

TRANSCRIPT OF TALK GIVEN ON 13th May, 1989, BY PROFESSOR PETER BEHAN  
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1. 50% of those who say they have ME DO NOT HAVE IT
2. It is a viral infection of the gut: the basic illness consists of an infection of the gut + gross exhaustion and fatigue + tachycardia + severe depression + malaise.
3. It is not a new illness: German physicians described it extremely well in the 19th century
4. It is linked to Polio (definitely an enterovirus), but other viruses are also implicated, eg EBV, HHV6. Polio attacks the CNS.
5. The real tragedy of ME is the far-reaching effects on the medical profession of two not very talented psychiatrists, one of whom had only just qualified (MacEvedy & Beard, 1977)
6. In genuine patients, those who don't have mental symptoms are very few: genuine patients do not usually have difficulty in remembering, but they do have difficulty concentrating
7. No genuine person with ME has weakness; the fatigue is not in the muscle. Fatigue is difficult subject to describe. Most patients do not have real fatigue. Fatigue can be caused by other diseases; it is important to distinguish psychiatric fatigue from ME fatigue. Fatigue is caused by oxygen not being supplied fast enough to the muscles, resulting in a build-up of lactic acid, but depressives also have a build-up of lactic acid; other conditions such as metabolic diseases, and other chronic infections cause fatigue, and pregnancy results in gross fatigue. The only way to diagnose fatigue is by MNR, but if positive, it is not specific to ME but could be demonstrating toxoplasmosis or brucellosis etc.
8. Muscle biopsies: Behan's team were struck by how often bizarre structures showed up on electron microscopy
9. While MNR studies measure the metabolism of muscles and can show post-exercise acidosis (in which patients with the true syndrome are all grossly abnormal), it is also possible to measure electrical impulses, which show irregularities. 80% of true ME have abnormal muscles. Even if virus is found in muscles on biopsy, and even if other abnormalities have been demonstrated, fatigue is NOT due to these abnormalities, but due to effects of virus in the brain, i.e. although the muscles may be abnormal, it is the brain which is causing the fatigue, which is identical to the fatigue in Multiple Sclerosis
10. After getting a virus infection, the first thing is fever, the second thing is aches and pains, the third is that you want to sleep. Sleep is caused by a hormone produced by the brain. The brain produces interleukin 1, which is a protein produced in certain cells as a result of the cell being stimulated by a virus. Interleukin 1 will cause the liver to be abnormal; it will affect cartilage and muscle; it will affect nerve cells, and it is found in extreme fatigue. In the majority of true ME cases, the IL 1 levels are extremely high; it acts predominantly on the part of the brain which controls the emotions; it controls sex, sleep, aggression, personality, moods, obesity; the chemical mechanisms which control these are all explained by changes in the hypothalamus, and chronic infection affects the hypothalamus.



Behan's team have looked at the brain of ME suicides, and the important thing is that the hypothalamus was abnormal. He has got the brains of 135 people who had polio (from all round the world) and of the 135, all had gross abnormalities of the hypothalamus. His current research on animals demonstrates this also: rats and mice are experimentally infected, then in one/two days, their hypothalamus is very abnormal. Rats are sent to Oxford for MNR to observe muscle changes.

11. Immune System is abnormal in true cases of ME; the staining of the cells by uptake of radioactive techniques shows that something is wrong, as in cancer and chronic viral infections.

Histocompatibility: certain markers are involved in certain diseases. Every single cell has its own marker; the markers themselves are involved. If you have the marker, you have the SUSCEPTIBILITY to the disease, eg, certain viruses. These markers play a role in killing the virus. IN PATIENTS WITH THE TRUE ME SYNDROME, THE MARKER IS DAMAGED.

The important thing is that the marker distinguishes those who have a histocompatibility with the antigen.

Markers are an integral part of the mechanism of the illness: expression of them is necessary to kill the virus (can't if they are damaged).

12. There is a tendency for the immune system not to be working as well as it should: this explains the high incidence of allergies.

13. ANTIBIOTICS: a lot of patients with the true syndrome develop allergies to antibiotics; Behan has seen it time and time and time again and there is no doubt about this. The mechanism is that the patient with persistent viral infection has developed an abnormality in prostaglandin metabolism, and PGs are necessary for breaking down antibiotics. Thus, EPO does have benefit for people with ME but it is not a cure.

14. Differences between ME & MS: MS happens when a virus hits a person with a genetic predisposition. Clinically, in MS there is paralysis, whereas there is no paralysis in ME; on lumbar puncture, the CSF is abnormal in MS but not in ME, but most importantly, there may be a similar mechanism with perhaps a common type of aetiology.

## CONCLUSION

There is still no one specific test for ME

There is no treatment for ME

Work is just beginning to unravel what looks like a most interesting neurological problem

There ARE abnormalities to be found if you look