

# Fightback

MND Association Norfolk, Norwich & Waveney Branch Newsletter  
Issue 89 October 2022

## 22 June, 2022: A party in memory of Sally Grapes

The party was organised by the book club that Sally co-founded with a group of friends more than twenty years ago. It was held in the garden of one of the members on a beautiful sunny evening in June. They were 'bowled over' by the sponsorship and donations of raffle prizes, some of which are shown in the picture. They were supported by various local businesses, including Jarrold, and by private individuals. The beautiful canapés were kindly provided by Brasteds. The wine was donated by a distant contact.



Rather than using paper raffle tickets they used painted pebbles which are far more attractive! Guests picked a pebble to see if they had won. The beautiful quilt shown was made by one of their members for the silent auction.



The funds generated reached £11,340 which has been shared equally between the Norfolk, Norwich and Waveney Branch to benefit local people living with MND and the MND Association to be spent on research. We were delighted to receive £5,670 to support the work of the branch in our area.

We are very grateful to Polly and Terry who generously gave of their time to do much of the organisation and opened their garden for the party.

An article appeared in the EDP with a lovely photo of Sally.

<https://www.edp24.co.uk/news/obituaries/norwich-book-clubs-tribute-to-sally-grapes-9097770>



## Thursday 7 July 2022 Wymondham U3A Coffee Morning

The coffee morning at Wymondham Central Hall was a very happy, successful and enjoyable event. It was lovely to see such a good attendance, many of whom made a special effort to attend, both branch members (including Bella the Assistance dog) and members of the U3A. Everyone was incredibly generous and together we raised £507.

We really appreciated the team who worked behind the scenes making the tea and coffee and washing up after us. Vivienne (on the right behind the cake table) and her amazing team of bakers produced a wonderful spread of cakes, which raised £175.60 over the course of the day (some were sold at the U3A meeting in the afternoon). The lemon drizzle cake was described as 'lush' – only crumbs remained!



John and grandson encouraged people to take part in our baking quiz and sweepstake, which raised £24 and £112 respectively. We are very grateful to The Community Matters Team at Wymondham Waitrose and Wymondham Garden Centre for their generous donation of the prizes. The winner of the first



sweepstake (pictured with Sue) was very pleased and surprised to win a £10 voucher from Wymondham Garden Centre. We were also pleased to receive two beautiful books, both of which sold during the morning. Donations totalled £69.40 and the sale of Association merchandise (pictured) made up the rest.

We are delighted that the money raised will support our work, but equally to have had the opportunity to raise awareness of motor neurone disease and the work of the branch.

Sue hopes to be back later in the year selling MND Association Christmas cards and merchandise at the Wymondham U3A coffee mornings from mid-October!





## Monday 11 July 2022 Barnard Charity Golf Day, Bawburgh Golf Club

The Barnard Charity Day has been run by the golf club for the past 30 years in support of various local and national charities, and has raised more than £250,000 during this time. The annual Barnard Charity Golf Day held at Bawburgh Golf Club raised an amazing £10,500.00 this year for the Norfolk, Norwich and Waveney Branch and Bawburgh Primary School.



We are thrilled to have received £8,000 of the total, and would like to thank everyone who made this day possible including Robert Barnard (pictured here with some of the many awards), the members of staff, the volunteers and teams. We are also grateful for a donation of £200 from the club's charity fund (BAGS). It was a really happy and successful day.



The golfers – and volunteers – were kept well fed with bacon butties mid-morning, refreshments at the half-way house (as pictured) followed by a splendid barbecue in the evening.

Twenty three teams took part on the day, raising money through team entries.



Malcolm's brother, Neville, entered a team named *Three pars and a bogey*, with one of the team (pictured on the right) winning an award.



Money was also raised through sponsorship opportunities, a putting competition, raffle and silent auction. A number of golf clubs across East Anglia supported the silent auction with donations of golf days as you can see in the photo on the previous page.



The day was rounded off with the presentation of the awards. This year's winning team was William H Brown – Simon Arnes, Giles Hart, Chris Rosindale, and Simon Richardson with a fantastic score of 99, seen pictured here.

