



Professional Guides

ME - The Illness and Common Misconceptions: Abuse, Neglect, Mental Incapacity

A summary originally produced for the legal profession

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Abstract

This document describes the disease of Myalgic Encephalomyelitis, contrasts it with Chronic Fatigue Syndrome and explains why young people with ME are commonly misunderstood as being abused or neglected by their parents, or as lacking mental capacity to know their own minds and make decisions affecting their lives.

It was written at the request of the Official Solicitor as a Judge's briefing.

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The World Health Organisation lists Myalgic Encephalomyelitis as a neurological disease, classification ICD10 G93.3. It is potentially very severe and chronic. Since the middle of the twentieth century it has been recognised by microbiologists, virologists and specialist researchers as a complication of a viral disease, with enteroviruses as the most likely cause. Enteroviruses live in the bowel and are related to poliomyelitis.

Some cases of ME have in the past been diagnosed as ‘nonparalytic polio’ or ‘atypical polio’ and the two diseases share a common symptom pattern and epidemiological features. A spectrum of severity is common to both; both are multi-system disorders, attacking the brain, organs and muscles. Children with polio (still found in India and other areas of the world)

can suffer paralysis, typically in the legs, and death due to damage to the breathing mechanism. Children with severe ME may suffer breathing difficulties, require tube-feeding if their swallowing mechanism becomes affected, may be bedridden for years and in constant pain. Mental or physical effort, such as graded exercise or rehabilitation treatment, typically exacerbates ME.

Medical specialists in ME are few in number these days as the term ‘Chronic Fatigue Syndrome’ (CFS) has taken over, incorporating ME under its wide umbrella. However, Californian virologist John Chia MD has now found enterovirus infestation in the stomachs of 81% of CFS patients using endoscopy to sample the stomach lining, which is expected to facilitate a diagnosis of enteroviral disease.

Confusion between Chronic Fatigue Syndrome and ME

The term ‘Chronic Fatigue Syndrome’ (CFS) was originally coined as a research tool. Researchers designed their own symptom profile, so CFS was never a disease in its own right, but a researcher’s profile.

Eventually the term CFS was taken into clinical use. Classic ME was caught under the CFS label because of

a key clinical feature - fatiguability (not fatigue per se). Patients exhibit an inability to make physical or mental effort without becoming more ill.

Genetic and other research has now shown up different subgroups under the CFS label, although this is not well known outside research circles.

Misunderstandings over Rehabilitation

Many misunderstandings have arisen amongst professionals without specialist knowledge of ME. Physicians usually consider the term 'ME' as another name for Chronic Fatigue Syndrome. Generally, they have not read the original virology papers, the historical records of ME epidemics or patient profiles.

This has had a knock-on effect on patients and on families whose children have classic ME. The loose symptom profile of CFS means that various causes of fatigue, some of which are of mainly psychological origin and respond helpfully to graded exercise therapy, are caught under its label.

Moves to standardise rehabilitation treatment for those with 'CFS' have proved counter-productive for patients fitting the classic ME symptom profile. Patient surveys show that of the people with CFS who have been given graded exercise therapy (GET) the majority saw an exacerbation of illness, rather than recovery.

A number of consultants have had to apologise when their patients, who were previously sufficiently recovered to walk, became wheelchair-bound after rehabilitation therapy.

Misunderstandings over Mental Capacity

SPECT scans on the brains of people with ME confirm that when mental or physical effort is made, blood flow to the brain decreases, which is the opposite of the normal pattern, where demand increases blood flow. Intellectual confusion and further illness typically result from too much effort; in practice this can be very little effort compared with a healthy person.

Principles of interviewing people with ME include the need for the interviewer to speak slowly in order for the words to be processed into sentences, and the need to avoid saying anything else while the brain is processing the previous remark. This is because a typical severe ME sufferer recognises words but is unable to process them into meaningful sentences unless sufficient time is allowed without other distractions.

Typically also, any interview needs to be short, and should be broken into shorter sections of around fifteen minutes maximum. Without such specialist techniques, the interviewer is unlikely to get a fair picture of what the patient can actually understand.

The patient usually forgets words, rather like someone with a mild stroke, and may not, to start with, say exactly what they mean to say. An inappropriately long interview is virtually guaranteed to exacerbate the illness. The patient may need someone who knows them well to speak for them due to severe exhaustion.

None of this means that a person with ME is not mentally capable of knowing how they wish to be cared for, or where they wish to be.

Misunderstandings over Parental or Carer Influence

Large-scale misunderstandings about parental influence exist amongst physicians, teachers and social workers with a poor understanding of classic ME, as professionals are not trained in this illness. The Trust's caseload of families seeking help would suggest that these misunderstandings are on the increase.

In 1999, the Trust's present Executive Director Jane Colby (a former Head Teacher) designed a questionnaire with the BBC which was sent to families whose children had ME. It received a 62% response and revealed that 7% of children from families questioned had been subject to child protection proceedings (court proceedings either threatened or carried out) and 4% had been labelled with Munchausen's Syndrome by Proxy. National Statistics at that time showed that MSBP

affected just one in 100,000 families so clearly this was a statistical anomaly. The Trust is not aware of any of these cases having, in the end, been shown to be due to parental interference with the child's medical condition, recovery or treatment.

Several years after the BBC survey, the Trust carried out its own survey 'Our Needs Our Lives' in the county of Essex, with a grant from Essex Community Foundation Local Network Fund. It revealed that 25% of families involved had faced the suggestion that parents were causing the illness, and 79% reported that doctors had misunderstood their illness as psychological. The Trust is not aware of any of these cases eventually having been found to be due to parents or to psychological factors.

These common misunderstandings appear to occur mainly because physicians and social workers have found it difficult to appreciate that severe and chronic disability could be due to a condition as benign sounding as Chronic Fatigue Syndrome. They often regard it as partly psychological, either in origin, in perpetuating factors, or both. CFS is often treated as if it were a mental health problem and professionals may propose that carers have in some way caused or exacerbated the illness or sabotaged recovery out of a personal need to keep the patient dependant. The Trust is not aware of any such suggestions having eventually been found to be the case in its own work.

The care and treatment of people with ME is greatly affected by the split in the medical profession between those who have knowledge of classic ME and the existence of subgroups of CFS, and those who do not.

It is therefore a misperception that the divide is between the medical establishment and the patient support fraternity. When the government Chief Medical Officer set up a Working Group to report on what the DoH now terms CFS/ME, the Trust's present Executive Director was an invited member of the Group and assisted specialist paediatricians to produce its Children's Chapter (Dept of Health 2002).

Common Misdiagnoses / Sensitivity to Medication

Common misdiagnoses are: anorexia nervosa; school phobia; Pervasive Refusal Syndrome; separation anxiety.

Sensitivity to medication is common and can produce side-effects; specialist doctors recommend smaller doses and/or alternative drugs.

Useful References

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