Condition Insight Report (CIR)

Myalgic Encephalomyelitis /Chronic Fatigue Syndrome (ME/CFS)

Version 1.3
Updated 01.12.23
Created in collaboration with CBME and ME/CFS Friendship Group Gloucestershire on behalf of ME local network

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Presenting Symptoms

Symptoms can include but are not limited to:

- Dysfunction/dysregulation of the central and autonomic nervous systems, neuroendocrine systems, including the Hypothalamic Pituitary Adrenal (HPA) axis, immune system, dysfunction of cellular energy metabolism and ion transport, cardio-vascular including orthostatic intolerance (OI) and postural orthostatic tachycardia syndrome (POTS), as well as genetic abnormalities and problems with the digestive system
- Pain, throughout their body, which is often unrelenting and unremitting
- Overwhelming symptom onset following any physical, cognitive, emotional or social activity, which becomes more profound with its characteristic delayed onset, and exacerbation of symptoms with prolonged recovery period
- Impaired cognitive functions, resulting in impairment of concentration, calculation difficulties; memory disturbance; spatial disorientation; difficulty with word retrieval and processing information and categorizing.
- Flu-like symptoms
- Post Exertional Neuroimmune Exhaustion (PENE) . Also known as Post Exertional Malaise (PEM) as per NICE NG206 or Post Exertional Symptom Exacerbation (PESE). PENE follows either physical or cognitive activity, and malaise, fatigue, pain and other symptoms are exacerbated and worsen. There is the characteristic delayed onset and a pathologically slow recovery period
- Headaches, muscle weakness (without deconditioning), cardio-vascular, immune, sleep dysfunction and unrefreshing sleep.
- Intolerances and heightened sensitivities e.g. to medication, anaesthetics, light, sound, heat/cold, food

Overview

What is the condition usually called / any abbreviations used?

Myalgic Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS) and ME/CFS

ME/CFS is now the recommended term, as used in the NICE Guideline. The term ‘chronic fatigue syndrome’ is outdated, is associated with the now-discredited psychogenic theory of the condition and is considered by the ME patient community to be stigmatising.

Brief overview of the condition

ME/CFS is classified by WHO as a neurological condition (ICD10 G93.3) and this classification is recognised by the Department of Health.

ME/CFS was included in the National Service Framework for Long Term Neurological Conditions. ME/CFS has a SNOMED-CT Concept ID code of 52702003 denoting it as a disease of the nervous system.

Evidence now suggests that ME/CFS has a prevalence of at least 0.2-0.4% of the population. The estimated figure of 250,000 has been in use for over 11 years of which 25% of people with ME/CFS are severely affected.

ME and CFS affects people of all ages, including children and young people, all of whom can become severely, or very severely affected.

There is no known cure, treatment, or specific diagnostic test for ME/CFS. Diagnosis is made through taking a detailed history, exclusionary tests and use of diagnostic criteria i.e. ME International Consensus Criteria (2011) for ME/CFS.

Some people with ME/CFS are sensitive to, or intolerant of, medications and are unable to take them e.g., for pain management or antidepressants for co-morbidities. Please be aware that absence of medication is not evidence of absence of a co-morbid condition.

What is the generally preferred term for someone with this condition?

A person with ME/CFS.

Watch a range of **short films of a lived experience of ME/CFS HERE**.

Fluctuations

As with many long-term conditions, people with ME/CFS experience different levels of severity, from mild to moderate, severe and very severe. All people with ME experience a multi-system, multi-organ illness, with little respite from the multitude of symptoms, and although for some it is a fluctuating condition, for others it can require 24/7 care and assistance with all their personal needs.

All severity levels are prone to prolonged relapses.

Think about exploring things like:

- **How has the condition been over the past 12 months?**

What changes have they seen, over what period of time did they experience any deterioration, what has this meant for their functional ability now compared to previous? Have their usable hours in day changed? Is their functional ability impact by infections or periods of stress?

- **What level of pain/fatigue?**

Can they quantify this, do they use a scale and can they describe it? Can they share what a 'typical' day might be for them? What are their triggers? Whilst exertion is a main trigger, what amount of exertion is enough to cause further limitation? How are triggers managed?

