



British Association of Clinicians in ME/CFS

Primary Care Guide to ME/CFS

December 2022

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Introduction

Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS) are interchangeable terms for the same condition and the current accepted name for the condition is ME/CFS.

ME/CFS is a condition which is defined based on a specific pattern of symptoms once other causes for the symptoms have been ruled out. There are currently no biological markers that can be reliably used for diagnostic purposes. It is recognised that ME/CFS is a heterogeneous condition with associations with many other health conditions.

ME/CFS is an illness that can present with multiple symptoms affecting many different body systems and it can have a very significant impact on a person's quality of life.

Making a confident diagnosis of ME/CFS is very important for the patient as it allows them to access appropriate information and support to help them manage their condition. It also allows the person and those around them to acknowledge, accept and adjust to having the illness as it will often require significant lifestyle changes to be made to manage the symptoms.

ME/CFS is not yet fully understood, however enough is known to provide a framework for making a diagnosis and distinguishing it from other conditions in which fatigue can be a primary feature. Research has made progress in helping us understand the disordered physiological processes that generate the symptoms that occur, and this knowledge can be used to help educate and inform patients about their condition and to guide them with implementing appropriate management strategies.

ME/CFS is a condition defined by symptoms which are caused by dysregulation in multiple dynamic systems in the body including the immune system, the autonomic nervous system, the endocrine system and the metabolic systems. All these systems interact with each other and when there is dysregulation or 'loss of balance' in these systems it results in a wide array of symptoms reflecting a lack of homeostasis at both a global and cellular level in the body.

More information about dysregulation is available from the document '[An Introduction to Dysregulation in ME/CFS](#)' published on the BACME website www.bacme.info

Diagnosis

As ME/CFS is a condition defined by a specific pattern of symptoms, detailed history taking will be required to make an accurate diagnosis. This may require several appointments over a period of time or a long appointment to fully evaluate all symptoms. The symptoms of ME/CFS overlap with other disorders, so other conditions need to have been considered and investigations will be required to rule out other causes for the symptoms or to identify contributing factors which may need to be addressed.

Fatigue

This is the central feature of ME/CFS and the pattern of fatigue in response to activity and rest is important to elicit.

In ME/CFS the normal recovery systems of the body are not working properly so unlike the 'normal' tiredness everyone can feel, the fatigue of ME/CFS is often described as feeling very different. It is also important to distinguish between sleepiness and fatigue.

Post-Exertional Malaise

In ME/CFS the key feature of the fatigue is that there is a clear activity related pattern. This is often referred to as Post-Exertional Malaise (PEM) or Post-Exertional Symptom Exacerbation (PESE). This is where there is a clear relationship between normal everyday activity levels causing a disproportionate escalation in fatigue which does not improve with rest and is slow to recover over several days. For some people the fatigue escalation can occur during or soon after stopping an activity but typically the significant escalation in fatigue is delayed and may occur hours or days after the activity which triggered it. This delayed escalation in fatigue is often accompanied by immune system mediated symptoms such as generalised flu-like malaise, tender lymph nodes, sore throats etc. Many patients also experience an escalation in other symptoms as well such as pain, headaches, brain fog, nausea, and sensory sensitivities.

Patients may not have recognised the delayed post-exertional pattern and may report a chaotic and fluctuating picture of better and worse days. Often what is happening is a 'Push and Crash' cycle whereby they push themselves to do more on a better day then feel more ill the following few days and are forced to reduce their activity levels due to the escalation in symptoms. Prompting patients to keep an activity/fatigue diary can help them to identify if this PEM pattern is present.

Additional symptoms

In addition to fatigue, patients with ME/CFS **will** have a number of other symptoms. It is important these symptoms are carefully evaluated to determine if further investigation is required to look for other possible causes of fatigue before attributing

them to a diagnosis of ME/CFS. It is also important to ascertain that the symptoms are new since the onset of the fatigue illness and are not pre-existing conditions.

