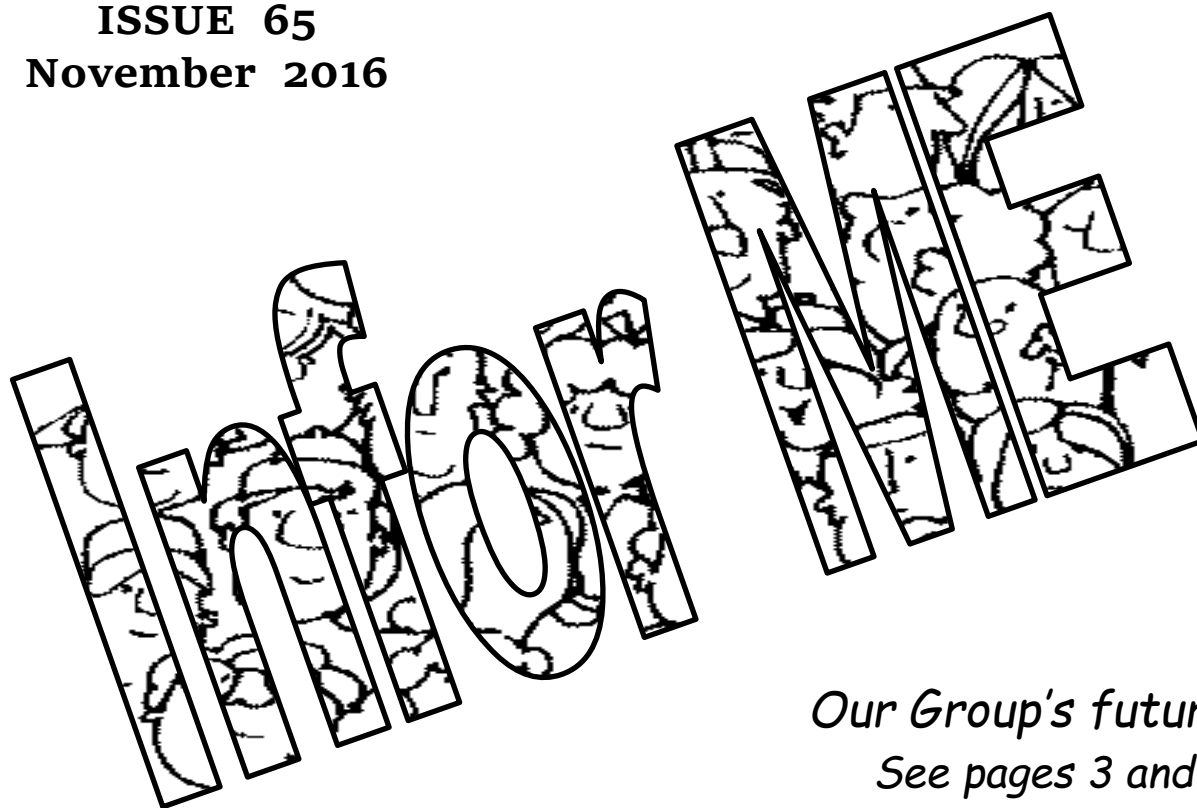


**WORCESTERSHIRE  
M.E. SUPPORT  
GROUP**

**ISSUE 65  
November 2016**



*Our Group's future  
See pages 3 and 4*

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## Worcestershire M.E. Support Group Informal Meetings

### Informal monthly meetings

If you have ME, CFS, PVFS or FMS, or you are a carer, relative or friend of someone who does, you are welcome to join us at any of our group meetings. Children are always welcome, under 18's to be accompanied by an adult.

Worcestershire M.E. Support Group currently has informal monthly meetings in Droitwich, Malvern & Worcester.

Dates and times - see page 22 of this newsletter, and our website - <http://worcsmegroup.weebly.com/meetings.html> . Please check with the area contact in case the meeting has had to be cancelled for any reason.

**Droitwich** - Methodist Church, Amphlett House, Worcester Road, Droitwich, WR9 8AW  
On the first Friday of each month - 1.30-2.30pm

**Worcester** - Wyevale Garden Centre, (previously Blooms Garden Centre), Droitwich Road (A38), Worcester, WR3 7SW. We will meet in the restaurant and there will be a notice on our table so that you can see where we are.  
On the second Wednesday of each month - 2-3pm

**Malvern** - The Malvern Cube, Albert Road North, Malvern, WR14 2YF  
On the second Thursday of each month - 2-3pm

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### Stourport Monday Night Group

Last year, the Stourport Monday Night Group celebrated 50 years of pantomime. They gave a donation to 90 groups - including us.

The Monday Night Group donates all their profits to local causes in the Wyre Forest area, Worcestershire - our group has received thousands of pounds over the years.

Please thank the Monday Night Group by telling your friends.

'Puss in Boots' Monday Night Group pantomime - 27 January to 4 February 2017, at the Civic Theatre Hall, Stourport.

Tickets are now available - Book online <http://mondaynightgroup.org/tickets/>, by post with the downloadable booking form, or phone 07593 175776.

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### DISCLAIMER

The committee and Worcestershire M.E. Support Group do not endorse or recommend any particular treatment, therapy or practitioner. Practitioners and treatments mentioned are for information only. Any treatment, tests or remedies mentioned may be tried at your own risk, but preferably after consultation with your GP. Views and opinions expressed in this newsletter, in any other circular, or given verbally, are not necessarily those of the editor, the Worcestershire M.E. Support Group, its members, or the contributors. The accuracy of any information given is not guaranteed. Worcestershire M.E. Support Group is not associated with any companies with a similar name.

Soon after our Annual General Meeting, we were pleased to announce on our website -

## Thank you - our group continues

### Our group is viable, and continues - but there may be some changes in the future.

Thanks to the publicity received from the ME Association, Action for ME, the Worcestershire local press, and everyone who forwarded our pleas for help - a few volunteers came forward at our AGM last Friday, 23 September. But, we still need more people to run the informal groups throughout the county.

Current informal meetings in Droitwich, Worcester and Malvern, will run until the end of 2016. There may be changes in 2017, so check this website. Lunches will continue - check for dates and venues. If you want informal meetings in all areas of the county - help is needed at the meetings, and we need more people to attend them. If you are able to help the group in any way, please contact email me or phone 01886 888419. Please leave your number if I am not available - many thanks.

Ian Logan (09.2016)

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## Chairman's Letter

Dear All,

### Our Group's Future

These are my thoughts and considerations of what must now happen with our ME Support Group. Regretfully, it will have to change from its present form, as we can no longer continue under our present constitution and group's aims. This is because we do not have enough people able to run the group and fill the official posts required by our constitution. We also do not have enough people to run meetings, produce a newsletter, answer emails, etc., or act as a back-up support when others are away or unwell.

For the last few years we have managed with diminishing numbers of both helpers and officials. Also the number of members and contacts has reduced. I think that this has been declining as other forms of support / information have become available via the web, emails, etc.

At the AGM things started to look better with three people volunteering to take up the necessary posts required to run the group, but as individuals were not able to continue due to health and energy levels and unforeseen family commitments, and so have had to step down. I thank them for their commitment to try and keep our group going when they themselves were unwell / carers. I also wish to thank all those who have helped the group, past and present, including members and those who wrote or telephoned their best wishes and thanks to our group, but felt too unwell to be able to help.

So what of the group's future?

The remaining committee intend that there needs to be an E.G.M to formally close the group in its present form under the group's constitution. This would leave the way clear for a 'new' group to start up in any form and without 'old' constraints. This 'new' group's form is for a future discussion and not intended to be part of this letter. However, those currently involved with our group would wish for a continuation in some form to still be available to ME/CFS/FM sufferers and carers.

The E.G.M. Agenda will have to include -  
Decision to discontinue the Worcestershire ME Support Group's use of the existing constitution, completely (or in part).  
The distribution of the group's current funds.  
Cancellation of insurance.  
Discharge the committee and officers.

