

## Hansard Transcript of the House of Lords Debate

22<sup>nd</sup> January 2004

### Myalgic Encephalomyelitis

1.39 p.m.

**The Countess of Mar** rose to ask Her Majesty's Government whether they subscribe to the World Health Organisation international classification of diseases for myalgic encephalomyelitis (ME) under ICD 10.G93.3 —neurological disorders.

The noble Countess said: My Lords, first, I must declare my interest as patron of a number of charities that represent people with myalgic encephalomyelitis. ME is not a new disorder. There are many reports in medical literature dating from at least 1934. ME has been classified by the World Health Organisation in the international classification of diseases (ICD) as a neurological disorder since 1969.

In 1978, the Royal Society of Medicine accepted ME as a distinct entity with discrete signs and symptoms. In 1988, the Department of Health and Social Security and the British Medical Association accepted ME as a legitimate physical disorder. In 2002, the Chief Medical Officer stated that ME should be classed as a chronic medical condition alongside multiple sclerosis and motor neurone disease.

Conversely, the WHO Guide to Mental Health in Primary Care, produced under the auspices of the Institute of Psychiatry, classifies ME as a mental disorder. I should explain that the Institute of Psychiatry is one of the World Health Organisation collaborating centres in the UK and, as such, is legitimately entitled to use the WHO logo. To the deliberately expedient or unwary, that can result—and, in the case of the classification of ME, has resulted—in confusion with the WHO in Geneva. Despite the fact that a senior civil servant in the

#### **22 Jan 2004 : Column 1181**

Department of Health has confirmed that it works to the ICD 10.G93.3 definition of ME/chronic fatigue syndrome, Ministers are providing false information to MPs by advising that it is the WHO itself that has reclassified ME as a mental disorder.

That is untrue. The WHO has confirmed in writing that the WHO Guide to Mental Health in Primary Care does not carry WHO approval and that it is "at variance" with the WHO's position on ME/CFS. The WHO has never classified ME as a psychiatric disorder and has confirmed that it has no plans whatsoever to do so.

Since 1992, one of the terms listed in the ICD as an alternative for ME is chronic fatigue syndrome. It is that term that is now used by international researchers and which has given rise to the confusing terms of ME/CFS and CFS/ME, a confusion that has served well the aims of a group of psychiatrists who assert that, whatever term is used, ME/CFS is simply medically unexplained chronic fatigue and that it should be classified as a mental disorder over which they should exert control.

How has that situation arisen? A very small group of UK psychiatrists, known colloquially as the "Wessely school", led by Professor Simon Wessely of Kings College, claims to specialise in ME—a discrete term denoting a discrete disorder, but a term that it uses interchangeably with chronic fatigue or tiredness; with psychiatric states of ongoing fatigue; with its own interpretation of chronic fatigue syndrome; and even with neurasthenia—all different terms representing different conditions but which that group insists are synonymous. That is despite the fact that chronic fatigue has been shown time and again to be biologically different from ME.

The group has gained dominance in the thinking about ME/CFS. Wessely is politically astute and, in conjunction with his colleagues, has gained respectability in medical and political establishments by producing vast numbers of papers that purport to be about ME. I am glad to inform the House that the matter may soon be settled once and for all. A new paper from Jason et al from the US demonstrates that ME is clinically distinct from CFS and that the current criteria for CFS do not select those with ME.

Since his arrival on the scene in 1987, Wessely has repeatedly and persistently played down, dismissed, trivialised or ignored most of the significant international biomedical evidence of organic pathology found in ME because it does not fit his psychiatric model of the disorder, for which he claims to have developed a more intensive form of the psychiatric intervention known as cognitive behaviour therapy (CBT). That consists of using intensive, mind-altering techniques to convince patients that they do not suffer from a physical illness. It also includes forced regimes of graded exercise to be supervised by a Wessely school-trained psychotherapist aimed at getting patients back to fitness.

Wessely school psychiatrists are about to receive £11.1 million, including £2.6 million from the Medical Research Council, in an attempt to strengthen the

#### **22 Jan 2004 : Column 1182**

weak evidence that his regime actually works for those with ME. Among his 53, largely undeclared, interests it should be noted that he is a member of the supervisory board of a company, PRISMA, that is supplying such rehabilitation programmes as CBT to the NHS for those with ME, even though such regimes have been widely shown, at their best, to be of limited and short-lasting benefit and, more importantly, at their worst, to be actively harmful to those with the disorder.

The constant theme running through the Wessely School's published papers is that ME does not exist, that CFS is a psychiatric disorder and that the factors that play an important role in the perpetuation of the disorder include female gender, too much focus on normal bodily sensations, discrete personality traits, avoidance behaviour, learned helplessness, faulty thought processes, lack of motivation, secondary gain, inadequate coping strategies, interpersonal conditioning and contagious sociological hysteria.

Wessely states that patients belong to,

"a cult recruited from the environmental subculture",

and that those with ME,

"feel no guilt about their condition: sufferers from mysterious illnesses that lie outside conventional medical practice no longer consider themselves to be oppressed by spirits and demons but by mystery gases, toxins and viruses".

