

Fightback

MND Association Norwich & Waveney Branch Newsletter
Issue 72 February 2017

Save the dates for our Open Meetings and Coffee Mornings!

Events in aid of the MND Association

25th September 2016, Cricket supports the MND Association by James Skilleter

The annual memorial cricket match for Richard O'Flaherty was held on Sunday 25th September at Ashby Cricket Club near Thurton against the James Skilleter XI. Team photos and a one minute silence preceded a 25 over match played in good spirit. Richard's brother Chris was in attendance to support the match.

Ashby batted first but only Pepper (12) managed double figures from the top six as accurate bowling from Simon Key (3-5) and 11 year old Oscar Skilleter (3-13) saw the Ashby batsmen struggle on a useful pitch. A late rally from Rusted (22) and Jakeman (12) took the home tally on to 92 before they were all out. Dan Littlechild took 2-12, with other wicket takers being Dan Taylor & Andy Baker.

In reply the Skilleter XI made a rapid start as brothers Lewis & Dan Taylor put the Ashby bowlers to the sword. Lewis (28) found the boundary four times including two huge sixes and Dan (25) found the boundary five times. Once both these retired, junior brothers Oscar Skilleter and 13 year old Harry Skilleter took over. Oscar was bowled for 2 but Harry played a mature innings of 17 also finding the boundary twice. Littlechild (4) came and went before Douglas Young (11 not out) and James Skilleter (4 not out) saw the Skilleter XI home by 7 wickets. Paul Thorburn was the stand out bowler for Ashby with 3-10.

The presentation of the shield to winning captain James Skilleter was made by Alan Cook along with Chris O'Flaherty. This was followed by a raffle. A total of £324 was raised for the MND Association. Thank you to everyone who came and supported the event.



2nd October 2016, MND Association Dog Walk

Jo Fuller organised a sponsored dog walk in support of the MND Association. The walk began at the Avenue Pub, Great Yarmouth, pictured on the following page. Jo suggested that perhaps a former MND patient was looking down on them as the sun shone and the weather could not have been better. The day went well! The walkers, with 16 dogs in total, raised £400. Thank you to everyone involved.



8th October 2016, Charity Autumn Ball

All those able to attend the Ball, at Marriott Sprowston Manor, had a very enjoyable evening. It was a lovely opportunity for friends to meet and chat, and in many cases remember those who have lost their lives to Motor Neurone Disease. Thank you to David Willis who provided the paparazzi experience where everyone was able to have their photo taken. The photos of people in their finery are available on the branch website; those who bought tickets to the Ball can use their password to download them. Thank you also to Cilla who delivered the beautiful floral displays.

The three course meal seemed to be enjoyed by all. Raffle prizes were drawn after we had eaten – Anthony and Lorna were delighted to win the first prize – the use of a Mini for the weekend. There was great interest in the bidding for football shirts with prices paid reaching £100+. We were entertained throughout by the Tesla Jets and a local DJ who provided music through to 1am when the dancing ended! We thank them for providing their services free of charge enabling more of the ticket price to be donated to the MND Association.

We would also like to record our huge thanks to Amie Godfrey for masterminding the organisation of the evening, and to those who helped behind the scenes. Thank you to Roger Widdecombe, Regional Fundraiser for East England, who provided support and joined us, with his partner, on the night. Thanks also go to those who provided prizes for the raffle, and to those who bought tickets and helped make the evening such a success. The evening raised £2,261.65.

29th October 2016, Inspire Races Steeplechase

The steeplechase, at Blackwater Farm, Great Witchingham, was a fun obstacle race involving mud and water wades in addition to the obstacles! It was possible to opt for a 5km or 10km race and what their website describes as 'The Notorious Pumpkin Run'. The weather was good, thankfully it didn't rain! Money was raised from the sale of cakes, a bucket collection, from people giving massages, the RAF display and from the sale of surplus pumpkins. In total £1,371.46 was raised for the branch. Thank you to Jodi and Ian Welch who organised the event.



The photo shows Penny, Malcolm and Judy, who performed the bucket collection on the day.

30th October 2016, Charity Football Match



Karley Block organised a Charity Football Match in memory of her father Mitchell, who died from MND in 2015. The 10:30am kick off took place at Wenhaston Playing Field between teams from Wenhaston and Halesworth; Wenhaston FC beat Halesworth FC 4-1. The photo above shows both sides and referee before kick off.

