Transcript of this week's Parliamentary debate on ME

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From Hansard, 2 February 2011.

4.13 pm

Ian Swales (Redcar) (LD): I begin by reading what a constituent of mine, Jan Laverick, who suffers from myalgic encephalomyelitis, wrote to describe her condition:

> "ME is sudden and extreme muscle weakness to the point of not being able to lift a glass. It is collapsing with exhaustion and not being able to move for hours. It is struggling to sit up long enough to eat a meal that has been placed in your lap. It is tachycardia, seizures, paralysis and black outs. It is sensitivity to light, sound and touch. It is extreme abdominal bloating, nausea, loss of appetite, excruciating stomach cramps...It is daily fevers and sweats. It is inflammation and horrendous joint, nerve and muscle pain. Imagine suffering from these symptoms only to find there is little research into the cause or cure, that you might not be taken seriously by your GP or the benefits system. Your condition might even have been dismissed as 'yuppie flu'."

I welcome the fact that the Department of Health now accepts ME as a genuine medical condition. However, it is clear from speaking to sufferers and medical professionals that diagnosis can still pose a problem because ME symptoms are similar to those present in several other medical conditions. I recognise that one of the main obstacles to the adequate treatment of ME is the lack of knowledge and consensus about the disease, and I will argue that funding and research must be focused on the biomedical factors involved, and not simply on managing the psychological symptoms.

James Wharton (Stockton South) (Con): I congratulate my hon. Friend on securing this important debate on a subject that I know is close to his heart. It has been raised with me, as it has with him, by a number of constituents who are concerned about it. I echo his comments and point out that, at present, no funding is available for biomedical research into the causation of ME. Does he agree-I believe he just said that he does-that this is an area we want the Government to look at again, and that we should encourage them to take seriously?

Ian Swales: I thank the hon. Gentleman; indeed, that is right. I am not sure whether no funding is available, but it certainly is the minority of funding, and that seriously needs addressing.

My goal is to see the Government-funded Medical Research Council work with ME sufferers and biomedical researchers to achieve a proper understanding of the condition's challenges and to change the unjust perceptions of it.

Annette Brooke (Mid Dorset and North Poole) (LD): I congratulate my hon. Friend on securing this debate. It is almost a year since I had a similar debate, but I am not sure that we have moved on since then. Recently, the MRC announced £1.5 million for research, but does he agree that there appears not to be an overall strategy to deal with research into ME, and that there still seems to be concentration on the symptoms and not enough attention given to the causes?

Ian Swales: I thank my hon. Friend. Yes, the lack of a strategy focused on the latest information is one of the problems.

I was delighted that two days after this debate was announced, the MRC announced £1.5 million for further research into ME-I am sure that it was just a coincidence. That important step shows that leading medical researchers and the Government are finally admitting that current thinking on ME is inadequate.

The condition affects an estimated 250,000 people in the UK. It is not a disease of the elderly: onset commonly occurs during the 20s to 40s in adults, and between 11 and 14 in children, wrecking the lives of so many young people. Studies show that the vast majority of patients never return to their pre-illness level of functioning, and relapses can occur several years after remission. ME is an extremely complex disease for which there is no scientifically proven cause or cure. The main symptom is severe fatigue following almost any mental or physical activity which does not go away with sleep or rest. That often leads to its being defined under the term "chronic fatigue syndrome". However, an important step in changing the misleading perceptions of ME is to recognise that CFS is a loose umbrella classification covering a wide range of illnesses of which fatigue is a prominent symptom, and that those illnesses may be neurological, malignant, infective, toxic, genetic or psychiatric in nature. Fatigue is a loosely defined symptom which can occur to some degree in a wide range of conditions.

Using that umbrella term has further compounded the already significant obstacles to the diagnosis and treatment of ME, which is now identified on the basis of at least nine different definitions. A major problem lies in the fact that different types of illness are also contained under the CFS umbrella. That makes sound scientific research difficult to conduct, as different illnesses have different biomarkers. A research group that consists of people with completely different physical and psychological causes of their fatigue or tiredness can have only limited use, and certainly cannot lead to the development of any sound findings on the causes of ME.

ME, on the other hand, has a clear definition. The term "myalgic" means muscle pain, while "encephalomyelitis" means inflammation of the brain and spinal cord and represents a clearly defined disease process which has been included in the World Health Organisation's "International Classification of Diseases" since 1969. That poses the obvious question of why research has been mainly focused on psychological symptoms, when the very definition of the disease refers to a physiological condition. "Fatigue" is also a clumsy way of describing a complex range of extremely debilitating symptoms. It is not the kind of fatigue that non-sufferers would recognise. ME, as we heard from my constituent, can involve sudden and extreme muscle weakness to the point of not being able to lift a glass. What recognition is there in the Department that ME is distinct and different from the much broader term CFS? Equally, in the light of the recent MRC funding announcement, I urge the Minister to encourage the Department to focus its research, as treating ME/CFS as a single homogeneous condition will only encounter the problems I have just outlined.

