

Wetenschap voor Patiënten (Science to patients)

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Seminar 21: ME/cfs and the heart

Prof. dr. Frans Visser, Dutch cardiologist. Broadcast 13th June 2013

My name is Frans Visser and originally I'm a cardiologist and have been for some 30 years. Yet these last five years I mainly focused on treatment, support and research of patients with ME/cfs. I have my practice in the location where we are at the moment, the Parkstad clinic in Amsterdam.

Chest pain

One could almost say that this is a cardiologic subject. And indeed many patients coming here with ME/cfs complaints, also suffer from chest pain. That pain may be squeezing or stabbing, and may go together with breathing. Of course its occurrence is extraordinary. Given the young age of patients, one doesn't actually expect them to have heart troubles, as chest pain usually has to do with the heart.

So chest pain occurs quite frequently. It is funny that two years ago research was done in England, to find out how often this occurred with ME/cfs patients. It was an interesting fact that with the patients in this study 80% of all people involved suffered from chest pain. This pain was located specifically on the left side of the breastbone, somewhere near the second and third ribs, close to the cartilage of the sternum. I think 80% a very high number, and of course I checked this systematically with ME/cfs patients. With my patients it occurs in 40 to 50 % of all cases. So it is a frequently heard complaint.

What causes chest pain?

That's a very good and interesting question.

First of all considering its location, it is most probably an irritation of the small joint in between sternum and rib. Yet in the English research a link has been suggested between this pain and the presence of large lymph vessels at that spot. Next to veins and arteries lymph vessels are a third kind of vessels. They drain redundant fluid from the tissues. The researchers suggested this pain mainly may have to do with the lymph vessels. A third possibility, in my opinion most interesting as well, is the occurrence of so called orthostatic intolerance complaints with ME/cfs patients. I'll come back to that in a later talk. One of the accompanying complaints is chest pain. In fact this is a pain signal generated by the brain; so it has nothing to do with e.g. a local inflammation. It's entirely a cerebral signal.

What can be done about chest pain?

What can be done about these pain complaints? Most importantly this depends upon the severity of the complaints. The more pain one has, the faster one is of course inclined to look for help from a GP or a specialist. Just for reassurance: by now I've seen some 2000 ME/cfs patients who also

had these chest pain complaints and - with a very rare exception - none of them showed severe conditions of the heart, such as venous obstruction, pericarditis or pulmonary complaints.

So although most of the time heart- or lung diseases aren't involved, it is common sense to visit a GP or a specialist when the complaints are severe, for further checkup. If results are normal, which once more is the case with the majority of all patients, for me pain killers are only appropriate when necessary, in the case of severe complaints.

What causes dyspnea?

Dyspnea is a common complaint with ME/cfs patients, and has been researched as well. Last year a large research study was published, comparing dyspnea complaints in ME/cfs patients with those in healthy people. It occurred in about 50% of all patients, and in just a few percent of the healthy controls. So compared with healthy individuals it occurs quite often.

Its cause is unclear. Dyspnea is a very complex interaction between heart, lungs, circulation but also the brain. Somewhere in the interaction between those four organs something goes wrong at a certain moment, and dyspnea arises.

Most important is what I have already said about chest pain: in people with ME/cfs, defects of the heart and especially of the lungs are actually hardly ever seen. So these don't cause the complaints. The interesting part is that chest pains are possibly part of the so-called orthostatic intolerance complaints. This again is a complaint generated by the brain. So it has no connection with the organs themselves. It is purely a wrong signal. Or rather a misplaced signal: one that fits in with a change in the brain.

What can one do against these complaints?

Once more most important is that a patient who suffers much from them, has himself examined by a GP or a specialist, to see if anything's wrong with e.g. the heart or the lungs. If that isn't the case, actually not much can be done against this complaint, and it comes down to reassurance. It is a complaint, but definitely not a severe one.

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Seminar 22: ME/cfs and palpitations

Prof. dr. Frans Visser, Dutch cardiologist. Broadcast 27th June 2013

What causes palpitations?

The main issue I want to talk about is that a lot of ME/cfs patients experience problems with a heart beating too fast when at rest. Moreover, one can also feel palpitations when the heart skips beats, beats irregularly or bolts for a while, but that will be discussed in talk 23. Right now I want to discuss the fact that with ME/cfs patients the heartbeat can be too fast while they are at rest.

The heartbeat when in rest

What's there to say about the heartbeat when at rest?

With healthy people without ME/cfs symptoms there's a tremendous range of heartbeats. With some people the heartbeat may be 50 beats a minute, with others it is usually 75 to 80 beats a minute. That differs from person to person and is normal. However, patients with ME/cfs symptoms can show a heartbeat that is faster than expected. Research has shown that the heartbeat of ME/cfs patients when at rest on average is faster than with healthy people. It should be noted though that here also we're seeing a wide range. Yet if a patient when at rest has a heartbeat above 100 – which does happen – it is of course a very abnormal phenomenon.

It is also important that this is a phenomenon occurring not only during daytime. For research also has shown that with ME/cfs patients their heartbeat is faster at night as well when they are resting and sleeping. So with ME/cfs patients this is a concrete phenomenon.

How can a faster heartbeat be explained?

Several factors are involved. First of all the heart and more specifically the heart rhythm is determined by two cranial nerves, a stimulating and a heartbeat inhibitory nerve. These two nerves are respectively called the nervus sympathicus and the nervus vagus. The nervus sympathicus causes the heartbeat to fasten and the nervus vagus slows down the heartbeat.

The balance between these two nerves determines the rate of the heartbeat under certain circumstances at a certain moment. When the nervus sympathicus – also called the stress nerve – starts to fire faster, the heart rhythm accelerates. But as the nervus vagus is firing at the heart simultaneously, it is possible that just if the nervus vagus starts to fire slower without change in the frequency of the activity of the sympathicus, the heartbeat rises. So in fact it's about a balance between these two nerves. And each disturbance or change in this balance causes a change in heartbeat. With ME/cfs patients it has been demonstrated that the sympathicus is more active,

but also that the nervus vagus is firing more slowly than in healthy persons. So both factors play a role. That is cause number one.

The second cause is the presence of stress-related hormones in the blood, called catecholamines. These hormones in the blood cause the heartbeat to accelerate. With ME/cfs patients has been demonstrated a higher rate of catecholamines in the blood compared with healthy people. So this factor contributes to a faster heartbeat as well.