The match was followed by a barbecue and raffle at Chippy's Sports Club in Halesworth. Malcolm attended on behalf of the branch, and took with him the Norwich City shirt that he had successfully bid for at the Autumn Ball – it was auctioned off after the raffle and made £142. The shirt, shown in the photo, was bought by another Norwich City fan and shows from left to right Sonia Ablett, Angie Sankey (who bought the shirt) and Wendy Hotchkiss.



The final sum raised was £1,834.72. That really is a great result; we would like to thank everyone who was involved in the event. A cheque was presented to Malcolm at Chippy's bar on the 1st of December. From left to right the photo shows Malcolm, Sonia Ablett, Paul Ablett, Karley Block and Carl Chinnery. Carl is the licensee of Chippy's Bar who generously added £100 to the sum raised at auction for the Norwich City shirt bringing the total to £242.

6th November 2016, Christmas Charities Fair

It was lovely to receive an email thanking the Norwich & Waveney branch of MND Association and our team of volunteers (Cilla Godfrey, Shirley Basey-Fisher, Sue and Jo Heal) for taking part in the Charity Christmas Fair at GreenAcres Woodland Burials, Colney. Together the Charities raised approximately £900.

Our stall raised £198.20, the highest stall total, which was very pleasing! We hope you agree that the stall (as pictured) looked very good, and that the new merchandise produced by the MND Association is of interest to many – certainly the bags help to raise awareness of the disease.



Beth, who was responsible for organising the day wrote, “It was a great day with a fantastic atmosphere, and more visitors than last year too (125+!), despite the pouring rain in the afternoon.” We enjoyed the event and were pleased with the result. GreenAcres provided match funding for £50.

This is the last Christmas Charities Fair organised by GreenAcres, although they will continue to welcome charities and organisations to hold events there. We are very grateful to them for allowing us to have a stall for many years.

7th November 2016, Duke of Wellington

Thank you to Sandra Mahn and the managers of the Duke of Wellington on Waterloo Road, Norwich. Initially they put MND Association collection boxes in their pub for six months from the start of September 2015 – but then kept them there for longer. They also hosted some fundraising events on our behalf and in memory of Sandra's brother who was living with MND.

When we first publicised the location of the collection boxes we hoped their clientele would be generous – indeed they were! On Monday 7th of November Malcolm went along to receive a cheque for £625. The photo shows him receiving the cheque from Sandra Mahn with Kay Edwards, licensee of the Duke of Wellington. Once again our thanks to everyone who helped raise funds and awareness of MND.



Sunday 20th November 2016, Wortwell Open Meeting

Forty people attended our open meeting at Wortwell. Hot drinks were offered on arrival. There was plenty of time to socialise and to meet with Alun Owen, Chair of the Board of Trustees. A number took the opportunity to buy Christmas cards and MND Association merchandise, and of course raffle tickets!

The Butchers Shop Swanton Morley cooked and served an excellent lunch of turkey with all the trimmings, a selection of vegetables, roast and new potatoes, followed by a traditional Christmas pudding with cream. The tables were decorated to provide some early festive cheer, and with some encouragement most pulled their Christmas crackers and donned party hats! There was a lovely atmosphere.

Terry and Linda gave a brief demonstration of the safe sip cup covers that Terry likes to use. Linda's first attempt caused everyone to laugh as she kept the straw straight and gave Terry an unexpected shower! With the straw bent the cup covers prevent the cups from leaking when they are knocked over. This should not be taken as an endorsement of the product by the MND Association, but if you are interested to see what it looks like then follow the link to <https://www.facebook.com/SafeSip/>. Terry then introduced Alun by suggesting that this was the time to leave or go to the bathroom – a little harsh!!



Alun gave a short address in which he spoke of his partner's death from MND. This motivated him to get involved with his local branch, and then later putting himself forward unsuccessfully to become a trustee. Fortunately for us all he was successful on his second attempt, and is now the Chair of the Board of Trustees. It was at this point that he realised that he could go to jail if ever there were problems with the Association, a powerful incentive to ensure that everyone involved behaves with integrity. He outlined some of the Association's achievements over the past years – and congratulated the Norwich and Waveney Branch on completing its first 21 years and raising £1,000,000 during that time. Malcolm was one of the founding members of the branch and still puts enormous energy into his role as Chairman.

