

## **Information Sheet 4: What is ME/CFS?**

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Myalgic Encephalopathy / Chronic Fatigue Syndrome (ME/CFS) is a neurological illness, a disorder of the central nervous system (World Health Organisation, 2016)<sup>1</sup>. An estimated 250,000 people in the UK and 17 million worldwide have it, of all ages and backgrounds, although it's more common women than men to a ratio of 2:1. It is characterised by severe and debilitating fatigue affecting both physical and mental functioning, with a wide range of other symptoms and can mean long term disability. Whilst the cause is still unknown, onset is most often linked to a viral infection, or can follow a period of persistent stress, or a physical trauma, although these are less common. It is not fully understood why this happens to some people but not others.

As a fluctuating and invisible illness, ME/CFS can be isolating, and hard for other people to understand, especially as people who have it may not 'look ill.' It is also not always well understood by medical practitioners. This can bring social, relationship, employment, practical and emotional challenges - communication is key to dealing with these issues.

### **What does the name ME/CFS mean?**

Partly because there is no single explanation for this condition, different names are used for it that vary worldwide:

- M.E. is an abbreviation of Myalgic Encephalopathy, which means muscular pain (myalgic) and significant disorder of brain functioning (encephalopathy).
- It can also be diagnosed as 'chronic fatigue syndrome' (CFS) but this name doesn't express the severity or diversity of symptoms, and can lead to misunderstanding.
- ME/CFS is not the same as chronic fatigue, or being 'tired all the time', which is a common modern issue that can be resolved with rest and lifestyle changes.
- It can also be diagnosed as post-viral fatigue syndrome (PVFS).
- In the UK charities and the NHS currently use the terms ME/CFS or CFS/ME. However some charities and patient advocates prefer M.E.

- In the USA and Canada it is known as Chronic Fatigue Immune Dysfunction Syndrome (CFIDS).
- New more descriptive names have been recently suggested: systematic exertion intolerance disease (SEID) and Neuro Immune Deficiency Syndrome (NIDS) but these haven't yet been universally adopted.
- Other conditions with overlapping symptoms that are believed by some experts to be on the same spectrum as ME/CFS are: postural tachycardia syndrome (PoTS), fibromyalgia, chronic Lyme disease and multiple chemical sensitivities (MCS).

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

The causes of ME/CFS are not well understood and research is carried out across many schools of medicine - endocrinology, neurology, gastroenterology, psychology, immunology and epidemiology - reflecting the wide range of symptoms that are experienced. Some experts and patients believe that ME/CFS is an umbrella term for a collection of 'syndromes' rather than one distinct illness. This is partly because variance between patients in severity and symptoms can make it seem like different illnesses. Many factors may contribute to who develops ME/CFS, and why it continues, such as disruption in the immune system or reactivation of a viral infection, for example the Epstein-Barr virus that causes glandular fever. It can be triggered by a bacterial infection, exposure to toxins or a vaccination, and some studies have identified a genetic component<sup>2</sup>.

There have been some important advances in research recently identifying differences in the blood, gut bacteria, cell mitochondria and immune systems of people with ME/CFS compared to healthy people. It is hoped that one of these may eventually lead to a diagnostic test. Other specialists are working on the theory that as ME/CFS is a neurological condition - treating an underlying dysfunction in the brain may 'reset' it back to healthy functioning and reverse the resulting symptoms.

While the causes are not yet clear, research conducted so far has shown that ME/CFS is not a purely psychological or psychosomatic illness as had been proposed by some doctors. Western medicine is starting to better understand how the mind and body work as a whole and that people with ME/CFS have a real physical illness that has symptoms across all its systems.

This lack of clarity makes communicating clearly how ME/CFS affects you day to day -physically, emotionally and practically - even more important. If professionals, friends, family and colleagues have read about ME/CFS or know someone else who has it, it is likely to be different to your experience.

### **What are the symptoms of ME/CFS?**

ME/CFS has a wide range of symptoms:

- severe fatigue that doesn't ease with rest
- disordered sleep

- many types of pain that can be difficult to control
- cognitive issues such as 'brain fog' and problems with short-term memory and concentration

Post exertional malaise (PEM) - the exacerbation of symptoms, or 'payback' after physical or mental exertion - is its defining characteristic. The impact of activity can be delayed and may last for days or weeks.

