mnda
motor neurone disease
association

Fightback

Norfolk, Norwich & Waveney Branch Newsletter

Issue 98 | October 2025

EDITOR'S NOTE

Happy autumn all! I hope you enjoy the photo from my garden on the top right. One thing I love about this time of year is all the cosy orange and yellow tones, especially those found in nature.

In this edition of Fightback, you'll find inspiring local donations and fundraising efforts, alongside broader campaigns and research. You can also discover upcoming events, meetings for coffee or a walk with other members of our community, and lots of other useful resources and info all in one place.

As always, if you have a story you would like to contribute, or any resources to share, please send your written piece and any photos (with permission from the subjects) to emfawkesmnda@gmail.com. **Please bear in mind the deadline which can be found on the Branch Information page.** We look forward to hearing from you!

Emma Fawkes

Contents:

Norfolk, Norwich & Waveney Branch Website:
https://www.mndassociation.org/support-and-information/local-support/branches/norfolk-norwich-and-waveney-branch

Facebook: @MNDANorwichWaveney

Twitter: @MNDANorWave

Blofield FC League Match | 16th August

On 16th August Blofield Football Club held a league match at home to Wells Town FC in which they contested for the Paddy Murphy Memorial Cup. They also held a raffle, auction of a Cole Palmer football shirt, refreshments, and BBQ, and a Cheese and Wine Quiz at their clubhouse. A total of £2,010 was raised for the Norfolk, Norwich and Waveney Branch of the Motor Neurone Disease Association.

Blofield FC won the match 2-0 and the photo shows Jenny Murphy presenting the Cup to club captain Ross Dawson.

Gressenhall Garden Party | 22nd August

Sue and Alastair Beattie opened their garden for friends and supporters to enjoy tea, coffee, cake, and Sue's homemade cherry plum jam in return for donations to our branch of the MND Association.

Alastair was diagnosed with ALS MND in February 2024 and is grateful for the support the branch has given him and Sue.

Altogether they raised £405 and plan to repeat the event next year, encouraging their village, church congregation, friends from Ovington Village, and the Heart of Norfolk branch of Oddfellows to attend. Our branch is the Norfolk branch of Oddfellows' charity of the year, having been nominated by Alastair and Sue.

Great North Run | 7th September

One of our branch members Cerys Maryan completed the Great North Run on Sunday 7th September 2025 and raised over £500 plus gift aid for the Motor Neurone Disease Association. Cerys completed it in a time of 2 hours 15 minutes. Congratulations and well done. Cerys is a biology PhD student at the University of East Anglia. She has a close family connection to MND, hence her wish to support our charity. The picture shows Cerys proudly holding her medal.

Sailing at Snettisham Beach

There is an opportunity for people living with MND to sail at Snettisham Beach Sailing Club on Friday afternoons until October, from 1:00 pm to about 4:30 pm. We hope after October there will be further opportunities next year. Ten people from the King's Lynn Coffee Group went to the Sailing Club, where three people went out sailing. Here are the details if you'd like to have a go!

They have adapted boats which are suitable for beginners who have never sailed before, or for more experienced sailors. They also have a team of trained volunteers and instructors to help. Adrian Tebbutt and the team of volunteers are very welcoming and helpful.

You will see that they are part of the Royal Yachting Association Sailability Scheme and hold the relevant safety qualifications. A good video shows you what it's like sailing on the lake. They also run a 'Sailability' training scheme, so you can arrange to go regularly and follow the syllabus for a sailing qualification.

A family member or carer is welcome to go along too. The address is 61-62 The Beach, Snettisham, King's Lynn, PE31 7RB, about midway between Hunstanton and King's Lynn. (The concrete road in to the sailing club needs to be taken very slowly as it's quite bumpy and you need your sat nav to find it!)

The Sailing Club is situated in a lovely part of Snettisham - by the sea, on the edge of the Wash. So it's definitely worth going to have a look on a Friday afternoon and enjoy the surroundings, whilst you consider the opportunity! I would still suggest that most people may prefer to go along to have a look at the access and facilities to see if it's suitable for you, before committing to sailing.

You can book a session for yourself; the cost is £12 for an hour for an individual booking. Click on the Accessible Sailing link on their website at https://www.snetbeach.co.uk/discover/about-accessible-sailing to bring up the relevant information and learn more about it. You would be helped on and off boats and accompanied by one of their volunteer sailors.