We would like to thank everyone for their generosity and involvement on the day, including our team of volunteers and volunteers from Bawburgh school, the twenty three teams that entered and the many people who made donations. Special thanks must go to Lovewell Blake for their continued support as main sponsor, as well as William H Brown, Floorbox, Collier Turf Care, BAGS, Mike Devlin and Caroline Blincoe. Molson Coors, Heineken, Adnams, Barsham Brewery and Peter Grahams Wines gave additional support.

From left to right Malcolm, Sue and Trish are pictured receiving a cheque for £8,000 from Robert Barnard accompanied by Jamie, who did so much to make the day a success.

### Sunday 7 August 2022 Hoveton Village Charity Fete



The Hoveton and Wroxham Lions Club organised a Charity Fete and kindly gave the branch a stall free of charge. Whilst we didn't raise a lot of money it was a good opportunity to speak with people and raise awareness of the MND Association and the work of the branch.

We were very grateful for the donation of a beautiful quilt, which you can see hanging at the back of the stall.

Guess the name of the toy eagle proved very popular. Mary Phillips, who was for many years the secretary for the neurology team at the Norfolk and Norwich University Hospital, kindly drew the winning name – Abigail.

Our thanks to everyone who volunteered on the day, especially Grace who also did a lot behind the scenes.



# Future events in aid of the Association

## Saturday 29 October 2022 Quiz night at Cawston Village Hall

Lynda Hind is organising a Quiz Night with ploughman's and pudding to raise money for the branch. It will take place at Cawston Village Hall, Cawston, NR10 4BW on Saturday 29 October starting at 7:30pm. Teams of up to 6 people are welcome, £10 per person includes supper (bring your own drinks).

The hall is a wheelchair accessible venue, please phone Lynda on 01603 879135 if you would like to enter a team. It should be a fun evening, she looks forward to seeing you there!

## **Take a Bow** – *thanks to the following for donations received by the branch*

- Anonymous donations - £293.93
- AC donation - £10
- Hoveton & Wroxham Lions Charity Day - £84.37
- LS, raffle at Sunnyfields Jubilee Party - £85
- ML, donations at Street Party in memory of John Orgill - £200
- Martin Burnell, 25% of proceeds at a car boot sale - £110
- Upton Open Meeting, raffle - £85
- Upton Open Meeting, sale of merchandise - £54.50
- 'Joyce Grenfell' - £10
- NFU Mutual - £3,189.50
- Sale of merchandise - £8

- G & DM, collection box at Blakeney Deli - £73

### **Donations in memory of**

- Cheryl Bell - £440
- Colin Burnell - £80
- Joyce Chamberlain - £25
- Agnes R. Davy – £421.72
- Colin Matthews - £777.23
- Dave Siggins - £25

### **Internal transfers**

- JustGiving - £183.75
- JustGiving Branch Emergency Funds page - £375
- Gift Aid - £75

We are extremely grateful for the donations totalling £724.52, which have been made to National Office for transfer to the Branch.

*My apologies to those who have made donations but whose names have not appeared, these figures will appear in the next edition.*

## **A donation from the Eliel Community First Revenue Fund**

The Branch is very grateful to have received a donation of £500 from the Eliel Community First Revenue Fund supported by Norfolk Community Foundation. The money, received in August 2022, is to be used to contribute towards operational costs. Branch funds help support people living with motor neurone disease, their carers and family, as well as covering the costs of open meetings and producing our newsletter.



Norfolk Community Foundation is an independent, registered charity that bridges the gap between those in need and those who can help. As part of a national movement of Community Foundations, Norfolk Community Foundation is working together with local philanthropists to make a difference to lives in Norfolk [www.norfolkfoundation.com](http://www.norfolkfoundation.com).

## **A reminder – we are still recruiting volunteers!**

We always need more Association Visitors (AV). You can find out more about the AV role and apply online at <https://bit.ly/3bmUUtb>. Training and induction will be provided and travel/direct cost expenses are reimbursable.



However, there are many other roles that might be of interest, and others that could be created to suit your skills.

Sue Heal, who has been editing and printing the newsletter for ten and a half years, plans to step down as **newsletter editor** after we have recruited a replacement.

Mike has been a wonderful volunteer **webmaster** since the branch first launched its standalone website in 2014. He has announced his decision to retire at the end of this year, can you help? This role involves having the computing capability rather than writing the information to be put online. We would also appreciate some help with our **Social Media**.

