

motor neurone disease

The magazine of the Southampton & Winchester Motor Neurone Disease Association Group

& Winchester

Group

October 2025 Issue



All the latest MNDA news from the Local Area Fundraising to the max!

see page 5



motor neurone disease association

- 2 MONTHLY MEETINGS MOVE ONLINE SOON
- 3 REMAP
- 3 TEA IN TOTTON
- 4 NEW GROUP STARTING
- 4 HILLIERS PARK PICNIC
- 5 A MASSIVE THANK YOU TO NICK
- 6 TEST VALLEY MOTORS FUNDRAISING
- 7 WORKING WITH MND
- 8 DECISION AID
- 8 ANNUAL STEPHEN HAWKING LECTURE
- 9 COLLECTING CHRISTMAS CARDS
- 9 CHRISTMAS AT CALMORE
- 10 NOTICEBOARD

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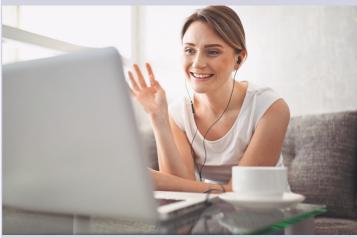
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If you have any comments or feedback about the magazine and its content, please do not hesitate to get in touch

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MONTHLY MEETINGS MOVE ONLINE SOON



It's that time of year again when we start to think about getting cosy, drawing the curtains earlier, settling down for the night straight after an evening meal and taking our Monthly Meetings online.

October's Group Meeting on Tuesday 14th October will be our last face-2-face gathering at Oasis Academy Lordshill as we switch our monthly event to its online equivalent.

Our final get-together sees representatives from Environmental Control take on the speaker hot seat and we invite all our local MND Community to join us for an evening of informative and social chit-chat.

From November onwards our Monthly Meetings will come into your inbox via a link and will remain on the second Tuesday of every month at 7:00pm until March 2026.

We hope to see as many of you at our last inperson meeting (although we do have our Christmas Party in December.... More information later in the magazine) as possible but we also look forward to seeing you all from the comfort of our own homes over the winter months.

REMAP

Speaking of our wonderful Southampton & Winchester Group Meetings - we were lucky enough to be joined by the very clever REMAP organisation in August who constantly astound and amaze us with their ingenious inventions and ideas.

REMAP - who stand for Resourceful Engineers Make Anything Possible, take referrals through health professionals to help individuals and families with specific issues that may be affecting their quality of life or independence.

There is no charge and no exclusions with REMAP providing full aftercare, advice and follow up reviews.

We love our visits from REMAP and learning all the new gadgets they have come up with and people they have helped - including our own people living with MND.

If you would like more information on the organisation please visit https://www.remap.org.uk or speak to your AV or health professional if you would like a referral.





TEA IN TOTTON

It was lovely to see such a big turn out at our Coffee Support Mornings at AFC Totton over the summer.

We feel very strongly that joining up over a good cuppa is a great mood booster and can be a valuable way of sharing ideas and experiences.

Thank you to all the volunteers, AV's and visitors that make this event possible and thank you to everyone who attends and makes these mornings the highlight of our week!

If you would like to attend our next **Coffee Morning** please pop along to AFC Totton, Snows Stadium, Salisbury Road, SO40 2RW on Monday 20th October 2025. For more details please see our 'Noticeboard'





NEW GROUP STARTING

Beginning this month, a new Support Group will be coming to the Winchester area.

Held on the fourth Tuesday every month at Otterbourne Village Hall and welcoming people living with MND, their family, friends, carers and professionals - the monthly event hopes to kick things off with a bang and get as many locals attending as possible.

If the other group events have always felt just a little to far for you or you'd like to try out another event too then please do come along.

For more information on the Support Group please see the attached poster or contact Pauline Rachman at pauline.rachman@mndassociation.org for more details.

the back page of the newsletter



HILLIERS PARK PICNIC

On Thursday 25th September the Southampton & Winchester MNDA Group held an Afternoon Tea at Sir Harold Hillier Gardens in Romsey.

