
EMEA Position Statement on Environmental Accessibility Requirements for People with Myalgic Encephalomyelitis (ME)

Rights-Based Disability Framework for Safe Access to Care, Work and Public Life

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1. Status and Authority of This Statement

This Position Statement is issued by the **European ME Alliance (EMEA)** as a **patient-led representative body advocating for the recognition of environmental accessibility as a required condition for equal participation in society for people with Myalgic Encephalomyelitis (ME)**.

The purpose of this document is to support people living with **Myalgic Encephalomyelitis (ME)** in accessing safe, equitable environments during medical appointments, work activities, conferences, and public or private services.

ME is a complex, multi-system disease recognised by the World Health Organization as a neurological condition since 1969. It is characterised by **Post-Exertional Malaise (PEM)**, termed **Post-Exertional Neuroimmune Exhaustion (PENE)** in the International Consensus Criteria, autonomic dysfunction, hypersensitivities and impaired physiological resilience.

A key and often overlooked aspect of ME is **extreme sensitivity to environmental stimuli**, which can trigger significant clinical deterioration.

For people with ME, exposure to environmental stimuli, including sensory input and chemical agents, constitutes a form of physiological exertion capable of triggering post-exertional disease mechanisms leading to "crashes" and increasing disability levels.

Most of these crashes are preventable, particularly those caused by human actions, even unintentional ones, such as denial of, or failure to accommodate, PEM, or lack of the assistance that patients need to break the cycle of continued energy depletion and stabilise.

As such, control of environmental conditions is not a matter of comfort, but a **clinical necessity and a requirement for environmental accessibility** under disability rights frameworks.

This statement is grounded in international human rights law, established clinical evidence and recognised disability inclusion frameworks.

It is intended for adoption and implementation by:

- Healthcare systems
- Public authorities
- Employers and institutions
- Educational and research environments

Effective implementation requires clear allocation of responsibility among public authorities, service providers, employers, educational and research institutions, and other organisations responsible for designing, managing, regulating or providing access to environments. These duty-bearers should establish appropriate policies, resources, accessibility standards, monitoring mechanisms and accountability processes, with meaningful participation by persons with disabilities. Accountability should ensure that Environmental Accessibility requirements are consistently implemented in practice, barriers are identified and remedied proactively, and avoidable harm arising from inaccessible environments and other remediable barriers to participation is prevented, thereby promoting equal access and participation.

*Exposure to environmental stimuli in ME should be understood as a form of **physiological exertion**, capable of triggering post-exertional disease mechanisms.*

2. Rights-Based Framework (Non-Negotiable Basis)

This statement is grounded in the **United Nations Convention on the Rights of Persons with Disabilities (CRPD)**, which establishes that:

- Disability arises from the interaction between impairment and environmental barriers
- States and institutions are legally obligated to remove barriers to participation
- Equal access requires effective and appropriate modifications to the environment

In this context, for people with ME:

Environmental stimuli such as chemical exposure, noise and light are disabling barriers when they trigger predictable and reproducible physiological deterioration.

Therefore:

Failure to provide environmental accessibility constitutes:

- A breach of equal access obligations
- A failure of reasonable accommodation duties
- A preventable exposure to harm in healthcare and public systems

3. Medical Recognition and Clinical Basis

Myalgic Encephalomyelitis is recognised by the World Health Organization as a neurological disease. It is characterised by:

- Post-Exertional Malaise (PEM), also known as Post-Exertional Neuroimmune Exhaustion (PENE)

- Dysregulation of autonomic nervous system function
- Multisystem impairment affecting energy metabolism
- Severe hypersensitivity to sensory and chemical stimuli

3.1 Sensory and Chemical Hypersensitivity

People with Myalgic Encephalomyelitis (ME) commonly exhibit marked intolerance to sensory and environmental stimuli, including:

- Light
- Sound
- Chemical exposures (e.g. fragrances, cleaning agents)
- Complex or dynamic environments

This intolerance is a recognised clinical feature of ME, as described in the Canadian Consensus Criteria (2003) and the International Consensus Criteria (2011), and is reported consistently across patient cohorts. Furthermore, clinical research demonstrates abnormal neurophysiological processing of stimuli in ME/CFS populations.

Importantly:

These responses are physiological and multisystem in nature, involving neurological, autonomic and metabolic dysfunction.

They are not adequately explained by behavioural or psychological models, and should not be interpreted as psychosomatic in clinical or institutional contexts.

3.2 Pathophysiological Basis (Current Evidence)

Emerging biomedical research in ME indicates:

- Impaired cerebral blood flow regulation, particularly under stress conditions
- Autonomic nervous system instability, affecting tolerance to environmental stimuli
- Abnormal neurovascular coupling and oxygen delivery
- Heightened vulnerability to sensory load due to reduced physiological resilience

These mechanisms provide a biologically plausible basis for:

- Reduced tolerance to sensory input
- Exacerbation of symptoms in stimulating environments
- Prolonged recovery following exposure

Clinical Implication

Exposure to sensory or chemical stimuli may:

- Trigger Post-Exertional Malaise (PEM), also known as Post-Exertional Neuroimmune Exhaustion (PENE)
- Induce neurological and autonomic destabilisation
- Lead to prolonged and potentially severe deterioration

Therefore, sensory and chemical hypersensitivity must be understood as:

A core functional impairment requiring environmental control, not a subjective sensitivity.

