



## South West Surrey Branch

Reg. Charity Number: 294354

Please reply to Secretary:

7 Rossmore Gardens  
Aldershot GU11 3XF

**Chairman:**

Bob Hodgson 01483 893588

**Treasurer:**

Alvin Hale 01252 310962

**Vice Chairman**

Mary Carr 01483 419774

**Secretary:**

Joan Hornett 01252 325851

**Assoc Visitors' Rep:**

Lucia Woodward 01428 643459

**Committee Members:**

Alison Husaundee

### July 2015 Newsletter

***The End of an Era!*** The last Branch meeting in Cranleigh was held on Monday 8th June. We are now transferring the meetings to the Education Centre at Guildford Cathedral. This is a more central location, and it has plenty of accommodation - a bright and airy room with provision for audio-visual equipment and a kitchenette suitable for light refreshments. The date of the first meeting here is Wednesday 16th September, from 2 to 4 pm, and meetings will continue thereafter every three months.

On Wednesday 10th June, AVs etc were invited to the Queen Elizabeth Foundation in Carshalton where we were shown the various types of wheelchairs which are available. Fiona Eldridge of the Foundation explained the varying uses and the differences between each one. We were also taken to see adapted cars and how the wheelchairs were able to fit in. They also had an aeroplane fuselage in which we were shown how people could be fitted into their seat by hoist. It was a very interesting and informative afternoon.

### INCOME

28th April: Charity Golf Day at West Byfleet - total raised £5200.00

15th - 17th May: Mary Hainline's garden event - total raised £1449.30

18th May: St Mary's, Send - Coffee Morning	-	£151.65
5th June: American School in England TASIS	-	£1,600.00
Money raised by pupils in Middle School		
R M Dyer - United Friends Football		£80.00
27th June: Cranleigh Carnival and Fun Day - Profit		£127.60

#### DONATIONS

Doug and Barbara Tidy		£5.00
Sheila Green		£50.00
Anon		£7.59

IN MEMORY of Norman Evans		£300.00
June Branch Raffle		£46.00

#### COLLECTION BOXES

Nisa Bramley		£74.98
Celebration Cakes, Cranleigh		£95.39
Bulls Head, Ewhurst		£48.27
Solent Cleaners, Farnham		£50.00

#### STREET COLLECTIONS

30th May Cranleigh		£780.44
13th June The Mall, Camberley		£478.15

#### JUNE 'THUMBS UP' CLUB

251	I Hay	£100.00
77	C Disley	£30.00
106	V Speers	£25.00
138	S Tidy	£20.00

If you would like to participate in the 'Thumbs Up' Club, please contact Sallie on 01483 274337 for a share number form to commence from 1st July 2015.

(£12 per share per year by cheque payable to MNDA Cranleigh "Thumbs up Club" or STO)

STREET COLLECTIONS to come

Saturday 11th July      Aldershot

Saturday 25th July      Guildford

Saturday 1st August      Woking

- More volunteers welcome! (Contact Mary Carr to put yourself on the roster)

PLEASE NOTE:

The 21st DROP IN session is on Wednesday 5th August especially for people with MND, their carers, family and friends, to have the opportunity to meet one another over light refreshments.

For the people it concerns, please drop in at any time between 2 and 4 pm at The Refectory, Guildford Cathedral. If you have any concerns about coming along, need help with transport, would like more information please contact Mary Carr on 01483 419774 or rhodgson357@btinternet.com

We are looking forward to seeing as many members as possible in Guildford in September.

Please note that included this month is a members 'blog' which is quite interesting and entertaining, together with a note on research which has been carried out by Dr Christopher MacDermott.

With kind regards,

Mary and Joan

National Office

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

Tel: 01604 250505 (email: [enquiries@mndassociation.org](mailto:enquiries@mndassociation.org))

MND Connect: 03457 626262 (email: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org))

## A Member's Blog

by Lucia Woodward

### Volunteering

I have been a member of this Branch since the beginning of 2002; my husband and I joined a couple of months after he was diagnosed with MND. We attended as many meetings as possible, until it became too tiring for him to leave home in the evening – or at all. The Branch's activities and the friends we made became an essential part of the support we received of the next few years, so much so that after he died at the end of 2005 I decided to work as a Volunteer.

I enjoy volunteering. I worked for the National Trust for so many years I cannot recall how many. That was great fun, so many different jobs to do in looking after one of our great 'Stately Homes'. I had to leave when MND began to devour my time like a hungry wolf.

