Professor Wessely's own lecture notes on ME (12 May 1994)

Margaret Williams 17th October 2003

To end speculation about authenticity, Margaret Williams has released her copy of Simon Wessely's own lecture notes from which she took the quotations in her recent article (Consideration of Simon Wessely's response to The Scotsman). In his notes, a * indicates where he showed illustrative slides during his lecture. The lecture was indeed audiotaped but the tape has never been publicly released.

Entitled "Microbes, Mental illness, the Media and ME: The Construction of Disease", the notes consist of twelve A4 pages and are annotated in Wessely's own handwriting. His manuscript states " NOT FOR CIRCULATION After reading the CFIDS piece I've changed my mind. Here are the speakers notes. If you must quote, do it accurately. I was v upset by CFIDS - currently meeting Counsel for the MDU (Medical Defence Union). I don't mind what people write about me, providing they are accurate with the facts".

Wessely is referring to the article by Eileen Marshall and Margaret Williams called "The Views of Dr Simon Wessely on ME: Scientific Misconduct in the Selection and Presentation of Available Evidence?" which was published in CFIDS Chronicle (Spring 1994, pp 14 - 17) and to Marshall and Williams' response to Wessely's reply, published in CFIDS Chronicle (Summer 1994, pp 77 - 79). The article presented actual quotations from Wessely's published works about ME/CFS; the response to Wessely's reply contained factual evidence (including quotations from his Eliot Slater memorial lecture) which refuted his reply. This exchange can be found in the CFIDS Chronicle itself, but is also contained in an Appendix to "Denigration by Design? A Review, with References, of the Role of Dr (now Professor) Simon Wessely in the Perception of Myalgic Encephalomyelitis: UPDATE". There are two volumes of "Denigration by Design?" by Eileen Marshall and Margaret Williams; Volume I covers 1987 - 1996 (pp 217) and Volume II covers 1996 - 1999 (pp 271). Both are available at cost price from DM Jones, 176 Perth Road, Ilford, Essex IG6 2DZ, UK. Together, they form a factual compendium of Simon Wessely's public record on ME/CFS during those years.

It is a fact that in 1994, Wessely personally threatened the UK distributors of CFIDS Chronicle with an injunction unless they removed the Marshall and Williams article before sending out that issue of the Chronicle in the UK. Fearful of Wessely's threatened litigation, the UK distributor removed the article before distributing it. UK subscribers then complained that copies for which they had paid in advance had been defaced. Copies distributed in the US were not defaced.