My personal thoughts are that we are still wanted by those who wish for personal contact and talk with others directly and those needing information and confirmation of, for example, symptoms and emotions. This is dependent on their being able to attend meetings.

The next best thing, in my opinion, is to be able to telephone and discuss problems directly. This has also the benefit of being anonymous, if wanted. These contacts could continue without having the burden of an 'office structure'. The website could also be passed on to the 'new group', but that is for others to decide. The reduction of our group over the years is also seen in other support groups, who rely on volunteers. It is not just ME groups that are affected. So we should not blame ourselves for the downturn.

I wish you all improving health and happiness  
Ian Logan, Chairman (07.11.2016)

**Please join us**  
**EXTRAORDINARY GENERAL MEETING**

to formally close the group in its present form under the group's constitution

**Monday, 5th December**  
from 2.00 pm to 4.00 pm,

in the Community Room, at Waitrose in Worcester  
223 London Road, WR5 2JG

(sign-in with your car registration number at their Welcome Desk,  
so your parking doesn't go over the 2 hour limit)

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**Group Membership Subscriptions**

Membership will be extended until the group ceases,  
for people who were members last year.

If you have recently joined,  
or renewed your membership for the year beginning 1 October 2016,  
the subscription will be returned to you,

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**Thank you**

On the previous page is our group's official letter, explaining the situation, which is being placed on our website, and is available for circulation.

I would like to add -

This will be the last newsletter to be sent out from our group, at least in this form. What will transpire after the EGM for next year will have to be decided afterwards. We will keep everyone informed of what is happening, but news will probably be in emails or posted as a news sheet.

My thanks go to Jill Pigott for producing this newsletter, rescuing us yet again by updating and extending Esther's draft. Thank you to both of you for this and all the previous secretarial jobs that had to be done.

My thanks also to Peter Goodbury, who has kept our accounts so clearly and accurately and reported at committee meetings, as well as guiding us on matters relating to our situation and constitution.

Warwick Davis has always contributed his help, despite poor health. Not forgetting all our group contacts who have run meetings for years, including Warwick Davis, Jackie Elston, Edwina Evans, Audrey Hammond, Phil Moss, Coral Shelley, Anne Smith, and Stephen Woodfield. Also, to Bernard Speakman who was our Treasurer for many years.

Thanks to Jill and Mark Pigott for their years of running our website and emails, etc.

I can think of so many others who have helped the group over the years despite their own poor health, it would fill a page.

So please let me say thank you to you all, members past and present, including partners, wives and husbands, who have had to endure.

Please let us know how you think we could continue in a simpler form.

Thank you all

*Ian Logan, Chairman*  
(08.11.2016)

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On behalf of members of the Worcestershire ME Support Group, past and present,  
a huge 'thank you' to Ian Logan, for 'being there' at meetings, and at the end of the phone,  
and for Karin being his support.

*Jill Pigott (08.11.2016)*

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At the end of August, we announced on our website -

### Group member's letter in ME Association magazine

#### Why the same figure year after year?

ME Essential Autumn 2016 (ME Association [MEA] magazine)

Letter from Warwick B Davis, Worcestershire ME Support Group,

I have suffered from ME for over 20 years and from the first months I have constantly heard or read that there are around 250,000 sufferers in the UK. Why still this figure?

Are there no new sufferers? Do people not pass away? Recently the press reported that one in 50 16-year-olds had some level of ME.

This is incredible. As an ex-teacher, I always felt that there was something else other than laziness in some pupils not performing.

If 250,000 continually gets quoted, the public do not understand how debilitating ME can be and the serious impact this illness has on our lives. As it is not a notifiable illness, it is difficult to know exact numbers.

Neither the public nor the NHS will ever take us seriously if the figures remain the same year after year. And how did it come about in the first place?

### Worcestershire NHS CFS/ME Local Multi-Disciplinary Team (LMDT) Service

**Contact Information:** 01684 612671,  
and - [WHCNHS.chronicfatigue@nhs.net](mailto:WHCNHS.chronicfatigue@nhs.net)

**Marina Townend - Occupational Therapist and Team Lead**, wrote to the group, letting us know that the Recovery and Management Group is now held on **the last Wednesday of every other month** at Ability House, Worcester. Please [check the NHS website for dates and topics](#). It now gives all 2017 information.

Marina confirmed that Julie Poulsen (part time Honorary Assistant Psychologist) has left the service, and Alice Brixey (part time Assistant Psychologist) will be leaving soon.

Also, Marina informed us that an OT student is now with the team -

"Sam Crockwell is a first year OT student from Worcester University who will be with us 1-2 days/ week until April 2017. She will be sitting in on appointments and groups, if patients are agreeable to this, gradually

taking on more responsibility under the team's supervision.

Having students is a great way of increasing awareness and understanding about CFS/ME, and hopefully will be carried into whichever area of practice they go on to work in the future."

The current team, from the end of Nov. 2016 is:

Marina Townend - (part time Occupational Therapist and Team Lead)  
Helen Ayres - (part time Clinical Psychologist)  
Sara Young - (part time Occupational Therapist)  
Kirsti Barnes - (part time Administrator)  
Sam Crockwell - (OT student)

Our thanks to Marina Townend, who joined us at our group meeting with Harriett Baldwin (MP for West Worcestershire) earlier this year, and also at our Annual General Meeting. Marina has also been to a few of our monthly informal meetings.

### New research: distinct biological differences in M.E.

**Action for ME (AfME) website article** - <http://tinyurl.com/gqsanxk>

September 02, 2016

Findings of research facilitated by the Open Medicine Foundation could be set to rock the world of medicine, writes Action for M.E. Volunteer Pharmacist Emily Beardall.

Published online in *Proceedings of the National Academy of Sciences of the United States of America*, and reported in UK press including the Telegraph and the Economist.

the study looked closely at the blood chemistry in people with M.E. with a research technique called "metabolomics."

This involves measuring the chemicals in our blood created by the different steps and by-products of metabolising, or breaking down, the energy and nutrients from our food into the chemicals that can be used for energy, hormones and building blocks of new cells.

## **Distinct biological differences in M.E (Contd)**

The research found 20 abnormal metabolic processes in people with M.E.; nine in both men and women with the illness, and a further eleven which varied between gender.

This means normal metabolites found in healthy people were found to be low in M.E., so the illness could be described as a “hypometabolic” disease and the body is effectively in hibernation.

The researchers suggest that many of these abnormalities might be part of the body’s own response to try to limit the spread and effect of viral or bacterial infection because cells are using alternative pathways to create the substances it needs. This is normally only seen in acute infection but this state is ongoing in M.E. patients.

### **What abnormalities did the researchers find?**

The disrupted processes that the researchers have found affect:

- cell building blocks sphingolipids and glycosphingolipids which are used by the body to form cell membranes in brain and nerve tissue
- cholesterol, which is needed for the production of cell membranes and steroid hormones such as cortisol and aldosterone
- bile acid, which is important for normal fat digestion; not enough bile acid secreted into the bowel can lead to a “leaky gut” where nutrients aren’t absorbed as efficiently
- mitochondria, the powerhouses of cells, leading to a lower reserve of energy and an inability to replenish high-energy stores after exertion
- the body’s ability to convert vitamins from food into the form needed by cells; those affected are vitamin A and the B vitamins riboflavin (B2), niacin (B3), pyridoxine (B6), folic acid (B9), and cobalamin (B12).

These vitamins are essential for energy production, new cell development such as red blood cells, and for normal nervous system function.

- a substance normally produced by the body as an antifungal and antibacterial, called HICA

A quarter of the abnormalities found were common to all the M.E. patients but the rest varied between individuals, giving each person their own characteristic pattern of abnormalities. The authors suggest that instead of focusing on the common disrupted processes in M.E. for developing a treatment, a personalised medicine approach, ie. giving each person a treatment for their own specific metabolic abnormalities, would be more successful.

The study also uncovered five different types of triggers for the illness:

- biological infections (viral, bacterial, fungal, and parasitic infections)
- exposure to toxic chemicals
- physical trauma
- psychological trauma
- and a category of unknown triggers.