With around 25 guests, the sun shone on what was a perfect location for such a lovely afternoon.

All the feedback we have received has been wonderfully positive so we hope to hold many events like this again.

Thank you to everyone who attended the afternoon, it was a real treat to see old and new faces alike!





A MASSIVE THANK YOU TO NICK

We want to shout from the rooftops about a wonderful local fundraiser who has not only been dedicating his time to gaining contributions for the charity but also spreading awareness far and wide.

Nick Smith's efforts have involved local sports teams, local businesses as well as family and friends to gain a total of more than £11,000!

Nick says, "The campaign gained support from a whole range of friends including Romsey Rotary Club, a group of ex Romsey Round Tabler's who cycled a stage of the Tour de France and the Captains of Wellow Golf Club who allocated a specific number of competitions to this appeal.

Romsey Rugby Club also launched a whole range of events starting with touch rugby sessions throughout the Summer and a family walk followed by a cycle ride to Winchester Rugby Club.

Aside from private donations, Southampton Rugby Club lent their support through a raffle at the club dinner, but perhaps the most endearing gesture came from the bar staff of The Cocky Anchor pub in Romsey who donated their tip jar! What a fantastic gesture from a group of young people."

Not content with changing lives through the money he raised, Nick also knows how important it is to create awareness of the disease so that we can get faster diagnosis and support for those living with MND.

Nick added, "My appeal has certainly attracted plenty of attention, in which I have tried to illustrate the severity of being so handicapped and the dependency on our carers.

BBC Radio Solent featured an early morning interview along with wonderful coverage via the Hampshire Chronicle group of newspapers with several articles which have all helped spread the message".

We can not express how grateful we are to Nick for all his hard work and dedication to our cause.

The difference you have and are making to local people living with MND is wonderful and we want to say another massive thank you. You're a star!



We would also like to say a big thank you to Michael Coombes who is the Chairman of the Test Valley Motor Enthusiasts club for presenting a cheque for £212 at the August Coffee Morning.

Southampton & Winchester MNDA Group members Ruth and Terry are long standing members of the club with Terry enjoying driving and working on classic cars before his diagnosis of Motor Neurone Disease.

Brothers, Ron and Wilf Hatch, members of the club and close friends of Terry, asked for donations for spare parts at various club events in aid of MND.

Unfortunately Terry was unable to be at the coffee morning but his wife Ruth was present to receive the donation.

Both Terry and Ruth are extremely grateful to the club for their generosity in raising money for MND and we echo their thanks for thinking for us and making such a lovely gesture.

Thank you to you all!

Working with MND Peer Support Group





Do you continue to work after your MND diagnosis?

This online peer support group enables people living with MND who continue to work to come together to share experiences in a safe and supportive way.

Tom who attends the group says "These meetings provide a safe space where we can share information about how MND affects work (or vice versa); the various challenges faced, solutions and workarounds found.

It's also nice simply to be able to talk with and listen to other people in similar situations to my own. The conversations can be very wide-ranging (today we even talked about trees), the atmosphere is very relaxed and welcoming, and there's no pressure to contribute anything unless you feel like it on the day. More often than not, a genuine mood lifter!! Why not give it a try? "

For more information please contact Jo Cunnah Community Support Coordinator jo.cunnah@mndassociation.org



mndassociation



@mndassoc

www.mndassociation.org

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Patient decision aids for genetic testing in Motor Neuron Disease

Researchers at the Universities of Sheffield and Leeds have developed two decision aids to support people to make informed choices on genetic testing:

Genetic testing and MND for people diagnosed with MND

Predictive genetic testing and MND

for people with a gene change linked to MND in their family

The decision aids are available as a website or they can be downloaded and used offline



Q https://mymndgenetest.shef.ac.uk x

If you have any questions, please get in touch with Jade:
||%| jade.howard@sheffield.ac.uk

The researchers are now asking anyone living with MND to read the decision aid and share their feedback by completing a survey



Q https://bit.ly/decisionaidsurvey x

This important feedback will help improve the decision aids







ANNUAL STEPHEN HAWKING LECTURE

Registrations are now open for the 2025 Annual Stephen Hawking MND Lecture, which brings together hundreds of people affected by MND and professionals to explore how to apply the latest research in MND care.

