16 April 2002

Chronic Fatigue Syndrome/ME

7.27 p.m.

The Countess of Mar rose to ask Her Majesty's Government what is their response to the report to the Chief Medical Officer of an independent working group on chronic fatigue syndrome/myalgic encephalomyelitis dated January 2002.

The noble Countess said: My Lords, in view of the publication in the British Medical Journal of 13th April 2002 of its survey of so-called "non-diseases" and the prominence given by the press to chronic fatigue syndrome/myalgic encephalomyelitis as a non-disease, this debate has come at a very appropriate moment. I declare an interest in that I am patron of several ME charities.

On 11th January 2002, the Chief Medical Officer is reported as saying that,

> "CFS/ME should be classified as a chronic condition with long term effects on health alongside other illnesses such as multiple sclerosis and motor neurone disease".

His choice of MS as an example is apt in view of the fact that this disease used to be known as "the idle man's disease". Like ME now, MS was dismissed as hysteria by some practitioners. The report contains the acknowledgement that,

> "CFS/ME is a genuine illness and imposes a substantial burden on the health of the UK population".

I shall be characteristically blunt. Since 1969 ME has been formally classified by the World Health Organisation as a neurological disorder. The WHO has confirmed that it has no plans to reclassify it as a psychiatric condition in the next international classification of diseases revision which is due in 2003. However, since 1987 Dr—now Professor— Simon Wessely has been relentless in his proposition that ME does not exist. For example, in the journal of psychological medicine in 1990 he claimed that ME exists only because well-meaning doctors have not learned to deal effectively with what he called "suggestible patients".

I have mentioned the article about non-diseases in the British Medical Journal of 13th April. I refer the Minister to a letter in the same journal, headed:

> "What do you think is a non-disease? Pros and cons of medicalisation".

It is signed by Simon Wessely, Professor. Only 570 out of more than 30,000 doctors voted on a list of some 200 so-called non-diseases drawn up by the BMJ. Only 72 doctors voted for CFS/ME, while 251 voted for ageing. Wessely has chosen to highlight CFS/ME in his letter and, of course, the press picked it up.

I feel truly sorry for the Chief Medical Officer. He is trying to do his best and is thwarted at every turn. It is extraordinary that this man and his group of followers, colloquially known as the Wessely school, have been allowed to dominate all debate on ME for 15 years. They have unquestionably been responsible for a relentless and sustained attack on the credibility of an increasing number of severely ill patients, dismissing and trivialising their suffering.

16 Apr 2002 : Column 895

As Nero fiddled while Rome burned, so the Wessely school fiddles the facts while people suffer and die. When Wessely's work is legitimately criticised by colleagues and his methodological flaws pointed out, he blames his peer reviewers for allowing his own errors to be published. Wessely is responsible for the accuracy, honesty, impartiality, quality and scientific integrity of the research which he has published.

There are many documented instances in which he is in direct conflict with other competent medical opinion. His tactics include manipulation, distortion, invention, misquotation, suppression, exploiting public ignorance and deliberately constructing his presentations to fit his audience. Rather than his having orchestrated a campaign against patients and their credibility, he claims it is patients who are orchestrating a campaign of vilification against him.

Professor Wessely seems to have taken it upon himself to reclassify ME as a mental disorder in the WHO Guide to Mental Health in Primary Care in his capacity as a member of the UK WHO Collaborating Centre for Research and Training for Mental Health. He has disingenuously amalgamated his own definition of chronic fatigue syndrome with ME by stating that ME may be referred to as CFS and is thus, he claims, a mental disorder.

The report concedes that there is huge confusion surrounding terminology. In reality it is simple. In 1992, the WHO included the term CFS as one by which ME is sometimes known, and indeed many international researchers now refer to ME as CFS. The patients whom they are studying resemble those with neurological illness. There is a long established acceptance that such patients are severely physically ill. However, since 1991, Wessely and his colleagues have been responsible for producing their own criteria for CFS, known as the Oxford criteria. They dropped all reference to physical signs. Physical symptoms suddenly became behavioural in origin as opposed to organic.

Simon Wessely and, in particular, Michael Sharpe, Anthony David, and Peter White—all psychiatrists—proceeded systematically to flood the UK literature with their own beliefs about the non-existence of ME. They commandeered medical journals and the media. They became self-designated experts in medically unexplained symptoms such as ME, Gulf War syndrome, and multiple chemical sensitivity. They have received disproportionate funding, amounting to over £5 million, for research into their own beliefs to the exclusion of virtually all research into organic causes.

