

Issue 2

October 2009

# AFFIRMMS *Trial Newsletter*

Poole Hospital   
NHS Foundation Trust

UNIVERSITY OF  
**Southampton**  
School of Health Sciences



*Approaches For Fatigue In Relation to Managing Multiple Sclerosis*

## Welcome to our second newsletter!

The aim of this newsletter is to update you on progress with the trial and introduce some of the Bristol team. Since the last newsletter we have been very busy: In March 2009, we reported the findings from the pilot research at a rehabilitation conference in Stockholm, Sweden and in May 2009 we gave a presentation about the trial at the MS Society Frontiers conference in London. Findings from the pilot research have recently been published in a journal (Patient Education & Counselling).

We are getting closer to our recruitment goal of 180 people - about three quarters of the way there! If you know anyone in Poole, Bristol or Portsmouth areas who you think might be interested in participating they can contact Sarah Thomas, the trial coordinator (01202 448617), or go to the MS Society website, 'Take part in research' section: '*People with MS fatigue sought for national research trial*'.

*"You can't describe fatigue. It's different every day, it's different for every part of your body....."*  
[Focus group member]

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The *AFFIRMMS* trial (Chief Investigator: Professor Peter Thomas; Trial Coordinator: Dr Sarah Thomas; Principal Investigators: Dr Rosie Jones & Dr Paula Kersten) is a three-centre trial (Poole, Bristol & Southampton) that is co-ordinated from Poole, Dorset. It compares two approaches for managing MS-fatigue:

- A group-based programme that incorporates a cognitive behavioural approach
- 'current local best practice' (approaches commonly used in neurology departments and MS services across the country).

The *AFFIRMMS* trial is the final phase of a four phase project.

#### The trial is suitable for:

*People who:*

- are over 18 yrs with a confirmed diagnosis of MS
- have fatigue that is impacting upon daily life
- can walk at least 20 metres (either with/without mobility aids)
- are not already taking part in a research trial/study



Bristol Docks

  
THE MEDICAL RESEARCH CHARITY

  
Multiple Sclerosis Society

  
Multiple Sclerosis Trust

## Introducing the Bristol team!

We would like to introduce you to the Bristol team working on the trial (from left to right):

First, it's me, Rosie (the little one!). My main role is to look after the Bristol MS Research Unit and to ensure that our part of the project runs smoothly. I'm a muscle physiologist by training, particularly interested in how muscles are made to work by the nervous system and how this becomes altered in disabling conditions like MS.



Next to me is Angela, who is the MS Unit's research physiotherapist, and who, without doubt, is the inspiration and glue that keeps us all on our toes in her role as local project organiser. To Angela's left is Jen, an Occupational Therapist (OT), with a keen interest in both the physical and emotional aspects of MS. On the far right of the photo is Charlie, who's also an OT and the one who keeps everyone's feet planted firmly on the ground, while making sure we get our fair share of fun. She works mainly with cancer patients but has found working on this project interesting and rewarding.

We are delighted to have the opportunity to participate in this trial and thank all participants who have painstakingly filled in questionnaires and worn ActivPALS™.

## What happens to the information stored on the ActivPALS™?



Hi, my name is Reuben Ogollah and I recently joined the MS fatigue trial team at Poole Hospital. I'm a Statis-

tician in my final year of PhD research at Bournemouth University, Dorset.

My PhD research involves examining the role of early life psychological factors in the development of chronic diseases in middle age using two large sources of data.

My role in the MS fatigue trial team involves extracting and analysing the information stored on the ActivPAL™ activity monitors. Everyone taking part in the fatigue study is asked to wear an activity monitor for a 48 hour period while they go about their day-to-day routines.

The ActivPAL™ software identifies time spent walking, sitting, and standing, and summarises these episodes over 1 hour periods in both graphical and numeric formats.

I transfer the numerical information to a statistical software package so that I can analyse it in much greater detail. We are interested in exploring how the ActivPAL™ data relate to levels of fatigue.

Along with wearing the ActivPAL™ activity monitor, we also ask participants to keep a detailed hourly diary of their daily activities for 48 hours. These diaries are crucial as they help us to interpret the findings from the ActivPAL™ and allow us to study the level of agreement between activities reported in participants' diaries and the information recorded by the ActivPALS™.

## “F\*\*\*\*\*d” ..... a symptom rather than a lifestyle choice

By Caroline Georghiou

**I**t starts with ‘F’ and ends in ‘D’, a neuropsychologist began her talk about being fatigued:

Fatigue, on a sliding scale, affects most of us with MS. It changes our everyday lives.

I think of myself as a reverse butterfly, brightly-coloured, ducking and diving, flamboyantly amazing, and impressing onlookers for about five minutes before I require a lengthy rest in my cocoon to re-establish my ability to string a sentence together.

