OMEGA membership survey on local NHS services for ME/CFS

Full Report

OXFORDSHIRE ME GROUP FOR ACTION (OMEGA)

April 2013

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1 Introduction

In early 2012 OMEGA[*] members were sent their annual subscription reminders together with a questionnaire about their experiences with local GPs, consultants at Oxfordshire hospitals (mainly the John Radcliffe Hospitals, including the Churchill – JRH, now called OUHT Oxford University Hospitals Trust) and other health professionals within the NHS including the Oxfordshire Community CFS/ME Team (OCCMET), the Chronic Fatigue Clinic operated by Infectious Diseases (ID) and the Mindfulness Meditation classes now provided by the Talking Space.

The purpose of this survey is to find out what experiences OMEGA members have had with the various services and how helpful they found them, and to find out more about the content of these encounters. This 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]. The findings are also compared with a local patient survey (80 responses) in 2002 [2] and those of a 2010 national survey of 4217 people with ME/CFS by the ME Association [3].

<u>The Survey:</u> Members were asked questions about how long they have been ill, details of how they were diagnosed and by whom, how helpful they found their GP, and about what NHS treatments they have had and how effective they were (from very unhelpful to most helpful). They were also asked to comment on: **A** the most and **B** the least helpful thing anyone in the NHS had said or done, and **C** a general comment about experience of the NHS.

Although about 70 OMEGA members responded to the 2012 questionnaire, only 56 members answered the majority of the questions, and this report is based on these 56 replies.

<u>The illness:</u> Myalgic Encephalomyelitis (ME) is classified as a serious neurological illness by the World Health Organisation. The National Institute for Clinical Health and Excellence (NICE) [4] stated in 2007:

‘The physical symptoms can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions.’

In 2002 the government’s Chief Medical Officer [5] said:

“CFS/ME is a relatively common condition that can cause profound, often prolonged illness and disability, and have a substantial impact on the individual and family.”

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[*] 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.
General enquiries: OMEGA, 4 Bursill Close, Oxford OX3 8EW. Website: www.oxnet.org.uk/omega

2 Questions Q1-Q6 and their Replies

Q1. The first question was: **How long have you been ill?**

Patients had been ill for from 3 years to 55 years, with an average of 19 years, and 90% of the respondents have been ill for between 5 and 30 years. The time distribution is shown in Figure 1.

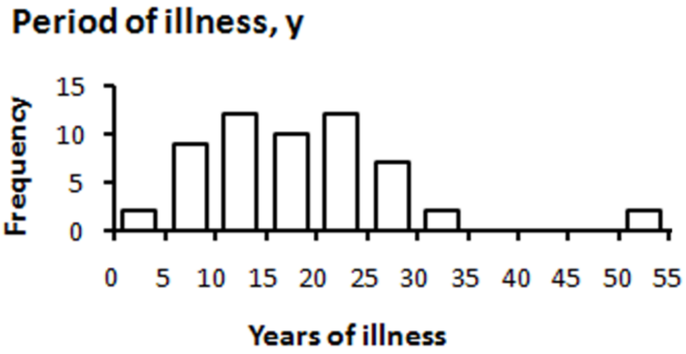

Figure 1. Duration of illness as of February 2012 for 56 OMEGA members.

Q2. The second question was: **What is your diagnosis?**

All 56 were diagnosed with ME or with CFS (or both) and 3 also with FM and 4 with other concomitant conditions.

Q3. The third question was: **Who diagnosed the illness?**

Diagnosis was carried out by the member's GP in 28 cases and by a JRH consultant in Infectious Diseases (ID) in 27 cases, and 12 of the latter confirmed the GP's diagnosis. A further 11 diagnoses were carried out by other (non ID) consultants and 3 of these confirmed the GP's diagnosis. The OCCMET GP (appointed in March 2006) carried out 2 diagnoses (1 of which was confirmatory), and other parties carried out 6 diagnoses (1 of which confirmed the GP's diagnosis). We do not know what diagnostic criteria were used for any of these diagnoses (except for those carried out by the OCCMET GP who makes use of the IACFS/ME Primer [6]).

Q4. The next question was: **When did you last see your GP <u>about your ME/CFS</u>?**

The purpose of this question is to estimate to what extent patients find consultations with their GP to be useful. It is also relevant to the PACE research trial [7] (and some previous trials) where treatments are compared with "Standard Medical Care" (SMC). PACE refers to SMC as seeing a specialist doctor once per month.

Out of our 56 replies only 10 members (18%) had seen their GP in the last month regarding their ME/CFS and this small number might be classed as receiving SMC. A further 18 (32%) had consulted their GP within 1 year, 11 (20%) between 1 year and 5 years, and 17 (30%) replied that it was greater than 5 years and some of these replied that they did not discuss ME/CFS with their GP at all.

Summary: 50% of patients had not consulted their GP about their ME/CFS for at least a year. Members report anecdotally that they think there is no point in seeing their GP – the survey data confirm this. (Also see the replies to **Q5** and the comments in the **Appendix**.)

Q5. The next question was about the *outcome* of GP consultations:

Please rate how helpful you find your GP about ME/CFS.

This is about the outcome of GP consultations, a slightly different question than the previous one.

Only 27% of OMEGA members surveyed found their GP to be helpful or most helpful. On the other hand, 73% either did not consult their GP about ME/CFS or found their GP not helpful or neither helpful nor unhelpful.

Summary: There is a wide spectrum of knowledge and understanding of Oxfordshire GPs with respect to ME/CFS. (See the LINk GP survey [1] which confirms this.)

It is disappointing that there is little sign of improvement over the 10 years since the 2002 survey when 51% of patients found their GP helpful [2].

Q6. The next more complex question was:

What NHS treatment have you had and from whom?

Members were also asked to give each treatment a Rating Score from 1 to 5 with categories defined in Table 1.

Table 1

Rating	Score
Very unhelpful	1
Unhelpful	2
Neither helpful nor unhelpful	3
Helpful	4
Most helpful	5

A Score of 5 is very good, while a Score of 1 is very poor, and a Score of 3 indicates that the treatment is neither beneficial nor harmful and this is taken as the baseline. A Score larger than 3 can be considered as beneficial, and less than 3 as having a negative impact. However, this scale is only a coarse measure of efficacy of treatment.

