

how to  
**float**  
1-0-1

a mini toolbox for  
new floaters

-AKA-  
**(PEOPLE WITH ME/CFS)**

Image Description: Cover art. A textured cloud with a piece of ripped notebook paper that says "how to float 1-0-1". A ripped piece of notebook paper underneath says "a mini toolbox for new floaters". There is another textured piece of cloth that has two clouds drawn on it. a ripped piece notebook paper says "aka (people with ME/CFS) highlighted. The cover is dark royal blue with a red light flare on the bottom. There is a black column on the right side.

my feet

haven't

touched the ground

since 2022,

sometimes

I like to think

||

am

floating

ZINE

BY

♥ fromBed

vee

Image Description: The inside cover shows a series of cut up pieces of paper with different words on them. It says "my feet" "haven't" "touched the ground" (vertically) "since 2022" "sometimes" "I like to think" "I" "am" "floating". Beneath this is a piece of crumpled paper that says "zine by Vee with a heart from bed". The cover has a vertical orange to black gradient with circular pieces of silver and gold metal pasted about like bubbles. The words "I am floating" are in the black.

## **How to Float 1-0-1**

A mini toolbox for new floaters (aka people with Myalgic Encephalomyelitis)

By Victoria C. – Empowerment through Community

### **Inside Cover**

my feet haven't touched the ground since 2022, sometimes I like to think I  
am floating

**Disclaimer:** This is not medical advice. Please continue to seek help from medical professionals regarding proper lab work and diagnostics for your health. Other conditions to be investigated include Ehlers Danlos Syndrome, Mast Cell disorders, Dysautonomia, various neuromuscular conditions, nervous system conditions, and others. This zine is an aid in your health journey.

This zine is rooted in Sins Invalid's disability justice framework and a belief in the abolition of the prison industrial complex. Resources are provided with this lens in mind. The zine provides resources for the United States.

**This is a free resource, however if you would like to donate to help fund our work please Venmo @empwrctc or email empwrctc@gmail.com for larger contributions. Salamat!**

## Floating Together

It's important to remember that although our experiences are unique, we are better together. That means caring about how each of us impact each other and the world we live in.

### Disability justice

According to Sins Invalid, a disability justice framework posits that “All bodies are unique and essential” while also being “confined by ability, race, gender, sexuality, class, nation state, religion, and more...”.<sup>1</sup>

[Click here to read Sins Invalid “What is Disability Justice?”](#)

Sins Invalid also created **10 Principles of Disability Justice**. The principles are Intersectionality, leadership of those most impacted, anti-capitalist politic, commitment to cross-movement organizing, recognizing wholeness, sustainability, commitment to cross-disability solidarity, interdependence, collective access, and collective liberation.<sup>2</sup>

[Click here to visit the Sins Invalid website for more on the principles of disability justice.](#)

---

<sup>1</sup> Sins Invalid. (2020, June 17). What is disability justice?  
<https://www.sinsinvalid.org/news-1/2020/6/16/what-is-disability-justice>

<sup>2</sup> Sins Invalid. (2019). *Skin, Tooth, and Bone: The Basis of Movement is Our People* (2nd ed.). Berkeley, CA.pp 22-26.

It is important for us to practice these principles especially when thinking about how to live with, manage, and treat this disease. I recommend looking at the description of each principle when you have the energy.

One other helpful concept is **organized abandonment**, a term expanded by Ruth Wilson Gilmore in her book “Golden Gulag”.<sup>3</sup> Beatrice Adler-Boltman describes organized abandonment as “the state's capacity to enable the organization, disorganization, or ‘outright abandonment’ of “various factors of production.”<sup>4</sup>

[Click here to view the full description of organized abandonment.](#)

Adler-Boltman & Gilmore discuss that organized abandonment is deeply intertwined with eugenics, as organized violence fuels and sustains abandonment “whether the violence is letting people die, compelling people to die, [or] sterilization...”<sup>5</sup>

[Click here to access the interview between Adler-Bolton and Gilmore.](#)

Disability justice and organized abandonment have everything to do with disease diagnosis, experience, and prognosis.

