

12 July 2000

## **Chronic Fatigue Syndrome and ME**

3.13 p.m.

**The Countess of Mar** asked Her Majesty's Government:

When the Chief Medical Officer's task force on chronic fatigue syndrome and myalgic encephalomyelitis is expected to report.

**The Parliamentary Under-Secretary of State, Department of Health (Lord Hunt of Kings Heath):** My Lords, the Chief Medical Officer's working group on CFS/ME is expected to report in the summer of 2001.

**The Countess of Mar:** My Lords, I am grateful to the noble Lord for that reply. However, is he aware that in the intervening period, there is no consensus on the treatment for ME? More and more cases are coming to my attention every day in which local authorities are invoking Section 47 of the Children Act, which indirectly accuses parents of abusing their children. In fact, it seems that the abuses are on the part of the local authorities. Parents are accused of having Munchausen's Syndrome by proxy. They are hounded into forcing their children to have treatments which make them more sick. Families are cracking up under the strain.

The noble Lord knows that I have already raised this matter in relation to South Wales. I still have not received an answer from the Welsh Office. Will he look into the possibility of holding an inquiry into the way in which local social services departments are handling those children?

**Lord Hunt of Kings Heath:** My Lords, I am well aware that there is no agreed method of treatment for that condition. That is why the work of the working group is so important and it is right that it is taking time to reach conclusions.

As regards the child protection issues which the noble Countess has raised, it is not appropriate for me to comment on specific cases, but I assure her that the working group is considering the principles involved. It is my hope that good practice guidance will result in improved management and understanding of the circumstances in relation to children.

**Lord Clement-Jones:** My Lords, in view of the Minister's statement that the working group is to take a year longer than originally expected to reach a conclusion, it seems that further research on this matter will be held up. There is only one piece of research of which I am aware, carried out by the University of Manchester, into the causes of ME and it appears that that will be held up by the delay in the publication of the report. Will the Minister assure the House that research will be commissioned in the

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meantime both by the MRC and the Department of Health, if necessary, so that we can tackle the ME issue rather more urgently than we appear to be doing at present?

**Lord Hunt of Kings Heath:** My Lords, it would be wrong to suggest that the working group is taking too long and is being too slow. There are extremely complicated issues. It is well known that there are many differing views about the causes and treatments of that very distressing condition. It is right that the working group should take its time to reach its conclusions.

As regards research, I can tell the noble Lord--and I am happy to write to him with the details--that the NHS Research and Development Programme has supported research projects on CFS/ME to a total cost of £221,000.

**Lord Turnberg:** My Lords, does my noble friend agree that in the absence of a known cause for this distressing condition and a diagnostic test for it, clearly more research is needed? Meanwhile, the NHS must focus on making resources available to ensure that that evidence-based treatment which is available, which seems to improve the majority or 75 per cent of patients--namely, cognitive behaviour therapy visited in a cautious way--should be made more freely available.

**Lord Hunt of Kings Heath:** My Lords, my noble friend has raised a very important point. I acknowledge that that has shown to be an effective treatment in certain cases. But before further guidance is issued to the NHS, it is better to wait for the outcome of the working group's deliberations. Certainly, we should then hope to take forward from the working group any subsequent advice which needed to be made to the NHS about treatment. And if the working group puts forward suggestions for further research, we shall consider those very carefully.

**The Countess of Mar:** My Lords, does the noble Lord recall that almost two years ago I raised the question of a particular case in the House with the noble Baroness, Lady Hayman, when she was the Minister? I was assured at that time that the results of a judgment in the Birmingham courts, which said that the parents were the prime people to give consent to treatment, would be handed down to social services departments.

In view of the length of time that the task force is going to take to respond, will the Minister instruct social services departments to lay off those families and to allow them to treat their children as they wish, instead of forcing them into treatments which do not suit them?

**Lord Hunt of Kings Heath:** My Lords, my understanding is that the high profile of some of the cases to which the noble Countess referred has resulted in the courts deciding in favour of parents and the right of the individual to consent to treatment.

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I shall take away the suggestion made by the noble Countess to see whether it is appropriate for guidance to be issued to social services departments. But, in the long term, I believe that it is better that we allow the working group to finish its deliberations and then we shall be in a much stronger position to give overall guidance to the NHS.

**The Earl of Listowel:** My Lords, is the Minister aware of the foundation today of the Life Neurological Research Trust, which has been set up in memory of Baroness Wharton? It will fund research into Alzheimer's disease, Parkinson's disease, multiple sclerosis, motor neurone disease, Creutzfeldt-Jakob disease, encephalitis and other encephalopathies?

**Lord Hunt of Kings Heath:** My Lords, I was not aware, but I pay tribute to the organisation and to the work of the late Lady Wharton in your Lordships' House. I shall be very interested to discuss with the noble Earl the details of that trust.