



BODILY DISTRESS SYNDROME

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**Bodily Distress Syndrome :
a biased, dangerous supposition.**

**Greg & Linda Crowhurst
(with grateful thanks to Susanna Agardy)**

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THE EXPERIENCE OF RETURNING

Bodily Distress Syndrome : a biased, dangerous supposition.

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(This article is endorsed by the 25% Severe ME Group & The Grace Charity)

*Greg & Linda Crowhurst
(with grateful thanks to Susanna Agardy)*

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BODILY DISTRESS SYNDROME (BDS) is an attempt by psychiatry to group patients with the physical diseases of Fibromyalgia, CFS (and by implication ME), Hyperventilation, IBS, Non Cardiac chest pain, Pain syndrome and patients labelled as having a somatoform disorder, under one collective mental health label, exclusively upon symptoms.

Given that its underlying hypotheses is one of an abnormal stress response WITHOUT corresponding abnormalities in specific peripheral organ systems, BDS places an emphasis on bodily distress with apparent *‘increased sensitivity to symptoms or sensations’* (Fink et al 2007).

According to an NHS pilot BDS scheme in Barnet, the illnesses above, specifically including Myalgic encephalomyelitis (ME), are treated through a *“Cycle of Change”*, based on behaviour modification, leading to recovery. Considering that the NHS itself states that there is no cure for “CFS” (in which it includes Myalgic encephalomyelitis), that is an astounding claim for to make.

It is also extraordinary, considering that so many world-class clinicians state that ME is either an infectious disease, or an auto-immune disease as a direct result of infectious insult and recognise ME as a complex neuro-immune disorder *accompanied by chronic low-grade inflammation, increased levels of oxidative and nitrosative stress*

(O&NS), O&NS-mediated damage to fatty acids, DNA and proteins, autoimmune reactions directed against neoantigens and brain disorders (Maes et al 2014, WillBeatCFS 2013), requiring a skilled biomedical response. BDS, however, appears to ignore this.

BDS, in line with everything else the so-called “psychiatric lobby” puts out, is skilfully wrapped in a self-fulfilling, circular argument, based on a fallacy, that is immensely tricky and slippery to untangle. It sounds plausible to some, acceptable to others and is accepted by those who do not have the integrity or discernment to look more deeply, with biomedical understanding.

For many years, the psychiatric lobby, which exercises immense influence over Government policy, has been aggressively promoting a conceptualisation of Myalgic Encephalomyelitis as a mental illness, a conceptualisation that also fits the needs of the medical insurance industry (cf. Pileki et al 2011) through :

1. a failure to distinguish between mental health disorders and physical diseases
2. a deliberate focus on fatigue rather than system dysfunction
3. research bias
4. suppression and deliberate exclusion of biomedical evidence
5. ongoing attempts to “eradicate” physical diseases by asserting that they are nothing more than an “aberrant illness belief”
6. denial that ignores significant symptoms and signs, especially cardiovascular, neurological and immunological
7. influence and functioning in areas of medicine in which they have no expertise such as immunology, vascular biology and muscle pathology (cf. Hooper 2010)

The result is a system that tries to make people with ME into mentally ill persons, with a psychiatric diagnosis. (cf. Nørgaard 2014) It has resulted in the medical neglect and mismanagement of tens of thousands of people with serious physical illness and even deaths.

A Dangerous Agenda

BDS plays to a dangerous psychiatric agenda. The questions designed to identify ME constantly use the term “*bothersome*”. Use of this term reveals how little the severity of the illness experience BDS actually describes, is understood. Severe ME, for example, has been compared to terminal cancer and last stage AIDS, hardly ‘bothersome’. ‘Bothersome’ aligns with the impression that something is irksome but not serious.

Expressions such as : “*Unfortunately, some patients feel that they have been misunderstood*” or “*if you feel something is wrong*”, are offensive and misrepresentative, given how many patients, in reality, ARE misunderstood by their doctors, specifically because of the powerful influence of psychiatry. It is not just a “*feeling of being misunderstood*” or “*a feeling of something wrong,*” it is a fact. There IS something very wrong.

