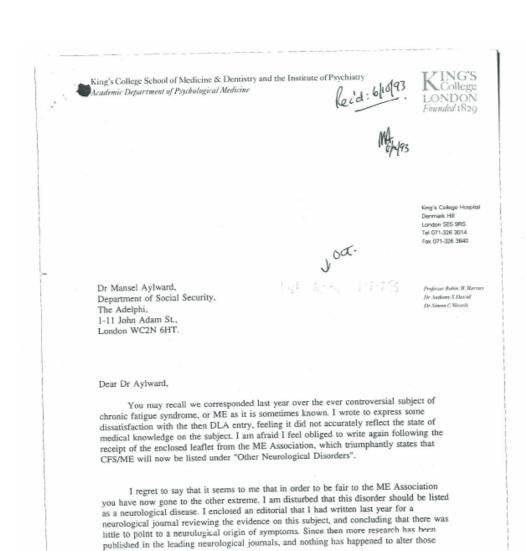
1. Documentation of academic-state exchanges

The National Archives data as presented below are accessible via Valerie Eliot Smith's blogsite (Eliot Smith, 2015). Valerie Eliot Smith is a UK barrister and a person with ME who succeeded in releasing government-redacted files, using the Freedom of Information Act. The data is also available on request, with fee payable, to The National Archives https://www.nationalarchives.gov.uk/

1st October 1993 Letter from Simon Wessely to Mansel Aylward



Instead I feel this decision represents the triumph of an effective lobby over scientific evidence. If CFS/ME is to be listed as a neurological disorder, I for one will begin to campaign via the mental health charities for schizophrenia and manic depression to be also listed under the same heading. Indeed, there is far more evidence suggesting that these disorders have a neurological origin than does CFS/ME.

conclusion

I also feel that this decision, if it has been made, reflects an undesirable stigmatisation of psychiatric disorders. The main difference between CFS and the major psychiatric disorders is neither aetiological, nor symptomatic, but the existence of a powerful lobby group that dislikes any association with psychiatry.

It is also a most unfortunate message to send sufferers. It colludes with the erroneous belief that this is a severe disorder of neurological functioning, for which there is little effect treatment, and a poor prognosis. It will discourage any sensible efforts at rehabilitation. As we, and now many other groups, have shown that the only determinant of outcome in this condition is strength of belief in a solely physical cause, then it will also itself contribute to disability and poor outcome. I cannot believe that is the intention of the Department, if only on grounds of cost!

I believe that the Department is making an error if it accepts the partisan views put forward by pressure groups as a basis for making medical decisions. I also believe that it is a decision that the Department will come to regret, since it seems likely the result will be an ever increasing stream of claims for permanent benefits in people who might otherwise have had a chance of recovery.

I am sorry to write to you again on this subject, and I know all too well how your spirits may well sink at receiving another letter on the topic. I also know from personal experience that coming to any decision on this subject that conflicts with the "party line" is not a recipe for a quiet life. Nevertheless, I would value your comments.

With kind regards,

Yours sincerely,

Dr Simon Wessely,

Senior Lecturer in Psychological Medicine.



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13 October 1993

Dear Dr. Wessely,

Very many thanks for your welcome letter of 1st October, and my apologies for not having been able to respond earlier.

I well remember our correspondence last year about the perplexing and controversial subject of chronic fatigue syndrome. Let me assure you that, as indicated above, I welcome your letter. In some ways some of your comments and advice, far from depressing one's spirits, provides an alterative view to those which have bombarded me, my colleagues in the Department and members of the Disability Living Allowance Advisory Board (DLAAB) in the past couple of years. Both Professor Grahame (Chairman of the DLAAB) and I are most grateful for your bringing our attention to the various points you raise in your letter.

You will, no doubt, have seen the letter by Charles Shepherd of the ME Association published in the 2nd October issue of the BMJ. For completeness, I enclose a photocopy of the relevant page of the BMJ together with a copy of a letter from Professor Grahame and me which we have submitted to the BMJ for publication in the letters columns.

Our letter is self-explanatory and expresses the profound dismay and disappointment we felt upon reading Charles Shepherd's inaccurate and unauthorized disclosure of certain selected parts of a draft version of a chapter for the Disability Handbook.

