

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

VOLUME 8 No 5 SEPTEMBER 2010



MS WALK AND WHEEL EVENT AT BRIGHTON

Branch members travelled to Brighton to take part in a sponsored Walk and Wheel along the prom.
Chairman Joyce Milton is pictured with Trudy Weller of the Foresters Friendly Society, which organised the event, and
Wendy Smith, Brighton branch Chairman.
Joyce's report is on page 4

A NEW DIRECTION FOR RESPITE CARE

MS Society report - pages 6 & 7

WORKING IN PARTNERSHIP WITH



SEPTEMBER 2010

MONDAY 6TH CENTRE OPEN 10.30 - 3.30
YOGA CLASS with experienced Yoga teacher
11.00 - 12.00

TUESDAY 7TH CENTRE OPEN 10.30 - 3.30

WEDNESDAY 8TH CENTRE OPEN 10.30 - 3.30
LUNCHING OUT @ HYDRO HOTEL 12.30 for 1.00pm
Please ring Margaret Davis on 482927 to book

THURSDAY 9TH CENTRE OPEN 10.30 - 3.30
LADIES GROUP 10.30 - 1.30
Games Galore or just coffee and chat

FRIDAY 10TH CENTRE OPEN 10.30 - 3.30

MONDAY 13TH CENTRE OPEN 10.30 - 3.30
YOGA CLASS with experienced Yoga teacher 11.00 -
12.00
**Seaford Group Meeting - Lunch at the Golden
Galleon @12.30**
For further details please ring Annifer on 01323
492788

TUESDAY 14TH CENTRE OPEN 10.30 - 3.30
Fundraising Committee Meeting @ 7.00pm
(Please contact Joyce on 01323 431593 for further
details)

WEDNESDAY 15TH CENTRE OPEN 10.30 - 3.30
LUNCHEON CLUB
Please ring Margaret Davis on 482927 to book

THURSDAY 16TH CENTRE OPEN 10.30 - 3.30
LADIES GROUP 10.30 - 1.30
Bingo with our favourite caller, Sue

FRIDAY 17TH CENTRE OPEN 10.30 - 3.30

SATURDAY 18TH COMMITTEE MEETING @ 10.30

MONDAY 20TH CENTRE OPEN 10.30 - 3.30
YOGA CLASS with experienced Yoga teacher 11-12
Meet to Share group meeting
@ The Royal Eastbourne Golf Club @12.30
Please contact Sue Austin on 01323 736359

TUESDAY 21ST CENTRE OPEN 10.30 - 3.30

WEDNESDAY 22ND CENTRE OPEN 10.30 - 3.30
LUNCHEON CLUB - **Cornish Pasties day**
Please ring Margaret Davis on 482927 to book

THURSDAY 23RD CENTRE OPEN 10.30 - 3.30
LADIES GROUP 10.30 - 1.30
**MS Christmas Catalogue sale with coffee morning
and raffle**

FRIDAY 24TH CENTRE OPEN 10.30 - 3.30

SATURDAY 25TH FUNDRAISING EVENT
AT THE BIG APPLE
(Please contact Joyce on 01323 431593 for further
details)

MONDAY 27TH CENTRE OPEN 10.30 - 3.30
YOGA CLASS with experienced Yoga teacher 11.00 -
12.00

TUESDAY 28TH CENTRE OPEN 10.30 - 3.30

WEDNESDAY 29TH CENTRE OPEN 10.30 - 3.30
LUNCHEON CLUB
Please ring Margaret Davis on 482927 to book

THURSDAY 30TH CENTRE OPEN 10.30 - 3.30
LADIES GROUP 10.30 - 1.30
**Repeat of our popular Auction - Please bring an
item new or good as new**

OCTOBER 2010

FRIDAY 1ST CENTRE OPEN 10.30 - 3.30

MONDAY 4TH CENTRE OPEN 10.30 - 3.30
YOGA CLASS with experienced Yoga teacher 11.00 -
12.00

TUESDAY 5TH CENTRE OPEN 10.30 - 3.30

WEDNESDAY 6TH CENTRE OPEN 10.30 - 3.30
Fish and Chip day
Please ring Margaret Davis on 482927 to book in
advance
Community Support meeting @ 11.00

THURSDAY 7TH CENTRE OPEN 10.30 - 3.30
LADIES GROUP 10.30 - 1.30

FRIDAY 8TH CENTRE OPEN 10.30 - 3.30

MONDAY 11TH CENTRE OPEN 10.30 - 3.30
YOGA CLASS with experienced Yoga teacher 11- 12

TUESDAY 12TH CENTRE OPEN 10.30 - 3.30

WEDNESDAY 13TH CENTRE OPEN 10.30 - 3.30
LUNCHING OUT@ **The Golfing Park with Carol**
12.30 for 1.00pm
Food orders must be placed in advance
Please ring Margaret Davis on 482927 to book

THURSDAY 14TH CENTRE OPEN 10.30 - 3.30
LADIES GROUP 10.30 - 1.30

FRIDAY 15TH CENTRE OPEN 10.30 -3.30

<p>'MAINSTREAM' is produced, published and edited by the editorial team for Eastbourne & South Wealden 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.</p>

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FROM THE CHAIR

I've now been your Chairman for nearly three months and I am just realising exactly how much hard work it entails . . .

