mnda
motor neurone disease
association

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

Southampton & Winchester Group

August 2025 Issue

All the latest MNDA news from the Local Area

Let's create more awareness!

see page 2

motor neurone disease association

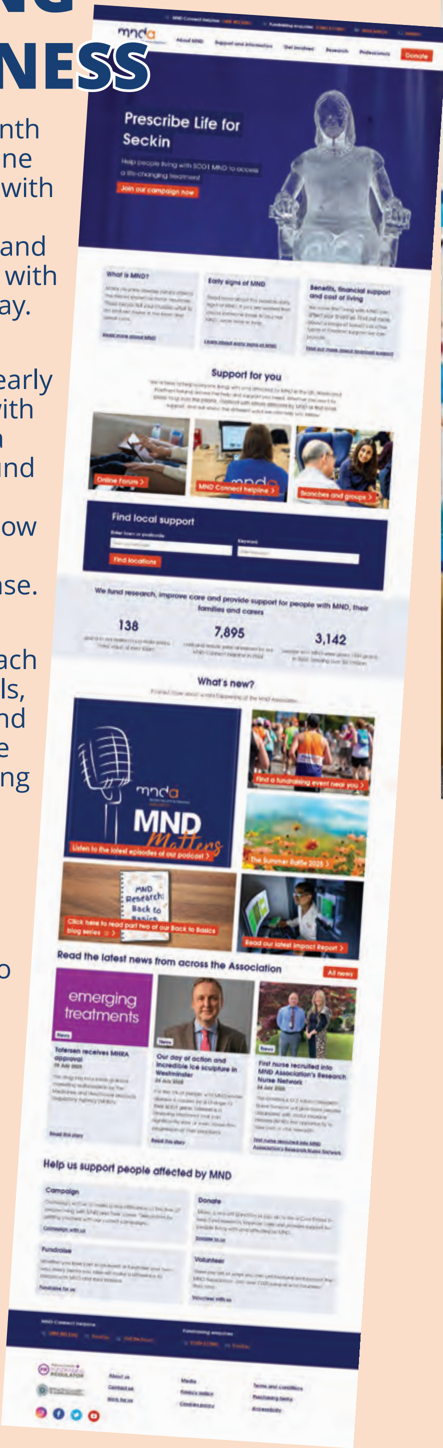
CREATING AWARENESS

June was a huge month for the Motor Neurone Disease Association with the whole country marking Volunteers and Carers' Weeks along with Global Awareness Day.

135 Support Groups continued to help nearly 1200 people living with MND in the UK but a recent study has found that around 61% of adults still do not know anything/know very little about the disease.

We still have a very long way to go to reach medical professionals, the general public and ensure MND is in the spotlight and receiving the attention it deserves within government and scientific research.

Thank you for everything you did to create awareness in June and we hope the results of survey next year reveal more promising signs.



Prescribe Life for Seckin

Help people living with SOD1 MND to access a life-changing treatment

What is MND?

Early signs of MND

Benefits, financial support and cost of living

Support for you

Find local support

We fund research, improve care and provide support for people with MND, their families and carers

138

7,895

3,142

What's new?

Read the latest news from across the Association

Tofersen receives MHRA approval

Our day of action and incredible ice sculpture in Westminster

First nurse recruited into MND Association's Research Nurse Network

Help us support people affected by MND

Campaign

Donate

Fundraise

Volunteer

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

Designed and Printed by:
TLC Online: 023 8024 3044
www.tlc-online.co.uk

ABP MARATHON CHEQUE

Thank you to the representatives from Rees' Leisure & ABP Southampton for popping in to our Monthly Group Meeting at Oasis Academy Lordshill to award the local MNDA Group with a £250 cheque for cheering on runners at the ABP Southampton Marathon back in April.

A team of MNDA Volunteers cheered at the Itchen Bridge and Finish Line at Guildhall Square throughout the race for a donation to help people living with Motor Neurone Disease in our region.

Thank you to everyone who took part and an even bigger thank you to all those who ran, pushed or walked one of the routes on the day and made their own contributions to the Southampton & Winchester MNDA Group's fundraising.

We look forward to seeing you all again at the race next year!

