



# **ME/CFS**

## **Information Booklet**

***Help Us Break Free***

## **Our Mission**

To provide services, information, support and advocacy for the people of NSW with ME/CFS and their families with the aim of improving or maintaining their quality of life.

## **Our History**

Each year we answer over one thousand phone calls for help and have done so for twenty years. The Society could not survive without the support of our staff and the generous volunteers who co-ordinate support groups across NSW, construct our website, contribute to our journal, and serve as elected representatives on our Management Committee.

## **Our Aims**

- To provide support, assistance and information to people with ME/CFS/FM, their carers, and families.
- To increase community awareness of the nature of ME/CFS/FM and the needs of people with the illness.
- To support medical research into ME/CFS/FM

## **Our Patrons**

**Patron-In-Chief**  
**Her Excellency Professor Marie Bashir AC**  
**Governor of New South Wales**

**Professor Lesley Wilkes PHD MHEd BScCM RN**

**Mr Leigh Hatcher Media Presenter**

### Our Affiliations

The ME/CFS Society of NSW Inc is a founding member of the *ME/CFS Association of Australia Ltd*, the national peak body representing members from autonomous state-wide ME/CFS Societies

- Australian Capital Territory
- Queensland
- South Australia
- Tasmania
- Victoria
- Western Australia
- Victoria
- Western Australia

**If you think you, a member of your family, a friend or a colleague may have ME/CFS you are probably going through a confusing and worrying time. This booklet has been compiled, in the hope that it will give you the information that you are looking for.**

## **Frequently Asked Questions about ME/CFS**

### **What is Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (M.E/CFS)?**

M.E/CFS is a complex, chronic, debilitating and potentially disabling disorder which affects multiple systems of the body. It affects the central nervous system, the neuroendocrine system and the immune system.

ME/CFS is characterised by profound pathological fatigue plus a range of other symptoms (see section, *What are the symptoms?*) The fatigue is described as a debilitating physical sensation, out of proportion to a person's level of activity and independent of mood. This pathological fatigue can be differentiated from tiredness.

### **What are the causes of ME/CFS?**

Despite ongoing research, the cause of ME/CFS is not yet clear. In fact, there may be a number of causes. In some cases, onset appears to be linked to a stress to the immune system such as an acute infection, chemical exposure or immunisation. Pathogens being studied include human *herpesvirus-6* (HHV-6), *Chlamydia pneumoniae* and *Mycoplasma*. It is thought by some that ME/CFS is not due to a single infectious agent but that it is caused by an abnormality in the body's response to one of several agents. There may well be an interaction between genetic susceptibility, environmental stressors and the basic health of an individual at a particular time which makes them vulnerable to developing ME/CFS.

### **What are the symptoms of ME/CFS?**

The hallmark of the condition is a prolonged (for more than 6 months) and disabling feeling of exhaustion. This fatigue is made worse by increased activity (both mental and physical). The fatigue is disproportional to the level of activity and often unrelieved by sleep.

Additional symptoms vary between individuals and fluctuate in presence and severity.

Symptoms could include:

1. flu-like symptoms - sore throat, fever and sore or swollen lymph glands, chills, night sweats
2. pain - muscle aches, joint aches, headaches (often of a severity, frequency and type not experienced before), chest pains and gut aches
3. sleep disturbance - insomnia, excessive desire to sleep, waking unrefreshed, disturbed sleep-wake cycle
4. increased sensitivities - to light and noise, skin, food, the environment (including common chemicals, dust and dust mites), heat/cold and climate changes, medication and food supplements
5. chest symptoms including palpitations and breathing difficulties
6. abdominal and pelvic symptoms - nausea, reduced bladder control, menstrual problems
7. motor symptoms - balance disturbances, dizziness and clumsiness
8. cognitive symptoms - impaired concentration and thinking skills, poor short-term or working memory, trouble finding words, poor reading comprehension, problems with number calculation or spatial orientation, mental fatigue sometimes called 'brain fog'
9. psychological symptoms - depression, anxiety, irritability and mood swings
10. other symptoms - orthostatic intolerance, problems controlling blood pressure, weight gain or weight loss, blurred vision or changes in eyesight (a new script may be required).

### **How is ME/CFS diagnosed?**

There is no single diagnostic test for ME/CFS at this stage. Diagnosis is made by excluding other illnesses and consideration of patient history. This can be a long and difficult process. Normally ME/CFS is not considered before a 6 month period so to eliminate other possible illnesses. It is invariably made more difficult if your health practitioner is still unfamiliar with, or even sceptical of, the reality of M.E/CFS as an organic illness.

The ME/CFS Society of NSW may help you to find a medical practitioner sympathetic to and experienced with managing ME/CFS.

The symptoms of ME/CFS overlap with those of a number of other illnesses, including *Fibromyalgia Syndrome* (FM), *Multiple Sclerosis* (MS), *Lyme disease* and *Systemic Lupus Erythematosus* (Lupus). Chronic fatigue is symptomatic of many diseases. ME/CFS is one of the less common explanations for persistent exhaustion.

