

## Isaac Umeed

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**From:** Camilla Milne <[REDACTED]>  
**Sent:** 25 October 2024 16:16  
**To:** Isaac Umeed  
**Subject:** Fw: POTS

Dr Camilla Milne  
Lead Clinician National Strategic Network for Long Term Effects of COVID-19  
**NHS National Services Scotland**  
 [Chat with me on Teams!](#)

Please note, I usually work Wednesdays and Thursdays.

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**From:** Camilla Milne <[REDACTED]>  
**Sent:** 25 October 2024 16:12  
**To:** Isaac Umeed <[REDACTED]>  
**Subject:** Fw: POTS

Dr Camilla Milne  
Lead Clinician National Strategic Network for Long Term Effects of COVID-19  
**NHS National Services Scotland**  
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**From:** Camilla Milne <[REDACTED]>  
**Sent:** 19 July 2024 15:54  
**To:** Claire Taylor <[REDACTED]>  
**Subject:** Re: POTS

Hi Claire,  
Apologies for late reply to this email. I saw it just before I went on leave, then was away for longer than expected. I'm aware of Lothian's advice on RefHelp and have already met with those involved to gather a bit more detail around their thinking process a few months ago.  
As I said in my other email to you, we're still keen to progress with an updated national guidance.  
Best wishes,  
Camilla

PS. I'd love to see your beautiful graphs. The more evidence the better!

Dr Camilla Milne  
Lead Clinician National Strategic Network for Long Term Effects of COVID-19

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**From:** Claire Taylor <[REDACTED]>  
**Sent:** 30 June 2024 15:58  
**To:** Camilla Milne <[REDACTED]>  
**Subject:** Re: POTS

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Dear Camilla

I'm sorry I couldn't make the meeting last week, I has patients coming from the western isles and England unable to change travel. Thursday is my clinic day. I can possibly change it with notice. However I wanted to bring this to your attention :

Postural Tachycardia Syndrome (PoTS) -  
RefHelp  
[apps.nhslothian.scot](http://apps.nhslothian.scot)



Lothian pots ref help.

I am shocked if I'm honest, and wanted to raise why.

The things that concern me are:

'There is no specific treatments for the symptoms of PoTS'

I have to disagree. There absolutely is and it is only someone skilled in managing PoTS who can do this.

Is it hyperadrenergic? Hypovolaemic? A mix? It does not fill the patient or GP with hope.

The 10 minute stand test will give a lot of information about what medication will work. If one combo doesn't, it needs perseverance to get the right one (s).

2- normal ECG and examination usually needs no cardiac work up. All PoTS patients should have an echocardiogram, especially if post Covid, in my opinion. Yes the pick up rate is low, but it's good medicine. I have patients found to have other cardiac conditions on echo with pots.

3- 'there is no secondary care PoTs service in Lothian'

Why not? For at least 20 years cardiology have done this. I learned about POTS in a cardiology job 10 years ago when I was assigned the tilt tests.

The next part

4- refer to ME/CFS service.

What if the patient does not have ME? Not all do. Even if they do have ME, why am I Doing most of the Lothian diagnosing and prescribing for POTS? Is it being diagnosed and treated in this clinic with medications?

5- 'If symptoms remain troublesome despite this, low dose beta blockers (e.g. Bisoprolol 2.5mg od) and Ivabradine (2.5 to 5mg bd) can be helpful in controlling heart rate. These can be trialled in primary care and do not require referral to secondary care. '

This is not how I would blanket manage pots with GPs unfamiliar with POTS and the meds.

I only have a couple of patients on this combo who are hyperadrenergic but bisoprolol is not controlling it well enough. Even then I'd probably add midodrine first. I assume this means to try one or the other but it I was reading this without prior knowledge I would assume to use both.

Using both bisoprolol and ivabradine is a recipe for bradycardia. Ivabradine has a very real risk of long QT syndrome even on its own ( I've seen it in several of my patients who have had medication started elsewhere and not had ECG follow up.) Obviously this puts patients at risk of long QT syndrome which can be fatal. Where is the ECG post starting ivabradine/both or just Ivabradine and whilst on it? These GPs would be leaving people with out ECG follow up, putting their careers at risk. The product literature for Ivabradine states ECG must be done before treatment, at dose change, at final dose. For a very good reason in my experience.

The doses are not optimal

In most PoTS patients bisoprolol is better split 1.25mg BD. It starts to wear off by evening. Ivabradine can go up to 7.5mg BD. What you really want to do is start ivabradine and titrate weekly to 7.5mg BD. Then ECG. That may be Enough.

If that is not enough depending on the stand test result you are far better looking at midodrine or fludrocortisone as long as BP is ok, rather than adding bisoprolol. There is a real risk of very low HR. I do it but only in selected patients and they are monitored closely.

Many patients cannot take bisoprolol- too low BP.

Many ,in fact most POTS patients, have a low resting pulse due to dysautonomia. The product literature for ivabradine states not to use if resting HR is less than 70bpm. Obviously clinical judgement must be used because that would discount nearly everyone. Are GPs going to start it the resting HR is 59bpm AND give bisoprolol 2.5mg.? What if the patient does not tolerate either ( common)?

