

専門医の方々の発言

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Professor in the Psychology Department at DePaul University, Chicago.

2006-2012 : a member of the USA Government Chronic Fatigue Syndrome Advisory Committee

2004-2009 : Vice-President of the International Association for CFS/ME

Dr. Nigel Speight :

Consultant Paediatrician in Durham for over 25 years

a medical advisor for The ME Association, The 25% Group, TYMES Trust, and the MEA of Wales

One of the authors of ['Myalgic Encephalomyelitis: International Consensus Criteria'](#)

Dr. Malcolm Hooper :

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lectures on ME/CFS to interested groups in UK and at National and International Conferences

“Voices from the Shadows”

Subtitles

1. Myalgic Encephalomyelitis (ME) is the descriptive name given to a serious physical illness. In many countries it is referred to as Chronic Fatigue Syndrome (CFS or CFS/ME). Confusion occurs because some psychiatrists use the same names CFS and CFS/ME to refer to completely different psychological and psychosocial conditions that share some symptoms.

Dr. Leonard Jason

26. This is as important as any other significant major illness, whether it's cancer, heart disease, AIDS.

Dr. Malcolm Hooper

28. It is a complex, chronic multi-system illness.

Subtitles

29. This inflammatory illness affects the brain and central nervous system. It occurs in epidemics, clusters and individual cases, usually following viral infections. It is comparable with MS, Motor Neurone Disease, Polio, Lupus and AIDS. Dysfunction occurs throughout the body as the immune, neuroendocrine, cardiovascular, musculoskeletal and autonomic systems are all affected.

Dr. Nigel Speight

33. Some doctors don't believe in it and if you don't believe in it and your patient has it, then, there's a problem.

Dr. Nigel Speight

45. This girl suffered abuse at the hands of professionals. She went into hospital moderate, and came out six months later severe, needing tube-feeding.

Subtitles

48. The world Health Organization has classified it as a neurological illness since 1969. This has been contested by some psychiatrists, who confuse it with mental and behavioural disorders.

Dr. Malcolm Hooper

50. It is NOT a psychiatric illness. It's not a illness which is associated with mental and behavioural disorders.

Dr. Nigel Speight

57. These are true horror stories where the families have really been abused by the professionals and by the court process, none of them have ever had any restitution, apology or damages.

Dr. Leonard Jason

61. We have a national catastrophe on our hands and we need to face that fact.

Subtitles

63. The illness has been trivialized – through deception, medical ignorance, and the stifling of biomedical research. Meanwhile thousands of patients remain severely ill. Disbelieved and blamed, many suffer medical neglect and abuse.

Dr. Nigel Speight

93. ME is really a clinical syndrome in other words it is a recognized pattern of symptoms. Many patients can have over 20 of these symptoms and they fall into a clear pattern where the cardinal symptoms is that the tiredness and all the other symptoms can be made worse by physical or mental exertion.

Dr. Nigel Speight

117. I think the basic problem from which all the other problems flow is the degree of disbelief on the part of the medical profession in the reality of ME as a physical illness. Everything else flows from that. Because the tests, the standard tests for this condition are usually negative, doctors are already prone to disbelieve in it and in general there's been a rejection of ME by organic medicine for the last 30 years. The vacuum has been filled by psychiatrists who like to make it part of their territory and this tension between the two parts of medicine continues today. And I could say that things are probably getting worse.

Dr. Nigel Speight

166. The condition itself covers a wide spectrum of severity but even the mildest cases deserve diagnosis and recognition because if they are given the wrong advice, or don't handle themselves correctly, they can become worse. At the more severe end of the spectrum there's a minority of patients who are truly in a pitiable state... some of them in hospital, some of them at home and this end of the spectrum is really one of the most powerful proofs to me of what a real condition this is and how it cannot be explained away by psychiatric reasons.

Dr. Nigel Speight

218. I think there's a real problem with current medical education both undergraduate and postgraduate. The textbooks don't have this condition right. One of the leading paediatric text books relegates ME to the section on child psychiatry and calls it one of the commonest somatisation disorders of childhood and that has influenced generations of newly qualified doctors, and in general it's not taught on in medical schools and is left as a sort of stigmatised disease which doesn't really exist! And this is what exposes patients to the disbelief that is still so widespread and possibly getting worse.

Dr. Leonard Jason

229. Getting it right in terms of the treatment that you involve patients in is critical. And if you get it wrong, if you basically put a person with ME on the wrong treatment regiment, you can do damage to that person. So we need to be so careful that we diagnose the person appropriately and give them the

appropriate medical treatment, as opposed to giving them something that actually might make their symptoms worse.

Dr. Malcolm Hooper

246. It is an inflammatory disease of the brain and the spinal cord associated with muscle pain, so there's a lot of muscle pain. In the early days it was described as a-typical polio. We now know that certain people with ME can suffer paralysis, so it is polio like, it does have paralysis associated with it. It does have inflammation of the brain and the spinal cord associated with it which you get with polio. The other neurological illness it has some affinity with is MS. And so both of these are major diseases.

