



Promoting effective joint working by ME and CFS organisations to maximise impact on behalf of all people with ME and CFS in the UK

Forward-ME Position Statement: Spinal Surgery and ME **30 September 2020**

Forward-ME is aware that major surgery to address possible spinal pathologies in patients with ME has become a topic of interest for some in the patient community.

The lack of biomedical research means that little is known about ME and possible subsets of the condition. Forward-ME's position therefore is that we advocate for biomedical research in any and all areas that may be of benefit to patients, but we have strong concerns about the potential harm from risky treatment options that are not supported by robust scientific evidence and, further, we call for more research of high quality such as the DecodeME study.

Summary:

Spinal surgery to relieve ME symptoms:

- is not currently supported by the scientific literature.

Spinal surgeries of this nature:

- permanently reduce neck and head movement (in the case of fusions).
- are major surgeries that come with a significant risk.
- come with a major financial cost that could be the patient's responsibility.
- offer no guarantee of any improvement to ME symptoms.

What are the concerns?

There is no evidence to support spinal surgery to treat symptoms of ME, or even ME itself. The only evidence is anecdotal. It comes from a small number of patients, some of whom had this surgery to treat one or more of several different diagnoses and reported relief from ME symptoms, while others report only temporary or no improvement.

Forward-ME believes that scientific evidence must come before any treatments – especially of this nature – are considered viable options by people with ME. At this time, surgeries that lack a strong evidence base should only be conducted as a part of regulated research trials.

Spinal surgery of the type being discussed may be suitable for people with neurosurgical diagnoses due, for example, to Ehlers-Danlos Syndrome, but the surgery still comes with a risk of complications.

Fusion of neck vertebrae results in life-long restricted head movement and carries significant risk of complications. Forward-ME does not support this surgery as an option for people with ME at this time, except for specific diagnoses where there is a strong evidence base and established procedures.

An ME patient with a diagnosed co-morbid spinal pathology may reasonably choose to access an evidence-based treatment for that problem following a suitably qualified doctor's recommendation, but they should not expect this to improve ME symptoms.

Neck-fusion surgery is not available routinely for patients with a primary diagnosis of ME. Where they are available for an appropriate diagnosis, experimental procedures can be very expensive. For established procedures, NHS healthcare and medical insurance will typically provide cover, but where there is a lack of scientific and medical support, it is more likely that this cost, and all associated risk, will have to be covered by the patient.



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Forward-ME is keenly aware that patients in the ME community are eager for a solution to their situation, but given the current lack of scientific evidence, caution and patience is urged as the campaign for more high-quality biomedical research continues. It is only through rigorous research that safe and effective treatments for ME will emerge..

Yours sincerely,

Margaret Mar and Denise Spreag

On behalf of Forward ME



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