



Multiple Sclerosis Society

**WYRE FOREST &  
DISTRICT BRANCH  
NEWSLETTER**

**SEPT/OCTOBER 2014**



## **90th Birthday Celebrations**

Phyllis Richards from Cookley, celebrated her 90<sup>th</sup> birthday in style by having a party for her family and friends. Phyllis asked for donations to the MS Society instead of presents in support of her Grandson Julian who has MS. Julian, who now lives in Shrewsbury, asked for the money to go to his Nan's local branch, and we received the sum of £520. Our grateful thanks go to Phyllis, Julian and their family and friends for this kind donation, which will go a long way in supporting local people affected by MS.

*Thank you!*



## Letter from the Chair

Hello Everyone,

Autumn is officially here, but I'm still in summer mode, running around carnivals & fairs raising money for the branch ably assisted by the crew of hard-working, dedicated members of the committee (I can see their heads swelling as I am typing). If you or anyone you know would like to get involved as a volunteer, then please pass on my details & get in touch, we always need helpers, especially during the summer months to either shake a can in the street/supermarket, or lend a hand on a stall, hours to suit yourself. Anyway, you might find that you enjoy yourself & you get to meet some really lovely people just by giving them a smile & a bit of a chat to. Come on down, you know you want to really; you will be made most welcome.

It saddens me to say, but we have lost a long time member, Frank Charlton. Our condolences to Linda & family at this sad time, our thoughts & prayers are with you all.

I don't know if you have heard, but Park Attwood has closed its doors & turned its back on people with neurological conditions. Jim Driscoll, of the "Shoe People" books, who was the owner, decided that after 3-4 years it was not worth ploughing any more money into, so he put it up for sale & the residents he had have now moved on to hopefully a more secure future. It is sad, that a place like that could not stand the test of time, as we need that resource, though you never know, someone/business might come along & hopefully carry on in that field of expertise. Let's hope though that if that is the case, then they know what they are doing, & how much it costs.

I feel that my page has been a bit doom & gloom, maybe I should tell a joke or attach a video for those that receive the newsletter by email of me doing the Highland Fling, well more the fling myself on the floor, than the Highland jig. But no, I don't think so. So, I am going to end my letter with a short quotation, which I hope you understand, here it is; "fell down 7 times, but got up 8". I saw this on a wall of inspirational one liners, & I just thought this was just right for us.

Best wishes.

*Julie x*

# NEWS

## A BACKWARD STEP FOR MS SERVICES: THE DRAFT NICE MS CLINICAL GUIDELINE

**Author:** MS Trust

**The MS Trust is concerned that recommendations in the NICE Clinical Guideline may set back the availability and quality of care for people with multiple sclerosis.**

In April 2014, NICE (National Institute for Health and Care Excellence) put out its draft Clinical Guideline on *The management of multiple sclerosis in primary and secondary care*, for consultation with registered stakeholders only, with a view to full publication in October 2014. This Guideline is due to replace the original published in 2003. The draft Guideline covers diagnosis, information and support, treatment of relapses, management of MS-related symptoms and provision of services in England and Wales. Developing the draft has taken three years, with a Guideline Development Group at its heart which consists of people with MS and MS health professionals.

The draft MS clinical guideline makes a number of recommendations about how MS and its symptoms should be managed. The MS Trust is deeply concerned about some of these recommendations, about omissions from the Guideline and about how usable the document will be for many health professionals, particularly those who may not specialise in MS. We are also concerned that it may give a negative message to those who commission MS services, giving them the impression that they can reduce service levels.

Additionally, we have considerable reservations about NICE's process for developing the Guideline, including a lack of transparency to interested stakeholders at key points in the development process and the short length of consultation time (6 weeks) allowed on the 600 page draft. The NICE process for developing Clinical Guidelines offers fewer opportunities for wider stakeholder engagement than its other process for appraising new treatments. Too much of the guideline development process happens without external scrutiny and validation of decisions by interested and expert stakeholders. As a consequence, this draft guideline fails to meet the needs of the MS community in its scope and its recommendations.

