

## Wetenschap voor Patiënten (Science to patients)

It is permitted to disseminate all transcripts within the project Wetenschap voor Patiënten (Science to Patients), under the explicit condition that the source ME/cvs Vereniging, <http://www.me-cvsvereniging.nl/> is clearly mentioned.

### Seminar 35: Introduction / Experience with ME

**Dr. Charles Shepherd. Broadcast 25<sup>th</sup> February 2014**

#### **How did you get involved with ME?**

My name is Dr. Charles Shepherd and my involvement with this illness dates back to personal experience, approximately thirty years ago. Like many doctors of my generation when I was in medical school I was told this illness was hysteria. In fact at the time I was at medical school a paper came out in the British medical journal describing ME, Royal Free disease at is was also known at the time as mass hysteria.

So we left medical school believing that we weren't going to see people with this illness and if we did it was all in their minds. And I had personal experience by catching ME from a patient. I actually got a very nasty dose of chicken pox from a patient who had shingles. That changed my mind about this illness. I had all the classic symptoms and yet like many people it took about two years before I got a diagnosis of this illness. During that time I didn't practice the right management, I didn't pace my activity, I had problems with benefits and employment. All the problems that people have to go through with this illness. So my views on ME, especially in relation to management, are very much based on personal experience.

#### **What do you do in relation to ME? (charity, political, research, services etc)**

This is very much based on my experience of dealing with vast numbers of people over the past thirty years with this illness. Either seeing them as patients or as dealing with them in my role as medical adviser to the ME Association which is the major adult support charity here in the U.K. So I have a lot of if you like clinical experience in dealing with people on a one to one basis, but I also have a lot of experience in many other areas in relation to my charity roles.

I'm involved in research, I have a particular interest in research relating to muscle abnormalities in this disease. And also the role of vaccinations in triggering this disease. Also within the charity sector we have to provide a lot of information to people with this illness as well as to health professionals. I help to supervise our Ramsay Research Fund which is a major research fund in the U.K. We're currently funding researches such as the ME bio-bank, post-mortem research, and muscle research. And we also have a very important role here in the U.K. in relation to political activity in this illness. We're part of the secretariat of the all-party parliamentary group on ME. And we also play a very important role in campaigning on benefits, which is a particularly important issue for people with this illness.

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### Seminar 36: What is the difference between ME and CFS?

**Dr. Charles Shepherd. Broadcast 25<sup>th</sup> February 2014**

#### **What is ME?**

ME stands for Myalgic Encephalomyelitis. And this is a name which came into medical usage following an editorial in the Lancet medical journal in 1956 and it was used to describe an outbreak of this illness that occurred at the Royal Free Hospital in London the previous year. The outbreak at that time was being called the Royal Free disease but the Lancet editorial named it myalgic encephalomyelitis. And it was the term that was used because these patients had muscle symptoms, which is where the 'myalgic' comes from, and they also had a lot of brain symptoms which is where 'encephalomyelitis' comes from. And in medical jargon encephalomyelitis means inflammation which is 'itis', within the brain which is 'encephalo', and 'mya' which means spinal cord. It means in pathological terms inflammation within the brain and spinal cord.

#### **What is CFS?**

Chronic fatigue syndrome is a name that was introduced by the medical profession during the nineteen eighties. Partly as a reaction to the fact that there was renewed medical and scientific interest in this disease, and partly because the medical profession decided that it did not like the term ME myalgic encephalomyelitis, because there has always been and there continues to be a considerable degree of controversy and uncertainty as to whether there is actually inflammation within the brain and the spinal cord.

So the medical profession in its wisdom decided to rename and redefine ME as chronic fatigue syndrome. And the way it redefined ME as chronic fatigue syndrome, is that it brought in a lot more people under this umbrella of chronic fatigue syndrome who previously would not have met the diagnostic criteria for ME.

A lot of patients of course dislike the term 'chronic fatigue syndrome', I dislike the term chronic fatigue syndrome, because I feel we've widened the diagnostic net as to who comes under this umbrella of chronic fatigue syndrome. And in a way it's rather like saying that everyone who has some form of headache whether it's a migraine headache or even a brain tumor headache can be put under an umbrella of a chronic headache syndrome. And so they all have the same cause and they all have the same form of management. Which clearly isn't the case.