Their influence pervades every aspect of ME sufferers' lives, including their ability to obtain social security and private medical insurance benefits, social services assistance and home tuition for children. Tragically, children with ME have suffered

disproportionately. As I have already explained, the prevailing perception of the illness is that it is bio-psychosocial, whatever that means. Children presenting ill-defined symptoms that do not improve quickly are regarded as having been harmed by their carer. Proceedings under the Children Act 1989 are instigated. Children are removed from loving families and made wards of court and severe gagging orders are placed on parents.

The Minister knows of my concerns in the field and I should be grateful if he would tell me what progress is being made with the inquiry by the Social Services Inspectorate into the cases that I have passed to his honourable friend, the Minister for Public Health.

My Lords, the influence of Wessely is clearly manifest in the report to the Chief Medical Officer. Not only is the terminology ambiguous and confusing, it specifically advises that vital investigations such as immunological and nuclear medicine scans are inappropriate and unnecessary. Those are the two areas which are delivering hard evidence of organic pathology and are the focus of intense investigations in the United States. How does such a report help patients? The answer is that it does not. I make no apology for having dealt with the Wessely problem at length.

It was the brief of the working group to,

> "develop good clinical practice guidance on the healthcare management of CFS/ME for NHS professionals".

Its report advises healthcare professionals that,

> "inaction due to ignorance or denial of the condition is not excusable".

In fact, the report's effect will be to compound inaction, ignorance and even denial: inaction in not investigating the patient's illness or not providing any treatment—management is not the same as treatment—ignorance by promoting inappropriate and possibly harmful interventions; and denial of the true nature of ME.

When it supposedly advises clinicians how to put its recommendations into action, the report's own authority is undermined by the fundamental disagreement about the recommended management benefits. Having highlighted the controversy and conflicting opinion about cognitive behaviour therapy (CBT) and graded exercises, the report's most serious flaw is that it offers no explanation or advice as to how health professionals decide whether a patient will benefit from or be harmed by the recommended management regime. Thus, by virtue of the conflicting opinions on risks and benefits set out in the report, the NHS exposes itself to the risk of treating patients unlawfully. Will the Minister please explain how that can be "good clinical practice" and why such flawed advice got through the scrutiny net?

The scientific evidence is that, at best, a total of between 22 and 28 people with CFS and no psychiatric illness have derived limited benefit from CBT—nine of them in just two trials. None of the trials studied those with ME who were severely affected or children. Professor Friedberg of State University, New York, says that, for those CFS individuals who do not have

16 Apr 2002 : Column 897

psychologically mediated reductions in activity, such a directed approach as CBT would be inappropriate and counterproductive.

Is the Minister happy to rely on such manipulation of the scientific evidence as appears in the report? Does he endorse management recommendations for patients with ME who do not have psychiatric illness that have been extrapolated from findings of studies on patients with a psychiatric diagnosis? Is the Minister aware that the organisers of a workshop and conference to take place at the John Radcliffe Hospital in Oxford on 18th April, entitled "Chronic Fatigue Syndrome: Research and Practice", state:

> "The recent government guidelines have endorsed the value of CBT and graded exercise as the most useful patient management approach so far".

That is an outrageous example of distortion of the facts and, as the seriously affected and children were excluded from the report, it is dangerous and irresponsible. Does the Minister endorse the claim by Wessely and his colleagues that ME/CFS is a mental health disorder? Is it Department of Health policy to lump together chronic fatigue with ICD-classified chronic fatigue syndrome?

Many of those who are severely affected feel let down by the apparent capitulation of the two major ME charities, which appear to accept the bio-psychosocial model of ME/CFS. The ME Research Group for Education and Support, MERGE, one of the charities of which I am patron, has given a cautious welcome to the report. It states:

> "While the Report may go some way towards improving recognition of the illness, MERGE considers that it has avoided serious consideration of the important issues surrounding the diagnosis and treatment of ME/CFS; that it has given undue emphasis to management strategies of limited applicability; that practical recommendations for social care are lacking and that, consequently, an opportunity has been lost".

The charity was started in 2000 by Dr Vance Spence, who is senior research fellow in medicine at Dundee University, and Robert McRae, a banker. They are both ME sufferers who have had to retire early, but Dr Spence is able to do limited research. He has already established that there is significant disruption to the biology of blood vessels and also to particular circulating white blood cells in patients with ME. That is significant because the results establish a biological mechanism for ME symptoms and unequivocally refute the dominant psychosocial explanations.

In their response that accompanied the report, the Government have handed responsibility for research to the Medical Research Council. May we know who has been appointed to the independent scientific advisory group? May I also have an assurance from the Minister that psychiatrists will not dominate the group, as they have done hitherto, and that there will be a reasonable balance of funding for biological research?

7.40 p.m.