The MS Trust considers that, as it stands, the MS Clinical Guideline will set back the availability and quality of care for people with MS and are encouraging NICE to halt the guideline development process and re-engage with stakeholders to improve its content and usefulness. The MS Trust and the MS Society share concerns about the draft guideline and have taken the unprecedented step of writing jointly to Ministers and senior officials at NICE.

In summary our main concerns about the content of the draft Guideline are:

- Many therapies have been undervalued or omitted because NICE does not rate the standard of evidence that is available about their value, for example, therapies where it is impossible to give a dummy treatment for comparison, such as many treatments for ataxia and tremor.
- Rehabilitation in general and specifically neuro-rehabilitation has been entirely omitted from the draft Guideline. Rehab is an essential element of an MS service and its absence from the Guideline is inappropriate and sends the wrong message to managers and commissioners of MS services.
- Two licensed symptomatic treatments, Sativex (nabiximols), and Fampyra (fampridine), were not recommended. Nabiximols is an add-on treatment for spasticity and fampridine can help people with walking where their mobility is starting to decrease. We believe these treatments offer different options for people with MS and should be available to those who might benefit.

- There is no discussion of the crucial issue of how services should be organised and what 'excellence' should look like. There is no recognition of the importance of specialist health professionals apart from neurologists; the implicit model of care remains very hospital-based, neglects community-based services such as MS nurse clinics in local health centres, barely mentions continence services or physiotherapy and occupational therapy services, and mentions speech and language therapists once.
- The scope of the MS clinical guideline deliberately omitted symptoms and treatments covered by other NICE guidance and technology appraisals, and that are common to other conditions. Thus, it omits completely disease modifying drug therapies, management of bladder and bowel symptoms and speech and swallowing difficulties, to name but a few. As it stands, any non-specialist health professional or an NHS manager arranging overall services will need to cross-reference many other NICE documents to build a comprehensive picture of how to manage this complex condition. Our concern is that they will not have time to do this, resulting in a risk of much poorer overall care for people with MS.

## HOME DELIVERY SERVICE FAILING TO DELIVER

**Author:** MS Trust

**Healthcare at Home delivers a number of MS drugs to people with MS. Over recent months there have been complaints about the quality of the service provided, with many people reporting that drugs have not been delivered when promised. As a result the company's helpline has been swamped by calls with many people either unable to get through or placed in unacceptably long call queues.**

Healthcare at Home is one of several medicine homecare services which are contracted by the NHS and pharmaceutical companies to deliver specialist medicines and medical devices direct to people with a range of conditions including multiple sclerosis.

The problems, which have been highlighted in articles published this week in the national press, have been put down to two issues: the outsourcing of distribution arrangements to another company in an attempt to extend its service to include weekend and evening deliveries, and the addition of almost 3000 extra patients which it took over when another provider withdrew from the market.

On the patient support website the company has said it is working to fix problems; in the meantime separate phone numbers have been set up to deal with enquiries concerning deliveries for specific conditions:

**Healthcare at Home deliveries for multiple sclerosis: 0800 055 6937 or 0333 103 9874**

For further information, the patient support website gives up to date information about the current service and steps being taken to improve deliveries and call queuing times.

\*Taken From the Open Door Website August 2014

## **WHAT'S COMING UP**

### **SOCIAL**

The following meetings have been arranged at the Brinton Arms, Stourport:-

**Wednesday 24<sup>th</sup> September**

**Wednesday 15<sup>th</sup> October**

**Wednesday 12<sup>th</sup> November**

**Wednesday 17<sup>th</sup> December – Christmas Meal**

All these will commence at 1pm with the chance to have a tasty reasonably priced meal, and to catch up on all the news. The Brinton Arms is wheelchair friendly and has a disabled toilet.



**Sunday 14<sup>th</sup> December – Christmas Meal at the Gainsborough House Hotel**

Get into the festive sprit with this annual event, everyone welcome. Watch this space for further details.

**19<sup>th</sup> December** - Kidderminster Town Hall – Berkley Square, a singing group with none other than our very own Claire Worboys. MS is one of the charities to share the proceeds from this concert. Please support.