---

<sup>3</sup> Gilmore, R. W. (2007). *Golden Gulag: Prisons, Prisons, Surplus, Crisis, and Opposition in Globalizing California*. University of California Press.

<sup>4</sup> Adler-Bolton, B. (2022, October 17). All are not well, all are not safe. Blind Archive. <https://blindarchive.substack.com/p/health-communism>

<sup>5</sup> Alder-Bolton, B. (2022, October 13). Organized abandonment w/ Ruth Wilson Gilmore (10/06/22). Death Panel Podcast.

If you have not been diagnosed with ME/CFS that does not mean you do not have ME/CFS. On the other hand, a clinical diagnosis does not rule out other conditions. The medical industrial complex-U.S. healthcare system is not accessible to all people in the same ways, sometimes it's not accessible at all. It is not your fault if you do not have a clinical diagnosis, and you deserve support with or without it.

## Part 1: So, what is ME/CFS?

“Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a **chronic neurologic disease...**” that often arises after an infection.<sup>6</sup>

[Click here to access the description of ME/CFS.](#)

The U.S. ICD (International Classification of Diseases) Code for ME/CFS is G93.32. Doctors can use this for billing your insurance and for disability benefits claims.

According to the National Institute of Health, ME/CFS is the **most underfunded illness** by disease burden.<sup>7</sup>

[Click here to view the article about ME/CFS funding.](#)

---

<sup>6</sup> Grach, S. L., Seltzer, J., Chon, T. Y., & Ganesh, R. (2023b). Diagnosis and Management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Mayo Clinic Proceedings*, 98(10), 1544–1551. <https://doi.org/10.1016/j.mayocp.2023.07.032>

<sup>7</sup> Mirin, A. A., Dimmock, M. E., & Jasonf, L. A. (2020). Research update: The relation between ME/FS disease burden and research funding in the USA. *Work*, 1–6. <https://doi.org/10.3233/wor-203173>

## Signs you may have ME/CFS:

- **Exhaustion after you do, think, or feel.** Exhaustion can feel like limbs that are too heavy to lift, an inability to stay awake, or as a Mayo Clinic article describes, “locked in my body”.<sup>8</sup> Exhaustion can happen after various forms of stimulation like thinking, feeling, and doing. This includes texting, activities that increase your heart rate, sitting up, exercising, and more.
- **Malaise after you do, think, or feel.** Malaise can include experiencing “flu-like symptoms”, feeling like a cold is coming on, and feeling like you are poisoned. Malaise often occurs simultaneous to exhaustion.

Other symptoms may include:

- Electric zapping or “wired but tired”
- Fluctuating temperature
- Sensory sensitivity
- Muscle pain
- Bowel issues
- Lymph node swelling

---

<sup>8</sup> Grach, S. L., Seltzer, J., Chon, T. Y., & Ganesh, R. (2023b). Diagnosis and Management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Mayo Clinic Proceedings*, 98(10), 1544–1551. <https://doi.org/10.1016/j.mayocp.2023.07.032>

**Post-exertional malaise or PEM** also called **Post-exertional neuroimmune exhaustion or PENE** is a unique symptom of ME/CFS and is defined as: “A flare in symptoms or the appearance of new symptoms after exertion, often manifesting after a characteristic 24-hour delay; however, 12 to 48 hours is common”.<sup>9</sup>

PEM can lead to permanent damage or lowered ability. When experiencing PEM you may also feel more depressive or anxious thoughts, these usually ease as the PEM eases. Please view the resources in the following pages for crisis help.

Every person has their own distinct and unique energy capacities and limits. One person's severity may differ greatly from another's. Two people with severe Myalgic Encephalomyelitis may have different limitations and mobilities.