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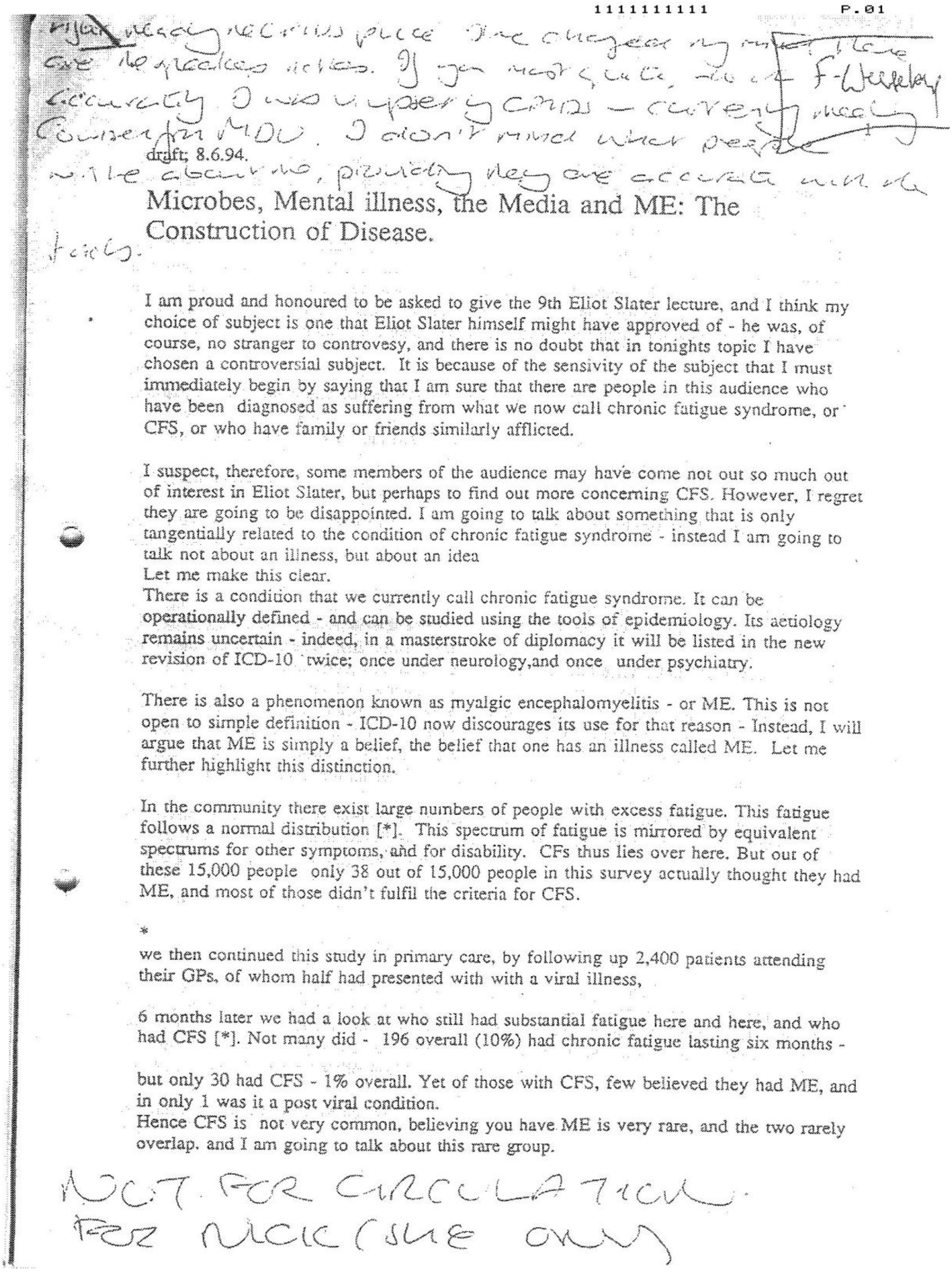
http://www.meactionuk.org.uk/wessely_speech_120594.htm



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Nigel [illegible] piece. The charges against my [illegible] are the speakers notes. If you must quote, do so accurately. I was upset by [illegible] – currently seeking counsel from MDU. I don't mind what people write about me, providing they are accurate with the facts.

Love S-Wessely

draft; 8.6.94.

Microbes, Mental illness, the Media and ME: The Construction of Disease.

I am proud and honoured to be asked to give the 9th Eliot Slater lecture, and I think my choice of subject is one that Eliot Slater himself might have approved of - he was, of course, no stranger to controvesy, and there is no doubt that in tonights topic I have chosen a controversial subject. It is because of the sensivity of the subject that I must immediately begin by saying that I am sure that there are people in this audience who have been diagnosed as suffering from what we now call chronic fatigue syndrome, or CFS, or who have family or friends similarly afflicted.

I suspect, therefore, some members of the audience may have come not out so much out of interest in Eliot Slater, but perhaps to find out more concerning CFS. However, I regret they are going to be disappointed. I am going to talk about something that is only tangentially related to the condition of chronic fatigue syndrome - instead I am going to talk not about an illness, but about an idea

Let me make this clear.

There is a condition that we currently call chronic fatigue syndrome. It can be operationally defined - and can be studied using the tools of epidemiology. Its aetiology remains uncertain - indeed, in a masterstroke of diplomacy it will be listed in the new revision of ICD-10 twice; once under neurology,and once under psychiatry.

There is also a phenomenon known as myalgic encephalomyelitis - or ME. This is not open to simple definition - ICD-10 now discourages its use for that reason - Instead, I will argue that ME is simply a belief, the belief that one has an illness called ME. Let me further highlight this distinction.

