

Northamptonshire Branch

JUNE 2017



Welcome to the summer issue of
our branch newsletter

RECENT EVENTS

AGM Sunday April 9th 2017



Eighteen members including our Guest Speaker attended the AGM. The business part of the meeting followed the protocol, with reports from the Chair, Secretary and Treasurer. Election of officers took place and two new committee members were elected. The Chair thanked all committee members and members, friends and families for their continued support throughout the past year without whose help and fundraising the branch would not be able to care for and support people living with MND and their families.

Jackie and Dave Atkins received their 20 year Long Service Awards from Dr John Smith our Patron.

Our guest speaker was Pete Collins a Volunteer Fundraiser from Derby who inspired us all with an account of how he got involved with the MND Association and his enthusiasm and drive when it comes to fundraising and how to get everyone involved particularly through the media, i.e. local radio, papers, facebook and twitter in fact anything that's available Pete will access it.



The afternoon finished with tea and cakes.

Kate Inchley



Walk to D'feet May 13th /14th

On May 13th Northants Branch took part in the annual International Waendel Walk around Wellingborough and surrounding villages as their Walk to D'feet.

In all fourteen people signed up. Six walking 6 miles, five walking 16 miles on Saturday and three walking 16 miles on Sunday 14th. The weather was kind but a bit breezy at times. A lady from Philadelphia, USA whose brother had died from MND was in London at the time and joined us along with a couple from Market Harborough who have connections with some of our members on the Saturday walk. We had a very enjoyable time walking and chatting, finding out about each other.



Kate Inchley



Concert April 7th Windmill Club Rushden

£410 was raised at the recent concert performed by Wollaston Singers. Ticket sales were less but supported by a very good raffle the audience enjoyed a great evening of singing.

Kate Inchley

80th Birthday Challenge

Approaching my 80th birthday I was wondering how to celebrate the occasion.

Do I have an afternoon tea? a cheese and wine evening? a buffet lunch? Many different friends. Would they all get on? so many questions.

I was planning on asking for donations for M N D research instead of presents but no party meant no donations. Why not do a challenge?

I had for a while fancied doing a **zip wire** so things seemed to fall into place. My son booked for the one at Wicksteed Park and my brother said he would do it with me. We set up a just giving page and obtained sponsor forms and tee shirts from head office and the money started rolling in.

The big day duly arrived with blue skies and glorious sunshine. Kate and her daughter, Jackie and Dave, family and friends turned up to support is. We duly registered, got fitted out in harness and hard hats and we were ready to go.



It was fantastic! Such an adrenaline rush. We would have liked to do it again.

There was good press coverage by the Evening Telegraph..I thought that was the end of it but apparently the manager of the new B and M store which was opening on the following Wednesday had seen about it and was so impressed that he wanted me to join the mayor in opening the store. More press coverage for motor neurone disease and a donation of £250 of B and M tokens for my zip wire fund.

What an amazing birthday. Having set a goal of £1000 it will be nearer to £2000 by the time all the money is in plus lots of publicity for the cause. A big thank you for all those of you who supported me.

Maureen Sanders

Tombola

On Monday May 1st we were ably assisted by Margaret and Derrick when we went to St Marks Church, Whitehills where we had a table at a May Day event, we did a tombola, and took some jigsaws to sell, Margaret took the doll for the ongoing name the doll competition. The event was extremely well supported and most of the tombola went to new homes along with the jigsaws. We were so busy Derrick took over on the name the doll and Margaret helped me find the numbers for the winning tickets, it was a very successful afternoon. Many thanks to Margaret for getting us invited to the event and the church for the invite, and as always the church people made us feel very welcome. The cream teas were delicious. We made £129.40 not bad for a couple of hours

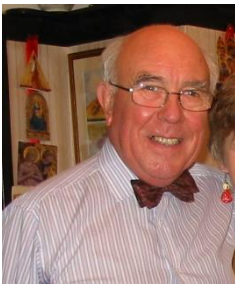


Jackie and Dave Atkins

TO CELEBRATE A LIFE

It's so sad that to celebrate a life we must lose someone we love dearly: in this case, someone who, when told that his diagnosis of MND was correct didn't think of what it meant to him but said "Oh well, there's always someone worse off than me because I've had a long life that I can look back on and remember the good things". That someone was Roger Smith and, to celebrate his good life, on the first anniversary of his death, a concert held in his memory was so well attended that the church of St Mary the Virgin in Wellingborough was packed – and that's no mean feat as it's not a small church.

