



LOCOMOTION Webinar 1 (20th February 2024) Q&A

Below are questions posted by attendees at LOCOMOTION Webinar 1 (20th February 2024), which were answered during or after the session by members of the LOCOMOTION panel.

Q. Can we get rid of Postural Orthostatic Tachycardia Syndrome (POTS)? I developed POTS after COVID back in 2023. It ruined my life, I cannot do anything that I like. I used to be super fit, love going to the gym. Nowadays I cannot go to the gym and do weightlifting anymore. I want to get rid of this. Can it be reversible?

A. It certainly improves with time and putting all treatments measures in place. Difficult to predict whether it's possible to completely get rid of it in everyone. Many patients are satisfied with outcomes long-term.

Q. Is Dysautonomia an actual condition in its own right? Are there specific management strategies and treatments for it? Can it be cured?

A. Yes, dysautonomia is an umbrella term, several different parts of the Autonomic Nervous System can go wrong. They are 'proper medical conditions', they are not 'in the mind'. The need to be screened for, identified, and treated, as POTS and OH can be as disabling, or more, as heart failure. There are non-drug treatments and drug treatments. Leading to significant improvements in function and allowing people to work and function.

Q. I have Orthostatic Intolerance (OI), however I feel terrifyingly unwell when I have a narrow pulse pressure of 13 which my GP dismisses as bothering him with anxiety. I already had Myalgic Encephalomyelitis (ME) from Glandular Fever in '95 and caught mild COVID during the first wave.

A. Narrow pulse pressure has been used in some studies. It depends whether other POTS or OH criteria have been met. A full 10-min Lean test should be completed, if it hasn't already.

Q. If this is the end of the study, how is this being fed into the NHS to assist Long COVID sufferers, or will it just be ignored? There are also rumours that the PCAS support will also end this year.

A. NHS sites are aware of the study. We will also share findings in a Long COVID conference next month.

Q. Why did both of my Long COVID clinics not assess me for POTS? I had all the symptoms but was not triaged, nor had a letter sent to my GP? I had an independent lean test and it resulted in being positive for POTS. Are the Long COVID GPs working from their own tick sheet?

A. We would recommend the lean test for everyone with Long COVID, it is low resource and can be quickly done in a clinic or home setting

Q. When do you recommend starting supine exercises?

A. These can be started provided that the physiological response is not excessive to what is expected.

Q. Were the mental health conditions [in the data shown in the presentation] present pre-COVID?

A. Yes in some of them, not all.

Q. Will Long COVID diabetes actually be acknowledged? As doctors place patients on courses to reduce the risk of diabetes, but in fact make patients worse and produce no change in the markers of prediabetes.

A. In my opinion we need to be screening people with Long COVID for diabetes, as there are increased rates of new diabetes reported in so many COVID studies

Q. Is there any push in the literature/clinical practise for standardising the NASA Lean Test (NLT) criteria for a positive diagnosis of POTS? i.e., increased bpm of 20/30 for a one/two minutes interval?

A. Excellent Q - we need further consensus. We have also asked for NICE guidance specific on autonomic dysfunction.

Q. Do you have an idea how much it costs to complete the NLT?

A. It should not cost much. We just need a HR/BP machine. Patients can do it themselves if they have access to a machine.

Q. I find it concerning still that patients and carers tell medical clinicians of the symptoms and they google it front of you, as they still don't understand the condition and feel gaslighted.

A. We are doing our best to raise awareness among clinicians and bring validation for the condition. This is a perennial problem for all conditions which do not have a definitive conclusive biomarker/ test/ investigation.

Q. Is Orthostatic Hypertension (OH) easier to be treated than POTS? Can both be healed? I think that heart drugs are just a band-aid. Is there any research on the autonomic nervous system?

A. There is considerable research in this area. OH is equally difficult to manage.

Q. What can you do when GPs don't even know about POTS.

A. Go to the charities mentioned and print out their info leaflets and take to a doctor.

Q. Have you noticed any correlation with undiagnosed Ehlers-Danlos Syndrome (EDS) and POTS?

A. Significant association. Hence need to raise awareness in EDS. The major issues in EDS are not due to hypermobility but due to autonomic dysfunction.

Q. What guidelines are there for GP's to prescribe medicated salt, and when should they refer on to GPs?

A. No specific guidelines as such. Please read POTS UK website.

Q. Is there a UK network of GPs with a special interest in POTS?

A. POTS UK. But we would recommend interested GPs to join the Long COVID society being set up by NHSE.

Q. If half of the positive patients were not symptomatic- they would not require intervention? Does this mean that it would be fruitless to test everyone?

A. We recommend that everyone with Long COVID is screened for dysautonomia. As it is so common and can be treated. People go from bedbound to active and able to work. Each case must be assessed individually as to what their main difficulties are as part of a holistic medical or health assessment.

