

**The 1996 Strasbourg Convention on Biomedicine and the reform of the UK Mental Health Act: have they anything to do with the attempt to re-classify ME and CFS as mental illness in the WHO Guide to Mental Health in Primary Care?**

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In their article entitled Functional somatic syndromes: one or many? (*Lancet* 1999;354:936-939), authors Simon Wessely, C Nimnuan and Michael Sharpe state that each medical specialty seems to have at least one “functional” syndrome; they list as examples hyperventilation syndrome, tension headache, multiple chemical sensitivity, fibromyalgia, irritable bowel syndrome, globus hystericus and chronic fatigue syndrome. Wessely et al suggest that the existence of such specific “somatic syndromes” is largely an artefact of medical specialisation rather than any real difference between patients. They state that “Functional somatic syndromes pose a major challenge to medicine” and that the symptoms “are associated with unnecessary expenditure of medical resources”. They state that “functional somatic complaints constitute a large...and costly health-care issue...that urgently requires...improved management”.

Wessely et al state that “many of these syndromes are dignified by their own formal case definition”; they question this “orthodoxy” and state their belief that in such syndromes there is always a substantially increased rate of emotional distress. They suggest that all functional somatic syndromes are in reality just variants of one general (psychiatric) syndrome which responds to the same therapies.

The authors are at pains to labour their point; they state that much of the current literature pertains to “specific syndromes defined by medical subspecialties”; they claim that “the acceptance of distinct syndromes as defined in the medical literature should be challenged” and that there should be “an end to the belief that each ‘different’ syndrome requires its own particular sub specialist”. Wessely et al conclude by stating that a previous generation of physicians noted overlaps in psychosomatic syndromes and they regret the disappearance of empirical support for such a view from current thinking, arguing for its reinstatement.

Wessely et al write “If we accept that functional somatic syndromes are considered together, we open the way for more general strategies for their management”.

This is perhaps the most significant sentence in the whole article, especially when viewed within the context of two major but under-reported changes which are taking place.

**The Strasbourg Convention of Human Rights and Biomedicine (1)**

On 19 November 1996 only three European countries abstained from signing the preliminary draft of the Council of Europe 1996 Strasbourg Convention on Human Rights and Biomedicine: Germany did not do so (ostensibly on moral grounds because of the atrocities committed there during World War II) and both Belgium and Poland did not do so (possibly on religious grounds, as both countries are almost entirely Catholic and the Convention provides for research on embryos). Britain was a signatory to the preliminary draft, as were 35 other countries.

This Convention had no public airing beforehand and has been little reported since.

In essence, the Convention confers certain rights on member states who sign the final document. The finalised Convention was signed by 20 countries on 4 April 1997; the UK did not sign on that date due to the general election, but ratification was to be dealt with by the in-coming Labour government and is thought to be on the agenda for the forthcoming parliamentary session (2001).

Of potential significance is the fact that the conferred rights include provision for drug and other medical trials on human beings which, in certain circumstances, could be carried out without the individual's consent. This would appear to pave the way for sweeping relaxation of informed consent to medical treatment and to annul the fundamental human rights which were enshrined in the Code of Medical Ethics drawn up in 1948 after the World War II Nazi atrocities, specifically that no-one should ever be forced to participate in an experimental trial again. Thereafter, voluntary consent became the corner-stone of medical researchers' principles.

Simultaneously to the European Strasbourg Convention, the United States government decided that in future, individuals can be enrolled in medical research programmes without their consent: new Food and Drug Administration (FDA) rules now allow the use of experimental treatment in certain situations (2), which are similar to those set out in the Strasbourg Convention.

The Strasbourg Convention and the new FDA rules seem to imply that for three groups of people in particular, such consent will not always be needed in the future:

- (i) those who are deemed to be mentally ill
- (ii) those for whom no other known treatment is effective
- (iii) children

There appear to be many possibilities for ways in which the "safeguards" can be manipulated to suit researchers: the Convention stipulates that in certain situations, "general interests" will take priority over those of the individual.

Dr Peggy North, Secretary of the European Doctors' Union, is critical of the lack of debate so far; she insists that "the basic rule should be that you cannot do research on someone without their consent" (3).

At present, it appears that many cases for compensation of vaccine damage remain unsettled, as do countless pesticide cases (including those damaged by the compulsory use of OPs) and chemical injury cases; in particular, the plight of the Gulf War veterans is paramount. By designating as "psychologically ill" those who suffer from any of the so-called "medically unexplained" syndromes, those working so tirelessly to achieve this objective may have a hidden and sinister agenda, because once the UK has ratified the Strasbourg Convention, under the Convention's rules it seems that there will be virtually no chance to prove negligence in cases categorised as "mentally or psychologically" ill.

Currently, some state benefits are reduced for those deemed to be suffering from psychiatric illness and some insurance companies (medical and permanent health) exclude those with mental illness from eligibility for benefit. To this existing injustice may be added another: those who suffer from a condition which carries a "mental illness" label may well lose their individual human rights if those in authority consider such individual rights to be secondary to "general interests" (1).

