

Fightback

MNDA Norwich & Waveney Branch Newsletter
Issue 69 January 2016

Save the dates for our Open Meetings and Coffee Mornings!

Events in aid of the MNDA

Beccles Indoor Bowls Club

Tony Gaze, from Thurlton, was diagnosed with Motor Neurone Disease in March 2015. He died later the same year aged 79 surrounded by his close family.

Kym, his daughter-in-law, had always wanted to do a skydive so the family decided to take part in a tandem skydive and raise money at the same time. Wayne (Tony's son), Kym and their son Ryan paid for the dive themselves so that all the money raised would go straight to the MND Association. They jumped on 15th August with their friends and family there to support them. Sadly Tony passed away the week before. In total five members of the family took part in the skydive.

Tony and his wife, Dinah, were both members of the Beccles Indoor Bowls Club where they played. Tony was President of the Beccles Indoor Bowls Club and Chairman of the Thurlton Outdoor Bowls club. The Beccles Indoor Bowls club held a raffle and collection to help raise money for the MND Association, and over the summer the Thurlton Outdoor Bowls Club also held fundraising events. A collection tin was present at Tony's funeral and at the funeral directors where people could donate. Kym also sold her home grown fruit and vegetables, and set up a JustGiving page. The family placed an article in the 14th August edition of the local paper, the Beccles & Bungay Journal, to talk about their fundraising and to raise awareness of Motor Neurone Disease.



Malcolm was invited to a cheque presentation at the Beccles Indoor Bowls Club on 16th November where he received a cheque for £1,441. There was a follow up article on 16th October in the Beccles & Bungay journal with a photo showing the family presenting the cheque for the final amount. Wayne commented, "Dad would have been very proud" - and rightly so! Thank you to the whole family for their generosity and to everyone who became involved.

The photo shows (from left to right) Tracey Bloomfield (Tony's daughter), Kym Gaze, Wayne Gaze and Dinah Gaze presenting the cheque to Malcolm Chubbock.

Mucky Races at Blackwater Farm 25 October 2015

Jodi Welch, along with her family and friends, organised a cake sale at WR Events' Steeplechase race at Blackwater Farm, Great Witchingham. The Steeplechase course involved running, jumping, scrambling and hurdling over and under 30 different horse jumps and negotiating a series of water obstacles! It also included a timed Pumpkin Run. Competitors were encouraged

to wear halloween costumes; there were certainly plenty of people in costume including one who looked more like Spider Man! A great many people took part on the day, and more were there to watch and offer support. Everyone we met seemed to have enjoyed themselves. The wet weather of the preceding week ensured the races were suitably mucky – the car park at least was decidedly muddy in places – yet, on the day, the weather was gloriously sunny and dry. A lot of hard work had gone on behind the scenes preparing for, and publicising, the event. It seems as if a team of bakers had been called upon as there were a wide range of delicious cakes available to buy. Jodi and her mother Rosie worked with a team of helpers serving refreshments throughout. Judy, Penny and Sue H were invited to help with collecting buckets – and were very happy to be asked to stay for coffee and cakes whilst the money raised was counted! The grand total was £1,350, which included money taken on the day from the sale of drinks and cakes, donations, and the proceeds from the sale of some of the surplus pumpkins after the event. The cake sale was held in memory of Jodi's dad, George Richardson, who sadly died of MND in August 2014.

Diana Buckingham held a party at Sprowston Sports and Social Club to celebrate her 80th birthday in November. She decided to have a collection, games and competitions in aid of the MND Association in memory of her husband Geoff, who died from MND in 2012. Diana raised £1,000 for the branch, including gifts on the night and subsequently. We are very grateful to Diana and her friends for their generosity.

From right to left the photo shows Richard Gurney (owner of the White House Farm, Sprowston where Geoff was farm manager), Diana Buckingham, Malcolm Chubbock and Mark Buckingham (Diana's son). Some of you may remember that Mark completed the London Marathon in 2013 raising £3,800 in aid of the MND Association.



Copperfield Freemasons Lodge Malcolm was invited to the Neonatal Unit of the James Paget University Hospital on 7th December to receive a cheque for £1,020. Copperfield Freemasons Lodge had raised money on their ladies' night for our branch of the MND Association. They had also raised money for the JPUH NHS Foundation Trust – hence the location of the presentation! We are very grateful to the Lodge for their generosity.