Q. Do you think treating a patient with positive NLT, even if no OI symptoms will improve overall wellbeing? i.e. does treating potential asymptomatic cardiovascular dysautonomia help non-cardiac dysautonomia?

A. If non-cardiovascular dysautonomia, it may need treatment directed to those aspects. However, as the blood supply goes to all organs, treating cardiovascular aspects may help non-vascular symptoms, e.g., the gut is commonly

affected by dysautonomia and so if you treat the low blood pressure or excessive heart rate, the blood supply to the gut may improve. E.g., supporting the blood pressure may improve blood flow to the gut. Often cognitive symptoms can improve if blood pressure and heart rate response are normalised.

Q. Can the rise in heart rate vary day to day? Also, how can we educate our GPs with treatments not to dismiss as anxiety etc.?

A. Absolutely, it is highly fluctuant and variable in presentation. Please take our papers to clinicians if that helps. We can write an accompanying lay summary of key findings if that is useful.

Q. Should we continue with NASA lean test? I contacted Professor Levine who developed Levine protocol for POTS, and he confirmed they assess using active stand test. I think it would be great to share your testing standards for assessing for orthostatic intolerance - perhaps we need a working group to draw up exclusion criteria and recommendations for understanding test results?

A. Thank you, sure, good suggestion. M.Sivan@leeds.ac.uk.

Q. Is there information about dysautonomia/POTS/OI/OH in CYP (children and young people)? I do wonder about screening many of the CYP presenting with 'anxiety'. I was misdiagnosed myself in my teens after EBV and wasted much time without appropriate treatment.

A. Abnormally increased heart rate and lack of blood to brain in autonomic dysfunction may appear like anxiety but anyone can have dysautonomia, whether they have anxiety or not! It should NOT be put down to anxiety.

Q. I was diagnosed with FND (Functional Neurological Disorder) with Long COVID. How much overlap is there between FND and OI? There seems to be a lot of fuzziness/similarities between the different diagnoses.

A. I would not recommend a diagnosis of FND for Long COVID symptoms per se.

Q. May I ask why? I spent two weeks in hospital and was eventually diagnosed with FND due to my symptoms (e.g., sea legs, jerky movements, near-fainting on standing or sitting, unable to put legs together without jerking violently side to side). Another specialist believes it is a brain injury which I think seems the most legitimate.

A. FND diagnosis is fine but alternative diagnosis such as dysautonomia should not be ignored

Q. What modifications in exercise for those with autonomic dysfunction and PEM?

A. Autonomic dysfunction requires different approaches to rehabilitative exertion. Often starting with supine exercise. Post-Exertional Malaise (PEM) requires a specific approach within the energy envelope. Look at World Physio statement and ME guidelines from NICE. PEM is a red flag which needs ruling out before advising specific exertion. The WHO living with COVID guideline has guidance on this.

Q. Can POTS be temporary and recede with recovery?

A. Yes definitely, many improve and in some completely resolves.

Q. I think there is very little awareness of POTS and OI in the medical profession and spreading of awareness will help the lengthy diagnosis time

A. Agree, COVID is an opportunity to upskill for clinicians. We also use home monitoring to look at the effects of exercise, food and other activities on heart rate response. This has been developed for many people to be able to use at home, whilst there are few specialist autonomic centres.

Q. Can you have both POTS and OH? What are the possible treatments? My doctor offers nothing at all for Long COVID testing or treatment. He says I'm fine, as when he tests my blood pressure it is not much lower than sitting (mine is always low) after standing for 10 minutes.

A. No. You can have only one of them. Once OH is diagnosed, POTS should not be given as diagnosis.

Q. Regarding the NLT presentation, if half are symptomatic, are current test criteria suboptimal? May it be worthwhile to add a test for assessment of cerebral perfusion?

A. Yes very good suggestion, funding is an issue for this. We need more research funding for cerebral blood flow.

Q. If doing the testing themselves, would you do the NLT or the aAP?

A. aAP is good test too - it is a series of NLT test during the day. NLT is a quick easy one-off test for all.

Q. Is it unusual for POTS to come and go? I can go for weeks with no (or mild) symptoms and then out of nowhere I have days where I'm symptomatic and feel awful. I have been assessed by a cardiologist as having 'probable POTS' through ECG.

A. Yes it fluctuates just like Long COVID symptoms fluctuate.

Q. Will the teams from the LOCOMOTION study feedback their findings and recommendations, and/or will this become part of the NHS format for assessing patients with Long COVID? I caught COVID in 2020, I'm still very ill, worsening in some areas, and would be satisfied that you could lead the COVID clinics forward in properly assessing patients.

A. Every clinic MUST test for autonomic function. Please engage in a dialogue with them if they are not taking this seriously.

Q. On a practical level, what as patients would you recommended on how to help ourselves, we want to get better but who do we ask, waiting lists are horrendous for hospital appointments and then for example I see a neurologist I'm dismissed "there's no such things as brain fog, we don't know what Long COVID is" or cardiology, "here's a handful of tables".

