

Thank you for taking the time to complete the following Condition Insight Report. These reports are very helpful to the Atos Healthcare Health Professionals who conduct the assessments on behalf of the DWP. These insight reports allow them to refresh their knowledge and build upon their understanding of the conditions.

Overview of the health condition or disability

Please provide a short, high-level description of the health condition or disability. Specifically:

What is the condition usually called?

Myalgic Encephalomyelitis (ME)

Are there any alternate names? Please list these:

- Chronic Fatigue Syndrome (CFS)
- Post Viral Fatigue Syndrome (PVFS) this is a term that GPs may often use in the early stages of the illness

What is the generally preferred term when referring to someone with this condition?

Myalgic Encephalomyelitis (ME)

ME and CFS are classified by WHO as neurological conditions (ICD10 G93.3) and this classification is recognised by the Department of Health. ME and CFS were included in the National Service Framework for Long Term Neurological Conditions. ME and CFS have a clinical read code of F286, denoting them as diseases of the nervous system.

There are an estimated 250,000 people with ME or CFS, of which 25% 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 single cause of ME or CFS, although for many it may be a viral trigger, and for some the infection may persist. Some may have a sudden onset, where for others it may be a slow and gradual process, with no easily identifiable trigger. There is no known cure, treatment, or specific diagnostic test for ME or CFS. Diagnosis is made through taking a detailed history, exclusionary tests and use of diagnostic criteria ie ME International Consensus Criteria (2011) for ME, and Fukuda et al criteria (1994) for CFS.



Common areas of daily life where functional restriction occurs

What areas of daily life will a person with this particular health condition or disability find challenging?

All aspects of daily life may be affected for those living with ME and CFS, from needing help from their carers with personal needs, such as washing and toileting, monitoring their condition, and administering medication, to having their carers do shopping, prepare meals, washing, changing clothes, bedding etc. , dealing with any visitors, letters, phone calls, health professionals, DWP etc., mobility will be impaired for those who are moderately/severely affected, from being able to walk short distances/using aids or wheelchair, to those being bed/housebound and needing a wheelchair for any mobility. The impact of doing any physical and /or cognitive 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.

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Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

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Commonly reported variability in functional restrictions

Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

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

As with other long term conditions, for which there is no cure, fluctuation of ME or CFS is usually between the different levels of severity, and all are prone to prolonged relapses.

Prognosis is often poor, with those who have been severely affected for more than 5 years having about 2% prognosis of any appreciable improvement (CMO Report on ME/CFS 2002) Windows of ability to do a task, even a small one, can often be brief, and the person will then suffer the impact of the physical and cognitive effort needed.

What aspects of daily living can be worse and what might be constant?

ME and CFS are potentially severe, disabling, complex and chronic long term neurological conditions which become, for many, multi-system and multi-organ. Symptoms can be overwhelming, and therefore all aspects of daily life are usually affected.

Pain, for most, is unrelenting and unremitting, with analgesics often seeming ineffective. Pain is often widespread and migratory including muscle and/or multi-joint pain, as well as abdominal pain, with most finding the pain in their head, or headaches of a new type, pattern and severity having a large impact on them.

People with ME or CFS experience sleep which is dysfunctional, and unrefreshing. Some may want to sleep much of the time, often in early stage of the illness, whilst others, although tired, find sleep almost impossible, even with medication, and also may have sleep reversal, or a chaotic sleep pattern. Vivid dreams and restless legs are also often reported. Along with other symptoms this impacts not only on their daily lives and their ability to cope, but also that of the carer, who has to see to their every need, including cooking a main meal if they are hungry in the middle of the night, toileting etc.

Many have gastro-intestinal problems, so nutrition can be challenging for all those living with ME or CFS due to lack of appetite, nausea, food sensitivities and/or intolerances.

For all those with ME or CFS there is no cure for their condition, nor a therapy/ treatment suitable for all, however monitoring of their condition, 24/7, day and night, is vitally necessary, as is supervision.

They are likely to need assistance with medication, not just reminders. They also need careful monitoring due to hypersensitivity and intolerance to medication and treatment, which can make managing, not only their ME or CFS, more complicated, but also any co-morbid condition. If they are able to tolerate the medication/treatment, it is likely to be at a reduced level to the usual therapeutic dose/amount. This is particularly important for the severely/very severely affected who will require monitoring and supervision 24/7.

Common misconceptions about the health condition or disability

What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance?

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It must be remembered that ME and CFS are complex and debilitating illnesses with a multitude of symptoms. Some HPs erroneously think that the illness is all about fatigue. It is more than that although the low energy thresholds, Post Exertional Neuroimmune Exhaustion (PENE) experienced and delayed onset, resulting in an inability to repeat tasks are one of the characteristic symptoms of ME.

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How often would you be able to do the task?

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What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

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How is it best to ask about these areas?

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What kind of medical evidence is likely to best convey the impact of this health condition or disability on an individual?

There is currently, and historically, an overwhelming national inequality of care in the NHS for people with neurological ME or CFS, with the majority having little or no specialist/medical care, and often not having a GP who understands the condition, feels sufficiently knowledgeable to manage the condition, or is supportive. This also results in difficulty for claimants to provide supportive medical evidence.

