DIAGNOSIS OF ME/CFS

THE IMPORTANCE OF HAVING AN EARLY AND ACCURATE DIAGNOSIS

APRIL 2022

THE IMPORTANCE OF HAVING AN EARLY AND ACCURATE DIAGNOSIS

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THE IMPORTANCE OF HAVING AN EARLY AND ACCURATE DIAGNOSIS

The information and guidance in this leaflet has been produced for people who want to know when a diagnosis of ME/CFS should be suspected – as well as how and where it should then be confirmed and managed. It also contains information on the whole diagnostic pathway for the benefit of health professionals working in general practice and in hospital.

The content is based on existing information from the MEA on the need for an early and accurate diagnosis and the recommendations on suspecting and diagnosing ME/CFS in the new (2021) NICE guideline on ME/CFS.

More detailed information on clinical assessment, differential diagnosis, investigations and physical examination can be found in the 2022 edition of the MEA purple book: ME/CFS/PVFS – An Exploration of the Key Clinical Issues.

INTRODUCTION

ME/CFS (myalgic encephalomyelitis or encephalopathy/chronic fatigue syndrome) is a complex multisystem disease with a probable population prevalence of 0.2% to 0.4%. We believe it affects around 404,000 people in the UK.

There is a wide range of symptom severity and functional impairment at all stages of the illness. Around 25% of people are severely or very severely affected at some stage – being house-bound or bed-bound. This can create additional challenges when making a diagnosis in relation to both their symptom profile and access to medical care.

Many people experience a long delay in obtaining a formal diagnosis. A 2016 MEA website survey involving 656 respondents found that of those who were diagnosed by a doctor:

- only 18 % were diagnosed within six months of the onset of symptoms
- 15% waited between 7 and 12 months
- 17% waited between 13 and 24 months
- 26% waited between 2 and 5 years
- 19% waited more than 5 years

The remainder could not remember, or had never received confirmation of the diagnosis from a doctor.

Diagnosis of ME/CFS - The importance of having an early and accurate diagnosis was written by Dr Charles Shepherd (pictured above), Trustee and Hon Medical Adviser to The ME Association.

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DISCLAIMER

We recommend that the medical information in this leaflet is discussed with your doctor. It is not intended to be a substitute for personalised medical advice or treatment. You should consult your doctor whenever a new symptom arises, or an existing symptom worsens. It is important to obtain medical advice that considers other causes and possible treatments. Do not assume that new or worsened symptoms are solely because of ME/CFS.

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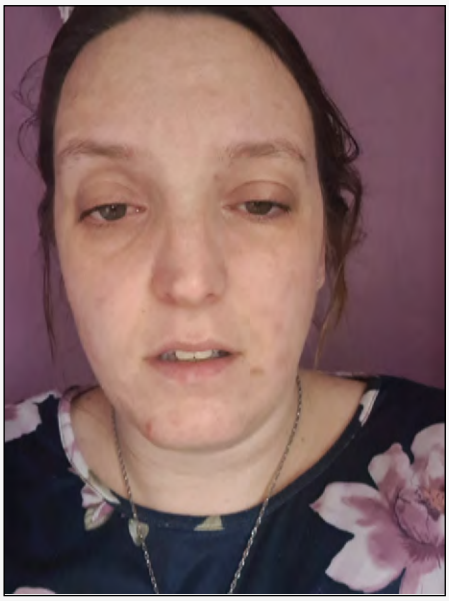
Fatigue is a very common symptom and some people with chronic debilitating fatigue are being misdiagnosed with ME/CFS when they have another, sometimes perfectly treatable cause. ME/CFS is a distinct clinical entity with a characteristic set of core symptoms. So it should not be used as a diagnostic label for people with unexplained chronic fatigue.



ME/CFS is a distinct clinical entity with a characteristic set of core symptoms

WHY IS MAKING AN EARLY AND ACCURATE DIAGNOSIS SO IMPORTANT?

- To reduce the likelihood of ME/CFS taking a more prolonged and severe course.
- To exclude other potentially treatable conditions that can present with similar symptoms.
- To prevent harmful approaches to management such as 'working through fatigue' and inappropriate exercise programmes.
- To quickly develop a comprehensive care and management plan involving activity and energy management; symptom relief; information and support relating to education, employment and sickness benefits.