The description of “*unpleasant feelings*” is an underplaying of the severity of pain and the ongoing assault and intensity of suffering and system dysfunction that patients experience without any relief or even basic treatment. The most severe need morphine, anti- epileptics and steroids to cope with pain. Even so, the pain is not diminished. Hardly “just unpleasant”.

It should be noted that there is not a diagnosis listed in the major psychiatric diagnostic manuals (such as ICD and DSM) that is associated with any sort of physical test, so, unlike the rest of medicine, aetiology appears to have an insignificant part to play in deciding upon the diagnosis of BDS (cf. Timimi 2011) A recent study, for example, has found that virtually all fibromyalgia patients would be classified as having a mental disease under the DSM-5’s new criteria for somatic symptom disorder and a substantial portion of rheumatoid arthritis patients would also met the threshold and be considered to have a mental illness under DSM-5. (Wilken 2014)

As Susanna Agardy points out: *Psychiatry is all too willing to attribute perverse motives to patients. The significance of physical symptoms is also misinterpreted: for example, if an ME patient is*

unable to walk, this is regarded as a behavioural choice. Psychiatry has required no evidence of itself for these preferred interpretations. There is no display of dispassionate, scientific assessment and no possibility of an alternative diagnosis or treatment is entertained in these cases. The patient is always judged to be in the wrong. Making these favoured interpretations help the practitioners perpetuate their own belief system but are devastating to the patients. (cf Agardy 2012)

The Diagnostic Process

A diagnosis of BDS rests purely on the knowledge, integrity or personal bias of the practitioner.

Fink et al have found four identifiers for BDS (2007) which are cast in the role of manifestations of BDS:

- 1: General symptoms such as headache, dizziness, fatigue, memory impairment and concentration difficulty
- 2: Symptoms from abdomen and intestines
- 3: Symptoms from muscles and joints
- 4: Symptoms from heart and lungs

To arrive at these identifiers a stratified sample of 978 patients was examined applying diagnostic questions based on the SCAN (The Schedules for Clinical Assessment in Neuropsychiatry) instrument, a psychiatric assessment protocol, which is ultimately dependent upon the interviewer's "clinical judgment".

The physical health chapter of the SCAN interview explores 76 physical symptoms distributed among seven symptom groups. The interviewer rates each symptom to be either absent, attributable to a medical condition/dysfunction, or functional (somatic). The section relating to fatigue for example, queries: "*Unwarranted fatiguability after even minor physical exertion. The emphasis is on feelings of bodily or physical weakness and exhaustion after only minimal effort, accompanied by a feeling of muscular aches and pains. Respondents experience the tiredness as unpleasant and distressing.*"

The repeated use of the word '*feeling*' illustrates the subtle jump from actually experiencing a symptom to just apparently 'feeling' that you are experiencing it. The wording may be misunderstood by patients being questioned, who obviously feel the impact of the symptom, but it is not just an emotional feeling, as inferred by the question - it is a PHYSICAL one. Feelings in psychiatry presumably primarily refer to emotion whereas the person experiencing the physical reality of exhaustion, for example, means they can actually feel it physically. They actually do not have enough energy.

Fink et al (2007) acknowledge possible explanatory factors such as '*hyperactivity of the autonomic nervous system*', '*malfunction of the reticular system located within the brain stem and the medulla*' '*The hypothalamic-pituitary-adrenocortical axis may be involved, as well.*' and attribute physical symptoms to "*Autonomic arousal & HPA axis hyperactivity 'alertness'*" According to BDS this leads to a stress state without involvement of the organs.

However the activity of the hypothalamus–pituitary–adrenal (HPA) axis – a major player in the neuroendocrine system that controls reactions to stress and regulates many body processes – is known to be blunted in ME (Crowhurst 2013).

