



## EDITOR'S NOTE

Welcome to this year's springtime edition of *Fightback*, the first newsletter overseen by your new editor, Emma Fawkes. I'm taking over from Jenny Sampson and am assisted by Sue Heal and Lisa Bagshaw in collating an inspiring issue filled with news of fundraising, campaigns, research, and events both previous and forthcoming.

I would like to note the recent merger of the King's Lynn Group with the Norfolk, Norwich and Waveney (NNW) Branch of the MND Association. This will in no way affect those we support and will ensure the continuity of a supportive network across Norfolk. Local volunteers will continue in their current roles and MND Association grants remain available to people affected by MND throughout Norfolk.

There will also be further opportunities to join support meetings. These will continue to be held every two months at Dobbies Garden Centre in King's Lynn, and monthly at Nottcutts Garden Centre in Norwich, Cherry Lane Garden Centre in Fritton, and online. Details can be found on page eight.

If you have a story you would like to contribute, please send your written piece and any photos (with permission from the subjects) to [emfawkesmnda@gmail.com](mailto:emfawkesmnda@gmail.com). We look forward to hearing from you!

*Emma Fawkes*



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## Norfolk, Norwich & Waveney Branch Website:

[www.mndnorwichandwaveney.org.uk](http://www.mndnorwichandwaveney.org.uk)

**Facebook:** @MNDANorwichWaveney

**Twitter:** @MNDANorWave

**Instagram:** @MNDNorfolk

**Sunday 19<sup>th</sup> November 2023**

The Open Meeting was held on Sunday 19<sup>th</sup> November 2023 at Wortwell Community Centre, and included a delicious festive lunch which was prepared for us by Kelda's Kitchen. Following lunch we held a raffle with lots of great prizes up for grabs, including one of the fabulous new Rob Burrow MND Roses.



Dr Charlotte Roy, Senior Research Information Co-Ordinator at the MND Association, joined us and provided a very informative presentation about all the latest research and trials which are being undertaken. This was followed by an open question-and-answer session for everyone.

Ticket sales for the raffle were very popular and raised £232. Christmas cards were on sale, along with a good selection of our Association merchandise.

A big thank-you to our supporters, organisers, and caterers for putting together such a fantastic afternoon.



**Advance Notice of AGM:**

Date: Sunday 28 April 2024

Time: 1pm - 5pm

It will be held at St Andrew's Church Hall, Eaton.



### Mayhem for MND | 28<sup>th</sup> August 2023

Across 2023, Emma Bailey and fundraising group The Predators organised several successful events in aid of our branch, including Bingo at Emneth and a Disco and Comedian evening, each raising over £3,000!

The most prosperous was their spectacular 'Mayhem for MND' Van Banger racing event, which raised an incredible £5,600! This was held at the end of the summer at the Adrian Flux Arena in King's Lynn, with Reliant Robin cars and 1500 cc Banger vehicles proclaiming their support in vivid spray-painted designs, from a *Finding Nemo* submarine to a rescue ambulance. Vehicles were flipped and towed in mess and maelstrom, making for much entertainment.

A massive thank you to Emma and the group, who contributed their time, energy, and resources to raise an outstanding total of £23,299 across the year, well in excess of their £20,000 target. You can follow and support The Predators' Facebook page at this link:

<https://www.facebook.com/groups/343637847661426/>



### Wymondham U3A Coffee Morning | 2<sup>nd</sup> Nov 2023

The Wymondham U3A regularly support our branch, and held a coffee morning last November at Wymondham Central Hall. Proceeds were raised through the sale of cakes, Christmas cards, and merchandise, as well as a tombola, raffle, guess-the-name-of-the-mouse competition, and a sweepstake with prizes which were generously donated by the Wymondham branch of Waitrose and Wymondham Garden Centre. Overall £1,073.75 was earned on the day!

