

False Allegations of Child Abuse in Cases of Childhood Myalgic Encephalomyelitis (ME)



The Queen's Award
for Voluntary Service

The MBE for volunteer groups

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Abstract

There is no cure for ME (Myalgic Encephalomyelitis). In its absence, management regimes are prescribed, typically based on cognitive behavioural therapy (CBT) and graded exercise therapy (GET). In the case of children this may involve the application of Child Protection powers to enforce treatment. NICE confirms that patients may withdraw from treatment without effects on future care, but parents who decline, or withdraw children from, management regimes, which may have worsened their illness, can find themselves facing investigation for child abuse or neglect, or have their child forcibly confined to a psychiatric unit. *Tymes Trust* has advised 121 families facing suspicion/investigation. To date, none of these families has been found to be at fault. Subsuming ME under the

heterogeneous term Chronic Fatigue Syndrome (CFS) has confounded research and treatment and led to disbelief over its severity and chronicity. As evidence points to persistent viral infection, recommendations have been made to separate ME from CFS. International consensus criteria for ME emphasise post-exertional deterioration as distinct from fatigue. If the child with ME deteriorates under management regimes, re-diagnosis with a psychiatric condition can mask treatment failure and lead to blame attaching to the parent. A more constructive redeployment of resources away from Child Protection investigations into appropriate practical support for these seriously unwell children, should be developed.

Key words

ME, CFS, chronic fatigue syndrome, Myalgic Encephalomyelitis, child abuse, neglect, child protection



Introduction

For some time, the *All Party Parliamentary Group on ME* (2010) has expressed concern that “Some children with M.E. and their families are caught up in unnecessary, damaging and distressing child protection conferences and care proceedings because there is misunderstanding about M.E. amongst teachers, social workers, health workers and other professionals.” ME is poorly understood and misunderstandings abound. “Myalgic encephalomyelitis has not uncommonly been mistaken for school phobia, anorexia nervosa, neglect, child abuse, Munchausen syndrome by proxy (fabricated or induced illness) or pervasive refusal syndrome.” (Colby, 2007). *The Service Users Joint Statement* reports that the

mis-use of Child Protection powers to remove children with ME from their homes and families is likely to produce a crisis of health and social impacts. It can impact negatively on the children themselves, their families, other professionals who are working with the children and indeed more broadly on the wider community (Wrennall *et al*, 2003).

There has been historic controversy over the nature of ME. In this paper we shall concentrate on the physiological basis of ME, for which there is now ample evidence. Where the disease is understood to be physiologically based, the psychological treatments so often prescribed are seen as inappropriate and exercise regimes are viewed as dangerous (Twisk & Maes, 2009; Maes & Twisk, 2010a; Maes & Twisk,

2010b; Speight, 2013a; Nunez, 2011; Kindlon, 2011). It is particularly regarded as inappropriate for contentious and potentially harmful medical regimes to be imposed through the use of Child Protection powers.

The year 2014 marks the 25th anniversary of the support organisation known originally as *TYMES (The Young ME Sufferer)* which became the charity *Tymes Trust* in the year 2000 and received the Queen’s Award for voluntary service in 2010, the MBE for volunteer groups. The Trust has, to date, had to assist 121 families of children with ME who have been the subject of varying degrees of suspicion, involving Child Protection investigations. They have faced bullying and forms of state oppression, such

Biographical note

Jane has worked with the *All Party Parliamentary Group on ME* and the *All Party Parliamentary Group on Abuse Investigations* in regard

to the issues raised in this paper. Jane is a former Head teacher. She was co-author of the largest epidemiological study of ME to date, and prepared the questionnaire for the BBC Panorama ME

documentary. She was a member of the *Chief Medical Officer’s Working Group on CFS/ME*. A former severe ME sufferer, Jane is also the Executive Director of *Tymes Trust*.

as being threatened with having their children removed from the family and subjected to enforced rehabilitation (typically in a psychiatric unit) or being taken to the very brink, with their children placed on the 'At Risk register.' This paper presents the findings from our experience with families, in the context of relevant research. It is argued that too often, Child Protection practice in relation to children with ME is not only lacking in an evidence base, but is running contrary to the evidence of Twisk & Maes (2009), Maes & Twisk (2010a), Maes & Twisk (2010b), Speight (2013a), Nunez (2011) Kindlon (2011) and (Carruthers et al, 2011) concerning what would be appropriate medico-social practice with these children. In particular, we stress the confounding of research, which has resulted from ME being subsumed under the ill-defined 'Chronic Fatigue Syndrome' (CFS).