## Useful information

**The Norfolk Assistance Scheme** helps people, regardless of their state of health, who are in financial hardship and cannot pay their living costs, for example whilst waiting for benefits or other entitlements to be sorted out. You will need to complete an application with evidence of your financial situation.

You can apply online at <https://www.norfolk.gov.uk/care-support-and-health/support-for-living-independently/money-and-benefits/norfolk-assistance-scheme>.

If you cannot complete an online application call 0344 800 8020.

**New Norfolk palliative care line opens** a new service offering palliative care advice to people across parts of Norfolk is now operating. Patients, families and carers can call 0330 158 8011 and select option 2. The service is available 365 days a year for patients in Norwich, North, South and West Norfolk. It will be run by the Norfolk Community Health and Care NHS Trust Specialist Palliative Care team.

In Great Yarmouth and Waveney, the 24 hour advice line number will stay as 0800 567 0111.

A specialist palliative care nurse can talk through your situation, and give both advice and information. They can also refer you to an on-call palliative care consultant and arrange follow-up help from community nurses or your GP team.

**Able Community Care** is a nationwide, live-in care provider established in 1980. Since 2019 they have given out free 'DO NOT KNOCK' door stickers to people who do not wish to answer the door to strangers. If you would like to receive one Sue has been given a small supply and will make them available at Notcutts and Wortwell. Although they contain the contact details of the company this should not be considered an endorsement by the MND Association.



**Holiday accommodation** Here are two links to holiday cottages in Norfolk that say they provide accessible accommodation for wheelchair users. They have been provided by an Association Visitor in the Cambridgeshire Branch, however, as usual we must add the proviso that this does not form a recommendation from the MND Association.

[www.church-farm-barns.co.uk](http://www.church-farm-barns.co.uk)      [www.hunstantoncottages.com](http://www.hunstantoncottages.com)

There is also a website called Ceiling Hoist Users Community which has a section on self catering holidays and hotels [www.chuc.org.uk](http://www.chuc.org.uk) under the tab *Accommodation*.

## News from National Office

**Care Information Update:** The following care information sheets have been updated:

1A – The National Institute for Health and Care Excellence (NICE) give recommendations about the treatment, care and support people with MND should expect to receive

8A – Support for breathing problems

8B – Ventilation for MND

8D – Air travel and ventilation for MND

You can request printed information sheets from the Care Admin team on 01604 611685 or by emailing [careadmin@mndassociation.org](mailto:careadmin@mndassociation.org). Alternatively they can be downloaded from <https://www.mndassociation.org/about-mnd/information-resources/>.

You can find a range of information using the new search feature on the MND Association website. It is designed to help you find information by need and list resources by subject. See the Care Information Finder at [www.mndassociation.org/careinfofinder](http://www.mndassociation.org/careinfofinder).

**Fundraising:** If you would like to talk to someone about fundraising please phone 01604 611860 or visit <https://www.mndassociation.org/get-involved/fundraising/>.

If you set up a JustGiving page, and would like the money raised to support the Norfolk, Norwich and Waveney Branch, please make it clear that we should be the recipient. Please let us know about your events if you are happy for us to share the news.

The Association regularly launches fundraising challenges. Read more on social media to see what is new at <https://www.facebook.com/mndassociation/> and <https://twitter.com/mndassoc>.

## Updates from the Norfolk MND Care and Research Network

**Factor-MND research study** by Polly Trucco

We would like to invite you to take part in the **FACTOR-MND** research study. This study investigates how the experience of being a family carer for someone living with MND impacts the carer's own wellbeing. Our results will help inform current MND services, and future carer support services.

Current MND carers are invited to complete an online survey at <https://uea.onlinesurveys.ac.uk/factor-mnd>. If you prefer a pen and paper version of the survey, please contact Polly Trucco (see contact details below). We are really pleased to share that 58 family carers have completed the **FACTOR-MND** survey to date. Our target is 92 carers, and we will be recruiting family carers until the end of this year. If you are interested in taking part and sharing your experiences, we would love to hear from you.

We are also inviting current carers to participate in an online or face-to-face interview about their experiences of caring for the person they support, and how they are coping with everyday changes. If you wish to take part in this interview study, please contact Polly Trucco for further information. A carer who took part said, "it was lovely to talk about these experiences, I've been heard and we need support in this area".

