



**INVOLVING PEOPLE
WITH ME AND OTHER
ENERGY LIMITING
CONDITIONS**

A GUIDE BY THE

World  Alliance

Involving people with lived experience of disability is vital to ensuring that projects and initiatives are successful and relevant. People with ME and energy limiting conditions face various barriers that can make it difficult for them to participate in events or meetings, whether online or in-person. In this guide, we will discuss the steps you can take to make your events and meetings more inclusive and accessible to everyone.

UNDERSTANDING ME AND ENERGY LIMITING CONDITIONS

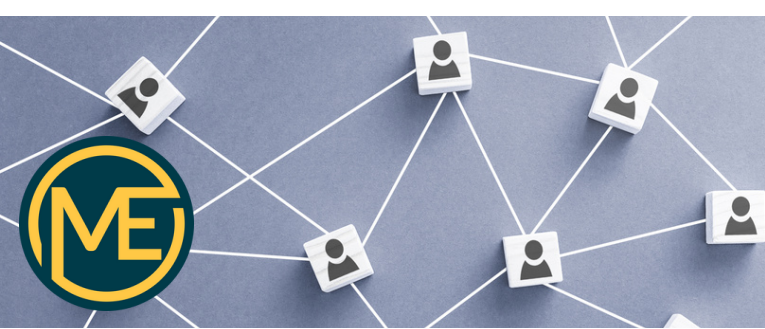
To make your event or meeting more accessible to people with ME and other energy limiting conditions, it's essential to understand what these diseases are and how they impact individuals. Myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), is a chronic disease. People with ME are not able to function the same way they did before they became ill. ME changes people's ability to do daily tasks, like taking a shower, preparing a meal or having a conversation. It often makes it hard to keep a job, go to school, and take part in family and social life. Find out more about ME by visiting worldmealliance.org/what-is-me.

Many chronic illnesses are energy limiting, but meetings and events can be made more accessible to this important section of the disability community. Enabling the disabled person to plan their energy use in advance is key to supporting participation.

COMMUNICATION AND ENGAGEMENT

To ensure that everyone can participate in the event/meeting consider the following:

- Provide clear communication before the event/meeting about accessibility accommodations that will be available.
- Explain what cognitive energy will be required of attendees, for example an event could require passive listening, active note taking, active responding in realtime or feeding back after the event.
- Provide a point of contact for individuals to ask questions and request accommodations.
- Consider providing an orientation or introduction to the event/meeting for individuals who may need it.
- Pre-record any presentations or introductory speeches and send these to participants in advance of your event/meeting. This will help with brain fog and enable individuals to process information in advance so they can engage in discussion.
- Encourage participation at a pace that works for individuals.



VENUE ACCESSIBILITY

If you're hosting an in-person event, it's crucial to consider the accessibility of the venue. Consider the following:

- **Wheelchair accessibility:** Ensure that the venue has wheelchair ramps, accessible parking, and accessible washrooms.
- **Seating and lying down:** Provide chairs for those who may need to rest, and ensure that the seating is comfortable. Provide space for those who need to lie down to do so.
- **Lighting:** Consider the lighting in the venue and ensure that it's not too bright.
- **Noise:** Consider the noise level in the venue, and provide a quiet space for individuals to rest if needed.
- **Temperature:** Consider the temperature in the venue, and ensure that it's comfortable for everyone.
- **Scent:** Prevent unnecessary exposure to smoke or chemical fumes (air fresheners, cleaning products, fresh paint) and ask attendees to refrain from wearing perfume or aftershave.
- **Pandemic precautions:** Ensure the ventilation of indoor spaces and enable use of face masks.

ONLINE ACCESSIBILITY

25% of people with ME are housebound or bedbound. To make your events or meetings accessible, consider holding it online or having a hybrid online/in-person event. There are several ways to make online events and meetings more accessible to people with ME and other energy limiting conditions:

- Provide captions or transcripts for videos and audio content.
- Ensure that the platform you use is accessible and compatible with screen readers.
- Provide a text-based alternative for any visual content.

CATERING

Some people with ME have food intolerances including dairy, gluten and nuts. If you are providing food, ask for people's dietary requirements upon registration. If you can't provide food, provide facilities for people to prepare/warm foods they have brought.

CARERS/PERSONAL ASSISTANTS

Make sure you enable carers and personal assistants to attend events/meetings. This could include asking if the attendee will be bringing a carer/personal assistant in advance of the meeting and ensuring there is enough seating. Or sending any online meeting/event information to the carer/personal assistant as well as the attendee.



QUIET SPACES, BREAKS AND LENGTH OF MEETINGS

Pacing is a vital management strategy for people with ME - for most people this means splitting up activities and taking rest breaks. To enable people to do this effectively provide a separate quiet room or space during in-person events.

Include a break in the agenda proportionate to the length of your meeting. For example, if you are holding a one hour meeting, include a ten minute break in the middle.

Consider the length of your event or meeting. People with ME often have limited capacity to concentrate for long periods. For example, some can only engage for 30 minutes or less, and can't commit to more than one meeting per week.

If you want to enable ongoing engagement, talk to your attendees with energy limiting conditions and make a plan for meetings together.

EXPENSES

Think about the costs of joining an event/meeting for the person with disabilities and create a method for repaying any expenses incurred.

Where possible, offer payment for time at a level that is commensurate with the nature and demands of the activity and that is fair when compared to other team members, to acknowledge the value of public involvement.

*Accessibility benefits all and
creates success*

Making events accessible to people with ME and other energy limiting conditions requires careful planning and consideration. By understanding the needs of individuals with these conditions and providing appropriate accommodations, you can make your event more inclusive and welcoming to everyone, and help your projects succeed.

Visit worldmealliance.org to find out more about ME and energy limiting conditions.