Other symptoms that may be experienced are:

- difficulties with speech and 'finding the right word'
- severe headaches
- dizziness and balance problems
- sensitivity to noise and light
- difficulty regulating body temperature
- nausea and digestive problems
- a compromised immune system
- tender and swollen lymph nodes
- sore throat
- painful muscles and joints
- general 'flu-like malaise

Patients rarely experience all of these, and symptoms can vary over time.

Anxiety is often experienced and this is partly due to the increased adrenaline production that occurs when people with ME/CFS try to go about daily tasks - creating anxiety-type symptoms such as rushing thoughts, palpitations, tightness in the throat and digestive problems. This is a physiological result of imbalances in the nervous system rather than a psychological process.

Anxiety can of course also result from the fear that naturally comes from living with unpredictable symptoms and the uncertain future that is a consequence of having a long- term condition. Low mood can be experienced, which may affect coping - see 'diagnosis' section below for more information on depression and ME/CFS.

### **Degrees of severity in ME/CFS:**

People vary enormously in their experience of ME/CFS: it fluctuates from day to day and patients can move up and down these levels over time, so it is important not to compare with others or make assumptions about the future.

- Mild ME/CFS - people with 'mild' ME/CFS often manage to function in paid or caring roles but may be unable to do much else
- Moderate ME/CFS - people living with moderate ME/CFS experience major restrictions to their activities and have difficulties with self-care
- Severe ME/CFS - people with severe ME/CFS are housebound and/or bedbound and can need full time care

People with ME/CFS at any level have a marked reduction in their quality of life. A useful detailed measure of functioning is the ME Association's Disability Assessment Scale<sup>2</sup>. This is helpful for communicating with doctors, employers, benefits and other agencies. It is also a useful concrete way to measure change, as it can be hard to remember how you felt at an earlier time with such a complex condition.

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

ME/CFS can take a long time to diagnose, sometimes due to lack of expertise but also because there is no specific test that confirms it. A number of other conditions can have similar symptoms, for example: thyroid problems, multiple sclerosis, Crohn's disease, and lupus. Diagnosis is reached by excluding all other possibilities through physical examination and blood tests.

Diagnostic criteria vary in different countries and there is controversy over some doctors diagnosing people with 'chronic fatigue' (being 'tired all the time') who don't have what is considered to be the defining symptom of ME/CFS: post-exertional malaise (PEM).

Clinical depression has many symptoms that overlap with ME/CFS - fatigue and problems with sleep, concentration and appetite - but there are important distinctions. Unlike depressed people, those with ME/CFS usually retain their desire and motivation to do things and ability to enjoy the things they can do, if they are unable to do activities it is due to physical limitations. Because of these similarities ME/CFS is sometimes misdiagnosed as depression or vice versa. It takes a practitioner who is both skilled in mental health assessment and knowledgeable about ME/CFS to understand these differences.

It is natural to have a strong emotional response to being ill - guilt, grief, irritability, anger and pessimism are common - and depression can result from the challenges of living with any chronic physical health condition. If you begin to struggle with low mood, self-criticism or experience any thoughts of harming yourself, seek help. It is important to take care of your mental health when living with ME/CFS as the risk of suicide is greater than in the general population.

Misdiagnosis sometimes occurs due to all the difficulties described, so it is important to seek further medical advice or a second opinion, especially if you experience a significant change in symptoms at any time. People with ME/CFS sometimes have coexisting conditions with overlapping symptoms such as irritable bowel syndrome (IBS), endometriosis and fibromyalgia.

### **What is the treatment for ME/CFS?**

Receiving a quick diagnosis - followed by the correct medical advice and support - helps in terms of making improvements. However, this can be difficult to access if you don't have a knowledgeable GP or local specialist service. If you are referred to an NHS ME/CFS clinic it is important to remember that there are currently no treatments for ME/CFS that have been consistently tested and proven effective in large replicable randomized controlled trials. However, many small-scale clinical trials have shown potential benefits from some drugs and supplements for symptom management which is often the starting point with ME/CFS, via your GP. See The ME Association's 'Purple Book'<sup>2</sup> for full details and our 'Living Well with ME/CFS' and 'Alternative Approaches' information sheets for strategies and complementary therapies that can help with symptoms.