Lord Clement-Jones: My Lords, I congratulate the noble Countess, Lady Mar, on initiating today's

16 Apr 2002 : Column 898

debate. I listened to her with considerable interest. I recognise the great strength of her feelings on the matter and her particular interest in the area. I declare an interest as a patron of the Tymes Trust, which supports children and young people with ME. It has an advice line that is manned by trained people with personal experience of the illness. Training days are run for various professionals, and the trust operates a professionals referrals service that enables doctors, teachers and others to consult ME specialists.

I became interested in ME more than 20 years ago when a close family member contracted the illness after having glandular fever. In those days, we had no idea what ME was. Over 20 years ago, there was some excuse for that, but now there is little excuse, least of all for members of the medical profession. ME is a serious illness, with no known cure. It has taken many years for that to be properly recognised. The illness has a profound effect on individuals and on entire families. In this country, it affects up to 25,000 children and, it is estimated, between 100,000 and 300,000 adults. Fifty per cent of long-term sickness absence from schools is attributable to ME. The cost of the illness is estimated at £4 billion.

I want to look forward from the chief officer's report. I will not dwell on the past in the same way as the noble Baroness did. I agree that Professor Wesley has not played a particularly glorious part in the controversy over ME, or indeed in that over Gulf War syndrome. However, I take a more positive view of the chief officer's report than the noble Baroness.

In 1998, the Chief Medical Officer set up a working party to examine the treatment and management of the illness. The document was published this year by the Department of Health. Despite the controversy—in a sense, the final outcome and the resignations may have been a good thing—and the year-long delay, the report came as a relief to sufferers. The new recommendations offer a major opportunity for change in the way that young people, in particular, are treated, supported and educated. The report acknowledges the disabling nature of the illness and the severe limitations that it can impose. It recognises the need for proper, multi-disciplinary assessment at the outset, so that a flexible treatment plan can be created.

The report was described by Val Hockey, the chief executive of the ME Association, as a wake-up call for the entire medical profession. I commend the chairman of the working group, Professor Allen Hutchinson, and the CMO on the outcome. It is also a testimony to doughty campaigners such as the noble Baroness, Esther Rantzen and all the voluntary organisations associated with ME, particularly Action for ME and the ME Association. We can look back at reports such as the 1996 report from the Royal Colleges of Psychiatrists, Physicians and General Practitioners as rather quaint anachronisms. It is a sign of the times that the Health Minister, Yvette Cooper, in an interview in Tymes magazine, published by the Tymes Trust, can be open and frank about how she suffered and recovered from ME in her early 20s. That was a terrific interview, and I told her so yesterday.

16 Apr 2002 : Column 899

Many questions arise from the work of the CMOs working group. First, there is the issue of training for doctors. Some recent articles written by doctors in the wake of the report are absolutely disgraceful and ignorant. I feel strongly about some of those reactive reports, and I shall also come later to the related issue of false allegations, which are relevant in this context. Often, such allegations arise from professional ignorance or, in some cases, sheer bloody-mindedness. We also had officials engaging in covert surveillance of people with ME. There are social workers and education officials who do not understand the condition. All those others need training. The department must say what plans it has. We need good practice guidance for social workers and other professionals, not just for doctors.

In February, I asked the Minister about the aftermath of the report. In particular, I asked how the Government planned to disseminate the findings and recommendations of the CMO's working group. The Minister replied that it would be put on the website and that there would be a report and summary for clinicians. He said that the Government might even consider NICE guidelines. We must be clearer than that.

The crux of the matter is that we cannot go on with a situation in which we have a report that, in many ways, acknowledges the condition and suggests how the treatment options should be taken forward without making certain that the report is taken seriously. Incidentally, I part company with the noble Baroness about the treatment options. They are options, and the report is not over-prescriptive about that. NICE guidance will be crucial, and I hope that, in the weeks between the date of my Written Question and today's debate, the department has considered whether such guidance will be commissioned. The department must proactively disseminate best practice.

I also asked what funding would be available for research. The Minister replied that the department had commissioned research into the diagnosis and treatment of CFS/ME and said that details were available on the national research register. He said that the department had asked the MRC to develop a broad strategy for advancing biomedical and health services research into CFS/ME. I welcome that, so far as it goes, but we need something concrete. We need a budget, and we need to know that the MRC intends to assemble a set of research proposals and put it out to tender, in a sense, to research bodies. That is extremely important. I would like the Minister to give us a progress report.

There are other issues. Will the Government change the incapacity benefit handbook for medical service doctors? It is written for doctors who provide advice to Benefits Agency adjudication officers in relation to incapacity benefits. I do not know the status of the handbook, and I do not know what it says now, but previous versions stated that there was no firm evidence to suggest that ME was a distinct entity from other forms of chronic fatigue syndrome. Nor was there firm evidence that CFS was a physical disease. I hope that the department will instigate a cross-governmental review to make sure that such statements, relating to benefits administered by other departments, will be changed.

