

Northamptonshire Branch

DECEMBER 2017



OUT AND ABOUT

On Sunday September 3rd, Dave and I met at Northampton Town Hall along with many others to cheer off runners from David Niven House along with other runners, all running for the MNDA in the Northampton Half marathon. David Solomon and Jo Cole were there and were pushed round the course. The event was very well supported by many runners from around the country. They set off at 9.30 and the start was also the 3 mile point, within 15 minutes the leaders were going past. The finish was at Delapre Abbey so we went there to cheer as the runners finished. The leader finished in 1 hour 14 minutes, soon to be followed by the others. It took about 2 1/2 hours for everyone to get back. When the MND team came towards the finish they were cheered by everyone. Well done Team MNDA, it was difficult towards the end for the wheelchairs but you all finished. It was a bit chilly but that was fine for all those running. The atmosphere was brilliant. A very successful day. Jackie Atkins



Paula Solomon writes “Dave and I have been busy again!

September 3rd (as above) saw us take part in the Northampton Half Marathon with a team from Run MND who travelled from all over England to join us. Dave had not planned to participate, but when he was asked an hour before the race if he was joining us his reply was 'ok then'. The course is not entirely wheelchair friendly, therefore we had to walk some bits to ensure the safe passage of Dave and Jo, but that didn't stop us all having lots of fun and raising awareness as we painted the town blue and orange. We finished in a time of 2h 44 minutes to a huge round of applause as we sprinted across the finish line.

10th September Paula and Mark Lewis took to the Streets of Newcastle, running the Great North Run with charity places for the MNDA. Raising well over £1500 between them. The MNDA had a great turnout at the run, The Great North Run was a favourite of David Solomon's, so Paula and Mark wanted to run it for him.

24th September We also took part in Cycle for Cynthia's 50 mile bike ride with Dave on an adapted wheelchair bike. A team from Northampton Road Runners took it in turns to cycle with Dave who was dressed in his usual orange wig and psychedelic trousers, not forgetting the oversized blue glasses. It is a tough course for anybody with some huge hills but as a team we got Dave round. and finished to another round of applause. we had a lot of laughs on route and would recommend that anybody in a wheelchair have a go on the Duet bike that can be hired from Pitsford Cycles. Make sure that you wear your helmet though.



Next it was the Great South Run, October 22nd Saw Team Run MND all travelling down to Portsmouth to paint the town Orange and Blue. We had a huge turnout of around 50 people, with around 15 of us crossing the finish line together with Dave and Jo in their wheelchairs, Again spreading a huge amount of awareness of Motor Neurones Disease and having fun. One life Live it!

Northampton Road Runners, our running club held its Annual Astrix Amble, a 15 mile cross country run. Paula organises the refreshments for the runners on their return which this year raised £290 for the MNDA. A bonus was the offer of help to man the stall so that Paula could run. A lovely morning was spent running around the fields of Northampton followed by hot soup, Sausage rolls and any runners favourite CAKE! sadly this event was definitely not wheelchair friendly, but Dave was there at the finish to greet the runners with his usual wave and smile.

In between all these events, we made a trip to London for the Parliamentary reception on Tuesday 17th October. sadly our local MP Michael Ellis had said he might come, but didn't show up. We had a wonderful time and were blown away by Charlotte Hawkins' talk on her experience of Motor Neurone Disease, and how it affected her and her family when her father was diagnosed and sadly passed away, there wasn't a dry eye in the room.

We met many wonderful people who we were able to share experiences with. The main topic of conversation was PIP re assessments and how people who are diagnosed with a life shortening progressive disease like MND should not be re assessed as it is very traumatic for the person living with the condition, and it is a total waste of money.

In the absence of a parliamentary representative from Northampton I have passed on information given on the day to local councillor Mike Hallam for Parklands.



London to Brighton

Some of you may know Julie Reece who was an Occupational Therapist (OT) based in the Multi Disciplinary Team (MDT) at Cynthia Spencer Hospice. Julie has a wealth of experience supporting people with MND and recently took part in the London to Brighton cycle ride.

Julie Reece, Milton Keynes MNDA Branch Secretary and her daughter Helena Carter who is newly opted onto the Branch committee rode the London to Brighton cycle ride earlier in September raising a further £1200 in addition to the previous £800 they raised in June. Neither were ardent cyclists before the event, but have now taken more of an interest in cycling. They put a lot of effort into their preparation and were very proud to report that they cycled all the way up Ditchling Beacon, and did not get off and push!