Immune system:

- tender lymph nodes
- recurrent sore throat
- recurrent flu-like symptoms or malaise
- new sensitivities to food, medications and/or chemicals

Neurological/cognitive:

- Poor concentration or “brain fog”
- Word finding and other language/communication difficulties
- Short-term memory problems
- Sensory hypersensitivity e.g., to noise and light

Autonomic Nervous System Dysfunction (Dysautonomia):

- Orthostatic Intolerance- symptoms which are worse in an upright position and improve with sitting/lying
- Dizziness/ feeling faint/ delayed postural hypotension
- Palpitations including Postural Tachycardia Syndrome (POTS)
- Urinary frequency/bladder dysfunction
- Nausea and irritable bowel symptoms
- Dyspnoea

Neuroendocrine:

- Difficulty regulating temperature
- Sweating episodes
- Intolerance of heat and/or cold

Sleep:

- Unrefreshing sleep
- Altered sleep rhythm – insomnia and/or hypersomnia

Pain:

- Headaches
- Muscles pains
- Joint pains

Mood:

- Anxiety
- Depression

NICE diagnostic criteria

There have been many different groups that have formulated diagnostic criteria to be used for diagnosing ME/CFS. It is important to recognise that criteria used for research purposes may differ to that used in a clinical setting.

In the UK the National Institute for Health and Care Excellence issued a new Guideline on ME/CFS in 2021 and it includes the following diagnostic criteria:

NICE Guideline on ME/CFS (2021)

When to suspect 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.

Diagnostic timescales

Time is an important diagnostic tool and if symptoms are progressive or rapidly changing that may indicate an underlying condition that requires further investigation and management. Post-viral fatigue may improve with time and eventually resolve. It can often take a long time before a confident diagnosis of ME/CFS can be made and that period of uncertainty can be very difficult for the person experiencing a wide array of debilitating symptoms with no apparent cause. It can therefore be helpful to recognise the symptoms early and consider having ME/CFS as a 'working diagnosis' while continuing to observe and investigate symptoms as appropriate. This will allow the patient to access appropriate advice on managing their symptoms which may be a protective factor in preventing deterioration.

NICE Guideline on ME/CFS

Suspect ME/CFS if:

- the person has had all of the persistent symptoms in box above 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.

Diagnose ME/CFS in children, young people and adults if:

- other causes of the symptoms have been confidently excluded and the symptoms in box above have persisted for over 3 months

It is important to recognise that the symptoms that occur in ME/CFS can also occur in many other illnesses. A diagnostic label of ME/CFS is only used when the symptoms cannot be attributed to another illness or condition.

Investigation

With a potential symptom list so long it is easy to feel overwhelmed at the potential differential diagnoses that need to be considered. Careful history taking about each symptom can often be the only investigation required.

All children in whom you are considering a diagnosis of ME/CFS should be referred to a Paediatrician.

The minimum tests required when investigating a patient with suspected ME/CFS are:

FBC
U&E
LFT
TFT
CRP
Hba1c

Calcium
Phosphate
Ferritin (aim for >50 in adults)
Coeliac Screen
Creatine Kinase
Urinalysis for glucose, protein, blood

Other tests which may be warranted:

ESR (especially >50ys to exclude myeloma)
B12
Folate

Vitamin D
9am cortisol
Serological tests for infection

In ME/CFS the above investigations are expected to all be normal. If any abnormalities show up, they require evaluation and appropriate investigation before making a diagnosis of ME/CFS.

Other investigations and referrals need to be considered based on the patient's presenting symptoms. When referring patients to secondary care it can be helpful to mention that you are considering a diagnosis of ME/CFS so investigations can be planned with this in mind.

It is also important to manage the patient's, and your own, expectations regarding what outcome you expect from referral and further investigation (e.g. to rule out a particular condition or to evaluate one specific aspect of their symptoms or abnormal results but not necessarily looking for an overall explanation or cure).

For people with existing ME/CFS it is important to remain vigilant for other conditions which may develop. If there is a significant change in the severity, nature or pattern of symptoms consider revisiting investigations to look for other causes before presuming it is due to their ME/CFS illness.

Common alternative or contributing conditions to consider looking for:

- ➔ Sleep apnoea
- ➔ Primary neurological sleep disorders e.g. Hypersomnia (sleepiness rather than fatigue)
- ➔ Rheumatological disease e.g. psoriatic arthropathy, Rheumatoid Arthritis, Lupus
- ➔ Hypermobility Spectrum Disorder (consider this in patients with symptomatic joint hypermobility and multiple additional symptoms)
- ➔ Mental health conditions e.g. primary anxiety/depression, OCD, PTSD, eating disorders, dysthymia.
- ➔ Neurodiversity e.g. Autism Spectrum Disorder, ADHD
- ➔ Medication side effects e.g. opiates
- ➔ Primary endocrine disorders e.g. Suboptimally treated Thyroid disorders, Pituitary dysfunction following head injury

With regard to mood symptoms, it is important to exclude psychiatric disorders that can result in significant fatigue, as the treatment of these conditions would be different.