- **For any impaired cognitive function**

How consistent is their presentation, how do they manage their memory deterioration, are they orientated, can they plan tasks as they used to?

- **The ability to do an activity**

Explore the cumulative effect of all Daily Living Activities taken over the course of one day and the likely impact of that activity over the following days/weeks. Living with an energy limiting chronic illness means rationing scarce units of energy to get through each day.

Also consider the fact that the impact of multiple health conditions is cumulative - they do not exist within a person in isolation.

Reliability

What specific areas should be covered to ensure a complete, reflective report?

SAFETY

Do they have any symptoms which could cause a safety consideration?

Safety considerations result from physical and cognitive symptoms. Cover how any risks are mitigated and if there is a history of incidents within activities 1, 2, 3, 4, and 12 to ensure you have addressed the needs of the individual claimant

TIMELY

For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?

People with ME/CFS may have impaired neurocognitive function. They will experience difficulty with concentration, or in processing information, which will become more profound, as will their short-term memory. Tasks which require exertion physically and even cognitively are likely to take longer, so it is critical this is fully explored.

What mitigation strategies are already employed by the claimant? Use of timers/diary /calendar/clock/notes on a mobile phone are often excessive.

ACCEPTABLE STANDARD

How have they adapted to completing tasks over time – is this different to what might be considered 'normal'?

Exploring **HOW** they complete the task in depth can help to draw out any compensation strategies which can then be explored further.

Exploring the extent of symptoms during an activity and how they are impacted after will help you to consider if whether this is acceptable.

If claimant has no one to help, standards will have to drop to "managing as best they can", not necessarily at an 'acceptable standard'.

REPEATEDLY

Are they able to repeat a task as often as required? Is this the same every day?

Due to fluctuation of the condition for the claimant, sometimes hour to hour, it may prove difficult to ascertain the level of functionality of the claimant for more than 50% of the time, and what they are able to achieve reliably, therefore more expansive questions may be needed about ability/functionality, along with talking to the carer, to ascertain overall impact.

Functional ability scale in ME/CFS

This tool is used to help people with ME/CFS describe and measure how much they can do. Please note that people's symptoms may vary day to day and every individual's needs are different so each case needs to be assessed on it's own merit.

100% FULLY RECOVERED
No symptoms, even following physical or mental activity.

90% MILDLY AFFECTED
No symptoms at rest. Mild symptoms following physical or mental activity - tire easily. Study/work full time with some difficulty.

80% MILDY AFFECTED
Mild symptoms at rest, worsened to moderate by physical or mental activity. Full time study at school/college is difficult, as is full-time work, especially if it is a crowded, noisy or busy environment.

70% MODERATELY AFFECTED
Mild symptoms at rest, worsened to severe by physical or mental activity. Daily activity limited. Part time study at school/college is very tiring. Part time work may be possible. With careful pacing of activities and rest periods, you may discover windows of time during the day when you feel significantly better.

60% MODERATELY AFFECTED
Mild to moderate symptoms at rest. Increasing symptoms following physical or mental activity. Daily activity very limited. Study with others or work outside the home difficult unless additional support is available (such as use of a wheelchair/quiet room for a rest period). Short (I-2 hours) daily home study/work may be possible on good days.

50% MODERATE TO SEVERELY AFFECTED
Moderate symptoms at rest. Increasing symptoms following physical or mental activity. Midday rest may still be needed. Simple, short (1hr) home study/home activity possible, when alternated with quiet, non-active social life. Concentration is limited. Not confined to the house but may be unable to walk much beyond 100-200m without support.

40% MODERATE TO SEVERELY AFFECTED
Moderate to severe symptoms following any activity. Care must be taken not to overdo anything at this stage. Unable to walk much more than 50-I00m, usually requiring aids such as walking stick/crutches. 3 or 4 regular rest periods are needed during the day. Only one 'large' activity possible per day – eg. friend dropping by, or doctor's visit.

30% SEVERELY AFFECTED
Moderate to severe symptoms at rest. Severe symptoms following any physical or mental activity. Usually confined to the house but may occasionally take a quiet wheelchair ride or very short, gentle walk in the fresh air. Most of the day resting. Very small tasks possible but mental concentration poor.

