

## Support Meetings

We hold support meetings in Swindon and Calne.

Swindon meetings are held at The Lawns Community Centre Guildford Road, Swindon, from 2.15-4pm. The next ones will be 29th May and 17th July. Contact Susanne Webb on **07776 126994** or email [susanne.webb@gmail.com](mailto:susanne.webb@gmail.com)

Calne meetings are held at The Masonic Hall, Stainer Road, Calne, from 2.15-4pm. The next meetings will be 19th June and 21st August. Contact Moya Wallis on **01380 859611** or email [moyawallis@hotmail.com](mailto:moyawallis@hotmail.com)

*All sessions are drop in. Come along to share ideas, meet other members and for a change of view! Volunteer helpers also welcome.*

## Chair's welcome

Now that the long winter months are behind us we are turning our thoughts to plans for MND Month of Awareness in June, and again we are hoping you will help us. In this issue you will find a range of ideas to help raise **awareness** and **funds**, and building on the ever-popular baking theme. 'Bake It' is back! More information and fabulous free information packs with recipes, invitations and all you need to hold an event are available at [www.mndassociation.org/bakeit](http://www.mndassociation.org/bakeit) or contact us at [info@mndnorthwiltshire.org.uk](mailto:info@mndnorthwiltshire.org.uk)

As a Group, we are working hard to support the national MND Charter campaign, holding signing events at groups and associations, local hospitals and fundraising events. We are currently writing to local councillors requesting their support for this vital initiative. You can read more about this and pledge your support at [www.mndassociation.org/mndcharter](http://www.mndassociation.org/mndcharter)

Enjoy reading all our news!

*Alison Aviss*

## June — Month of Awareness

**It's time to plan!** June, the MND Month of Awareness, is fast approaching. The two 'set piece' events are Bake It! and Walk to d'feet. But you could do anything to raise awareness of MND and/or funds.

**Bake It!** Why not bake some cakes or savouries and host a coffee morning/tea party or sell them at work? For ideas and tips, a fundraising pack can be ordered from [www.mndassociation.org](http://www.mndassociation.org)

Details of this year's sponsored **Walk to d'feet** will be posted on the Group website [www.mndnorthwiltshire.org.uk](http://www.mndnorthwiltshire.org.uk) once

arrangements have been finalised.

Or – what can you dream up? Perhaps a sponsored slim, swim or silence? Or a car wash or garage sale? Let your imagination run wild!

Official sponsorship forms are available from [www.mndassociation.org/get-involved/fundraising](http://www.mndassociation.org/get-involved/fundraising). Be sure to tell them you are raising funds for the North Wiltshire Group.

Please post any funds raised as a cheque made to 'MNDA' to National Office at **MNDA, PO Box 246, Northampton NN1 2PR**, clearly marked 'for North Wiltshire Group'.

## Campaigning for plwMND in North Wiltshire

The North Wilts Group now has a campaigning team to support the MND Association's national calls for action! Heather, Usha and Sam are our team of three. Heather, our Campaign Co-ordinator, will be making sure we have all the up-to-date information and materials to support the campaign messages and, working with Usha and Sam, will be asking people in North Wiltshire for help!

Our campaign team are focussing initially on raising the profile of the MND Charter and getting as many people as possible to sign it. The Charter aims to raise awareness of the needs of people living with MND. By gathering signatures in support of the Charter, the MNDA is more empowered to debate with Government and health care providers that plwMND need to receive the right care in the right place at the right time.

The Charter campaign runs until the General Election in May 2015. The next phase of gathering signatures is to target the upcoming Local Elections on 22nd May and get as many councillors and candidates to sign the Charter as possible. If you can help with our letter writing campaign, please get in touch with us! There are template letters to use and we can help you find out who your councillor is, or who your candidates are if there is an election in your local ward.

For more information about the MND Charter, see: <http://www.mndassociation.org/get-involved/campaigning-influencing/MND+Charter>

## New Patient Transport Services

All change! Arriva Transport Solutions is working with the Clinical Commissioning Groups in the South-West to provide non-emergency patient transport services (NEPTS) across Wiltshire and Swindon, Bath and North-East Somerset, and Gloucestershire, taking eligible patients to and from NHS funded services. The service provides NEPTS for eligible patients who are registered with GPs located in these areas. This includes outpatient appointments, day case inpatient admissions, discharges from centres, inter-hospital transfers, and A&E/Minor Injury home returners. It replaces the earlier fragmented system, and runs 24/7.

For a journey to your treatment centre, transport can be booked over the telephone on 0845 600 6068 or online at <https://pts.arriva.co.uk>. To use the online system, you must have a username and password, which can be obtained by clicking on the link above.

The information usually required is:

Name of patient

Date of Birth (DOB)

NHS number (wherever possible)

Pick up and destination, both with post codes

Date of journey

Type of transport required (wheelchair, assistance needed, etc)

Bookings should ideally be made before 15:00 (3pm) on the working day prior to the intended day of travel – but advance booking is welcomed.

Patients requiring a return journey from their treatment centre to their home or nursing home will be 'booked ready' by the unit following the appointment or treatment, with collection within one hour. It is a door-to-door service.

*Local support for local people*

## Stair-lift versus through-floor lift – key decisions

*by Colin Moss*

When I moved back to the Swindon area in 2010 we initially searched for a bungalow, but in the end settled for a house for reasons of value and rural location.