TIMELINE

When should a diagnosis of ME/CFS be suspected and what should a doctor then do?

Most people who develop ME/CFS predate the onset of their illness to an acute viral infection, or another event involving what is called an immune-system stressor (e.g a vaccination). Where the onset clearly relates to a viral infection the term post-viral fatigue syndrome (PVFS) may also be used during the first few weeks or months while a diagnosis of ME/CFS is being considered.

Almost all of the published ME/CFS diagnostic criteria stipulate that a diagnosis should only be made after six months of symptoms. However, this is not a sensible approach in clinical practice and doctors should normally be aiming to confirm the diagnosis when key symptoms have been present for three months.

A working or interim diagnosis is far better than no diagnosis at all and allows for active management to begin. A confirmatory diagnosis often needs to be pieced together through a series of consultations.

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The 2021 NICE guideline used the Institute of Medicine (IoM) diagnostic criteria as the basis for creating their recommendation that a diagnosis of ME/CFS should be based on the presence of four out of five of the core symptoms that are included in the IoM diagnostic criteria. These are:

- debilitating fatigue,
- post-exertional malaise,
- unrefreshing sleep and
- cognitive difficulties.

The new NICE guideline also contains very specific recommendations on when to refer to a specialist team/service and how a person with ME/CFS should then be managed, especially in relation to activity and energy management.

2021 NICE guideline recommendations on suspecting ME/CFS:

1.2.1 ***Explain to people presenting with possible symptoms of ME/CFS that there currently is no diagnostic test for ME/CFS and it is recognised on clinical grounds alone.***

1.2.2 ***Suspect ME/CFS if:***

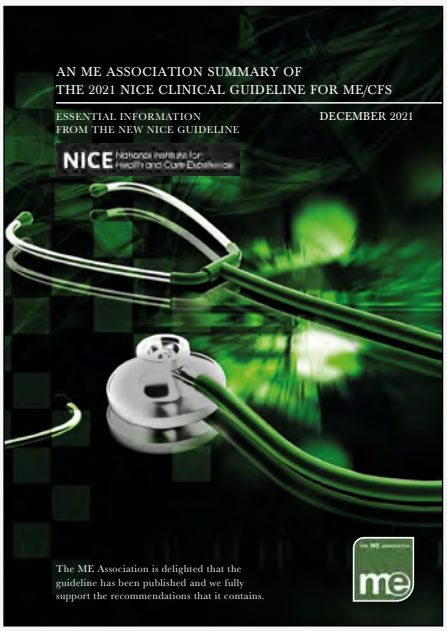
- ***the person has had all of the persistent symptoms below for a minimum of 6 weeks in adults and 4 weeks in children and young people and***
- ***the person's ability to engage in occupational, educational, social or personal activities is significantly reduced from pre-illness levels and***
- ***symptoms are not explained by another condition.***

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.***



The ME Association has produced a free booklet summarising the NICE clinical guideline that can be downloaded here:

https://meassociation.org.uk/istd

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***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.*

NB: These 4 core symptoms, along with other symptoms that may be present in ME/CFS, are described in more detail in section 4.2.

1.2.3 If ME/CFS is suspected, carry out:

- ***a medical assessment - including symptoms and history, comorbidities, overall physical and mental health (see sections 4.3 and 4.4)***
- ***a physical examination (see section 4.5)***
- ***an assessment of the impact of symptoms on psychological and social wellbeing***
- ***investigations to exclude other diagnoses (see section 4.6)***

***1.2.5** Primary healthcare professionals should consider seeking advice from an appropriate specialist if there is uncertainty about interpreting signs and symptoms and whether an early referral is needed. For children and young people, consider seeking advice from a paediatrician.*

1.2.6 When ME/CFS is suspected:

- ***continue with any assessments needed to exclude or identify other conditions***
- ***give the person advice on managing their symptoms in line with the section on advice for people with suspected ME/CFS.***

***1.2.7** When ME/CFS is suspected in a child or young person based on the criteria in recommendation 1.2.2 and the assessment in recommendation 1.2.3:*

