



The South West Impact of MS Project: a long-term study of the impact of MS and CIS on those living with these conditions in Devon and Cornwall



**Welcome to the Spring 2014 newsletter.** Once again we must thank you for your truly amazing efforts in completing the SWIMS questionnaires. This month the total number of people joining SWIMS reached 1700 and we are grateful to each and every participant for contributing to this research. Please keep up the good work as we approach the ten year anniversary of SWIMS starting. Every questionnaire booklet that you complete adds to the picture of MS over time. If you have any queries about anything related to SWIMS please do contact us and we will do our best to help!

## First nurse-led MS study at Plymouth Hospitals NHS Trust



Mike Visick, Senior Nurse for Derriford Neurology Research Team, will be the Principal Investigator for a new study: the *Pain Experience in MS (PEMS)* study.

You may be aware that the MS Society recently published the top ten research questions which people affected by MS wanted researchers to investigate, one of which was, "Which treatments are effective for pain in people with MS?".

Together with Marie Roy (MS Research Nurse and Study Coordinator), Mike is looking to recruit people from **across the South West** who have MS and experience various types of pain.

By asking people with MS about their pain and how it affects them, the PEMS study aims to improve pain management.

If you are one of the first to take part you might receive a £5 Marks & Spencer's voucher as a thank you.

Full details of this new research study are on **page 2**.



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*The SWIMS Project is currently funded by the Multiple Sclerosis Society of Great Britain and Northern Ireland*

## ***Pain Experience in MS (PEMS) Study***



### **What's the PEMS study about?**

This study is part of a larger research project that is being conducted by researchers at The Institute of Psychiatry at Kings College, London, in collaboration with the MS Society.

The project aims to develop and evaluate a new way of supporting pain management for people with MS. The study will improve understanding of MS pain and provide a potential tool to empower people with MS to manage this symptom better in the future.

Research has shown that people with MS experience different types of pain. Researchers are interested in how people with MS experience their pain, how much it affects them, and how they deal with it from day-to-day.

### **What would you be asked to do?**

You would be asked to complete a one-off survey about your pain, how it affects you, and how you deal with it, alongside other more general questions about your health.

There are no right or wrong answers - the researchers want to find out about your views and experiences.

The questionnaires should take around 20-30 minutes to complete and are available online, over the telephone or by post. Mike and Marie would like to make taking part as convenient as possible for you and, to thank you for your time, they can offer the first participants a £5 Marks & Spencer's voucher.

### **Who can take part?**

If you are 18 or over, with a diagnosis of MS, and experience some form of pain related to your MS, Mike and Marie would be really interested to hear from you.

### **Interested?**

If you would like to find out more about this study please contact Marie Roy.



Telephone: **01752 315261**



Email: **plh-tr.N7Research@nhs.net**



Marie Roy, N7, ITTC Building 1, Plymouth Science Park, Plymouth, PL6 8BX



## ***Are you interested in other research into MS at Derriford Hospital?***

**If yes, register with Mike and Marie!**

Mike and Marie are always keen to hear from people interested in taking part in local MS research and, with permission, will keep a record of those who might be interested.

This allows them to quickly identify who would like to be notified about new trials that are recruiting people with MS.

If you are interested in joining this register please contact Marie.



Telephone: 01752 315222



Marie Roy, N7, ITTC Building 1, Plymouth Science Park, Plymouth, PL6 8BX



Email Email: [plh-tr.N7Research@nhs.net](mailto:plh-tr.N7Research@nhs.net)

## ***A new symptoms checklist in SWIMS booklets***

In our last newsletter we mentioned that we had been looking at all the responses you have given for the 'symptoms checklist' in SWIMS questionnaire booklets. To help people complete the checklist, and reduce the amount of time needed for you to tell us about 'other symptoms', we have decided to expand the checklist to include more options.

We did think long and hard about whether to increase the list because we realise that reading such a long list of symptoms could be alarming for some. As with other questions in the booklet you may find that some or most of this section on symptoms is not relevant to you. If you have any queries or concerns please do get in touch.

When we reviewed the 'other' symptoms that SWIMS participants were writing about we realised that some were reported by several participants e.g. headaches or dizziness. We decided that the best way to find out how many people had these "other" symptoms was to include them in the actual list. We hope to get a clearer picture of the variation in symptoms across all types and stages of MS.

We are also removing from the checklist the option to add any symptoms that are not included in the list. We know that there may be some very rare symptoms we have overlooked but we need to focus on examining common patterns in the symptom data. We will, of course, continue to anonymously record any comments or additions that you wish to add to your questionnaire.

We have tried to add a little bit more detail to some of the symptom descriptions, to clarify what we mean and help participants decide which boxes should be ticked.



## Pilates and MS

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### Does Pilates improve balance and mobility for people with MS?



'Pilates' is a group of exercises which mostly focuses on training the abdominal muscles to improve 'core stability'. Physiotherapists often use Pilates exercises to help improve balance and mobility for people with MS, however until recently there has been very little research to assess the benefits of these exercises and ascertain whether Pilates is of more benefit than other physiotherapy exercises for people with MS.

