



Marathon Madness!

All the latest MNDA news from the Local Area

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

We will be marking Global MND Awareness Day once again this year on Sunday 21st June 2026.

Global Awareness Day . 2	
Mammoth Marathon	
Month	3
Club Collection	5
Sinfield Speaks in	
Southampton	6
Monthly Meetings	7
Otterbourne Group	
Meeting	8
Catch up over coffee	8
Let's sing Choir Charity	
Night	9
Alison McGregor Add-ons	
.....	9
Hospice UK	10
Happy Birthday Eve	10



For people with Motor Neurone Disease we know every day matters - from special days such as birthdays or Father's Day (which Global MND Awareness Day falls on this year) to the seemingly mundane days that people living with MND find challenging in many different ways - so this year's Global Awareness Day focus will be the moments that matter to you.

Please help us by sharing your stories on a local or national level through either social media, our newsletter or via your AV, family and friends - to show how everyday truly matters to you when you are living with MND.

We also haven't forgotten about our Volunteers and Carers who each get their own consecutive week at the beginning of June.

We thank and celebrate you every day but this month please know how valued you are! We appreciate you and all you do so much. Keep an eye out for special posts and mentions throughout the month!

Magazine Editor:

Sara Al-Ras 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



Mammoth Marathon Month



1. Frank 2. Gaby 3. Nicky 4. Rosies Daughter Emma - Brighton Marathon

April was a month of running with many of our supporters and volunteers taking on challenges across the country to raise awareness and much needed funds for the MND Association.

Here in Southampton, ABP held a combined distance Marathon festival where runners could take on the full or half distances or a more moderate five or ten kilometre race all over the city. MND Volunteers lined the streets and were happy to catch quite a few blue and orange MND vests whizzing by as they cheered on the steadfast folk of Southampton.

Thank you to everyone who came out to support MND that day - whether it was in the race or at the sidelines ... and a special mention must go to Chris Lamb who was running on the day after completing the Thames Ring 250 Race which is the equivalent to 10 back to back marathons in itself!

A big thank you to you Chris (and partner Gwenda too!) for taking on such an amazing feat over 96 hours ... and then the ABP Southampton Marathon not long after! Altogether Chris and his wonderful family and friends raised

£1000 for the local MND Group in honour of David Baker who is living with MND in our area.

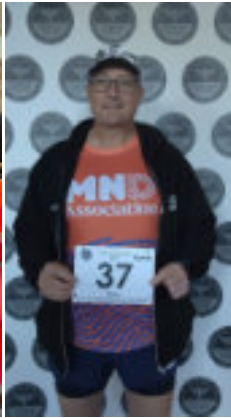
Thank you again Chris - what a star you are!

Speaking of David Baker - along with wife Alice, they are no strangers to running Marathon's themselves. Now David has swapped his trainers for a specially equipped running wheelchair, both he and Alice took on the Rob Burrow's Leeds Marathon. We heard it was incredibly tough but incredibly inspiring to be a part of as everyone came out to support the event in tribute to the Rugby hero.

Running over 26 miles is a massive challenge but to push a wheelchair too takes an extra amount of grit and determination and we are just all so proud of you both for completing the race! Well done guys!

Alice and David Baker were not the only locals heading north for the event though, as MND Supporter Jonny Syvret decided to pound the pavements

Continued overleaf 



1. Chris Lamb, with David & Alice 2. Chris Lamb 3. Jonny Syvret 4. ABP



and fundraise for the Southampton & Winchester MNDA Group after receiving support from our AV Jen when his older brother Andrew was diagnosed with Motor Neurone Disease.

We knew Jonny would smash his mission after several members of the Syvret family have also taken on challenges and very kindly donated to the local groups fundraising efforts. Jonny's goal is to get to £8,000 on his Just Giving page to help find a cure for the illness after Andrew died in 2025.

Thank you also to MNDA member Rosie Perrett's daughter Emma who ran a little closer to home at the Brighton Marathon. Proudly wearing her MNDA running vest, Emma crossed the finish line, created even more awareness of Motor Neurone Disease in the South and raised £1800 for the cause. Thank you Emma and thank you if you too ran or supported at an event these past few months - we couldn't do this without you!

We wish Jonny lots of luck in reaching his target and urge anyone who is able to please visit: <https://www.justgiving.com/page/jonathan-syvret-3?msocid=1ea8de6c0b0a65461bbebc3f0a3264cb> to find out more about Jonny's day at the Leed's Marathon.



Club Collection

On Saturday 11th April, AFC Totton very generously allowed a 'Bucket Collection' at their football ground during a home match against Dorking Wanderers.

Thank you to all our wonderful volunteers who collected all the lovely contributions and held a Stall on the day as £308.65 was raised - and the Club won 2-1 against the visitors!

AFC Totton have been very good to the Southampton & Winchester MNDA Group with hosting our Coffee Morning's every month and now offering days like this and another set for September. If you would like to join our volunteers for the next event please get in touch!