In the community there exist large numbers of people with excess fatigue. This fatigue follows a normal distribution [*]. This spectrum of fatigue is mirrored by equivalent spectrums for other symptoms, and for disability. CFs thus lies over here. But out of these 15,000 people only 38 out of 15,000 people in this survey actually thought they had ME, and most of those didn't fulfil the criteria for CFS.

*

we then continued this study in primary care, by following up 2,400 patients attending their GPs, of whom half had presented with with a viral illness,

6 months later we had a look at who still had substantial fatigue here and here, and who had CFS [*]. Not many did - 196 overall (10%) had chronic fatigue lasting six months -

but only 30 had CFS - 1% overall. Yet of those with CFS, few believed they had ME, and in only 1 was it a post viral condition.

Hence CFS is not very common, believing you have ME is very rare, and the two rarely overlap. and I am going to talk about this rare group.

NOT FOR CIRCULATION.
FOR NICK (SUE ONLY)

CFS is therefore more important - and certainly it is a subject in which we have a considerable interest - and I say we deliberately. [*] The range of talents involved in tackling this problem is vast - this emphasises the multidisciplinary nature of the subject, and also gives me an opportunity to acknowledge my collaborators - let me point out not just my psychiatric colleagues, but Bill Garnder in Thoracic medicine, Mark Peakman in immunology, David Wright (in microbiology, now Eileen Joyce and Stephen Blumenthal in neuropsychology. - and perhaps most of all Trudie Chalder and Alicia Deale, who, alone amongst this range of talents, know how to help the sufferer:
a range of talents for a complex unresolved problem - and that's the subject of next years talk.
[*]
Instead, my text for today comes from the Readers Digest,

it is our introduction to ME, and first link with Eliot Slater.

*REeders Digest....

now I use her as a case history because she exemplifies the differences I have been emphasising .....

Sam Guze in particular - inspired, we learn in his reminiscences, by his correspondence with the Editor of the British Journal of Psychiatry, who was, of course, Eliot Slater.

So where did this label of ME come from?
It was first proposed in 1955, but never really took off, and after 1960 ME made a minimal impact on the medical scene, and none at all in the media.
The breakthrough came as a result of several prominent articles in the national press during 1986, and in particular an article by Sue Finlay, then the wife of the Scottish poet, Ian Hamilton in the Observer. in the following days over 14,000 fact sheets were requested, events which culminated in the setting up of the ME Action Campaign.

ME went from strength to strength. The ME Association became Britain's fastest growing charity. BY 1990 insurance and disability claims were doubling every year, and the figure of 150,000 sufferers is commonly given.

Much the same happened in the USA. An article in the Rolling Stone [*] is credited with the same impact as the Observer articles. The label spread with even greater alacrity in the States and is now firmly established.

Why? perhaps it really is a new problem - the rise in media attention thus being an accurate reflection of a new health problem. However, I shall argue that this is not so. Diseases do occasionally rise and fall, but in general when there is a dramatic change in the incidence of any diagnostic label it reflects not any change in the world itself, but a change in the way we view the world.

so what has changed to give us ME?
[*]

Let us look at the original articles ; note the headline - what do if your doctor doesn't believe you . Right from the start ME has been identified with a dissatisfaction with medical care - of a refusal to accept the doctor's verdict. The historian Edward Shorter links the rise of ME with the general fall in the respect and authority of the physician - if dissatisfaction with doctors is nothing new - but its public expression is new [*] - I don't know if you have ever studied the sign above the door for our local Community Health Council - but it is very much a sign of changing times in the relationship between doctor and patient. When Gael McLean interviewed leading medical journalists they explained that ME had become a media favourite because they viewed it as part of the general reaction against medical paternalism - the image of the authoritarian doctor, who knows what is best for you, was no longer acceptable.

next, the changing nature of our beliefs about illness;

Let us start with neurasthenia - nervous exhaustion - the precursor of modern ME. It was formulated between 1870 and 1880 by American neurologist George Beard. Beard built neurasthenia on the basis of the prevaliming and exciting scientific ideas of the time. These included the discovery of the reflex arc, the electrical nature of the nervous impulse and the second law of thermodynamics - Beard's genuis was to create almost a parody of these advances- neurasthenia thus spread by reflex irritation to the brain, depleted of its finite electrical energy supply.

