



# 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 4 AUGUST 2008

THE SIXTH YEAR OF 'MAINSTREAM'

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

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Scooter & Wheelchair Action Group report from Shirley



# 720 TAXIS



# 01323 720 720

Supporting Eastbourne & South Wealdon MS Society

WORKING IN PARTNERSHIP WITH



**AUGUST 2008**

**WED 6<sup>TH</sup> LUNCHEON CLUB**  
*Please ring Joyce to book*  
**Community Support meeting 11am**

**THURS 7<sup>TH</sup> LADIES GROUP 10.30 - 2.30**

**FRIDAY 8<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
*Please note: No Yoga today*

**SUN 10<sup>TH</sup> CHARITY CRICKET MATCH**  
*Sidley Cricket Club*

**MON 11<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**

**TUES 12<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
**TIME2TALK Drop-in & Phone-in Sessions**

**WED 13<sup>TH</sup> LUNCHEON CLUB**  
*Please ring Joyce to book*

**THURS 14<sup>TH</sup> LADIES GROUP 10.30 - 2.30**

**FRIDAY 15<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
*Please note: No Yoga or Physio today*

**MON 18<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
**Monday Men Lunch at Centre - from 11am**

**TUES 19<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**

**WED 20<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
**LUNCHING OUT**  
 Sunrise Senior Living Centre  
**Pre-orders ESSENTIAL**

**THURS 21<sup>ST</sup> LADIES GROUP 10.30 - 2.30**

**FRIDAY 22<sup>ND</sup> CENTRE OPEN 10.30 - 3.30**  
*Yoga commences 9.30*  
*No physio group*

**SAT 23<sup>RD</sup> COMMITTEE MEETING**

**MON 25<sup>TH</sup> BANK HOLIDAY**

**TUES 26<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
**'SCOOTERBILITY'**  
*Devonshire Halls 10.30 - 12*

**WED 27<sup>TH</sup> LUNCHEON CLUB**  
*Please ring Joyce to book*

**THURS 28<sup>TH</sup> LADIES GROUP 10.30 - 2.30**

**FRIDAY 29<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
*Yoga commences 9.30*

**SAT 30<sup>TH</sup> 'THOSE YOU HAVE LOVED'**  
 Concert - see page 9 for details

**YOUNG CARERS OUTING TO LONDON ZOO**

**SEPTEMBER 2008**

**MON 1<sup>ST</sup> CENTRE OPEN 10.30 - 3.30**

**TUES 2<sup>ND</sup> CENTRE OPEN 10.30 - 3.30**

**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 - 2.30**

**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 - 2.30**

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

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

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

**NEXT 'LUNCHING OUT' - AUGUST 20<sup>TH</sup>  
 PRE-BOOKING IS ESSENTIAL**

**AUGUST 30<sup>TH</sup> YOUNG CARERS  
 SUMMER OUTING TO LONDON ZOO**

'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

**COME AND JOIN US FOR LUNCH AT THE CENTRE - GOOD COMPANY AND GOOD FOOD**

## Are you a Carer?

CRESS can give you peace of mind

Many carers worry about what would happen to the person they care for if, for example, they became ill or were involved in an accident. The pilot CRESS (Carers Respite Emergency Support Service) project is intended to provide carers with peace of mind by ensuring that alternative short-term, home-based care can be put in place in the event of an emergency.

As part of a Carers Assessment, carers can record a contingency plan which will need to be in place within 2 hours and will last up to 48 hours (72 if over a bank holiday) while longer term support is arranged. Ideally carers will identify three people/care providers who will be able to step into the caring role. This could be a friend, relative or a care worker already known to the family. In the event that none of these options is available, substitute care will be provided by East Sussex County Council's own Directly Provided Service.

All carers are legally entitled to have an assessment of their own needs. They do not have to live with the person they are caring for. To access CRESS, carers will need to have a **Carers Assessment** and complete a contingency plan, this will then be registered with CRESS.

CRESS provides free home-based emergency support.

To find out more about CRESS contact Social Care Direct:

**Telephone: 0845 60 80 191**

or email:

[socialcaredirect@eastsussex.gov.uk](mailto:socialcaredirect@eastsussex.gov.uk)

## Are you a Carer?

Carers Emergency Card from the MS Society

A carer is anyone providing care and support to a relative or friend with MS. It might feel strange at first, thinking of yourself as a carer, and while you want to do all you can to help, you need to make sure that your needs are met as well.

It pays to plan ahead and the MS Society's Carers Emergency Card can help you do just that. We'll help you think about who you would want to contact and what you would want to happen in an emergency. And once you've got your card, you'll have call centre back up, 24 hours a day.