Don't forget that MND Association Quality of Life grants are available for this sort of leisure activity - but just apply two or three weeks before hand as they can't do grants retrospectively. You could apply for, say, £120 to cover ten sessions (providing you meet the criteria). The maximum total for all grants from the Association is £3,000 per 12 months - although the Cost of Living grants are additional to that £3,000. Information and application forms are on the national MND Association website.

Adrian Tebbutt from the Sailing Club has previously explained a few things which you may wish to be aware of :

A) Accessible sailing would be on the lake (although the Club also has sea sailing adjacent.)

B) Sessions would be held between 1:00 pm and 5:00 pm on Fridays – please book and pay by credit card on their website.

C) Individual or group sessions can be booked - £12 per hour for an individual, or £90 for a group two-hour session of six to ten people.

D) Typically it would be one person in a Hansa boat, with the instructor - although they have Wayfarers too, which can take two people plus instructor (so a person living with MND could be accompanied by a family member or carer if arranged in advance.)

E) A family member or carer is welcome to go along - there's a viewing area over the lake.

F)There's a cafe on site, open on Fridays after 4:00 pm.

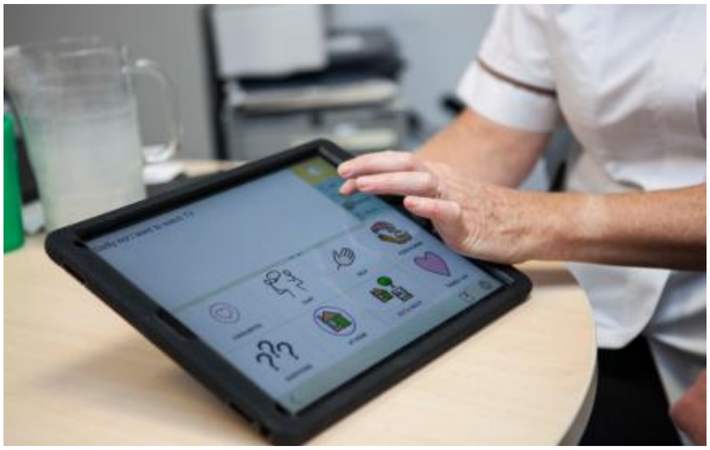
G) There is a fairly steep slope down to the pontoon & lake, so manual wheelchairs would be attached to a winch, for safety, to go down the slope.

H) Where required, they have a hoist to lift people from the pontoon into the boat (max weight for hoist 119 kg.) There is other simple equipment to help transfer to the boat.

