

Chronic fatigue syndrome

Physiotherapy Department Patient Information Leaflet

Introduction

This leaflet is for people who have a condition known as chronic fatigue syndrome (CFS). It gives information about what the condition is, what the symptoms are and how it can be managed or treated.

What is CFS?

Chronic fatigue syndrome is also known as myalgic encephalomyelitis (ME) or post-viral fatigue syndrome (PVFS). It is a condition that is largely characterised by excessive tiredness known as fatigue. It is a long term condition that can affect both children and adults.

What are the symptoms?

Persistent fatigue, which is not eased by rest or sleep, is the main symptom of CFS. The fatigue is both a mental and physical fatigue.

Sufferers of CFS also report a number of different symptoms all of which may or may not be present, these are:

- Mental fatigue sometimes referred to as 'brain fog'
- Poor concentration
- Poor memory
- Sleep difficulties – too little or too much sleep, or altered sleep patterns
- Pain in muscles or joints
- Nausea
- Loss of appetite
- Frequent sore throat

How is it diagnosed?

There is no definitive test to diagnose whether someone has CFS but there are clear guidelines to help doctors diagnose the condition. People may be sent for a series of tests to rule out other conditions before a diagnosis of CFS can be made. Doctors put together a detailed history of a person's symptoms and this is a key factor in diagnosing CFS.

What is the treatment for CFS?

There is no known cure for CFS but a lot can be done to help relieve your symptoms to improve your quality of life. These include:

Pacing

Pacing may be a useful way of controlling CFS symptoms. It involves balancing periods of activity with periods of rest, to reduce the highs and lows of day to day symptoms. It is a way to avoid the 'boom and bust' cycle when a person with CFS does too many activities one day only to find their symptoms worsen as a consequence. This causes more fatigue, less activity and slows down your progress in the long term.

It is a bit like the energy stored in a battery such as a mobile phone. If it is used up quickly, in one go, it takes a long time to recharge. However, if only some of the battery energy is used, with regular top ups, the recharging only takes a short time before the phone is ready to be used. Using pacing should help prevent setbacks or making CFS symptoms worse.

Cognitive behavioural therapy (CBT)

CBT is a therapy that has been recognised as a method of treatment that can benefit patients with CFS (PACE Trial, 2011). It helps by looking into and challenging a person's thoughts and perceptions of their illness. Certain thoughts and perceptions may have a bad effect on the body and a person's ability to cope with long term illness.

CBT aims to give you a different way of looking at various aspects of your condition. It offers coping strategies to deal with difficulties in a more positive way which should improve your quality of life.

Graded exercise therapy (GET)

GET may be better thought of as 'graded activity' rather than exercise. It is a method of gradually increasing activity levels without causing your symptoms to worsen.

At first, we need to find out what activities you can comfortably do already (the baseline). Once the baseline is set, the programme of graded activity can begin. The aim is to start with an appropriate activity and then very gradually increase the amount of activity to a level that you can tolerate.

Trials have shown that a combination of **CBT and GET** gives the best improvement in management of symptoms and quality of life (PACE Trial, 2011).

Sleep

It is common for the sleep pattern to be disturbed in people who are suffering with CFS. They either have too much sleep, not enough sleep or poor sleep quality. This is often made worse by poor sleep habits.

In order to combat this, it is important to adopt helpful sleeping habits also known as good sleep hygiene. This can include getting up at the same time every day and going to bed at the same time every day. Try to avoid napping in the day and limiting it to no more than 30 minutes if you do.

It is also useful to adopt a sleep ritual to prepare for sleep, such as a warm bath, listening to relaxing music, practising relaxation and avoiding the use of computers, tablets or phones before bedtime.

Other important things to consider are avoiding caffeine in the evening, not eating a heavy meal late in the evening, reducing the amount of alcohol you drink and stopping smoking.