A third and interesting factor is that with ME/cfs patients a lower blood volume in the body has been demonstrated. Where the bodies of healthy persons with a medium stature contain about five liters of blood, several researches showed the quantity of blood in the bodies of ME/cfs patients to be lower. I myself have been able to research this in the past as well, and the body of one patient contained even one third less blood. It can be shown with all sorts of intricate methods, but that's beside the point here. If less blood circulates through the body, the quantity of blood flowing to the heart with each beat will be smaller. Every beat less blood than normal is pumped out of the heart. Heartbeat and heart are one thing, but the quantity of blood the body requires is mainly determined by the request for oxygen and nutrients by all organs together. So if the quantity of blood per beat is less, the heart has to raise its beat to deliver a certain quantity of blood to the body. That's the third cause.

With ME/cfs patients, most probably caused by the lower quantity of blood in the body the beat will rise, to compensate for the lower quantity of blood the heart is pumping out. At last, and this has been demonstrated quite often as well, it's a fact that the immune system of ME/cfs patients is disturbed, and quite often activated. Activation of the immune system usually comes with an increase of the heartbeat. That's the fourth cause.

To summarize: the cranial nerves, the quantity of stress-related hormones in the blood, the quantity of blood in the body and the activation of the immune system simply cause the frequency of the heart to be higher when at rest.

What can be done about this?

How can this high heartbeat be put right?

First of all it is important to exclude all other causes of an increased heartbeat, at least if people suffer from it. If you're feeling the beat to be higher, it is common sense to have yourself examined by a GP or a specialist. Because anemia, a hyperactive thyroid and nervousness are all able to raise the heartbeat. So these have to be excluded first of all. Once these have been excluded and it forms an intrinsic part of the affliction, two possibilities are open. First of all by way of reassurance one can say: 'I know this is part of me, I know this is part of my ME/cfs problem'. If it doesn't bother you too much, it is best to reassure yourself without the use of medication.

But if it bothers someone highly, with heartbeat lowering medication like beta-adrenergic blockers such as Metoprolol, calcium antagonists like Verapamil and the completely new drug Ivabradine, one could try to lower the heartbeat. This is effectual, but there's one 'but' here. If the faster heartbeat is caused by a lower quantity of blood within the body and you start to diminish the

beat, you also lower the circulation of the blood and the quantity the heart pumps out. This can be a double-edged sword. With some persons that's not the case, and activation of the nervous system and the brain is the greater culprit. Those persons may benefit from it. So if the complaints aren't too many, I would simply do nothing about it. And if it's very disagreeable one could take medication and observe closely if this has the desired effect.

What causes the pounding of the heart?

What does exactly cause the pounding sensation of the heart?

As I have said before, the amount of stress-related hormones in the blood - the catecholamines - is higher, and they don't just accelerate the heartbeat but also the contraction of the heart. The heart may beat much more powerfully with every beat, and patients may feel this. Moreover it occurs quite frequently that with a more powerful beat the heart slightly touches the chest, as it were. Besides an unpleasant feeling that may definitely cause the pounding sensation. So this is a harmless and normal symptom which is interconnected with the contraction power of the heart.

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Seminar 23: ME/cfs and cardiac arrhythmias

Prof. dr. Frans Visser, Dutch cardiologist. Broadcast August 22nd 2013

What do cardiac arrhythmias feel like?

Today I would like to discuss cardiac arrhythmias. Last time we spoke about the accelerated heart rhythm one can feel, but now the subject specifically is disturbances in the regular rhythm of the heart.

To patients this may feel as if the heart comes to a standstill for a moment or palpitates all of a sudden, skips a beat, stands still and continues, and sometimes they also feel as if the heart beats far too fast or races, and it is also like a butterfly fluttering inside their breast. All these complaints may stem from the presence of an arrhythmia.

What is a regular heart rhythm, and which disturbances do occur?

What's a regular heart rhythm? When wishing to discuss arrhythmias, of course we have to discuss the regular rhythm first. A regular heart rhythm actually originates from one spot, high in the right atrium. An electrical impulse is generated there, which is conducted through both atria to the ventricles. That electrical activity, those electrical impulses from the heart cause the heart to contract, and actually that's the most important fact. So the electrical activity of the heart always precedes the heart's contraction.

If another spot than the one in the right upper side of the right atrium generates a beat, we call it an arrhythmia. In that case the initial activation starts at a different spot from the sinus node high in the right atrium. That is one type of arrhythmia.

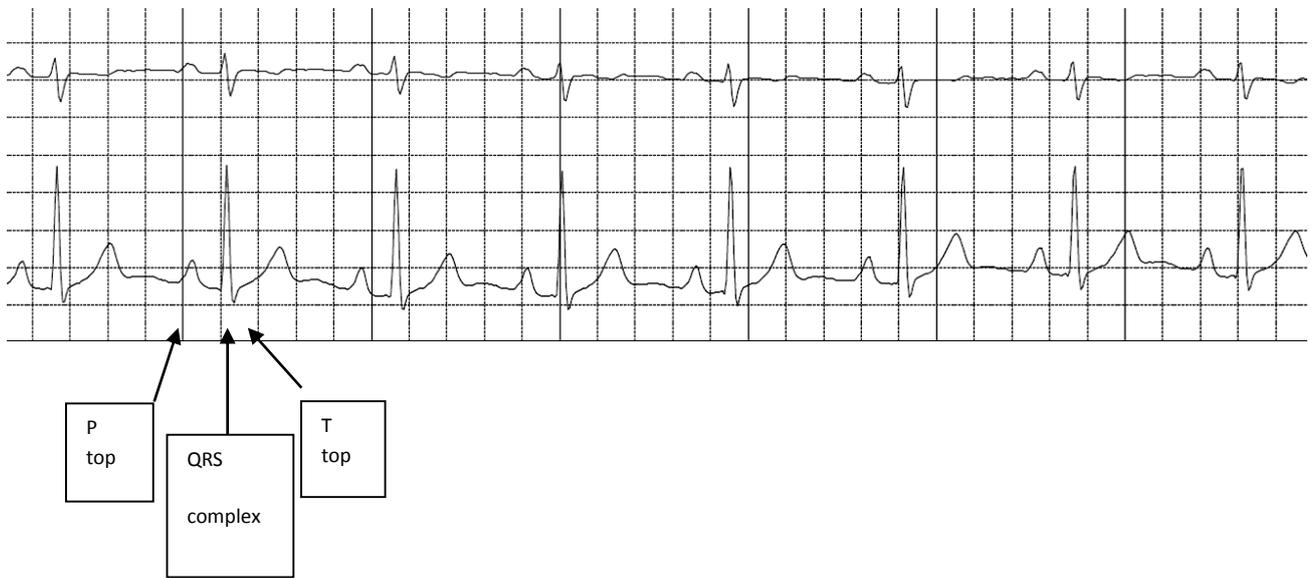
A second type of arrhythmia is the one where the heart beats too fast or too slow given a certain situation.