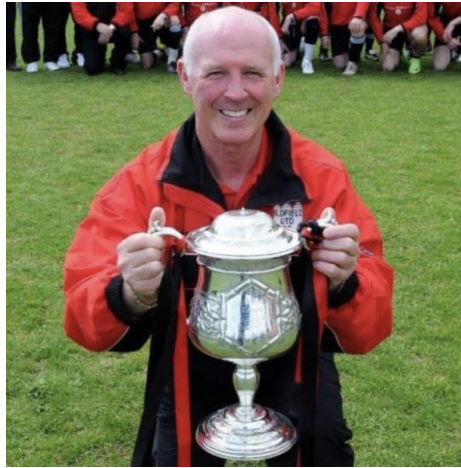
### Chiltern 50 Ultra | 23<sup>rd</sup> September 2023

Emily and Claire set up a JustGiving fundraiser at <https://www.justgiving.com/page/emilyjasonrobinson> to sponsor their 50 km walk with Jason and Pete across the Chiltern Hills in support of the MND Association.

The Association means a lot to Emily and Claire as their grandmother Dorothy passed away from motor neuron disease in 2003 and sadly their wonderful dad Stephen was diagnosed in 2022. The walk took place in September of last year and their £1,600 target was increased by 477% with an outstanding £7,644 total! Well done to all four walkers for their amazing hard work!

### Danny's Fundraiser | 15<sup>th</sup> February 2024

Last Christmas, students at Wetheringsett Manor School in Suffolk received £10 from the Student Council to invest individually in a project to raise funds for charity. The student who raised the most during this venture would be allowed to nominate the charity to benefit from the fundraising. The students at the special needs school worked very hard with innovative ideas, and raised a total of £300. The winner was Danny who lives in Aylsham and is pictured below presenting the cheque to our chairman Malcolm. Danny nominated the NNW branch of the MND Association as a close friend of his Mum had motor neurone disease.



### In Memory of Paddy Murphy | November 2023

In November 2023 the family of Paddy Murphy, manager of Blofield FC for 22 years who helped them win 7 trophies, started a JustGiving page in his memory. Their target of £500 was exceeded by 376%,

with £1,882 raised on the page as of March this year. Further to this, £2,236 was donated to J Gedge and Sons Funeral Directors, with a total of £4,118 coming to the NNW branch.

Paddy's relative Pam Downs described the branch as 'a source of practical help and comfort during a time of despair' and 'a lifeline for local people struck down with MND.' The money raised by Paddy's loved ones and community will make a massive difference to ensure we can continue to benefit people affected by MND, and we would like to say a huge thank you to everyone who contributed. Their JustGiving page can be found here:

<https://www.justgiving.com/crowdfunding/pamela-downs>



### Gary's Run | 3<sup>rd</sup> - 5<sup>th</sup> May 2024

This spring, Gary Wood plans to run the entire 84-mile Norfolk Coastal Path from Hunstanton to Hopton-on-Sea to raise money for the MND Association. The charity is close to Gary's heart as he sadly lost his mum Dawn to motor neurone disease just over 12 years ago, and will begin his run at the bench dedicated to her memory next to Hunstanton Lighthouse.

Here is the link to Gary's JustGiving Page where you can read more about his story and donate:

<https://www.justgiving.com/page/gary-wood-1688242410787>

Holly Cosseys' *Charity ball*

In aid of MND association,  
Norfolk, Norwich and Waveney branch and MND research

On 15th June 2024  
At Mercure Hotel, Norwich  
6:30pm arrival

Tickets are £45. This black tie event includes a 3 course tinner, glass of prosecco, DJ and dancing. You will have the chance to win some amazing prizes in the raffle and a chance to bid on the auction. Paul Colella will be there on arrival to take entry pictures which can be purchased and printed for £10 (with proceeds going to charity)

For more details, to donate a prize or buy tickets, please call Holly on 07496000113 or email on [hollynorman96@hotmail.co.uk](mailto:hollynorman96@hotmail.co.uk)



### Farewell to Jane | 31<sup>st</sup> December 2023

With the year ending and the branches merging, Jane Lewis stepped down from her post as chairwoman of the King's Lynn Support Group, leaving behind an amazing legacy of 26 years' volunteering and receiving a send-off worthy of her achievements.

