

mnda

motor neurone disease
association

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

Southampton & Winchester Group

June 2025 Issue



**All the latest
MNDa news from
the Local Area**

MARATHON MILES

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Magazine Editor:

Sara Al-Rashed
sara.alrashed12@gmail.com

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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Global Awareness Day 21st JUNE

Once again this year we come together with the wider MND Community to mark Global MND Awareness Day - a time to shine a bigger spotlight on the disease and create awareness of our fight to find a cure.

This year's theme is centred around the hidden realities of living with MND, with lots of individuals and families set to share their stories.

Supporters, volunteers and people living with Motor Neurone Disease can get involved in a variety of ways - from sharing posts and case studies online to bigger fundraising events and inviting your MP to our parliamentary event (below).

The official MND Association website will be updating throughout the month with everything gearing up to the big day on the 21st June.

Please let us know if you are planning any events locally so that we can share the news with everyone and report on your success after too!



MND Awareness Event in Parliament

On Thursday 19 June, the MND Association will be holding a Global Awareness event in Parliament.

We would love to have as many MP's in attendance as possible to keep our cause at the forefront of decisions and changes that are made by the Government.

MP's will be able to drop in and find out about the most important challenges and issues facing the MND community - and how they can make a difference with their role in Parliament.

To invite your MP to attend on the day please complete this form - act.mndassociation.org



2nd – 8th June
2025

#VolunteersWeek

As this Magazine reaches you, we will be thick into Volunteers Week.

Celebrated every year from the 2nd-8th of June, we always take this opportunity to celebrate and acknowledge all the fantastic work our own MND volunteers do in our region.

From local Association Visitors (AV's) to Coffee Morning organisers, each and every volunteer dedicates their own time and skills to support people living with MND in our area.

We are so grateful to them and all they have done and continue to do that we want to say a massive thank you this week - and always we couldn't continue the Southampton & Winchester Group without you!



Carers Week

Following Volunteers Week, we recognise our most valuable care-takers in National Carers Week starting on the 9th June 2025.

This year Carer's Week is looking at the inequalities un-paid carers face and the challenges they come across in daily life.

At MNDA we have taken this fight to the very top and continue to campaign for unpaid carers to be given more financial contributions.

To find out more, details on what you are entitled to as an unpaid carer or to join our campaign please visit mndassociation.org

Marathon Miles

Did you know that this Marathon season has raised over one million pounds for the MND Association?

With Marathon's taking place in London, Leeds and Manchester all in the last few weeks, you could be forgiven for forgetting Southampton had its very own Marathon event too!

Taking place on Sunday 6th April, runners (and wheelchair pushers) were able to sign up for the 5 and 10k routes, half or full marathon with organisers ABP Southampton.

Pounding the streets, runners took on the challenge for charities all over the country with a few surprise faces even choosing to run for MND here too! Together with our own volunteers who formed a cheer team to get them through, lots of money and awareness was raised.

We want to say a massive thank you to all our volunteers who came to support on the route and at our 'cheer station' and an even bigger well done to everyone who ran - especially if it was on behalf of MND.

A special mention must go to David and Alice Baker who not only took part in the 10k course at Southampton along with endless ParkRun's up and down the country, but who finally got a place to take part in the London Marathon too!

Those who have been following David's blog 'MND Can Get in the Sea' will be up to date with the couple's adventures but David very kindly gave us a report of the day too ...



David says, "Alice, my daughter Anna, and our friends Andy and Martin were Team Baker, and they took it in turns to push me in a race chair made by Delichon in the New Forest.

As a former marathon runner that had been unsuccessful in the entry ballot for many years, the opportunity to take part was a dream come true for me, and it was made possible by the MNDA, Challenging MND, and Whizz Kidz charities.

The atmosphere out on the course

was unbelievable and we had a special cheer from the MNDA cheer squad.

At the finish line, I got out of my chair and was helped to walk over the line which I was determined to do.

We really did have the best day, and raised nearly £2,000 for charity. What an experience! We even got on the telly as the BBC showed an emotional Team Baker crossing the finish line."



Monthly Meetings

A big hello to all the new faces who have been joining us at our Monthly Group Meetings. Now we are back to face-2-face get-togethers for the lighter and brighter months, it has been wonderful to welcome all our new guests and speakers to the Group.

This month we will be hosting representatives from the ABP Marathon who organised the event in April and who will be presenting a cheque to the Southampton & Winchester Group for our volunteers help lining the route and cheering everybody on throughout the day.