ME/CFS and depression are different conditions, but it is common for them to coexist. The precipitant to ME/CFS may also have triggered a depressive illness, or depression may be secondary to the chronic nature of the condition, such as adjustment difficulties, loss of job, loss of status, strain on relationships, etc. Some patients also develop significant anxiety symptoms secondary to or alongside ME/CFS.

Pointers to a depressive illness are anhedonia, diurnal mood variation unrelated to activity, loss of motivation, changes in appetite, low libido, low self-esteem, irritability, hopelessness, and suicidal ideation. It is also worth bearing in mind that patients with co-existing depression which is only partially treated may also continue to experience fatigue.

Anxiety disorder is a common comorbidity in patients with ME/CFS, but also can be a differential diagnosis for the symptoms. Severe anxiety states including PTSD can have a significant negative effect on ME/CFS symptoms and hence it is essential that appropriate treatment is sought for these problems through mental health services.

Referral

Children and young people: all children and young people in whom you suspect a diagnosis of ME/CFS should be referred to a paediatrician. If available, once a diagnosis has been confirmed, they should be referred to a specialist ME/CFS service for support with management.

Adults: Most adults who are newly diagnosed with ME/CFS are likely to benefit from referral to a specialist service to support them with learning appropriate management strategies.

Provision of specialist ME/CFS services varies greatly across the UK and it is recognised there are some areas that have no access to specialist ME/CFS services, especially services for children and young people or for people who have severe ME/CFS.

The [BACME website](#) holds information about specialist ME/CFS services and you can use our [services map](#) to locate your nearest service.

You could also consider contacting your local commissioning organisation to ask what specialist ME/CFS service provision is available in your area.

ME/CFS service structure

NHS specialist services vary greatly in terms of size and the clinical backgrounds of the staff working in them. Not all services have doctors on their team and it is likely that services without medical input will require the diagnostic responsibility to remain with primary care.

Some services will be able to arrange appropriate investigations, however many services do not have access to investigations or prescribing so these will need to be done via primary care. Services may be able to provide guidance to support management in primary care.

Blood tests

The majority of specialist services request that the basic fatigue screen set of blood tests have been conducted in the 6 months prior to referral.

It is best to check the blood test requirements of your local service. The usual minimum tests required are:

FBC
U&E
LFT
TFT
CRP
Hba1c

Calcium
Phosphate
Ferritin (aim for >50 in adults)
Coeliac Screen
Creatine Kinase
Urinalysis for glucose, protein, blood

In ME/CFS these tests are expected to be normal, so it is important any abnormalities are appropriately investigated and treated prior to confirming a diagnosis of ME/CFS and before referring on to a therapy programme.

Access Issues

Many services are now able to offer remote consultations via video call or telephone. This can be of benefit to people with significant fatigue where the demand of travelling to the service and engaging in the appointment could result in an escalation in their symptoms. Some people with ME/CFS find face to face consultations preferable and most services are able to offer a choice.

Not many services offer home visiting to people who have severe or very severe ME/CFS but they may be able to provide guidance to local services that could provide support such as community therapy teams. It is worthwhile contacting your local service for guidance on what they can provide.

Ongoing care in Primary care following referral

ME/CFS is a complex multisystem condition and any additional co-morbidities will also play a role in the ME/CFS symptom patterns and severity.

Symptom management and addressing other co-morbidities will be best done through primary care even after a referral to a secondary care ME/CFS service has been made.

Maintaining continuity of care will improve the quality of care delivered. Medical consultations are exhausting for people with ME/CFS so having to explain their condition or problems repeatedly to new people is a significant barrier to them accessing care.

The majority of patients will still be managing ME/CFS symptoms when they are discharged from a specialist service and ongoing support from primary care staff will be invaluable including offering annual reviews in line with other long-term conditions.

Management

In primary care a consistent approach from an interested and supportive GP will be an invaluable part of the management plan.

The process of making a confident diagnosis of ME/CFS can take a long time especially if referrals and further investigations are required. This period of uncertainty is a very difficult time for the patient especially if they are off work or school or unable to manage their usual activities. During this time, they are vulnerable to the conflicting beliefs that exist about this condition and this can lead to them developing unhelpful behaviours and thoughts towards themselves, the illness and professionals involved in their care. Equally other people in their lives can have unhelpful attitudes towards their illness. Continuity of care from a supportive GP can help mitigate against some of these difficulties. This will make it easier for the patient to access appropriate help and be better prepared to put in place the behavioural strategies that are needed to manage this condition.