The tests your health practitioner orders will usually be routine blood tests plus those that exclude possible alternative diagnoses. Although there are many symptoms associated with ME/CFS, to diagnose ME/CFS, health professionals will look for a certain pattern of symptoms. A copy of the widely respected, 'ME/CFS A Clinical Case Definition and Guidelines for Medical Practitioners' (which is an overview of the Canadian Guidelines) can be downloaded free of charge from the Society website [www.me-cfs.org.au](http://www.me-cfs.org.au) (look in the 'brochures and fact sheets' tab).

### **Who gets ME/CFS?**

ME/CFS is a condition that knows no social, racial, economic, geographic or age boundaries. It affects people of all backgrounds and ages. Figures suggest, however, that it is most common among 20 to 40 year olds and that women outnumber men. Approx 3 in every 1000 people within the general community are affected by ME/CFS and 1 in 3000 are severely ill with ME/CFS (Professor John Dwyer May 04).

### **How long does ME/CFS last?**

The duration of ME/CFS is impossible to predict and will vary from individual to individual. Symptoms can last from six months to many years. Some people improve gradually and, in time, make recovery to return to their pre-ME/CFS lives. Some modify their lifestyles to cope with their reduced health and will lead near-normal lives. Others never fully recover.

It is thought that those who are diagnosed early in their illness and who pace their activity levels against adequate rest during the early stages have the best chance of recovery.

### **Is there a cure for ME/CFS?**

At this stage there is no cure. Until we know the cause of ME/CFS, a cure is unlikely to be found. At present, treatments are directed at relieving symptoms. The optimal treatment regimen for each individual is often found by trial and error

(See *Managing ME/CFS*).

### **Is ME/CFS a new illness?**

No. Although the incidence is thought to have increased in the past half-century, the syndrome itself has probably been around for thousands of years. Medical texts from ancient days mention clusters of symptoms similar to those of ME/CFS. ME/CFS is probably the disease referred to in 1745 as *febricula*, and in the nineteenth century *neurasthenia*. Twentieth-century names have included *Epidemic Neuromyasthenia*, *Tapanui flu* (New Zealand), *Royal Free Disease* (named after London's Royal Free Hospital) and *Chronic Epstein Barr Virus*.

The term *ME* was introduced in London, UK in 1956. The term *CFS* was introduced in the late 1980s in the United States of America (US). The condition is increasingly known as *ME/CFS*.

### **Why is there scepticism about ME/CFS?**

Because there is no definitive diagnostic test, some people claim ME/CFS is 'all in the mind'. However, scientists have found a number of abnormalities in people who have ME/CFS which show that it is a 'real' biological or organic illness, even though the cause is still unknown.

In ME/CFS, as with other illnesses, the physical and the psychological intermesh. Numerous illnesses are associated with depression. Many patients with ME/CFS find the symptoms themselves and the unpredictable nature of relapses difficult and disturbing. Like any chronic illness, ME/CFS can disrupt the ability to work and reduce enjoyment of social activities leading to frustration, anxiety and stress.

Cognitive disturbances including fuzzy thinking, memory disturbances, and poor concentration can also be depressing. Some of the symptoms of ME/CFS, including fatigue, do overlap with those of major depression. However researchers have found clear evidence of a number of distinct differences between the two conditions.

### **What is the difference between ME/CFS and Fibromyalgia?**

Fibromyalgia (FM) is a form of muscular rheumatism characterised by tenderness, soreness, pain and muscle spasms. Epidemiological studies indicate that 2 - 10% of the general community are affected by FM (Carruthers and van de Sande, 2006). This equates to hundreds of thousand sufferers in Australia.

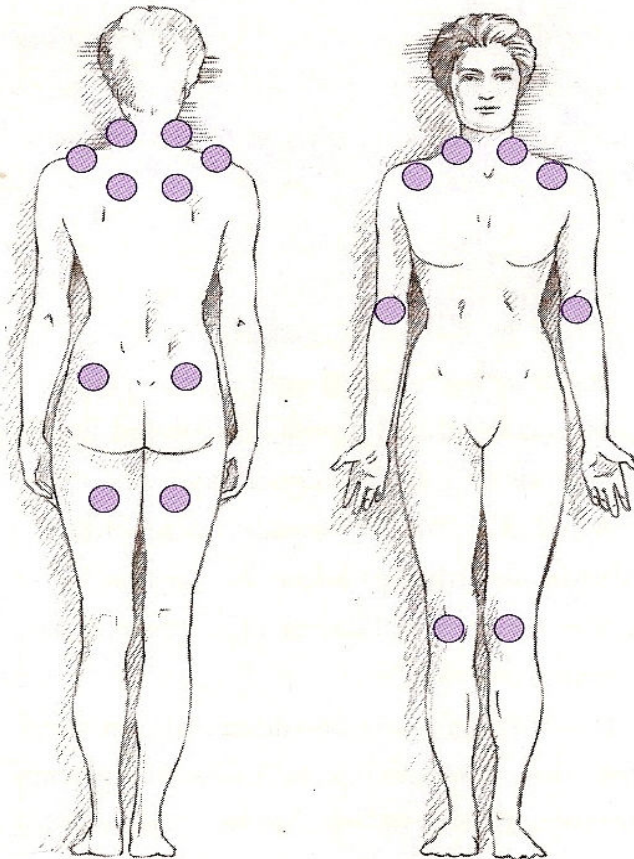
FM and ME/CFS share many similarities; which is the reason why ME/CFS Societies' extend support to people living with Fibromyalgia.

