

## How you can help

### *Offer practical help*

Everyone responds to the offers of practical help in different ways. Talk about what help you can offer and allow your friend to decline practical assistance if that is what suits them best. Help maybe as elementary as being kept up to date with what is going on with other areas of life.

Do not add to the burden by offering to do jobs that will leave your friend unable to repay you or even express any gratitude. Housework, garden maintenance, advocacy, child care, pet care, social opportunities may all lend themselves to help, but be thoughtful and realistic about what real help might be.

If you already go to a library, walk a dog or share the same nature strip your offer of help maybe welcome in one of these areas. A casserole in a heavy pot, perhaps with ingredients that your friend cannot tolerate may not be helpful. If your child attends the same school you may be able to liaise with the school to send good wishes as well as news and some work home. Again check with your friend first.

Finding out as much about the illness as you can by reading science-based information maybe helpful. Do not believe what you read in the press about miracle cures or how an elite sports person overcame illness. Non judgemental acceptance may be all you can offer. Reassurance that you want to share their misfortune may be the first step in building a new sort of friendship.

### *Join ME/CFS Australia (Victoria)*

Make time and space in your life for thoughts for this person in their new state. Learn to recognise the small signs which indicate how the person is feeling (when they sink low into the couch it maybe time to leave).

**Address:** 21 – 23 Livingstone Close, Burwood VIC 3125

**Administration:** (03) 9888 8991; admin@mecfs-vic.org.au

**Support Line:** (03) 9888 8798

**Website:** www.mecfs-vic.org.au

## Understanding ME/CFS A Guide for Family and Friends



Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a severe and debilitating illness. It is defined by a cluster of symptoms that must have persisted for over six months with no other medical explanation. Post-exertional malaise is a key indicator.

The name CFS can be misleading. Often people think that ME/CFS is just being very tired. This is incorrect. Sufferers are sick, not simply exhausted. Some people have the illness severely and are bedridden. In its mildest form some people may be able to continue work and do other activities with care.

Some people do not always act with care and may choose one or two activities at the expense of others. Most people come to find a balance and are capable of 3 to 4 hours of light activities, with rests in between. Rest does not cure the illness but it is essential in order to prevent exacerbation of the symptoms.

Sufferers need to change their lifestyles considerably. Sufferers do not always look unwell. ME/CFS is not a mental illness, some sufferers do become dispirited, and some can experience depression, but not as many as one would think. ME/CFS is a chronic illness with no cure.

## Symptoms

Below is a list of symptoms associated with ME/CFS taken from the Canadian 'Clinical Case Definition and Guidelines for Medical Practitioners' document. A complete copy of this document can be found at <http://www.mefmaction.net>.

### **Fatigue**

The patient must have a significant degree of new onset, unexplained, persistent, or recurrent physical and mental fatigue that substantially reduces activity level.

### **Post-exertional malaise and/or fatigue**

Following physical and mental exertion there is a worsening of symptoms. There is a slow recovery period – usually 24 hours or longer.

### **Dysfunctional sleep**

Unrefreshing sleep, inability to fall asleep, excessive sleep, fragmented sleep, restless legs, abnormal sleep rhythms.

### **Pain**

There is a significant degree of myalgia. Pain can be experienced in the muscles, and/or joints, and is often widespread and migratory in nature. Often there are significant headaches of new type, pattern or severity.

### **Neurological/cognitive manifestations**

Confusion, problems with processing and recalling information; difficulty with finding the right word, reading, writing, mathematics and short term memory; disorientation; inability to concentrate; muscle weakness is common; sensitivity to light, touch and sound.

### **Autonomic manifestations**

Orthostatic hypotension – light headedness on standing; dizziness; disturbance of balance; extreme pallor; nausea; bowel and bladder dysfunction; palpitations; shortness of breath with exertion.

### **Neuroendocrine manifestations**

Loss of homeostatic stability – sweating, feverishness and cold extremities; intolerance to extremes of temperature; marked weight change – abnormal appetite; loss of adaptability and worsening of symptoms with stress e.g. infection, travel, anaesthetic, physical or mental exertion.

### **Immune manifestations**

Tender lymph nodes, recurrent sore throat, recurrent flu-like symptoms, general malaise, new sensitivities to some foods, medications and/or chemicals.

### **The illness persists for at least six months**

It usually has a distinct onset, although it may be gradual. An early diagnosis may be possible. Three months is appropriate for children.

## Loss

ME/CFS sufferers have to make changes to their lifestyles. Although some people recover and others improve, many have the illness for years. Lifestyle changes mean that a great deal is lost from people's lives.

Grief and its associated feelings of frustration, anger, denial, disappointment, sadness and guilt have to be dealt with. Not being able to continue with life and its activities as before can also contribute to social isolation. There may be the loss of:

- Work-status, self esteem, being the bread winner;
- Education and the opportunities and experiences this brings;
- Income and all this entails;
- Sport and hobbies;
- Travel and holidays;
- Social events and family gatherings;
- Friends, workmates and colleagues;
- Identity and self esteem which went with life before ME/CFS;
- Independence

Be aware that as a friend or family member you may also experience feelings associated with grief too. The loss of your 'old' friend may be difficult to come to terms with. Your friend may now have to adopt a new set of values and priorities. Finding ways forward together is a real test of friendship.