Expecting a small event at the Harbour Rooms in Blakeney, Jane was surprised by many current and former volunteers from the Group, alongside Malcolm and Sue from the NNW Branch, Area Support Co-Ordinator for East Anglia Liz Cooper, and CEO of the Association Tanya Curry, who enjoyed a buffet lunch together. Jane is pictured opposite with Tanya (left) and Malcolm (right).

She was also presented with a Rob Burrow MND Rose and a voucher for her favourite delicatessen to commemorate her hard work and dedication to people affected by MND for over two decades. It was a lovely occasion enjoyed by everyone, and we wish her every success with her future endeavours.



### Emma and Tallulah's School Project | February 2024

Students Tallulah (left) and Emma (right) recently took part in Genius Hour at Wymondham College, a competition between all year sevens to determine who can make the best project on a subject of their choice. The girls decided to cover motor neurone disease as Tallulah's auntie has the condition and they wanted to spread awareness, and they were asked many questions by the judges. Unfortunately the girls didn't win their category, but they got a special mention and 25 school positive points. Importantly, they enjoyed making their display and talking to parents and staff about everything they learnt throughout. Tallulah's auntie also came along to the event and was amazed by their efforts to raise awareness. Well done to them both!

### Wheelchair Available

Keith Tomlinson is donating a Careco Ergo Pro Transit wheelchair of 20 inches in width, pictured opposite. It has only been used a few times since it was bought new in November 2023, and Keith hopes someone living with MND can make use of it. If interested, please contact him at [keith.tomlinson58@yahoo.co.uk](mailto:keith.tomlinson58@yahoo.co.uk)



### Secretions Research Development

The Norfolk and Norwich University Hospitals (NNUH) are seeking advice from people affected by MND to help guide a research project that will improve the care and management of saliva and phlegm related problems, also known as 'secretions.'

The title of the study is *Secretion Management in Motor Neurone Disease: What works, for whom, and in what circumstances?* Its aim is to find out more about current care practices and how treatment decisions are made, using this information to ensure the best decisions about care and treatment can be more easily made in the future.

In forming the study, the NNUH would like to speak to people who either experience the problem firsthand or care for someone who does, to ensure that they're aware of what's most important when thinking about secretions care. To clarify, the information will be used to design the research project and will not form the results of the project itself.

This would ideally be a face-to-face meeting but there are also remote options, including video/phone calls or email. Additionally, this can be in either a group setting or one-to-one depending on what's preferred. As a thank-you, participants will receive a £25 gift voucher. Helping is entirely voluntary and participants can withdraw at any time.

The NNUH hope this will form a positive experience but recognise that living with MND is difficult and talking about it can be upsetting. The researcher is specialised in the care of MND and trained in talking to people with serious illnesses. There is further, independent support available from the MND Association Connect helpline at 0808 802 6262 or [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org).

If you are interested, please either email [caroline.barry@nuh.nhs.uk](mailto:caroline.barry@nuh.nhs.uk) or [helen.copsey@nuh.nhs.uk](mailto:helen.copsey@nuh.nhs.uk), or phone 01603 647221 to discuss the next steps.



## MND Matters: The MND Association Podcast

Did you know that there is an MND Association podcast?

The MND Matters podcast is a space for people who are affected by MND to share their experiences and support one another. Hosted by Chris, Helen, Nick, and Steph, this podcast brings humour, emotion, and always honesty to its audience members. They tackle a whole host of topics with the aim of offering informal advice and support to their listeners whilst raising awareness of MND.

You can catch up with the most recent episode now or listen to previous episodes by following this link: <https://www.mndassociation.org/media/mnd-matters>, or by searching for 'MND Matters' on your chosen podcast platform.