There are no longer enough days in a week. I find I'm out on something to do with MS business for three or four days, and for three out of four weekends during August I've been representing our Branch on either the Saturday or Sunday. When I'm at home there are letters to write, emails to send and phone calls to take. Work extends well into the evening and I find I'm working harder than I used to when doing a full time job! However, this is giving me a tremendous amount of satisfaction, and my own MS is the least of my worries. I live on my own and as for housework – well what's that?

One thing I have realised is just how much support I need, not just from the Committee but from you – our members. I am somewhat downhearted that despite pleas in last month's MainStream for ideas of how to spend the Mayor's Fund money, fundraising ideas, raffle prizes, support for the Wheel & Walk and articles for MainStream etc, not one new person from our membership of nearly 300 has come forward.

Does this mean that you are just not interested? That you don't have time? That your health prevents you contributing? That you feel we don't do enough for you or some other reason?

We have a loyal but small band of supporters who can always be relied on to represent us when needed, but what about the rest of you? This is your Branch and you know that we are always here to offer help or advice. Even if you haven't needed our services, you may one day find yourself in the position of having to ask for help. We can only succeed with your help and support – so please have a think and remember, we need YOU.

We do have one more invaluable volunteer on board – welcome Jim. Some of you may already know Jim as he was instrumental in sorting the allotments with raised beds for disabled gardeners at Gorrington Road. Jim drove us to Brighton for the Wheel & Walk and collected for us on the day. He is also a member of our new fundraising group.

Let's give a big hand for Jim – I only wish a few more like him would come forward . . .

The first meeting of the fundraising group took place in August and I am pleased to say that it looks like being a great success. The ideas were coming thick and fast and everyone worked well together. This doesn't mean that we no longer need your ideas – you're not getting off the hook that easily!

On a lighter note, I must tell you about a 'ladies only' night out in July. Margaret Barrett, Sue Austin and yours truly went to the O2 Arena in London for a Bon Jovi concert. Yes, I did say Bon Jovi. With two of us being of pension age and the third getting there, we booked out tickets (one free as Margaret came as 'carer' for Sue and I, who both have MS). Mark Lester drove us there and back – thank you Mark. Before the big event we had a meal (an early-bird special Thai meal for £8.50) and mentally prepared ourselves to revert to our younger rock-star-mad selves . . .

We joined 30,000 other fans in the stadium and, boy, did we rock! It was a fantastic concert, we had great seats and a brilliant view of the stage. The oldest swingers in town had a wonderful time – and as Margaret emailed me the next day "last night I felt 25, today I feel 95". Ah, that's life. In the words of Jon Bon Jovi perhaps we're "Living on a Prayer".

Joyce

'MAINSTREAM'
ONLINE EVERY MONTH
www.mssesw.org.uk

The World of Art

Margaret and I recently went to East Dean when we accepted an invitation to the home of Norman and Yvonne Clarke where an exhibition of art was taking place and a raffle was held of a painting and planter with the proceeds coming to our Branch.

It was a lovely sunny Sunday afternoon and we were made really welcome. Yvonne has MS and this lovely couple were only too pleased to do something for us. The raffle raised £70.00 for our funds and we have visited again to collect two painting and two planters to use as raffle prizes. Thank you Norman, Yvonne and your delightful friends and neighbours for your support, if only we had more like you our life would be much easier. Joyce

Brighton Walk & Wheel

It was a dry but cloudy and windy Sunday when our intrepid band of volunteers set out for Brighton. Jim, our new volunteer driver, took us in our own minibus. The whole Boddy family were to do the walk, with me, my son Christopher, and Pete Middleton to provide support and man the collecting tins. The event was organised by the Foresters Friendly Society and the proceeds will be split between the Eastbourne and Brighton Branches. This was the first time ever we have had a joint event with another Branch and I am pleased to say it was a great success. I got along very well with Wendy Smith, the Brighton Chairman and we are already talking about other joint events.

Peter Boddy was joined by his lovely wife and two teenage sons and together they completed the four mile walk. Peter is planning to walk the Brighton marathon next year, so this was something of a training event for him.

We don't know yet just how much we raised, but I do know that the collecting tins held around £517.00. Thanks must go to Trudy Weller of the Foresters for organising the walk for us, it was hard work but well worth it.

Joyce

Branch Transport

As expected, the Iveco was sold at auction last month. Very sad, but it had to be done. The good news is that the Mercedes passed the very stringent MS Society audit with flying colours.

Correction – I have been asked to point out an error in last month's MainStream: volunteer drivers need a D1 category licence not a D, so please come and drive for us . . . Joyce

Can we *really* afford to lose 35% of our income?

As your Chairman I have had to give a lot of thought to the AGM later this month.

Normally I would not dream of trying to influence the way you vote, but there is one resolution this year that, if not implemented could change the services we provide for ever.