This loss of energy could come from infection, but also from the pressures of modern life, in particular industrialisation, steam power, the telegraph and the education of women. This was how Beard claimed society overloaded the nervous system.
How did the individual contribute - by overwork.
The energetic man of business developed neurasthenia because of devotion to duty and the excessive demands made by modern life. The victims of neurasthenia were described by one physician as "Captains of Industry".

What Beard was doing was skilfully mixing scientific advances with social concerns and constructing a single disease entity, designed to appeal to the concerns of the age, but couched in contemporary acceptable scientific terminology -

What about now? (* disease of the 80s, 90s) neurasthenia was the disease of modern life, so is ME. The Victorians lived in an age of fatigue, we now leave in the ME generation.

[*] This article entitled "the ME Generation" opened with the words "What is modern life doing to us?" (look at all the images and icons of modern living - stress, poor diet,pollution and so on). The magazine Arena also asked What is modern life doing , and answered that ME is very much a disease of our time - an it is an attack on the immune system exacerbated by stress, pressure and the demands of twentieth century life" . In this book (*Steincamp) we learn that ME is "an overload disease unique to this century" Nowadays the overload is due to what? Not the wireless telegraph, but [*] pesticides (toxic sheep dip), dental amalgam (mercury fillings) allergies, electromagnetic radiation (Campaign against pylons), chemicals, over refined diet, pollution, , not to mention new viruses (* How to beat the new bugs) , antibiotics, immunisations., candida and so on.

here are all of them brought together to cause ME [* Interaction model} images - perfumes, aerosols, food additives, radio waves - the pill - antibiotics -

ME thus reflects what may be our appropriate concerns with the state of the food we eat, the water we drink and the air we breath, translated into a disease idiom -

Beard would have understood the use of contemporary scientific discourse to underline essentially social metaphors. Those stressors which, in Beard's day, acted to deplete nervous capital and nervous energy, now deplete immune function and impair the body's defences against infection.

and what lies behind all this talk of viruses and immunity? The rise of ME followed behind the rise of that other disease in which viruses do affect the immune system with catastrophic results - HIV. [montage slide*] In consequence talk of viruses and the immune system is deeply embedded in popular consciousness. These links are made entirely explicitly in the States

What about Beard's second theme, that of overwork?
[*] - my vision of Mr Major's Britain - tradition and modernity - by the through away line in the text - she got ME from doing too much ...

One sufferer told last year's Daily Mail that "until my symptoms started I gave 120% to every aspect of my life". The Vice President of the ME Association said that sufferers are prone to be over active, "the last people to take time of work for no good reason" Another told Vogue that Sufferers "work until they drop. whilst everyone else creeps to bed with the slightest sniffle.... lazy people don't get ME". In Social Work Today ME patients are always "active, energetic, capable, competent" -

These stories are cautionary tales - this will happen to you if you don't take care of yourself - but they have a further symbolic meaning - all of them emphasise devotion to duty - hours worked - pushing oneself - Hence the typical Victorian neurasthenia sufferer was the Captain of Industry, the officer and the doctor- the officer class has vanished, but not the businessman or the doctor- the apparent over representation of doctors and nurses figure prominently in most ME literature,

Remember, that these observations should not be taken as epidemiological facts, but have a symbolic significance, a stereotype - don't tell anyone, but actually doctors and nurses don't work any harder than lawyers or steel workers, but at the moment doctors and nurses still remain the modern example of long hours and devotion to duty. These are stereotypes, to be contrasted with another stereotype, those people who do none of these things and possess none of these attributes - our patients

* low will power ; ME versus depression

waht about psychiatry and ME?

* pie chart;
* reaction to illness - so is it illness behaviour - simply the result of going to Queen

Square?
* primary care
* and our cohort study of post viral fatigue.

inevitable - not cause and effect - but because of the way in both concepts have been constructed, the similarities of the criteria and the measures used to define them. It does not imply that one causes the other, or that psychiatric disorders and CFS are the same - however, imply that operational criteria will be of little assistance in making the distinction.

