

Autonomic testing at NHNN, London – My blog

By Siana Wrighton

So some of us are having autonomic tests at NHNN quite close together so I thought I'd share my experiences of them so you guys know what to expect and hopefully make it less daunting for you.

So mum and I got the train to London and have been given a room at the Holiday Inn Bloomsbury, right next to Russell Square. Thought we'd be ok on the underground as hotel is spitting distance from underground. How wrong was I! There were no lifts throughout the underground journey apart from at Russell Square. Stairs and I are not great friends at the moment. Mum is also recovering from breast cancer and all that comes with that so she's now sore from lifting a little case up and down stairs. Think we're getting a taxi back to Waterloo on Friday! So if anyone is planning on using the underground check which stations have disabled access including those you're changing lines at. Or just don't do it at all!

The Holiday Inn is lovely, have a twin room with breakfast included which starts at 6:30 so perfect for tomorrow when I have to be at NHNN for 8 am. The other days I have to go hungry but at least mum can eat before the appointment.

Will let you know what's involved tomorrow. x

Day 1

Oh my word it's early! So got up, had an awful tachy in the shower. Sadly didn't leave enough time for a bath as I seem to get on better with them. After breakfast we headed off. There's a shuttle service from the holiday inn and I suspect the cotton rooms. I was told be ready for 7 am but he'd likely turn up at 7:15. Got to us at 7:25. Drops you right outside the entrance for the hospital of integrated medicine and nhnn day care is on the 2nd floor. Was asked to take a seat in chair number 1. A lovely nurse came along, introduced herself, did my obs, put a name bracelet on, did some paperwork and gave me an info sheet of the tests I'd be having. A porter will come and get me at 9 and take me to have my bp monitor fitted and then I'll see a dr. Quite pleased I'm seeing a dr as I'll hopefully be able to ask some medication advice. My beta blockers aren't as effective as they have been despite a recent increase to 10mg which has caused me to be off work for the whole of January so far. I'm a midwife so this really affects my ability to work clinically. After that we're free to go. Not sure what I feel up to doing but a nap may be in order!

Everyone here is great and you'll be well looked after. There's loads of waiting around so bring something to distract you. I'll post about the bp monitor in a bit. Just waiting to see the Dr and have to do a 3 min brisk walk at 11...oh I'm so looking forward to that!!

So...The bp monitor. Oh what fun this is! So after doing paperwork etc a porter or nurse (whoever is available I think) will take you over to have your bp cuff fitted. This place is a rabbit warren and I got brought back a different way to getting there! So they take you to where the autonomic testing is done and someone will call you into a room. There they go through the care of the monitor and put it on an arm of your choice. As it will be taking readings I highly suggest your non dominant arm. The tubing is then placed over your shoulders and attached to the box. This is placed in a little bag that you can wear like a handbag or round your neck, however you want really. Just don't pull the tubing too tight and try to avoid kinks in it. Now...I thought this would be just wearing it and having readings every 20 minutes. How wrong was I! Throughout the day you have tasks to perform. These include laying, sitting, standing bp's, there's also a reading before and after a brisk 3 minute walk, before and after meals, after going up a flight of stairs and a final one before bed. The monitor switches to hourly readings at 11pm and you can have 1 half hour break for a bath or shower. Then in the morning a reading after getting up. If you're heading back to nhnn for tilt table etc then leave it on and they'll take it off. You have to record what you're doing and if symptomatic, at every

reading apart from at night. Still waiting to see the Dr, she's busy today bless her.

You will have a diary to fill in...which acts as a prompt. As does the bp cuff when it goes off. Not gonna lie, not the most comfy thing in the whole wide world. And there really is quite a wait to see dr. From what I've overheard they see those having infusions first then autonomic patients.

The BP cuff is quite discrete. You can wear the box under a baggy top with a scarf under. Not much noise, beeps before and after to warn you. The pub nearby was quite quiet at 5 yesterday and there's some booths to sit in. Also they do room service for the hotel restaurant. Can do that for breakfast too.

At 15:00 I have to go up a flight of stairs. Nothing else planned really as didn't know how long we'd be here for, or how I'd feel. The Dr just came to get me but no rooms available. They are really busy today. Might mooch somewhere tomorrow after tilt if I feel ok, won't be attached to anything then either.

