

# The case for the prosecution of chronic fatigue syndrome



### Curriculum Vitae

Chris qualified from Charing Cross Hospital Medical School, University of London and has been in general practice in England, Canada and, for the last 20 years, in southern Africa. He is CME editor of South African Family Practice and works part-time in the Department of Family Medicine at Medunsa.

### Summary

*A case of Chronic Fatigue Syndrome must fulfil two major criteria and six or more of the 11 symptom criteria and two or more of the three physical criteria; or eight or more of the 11 symptom criteria. The prosecutor argues that, in this case, biomedicine has gone a bridge too far.*

**C Ellis**

MBBS, MRCS, LRCP, MFGP, MD

S Afr Fam Pract

1996;17:00-00

### KEYWORDS

Neurasthenia;

Chronic fatigue

syndrome;

Physicians, family.

My proposal to you, the jury, is that:

Chronic Fatigue Syndrome is the end of the road down which Cnidian classification, Cartesian dualism and the Newtonian mechanistic framework has lead to modern scientific medicine (also referred to as 'biomedicine').

And that the label chronic fatigue syndrome represents only a partial truth.

My credentials for pursuing this prosecution are impeccable. I am a rural general practitioner, knee deep in fatigue.

I will lead the arguments, firstly with the ringing of three alarm bells and then go on to call witnesses, some of whom will incriminate themselves.

### The first alarm bell

The first alarm bell that is ringing is that a syndrome should be useful and practical. It appears that there are so many major and minor criteria for this condition and they are so ubiquitous and vague that most working general practitioners do not remember them and do not have the time to look them up and work out the formula on each

# Chronic fatigue syndrome

occasion. This is not to say that we do not make this 'diagnosis' from a vague background of medically imprinted formulae.

## The second alarm bell

The second alarm bell is positively tolling for the demise of Chronic Fatigue Syndrome because it is the very name that is at stake. It has enough synonyms and acronyms to fill a bucket.

There is myalgic encephalitis (ME), epidemic neuromyasthenia (EN), post viral-syndrome (PVS) and the old neurasthenia. If there is dissension about what to call or label something then one must be careful that what one is trying to catch (like the abominable snowman) actually exists.

## The third alarm bell

The third alarm bell is that there is no treatment for it ... because it is a theoretical construct and you cannot treat theoretical constructs. You can only treat people and people (not diseases or theories) itch and scratch, get tired and ache, etc. Of course, there is 'treatment' for 'it' in that 'it' and 'treatment' are in an objective paradigm and that it is part of the problem. Biomedicine is continually trying to objectify and classify human beings.

## THE WITNESSES

I would now like to call my witnesses.

My first witness is **ARISTOTLE**. I realise that it is a bit late in the day to call in **ARISTOTLE** as he lived between 384 BC and 322 BC but this whole thing is basically his fault. It was he who built on the ideas of Thales, Anaximander and Anaximenes, who themselves formulated theses on the nature of the world but it was he and the lads down at the Lyceum, who are to blame.

**ARISTOTLE** is known as the 'father of classification'. He was an assiduous

collector of all kinds of data and thought that science could and should be built up on the basis of observation refined by generalisation.

He himself founded zoology by observing and classifying individual specimens. These endeavours are written up in his **Physics** and **Enquiry into Animals**.<sup>1</sup> His systems of classification have been refined by such as Linnaeus in the 18th century and culminating, perhaps, in the apotheosis of classification – the Diagnostic and Statistical Manual of Mental Disorders,<sup>2</sup> which is the most modern attempt made to classify the unclassifiable.

**ARISTOTLE**, I believe, would be pleased with the classification of Chronic Fatigue Syndrome with its two major criteria of fatigue and exclusion of physical and psychiatric conditions and with its well defined minor criteria.

I am now going to call a number of witnesses in rapid succession.

The first is **CLIFTON MEADOR** who wrote a paper in 1965 in the New England Medical Journal called The art and science of non-disease.<sup>3</sup> He proposed that a great many patients do not have a disease in any other sense than that they are not 'at ease'. The inclusion of non-diseases among our alternatives frees the doctor from the prejudice that because a patient makes a complaint there must be something medically wrong.<sup>1</sup> Many of us in general practice have come to accept uncertainties of this kind that never get to a diagnosis. We form hypotheses that fade with time. Fatigue continues as a symptom in several of my patients yet its meaning alters with the journey. It may remain as an 'entry ticket' symptom that we dispose of almost like a greeting and get on with the main business of communication distress and loneliness through the medium of physical symptoms.