- ***refer them to a paediatrician for further assessment and investigation for ME/CFS and other conditions***
- ***start to work with the child or young person's place of education or training to support flexible adjustments or adaptations.***

Primary healthcare professionals should consider seeking advice from a specialist if there is uncertainty about interpreting signs and symptoms of ME/CFS

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1.3 Advice for people with suspected ME/CFS

1.3.1 When ME/CFS is suspected, give people personalised advice about managing their symptoms. Also advise them:

- ***not to use more energy than they perceive they have***
- ***they should manage their daily activity and not 'push through' their symptoms***
- ***to rest and convalesce as needed (this might mean making changes to their daily routine, including work, school and other activities)***
- ***to maintain a healthy balanced diet, with adequate fluid intake.***

1.3.2 Explain to people with suspected ME/CFS that their diagnosis can only be confirmed after 3 months of persistent symptoms. Reassure them that they can return for a review before that if they develop new or worsened symptoms, and ensure that they know who to contact for advice.

The commonest age of onset for ME/CFS is during the early 20s to mid-40s

CLINICAL ASSESSMENT

How is a diagnosis of ME/CFS confirmed?

As with most medical conditions, a formal diagnosis is made by piecing together, often over a number of consultations in the case of ME/CFS, information from a medical history, a thorough physical examination and results of blood tests and other investigations.

The importance of taking a good clinical history

The commonest age of onset for ME/CFS is during the early 20s to mid-40s. However, all age groups, including children and adolescents – where it is one of commonest causes of long-term sickness absence from school - can be affected. ME/CFS affects all social classes and ethnicities.

ME/CFS is often triggered by an acute viral infection but it can also be triggered by non-viral infections such as giardia or toxoplasmosis. This is followed by a 'failure to recover' with on-going flu-like symptoms, feeling generally unwell and the development of a cluster of characteristic ME/CFS symptoms.

Other immune-system stressors – including drug reactions, pesticides, vaccinations, surgery and trauma – occasionally trigger ME/ CFS.

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A gradual onset occurs in a minority of people with no clear precipitating event – although there may be a series of minor infective episodes over a period of time.

Doctors must therefore allow adequate time for taking a detailed history. This should include:

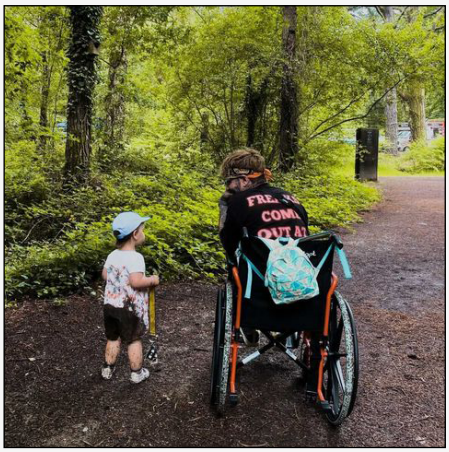
- **Past medical history**
- History of having a **blood transfusion** before September 1991 – to help exclude the possibility of hepatitis C infection, which can cause ME/CFS-like symptoms
- **Family history** – especially whether other members of the family have ME/CFS, or an inflammatory or hormonal condition that can cause ME/CFS-like symptoms
- **Social history** – and where appropriate the possibility of an HIV sero-conversion illness that can cause a glandular fever-type reaction with fatigue, fever, sore throat, headache and lymphadenopathy
- **Recent overseas travel** – post-viral fatigue syndromes can be triggered by tropical infections such as chikungunya, dengue fever and zika virus
- **Tick bites** – possibility of Lyme disease
- **Contact with farm animals** – Q fever/Coxiella burnetii can cause an ME/CFS like illness
- **Medication use** – including supplements and alternative treatments
- **Athletic overtraining**
- **Psychological and mental well being**
- **Impact of symptoms** on family life, education or employment

Where symptoms are atypical or 'red flag' in nature, occur in more elderly people, or are more pronounced than is normally found in ME/CFS, a more thorough clinical assessment is essential.

Diagnostic criteria for ME/CFS

Over 20 different symptom-based diagnostic criteria for ME/CFS have been published. Most of these criteria are designed for selecting homogenous groups of people for research purposes. They often have significant limitations for diagnosis in clinical practice – where a more pragmatic approach is required.

