The Five Myths

that underpin official UK ME policy

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The Five Myths

Greg Crowhurst

If you seek to campaign for a Public Inquiry into ME you should be very aware of the **five myths** that underpin official UK policy :

Myth 1 : CFS and ME are the same.

Comment: CFS and ME are, in fact, different terms encompassing different conditions and symptoms, with different sets of treatment requirements. ME and CFS need to be separated in order to respect the differences and ensure safety of patients.

Using the names synonymously, when they have different identification criteria, impacts negatively on both the National Health System and the Benefit system for people with ME.

The Grace Charity reveals how according to the National Archive Document BN141/1 the Government was ready to make M.E. separate from other chronic fatigue syndromes by classifying M.E. as neurological in the DLA Handbook (Disability Living Allowance). But just as it seemed ready to do this, it did a U-turn and kept M.E. under the general heading chronic fatigue syndromes,.http://www.thegracecharityforme.org/documents.asp

Currently the generalised psychosocial NHS treatment pathway for all is failing people with ME, resulting in neglect and harm.

Why ME and CFS need to be clearly separated in government policy:

ME must be treated as a separate condition:

Although they are used synonymously unfortunately ME and CFS are not equivalent terms. ME is a neurological disease, CFS is a made-up term that encompasses a wide range of fatigue conditions.

CFS includes Chronic Fatigue, a mental illness, as well as some people with ME, a neurological disease, others with neurological ME may unfortunately be wrongly diagnosed as having functional somatic disorder; it is therefore unsafe, unreliable and unrealistic to equate CFS with ME, given they are identified by different criteria.

Currently some people use the term synonymously to mean both are mental health conditions, some interpret it as neurological; doctors and health and social service practitioners can chose which interpretation they use. This is unacceptable and dangerous for all.

ME does not exist on a continuum with Chronic Fatigue or CFS any more than Cancer , or Multiple Sclerosis does.

ME is not a fatigue illness , in the way it is contextualised in CFS; you don't even have to have fatigue to have ME. ME is identified by its unique post exertional autoimmune response and post exertional fatigue, which is quite different from ordinary fatigue - particularly the way it responds deleteriously to exercise.

A service cannot safely identify and aim to treat WHO-ICD-10-G93.3 ME/PVFS patients whilst also using the CDC/Fukuda CFS definition, which inevitably includes people with other conditions as well , without doing a gross disservice to taxonomic logic .

The criteria for ME are very specific,whereas the CDC/Fukuda criteria for CFS are far too vague, undefined, unreliable , too broad to be of any practical value.

The International Consensus Criteria (ICC) is very clear that 'fatigue syndrome' or 'chronic fatigue syndrome' are not to be conflated with ME/PVFS WHO-ICD-10-G93.3, yet the UK government continues to do so ; this urgently needs addressing.

The WHO have repeatedly clarified that diseases cannot be encoded under more than one rubric: for example on 4th February 2009, Dr Robert Jakob, Medical Officer (ICD), Classifications, Terminologies and Standards, WHO Headquarters, confirmed:

"CFS is a broad umbrella. This needs to be clarified. It is not possible to make a deduction from CFS. Volume I is the relevant volume for ME. ME is classified at G93.3 and is a specific disorder. The term CFS covers many different conditions, which may or may not include ME. The use of the term CFS in the ICD Index is merely colloquial and does not necessarily refer to ME. It could be referring to any syndrome of chronic fatigue, not to ME at all."

The hallmark symptom of ME- the Post -Exertional impact of any activity is ignored by CFS criteria; the hypersensitivity, the neurological , the endocrine, the cardiac and autonomic dysfunctions are also ignored, putting peoples health and lives at risk.

The techniques used in the therapeutic treatment of Chronic Fatigue are not just inappropriate but potentially damaging, dangerous -even life-threatening to someone with ME.

Because of the imposition of the CFS label upon their disease, people with ME are seriously deprived of proper medical tests, treatments and research . Essential tests are proscribed in the NICE guidelines. This is cruel and unacceptable, wrecking lives , leaving numerous patients suffering for decades with no hope of a cure or treatment.

Under the CFS label there are countless daily cases of psychosocial abuse and needless suffering to ME patients,; there is no reasonable logic to this neglect of ME patients.