An altered function of the hypothalamic-pituitary-adrenal (HPA) axis and the sympathetic nervous system is also implicated in IBS (Chang et al 2008). Furthermore Fibromyalgia is related to a neuroendocrine disorder characterised by hyperactive pituitary ACTH release and a relative adrenal hyporesponsiveness (Griep et al 1993), while an exaggerated inflammatory process is considered an important pathophysiological feature of complex regional pain syndrome. (Park & Ahn 2012)

BDS seems unaware of the systemic immune and metabolic imbalances, that voluminous evidence in ME or 'CFS' research has uncovered. They seem comfortable to conclude that '*... the various functional somatic syndromes may thus simply be an artifact of medical specialisation reflecting the referral process and specialists' tendency to focus only on symptoms pertinent to their specialty.*' (2007)

The bias inherent in psychiatric diagnosis seems to have escaped their attention. Psychiatry, with no objective markers and totally reliant on the subjective opinion of its practitioners is so much more vulnerable to misdiagnosis through bias than any other specialty.

People with ME, or so-called CFS who supposedly have 'all tests normal' do indeed experience many symptoms related to the BDS identifiers. However, there is also evidence of physical problems in particular organs, as well as systemic problems offering possible explanations for the symptoms experienced:

Neurocognitive problems which are one of the most frequent and disabling symptoms associated with ME. Up to 90% of patients, in studies, report having memory/attention deficit problems, made worse by physical or mental exertion. (Cockshell and Mathias 2010) Evidence of neurological issues have been found by Barnden et al found evidence of brainstem dysfunction and altered homeostasis (2011) Schutzer et al found Cerebrospinal Fluid Proteomes which differentiated 'CFS' patients from those with Lyme disease and controls.

Neuroinflammation has been found to be higher in ME patients than in healthy people; inflammation in certain areas of the brain - the cingulate cortex, hippocampus, amygdala, thalamus, midbrain, and pons has been found to be elevated in a way that correlates with symptoms. (Nakatomi Y et al 2014)

Cardiovascular dysfunction. with associated autonomic nervous system dysfunction has long been proposed as part of the ME disease process. This could be a result of relative inactivity, however it could also be associated with a primary myocardial deficit. (Breakthrough Autumn 2012) A study by Peckerman et al showed that patients with severe CFS had significantly lower stroke volume and cardiac output than the controls and less ill patients. (2003). Cardiovascular dysfunction in ME patients has been well documented for many years, even so there has been little formal research on heart abnormalities in ME.

Professor Julia Newton and colleagues found that the hearts of ME patients have to work harder during prolonged standing, than in

healthy people. They also found that the left ventricular mass was substantially reduced by 23% compared to controls. In addition “blood pool” volume was lower by 26% and cardiac output lower by 25% compared to controls.

Cardiac output in normal people will vary from 7 litres per min to 5 litres per min between standing and supine. In healthy people this drop is not enough to affect function. But in ME sufferers Peckerman found that the drop may be from 5 litres lying down to 3.5 litres standing up.

At this level, people with ME may be in borderline heart and organ failure.

A person with ME will often have cold hands, cold feet and low blood pressure, even if they are overweight- this is highly abnormal - and their heart rates are often increased (10-12 beats a minute faster than in healthy people). Low blood pressure and high heart rates when standing signify a condition called ‘POTS’ postural hypotension (tachycardia) syndrome.

One of the key difficulties facing people with ME is standing still; it can bring on dizziness, altered vision, nausea and fatigue, indicating possible autonomic nervous system dysfunction - POTS is an aspect of autonomic dysfunction that can produce substantial disability. (Breakthrough Autumn 2013).

It has been suggested that postural orthostatic tachycardia syndrome (POTS), relatively common in patients, be considered in the differential diagnosis of ME; currently, measurement of haemodynamic response to standing is not recommended in the UK NICE CFS/ME guidelines, unfortunately.

Hoad et al (2008), for example, found significant POTS could be measured in a high proportion (27%) of ME patients, but in only 9% of controls. Moreover, the POTS observed in the ME group was associated mainly with an increased heart rate to more than 120 beats per minute on standing, while increasing fatigue was significantly associated with the increase in heart rate.