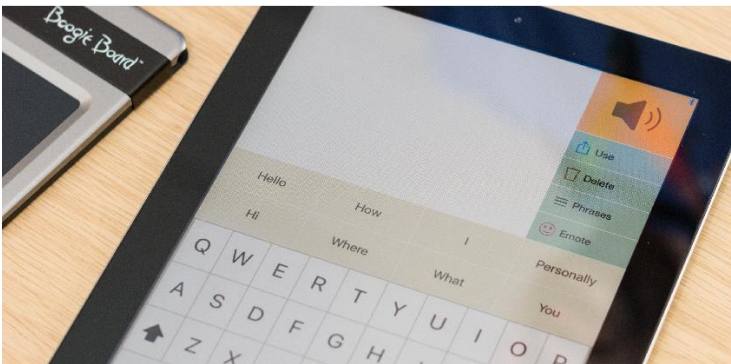


## The MND Association Online Forum

The online forum is another resource for anyone affected by MND. It is hosted by the MND Association, but the content is created by a wide range of people with the aim of offering first-hand experiences and medical, emotional, and practical support. It's worth mentioning that some may find the content difficult and/or distressing.

Anyone can access the forum to read the posts and gather information, but if you wish to post yourself, you will need to register.

To access or register, simply follow the link here: <https://www.mndassociation.org/support-and-information/our-services/online-forum>



## MND Connect Helpline

The MND Connect team offer support and information on all aspects of motor neurone disease (MND), including practical management, symptom control, improving quality of life, clinical research, and signposting to other organisations.

The MND Connect Helpline **0808 802 6262** is available Monday to Friday between 9am – 5pm and 7pm – 10:30pm. Calls to this number are free from landlines and mobile phones within the UK and do not appear on itemised bills. Or you can email the team on: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

To find out more information, follow the link to the webpage: <https://www.mndassociation.org/support-and-information/our-services/mnd-connect>



## Dates for Your Diary

### 2024 Coffee Mornings and Afternoons - Held on Wednesdays

**April** 10<sup>th</sup> for Online | 17<sup>th</sup> for Notcutts | 24<sup>th</sup> for Cherry Lane

**May** 8<sup>th</sup> for Online | 15<sup>th</sup> for Notcutts | 29<sup>th</sup> for Cherry Lane | 15<sup>th</sup> for Dobbies

**June** 12<sup>th</sup> for Online | 19<sup>th</sup> for Notcutts | 26<sup>th</sup> for Cherry Lane

**July** 10<sup>th</sup> for Online | 17<sup>th</sup> for Notcutts | 31<sup>st</sup> for Cherry Lane | 17<sup>th</sup> for Dobbies

**August** 14<sup>th</sup> for Online | 21<sup>st</sup> for Notcutts | 28<sup>th</sup> for Cherry Lane

**September** 11<sup>th</sup> for Online | 18<sup>th</sup> for Notcutts | 25<sup>th</sup> for Cherry Lane | 18<sup>th</sup> for Dobbies

**October** 9<sup>th</sup> for Online | 16<sup>th</sup> for Notcutts | 30<sup>th</sup> for Cherry Lane

**November** 13<sup>th</sup> for Online | 20<sup>th</sup> for Notcutts | 27<sup>th</sup> for Cherry Lane | 20<sup>th</sup> for Dobbies

Hopefully we will not need to cancel any meetings due to unforeseen circumstances, but updates will appear on:

<https://www.mndassociation.org/support-and-information/local-support/branches/norfolk-norwich-and-waveney-branch/>

There is no need to let us know you are coming to the coffee mornings. For face-to-face meetings, please take a lateral flow test on the day to reduce the risk of spreading infection to people with MND. We will replace this when you arrive so you are not out of pocket.



### Online Zoom Coffee Mornings:

Time: 11:30 – 13:00

These are friendly informal gatherings hosted by Malcolm, Sue, Clare and other volunteers, for people with MND, their carers, and friends. Drop in at any time and leave when you need to.

Email [sueheal@btinternet.com](mailto:sueheal@btinternet.com) if you would like to receive the link. Newcomers are always welcome!