---

<sup>9</sup> Grach, S. L., Seltzer, J., Chon, T. Y., & Ganesh, R. (2023b). Diagnosis and Management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Mayo Clinic Proceedings*, 98(10), 1544–1551. <https://doi.org/10.1016/j.mayocp.2023.07.032>

## Part 2: Hypotheses

Although this zine won't get into the nitty gritty of what causes ME/CFS there are researchers looking into just that. Researchers have hypothesized that viruses, such as COVID and Epstein Barr cause ME/CFS. Others believe it may be caused by mold damage or sustained trauma. Here are a few resources for ongoing hypotheses, this is not a comprehensive list:

[Click here to access the ME/CFS Research Roadmap Webinar Series on Physiology](#)

[Click here to access a list of articles on Long Covid and/or ME/CFS created by Amanda Francey.](#)

[Click this to access Remission Biomes website.](#)

Neuroinflammation

- [Click this link to visit Jarred Younger's lab](#)

Metabolic Trap

- [Click this to access the work of Ron Davis](#)

Mechanical Basis

- [Click here to watch Unrest](#)

Mold Damage

- [Click here to read about mold and ME/CFS](#)

Mitochondrial Dysfunction

- [Click here to access an article about mitochondria and ME/CFS](#)

## Part 3: Common Myths and Misconceptions about ME/CFS:

### You're just experiencing deconditioning or stress.

Deconditioning is defined as “changes in the body that occur during a period of time when you are not active (inactivity)”.<sup>10</sup>

[Click here to access this definition of deconditioning.](#)

Although deconditioning can occur over time for floaters (and others unable to stay on their feet for prolonged periods of time), it is not the cause of or same as damage caused by Myalgic Encephalomyelitis. Unlike other conditions where graduated exercise (GET) may help one's condition, exercise is **not** recommended for people with Myalgic Encephalomyelitis.<sup>11</sup>

A collective called Physios for ME have a number of trainings and resources for you, your caregivers, and medical professionals.<sup>12</sup>

[Click here to access the Physios for ME website.](#)

---

<sup>10</sup> Elsevier's Healthcare Hub. Deconditioning. (2022, Oct 10.). <https://elsevier.health/en-US/preview/deconditioning>

<sup>11</sup> Mirin, A. A., Dimmock, M. E., & Jasonf, L. A. (2020). Research update: The relation between ME/FS disease burden and research funding in the USA. Work, 1–6. <https://doi.org/10.3233/wor-203173>

<sup>12</sup> <https://www.physiosforme.com/>

Likewise, ME/CFS is not “just stress”, trauma, hysteria, or “just your imagination”. Although Cognitive Behavioral Therapy (CBT) may be one therapeutic option for individuals to be used in tandem with other medicines and supplements, it has not been shown to be an effective stand-alone treatment or cure for ME/CFS and should not be treated as such.<sup>13</sup>

[Click here to access the article on how recommendations for GET and CBT may be harmful for floaters.](#)

Moreover, although CBT is often the *normative* tool suggested by doctors (who may not be trained or well-versed in therapeutic modalities), there are many other tools that may be used to help manage stress and trauma including somatic practices, Eye Movement Desensitization and Reprocessing, and ancestral and indigenous practices that may work better for your specific situation.

It may be helpful to research or get help researching various tools, or consulting with those trained in these practices to learn about all your different options.

Existing in a world with chronic illness plus capitalism, racism, genocide and other forms of oppression and violence can be very traumatic. You deserve support in all facets of your life. Receiving help for your mental health does not mean you are less deserving of other forms of treatment

---

<sup>13</sup> Vink, M., & Vink-Niese, A. (2022). The Updated NICE Guidance Exposed the Serious Flaws in CBT and Graded Exercise Therapy Trials for ME/CFS. *Healthcare*, 10(5), 898. <https://doi.org/10.3390/healthcare10050898>

and medicine. Not wanting help from psychologists or therapists does not mean you do not deserve treatment for ME/CFS.