There are differences between, for example, major depression and CFS - these reflect the considerable variation within affective disorder - this has been elegantly shown by

Jenny Bearn, Veronica O' Keane, working with Alan Mcgregor's unit,[*]

What we used was D-fenfluramine, a drug that acts to stimulate 5HT release and what we are looking at are the cortisol and prolactin responses to such stimulation - this is the cortisol graph.

this top line, recruited by Tony Cleare, have classic major depression, weight loss, anorexia the works, - hence this is a flattened response curve due to hypercortisolaemia, as expected.

here are King's Medical Students attempting, as usual to impersonate normal controls,

and here are our CFS patients chosen because they were not depressed - and what they have is low cortisol responses to 5 HT stimulation. Now by looking also at the prolactin responses as well, which indicate as expected that 5 HT neurotransmission is reduced in depression, normal in controls, and are enhanced in CFS in the absence of depression,

That's great, but, outside the world of psychopharmacology, who will get excited about these results? Does it really matter if the 5HT neurotransmission is enhanced (that's CFS) or suppressed (that's major depression) - what a little up or down regulation among friends?

Everything - I will argue that this line here represents not the line between low and high cortisol responses, between one set of patients and another, but the line between real and unreal illness.

let us look how depression appears in the world of ME: A doctor and ME activist says that ME depression is "a different form of depression. It's not something patients have control over, it's not something they did to themselves and they can't wish it away" hence psychiatric depression the patient can control it, did do it to themselves, and could wish it away if they wanted.

so those accounts of devotion to duty are making a statement - that I don't have psychological disorder - I'm not that type of person the drive to separate depression and ME is intense -

* use antidepressant slide

but depression is not the only threat facing the self esteem of the ME patient, and is not the most serious - there is another condition with which ME might easily be confused, and takes us into Slater country.

it is hysteria (* "fatigue that viral not hysterical")

Hysteria, the mention of the word in the context of ME brings me palpitations and makes me worried about the safety of my family, but how, in a lecture in honour of Eliot Slater, can one ignore the topic -
Slater largest contribution to scientific psychiatry was in genetics - but I submit that his single best known work, whose impact is difficult to overestimate, is his papers of hysteria, that fierce assault on the idea of hysteria that we all know well.

so how did hysteria get into ME at all?

From the time of the Royal Free epidemic in 1955 and the introduction of the label ME, the possibility that it represented transmitted emotional distress was always present. Many of those who advocated the new label discussed at great length whether or not ME and hysteria were the same, concluding, naturally, that they were not. Some doctors also at the Free took an opposite view but usually preferred to keep their own counsel. Paul, the historian of polio, also concluded Royal Free disease was mass hysteria. But who reads history anyway?

It was the work of two psychiatrists, Colin McEvedy and Bill Beard, in 1970, that reopened the debate. Beard provides us with another link to Eliot Slater, since he is probably best known not for Royal Free disease, but as Slater's collaborator on his seminal studies of schizophrenia and epilepsy -

McEvedy and Beard suggested that certain epidemics, were due to mass hysteria, whilst others were not epidemics at all, but due to altered medical perception of normal psychiatric morbidity. This was a public statement - the first article in the first BMJ of 1970

It is sad that they did, since the passion that their paper injected into the almost dormant subject might be said to have given it a new lease of life - a slur to defend, or even a myth to continually escape from. [escapes myth*]. on this occasion a giant mitochondria does the needful

We will never now know what happened, since Royal Free disease is itself part of the world of myth. Perhaps it doesn't matter anymore, since Royal Free Disease was very different from modern CFS - and it is a tragedy that the label of ME has been transferred from one to the other, and brought with it its burden of hysteria.

and what a burden it is - because one has to agree, and indeed extend, Slater's criticisms of hysteria.

take some examples [*] - the BBC play "Wide Eyed and Legless" , seen by 9 million people, is based on the book Diana's Story written by journalist Deric Longden. It concerns his wife's mystery illness, which began with exhaustion after flu, worsened over many years, until she develop paralysis immediately after a routine muscle biopsy.

