

# mnda

motor neurone disease  
association

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

## Southampton & Winchester Group

October 2023



All the latest  
MND A news from  
the local area

## You Can't Beat Nanny Reet!

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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

**Designed and Printed by:**

TLC Online: 023 8024 3044  
www.tlc-online.co.uk

# The cost of living with MND



## THROUGH THE ROOF

As we enter Autumn and Winter fast approaches, the Motor Neurone Disease Association has been looking at how this time of year can put an extra burden on homes living with MND.

After extensive research and publishing a recent report, the MNDA found the cost of living crisis is not over and people living with the illness are still disproportionately affected. This has resulted in many people having to make difficult and impossible choices between fundamental living expenses and maintaining their own health and well-being.

Due to these findings the Association has set up or extended financial help and this month we are focusing on two of those aids that may be able to provide extra support to people living with MND in our region ...

### QUALITY OF LIFE GRANT

The Motor Neurone Disease Association's 'Quality of Life' Grant is for equipment and or services that would help to improve the quality of life of a person with MND.

Stretching to up to £500, people living with the disease are able to apply to cover the cost of valuable, beneficial and needed facilities or practices that may not be possible to afford in times of hardship.

For more information, please contact the MNDA Support Services team on 0808 802 6262 who are able to offer advice and assistance before submitting an application.

## THROUGH THE ROOF CAMPAIGN

As the popular phrase goes 'energy prices are through the roof' – but no home feels that more than one with someone living with MND.

Significant rises in household bills means that anyone using or needing equipment that is plugged in, turned on and constantly in use – are once again excessively and unreasonably charged.

The Government had promised to consult on proposals for more targeted energy support – such as the Energy Social Tariff – throughout 2022 and 2023. But this has still not happened. MNDA are asking the UK Government not to renege on their promise and to urgently publish the consultation.

Our community needs Parliament to understand our struggle so please help by writing to your MP to discuss and implement more targeted support for MND households.

Use our template here to send a message to your MP - <https://ecampaigns.mndassociation.org/page/133215/action/1?ea.tracking.id=hub>



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## End of year monthly meetings and coffee mornings

Thank you to everyone who has attended our face-to-face Monthly Meetings at Oasis Academy Lordshill and our Support Coffee Mornings at Sir Hillier Gardens each month so far this year! It was great to see you all and meet so many new faces too.

As the dark nights now draw in, we will take our Monthly Meetings online once again until the Spring of 2024 - but we promise they will still be jam-packed with lots of information and chatter.

Starting this month, our guest speakers will join us via Zoom to share their expertise and answer questions. Wheelchair Services champion Anne Buchanon is up first on Tuesday 10th October from 7:00pm and is looking for all your queries, issues and problems accessing, dealing with and using wheelchair services.

She will then be followed by Helen Farmer from the Princess Royal Trust on the 14th November before we meet for the last time this year at our Christmas Party on Saturday 16th December (more information under **'SOUTHAMPTON & WINCHESTER MNDA GROUP CHRISTMAS PARTY'**)

Please get in touch for the link to our Zoom Meeting each month.

Our Support Coffee Mornings are still able to go ahead at Sir Hillier Gardens in Botley as they are earlier in the day and more accessible at this time. We hope you will still be able to join us here for a cuppa and a natter on the third Monday each month. Please see our Poster for all the information!

# Nanny Reet Can't Be Beat!

Speaking of great Coffee Mornings, we would like to say a huge well done and congratulations to Southampton & Winchester MND Group member Rita on another hugely successful fundraising event!



Adding to her unstoppable 'Nanny Reet' Go Fund Me fundraising campaign, members of the St.John's Church put on a fabulous Cake & Coffee Morning that was wonderfully attended and raised a staggering £1035!

Rita said, "What an amazing morning we had, so many people came to support MND.

Members of St John's Church were

so organised with Jackie Murley managing to arrange everything. All the cakes were sold and not a crumb left.

So many thanks to everyone."

We would also like to extend our thanks to everyone who organised and attended the event. Your support for Rita and the wider MND community in our region is fantastic. Thank you so much!



Thank  
you!