### **There's nothing doctors can do for you.**

This is not true. There are many different medications and supplements that can be trialed in efforts to try and improve your quality of life. [Please access the Mayo Clinic article \(that has been cited in this zine throughout\) for more information.](#)<sup>14</sup> Additionally, [Click here to visit patient led coalitions like Remission Biome for other ideas.](#)<sup>15</sup>

Know that there is power in our stories. It is devastating to know that people with our disease have been hospitalized without adequate care, leading to starvation and sometimes even death. Doctors have discriminated against people with ME/CFS which has led to the withholding of life-saving treatments like port catheters, tube feeds, and sensory accommodations. We must continue to refuse and resist these forms of discrimination and ableism.

Talia A. Lewis defines **ableism** as “**a system of assigning value to people's bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and fitness. These constructed ideas are deeply rooted in eugenics, anti-Blackness, misogyny, colonialism, imperialism, and capitalism. This**

---

<sup>14</sup> Grach, S. L., Seltzer, J., Chon, T. Y., & Ganesh, R. (2023b). Diagnosis and Management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Mayo Clinic Proceedings, 98(10), 1544–1551. <https://doi.org/10.1016/j.mayocp.2023.07.032>

<sup>15</sup> <https://Remissionbiome.org>

**systemic oppression that leads to people and society determining people's value based on their culture, age, language, appearance, religion, birth or living place, "health/wellness", and/or their ability to satisfactorily re/produce, "excel" and "behave." You do not have to be disabled to experience ableism.<sup>16</sup>**

[Click here to access Talia's definition of ableism.](#)

Our ability to share our stories with one another helps us to create and gain shared wisdom which supports the larger collective— helping us fight ableism and restructuring socially constructed ideas about who we are and what we deserve. You are not obligated to share your story with anyone, but know that people are here to support you if you ever do choose to do so.

### **All it takes is discipline.**

Far from the truth. While you are on this journey, you may feel weighed down by information. Additionally, medical and even management frameworks for ME/CFS may make you feel like getting better, or avoiding getting worse, relies on your own ability to manage your energy properly.

While energy preservation practices can be helpful, it is important to acknowledge and add context to the real-world use of these tools.

---

<sup>16</sup> Lewis, T. A. (2022, Jan). Working Definition of Ableism January 2022 Update. *Talia A' Lewis' Blog*. <https://www.talilalewis.com/blog/working-definition-of-ableism-january-2022-update>

Many people do not have the choice to to stop everything and rest, even if others think they are physically capable of doing so. Others have no choice in stopping, as their body involuntarily shuts down into a paralysis-like episode. Both of these realities are common for people with ME/CFS, and we each face discrimination because of it. However, as disability justice and organized abandonment posits, there are many forces at play beyond our own individual will.

“We hurt because we were oppressed. Healing justice reclaims the ancient knowledge that just as harm is collective, healing is not an individual act”

<sup>17</sup> - Aurora Levins Morales in the book *Healing Justice Lineages*.

If you get worse, or are not getting better, it’s not your fault. We are humans deserving of a dynamic and worthwhile life. There are many forces that continue to work against us, and each of us have varied degrees of privilege, access, and marginalization.

Collective support and resistance will continue to be vital for our survival. Sadly, it is the case that many of us float alone in our physical realms, distanced from loved ones due to disability, abuse, neglect, and even ignorance. There is a community of us out here to support you in the ways we can.

---

<sup>17</sup> Page, C., & Woodland, E. (2023). *Healing Justice Lineages*. North Atlantic Books.