You can well imagine how we now feel when reading the ME Association's leaflet which you kindly enclosed with your letter. That disturbing leaflet is a glowing expression of what the lobby would like to be the truth rather than what is the truth.



The draft version of the Handbook's chapter was sent to groups representing people with ME as part of the customary confidential consultation procedures followed by the DLAAB when soliciting the views of interested parties on provisional revisions of the text of the Disability Handbook. The DLAAB, and the DLAAB alone, is charged with advising the Secretary of State on the contents and format of chapters for the Handbook. The DLAAB has not yet reached a decision on the final text of the chapter mentioning ME which it will recommend to the Secretary of State for inclusion in the Handbook.

A plenary session of the DLAAB will take place at 10.00a.m. on Tuesday, 2nd November at Richmond House when the Minister of State, The Rt. Hon. Nicholas Stott MBE MP, will be attending. Among other matters on the agenda will be a talk by Professor Thomas of the Royal Free Hospital on the subject of chronic fatigue syndrome. Professor Thomas's contribution will also assist the DLAAB in its deliberations on the final text of the chapter concerned with ME. Both Professor Grahame and I would be delighted if you could attend too. If you are able to come could you please get in touch with Dr. Mida McGrath (Tel: 071 962 8045) at the above address who will be pleased to give you details of the agenia and copy you with the relevant papers.

I am sure that the matters you raise, and in particular your views on the listing of chronic fatigue syndrome under "Other Neurological Disorders", will serve to fuel the debate at that meeting.

With kind regards,

Yours sincerely

Dr. Mansel Aylward

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The Medical College of Saint Bartholomew's Hospital

University of London

Department of Psychological Medicine

Head of Department: Professor Ted Dinan MD PhD

10 November 1993

M 15/xi

Mr Rodney Grahame and Mr Mansel Aylward Disability Living Allowance Advisory Board London WC2N 6HT

Dear Mr Grahame and Mr Aylward,

Description of ME in Disability Handbook

I read your letter in the British Medical Journal of 23 October this year. I was worried to learn that the Disability Handbook "will probably conclude that myalgic encephalomyelitis is a separate entity within the group of disorders encompassed by the chronic fatigue syndromes and that some affected people remain disabled, make little or no progress, or even deteriorate over time".

I am a psychiatrist who has been studying fatigue, particularly fatigue following infections like glandular fever, for nine years. From my own work, as well as my reading of the world literature, I would not agree that there is a consensus that "ME" and the chronic fatigue syndrome are separate conditions. Because of my research and clinical experience of helping to reduce disability in the chronic fatigue syndrome, I suggest that separating the two conditions may enhance disability. The reason for this is that those who believe in the separate existence of "ME" believe this is a totally physical condition, probably related to immune dysfunction or persistent viral infection, for which no treatment is available. On the contrary, I think the present evidence suggests that the chronic fatigue syndrome is a genuine discrete syndrome and treatments and rehabilitation programmes are available which address both the physical and psychological factors that maintain this syndrome.

For this reason, I would ask you to reconsider separating the two conditions. I would be happy to have further discussions with you about this.

Yours sincerely,

DOWNE.

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CHRONIC FATIGUE SYNDROME

SUMMARY

OF THE TALK GIVEN BY PROFESSOR P K THOMAS CBE DSc MD FRCP AND DR S WESSELY BM BCh MRCP MRCPsych on 2.11.93.

AT A FULL BOARD MEETING HELD IN RICHMOND HOUSE IN THE PRESENCE OF THE RT HON NICHOLAS SCOTT MBE MP.