Dr. Leonard Jason

270. The situation is grave. There are individuals who have the most significant medical problems and they are being treated poorly. We have a healthcare system that is not attending to the needs that they have. Many individuals have given up. Many individuals have basically felt that their healthcare system, their governments, have abandoned them. These are individuals who are stigmatised, alienated, they've had the trauma of an illness and then the trauma of the healthcare system and often family members as well as co-workers, who don't get it. The reason they don't get it is because there's so much stigma against this illness. We have to change this.

Dr. Nigel Speight

315. There is a kind of doctor who does believe in ME, but then goes on to believe too strongly in the efficacy of current treatments, particularly graded exercise. So they can have a moderate case of ME under them, subject them to graded exercise which makes the patient worse and then they either disbelieve in the basic diagnosis and send them to psychiatrists or they increase the forcefulness of the graded exercise or they abandon them or they subject them to care proceedings, or in some way blame them for not responding to their treatment. A bit like First World War Generals, who blamed the men for cowardice when the generals' plans failed.

Dr. Leonard Jason

380. There is a consensus in the scientific field, that individuals have incredible functional limitations. Many studies point that out, but in addition we see studies from the immune system, where there seems to be irregularities a Th1 /Th2 shift. We see irregularities also in the neuroendocrine system, where cortisol levels seem to be abnormal and that's again an indication that there's something biologically wrong. We see indications in cardiac functioning that there's something wrong, particularly low blood volume. We also see indications within the brain, with functional MRIs, PET scans and a number of different instruments. We see irregularities in study after study after study. We know there's something happening and that's the challenge – to put all these different pieces together.

Dr. Nigel Speight

427. It's important to recognise there's a minority of extremely severe cases, of which I've seen a large number and the vision one has of these is of people lying in darkened rooms in continual pain all over their bodies, lying on ripple beds, needing to be tube fed, needing pain killers, all sorts of extra nursing care and this can continue for years. The paradox is they're the ones actually being treated the worst who are most at risk of being abandoned by specialists, left to simple GP care and ignored by the system and by the media. They're even at risk of having their benefits cut. This small minority of patients are being neglected by official medicine.

Dr. Leonard Jason

456. This is an illness that has limitations that are as severe as any of the most serious illnesses and yet individual who have this illness, basically are not believed. They have a very significant illness and yet

have a medical establishment that doesn't really understand the significance of it. So the fact that you've got these two clashing points of view makes it an extremely important thing for scientists such as myself to get involved and figure out, Why? What's the reason for that? My interest is to try to find out why there's so much stigma, why there's so much disbelief, why you have people who are being considered as malingerers when they actually have a very significant debilitating illness, that's not a psychological illness. This is a medical illness.

Dr. Malcolm Hooper

502. In 1969 the World Health Organisation included Myalgic Encephalomyelitis under the heading of Neurology. It recognised the illness. It recognised the work that had been done on the illness and there it is sitting in the neurology chapter of G93.3 as a neurological illness. So there we have a clear understanding of what this means and it means inflammation of the brain and the spinal cord with muscle pain. That's what it means. What comes after that is this persistent attempt starting in the 70s and 80s to reclassify this illness as a psychological or psychiatric illness and that required different terminology. And the terminology that was introduced against the wishes of the people in the States, and it was done in the States in the first place. It was a 1988 conference where the term Chronic Fatigue Syndrome was adopted. The consequence of this is that by just either dropping the chronic or dropping the syndrome, you can move the whole understanding of the disease and the whole basis of the classification of the disease from neurology to mental and behavioural disorders. And Chronic Fatigue Syndrome is now the reason why we are struggling with a big debate in science and medicine and where patients have been absolutely sidelined. Chronic Fatigue Syndrome is a very trivialising name.

Dr. Leonard Jason

532. Chronic Fatigue Syndrome is really like calling someone who has Emphysema or Bronchitis, chronic cough syndrome. It just is not the symptom that really signifies the significance of those illnesses. ME is an illness that's extremely devastating and really has incredible functional limitations for patients. The fact that fatigue is so common in the population undermines its significance

Subtitles

540. Children and their families are particularly vulnerable in the current climate of medical ignorance and disbelief.

Dr. Nigel Speight

541. In childhood ME, I've seen a lot of cases where initial belief turns to disbelief, especially when tests come back normal. And then there's a variety of reactions. Sometimes the paediatrician simply rejects the patient and sends them back to their GP, sometimes they give them a one way ticket to psychiatry and in general these patients are more fortunate than the minority of cases who are extremely unfortunate where the professionals turn against the family and come up with really nasty explanations for this illness, such as Munchausen's Syndrome by Proxy, that the mother is making the child ill to fulfil her own needs. Once they set the child protection machinery into motion, it is extremely upsetting for the family, and I've been involved in over 25 cases of actual care proceedings where children have been threatened with removal from their families, sometime have actually been removed and placed in foster care and then of course failed to get better. And this is really child abuse by professionals. I've been involved in the care of a young lady who was actually diagnosed officially with ME and went into one of these specialised ME treatment centres in hospital and was subjected to quite aggressive graded exercise treatment and was made much, much worse over six months. This was under a threat of a court order that the parents had to co-operate and she was made much worse and is now at home very slowly recovering.