26th November 2016, Bucket Collection at Notcutts

A team of 6 volunteers braved the cold on a Saturday in November to collect in aid of the Norwich & Waveney Branch of the MND Association. The grand total raised was £242.79. We were pleased to meet volunteers from Marie Curie, who were also holding a collection at Notcutts, and to learn a little more about their work. Marie Curie provides care and support to people with terminal illnesses and their families, including people living with MND in Norfolk.

We have agreed to hold a further bucket collection at Notcutts – any one who would like to volunteer to help should contact Sue Heal by email. The date is yet to be confirmed.

15th December 2016, Charity Giving Night

Francis of Lorraine Lodge No 6906 is based in Norwich and the picture shows the Charity Steward Peter Leggett (left) and Worshipful Master David Clarke (right), presenting the £500 donation. This was part of a Charity Giving Night where a total of £6,000 was donated to eleven local charities. The money was raised by the members, friends and families at lodge meetings, social events and personal donations.



Sue and Jo Heal were pleased to attend the event to collect the cheque on behalf of the branch; we were made very welcome. Sue was invited to say a few words about the work of the MND Association. We are very grateful for their contribution to our work.

21st December 2016, VivaVoices Support the MND Association

For those of you living in Suffolk, this is just a flavour of the wonderful fundraising supported by the MND Association Suffolk Fundraising Group. Graeme Hopson and his choirs, who sing under the name VivaVoices, raised £2,300 for the MND Association at their concerts spread across Norfolk and Suffolk. This is a record amount for them to raise in their concerts. The photo shows Janet Oliver receiving a cheque from Graeme.



Future events in aid of the MND Association

24th February 2017 Quiz and Chips Night

Karen Francis, Karen Morning and Ian Egerton of Heritage Will Writers attended our January coffee morning at Notcutts to discuss the possibility of supporting our branch. We were delighted when they tweeted to say, "Heritage's charity committee has confirmed that the business will be supporting Motor Neurone Disease Association".

Their first fundraising event is a Quiz and Chips Night at their offices, 13 Hellesdon Park Road, Drayton Road, Norwich NR6 5DR Tel: 01603 894500, time to be confirmed, but probably around 7pm. The cost is £2.00 per person, a selection of food from fish & chips at £5.30 to jacket potato and cheese at £2.55 will be available. They are hoping for teams of 8. If you are interested please contact Karen Francis by email: kfrancis@heritagewills.co.uk or telephone 01603 894511. We really hope there will be a high level of branch involvement in Heritage's first event for us.

1st May 2017 – MK Marathon

Phillip Laurier will be running the MK Marathon to raise funds for the Norwich & Waveney Branch of the MND Association. The marathon starts and finishes at StadiumMK in Milton Keynes, Buckinghamshire. Phillip will have sponsorship forms nearer the time.

Thursday to Sunday 15th – 18th June 2017 Bucket Collection

Sainsbury's have kindly offered us a four day slot during June, MND Awareness Month. Volunteers are needed to hold a bucket at Queens Road Sainsbury's, 1 Brazen Gate, Norwich, NR1 3RX. If you are able to help for an hour or two please email Sue Heal. We need to provide the store with a list of names of people who will be collecting about a month before the event.

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

Donations and fundraising

- Mr & Mrs M. J. Beck - £50
- Alan Bagley - £25
- Sale of Merchandise at Sprowston Family Fun Day - £31.50
- Ice Bucket Challenge in memory of Barry Norman - £368.80
- Jill Nursey & Val Baker, coffee morning in memory of Ian Basey-Fisher - £1,041.51
- Wroxham & Hoveton Lions Club, prize from monthly charity shop draw - £100
- David & Kathy Smith, Neatishead Bridge Group Halloween Event - £100
- Linda Tipper, fundraising evening - £33.56
- Anonymous donations - £93.77
- Pamela Knight - £20
- C. Gurney - £100
- J. M. Howes - £20
- Sue Kitson - £100
- Rosalind Wilkinson, sale of handmade cards in memory of Maureen Peel - £159.40
- Mary King, proceeds of sale of fruit & vegetables - £603
- Thelma Pointer, donation and proceeds of plant sale - £100
- Anglian Building Products, in lieu of sending each other Christmas cards - £50
- Emma Pickess, Waveney DC Housing Benefit Dept. in lieu of sending Christmas cards to colleagues - £90
- David & Joan Claxton, in lieu of presents for their Silver Wedding Anniversary - £504.85
- Norwich Petanque Club, tournament and raffle in memory of Norman Guest - £156
- Caroline Thurtell and Ella Baragwanath, coffee morning in memory of Sarah Baragwanath - £600
- Shirley Basey-Fisher, donation in lieu of Christmas cards - £20

