

Chronic Fatigue Syndrome or Myalgic Encephalomyelitis

Unlocking the Mysteries

The Simple Guide for Professionals working with Chronic Fatigue Syndrome

Introduction

I have been working with Chronic Fatigue Syndrome or commonly, ME (short for Myalgic Encephalomyelitis) for 5 years.

In the early days I had no idea what to do with it specifically. But I sat and listened. I was lucky. The doctors also had no idea what to do with it and discovering they had a new ‘hypno’ in town, sent me half a dozen clients.

Working with the GP’s we managed to get funding for 4 of these clients from the Primary Care Trust, and that was the start of my relationship with the GP’s in our locality. This funding opened the flood gates to more funding and invited several dozen more to come for to me for hypnotherapy on the NHS.

I subsequently offered my in house services in their practice and have seen several hundred of their patients: many of course, with ME/CFS.

Hypnotherapy?

Now I feel I’m not giving you the whole story. If hypnotherapy were all I did, I’m sure my CFS clients wouldn’t be as well as they are.

Any approach in its purity, is often limited in its application. It simply does not suit everyone no matter how many cartwheels we turn to make it so.

How many times have I seen hypnotherapists feeling responsible or guilty because they couldn't get their techniques to work on this or that client? Or feeling bad because they took a client too far, or not far enough? And so on. There is incredible self doubt within the hypnotherapy profession and I believe much of that is about a lack of personal work on a therapists' own ghosts and demons.

Many without any other knowledge to fall back on, find themselves stuck with partial knowledge of the human condition.

Prior to working with clients, and in fact during, we owe it to ourselves as therapists to have explored our own demons and to have realized our own humanity as much as we possibly can.

Working with ME/CFS clients this last 5 years, with an eclectic, integrative perspective, has enabled me to treat, not just those clients who are supremely motivated to be well, but also those who doubt they can be and, even, those who may also benefit from staying unwell.

What is CFS/ME?

The majority of us know what this syndrome is but just in case some of you don't I'll summarise it briefly here.

Originally called ME, and latterly termed CFS, this 'syndrome' consists of extreme fatigue which is not relieved by sleep nor rest. Along with this main element of ME, sufferers report a wide range of symptoms from:

Fuzzy thinking

Blurred vision

Numbness

Pins and needles

Shortness of breath

Aches and pains

And many similar non-illness-specific symptoms

Some may also experience more measurable symptoms such as:

Heart palpitations

Thyroid problems

And so on.

There is as yet, no test for ME. Certain tests will show that, for example, cortisol levels are very low, and studies have observed an increase in immune system killer cells (cytokines), but generally there is no one test for ME.

Clients are often sent for a round of tests to ensure that nothing more insidious is happening to them: for example, MS or MND or inner ear problems and so on.

The symptoms can be quite frightening for anyone but especially those whose life is incredibly structured and demanding and requires their full

attention: something that becomes impossible with the onset of ME symptoms.

Mental and Emotional Profile

Many sufferers and ex sufferers balk at the notion that they might fit into a mental and emotional profile. And I don't blame them. There is nothing worse in psychiatry than the labelling of people with spurious mental health conditions, and at times, the forcible ingestion of mind altering drugs. In my opinion, and I have many of them, this is an abuse of human rights.

Descartes

So I'd like to call firstly, Descartes to account. Descartes was one of the most influential thinkers in modern medical science. He wasn't the first to make the following claims but he was the most influential thinker to medical philosophy at that time. He claimed that the mind was about self awareness and consciousness while the brain was the control centre for the body – a real physical entity made of neurons and neurotransmitters – apologies for the anachronism. He said that the mind in itself is immaterial because it is not a physical entity. Not being a physical entity therefore, it cannot interact with the physical entity of our brain and cause any changes to us. (Many counter arguments have emerged since but the dualism of the mind body split still dominates modern medical science).