The treatments (or services) most widely used were: GP (42 members), ID Clinic at JRH (30), Cognitive behaviour therapy (CBT, 22), OCCMET (21), Mindfulness Meditation (MM, 14), and other NHS (16) including Counselling (1) and the Expert Patient Programme (1). The PACE trial (4) had very few participants from our sample.

There were a total of 149 NHS treatments or use of services by the 56 patients, an average of 2.7 per patient. Almost 80% had more than one treatment and 25% had more than 3 treatments.

Summary: These figures suggest that some of the treatments or services are not helpful and patients needed to try one or more of the others available.

Figure 2 shows graphical distributions for the 6 most widely used treatments.

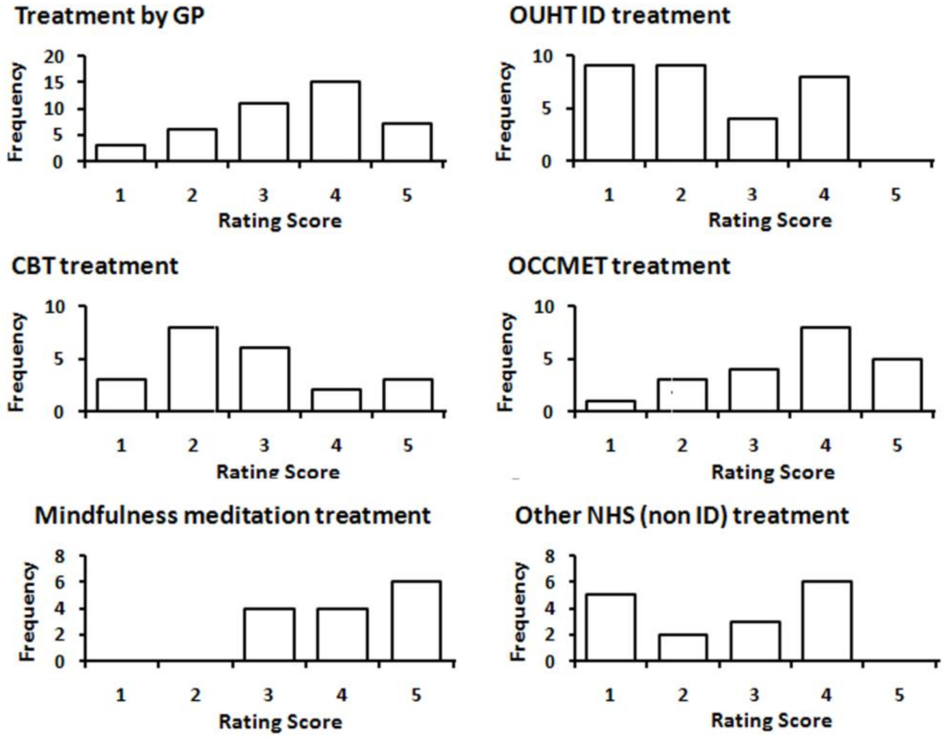

Figure 2. Plots of Rating Scores of the principal therapeutic treatments.

Table 2 lists in ranked order the mean value of the rating scores with their standard errors (standard error of the mean, SEM). For completeness we also include the result for the PACE trial in Oxfordshire which had only 4 participants in our sample.

Table 2

Treatment	Number	Mean Rating Score (± SEM)	%age Helped
MM	14	4.14 ± 0.23	71 ± 13
OCCMET	21	3.62 ± 0.25	62 ± 11
GP	42	3.40 ± 0.18	52 ± 8
CBT	22	2.73 ± 0.26	23 ± 9
OTHER	16	2.63 ± 0.33	38 ±13
ID	30	2.37 ± 0.22	27 ± 8
PACE	4	1.75 ± 0.75	25 ±25

We also show in the last column the percentage of patients who felt that the treatment (or service) had a positive or beneficial effect (i.e. Rating Scores of 4 or 5). The errors in this column are binomial errors, reflecting the fact that for each treatment or service the patients have been divided into 2 groups: those that found the treatment helpful (Rating Scores 4 or 5), and those who found the treatment not beneficial (Rating Scores 1 or 2 or 3).

One way to summarize these results is the way used by NOD, the National Outcomes Database [8] (also used in the PACE trial [7]), saying that a Rating Score = 3 means no change. A change in the mean value is significant only if it is at least as large as the 95% confidence interval (1.96 SEM). The results of this method are shown in Figure 3 where the error bars correspond to the 95% confidence intervals.

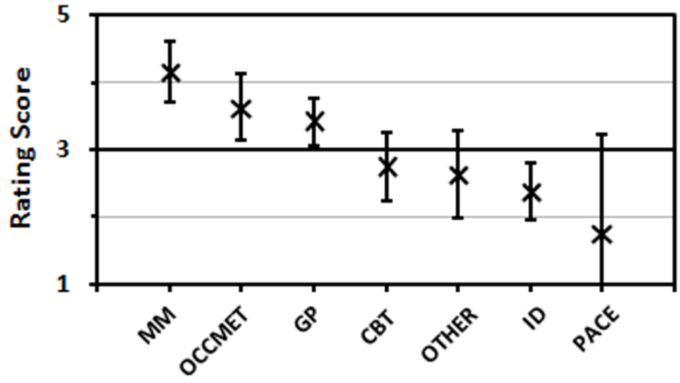

Figure 3. Mean Rating Scores from Table 2 and 95% confidence intervals for the distributions in Figure 2 and including the PACE trial result.

The only significant positive changes are for GP (just barely), OCCMET and MM. The only significant negative change is for ID. With a larger number of participants the 95% confidence intervals decrease as the square root of the number in the sample, so clinical trials such as PACE need a large number of participants.

Note that comparing the mean Scores as in this method does <u>not</u> tell you what fraction improved and what fraction got worse. In our analysis this information can be extracted from Figure 2 and the numbers are given (with binomial errors) in the last column of Table 2. Note that in this method CBT is ranked in 6th place, below OTHER and slightly below ID. This method has been used in a number of other clinical trials (e.g. [9-10]). Our results with this method are plotted in Figure 4.

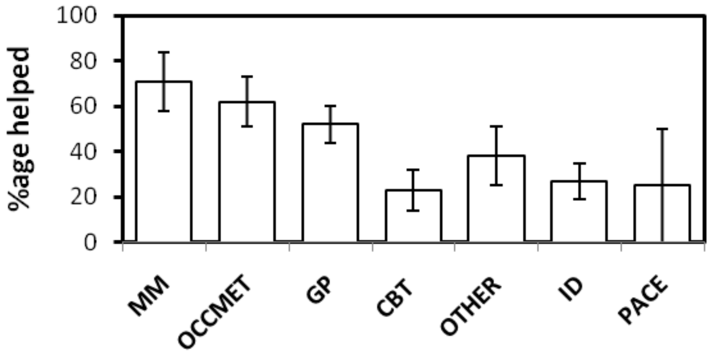

Figure 4. Percentage of patients who found a particular treatment (or service) helpful or most helpful.

