

PATIENT INFORMATION

An Overview of ME/CFS

(Myalgic Encephalomyelitis/Chronic fatigue syndrome)

Information for patients and carers



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Torbay and South Devon ME/CFS Service.

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Reading this information with mental fatigue

It is common for people with ME/CFS to have problems with mental fatigue. The problems reported are reading for long periods, poor concentration, unable to remember things. Consider when reading this manual.

- **How much** you can read before your fatigue level starts to increase.
- **Stop** reading when you have read the number of pages you can read without increasing your mental fatigue. Mark the point you have reached.
- **Put the booklet down** at this point and do something else or rest for a while.

What is ME/CFS

ME/CFS is a complex, long term (chronic) medical condition affecting multiple body systems. Its pathophysiology is still being investigated. The causes (aetiology) and disease mechanisms (pathogenesis) are unclear and varied.

Current research points towards a range of systems and responses that may be dysregulated or not responding in the expected way (dysregulation of multiple body systems). Meaning, the dynamic systems in the body that are supposed to work together and regulate each other to keep us well or in homeostasis are now dysregulated and may work in opposition to each other. Many patients describe that their brain wants to go but the body wants to stop. (BACME (British Association for ME/CFS) An introduction to dysregulation in ME/CFS. August 2021. pp.3) at <https://www.bacme.info/>

For more detailed information about dysregulation please follow this link - <https://www.bacme.info/>

ME/CFS is a 'label' or 'umbrella term' given to a specific collection of symptoms. Symptoms commonly include, fatigue, pain, muscle pain, sleep disturbances, disturbances of memory and concentration, irritable bowel, abnormal temperature control (see section below on symptoms)

ME/CFS assumes many different forms and is highly variable in levels of severity and duration. Currently there is no diagnostic test or one mechanism that is measurable. It is recognized on symptom presentation and significantly reduced daily functional.

The National institute for health and Care excellence (NICE) (2021) guideline for ME/CFS state when suspecting a diagnosis of ME/CFS all of these symptoms should be present:

- Debilitating [fatigue](#) that is worsened by [activity](#), is not caused by excessive cognitive, physical, emotional or social exertion, and is not significantly relieved by rest.
- [Post-exertional malaise](#) after [activity](#) in which the worsening of symptoms:

- is often delayed in onset by hours or days
- is disproportionate to the activity
- has a prolonged recovery time that may last hours, days, weeks or longer.
- [Unrefreshing sleep](#) or sleep disturbance (or both), which may include:
 - feeling exhausted, feeling flu-like and stiff on waking
 - broken or shallow sleep, altered sleep pattern or hypersomnia.
- [Cognitive difficulties](#) (sometimes described as 'brain fog'), which may include problems finding words or numbers, difficulty in speaking, slowed responsiveness, short-term memory problems, and difficulty concentrating or multitasking.

There currently is no diagnostic test for ME/CFS. It is recognised on clinical grounds alone.

- The above symptoms need to be present for a minimum of 6 weeks in adults.
- The person's ability to engage in occupational, educational, social or personal activities is significantly reduced from pre-illness levels
- Symptoms are not explained by another condition.

The NICE guidelines state ME/CFS.

- is a fluctuating medical condition that affects everyone differently, in which symptoms and their severity can change over a day, week or longer
- varies in long-term outlook from person to person – although a proportion of people recover or have a long period of remission, many will need to adapt to living with ME/CFS
- varies widely in its impact on people's lives, and can affect their daily activities, family and social life, and work or education (these impacts may be severe)
- can be worsened by particular triggers – these can be known or new triggers or in some cases there is no clear trigger
- can be self-managed with support and advice
- can involve [flare-ups](#) and [relapses](#) even if symptoms are well managed, so planning for these should be part of the energy management plan

Definitions of severity levels

Mild ME/CFS

People with mild ME/CFS care for themselves and do some light domestic tasks (sometimes needing support) but may have difficulties with mobility. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often have reduced hours, take days off and use the weekend to cope with the rest of the week.

Moderate ME/CFS

People with moderate ME/CFS have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work or education, and need rest periods, often resting in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.

Severe ME/CFS

People with severe ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They have severe cognitive difficulties and may depend on a wheelchair for mobility. They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed and are often extremely sensitive to light and sound.

Very severe ME/CFS

People with very severe ME/CFS are in bed all day and dependent on care. They need help with personal hygiene and eating and are very sensitive to sensory stimuli. Some people may not be able to swallow and may need to be tube fed.