Thus it was deemed unusual or abnormal behaviour must have a physical causation, be treated as such, and can have nothing to do with the mind. This has enabled psychiatry to be able to observe behaviour, identify a number of definitive symptoms, ie: thought patterns, behaviour patterns etc and to treat on the hypothesis that there is an inherent malfunction of brain chemistry that needs correcting with drugs.

Those of us that work in this field, and certainly in the alternative field, may find the hypothesis quite shocking; that is, that it all boils down to brain chemistry. There is certainly no room for 'soul' or 'spirit' in modern medical thinking: indeed, mention that to a psychiatrist and they will label you with one of their Bipolar Disorder or Psychosis and write out a prescription for you!

Mental Health conditions are frightening not only for the sufferer, but for those who have absolutely no experience of mental ill health themselves. They are so frightening in fact, a bit like those who've had a death in the family, we avoid people with mental ill health: or we bemoan the fact they have been 'let back out into the community', etc. So alien is mental ill health to the majority of us, even to the psychiatrists themselves, that it is perceived as mad, bad or sad.

Descartes and ME/CFS

So how can poor old Descartes more than 3 centuries after his death, be so important to people with ME/CFS? Because in my observation, the mind and the body are inherently linked in this condition, and currently there is no ‘discipline’ anywhere that identifies the whole person, treats them as an integrated whole, and can offer support. Indeed, so ingrained is this separation of the mind from the body and the stigma attached to things of the mind, that no segment of society, not even the sufferers themselves, can understand what relationship they have between their own minds and bodies. The moment a person is diagnosed with ME they become effectively untreatable. The longer they claim that they will not look at the role of the mind in their condition, the longer they will stay ill. Some of the more stubborn protestors who suffer this condition, eaten up with bitterness and resentment at the failure of medical science to help them, will remain as if glued to their beds for many years. Even medical science itself publishes figures that are dismally depressing for the successful treatment of ME. (see Appendix 1).

And why should they be tempted to look at the role of the mind? Look what personal rights psychiatry could strip away? Look what kind of stigma is attached to mental ill health? And in anyway, who said it *was* mental ill health? The physical symptoms are real enough of course, so why on earth would the mind have anything to do with this?

See how deeply the dualism of mind and body has been etched into our collective psyche? This either/or truce that we refuse to bow down in front of.

Sufferers of ME/CFS

So who are these unfortunate sufferers of ME/CFS? What is it about the mind that causes the disengagement from the body? Why only people with ME/CFS?

Lots of questions I asked myself when I first started working with it. I had no idea what the condition was and what might underpin it. They told me. My clients. And I started to see the similarities between every client I met. This was obviously aided and abetted by the fact that I saw several dozen over a short span of time, courtesy of our GP's, and was able to identify very clearly what the commonality was.

My First ME/CFS client

My first lady came to me for anxiety. She claimed she really didn't want any help with her ME; she had been disappointed too many times by people making a claim that they could 'cure' it. She had been on the alternative quest but only from the physical point of view: reflexology, nutrition, bach flower remedies, acupuncture etc. She was quite terse and strict that I

should not attempt to treat her condition. Of course, I wouldn't. I had no idea what it was. So we worked with the anxiety.

She revealed her sad childhood to me that caused her great stress. Being a sensitive soul, she had developed coping strategies that kept her safe. She was entirely outwardly focused. How could she stay safe, get the approval of people around her, make herself useful, ensure no one thought badly of her....any of her own feelings about herself and her position remained strictly censored and under wraps. The suppressed emotions threatening to rear their heads in her anxiety. She carefully chose her friends, kept unsavoury people away from her, devoted herself to her 3 children and husband, and guarded her fragile world avidly. Phew! What a stressful way of living!! How tiring!

Kate's inner world was unconscious. Her coping strategies so deeply ingrained they were normal. Her extreme stress levels normal. Her concern for others at her own cost, normal. Kate was, and is, a beautiful person whose only failing was that she had come to care too much for others, because she had no care when she was young.