Summary: Patients find Mindfulness Meditation and OCCMET treatment to be the most helpful, some GP consultations are helpful, and that other treatments, particularly the ID clinic, were unhelpful.

<u>Comparisons with the OMEGA 2002 survey [2]:</u> OCCMET did not then exist and Mindfulness Meditation was not provided. Patients were mainly referred to specialists: 22% to ID, 41% to a Psychiatrist, 16% to a Neurologist and 21% to a Counsellor or other professional.

Summary: There has been some improvement in treating patients since 2002 [2]. At that time 76% reported that they felt worse or had no change after referral to a specialist service, while in 2012 this has fallen to 57%, mainly due to MM (29%) and OCCMET (38%).

3 Question Q7 and Summary of Responses

This consisted of 3 open questions:

A. What was the most helpful thing anyone in the NHS said or did?

B. What was NOT helpful that anyone said or did?

C. Is there anything else you'd like to tell us about your experience of the NHS?

These are to give information about the *content* of consultations with GPs, consultants and other health professionals. We include the responses in full in the **Appendix** where each member replying is given a number (#), and the replies are sorted according to period of illness (beginning with the longest). There is one exception; # 61 is placed at the end because this is a young person who has been ill for 6 years, since he was 11 years old, and the questions are answered by his mother. As summarised in **Table 3** we classified the responses into ten categories, and within each of these ten, either positive or negative.

Table 3

Summary of members' comments on NHS services and providers

Category	Positive comments		Negative comments	
	Nature of comments	No.	Nature of comments	No.
Diagnosis and belief	diagnosis and belief	11	lack of diagnosis lack of belief in ME or in patient's description of symptoms	22
Emotional support	emotional support positive attitude to patient	10	lack of emotional support negative attitude, bullying, belittling, being laughed at	18
Practical support, help with benefits	practical advice help obtaining benefits	10	lack of domiciliary services lack/refusal of help with benefits	4
Referrals	writing referral letters	6	refusal to write letters of referral	5
Advice -especially on pacing & exercise	helpful advice	9	unhelpful advice	15
Waiting times		0	long waiting times	4
Treatment/medication (sometimes for specific symptoms)	treatment/medication that helped	11	treatment/medication that made things worse	11
Information	accurate and helpful information	2	lack of information, wrong information	4
General experience of NHS help with ME/CFS	only positive experience	2	only negative experience	28
Access to help		0	difficulty accessing help	8

The categories are somewhat overlapping (e.g. telling a patient that *'ME does not exist that it is a Mickey Mouse illness'* is showing not only a lack of diagnosis and belief, but is also factually incorrect and shows a negative attitude/lack of emotional support). Nevertheless, we felt that it was useful to categorise them by their main attribute. Despite the fact that we specifically asked for examples of both helpful and unhelpful words and actions, there are more unhelpful examples given. In some cases patients gave more than one example, these have been categorised separately. In some cases patients could not think of any example of helpfulness in their treatment.
We now briefly discuss the categories of **Table 3** and the conclusions we can draw from the contents.

Diagnosis and Belief

Listening to the patient, believing what they say and coming to an accurate diagnosis would seem to be the most basic starting point for any effective treatment or help. However this is not the case for many ME/CFS patients. 39% mentioned lack of diagnosis and belief as the most unhelpful thing. 20% mentioned being believed or getting a diagnosis as the most helpful. A number of members also mentioned the delay in diagnosis - though this was counted as the most positive thing by them as in one case they had a diagnosis within 6 months. In the other cases it was to finally get a diagnosis after 15 - 20 years. The fact that these are counted as the most helpful things for these patients may show what a positive attitude they had, as in many illnesses such as delay would be seen as unacceptable.

Unhelpful

> *(Being told) 'I could get better if I wanted to. ME did not exist - it was a Mickey Mouse condition.'*
>
> *'Most NHS staff seem unwilling to understand the awfulness of ME, eg the pain (chronic and severe much of the time), the lack of energy (which impedes even the basics of living/life)...'*

Helpful

> *'The consultant who told me I had ME after 9 years of it'*
>
> *'Telling me I had a physical illness and it was real.'*

Emotional Support

This is taken to mean ordinary respect and kindness that you would expect doctors and other health workers to show any patient with any illness and not the specialist support for psychological problems, although a few members mention counselling as being helpful.

Instead people with ME/CFS have experienced *'aggression and rough treatment', 'incompetence and cruelty'* or found NHS staff to be *'undermining and neglectful'.* A number of members mentioned being laughed at or made to feel stupid.

Helpful

> *'My new GP...asked how it affected me - first time I've ever been asked.'*

Unhelpful

> *'Being laughed at, somewhat mocked and belittled when I asked for a blood test for thyroid (as advised by disability claims doctor).'* (Indeed this is one of the recommended elimination tests).
>
> *'GP (said): "Ah, another case of Correction Fatigue Syndrome". (I was a school teacher at the time).'* (Implying that she was just tired with doing marking).

Practical Support

Most people who are ill with ME/CFS need practical support to enable them to function in their daily lives - from wheelchairs and parking badges to help in the house, and also help with filling in forms for benefits, as brain work is often very difficult for people with ME/CFS. 18% said practical support was the thing that was most helpful and 7% of respondents mentioned lack of practical support as the least helpful.

Helpful

> *'OCCMET helped with DLA forms.'*
>
> *'GP attended meeting with my son's school and also wrote letter of support when the school threatened legal action. ''Writing a letter to the school to say I couldn't manage such long lessons at home, and recommending suitable education.'*

Unhelpful

> *'GP refused (*help getting the blue parking badge) - *said I could walk short distances.'*
>
> *'No domiciliary help. (I'm bed-bound).'*

Referrals

Often the treatment of a patient is dependent upon the health professional writing a letter of explanation or to refer. 11% said this was the most helpful thing that anyone had done or said. However 9% of the respondents mentioned health professionals refusing to refer to appropriate services as most unhelpful. It is hard to understand why these types of support should be refused, especially where one of the refusals was to the specialist Community CFS/ME service.