Professor Thomas:-

- The term Myalgic Encephalomyelitis (ME) was introduced at the time of the epidemic in the Royal Free Hospital in 1955. There can be no doubt that this epidemic represented mass conversion hysteria. The epidemic was triggered by asmall number of cases of genuine neurological disorder, such as MS or post infective acute disseminated encephalomyelitis. In 1962 when Professor Thomas started working in the Royal Free Hospital there were still a number of symptomatic cases. The dominant symptoms were weakness, fatiguability and muscle pain.
- The cases now seen in the UK are a variety but one thing is certain they do not have Encephalomyelitis. This term means inflammation of the brain and spinal cord, for which there is no evidence whatsoever. Their symptoms are Myalgia, Fatigue and some Psychiatric symptomatology.
- Fatigue is a symptom in a wide variety of conditions and it is vitally important to establish a precise diagnosis. Many cases have been labelled as having ME when the diagnosis on further investigation was found to be eg Myasthenia Gravis, Hypothyroidism, Brain tumour, Occult infection, Metabolic neuropathies etc.
- There are different types of fatigue. Fatigue is the inability to maintain the necessary output of force by muscles. a). Peripheral Fatigue that is due to problems with the muscles themselves, the neuro-muscular junction or with the spinal cord.
 - b). Central Fatigue refers to difficulty in maintaining an output of muscle force because of problems in the activation of the nerve pathways that run from the brain to the spinal cord.

- c). Objective Fatigue is something that can be demonstrated by physiological recordings, which measure the declining force from the muscle.
 - d). <u>Subjective Fatique</u> refers to the situation where the delivery of the required force cannot be maintained because of uncomfortable sensations, not in the muscles themselves but in an indefinable way that affects drive and motivation.
- 5. The features of the chronic fatigue syndrome are multifarious and variable between different parts of the world. They have also changed over time. Definition thus becomes a problem, however symptoms should have persisted for at least six months. This is arbitrary but it does exclude patients who have the fatigue that normally follows many acute illnesses.
- 6. The dominant symptom is FATIGUE, both mental and physical. They are unable to work and many spend most of the day in bed or resting elsewhere. They have great difficulty in undertaking even mild exercise. Careful studies, in particular by Professor Richard Edwards in Liverpool and by a group in Sydney, Australia have shown unequivocally that the fatigue these patients experience is SUBJECTIVE. That is they have no muscle weakness, there is no difference between normal and CFS subjects in the decline and recovery of muscle force/contraction.
- 7. The second important symptom is MYALGIA or muscle pain. Characteristically this follows exercise rather than occurring at the time, it is the same as the pain which is suffered by physically unfit people after exercise. These patients are not active and therefore experience post-exercise myalgia after quite mild activity. It is related to muscle damage during what is called eccentric contraction. MUSCLE BIOPSY shows no abnormalities other than those related to the effects of inactivity ie type 11 atrophy of muscle fibres. The symptoms of CFS are therefore NOT due to heuromuscular dysfunction.
- 8. MENTAL FATIGUE is associated with emotional disorder. All studies have emphasized the high rates of psychological disorder in patients with CFS. Major or minor DEPRESSION is the commonest, however the following occur as well, somatization disorder, anxiety, hypochondriasis, hyperventilation and a few hysterical conversion syndromes. There is no psychiatric disorder in 23% of cases. CFS IS NOT DUE TO MALINGERING. It must be pointed out that fatigue is a symptom of depression and can be the initial symptom of depression.

- One feature that tends to distinguish patients with CFS from other patients with depression is a lack of self blame or self deprecation which is often a conspicuous aspect. Patients with CFS are desperate to find some reason outside themselves which has caused their symptoms.
- CFS is NOT related to chronic viral infection, previous claims have been shown to be faulty.
- Prognosis is not clearly understood and is determined by many factors, such as :- Psychological, social and cultural influences.

 Certain factors are associated with a poor prognosis, these are:- long duration of illness, high emotional distress, illness beliefs eg viral persistence or muscle disease, and poor clinical management.
- Clinical management MUST include identification of the underlying depression and persuasion of the patient to accept this explanation. It must be treated as it could lead to suicide.

 ACTIVE management is important, with graded rehabilitation towards achievable targets. Graded exercise does and will help. Patient support groups do not help as they tell patients that at all costs they must avoid exercise as it will make them worse which is totally untrue.

 There is no difference between ME and CFS except in the patient's belief.

Dr Simon Wessely:-

- There is no evidence of primary muscle dysfunction ie it is not a neuromuscular disorder or a neurological disorder. There is no evidence of inflammation of the CNS. There is no evidence of hysterical or feigned origin to symptoms.
- It is associated with high rates of psychiatric disorders which are well in excess of what might be explained as a reaction to physical illness.
- 3. There is little evidence that it is due to a persistent virus. The only infective association is that it may be triggered by the Epstein Barr virus. Post viral fatigue after other viral illnesses should not last longer than six months.