Wessely has made numerous statements about the non-existence of the disorder that can only be described as savagely cruel to the ME community. For example, he refers to ME as a "myth". He believes that it,

"should not be dignified by [its] own formal case definition and body of research".

He asserts that symptoms found in ME,

"have no anatomical or physiological basis",

and that "muscle weakness is simulated". He advises that, to the majority of professionals, ME symptoms,

"are indeed all in the mind".

I can provide corroborative evidence of all those statements.

Neither the fact that they may be wrong nor the well documented errors of psychiatrists in the past who authoritatively misdiagnosed Parkinson's disease, multiple sclerosis, epilepsy, diabetes and thyrotoxicosis as mental disorders before medical science revealed their true aetiology, seem to have occurred to the Wessely school. It is certain that it, and it alone, is right. As the world-renowned psychologist, Dr Dorothy Rowe, pointed out:

"People who know absolutely that they are right are very dangerous".

The group's activities have stifled access to research funding for any UK researchers who want to consider organic causes of the disorder. Crucially, researchers have shown that ME may be either virally or chemically induced. There is substantial and significant published evidence not only of neurological deficits, including cerebral hypo-fusion and hypo-metabolism, but also of endocrine dysfunction, immune system dysfunction, vascular disturbances and convincing laboratory evidence of serious

**22 Jan 2004 : Column 1183**

abnormalities in muscle, including abnormal recovery after exercise—not the result of de-conditioning through voluntary lack of use, as Wessely claims.

There is evidence of pathology of both the central nervous and the immune systems. In particular, there is new evidence of changes in about 50 genes involved with the immune system. As long ago as 1994, Professor Paul Levine from the US National Cancer Centre stated that,

"the spectrum of illnesses associated with a dysregulated immune system must now include ME/CFS".

The recently published Canadian case definition, based on a study of more than 20,000 ME/CFS patients, provides definitive evidence for clinicians to assess and diagnose patients accurately. Wessely, the self-proclaimed "world expert" in ME/CFS, does not accept that case definition. He has said that the authors, who are universally recognised world-class experts, are not "unbiased scientists" and that there is no need for any more "poor quality science".

Some of Wessely's studies and trials are known to be seriously flawed and his claims have been described in the British Medical Journal by Angela Kennedy, lecturer in social science, as,

"unfortunately incomprehensible, incoherent, and empirically inadequate".

Wessely's response is that those who disagree with him are "radicals" who are fighting for a "lost cause" with "lies and gross distortion". Such is that man's influence that, when faced with ME patients, clinicians now collude with each other to ensure that patients receive no investigations, support, treatment, benefits or care—in fact, nothing at all. Patients are effectively abandoned. They have been badly let down by their main charity, Action for M.E. It is now supporting the Wessely "management" programme and is, I see, to be actively involved in the development of the new treatment centres. I have serious reservations about the activities of that organisation, but now is not the time to air them.

Wessely has, rightly, been compared with Professor Sir Roy Meadow, who is currently in the news. He has stated that children do not get ME. When confronted by a child with ME, medical practitioners, social workers, teachers, policemen and lawyers have all been conditioned by Wessely and his like-minded colleagues to believe that the illness has been fabricated by the child's mother.

I need not elaborate on the consequences of the scenario. Press reports are currently full of heartbreaking histories—histories that I have been hearing and seeing for years, and which successive Ministers have refused to investigate properly.

I am pleased that the noble Lord, Lord Turnbull, has put his name down to speak. I wonder whether he can recall just how many times ME sufferers or their carers wrote to him while he was president of the Royal College of Physicians, asking him to withdraw the notorious document, the Joint Royal Colleges' report on CFS published in October 1996. That was internationally acknowledged to be biased and flawed.

**22 Jan 2004 : Column 1184**

I wonder whether the noble Lord recalls some of his responses. Is it still the case that "We will have to agree to differ" and that "It is helpful continually to return to areas of disagreement which can only perpetuate polarised views"? Will the noble Lord explain why those with ME are banned for life from being blood donors, when those with psychiatric disorders are not?

Will the Minister ensure that the newly produced second edition of the WHO Guide to Mental Health in Primary Care is withdrawn from circulation until it can be reprinted without ME/CFS listed as a mental disorder, given that the Department of Health accepts that it is not? Will he also ask the Chief Medical Officer, as a matter of urgency, to circulate to all medical practitioners and the NHS information authority the correct classification for ME/CFS and to withdraw the current advice?

**1.50 p.m.**

**Lord Turnberg:** My Lords, I am most grateful to the noble Countess, Lady Mar, for introducing this important topic. I am afraid that we must continue to disagree. I can answer directly her question about the response some years ago to the report by the Royal College of Physicians on CFS/ME. We had few, if any, adverse comments. In fact, as a result of the report, I was asked to write the foreword to a patients' advice booklet by a CFS/ME patient group, so the report received a favourable response in some quarters at least.

It is an unfortunate fact that, despite a lot of research and speculation, we do not yet know the cause or causes of chronic fatigue syndrome or myalgic encephalomyelitis—I hope that noble Lords will not mind if I call it CFS/ME. But the important point is that, whatever the cause, there is no doubt that it is a serious and debilitating disorder, and patients suffer severely from it. I am sure that the noble Countess, Lady Mar, will agree with that, at least.

