

# ME/CFS GUIDE FOR PRIMARY CARE

## INTRODUCTION

### ME/CFS IS A COMPLEX MULTISYSTEM DISEASE THAT INVOLVES THE BRAIN, MUSCLE AND IMMUNE SYSTEM.

- It affects at least **250,000 people in the UK** and often has a significant impact on functional ability and quality of life.
- All age groups are affected - including children and young people. The commonest age of onset is during early and mid adult life.

- Around 25% of people are severely or very severely affected - meaning they are housebound and in some cases bedbound.
- This provides an overview of what to do in primary care and when to refer to secondary care - the information is based on the new NICE guideline on ME/CFS.
- ME/CFS is recognised in the NHS SNOMED-CT coding system.

## SUSPECT ME/CFS



- When a patient is failing to return to normal health after a viral infection - the commonest triggering factor.
- ME/CFS can also be triggered by vaccinations and other immune system stressors.
- In a minority there is no clear triggering event and symptoms develop gradually.



## DIAGNOSE ME/CFS



### When the following symptoms, which often fluctuate in severity, persist for three months or more and there is no other explanation:

- Debilitating fatigue that is made worse by minimal exertion.
- Post exertional malaise / symptom exacerbation - where there is a delay in exacerbation of symptoms after physical or cognitive activity and a prolonged recovery period.
- Unrefreshing sleep or sleep disturbance.

- Cognitive dysfunction ('brain fog') involving problems with short-term memory, attention span, information processing, word finding ability.
- Orthostatic intolerance or other symptoms relating to dysautonomia.
- People with ME/CFS will often report feeling flu-like with sore throats and tender glands and are generally unwell.

Many of these symptoms also occur in Long-Covid and a significant proportion of people with Long Covid meet diagnostic criteria for ME/CFS.

## RED FLAGS



A more thorough clinical assessment is required in older age groups, where there is no clear triggering event, and where there are more unusual or prominent symptoms, abnormal examination findings or abnormal blood test results.

For example:

- Weight loss
- Painful swollen joints
- Enlarged lymph glands
- Raised inflammatory markers - ESR and CRP

## DIFFERENTIAL DIAGNOSIS

This should always include common conditions that produce fatigue and ME/CFS like symptoms and less common conditions where the history, examination or blood test findings are not typical of ME/CFS.

Examples:

- Addison's disease
- Fibromyalgia
- Hypothyroidism
- Hepatitis C infection
- Lyme disease
- Multiple sclerosis
- Primary biliary cirrhosis
- Sleep apnoea

## ASSOCIATED SYMPTOMS



May include:

### Central nervous system



- Alcohol intolerance
- Dysautonomia - postural orthostatic tachycardia syndrome/POTS, cold hands and feet
- Fasciculations and myoclonic jerks
- Headaches

- Hypersensitivity to light, sound, touch and some medications
- Poor temperature control
- Pain - which can affect muscles, nerves or joints

### Ear, nose and throat



- Tinnitus

### Gastrointestinal

- Irritable bowel type symptoms



## CO-MORBID CONDITIONS



May include:

- Endometriosis
- Hypermobility
- Interstitial cystitis
- Irritable bowel syndrome



- Mast cell activation syndrome
- Migraine type headaches
- POTS



## INVESTIGATIONS



The following investigations should always be checked, and reported as normal, before confirming the diagnosis:

- C-reactive protein and/or ESR
- Calcium and phosphate
- Coeliac screening
- Creatine kinase
- Full blood count
- HbA1c
- Liver, renal and thyroid function
- Serum ferritin
- Urea and electrolytes
- Urinalysis for blood, protein and glucose

### Further investigation required in selected cases. Examples:

- NASA lean test - if POTS is suspected
- Vitamin B12
- 9am serum cortisol for adrenal insufficiency

## WHAT CAN THE PRIMARY CARE TEAM DO?



- Make an accurate and early diagnosis
- Believe and empathise with the way in which ME/CFS is impacting on all aspects of normal life
- Provide information and guidance on activity and symptom management in line with the updated NICE guidance on ME/CFS
- Help with benefits, disability aids, education, employment, social care
- Carry out regular monitoring and review.

## SPECIALIST REFERRAL SERVICES

- The NICE guideline on ME/CFS recommends that GPs should refer people with ME/CFS to a specialist ME/CFS service to confirm the diagnosis and provide a care and management programme.
- This should include a domiciliary service for people with severe or very severe ME/CFS.
- People with severe ME/CFS often experience difficulties with eating, swallowing and digestion and require expert guidance on nutritional support.
- The MEA website has a directory of all the UK ME/CFS referral services.

## INFORMATION AND SUPPORT

The ME Association is one of the leading charities that provides information and support to people with ME/CFS and their carers - through the website, social media channels and ME Connect helpline and message service.

We provide a range of literature that is available as free downloads and using our medical education budget, we can supply free resources for healthcare professionals. Please scan the QR code for more information.



meassociation.org.uk

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