



# Newsletter

## Oxfordshire Branch

Website: [www.mndoxfordshire.org](http://www.mndoxfordshire.org)

### Positive News for the Branch Brings in 2010

Saturday January 23<sup>rd</sup> saw a well attended and happy branch meeting take place at the Holiday Inn Oxford. Not only was this the first get together of 2010 it was an opportunity to hear from people who had attended the Berlin International Symposium on MND in December.

Dr Kevin Talbot spoke with enthusiasm about the symposium and the huge opportunities it presented for scientists, doctors and researchers to explore and discuss latest research findings together. Kevin also explained some of the recent research developments in MND and their significance.

From the symposium Jenny Rolfe, occupational therapist, explained how she is now planning to map out individual needs and types of wheelchair a person may require at different stages of their journey living with MND.



There was a demonstration of the new cough assister machines – see page 2.

During the afternoon David Cairns received cheques presented by Chris Boyer on behalf of her husband’s memorial for the local branch. Pieteke Marsden delighted us all with a musical interlude singing and playing her guitar adding yet another dimension to the occasion. We

hope, Pieteke, you will come again! Following the music everyone enjoyed drinks and homemade refreshments always a special opportunity for catching up with friends and having a chat. What a fantastic start to 2010!



Thank you to all who attended on January 23<sup>rd</sup> and to those who contributed in so many different ways. If you have not attended a Friends and Family Event do come along and join us; we look forward to seeing new faces this year.



### April

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**Springtime Greetings from the Oxford Branch Committee**



**FIGHTING MOTOR NEURONE DISEASE**

*Our Thumbs Up symbol represents David Niven's last defiant gesture. It remains our symbol of hope.*

## Future Dates for Branch and Family Friends Group Events

**Saturday June 19<sup>th</sup> - Visit to Bledlow Manor Gardens ( Home of Lord Carrington)**

Contact Richard Coleman 01494 713861  
[rosswynassociatesltd@vigin.net](mailto:rosswynassociatesltd@vigin.net)

S. Bucks Branch

**Wednesday 7<sup>th</sup> July Family and Friends Group- Visit**

**Saturday 17 July**

**Coffee morning and cake sale-** ( please bring a cake if you can) 10.00am Methodist Church, Witney.

Contact Barbara Farrar for details 01993 704200

**Saturday 11<sup>th</sup>/ Sunday 12<sup>th</sup> September National Association AGM, Nottingham**

**September— Branch Walk**

**Friday 8th October- Aromatherapy**

**Thursday 25th November**

**Family and Friends Group**

**Pub social evening - come and buy MND Association Christmas cards**

**Contact: Lesley Ogden**

## Photo Montage

The local branch has been delighted to be able to raise funds for the provision of three cough assister machines. The cough assister was demonstrated by Liz Bellido and Jenny Rolfe. Liz explained how the cough assister worked and how it can be of huge value to people living with MND in specific circumstances. It was great not only to see the machine but how it worked. Dr Kevin Talbot reinforced the value of these machines and the help they can provide in the care and management of MND. Thank you to all fundraisers.



During December 2009 David Cairns and Lesley Ogden visited AWE Aldermaston, to collect a cheque from the Community Committee for £5000. A popular and long serving member of their staff (who lives in Oxfordshire), had recently been diagnosed with MND. David expressed our deep appreciation for the donation and assured those present that it would be used to support people in Oxfordshire



£262 was the final sum raised through the raffle at the event held by Sheila Jones.

2009 November Family & Friends event at The Bear and Ragged Staff, Cumnor



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## Interview with Val Russell

### - DeNDRoN Nurse

“I’ve met so many lovely people!” said Val Russell when asked about her role as Research Nurse with DeNDRoN at the JR Hospital in Oxford. DeNDRoN is the Dementias and Neurodegenerative Diseases Research Network which aims to raise the profile of research and make it become part of medical practice and clinical care. Val, who is a highly experienced nurse and has worked in neurosurgery since qualifying in 1985, told me she had been working for DeNDRoN since August 2008. At first this was for one morning a week and now for a day a week. Three days a week Val works as a Macmillan nurse also at the JR, another day Val spends with her Mum who has Parkinson’s Disease.