16 Apr 2002 : Column 900

The issue of expert patients is important. The report emphasises how important it is that patients who have suffered—or are suffering—from ME are consulted about management and treatment. It is important that there should be such ongoing involvement, and I would like to hear what the Minister has to say on the subject.

In our debate last October, we heard about false allegations. I am sure that all of us have heard terrible examples of how parents of children with ME have been accused of abusing their children or allowing them to play truant. Parents have been diagnosed as having Munchausen's syndrome by proxy, and children have been put on the at-risk register. There have been secret case conferences and so on.

Last October we debated the issue of child abuse and discussed the guidance issued for consultation on children in whom illness is induced or fabricated by carers with parenting responsibilities. At that time, the guidance was in draft form and was out for consultation.

Can the Minister say what is the current status of that guidance? It is extremely relevant in the case of ME because so many parents of children with ME have had problems with the authorities in this respect. Will it recognise the issue of ME and possible false allegations? It is vital that it does. Enough injustice has been done over many years. Stigmas are created which take years to expunge, let alone recovering from the emotional upheaval involved.

I believe that the CMO's report is a huge first step in regaining a balance in the area. However, the department cannot stop at this point. A huge amount remains to be done and I look forward to hearing what the Minister has to say in that respect.

The Countess of Mar: My Lords, before the noble Lord sits down, perhaps I may reassure him that I recognise that the report is for recommendation. However, as I tried to illustrate with the conference to be held at the John Radcliffe Hospital, it is being misinterpreted already.

Lord Clement-Jones: My Lords, I entirely agree with the noble Countess. That is why it is so important to ensure that we get it into the professional bloodstream and that there is no question about the CMO's recommendations being taken seriously.

7.51 p.m.

Baroness Noakes: My Lords, I congratulate the noble Countess, Lady Mar, on initiating the debate today. It is an important subject and it raises many issues. The noble Countess concentrated on the different approaches to CFS/ME, in particular the

16 Apr 2002 : Column 901

different schools of thought—the biomedical and the bio-psychosocial—where there are clearly different approaches and marked fault lines between them. Indeed, I am shocked by the way in which the debate appears to have been conducted in the past. One hopes and prays that peace might break out and that the medical world might come together to find agreed solutions for this distressing illness.

In preparing for the debate, I tried an Internet search for chronic fatigue syndrome and got 284,000 hits world-wide and more than 17,000 in the UK. I tried NHS Direct and got a more manageable 1,089 references. I also tried searching for myalgic encephalomyelitis, which produced fewer hits wherever I tried. But interestingly, when I tried NHS Direct it asked me whether I meant "imagined encephalomyelitis".

That is a significant piece of programming embedded within NHS Direct. Part of the problem has been that CFS or ME has not been regarded as a definite illness by a large number of healthcare professionals. That has led to many of the problems to which the noble Countess and the noble Lord, Lord Clement-Jones, referred. The report is welcome for its clear recommendations that the NHS and healthcare professionals should treat CFS/ME as a chronic illness, with all that flows from that. While I cannot take part in a debate on the science of the causes or the way in which CFS/ME should be approached, we should recognise that the report has done a service in identifying it as a chronic illness and producing a number of recommendations. I want to talk about those today.

The working group correctly recognised that considerable further research was urgently needed into a whole range of issues including aetiology, therapeutic interventions, cost-effectiveness studies and many other areas. The Government's response was to endorse the need for more research and to note that the Medical Research Council has been asked to develop a strategy for biomedical and health services research. They stated that the MRC would appoint an independent scientific advisory group and the terms of reference and a timetable were to have been agreed by the end of February 2002.

Since then, there appears to have been a deafening silence. I could find no trace of an advisory group, terms of reference or a timetable. Certainly the MRC's website is completely silent on those aspects. Like other noble Lords who have spoken today, I hope that the Minister will be able to enlighten us on the status of the programme and when the members of the working group will be reporting and what they will be covering. I remind the Minister that that work was described as "urgent" by the working group.

The working group made a number of recommendations concerning treatment and care. One of those was that healthcare professionals should have sufficient awareness, understanding and knowledge of CFS/ME. The noble Lord, Lord Clement-Jones, referred to that. The department's response was that it recognised that knowledge and

16 Apr 2002 : Column 902

skills needed to be improved. I join the noble Lord, Lord Clement-Jones, in asking the Minister to say specifically what actions will underpin this part of the Government's response. How will the knowledge and skills be improved and over what timescale?