To help answer these questions a clinical trial was recently performed by researchers from the School of Health Professions, Plymouth University. One hundred people with MS volunteered to participate and were randomly allocated to a twelve week programme of therapy sessions and home exercises consisting of one of the following:

- \* Pilates-based core stability exercises
- \* Physiotherapy exercises
- \* Placebo - a relaxation exercise

Before and after the twelve week programme, participants performed a variety of assessments, including a timed walking test, balance tests and questionnaires to assess their balance and mobility.

Pilates and physiotherapy exercises both significantly improved many aspects of balance and mobility, whereas the placebo relaxation exercise did not. The people who performed the physiotherapy exercises showed bigger, and more long-lasting, improvements across more assessments than those performing Pilates only.

In summary, a twelve week period of Pilates or physiotherapy exercises was shown to help to improve balance and mobility in people with MS. In order to maintain these benefits it is necessary to continue performing the exercises.

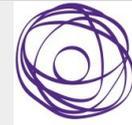
This research has been published and the full article can be accessed online at:

[http://www.mstrust.org.uk/professionals/information/wayahead/articles/18012014\\_03.jsp](http://www.mstrust.org.uk/professionals/information/wayahead/articles/18012014_03.jsp)

If you would like a paper copy, or any further information, please contact Esther Fox (telephone: **01752 587599** or email [esther.fox@plymouth.ac.uk](mailto:esther.fox@plymouth.ac.uk)).



## News around the region: The Merlin MS Centre



**Merlin  
MS Centre**

UK Charity Reg No: 1093691

For this newsletter we asked The Merlin MS Centre in Cornwall to provide SWIMS participants with some information about the services they provide.

### About the Charity



The Merlin MS Centre is an independent charity located in mid-Cornwall, which provides a range of expert care, support and therapies predominantly for people whose lives are affected by MS, but also for those with other neurological conditions such as Parkinson's disease, stroke, ME/Chronic Fatigue Syndrome.

There are, on average, 60 people a day who come to the Centre. The charity receives no Government funding and therefore derives its income from fundraising activities in the community; hiring of the Centre's conference and therapy rooms to external clients; plus income from grant making trusts.

The therapies provided by our organisation include individual and group physiotherapy; occupational and exercise therapy; podiatry; hyperbaric oxygen therapy and complementary therapies. The support services include counselling, carer support, advice and information (the Centre is an information hub for the MS Society) and the charity also has a free adapted mini-bus service. All services are heavily subsidised or provided free of charge.

### Daily Respite Care Service

We have recently launched a new daily respite service - this is a specialised service which can enable individuals to gain new skills; improve social interaction and self-confidence; and reduce depression and isolation. The service provides users with a structured day of activities to include a choice of therapies, exercises, workshops, outings, lunch and rest periods.



The service runs from 10am-4pm and the days start with participants being given an outline of the day's activities. There is then the opportunity to receive one of the therapies available, before having a lunch break. The afternoon gives people the option of participating in a further range of therapies including holistic massage, Indian head massage, clinical hypnotherapy, reiki and manicures or pedicures. Refreshments are available throughout the day and reclining chairs are available for people to rest if they feel fatigued. A significant focus of the day's activities is on sociability.

For more information please go to [www.merlinmscentre.org.uk](http://www.merlinmscentre.org.uk)

or call **01726 885530**

The Merlin MS Centre, Bradbury House, Hewas Water, St. Austell, PL26 7JF



## Managing falls

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One of our colleagues, Hilary Gunn, would like to invite SWIMS participants to contribute to her continuing work investigating falls amongst people with MS. This project is supported by the Multiple Sclerosis Society in the UK.

### Can you help to find a better way to manage falls?

Falls are a significant issue for some people affected by MS. We want to find a better way to manage falls and falling. We are looking for volunteers to help us to do this by developing a programme tailored to the needs of people with MS.

Through a series of workshop events, we aim to combine scientific evidence that has already been published with the views of people affected by MS, health professionals and commissioners of services.

Being involved in this project will entail attending two one-day activities. Initially, you will be invited to a training day to introduce the project and the processes that will be used during the workshop. At the second day, the participants will be encouraged to discuss and debate the practicalities of how a falls management programme should be structured, delivered and supported. Meetings will be held in Exeter, St Austell and Plymouth; places are available at the **Exeter** and **St Austell** workshops. Funding is available to support travel expenses.

If you have MS and are interested in this project, we would be keen to hear from you.

**You are able to take part in the study regardless of whether you fall or not.**

**St Austell** venue: Merlin MS Centre, Hewas Water, St Austell.

Dates: May 9<sup>th</sup> 10am-2pm AND May 20<sup>th</sup> 10am-4pm

**Exeter** venue: Exeter Community Centre, St Davids Hill EX4 3RG.

Dates: 29<sup>th</sup> April 10am-2pm AND May 6<sup>th</sup> 10am-4pm

Further information is available from Hilary on telephone number **01752 588825** or by email **hilary.gunn100@plymouth.ac.uk**

SWIMS Project , Room N16, ITTC Building, Plymouth Science Park, Plymouth, PL6 8BX  
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