Huge thanks are due to so many people, all of whom helped to make the memorial concert such a success: the organists and pianist who worked so hard to provide a brilliant concert including Lee Dunleavy, the current Director of Music at St Mary's, Christopher Colby and Mark Raban, all of whom provide the wonderful accompaniment at the Sunday services and who all played pieces loved by Roger, Pamela Rawlinson who gave us a piano recital and Simon Bland, a former organ scholar at St Mary's (who will be giving a concert at St Mary's on 10th June to celebrate "Music for Her Majesty" as it's the Queen's official birthday). Praise is also due to the Wellingborough Orpheus Choir for their singing and to everyone from St Mary's who helped make and serve the refreshments provided during the interval.



There was also as "mystery guest" at the recital who had nearly everyone in tears – a film of Roger himself playing the organ (taken before he developed MND of course).

At the retiring collection, thanks to everyone's generosity, we raised £887.13, all of which went to support the Northampton Branch of the MNDA.

Diana Smith



CHERYL CORRODUS at the Royal Garden Party

Cheryl, who is a Palliative Care Occupational Therapist, says she was amazed to win two Quality Care awards at a ceremony held last year by Northamptonshire Healthcare Foundation Trust “but I never in a million years thought I would then be invited to Buckingham Palace”.



Cheryl took her mum to her special day, the sun was shining, the band was playing “and to have actually seen the Queen and other members of the royal family was spectacular”.



Although Cheryl has worked mainly in the Cynthia Spencer Hospice for over 17 years, she also has a large caseload of people she visits in the community. Dr Bhavyang Acharya, Consultant in Palliative Medicine at the hospice said “Cheryl takes a personal interest in improving her patients’ functional ability and making their lives as comfortable as possible. Most importantly she does all this with a big smile on her face and in a manner that makes patients and their families feel that nothing is too much trouble.”

Care News

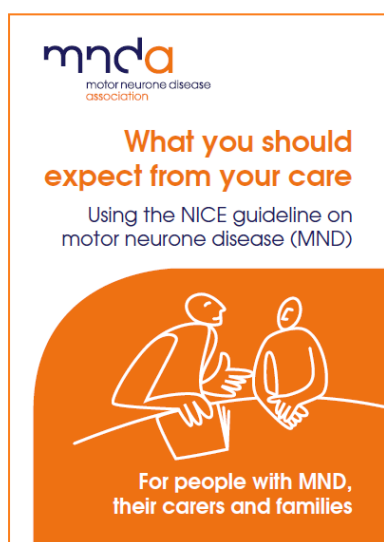


New and updated care resources

We have some new care resources available:

- [Eating and drinking with MND](#)
- [What you should expect from your care](#)

You can order copies from the care admin team by emailing careadmin@mndassociation.org or calling 01604 611812.



New guide to getting the right care

We are delighted to announce the launch of our new publication, *What you should expect from your care*.

This small booklet can be carried in a pocket, purse or wallet. It features key points from the NICE guideline on motor neurone disease to help open discussions with professionals about treatment and care.

NICE guidelines are produced by the National Institute for Health and Care Excellence. Each guideline offers recommendations to help health and social care professionals better support a specific condition, like MND.

The aim of our new pocket booklet is to help people gain better outcomes at appointments and raise awareness for the new guideline.

“You cover so much in this little leaflet that is essential to a newly diagnosed person.” Carer, supporting a person with MND

You can order a printed copy of the new pocket booklet or other publications from our MND Connect helpline:

