



Coping *with* Chronic Fatigue

Misunderstood, misdiagnosed and difficult to treat, CFS can be extremely hard to live with, David Goding discovers.

Chronic fatigue syndrome is one of the most difficult ailments to grasp. There is usually no concrete cause, the symptoms vary from person to person, making it extremely difficult to diagnose, and the treatments of the past have often been ineffective.

On top of that, CFS is regularly disregarded and dismissed by medical professionals, as well as friends and family, leaving sufferers stuck in a cocoon of debilitating and seemingly endless fatigue.

Dan Neuffer knows the feeling only too well. About 18 months after going through the trauma of the near-death of his wife in childbirth, Neuffer had a vaccination. Within days, he began to develop flu-like symptoms and severe exhaustion, unlike anything he had experienced before.

“I went to see the local doctor, who explained to me that my illness was due to a throat infection. I was surprised, because I had no throat pain or discomfort. The doctor explained that my throat was extremely red and inflamed and prescribed me antibiotics and painkillers. That was my first experience with doctors not believing me.”

“My illness continued during the next four years. I skipped from one doctor to the next in the desperate hope that someone could work out what was wrong and help me.

“I repeatedly had to take time off work and any time at work was a struggle. I ceased all exercise and my life consisted of dragging myself to work and crashing on the sofa as soon as I came home. Nobody could give me any answers and after a while I realised that nobody appreciated the full extent of my symptoms. It was during this time that I finally accepted that I had CFS.”

After a long battle, Neuffer emerged from the fog of fatigue and wrote *CFS Unravalled*, about his experience, what worked for him and why other sufferers shouldn't give up hope.

“The key thing for me was understanding how the illness worked,” he says. “That not only opened up a whole range of treatment options that allowed me to get further help, but ensured that I followed through when I had setbacks during my recovery. It is easy to lose hope when one has been ill for a long time.”

How do you know it's CFS?

Diagnosing CFS is problematic to say the least. Many people are not diagnosed for years and some manage to live with it, without ever knowing exactly what they've got.

There is also some confusion between CFS and fibromyalgia (FM), as well

as myalgic encephalomyelitis (ME), multiple chemical sensitivity (MCS) and chronic fatigue and immune dysfunction syndrome (CFIDS). All are often grouped together under the banner of CFS, and for good reason.

“CFS and FM are very similar,” says Dr Lynette Bassman, author of *The Feel-Good Guide to Fibromyalgia and Chronic Fatigue Syndrome*. “A diagnosis of CFS is based on fatigue and flu-like symptoms, while a diagnosis of FM requires a certain number of tender points on specific parts of your body. But most people with FM will tell you that they have fatigue and most people with CFS will tell you that they ache all over.

“Because FM often follows a physical trauma, such as an automobile accident, and CFS often follows an illness, such as mononucleosis or a severe flu, it may be that the terms FM and CFS are actually names for two subgroups of the same syndrome, triggered differently.”

Along with the common flu and fatigue symptoms, sufferers may (or may not) experience a difficulty in concentrating or remembering details, headaches, joint pain, a sore throat, anxiety, night sweats, nausea or bloating.

Diagnosis is achieved by a process of elimination, as there are a variety of disorders that can masquerade as CFS.

NO ORDINARY TIREDNESS

You can have chronic fatigue without having CFS. In fact, one in five people consult their doctor about feelings of tiredness at some point in their lives.

Living with CFS

CFS affects around 250,000 Australians, and that's just the ones we know about. With an estimated 80 per cent of CFS sufferers going undiagnosed, the true figure is likely to be considerably higher.

Living with CFS is extremely debilitating for all concerned – not just for the person living with it but also for partners and family members as well.

“One of the key things that partners and ill people need to ensure is that they try to make the most of every day regardless of how they are feeling and what is going on,” says Neuffer.

“One of the best things a partner can do is help learn about the illness. In this way they can start to better understand the nature of the illness and hence their partner. This will allow them to support their partner appropriately and any improvement in health will affect everyone positively.

“I also think it's really important that partners get a break sometimes. So it's ok for a partner to attend a social gathering while the person with CFS stays home to rest.

“Often people don't recognise just how difficult it is for the partners of people with CFS.”

Neuffer emphasises the need to maintain hope, even when all seems lost.