ME as a Physiological Disease

Evidence of the physiological basis of ME is long standing. Dowsett (1988) argued that there was evidence of a persistent enteroviral infection and Dowsett *et al* (1990) found that of 420 patients who met the criteria for ME "Coxsackie B neutralization tests, in 205 of these, demonstrated significant titres in 103/205 (50%), while of 124 additionally investigated for enteroviral IgM, 38/124 (31%) were positive." Kennedy *et al* (2004) found increased neutrophil apoptosis (cell death) indicating that patients "appear to have an underlying abnormality in their immune cells." Natelson *et al* (2005) found spinal fluid abnormalities. Also in 2005, JKS Chia reviewed the evidence on enteroviruses. After explaining the coining of the term Chronic Fatigue Syndrome in the 1980s, he stated, "Initial reports of chronic enteroviral infections causing debilitating symptoms in patients with CFS were met with scepticism, and

had been largely forgotten for the past decade. Observations from in vitro experiments and from animal models [have] clearly established a state of chronic persistence through the formation of double stranded RNA, similar to findings reported in muscle biopsies of patients with CFS. Recent evidence [has] not only confirmed the earlier studies, but also clarified the pathogenic role of viral RNA [...]" (Chia, 2005). Pointing out methodological flaws with studies that once threw doubt on the enteroviral connection, he concluded, "Thus, renewed interest is needed to study further the role of enterovirus as the causative agent of CFS." (Chia 2005). Subsequently, Chia & Chia (2008) demonstrated that ME is associated with chronic enterovirus infection of the stomach.

Physiological findings pertaining to ME in adults are mirrored in children. "Biomedical anomalies seen in adults with CFS/ME—increased oxidative stress and increased white blood cell apoptosis—can

also be observed in children with clinically diagnosed CFS/ME compared with matched controls.” (Kennedy *et al*, 2010a). The findings were affirmed to be consistent with the presence of a persistent viral infection and children with ME questioned by Kennedy *et al* (2010b) did, in fact, report a perceptible infectious onset in 88% of cases.

Historically, the move away from the traditional name ME to CFS, focusing on fatigue as the main feature of an over-widely defined condition that increasingly, and inappropriately, came to be regarded as psychological, proved counterproductive both for research and treatment. More recently, an *International Consensus Panel* consisting of clinicians, researchers and medical faculty, was formed “with the purpose of developing criteria based on current knowledge.” (Carruthers *et al*, 2011). As Carruthers *et al* report, the panel represented thirteen countries, an extensive range of specialties, hundreds of peer-reviewed

publications and among them, had diagnosed or treated approximately 50,000 patients with ME. Independent of corporate sponsorship, the panel was able to achieve 100% consensus through a Delphi-type methodology. The panel determined that “In view of more recent research and clinical experience that strongly point to widespread inflammation and multisystemic neuropathology, it is more appropriate and correct to use the term ‘myalgic encephalomyelitis’ (ME) because it indicates an underlying pathophysiology. It is also consistent with the neurological classification of ME in the World Health Organization’s International Classification of Diseases (ICD G93.3).” (Carruthers *et al*, 2011).

The panel also stated, “Using ‘fatigue’ as a name of a disease gives it exclusive emphasis and has been the most confusing and misused criterion. No other fatiguing disease has ‘chronic fatigue’ attached to its name – e.g.

cancer/chronic fatigue, multiple sclerosis/chronic fatigue – except ME/CFS.” (Carruthers *et al*, 2011). With its strong evidence base demonstrating the underlying neurological and microbiological pathology, ME is far removed from the nebulous CFS, and even further removed from the commonly used term ‘chronic fatigue’. Fatigue can be a symptom of numerous conditions including heart disease, cancer, and a number of viral illnesses whose post viral effects are relatively short (months as opposed to the years common in cases of ME).

