

Living with Chronic Fatigue Syndrome (CFS), also known as Myalgic Encephalomyelitis or ME

This pamphlet has been produced by Clyst Vale Community College Counselling Service. This is not intended to be a definitive guide, but does hope to provide information about CFS/ME to families or a young person.

First of all it should be recognised that the name of this condition varies. CFS is also known as ME or Yuppy flu. This leaflet will refer to the condition as CFS. It is thought CFS is a description of many different conditions, all covered under the umbrella term CFS. The number of Britons suffering from this condition is not known for certain, but is believed to be anywhere from 135,000 to 250,000.

Symptoms

The overriding symptom of CFS is fatigue. In fact one of the main ways of determining whether someone has CFS or not is the presence of fatigue that persists for six months or longer and cannot be accounted for by any other known cause.

Young people and CFS

Commonly, this condition can appear at an age between 13 and 15, though can strike anyone at any time.

Fatigue

The tiredness of a patient suffering from CFS is usually ongoing and persistent, and not relieved by sleep. Sufferers often feel the fatigue to be like trying to run a car on an empty petrol tank. The degree of tiredness can vary from mild to very severe; about a quarter of all sufferers experience very severe fatigue.

Foggy thinking

Another common symptom is cognitive impairment, that is the inability to think straight or recall words or memories. This seems to come and go, there will be good days and bad head days. Some sufferers liken this aspect to a blanket being put over their brain.

CFS and depression

Usually someone suffering from CFS will experience a degree of depression. In fact depression can be the first diagnosis a doctor may suggest as the symptoms are so similar. A doctor may prescribe antidepressants at first. If the patient continues to feel fatigued it's usually only then that CFS is considered as a possible cause.

Diagnosing CFS

Diagnosing CFS is very tricky and usually a long process as a doctor must eliminate all other possibilities before they can conclude CFS is the cause.

There is no cure for CFS

Sadly there is no magic pill for this condition. The medical profession will try to ease the symptoms and promote recovery.

Recovering from CFS

This can be a long and very frustrating process. There are several suggestions to ease symptoms and promote recovery. First and most importantly, the sufferer needs to be aware of the risk of worsening or prolonging their condition.

Bust and boom

The sheer frustration of not being able to do what you want can lead most sufferers to do too much when they feel they have a little energy. It's a bit like suddenly putting a drop of fuel in the empty petrol tank and trying to dash around to get as much done as possible before it's all used up again. This needs to be avoided! Part of getting better involves accepting you are not well!

When a sufferer feels a little better they need to explore their energy very carefully. It is recommended that a gradual increase in activity is best, and must be carefully monitored. The degree of increase may be as little as adding a 5 or 10 minute walk to their daily routine and then seeing what effect this has over a few weeks before considering adding any more activity.

Doing too much too soon will often set back recovery. A good trick is to acknowledge you are feeling better on a particular day, but not 'spend' all the extra energy you have.

Draining feelings

Intense feelings can be very tiring. Excitement, joy, enthusiasm or anger can use up the petrol in the tank. Even watching an exciting or action packed film can lead to added tiredness. Try to intersperse a short period of light activity with a much longer period of rest.

Routine

Developing a routine can be very helpful and make planning of activities a little easier.

Knowing where to draw a line

Many sufferers experience their energy levels as being an invisible line, which if they cross will set them back. The frustrating aspect here is the line can only be sensed dimly, is paper-thin and tends to move! Often they only know where the line is when they're right up against it. Learning to detect this imaginary line is one of the first things a sufferer needs to do. Staying within it is the second thing.

Psychological

Doctors have long thought this condition exists only in the sufferer's mind. This can be extremely unhelpful and even dangerous. Being told its all in your head tends to make the sufferer try to spend more energy than they have and often results in worsening the condition. However there does seem to be a common psychological profile of sufferers. Over achieving and pushing themselves are common traits.

Resilience

A sufferer needs to understand that their resilience, the ability to bounce back, is severely affected. There is only so much bounce in a body. If you have used yours up, you need to rest, take things easy as it builds up again. This can take a long time.

Counselling

Counselling, specifically using a cognitive based approach, can help alleviate symptoms and make it easier for a sufferer to adjust. Do come and see one of the counsellors.

Useful website

<http://www.nhs.uk/Conditions/Chronic-fatigue-syndrome/Pages/Introduction.aspx>

www.meassociation.org.uk