



United Kingdom

Email: [Redacted]

Dear Mona Svanteson

20/3/26

RE Norwegian Directorate of Health draft guidelines for “Longterm Fatigue,
including ME/CFS”
Case Number 24/13487

I am a senior paediatrician with a longstanding major interest in ME/CFS, and have lectured widely in Europe including in Norway, Sweden, Holland, Iceland and Australia. I have also attended court in contentious cases in Norway, Germany and France and of course the UK.

I have been told that your Directorate is open to opinions on your draft, including from other countries, for which I am grateful.

I am writing to express my concern at the fact that the draft guideline proposes to merge ME/CFS with other causes of long term fatigue.

ME/CFS is a unique condition which requires specific approaches. For too long, ME patients in both our countries have been subjected to disbelief, neglect, mismanagement in terms of Graded Exercise Therapy (GET) and CBT, undue emphasis on alternative psychological issues and at worst threats by social services to remove children from their families. At the very severe end of the spectrum we have had a tragic series of deaths due to medical neglect and mismanagement.

In view of this sorry state of affairs, I would regard it as vital that in both our countries there is a specific guideline for this condition to improve matters. Fortunately, in the UK we have the excellent 2021 NICE Guidelines (206) which I commend to you.

Such a future guideline should restate emphatically that ME/CFS is a **genuine medical illness**, albeit poorly understood. By doing so it will protect patients from the proponents of the “Biopsychosocial Hypothesis” who so often in the past have treated ME/CFS patients as if all their problems were psychological.

The problem with the proposed merger of ME/CFS with other causes of fatigue is that often the other causes of fatigue (eg depression) may respond to management approaches such as GET that are positively harmful for patients with ME/CFS. This is because ME/CFS patients suffer from PEM (Post-Exertional Malaise), which NICE recognise as the cardinal symptom of this condition. Patients need to be protected from over-exertion rather than subjected to exercise programmes.

Clarity of a diagnosis of ME is essential for young people. Any blurring of the issue, as for instance happens when doctors instead refer to a “fatigue state”, denies the young person the protection they deserve. Without it they can be subject to pressure to attend school, receive damaging exercise programmes, be inappropriately referred to psychiatrists and at worst be threatened with removal from their families due to the parents being accused of fabricating the illness

As I said above, ME/CFS is an absolutely unique condition requiring its own specific management approaches. As NICE states, there is no curative treatment available, GET is contraindicated and the correct supportive approach is Pacing, whereby the patients attempt to stay “within their own energy envelope”.

In the UK, we have found that since NICE prohibited GET, some of its proponents have continued to prescribe GET in a camouflaged form, often relabelled “Activity Management”. This could well happen in Norway if your current proposed merger of all the causes of fatigue were to occur. ME/CFS patients deserve the protection of a firm diagnosis combined with clear guidelines on management that are specific for this condition.

I wish you well in your continued work on this subject

Sincerely



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Paediatrician