The Harmful Effects of Imposed Medical Regimes

Despite the microbiological and neurological evidence regarding ME, no cure has as yet been developed. Hooper (2007) and Carruthers *et al* (2011) have pointed out that research has been impeded by failure to come to grips with the microbiological and neurological aetiology of ME and by the

conflation of ME and CFS. NICE states “There is no known pharmacological treatment or cure for CFS/ME” (2007a, p.39). This is why management regimes have grown up. But since they are not cures either, there can be no medical justification to force them on anyone, in particular upon children.

Management regimes applied to patients with ME frequently involve a combined approach consisting of Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET). Where children are involved, parents consistently report to Tymes trust that a graded school attendance programme is imposed, progressing by increments (in effect, a form of graded exercise in a school setting) in which benign terms like ‘activity management’ may replace ‘graded exercise’. Physiotherapy may also be involved. In effect, these approaches all involve incrementally increased effort. Graded school attendance and graded exercise are just two forms

of the same problem.

Van Ness (2014) explains that “The role of exercise and activity management in ME and CFS has been a source of great controversy for many years – widely accepted as beneficial by many healthcare workers but questioned by many ME charities and patients who have personally suffered adverse consequences caused by overactivity.” Not only is it argued that “the evidence-based claim for proven effectiveness of CBT/ GET for ME/CFS cannot be substantiated,” (Twisk & Maes, 2009:295), but years before Van Ness (2014) came to demonstrate the post exertional amplification of symptoms in ME patients, it was already considered that “there is compelling evidence that CBT/ GET is potentially harmful for many ME/CFS patients” (Twisk & Maes, 2009:295). It was indeed reported as long ago as 2001 that “doctors have been advised by their medical defence unions that prescriptions for exercise must be given with as much care as those

for medication” and that “surveys by national [ME] patient groups have shown that 60% of patients either find graded exercise therapy ineffective, or report that it has caused them harm.” (Colby, 2001).

Classic ME patients suffer from a “post-exertional malaise with a decreased physical performance/ aerobic capacity, increased musculoskeletal pain, neurocognitive impairment, “fatigue”, and weakness, and a long lasting “recovery” time.” (Twisk & Maes, 2009:284). A proposed explanation for the adverse effects is that, “exertion may amplify pre-existing pathophysiological abnormalities underpinning ME/CFS, such as inflammation, immune dysfunction, oxidative and nitrosative stress, channelopathy, defective stress response mechanisms and a hypoactive hypothalamic-pituitary-adrenal axis.” (Twisk & Maes, 2009:284). Twisk & Maes (2009:284) therefore concluded, starkly, “that it is unethical to treat patients with ME/CFS with ineffective,

non-evidence-based and potentially harmful “rehabilitation therapies”, such as CBT/GET.” *The International Consensus Panel* stated, “The pathological low threshold of fatiguability of ME [...] often occurs with minimal physical or mental exertion and with reduced ability to undertake the same activity within the same or several days.” (Carruthers *et al*, 2011). Kindlon (2011) explains that “both GET and CBT models are based on a model of inactivity/ deconditioning as the major driver in perpetuation of CFS symptoms”. However, a Randomised Controlled Trial conducted by Nunez *et al* (2011) found that imposed exercise did not improve quality of life but that it reduced both functionality and increased pain. This is scarcely surprising because, as Carruthers *et al* (2011) reported, “Numerous papers document abnormal biological responses to exertion.”

Using the Workwell 2 day testing protocol, Van Ness (2014) has clearly

demonstrated the objective reality of the “post exertional amplification of symptoms in ME patients; a hallmark symptom of ME. This damage to the aerobic energy system means that it is utterly counter productive to try to use aerobic exercise, such as graded exercise therapy, to improve health in these patients.” In his *Reporting of Harms Associated with Graded Exercise Therapy and Cognitive Behavioural Therapy in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome* (2011), Kindlon looks forward to “a greater focus on the reporting of harms in ME/ CFS, not just those that might be associated with GET or CBT, but from any posited treatment.”