Similarities include:

- The illnesses share common symptoms of sleep disturbance, pain, fatigue and cognitive difficulties.
- The illnesses have a medical history of being misunderstood.
- Diagnosis is difficult
- There is no blanket 'cure' for either ME/CFS or FM
- Women are more likely to be affected than men
- Some treatments may alleviate some symptoms
- Like management for ME/CFS, effective management of FM may include a nutritious diet, reducing stress and reducing or stopping alcohol and tobacco use.

The main difference between the two disorders is that patients with FM report more muscular and joint pain (both sides of the body, above and below the waist), whereas people with ME/CFS have greater fatigue and are more likely to have fever, swollen glands, blood abnormalities and evidence of infection.

The majority of people with ME/CFS also meet the criteria for FM.



JOINTS USUALLY AFFECTED BY FIBROMYALGIA ;

## **ME/CFS and Research**

Although no cause or cure has yet been found for ME/CFS, researchers have been studying the illness since 1938. The number of articles about ME/CFS in scientific and medical journals internationally has mushroomed in the past few decades. In Australia there are teams from various universities studying biochemical abnormalities, muscle abnormalities, possible genetic links and links between ME/CFS and infections such as *Epstein Barr virus*, *Q fever* and *Ross River virus*.

Experts believe that there may not be one single cause but a number of causes, or perhaps a combination of factors, which cause the illness. Many also believe that ME/CFS is not one single disease but either a number of diseases or one disease with a number of subsets.

Following studies of abnormalities in gene expression for people with ME/CFS, advances have been made. At the end of 2007, Dr Jonathan Kerr and his team from St George's University of London identified differential expression of 88 human genes in ME/CFS patients. By analysing the protein types in the blood, they were able to show different levels of specific gene activity when compared with a healthy sample. This could potentially lead to the development of a diagnostic blood test which would reduce the difficulty of gaining a diagnosis and help to end the scepticism about the illness. It is hoped that the markers will also lead to a better understanding of the causes of ME/CFS.

A number of other abnormalities have been found in people who have ME/CFS such as increased immune activation and low blood flow in the brain but these are not clearly unique to the illness.

The ME/CFS Society of NSW Journal, EMERGE (shared with the ME/CFS Society of VIC) features regular articles on research so that members can be kept up-to-date on the latest developments.

## **ME/CFS and your Feelings**

Your reaction to a diagnosis of ME/CFS will be as individual as you are. To some people, it can come as a blow, as can the diagnosis of any chronic illness. To others, it can come as a relief to be able to finally put a name to the compilation of symptoms they've been feeling for so long. You may feel a number of conflicting emotions. Illness and disability are forms of loss, so you may mourn for the health

and lifestyle you once had as you work on the process of adjusting your activities to your condition.

Your self-image and self-esteem may also be lowered. Don't be surprised if you feel angry - with yourself for having ME/CFS, with others for not having it, with health practitioners for not helping enough, or simply at life in general. These feelings are normal as are regret, resentment, anxiety and longing for what might have been. Intense emotions of any type can be hard to handle, and while the support and understanding of family and friends are important, counselling can also be of great help, as may talking with other people with ME/CFS. Joining a support group or an on-line internet chat site for sufferers is something to try.

### **ME/CFS and Others**

Telling other people that you have ME/CFS is not easy. There are still many people who do not accept that it is an organic illness. With increased awareness and education this situation is changing, but knowing who, when and what to tell other people can present a problem. Even those people who want to be sympathetic and do accept that ME/CFS is a real illness find it very difficult - even impossible - to really understand.

#### **Your family**

Your family's initial reaction may mirror yours, that is, a mixture of grief and relief. Partners and children may have been harbouring fears so scary they could not even mention them. Young or old, the people you live with need to know how you feel, physically and emotionally, if they are to provide support and come to terms with your illness.

Because of its unpredictable and wide-ranging effects, living with ME/CFS can be difficult. So can living with and caring for someone with ME/CFS, and personal relationships may come under strain. Family members can often be resentful and angry because you can't do the things you used to do. Some will be disbelieving, especially if you are able to function fairly normally at certain times but not at others. Partners and other carers often benefit from talking to your health practitioner or the Social Welfare Officer at the Society. Reading about ME/CFS can help them as well. The Society's Journal EMERGE can be of use here.

There will always be some people who don't believe you. This can be very painful but you might just have to learn to accept it. Sometimes even these sceptics

eventually come to understand.

