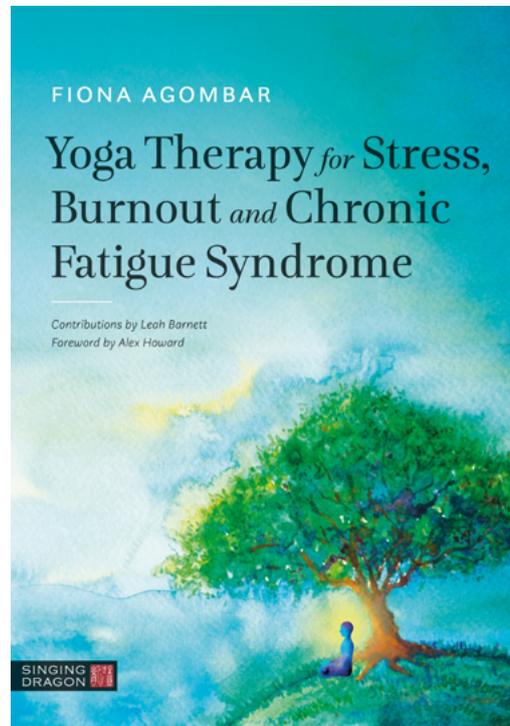


# Fiona Agombar: What Chronic Fatigue can teach us about recovery from long-Covid

*Notes for 30th May 2021 4.30 BST*



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- This is a love letter to those who work with or are helping those with long-Covid, as there is so much we have learnt about ME/CFS through mistakes that have been made in the past 20 years. Yoga has a huge role to play here, but we need to make things better not worse. With a little careful guidance we can really help people to heal.
- The most troublesome symptom of long-Covid is fatigue and, although I will talk about other symptoms such as breathing difficulties, this talk is about how we can help to re-establish prāna – the flow of energy around the body.
- **How do we define chronic fatigue?** A spectrum with burnout at one end and fatigue that may need hospitalization at the other. This includes fatigue from stress, cancer, MS, Parkinson's, Lyme FM, Post gulf syndrome, post-viral fatigue, and long-Covid fatigue, and also what we know as ME/CFS. Fatigue that lasts longer than 6 months is defined as Chronic Fatigue Syndrome (CFS) whereas at the moment, a long-Covid diagnosis is given after 3 months.

- ME/CFS is often misunderstood as something which is just fatigue. However, it encompasses many other symptoms similar to long-Covid including: brain fog, strange unexplained symptoms such as head vibration, weakness, digestive disorders, headaches, insomnia, cardio myopathy, mast cell disorders, low blood pressure, extreme fluctuating exhaustion with a relapse remission pattern, muscle and joint aches, general malaise (a feeling of being poisoned), hyperventilation pattern and post-exertion fatigue, especially after exercise.
- The main difference from long-Covid to ME/CFS is: breathing difficulties (especially breathlessness) together with thoracic, sternum, upper back and chest pains and heart palpitations. The brain fog and fatigue pattern is the same – severe at times with a pattern of relapse and remission.
- 1 in 10 people who have Covid may develop long-Covid (National Office of Statistics). So we may have an epidemic unless we are careful. Up to 10 million people are predicted to have long-Covid worldwide. (Dispatches, March 2021 Channel Four.) The ONS suggests up to a million people in the UK already have long-Covid. However that is using the criteria of ‘symptoms lasting more than 3 months.’
- There are many triggers for ME/CFS but a major one is a viral infection – in other words ME/CFS and long-Covid are similar, so a similar approach is needed – especially as we are dealing with prāna. However, yoga therapy is always an individual approach.
- Mitochondria and the Cell Danger Response (Robert Naviaux et al 2016) maybe gives us the answer to the profound fatigue that we see in long-Covid. The CDR also gives us some ideas about how to proceed in a yoga class for this condition. There is more about this in my book: Yoga Therapy for Stress Burnout and Chronic Fatigue Syndrome (Singing Dragon 2021).
- Doctor Robert K. Naviaux, Professor of Medicine at the University of California, suggests that it is how the mitochondria function that is the answer to chronic fatigue states. This is a thesis.
- Mitochondria are organelles – the energy spark of the cell. They produce ATP (adenosine triphosphate) which is fuel for the cell and which needs certain nutrients including oxygen. (The slower we breathe the better the oxygen uptake to the cell as we are not losing so much carbon dioxide. This, of course, equates to yogic breathing, mindfully and gently through the nose from the diaphragm – which helps with the uptake of prāna.)
- Naviaux’s research has shown that as well as producing energy, the mitochondria are also involved in defending each cell of the body if we perceive that we are under threat.
- The more that mitochondria are needed to work in defense mode, the less energy they produce. Naviaux calls this ‘the Cellular Danger Response’ (CDR).
- Therefore - the more that mitochondria have to defend us from something, the less energy we have, as cells are caught in a repeating loop of incomplete recovery and re-injury, unable to fully heal. They need to rest before they can produce more ATP, which explains the relapse/remission pattern.