- Shirley Basey-Fisher, sale of merchandise - £124.25
- Shirley Basey-Fisher, coffee morning in memory of Ian Basey-Fisher - £55
- C. M. Howes, Fakenham Christmas Tree Festival - £357.82
- Carol Saunders in memory of her husband, Vic - £100
- SMT Motors, donation in lieu of Christmas cards - £50
- SMT Motors, collection box - £60
- Horsford Bowls Club - £88.38
- Raffle at Wortwell Open Meeting - £143
- Sales of merchandise at Wortwell Open Meeting - £361.75

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

The John Jarrold Trust

The branch committee is very grateful to Caroline Jarrold, Secretary to the John Jarrold Trust, and the trustees for their consideration of our application for a grant. We received a donation of £1,000 in support of the ongoing work of the Norwich and Waveney Branch of the MND Association.

JARROLD
The John Jarrold Trust

The Norfolk and Norwich University Hospital will become the MND Association's 21st Care Centre

On Sunday 27th November, the MND Association agreed to provide funding for the hospital to develop an MND Care Network to provide specialist MND clinics across Norfolk. The clinics should be multidisciplinary, having other professionals within them such as dieticians and occupational therapists. The grant should also lead to the development of community based respiratory support for people with MND. An MND coordinator will ensure they work together effectively. This should greatly improve the patient experience. Recruitment to the key posts has begun, and it is hoped that the new staff will be in place by April if not before. The Care Centre will also work closely with the University of East Anglia to extend the opportunity for patients to participate in research. The grant will be funded by Ice Bucket Challenge money.

Headway Suffolk Neuro Conference 2016 by Brian Cloke

There were three Professors listed to speak at this conference, but the one I most wanted to hear was Stephen Hawking. The day did not start well with the announcement that he was ill in Cambridge and unable to travel, but an hour or so later it was announced that he was on his way and there was a loud cheer when he finally came on stage to address a very large audience.

Introduced as the brainiest man in the world he certainly gave a wonderful speech ranging from when he first noticed a problem with a foot whilst he was at university to his eventual diagnosis of MND two years later, right up to the thought of space travel. Stephen Hawking is still looking forward and considers that to survive the human race must go out into space at sometime. He has a place booked on Virgin's trip into space by courtesy of Richard Branson. He claimed that his proudest achievements were his three marvellous children.

Whilst he is keen on modern technology, his voice machine is now seen as old hat and out of date and he has had several offers to provide him with the very latest machine that money can buy, but his response is always the same to these brilliant voice box designers. "Everyone knows me by this voice and I think of it as mine. How would you like it if I offered to change your voice?"

As he finished his speech the audience rose to give him a long standing ovation. It was an experience that I shall never forget.

Free memberships available for audiobook library service

Audiobooks are a lifeline for many people who struggle to read in the usual way, providing vital access to the comfort, relaxation and joy of reading; do you know someone who would benefit? Listening Books is a national charity that provides a postal and online audiobook library service to children and adults who struggle to read or hold printed books due to an illness, disability, mental health or learning difficulty, and they have recently received funding to offer a number of **FREE memberships** to people living in Norfolk and Suffolk who would find the usual membership fees (from £20 - £45 per year) a barrier to joining the service.

The library has a huge range of brilliant fiction, non-fiction and educational audiobooks including new releases and bestselling authors. Titles are available as **MP3 CDs** sent through the post (all postage is included in the membership), and by **downloading** and **streaming** through the website or app which can be accessed on computers and portable devices such as tablets and smartphones.

You can apply by contacting Jo Cord on **020 7407 9417** or email jcord@listening-books.org.uk. You can also apply online by visiting <https://www.listening-books.org.uk/join-us.aspx> and ticking the box to apply for a free place.

News from National Office

New MND alert wristband and revised guide

Our new MND alert wristband is now available. This simple silicon band can be worn by a person with MND, at all times if required. It is designed to let emergency and hospital staff know the wearer has MND.

The wristband carries a clear caution to let emergency teams know that oxygen therapy may put someone with MND at risk (as they are more likely to retain carbon dioxide if they have breathing problems). A web address on the wristband directs professionals to more information about urgent and acute care support for MND, as they may be unfamiliar with the condition.