If you have a carer, you may wish to ask the Society for a *Carer's Manual*. This manual contains lots of helpful information about issues for carers of people with ME/CFS and available support services.

### **Your friends**

Many people find that by having ME/CFS they lose some friends and gain others. Some friends don't or are simply unable to understand what's wrong with you, especially if you seem quite well and act normal at times and are ill and unable to do things with them at other times. Some friends will gradually drop away if you are unable to see them as often as before, to reciprocate their social efforts, join them in activities or even listen to their problems. If you find yourself getting more and more isolated and lonely and it's making you more depressed, there are some steps you can take to reverse that slide. Sometimes friends need to have it spelled out to them that you need their support. You could ask them to come around and bring a DVD, which you can watch together. Ask them to pick you up and take you out to a café or a movie. People are usually happy to help if they are asked. You may find that although some friends disappoint and hurt you, others become very supportive and close.

Many people make new friends through the Society's Support Groups. They find it relaxing to be with people who understand all the little things that living with ME/CFS entails - not having to always explain or excuse. Unfortunately there are some who are too ill to go to support group meetings or who don't have a support group near them. There may be the opportunity to talk to someone else with ME/CFS on the telephone (contact the Society). Internet Forums also provide contacts for people with ME/CFS.

### **Your health practitioner**

Let's be honest, people with ME/CFS are not the easiest patients in the world for a health practitioner. The condition is chronic, the symptoms varied, the severity constantly fluctuating, and there is simply no magic pill or procedure that offers a cure. Your relationship may already be strained, especially if reaching a diagnosis has been a difficult process. There are still some health practitioners who reject ME/CFS as a biological illness. Fortunately, there is an increasing number who are interested in the illness and its management who can provide help. Having a supportive health practitioner can make a huge difference. If you are having problems finding a sympathetic health practitioner talk to the Society. Many health practitioners are sympathetic to ME/CFS but haven't had the opportunity to

find out much about it, so they will often be quite happy if you bring them articles from the *EMERGE* Journal or other medical journals to read and discuss.

### **Your employer**

What and how much you tell your employer and workmates will vary according to your situation and symptoms and can be tricky to assess. Some employers and colleagues are supportive; unfortunately others are not. Some people with ME/CFS are simply too ill to work, especially in the acute stages. If you are working and need to rest during work hours, take a lot of sick leave, are often late getting to work or your work itself is affected, it's best to be upfront, or the reasons for these behaviours may be misinterpreted and your job jeopardised. As far as sick leave is concerned, the situation is the same as with any other chronic illness. If you need lot of time off, try to negotiate an arrangement with your employer. If you belong to a union or work for the public service you will have certain rights such as the right to 'light duties', permanent part-time work, long service leave or extended sick leave. Talk to your union or the relevant public service officer about this. Again, if you have problems in this area, the Society may be able to help.

### **Children, Adolescents and ME/CFS**

Youth is no shield against ME/CFS, and the condition can create special problems for children and young people. It's rarely found in under-fives but adolescents seem particularly vulnerable. In the 5 to 12 year age group onset is often slow, but in adolescents it can be acute and linked with a flu- like illness. Many of the symptoms of ME/CFS are the same as for adults, but in young people ME/CFS can, of course, affect school performance.

Students may need to reduce workload, switch to distance learning or have time out from study. Even if this is not the case, poor concentration and impaired thinking skills can affect both learning ability and behaviour. Be open with the school from the start. Misunderstanding and a reluctance by individuals and school bodies to accept ME/CFS as a real illness have led to situations where children have been labeled lazy or 'school phobic'. There have even been instances where parents have been accused of neglect for 'not sending' their children to school.

Be aware, too, that even when they are told of the diagnosis, teachers and other staff may be unaware of the implications or the unpredictability of the illness in

terms of school life. The Society has information to help schools, teachers, parents and students.

In adolescents the urge to be part of the group and the pain of being 'different' can add to the difficulties. It's important for young people affected by ME/CFS to maintain social contact with their peer group as much as possible. The Society has a 'Youth Pack' which may be helpful.

## **Managing ME/CFS**

It is important to note that what works for one person with ME/CFS may not work for another, or may even be harmful. Therefore, close monitoring of any changes to lifestyle, supplements, medication, etc. is essential. You may find keeping a log or a diary of your symptoms is a helpful way of understanding why you experience a particular symptom at a given time.

### **Treating Symptoms**

Until a cure or definitive treatment for ME/CFS is found, the most important thing a person with the illness can do is learn how to manage it. The first thing to do will be to find a health practitioner, usually a GP who is sympathetic to the illness and has some experience in treating it. (The Society can help with this if you are having difficulties) You and your GP can then try to find treatments that relieve your symptoms, one by one, perhaps starting with the worst ones.

### **Medication**

People with ME/CFS are often very sensitive to medications, so it's wise to start treatments with a very low dose and gradually build up the dosage. Your GP should be able to suggest or prescribe various medications for pain relief, from over-the-counter analgesics to non-steroidal anti-inflammatory drugs or mild narcotics. The same is true for gastro-intestinal and bowel problems. Sleep problems can sometimes be relieved with the use of over-the-counter medications, antihistamines or short-term use of prescription sleep medications.