“But no matter how hard I try, my personal choices cannot upend oppression. The exhaustion that I feel from navigating the loss of my Gramma has only been compounded by Israel's genocide of the Palestinian people, the ongoing mass displacement of the Sudanese and Congolese people, the hyper-vigilance required to navigate a "post-COVID" COVID-19 world, all while laboring under capitalism to ensure that my most basic human needs are met...”<sup>18</sup> – Trey Washington in his article “Rest is not resistance, and that is okay” in Scalawag Magazine. [Click here to access the article.](#)

Although we fight for treatments, we must continue to struggle towards the dismantling of all institutions and ideas that lead to mass suffering and organized abandonment. What is medicine without access, affordability, and other forms of support? Biomedical tools will always be just one piece of the larger struggle for equitable care, justice, and liberation.

---

<sup>18</sup> Washington, T. (2024, March). Rest is not resistance, and that is ok. *Scalawag Magazine*. <https://scalawagmagazine.org/2024/03/rest-is-not-resistance-and-that-is-ok/>

## **Part 4: Tools for Getting By**

There are no current FDA approved treatments for ME/CFS. Currently, we live in a world fractured by the imaginations of people who have turned their backs on others for the sake of acquiring capital. We live on stolen land, in a country with a deeply complex and devastating history. Yet, there are those who continue to fight for and with us, so that we may one day experience a better quality of life.

Here are some tools to keep in your toolbox. Keep in mind the principles of disability justice when reading through or viewing these tools, as there continues to be a lack of recognition and analysis about the ways larger systemic issues impact our individual and collective health.

### **Pacing and Energy Management**

In 2021 advocacy group ME Action Network created a Pacing Guide. Pacing is defined by ME Action as “a self-management strategy for activity”. They state that “patients who pace well are active when able, and rest when tired. They may plan extra rest ahead of strenuous activities”.<sup>19</sup>

The guide also says that the goal of pacing is to minimize PEM. Other tools they suggest include radical rest which is described as “being inactive before planned exertions, such as attending a wedding or giving a talk can help mitigate the effects of post-exertional malaise” as well as cutting

---

<sup>19</sup> Seltzer, J. (2022). Pacing and Management Guide For ME/CFS. In *ME ACTION*.  
[https://www.meaction.net/wp-content/uploads/2021/02/Pacing-and-Management-Guide-for-ME\\_CFS-9.pdf](https://www.meaction.net/wp-content/uploads/2021/02/Pacing-and-Management-Guide-for-ME_CFS-9.pdf)

activity in half, monitoring “objective” values like heart rate, and breaking necessary activities into manageable tasks.

[Click here to access the pacing guide.](#)

ME Action Network also has a video series on pacing so that you can learn more.

[Click here to access ME Action Networks YouTube.](#)

For many, these energy preservation strategies and tools have been the primary way to keep ME/CFS from progressing. However, guides like this often do not acknowledge the barriers to resting including the capitalist exploitation of people's time and energy, lack of disability benefits due to bureaucratic barriers, parenting responsibilities and needs, caregiving responsibilities, neurodiversity, complex trauma, and poverty amongst others. Quite simply, for some it is not easy to “pace well”, it may even feel impossible.

It is possible that these strategies may lead you to feel like you are doing a poor job at managing ME/CFS because there is little discourse around systemic oppression. However, there are many community members who express these challenges everyday.

**You are not alone. Do the best you can within the realities you live and exist in.**

As Trey Washington states in his article about resting, **“Resistance must be centered around dismantling the systems that rob us of choice, while building care networks to ensure equitable access to choice”**.

Energy preservation frameworks must shift to include the significance and necessity of receiving community help and other forms of support. Keep doing your best.

Here are some additional tips that have helped me navigate energy boundaries and limitations.

- Ask others in your family, friends, or virtual relationships for more support if you are able.
- Prioritize restful time over a leisure activity if necessary.
- Find different ways to manage hygiene such as using buckets and portable camping shower heads in bed, using mobility aids like shower benches, using ear plugs, or washing body parts on different days.
- Explore new ways to understand and manage other things that may impact your energy. For example, if you experience episodes of hyperfocus like me, sometimes I hide my phone to break my focus. Others have used alarm clocks.
- Sometimes people are unable to be in complete silence so they find that listening to audiobooks while their eyes are closed works for them, or that trying to rest one “sense” at a time (vision, auditory, etc) works best.
- Use mobility aids like stretcher transport and wheelchairs to get around.