Wristbands can be ordered through the care admin team by emailing careadmin@mndassociation.org or calling 01604 611812.

The wristband is also supplied with the larger guides, including *Living with Motor Neurone Disease*, which has recently been revised. The guide now includes details about the NICE guideline on MND and other updates. The revised version can be ordered in hardcopy by phoning CONNECT on 0808 802 6262 or downloaded by visiting <http://www.mndassociation.org/wp-content/uploads/2015/07/living-with-mnd.pdf>.

Special thanks to volunteer Sarah Lannie who helped the care team to produce this resource.

NICE Guideline The MND Association has developed an information sheet on the NICE Guideline. It details the key information and how it can be used by people living with MND, to recognise what good care looks like and to have better informed discussions with healthcare professionals. It can be downloaded at <http://www.mndassociation.org/wp-content/uploads/01a-nice-guideline-on-mnd.pdf>.

The MND Association is working with service providers to ensure standards meet those specified within the guideline.

New care information sheet

11D – Managing fatigue. It provides guidance on how MND may cause fatigue and ways to reduce its impact.

You can download information sheets at <http://www.mndassociation.org/life-with-mnd/publications-pabmnd/information-sheet-range/> or order hardcopies from the care admin team by calling 01604 611685 or emailing careadmin@mndassociation.org.

If people living with or affected by MND wish to order direct, they can contact the MND Connect helpline by calling 0808 802 6262 or emailing mndconnect@mndassociation.org.

ESA reassessments scrapped

On 1st October 2016, the Government announced that people with severe, life-long health conditions will no longer have to face unnecessary re-assessments for Employment and Support Allowance (ESA) – a benefit for people who cannot work because of ill health or disability.

The MND Association has campaigned alongside other charities for people with progressive diseases like MND to be exempt from reassessment and welcomes this announcement. It will now be working to ensure the exemption criteria drafted by the Government are appropriate for people with MND.

Benefits Advice

Following the two successful pilots in Manchester and the Midlands the MND Association has designed a future model that will help us ensure that people with MND are able to obtain the advice about benefits that they need. Implementation will take place over the next few months and, all being well, the new national service will go live in April. Hopefully more detailed information will be available for the next edition of the Fightback.

Strategy Launch

The MND Association Strategy 2017/2021 has been published. *Going further together towards a world free from MND* sets out a plan across our three mission areas.

- We improve care and support for people with MND, their carers and families
- We fund and promote research that leads to new understanding and treatments and brings us closer to a cure for MND
- We campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society

The strategy also stresses the importance of how we need to work together with others to achieve our goals. The six strategic goals detailed in the document have been developed alongside people with MND, our trustees, volunteers, health and social care professionals, the research community, our members and staff.

You can access an e-copy of the Strategy at <http://www.mndassociation.org/get-involved/volunteering/volunteer-zone/news-2/strategy-launch/>. Ask Helen Devlin if you would like to read it from a hard copy.

Campaigns

Government drops plans to reform Attendance Allowance

After months of campaigning, the MND Association is delighted that the Government has listened to the needs of older people with MND. It has dropped plans to hand the administration of Attendance Allowance to local councils in England, the administration of this benefit will remain as it is. Nearly 300 Association supporters emailed their MP, and over 100 people with MND, their carers and families travelled to Westminster to talk to MPs about the proposed changes to Attendance Allowance and urge the Government to drop its plans.

Thank you to everyone who took part in this campaign and helped make the Government listen to our concerns and abandon its plans to devolve administration of Attendance Allowance.

Take Action!

Continuing Healthcare (England only): People with MND are missing out on vital continuing healthcare (CHC) at what can be the most difficult time in their lives and when they need the most support. Help us to put pressure on the Government and the NHS to improve the system. Email your MP and clinical commissioning group by visiting <http://e-activist.com/ea-action/action?ea.client.id=138&ea.campaign.id=58532> and help us raise these concerns.

Suffolk County Council supports the MND Charter by Liz Cooper

Thanks to the efforts of Linda Tipper, Ann Franklin (and her sister, Councillor Barker) the motion put to Suffolk County Council on 8th December by Councillor Patience, asking them to adopt the MND charter, was agreed unanimously!

Norfolk County Council supports the MND Charter by Sue Heal



From left to right: Cllr Borrett, James Bullion, Malcolm Chubbock, Shirley Basey-Fisher, Sue Heal and Cllr Mooney.

