

## Guidance for Early Diagnosis of ME/CFS and Post Covid Fatigue and referral to the team

If you have a patient with disabling fatigue that is not the result of exertion, not relieved by rest and typically suffers from delayed setbacks after physical and mental activity, they may have Myalgic Encephalomyelitis/Chronic Fatigue (ME/CFS) or Post Covid fatigue syndrome.

A positive diagnosis can only be confirmed by recognising the presence of a characteristic set of symptoms, together with the screening for, and exclusion of, alternative diagnoses.

ME/CFS guidelines recommend early diagnosis and intervention to increase the likelihood of successful management.

### **Main characteristics of ME/CFS and Post Covid fatigue include:**

- Primary complaint of unexplained and debilitating, persistent or relapsing, fatigue (not caused by conditions such as inflammation or chronic disease):

1. of definite / new onset but of a minimum of 3 months duration.
2. not due to on-going exertion and not substantially relieved by rest
3. severe enough to cause substantial reduction in previous levels of occupational, educational, social, or personal activities

- Symptoms are worsened by increased physical or mental exertion often with a delayed impact (i.e. it is felt later the same day or next day), and lasting for more than 24 hours. Recovery from such relapses may take days, weeks or even months.

### **Additional characteristic symptoms include:**

- Frequent sore throats
- Memory / concentration / wordfinding problems
- Unrefreshing / disturbed sleep
- Tender lymph nodes
- Nausea
- Dizziness
- Flu-like symptoms
- Multi-joint pain without swelling or redness
- Headaches of a new type, pattern or severity
- Muscle pain or twitching (Fukuda diagnostic criteria includes at least 4 of the above symptoms present in addition to the fatigue)

### ***Differential diagnoses***

It is important to ensure there is no clinical evidence of other causes of fatigue, including:

- Adrenal insufficiency
- Anaemia
- Chronic infection
- Coeliac disease
- Immuno-deficiency
  - Malignancy
- Primary mental health problem
- Major neurological diseases
- Primary Sleep Disorder / sleep apnoea
- Rheumatic diseases
- Thyroid Disease
- Somatisation
- Organ failure (eg emphysema, cirrhosis, cardiac failure)
- Reversible causes of fatigue (eg medication, recent surgery)
- Eating disorders

If in doubt about diagnosis do not hesitate to contact the service for advice.

### **Referral to the Children & Young People's Specialist ME/CFS and Post Covid Service**

If the patient is under 16 years old, referrals must be made by a local paediatrician and will need to include all the information listed below.

A young person aged 16 to 18 years can be referred directly by their GP.

If you are a GP and wish to refer a patient to the service, we do require a referral letter, which includes the following information, as well as the results of the screening tests.

As we are a therapy service, we have no facilities for carrying out any investigations and rely on detailed referral information to enable us to triage referrals adequately.

If you do not include this information, we will not be able to accept the referral:

- Reason for referral to the Service
- Provisional diagnosis of ME/CFS
- Narrative of the illness
- Relevant past medical history including mental health
- Information about interventions already tried
- Current medication
- Minimum requirement of the following tests having been carried out (see below)

### **Screening tests**

All people who are referred to the service must have a set of screening tests done within the previous six months. If you do not include copies of the results of these tests, including their values and the date taken, we will not be able to accept the referral.

- Full blood count and film

- ESR
- CRP
- Urea and electrolytes
- Serum Creatinine
- Liver function tests
- Thyroid function tests
- Urinalysis for protein, blood and sugar
- Serum glucose
- Calcium profile
- Creatine Kinase
- Immunoglobulins
- IgA tissue transglutanimase Ab / Endomysial Antibody IgA for coeliac disease

***Exclusion criteria for the ME/CFS Service:***

- Major psychiatric illness with psychotic or manic features
- Concurrent rehabilitation from another service
- Ongoing medical investigation
- Eating disorders

Please send referrals to:

Dr C A Mackenzie  
Consultant Paediatrician  
Children & Young People's Specialist ME/CFS & Post Covid Fatigue Service  
Sheffield Children's Hospital  
Western Bank  
Sheffield  
S10 2TH  
Email: [scn-tr.cfstherapy@nhs.net](mailto:scn-tr.cfstherapy@nhs.net)