If your health practitioner suggests you try antidepressants this does not necessarily mean he or she thinks you're depressed or that your illness is 'all in your head.' If you *are* depressed, either because you have ME/CFS or as a result of the illness itself, an antidepressant could help. There are a number of different types of antidepressants and several varieties within each type, so you may have to test quite a few until you find the one that works best for your

symptoms. Care needs to be taken when coming off antidepressants, so make sure you consult with your health practitioner.

## **Supplements**

Some people swear by supplements such as evening primrose oil, vitamins (including vitamin B12 by injection), minerals and trace elements. But again, the effect on individuals is variable and unpredictable, and scientific trials have yet to come up with firm and consistent conclusions. Remember that side-effects and sensitivities can occur with natural chemicals just as they can with synthetic substances. Self-supplementation without the guidance of a qualified health practitioner who knows your medical history is not advised.

## **Complementary therapies**

Responses to therapies such as acupuncture, acupressure, massage, herbs, homeopathy and others are also variable. Some people with ME/CFS discover that certain treatments help; others find that their symptoms become worse or remain unchanged.

Beware of emotional blackmail along the lines of 'If you were really serious about getting better, you'd try this' and any promises of cure. Also be very careful about spending a lot of money on unproven therapies. Some so-called scientific studies and 'papers published in scientific journals' have proven to be hoaxes.

## **Nutrition**

A good, balanced diet is important to good health. Consideration may need to be given to what you are eating and drinking, when you eat, how often you eat and the size of each meal. Often ME/CFS patients develop food sensitivities and/or allergies. If so, dietary changes could help with symptom relief. If you do develop food sensitivities, it may be difficult to structure your diet to ensure you get the nutrition you need. Consult a trained nutritionist, allergy specialist or dietitian if necessary.

## **Relaxation techniques**

These range from simple muscle relaxation to more formal techniques such as meditation and visualisation. The Society's library stocks guided meditation/relaxation CD's if you would like to try. A number of people with ME/CFS find these techniques helpful. There are many books, tapes and courses available that teach relaxation and meditation. There are also other less structured forms of relaxation such as listening to music, sitting in the garden or watching a movie. Some people find it relaxing to write poetry or do needlework,

while others find these activities impossible. Laughter is an excellent form of relaxation, so be on the lookout for things that will make you laugh.

### **Allergies and sensitivities**

From chocolate cake to hairspray, there's a wide range of foods, natural and synthetic chemicals that can spell trouble for some people with ME/CFS. In a significant number of individuals intolerances develop to certain foods, additives and chemicals, and these can trigger symptoms. Pre-existing sensitivities can be heightened. Allergies can sometimes be managed with allergy medications such as antihistamines.

One way to tell if your symptoms are linked to particular foods or chemicals is to avoid consumption of or contact with, one thing at a time to see if your symptoms are alleviated. Alternatively there are companies that provide testing services, the Australian Biologics Testing Services Pty Ltd (02 9283 0807) is one of these companies. If you suspect you may have food sensitivities consult a qualified dietitian or an allergist who can arrange a series of food trials and devise a diet that meets your nutritional needs.

### **Sleep**

Sleep problems are common in ME/CFS. Perhaps you wake feeling exhausted or worse than when you fell asleep. Perhaps you have difficulty falling or staying asleep. Some people feel they sleep very lightly or have such vivid dreams and nightmares that they wake up agitated and upset. Night sweats and 'restless legs' are also common symptoms. Pain disturbs sleep in some individuals; others find their sleep-wake cycle is completely disrupted.

Getting enough quality sleep is one of the most important ways to alleviate the symptoms of ME/CFS. If you've tried all the usual ways, such as relaxation, warm milk, avoiding caffeine, sugar drinks and so forth, and still aren't getting enough sleep, talk to your health practitioner. Prescription medication may help you with your sleep problems.

### **Accepting ME/CFS**

Accepting that you have a chronic condition and making the necessary adjustments in your life can not only reduce the stress but might also increase the likelihood of eventual recovery. Yearning for what was or what might have been, although normal, might not be helping. Instead, try to come to terms with the situation as realistically and practically as you can. This may mean changing the way you think about yourself and your life. This can be difficult to do, but it helps to know that it's in your own power to do it. It might mean finding a new purpose

in life, especially if you've had to give up a career or study. It will mean defining yourself in terms of who you are rather than what you achieve. Some people get to this point through their religion or by exploring spirituality. Others use professional help, read books or try introspection.

