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Insights into approaching Chronic Fatigue Syndrome/ME and related illnesses in clinical practice



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There is no doubt that Chronic Fatigue Syndrome (CFS) also known as Myalgic Encephalomyelitis (ME) is one of the most challenging and complex illnesses that we practitioners face in our clinical practice. Patients with CFS/ME can be some of the most confounding, difficult and demanding cases we can take on. As many know, there is currently no biomedical marker and diagnosis based on self-reported patient symptoms. The medical community still states CFS/ME has an "unknown aetiology" and there is still a stigma around the illness in the general population and amongst GPs that the patient is "just depressed" or even "making it up" for attention.

Despite this, epidemiological studies confirm the illness is as debilitating for sufferers as patients with diabetes, end stage renal disease, multiple sclerosis and congestive heart failure. In the US the number of sufferers is between 1 and 4 million, in the UK a very conservative ¼ million is estimated, although it is more likely to be 3 times that amount. Studies in the UK suggest the cost to society of total lost productivity is between £3-4 billion and between \$19-\$24 billion in the US. It is no wonder the Chief Medical Office in the UK in 1998 stated "I recognize chronic fatigue syndrome is a real entity. It is distressing, debilitating, and affects a very large number of people. It poses a significant challenge to the medical profession."

Despite many, many clinical studies now confirming abnormalities in multiple systems in subgroups of patients including findings of accelerated oxidative molecular injury (over 20 studies), HPA axis imbalances, channelopathies, mitochondrial malfunction, reduced grey matter in the brain, autonomic

nervous system and heart function abnormalities, viral infections, chronic immune activation and a skew towards TH2 dominance, CFS/ME is still classified as a psychiatric illness in the UK and the NICE guidelines are based on the psycho-social model including graded exercise therapy, CBT and antidepressants. These approaches are highly unpopular with patients who consider them primarily palliative.

Part of the reason this has occurred is a failure to take a "systems biology" approach to human health which would be based on understanding of complex adaptive systems. The linear "Newtonian" conventional scientific thinking demands that a "true" disease must have a single cause such as structural anatomical or serological abnormality, an infectious organism, a single physiological problem localized to a single organ or a genetic inborn error of metabolism. If one of these cannot be found, then either the illness is non-existent or the illness belongs to the realm of psychiatry. As the famous quote from Einstein states:

"We can't solve problems by using the same kind of thinking we used when we created them."

Despite clear scientific support for the fact that human biology shares many of the characteristics of complex adaptive systems, which requires a systems biology approach for full understanding, the orthodox linear medical model, which sees the body as a machine with simple effects localised to a single cause, persists strongly in conventional medical approaches to healthcare and ME/CFS and it still strongly influences approaches in the CAM world as well.

Complex adaptive systems are known to

be highly flexible and are constantly poised on the edge of being a coherent organized system and collapsing into what appears like chaos. They thrive in their instability allowing them to adapt at the edge of chaos. They are non-linear, and attempts to control them can be destructive. They cannot be broken down into separate, more simple parts and small stimuli can lead to disproportionately large changes in the entire system.

A good example of such a system is the human autonomic nervous system as measured by heart rate variability. It is well understood that when a human heart beats healthily, it follows a chaotic pattern. When it beats too uniformly, it is a sign of chronic stress and ill health.

Another example is the human immune system and especially how it interacts with the complex adaptive system known as the gut microflora "ecosystem." Scientists are now starting to use quantitative computing methods based on non-linear models of dynamic complexity theory to predict the changes resulting from stimuli on this internal ecosystem.