‘Vaso-active’ (blood vessel effecting) substances such as hydrogen sulfide, nitric oxide and carbon dioxide, according to Dr. DeMeirleir, could be causing a permanent increase in the size of the larger blood vessels in ME/CFS patients. As those blood vessels become flaccid the blood pressure drops forcing the small blood vessels to tighten up in an attempt to squeeze blood to the organs and muscles.(Johnson 2013)

Dr Paul Cheney points out that there are two kinds of heart failure. There is the kind that “any cardiologist can diagnose in about a minute”, this kind, people with ME do not have, rather they have “Compensated Idiopathic Cardiomyopathy” (ICM), which is different. (Sieverling 2005)

Dr Cheney explains that in the medical literature, at least 35% of those with a diagnosis of ICM will die within 5 years unless they receive a transplant, yet he has been following ME patients for 20 years and has never seen or heard of one person going on to transplant. It seems that it is their ME which prevents the person developing complete heart failure.

Cheney concludes that the disease (ME) itself “ is protecting you from a deeper problem that has been totally missed, including by me. I missed it, too. Because it's so well-hidden.”(Sieverling 2005)

Studies have shown that the baroreflex response that regulates blood pressure is under performing in ME. (Peckerman et al 2003) The heart’s job is to maintain blood pressure. If the blood pressure falls, organs start to fail and are shut down in terms of priority. As these organ systems shut down, this creates further problems for the body in terms of toxic overload and susceptibility to viruses thus exacerbating all the problems of the ME sufferer. (Myhill 2003)

A study showing that the mean age of ME patients dying from heart failure is significantly lower than the age of those dying from heart failure in the general US population, implies that ME is a risk factor to cardio-vascular disorder.(Maes and Twisk 2009)

The **autonomic nervous system** is the part of the nervous system which controls involuntary functions. It is composed of two sections,

the parasympathetic nervous system and the sympathetic nervous system. In many chronic illnesses, this autonomic balance is impaired with an excessive sympathetic nervous system response and under-active parasympathetic nervous system response.

Research on those with ME suggests the parasympathetic nervous system relaxation response is under-active and the sympathetic nervous system's 'fight or flight' activity is either depressed, associated with exhaustion of the stress response system, or over-reactive. As the autonomic nervous system is one of the major regulatory systems in the body, this is a huge problem. (Graham 2009).

Autonomic Nervous System Dysfunction could account for many of the perplexing and widespread symptoms in ME. This is because the Autonomic Nervous System affects every system of the body: pain sensation, immune system, heart rate, blood flow, blood volume, digestion, saliva, temperature regulation, ability to exercise. Problems like immune dysfunction, oxidative stress, toxic accumulation, cellular dysfunction can all be linked to a dysfunctioning Autonomic Nervous System NS. (Neuffer 2013).

When the Autonomic Nervous System goes wrong, the consequences can be severe; for instance, one of the main consequences is orthostatic intolerance; i.e., the inability to remain standing for long without suffering ill effects. (Breakthrough Summer 2007)

Well known “**gut**” **issues** characterised by pain, diarrhoea, bloating and sensitivities to certain foods are a major feature of ME, A Norwegian study, for example, examined 84 patients, all with a main diagnosis of “gastrointestinal symptoms self-attributed to food sensitivity”. Of these patients all but one were diagnosed with Irritable Bowel Syndrome (IBS) – the majority (71%) also had musculoskeletal pain and the chronic fatigue found in ME. The authors of the study speculate whether an underlying intestinal dysfunction may be at the root of ME and IBS. (Breakthrough Autumn 2012)

The frequent association between ME and Irritable Bowel Syndrome could well be governed by elevated circulating pro-inflammatory cytokines acting either locally or on the brain-gut axis.

Studies confirm that the state of our gut can impact many areas of our health, for example in diabetes the ratio of two bacterial families causes an imbalance and disturbs metabolism. (Lassen 2013)

Lower bacterial diversity is also associated with Crohn's disease. In HIV-infected individuals the gut wall is leaky exposing bacteria to the blood, causing inflammation. Irritable bowel syndrome can develop following recovery from intestinal infections.

