

Northamptonshire Branch

MARCH 2015



welcome
to the  edition
of our local branch newsletter

RECENT EVENTS

On Saturday November 29th Dave and Jackie assisted by Margaret and Derrick went to The Parochial Church Rooms at Wollaston to do a table top sale. Peter had set up the MND banners etc when we arrived and Kate came soon after. It was quite well supported and we raised £29.55. There was a lovely friendly atmosphere and some yummie cakes to be had with the tea/coffee.

Jackie Atkins

CHRISTMAS SIX GO SINGING

On Sunday 21st December 2014 Jay Lucas presented a marvellous Six Go Singing evening concert at the Roade Community Centre proceeds going to the MNDA. It was well-supported by family, friends and the local community. The usual cast of Six Go Singing were Jay, Louise, Lorna, Jon, Sue and Mindy. Also appearing at Jay's concert was a Vocal Harmony Group called 'JINX' providing suburb harmonies.

With Mulled wine, tea, coffee, mince pies etc., a wonderful evening was had by all including the twins (with Jay below).

A raffle raised funds for the MNDA and with the total of Jay's commitment of fund raising and Santander a total of £1600 has been raised through 2014.

May I wish you all A Good and Happy 2015.

Margaret Robinson AV



CHRISTMAS PARTY BUFFET LUNCH



Sunday December 13th 2014

Over 60 members of the branch enjoyed the annual buffet lunch, this is an opportunity for people living with MND, carers, family and friends, committee members, association visitors and guests to come together meet, have lunch, enjoy a drink, chat and be entertained. The event is always well supported, and we see people we haven't seen throughout the year.

Dave and Jackie again organised the amazing raffle which raised £201 20p a wonderful effort. Thanks go to Shirley, Maureen, Margaret, Priscilla and others who made mince pies/cakes,

make the tea and coffee, to Rob and Kevin (above) who run the bar, Jackie and Dave, the association visitors for special food, Peter who sold the remaining Christmas Cards, chutneys and jams and Wollaston Singers (below) for the entertainment and last but by no means least to Walter Loweth and all the other gentlemen who set the room out and help clear up afterwards. A special thank you to Walt and Shirley who open up the hall for us on our Sunday open meetings. We look forward to a successful 2015.

Kate Inchley



Theory of Everything Film Release



On Friday January 2nd 2015 we were invited by Cineworld to take a bucket collection to coincide with the general release of the film about Stephen Hawking and his first wife Jane Wilde. Professor Stephen Hawking as we all know, went on to develop MND at a very young age and is Patron of the Association.

The Northants Branch went along to Cineworld at Sixfields, Northampton. Peter, Kate and Rob from the branch went along helped by Trudi Sadler Community events Fundraiser

and her husband Martin, Paula McGrath Thumb Print Editor, Amanda Stredwick MND Connect Financial Support, Belinda Cupid Head of Research. Paula's husband came and took photos. We covered four viewings of the film from 12.30pm - 10pm and raised £293.59. Our grateful thanks to all staff at David Niven House without whose help we would have had along and tiring day.

Nationally, collections took place at 75 cinemas, raising almost £25,000.

Your help is needed

We do find it difficult at times to get enough people to cover events such as the one above

If you would like to add your name to a list of people we could call on occasionally please contact

Kate: on 01399 667616 07786 686 177 mob inchleyk@gmail.com

Thank you.
Kate Inchley

SPOTLIGHT ON ASSOCIATION VISITORS (AVs)



Joan Randell

A conversation with a friend seven years ago led Joan Randell to take on a volunteering role which she says has changed her perspective on life.

Joan became an Association Visitor (AV) in 2007, and since then she has supported 18 families affected by MND.

“My knowledge of the health care and social care system and experience of being a carer for my husband have been a tremendous help to me, but what is important is that all AVs have different personalities, approaches, experience and skills,” she said. “Above all, to become an AV you need to like people and want to help people. It’s important to be able to engage with individuals in all circumstances and to be prepared for different environments, lifestyles and approaches.”

Joan currently spends around three hours a week on her AV duties, although the amount of time committed to the role varies significantly from one volunteer to another. “I support people living with MND, their carers and the extended family,” explained Joan. “I offer face-to-face and telephone support and also communicate with people via email. I see myself as a befriender and listener. I have become part of the journey that people with MND have to make, but at the same time I have to remain apart from it. My role is to give people the opportunity to talk about their fears and anxieties, empower them and to be non-judgemental.”

