



# MainStream

The magazine of Eastbourne & South Wealden MS Society  
and the Eastbourne MS Community Resource Centre

MAP House • 34-36 St Leonards Road • Eastbourne • East Sussex • BN21 3UT  
Registered Charity Telephone: **01323 439447** Number: 207495

**FULL BRANCH DIRECTORY ON BACK COVER**

**Queen's Award for Voluntary Service 2007**

**VOLUME 6 No 5 SEPTEMBER 2008**

visit our website: [www.mssesw.org.uk](http://www.mssesw.org.uk)

## Care Support Independence

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With contributions from: Joyce..Shirley..Judy..Margaret..Ian..Margaret-Clare..Janet & Barbara



## 720 TAXIS

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Supporting Eastbourne & South Wealdon MS Society

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SEPTEMBER 2008

**WED 3<sup>RD</sup> LUNCHEON CLUB**  
*Please ring Joyce to book*  
Community Support Meeting 11am

**THURS 4<sup>TH</sup> LADIES GROUP 10.30 - 1.30**  
Centre open until 3.30

**FRIDAY 5<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
*Yoga commences 9.30*

**MON 8<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
(Seaford Newly-diagnosed Lunch Meeting)

**TUES 9<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
*TIME2TALK Drop-in & Phone-in Sessions*

**WED 10<sup>TH</sup> LUNCHEON CLUB**  
*Please ring Joyce to book*

**THURS 11<sup>TH</sup> LADIES GROUP 10.30 - 1.30**  
Centre open until 3.30

**FRIDAY 12<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
*Yoga commences 9.30*  
MS SWAG MEETING 11am

**SATURDAY 13<sup>TH</sup> & SUNDAY 14<sup>TH</sup>**  
NATIONAL AGM - LONDON

**MON 15<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**

**TUES 16<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**

**WED 17<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
LUNCHING OUT - BOOKING ESSENTIAL  
With Carol at the Golfing Park  
*Please ring Joyce to book*

**THURS 18<sup>TH</sup> LADIES GROUP 10.30 - 1.30**  
Centre open until 3.30

**FRIDAY 19<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
*Yoga commences 9.30*  
RELAPSE SUPPORT MEETING 11am

**MON 22<sup>ND</sup> CENTRE OPEN 10.30 - 3.30**  
MONDAY MEN LUNCH AT CENTRE  
MEET FROM 11am

**TUES 23<sup>RD</sup> CENTRE OPEN 10.30 - 3.30**

**WED 24<sup>TH</sup> LUNCHEON CLUB**  
*Please ring Joyce to book*  
The Luncheon Club is open to all - do come and  
join us for good food and good conversation

**THURS 25<sup>TH</sup> LADIES GROUP 10.30 - 1.30**  
Centre open until 3.30

**FRIDAY 26<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
*Yoga commences 9.30*

**MON 29<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**

**TUES 30<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**

OCTOBER 2008

**WED 1<sup>ST</sup> LUNCHEON CLUB**  
*Please ring Joyce to book*  
Community Support Meeting 11am

**THURS 2<sup>ND</sup> LADIES GROUP 10.30 - 1.30**  
Centre open until 3.30

**FRIDAY 3<sup>RD</sup> CENTRE OPEN 10.30 - 3.30**  
*Yoga commences 9.30*

**MON 6<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
MONDAY MEN LUNCHING OUT  
Venue to be arranged - somewhere nice - of course!

**TUES 7<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
*TIME2TALK Drop-in & Phone-in Sessions*

**WED 8<sup>TH</sup> LUNCHEON CLUB**  
*Please ring Joyce to book*

**THURS 9<sup>TH</sup> LADIES GROUP 10.30 - 1.30**  
Centre open until 3.30

**FRIDAY 10<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
*Yoga commences 9.30*

**COFFEE MORNING 11am - 1pm**  
MS CHRISTMAS CATALOGUE ORDERS

PLEASE BOOK WITH JOYCE FOR BOTH THE  
'LUNCHEON CLUB' AND 'LUNCHING OUT'

NEXT 'LUNCHING OUT' - WED 17<sup>TH</sup> SEPT  
PRE-BOOKING IS ESSENTIAL

'MAINSTREAM' is produced, published and edited by Bernard Curtis (01323 508969) for the Eastbourne & South Wealden branch of the MS Society. The views expressed, unless clearly shown to be those of the Multiple Sclerosis Society, will be deemed to be those of the author. The editor reserves the right to edit submitted material. Permission must be sought for the reproduction of original material. Printed by Custard Design 01323 733378

## Care Support Independence

Three words that sum up the feelings of so many folk with MS and their Carers.

Three words that will be central to future Government legislation *and you can help in shaping that legislation.*

Remember, *you* are the experts when it comes to how MS affects *you* - as a person with MS, a Carer or a family member or friend.

The care and support system takes in things such as meals on wheels, domiciliary care, day care, care homes, counselling and occupational therapy, support for carers, home adaptations, support for independent living, and the benefits that help people with the costs of disability in later life.

In other words, all issues that affect you from the time you wake up in the morning. The issues that we sometimes find so very hard to resolve because of the lack of government resources *or understanding.*

Think about what would help you take more control of your life and jot down a few lines (*or a lot of lines!*) in a letter or an email.

A leading role in this consultation process is being taken by the MS Society - and mega support from people affected by MS would truly strengthen their case. *Please do not leave it to others.* If you need help preparing a letter, just give us a call, we will be more than happy to assist you.