### Locations:

**Notcutts Garden Centre:** Daniels Rd, Norwich, NR4 6QP **Time:** 11:00 – 13:00

These informal gatherings are hosted by Malcolm, Sue, and others, for people with MND, their carers, and friends.

**Cherry Lane Garden Centre:** Beccles Rd, Fritton, Gt Yarmouth, NR31 9EU **Time:** 11:00 – 13:00

These informal gatherings are hosted by Judy and Colleen for people with MND, their carers, and friends.

**Dobbies Garden Centre:** Campbells Meadow, King's Lynn, PE30 4WQ **Time:** 14:30 – 16:30

These informal gatherings are hosted by Jane and others, for people with MND, their carers, and friends.

### Donations

Anonymous donations - £105.40

Yaxham Monday Night Sequence Dance Club - £100.00

U3A Coffee Mornings – £1,053.75

Cath's Cards - £20.00

P & DG - £230.00

Pétanque Club - £135.00

Tribute Fund for Dawn P Gower - £1,450.00

JE Sale of Cards - £162.00

Collection Boxes - £44.03

AW's Tombola at Eaton Craft Fair - £211.62

R & M's Drive IMO Justin Hammond - £7,113.00

Apollo Lodge 305 - £1,000.00

Wymondham Ukulele Group – £629.33

### Donations & Fundraising

received with thanks

Fakenham Christmas Tree Festival IMO

Ashley Wright - £625.26

P W-F Donation - £20.00

J McM Donation - £20.00

E G Donation - £14.64

C C Donation - £50.00

Wymondham Lions International - £200.00

J F Donations in lieu of Birthday Presents - £385.00

R J & Aunt B Donations - £40.00

Norwich Rotary Club - £1,000.00

Aylsham Show - £250.00

A J M Sale of Cards and Tea Towels - £100.00

Predators - £3,796.00

Norfolk Institute Dinner - £875.00

Wetheringsett Manor School Student Fundraising - £300.00

Horning Amateur Panto - £500.00

**Donations in Memory of**

Keith Christopher Bonner - £416.10

Wendy Devlin - £710.00

Paddy Murphy - £4,090.07

Mrs Joan Mildred Wallace - £68.50

Paula Osler - £210.00

Lorna T - £17.00

Maureen Peel - £160.00

**Internal Transfers**

Gift Aid - £2,836.53

Charities Trust - £50.00

Emergency Fund - £435.00

Bank Interest - £307.71



### What's Happening on Riluzole?

The Association has been receiving reports of challenges accessing Riluzole since September 2023. In December, our Chief Executive Tanya Curry wrote to the Secretary of State, Victoria Atkins, to ask what steps her Department is taking to tackle shortages of Riluzole. The Association shared evidence of shortages with the Department of Health and Social Care (DHSC) Medicines Supply Team and engaged with Community Pharmacy England to understand the challenges they face.

The Association has also had a number of conversations with medicine supply agencies and the DHSC as well as raising concerns through the All-Party Parliamentary Group on MND, with submission of a Parliamentary Question. They have also worked with the media to highlight the issue, which has been widely covered in the press and on TV – thank you to everyone who has raised this.

The Association's update on 21 February suggests there is a reduction in the number of reports from people who have struggled to have their prescriptions fulfilled, suggesting the situation is improving. They are continuing to work with Community Pharmacy England, and to monitor the situation. Further information and updates can be found at: <https://www.mndassociation.org/media/latest-news/update-supplies-riluzole>



### UK MND Research Institute

Launched in November 2023, the UK MND Research Institute (UK MND RI) brings together a national network of MND labs, clinical centres, and researchers across the UK to accelerate the discovery of treatments and ultimately a cure for MND.

The Institute is being directed by MND clinician researchers Professor Ammar Al Chalabi and Professor Christopher

McDermott, and has been driven forward in part by David Setters who lives with MND and believes in the hope the Institute will embody for people affected. The three pillars of research are understanding the patient and disease process, identifying possible drugs to treat MND, and testing new treatments in clinical trials.