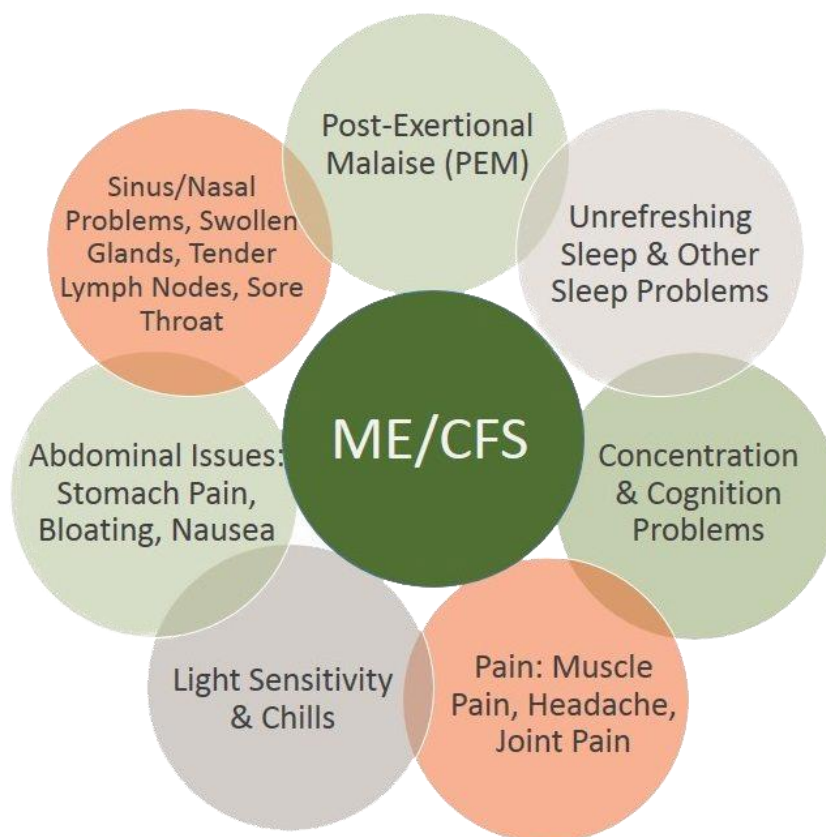
Symptoms

We hold the view that every patient's experience is unique. Their illness must be treated flexibly in its own right, from a range of options that are generically applicable to the disorder but individually adapted.

Patients with ME/CFS experience an individual array of symptoms from the overall range seen in the illness. Some, such as physical and/or cognitive fatigue are seen in almost all patients, though

their extent can vary. Others are very common, such as pain, disturbed sleep, and gastrointestinal disturbance.