(Extract from MK Branch newsletter)

Waitrose Wootton Cheque Presentation



In September members of the branch who attend the Drop-in lunches sessions went next door to the Waitrose Store to receive a cheque to the value of £420.00 this was collected as result of the Community Matters Green Box tokens. Our grateful thanks to all who contributed to the branch through this very worthwhile scheme.

Kate Inchley



The annual Coffee Morning on October 21st was another very successful event. We had a very good raffle, a fantastic cake stall and Jackie managed to sell yet more of her baby jackets. Peter had great sales with MND

Christmas Cards and his jams, chutneys, pickles and beetroot went down a storm. We had lots of people and raised a magnificent £806.45.

Our thanks go to all who supported us in any way

Kate Inchley



Long Service Award

Neil Penson V.D.C. attended the Drop-in on Wednesday October 6th with a very special award for a special lady.

Chris Hull, our branch newsletter Editor, was due for her five year, long service award and we agreed with Neil that the Drop-in Lunch was an appropriate place for Chris to receive this award because 4 years ago it was the initiative of Chris's

to start the drop-in, where people living with MND and their carer's could informally meet, have lunch and exchange their experiences. The Drop-in has been the greatest success and goes from strength to strength.

All of this time Chris has been our newsletter editor and what an amazing job she does in producing a very informative and interesting newsletter. Well done to Chris and well deserved award and recognition.

Kate Inchley

Meeting Sally Light C.E.O.



What a lovely morning we had on November 9th at the Cynthia Spencer Day Hospice Care Centre. Twenty seven members of the branch gathered for coffee tea and cake for an informal meeting with Sally Light.

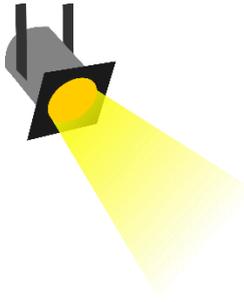
Members included people with MND and their carers, committee members and

association visitors, friends of the group and our RCDA . As refreshments were served everyone chatted together whilst Sally made a point of speaking to everyone either individually or in the small groups where they were sitting. It was a very relaxed atmosphere and gave everyone the chance to meet our Chief Executive.



Our grateful thanks to the Manager of the Day Hospice Care Centre who gave permission for us to hold the event here.





SPOTLIGHT ON

My name is **Teresa Deacon** and I am the main receptionist at the MND Association in Northampton, along with my colleagues Nina Smith and Rebecca Grayson.



I started working with the Association in January 2015 with very little understanding of Motor Neurone Disease. Nearly three years on... working with the association has opened my eyes completely..

The main reception desk can be the first point of call for many reasons, such as:

- A person who has just been diagnosed with MND and wants to talk
- A family member who needs support and advice
- Families who need to report a loved one lost to MND
- Fundraisers who desperately want to raise awareness and money for the Association
- Voice banking
- Research Questions
- ... And many more

All calls are very special and listened to with great compassion and I can honestly say I have shed more than one tear whilst taking these calls.. The Connect Team are the main helpline and also take all these calls (08088026262)

Meeting and greeting is always my favourite on reception, I meet so many wonderful people and I adore this side of my job... Visitors, Trustees, Suppliers, London Office, people with MND and their families, fundraisers and again many more.

Being more involved with the MND Association is my goal.. so this year I had the pleasure to visit the MND Association Care Centre in Cambridge and was accepted to sit in on the consultations of those with MND, The care and support I witnessed at the care centre was truly amazing and so important for those affected with MND.

I was also invited to attend the Northampton Branch drop in session at the Wyevale Garden centre in October and loved every minute.. lots of positive energy, smiles and a great sense of a family feeling... I now feel part of this family xx

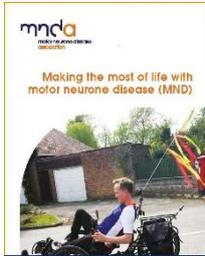
I do have a funny side in me! ... For Silence Speaks.. I have lost my voice for 8 hours, I have waxed members of staff and charged them if they screamed, and carried out an outside fitness class for staff and charged them if they moaned !!