#### Medication for symptom management:

Your GP or consultant may prescribe medication to help you manage the symptoms of ME/CFS. There may be a process of trial and error to find what is right for you as every person's symptoms are different.

#### **Sleep problems:**

Sleeping tablets such as nitrazepam and zaleplon are limited to short term use as they carry a high risk of side effects and physical dependence. Melatonin may be given to help regulate the sleep cycle. Antidepressants are sometimes prescribed for sleep problems and pain, see next section. See our 'Living Well with ME/CFS' information sheet for natural sleep strategies.

**Pain:** Over-the-counter painkillers such as non-steroidal anti-inflammatories (NSAIDs) and

paracetamol can help relieve headache, muscle and joint pain, however these can cause stomach problems with long term use. Your doctor may prescribe stronger drugs but these can have problematic side effects such as increased drowsiness, constipation and tolerance issues. Muscle relaxants are sometimes used, but can have unpleasant side effects and cause dependence. A portable TENS (transcutaneous electrical nerve stimulation) machine can sometimes be helpful for ME/CFS pain.

Tricyclic antidepressants can be useful for pain or difficulties with sleep, for example amitriptyline, but these can have side effects. Being prescribed an antidepressant does not necessarily mean you are depressed, they are given at a lower than therapeutic dose when used for sleep and pain, but if you are unsure ask your doctor. If you do become depressed as a result of living with ME/CFS, which can happen as with any difficult life situation, then this needs specific treatment, usually counselling initially.

#### **Digestive Issues:**

Anti-emetics may be given for persistent extreme nausea, but ginger root found in supermarkets' vegetable aisle taken in tea or grated into food can also be effective. If nausea is preventing you from eating, medical intervention may be required to ensure you get the nutrients and calories you need.

Other problems with the digestive system may be treated with antispasmodics or tricyclic antidepressants, depending on how they are experienced. Dietary changes and peppermint oil can also be helpful, see our 'Alternative Approaches' information sheet for more on this.

#### NHS Treatments:

There are specialist multi-disciplinary ME/CFS and Fatigue Clinics in some parts of the UK. If these are not accessible, and your GP is your main medical support, it is important to have one who is knowledgeable and supportive about ME/CFS. You have the right to request a different doctor if you don't feel you are getting the support you need.

Research carried out on the NHS treatments listed below has recently been disputed and some of the leading charities members' surveys have consistently shown conflicting opinions on their effectiveness. The National Institute for Health and Care Excellence (NICE) Clinical Guideline 'Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management'<sup>3</sup> is a guide to how UK NHS services offer treatments. This was published in 2007 and is under review in the light of recent proposed changes to diagnostic criteria and disputes over trials of these treatments. NICE will decide whether their ME/CFS guidance needs updating during summer 2017.

### **Graded Exercise Therapy / Graded Activity.**

Graded Exercise Therapy (GET) is the individualised gradual increase of physical activity from a current baseline of limitation. It is **not** going to the gym as if nothing was wrong with you, 'pushing through' or being told to 'just exercise and you will be fine.' Some people with ME/CFS report that their condition deteriorated after following a programme of graded exercise, so many ME/CFS organisations and advocates are completely opposed to it. However, there are people who have found that it has helped them to improve. When delivered by trained specialist ME/CFS practitioners, GET involves tiny incremental increases in activity levels not just of exercise, but all activities that use energy, including standing and concentrating. For example, depending on your level of illness you may start by sitting up in bed for a few minutes, or walking slowly across a room. Risk of relapse is minimised by staying within your stamina levels so that the activity does not push you into 'overdoing' and result in increased symptoms or post exertional malaise.

**Activity Management** is also delivered in some NHS specialist clinics which is similar to pacing, see below, which has been found to be beneficial by many people with ME/CFS.