Although diseases such as Alzheimer’s, Huntington’s, Parkinson’s and MND have been known to exist for a long time, Val explained, there has been very little information about them. DeNDRoN is striving to bring together information and share it amongst the medical and health communities. Val’s main duties are recruiting people into the research trials, making known to patients and families and carers some of the trials that she is involved with and sign-posting people towards other studies. Val is there to encourage, motivate and support people whilst they are involved in the trials.

DeNDRoN research is thorough and focuses on unifying clinical care with research. “It’s not a snazzy area but collecting information is crucial to organising research and investigation. The team are so enthusiastic here and keen to communicate with families and people living with MND.” That enthusiasm, care and concern certainly came across from Val who was keen to add that her role is always to put the person and their health into the equation. “People shouldn’t be harmed by the research and there are many ways to participate.” Questionnaires would be an example of this. The DNA database allows not only the person living with MND to take part but carers and families as well who act as an environmental control. DeNDRoN is bringing a new look to these areas of research.

Laughing at the question, “What made you want to become a nurse?” Val recognised that it was what she had always wanted to do. Val started work as a nurse at the old JR Infirmary. The added experience of working at Witney Community Hospital gave her confidence to become a Macmillan and then a DeNDRoN nurse. Val saw how people could be helped to go through extremely difficult circumstances and emotions. She became interested in looking at the research as a way forward. Val explained that there is a difference between treating a situation and managing a situation. There are different types of symptoms controls. Information, education and support for the families are imperative in MND so that people understand what is happening throughout the course of the illness.

Working in Oxford is a big plus for Val; often people living with MND come long distances to the clinic and are keen to take part in trials. “Our patients come from as far as Dorset, Bristol and Southampton.” There is no pressure to take part in research and not everyone is suitable to take part in different trials. Inclusion criteria for participation are very strict. Respect for the individual by the consultants and the entire team is high on the agenda. DeNDRoN is a dynamic and highly motivated organisation and Val is proud to be part of that team. We talked about the fact that MND is a difficult disease and that there are many unknowns. Val spoke about some of those challenging areas and witnessing the gradations of the disease and its effects on everyone involved. However Val has seen how strong bonds in families and with carers and people living with MND become stronger and stronger.

The number of studies being undertaken by DeNDRoN is on the increase and the intention is that they will lead to earlier intervention, actions to improve the quality of life and, in the long term, a cure.

Thoroughly embracing her specialist nursing work and at the forefront of some significant developments, Val is a nurse making a real difference to peoples’ lives and in her words, “she hopes people find the clinic as inspiring as I do”. One thing is for sure meeting Val certainly is!

**Thanks to Val for the interview**



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## MND at the Oxford Science Festival



Many interesting stalls and a huge stage appeared in Broad Street, Oxford to launch the Science Festival with events related to 'Science in your World'.



Our stall entitled 'Enabling Communication', decked out with colourful balloons, attracted many people to try out various aids to help people who have difficulties in speaking. The latest eye controlled technology was extremely popular with both children and adults. Using only a small eye movement to activate the screen they sat unusually still demonstrating how little physical movement was needed. Other aids tried out by the public were lightwriters, palmtops and a letterboard all invaluable aids currently being used by people affected by loss of speech. Adaptations to computers were also shown making communication easier for people with MND and other disabilities.



Our volunteers were able to talk to many people about MND and its effects and pages of signatures were collected for the petition to be presented to government calling for a National Strategy to set standards for care of people with MND.



To represent a motor neurone a Chinese whispers game was played along Broad Street at the end of the afternoon. There were not quite enough people to break the world record of 1330 people, but the attempt was fun and was successful in raising awareness of motor neuron disease and the Association.

Thanks to all at the Care Centre and all Branch members who supported this cold but successful and enjoyable event.



## Family and Friends Support Group meetings

If you have an interest in MND you will be very welcome to these popular 'get togethers' held by the Oxfordshire Branch.

