

Patients who join the PACE trial will get one of the following treatments.

- Specialist medical care
- Specialist medical care *plus* adaptive pacing therapy
- Specialist medical care *plus* cognitive behaviour therapy
- Specialist medical care *plus* graded exercise therapy

If you would like to know more, please ask your clinic doctor for a leaflet.

### **What if I have more questions?**

If you have questions about this leaflet or your attendance at this clinic, we will be happy to answer them when we see you next.

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Website for Bart's CFS services:

<http://www.bartscfsme.org/index.htm>

Website for the Pace trial:

<http://www.pacetrial.org>

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## **Patient Clinic Leaflet**

***Basic information on your illness  
and the treatments we can offer you for***

**chronic fatigue syndrome  
(CFS)**

***also known as***

**myalgic encephalomyelitis  
or myalgic encephalopathy  
(ME)**

Chronic fatigue syndrome (CFS) is an illness with a recognisable pattern of symptoms. The main symptom is fatigue – which you feel as tiredness, exhaustion or lack of energy. It is common to have muscle and joint pain, memory and concentration problems, disturbed sleep, headaches, and sore throats, and sometimes sufferers have tender lymph glands. Symptoms often get worse if you exert yourself.

This illness is also known as post-viral fatigue syndrome, myalgic encephalomyelitis (ME), and myalgic encephalopathy (ME).

Medical authorities are not certain that CFS is exactly the same illness as ME, but until scientific evidence shows they are different they have decided to treat CFS and ME as if they are one illness. We do the same at this clinic, and in this leaflet we will be calling this illness CFS/ME for short.

People with CFS/ME are sometimes afraid that people will not believe that their symptoms are real. In this clinic we believe CFS/ME is a real illness.

cannot recommend these therapies, because there is no scientific evidence that they are effective.

### **Which treatments are available in this clinic?**

We offer specialist medical care, as described above. We may also offer you these therapies as well as specialist medical care:

Occupational therapy, physiotherapy, cognitive behaviour therapy and other psychological therapies. These options may include pacing and graded exercise therapy.

You also have the option in this clinic of putting yourself forward for the PACE Study, which is described below.

#### ***The PACE trial***

This clinic is helping with a study of different treatments for CFS/ME called the PACE trial. The formal title of this trial is: *Pacing, graded Activity and Cognitive behaviour therapy – a randomised Evaluation.*

The PACE trial will tell us about the benefits and possible drawbacks of various treatments for CFS/ME. It could also tell us why successful treatments work and whether different people need different treatments. It may lead to a more effective treatment for CFS/ME.

### ***Cognitive Behaviour Therapy***

Cognitive behaviour therapy is about examining how your thoughts, behaviour and CFS/ME symptoms relate to one another. Usually you see a cognitive behaviour therapist, who helps you to understand your illness and change the way you manage it. In between sessions you would try out new ways of managing your CFS/ME. The aim of this therapy is to help you manage your symptoms more effectively and do more.

### ***Graded Exercise Therapy***

Graded exercise therapy is about gradually increasing your physical activity. Usually, you see a physiotherapist who helps you work out a basic activity routine, then together you plan to gradually increase the amount of physical activity or exercise you do. The gradual increase takes into account your symptoms, fitness, and current activity levels. The aim of this therapy is to help you do more and feel better.

### ***Self-help guides***

There are self-help guide books available that you might choose to read.

### ***Complementary and alternative therapies***

Some people take complementary or alternative therapies that are not available from the NHS – and some say they benefit from them. Yoga and aromatherapy are two examples. However, we

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

There are several descriptions of the typical symptoms. Doctors call them case definitions, and all these definitions agree that people with CFS/ME:

- have the main symptom of fatigue that is often made worse by exertion
- often have other symptoms – including headaches, sleep disturbance, sore throat, muscle or joint aches and pain, and tender lymph glands
- have usually had these symptoms for more than six months
- cannot lead a normal life because of these symptoms.

When doctors recognise this pattern of symptoms, and when they can rule out all other causes, then they diagnose CFS/ME.

### **What causes CFS/ME?**

We don't know what causes CFS/ME, although there are various theories – well-informed scientific ideas that have yet to be proved or disproved.

However, we do know that most illnesses have a number of causes that are often interlinked in complicated ways – and this is probably true for CFS/ME. This complexity means doctors prefer not to talk of causes in the everyday sense. They

use the more accurate term 'factors', and they divide up factors into three types.

- Factors that make someone more likely to get the illness. An example might be their sex, as more women than men develop CFS/ME. Doctors call this a PREDISPOSITION
- Factors that bring on the illness in the first place. An example might be an infection. Doctors call this a TRIGGER
- Factors that stop people recovering from the illness. Sleep disturbance might be an example. Doctors call this a MAINTAINING factor.

What is a factor for one person may not be a factor for somebody else. For instance, sleep disturbance may be a maintaining factor in one person and not in another person.

### **What are these theories you mentioned?**

These are the main theories about factors that trigger or maintain CFS/ME.