Contact details: Polly Trucco email [mnd.research@uea.ac.uk](mailto:mnd.research@uea.ac.uk) or phone (+44) 07825863389 @FactorMND

*A huge thank you to all the people who have already taken part in FACTOR-MND!*

# Campaigns

**Cost of living crisis; Personal stories:** Do you know somebody living with or affected by MND and struggling due to the cost of living crisis? We understand the current support is inadequate and people in power need to hear from you so they understand. We are looking for some personal stories on how the cost of living crisis is affecting people living with MND. If you're interested in sharing a story, please email [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org).

The Association is supporting the Joseph Rowntree Foundation's campaign to raise awareness of the current cost-of-living crisis. Following the publication of their report, which aimed to highlight current hardships, the Association has signed a joint letter alongside various charities urging the new Prime Minister to increase the current support package for those on means-tested benefits. The letter also emphasises the need for the new administration to commit to making debt reduction rates from benefits more affordable.

Read the Joseph Rowntree Foundation's full report here <https://www.jrf.org.uk/press/new-evidence-'year-financial-fear'-being-endured-uk's-low-income-families>.

**Social Care Isn't Fixed:** The Association echoes calls made by the Levelling Up, Housing and Communities Committee that Adult Social Care needs an immediate funding injection and long-term plan. It continues to work as a member of the Care and Support Alliance to highlight how social care isn't working for people living with MND and their carers.

You can read more about it at <https://committees.parliament.uk/committee/17/levelling-up-housing-and-communities-committee/news/172670/adult-social-care-needs-immediate-funding-injection-and-longterm-plan-says-levelling-up-committee/>.

**#United2EndMND:** After a long period of negotiations, the United to End MND Coalition has reached a compromise with Government officials on how the promised £50 million funding into targeted MND research will be accessed. Originally, the coalition of patients and charities wanted the Government to recognise that the most efficient way to develop the national coordinated infrastructure is via single application. However, whilst a single application isn't possible, three to four applications will be made by scientists every year to access the £50 million funding. By cutting down the bureaucratic burden of several applications, this will provide scientists with more time to spend finding a cure for MND.

We were really pleased to see that Boris Johnson reiterated the Government's commitment to our United to End MND campaign before stepping down as Prime Minister. He has ensured that the £50 million funding for targeted MND research will be ring fenced and available to researchers during the new administration. This was also confirmed in Hansard on 5 September. You can read more at <https://united2endmnd.org/2022/09/07/important-uk-government-statement/>.

**Update on the Scrap6Months campaign:** The Social Security (Special Rules for End of Life) Bill has completed all stages in the House of Commons on the 8th of September and is now waiting to receive Royal Assent before it is passed into law. As a result, more people living with MND and other terminal conditions will be able to access financial support quickly and easily, without going through lengthy assessment processes. We would like to thank everyone who helped achieve this success.

You can read more at <https://www.mndassociation.org/scrap-6-months-success/>.





**Act to Adapt:** The campaign has three main aims to:

- Introduce a fast-track process for people with MND
- Remove financial assessments for Disabled Facilities Grants for people with MND
- Maintain a register of accessible homes for people to move into

In August, the national campaigns team wrote to every councillor in England with a responsibility for housing asking them to review existing housing assistance policies and administration of Disabled Facilities Grants (DFGs) to ensure the local authority is meeting the needs of people living with motor neurone disease (MND). This comes after updated DFG guidance issued by the Department for Levelling Up, Communities and Local Government was released earlier in the year – as reported in an earlier edition of Fightback. The guidance published for local authorities in England contains clear and specific recommendations to help councils best support constituents living with MND to access safe and accessible homes. Locally we continue to talk with councillors in our area about the needs of people living with MND.

**NHS Continuing Healthcare:** This item also appeared in the last two editions of Fightback. Continuing Healthcare (CHC) is a package of care arranged and funded by the NHS. It is available to people who have been assessed as having a ‘primary health need’.

Whilst some people receive wonderful support through CHC we are mindful of the difficulties some people face accessing CHC and problems around sourcing appropriately trained carers. Always speak with us if you are experiencing difficulties as, whilst we don’t have a magic wand, we may be able to help.

The Association has produced a useful guide to CHC, which you can download – alternatively phone MND Connect 0808 802 6262 to request a copy of the information sheet.