Regardless of what triggered someone’s M.E., the underlying disease process was found to be exactly the same, contributing to the distinct chemical signature found for the condition.

Such a huge amount of biological processes in people with M.E. being affected could be the game-changer so desperately needed to move research forward to find treatments and change attitudes towards M.E.

### **Further information**

If you would like to know more about this research study, visit the [Open Medicine Foundation](#) for commentary from Prof on Davies and a Q&A with the principal researcher, Robert Naviaux.

To learn more about related “-omics” research, read the summary of Prof George Davey Smith’s presentation at the [2015 UK CFS/M.E. Research Collaborative conference](#), and the planned big data study by the [M.E./CFS Epidemiology and Genomics Alliance](#).

# ***The 'all in the mind' myth of myalgic encephalomyelitis/chronic fatigue syndrome | Nursing in Practice | 27 June 2016***

Extracts from -

ME Association (MEA) website article - <http://tinyurl.com/hdmngxx>

From ***Nursing in Practice*** | 27 June 2016 | Article written by Dr Keith Geraghty

## **The 'all in the mind' myth of myalgic encephalomyelitis/chronic fatigue syndrome**

Health professionals should be made aware that ME/CFS is not a psychological illness and in order to improve patient care, nurses need to better understand this illness and its impact on patients.

Nurses often witness close-up the impact of acute and chronic illness on patients. Myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS) is one illness that nurses may encounter that causes profound life changes for many sufferers. This controversial illness is sometimes presented as a psychosomatic disorder that requires psychological treatment. However, there is no compelling evidence that ME/CFS is a mental health condition and increasing evidence shows it is a biological disease with a range of complex symptoms. This article discusses how the 'all in the mind' myth of ME/CFS has permeated both medical discourse and popular culture, with negative consequences for patients living with this poorly understood condition.

### **1. Is ME/CFS really a mental illness?**

In a recent *Nursing in Practice* article, Roberts (2016)<sup>1</sup> suggests that ME/CFS is a psychosomatic disorder, best treated with psychotherapy and mindfulness. The erroneous idea that mindfulness is an optimum treatment masks a hidden and more important story; that very little is understood about ME/CFS and many health professionals are skeptical about whether ME/CFS is even a real illness. For example, NICE guidelines do not mention mindfulness.<sup>2</sup> A GP once exclaimed to me that 'all these patients need is anti-depressants and a good pair of running shoes'. While discussing my ME/CFS research at a hospital in Leicester a nurse offered me a similar opinion by suggesting that 'ME/CFS patients would get out of bed if you paid them £5000 per day'.

Such negative views among doctors and nurses are not uncommon and are perhaps fueled by misinformation about the illness being psychological.

In a recent book, *All in Your Head: True Stories of Imaginary Illness*,<sup>3</sup> Dr Suzanne O'Sullivan, a London-based consultant neurologist, includes a chapter on ME/CFS. O'Sullivan argues ME/CFS is strongly associated with psychological complaints and illness beliefs.

In contrast, a growing body of scientific evidence suggests that ME/CFS is not an imagined illness, nor is it a psychological condition, but a complex biological disease that is often triggered by an infection that causes observable neuro-immune dysfunction. Far from being 'all in the mind', sufferers often experience life-changing and disabling physical symptoms and physiological abnormalities (see Table 1).

Table 1:

Biological abnormalities observed in ME/CFS

- Alterations in grey and white brain matter.
- Muscle cell dysfunction.
- Immune cell abnormalities.
- Raised inflammatory markers.
- Cellular and oxidative stress.
- Autonomic irregularities.
- Cardiovascular deficiencies.
- Orthostatic intolerance.

The World Health Organization (WHO) classifies ME as a neurological disorder in the International Classification of Diseases (ICD-10: G 93.3; WHO, 1992).<sup>4</sup>

The US Institute of Medicine (2015) conducted an extensive review of the evidence and concluded that ME/CFS is 'a serious, chronic, complex, systemic disease'.<sup>5</sup>

The US National Institutes for Health confirmed ME/CFS as a disabling physical illness and stated that the medical profession has been responsible for causing distress to patients with ME/CFS by ignoring patients' calls for medical help and failing to adequately research the disease.<sup>6</sup>

## **2. So why is ME/CFS treated with psychotherapy?**

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Psychiatrists have long been interested in attempting to explain the medically unexplained. Sigmund Freud, the father of modern psychiatry, explored the connection between the mind and health. The famous French neurologist J. Charcot believed traumatic life events may bring about a form of hysteria or paralysis in patients; while George Beard put forward the theory of neurasthenia (exhaustion of energy within the nervous system).<sup>7</sup> These theories continue to influence how doctors perceive medically unexplained illnesses, particularly ME/CFS.

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## **3. So, does cognitive therapy or exercise therapy help anyone with ME/CFS?**

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The answer to this question is rather complex. ME/CFS is an umbrella term often used for patients with ongoing unexplained fatigue. Hooper (2006) points out that 'Amorphous definitions and diagnostic symptom criteria have contaminated study cohorts and corrupted research data'.<sup>11</sup> Essentially, it may be difficult to differentiate patients with ME/CFS from patients with fatigue or depression, given the generality of the diagnostic criteria for CFS: patients are often lumped together in studies, with depressed patients responding better to CBT compared with ME/CFS patients.<sup>12</sup>

In addition, CBT may help with the secondary depression or anxiety that occurs in most illness states. Clinical trials of CBT and GET tend to recruit mild to moderately unwell CFS patients, as more severe cases are too unwell to take part. Yet, even if we accept these research biases, the evidence for the success of psychological or exercise therapies in ME/CFS is unconvincing:

### **Cochrane review:**

A meta-analysis found that while CBT and/or GET may benefit some patients with ME/CFS in the short term, the benefits are short-lived and have little impact on restoring physical function over the long term.<sup>13</sup>

### **PACE trial:**

The largest clinical trial of CBT and GET for CFS reported that 22% of patients recovered following CBT/GET added to standard care, while only 7% did after standard care alone.<sup>14</sup> However, 'recovery' here did not mean a return to normal physical function. A patient could be deemed recovered with a SF-36 (quality of life) score of 60/100 or higher,<sup>8</sup> even though a score of 65/100 indicates severe disability with 57/100 being a score of patients with Class II congestive heart failure.<sup>15</sup>

At follow-up, two years after treatment, there was no clear benefit of adding CBT or GET to standard medical care.<sup>8</sup>

### **FINE trial:**

A study of nurse-provided community-based CBT and GET for 296 CFS patients failed to find any evidence for the long-term effectiveness of these therapies.<sup>16</sup> FINE stood for 'Fatigue Intervention by Nurses Evaluation'. CBT-GET was compared against a supportive listening treatment. The FINE investigators found no statistically significant benefits to either pragmatic rehabilitation (CBT-GET) or supportive listening at 70 weeks. The authors concluded that the community setting was inappropriate, rather than the psychotherapy treatment.

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## **4. Why is it important to know the facts?**

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In a recent Centers for Disease Control 'Grand Rounds' event (2016) discussing ME/CFS research, Professor Anthony Komaroff of Harvard University stated that the medical profession were wrong to adopt the name Chronic Fatigue Syndrome in 1988, as this term led to inaccurate perceptions of the illness. Komaroff points out that there are thousands of published articles on biological dysfunction in ME/CFS, with no compelling evidence to suggest the illness is psychogenic (an illness of the mind).<sup>16</sup>

Many ME/CFS sufferers and advocacy groups are deeply concerned about the portrayal of the disorder as a psychological illness in medical publications and the wider media. Misinformation may negatively impact patients.

Patient surveys consistently reveal that many ME/CFS patients experience medical scepticism, difficult interactions with health professionals and poor care quality (AfME, 2001).<sup>17</sup>



## **The 'all in the mind' myth of ME/CFS (Contd)**

Sufferers report finding it difficult accessing benefits and social care and often have to fend off accusations of laziness and hypochondria - perhaps a consequence of the perception that the illness is a self-generated psychological illness.