We are working with an organisation called Welbeing, who are very experienced in providing high quality call centre support for carers and people with disabilities.

When you register you can provide information about the needs of the person with MS and what you want to happen in your absence.

We will give you a card with a unique ID number. If you or someone with you calls the telephone number on the card, the trained staff at the Welbeing call centre will use the details you have provided and put in place the alternative arrangements you have specified.

This service is FREE to all carers of people with MS.

For more details of the MS Society's Carers Emergency Card contact Welbeing on:

**Freephone 0800 085 8344**

## **Oh, How Careful We Have To Be!**

**from our Vice-Chairman Joyce Milton**

*I seem to spend an awful lot of time appealing for volunteers, donations, money and goods to raffle or sell to maintain our MS Centre and the many services we provide.*

You all need to be confident that your donations are being used in the manner you intend, so I'll try to explain a little about how we ensure that our fundraising meets the high standards you rightly expect from us.

### **Fundraising Standards Board (FSB)**

As members of the FSB, we have promised to commit to the highest standards of fundraising practice, and ensure that our activities are fair, honest and legal. We must comply with all relevant laws, including those which apply to data protection, health and safety and the environment. We have promised to be honest and open: tell the truth and not exaggerate; do what we say we are going to do and answer all reasonable questions about our fundraising activities and costs. In addition we have to be clear about how your gift is used.



We respect the rights, dignities and privacy of our supporters and beneficiaries and we will not put undue pressure on you to make a gift and if you wish to cease giving we will respect your decision. We take care not to cause unreasonable nuisance or disruption.

We are accountable and have a complaints procedure. If we receive a complaint we cannot resolve, we accept the authority of the FSB to make a final adjudication.

### **Charity Commission**

I'm sure many of you know that we have to operate under the laws of the Charity Commission, and it has issued a Memorandum of Understanding relating to the Fundraising Standards Board. This sets out how the two organisations have agreed to work together to help the charity sector achieve the highest standards in fundraising and to help to make the self-regulation of fundraising a success.

If all this appears to be just more 'red tape' I would reassure you that our Branch prides itself on being open and honest, and we are pleased to comply with anything which helps us attain this. Whenever I am asked about a new fundraising idea I always check the Charity Commission website to ensure that it is legal, and you'd be surprised at how often I have to say we can't go ahead! A good example is sales: we can offer goods for a 'suggested donation', providing we are prepared to give them away free of charge. We cannot offer goods for a 'minimum donation'. This simple point demonstrates how easy it is to fall foul of the law, and we actually welcome anything that ensures we do not, in ignorance, do anything which might damage our good name and reputation in the community. We need to be sensitive to public opinion and criticism which can damage our Branch and reduce public confidence in us.

People are entitled to know the reason for our fundraising. It is misleading the public if they think they are supporting a particular project (for example, last year's minibus appeal) when in fact the money is to help our community support programme.

It is vitally important that our volunteers know they are operating to the highest standards, and that we use all the information available to us to help them to achieve this. If this makes us unpopular sometimes, that's the price we have to pay for ensuring that our Branch continues to successfully raise the funds we need.

**Joyce**

Hello everyone,  
I came to the Centre recently to meet Margaret and Bernard to discuss my offer of providing counselling to members of the Eastbourne & South Wealden MS Society. Having reached agreement on this they invited me to write a piece for this edition of 'Mainstream' as a means of introducing myself to you.

However, before I do that I would like to thank the small group of ladies I met that day who had no idea who I was but who made me feel so instantly welcome and ensured a drink was in my hand within minutes!

Counselling can provide a safe place in which to explore difficult thoughts and feelings - some of which may have been hidden for years. You will not be judged or told what to do and many people find it a relief to talk to someone totally outside their situation. From this you may begin to view things differently, make changes or come to terms with things you cannot change.

In the 1990's I spent 7 years working as Centre Manager at an MS Therapy Centre in Hertfordshire. During that time I came into contact with many people whose lives had been affected by MS - and it was while listening to the many and varied experiences and struggles that people were going through that my interest in counselling was stimulated.

It seemed to me that a lot of emphasis was directed at the physical symptoms of MS - and rightly so, but what I was also hearing about was how people felt about those symptoms and how they affected their lives at home, at work and socially. I was particularly aware of the problems encountered by people with few obvious symptoms who often felt frustrated by others lack of understanding during the 'bad times' and torn between being perceived as someone needing help or someone who was managing well.