3.3 Autonomic Dysfunction and Environmental Intolerance

Studies show:

- High prevalence of orthostatic intolerance and autonomic instability in ME

Example evidence:

- van Campen et al., 2018 to 2021: cerebral blood flow impairment worsened by physiological stressors
- Stewart et al., autonomic dysfunction literature in ME/CFS cohorts

3.4 Post-Exertional Malaise (PEM) and Post-Exertional Neuroimmune Exhaustion (PENE)

Post-Exertional Neuroimmune Exhaustion (PENE) is the compulsory, cardinal feature of Myalgic Encephalomyelitis (ME) as defined by the **International Consensus Criteria (ICC, 2011)**, and corresponds to **Post-Exertional Malaise** in the **Canadian Consensus Criteria (CCC, 2003)**. The NICE guideline describes similar symptoms as post-exertional malaise (PEM) or post-exertional symptom exacerbation (PESE).¹

PEM/PENE is triggered not only by physical exertion but also by:

- Sensory overload

¹The worsening of symptoms that can follow minimal cognitive, physical, emotional or social activity, or activity that could previously be tolerated. Symptoms can typically worsen 12 to 48 hours after activity and last for days or even weeks, sometimes leading to a relapse. Post-exertional malaise may also be referred to as post-exertional symptom exacerbation. <https://www.nice.org.uk/guidance/ng206/chapter/recommendations#post-exertional-malaise>

- Chemical exposure²
- Cognitive and environmental stressors

4. Clinical Guidance Consensus

This position is aligned with:

- **National Institute for Health and Care Excellence (NG206, 2021):** recognises the need to reduce sensory overload and individualise environmental conditions.
- **Bateman Horne Center:** recommends strict reduction of sensory and chemical triggers to prevent symptom exacerbation.
- **ME Association Ireland:** identifies environmental hypersensitivity as a functional impairment affecting daily life.
- **International Consensus Criteria (ICC, 2011):** identifies hypersensitivity to sensory input and chemicals as a diagnostic feature.

5. Definition: Environmental Accessibility

EMEA defines:

Environmental Accessibility as a legally and clinically required condition in which sensory, chemical and physical environmental exposures are controlled to prevent physiological harm in people with ME.

This includes the establishment of mandatory environmental guidelines.

6. Mandatory Environmental Requirements

To ensure equal access and prevent harm, the following are required:

6.1 Sensory Load Control

- Reduction of ambient noise and sudden auditory stimuli
- Avoidance of fluorescent or flickering lighting

6.2 Chemical Safety (Fragrance-Free Standard)

- Absolute avoidance of perfumes and fragranced products
- No air fresheners or scented cleaning agents
- Preference for low-emission, non-irritant materials

²This **sensitivity to chemicals, foods and medications** is recognised as a key symptom of underlying immune and neurological dysfunction.

6.3 Physiological Stability

- Stable temperature regulation
- Avoidance of sudden environmental fluctuations

6.4 Access Adaptations

- Quiet or low-stimulation waiting areas
- Flexible scheduling and pacing
- Remote participation options where feasible

7. Legal and Institutional Obligation

Under the CRPD framework:

Environmental accessibility is not optional. It is a binding requirement for equal participation and non-discrimination.

Institutions that fail to provide such accommodations:

- Create indirect discrimination
- Exclude individuals from essential services
- Contribute to preventable deterioration of health

8. System-Level Implication

EMEA asserts that:

Environmental accessibility must be recognised as a core component of disability inclusion policy, equivalent to physical accessibility measures such as ramps or lifts.

Sensory and chemical barriers must be treated with equal seriousness.

9. Conclusion

For people with Myalgic Encephalomyelitis, and for people with other illnesses:

Environmental conditions are not contextual. They are determinants of health, function and access.

The establishment of low-stimulation, fragrance-free and chemically safe environments is therefore:

- A clinical necessity
- A human rights obligation
- A non-discretionary requirement for equal access

Elevated risk: large population registry studies, such as research from King's College London, have found that suicide incidence is nearly sevenfold higher among those with ME/CFS. <https://clinician.nejm.org/relatively-high-suicide-rate-among-people-chronic-fatigue-syndrome-nejm-jw.NA40492>

The recognition of Environmental Accessibility is only the first step. To achieve meaningful equality of access, these principles must be translated into institutional policies, professional practice and effective implementation frameworks. EMEA calls on governments, healthcare providers, employers, educational institutions and international organisations to work collaboratively with patient organisations to ensure that Environmental Accessibility becomes a recognised and enforceable component of disability inclusion.

Environmental Accessibility measures should be developed in consultation with affected communities and implemented in ways that recognise the diverse and sometimes differing accessibility needs of people with disabilities, ensuring that measures benefiting one group do not unintentionally create barriers for another.

