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**Understanding Chronic Fatigue, CFS/CFIDS/ME
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What is Chronic Fatigue Syndrome

Chronic fatigue syndrome (CFS) causes severe disabling persistent mental and physical fatigue (exhaustion) that affects everyday life and doesn't go away with sleep or rest. It also causes a range of other symptoms including pain, sleep disturbance and allergy. (For a detailed list of symptoms please see reference 2 below).

CFS is also known as ME, which stands for myalgic encephalomyelitis/encephalomyelopathy . Myalgia means muscle pain and encephalomyelitis means inflammation of the brain and spinal cord. UK national organisation, the ME association recommends the name encephalomyelopathy as though there is evidence of a process affecting the brain, there is little evidence of an inflammation component.

CFS/ME is also sometimes diagnosed as Post Viral Fatigue Syndrome (PVFS) where it follows on from a viral infection. Post viral fatigue is common and usually self limiting, though may be rediagnosed as CFS/ME if it fails to resolve.

CFS/ME is known by other names elsewhere in the world; in the US it is known as Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS).

How does it Start?

CFS/ME usually starts with a normal viral infection, including flu, glandular fever or even a cold. Sometimes onset is more gradual, with no obvious precipitating cause.

What is the Cause?

Research has revealed a number of abnormalities in some people with CFS/ME. Findings include: evidence of abnormalities in muscle structure and function, changes to nervous tissue and low levels of certain hormones eg cortisol. The model which I work with using the Lightning Process ® is outlined below.

What is the Treatment?

Most treatments aim to ease symptoms, including muscle pain and headaches. NHS recommended strategies, which include pacing and graded activity. Cognitive Behaviour Therapy can assist with coming to terms with the condition and managing chronic symptoms like pain or sleep problems.

Managing a chronic condition can be frustrating and difficult, and in some cases lead onto secondary problems like depression which may also need treatment. (For further information see reference 1 below).

There now are new approaches. The Lightning Process ® is a training programme that is undergoing trial at the moment.

Who is Affected?

Around 250,000 people in the UK have CFS/ME. Anyone can get this condition. It is more common in women than in men and usually develops in the early 20s to mid-40s. Children can also be affected, usually between the ages of 13 and 15.

How it affects Quality of Life

Most cases of CFS are mild or moderate, but up to one in four people with CFS have severe or very severe symptoms:

- Mild: you are able to care for yourself, but may need days off work to rest.
- Moderate: you may have reduced mobility, and your symptoms can vary. You may also have disturbed sleep patterns, and sleep in the afternoon.
- Severe: you are able to carry out minimal daily tasks, such as brushing your teeth, and may need to use a wheelchair. You may also have significant difficulty concentrating.
- Very severe: you are unable to carry out any daily tasks for yourself and need bed rest for most or all of the time. Often, in severe cases, you may experience intolerance to noise and become very sensitive to bright lights.

Why is CFS/ME so Controversial?

Reasons include:

- There are such a variety of symptoms involved in CFS/ME that it is difficult to define clearly.
- There are no clear tests to diagnose CFS/ME- it has to be diagnosed by doctors using 'clinical judgement' ie listening to the patient's description of their symptoms.
- There is very little satisfactory 'orthodox' medical treatment for ME.
- Some of the symptoms of CFS/ME overlap with conditions that doctors' label as 'psychiatric' disorders so CFS/ME has tended to be lumped in with these conditions in the past.
- Lots of people with CFS/ME have been told they are lazy, have a psychiatric disorder or are malingering. Some clients prefer the name ME to CFS as ME implies physical cause.

Outlook

Symptoms may naturally improve over time, following a slow fluctuating course towards recovery. Some people make a full recovery and return to work and normal activities. CFS/ME can last for years and many people never recover fully. A small but significant minority remain severely disabled. The outlook is improving as new approaches are developed.

How Should I Manage a Client Affected by CFS/ME?

Many practitioners work very successfully with clients with ME or their carers. However practitioners can accidentally break rapport. For example they may offer treatment that doesn't work for a client because of the symptoms of the condition. I would recommend carefully assessing a client with CFS/ME, before deciding whether your approach is suitable for them or whether to refer them on for a specialist approach. Also check for a medical diagnosis - fatigue is a symptom of many conditions.

The needs of a newly diagnosed client might be very different than one who has had this condition for a while are often experts in managing their condition and may have come to you to work on a specific issue where they have heard left can help with eg pain, anxiety, past trauma.

Some things to consider:

- The fatigue experienced by many people with CFS/ME is quite different from the straightforward 'tiredness' most normal people have experienced. They may describe themselves as being "totally drained of any energy".
- It is important to have an indication of the needs of your client before you meet them. Does the consulting room need to be down stairs? How long can they manage? For some people the language and repetitive activity like tapping may cause very severe mental and fatigue. The skin may be/ or become sore to tap. For more mildly affected clients tapping may be OK. You may sometimes need to tap on a client, the client may press on a point/points rather than tap, use finger tapping or no hands tapping techniques or you may need to just let them rest.
- Clients may be very pale, but often don't look as unwell as they are feeling. There are typically no signs of physical abnormality eg muscle wastage.
- Clients have experience of physical activity making things worse. They may appear to be able to do quite normal things yet complain of fatigue and muscle problems. They have found that they pay price for exertion - perhaps days in bed recovering.
- Some people with CFS/ME have learnt to 'save up' energy so they are able to do things. They know how much they can do and the price they will probably pay afterwards. Sometimes clients will need to be seen at home, or will ask for the first appointment of the afternoon so that they won't get tired due to waiting. It's as if the muscles/brain have a limited energy supply, when this runs out things stop functioning and the body needs times to recharge.
- The head symptoms experienced by people with CFS/ME include: headaches, dizziness, loss of concentration and short term memory problems.
- Your client may forget things you have just told them and will find it hard to take in new information especially if it's complicated. Sometimes they may appear stupid because they don't seem to be taking in what you tell them. These are symptoms of the condition and will vary according to how ill the person is feeling and how exhausted they are.
- Slow down your conversation and if necessary, say, or explain things a second time, or give written/taped information. Your client might get cross or upset at their limitations. They may agree to something they are not following so as not to cause offence. They might forget appointments!
- Sometimes changes in brain chemistry, people with CFS/ME may be emotionally sensitive. Often someone with CFS/ME will be up and about when you or I would be in bed as we felt ill with the flu. Try to take this into account if a sufferer is irritable or tearful for no obvious reason.
- There are a wide range of other symptoms including alcohol and caffeine intolerance and multiple allergies. If you offer a hot drink, make sure there is something caffeine free! Your client may feel cold very easily and generally over react to heat and cold.