The Institute was brought about by the United2End MND campaign which started in 2021 and called on the UK government to pledge £50m for research into MND. This money continues to support programmes and initiatives within the Institute.

There are also peer-reviewed research programmes taking place, which have been funded by the MND Association thanks to money raised from Kevin Sinfield's challenges across the past few years. Further funding is coming from MND Scotland, My Name's 5 Doddie Foundation, LifeArc, the National Institute of Health and Care Research (NIHR), and the Medical Research Council (MRC).

### Act to Adapt

Our campaign on improving the housing adaptation processes for people affected by MND is ongoing. It will form part of our message for General Election candidates. We will be calling on the next Government to increase the current Disabled Facilities Grants. As you will see from the next article, Sue Heal, Branch Campaigns Contact, is using every opportunity to encourage local councils to meet our three requests:

- Introducing a fast-track process for people with MND
- Removing financial assessments for Disabled Facilities Grants under £5,000 for people with MND
- Maintaining a register of accessible homes for people to move into



### Support MND Carers

People looking after a person with MND, or any other condition are entitled to a 'Carers assessment' by their local authority. These assessments do not judge a person's capacity as a carer, but offer an opportunity to discuss how being a 'Carer' affects their lives, health, and wellbeing with someone who understands. Information advice and support personal to each individual is offered. Carers Matter Norfolk are commissioned on behalf of Norfolk County Council to offer Carers Assessments.

Evidence from the MND Association was included in a report published in 2022: *Understanding the Experiences of Unpaid Carers of People Living with MND*. Of those surveyed only 25% of carers of people with MND nationally had either received a carer's assessment or were in the process of having one and 40% were unaware of their right to one.

On 23 November 2023, Carers Rights Day, the Association launched a second report, *State of Carer's Assessments*. It was based on responses to freedom of information (FOI) requests sent to local councils. It focused on four themes: Identification, Quality, Timeliness and Prioritisation.

Campaigns Volunteers with an interest in this issue were asked if they would pilot the use of the FOI data for their councils to campaign for improved support for MND Carers in their area. Sue Heal, Campaigns Contact for the Norfolk Norwich and Waveney Branch, agreed to take part in the pilot. She reminds us that campaigning for change can take a long time to achieve its objectives! The strategy involves a number of stages – working with Norfolk County Council, local Councils, and later, other charities who provide support for carers in Norfolk.

Sue attends the Norfolk County Council (NCC) Health and Wellbeing Board meetings as an observer whenever she can. After their meeting in November she was able to speak with the Interim Executive Director of Adult Social Services about the need for speed in providing a carer's assessment and for reassessments as needs change.

As a result of this conversation Sue was able to meet with Marie Smith, Operational Business Lead for Carers, Adult Social Services with Norfolk County Council a few weeks later to discuss the needs of people living with MND and their carers. We were delighted that Marie was able to join us, in her own time, at our Notcutts coffee morning in February to hear directly from people living with MND and their carers. Sue looks forward to continuing this positive engagement.

A reminder: If you are in touch with adult social care services at NCC, please make sure you mention MND early in the conversation if it is appropriate to your circumstances.

Carers Matter Norfolk are commissioned on behalf of Norfolk County Council to offer Carers Assessments. *Norfolk* magazine Winter 2023, encourages all carers to create a Carers' Emergency Plan to prepare for the unexpected. You can make your plan at [www.norfolk.gov.uk/carersemergencyplan](http://www.norfolk.gov.uk/carersemergencyplan). Once complete, you will



**Your right to a carer's assessment**

motor neurone disease association

For more information visit [MNDAssociation.org/CaringSupport](http://MNDAssociation.org/CaringSupport)

A carer's assessment enables you to tell adult social care services how your caring role could be made easier. You should be offered an assessment once you have been identified as a carer, or you can ask for one.