<https://www.mndassociation.org/app/uploads/2015/06/10D-NHS-Continuing-Healthcare.pdf>

The Association is looking to improve people’s awareness of CHC and their experience of accessing care. Work is already underway to review the information that we provide and the ways in which it can be more widely publicised both for people living with MND, volunteers and health and social care professionals. We are also looking at ways in which people might best be supported during the application process. We continue to work closely with the Continuing Healthcare Alliance and other charities.

*Research by Dr Aidan Nicholson*

### **Therapy**

#### **B12 Slows Functional Decline in Early Stage MND – June 2022**

Recent results from a stage 3 trial in Japan have corroborated with a previous phase 2/3 trial pointing towards the potential use of ultrahigh dose methylcobalamin (the active form of vitamin B12) in the treatment of early stage MND. In the phase 2/3 trial although there was no initial obvious difference between the placebo and B12 group after further analysis people with early MND had a much slower disease progression when on B12 rather than the placebo. A year later a phase 3 trial was performed where 90% of the participants were also taking riluzole. A 43% decline in ALSFRS-R scores (a MND function rating score) was observed in the B12 group and a 45% slower decline in participants taking both B12 and riluzole. Although these results are promising, researchers cautiously note that future studies with a larger sample are needed to confirm.

See more at: <https://alsnewstoday.com/news/high-dose-b12-slows-functional-decline-early-stage-als-data-show/>

### **Tegoprubart Enters Phase 2 Trial Showing High Promise – June 2022**

According to new data from a Phase 2a clinical trial, tegoprubart, a new antibody-based therapy effectively reduces levels of inflammatory biomarkers in people with MND. Further findings suggested that the lower levels of biomarkers were associated with slower disease progression. Tegoprubart is a lab made antibody administered intravenously. It is designed to suppress inflammation of neurones by preventing the interaction between two types of immune cells, CD40 ligand and CD40 receptor. The binding of these two immune cells have been shown to boost pro-inflammatory responses and the signalling between these two were found to be increased in 56% of MND patients in past studies. Additionally, levels of CD40 ligand in a person with MND's circulation was found to be associated with increased rate of progression. It is hoped that future trials with this new medication bring forward more promising results.

See more at: <https://alsnewstoday.com/news/markers-als-disease-progression-shown-reduced-tegoprubart-trial/>

### **Feasibility Trial started to test Terazosin – August 2022**

Research at the University of Edinburgh has shown that the medication terazosin protects against the death of motor neurones in zebrafish, mice and stem cell models by increasing energy protection. Terazosin works by increasing an active enzyme in cells called PGK1 involved in the production of energy. Motor neurones grown in a dish were shown to be protected when terazosin was introduced by increasing the cells energy levels. Additionally in mouse models of MND it has shown to improve survival and delay the progression of paralysis.

These encouraging results have led to a small feasibility trial to test Terazosin in MND. The study has begun recruiting 50 participants from the Oxford MND Care Centre. Terazosin is already approved to treat high blood pressure and benign prostatic hyperplasia, an example of how an existing drug could be repurposed for MND.

See more at: <https://news.sky.com/story/important-new-step-in-finding-treatment-for-motor-neurone-disease-scientists-reveal-12669932>

### **Real-World Data Analysis of Survival with Edaravone Announced – August 2022**

Results from a paper analysing the use of intravenous edaravone treatment in MND and survival has suggested that continued treatment with edaravone in people with MND was associated with prolonged survival compared to those not treated with the drug. A more in-depth description of results showed that treatment with edaravone was associated with a six month longer median survival compared to those not treated with edaravone. Additionally, risk of death was 27% lower in those treated with edaravone compared to those who weren't. Although exciting it is important to note that the results of the study cannot be generalised and do not provide definitive conclusions about the effects of treatment. However, it is a promising step-forward in the treatment and hopefully an eventual cure of MND.

See more at: <https://www.mt-pharma-america.com/2022/08/15/mitsubishi-tanabe-pharma-america-announces-real-world-data-analysis-of-survival/>



## **EU Funding Helps Advance a Prototype Vaccine for C9orf72 MND – July 2022**

Intravacc and DZNE both world leading organisations in the development of vaccines have been granted funding of 2.5 million euros from the EU to develop a prototype for an MND vaccine. DZNE have developed a vaccine which instructs the immune system to produce antibodies against harmful molecules which may contribute to the development of MND. This would only be effective in patients with the specific gene C9orf72 who, even when asymptomatic, are at risk of developing the condition. It is hoped similar vaccine concepts could be applied to related conditions such as frontotemporal dementia.