- The thesis is that abnormal persistence of the CDR lies at the heart of many diseases, including burnout and chronic fatigue states – which is why labels may not be so important.

### **What triggers the Cell Danger Response?**

- This response is triggered by encounters with chemical, physical or biological threats.
- Inflammation from chronic stress (emotional and physical stress, over-doing things or exercising too much).
- Toxins.
- Pollution.
- Some medications.
- Viruses.
- Because of the CDR, long periods of rest are important to help the cell to regenerate. Too much exercise/activity causes stress in a depleted organism, which puts the system back into the CDR and leads to the push-crash scenario.
- It's very important to note that people with ME/CFS and long-Covid are exercise intolerant – because of the CDR they will relapse if they do too much too soon.
- People can take activity/exercise when they are better, but my long-Covid and fatigue classes are about pacing, resting, recovery and not exercise. Obviously some movement is important for the lymph etc. but gentle walking or swimming can provide that when the time is right.
- Stress and the CDR - I find that many of my clients with these extreme fatigue conditions may be running a sympathetic nervous system response from chronic stress, driven by hyperventilation. Or they swing from sympathetic to a parasympathetic shutdown response, which is explained better by Polyvagal theory (re Dr Stephen Porges)
- Published research with ME/CFS, available on PubMed shows that early intervention leads to recovery. This intervention means proper convalescence and rest. Unfortunately, until recently, this was not part of the NHS protocol and the NICE guidelines in the UK of graded exercise (later changed to graded activity) combined with anti-depressants has caused many to relapse and not recover. This was only revised last November, in spite of pressure from the ME charities.
- I believe that recovery from long-Covid can happen if lessons from this are learned.
- For example, sensibly, the military protocol in the UK suggests 2 weeks rest followed by mindfulness and pacing. This is followed up by significant periods of rest followed by lifestyle intervention such as good nutrition.

- The current attitude around Chronic Fatigue needs to be acknowledged if we are to build a healthier society. The historical culture around ME/CFS is that people have been disbelieved, ridiculed and called names: ‘monomaniacs’, ‘malingerers’, ‘lazy’. This has been my experience and that of many of my students. Even some of the press and much of the medical establishment have been hostile to those with these conditions. When I was a Trustee of Action for ME in the ‘90s, one of our jobs was rescuing children with ME who had been sectioned – their parents accused of making their children sick. One child was even famously thrown into a swimming pool because the psychiatrist involved believed that it was in his head and said the child should swim. We don’t want to see this happening again.
- The word ‘gas-lighting’ was invented for those with CFS/ME as the experience has commonly been denied. Very toxic culture around ME/CFS. Why is there this stigma? It’s because fatigue is something that is not respected in our culture. People may be perceived as being lazy and worthless so we distrust the idea of taking breaks. We are meant to have grit. Consequently people with ME/CFS may have sense of shame and feel marginalised. This means that people with fatigue consequently struggle to pace – they believe they should push through to be worthy, acceptable and to get better – and we see this in a yoga class including with those with long-Covid. Therefore we have to teach yoga in a specific way which I will explain later towards the end.
- Anecdotally there are some reports of similar attitudes towards those with long-Covid – that doctors are not taking this seriously, or people are being advised to push through, or even that it’s in their heads or they have depression. This kind of gas-lighting has been reported by George Monbiot, a Guardian journalist who is himself recovering from long-Covid. He suggests that this is partly a problem of the patriarchy, since more women than men get ME and long-Covid. Anecdotally, one of my yoga teachers who works in a Covid clinic for the NHS also reports some GPs do not always believe the experience of their patients. Monbiot’s short presentation is well worth watching: <https://youtu.be/qifn7dgVdTg>
- So if we want to help people with Covid to recover, it is very helpful to consider the saṃskāras of our society.
- The current culture leads us to strive, push through, achieve and to be constantly ‘doing’. If people with long-Covid don’t question and see this pattern, they are likely to keep relapsing as they go back into a world which has high expectations around achieving. Historically, ideas around resting, taking time out and pacing are less acceptable and may even be equated with being lazy. There needs to be a cultural shift. (One very kind and well meaning physiotherapist from a hospital who refers long-Covid patients to me talked about needing to manage ‘high activity’ with rest. Personally I see no role in high activity during recovery from such a virulent virus!)
- When we consider our own patterns of succeeding in the world, we need to reflect on the family we are born into, country, climate, where we live, peer group, schooling, diet, wider community, what media we are exposed to etc.
- We live in a fear-based consumer society, which operates by giving us messages that we are not good enough, in order to get us to buy things. Since the Industrial Revolution, the patriarchy (and men are victims of this as much as women) has created a society, which is analytical, heady and that doesn’t give attention, empathy or respect to emotions – or to being sick.

