



Exercise Template

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Name

Address

email

Dear Dr Spock,

Explanation of personal circumstance


1. Serious Risk of Patient Harm – Exercise is Contraindicated for a large subset of Long Covid Patients

The first and most important point is that exercise, exertion, or any activity is potentially dangerous for a significant percentage of those with Long Covid. Dangerous means that there is a risk for a worsening of symptoms both in the short and long term. We need to listen to both patient testimony & scientific research.

There are relevant and recent studies published that indicate the need for caution with physical exercise. Leeds University investigated 477 people with Long Covid and found that physical activity worsened symptoms by 74.84% (Wright et al., 2022). The Patient Led Research Collaborative for Long Covid published in The Lancet (Davis et al., 2021) that 89% had Post Exertional Malaise and 72% had PEM at 7 months. PEM is prevalent in Long Covid patients who haven't been hospitalised and have not experienced deconditioning after a long hospital stay which the CISCO21 study includes as a subset:

The message of Stop, Rest, Pace is vital public health messaging after a viral infection.

Yet this isn't just an unknown mechanism we are already gaining insights into why exercise is physically harmful and contraindicated for Long Covid. Putrino (Wood et al., 2021) found an overproduction in Reactive Oxygen Species (ROS), the exhaust fumes of the mitochondria. Invasive Cardiopulmonary Exercise Testing (Singh et al., 2022) found reduced peak VO₂ which is associated with impaired systemic oxygen extraction and persistent exertional intolerance. Published in Blood Advances (Prasannan et al., 2022) found elevated VWF (Ag);ADAMTS13 ration(>1.5) in a third of the cohort with elevation being x4 more likely in those with impaired exercise capacity.

Patient testimony is also a vital consideration that can give adequate warning signs that exercise is not beneficial to the improvement of symptoms. Many with Long Covid are showing PESE, Post Exertional Symptom Exacerbation – exertion here doesn't even have to mean exercise but anything that takes energy be it standing up, reading, light, washing, travelling – everyday basic tasks. A collection of personal testimonies demonstrating relapse and a worsening of symptoms was taken via Twitter and can be viewed in full (Long Covid Advocacy  [\[@LongCovidAdvoc\]](#), 2022) Some key testimony include:



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“Having had professional training for endurance cycling I echo the statements about LC breaking the link between stressing the body, recovery, and the training effect. It doesn't work anymore. Any form of pushing causes a poly symptom relapse” Prof Brendan Delaney

“Did some pull-ups 2 weeks after infection. Woke up the next day with a huge amount of inflammation all over my body. Extreme fatigue. I was advised to slowly increase my steps each day by my GP. Each time I went for a walk I got worse. 16 months later I can't walk anywhere.” Jordan Taylor

“Month 5 post initial Covid infection I returned to teaching 5 fitness classes a week plus walking every day. After 4 weeks had to reduce activity & by month 8 had to stop completely due to PEM, fatigue, body pain, tachycardia & cyanosis. 25 months on... wheelchair bound.” Rebecca Logan

It is straightforward to conclude through the recent scientific literature & Long Covid patient testimony that there are damaged physical mechanisms that mean that a significant subset are Exercise Intolerant and activity is harmful. Therefore, if patients with Long Covid are given exercise as a therapy as part of the CISCO21 study there is significant risk that patients will be harmed and will deteriorate.

2. What is PEM/PENE/PESE?

We can see from the above section that up to 89% of Long Covid patients have PEM and it is one of the most prominent symptoms reported anecdotally in the Long Covid community.

Within the scientific literature that studies PEM in MECFS we can see measurable negative effects on the body that lead to a deterioration of health. These include patient abnormalities in endogenous pain inhibition (Meeus et al., 2010); cognitive functioning (Blackwood et al., 1998); altered immune response; altered gene expression (Light et al., 2012); & affected microbiome (Shukla et al., 2015). An excellent and comprehensive examination of PEM can be found on the [MePedia](#) site which is important reading.