From left to right the photo shows Des Millward, Malcolm Chubbock, Bridget Tooley, Simon Tooley and Paul Rackham. Des, Simon and Paul are members of Copperfield Lodge. Paul recently lost his father to MND, and has also lost an aunt to MND.



A charity football match was held on 27th December at Halesford, in memory of Mitchell Block who died of MND earlier in the year. It was organised by Mr and Mrs Ablett and raised £2,020. A visiting team from Lowestoft played the Halesford team in a match where all the players were aged over 50, and one of the goal keepers was aged 73! There were around 250 spectators who contributed generously to a bucket collection and bought raffle tickets for a chance to win one of the 100 prizes. Thank you to everyone involved. We hope to feature photos of the formal presentation of the cheque in the next edition of Fightback.

Max Burgess and dad, Barrie, completed a 50 mile bike ride round Norwich for the MNDA
They had a perfect September day for it, sunny but not too hot and no breeze. In the end it was 57 miles!! Poor Max had a bit of a wobbly about 42 miles so he was counting down to 50 and when he reached it there was no end in sight! He continued and was very relieved to see the finish line up ahead!

Max wrote on his JustGiving page “I’m cycling to support the amazing work that Motor Neurone Disease Association do. Mum has MND, it is hard for her and us as a family because every day she gets a little bit worse and there is nothing anyone can do about it. It took 3 years to diagnose because there isn't one test and as it's rare GPs don't know much about it. Mum is 'lucky' as she has a rare type that is slower burning.” Ann spoke very movingly at the Lowestoft Study day in November 2015 about living with MND, and the support of her family.



Max raised £232 on his JustGiving page (including gift aid), and has already presented the Norwich and Waveney Branch with a cheque for £494 raised offline. In due course this total will rise as the gift aid is recovered from HMRC – something that can take a while!

Future events in aid of the MNDA

Save the dates 13th & 14th August 2016, when the branch will have a stall at the Norwich Motor Show. If you are able to volunteer for an hour or two please let Cilla know.

The Branch is applying to hold a bucket collection at Norwich Railway Station this year.

Jodi tells us that the Steeplechase will be happening again this year. They plan on doing a cake sale again and collecting donations. There may be a chance for the MNDA to provide marshals to help out at the race – we will need volunteers! More details to follow.

Please let us know if you are planning an event for 2016 so that we can publicise it in our newsletter and on the website at www.mndnorwichandwaveney.org.uk.

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

Donations and fundraising

- Aviva staff restaurant collection box - £19.73
- Ernst & Young fundraising - £79.50
- Unthank Arms collection box - £74.26
- Judy Burns-Thomson, donations in lieu of birthday presents - £1,045
- Shirley Basey-Fisher, Ice Bucket Challenge and BBQ event - £150
- Royal Scottish Country Dance Society, donations from members - £200
- Carol & Arthur Bloomfield, proceeds of coffee morning - £260.18
- Mary King, sale of hagstones - £250.50
- Mary King, sale of fruit and vegetables - £828.31
- Lions Motor Show and MNDA stall at Sprowston Family Fun Day - £417.60
- Greenacres Burials Christmas Charity fair - 193.50
- Greenacres Burials match funding - £100

- Pulham St Mary Horticultural Society, proceeds of a charity evening - £200
 - Hilary Farnbrough, proceeds of a concert to celebrate David O'Neale's life - £615
 - SMT Motors collection box - £24.37
 - SMT Motors, in lieu of sending Christmas cards - £50
 - Mr & Mrs Hayes, in lieu of a Christmas present for Mr Hayes' sister - £35
 - Diana Buckingham, money raised when 4 ladies participated in a weekly weigh-in arranged by Mrs Rae Tuffen at Sprowston Manor Marriott Hotel & Country Club - £35.00
 - Brenda & Mike Beck - £30
 - Sue & Paul Richardson - £20
 - Carol Powell - £7
 - Denise Bell - £10
 - J M Howes - £20
 - Wendy Slaughter - £20
 - Thelma Pointer, proceeds of a plant sale and donations - £100
 - Rosalind Wilkinson, sale of handmade Christmas cards in memory of Maureen Peel - £158.40
 - Open meeting at Wortwell, raffle - £125
- Donations in memory of
- Mr Kenneth Morgan - £520
 - Mr Timothy Cloake - £180.50
 - Mrs Wendy Lemin - £192
 - Mr Mick Ransom - £347.07
- Internal transfers
- Interest - £42.79
 - Charities Trust - £40.89

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

News from National Office

Silence Speaks The association is developing downloadable resources for those interested in organising 'silent' fundraising events in 2016; we will publicise details and provide a link to them when they are made available.