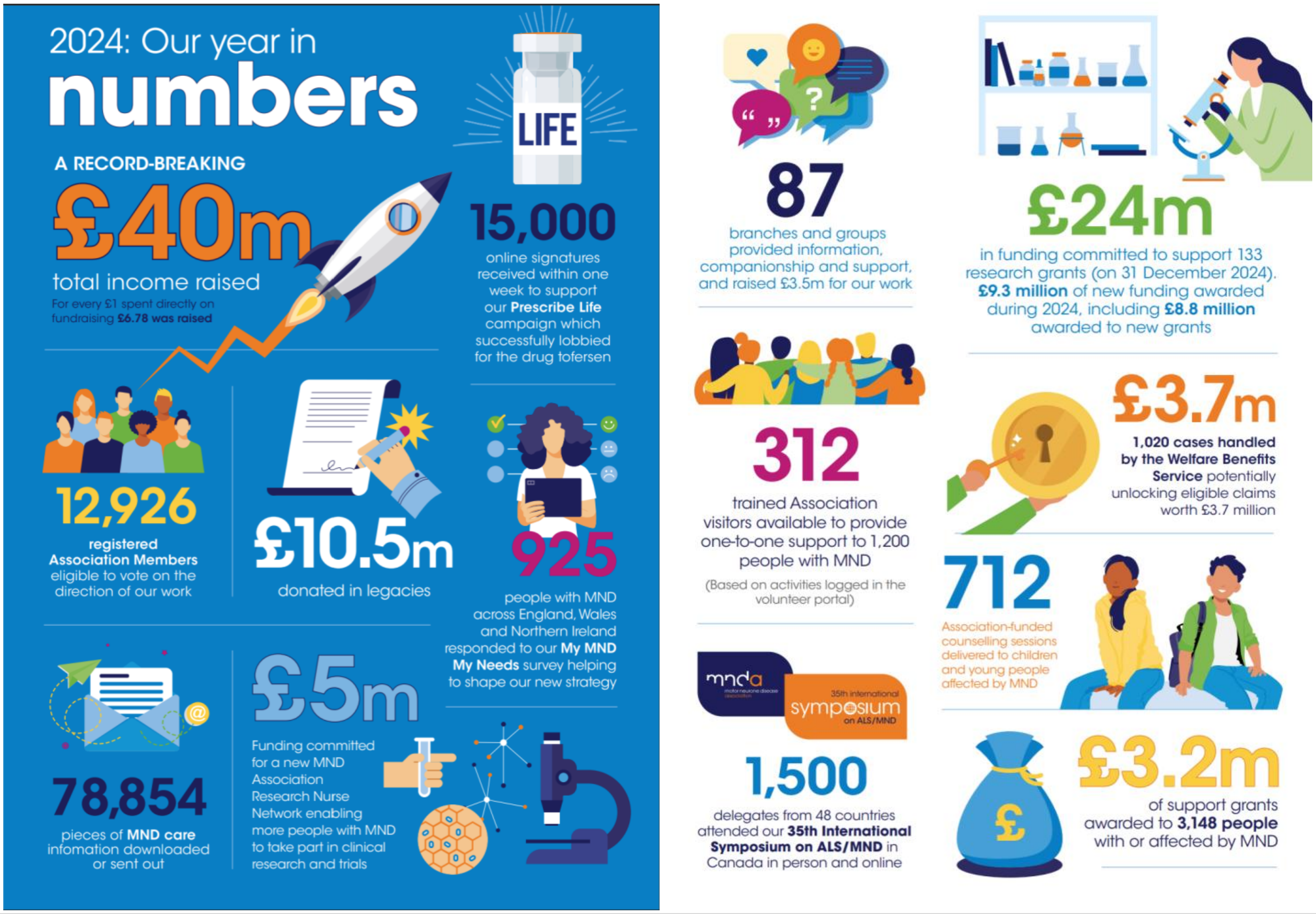
I) At present the toilet facilities are not fully accessible, so there would not be space to accommodate an electric wheelchair. One option discussed was to transfer from wheelchair to toilets using a walker, where appropriate.

J) The Sailing Club would provide buoyancy aids and suitable clothing - you shouldn't get wet, unless it's raining!

Tech Skills for Life



If you struggle with or want to learn how to use technology and/or the internet, Tech Skills for Life could help you if you live in the West Norfolk, North Norfolk, King's Lynn or Great Yarmouth areas. It's a partnership led by Norfolk County Council, working with the NHS, volunteer groups, and local community organisations to help people use computers, smart phones, and tablets, and navigate the internet safely with skills and confidence, whether as a refresher or an introduction. There are free sessions with community tech coaches to do this, who can also help you access technology and mobile data and give advice about affordable broadband. To get in touch, please call 01485 536420 or 01493 448246; lines are open Monday-Friday from 9:00 am – 5:00 pm. A community tech coach will answer your call or you can leave a message. Alternatively you can complete an online form at https://www.norfolk.gov.uk/38923 where further information can also be found. Coaches normally meet clients in designated libraries but home visits may be possible. There is currently a high volume of requests; someone will be in touch as soon as possible.



2024: Our year in **numbers**

A RECORD-BREAKING **£40m** total income raised

For every £1 spent directly on fundraising **£6.78 was raised**

15,000 online signatures received within one week to support our **Prescribe Life** campaign which successfully lobbied for the drug tofersen

12,926 registered **Association Members** eligible to vote on the direction of our work

£10.5m donated in legacies

925 people with MND across England, Wales and Northern Ireland responded to our **My MND My Needs** survey helping to shape our new strategy

78,854 pieces of **MND care** infomation downloaded or sent out

£5m Funding committed for a new MND Association Research Nurse Network enabling more people with MND to take part in clinical research and trials

87 branches and groups provided information, companionship and support, and raised £3.5m for our work

£24m in funding committed to support 133 research grants (on 31 December 2024). **£9.3 million** of new funding awarded during 2024, including **£8.8 million** awarded to new grants

312 trained Association visitors available to provide one-to-one support to 1,200 people with MND

(Based on activities logged in the volunteer portal)

£3.7m **1,020 cases handled by the Welfare Benefits Service** potentially unlocking eligible claims worth £3.7 million

712 Association-funded counselling sessions delivered to children and young people affected by MND

1,500 delegates from 48 countries attended our **35th International Symposium on ALS/MND** in Canada in person and online

£3.2m of support grants awarded to **3,148 people** with or affected by MND

Any Other News

The MND Association Online Forum

The online forum is a 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, follow the link here: https://www.mndassociation.org/support-and-information/our-services/online-forum

MND Matters: The 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.