**Information Day** for patients/carers etc on Friday 5<sup>th</sup> December. This will be at Perdiswell Young Persons Centre from 10-3 and is a drop in session for people. Complimentary refreshments will be available all day. The day is an Open Day on Bladder, Bowels and Sexual Dysfunction. There will be lots of information for people to obtain, and professionals to speak to if you want to. But it is very informal so people can turn up as and when they want to.

### **Yoga**

We are still running the weekly yoga sessions which is held on a Thursday afternoon 2pm – 3pm at St Cecilia's Church, Hoo Road, Kidderminster. It is all done either sitting or lying down. To book your place please contact Denise, come along & give it a try.

## MINI BUS TRIPS

Wednesday 22<sup>nd</sup> October – Ruskin Glass Centre

Book your place with Denise on 0300 9991011.

We are always in need of volunteers in all areas, but is there anyone who would like to help as Escorts/Wheelchair Pushers to go on trips etc? Please contact Denise.



## FUNDRAISING PLANNED

The following dates are now booked for collections and fundraising activities:

**Saturday 27<sup>th</sup> September** – Stourport Town Street Collection

**Saturday 4<sup>th</sup> October** – Co-Op, Franche, Store Collection

**Sunday 2<sup>nd</sup> November** - Halloween Cake Break at the Gainsborough House Hotel, starting at 13.00 – 17.00. Come along for some spooky fun and games.

More dates will be arranged – you will be advised of these in the future Newsletters. We have a couple of new collectors who say its good fun and they really feel that they are making a difference, so if you would like to help, please contact Julie on 01562 851172. Make sure you put all these dates on your calendar or diary.

## Collecting Tins

Let's make a real effort to think of places to put our collecting cans! We still have a very long way to go to reach our target of placing 60 Collecting Tins, which was last years target, but we have adopted for this year. Don't be frightened to ask a shopkeeper, or the customer services in a supermarket. What about your local pub, fish and chip shop, restaurant? You have been very quiet – surely you must know somewhere where we can place a box. Please put your thinking caps on and let us know where a box can to be placed.

## Sponsored Activity

Is there something that you could do and be sponsored for? Maybe you can knit or perhaps a sponsored silence! That challenge is only open to the noisy ones though! What about a tandem parachute jump like Rosie did last year? Or perhaps you have a friend or family member who could do a sponsored swim, walk, cycle ride, read, dance..... the list is endless! If you would like sponsor forms, get in touch with Julie on 01562 851172.

## Next year the branch will be 40

Do you have any ideas or how would you like to celebrate our 40<sup>th</sup> Birthday contact Julie or Richard, details on back page and tell us what you would like us to organise



## Donations of Unwanted Items

Thank you to all the people that have already donated items which they no longer need or want. But, we are asking again for more items, especially cuddly toys, which will be used as raffle or tom bola prizes. Please, please, please, have a look in your cupboards and drawers to see if you have anything – we are desperate for items. Don't forget, at the Christmas Meal in December, we have a huge raffle and need around 50 prizes for this alone. We can come and collect if necessary, so don't put off doing that spring cleaning and give us a call.

### Broadwaters Fair

£49.40

-o0o-

### Happy Staffie Rescue

£6.50(not our fault)

## FUNDRAISING SUCCESS

Thank you to everyone that helped

On the day, it was well worth it!

### Bewdley Town Collection

£143.57

-o0o-

### Stourport Carnival

£115.94

## Do You Need Financial Help?

The Society has money available to help members financially.

The procedure is easy and totally confidential.

For grants under £200 you need only send a letter stating how much is required and for what purpose to Denise. The request will be discussed and voted on within 28 days. **NB We cannot award retrospectively so do not order the item before applying for help.**

**NB** We are constrained by Head Office so that we can only contribute to ONE session per person per year for Respite Care.

For larger amounts Head Office requires that we use an application form which Denise will help you to complete if necessary. The request will be considered by the Committee in complete confidence (no names used) and a decision made as to whether we can meet the request ourselves as a branch, whether we need to apply to other grant-giving organisations or if we will ask Head Office for additional funds. In the case of larger grants we will need a letter of support from your social worker or doctor.