## **Learning about ME/CFS**

Many people feel they're more in control if they find out as much about ME/CFS as they can. There's a list of helpful resources at the end of this booklet. The Society library has some of these items; if you are a member of the Society you can arrange to borrow them by post. Your local library may have these or others. The Society's Journal always provides helpful information, not only about the medical aspects of the illness, but also about how others have learned to cope. The Internet has a huge amount of ME/CFS information of varying quality. You could start with the websites of other Societies, both here and overseas which should have higher quality information on ME/CFS. Some of these include:

[www.cfids.org](http://www.cfids.org) U.S ME/CFS Society

[www.meassociation.org.uk](http://www.meassociation.org.uk) U.K ME/CFS Society

[www.mereseach.org.uk](http://www.mereseach.org.uk) MERGE's website for research overviews and bibliographies on M.E/CFS

[www.immunesupport.com](http://www.immunesupport.com) General and dietary information for ME/CFS/FM patients.

[www.mecfs.org.au](http://www.mecfs.org.au) National Australian Website

[www.mecfscanberra.org.au](http://www.mecfscanberra.org.au) A.C.T Society Website

[www.me-cfs.org.au](http://www.me-cfs.org.au) NSW Society Website

[www.users.bigpond.com/mefmtba](http://www.users.bigpond.com/mefmtba) QLD Society Website

[www.sacfs.asn.au](http://www.sacfs.asn.au) SA Society Website

[www.vicnet.net.au](http://www.vicnet.net.au) VIC Society Website

## **Pacing**

Learning how to pace yourself or prioritise your activities is another important way of coping with ME/CFS. Some people find that carefully monitoring how much they can do without negative consequences and stopping just before they reach that point is a useful technique. Others find this impossible because of the unpredictable nature of the illness and would rather do what they can when they have the energy and accept the consequences, knowing it might cost them a day or more in bed. During this stage of your life, you have to make choices about your activities. You may only be able to do half, or less, of what you could do when you were well. It may take time to come up with a program that works best for you.

## **Counselling and support**

Trained counsellors are well equipped to help you through your journey. There are various counselling styles but a key in all counselling is the element of listening. To be listened to without judgement can be a very powerful experience. The NSW Society has a Social Welfare Officer that is able to offer support. If you would prefer a face to face meeting, the Social Welfare Officer can help to find someone else that is right for you.

At times you may benefit from simply confiding in a friend. Talking with others perhaps at a Support Group, (if you have one in your area) may offer valuable ideas and suggestions.

## **Rest and exercise**

How much exercise versus how much rest someone with ME/CFS should have is one of the most controversial issues in ME/CFS management. Research studies looking at the effects and benefits of formal exercise programs (known as Graded Exercise Therapy - GET) have produced contradictory results. Some have found differences in exercise physiology measures between ME/CFS patients and age, gender and similarly sedentary matched control subjects. These studies have indicated that tolerance of formal exercise is reduced in ME/CFS patients. Other research has indicated that GET can be of benefit to those who are able to tolerate it.

'Rest' is often equated to 'bed rest'. Rest, however, can vary from having frequent breaks, to going to bed early, to reducing work/school to part-time or changing working hours to times when energy is higher.

Similarly, 'exercise' means different things to different people. To some, it means going to the gym and doing aerobic classes and weight training. To others, it means walking for half an hour every day. To someone who is very ill, it means walking to the toilet or the letterbox. Any activity is a form of 'exercise' and that includes emotional and mental activities, activities of daily living and formal programs of physical exercise.

You will certainly need to rest during the early and acute stages of the illness. If you can rest during the first few months it might even shorten the duration of the illness. You will also need to rest during relapses of ME/CFS.

In time, during the chronic stages of the illness, you will probably find a balance between rest and activity unless your illness is very severe. If you can exercise, do so, but make sure that you are aware of, and work within your limitations. Look

for an activity that not only suits your condition but offers satisfaction and relaxation too. Swimming, walking, gardening and gentle forms of exercise such as tai chi or yoga may appeal.

Remember when planning activities that the effects of any exercise may hit you some time after doing it. Your exercise tolerance level can also vary at different times, and there may be periods when even putting on your shoes may be exercise enough. Listen to your body and be guided by it.

## **Stress**

Stress can take many forms – physical, emotional, mental or a combination of these – and with ME/CFS it's very much a chicken-and-egg situation. The condition is not likely to make handling stress any easier, and stress is not likely to make handling the condition any easier. Stress may also make your symptoms worse. So, make it a priority to minimise stresses in your life. This may mean deciding to avoid contact with certain people or situations.

## **Other illnesses**

The impact of ME/CFS on your immune system may mean that your body's natural defence system isn't as effective as before, so you may become more susceptible to minor ailments. The effects of these on you may also be worse. For some people any viral or bacterial infection causes a relapse.

Make sure you continue to have regular health checks-ups. Not all symptoms are caused by ME/CFS, so if you develop any new ones or old ones get worse, see your doctor.

## **ME/CFS and Day-to-Day Life**

### **Changes in Lifestyle**

ME/CFS can cause major lifestyle changes. If you are still able to work you may have to give up some of your social or recreational activities to have enough energy to go to work, or you may be able to change to part-time hours. Many people find they have to give up work which can be traumatic. There is loss of income, loss of social contacts and often a loss of sense of purpose. There might be a subsequent need to move house for financial reasons. Sometimes other interests or activities that form part of your identity have to be put on hold. Any of these changes can be stressful and can sometimes bring on depression. It is important to recognise this and get professional help if you need it. Many people, though, find that after some time they do adjust to their new life and learn to build a new lifestyle. They find alternative activities that they enjoy and from which they get satisfaction. (See *Managing ME/CFS*)

## **Getting Help**

Whatever your circumstances, you will need extra help. If you can, get family and friends to help you. You might have to ask them for specific things, as they might not know what to do or how much help you need.

