

## OXFORDSHIRE ME GROUP FOR ACTION (OMEGA)

# OMEGA membership survey on local NHS services for ME/CFS

April 2013

## Summary of Full Report

ME/CFS patients in Oxfordshire were surveyed in early 2012 about how helpful or unhelpful they found various NHS services including their GP. The responses of 56 members of OMEGA<sup>1</sup> are presented (Note 1). The current survey complements a survey of Oxfordshire GPs funded by LINK and carried out in 2012 by independent researcher Margaret Melling on behalf of OMEGA [1], and the book *Poetry from the Bed - Life with ME/CFS*; accounts of patients' experiences of the illness [2].

### Main findings:

- There is a wide spectrum of knowledge and understanding of Oxfordshire GPs and other health professionals with respect to ME/CFS.
- Only about a quarter of GPs were positively helpful. Comments show that many GPs have little understanding of ME/CFS. Some do not recognize that it is a real, serious illness. Some respondents reported that there was no point in seeing their GP about ME/CFS.
- Most shocking are the negative and hostile comments that patients experienced. *'Aggression, rough treatment, incompetence and cruelty'* were reported as was bad advice which made their condition worse. It is shocking that this has to be made explicit in the current climate, following the Francis Report [3]. 39% of respondents mentioned lack of diagnosis or lack of belief in the illness as the most unhelpful thing. Overall, **most** patients received negative comments, wrong advice and/or weren't believed.
- On the other hand, when patients were believed, received a diagnosis or were given good advice, this was found to be very helpful.
- Treatments provided by OCCMET and Mindfulness Meditation, and to a lesser extent by the GP, had significant positive reports, although treatment by GPs was very variable. Treatment by the hospital based Infectious Diseases Chronic Fatigue Service had a significant negative report, while CBT and other treatments had no significant effect. Graded or forced exercise was specifically mentioned as unhelpful by some patients.
- Patients reported twice as much negative experience as positive. Very few patients had an overall positive experience.
- Many patients commented on the difficulty of getting any help at all, of lack of referrals and help getting treatments or practical help.

Note 1: The full Report sets out each question and the analysis of responses, conclusions and recommendations. The Appendix contains verbatim responses to an open question about the most and least helpful thing anyone in the NHS had said or done. References are given where appropriate.

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<sup>1</sup> OMEGA (Oxfordshire ME Group for Action) is the Oxfordshire patient support group for those with Myalgic Encephalomyelitis and Chronic Fatigue Syndrome (ME/CFS). OMEGA played an essential role in setting up in 2004-05 the community service OCCMET.

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## **Recommendations R1-R7:**

### **R1 Training**

#### **There is an urgent need for training for GPs and other health professionals**

GPs should be given one of the two primers recently published by international teams of scientists and scientist-practitioners (both available electronically – see Note 2) [4,5]. We suggest that the OCCMET GPwSI could also visit surgeries and give seminars on ME/CFS. Any such training should include case-study input by patients, and advice about pacing and activity management.

### **R2 Best practice - listening; belief; diagnosis; emotional support; basic care**

Patients should be listened to carefully and believed, not patronised or insulted (see Francis Report [3]). Helpful questions should include how the illness affects the patient's life. Then a timely and accurate diagnosis can be made, using up-to-date, internationally recognised guidelines [4,5].

### **R3 Practical support**

The survey shows that helping access practical support is one of the most helpful things GPs can do. We encourage health professionals who see patients with ME/CFS to inform them about the patient group OMEGA, so that they can have the option of support from such a group. Such support helps to combat the isolation which is a common consequence of this illness.

### **R4 Referrals & letters**

Patients need to be referred to the appropriate service. Some GPs still do not refer to OCCMET and patients who attend the JRH are not told about or referred to OCCMET. Appropriate letters are needed for obtaining practical support such as benefits, help with aids and home care.

### **R5 Treatments offered and Advice and Information**

**A. The ID service:** Very few respondents found the ID service helpful. It provides inadequate advice and relies too heavily on CBT and GET. Careful diagnosis and individually tailored and monitored programmes are needed. The service should be reviewed to see if it can meet the needs of patients.

**B. Mindfulness Meditation:** This therapy is not a cure for ME/CFS, but can help patients to manage this serious condition, and allow them to have a better quality of life. Access should be simplified and attempt made to suit the needs of the more seriously ill.

**C. The OCCMET service:** This service needs to be strengthened, and also extended so that it can treat children and young people under 14 years of age. Attention needs to be given to the particular stresses that children and their parents are placed under.

### **R6 Easy access to help**

The NHS needs to make it easy for people with ME/CFS to access help. Clinics should be easily accessible, and community teams should have sufficient staff and appropriate skills base.

### **R7 Monitoring and Feed-back**

Members report that they are unwilling to criticise a service because they think that it may result in them becoming labelled a 'problem patient' and which may then lead to difficulties with their treatment or benefits. Patients should be involved in designing services and monitoring processes.

Note 2: A hard copy of the IACFS/ME Primer [4] has been sent by Oxfordshire LINK to every GP practice in the county.

**References:**

[1]. *Research into the views of GPs in Oxfordshire on services for patients with CFS/ME, November 2012*, Oxfordshire LINK, [www.oxfordshirelink.org.uk](http://www.oxfordshirelink.org.uk)

[2]. *Poetry from the Bed - Life with ME/CFS*; Oxfordshire ME Group for Action, 2012.  
ISBN: 978-0-9574170-0-7

[3]. *Final Report of the Independent Inquiry into Care Provided by Mid Staffordshire NHS Foundation Trust*, <http://www.midstaffsinquiry.com/pressrelease.html>

[4]. *ME/CFS: A Primer for Clinical Practitioners*, © 2012 International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis, [www.iacfsme.org/Home/Primer/tabid/509/Default.aspx](http://www.iacfsme.org/Home/Primer/tabid/509/Default.aspx)

[5]. *Myalgic Encephalomyelitis – Adult & Paediatric: International Consensus Primer for Medical Practitioners*, © 2012: Carruthers & van de Sande, ISBN 978-0-9739335-3-6, available at [www.investinme.org/Documents/Guidelines/Myalgic%20Encephalomyelitis%20International%20Consensus%20Primer%20-2012-11-26.pdf](http://www.investinme.org/Documents/Guidelines/Myalgic%20Encephalomyelitis%20International%20Consensus%20Primer%20-2012-11-26.pdf)