20% SEVERELY AFFECTED
Fairly severe symptoms at rest. Weakness in hands, arms or legs may be restricting movement. Unable to leave the house except very rarely. Confined to bed most of the day but able to sit in a chair for a few, short periods. Unable to concentrate for more than one hour a day but can read for about five to 10 minutes at a time.

10% VERY SEVERELY AFFECTED
Severe symptoms following any activity. Weakness and pain in arms or legs. In bed most of the time. No travel outside the house.

0% VERY SEVERELY AFFECTED
Severe symptoms on a continuous basis. In bed feeling extremely ill even with permanent rest. Severe dizziness makes it impossible to be propped up in bed for longer than a few minutes. Light and noise are very painful to the eyes and ears. Severe pain almost anywhere in the body. Unable to care for self at all. Nausea and severe fatigue make eating extremely difficult. Liquid based food preferred.

Sensitivities

What areas might they find difficult to mention or perhaps understate the impact of?

- Due to misinformation given to many HPs over the years about ME/CFS, patients have often experienced prejudice and assumptions about, not only their condition, but themselves as people for having the condition. As a result they may find it difficult to talk about their condition at all depending on the presentation of the assessor.
- People with ME/CFS may have rested for many days to enable them to do the assessment, whether they are able to attend a centre, or are having a home visit, and may experience an exacerbation of symptoms for many days/weeks following assessment.
- You should remember that many claimants diagnosed with this condition have made substantial adaptations to their lives and living environment and consequently feel passionate about this being explored appropriately during the assessment.
- Be aware of signs of deterioration during the assessment. Loss of words, stumbling over words and asking their carer to assist are all signs that their PENE has started. This will only worsen as the assessment proceeds, impacting greatly on recovery times.

Customer Care

How is it best to ask about any sensitive topics and what are the common courtesies?

In general

- Speak clearly, and if necessary more slowly, in a kind, calm, reassuring manner, and make eye contact
- All contact (in person, telephone or virtual) with the claimant requires the understanding that they will have a finite length of time that they will manage to concentrate fully on the questions or giving their responses. Hesitation, loss of words or the inability to verbalise are all signs of cognitive difficulties.
- Do not drop ‘Syndrome’ from Chronic Fatigue Syndrome (CFS) to use the term Chronic Fatigue (CF) as claimants may feel offended and that the assessor does not really understand their condition
    - – CFS has a neurological classification whereas CF is classified as a somatoform disorder
- Involve any companions as they can likely elucidate on the reality of what the claimant can actually achieve
- A warm and friendly welcome, and reassurance will hopefully make the experience less intimidating and more relaxed. Avoid wearing perfumes and aftershaves as some are sensitive to smells.
- Be clear you are going to assess how their condition impacts on their daily lives, not the condition itself. Try to avoid using the word “functional” in the assessment as this can have unfortunate connotations for people with ME/CFS. Please try to use an alternative word such as ‘practical’.
- Try and recognise, if possible, when the claimant is deteriorating and becoming more physically and cognitively distressed – ask if they want to stop, take a break etc.

During face to face interactions

- Ask whether there is anything you can do to support any heightened sensitivities. They will have pain and even light touch can be very painful; they may well have sensitivity to light and so will need blinds/ curtains drawn and artificial lights low; temperature dysregulation, some will find a room too hot, some too cold; have a heightened sensitivity to noise, so a soft low tone would be appreciated, and a quiet environment.
- Explaining where the disabled toilet is, and a rest area if available, and offering assistance generally is helpful. If the person says that they have ME, use that term throughout the assessment and report, if they state that they have CFS, again use that term throughout the assessment and on your forms.

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 1: Preparing food

The moderately affected will be restricted in their ability to prepare and cook a simple meal. The severely/very severely affected will be unable to prepare or cook a simple meal.

Some individuals may batch cook to manage their symptoms. Please consider if they would be able to repeat this activity on the majority of days.

