

## Senate Community Affairs Committee

### ANSWERS TO ESTIMATES QUESTIONS ON NOTICE

#### HEALTH PORTFOLIO

#### Budget Estimates 2017 - 2018, 29 May 2017

Ref No: SQ17-000646

**OUTCOME:** 1 - Health System Policy, Design and Innovation

**Topic:** ME / CFS

**Type of Question:** Hansard Page 141, 29 May 2017

**Senator:** Ludlam, Scott

**Question:**

Senator LUDLAM: You mentioned before the National Institutes of Health in the United States. We danced around this area last time, in that some research money in past years has been spent by the NHMRC in New South Wales on research and treatments that encourage people to exercise, and that that is incredibly damaging for people with this condition. The director of the National Institutes of Health, Dr Francis Collins, has said that any exertion just makes you worse, and that is why I am harping on about it, even though I am not doing a particularly articulate job of it. The sooner we can get solid, consistent information into the hands of GPs, the sooner people with this condition will not be prescribed harmful treatments. Does that need to wait for a targeted call for research, or could that happen much sooner on the basis of already-existing evidence?

Prof. Kelso: I do not think I can answer that question. I do not have the detailed scientific expertise, and that sounds like a clinical question that would be beyond our remit.

Senator LUDLAM: Whom can I put that to? That is probably an unfair question as well. Is there anybody else at the desk who could answer? I know it is late.

Prof. Murphy: We will take it on notice. It is a very disputed area. I think there are still some Australian experts on this disease who would dispute the assessment that you describe, but I have not looked at the evidence recently.

Senator LUDLAM: There are no patients who dispute it, though.

Prof. Murphy: I am sure there are patients who dispute it too. I am very happy to take on notice and review the basis of the evidence for that statement by Dr Collins and get back to you.

**Answer:**

The Canadian guidelines do state that graded exercise programs can be harmful and should be avoided. This statement is based on cited published evidence of altered physiological responses to exercise in Me/CFS sufferers. These guidelines do not, however, cite any published evidence of patient harm from such exercise.

The Australian Guidelines, in contrast, state that “Graded exercise programs have been shown to be beneficial for some people with Me/CFS, and can improve functional status”. This statement is consistent with published evidence of trials of graded exercise. The UK NICE guidelines contain a similar statement. Both of these guidelines stress the importance of tailoring exercise programs and proper and careful supervision.

In April 2017, a Cochrane systematic review of all the evidence on exercise in Me/CFS was published:

The review Authors concluded the following:

*Patients with CFS may generally benefit and feel less fatigued following exercise therapy, and no evidence suggests that exercise therapy may worsen outcomes..... Randomised trials with low risk of bias are needed to investigate the type, duration and intensity of the most beneficial exercise intervention.*

There have been criticisms of the conclusions of the Cochrane review, given the weight it gives to the previous UK PACE trial. The PACE trial has been subject to criticisms about possible overstatement of the benefits of graded exercise therapy.

The role of graded exercise in ME/CFS therefore remains contested. Despite individual patient stories and media articles, there is no high quality scientific data to support the contention that Graded Exercise is harmful. On the contrary, some data do suggest benefit for some patients (as stated in the Australian Guidelines).

Accordingly, there is not evidence, at this time, to support a change in the recommendation in the Australian Guidelines on this point. Given the age of the Guidelines and their outdated evidence base, they should be updated at some stage.

The Department of Health can find no statement by Dr Francis Collins (NIH Director) saying that exercise programs may be harmful (but would be pleased to receive evidence of such a statement). Dr Collins clearly has significant interest in this disease and is promoting and funding important research into determining the underlying aetiology of the disease.

From some of the correspondence received from ME/CFS patients/groups, it would seem that there is an underlying concern that the use of graded exercise as part of treatment implies a belief by treating clinicians in a (bio)-psychosocial model of the aetiology of MeCFS. The Department does not agree with this contention and believe that it has caused problems in the objective assessment of the science.

There are many medical conditions, with a well-defined biological cause for post exertional fatigue, for which carefully supervised exercise may be of benefit in functional maintenance and improving exercise capacity.