Last year a resolution of was passed that 35% of MS Society income be used for research. Many people did not realise that this would include Branch income. The position has now been clarified and it would mean that for every £1.00 we raise we would lose 35p – leaving us just 65p; every £100 would leave £65 and every £1000 would leave £650. This would put a huge strain on our budget and we would be forced to cut back on the support we give – even our beloved MainStream would be affected .

The fact that *all* the money we raise goes to help local people has always been a major factor in persuading local people to support us. It could be argued that 35p in every £1.00 going to research would encourage people to give more, but I'm afraid I'm not convinced that in the current economic climate this would happen.

No-one would argue that research isn't important, but we have always felt that supporting local folk affected by MS is our main focus. The MS Society at national level spent more than £4.2 million on research in 2009, and would also have to cut services to members by 35%.

I would urge you to use the ballot papers you have received to support Resolution 6.7 which states that "The Board should continue to increase investment in research and not be bound to spend a set percentage of the Society's income on research each year".

Please use your vote wisely. Normally only a small percentage of the membership vote, let's be different this year – vote for the resolution which could effectively save Branch life as we know it. ***Don't let apathy rule.*** Joyce

NEWS FROM OUR DAY SERVICES MANAGER

Following on from last month's magazine, the Ladies Group Open Day on the 26th August was a great success and very well supported. There was plenty of chat, and we all enjoyed delicious cakes with loads of calories as we devoured Cream Teas. Thank you to Eve for all her baking and hard work, the scones were absolutely fabulous. Joyce and Doreen helped on the day and Val very kindly organised the raffle for us. There were loads of prizes and thanks go to Joyce, Eve, Heather and Joyce B for bringing prizes to the Centre, thank you to everyone for supporting us it was a most enjoyable day.

Over the last 6 weeks a lot of my time seems to have been consumed by Health and Safety regulations. First there was the Transport at the end of July and this week we have just finished a very intense audit regarding our Community Centre. There were more forms and boxes to tick than you could ever imagine, at home we take everything for granted, just using our common sense and getting on with life. No such thing in a public place - and to be honest we have no choice but to just adopt the appropriate policies. Everyone's safety has to be upper most in our thoughts.

All the new system is now in place and we just have to catch up with some of the administration with a time period for completion. So thankfully I have decided to put this to one side for a while as I was beginning to feel that I had gone totally boss-eyed with checking the boxes and the Centre!

Allan Matthews the Acting Local Support Development Officer from our local Surrey and Sussex Region has been very supportive - which has been so helpful.

Recently I have been engaged in correspondence regarding the correct and appropriate details to be endorsed on a Will or an Order of Service regarding donations or legacies following the death of

a loved one or our own personal wishes. For anyone considering donating monies in this way to the MS Society it is most important to decide on whether you wish to support your local MS branch or the MS National Centre...

This all comes down to personal choice; however, the wording must be correctly endorsed to ensure your wishes are duly carried out.

Please do not hesitate to contact us or the MS National Centre for advice. I appreciate this is a sensitive subject but I have been requested by a member to mention this in my article this month. They found the advice most helpful and reassuring and I have appreciated their kind and thankful correspondence...

In the next Mainstream I will let you know the date for an **OPEN DAY** in the Centre extending an invitation for everyone to attend a **Wednesday luncheon day**. These Open Days are our way of promoting our services in the Centre for you all to enjoy and feel part of "The MS Family". The original idea of the Centre was to promote our services and for everyone to feel included in the branch activities.

I will finish by letting you know the date for our annual **Christmas Catalogue Sale** event. Our Janet from the Ladies Group thought this date was too early on **Thursday 23rd September - MS Christmas Catalogue sale with Coffee morning and raffle**. With the support from Sue Metcalfe we get together and browse through the MS Xmas Catalogues and order goodies for ourselves or others.

Janet - just for the record I spotted the first mince pies for sale on August 21st - any advances on this date please?
Everyone is welcome to join us.

With kindest wishes to you all - Margaret

DIARY DATE

**The Branch annual Christmas Lunch will be held at the Langham Hotel on:
Sunday 12th December @ 1.00pm
Further details to follow in due course**

A new direction for respite care

On 9 June 2010 the MS Society's Board of Trustees decided on the new direction for the Society's respite care strategy, following the respite care review.

The Society says the new approach will help reach more people affected by MS, wherever they live in the UK, and support them to access the short breaks and respite care they choose.

At their meeting in July the Board received an update on progress on the new strategy. The key points from the update are below, or you can read the full Board paper on the Society's website – search for 'Board meeting July 2010'. The Board also unanimously voted to ratify their decision on the Society's new approach to respite and personalised short breaks.

- Since the decision they have received about 300 letters, emails and phone calls. Each receives a personal response, and the Board reviewed all correspondence before their meeting in July.
- The review and the decisions made by the Board have been supported by a number of national organisations, including the Princess Royal Trust for Carers and Crossroads.
- More than 20 organisations have expressed interest in taking on one or more of the centres, and the Society is working with a specialist property consultancy to market the centres.
- As Leuchie House is not taking bookings beyond 3 December 2010, they have set up a group of support officers who are contacting each Leuchie guest individually by phone to offer information and support to find alternatives.
- Task groups are being established to lead work on: co-ordination of information about options for short breaks; accreditation of services; individual support and signposting; influencing change in services; grants; and partnerships in service provision. Each group is UK-wide, and involves people with MS and volunteers.

