

How to Help - ME/CFS

These notes are taken from the course notes for 'Understanding How to Help'. Click for further details of the Understanding Yourself courses.

Description

There are currently three different terms for the condition:

- chronic fatigue syndrome often used and preferred by doctors as there's little evidence of brain and spinal cord inflammation, which the term ME suggests; ME is also thought to be too specific to cover all the symptoms of the condition
- myalgic encephalomyelitis (ME) preferred by those who feel CFS is not specific enough and
 doesn't reflect the severity and different types of fatigue, and implies that fatigue is the only
 symptom (myalgic encephalopathy is sometimes also used)
- systemic exertion intolerance disease (SEID) a new term suggested in a 2015 report by the
 US Institute of Medicine, which implies that the condition affects many systems in the body
 (systemic); It is thought that the word 'disease' highlights the serious nature of the condition
 in some people.

We will use the term CFS throughout these notes.

CFS is characterised by a range of neurological symptoms and signs, muscle pain with sometimes intense physical or mental exhaustion, relapses and specific cognitive disabilities.

It is estimated around 250,000 people in the UK experience CFS and over 1 million in the USA - more than have HIV infection or multiple sclerosis. Women are more likely to be affected than men, and CFS affects all social groups and all ages, including children. Most patients are unable to work full- time, and up to a quarter of ME patients are housebound or bedbound. It usually develops when people are in their early 20s to mid-40s. Children can also be affected, usually between the ages of 13 and 15.

What are the roots of CFS?

Are the roots physical or do they lie within the person's emotional structure?

There have been many claims over the years that it has been demonstrated beyond doubt that CFS has physical roots. Typical of such articles was one that appeared in the health section of the Mail Online on Tuesday 21st February 2015, carrying the headline, 'Proof at last that "Yuppie flu" is a real illness: Study finds chronic fatigue commonly seen among professionals is not just in the mind.' Written by Fiona Macrae, the article states that the condition 'does trigger a distinctive immune response in the body.' She goes on to claim that, 'the discovery paves the way for treatments that, given early enough, could prevent years of ill health.' The researchers, from Columbia University in New York, analysed hundreds of blood samples taken from ME patients and healthy people. The blood from those with ME showed a distinct 'chemical signature'.

In my view, these statements beg the question: is the chemical signature the cause of CFS, or is it a response to strong internal psychological forces?

Indeed, the article goes on to sound a cautionary note: 'However, the work is still preliminary, and many questions remain to be answered, including why the chemical markers show up only in the blood of patients in the relatively early stages of ME. Dr Hornig's team is now looking for signs of the infection



that triggered the immune response. Scientists have long thought a virus is to blame but have failed to find the culprit.'

Fiona concludes her article with, 'But some experts cautioned that the findings are preliminary and that ME research has been "bedevilled with false dawns" for decades.'

There is no specific diagnostic test for the condition; rather, a diagnosis is usually reached by a set of clinical criteria (NICE Clinical Guideline 2007), that is based on the patient's symptoms. There have been many, often conflicting, articles but the NICE diagnostic criteria are established practice.

Two personal observations

- 1. All the people I have known with CFS have the Melancholic temperament.
- 2. The Melancholic temperament is coupled with either of the two outgoing temperaments, making a combination of extrovert and introvert.

This combination is the key to understanding CFS because it is in the interaction of the two temperaments that we will find the cause of this condition.

What is really going on?

CFS used to be flippantly called, 'yuppie flu' because so many professionals were affected as they drove forward in their careers or pursuits. But there was a side to these people that others were hardly aware of - and that was a deeply feeling, sensitive side, with the capacity for depression. The need to drive forward in life and, often the person's lack of awareness of this part of their personality, meant that this side was undeveloped and therefore provided a 'dragging effect' within their personality.



The result is comparable to a car being driven with the brakes on. The driver wants to reach his destination. He pushes hard on the accelerator. The whole system is under stress. He hits a pothole or has to pull up at a road junction — and the car grinds to a halt in a cloud of steam. If the driver, for some reason, had been unaware of the brakes being on, it would be all too easy to think that the pothole or having to stop at the junction was the cause of the problem. It isn't the cause but a trigger that brought out the underlying tension.

If we pause and reflect on the dynamics between the two temperaments within one person, we will begin to see how these enormous contradictory forces can produce such powerful physical effects.