We would also like to say a big thank you to our Music Festival fundraisers who handed over £800 to the local Group after all their hard work collecting on behalf of the charity.

We are so grateful for all your support and the time you give to helping people with MND.

We couldn't do it without you all!

Please note – 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.

## Bon Voyage for Another Year



Story overleaf ➔



The last of our free outings aboard the Alison McGregor took place last month and what a way to finish the year!

With perfect weather and views for miles, we are sad to say goodbye to our special trips this year but look

forward to the possibility of more voyages in 2024!

Thank you once again to Rosemary Rockett for all the organisation and planning that goes into putting on these mini cruises – everyone had a joyous time!



## RADAR KEYS

Do you know about RADAR Keys?

The Royal Association of Disability And Rehabilitation (**RADAR**) provide keys that can open the lock to around 10,000 disabled public toilets throughout the UK.

These can be invaluable when travelling and great to have as part of your health tool-kit for peace of mind.

The Southampton & Winchester MND A Group now has a small stock that we are able to give out to anyone who would like to have this useful key added to their own keychain.

Please contact Jean Block at [petejeanblock@btopenworld.com](mailto:petejeanblock@btopenworld.com) for more information.



## Getting ready for Christmas

With this being the last issue before Christmas, we don't feel so bad about saying the festive c- word so early. At the Association's National Office they are already ahead of us too – getting together all the Christmas stock and delivery dates.

From cards to wrapping paper and gifts, the MND Online Shop now has everything you could possibly want and need to get yourself ready for the holiday period.

With all money going back into the charity, the season of goodwill takes on a bigger meaning through these purchases and not only benefits people living with MND but all the Christmas Cards available online are manufactured in the UK, fully recyclable and made from FSC

(Forest Stewardship Council) Certified materials.

This means that the materials used are from a forest that is being managed in a way that preserves biological diversity and benefits the lives of local people and workers, while ensuring it sustains economic viability – therefore helping even more people.

Pop over and browse through the shop at [https://shop.mndassociation.org/charity-christmas-cards/?dm\\_i=40VS,1KRC6,2S9FU2,5X2VW,1](https://shop.mndassociation.org/charity-christmas-cards/?dm_i=40VS,1KRC6,2S9FU2,5X2VW,1) and don't forget to order before the 1st December to ensure everything arrives in time for the big day!



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# Southampton and Winchester MNDA Group Christmas Party

A date for your diary!  
Please join us on Saturday  
16th December from  
2:00pm-4:00pm at Calmore  
Community Centre for our  
annual Christmas Party!

We are inviting all our  
members, their carers/  
family and friends as  
well as our supporters  
and volunteers to come  
together before the year  
ends - and celebrate!

It is our chance to say  
a big thank you, get to  
know everyone and finish  
the year on a high as we

enjoy the entertainment,  
hopefully win a few prizes  
on the raffle and stuff our  
faces with lots of food and  
drink as tradition calls for!

Entrance is free and  
transport assistance can be  
provided to people living  
with MND if it is a barrier to  
attending the event.

More information will be  
available soon but we hope  
to see as many of you there  
as possible!





In September we had the pleasure of welcoming 'Jumbulance' to our Monthly Group Meeting.