CFS/ME is not alone in being baffling. We do not know the cause of most cancers and many inflammatory diseases, from arthritis to colitis, from asthma to Alzheimer's, but that lack of knowledge has not stopped us seeking the best forms of treatment that we can muster. Indeed, many of those diseases are treated well, and some are cured, although we do not know the cause. But we seem to have got ourselves into a semantic argument that, to all intents and purposes, is irrelevant to what patients need and want. They want treatment and cure, and need more research into potential causes so that more accurate diagnoses can be made and better treatments developed. Meanwhile, they want the best treatments currently available.

In the old days, when we did not know the cause of a disease, we named it after a doctor or patient—for example, Parkinson's disease or Crohn's disease. If noble Lords will forgive me, I am reminded of the story of the little boy who, when asked what his dog's name was, replied, "I do not know his name, but we call him Rover". Perhaps we would do better to call CFS/ME "Mar's disease" or even "Wessely's disease". As we do not know the cause, I prefer to refer to it as chronic

**22 Jan 2004 : Column 1185**

fatigue syndrome, because at least the term describes how patients feel. Myalgic encephalomyelitis suggests that there is an inflammation of the brain, when there is no evidence that patients' brains are any more inflamed than anyone else's. I certainly would not focus any arguments on the issue. Indeed, most authorities now seem content with the term CFS/ME—sitting on the fence.

Be that as it may, most of those in the field who have studied the disease agree that, as with every other illness, there is likely to be a mixture of physical and psychological disturbances. To deny that patients may be depressed when they have a chronic long-term debilitating illness seems to fly in the face of experience. Just as it would be unwarranted to deny a depressed patient with cancer or rheumatoid arthritis an anti-depressant, so it would be unwarranted to deny an anti-depressant to a patient with CFS/ME who is also depressed. It is quite different from suggesting that depression is the cause, because it clearly is not.

I hope that noble Lords will forgive me for going on about the issue, but there is a tendency to believe that it is somehow a betrayal of patients even to admit a psychiatric component in the suffering of patients with CFS/ME. I cannot subscribe to that view because I know that there is always a psychological component in every illness, even if it is only a response to that illness. That is not to deny that there may be physical components in CFS/ME—almost certainly there is—but the problem is that, at present, we do not know what it is, or what they are. Efforts to uncover an inflammatory, infective or immunological cause have given tempting glimpses, but nothing clear has emerged. Clearly, more research is needed. Perhaps equally unfortunately, no new treatments based purely on those types of possible causes, and that make any difference, have emerged. Antibiotics, antivirals, vitamins, supplements, anti-inflammatory drugs and even steroids do nothing unless they are specifically indicated.

Despite anecdotes to the contrary, I am afraid that the only treatments that have shown any benefit in large-scale carefully controlled clinical trials are: cognitive behaviour therapy, which involves a careful, encouraging confidence-building effort with slowly increasing exercise based on what patients can achieve, without symptoms at the time; and antidepressants, if the patient is also depressed—it is no wonder that many are. Those are currently the only treatments shown to be effective. Many—but, unfortunately, not all—patients are helped by that approach.

It so happens that Professor Simon Wessely and his colleagues, whom the noble Countess denigrated so mercilessly, have led the field in that form of therapy. I have the greatest respect for the noble Countess, but on this matter I must disagree profoundly with her. Rather than doing a disservice to patients, Wessely is doing them an enormous service and has devoted much of his life to caring for them. That is why large numbers of patients flock to his clinic, probably the largest in the UK, from all over the country in the hope that he might be able to help them, and he often does. He is the first to admit, as he does in his many writings

**22 Jan 2004 : Column 1186**

on the subject, that treatment for those unfortunate patients is difficult and imperfect, and that not everyone is helped, but enough are to make it worthwhile. Until something better comes along, that is the treatment of choice.

Wessely set up the first NHS clinic and service devoted solely to CFS/ME patients and has been active in service developments ever since. The NHS Centre for Previews and Dissemination and the Cochrane Centre have endorsed his approach as best current practice, as have American reviewers. Furthermore, the largest patients' charity, Action for ME, is working closely with Wessely and his colleagues on new research initiatives funded by the MRC and the NHS. He has been given a research medal by the Royal College of Physicians for his work on the disease and a commendation in the last research assessment exercise. He published the first evidence of neuroendocrine abnormalities that clearly differentiate CFS/ME patients from those with straightforward depression. He is busily engaged in a research programme into the biochemistry, immunology and neuro-imaging of those patients. That does not sound to me like someone who either denies the existence of the disease or believes that it is all in the mind—surprisingly, it is something of which he is accused. Wessely's articles in prestigious journals such as the Lancet strongly attest to his view that both the physical and psychological components of the illness are important. This is a man absolutely committed to caring for those patients, and if anyone came up with new or better treatment I am sure that he would grab it with both hands.

The noble Countess's Question focuses on how the condition should be described. I hope that I have said enough to suggest that it is rather more important to be concerned that more research is carried out into the cause of this distressing condition, whatever it is called, and that meanwhile we should treat it as best we can.