Usually there is a speaker and a topic of interest to appeal to everyone. There is always plenty of time to chat over refreshments.

Association Visitors, members of the committee, the Regional Care Development Adviser, Fiona Turner, as well as local health specialists and Rachael Marsden often come to the meetings. Sometimes people who have had experience of MND in the past will join us and like to keep in touch.

If you have MND, are living with MND as a carer, relative, or friend do join our friendly meetings, and remember that if you would like to attend and have difficulties with transport or care, the Branch may help with costs and advice.

### **MND CARE CLINIC**

The West wing, John Radcliffe Hospital, Headington, Oxford.  
For further details contact Rachael Marsden 01865 737460

### **Next meeting:**

**Thursday 13<sup>th</sup> May - Legal advice** Joint afternoon meeting in Thame with the S.Bucks Branch. Topics will include legal aspects of Care, dealing with Local Authorities, Enduring Power of Attorney, Court of Protection, Advance Directives

For other dates in the calendar see Page 2



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## Keep Communication Going !

People living with MND often have problems with speaking and communication. Moira and Jeanette had got to know each other through their illness and liked to meet up. Jeanette asked me if I would take her to see Moira for a "chat" in November 2009.

Jeanette who had no speech used a Palmtop communication aid with speech. Moira used a laptop with synthesised speech.

Being a bit naïve (retired speech therapist!!) I thought the conversation would be a bit stilted but we had so much fun, a real "girlie" chat. You learn a lot about people, like comparing notes about dating agencies in the 90s (Jackie and Moira) and the trials and tribulations with carers (Jeanette and Moira). We also swapped a lot of gossip from our lives.

We were only interrupted by Moira's son who came home from school with some friends. They all took it in their stride.

Sadly Jeanette died on April 5<sup>th</sup> but this is the way we will fondly remember her.

If you do not have a communication aid and need one, you can get an assessment from the Oxford Centre for Enablement. The equipment is costly but the MNDA and the Oxfordshire Branch will help with loan equipment or part fund the purchase.

Jackie Reeves



## Our Website



Thanks to **Pirminder Mann** who has taken over our popular website. Overwhelmingly the website should reflect your views and experiences, so please keep sending them!

### We need you!

All items for the website can be sent to **Pirminder** at:

[Pirm\\_mann@yahoo.co.uk](mailto:Pirm_mann@yahoo.co.uk)

You can access the website by first going to the main MND Association website:

[www.mndassociation.org](http://www.mndassociation.org)

or directly to the Branch website:

[www.mndoxfordshire.org](http://www.mndoxfordshire.org)

## I Never Thought of That!

The Holiday Inn saw another Family & Friends Group event take place on Friday February 26<sup>th</sup>. It was part of the Oxfordshire MND branch calendar of activities. The event was geared around the theme of gardening as suggested by a member of the local branch.

The main business of the afternoon was in two separate parts led by Susan and David Batt-Rawden and Susan Williams-Bradley. David presented illustrations of a wide range of wonderful gardens to visit and shared with everyone the experiences of family outings and disabled facilities. The beautiful and varied venues were diverse and full of adventure. The research around accessibility at each place was inspirational.

Fun was a theme in Susan Williams-Bradley illustrated talk. Susan explained ideas how to make gardening possible for all. Susan talked about planning being pivotal to managing the garden and ensuring it continues to be a pleasure and fun, not a burden for anyone. Marvellous practical ideas were put across for gardening at different heights and with different plants. Susan offered her services to those who might welcome a little personal input.



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**MND Connect is available 9am to 5pm and 7pm to 10.30pm Mondays to Fridays. Calls charged at local rate.**

**MND Connect  
08457 626262**



**Fund Raising for  
Oxford in California**



Left, Sophie Gardiner, age six, and her sister Tessa, nine, sell cookies and lemonade from their stall in their local park in California in aid of the Oxfordshire MNDA walk. MND is known as Lou Gehrig's Disease in the USA.

