

Wetenschap voor Patiënten (Science to patients)

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On Friday June 20th 2014 Prof. dr. Julia Newton answered questions in a chatwing-session. These are the Q&A of this session.

Q: It has been proven in ME/CFS patients that the blood flow to the brains and muscles is low. What are the effects of low blood flow in the long term?

A: It's not known. But we would hypothesise that this leads to cognitive problems.

Q: Just in order to be sure: do you mean by autonomic disorder a disorder of the autonomic nervous system?

A: Good point. Not necessarily an autonomic neuropathy i.e. disorder of the nerves themselves, but perhaps a problem with blood flow and how it gets to our organs and the regulation of this by the autonomic nervous system.

Q: Do you have any idea what the effects are on the brain when you have Orthostatic Intolerance?

A: We know in patients with orthostatic syndromes that they are more likely to have structural brain abnormalities and that they perform worse on memory tests.

Q: Does adrenaline get tested during or after exercise test of half a day? And are you doing that?

A: We don't measure adrenaline because it is known to be a very unreliable measure and very much influenced by posture etc. If we could come up with a better, standardised measure perhaps in response to a specific stimulus that would be interesting

Q: I am diagnosed with POTS and my eyes hurt. Is this a common symptom in POTS and is this due to low blood flow in the brains ?

A: POTS is a really interesting condition that is not well understood, but it does seem to occur with increased frequency in ME. Eye problems related to blurred vision are common. POTS is more common in Sjogrens syndrome where dry eyes are a problem.

Q: I have OI probably for a couple of years but how can I find out if my brain is effected by this?

A: Interesting . One way would be to treat the OI and see whether it makes any difference to your brain – to memory and concentration. An MRI would help identify whether there are structural brain problems such as white matter lesions.

Q: Do you know of any known or theoretical physiological similarities in the way the brain responds to hypoglycaemia and dysautonomia? Standing upright for too long causes very similar symptoms in my brain to hypoglycaemia (I have T1 diabetes) even though my BS are not low e.g. 7-8 when standing.

A: People with OI often describe craving sugar. We believe that this is because insulin (released when we eat sugar) also increases your blood pressure. So it is one way that your body can try and increase BP if it is low.

Q: You suggest that abnormalities of the autonomic nervous system are probably the underpinning phenomena that explain many/all the symptoms of ME. What causes those abnormalities of the autonomic nervous system? Is this one particular reason, are there many reasons, a chain of reactions? And where does it start?

A: We don't currently know what causes the autonomic nervous system abnormalities. However, our recent study has set out to look at trying to pin point where the problem is. We have now finished recruiting and studying people in this study and are now moving onto the analysis. So hopefully we will have more answers soon.

Q: My heart is checked completely, but there were almost no tests done standing. Could it be possible that the standing results of a good heart condition are different.

A: It is vital to look at how the heart and particularly the heart rate and the blood pressure respond to standing.

Q: As you say abnormalities of the autonomic nervous system are the underpinning phenomena. How is this to relate to the fact that symptoms of ME deteriorate after physical and mental activities?

A: If we exercise or perform a cognitive test, more blood goes to aid performance in that organ and as a result there might be less to go to our brain/heart/muscles. Which is why I believe problems of autonomic dysfunction get worse after exercise: all the blood is going to the muscles to keep them working ... or not...

Q: I had an MRI 6 years ago. Maybe it's a good idea to have one again to see if there are any changes in my brain. For the OI I wear "super socks" at the moment.

A: Great. Support stockings with graded elasticity are the best.

Q: Is it wise to wear the support stockings type Duomed grade 2 all day? Also if you're most of the time bedridden? Or are there risks?

A: Duomed grade 2 are best worn when upright, as they are intended to reduce blood pooling in the legs on standing.

Q: Does it do harm to wear support stocking when lying in bed? What are the risks?

A: Unlikely to do harm. But if you are lying in bed it's not sure if it will necessarily help with OI symptoms.

Q: I read about tilt training, Nowadays I bicycle half an hour a day. Is tilt training a good advice to try in POTS ?

A: Tilt training is a good idea . There is evidence that tilt training 'resets' some elements of the autonomic nervous system and helps with symptoms. We have also trialled it in ME and found people are able to do it, and it works to help with autonomic problems.

Q: Why do 90% of the ME patients describe symptoms of orthostatic intolerance and only around 30 % POTS? May this be due to stages in the disease?