The Care Survey From early January, the association will be asking people with MND to say what it is like to access support from NHS, social services and the MND Association. The Care Survey is run every few years to help give a picture of care across England, Wales and Northern Ireland. This in turn informs the association's priorities for action to raise standards of care and equips us with evidence to influence statutory services.

People with MND, for whom the association has contact details, will have received (or will shortly receive) a questionnaire sent either by email or in the post, from the Picker Institute, who are carrying out the survey on behalf of the association.

Please take part and use the opportunity to tell us how you feel about the services you receive and equip the association with the evidence needed to push for change.

Riluzole There is now a liquid form of riluzole in the UK. The product is called Teglutic. It has been developed in Madrid and is being made available in the UK by Martindale Pharma. It will be the decision of the care team of the person living with MND whether this drug is prescribed, but its availability may make taking riluzole easier for some people living with MND.

Welfare Benefits Project The association is piloting a project in Greater Manchester in partnership with Manchester Citizens Advice Bureau to offer home visits, by a specialist benefits adviser, to assist in completing Personal Independence Payment and Attendance Allowance claim forms. Initial indications are that the service is appreciated and is effective. In the first six weeks of operation, they were able to claim benefits for people with MND and their carers worth over £100,000 a year. We hope that the learning from this pilot project will see the service developed in other areas over the next two years.

Research Most weeks there is a post on the Research Blog. During the 26th Annual Symposium, held from 11th to 13th December in Orlando, USA there were 90 oral research presentations and 350 research posters with several posts appearing each day. I would encourage anyone who is interested in reading more to register at <https://mndresearch.wordpress.com/how-to-use/> to see what is available. What follows is a small selection from the articles posted.

Sheffield Support Snood update posted on 23rd November 2015

<https://mndresearch.wordpress.com/2015/11/23/heading-in-the-right-direction-sheffield-support-snood-update/>

The MND, together with the National Institute for Health Research 'invention for innovation' programme, are funding a research team in Sheffield which has developed a new type of neck support for people living with neck muscle weakness as a result of a neurological condition. They have worked with people living with MND to develop the Sheffield Support Snood.

The results from a small pilot study of the snood were presented in 2014. The next step is the 100 Collars Project that began with a training day for physiotherapists and occupational therapists from MND care centres to see the collar, receive training on how to put it on, and find out about the project. One hundred people with MND who experience neck weakness and 50 people who have neck weakness linked to another condition will test out the latest design of the snood.

How can you take part? MND Care Centres at locations including Addenbrookes, Cambridge are taking part. People who attend one of these centres will be able to speak to someone about this project at their next appointment. Snoods are expected to be available to those taking part from **late November 2015**. Those who do not currently attend a participating centre, but are interested in taking part, need to speak to their neurologist about a possible referral to one of these centres.

What does taking part in the project involve? People taking part will be asked to commit to two visits to their participating centre, one month apart, to complete two questionnaires and have the snood fitted. Those taking part will initially fill out a questionnaire asking about any collar(s) they currently use and their level of neck weakness. After one month of using the Sheffield Support Snood, participants will be asked to fill out another questionnaire giving information on how they found the snood, assess the quality of support it gave and how comfortable it was. They can continue using the snood after this trial month if they find it suitable.

The 100 Collars Project is needed to provide potential manufacturers with evidence on whether the support snood is a good product and a feasible alternative to collars that are currently available. It is hoped that once a manufacturer is found that the snood could then be available more widely to anyone with neck weakness, including people who have MND.