They learned of the charity walk in Oxfordshire. They set about, under their own volition, to make home-made lemonade, cookies and brownies for sale in their local park. To this end, they designed placards publicising the walk and waylaid passing pedestrians and motorists in an effort to solicit contributions. Their efforts raised \$ 100!

## Famous last words...

### “It never snows in January!”

These words I will never be allowed to forget especially when organising an event which requires people to travel from all over the country to a very snowy Oxford!

The Oxford MND Care Centre with the Specialist Disability Service and the MNDA organised three days of study for Health Care Professionals who care for people living with MND. There was a great response from people far and wide.

We called it ‘Pick and Mix’ days because people were able to choose which days they wished to attend, one two or all three. The first day was about specialist communication aids. Every one divided into small groups and had the opportunity to try out some basic forms of communication through to the very latest technology.

The second day addressed practical management issues. Jenny Rolfe demonstrated different pieces of equipment such as: wheel chairs, neck collars, mobile arm supports. Bridget Taylor talked about her PhD study and how equipment can affect people’s relationships; she encouraged therapists to think about all aspects of a person’s life .

The third day was about respiratory care. Candidates had to chance to try out a cough assist machine and learn about non invasive ventilation. Liz Bellido talked about the most up to date research in to exercise for people living with MND.

Each day had a key note speaker. Dr Kevin Talbot gave an introduction to MND.

Dr Martin Turner talked about the latest advances in MND research including his own BioMOx study and on the last day Prof John Stradling talked about respiratory care for people living with MND.

Despite very hazardous weather conditions people made an amazing effort to attend. The feed back from those who attended was really excellent and I would like to thank every one who took part, especially our local Oxford branch.

- Rachael Marsden

## Last-minute fund raising comes up trumps!

I only learned on a Wednesday evening that my two daughters, Claire and Bryony, intended to participate in a ten-mile charity walk on Saturday. The event, held in Cornbury Park, near Charlbury was in aid of the local branch of the MNDA. Why don’t you try and raise some sponsorship on our behalf they pleaded? You have lots of friends you can ask for support.

I am a member of a City Livery and we publish a Year Book listing everyone’s e-mail address. Furthermore, Liveries have a strong tradition of charitable giving extending back hundreds of years.

The response was far better than I could have hoped for, and my friends proved exceptionally generous, considering the walk was only two days away. There were even two fund-boosting promises from a couple of City-based charitable trusts.

In this instant electronic age, it is not difficult to communicate to members of your family what you are doing, even if they live in California. When all the cheques are in, this last-minute effort to raise funds will have netted more than £2,500. It has also made scores of people more aware of MND.

- C McCombe MBE



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## Letters From Our Readers

### On the Subject of Toilets and Toileting

It is my view that not enough is spoken about the routine daily occurrence of going to the toilet. Everybody does it, but when it comes to talking openly about problems that disabled people face it becomes a taboo subject. By making it a taboo subject this writer believes that solutions, much happiness and freedom can be lost to the disabled person, so it is time to “bring it out into the open” not literally though! - This writer believes that it is as much the responsibility of the disabled person to ask for help as it is for those that care for them to offer help.

People with MND will find it increasingly more challenging to go to the toilet. At first it maybe the problem of getting up from the seat, later it is will be what to do when in the wheelchair. Healthcare professionals are there to help and are not at all embarrassed to talk, so talk to them as things progress and before needs arise.

The first challenge is dealing with the issue of dignity. This writer suggests two things. Firstly think of toileting as a journey with the destination being the aim. Tell yourself “I want to go to that theatre and see the show” - what do I need to do to ensure I can go to the toilet when I am there? Secondly focus on where you want to get to and the outcomes. Anything can be endured if focus is put on where you want to get to not on the challenges of the journey needed to get there.

The loved ones around the disabled person can help with this process and reinforce positives. Disability is the time for a loved one and or carer to put aside petty thoughts of their own feelings about what is dignity and focus their attention on the fundamental needs of the person who needs help.