#### **What does the combination ME and CFS stand for?**

The combination-term of ME/CFS is really a messy compromise to try and keep the medical profession on side, who certainly in the UK, and I think this will be true for the USA and

many parts of Europe where this illness is recognized; to keep the medical profession on board who wants to use the term CFS, and the patients who not surprisingly-and I agree with them-want to use the term ME. So we have this messy compromise of ME/CFS. And in actual fact I think what we have also is an umbrella which is covering a wide variety of clinical presentations. And equally it's covering a wide variety of disease pathways or subgroups. So it's going back to this headache syndrome or joint pain syndrome.

We're trying to put everyone who has some sort of chronic fatigue under this ME/CFS umbrella. And I think we're very wrongly saying that they probably all got the same cause, so that they all got the same form of treatment. And what I think we've got to do, which is I think what the research community is now taking on board, is to go back several steps and try and subgroup these people who come under this ME/CFS umbrella into clinical subgroups, pathological subgroups. So that we can find effective treatments for these different subgroups under this umbrella, because quite clearly not everyone under this umbrella is going to respond in the same way.

### **Why do most doctors prefer CFS to ME?**

I think the vast majority of my medical colleagues remain convinced that ME is not an appropriate name for this illness, largely because this problem with encephalomyelitis and the lack of pathological proof or evidence that there is an inflammation taking place within the brain and spinal cord. There are certainly abnormalities taking place within the brain, and we know that from research. But we don't have any hard scientific evidence to demonstrate inflammation in the brain and within the spinal cord.

### **What would you call the disease?**

My way round this is to propose that we actually rename Myalgic Encephalomyelitis Myalgic Encephalopathy, which would take the inflammation out of the encephalomyelitis and imply that we have an illness here which is affecting muscle and brain function which is what encephalopathy is but without the widespread inflammation. So I have proposed that to some of my colleagues. It is something which is accepted here by the government, the department of Health, NICE but it hasn't yet achieved any sort of degree of widespread acceptance. So at the moment we remain in this very unsatisfactory position where we have patients calling the illness ME, and doctors calling it CFS. And those who want to try to make some sort of compromise are calling it ME/CFS.

My preference is to use the term ME as myalgic encephalopathy which takes the heat out of the argument and I find when I use this in the presence of my medical colleagues it is accepted normally without any great problem. But if I go and talk to my medical colleagues about myalgic encephalomyelitis, instead of actually talking about the illness, talking about how to diagnose it, talking about how to manage it, it just stems back into an argument about the fact that there is no encephalomyelitis. And I think as long as my medical colleagues remain so unconvinced and even hostile to the concept of encephalomyelitis I think we have a major problem. Because all that results in is my colleagues abandoning the term ME and using what I regard as this awful term 'Chronic Fatigue Syndrome'.

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### Chat: questions and answers

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

**Q:** You are saying that it is uncertain as to whether there is an actual inflammation within the brain and the spinal cord. I think most (99,9 %) of the patients didn't get any testing for that. So how can you say there is no inflammation of the brain? I myself feel it every day.

**A:** I am one of the few doctors who is involved in post-mortem research, and the results from a small number of these post-mortems have been published. The bottom line here is that encephalitis (widespread inflammation in the brain) has not yet been found in these PMs. Neither has widespread inflammation in the spinal cord been found.

What we have found is dorsal root ganglionitis - inflammation of tiny nervous structures that lie just outside the spinal cord in the peripheral nervous system and are responsible for processing sensory information like pain and touch.

**Q:** It can't be found on scans?

**A:** You can make a diagnosis of an acute encephalomyelitis through a combination of clinical history, examination findings and abnormalities on neurological investigations, including scans. But you do not see this combination in people with ME/CFS.

**Q:** You are saying in your video using 'opathy' takes the "heat" out the situation - of course it does, for it still leaves the diagnosis wide open to how you want to choose to interpret it : mental or physical. Because the word 'opathy' , exactly like CFS, has a dual interpretation : it can be interpreted physically and/or psychiatrically. So how do you make clear which one is which?