We need more education around fatigue and how to deal with it. If I, as someone with MS, find it hard to explain or even understand then how can people we work, play and associate with get to grips with the Macavity-like symptoms or understand necessary reasonable adjustments.

Dealing with such an unknown quantity may elicit fear or guilt, frustration or anger - and that’s just me! Before we can deal with all the questions that arise, we need to know more. Knowledge is power and one of the best ways to manage our own condition is to learn from others who know how it feels. On a Fatigue trial you are not alone!

Help to manage fatigue is often absent and The MS Research Unit based at the Bristol and Avon MS clinical centre (BrAMS) is one of three centres running a trial to deal with one of MS’s major symptoms. Funded by the MS Society and supported locally by the Bristol-based charity ‘MS Research, Training and Education’ the study also reveals the aims of the professional enthusiasts who know the importance of educating, entertaining and empowering, not

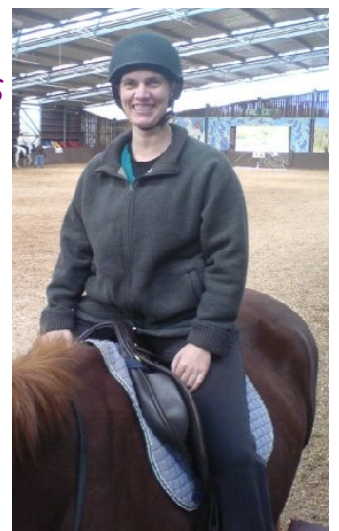
only the people living with MS, but all those who meet us.

We may find ourselves in a Catch 22 situation, we want to be treated as “normal” and yet the need for explanation is clear. People point out “you could do it yesterday, why not today?” Worse still your GP may say that your fatigue will “burn itself out”.

Each one of us has our own story. Short of educating the masses, we can at least enlighten our health care professionals, social workers, families and friends who can learn from us about unseen disability. Together research and education can make all the difference to our lives, our jobs and our relationships. It could mean better understanding and prevent a whole heap of misunderstandings and even full on catastrophes.

Rolling out Holistic thinking, preventative medicine and taking the power back from a potentially life-disabling symptom can only be a win-win situation for all of us, but particularly for those who understand all too well the Rolling Stone’s song “Shattered”!

*NOTE: Caroline has been a lively participant in one of the MS fatigue groups. We hope her comments will help everyone to appreciate the potential value of any sound methods that might help individuals to manage their MS and take control for themselves.*



## Being an active partner in MS studies....

Hello, my name is Geoff and I am one of the people with MS (PwMS) who have been “attached” to the Fatigue Management project since the start.

I have lived with MS for 26 years and the opportunity to help (a little) in the battle against fatigue was too good to pass up. I was fortunate not to be dealing with fatigue when I was invited to participate in the project (how ironic would that have been?) and so I “jumped” at the chance to join in.

My background is as a volunteer tutor for the Expert Patient Programme and so my input has been from the perspective of a PwMS who has experience of a self management programme.

The whole process of bringing a project like this to the light of day is quite mind-boggling in its intensity: arranging meetings, meetings about meetings, ethics approval, securing funding, securing staff,

recruitment for the trials, finding suitable venues and many other challenges have to be met (not by me I have to say).

I think that in these times of “increasing personal healthcare choice” this project has a great relevance for PwMS. Knowledge and behavioural based management of conditions such as MS will play an increasingly prominent role in our healthcare.

The self-management techniques covered by the course can and will make a positive difference to the lives of the people who use them. Positive self-management techniques are simple, “portable”, allow you to regain some control and will last you many years.

So, all those in favour of managing their life say “aye”.

“AYE !”

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## ....from the Bristol MS research team

Geoff is being very modest. His help and that of Tim, his colleague, who also draws upon his experience of MS as an advisor to the fatigue trial, has been invaluable and extremely helpful in designing and running this trial. Their insightful comments during steering group meetings and enthusiastic participation overall have added considerable value to the research.

We add our very grateful thanks to both of them. We encourage anyone who feels they can offer their valuable experience to research project priorities, design and delivery to speak to Rosie Jones at the research room in BrAMS (Bristol & Avon MS) or by calling 0117 340 6403.

*Please note our move to BrAMS & new telephone number (some activities will still take place at Bristol General Hospital).*

*If you:*

- *wish to be removed from this mailing list or have a change of address*
- *would prefer to receive an e-newsletter*
- *would like to contribute to the next newsletter/have ideas for content of future issues*

*Please email the AFFIRMMS trial administrator, Louise Ward ([louise.ward@poole.nhs.uk](mailto:louise.ward@poole.nhs.uk)).*