Using video messages to help leave a digital legacy posted on 6th November 2015

<https://mndresearch.wordpress.com/2015/11/06/using-video-messages-to-help-leave-a-digital-legacy/>

Oliver Clabburn lost his father to MND. He is now completing his PhD looking at children and young people who provide care for family members with MND, and also young people bereaved due to the disease. One aspect of his work investigates the use of videos to leave a digital legacy. People with MND record a series of video clips about their life, memories, accomplishments and messages for children in their family. These videos are then exported to a DVD or digital source, and given to the young person to watch whenever they feel the need to reconnect with the person they care for, or remember the person that may have passed away.

His study is investigating the experiences of creating and using a digital legacy with people affected by MND. To do this, he will be interviewing around 10 people from the following three groups **from now until April 2017**

- People with MND who are recording or have already recorded a digital legacy for a child or young person in their family;
- Young people (aged 11-24) who are currently caring for a family member with MND and use a pre-recorded digital legacy as a means of support;
- Young people (aged 11-24) who are bereaved due to losing a family member who had MND and are using a pre-recorded digital legacy to support them whilst they grieve.

The interview will take place either face-to-face or through Skype, whichever is preferred by those taking part. The interview will last about 30 minutes and will be informal making it feel like a conversation.

There are many digital legacy computer programs available to download, one of them, called RecordMeNow, was presented at the ALS/MND symposium last year in Brussels. It is a free app to download for your computer at www.recordmenow.org, or from the Apple App store for your iPad or iPhone. It is specifically designed to leave a video legacy for children and provides a selection of prompting questions that you can add to, modify or delete as required. It is completely independent from Oliver's research.

If you would like to take part in Oliver's study, or know a young person that may like to be interviewed, please contact him (and mention the research blog) by phoning 01695 654316, emailing clabburo@edgehill.ac.uk or looking at www.facebook.com/mndlegacy.

Clinical trials update from Symposium posted on 14th December 2015

<https://mndresearch.wordpress.com/2015/12/14/clinical-trials-update-from-symposium/>

Clinical trials determine if potential treatments are safe and aim to prove beyond reasonable doubt whether a drug is beneficial. This year the symposium session on clinical trials looked at three drugs and one therapy. The summary of the results from the drugs and treatments discussed is given below, with a separate piece on edaravone based on Dr Dickie's blog post.

Ibudilast Over the course of the study, the researchers found that this drug was safe and well tolerated in those who were not using non-invasive ventilation. However, these are results from an early stage trial so more research is needed to establish possible long term benefit.

Methylcobalamin (Vitamin B12 injections) If this treatment is given early (within 12 months of diagnosis) then it showed an effect at increasing survival in a small sub-group of those taking part in the trial. This effect was not seen when the treatment was given further on from diagnosis.

Stem cell therapy This small, early phase 1/2 trial was testing the safety of bone marrow derived stem cell injections into the spinal cord. The researchers found this treatment had no major side effects. Further studies are needed to evaluate the effectiveness and safety of this treatment over the long term.

Edaravone trial update from Symposium posted on 13th December 2015 by Dr Brian Dickie

<https://mndresearch.wordpress.com/2015/12/13/edaravone-trial-presentation-sparks-interest/>

Bar a few bacteria, every living cell in the human body needs oxygen. Some cells need more oxygen than others, dependent on how much energy they need to produce to function. Motor neurones are amongst the most energy hungry of all. In the process of producing cellular energy, a small but constant amount of waste products called free radicals can build up in the cells. As we age our energy production processes become less efficient so more free radicals are produced, and our cells become less effective in dealing with them. When neurones are damaged this is exacerbated, causing oxidative stress. There is evidence this plays a role in MND.

Several antioxidant treatment strategies have been tested in clinical trials, but none have been effective. However, Japanese clinicians ran a nine month study of the free radical scavenger edaravone. The trial involved over 200 MND patients (half taking the drug, half a placebo). The trial did not show any statistically significant benefit, although there was a trend towards slower progression with the drug. This led the investigators to analyse the data more thoroughly and they identified a subgroup of patients that appeared to obtain some benefit. The next step was to carry out a further study focused on the subgroup of patients. Over 130 participants took part in this trial, receiving intravenous infusion of edaravone. The results showed a statistically significant slowing of disease progression (assessed using the Revised ALS Functional Rating Scale) over the 24-week treatment period.

