

Northamptonshire Branch

## SEPTEMBER 2017



Welcome to the autumn issue of our newsletter  
but maybe there is still summer sunshine to come

## **MND Association Annual Conference and AGM Saturday July 8<sup>th</sup> 2017**

held at the Raddison Blu Hotel, East Midlands Airport

Members of the Northants Branch attended, we were welcomed by the Chair of Trustees, Alun Owen.

C.E.O. Sally Light reflected on 2016, thanked Volunteers and Supporters for their hard work and commitment.

Chris James, Director of External Affairs, Steve Bell and Karen Pearce Directors of Care North and South presented Transforming MND Care and the impact of the NICE guidelines on MND.

We then transferred to one of the four learning workshops

1. Fundraising -- Money for nothing  
Kathryn Sheldon and Richard Shackelford - Regional Fundraisers
2. Care Update ---Benefits, Communication Aids and Voice Banking  
Matthew Hollis Communication Aids Co-ordinator and Vicky Eales Speech and Language Therapist
3. Are we there yet? The journey from awareness to Action  
Chris James and Colin Morris Head of Communications
4. Local and Regional Finance  
Linda Cherrington, Director of Finance and Andrew Zielinski Head of Finance

These workshops were very well received by members.

The AGM and questions followed after lunch. .

The Guest Speaker for the day was Professor Ammar Al-Chalabi

The afternoon ended with final thoughts, networking and refreshments

To find out more about the 32<sup>nd</sup> Conference and AGM go to the website  
[www.mndassociation.org](http://www.mndassociation.org)

Kate Inchley

## RAISING AWARENESS

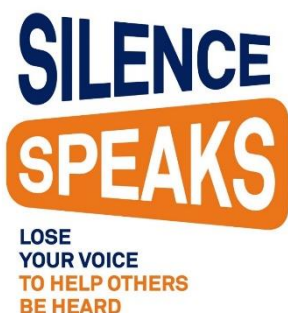
I was asked if I would go to an induction day for the MNDA by Emma Johns, communication manager at David Niven house, to meet and have a chat with new employees to try and give them an insight into someone living with MND.

I think it went ok we had an open discussion with no questions off limits, Janette was also involved with the partner and carer side of things.

It was a quite emotional day for ourselves and also for some of the staff, but if they went away with a little more knowledge and understanding of the people their work is helping it was worth it.



Brian Mathie



... sign up as an individual, team, school or workplace and raise funds and awareness for your local branch or group in **OCTOBER** this year!

To find out more visit [www.mndassociation.org/silencespeaks](http://www.mndassociation.org/silencespeaks) and register for your pack or contact us at [fundraising@mndassociation.org](mailto:fundraising@mndassociation.org)





*Paula and David Solomon were featured in the recent national campaign to raise awareness and they do a lot to raise funds for the Northants branch*

I am taking part in the Northampton Half Marathon on Sunday 3<sup>rd</sup> September, David will be coming along to spectate.

Mark Lewis and I will be going up to Newcastle on the 9th September to take part in the Great North Run.

Mark Lewis is organising another Kingsthorpe running pub crawl, starting and finishing at the Obelisk Centre. This will take place on Friday 29th September. Last time we raised £500, Dave will be coming along in his wheelchair.

The 71st Northampton Girl Guides group will be doing a sponsored walk, 9 miles, starting and finishing at the Obelisk Centre. Half of the money will go to their trip to Disneyland next November and the other half to the MNDA, Northampton Branch.

Dave and I have an article going into Woman's Weekly on the 12th September

I have just signed up for another 100k walk. The Wye Valley. 11/12th August next year! this will be my 5th 100k.

Paula Solomon

## The MND Charter Campaign

As many of you will be aware, the MND Association launched the next stage of the MND Charter campaign, 'Champion the Charter on your doorstep' on March 1<sup>st</sup>, 2017.

The aim of the Charter is to ensure that Councils (and other statutory bodies) are better informed and understand the needs of people with MND and work towards achieving the right care, in the right place, at the right time for people with the condition. All over the country, volunteers, supporters and staff have been approaching their councillors and asking them to adopt the Charter and then, having done so, encourage them to outline how they can make the positive changes that are needed.

The MND Charter is a statement of the respect, care and support that people living with MND and their carers deserve and should expect. The five points of the Charter are:

1. The right to an early diagnosis and information
2. The right to access quality care and treatments
3. The right to be treated as individuals and with dignity and respect
4. The right to maximise their quality of life
5. Carers of people with MND have the right to be valued, respected, listened to and well-supported.

The eagle-eyed amongst you will have realised that not all the five points of the charter are totally relevant to local councils – diagnosis, information and access to quality care and treatments fall under the remit of the NHS – but there are things that councils *can* do. For instance, councils are responsible for **Disabled Facilities Grants (DFGs)** to help people pay for alterations to their homes as the disease takes hold -for example, to widen doors for wheelchair access or create accessible wet rooms (although most people with MND do not pass the 'means test' and have to fund the work themselves or with a grant from one of our local groups.) These can take an awfully long time to process, so by undertaking to fast-track applications from people living with MND, councils can make a huge difference. Other things that councils may be responsible for include:

- Council Tax,
- Housing Benefit,
- Housing Association Homes,
- Adaptations to council properties for people with mobility problems,

- Older Person's bus pass,
- Blue badge,
- Community Alarms,
- Changing council tenancy,
- Care at home,

And each of these things may be made better or streamlined for people living with MND if the council understands and commits to meeting the special needs that people have.

At the beginning of July, I approached local Borough Councillor Anna King and asked if she would present a motion to Northampton Borough Council, asking them to adopt the Charter. I have to say that Anna was incredibly supportive and 'on board' with the idea straight away. Things moved quite quickly after that: a motion was tabled for the next Council meeting on the evening of Monday 10<sup>th</sup> July and I was asked to speak at the meeting to explain the purpose of the charter and why the council could make a difference to people living with MND.