Melancholic

The Melancholic is creative, a reflective thinker and deeply sensitive. He is perceptive and picks up things clearly. He has a strong sense of justice and can be loyal and self-sacrificing. He has high standards for himself and others.

A major factor in the dynamics between this temperament and his extrovert is how naturally negative he is about himself. He will probably struggle with feelings of worthlessness and be prone to moods and depression. He can feel himself to be a 'bad person' who doesn't deserve anything good to happen to him but rather expects punishment. His high standards can become a quest for perfection that puts



him and those around him, under pressure. He usually prefers his own company and easily retreats into his own world.

Choleric

The Choleric, on the other hand, can be outgoing, dynamic, optimistic and full of ideas. Being goal-orientated, he is usually either doing something or going somewhere. He is strong, determined, self-sufficient and quite willing to take the lead. He is a visionary, but his vision may be narrow. He will be competitive, and he has to be the best. Although he feels everything deeply, he controls his emotions by suppressing them and regards those who display their emotions as 'weak'. He tends to work on a mental level and rely heavily on logical thinking.

Choleric Melancholic

Imagine those two people living in one house! How does the Choleric Melancholic cope with having to be the best and feeling the worst! No wonder it feels like trying to drive the car with the brakes on.

Unless there was a very good understanding in the home of this child, then the chances are that he would rely heavily on the Choleric temperament for everyday living. It is also clear that the Choleric's way of handling any awareness of the Melancholic feelings would be to condemn the 'weakness' and suppress the feelings. The Choleric does to the Melancholic what he does to his own emotions – crushes them. Thus, that deeply sensitive side, which is already negative towards itself and full of feelings of unworthiness, increasingly feels the pressure. Personal criticism and the external pressures of life, including physical illness, can act as triggers that bring those powerful dynamics to the surface. Instead of the qualities and talents of the Melancholic being expressed creatively, they go round and round within, consuming enormous amounts of emotional energy.

In order to survive, the Choleric Melancholic is driven to depend on the outgoing temperament until the system 'overheats' and all the pent-up pressures of worthlessness, pain, and inadequacy, break through and engulf him with feelings of helplessness, lethargy and exhaustion. Even the normal environment can become too much, and darkened rooms may be necessary. Steps forward are taken – sometimes large and sometimes small but often the feelings of weakness rise and overwhelm him again.

The problem for the Melancholic is that he cannot switch those feelings off. That is why I believe I have never met an extrovert with the Phlegmatic as his introvert who has ME because he can 'switch off' what he feels.

Sanguine Melancholic

Much of what has been said concerning the Choleric Melancholic applies here because the Sanguine is also an outgoing temperament. There is a difference. The Choleric expresses feelings through his mind, in thoughts and words, while the Sanguine expresses them physically.

Another factor to bear in mind for the Sanguine Melancholic is that if he has lived predominantly in his Sanguine, then his Melancholic will contain many unprocessed emotions that can express themselves in a variety of physical ailments, sometimes running alongside the CFS.



How to help

Using the analogy of the car with the brakes on, the task is clearly to release the brakes. This can be done as follows:

- 1. Help him identify and understand his separate temperaments and then the effect of them pulling against each other within him.
- 2. Within that context help him to recognise:
- a. That it isn't wrong to express what you feel you can allow yourself to be human even if the Choleric, or others, don't like it. He will need to talk regularly with someone he trusts and who understands him.
- b. The natural downward pull of negativity within the Melancholic. He feels himself to be a 'bad person' who deserves to be punished. When things go wrong well, that is what he would have expected. Struggling with CFS can easily become something he deserves.
- c. The qualities of the Melancholic including accurate perception and insight. Make a distinction between the validity of the emotion that he feels and how he interprets it. Help him to see his Melancholic as a valuable part of who he is.
- d. The need to not turn what he sees and feels back on himself in other words, to properly process his emotions in a way that has a positive outcome.
- e. Phrases that are used to run himself down. Encourage him to eliminate them from his thoughts and words.
- f. Constant apologising don't do it.
- g. The need to gradually build structure into his life, short term and long term. He will need something to aim at, but it mustn't degenerate into a restless striving, rather a natural expression of his creativity.

This is clearly not a five-minute fix but an opportunity to journey with this person as they change their view of themselves to such a point that they are comfortable with themselves, thus removing the inner conflict which lies at the root of CFS.