Chat with others to share tips and tricks on what works. These tips may change over time. Try to be mindful of your experiences and give yourself grace.

**When you cannot rest that does not mean you are doing something inherently wrong. When you do rest, that also does not mean you are doing something wrong.**

Rest is necessary.

Rest is nuanced.

Rest is liberating.

Rest is impossible.

Rest is resistance?

Rest is refusal.

Rest is healing.

Rest is commodified.

Rest is inaccessible.

Rest is not nourishing.

Rest is peaceful?

Rest is consuming.

Rest is:\_\_\_\_\_

Rest is beckoning.

Rest now.

## **Community and Communication**

Having ME/CFS can feel extremely isolating. Many of us have either never had a chance to build community or have had our access to community limited. Virtual spaces have given us opportunities to come together, however it is still difficult for the most severe of us.

Having caregivers or friends join in to virtual spaces can be helpful for those most severe, and so can shifting our spaces to prioritize those most impacted by the disease. This will be an ever evolving endeavor.

Building and sustaining community may include one-way communications, making sure the most severe know they are remembered, valued, and advocated for even if they can't respond. It may include using text-based communications, touch-based communications, or audio only communications. We meet each other where we are.

There are virtual communities on X, Facebook, Bluesky, Reddit, Discord, and through local ME Action groups available for community support. Use the hashtag #pwME #NeisVoid or search for Myalgic Encephalomyelitis on your browser to find more.

Here are some other transformative justice tools that have been helpful for me:

- **Pod mapping.** This section pulls from Mia Mingus' article on Pod Mapping [which can be accessed by clicking here](#).

Pod mapping was created by the Bay Area Transformative Justice Coalition in 2014 as a way to help people chart their “pods”. Pods are defined as **“the people that you would call on if violence, harm or abuse happened to you; or the people that you would call on if you wanted support in taking accountability for violence, harm or abuse that you’ve done; or if you witnessed violence or if one you care about was being violent or being abused.”**<sup>20</sup>

Pod mapping is one tool that be helpful for asking for support, preparing for crisis situations before they happen, and building out trusting relationships.

Mingus acknowledged that there are many who do not have adequate community support “...because of how capitalism, oppression and violence shape our lives.” As such pod mapping is a way to build and grow pods that do exist which may “...help build the conditions to be able to support people who do not have pods”.

---

<sup>20</sup> Mingus, M. (2016, June). Pods and Pod Mapping. *Bay Area Transformative Justice Coalition*. <https://batjc.wordpress.com/resources/pods-and-pod-mapping-worksheet/>

There are also worksheets and guides created by Spring Up for emergency preparedness, living with others, and handling conflict.<sup>21</sup>

[Click here to access the resources.](#)

- **Adjusting communication.** To preserve energy, or due to illness severity, many of us cannot communicate through verbal communication. Bateman Horne created a guide with crash cards to help.<sup>22</sup> You do not have to cut out each card, you can use them how they best suit you.

[Click here to access Bateman Hornes ME/CFS Guidebook.](#)

It may also be helpful to come up with or use other ways of communicating such as through different patterns of blinking, tapping on the bed in different rhythms, using sign language or braille, or any other forms of communicating. There are also text-based services like Relay and TTY that help disabled users communicate. Do what works for you.

## **Accessing Institutional Support and Funding for ME**

As it stands there are few official charities used to help fund those with Myalgic Encephalomyelitis. One foundation AMMES started a fund for individuals.<sup>23</sup>

---

<sup>21</sup> <https://www.timetospringup.org/resources>

<sup>22</sup> <https://batemanhornecenter.org/education/mecfs-guidebook/>

<sup>23</sup> <https://ammes.org/>

[Click here to access individual grants for people with ME/CFS from AMMES.](#)

Our community often relies on mutual aid efforts to raise money. Please email [empwrtc@gmail.com](mailto:empwrtc@gmail.com) to get specific names of ME/CFS specific mutual aid social media accounts.