Whilst these results give a glimmer of hope, there are questions that need to be answered. Why does the drug only appear to show some effect in a subgroup? Can the trial results be confirmed and, if so, can a longer term effect be demonstrated? Does the drug have an effect on survival? The drug has to be given intravenously, which may be impractical, and there are key differences in the way the Japanese population metabolises drugs compared with Caucasians, so very different doses may need to be considered for different populations. Hopefully, some of these questions will be answered through another study. The Dutch company Treeway is developing a formulation that can be taken orally and has been shown to be safe in preliminary (phase 1) studies. The company is aiming to start a phase 2/3 study this year.

MND STUDY DAY 27th November 2015 written by Di Dann (Care Service Navigator)

Association Visitors and Care Service Navigators went to Lowestoft for an MND Study Day, organised by Lindsay Goward (Regional Care Development Adviser) and chaired by Jo Fuller (Neurological Nurse Specialist). It was an excellent event with attendees from a wide range of health and social care professions as well as volunteers.

Lindsay spoke about the impact on families affected by MND, the work of the MND Association and the Care Centre at Addenbrookes. This was followed by a presentation from a Registrar Specialist in Neurology from the Norfolk and Norwich University Hospital, who explained the symptoms, the clinical signs of MND and also the various investigations which might be needed before diagnosis can be confirmed. He then went on to explain the treatments for the symptoms. This was followed by a presentation on cognition and dementia given by Eneida Mioshi. She talked about symptoms associated with changes in cognition and dementia that can be explained by MND. There are now cognition summary tests to help determine the condition, so for example tactless remarks are attributed to disinhibition which is a recognised sign of cognitive deterioration. The evidence collected from these tests should be used in quantifying additional support for the carer as well as the patient.

We also had a presentation given by the Association Visitor, Colleen, for Ann Franklin who had written the words. Ann has been coping with MND for nearly 10 years, the disease was diagnosed when her son was 5 years old. It was an incredible story of bravery. Ann gave her own warm acknowledgment of Colleen's friendship and support. Sue Heal also talked to us about her family's journey with MND, describing the highs and lows in the treatment of her late husband by the many professionals involved in his care. She hoped to remind people of the positive impact that can be delivered from best practice and to help them avoid the unintended consequences of ill timed remarks. We also had a very useful talk by Jeramy Philpott from St Elizabeth's Hospice in Ipswich who talked about advanced care planning and those difficult but essential conversations.

The afternoon was given over to workshops centred around nutritional support and communication; respiration and the integrated approach towards MND care. I would have liked to have gone to every workshop but chose the Nutritional Support workshop. I learnt about the importance of eating the correct foods to avoid swallowing difficulties. It was good to meet the “SaLTs” (speech and language therapists) and it was an excellent chance to remind myself that if you take the skin off a sausage you can then mash it and it becomes a soft food! Peas too can become soft foods if you take them out of their shells. The Respiration workshop looked at the importance of early assessment and treatment options. The third workshop talked about the importance of multi-disciplinary working and early interventions.

This was the third MND conference arranged by a partnership of the MNDA and Suffolk Social Services. We would like to express our thanks to the following for organising such an interesting day: Lindsay, one of our Regional Care Development Advisers (staff at the MNDA National Office also provided support behind the scenes); The neuro nurse team of East Coast Community Health Care, especially Jo Fuller, who chaired the conference, and Jean Lindsay; Catrin Sutton of Suffolk County Council Adult and Community Services. Apologies if we have left anyone out!

Updates to the Branch Website If you have visited the website recently you will notice the appearance of a new page under the tab 'Useful links'. Following the open meeting at Wortwell in October, and an interesting presentation by Kevin Vaughan of the Carers Agency Partnership (CAP), it was clear that there was a lot of useful information online for carers and people living with MND. We have added a link to the CAP website with a brief outline of the services they offer. The details are reproduced below.

Carers Agency Partnership If you live in Norfolk and are looking after someone, there are many organisations providing services that can help and support you. The Carers Agency Partnership aims to help you find out about your rights, take up your entitlements and get in touch with organisations quickly and easily.

They say, “We can help you ...
When you need to talk to someone;
When you need a break from caring;
When you need practical support”.