Our Experience at Tymes Trust

As we have observed, it is in the absence of curative treatment that management programmes have grown up. These are not cures either. Failure to keep this one essential fact to the fore has led some professionals down an oppressive path, one that

puts them in conflict with patients, that sees children forced into a management straightjacket and parents accused of neglect or child abuse when it fails. This is happening despite the NICE Guideline reminding physicians about patient choice over treatment. The *Quick Reference Guide* states: “Be aware that people with CFS/ME have the right to refuse or withdraw from any component of their care plan without this affecting the provision of other aspects of their care, or future choices about care” (NICE, 2007b:9). The *Full Guideline* refers to the “patient’s preferences and views firmly driving decision making” (NICE, 2007a:7). In the child’s case this will usually be the parent. Yet patients and families of children with ME are expected to keep to restrictive and often punitive regimes. Not only are they deprived of choices, but treatments are coercively imposed through the use of Child Protection powers (Wrennall, 2007:962). We question why this is, given

that patients can manage their own lives perfectly well with practical support, once they have worked out what makes them worse. From what they report to us, and from the evidence of Twisk & Maes (2009), Maes & Twisk (2010a), Maes & Twisk (2010b), Speight (2013a), Nunez (2011) Kindlon (2011) and (Carruthers *et al*, 2011), it is often the regimes themselves that are worsening patients' health.

Whatever the reasons behind the misapplication of Child Protection powers onto children who are genuinely suffering from ME, a bias would appear to have been introduced into the claimed recovery rates from the management regime of the professional's choice, whereby blame for treatment ineffectiveness or failure is shifted onto the children and their families. Kindlon (2011:59) has asserted that harms have been under-reported in the CBT/GET treatment trials. Wrennall (2007:962) documents assertions that false allegations of child abuse have arisen in disagreements over

treatment, because the "mis-use of Child Protection powers is part of empire building, promoting careers, professional allegiances and turf wars between competing professional interests." Patient choice is undermined by the use of Child Protection powers which add coercive weight to enforce the treatment provided by some professionals against the competing regimens of other professionals, so much so that patients can be discouraged, or even legally prevented, from obtaining second opinions.

At *Tymes Trust*, we found that to date not a single case on which we advised regarding Child Protection allegations in relation to ME has been found by the authorities to have merit. We reported this statistic to the Minister for Children and Families at a meeting in the *House of Lords* this Spring (*Forward ME Group Minutes*, 2014, para 2.8). We asserted that for 100% of these families to be innocent, something is gravely wrong with the methods

through which children with ME are selected to be the subject of Child Protection investigations and with the conduct of these investigations. Seriously ill children who are at no risk from their parents are facing anxiety, distress and misery during the investigation, with the prospect of a harmful removal from their social support networks and the imposition of potentially destructive and inappropriate medical regimens. Families appear to be facing an arbitrary, punitive, threatening and destructive state juggernaut. The harmful impacts of the Child Protection system are now clearly documented (Wrennall *et al*, 2003). We are usually working on at least one of these Child Protection 'firefighting' cases. As I write, there are four, with a fifth in rapid succession. The Trust is currently waiting to hear whether one of these cases will proceed to court, with professionals aiming to take children from the parents for enforced treatment.

Parents of children suffering from ME are often

faced with intrusive legal action. In some cases the threat of legal action is to enforce school attendance instead of putting into place the children's entitlement to education in the home while they recover from a very serious illness. In others it is to force them into the controversial and potentially harmful treatments that have been evaluated earlier in this article. Some parents have found themselves labelled as neglectful or abusive. Some are warned that their children will be made *Wards of Court* if they do not agree to them going into psychiatric units, with restricted parental access, or undertaking these disputed treatments which, especially for the severely ill, are unproven and potentially damaging. In *The Doctor's Guide to ME in Children and Young People*, Franklin (2003) stresses the importance of rest for severely ill children, cautioning that "Forced exercise, particularly any exercise producing a prolonged after-effect, can be counter productive and can be damaging. It

can be instrumental in causing a deterioration, despite reports to the contrary," (2003:8). Dowsett explained that ME responds to convalescence. In her advice on relapses, she states that it is "inadvisable for sufferers to return to school, college or work without adequate convalescence" (Dowsett, 2000:1). The implications for management are "most important", she continues. The main principles of management are "Conservation of energy, reduction of stress, simplification of work" (Dowsett, 2000:3). Parents report to *Tymes Trust* that where they have put these common sense principles into practice, even very severe cases do improve. Conversely, where parents are pressurized into making their children overexert themselves, the disease worsens. The experience reported to us, therefore confirms the research of Twisk & Maes (2009), Maes & Twisk (2010a), Maes & Twisk (2010b), Speight (2013a), Nunez (2011), Carruthers et al (2011) and Kindlon (2011)

that over-exertion is to be avoided.