There is no generally agreed diagnostic criteria for ME/CFS in a clinical setting and most diagnostic criteria concentrate on the presence of several core symptoms. Making a diagnosis



Allow plenty of time to take a detailed history, including the impact ME/CFS has on family life

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therefore has to be based on characteristic symptoms along with a careful consideration of other possible explanations.

One of most recent and influential diagnostic criteria comes from the Institute of Medicine (IoM) in America. This was used as a basis for the NICE guideline recommendation on diagnosis.

Two major criticisms of the IoM criteria are that it requires symptoms to be present for at least six months and very little attention is placed on the importance of considering the possibility of other causes of an ME/CFS like illness.

A clinical diagnosis requires an inclusive approach – so it is important to be able to include people with a co-existing diagnosis of other conditions that can cause chronic fatigue and ME/CFS-like symptoms in a way that many of definitions used for research purposes exclude.

Characteristic and common symptoms

The list of key symptoms below is based on the five key diagnostic symptoms – disabling fatigue, post-exertional malaise/symptom exacerbation, cognitive dysfunction, orthostatic intolerance, unrefreshing sleep – in the IoM diagnostic criteria.

The 2021 NICE guideline uses the IoM criteria as the basis for creating their recommendation that a diagnosis of ME/CFS should be based on the presence of four core symptoms: debilitating fatigue, post-exertional malaise, cognitive dysfunction and unrefreshing sleep. NICE does not require the presence of orthostatic intolerance.

The key diagnostic features of ME/CFS are:

- **Post-exertional malaise/symptom exacerbation** whereby symptoms are amplified by physical and/or mental exertion with a delayed impact – later the same day, the next day, or even later. This is then followed by a slow recovery period. The amount of activity that provokes symptom exacerbation can be very minimal.
- **Activity-induced muscle and brain fatigue** whereby there is a failure to create enough energy to continue with and sustain a wide range of physical and cognitive activities that would not normally cause any problem. There is no loss of motivation – as occurs in the chronic fatigue that often accompanies depression.
- **Cognitive dysfunction** involving problems with short-term working memory, concentration and attention span, information processing and retrieval, planning and organising thoughts,

Diagnostic features include:

Post-exertional malaise

Muscle and brain fatigue

Cognitive dysfunction

Unrefreshing sleep

Autonomic nervous system dysfuntion

Muscle, joint and nerve pain

Ongoing flu-like symptoms

Sensory and digestive disturbances

Headaches

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word-finding ability and dysnomia. This is also known as 'brain fog'.

- **Unrefreshing sleep pattern** may include hypersomnia (i.e excessive sleep requirements) in the early post-infection stage, fragmented sleep and myoclonic movements, or restless legs syndrome, later on. In more severe cases there may be a reversal of normal sleep rhythm (i.e, being awake at night but sleeping during the day). Excessive daytime sleepiness should raise the possibility of obstructive sleep apnoea - especially where there is snoring, early morning headaches and the person has a collar size above 16 inches (female) or 17 inches (male)

- **Autonomic nervous system dysfunction/dysautonomia** involving orthostatic intolerance - an inability to sustain physical or mental activity whilst standing. This can produce symptoms such as lightheadedness, feeling faint, blurred vision, palpitations, sweating and nausea. In some cases there is postural hypotension (a fall in blood pressure from lying/sitting to standing resulting in dizziness or feeling faint) or postural orthostatic tachycardia syndrome (a significant rise in pulse rate on standing)

Other symptoms that are frequently reported include:

- Pain which can affect muscles (myalgia), joints (arthralgia) and nerves (neuropathic) but is minimal or not present at all in a minority of people. Pain is often difficult to alleviate with simple analgesics and may be accompanied by sensory disturbances/ paraesthesiae.