In addition to arrhythmias due to the generation of an impulse in a different spot in the body, we also have arrhythmias where the rhythm of the heart is too fast or too slow, compared to how the heart should actually function at that moment. The heart beating too slow is a separate subject which is not dealt with here, but the heart beating faster than it actually should, is a well-known symptom with ME/cfs and is called Postural Orthostatic Tachycardia Syndrome or POTS. This affliction we'll come to speak about in a later talk.

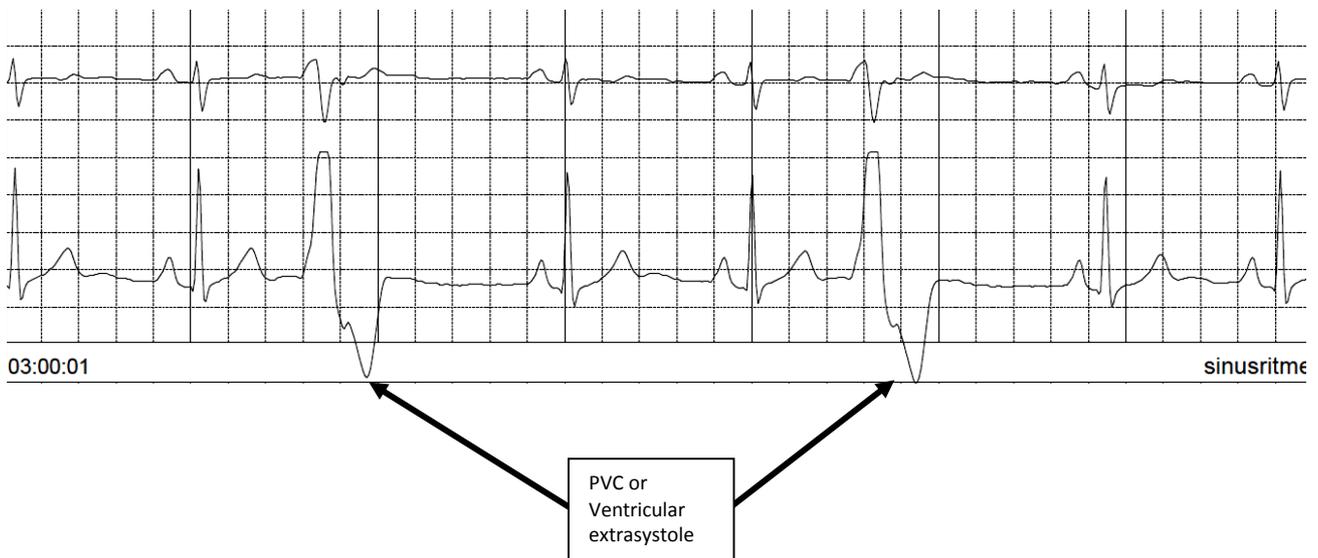
What does an ECG show?

Actually the ECG is a registration of fluctuations of the electrical activity in the heart. The first image shows a normal, regular rhythm. As can be seen, there are small and larger eruptions, which are called P-top, QRS-complex and T-top. This electrical activity of the heart causes the heart

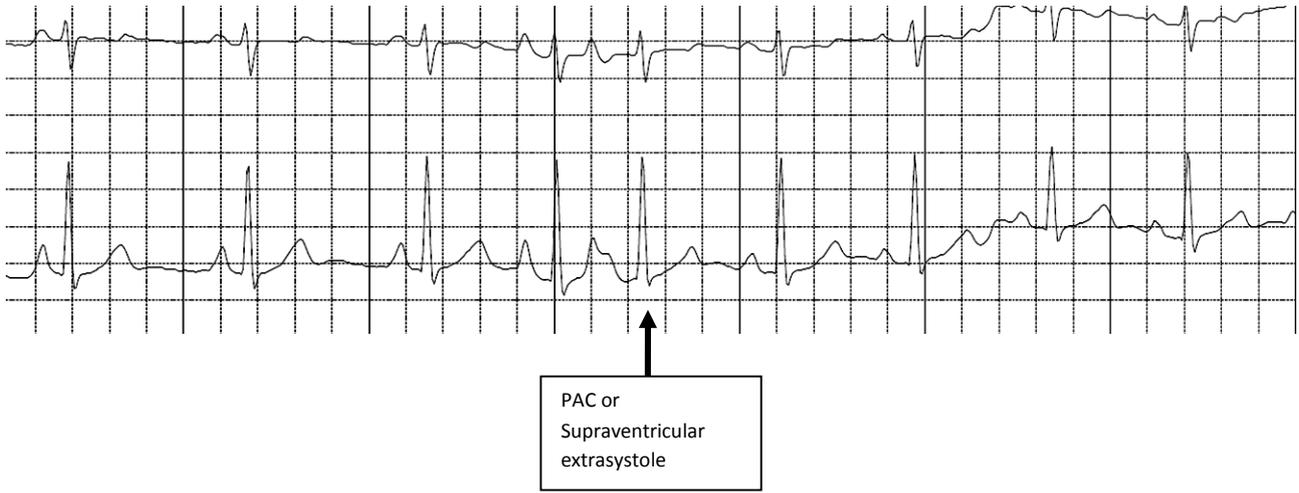
muscle to contract. As can be seen the activity of the heart takes place with regular intervals, with consequently a regular contraction of the heart.