No one knew what was wrong, but now, after her death (she died, not from terminal ME as stated here (*), but either accident or suicide - the play is ambiguous) we know that it was ME all along.

but would everyone have seen it that way? She was paraplegic. Furthermore, when admitted to this hospital [*] - that shows what you can get away with in fiction - [that's a To Let sign - maybe the BBC knows something we don't] she has a series of grand mal convulsions - not classic of ME, by the way. We also know from the book, but not the film, that her EEG was normal, this was taken by the author as further evidence for how baffled doctors were by the mystery illness - but can we really believe that neither here, nor at Queen Square, were doctors unaware of the significance of this observation, and never thought of non epileptic attacks? I don't know, but it is hard to believe, isn;t it? Yet if they did, they kept it to themselves, since all the doctors are, even here, for once, sympathetically described. Perhaps they knew what they were doing, becuase the villain of the piece is the the psychiatrist back in Sheffield did make a diagnosis of hysteria and told the family - - what happened - [*] in a episode which must represent every ME patients dream, the consultant allowed Julie Walters to borrow her notes, knowing what would then happen. Here she is, those are the notes, she is removing the 5 page psychiatric opinion (psychiatrists are as verbose in Sheffield as the Mausley!), and then she will flush them down that toilet there.

Here is the problem. a diagnosis, which, accurate or not, dare not speak its name - a diagnosis that, from the patient's point of view, belongs metaphorically and occasionally literally.down the toilet. As Tony David has called it, it is the H word, never spoken, but always present in the ether between doctor and patient.

It is the sniff of hysteria that makes it almost impossible to use any psychological term - hysteria is out, but so is depression, and anxiety, unless properly sanitised - because anything else could be that dread phrase "all in the mind" which dominates the reporting of ME.

Slater based his argument against hysteria on the results of his research - that many cases of hysteria ultimately proven to be either organic, or psychological.

so Slater warns us that in every generation a condition thought to be hysterical is recognised as of organic origin, admitted to the Pantheon of real diseases and its previous adherents mocked - but it's more complex than that, since there is also an equal and opposite flow, as organic diagnoses loose their credibility as their psychological causes are recognised. Floating kidneys, visceral proptosis, autointoxicating colons , grumbling appendices etc, no longer are a passport to surgical care. Thank God, since no longer will thousands of young women loose their colons, kidneys and ovaries in pursuit of an focal

infection or floating organ. Few now remember Willie Lane. He was a surgeon working up the road at Guy's. He firmly believed in autointoxication as a cause of neurasthenia, and removed hundred's of women's colons for this reason. What happened to the women? 10% of them died, standard mortality for abdominal surgery then. What happened to Willie Lane? He became Sir Arbuthnot Lane, a fashionable and successful surgeon at Guy's Hospital, now forgotten. Well, not quite.
[*]
This is first newsletter ever issued by ME Action Campaign in 1988 It reproduces Willie Lane's Lancet paper on autointoxication : fortunately the only danger now facing the British colon is from irrigation and not surgery.

Medicine thus is not always a march of progress, from the psychological to the organic, but often moves in a more circular fashion, as Slater himself knew well.

Slater also, I suspect, knew that hysteria would survive - not in the professional literature, Slater saw to that,

but in the popular literature, it is ever present - article after article uses hysteria as proof of medical insensitivity, malice and ignorance - the doctors said it was hysteria, but I know they are wrong

I proved them wrong..

but how - how do you prove that you are not hysterical? You must convince the doctor that you really are ill - organically ill - so that even this stubborn doctor/neurologist, who keeps on saying it is just depression, functionalm, supratentorial or whatever the current euphemism is, notices - the arm becomes more floppy - the leg weaker, the sensory changes more bizarre. yet what is the result of this - it is exactly the opposite - the neurologist, who is not a fool, is now convinced that the problem is functional or supratentorial - ; the first patient account of ME that I have been able to trace, back in 1982, describes this perfectly: "the more desperate I got for a diagnosis, the more outrageous and unacceptable became my behaviour, and the more doctors called me manipulative".