The prevalence of CFS/ME was estimated in the report to be between 0.2 and 0.4 per cent. That means that most general practices will have several patients with the illness. Therefore, it is important that there is an acceleration of skills and knowledge. When do the Government believe that all general practices will be adequately equipped, based even on the current level of knowledge about the illness? Will it be this year, next year or when?

Hazel Blears, a health Minister, stated in a Written Answer in another place:

> "A useful way forward at a local level could be for clinicians and patients to develop clinical learning networks that will allow them to develop expertise".—[Official Report, Commons, 12/3/02; col. 1008W.]

That approach signally fails to recognise that a step change is needed. It cannot possibly be left to small groups of clinicians and patients to do some group learning all over the country. That would be postcode treatment of the very worst kind.

The working group report dealt fairly extensively with the two therapeutic approaches about which most is known. We heard from the noble Countess, Lady Mar, of her doubts about one of those; that is, cognitive behavioural therapy. Putting those doubts aside for one moment, there are in practice few specialists. That means that those therapies are hard to obtain and I understand that waiting lists run to more than two years. The expertise base is even smaller for alternative therapies. Will the Minister say what the Government intend to do to increase the number of specialists and therapeutic options that are available?

The working group also said that sufficient tertiary level specialists should be available to advise and support primary and secondary care colleagues. Will the Minister say how many tertiary level specialists exist currently and whether they provide the basis of adequate support to primary and secondary care? And anticipating that that cannot be answered positively at this stage, will the Minister say what is to be done about this? The Government's response to the working group in this area was non-existent.

The working group stated that strategic health authorities should make provision for secondary and tertiary care based on an annual prevalence rate of approximately 4,000 cases per million. Based on our discussions at the Committee stage of the National Health Service Reform and Health Care Professions Bill about strategic health authorities, I rather doubt that those authorities will be making any provision themselves. It will no doubt be left to PCTs. We on these Benches have expressed considerable doubts about the readiness of PCTs for commissioning generally and have no confidence in highly specialised commissioning for an illness which is not even widely acknowledged to be an illness. Will the Minister say how that is to be done and whether he believes that PCTs will be up to the task?

Regardless of the technical aspects of commissioning, there will be a real issue about money, as the noble Lord, Lord Clement-Jones, has said. Conspicuous by its absence from the Government's response to the working party's report was any mention of money. It is apparent that extra funds will be required if the recommendations of the working group are to be implemented. The noble Lord, Lord Clement-Jones, referred to an overall cost to the economy of £4 billion. The figures I have seen suggest a cost of around £1 billion. However, whether it is £1 billion, £4 billion or something in between, it is a very large sum of money. Thus it is clear that moneys invested in research and treatment for CFS/ME should be cost-effective as well being desirable on health grounds.

Underlining what has already been asked by the noble Lord, Lord Clement-Jones, my final question for the Minister is this: how much will the Government invest in research, in education and training, in service provision, and over what time-scale? I hope that the Minister will not disappoint us because this is a very real health issue which will need positive action and funding from the Government if progress is to be made.

Lord Rea: My Lords, before the noble Baroness sits down, perhaps I may refer to a point she made earlier in her remarks. The noble Baroness said that when she contacted NHS Direct about myalgic encephalomyelitis, the representative responded by asking, "Do you mean, imagined myalgic encephalomyelitis?" That sounds like a rather derogatory and insulting response.

However, the condition displays no actual clinical or pathological signs of encephalomyelitis which would always be present when someone has a true diagnosis of the condition. That is why the term "chronic fatigue syndrome" is much preferred. I do not suggest in any way that the condition is not an entity; that it does not exist. We do not yet know what causes it, and there may indeed be multiple causes.

8.2 p.m.

The Parliamentary Under-Secretary of State, Department of Health (Lord Hunt of Kings Heath): My Lords, first I echo the words of other noble Lords in thanking the noble Countess, Lady Mar, for initiating this debate. Her speech was indeed hard-hitting, but I pay tribute to the way in which she has continued to raise issues relating to CFS/ME in your Lordships' House. I congratulate the noble Countess on giving us an opportunity to discuss in some detail the report of the independent working group and the Government's response to it.

In doing so, I should first acknowledge the tremendous work undertaken by the working group. I do not think that anyone should be under the misapprehension that the working group was faced with anything other than a very difficult task. It is right for me to pay tribute to the chairman, Professor

Allen Hutchinson, Dr Timothy Chambers, chair of the children's group, and the deputy chair, Professor

16 Apr 2002 : Column 904

Anthony Pinching. All the members of the group, from whatever background they came, made a great effort to accommodate a wide range of views and opinions, as expressed in the final report. I know that the work took longer than had been expected but I am convinced that the time taken by the group was well worth while. Although I fully accept that the report has not provided all the answers that noble Lords would have desired, it has moved the debate on considerably.