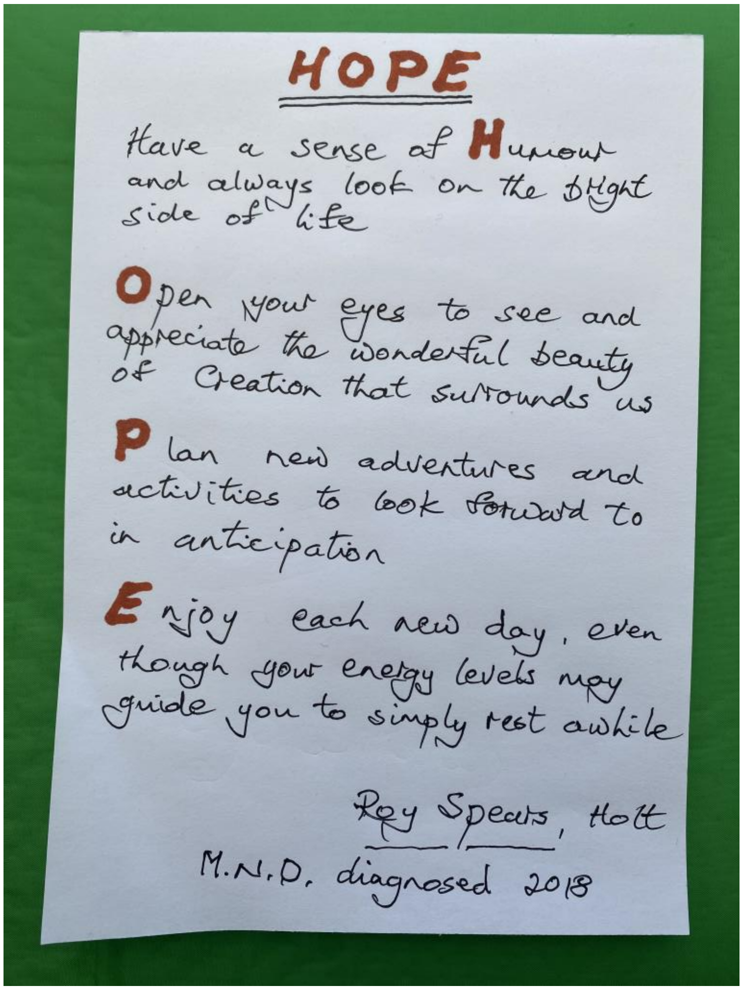
You can catch up with the most recent episode now or listen to previous episodes by following this link: https://www.mndassociation.org/media/mnd-matters or by searching for 'MND Matters' on your chosen podcast platform.

MND Connect Helpline

The MND Connect team offer support and information on all aspects of 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 9:00 am – 4:00 pm. Calls to this number are free from landlines and mobile phones within the UK and do not appear on itemised bills. They are also confidential. Alternatively, you can email the team at 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



HOPE

Have a sense of Humour
and always look on the bright
side of life

Open your eyes to see and
appreciate the wonderful beauty
of Creation that surrounds us

Plan new adventures and
activities to look forward to
in anticipation

Enjoy each new day, even
though your energy levels may
guide you to simply rest awhile

Roy Spears, Holt
M.N.D. diagnosed 2018

Roy's Poem

Opposite is some short verse submitted by Roy Spears, diagnosed with MND in 2018. Roy hopes that his work, written to encourage a newly diagnosed person with MND, helps others in their journey. He considers it a contribution from himself on this challenging route. Many thanks to him for sending it in to us.