Because there are multiple dynamic systems contributing to the symptoms of ME/CFS there is not a direct treatment or strategy that will fix the problems. However, it is possible to identify factors which aggravate dysregulation and strategies which can help improve stability. The aim of management is to recognise which demands are causing symptom fluctuations and aim to manage those demands in a more controlled way along with looking at general factors like nutrition and sleep quality which will provide an environment for the body where healing and stability can occur. The pattern of symptoms and the body's response to different demands can vary over time so it will require a degree of experimentation to find strategies that help support recovery.

Education about ME/CFS

Patients will need to develop an understanding of their condition to learn how to manage it. Diary keeping can be a useful tool and can be applied to many symptoms including fatigue, sleep, diet etc.

Explaining how symptoms may arise can also help patients to understand their condition better and validate their experiences. Immune system dysfunction can give rise to symptoms of malaise, pain and fatigue. Autonomic System dysfunction can give rise to orthostatic or postural symptoms including fatigue, pain and palpitations. Autonomic problems have been found to be associated with reduced cerebral blood flow which is likely to be involved in the cognitive symptoms and brain fog that is experienced. The Autonomic System is also involved in regulating digestive processes including gut motility and blood sugar regulation so this can contribute to the gastrointestinal symptoms experienced and the symptom fluctuations that can occur in response to eating and fasting. Disruption to the normal sleep cycle can mean sleep is no longer restorative and hence why recovery after activity is compromised.

Demands

Understanding the different physiological systems involved can help with recognising the wide array of demands on the body which can influence symptoms patterns.

There are everyday internal demands including physical activity, hunger, thirst, sleep, thinking, feeling, stress etc. There can be additional internal demands due to infection, illness, injury, or disease. There are also external demands which our bodies must respond to including the effect of gravity on the body, environmental temperature change and changes in air quality.

Activity vs exercise

It is important for patients and clinicians to recognise that all types of activity are relevant when considering fatigue symptoms and management. Physical exercise is only one aspect of activity and cognitive activity, emotional activity and social activities all need to be considered.

Pacing

Pacing is the basic principle that underpins ME/CFS management.

Complete rest will not make ME/CFS better – although patients will need to rest when their symptoms are severe, complete rest in the long-term will result in deconditioning and escalation of fatigue. Spending long periods of time lying down will result in the Autonomic Nervous System responses becoming more dysregulated in response to the gravity demand of being upright.

Equally, increasing exercise or other activities will not make ME/CFS better and can often trigger episodes of Post-Exertional Malaise which may lead to further dysregulation and cause an escalation in a patient's symptoms which can sometimes persist long-term.

Finding a careful balance between rest and activity throughout the day, every day is the basis of pacing. The concept of rest may need to be clarified to ensure patients are relaxing and resting both mind and body.

Patients will need encouragement to learn to rest frequently throughout the day, a helpful phrase is '**Rest before symptoms increase**'. When planning activities, it is helpful to break tasks down into short sections interspersed with rest periods, and change between different types of activity. For example: do 10 minutes of housework followed by 10 minutes rest followed by 10 minutes of reading followed by a further rest period.

How pacing is done will depend on each individual patients' symptoms, their personal demands (e.g., work, school, care roles) and also the stage of their illness. In the early stages of the illness the primary aim is to achieve stability so the same level of activity can be performed every day without making symptoms worse. Once this has been achieved some patients can start to carefully grade up their activity.

Grading up is done slowly over a long period of time with monitoring to ensure it is not causing any escalation in symptoms.

Some patients can also experience relapses and it is important they learn to recognise them and have strategies in place to manage them.

Symptom management

It can be helpful to adopt a problem-solving approach to the multiple symptoms a patient may be struggling with. Consider asking them to prioritise which symptoms are causing the most distress or interference in daily life and see what creative solutions you can develop together.

Medication can be helpful for some of the symptoms that occur in ME/CFS. However, it is important that both the doctor and patient have realistic expectations about what the medication is aimed at rather than having the unrealistic expectation that one pill will cure all the problems.

Some patients with ME/CFS develop intolerance to multiple medications. It is therefore prudent to start any new treatment at the lowest possible dose and titrate up very slowly. Liquid medications are ideal as they often have less excipients and allow for very small dose changes. '**Start low and go slow**'. Make sure patients know to return for review so dose adjustments can be made and medication that is ineffective is stopped.