On 7th November 2016, I wrote to Joe Mooney, my local County Councillor. I asked for a meeting to discuss how he could show support for local people living with motor neurone disease (MND) by raising awareness of the disease among councillors and asking them to adopt

the MND Charter. He replied promptly suggesting a meeting on the 11th November. I had prepared information for him after discussion with Alice Fuller, Campaigns Manager (East). Cllr Mooney was pleased to be asked to support the MND Charter, and readily agreed to help.

Over the coming weeks we worked on a motion in support of the Charter, which was added to the agenda for a meeting of the full Council on 12th December. The motion proposed by Cllr Mooney was seconded by Cllr Alison Thomas, Deputy Leader of the Council. I wrote a personal statement and Alice prepared a briefing for councillors. It included information provided by Lindsay Goward, Regional Care Development Adviser, about the services available for people living with MND and their carers.

On the 5th December, Cllr Mooney took me for a tour of County Hall and talked through information I would need to give those who wished to attend. He arranged for Stuart Anderson, a reporter from the Archant group, to meet us at my home to discuss the launch of the campaign to have the MND Charter supported by Norfolk County Council. Stuart arranged for a photographer. Subsequently the launch of the Charter was publicised by the Eastern Daily Press on 9th December, and the Norwich Evening News of the same day. We were given the front page of the Wymondham Mercury on 15th December (a source of much amusement to, and gentle ribbing from, my neighbours!). I had prepared a pack of information about MND and the charter for Stuart, and was pleased to see that although there was not space for everything he included the MND Association website at the end of each article.

However, just before our meeting with the press, Cllr Mooney received a phone-call to say that the motion had been removed from the agenda for 12th December as the agenda was too long. The silver lining was that it could come before a meeting of the Council's Adult Social Care Committee (ASCC) on 23rd January 2017. Any decision made by the ASCC would be binding on the full council. As Cllr Thomas was not a member of the ASCC, Cllr Mooney needed to find a new seconder. Fortunately Cllr Bill Borrett, Chair of the ASCC, was happy to second the motion.

Cllr Mooney spoke with many councillors ahead of the meeting to gather support for our motion. Alice updated her briefing for the councillors, which together with the MND Association Champion the Charter brochure and my personal statement formed a pack which Cllr Mooney distributed to all members of the ASCC before the meeting.

On Monday 23rd January, Alice, Lindsay, Malcolm, Shirley and I met with Cllr Mooney, Cllr Bill Borrett and James Bullion, the new Director of Adult Social Care in Norfolk. Sue Starling, Lead Communications Officer at Norfolk County Council, took photos to add to the press release that I had drafted.

Before the meeting Alice, Lindsay, Malcolm, Shirley and I had an opportunity to speak with some of the councillors. Cllr Adrian Dearnley spoke of the loss of a family member to MND and Cllr Margaret Stone, who had originally trained as a nurse at Addenbrookes in Cambridge, expressed her support and pleasure that we were raising awareness of a disease that she understood. James Bullion expressed his willingness to publicise the five points of the Charter amongst members of staff employed by the council. Cllr Mooney presented our case in the meeting and quoted from a letter written to him by Ann Franklin, one of our members, who described MND as 'an evil disease'. Before the vote councillors were invited to comment, we were delighted that Councillors Dearnley, Garrod, Perkins, Sands, Seward and Watkins took the opportunity to voice their support and, by what they said, had clearly taken time to read our briefing. The committee voted unanimously to support the MND Charter.

Cllr Joe Mooney said: “I am very pleased that members of the Adult Social Care Committee voted in favour to support the excellent MND Charter. It will help raise awareness of the needs of local people living with this devastating disease and for that very reason I am very happy with the outcome of the meeting.” Cllr Bill Borrett, said: “I fully support this Charter and with the full backing of the Committee, we can actively support the work of the Motor Neurone Disease Association, to make a real difference and improve the lives of people living with this fatal disease.” The Charter will now go to full Council in April for ratification.

I wrote to thank Cllr Mooney for his work behind the scenes, his patience and support throughout the process. I also wrote to the other 16 councillors who attended the meeting. Julie Brociek-Coulton, Mike Sands, Eric Seward, Margaret Stone, Brian Watkins and Adrian Dearnley replied and reiterated their support and willingness to help raise awareness.