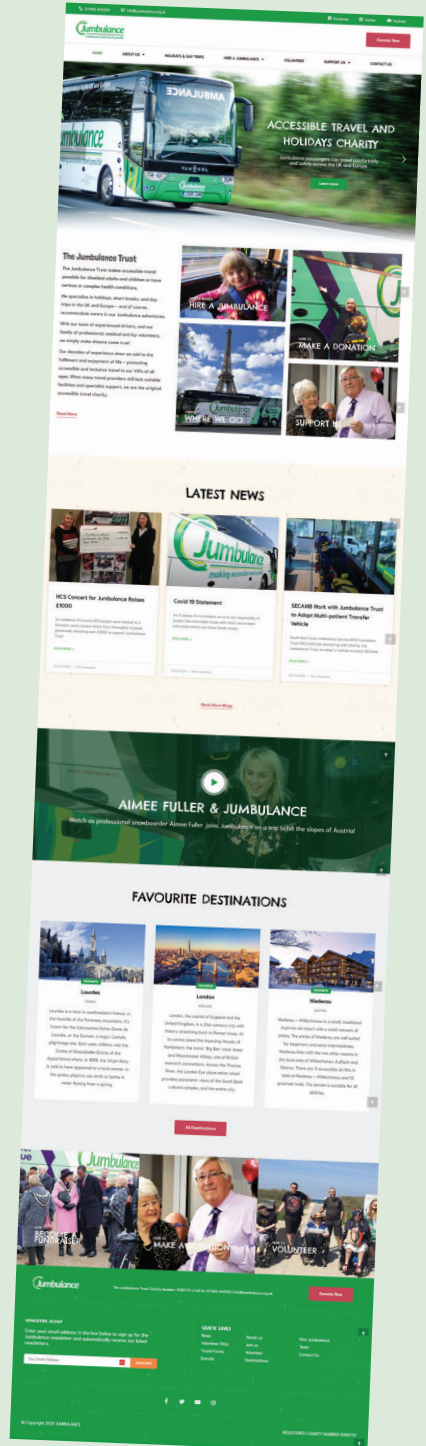
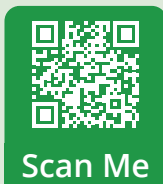
Making accessible travel possible for disabled adults, children and those who have serious or complex health conditions - the Jumbulance Trust specialise in holidays, short breaks and day trips in the UK and Europe.

With a team of experienced drivers and professional medical volunteers, the scheme enables people who would not now be able to travel, the chance to still fulfil their dreams!

It is a magnificent charity that can and has taken people living with MND on long and short holidays with their specialised equipment and wheelchairs.

As we learn more about their planned itinerary for 2024 we will share the information with everyone but in the meantime please take a look at their website at <https://www.jumbulance.org.uk> to see an idea of the journeys they have been on before!

We'll keep you posted on all things Jumbulance in 2024!



## MND care centres and networks

The MND Association provides funding towards MND care centres and networks across England, Wales and Northern Ireland. These are centres of excellence that bring together internationally recognised expertise in the diagnosis and symptom management of motor neurone disease (MND).

MND care centres and networks are committed to person-centred care. They coordinate the care of people with MND, involving a range of different professionals and community services. They also conduct research into MND and improving care.

Locate your nearest care centre or network at [www.mndassociation.org/carecentres](http://www.mndassociation.org/carecentres)



### Care centres and networks:

- develop expertise in the management and treatment of MND including, for example, nutritional and respiratory support
- conduct groundbreaking research into care management, and world-class clinical trials and biomedical research
- provide a resource for health and social care professionals – through information, education and sharing good practice about MND.

# NOTICE BOARD

## NoticeBoard –

**Monthly Meetings - Second Tuesday of every month - 7:00pm-9:00pm - Now online!**

**In Person** - Oasis Academy Lordshill  
Redbridge Lane (off Romsey Road)  
Southampton  
SO16 8FA

**Online** – Please get in touch for the link.

**Coffee Mornings – Third Monday of every month**

## Volunteering Roles –

Please contact **Dawn Pond** - dawn.pond@mndassociation.org

**Southampton Care Centre** - uhs.southamptonmndcarecentre@nhs.net

**Wheelchair Queries** - Ann Buchanan – 01604 611694  
wheelchairqueries@mndassociation.org

## YOUR CONTACTS

### Banker of Donations and Main Contact

**Mrs D Pond**

64 Salisbury Road, Totton,  
Southampton, So40 3JB

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

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

**Twitter:** @MNDASoton

MND Connect **T:** 0808 802 6262

Registered Charity No. 294354







**MND Coffee Morning**  
**Hilliers Garden Centre**

**3rd Monday of Each Month 11:00 -13:00**

Time to talk  
Time to Meet others  
Opportunity to look around a lovely garden Centre.

**Hilliers Garden Centre, Botley**  
**SO30 2EZ**

[www.mndassociation.org](http://www.mndassociation.org)

MND Association Francis Crick House, 6 Summerhouse Road, Northampton,  
NN3 6BJ | Registered charity no. 294354 | Created in RightMarket - 14/2/2022 - 12:37:15