

To CFS Advisory Committee:

Pathways to Prevention: Advancing the research on ME/CFS

Public Comment on the Panel's Draft Report

Dear Sir/Madam,

I am enclosing comments on the P2P Draft Report on ME/CFS.

Firstly, I would like to thank the authors for having, in many parts, described the ME/CFS field in a very accurate way, and for pointing out important needs in order to facilitate some much needed progress.

However, I would like to draw your attention to one very important issue. Based on the clinical experience from Stockholm, Sweden, and patient reports from the patient organization RME Stockholm, we strongly recommend that all recommendations for 'multimodal therapy' be taken out of the report.

In the Draft Report, 'multimodal therapy' is mentioned several times:

113-116 Existing treatment studies (cognitive behavioral therapy [CBT] and graded exercise therapy [GET]) demonstrate measurable improvement, but this has not translated to improvements in quality of life (QOL). Thus, they are not a primary treatment strategy and should be used as a component of multimodal therapy.

303-306 We believe ME/CFS is a distinct disease that requires a multidisciplinary care team (e.g., physicians, nurses, case managers, social workers, psychologists) to optimize care. Thus, properly training that workforce is critical

350 Future treatment studies should evaluate multimodal therapies.

370-371 We believe there is a specific role for multimodal therapy.

This has already been tried in Stockholm, and the conclusion is clear: Multimodal therapy by a multidisciplinary team does not help patients with ME. In fact, many patients report physical deterioration caused in part by the many visits to the clinic to meet all of these professionals, and in even greater part by the exercise therapy included in most of these programs. Many patients were left in much worse shape and with greater disability than when they first sought treatment.

There is now agreement across the board (Health Board members, caregivers, patients) that the multimodal unit is to be closed and, instead, all resources should be directed towards the main need of patients with ME: specialist care by physicians with a good understanding of the biomedical underpinnings of ME. Also, resources will be earmarked for biomedical research into ME.

The Stockholm experience:

In 2010, the Stockholm Health Board (responsible for the organization of health care in the Stockholm region) decided to see if the health care needs of ME patients could be met by a multimodal therapy

model. They initiated a project with a multi-team, involving a nurse, a physiotherapist, a psychologist, a case manager/social worker. Now, 5 years later, the project has been evaluated and it has been concluded that this model did not at all meet the needs of the ME patients. Many patients actually experienced deteriorated health.

The multimodal model clearly did not serve the ME patients well. In Stockholm, there is now agreement between the multi-team project management and other caregivers, patients and politicians that what is needed, instead, is biomedical specialist care. While psychologists, social workers, physiotherapists can be useful for ME patients (if they are knowledgeable about the biomedical disease mechanisms in ME, Post-Exertional Malaise, pacing/envelope theory, etc), the money is much better spent on a multi-disciplinary team of physicians, including a neurologist, an immunologist/infectious disease specialist, a rheumatologist, etc.

The politicians in Stockholm have announced that a new ME centre will be established, focusing on biomedical specialist care with only one nurse/administrator and all the other resources spent on ME knowledgeable physicians/specialists. (Expressen in this link, in Swedish: <http://stockholm.kristdemokraterna.se/det-har-lovar-vi-for-me-patienter/>)

Based on our experience, it is clear that it would be unwise to keep the recommendations about 'multimodal therapy' and 'multidisciplinary care teams' in the report. If the multimodal treatment model were to be tried in more places, it would mean an unnecessary toll on ME/CFS patients and an unnecessary use of financial resources. All available resources are needed for creating biomedical Centres of Excellence focusing on providing adequate specialist care and for biomedical research.

Kind regards,

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