The greatest abuse of all, is that the NHS provides no biomedical service for people with ME, only psychiatric intervention, as the Countess of Mar pointed out recently in the House of Lords :

I have been assured that Her Majesty's Government accept the WHO's categorisation of ME as a neurological condition. The CMO report of 2002 described it as a "genuine illness" which,"imposes a substantial burden on the health of the UK population".? The NICE guideline of 2007 stated that: "The physical symptoms can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions".? Yet there is no provision to examine the neurological aspects of this illness. Patients are simply allocated to either the CFS/ME group, where they are offered psychological therapies, or to various ad hoc diagnostic categories containing patients with neurological symptoms of unknown aetiology. In practice, these can be considered dustbins where no further investigations are considered necessary.?

Countess of Mar (2012) House of Lords - Neurological Services Debate - 20 November 2012
http://forums.phoenixrising.me/index.php?threads/house-of-lords-neurological-services-debate-20-november-2012.20550/

It is very likely that many patients with a generalised CFS label have not been adequately tested and may have curable illnesses, not ME or Mental health Chronic Fatigue at all.

The only way to justify psychiatric dominance is to wrongly equate CFS with ME - and to wrongly treat ME as a fatigue condition .

Q. When will the Government recognise ME and CFS are not equivalent and act to stop the abuse and neglect, the misinformation and misrepresentation of people with ME in the UK?

Q. When will the DOH and the Government acknowledge its policies have been wrong for patients with ME and when will direct and necessary biomedical investigations, tests and treatments be offered to those suffering specifically with ME ?

Myth 2 : Membership of the CMO's independent working group on CFS/ME, whose report laid the foundations for current CFS/ME policy, included members representing a wide range of health professions and clinical areas, as well as service user representatives.

Comment: The confusion concerning ME and CFS; the creation of a biopsychosocial pathway instead of a biomedical one, in the NHS, arose specifically from the inappropriate involvement of psychiatrists in ME since the 1980's. Before this time the UK government took ME seriously and did not confuse it with fatigue or a mental health condition.

The CMO working group included a predominance of psychiatrists, please see below.

Although the CMO report highlighted and stressed the neglect particularly of the severely affected in 2001, the government has done nothing since to improve the prognosis or treatment of this neurological disease. Until psychiatry is removed, the confusion, the gross neglect, the misrepresentation as a fatigue/ mental health condition, will continue and the government will continue to justify its position quite wrongly, based on this misrepresentation from psychiatric input.

Controversy over psychiatric input

Controversy surrounded the CMO Report; as Professor Hooper points out, the group was far from independent :

.. its membership .. was dominated by the Wessely School psychiatric lobby including Simon Wessely himself, Peter White, Anthony Cleare and Trudie Chalder, supported by child psychiatrist Elena Garralda and Harvey Marcovitch .. The Working Group was partly funded by the Linbury Trust, which since 1991 has financially supported the Wessely School psychiatrists and their studies of "chronic fatigue".

(Hooper M (2001) THE MENTAL HEALTH MOVEMENT : PERSECUTION OF PATIENTS? http://www.meactionuk.org.uk/select_cttee_final_version.htm)

In October 1993 Simon Wessely stated that :*"If CFS/ME is to be listed as a neurological disorder, I for one will begin to campaign via the mental health charities for schizophrenia and manic depression to be also listed under the same heading. Indeed there is far more evidence suggesting that these disorders have a neurological origin than does CFS/ME."* National Archive Document BN141/1

The only way to justify psychiatric dominance is to wrongly equate CFS with ME and to give authority to the misinformation of ME as a fatigue condition in a continuum with other fatigue conditions and then it is easy to justify the wrong treatment of ME through a biopsychosocial pathway.

Q. When will the DOH acknowledge its policies have been wrong for patients with ME, specifically because it has listened to the wrong people and given too much authority to psychiatry inappropriately, ig-

noring medical evidence?

Q. When will direct and necessary biomedical investigations, tests and treatments, be offered to those suffering specifically with ME ?

Myth 3 : The NICE Clinical Guideline on the diagnosis and management of CFS/ME recommends the use of CBT in patients mildly or moderately affected by CFS/ME on the basis that this was one of the interventions for which there was the clearest research evidence of benefit. A number of other statements, including particular drugs, vitamin supplements and complementary therapies were not recommended because there was not enough evidence to suggest that they were effective.