In paying tribute to the working group, one has to recognise how distressing and debilitating this condition can be for individuals, their carers and their families. Of course, even if the actual illness is not in itself problem enough, as the noble Countess, Lady Mar, made abundantly clear—and as was made clear in the report—many patients find it very difficult to get the treatment and care they need to help them manage their illness and make a recovery. That is a double whammy, if you like. One's heart goes out to the many thousands of people who over the years have found that the health service has not been as supportive as it ought to have been.

That is why the independent working group gave such a high priority to harnessing the views of patients, parents, families and carers to underpin the guidance. The noble Lord, Lord Clement-Jones, raised the issue of patient and public involvement. He knows that we are in the middle of a fascinating debate about how the Government intend to improve public and patient involvement. However, in particular in relation to CFS/ME, I should like to highlight the two sounding board events held by the independent working group to enable patients to participate in the development of the report. These events were designed to capture some patient voices and to ensure that major stakeholders could identify issues that are pertinent to people who live with CFS/ME.

I accept the challenge that, as we move on and encourage the NHS to develop appropriate services, the principle of patient and relative partnership will be absolutely crucial at the local level. Although the noble Lord, Lord Clement-Jones, has reservations about some aspects of our proposed developments with regard to patient and public involvement, we believe that the particular value of patients forums will be in enabling those people who are experiencing services at the sharp end to be able to make a major input into policy and service development.

Voluntary organisations also contributed to the working group by providing material and sponsored surveys which have informed the report throughout. The group aimed to capture views from individuals with special interests or expertise and from a wider constituency, then to structure the material to reflect the range of opinion.

It is worth acknowledging that, while many thousands of people have felt let down by the system, some patients have had a positive experience and have

16 Apr 2002 : Column 905

worked with health and social care professionals to manage their own care. The report contains one or two positive quotes. One patient said that,

> "a diagnosis of CFS was made and I was advised how to manage my energy".

Another patient said:

> "My GP was brilliant. He said he did not know how to cure me, but we would work together to make me better".

That sends a positive message and demonstrates that the NHS can meet the challenge. While I certainly accept that both the noble Countess, Lady Mar, and the noble Baroness, Lady Noakes, have identified potential shortcomings—there are issues with regard to the future training of nursing staff, GPs and social workers—we are at least building on some pockets of excellence and the good common sense displayed by some GPs in supporting their patients.

We want everyone with CFS/ME to get the treatment and care they need, when they need it and where they need it. Like the patients quoted in the report, we want people with CFS/ME to be listened to when it comes to decisions about what type of treatment and care will best meet their individual needs.

I listened with a great deal of interest to the noble Countess when she referred to articles written in the British Medical Journal. The noble Baroness was right to point out that those articles represent the views of a very small number of doctors in relation to the totality of the medical profession in this country. It is important to underscore that. On behalf of the Government, I should like to make it absolutely clear that we endorse the view of the working group that this is a chronic illness, that health and social care professionals should recognise it as such and that the Government welcome the publication of the report as a start to the process of improving awareness and understanding of CFS/ME. I am happy to reiterate that to the noble Countess. We stand by the report.

The Countess of Mar: My Lords, I am enormously grateful to hear the noble Lord say those words. I know too that thousands of ME sufferers around the country will also be grateful.

While I am on my feet, perhaps I may say that it was my own GP who understood OP poisoning and worked closely with me on that matter. He then pointed me in the direction of ME sufferers who were also not receiving appropriate services.

Lord Hunt of Kings Heath: My Lords, I thank the noble Countess for that. She raises a rather wider question, to which the noble Lord, Lord Clement-Jones, referred, in that very often when people go to their GPs and are diagnosed with an illness, the health service is not as good as it ought to be in referring people to self-help and support groups. One of my great hopes for the new arrangements, particularly through the work of patient advisory liaison services, is that they will ensure that we are much better at referring people at the first practical moment to the wonderful range of self-help groups that we have in this country.

16 Apr 2002 : Column 906

There is no doubt that the working group faced a difficult task. There is widespread uncertainty surrounding this condition. There is controversy, disbelief and disagreement about the best way to treat it. The kind of issues raised by the noble Countess have surrounded the debate over many years.

We have to recognise that real challenges face clinicians who have the responsibility for caring for people with CFS/ME. First, there are no agreed diagnostic criteria. Diagnosis is often made by eliminating other conditions through a series of tests. But there is agreement that overwhelming fatigue is one symptom that characterises CFS/ME. There is continuing debate about which other factors should be taken into account when making the diagnosis.

Secondly, we do not know the cause of CFS/ME, although there are many theories about it. Research has demonstrated endocrine, immune, musculoskeletal and neurological abnormalities and that physical, psychological and other factors are interrelated. No one yet has provided conclusive evidence to support either view and it seems possible that the syndrome represents a spectrum of illnesses.