It is also important to listen to patient testimony on the effects of PEM. It is unlike what most people have ever experienced and goes far beyond the normal experience of tiredness, fatigue, or malaise. It is more like a multisystem body shut down on intense suffering that can lead to a permanent worsening of symptoms and disability. This is what you are risking by going ahead with this study.

Testimony from Exercise and Rehab programs in Germany (Treat Long Covid [[@TreatLongCovid](#)], 2022)

“Max, 27 years old Symptoms: Fatigue, PEM, sleep disorders, brain fog ... Therapy: Swimming and long walks Result: Bedridden and no longer able to use his smartphone.

Bettina, 35 years old Symptoms: Fatigue, PEM, muscle twitching, headache. Therapy: Walking with weights on her feet Result: Housebound and unable to care for her kids

Rob, 24 years old Symptoms: Muscle pain, fatigue, PEM, sleep disturbances Therapy: Running on a treadmill Result: Bed bound and unable to communicate via smartphone.”

Many won't even know what PEM is. Stating that the patient can stop at any time and even adopting a collaborative approach where the patient is in 'control' is strewn with difficulties and risk; the patient might be unaware of PEM, PEM is notoriously difficult to predict and can be variable, there is no effective and easy way to monitor the risk zone of when the patient enters PEM, by its very nature the effect is delayed so there are not always immediate physical signals as the deterioration comes 24, 48 or even weeks later.



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3. Importance of familiarity of the relevant scientific literature in Long Covid and ME/CFS

So we have established that a significant subset of Long Covid patients experience PEM (89%) & that exercise can be harmful (74%). It is therefore vital that the Clinicians, Physiotherapists and Consultants treating those with Long Covid are familiar with the recent and historical scientific literature of the use of exercise as a treatment in Long Covid and in the other disease that has PEM – MECFS.

It is becoming apparent in the Long Covid Scientific literature that there is a significant crossover of Long Covid with MECFS. Multiple sources are confirming that c. 50% of those with Long Covid are meeting the criteria for MECFS: 46 % in the Mancini paper (Mancini et al., 2021); 50% in a German study (Kedor et al., 2021); 50% in a study in the Journal of Translational Medicine (Haffke et al., 2022) and 58.7% met the PEM scoring thresholds used in people living with MECFS in a study released in April 2022 (Twomey et al., 2022). Therefore, it is imperative to understand that a significant subset of the Long Covid study will meet an MECFS diagnosis. We know the historical harm that giving exercise to ME has and this must be considered.

Firstly in Long Covid a key paper that addresses these concerns of Exercise therapy is: 'Humility and Acceptance: Working Within Our Limits With Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome'. (Décary et al., 2021)

"We observed a growing number of patients with long COVID who experienced adverse effects from exercise therapy and symptoms strikingly similar to those of myalgic encephalomyelitis (ME). Community-based physical therapists, including those in private practice, unaware of safety issues, are preparing to help an influx of patients with long COVID. In this editorial, we expose growing concerns about long COVID and ME...Clinicians may be promoting a dangerous message that could lead people with long COVID down a path of endless cycles of overexertion and relapse"

Another key read is: "The evidence base for physiotherapy in myalgic encephalomyelitis/chronic fatigue syndrome when considering post-exertional malaise: a systematic review and narrative synthesis' (Wormgoor & Rodenburg, 2021) This collates and critiques the field for physiotherapy interventions when PEM is involved and the issues of what criteria (Oxford, Fukuda, IOM/NAM, ICC, Canadian) is used to define MECFS. Any positive intervention effects were diminished significantly when the criteria became more specific and included PEM.

"Conclusion Currently, there is no scientific evidence when it comes to effective physiotherapy for ME patients. Applying treatment that seems effective for CF or CFS patients may have adverse consequences for ME patients and should be avoided."