Branch meetings

The Society is meeting with branches local to the centres during August and September to discuss the review and new ways of working in the future.

They are very keen to meet with branches right across the UK to discuss opportunities for service development locally. These will happen towards the end of this year and the start of 2011. If you are keen to be involved with these, please contact the care services team on respitcare@mssociety.org.uk or talk to your LSDO.

AGM

By now you will have received your AGM pack, containing the AGM booklet and voting forms. You'll see there are two resolutions on the respite care review: one supporting the Board's decision and one asking for it to be suspended. We want all of our members to have their say about how the Society should use its resources to help people living with MS. If you haven't had a chance to read about the review yet, please do so before casting your votes.

To help you make an informed vote, some key points about the review have been included here. There is much more information than we can print in Teamspirit, so please see the details at the end of this article to find out more.

Key facts about the review

- On 9 June 2010 the MS Society's Board of Trustees decided on the Society's new strategy for respite care – not before. The Board's decision was based on the outcomes of the year-long respite care review, which included consultation with people with MS and carers to find out what they need and want from respite and short breaks.
- The Society's new approach will give people more choice and control, and ensure we support many more people with MS to access the short breaks and respite they need across the whole of the UK.
- At the moment our four centres between them support about 1,300 people in total each year. But there are many more thousands of people, including those with complex care needs, who get no support from the Society to access respite and short breaks – and that's not good enough.
- The staff at all our centres offer excellent services, delivered with expertise and professionalism. For some people, this is the where they prefer to go for a break, and we would like to see these services continue, which is why we are looking to transfer the centres to other providers.
- It's not good enough for an organisation like the MS Society to push a 'one size fits all' solution. The respite care review has told us we must do more to support more people living with MS to have choice and control over how they take a break – wherever they live in the UK.
- To do this we will focus on five key areas: providing better information and signposting, accrediting other services, giving grants, campaigning for better services and influencing providers to improve their services for people with MS.

Key facts from the MS Society about respite and short breaks

- The Society estimate that around 30,000 people with MS in the UK are in need of respite. In 2008-9 the MS Society invested approximately £2.7m to support 1,385 people with MS for respite care or short breaks through our four respite centres.
- No one from Northern Ireland and just four people from Wales used the MS Society's centres during that time.
- People with MS and their carers have clearly said that the Society needs to change how it supports people get the respite care and short breaks they need, wherever they live in the UK
- Currently, thousands of people with MS and carers in Northern Ireland, including those with very complex needs, receive no support from the MS Society to get the respite they need.
- Through the new approach the Society will support each person to make the right short break choices for them. That support might be financial, through grants; practical, by giving advice; or being a voice for people with MS by lobbying for better services.
- The MS Society believes that access to respite care and short breaks is an essential means of supporting people with MS and carers. Regular, appropriate breaks are crucial for maintaining the wellbeing of both the carer and the person with MS. Short break services around the UK vary in quality, and the MS Society has a key role to play in improving services for people with MS.

The MS Society's new approach short breaks

The MS Society's new approach will support people to make the right choices for them. It will focus on:

- **Providing information:** The Society will do more to signpost people to existing services and guide them through the process of accessing their choice of short break or respite.

- **Accreditation:** the Society will accredit short break and respite services so that people with MS and their carers can be assured of high quality services.
- **Giving grants:** The Society will support more people with MS financially to get the short break or respite that they want through our grants programme.
- **Campaigning for better services:** the Society will campaign for improved care and services for people with MS and carers, including campaigning for access to properly undertaken carers' assessments.
- **Influencing other providers:** The Society will work with other organisations to make sure people with MS have access to respite care and short breaks, that meet their needs, wherever they live.

Wherever possible the Society will work on the issues above together with partner charities and other organisations. Parkinson's UK and the Motor Neurone Disease Association have agreed to work together with the MS Society to ensure better provision of respite care and short breaks.

About respite and short breaks

- The term 'respite care' is used to describe a period of 'respite' for the carer of someone with a disability when that person would be cared for by someone else. However, the term and approach has negative connotations for some people.
- The term 'short break' encompasses a wide range of different short term services. The common factor is not what service is provided but its purpose - to provide a break which is a positive experience for the person with care needs and the carer where there is one. This may be offered in a variety of ways including a single period or a planned programme which can extend from a few hours to a few weeks

Contact the MS Society

Write to: Care services MS Society
372 Edgware Road London NW2 6ND
Email: respitecare@mssociety.org.uk
Phone our Helpline on 0808 800 8000

Edited Minutes of the Committee meeting held on 21st August 2010, at Eastbourne MS Community Resource Centre, MAP House, 34-36 St Leonards Road, Eastbourne, BN21 3UT, at 10.30am.

Due to the confidential nature of much of the Committee business discussed, it has been necessary to make a drastic reduction in the amount we can share with you at this time

Present: Joyce Milton, Caroline Holdcroft, Peter and Sue Austin, Janet Forshaw, Margaret Davis, Annifer Hatcher

Apologies: Andy Dixon, Anita Keall, Margaret-Clare Fuhrmann

Joyce welcomed and thanked everyone for attending.