“AVs signpost to, and liaise with, professionals. Sometimes, people affected by MND don’t know their way around the health or social care system so I help them find the information and resources they need,” she explained. “Above all we give people the permission to share with us how they feel. They share their innermost thoughts and it’s a privilege that they allow me into their lives and homes.” While Joan acknowledges conversations can be challenging, she says on-going training and support means she is well prepared. She says it’s a rewarding role and one she would recommend to others. “I feel privileged to be able to make a difference to people’s journey and life through this awful disease. I’m very passionate about what I do”.

We are recruiting AVs

The number of people with MND that the association is in touch with is increasing and we have ambitious plans to recruit many more AVs and to explore other caring roles and activities to meet their changing needs.

Would you like to find out more about the AV role?

Please contact us on 08456 044150, email volunteering@mndassociation.org or visit www.mndassociation.org/associationvisitors

(Joan is an AV in the Northamptonshire area. The above is an extract from an article in the MND Association’s Thumb Print Magazine)

CARE INFORMATION

The MND Association have an excellent range of Information sheets. The information is regularly updated and reviewed to reflect national changes. It is recommended you download or order information sheets when you need them rather than building up your own supply to ensure that you have the latest version at all times.

The redeveloped Information sheet 22A – Benefits and entitlements has been launched. It includes a new feature to easily see which benefits might be suitable and keep note of when applications are made.

Information sheets 14A – E about breathing and ventilation for MND are also available following revision. This range now includes a wider view of breathing therapies and how decision making may affect future care.

Download publications [here](#) or order on 01604 611812 or careadmin@mndassociation.org

COMMUNICATION AIDS

To ensure we capture both good and bad experiences of accessing communication aids on an on-going basis, the association has created an easy to use [online form](#). Please help promote this and encourage people with MND, carers, former carers, family members, volunteers and professionals to share their experiences.

We will use the information to identify areas of good practice and areas in need of additional support. If you have any queries please email: communicationaidsque@mndassociation.org

WHAT'S ON?

Wednesday 4th March 12.30 – 2.00 pm	Drop-in Lunch Garden Centre Wootton NN4 6HP
Saturday 7th March 10.00 – 12.00	Table Top Sale at Kingsley Park Methodist Church Kettering Road Northampton
Wednesday 1st April 12.30 – 2.00 pm	Drop-in Lunch Garden Centre Wootton NN4 6HP
Sunday 12th April 2.30 5.00 p.m.	Branch Annual General Meeting St Matthews Church Centre Northampton NN1 4RY
Wednesday 6th May 12.30 – 2.00 pm	Drop-in Lunch Garden Centre Wootton NN4 6HP
Wednesday 3rd June 12.30 – 2.00 pm	Drop-in Lunch Garden Centre Wootton NN4 6HP
Sunday 14th June 2.30 – 4.30 pm	Open Meeting St Matthews Church Centre Northampton NN1 4RY

SERVICES EXPLAINED

National Office

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

Telephone: 01604 611860

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 – 08457 626262 - 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) Rachel Boothman – 08453 751830 rachel.boothman@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

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.

Lunch Drop-In is another opportunity to meet informally. It is usually held on the 1st Wednesday of every month from 12.30 – 2.00 pm at the restaurant in the Garden Centre, Newport Pagnell Road, Wootton, Northampton NN4 6HP. There is no need to book – just come along. Free for the person with MND and their carer.

NORTHAMPTONSHIRE BRANCH CONTACTS

Patron Rev 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, William Standerwick, Angela West, Margaret Robinson, Joanne Burkimsher, Tracey Dixon and Annette Liddon

Committee Members

Kevin White, Derrick Peasland, Jackie Atkins, Dave Atkins, Maureen Sanders, Christine Hull, Priscilla Davies, Ali Buttress and Sally Wilkins

E-mail address: enquiries@mndnorthants.org.uk

Website: www.mndnorthants.org.uk

Registered Office:
Motor Neurone Disease Association
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10-15 Notre Dame Mews
Northampton NN1 2BG

Registered charity number – 294354