Recently before the current MECFS Guideline change NICE formed a committee to conduct a rigorous and thorough review (*Evidence-Review-7.Pdf*, n.d.) (*No More Mr NICE Guy... - The Science Bit*, n.d.) of the research in favour of the findings for exercise therapy and CBT for MECFS. There were 64 Exercise studies for MECFS and they were all ranked of a 'low' (19%) or 'very low' (81%) research status. This shows that in the recent and historical research literature there is not sufficient evidence to claim that exercise is effective in helping a disorder that has PEM – MECFS. In light of this exercise as a treatment has been dropped from the new MECFS NICE Guidelines. (*Overview | Myalgic Encephalomyelitis (or Encephalopathy)/Chronic Fatigue Syndrome*, n.d.)



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In summary when an adequate review of the literature ([summary](#) provided) regarding PEM, Long Covid, MECFS and exercise therapy it is very clear that exercise leads to measurable physical abnormalities, is harmful to the patient and there is no reliable evidence that exercise is a beneficial treatment. This has been attempted to be proven for decades and still there is no scientific evidence or patient testimony. It is an old, outdated paradigm that needs to be abandoned for the sake of patients and researchers' reputation.

“If anyone deserves an apology it is the people with ME/CFS, many of whom have experienced years of being told that their symptoms are “all in the mind” and given no meaningful medical management – mainly as a result /of the dominance of the psychosocial model of causation. As a result, progress involving biomedical research into the underlying cause of ME/CFS has been severely hampered.” (*Charities, Patients and Researchers Are All Working Together to Find the Cause and Effective Treatments for ME/CFS*, 2022)

It is important to note that the WHO Guidelines for the ‘Clinical Management Covid 19 Patients’ (*MAGICapp - Making GRADE the Irresistible Choice - Guidelines and Evidence Summaries*, n.d.) it has very clear guidance for patients with PEM/PESE:

“For the clinical rehabilitation management of PESE in adults with post COVID-19 condition we suggest using education and skills training on energy conservation techniques such as pacing approaches. The provision and training in the use of assistive products and environmental modifications may be useful for people experiencing moderate to severe PESE”

And with fatigue:

“For the clinical rehabilitation management of fatigue in adults with post COVID-19 condition we suggest using a combination of education, skills-training on energy conservation techniques such as pacing approaches and, in the absence of PESE, a cautious return to symptom-titrated physical exercise training”

Therefore this clarifies that energy conservation techniques are paramount and that physical exercise should not be given.

4. Listening to the extensive testimony that exercise does not help conditions with PEM, MECFS.

There is also the patient testimony which is powerful and heart-breaking; that attests to the damage and permanent harm that can come through exercise with PEM. Patient evidence was also submitted to NICE regarding the MECFS Guidelines that was analysed by Prof Helen Dawes and her team at Oxford Brookes University (*NICE-Patient-Survey-Outcomes-CBT-and-GET-Final-Consolidated-Report-03.04.19.Pdf*, n.d.) (mayfly, 2019) and found that exercise worsened symptoms.

There is also an implicit understanding that is conveyed to the patient that exercise will benefit them. This is not accurate and there is a danger that pacing and staying within their energy envelope will not be a priority and a more ventured more gained mindset will form. GET is an extreme form of exercise intervention yet even milder forms of exercise can cause permanent damage. There have been many complaints of patient harm and people being made considerably worse and going down the disability scale from mild/moderate to severe/very severe and never recovering.

Tom Kindlon a prominent MECFS patient advocate has collated a resource showing the harm that has come to people with MECFS when prescribed exercise: (*Pinterest*, n.d.) and a report on the harms of exercise and CBT (Kindlon & Me, n.d.)



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“I trusted my healthcare provider, who prescribed exercise and behavioural therapy as treatment. After 6 months of carefully following their advice, I became so disabled I spent a year of my life bedridden.”

“In 2015 I was told Graded Exercise would cure me and was not warned of the risks. I suffered a severe relapse and went from being able to work and walk 30 mins to being unable to shower or care for myself. I never regained any of that lost function.” Adam

When someone joins the 25% ME Group they are asked if they have tried exercise and CBT. When asked if they were made worse by exercise 86% responded Yes. ((1394) *Pinterest*, n.d.)
(*25-ME-Group-Stance-on-Exercise.Pdf*, n.d.)