More info from Norfolk County Council: [www.norfolk.gov.uk/care-support-and-health/get-help-with-looking-after-someone/support-for-carers](http://www.norfolk.gov.uk/care-support-and-health/get-help-with-looking-after-someone/support-for-carers). Or call Carers Matter Norfolk on 0800 083 1148

You have a right to a carer's assessment whether or not you live with the person you support. You may provide care full-time or part-time, or combine care with paid work.

The person you support doesn't need to have had a social care assessment.

The assessment does not judge your capability as a carer, but allows you to review your caring role:

- Do you need help and are there services that could support?
- Are you willing and able to carry on caring?
- Can you continue to give increasing levels of care?

**An assessment will help you find out about:**

- care services, benefits advice and local voluntary organisations
- planning for respite, urgent or emergency care
- assistance with travel
- how to maintain your own interests, studies or activities while caring
- suggestions for counselling or support groups.

Motor Neurone Disease Association  
Francis Crick House,  
6 Summerhouse Road,  
Moulton Park, Northampton NN3 6BJ. UK  
[www.mndassociation.org](http://www.mndassociation.org)  
[MNDAssociation.org/SupportMNDCarers](http://MNDAssociation.org/SupportMNDCarers)

**SUPPORT MND CARERS**

receive an emergency carer's card, including the emergency plan number and helpline. The Spring 2024 edition answers questions about carer's assessments on Page 19 and provides a link to find out more: [www.norfolk.gov.uk/carersassessment](http://www.norfolk.gov.uk/carersassessment).

Sue emailed District, City and Borough councillors who sit on the Norfolk County Council Health and Wellbeing Board to share the *State of Carer's Assessments* report and to request a meeting; three kindly agreed to meet.

Sue met with Cllr Wendy Fredericks of North Norfolk District Council (NNDC), to discuss a wide range of issues and ways in which NNDC can support carers and people living with MND. Some of you may remember that NNDC adopted the MND Charter in 2019; soon afterwards Cllr Fredericks was one of two councillors who attended an Association webinar on the Act to Adapt Campaign. Cllr Fredericks was able to confirm the availability of two different discretionary grants without a means test, one a fast-track end of life (12 months or less) 'minor adaptations' grant of up to £1,000, the other of £5,000 for which an occupational therapist's assessment is needed. There are priority routes for all grants. It was really good to hear that the council have adopted the key asks of our campaign and that they are not limited to those living with MND. Sue and Cllr Fredericks agreed a number of actions and a follow-up meeting is in the diary for April.

Sue met with Cllr Jo Rust of the Borough Council of King's Lynn and West Norfolk. It was a very positive meeting. The council have not yet adopted the MND Charter, but she agreed to see what might be possible. Cllr Rust has also agreed to look at our Act to Adapt campaign requests. It was good to hear her understanding of the needs of carers, and to receive her support for the aims of our campaign. Sue and Cllr Rust will continue to work together.

Sue was invited by Cllr Tristan Ashby, of Breckland District Council, to attend a Breckland Health & Wellbeing Partnership Board meeting. On 1 March, she gave a presentation on the work of the Association and our role locally, and to look at the ways in which the partnership might support us. The talk was well received with expressions of support for our work, and an understanding that we would continue to work together.

Of course, there is always more to do – and other councils to engage with. Sue will continue to request meetings with other councillors.

### All-Party Parliamentary Group (APPG) on MND

Parliament is changing the rules on how APPGs form, so it was particularly important that people wrote to their MPs to encourage them to join the group. Thank you to everyone who was able to do this.

The AGM of the APPG on MND took place on 13 March 2024. Sue had emailed an invitation to all 10 MPs with constituencies in Norfolk and Waveney. Our branch area was well-represented. James Wild (North West Norfolk), Peter Aldous (Waveney), and branch patron, Sir Henry Bellingham, were able to attend. Look out for the minutes of the meeting at: <https://www.mndassociation.org/get-involved/campaigning/all-party-parliamentary-group-appg-on-mnd>.