Donations & Fundraising

received with thanks

Donations

PEW - £30
JMcM - £20
EG - £9.76
FP - £30
Lions District 105CE - £2,304.75
NB Wife's Family - £70
GB for MND Research - £270

Collection Box

£43.46

Sale of Merchandise

£46.66

Fundraising

Hoveton Summer Fete - £65

Blofield FC imo Paddy Murphy - £2,010
SB Coffee and Cake Morning - £405
Norwich Pétanque Club - £209

Donations in Memory of

Dot Russell - £1,500
Janet May High - £1,500
Alison Jayne Twell - £280.51

Miscellaneous

Bank Interest - £284.20
Gift Aid - £67.62

2025 Coffee Mornings and Afternoons - Held on Wednesdays

October 15th for Notcutts | 29th for Cherry Lane

November 19th for Notcutts | 26th for Cherry Lane | 19th for the Range

Hopefully we won't 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's no need to let us know you're 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'll replace this when you arrive so you're not out of pocket.

Locations:

Notcutts Garden Centre: Daniels Rd, Norwich, NR4 6QP **Time**: 11:00 am – 1:00 pm. These informal gatherings are hosted by Malcolm, Sue, Clare, Anne, and others for people with MND, their carers, and friends.

Cherry Lane Garden Centre: Beccles Rd, Fritton, Gt Yarmouth, NR31 9EU **Time**: 11:00 am – 1:00 pm. These informal gatherings are hosted by Judy and Colleen for people with MND, their carers, and friends.

The Range: Unit C, Hardwick Retail Park, King's Lynn, PE30 4NA **Time**: 2:00 pm – 4:00 pm. These informal gatherings are hosted by Jane and others for people with MND, their carers, and friends.

Online Support Groups:

The Association runs a variety of online support groups for wider geographical areas including the southeast region. Follow the link as dates can be subject to change: https://www.mndassociation.org/online-support-groups. We would like to highlight the Continuing Healthcare support meetings which can be found under the 'Open Across England' tab.

Coffee and Walks for Bereaved Family and Friends

Informal meetups for walks and coffee are taking place bimonthly at 10:30 am in The Restaurant in the Courtyard in Sandringham, PE35 6EN. The remaining date for this year is 13th December.

For more information, please email Jane Lewis at janelewis321@btinternet.com or phone 07887 675458.

Advance Notice of Next Open Meeting

Date: Sunday 16th November 2025

Time: 12:00 am - 4:00 pm

Location: Wortwell Community Centre, Tunbeck Close, Wortwell, IP20 0HS

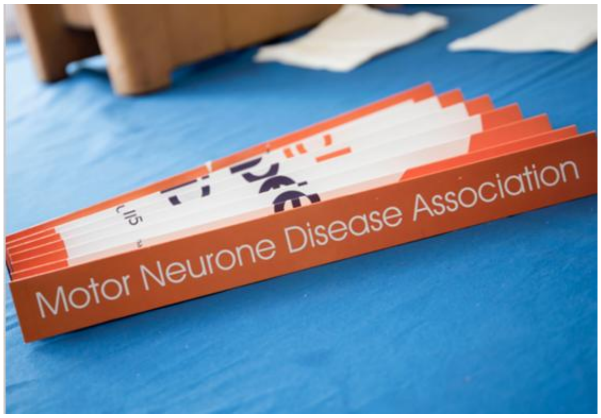
Advance Notice of Next AGM

Date: Sunday 19th April 2026

Time: 1:00 pm - 5:00 pm

Location: St Andrew's Church Hall, 41 Church Lane, Eaton, Norwich, NR4 6NW

Kyle's Story - An Update



In the last edition of Fightback, we reported on Kyle's story, with a petition to urge his local authority to prioritise finding a suitable temporary home to accommodate his disabilities.

Kyle is 14, and is believed to be the youngest person in the UK living with ALS, the most common type of MND. King's MND Care and Research Centre in London is taking part in the FUSION trial, recruiting patients investigating whether a drug, ulefnersen could slow or halt disease progression in patients with FUS-ALS. Although FUS-ALS is very rare, it is the most common cause of ALS in childhood and early adulthood. It is a specific **genetic** form of ALS caused by mutations in the fused in sarcoma (FUS) gene.

Kyle is supporting the trial as a research participant at the NIHR King's Clinical Research Facility. I am sure we all join Kyle in hoping that the results will lead to a positive outcome.