Helpful

> *'GP wrote letter of referral after I asked (NOT offered by GP).'*

Unhelpful

> *'...even refused OCCMET referral.'*
>
> *'...denying palliative care.'*

Advice

Over a quarter of the respondents (27%) mentioned bad advice as the most unhelpful thing. In many cases they felt that following this advice, particularly to push themselves doing excessive exercise, led to a permanent worsening of their health. Other advice given is not what would be expected for any other illness, and ranges from being irrelevant to insulting. Helpful advice is mentioned by only 16%.

Helpful

> *'Advice...on how to cope, pacing, living in the moment and not looking too far ahead.'*

Unhelpful

> *'Locum (*doctor) *told me to get off arse and get some exercise.'*
>
> *'Consultant Professor X said I should try stacking shelves at Tesco's.'*
>
> *'That I should go on a coach tour round Europe, and that I would be OK when I had grandchildren.' - JRH consultant.*

Waiting Times

Four members (7%) mentioned long waiting times for treatment as being the most unhelpful thing. No-one mentioned waiting times as being helpful. This does not mean that most patients did not have to wait for treatment, rather that given all the other unhelpful things, most were grateful to get any real help at all whenever or *if* ever it came. Members also commented on how much they had to wait and push to get any help at all. This has been included in the final category.

Unhelpful

> *'Waited 18 months for CBT, but was not accepted until I agreed to go for physio which made me much worse.'*

Treatments and Medications

The helpfulness of different services (which offer different treatments) was discussed in question **Q6**. Nevertheless, 20% of members specifically mentioned treatments that were helpful or unhelpful.

Helpful

> OCCMET treatment: three members (plus two members mentioning helpful advice from them), Mindfulness meditation: 2, CBT: 2, physiotherapy: 2, sleeping pills: 2; and with one member each mentioning an anti-depressant and alternative treatments to help with relaxation and pain.

Unhelpful

> There are many comments about the unhelpfulness of graded exercise (5 members) and forced exercise (3 members) (total 8 = 14%). Two members mentioned CBT, and a number said that they thought these therapies were not suitable. A few members also mentioned the irrelevance of antidepressants, with one claiming this had caused inappropriate behaviour leading to a worsening in health.
>
> *'The activity-graded exercise did not work. Most in the NHS tried to increase activity too quickly.'*
>
> *'When first diagnosed I was told I was depressed. Because of this I took antidepressants and pushed myself physically. This was inappropriate and put back my recovery. I only started to make progress when I got in touch with other OMEGA members.'*

Information

Patients look to health professionals for information about their condition. In this case we find some patients being given wrong information, or no information at all.

Helpful

> *'Information on pacing - no boom or bust. ''A locum GP admitted she knew nothing about ME. At least she was honest.'*

Unhelpful

> (Doctor said) *'When I go for a run, I get tired and that's a good thing. You need a forced exercise regime.'*
>
> *'They did blood tests, but they did not tell me what they were testing for and what the results were.'*

Quality of Help

When asked for other comments about their experience with the health services, only two members gave positive comments (one about OCCMET, the other about the CFS/CBT service); while over half gave totally negative comments. The others either did not answer the question, gave both positive and negative comments or gave other comments.

Unhelpful

> *'NHS seems to have very little to help me.'*
>
> *'Very little compassion or advice given.'*
>
> *'Inadequately informed GPs.'*
>
> *'They simply do not recognise how unwell people are.'*

Other Comments

> *'GPs vary enormously in quality.'*
>
> *'There needs to be a quicker referral system between GPs and being seen by a specialist.'*
>
> *'Services for ME/CFS have to be available locally or at home. Hospital based services for patients are impossible on a regular basis.'*

Access to Help

Comments often mentioned how difficult patient's experience of getting help was, although two members mentioned that things were improving slowly in the NHS.

Unhelpful

> *'I am left to work it out for myself, suffer and fight for the things I do need.'*
>
> *'Having to constantly push to get any help or advice.'*
>
> (At hospital consultant) *'No mention of OCCMET.'*

4 Conclusions from Q7 Responses

Over half of respondents found their overall experience of the NHS treatment for ME/CFS to be negative. There are many examples of lack of help and support, with many people experiencing negative attitudes and lack of respect by some medical professionals. There are also some examples of good practice, although only two members (4%) found it to be positive overall.

For 50% of the members, diagnosis was carried out by their GP. In about half of these cases the diagnosis was confirmed by a consultant or other party. Comments in the **Appendix** reveal that in some cases there is a long time interval between becoming ill and receiving a diagnosis. We have no information (except for OCCMET) on what diagnostic criteria were used, or the reliability of any diagnosis.

Among the treatments (or clinical management protocols) only those provided by the GP, by OCCMET and Mindfulness Meditation were reported as helpful, i.e. had any significant positive effect. Treatment by the Infectious Diseases Chronic Fatigue Service had a significant negative effect (reported as unhelpful or very unhelpful), while CBT and other treatments had no significant effect. These findings are similar to those of the ME Association 2010 survey of 4217 people with ME/CFS [3].

Only about a quarter of GPs in the current Oxfordshire survey were rated as positively helpful. The comments in the **Appendix** show that many GPs and other health professionals have little understanding of ME/CFS and some still seem to not recognize that it is a real, serious illness. Other comments in the **Appendix** show that this is also the case for some consultants, even those to whom patients are referred as experts in the diagnosis and clinical management of this illness.

5 Discussion

This report highlights some shocking findings about the experiences of people with ME/CFS in Oxfordshire. ME/CFS is a serious and troubling condition, with many symptoms. The National Institute for Clinical Health and Excellence (NICE) stated in 2007 that: 'The physical symptoms can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions.' [4]

The Sample: We may ask – how typical of ME/CFS patients is this sample? Most patients in this local sample had been ill for between 5 and 30 years whereas 36% in the national MEA survey had been ill for less than five years, yet the results of this survey are comparable with theirs. The 25% M.E. Group [11] has shown that a quarter of patients are severely affected, often for a long period. Several research studies on the prognosis of ME/CFS have been published and find that ME/CFS often becomes a chronic and very disabling illness with complete recovery occurring only in a small minority of cases [12].

