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## Chronic fatigue syndrome (CFS)

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### Summary

- Find a doctor who understands ME/CFS.
  - The main symptom of ME/CFS is having flu-like symptoms after exercise. ME/CFS is much more than feeling tired or 'fatigued'.
  - The causes of ME/CFS are complex and not yet fully understood. There is no cure yet.
  - There are a number of subtypes of ME/CFS, so treatments will affect people differently.
  - A self-management course can help you learn how best to manage your ME/CFS.
  - Exercise can help some, but not all, people with ME/CFS.
  - Only make very small increases in the frequency, duration and intensity of your exercise program.
  - Set realistic activity goals and congratulate yourself on any gains you make, no matter how small.
  - Listen to your body – if you don't feel up to exerting yourself on a particular day, don't.
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Chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME), is an illness that affects a person's nervous system (commonly called a 'neurological illness'). It can occur at any age and can affect children as well as adults. At least 35,000 Victorians have ME/CFS.

The term 'myalgic encephalomyelitis' means pain in the muscles, and inflammation in the brain and spinal cord. ME/CFS is a complex illness and we do not know the cause. For some people, the condition may be triggered suddenly by a viral infection, toxic exposure, anaesthetic, immunisation, gastroenteritis or trauma. In other people, ME/CFS may develop slowly over months or years.

There are many subtypes within the spectrum of ME/CFS, which means that a management plan must be developed for each person with the condition. Applying a particular treatment for one subtype can be very damaging to another subtype. An individual management plan must be developed for each person with ME/CFS.

Around 25 per cent of people with ME/CFS will have a mild form and be able to get to school or work either part-time or fulltime, while reducing other activities. About 50 per cent will have a moderate to severe form of ME/CFS and not be able to get to school or work. Another 25 per cent will experience severe ME/CFS and have to stay at home or in bed.

### Symptoms of chronic fatigue syndrome

The main feature of ME/CFS is a type of exhaustion known as post-exertional malaise, 'crash' or 'payback'. This means having flu-like symptoms after exercise and not having enough energy for daily activities.

Research shows that people with ME/CFS have a different physiological response to activity or exercise from other people. This includes abnormal exhaustion after any form of exertion, and a worsening of other symptoms. The response may be delayed, perhaps after 24 hours. Depending on the amount and type of exercise, it may result in post-exertional malaise for a few days, or serious relapses lasting weeks, months or even years.

People with ME/CFS find that activities they once took for granted take an enormous toll on their health. For example, a short stroll, coffee with a friend, getting their child ready for school or catching the train to work, which caused no fatigue before, is followed by unusual tiredness that takes longer than usual to go away.

Because ME/CFS is a very complex, multi-system, chronic illness, many other symptoms will occur and must be present for diagnosis. These include:

- problems with thinking, concentrating, memory loss, vision, clumsiness, muscle twitching or tingling (sometimes called 'neurocognitive problems')
  - disrupted sleep
  - pain or aches in the muscles, joints or head
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- a drop in blood pressure, feeling dizzy or pale
- palpitations, increased heart rate or shortness of breath with exertion or on standing
- allergies or sensitivities to light, smells, touch, sound, foods, chemicals and medications
- gastrointestinal changes such as nausea, bloating, constipation, diarrhoea
- urinary problems
- sore throat, tender lymph nodes and a flu-like feeling
- marked weight change – extreme loss or gain
- inability to cope with temperature changes.

A person's symptoms will fluctuate over short periods of time, even from hour to hour.

### **Causes of chronic fatigue syndrome**

Scientists are starting to understand the biological causes of ME/CFS, although they have not yet found a prevention or cure. Genes appear to be a factor in many cases.

Over 4,000 research articles have found that ME/CFS is associated with problems involving:

- the body's ability to produce and transport energy
- the immune, neurological and hormonal systems
- viral or other infections
- blood pressure, the circulatory and cardiac systems
- digestion
- biochemical abnormalities.

### **Diagnosis and treatment for chronic fatigue syndrome**

Currently, there is no single test to diagnose ME/CFS. Doctors make a diagnosis by excluding all other illnesses after a person has had symptoms continually for six months. The person's results from routine medical tests will often be normal, but additional tests will show abnormalities.

People who receive an early diagnosis and early treatment tend to do better. Having a supportive community of family, friends, school, work, employers and health workers, who understand the potential seriousness of ME/CFS, can improve recovery for people with the condition. It is important to find a doctor who is not only sympathetic to ME/CFS, but can suggest ways to manage with the condition. Treatment choice will vary and will depend on the results of the additional testing.

### **Effects of chronic fatigue syndrome**

ME/CFS can cause different levels of disability in different people. Like all other chronic illnesses, ME/CFS can be anywhere from mild or moderate to severe, meaning:

- mild – the person's activity is reduced by at least 50 per cent
- moderate – the person is mostly housebound
- very severe – the person is bed-bound and dependent on help for all daily care.