Sinfield Sparks in Southampton

The evening of Thursday 14th May was a special night for the local MNDA Community as many of us joined Rugby player - and national hero, Kevin Sinfield at Central Hall in Southampton.

Sharing his story from his young days coming up the ranks in Rugby to making captain, representing England and being nominated for Sports Personality Of The Year - to his friendship with Rub Burrows, discovering his illness and subsequent MND diagnosis and his fight to help find a cure, Kevin Sinfield's motivation and poignant tales captured us all.

The evening began with a 'Meet & Greet' with the main man before flowing into an interview style conversation that allowed Kevin to delve into his memories and answer questions along the way.

It was a very polished and intimate occasion with the audience sat close and able to join in at certain points.

They also held a unique auction that involved 12 winners (!) a raffle and sold MNDA and Kevin's own charity merchandise that goes to the Motor Neurone Disease Association

Local Av Jen said, "Kevin was a fantastic speaker and such a genuinely lovely bloke, so modest and unassuming. Wish we could bottle his good nature."

Apart from inspiring the whole crowd, the best piece of information we gained from the evening was that Kevin would love to run in Southampton and plans to bring one 'leg' of his challenge to the city.

This will be fantastic for our community

as we raise even more awareness and gather more attention for MNDA due to Kevin's natural media following. We'll be keeping our ears to the ground for any announcements next year!



Monthly Meetings

A big welcome back to our face-2-face Monthly Group Meetings at Oasis Academy Lordshill.

Last month we were joined by two speakers who shared their wisdom and knowledge on how their skills can help people living with MND.

Firstly, dietician Lisa Ross gave an informative talk on feeding tubes. Lisa spoke about everything from when the right time for you might be to have a feeding tube fixed, how they have changed and operate and new modern feeds that cater for different diets and allergies.

If you missed the meeting or would like more information about this topic, please visit mytube.mymnd.org.uk

Suni Narayan then took over and sent everyone into a calming state as her background in yoga practices showed the Group how you can take part in exercise whatever your mobility levels may be.

Yoga has been proven to help with wellbeing and with Suni also being a MND physiotherapist at Southampton General Hospital, many of our

community may have already come into contact with her work - whether it be as a patient or as someone caring for a loved one with the disease.

One of our members has also recently been given an MNDA Grant to help with their wellbeing and uses the extra cash to attend Suni's Yoga Sessions. If you would like to find out more please talk to your AV or visit suniyoga.com

This month we will be welcoming the organisers of the ABP Marathon who will present the S&W Group with a cheque for supporting at the event (please pop along and join us for the photo!) - as well as an MNDA Research Nurse and a representative from Silvertime Legal who will help with any affairs you will need to put into place.

Everything we offer is free advice from experts in their field and we always have a good chat and a raffle after to fill our social cups up too! Join us on Tuesday 9th June from 7:00pm and Tuesday 14th July when we will be hosting Remap.

For more information please take a look at our Noticeboard.

For further information please visit mytube.mymnd.org.uk or scan the QR code below with your tablet or mobile device.



Otterbourne Group Meeting



informal group where you come along and have a cuppa and get to meet our trained volunteers, who can support you with any questions you may have.

We understand coming to a support group for the first time can be daunting but please be assured everyone who has come along have found it helpful."

Our friends a little further north of the region would like to remind you about their lovely Monthly Support Group too!

If getting to Oasis Academy Lordshill is a little too far for you - or you would like to attend another social group too, please join the Otterbourne Group on the fourth Tuesday every month from 2:00pm-4:00pm.

Pauline and her team are waiting to welcome you, she says "It's an

Our Otterbourne location also has a sunny garden area so everyone can enjoy the nice weather over the summer months!

Please don't ever let transport be a barrier to any of our MNDA events, we have our support grants that cover any additional costs for transport so do get in touch!

For more details on the Otterbourne Group Meeting please see our Noticeboard,

Catch up over coffee



With our Monthly Meetings at Oasis in the evening and in Otterbourne in the afternoon, if you're more of an early bird we have just the event for you too!

Please pop along to one of our Coffee Support Mornings at AFC Totton at Snows Stadium, Salisbury Road, SO40 2RW on the third Monday of every month!

Our next get togethers are on Monday 15th June and Monday 20th July 2026. All information can be found on our 'Noticeboard'.

Let's Sing Choir Charity Night



On the 15th May, Let's Sing Romsey Choir hosted a charity night at Romsey Golf Club in honour of Nick Smith who is living with MND.

The fundraiser was attended by around 100 people who all came together to hear excellent performances from the Choir and Nick himself speaking about the impact Motor Neurone Disease has and the support he and his family

receive from the local Southampton & Winchester Group. Along with a raffle and quiz, the evening managed to raise £1,265

A big thank you must go to Louise from Let's Sing Romsey Choir, her team and everyone at Romsey Golf Club who supported and attended the event! What a fabulous amount to add to our pot! Thank you!