Role of Doctors: Patients turn to medical professionals for help to manage this difficult condition, but many of them instead have had to cope with disbelief and humiliation. Some members felt trying to get help from the NHS was 'a *waste of time and energy'.* Patients with ME/CFS need and deserve the same respect as other patients. Patients have the right to be treated with dignity - whatever their medical condition. The uninformed, negative or hostile attitude that many people with ME/CFS have experienced is not only extremely stressful and detrimental to their health and well-being, but it also can put them off seeking treatment that might be able to help. This includes treatment for particular symptoms such as pain, sleep disorder, digestive problems, and muscle cramp.

One effect of this may be that many patients seem to have low expectations of their GPs or other professionals, and are not getting good advice for managing this illness, nor treatment for some of the more treatable symptoms. Part of the problem is that many GPs lack information about ME/CFS and how to treat it, which GPs themselves have identified as a difficulty (in the recent LINk-funded survey of Oxfordshire GPs [1] the vast majority (93%) recognise CFS/ME as a clinical entity, and three-quarters (74%) call for more information to be provided and said there is a need to clarify and improve the guidance to GPs and improve awareness of CFS/ME services).

The Experiences of Patients: The findings reported here are in line with the findings from the ME Association 2010 survey of 4217 people with ME/CFS [3], which found that Pacing (71%) and Meditation/Relaxation Techniques (54%) were the two therapies which produced the greatest improvement. 26% of their sample found CBT gave improvement and 22% for Graded Exercise (although Graded Exercise was also the treatment which made 57% *worse*). Those findings are supported by this survey where Graded Exercise also was the least helpful thing for a number of the respondents, and not mentioned as helpful by anyone.

People who have a long-term and little-understood illness naturally tend to join patient groups and gain the well-attested advantages of support and advice about coping with such an illness. Patients in this sample may have been ill for longer than the average, but they are not getting needed support from the NHS at present. The survey allowed people to include experiences from the entire time that they have been ill, and more research is needed to ascertain whether this type of treatment is still common. Although there were a couple of comments that things had improved slightly in recent years, we still find that the person who had been ill for the shortest time (3 1/2 years) was still told that *'The disease is all in the mind. The more you do, the better you will be.'* This is an example of wrong information and advice, contradicted by research. This is just one example of anecdotal evidence from our members that there are still health professionals in Oxfordshire who are exhibiting prejudiced behaviour. The information and advice are wrong, and contradicted by research.

These reports of pejorative comments are unacceptable and shocking. It should hardly be necessary to point this out, especially in the context of the Francis Report [17] and the current emphasis on patient based services.

Recent Research and Guidelines: There is clearly a lack of knowledge by clinicians of results of recent research into ME/CFS. The two recent international guidelines [6,13] contain much useful scientific information and more than 150 references. Recent work (co-authored by an OMEGA member) [14-16] shows that patients diagnosed with ME/CFS have mitochondrial dysfunction and most of these also have abnormal tissue damage. This offers a very likely explanation for the post-exertional malaise which is a feature of ME/CFS, and the damage caused by over-exertion for the moderately to severely ill patients.

6 Recommendations R1-R7

R1 Training

There is an urgent need for training for GPs and other health professionals – GPs want this too (see above).

We recommend that all GPs be given one of the two primers recently published by international teams of scientists and scientist-practitioners (both available electronically) [6,13].[1] 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, as well as exclusion tests, diagnostic criteria and the particular symptoms which patients with ME/CFS may have which GPs can help with.

Health professionals, including consultants, GPs and therapists need to take account of the patients' experience. It needs to form a key strand in teaching for medical students and for any relevant therapists, and also to be included in the continuing professional development of any health professional, especially those who deal with people with ME/CFS on a regular basis. This should include evidence from case studies, DVDs [18] and printed materials [19] from the patients' point of view.

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

These patient comments show that there are positive ways in which the GP, consultant or other health professional can help the ME/CFS patient. First, the patient must be listened to carefully and believed. Helpful questions include how the illness affects the patient’s life. Then a timely and accurate diagnosis can be made, using the most up-to-date, internationally recognised guidelines [6,13]. This is what basic medical care should be, yet too often people with ME/CFS do not receive this.

R3 Practical support

This survey shows that writing letters and helping access practical support is one of the most helpful things GPs can do. (Despite the evidence that some GPs feel that they cannot do anything for their ME/CFS patients [1].)

We would encourage all 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. One of the reasons that respondents in this sample had been ill so long was that it usually takes a long time for patients to discover OMEGA.

People with ME/CFS need practical support, many need help with Activities of Daily Living (ADLs), including help in the home, help with aids, and with obtaining all the benefits they are entitled to. This leads to increased independence and improved ability to do things and cope and have a better quality of life. (Such help does not, as some fear, lead to dependency and reduced ability.)

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[1] Hard copy of IACFS/ME Primer sent to all GP Surgeries by LINk in January 2013.

R4 Referrals & letters

It should go without saying, but the survey indicates that it needs to be emphasised, that patients need to be referred to the appropriate service. We are concerned that some GPs still do not refer to OCCMET. GPs need to be aware of OCCMET, and encouraged to refer patients there [1]. We are also concerned to learn from the survey that people who attend the JRH are not told about or referred to OCCMET. There seem to be very few if any referrals and this should be remedied.

R5 Treatments offered and Advice and Information

A The ID service: Very few respondents found it helpful. Referral to other services from ID was the main thing mentioned specifically as helpful. The ID service provides inadequate advice and relies too heavily on CBT and GET. Pejorative comments to patients, as reported in the **Appendix**, are unacceptable. It should hardly need stating (post Francis Report) that staff should believe what patients tell them about their symptoms and experience of the illness. Careful diagnosis and individually tailored and monitored programmes are needed. The service should be evaluated regularly using patient feedback, in particular focusing on accuracy of information, helpfulness of advice and treatment and supportiveness of staff. (These aspects are not covered by the NOD reporting system [8].)

B Mindfulness Meditation: This therapy is not a cure for ME/CFS, but can be very helpful in helping people manage this serious condition, and allow them to have a better quality of life. Meditation courses should be provided without needing to go via psychiatric services. (Also CBT should be available without having to go through Meditation classes, especially where patients already have meditation experience). These should be accessible e.g. in local area clinics. Duration of classes should be flexible (not too long at a time), so that more than the mildly ill can take part. Consideration should be given to teaching relaxation/meditation techniques in other ways to be accessible to the severely ill - e.g. through CDs/ Skype/phone etc. OMEGA has experience in this area and could advise.