I now call **VICTORIA SWIGERT** and

Symptoms of underlying problems of living.

A syndrome should be practical and useful.

Patients always ask for a name for their disease.

# Chronic fatigue syndrome

**RONALD FARRELL.**<sup>5</sup> They will say that once labelled a condition goes onto another level of significance. It acquires criteria and limits and obtains a model that is recognised by its community of sufferers and healers. In their definitional theory of deviant behaviour they state that individuals and groups start to organise their lives and identities around the definition (hence the formation of ME societies). It becomes self fulfilling.

As soon as chronic fatigue syndrome acquired its name or was 'languaged' it acquired status and position. The person submerged under this label may then become irrelevant to the label itself, which takes precedence.

My three patients labelled as 'ME' can almost explain anything under the label. I don't think I could ever convince them of anything else. This is not altogether bad as will be explained by the counsel for the defence.

The next witness carries on this line of argument as he says that persons thus labelled gain an expected type of behaviour. He is **THOMAS SZASZ**, who quotes from his book **The Myth of Mental Illness**<sup>6</sup> that once a diagnosis is made the patient may alter his or her behaviour to fit the diagnosis and a social game ensues in which the doctor may unconsciously be involved as he manipulates presentations to fit the diagnosis. I may do this because of tiredness in myself. It is often easier to acquiesce to the strength and force of the diagnosis of ME.

To strengthen my case here I was going to call experts to debate the concepts and dimensions of disease, illness, sickness and illness behaviour but there are too many of them and I cannot afford their travel expenses so I am going to keep them in reserve in case of an appeal. Neither can we go into the sick role, secondary gains and hidden agendas in the opening statements.

I have though – waiting in the wings – a whole gallimaufry of medial anthropologists – I'm not actually sure what the collective term is, members of the jury, for medical anthropologists, but I'm sure you get the gist of the gathering. Medical anthropologists, like general practitioners, are daily confronted with unruly bodies and chaotic symptoms that disrespect our diagnoses and breach the boundaries of our categories. The bodies and minds of our patients – here in the real world – are naturally subversive and refuse to conform to two major criteria and eight out of 11 minor criteria. These, they say, are doctor-centred and disease-centred agendas. Beyond the penetrating eye of the X-ray machine, the ECG and the CAT scan lies the cryptic language of modern distress. They are of the opinion that this language is expressing modern man's submerged anger and impotence by 'somatising' these feelings into the body and rendering them authentic and negotiable by collusion with modern medicine. Frustration, resentment and alienation are, in this way, 'domesticated' and transformed into 'diseases'.

As I said these ladies and gentlemen are waiting by their telephones but for the time being I am going to call – but only briefly – an interesting man called **LAING**<sup>7</sup> who felt that words, especially medical words, kept the patient at a distance from the doctor because they isolated and circumscribed the meaning of a patient's life. The words were abstracta and falsely delineated man rather than describing relationships or unitary wholes.

I am quickly going to get Laing out of the box and get my next witnesses in, because I do not want you, ladies and gentlemen of the jury, to lose the thread of this argument because the issue of language is all important to this thesis.

Communicating distress and loneliness through the medium of physical symptoms.

Like Pygmalion who fell in love with his own sculpture, medicine could have fallen in love with the sculptured criteria of CFS

# Chronic fatigue syndrome

**ARISTOTLE** now comes on for a short encore because he was, in part, responsible for reductionistic logic by his grammar. Aristotlian grammar analyses phenomena into subjects and predicts as opposed to relational grammar which describes the world in terms of process. Thus the structure of **ARISTOTLE'S** logic is focused and isolates the world into nameable pieces rather than the more holistic world of process, which expresses interrelatedness and whole interacting and interdependent systems.<sup>8</sup>

Aristotle would again be pleased with the objectivity and focus or the 'diagnosis' of Chronic Fatigue Syndrome in my Mrs Blue or Mr Black whereas **LAING** would worry about their empty and unfulfilled lives and the problems they have with their children.

Apart from the reduction and focus that takes place with a label or name, there is a lot of mystery and power (or is it a gaining of power?). Man has always wanted names partly because of this. For instance, Moses, you will remember, told God that the Hebrews would not believe that God had sent him unless he could tell them God's name. Patients similarly ask for names, "what have I got doctor?"