**1.58 p.m.**

**Lord Colwyn:** My Lords, I, too, thank the noble Countess for introducing this subject. I hope that I will not waste the House's time. Having listened to the debate so far, I have an awful feeling that perhaps I will be a little controversial. I am delighted to hear that the noble Lord, Lord Walton of Detchant, may speak in the gap—no doubt, he will tell me whether I am right or wrong on that. I do not know the answer to the question that the noble Countess asks. Perhaps the Minister could pre-empt the debate by saying "Yes", but I do not know what he will say. I wish briefly to support the concept that ME is a neurological disease and should be classed as such.

We have heard that ME is a chronic, disabling illness, which affects 100,000 or more people in the UK. The noble Countess said that it was recognised by the World Health Organisation in 1969. I thought that it was more recently than that that the WHO classified it and recognised it as a disease of the nervous system.

**22 Jan 2004 : Column 1187**

While victims of the illness are slowly winning the battle for recognition of ME as a genuine illness, there is still disagreement about the best way to treat it.

In 1948, a polio-like illness in New York State resulted in the identification of a new virus that was called Cocksackie, after the town on the Hudson River. The disease was called atypical polio because its symptoms identified it as a kind of polio, despite the virus being different. This kind of polio has since been renamed ME and more recently chronic fatigue syndrome. It remains a type of polio, despite the change of name. Technology has shown the generic similarities of the most frequent

agent that causes it. These techniques place Coxsackie, the virus most often implicated in ME, into the polio family tree, along with so-called echo viruses. Coxsackie has been further subdivided into types A and B. In total, there are at least 72 enteroviruses. Maybe there are more viruses now, if the research has moved on. Some of the points that I am making are based on research by Jane Colby, who wrote a book called ME—The New Plague.

True ME, as opposed to fatigue symptoms, is clinically polio-like, and has often been diagnosed as non-paralytic polio. Patients have weakness, back pain and they are systemically ill. It has been unfortunate that some of these patients have been labelled as having chronic fatigue, as true ME is a neurological condition that usually originates with a gut virus infection such as Coxsackie, which in some cases can be demonstrated. The requirement to put off diagnosing ME for six months after the patient falls ill has made this difficult. If the tests are not done quickly, it is too late to identify the virus. Research now supports the view that ME is probably a persistent viral infection causing inflammation throughout the central nervous system and disturbance of hypothalamic function.

If ME is a type of polio, why does everyone exposed to the viruses not develop ME, just as they did with polio? In fact, only a small number of those with the polio virus became paralysed. About 90 per cent did not realise that they were suffering from anything more than a cold or flu. With both polio and ME, the state of the immune system governs susceptibility.

By altering the population's resistance to particular organisms, we alter the balance of infectious agents in the environment. Polio has declined through vaccination, but this has left us open to other polio-related viruses. It is therefore not surprising that since the late 1950s the incidence of ME has risen. Many experts have predicted that it will be the neurological disease of the 21st century. By suppressing the spread of a few enteroviruses, we have opened the door to the rest.

Papers investigating the epidemiological aspects of ME/CFS have revealed further convincing parallels between the behaviour of this disease and polio. ME is described as being ushered in by a minor, flu-like illness which is identical to and has all the features of the minor illness of abortive poliomyelitis. In comparisons with epidemic polio, we see similar

#### **22 Jan 2004 : Column 1188**

features, including the incidence of the disease decreasing between January and the summer, and peaking between August and October.

ME, or atypical polio, is a serious and debilitating multi-system malfunction leading to such profound weakness in some children that they are unable to speak and must be tube-fed—but they can breathe. Enteroviruses have an affinity for certain tissues, and many do not attack the respiratory centre causing its paralysis, as in polio itself.

What are we doing to our teenage ME sufferers when we force them back to school, deny home tuition and tell them to exercise as a form of therapy? What will happen in 30 years to children now getting ME in a climate where they are disbelieved and told to pull themselves together? The condition post-ME, which we are now seeing in adults, may occur many years after infection, like post-polio.

This is far too complex a subject to be debated in one hour. I hope that the Minister will be able to confirm that ME is now classified as a neurological disease. I was delighted to read in the Times a couple of days ago that new centres are being put in place to undertake new research. I hope that he can confirm that they will be for research and treatment. If polio victims had been able to breathe, would we have ever taken that disease seriously?

**2.5 p.m.**

**Lord Walton of Detchant:** My Lords, I apologise to the House for the fact that it was not until late yesterday evening that I felt able to contribute briefly to this debate. I am grateful for the opportunity to do so at this stage. I declare an interest as a practising neurologist until 12 years ago. During my career, I saw many patients diagnosed with ME. Also, when I was president of the World Federation of Neurology, I consulted on behalf of that organisation with the World Health Organisation on the revised international classification of diseases, ICD-10.

Medical diagnosis is not an exact science. One of the problems with ME is that attitudes and views about its nature, causation and treatment have continued to change profoundly over the years. As the noble Countess said, diseases that were so diagnosed began to emerge in the 1930s, and then many more occurred in the 1950s. There were a number of notable epidemics in various countries across the world, so that in certain circumstances the condition became known as Icelandic disease. There was the notable epidemic in the Royal Free Hospital in London among the nurses, and subsequently the medical staff, in the 1950s.