- Sleep may be disturbed, including complete sleep reversal – ask what time of day is best for an appointment.
- CFS/ME typically fluctuates, and can be significantly worse due to viral infections, stress or unexpected commitments. This can last a few days or be very long lasting. Your client may need to cancel at short notice or for long periods.
- The life of a close family member is often turned upside down by CFS/ME. They can feel just as trapped, lonely and frustrated. People may disbelieve the seriousness of the disability and a carer may feel unsupported. They may need to fight battle with professionals who they feel should be working with them, sometimes unsuccessfully. A family, or carer might need to make significant adjustments to reduced income, 2 salaries may be reduced to state benefit as a carer has to give up their work. Roles may change - a carer may have 2 jobs - one at home, and work. In families the rest of the family may take a back seat, leading to a sense of conflict and guilt in a carer. A carer may not look after their own needs as the focus on their caring role.

Specialist Approaches

There are approaches which are applied by a specialist practitioner. One of these is the approach that I use when I work with clients, the lightning process. I trained to work with clients as I became aware of unusually successful outcomes.

The Lightning Process ® training programme takes over 3 consecutive days. It views CFS/ME as a physical condition with key involvement of the body's physical emergency response system. It is an approach which is very different than the current orthodoxy, and so may not be suited to all clients.

Physical Emergency Response (PER)

This is when the body experiences an emergency or threat to its safety and wellbeing, which could include;

- Physical injury or extreme environmental conditions such as burning or freezing
- Poisoning, due to viruses, bad food, drug reactions etc.
- Emotional shock and trauma

The body then naturally produces the PER, the fight and flight response, to deal with the threat and to find a way to recover or stay safe.

There are a number of key ways the PER affects the body. It stimulates the sudden:

- Activation of the Sympathetic Nervous System
- Production of powerful hormones: adrenaline, nor adrenaline, dopamine, cortisol and Dehydroepiandrosterone (DHEA).

This is what needs to happen to help us deal with the threat. The PER does this by primarily giving our muscles an extra burst of speed and strength and affecting the nervous system's synapses and their neurotransmitters. Temporarily this is an excellent solution for dealing with most threats, but unfortunately long term arousal of this system has been long known to have a detrimental effect on many other body systems, and this causes disruption to normal immune, muscle and digestive system function and changes the way our nerve cells transmit nerve signals.

Physiological Catch 22/Destructive spiral - Having understood the PER and the importance of these systems, this allows us to make sense of the 'Physiological Catch 22', or as it is also called, the destructive spiral. This is one important element of the Lightning Process, and is derived from Phil Parker's identification of the following downward spiral in people with ME/CFS, MS, Fibromyalgia and many other conditions.

1. Exactly how the problem started can be quite variable from one individual to another. – but can include responses to viruses, operations, vaccines, or even emotional stress. This onset 'event', whatever it's cause, is seen as a **threat** by the body.
2. This threat causes a PER, which stimulates the Sympathetic Nervous System and the production of adrenaline, noradrenaline, dopamine, cortisol and DHEA, as described previously.
3. This means the body is now having to deal with a combo of physical changes and threats:
 - **The effects of the original 'event' are now combined with**
 - **Direct effects of the symptoms**
 - **And the effects of the PER**
4. In some cases for various reasons which are not always clear, this combination of threats and changes produces an increased and prolonged PER. The long-term stimulation of this system, has a detrimental effect on the way the immune, muscular, digestive and nerve signal transmission system and many other body systems function.
5. Any disruption to the immune system in particular makes any healing more difficult. This takes the body back to step 2 again setting up a downward health spiral. This spiral can be further worsened by the added effect of the emotional distress of being unwell and all the questions and uncertainties which that can raise about one's future.

When viewed with this understanding of some of the physical processes that go on as a response to ill health, it becomes clear that a training programme, such as the Lightning Process, which teaches clients how to influence these physical processes, can open up a whole new set of options and choices for health and health and life.

References and Further Information:

1. For a downloadable leaflet on all aspects of the condition, including treatments <http://www.actionforme.org.uk/Resources/Action%20for%20ME/Documents/get-informed/All%20about%20ME%20booklet.pdf>
2. NHS/NICE guidelines <http://www.nice.org.uk/nicemedia/live/11824/36190/36190.pdf>
3. For more information on the Lightning Process ® and the PER visit the Lightning Process ® website at www.lightningprocess.com or my website at www.generatingchange.org. There is more info in the Introduction to the Lightning Process ® book ISBN9780955648205



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