"I'm afraid your body aches and you feel tired because life is difficult" is not an answer easily accepted by my 20th century patients or by biomedicine's drive for finite truth.

By the way, I have no intention of calling Moses as a witness. I think he would be mightily offended and perplexed by modern courtroom antics.

## THE COUNSEL FOR THE DEFENCE

At this stage I am anticipating the counsel for the defence to rise with the argument that a label or diagnosis has many advantages because it gives

a sense of security over the unknown and naming an illness lessens anxiety in many contexts because it is removed from the realm of the unknown. A diagnosis also externalises the condition and can relieve both the doctor and the patient from responsibility, which is shifted onto the disease or diagnosis. The counsel for the defence will emphasise that without labels you cannot communicate anything.

This, I graciously, do not dispute. Whether it is, though, a good thing or not **in this case**, is for you, the jury, to decide. Language connects us but it **also keeps us apart**.

The next attestant is **WILLIAM HUDSON O'HANLON**, who I have had flown over from the United States of America. He feels that doctors are convinced that the observations they make during their consultations are 'real' and objective. They are certain they have found **real** problems. He calls this 'delusions of certainty' or 'hardening of the categories' and refers to new syndromes such as the Chronic Fatigue Syndrome as 'inventities'.<sup>9</sup>

There are several persons I have briefed, 'just in case'. I may, for instance, need to call **PYGMALION**, a sculptor from Greek mythology, who created a sculpture of a woman that was so lovely he fell in love with it. The gods were impressed and brought her to life for him. It has been easy for medicine and society to fall in love with the sculptured criteria of the Chronic Fatigue Syndrome and bring them to life in our patients. This has been called the **PYGMALION** effect.<sup>10</sup>

I am also keeping in reserve the philosophical and religious schools of the Orient, for it was **BUDDHA**, who speaking on such a reductionism and classification said: "In the sky there is no distinction of east and west; people create distinctions out of their own minds and then believe them to be true."

The Chinese Tao, the Hinduist Brahman

...vague symptoms from a vague background.

Enough synonyms and acronyms for CFS to fill a bucket.

# Chronic fatigue syndrome

and the Bhuddist Dharmakaya all include this concept of an all-embracing unity and oneness to life and care as opposed to an atomistic approach.<sup>11</sup> I would be reluctant, as was the case with Moses, to subpoena **BUDDHA**. It would seem somehow inappropriate.

## The counsel for the defence rises again

I believe the counsel for the defence will rise again at this point and eruditely map out the many important benefits that classification and categorisation has brought to medicine. It has enabled clinicians to communicate their findings to each other, make inferences about causes, predict outcomes and guide the prescription of specific therapies for diseases. Classification is vital if medicine is to work. Medical research depends on it, for unless we can predict outcomes we cannot know whether or not our interventions are effective or not.

All this and more, members of the jury, I agree, is beyond dispute. This holds true for the biomedical model, the treatment of the body as a 'broken machine' and for the diseases that the flesh is heir to.

It is whether there is a limit to this drive to categorise all matters of our living on this earth into neat parcels, that is in dispute. Is it appropriate in the case of your so-called Chronic Fatigue Syndrome or have we overstepped the mark? Are we trying to catch the wind with a butterfly net?

## The final witnesses

I will end my arguments with **MICHAEL BALINT** (the Moses of family medicine) and **IAN McWHINNEY**, professor of family medicine at the University of Western Ontario.

**MICHAEL BALINT** will say that illnesses are described by 'hospital tags' which only represent superficial symptoms

and may be 'offers' that prevent us reaching the 'deeper' diagnosis. It is carrying the language and diagnoses of the hospital and the medical school outside their intellectual walls and applying them inappropriately to general practice.<sup>12</sup> **IAN McWHINNEY** will remark that classification is a generalising process that tacitly ignores individual differences by reducing complex phenomena of illness and behaviour to relatively simple categories.<sup>13</sup> He may state that these criteria laid down for the diagnosis of chronic fatigue syndrome may represent 'symptoms of underlying problems of living'<sup>14</sup> and the criteria of major and minor symptoms addresses the doctor's disease-orientated agenda while ignoring the patient's agenda. He will also warn, though, that the doctor must always beware of becoming insensitive and unaware that these patients are suffering although the data is subjective.