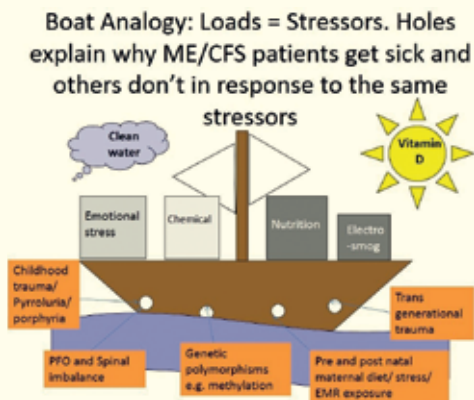
Although many CAM practitioners have trained in "functional medicine" which is based on a systems biology approach, interventions and approaches in CAM are still strongly based on linear thinking. The linear "germ theory" of disease, the idea a single bug causes CFS/ME, still pervades CAM approaches leading to simply recommending natural forms of antivirals and antibiotics (such as garlic and L lysine) rather than understanding in systems theory this is still treating symptoms and not the underlying causes. The key question is, when exposed to a microbe why do some people have resilience and clear it within a few weeks, and for someone else this triggers a decade of illness?

Another linear approach which is very popular in the CAM world at the moment is mitochondrial malfunction in relation to CFS/ME and related supplements which can "reboot" mitochondrial function. This smacks of another linear mechanistic approach where a closed system like a car breaks down because of a fault in a single piece of equipment. In reality the human body is an "open system" meaning environmental factors influence the workings of the

mechanics, and poor mitochondrial function is a down-stream result of a combination of environmental stressors with a genetic predisposition for weaker adaptive capacity in the face of these stressors.

An analogy for a Complex Adaptive Systems Approach

Rather than a car, a boat is a better analogy for approaching CFS/ME. A recent change of direction in the latest research strongly suggests CFS/ME is likely to be reclassified soon as an autoimmune disorder. A very large amount of increasing evidence is showing that the majority of autoimmunity is induced by environmental toxins and proposals are in place with the WHO to this effect. With this in mind, we need to concern ourselves with understanding what are the stressors (loads on the boat) which increase toxic load on the body and decrease the body's ability to detoxify effectively which need "unloading", and what are the predisposing factors (holes in the boat) which are making the CFS/ME patients' boats sink faster in the face of these stressors than the normal population which need "bypassing:"



Stressors include emotional stress and personality types (e.g. "achiever" and "perfectionist"), dietary, and lifestyle factors, exposure to Electromagnetic Stress (EMFs) and exposure to chemicals. Predisposing factors include genetic polymorphisms in the methylation cycle polymorphisms in genes related to phase 1 and 2 liver detox, emotional trauma and abuse in childhood, predisposition to develop pyrroluria and porphyria which are both abnormalities in heme molecule production (most practitioner

don't realise 40% of all heme molecules go to producing the CYP/450 liver enzymes), prenatal diet, lifestyle and maternal stress, structural abnormalities including patent foramen ovale (PFO) which 30% of the population are born with and inborn or acquired spinal imbalances which can lead to poor lymph flow.

To obtain Niki's full 2-part article with over 400 references expanding the concepts in this article including clinical pearls on how to deal with CFS/ME sign up to the completely free newsletter at her practitioner website www.ExpertPractitioner.com.

A fully referenced article in pdf format is also available on request from lucy.sherley-dale@naturaldispensary.co.uk

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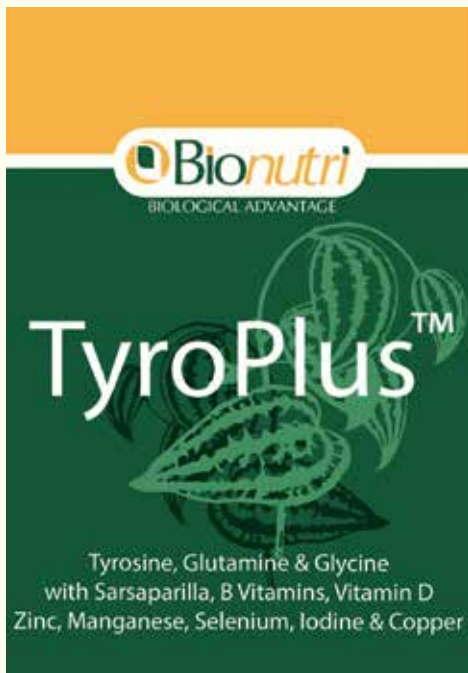
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