The Grace Charity for M.E.

20 Dickens Close
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May 12th 2026

Dear NHS Learning Hub,

Re: Courses relating to ME/CFS.

Although the courses are generally speaking an improvement compared to previous ME/CFS education, **our charity respectfully requests that the recommendation of psychology, in the first two courses, is removed as a treatment for ME/CFS.**

1) **Course No.1 'An Introduction to ME/CFS' and Course No.2 'ME/CFS guidance for community-based healthcare practitioners'.**
In the above courses, psychology is recommended as a treatment[1].
But in the third course, 'Managing severe ME/CFS' psychology is not a recommendation. This is contradictory. If an illness is seen, wrongly in this case, as psychological, then why is the psychological component removed altogether if the illness progresses? The promotion of psychology as a treatment shouldn't be there at all; instead, recommending a psychologist for ME/CFS promotes the very stigma that the Government Delivery Plan,[2] along with the Learning Hub course, say needs to be broken.[3]

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[1] NHS Learning Hub 'An Introduction to ME/CFS', under *How is ME/CFS managed? /Referral);* 'ME/CFS guidance for community-based healthcare practitioners', under *Management and Support/Supportive Care and Information.*

[2] My full reality: the interim delivery plan on ME/CFS - GOV.UK re: Attitudes and Education of Professionals

[3] NHS Learning Hub **'**An Introduction to ME/CFS' under '*How does the stigma around ME/CFS affect people?' (*'What is ME/CFS?') states, 'This has led to an unprecedented amount of stigma around the disease.'
Additionally, under *'How is ME/CFS diagnosed?' Key Points*, it states, 'Normal test results does not indicate that symptoms are psychosomatic.'
A paper demonstrating the distress caused to sufferers when their illness is wrongly viewed as psychosomatic. Myalgic encephalomyelitis/chronic fatigue syndrome and the biopsychosocial

2) **The wrongful claim that little is known about the condition**.[4] In 2015, the U.S. National Institute of Health Pathways to Prevention, along with The Institute of Medicine, concluded through 9,000 peer reviewed papers that ME/CFS is a serious physical disease, not psychological [5]
In addition, Professor Anthony Komaroff, promoted as an authoritative voice on ME/CFS in the NHS Learning Hub[6] has had a peer-reviewed article stating,

*'Over the past 35 years**, thousands of studies** from laboratories in many countries have documented underlying biological abnormalities involving many organ systems in patients with ME/CFS, compared with healthy controls: in short, there is something wrong.'*[7]

In 2025 the world's largest study on ME/CFS, DecodeME, aimed to find genetic causes of why people become ill with Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS). Their results concluded:

'Three of the most likely genes produce proteins that respond to an infection. Another likely gene is related to chronic pain. None are related to depression or anxiety. We found nothing to explain why more females than males get ME/CFS. Overall, DecodeME shows that ME/CFS is partly caused by genes related to the immune and nervous systems.' [8]

Our charity therefore requests:

i) that the acknowledgment of thousands of studies showing biological abnormalities in many organ systems of ME/CFS sufferers, is written into the course.

ii) that the results of DecodeME are acknowledged, thereby keeping up with current research which the NHS Learning Hub states is essential. [9]

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model: a review of patient harm and distress in the medical encounter: Disability and Rehabilitation: Vol 41 , No 25 - Get Access

[4] NHS learning Hub Course No.1 'An Introduction to ME/CFS ', *under What is ME/CFS? / What do we know about ME/CFS? ' …*there is much that remains unknown about it.'

[5] FIGURE 1-1, Initial results (as of January 2014) of the committee's broad literature search - Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome - NCBI Bookshelf

[6] NHS learning Hub *Is ME/CFS a new disease? Slide 3 Chronic Fatigue Syndrome*

[7] Advances in Understanding the Pathophysiology of Chronic Fatigue Syndrome, JAMA 2019 Anthony L Komaroff. Prof. Komaroff is promoted on 'What is ME/CFS? '

[8] Initial DecodeME DNA Results | DecodeME : The world's largest ME/CFS study | Institute of Genetics and Cancer

iii) **that the phrase 'unproven theories' is removed in relation to the list of physical causes of ME/CFS symptoms.** [10]

3) The lack of acknowledgement of the severity of pain in ME/CFS and its causes. We are concerned about the claim that pain has no apparent reason with unexplained muscle pain[11]. The word myalgia (in Myalgic Encephalomyelitis) *is muscle pain*. Research has demonstrated the following reasons for pain in ME/CFS:

   i) damage to the Central Nervous System causing dysfunctional processing areas of the brain. Ganglionitis has been found in the post-mortems of M.E. sufferers.[12]
   ii) a build-up of lactic acid which causes pain[13]
   iii) a lack of oxygen to the muscles; blood vessel constriction; blood pooling[14] [15]
   iv) neuropathy[16]
   v) Myalgia (muscle pain) is a constant and dominant feature of M.E.[17]

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[9] NHS Learning Hub Course 3, 'Managing Severe ME/CFS', *under Summary and Further Information.* 'Our understanding of ME/CFS is still developing, which is why it is essential that we stay informed about current and emerging research, so that empathic, informed and compassionate care can be provided, and outcomes improved.'