Princess Royal Trust
for Carers in Hampshire

MONTHLY MEETINGS

Speaking of our Monthly Group Meetings, we would also like to thank the Princess Royal Trust for visiting us in June to explain how they are helping people living with MND in Hampshire.

Although not available to people living with MND in Southampton, the Princess Royal Trust is able to provide an Emergency Care Plan along with support and advice to anyone who lives in the wider Hampshire area.

Online Groups focusing on singing, reading and painting are also provided by the Trust and can be an extra source of comfort to carer’s and family members alike.

For more information please visit https://carercentre.com/

Our next Monthly Meeting will take place on Tuesday 12th August at Oasis Academy Lordshill.

Please join us for lots more information and advice - as well as a good natter from 7:00pm - 9:00pm.

Our location is fully accessible and we welcome people living with MND as well as family members, carers, volunteers and interested parties! Please see our ‘Noticeboard’ for more details.

COFFEE & A CATCH UP

We are pleased to report our Coffee Support Mornings are also building in popularity and receive the odd special guest too!

Every third Monday of the month at AFC Totton, Snows Stadium, Salisbury Road, SO40 2RW, we welcome you to join us in a more informal get together.

This month we have Phil from the Testwood Lakes Sailabilty (TLS) organisation joining us for a chat about disability sailing and how we can get involved.

We can’t wait to see you all and hear all about TLS so please do come along on Monday 18th August.

More information on our Coffee Mornings can also be found on our ‘Noticeboard’ page.

Jumbulance
REUNION

With many of our members having attended a Jumbulance outing or holiday, we know you may be interested in being part of the Jumbulance Reunion Party on Monday 11th August...

Running from midday until 5:00pm, the two course BBQ lunch will be hosted by Chris and Ian at Oakfield at Romsey and includes a welcome drink.

The cost of the party is £20 per person and has a choice of meat and vegetarian options.

Chris says "*It will be a lovely opportunity to renew the friendships you made on past holidays, pilgrimages and day trips with us and to meet new people coming on the September holiday.*

Later in the afternoon we will have a raffle and tea and cake will be served in the garden where everyone can continue to relax and mingle.

We hope those that are able, will explore our 2 acre garden and wild garden with a stumpery and the walled potager."

If you would like to attend please email cookchrisr@aol.com or call 0788 774 8224 with your dietary requirements by the 2nd August.

WILL ADVICE

A practicality that no one ever really wants to think about is writing a Will. This is even more of a priority for people living with MND and their family members.

Our AV's and volunteers are well versed in providing information that may be needed for this - and Lasting Power of Attorney, but even we were pleased to discover the Citizens Advice Bureau offer an almost free service thanks to our own MNDA member Alice who had been through the process herself.

Alice says, "I was struggling to complete the online forms so was referred to the Citizens Advice Bureau (CAB) by the Palliative Care Team.

A woman from CAB came out to my house the next day. She brought a laptop and did all the forms with us and the next day, as we do not have a printer, she returned with the forms printed out to be signed. She even put a post-it note on all the boxes to be signed and by who and provided an envelope. Her service was free and it only cost us the registration fee.

She did both our wills for us via a service called Fairwill - again, she went through the whole thing with us and it was £160 for both wills."

We know that even organisations that provide a subsidised service charge much more than what Alice experienced and we are delighted to hear that someone is able to visit you at home when mobility can be an issue.