That blurring can also lead to a uniform approach to treatment, which is unreasonable and even dangerous. An indiscriminate, blanket approach to treatment was advised by the National Institute for Health and Clinical Excellence in 2007, no matter what the disease process, infectious agent or psychological condition. Again, the symptom of fatigue gets flagged up and treated in the same way in nearly all cases. That can be ineffective for many, and positively dangerous for others. That lack of recognition of ME specifically happens at every level; yet I believe it essential that GPs have the ability to spot ME early and to prescribe appropriate, tailored advice. I would like the Government to recognise the many differences between and subtleties of ME and CFS, and urge the Minister to do the same, as the current treatment guidelines are completely unacceptable.

I decided to call for this debate because the issue has been under-researched. The lack of understanding and stigma surrounding ME have meant that sufferers have had to live with the condition without recourse to the treatments and research they deserve. I initially tabled early-day motion 778 to gauge support, and I am delighted to report that, as of yesterday, 100 colleagues from all parties have put their names to it. That shows the strong feeling in Parliament that significant changes need to be made. There has been a distinct lack of funding into ME research in the past decade. Between 2000 and 2003, not a single penny was spent by the MRC on researching the condition. Things did improve, peaking with just over £1.3 million allocated in 2007-08, but that dropped to just £109,000 in 2009-10.

I welcome the recent funding announcement. However, more than 80% of the MRC's expenditure on ME research so far has been allocated to psycho-social therapies, instead of biomedical studies to prove the existence of a physical cause. That research has continued to pursue a well-trodden path and ignored a vast landscape of other, potentially more rewarding areas. I am concerned to see whether the new MRC funding will focus on that biomedical work. Not only has there been a palpable lack of funding for research; a past study commissioned by the Department of Health found that the quality of research was poor. For a long-term condition that affects 250,000 people in this country, with no known cause or cure and huge costs to the NHS, the amount of research funding dedicated to it, even with the recent announcement, is pitiful.

Misinformation, widespread confusion and ignorance about ME and CFS have resulted in people with entirely different illnesses receiving the same diagnosis. A London sufferer, David Eden, drew my attention to some interesting research that has been taking place in the United States. Recent studies by the Whittemore Peterson Institute, the National Cancer Institute and the Cleveland Clinic have linked ME with the presence of a newly discovered retrovirus. Blood from 68 of 101 ME patients was found to contain a human gammaretrovirus, xenotropic murine leukaemia virus-XMRV-while only eight of 218 healthy patients were found to have the same retrovirus. While that result grabbed headlines, most subsequent studies have been less clear, although one other study did support the original findings. It remains uncertain as to whether XMRV is linked to ME and is involved in causation. I would like to encourage the Minister, therefore, to explore other areas of research, such as retroviruses, in order to ascertain once and for all whether they play a part in ME. To judge by the contact I have had with sufferers, there is constant frustration that the Government are failing to fund research into key areas.

Another, more practical consideration is the recognition of ME by the benefits system. Currently, disability living allowance is assessed by severity of condition, and ME is treated like the vast majority of other conditions. Due to the lack of overt clinical findings, much of the assessment rests on anecdotal evidence and whether the person's description of their disability is consistent with their daily activities. However, despite the guidance on conducting these interviews, an ME sufferer will only be able to attend such a session on a good day. It is therefore impossible to judge accurately the severity of the condition at the assessment interview. I would argue that a more flexible approach to ME is needed. The effects of the condition can wax and wane unpredictably, meaning that often, a person's DLA is withdrawn because of a short-term respite of the symptoms. There needs to be more consultation with and input from GPs and other medical professionals who are in contact with the individual over a prolonged period. Obviously, I understand that this issue is not directly the Minister's responsibility. However, I strongly urge him to make representations, and to make this case, to the Department for Work and Pensions.

I thank hon. Members and the Minister for listening. To end the plight of ME sufferers, appropriate and correctly targeted biomedical research into the causes of the disease must be funded. GPs must be properly apprised of the specifics of ME; sufferers' disability must be recognised in the benefits system, with the support of GPs; ME and CFS must be properly classified; and fatigue must no longer be used as a catch-all symptom. The current situation, which has endured for decades, cannot be allowed to continue. As things stand, 250,000 men, women and children, their families and carers, face terrible injustice and neglect. I call on the Government to put that right.