I and my colleagues in Newcastle-upon-Tyne studied an outbreak which was believed to be "the Royal Free disease", in a closed community of trainee teachers in a convent in Newcastle-upon-Tyne. We subsequently published an article in the Lancet, "An Epidemic of Benign Myalgic Encephalomyelitis in Newcastle-upon-Tyne": "benign" because patients ultimately recovered, but they were left with considerable fatigue; "myalgic" because many of them

**22 Jan 2004 : Column 1189**

complained of muscle pain; and "encephalomyelitis" was based on a much less secure foundation. There was no evidence in these cases, despite what the noble Lord, Lord Colwyn, said, of any consistent abnormality in the cerebral spinal fluid. Variable abnormalities were seen in the blood, but no consistent viral aetiology was ever demonstrated in these cases in the way that had been demonstrated in patients suffering from Coxsackie A and Coxsackie B infections to which he referred.

Unlike pre-paralytic, or non-paralytic poliomyelitis, in which there were always abnormalities in the cerebral spinal fluid, abnormal cells and so on, none of these patients showed that kind of condition. Apart from finding certain curious electromyographic abnormalities, meaning abnormalities on electrical examination of the voluntary muscles, no consistent neurological signs were ever clearly demonstrated in these patients. My experience over the years convinced me that there was often an organic component, commonly post-viral, so that the condition later became known as post-viral chronic fatigue syndrome. "Post-viral" was subsequently dropped, so that it is now called chronic fatigue syndrome.

In many cases, there was a profound psychiatric disturbance. Looking back, I am satisfied that much of what I saw in that closed community in Newcastle was based on a chronic hysterical reaction, preliminary to an early viral infection. In the many other patients whom I subsequently saw, I found that a number, as the noble Lord, Lord Turnberg, said, responded effectively to anti-depressant medication. That is not to say that the condition was caused by depression.

I share with the noble Lord my admiration for the work of Simon Wessely, because it is the most solidly based and well-founded research that has been done on this condition. That there is an organic component I am in no doubt, but equally, in many cases, there is a profound overlay of psychiatric manifestations. The greatest hope lies in the kind of treatment to which the noble Lord, Lord Turnberg, refers.

**2.10 p.m.**

**Lord Addington:** My Lords, I must admit to feeling as if I have put my head in a noose. We have medical disagreement raging across the Chamber and the use of words that I will not even attempt to understand. One thing is clear: the noble Countess's historical basis for complaint is solid. There is a tremendous tradition, when we do not know the medical or physical causes of something, of bringing in the quacks, to put it bluntly. That has happened on numerous occasions.

I shall give the House an example to add to the one that the noble Countess gave. Dyslexia is the one that I know most about. I can remember being told in the mid-1970s that my inability to read and write at the same rate as others was due to the fact that I came from a single-parent family. There are others examples, so I suggest that we take a sceptical look at things. With regard to the noble Countess's speech, I suspect that there are many libel lawyers who, on hearing our

**22 Jan 2004 : Column 1190**

debate, will react in the same way as someone on a diet looking at a cake shop window. It is a lovely feast that they cannot get at.

We must face facts. There have undoubtedly been occasions on which mental health problems have been suggested for things that turned out to be physical conditions. That has occurred. The fact that ME has a physical component—an initial physical component, at least—has been agreed by, I think, everybody here. If the noble Lord wants to correct me, he can.

**Lord Turnberg:** My Lords, I wanted only to say that I am in entire agreement, and so is Dr Wessely. There is a physical component, and it would be nice to get a grip on it.

**Lord Addington:** My Lords, it is nice to know that I was not as lost as I thought.

The fact remains that, if treatment is going on, we should be very sure that we do not say to people that we are just dealing with a perceived or psychological disturbance. I believe that this is at the heart of the noble Countess's criticism. It is a perfectly normal side-effect for someone to have depression because he cannot move or function in his job. That is all that it is: a side-effect. Those with disabilities and debilitating illnesses probably have more to get depressed about than others. It

is natural. It is in that secondary light—I hope that the Minister will confirm this—that treatment should be offered, not as the primary mover. That is a key consideration.

Will the Minister give us some assurance that children who are faced with the condition will be given guidance that means that they are not placed under extra stress? From the limited reading and research that I have done on the subject, stressful situations and the inability to handle them seems to make the condition worse. Every effort must be made to reduce that risk. If that means that children must be taught at home, that must be done. If it means that they must be taught by distance learning or with a reduced syllabus, it must be done.

I do not care what Doctor X says to Doctor Y; I do not mind how they rage and tear at each other. The fact is that children who are placed in stressful situations will fail, if they are placed in an educational situation that they cannot handle. It would be better for someone to pass a few subjects and develop core skills so that they can pick up their education later than for them to be told, "You can do it" and receive extra work. I come back to the example of dyslexia. People are told, "Work harder and you will achieve". I am sure that that is a way of bringing on a stress-related illness for people who, in fact, have a different learning pattern. It happens. The Minister should make sure that people are given learning patterns which they can actually achieve. That should be done, and the Minister can give us some assurances on it.