There are no unusual or specific medications that are recommended for ME/CFS; most of the prescribing will be with common agents such as SSRIs for mood symptoms, amitriptyline /simple analgesics for pain. Opiates are not recommended for chronic pain conditions and can contribute to fatigue issues so are not recommended for the management of ME/CFS related pain.

BACME have produced a [symptom management guide](https://www.bacme.info/symptom-management-guide) available from the BACME website www.bacme.info.

Dysautonomia symptoms

Most patients with ME/CFS will have a degree of altered Autonomic Nervous System function. There are several behavioural strategies that can help support more stable Autonomic function sometimes referred to as 'orthostatic tolerance' measures:

- **Fluid** Research has shown that people with autonomic dysfunction do not retain fluid in their circulation very well, so drinks need to be taken every 2-3 hours throughout the day aiming for 2-2.5l per day. Having 500ml of fluid on rising in the morning and prior to doing an activity can help reduce the risk of a drop in Blood Pressure.
- **Salt** If there is no evidence of high blood pressure then increasing salt intake can also help -aiming for around 6g/day (approx. 1.5teaspoons).
- **Electrolytes** Having electrolyte-based drinks can also help retain fluid in circulation better.

- **Compression** Some people find wearing long compression stockings (i.e., thigh or waist length) or tight clothing and/or underwear, can reduce the severity of their orthostatic symptoms by reducing blood pooling.
- **Bed elevation** Some people find that elevating the head of the bed by 4-6 inches is of help. This is because it alters the circulation to the kidney resulting in a reduction in the amount of urine produced overnight and reduces salt excretion. This can help sleep by reducing the number of times needed to get up to empty the bladder and because it reduces the level of morning dehydration. It may take a few weeks for the benefit to be apparent and the strategy should be abandoned if it appears to be causing more disrupted sleep or any other escalation in symptoms.
- **Eating patterns** Eating small amounts of food regularly or 'grazing' and avoiding eating sugary foods on their own can help to stabilise blood sugar levels. Reducing or eliminating caffeine is worth considering. Lying down after eating can help people who experience an escalation in fatigue after eating.
- **Lying/Sitting/Standing** Because of the problems with being upright, taking rest lying down will be beneficial when symptoms start to escalate. However, spending long periods of time lying flat can lead to the body being less able to tolerate the effects of gravity when upright so it is important to find a careful balance between taking planned, structured rest periods laid down and then having other rest periods sat with your feet on the floor and then short periods of time standing or walking followed by a further rest period.
- **Breathing exercises** Doing deep, slow diaphragmatic breathing regularly can help activate the parasympathetic nervous system and hence can help to reduce the symptoms that come about due to exaggerated sympathetic nervous system activity. Doing regular breathing exercises over time can gradually improve sleep quality which in turn may help fatigue issues. One option is to spend 10 minutes twice a day doing deep slow breathing, breathing through the nose for 4 seconds while breathing in and 6 seconds breathing out. There are various apps which can support doing relaxation breathing exercises.

Exercise

Deconditioning is not the cause of the symptoms of ME/CFS, but unfortunately the loss of muscle bulk and fitness which can happen because of the fatigue will aggravate the situation. Exercise needs to be done extremely carefully considering the principles of pacing i.e. stopping before the point of exhaustion and exercising at a level that does not provoke an escalation in symptoms. Research has shown some people with ME/CFS have altered aerobic pathways which means pushing to do more aerobic exercise can be counterproductive. Exercising while lying or sitting down can sometimes be more tolerable and trying things like gentle muscle strength work using resistance bands can be a good starting point. It is important that the starting point is a very small amount of activity that can be sustained every day or most days without causing any escalation in symptoms.

Nutrition

There is insufficient evidence to recommend any specific diet for the management of ME/CFS. General principles are to ensure good nutritional intake and having foods which have anti-inflammatory effects such as brightly coloured vegetables and fruit which may be of benefit along with minimising highly processed foods. Having a variety of different foods can also help support a diverse gut microbiome. Patients may struggle to maintain a good diet due to the fatigue limiting their ability to shop, prepare and cook meals or because of the severity of their gastrointestinal symptoms. It can be helpful to look for easy options such as tinned and frozen vegetables and freezing portions of meals, along with asking family and friends to help by preparing extra portions of their meals.

Patients who have significant bowel symptoms may try dietary alterations to see if this improves their symptoms. If a patient is excluding significant food groups from their diet for a long period of time, then it would be wise to refer them for dietician assessment.

