

## Wetenschap voor Patiënten (Science to patients)

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### Webinar 48: Ageing and ME

**Prof. Julia Newton. Broadcast July 29<sup>th</sup> 2014**

#### **Which ME-symptoms worsen when getting older?**

In my clinic I see adults and older people with ME. At the current time we don't have a clinic where I see children. So it's difficult to know what the differences are between children and adults in terms of symptoms. My impression when looking at adults and older people is that there are very little differences between the presentation of ME in older people compared to younger people, and the impact and the severity of their symptoms tends to be very similar.

#### **Do children, adults and elderly people with ME have different symptoms?**

ME is an interesting illness because it can affect any age group. It always used to be thought that it was a disease of younger people, but it is becoming clear that it can affect all age groups, including older people. We have now looked at those people coming to our clinic and found that a significant proportion are presenting for the first time over the age of 50. Up to 20% of patients coming to the clinic. So a quite significant number.

It is not really fully understood whether or not the disease is the same disease in older people as it is in younger age groups. In our study where we matched older people to younger people who had had the disease for the same length of time. Which was very important: it got rid of the confounding issues of length of illness. We did not find that patients had any significant difference in the symptoms they were experiencing. So the symptoms were as bad and had as great an impact in the old versus the young. But the real, significant differences were when we tested the autonomic nervous system and found that there were more profound abnormalities in the older age group. Which are perhaps the things that put that individual at risk of developing this fatigue associated disease.

#### **Is there a difference of loss of memory due to age or due to ME?**

Understanding why memory changes in patients with ME is very important. It may be that there is a relationship between what happens in people with ME and their cognitive function, and what happens in the brain as we age. We've done studies here in Newcastle looking at dementia and age-related changes in the brain, and been able to show that autonomic dysfunction associates with cognitive problems as we age. And that the severity of the autonomic dysfunction predicts how your memory will change over time. So we're beginning to see very similar abnormalities in patients with ME, which might suggest that people with ME have a kind of accelerated aging phenomena. And that that is associated with the presence of abnormalities of the autonomic nervous system.

## **Should there be different diagnostic criteria between the old and the young?**

Good question, should there be different diagnostic criteria between the old and the young. I think that raises the question of whether or not the diagnostic criteria we have at the moment fit the purpose. And I would argue that they probably are not. They are based on symptoms experienced by patients rather than anything biological or physiological. As a result I suspect we put together into one diagnostic group lots of different diseases. That makes it very difficult as a clinician understanding what are the right types of treatment for patients. And as a researcher it makes it very difficult to be sure that the research we are doing is with groups that are the same, that is homogeneous.

What tends to happen is that everybody who fits the symptomatic diagnostic criteria, like the Fukuda, gets put lumped together into a clinical trial, and then we are surprised when the trial does not show benefits for patients. If we were to understand the different types of disease that are under this umbrella diagnosis of ME or CFS, then that would allow us to begin to understand the pathophysiology of these diseases and direct more specific treatments. So for example, at the moment we clearly understand that there are autonomic phenotypes. So there are patients with POTS, there are patients who dropped their blood pressure or have a Neurally Mediated Hypotension.

We know that there are different types of sleep phenotypes, probably four different types. And we are also beginning to understand that there are at least two different muscle phenotypes. So all these different things are all lumped together into the one diagnostic category of ME or CFS. But really if we are to understand these diseases more fully and get better treatments, rather than lump them together we need to actually pull them apart and begin to do experiments with specific phenotypes, rather than the whole diagnostic group of ME or CFS.

## **Are ME-patients expected to live shorter than healthy people?**

There is still very little known about the natural history of ME. Sometimes we see reports on the television or in magazines about people who have died very young with ME. So we really do need better studies where we follow up patients with ME for long periods of time. So that we can see whether or not they have an excess mortality by virtue of the fact they have ME.

Interestingly in the work we have done in patients with the fatigue associated disease called primary biliary cirrhosis, which is an autoimmune liver disease, in those patients we have been able to show that those who are fatigued over a decade were significantly more likely to die compared to those who were non-fatigued. So that suggests that fatigue is something that is associated with an excess mortality. And that fatigued patients certainly with PBC are likely to live shorter lives than those who are non-fatigued.

## **What is your definition of fatigue?**

Fatigue is a strange symptom and it means different things to different people. When I am in clinic I will always ask people 'what does fatigue mean to you?'. Some people will describe it as a sensation of sleepiness or excess sleepiness, particularly during the day. For some people it is brainfog, for some people it is muscle malaise or aches and pains. Interestingly in

the studies that we have done, looking at blood pressure regulation where we have done tilt table testing in people with ME and fatigue associated diseases, it did set out to drop people's blood pressure using a tilt table.

And when we do that we always routinely ask patients: "What symptoms are you experiencing?" at the time that their blood pressure was low. What is interesting to me is that often when we say to people: "what are you feeling at the moment?" they will say: "These are my symptoms, this is exactly what I feel." And we see that this is something that they are experiencing in association with a low blood pressure.

So people have a perception that this is their symptom, their fatigue, their disease, their ME, but in fact what we are seeing is that their symptom is associated with a low blood pressure. And that to patients who will come and see us who have dropped blood pressure it is: "my blood pressure". They do not recognize the fact that this might be something that could be diagnosed as ME or CFS.