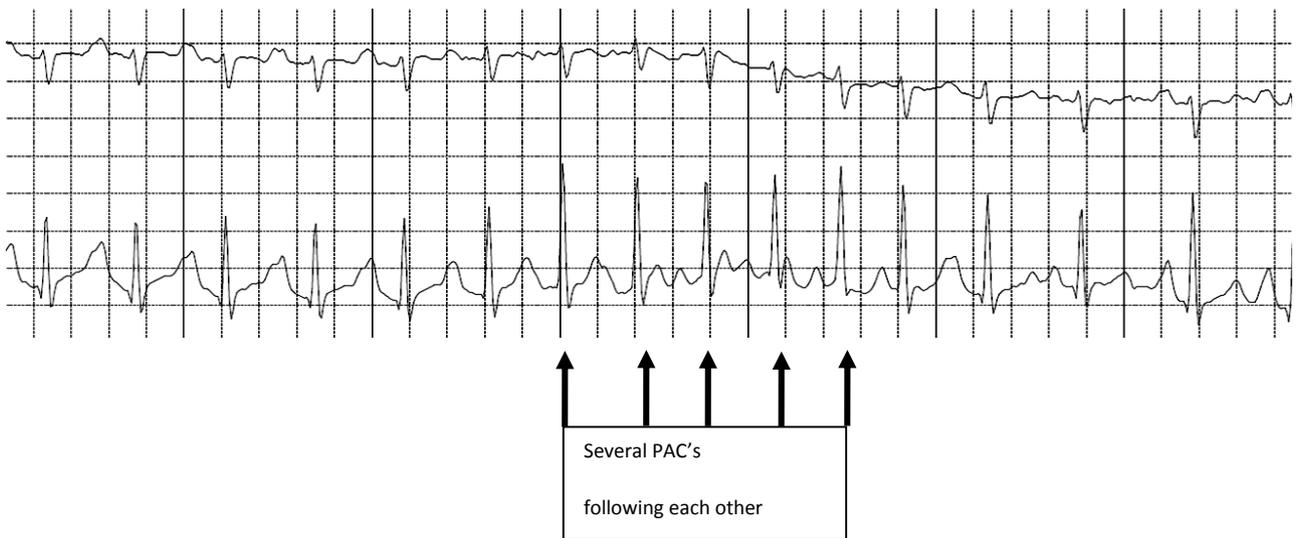
It's totally different in the next image. Also here initially you can observe a normal, regular and quiet rhythm. But at the two black arrows the normal electrical activity of the heart all of a sudden shows a completely different shape. This we call an arrhythmia where extrasystoles are involved, originating from the ventricle. Premature ventricular complexes they are called, and also ventricular extrasystole. So this arrhythmia comes from the ventricle.



And at the arrow in the next image an arrhythmia appears which originates in the atrium. At the start of the heart rhythm strip one can see a normal, regular rhythm, but then all of a sudden a QRS-complex appears much earlier than one should expect based on the regular rhythm. This is an arrhythmia from the atrium of the heart.



This may occur once, but the last image shows it's possible to occur several times at a stretch. Here five abnormal beats following each other can be seen, without the normal rhythm seen in between. This is called a short supraventricular arrhythmia or atrial tachycardia or supraventricular tachycardia - it has several names.



Do arrhythmias occur frequently with ME/cfs?

Do arrhythmias occur frequently with ME/cfs? When listening to my patients they often complain about the heart skipping beats, about extra beats, or about a heart that races. So indeed these arrhythmias occur quite frequently. They complain of the heart stopping for a moment and banging. This may be caused by an extra beat, followed by a short interval, after which the regular rhythm is resumed. The feeling that the heart is racing or the feeling of a butterfly in the heart may be due to the fact that a number of those abnormal beats occur swiftly after each other. This stops automatically, after which the rhythm takes its normal course again.

It's interesting that in spite of this happening quite frequently, in medical literature there's hardly any to none research at all to be found which focuses on arrhythmias in ME/cfs-patients. On different forums on the internet certainly something about it can be found, but not in official medical literature.

In my own practice I have compared the arrhythmias of cardiac patients with ME/cfs patients and actually with the latter, arrhythmias occur by and large slightly more frequently than with heart patients or patients who might suffer from heart problems. But as usual with these things there's a huge overlap: some patients hardly have any arrhythmias, others quite a few. This also applies to healthy people.

How do cardiac arrhythmias arise?

How do cardiac arrhythmias arise. What's the cause of these disturbed rhythms?

Actually there are two explanations. First the hearts of both healthy people and ME/cfs patients skip beats quite often. The big difference with healthy people is, in spite of the fact that their hearts do skip beats, healthy people don't feel it. This is the case with a large majority of people. Patients with ME/cfs complaints also skip beats, but they have grown accustomed to carefully watch their bodies, e.g. to avoid overburdening, overexertion or other complaints. So it might well be that ME/cfs patients feel it better because their focus on their own body is stronger.

A second and different explanation is that with cardiac arrhythmias not just the heart but also the nerves of the heart are involved. And as I said earlier, with those nerves, the sympathetic nerve and the vagus nerve abnormal reactions may occur. They may fire too fast or too slow. Most probably it is due to the fact that an abnormal nervous system is involved, that arrhythmias occur more frequently in ME/cfs patients than in healthy people.

So both heightened awareness of the heart skipping beats and the involvement of the central nervous system with an arrhythmia explain the occurring of arrhythmias.

How can arrhythmias be treated?

First of all this too depends on how much, how often and how seriously the arrhythmias and the skipping of heartbeats do bother you. If they bother you a lot, it is always wise to have the cardiac rhythm examined by means of an ECG or a long-term registration of the ECG, which can be done by a GP or a specialist like a cardiologist. If for the rest the heart is healthy, the arrhythmia in itself cannot cause much harm.

With people who have a healthy heart, a heart which functions well with heart valves which function normally, a large number of arrhythmias may occur without the heart being damaged by them in the least. In such a case recognition of the complaints and reassurance suffice. If that's adequate enough, you don't have to do anything else. If people are troubled a lot, the arrhythmias can be treated with several drugs. But like every drug these come with side effects in a certain percentage of people. Therefore it's always important to compare the advantages of treatment with e.g. a beta-adrenergic blocker or a calcium channel blocker with the possible disadvantages of side effects. Actually it again depends on the degree and seriousness of the complaints if someone wants or has to be treated or not.

Finally: this is just a limited number of arrhythmias which may occur. If different, serious arrhythmias occur, of course I think research and treatment are always necessary.