The category for driving a minibus is actually D1 not D so the minutes were revised to show this.

Nigel Waterson has been a superb help with a very difficult case.

The Iveco has been sold at auction. The Mercedes passed the MS audit with flying colours.

The first fundraising meeting has taken place and lots of ideas were raised. Someone needs to be found to lead the group.

The new driver Jim has been doing very well and has been very helpful.

A qualified first aider needs to be in the Centre whenever there are people present. Joyce has provisionally booked 6 places on a first aid course in October with EAVS.

Change in MS Society Respite Care Policy – Branch Response: It is up to the individual how to vote at the AGM

The Mayor's Fund: No suggestions have been received from members.

A support fund could be created for needs that Vicky identifies.

Purchasing a smaller second-hand vehicle would be an option that would benefit a lot of people. The vehicle would need to be sprayed and sign-written and could also mention that it was donated through the Mayor's Fund. It would be easier to find drivers for a smaller vehicle; Sue said she would drive a smaller vehicle if there was an escort to assist and secure the wheelchairs. Joyce will research the costs. A laminator would be useful as Bernard used to do all the laminating. A shredder is also needed in the Centre unless Margaret brings hers back and a microwave thermometer is required.

Welcome Aboard Session for New Volunteers – 11/09/2010: It is important for new Committee members to go to the session. Peter, Caroline, Annifer and Margaret Clare are going. Joyce will contact Mark Lester to see if he can provide transport.

Fundraising Update: A quiz will be arranged for around the end of October. The fundraising group looks like it will be very good.

A Minutes Secretary is needed for the Committee meetings as Elisabeth's baby is due at the end of October. Peter will put something in Mainstream.

Correspondence and Any Other Business: Chaseley are holding a seminar on 8th September, called 'Our World – Our Choice' from 9am-4.30pm. They have offered the Branch a stand for free instead of the usual £20, so people are needed to man the stand. It is aimed at health and social care professionals, so the stand is mainly for information, although Joyce will ask if they can have collection tins.

Peter had a meeting with a lady from Brighton University who is in charge of the physiotherapy students there. They ran a series of sessions with the elderly there to give tips on fitness etc. They may be looking for a group like the MS Society to run another series of sessions. Peter will feed back that the Branch would be interested.

Date of Next Committee Meeting: The next meeting will take place on Saturday 18th September at 10.30am at the MS Community Resource Centre.

Ladies Support Group

We have a programme up to October as follows:
Thursday 9th September Games Galore, or
just coffee and a chat.

Thursday 16th September Bingo with our
favourite caller, Sue.

Thursday 23rd September Start your preparations
for Christmas with
our M.S. Christmas
catalogue sale and
coffee morning.

Everyone
welcome.

Thursday 30th September Repeat of our popular
auction. Bring
along an item (new
or good as new)
that we can auction
off for a bit of fun.
(As well as raising
funds!)

Thursday 14th October 'Call my Bluff'.
That fun
game organised
by our very own
Margaret-Clare.

As ever, everyone is always most welcome. We
will be at the centre every Thursday for a cuppa
and some good company, even if there is no
specific programme, so come along anytime.
And if you haven't been before, we look forward
to meeting you. If you have any brilliant ideas for
our programme, we are always open to
suggestions, just be sure to come along and let
us know.

There is no limit to numbers at any of our
gatherings, but if you have any queries, just give
me a call on 01323 439447.

As always, ALL LADIES WELCOME every
Thursday 10.30 – 1.30pm.

And I look forward to seeing you soon

Janet

PERSONAL AD

Male pensioner (with long hair), charming and
intelligent, wishes to thank the Ladies Group for the
exceedingly warm welcome he received when he
visited last month.

If the Group had been a Dating Agency, any man
would have thought he was in Heaven! So many
beautiful women all assembled in one place. There
again – I am a pensioner and my sight is not so good
these days!!!!!!!!!!!! Love ya all

Young Carers

As I write this, our Young Carers are looking
forward to a trip to Legoland, Windsor on the last
Sunday of their school holidays. I certainly hope
that they have some good weather for it!

As the long school holidays come to an end, all
children will be experiencing change and new
challenges as they go up a year in school.
Especially those changing schools (any eleven
year olds). Going to a Secondary school for the
first time can be quite an exciting experience,
and we wish them all the very best.

And, as always, if any youngster feels the need
to talk in confidence, on any issue, (especially at
this time of year), our experienced team is
always here at the end of a phone line, ready
with any help, advice or support (or just for a
chat.) If anyone wants to talk, just call 01323
439447 to talk to Janet, Lynne or Clare, and we
will be happy to call you back.

The Judy Parker Column

Quite an eventful month August has been and
still a few days to go!! I refer to the Thursday
Ladies group on August 19th when we had quite
a lively attendance and welcomed our popular
quiz master Steve for a Fun Music Quiz. Some
of us had better memories than others. . .
The most fascinating moment for me, and
missed by so many, was seeing our very
own Day Services Manager descend on all
fours and clamber under the table to emerge the
other side and carry on with her ascent to 2 legs
again!!! Yes we did have a lively attendance
and space was hard to find!!