Other than that, when can we expect to have a definitive—I hope—study programme in place? When can we expect the reports, at least? I say that because generally in such arguments, one side is eventually

#### **22 Jan 2004 : Column 1191**

battered into submission but will still have a few adherents who go on until their dying day. That is the usual pattern. What emphasis has been given to finding definitive answers? It strikes me that labels are getting in the way of effective treatment. If people are told that this is a predominantly psychological condition, when it is a secondary one, as seems to be the consensus—I am surprised that there is consensus, but there seems to be—that will get in the way of effective treatment. If that can be established and made plain to everybody involved, we will probably achieve a way of living with the condition, even if we go on researching it for a long time. I call for that assurance from the Government. They may not be able to change the progress of scientific knowledge, but they can certainly establish a pattern for dealing with the by-products and effects of a condition that we have identified as a real one.

**2.15 p.m.**

**Earl Howe:** My Lords, this is an unusually difficult debate for non-medical parliamentarians such as myself, who come cold or nearly cold to what is, by any standards, a highly technical subject. However much background reading I may do on the clinical character of ME—I have done a good deal—I am aware that it does not qualify me in any way to pontificate on those matters and certainly not to pronounce on the essentially aetiological issues underlying the noble Countess's Question. The noble Countess, on the other hand, is in a quite different position, as she is of course

steeped in the subject. She deserves to be listened to with particular care; and it is not surprising that I should find myself impressed by what she has said today.

In trying to summarise her concerns, I hope that it is not too colourful to say that we are looking at a doctors' battleground; for it is apparent that, for some years, there has been a sharp division of opinion in the world medical community about what ME actually is. Since 1969, as the noble Countess said, ME has been formally classified by the WHO in its international classification of diseases as a neurological disorder—in other words, an organically based condition, albeit with psychiatric components. To others, it is first and foremost a psychiatric or behavioural diagnosis, albeit with a range of physical symptoms that are psychosomatic in origin. I hope that that is not too simple a way of describing the essential difference of view.

It is a difference, as we have heard, that has profound implications. For legal and medico-administrative purposes, the formal classification of a disease determines who treats the patient and how—in other words, whether one is referred to a psychiatrist or to another specialist such as a neurologist. If ME is an organic, physical illness, a psychiatrically oriented response, particularly one focusing on cognitive behavioural therapy, might not, to a layman, appear to get to the root of the difficulty, although I take note of everything that the noble Lord, Lord Turnberg, said in that context.

#### **22 Jan 2004 : Column 1192**

The WHO guide to primary care is one of the key sources of guidance for English-speaking doctors in general practice. That is why it was with surprise that patient groups noted a couple of years ago that the guide and its associated web guide appeared to take a stance completely opposite to the official WHO line, classifying ME under the heading of "Mental and Behavioural Disorders". The diagnostic criteria for ME as listed in the guide were totally inconsistent with the internationally accepted criteria, omitting to mention numerous biological abnormalities and placing undue emphasis on lifestyle factors. How were such inconsistencies to be explained? It turned out that that part of the WHO guide had been compiled by the Institute of Psychiatry at King's College Hospital, London, and the Department of Psychiatry at Oxford University, where a number of the proponents of the "psychiatric abnormality" school of ME are based. In September 2001, the WHO issued a statement effectively repudiating the classification of ME in the WHO guide and on the website.

When I was in the Ministry of Defence, I heard nothing but good about Professor Simon Wessely, and it is no purpose of mine to make his position difficult. I take no pleasure in, and set no store by, the suggestion that Professor Wessely effectively hijacked the WHO logo to give credence to his own view of ME as a mental illness. Nevertheless, I am uncomfortable that the professor does not appear to be doing his utmost to clear the air on this issue.

The noble Lord, Lord Turnberg, was kind enough to give me some papers that defend Professor Wessely's position, the tenor of which he reflected in his speech. I have to say that I did not find those papers as useful as I had hoped. While making clear that the professor does indeed regard ME as a real condition—I accept, of course, that he does—they not only gloss over many of his numerous published pronouncements but also skirt around the key issue of what he regards the nature of ME as being. That is important because of the very considerable influence exercised over government policymaking by those who believe that ME is an inherently mental illness.

If in the UK not enough emphasis is being placed on the WHO definition, it is likely that research on ME, which everyone agrees is vitally necessary, may be wrongly balanced. I should be interested to hear from the Minister how much research is being directed to the possible neurological and physical causes of ME as opposed to other possible causes.

There are other consequences too. If the UK, for some reason, departs from the long established WHO line, there is an obvious potential impact on disability benefits. I understand that, at present, the mobility component of DLA is not available to physically incapacitated individuals diagnosed with ME. It would be helpful to hear from the Minister why that is.

I am concerned, too, that if the definition of ME as a mental disability gains further ground, there will be profound implications in the context of the reform of the Mental Health Act. The Government's original proposals included a power to enable doctors to

**22 Jan 2004 : Column 1193**

impose compulsory treatment orders on adults and children. I have considerable difficulty with the concept of compulsory treatment orders in any case, without the thought that they might capture those who should not be classified as being mentally ill in the first place.

