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A new look at Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME)

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Abstract

It has been three years since the Chief Medical Office reported on CFS/ME and the time has come for a thorough investigation by an All Party Group drawn from the House of Commons and the House of Lords. We have received many written submissions and are engaged in taking oral evidence in 2-hour sessions, which we open to the public as well as interested groups. The group has received a fantastic response to its requests for written evidence over the last few months. Questions that arise for a government response are the lack of provision and support for CFS/ME patients, the issue of the clinical definition of CFS/ME, the need for a diagnostic test for CFS/ME, effectiveness of the NICE guidelines, and criteria used to decide which treatments are best for patients with CFS/ME.

There are some challenges in life which are met by the response – you must be mad! Such was the reaction I received from colleagues and others when I stated the need for an inquiry into Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME) following discussions with various constituents and medical friends. This made the challenge to get together a group of people who were truly independent (if there are any) and to have an inquiry, including everyone possible, even more tantalizing.

It has been three years since the Chief Medical Office reported on CFS/ME. I saw this as an important step in recognizing the seriousness of the condition and therefore it seemed right that we now continue his work and looked at where we had got to in the UK. I still remember the rather unsatisfactory debate in the House of Commons when ME was discussed and an All Party Group set up to move things forward. CFS/ME never figured in all the debates and future plans for studies by the Health Services and Research Councils. Well at least it never achieved a priority rating despite some research funding being available. Two hundred and forty thousand people at least in the UK are suffering with the condition and a conservative estimate is that it costs £35 billion per annum. It seemed to me that political action was needed in the same way as cancer, heart disease and mental health featured on our research radar screen, the economic and social benefits were being ignored.

The time for a thorough investigation had come and as I said in a press release announcing the formation of an investigative group: ‘the group aims both to stimulate public debate and interest in ME and act as catalyst for increased funding into the research of ME which I hope will one day lead to a cure for those suffering from this illness across the UK and around the world’.

The terms of reference for the group were

- * To look at the causes of CFS/ME
- * To establish a programme of research on all aspects of the condition
- * To secure adequate investment for research
- * To increase public understanding of the scientific research into CFS/ME
- * To identify research and funding requirements in establishing the causes of CFS/ME

The membership of the committee was problematic given that after the announcement of the inquiry I received all sorts of advice on who or who should not sit on the board and who should give evidence. The CFS/ME problem, I have learned, is surrounded by anger, frustration and conspiracy theory. Some of the advice was helpful, a lot was vitriolic and many people, while being grateful for the inquiry, said in no uncertain terms who should not be on the committee. As someone whose task was to use their personal influence to persuade those involved to give up a substantial amount of free time over a substantial period, such comments were often inhibitory in influencing peoples’ willingness to serve and indeed made one contemplate if in such an atmosphere anything positive could be achieved. Even my original clerk was subjected to the vitriol since he had served as clerk to the ‘discredited’ (in the eyes of some) All Party Group. The group had to be All Party obviously, and draw on support and experience from both the House of Commons and

the House of Lords. Experience of inquiry-type questioning and a degree of political acumen were essential. The following is the committee, which although biased in the party political make-up, is pretty balanced as to independence of spirit and to experience of various inquiries.

1. Dr Ian Gibson (Chair) – Labour
2. Dr Richard Taylor MP (Vice-Chair) – Independent
3. Ann Cryer MP (Secretary) – Labour
4. Dr Des Turner MP – Labour
5. David Taylor MP – Labour
6. Lord Turnberg – Labour
7. Baroness Cumberlege – Conservative
8. Countess of Mar – Independent
9. Michael Meacher – Labour

The members were sharp, interested and keen to help resolve the issues. Each member had individual interests in the field – some support organophosphate bans, some are interested in Gulf War Syndrome, and some have relatives, constituents or even patients with ME. It is a mixed bag, but as Chair, I have great confidence in the possibility of coming up with a forward-looking report.

So the inquiry committee has set about 5 sessions of cross-questioning with the aim of understanding CFS/ME despite serious internal disagreements about what the condition is and how it should be treated. As Chair, I have consulted with the committee to ensure all voices are heard and to curtail attempts of some to suppress what they hear and what they see written down and to keep their vitriolic actions and comments at bay.

We have received many written submissions and are engaged in taking oral evidence in 2-hour sessions, which we open to the public as well as interested groups. Our written evidence has come from sufferers, charities, research groups and other organizations, which with the evidence collected at the groups' five oral hearings, will form the basis of a final report, which we hope to release by the Autumn. Let me quote again from the press release after the first hearing:

'The group has received a fantastic response to its requests for written evidence over the last few months. A significant part of this has been made up of letters from sufferers and carers explaining the terrible situation they find themselves in due to the debilitating nature of CFS/ME. The group want to hear evidence first hand from these sufferers and the broad spectrum of organizations that represent them. Through this and the written evidence we have received, we hope to form a true picture of CFS/ME sufferers' hopes and concerns over the current work being undertaken in the treatment and research of CFS/ME. It will be from this base that we begin our investigation and from which we will question leading medical experts and government officials in the field' (Ian Gibson).

Our first two oral sessions have taken place, more are to take place over the next month and will hopefully include a Minister of Health. In the first session, we spoke to ME

sufferers, charities and voluntary organizations. The next session involved specialists from the USA, Canada and representatives of the National Institute for Clinical Excellence (NICE). The experts are working in the fields of treatment and research. It was clear that there was a consensus in some areas but not in others. Guidelines are being drawn up in government and we hope the inquiry will aid this. The sessions so far have been mind-blowing. They have confirmed the suspicion that I felt before the sessions; namely, that not enough is being done to support those who suffer the condition. It has indeed been devastating on relationships, careers and self-confidence.

At the end of the inquiry, of course there remains the possibility of disappointment with complete disagreement or lack of direction for future research or treatments. However, as it is shaping up at this moment, there are a number of themes that are eliciting concern and debate. It is looking most interesting and a number of questions arise for a government response.

1. The lack of provision and support – in terms of access to social security and health care is very worrying.
2. Should we be concerned that the UK definition of CFS/ME differs from that set by the World Health Organisation (WHO).
3. Why are there no diagnostic tests for CFS/ME in the UK?
4. Can a consensus be reached about the definition of CFS/ME to assist in diagnosis? And, is such a consensus desirable?
5. Are the NICE guidelines for diagnosis effective? And, what evidence base was used to form the guidelines?
6. What criteria do healthcare professionals use to decide which treatment methods are best for ME sufferers? And what criteria (if any) are used to assess the effectiveness of the varying treatment methods available (nutrition, exercise, cognitive behavioural therapy, etc).

It is opportune that we are ensuring the progress of knowledge into CFS/ME and in publishing the research questions necessary to facilitate an approach to treatment. It remains amazing that many general practitioners (GPs), perhaps because they don't understand it, still have not sympathy with recognition of the illness, and therefore give no advice and defer to others. I feel they are wrong and in their training must have CFS/ME referred to and recognized. The next few months promise to be exciting.

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