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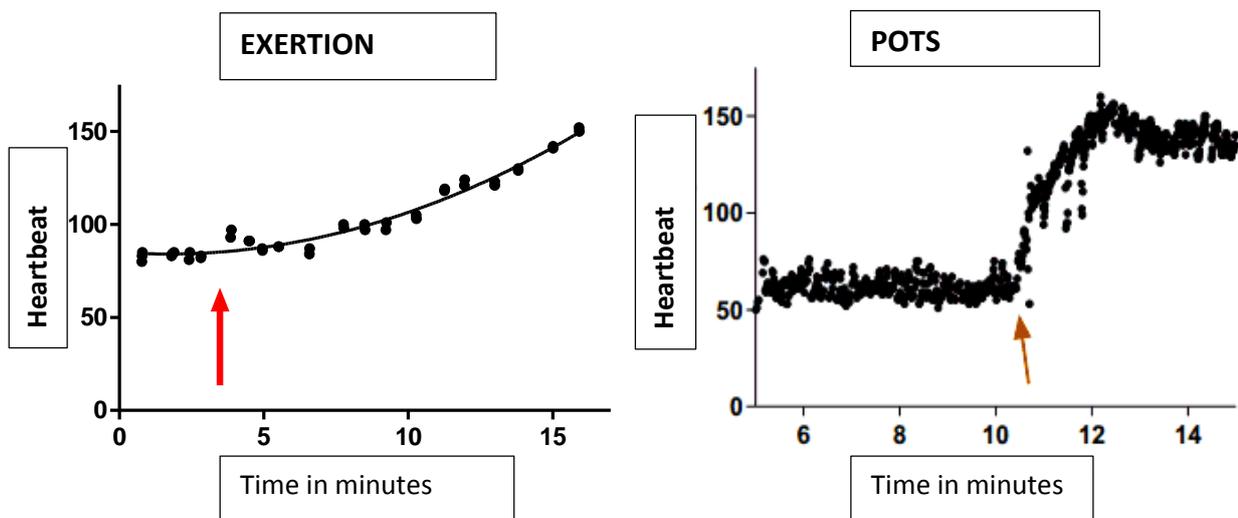
Seminar 24: ME/cfs and POTS (Postural Orthostatic Tachycardia Syndrome)

Prof. dr. Frans Visser, Dutch cardiologist. Broadcast 4th September 2013

What is POTS?

In the last lecture we talked about arrhythmias caused by the heart skipping a beat now and then. In this talk we'll discuss a very special arrhythmia which only the last few years aroused a lot of attention, and that is POTS or Postural Orthostatic Tachycardia Syndrome.

A POTS is an atypical increase of the heartbeat during a situation in which the heart should be in rest. To illustrate the difference between POTS and a rise of the normal physiological heartbeat, I'd like to show the next two illustrations:



In the first illustration the beat is registered at the moment someone starts to exert himself. At the red arrow the exercise starts, in this case on a bike, and after he starts cycling you can see the heartbeat rising slowly and steadily up to a certain maximum. This is a regular physiological phenomenon, which is as it should be.

But let's compare this to the occurrence of POTS or Postural Orthostatic Tachycardia Syndrome. Here I have included an illustration of the heartbeat of someone who underwent a tilt-table test.

Left of the arrow we see somebody in rest. The focus here is on the heartbeat, which averages 50 to 60 beats a minute. At the red arrow the tilt-table is turned into a vertical position, and very shortly after putting someone upright, within a few minutes, in this case the heartbeat suddenly rises from 60 to 150. This is a very abnormal reaction.

POTS is a phenomenon that only these last few years caught the attention. It was described already in the early nineties, but only the last three years a tremendous flood of publications on it appeared in medical literature. I've looked it up. Of all publications in the last 23 years 40% appeared in the last three years. This indicates what an enormous interest there is in POTS at the moment.

When do we talk of POTS?

These last years very conclusive standards have been developed to determine whether someone suffers from POTS or not. Most important is that after tilting the table, within ten minutes the heartbeat must rise with at least 30 beats. This increase shouldn't go together with a decrease of the blood pressure such as a decrease of the systolic pressure of over 20 mm of mercury. This criterion has been developed because when pressure drops, the heartbeat rises automatically. So within 10 minutes an increase of 30 beats, without the pressure lowering. Moreover it's important that a separate criterion for children has been developed. With them it's a matter of an increase of 40, not 30 beats per minute.

Of course some criticism on such a standard is justified. Why 30 beats? In other research - for instance- 27,5 beats have been used as a criterion. It's of course a rather black and white standard. If your heartbeat increases with 31 beats you suffer from POTS and with 29 beats increase after tilting nothing's wrong. This of course isn't realistic, but it is better to have a standard than no standard at all.

Does POTS occur frequently?

Does POTS occur frequently? Before talking about the frequency of POTS occurring with ME/cfs patients it's important to consider the fact that POTS doesn't occur only with ME/cfs patients, but with other afflictions as well. An incredible lot has been published about it the last few years. POTS doesn't occur only with patients suffering from ME/cfs, but also with fibromyalgia, MS, psychiatric syndromes, hyperventilation, following an operation and you name it. Besides this, links have been suggested with female hormones for example and it has been discovered that more than one gene is involved. The genes which play a part in the regulation of the blood pressure are involved. In short, POTS does occur in tremendously many syndromes. Recently POTS has been discovered in a new kind of fibrous tissue disease. It occurs with all kinds of syndromes and in all kinds of circumstances. Most probably with the current state of affairs more causes and connections will be discovered in the coming years.

To return to the question how often POTS occurs with ME/cfs patients. In medical literature a large variety of frequencies has been described. In one study 10% of the persons have POTS, and in another one a maximum of over 40% of the persons suffering from ME/cfs have POTS.

I myself have done quite a lot of research on this amongst ME/cfs patients during the tilt-table test, and have discovered it to occur with only 5%. So there's an insanely vast difference between researchers and research centers regarding the occurrence of POTS. This is most probably due to the fact that we don't know exactly in what context a patient comes to a center. How often he has been examined and which symptoms have been examined. Officially this is called inclusion bias. Large variations, but as for me it occurs with a minority of all patients.

Which complains are characteristic for POTS?

More important than the phenomenon itself are of course the accompanying complaints. First and foremost when your heartbeat rises for example from 60 to 150 beats a minute you obviously will have palpitations. But it invokes a number of other complaints as well, which we can summarize as orthostatic intolerance. Like complaints of dizziness, lightheadedness, nausea, transpiration etc. Complaints of orthostatic intolerance will be discussed in a later talk.