Recognising the serious public issue that has arisen over the application of Child Protection powers to children with ME, the report of the *CFS/ME Working Group* to the *Chief Medical Officer* has noted that, "neither the fact of a child or young person having unexplained symptoms nor the exercising of selective choice about treatment or education for such a patient by the parents/carers and/or young person constitutes evidence of abuse." The report goes on to recommend that: "In cases of CFS/ME, evidence clearly suggestive of harm should be obtained before convening child protection procedures or initiating care proceedings in a family court," (*CFS/ME Working Group*, 2002, 5.2.8:64) tacitly indicating that this evidence has not necessarily been obtained in the past.

A briefing by the Trust in 2006 for the *Archbishop of York* (Colby, 2006) whose geographical area was among those affected, raised several

important concerns about the application of Child Protection powers to children suffering from ME. We noted that ‘guilty until proven innocent’ appeared to be the default position, turning on its head the principle of the presumption of innocence in English law that has stood the country in good stead for centuries. In the briefing we documented once again the advice of doctors Franklin and Speight, both of whom were members of the *CFS/ME Working Group* to the *Chief Medical Officer*. We concurred with their advice that “neither the fact of a child or young person having unexplained symptoms nor the exercising of selective choice about treatment or education constitutes evidence of abuse,” and we observed that misinterpretations on these points are common. We again endorsed the recommendation that “in cases of CFS/ME, evidence clearly suggestive of harm should be obtained before convening Child Protection conferences or initiating

‘Care’ proceedings in a family court.” (*CFS/ME Working Group*, 2002, 5.2.8:64).

Child Protection investigations are experienced by children and parents alike as overbearing and traumatic. This was already known in the literature, (Farmer & Owen, 1995; Butler-Sloss, 1988) and is evidenced in cases of which we have experience. The effects are long lasting. It is not unusual for parents who are deeply shocked by punitive and inappropriate Social Services investigations to state that they are terrified of taking their children to doctors ever again. Many families are also shocked to see what has been written about them when they access their child’s school and/or medical records, as is their right. Dr Speight, already known for his work on childhood asthma (the existence of which, like ME was once denied) commenting on these inappropriate and heavy-handed Child Protection investigations and the application of inappropriate treatments,

stated: “This is child abuse by professionals,” (Speight, 2013b).

The collective attack upon these families, involving such extreme and traumatic measures, is clearly counterproductive in cases of genuine ME. From our Advice Line Records we can see that three common misperceptions appear to be driving this trajectory of stigmatisation by professionals:

1. The misperception that ME is not a physical disease, but a mental health disorder.
2. The misperception that treatments such as Graded Exercise Therapy (GET) or graded activity and Cognitive Behaviour Therapy (CBT) can always be expected either to *cure*, or *substantially improve* the condition, and certainly will do no harm.
3. The misperception that the illness is neither long lasting (chronic) nor severe.

One or more of these misperceptions seems to lie at the heart of all these cases. Despite assertions given to the families we

advise by proponents of the rehabilitation therapies discussed in this paper, often predicting robust and speedy recovery, with assurances that symptom exacerbation is not harmful, we note that “Postexertional neuroimmune exhaustion is part of the body’s global protection response” and that “Prognosis cannot be predicted with certainty”. (Carruthers *et al*, 2011). Behind the misperceptions themselves is the adoption of the name Chronic Fatigue Syndrome (CFS), an umbrella term under which ME has become subsumed. It is widely recognised that the term is heterogeneous i.e. it comprises more than one pathology (Carruthers *et al*, 2011:328). There are also several definitions of CFS, some wider than others. How ironic it is that a condition with the word ‘chronic’ in its name should be so often confused with child abuse or neglect, with the length of the child’s illness often given as *reason for suspicion*. The child has been ill for too long for this to be genuine

