

Quotable Quotes about ME/CFS

compiled by Margaret Williams

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Many more could have been included, but the following are significant

1956

In nearly every patient there are signs of disease of the central nervous system

(A New Clinical Entity? Editorial: Lancet 26 May 1956)

1988

Allergies are a common feature of patients with the chronic fatigue syndrome. Among the features of this syndrome is a high prevalence of allergy, an allergy that appears to be substantial

(Stephen E Straus et al: National Institutes for Allergy and Infectious Diseases: Allergy and the Chronic Fatigue Syndrome. J Allergy Clin Immunol 1988;81:791-795)

1989

For the patients, there is no question that the illness exists. For the physicians who see these patients, the similarities among them allow ready identification of a distinct clinical illness. For those who scoff at this concept, one can only query as to what happened to their curiosity and their ability to listen to their patients

(James F Jones: Physician, National Jewish Centre for Immunology, Denver, Colorado: Statement to the House Appropriations Subcommittee, 25th April 1989; published in CFIDS Chronicle, Spring 1989 pp 28-30)

1989

Many of the immunological and physical features of ME/CFS can t be explained by mental illness

(Stephen E Straus of the National Institutes for Allergy and Infectious Diseases, USA, Progress toward an answer to Chronic Fatigue: an interview with USA Today , 13th April, 1989: reported in CFIDS Chronicle, Spring 1989, pp77-78)

1989

It is a real organic problem and people who have it don't need the additional stress of hearing doctors tell them they are crazy

(John Esdale, Rheumatologist, Montreal General Hospital; Chronic Fatigue Syndrome wrecks havoc with victims' lives: The Gazette (Montreal, Canada) 15th November 1988; reported in CFIDS Chronicle, Spring 1989, p 79)

1989

The most obvious factor is of course the severity of CFIDS

(David S Bell: Instructor in Paediatrics, Harvard Medical School: CFIDS in Children. CFIDS Chronicle, Spring 1989, pp34-37)

1989

The abnormalities we found provide evidence for central nervous system and neuromuscular involvement

(Carloyn L Warner: Neurology, March 1989;39:3: Suppl 1: 420; Presentation at the American Academy of Neurology Conference, Chicago, April 1989:

1989

The disabling weakness and exhaustion a patient with ME/CFS experiences is so profound that fatigue is probably an insult

(J Cuozzo: Chronic Fatigue: JAMA 1989;261:5:697)

1989

The crucial differentiation between ME and other forms of postviral fatigue syndrome lies in the striking variability of the symptoms not only in the course of a day but often within the hour. This variability of the intensity of the symptoms is not found in post viral fatigue states

(Dr Melvin Ramsay, President, UK ME Association. ME Association Newsletter, Winter 1989: 20-21)

1990

A news release in the July 4 packet confused chronic fatigue with chronic fatigue syndrome; the two are not the same. We regret the error and any confusion it may have caused

(John Hammarley: AMA Science News Editor, JAMA 1990)

1990

The results suggest that (ME)CFS is a form of acquired immunodeficiency
(Nancy Klimas, Professor of Medicine, University of Miami School of Medicine: Director of Immunology; Director of AIDS research and Director of the Allergy Clinic at Miami: Immunologic Abnormalities in Chronic Fatigue Syndrome. Journal of Clinical Microbiology, June 1990:1403-1410)

1991

The NK (natural killer) cell is a very critical cell in (ME)CFS because it is clearly negatively impacted. The most compelling finding was that the NK cell cytotoxicity in (ME)CFS was as low as we have ever seen it in any disease. This is very, very significant data. (In (ME)CFS) the actual function was very, very low --- 9% cytotoxicity: the mean for the controls was 25, In early HIV and even well into ARC (AIDS related complex, which often precedes the fully developed condition), NK cytotoxicity might be around 13 or 14 percent. (ME)CFS patients represent the lowest cytotoxicity of all populations we ve studied