Many people with ME experience pain, diarrhoea, bloating and sensitivities to certain foods. These symptoms can be triggered or made worse by physical and mental exertion. These are important clues to what may cause and sustain ME. (CIFDS 2013)

Dr. Chia suggests that enteroviral infections, which can result in the manifestation of ME, are a major problem in his patients; 55% of whom were found to have a chronic enterovirus infection. (Chia 2011) Enteroviruses are responsible for a wide variety of human diseases ranging from mild gastroenteritis to full multi-organ failure. They are commonly considered to be the cause of Myalgic Encephalomyelitis and include Polioviruses, Coxsackieviruses A&B, Echoviruses and E71. While Poliomyelitis has virtually been eradicated in the Western world, others of the genera have filled the vacuum so created. Enteroviruses, remarkably resistant to its harsh conditions, persist in the gut. Throughout the second half of the 20th century there were several Enteroviral pandemics with consequential ME.

Studies examining the microecology of the gastrointestinal (GI) tract have identified specific microorganisms whose presence appears related to ME, which is associated with marked alterations in the gut microbiota, with lower levels of Bifidobacteria, one of the major genera of bacteria that make up the colon flora and higher levels of aerobic bacteria. A CFIDS Association of America pilot study, for example, found greatly increased ratios of Firmicute / Bacteroidetes bacteria before and after exercise in ME. (CIFDS 2013) .

Reports also suggest that ME patients may have a major drop in all E.Coli species - in contrast to Crohn's Disease where over 95% of the invasive species are E.Coli. (Lassen 2013) In IBS, frequently comorbid with ME, there is also considerable physical evidence of

sensitizing pro-inflammatory and lipotoxic lipids, their products and their receptors are increased in tissues of IBS patients with colorectal hypersensitivity. (Feng B et al 2012)

Post-exertional malaise or Post-Exertional Neuroimmune Exhaustion (PENE) is implicitly dismissed by the SCAN question which refers to '*Unwarranted fatiguability after even minor physical exertion*' It implies that there is no reason for a person to be fatigued after minor exertion and implies that all medical causes have been excluded. This is not the case.

PENE is central to ME and is characterised by a pathologically low threshold of physical and mental fatiguability, exhaustion, pain and an abnormal exacerbation of symptoms, involving a profound dysfunction of the regulatory control network. (Carruthers et al 2012). This condition has not been tested for in the BDS testing. Van Ness et al (2003) observed that their study 'supports the stratification of patients based on quantifiable measures of physiological response to exercise.' For example, they found that '... the peak heart rate obtained during exercise showed progressively decreasing values for the more impaired groups.' and 'Peak VO₂ values were less than predicted for all (levels of impairment) groups.'

The test for BDS also miss the point in ME of a worsening of physical performance on a subsequent day of exercise. Van Ness et al also concluded that given the fact 'that the CFS patients could not reproduce their performance on the first test is indicative of the post-exertional malaise that may be unique to this illness. The control group actually improved slightly from test 1 to test 2.' (2007). Such evidence should give pause to diagnosing BDS without these tests. Yet, these tests have been ignored by the psychiatric profession. However, the most severely affected, who BDS appear to be targeting would be too ill to undergo these tests at all, leaving them even more vulnerable to misinterpretation and misdiagnosis.

The danger to people, then, who experience PENE is that they will be misdiagnosed as BDS or other somatoform disorder, because this cardinal symptom is being ignored.

In the tradition of 19th century Insane Asylum medicine (Wallis 2012), BDS is again claiming paralysis as its own, under this new name, leaving people with Severe ME, particularly, vulnerable and open to psychiatric misinterpretation and potential harm: *“Patients ... experience completely different problems in daily life according to the nature of their most bothersome symptom whether it be e.g. paralysis, ..”*(Aarhus University Hospital 2011) .

Meantime most mainstream definitions for ME ignore paralysis. Paralysis, sadly neglected and down- played by medicine in ME, needs medical investigation and research, not psychiatric interpretation. Our consultation with ME patients shows that they commonly experience temporary partial or total paralysis. This symptom could be one of the major features of Severe ME. (Crowhurst 2013)

There are many possible reasons other than nerve damage for the paralysis in Very Severe ME; it may be linked in some way to Polio, given that ME was initially called Atypical Polio and has been linked to enteroviruses or it could be linked to the dysfunction of the autonomic nervous system, mitochondrial dysfunction, environmental poisoning or channelopathy. There may be others.

