

## Mini-Update on current news items about ME / CFS

Margaret Williams 17<sup>th</sup> February 2001

Acknowledgement is given to Mette Marie Anderson, MD; Frank Albrecht PhD; Carolyn Kiefer (SSA / US Govt); Jean Linn and Carole Ann Damon for their postings as mentioned.

### Diagnostic Code for CFS

On 16<sup>th</sup> February 2001 the US SSA provided instructions as of 8<sup>th</sup> February 2000 (*the posting does say 2000, not 2001*) that CFS now has its own diagnostic impairment code (9330), which mirrors the World Health Organisation's classification of ME (CFS) as a neurological disorder (ref ICD 10 G.93.3). (Carolyn Kiefer@SSA.Gov)

### re Name Change

ME and CFS are not the same illness --- CFS is not a disease entity but a name given (disastrously) to a collection of symptoms which often co-occur. No one disease entity underlies this collection of symptoms, so to say that CFS is or is not the same as ME is to reify a faulty concept.

A large majority of those meeting the Oxford criteria (Sharpe M, Wessely S et al 1991) for CFS do not meet the criteria for ME. The criteria for ME (the London criteria of Dowsett et al) are extremely important and consist of the following:

1. Exercise-induced fatigue precipitated by trivial exertion (physical or mental)
2. Impairment of short-term memory and loss of powers of concentration, usually coupled with emotional lability, nominal dysphasia, disturbed sleep patterns, dysequilibrium and / or tinnitus
3. Fluctuation of symptoms, usually precipitated by either physical or mental exercise; typically, the symptoms vary capriciously from hour to hour and day to day

These three criteria must be present for at least six months for a diagnosis of ME; it typically starts with an infection (usually viral) but it is also triggered by immunisation, trauma and exposure to chemicals. It is absolutely characteristic that symptoms are exacerbated by physical or mental exertion. Additional symptoms include bouts of sweating, Raynaud's phenomenon, postural hypotension, bowel problems which are indistinguishable from irritable bowel syndrome, episodes of low-grade fever, sore throat, joint pain, photophobia, blurred vision and urinary problems. There is an intolerance to alcohol and a highly specific hypersensitivity to drugs.

Americans should be supporting British efforts to retain the ME name and definition.  
(franka@bluecrab.org)

Most US sufferers from “CFS” in fact meet the London diagnostic criteria for ME; the waters are muddied when US researchers claim they are looking at “CFS” but then study patients who do not meet the London criteria.

The CDC definition (Fukuda, Sharpe, Wessely et al, 1994) has created a heterogeneous group of patients which includes people with primary depression and other disorders. We go round in circles as the CDC continues to water down the definition: researchers include more patients who do not have ME and then draw conclusions that do not fit ME patients.

Unless the London ME criteria are adopted and distinctions are made between ME and CFS, simply changing the name from CFS to ME would not solve the problem (of patient selection). (Jean.Linn@WorldNet.ATT.Net)

### **Abstract from Drs Cheney & Urnovitz / AACFS, Seattle, January 2001**

Abstract entitled RNA in the plasma of patients with Chronic Fatigue Syndrome: A novel mechanism for chronic illness expression with both treatment and diagnostic implications.

Objective: to determine the presence or absence of plasma RNA in CFS and to determine if the amplified RNA sequences were similar to or different from Gulf War Syndrome.

Conclusion: all chronic illnesses so far studied, including CFS, GWS, AIDS and multiple myeloma, show prominent circulating plasma RNA not observed in normal controls. Prominent RNA bands so far sequenced show homology with human genes which are noted for their tendency for gene re-arrangement under severe physiologic stress. The most prominent sequences appear to be disease specific and vary by < 1% between individuals with the same illness. (mma@INFORM.DK)

### **Petition asking for the Oprah Winfrey show to present the reality of ME (CFS and Fibromyalgia)**

According to her web site, Oprah Winfrey was apparently planning to do a programme on CFS under the banner of “health problems because you lost your spirit”.

This suggestion was subsequently removed from her web site.

A letter written by Carole Ann Damon and co-signed by others made important recommendations, in which (based on her power to increase public awareness) Oprah Winfrey was encouraged to take a more positive and pro-active role in depicting the reality of these devastating illnesses.

She was urged to portray the reality of the disability experienced by sufferers and to discuss the inaccuracy of the trivialising name “CFS”, and to point out that ME / CFIDS / CFS is more common than lung or breast cancer, multiple sclerosis or HIV infection.

She was informed that besides incapacitating tiredness, frequent exhaustion and debilitating sleep disorders, patients also suffer from constant and at times intolerable pain, chronic flu symptoms, cognitive dysfunction (information processing and concentration problems), visual problems, disabling and complicated orthostatic intolerance symptoms (just standing up can result in a rapid drop in blood pressure with dizziness, nausea and difficulty breathing, as well as severe pain in muscles), gastrointestinal and pelvic problems, headaches, multiple chemical sensitivity and exacerbated allergies.