This year, Professor Ammar Al-Chalabi will discuss the role of genes in MND, including how genetic testing may help predict or diagnose the condition.

The lecture will take place at the Royal Society of Medicine in London on Tuesday 4 November and will also be live-streamed, so guests can attend either in person or online.

For more information please visit the Association website.





COLLECTING CHRISTMAS CARDS

It may only be October but the Association are already getting ready for Christmas and all that it brings.

With Christmas cards needing to be written and sent out before the big day it is always wise to be organised and have your stash of stationary ready to send out before the festivities catch up with you.

To allow for this MNDA now have all seasonal cards available to buy online so you can pick, choose and be prepared without worrying as the weeks close in.

Please take a look at this years selection and consider sending one of our charity cards where the money raised goes towards our fight and helping those who need it the most.

CHRISTMAS AT CALMORE

It would be a miss for us to not mention at this point our own annual Christmas Party.

Returning again to Calmore Community Centre, this year the Southampton & Winchester MNDA Group welcome you to join us on Saturday 6th December for an afternoon of fun and laughter - and lots of prize giving!

More information will follow soon but please put the date in your diary and let us know if you are living with MND and require transport to the event.



MND Association care information

We produce a wide range of care information to help people with motor neurone disease (MND), their carers and families, including children and young people. Our aim is to help everyone involved achieve the best possible quality of life while meeting the daily challenges of the disease.

Our range includes:

- guides
- larger publications, offering comprehensive overviews to help throughout the course of the disease
- information sheets shorter publications, which focus on specific symptoms or subjects such as welfare benefits
- leaflets and cards to help with specific needs, including a card to make people aware that a person has MND.



Find our publications online at: www.mndassociation.org/publications or contact our MND Connect helpline to order printed copies.



For support and further information:

MND Connect 0808 802 6262

www.mndassociation.org

CP/09/15

NOTICE BOARD

NoticeBoard -

Monthly Meetings - Second Tuesday of every month - 7:00pm - 9:00pm

Face-2-Face at -

Oasis Academy Lordshill Redbridge Lane (off Romsey Road) Southampton

Southamptor SO16 8FA

Coffee Mornings – Third Monday of every month.

AFC Totton Snows Stadium Salisbury Road

Totton SO40 2RW

Online - Please get in touch for the link.

Volunteering Roles

Group Contact: Dawn Pond dawn.pond@mndassociation.org

Southampton Care Centre: southamptonmndcarecentre@uhs.nhs.uk

MND Connect: Ann Buchanan – 01604 611694 Wheelchair Enquiries: please contact MND Connect

YOUR CONTACTS

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Fundraising:

All money raised for MND goes to the Association but only funds specified for the Southampton & Winchester Group will directly support local people in our region. We are so appreciative of any contributions but if you would like to direct your fundraising locally please stipulate the Southampton & Winchester Group on all cheques and JustGiving donations.

Group Websites:

W: https://www.mndassociation.org/support-and-information/local-support/

branches/southampton-and-winchester-group

W: justgiving.com/mndasouthampton

Facebook: facebook.com/mndsouthampton

Twitter: @MNDASoton

MND Connect **T**: 0808 802 6262 Registered Charity No. 294354





To be held the fourth Tuesday of every month Between 2pm and 4pm at Otterbourne Village Hall Our start date is TUESDAY 28TH OCTOBER 2025

Contact pauline.rachman@mndassociation.org





www.mndassociation.org