Comment: Unfortunately the recommended use of CBT as an aid to coping for people with mild or moderate ME, is not the way CBT is used in the treatment of ME. Unlike in other illnesses, it is used to alter wrong illness belief, assuming that people are ill because they think they are.

Without adequate or specific ME testing it is almost impossible for the genuine ME sufferer to gain proof of the underlying system dysfunction and leaves them open to misrepresentation as a fatigue condition and vulnerable to wrongly applied CBT, not intended to be used in this way, even by NICE in their guidance.

Condemnation of NICE guidelines

Almost all the UK ME Charities condemned the Guideline as unfit for purpose: such was the outrage and disgust throughout the ME/CFS community at the way that NICE had deliberately ignored so much evidence about ME/CFS.

Over twenty renowned ME experts later provided Statements to the Court (Judicial Review of the NICE Guidelines) challenging the validity of the research that NICE used for its Clinical Guidelines. NICE relied on a handful of low quality Randomised Controlled Trials that were methodologically flawed.

NICE's recommendation that people with severe CFS/ME "should be offered an individually tailored activity management programme as the core therapeutic strategy, which may: "draw on the principles of Cognitive behavioural therapy and Graded exercise therapy (1.9.3.1), is extraordinary - but no surprise given that Guideline Development Group (GDG) excluded from its membership all NHS specialists experienced in treating adult ME patients . As Kevin Short comments : "This is shocking by any standards: imagine the media outrage if a NICE guideline on infectious disease excluded all virologists from its production or a guideline on breast-cancer excluded all oncologists?" Kevin Short(2012) A CALL FOR A PARLIAMENTARY SELECT COMMITTEE OF INQUIRY INTO UK ME & CFS POLICY http://www.angliameaction.org.uk/docs/wessely-misleading.pdf

The NICE Guideline on ME :

1. Failed to grasp the full nature of neurological ME and the implications for management, and also failed to provide adequate guidance for diagnosis.

2.Recommended widespread use of the psychosocial rehabilitative treatments of CBT(Cognitive Behavioural Therapy) and GET (Graded Exercise Therapy) in spite of reports of harm from ME

patients. At best this means that the main thrust of the guidelines are irrelevant for most people with ME, at worst dangerous.

3.Failed to consider the relevant evidence about the illness.

4.Placed undue emphasis on two treatments - cognitive behavioural therapy (CBT) and graded exercise therapy (GET) - for which the underlying evidence is inadequate and unrepresentative.

5.Did not agree to recognise the World Health Organisation's classification of M.E. as a neurological illness.

6.Did not convey or reflect the impact which the illness can have on the lives of those people who are most severely affected by M.E

7.Did not study the aetiology and pathogenesis of ME, this meant that thousands of papers could not be discussed as part of the process. NICE ignored the international evidence that ME/CFS is a biomedical, not psychiatric, disorder, claiming that studying this evidence fell outside its remit.

8.Relied upon an "evidence-base"which has been exposed as deeply flawed by virtue of the heterogeneous populations studied; the methodological inadequacy; the corrupted data; the high drop-out rates; the undeniable ineffectiveness of CBT/GET as shown by the outcomes measures, and the finding that the claimed benefits may have been illusory,

(see: "Inadequacy of the York (2005) Systematic
Review of the CFS/ME Medical Evidence Base" by
Malcolm Hooper & Horace Reid at *
http://www.meactionuk.org.uk/FINAL_on_NICE_for_Gibson.html)
:

9.Created a wholly inaccurate picture of ME : a serious disabling neurological and multi-system dysfunction disease; the Guideline more accurately describes patients suffering from idiopathic fatigue, as outlined by the WHO at ICD-10-f48.

Significantly NICE proscribes the use of supplements and vitamins in the treatment of ME. Specifically it states : There is insufficient evidence for the use of supplements – such as vitamin B12, vitamin C, co-enzyme Q10, magnesium, NADH (nicotinamide adenine dinucleotide) or multivitamins and minerals – for people with CFS/ME, and therefore they should not be prescribed for treating the symptoms of the condition. (NICE Clinical guidance 53)

Margaret Williams comments : “the proscribing by NICE of appropriate testing and its stipulation that any vitamin or mineral deficiency must not be corrected by prescription would seem to constitute a real and even life-threatening danger to people with ME/CFS.”