Asthmatics? Yes it's cardioselective beta blocker but GPs do not like prescribing with asthma.

6- midodrine, fludrocortisone and pyridostigmine can do excellent things for POTS. They do more than alleviate symptoms they are correcting abnormal physiology. It would be unfair for patients to miss out on potential life changing treatments because it's not there, or the GP does not know how to use them.

7- I am still doing all the prescriptions for Lothian. A few GPs are which is great. Everyone else is having to pay. Clearly this guide is not helping.

In my opinion this should be pulled for safety reasons due to the wording not being clear on whether to use both medications or one and lack of Guide on what heart rate/ BP they should be used and lack of ECG monitoring for ivabradine.

8- no antihistamines. Recent case report of PoTS patient symptoms resolved with anti-histamine.

POTs treatment works better with anti-histamine type 1 and 2, if there is even a small suggestion of mast cell dysfunction. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10990027/>

I assume someone with some Knowledge of POTS put it together. As I've said before I estimate I have treated well over a thousand patients in the last couple of years and a ref guide like this, putting the onus on the GP who likely has little knowledge of these meds to start meds with issues above is unsafe.

It is also not fair to patients to start a sentence with there is no specific treatments for the symptoms of pots. I have yet to meet anyone where it has been satisfactorily treated with fluids, electrolytes and compression alone. Not one.

I have some beautiful graphs patients have done for me pre and post treatment with various treatments I'd love to show you. I had one last week bedbound in February. He has just been to a pop concert with the correct combo.

I'd welcome the Chance to speak to you about this if you have any Knowledge of this online document as it as it concerns me.

I'm off on leave all week if you are free.

Sorry for tiny text I'm on my phone and when I cut and pasted it all went tiny!

I'm really desperate to help get something that works for patients asap. I've seen what the correct treatment can do. University, holidays, work. Things people never thought they would do again. It has to be done right. I'm meeting with Prof Mathias this week, an autonomic wizard, for discussion of patients who don't tolerate or improve with all of the above medications.

I'm still not sure why cardiologists are not doing this. I imagine the number of people with pots is just climbing all the time and who to see them? Are LMCs and cluster groups being consulted? Is teaching being given?

Best wishes

Claire

Sent from my iPhone

On 21 Feb 2024, at 09:41, Camilla Milne <[REDACTED]> wrote:

Hi Claire,

Your point about who isn't accessing clinics is a good one. We're looking at this as part of our evaluation of clinics already. I'll ask those looking into it to consider if there's a correlation between disease burden and not accessing NHS clinics. We've also recently had the results back of some qualitative research we commissioned The ALLIANCE to do about disengagement from services. You and I could probably make a good guess as to why this happens, but it's very useful to have the actual research rather than assumptions when trying to move things forward. Here's the link if you're interested.

<https://www.alliance-scotland.org.uk/blog/resources/long-covid-report-accessing-long-covid-services-in-scotland-to-be-believed-listened-to-and-supported/>

I've heard back from the chair of the Clinical Subject Matter Expert Group so will get out dates and times of meetings and Terms of Reference to you shortly.

The POTS group are happy to have you join them too. They're hoping to meet in a few weeks to discuss some work they've been doing and will get back to you about dates after this.

Best wishes,

Camilla

Dr Camilla Milne

Lead Clinician National Strategic Network for Long Term Effects of COVID-19

**NHS National Services Scotland**

[<Outlook-oofpgf20.png>](#)

[Chat with me on Teams!](#)

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**From:** Claire Taylor <[REDACTED]>  
**Sent:** 16 February 2024 12:19  
**To:** Camilla Milne <[REDACTED]>  
**Subject:** Re: Follow up from today's meeting

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Dear Camilla

It was lovely to meet finally! Thank you for contacting the POTS group and clinical subject matter expert group. I would be very interested in being involved in this. If anyone can help analyse my data it would I am sure be useful. What we didn't get into in our discussion is that I think I am seeing the most severe cases due to doing virtual calls with patients or carers. These people don't tend to be well enough to access nhs clinics. It would be helpful to the patient community I am sure to know the % we have that are not accessing clinics.

Thank you for all the work you do, I am sure like all of us doing this it is not easy but if we keep working on it I hope we can improve things for patients.

Best wishes

Claire

Ps will let you know as soon as I get my email back!

Sent from my iPhone

On 14 Feb 2024, at 16:53, Camilla Milne <[REDACTED]> wrote:

Hi Claire,

It was lovely to finally meet and chat with you today.

I've dropped a note to those working on POTS and the chair of our Clinical Subject Matter Expert Group letting them know that you'd be interested in joining. When I hear back, I can let you know dates and times of meetings and Terms of Reference etc.

When the Data and Intelligence Group next meet, I'll put a shout out if they know of anyone who could help analyse your cases.

Will get back to you when I have a bit more info.

Best wishes,

Camilla

**Dr Camilla Milne**  
**Lead Clinician National Strategic Network for Long Term Effects of COVID-19**  
**NHS National Services Scotland**

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