Thirdly, there is no one form of treatment to suit every patient, but treatment to relieve the wide variety of symptoms which individuals can experience has to be a matter for individual doctors, to be taken in consultation with their patients.

Fourthly, we are aware that there is controversy about some of the approaches used for managing CFS/ME. What we have to do now is to ask all stakeholders to work together and establish what treatment, or combination of treatments, will help patients to get better. I could not agree more with the noble Baroness, Lady Noakes, when she refers to the tone of some of the arguments within the medical profession. There is a challenge for the profession to do what it can to get the debate on to the right constructive lines.

We have to remember the impact on patients rather than the niceties of professional argument.

One possible way forward would be to develop clinical learning networks that would allow clinicians and patients to develop expertise in this area. The potential to develop service networks between tertiary and secondary care is an area that we would ask strategic health authorities to explore.

The noble Baroness, Lady Noakes, took us back to the debates that we have been having about the role of strategic health authorities. She will remember that I argued in Committee that the whole point about the size of strategic health authorities is that, by and large, they cover areas containing many care networks, and CFS/ME could well fit into that pattern.

As to the PCT commissioning route, I have confidence in PCT specialised commissioning because, as the noble Baroness said, according to the reports and estimates the number of patients involved will be huge. Surely that must mean it is in the best interests

16 Apr 2002 : Column 907

of GPs to work together collectively to ensure that they have the right approach in terms of referrals and a systematic approach to providing services.

Baroness Noakes: My Lords, given the current lack of understanding among the medical profession of this condition—even in identifying it as an illness—does the Minister still believe that PCTs can undertake effective commissioning of services to deal with CFS/ME?

Lord Hunt of Kings Heath: My Lords, it will be a challenge. No one can pretend that it will be easy. The working group report is the start of the process. I shall come on to the issues of research and the potential referral to NICE, which could provide guidance on development to PCTs.

The noble Countess, Lady Mar, referred to cognitive behaviour therapy and to what has been described as "pacing". The report shows that in certain circumstances particular treatments can be effective. It also shows that no one can be dogmatic or definitive. It is quite clear that a range of therapies are on offer. We need to—and must—ensure that this range of therapies is available and that patients do not feel themselves forced into the position of having to accept only one particular therapy. That seems to be the thrust of the working group's report.

The Countess of Mar: My Lords, one of the problems with these therapies in the past—I hope that it will not happen in the future—is that social security benefit payments are dependent on agreement to do CBT and graded exercises. The treatment of children is dependent upon the parents agreeing to this, even when the child demonstrates that it is getting sicker.

Lord Hunt of Kings Heath: My Lords, I understand those concerns. The noble Countess will know that a copy of the report has been sent to the DWP, which will obviously give it consideration. My understanding is that the DWP recognises CFS, including ME, as potentially debilitating illnesses. The department's chief medical adviser constantly evaluates the latest developments in the understanding of those conditions. I hope that the independent working group report will help to inform the Department of Work and Pensions in the future.

I understand that the application of the assessment to people who have a medical condition that fluctuates or varies in its severity, such as ME, is already addressed in the training and guidance given to medical services doctors who provide advice to decision makers in the field of benefits at the DWP.

This debate raises the issue of research. It is clear from what I have said about the challenges facing clinicians that we agree with the working group that the evidence base is poor. The report states that in relation to pacing, cognitive behaviour therapy and other therapies the research base is poor. We endorse the need for more research on a wide range of aspects of CFS/ME and we have asked the MRC to develop a broad strategy for advancing biomedical and health services research on CFS/ME.

16 Apr 2002 : Column 908

I shall not be able to give specific answers today to all the questions that noble Lords have asked me. The position is that the MRC is currently in the process of appointing an independent scientific advisory group, which will include scientists with expertise in areas such as epidemiology, physiology, immunology, infections, clinical trials and psychological medicine.

I understand the noble Countess's point about not wanting psychiatrists to dominate, but noble Lords will understand that this is a matter for the MRC and that it would be wrong for me to intervene. However, I shall ensure that a copy of Hansard is sent to the MRC in order that it may consider the points raised in this debate.

The scientific advisory group established by the MRC will draw on the working party report and other recent expert reviews. The MRC will also consult with its consumer liaison group members as to the best means by which patient and charity perspectives can be taken into account.

As to resources, the noble Lord, Lord Clement-Jones, asked me about budgets. He will be aware that it is a long-standing and important principle of successive governments that they do not prescribe to the individual research councils the detail of how they should distribute resources between competing priorities. That is a matter best decided by researchers and research users. In view of the debate that we had during the passage of the NHS reform Bill, when the criticism was expressed that the Government seek to intervene too much in organisations such as these, I am sure that the noble Lord will endorse the broad principles that I have enunciated.