- The prognosis for those who acquire the label of "ME" is at the moment poor. The only three prognostic studies conducted to date all suggested that poor prognosis, and failure to improve, is closely related to illness beliefs of a solely physical origin to symptoms.
- 5. It seems likely that the greater the disability, the more likely is the disorder to be associated with either misdiagnosed psychiatric disorder or poor illness management. Many are iatrogenic ie Doctors contribute in perpetuating the disease and its symptoms.
- 6. TREATMENT is difficult, extraordinary sensitivity is necessary. Great flexibility is essential in treating these patients, each case is different. It is a treatable disorder but its management is deplorable at present, the worst thing to do is to tell them to rest. Rehabilitation is essential, exercise is good for these patients, prolonged inactivity causes adverse physical and psychological consequences.
 Most cases can be expected to improve with time.
- As regards benefits:- it is important to avoid anything that suggests that disability is permanent, progressive or unchanging. Benefits can often make patients worse.

Dr M McGrath Secretary DLAAB

2. Academic-corporate documentation

The following documentation is made available by Maxwell Head: https://issuu.com/maxhead/docs/unum_cmo_report_2002/18

Michael Sharpe's contribution to 2002 UnumProvident 'Trends in Health and Disability' brochure (Sharpe, 2002)

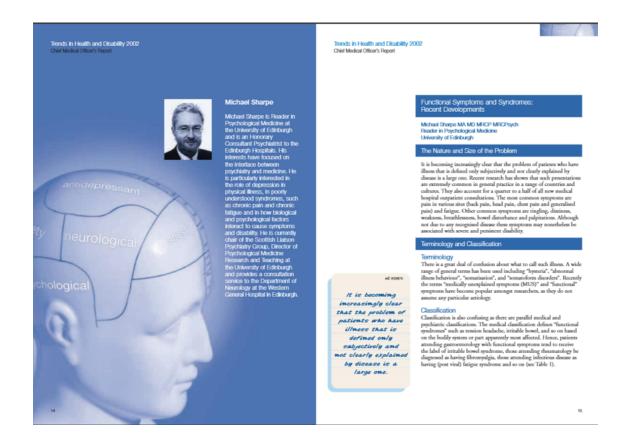


Table 1: Common medically defined functional syndromes listed by medical speciality		
Gastroenterology	Irritable bowel syndrome (IBS), non-ulcer dyspepsia (NUD)	
Gynaecology	Pre-menstrual syndrome (PMS), chronic pelvic pain (CPP)	
Rheumatology	Fibromyalgia (FMG)	
Cardiology	Atypical or non-cardiac chest pain; benign palpitation.	
Respiratory medicine	Hyperventilation syndrome (HVS)	
Infectious diseases	(Post-viral) fatigue syndrome (CFS)	
Neurology	Tension headache	
Dentistry	Temporal-mandibular joint dysfunction, atypical facial pain	
ENT	Globus syndrome	
Allergy	Multiple chemical sensitivity	

There has recently been increased awareness that these individual "functional syndromes" are not as separate as they seem. There is not only overlap in the symptoms patients report but also in associated characteristics and response to treatment (see below). It has therefore been proposed that these conditions be considered together as a "general functional somatic syndrome". Whilst this may be too extreme a view. substantial commonality the substantial commonality of the second because of a treatable but an all patients will meet criteria for depressive or anxiety disorders and most of the remainder of those for the so-called somatoform disorders of which hypochondrissis (sever anxiety about disease) and somatistion disorder (a long term tendency to present repeatedly with a range of medically unexplained symptoms) have most clinical utility.