- There is no doubt about a culture of overwork and burnout, which we didn't have 70 years ago. We are expected to 'man up' 'push through', to be 'gritty' and 'resilient'. Success is measured by 'doing' and 'achieving' and this is seen as something which is financial. This influences our behaviour, how we can get well (or not) from a chronic illness and how we react within this paradigm.
- If we are unconscious to this and just go along with the rest of society, we may get trapped and keep repeating destructive behaviour. We can see this with our relationships, money, health etc.
- Part of my love letter from the ME community then, is a universal message to slow down – and to bring back the idea of proper convalescence. I think here of Karen Brody who teaches yoga nidra – and her 'Daring to Rest' programme. Do we actually need to 'dare' to rest? Maybe we should all be Rest Activists like she suggests!
- Some saṃskāras are beneficial to our health and some are not. Some may make us more inclined to illness or make it harder to recover from illness. Our saṃskāras impact how we practice yoga and even how the yoga community is.
- What I often see on the yoga mat with my fatigue community is: people pleasing (the teacher) rather than listening to the body, being competitive, being self-critical, being rushed, approaching yoga as 'doing' or a 'goal,' not being able to pace, finding it hard to rest or stop. Also hyper-vigilance (maybe from trauma), not feeling safe, driven, type A, ambitious, needs to be seen to be doing in order to justify worthiness, lack of self compassion, putting others first, poor boundaries, controlling, detached from body and consequently less tuned in to the sense of self and more tuned in to external cues. All this may be exacerbated by the breathing pattern.
- This is absolutely not to blame people with these conditions or give them some kind of psychological profile as these kinds of behaviours are common in many of us, because of the saṃskāras of our modern society. Rather it is to point out that it can interfere with our healing. This is something we can address on the yoga mat by encouraging participants to rest between activity, to listen to the body and to not push through or compete – and to then take this more compassionate attitude off the mat. I will talk more about the specific yoga tools later.
- We know people CAN recover from long-Covid if they rest, pace and convalesce. The problem is that our society is not currently set up for recovery – it is set up for chronic illness, because of the culture of push, work, drive, succeed.
- We need to introduce proper convalescence, which means not rushing back into work, activity or exercise. We may need to do this convalescence thing for a long time if we've had Covid. Months even! This sounds quite radical. However, in 1970 I had glandular fever and was put on bed rest for 6 weeks and told to be careful for the next year. How have we lost that? Now it's about taking a Lemsip and going back to work ASAP.
- So I hope the medical community doesn't make the mistakes of earlier – pushing graded activity et al which have made people very ill. High activity is not appropriate for someone recovering from Covid – and I say this as someone who lives well with chronic fatigue. We know people with ME/CFS recover if there is intervention early enough. So any protocol for long-Covid needs to be patient led, with the patient's reality listened to and respected.