The label of hysteria can be self fulfilling;

How else can you prove the doctor wrong? Well, the one thing you might not do is get better, since that might be intepreted by the unsympathetic [?neurologist] as proof that it was all in the mind after all.
This the mere existence of the word might condemns the sufferer to a life time of non recovery, if only to prove the doctor wrong

So how does the sufferer get better?

and make no mistake, that is what they want - but unfortunately treatments for the virus or the immune system don't work.

[check time; if late skip next section]

Weir Mitchell and the rest cure ...... role of charisma in medicine

However, such larger than life chararcters as Mitchell have largely vanished from the more anoynmous modern medical scene, but the modern patient still has access to charismatic cures, which often represent the only avenue out of their dilemna.

here's an example, [*]: published in last months Independent..she works in the silicon valley around Cambridge, She suddenly felt weak during her nightly aerobics class. She then had a flu jab, and the next day woke up paralysed, unable to move even a hand. Most of the time she was too weak to open her eyes, and only occasionally could she even be pushed about in a wheelchair. A doctor said she had ME.

Nothing helped -
All that was left the Rev Bill. who, as well as a charismatic healer, is , according to the paper, an Oxbridge educated haematologist. She knelt with him, and they prayed - her for new muscles and brain. She was told she could walk again - although one wonders how much was the result of his second intervention, to start aerobics.

an awkward story for us, isn't it? makes us feel uncomfortable...
what he did was something that no one else in this room could do -and certainly not in one session.

(fundholder story)

But even this is ambiguous - it actually does not add to the medical provenance or legitimacy of ME, and for some does the opposite -

and what about this? [*] almost identical story - severe ME, confined for years to a wheelchair, dramatically cured by faith healing...

but look at the headline - to be cured of ME could be a miracle, or could mean, according to the paper, that she was a malingerer all along - and the story goes on to say that following her cure she was ostracised by her friends, and faded from the ME scene. Miracles cures don't help the cause - and another avenue closes for the patient

So these examples confirm what Slater was saying, that hysteria is fraught with difficulties - Slater argued that hysteria failed the first law of diagnosis - it wasn't an accurate reflection of the real world -

I now propose that it fails the second law of diagnosis - a diagnosis should not create more problems than it solves - hysteria does exactly that in the modern society.

and yet although I now join the chorus of my predecessors and betters in calling for an end to the word, it is a tough old beast that has outlasted better people that me...

I now come to my conclusion, and to the final strand in the rise of ME, implicit throughout my talk is the misunderstanding of psychological medicine

[*: INteraction; dustbin of medical profession, psychiatry etc...]
for Claire Francis Psychiatry is the dustbin of the medical profession -

for our colleagues such views are, I hope, less prevalent, but if we are not the dustbin, we are, for many doctors, the dustbin men. There are numerous examples like the doctor who told a medical conference that "ME is an imaginary disease... for which the best treatment is psychiatric". Both ME patients and anti-ME doctors may share the same prejudice that psychiatrists treat imaginary, malingered or non existent diseases.

my referall - "simon.. please see these lady with ME - there is nothing wrong her" ...
what a prospect - how did that sound to the patient .. will she come and see me.....

no wonder many sufferers never go near a psychiatrist.

One self help book said that being referred to a psychiatrist is "being blackballed" ; in the BMJ a sufferer describes how she felt on trial, and another told the ME Action magazine that being a psychiatric patient was a little like being imprisoned for a crime I didn't do"

and being on trial is how ME patients feel:

[*; burden of proof]
like in a court of law - the sufferer feels "the burden of proof"

[*newspaper montage] like in a court of law, the atmosphere is full of anger, fury, hate, protest, controversy

[*]- it's a polarised adversial world - the Guardian calls for justice for the neglected and maligned...
the accusation - mental illness

how is the verdict arrived at -
by a breakthrough [* breakthrough slide]
a breakthrough in the world of ME is rarely a treatment, but usually the arrival of another test [*]
[brainwaves prove it is not a psychiatric illness] surprise to the neuropsychiatrists in the audience...

