

Clare R McDermott and Sarah Frossell

Above: Sarah Frossell(right) working with a group member.

## Aims

This study set out to answer the question, 'How can the experiences of patients who have recovered or substantially improved from CFS/ME be used as a resource to help current Chronic Fatigue Syndrome/ME (CFS/ME) patients?'

## Plain English summary

**BACKGROUND:** Severe Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) can result in patients becoming housebound, wheelchair or bedbound. There is currently little evidence based treatment available for this severely disabled patient group.

**WHAT & WHO?** We conducted 5 learning cycles over two and a half years using Patient and Public Involvement from over 40 current and recovered patients, carers, local patient support groups and specialist CFS/ME clinicians.

A series of development groups met in half day workshops with the goal of understanding and modelling the key elements and skills required for recovery from CFS/ME, drawing on the lived experience of patients.

Group sessions were facilitated using the conceptual model of 'modelling success' from Neuro-Linguistic Programming. Within the groups, all members acted as equal peers, contributing individual insights and experience to the process.

**RESULTS:** Group members identified key recovery skills, and how best to communicate these in ways which are meaningful to those with CFS/ME. Barriers to effective communication were identified and creative ways of addressing these issues were discussed.

Insights generated by this development group have been used to devise and refine a community based intervention for patients with severe CFS/ME. This intervention is the subject of an NIHR funded feasibility study which is currently recruiting patients in Dorset and Oxford.

# Development of a new intervention for patients with severe Chronic Fatigue Syndrome/ME: a collaborative approach based on patient and public involvement.

## Key impacts

The findings from this project and plans for future work were presented to the All Party Parliamentary Group on ME at Westminster in March 2013 by Clare McDermott (Researcher), Sarah Frossell (Group Facilitator) and Tim Stirgess (Chair of the Dorset ME Support Group).

Ideas on recovery skills and communication generated by the development groups have been used to design a new community based intervention for patients with severe CFS/ME. A feasibility study evaluating this intervention is currently being conducted in Dorset and Oxford. This study is funded by the National Institute of Health Research and peer reviewed by the National School of Primary Care Research. Results from this study are expected in 2016.

Insights on communication skills generated by the development work have been used to design a training programme for specialist CFS/ME health professionals, titled 'Recovery focussed communication for CFS/ME'. The group facilitator, Sarah Frossell, delivered this training to the Dorset CFS/ME Service team in 2009 at their request. The training has been evaluated by a research team involving independent researchers from the University of Southampton, The University of Cumbria and Bournemouth University. This study, which used an action research approach, has been submitted for peer reviewed publication. Training has also been provided to health professionals from the Oxfordshire CFS/ME Service and the Dorset CFS/ME Service for Children and Young People.

Members of the development groups have also contributed to the design of a national scoping exercise on service provision for patients who are severely affected by CFS/ME. This study has been recently accepted for publication by BMJ Open.

## Collaborations

This development project is supported by the Dorset ME Support Group and has involved over 40 individuals with CFS/ME and carers in Dorset and Hampshire.

## Outputs

The action research study on 'Recovery focussed communication in CFS/ME' was presented as a short oral presentation at the annual conference for College of Occupational Therapy (Glasgow, 2012), and as a poster presentation at the National Conference for the British Association of CFS/ME (Milton Keynes, 2012). Full paper currently submitted for publication.

McDermott C, Al Haddabi A, Akagi H, Selby M, Cox D, Lewith G. What is the current NHS service provision for patients severely affected by chronic fatigue syndrome/myalgic encephalomyelitis? A national scoping exercise *BMJ Open* 2014;4:e005083 doi:10.1136/bmjopen-2014-005083.



Left: Lead facilitator, Sarah Frossell, with some of the contributors to the project.  
Below: Clare McDermott.



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## School for Primary Care Research

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