Mood

If a patient has significant mood or anxiety problems, it is important to treat them and depending on the severity, consider referral to appropriate primary or secondary mental health services.

Support at school or education establishment

Children and Young people with ME/CFS will need information provided to education staff regarding their illness and what adjustments need to be made to accommodate for it. There are many aspects of school that can aggravate fatigue symptoms. Some examples are: the effort of getting to and from school, the noise and demands of being around lots of people, the cognitive demand of listening and learning, the expectation to work and behave as normal, worries about falling behind, failing exams or missing important lessons or projects, engaging in social activities.

The adjustments required will depend on the individual person's situation and the severity of their ME/CFS symptoms. Common adjustments recommended are identifying times and places to take quiet rest breaks preferably lying down, allowing the young person to take a break when they recognise their symptoms escalating, reducing work commitments and reducing the amount of time spent in school e.g. later start time, providing work to complete at a slower pace at home, not participating in sports or PE if it causes an increase in symptoms, having access to drinks and snacks at all times during the day, using a laptop if less fatiguing than writing. Similar adjustments can be made when young people are sitting exams such as paced out exams i.e. avoid two a day or on consecutive days, extra time for an exam and time for rest breaks, quieter rooms with access to be able to lie down if required, to be able to take food and drink into the exam setting.

Children and young people who are severely affected by ME/CFS will not be able to attend school and may have very limited capacity to engage in educational activities at home. Multidisciplinary teams should be involved in their care and advise on what options are appropriate to support the young person to access education if they are able to.

Support at work

When ME/CFS symptoms are having a significant impact on a person's level of function they will need to be signed off sick from work. Many people who develop ME/CFS are unable to pursue their career plans as a result of their illness and a significant number of people with ME/CFS will be unable to work on a long-term basis. However, if appropriate adjustments are made, some people with ME/CFS will be able to continue working or return to work once their condition has stabilised. It will be beneficial for them to have support and guidance on how to manage their ME/CFS in the workplace and Occupational Health staff should be involved.

ME/CFS is a long-term, fluctuating condition so there may be times when someone with ME/CFS can sustain work and other times when they can't. Other illnesses such as an infection can be a common trigger for an escalation in ME/CFS symptoms and recovery from infection is often much slower so they may need longer off work than would normally be expected.

If someone with ME/CFS has been off work, it will be beneficial for them to have a phased return to work, and this may need to be done very slowly and gradually while monitoring how their ME/CFS symptoms are responding to the increased level of demand.

If someone with ME/CFS is well enough to be at work, then they will benefit from adaptations that help support the management of their condition.

Work adaptations could include: flexible working such as the option to work from home and working flexible hours, opportunities to take regular breaks throughout the working day including taking short naps if required, having a quiet undisturbed place to rest preferably with the option to lie down or elevate their legs, reduction in workload, consideration of environmental demands such as lighting and noise, consideration of travel demands and physical demands in the workplace such as stairs or prolonged standing, access to drinks and snacks throughout the day. Switching between different types of tasks can also be helpful e.g. avoiding having consecutive meetings, switching between written work and telephone calls or face to face interactions.

Support for family members and carers

ME/CFS is an illness that can impact significantly on every aspect of a person's life. Consequently it also impacts on the lives of those around them. Primary care staff can play a vital role in educating and supporting the other people involved in the life of the person with ME/CFS.

Severe ME/CFS

ME/CFS is a dynamic condition with fluctuating symptoms on a day-to-day basis and over longer periods of time. The severity of the illness can vary greatly between different people and the severity can also vary over time.

There are some people with ME/CFS who become very severely affected and this will mean they are bed bound most or all the time. They often have severe sensory sensitivity so will struggle to tolerate normal levels of light, noise and movement and will need adjustments made to accommodate for this. They will be dependent on care being provided by family, friends, or care agencies. Both children and adults can develop severe or very severe ME/CFS.

Many people with severe ME/CFS have other co-morbidities which can be difficult to manage in the context of them also having severe fatigue to the extent they will struggle to engage in conversations and may have significant medication sensitivities.

Some people with severe ME/CFS can have significant gastrointestinal problems which can lead to compromised nutritional intake. It is important to be alert to the risks of malnutrition even in people with normal or high BMI.