## CONCLUSION

In conclusion, ladies and gentlemen, I propose to you that Chronic Fatigue Syndrome/Myalgic Encephalomyelitis is a product of biomedicine's entrenched search for the **universal pattern**. This is similar to the physicist's search for the elusive Grand Unified Theory (GUT) or the Theory of Everything (TOE) in which attempts are made to squeeze divergent phenomena of life into the same square box.<sup>15</sup>

The tradition in medicine is that treatment should not be started before a diagnosis is made. This is justified if the diagnosis really describes a pathological process, that is to say, if it gives much more than just a name into the hands of the doctor. The diagnosis, Chronic Fatigue Syndrome, is a kind of magic name and there is no evidence to support this medical label or grouping of criteria under any name. They could as well be representations

Many patients do not have a disease in any other sense than that they are not 'at ease'.

So often just the entry ticket...

# Chronic fatigue syndrome

of existential anxiety,<sup>16, 17</sup> unhappiness<sup>18</sup> or despair.<sup>19, 20</sup>

I would ask you to just read briefly some of the symptoms of the minor criteria: muscle discomfort, joint pains, headaches, muscle weakness, sleep disturbances, fatigue, mild fever, sore throat and painful neck.

They could be representations of almost anything.<sup>21</sup>

I realise, my Lord, that the court must now recess.

I rest my case and await the full response of the defence.

## References:

1. Ross WD, Smith JA, editors. The works of Aristotle translated into English. Twelve vols. Oxford: Clarendon Press, 1908-52.
2. Diagnostic and statistical manual of mental disorders. DSM 111R. 3rd rev ed. Washington, DC: American Psychiatric Association, 1987.
3. Meador CK. The art and science of non-disease. *New Engl J Med* 1965;272:92-5.
4. Scott AJ. Diagnostic accuracy would be improved by developing more categories of 'non-disease'. *Medical Hypnosis* July, Aug 1977;3:135-7.
5. Swigert VL, Farrell RA. The substances of social deviance. Palo Alto, California: Mayfield, 1979.
6. Szasz TS. The myth of mental illness. Foundations of a theory of personal conduct. Frogmore, Herts: Paladin edition, Granada Publishing, 1972.
7. Laing RD. The divided self. An existential study in sanity and madness. Harmondsworth: Penguin Books, 1960.
8. Dell PF. The Hopi family therapist and the Aristotelian parents. *Journal of Marital and Family Therapy*, 1980;6:123-30.
9. O'Hanlon WH. A grand unified theory for brief therapy. Putting problems in context. In: Zeig JK, Gilligan SG, editors. *Brief Therapy. Myths, Methods and Metaphors*. New York; Brunner/Mazel, 1990:78-89.
10. Rosenthal R, Jacobson L. *Pygmalion in the classroom; Teacher expectation and pupils' intellectual development*. New York: Holt, Rinehart & Winston, 1968.
11. Capra F. *The Tao of physics. An exploration of the parallels between modern physics and eastern mysticism*. 3rd ed. London: Flamingo, 1992.
12. Balint M. *The doctor, his patient and the illness*. 2nd ed. London: Pitman Books, 1964.
13. McWhinney IR. *A textbook of family medicine*. New York: Oxford University Press, 1989.
14. McWhinney IR. *Beyond diagnosis: an approach to the integration of behavioural science and clinical medicine*. *N Engl J Med* 1972;287:384-7.
15. Appleyard B. *Understanding the present. Science and the soul of modern man*. London: Pan Books, 1992.
16. Boss M. *Normal Anxiety*. In: Kruger D, editor. *The changing reality of modern man: essays in honour of J H van den Berg*. Cape Town: Juta, 1984.
17. Maddi SR. The existential neurosis. *Journal of abnormal psychology* 1967;72: 311-25.
18. Ellis CG. An investigation into the phenomenon of chronic unhappiness as presented in family practice. Doctoral thesis in family medicine. Medunsa 0204: Medical University of Southern Africa, 1992.
19. Kierkegaard S. *The sickness unto death*. London: Oxford University Press, 1944.
20. Camus A. *The myth of Sisyphus*. Great Britain: Hamish Hamilton, 1955.
21. Richmond C. Myalgic encephalomyelitis, Princess Aurora, and the wandering womb. *Br Med J* 1989;298:1295-6.