Details of where and how you can send your response as follows:

The government's consultation lasts until November. To help inform the MS Society's response, please send your letter or email to the MS Society. The Society will send it on to the government.

Send your letter to:

Department of Health  
c/o Campaigns, MS Society,  
FREEPOST LON 12519  
London NW2 2YR

Or email: [campaigns@mssociety.org.uk](mailto:campaigns@mssociety.org.uk)

If possible, also send a copy of your letter or email to your MP.

**BC**

***'Listening...or spinning? Read BC on page 15***

## The 'BC' years are drawing to a close

I have had a number of emails and telephone calls asking me to clarify the 'chair' position in the branch. So, let's start with the MS Society's comment on the situation:

***'The Board along with many others within the Society are clear that while we are not a 'rule-bound' organisation, those rules that we do have, we should adhere to'.***

**Head of Local Support MS Society**

And with that statement from the MS Society, in response to representations made by your committee, the axe falls on your 'BC'.

My first thoughts regarding the MS Society ruling were, *'That's like getting the sack.'* Our committee acted in the belief that the overwhelming majority of members would support their representations and that our members had the right to independently choose their own chairman - not the MS Society.

That said, we are, at the end of the day, a franchise of the national MS Society...we operate under their charity number and I expect somewhere in the small print we have agreed to abide by the rules when we pay our fiver each year.

I have to take responsibility. To help secure our future, as your chairman, I started work on a three year plan for the branch. This included involvement at many levels with the statutory and private sector. I confess I totally ignored any MS Society 'six-year' rule regarding the chairmanship; if the majority of members were happy...it didn't seem either applicable or important.

It would be churlish now to take any other view than that the MS Society is acting within the constitution, but to be honest, fixing something that isn't broke is now causing unnecessary disruption. *We must assume this six year rule is being enforced nationwide.*

This is not exactly 'goodbye' - I have half a year to go yet, but in that time, we need to find a new chairman. The last appeal produced not one person, which didn't particularly bother any of us. I can assure you that you already have a dedicated chairman and a dedicated committee. This current upheaval will certainly put our volunteer spirit to the test.

**BC**

## From our Vice-Chair Joyce

### ***How has it come to This?***

The question of our Branch Chairmanship is at the forefront of many people's minds at the moment.

The following observations are purely personal and Bernard is not aware that I'm putting my thoughts, and those of many others, into writing. I would add that several Committee members have said that they will resign if Bernard leaves. Such is the commitment he inspires in us.

I've written before about the many things Bernard has done for our Beloved Branch, and I don't intend to repeat myself.

We did try to put forward an amendment to the Constitution in time for the national AGM, but due to matters beyond our control, and mentioning no names, this did not happen.

A constitution is essential for the smooth-running of the MS Society; it makes nonsense if we have to lose such a valuable, hardworking chairman just because a few words say he has to stand down after six years.

I have downloaded a copy of the MS Society job description for the role of Branch Chair – it makes really interesting, if somewhat unrealistic reading! For *example* "Time commitment, 4-5 hours per week in addition to attending committee meetings".

We all know that Bernard works almost 24/7 on our behalf; if he worked for only 4-5 hours, where would we be? The answer to this will be known only by those who joined the Branch more than 6 years ago!

The constitution states that a chairman must stand down for at least a year before he can stand again. We may yet end up with President Bernard – a title which he may like so much that he never wants to become chairman again!

On a serious note, I find it a travesty that someone so committed to our cause, and who feels he needs just another three years to complete his plans, should be unceremoniously dumped! *If the members so wish, Bernard should continue . . .*

**Joyce**

### ***Fundraising - Here I Come!***

At our last Committee Meeting we decided that there is a need for someone to be Fundraising Officer and co-ordinate our various fundraising activities.

As I have been involved in various money-making schemes for the Branch, I found myself volunteering. This is in addition to my post as Vice-Chairman and such duties as looking after the Centre, giving benefits advice and organising transport for the Luncheon Club. Fundraising is the lifeblood of any voluntary organisation, and with our membership of the Fundraising Standards Board, we feel our efforts now need a more formal approach.

Certain aspects are working well, such as Barbara looking after the collecting tins, but others need a more structured approach. For instance, any member wishing to hold an event is advised to contact me to discuss the viability of their idea. We will no longer be able to store items for sale or raffle in the Centre as Health and Safety regulations preclude this. Space in our Centre is also restricted and there is a need for a clear administrative area.

I would encourage any of you to hold coffee mornings and similar private events in aid of the Branch, as this type of events not only raises money but also awareness of MS. If anyone has any fundraising ideas, my contact details are on the back page and I'd love to talk to you. We have raised considerable sums of money this year through individual efforts – more of these please!

We will continue to apply to Charitable Trusts for funding, but this is becoming increasingly difficult as there are so many charities chasing the same money. We know how important the Centre and our services are to so many of you, but the outside world does not always seem to agree. Application to these Trusts is extremely time-consuming with only a small chance of success.

This new responsibility is definitely a challenge for me and no doubt it will take a while to get my head round all the things I have to do, but with help from Bernard and Margaret I'm sure I'll succeed.

**Joyce**



**THE SCOOTER & WHEELCHAIR ACTION GROUP OF  
EASTBOURNE & SOUTH WEALDEN MS SOCIETY**

**MS SWAG Chairman: Shirley McCall**

Our last wheelchair PCT Strategy Meeting at Lewes was in July and due to the Holiday season our next meeting is October 3<sup>rd</sup>.