Relaxation

Stress and anxiety can make CFS symptoms worse; therefore, we advise using relaxation techniques to help reduce the effects of stress and anxiety. Periods of relaxation are often best included within your daily routine. There are many forms of relaxation that can be beneficial and it may be useful to try different types of relaxation or meditation methods to find the ones that suit you best.

Diet

There is no specific food or diet that has been identified to help CFS. However, it is important that a healthy varied diet is eaten, with regular meal times. It can be tempting to skip a meal or eat convenient 'junk' foods when feeling tired, leading to poor eating habits and poor nutrition.

We recommend that you eat a balanced diet with plenty of fruit and vegetables, protein such as meat, cheese, eggs, fish, milk and beans, and carbohydrates such as pasta, rice, potatoes and cereals. Sugary food and drinks are best avoided. This is because these can give a sudden increase in blood glucose levels followed by a drop in blood glucose levels, leaving you feeling tired and lethargic.

Many people with CFS find alcohol and caffeine can make their symptoms worse so these are best avoided or only consumed in moderation.

How can I manage setbacks and relapses?

There may be times when your symptoms of CFS seem worse. This is characteristic of the condition but it is important to realise that it does not necessarily mean the condition has become worse.

Relapses or setbacks can occur for a variety of reasons. It may be from overdoing things as with the 'boom and bust' cycle or it may be if you are feeling unwell such as having a cold.

A useful way to minimise the effect of a setback is to make a setback plan. A setback plan should outline strategies to minimise the effect of the increased fatigue, whatever the reason for it might be. The plan will make adjustments your daily activities to cope with your increased fatigue, such as giving yourself more breaks than normal. It will give you options to help you cope, with the aim of getting back to your normal routine as soon as possible.

The healthcare professional who is helping you manage your condition will explain and guide you through the process of making a setback plan.

Who can help?

Doctor/specialist – will be involved in diagnosing CFS and in excluding other causes for your fatigue. They may also prescribe medication to help improve some of the symptoms of CFS.

Psychologist – can offer CBT and help you to cope with the condition, either in a group setting or on an individual basis.

Physiotherapist/occupational therapist – will be able to help with pacing and GET.

Other support – if your symptoms are severe, you may need nursing support or carers at home.

What is the outlook?

How CFS affects people is variable as everyone is different. Most people will show some improvement within two years while others may remain ill for many years.

With treatment and management of symptoms, the condition will have less impact on the lives of those suffering from it. Ultimately, they will therefore make a better recovery. However, sufferers rarely return to their pre-illness levels of health and fitness. Children and young people usually recover better than adults.

Can I find out more?

You can find out more from the following websites:

NHS Choices

[Chronic fatigue syndrome](#)

NICE guidelines

www.nice.org.uk/guidance/CG53

Patient.co.uk

patient.info/health/myalgic-encephalomyelitischronic-fatigue-syndrome-mecfs-leaflet

British Association for ME and CFS

www.bacme.info

Action for ME

www.actionforme.org.uk

Association of Young People with ME

www.ayme.org.uk

M.E. Support

www.mesupport.co.uk

ME Association

www.meassociation.org.uk

The Sleep Council

www.sleepcouncil.org.uk

Get Self Help

www.getselfhelp.co.uk

Reference

Vlaeyen JW, Karsdorp P, Gatzounis R, Ranson S and Schrooten M (2011). *The PACE trial in chronic fatigue syndrome*. *Lancet*. 28;377(9780):1834

If you have any questions, or if there is anything you do not understand about this leaflet, please contact:

Therapy Services on 01384 321605 (8.30am to 4.30pm, Monday to Friday)

Russells Hall Hospital switchboard number: 01384 456111

This leaflet can be downloaded or printed from:

<http://dudleygroup.nhs.uk/services-and-wards/physiotherapy-community/>

If you have any feedback on this patient information leaflet, please email dgft.patient.information@nhs.net

This leaflet can be made available in large print, audio version and in other languages, please call 0800 073 0510.

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