mndconnect
0808 8026262
mndconnect@mndassociation.org

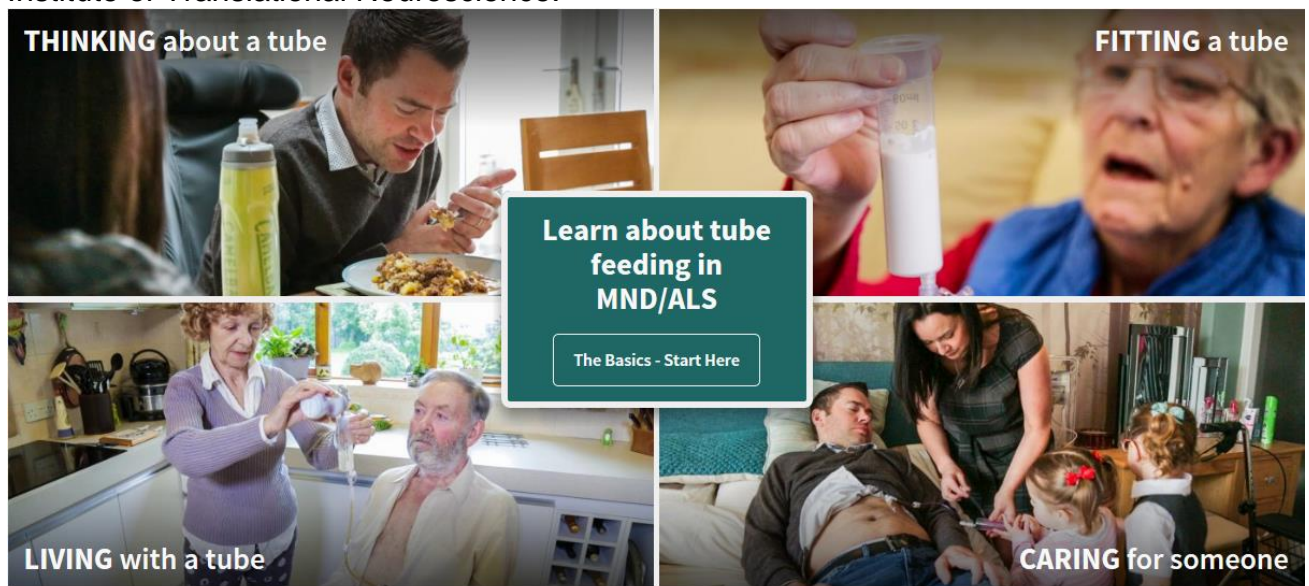
Update on online services for young carers

We recently discovered that the Carers Trust online services for young carers and young adult carers, Babble and Matter, are now closed. However, there are other organisations that can support children and young people affected by MND. Hope Support Services is a charity that provides online support for young people when a family member is diagnosed with a life-threatening illness. You can find out more at: www.hopesupport.org.uk

Young carers can also contact local young carers organisations for practical support and activities. They can find local young carers services through websites like Carers Trust at: www.carers.org or Carers UK at: www.carersuk.org or, they can contact their local authority, or in Northern Ireland their local health and social care trust.

New online resource to help making decisions around tube feeding

We are now referencing out to myTube, an online resource that explores decision making and usage of tube feeding through video and information content, in our information and webpage. The resource was developed by SITraN – the Sheffield Institute of Translational Neuroscience.



The website has been made in collaboration with people living with MND who wanted a way to 'meet' people and see their feeding tubes in use. Hearing their experiences and personal stories on myTube can help when making decisions about whether to have a feeding tube fitted or not.

The Oxford MND Care Centre Steering Group

You might not have known that Oxford's MND Care Centre, has a "Steering Group"; but it does. It meets twice a year. It's made up of local MND consultants, coordinator, specialist nurse, physio and OT, as well as various MNDA regional bigwigs – and our hard-working Oxford branch secretary, Lesley, and a patient representative, i.e. me (*Michael Wenham*)

My understanding is that the patient rep is meant to bring comments from patients about the functioning of the centre to the group. Should you want to, please feel free to contact me. I'll pass on concerns and compliments! It's nice to feel I'm being useful. I have a Facebook page and an email account (michaeltwenham@gmail.com), or if you prefer the phone 01235 760094.

From my very sketchy notes from the October meeting, I see there is still plenty on the research agenda in Oxford: a cooperative monitoring project between GSK, the pharmaceutical company, and Maclaren, the F1 racing company; looking at the genetic basis of MND; AMBRoSIA (a multicentre biomarker research project); BioMOX; stem cell and mouse models, and bowel habits study (about which my memory is a blank).

The amount of research raised the question as to whether it was changing the nature or the feeling of the clinic – which the consultants and staff definitely did not want to happen. At the moment the emphasis is very much on managing the disease and caring for us. Although many of us keen to contribute to research, it does affect appointments, with more paperwork and more tests. So the questions are: do we feel that this is happening? Do we mind? Would we mind more happening? Would we feel under pressure, about taking part in research? **This is where I really need your feed-back, please.**

Among other matters discussed were the UK National Registry of MND (and datasecurity), having a clinic audit (i.e. consumer satisfaction survey), two further study days are planned for those affected by the familial form of MND, and for PLS.

I reported feedback from the PLS day in Oxford, the service provided during Jenny Rolfe's maternity leave, and raised the problems encountered when dealing with authorities and agencies when you have lost your voice. Rachael and Jenny were intending to work with Moira McIver towards a widely helpful solution. When you're unable to articulate, let alone nuance, your needs, it is the most horrible frustration.