A very important study in my view shows that persons not only have complaints from POTS, but in persons who have a POTS-reaction during the tilt-table test it has been registered that also the higher functions of the brain or the cognitive functions do decrease. So POTS not only causes complaints but also a number of measurable deviations in processes like thinking, memorizing etc.

What can be done against POTS?

As stated before we talk about multiple causes and connections. It's not that simple to do something about it, because possibly many causes and illnesses lay at its basis.

Generally speaking one thing is important, which is something very simple to do. POTS also occurs with underfilling. If one drinks too little, a POTS-reaction definitely may occur during the tilt-table test. So drinking sufficiently is a very important and simple hygienic dietary measure.

Secondly if in spite of adequate filling POTS occurs, one could try to prevent the abnormal rise of the heartbeat with drugs. This is possible with drugs like beta blockers, Verapamil or Ivabradine. A whole gamut of other drugs has been tried out, and presently there are both positive and less positive results. Actually if one has complaints of POTS and one is severely bothered by them, it is just a matter of trying out drugs, and finding out which one helps.

Are long term complaints of POTS harmful to the heart?

The question is if POTS harms the heart if it occurs over a long period of time. There is no indication at all that a fast heartbeat over a long period of time is harmful to the heart. Although this has not been researched extensively in medical literature, I think the effects are not particularly bad. Secondly it's a fact that ME/cfs patients especially stand less, rise up less and walk less than other patients. So in my opinion it's not harmful to the heart.

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Seminar 25: ME/cfs and the blood flow in the brain

Prof. dr. Frans Visser, Dutch cardiologist. Broadcast 19th September 2013

What causes the feeling of dizziness?

In this talk I would like to discuss the blood flow in the brain. One of the complaints which actually struck me from the very start, was patients suffering a lot from dizziness. Not only while standing up, which healthy people experience quite frequently too, but also while standing on their feet for a longer period of time, walking or after any exertion. To such an extent that patients if they don't take proper notice, could faint. That's an abnormal phenomenon.

Generally speaking about the cause of dizziness: at the moment a person feels dizzy, the blood flow to the brain is being somewhat insufficient. That is, as far as the blood flow is concerned, and as a cardiologist you focus on the heart and vessels. That's why I investigated it further.

By the way it is quite striking that - as far as my experience goes- in spite of over 50% of people having complaints of dizziness when getting up, standing on their feet, walking etc. it is brought forth very summarily in the guidelines. Like in the new International Consensus Criteria, in the last criterion D, concerning transport capacity and energy production, only some mention of dizzy spells is made somewhere.

In my opinion it doesn't get the place it deserves in those criteria. As I will show later on, quite important deviations have been found with this kind of patients.

Is there an explanation for an abnormal drop of the blood flow?

Actually at present that's not quite known. I personally think there is more than one explanation.

The first one is that the cranial nerves are involved in the regulation of the blood flow to the brain. In these, deviations are possible. In that case the regulation of the blood flow -for example- isn't in harmony with the need for blood of the brain itself.

Secondly, as I already said before, a possible explanation is that the total quantity of blood in the body is less. It's easy to imagine that if someone stands up or starts walking, more blood flows to the legs, which may well be at the cost of the blood supply to the head.

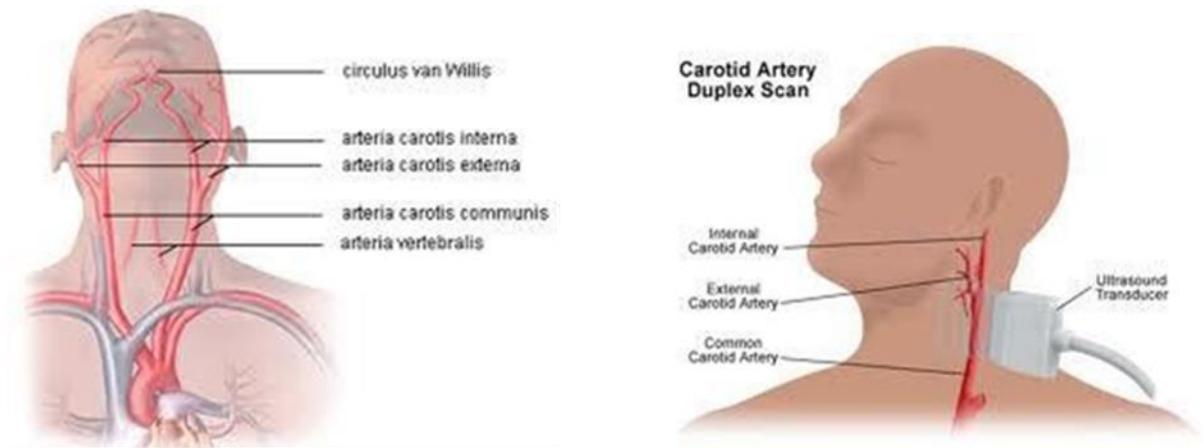
Thirdly I also discovered that when with a tilt table test you look at the quantity of blood returning to the heart from the legs and the belly, you notice it has lessened. Though I don't have exact figures, I have the impression that this goes together with a lower quantity of blood. About the reason why less blood gets back to the heart of the patient, due to the fact it remains behind in the legs and the belly, we can at present only speculate.

How can you measure the blood flow of the brain?

Blood flow through the brain can be measured with all kinds of intricate and expensive equipment such as an MRI, Positron Emission Tomography and Single-Photon Emission Computed Tomography or SPECT. These are all quite expensive and intricate research methods. The last two of them also make use of radioactivity.

But there's another - much simpler- method , which is to measure the blood flow by means of echoscopy. That's a test I've done with a lot of patients in different positions. I did it while they were laying down, sitting and standing, during the tilt table test and even while exercising. Now I will go into somewhat more detail about the way I did it and with what results.

Two images to illustrate this.