We plan to meet with James Bullion to discuss ways in which we can work in partnership with the council. In preparation for this we would like to hear from people living with MND, family members and carers with stories of which council services have worked well, and need to be protected, and which areas could have been improved. Please email any suggestions to Sue Heal at sueheal@btinternet.com.

The MND Charter is a statement of the respect, care and support that people living with MND and their carers should expect. More detail about what the MND Charter means in practice can be found on our National Office website at www.mndcharter.org.

Research

If you want to get involved in research you can look here for the latest opportunities: <http://www.mndassociation.org/research/mnd-research-and-you/get-involved-in-research/>.

Dublin Symposium 7th – 9th December 2016

There were over 35 hours of presentations and nearly 500 posters for discussion. It is impossible to do justice to the wealth of material presented; I will highlight two of the posters that I understood! For those with a scientific background or interest in finding out more go to: <http://www.mndassociation.org/research/international-symposium/symposium-live-2016/>.

The Development of Evidence-Based Recommendations for Supporting Informal Carers of People Living with Motor Neurone Disease - Susan Bergin and Carole Mockford, Warwick

The introduction noted that people living with MND are often given specialist care by informal carers in their own home. They noted, “Carers often experience deterioration in their own well-being and quality of life through the physical and psychological burden they experience”. Their review aimed to provide evidence to allow healthcare professionals to improve the support they can offer to carers, and improve their well-being and ability to provide care.

Four themes emerged that were developed into recommendations which are quoted below.

1. Palliative care services offer support to the patient and their families in coping with illness and should be provided to all people with MND and carers early in diagnosis and with increasing input for physical and psychological support to limit development of prolonged grief disorder.
2. Healthcare professionals need to be proactive in informing carers how and where they can access information regarding MND and the services available to support them.
3. Carer quality of life improves when they feel gratitude and appreciation of their role from the person with MND and healthcare professionals can support the person with MND in expressing this while offering respite stays and sits to free the carer's pursuit of social interaction and activity.

4. Keeping people with MND at home requires the provision of specialist aids which carers are expected to operate e.g. hoists, speech aids and PEG feeding pumps. There is need for consistent support from healthcare professionals to supply these and train the carer to use them effectively and safely.

How stories communicate daily living with ALS – Jeppesen, Rahbeck, Gredal, Ploug Hansen, Denmark

The researchers wanted to complement clinical and therapeutic knowledge about symptoms, prognosis and the social implications of ALS (MND). They wanted to explore how stories could help capture the unique individual impact of daily living with the disease and compensate for the progressive loss of ability to speak that some people develop.

Numerous interviews with six people living with ALS were made into narrative journalistic stories, which were then shared with health professionals chosen by the six. The results: “The stories communicated daily living with ALS as a continuous process of creating a new normality of everyday life.” They revealed that patients and professionals held conflicting views about information about the disease and prognosis.

In their conclusions the researchers suggested that the use of stories can maintain or restore communication as the ability to speak deteriorates, and may enhance patient involvement. The approach can be used over time to get an in-depth understanding of patients that informs individual healthcare professionals' engagement with them.

We need more Association Visitors (particularly in Suffolk) and Care Service Navigators

What is an Association Visitor (AV)?

Motor Neurone Disease Association visitors are volunteers who are provided with thorough training in order for them to be able to act as the main contact for people living with Motor Neurone Disease, their families and their carers. They can provide support throughout the journey with MND.

What is a Care Service Navigators (CSN)?

Care Service Navigators are volunteers who are provided with thorough training to enable them to give short term and task focussed support to people living with MND, their families and their carers, to help access services and support.

Can you help?

Do you enjoy listening to people?

Can you offer free and confidential emotional support to people affected by MND?

Can you follow up support requests to statutory or voluntary agencies?

Do you have knowledge of the effects of MND, our Association or the willingness to learn?

Are you an existing or former health and social care professional?

Are you looking for a volunteering role to fit around your family, studies or other commitments?

If you can answer yes to **one or more** of the above then we would really like to hear from you.

For the **CSN** role we are seeking current or former health and social care professionals.

The benefits to you

As an AV or CSN you can further develop existing skills in your personal and professional life, such as listening, empathy, tact, sensitivity and dealing with a wide range of people from all walks of life. Award winning training, on-going development opportunities and support are provided. All out of pocket expenses are reimbursed.