Support should be sought from relevant specialists to ensure people with severe ME/CFS have access to high quality health care. However, this can often be difficult to access due to their inability to attend hospital appointments or even engage in verbal consultations. It is likely that a range of different professionals would need to be involved and hospital admission should be considered if there are serious nutritional difficulties which cannot be managed safely at home. It may be helpful for primary care staff to liaise with secondary care staff through advice and guidance requests or direct contact if the person with ME/CFS is not well enough to engage in or attend a consultation themselves.

If a person with severe ME/CFS requires hospital admission it can be helpful to provide information to the hospital staff regarding their care requirements so adaptations can be made where possible in the hospital setting e.g., to minimise exposure to noise and light where possible.

Prognosis

There is a lot of active research in the field of ME/CFS, but the reality is it currently remains a difficult condition to research due to the lack of consistent biological markers of illness. Consequently, data on recovery is limited.

Some patients with ME/CFS do recover so it is important to adopt an optimistic approach to its management. However, the reality for many patients is that it affects their lives for many years, and some do not make a good recovery, so it is helpful to adopt a Long-Term Condition management type approach.

It has been suggested that approximately 5-20% of people with ME/CFS may eventually make a full recovery, but this may take years and involve making significant life changes. Around 60% of people with ME/CFS may see improvement in symptoms and/or level of function over time but will need to continue to manage their condition. Approximately 20% of people with ME/CFS continue with long term debilitating symptoms. A proportion of patients will recover sufficiently to a good level of occupational / social function but may experience relapses or setbacks triggered by a number of factors such as viral or bacterial infections or other illnesses and significant life stresses.

Prognosis may be different for children and adults and it is generally accepted that children are more likely to see improvement or recovery over time.

It can be helpful to reflect with patients about what recovery may look like. For some patients, the stressful or busy lifestyle they were leading before becoming ill may have contributed to their symptoms once they became unwell. Consequently, recovery would not be aimed at returning to that same lifestyle but more a moving on to a different way of managing demands.

Accessing Primary Care

Attending healthcare appointments can be a big energy demand for people with ME/CFS and can often trigger an episode of Post-Exertional Malaise.

This adds to the difficulties people with ME/CFS have accessing help, support and appropriate healthcare for their ME/CFS and also any other health conditions they have. Continuity of care should be provided whenever possible.

Mode of contact

Primary care staff can support people with ME/CFS to access healthcare by having a flexible approach particularly regarding what mode of contact is used. Some people with ME/CFS will find telephone or video calls beneficial as it removes the demand of travel and waiting etc. Some people may find it easier to use written communication such as e-consults. However some people with ME/CFS find it more energy demanding to communicate via these methods so may prefer to attend in person but may find the environment of the waiting room problematic. People with severe fatigue may need to nominate someone else to speak on their behalf.

ME/CFS is a fluctuating condition which means patients may sometimes need to cancel appointments at short notice or may not attend as a result of their fatigue escalating to the extent they feel unable to attend the consultation at that time. It is important this is not dealt with through a disciplinary approach as that can cause a breakdown in trust and the therapeutic relationship and it will create further barriers to the person with ME/CFS being able to access healthcare.

It is worth finding out if there is a time of day that the person with ME/CFS is more likely to be able to manage a consultation. Someone with significant fatigue, hypersomnolence or very disrupted sleep cycles may struggle to access early morning appointments.

At the surgery

Providing a quiet place to wait, possibly with access to a bed to lie on while waiting may be a useful strategy for some people. This will mean they are not as fatigued when entering the consulting room and will be better able to engage in the consultation. The cognitive demand of engaging in a consultation could result in their fatigue escalating and this can affect their concentration, short term memory and mood. Providing written notes for what has been agreed may help some people.

Educating primary care staff about a patient's need to wear dark glasses and/or ear defenders to help reduce the demand of sensory stimulus can help to reduce the unhelpful judgements and comments that may sometimes happen.

Longer appointments may be required, especially at the diagnostic stage.

Home Visits

Although the demand on primary care time is high, it will be appropriate for some people with ME/CFS to be seen at home. It is possible that someone with moderate ME/CFS may have times when they can leave the house and that can lead to them not being classed as housebound and therefore judged as not eligible for home visits. However, as ME/CFS is a fluctuating condition it is important to respect the patient's report of how badly they are affected at the time they are trying to access care and the potential detrimental impact that the demand of attending the surgery will have on their symptoms.

Home visits can often provide very valuable insights into the home situation and may also provide contact with formal and informal carers which will all add to the quality of care being provided.

