

# **The Rough Guide to ME/CFS**

This booklet is designed to help those with ME/CFS to understand what it means and how it feels. It can also be used by carers, supporters and families to assist you.

This is a 'Rough Guide' only. ME/CFS is a unique experience to every individual. This booklet should not be used to make a diagnosis. It has been produced to help you understand and manage your condition with help from the Norfolk and Suffolk ME/CFS Service with your named practitioner.

The information contained is based on information taken from ME/CFS a Clinical Case Definition and Guidelines for Medical Practitioners, Bruce M. Carruthers, Marjorie I. van de Sande, An Overview of the Canadian Consensus Document.

**How did I get ME/CFS?**

It is often triggered by a viral infection that feels like you never got over it. It can follow a period of a lot of stress. Sometimes it is not clear what triggered it.

**Can you do a test to show I have it?**

Currently there is no test.

Your GP will have done a series of blood and other tests to RULE OUT other conditions.

**So how do you know that I have ME/CFS?**

Your doctor will already have looked for other causes. After this we look at your symptoms, for example ongoing exhaustion, muscle pain, new headaches, etc.

As you already have a diagnosis it means that your symptoms fit the criteria for a diagnosis.

## **Symptoms and what they mean**

There are many symptoms of ME/CFS. The following is a list of symptoms and what they mean.

### **Sudden onset fatigue, exhaustion and unrefreshing sleep.**

This means that you start to feel exhausted and no matter how much sleep you get you still feel exhausted. People vary and for some just doing a little activity can make you feel ill/exhausted immediately. For others the exhaustion may come in the next day or the day after. Even with lots of sleep you feel exhausted.

#### **What causes exhaustion?**

Energy for everything you do and feel comes in the form of something called ATP. Every cell in your body needs this.

Your oxygenated blood goes to each cell and the energy factories in the cell (Mitochondria) get to work to produce and store energy.

In ME/CFS the energy factories seem to struggle to recycle the energy or store it. So anything left over goes into the waste system and passes out of your body.

When you do activities with your mind and with your body – you will get to the stage where you simply don't have enough ATP. Your ATP suddenly falls – 'CRASH'.

It takes at least three days for you to build up the levels of ATP again for you to have a better day.

### **Why is my sleep unrefreshing?**

We know that people with ME/CFS go through more frequent sleep cycles. So you get less deep sleep and in shallower sleep you have a very active mind! Vivid dreams and frequent waking are common – so you are using lots of ATP in your sleep!

Even in deep sleep your mind acts as if it is awake from time to time – so even more ATP!

In short, your sleep does not replenish you, physically or mentally.

### **Swollen glands, recurrent sore throats, ear infections etc feeling fluey.**

Often people have repeated swollen glands, especially in the neck. You may have had lots of throat/ear infections. Also people often feel very ill and fluey. GP's often do tests to look for infections and they all come back as okay!

### **So I don't have an infection/virus. Why is my body acting like I have?**

Because when you first became ill your immune system reacted to your illness and was 'activated'. Your immune system has not reset itself to 'normal' and will often act as if you have an infection/virus/flu/throat/ear infection – even when tests reveal this is not so.

### **Cognitive difficulties – What does this mean?**

You may find that you can't concentrate for very long, read like you used to, cannot remember things very well, and struggle to finish sentences. Struggle to think of words, feel exhausted after concentration. Occasionally people feel they have time lapses – they are suddenly aware time has passed but can't remember it. People find these things scary and they make them feel anxious and panicky. THE IMPORTANT THING IS THAT YOU ARE NOT GOING MAD OR LOSING IT!!

## **Dizziness/Vertigo**

Feeling dizzy, weak and shaky and overwhelmed is a problem for a lot of people. Sometimes it happens when standing up, standing still for a period of time, even lifting your head off a pillow. It can come and go or it can hang around just making you feel awful. Sometimes you have to lie down immediately.

### **What causes cognitive difficulties and dizziness?**

It is all caused by the lack of good quality oxygenated blood reaching the parts of your brain it needs to. It is also to do with the volume of blood in your body. Women have 38% less blood volume than men anyway! ME/CFS studies have shown that it is common to have a lower blood volume – i.e. less blood is spread out to try and reach all areas. In some areas it's just not enough so the brain doesn't have the fuel it needs to remember all the time. It doesn't have the energy to put new information into the working memory or the long term memory.

### **Oh and Gravity.**

Gravity affects everyone – it is a force that pulls things down. So it naturally acts on our blood, pulling on the blood supply to pull it down to our lower limbs. When we sit up or stand up our heart beats a bit faster and other systems kick in to push the blood around the body, especially to get blood up to the brain. In ME/CFS the heart can beat wildly and the other systems do not work as well, and this means we feel very dizzy. People often have this when they have been standing still. In ME/CFS the body can't create the energy to push the blood around the body.

## **Muscle and Joint Pain and Headaches**

People can feel aching and painful muscles and joints. Sometimes this can be a severe type of pain.

People also describe that limbs feel heavy and that they just don't want to do what you tell them!

Joints can feel stiff. You may feel you struggle to hold things. Using your body can be painful. Headaches are a problem for many with ME/CFS. They can be migraines, pain 'behind' the eyes, pains to the front of the head etc.

On the whole these types of symptoms are caused by Neuropathic Pain. This means that pain comes from actions of your nerves and is not due to a physical cause. Aching to muscles is also caused by poor blood supply.

**Okay – So why do my nerves cause these pains?**

The area of your nervous system that sends news of pain signals has got its wiring system muddled! So the brain and the body send signals to each other that are incorrect – the result is that your brain and body produce a pain response.

**What about my aching/heavy muscles?**

Well, you are not getting enough oxygen and nutrients to your muscle cells. So after a while your muscles have to do work without as much oxygen – this causes a muscle ache or burning feeling.