Before moving in we had to install a lift of some kind. We considered a stair-lift and through-floor lift. Although I chose a stair-lift, it has more limitations than a through-floor lift. The obvious limitation of a stair-lift is that once the plwMND becomes unable to transfer to and from it, it effectively becomes redundant and they can no longer use the upper floor. This, together with the fact that MND often progresses rapidly, is why most OT's recommend a through floor lift for plwMND.

My reasons for selecting a stair-lift were as follows:

1. When I looked into the costs, a through-floor lift was much more expensive at around £9,500 compared to stair-lifts, which ranged from around £800 for straight stairs and from around £3,000 for curved stairs. We bought a reconditioned curved one from Bespoke Stair-Lifts with two bends and a hinged end for £3,600.

2. Lack of space: A through-floor lift needs

a 1.5m x 1m space in two rooms, one above the other, avoiding doorways, radiators and other obstacles. We had no suitable place without ruining our small lounge and losing the use of one of the bedrooms and front door.

3. I was diagnosed about 8 years before I was no longer able to negotiate stairs, so I took a gamble that my progression would continue to be slow enough to avoid the limitations of the stair-lift for at least three years.

4. Crucially, I also had a 3-year plan to save up enough to build a ground-floor bedroom and wetroom extension (see issue 24).

5. The last reason was our existing first floor bath/shower room is too small for wheelchair access, so even if we had a through-floor lift we would have also needed to either modify the bathroom or convert two bedrooms into one with a disabled toilet and shower cubicle with pumped waste and the additional cost that would bring.

*Colin was diagnosed with MND in 2002—Ed.*

### 'Tis the season ... for chicks!

Colleagues at the Lend Lease regional office in Solihull were so 'eggcited' when they saw our MNDA Easter Chicks that additional clutches were ordered immediately! So far they have contributed over £129 with more donations to follow. The chicks have made themselves at home in various places around the office, including hiding in some of the planters.

All cash received from the sale of the chicks goes directly to MNDA, as they are knitted free of charge by an army of volunteers across North Wiltshire, while the creme eggs are generously donated by local supermarkets. Many thanks to Lend Lease for their support.

### And

Good friends of the North Wiltshire Group, Sue and Sarah Occleshaw, held an Easter Chicks sale at Sainsbury's in Royal Wootton Bassett, raising an amazing £168.84. Both avid knitters, the chicks were accompanied by bunnies, hatching eggs and a range of children's clothes that were irresistible to the shoppers and a perfect Easter gift. Thank you both, and to the store for donating the creme eggs.

**And** Glen Woodman who raised a brilliant £377 selling chicks and other knitted items at Wilkinson's in Chippenham.



## Useful Contacts

N Wilts Group website  
[www.mndnorthwiltshire.org.uk](http://www.mndnorthwiltshire.org.uk)

N Wilts Group contact  
[info@mndnorthwiltshire.org.uk](mailto:info@mndnorthwiltshire.org.uk)  
or phone MND Connect

Facebook <http://www.facebook.com/MNDNorthWiltshire>

Twitter @MNDNorthWilts

Letters will be forwarded from:  
**North Wiltshire Group, c/o MNDA,  
PO Box 246, Northampton NN1 2PR**

**MNDConnect 08457 626262**

**MNDA national website  
[www.mndassociation.org](http://www.mndassociation.org)**

**MNDA Volunteering Team  
01604 611681**

**Hilary Fairfield, MNDA Regional Care  
Development Advisor 08453 751828 or  
[hilary.fairfield@mndassociation.org](mailto:hilary.fairfield@mndassociation.org)**

**Prospect Hospice 01793 813355**

**Dorothy House 01225 722988**

## Support for You

### What's On?

**29th May**  
Swindon Support Meeting, The Lawns

**June**  
Month of Awareness

**5th June**  
Committee Meeting, Prospect Hospice, 7pm

**19th June**  
Calne Support Meeting, Stainer Road

**3rd July**  
Committee Meeting, Prospect Hospice, 7pm

**17th July**  
Swindon Support Meeting, The Lawns

**7th August**  
Committee Meeting, Prospect Hospice, 7pm

**21st August**  
Calne Support Meeting, Stainer Road

**4th September**  
Committee Meeting, Prospect Hospice, 7pm

**18th September**  
Swindon Support Meeting, The Lawns

### Golf Day

Neil and Deb Watkins from Neston held an invitation golf day at The Manor House Golf Club, Castle Coombe, on 28th March, to raise funds in tribute to Neil's brother who had MND. Despite the spring storms and wind, the golfers had a great day with some excellent scores recorded. The day was rounded off with a lovely supper, an auction and a raffle. The event raised an amazing £1,550, and we sincerely thank Neil, Deb and their family and friends.



Left to right:  
Stewart Pyke,  
Geoff Good,  
Andy Robbins,  
Neil Watkins



**This is YOUR Newsletter. If you have any comments, suggestions or news items please do contact me on [AndrewRSargent@gmail.com](mailto:AndrewRSargent@gmail.com)**

The deadline for submission for the next issue will be **5th July 2014**.

*Andrew Sargent*



**We never lose hope. We strive to find a cure for MND, and to support everyone affected by this devastating disease**

Registered Charity No 294354