

## **The Countess of Mar**

### **The Countess of The Cause in action in the Lords, 16th Feb 2000**

*4:10pm : The Countess of Mar*

My Lords, we all know of and respect the expertise of the noble Earl, Lord Russell, in this field and I am grateful to him for drawing the Rowntree Report to our attention today. I intend to concentrate upon a group of individuals who are spread across the whole age range of this report. They are men, women and children who are suffering from what are categorised as illnesses with "ill-defined symptoms". Among them are CFS/ME, multiple chemical sensitivity, Gulf War illnesses, fibromyalgia, sheep dip poisoning and irritable bowel syndrome. The severity of their symptoms fluctuates from day to day.

I have spoken about the predicament of these people on many occasions in your Lordships' House but never in this context. Prevailing medical opinion has it that their illnesses are the result of "functional somatisation". As I understand it, this definition may be loosely translated in this way: these patients have a personality defect that leads them to complain of physical symptoms in order to obtain sympathy and attention. Prevailing medical advice is that once known causal factors for the symptoms are eliminated, there is no point in doing further clinical investigation. Some leading psychiatrists are of the opinion that the best way to treat patients is with antidepressants, cognitive behaviour therapy and, in the case of CFS/ME patients, graded exercise.

There is very little sound evidence that this regime is effective. In fact, it has been criticised severely by researchers outside the UK. Patients who attempt and fail in this regime or who, having heard of its unfavourable results and refuse treatment, are effectively branded as frauds. As a result, they are all too frequently stigmatised and become socially excluded.

I am not aware of any UK studies that have looked at the quality of life of people with CFS/ME. I do have papers relating to one study from the USA and another from Australia. The American paper found that:

"Over-all scores on the quality of life index were significantly lower in CFS than for other chronic illness groups".

And that:

"The findings suggest that the quality of life is particularly and uniquely disrupted in CFS".

In the Australian paper the researchers found:

"Results from both the SIP [Sickness Impact Profile] and the interview revealed that CFS subjects had significantly impaired quality of life, especially in areas of social functioning. These findings highlight the importance of addressing the social isolation and loss of role functioning experienced by CFS sufferers".

My extensive contacts with sufferers from all the illnesses I have mentioned gives me the distinct impression that CFS sufferers are not alone in their plight. As successive Ministers for the Department of Health and the noble Baroness the Minister know only too well, for they have to respond to some of my letters, there are many in the community who are deprived of treatment, social services support and social security benefits. These people are not whingers and spongers. Many are seriously ill. The Australian study found that:

"Forty-six of 47 patients diagnosed with CFS were classified as having severe illness impairment, independent of their age, sex, education level or length of their illness. It is noteworthy that this degree of impairment, as reflected by overall SIP scores, is more extreme than the over-all impairment reported by patients with untreated hyperthyroidism, end-stage renal disease and heart disease ... it is also more extreme than the over-all levels of impairment reported by a comparable group of MS sufferers".

Let us not forget that between the two world wars MS sufferers were branded as suffering from a lazy man syndrome. The American study of 110 subjects found that:

"All participants related profound and multiple losses, including loss of jobs, relationships, financial security, future plans, daily routines, hobbies, stamina and spontaneity, and even their sense of self because of CFS".

I have a large folder of case histories. Patients, parents and doctors write to me in a desperate attempt to obtain recognition and help. They ask what they must do to obtain funding for treatment outside the NHS when they know from experience that the treatment works, but they have exhausted their private funds or their health authority or GP has withdrawn funding.

I had just such a letter today. This lady has been a patient at the Breakspear Hospital for 20 years. She suffers food and chemical sensitivities and is acutely sensitive to drugs. The treatment has enabled her to function socially and in the home. For seven years West Sussex Health Authority paid 2,000 pounds a year towards her treatment costs, which amount to about £5,000. The balance she has found herself. Despite the support she has from her GP, the health authority have now withdrawn its support, citing among other factors a shortfall in its finances.

Over the years she has been referred to innumerable consultants who, her GP states, "have failed to help her in any way". He has reminded the health authority that the effects of her illness mean that, without treatment, she is a suicide risk. I shall be writing to the Minister's noble friend about this.

The noble Earl spoke about suicides and we know that the suicide rate among farmers is extremely high. There is anecdotal evidence of many suicides among ME sufferers and Gulf War veterans. Are

there statistics which link the illness of the patient prior to the suicide with the actual suicide? I know that suicides are listed by occupation, but I wonder whether there is any other information about them.

The noble Baroness may recall that I have written to her on many occasions about social security clients who are made to travel long distances to attend Benefit Agency offices, medical examinations and appeal tribunals. Even after going through all the hoops at great personal financial and physical cost, these people are deprived of their benefits and are told that they must seek employment. What employer would even consider taking on a person who does not know from one day to the next how much he will be able to do? I have also written to the noble Baroness about Gulf War veterans who are having difficulty with their war pensions and other social security benefits.

While I know that the noble Baroness is a kind and sympathetic person and that she tries to be as helpful as possible, I have now stopped being surprised by the chilly responses I receive. Her colleagues in the Department of Health are aware that there are parents who are being accused of exhibiting Munchausen's syndrome by proxy because they refuse to force their children to undergo the recommended regime; that these children are placed on the "at risk" register; made wards of court and forced to undergo what is, to my mind, a barbaric course of cognitive behaviour therapy and exercise. She must know of the children who are isolated at home, missing out on their schooling and contact with friends because their illness is not recognised.

Fortunately, there are some medical practitioners and researchers who are not, to use current language, "on message". They are conducting in-depth clinical examinations of patients who present with multiple symptoms. They are finding organic causes for those symptoms. Some are finding clear causal relationships between exposure to a variety of chemical and biological toxins and the development of illness. Others are successfully treating patients with a variety of complimentary medical procedures. Unfortunately, too often they are either ignored or denigrated by those who prefer the "quick fix" of a psychiatric diagnosis. It seems that nobody will listen to them or to their patients.

Despite the assurances given by the Director of the Benefits Agency Medical Services that all their doctors are trained to recognise these illnesses and that they are aware of the fluctuating nature of the symptoms, it is clear that some of these doctors are not following the guidelines. As a result, sick individuals find that they are not believed by relatives and friends or by their GPs. They struggle to exist in a social vacuum on minimal incomes and little, if any, medical support.

While I am aware that there is a task force in the Department of Health looking at ME/CFS, I ask the Minister to recognise the plight of all the men, women and children who fall victim to these illnesses and to work with her colleagues, to listen to, and actually hear, the sufferers and their professional carers and to examine all the means of lifting from them the stigma of social exclusion.

I speak from the heart. Noble Lords will know that I suffer from organophosphate poisoning. I spent two years being socially excluded. Fortunately, I have good friends and other helpful people. I have been treated and have recovered. I believe that I am now making a useful contribution to society. There are hundreds of people in the world who could make a similar contribution and I ask the noble Baroness to listen.

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