Please let me know if there is any matter pertaining to wheelchairs and special seating that is not already being dealt with and which you think needs bringing to the Strategy Meetings attention and I will present it for you.

Our next MS Scooter and wheelchair meeting SWAG will be held at our Centre in Map House on Friday September 12 commencing at 11.00.a.m..

I am pleased to say that amongst our usual representatives of organisations will be Kirsty from Southern Rail who is coming to talk about facilities available for disabled rail travellers and to answer questions.

Monica Elsen Chairman of Eastbourne Borough Council's Disability Involvement Group (DIG) is also coming along to join us as her group also deals with many aspects that we are involved in and which the EBBC need to be aware of.

After having a problem about access to checkouts at Marks and Spencer's highlighted to me at our last Swag meeting I have now had a meeting with the manager and I am hopeful that there will be a few improvements in time especially in the New Year when I believe the store is due for a re-fit.

Accessibility to our Hotels in Eastbourne is and always has been a night mare for people confined to a wheelchair and we at Swag are very much aware of this mammoth problem, not only for us residents but for visitors to our town. We have been trying to get a representative from the Eastbourne Hotels Association to attend our bi-monthly meetings but have had no joy for over a year now however we will persist in our efforts as there are so many aspects to do with our hotels that need high lighting.

We are also going to endeavour to instigate or assist with a campaign to try and improve the dropped kerb situation in Eastbourne and surrounding areas also broken paving slabs and

tarmac areas that have not had any attention because of lack of funding for years.

Access to and through our lovely Hampden Park is a disgrace and in places extremely dangerous for wheelchair users and mothers pushing prams.

Please don't forget to let Swag know if you have a particular problem and although we can't promise to wave a magic wand we will bring it to the necessary authority's attention.

**Shirley**

### **MS SOCIETY AGM 2008**

**13/14 SEPTEMBER LONDON**

Six members of your committee will be attending the national MS Society AGM in London this year:

Bernard Curtis  
Margaret Barrett  
Ian Westgate  
Joyce Milton  
Barbara Smith  
Doreen Whitfield

### **CHECK OUT THE WEBSITE!**

**[www.mssesw.org](http://www.mssesw.org)**

You certainly have been! An increasing number of folk are accessing the site and we created a 'first' for the branch last month! Unfortunately, 'Mainstream' was late back from the printers and consequently posted out later than normal. However, I do shoot it across from my computer to Andrew as soon as it is complete - with the result that last month more people were reading 'Mainstream' online - long before it went out in the post!

With Andrew, I have created a 'Volunteer of the Month' section on the website. However, I will make sure that anything on the website is also reproduced in 'Mainstream' - including the new 'Volunteer' section.

We do welcome your comments. Donating to the branch online is simple - please advise all your generous friends and contacts! If you have any photos (in jpeg format) that you would like to send PLEASE ensure that you email them to: **[info@mseastbourneandsouthwealden.org.uk](mailto:info@mseastbourneandsouthwealden.org.uk)** Please *do not* send them to personal email addresses *and* please advise us that you are sending them. Thank you.

**BC**

**SCOOTER OR WHEELCHAIR PROBLEM? COME ALONG TO THE MSSWAG MEETINGS**

**From our Minister**  
**Rev. Dr Gerald Munro BA MA Dphil**

Dear Friends,

Greetings to you all once more! Despite its somewhat low profile, the last Saturday in September is Grandparents Day. If you didn't know that then you can now tell your Grandchildren what is expected of them - and from them on Grandparents' Day. Like Mothers' day and Fathers' Day, Grandparents' Day has its commercial side, it is even sponsored by the makers of some greetings cards and chocolates, but it also has a serious purpose.

Grandparents' Day was put in the calendar in 1990 by Age Concern which considers that grandparents are a threatened species. The charity blames social mobility - families far-flung, and the increase in divorce - families divided. Since then it has conducted a survey of grandparents which has revealed that older grandparents have more grandchildren but see them less frequently. All is not gloom, however. More than half of all grandparents see their grandchildren at least once a week. But as grandchildren grow older and move away to live independent lives they grow out of touch with their grandparents. This, says Age Concern, is a matter for concern because grandparents now live longer than in previous generations and could face lonely futures if families lose touch.

Grandparents' Day is an attempt to avert such unhappiness. Its purpose is to remind us all, young and old alike, that grandparents are very important people precisely because they have been around for a long time. They know what went before and children long to know about their family history.

Indeed, for countless grandparents, the last Saturday in September is not really Grandparents' Day at all: rather it's Grandchildren Day, yet another excuse for making a fuss of them. It is not indulgent. It is a reminder that family life is our real history. It is the context of living. And to be excluded from the enjoyment of that, at either end of your life, is to be diminished.

There has been much talk lately of restoring family values, and I'm all in favour of that. Every family is an old family because we all go back

forever, or at least as far as evolution will allow. We all have ancestors and most of us will be ancestors. If we are grandparents we already are. There is a lot to be said for having good relations with your relations. Perhaps we should look upon Grandparents' Day in the same way we look upon Christmas, but concerned not simply with the Holy Family but with every family.

With best wishes to you all.

