

PATIENT INFORMATION

General Information Fact Sheet for ME/CFS

(Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome)

What is ME/CFS?

- Is a complex, chronic medical condition affecting multiple body systems and its pathophysiology is still being investigated.
- Affects everyone differently and its impact varies widely – for some people symptoms still allow them to carry out some activities, whereas for others they cause substantial incapacity.
- Is a fluctuating condition in which a person's symptoms can change unpredictably in nature and severity over a day, week or longer.
- Can affect different aspects of the lives of both people with ME/CFS and their families and carers, including activities of daily living, family life, social life, emotional wellbeing, work and education.
- 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.
- 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 managed, so planning for these should be part of the energy management plan. (NICE (National Institute for Health and Care Excellence), Guidance ng206. August 2021. Section 1.1.1 Awareness of ME/CFS and its impact and section 1.6.4 Information about ME and CFS at <https://www.nice.org.uk/guidance/ng206>).
- Current research indicates dysregulation of several systems in the body which may explain the wide range of symptoms that people experience. (BACME (British Association for ME/CFS) An introduction to dysregulation in ME/CFS. August 2021. pp.3) at <https://www.bacme.info/>.

Further information on dysregulation can also be found on the understanding ME/CFS document on our website (see contact details at the end of this leaflet).

Key clinical indicators:

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. (NICE (National Institute for Health and Care Excellence). August 2021. Suspecting ME/CFS, Box 2 Symptoms for suspecting ME/CFS at <https://www.nice.org.uk/guidance/ng206> .

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. (NICE (National Institute for Health and Care Excellence). August 2021. Suspecting ME/CFS 1.2.1, 1.2.2 at <https://www.nice.org.uk/guidance/ng206> .

People have also reported the following symptoms associated with ME/CFS. They may not be exclusive to ME/CFS.

- **Orthostatic intolerance and autonomic dysfunction**, including dizziness, palpitations, fainting, nausea on standing or sitting upright from a reclining position.
- **Orthostatic intolerance may include Postural Orthostatic Tachycardia Syndrome (POTs)**. This is a significant rise in pulse rate when moving from lying to standing and postural hypotension, which is a significant fall in blood pressure when moving from lying to standing. People with severe orthostatic intolerance may find they are unable to sit up for any length of time.
- **Temperature hypersensitivity** resulting in profuse sweating, chills, hot flushes, or feeling very cold.
- **Neuromuscular symptoms**, including twitching and myoclonic jerks.
- **Flu-like symptoms**, including sore throat, tender glands, nausea, chills or muscle aches.
- **Intolerance** to alcohol, or to certain foods and chemicals.
- **Heightened sensory sensitivities**, including to light, sound, touch, taste and smell.
- **Pain**, including pain on touch, myalgia, headaches, eye pain, abdominal pain or joint pain without acute redness, swelling or effusion. (NICE (National Institute for Health and Care Excellence). August 2021. Suspecting ME/CFS 1.2.4 and Terms used in this guideline. At <https://www.nice.org.uk/guidance/ng206> .

Functional impact:

The experience of a chronic condition such as ME/CFS can commonly affect mood and emotional well-being. This may be in the form of anxiety, anger, increased stress, or low mood/depression. There may also be a reduction in self-confidence. Due to a reduction in energy levels, leisure and social pursuits are commonly limited or stopped in order to attempt to keep up with responsibilities.

Definitions of severity:

Definitions of severity are not clear cut because individual symptoms vary widely in severity. People may have some symptoms more severely than others. The definitions below provide a guide to the level of impact of symptoms on everyday functioning.

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. (NICE (National Institute for Health and Care Excellence). August 2021. Box 1 Severity of ME/CFS at <https://www.nice.org.uk/guidance/ng206> .

The emotional and physical support of family/friends/health professionals is likely to be helpful to support the person adjust and adapt their lifestyle and manage their condition.

The Torbay and South Devon ME/CFS Service can provide, assessment, treatment, advice and information.

Please refer to the website for more information:

- Introductory session for patients and carers (video).
- Introduction to ME/CFS.
- Guided relaxations and mindfulness practices.
- Further information leaflets – including service provision and work.
- Activity Management workbook.

Contact Details:

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For further assistance or to receive this information in a different format, please
contact the department which created this leaflet.