I met several people who had been diagnosed for some while but had managed to hide their MS from their family and friends - often to protect them from painful reality but also fearing the change in attitude they foresaw - 'being treated like an invalid'.

Living a lie in this way often created even more problems and as I listened to more and more people with MS talking about their daily lives I started to appreciate the complexities of each individual's experience.

I subsequently worked for 4 years for another MS charity - the MS Research Trust - which again brought me into contact with problems faced by people with MS. When I left there I decided to begin training as a counsellor and 4 years later in 2006 I attained the Diploma in Therapeutic Counselling.

Since qualifying I have been interested in working again with people with MS as I feel that my background gives me at least some idea of the difficulties that people may face, although of course everyone has their own unique experience.

I am happy to volunteer my time, but to work ethically, safely and professionally I have to have supervision which has to be paid for. To cover this I will operate a sliding scale of charges from £5 - £10 per 50 minute session which will help towards that cost. This can be discussed at our first meeting which will be free of charge. At that meeting we can find out more about each other and explore how best to approach your difficulties. You can then decide if counselling feels right for you and whether you feel we can work together. Initially sessions will be at the Centre on Friday afternoons between 2 and 4pm with the first date being Friday 5<sup>th</sup> September. If you would like to discuss making an appointment please phone: 07813 093117.

Best wishes to you all,  
**Jane Bradley**

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

Dear Friends,

Greetings to you all once more!

I was sitting in my doctor's waiting room a few days ago and picked up a magazine to idle the time away until my name was called, when the following question jumped out at me from its pages, *'If you had an hour to live and could make just one phone call, who would you call, what would you say - and why are you waiting?'* What a powerful question! Who knows what we are waiting for? I hear so many lovely words of love and appreciation at funerals; I wonder whether these loved ones heard them for themselves while they were here with us.

It is often the same with the beautiful floral tributes that rest next to the grave: much better in a vase in our loved one's homes where they can see them and smell them while both the flower and the love one's live.

Perhaps we want to believe we will live forever, or that someday we will get around to telling the people we love how much we love them. Whatever the reason, most of us simply wait too long. There is never a good reason to wait. Now is the time to let people know how much you care. Ideally, you can tell someone in person or over the phone. Imagine just how wonderful it would be to receive a telephone call with no other message except to say *'I've just called to tell you how much I love you'*.

If you're too shy or self-conscious to make a phone call, write a heart-felt letter or send a few well-chosen words in a card. Either way, you may be surprised that almost nothing in the world means so much to a person. Go on, try it...make someone's day!

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 736359**

or email: SueAustin50@aol.com

All calls are confidential

*Talking really can help!*

**'SCOOTERBILITY'  
 COMES TO EASTBOURNE**

Are you thinking of buying or hiring a motorised scooter/buggy - or MV as we call it?

Join one of the FREE courses today and learn to navigate your way through everyday scooter hazards in comfort and safety.

- <> Find out what to look for in a motorised scooter
- <> Let the experts tell you about Servicing your MV
- <> Hear what's legal and what's not
- <> Try an MV safely on our indoor course

**LAST TWO COURSES  
 AVAILABLE!**

**26<sup>th</sup> August 10.30am to 12 noon**  
**Devonshire Halls, The Winter Gardens**

**26<sup>th</sup> September 2.30pm - 4pm**  
**Willingdon Trees Community Centre**

**To book your place, contact:**  
**Denise on 01323 415265**

*'Scooterbility' is organised by the Disability Involvement Group (DIG) of Eastbourne Borough Council and is supported by the Eastbourne & South Wealden MS Society*

**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

**CHECK OUT OUR WEBSITE...  
 AND LET US KNOW WHAT YOU THINK!**

**www.mssesw.org.uk**



I attended the PCT Wheelchair and Special Seating Service Strategy Group meeting on July 11 and was as always made to feel very welcome as was any comments or remarks I had to give about the service experienced by our members.

I spoke about the lack of telephone contact at the Conquest office after leaving several messages and have been assured that the answering message is to be changed and there will be an improvement on the times when the telephone is actually manned.

I also mentioned that it would be useful for clients to have both Eastbourne and Hastings numbers so that hopefully if they cannot access one they can try the other.

Apparently Hastings deals with EPIOC issues for both East Sussex and Weald, and Hastings and Rother, and Eastbourne with manual wheelchairs and seating etc.

Please let me know of any problems you are experiencing connected to the wheelchair service and I will be happy to pass them on at the next meeting in August.

