



ME COVER-UP

Stonebird

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**In support of the 25% Group
Severe ME Awareness Day
Cover-Up Campaign 2014**

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THE EXPERIENCE OF SEVERE ME

ME Cover-Up by Linda Crowhurst

IN THE PAST TWENTY years since I have had it, Myalgic Encephalomyelitis has been covered up so that no one can really say with absolute certainty what it is anymore or who actually has it, what it means or how to help people with it, because there are so many different meanings and interpretations of “ME”, including misdiagnoses.

It is a travesty. A person with genuine ME, nowadays, will most likely have the label CFS attached to their illness, be treated as if their illness is one of many poorly defined fatigue conditions and pushed down the NHS psychosocial pathway : "Oh yes, you feel ill" , " You feel as if you paralysed", "You just need reassurance"...."It's nothing serious"...etc. if you are considered to be mildly or moderately affected you will be offered Cognitive Behaviour Therapy to change your thought patterns and Graded exercise for deconditioned muscles, ignoring your physical disease.

When I first became ill I was treated very badly by my GP, who did not believe in ME.

The most unfortunate thing that has ever happened for people with ME is the complete failure of the medical profession to protect the name and the patients who have ME, instead choosing to rename the disease CFS, allowing psychiatry to waltz in and claim it as their own, making CFS into an umbrella term, not even a specific disease, with a variety of vague and differing criteria to supposedly identify it, with fatigue the primary symptom... And no acknowledgment of the more severe symptoms whatsoever, nor the important difference between fatigue and post-exertional fatigue.

It has been a well orchestrated fatigue take over, that has led to the almost complete pushing out of genuine ME patients from any medical pathway or appropriate treatment path in the UK. It has resulted in a denial of the most severe symptoms; paralysis, for example, is not even mentioned in any of the criteria currently in use, despite being

apparently quite widespread in the patient community, to varying degrees. (See Stonebird Paralysis study 2013)

It has become a mechanism for neglecting the most severely ill, to not understand their illness or comprehend their need, for the focus has become firmly entrenched upon fatigue, treated primarily by the psychiatric therapies of Cognitive Behaviour Therapy (CBT) and Graded Exercise Therapy (GET).

If only, when they changed the name, they had kept the illness criteria the same and kept psychiatric fatigue out of it, to ensure that even if it were called CFS it was still ME. This did not happen. ME and CFS are not equivalent, this is why there is so much confusion and misdiagnosis and mistreatment now.

I was shocked then, I am still shocked now, that even twenty years on, G.P's and other professionals can still choose how they interpret a persons illness, based purely on their personal belief and on the psychiatric misinformation and misrepresentation of ME. The NICE guidelines, deplored by most genuine ME sufferers and charities, promote a ridiculously inappropriate psychosocial fatigue pathway, that includes patients with psychological fatigue alongside Myalgic Encephalomyelitis, a neurological disease, under the one label CFS /ME, primarily through poor identification criteria.

Myalgic Encephalomyelitis has been medically covered over and misrepresented as a chronic fatigue condition, so that to actually find it within CFS, is to look for a needle in a haystack, only this time it is a fatigue haystack, full of people with different, poorly identified illnesses, who are therefore not receiving adequate medical input.

Instead of finding a clear patient cohort with Myalgic Encephalomyelitis, you will most likely find people with undiagnosed Lyme Disease, Fibromyalgia, untreated hypothyroidism, undiagnosed adrenal insufficiency or even Addison's Disease and other rare diseases possibly, such as Periodic Paralysis and mitochondrial disease, there will be others, all unrecognised and inaccurately diagnosed, alongside allergy, burn out, hyperventilation and mental health chronic fatigue, all potentially coming under the umbrella term CFS. This is shocking and unacceptable and helps no one.

No one is getting the right treatment, yet some could possibly be helped if accurately diagnosed; even the people with mental health issues were not cured by the CBT/ GET regimes in the extremely expensive psychiatric led research, the PACE trial.

It is bad enough that people with mild and moderate ME are recommended CBT and GET by NICE, despite the great risk of harm to their health, for the fatigue interpretation ignores the post- exertional reaction and does not acknowledge that ME is a neurological disease, but equally serious, the symptoms of everyone with ME are being ignored and even the most severely affected have little or no biomedical input into their disease.

