk on supporting families, when a parent is dying with MND and hope to raise awareness amongst healthcare professionals about the principles of good communication with children.

Finally, now I am substantive, I am really keen to progress our research proposal to investigate the experiences of living with PLS. I will provide a further update when there is more to say.

Warm regards to you all.

Save the date: 10 October 2026

Branch Walk at Blenheim Palace Park
More information coming soon!

Family & Friends Support groups

Our Spring meeting in March in Abingdon brought together a number of people living with MND from Chipping Norton, Wantage, Abingdon and seven from Oxford.

Our popular massage therapist, Amanda, was kept busy offering simple, soothing massages to many who were keen take up her offer. As usual, experiences were shared and refreshments enjoyed with those who understand the difficulties MND can bring.

As we have a number of people living with MND in the Witney area now, there will be a get -together there on **May 20th at Burwell Hall, Witney, OX28 5NP from 2:30 to 4:30pm**. This accessible venue has ample free parking. A warm welcome to all, of course and invitations will also be sent in May.

For all our members to look forward to, we have our Summer Event and Lunch on **Saturday 13th June, starting at 12 noon at the Barn at Christ Church, Abingdon**.
There will be a group meeting in **Banbury at the Cricket Club on Tuesday 16th June 2:00 to 4:00pm.**

Then, another visit is to be arranged on **15th July to the Yarnton Home and Garden Centre 2:00 to 4:00pm**, which will include a get-together in the café . It proved popular 2 years ago and we hope to see new people there, as well as regular friends.

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