

Chronic Fatigue Syndrome and Fibromyalgia - an Understanding

The Cruelty of CFS/FM

- Anne Mills

It is a striking characteristic of CFS/FM that people have such incredible difficulty in accepting that someone with CFS/FM is really ill. While being assailed by hideous assaults on body, mind and an individual's very being, sufferers face yet more staggering obstacles created by the lack of true understanding from other people. This is a very real situation that has to be faced by many sufferers, and can be a crushing impediment to improvement.

Sufferers face a huge struggle in trying to convey the despair and helplessness felt when in the grip of CFS/FM, while being confronted with disbelief, allegations of malingering or pathetic weakness, blame for bringing illness on themselves, insinuations that the illness is purely psychological or just imagined, claims of attention-seeking, or any number of harsh judgments rising from ignorance or lack of compassion.

Many people can only relate to their own experiences, so are incapable of understanding. Others are unable to see beyond the superficial veneer of "you look well". Some insensitive, some only self-interested, some just bored or impatient when you are not 'over it' quickly, some just incredibly thoughtless, cruel...

"Are you better, yet?" is a question that is often asked of a CFS/FM sufferer and, despite its frequency, can be a very difficult question to handle. It is a hurtful reminder of an incredibly unpleasant, intrusive illness without an effective end in sight. How does one point out that it is an illness without a cure, politely? How does one explain that they may look fine but feel as if they are crumbling away inside, without sounding pathetic? And how does a sufferer convey the despair of waking each and every morning knowing they are not yet 'better'?

More often sufferers cannot articulate any explanation at the time, and sometimes not even some time afterwards! Sensitivities may be especially tender or general outlook significantly depressed; there may be some guilt about imposition on others despite it being beyond the sufferer's control. The affects of this illness can cause abnormal reactions. However, would the same people ask this question of someone they knew had an incurable disease, or of someone who could no longer walk?

Because sufferers often “look well” or are able to participate in some activity, it is common for assumptions to be made that ‘they *must* be well’. As symptoms fluctuate and energy levels vary, each and every day is a separate challenge. People generally do not see the days spent carefully conserving energy so a day out may be possible – they are unlikely to witness the depressing disappointment when a special day arrives and either symptoms flare or energy is simply insufficient.

Most people that make hurtful comments or pass unfair judgement mean no calculated harm, however even simple thoughtlessness can have quite massive ramifications on someone that is actually ill. Then again, it can be astounding the number of people that question professional opinion or insist that they know the reason a sufferer has CFS/FM.

Poor understanding and lack of sensitivity is not confined to uninformed or unqualified people. Many sufferers cite cases of extreme coldness, rude disrespect or offensive dismissal from medical practitioners, medical personnel, therapists or other ‘professionals’. “It’s all in your mind” or “just get over it”, accusations of hypochondria, delusion, laziness and self-absorption have been thrown at sufferers of CFS/FM.

As a syndrome with mystifying causes, bewildering symptoms and no proven cure it seems easy to dismiss CFS/FM as ‘not a real illness’. The reaction is, understandably, for the sufferer to hide away from unkindness. While in the worst phases of CFS/FM there is little else possible. Isolation and feelings of helpless hopelessness can be significantly extended due to the perception that no one other than a fellow sufferer can possibly understand the daunting experience of CFS/FM.

CFS/FM is not a fatal illness. Sufferers’ are generally thankful that this illness is not as threatening or possibly as painful as progressive or terminal conditions. With no intention of taking anything away from others’ suffering, whatever that may entail, CFS/FM sufferers simply seek acceptance and some understanding.

For people to do some simple, easy research about CFS/FM before offering opinions would go a long way to providing a little positive support to sufferers and their carers who already have sufficient burdens.

*Bullfight critics ranked in rows
Crowd the enormous plaza full
But only one is there who knows
And he’s the one who fights the bull*

- Robert Graves, poet