Other testimonials & concerns can be found on Kirstie Sivapalan's page (*GET Lost – KIRSTIE SIVAPALAN*, n.d.), ME Action #StopGET page ((5) *#stopGET Campaign (@stopGETteam) / Twitter*, n.d.) and the MAIMES campaign

It is a form of testimonial injustice not to listen to patients with PEM who have been harmed by exercise. The complication for this is that there is no way to adequately make a complaint about this type of harm as the MRHA yellow card scheme does not include exercise.

Therefore, **INSTITUTION/NAME** is taking a huge and unnecessary risk in prescribing exercise to people with Long Covid – when a significant subset have PEM.

5. Wrong hypothesis: treatment based on the Deconditioning Model

We can see that exercise is often given as a treatment in ME and Long Covid due to the hypothesis of muscle loss and wasting ie Deconditioning. This was a common hypothesis for the cause of post viral illness proposed by the Biopsychosocial School in the 80s and 90s. According to that model all symptoms of PVS or MECFS came from deconditioning and inappropriate behavioural responses. Therefore, exercise was prescribed for the deconditioning and CBT for the fear response to activity. We can see an out-of-date hypothesis that still influences research to this day.

This deconditioning model though has been abandoned due to several key studies (Van Campen & Visser, 2018) (Stevens et al., 2018) (Schmalting et al., 2005) (Bazelmans et al., 2001) the high rates of patient harm and its ineffectiveness.

We can see from the 2 day CPET study (Stevens et al., 2018) the abnormal response to exercise when PEM is present. Deconditioning cannot explain the dramatic drops in energy production on the 2nd day. Dr Rowe states (Johnson, 2018) that this study should end the myth of deconditioning once and for all in MECFS. This should then stand for other Post-Acute Viral Syndromes such as Long Covid that have PEM.

The reasoning for the deconditioning model comes from the overlapping symptoms; muscle loss, muscle wasting, abnormally high heart rates at baseline and low stroke volumes when tilted, smaller less muscular hearts and carotid arteries. Long Covid and ME patients do have deconditioning due to lack of activity, but it is crucial to realise that the deconditioning is not causing the symptoms of the disease. We are deconditioned because the energy system of the body is broken - if we exercise more harm and damage arises. The deconditioning is not reversible and cannot explain the pathophysiology we are seeing in ME and Long Covid patients ie the venous compliance, reduced blood volume and the abnormal autonomic nervous system functioning.



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It is vital for Long Covid patients that the scientific community moves on from the simplistic deconditioning model in Post-Acute Viral Syndromes. If PEM is present, then there is a serious risk of patient harm.

6. Vulnerable to legal challenge

There was a change to UK law in 2015 relating to informed consent and medical negligence. Prior to this the Boleyn case-law principle held that a Dr would not be negligent if information/treatment given to a patient was compatible with a reasonable body of medical opinion. In 2015 the Boleyn case-law principle was replaced by the Montgomery case-law, which states that: “The doctor is under a duty to reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatments.” This means that the law requires any risk to be disclosed to the patient and the source of these risks can not be limited to the views of just some doctors or government guidelines. This applies to all medical personnel (‘Montgomery (Appellant) v Lanarkshire Health Board (Respondent) (Scotland)’, 2015) and not just Doctors. All are required by law to comply with the update and ignorance of the law is no defence in law. Any breaking of this law and successful prosecution would lead to a criminal record which would impact a clinician’s professional insurance and their ability to practice medicine.

INSTITUTION/NAME does not make the patient aware that there is a material risk from participating in exercise. There is no screening or referral to PEM (Post Exertional Malaise) or any reference that there is a risk of deterioration, temporary or permanent or any of the side effects of PEM – pain, sleep problems, inability to move, loss of functionality, flu-like symptoms, muscle weakness or increased sensitivity to light, sound, or touch. This puts **INSTITUTION/NAME** at risk of legal challenge.

Yours sincerely

Joanna Bloggs



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