

**Opposition to Oxford Health NHS Foundation Trust: “Coping with Coronavirus: Fatigue”**

We, the undersigned, request immediate withdrawal of the Oxford Health NHS Foundation Trust leaflet “Coping with Coronavirus: Fatigue” for the following reasons;

- The leaflet conflates post viral fatigue with myalgic encephalomyelitis (“ME”)
- The leaflet purports to provide information for post-COVID-19 rehabilitation but is predominantly comprised of rehabilitation advice for ME / CFS
- The information provided is incorrect or misleading
- The advice provided is potentially detrimental to patients and may result in deterioration and exacerbation of disability

A detailed explanation of our concerns can be found below.

**Rest**

The leaflet states:

*Resting too much, for example spending most of the day in bed or doing very little, will lead to loss of fitness and muscle strength. When you then try to resume normal activities, you may find that you cannot do as much as you expect to do, and then rest more, causing further loss of fitness in a vicious cycle.*

*When very fatigued and unwell, it makes sense that people change the way they do things. Some may reduce the hours they work or stop altogether. Others may do fewer enjoyable activities, particularly socialising and physical exercise. Others avoid doing anything new and rest more during the day. Gradually, they can become less fit.*

*(Page 3)*

These comments are in contradiction to advice for post viral fatigue, which is to have adequate rest and pace activities within the energy available.

In relation to ME these comments suggest that ME is a condition caused by deconditioning. However, a vast amount of research has now identified that people with ME have abnormalities

in the central nervous system such as neurocognitive, sleep, autonomic and sensory disturbances. Cognitive impairments including slow processing of information, poor attention, word finding, and working memory are some of the most functionally disabling symptoms<sup>1-8</sup>. Research has also shown abnormalities in the immune system<sup>9-11</sup>, in the endocrine (hormonal) system<sup>12,13</sup> and in muscle (causing energy metabolism impairment)<sup>14,15</sup>.

Therefore, ME is *not* a condition that is caused by deconditioning, and rest is *not* harmful for people with ME who need to allow their bodies to address these neurological, immunological, hormonal and metabolic abnormalities. In fact, people with ME state that they wish they had been told to rest in these early stages of the condition<sup>16</sup>.

### **Graded Exercise Therapy**

One of the recommended treatments detailed in the leaflet is Graded Exercise Therapy (“GET”).

*“Graded exercise has been shown to be effective in reducing fatigue and getting back your fitness after CFS.”*

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The leaflet suggests starting at a low level and gradually building up, and states that exercise should be:

*“Performed every day - good days and bad - otherwise the benefits of the activity already gained by your body will be lost.”*

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Graded Exercise Therapy (GET) is again based on the theory that ME is as a result of deconditioning.

However, ME charities do not recommend GET as it has been found to exacerbate symptoms for people with ME and can cause long term harm. This was highlighted in a survey by ForwardME along with academic research group in Oxford, who found that 80% of people with ME reported having adverse events after GET<sup>34</sup> and led the report to conclude: “GET is shown to cause considerable deterioration in physical and mental health.”

Research has shown that exercise in people with ME leads to abnormal physiological responses including:

1. reduced maximum heart rate<sup>17-19</sup>
2. reduced maximum oxygen consumption<sup>19-21</sup>
3. reduced cardiac output<sup>17,18,22</sup>

4. insufficient blood pressure increase on exertion<sup>20,23</sup>
5. decreased capacity to use oxygen<sup>17</sup>
6. anaerobic threshold and maximum exercise are reached at much lower oxygen capacity<sup>19,24</sup>
7. exhaustion reached more rapidly and accompanied by relatively reduced intracellular concentrations of ATP<sup>25</sup>
8. increased intracellular acidosis in exercising muscles and reduced post-exercise recovery from acidosis<sup>26,27</sup>
9. activation and worsening of symptoms which can be immediate or delayed by several days<sup>28,29</sup>
10. when exercise is repeated the next day, abnormalities are more severe<sup>30</sup>
11. decreased cognitive functioning and prolonged reaction time<sup>31</sup>
12. prolonged recovery period: usually 24 hours, often 48 but can last days, weeks or cause a relapse<sup>17,30,32</sup>

Physical exertion elicits a reaction so distinctive that many researchers use exercise as a way to aggravate the illness so that it can be studied.<sup>35</sup>

### **Cognitive Behaviour Therapy (“CBT”)**

Another treatment recommendation stated in the leaflet is CBT.

*“To help with difficulties in pacing activities Cognitive Behaviour Therapy (CBT) is a form of therapy which has been shown to be helpful for CFS/ME. It helps you to identify thoughts and beliefs which maintain the problems, and gradually test out ways of changing these. CFS/ME may relate to longstanding problems such as depression, chronic worry, perfectionism or low self esteem.”*

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Any treatment that addresses the physiological symptoms of ME as psychological will perpetuate the detrimental processes caused by over exertion, as described above.

Following the Forward ME patient survey, the report concludes that “while [CBT] may be effective for a minority in helping with mental health challenges such as depression or anxiety, it is shown to be ineffective in a considerable proportion of people and even led to almost half of respondents reporting worse symptoms.”

## **What should be recommended**

Work is currently underway to produce appropriate guidance for post-COVID rehabilitation to allow for identification and management of post viral fatigue syndrome to avoid exacerbation of symptoms and progression towards developing ME. **We would be happy to share this with you once finalised so that it can be used as a replacement for this publication.**

The emphasis should be on management of post Covid-19 fatigue and preventing the development of ME/CFS. This comes from effective management of post viral fatigue, in the form of paced activity, adequate sleep and nutrition. Inappropriate management may result in development of ME and reduces the likelihood of people being able to return to work<sup>36</sup>.

The recommended treatments of CBT and GET do not improve employment and illness benefit status. As a matter of fact, a systematic review of available data found that after CBT and GET more patients were unable to work and more were receiving illness benefits<sup>36</sup>.

In brief, patients are advised to practice pacing techniques, which are a primary tool for managing energy and avoiding post exertional malaise. While some pacing guidance advocates a “quota-contingent” approach (undertaking activities according to an amount/distance/goal with the aim of improving function) for someone with ME, or recovering from a viral infection, this will ultimately push them beyond their limits and cause a symptom exacerbation and subsequent decline in abilities.

The recommended pacing technique is “symptom contingent” where activities are driven by perceived symptom levels, with the aim of avoiding symptoms and conserving energy. Patients who are given a period of enforced rest from the onset have the best prognosis. Moreover, those who work or go back to work should not be forced to do more than they can to try and prevent relapses, long-term sick leave and medical retirement<sup>36</sup>.

Pacing approaches that utilize wearable heart rate monitors also may be effective to manage energy levels before symptoms present. This approach helps patients avoid functional activities that exceed the heart rate at ventilatory anaerobic threshold, and therefore may help patients avoid accessing a dysfunctional aerobic energy system.

If a person is able to pace their activities to avoid symptom exacerbation, they may move on to low level, functional stretches and exercises that have been prescribed by a physiotherapist who is skilled in understanding ME management. Further information is being collated and produced in conjunction with the Chartered Society of Physiotherapists along with other specialists involved with this letter, and will be available as soon as possible.

## **Conclusion**

The information and advice provided in the Oxford Health NHS Foundation Trust leaflet “Coping with Coronavirus: Fatigue” is inaccurate, misleading and contains potentially harmful recommendations.

We urge immediate withdrawal of this publication.

Suitable guidance will be produced and made available for distribution.

## Signed

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