As always, the recent issue of MainStream was
a good read and I was particularly interested to
read the article on page 11 that states cannabis
treatment has been licensed for M.S.

I have read similar articles in other publications
and as a sufferer from regular spasms would
welcome anything that would alleviate this
unpleasant feeling.

Also interesting and rather alarming on the same
page was the article stating that U.T.I. was
becoming resistant to antibiotics. It is a silent
infection often without any outward symptoms'
only recognizable by those closest to you and
can leave you hospitalized for some time.

On that cheery note I will close for this month
but always appreciate any comments/additions
you'd like to make here. The shops will no doubt
be selling Christmas produce soon!!! **Judy.**

Tough New Medical Tests For Disability Living Allowance Claimants

In a bid to cut billions off the welfare budget, the coalition government plans to introduce tough new medical tests from 2013 for new and existing claimants of **DLA** so that fewer people claim and more go back into the workforce. They aim to cut the number of **DLA** claimants by 20%

Three times as many people are claiming **DLA** than when it was introduced 18 years ago. The cost of paying the benefit has quadrupled in real terms to £11bn making it one of the largest areas of government spending.

Chancellor George Osborne said "those with the greatest need will still continue to get **DLA** while significantly improving incentives to work for others." He said the new test would be simpler and there would be less form filling.

The medical criteria for getting **DLA** will change and a new points system introduced to decide who should get **DLA** and at what rate. The medical assessment will be based on the much criticised **Work Capability Assessment (WCA)** which is used to decide claims for **Employment and Support Allowance (ESA)**.

For existing **DLA** claimant there is a glimmer of hope. If the new assessment really does follow a similar process as the **Work Capability Assessment**, this should mean that if you are currently in an exempt group for Employment and Support Allowance as having been assessed as 80% disabled for **Severe Disablement Allowance (SDA)**, or you are in receipt of the higher rate of **DLA**, Constant Attendance Allowance, (intermediate or exceptional rate), or one of the other various exemptions for various medical conditions; for example advanced MS, then you should still get **DLA**. However this is presuming a logical path is taken and does nothing for new claimants.

The new system will not be introduced until 2013 so there is still time for challenges and support voluntary campaigns or contact your MP to protest about these plans.

Thousands With MS Told To Look For Work.

Thousands of people with MS and other conditions have had their applications for **Employment Support Allowance (ESA)** rejected and been told to look for work.

ESA replaced incapacity benefit in October 2008 and all new claimants have had to face a tough new medical test in order to qualify/

About 8,000 people a month are challenging the decision and almost half are winning their cases.

An academic behind the new benefit system, Paul Gregg, Professor of economics at the University of Bristol is concerned that large numbers of claimants who fail the **Work Capability Test** are left languishing on **Job Seeker's Allowance** with no prospect of work. He said a lot of adjustments need to be made if the new system is to work properly.

Many companies reject people with a disability who have been on Incapacity Benefit and have a broken work record, who can be put into the same category as jobseekers with a criminal record.

Only 5% of Patients Unfit To Work

The private company carrying out the Work Capability Tests, **Atos Healthcare**, find that on average only 5% of claimants are unfit to work and eligible for the new Employment Support Allowance, with a further 13% referred for 'work-related activity' such as training, but still able to claim ESA.

39% are judged as fit for work and put on **Jobseeker's Allowance** and the remainder dropout during the process. However, **ESA** is now the benefit most commonly subject to appeals, then work tests are being carried out by doctors and nurses at the rate of around 50,000 a month.

LINK BETWEEN POSTURE AND MS RELAPSES

The first results looking at posture and MS appear to show a clear connection between different postures and MS relapses or worsening of symptoms.

The survey involving more than 100 people and carried out by Andrew Fletcher showed that most MS relapses or deteriorations were found to happen in the morning on waking or getting up from bed in the morning. The lowest number took place at night while trying to get out of bed.

Findings have been forwarded to Professor Paolo Zamboni and Dr Franz Schelling, an Austrian doctor with an interest in CCSVI (note the link between this study and the Chronic Cerebrospinal Venous Insufficiency article last month).

Dr Shelling said the discrepancy between the deterioration noticed at night while trying to get out of bed and that of getting out of bed in the mornings were "remarkable". He said he would be interested to learn more about the effects of raising the beds of patients with MS at different angles and how bed angles affected stenosis (narrowing of veins) found in CCSVI.

Andrew Fletcher said he was hoping to involve a university in publishing the survey results. He is also hoping to double the number of people taking part in these surveys.

Source MSRC New pathways July/August 2010

Multiple Sclerosis and Risk of Cancer.

It was previously thought that patients with MS had a slightly reduced risk of developing cancer but a paper published earlier this year challenged the theory and concluded there was no difference in cancer risk between patients with MS and the general population. Here, the authors performed a meta-analysis, investigating all studies published in the last 15 years reporting measures of the risk of cancer for an MS cohort relative to population controls, including studies from the UK, Sweden, France, Denmark and Norway. By pooling the data from all available studies they found that there was a small, but significant decrease in risk of all cancers in patients with MS relative to controls

Source: Neurology, Neurosurgery, Psychiatry 19-08-10

RADAR (the key people)

RADAR has produced a new booklet exclusively for Parliamentarians. It is the MP's Guide on Disability and is packed with what must be startling revelations for MPs such as "***each and every MP represents some constituents with disability***". In fairness the booklet contains information that all MPs should either know already or take note of and learn from. I wonder if they will.