I travelled to London with staff to Credit Suisse to gain our votes to win their Charity Of the Year 2017.. with the goal for Credit Suisse to raise 600k... and I am pleased to say we won....

I hope this gives you a small introduction to me... and I looked forward to speaking and meeting you all in the future.

Teresa Deacon

Information updates

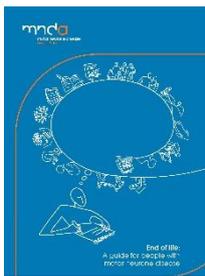


Making the most of life with MND: our new A5 booklet explores ways to adapt to life with the condition and maintain interests. Feature pages introduce people living with MND and their carers, who share their approaches to life, hobbies and experiences.

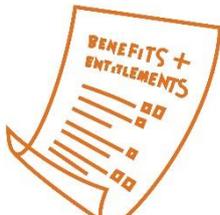


Carers hub: following work on our *About MND* web pages, our hub for carers, family and children has also been redeveloped. Finding the information you need should now be easier, with simple drop-down selections. Explore the hub at:

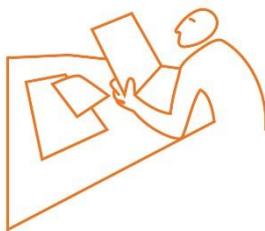
www.mndassociation.org/carers



End of life – a guide for people with motor neurone disease: our award-winning guide has been revised and updated. This resource is helping to build a bridge between families and professionals, during difficult conversations about end of life decision making. It now includes references to the NICE guideline on MND.



Information sheet 10A – Benefits and entitlements: this popular sheet has been revised and condensed to make it easier to reference. It now includes guidance about our new Benefits Advice Service.



Information sheet 10E – Work and MND: we have updated our guidance for people with MND and carers, on decision making about continuing or leaving employment, and your rights.

You can download our resources at: www.mndassociation.org/publications or order printed copies from our MND Connect helpline: 0808 802 6262, mndconnect@mndassociation.org

Forthcoming Events

Friday December 1st Craft Fair 2.30 pm
Sunnyside Primary School Northampton NN2 8QS

Wednesday December 6th Drop In Lunch 11.45am --- 2pm
The Garden Centre Newport Pagnell Road Wootton NN4 6HP

Sunday December 10th Christmas Buffet Lunch 1.30pm ---5pm
St Matthews Church Parish Centre 27a The Drive Northampton NN1 4RY

Sunday 17th December Family Yuletide Concert 7.30 pm
Village Hall, Roade, NN7 2LS

Wednesday January 3rd 2018 Drop In Lunch 11.45am --- 2pm
The Garden Centre Newport Pagnell Road Wootton NN4 6HP

Wednesday February 7th Drop In Lunch 11.45am --- 2pm
The Garden Centre Newport Pagnell Road Wootton NN4 6HP

**Saturday March 3rd 2018 Concert at St Mary's Church Knox Road Wellingborough in
Memory of Roger Smith .More details later**

Wednesday March 7th 2018 Drop In Lunch 11.45am --- 2pm
The Garden Centre Newport Pagnell Road Wootton NN4 6HP



Christmas Buffet Lunch

Our annual Christmas Celebration will take place on

Sunday December 10th 2017 1.30pm –5pm
at St Matthews Church Parish Centre
27a The Drive Northampton NN1 4RY



We are delighted The Mayor and Mayoress of Northampton will be among the guests

There will be entertainment by Wollaston Singers

There is a small charge for friends and family of £4.00,
of course people living with MND and Carer and our guests are complimentary

We hope to see as many of you as possible there

Lucas Productions



"Passion For Performance"

In Association With

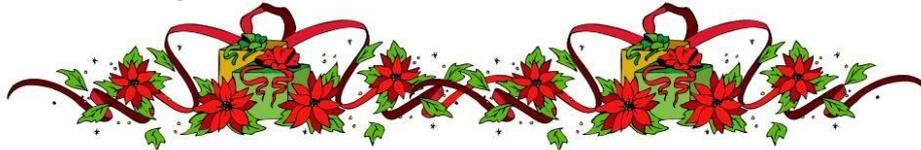
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FOR ALL THE FAMILY

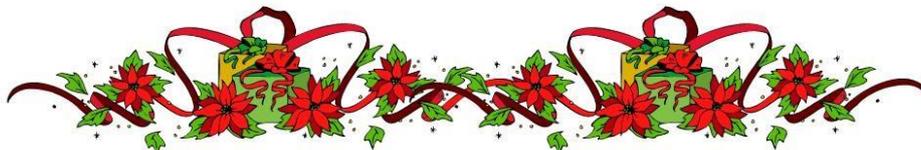


7:30pm ~ Sunday 17th December

Road Village Hall, Northants

All Tickets Just £7

Available On The Door Or Call: 01604 862634



Join Us For Mulled Wine, Mince Pies & Lots Of Festive Spirit...

