



## **How to Protest with ME And other Energy-Limiting Chronic Diseases**

### **What is this?**

This is a guide for people who are planning a protest, demonstration, or activism to include people with ME and other energy-limiting chronic diseases. The second part is a guide for those planning to attend a protest that have ME/CFS.

### **Who is it for?**

This is for movement spaces, activists, organizers, organizations, institutions, and/or any individual, group, or community. It is also for people with ME who are planning to attend an action. We hope it will also be useful for those with other chronic diseases or disabilities.

### **Why?**

All people deserve to have a voice and speak out for what they believe in or ways they want to seek change. Not everyone has equal opportunities to do that. Often some of our most important voices get left out of the collective. We need to ensure all people and their voices, no matter how they need to be expressed, are included.

### **Considerations:**

There are many things currently happening in our government that are harming people with ME as well as the broader disability community. We must take collective action to ensure that people with ME and other disabilities are protected, supported, and allowed to live meaningfully.

We hope this guide can help activism become more intersectional and enable those attending events to do so as safely as possible.

There will be grief as a movement. There will be much needed self-care. That is why collective action matters.

### **Pacing:**

Please refer to our pacing guides and always remember to Stop Rest Pace.

## **From Bed**

When designing an action, protest, or activity for people with disabilities or chronic illnesses, it is always important to consider what can be done from bed, from home, from not going out on the streets.

Energy will be different for everyone and it is important to manage your own energy when participating in action.

## **Actions that can be taken from home**

Calling elected officials

Petitions

Emails

Asking friends and family to join the movement

Here is a [long list](#) of ways to be in the struggle beyond the streets

**When organizing a protest, consider what can be done and what is needed to protest from bed/couch/home.**

**Here is a good checklist:**

### **Remote From Home - Bed or Couch**

- What tools utilize for participation - phone, computer, tablet
- What can do/prepare in advance - t-shirts, posters, art projects, pictures, videos, writing/poems,
- Share information with caregivers, family members, friends
- Storytelling strategies - how to tell stories and have our voices heard

*If you are planning a protest or planning on attending a protest in-person, this section is for you:*

## **In Person**

Many people with ME do not have the spoons to attend in-person protests, especially if they are organized by movement spaces that center able-bodied activists, and do not address the access needs of people with disabling chronic illnesses.

Still, governments at all levels, whether directed or emboldened by the current administration, are taking daily actions that harm disabled, BIPOC, women and LGBTQAI+ people and threaten social safety net programs we depend on to survive. They are halting and suppressing vital public health surveillance and communications, and dismantling critical biomedical research. Given this, we understand that at some point you might want to use your limited spoons to attend in-person protest(s). We want to support you with tools that center your care and safety.

### **Before the protest**

While not always possible, planning and pacing in the week(s) or days before a protest can prepare you to participate in the way that is most accessible and harm-reducing to you. Because in-person protest is not designed with us in mind, preparing for it can be a heavy load. Do the best you can, share the load with others, and give yourself and others grace at all steps.

- **Ask other able-bodied and disabled friends, allies, and caretakers to join with you in planning to join a protest safely.** One of our biggest resources is each other. By reaching out for help and/or sharing the load of planning to attend an in-person event, we strengthen community and help manage our energy and symptoms leading up to it.
- **Learn what you can about the protest plan, directly from the organizer's event page and communications.** Consider: do they list the timeframe and starting or stopping locations; what route will it take or is it situated in a particular location/block; are there wheelchair user accommodations or other access notes already in place; for LGBTQ+ and/or BIPOC protesters, are there affinity groups to connect with; are there guidelines for sign-making; are there pre-protest information sessions and a Know Your Rights training you can attend, etc.?
- **Direct important questions or needs to the protest organizer(s) ahead of time.** Tell the organizer if you plan to arrive with a mobility aid or have other access needs. You may want to ask: what kind of support will be on-site for protesters? What do they know about wheelchair access at the protest location? Are there places along the protest route where people will be able to rest (a park with a bench), etc.?
- **Secure a wheelchair/mobility aid and other needed aids, if you do not already have them.** Because of energy limitation, PEM, and orthostatic intolerance, an

in-person protest may become more accessible to you if you use a wheelchair (*even if you normally don't*). If you don't already have one, consider renting or borrowing one. Make a sign that you can attach to your aid, or that you can hold more easily by attaching it to a post/stick. If noise-sensitive, bring earplugs. If it will be a sunny day (or even if it won't), bring sunglasses. Pack water with electrolytes, and any medicines you may need. Make a packing list and, if you can, ask for help to complete it.

- **Get a protest buddy(ies).** Because protests are energy-intensive events that often cause sensory overload, an able bodied ally that can help you manage personal items, interact as needed with protest coordinators and participants, and check in and advocate for you as needed can be an important support to line up prior to the day.
- **Prepare 2-3 contacts** in case needed during protest for emergency or bail.
- **Create a travel plan and exit plan.** Decide when you will depart for the protest and where to park if applicable. Also decide the maximum amount of time you will stay, and how you will communicate with your protest buddy(ies) about departure, ahead of time.
- **If you can, publicize the protest** through social media and your networks to spread the word and/or ask your networks to help you do so.
- **As best as you can, pace out all these activities.**

### Day of the protest

- **Scope out the landscape.** Identify protest coordinators. Take note of where you might go for a break if you need one. Review with your protest buddy(ies) your communication and exit plans.
- **Prioritize self care and maintain boundaries.** It is easy to get wrapped up in the energy of the event and forget about your own health needs when your adrenaline is pumping. As best you can, keep to the boundaries you set with yourself beforehand. This may mean attending and chanting for 15 minutes before leaving. Do not hesitate to wear a mask for your own protection, even if no one else is.
- **Rest and Pace.** Rest, hydrate, and take medicine when you need to. Take chanting breaks when you need to. Take a complete break when you need to. Leave when you need to.
- **Communicate with protest buddies.** Check in with them regularly. Remain honest about how you feel and what you need.
- **Take pictures of the protest,** or ask your protest buddies to take pictures. This is a great way to extend the messages and power of the protest beyond the irl location itself, and it can happen even if you are at the protest for a short time.

### After the protest

- **Set aside recovery time.** Try not to schedule appointments for the days(+) following the protest. Rest. Take time. Be gentle. Practice self care. You just did a big thing. Let

yourself recover back to baseline. Let yourself feel the feelings when you have them. Reach out to a self care buddy if you need to.

- **Share protest pictures.** When you're ready, share pictures you took at the protest on your personal accounts and with the organizers. Use hashtags to extend your reach.
- **Share lessons learned.** If you want, you may want to share with others in your ME community your takeaways on what helped and didn't help make this protest a reality. You can also give the protest organizer feedback about what they could do next time to make the event more accessible to people like you.

If you will be traveling to an action, please see helpful travel information here:

<https://www.meaction.net/2022/08/26/facets-of-me-travel-tips/>

To take action now, please see our actions page, which we will keep updated as things progress: