

## **House of Lords debate on the role of allied health professionals for long-term neurological conditions - 11 October 2010**

**The Countess of Mar:** My Lords, the noble Baroness, Lady Gardner of Parkes, has chosen an appropriate moment to table this Question and I am grateful to her. I declare an interest, as I have a diagnosis—finally—of organophosphate poisoning leading to autonomic dysfunction. I am a patron of several charities and groups that represent the interests of patients with myalgic encephalomyelitis, also known as ME or CFS, but which I will call by its common abbreviation, ME. I am also chairman of Forward-ME.

Arising from my own illness and the battle that I and others had to get the toxicity of the once ubiquitous organophosphates recognised—a battle that I am sure the Minister well recalls—I became interested in other medical conditions, such as fibromyalgia and Gulf War illnesses, for which there was no diagnosis or treatment, let alone recognition. Foremost among these is ME. ME has been categorised as a neurological condition at least since 1968. It is recognised as such by the World Health Organisation and the United Kingdom Government. However, for all these years, sufferers from this awful debilitating illness have been ignored, derided and mistreated. The soubriquet "yuppie flu", acquired in the 1970s, has stuck in the minds of the public and, unfortunately, in the minds of far too many members of the medical and allied health professions. Too often I hear statements such as: "Sometimes I felt that the therapist did not appreciate how physical and biological the symptoms are. She said she understood but then suggested that a lot could be cured just by thinking differently. I don't think she really appreciated how severe the symptoms are, or that when I said I couldn't do something I really meant that I couldn't do it. She also talked a lot about needing to get fitter, which I thought completely missed the point".

Many thousands of peer-reviewed scientific papers from researchers around the world demonstrate that ME is a physical disease which has endocrine, immune and cardiovascular effects, as well as neurological symptoms, albeit with some of the psychological aspects common to many chronic diseases. It is distinct from chronic fatigue which is a symptom of many diseases—depression or cancer, for example. Despite this, there is a school of thought, dominant through the last three decades, that this is a psychosocial behavioural problem, easily dealt with by cognitive behavioural therapy and graded exercise. On many occasions I have spoken about the failure of successive Administrations to recognise ME for what it is: a chronic illness with fluctuating symptoms of unknown or uncertain origin and of variable severity. There are theories that it has its source in a viral or bacterial infection that persists and eventually affects all the major bodily systems. Others think its source may be environmental—caused, for example, by those ubiquitous toxic chemicals such as OPs, which are, incidentally, designed to attack the nervous systems of their target species. The simple answer is that we do not know.

In the UK, funding for research into ME has concentrated on its psychological aspects. There is a school of psychiatry determined to claim the condition for its own, both in the UK and internationally. After many years of working in this sphere, I have observed the means by which any valid arguments for a biological cause are mocked and eventually overwhelmed by the noisier medical opposition. They ignore internationally recognised science on the grounds that it is not scientific. They find every reason to reject small-scale scientific research projects

conducted in the UK because they are not representative. Members of their own profession who have a considerable degree of success in treating patients with ME are hounded out of business. By writing numerous papers which, of necessity because there is no one else to do it, are peer reviewed by their colleagues, they appear to have proved that there is no need for further research and that the doctors responsible for diagnosing and treating ME do not need to conduct any more than the basic range of tests on their patients.

The previous Administration did try to help patients with ME. The Chief Medical Officer commissioned a report, published in 2002, on the subject. It recognised that ME is an illness that is as chronic and disabling as MS. It recognised the shortfall in research and in NHS provision, particularly for children. The Chief Medical Officer recommended the setting up of specialist centres to diagnose and treat people with ME-£8.5 million was allocated for the purpose. There developed small pockets of excellence where patients were pleased with the provision. These tended to be fine for patients who were able to get to the centres, usually hospital-based, but for the 25 per cent of patients who are housebound and, worse still, bed-bound, there was little help. Some health authorities were so slow that their projects failed to get off the ground before the funding had dried up; others, based on psychiatric units, were regarded with suspicion by patients. What I am saying is that, because of the way that people have behaved over this illness, patients with ME are not getting access to ancillary helpers in the NHS.

Two later reports, the latest published earlier this year by the All-Party Parliamentary Group on ME, of which I was a member, again highlighted the lack of NHS provision for patients with ME. Both reports stressed the failure of the NHS to provide for children and the severely affected. NICE, in its CFS/ME guidelines, also recognised the variable severity of the illness and the lack of treatments available. It recommends that treatment should be tailored to the patient with the patient's consent and that allied health professionals such as physiotherapists and psychologists must have knowledge of ME and be experienced.

Current NHS treatments depend upon a multidisciplinary approach. I know from experience that a hospital referral can be very unsatisfactory unless the consultant has an open mind and looks at more than just one "bit" of a patient. All too often when a patient fails to respond to the recommended treatment, he or she is blamed for the failure and a psychiatric referral ensues. There is no passing patients on to people who might be able to help them, such as cognitive behaviour therapists. There are an estimated 250,000 people with ME, most of whom are treated by professionals with very little, if any, understanding of their illness. Since specialist services are inadequate, many patients are left to fall upon their own resources. Some are fortunate, such as the patient who said, "By understanding how I could approach my daily activities in smaller chunks and hence planning for this, including fun activities, I ultimately became stable and could build from there", or another who said, "One-to-one supervision from a very skilled and experienced therapist kept me on track, pulled me up when I needed it and gave me encouragement. They listened to me, believed in me, reflected my progress to me at times when I couldn't see it".

I cannot say how important being listened to and being believed are. I am pleased to see that the coalition intends that patients should have more say in the NHS provision of services. I also see that it is to discuss professional training with the royal colleges. However, until there is a cultural

change among health professionals, patients with ME will continue to find it difficult to find help within the NHS. Until the professionals take time to listen to patients and to believe them, they will never develop the skills needed to enable them to help patients along the road to recovery.

I wish I had the solution to the suffering of people with ME. It seems that, no matter how often Ministers and senior officials confirm their acceptance of the seriousness of this condition, nothing will change until the culture both within and outside the NHS changes. I believe that in this particular case the patients, some of whom have experienced illness for decades while others have made excellent recoveries, have a huge amount of knowledge to impart. The Canadian guidelines to diagnosis and treatment of ME have, for reasons that have never been explained, repeatedly been rejected by health professionals and yet they are regarded by patients as providing the best course of action.

May I ask the noble Earl whether the coalition continues to accept that myalgic encephalomyelitis is a neurological illness as categorised by ICD10 G93.3? If he does, will he say how Her Majesty's Government will ensure that there is sufficient qualified medical and allied professional expertise to treat patients with illnesses such as ME with the effectiveness and dignity they deserve?

**The Parliamentary Under-Secretary of State, Department of Health (Earl Howe):** I thank my noble friend for calling this debate and for introducing it so authoritatively. As she indicated, this is a welcome opportunity to outline the valuable role that allied health professionals play in health and social care in delivering our ambition for world-class healthcare outcomes and, in particular, for people who have long-term neurological conditions.

First, let me set out some background about the allied health professions. They are a diverse group of 12 professions—in fact, three of the professions mentioned by my noble friend are, strictly speaking, not classified as allied health professions. These registered practitioners deliver high-quality care to patients across a wide range of care pathways and settings from public health through to recovery, rehabilitation, reablement and end-of-life care. Some of the most well known professionals are occupational therapists, physiotherapists, speech and language therapists and podiatrists.

Over 84,000 allied health professionals are working in the NHS in England and just under 2,000 occupational therapists are working in social services. From day one, these are skilled practitioners in their profession of choice. They assess, diagnose, treat and discharge throughout the care pathway from primary prevention through to specialist disease management and rehabilitation. They often work with the more vulnerable and marginalised in society. They treat some of the least recognised problems—for example, incontinence. I agree with my noble friend that their approach is very person-centred. Their particular skills and expertise can be the most significant factor in helping people to maintain their independence through physical and mental rehabilitation.

Long-term neurological conditions affect children, adults and older people. These conditions cover a wide range of care groups and include multiple sclerosis, motor neurone disease, Guillain-Barré syndrome, epilepsy, cerebral palsy and Parkinson's disease. We know that an estimated 8 million people in England are living with a neurological condition. They account for approximately 20 per cent of acute hospital admissions. Neurological conditions are the third most common reason for seeing a GP. An estimated 350,000 people across the UK need help with activities of daily living because of a neurological condition and 850,000 people care for someone with a neurological condition.

Allied health professionals work with partners in social care, education and voluntary organisations to support individuals with long-term neurological conditions to manage those conditions and to support their carers to manage them. They focus on achieving clinical outcomes that are about maximising the individual's functional abilities and participation in home, work and social life—for example, enabling a young mother with multiple sclerosis to manage the physical challenges of family life alongside the impact of the condition on mobility and other activities of daily living, or supporting a person with newly diagnosed epilepsy to return to work, often working with the employer in assessing the suitability of the work environment or facilitating a phased return to work.

People with long-term neurological conditions usually require the services of all the allied health professions at some point during the management of their condition. For example, a person with multiple sclerosis might see the physiotherapist for assessment, diagnosis and treatment of mobility problems and an occupational therapist for assessment, diagnosis and treatment of residual impairments impacting on activities of daily living and to be assessed for environmental adaptation in preparation for discharge. A speech and language therapist would assess, diagnose and treat swallowing and communication problems. The arts therapists would use psychotherapeutic interventions to gain insight into and to promote resolution of behavioural and emotional difficulties, such as depression.