We hope as many of you will be able to tag along to this month's meeting (or to any of our up and coming Monthly Meetings) we meet on the second Tuesday of every month at Oasis Academy Lordshill, Southampton from 7:00pm - 9:00pm.

The building is fully accessible with appropriate toilets and facilities and we welcome people living with MND, their families, friends, carers and professionals in the field.

For more details please see our 'Noticeboard' section.

Fancy a Cuppa and a Chinwag?



Our Support Coffee Mornings have also been getting a great turn out. Coming together every third Monday of the month at AFC Totton, Snows Stadium, Salisbury Road, SO40 2RW, we arrange a daytime meet up for anyone who isn't able to make the later timed Monthly Meetings.

Everyone is always in good form and we often receive visits from brilliant fundraisers such as Roger Chambers who visited us recently from the Bramshaw Golf Club after raising almost £10,000 in the name of the Southampton & Winchester MNDA Group.

MNDA Member John Wright kindly accepted on the Group's behalf at the Coffee Morning and we would like to extend our thanks once again to everyone at Bramshaw Golf Club who contributed to this wonderful amount.

This will help so many local people living with MND - thank you very, very much!

Ahoy! The Alison MacGregor!

With one boat trip down and another scheduled for later this month - our time aboard the 'Alison MacGregor' especially equipped vessel will soon come to an end for another year.

Every voyage onboard the 'Alison MacGregor' is free of charge to people living with MND and their guest - and sails a different route according to the tide and weather of the day.

We've already had great fun taking in the sights of the Solent, cruising past vast liners and bobbing up the river Test so we look forward to hearing where the last outing takes our guests on Sunday 22nd June.

All passengers should meet at Hythe Marina for 2:00pm but for more detailed information or to book yourself on next year's roster, please contact Jean Block at jean.block@mndassociation.org



MND EnCouRage

MND EnCouRage UK, is a new two-day research event that invites the MND community to participate in roundtable discussions on clinical trials and new papers as well as being presented with new research developments in non-scientific terms.

Registration is now open for the 16th July event but places may go quickly so please make your interest known at mndassociation.org



Family Resources



Privacy notice

The Motor Neurone Disease Association is here for everyone, whether you are living with MND yourself or know someone who is.

This ranges from the oldest of us to the very youngest so information is tailored to provide manageable information in a form that is appropriate for that age range.

This is especially important for young children so many of our resources have been adapted or new ones added to the website to help little minds and hearts understand.

The MND Buddies activity hub on the MNDA website features the Why are things changing? storybook, which is a perfect companion to When someone close has MND: a workbook for children aged 4 to 10 - which are both great to check out through MND Connect.

Not forgetting MNDA's partnership with 'Featherbed Tales' - a digital book publishing company who provide families free access to record stories and other digital content and who have now just added greeting cards, poems and recipe books that can be passed down through the generations.

The online platform enables families to create memories to keep forever with all their content.

Please contact our Children and Young People's Team to receive a QR code and weblink for free.



Mobility Scooter



Do you - or anyone you know, need a mobility scooter?

Our very kind volunteer Mike is offering the twice used vehicle free of charge to anyone who would make use of this very handy piece of equipment.

The battery charged mobility scooter is able to breakdown and be disconnected so it can be transported in a regular car and anyone interested in finding out more is welcome to give Mike a call on 07395 537 902.

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

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
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

jean.block@mndassociation.org

Southampton Care Centre

southamptonmndcarecentre@uhs.nhs.uk

Wheelchair Queries

Ann Buchanan – 01604 611694
wheelchairqueries@mndassociation.org

YOUR CONTACTS

Magazine Editor

Sara Al-Rashed

E: sara.alrashed12@gmail.com

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



Scan Me

Community Support Volunteers Needed

Could you make a difference in your community?

Can you spare 2-5 hours a month?

We are looking for Volunteers to join our local group

The Role is to ensure people living with MND are aware of all the support on offer.

Full training given online

All expenses paid

We look forward to hearing from you and it would be lovely to have you join our Team.

If this is not the role for you there maybe other opportunities so please dont hesitate to get in touch.

Dawn.pond@mndassociation.org

 [mndassociation](https://www.facebook.com/mndassociation)  [@mndassoc](https://twitter.com/mndassoc)

www.mndassociation.org

Francis Crick House, 6 Summerhouse Road, Northampton, NN3 6BJ

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