

Wetenschap voor Patiënten (Science to patients)

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Seminar 21: ME/cfs and the heart

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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.