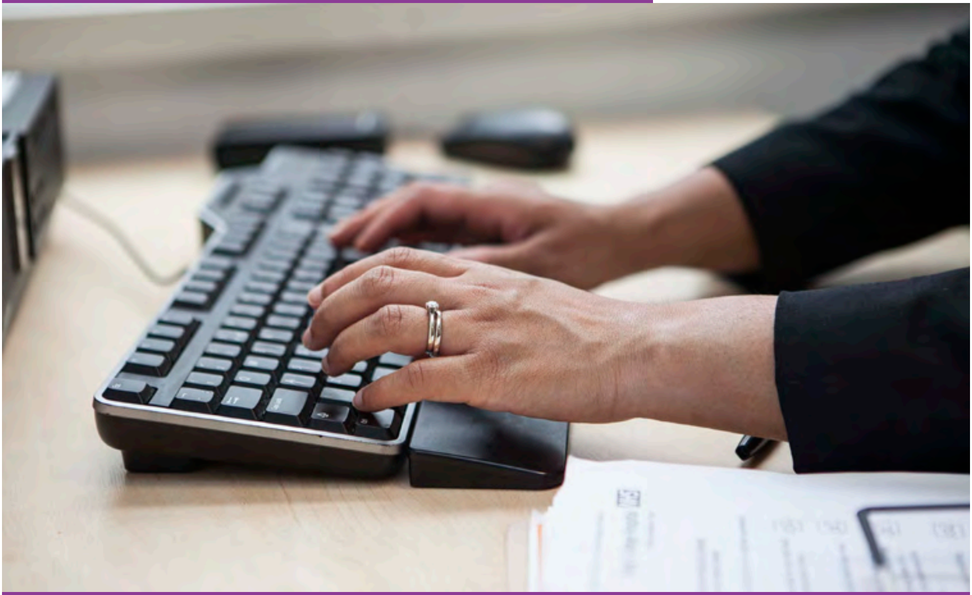
If you are going through this process and have received a great service we would love to hear from you.... let us know your feedback and we will pass this on to other people living with MND.

We would like to say a special thank you to the ladies who volunteered their time at AFC Totton’s Fun Day in July.

Braving extreme downpours with no shelter - our volunteers were still able to create some awareness on the day and we thank them for giving up time on a miserable Sunday to support our cause. Thank you!

Working with MND Peer Support Group

mnda
motor neurone disease
association



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

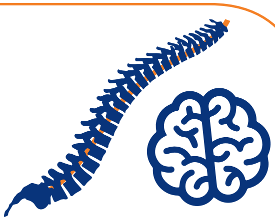
www.mndassociation.org
Francis Crick House, 6 Summerhouse Road, Northampton, NN3 6BJ
Registered charity no. 294354 | Created in RightMarket - 17/7/2025 - 07:39:04

Registered with FUNDRAISING REGULATOR

mnda
motor neurone disease
association

Motor neurone disease kills a third of people within a year and more than half within two years of diagnosis.

MND is a fatal, rapidly progressing disease that **affects the brain and spinal cord.**



MND attacks the nerves that control movement so muscles no longer work. It **does not usually affect the senses** such as sight, sound, feeling etc.

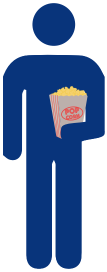
MND can leave people locked in a failing body, **unable to move, talk and eventually breathe.**

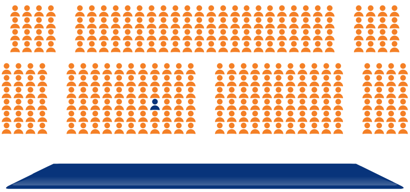
Around **50%** of people with MND experience some form of cognitive change while living with the disease. This can affect their thinking or behaviour.

The percentage rises to around **80%** for people who are in the advanced stages of the disease.

MND affects people **from all backgrounds.**

A person's lifetime risk of developing MND is around 1 in 300. That's one person in an average size cinema screen.





It affects more than **5,000 adults** in the UK at any one time.

x6 every day

Six people are diagnosed every day. More than 5,000 people are fighting MND at various stages of the disease. **Six people die each and every day.**

MND - there is no cure.

The MND Association focuses on improving access to care, research and campaigning for those people living with or affected by MND in England, Wales and Northern Ireland.

For further information or support please contact our helpline:

mndconnect
0808 8026262
mndconnect@mndassociation.org

MND Association
Francis Crick House
6 Summerhouse Road, Moulton Park
Northampton NN3 6BJ

Telephone: 01604 250505
Email: enquiries@mndassociation.org
www.mndassociation.org

Registered Charity no. 294354

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.or

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

mnda
motor neurone disease
association

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

f mndassociation @mndassoc

www.mndassociation.org
Francis Crick House, 6 Summerhouse Road, Northampton, NN3 6BJ
Registered charity no. 294354 | Created in RightMarket - 22/4/2025 - 11:29:20