#### ***Infection***

People often say their CFS/ME started after a flu-like illness. There is evidence that CFS/ME can be triggered by certain infections, most of them viral. There is no strong evidence that these infections are maintaining factors in CFS/ME.

- *Avoid extremes of activity.* Many people with CFS/ME get into a pattern of being very active and then very inactive. It is better to give yourself a pattern of activity that you can keep going. This may be a lower level of activity you are used to.
- *Set a daily level of activity.* It will help to set a simple level of activity that you do every day. Stretching exercises, for example, will minimise the weakening effects that creep up if you don't use your muscles for a time.
- *Make only gradual changes to your activity level.* If you feel you can increase your level of activity, and not everyone does, make changes carefully and gradually. A sudden increase in activity may make your symptoms worse.
- *Try to reduce stress in your life.* When we are ill, stresses such as excessive work demands don't help us. If you can reduce these stresses, it will help you recover.

#### ***Pacing – Adaptive Pacing Therapy***

This approach is about pacing yourself – matching your activity level very carefully to the amount of energy you have. Usually, an occupational therapist works with you, helping you monitor your activity and symptoms so that together you work out just how much activity you can manage without making your condition worse. The aim of this therapy is to improve your quality of life and give you the chance of a natural recovery.

## **How soon will I get better?**

Most people with CFS/ME improve over time with treatment, but we can't predict how long this will take.

## **What treatments are there for CFS/ME?**

There is no agreed treatment for CFS/ME, and no drug has been found that is generally effective. There are various treatments that may help people to cope better, and they may help some people to recover. These treatments are usually given as *well as* specialist medical care. However, advice and support from a specialist CFS/ME doctor on its own may be just as good. Here are brief descriptions of the main treatments that are used in the NHS to treat CFS/ME.

### ***Specialist Medical Care***

Specialist medical care is the most usual treatment for CFS/ME, and it helps many people improve. You get a confirmed diagnosis, an explanation of why you are ill, and general advice about managing your illness. Your specialist might either prescribe medicine to help you manage troublesome symptoms such as insomnia and pain or advise your GP about what medicine is appropriate.

Here is some of the advice you may get as part of specialist medical care.

## ***The immune system***

Minor abnormalities of the immune system are commonly found in people with CFS/ME. These abnormalities may be a factor in CFS/ME, or they may be an effect of having the illness. We don't know for sure.

### ***Stress hormones and the hypothalamic-pituitary-adrenal (HPA) axis***

The hypothalamus and the pituitary gland are organs at the lowest part of your brain that work with your adrenal glands as an 'axis' to control your reaction to stress. For instance, they control how much of the stress hormone cortisol is produced by your adrenal glands. Some research suggests that this axis works less well in people with CFS/ME. However, we don't know whether problems with the HPA axis predispose you to developing CFS/ME, maintain CFS/ME or are just an effect of the illness.

### ***Stress***

Stress may predispose you to all sorts of illness, and stress plus an acute infection can probably trigger CFS/ME. Once you have CFS/ME, this in itself will add to your stress, because you have to cope with disability, and other people may not understand or believe that you really are ill. Modern life doesn't give people much time to recover from illness, either, which may add to your stress.

### ***Sleep disturbance***

Many people with CFS/ME have problems sleeping. They may find it hard to fall asleep or stay asleep, and they can wake up unrefreshed. Poor sleep may delay your recovery from CFS/ME.

### ***Doing too much and doing too little***

People with CFS/ME often do too much and then feel ill – which forces them to do less. Alternating between too much and too little activity is called a ‘boom-and-bust’ pattern. This pattern may delay your recovery.

### ***Loss of physical fitness and strength***

After a period of being less physically active than usual, your body will become less fit. This can make it more difficult for you to do things you could once do easily. This loss of fitness may delay your recovery.

### ***Food intolerance***

Some people with CFS/ME say certain foods make them worse. But there is no good evidence that food intolerance triggers or maintains CFS/ME.

### ***Other possible factors***

Many other things are said to be linked to CFS/ME, and some get a lot of publicity – even though nobody has *proved* they are factors in CFS/ME. These include magnesium deficiency, overgrowth of the yeast *Candida* in the bowel, and low blood sugar (hypoglycaemia).

### **Is it true that CFS/ME leads to other illnesses?**

Other illnesses often go together with CFS/ME – but we don’t know that people get them *because* they’ve got CFS/ME. The main three such illnesses are described below.

### ***Fibromyalgia***

Fibromyalgia is like CFS/ME, but with more muscular pain and tenderness.

### ***Irritable bowel syndrome***

If you have bloating, cramps, and constipation alternating with diarrhoea you may be diagnosed as having irritable bowel syndrome (IBS).

### ***Anxiety and depression***

People with chronic illnesses such as CFS/ME often become understandably anxious or depressed.

### **How do you make or confirm a diagnosis?**

We ask about your symptoms, how your illness started, and how it developed. We may give you a physical examination. We automatically do a set of standard blood and urine tests to make sure nothing else could be causing your symptoms – unless another doctor has done these tests recently. We also do specialist tests if they are necessary.