If you think you might be able to support us or would like to know more about these or any other roles please get in touch with:

Volunteering team, telephone: 01604 611681

Email: volunteering@mndassociation.org

Other opportunities to volunteer can be found by following the link:

<http://www.mndassociation.org/get-involved/volunteering/>

Suffolk Invitation – keep these dates for 2017

Suffolk drop in support meetings 2017

The Suffolk Group have extended an invitation to members of branches on the borders of Suffolk. People living with MND, families and professionals involved in supporting families are all welcome! Feeling isolated or unsure about support and services available? Come along to these informal get togethers where you can share ideas and support over a cuppa. MND Association representatives and nurse specialists will generally be on hand to advise.

Meetings in **West Suffolk** will be held at Hawstead Village Hall, The Green, Hawstead, IP29 5NP on the following dates and times:

Wednesday 1st March 2017 2-4pm

Wednesday 3rd May 2017 2-4pm: MND Association Research Presentation

Wednesday 5th July 2017 2-4pm

Wednesday 6th September 2017 2-4pm

Wednesday 1st November 2017 12-2pm *

***light lunch to be provided in November so an idea that you are coming would be helpful.**

If you would like to come along please email Janet Oliver on ooliverjanet@btinternet.com or contact West Suffolk Neurological Nurses, Nicky McGreavy or Sarah Ward by telephoning: 01284 748848.

The Ipswich support groups will be held at The Atrium, St Elizabeth Hospice, Ipswich on the following dates between 5pm and 7pm:

Monday 20th February

Monday 17th April

Monday 19th June

Monday 21st August

Monday 16th October

Monday 18th December

For the Ipswich meeting please contact Kate Barber on 01473 707962.

Suffolk MND Association contacts are Janet Oliver 01359 241084 and Liz Cooper 0345 375 1827. Suffolk Direct (for access to social care services) call 0808 800 4005.

Branch News

Open Meeting: Sunday 19th March, between 12:45pm and 4:30pm. The **Annual General Meeting** will be held at St. Andrew's Eaton Church Hall, Church Lane, Norwich, NR4 6NW. We are very pleased that Sally Light, CEO of the MND Association, has agreed to be our speaker. Cllr Joe Mooney, will also be attending.

Advance Notice: Open Meeting on Sunday 11th June between 2pm and 5:30pm at Upton Village Hall, Upton, Norfolk, NR13 6AU.

Coffee mornings

At Notcutts coffee shop: The next coffee morning will be held on Wednesday 15th February from 11am to 1pm. As usual we are hoping that many who are currently caring for, or who have previously cared for, people with MND will be able to attend an informal get together. Of course people living with MND are always welcome. Refreshments can be purchased in the coffee shop.

Advance notice of 2017 dates for Notcutts, Daniels Road, Norwich, NR4 6QP

March 15 th	April 19 th	May 17 th	June 14 th	July 19 th
August 16 th	September 20 th	October 18 th	November 15 th	

At the Cherry Lane Garden Centre: The next coffee morning will be held on Wednesday 22nd February between 11am and 12 noon. It is an informal gathering for people with MND and their carers.

Advance notice of 2017 dates for Cherry Lane Garden Centre, Beccles Road, Fritton, Great Yarmouth, NR31 9EU

March 29 th	April 26 th	May 31 st	June 28 th	July 26 th
August 30 th	September 27 th	October 25 th	November 29 th	

Website: www.mndnorwichandwaveney.org.uk We are always happy to add information about events you are planning in support of the Norwich and Waveney Branch of the MND Association (and would welcome content from the Suffolk Fundraising Group).

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

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

Newsletter Editor: Thank you to all who have sent photos and stories for inclusion in our newsletter. The next deadline for receipt of articles is **21st April** for the May 2017 edition.

Useful Numbers

Regional Care Development Advisers share an email address

eastangliarcda@mndassociation.org

Norfolk – Lindsay Goward 03453 751829. Lindsay works Tuesday, Wednesday morning, Thursday, and Friday morning

Suffolk – Liz Cooper 03453 751827. Liz works Monday and Wednesday

Care Service Navigators

Jo-Ann Dawson email jo-ann.dawson@mndassociation.org

Trish Moore 07813 094 820 email trish.moore@mndassociation.org

Please pass this newsletter on to people who may be interested and together we will fight for our vision of a world free of MND.

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 helen_devlin@tinyworld.co.uk, or write to her at the address given on the back page or write to Norwich and Waveney Branch, c/o MND Association, PO Box 246, Northampton, NN1 2PR