A: POTS is one form of OI. There are others such as neurally mediated hypotension and orthostatic hypotension. So OI is the symptom (which is common), whilst POTS or OH or NMH is the objective diagnosis.

Q: Is there anything known about pressure in the ears by me-cvs patients?

A: Pressure in the ears and ear problems is not something I am familiar with.

Q: If orthostatic intolerance is not yet officially diagnosed by a doctor, can an ME patient suffering from the symptoms of orthostatic intolerance start with the conservative advice without problems?

A: Absolutely. Starting with the conservative advice will be a good starting point and sometimes we recommend that to patients without the formal diagnosis.

Q: The skin on my upper legs is almost constantly burning, like of a sun burn. What can cause this? Is the blood circulation involved?

A: Sounds like some form of painful neuropathy.

Q: Do you ever test for autonomic nervous system antibodies in your patients with OI?

A: Sometimes, but not routinely we do in patients in the clinic with autonomic failure.

Q: Can you test for autonomic dysfunction in patients who can't stop taking Florinef as they take it for adrenal insufficiency? Would this invalidate testing?

A: Not necessarily invalidate testing. You just need to take it into consideration when interpreting the results, although having adrenal insufficiency is an exclusion for a diagnosis of ME.

Q: About the 'tilt training' you mentioned: I think many of us (with ME and POTS/orthostatic intolerance) are not able to stand for 30 minutes. The symptoms will get much worse and people will have fainted within that time. How can this training help? Should you increase the 'standing time' slowly?

A: Tilt training is 'up to' 30 minutes. Some people manage only seconds. It is for as long as you can do it without getting symptoms up to 30 minutes. So you stand until you get symptoms at which point you stop. If you go to the Newcastle Hospitals website and search for tilt training the procedure is there.

Q: Dichloroacetate (DCA) has been shown to reverse the muscle accumulation of acid in patients with ME/CFS. Is there a less toxic supplement we can use that also stimulates the pyruvate dehydrogenase enzymes just like DCA?

A: Not yet . That's the focus of our research at the minute.

Q: In the Netherlands ME/CFS is also considered to belong to a group of so called "not medically understood complaints". Like amongst others fibromyalgia. Would you agree in considering ME/CFS as a complaint which isn't understood, and develop research for ME as if belonging to that group?

A: Yes. But I would suggest caution. Not medically understood is not the same as not medically existent.

Q: If the blood flow to the brain isn't working good, shouldn't the blood pressure rise when I stand up to compensate the blood pooling in my legs? Instead of the blood pressure dropping?

A: Under normal circumstances perhaps . But in humans there are separate systemic (peripheral) and cerebral (brain) circulations that are regulated independently. I.e. when your systemic blood pressure drops there should be autoregulation to maintain brain blood flow. It is possible there is a problem with this in ME.

Q: In patients with say thyroid disease or adrenal insufficiency where treatment is deemed adequate but the patient has ongoing symptoms they often get diagnosed with comorbid ME/CFS. Would you exclude such patients from your clinic?

A: Generally I do not exclude them. My clinic is a fatigue clinic rather than an ME/CFS one. So we see all patients, whatever the cause of their fatigue.

Q: In the previous chat you mentioned that maybe there is a problem with the cerebral autoregulation. Can you explain why do you think there might be a problem for ME patients with this system?

A: In OI patients (specifically the ones with NMH) studies have shown there are problems with cerebral autoregulation and our MRI studies suggest that there might also be in ME patients. This is part of the current study and we are doing the analysis now.

Q: You said that people with 'POTS' could take beta blockers to slow down the heart rate. But I thought the rising of the heart rate is a compensation mechanism for the decrease in blood flow to the brain in an upright position. If you reduce the heart rate won't that even worsen the lack of blood flow to the brain?

A: We use very low doses of beta blocker which are there to reduce the heart rate but don't reduce the blood pressure. In POTS however the heart rate increase is inappropriate, so not always secondary to reduced BP.

Q: If the blood flow is (rather) constantly changing and cognitive functions relate to blood flow, why do the problems with cognitive functions not constantly change? In my experience those problems occur after having been active (physically and mentally). Therefore it does not seem logic to me that they directly depend on blood flow.

A: Yes I agree. But there is also the possibility that over time the changing blood pressure will lead to permanent damage to the brain.

Q: Not a question but a comment. I really like the way that you give credit to your team and "big up" your junior researchers when talking about the research you are conducting. I think this is a great way to get younger researchers involved. What young scientist wouldn't want to be involved in a team with such a leader.

A: Thanks, I love my work and I work with some great people.