You are like an athlete who has used up all their oxygenated blood in a race, and finishes the race by pushing through the pain barrier and their muscles burn and ache. Unlike our athlete – you are doing it every day – you are like the Marathon Man/Woman.

## **SO WHY CAN'T I GET TO SLEEP IF I AM SO EXHAUSTED?**

Many people with ME/CFS actually find getting to sleep very difficult. They feel exhausted and ache from head to toe but they feel that their mind will just not 'shut up'! People can go for days hardly sleeping at all, and then they crash and can hardly stay awake.

### **The Stress Response – active minds and anxiety**

When the brain detects a threat (a stress) it will react with a stress response. This response helps you deal with the immediate danger - Your muscles tense, your heart pounds, blood whooshes around the body, your brain is stimulated and your immune system is suppressed. Afterwards you will then feel anxious and shaky.

If you have lots of physical stress – like low levels of energy – and/or psychological stress your EMERGENCY STRESS RESPONSE will flick on most of the time and will be harder to shut off.

Through the day it will be triggered repeatedly – it loads your brain with more and more signals and chemicals to make your mind be active. At the end of the day there is so much of this stimulation in your brain that it really can't shut up – it's still whirring away whilst your body is exhausted.

The stress response can trigger a crash as it is 'on' too often for too long and eventually total physical exhaustion is overwhelming and you can hardly do anything!

### **Feeling hot and feeling cold**

Sometimes people feel cold and cannot warm up. Often people feel hot and sweaty and cannot cool down.

This is due to mixed messages from the nerves making it difficult for the body to achieve the right temperature.

### **Sensory Overload – Noise, crowds and busy environments and conversations**

Sometimes people feel they just cannot listen to what someone is saying. In a group people may find it difficult to focus on the thread of the conversation. Crowds and busy environments can make people feel unwell. Supermarkets and shops which are full of people, colourful items are often intolerable. This is called sensory overload.

#### **So what causes Sensory Overload?**

Before you became ill your brain did a very good job of sorting the important bits of everything you see and hear and ignoring the unimportant bits. In ME/CFS the brain is not very good at sorting things out. It does not tell you what is important or unimportant. So your brain works harder as it treats everything – each noise, movement, sound – with equal importance. It becomes overloaded with all this information – making you feel unwell and overwhelmed.



## **There is so much going on in my body – what can I do? Where do I start?!!**

### **With Activity Management / Pacing**

Every waking hour, as far as possible, you need to take 10-15 minutes rest. If you feel 45 minutes of activity is too much then decide how much activity you could do i.e. 30 minutes and then take a 15 minute rest.

### **What is activity?**

It is anything you do when you are NOT sitting quietly, calming your mind. So activity is watching TV, going on a computer, flicking through a magazine etc.

### **What is rest?**

Rest is minimal brain and body activity – so unless you are sitting calming your mind – everything else is activity – even sleep!

### **How do I calm my mind?**

Many people find that they cannot sit for 15 minutes as they worry too much, feel anxiety or feel like their brain is racing. An overactive brain uses a lot of energy. So to get good quality rests you need to learn to calm it down.

Things people have found useful:

- Watching nature
- Listening to melodic, calming music. Three tracks of gentle songs = one rest break.
- Using applications and downloads off the computer – especially iTunes.
- Guided relaxation and medication CDs and downloads
- Listening to calming sound tracks e.g. waterfalls, the sea etc. Freely available on the internet.

- If you have a laptop search for all of these on YouTube and save them in favourites – most are ten minutes long.
- Many people find using an iPod, MP3 player or phone ideal – Download your tunes on to these and you can take your 15 minute rest anywhere – Sit down and close your eyes with your headphones in.

### **What does activity management do?**

Minimal brain and body activity allows you to begin to produce sufficient ATP, not to use your energy so fast, and then to sustain it over time. As you calm your mind and get better at it you begin to control your stress response. You will also begin to sleep better.

### **But I sleep loads anyway and spend days doing nothing anyway**

At this point in time your sleep is NOT restorative – good activity management is. On days you are doing nothing you still need to actively pace every hour as on these days your energy levels are extremely low.

### **So what are you saying?**

Very simply:

*Activity/Rest/ Activity/Rest/ Activity/Rest/ Activity/Rest/ Activity/Rest/ Activity/Rest/  
Activity/Rest/ Activity/Rest/ Activity/Rest/.* On good and bad days.

### **Can I do any activity I like?**

Activity management is not about stopping activity – it is about taking frequent good quality rest breaks.

You will already know the things that really make you suffer and for the time being it is probably best not to do these things, or only for a very short period of time.

You should not be taking on new activities or increasing activity. You need to pace to find a baseline for your energy.

Remember using your brain will fatigue and exhaust you just as much as using your body – so don't be tempted to spend hours on computers, Xboxes or watching TV without regular rest breaks.

Always plan to do some of the activities that you really like in some way – even if you can't play your favourite sport at the moment – go as a spectator or help in some other way. Keep in contact with friends in ways that don't exhaust you!

### **Do I have to manage activity forever?**

You need to manage activity till you reach a steady pattern of energy. So you no longer get very active days and very poor days – you are spreading your energy out evenly every day.

When this happens, with help and advice, you can start to introduce and increase activity and rest less frequently.

NB: For the first week or two of activity management you may be slightly worse. This is normal. You are allowing your body to feel as exhausted as it really is. This will pass and then you will be much more in control.

### **– LAST WORD –**

At the moment your ME/CFS controls YOU. It makes you lose three or more days of your week.

Activity management is a way for you to manage I. To get those days back and to help you achieve a GOOD QUALITY OF LIFE.

**ACTIVITY REST ACTIVITY REST  
EVERY WAKING HOUR**