"virus research doctors"
[*]
whose function is to prove we are really not sick, and not the psychiatric shirkers - and this applies to all of us - given a choice - which would you rather be : "a shirker, or really sick" - that wasn't a hard one, was it?

* [postviral puzzle] genuine or neurotic
viruses are an attribution free from blame- how do we get a common virus - here I quote a leading authority on the subject, my mother -not wrapping ourselves up on a cold day - sleeping with the window open - a sin certainly, but not a mortal one. - there's no blame, no shame and no stigma..

[*] and here is the virus research doctor himself to protect us from that shame, white coat, microscope the lot - and what is it he delivers - respect

The test is therefore crucial to respectability and legitimate occupation of the sick role:

Without it ME sufferers exist on the margins of illness and disability, and it is a matter of shame to us all that psychiatric patients, almost by definition, are denied that fundamental respect, and are not in a position to campaign for it - the stigma, derision and intolerance feared by the ME patient are the daily lot of our patients. ME patients may succeed in escaping these views, they cannot.... [check time again]

and when the ME patient is denied that test, -comes the struggle - and it is a tangible and practical one - One sufferer told the Independent on Sunday 27th June 1993 how he was refused sickness insurance benefit because his policy excluded depression, of which he had a past history. His claim to be now suffering from ME was rejected, although he was informed that this decision would be changed if a test for ME were to be developed and he tested positive.

patients cannot afford to be depressed - literally......

We can therefore understand the delight when another sufferer found out she had a low IgG, probably of no significance, but she knew that "the difference between a crazed neurotic and a seriously ill person is simply a test", and now hers was positive. and what did she then do? - "I was writing a letter to the medical journal - it was perhaps the first blow in a life time battle". You see the problem - it is for life. Look at this - you moight imagine that the result of learning one had an incurable virus would be distress - but no, the Chicago Tribune article began - "The day Naomi learned she had an incurable disease, she rejoiced".

Nancy Kaiser also rejoiced, but before then she had to visit 211 doctors - you think she might have given up, don't you - after 100 - these doctors are no good - but no matter how bad doctors are, but sufferers still need to keep going - doctors are still the main passport to acceptance and validation of suffering, not least because we control access to support and benefits.

so Nancy Kaiser got her respect, but at what price - [*; newsweek] ...

for her illness is now the cause - a culture emerges in which ME is the common currency, illness the focal point - here is perhaps the most poignant slide of all [*] - people redefining themselves in terms of illness....

and these views matter - they affect outcome, look at these studies of prognosis - notice the key variables ....
* prognosis;

hence our virus doctor [*] exists not to hold out hope of cure - but to give legitimacy to distress, a legitimacy that is denied our patients - it is his task to break the link between psychiatry and ME - and hence the white coat, and microscope [*] the antithesis of the psychiatrist:

of course, we are a sophisticated psychiatric audience, and would never fall for this old chiche - or would we - and for this last observation I am indebted to Tony David, as I am for so much else - here he is again, our onw handbook, we ourselves use just the same image to present ourselves to the world.

so to conclude - in the population, that word so beloved of epidemiologists, we don't yet know whether or not CFS exists as an independent nosological entity - I am inclined to think it does, particularly in the light of Peter White's research on EBV, but the case is by no means proven. Doctors are entitled to express their scepticism about the status of the diagnosis, and even to suggest that these illnesses are already adequately covered in the psychiatric classifications - but they are not entitled to go on to transfer this scepticism to the distress of chronically fatigued patients - when they do, and they do, the combination of personal outrage and the modern media will ensure that ME is the result.

[end there - go on if not 6.30]
need ending...

In this talk I have identified a problem with psychological medicine, one which SLater would have been more than aware - but I am reminded of Saki's introduction to his short stories - "if I point out a problem, at any rate I suggest no remedy". I have no remedy - I don't think there is one.

?? We are stuck with each other.
?? For as long as psychiatry exists in the public imagination as it does now, then each generation will find it necessary to discover its own ME.