Environmental Accessibility Rights for People with Myalgic Encephalomyelitis (ME)

This person has **Myalgic Encephalomyelitis (ME, sometimes referred to as ME/CFS)**, a neurological disease recognised by the World Health Organization.

Under the United Nations Convention on the Rights of Persons with Disabilities (CRPD), **exposure to harmful environmental conditions constitutes a barrier to access and must be prevented.**

In ME, environmental exposure functions as physiological exertion and must be controlled to prevent harm and ensure accessibility.

MANDATORY: PREVENT HARMFUL EXPOSURES

PLEASE DO NOT

- Wear perfume, cologne or fragranced personal products
- Use air fresheners or scented cleaning agents
- Create avoidable noise or disturbances
- Expose them to strong chemicals or volatile substances

REQUIRED ENVIRONMENTAL CONDITIONS

- Quiet, low-stimulation environment
- **Fragrance-free, chemical-minimised space**

CLINICAL BASIS

Aligned with:

- National Institute for Health and Care Excellence (NG206, 2021)
- Bateman Horne Center

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• Soft or natural lighting (avoid fluorescent or flickering light) • Stable, moderate temperature • Minimal interruptions and controlled interaction	• International Consensus Criteria (ICC, 2011) • ME Association Ireland
CLINICAL RISK Exposure may cause: • Neurological overload • Autonomic dysfunction (e.g. orthostatic intolerance) • Post-Exertional Malaise (PEM), also known as Post-Exertional Neuroimmune Exhaustion (PENE) • Prolonged and severe clinical deterioration These are documented physiological effects , not sensitivities or preferences.	LEGAL STATUS This constitutes a necessary accessibility measure under the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Failure to provide these conditions may result in: • Denial of access to services • Health deterioration • Discriminatory exclusion

THANK YOU FOR YOUR COOPERATION

Providing a low-stimulation, fragrance-free environment is:

A medical necessity and a requirement for equal access

European ME Alliance (EMEA)

Scientific References

A. Core Clinical Guidelines

- National Institute for Health and Care Excellence. Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management (NG206), 2021.
→ Recommends reducing sensory overload and respecting individual tolerance limits.
- Bateman Horne Center. Clinical Care Guide for ME/CFS (2025).
→ Emphasises environmental control (light, noise, chemical exposure) to prevent symptom exacerbation.
- ME Association Ireland. ME Clinical and Patient Guidance.
→ Identifies hypersensitivity to environmental triggers as a functional impairment.

B. Diagnostic Framework

- Carruthers BM et al. (2011). International Consensus Criteria for Myalgic Encephalomyelitis. *Journal of Internal Medicine*.
 - Defines Post-Exertional Malaise (PEM) / Post-Exertional Neuroimmune Exhaustion (PENE).
 - Includes hypersensitivity to sensory input and chemicals as a diagnostic feature.

C. Sensory and Environmental Intolerance

- Carruthers BM et al. (2011). International Consensus Criteria for Myalgic Encephalomyelitis. *Journal of Internal Medicine*.
 - Identifies hypersensitivity to sensory input and chemicals as a diagnostic feature.
- Rowe PC et al. (2014 to 2021). Research on orthostatic intolerance and daily functional limitations in ME/CFS.
 - Demonstrates physiological triggers of symptom exacerbation, including environmental stressors.
- van Campen CLMC and Visser FC (2020 to 2022). Studies on cerebral blood flow reduction in ME/CFS.
 - Show objective impairment in cerebral perfusion, worsened under stress.
- Wirth K and Scheibenbogen C (2020). A unifying hypothesis of the pathophysiology of ME/CFS. *Autoimmunity Reviews*.
 - Links vascular dysregulation and energy metabolism impairment to symptom exacerbation.
- Komaroff AL and Lipkin WI (2021). Insights from myalgic encephalomyelitis/chronic fatigue syndrome may help unravel the pathogenesis of postacute COVID-19 syndrome. *Trends in Molecular Medicine*.
<https://doi.org/10.1016/j.molmed.2021.06.002>
 - Confirms multisystem biological dysfunction and rejects purely psychological explanations.

D. Autonomic Dysfunction and Physiological Instability

- Stewart JM (various publications). Orthostatic intolerance and autonomic dysfunction in ME/CFS.
 - Demonstrates physiological instability under environmental and positional stress. Environmental stressors can worsen autonomic instability, with a direct link to symptom exacerbation and functional impairment.

E. Environmental Triggers and Symptom Exacerbation

- Jason LA et al. (multiple studies).
→ Identifies environmental and exertional triggers of symptom worsening.
- Komaroff AL and Lipkin WI (2021). *Trends in Molecular Medicine* (see section C).
→ Biological basis of multisystem sensitivity. Reinforces the non-psychological nature of symptom triggers.

F. Rights and Accessibility Framework

- United Nations. Convention on the Rights of Persons with Disabilities (CRPD).
- World Health Organization. Global Disability Action Plan / WHO Europe disability framework.
→ Defines disability as an interaction with barriers. Establishes the obligation to remove environmental barriers.