I am pleased to say that Kirsty "Assessability Manager" for Southern rail and Constance from Eastbourne Railway Station came to see me at home recently to discuss several problems being experienced by wheelchair passengers

Some of the items discussed were the reluctance of some guards to put the ramp out at Hampden Park and leaving wheelchair passengers behind on the platform. Failing to get out of the train to check that all passengers had boarded. On some services leaving Eastbourne some guards stay in another carriage and do not come to the disabled section and on more than one occasion the train has gone on to the next station with a wheelchair passenger still on board.

Another very important issue I raised was the obligation of Southern Rail to ensure that in the event of engineering works buses provided

should have ramped access for wheelchair passengers. On this subject I have been assured that the bus company providing alternative transport will be asked to supply at least one bus- an hour that is accessible to all.

Councilor Andrew Goodwin Disability Champion has also had a meeting with some management of Southern Rail and has been assured that all of our criticisms and suggestions have been noted and will be acted on.

Our recent SWAG meeting went well and we covered seven items of current issues Bernard and I are involved in.

These include:-

- Southern Rail
- Access to Roseberry Avenue
- Wheelchair Service
- Eastbourne National Advert
- Access to Royal Eastbourne Golf Club
- Report on ESCC dropped-kerb progress
- Scooterbil;ity

Andrew Tilney Park Ranger is meeting up with me, Jean and Gary from ESDA to take a look at the paved and road areas we are so concerned about when we try and access the Park. He will hopefully then be able to tell us who we can lobby to get a reasonably comfortable journey to the park without the worry of being tipped out of our chairs along the way due to the disgraceful state of paving slabs and tree roots.

Watch this column for more updates.

**Shirley**

### ***Service of Remembrance and Thanksgiving***

My sincere thanks to the staff at Eastbourne Cemeteries & Crematorium for making us their charity at this service. I attended with Margaret and Joyce, and we agreed it was one of the most spiritually moving multi-faith services we had been part of in a long time.

I know other members of the branch attended in a private capacity - I trust you drew comfort from the spoken words, the hymns and the prayers.

It was a month ago, and yet I can still bring to mind the sense of peace and serenity from that afternoon.

**BC**

## **MP PLUMBING AND HEATING**

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### **Vet2u home visits**

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## **FOR SALE**

### **INVACARE TWISTER POWERCHAIR**

*Tilt in space, hi-low, good condition*

**£450 ono**

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**ADJUSTABLE WITH ARMS, AS NEW**

**£25 ono**

### **SHOWER STOOL**

**COLLAPSIBLE, ADJUSTABLE LEGS**

**GOOD CONDITION £25 ono**

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**With frame for Ford focus 06**

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**CONTACT: PETE OR JACKIE**

**01323 471350 OR OUR MS CENTRE**

*Donation from each sale to be made to our Branch*

## **FOR SALE**

### **INVACARE**

### **HAND CONTROLLED POWER CHAIR**

**Very good condition**

**With charger and cushion**

**£400.00**

**Telephone: Phill Hooker**

**01424 838371**

**Mobile: 07977 546809**

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54 Hammond Drive Eastbourne East Sussex

**Telephone (01323) 724725**

Recommended by Eastbourne & South Wealden MS Society

### **MS Society HELPLINES**

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

**PHONE: 0808 800 8000**

**East Sussex residents can phone one  
number to get information about  
adult social care  
Social Care Direct 0845 60 80 191**

CHECK OUT THE LATEST  
PHOTOS ON OUR WEBSITE  
[www.mssesw.org.uk](http://www.mssesw.org.uk)



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

**MONDAY JULY 28<sup>TH</sup>**

Sincere thanks to Len and Brian for driving us all over to Brighton Marina on a blistering hot day...what would we do without two vehicles now? It's really good to be turning the Monday Men trips out into an opportunity for others to join us. Good company...good food...who could ask more? As from September we will arrange dates for lunches out to take us through the winter months. The next meeting for us will be:

**MONDAY AUGUST 18<sup>TH</sup>**  
LUNCH AT THE CENTRE  
(Meet from 11am)

**PLEASE NOTE:**

Lunch at the Centre will be for Gentlemen only. On the trips out all Gentlemen are encouraged to bring a lady-friend, man-friend or mistress...**OR** please feel free to bring your wife!

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

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

**IN MEMORIAM**

**GEOFF MOXON**  
1930 - 2008

It is with great sadness that we report the passing of Geoff Moxon, a long-serving member of our branch. To all of us, Geoff was a true gentleman with a great sense of humour. Our love and prayers go to his wife June and family at this very sad time.