Table 2 : DSM-IV and ICD unexplained syndromes	-10 categories for medically	
DSMIV	ICD-10	
Somatoform disorders	Somatoform disorders	
Somatisation disorder	Somatisation disorder	
Undifferentiated somatoform disorder	Undifferentiated somatoform disorder	
Conversion disorder		
Pain disorder	Persistent somatoform pain disorder	
Hypochondriasis	Hypochondriacal disorder	
Body dysmorphic disorder		
Somatoform disorder NOS	Somatoform autonomic dysfunction Other somatoform disorders Somatoform disorder unspecified Dissociative (conversion) disorders Disorders of movement and sensation Other neurotic disorders	
Neurasthenia		
Depressive disorders	Depressive disorders	
Anxiety disorders	Anxiety disorders	

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Neither classification is ideal. However, the psychiatric classification has important treatment implications. Because patients present somatically (and may not want a psychiatric diagnosis) this may be missed. Hence, patients may become chronically diashed because of a treatable but untreated psychiatric disorder. This is not an uncommon finding both in clinical practice and in IMEs. We need better (assifications—in the meantime, the best practice is to always seek evidence for and record diagnoses from both medical and psychiatric systems for example "irritable bowel syndrome with anxiety".

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The Aetiology of Functional Syndromes

The best ways of understanding such syndromes is to consider a range of biological, psychological and social factors. Table 3 illustrates such a approach to chronic fatigue syndrome.

Table 3: Possible causal factors in chronic fatigue syndrome				
	Predisposing	Precipitating	Perpetuating	
Biological	Genetic Previous depression	virus	HPA axis disturbance inactivity	
Psychological	Personality (perfectionism)	response to stress	disease attribution, avoidant coping style	
Social		stresses	life conflicts, iatrogenic factors	

there is strong symptoms and disability are shaped by psychological factors.

Biological factors

Recent research using functional brain imaging (PET and fMRI) has started to identify altered brain functioning in patients who have functional syndromes (as well as in those with depression and anxiety). This does not mean the patients have brain disease, but that their experience of symptoms has a neurophysiological correlate. On the one hand this is merely evidence of mind-brain identity, on the other hand it does remind us that these symptoms are not purely psychological phenomena but that they have a biological reality, albeit a potentially reversible one.

Psychological factors

Whatever their biological basis, there is strong evidence that symptoms and disability are shaped by psychological factors. Especially important are the patients' beliefs and fears about their symptoms. Research in several functional syndromes has found that a strong belief and prococupation that one has a "medical disease" and a helpless and passive attitude to coping is associated with penistent disability (as it is in recovery from acute medical condition such as myocardial infarction). The presence of depression is similarly associated with greater disability and worse outcome. Some persons appear to exaggerate symptoms but this is often hard to prove.

Although harder to research, social factors are almost certainly of great importance in shaping functional illness. Relevant factors include the information patients receive about the symptoms and how to cope with them. This information may be helpful or may stress the chronicity of the illness and promote helplessness. Such unhelpful information is found in "self-help" (1) books and increasingly on the Internet (see for example wow.meassociation.org uk). Unfortunately, doctors and especially "specialist private doctors" and complementary therapists may ask a point of the social factors that perpetuate illness are anger with the person or organisation the illness is attributed to, or toward the insurer for not believe in the provise insurers pay people to remain ill. Litigation for poorly understood and functional illness appears to be on the increase and a recent large study from Canada provided evidence that it does increase the duration of so-called whiplash symptoms.

7

Evidence based treatment
Recent systematic reviews of randomised controlled trials have
confirmed that psychologically informed rehabilitative treatments (often
called cognitive behaviour therapy or CBT) and 'antidepressant' drugs
have some effectiveness in treating most functional syndromes. There is
however a great shortage of skilled providers of CBT in particular and
rehabilitative facilities in general.

rehabilitative facilities in general.

Obstacles to recovery
In practice, even if treatment is available, there may be obstacles to recovery. Over time, the patient's beliefs may be become entrenched and be driven by anger and the need to explain continuing disability. The current system of state benefits, insurance payments and litigation remain potentially major obstacles to effective rehabilitation. It is often unrealistic to expect medical treatment alone to overcome these. Furthermore patient groups who champion the interest of individuals with functional complaints (particularly for chronic fatigue and fibromyalgia) are increasingly influentials they are extremely effective in lobbying politicians and have even been threatening towards individuals and organisations who question the validity and permanence of the illness they champion. Again the ME lobby is the best example.

The current system of state benefits, insurance payments and litigation remain potentially major obstacles to effective rehabilitation.

