



Multiple Sclerosis Society

Newsletter No. 3 - November



In this Newsletter

Page 3 & 4 Note from the Chairwoman

Page 5 & 6 Note from the secretary

Page 7 Beau Sejour Exercise Class by Margaret Le Patourel-
Sharp

Page 8 & 9 Article on fatigue by MS nurse, Debbie Robilliard.

Page 10 My fatigue by Gill Ford.

Page 11 Events till the end of the year.

Page 12 50 European Countries Word Search Puzzle

Page 13 The answers

Note from our Chairwoman

Already it is nearly three months since I took over from Steve Le Page as your chairman, and I am a little more familiar with what is what! I have met a few of you at Liz Hendry's monthly coffee afternoons and look forward to meeting more of you at other events and occasions.

So what has been happening? Gill (our secretary) sent a survey to you all a few weeks ago and thank you to all of those who responded – If you haven't responded/lost your form/never received it, please let Gill know and we will send you another. Your answers are helping us to understand what is working, where there are gaps and most critically what are the things most important to each of you. We will use this information in our discussions with the States, deputies, doctors and any other relevant bodies. Your direct views carry so much more weight than just our opinion, and furthermore, can be verified (anonymously of course!) However please do keep us informed of all issues important to you, at any time. All the committee's contact details are on the website: www.guernseyms.com.

The BIG event currently going on is "Million miles for MS" or as it is also known, "Do it for DIL". This idea was put forward by Dil's (the late Paul Diligent) family who wanted him to be remembered in a way that he would have enjoyed. I never had the privilege of knowing Dil, but I gather he was a big personality with a lust for life. He loved people and thrived when involved with some activity. This event started on Sept 3rd (the second anniversary of Dil's death) and continues till Sept 30th. The plan

is that EVERYONE should do some activity and then 'log' this with a view to trying to see if people in Guernsey can cover 1 million miles in September. Anything and everything is counted e.g. walking, running, swimming, rowing, cycling, scooting, skateboarding etc – the list is almost endless! The only exception is motorised transport EXCLUDING mobility scooters and powered wheelchairs. It is a very challenging target and that is one of the reasons Dil would have approved – he was always up for a challenge! Any monies raised will be split equally between Guernsey MS Society and Guernsey Cheshire Home (where Paul was latterly a resident).

As of last week this is how the running totals looked:

- 62,097.50 miles with lots more to be logged
- 402 people registered and 39 teams
- £5,468.42 raised.

Isn't that brilliant!! To find out more, go to the MS Guernsey website and on the 'Home' page there is an entry about 'Do it for Dil' – follow the link, and that will take you to Maddy Diligent's website which has loads more information.

Finally, don't forget we have the MS Christmas Fayre (probably December 2nd) and the MS Children's Party (either Dec 9th/10th). If you are able to help with either of these events, please contact a member of the committee.

Bye for now.....

Note from your secretary

Firstly, a very big thank you to all of you who filled in and returned your surveys.

The committee will try and address all the issues and concerns raised, but as one of you wrote we are a new and small committee so your patience is very much appreciated.

So to look at the main points raised so far;

- 1) Guernsey, at present, does not have a resident neurologist, however we have a neurologist visit the island once a month. He sees anyone who has a neurological problem, meaning he covers many areas and is not an expert in MS. If you would like to see him and have a chat, your course of action is through your GP. I personally have asked my GP to refer me to the neurologist which I know he has done. If you need any help with this, please feel free to ask us.
- 2) Website and Facebook page. A number of you mentioned that these do not get up-dated very often. I am looking into this, so will keep you posted about how that goes, but social media for me, is a 'steep learning curve', but I'll do my best!

The committee has looked at priorities and we have agreed on having three main ones to start with:

- a) Improving our choice of Disease Modifying Drugs.
- b) Communication
- c) Fundraising and raising awareness.

We will keep you informed on the progress we make. If you have any comments or suggestions please let me know by emailing secretary@guernseymms.com

Beau Sejour Exercise Class by Margaret Le Patourel-Sharp

A direct quote from one of our members.

‘I went along to one of two weekly exercise cases held at Beau Sejour this morning. Really good and would thoroughly recommend our members to attend. Held in a spacious, easily accessed gym, you may have recently seen it on Channel news. The instructor, Emma Kimber, is lovely and extremely helpful’.

Knees up and pull to the end of the machine!



These sessions are open to all our members. If you are interested in these please contact me at: secretary@guernseymms.com

Fatigue by Debbie Robilliard



Hi all. I hope you are all keeping well. I have been asked to write a page on MS fatigue.