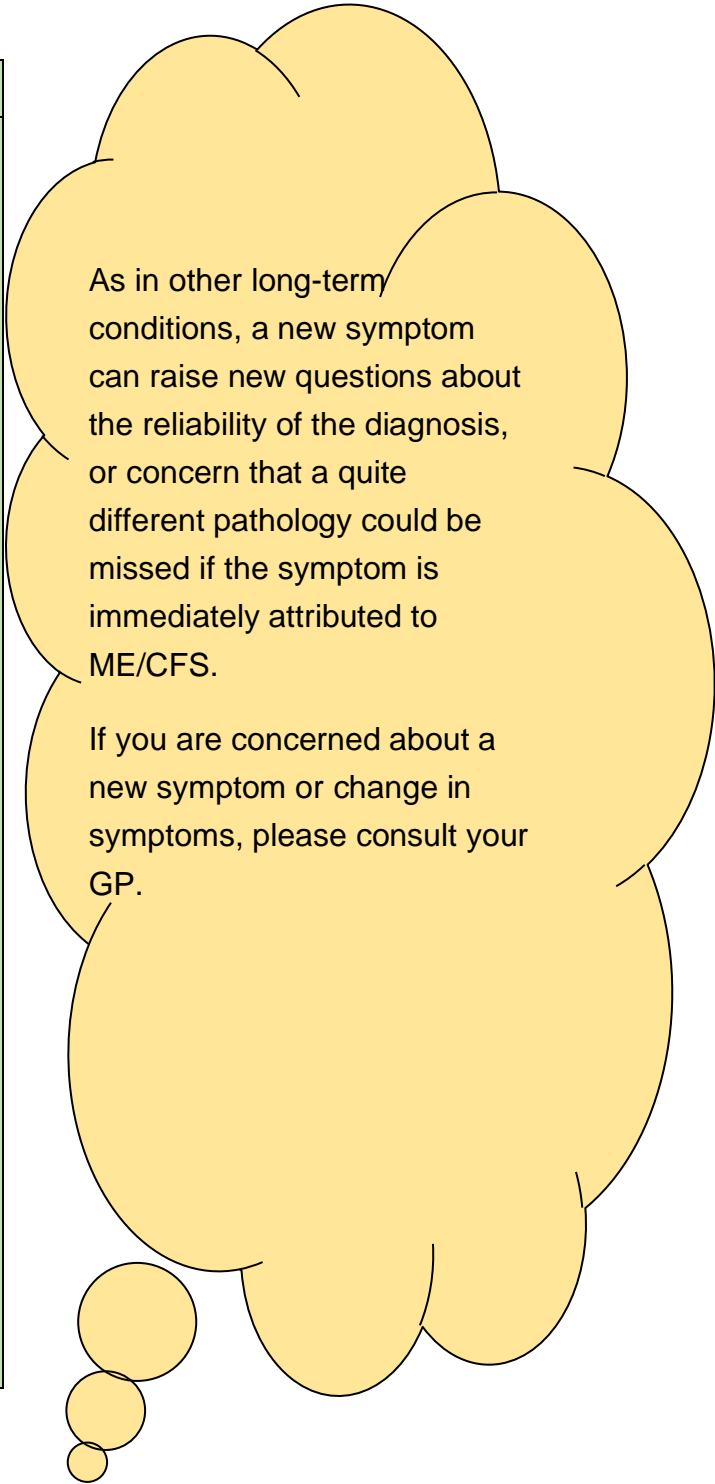
In addition to symptoms that occur in the majority, individual symptom complexes may vary according to the individual's medical history and activity pattern.



The symptoms shown below are those reported by patients on a regular basis to the Torbay and South Devon ME/CFS Service.

Symptoms

Fatigue
Alcohol intolerance
Bloating
Confusion
Dizziness
Eyesight problems
Feeling drunk/ more clumsy
Food intolerances
Headaches/ migraine
Heaviness
Light intolerance
Loud noises in head/Tinnitus
Memory problems
Muddled words
Muscles twitching, spasms, jerking
Muscle pain
Muscle weakness
Noise intolerance
Numbness
Pins and needles
Poor temperature control
Problems with digestion (Diarrhoea, constipation)
Sleep problems
Sore throat
Swollen glands
Vivid dreams
Word finding difficulties



As in other long-term conditions, a new symptom can raise new questions about the reliability of the diagnosis, or concern that a quite different pathology could be missed if the symptom is immediately attributed to ME/CFS.

If you are concerned about a new symptom or change in symptoms, please consult your GP.

Post-exertional malaise

Post-Exertional Malaise (PEM) occurs when there is a significant increase in the level of fatigue after doing your usual level of activity. This fatigue does not quickly improve with rest. There can often be a delay between doing the activity and the fatigue increasing which can make it harder to spot the connection. (NICE 2021)

BACME (2021) describe the features of PEM as:

- The fatigue of PEM is different to normal tiredness. It is a feeling of complete exhaustion often leading to an inability to carry out usual daily activities.
- PEM can include increased pain, symptoms of 'brain fog' (cognitive difficulty), headaches, dizziness, sore throats, tender glands and feeling like you have flu, reduced muscle power, nausea and increased sensory sensitivity.
- An increase in symptoms can start while doing an activity, several hours or even a day or more later. Some people feel OK while doing the activity then experience an increase in symptoms and a reduced capacity to function the next day or up to 3 days later which can last for days or weeks.
- PEM can be triggered by any type of activity which includes physical activities, thinking activities, talking and social activities or emotional stressors.
- When PEM is present, rest does not usually have an immediate benefit in reducing the feeling of fatigue. Many people experience a further increase in PEM symptoms even while resting.

PEM can also be referred to as post exertional symptom exacerbation (PESE)

Functional Impact of ME/CFS

Effect on life (reported by patients to the Torbay and South Devon ME/CFS Service)

Reduced/changed daily activities
Reduced social contact
Having to prioritise more
Not finishing/starting tasks
Change of roles
Change of routines and habits
Needing more support from others
Using equipment and aids
Changes in weight
Having to cope with variability and uncertainty
Sense of achievements reduced
Low self esteem
Fear of crowded places
Feeling misunderstood
Loss of confidence
Reduced safety
Reduced motivation
Value health more
Changes to sleep

A brief overview of self-management strategies.