C The OCCMET service: **The OCCMET 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, with examples in this survey of children being threatened with being sectioned or with legal action from the school.

We are pleased to see that none of the insulting comments to patients were reported from OCCMET staff. OCCMET needs to continue to take into account patient feedback, so that its service can continue to improve and thereby increase the number of patients finding it helpful.

R6 Easy access to help

Finally the NHS needs to make it easy for people with ME/CFS to access help. One of the key features of this illness is profound exhaustion, yet trying to get help is often an exhausting process in itself, with obstacles thrown in the way. Some people have mentioned that doctors *'aren't interested'*, and many have commented on the struggle to get any help at all.

The hospital-based services are not accessible to more severely affected patients. Therefore it is of paramount importance that hospital-based services are as supportive as possible, that clinics should be easily accessible, and that community teams have sufficient staff and appropriate skills base.

R7 Monitoring and Feed-back

These changes should be implemented, and the results monitored, to ensure that patients are no longer treated in patronising and damaging ways, and that they can receive the help they need. In collecting information from patients, it is important to do so anonymously. 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.

7 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

[2]. *Second Survey of ME/CFS Patients in Oxfordshire*, OMEGA, November 2002.

[3]. *Managing my ME – What people with ME/CFS and their carers want from the UK's health and social services*, ME Association 2010, http://www.meassociation.org.uk/?page_id=1345

[4]. NICE Guidelines 2007, http://www.nice.org.uk

[5]. *The Chief Medical Officer's Working Group Report on CFS/M.E.*, 2002, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4064840

[6]. *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

[7]. White PD, Goldsmith KA, Johnson AL, Potts L, Walwyn R, DeCesare JC, Baber HL, Burgess M, Clark LV, Cox DL, Bavinton J, Angus BJ, Murphy G, Murphy M, O'Dowd H, Wilks D, McCrone P, Chalder T and Sharpe M. *Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial*. Lancet 2011; 377: 823-836.

[8]. National Outcomes Database (NOD) www.bacme.info/nod/

[9]. Sharpe M, Hawton K, Simkin S, Surawy C, Hackmann A, Klimes I, Peto T, Warrell D and Seagroatt V. *Cognitive behaviour therapy for the chronic fatigue syndrome: a randomised controlled trial*. BMJ 1996; 312: 22-26. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2349693/

[10]. Fulcher KY and White PD. *Randomised controlled trial of graded exercise in patients with the chronic fatigue syndrome*. BMJ 1997; 314: 1647-1652. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2126868/

[11]. 25% M.E. Group, http://www.25megroup.org/

[12]. Shepherd C and Chaudhuri A. *ME/CFS/PVFS An exploration of the key clinical issues*. http://www.meassociation.org.uk/?page_id=1666meassociation.org

[13]. “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

[14]. Myhill S, Booth NE and McLaren-Howard J. *Chronic fatigue syndrome and mitochondrial dysfunction*. Int J Clin Exp Med 2009; 2: 1-16. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2680051/

[15]. Booth NE, Myhill S and McLaren-Howard J. *Mitochondrial dysfunction and the pathophysiology of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)*. Int J Clin Exp Med 2012; 5: 208-220. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3403556/

[16]. Myhill S, Booth NE and McLaren-Howard J. *Targeting mitochondrial dysfunction in the treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) - a clinical audit*. Int J Clin Exp Med. 2013; 6: 1-15. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3515971/

[17]. *Final Report of The Independent Inquiry Into Care Provided By Mid Staffordshire NHS Foundation Trust*, http://www.midstaffsinquiry.com/pressrelease.html

[18]. *Voices from The Shadows* – DVD about severe ME, http://voicesfromtheshadowsfilm.co.uk

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

8 Appendix

Q7. Members of OMEGA were asked regarding their ME/CFS:

A. **What was the <u>most helpful</u> thing anyone in the NHS said or did?**
B. **What was <u>NOT helpful</u> that anyone said or did?**
C. **Briefly outline anything else you'd like to say about your experience of the NHS.**

Replies: (in order of decreasing length of illness)

Member # 27 – ill 55 years

A. Too much to write down here or to think about.
B. That there was nothing wrong with my health.
C. Very poor, but improving.

Member # 74 – ill for 53 years

A. Wrote report that gave me early retirement benefits from my occupation.

Member # 72 – ill for 32 years

A. "Do one thing on a bad day and do less than you think you can do on a good day." – GP
B. That I should go on a coach tour around Europe, and that I would be OK when I had grandchildren – JRH consultant
C. GPs don't seem to have much knowledge about ME/CFS, and some other health care practitioners don't know much.

Member #22 – ill 31 years

A. It would take too long. Perhaps I will write an article for the Newsletter when I feel better.

Member # 6 – ill 30 years

A. A locum GP admitted she knew nothing about ME, etc. At least she was honest. Mostly it is ignored.
B. You must be depressed. You look alright.
C. I am a nurse, so luckily know my way around the system. Otherwise I would have to say there is very little compassion or advice given.

Member # 39 – ill 30 years

A. Advised me to continue alternative treatments that help relaxation and pain: Alexander technique, acupuncture, reflexology, massage and chiropractic for back problem.
B. Female Dr telling me it wasn't ME; it was hormonal and suggested HRT.
C. Inadequate blood testing in the beginning. I have benefitted from private blood tests. Sadly, my private Dr has emigrated.

Member # 34 – ill 27 years

A. That I had a great quality of life – if not quantity of things in my life.
B. "Try not to be a perfectionist."
C. Had to go through 'listening ear; talking point' (irrelevant) and sent off Mindfulness group as I already had 13 years meditation group experience. Had good CBT with Barnes unit consultant psychologist, but perseverance needed – took months.

Member # 38 – ill 27 years

A. A small daily dose of the antidepressant Mirtazapine seems to keep me on an even keel.
B. My very supportive GP referred me to the eminent Oxford psychiatrist who specializes in ME. I filled out a question and answer paper for him. He looked at it and said, "Your

condition is not serious enough to interest me." No one else was present, otherwise, as a journalist I would have been sorely tempted to quote him.

Member # 64 – ill for 27 years

A. Counselling support
B. Can't think, sorry.

Member # 18 – ill 26 years but only diagnosed 12 years ago

A. Nothing! Very little, if any, help offered – even refused OCCMET referral. I was also lied to by specialist.
B. Having to constantly push to get any help or advice. Referrals not made or refused with no reason. Supposed JRH specialist knew little, lied and I'm still waiting to hear back about blood tests 10 months ago.
C. The NHS does NOT treat or advise on ME! I am left to work it out myself, suffer and fight for things I do need. And, as Social Services require professional evidence, I'm stuck and getting worse. I've been appalled and disgusted by my treatment and lack of!