You can claim travel expenses only if you have ESA. If you do, you need your receipts, ESA proof of benefit, travel claim form signed by the clinic and that's it. You can't claim for taxis though, but you can claim for your carer.

Ahhh have finally seen the Dr and she's going to ask Dr Ingle's registrar about my medication. She asked about symptoms, went through the tests and listened to my heart and lungs. I'll see her again tomorrow after the tilt. Now lying down on my bed...lush!

Day overall has been long and boring to be honest! The bp cuff was fitted quite quickly it was just the waiting around to see the Dr. I was given the choice to go and see her tomorrow but there might be just as long a wait tomorrow so decided to hang around and we had nothing planned. Others went so I was the last one standing lol. The bp cuff can be annoying at times and I have forgotten to do tasks on time or take the pre meal reading! Managed to wing it with dinner as only had a few mouthfuls before I realised. I'm just quite tired and know I'm not going to sleep well tonight. Hopefully it won't be crazy busy when you're up but bring distractions just in case.

Well that's all bp tasks done for the day. Just a final before bed reading and then hourly from 11pm. Did the last 2 tasks the wrong way round, but they're half hour apart so didn't think it would matter. Mum's knackered and really sore, she needed to bed down and didn't need me coming and going from the room to find stairs. I'll let you know how the night goes in the morning x

Day 2

I'm not having the exercise bike test. Coming by public transport didn't bother me hence why I didn't request (didn't know I could request either) it. Was just the underground that was a struggle but lesson learnt. Taxi to station on way back. I certainly wasn't up to much yesterday after a 7 hour wait to see the Dr and doubt I'll be up to much after the tilt table. I'm just going to want to nap as there's very little sleep going on right now! They did tell me about the ambulance shuttle. Using it again in the morning.

They were really busy bless them. Had nothing else to do so just chilled out. I'd thought I'd be asleep too but had a really rough night. Not related to the bp monitor so ladies still to have it don't worry! For some reason my bowel is in spasm and it's rather painful. Have never had it before and don't know what to do with myself. I also had some gastroparesis issues...my dinner was seen again 8 hours later. No idea why again. So with that lot and the bp monitor not really allowing me to curl up I stopped it. I needed to sleep so after 3:15 reading it was turned off and taken off. Have had a little sleep but bowel is still in spasm. Gonna have a bath and see if that helps x

Well...day 2! In lucky chair number 7 today! Feeling rough but that's down to my bowel issues overnight and not the 24 hour bp. I'm starving!! Looking forward to lunch that's for sure. Lovely nurse is on again today. Go for my tilt at 9am then see the Dr again who hopefully has some answers about my meds.

With the BP cuff, you can just sleep through...With a straight arm so get practising sleeping with your arm straight. During the day it beeps at you before and after to prompt you to write in the diary then at night it stops beeping and just goes off once an hour. Just had tilt table...I'll report back when I've eaten!

Right then. Are you sitting comfortably? So for the tilt table you need to have not eaten 4 hours before the test. You'll be taken to the same place the bp monitor is fitted by a porter. First they'll have a chat to about symptoms, when it all started etc then go through what the tests entail. They will need to get to your ankles so don't wear tights. Also I didn't wear nail polish, just because I couldn't be arsed, but was helpful as they could see my nails go blue!! So may be worth going without. First they do laying and standing blood pressures, get you used to the room and relaxed etc. They ask you to let them know if/when you get symptomatic. Next they'll pop a small sized cannula in if you're having catecholamine levels checked, with a syringe attached. Next is all the monitoring equipment. So you will have a bp cuff on the non cannula arm, a finger probe, a thing on your wrist and ecg leads - one on each ankle and 3 on your chest (you won't need to take anything off for this, just wear comfy loose fitting tops).

The first part of the test involves doing some activities to see how your body responds, all done lying down. These include: slow steady breathing, panting, squeezing a bp cuff to see how much pressure you can put into it, then a sustained squeeze, breathing into a bp tube and holding at a certain pressure, placing your hand on an ice pack (very very cold) and mental arithmetic. All the while they're taking readings and you're telling them if your experience any symptoms.

After that they give you a rest break and this is the best time to pop to the loo again. Don't worry about all the monitoring equipment, they don't mind taking it off for you. Just be careful of your cannula when you're out.

Next is the actual tilt. Monitoring equipment is placed back on. You're strapped in quite securely around the legs and abdomen. When you first get on the table you'll be asked to scoot down so that your feet are flat on the foot plate.