[10] This is under *'Key Points'* of What Causes ME/CFS?' in Course 1, An Introduction to ME/CFS.

[11] Under 'How is ME/CFS diagnosed?' *Other Symptoms, Pain*

[12] Dorsal root ganglion - MEpedia Severe M.E. sufferers Lynn Gilderdale, Sophia Mirza and Meryn Crofts had a diagnosis of ganglionitis in their autopsies.
Also, see *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. A Clinical case Definition and Guidelines for Medical Practitioners. An Overview of the Canadian Consensus Document* by Bruce M. Carruthers and Marjorie I. van de Sande, 2005, page 4, published by Carruthers and van de Sande ISBN: 0-9739335-0-X

[13] CFS - The Central Cause: Mitochondrial Failure - DoctorMyhill;
Elevated blood lactate in resting conditions correlate with post-exertional malaise severity in patients with Myalgic encephalomyelitis/Chronic fatigue syndrome - PMC; Abnormal blood lactate accumulation during repeated exercise testing in myalgic encephalomyelitis/chronic fatigue syndrome - PubMed

[14] *Journal of Chronic Fatigue Syndrome* 2003, Page 75, Haworth Press
Journal of Chronic Fatigue Syndrome: Volume 11, Issue 1, 2003 - MEpedia

[15] *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. A Clinical case Definition and Guidelines for Medical Practitioners. An Overview of the Canadian Consensus Document* by Bruce M. Carruthers and Marjorie I. van de Sande, 2005, page 6, published by Carruthers and van de Sande ISBN: 0-9739335-0-X

[16] ME Research UK Autumn 2024, pages 26 -28, Small Fibre Neuropathy (SFN) and ME/CFS
Dysautonomia and small fiber neuropathy in post-COVID condition and Chronic Fatigue Syndrome - PMC

4) **The lack of acknowledgement about M.E. pathology.** Dr. Byron Hyde, an M.E. expert, has demonstrated that the brain cortex is always damaged in M.E.[18]
Decreased brain perfusion (low blood flow to the brain) has been demonstrated repeatedly over the decades. [19]
M.E. researcher Margaret Williams states that there is 'proven pathology' of M.E.[20]
Dr. John Richardson has recorded his experience of M.E. patients in his book *Enteroviral and Toxin Meditated Myalgic Encephalomyelitis /Chronic Fatigue Sundrome and other Organ Pathologies,* specifically under Central Nervous System Effects of Viral Origin, Chapter 3. [21]

We look forward to the NHS learning Hub acknowledging and supporting further scientific discovery for ME/CFS.

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[17] Muscle in M.E. Dr. Vance Spence, page 5, MERGE Breakthrough Magazine 2005 meresearch.org.uk

[18] Byron Hyde untitled , The Nightingale Myalgic Encephalomyelitis (M.E.) Defintion, page 7, Invest in M.E., the Nightingale Foundation Definition 2007. **Brain cortex injury within the limbic system in M.E. sufferers.** Studies of brain hypoperfusion, especially the work of Dr. Jay Goldstein and Dr. Ismael Mena The Clinical and Scientific Basis of Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome Byron M. Hyde, M.D. | PDF | Chronic Fatigue Syndrome | Poliomyelitis 1992

[19] Costa DC et al. Brainstem perfusion is impaired in chronic fatigue syndrome. *Quarterly Journal of Medicine* 1995; 88: 767–73. Also, see Schwartz RB et al. Detection of intracranial abnormalities in patients with chronic fatigue syndrome: comparison of MR imaging and SPECT. *AJR* Am J Roentgenol 1994; 162: 935–41.

Limbic Perfusion Is Reduced in Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) - PMC Nov 1, 2021, Xia Li et al.

[20] Examples of 'proven pathology', page 1, *The Historic Evidence of ME*, by Margaret Williams, June 2025 https://www.margaretwilliams.me/2025/historic-evidence-of-me.pdf

[21] Enteroviral and toxin mediated myalgic encephalomyelitis/chronic fatigue syndrome and other organ pathologies : Richardson, John, 1915-2002 : Free Download, Borrow, and Streaming : Internet Archive Published 2001, the Haworth Press

Please contact us if you wish to do so. We would like to assist with addressing the points we have suggested.

Yours sincerely,
Catherine and John Ashenfelter (Trustees)

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