Member # 25 – ill 26 years

A. Consultant's advice re meditation (ca. 1990)
B. Locum told me to get off arse and get some exercise. This set the seal on my never recovering I think, as I went walking up mountains in Italy (ca. 1988)
C. Research groups locally are blatantly "Jobs for the Boys." They are quite transparent about it I approached my MP who was immensely sympathetic, but the "Boys" are still there wasting £millions.

Member # 3 – ill 25 years

A. GP wrote letter of referral after I asked (NOT offered by GP).
B. Unwilling to offer anything outside of CBT & GET other than antidepressants (inappropriate ways of dealing with ME)
C. Most NHS staff seem unwilling to understand the awfulness of ME, e.g. the pain (chronic and severe much of the time), the lack of energy (which impedes even the basics of living/life), and the need for massage and appropriate exercise.

Member # 5- ill 25 years

A. Initial referral to JRH – many tests, examinations, etc. GP referral to a counsellor who obtained blue disablement benefits.
B. GP refused the above – said I could walk short distances.
C. After initial investigations, told nothing else could be done, but go back if get worse. No further help.

Member # 42 – ill 25 years

A. The consultant who told me I had ME after 9 years of it.
B. I could get better if I wanted to. ME did not exist – it was a Mickey Mouse condition (20 years ago).
C. I am 81 now. GPs in the past have been very helpful. One consultant was most rude and unhelpful (20 years ago). One consultant was very helpful 15 years ago.

Member # 68 – ill for 25 years

A. My new GP (of 2 months) said he had a number of ME patients, some of whom didn't even realise they had ME. Asked how it affected me – first time I've ever been asked.
B. Infectious Diseases laughed at me. GP of 20 years ago: "Well of course there's nothing I can do!" GP of 15 years ago would never use the term ME or anything else.

C. I got ill in the early days when the NHS knew nothing. They're learning slowly. The physio at OCCMET was brilliant; the OCCMET GP very kind, but tired me out with long session.

Member # 10 ill-24 years

A. Diagnosis
B. Offer CBT

Member # 54 – ill for 24 years

A. I'm afraid I haven't the energy to respond adequately to these – I don't know where to begin

Member # 71 – ill for 24 years, but 99% recovered

A. "I don't mind trying anything so long as I don't think it is potentially harmful."
B. "I think your depression may be at the root of your symptoms." (i.e. total misunderstanding of cause & effect)

Member # 11 – ill 23 years

A. Advice from part-time Dr after being diagnosed, on how to cope, pacing, living in the moment & not looking too far ahead. Was very grateful for this initial advice.
B. Being laughed at, somewhat mocked and belittled when I asked for a blood test for thyroid (as advised by disability claims Dr) and disbelieved when in stress with severe breathing difficulties. Was given no help at all.
C. Later, after that home visit my daughter (a Dr) met this GP at a medical meeting, and he admitted that he had not handled things well for me. I was very upset & distressed and changed practices.

Member # 21 – ill 22 years

A. Defending me when another Dr wanted to section me! Supporting benefits & Social Services appeals. Writing a letter to the school saying I couldn't manage such long lessons at home and recommending suitable education.
B. "If you don't go into hospital your Mum will have a breakdown." "There's nothing physically wrong." "If you've had glandular fever it can't be ME." "It's deconditioning." "Now you've come into school, you can come for longer next time."

Member # 46 – ill 21 years

A. "I'm sorry; we don't know more about this condition."
B. "Look at you – you are in a wheelchair." This was when I was well enough, after 5 years, to be out of the house for 2 hours to get taken to the JRH to see a consultant – deeply insulting.
C. GP as helpful as she can be. Has tried things and referred me on my request. Hospital consultant patronising, did not take seriously how ill I was.

Member # 56 – ill for 21 years

A. A previous GP said "You just have to learn to live with your disability. Don't stop trying to do things because you're applying for DLA."
B. Being told by consultant not to lie down. "What has she been reading now?" was the reaction from him when I told him that my mother wondered if I had allergies (there are allergies in the family).

Member # 70 – ill for 21 years

A. Said "pace yourself"
B.

C. I am in my mid 80's and say 70% recovered. In our present state of ignorance about the disease I don't think the NHS can do more for me.

Member # 7 – ill 20 years

A. Ms X at OCCMET assisted filling in the DLA forms

Member # 29 – ill 20 years

A.
B. Consultant Professor X said I should try stacking shelves at Tesco's.
C. When first diagnosed I was told I was depressed. Because of this I took antidepressants and pushed myself physically. This was inappropriate and put back my recovery. I only started to make progress when I got in touch with other OMEGA members.

Member # 33 – ill 20 years

A. Acknowledge that CBT/Mindfulness has altered since first delivered about 20 years ago. Also, continued to see me for long time.
B.
C. It is basically limited to Mindfulness/CBT.

Member # 49 – ill for 15-20 years (had glandular fever when 17 years old)

A. That as of Nov 2011 finally got official diagnosis of ME by OCCMET GP.

Member # 65 – ill for 19 years

A.
B. Put pressure on me to attend outpatient dept when I knew I had hypertension
C. Inadequately informed GPs, no domiciliary help (I'm bed-bound)

Member # 51 – ill for 18 years

Member # 52 – ill for 18 years

A.
B. Graded exercise.
C. Useless, don't listen, positively damaging. Lack of integrated approach to physical & mental health.

Member # 66 – ill for 18 years

A. Initially, information on pacing – no boom and bust
B. "There is nothing biologically or clinically wrong with you." – NHS clinical psychologist
C. Poor – waste of time and energy - generally not believed. They have little to offer.

Member # 31 – ill 17 years

A. Confirmation that I had ME – reassurance
B. First consultant (a psychiatrist now long retired) said: "You must walk every day regardless of how you feel"
C. JRH CFS/CBT service was helpful to me as it gave me a sense of reassurance and support and confirmation re illness.

Member # 35 – ill 16 years

A. Prescribe sleeping pills.
B. "You need to get back on your bike." – in 1996
C. GPs vary enormously in quality.

Member # 28 – ill 15 years

A. OCCMET – therapy
B. Five GPs before the diagnosis and three afterwards – undermining and neglectful.
C. One of five physiotherapists very knowledgeable about ME. Also, excellent dentist from Oxford Brookes.