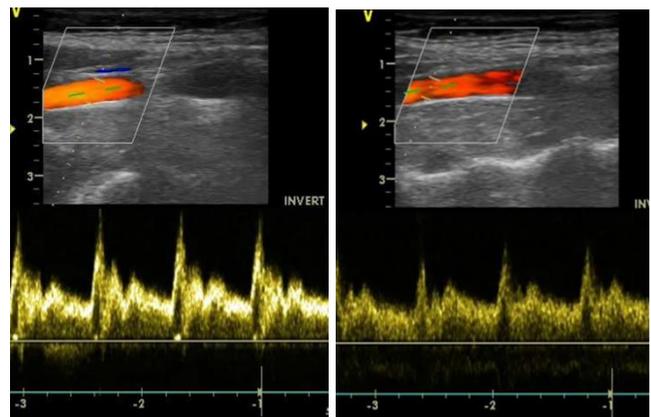


The first image shows the course of the blood vessels leading to the brain. They are arteries. Actually four arteries from the heart are involved in the blood flow to the brain. In this image it is indicated in red how from deep down within the breast vessels on the left and on the right lead to the neck. They are called the arteria carotis externa and interna. The arteria carotis interna is the artery leading to the brain, and is situated on the front side. One can vaguely see two other arteries, which are the arteria vertebralis, left and right. They run on the hind side, through a hole as it were between the prominences of the cervical vertebrae. These four arteries provide the brain with blood.

Now how can this be measured? As I said, with the help of echoscopy. In the right half of the picture you can see the recording head of the echoscopy device being put on the artery. An echoscopy is simply based on transmitting and receiving sound waves. In this way you're able to chart images of the arteries leading to the head.

The next picture shows an example of such a recording.

In this picture we see two recordings, one on the left side and one on the right. The one on the left is a recording of a patient laying down and the one on the right after he's been put on his feet during a tilt table test.



Top left an orange spot can be seen. That's the registration of the blood flow within the artery of the neck. In this case it is the arteria carotis interna. It's a bit of a peculiar image, but on the right side the breast is indicated and on the left side the head. Halfway between the breast and the head the artery can be measured, and within that artery the flow rate of the blood can be determined. Those flow rates are shown at the bottom of the picture. One can see the flow rates, shown in yellow, increasing and diminishing again. That is cyclic. That increase and decrease are entirely due to the activity of the heart. When the heart pumps out blood, all of a sudden there's more blood in the arteries of the neck. Which subsequently decreases until the next beat.

On the left side a resting position is shown, on the right side a registration of the same patient, but during tilting. In that flow rate picture one sees that particularly after tilting somebody the blood flow rate is considerably lower than when he's lying down. With this patient it was diminished with some 23 %, if I remember rightly. So a decrease of the blood flow of 23% with tilting – that's considerable, and more than has been recorded in healthy people.

In this way the flow rates can be made visible in many different ways. I did so with a large number of patients. At first simply while they were laying down or sitting. Then the blood flow appeared to decrease with about 12% when someone was sitting, compared to when he was laying down. Actually this is quite peculiar. Just put somebody with the upper part of his body in an upright position and you already see a decrease of on average of 12%. When persons are actively standing up without a tilt table test, the decrease is 18% and with the tilt table 19%. These decreases are much larger than one should expect from what is known from publications.

To give an example: when one gets up the blood flow rate can decrease with 10-12% at most. When one sits down the blood flow rate can decrease with 5-9 % at most. In other words, with ME/cfs patients a decrease in blood flow occurs much more often than one would expect from medical literature.

What can be done about a decreased blood flow within the brain?

What can be done to a decreased blood flow within the brain right now? This is all quite new and it actually boils down to the fact that there are absolutely no drugs available to enhance the blood flow within the brain.

Research on a number of drugs is scant, and the ideas about this subject still have to crystallize. Very little can be done about this with drugs. Right now the most important thing is to be aware of complaints that occur, like dizziness, which can be a signal for worse situations like fainting. And that one should absolutely take precautions.

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Seminar 26: ME/cfs and neuropsychological symptoms

Dr. M. Vollema, Broadcast 3th October 2013

I'm Meinte Vollema. I'm a clinical neuropsychologist. That is someone who's specialized in the relation between our brain and our behaviour. Someone specifically involved with a variety of cerebral functions like attention, concentration, speech and higher mental capacities like planning and organization. A clinical neuropsychologist researches and diagnoses them, and tries to invent and implement all kinds of treatment.

I'm working as a psychologist in a large mental health facility and besides that I'm a member of a private practice of psychologists.

The main part of my job consists of diagnosing and treating people with all kinds of dysfunctions of the brain which occur more or less frequently. They may include ADHD, autism, whiplash, epilepsy, schizophrenia or dementia. Through other people I came into contact with professor Visser and took a neuropsychological interest in people with ME/cfs.

What is known about neuropsychological symptoms with ME/cfs?

What is known in scientific literature about cognitive disorders with ME/cfs? Last year I dived deeply into this and found a lot of articles about this subject. I can be brief. Just recently, in 2010, a very large survey in this field was published on the relationship between ME/cfs and cognitive disorders. Which is another term for neuropsychological symptoms. In this extensive survey 52 smaller studies have been examined, with the conclusion that rather severe so-called cognitive disorders have been shown to exist in people with ME/cfs. First and foremost of these is the problem of data-processing. Particularly that the processing of data is delayed. Secondly there's a serious problem with attention deficit disorders.

That's what is generally known from the literature and can be seen quite frequently as well. You can also distinguish a difference in proportion. Delayed data-processing disorders come first, followed by attention deficits.

What do you as a practicing neuropsychologist notice in people with ME/cfs?

First of all I've seen only twenty people, so my experience isn't that broad. But if I'm permitted to summarize, I'm noting exactly the same things which literature sums up. I do notice serious attention deficits and problems with data processing.

I can briefly elaborate on this. I notice that while processing data problems especially occur due to a delay. People show a delayed process of information handling. That is to say, they read more slowly, write more slowly and absorb information more slowly and they react more slowly to visual impulses. This really takes place much more slowly than with an average normal person without ME/cfs. They show a very slow reading speed, to summarize.

Secondly I notice serious attention deficit disorders. Visual attention is disturbed. Patients can't keep attention at a certain high level over a period of time. Fluctuations in attention occur. At times it is sharp; at times less sharp.

Thirdly with the twenty persons I've seen I noticed a lot of problems with their alertness. Many visual impulses offered to people with ME/cfs don't seem to get through. They are missed or not picked up in one way or the other. That may be quite disadvantageous and quite a nuisance. Just think of traffic and driving a car. Those three aspects of attention deficit disorders and the problems people have with these, have struck me in a large number of the people I've seen.