### **Cognitive Behavioural Therapy.**

CBT is a psychological therapy based on the theory that thoughts and feelings influence behaviour. There has been criticism of this approach being used with ME/CFS patients, because of the implication that ME/CFS is 'all in the mind' and some practitioners' opinion that it is caused by 'negative illness beliefs.' This originates from therapists with a lack of understanding of the physiology of ME/CFS applying techniques designed to treat depression - such as behavioural activation (increasing activity) - to detrimental effect. However, when delivered by professionals such as Occupational Therapists specially trained in ME/CFS, CBT can be a useful way to learn strategies to adapt and manage illness using pacing, sleep strategies and goal setting, as it is with chronic pain and cancer patients. Activity management, pacing and integrative psychological therapy delivered by an experienced ME/CFS professional who understands the physiology of the condition, can be very helpful in improving coping and even reducing symptoms. See our 'Living Well with ME/CFS' information sheet for more on this.

### **What can I do to help myself?**

- Finding out about ME/CFS can be difficult and confusing, especially if this is done online. There is a lot of controversy about cause and treatment approaches so it is important to find good sources of up to date information on research and support, such as national charities Action for ME<sup>4</sup> and The ME Association<sup>5</sup> who offer e-newsletters, leaflets and websites. Hampshire Friends with ME have a Facebook page sharing articles and research.
- Developing a strong support network of friends, health care professionals, specialist charities, social media advocates and other people living with chronic conditions can really help. It is important to be wary of the negativity of some support groups and online chronic illness communities. While anger and frustration are a real and understandable response to living with a misunderstood invisible illness, they are not helpful to focus on if you are living with fatigue. Positive websites and social media resources such as Pajama Daze<sup>6</sup> offer support, information and creative inspiration to help you work out what you 'can do.'
- Learning to 'pace' yourself - breaking the 'boom and bust' pattern to find a better balance of activity and rest - is something the majority of people with ME/CFS find beneficial, see our information sheet 'Pacing for ME/CFS' for details.
- Other evidence based self-management strategies that can help include relaxation, sleep hygiene, mindfulness, and dietary changes. Trying a combination of these to find out what works for you can bring an increased sense of control and an improved quality of life. This can take time and require the support of others. All these issues are discussed in our other information sheets.

### **How can I help others to understand?**

It can be difficult to explain ME/CFS: it is complex, unpredictable, invisible, not well understood, and affects your cognitive functioning. Finding a simple explanation that you can give to loved ones and employers is useful, you can find these in leaflet form from the charities listed in the references section or you could try the book 'CFS/ME: Support for Family and Friends'<sup>7</sup> written to help the loved ones of people with ME/CFS understand symptoms and the social, physical, emotional and financial impact it can have. It includes case studies and advice from people living with all levels of the illness. Clearly communicating how ME/CFS affects you and what you need is an important part of getting the right support from others, whether from professionals or loved ones.

However, it is also important to realise that some people will still struggle to support you, whether through distress, helplessness, ignorance or fear. This can feel hurtful and cause you sadness and anger. It is important to try to use your limited energy to engage with people who are able to support you and let go of trying to make others understand.

### **Do people recover from ME/CFS?**

As ME/CFS is so diverse, strategies and treatments can work for one person but not another, so it can take time to find out what is helpful. Whilst full recovery is rare, with the right strategies and support people often improve over time. Relapses can occur following stressful life events, operations or infections. In a very small number of cases, people with severe ME/CFS remain

severely affected needing full-time care. You may have read about cases of death resulting from complications from ME/CFS, however these are extremely rare. While some people find that they don't go back to how they felt before they became ill, it is possible to adapt sufficiently to lead a fulfilling life, similar to other chronic illnesses.

## References:

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<http://www.who.int/classifications/icd/en/>.
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- 3) NICE clinical guideline for Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management. 2007.  
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- 6) Pajama Daze: motivational and inspirational resource for people with chronic illness, pain and fatigue [www.pajamadaze.com](http://www.pajamadaze.com) Twitter @PajamaDaze Facebook: Pajama Daze
- 7) 'CFS/ME - Support for Family and Friends' Elizabeth Turp. (2011) Jessica Kingsley Publishers: London, Philadelphia.

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