Call the **Carers Agency Partnership Helpline on 0808 808 9876**. The helpline is local with experienced staff to give you all the information you need to help you look after someone. It is a freephone number from a landline, open 9-5 Monday-Friday; 10-2 Saturday. An answer phone is available at other times.

Visit their website at www.carersagencypartnership.org.uk where you can view information for carers on a wide range of topics including, but not limited to, having a Carer's Assessment, Practical Help at Home, Getting About, In an Emergency and Money Matters. This is a website you may find worth including in your favourites!

If you prefer to have the information in print then phone the helpline to request a copy of the Norfolk Carers' Handbook 2015 to 2016, alternatively you may be able to pick up a copy at your GP's surgery.

Norfolk Coastal Centre One of our members, Cathy, visited the Norfolk Coastal Centre near the James Paget University Hospital. The facilities are designed to allow people to see the sorts of adaptations and equipment that are available for people living with disabilities. An outline of what is available is described on the website and is given below for reference. The independent living centre is managed by the Red Cross.

British Red Cross, Norfolk Coastal Centre, Woodfarm Lane, Beacon Park, Norfolk, NR31 9AQ
Telephone 01493 663 626 Fax 01493 604 701
Email enquiries@norfolkcoastalcentre.co.uk Website <http://www.norfolkcoastalcentre.co.uk>

The demonstration service and assessment training venue are actual rooms. When Cathy visited she had a quick look at all the rooms and was able to ask a visiting occupational therapist some questions. Here is her description of each of the rooms; as she put it, not a professional description but as seen by a lay person. Ideally you should make an appointment and be with a professional occupational therapist who is able to explain all you need to know about the equipment.

Sitting room – mainly furniture adaptations and chairs.

Kitchen – shows raising and lowering work surfaces, low level cookers and hobs. Adapted kitchen cupboards with easy reach baskets. Kettle stands to help with pouring and filling a normal kettle, special gadgets for opening jars and bottles – great for hands with painful joints. And many more things which need more time for a full explanation!

Bathroom – wet room facility, walk in bath design, various chairs and lifts, adaptations, commodes, jet shower, self flushing loos and ones that clean 'your bits and bobs'!

Bedroom – specially designed bed and hoists.

East Anglian Driveability is an independent charity that specialises in enabling outdoor independence for people who have a disability or who need help getting back to driving. Their services include assessment of fitness to drive as well as specialist advice, information and recommendations regarding car adaptations for passengers. They operate from three centres in Thetford, Spalding and Colchester as shown on their website <http://www.eastangliandrivability.org.uk>.

All assessments are booked through the Thetford assessment centre on their main number 01842 753 029; opening hours Monday to Friday 9am – 4:30pm. Where applicable there is a subsidised fee for individuals so please ask about any costs at the time of booking.

For six months they are trialling outreach centres at Gorleston and Kings Lynn.

Gorleston operates on the 1st and 3rd Thursday of every month at the Norfolk Coastal Centre, NR31 9AQ.

Kings Lynn operates on the 2nd and 4th Thursday of every month at 11 Acer Road, PE34 3HN

The Norfolk Wildlife Trust has a new visitor centre at Cley Marshes (thanks to Di Dann for the following article)

The Simon Aspinall Wildlife Education Centre is the brand new facility designed to help visitors explore, discover and be inspired by wildlife. The Aspinall Centre has allowed the NWT to expand and develop their programme of events and it sits beside the NWT Visitor Centre at Cley Marshes in North Norfolk. Both buildings have accessibility and you can sit and enjoy the outlook over the Marshes, either inside or outside. There is disabled parking near to the entrance of the visitor centre with a lift providing access up to the café and the facilities of the Education Centre beyond it. The Centre was opened in May 2014 by Sir David Attenborough.

Reading about Simon Aspinall (1958 – 2011) – “Every now and again someone comes along who touches our lives and makes a difference. Simon Aspinall was one such person. When he died in October 2011, after bravely living with motor neurone disease for four years, the Middle East, and its birds, lost a true friend. He was 53.”