Then there are memory problems. I consider those to be a reaction. I don't see primary memory disorders. I notice problems with memory, but these are mostly the result of people who cannot concentrate. Maybe that's why they can't listen to others quite well, and as a consequence can't recall things that well. But as far as I - as a relative newcomer in this field- can say something about this, the primary basis seems to be a serious delay in data processing and in attention deficits.

Which consequences do these neuropsychological dysfunctions have in daily life?

The question is which consequences these neuropsychological dysfunctions have in daily life. Of course this can vary from one ME/cfs patient to the other. On the one hand it depends upon the kind and the extent of the cognitive disorders, on the other hand it of course also depends upon people's expectations of daily life. Of the functions, jobs, hobbies, etc. they still want to be able to do. But from the 20 people I've seen, in general it can be stated that because of the attention deficits and the problems with data processing severe invalidating phenomena may occur in daily life. Like study activities proceeding problematically or not at all, a job which can hardly be done or not at all anymore and disappointments while working on ones hobbies.

One should know that the data processing system in people with ME/cfs is seriously delayed. That's why everything surrounding these people probably goes too fast for them, as far as I can judge. They're living in a world which is far too fast and hasty. So having a normal conversation with someone is a disaster, it's hard for them to read a newspaper. One thing people often tell me, is that they can't follow the subtitles of a film etc. These are very obvious, bothersome, invalidating consequences. If you suffer from quite a number of such cognitive disorders which subsequently all hinder you, you may end up not being able to continue your study or job, and you may become homebound.

Are these cognitive disorders known to be permanent?

I know little about that. In any case from what I've read and also see daily, many patients with ME/cfs suffer from cognitive disorders. These two things go hand in hand, are strongly correlated, are mutually strongly associated as we call it. But it is rather hard to tell their causal relationship; which comes first, the chicken or the egg? Do these cognitive disorders possibly stem from ME/cfs, or is it the other way round and do these cognitive disorders cause ME/cfs? Or is there a third, unknown, missing, clarifying factor laying behind this? We don't know.

We also don't know whether they're permanent. What I hear from patients I talked to, is that the cognitive disorders I find in them, some of them have been suffering from for five or even ten

years These are indications of the chronic, long lasting existence of the disorders. How developments would be if there were an adequate treatment we of course don't know.

Does your specialism provide a treatment for these neuropsychological disorders?

The question is if there are neuropsychological treatments for ME/cfs-patients. I will sum up a few things I'm doing and trying, emphasizing the word trying to be honest. Presently there's no curing treatment for ME/cfs. This also includes my specialism which is rather new within the field of ME/cfs and is focusing in the first instance on diagnostics, on examining people.

I can mention a couple of things. I'm giving so-called psycho-education. This implies an extensive neuropsychological examination, the results of which are discussed with the patient, so as to let him or her recognize certain things. Maybe to get a better insight in his or her problems regarding attention span and possibly memory as well. This insight is something to start from.

But from my specialism I know that with a certain group of drugs very specific attention deficits can be remedied. In some ME/cfs patients we notice specific attention deficits regarding concentration. They may be remedied with certain drugs. I'm not sure, only little has been written about it. It is at least worth a try. I also know that in my field of expertise digital cognitive trainings have been developed for people with brain damage and cognitive disorders, attention deficits. We could also try and test them with people with ME/cfs. They might work or not, no one knows.

Another thing which we could do from a neuropsychological point of view is to make people more aware of their possible cognitive disorders so as to learn to accept them. And we could try to offer them a kind of compensating supporting treatment. So we can bypass those weak aspects and fortify others.

In a nutshell these are a couple of things I can tell about this.

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Seminar 27: ME/cfs and orthostatic intolerance

Prof. dr. Frans Visser, Dutch cardiologist. Broadcast 17th October 2013

In this talk I would like to pay attention to the complaints and symptoms which are specific for orthostatic intolerance.

That's a very difficult word of Greek origin, but it just means one isn't able to stand on one's feet very well and is getting complaints from it.

To start with a question to those who suffer from ME/cfs: do you also loathe to queue up at a cash desk? Well, I do, because I for one always seem to choose the wrong desk. Sufferers from ME/cfs may not only choose the wrong queue, but may have a whole gamut of complaints as well, like dizziness, nausea, sweating, pain on the chest, dyspnea etc.

All these complaints together, which are typical for a certain posture or change of posture are called orthostatic intolerance.

Which complaints belong to orthostatic intolerance?

So it may be that patients don't just complain of dizziness or lightheadedness, but also of muscle weakness, decrease of sight, pain in neck and shoulders which is a very characteristic phenomenon called "The Coat Hanger" phenomenon. Patients can also start to suffer from dyspnea, remember talk 21 about that subject; they can get nauseous, get a tingling skin which may even change colour, they can get palpitations – see talk about POTS – become increasingly tired, start perspiring, get auditory disturbances, chest pain, low-back pain, cold hands, headaches or pressure on the chest. In short a large number of complaints may be linked to orthostatic intolerance.

How does orthostatic intolerance arise?

How does orthostatic intolerance arise? If you have listened to my talk on the blood flow within the brain, you may suspect that orthostatic intolerance has to do with the blood flow within the brain. I compared patients who got complaints during a tilt table test with those who didn't, regarding the flow within the brain. And it resulted in the finding that with patients complaining of orthostatic intolerance the blood flow to the brain decreased much more than with patients without those complaints. So orthostatic intolerance is connected with the blood flow of the brain.

We discussed that in the last talk as well.

This decrease of blood flow within the brain may occur in many spots. That's why I think the diversity of complaints and symptoms has to do with a lower blood flow in parts of the brain.

Something I didn't mention before and which is rather characteristic, is people at a given moment being unable to stand on their feet while taking a shower. This is caused exclusively by the skin getting warm during a shower and more blood flowing to the skin. This probably takes place at the cost of the flow within the brain. These are typical complaints fitting into the frame of orthostatic intolerance.

What can be done about these complaints?

What can be done about these complaints? As I said earlier, presently the blood flow within the brain can't be influenced with drugs. Most important is recognizing these complaints, because when they get worse, they may cause someone to faint. Moreover, drinking sufficiently has been mentioned before as well. It is important to prevent an underfilling of the body.

Finally there are signs that compression socks used by athletes may improve the complaints one has from orthostatic intolerance. These aren't hard facts as yet, but it's surely worth a try.