**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 6 week course gives you the opportunity to...

- > learn new skills to cope with your illness
- > learn more about exercise, relaxation and healthy eating
- > improve your quality of life and plan for the future
- > manage emotional changes that may result from your condition

The course 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**

**'THESE YOU HAVE LOVED'**  
*An evening of favourite melodies*

~~~~~

**Saturday 30<sup>th</sup> August 7.30 at**  
Upperton United Reform Church  
Upperton Road Eastbourne

*Presented by acclaimed local talent*

ALL PROCEEDS TO  
EASTBOURNE & SOUTH WEALDEN MS SOCIETY

TICKETS £5 IN ADVANCE OR £6 ON THE DOOR  
Available from MS Centre MAP House  
or telephone: 01323 728197

**IAN'S INFORMATION DESK - TELEPHONE 01323 763226**

**DID YOU KNOW?**

Between 2010 and 2020 the State Pension Age for women is going up gradually from 60 to 65.

Between 2024 and 2046 the State Pension Age for both men and women will rise in steps to 68.

If you reach State Pension Age on or after 6<sup>th</sup> April 2010, you'll only need to have 30 qualifying years of contributions or credits to qualify for a Full Basic Rate State Pension – currently men need 44 qualifying years and women 39.

If you reach State Pension age on or after 6<sup>th</sup> April 2010 you'll be able to get some Basic State Pension for each qualifying up to 30 – currently men normally need at least 11 and women at least 10 to get any Basic State Pension at all.

New credits are being introduced from 6<sup>th</sup> April 2010 for people receiving child benefit for children under 12, approved foster carers and those caring for severely disabled people for at least 20 hours a week to help them build up their Basic State Pension and State Second Pension.

For more information is available at [www.thepensionservice.gov.uk](http://www.thepensionservice.gov.uk) or the Pension Helpline on **0845 600 0800**

Source DWP website 22<sup>nd</sup> July 2008

**NHS failing people with MS**

09 Jul 2008

**A recently published report by the Royal College of Physicians (RCP) and the MS Trust states the NHS is failing people with multiple sclerosis.**

The report identified that the estimated 85,000 people in the UK with MS are subject to a "postcode lottery", with access to basic services - including pain relief - a matter of geographical location

The NHS is still failing to implement 2003 National Institute of Clinical Excellence (NICE) guidelines on the management of the condition.

An audit of services revealed that only 36% of people with MS had access to neurological rehabilitation facilities and long delays mean 50% of patients are waiting more than 20 weeks to be diagnosed after a GP referral.

Simon Gillespie, chief executive of the MS Society said: "It's vital that health services are held to account and this latest audit confirms what our 40,000 members tell us - people with MS need access to more and better care.

"The NICE guideline sets out a laudable range of care and support on paper but it needs to be backed up in practice."

Source MS Society website 20<sup>th</sup> July 2008

**MOTABILITY – AGAIN**

In April I wrote an article on '**MOTABILITY – THE CAR SCHEME**'. Like all my articles I extensively research the subject before going to print and the Motability scheme was no exception. During the course of researching this subject I became more and more convinced of the benefits of the scheme. So much so that I visited a local car dealer and set about the practicalities of becoming a Motability customer.

The process proved to be even easier than I imagined and having chosen a vehicle, just 5 weeks later the car was ready for me complete with a hoist for my powerchair so after paying the advance payment and signing a few forms I became the proud keeper of a car I could not afford to buy, insure privately and certainly wouldn't be able to pay for any repairs on. The car is festooned with computer systems, the workings of which I cannot understand but know to be safety features. If anything should fail I do not have to worry and every moment the car is off the road for service or otherwise, a courtesy car is all part of the deal.

I am truly amazed how easy the process was and I wish I had done it earlier. It is early days yet but I feel confident the scheme will prove to be every bit as good as the advertisements claim so I will keep you posted on developments (if any) while suggesting that any of you with **Higher Rate DLA Mobility Allowance**, thinking about a new car, take the first step and visit the car showroom of your choice to see what Motability can do for you. It's as easy as that!

*lan*

## Small Study Shows Caffeine Could Prevent MS

MS Society website 01 Jul 2008

**A small study published in the Proceedings of the National Academy of Sciences journal has shown that mice given the equivalent of six to eight cups of coffee a day were less likely to develop a condition similar to multiple sclerosis.**

It is hoped that this type of research could lead to insights into how to prevent MS in humans. MS is caused by immune cells entering the central nervous system (CNS) and attacking nerve fibers. The research reported that the caffeine appeared to prevent damage to the CNS.