Some people with ME/CFS are too ill to work, go to school, socialise, and manage their family or their own affairs. A person's finances may be seriously affected. Some people in the community think wrongly that a person with ME/CFS is 'just being tired', that the illness is 'in their head' or that they should 'just push through'. This misunderstanding is not helpful and can often cause a person to keep pushing beyond their limits, which will cause relapses and make their condition worse.

### **Chronic fatigue syndrome and exercise**

People with ME/CFS react to physical activity differently. Exercise can be a problem for some people, because physical activity can worsen their symptoms. Medical opinion has been divided on whether people with ME/CFS should attempt regular exercise or not.

Vigorous aerobic exercise is helpful for many chronic illnesses, but people with ME/CFS can't tolerate traditional

exercise routines due to post-exertional malaise and must learn to pace activities. It is important that they work with their healthcare professionals to create a weekly routine that is especially for that person and focuses on doing as much activity as is possible, without any worsening of symptoms in the following days or weeks.

A person with ME/CFS should never be coaxed to push past their limit as it can be dangerous and cause long-term relapse. The goal is to balance rest and activity to avoid decreasing fitness levels from lack of activity and flare-ups of illness due to overexertion.

For some people with ME/CFS, as time passes and their condition improves, they will find they can do more, but it is a slow and gradual process.

It is very important that any activity plan be started slowly and increased slowly. When beginning an activity program, some people with ME/CFS may only be able to stretch for as little as a few minutes.

### **Pacing exercise for people with chronic fatigue syndrome**

Pacing, or keeping within your activity limits, will help you make sure that you don't overdo activity or exercise. Suggestions on how to pace yourself include:

- Establish the total activity level over the course of a week that you are capable of, without any negative effects or post-exertional malaise. A pedometer for those with less severe ME/CFS, which measures how far you walk, run or bike, may be helpful in measuring the amount of physical activity you have done on any day. Using a heart rate monitor will help guide your intensity.
- To begin with, you need to do less than you think you can do, so that eventually you increase the chance of doing more.
- Maintain a level of activity that you can manage and stay on this plateau until you have a reserve of energy and are feeling very comfortable. The correct level of activity or exercise is that which can be repeated the next day without any flaring of symptoms (including physical, cognitive or emotional).
- Do not move to the next level of activity or exercise until you have the reserve which means you can increase your activity level without a symptom flare. No one can tell you what your limits are, it must be guided completely by you and your symptom response. A person encouraging you to 'push' might sound positive, but it can be dangerous if they encourage you to push past your limits.
- Repeat the pattern of staying at the next plateau of activity or exercise until you are able to increase it without any harmful consequences. You may reach a limit that should not be exceeded. Some may not be able to increase further and may need to stay at this level of activity.
- Balance physical, mental and emotional activity with rest, dividing activity into short segments, alternated with rest. Remember emotions will take from your energy pool. Rigid programs of activity or exercise should be avoided, and activity should be tailored to your level of ability. For some, this may mean sitting up for a few minutes once or twice a day.
- If you have overdone activity or exercise, or suffer a relapse for any reason, decrease the level of participation and rest more. Repeatedly overdoing it may cause a severe and long-lasting relapse, bringing with it a worsening of many ME/CFS symptoms.

### **General exercise tips for people with chronic fatigue syndrome**

Be guided by your doctor or specialist, but general suggestions include:

- Experiment to find the type of exercise that works best for you. Choose from a range of gentle activities such as stretching, yoga, tai chi, walking and light weight training.
- Keep an activity diary so you have a long-term picture of your performance levels and factors that might impact on your symptoms.
- Stop the physical activity well before you feel any symptom flare. Pacing yourself is very important.
- Remember that the amount of exercise you can do will change from one day to the next.
- Listen to your body – if you don't feel up to exercising on a particular day, don't.
- Find out as much as you can about your ME/CFS. Make sure you consult with health professionals who fully understand ME/CFS as a 'real' biomedical condition.

## Support for people with chronic fatigue syndrome

Everyone involved in support and treatment needs to understand that people with ME/CFS have an abnormal biological response to exercise or activity.

People with ME/CFS who have a thorough knowledge of the illness tend to manage their condition better and have a more positive outlook. Find out as much as you can about ME/CFS. You could consult with your doctor, physiotherapist or ME/CFS association, read books on the subject or browse through reputable ME/CFS sites on the internet.

Helpful services include:

- Information, advocacy, support and research
- Community and professional education sessions
- Early intervention self-management courses (face to face, or via telephone for people in rural areas or people who are housebound)
- Information on doctors who specialise in ME/CFS
- Support programs, including those for young people.

### Where to get help

- Your doctor
- Physiotherapist
- **Emerge Australia** Tel. (03) 9529 1344

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