As a member of the Branch I 'volunteer' for quite a few of our activities. My main part is as Association Visitor – a part so varied and rich I cannot go into the details right now. A future blog will do. There is also the fund raising work: you can see in another part of this Newsletter how many locations we cover with the street collections. By 'we' I mean the six or eight of us 'volunteers' who also sit on the Committee, or look after the catering at the Branch meetings; often the same volunteers who bake cakes and biscuits for the Flee Market, who sell bric-a-brac and plants at the fairs and 'carnivals'; who write minutes and agendas and reports, who fill forms and chat for hours to family members, carers and health-care professionals; who attend meetings and gatherings and follow the twists and turns

of the journey faced by people with MND. It's interesting, it's fun, it's being busy and caring and 'alive' – it is also tiring and we need more of us in the field, which means more of you members to join us. You can contribute ideas; you can contribute a bit of your time and energy and resources [mental and physical!].

Volunteering is also rewarding, and not in a self-congratulatory way. It brings friendship to the fore, it brings sharing the plus and cons, the laughter and the tears; it brings the satisfaction of a job well done, of a positive contribution to a specific purpose. And sometimes it brings 'recognition from above'.

Here I digress from my work as an MNDA volunteers to mention my other hat: volunteer work for the Educational Museum in Haslemere. We are a large group, there, spread out over many jobs and many roles. I started in the Archive over 20 years ago and covered a huge portion of the collections by recording, entering on data base, transcribing... Well, early in June we gathered at a lovely garden party and buffet lunch [it was Volunteers Week!] and we were told that we had actually been awarded *The Queen's Award for Volunteering Work!!* We could hardly believe it – after all, it is the equivalent of the MBE for individuals! The actual presentation of the Award and Certificate will follow – watch this space. In the meantime, if you feel like joining us volunteers, there is enough in this Branch to suit all; or you can go on line to [www.mndassociation.org/volunteerszone](http://www.mndassociation.org/volunteerszone).

I can't guarantee you'll get an MBE but you **will** enjoy it!

## **Gardening**

Somebody has got it right!! Combining volunteering with gardening must be the best of both worlds – well that's what I think and I am not alone. Martin Anderson, a founder member of our dear MNDA, has done it and with the best results ever. Not only has he been awarded the MBE for his 25 years with the Association but has also won two Gold Medals [yes, two] at the Chelsea Flower Show with the gardens he designed for us in 2008 and 2013. This year we got the Silver. I liked *The Old Forge* garden; very poignant in a quiet and gently sad way.

Lucia

**Research carried out under the leadership of Dr Christopher McDermott, based at the Sheffield Institute for Translational Neuroscience (SITraN), and published on 29 May 2015 in the *Lancet Neurology*, highlights that better weight management in MND is key to survival.**

Following on from initial results presented at the 25th International Symposium on ALS/MND in December 2014, the Prospective Gastrostomy (ProGas) study in MND aimed to investigate the optimal timing for gastrostomy in MND due to the lack of evidence available.

In some people living with MND, the muscles involved in swallowing can become slow, weak and/or uncoordinated. This can cause difficulty when eating and drinking, resulting in slower meal times and insufficient intake of nutrients. The result can be weight loss and increased burden for carers.

To ease these problems alternative feeding methods such as gastrostomy can help. Feeding by gastrostomy involves a tube inserted directly into the stomach through the abdomen. There are three main types of gastrostomy, percutaneous endoscopic gastrostomy (PEG), radiological inserted gastrostomy (RIG) and post oral image-guided gastrostomy (PIG), which is a 'hybrid' of the previous two methods.

Current practice of gastrostomy feeding in MND is largely varied across the UK, and is based on individual preference and expert opinion. There is a lack of evidence to suggest what the optimal timing for gastrostomy is, or which method is most appropriate.

Funded by the Association, the ProGas study aimed to develop evidence-based guidelines to identify the most appropriate method and timing of gastrostomy in people living with MND in the UK. Although there was no difference in the three methods of gastrostomy tested, the ProGas study identified two factors that affected survival: age at onset of MND and percentage of weight loss at time of gastrostomy since diagnosis.

The researchers found that people who had less than 10% weight loss since diagnosis and before gastrostomy benefited most from the procedure and had an increase in survival compared to those who had 10% or greater weight loss before undergoing gastrostomy. This effect of weight loss on survival following gastrostomy has led the researchers to recommend that people living with MND should undergo early gastrostomy before a marked weight loss of 10%, preferably at about 5% to ensure better survival.

Although there was no difference in survival between the three gastrostomy methods, the findings from the study indicate that PEG may be the optimal method, before respiratory problems arise, due to the ease of post-insertion tube management.

Dr McDermott said: *“PEG is the preferred method of gastrostomy, when someone has good respiratory function and is able to lie flat and be sedated for the procedure, or PIG/RIG when there is significant compromise of respiratory function.”*

Director of Research Development, Dr Brian Dickie commented: *“Dr McDermott and his colleagues are keen to use these results to develop specific guidance on the use of gastrostomy in MND, to improve consistency of practice across MND clinics and therefore outcomes for patients.”*

*“The findings can also be presented to the National Institute for Health and Care Excellence (NICE), which is currently in the process of creating broader, multidisciplinary Clinical Guidelines for the Assessment and Management of MND, due to be published next year.”*