A. Please engage with your local Long COVID clinic and have a dialogue with clinicians on how to move this field forward.

Q. Did you consider, or are you considering, using the AAP on everyone ?

A. I helped a specialist adapt it for people with Long COVID to use at home and I would advise it to anyone with post COVID symptoms. It's so easy to use and highly informative, and it can then be used to give advice and treatment.

Q. Is there any study on the NHS about the stimulation of the vagus nerve with external equipment? Do they work?

A. Yes, there are a few ongoing studies at the moment.

Q. We are using adapted Autonomic Profile (aAP) test but find many "positive" results are due to exercise. How can you differentiate between heart rate and blood pressure increase due to exercise or due to POTS?

A. Check for responses with other triggers (position, food, cognitive/emotion exertion), that will help differentiate whether response is specific to exercise or a global autonomic nervous system response.

Q. My Long COVID clinic offers mental health support and physiotherapy, my Long COVID clinic asked to refer me to Chronic Fatigue Syndrome (CFS) clinic, and 3 months later they're still batting it back between them, I feel helplessness.

A. I think Long COVID and CFS services need to collaborate and merge. That will help advance and understand this whole area better. Separate services and separate terminologies cause more confusion and dilute the area.

Q. I'd like to ask if there is any advice (on behalf of my partner) on how to look after someone like me with Long COVID?

A. Please do look at the Long COVID Support website (www.longCOVID.org), who run a peer support group (link on the website) and there is also a support group for carers, in addition to various other resources on the website.

Q. Do you consider OI/POTS to be evident in other potential post viral conditions such as ME/CFS?

A. Absolutely, it is integral to post viral syndromes.

Q. I've been discharged twice now, I asked for follow up and tests and refer to neurology and others and was refused. Ironically, they said if I need to return for help, to ask the GP for a referral, to wait 6 months and a repeat performance of refusals by them is not good for mental health.

A. That is not ideal. Long COVID clinics must have an open discharge policy whereby patients can contact their Long COVID clinic and seek advice directly at any point after discharge

Q. My blood pressure is on the low side any time but especially in the morning and on standing. It leaves me feeling totally drained and fatigued. I improve as the day goes on. However, my heart rate also rises quite a bit when I stand. Is it likely I have POTS or OH? How do I check? What do I ask my GP to do.

A. Refer to local Long COVID clinic. Or perhaps ask your GP to do the Lean Test themselves?

Q. The terminology is often misleading. Many people outside the 'Long COVID world' use the term 'brain fog' without understanding what our experience actually is and therefore trivialise it; it is a brain injury, surely? Although the tests are not yet available to identify cause and effect, it should not diminish the validity of patient experience.

A. Cognitive impairment can be used too. There is substantial evidence on reduced cerebral blood flow in Long COVID patients.

Q. How do you get access to this tool, as a Post COVID syndrome pathway?

A. C19-YRS is free to use, available on the web. Please use the modified version.

Q. My GP has said that there is no point testing for fibromyalgia, ME, or following up for a dysautonomia diagnosis because they are all showing similar symptoms and as I already have Long COVID I don't need to. Is this correct?

A. Correct in a way, as long as there are management strategies in place (as management is similar in all of these – pacing, hydration, desensitisation, meds for some symptoms, etc.

Q. How can we capture emotional and cognitive exertions objectively for Long COVID patients? Are there any practical tools we can use in community-based clinical setting?

A. Yes, use any of the PESE questionnaires. There is one we developed in Leeds which is a modification of dePauls.

Q. Is there a role of venous compression disorders in autonomic dysfunction post-COVID due to structural changes in connective tissue?

A. The problem is venous pooling, not necessarily a structure compression issue. I am aware there is May-Thurner syndrome described in the literature, which could be considered in differentials but this is not present in all.

Q. Do you have any advice that can help me get over the line for ill health retirement from Teacher pension. I have had Long COVID for over 2.5 years and I am no better, but they just say it is a new condition and I might get better!

A. You should seek input from your local Long COVID clinic, if you have not already.

Q. Important to acknowledge that GPs are still not taking post viral conditions as physical and not solely Psychological, and telling patients to stay away from support groups(!)

A. Not an ideal situation. I hope awareness improves.

Q. Many many people are discharged from their Long COVID clinic after a few months as there “is nothing they can do”. I was told I should be discharged but wasn’t as I am a GP (as a favour). I am concerned that many thousands will not be followed up. I am 4 years in and very much clinically how I was at the beginning.

A. This is where we need to bring all related conditions on to one platform, Chronic Fatigue Syndrome, Long COVID, etc., and develop strong guidance/ recommendations.

Q. Is there a role of supine vs standing norepinephrine testing, 24h sodium testing, and aldosterone testing to help tailor POTS treatment to underlying pathology?

A. Absolutely, these tests are done in specialist autonomic centres. But we need to start first with recognition and putting simple measures in place. These can be done without these blood tests.