The bed is raised up and then tilted to 60 degrees. It feels odd and you feel that you can't trust it to hold you but it does so just let your body relax into the table and foot plate. They'll start monitoring and ask that you tell them when you feel symptoms. If you want them to stop at any time they will. The tilt is on for a minimum of 9 minutes and a max of 45 minutes. Thankfully I got symptomatic quite quickly and was down at 9 minutes!

Tell them everything even if you think it may not be relevant. I got tinnitus so told them. This usually only happens after I've been stood up so was odd to experience it when upright. I also had to take deep breaths as I didn't feel I was getting enough oxygen. This was picked up and they asked me some questions about it. At one point I looked down to see blue toe nails! Never noticed it before.

If you're having bloods done they'll be done at the start and just before being laid flat again.

So then you're laid flat, it'll feel like your head is lower than your legs but you're not. Just feels really odd.

All equipment is taken off, cannula taken out and you're done! Just go slow getting up and take your time, they don't rush you. They don't say anything about anything afterwards, they need to interpret everything though I know my tilt was a positive result.

Take a snack down with you to eat on your way back or waiting for the porter. I felt quite weak and shaky, but then I'd been unwell in the night so that may have contributed to feeling so rubbish. I didn't see the Dr today but will tomorrow.

So was then free to go, via the canteen to stuff my face! Go easy and pace yourself. I wouldn't plan anything for after your tilt. If you feel ok, bonus. But I wouldn't plan anything specific. I was down there for 2 hours, so it could be longer if your tilt lasts longer.

Came back to the hotel and had a nap, man was it a good nap!

Milk, complan and glucose tomorrow! That's not until 3pm so can have a lie in AND breakfast! Bonus! Again I can't eat anything 4 hours before the test.

On the whole it wasn't too bad and the ladies doing the tests were great. Really friendly and chatty, really put you at ease.

The final instalment from the comfort of my own bed!

My meal test wasn't until the afternoon so mum and I had a well deserved lie in after 2 early starts and us both being up in the night. I did also have a cheeky nap after breakfast! Checkout at the Holiday Inn isn't until 12 so no rushing around which was lovely. There's also a place to store bags if like me your last day has an afternoon appointment.

I saw the Dr briefly, they want me to continue on bisoprolol and not to increase it again eve. If it become less effective.

The meal test is over in the autonomic unit, same place as the others. So there seems to be at least 3 ways to get there! Always always have a porter walk you there and back.

Another lovely lady went through the test and answered questions.

No need to have ankle/feet access for this one (unless they couldn't see them on the tilt table). But still need a loose fitting top for monitoring equipment.

Unfortunately this test involves being tilted twice, for a maximum of 10 minutes each time. You need to have been water only for 4 hours before the test.

So first off you lie on the tilt table and are hooked up to all the same monitoring equipment as during the tilt table, minus the cannula. First off you have some baseline readings then your first tilt. Strangely I didn't become symptomatic with this tilt and managed the whole 10 minutes. That's a baseline tilt so they can compare your post meal tilt to see any changes.

Then you have your meal. By this time you'll be quite hungry and happy for anything lol. It was milk, complan and glucose. It was actually really nice. Quite sweet. You have 5 minutes to drink it via a straw as you're still lying down. If you are lactose intolerant, just make sure they know

as they can use soya milk, or just miss the complain out and do the other 2. You are then left to chill and let your body start digesting the drink for 45 minutes. That clock starts with your first swallow of the drink. You'll be monitored throughout the 45 minutes and if you feel symptomatic, let them know. I noticed my arms and legs went quite cold.

After 45 minutes you're tilted again. Another 10 minutes, however I only managed 5 minutes and my symptoms came on with a vengeance. Lovely lady was more than happy to stop it and got me back down to horizontal again. You will feel your head is lower than your feet but it's not. All monitoring equipment is removed and you can get up in your own time.

So that's what happens during a 24 bp monitoring, tilt table and meal test. It is quite a tiring few days but everyone is so nice and understanding.

My case will now be discussed at a team meeting next week when all the results have been reviewed etc. Many things can happen after that. Either a phone consultation, face to face consultation, bring forward of my follow up in July, a letter...no one knows how they'll be in touch until they've had the meeting.

Time to sit, wait and see what happens.