(More potential dangers of the UK NICE Guideline on "CFS/ME" for people with ME/CFS Margaret
Williams http://www.meactionuk.org.uk/Dangers_of_NICE_for_MECFS.htm)

NICE’s proscription, although only guidance, is quite extraordinary , in light of the evidence- here , briefly, is some of it :

Magnesium is involved in over three-hundred enzymatic reactions in the body. It is essential for energy production, nerve conduction, muscle function, and bone health. Supplemental magnesium can improve energy levels and emotional states, while decreasing pain. Magnesium deficiency has been found to be common in M.E. and that 80% of sufferers could benefit from intramuscular magnesium injections. (Lancet 1991 Mar 30;337(8744):757-60)

Coenzyme Q10 is necessary for energy production, immune function and repair and maintenance of tissues. Coenzyme Q10 deficiency in ME is related to fatigue, autonomic and neurocognitive

symptoms and is a risk factor explaining the early mortality in ME/CFS due to cardiovascular disorder. The mean age of ME patients dying from heart failure (58.7 years) has been found to be significantly lower than the age of those dying from heart failure in the general population. (http://www.stonebird.co.uk/obama/index.html)

Vitamin C boosts immune function and helps detoxification pathways ; some long-term M.E. patients report significant improvements with very high dose vitamin C treatment.
In some studies it has been shown that people with ME have a specific kind of B12 deficiency in the cerebral spinal fluid, the same as that found in Alzheimer's.

IIt has been demonstrated , through MRI spectroscopy, that people with ME , exhibit an ATP deficiency, in particular after even a low level of physical exercise. NADH (the reduced form ofnicotinamide adenine dinucleotide, also known as Coenzyme I , is the biological form of hydrogen which reacts with the oxygen we breathe to produce energy in the form of ATP; one mol of NADH will form three mols of ATP.

IIn one study monitoring the effect of nicotinamide adenine dinucleotide (NADH) on people with ME , twenty-six subjects were given the reduced form of NADH for four weeks and a placebo for an additional four weeks. Thirty-one percent showed improvement when on NADH, while only 8 percent improved when taking the placebo.

In 2002 De Meirleir and Englebienne published a biological overview of ME. They found that Vitamin B 12 from 1000 to 5000 u showed symptom improvement in 2 to 3 weeks. This is administered by injection every 2 to 3 days. A rationale for the effectiveness of vitamin B 12 is that it is a scavenger for nitric oxide and its oxidant product peroxynitrite , which may be responsible for ME symptoms.

They found that Vitamin C enhanced Natural Killer (NK) cell activity in people with ME, was improved when DHEA, a steroid hormone, was added.

Where muscle pain is a key symptom magnesium combined with malic acid was found to be useful.

Greg Crowhurst (2012) : Care for Someone with Severe Myalgic Encephalomyelitis , Stonebird , Chp 4 : ME, a Biomedical Overview.

Q. Will the DOH look again at its underlying assumptions about ME and acknowledge it has not got treatment right for this vulnerable, physically ill group of patients?

Q. Will the DOH recognise the treatment pathway promoted on the NHS is currently flawed, inappropriate and dangerous for patients and needs reviewing from a biomedical perspective?

Myth 4 :The PACE Trial looked at the potential benefits of CBT in treatment of CFS/ME. The results of that trial, which were published in the Lancet on 17 February 2011, demonstrated that CBT and graded exercise therapy were moderately effective outpatient treatments for CFS/ME when added to

specialist medical care, as compared with adaptive pacing therapy or specialist medical care alone and that all four treatments were safe.

Comment : It is impossible to understand how the PACE trial was allowed to progress , given that the Wesley school psychiatrists clearly state they believe CFS/ ME to result from maladaptive thinking and deconditioning, neither of which represents the physical disease Myalgic encephalo-myelitis; a neurological disease with multi-system dysfunction.

PACE and FINE Trial travesty

The FINE and PACE Trails, two studies funded by the Medical Research Council (MRC) and by the Department of Works Pensions (DWP), set out to prove the effectiveness of CBT and GET, based upon the 20 year old, obscure Oxford Criteria . Their intention was to prove that they could change the behavioural and cognitive factors assumed to be responsible for perpetuation of the participant's symptoms and disability , at a £5 million cost to the taxpayer , “did no such thing”, as the Countess of Mar points out :

“There is no indication in the trial results that one single person fully recovered after a year of CBT and GET. There is no indication that any who were not working went back to work or, in fact, that there was more than a very modest improvement in those whose health was deemed to have improved.

