

## 2

# What should it be called and why?

### ➔ Key points

- ◆ There are many names for this illness, which can be confusing
- ◆ Most doctors prefer the name chronic fatigue syndrome (CFS)
- ◆ Many patients prefer ME (myalgic encephalomyelitis/encephalopathy) or CFIDS (chronic fatigue and immune system dysfunction syndrome)
- ◆ Like most recent official reports, we use the name CFS/ME

### What's in a name?

Various names are used for this illness, which can be very confusing. What are the different names, and where do they come from? Do they all mean the same thing? What name should we use? Well, to start with the first question (and ignoring the disgusting and inaccurate 'yuppie flu'), the names used for this condition can be:

#### Chronic fatigue syndrome (CFS)

Chronic fatigue syndrome (CFS) is now the name most generally used by doctors and the one they mostly prefer. In medical language, 'chronic' means that an illness has been present for a long time, usually more than 6 months. 'Chronic' is distinguished from 'acute' (which means an illness of rapid and severe onset but often of short duration). A syndrome is an illness or condition that is diagnosed on the basis of a combination of symptoms and/or signs (as opposed to abnormalities on tests). In CFS, the symptom shared by all sufferers is severe fatigue. Other symptoms commonly present are muscle



## Chronic fatigue syndrome (CFS/ME) the facts

aches, poor concentration, and feeling unwell after exertion. (We will look at other symptoms in Chapter 3). Hence the term ‘chronic fatigue syndrome’ for a condition that has been present for 6 months or more and is diagnosed on the basis of symptoms of which a major one is fatigue.

## Myalgic encephalomyelitis/encephalopathy (ME)

This name is also used. It was originally given to an acute, medically unexplained illness that occurred among the staff of the Royal Free Hospital, London in the 1950s. Many doctors do not agree with applying this name to patients with chronic fatigue symptoms for two reasons. The first is that many of the symptoms of the Royal Free outbreak were different from those experienced by CFS patients today. The second is that this name is potentially misleading as, although many patients do have myalgia (this simply means muscle pain), there is no good evidence that they have encephalomyelitis (inflammation of the brain and spinal cord). An alternative term ‘myalgic encephalopathy’ has been suggested to avoid the implication of inflammation, but this still implies an unproven brain disease. Despite these reservations ‘ME’ is a name commonly used by patients, the general public, the media, and some doctors.

## Chronic fatigue and immune dysfunction syndrome (CFIDS)

Patients and some doctors in the USA use this name. It highlights not only the fatigue but also changes in the immune system. Whilst relatively small changes have been found in the functioning of the immune system in some patients (as they can be in many illnesses), it is still not clear how important these are in causing the symptoms. Furthermore, the apparent similarity with the term AIDS (acquired immune deficiency syndrome), in which there is an important and severe disturbance of immune functioning, is potentially misleading (and unnecessarily worrying).

## Post-viral fatigue syndrome (PVFS)

This label is sometimes used by doctors in cases which appeared to have started with a viral illness. ‘Post-viral’ simply means after a virus. It does not necessarily mean that a virus is causing the continuing condition. As viral infections are very common, it can be difficult to be certain that any viral infection was the cause or not. The term does not really mean anything different from CFS.

## Neurasthenia

This name was used in the late 1800s to describe a condition that was probably much the same thing as CFS. The term literally means ‘weak nerves’.



Later on this diagnosis fell out of favour—although doctors still occasionally use it.

### Names of epidemics

Some other names refer to places where a number of patients became ill with something similar—Los Angeles and Akureyri are examples. The relationship of these apparent epidemics to the more common cases is unclear. These names are therefore best avoided in routine use.

### Why do most doctors call it ‘chronic fatigue syndrome’?

The term ‘chronic fatigue syndrome’ was officially coined in the late 1980s. Prior to that time people suffering from severe and chronic fatigue that could not be medically explained were given a variety of diagnoses. One common diagnosis was infection with Epstein–Barr virus (EBV), the virus that causes glandular fever. Other infections blamed included chronic brucellosis (a rare infection transmitted from cows).

By the 1980s the accumulating scientific evidence showed that these infections were not the cause of the chronic fatigue in most cases. In 1988 a group of physicians met at the Centers for Disease Control (CDC) in Atlanta, USA to discuss this matter. They chose the name chronic fatigue syndrome (CFS). They chose this name because it simply described the illness (although admittedly emphasizing one symptom) and did not make any assumptions about the cause, which they agreed was unknown. Researchers in the UK and Australia also independently agreed to use this name. It was hoped that having one name that simply described the illness would make it easier to compare research findings.

### What is wrong with the name ‘chronic fatigue syndrome’?

Although it has become the most commonly used name, some patients are unhappy about their illness being called chronic fatigue syndrome. Two main reasons are given for this. First, naming the illness only after a symptom and not a disease process is seen by some as implying it is not a real illness. Secondly, mentioning only fatigue is seen as failing to convey the severity of



## Chronic fatigue syndrome (CFS/ME) · the facts

illness and range of symptoms patients with CFS may suffer and encourages comments such as ‘Well we all get tired you know’.

Given these feelings, it is not surprising that there have been campaigns to have the name changed. Alternatives proposed include eponyms—using the name of someone well known who has studied the illness (such as Melvin Ramsay) or someone who apparently suffered from it (such as Florence Nightingale). Others have favoured a name that sounds more like a medical disease than CFS (such as myalgic encephalopathy—a different version of ME).

Whatever the arguments for and against CFS as a name, changing it would not be easy. It has been helpful to researchers to have an agreed name, and the term CFS has become established in medical journals and textbooks (and on most scientific databases). It would be a major task to convince doctors and researchers that more benefit than harm will result from changing it. It seems likely that any change in name will have to await a better understanding of the cause of the illness or illnesses that are currently referred to as CFS.

## So do these names all refer to the same illness?

The names in common usage today probably do all refer to much the same collection of symptoms, though they differ in their historical origins and in what they imply about the nature of the illness. However, it seems increasingly likely that patients with CFS do not all have exactly the same condition even though they may experience somewhat similar symptoms. This is what doctors mean when they talk of a ‘heterogeneous’ condition. In time, different subgroups may be identified.

Some people believe that there is a subgroup of patients with CFS who have a particularly severe illness (which they would prefer to be called ME), which should be researched and treated differently from CFS. This suggestion may be correct, but it has not yet been proved.

## The name we are using

Chronic fatigue syndrome (CFS) is the current medically preferred name for the illness and so we will use it. However, the term ME is also used very often to refer to the same illness (particularly by patients), so we will use the now commonly used combined term ‘CFS/ME’ in this book.



There are a number of different names that have been or are still being used to label this illness. In general they refer to similar if not identical conditions and so are largely interchangeable. In due course, research may allow the illness to be split into different subtypes. At present, chronic fatigue syndrome (CFS) is the name most favoured by doctors. Some patients prefer ME. In this book, we will use the combined term CFS/ME.