- Poor temperature control/thermoregulation including increased sensitivity to hot and cold environments, sweating episodes, feeling feverish

- On-going flu-like symptoms including sore throats and tender glands without pathological enlargement

- Intolerance or increased sensitivity to alcohol, chemicals and medications – especially psychotropic (antidepressant) drugs

- Headaches of a new type or severity that may have a migrainous quality

- Sensory disturbances including paraesthesiae ('pins and needles') and increased sensitivity to touch, noise (hyperacusis) and bright light (photophobia)

- Digestive disturbances consistent with irritable bowel syndrome (i.e. abdominal pain, bloating, change in bowel habit) which may develop following the onset of ME/CFS and can be exacerbated by certain foods

Other symptoms include intolerance or increased sensitivity to alcohol, chemicals and medications, especially antidepressants

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People with severe or very severe ME/CFS are often very sensitive to bright light, noise, movement, touch, chemicals and smell. They may have substantial neurological impairments including atypical seizures, unwanted muscle activity/myoclonus and speech problems. Swallowing difficulties may require nasogastric (tube) feeding.

Symptoms characteristically fluctuate in severity, throughout the day, day to day, and from week to week. The pattern of symptoms, along with severity, may change over time. So people will often describe a pattern of 'good days' and 'bad days'.

Where the diagnosis has been delayed, the clinical presentation is likely to be more complex with a wider range of symptoms and symptom severity.

Overall, there should a substantial (i.e. 50% or more) and sustained reduction in both physical and cognitive/ mental activity. This results in a significant reduction in the person's ability to carry out pre-illness levels of occupational, educational, social or personal activity.

Exacerbations and relapses are commonly caused by infections, trauma and other immune-system stressors. This can include a pre-menstrual or menstrual exacerbation in some cases.

Physical examination

A full clinical examination should include:

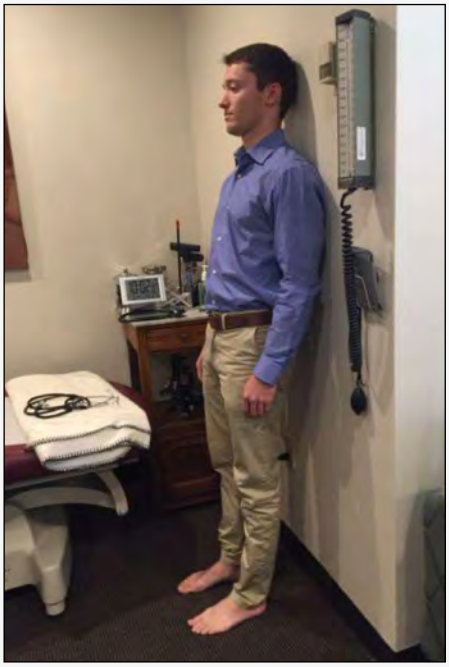
- Checking for anaemia, thyroid gland enlargement, pathological lymphadenopathy (lymph node enlargement) and skin signs of systemic disease such as those found in Addison's disease (adrenal gland failure)
- Pulse and blood pressure supine and standing and/or a 10-minute NASA lean-to test:

https://tinyurl.com/59w6t7ar

- Checking for joint hypermobility in younger patients
- Recording and monitoring weight in children and people with severe ME/CFS

People with ME/CFS show characteristic abnormalities that are consistent with post-exertional malaise/symptom exacerbation when they carry out a two-day cardiopulmonary exercise test (CPET). This test has the potential to be used for both diagnosis and management (Keller BA *et al* 2014). CPET testing is not widely available in the UK for people with ME/CFS.

People with severe or very severe ME/CFS are often very sensitive to bright light, noise, movement, touch, chemicals and smell.



10-minute NASA lean to test

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Baseline investigations

There is no diagnostic blood test for ME/CFS. However, a number of baseline investigations should be carried out to check for common conditions that can cause chronic fatigue and ME/CFS-like symptoms.

- Full blood count and differential
- Serum ferritin
- Erythrocyte sedimentation rate (ESR) or plasma viscosity
- CRP (C-reactive protein)
- Metabolic screen for calcium and phosphate, urea and electrolytes, total protein, albumin and globulin
- Coeliac disease screening test – IgA endomysial or tissue transglutaminase
- Creatine kinase (an enzyme biomarker for muscle disease)
- Random blood sugar and/or HbA1C
- Serum creatinine
- Liver function tests
- Thyroid function tests
- Urinalysis for protein, blood and glucose

The results should all be within normal limits. Where abnormalities occur, consideration must be given to other diagnostic explanations.