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Due to the hypersensitivities and intolerances many experience as a result of their ME or CFS, co-morbid conditions may become much more difficult to manage and treat e.g. often cannot tolerate medications, or not at normal/therapeutic dosage and would have to be given these at a reduced level. If an operation is necessary this can cause difficulties as many have an intolerance of, or bad reaction to, anaesthetics.

Presenting symptoms

Please describe any common symptoms that an individual with this health condition or disability might exhibit when presenting at a face-to-face consultation.

ME and CFS are complex, chronic, disabling and individualistic neurological conditions, which are still very misunderstood by Health Professionals. There is no known cure, treatment, or specific diagnostic test for ME or CFS.

Many surveys of thousands of people with ME or CFS overwhelmingly show that a biomedical approach of symptom management, pacing, and on-going care by supportive and understanding HPs, is found to be most beneficial and helpful approach to living with, and managing, their ME or CFS.

Research has shown that people with ME or CFS experience dysfunction/dysregulation of the central and autonomic nervous systems, neuro-endocrine 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.



People with ME or CFS usually experience pain, throughout their body, which is often unrelenting and unremitting, along with overwhelming fatigue with any physical or cognitive activity, which becomes more profound with its characteristic delayed onset, and exacerbation of symptoms. This causes a profound impact on basic daily activities such as bathing themselves, preparing and/or eating a meal, mobility etc.

People with ME or CFS experience sleep which is dysfunctional, and unrefreshing. Some may want to sleep much of the time, often in early stage of the illness, whilst others, although tired, find sleep almost impossible, even with medication, and also may have sleep reversal. Vivid dreams and restless legs are also often reported. Along with other symptoms this impacts not only on their daily lives, but also on their ability to cope with an assessment.

They have impaired cognitive functions, resulting in impairment of concentration, calculation difficulties; memory disturbance; spatial disorientation; difficulty with word retrieval and processing information and categorizing.

A core symptom of ME and CFS, in addition to eg pain, and flu-like symptoms, is Post Exertional Neuroimmune Exhaustion (PENE). 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.

Normal fatigue, seen in healthy people, is proportional to the intensity and duration of activity, followed by a quick restoration of energy. For people with ME or CFS, PENE is characterized by a pathologically low threshold of physical or mental fatigability, exhorting pain, and an abnormal exacerbation of symptoms in response to exertion, followed by a prolonged recovery period.

The underlying pathophysiology of PENE involves a profound dysfunction of the regulatory control network within and between the nervous systems. This interacts with the immune and endocrine systems affecting virtually all body systems, cellular metabolism and ion transport. The dysfunctional activity/rest control system and loss of homeostasis result in impaired aerobic energy production and an inability to produce sufficient energy on demand.

The impact of PENE on the daily life of someone with ME or CFS, is an abnormally quick reaction to any activity or physical/mental exertion, leading to a prolonged adverse reaction on their symptoms. This post-exertional exhaustion and symptom flare can be immediate or delayed, and is not relieved by rest. There are measurable, objective, adverse responses to normal exertion, resulting in exhaustion, extreme weakness, exacerbation of symptoms, and a prolonged recovery period. Therefore a person may achieve a task or conversation etc for a shorter amount of time than normal, but will then, usually, be unable to repeat this task again later that day, the next day, or possibly in subsequent days.

All with ME will be affected by PENE/fatigue as a result of physical or cognitive activity, as well as multiple other symptoms which includes; pain (which can be unrelenting and unremitting), flu-like symptoms, dysfunction of central and autonomic nervous systems, cognitive dysfunction, headaches, muscle weakness (without deconditioning), cardio-vascular, immune and sleep dysfunction, and intolerances and sensitivities e.g. to medication, anaesthetics, light, sound, heat/cold, food.

For all those with ME or CFS there is no cure for their condition, nor a therapy/ treatment suitable for all, however monitoring of their condition is vitally necessary, as is supervision. They are likely to need assistance with medication, not just reminders. They also need careful monitoring due to hypersensitivity and intolerance to medication/treatment, which can make managing not only their ME or CFS more complicated, but also any co-morbid condition. If they are able to tolerate the medication/treatment, it is likely to be at a reduced level to the usual therapeutic dose/amount due to the intolerance/sensitivity. [REDACTED]

As with all people with long term conditions, people with ME or CFS can have pre-existing, or develop co-morbid conditions, which can add extra complexities to the impact on their daily lives, and must be taken into consideration.

Recommended communication approach to a claimant at a face-to-face consultation

What are the best communication approaches necessary to engage with someone with this health condition or disability?

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Etiquette and common courtesies

Please describe the general etiquette or any common courtesies that would make an individual feel more comfortable in a face-to-face consultation, either in a Consultation Centre or at home – e.g. when to offer assistance, advising on basic facilities such as accessible toilets.

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Additional information

Please provide any links to relevant information that we can reference for further reading:

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

BRAME Information and Symptoms of ME leaflet (2015)

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