



Impact Statement template resource Updated December 2025

You can use this template to communicate how ME impacts you and what adjustments you need to access the services and support you are entitled to.

How to use this template

Read it through and check it's the correct resource for your purpose. Please remember to pace yourself and be mindful of the fact that thinking about the impact of symptoms on you may be difficult. If you need to talk to someone about how you are feeling, you can reach out to a The Samaritans. Call 116 123 at any time to talk to a trained volunteer who will listen without judgement. You can also email jo@samaritans.org or visit www.samaritans.org

There are three tables, and you can choose which of them and/or which parts of them you complete, then delete the rest.

1. Symptoms of ME as outlined in the NICE guideline ([section 1.2](#)) on pages 3 to 5
2. Symptoms of ME as outlined in the NICE guideline ([section 1.17](#) on severe to very severe ME) on page 6 and 7
3. Impact of Severe ME as outlined in the NICE guideline ([section 1.17.2](#) on severe to very severe CFS/ME) on pages 8 and 9

You do not have to complete every part of the tables showing how ME impacts you. Instead, you can choose the symptoms that have the most impact on your daily life, and the adjustments that can help you access the service/support you are seeking.

We have added EXAMPLES to the template below which you can edit and/or delete, and add further information about your own experience and needs.

You can use the following questions to help you think about how to complete the template:

- How often do you experience this symptom? Frequently / Sometimes / Rarely
- What impact does this symptom have on your day-to-day life?
- What activities does this limit?
- Is there anything that supports you/would support you with managing this symptom?

Add your name to the first sentence on page 2 and delete this page before sharing with professionals.

**My name is
charity Action for ME.**

and this is an Impact Statement I completed using a resource provided by UK

I live with Myalgic Encephalomyelitis (ME), sometimes referred to and diagnosed as Chronic Fatigue Syndrome (CFS). This is a chronic, fluctuating disease, causing symptoms such as post-exertional malaise, sleep problems, and problems with thinking and memory (brain fog).

ME/CFS is noted in guidance to the Equality Act 2010 (Section A5) as an impairment which can give rise to a disability:

<https://www.gov.uk/government/publications/equality-act-guidance/disability-equality-act-2010-guidance-on-matters-to-be-taken-into-account-in-determining-questions-relating-to-the-definition-of-disability-html>

By law, service providers must make reasonable adjustments to ensure disabled people are not at a substantial disadvantage due to their disability. Required adjustments could include changes to policies, physical features, or equipment that remove or reduce a barrier.

This statement provides some key information about ME, how ME impacts me and information about the reasonable adjustments you can put in place to support me.

The 2021 NICE guideline for ME/CFS: diagnosis and management (NG206) [www.nice.org.uk/guidance/ng206] draws attention to the fact that Myalgic Encephalomyelitis (ME, also known as chronic fatigue syndrome or ME/CFS):

- is a complex, chronic medical condition affecting multiple body systems and its pathophysiology is still being investigated
- affects everyone differently and its impact varies widely – for some people symptoms still allow them to carry out some activities, whereas for others they cause substantial incapacity
- is a fluctuating condition in which a person's symptoms can change unpredictably in nature and severity over a day, week or longer
- can affect different aspects of the lives of both people with ME/CFS and their families and carers, including activities of daily living, family life, social life, emotional wellbeing, work and education. [section 1.1.2]

The 2021 NICE guideline for ME/CFS advises health and social care professionals that people with ME “may have experienced prejudice and disbelief and could feel stigmatised by people (including family, friends, health and social care professionals, and teachers) who do not understand their illness.” [section 1.1.3]

TABLE ONE Symptoms of ME as outlined in the NICE guideline (section 1.2)	How these symptoms affect me	Changes you can offer to make your service/support accessible to me
Fatigue: Debilitating fatigue that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion, and is not significantly reduced by rest.	EXAMPLE I experience fatigue every day which affects activities such as washing, dressing and eating.	EXAMPLE Offering breaks, keep each activity to one hour, ability to vary tasks.
PEM: Post-exertional malaise after activity in which the worsening of symptoms: <ul style="list-style-type: none"> • 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. 	EXAMPLE I frequently experience PEM which limits my ability to carry out day-to-day activities. I am sometimes unable to move or communicate verbally.	EXAMPLE Allow me to communicate in alternative formats, for example by text or email.

<p><u>Unrefreshing sleep</u> or sleep disturbance (or both), which may include:</p> <ul style="list-style-type: none"> • feeling exhausted, feeling flu-like and stiff on waking • broken or shallow sleep, altered sleep pattern or hypersomnia. 	<p>EXAMPLE I often feel more tired when I wake up than I did before going to bed. Unrefreshing sleep often affects my ability to complete activities, especially in the mornings.</p>	<p>EXAMPLE I need an afternoon appointment.</p>
<p>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.</p>	<p>EXAMPLE I experience 'brain fog' sometimes, this affects my communication. I may pause when speaking, and it may take me longer to respond to questions or process information.</p>	<p>EXAMPLE Allow extra time for me to respond, where possible please let me know information in advance of meetings.</p>

Orthostatic intolerance and autonomic dysfunction; including dizziness, palpitations, fainting, nausea on standing or sitting upright from a reclining position.	EXAMPLE I frequently feel faint and dizzy when standing from a seated position. It is worst in the morning when I get out of bed but happens throughout the day also.	EXAMPLE I require wheelchair access so that I can always remain seated.
Temperature hypersensitivity: resulting in profuse sweating, chills, hot flushes, or feeling very cold.	EXAMPLE I am often cold and find it difficult to warm up, this can cause fatigue, pain and brain fog.	EXAMPLE I need a warm space to work.
Neuromuscular symptoms, including; twitching and myoclonic jerks.	EXAMPLE I experience muscle weakness all the time, making it extremely difficult to support myself to sit or stand.	EXAMPLE I need a virtual appointment.