Member # 48 – ill for 14 years (1994-2008) but now recovered

A. Working with CBT and Mindfulness meditation helped me to be more present in the moment and over-ride any negative thinking and emotions.
B. The activity-graded exercise did not work. Most in the NHS tried to increase activity too quickly.
C. My experience with NHS was just part of my recovery path. I have mainly worked with healing (plus some other therapies) to work on every aspect of myself – physically, emotionally, mentally & spiritually. I firmly believe in a holistic approach.

Member # 60 – ill for 14 years

A. Referral to have nerve tests.
B. "There is a problem, but don't know what it is."
C. Hospital consultant made light of my problem with nerve pain.

Member # 69 – ill for 14 years

A.
B. Gerontologist didn't understand ME & I found him condescending
C. I now realise that I could try to approach my GP for referral to JRH again as there must be a different clinic.

Member # 9 –ill 13 years

A. "Take everything like a grain of sand. You have time on your side."
B. Would not acknowledge that my symptoms related to ME
C. The lack of knowledge between ME, CFS – in fact all of it.

Member # 41 – ill 13 years

A. Recently – sympathy, warmth & help from our District Nurse. So helpful & boosted my confidence.
B. Consultant Professor's advice (12 years ago): "Try not to mind being ill and in pain." Aggression and rough treatment at Horton Hospital.
C. Waited 18 months for CBT, but was not accepted until I agreed to go for physio which made me much worse (in 2000).

Member # 59 – ill for 13 years

A. Nothing helpful from NHS.
B. "When I go for a run, I get tired and that's a good thing. You need a forced exercise regime."
C. I don't anticipate finding the depth of my disgust for the incompetence and cruelty of the NHS's approach to treating ME, and denying adequate palliative care.

Member # 37 – ill 12 years

A. Referral to JRH.
B.

Member # 40 – ill 12 years

A. Physiotherapy, and consultant Professor wrote a nice letter.
B. Consultant Professor touched a nerve and made me feel inadequate about my academic qualifications. At CBT I was told that my symptoms were part of normal health. Also, at CBT

they kept messing around with my work times while failing to address my physical health problems.
C. Poor – they simply do not recognise how unwell people are.

Member # 57 – ill for 12 years

A. Support from my GP in finally diagnosing me with ME.
B. I kept being dismissed by previous GPs which was very frustrating.
C. There needs to be a quicker referral system between GPs and being seen by a specialist.

Member # 2 – ill 11 years

A. Referral to PACE trial. I got my illness confirmed by one of their team
B. GET! and CBT!
C. GET no help

Member # 47 – ill 11 years

A. Telling me I had a physical illness and it was real (consultant) – tropical medicine offered CBT and Mindfulness.
B. That I needed to see a psychiatrist, it was a neural disorder (GP locum), and after I was diagnosed too!
C. Took me 6 years to be diagnosed – nobody much help until then. I was retired so nobody had to sign me off sick – so my condition could be safely ignored.

Member # 12 – ill 9 years

A. CBT referral by JRH to Ms Y
B. GP (Dr Z): "Ah, another case of Correction Fatigue Syndrome" – (I was a schoolteacher at the time).
C. I'm on patient engagement exercises by OUHT

Member # 16 – ill 8 years

A. Mindfulness Meditation course
B. CBT
C. Very little understanding of ME.

Member # 30 – ill 8 years

A. Believed me from start.
B.
C. Diagnosed moderate to severe.

Member # 36 – ill 8 years

A. Consultation with OCCMET Dr and her letter to my GP confirming ME.
B. Assumption that GET or Pacing could bring about an improvement.
C. My GP was not interested in diagnosing cause of my extreme fatigue other than a thyroid test. I had to keep coming back to the surgery to push for a referral – little has changed over the last 8 years.

Member # 44 – ill 8 years

A. Referrals, letters & reports written.
B. "Why don't you cycle here next time?" (12 miles round trip to JRH). "Going around in circles – I haven't got time for this". "You are not my patient, Dr XX's." "Do more driving."
C. Took two years to be diagnosed, and a further 18 months to receive written diagnosis.

Member # 53 – ill for 7 years

A. Write letters to me & let me take notes as had to use these because of brain fog. Listened to me.
B. That lying down all the time may lead to muscle problems when this is what I had to do for all of the day.
C. That when I am asked “Can you do ...?” I have to think can I do that most of the time but I know that others do not do this and need to.

Member # 43 – ill 6 years

A. Advice from OCCMET.
B. Only offer from hospital consultant was CBT. As a psychologist, I felt this totally inappropriate. The alternative was to see him again which was even worse! No mention of OCCMET.
C. Services for ME/CFS have to be available locally or at home. Hospital based services for patients are impossible on a regular basis.

Member # 58 – ill for 6 years

A. Being diagnosed at breast clinic with costochondritis which started at same time as ME/CFS.
B. Advice from consultant neurologist to stop worrying as I only had CFS, & if I played a little badminton each day I would soon be better!
C. NHS does not seem to have anything to help me. Treatment by consultants is disrespectful and simplistic in the extreme. “Go away, relax & enjoy yourself & you will soon feel better”!!!

Member # 67 – ill for 5 years

A. OCCMET advice and writing letter to my employer.
B.
C. I strongly support the work of OCCMET – incredibly important to keep this (service) & improve scope if possible to help more people.

Member # 19 – ill 3 1/2 years

A. Refer for tests for symptoms to rule out other diseases
B. “The disease is all in the mind. The more you do, the better you will be.”
C. The specialists told me what I knew already. They did blood tests but they did not tell me what they were testing for and what the results were. Referred me to a psychologist to do more activity. No other advice.

Member # 61 – ill for 6 years (since age 11 – questions answered by his mother)

A. GP attended meeting with my son’s school, and also wrote a letter of support when school threatened legal action.
B. Consultant Professor saying that if my son would just do more, he’d feel better, and that he needed to get away from his Mother more!!
C. Grateful for a quick diagnosis (within 6 months of my son falling ill), and encouragement from 4 different paediatricians over the 6 years. It was unhelpful to have all the changes of paediatricians as had to restart with each one. Sorry we weren’t able to get a referral to OCCMET as might have been helpful.
D. Just to say, my son is now back in school full time (3A levels) – doing really well, probably at 90% recovery now. Got there through careful pacing over the years.