**Gerald**

**NEWLY DIAGNOSED WITH MS?**

If you are newly-diagnosed with MS and feeling a bit low, and have no one to talk to - please just pick up the phone and give me a call. **Sue on: 01323 439447**

or email: [SueAustin50@aol.com](mailto:SueAustin50@aol.com)

All calls are confidential

*Talking really can help!*

**CHECK OUT OUR WEBSITE...**  
**REGULARLY UPDATED WITH NEW PHOTOS**  
**[www.mssesw.org.uk](http://www.mssesw.org.uk)**

**DISABILITY LAW SERVICE (DLS)**

DLS runs a national Adviceline:

Mon to Fri - 10am - 1pm & 2pm - 5pm

Tel: 020 7791 9801 Email: [advice@dls.org.uk](mailto:advice@dls.org.uk)

**20 YEARS OF CARE & REPAIR**

A special thank you to Stephen Will, Director of Eastbourne Care & Repair for inviting Margaret and I to their celebration lunch. Prior to being your chairman, as branch visitor I used to be regularly involved with Care & Repair and I have watched them grow into the hugely successful charity they are today.

Care & Repair help homeowners and some private tenants who are older or disabled to remain in their own home, living independently. They advise on any improvements, repairs and adaptations that clients may need in their homes.

We sincerely wish them well for the future and I hope we will remain associated with them and support them wherever we can in the coming years.

**BC**

## The Judy Parker Column

Hello friends and MS family - here's the first personal report from your "Roving Reporter".

I start with a lavatorial issue . Some years ago I decided to have a radar key for easy access to the disabled toilets in both Eastbourne and Polegate. Impossible to mount a flight of stairs in the Arndale Centre to purchase the key in the first place - thank goodness I had Hugh with me at the time ! Have you tried opening a door outwards whilst you manoeuvre a scooter ? Similarly difficult to open same door towards you when you try to leave! I'm sure many of you trying to retain independence know exactly what I mean. Same problem here in Polegate-I have accosted many innocent by-passers when asking for help with "the" door. Have also spoken to local Councillors to no avail.

My next issue is with foreign students during the busy Summer season. The majority have no concept of the elderly, disabled or infirm - they'd rather block all pavements and are totally oblivious to us people trying to move around ! They also have no comprehension of the English language when we politely ask them to move over to enable us to pass !

My final issue in this first report is "feet!" Like many others I cannot reach my toes to cut my nails (know the feeling?) I found the details of a local chiropodist in Hospitality which is the quarterly magazine of the Friends of the Eastbourne Hospitals. The lady's name is Christine Barton who visits at home. She came to me today - stayed for half an hour and did a wonderful job. Her home phone number is 01323 502867. Christine's fees are also very reasonable.

That's all for this, my first report.

**Judy.**

---

*Judy felt the urge to respond to my appeal for a reporter - thank you Judy. Just tell it as it is on the local scene...it's about time somebody did. BC*

## Cycling Stars .....

### Martin and John raise £1,788.50

Not only do we have a 'star' in Anita, our Community Support Officer, but Anita has a 'star' of a son, Martin, who, with his friend John raised an amazing £1,788.50 for us cycling from Cambridge to London. Martin writes:

*"We started off at 8 o'clock on a warm Sunday morning, having each consumed almost 1000 calories in the form of 'Nutrition Shakes' and breakfast bars.*

*After perhaps a slightly too brisk start John and I settled into our rhythm overtaking plenty of cyclists. Soon, having completed a fair few miles the 20 mile mark was passed which in my mind is the point where you are fully warmed up.*

*We had decided not to stop at any of the refreshment stops and just push on in search of a good completion time, the 40 mile mark is where we started to feel the pinch, especially as the biggest hill with three hidden crescents was located within.*

*Needless to say we pushed on and completed the 59 mile course in 3h 16m 15s at an average speed of 18.1 mph.*

*We came in the top 20% of the four thousand riders and enjoyed a thoroughly good day in the name of a great cause."*

Congratulations to them both and sincere thanks for all the money raised. **BC**

**CHECK OUT THE PHOTOS OF MARTIN AND JOHN (AND ANITA!) ON OUR WEBSITE**  
[www.mssesw.org.uk](http://www.mssesw.org.uk)

### A WARM WELCOME AT SUNRISE!

Sincere thanks to all the staff at Sunrise Senior Living for such a warm welcome when we lunched there last month. The Lunching Out Group really enjoyed themselves and the food was excellent. It is a beautiful place where no expense is spared on comfort and care.

There were some mutterings about the result of the quiz which **John, Joyce and I won fairly!!!** Such envy from our fellow diners when we were given our prizes (a very nice compass in a case) was not becoming at all...**LOSERS!!!! Love BC**

## **MP PLUMBING AND HEATING**

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(Reg. Charity No. 207495)

### **Brambles Respite Care Centre**

Suffolk Close Massetts Road Horley Surrey RH6 7DU

Brambles Respite Care Centre offers a warm,  
safe and comfortable environment for people  
with MS, allowing a worry free break for their  
carer's and families.

To make a reservation please telephone:

**01293 771644**

or email: [enquiries@brambles.org.uk](mailto:enquiries@brambles.org.uk)

### **VEHICLE FIRE EVACUATION**

Thank you to every one of our drivers and  
escorts plus Margaret and Sue for attending the  
Vehicle Fire Evacuation course held at our  
Centre last month. Under the guidance of two  
instructors from the London Fire Brigade we all  
benefited from the course. A fire on one of our  
vehicles, with disabled passengers on board,  
would be our worst nightmare - learning about  
emergency procedures is vital to those of us  
responsible in any way for transporting our  
people.