CFS, the physician will argue. What does the word ‘chronic’ mean, if not long lasting? At this point many families report being given a *re-diagnosis*, as if the CFS had somehow ‘gone away’, leaving the child with some form of psychiatric illness in its wake. It would appear that these changes in diagnosis are, in effect, serving to prop up claimed CFS recovery statistics. The child may be re-diagnosed with a case of Munchausen’s Syndrome by Proxy (MSBP)/ Fabricated or Induced Illness (a form of medical child abuse) or the more benign sounding Pervasive Refusal Syndrome (PRS). In the former, parents are accused of imagining or causing the child’s problems. In the latter, the parents are still under suspicion of causing or perpetuating the child’s mental health problem, perhaps through abuse or neglect. Often unaware of the complex discursive narrative that underpins the professional projections onto them, parents cannot understand why the child must be institutionalised in a psychiatric unit, with

parental visits severely restricted. Once the child is in the psychiatric unit, those in charge of the case will be working on the presumption that, if the child is not improving out of the sphere of influence of the parents, it is the child’s own mental health problems that must be interfering with recovery, rather than ongoing physical disease and physical disability.

One particular form of overexertion to which child sufferers of ME are routinely exposed is the pressure to attend school when they may be physically unable to do so without deterioration. Kennedy *et al* (2010b:1324) found that the children’s quality of life was significantly worse than children suffering with other illness (type 1 diabetes mellitus and asthma) with only one child out of 25 able to attend school full time. This in turn echoes the findings of the Dowsett/Colby schools study of 1997 which found that ME/CFS is the biggest cause of long term sickness absence from

school in both pupils and staff (Dowsett and Colby, 1997:29). We studied a school roll of 333,024 pupils and 27,327 staff, making it the largest study of its type ever conducted. In her discussion of our study, Dr Dowsett wrote of her concern about inappropriate management of children's education: "discouragement of Home Tuition, encouragement of early return to school, intervention with anti-depressant therapy and graded exercise may well leave us with a generation of young people suffering from educational deficit" (Dowsett, 1997:6).

Conclusion

There is no cure for ME, but the perception that there is, continues to haunt families. For many, state intrusion has impacted negatively on their ability to care for, nurse and educate their children at home during what may be a long recovery period. The inappropriate use of Child Protection powers is traumatically experienced by families as intimidation and coercion into regimens

of treatment that they believe can be harmful to their children. Moreover, the substantial body of research evidence covered in this paper, supports the views of the families and the charities who have presented the families' views over the past few decades.

Contention over ME persists however and where there is medical disagreement, the legal precedent set by Justice Judge in *R v Cannings [2004] EWCA Crim 01*, established that it would normally be "unsafe and therefore unwise," for Child Protection proceedings to be brought in the Family, or in the Criminal courts. Given that ME is still the subject of considerable disagreement, the targeting of children with ME by Child Protection investigations may be regarded as an inappropriate use of resources dedicated to children's services. Optimistically, these resources may be more constructively redeployed to support the practical needs and rights of children

who are the subject of this disabling illness.

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Editorial note

This paper is published in good faith as an academic statement on a matter of general public interest following independent peer review. Nothing in this paper should be construed as relating to actions by individuals. Furthermore, the paper must not be construed as offering legal advice to persons aggrieved by actions described in the paper or otherwise.

About The Young ME Sufferers Trust

2014 is our 25th anniversary year. Started by two youngsters reaching out to offer companionship, TYMES grew into a national charity, honoured in 2010 with the Queen's Award for Voluntary Service: the MBE for volunteer groups. It was for pursuing the educational rights of children with ME and advancing their care.

The Tymes Trustcard

Launched by Lord Adonis, when Parliamentary Under-Secretary of State for Schools. Endorsed by the Association of School and College Leaders. A 'pass card' signed by the child's Head Teacher, carrying the child's photograph. It states that the child has permission to use the school's disabled facilities (eg lifts) or obtain other assistance. Application forms require confirmation of diagnosis. Please support the use of the Tymes Trustcard by young ME patients.

Free publications : www.tymestrust.org

Advice Line : 0845 003 9002



**The Queen's Award
for Voluntary Service**

The MBE for volunteer groups