Remember in PIP…

Consider how they manage this activity, rather than just **if** they can do it. How long does it take them to cook? Do they require regular breaks? Does this increase their symptoms? How do they feel after? How long does it take to recover? Are there any risks within the kitchen secondary to their ME?

Activity 2: Taking nutrition

People with ME/CFS may have problems eating; finding eating too exhausting, suffer from nausea, some may have reflux issues which affect swallowing, some may choke, or lose the ability to swallow, and may be tube fed.

Remember in PIP…

You need to have established the individual's ability to be nourished, either by cutting food into pieces, conveying it to the mouth and chewing and swallowing; or through the use of therapeutic sources. Spilling food, motivation to eat and risk of choking should be explored.

Activity 3: Managing therapy and monitoring a health condition

They may need assistance with managing medication for other conditions. This is particularly important for the severely/very severely affected who will require monitoring and supervision 24/7.

Please remember that absence of medication is not absence of condition. They also may not be able to tolerate certain medication or be at a very low dose.

Remember in PIP...

You must consider if there is therapy taking place within the home, do they require assistance with it and how long is this assistance for? Also, can they manage their own medication? Can they remember to take it and physically get it out of the packet to administer?

Functional Impact

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Activity 4: Washing and bathing

The severely/very severely affected will be unable to bathe themselves and will usually require assistance to wash their whole bodies, they will use aids and will have reduced the number of times they bathe. Sitting will cause them to feel unwell, and the experience will be exhausting, and could take days to recover from. Even with moderate ME/CFS gentle shower can cause great pain. Washing/bathing may be drastically reduced to months between washing hair due to the pain and exhaustion, or that they may only have a bath/ shower once or twice a week, or even less if an acute relapse has occurred. Those with moderate ME/CFS may need aids to wash and may also have reduced the amount they wash/bathe.

Remember in PIP…

Can they wash and bathe majority of days? Can they reach all areas of the body? How long does it take them? Do they sit down, if so why? Can they get in and out of an unadapted bath? Can they overcome restrictions with aids or do they require assistance? How do they feel after? Does it increase symptoms? What is their recovery time?

Activity 5: Managing toileting needs and incontinence

The moderately affected may have incontinence and require assistance with managing this. For the severely/very severely affected they will be unable to see to their toilet needs independently, requiring help and support.

Some may use a bedpan or commode by the bed, whilst others will try, with assistance, to make it to the toilet if close by, others may be catheterised or wear incontinence pads.

Remember in PIP…

Mobilising to the toilet is not considered within the scope of the activity. Do they have incontinence? Can they manage this themselves? Can they sit and stand from the toilet and clean themselves after?

Activity 6: Dressing and undressing

The moderately affected may require some assistance or aids, or may have adapted clothes for ease. For the severely/very severely affected they will require assistance with all dressing and undressing, and some may be unable to achieve anything on their own.

Clothes are often painful to wear so they will adapt their clothes.

Remember in PIP…

Sitting down is considered acceptable within the scope of the activity. Does this reduce their symptoms? How long does this activity take? How do they feel after? Can they dress their upper and lower body? Do they have grip and are they able to maintain this for the activity? Can they bend? Do they experience pain? Do they have aids or require assistance?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 7: Communicating verbally

When communicating, the claimant may struggle to understand a question or someone who speaks quite fast. As the conversation continues, the individual will find it increasingly difficult to communicate as they become more physically and cognitively fatigued. A classic situation will be when the claimant will be speaking and half way through a sentence they will suddenly go blank and not know what the next word is, or what they have just said, or what they were going to say or what the subject matter was at all. Even with prompting, they usually cannot recall and the carer then needs to complete what they were trying to say. The classic statement from anyone with ME/CFS in this situation is 'sorry ME/CFS brain'.

Remember in PIP...

A claimant must be able to both express **and** understand verbal information. Retention is not considered, however, they must be able to comprehend what is being said to them.

Activity 8: Reading and understanding signs and symbols

Consider any impact of their cognition changes and if any coping strategies are being used.

Remember in PIP…

That there are specific boundaries for what is considered basic and complex. Ensure to explore for specifics where a restriction is reported to determine if simple and/or complex criteria is met.