Reputable doctors of my acquaintance will say that in treating a patient with ME, the best approach by far is a holistic one, involving mind and body, in which the patient feels that the doctor has a real empathy for him and that all his concerns are being taken seriously. But that is far from being the universal experience. There is a risk of my being too anecdotal, but I have read numerous accounts of patients who have presented to their doctor with the debilitating and distressing physical symptoms that are ascribed to ME, and who have been told, in essence, that the symptoms are psychosomatic and that they should stop making a fuss and go home. Once we get onto that kind of territory we are on a dangerously slippery slope.

I have a particular concern for children with ME. A child presents with symptoms consistent with ME and is classified not as having an illness with an organic cause, but as being mentally disturbed. So the question is asked: what is making him mentally disturbed? All too often, the answer is that it is the parents; that is, that a parent is in some way inducing the symptoms in the child. If a parent is inducing them, the cause is clear. What is behind it is Munchausen syndrome by proxy—that ill-founded diagnosis which is so flimsy yet so powerful and which, as recent criminal cases have shown, has been instrumental in bringing about desperate travesties of justice for mothers and families. So instead of asking how the child should be treated, the question becomes: is the child safe to be left with the parent? Should care proceedings be considered? That is a train of thought that in general practice and social services is far from uncommon; and all because children who are genuinely physically ill are classified as though they are not.

Those are the issues that we have to confront. I hope that the Minister will do so head on and that in his characteristically thorough way he will take away with him the many important questions raised in this debate and ensure that they are followed up with a proper reappraisal of this distressing and complex condition, and the guidance that is given on it. What matters is that patients with ME are treated appropriately and well. In turn, that depends on clarity from academics and evidence-based

treatment guidelines. It is clear from this debate that we have some way to go before that point is reached.

**2.24 p.m.**

**The Parliamentary Under-Secretary of State, Department of Health (Lord Warner):** My Lords, I, too, thank the noble Countess for initiating this debate, primarily because it provides me with an opportunity to state the Government's position on CFS/ME. I know well the noble Countess's particular interest in ME and her commitment to improving the experience of people with this condition. I share the same predicament as the noble Earl, Lord Howe, of

**22 Jan 2004 : Column 1194**

not being an expert in this subject. However, I shall pluck up my courage and nervously tiptoe into what he called the medical background. As regards his point about disability living allowance, I do not know the answer, but I will make enquiries and write to the noble Earl.

I begin by recognising how distressing and debilitating this condition can be for individuals, their carers and their families. I will go on to outline the actions that we are taking to improve services for this patient group. I am sure that we all agree that the most important thing is to ensure that patients receive the treatment and care that they need. It is certainly difficult to disagree with the point made by the noble Earl, Lord Howe, that, in these circumstances, a holistic approach probably is the right way forward.

I must emphasise again that my primary concern is the treatment of patients and the research associated with the condition, and not a semantic argument, as my noble friend Lord Turnberg eloquently explained. I certainly defer to the scientific and historical knowledge of the noble Lord, Lord Walton, in what I thought was a very helpful and clear set of remarks. We should all have regard to his background and knowledge in this area.

I understand that there are a wide range of views about the most appropriate ways of providing care and treatment for patients with CFS/ME. We want to gain a better understanding of this condition and the best ways of treating it. I hope that we can all acknowledge that, in general, doctors and other professionals working in this field are highly committed to providing the best possible care for their patients. It is worth putting clearly on the record that therapies such as graded exercise, cognitive behaviour and pacing came from an independent working party. They were not all invented in the head of Professor Wessely.

I turn now to Professor Wessely who has featured rather prominently in our debate, and on whom the noble Countess launched a rather unfair personal attack. He has a very good reputation for the work that he has done over many years, which my noble friend Lord Turnberg explained and, rightly, defended Professor Wessely's reputation. His research has taken forward our understanding of CFS/ME in many respects and has widespread respect from the medical/scientific profession. He has received a research medal from the Royal College of Physicians—not, I hasten to add, the Royal College of Psychiatrists; he has been elected to the Academy of Medical Sciences; and he has received a commendation in the last research assessment exercise, all for his CFS/ME research.

I must tell the noble Countess that I met Professor Wessely after her last attack on him and tried to understand what might have upset her about his approach. I came away impressed by his responses, arguments and deep concern for the welfare of patients. I think that noble Lords should also be aware that Professor Wessely started the very first NHS service solely for CFS/ME patients, and has been active in service development and NHS care for CFS/

**22 Jan 2004 : Column 1195**

ME ever since. I understand that he has also worked closely with Action for ME, also attacked—again, I thought, unkindly—by the noble Countess. I believe that we should focus on the best ways to assist and support patients with CFS/ME and not on attacking individual clinicians.

I turn now to the issue of classification and stress that it is not the Government's role to endorse or otherwise the classification of individual diseases. That is something that is best decided by the WHO following consultation with interested parties. Of course, the UK plays a full part in the work of the WHO through its membership on its executive board where the UK's representative is Professor Sir Liam Donaldson, the Chief Medical Officer.