### Through the Roof

Thank you to everyone who contacted their MP to share key findings from the Through the Roof campaign and invite them to attend the APPG on MND meeting on 15 November. It was well-attended and provided an opportunity to discuss the Association's call for the government to implement more targeted energy support.



In October, members of the MND Association's Policy and Public Affairs Teams met with Amanda Solloway, a minister in the Department for Energy Security and Net Zero, to discuss their research and recommendations. They set out how people living with and affected by MND are being disproportionately affected by the cost-of-living crisis, and suggested policy measures for the minister and her department to consider – such as the energy social tariff. It was a positive meeting with the minister who was well-prepared and receptive to the ideas being shared. She also agreed to share a recommendation to extend the NHS rebate scheme for powered equipment with the Minister for Social Care, Helen Whately (with a follow-up taking place after the November meeting of the APPG on MND).

Despite some politicians still calling for a government consultation on the tariff, the campaigns team now believe it is unlikely that the current government will commit to an energy social tariff as politicians across the UK are now focused on the general election. They remain very aware that the cost-of-living crisis has not gone away and that people with MND are still feeling its effects, so they are still actively looking into options for dealing with the high energy bills faced by people with MND – such as an improved NHS rebate scheme for powered equipment. They are also working closely with other organisations such as Marie Curie and The Joseph Rowntree Foundation, who share similar goals.

If you, or someone you know, would like to share your story about how the cost-of-living crisis has affected you, please contact the campaigns team at [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org).

Remember, the MND Association offers a range of financial support grants, including a Cost-of-Living Support Fund, and you can find out more about each of the grants and how to apply at:

<https://www.mndassociation.org/support-and-information/our-services/financial-support-information-for-people-with-mnd>

### Norfolk County Council Consultation

Closer to home, the Your Norfolk magazine gave us Norfolk in numbers, one of which was the £1.803 bn annual revenue budget for Norfolk County Council. Each year, the Council reviews its budget and proposes the savings it will need to make for the following year to balance its budget. It has proposed £41.5 m of new savings, some of which require further consultation. There are two consultations that will still be open when you receive Fightback that you might wish to use to share your views.

- A consultation on the proposal to charge an arrangement fee to people who self-fund their social care for sourcing, contracting and invoicing on their behalf where there is a duty to meet that person's needs. It opened on 19 February and closes on 17 May 2024. Find out more at: <https://norfolk.citizenspace.com/consultation/arrangement-fee-consultation/>
- A consultation asking for your views on NCC's proposal to change the non-residential Charging Policy by reducing the Minimum Income Guarantee (MIG) in line with the Government's rates. The MIG is the term used to describe the minimum level of income that people receiving local authority arranged home care need to cover their living costs. It is the minimum amount people need before a charge can be applied by Norfolk County Council. It opened on 19 February and closes on 17 May 2024. Find out more at: <https://norfolk.citizenspace.com/health/non-residential-care-charging-policy/>



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**Disclaimer:** *The views expressed in this newsletter are not necessarily those of the MND Association. The products and services mentioned or promoted should not be taken as recommendations by the Association, who cannot be held responsible should any complaint arise.*

*We would like to keep in contact with you about the important work we do. If you do not wish to receive further information, please contact Grace Fleming at [mnda.norfolkwaveney@gmail.com](mailto:mnda.norfolkwaveney@gmail.com) or write to Norfolk, Norwich and Waveney Branch, c/o MND Association, Francis Crick House, 6 Summerhouse Road, Moulton Park, Northampton, NN3 6BJ.*

*Please pass this newsletter on to people who may be interested.*



**Newsletter Editor:** Thank you to all who have sent photos and stories for inclusion in our newsletter. The deadline for receipt of articles for the next edition is **1<sup>st</sup> June 2024**.



If you would like to talk to someone about MND,  
please contact our MND Connect team on **0808 802 6262** or email

**[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)**

Visit our online forum **<http://forum.mndassociation.org/>**

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

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