When we met, Kate was pretty much incapable of thinking any further than her next sleep. Now she is working as a learning mentor for young people and thoroughly enjoying it. Just yesterday she said, "sometimes I think I've woken up in a dream. I love what I'm doing!".

Meanwhile, other clients queued up in droves telling me such similar stories to Kate's. It was fascinating to hear, without even having to ask, the same story over and over again. For the first year or so, I was convinced that this must be THE definitive ME/CFS profile. A childhood where only what you were worth to others was of any use to you. An adaptive child who became vigilant, learned to watch, learned to be careful, learned to put their needs last to get what they needed: love, affection, warmth. All of the essential nurturing needs that only, usually mum, could supply.

And then I started to meet people who didn't fit this profile. Hmmm... What was going on there? I listened again carefully. More carefully still, I watched their style, their modality, their words, what they said about themselves, but more importantly, how well connected they were to their inner world. I asked myself the question, why would these people develop the same kind of style as the other group who so clearly fit into this profile?

The High Achiever

Yes. The old Yuppie Fluers!! Terrible term of the 80's. Of Thatcher's Britain. And a symptom of the whole world in those years. The Upwardly Mobile element of society. The Get Rich Quick squad. Well, you get my drift.

I started to take in clients who appeared to have a charmed childhood. Everything they wanted they could get. Whatever they strived for they achieved. Whatever they felt, they ignored.....

Often supported and motivated (read also pressured) by loving and devoted parents, these people had hardly ever met failure in their lives. Hadn't often had to consider difficult or unpleasant emotions: and certainly none they couldn't do something about and have an effect on. The doers, the naturally high, the aspiring, the self neglecting....

The onset of ME/CFS symptoms for this portion of the spectrum is often dramatic and sudden. A virus, a shock, or a trauma. And the collapse of the body into unspecified and frightening symptoms that threaten their livelihood and their modus operandi.

And a complete lack of understanding how stressed their bodies have become and how little mental attention they pay to that stress. It appears these people will go as far as they can looking for physical answers to their problems, but will stay motivated to find AN answer that works for them. They haven't yet failed. They aren't going to fail at this challenge.

However, the threat of failure will cause the very cyclic worry loop to set in that the former group suffers from. Being measured often only by their outward achievements, these people too, are threatened with their loss of approval, loss of acceptance, loss of esteem. But more definitive, they are unconscious that these fears are underpinning their anxiety loop.

The Separation of the Mind and the Body

ME/CFS is medical science's proudest endorsement. The complete separation of the mind from the body. While the body protests that it is not being heard, the mind sticks it's fingers in it's ears shouting, 'nah, nah, nah, nah, nah!'. The more it protests, the more the mind refuses to listen and to 'give in' to the body. Redressing this imbalance of importance of the body to the mind is often quite a humbling experience for me and my clients alike.

However, before I made any huge claims I had found the answer, I thought I'd better do a little bit of research in the realm of science to see if there was any bits of evidence anywhere that would support the mind body link. And I came up with loads! All disjointed and separate from each other, surprise, surprise, but linked up, painting the whole picture clearly.

The Effect of Compassion Fatigue on the Body

I will not give you chapter and verse here. However, to demonstrate simplistically, when we are stressed the body reacts in any one of many different and varied ways that are indeed, physical symptoms. Take for example, something as obvious as performance anxiety. We may rush to the toilet several times before a performance or public talk. The body is ridding itself of its contents because the body perceives it is in a threatening position: a fight flight position. This is a direct attributable link between the workings of the mind and the functioning of the body.

Hans Selye's General Adaptation Syndrome, describes how long term adaptation to stress, causes all of the symptoms of Chronic Fatigue Syndrome.

