

Wetenschap voor Patiënten (Science to patients)

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Seminar 40: ME & possible treatments

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What are the most common symptoms in ME?

The most common symptoms in ME are I think grouped under three main headings: the brain symptoms and in particular here we have what we call cognitive dysfunctions. This is problems with normal mental activity, problems with short term memory, concentration, attention span, being able to process new information and retrieve information. Balance problems are a characteristic feature of this illness. People don't describe this as sort of feeling dizzy, spinning round, but they say that they feel as though they're constantly unsteady when they're walking along. As though they might be walking on rubber or so they probably had too much to drink. We know that the balance centers in the brain may be disturbed in this illness.

A third part of the brain abnormalities in this illness causing brain symptoms, is what we call symptoms relating to the autonomic nervous system. In medical jargon we call this orthostatic intolerance. This is problems related to being able to stand up for a long period of time. Or symptoms relating to changing posture from being flat or lying down to standing up. In which case there may be a change in or lowering of blood pressure causing what we call orthostatic hypotension; fall in blood pressure when changing posture. This causes problems such as feeling faint, sweating or even feeling sick.

So we have this group of important neurological symptoms, which I think fully justifies this disease being called a neurological illness by the WHO. We then have the very characteristic muscle symptoms which I already described, the exercise-induced muscle fatigue, pain which can be very severe in some people. It's not always present as muscle pain but muscle pain can be a very major feature of this illness. We then have what I call the infective immunological type symptoms; a feeling as though you got a sort of ongoing flu-like illness which may be accompanied by feelings of sore throats, enlarged glands.

And then finally, I think the other key symptom of this illness is the sleep disturbance. So I think you cannot have this illness without some form of sleep disturbance. It's interesting that in the very early stages this sleep disturbance may be an excessive requirement to sleep what we call hypersomnia, particularly in the early post viral stage. Then this quite often moves on to another type of sleep disturbance where people have either difficulty initiating sleep, getting off to sleep, they have erratic sleep, they wake up early in the morning. But they're no longer having to sleep 12-14 hours a day. Whatever type of sleep disturbance they have, they will describe the fact that they wake up and feel unrefreshed, they have unrefreshing sleep whatever type of sleep disturbance they have.

So those I think are the key cause symptoms of this illness. There are many other symptoms which are associated with it: increased sensitivity to light and noise, increased sensitivity to alcohol is a very interesting symptom which I think is diagnostic of this illness. But I think the brain, the muscle, the infective and the sleep symptoms are the core ones you would make the diagnosis on.

Which symptoms can be treated?

The symptoms that can be treated, and I think really should be treated by a doctor when they occur, are pain and sleep disturbance, and if it actually occurs as part of the illness then obviously any sort of depressive component. So as far as pain is concerned there are a number of drugs which doctors can consider prescribing when ordinary types of pain reliever like aspirin, brufen and paracetamol are found to be ineffective. And we have a, if you like this, step ladder of pain killing drugs available on prescription which could be considered when these sort of ordinary pain killers aren't working.

Examples of the sort of drugs which might be used, there is a drug called Amitriptyline, which is a sedating tricyclic anti-depressant drug, which is used at very low doses, not used as a depressive, the sort of dose you would use to treat a depression. It's used at a very low dose and at the very low dose it can help with pain, it can help with muscular pain, neuropathic nerve pain, and it can also - because it has a sedating effect - help with sleep disturbance. So that is one drug that can certainly be discussed with the patient. If pain is more severe then there are other drugs which pain relief doctors who are specialized in this type of medicine might consider using. One of which is called Gabapentin. This is a drug which is actually normally used to treat epilepsy, but it's also been found, again as a different type of dose and regime, to be very helpful and sometimes in pain relief particularly pain relief when that involves nerve pain.

There are various drugs which can help with sleep disturbance in addition to possibly Amitriptyline. There are groups of drugs which can help people, there are short acting drugs, they can help people get off to sleep and they are just used for a very short period of time. There is also some evidence that the drug melatonin, which is used to help people cope with jetlag, can be helpful in some people with this illness. And people with this illness who have a very disturbed form of sleep disturbance, sometimes they gather a complete reversal of sleep rhythm, that is something that could be considered in those circumstances. And as I say if someone has a clinical depression with this illness, and a clinical depression is something that can occur with any long-term illness, especially when you're having all the problems that you're having with an illness like ME, then that always has to be taken seriously. Because we know that sadly some people with ME who are very upset because of all the things that are happening around them, do actually contemplate and just occasionally even commit suicide.

So depression, clinical, true clinical depression as opposed to just feeling fed up with this illness must be taken seriously. And again if necessary treated with antidepressants. Sadly at the same time we have groups of symptoms which are not amenable to drug treatment. One example there would be the problems that people have with cognitive function, problems with memory, concentration and it would be wonderful if we as doctors had some sort of drug that we could help people with that type of symptom cope with better.

What other treatment suggestions can you give?

Other treatments in addition to the key aspects of management which of course are activity management and pacing and dealing with symptoms such as pain and sleep disturbance are, I think that any doctor who is dealing with this illness has to deal with the many practical aspects that this illness creates for their patients. So I think they have to be very pro-active and supportive in relation to things like helping them with their benefit applications, giving them a suitable advice on what they should do in relation to work and employment. And in the case of children and adolescents helping them with their education which might involve trying to get home tuition, if a child is able to do so, and integration back into school at a very gradual level if the child is well enough to start returning to school.

What help can be given to very severe ME-patients?

Help for people with severe ME is very sadly lacking, certainly here in the UK, and I suspect the same picture applies throughout the rest of Europe. Many of these people who are wheelchair bound, house bound or bed bound have no access to medical services. They are unable to get to hospital clinics for appointments obviously and at the same point we have a number of specialist referral hospitals based services here in the UK now, but these clinics by and large are not providing home visiting domiciliary services for people with severe ME. So there is a major problem for this group of patients in accessing medical services and it is something that really should be addressed as a matter of urgency. We have tried to do that through the all-party parliamentary group on ME, but it very much relates to the willingness of physicians and people looking after patients at a hospital based level to try and set this in motion, And sadly that is not happening.