The Minister of State, Department of Health (Paul Burstow): It is a pleasure to serve under your chairmanship, Mr Hancock, with the coincidence of speaker and respondent in the debate.

I congratulate my hon. Friend the Member for Redcar (Ian Swales) on securing the debate, and thank him and other hon. Members for their contributions. This is not the first time the House has debated these issues. My hon. Friend the Member for Mid Dorset and North Poole (Annette Brooke) raised them-as have others, including me-when in opposition. My local ME support group has been encouraging, and what it has taught me has been an invaluable part of how an MP gets an insight into a condition they might not personally suffer.

I realise that this is a difficult and controversial subject, and I can understand why feelings run high. I appreciate the difficult and desperate struggles that people often face to achieve clinical recognition and relief from the condition, and a sense of hope that there is a direction of travel toward understanding the underlying causes, and eventually getting a cure.

I will ensure that the comments of my hon. Friend the Member for Redcar about benefits are passed on to ministerial colleagues at the Department for Work and Pensions. Although he made some important points in that regard, I will not address them as they are above my pay grade-or certainly outside it.

The basic challenge is that we do not know with any confidence what causes the distressing symptoms-indeed, the condition itself-that my hon. Friend so clearly described. That is why he is right, as is the hon. Member for Stockton South (James Wharton), to highlight the need for research. On my hon. Friend's point about defining the condition, until we have a strong clinical evidence base, we have to keep an open mind about whether this is one condition or a number of conditions with similar symptoms but different causes. The Department does follow, and will continue to follow for the time being, the World Health Organisation convention in how we describe and refer to the condition-that is, to call it CFS/ME. That is the WHO definition; it is not a specific term that the Department of Health has alighted on and no one else uses. It is important that that be understood.

On present understanding, that definition best captures the spectrum of symptoms and effects that characterise the illness. As yet, there is no cure nor any consistently effective treatment for the condition. As my hon. Friend rightly said, we do not even have a standard diagnostic test to confirm the condition. Diagnosis is possible only through excluding other illnesses with similar symptoms. There is, however, strong international consensus that CFS/ME is a chronic and disabling neurological illness. I want to stress that it is a neurological illness; it is not a mental health problem. I know that that suggestion causes great concern-and, arguably, offence-for many sufferers who have campaigned vociferously against it. The strength of many people's reaction to that label says a lot about the stigma that is still attached to mental illness, and about the attitudes of health professionals towards it. We seek to tackle those two problems in the mental health strategy that the Government have published today.

Although CFS/ME has no psychological foundation, that does not mean that we cannot gain lessons and insights from cognitive behavioural therapy, and that where appropriate, it should not be used as part of a treatment plan, just as it is for many other long-term health conditions. The NICE guidelines, to which my hon. Friend has referred, include counselling and graded exercise as possible treatment options. Let me emphasise the words "possible" and "guidelines." Neither of those things is mandated, but they could form part of a conversation between the clinician and an individual about the appropriate, personalised approach to their situation.

The guidelines seek to help a person to manage their symptoms as much as possible. In lieu of any clinical cure, that is about social recovery and helping people to manage their symptoms, be clear about their goals and define their own recovery, rather than simply prescribing a clinical treatment. We know that the treatment in the guidelines helps some patients but, as my hon. Friend has said, for many people it does not help at all, and some people find it offensive. The obvious point-I will return to this in a moment-is that a doctor needs to work with the patient to find the most appropriate way forward. That is why personalisation is at the heart of our general approach to long-term conditions, which is critical in this debate.

With no cure, research is naturally a source of hope for those with the condition, and my hon. Friend has made a powerful and compelling case for further investment. However, it is not as simple as the Government saying, "We will the end but we are not clear about the means when it comes to research," and it is not a case of allocating a research pot to a specific disease type. Down that road lies poor research, not discovery and real change.

We are protecting health research budgets overall. That decision was taken from the centre and made by the Chancellor in the spending review. However, decisions about how money is allocated remain-rightly-with the Medical Research Council and other funding bodies, not with a Minister behind a desk in Whitehall. That must be the case with other funding bodies.

The MRC has nominated CFS/ME as a strategic priority area for several years. Indeed, it has set up an expert group to focus specifically on the condition in a way that did not happen previously. The group comprises leading academics from across the country, as well as representatives from several organisations that have direct experience and interest in the condition. They are working together to improve the capacity and opportunities for research in the area.