Flu-like symptoms: including sore throat, tender glands, nausea, chills or muscle aches.	EXAMPLE I experience a frequent sore throat which can affect my ability to communicate verbally.	EXAMPLE I need to use written communication rather than verbal.
Intolerance to alcohol, or to certain foods and chemicals.	EXAMPLE I experience multiple chemical sensitivities and cannot tolerate products such as perfume and cleaning products.	EXAMPLE Please do not use scented products when supporting me.

<p>Heightened sensory sensitivities: including to light, sound, touch, taste and smell</p>	<p>EXAMPLE I am unable to tolerate bright/harsh lighting. When possible, I will avoid places with harsh lighting.</p>	<p>EXAMPLE If possible, have soft lighting</p>
<p>Pain: including pain on touch, myalgia, headaches, eye pain, abdominal pain or joint pain without acute redness, swelling or effusion</p>	<p>EXAMPLE I experience generalized pain daily, this causes me to need support with changing, washing and preparing food.</p>	<p>EXAMPLE I need specialised equipment that supports my body and provides a bit of comfort</p>

TABLE TWO Symptoms of ME as outlined in the NICE guideline (<u>section 1.17 on severe to very severe ME</u>)	How these symptoms affect me	Changes you can offer to make your service/support accessible to me
Severe and constant pain, which can have muscular, arthralgic or neuropathic features	EXAMPLE I have periods of experiencing stabbing pain and burning sensations. When this happens, I need to rest.	EXAMPLE I need to be able to cancel an appointment at late notice
Hypersensitivity to light, sound, touch, movement, temperature extremes and smells	EXAMPLE the lightest touch can feel very painful to me. This happens every now and then when I am in a severe crash/relapse	EXAMPLE Please ask before touching me
Extreme weakness, with severely reduced movement	EXAMPLE I cannot get out of bed	EXAMPLE I need to be able to have virtual or home visits/appointments

Reduced ability or inability to speak or swallow	EXAMPLE I cannot swallow food that well which can risk me choking	EXAMPLE I need to eat a special diet
Cognitive difficulties that limit the person's ability to communicate and take in written or verbal communication	EXAMPLE I cannot absorb verbal communication	EXAMPLE All communication needs to be written and/or through gesture if in person

<p>Gastrointestinal difficulties such as nausea, incontinence, constipation and bloating</p>	<p>EXAMPLE I feel sick a lot of the time</p>	<p>EXAMPLE I need extra time to eat my lunch slowly</p>
<p>Neurological symptoms such as double vision and other visual disorders, dizziness</p>	<p>EXAMPLE I can get blurred and double vision, especially near the end of the day</p>	<p>EXAMPLE I need to be able to work flexibly</p>

TABLE THREE Impact of Severe ME as outlined in the NICE guideline (<u>section 1.17.2</u> -severe to very severe CFS/ME)	How these symptoms affect me	Changes you can offer to make your service/support accessible to me
<p>Need a low-stimulus environment, for example a dark quiet room with interaction at a level of their choice (this may be little or no social interaction)</p>	<p>EXAMPLE I experience nausea and headaches if I am in a room with too much noise and bright light</p>	<p>EXAMPLE Soft lighting and a quiet environment</p>
<p>Are housebound or bedbound and may need support with all activities of daily living, including aids and adaptations to assist mobility and independence in activities of daily living (for example, a wheelchair)</p>	<p>EXAMPLE I need to use a wheelchair whenever I leave my home</p>	<p>EXAMPLE Wheelchair access</p>

<p>Need careful physical contact when supported with activities of daily living, taking into account possible sensitivity to touch</p>	<p>EXAMPLE I cannot have things touch my lower arms and hands such as clothes or peoples' touch</p>	<p>EXAMPLE Every effort must be made to avoid touching my lower arms and hands. If it is essential to touch that part of my body, explicit consent must be gained</p>
<p>Cannot communicate without support and may need to choose someone to be their advocate and communicate for them</p>	<p>EXAMPLE I need my mum to speak for me and aid communication between us</p>	<p>EXAMPLE I need your organisation to speak to my mum on my behalf</p>
<p>Are unable to eat and digest food easily and may need support with hydration and nutrition (see the recommendations on dietary management and strategies)</p>	<p>EXAMPLE I cannot eat a big meal</p>	<p>EXAMPLE I must eat small and often</p>

Have problems accessing information, for example because of difficulty with screens, sound and light sensitivity, headaches affecting their ability to read, or brain fog affecting their concentration	EXAMPLE Using a computer screen for too long makes me feel sick and get a headache	EXAMPLE I must be able to limit my screen time at work

If you would like information or resources about ME, or talk to someone about services and support available for patients and the professionals supporting them, contact Action for ME on 0117 927 9551 (choose option 1 to request a call-back), email infosupport@actionforme.org.uk or visit www.actionforme.org.uk



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Fundraising: fundraising@actionforme.org.uk

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www.actionforme.org.uk/donate/



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