The only difference is, that sufferers are NOT AWARE of the stress that they have had in their bodies since children. Outwardly focused and dependent on achievements daily, small and large, sufferers worst subconscious fear is that they might become useless. When the body starts to show signs of fatigue, or more unspecified symptoms, the anxiety loop sets in and the stress turns to anxiety, the anxiety compromises even further the immune system, and then full blown ME/CFS may set in. You'll find more about the Anxiety Loop in my Open Mind Guide to Dealing with your anxiety on www.theopenmindguide.com/products.

And then of course, the physical body needs as much support as the mental and emotional. And if you do not have the knowledge yourself, this is where it is worth working together with a nutritionist, homeopath or body worker such as Bowen technique.

Treatment Programme

Now, if you were to deliver these lofty assertions to most sufferers in or out of therapy, they would spit in your face!! So how do you deliver a treatment programme that is individual, sensitive, relevant, motivating and rewarding?

The aim of any treatment programme, in my opinion, is to give your client the power to understand what they can do to help themselves. The word ‘do’ there implies that they need to take some action. But often, the reverse is true. Clients need to listen more carefully to the messages from the body. We need to understand how those messages have become scrambled for them. And how they can start listening to them again whilst still maintaining their unique personalities. “Doing” needs to be translated to “being”. In effect, we need to become as one with ourselves and take some lessons from Eastern philosophy. And we need to access the uniqueness of each individual, and engage them in their own recovery programme. If you know how, you can tailor make every treatment programme specifically to them. No scripts. No formulas. Just the benefit of insight into a client’s psyche and the right words, tools, techniques at the right time to suit that unique client’s perspective.

In my experience, clients of all different minds and mental sets, move on fairly progressively. In some cases, even if symptoms are only slightly reduced, the shift of consciousness away from their suffering and onto more creative endeavours is a huge achievement. Many are motivated to actualize their lives with or without symptoms. Prior to treatment, most succumb to the daily grind of wondering if they’ll be too tired to...or too fuzzy headed to... etc etc.

Using integrated models of therapy with one flexible and relevant approach tailored to each client, is a very advanced therapeutic skill. It facilitates the therapists being able to tailor each session on the hoof, it responds,

unscripted, in the here and now to the client's concerns, and paradoxically takes the headwork and worry out of your practice.

If I have already given you enough information to point you in the right direction to be able to successfully treat CFS then I am pleased that we are elevating together, the profile of Hypnotherapy/integrative therapy for the treatment of CFS/ME. If you feel you need more, my next course is on the 31st October, and 1st and 2nd November 2009. You can also get a lot more insight from the video which is available on www.openmindtherapy.co.uk/cfstrainingvideo.html. I have many different ways of working that I can show you as and when you need or want to know more. Thanks for your interest in this work. Jenny Lynn

Appendix 1

Management and Treatment

Pacing and rest were reported to have been most beneficial and graded exercise was reported to be the treatment that had made most people worse.

	Helpful	No Change	Made Worse
Drug medication for pain	61%	28%	11%
Drug medication for sleep	67%	17%	16%
Pacing your activities	89%	9%	2%
Graded exercise	34%	16%	50%
Diet change	65%	32%	3%
Nutritional supplements	62%	36%	3%
Rest, including bed rest	91%	8%	1%
Cognitive Behavioural Therapy	7%	67%	26%
Other	75%	11%	14%

Private Practitioners

There was evidence of extensive use of non-NHS practitioners, with only homeopaths and herbalists receiving a less than 50% response of having proved beneficial.

	Helpful	No Change	Made Worse
Doctor	50%	39%	11%
Counsellor/psychotherapist	52%	36%	12%
Osteopath/chiropractor	58%	29%	13%
Homeopath	44%	45%	11%
Herbalist	41%	46%	13%
Nutritional therapist	60%	33%	7%
Healer	51%	44%	5%
Other complementary therapist	61%	29%	10%

Action for ME "ME in the UK" Severely Neglected. Membership survey 2001