The researchers used mice with an MS-like condition (called experimental autoimmune encephalomyelitis or EAE) to mimic the development of MS in humans. Caffeine affects the function of a molecule called adenosine, which plays a role in sleep and energy production. When mice were dosed with caffeine, changes in adenosine appeared to have an indirect effect on the ability of immune cells to enter the CNS and the mice did not develop EAE, though the precise reason this happened was not clear.

Dr Linda Thompson, who led the study, said that the next step was to see if humans who drank plenty of coffee showed any signs of being less prone to MS. "If you found a correlation between caffeine intake and reduced MS symptoms that would point to further studies in humans."

***However, even if this were established, coffee might not be a good way to prevent MS. Experts recommend no more than five cups of coffee a day, amid evidence higher doses can worsen diabetes and could also be physically addictive. The Department of Health has also set a limit of six to eight cups a day.***

***Dr Lee Dunster, Head of Research at the MS Society was also cautious: "Over the years there have been numerous discoveries that have prevented EAE in mice but turning this into effective therapies for humans remains a challenge. Based on the results of this study, we wouldn't advise people to change their caffeine intake."***

### **Interferon {beta} therapy increases serum ferritin\* levels in patients with relapsing-remitting multiple sclerosis.**

Sena A, Pedrosa R, Ferret-Sena V, Cascais M, Roque R, Araújo C, Couderc R.  
Departamento de Bioquímica, Faculdade de Ciências Médicas, Lisbon, Portugal; Service de Neurologia, Hospital dos Capuchos, Lisboa, Portugal. armando.sena@fcm.unl.pt.

Serum ferritin levels have been found to be increased in patients with active progressive multiple sclerosis. However, its levels are reported to be unchanged in stable and in active relapsing-remitting (RR) form of the disease. No research to date has assessed the influence of interferon beta (IFN-beta) on ferritin concentrations. In this study, serum ferritin levels were measured in 43 individuals with RR-MS and 38 age and sex-matched control volunteers. There were no significant differences between controls and patients under stable and untreated conditions. In patients at 12 months after the beginning of IFN-beta therapy, ferritin levels were higher in women and in men, in comparison with baseline. The results suggest that larger prospective studies are required to evaluate the role of serum ferritin in MS and its potential usefulness in monitoring responses to immunomodulatory therapies.

\* Serum Ferritin is a non toxic iron carrying protein

Source PubMed June 23 2008

## YOUNG CARERS

Our Summer outing to London zoo is fully booked, with a full coach as well as one of our minibuses going on Saturday 30<sup>th</sup> August. Our application has now gone in to Four Acre Trust to extend our fund so that we might continue with our fun activity programme for next year. So now we are awaiting the outcome with baited breath!

As ever, if anyone is aware of any Young Carers who are not on my mailing list, please do get in touch and let me know. 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 currently have no programme as such through August since many of our members will be away taking a holiday. But please do still come to meetings at Map House on Thursday mornings, we will still be there for a welcoming cuppa and a chat. And you could help us to plan the programme for September. I look forward to seeing you there.

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

### ***'MS awareness taken into schools'***

SEE THE JANET AND CLARE STORY  
AND PHOTO ON OUR WEBSITE

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

## NEWLY DIAGNOSED

### Newly - Diagnosed Group in Seaford

I have arranged lunch on:

MONDAY 8<sup>TH</sup> SEPTEMBER 12.45pm

The Premium Inn, The Drove, Newhaven  
Hope to see you all there. Can you please phone to acknowledge you would like to join us as I have to make a reservation.

Telephone Sue on: 01323 736359

### YOGA AND PHYSIO

PLEASE MAKE A NOTE IN YOUR DIARY..NOW

Yoga - there will be no Yoga on:

8<sup>th</sup> August & 15<sup>th</sup> August

Physio - there will be no Physio on:

15<sup>th</sup> August & 22<sup>nd</sup> August



### THE SAD POEM

JUST WHEN THINGS ARE GOING BAD,  
AND YOU ARE FEELING A LITTLE SAD.  
DON'T GIVE UP - AND WEAR A SMILE,  
AND THINGS WILL IMPROVE IN A WHILE.  
AS YEARS PASS ON, YOU WILL SEE,  
THAT THIS TIME WAS MEANT TO BE.  
SO GIVE STRENGTH IN ALL YOU DO,  
SO TOMORROW YOU CAN START ANEW.



Diane Hewitt

**FUNDRAISING & DONATIONS  
MONTHLY UPDATE FROM MARGARET**

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

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**FUNDRAISING JULY 2008**

Thank you to the member who completed the London to Brighton bike ride - **£70**

The Gilbert and Sullivan cheque presentation of £550, making a grand total in excess of **£900** - special thanks to Bernard

Rebecca Corteling-Rice Skydive money raised to date **£1,087**

Memorial and Thanksgiving Memorial Service - Retiring Collection - **£258.76**

Hailsham Lions Fun day **£410.66** - With our special thanks to Dave, Sue, Carrie, Val, Heather, Liz and Brian