Paralysis is also associated with Lyme Disease, another disease with similar symptoms to ME, which is not been adequately tested and appears to be frequently incorrectly diagnosed as ME.

Of particular interest is the possible association with potassium imbalance which causes muscle paralysis, known as Periodic Paralysis and is often triggered by the following stimuli: noise, exercise, rest, sleep, food, cold. (Crowhurst 2013)

The BDS diagnosis protocol presumes that the interviewer is fully up to date on current medical research, is not ignoring that knowledge, or falling victim to bias. The concern is that the questioner intending to diagnose BDS may be either unwilling to accept the existence of ME as a clinical condition- or may already have decided that ME is purely a somatoform disorder.

This is also a concern for the other physical diseases mentioned in the identification of BDS.

The Risks of a BDS Diagnosis

The WHO Schedules for Clinical Assessment in Neuropsychiatry - Glossary version 2.1 is crystal clear that if " *the examiner considers that there is, or probably is, a physical explanation for all the clinically significant symptoms described.... skip out of the Section altogether. The cut-off point is always passed if there is any doubt.*"

The burden of proof is always upon the examiner to show that there is no physical explanation for all the clinically significant symptoms. If they cannot prove it then BDS is no better than "specious speculation". Given this expectation, it is hard to see any justification for the inclusion of these physical illnesses under BDS in the first place.

As Natalie Boulton points out :

It is imperative that these complex clinical cases should be accurately diagnosed, monitored and medically treated where possible; not just dismissed and ignored as so often happens when the patient is presumed to be paying too much attention to and exaggerating their symptoms. Medical negligence is resulting in severe treatable illness being misdiagnosed as 'just ME' and ignored.(Boulton 2013)

Psychiatric disorders, like BDS, are not scientifically demonstrated medical diseases, despite their efforts to make it so. There are no lab tests, brain scans, X-rays or chemical imbalance tests that can verify any mental disorder is a physical condition. (The Citizens Commission on Human Rights (CCHR)). This in itself should bring into question the validity of BDS, however, BDS is trying to assert that physical disorder is a mental health condition itself, something quite different altogether.

Medicine, unfortunately, has a long history of giving a false psychogenic attribution to diseases, such as hysteria or conversion

disorder, to diseases before their actual physical causes are known. (Pall 2007) Those explanations are almost always, fatally flawed, both scientifically and logically. Their widespread, uncritical acceptance and use has had serious and specific adverse effects on the people upon whom they are used. (Kennedy A 2012)

The Fallacy

In their emphasis on bodily distress, as opposed to possible physical abnormalities, Fink et al state, *‘Ignorance of or insufficient knowledge about such bodily distress reactions may cause the symptoms to be misinterpreted as physical disease located in peripheral organs and medical attention to be misdirected with the ensuing risk of exposing the patients to iatrogenic harm and further distress.’* (2007) But what about the potential iatrogenic harm from misdiagnosis or misinterpretation as BDS?

Many patients are at risk of becoming victims of this fallacious diagnosis.

As Natalie Boulton (2013) points out in regard to ME :

“No one knows how many patients from all walks of life, including doctors, nurses, teachers and social workers themselves, have been physically disabled and even traumatised by the treatments they have received, been made utterly dependent on others for their care, and denied any recognition of, or apology for, the harm caused to them - including the loss of decades of their lives.”

How many more people will fall victim, if BDS is formally validated across the NHS?

Allen Frances, Chair of DSM-IV and critic of DSM-5 says in relation to new criteria: *‘Do no harm - revise the system with a light and cautious touch only when you are sure of what you are doing after a thorough risk/ benefit analysis.’* (AAPP 2011) This risk- assessment approach should apply strongly to the diagnosis and treatment of poorly identified conditions. He adds, *‘No decision can be right on narrow scientific grounds if it winds up hurting people.’*

A BDS diagnosis cannot even be claimed to be based on science and the potential for harm is great.

