

A Rose By Any Other Name

ME has already been called the 'Disease of a Thousand Names', yet, in the Spring of 2001, one of the ME Charities has just applied to the Charities Commission for another change. This time, it is from Myalgic Encephalomyelitis to Myalgic Encephalopathy, that is: from muscle pain accompanied by inflammation of the brain and spinal cord to muscle pain and damage to the brain and spinal cord of unknown origin. This clumsy euphemism will not only bloom less sweetly than its predecessors but does not fit the facts. For example, in reply to questionnaire sent to the most severely affected patients with ME in the UK, 2/3 ascribed their present condition to a virus infection.¹ Moreover, this change will not benefit research nor relieve the confusion and disbelief which blocks access to standard medical care for these patients. It will, however, preserve the acronym 'ME' – a historical logo which still retains its integrity in many parts of the world and which, if replaced, would not only add to the present chaos, but prove extremely expensive in terms of office stationery.

Historical Background: The earliest definitions were brief but succinct, based on clinical observation and accompanied by a checklist of symptoms. WALLIS (1995) provided a concise list with appropriate variations for children and adolescents, while RAMSAY (1956) introduced the descriptive term (Myalgic encephalomyelitis), which has stood the test of time over half a century in the UK, Europe, Canada and Australasia.

Fatigue States: These definitions first arose in the USA following the 1984 Lake Tahoe epidemic (which was misattributed to a Herpes Virus infection). Both the earliest definition (HOLMES et al, 1988) and its revision (FUKUDA, 1994) elevated tonsillitis, glandular enlargement and fatigue to unreal importance while overlooking the characteristic encephalitic features of the genuine illness. These mistakes also inflated the possibility of a psychiatric diagnosis, leading to the incorporation of such a heterogeneous population of psychiatric and non-psychiatric causes later on, that research groups of different persuasions were unable to compare results or evaluate treatment.

What Are the Facts: the tools we can use today to study the brain offer possibilities which were unimaginable 50 years ago². These include Molecular Biology: for example PCR – a microbiological technique capable of amplifying and identifying minute fragments of viral genes, hidden away in internal organs (such as brain, heart or muscle ³) while a test for rapid diagnosis (within five hours) is currently available. These tests indicate that viruses from the polio group, or related to it, are involved both in the late effects of ME and the Post Polio Syndrome ⁴. Brain Imaging: the use of CT, MRI, SPECT and PET scans clearly indicates that metabolic dysfunction in the brain stem and the spinal nerve radiations which transverse it, are initially associated with viral (inflammatory) damage and are the major cause of the cardinal symptoms of ME – central fatigue, stress induced weakness, autonomic nervous dysfunction and the breakdown of homeostasis over hormonal and other vital functions⁵.

Conclusion: Modern technology has now served to confirm and to detail the meticulous clinical and scientific observations made about ME before 1988! We can rest assured that this serious disability can arise (like polio) from an initially trivial infection which has epidemic and pandemic potential but we need to give further thought to any name change. We should, instead, be making maximum use of modern and effective means of diagnosis, prevention and management.

References:

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