The 25% ME Group, a charity that supports the most severely ill sufferers, state that the medical establishment has largely ignored these ME/CFS patients.<sup>18</sup> Many are housebound or bedbound, with family members as full-time care-givers.

We must consider the harrowing case of Miss Sophia Mirza, a young ME sufferer forcibly removed from her home and sectioned under the Mental Health Act to impose psychiatric treatment on her. Miss Mirza died in 2005 and is one of the first patients in the UK to have ME as the official cause of death. The reality that ME/CFS kills some patients and dramatically shortens life expectancy is rarely reported in the media. In addition, ME/CFS sufferers are six times more likely to commit suicide compared to the general population;<sup>19</sup> most likely as the result of having to deal with debilitating symptoms, such as chronic pain and sleep deprivation, but perhaps also having to deal with feelings of social isolation and poor medical treatment.

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### **5. What can nurses do to support ME/CFS patients?**

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Many nurses will encounter ME/CFS patients, particularly in primary care. Nurses often have the capacity to form close therapeutic relationships with patients. Offering empathy and understanding to patients experiencing distressing symptoms is a central part of the nursing role. In the absence of a cure for ME/CFS, nurses are well placed to provide supportive care. By understanding the symptoms generated by the illness, nurses may be able to offer patients better care. ME/CFS severity varies from mild to severe and patients experience the illness in different ways.

Some sufferers may be able to continue work on a limited basis, while others may be bed-bound, reliant on family and carers. Retired nurse Greg Crowhurst, a care-giver to a wife with severe ME/CFS, writes eloquently about how nurses may support patients with the illness.<sup>19</sup>

Practical tips for nursing practice are as follows:

Sufferers experience profound fatigue - nurses may be able to ensure patients are not left in waiting areas for long periods of time.

Sufferers experience cognitive problems - nurses may assist patients in medical consultations, perhaps asking whether the patient understands the information provided.

Sufferers experience sensory overload - nurses may ask patients if they require a quiet area or darkened room, or on home visits, nurses may avoid causing sensory distress by speaking quietly and ensuring mobile phones are turned off.

Sufferers symptoms vary and fluctuate - nurses should liaise with family members or care-givers to get a personalised account of the patient's health status and care needs.

Sufferers often feel disbelieved and anxious - nurses may reassure patients, particularly if they convey empathy and knowledge of the illness to the patient.

Nurses also have an another important role as advocates for ME/CFS patients, helping to liaise between the patient and doctor and also helping to promote the patient voice in the public domain. However, to fulfil this important role, nurses need to better understand the illness and to understand that ME/CFS is by no means 'all-in-the-mind'.

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### **Conclusion: The key message for nurses**

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Most people feel fatigued following illness, stressful events, or after working long hours. This is quite different from the severe fatigue and the range of symptoms that patients with ME/CFS endure, including: unrelenting painful joints and muscles; cognitive dysfunction, including memory problems; gastrointestinal complaints; transient paralysis; hypersensitivity to light, noise and touch; unrefreshing sleep; post-exertional malaise after minimal effort; and the inability to maintain an upright posture for any significant period. Overwhelming evidence shows that these symptoms are not psychosomatic.

## **The 'all in the mind' myth of ME/CFS (Contd)**

Nurses have a valuable role to play in assisting and supporting patients with ME/CFS. Nurses should not underestimate the power and importance of the nursing position to relieve suffering, prevent harm and promote better care for ME/CFS patients.

## **References (available on the MEA website).**

*About the Author -*

**Dr Keith Geraghty**

**Honorary Research Fellow, Centre for Primary Care, University of Manchester**

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## **ME/CFS and the flu jab this year**

### **Should people with ME/CFS have a flu jab this year? | Dr Charles Shepherd weighs up the evidence | 6 October 2016**

ME Association (MEA) website article - <http://tinyurl.com/jceqrk5>

The ME Association has a leaflet that covers flu vaccination and ME/CFS in detail. It can be obtained from the MEA website online shop: [www.meassociation.org.uk/shop/management-leaflets/flu-vaccination/](http://www.meassociation.org.uk/shop/management-leaflets/flu-vaccination/)

We also have a leaflet covering the research that has examined the link between vaccines and ME/CFS

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#### **Key points from our flu vaccine leaflet**

- 1 A dose of flu can easily cause a significant relapse of ME/CFS. If this has happened in the past then a flu vaccine is well worth considering – especially if you are in contact with people who may be infected.
- 2 People with ME/CFS who have other chronic illnesses affecting the heart, kidney, immune or respiratory function, where a dose of flu could cause serious complications, should also discuss having a flu vaccination with their doctor.
- 3 ME/CFS is classified as a neurological disease - so you should be able to have one on the NHS (in England) if you decide to do so

*Confirmation from Dame Sally Davies,  
Chief Medical Officer for England:*

“As you know, the risk of serious illness from flu and consequent hospitalisation and death is higher among those with underlying health conditions such as M.E..

We know that people with chronic neurological conditions are approximately 40 times more likely to die if they develop flu than individuals who have no other underlying health conditions.

“The best way for people at risk from flu to protect themselves and their families is to get the flu vaccine. People with clinical risk factors are eligible to receive the seasonal flu vaccine free each winter.”

- 4 On the other hand, people with ME/CFS do sometimes report having a relapse or significant exacerbation of symptoms following a vaccination - especially when they are experiencing flu-like symptoms. This may be related to the fact that some research evidence indicates that there is low level activation of the immune system in ME/CFS - rather than immune system deficiency. But if you do have evidence of lowered immunity due to another illness then this is another recognised indication for having a flu jab on the NHS.
- 5 The MEA website ran a poll in 2009 which asked for feedback from people with ME/CFS who have had a flu vaccine.
  - How did your flu jab affect your ME/CFS symptoms?
    - I felt the same (45%, 86 Votes)
    - I felt much worse (27%, 52 Votes)
    - I felt slightly worse (22%, 42 Votes)
    - I felt slightly better (4%, 7 Votes)
    - I felt much better (2%, 4 Votes)

## **ME/CFS and the flu jab (Contd)**

- 6 Flu vaccine causing ME/CFS-like side effects: [www.dailymail.co.uk/health/article-2054160/300-000-doses-flu-vaccine-Preflucel-withdrawn-alert-effects.html](http://www.dailymail.co.uk/health/article-2054160/300-000-doses-flu-vaccine-Preflucel-withdrawn-alert-effects.html)
- 7 Should influenza vaccination be mandatory for healthcare workers? We report two cases of Chronic Fatigue Syndrome (CFS) after Swine Flu vaccination.  
[www.bmj.com/content/347/bmj.f6705/rr/687260](http://www.bmj.com/content/347/bmj.f6705/rr/687260)
- 8 Information from NHS Choices website:  
Under the guidelines drawn up by the Department of Health people living with CFS are entitled to the seasonal flu vaccine as they are defined as living with a serious long-term condition.

Though there may be both pros and cons associated with vaccination. Catching the flu when you are already experiencing symptoms such as fatigue can be very debilitating so vaccination can protect against that.

On the other hand some people with CFS who received a vaccine reported that the vaccine appeared to make the symptoms of CFS more severe.

In a small survey carried out by the ME Association, just under half of people said vaccination made no difference to their symptoms, a fifth said it made it slightly worse and a quarter said it made it much worse. A small minority of those surveyed (6%) said vaccination appeared to make their symptoms better.

Dr Charles Shepherd, Hon Medical Adviser  
The ME Association

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## **A Group Member Shares 'flu jab Experiences**

Anyone who does decide to have a 'flu jab, may not find it easy to persuade their GP that they qualify for a free one. Despite the Department of Health stating quite clearly that those with neurological conditions are entitled to a free jab, three years ago my GP's surgery in Malvern suddenly decided I no longer qualified - because ME/CFS was not specifically mentioned in the DoH guidelines.