People with severe and very severe ME/CFS will need home visits and any staff attending will need to be aware of the impact of their visit as it is likely to trigger an escalation in ME/CFS symptoms. It is helpful to respect requests to minimise movement and noise for people who have severe sensory sensitivities and keeping visits brief or taking breaks during the consultation if longer or more challenging conversations are needed.

Try to visit at a mutually agreed time as the person with ME/CFS will have needed to organise their day to conserve enough energy to be able to engage in the consultation effectively. Some people may find it helpful to prepare written information in advance.

Primary Care Reviews

For the majority of people, ME/CFS is a long-term condition. It is an illness that impacts on every aspect of a person's life: education, work, family life, social life, hobbies, sport etc and it can have a significant impact on their quality of life.

It is important that ME/CFS is coded as a diagnosis on a person's primary care record.

In line with other long-term conditions, it is important to offer adults with ME/CFS an annual review as a minimum level of care. Children and young people with ME/CFS should be reviewed every 6 months as a minimum. It is worthwhile adding an ME/CFS annual review recall code onto their medical record.

The NICE Guideline on ME/CFS has further information on primary care reviews and these are the things that should be covered in addition to any other factors relevant to that individual:

- their condition, including any changes in their illness and the impact of this
- symptoms, including whether they have experienced new symptoms
- self-management – ask about their energy management plan and (if relevant) their physical activity or exercise programme
- who is helping them and how they provide support
- psychological, emotional and social wellbeing
- any future plans – ask if the person is considering any changes or if they have any challenges ahead.

If a child or young person with ME/CFS is no longer under the care of a Paediatrician, then a review should be conducted in Primary Care but it may be appropriate to seek guidance from a specialist service. When reviewing children and young people with ME/CFS you will involve their parents or other family members but always endeavour to make sure the voice of the child or young person is heard, while also respecting the severity of their condition and how that may impact on their ability to communicate. Additional factors to consider regarding the review of children and young people:

- their developmental stage
- transitions, such as changing schools or exams
- the severity and complexity of symptoms
- the effectiveness of any symptom management.

Useful Website Links

NICE Guideline for ME/CFS: www.nice.org.uk/guidance/ng206

NICE guidance on ME/CFS for patients/public:
www.nice.org.uk/guidance/ng206/informationforpublic

BACME British Association of Clinicians in ME/CFS: www.bacme.info

Website has resources available to download and membership is available to UK based clinicians who have a role in providing care to people with ME/CFS

Guides available:

An introduction to Dysregulation in ME/CFS

Primary Care Guide

Symptom management Guide

Therapy Guide

Severe ME/CFS guide

Post-viral fatigue management (available in several different languages)

UK services map

Action for ME www.actionforme.org.uk/

provide helpful booklets on the condition, pacing, employment and have welfare rights advice and provide support for children and young people with ME/CFS

ME Association www.meassociation.org.uk/

links to local groups and telephone line for information and support

Dialogues for a neglected illness <https://www.dialogues-mecfs.co.uk/>

Website with lots of information about the condition and video on topics such as Post-Exertional Malaise

CFS/ME Research Collaborative 2020 conference presentations
<https://www.youtube.com/playlist?list=PLJV2oZMsotON2WJSXHBx-e09WUhkKdhCI>

British Dietetic Association <https://www.bda.uk.com/>

provides basic dietary advice on a wide range of subjects including a food fact leaflet for ME/CFS and various food intolerances/allergies.

Autonomic dysfunction

www.potsuk.org/ is a UK site specifically about Postural Tachycardia Syndrome.

www.dysautonomiainternational.org Large American charity providing information and advice for managing autonomic dysfunction

www.thedysautonomiaproject.org American website about dysautonomia conditions

Hypermobility

Hypermobility Syndromes Association: www.hypermobility.org

RCGP Ehlers Danlos Syndromes Toolkit (includes information about Mast Cell Activation Syndrome) : <https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/ehlers-danlos-syndromes-toolkit.aspx>

Mast Cell Activation Syndrome (MCAS)

Mast Cell Action <https://www.mastcellaction.org/>

Post-Viral Fatigue/Post-Covid management

Royal College of Occupational Therapists post-viral fatigue guide for patients from www.rcot.co.uk: <https://www.rcot.co.uk/how-manage-post-viral-fatigue-after-covid-19-0>

BACME Post-Viral Fatigue management guideline available from BACME website in several different languages: [Post-Viral Fatigue - A Guide to Management](#)

Covid 19 Post-hospital rehabilitation guideline from Lancashire Teaching hospital: <https://covidpatientsupport.lthtr.nhs.uk/#/>

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