In the first instance please contact your MS Support Officer

Mrs Denise Bedrock 15 Coniston Way, Bewdley, Worcs, DY12 2QA Tel: 0300 9991011

## Christmas Catalogue

September sees the launch of the new Christmas catalogue. This year National Centre have produced the catalogue themselves with a smaller number of products. They have a range of Christmas cards, wrapping paper and a couple of other items MS related.

Even though the catalogue has changed, the branch still receives incentives, getting 25% of the value of purchases made against our branch code. So, if you decide that you want to order out of the catalogue, then please can you use code **CMA391**. The code must be clearly written on the catalogue order form, quoted over the phone or entered at the online check-out ([www.mssociety.org.uk/christmasshop](http://www.mssociety.org.uk/christmasshop)) at the time of ordering – unfortunately they are not able to add it to orders afterwards. Codes are valid from 13<sup>th</sup> September 2014 to 31<sup>st</sup> December 2014.

When you receive it, don't be too disappointed by the lack of goods, but just think of the good you are doing by ordering your cards and wrap – **DON'T FORGET THE CODE!!!!**

## RESEARCH

Taken from the MS Society WebPages

# VITAMIN D

TAKEN FROM THE MS SOCIETY WEBPAGES

Several studies have suggested that vitamin D deficiency plays a role in the risk of developing MS – but it's not yet clear exactly what this might be.

## HOW MIGHT VITAMIN D BE LINKED WITH MS?

We get most of our vitamin D through exposure to the sun. It is made by our bodies in reaction to sunlight on our skin.

MS is more common in areas further away from the equator where there is less sunshine, which suggests that there is a relationship between vitamin D and the risk of developing MS.

Some recent research studies suggest that a lack of vitamin D in early childhood or before birth might increase the risk of developing MS later in life. This is not yet confirmed however, and is the subject of ongoing research.

Where someone already has MS, it's not currently clear whether vitamin D plays a role in managing MS. A number of studies have suggested that it may help, but more research is needed before we know for sure.

## HOW DO I GET IT INTO MY DIET?

Most people get the majority of their vitamin D from exposure to sunlight.

It's also available (in smaller amounts) in food. Good food sources of vitamin D include oily fish, such as salmon and sardines, fortified breakfast cereals and eggs. Small amounts are also found in margarine and full-fat milk.

Bear in mind, though, that it is almost impossible to get all the vitamin D you need through diet alone.

## HOW MUCH DO I NEED?

Opinion is divided over how much vitamin D we need, and how much sunshine we need in order to make it.

Some people suggest that around 15 minutes of sunlight a day on bare skin during the summer months, along with a balanced diet, is enough to produce enough vitamin D to last through much of the winter as well.

But this is just an average, and might not be suitable for everyone - it depends on factors like how much skin is exposed to the sun, and how dark your skin is.

Your body also can't produce vitamin D when you're wearing sunscreen, so you should aim for at least a few minutes of sun exposure each day without sunscreen – taking care not to burn. Over-exposure could lead to other problems, including skin cancer.

Vitamin D can help to reduce the risk of osteoporosis, so it's important to make sure that you're getting enough – particularly if you're less mobile, or have taken long courses of [steroids](#).

## CHECKING YOUR VITAMIN D LEVELS

If you're concerned about your vitamin D levels, you should ask your GP for a blood test. If you are found to be deficient in vitamin D, they may recommend a supplement.

## VITAMIN D SUPPLEMENTS

You should aim to get enough vitamin D through exposure to sunlight and through diet, but there might be times when you need to consider a supplement – for example, if it's difficult for you to get outside.

**However**, it's not yet clear whether supplementation with vitamin D can actually help with managing MS.

Things we don't yet know include:

- the levels of vitamin D that might help in preventing or treating MS
- if this can be achieved through supplementation
- what dosage would be needed, at what stage in life this would be beneficial and whether the [dose](#) required is safe

Certain groups of people are advised to take vitamin D supplements. These include women who are pregnant or breastfeeding, and people over 65.