Activity 9: Engaging with others face to face

Some people with ME/CFS have associated mental health conditions and may find it difficult to engage socially and either avoid them or rely on others for support. Some may be isolated due to their condition which can impact on their mental health.

Remember in PIP…

Prompting can be considered as social support. Does the claimant have other conditions that may impact their ability to engage? If so, who can they engage with? How do they feel engaging with unfamiliar people? Who can support them to engage? If someone specific, why is this?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 10: Budgeting

Consider any impact of their cognition changes.

Remember in PIP…

A person needs to be able to make simple and complex budgeting decisions. How do they manage their bills? Can they plan for a future payment? Do they use reminders/diary/timers to assist? Can they manage their own food shopping?

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Activity 11: Planning and following a journey

Consider any impact of their cognition changes and some claimants with ME/CFS may have mental health conditions, in addition to their ME/CFS diagnosis Understand the cumulative impact that an impairment of concentration and calculation difficulties has in an energy limiting condition.

Every action taken on any day, whether large or small, causes Post Exertional Neuroimmune Exhaustion (PENE) and has a cumulative impact for the rest of that day, their sleep and possibly will affect the next few days (for people with moderate ME/CFS) or weeks and months (for individuals with severe or very severe ME). The condition is fluctuating and variable. What can be managed on one day, may not be possible on another, especially not consecutive days.

Remember in PIP…

Where there are associated conditions you must explore the 4 stages to a journey 1. Frequency and type of outings 2. before a journey 3. during a journey and 4. post a journey.
Any social anxiety and/or anxiety related to change? If so to what extent, how and when does this manifest, how it is managed, is it present on all journeys or just unfamiliar ones? Are there any cognitive changes which could affect their ability to plan and follow a route? How would they plan a route to get to an appointment at a specific time? How would they manage any changes that occurred?

Activity 12: Moving around

Mobility will be impaired for those who are moderately/severely affected, from being able to walk short distances, to those being bed/housebound and needing a wheelchair for any mobility. The impact of doing any physical activity will mean that they will be unlikely to be able to repeat the task,and may be unable to do so for many days after. Their condition can easily change not only from day to day, but from hour to hour, meaning if they feel a little better, they could get up for a while and maybe do a small task, an hour later they may be feeling so ill that they will be back in bed again. For the very severely affected, they will be bedbound and rarely leave their room.

Remember in PIP...

STAR is imperative, especially with conditions that may cause symptom increase. How far can they walk? How long does this take? What pace do they walk at? Can they repeat this? Is this at the same or a reduced pace? How many times could they repeat it? How long does it take to recover? Do they need an aid? Even with an aid can this be repeated to an acceptable standard?

Additional reading or other resources

EXTERNAL

- Myalgic Encephalomyelitis International Consensus Primer for Medical Practitioners (2012). This invaluable document can be downloaded from: www.hetalternatief.org/ICC%20primer%202012.pdf
- Which includes the International ME Consensus Criteria (2011): http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2796.2011.02428.x/pdf
- Canadian Consensus Guidelines - A Clinical Case Definition and Guidelines for Medical Practitioners (2003): http://sacfs.asn.au/download/consensus_overview_me_cfs.pdf
- For further information, see NHS Conditions and Treatments: https://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/
- https://www.unrest.film/watch
- Watch TED talk on ME https://www.youtube.com/watch?v=Fb3yp4uJhq0
- Voices from the Shadows (https://voicesfromtheshadowsfilm.co.uk/)
- The Tangled Story of ME/CFS

INTERNAL

- Desktop Aid – Activity 12, Activity 6, Fatigue

Version control

Version	Date	Signed off by	Comments
1.0	07.10.21	Dr Shah Faisal	New re-banded document
1.1	09.02.23	Rebecca Sparks & Dr Shah Faisal	Updated document. Changes made to functional activities
1.2	25.05.23	Rebecca Sparks and CBME	Amendments made to, customer care page, fluctuation statements regarding the condition and links added to external resources
1.3	02.01.24	Jade Mayfield, Dr Shah Faisal and ME/CFS Friendship Group	Updated document, amendments made to overview, customer care, fluctuations, STAR, functional impact and links to external resources. Functional ability scale added.