There is no justification for trying to subsume physical diseases, without a shred of proof, under psychiatry apart from a desperate attempt to claim them. Who will benefit? Not the ill person, who will almost certainly be harmed. If someone has Cancer, for example, what would be the dreadful consequences if Cancer was suddenly decided to be called a somatisation disorder and treated psychiatrically, just because someone thought it was good idea for research purposes to add it to the list, ignoring any physical tests proving that it is an organic disease?

There appears to be no logical, methodological case for BDS apart from personal opinion and the decision, for whatever reason, to discount everything else.

It should be noted that any registered medical practitioner – consultant or GP who chooses to dismiss or ignore widely available biomedical evidence, is in clear breach of the legal requirement for doctors to keep up to date with developments in medicine and medical science and this consequently raises issues of medical indemnity. In other words any doctor who dismisses ME as a psychiatric condition, is potentially in breach of GMC regulations. (Hooper 2010)

Given this, it is surprising to find BDS being introduced into the NHS for the incorrect treatment of ME as a behavioural disorder.

Incredibly BDS claims it can cure diseases or injuries like Fibromyalgia, IBS, Whiplash, Pain Syndrome, CFS. On what possible basis can this claim be made? Where is the proof that patients are getting “completely well”?

The Centre where BDS was conceived has apparently had “contact with 74 patients with chronic fatigue syndrome since they started in 1999. None of these patients have been cured or returned to full-time work.” (Hansen 2013) The incarceration of Karina Hansen, who has Severe ME, raises serious concerns. It has been estimated to cost Danish tax payers approximately £1500 pounds a day- almost half a

million pounds has been spent so far with no hint of success – yet BDS is being introduced into the UK as a cost effective solution !

As Dr John Whiting states : *the fact that Karina “is still in hospital and is no better and by the sound of things, is much worse than when she was admitted to hospital, in itself, is evidence that her care givers have no idea about the illness that they are trying to treat. How many illnesses do we know of, that require such lengthy in hospital care?”*(Whiting 2014)

Karina's parents describe her “treatment” : *“She is daily exposed to physical retraining and sense-therapy. She is not asked if she can manage this or that, but is ordered to do it. No matter how she tries to protect herself against these abusive actions and mistreatment - like crying, turning around, scratch the ergotherapist . She is up against a bigger force that has control over her and has deemed her to be a psychiatric case.”*(Justice for Karina Hansen 2014)

This clinic has created so much patient dissatisfaction that 16 patient associations, reportedly, have requested that the clinic be investigated. (Help ME Circle 2014) Such is the outcry that the Danish Parliament debated the situation on 19th March 214.

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The propagators of BDS would do well to take note of fellow psychiatrist Allen Frances, chair of DSM- IV and critic of DSM-5. Frances says: *‘ A diagnosis is a call to action with huge and unpredictable results’*. (AAPP 2011) This should serve as a caution in proceeding to treat a condition as psychiatric when it is in fact physical. Many patients have paid the price for this.

This is indeed the case with treatment of ME ; Karina Hansen is the subject in an open-ended experiment she has refused to consent to, or as Dr John Whiting puts it is she *“is is literally becoming the sacrificial lamb in the name of psychosomatic illness.”* (Whiting 2014)

Unless you understand the horror of Very Severe ME, you could not possibly comprehend the harm that is potentially being done to Karina.

Jennie Spotila (2014) statement : “I reject the psychogenic hypothesis because the data is not there”-is a perfect summary of this paper's argument, which has tried to show how ME and the other illnesses are not “medically unexplained” but medically neglected.

Conclusion

BDS is a dangerous attempt by psychiatry to redefine physical illness as mental disorder.

It may try to wrap itself in eloquent sounding language, but BDS cannot say very much at all to justify itself, once you untangle it. The potential harm likely to be inflicted upon a vast range of vulnerable patients, especially the most severely affected, though, is very real. Anyone representing ME interests in the UK should take note, then action to stop this audacious attempt by psychiatry to completely impose a psychiatric label on people with ME. BDS is a game changer. It must not be allowed to spread.

It should serve as a resounding wake-up call to the ME Community to clearly separate ME from CFS and not compromise in demanding a full biomedical service for this devastating neurological disease .

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