Results from a study of blood samples collected by the ME/CFS Biobank indicate that the level of **creatine kinase** (an enzyme that is an indicator of muscle inflammation) can be significantly reduced in people with severe ME/CFS and this may be a potential biomarker for severe ME/CFS (Nacul L *et al*, 2019).

A wide range of immune-system abnormalities can occur in ME/CFS, including changes in cytokine status and the presence of low levels of some autoantibodies. However, none of these abnormalities are sufficiently sensitive or specific to be used as diagnostic biomarkers in our current state of knowledge.

Indications for carrying out a more detailed assessment and investigation include:

- Atypical symptoms (e.g. joint pain accompanied by swelling)
- Red-flag symptoms or signs (e.g. weight loss, significant lymphadenopathy, fever, focal neurological signs, muscle wasting, generalised pruritis/itching skin, dry eyes and mouth)

Joint pain accompanied by swelling is one of the indications for carrying out a more detailed assessment and investigation

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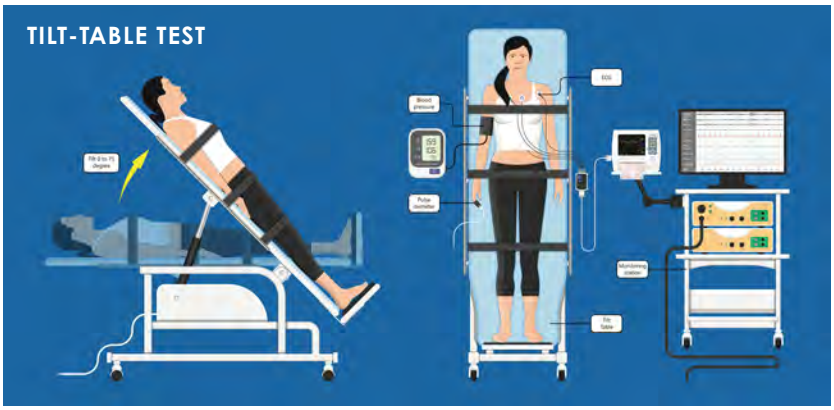

- Symptoms not normally associated with ME/CFS (e.g. breathlessness or chest pain suggestive of cardiorespiratory disease)
- History, examination or baseline test results which suggest other possible diagnostic explanations

Examples of further investigations that may be appropriate depending on the clinical history and examination findings:

- Autoantibody screen – where a rheumatological or autoimmune condition is possible
- Schirmer's test for dry eyes – possibility of Sjögren's Syndrome
- Screening for specific infectious diseases – giardia, hepatitis B/C, HIV, Lyme disease, Q fever/Coxiella burnetii, toxoplasmosis
- 9am cortisol and/or Synacthen test – where adrenal insufficiency/Addison's disease is a possibility
- Serum hydroxyvitamin D – in housebound patients
- Vitamin B12 if pernicious anaemia is a possibility
- Tilt-table testing where there is more significant autonomic system dysfunction
- Epworth sleepiness score or the Pittsburgh Sleep Quality Index where a primary sleep disorder is possible
- Polysomnography where sleep disturbance strongly suggests a primary sleep disorder such as sleep apnoea

Differential diagnosis and misdiagnosis of ME/CFS

Patient evidence and data collected by NHS specialist referral services indicates that a significant number of people are being misdiagnosed as having ME/CFS. Of 260 people who attended the Newcastle ME/CFS referral service with a possible diagnosis of ME/CFS, 40% were found to have another explanation. 47%

Symptoms of Sjögren's Syndrome

Dry eyes, mouth, skin or nose

Skin rashes

Swollen salivary glands

Tiredness

Persistent dry cough

Vaginal dryness

Difficulty speaking

Problems chewing

Sensitivity to light

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had another medical disorder; 20% a primary sleep disorder; 15% psychiatric/psychological illness and 4% cardiovascular disease (Newton JL *et al*, 2010). This is often due to a failure to carry out a proper clinical assessment and consider other possible explanations for an ME/CFS-like illness. Examples of conditions that can be misdiagnosed as ME/CFS include:

Addison's disease
Coeliac disease
Depression
Fibromyalgia
Haemochromatosis
Hepatitis C
Hypothyroidism
Malignancy
Multiple sclerosis
Myasthenia gravis
Narcolepsy
Pituitary disease
Primary biliary cirrhosis or cholangitis
Q fever
Primary sleep disorders such as sleep apnoea
Rheumatic disease – e.g. Sjogren's Syndrome
Sarcoidosis
Sjögren's Syndrome
Vitamin D deficiency

Although unlikely, it should be noted that the common conditions being checked for do sometimes co-exist with ME/CFS. So having hypothyroidism does not automatically mean that the person could not have ME/CFS as well.