Research has shown that ME / CFIDS patients have the lowest quality of life of all ill subjects, including those undergoing chemotherapy or haemodialysis, as well as those with HIV, liver transplants and coronary artery disease.

ME / CFIDS research has begun pinpointing abnormalities in almost every body system. It has been shown that there is a marked decrease in circulating blood volume. Heart abnormalities in ME / CFIDS are indicative of a viral cardiomyopathy; these studies characterise the “fatigue” of ME / CFIDS as a state similar to that of cardiac invalids, not as those who are simply “tired”.

Various researchers have found evidence of brain dysfunction on MRI, MRS and SPECT scans of ME / CFIDS patients, as well as immunological abnormalities.

People are often unaware of the chronic pain experienced by those with ME / CFIDS and FM; this pain alone can be very demoralising and is the prime reason why some patients have tragically committed suicide to escape the daily agony.

The stigmatisation of ME / CFIDS causes isolation and innumerable losses of what most people take for granted.

There are no viable rehabilitation options. It is an illness of uncertainty, isolation, loss and loneliness.

Adults and children alike often suffer without receiving any treatment or support.

An informed programme would exclude contributions from those who push incorrect beliefs that psychotherapy and exercise regimes are cures for the dysfunctional illness beliefs of sufferers.

A knowledgeable and focused programme would be much appreciated by the community of very sick people whose quality of life has been so drastically diminished. (<http://www.PetitionOnline.com/cad201ow/petition.html>)

### **Article in the British Medical Journal / 17<sup>th</sup> February 2001**

Randomised controlled trial of patient education to encourage graded exercise in chronic fatigue syndrome. Pauline Powell, Richard P Bentall, Fred Nye, Richard HT Edwards. *BMJ* 2001;322:387

This week's BMJ carries another article co-authored by Richard H.T. Edwards, Professor of Medicine at the University of Liverpool, UK (who has a long track record of discrediting sufferers of ME, having claimed in 1988 that their problems arise from "*the consequences of reduced habitual activity*", ie. inactivity).

The authors believe that many patients with CFS have inaccurate illness beliefs.

The present article describes a study using those who fulfill the Oxford criteria for chronic fatigue syndrome (to which Edwards was a signatory together with psychiatrists Michael Sharpe, Simon Wessely et al). Perhaps significantly, subjects were excluded from the study if they were confined to a wheelchair or bed. 14% of the 148 eligible patients dropped out of the study during "treatment".

The authors state that "*attributing symptoms to ongoing physical disease is an important predictor of poor prognosis*" and they emphasise that "*extensive research has failed to find any serious underlying pathology*" and that "*inaccurate illness beliefs*" which encourage inactivity may "*perpetuate the condition*".

The authors state that they have developed a "*treatment*" for chronic fatigue syndrome, consisting of educating patients about the medical evidence of the physical and psychological effects of physical deconditioning, with the intention of encouraging a self-managed programme of graded exercise (this is promoted as being less expensive than cognitive behaviour therapy, as it requires less therapist skill).

The authors claim that overall, their "treatment" convinced 94% of the patients to carry out graded exercise activity (but admit that 32% of patients still complained of fatigue after one year).

The authors conclude that their approach may be a cost effective and beneficial treatment for CFS, and state that changing a patient's illness beliefs, together with graded exercise, helps some patients.

This study was financially supported by the Linbury Trust.

The Linbury Trust is a Sainsbury (supermarket) charity and Lord Sainsbury is currently Minister for Science; he is said to be a personal friend of Simon Wessely. It is certainly true that the Linbury Trust has shown a strong preference for dismissing the existence of ME and for supporting Wessely's well-published view of CFS; it has funded £4 million for research into CFS (almost all of it in the psychiatric field).

It is the Linbury Trust who have funded Wessely's latest book, the very title of which is significant in that it refers only to "Chronic Fatigue", yet the book claims to be about chronic fatigue syndrome: "*This book is directed at people suffering from chronic fatigue syndrome*". (New Research Ideas in Chronic Fatigue. Ed. Richard Frackowiak and Simon Wessely. Pub. 2001, Royal Society of Medicine, London). The book claims that patients are merely experiencing an

*“exaggerated self-awareness of every physical feeling, to the point where symptoms become distorted”* and that patients have unhelpful illness beliefs.

Professor Wessely has recently written an article in which he compares patients with CFS with patients attending a fracture clinic. He finds that patients with CFS are more likely to make somatic attributions for their symptoms than patients attending a fracture clinic, who ascribe their symptoms to an accident. He concludes that a tendency to make somatic attributions may be a vulnerability factor for the development of CFS. (Causal attributions for somatic sensations in patients with chronic fatigue syndrome. *Psychol Med* 2001;31:97-105).

As far as ME / CFIDS is concerned, bad science continues unabated and deserves to be criticised; as ever, it seems to be left to sufferers to challenge it.