Very worryingly the most severely affected are at increasing risk of being carefully channelled into a more extreme psychiatric misinterpretation of their illness, with Bodily Distress Syndrome (BDS) now being dangerously pedalled as the new psychiatric platform to potentially wrongly incarcerate the more severely affected. Read Karina Hanson's story (Severe ME featuring Justice for Karina Hanson) and read Bodily Distress Syndrome : a biased dangerous supposition : all links at the ed of the article.

It is easy to cover over the truth of physical illness if you do not do the correct testing to show up the physiological dysfunctions. That is exactly what is happening.

The ways that ME is being covered up and side-lined are countless and shocking, once you start to look, with the most severely ill the most harmed by wrong interventions, ignorance, misinterpretation and mistreatment or by being completely neglected, some even dying from lack of proper investigation and appropriate medical pathway or wrong treatment protocols.

Some take their own lives from the sheer physical torment and despair that comes from institutionalised medical neglect.

The very real illness and serious symptoms of people with Severe ME are not being represented adequately, by the main charities. No one in power is actually listening to us anyway or taking effective, just, action.

The government, despite accepting ME is neurological, does nothing to challenge the psychiatric status quo. This is particularly surprising in the light of a High Court ruling back in 1996 in a motor accident case (Hooper 2014) where the physical vs psychiatric interpretation of ME was argued, by well known practitioners on both sides, the physical interpretation being finally ruled as correct.

The NHS information on ME is shockingly inadequate and misrepresentative. If you cannot afford private testing you are open to misinterpretation, medical and social isolation and misunderstanding and no hope of biomedical treatment.

Having ME is possibly one of the worst diseases to have in the 21st century because the most severe are medically ignored, the less severe are mistreated and no one really gets the biomedical treatment or medical respect they deserve and need.

The NHS is not providing a medical treatment pathway, a biomedical specialist service, consultant home visits for the most severe, appropriate ME specific tests or investigations of underlying dysfunction and the disease process - even rare diseases are not being properly tested and ruled out. They are offering a fatigue service for Chronic fatigue.

It is a ludicrous place to be in, to be so ill that you cannot get to hospital, despite you need to, because you are too extremely physical ill to try or at risk of deterioration if you do try, yet you need treatment more than many of the people who go there, who may only go for check ups, follow ups, illness prevention, whilst the most ill get little or no effective medical support or input for their disease; a serious disabling neurological disease impacting multiple systems of their body.

The best it seems that most can hope for, but do not necessarily get, is to be believed and possibly given some sleeping pills and pain medication or more investigation of a single symptom by some other -than- ME-specialist.

The most severely ill become too ill to see anyone and are harmed by the environment. Intense hypersensitivity to touch, noise, light, chemicals, motion, makes it impossible or dangerous to try. Any effort results in indescribable post- exertional physical deterioration, which in the case of the most severely affected can be extreme and life threatening even. Their

severe symptoms are often ignored, not properly investigated or explained, certainly not treated.

No one knows how to help them. Their illness is down graded and neglected. Those who try to access help are often harmed or dismissed or simply believe nothing more can be done or are risk of harm through ignorance. They are disillusioned by medicine yet longing for medicine to find an answer.

They are left to cope as best they can at home, often struggling to access basic care, dental treatment, optician and medical support. Yet this is still often preferable than to be harmed by a system that does not know about your illness, does not understand the physiological dysfunction in your body, does not provide the safe environment needed and will freely and frequently misinterpret ME as CFS then assume it is a psychiatric condition or simply not know what to take into account how to keep you safe and not make you worse. The more complex and extreme your symptoms, the more hard it is for people to comprehend them or their own impact upon them. It is too easy to unintentionally cause deterioration and intense suffering. This is how ME is covered over and our secret hidden tormented lives are covered up with it, as few or no one sees us as a consequence of the severity of our illness.

The psychiatric lobby dominates the NHS, their influence spreads far and wide across all spectrums of society and the media.

What can we do then to re-establish the truth?

We can :

- speak up.
- formally complain.
- lobby M.P's.
- ask the right questions.
- fight back with advocates speaking the truth on our behalf.
- look after ourselves by refusing wrong treatment pathways.
- keep asking for right medical support and a new biomedical pathway.
- Keep demanding accurate criteria that separate ME from Chronic fatigue and other fatigue conditions.