Reform of the UK Mental Health Act (1983)

Proposals for the reform of the Mental Health Act (4) were drawn so widely that they would give psychiatrists far greater powers to enforce compulsory psychiatric treatment upon both adults and children: proposals included provision for psychiatrists to be able to drug people (including children against the wishes of their parents) if they have “any disability or disorder of the mind or brain, whether permanent or temporary, which results in an impairment of mental functioning” (5). That seems a chillingly watertight definition.

This reformed legislation might do away with the current safeguard which states that people can only be given treatment against their will if they show “seriously irresponsible or abnormally aggressive behaviour”.

#### How does this relate to ME/CFS?

Although ME (also known as Postviral Fatigue Syndrome and as the internationally-defined CFS, which is not the same as “chronic fatigue”) is formally classified as a neurological disorder at section G 93.3 of the World Health Organisation International Classification of Diseases (ICD 10), already Simon Wessely (Professor of Epidemiological and Liaison Psychiatry at King’s College, London) and colleagues have spectacularly attempted to re-classify ME / CFS as a mental illness under section F 48 (Mental and Behavioural disorders) without such a change of classification having been approved by the World Health Assembly and thus without the sanction of the WHO: their strategic use of the WHO logo on their various websites which contain and promote their own contribution on CFS to the WHO Guide to Mental Health in Primary Care (*November 2000*) clearly implies WHO approval for their own re-classification of ME / CFS as a mental illness, but the WHO has confirmed that there has been no such re-classification.

Significantly, it is these same psychiatrists who are so influential on the Chief Medical Officer’s Working Group on CFS/ME, the Report of which is awaited but which is believed to recommend psychotherapy for all those with CFS/ME who are able to attend

a hospital outpatients’ department (in apparent disregard of the extensive anecdotal evidence that such regimes involving cognitive behavioural therapy and graded exercise may be harmful).

On 4 May 2000 a letter from the Minister of State at the Department of Health (signed by John Hutton) seemed not to rule out future re-classification of ME: concerning the reforms to the Mental Health Act he wrote: “*it is highly unlikely that (CFS/ME) sufferers would qualify for detention under the Act - even if it were reclassified as a mental rather than a physical disorder*”.

It is entirely possible that those suffering from such disorders would come within the framework of the Strasbourg Convention if not within the reforms of the UK Mental Health Act if these psychiatrists and their supporters are eventually successful in getting all conditions with “medically unexplained symptoms” (including ME/CFS, multiple chemical sensitivity, fibromyalgia and Gulf War syndrome) re-classified as “psychiatric” by the World Health Organisation, which they have been endeavouring to do for many years (6), claiming in the *Lancet* that “*The inclusion in the tenth revision of the International Classification of Diseases (ICD 10) of benign myalgic encephalomyelitis...under Diseases of the Nervous System seems to represent an important moral victory for the self-help groups in the UK...neurasthenia remains in the Mental and Behavioural Disorders chapter under Other Neurotic Disorders (and) neurasthenia would readily suffice for ME. Applying more stringent criteria for CFS in the hope of revealing a more neurological subgroup succeeds only in strengthening the association with psychiatric disorders. We believe this latest attempt to classify fatigue syndromes will prevent many people from seeing the world as it actually is*”.

In the light of the heavy emphasis on psychiatric problems by this particular group of psychiatrists --- as memorably expressed in the 1996 Joint Royal Colleges’ Report on CFS and in over 200 published

papers by Wessely himself---such a possibility cannot be discounted. Certainly, children and adolescents with ME/CFS are being forcibly removed from their parents and placed in psychiatric care, sometimes with the backing of a Court Order (7).

It seems likely that these two momentous changes determine the intended direction of government policy.

Do they explain why Professor Tony Pinching (Deputy Chair of the CMO's Working Group on CFS/ME) said at the Sounding Board Event at the Department of Health on

7 June 2000 (apparently arranged so that invited adults might have some input into the CMO's Report) that there is no need for research into CFS/ME?

Do they explain why despite the international evidence of compelling biomarkers of organic pathoaetiology, Wessely and colleagues appear to have carte blanche in all matters relating to ME/CFS, MCS and GWS?

Do they explain Wessely's position on the Supervisory Board of PRISMA (the insurance company which promotes cognitive behavioural therapy for all medically unexplained symptoms)?

Do they explain why the Linbury Trust (the family trust of the Sainsbury supermarket family: Lord Sainsbury has been Minister for Science in the present Labour government) has funded over £4 million for mainly psychiatric research on "CFS" and why the Linbury Trust has so many of those whose psychiatric research it has supported on the CMO's Working Group on CFS/ME and why the Linbury Trust is financially supporting the CMO's Working Group?

Is it the case that "general interests" are already taking priority over those of the individual? Are those "general interests" economically and commercially determined?

Is it this likely direction of **government policy** which all along underlies the directive of denial?

## References

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7. How the law is being abused to force treatment on children - parents of ME sufferers are being victimised by the Children Act. The Countess of Mar. *Daily Telegraph*

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