SERVICES EXPLAINED

Motor Neurone Disease Association, PO Box 246, Northampton NN1 2PR

Telephone: 01604 250505

Membership – This is free to people living with MND and their carer. As a member of the Association you will receive a membership card, our regular magazine *Thumb Print*, full of information - the latest news in care and research, as well as features on how some families cope daily with MND. Automatic link to your nearest branch/group and opportunities to get involved at a local level. Invitations to the conferences and seminars we organise. Our *Annual Review/Impact Report* which outlines our progress made over the last financial year and our plans for the year to come. Full membership also entitles you to elect Association trustees and vote at the Annual General Meeting. If you are interested in becoming a member, please contact MND Connect

MND Connect – 0808 8026262 - a helpline available Monday - Friday 9am -5pm, 7pm - 10.30pm (charged at local rate) and email service mndconnect@mndassociation.org. Provide advice on all aspects of MND. They can also post information about MND and support available

Regional Care Development Adviser (RCDA) Scott Maloney – 07501682095 scott.maloev@mndassociation.org – assisting with advice and support on care management and service development in your area.

Volunteering Development Co-ordinator (VDC) Neil Penson 01604 611686 neil.penson@mndassociation.org VDCs work with existing branches and groups to develop and build on good practice. This includes the recruitment and induction of branch officers. They are also involved in setting up new branches and groups in areas where there is little support for people with motor neurone disease.

Equipment Loan - a limited range of equipment is available where not obtainable from statutory services. Requires a written referral from the relevant health or social care professional

Financial Support - towards items not available from statutory services. Requires referral from relevant health or social care professional

Registered Office: Motor Neurone Disease Association
David Niven House, 10-15 Notre Dame Mews Northampton NN1 2BG
Registered charity number – 294354

Northamptonshire Local Branch

Open Meetings Local support from people in the area who are familiar with the affects of MND. The branch holds bi-monthly meetings for anyone with, or interested in, MND at St Matthews Church Parish Centre. (Contact details on next page).

Association Visitors (AVs) are volunteers who offer advice and support to anyone affected by MND, either face to face, via telephone or email. Please contact your RCDA on the number above for more information.

Social Gatherings are occasional opportunities for people affected by MND to come together informally in a safe, friendly environment. Transport can be arranged if necessary.

Lunchtime Support Group is another opportunity to meet informally to share experiences.

It is usually held on the 1st Wednesday of every month at the restaurant in the Garden Centre, (next to Waitrose) Newport Pagnell Road, Wootton, Northampton NN4 6HP. There is no need to book – just come along but, if possible, please arrive by 11.45. Free for anyone with MND and their carer.

NORTHAMPTONSHIRE BRANCH CONTACTS

Patron: Dr John Smith

Chair:	Kate Inchley	01933 667616 inchleyk@gmail.com
Vice Chair:	Robert Nixon	01933 229602 robchnixon@talktalk.net
Secretary:	Gerry Skipper-Byer	01536 723304 07861 610323 gedda1064@gmail.com
Treasurer:	Colin Byer	07779 225760 colin.byer@yahoo.co.uk
Branch Contact:	Kate Inchley	01933 667616 inchleyk@gmail.com
Newsletter:	Chris Hull	chull1@waitrose.com
Website:	Derrick Peasland	01604 454870 dellpea@ntlworld.com

Association Volunteers (AVs): Joan Randell, Angela West, Margaret Robinson, Annette Liddon and Deborah Bull

Committee Members: Kevin White, Derrick Peasland, Jackie Atkins, Dave Atkins, Maureen Sanders, Priscilla Davies, Ali Buttress, Sally Wilkins, Diana Smith and Paula Solomon.

Website: www.mndnorthants.org.uk
Email: enquiries@mndnorthants.org