The WHO's internationally recognised international classification of diseases—ICD—is a system that enables deaths, injuries and diseases to be identified and monitored in a consistent and comparable way over time and across geographical boundaries. It is not diagnostic criteria and it is not used by clinicians as such. The current version, ICD-10, classifies CFS in two places: as neurasthenia in the mental health chapter, F48.0; and as myalgic encephalomyelitis in the neurology chapter, G93.3. The diagnostic criteria used in ICD shows that the WHO has essentially put the same condition in both places, apart from an explicit mention of viral causation in G93.3. That is the WHO's formal position.

**The Countess of Mar:** My Lords, I am sorry to interrupt, but I have it in writing from the World Health Organisation in Geneva that any CFS is under neurological diseases and cannot be categorised in two places. The WHO does not categorise one disease in two different places.

**Lord Walton of Detchant:** My Lords, before the Minister sits down, I was involved in the revision of the international classification of diseases. The international neurological community had no doubts about putting ME in the neurological chapter. It was a specialist in infectious disease who insisted on having a chronic fatigue syndrome of a post-viral nature in the section on infectious disease. So they were put there by two separate groups of scientists.

**Lord Warner:** My Lords, I am grateful to the noble Lord and the noble Countess. If she sends me her letter I shall certainly look into the matter. As a poor layman I am giving her the medical advice I have been given, and I will stand by it until I receive some evidence to the contrary.

Following the publication of the WHO guide in 1996 an extensive programme of adaptation and updating took place in preparation for the next edition. Consensus multidisciplinary groups adapted each individual guideline for the UK, added the evidence base, made the guidelines more multidisciplinary and added information about relevant charities and resource materials, as well as good general practice based material.

**22 Jan 2004 : Column 1196**

Around 30,000 copies of the guide have been sold. It has generally been found to be useful and helpful. The noble Countess made some serious allegations that the department has misled people in this area. If she will provide me with the corroborative evidence I will investigate.

I turn to improving services for patients with ME. The independent CFS/ME working group in its report to the Chief Medical Officer in January 2002 made it clear that there was no simple cure, but that many patients had found it difficult to receive the treatment and care they needed to help them manage and to alleviate their illness. The Government welcomed publication of its report as the start of a process for improving awareness and understanding of CFS/ME.

We now want to move to a situation where everyone with this condition obtains the treatment and care they need, when they need it and where they need it. I want to make it absolutely clear that we fully endorse the view of that working party that this is a chronic illness. Health and social care professionals should recognise it as such. Only this Tuesday, 20 January, the Government demonstrated our drive towards improving CFS/ME services when my honourable friend Stephen Ladyman announced 12 new centres and 28 local support teams for people with CFS/ME.

Funded by the £8.5 million cash injection announced by my right honourable friend Jacqui Smith last year, the 12 centres will be based in Newcastle, Leeds, Liverpool, Manchester, Sheffield, Birmingham/West Midlands, East Midlands, East Anglia, North London, Surrey, Bath/Bristol and Cornwall/Devon. The centres and local teams will champion and support the development of local services to improve the care and treatment of the many people with CFS/ME.

The centres will be led by clinical champions who are local CFS/ME specialists and will provide access to specialist assessment, diagnosis and advice on treating the condition; develop education and training resources for health professionals to improve the knowledge and skills of staff; and support clinical research into the causes and treatment of CFS/ME.

In addition, the 28 local support teams are spread throughout the country and will provide services and support to those individual patients who need their care, including a network of local domiciliary services that will help people who are house-bound or bed-ridden. There will be full support for children's services in the arrangements.

These new centres and local teams are an important step in the development of NHS services and will bring real benefits to patients. I will send more details of the announcement to noble Lords who have spoken in the debate. The noble Lord, Lord Addington, and the noble Earl, Lord Howe, asked about research. I reassure them that we fully support the need for more research into this condition on a wide range of aspects. We have asked the Medical Research Council to develop a strategy for advancing research on CFS/ME. I think that all noble Lords will accept the independent nature of the MRC, whatever its views on this condition.

**22 Jan 2004 : Column 1197**

The MRC published its research strategy for CFS/ME in May 2003. It will enable researchers and funders to develop research proposals on all aspects of this illness. In response to the strategy the MRC announced two initiatives. One was a notice to the research community welcoming high quality proposals across the entire spectrum of CFS/ME research. The other was a scientific meeting to

discuss the potential to use existing UK resources and infrastructures to undertake epidemiological studies in this country.

I am sure that noble Lords are aware that it is a long-standing and important principle of successive Governments that they do not prescribe to individual research councils the detail of how they should distribute resources between competing priorities. That is something which researchers and research users best decide.

The MRC also announced, in May 2003, funding for two trials that will look at the effectiveness of various treatments for CFS/ME. These will assess a variety of treatments and the results will help patients and their doctors to choose the best treatment. I hope that noble Lords will accept that the Government are committed to independent research of this condition and to obtaining the best possible evidence base for the way in which it is treated. We are determined to put in place, as I have outlined, treatment services and diagnostic services that meet the needs of patients with this condition wherever they may be.

In conclusion, I hope that the noble Countess will agree that we are sympathetic to the needs of patients with CFS/ME. I appreciate her concerns over the classification issue, but I disagree strongly with her personal attack on Professor Wessley. The most important message is that we are investing in improved services for CFS/ME patients and in research and this should make a difference to the lives of the many people affected by this condition. That is the Government's priority.

**Debate Ends**