Turning to the subject of children, I acknowledge the work of the Times Trust, and I pay tribute to the noble Lord, Lord Clement-Jones, for his work in that area. Of course, children with CFS/ME have special needs. I agree that nearly all children who are severely affected with CFS/ME, and many who are moderately affected, will require special educational support. Clearly, a critical element of the child's management is assessment and the provision for educational needs.

The Department for Education and Skills produced guidance in November 2001 entitled Access to education for children and young people with medical needs. The report makes specific mention of the needs of children with CFS/ME.

That brings me to the extremely difficult and contentious issue of child protection. We have debated the matter and I have had discussions with the noble Countess. I am aware of the concerns regarding child protection issues. I hope that the good practice guidance produced by the Children's Group, which appears in Annex 6 and Annex 7, will result in improved management and understanding of this condition. I am aware that on occasions families of child sufferers have been subject to protection concerns.

16 Apr 2002 : Column 909

The annex makes it clear that, where medical opinion is divided, a further opinion can be obtained from an expert medical practitioner. That goes some way at least to meeting one of the concerns raised by the noble Countess.

She asked me about the particular cases that she raised with me. I can confirm that they are being followed up by the Social Services Inspectorate. My honourable friend Mrs Jacqui Smith, the Minister concerned, will be in a position to reply to the noble Countess shortly on the matter.

At this stage I ought to turn to the issue of professional education, which I agree is of vital importance. I have stated that, because GPs are likely to be facing many patients with this condition, it is clearly in their best interests to ensure that they are up to date. We need to do everything that we can to help them in that regard.

Noble Lords will know that responsibility for the contents, standards, management and delivery of medical education is shared between regulatory bodies. I believe that the Government would find it impractical—going back to our debates on the role of government—to prescribe the exact training that any individual doctor would receive. Equally, we have a responsibility to encourage those authorities to take account of the report of the working group, and we shall do so.

We also expect GPs to keep up their professional skills. The continuing professional development and continuing medical education programmes that we are instituting should help them to do so. I accept that we need to ensure that we give as much help as possible. We shall be seeking to do that in the future, not just for GPs but for other professionals as well.

I agree that in relation to social workers, for instance, we may need to refer the report to the General Social Care Council. It is opportune that my noble friend Lady Pitkeathley is in her place. Clearly, in regard to child protection procedures advice is now coming forward as a result of the special annex on children's services that in areas of medical controversy second medical opinions are available. That is an important matter.

The other important matter to consider—returning to the question raised by the noble Baroness, Lady Noakes—is how we can make improvements in the provision of services. I believe that the publication of the report will help in itself. It will improve the way in which health professionals will feel about service support. It will make them feel more confident about how they should care for these patients.

The report is not a comprehensive clinical guide and has not been developed as such. That is why a referral to the National Institute for Clinical Excellence to provide guidance on management and treatment is currently being considered. Thought also needs to be given to what is the most appropriate clinical tool for helping patients with this condition.

16 Apr 2002 : Column 910

We will also ensure that the external reference groups which will develop the two national service frameworks for children's services and services for adults with long-term conditions will consider the report and its recommendations for improving treatment and care. Given the importance of national service frameworks in terms of setting a consistent pattern of service provision and the knock-on effect that that has in terms of our workforce planning, I believe that this is a way of getting fully established in the service a proper approach to commissioning—in terms of PCT commissioning, in picking up the role of the strategic health authority in performance management and in making sure that specialist services are indeed covered through the NHS; and in picking up such issues as the number of specialists who need to be appointed and the general training of GPs and social workers.

While that will inevitably take a little time, there is much to be said for the approach of the potential referral to NICE. I cannot say now what decision the Government have made. However, alongside a potential for referral, the two national service frameworks—long-term conditions and children's—will be able to pick up these issues more substantively.

I realise that I have exceeded my allotted time, but I believe it important to give as full a response as possible. In relation to the issue of resources mentioned by the noble Baroness, Lady Noakes, I do not agree with her. I am surprised that she should even suggest such a thing. She was really suggesting central earmarking in relation to CFS/ME. That is not the route down which we need to go. This Government are committed to decentralisation. That is why we want 75 per cent of the entire NHS budget to get down to PCTs by 2004. We need to make sure that PCTs have the tools and the information then to make the right judgments about commissioning. In that area, I accept that we need to do more. The working group report has taken us a long way, but we need to do more. The national service frameworks will help. We need to improve education and training. But overall what has been an incredibly difficult subject has been helped enormously by the work of the working group. I am again indebted to the noble Countess for allowing us to discuss these issues.