On the subject of getting more help, well there is too much to list but here are some suggestions all of which I have tried. How many people with MND have gone into a disability equipment shop and said “what have you got to help us go to the toilet?” - .One solution cost £3. How many have raised the toileting issue with a room FULL of health professionals? How many disabled persons carry a RADAR key that can open 7,000 locked toilets in the UK ([www.radar.org.uk](http://www.radar.org.uk)). How many have heard of the network of toilets with hoists and everything you need called Changing Places ([www.changing-places.org](http://www.changing-places.org)). How many have tried different approaches with their loved one with MND, had some set backs, had some failures, but helped to reach a solution to toileting relevant to current disability?

When was the last time you went out from home with no concerns about toileting getting in the way of enjoying yourself? If your answer is TOMORROW, you have overcome the first barrier to successful toileting; the NEXT toilet visit is the one you have to manage better not the one that has just gone.— **Mr Thoughtful.**

### Continuing NHS Health “Care”

Recently I have had the privilege to meet several families living with MND and am appalled at the problems they are having with arranging funding for care. The continuing care budget in Oxfordshire as stated on their website is meant to be “a package of care arranged and funded solely by the NHS because an individual’s need is primarily a health need rather than a need for care and accommodation.”

I have heard recently in Oxfordshire of people in the later stages of MND being refused NHS care in their homes or in a nursing home. Someone has received free care only at a review to have it taken away. Only two years ago someone I knew in Oxford had their whole care package funded at home and backdated. It is definitely a post-code lottery.

What is happening? Has MND suddenly not become a health need? And what about the terminal care element? If you do not receive Health Care you will be means tested by Social Services for your care package. My suspicions are that the government never allocated enough money and the guidelines have been subtly changed so that only very few people qualify for Continuing “Care”. A family living with MND needs to be treated with compassion!

Gordon Brown announced that there will be free care for the elderly and disabled so that they can remain in their homes. Where is this extra money coming from? If you feel as strongly as I do please write to your MP, The Oxford Times, a daily newspaper or the NHS in Oxfordshire via their website <http://www.oxfordshirepct.nhs.uk>

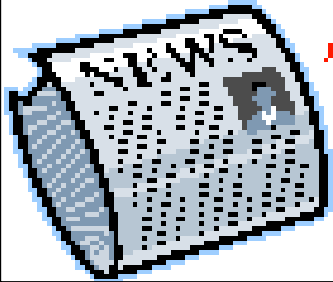
- Jackie Reeves



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## Newsletter



Thank you to anyone who has contributed to the Spring edition of the newsletter.

Please send letters, articles and pictures for inclusion in the next newsletter to Jane Street at:

[jbskirkella@yahoo.com](mailto:jbskirkella@yahoo.com)



For information, advice and support on all aspects of MND contact:  
MND Connect  
08457 626262

## Branch Contacts

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## Association Visitors

Hello from the Association Visitors in the Oxfordshire Branch.

There are six of us and most of us have direct experience of caring for a friend or relative with MND; so we are aware of the practical, financial and emotional issues, the implications of living with the disease and the problems this can bring. We cover the whole of Oxfordshire from Banbury in the north to Henley in the south and from Thame in the east to Burford in the west. As a group we meet regularly to keep ourselves up to date and usually the Regional Care Development Adviser, Fiona Turner, attends the meetings. We also have direct contact with the Care Centre through Rachael Marsden. We set up a Carer's Group in 2005. These meetings, which we continue to support, are currently held every three months.

Our referrals come from the MND Care Clinic or our Regional Care Development Adviser Fiona Turner. We are here and usually available and if we cannot help we probably know someone who can. **For further information contact Fiona Turner.**

## National Strategy for MND

PLEASE SIGN UP!

MAKE MND Matter 2010

A National Strategy is urgently needed to ensure equity of access to services and enable people with MND to achieve the highest quality of life.

Go to [www.MND2010.org](http://www.MND2010.org) to find out more and subscribe to the petition on line. It will be presented to the Prime Minister in MND Awareness week in June. It can be supported by a letter to your MP.

[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org) website: [www.mndassociation.org](http://www.mndassociation.org)



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