(Nancy Klimas, Professor of Medicine, University of Miami School of Medicine; Director of Immunology; Director of AIDS research and Director of the Allergy Clinic at Miami. Presentation: Immunological Markers in (ME)CFS. The CFIDS Association Research Conference, November 1990, Charlotte, North Carolina. Reported in CFIDS Chronicle, Spring 1991; pp 47-50)

1991

Once one is familiar with the concept of post-viral fatigue syndrome (ME/CFS), such patients are in practice not too difficult to differentiate from those with true psychiatric illnesses. The physical symptoms should be an aid to diagnosis, although they may be wrongly attributed to primary psychological illness unless care is taken in eliciting them

(Professor Rachel Jenkins: Assessment and Diagnosis of ME in the Psychiatric Clinic. In: Postviral Fatigue Syndrome; British Medical Bulletin 1991:47:4:241-246)

1992

Patients with ME/CFS may have been experiencing a chronic, immunologically mediated inflammatory process of the central nervous system

(Buchwald D, Cheney P, Peterson D et al: A chronic illness characterized by fatigue, neurologic and immunologic disorders, and active human herpes type 6 infection. Ann Int Med 1992:116:103-116)

1992

A patient examined in the morning might have nystagmus, which would disappear at midday, recur later, disappear later and recur the next day

(A. Jain: Clinical Observations of Central Nervous System Dysfunction in Post-Infectious Acute Onset ME/CFS. In: The Clinical and Scientific Basis of Myalgic Encephalomyelitis Chronic Fatigue Syndrome ed: BM Hyde, J Goldstein, P Levine pub: The Nightingale Research Foundation, Ottawa, Canada 1992)

1992

CFIDS has an organic basis; it is not a psychiatric illness. Our Surveillance Study does not support the notion that (ME)CFS is a psychiatric illness, and in fact, suggests that it has an organic basis

(Dr Walter Gunn, Principal Investigator of (ME)CFS studies at CDC: CFIDS Chronicle, February 1992, page 1)

1993

The performance of the CFIDS patients was sevenfold times worse than either the control or the depressed group. These results indicated the memory deficit in CFIDS patients was more severe than assumed by CDC criteria. A pattern emerged supporting neurological compromise in CFIDS

(Curt Sandman, Professor of Psychiatry and Human Behaviour, University of California School of Medicine: Memory deficits associated with chronic fatigue immune dysfunction syndrome: Biol Psych 1993:33:618-623)

1993

The worst cases have both an MS-like and an AIDS-like clinical appearance. The most difficult thing to treat is the severe pain. Most have abnormal neurological examination. 80% of cases are unable to work or attend school. We admit regularly to hospital with an inability to care for self

(Paul Cheney, Professor of Medicine, Capital University, USA: Testimony Before the FDA Scientific Advisory Committee, 18 February 1993)

1993

Recent public statements by Dr Stephen Straus at NIAID regarding the severity of CFIDS and its classification as a real, organic illness make patient leaders hopeful that this growing public health concern will finally be taken seriously

(Press Release 8th February 1993: CFIDS Association of America: Government finally confirms private sector research: Immune Abnormalities Found in Chronic Fatigue Syndrome)

1994

The spectrum of illnesses associated with a dysregulated immune system must now include (ME)CFS

(Paul H Levine, Research Professor of Epidemiology and Biostatistics, George Washington University, Washington DC: Summary and Perspective: Epidemiology of (ME) Chronic Fatigue Syndrome: Clin Inf Dis 1994:18: (Suppl 1):S57-S60)

1994

Abnormalities of immune function, hypothalamic and pituitary function, neurotransmitter regulation and cerebral perfusion have been found in patients with (ME/CFS). Recent research has yielded remarkable data. The symptoms of (ME)CFS have long been viewed as a neurologic pattern, as confirmed by other names such as myalgic encephalomyelitis. A link is being forged between the symptoms pattern of (ME)CFS and objective evidence of central nervous system dysfunction. The view that (ME)CFS is a primary emotional illness has been undermined by recent research

(Dr David S Bell: Instructor in Paediatrics, Harvard Medical School: Chronic fatigue syndrome update: Findings now point to CNS involvement: Postgraduate Medicine 1994:98:6:73-81)