Because I would only have 3 minutes (!) to talk, Alice Fuller and the Campaigns team at the Association kindly furnished me with a range of campaign material that were distributed to all the councillors beforehand.

It's probably fair to say that I am not a natural public speaker and I did find the grandeur of the council chamber a little intimidating when I got up to speak. Luckily for me, I was enormously supported by the presence of local Branch members Jackie and Dave Atkins who had given up their Monday evening and were resplendent in their MND Association T-shirts. Huge thanks to them both!

Once I started speaking, the 3 minutes seemed to pass in a flash and almost before I knew it, my time was over. Our motion was only the second of many to be debated that night and as the debate would not start until all the motions had been heard, Jackie, Dave and I took our leave and slipped quietly out the back of the room. Later that evening, Cllr Anna King contacted me to say that the motion had been passed with full, cross-party support!



Just over a week later, Cllr King and Alice appeared on the Helen Blaby BBC Radio Northampton show talking about the council's adoption of the Charter.

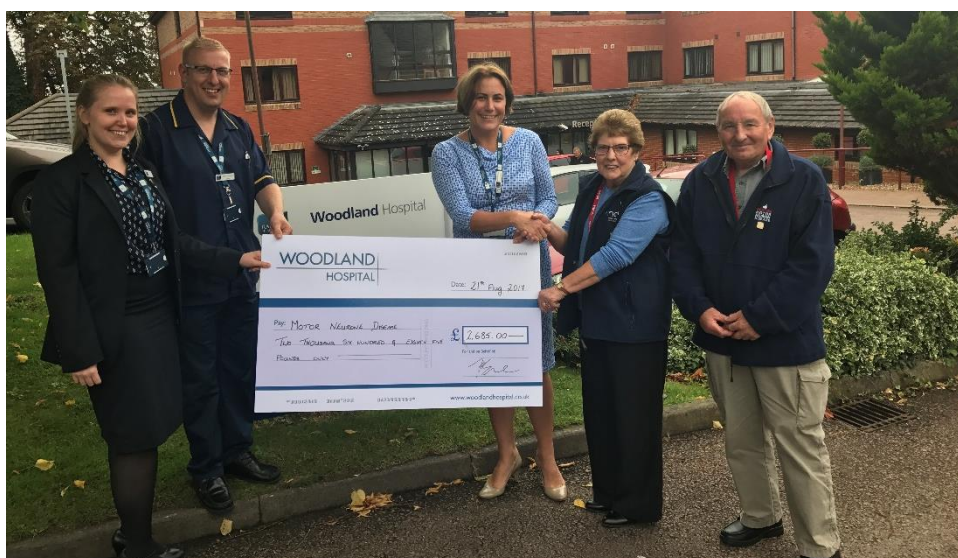
Over 50 Councils have adopted the Charter so far, with lots more having been approached and considering adoption.

Northampton Councillor Anna King, cabinet member for community safety and engagement, said: *"We want everyone who calls Northampton home to have access to quality services that allow them to make the most of life. Motor neurone disease progresses incredibly quickly so it's important that the right support is available to people when they are diagnosed."*

You can find out more about the charter here: <http://www.mndcharter.org/>

**Scott Maloney**  
RCDA for Central Midlands

## Cheque Presentation



On August 21<sup>st</sup> Peter and I went to the Woodland Hospital Kettering to receive a cheque. The Woodland is a private hospital but also serves NHS patients. Each year the staff support a chosen charity by fundraising, this past year the Northants Branch have been the chosen charity. They fund raise with many initiatives - quizzes, bake sales, raffles, lottery balls and lots more. The total money raised for our benefit was £2,685 for which we are extremely grateful. The money will be a helpful uplift to our funds, helping us to support more people living with MND in Northamptonshire.

Kate Inchley

# **DATES FOR YOUR DIARY**

## **Drop-in Lunch**

**Wednesday September 6th 12.00-2.00pm**

Garden Centre, Wootton Northampton NN4 6HP

## **Drop-in Lunch**

**Wednesday October 4th 12.00-2.00pm**

Garden Centre, Wootton Northampton NN4 6HP

## **Open Meting**

**Sunday October 8<sup>th</sup> 2.30pm – 4.30pm**

Social Afternoon

MND Christmas Cards for sale

St Matthews Church Parish Centre

27a The Drive Northampton NN1 4RY

## **Coffee Morning**

**Saturday October 21<sup>st</sup> 2017**

7 Francis Dickens Close Wollaston 10am ---12,30pm

Cakes, Raffle, MND Christmas Cards Proceeds to branch funds

## **Drop-in Lunch**

**Wednesday November 1st 12.00-2.00pm**

Garden Centre, Wootton Northampton NN4 6HP

## **Drop-in Lunch**

**Wednesday December 6th 12.00-2.00pm**

Garden Centre, Wootton Northampton NN4 6HP

## **Branch Christmas Buffet Lunch**

**Sunday December 10<sup>th</sup> 2017 1.30pm --- 5pm**

Entertainment

The Northampton Mayor and Mayoress will be attending

St Matthews Church Parish Centre

27a The Drive Northampton NN1 4RY

## **Sunday December 17<sup>th</sup> 2017**

Six –Get Festive Christmas Entertainment

Roade Village Hall . (more details later date )



# 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](mailto: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.maloney@mndassociation.org](mailto:scott.maloney@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](mailto: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 1<sup>st</sup> 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**

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

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

**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](http://www.mndnorthants.org.uk)  
**Email:** [enquiries@mndnorthants.org](mailto:enquiries@mndnorthants.org)