I have to admit to being impressed, not least by the concern of the clinic professionals to put patients first. **Do let me know if you would like me to feed anything back to the group. Thank you.** *Michael Wenham*

(Seen in a recent Oxford branch newsletter and amended with the permission of Michael Wenham)

FUTURE EVENTS

MOVE THE WORLD CHALLENGE

When Jay Lucas worked out the circumference of the earth was approximately 24,881 miles long, he had a crazy thought - and within a few days he'd created a virtual fundraising challenge. Jay, from Northampton, is leading a team of 48 who are hoping to clock up the miles around the world in 365 days for charity. Jay, who has been raising funds for the MND Association since his father died from the disease in 2008, took to Facebook and within a few days the MND Move the World Challenge was created.



Starting on 6th May, 2017 Jay's friends, family and Facebook acquaintances from the UK and overseas will attempt to run, swim, row, cycle, jog or walk the whole distance of the earth's diameter within one year.

Each time they 'move' their distance will be logged on a specially designed website (www.mndworld.co.uk) where they'll be able to keep track of how far they've covered.

Jay said: "For the vast majority, Motor Neurone Disease (MND) is a death sentence and for some it is a lifetime of reliance on others. "Sadly, for my Pops, his fate was the former and a little over a year after his formal diagnosis, he died. "Until it hit our family like a thunderbolt, I knew nothing of what MND was and how this cruel disease can affect how you walk, talk, eat, drink and breathe. "Although there is currently no cure for MND, symptoms can be managed to help achieve the best possible quality of life and that is the point of this challenge.

Jay said: "In the team, we have many people affected by and some diagnosed with MND. "I'm overwhelmed by the support I've had so far and it will be fantastic to see how well we all do over the next year, moving around the world to raise invaluable funds to help those with MND who may now be struggling to move, and also support further research into this horrendous, indiscriminating illness.

" Sharon King, regional fundraiser for the MND Association, said: "Jay is such a dedicated and inspirational supporter. "Without people like him the MND Association simply would not be able to provide its vital support services and fund research to find a cure. "Together we are making a real difference for people affected by this devastating disease."

To support the MND Move the World Challenge team and make a donation visit www.justgiving.com/fundraising/mndworld or text to donate: MTWC99 £5 to 70070 (extract from Northants Telegraph)



Round the Island Race

in association with

CLOUDY BAY
NEW ZEALAND

This annual one-day yachting extravaganza with upwards of 1,500 yachts and 12,000 sailors competing, is managed by the Island Sailing Club in Cowes and the vast fleet circumnavigates the 50nm course westabouts around the beautiful coastline of the **Isle of Wight**. This year's race takes place on Saturday 1st July and marks the 86th anniversary of the first race.

The Race is an all-encompassing event that caters for and embraces first timers, families, amateurs and professionals competing at the highest level.

My nephew, Ian Hull, will be entering the Round the Island Race in his boat "*Continuity*" and has nominated the MND Association as his charity. Ian is a seasoned yachtsman but it will be the first time as a crew member for my youngest son Roger.



Ian has set up a fundraising page at

<http://uk.virginmoneygiving.com/IANHULL>

all donations will go to the MND Association.

Chris Hull

STOP PRESS

We have been selected by Waitrose Community Matters at Wootton (next to the Garden Centre) so if you are shopping there this month, please put your green token in our box.

DATES FOR YOUR DIARY

Drop-in Lunch

Wednesday June 7th 12.00-2.00pm

Garden Centre, Wootton Northampton NN4 6HP

Open Meeting

Sunday June 11th 2.30pm – 4.30

Jay Lucas- Move the World

St Matthews Church Parish Centre

27a The Drive Northampton NN1 4RY

Concert

Friday June 16th 2017 7.30pm

Masque Theatre Barton Seagrave Kettering

A concert by Voices Aloud Musical

Director Hughie James

and The Seagrave Singers Musical Director Sue Peel

supporting Northants Branch MND Association .

Tickets £9 .00 online at www.Masquetheatre Kettering

Drop-in Lunch

Wednesday July 5th 12.00-2.00pm

Garden Centre, Wootton Northampton NN4 6HP

Drop-in Lunch

Wednesday August 2nd 12.00-2.00pm

Garden Centre, Wootton Northampton NN4 6HP

Open Meeting

Sunday October 8th 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 21st 2017

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

Cakes, Raffle MND Christmas Cards Proceeds to branch funds

Branch Christmas Buffet Lunch

Sunday December 10th 2017 1.30pm --- 5pm

St Matthews Church Parish Centre

Sunday December 17th 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. 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 – 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 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
Email: enquiries@mndnorthants.org