Daisy Chain Nursery & Montessori School fete and sports day - **£525**

Ladies group candle party - **£40**

Peter Boddy Skydive money raised to date - **£102.50**

General donations to skydive from Debbie and Christine - **£30**

General donations of **£20, £50, £5** and **£10**

Eastbourne Choral Society - **£50**

Mr Terry Thow - **£1,000**

In memoriam - the late Mrs Tricia Mole - **£15**

With our grateful thanks to all concerned - Bernard and Margaret

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

**BOOK REVIEW FROM JUDY**

" I referred to a book I would recommend to you all in July's edition of 'Mainstream' - written by an author living in Massachusetts U.S.A . He is at the Secondary Progressive stage of MS and has had the condition since late teens - sound familiar ?

The book is entitled " Life Interrupted - It's not all about me . " His name is Chris Tatevosian and his book is both heartwarming and sensitive but in no way gushy. A friend at the Centre asked me whether he runs marathons in his spare time !! An attitude we Brits can have sometimes about our American neighbours . In this case I can assure you that this is not the case and I urge you to read the book for yourselves. It is brief and concise and covers all the aspects of MS that we've had to learn to live with , along with our families and friends. The chapters are such that you'll find yourselves "dipping in and out" as your mood and emotions dictate. Have done it myself many times . .

I am awaiting delivery from Amazon as I type and am giving one copy to Branch for your perusal. If anyone would like a copy of their own (cost for paperback just under £6 - the more I order - p&p comes free !) Please call me on:

01323-486478 or email me at:  
judyparker@hotmail.co.uk

**Judy Parker.**

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**CHECK OUT JUDY...NEXT MONTH!!**

I love it! I just knew that somewhere out there in 'membership' land *somebody* would respond to last month's appeal for a reporter for 'Mainstream'. Thank you Judy! Was it the pay? Was it the prestige? Of course not! Judy and I have known one another for a long time - we fought a battle together, with Cllr. Shing, over banking for the disabled in Polegate.

Next month Judy will tell you all about her introduction to the MS world - and then I will have *three* rockin' contributors to 'Mainstream': Margaret Barrett...Joyce Milton *and* Judy Parker! Three ladies who pull no punches in our MS world...three ladies who probably tell their friends (with pride) '*I work with BC!!*' **BC**

**MAY WE RELY ON YOUR SUPPORT? ... IT WOULD BE APPRECIATED.**

## MAINSTREAMING WITH MARGARET

Bernard and Joyce have both written articles on the new volunteering policy and the need for more volunteers. We have used the magazine and also the website with loads of information to encourage people to volunteer and therefore help us and hopefully promote our work at the same time.

You could say that we are touching a captive audience in trying to encourage our own people and supporters. However, life is so difficult in our world of volunteering; commitment is the key to everything. The continuation of our services and our work is all to us. The Society was there when I needed it the most, and I hope and pray that it will be there for others in need for a very long time.

I find it so strange myself; I have actually been a volunteer for over 30 years, 20 years of which have been with our local MS group - I joined the Society when David was diagnosed with MS.

I have been so fortunate with the people I have met and the support I have personally received. However, although my life like many others has been affected by MS I have always thought of those in need today, and for those who may be in need tomorrow or in the future.

I had planned to write my article this afternoon and there is usually something that comes to mind to chat about. When we were talking about volunteering today someone said "Bernard and you are a difficult act to follow" and those words have stayed with me.

Bernard and I have met some dedicated people, who have worked many years and hours behind the scenes and in the past. One couple in particular used to be responsible for welfare visiting in their area and although of mature years now, they are still loyal supporters of the Branch and its Centre. However, they financially support it for others and not themselves.

Perhaps they also will be a difficult act to follow.

Shirley McCall, who was our previous Chairman, is now the Chairman of the MS Swag group.

Shirley is the past and she is also the present,

there are many people who are difficult acts to follow.

We must all do our best to secure health and social care services, because the loss of services in the statutory sector is worrying. The Committee will be reviewing our campaigning programme for volunteers and we will do our best to outreach to the wider community. We hope to hold a volunteering awareness event and to do some advertising as well, we will try and do as much as we can. Would you do the same for us please? I am personally asking you to outreach to friends, family and contact anyone you know who may like to join us for a few hours a week. Thank you.