These guidelines give a list of the categories of conditions covered and a few examples of specific conditions.

Despite the guidelines stating quite clearly that the list is not exhaustive, I was told that, because the ME/CFS is not specifically listed, the South Worcestershire Clinical Commissioning Group (CCG) doesn't recognise it as qualifying for a free jab.

Thanks to a lovely man at the DoH and one really good Dr. in the practice, that practice did acknowledge the condition as qualifying, but it was a long, hard and stressful struggle.

I hope that sharing this will help others.

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## **Group's Meeting with Harriett Baldwin, West Worcestershire MP**

We are grateful to Harriett Baldwin, for joining us at our group meeting, held at the Malvern Cube on 3 June 2016. At this meeting - ... ..

Harriett Baldwin, said she is willing to help people diagnosed with ME/CFS who experience difficulties with the benefit system.

Harriett Baldwin will be following up a question concerning M.E. Research.

Harriett Baldwin will be following up a question on the number of people with a diagnosis of M.E./CFS. A recommendation in the Inquiry into NHS Service Provision for ME/CFS (March 2010) - "The Department of Health should undertake research to determine accurately the numbers of patients with ME/CFS."

A full report, by Caroline Carver, is available on our group website - <http://tinyurl.com/jngk3nj>

## ME/CFS Epidemiology and Genomics Alliance (MEGA) project

Following from ME Research UK (MERUK) website -  
<http://tinyurl.com/hv82anw>

**MEGA study - Q&A** Posted on 16 Oct 2016

The ME/CFS Epidemiology and Genomics Alliance (MEGA) project was launched at the recent UK ME/CFS Research Collaborative conference 2016 (read more). It asks people to pledge their support for a potential 'big data study' of 12,000 men, women and children with ME/CFS. MEGA explains that the study will investigate, in terms of DNA, RNA and other molecules, the distinctive genetics, epigenetics, proteomics and metabolomics of people with ME/CFS, using a very large number of samples. "Such studies are the latest trend in population-based scientific research and are the way to generate the most useful data and the most productive research."

To date, around 2400 people have added their names in support on the MEGA page, which includes news updates on the project. The latest update has Questions and Answers (also listed below) about the project and its plans. MEGA members will also be launching a series of blogs outlining why they joined MEGA and what their expertise and field/discipline has to offer.

The organisers explain that, for the MEGA project to have a high chance of success when it applies for funding next year, there has to be evidence that ME/CFS patients in the community support the idea. Asking potential volunteers to pledge their support in this way is certainly a novel way of gauging interest. As the MEGA team says, "A study of this scale will require considerable funding but we are not asking for your money. Instead, we are asking for your voice".

As one of the four charities represented on the CMRC Executive Board, ME Research UK believes that the MEGA project has potential. We like the idea of the 'big team' approach, a collaborative effort between established scientists with a proven record in their own fields of research. At this initial stage, we feel that the aims of the project are worth supporting, whilst the level of patient support is being gauged and a protocol developed.

It must be stressed, however, that the project is still at the planning stage, and the development of the protocol will depend on the expertise and resources available as well as cost constraints.

At present, MEGA includes experts from a range of disciplines (epidemiology, metabolomics, immuno-pharmacology, health informatics, epigenetic etc.), but as more come on board a larger multidisciplinary proposal may develop, and this should be welcomed. Also, the issue of patient selection is an important consideration. Because a 'big data' project needs to recruit a wide spectrum of patients, it's vital to have robust clinical information on each person to allow subgrouping on the basis of specific criteria (from NHS diagnostic criteria to ICC), disease severity (from mild to severe) and other factors important for the interpretation of ME/CFS data, such as mode of onset (infectious, insidious etc.) and duration of illness.

The recruitment of very severely affected patients will be a particular challenge as they are rarely seen at NHS clinics, but it should not be overlooked, and one option is obtain appropriate already-collected and well-characterised samples from the UK ME/CFS Biobank.

Prof Stephen Holgate has now contributed some thoughts on these issues in the first of the project blogs; as he says, "to find causative pathways and uncover molecular mechanisms we need a broad range of disease severity and clinical manifestation. The key as far as I see it is to ensure that each patient is deeply phenotyped and with the same standard operating procedures (read more)". Clearly, there is considerable work to be undertaken and the MEGA team are working together to identify the best approach for this study.

MEGA was established following a Grand Challenge workshop convened by the UK ME/CFS Research Collaborative in May 2016 (read the report), and the collaborators aim to submit an application for funding in the next few months if target for patient numbers is reached: "We want to investigate not just the causes and underlying biology of ME/CFS, but also its different types (sub-phenotypes) which may be caused by different underlying mechanisms.

This research will be the first of its kind and MEGA is committed to meaningful engagement with people with ME and those that support them.

## **(MEGA) project** (Contd)

This will include establishing two patient advisory groups, one for adults and one for children and young people with ME/CFS.”

### **Further reading**

Big data, better health. New Scientist, 2015 ([read more](#))

Why broad definition should be used as a starting point, by Prof Stephen Holgate ([read more](#))

Give this MEGA project a chance to fly, by Dr Charles Shepherd ([read more](#))

Report of a Grand Challenge workshop. UK CMRC, May 2016; pdf ([read more](#))

Can Big Data Tell Us What Clinical Trials Don't? New York Times, 2014 ([read more](#))

### **Questions and Answers provided by the MEGA organisers**

Many of you have asked us questions about MEGA. We have not yet applied for funding and the patient advisory groups have not yet met to provide advice. So these are our preliminary thoughts at the moment. Some of this will change as we work on the first application (see below) and during consultations prior to future applications.

We want to engage with as many people as possible especially in the current planning phase.

#### **Has the study been funded yet?**

No. We are planning to apply for funding in 2017 for the first stage of the study, setting up the world's largest Bioresource of data and samples from CFS/ME patients. Our aim is to create a resource that all researchers all over the world can use. We will then apply for further funding for the subsequent omics-based stages of our study - searching for the biological basis to ME/CFS - once the Bioresource is set up.

#### **Will the data be open access?**

Yes. Subject to individuals' consent, the data and the samples will be available for researchers to use. We want to rapidly increase effective research (by us, by anyone) to understand the biology, causes and different types of CFS/ME.

## **What case definition will you use?**

To do the genetic studies that we want to do, we think we need to recruit at least 10 thousand adults and 2 thousand children.

The only way to do this is to recruit patients through NHS clinics throughout England. England is the only place in the world that can collect this large number of patients in a short time frame.

Patients with CFS/ME will be identified by clinicians in the NHS clinics. The clinicians will be asked to identify patients they judge from NICE criteria to have CFS/ME. This means patients with other causes of fatigue will not be recruited including (for example): those with thyroid disease, diabetes or depression that is sufficiently severe to explain their fatigue. Patients will have been examined, a full history taken and they will have had screening blood tests (to ensure other causes of fatigue have been excluded).

We will collect sufficient information on each patient to be able to say whether they have CFS/ME using other research diagnoses (for example, the CDC [Fukuda 1994] diagnostic criteria, the IACFS criteria, Canadian criteria and so on). This is in addition to the diagnoses of CFS/ME that patients will get following NICE guidance. We will listen to our patient advisory group in terms of how much data we can collect on different diagnostic criteria. Our patients advisory groups may recommend collecting less data as patients are so ill.

#### **Why use broad criteria?**

As the symptoms and genetics of CFS/ME are highly heterogeneous we think it makes sense to build a Biobank of samples from all people diagnosed with CFS/ME (diagnosed with NICE criteria, without other causes of fatigue, as above). This is because our experience from other diseases is that the genetics found for one set of people with CFS/ME will be relevant to the genetics found for another, and even to the genetics of the population at large.

But afterwards, in the computer, we will separate out various subsets of people with CFS/ME according to different diagnostic criteria. This will tell us which diagnostic criteria are more effective for which people.