Thanks to Margaret for organising this course  
through the MS Society - it was a truly worthwhile  
day with two excellent instructors.

**BC**

### **MS Society HELPLINES**

**EMAIL: [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)**

**PHONE: 0808 800 8000**

**CHECK OUT THE VEHICLE FIRE SAFETY PHOTOS  
[www.mssesw.org.uk](http://www.mssesw.org.uk)**

**FUNDRAISING & DONATIONS**  
**MONTHLY UPDATE FROM MARGARET**

**THANK YOU TO YOU ALL FOR YOUR SUPPORT**

Money transferred from the National centre by  
BACS **£198.92** Gift Aid for Eastbourne

Donations:

**£150** Tandem Parachute Jump - Peter Boddy  
**£130** - - Rebecca Corteling Rice

Churches Together Fete **£92**

Shop collecting tins organised by Barbara **£102**

Diageo Foundation Grant **£100**

Shetland Pony Event at Berwick **£170**

Donation from Wendy Lloyd **£20**

Donation from coins in jar **£12**

Martin and John sponsored bike ride Cambridge  
to London **£1788.50**

IF YOU CAN HOLD A FUNDRAISING EVENT FOR  
US, PLEASE REMEMBER TO CONTACT  
MARGARET OR BERNARD FOR SUPPORT  
MATERIAL, DISPLAY STANDS, ETC.

**Expert Patients Living  
Well Course**

**A FREE course for people living  
with any long term condition**

East Sussex Downs & Weald PCT and  
Hastings & Rother PCT are re-starting the  
Experts Patients Programme with a series  
of '**Living Well**' courses

The courses are free and are six weeks in  
length. Local courses are as follows:

**Eastbourne:** Tuesday 7<sup>th</sup> Oct to  
Tuesday 11<sup>th</sup> Nov 10.30am - 1pm  
ESDA 1 Faraday Close Eastbourne

All enquiries can be made to the  
**Expert Patient Information Line on  
01273 403540**



AN ASSOCIATION OF GENTLEMEN REPRESENTING  
THE EASTBOURNE & SOUTH WEALDEN MS SOCIETY

**SEPTEMBER 1<sup>ST</sup> LUNCHING OUT**  
Golden Galleon

**SEPTEMBER 22<sup>ND</sup> LUNCH AT CENTRE**

**OCTOBER 6<sup>TH</sup> LUNCHING OUT**  
*Venue to be arranged*

**OCTOBER 27<sup>TH</sup> LUNCH AT CENTRE**

**PLEASE NOTE:**

Lunch at the Centre will be for Gentlemen only

FOR LUNCH OR OUTINGS *PLEASE* LET US KNOW  
NUMBERS IN ADVANCE...THANK YOU.

**ALL GENTLEMEN WELCOME...COME AND JOIN US.**  
Contact BC on 439447

**FROM OUR WEBSITE Aug/Sept**

*We are featuring a volunteer online each month*

**Introducing our Volunteer of Month  
Barbara Smith**

"Having taken care of my husband (who has MS) for 38 years, it was necessary for him to enter a nursing home. I was then asked by our chairman Bernard to join the branch committee. My first position was care for the carers as I had a great deal of knowledge to pass on. Having a sense of welfare I also joined the team who work in the community supporting all people affected by MS.

One other item needed to be covered, and that was donation boxes in local shops, which I collect and replace then count the contents and bank. I also help with our Young Carers who we try to support by giving them some space to join in the different activities provided such as outings to bowling, swimming, Panto, etc. Occasionally I cover our centre when the centre manager and the chairman have to attend meetings. One of the things I enjoy about being a volunteer is that I have made so many good friends. So, if you have a few hours to spare, why not give it a go and join our team of Merry Men and Women! I am sure you wont regret it - you have nothing to lose but you will gain a lot."

**IAN'S INFORMATION DESK - TELEPHONE 01323 763226****Adult stem cells reprogrammed to become myelin-making cells**

31 Jul 2008

**Research published in Nature Neuroscience (June 29, 2008, electronic publication ahead of print) has shown that adult stem cells in mice that are developing into nerve cells can be redirected to turn into myelin-making cells by changing a single gene. This type of research may some day help repair the damage to myelin which occurs in multiple sclerosis.**

In people with MS the immune system can attack both myelin and myelin making cells (oligodendrocytes). Limiting the number of myelin making cells impairs the capacity to repair the damage to myelin. One potential treatment option currently being investigated involves encouraging immature stem cells that reside in the adult brain, called neural stem cells, to move to areas of damage and repair myelin.

When neural stem cells are grown in the laboratory scientists have been able to reprogramme them to develop into several different types of brain cells, including oligodendrocytes. This latest research which took place in The Salk Institute for Biological Studies in California sought to determine if it would be possible to repeat these experiments in the brain.

A gene called *Asc1* which is associated with oligodendrocyte development was introduced into the stem cells in the brain and caused neural stem cells to develop into oligodendrocytes.

This study confirms that adult stem cells in the brain retain their ability to be converted to certain other types of brain cells. Further research is needed to determine the significance of these findings to myelin repair in people with MS.