Simon's passion for birds started as a schoolboy in England. Graduating in environmental sciences from the University of East Anglia, he first visited the Middle East in 1991, stopping off in the United Arab Emirates during one of his world birding trips. Later he was to work there for over 15 years, first for the then National Avian Research Centre and later as an environmental consultant, bringing a wealth of experience from his time with the RSPB and the Nature Conservancy Council, much of it in Scotland. Simon lived for travel. In the Middle East and Central Asia he journeyed to most countries, studying birds, working with UNESCO on plans for nature reserves and taking part in BirdLife International's surveys on Socotra and helping their programme in Syria training young biologists from Nature Iraq. He was a prolific writer, authoring or co-authoring over 100 papers and books, notably on the Middle East, its birds and ecology. Whilst his main interest was birds, 'our feathered friends' he called them, Simon took a keen interest in all of natural history.



Most of all he was courageous, continuing to travel, latterly with sticks and wheelchair, to the Middle East and far-flung corners of the world, never once complaining. That spirit and his contribution to ornithology and conservation is the legacy he left behind and now with this new Centre, it gives everyone an opportunity to enjoy this most special landscape. The photo shows the view of Cley Marshes taken from the Centre.

For more information, telephone 01263 740 008, or visit the website at www.norfolkwildlifetrust.org

Branch News

AGM Sunday 6th March 2016, 12:30 for 1.00pm until 4.30pm at St. Andrew's Church Hall, Church Lane, Eaton, Norwich NR4 6NW. Isabel Coe of East Anglian Driveability will be our guest speaker. We are anticipating that she will cover the following topics.

- What is Driving – what does it involve?
- Current DVLA legislation, Medical Standards of Fitness to Drive and licensing issues
- Driving assessment in the UK – The Forum of Mobility Centres
- East Anglian DriveAbility
- The assessment process
- How and who to refer
- Adaptations to vehicles for people with physical disabilities

Sue Kitson, who has been the branch secretary for 21 years is standing down after the AGM. We would like to record our thanks to Sue for her dedication and huge commitment to the branch for so many years – we will miss her.

We are very fortunate that Helen Devlin has offered to take over the role. Helen was co-opted onto the committee on 5th January by a unanimous vote and will be acting secretary from 1st February 2016. In line with the Branch Charter we are required to hold a vote at the AGM to formalise Helen's position, we hope you will feel able to support the motion to accept her onto the committee.

As always we will be asking for volunteers wishing to join the committee. If this is something you have considered but are not sure about please talk to Malcolm or Judy to discuss what is involved. For those who feel this would be too much of a commitment we are also interested in creating a list of people who would be happy to 'hold a bucket' or help occasionally for an hour or two at fundraising events.

Advanced notice of our open meetings for 2016

Sunday 19th June, 2 to 6pm for afternoon tea at Upton Village Hall, Upton, Norfolk, NR13 6AU.

Sunday 20th November, 12 noon for 1pm (to allow time to purchase Christmas cards and merchandise) at Wortwell Community Centre, Tunbeck Close, Wortwell, Norfolk IP20 0HS. This year we are hoping to host a Christmas lunch.

Coffee mornings

At Notcutts coffee shop. The next coffee morning will be held on Wednesday 20th January 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 2016 dates for Notcutts, Daniels Road, Norwich, NR4 6QP

17 th February	16 th March	20 th April	18 th May	15 th June
20 th July	17 th August	21 st September	19 th October	16 th November

At Cherry Lane Garden Centre. The next coffee morning will be held on Wednesday 27th January between 11am and 12 noon. It is an informal gathering for people with MND and their carers.

Advance notice of 2016 dates for Cherry Lane Garden Centre, Beccles Road, Fritton, Great Yarmouth, NR31 9EU

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

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 15th April for the May 2016 edition.

Useful Numbers

Regional Care Development Advisers share an email address

eastangliarcda@mndassociation.org

Norfolk – Lindsay Goward 03453 751 829. Lindsay works Tuesday, Wednesday am, Thursday and Friday am.

Suffolk – Liz Cooper 03453 751 827. Liz works Monday and Wednesday.

Care Service Navigators

Isobel McCarthy 07714 077671 email isobel.mccarthy@mndassociation.org

Jo-Ann Dawson 07872 161747 email jo-ann.dawson@mndassociation.org

Di Dann 01328 878 196 email di.dann@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.

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