See more at: <https://www.prnewswire.com/news-releases/intravacc-and-dzne-awarded-eu-funding-to-develop-vaccine-against-genetic-als-variant-301580780.html>

## **Aetiology**

### **New Publication Finds a New Key Deficit in MND – August 2022**

New research findings have found that deficits in axonal transports have been detected at pre-symptomatic stages of mouse models of MND. This would suggest that impairments in this process are key to the formation and progression of this condition. Axons are the ‘messengers and connectors’ between neurones closer to their origin (central and peripheral nervous system) and further away (e.g. hands and feet). This new data seems to indicate that in patients with the SOD1 gene specific types of motor neurones (fast ones) aren’t able to signal to their partner neurone. The significance is that this research has identified a new key deficit in MND which can be used as a target for future treatment.

See more at: <https://actaneurocomms.biomedcentral.com/articles/10.1186/s40478-022-01418-4>

### **A Viral Protein Called HERV-K ENV has been Implicated in MND – July 2022**

Ancient viruses (called retroviruses) entering our bodies throughout generations are thought to have changed and left their genetic footprint in our DNA. One of these retroviruses, called HERV-K, is thought to contain the schematics of a protein called HERV-K ENV which when reactivated could lead to the development of MND. New research has found that neurones with HERV-K ENV have led to the reduction in overall neurone survival and that the ones that survived were damaged. However, new antibody treatment called GN-K01 which binds to this protein has been developed in order to prevent these toxic effects. It is hoped that further trials of this treatment will assess its safety for use as a future treatment of MND.

See more at: <https://onlinelibrary.wiley.com/doi/10.1002/ana.26452>

**Take part in research:** The best advice is to talk with your care team to find out which research studies are recruiting locally and are appropriate to your situation.

**A study with a difference recruiting now:** A researcher from Imperial College London is looking for people living with MND and people over 65 to take part in a study aimed at developing new technologies to help people with long-term disease live in their homes for longer. Taking part involves a 2.5 hour visit to Imperial College in London to complete a range of activities in an artificial apartment kitted out with smart technology, called the Living Lab. If this is something that interests you then find out more – including sign up details at

<https://www.mndassociation.org/research/get-involved-in-research/take-part-in-research/living-lab-protocol/>

**Online research pages:** Find the most up to date research news at <https://www.mndassociation.org/research/latest-news/>

Find information on MND clinical trials, including the latest news, recruitment status, outcomes at <https://www.mndassociation.org/research/clinical-trials/treatment-trials/>.

Alternatively phone the Research Development team on 01604 611880 where you can ask about opportunities to get involved

### **Coffee mornings – now we can offer greater choice of groups**

**The branch will continue to offer monthly coffee mornings on Zoom** from 11:30 – 13:00 on the third Wednesday of each month until the end of 2022. In 2023, the coffee mornings at Notcutts will take on the regular slot on the third Wednesday. The online meetings will be on the second or fourth Wednesday of the month – see 2023 dates. They will continue to be friendly informal gatherings hosted by Sue, and other volunteers, for people with MND, their carers and friends, there is no agenda. You can drop in at any time and leave when you need.

Dates for 2022: 19 October 16 November 14 December

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

**Coffee mornings at Notcutts**, Daniels Road, Norwich, Norfolk, NR4 6QP, from 11:00 – 13:00 on the following Wednesdays. These informal gatherings are hosted by Malcolm, Sue and others, for people with MND, their carers and friends.

Dates for 2022: 12 October 23 November No meeting in December

**Coffee mornings at Fritton Village Hall**, Hill House, Beccles Rd, Fritton, Great Yarmouth NR31 9HB from 11:00 – 13:00 on the following Wednesdays. These informal gatherings are hosted by Judy and Colleen for people with MND, their carers and friends.

Dates for 2022: 26 October 30 November No meeting in December

Hopefully we will not need to cancel any meetings due to COVID-19 or other circumstances; updates will appear on <https://www.mndnorwichandwaveney.org.uk/events.htm>. There is no need to let us know you are coming to the coffee mornings.

