

Wetenschap voor Patiënten (Science to patients)

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On Friday 28 March 2014 dr. Charles Shepherd answered questions in a chatwing-session. These are the Q&A of this session.

Q: My ME/cfs was probably triggered 13 years ago due to being pregnant. After 1 1/2 year I felt better, but always very tired. It never went away. Inflammations. Is this also known as a trigger for ME? What do hormones have to do with it? Now that I am 44 years old, there is a new inflammation of ME since 1 year. Do hormones maybe play a role again?

A: A number of what we call immune system stressors can trigger ME/CFS - one of which is pregnancy. The explanation probably involves a combination of immune system and hormonal changes that occur in pregnancy. Also interesting to note that a significant number of women with ME improve when pregnant.

There is also some research information (paper in The Lancet from gynaecologists Studd and Panay) to indicate that changes in female hormone patterns can affect ME/cfs symptoms. It's referenced in the MEA purple booklet: Studd J and Panay N. Chronic Fatigue Syndrome. Lancet, 1996, 348, 1348.

Q: How do pregnancies usually progress for women with ME/CFS? How common is it that there is an improvement? And does this improvement last after the pregnancy? And are there risks?

A: Most (but not all) women notice an improvement (sometimes quite significant) during pregnancy. Unfortunately, many then return to their normal state of ME/CFS once the baby is delivered and life gets more physically and mentally demanding! Are you involved in getting pregnant when having ME/CFS? A good review of what happens to women with ME/CFS during pregnancy you'll find in this paper - Schacterle RS and Komaroff AL. Archives of Internal Medicine, 2004, 164, 401 - 404.

Q: In your college you mention several possible causes of ME of CVS. What do you think of the role of ongoing stress? Can it be a cause of ME/cvs?

A: To clarify: I am saying that there are a number of factors that involve a stress on the immune system response which appear to be involved in triggering ME/CFS. Infections (viral more than bacterial) are the most common - but other triggers include vaccinations, trauma, operations, pregnancy and pesticide exposure. Mental and/or physical stress can be an important factor in both helping to trigger ME/CFS when, say, you have an infection. Ongoing stress can also be an important factor in preventing or delaying any natural recovery process that may be taking place. And this is why stress management (through relaxation, meditation etc) is an important part of management if/where stress is playing a role in maintaining the illness.

Q: In your college you mention a large number of possible causes. How is it possible that so many various illnesses all can cause the same illness ME in the end?

A: There isn't a single underlying problem in ME/cfs. The illness is maintained by a complex interaction involving a number of brain abnormalities plus abnormalities in the immune system, hormones and a biochemical deficit in the way the muscles produce energy.

Q: Do I understand well that physical stress has the same impact on the brain as other stress, such as fright?

A: There are similarities and differences as to how the body responds to physical and mental stress. With mental stress part of the nervous system called the autonomic nervous system goes into overdrive with the production of chemicals (e.g. adrenaline) that produce symptoms such as raising the pulse rate and sweating.

Q: Is it possible that the hormonal changes during the menopause cause less bowel problems due to ME/CFS, such as chronic diarrhea?

A: I don't think you can easily link hormonal changes during the menopause to the very common irritable bowel type symptoms that occur in ME/CFS. This is more likely to be due to a disturbance in a part of the autonomic nervous system that controls the emptying activity in the bowels. Changes in a chemical transmitter called serotonin may also be involved in the irritable bowel type symptoms that often occur in ME/CFS

Q: Do the hormonal changes during the menopause commonly cause no changes in ME/CFS symptoms?

A: Hormonal changes that take place during the menopause can cause a number of symptoms that also occur in ME/CFS (e.g. sweating, fatigue, problems with memory and concentration) So it is quite common to find that women going through the menopause report an exacerbation of their ME/CFS as well.

Q: What is the SMILE-trial actually about?

A: The SMILE trial is a UK trial that has been looking at the feasibility of using the controversial Lightning Process as a form of treatment for young people with ME/CFS. The MEA opposed the trial for a number of reasons and argued that if a trial was going to take place it should involve adults, not children.

Q: Is the main question: where do the abnormalities start, in the brain or peripheral?

A: I think the sequence of events is that a triggering infection causes an abnormal immune response (possibly involving over-production of chemicals called cytokines) which then affects various parts of the brain and the brain-hormone systems (especially hypothalamus and cortisol production).