“People who are sick for a long time lose hope about their chances of recovery, as do their partners, doctors and other family,” he says. “Staying positive and hopeful can be hard to do, but all I can say is recovery is absolutely possible, even after years of illness. The key is to educate yourself and get help and take action.”





Tracking down a cause

CFS is less of a mystery than it once was. Sure, there's still much that scientists don't know about the illness, and there is a long way to go before a sure-fire treatment is developed, but there is a growing understanding of just what triggers it and how it works.

"Family members of patients with FM and CFS display a higher than average frequency of the syndromes as well as conditions related to them, including irritable bowel syndrome, migraine headaches and mood disorders," says Dr Bassman.

Interestingly, people with CFS tend to show higher than normal amount of childhood trauma and may also be more driven and high-achieving as adults.

"The group also seems to contain a higher than average number of people with a strongly goal-oriented approach to life," says Dr Bassman.

CFS often develops as an after-effect of a seemingly non-related illness, such as glandular fever, the flu or even a reoccurring viral infection, such as shingles.

"If the immune system is compromised, it can't fight off infection as well as normally and an infection can become chronic," says Dr Bassman.

But just how these triggers end up becoming CFS is hotly debated.

Neuffer believes the answer lies in the autonomic nervous system.

"We know that intense psychological stress is usually involved at the outset of CFS. We understand the connection between stress hormones such as adrenalin and cortisol and bodily dysfunction. The question is: If the initial

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For more information about CFS, go to the national organisation ME/CFS Australia at mecfs.org.au

For more information about Neuffer's journey and research go to cfsunravelled.com

stressor has subsided, then why does the dysfunction continue?"

Neuffer argues that one or more of these triggers causes a dysfunction of the autonomic nervous system, "which produces an inappropriate stress response and relaxation response to a variety of inappropriate triggers, which perpetuates these symptoms, creating a perpetual cycle of illness."

Your treatment options

There are just as many treatments for CFS as there are symptoms, which is just as well – because it usually takes a combined effort to achieve any level of sustained success.

"Traditionally, cognitive behavioural therapy, graded exercise therapy and pacing have been main strategies for recovery," says Neuffer. "Many doctors have also prescribed anti-depressants and a variety of other medications such as sleep medication, pain medication, hormonal supplementation and so on.

"Given that the treatments focus on the symptoms and not the cause of the illness, they only tend to offer temporary relief in most cases.

"Surprising to most people, diet, nutritional supplementation and lifestyle changes appear to have a great effect."

Many people with CFS don't make a full recovery, although the rate is better early on when onset is sudden, diagnosis accurate, and treatment starts immediately. After having CFS for more than two years, your chances of making a full recovery decrease, although many are able to reduce severity of symptoms considerably.

Even after a period of partial recovery, CFS sufferers are still vulnerable to a relapse when exposed to perceived stress triggers.

Stress could be anything from physical stress (physical exertion), mental stress (excessive work hours) or even emotional stress (grief, a breakup). Neuffer asserts that stress resulting from the CFS symptoms, such as hypoglycaemia and gut dysfunction, can also be an important factor in why the illness perpetuates.

"It is my view that people need a deeper understanding of how their symptoms are triggered and then have a multi-faceted approach that addresses all the physical, physiological and mental stressors that trigger what I describe to be the cause. I believe that all these triggers need to be addressed simultaneously, which I believe was the critical part of my recovery," he says.

"It's also important to re-engage with your doctor and naturopath and listen to medical advice.

"You need a large variety of strategies to build a recovery plan, and this needs to be tailored to the individual's needs." **NH**

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- GORD
- Gout
- Haemorrhoids
- Hay fever
- Headaches
- Heart disease
- High blood pressure
- Hunger
- IBS
- Inflammation
- Insomnia
- Kidney stones
- Osteoporosis
- Overweight
- Persistent & Frequent colds & flus
- Poor circulation
- Premature aging
- Ulcers
- Urinary infection



Traditional medicine cannot always explain the aforementioned symptoms. However, many natural therapy practitioners propose that these symptoms manifest from the weakest link in your body and the cause is over-acidification of your body. This is why many health practitioners advocate an alkaline diet to eliminate acid from your body. This means the exclusion of sugar, meat and grains (rice, bread and pasta). Or at least dramatically cut them down from your diet.

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