Alison McGregor Add-ons



Great news! We have another date to add to our Alison McGregor trips along the Solent.

Now reserving spaces onboard for Saturday 22nd August at 2:00pm - this journey joins our other two voyages on Sunday 7th June and Saturday 18th July.

People living with MND, their family and carers are welcome to book a free space onboard the vessel for an enjoyable jolly along the coast!

All dates begin and end at Hythe Marina but each trip will take its own course according to the tide, solent traffic and weather conditions of the day.

With enough space for six wheelchair users and their guests on each crossing, the wonderful crew provide a highly knowledgeable tour, hand out refreshments - and on occasion, even let you drive the boat!

For more information - or to book your place, please contact Jean Block at jean.block@mndassociation.org



HospiceUK

Visit Hospice UK website
<https://www.hospiceuk.org>
or scan the QR Code



Hospice UK, have announced they are doing a piece of work on patients and their loved ones understanding of how and when they can access their local hospice while they are living with a progressive neurological condition.

They say clear information can make a real difference when you are living with a progressive neurological condition or supporting someone who is -but there is currently no clear, accessible resource that explains the role of hospice care,

how it can help at different stages of an illness and where it fits within the wider system.

Hospice UK would like to work to address this gap by developing a resource that brings this information together in a simple, accessible way but to make sure it reflects what matters most, they want to hear directly from the people who know these conditions best.



Please fill out the below survey to be a part of this change -
https://forms.office.com/Pages/ResponsePage.aspx?id=gV3Qu7q2-USFp6wt2wU_SlXrhIvrB39Bh-XxlxdgCHpUMVISUUZJNTk4Rzc5QlhJNTNYN1U2N05TQS4u

Happy Birthday Eve

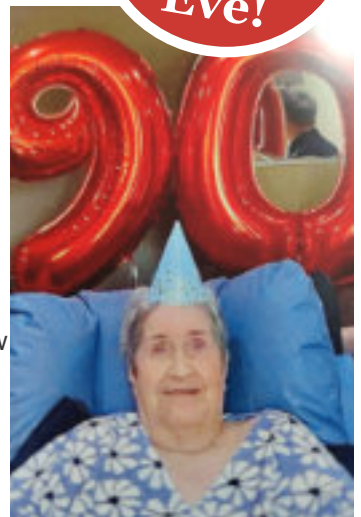


A massive Happy 90th Birthday goes to Eve Eades who celebrated the momentous date back in March with a wonderful party attended by all her family.

Eve has been living with MND for over 20 years now and is now unable to attend any local events or activities but we know she receives our magazine so wanted to wish her many happy returns from us all!

A Southampton local for most of her life, Eve attended St. Anne's Girls School after passing her 11 plus and then went on to Secretarial College before working for Misselbrook & Weston. When she married Mick, three lovely children followed who are now all grown up with children of their own and who visit Eve every week now her mobility is limited. With four great grandchildren too, the party was a jam-packed soiree but the perfect way to celebrate such a landmark birthday.

We wish Eve and her family all the very best and hope you continue to enjoy your time all together!



Notice Board

Monthly Meetings:

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

Face-2-Face From June 2026

Oasis Academy Lordshill

Redbridge Lane (off Romsey Road), Southampton, Hampshire SO16 8FA

Coffee Mornings Third Monday of every month.

AFC Totton

Snows Stadium

Salisbury Road

Totton

SO40 2RW



Otterbourne Monthly Meeting - Fourth Tuesday of every month

Otterbourne village Hall

Cranborne Drive

Otterbourne

SO21 2ES



Volunteering Roles:

Group Contact: Dawn Pond:

dawn.pond@mndassociation.org

Southampton Care Centre:

southamptonmndcarecentre@uhs.nhs.uk

Wheelchair Enquiries:

please contact MND Connect

Your Contact:

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](https://www.justgiving.com/mndasouthampton)

Facebook: [facebook.com/mndsouthampton](https://www.facebook.com/mndsouthampton)

Twitter X: @MNDASoton

MND Connect T: 0808 802 6262

Registered Charity No. 294354

Scan Me



What is motor neurone disease (MND)?

Motor neurone disease (MND) is a progressive, life-shortening condition that affects the motor neurones in the brain and spinal cord.

As motor neurones become damaged, the muscles they control weaken and begin to waste away. This can affect how a person walks, talks, eats, drinks and breathes.

However, not all symptoms necessarily happen to everyone and it is unlikely they will all develop at the same time, or in any specific order.

Although there is currently no cure for MND, symptoms can be managed to help improve quality of life.



MND can cause:

- weakness and increasing loss of movement in limbs
- twitching and rippling sensations under the skin
- muscle tightness, cramping and pain
- problems with breathing and fatigue
- difficulties with speech, swallowing and saliva
- problems with thinking, understanding, learning and emotions.

For support and further information:

MND Connect 0808 802 6262

www.mndassociation.org