You can read the full article at https://www.kch.nhs.uk/news/14-year-old-als-patient-supports-research-trial-aiming-to-find-new-treatment/

All-Party Parliamentary Group (APPG) on MND

The next meeting of the APPG on MND is scheduled for 12th November. The e-action to invite your MP to attend can be found at https://act.mndassociation.org/2025-11-APPG? which should have been launched by the time you are reading this! Although Sue, the branch campaigns contact, will send an invitation to all the MPs in the Norfolk and Waveney area we know they are more likely to respond to hearing from their own constituents. Please help by encouraging them to attend and learn more about the realities of living with MND, and be kept up to date with our campaigns. We anticipate the Association's new housing report will provide the main focus of the meeting, though of course other issues will be raised.

Prescribe Life Campaign

Tofersen is a revolutionary new treatment that is available for the 2% of people with MND whose disease is caused by a fault in the SOD1 gene. As we reported in the last edition of Fightback, tofersen has been approved by the MHRA (Medicines and Healthcare products Regulatory Agency) for the treatment of SOD1 MND. In the meantime, the manufacturer has made it available to patients through an Early Access Programme, meaning the drug is free of charge as long as the NHS provides the staff time and resources.

More trusts are now providing this support, which is encouraging. However, there are still too many who are failing to provide the treatment because their local services do not have capacity to give it to them via the required monthly lumbar puncture. We continue to call on the Government to take urgent action so everyone who needs tofersen can access the Early Access Programme.

Party Conference Season

Hopefully many of you invited your local MPs to engage with the MND Association at their party conference. The Association sent representatives to the Labour, Conservative, and Liberal Democrat conferences. MPs from other parties were invited to contact Niall Murphy at the MND Association to set up a meeting to learn more about our campaigns and the support they can offer to people living with and affected by MND.

20 Liberal Democrat MPs made time to talk with Association staff at their party conference – though sadly Steffan Aquarone did not appear on the list!

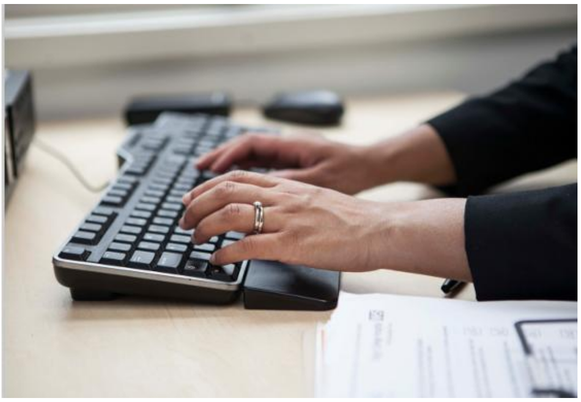
As yet, Sue, campaigns contact, has not seen the names and numbers of attendees talking with Association staff at the Labour Party Conference. However, we can report that the MND Association put genetic testing and precision medicine in focus, hosting our first-ever fringe event on MND at their conference in Liverpool.

The panel at the Labour Party Conference event on MND included our Chief Executive Tanya Curry and trustee Marc Barlow, who is living with MND. The debate centred on what needs to happen across research, regulation and clinical delivery to ensure people with MND have targeted and effective care. The focus on genetic testing ties in with the development of tofersen for SOD1-MND referred to earlier, and to promising trials like the FUSION trial referred to in Kyle's story for FUS-MND. We were also encouraged to hear, at a recent Let's Talk Event, hosted online by the Association for volunteers, that there are a number of other trials in progress looking at targeted treatments for other genetic forms of MND.

The MND Association set out four policy recommendations to remove barriers to genetic testing for people with MND:

- Urgently review and standardise the MND genetic testing pathway, prioritising fast-track testing at the point of diagnosis, consistent referrals, and access to genetic counselling.
- Put in place standardised testing pathways for MND genetic testing in England, Wales and Northern Ireland, supported by appropriate guidance for clinicians and information for patients.
- Ensure the forthcoming NHS Workforce Plan delivers long-term investment in the recruitment, training and retention of the genomics workforce to ensure future demand for genetic testing is met.
- Engage directly with people living with MND, and other conditions with a genetic or inherited component, in the development and implementation of the NHS Genomics Strategy, the forthcoming NHS Workforce Plan, and the NHS 10 Year Plan.

The Conservative Party conference is taking place as Sue writes.



People with MND Help Shape Future of Adult Social Care in Government Review

The MND Association has addressed the independent Casey Commission into adult social care, which will report to the Prime Minister in 2028. Chaired by Baroness Louise Casey, the commission's work aims to make recommendations on reforming the adult social care system to meet current and future needs. It represents a key opportunity to achieve improvements in the care and support available to people living with MND and their families.

