

# Wetenschap voor Patiënten (Science to patients)

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# Seminar 38: ME and its triggers

Dr. Charles Shepherd. Broadcast 25th March 2014

## What role do infections play in ME?

Infections play a very important role in this illness. I think it's probably helpful just to recap on how this illness probably develops. And I think there are three stages to this illness: there are things that predispose towards this illness, particular genetic factors, there are things that precipitated or trigger it and then there are things that perpetuate it or keep it going. The role of infection comes into the second stage, things that perpetuate things that precipitate or trigger this illness. And we know that in round about 75% of cases people will predate the onset of their ME to a very clear cut infective episode. They will describe an infection. It may be something quite straightforward like a flu-like illness or a respiratory tract infection, gut infection. It may be a rather more specific infection like glandular fever or chicken pox. And they will say "I got that infection and I never recovered from that infection".

We know as I say that there are a number of viral infections, particularly viral infections, that seemed to do this. But at the same time there also a number of cases where non-viral infections seem to trigger ME. We know that Q fever can cause an ME like illness. We know that some people develop ME from salmonella infections, although these are rare. It is primarily viral infections that seemed to trigger ME. So that is somewhere where we have a great deal of certainly. Where things become rather more complicated and uncertain and the research evidence is somewhat conflicting, is whether these infections that actually trigger ME then go on to persist in the body and play a role in keeping the illness going. In other words do persisting viral infections also play a role. And as I say the evidence here is somewhat conflicting.

The other aspect to infections is that part of the perpetuation of this illness seems to be involving the role of the immune system. On a way that the immune system triggers and kicks in once you have the precipitating viral infection. Part of the immune system disturbance in ME may involve what we've call reactivation of latent viral infections. So these are infections that you already had hanging around in the body that particularly herpes virus infections like Epstein Barr virus and human herpes virus type 6. And there is certainly some evidence from the research studies that are being carried out, that once the viral infection has taken place, the immune response has taken place, that some of these latent viral infections then become as it were reactivated more active again. So it could well be that the viral infection that triggers this illness off, is not playing any further role in keeping the illness going. But as part of the immune system response to that viral infection there is reactivation of latent viral infections within the body. So it's quite a complicated picture.

And of course this is something that really does need to get resolved because there are quite powerful anti-viral drugs which can help as a possible form of treatment for this illness, if viral infections are involved in keeping it going. All these reactivated viral infections are involved. And one such drug is called valganciclovir and there have been some small clinical trials taking place. Another one was recently reported from Jose Montoya's group in Stanford in California suggesting that there may be benefit from giving an anti-viral drug, particularly if you get the right subgroup of patients with the reactivated viral infection, you give them a course of valganciclovir, valcyte. So that is an interesting approach to the role of infection in this illness.

### Are there other possible triggers for ME?

I think there are other things that trigger this illness of in addition to the viral infections that we've already been talking about. These are things that we would term immune system stressors. And I have a particular interest in the role of one particular immune system stressor which is a vaccination. Which is essentially mimicking the effect on the body's immune system of an infection. And we know that a small but significant number of people with this illness will either predate the onset of their illness to a vaccination, although they describe a very significant exacerbation of symptoms, or a relapse following a vaccination. It's quite interesting when you look at reports from people who describe the onset of their ME following a vaccination, that there is certain vaccinations which seem to be heavily weighted in this respect. One vaccine in particular is Hepatitis B vaccine which seems to be a trigger factor for this illness. Quite a considerable number of people that I've collected over the years. So whether there is something slightly strange about Hepatitis B vaccination in relation to ME, we're not quite sure at the moment, but it certainly has been linked to the onset development of other autoimmune disorders such as SLE in the medical literature.

Having said all that I think it's important also note that in addition to all 75 % of people who predate the onset to a fairly clear cut infection or perhaps a vaccination, we have a group of a significant minority who develop this illness in a rather more gradual fashion and do not predate the onset of their illness to any particular event whether it's infection, vaccination or whatever. They may describe a series of infections after which they become more and more unwell and eventually if you like slip into a ME/cfs like illness. But they don't have a clear cut factor which seems to be triggering their illness.

#### Can a trauma be a trigger?

Trauma can occasionally be a trigger factor in the development of this illness. And just like infections and vaccinations it can sometimes cause a major relapse or exacerbation of pre-existing symptoms. So we do have a small number of people who will predate the onset of their illness to perhaps a major road traffic accident. Another form of physical stress if you like which sometimes is described as an onset to this illness is in people who undergo major surgery general anesthetics. So I think you could bring those people into this group as well.