

Long Covid Autonomic Dysfunction

Advice for Patients



Following the initial surge of Covid-19 infection, we noticed that patients attending our syncope clinic consistently described the following plethora of complex symptoms:

- shortness of breath
- palpitations
- chest pain
- fatigue
- insomnia
- temperature dysregulation
- reflux and diarrhoea/constipation



The preliminary findings from the initial five patients undergoing specialist tilt table testing (a detailed investigation of heart rate and blood pressure responses when the body is in different positions, including standing) were published on 1 January 2021 in an article, freely accessible on the link below:

<https://www.rcpjournals.org/content/clinmedicine/21/1/e63>

Since this initial observation, many more patients have come through our clinical service, with a similar clinical presentation and almost identical tilt table test findings. They are described in more detail in the article referenced above.

In summary, it is believed that some of the multiple symptoms (which appear to be coming from different organ systems) may have an underlying basis rooted in dysfunction of the autonomic nervous system, triggered by Covid-19 infection.

— What is the autonomic nervous system?

The autonomic nervous system is the subconscious nervous system that controls all the bodily functions we do not normally have to think about on a day-to-day basis. This is separate from the somatic (or conscious) nervous system, which governs all our conscious efforts, for example moving your hand to pick up a pencil to write, walking or controlling your vocal cords to speak. In contrast, the autonomic nervous system automatically controls the bodily functions that we don't have to think about such as: heart rate, respiration rate, depth of breathing, temperature regulation, bowel movements, and sweating.

The subconscious nervous system is influenced by emotions, and one example of this experience is the feeling of rising butterflies in your chest prior to giving a speech, attending a job interview or sitting an exam. One might also feel the need to urinate or defecate several minutes before such an important event, which underscores how

important it is that any emotional state of nervous tension can have a direct influence on bodily functions and influence heart rate control and bowel movement.

— So how does Covid affect the autonomic nervous system?

We don't really know is the honest answer! However, we see parallels between infections triggering another very similar condition termed postural orthostatic tachycardia syndrome (POTS) which is a form of autonomic dysfunction. In POTS, symptoms are triggered typically after a stressful event or a chronic infection (which need not be Covid). In fact, POTS has been known by several other names over the years including Soldier's Heart, post-traumatic stress disorder, Da Costa Syndrome (named after an American Civil War doctor who noticed a very similar constellation of symptoms presenting in soldiers returning from the front line in the American Civil War in the mid-1800s), Vietnam war syndrome.

https://en.wikipedia.org/wiki/Da_Costa%27s_syndrome

Essentially, if the group of symptoms that you experience are significantly exacerbated by standing upright and relieved by lying down, then you may well have a degree of orthostatic intolerance. Orthostasis is derived from a Greek word meaning 'to stand upright' and the term orthostatic intolerance simply means inability to tolerate standing upright due to worsening symptoms.

One plausible explanation for this is that Covid has somehow readjusted the body's response to orthostasis, and instead of a healthy response, with anti-gravity mechanisms in play to immediately correct the pooling of blood in the lower limbs on immediate standing, a patient who has developed autonomic dysfunction after Covid may no longer be able to readily recover their blood pressure when standing up due to blood pooling in the lower limbs due to gravity.

As a result, the body's reaction is to engage a very strong 'fight or flight' response, which releases stress hormones including adrenaline and cortisol which serve to increase heart rate, and increase vasoconstriction (squeezing the blood vessels to return pooled blood to the heart) which would normally help to combat the slight drop in blood pressure one would expect with standing upright.

In autonomic dysfunction, the 'fight or flight' response is enhanced, and the adrenaline and cortisol responses are maintained throughout much of the day, which eventually lead to the multiple effects described above including shortness of breath, fatigue, palpitations, dizziness, and insomnia. Think of it this way. Your body is constantly in 'fight or flight' mode and without the ability to wind down and relax, you continue to dial up the adrenaline and manifest a side-effect profile from having a heightened adrenaline state throughout the day and night time which can impair sleep, despite feeling extremely fatigued.

— So how do you know if you have autonomic dysfunction in long Covid?

The first thing to recognise and to try and figure out is whether or not your long Covid symptoms are caused by autonomic dysfunction. One strong clue could be that your symptoms are worse when you stand up and improved when you lie down, particularly when you elevate your feet, for example placing your feet on the armrest of your sofa whilst lying down. By doing this, you are effectively returning blood to your heart from your lower limbs with the help of gravity.

If you frequently feel your symptoms worsen whenever you stand up, you may well have a phenomenon of autonomic dysfunction post long Covid in the next steps are as follows:

1. Measure your blood pressure and pulse rate while both seated and standing upright. This can usually be done simply by using an upper arm blood pressure cuff and taking repeated measurements in both sitting and standing stages. For example, take measurements on three occasions whilst seated one minute apart, and take a further five measurements whilst standing up over 5 minutes, with your legs at shoulder width apart, without fidgeting and standing still.
2. Assess your symptoms while seated on standing upright, in conjunction with the blood pressure changes
3. If your blood pressure is low normal at rest (ie less than 120/80mmHg) and your heart rate accelerates (for example 70 beats per minute at rest seated, increasing to 110 beats per minute while standing), associated with symptoms, you may well have a degree of autonomic dysfunction with the heart rate rise being a marker of the stress response being initiated purely by standing. In this scenario, the blood pressure can either be stable at baseline values or decrease or even increase slightly with your symptoms.
4. Finally, lie down after five minutes and assess if your symptoms are improved shortly after you lie down, particularly if you elevate feet above chest height.



— Top tips for improving autonomic dysfunction in long Covid

If you do have autonomic dysfunction in long Covid, and in particular if you have low (<100/70mmHg) or low-normal blood pressure (<120/80mmHg), and symptoms which worsen significantly on standing, then consider the treatment strategies as below:

1. Increase fluid intake aiming for 2 ½ to 3 L a day, minimising caffeine and alcohol
2. increase salt intake aiming for 1 to 2 teaspoons a day
3. Consider wearing compression stockings which should be lower limb compression to the thigh or abdomen (grade 2)
4. Consider wearing abdominal binders – (google medical hernia binders), which help maintain constriction to return blood pooling from the abdomen and intestines back into the heart - this can be particularly useful for patients who develop significant symptoms after eating large carbohydrate meals.
5. Consider performing a mindfulness-based meditation approach
6. Slow your breathing down aiming for a 5 to 6 second breath in, followed by a 5 to 6 second breath out, and calm the mind by expressing positive emotions (think of this as doing the opposite of preparing for that

nerve-wrenching job interview public speech or and its associated physical symptoms). Read more about how to practise regulating your breathing at [🔗 https://stopfainting.com/breathe-yourself-better](https://stopfainting.com/breathe-yourself-better).

Other useful resources

Finally, we advise you to check out the resources as outlined below. Observing other patient stories and having some common threads will help you to know that you are not alone, and there is light at the end of this tunnel. We hope that you will develop expectation of recovery as you understand more and more why you may be experiencing some of these varied symptoms from different organs which are all driven by a disorder in the autonomic nervous system, triggered by Long Covid.

- 🔗 www.stopfainting.com
- 🔗 **Louisa's story - a long-haul Covid recovery journey!** Long Covid Recovery: a patient journey to recovery from Long Covid [🔗 https://www.hearhythmalliance.org/stars/uk/video-series](https://www.hearhythmalliance.org/stars/uk/video-series)
- 🔗 <https://www.longcovid.org/resources/patients>