RADAR 2010

Mental Activity may protect against MS Memory Problems

A mentally active lifestyle may protect against MS memory and learning problems. A US study found that learning and memory ability remain "quite good" in people with MS who do a lot of reading and take part in educational activities – even if they have a lot of brain damage.

In contrast people with lesser mentally active lifestyles are more likely to suffer learning and memory problems, even at milder levels of brain damage.

The findings are similar to research on people with Alzheimer's disease, according to study author James Sumowski, who said that studies on ageing had shown that taking part in leisure activities, such as reading books or playing games, protects against the effects of Alzheimer's disease. More research is needed to investigate the contribution of specific leisure activities to 'cognitive reserve' in people with MS, he added.

Source: American Academy of Neurology, July 2010

Letter from our Minister
The Rev. Dr Gerald Munro BA MA Dphil

Dear Friends,

Greetings to you all! In matters of faith, many people today occupy the borderlands; that is they are agnostic. Some give church and Christians a wide berth yet still linger in the borderlands because they cannot set aside the feeling that there must be some sort of spiritual reality out there. Maybe a breathtaking glimpse of natural beauty, or a sense of longing gives a nudge towards something that must exist beyond the everyday routine of life – but what?

Big issues – like the birth of a child or the death of a loved one – raise questions with no easy answers. Is there a God? A life beyond this life? Is religious belief only a crutch, or a path to something authentic? Many Christians would find it difficult to explain why they believe as they do.

Perhaps they absorbed faith as part of their upbringing in a churchgoing family, or perhaps they simply find church an uplifting place to visit on Sundays. But if asked to explain their faith to a Muslim or an atheist, they would not know what to say.

Does religious faith make sense in a world of complex technology and highly developed scientific knowledge? Have we figured out the basics of life or is some important ingredient missing? To me, the great divide separating belief and unbelief reduces down to one simple question: is the visible world all there is?

Those unsure of the answer to that question live in the borderlands. They wonder whether faith in an unseen world is wishful thinking. Does faith delude us into believing in a world that does not exist, or does it reveal the existence of a world we cannot see without it? There are so many contradictions in all of this.

If, as all religions tell us, this is God's world, why doesn't it look more like it? Why is this planet so messed up? How might the visible and the invisible worlds interact and affect our daily lives? Does the Christian way represent the best way to live your life on this earth? These and many other questions continue to occupy much of my thinking. I believe this is true for many people today.

I am at times a reluctant Christian, buffeted by doubts and unanswered questions. Possibly the questions are without answers. I am fully aware of all the reasons not to believe, yet I do. The great Russian writer Fyodor Dostoyevsky sums this dilemma up for me in the following way:

*'Every ant knows the formula of its ant-hill,
 every bee knows the formula of its beehive.*

*They know it in their own way,
 Not in our way.*

Only humankind does not know its formula.'

With every good wish to you all.

Gerald

We invite contributions to 'Mainstream' from representatives of all religions and none. Just send your copy by post or email.

Thank you Gerald...

Last month Gerald, our Minister, celebrated 25 years in the Ministry and a special service was held at Upperton United Reform Church conducted by the Rev. John Kimberley.

Sincere thanks Gerald for the pleasure in taking part in the service and for inviting us to the lovely Celebration Lunch afterwards; we were honoured to be with you on your special occasion.

Thank you also for the support you have given to so many people affected by MS over the past decade. We send our love to you and Janice.

Bernard & Margaret

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

All calls confidential

Talking really can help!

VISUAL IMPAIRMENT CONTACT NUMBERS

Eastbourne Blind Society 729511

East Sussex Assoc. for the Blind 832252

RNIB Helpline 0845 766 9999

'MAINSTREAM'
ONLINE EVERY MONTH

FUNDRAISING & DONATIONS MONTHLY UPDATE FROM CAROLINE

July / August 2010 Fundraising Update:

Parkfield Public House - £34.00
 Coffee morning by Cycle Touring Club -
 £85.00
 Coins in bag - £3.89
 Collecting tins - £90.00
 Other sundry donations - £84.39
 BACS transfers from National Centre for
 July reference Membership / Donations -
 £392.86
 General donations - SO and DC - £482.00
 Just Giving - £9.26
 MERC obo Vicky Lester day - £300

Come and Join us for a Rocking Good Evening . . .

Last month I told you about the music gig being held at the Big Apple.

Tanja Woodgate and I went along to see how suitable the venue is for our members. The good news is that it is completely wheelchair accessible, with a very good disabled toilet and no steps anywhere.

Saffron, the bar manager, made us very welcome and is looking forward to the event. She also came up with some good ideas for raising money on the night. We are collecting prizes for a grand raffle and look forward to welcoming as many of you as possible on the evening of 25th September

As I told you before, The Mysterons will be performing live rock music from the last four decades. The only problem, for me at least, is that Mark has told me they're a Bon Jovi free zone . . . oh well, I suppose you can't have everything.