When it comes to a health and social care model for long-term conditions, there are three levels. Allied health professionals work at all three levels and their impact is directed to keep patients in the lowest tier appropriate for their condition. Level 1 is self-management, with allied health professionals supporting individuals to take an active role in managing their condition. Level 2 is disease management and the focus for allied health professionals is preventing complications and promoting well-being. At level 3, an individual will have a case manager, who may be an allied health professional, to co-ordinate a multidisciplinary, multiagency care package to meet complex needs.

Perhaps rehabilitation and reablement is where the unique role of allied health professionals lies. It is important not just for people with long-term neurological conditions but for everyone with long-term conditions and, indeed, those with acute health problems to optimise health and well-being. Rehabilitation is aimed at enabling individuals with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Reablement is intensive intervention to optimise function, often focusing on independence in activities of daily living, including acute exacerbations of a long-term condition.

Allied health professionals deliver rehabilitation and reablement and they may train patients, carers, support staff and others to develop their skills in rehabilitation. Rehabilitation and reablement reduce length of stay and minimise hospital readmissions. Vocational rehabilitation supports individuals to return to work and become economically active.

On 5 October, my right honourable friend the Health Secretary announced that Â£70 million of extra funding will be allocated to primary care trusts to be spent this financial year across the health and social care system to enable the NHS to support people back into their homes after a spell in hospital through reablement. PCTs will work closely with trusts and local authorities in delivering this.

Allied health professionals also have a broader role in public health and health promotion. It is clear that this is important for those with long-term neurological conditions and other long-term conditions. Some allied health professionals work in public health to reduce the risk factors that may impact on health and well-being. Allied health professionals' services are actively engaging and brokering services with the third sector. An example of this is in County Durham, where the therapy services are working with the Multiple Sclerosis Society to offer a lifestyle programme, including diet and exercise advice, to improve general health and social engagement.

I now turn to some of the questions that were posed in this debate-I suspect that there were too many for me to answer now-not least the extremely important issues raised by the noble Baroness, Lady Finlay, about multidisciplinary teams, on which a lot of work is currently going on in my department. Suffice it to say at the moment that for all the reasons given by the noble Baroness it is imperative that the future commissioning arrangements ensure wide engagement with all clinical professionals, including allied health professionals. As she said, part of this will depend on the development of tariffs for long-term conditions. We are working to improve the tariffs for community services and mental health, in particular, and I undertake to keep the noble Baroness apprised of our progress.

The noble Baroness, Lady Thornton, spoke about the context of the White Paper and questioned whether the architecture outlined in it could satisfactorily address the need to ensure multidisciplinary and integrated working. Effective GP-led commissioning will require the full range of clinical and professional input alongside that of local people. Nurses, allied health professionals and others will all have a vital role to play, with a real opportunity to develop services and improve the health outcomes of their local populations. As the Government have made clear, healthcare will be run from the bottom up, with ownership and decision-making in the hands of professionals and patients. It is only by putting patients first and entrusting professionals to design and configure services that we will drive up standards, deliver better value for money and, ultimately, create a healthier nation.

My noble friend Lord Alderdice talked about key workers and the need to avoid multiple referrals. He is absolutely right. There are many examples of allied health professionals working as key workers, particularly occupational therapists. Multiple referrals can also be avoided through the greater use of self-referral to allied health professional services. This has been available on the NHS for many years but is an option that is perhaps not as well known as it should be. He asked how we can reduce turnover in nursing and physiotherapy and thus ensure

long-term continuity of care. We are concerned to ensure this. Through the new architecture of commissioning, I want to see allied health professionals and community nurses re-engaged with commissioning decisions to ensure that services really are commissioned right through the care pathway and across sectors such as health and social care. My noble friend also asked what news there is about the registration of psychotherapists and counsellors. Strictly speaking, so I am advised, they are not classified as allied health professionals. Be that as it may, the news on this has to reach my ears, so I need to write to him about it.

The noble Countess, Lady Mar, asked whether the coalition accepts that CFS/ME is a neurological condition. The Government accept that it is a neurological condition. In many cases, allied health professionals will have a role to play and it goes without saying that all of them should treat patients with respect and dignity, whatever their diagnosis.

The noble Baroness, Lady Finlay, pointed to a shortage of speech and language therapists. Admittedly the latest official figures that I have are rather historic, but I am advised that the vacancy rate as at September 2009 was 0.6 per cent, which does not sound very large to me. The noble Baroness, Lady Greengross, raised the issue of dementia training. This care is covered in the training of all the allied health professions at an appropriate level for the profession concerned.

I hope that, in the time available, I have illustrated the valuable contribution that these professionals make not only to people with long-term neurological conditions but also in meeting the health and social care needs of the wider population. I recognise that allied health professionals could and should be playing a greater role in service redesign to deliver the true outcomes that people want from healthcare, as well as improving productivity.