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Possible new functional syndro are likely to include those associated with pollution of the workplace... and work stress

The demands such ersons make on health service, social benefit systems, and insurers are likely to increase.

Functional symptoms are not going to go away. They will be driven by factors such as work stress and distiffection, information about new illness from the media and the Internet and the persisting sigma of psychological problems. However, the form that they take is likely to continue to change. Although there are a limited number of symptoms that people can have, there are an almost infinite range of factors that these symptom can be attributed to. Such illness attributions tend to be toternal factors and often those, which individuals feel fearful of, wronged by and which are outside their control. Possible new functional syndromes are likely to include those associated with pollutar (chemical, biological and radiological) of the work place and work stress, and perhaps now in relation to "terrorism" and fear of terrorism.

A shift towards a more consumer-based approach to health is also likely to increase the prominence if not the prevalence of such syndromes as the authority of medicine to define what is a legitimate illness is diminished. Indeed, increasingly consumer oriented and privatised doctors will collude with the patient's views that they have a disabling and permanent disease. In other words, it may be difficult for those who wish to champion rehabilitation and return to work to "hold the line" without seeming to be "anti-patient".

The demands such persons make on health service, social benefit systems, and insurers are likely to increase. It is hard to see how an increasingly pressed health service will be able to deal effectively with the demand. An increase in insurance claims is to be therefore anticipated.

Generally

It will be imperative that health and social policy addresses this problem
Benefits and medical services need to be more rehabilitation orientated.

This will not be easy. However, there are glimmers of progress.

Benefits and medical services need to be more rehabilitation orientated.

Medical

An example is recent developments in the politics of CPS. After a failure of patient organisations to accept a report on the condition produced by the Royal Colleges, the persions CMO for England set up a working patient included both patient advocates and professionals that included both patient advocates and professionals and accept the final report. Nonetheless, the current Chief Medical Officer released the report early in 2002 (www.dob.gruxik.com/ofsmereport). It is "mixed", in terms of the relationship of its contents to the research ending the content of the relationship of the contents to the research under the content of the relationship of the contents to the research of the contents of the relationship of the contents to the research of the contents of the relationship of the contents to the research of the contents to the con

as long as the economy remains strong and skilled workers are sought after, it will be in employers' interests to rehabilitate sick but valued employees.

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If the claimant becomes hostile toward employer or insurer the position is likely to be difficult to retrieve.

major patient charities (Action for ME) is aligning itself with a more evidence-based approach. These are early days but if this convergence of rehabilitation oriented clinicians and a patient advocacy group is successful, there could be very positive implications for patients and for insurers.

There is a major need for effective rehabilitation for treatable patients. Existing pain and rehabilitation services would provide a useful basis. However, their capacity and skills are currently far too limited. Funding of rehabilitation by commercial bodies has begun in the UK (with organisations such as PRISMA) and is likely to continue. As long as the economy remains strong and skilled workers are sought after, it will be in employers' interests to rehabilitate sick but valued employees.

By the insurance industry

From the insurance point of view, efforts need to be made to minimise the risk of their policyholders getting ill and to minimise the obstacles to their recovery. There are implications for pre-acceptance medical assessment and for the work practices of employers. When policyholders de fall sick with a functional syndrome it is likely to help if both insurer and employer maintain a positive relationship with the claimant. An early but positively planned return to work (even in a very limited capacity) is desirable. If the claimant becomes hortile toward employer or insurer the position is likely to be difficult to retrieve.

Much could be gained from having an early biopsychosocial assessme of patients that ensured the identification of psychiatric as well as medical diagnoses. There is also a need to minimise iatrogenic harm both from family doctors who misquidedly encourage the patients to "take time off" at the insurer's expense and from certain "specialists".

For those with established disability an increased availability of rehabilitative treatment facilities is highly desirable. The NHS is not likely to pay for these.

Summary

how much is it costing you doing nothing? The problem of medically unexplained or functional illness is a large one. It is not going to go away and it is likely to get bigger. Social factors are more likely to influence the trunds in the prevalence, presentation and cost than are medical developments. Both health services and insurers now need to take a more positive approach. To those who say that this will cost money! I would reply – how much is it costing you doing nothing?