If you receive benefits, are pregnant or under 18, you might be able to get any supplements you need free of charge through the government's [Healthy Start](#) scheme.

## FURTHER INFORMATION

[NHS Choices](#) has more information about sources of vitamin D and what they consider safe amounts if you use a supplement. If you're thinking of using a supplement, speak to your GP, [MS nurse](#) or dietician for advice.

## **INFORMATION ZONE**

**Our Website** Don't forget our website - have a look at it regularly – it contains a lot of useful information, dates, contacts etc. If you have any information that you think would be good to be included on the site, please contact Val and I will pass it onto Phil Lench our Webmaster. <http://www.wyreforestmsgroup.org.uk/>

**Our Facebook Page** Have you been having a look at our Facebook Page? If not, have a look – it gives you lots of information on Social and Fundraising Events, as well as links to other useful sites. [en-gb.facebook.com/MsSocietyWyreForestDistrictBranch](https://en-gb.facebook.com/MsSocietyWyreForestDistrictBranch)

## Last month Quiz Flowers answers

1. Industrious Queen (4, 6). – **Busy Lizzie**
2. Bovine takes a Tumble (7) 6 - **Cow Slip**
3. She's close to her pupil (4). - **Iris**
4. A new one sweeps clean (5) - **Broom**
5. Is it found at the Forge? (3,3,5) - **Red Hot Poker**
6. Enclosure in criminal court for prisoner (4) - **Dock**
7. Modest Miss (8). **Primrose**
8. Foreign kitchen gloves(6,9) **French Marigolds**
9. Pussy likes polos (7). – **Catmint**
10. Curse the bird! (6). - **Crocus**
11. Just not enough hours in the day (5). **Thyme**
12. These would keep Basil's paws warm (9) **Foxglove**
13. Used in thickening sauces (10) **Cornflower**
14. Lass of the Vale (4, 2, 3, 6.) – **Lily of The Valley**
15. Romantic encounter in the fog (4,2,1,4) . – **Love In The Mist**
16. Receptacle for dairy product (9) **Buttercup**
17. He is such a good boy (5,7) . **Sweet William**
18. Facial hair on an Octogenarian (3,4,5) - **Old Mans Beard**
19. Caused by cold in the Belfry (8). **Bluebell**
20. Males on bikes (8) **Cyclamen**

This months Quiz What do you Know about England?

1. Which Two Colours make up the flag of England?
2. What is the national emblem of England?
3. Who is the patron saint of England?
4. A Novocastrian is a person from which English city?
5. Which is England's most Southerly county?
6. Which sporting event takes place on the last week of June and the first week of July?
7. The film the Full Monty is set in which English city?
8. Which Roman fortification stretches from Wallsend to Bowness?
9. The Avebury stone circles are in which English county?
10. The Goose Fair is held each year in which city?

## Joke

I pulled into the crowded parking lot at the local shopping centre and put the car windows down a bit to make sure my new pup had plenty of fresh air.

She was stretched out on the blanket on the back seat and I wanted to impress upon her that she must remain there. I walked to the kerb backward, pointing my finger at the car and saying emphatically, "Now you stay. Do you hear me?"

"Stay! Stay!"

A young blonde, who happened to be walking past at the time, gave me a strange look and said...

..."Why don't you just put the handbrake on?"

## Cricket Explained

- You have two sides, one out in the field and one in.
- Each man that's in the side that's in the field goes out and when he's out comes in and the next man goes in until he's out.
- When a man goes out to go in, the men who are out try to get him out, and when he is out he goes in and the next man in goes out and goes in.
- When they are all out, the side that's out comes in and the side that's been in goes out and tries to get those coming in out.
- Sometimes there are men still in and not out.
- There are men called umpires who stay out all the time, and they decide when the men who are in are out.
- Depending on the weather and the light, the umpires can also send everybody in, no matter whether they're in or out.
- When sides have been in and all the men are out (including those who are not out), then the game is finished.

## USEFUL CONTACTS



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