REFERRAL TO SPECIALIST TEAMS/ SERVICES FOLLOWING DIAGNOSIS

The 2021 NICE guideline recommends that once a diagnosis has been made at three months, adults and children should then be referred to a specialist team/referral centre to confirm the diagnosis and the production of a care and management plan.

If there is not a suitable ME/CFS referral service nearby, the Countess of Mar has established through a House of Lords parliamentary question that people with ME/CFS can be referred elsewhere to an NHS service/consultant of their choice:

https://meassociation.org.uk/908n

Once a diagnosis has been made, adults and children should be referred to a specialist team/referral centre

2021 NICE Guideline recommendation

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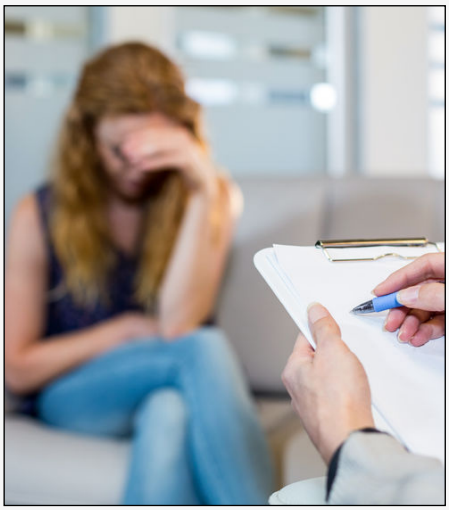
The NHS website also has helpful information on how you can choose where and who you want to be referred to:

https://tinyurl.com/fbvdzmsm

The MEA website has contact details for all the multidisciplinary hospital-based referral services for adults and children throughout the UK. While there are a considerable number of adult services in England many people are still without a local referral service. There are very few NHS referral services in Northern Ireland, Scotland and Wales. Paediatric referral services are very limited throughout the UK.

Hopefully, as a result of the recommendations in the 2021 NICE guideline, new services for both adults and children will now develop in parts of England, Wales and Northern Ireland where none currently exist and NICE guidelines apply. The Scottish NHS is currently considering whether to also use the new NICE guideline in place of the Scottish Good Practice Statement.

https://meassociation.org.uk/nhsspecialistservices/



The MEA has an information leaflet covering **Specialist Referrals** in more detail:

https://meassociation.org.uk/s40n

KEY POINTS ON DIAGNOSIS AND POST-DIAGNOSIS REFERRAL AND MANAGEMENT FROM THE 2021 NICE GUIDELINE ON ME/CFS:

1.4.1 Diagnose ME/CFS in a child, young person or adult who has the symptoms in recommendation 1.2.2 (as above) that have persisted for 3 months and are not explained by another condition.

1.4.2 Primary healthcare professionals should consider seeking advice from an appropriate specialist if there is uncertainty about interpreting signs and symptoms at 3 months and whether further investigations are needed.

1.4.3 Refer adults directly to an ME/CFS specialist team to confirm their diagnosis and develop a care and support plan.

1.4.4 Refer children and young people who have been diagnosed with ME/CFS.

7 ME/CFS in children and adolescents

- ***ME/CFS has been reported in children as young as five. There appears to be a peak onset around 13 to 15.***
- ***ME/CFS is reported to be the commonest cause of long-term sickness absence from school.***