## Here are my yoga recommendations:

- Firstly, in yoga we are working with the person not the disease and we see the person as a whole system. So a one-to-one approach may be best because a person centered approach is most beneficial.
- I work with some people from their bed on Zoom. Obviously if we are working one-to-one we can tailor things more, and maybe add in gentle asana for the less affected end of spectrum. But we have to change perception of yoga to something that is not exercise or asana focused.
- A very gentle approach is valuable as it helps many of the symptoms. In the last year my students requested no standing postures and to make things even more gentle. We are aiming at restoring para-sympathetic function as opposed to sympathetic function.
- If we see a definition of yoga as the mind becoming less hectic and distracted (citta vritti nirodha) then we want to work with prāna to focus the mind and relax and heal the whole system. A disturbed mind (which our current way of living encourages) is exhausting and we want to offer an antidote to that.
- So yoga is about understanding prāna and its restrictions (granthis) and how we can soften those. I am sharing yoga teaching ideas from an energy perspective, and for that we need understanding of how yoga sees the being, which is very different from the western model. (There is more in my book in Chapter Six on the panca maya kosha or the five qualities.)
- It's really helpful to work with the energy of apāna - the exhalation - and not over-stimulate the system. This is about letting go, releasing, detoxing, with the exhalation encouraged to be long, smooth and gentle.
- Teaching healthy, slow, calm nostril breathing, which takes the student out of a hyperventilation pattern, is of huge benefit. I encourage breath awareness (hands on heart and belly and if students are nervous about the breath they focus on the gently rise of the belly). I avoid complicated pranayama for those with long-Covid and I encourage any movement to be coordinated with the breath.
- Very gentle stretching and opening to help the rib cage to be mobile, to assist with diaphragmatic breathing can be helpful. For example, inhaling, opening arms wide to the side and then bringing them back to the heart or into a hug on the exhale.
- Nyāsa, or hand placement is helpful. Touch helps the limbic system to feel safe. For example, take hands to any painful area and visualize healing light pouring in from the hands.
- People often feel disembodied so an approach exploring the body and surface is helpful. Somatic, floor based practices which focus on grounding are useful, (Mūlādhāra chakra work) guiding students to explore their relationship with the floor and the body.

- I encourage students to work at their own pace rather than following what I say. They stop and rest when needed. This gives them agency.
- Lots and lots of deep rest usually on the back – modified to make them comfortable with appropriate padding is vital. We have to be careful about lying on the front for those with Covid as this may make the breath too restricted. Lying down can be modified as necessary, for example using Constructive Rest Pose (bent knees) for those with back pain.
- I suggest a yoga nidra practice everyday. (I direct my students to the many free recordings on the web including my own.) Relaxation (śavāsana) is considered the most important posture in yoga and needed for us to regenerate. It teaches us not to rush, burnout and crash.
- I like to incorporate a Bhāvanā or a focus in my class. This might be peace, love, mother-earth or self-compassion for example and then I design the practice around that theme. I incorporate this with a simple mantra – but only for those who are happy with mantra. This can help the exhalation to be longer and smooth as well as set up a healing vibration, which helps with vagal tone.
- Yoga for this client group should be trauma informed. Therefore we always offer people choice and remind them of their agency. We encourage them to feel safe in their body (because this might not be the case). We help them to find a resource (softness of the hands, thinking of a safe place or a friend for example if they find focusing on the breath or body too overwhelming, which is the case for some with PTSD). Having long-Covid can be very traumatic in itself because of the losses and changes it brings. We might encourage them to follow the breath or close their eyes, but we are aware that if they have had trauma this could make them more anxious. If we are teaching on Zoom (which will be more appropriate for those with long-Covid who may be too tired to get to a class) we have to be extra careful not to do anything that might increase anxiety.
- Working on acceptance and even more importantly, self-compassion through a mindful approach (curiosity, exploring certain sensations and body parts in the present moment) is vital. Acceptance of pain, energy levels, current life and bringing both curiosity and compassion to what is manifesting right now in the present moment really helps with healing.
- Having lots of micro-breaks throughout the practice is very important. I then suggest this attitude of stopping to rest between activities is taken off the mat.
- Reminding the student to pace not to push and to develop their own internal cues of what their body needs rather than what the teacher is saying is helpful so they understand that everything is a suggestion. Above all – personal agency.
- In summary, the session should be yoga that soothes the system and engenders a feeling of being safe, relaxed and present as well as a deep acceptance of the current experience. Silence is important and helping the student to develop inner peace as well as self-compassion is part of the practice. I don't talk too much as people get fatigued with too much description or instruction.

So – my love letter is that I really hope there is cross-pollination from what we've learnt with ME/CFS. I hope as a society we learn to slow down and that we hold those with long-Covid with compassion, that we honour their experience and that we honour that it's OK to rest and convalesce properly for the appropriate length of time. That activity and doing can wait, and that life in future can be more mindful, spiritual and less frenetic.

**My website [www.fionaagombar.co.uk](http://www.fionaagombar.co.uk) has details of my classes, my book and some free downloadable resources.**