Now, I would like to tell you about an event that was absolutely magical, and it was something that Bernard and I enjoyed immensely. The Daisy Chain Nursery and Montessori School at Dallington held a fundraising school fete / sports day in our name. We were invited to a cheque presentation and to the "end of term nursery school production". Bernard and I even had the small school chairs to sit on and marked "reserved" and in the front row!!

It reminded me of my young school days as I first went to school at Herstmonceux, which is only a stone's throw away, and my dad actually came from Dallington. It was a little trip down memory lane and it was the most wonderful cheque presentation that I have had the pleasure of attending.

The Centre is going very well, please join us if you are able at anytime. The luncheon club is a really good meeting place, and just to let you know that with the people attending and the committee they have just agreed a slight rise in the donation price to £3 per head. Thank you to everyone for their support, the Yoga on a Friday is also £3 per session.

Everyone is most welcome to join us at the Centre at anytime.

Take care

Kindest wishes **Margaret**

**'All things, by a law divine...'**

The month of July came...a blur of events...and the month of July went! I ended the month with a couple of lines from Shelley stuck in my head:

*'The winds of heaven mix for ever  
With a sweet emotion...'*

July was certainly a mixed month. It started with the first of the 'Scooterbility' workshops at the Devonshire Halls and a chance to meet our new Mayor of Eastbourne Greg Szanto. Really lovely fellow.

The throttle went on our Iveco vehicle, the washing machine packed up at home but Mick, a good friend of the branch, found a garage we could rent for all the branch items currently piled up at the Centre and in our homes.

Wonderful remembrance service at the Crematorium and an interesting meeting with folk from our MS National Centre and Social Services regarding a proposed pilot Relapse Support Service.

Birthday month for our driver Brian, our Vice-Chair Joyce, the lovely Joyce Dray and, of course, your 'BC'. Meeting with Ann Richardson and Jane Petty from the MS National Centre regarding a proposed new exercise scheme for MS folk.

Our fundraising crew over at the Hailsham Lions event supported by Dave Tubbs, a wretched cat killed a bird in our garden, and a lovely man called Jim phoned to book me in as a speaker for a *November event!*

Very interesting day at the Congress Suite for the debate over 'Access Eastbourne'. Two presentations were given (Brighton & Hove's Federation of Disabled People and Disabled Go a national web-based enterprise). Gave us all some food for thought and a desire to see accessibility information for our town available online.

Lunching out at 'Simply Italian' with a good crew, the sign writing now completed on both vehicles and a cheque presentation from the Gilbert & Sullivan Society at our Centre...over £900 raised in total...appearing on stage for a week is the most unusual fundraising activity I have ever taken part in for the branch! Good to see some of the G&S folk again. The heat got to a number of our folk during the week.

The month raced on and a trip to the Daisy Chain Nursery at Dallington proved to be one of the loveliest cheque presentations I have ever attended. Charming little folk putting on a play, lovely group of parents and a cheque for £500. Sebastian Bear enjoyed his trip out! Then a mad dash back to Eastbourne for a SWAG meeting, (our Margaret has all the makings of a Lewis Hamilton!!) and then a full committee meeting on the following day.

A morning with Andrew sorting out the website...he is very patient with me! Carol's friend Terry donated another £1,000 to the branch and my dear friend Tony was admitted to St Wilfrids Hospice - what wonderful people there - and so many of them are volunteers!

To the Old Town area of Hastings for a morning with our Sue - as a native of the area Sue really made it an interesting visit. My purpose was to take photos of another area of my beloved Sussex - good break for a few hours.

The month starting to run out...panic sets in...not one word of 'Mainstream' on the computer yet! Over to Brighton Marina for the day with the Monday Men and a lovely group from the branch. Good day...incredibly hot...then home and the first of a few spells into the small hours with the beloved 'Mainstream' and some very yummy bottles of Australian Red!! (It is actually 2.35 am as I tap out this last page!!). Sebastian is nodding off!

A sad end to the month with the funeral of our much-loved Geoff Moxon...our hearts and prayers go out to June and family. Regular trips now to St Wilfrids Hospice...a fox with cubs just wandered through their lovely garden!

Working with the MS National Centre on a campaigns policy and, with their help, the local NHS Trust have been approached about matched-funding for our physio programme.

My Carol...as busy as me! We spent one Saturday and two Sundays together during the month...July has seen my stock of ironed shirts seriously depleted...I say nothing!! Thank you to Margaret for looking after me and for sharing my enthusiasm...thank you to Joyce and the Monday Men for my 'Born To Sin' bandana!...a new month...a new picture on the calendar...and off we go again.

**BC**

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