People with ME/CFS can be eligible for *Meals-on-Wheels*. The meals provided are nutritious and can be a great help, especially when you are in an acute phase of the illness or are having a relapse. The time and energy you would have used for shopping and cooking can be used to rest or do something enjoyable. Ask your GP for a referral. There are also private companies who will deliver nutritious frozen or fresh meals on a weekly basis. Consider cooking double quantities when feeling more energetic and freezing the spare half to build up a collection of meals to use when you are too busy or too tired.

Local councils also have a number of services to help people with disabilities such as help with cleaning, shopping, gardening and transport. Ask your local council for a copy of their Community Services Directory - this contains very handy information about all the services for people with disabilities in your area.

Your local Commonwealth Carelink Centre also has information about services in your area. They can be contacted on 1800 052 222. Your call will be automatically be redirected to the centre which is closest to you.

## **Weight gain and loss**

Weight gain and weight loss can both be features of ME/CFS. Carrying extra weight adds to fatigue and, while ME/CFS may lead to you stacking on the kilos due to enforced lowered activity levels, it's also likely to leave you unable to exert yourself enough to exercise them off again. On the other hand, some people in the early stages of ME/CFS, particularly teenagers or those who are trying special diets; seem susceptible to weight loss.

## **Hormones**

Women with ME/CFS may find that their hormonal system is affected. ME/CFS symptoms can worsen cyclically. Periods may become painful, irregular, heavier, lighter or even stop altogether in the acute phases of ME/CFS. If you already suffer from *Premenstrual Syndrome* (PMS), you may find it becomes worse. The Pill may be tolerated well by some women, but others may find they fare better with another form of birth control. Menopause can also signal new problems. Like puberty, menopause is a major life change and puts additional stress on the body, so some symptoms may be exacerbated.

## **Sex**

Lovemaking can be an intense and exhausting experience, so it's not surprising that both men and women with ME/CFS shy away from it at times. For women, persistent thrush and a susceptibility to cystitis may rob sex of much of its pleasure. Sex may also be the last thing on your mind if you are in the grip of extreme fatigue, and men may suffer performance anxiety, worrying about getting or sustaining an erection.

Another side effect of ME/CFS, as with many chronic illnesses, may be a reduction in sexual desire. This can leave your partner feeling unwanted and unloved, putting extra strain on your relationship. But not all lovemaking need mean intercourse. Don't underestimate the value of cuddling, and make time for plenty of hugs and physical closeness. Try to be aware of the best times of the day for you, and let your partner know.

## **Pregnancy**

Most experts agree that ME/CFS does not pose a risk to the mother or the baby's health. However, it makes sense that women with the illness wait until their acute symptoms have subsided before they try to get pregnant. But this must be an individual decision based on factors including age and the severity and nature of symptoms. Be aware too that, in some cases, women have waited so long for their symptoms to stabilise that they have run out of childbearing time.

The effect of pregnancy and birth on a mother with ME/CFS is unpredictable. Some women enjoy a remission during pregnancy. However, a few have reported that the condition worsened, and pregnancy should never be regarded as a way of trying to get better. The stress of labour itself can exacerbate symptoms or bring on a relapse.

It's clear that motherhood and ME/CFS are a difficult combination, and the decision to have a baby requires careful thought and good planning. It's wise to plan for as much help as possible for when the baby is born. Lack of sleep, hormonal changes, postnatal depression and breastfeeding can all drain resources and contribute to fatigue and other symptoms. Having a partner or other helpers ready to step in to allow a new mother to get as much rest as possible can make an enormous difference, especially if there are older children to look after too. Contact the Society for more information about pregnancy and ME/CFS.

## **Driving**

Some people with ME/CFS find that their driving ability is impaired. While this will vary between individuals, be aware that you may be functioning below par on the road, so take extra care. You may also be eligible for a disabled parking permit, available from the *NSW Roads and Traffic Authority* (RTA) on 13 2213. You will need to get your GP to sign the relevant form.

## **Household chemicals**

Use of chemicals in and around the home can pose problems not only for individuals but for the environment too. Some people find that exposure to household chemicals, perfumes and cosmetics make their symptoms worse. Whenever possible, look for alternatives to chemical sprays and other products. The *Total Environment Centre* can help with suggestions. You can contact them on (02) 9261 3437 or [www.tec.org.au](http://www.tec.org.au).

## **Alcohol and other drugs**

Alcohol and other recreational drugs, including tobacco, can intensify symptoms. At the same time, the condition itself may reduce your tolerance levels. The key is to reduce your exposure to any unnecessary chemical contact.