My hon. Friend has acknowledged as good news the fact that the MRC is making up to £1.5 million available to support research into the causes of CFS/ME, which is welcome. Decisions on funding will continue to be made purely on the quality of research funding received. Critically, as in any area where we need more research, that sends a clear signal that the money is there and that there is a willingness to commit funds to research. The gauntlet has been thrown down to the research community to rise to the challenge and ensure that there are enough bids of sufficient quality to draw in that funding.

The funding call will focus on six priority areas identified by the expert group- autonomic dysfunction, cognitive symptoms, fatigue, immune problems, pain management and sleep disorders. I will ensure that the MRC and other research bodies look at this debate and see the additional points that have been made about biomedical research, so that that can be taken into account by the expert groups.

The call will also seek to build up research capacity, because one of the challenges has been attracting more researchers into the field. The expert group can only achieve so much on its own and, if I may be blunt, there has been a history of fractiousness and fragmentation between different groups with an interest in the area. Often, it is easy to agree on what we do not like, but harder to agree on the common ground and what the course of action should be to change things. I understand the heightened emotions that are often articulated by constituents who suffer from the condition, and I have spoken about that to people in my surgery. However, we will not achieve anything if organisations do not work together and engage with one another to find common ground and build alliances.

All patient groups need to look outwards and be positive about how they can work with the NHS, the Department, medical researchers and each other to influence change. One big challenge is to get more researchers interested in that area of work, but we are sometimes in danger of shooting ourselves in the foot by failing to show a united front.

Everyone with a stake in this area has an interest in ensuring that a constructive and supportive environment exists for research-that is key. Division and discord will not accelerate the pace of change, and I hope that the reconstituted all-party group on Myalgic Encephalomyelitis will play its part in facing that challenge and driving us forward.

My hon. Friend has mentioned the XMRV retrovirus, and I want to underline his point. It is an area in which research is not conclusive and where further research is being pursued to establish whether there is a link. At this time, however, there is no robust evidence to suggest such a link. Research can provide hope for the future, but we need to do more now to improve care for people with the condition.

The NHS does not always get it right for people with long-term conditions in general, let alone those with CFS/ME. The problems faced by people with CFS/ME are consistent with those caused by other conditions. Care is fragmented rather than integrated, and people struggle to be referred to a specialist in a timely and appropriate way. Most importantly, there is a sense that health professionals see the condition, rather than the person in front of them. Although this debate is about how we describe CFS/ME, it taps into some basic ideas. All too often, the label ends up mattering more than the person. Health professionals decide how people are treated and to which services they should be referred, but that should not be the most important determinate. We want the patient and doctor to work in partnership in the consulting room, meeting as two experts-one on the person, and one on the appropriate ways to support and treat them.

The greater use of personalisation and care planning can play a part, and that must be an explicit part of the Government's plans for the NHS. However, it goes deeper than that, because it is really about patients being given the power of self-determination. The idea of, "No decision about me, without me," should be a governing principle of the NHS. People should be asked to set their own personal goals and work together with professionals to achieve them. Everybody is different, and we must ensure that the care they receive reflects that.

My hon. Friend did not mention commissioning, but it is important to touch on that issue. To achieve these changes and get the right services and specialists, we must make sure that support is available. I know from my own constituency that excellent work is done in specialist CFS/ME clinics to integrate care for patients. Nevertheless, there is patchiness around the country that compromises the quality of treatment and reduces the options available. That is why we must improve commissioning, and GP consortia can help us involve patients much more in how local services are shaped.

I stress that the future of the NHS is local, not national. It is about local NHS and local GP consortia working with local patients' groups and making decisions based on a clear understanding of their needs and local needs. To commission effectively, GPs must understand the needs of patients with long-term conditions.

I hope that the Neurological Alliance can play an important role in that. Nationally and regionally, it has support networks that can make a huge difference by levering change in the commissioning of neurological services. I urge groups with an interest in CFS/ME to engage with the Neurological Alliance, use it, work through it and form connections with it, as a way of shaping and changing services in the future.

In conclusion, there are real opportunities ahead, and a real chance to address some of the frustrations and misery experienced by people with this condition. My message, and that of the Department of Health, is that there is an open invitation for representative groups to get involved in shaping the future of the NHS. We want the Neurological Alliance to be a key source of advice and support for GP consortia and health and well-being boards at local level. I am sure that the new NHS commissioning board will be keen to build links with the alliance in forming national policy.

The urgency exists, and the additional commitment to drive long-term conditions to the top of the agenda is one of the Government's ambitions. I thank my hon. Friend for raising these issues, and we will continue to work together to make sure that we improve the lot of his constituents and those of other hon. Members.

Mr Mike Hancock (in the Chair): Thank you, Mr Burstow. I ask those hon. Members who are not involved in the next debate to leave the Chamber quietly and speedily.