

A dangerous model abandoned as NICE seeks to reform care for ME/CFS patients in 2021

Transcript of Prologue to Dialogues for a neglected illness - a website and videos addressing the challenges of ME/CFS from the perspectives of doctors, researchers, patients and carers.

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www.dialogues-mecfs.co.uk

Conflicting views about ME/CFS have riven the medical community for seventy years. While the World Health Organisation recognises ME/CFS as a physical disease, some influential psychiatrists and their colleagues developed and promoted graded exercise therapy (GET) and cognitive behaviour therapy (CBT) as curative treatments.

The cognitive-behavioural model of ME/CFS, as maintained by faulty illness beliefs and behaviours leading to reversible deconditioning, is rooted in bad science but it has pervaded the UK healthcare system for the last twenty years. This has had a massively damaging impact on patient care and biomedical research funding.

The revised 2021 NICE (National Institute for Health and Care Excellence) guideline encourages safer management of the disease and attempts to enable more reliable and earlier diagnosis of ME/CFS.

Prof Brian Hughes: One of the things that most concerns me is the self-perpetuating nature of bad science and the way that the most vulnerable members of our society, who should be the people we serve as scientists, are left by the wayside in order to preserve the reputations or status of the elite scientists and the people who are on the one hand promoting high standards but on the other hand operating in very self-serving ways.

Carol Monaghan MP: There's currently no cure and many with the condition experience inadequate care and support, but there are an estimated quarter of a million people in the UK suffering from ME and currently we are letting these people down.

Karen Lee MP: Many primary care professionals receive minimal training on ME... and are therefore occasionally prone to holding stigmatised misinformed opinions about the illness.

Dr Nina Muirhead: Most doctors don't know what ME/CFS is and 40% of doctors don't actually believe it's a real condition.

Prof Jonathan Edwards: A lot of doctors make that mistake of not recognising that there is specific illness, a specific physiological abnormality if you like.

Dr Charles Shepherd: Many doctors believe that it's just tired-all-the-time, people being fatigued all the time and that is just not the case. This is a multisystem disease with a lot of different symptoms and fatigue as many doctors understand it, is not really what we're talking about. It's a misnomer.

Dr Luis Nacul: ME is classified as a neurological disease by the WHO (World Health Organisation) but I would say there are abnormalities not only in the central nervous system and autonomic nervous systems, but also the immune system, and the metabolism of people affected.. particularly energy metabolism

Dr Charles Shepherd: These patients have an inability to create energy for physical and mental activities that they want to do.

Dr Luis Nacul: On average people with ME/CFS have lower quality of life compared to people with multiple sclerosis, rheumatoid arthritis, cancer or depression.

Dr Nina Muirhead: The pain was immense. There would be days when I could barely move, turning in bed was painful. Even having someone walking around in the room, the rustling would be too much noise for me and too much sensory input. I couldn't concentrate. I couldn't hold my phone to have a conversation by phone, I couldn't even work out how to answer my phone when it rang.

Dr Charles Shepherd: We want people with this disease to get an early and accurate diagnosis. Sadly this isn't happening at present.

Dr Luis Nacul: Unfortunately there is no biomarker for the disease. There's no diagnostic test that will confirm the diagnosis and the routine test that are usually carried out will come back within the normal levels.

Dr Charles Shepherd: Around about 40% of people with an initial diagnosis of ME/CFS, do turn out to have a completely different condition.

Many symptoms of ME/CFS occur in other conditions, leading to high levels of misdiagnosis. But crucially, in ME/CFS there is an abnormal response to even minor physical and cognitive exertion. This causes a distinctive, delayed, post-exertional exacerbation or worsening of symptoms - post-exertional malaise or PEM - with an abnormally slow recovery time.

Post-exertional malaise (PEM) is totally different from the usual aches and pains and fatigue after exertion, often experienced by healthy people and those with other conditions.

It is now recognised as **essential** for making a diagnosis of ME/CFS, in conjunction with other key symptoms.