**Evening online support group for carers of people with MND.** These meetings take place on the last Wednesday of the month at 6:30pm – the next will take place on 30 November. If you would like to be emailed the zoom link please contact [alli.anthony@mndassociation.org](mailto:alli.anthony@mndassociation.org) or [carmen.brown@mndassociation.org](mailto:carmen.brown@mndassociation.org).

**Daytime online support group for carers of people with MND.** These meetings are run by one of our Area Support Coordinators, you are invited to join a virtual cuppa for a friendly chat with other carers of people with MND in London and the South East. Meetings take place on the first Tuesday of each month at 11:00am. For more information and to receive the zoom link please contact [ahmed.abdeldayem@mndassociation.org](mailto:ahmed.abdeldayem@mndassociation.org).

Dates for 2022: 1 November 6 December

**Under 50s Group.** These meetings are for people with MND under 50 and their loved ones. This friendly group provides an opportunity to meet others in a similar position, exchange information and share knowledge. Meetings take place on Zoom every fourth Tuesday of the month at 6:30pm. For more information and joining details please contact [ahmed.abdeldayem@mndassociation.org](mailto:ahmed.abdeldayem@mndassociation.org) or [david.whalley@mndassociation.org](mailto:david.whalley@mndassociation.org).

Dates for 2022: 25 October 22 November 13 December



## Advanced dates for Branch Coffee Mornings 2023 – all on Wednesdays

<b>January</b>	Online 11 January; Notcutts 18 January; Fritton Village Hall 25 January
<b>February</b>	Online 8 February; Notcutts 15 February; Fritton Village Hall 22 February
<b>March</b>	Notcutts 15 March; Online 22 March; Fritton Village Hall 29 March
<b>April</b>	Online 12 April; Notcutts 19 April; Fritton Village Hall 26 April
<b>May</b>	Notcutts 17 May; Online 24 May; Fritton Village Hall 31 May
<b>June</b>	Online 14 June; Notcutts 21 June; Fritton Village Hall 28 June
<b>July</b>	Online 12 July; Notcutts 19 July; Fritton Village Hall 26 July
<b>August</b>	Notcutts 16 August; Online 23 August; Fritton Village Hall 30 August
<b>September</b>	Online 13 September; Notcutts 20 September; Fritton Village Hall 27 September
<b>October</b>	Online 11 October; Notcutts 18 October; Fritton Village Hall 25 October
<b>November</b>	Notcutts 15 November; Online 22 November; Fritton Village Hall 29 November
<b>December</b>	Online 13 December.

## Branch News

**Open Meeting:** Sunday 13 November 2022, 12:00 – 16:00 at Wortwell Community Centre, Tunbeck Close, Wortwell, IP20 0HS. We will be providing a cooked lunch around 13:00, the time beforehand is for conversation and provides an opportunity to purchase Christmas cards. As always we will hold a raffle and have Association merchandise for sale.

**Advance Notice of AGM and Open Meeting:** Sunday 23 April 2023 12:30 – 16:00, will be held at St Andrews Eaton Church Hall, Church Lane, Norwich, NR4 6NW. We will be providing a hot lunch. A guest speaker will be confirmed nearer the time.

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

We are always happy to add information about events you are planning in support of the Norfolk, Norwich and Waveney Branch.

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

**Twitter:** [@MNDANorWave](https://twitter.com/MNDANorWave)

**Instagram:** [@MNDNorfolk](https://www.instagram.com/MNDNorfolk)

**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 **10 February 2023**.

**MND Connect** – 0808 802 6262. If you, or someone you know, has MND and you need help, information or support, call the MND Connect Helpline (Monday to Friday, 09:00 to 17:00 and 19:00 to 22:30) or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

**Area Support Coordinator** Liz Cooper 01604 800620 [liz.cooper@mndassociation.org](mailto:liz.cooper@mndassociation.org)

**MND Coordinator** Helen Copsey 01603 647221 [helen.copsey@nnuh.nhs.uk](mailto:helen.copsey@nnuh.nhs.uk)

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**Care Service Navigator** Trish Moore 07813 094820 [trish.moore@mndassociation.org](mailto:trish.moore@mndassociation.org)

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

**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.