## **(MEGA) project** (Contd)

### **Why are psychiatrists involved?**

The MEGA consortium has brought together many experts from a wide range of different disciplines from across genetics, genomics, metabolomics, pain research, proteomics, psychiatry, sleep research and transcriptomics. Psychiatry needs to be there to complete the big picture yet it is just one minor aspect.

MEGA will always be a Big Data 'omics study, and will never be a psychiatric study.

### **What data will you collect?**

We will collect symptom data on all patients to allow us to identify which patients will be identified as having CFS/ME using different diagnoses. We will also include data on fatigue, disability, anxiety and depression. We would like to collect detailed data on pain. How much data we collect will depend on what our patient advisory group says will be acceptable to consenting patients and how much funding we get.

### **Will you be doing additional tests?**

We would like to do additional, more time-consuming and expensive tests on a sample of patients that will help us more finely phenotype (describe CFS/ME more carefully) those recruited into the study.

We don't think we will have the money to do this for everybody or for everything. We would like to do additional studies to collect more data on pain, exercise-induced stress and sleep studies and possibly some imaging. We also want to be as sure as we can that we have carefully excluded other diagnoses such as depression and anxiety as a cause of fatigue. We haven't worked on the details for this but will be asking our patient advisory group about what they think would be feasible and acceptable given the funding limits.

### **What samples will you be taking?**

We will take blood and urine samples that allow us to look at the genetics, the epigenetics (how genes are modified chemically), transcriptomics (identifying which genes are turned on and which are turned off), proteomics (the proteins in the blood), and the metabolomics (what small molecules are made by our enzymes and other proteins). We will use standard procedures for collection of these samples developed previously for many other studies.

### **Please explain why different members are part of the MEGA team?**

We will upload a list of biographies and what members have to contribute in the next few days.

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## ***New MEGA website to feature improved accessibility and engagement***

November 03, 2016

Recent MEGA news from the Action for ME (AfME) website - <http://tinyurl.com/j2hx5a6>

The [change.org](http://change.org) site for the MEGA research project has been taken down while a new website dedicated to the project is being developed. This is following feedback that the [Change.org](http://Change.org) site was not accessible for everyone.

The new website will be live in the next week or two, according to the MEGA team, and is being designed to allow easier access to information about the project for people who don't necessarily want to pledge their support for the project but want to keep up to date with the latest news.

Regular updates and blogs from the researchers involved will be posted and the new website will have the facility to ask questions and engage with the MEGA team.

Information on how people with M.E. can become part of the patient advisory panel is also expected soon. The panel will work with the researchers to inform the application and protocol for the MEGA study.

*In the June newsletter, you heard that The ME Association's paediatric medical adviser Dr Nigel Speight had conditions attached to his licence to practice by a panel of the General Medical Council on Wednesday (April 20). We now have good news from ME Association-*

### **Dr Nigel Speight - some excellent news from the General Medical Council | 12 October 2016**

ME Association (MEA) website article - <http://tinyurl.com/jxr636u>

We are delighted to be able to report some very good news about Dr Nigel Speight. Dr Speight has just been before a review panel at the MPTS (Medical Practitioners Tribunal Service). The panel decided to overturn all of the restrictions that were imposed on him last April by the General Medical Council (GMC).

These restrictions were to the effect that Dr Speight was not allowed to see any cases of ME, or to give any advice, or to have anything to do with the subject. This was provisionally to be for a period of 15 months.

The barrister representing Dr Speight at the tribunal stated that the whole issue revolved around a single complex case, and involved an area of medical controversy on which the GMC should not take sides. She stated that there was no evidence of patient harm, indeed the evidence was to the contrary, and that the patient had improved considerably since Dr Speight's intervention.

The barrister also emphasised how these GMC restrictions had led to the ME community being 'deprived of choice'.

The charities he supports (including the MEA) had not been able to find a replacement for him and so there is no one to support families in contentious cases involving children and adolescents, as no other doctor wishes to 'put their head above the parapet'.

The panel then decided to remove the restrictions in their entirety and without qualification.

Once the GMC has confirmed the situation, Dr Speight will be able to return to his position as Honorary Paediatric Medical Adviser at the MEA

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#### **"This comes as a great relief" - Dr Speight**

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Nigel Speight commented:

"As you can imagine this comes as a great relief.

Needless to say, I am exceedingly grateful to all who wrote in to the GMC in my support, and it was mainly because of them that I chose to contest this issue.

Best wishes and thanks to you all  
Nigel Speight"

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### **Action for ME's response to 'psychosomatic' comment - in the BMJ**

#### ***Sonya Chowdhury responds to 'psychosomatic' comment***

Action for ME (AfME) website article - <http://tinyurl.com/zs7owug>

October 10, 2016

Action for M.E. Chief Executive Sonya Chowdhury has challenged a comment posted on the *British Medical Journal (BMJ)* website which suggested that for M.E. patients, the condition is "all in their heads".

Dr Jordan, a medical doctor from Edmonton, Canada, posted his comment in response to an article titled *Freedom of information: can researchers still promise control of participants' data?* The article by Nigel Hawkes pertained to the recent judgment that Queen Mary University must release data from the PACE trial.

Dr Jordan said:

"The action taken against the researchers appears to be a continued attempt to justify the condition as a disease entity, thereby creating an environment in which some form of personal gain may be achieved. Whether that gain is in the form of a financial incentive or to manipulate the research findings as a way of placing some distance between a possible underlying mental health or psychosomatic illness and a true physical illness is unknown. It obviously helps satisfy alleged sufferers to hear that it is not all in their head and that what symptoms are experienced must be seen as real and part of a real disease process.

### Action for ME's response (Contd)

Arguments against the sceptics and critics must be answered with facts, according to one's own definition of the facts."

In her response, Sonya expressed disappointment with Dr Jordan's comments, stating:

"Such comments propagate the long-standing myth that M.E. is not a true physical illness, and perpetuate the disbelief and stigmatisation that people with M.E. are subjected to.

"For M.E. patients, who often struggle to find acceptance and support from friends, family, colleagues and social and welfare services, this can cause a great deal of harm and prevent them from accessing the medical, financial and emotional support they desperately need, which is something I hope Dr Jordan recognises.

"Dr Jordan's opinion is at odds both with the research evidence that supports M.E. as a true physical illness, and with an appropriate medical stance."

You can read Dr Jordan's and Sonya's comments in full [on the BMJ website](#)

## #MEAAction Denounces Use of CBT in Treatment for Chronic Fatigue Syndrome

MEAAction article - <http://tinyurl.com/jexhtdv>

November 2, 2016

*Patients with ME/CFS Urge NHS to Adopt Scientifically-Sound Approaches to Treatment*

### Study Finds No Difference in Treatment for ME/CFS Patients At Long-Term Follow-Up

According to reports in [The Guardian](#) and [BBC](#) yesterday, hundreds of young patients in the UK suffering from myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) are set to receive online psychological therapy.

FITNET will cost £1million, to be funded by British taxpayers - yet the Dutch study on which the trial is based found no difference in patients at long-term follow-up.

[#MEAAction](#), an international network of ME patients, along with other patient groups and scientists from around the world, condemn the waste of resources on such inherently flawed studies. Arguing that an intervention that consistently shows null results at long-term follow-up is not worth pursuing further.

The proposed study - known as 'FITNET' - shares many flaws with the [debunked PACE trial](#), which was described as "the height of clinical trial amateurism" by Dr. Bruce Levin of Columbia University. It was subsequently discovered that scientists misrepresented the efficacy of cognitive behaviour therapy and graded exercise therapy in ME patients - but only after a protracted battle to obtain the open-sourced data.

It's "more meaningless research based on flawed assumptions and bad studies," said **David Tuller, of University of California, Berkeley**. "What a huge waste of time and money! When will these people let go of their dysfunctional and delusional belief that CBT is the pathway to 'recovery' from this disease? It's complete nonsense."

"Time and again, research has shown that graded exercise and cognitive behavioral therapy are not effective treatments for those suffering from ME," said **L.A. Cooper of #MEAAction Network UK**. "To state that it is curative would be misleading, and ultimately very damaging."