Dr Chris Snell: Post-exertional malaise is a primary symptom of ME/CFS. It consists of a decreased function and an exacerbation of symptoms usually following a physical event, but it can also follow a cognitive or mental event, and even an emotional event.

Dr Nina Muirhead: It can literally be just concentrating for an hour on something, can be enough to trigger it. Likewise if I just walked a couple of hundred yards. To begin with that can often start with headaches, or a sore throat coming on, feeling like I'm getting flu like or coming down with something, and then a couple of days later it really hits me and I literally can't get out of bed and I feel as though I'm concussed. I can't concentrate, and my level of functioning has to be taken down a couple of notches.

Chris Snell: Post-exertional malaise involves a number of facets and one of those is a reduced capacity to function or to do work or to generate energy. And I'm sure there are no physicians out there that would willingly hurt their patients, but recommended graded exercise can be very, very dangerous.

NICE assessed the research evidence for GET and CBT as treatments for ME/CFS and found it to be of 'very low' or 'low' quality! In line with the Centres for Disease Control in the US, the revised NICE guideline 2021 emphasises the dangers of GET and CBT, the treatments it previously recommended for patients, stating:

“Do not offer people with ME/CFS:

- any therapy based on physical activity or exercise as a cure for ME/CFS....
- physical activity or exercise programmes that are based on deconditioning and exercise avoidance theories as perpetuating ME/CFS.”

“The importance of ensuring that people remain within their energy limits when undertaking activity of any kind is also highlighted.”
(NICE website)

The rationale for using GET and CBT as treatments is provided by the cognitive-behavioural model of ME/CFS. This model is harmful, because it ignores the biological abnormalities of the disease and the cardinal symptom – an exacerbation or worsening of symptoms after any kind of exertion. Patients who keep trying to push themselves, or whose life conditions and environment are too demanding, can deteriorate badly.

Carol Monaghan MP: The recommendation of graded exercise has caused untold physical damage to thousands of people. In fact a 2018 survey found that 89% of ME sufferers experienced worsened symptom after increasing activity. Now if graded exercise were a drug it would have lost its license.

Prof Mark VanNess: It's huge paradigm shift for anyone to understand. In many illnesses exercise therapy, aerobic conditioning is very beneficial. In ME/CFS it isn't and in fact, exacerbates the illness.

Dr Ben Marsh: When I first experienced this fatigue and I tried to push through it... and it just gets worse and worse and worse... and then would last much longer and I would have to rest for so much longer. And I've never experienced anything like it.'

Tom Kindlon: Patients organisations knew that some people were getting worse, but it wasn't really being reported. So I sort of collated the data and 1000s of people have been made worse - 51% on average had been made worse by GET. And people shouldn't be coerced, because it's unfortunate, people can be coerced in all sorts of situations to exercise, and that shouldn't be allowed.

Once ME/CFS was framed as a psychosocial condition, patients were dismissed as unreliable witnesses who paid too much attention to their symptoms, spurned as malingerers and were even demonised by the media. This has thwarted biomedical research and funding for decades, creating a vicious cycle of ignorance, harm and neglect.

Early management of ME/CFS appears to be crucial, but many young people had no say, no choice in their treatment and were made severely ill - for decades. The cognitive-behavioural model of ME/CFS which has been dominant in the NHS, has harmed many thousands of patients and their families.

NICE Guideline for ME/CFS 2021

1.1.2 Recognise that people with ME/CFS may have experienced prejudice and disbelief and could feel stigmatised by people (including family, friends, health and social care professionals, and teachers) who do not understand their illness. Take into account:

- the impact this may have on a child, young person or adult with ME/CFS
- that people with ME/CFS may have lost trust in health and social care services and be hesitant about involving them.

“The impact of the errors of the past on patients and their families has been immense”

D. Pheby, K. Friedman, M. Murovska & P. Zalewski. Editorial: Medicina Sept. 2021

To learn more about ME/CFS from specialist doctors, exercise physiologists, biomedical researchers and patients, go to

www.dialogues-mecfs.co.uk

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