## **Medical insurance**

Medicare will, of course, pay your usual medical bills as will your private health insurance if you have it. If you wish to take out new private insurance you are required to disclose a pre-existing condition such as ME/CFS.

## **Other insurances, income protection, superannuation**

The success of claims depends on the type of cover and the company. Many people have had problems in this area, and the insurance companies are often reluctant to pay. People who were employed in the public service often do qualify for and obtain invalid retirement, sometimes after one or more appeals, but it can be a long hard struggle. Some people in the private sector have had to take their cases to court. If you have problems in this area talk to the Society.

## **Sickness Benefits and Disability Support Pensions (DSP)**

People with ME/CFS can be eligible for Sickness Benefits and the Disability Support Pension, which are means tested. Claims for these can be slow and difficult, and it's often necessary to appeal if your claim is knocked back. For further information about these payments contact *Centrelink* on 13 2717. For information about the unemployment benefit contact *Centrelink* on 13 2850.

## **Aids and appliances**

People with ME/CFS may benefit from using a range of aids and appliances. These include wheelchairs, crutches, walking frames, walking-stick seats, and facial masks to filter out environmental allergens. For information about other equipment contact the *Independent Living Centre* on 1300 885 886.

## **Helpful Resources**

***The following resources are available from bookshops or via the internet. Some are available from the ME/CFS Society of NSW Inc Library.***

Anderson, K (2008) *Creative for a Second creative works by people living with CFS/ME*. Available for free download <http://creativeforasecond.com/>

Donohoe, Dr M (1998) *Killing Us Softly Chemical Injury and Chemical Sensitivity* Free Acrobat book download  
<http://web.mac.com/doctormark/DoctorMark/KUS.html>

Jackson, Dr A (2000) *Understanding Chronic Fatigue Syndrome: Better Ways of Managing your Lifestyle*. Allen and Unwin Sydney (This author is a GP who has had ME/CFS)

Kilcoyne, M (2007) *Defeat Chronic Fatigue Syndrome You don't have to live with it, An eight step protocol* Triple Spiral Press

Lisman, S and Dougherty, K (2007) *Chronic Fatigue Syndrome for Dummies* Wiley Publishing Inc

Mann, M (2007) *Verity Red's Diary, A story of surviving ME* The Janus Publishing Company

Nassar, G (2005) *CFS is a call for Soul work*. Cold Tree Press

Puri, Prof B (2006) *Chronic Fatigue Syndrome A Natural Way to treat ME* Hammersmith Press UK

Snyder, K (2000) *I Remember ME*, Documentary

Staud, R (2007) *Fibromyalgia for Dummies* Wiley Publishing Inc

Wall, D (2005) *Encounters with the Invisible: Unseen Illness, Controversy and Chronic Fatigue Syndrome*. Medical Humanities.

## Services of the ME/CFS Society of NSW Inc

- **Support Groups**
- **Health Practitioner's database** (ME/CFS 'friendly' practitioners)
- **Printed information**
- **Advocacy**
- **EMERGE quarterly newsletter**, publishes the latest research into ME/CFS, Society news, articles on managing ME/CFS/FM, support group information and readers' contributions
- **Library** books, periodicals, CDs and DVD's on ME/CFS/FM
- **Community education seminars and workshops** providing information on ME/CFS/FM and various issues
- **Special events** such as International ME/CFS Awareness Week (May 12<sup>th</sup>)

## You Can Help

The ME/CFS Society of NSW Inc depends on your support. You can help us in one or more of the following areas.

### **Join the Society**

As a member of the ME/CFS Society, you will be entitled to receive the quarterly journal, EMERGE as well as the services listed.

### **Volunteer with the Society**

Help us by distributing information in your local area, working in the office, joining the Management Committee, starting a support group, hosting a fundraising event or contributing to the Journal. Contact the office to register your interest.

### **Become a Corporate Sponsor**

As a corporate sponsor of the ME/CFS Society, you can be assured that your funds will be managed in a responsible manner. As the Society is a registered charity all donations are tax-deductible. You will receive full recognition of your support in our campaigns and all promotional material.

## **Become an Individual Sponsor**

The Society depends upon donations to survive. If you are in a position to assist us, your contribution would be warmly welcomed. Donations of \$2 or more are tax deductible.

## **Support the Society's Future**

It is not unusual to be uncomfortable about discussing a will, but including a bequest to the ME/CFS Society of NSW Inc in your will ensures that your memory will live on through the lives of those who benefit from your contribution to their care. To make a gift to help those with ME/CFS, simply insert into your will the following:

"I give, devise and bequeath, the amount of, \$..... to the ME/Chronic Fatigue Syndrome Society of NSW Inc for the general purposes of the Society and I declare that:-

- a) I have a general charitable intent
- b) A receipt from the Society will be a full and sufficient discharge to my Trustees
- c) My executor shall not be concerned or obliged to see or inquire into the application of monies which are the subject of the gift."

**ABN: 28 688 072 304**

**Charitable Fundraising Number: 11191**

## **Contact Us**

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