However, I must say that the spin on the results has had a very deleterious effect on the public perception of the illness and on the provision of health and social care for people with ME. “

Countess of Mar (2012) House of Lords - Neurological Services Debate - 20 November 2012
http://forums.phoenixrising.me/index.php?threads/house-of-lords-neurological-services-debate-20-november-2012.20550/

Greatly criticised by the ME Community and virtually all ME Charities, the (PACE and FINE) trials :

1. Brought together (conflated) two diseases that the WHO rightly categorizes separately - neurological "ME/PVFS" (ICD-10-G93.3) and psychiatric "Fatigue Syndrome" (ICD-10-F.48.0) - and misrepresented the latter as the former. (Hooper 2011)

2. Mixed at least three taxonomically different disorders in the trial cohort - those with ME/CFS (ICD-10 G93.3), even though the entry criteria exclude such patients; those with fibromyalgia (ICD- 10 M79.0) and those with a mental/behavioural disorder (ICD-10 F48.0).

3. Excluded children and those who are severely affected. The results of any trial t hat excluded those who are severely affected cannot be taken seriously. (Hooper 2011)

4. Included, (PACE Trial) a large number of participants , 47% - who were found to be suffering from one or more psychiatric disorders .

5. Took no biological measurements. Studies of CBT in other conditions including HIV/AIDS and cardiovascular disease, routinely collect data on immune markers or other biological measures in an attempt to understand how and why CBT works in the context of the condition studied.

6. Abandoned the use of an actometer, an instrument to measure activity , which would have provided unequivocal objective evidence of improvement or non-improvement.

7. Found that "pragmatic rehabilitation" (based on CBT/GET) was minimally effective in

reducing fatigue and improving sleep only whilst participants were engaged in the programme (FINE Trial) and that there was no statistically significant effect at follow-up.

8. Did not conclude CBT/GET/PACING were even cures for the loosely defined CFS or even "effective" treatments for it; they said they were "only moderately effective".

9 Did not return the participants to their health or even close to it.

10. The only reported improvement , an increase of being able to walk an extra 20 steps,(PACE Trial) , cost the nation £5 million.

11 Did not study ME.

Greg Crowhurst (2012) : Care for Someone with Severe Myalgic Encephalomyelitis , Stonebird , Chp 4 : Severe ME : the Political Context

Q. How can the DOH say that these treatment pathways are safe, for people with ME, given the trial did not actually study ME specifically?
Q. How can the government justify spending £5 million on a trial using money set aside for ME, when the researchers themselves were forced to publicly admit it did not study ME? Q. Why was this allowed to happen and why there has been no outcry from within government about it?

Myth 5 : The Oxford definition of CFS/ME is the most straightforward to use in clinical use.

Comment : the use of the term CFS/ME is inaccurate and inappropriate and confuses general fatigue conditions and mental health issues with ME, a neurological disease. The Oxford are too vague and fatigue focussed to safely identify anyone with ME. They also exclude neurological illness which ME is and lead to a confusion over who is being studied and what illness they have.

The ICC criteria are currently the most appropriate criteria, as they acknowledge the multi system dysfunction, including importantly the post- exertional autonomic response,which are ignored by the Oxford criteria and yet which are key to identifying ME patients and separating them from mental health and other fatigue conditions.

Use of Oxford criteria leads to confusion

The use of the Oxford criteria in the PACE and FINE trials was a farce because although the research was supposed to include people with ME, the Oxford Criteria do not identify ME.

ME is a neurological disease, yet the PACE and FINE trials, based upon the Oxford Criteria, which exclude neurological symptoms, did not study people with ME, yet they are being used to justify the psychosocial treatment of ME.

On 17th May 2011 Zoe Mullan, Senior Editor at The Lancet, sent an email to Professor Hooper in The Facts : to the complaint he submitted about the PACE Trial article published online by The Lancet on 18th February 2011 and subsequently in the journal on 5th March 2011.In her email, Zoe Mullan wrote: “We asked the authors of the PACE trial to respond to your concerns, which they have duly done. Your complaint and their The Facts : were discussed at the highest management level and this group of executive editors was fully satisfied that there were no grounds whatsoever on which to take further action. We attach the The Facts : provided to us here. From an editorial perspective, the case is now closed”.