Key facts

- Most common symptom (75 - 97%)
- Reported by 40-60% as worst problem
- Under recognised and often a 'hidden' symptom
- Can occur at any stage of MS
- Occasionally signals the onset of MS
- Can be present at all times
- Fatigue mechanism is poorly understood
- Can relapse and remit

As fatigue is mainly hidden for many people, it can start affecting all aspects of life including some of the following.

- Activities of daily living
- Driving
- Major reason for unemployment
- Difficulty with parenting
- Relationships/sex life
- Leisure and social activities
- Prone to misunderstanding by others
- Dependence on others
- Cognitive abilities (capacity for memory, learning, attention and concentration)

Did you know there were different types of fatigue with different triggers? Do you know your triggers?

MS related fatigue

Primary:

- related to disease process

Secondary:

- not caused by the disease process
- associated with disease related factors

'Normal' activity related fatigue

Triggers

- | | |
|----------------------------|----------------------------------|
| • Heat | Infection |
| • Poor Posture | Poor sleep patterns(eg nocturia) |
| • Other medical conditions | Pain |
| • Doing too much | Taking insufficient breaks |
| • Medications | Relapse |

1. Efficient energy expenditure

- Pacing & planning
 - Help
 - Sitting often
 - Analyse and modify Home & work and leisure activities
- Prioritising
 Correct posture
 Rest and recuperation

Principles and strategies

- Conserve energy
 - Adapt environment and equipment
 - Posture
 - Utilise support network
- Simplify work
 Recognise individual limits
 Avoid exacerbating factors
 Use energy on chosen activities

2. Time Management

Analyse how time is spent

- Plan and set goals
- Reduce time pressures
- Identify time wasting activities
- Identify activities to delegate
- Re-allocate time

3. Exercise

- Develop weekly activity programme
- Include suitable forms of exercise and activities
- Adopt safe approaches to exercise
- Monitor fatigue levels
- Maintain levels
- Exercise and activity benefits
 - Disability
 - Deconditioning
 - Sleep patterns
 - Psychological

4. Aids and devices

- Look at alternatives such as home delivery or internet/catalogue shopping

Consider mobility aids

- Crutches
- Walking stick
- Rolators
- Wheelchair
- Motorised scooters
- Obtain disabled badge

For more information on fatigue management please go to the following link provided by the ms trust
<https://www.mstrust.org.uk/a-z/fatigue>

My Fatigue by Gill Ford

For me fatigue is one of my worst problems. On the outside I look fine so it can be difficult for people to understand how I am feeling on the inside.

To cope, I have tried many different strategies, but I finally realized I needed to reduce my working hours. I now work mornings only which gives me the opportunity to rest, if I need to, in the afternoon before preparing the evening meal and everything else that needs to be done. I have also trained myself to sit, even for 10 minutes and take a break in between activities. I was a very keen long distance runner so I found this hard, but I have learnt to take that afternoon nap if I need one!

In addition to the MS trust, the MS Society UK has information about fatigue. If looking online is not your thing then I have small booklets on fatigue from the MS Society that I can give you, just email me if you would like one and I'll pop it in the post.



Events, so far, for the rest of 2017

19th October - Liz Hendry's Tea/Coffee afternoon (The Cotils)

16th Nov - Liz Hendry's Tea/Coffee afternoon
(ThejCotils)

2nd December - Christmas Fayre, Cobo Community Centre

TBC December -Children's Party

21st December - Liz Hendry's Christmas Party

For further details about Liz Hendry's coffee afternoons, please contact her directly at lizhendry@cwgsy.net

50 European Countries Word Search Puzzle



You can find the words in the grid by looking Diagonal, Forward, Backward, Up, and Down. The words are on the next sheet. Hope you enjoy this one!

ALBANIA	GERMANY	NORWAY
ANDORRA	GREECE	POLAND
ARMENIA	HUNGARY	PORTUGAL
AUSTRIA	ICELAND	ROMANIA
AZERBAIJAN	IRELAND	RUSSIA
BELARUS	ITALY	SAN MARINO
BELGIUM	KAZAKHSTAN	SERBIA
BOSNIA HERZEGOVINA	LATVIA	SLOVAKIA
BULGARIA	LIECHTENSTEIN	SLOVENIA
CROATIA	LITHUANIA	SPAIN
CYPRUS	LUXEMBOURG	SWEDEN
CZECHIA	MACEDONIA	SWITZERLAND
DENMARK	MALTA	TURKEY
ESTONIA	MOLDOVA	UKRAINE
FINLAND	MONACO	UNITED KINGDOM
FRANCE	MONTENEGRO	VATICAN CITY
GEORGIA	NETHERLANDS	