

## Wetenschap voor Patiënten (Science to patients)

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## Webinar 54: Treating and managing ME

**Prof. Leonard Jason. Broadcast October 7<sup>th</sup> 2014**

### **What is the role of a psychologist in the treatment of ME?**

Psychologists and mental health professionals have an important role to play in the treatment of any patient with chronic illnesses, ME included. What we need to do as mental health professionals is first validate the patient's experience. We have to listen and become an ally of that individual. And we should really try to understand what they are going through, to build an empathetic bond.

That's so important because particularly patients with ME have often been so victimized by the medical community and others, so that particular relationship is critical to let that person know we believe in him. And that we care about him. I think without that basic trust you make very little difference, and you as a mental health professional will actually be harmful to the patient, without building that trustful relationship.

### **How can it be avoided that the psychological approach gets the upper hand?**

Patients with ME need to have the best team possible, involving multi-disciplines, to have a good chance of getting quality care. You can't just send someone with ME to a psychiatrist or a psychologist. The reason being they probably need many other services to help them deal with the many different symptoms of this illness. Just think about it: if a person with cancer came to a medical doctor and the doctor would say: "Go and see a psychiatrist or psychologist, that's all you need.", that patient would be terribly upset. And that's exactly what's happening with patients with ME throughout the world.

### **What are useful treatments for ME in your opinion?**

There are many different types of treatment for ME. And I'm going to talk a little bit more about what I think of a kind of lifestyle area. The reason is that I'm a psychologist. But in the medical area there are also many good treatments for symptoms like pain and sleep difficulties.

But in terms of lifestyle issues, patients often feel like they have the energy of maybe 10 or 20 percent they had formerly in their lives. So their battery, their storage of that kind of electrical life force has been reduced. And yet due to their obligations they often have to do twice as much work as they have the energy for. And that's a problem.

So in terms of lifestyle management, how do we get patients so far that they're not doing too much? So that they won't exhaust themselves and possibly enter into post exertional

malaise. So I think learning them how to stay within their energy envelope, as we call it, is critical to allow that battery not to get further depressed, depreciated. That's I think what we need to do. A lot of patients are somewhat like a yo-yo. So what happens is they are really sick, they don't do much, they're really careful, and then they feel a little bit better and they do too much. And then they crash. That's a yo-yo effect. Everything possible to let that not occur is really critical in the lifestyle management of patients with ME.

### **What are the advantages and disadvantages of CBT and GET?**

Cognitive behavior therapy is something used with all types of medical illnesses with some very positive results. Why is it so controversial with patients with ME? Because often that's all which is being provided. For example, if a person with epilepsy who needs medications, is said 'we'll just use cognitive behavior therapy', that patient would absolutely be furious. But that's what's happening with ME patients.

They're having needs that are far beyond just psychiatric issues. They have somatic problems. They've got physical dysfunctions. They've got irregularities that are biological. They need the best of medical care and treatment. And yet they're being siphoned to a very narrow type of perspective. That's why they're upset. Because they're not being given what's appropriate medical care. They're being given inappropriate medical care, that isn't meeting their needs.

### **What is pacing, what is enveloping, and what are the differences?**

A number of people have been talking about pacing. Some developments Ellen Goudsmit in Great Britain has written about. We in the United States have used a term called the energy envelope. I think there's a lot more similarities than differences between these approaches. What they both are suggesting is that we need to help patients learn to manage their available energy in a very sensitized tailored contextualized way. For example someone has a battery that's loaded for twenty or thirty percent while he once had a battery that was a hundred percent. Now it's just a fraction of that. How do you do all the tests of life on such a small amount of available energy?

So what we try to say is pacing or staying with the energy envelope, is trying to stay within that available energy, to not exceed it, to not push oneself. Because if one does, ultimately I think one experiences more crashes, more post exertional malaise, which I think ultimately causes more oxidative stress to the brain. And I think it will have some very negative consequences for the patient. So pacing and an energy envelope are the appropriate types of lifestyle changes that can cause improvements. Not cures, but improvements to many patients.