Joyce

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Meet to Share

SOCIAL AND SUPPORT GROUP FOR LADIES

Our August meeting was at Favolosa in Carlisle Road where members made the most of the cafe's speciality ice cream desserts!

We next meet on Monday, September 20 at 12.30pm when lunch will be at The Royal Golf Club in Paradise Drive. The surroundings are lovely, and we have been made very welcome on our previous visits there.

Do let me know if you would like to come along.

Sue

TELEPHONE: 01323 736359

EMAIL: SueAustin50@aol.com

SEAFORD GROUP

We once again had a lovely time at Exceat Farmhouse for cream teas, and the owner of the restaurant made a cash donation to the Society.

It was a warm sunny day, which made our afternoon more enjoyable.

The group continues to grow in numbers, with another new member joining us last month. We are a friendly bunch and always enjoy our meetings. If you live in Seaford and would like to come along, then give me a call on 01323 492788.

Our next outing is for lunch at the Golden Galleon Exceat at 12.30 on Monday 13th September.

Annifer

YOGA – PLEASE NOTE NEW DAY

**Yoga Classes with experienced tutor
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 more able**

The Yoga classes are now being held
 on Mondays

The cost is £4 per session and the time is
 11.00 - 12.00

There will be a summer break from 26th July
 with classes reconvening on 6th Sept.

The venue is our Community Centre in
 St Leonards Road

Please contact Anita Keall on 01323 648303
 (Anita states "it is a cure"!).

All welcome to join our friendly group

From the pen of
Margaret Clare

I found August's MainStream
 Full of interest
 And challenges and appeals
 For all of us to do our best
 To support our Eastbourne Branch
 So let's give ourselves no rest
 Let's look at each request:
 Fundraising Committee –
 It's ideas they need
 From over 300 members
 Some ideas will succeed!
 In our "attics" and such
 There's surely some cash
 In all those bits and pieces
 We've ever use – be rash!
 A personal letter or an e-mail
 To our MP
 Can hardly fail
 When politely worded
 To draw attention
 To our needs –
 Vicky – we must mention
 There was so much in the August mag
 I'll keep it by me to remember
 But then I always do keep most
 Still got them from last December

Towards an alternative September . . .

Making the time to:
 Admire the sparkle
 of the spiderwebs
 catching the sun's rays
 through the mist
 Watch as the green leaves turn
 to reds and golds
 then see them hustled off
 by the autumn winds
 Notice the fruit trees laden
 with apples and pears
 juicy-ripe and ready
 for the harvest
 Enjoy the long shadows from
 The equinox sun
 Bringing our lovely South Downs
 Into sharp relief
 Oh – and no-one, but no-one
 mention Christmas
 (yet!)

From the pen of
Janet Forshaw

The Summer holidays are almost over,
 And it's back to school we go,
 It will be good to see friends again,
 Since I have missed them so.

We'll soon be seeing our teachers too,
 Now is my homework done?
 Or did I forget it altogether
 While I was having fun!

How do I do that algebra,
 I really can't remember.
 Or speak in French 'Je ne sais pas quoi'
 Will it come back before September?

But I'll be ready for that bus
 My uniform clean and neat,
 To join my pals without a fuss,
 And to take my usual seat.

Yes, we're all of us going back to school,
 To a higher year group it's true.
 And I really can't wait, to get through the gate,
 As everything will be exciting and new!

Work Life website

A new website called 'Work Life' –
www.yourworkhealth.com – was recently
 launched by the MS Society and a number of
 other charities, employment organisations,
 healthcare professional and the Department for
 Work and Pensions (DWP) to help people with
 long-term fluctuating health conditions remain in
 work.

The website provides information to employees,
 employers and health care professionals. It
 brings together examples of best practice in the
 work place, guidance, research and case
 studies from across the employment sector and
 from around the internet into one dedicated, free
 to access website.

Work Life is the first of its kind and ultimately
 aims to help people with conditions like MS,
 Parkinson's and arthritis to remain in work for as
 long as they wish and to lead independent
 lifestyles.

The website can be viewed at
www.yourworkhealth.com

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glams_ukgroup@hotmail.com

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NEWLY DIAGNOSED SUPPORT Sue Austin sue@mssesw.org.uk

LADIES SUPPORT GROUP Janet Forshaw

LADIES SOCIAL GROUP 'Meet to Share' Sue Austin sue@mssesw.org.uk

MEMBERSHIP ENQUIRIES Contact Branch Secretary

HEALTH & SAFETY Contact the Day Services Manager or Chairman

MS NATIONAL HELPLINE 0808 800 8000

ADULT CARERS Contact the Day Services Manager or Chairman

YOUNG CARERS Janet Forshaw

MS INFORMATION Ian Westgate ian@mssesw.org.uk

TRANSPORT Contact the Chairman

PRESS & PUBLIC RELATIONS Peter

PHYSIOTHERAPY Ian Westgate ian@mssesw.org.uk

MS COLLECTION TINS Ted Scott

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nigel@nigelwaterson.com

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