**A:** I obviously have considerable sympathy with people who believe this illness should be called M encephalomyelitis as my own illness was triggered by a chickenpox encephalitis. But in our current state of knowledge I do not believe that M. encephalomyelitis is a correct way of describing the pathology. This is why I have advocated the use of the term M. encephalopathy - as this is consistent with the abnormalities that have been published

**Q:** How can the large differences between patients be explained? Why are some patients bedridden, while others still are able to work and have some social life?

**A:** Nobody has a satisfactory answer as to why some people with ME/CFS improve, others remain more static and variable, whereas others become severely affected. Partly because so little research has been done on people with severe ME/CFS.

The MEA has funded research into factors that may be involved in severe ME/CFS and the ME (blood sample) Biobank at UCL in London that we are funding is collecting blood samples from people with severe ME/CFS to see if there are any characteristic differences in severe cases.

**Q:** You said you caught ME from a patient. Is ME contagious?

**A:** I caught chickenpox virus from a patient of mine who had shingles (same virus). The CP virus then triggered my ME. It is the triggering infection that can be spread to other people. There is no evidence that ME/CFS can be passed from person to person.

**Q:** So you mean that ME is the outcome of a disease instead of a disease itself. It can have numerous causes?

**A:** A large number of viral infections, including hepatitis, can trigger ME/CFS. It can also be occasionally triggered by non viral infections (e.g. salmonella) and other types of immune system stressors such as vaccinations. I have a large collection of people with ME/CFS who predate the onset to a vaccination - health workers following hepatitis B vaccine in particular.

**Q:** And is the trigger that causes the ME responsible if you get mild or severe ME?

**A:** Think of ME/CFS as a three stage process involving 3Ps. Genetic factors that Predispose to its development. Immune system stressors (e.g. infections) that Precipitate the illness, And a complex range of resulting abnormalities involving brain, immune system, endocrine system that Perpetuate the illness.

**Q:** Are there perspectives in the development of a medicine or are the researchers groping entirely in the dark where the disease is lodged in the body?

**A:** ME/CFS is perpetuated by a complex interaction between abnormalities involving brain, muscle, endocrine/hormone system and immune systems. Until we understand more about these abnormalities and how they interact it is going to be difficult to find a drug treatment that deals with the underlying disease process.

One promising lead which you may have heard about is a drug called Rituximab. This is normally used to treat people with lymphoma - a type of cancer. But some Norwegian doctors have found that it appears to benefit a subgroup of people with ME/CFS. The reason for this may be due to the fact that Rituximab dampens down a part of the immune system that produces autoantibodies - harmful antibodies that can attack/damage healthy tissues and organs.

**Q:** Are you cured from ME or are you coping? And what is your secret?

**A:** I am not 'cured' of this illness. Like many people I see I have made a degree of recovery but have now hit a 'glass ceiling' whereby I function at around 60% to 70% of my normal healthy self - with occasional ups and downs, often triggered by an infection.

I don't have any secret solution. I don't take any drugs or supplements. The main factor in achieving a degree of recovery has been learning how to correctly pace my mental and physical activity and (I know it's not easy) staying positive. Also having good support from family and friends

**Q:** What do you think of the use of valganciclovir?

**A:** There are certainly some interesting results from small clinical trials involving valganciclovir and I have been over to America and met one of the doctors using valganciclovir. I have also had a meeting here in the UK with the drug company involved to try and persuade them to set up a clinical trial - but no luck so far.

What we need are some larger clinical trials carried out by other clinicians to see if this drug might be a safe and effective option for a subgroup of people with ME/CFS, possibly those

who have evidence of reactivation of HHV-6 infection coupled with 'infective' type symptoms.

**Q:** Yes I have heard of it, but it can be dangerous too. Is it possible to try it ? And how do I get it if it is possible?

**A:** Here in the UK doctors would be very reluctant to prescribe an antiviral drug like valganciclovir - unless there was a very good reason for doing so. This is because these drugs can have quite serious side-effects. I suspect that a similar situation exists in other parts of Europe.

**Q:** Is there any treatment with medication you would advise ?

**A:** In our current state of knowledge I am reluctant to either use or recommend what are best described as speculative forms of drug treatment. Drug treatments do, however, have an important role in helping to relieve symptoms such as pain, sleep disturbance and irritable bowel type symptoms - as well as depression if it occurs.