Meanwhile, researchers worldwide continue to forge ahead with groundbreaking discoveries in ME/CFS: Fluge and Mella of Haukeland University have shown that an anti-cancer drug causes remission in a significant percentage of patients; Ian Lipkin and Mady Hornig of Columbia University have shown disturbed cytokine production patterns that differ early versus late in the illness; and numerous researchers in the US and UK have identified metabolic abnormalities in patients that differ vastly from controls, including Naviaux, who memorably stated that patients' cells appear to be in a form of metabolic hibernation.

Last year's US [Institute of Medicine Report](#) unequivocally stated that ME/CFS is not a psychological illness after critically reviewing over 9000 pieces of scientific literature.



## **#MEAction Denounces Use of CBT in Treatment for CFS (Contd.)**

The US Agency for Healthcare Research and Quality downgraded its recommendations for CBT and GET, stating that there was not enough evidence to label them effective treatments for ME/CFS.

"We can't continue to feign ignorance and pretend other countries aren't speeding ahead.

The concept that ME can be improved with solely behavioural techniques is decades old, and frankly, an embarrassment to the nation's scientific and patient community," **added Cooper.**

The above article is response to the University of Bristol press release -

Testing online treatment for chronic fatigue syndrome (CFS/ME)  
<http://tinyurl.com/j52e874>

Press release issued: 1 November 2016

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## **Interviews on the day of the BBC 'FITNET' announcements on 1 November**

Ian Logan, Worcestershire ME Support Group Chair, received a phone call from Andrew Easton of **Hereford & Worcester Radio**, on 1 November. **You can listen to the interview - available until the end of November** (starting at 1 hr 17 mins, and lasting about 5 minutes).  
<http://www.bbc.co.uk/programmes/p04bwgkz>

Jane Colby (Tymes Trust), Mary-Jane Willows (AYME), Professor Dr Esther Crawley and a CFS/ME sufferer, were interviewed by Joanna Gosling on the Victoria Derbyshire programme. **You can watch the Interview** - available on the iplayer, until the end of November. starting at 1 hr 10 mins., and lasting about 12 minutes.  
<http://www.bbc.co.uk/iplayer/episode/b0817fqg/victoria-derbyshire-01112016>

## **The MEA and AfME both have 'FITNET' articles -**

### **ME Association comments on today's news reports about the online CBT Trial for children | 1 November 2016**

The ME Association position on CBT, GET and Pacing is made very clear in the summary of the MEA 'patient evidence' report on CBT, GET and Pacing: MEA website article - <http://tinyurl.com/hkf3scm>

### **New FITNET trial announced for young people with M.E.**

Action for ME (AfME) website article - November 02, 2016 / <http://tinyurl.com/j7l3v37>

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## **NICE takes a dim view of foreign research into ME/CFS | Robin Ellis Freedom of Information request | 24 October 2016**

ME Association (MEA) website article - <http://tinyurl.com/htju93g>

The main supplier of England's drugs and treatment guidelines, the National Institute for Health and Clinical Excellence (NICE), tends not to take foreign research into account when it produces work on ME/CFS.

In internal correspondence released this month under the Freedom of Information Act (FoI), the agency admitted that it has not yet considered the results of important US studies when deciding what is best for British M.E. patients.

NICE are holding back the review of their guidelines on ME/CFS until some time in 2017, saying the evidence to justify earlier reconsideration isn't strong enough.

"It is not really for the NHS to respond to a report commissioned in another country and not yet examined by its commissioner", the agency's director for clinical practice wrote to colleagues as they were assembling their reply to a FoI request from Robin Ellis.

## Fol Request (contd)

Professor Mark Baker wrote: "We would take seriously the views of the relevant esteemed medical associations in the UK, principally the RCP (Royal College of Physicians) and the RCPsych, (Royal College of Psychiatrists) when looking at reviewing this guidance.

"I am not aware of any reason to do anything before then unless some major new evidence on treatment emerges, and we know that no major studies are in progress".

The applicant, Mr Ellis, filed three Fol requests earlier this year seeking the release of information held by NICE about the PACE Trial.

This time he wanted to know if NICE allowed its thinking on M.E. to be influenced by overseas research using easily observable symptoms - like testing for post-exertional fatigue using the 48-hour exercise test - the 2015 US Institute of Medicine report on the "devastating severity" of M.E - and the National Institutes of Health report which "retired" the Oxford criteria for CFS believing it to be harmful to people with the illness.

Mr Ellis also pointed to another US agency that had recently determined that CBT and GET were ineffective treatments given the poor outcomes reported all round - including in the PACE Trial.

Mr Ellis's latest Fol request was formally entitled: *Unique characteristics of pw ME/CFS as defined by the CCC and ICC and exercise physiologist experts eg Workwell Foundation, Snell, VanNess, Stevens, Klimas*. He wanted to see what papers were held by NICE on these matters.

In the papers released by NICE, there is an intervention from the Countess of Mar, who chairs the Forward ME Group of charities.

The Countess wrote to NICE:

"I have to assume that you must agree that patients with ME/CFS are very much the same wherever they are in the world, and that there will be no difference between UK and US patients.

"I also assume that you must agree that very many more resources have been applied to this issue in the US than in the UK. Professor Baker reiterated his belief that there is no evidence that GET makes some patients worse.

"Absence of evidence is no evidence of absence, and there is plenty of evidence from the two major charities in the UK - Action for ME and the ME Association - which have both done major surveys of their members..."

Professor Baker replied to her that NICE will conduct a critique of the American work to consider "whether it adds anything to what we already know". He added: "You will be aware that the British academic establishment holds an entirely different view, though not necessarily any better informed."

On October 19, Mr Ellis formally requested an internal review of NICE's handling of his Fol request. "I asked for information around the decision NOT to update the NICE Guidelines, none was provided."

The full exchange of correspondence can be read here: <http://tinyurl.com/jqj2uqb>  
The papers released can be read here: <http://tinyurl.com/zrjc645>

The papers have been slightly redacted by NICE. The agency wrote that it did not want to show details of junior staff involved in the correspondence nor of "a third party" who was consulted as part of the exercise.

## Tymes Trust (The Young ME Sufferers Trust) -

Tymes Trust 2016 publications - from their website - <http://tinyurl.com/zvbctyl>

### **The T Rex In The Room and Paediatric ME, CFS, SEID For Families And GPs**

Our 2016 leaflet and Jane Colby's speech given at the House of Lords to introduce it. Are there risks with graded exercise therapy? NICE Guidance and education. *Printed copies free for a limited period.*

**The Tymes Trust Trifold leaflet has been updated.**

### **Quick Tour of ME Symptoms, Management and Tymes Trust Services (Updated 2016)**

"Mum uses your leaflet to explain the illness to people, like my care manager. It's the best leaflet on ME we've seen!" *Printed copies available from Tymes Trust.*

## Worse Than the Disease

A popular therapy for chronic fatigue syndrome made many patients worse.  
Adding insult to injury, research supporting it is now unraveling.

10.27.2016 / By David Tuller

<http://undark.org/article/chronic-fatigue-graded-exercise-pace/>

a few extracts from  
David Tuller's in depth article

"Chronic fatigue syndrome has been controversial ever since the U.S. Centers for Disease Control and Prevention published its first major journal report on the illness, in 1988. For decades, patients have confronted enormous skepticism and doubt about whether their illness even exists. Yet a significant body of research has demonstrated that the disorder has a physiological basis and does not result from deconditioning or psychiatric problems. In August, a study in the Proceedings of the National Academy of Sciences reported finding distinctive metabolite patterns in the blood plasma of patients with chronic fatigue syndrome, suggesting that multiple metabolic pathways are out of whack."

"Last October, Virology Blog, a popular science site hosted by the Columbia microbiology professor Vincent Racaniello, published my lengthy investigation of the major flaws in a British clinical trial called PACE — the largest and, supposedly, the definitive study of treatments for chronic fatigue syndrome. The main results were published in The Lancet in 2011 and the journal Psychological Medicine in 2013.