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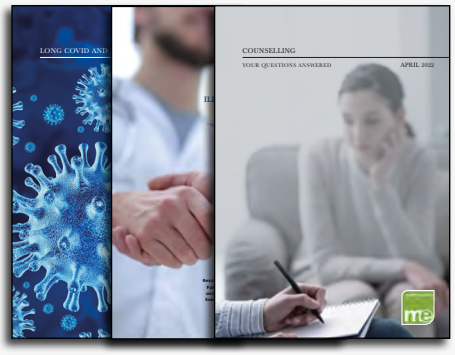
- ***ME/CFS can be misdiagnosed as a behaviour problem or school phobia.***
- ***Children and adolescents may present differently to adults. Symptoms that are more common or prominent include stomach pain, nausea, headache and loss of appetite. There is evidence to indicate that hypermobility syndromes are more common in children and adolescents.***
- ***When working with children and young people with ME/CFS ensure their voice is heard by taking a child-centred approach, with the communication focusing on them.***
- ***Discuss and regularly review with them how they want to be involved in decision-making about their care.***
- ***Children should be known to community paediatric services and under consultant care if they are unable to attend school on a regular basis.***
- ***Health and social care professionals should follow the Department for Education's guidance on supporting pupils at school with medical conditions or equivalent statutory guidance.***

LONG COVID AND ME/CFS

As already noted, any viral infection can trigger ME/CFS and this includes coronavirus infections such as COVID-19. People who have gone on to develop Long Covid often have some or all of the key diagnostic symptoms of ME/CFS - disabling fatigue, post-extertional malaise, cognitive dysfunction, dysautonomia and unrefreshing sleep - sometimes in the absence of any COVID-19 symptoms affecting the lungs, heart or other organs. Consequently, we are now dealing with people who were initially diagnosed as having Long Covid but now meet diagnostic criteria for ME/CFS. We have an MEA information leaflet that provides more information on the clinical and pathological overlaps between Long Covid and ME/CFS and the management of ME/CFS where this has followed COVID-19 infection.



MEA Literature

The ME Association has the largest selection of free ME/CFS advice leaflets in the UK on:

Medical Management
Mental Health
Diet & Nutrition
General Information
Fundraising Leaflets
Benefits & Social Care
'To Whom It May Concern' letters and leaflets written by ME Connect

https://meassociation.org.uk/fdwc

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FURTHER INFORMATION

Recommendations on the diagnosis and management of ME/CFS in the new (2021) NICE guideline are now fully consistent with the information and guidance that the MEA has provided for many years.

https://tinyurl.com/4y7datwr

The ME Connect helpline, which is open every day of the week, provides information and support to people with ME/CFS. Contact details can be found on the MEA website:

https://meassociation.org.uk/MEConnect

References:

Institute of Medicine Report:

Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome; Board on the Health of Select Populations; Institute of Medicine. Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness. Washington (DC): *National Academies Press (US)*; 2015 Feb 10. Summary. Available from:

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Nacul L *et al.* Evidence of clinical pathology abnormalities in people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) from an analytical cross-section study. Diagnostics 2019,June; 9 (2): 41. Published online on April 10 2019: doi: 10.3390/diagnostics9020041

Newton JL *et al.* The Newcastle Chronic Fatigue Syndrome Service: not all fatigue is the same. *Journal of Royal College of Physicians Edinburgh*. 2010, 40, 304 – 307

Keller BA *et al.* Inability of myalgic encephalomyelitis/chronic fatigue syndrome patients to reproduce VO2 peak indicates functional impairment. 2014. *Journal of Translational Medicine* 12: Article number 104

Become a Member of the ME Association

For a small subscription you can receive quarterly issues of **ME Essential** magazine, keep updated with the latest information on ME/CFS and with stories from other members of the charity.

You don't have to be personally affected by ME/CFS to join the ME Association. Membership is available to carers, family members, and anyone with a professional interest in the condition.

Visit our website to find out more:

https://meassociation.org.uk/mea-membership/

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THE ME ASSOCIATION

ME CONNECT

The Support and Information Service for people affected by ME/CFS/PVFS and Long Covid

Freephone 0808 801 0484

For opening hours visit:
meassociation.org.uk/me-connect

Contact ME Connect
3 WAYS TO GET IN TOUCH:
by phone, email
or social media private message

HERE TO LISTEN

We are here to listen, validate and empathise with any issues you might be facing.

VITAL SUPPORT

We are here to help you reach an informed decision.

We're here for you!

SAFE ENVIRONMENT

We provide a safe, confidential and understanding environment where you can be heard and understood.

meconnect@meassociation.org.uk
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instagram.com/meassociation