MS Society website 27<sup>th</sup> August 2008**THE FINAL CURTAIN IS ABOUT TO FALL**

Do you remember when, in April 2007, I started an audio library of tapes and CDs covering a wide range of topics from classic novels to crime mysteries to comedy? Sadly no-one seems to share my interest in these timeless audio treats and the interest I had hoped for just didn't materialise so it is with reluctance that I have to admit I must be one-of-a-kind or maybe just a bit weird and accept the idea was a bad one.

I must however thank all the good folk who contributed their surplus discs and tapes to the library and should they want any returned I will be happy to oblige.

For the future I will ask if anyone would like to borrow a disc or tape before they are committed to storage - or worse - there will be a last opportunity to borrow one or more until the deadline (End of November) is upon us. I cannot publish the list in this edition of *Mainstream* because it will run to several pages but there is a copy available in the Centre and for those who cannot get there I will be happy to receive a 'phone call on **01323 763226** and I will be happy to run through a list of recordings in the collection.

Ultimately I suppose they will all have to be given away but not until I have listened to as many as I can!

## Milestone for cannabinoid MS study

MS Society website 21 Jul 2008

**The CUPID (Cannabinoid Use in Progressive Inflammatory brain Disease) study at the Peninsula Medical School (*Universities of Exeter and Plymouth together with the NHS trusts of Devon and Cornwall*) has reached an important milestone with the news that the full cohort of 493 patients with MS has been recruited to the programme.**

CUPID is a clinical trial part-funded by the MS Society, which will evaluate whether tetrahydrocannabinol (THC) – the main active ingredient in the cannabis plant and one of many compounds found in the organism – is able to slow the progression of MS.

It is an important study for people with MS, because current treatments either target the immune system in the early stages of MS, or ease specific symptoms such as muscle spasms or bladder problems.

Dr Laura Bell, research communications officer for the MS Society, said: “People affected by MS are keen to know whether there’s any truth in the suggestion that elements of the cannabis plant can help ease the symptoms and slow down progression of the condition.

The CUPID trial follows an earlier study – Cannabinoids and Multiple Sclerosis (CAMS) – which established a link between THC and the slowing of MS. The CAMS trial saw participants take THC for a year – the CUPID trial will last for longer and aims to assess the affect of THC on progressive MS.

It has taken two years to recruit the 493 patients, and they will take part in the trial for three years; in some cases three and a half years. After data cleaning and analysis the results should be available by spring/early summer 2012.

Professor John Zajicek from the Peninsula Medical School, who heads the team carrying out the CUPID study, said: “We are delighted to have achieved the correct number of patient participants for this trial. Patients have been recruited from 27 sites across the UK.

“If we are able to prove beyond reasonable doubt the link between THC and the slowing down of progressive MS, we will be able to develop an effective therapy for the many thousands of MS sufferers around the world.”

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## Cannabis use in Spanish patients with multiple sclerosis: Fulfilment of patients' expectations?

Medicinal use of cannabis in chronic neurological diseases is a controversial topic of medical research. The aim of this study was to evaluate the prevalence of cannabis use, related factors, and degree of satisfaction in Spanish patients with multiple sclerosis prior to the establishment of medically supervised use.

A cross-sectional, questionnaire-based survey provided during routine medical visits to consecutive patients in two university-based neurology clinics was the chosen format for this project and was returned by 175 MS patients. The prevalence of recreational use and medicinal cannabis use were 43% and 17.1%, respectively. First cannabis consumption was after MS onset in 15 medicinal users. Clinical improvement was reported by 14 medicinal users. Smoking use, awareness of cannabis' potential benefits, pain, higher disability, and lower age were independently associated with the medicinal use of cannabis. Most patients would support a future legalisation of cannabis for the control of their symptoms and were willing to receive cannabis under medical control once legalised.

Almost half of the MS patients had tried cannabis at some time. However, medicinal use was low and clinical improvement after cannabis use was only reported by a subset of patients. Overall, MS patients were highly motivated for a future medically controlled use.

Source: Neurology Service, Hospital del Mar, Institut Municipal d'Investigació Mèdica (IMIM), Barcelona, Spain.

## YOUNG CARERS

Our Summer outing to London zoo went exceedingly well, and was enjoyed by all. Though I'm saying this in optimism that it did, as I write this on the 25<sup>th</sup> August, and it hasn't happened yet! No, seriously, I will give you more details next month. I will also give you the outcome of the application to Four Acre Trust. So not a lot to report this month, as we haven't even arranged the continuation programme yet, so be sure to catch up with us for the news next month. If you have any queries please don't hesitate to contact us. Just call Janet or Lynne on 01323 439447

## LADIES SUPPORT GROUP

The ladies had no programme as such through August since many of our members were away taking a holiday. But we still enjoyed our coffee and chat meetings at the centre. Even so, a small group of us went to the theatre to see 'Magic of the Dance', which was excellent. Our programme will get under way again in September, so do get in touch if you want an update.

As always, ALL LADIES WELCOME every Thursday 10.30 - 2.30pm.

If you have any questions give me a call on 01323 439447.

Best Wishes, Janet

**CHECK OUT OUR WEBSITE...  
AND LET US KNOW WHAT YOU THINK!  
'MAINSTREAM' IS ONLINE EVERY MONTH  
[www.mssesw.org.uk](http://www.mssesw.org.uk)**

## CHRISTMAS CATALOGUE COLLECTION PLEASE SUPPORT YOUR BRANCH *The MS Christmas Collection Catalogue Event 2008*

**Friday October 10<sup>th</sup> at our Centre  
Coffee morning 11am - 1pm**

Please join us in the Centre and order your cards and gifts for Christmas from the MS Christmas Collection Catalogue  
With all sales, 25% of monies will be transferred to the Branch account in support of our services. Please order through us.

