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Bwrdd Iechyd Prifysgol
Cwm Taf Morgannwg
University Health Board



Freedom of Information Request: Our Reference CTMUHB_129_24

You asked:

1. Please can you let me know what is the process of receiving a diagnosis of ME/CFS if a patient is presenting with symptoms, and what further treatment and/or medication is available post-diagnosis?
2. Also, what is the process of receiving a diagnosis of Long Covid if a patient is presenting with symptoms, and what further treatment and/or medication is available post-diagnosis?

Our response:

The process of receiving a diagnosis of ME/CFS or Long Covid if a patient is presenting with symptoms, is by diagnosis of exclusion (investigations to rule out other diagnosis) in Primary Care by a General Practitioner, in line with current NICE guidelines:

For Long Covid:

Signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body. Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.

For 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.*

If there is diagnostic uncertainty, but presumed ME/CFS or Long Covid, the case can be referred to the Primary Fatigue Service, which is a multi-disciplinary team assessment, that also offers self-management support for people living with these conditions.

Following the investigations completed in Primary Care, any abnormalities detected are treated accordingly, on a case-by-case basis, or referred to a suitable specialist in Secondary care, e.g. Cardiologist following ECG results.