On August 27th, Sue joined Association staff, people living with, and people affected by MND at a round table event with members of the Baroness Casey's team to share the key issues many in our community face. The discussion was wide ranging and, at times, emotional. Among the topics covered were access to funded social care services, including the importance of properly funded care packages delivered by skilled and experienced staff; the impact of changing personal circumstances on continuity of care; NHS Continuing Healthcare; Disabled Facilities Grants (DFGs) and home adaptations in privately rented housing. The discussion also touched on the challenges faced by specific groups of people affected by MND, including those who live alone, working age families and older people. It also addressed the difficulties of communication, and the challenges associated with the complexity of systems in place to access support. There was general agreement that for many, social care is essential for maintaining quality of life, and yet current provision for people with MND is often too slow, disjointed, and lacking expertise.

Follow-up meetings were held with individuals. Sue was invited to meet with a member of Baroness Casey's team on 26th September, to talk in more detail about her own experiences caring for her late husband, and also to draw on her experience hearing some of the problems faced by people living in Norwich drawn from the last ten years. The empathy shown by the team member and recognition of the issues raised was encouraging, as was the offer to stay in touch and keep us updated with the work of the Commission.

The Association has made a number of policy suggestions including:

- Mandatory Specialist Training: Equip social care staff with the skills to understand and manage the complex care needs of people with MND.
- Fast-Track Care Assessments: Legislate for accelerated care assessments for people with rapidly progressing diseases.
- Integrated Care Planning: Require joint NHS and social care planning and shared digital records for people with complex conditions.
- Data and Accountability: Improve data collection on MND care access, delays, and outcomes — and publish annual progress reports.

You can read more here: https://www.mndassociation.org/media/latest-news/people-mnd-help-shape-future-adult-social-care-government-review

NHS Funded Continuing Healthcare (CHC)

The work of the Association's CHC Action Group continues, with dates for regular meetings already on the calendar stretching into 2027; CHC will not slip off the agenda!

A reminder for those who haven't heard of CHC: "NHS continuing health care (CHC) is a package of health and social care provided outside hospital, such as in an individual's own home or in a care home, which the NHS arranges and funds. If someone is assessed as eligible for CHC, the integrated care board (ICB) in that person's area must pay for all of their associated health and social care costs. It is for people aged 18 or over who have significant ongoing care needs that arise from a 'primary health need'." This quote is taken from the Nuffield Trust Research report September 2025 *All or nothing? Access and variation in NHS continuing health* care.

The Association webpage with up-to-date information and links to support provides a useful starting point for anyone considering CHC: https://www.mndassociation.org/professionals/management-of-mnd/nhs-continuing-healthcare-chc

Our online CHC peer support group takes place every 6 weeks on Monday from 11:00 am and is a good place to share experiences and find out more. The next meeting is on 24th November 2025. To receive the link please contact chc@mndassociation.org

Our New Campaign on Accessible Housing is Launching Soon

Accessible housing is vital, not a luxury for people living with MND. Stairlifts, wet rooms, ramps and widened doorways are just a few of the many changes that may be needed to increase accessibility, reduce accidents and prevent isolation. Funding for these adaptations is available from local councils in the form of Disabled Facilities Grants. However, people living with and affected by MND face means testing when they apply for a grant, often long waiting times and seemingly endless bureaucracy. The maximum grant in England has not kept up with inflation – it has been £30,000 since 2008!

This is why we are launching a new campaign for accessible housing. If you have a story to share – good or bad – about applying for a DFG, would you like to share it with us? Domonique Dickens, our Personal Stories specialist at the MND Association, would love to hear from you. With your permission, she can help use your experience to support this or other campaigns and, by doing so, potentially help others. You can email her at domonique.dickens@mndassociation.org

Branch Information

Branch Contact

Malcolm Chubbock
01603 960206
malchubbock@hotmail.co.uk
Norfolk, Norwich and Waveney Branch,
c/o MND Association, Francis Crick House, 6
Summerhouse Road, Moulton Park,
Northampton, NN3 6BJ

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 grace.fleming@mndassociation.org

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 **25th February 2026**.

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

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

Website: **www.mndassociation.org**

Registered Charity no. **294354**

Registered Address: **Motor Neurone Disease Association, PO Box 246, Northampton, NN1 2PR**

MND Association National Office: **01604 250505**