1995

In my experience, (ME/CFS) is one of the most disabling diseases that I care for, far exceeding HIV disease except for the terminal stages

(Dr Daniel L Peterson: Introduction to Research and Clinical Conference, Fort Lauderdale, Florida, October 1994; published in JCFS 1995:1:3-4:123-125)

1995

I take great issue with the current recommendations that no additional testing should ever be done. I believe there are indications for more advanced testing

(Dr Daniel Peterson: [a Diplomate of the American Board of Internal Medicine who first identified CFIDS during an outbreak in Incline Village, Nevada, in 1984] JCFS 1995: 1:3-4:123-125). At the Second World Congress on ME/CFS and related disorders, held in Brussels in September 1999, Peterson said he was amazed at the misconceptions that existed about ME/CFS; he said that ten years ago, he believed ME/CFS would be resolved by science; he had now changed his mind and believed it could only be resolved by politics)

1997

The most seriously affected individuals may be bed-ridden most or all of the time and can do little or nothing for themselves. Recent research has made it clear that the view that there were no specific changes demonstrable in patients with ME/CFS has become untenable

(Dr Derek Pheby: Director, Cancer Epidemiology Research Unit, Bristol University: CFS: A Challenge to the Clinical Professions. *Physiotherapy* 1997;83:2:53-56)

1997

The signal abnormalities in ME/CFS patients most closely resemble those seen in AIDS encephalopathy. Patients often experience rejection by family, friends and physicians. The illness is hardly imaginary

(Anthony Komaroff, Assistant Professor of Medicine, Harvard Medical School: *Clinical Crossroads: Conference Report: JAMA* 1997;278:14:1179-1185)

1999

The most important thing is not to have (patients) do aerobic exercise. I believe that even progressive aerobic exercise is counter-productive. If you have a defect in mitochondrial function and you push the mitochondria by exercise, you kill the DNA

(Paul Cheney, Professor of Medicine, Capital University, USA: Presentation in Orlando, Florida, February 1999 at the International Congress of Bioenergetic Medicine)

2000

In summary, there is now considerable evidence of an underlying biological process in most patients (which) is inconsistent with the hypothesis that (the syndrome) involves symptoms that are only imagined or amplified because of underlying psychiatric distress. It is time to put that hypothesis to rest

(Anthony Komaroff: Assistant Professor of Medicine, Harvard Medical School: *Editorial: Am J Med* 2000;108:2:169-171)

2001

In ME, there are chronic sequelae and the effects may be neurological, hormonal, autoimmune and myalgic, which may affect the myocardium

(Dr John Richardson: Enteroviral and Toxin Mediated Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Other Organ Pathologies. The Haworth Press Inc, New York, 2001)

2001

There is considerable evidence already that the immune system is in a state of chronic activation in many patients with (ME)CFS

(Anthony Komaroff, Assistant Professor of Medicine, Harvard Medical School: American Medical Association Statement, Co-Cure, 17 July 2001)

2001

New Survey reveals Chronic Fatigue Syndrome (ME) is as disabling or debilitating as lupus, multiple sclerosis and rheumatoid arthritis. Many medical professionals are acknowledging it as a seriously disabling condition. Three quarters of medical professionals responding to the survey believe that (ME)CFS, also known as CFIDS, is as or more disabling than other chronic diseases

(Press Release, CFIDS Association of America, 15th November 2001)

2004

CFS/ME patients are sensitive to the endothelium-dependent Ach. Such sensitivity is unusual if not unique and it is clear that the sensitivity is specific to CFS/ME patients

Dr Vance Spence: Senior Research Fellow in Vascular Medicine, University of Dundee; Julian Stewart, Professor of Paediatrics and Physiology, New York Medical College: Standing up for ME: Biologist 2004:51:2: 65-70)

There is no word in the English lexicon that describes the lack of stamina, the paucity of energy (and) the absolute malaise that accompanies this illness

Charles Lapp, Professor of Community and Family Medicine at Duke University, USA (and a world expert on the disorder): Co-Cure, 3rd June 2004