In their letter, Peter White et al state: “The PACE trial paper refers to chronic fatigue syndrome (CFS) which is operationally defined; it does not purport to be studying CFS/ME”.

The sentence continues by stating that the PACE Trial studied: “CFS defined simply as a principal complaint of fatigue that is disabling, having lasted six months, with no alternative medical explanation (Oxford criteria)”.

This is exactly what the ME/CFS community has been saying from the outset, namely that the PACE Trial was not studying those with ME.

Hooper M (2011) Initial The Facts : by Professor Malcolm Hooper to an undated letter sent by Professor Peter White to Dr Richard Horton, Editor-in-Chief of The Lancet
http://www.meactionuk.org.uk/Hoopers-initial-The Facts :-to-PDW-letter.htm

The Oxford criteria, drawn up by psychiatrists and published in 1991 , broaden the 1988 CFS criteria , to include all those with psychiatric chronic fatigue , while specifically excluding those with neurological disorders; it states: “The following guidelines were agreed. There are no clinical signs characteristic of the condition. Psychiatric disorders are not necessarily reasons for exclusion”. Effectively, then, the Oxford Criteria open the door to the world and his wife being diagnosed with CFS; if they feel chronically tired for longer than six months without any medically determined cause .(Margaret Williams 2004)

Used by a small group of English psychiatrists and by the University of Nijmegen, Netherlands , the Oxford criteria , by definition, exclude all those with authentic ME from study - yet they are hugely influential in the UK, because they underpin the “psychosocial” treatment regime - the application of Cognitive Behaviour Therapy (CBT) and Graded Exercise Therapy (GET), to “cure” maladaptive thinking and underlying patterns of “illness beliefs”.

The Oxford Criteria, by definition, should not be used to define ME policy and treatment practices within the NHS, yet they are highly influential.

The new biomedical ME International Consensus Criteria (ICC), on the other hand, an attempt to identify the unique and distinctive characteristic symptoms of ME (Carruthers et al 2011), uses the original clinical term of Myalgic Encephalomyelitis , in stark contrast to the prevailing vague, fatigue-based Oxford and CDC criteria which dominate at the moment and use the ‘CFS’ or ‘CFS/ME.’

The International Consensus Criteria provide a framework for the diagnosis of ME that is consistent with the patterns of pathophysiological dysfunction emerging from published research findings and clinical experience.

Greg Crowhurst (2012) : Care for Someone with Severe Myalgic Encephalomyelitis , Stonebird , Chp 4 : Severe ME : the Political Context.

All the time that the Government and the NHS focus on general fatigue they will be omitting and neglecting people with ME, who will continue to be negated, and harmed. This is a matter of life and death for patients.

Summary :

The CMO emphasised the neglect of people with ME back in 2002, yet things have not changed. This is because the ME community has for many years suffered, perhaps uniquely, from the effective psychiatric takeover and denial of their illness, which this Government seems to have no intention of challenging.They have achieved this through creating confusion over the name

and the patient cohort through the use of vague fatigue criteria , excluding neurological yet at the same time, taking over the name ME and wrongly applying a mental health interpretation, leaving doctors and patients floundering in a sea of misrepresentation,misinterpretation,mistreatment and misdiagnosis.

Under the ongoing influence of powerful vested interests, ME has become inextricably tangled with psychiatric Chronic Fatigue to such an extent that truth seems false and genuine need is misinterpreted as intentional dependency :

1. The true number of symptoms in ME are constantly denied or ignored.
The physical tortuous reality of neurological ME is constantly denied, diminished, negated and ultimately neglected .

2. People are constantly not treated fairly ,with equality, because their true reality is denied. Their equality is denied right across the board and they are disempowered. They do not have an equal voice , they are not considered equally valid in what they have to say and their complaints and demands for fair treatment are twisted and potentially made into “deviance” and “non- compliance”.

Meantime Severe ME patients are simply dismissed or abandoned without support (Hooper et al 2005), for there is no appropriate biomedical NHS treatment facility anywhere for patients in the UK.

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The lived experience of severe me

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