***We look forward to seeing you on the day - transport will be available***

ANY QUERIES - PLEASE RING MARGARET  
ON 01323 439447



### THE SUN POEM

THE SUN IS YELLOW, AND IT'S BRIGHT,  
IT MAKES YOUR ROOMS SEEM VERY LIGHT.

THE SUN IS HOT, AND MAKES YOU TAN,  
SOMETIMES YOU REQUIRE A FAN.

THE DAYS SEEM LONGER WHEN IT'S OUT,  
IT MAKES YOU WANT TO SCREAM AND SHOUT.

"HOORAY", THE SUN IS OUT TODAY,  
ALL CHILDREN GO OUT AND PLAY.

Diane Hewitt

### ***With thanks from Barbara and Don***

Don and I would like to thank you all for your kind and generous gift to celebrate our 'Golden Wedding'.

Also many thanks for all the phone calls and cards telling us how much you enjoyed yourselves, especially the entertainment.

We feel blessed to have so many friends.  
Love Barbara & Don

## Taking the leap...

by Margaret-Clare Fuhrmann

I remember, it was when hills became mysteriously steeper and the road to the local shops puzzlingly longer, that I first thought about getting a motorised wheelchair or scooter. I had been admiring the expertise of my friends at the MS Centre - the ease with which they manoeuvred in tight spaces - and thinking that I would never learn to reverse like that; but they were very encouraging.

Isn't it strange how you never notice something until you become interested in it? Once I'd admitted my need for a motorised '*something*' I saw notices in the paper and, most of all, the article in '*Mainstream*' (thank you Ian) concerning the Motability Scheme.

I had thought this scheme was just about cars but then realised it was for wheelchairs and scooters too. I had the requisite higher Mobility Allowance on DLA, so I telephoned and found everyone so friendly and helpful. I was asked about my requirements (physical and practical) and, when I said I had spinal problems as well as MS, I was helped to the conclusion that I needed a wheelchair rather than a scooter.

In about two weeks a '*very nice man*' arrived with a choice of two. He gave me a demo' and then, within a very short time, I was practising in my driveway and up and down the pavement. He said '*That's why I love this job - to see the smile on someone's face when they find how easy it is and realise the freedom they'll have.*' I fell in love with this first wheelchair (which shows how carefully the Motability people had listened to my needs). It is an armchair on wheels, so comfy!

My chair was ready for delivery before my new door with low threshold was finished but they were happy to hold it for me until all was ready.

I've had it about five weeks now and, yes, it has been a learning curve. Some of the dropped curbs are an unfunny joke and the pavements are so uneven my feet were nearly shaken off the foot-plate but, as I learnt to take any hazard slowly, I began to appreciate what my wheelchair is able to tackle - it's wonderful!

I have to admit I'm still finding reversing a challenge but as long as I go real slow, I'm

getting better (I had problems reversing my car, even after 32 years - it's probably not my thing!)

To go where I want to, whenever I wish, to enjoy a trip along the seafront or a shop-around a supermarket etc. etc. has made my life a LIFE. If you're hesitating about getting your own personal wheelchair or scooter - GO FOR IT! It will truly change your life.

**Margaret-Clare**

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## TO PROTECT IT - REGISTER IT

**[www.immobolise.com](http://www.immobolise.com)**

Thousands of items of property are lost or stolen in the UK each year.

Register your property at:

[www.immobolise.com](http://www.immobolise.com)

It only takes a couple of minutes and is FREE. With mobile phones you will need your IMEI number. If any item of registered property is stolen report it to the Police.

If your registered property is recovered the Police or Immobolise will contact you.

**[www.immobolise.com](http://www.immobolise.com)**

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## DROP THAT KERB!

Back in May a number of us from the branch attended the ESCC Scrutiny review of dropped kerbs. It was an extremely interesting meeting chaired by Councillor Godfrey Daniel.

The various problems we all have with dropped kerbs (or lack of them) across the county was discussed of course, but the interesting fact that came out was that ESCC do not have a dedicated budget for dropped kerbs.

Naturally, we all felt that such a dedicated budget should exist and that recommendation was considered by the East Sussex County Council Cabinet on July 8<sup>th</sup>.

The Cabinet response was that they did not wish to reduce the existing budget for road/pavement maintenance and additional funding would need to be found elsewhere to create a specific budget for dropped kerbs.

The Council's budget process will be completed by February 2009 and we will then know if money has been found specifically for dropped kerbs. I will keep you posted in '*Mainstream*' as to the outcome. The situation in our area regarding dropped kerbs is pretty grim! **BC**

## MAINSTREAMING WITH MARGARET

The early part of August started with a training course from the London Fire Brigade on emergency fire evacuation and what a truly amazing day that turned out to be. The day was arranged by the National Centre's Ann Richardson and was led by two visiting members from the London Fire Brigade.

They made us all very aware of fire safety and their presentation was excellent. It was a most interesting day, and enjoyed by us all.

When I first started working with Ann Richardson (MS National Centre's Day Service Co-ordinator) I thought everything was crazy. Looking at this and that, risk assessments, health and safety, first aid, sometimes it seems an endless list. However, I have changed my attitude and openly accept we have to monitor so much in this day and age, in our efforts to support and protect others. Therefore, if sometimes actions may seem unnecessary, I can guarantee there will be a reason.