Dr. Malcolm Hooper

676. One of the problems around the whole issue of ME is the way in which the illness has been defined.

Dr. Leonard Jason

679. All science is based on having the same types of individuals so that we can make statement about their biology and statements about the different ways they react to treatments. So it's critically important to figure out who has this illness. The Oxford Criteria and the Fukuda Criteria are frequently used in Great Britain and other countries. The key problem is these are very large types of categories and they could bring in to the category of ME people who don't have this illness. ME is often very similar to some of the symptoms of major depressive disorder – one of the most popular, prevalent psychiatric illnesses in this country and in my country the United States. So it's critical to differentiate major depressive disorder from ME/CFS, and if you don't do that, you're going to start mixing some of those people with major depressive disorder into this category that we think of as ME.

Dr. Malcolm Hooper

697. For me the important description of ME is that it is a complex, chronic, multisystem illness and that's reflected in the very best criteria for diagnosing and understanding the illness, the Canadian Criteria. They are more specific.

Dr. Leonard Jason

703. It's not a question of having some symptoms and not having other symptoms. You have to have things like post-exertional malaise. You have to have some of these neurological symptoms. You have to have the sleep difficulties. So in that sense it's going to identify people who have the classic symptoms.

Dr. Malcolm Hooper

710. The Canadian Criteria are a clinical consensus drawn up by clinicians from North America, from Canada and United States and from Europe. So this represents a profound understanding of the illness, from clinicians who are engaging with it on a daily basis. There's thousands and thousands and thousands of hours of patient care and patient monitoring and patient testing that's reflected in these criteria and the fact they're not being adopted is of great concern to me and to people with ME. The Canadian Criteria are for clinicians, by clinicians and clinicians should need to use them to examine their patients.

Dr. Leonard Jason

722. We want to make sure we study people with ME and not major depressive disorder. And why that's so important is - if you give an aerobic exercise or graded exercise or have an activity as one of primary things that you're pushing people to do more and more people with major depressive disorder actually feel better, people with ME feel worse. This is an incredibly important differentiation to treatment and yet it's possible to put these two illnesses together because they share some symptoms and that would be a major dis-service because these two illnesses are different.

Subtitles

959. Sophia's spinal investigation concluded: "Definite pathological changes are identified, in particular there is a dorsal root ganglionitis in three out of four dorsal root ganglia sampled." This could be expected to cause severe pain and hypersensitivity. Similar evidence of neurological inflammation has been found at post-mortem of other ME sufferers.

Dr. Malcolm Hooper

975. The deaths that are coming from ME are really frightening, because the suggestion that no one dies from ME is just simply untrue. The present attempts to treat ME as a mental and behavioural disorder have completely failed. And it's been a failure that's been supported by the refusal of the MRC to fund

any research at all into biological causes of the illness. One of the worst statement I've ever seen is that government funds to support policy, and this is policy! It's wrong policy! It's bad policy! It's destructive policy! It's deceptive policy! But we fund to support it because we are the Government. And Government actually has committed itself ideologically, in an almost Orwellian sense, to ensuring that this illness is really to be regarded as mental and behavioural. And that is where the fault lies.

Dr. Nigel Speight

991. My personal impression is that currently things are actually getting worse rather than getting better. And I think people are interpreting the NICE Guidelines to feel compelled to involve psychiatrists and a multi-disciplinary approach and to have too much faith in graded exercise and cognitive behavioural therapy. There is an additional problem, in that with the orthodoxy of the NICE Guidelines coming in a lot of doctors who are at the forefront of supporting and treating patients with ME, both adults and children, seem to be at professional risk of having complains made about them to the GMC. Their patients are being deprived of their services and other doctors are operating in a climate of fear. There seems to be a sort of new Stalinism coming into British medicine.

Dr. Malcolm Hooper

1007. The whole deception that's been practiced to maintain this stance is, I think, unacceptable now. We must really get to grips with the illness and listen to the people who've published thousands of papers showing it is a physical illness, with a physical basis that can be addressed

Dr. Nigel Speight

1013. I think what's needed now is for the medical profession to take this illness on board, to accept responsibility for it as a physical illness, to do more research looking for biological causes for it, to downgrade the emphasis on psychiatry and to improve medical education along these lines. If this condition hadn't been hijacked by psychiatry for 30 to 40 years, we would have found the cause for it by now. Things would be in a far better state.

Subtitles

1023. During the making of this film, some of the people shown have deteriorated inexorably. For many ME sufferers, time is running out....