The trial was led by some of the same experts who had developed graded exercise therapy in the first place, and not surprisingly, their publicly reported findings represented an endorsement of their theories about deconditioning and "unhelpful" illness beliefs."

"In September, the university finally released some PACE trial data under a court order involving a freedom-of-information request that a patient had pursued for two years. A small group of patients and academic statisticians analyzed it and published their findings on Virology Blog. And with that, the PACE trial's 22 percent recovery rates "went up in smoke," wrote Julie Rehmeyer, a journalist who is also an ME/CFS patient, in a compelling article on how "bad science misled millions" for STAT, a health news site connected to The Boston Globe. In fact, in the new analysis the "recovery" rates fell to single digits, and the results were not statistically significant."

"In their own re-analysis of the results, posted online by the university, the authors reported that with the original protocol methods, the graded exercise therapy and cognitive behavior therapy groups were still more likely to produce "improvement" than the other two groups, at a rate of about 20 percent. Patients quickly pointed out that this was a third of the "improvement" rates the PACE team had reported in The Lancet."

### Please sign this Petition - Suspend all trials of graded exercise therapy

**Petition Suspend all trials of graded exercise therapy in children and adults with ME/CFS**  
<https://petition.parliament.uk/petitions/166601>

In surveys hundreds of patients have reported harm - some becoming housebound or bedbound, indefinitely - from graded exercise therapy (GET). The Government must demand that research and funding bodies suspend all trials of graded exercise therapy for ME/CFS until the evidence has been reassessed.

Clinical trials such as MAGENTA still use graded exercise therapy, even in children, but are being justified on the basis of the flawed PACE trial. Scientists have severely criticised PACE, the major adult trial that claimed the therapy to be safe and effective. Thousands have demanded retraction of PACE's "misleading" analyses and 24 ME/CFS charities from 14 countries demanded that its data be released for reanalysis. PACE is no basis for a trial in children or adults. Read more at [www.stopget.org/](http://www.stopget.org/)

# Worcestershire M.E. Support Group

for people affected by ME, CFS and FMS

Group Website	http://worcsmegroup.weebly.com	
Group Email	worcsmegroup@yahoo.co.uk	
Chair	Ian Logan, 1 The Old School House, Church Lane, Martley, WR6 6QA	01886 888419
Vice Chair	Warwick Davis, 21 Farmcroft Road, Stourbridge, DY9 9ER	01384 892442
Treasurer & Membership Secretary	Peter Goodbury, Willow Cottage, Lower Dingle, West Malvern, WR14 4BQ	01684 563868
Secretary	VACANCY	
Committee	Ian Logan, Warwick Davis, Peter Goodbury, (We need more committee members please, all welcome)	
Webmaster	Mark Pigott	worcsmegroup@yahoo.co.uk
Newsletter Editor	VACANCY	
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	Hagley ..... Warwick Davis	01384 892442
	Malvern ..... Ian Logan	01886 888419
	Worcester ..... Ian Logan	01886 888419
Area Contact (email)	Wyre Forest ..... Coral Shelley	denshelley@btinternet.com
Patrons	Harriett Baldwin, MP for West Worcestershire; Mark Garnier, MP for Wyre Forest; Sir Peter Luff, (former MP for Mid-Worcestershire); Karen Lumley, MP for Redditch.	

**DATA PROTECTION ACTION:** Names and addresses are kept by the Worcestershire M.E. Support Group. This information is treated as confidential. However, if people want to be put in touch with others with M.E. please let us know. We can, with your consent, pass your details onto people in your area. This will only be done with your written authority. If you have sent information to us and do not want it kept on computer records please inform us.

**EDITORS:** Any material from this newsletter may be used as long as the original source is acknowledged.

## Useful Organisations and Contacts

### **Benefits Advice:**

Disability Information and Advice Line (DIAL):

DIAL South Worcestershire: 01905 27790      [www.dialsworcs.org.uk](http://www.dialsworcs.org.uk)

DIAL North Worcestershire: 0845 200 1072      <http://nwdial.org.uk>

Citizens' Advice Bureau:

Worcestershire CAB Advice Line: 08444 111 303      [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

### **Other:**

25% ME Group (for those with severe ME): 01292 318611 / [www.25megroup.org](http://www.25megroup.org)

Action for ME (AfME): 0117 927 9551 / [www.afme.org.uk](http://www.afme.org.uk)

Association of Young People with ME (AYME): 0845 123 2389 / [www.ayme.org.uk](http://www.ayme.org.uk)

Fibromyalgia Action UK (FMA UK): 0844 887 2444 / [www.fmauk.org](http://www.fmauk.org)

Fibromyalgia Support: Hereford & Worcester FMS Helpline: 0871 750 1725

Herefordshire CFS/ME/FMS Group: 01885 482966 (Kay) / [www.mefmsgroup.wordpress.com](http://www.mefmsgroup.wordpress.com)

ME Association (MEA): 0844 576 5326 [www.meassociation.org.uk](http://www.meassociation.org.uk)

ME Research UK (MERUK): 01738 451234 [www.merereasearch.org.uk](http://www.merereasearch.org.uk)  
(We are a "Friend of ME Research UK" Group)

The Young ME Sufferer (TYMES Trust): 0845 003 9002      [www.tymestrust.org](http://www.tymestrust.org)  
(We are a "Partner of Tymes Trust")

Walsall Fibro and ME Link:      [www.walsallfibroandmelink.org.uk](http://www.walsallfibroandmelink.org.uk)  
email: [walsallfibroandmelink@gmail.com](mailto:walsallfibroandmelink@gmail.com)

Worcestershire Association of Carers: 01905 26500 [www.carersworcs.org.uk](http://www.carersworcs.org.uk)

Worcestershire Social Services: 0845 6072000 [socialcare@worcestershire.gov.uk](mailto:socialcare@worcestershire.gov.uk)

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### **Best wishes to Everyone for Christmas and the New Year**

Buy your Christmas cards from ME Research UK, who say - <http://tinyurl.com/gw5amkz>

Our selection Christmas card selection for 2016 is now available. There's 8 designs and two notecards to choose from, and each card not only helps raise funds but spreads awareness too.

You can view the cards at our dedicated [Christmas card 2016](#) page, and there is an order form there too.

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## Dates for your diary - Area meeting dates 2016

### Droitwich Meetings

First Friday of each month - except January & August

Area contact: Stephen Woodfield - 01905 798671

Venue: Methodist Church, Amphlett House, Worcester Road, Droitwich, WR9 8AW

Time: 1.30pm - 2.30pm

Friday: 4 November  
2 December

### Worcester Meetings

Second Wednesday of each month - except January & August

Area contact: Ian Logan - 01886 888419

New Venue: Wyevale Garden Centre (previously Blooms Garden Centre), Droitwich Road, (A38), Worcester, WR3 7SW

Time: 2pm - 3pm (Meetings may continue until 4pm)

Wednesday: 9 November  
14 December

### Malvern Meetings

Second Thursday of each month - except January & August

Area contact: Ian Logan - 01886 888419

Venue: The Malvern Cube, Albert Road North, Malvern, WR14 2YF

Time: 2pm - 3pm (Meetings may continue until 4pm)

Thursday: 10 November  
8 December

### Group Lunches 2016 - from 12.30pm

November - Monday 28th - David's Nurseries, Ash Lane, Worcester, WR3 8TB

December - No group lunch. (Please see the website for further dates.)

Join us for lunch, or just a cuppa and a chat -  
it is a social event, not necessarily on ME.

### Keeping in Touch - our Members' Internet Forum

The 'worcsme-network' members only discussion forum was formed to enable members of the Worcestershire M.E. Support Group to share and discuss local issues, as well as feel they are able to talk about all matters relating to living with ME, CFS and FMS. Literature, including Group newsletters are available on the forum in the 'Files' section.

**Do you want something similar in the future?**  
***Please let us know***