I have also been working on statistics for the National Centre regarding the various waiting times with regard to the provision of services in respect of powered indoor/outdoor wheelchairs. There seems to have been an historical backlog in this area but we are now told that all backlogs will be cleared by April 2009. So that is good news, let us hope we keep "on track" as they say.

The work I have mentioned above is some of the "behind the scenes activities" but it is a fundamental part of the services and support we provide.

In last month's Mainstream Jane Bradley introduced herself to you all with regards to Counselling - please refer to page 5 of the August edition of Mainstream. Jane comes from an experienced MS background as a

Centre Manager for an MS Therapy Centre and she also worked for the MS Research Trust. Please feel free to contact her on 07813 093117 if you wish to discuss any aspects regarding counselling. Thank you.

Support comes in many ways; it can be a chat at the luncheon club or a phone call or a coffee at the ladies group. I think whatever works for us as individuals, is the right way. However, I think we all need support in some form or another - so please remember we are all here if you need us.

I cannot believe that Christmas is being so well advertised; this evening Mum and I have seen booking leaflets in respect of Xmas Day dinner. With this in mind the branch MS Society Xmas collection 2008 catalogues have been received and we will be holding a coffee morning on the 10th October between 11.00 and 1.00pm. Please pop along and join us, place your orders and enjoy a cup of coffee. The Festive Season really does take on a life of its own and the children are still on their summer break!

**Moving into my Secretarial role and in a more serious tone, in a couple of week's time a strong contingent from your local Committee will be attending the MS National AGM which is being held in London on the 13th and 14th September. This Branch has made major steps forward in the services and opportunities that it now provides to its members. Awards have been won for our dedication and hard work, and recently our website has been designed and has received 2,000 hits in a month.**

**The branch is now under review with the Chairmanship issue, volunteers are more difficult to recruit, and monies are more difficult to find. The months ahead may now see changes in many ways.**

**Margaret**

## Listening... or spinning?

Having spent many years of my life with people affected by MS, both as Home Visitor and as your Chairman, I feel genuinely qualified to contribute to the consultation on 'Care Support Independence' (see page 3). I am urging you to do the same because under the heading 'Achieving Our Vision' there is the statement from the government:

*'The Government created the principles by listening to what people want from care and support.'*

(Check out: [www.careandsupport.direct.gov.uk](http://www.careandsupport.direct.gov.uk))

But have they ever really listened? Not in my view. Let's take a look at the real world that I operate in every single day. Let's see what prevents our people from living independently so that they can *'participate as active and equal citizens'*. For that is the Government's 'vision' apparently. So, here's just seven reasons why successive governments have actually prevented people affected by MS from being included in the wider community:

1. The shameful amount that Carers are paid
2. The failure of health and social care to work together in the interests of their clients
3. Successive governments have failed to recognise the true cost of disability.
4. The current DLA application form still fails to take into account the diversity of MS; in particular fatigue and relapses
5. The unacceptable wait for a wheelchair assessment
6. The unacceptable wait for a wheelchair after the assessment
7. The toothless bit of legislation known as the Disability Discrimination Act. There is nobody appointed to implement it and it is widely ignored

Seven issues that *have not* been addressed that collectively affect the quality of life of disabled folk and their carers. We have campaigned for years on all these seven points along with the shortage of specialist nurses, the social care postcode lottery and the failure of central government to sufficiently fund local government to meet these needs. Now, another consultation - hopes raised all over again.

And please do not think this is the only consultation on the boil. Oh no! Currently we also have the government's National Carers Strategy '*Carers at the heart of 21<sup>st</sup> century families and communities.*' Once again the government said it has listened to what we want - once again its all vision and strategy. Once again there is no move to raise Carers Allowance - it will be *reformed* after *talking to people on how best to do it!* Simple! Take into account how much the government saves and then make the allowance a realistic amount, let's say £150 for full time care - there we are, end of consultation!

I sincerely believe that the seven points I have listed are seven *obstacles* to people with MS and their Carers. Continued failure to overcome these obstacles makes it difficult to take any new *consultation* seriously.

When all else fails, turn the tables around - in this case, ask disabled folk and their Carers *what responsibility they think **they** have in the area of social care?* Wouldn't it be fair to say that Carers have long taken *their* responsibilities very seriously. Wouldn't it also be fair to say that folk with MS have long taken *their* responsibilities very seriously. Many of our folk with MS and many of our folk who are Carers *have been giving up their time, voluntarily, for years to our Community Support Team.* That team is in existence simply because the government *has not been listening!* Instead it has brought out White Papers, Green Papers and Sky-blue pink Papers dripping with promises and visions.

**Ten years ago** this branch was campaigning on the issues of the wait for a wheelchair assessment and the disgraceful year-long wait for a wheelchair after assessment. What's changed? **Ten years ago** I was told that the Carers Allowance was under review - how long does a pittance remain under review?

Let's assume *they are* listening this time and not spinning. Please register your views. In the meantime we will use our influence to speed up the process for our members waiting many months for a cushion for their wheelchair, a simple ramp, a couple of grab-rails, a home physio visit, access to a public building, etc. etc. You know - the real world that I mentioned at the beginning. The very world that we *consulted* on years ago! **BC**

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