- demand better testing, including testing for Lyme Disease, which is also being medically ignored, to ensure people have accurate diagnoses.
- make sure our libraries and doctors surgeries have the right information about our disease, especially Severe ME, not psychiatrically interpreted CFS.
- really get to grips with why using the term CFS serves no one except the psychiatric and fatigue lobby and stop accepting the use of the term.
- demand that there is proper safe diagnosis with the best criteria available: currently the ICC Criteria, which separated ME from CFS.
- demand change again and again till it happens.
- try to be up to date as possible ourselves on research and medical break- throughs.
- make formal complaints if possible for you and appropriate.
- challenge the NHS to offer biomedical clinics, based medical principles.
- try and get awareness and change happening beyond the ME community, for this is where change needs to happen: in politics, healthcare and social care, within our local communities, friends and families.
- check what library books are being stocked in your local library and make sure they represent accurate information on Myalgic encephalomyelitis.
- if you can, check what information and posters your local health surgery has available and make sure it is appropriate.

None of this is easy in reality, with such severe illness and the cognitive dysfunction associated with ME. Yet we are not getting our heeds met. We are not being heard. We are not being effective enough, despite knowing the need ourselves.

We need to try and be aware of who genuinely represents and supports ME, it may not be as many as it seems at first glance....do your own research if possible, do not trust, where trust is not deserved. Understand peoples language and meaning.

Don't sell us short. Don't ask for less than the best. Do not compromise the truth of ME or it will disappear without a trace and psychiatry will

have won. Be very careful not to be harmed by people who do not understand your illness. Make sure they mean neurological Myalgic encephalomyelitis when they say ME, not a vague fatigue condition that fits the generalised CFS label. Make sure people understand the risk to your health if they get things wrong. Check everything and everyone out. Never take people for granted. Your health is at stake. Great harm is easily done through ignorance and quite possible, especially the more frail and severely ill you are.

It is easy to feel deflated, desolate, down trodden, disappointed and hopeless, with the lack of real progress. Never give up hope, though. Eventually we have to win. But the way to really do that is to see the truth, what is really going on, how little is really being offered, demand that ME is once and for all separated from CFS and removed from the possibility of fatigue misinterpretation and mistreatment and that psychiatry is removed from intervening. Demand this from every institution and group and person involved with covering up the truth of Myalgic encephalomyelitis.

What we need is to demand that a new medical pathway is created, with serious, aware, and experienced medical specialists, preferably from the field of other rare diseases, who will visit the most ill at home, who will look at the physiology of the body and try and develop new understanding of the malfunctions and offer treatments for the causes of ME.

What we need is biomedical clinics not psychosocial ones.

What we need is the complete removal of psychiatry from our disease. Let psychiatry treat psychiatric illness, not Myalgic encephalomyelitis.

We need better specific research, but it needs to be for ME, not CFS, using clearly identified ME patient research cohorts, with accurate criteria that intend to separate ME clearly, not focusing on fatigue, but on the cause of the illness and the specific severe symptoms people have, including paralysis. Anything less continues to cause confusion, lack of clarity serves no one's health needs ultimately.

In the meantime:

ME is not easy to understand...help people to understand it.

ME is being misrepresented as Chronic Fatigue...make sure you represent it as a neurological disease.

ME is a complex disease and the most severely affected are the most hidden and misunderstood...make sure you speak the truth for yourself and them.

ME is being compromised away....never compromise, lives are at stake.

Know that you have a physical disease that is not getting the medical support it needs and deserves, because quite simply it is being covered up. Keep looking for answers. You never know if you have been misdiagnosed and could get treatment!

We all deserve correct medical support and correct provision for the severity of our illness. It is simply, disgracefully. not there currently.

Most importantly look after yourself and demand a new medical pathway for ME.

Let us expose the ME cover up once and for all. Let us ask for a new biomedical pathway for people with neurological Myalgic encephalomyelitis. Nothing else will suffice.

I simply do not want a psychosocial pathway for ME. Do you?

If there is to be better inclusion of the more severely affected in services in the future, then we have to be clear now that the services themselves need to change. They are not suitable. We need new services, we need change. We need better trained aware specialists, willing to investigate, grow and learn to create medically supportive centres of excellence for ME. Ones that really do meet medical need and offer environments that are safe and incorporate new ways of working that will reach out to the bed bound and not risk harming them further.

We have to stop the cover up!

Links :

Hooper 2014 : http://www.meactionuk.org.uk/ME_Judgments.htm

Severe ME featuring Justice for Karina Hanson :
<http://www.stonebird.co.uk/severemebook/severeme.html>

Bodily Distress Syndrome : a biased dangerous supposition :
<http://www.stonebird.co.uk/bds.pdf>

See Stonebird Paralysis study 2013
<http://carersfight.blogspot.co.uk/2013/08/paralysis-qualitative-study-of-people.html>