Please see our activity management workbook for our full explanation of self-management strategies and approaches.

Activity/Energy management – The most common symptom of ME/CFS is fatigue. Levels of fatigue can fluctuate and can be worsened by increasing physical, mental and emotional activity.

Activity management is not necessarily about increasing or decreasing activity. It is about doing things differently or replacing activities of relatively high energy expenditure with those of less demand. Importantly it can support a reconnection with valued and meaningful activities in turn supporting wellbeing and quality of life.

Reduced energy and the varied symptoms can cause a change in the day-to-day routines, habits and activities. Activity/energy management strategies that consider the demands of activities (physical, cognitive, emotional and social) and look at the individual's energy limits can be helpful.

Activity/energy management can help to explore ways to gain a sense of balance between the energy supply and the demands we face. It can also help to identify a sustainable level of activity to reduce boom and bust and reduce the risk of PEM. A flexible approach is needed to any activity/energy management plan. The environment needs to be considered as it can impact on the demands of the activity.

Sleep – Sleep problems are common in ME/CFS. These include problems such as difficulty going to sleep, waking during the night and early morning, and sleeping during the day. As well as unrefreshing sleep.

Developing regular sleep habits and routines can be helpful. Consider the need for sleep during the day balanced against sleep at nighttime. Sleep patterns and management strategies may need to be reviewed regularly as part of the individual management plan. Establishing a routine can help your body clock get used to certain things happening at regular times. A regular sleep wake cycle will help to regulate your body rhythms.

Rest - Building regular rest into a daily routine can be helpful. Rest is part of the activity/energy management plan. Relaxation techniques as part of the rest period could be helpful.

Rest is helpful to regulate the nervous system and engage the parasympathetic response. Often people report an experience of sensory overload. Calming the nervous system can improve clarity of thinking and improve levels of awareness. This can inform choices to respond helpfully instead of reacting.

Emotional wellbeing – The experience of living with a challenging long-term condition like ME/CFS understandably affects mood. This can be in the form of anxiety, irritability, anger or low mood and frustration. There is also often a reduction in self-confidence and self-esteem. Self-management strategies are known to indirectly support and improve emotional wellbeing.

Flare-ups and relapses – Flare ups and relapses can happen even if the symptoms are well managed. Many people will experience episodes of increased symptoms that may persist for several days or weeks. It is disheartening and worrying when this happens. Symptoms can flare up ‘out of the blue’ or there may be triggers that make an increase more likely.

For example:

- If you get another illness
- Major life events like moving house or changing jobs; sometimes they may be pleasant events such as a wedding or holiday
- Changes in your routine such holidays, changes in weather or clocks
- Increased pressures such as exams or work deadlines

The NICE guideline for ME/CFS (2021) describe flare ups and relapses as:

Flare-up

A worsening of symptoms, more than would be accounted for by normal day-to-day variation, which affects the person's ability to perform their usual activities. Flare-ups

may occur spontaneously or be triggered by another illness, overexertion or other triggers. Flare-ups usually occur as part of post-exertional malaise, but it is possible for other symptoms, such as pain, to flare-up without post-exertional malaise. The worsening of symptoms is transient, and flare-ups typically resolve after a few days, either spontaneously or in response to temporary changes in energy management or a change in treatment. A [relapse](#) lasts longer than a flare-up.

Relapse

A sustained and marked exacerbation of symptoms lasting longer than a flare-up and needing a substantial and sustained adjustment to the person's energy management. It may not be clear in the early stages of a symptom exacerbation whether it is a flare-up or a relapse. Relapses can lead to a long-term reduction in the person's energy limits.

It can be helpful to have a plan to manage flare-ups and relapses in your individual care and support plan.

In any health difficulty the emotional and physical support of family/friends/health professionals is essential to help the person adjust and adapt to a new lifestyle and the management of their condition.

References/Recommended Reading

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- Full Catastrophe Living. How to cope with Stress, Pain and Illness using mindfulness meditation. Kabat-Zinn, J. (2001) London: Judy Piatkus Ltd.
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- (BACME (British Association for ME/CFS) An introduction to dysregulation in ME/CFS. August 2021. pp.3) at <https://www.bacme.info/>

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