**Mutual aid is described as “a collective effort to meet the community’s needs—usually with the understanding that the existing power structures are not meeting these needs.”<sup>24</sup> It is a form of survival work.**

[Click here to access the study guide for Dean Spades book Mutual Aid Building Solidarity During This Crisis \(and the Next\).](#)

Remember that crowdfunding may impact your SSDI/SSI or Medicare benefits. You may need to consult with or research other options including trusts, and ABLE accounts.<sup>25</sup>

[Click here to learn more about ABLE accounts.](#)

Of course, you may need help with filling out forms, getting access to social services and more. There may be free patient advocacy programs near you

---

<sup>24</sup> Welles, A.D. (2020, Jan). A study guide of Dean Spade’s 2020 book ‘Mutual Aid: Building Solidarity During This Crisis (and the Next)’. Radical In Progress. <https://www.radicalinprogress.org/spade-2020-1>

<sup>25</sup> <https://www.ablenrc.org/what-is-able/what-are-able-accounts/>

such as the patient advocacy foundation, or you can enlist help from others in our community.<sup>26</sup>

[Click here to access the Patient Advocate Foundation, Free Case Management.](#)

You may also need to contact your local legal aide office, local state bar referral program, or organization like the Legal Services Corporation.<sup>27</sup>

[Click here to access the Legal Services Corporation to learn more.](#)

Here are a few organizations that may be able to help further.

- National Disability Rights Network

[Click here to access the National Disability Rights Network](#)

Web address: <https://www.ndrn.org/>

- HCBS South

[Click here to access the Home and Community Based Services South website.](#)

Web address: <https://www.hcbssouth.org/>

---

<sup>26</sup> <https://www.patientadvocate.org/>

<sup>27</sup> <https://www.lsc.gov/>

- National Organization of Social Security Claimants' Representatives

[Click here to access the National Organization of Social Security Claimants' Representatives](#)

Web address: <https://nosscrhelp.org/help-me-find-a-representative/>

- National Disability Institute

[Click here to access the National Disability Institute.](#)

Web address: <https://www.nationaldisabilityinstitute.org/financial-resilience-center/benefits/>

## Part 5: Tools for Crisis and Emergencies

Emergency cards may be helpful to use when needing to communicate with emergency personnel. I have created cards with premade notes for your use.<sup>28</sup> [Please click here to access the cards.](#)

During medical emergencies it is also helpful to have masks ready for the trip. Contact your local mask bloc for help accessing personal protective equipment.<sup>29</sup>

[Click here to access a list of mask blocs.](#)

Sometimes you don't need to go to the emergency room, but need access to lab work in the home. Please research in home phlebotomy companies and self order-able labs. They do exist!

Preparing for emergencies may include filling out both Durable Power of Attorney forms and advanced directives to decide who gets to make decisions about your health if you are unable, and to what extent.<sup>30</sup>

[Click here to access AARP's list of advance directive forms per state](#) and [click here to access more information about power of attorneys.](#)

---

<sup>28</sup> <https://vashetc.com/collections/all>

<sup>29</sup> <https://maskbloc.org/>

<sup>30</sup> <https://www.aarp.org/caregiving/financial-legal/free-printable-advance-directives/>

## Psychiatric Holds

Some people with ME/CFS have been involuntarily institutionalized due to discrimination. This is a gross violation of human rights. Fighting for larger policy changes around institutionalization is critically important.

Organizations have created different informational resources for those experiencing psychological emergencies, psychiatric holds, or living in in-patient facilities.

- [Click here to access Blackline, a crisis support line that does not report to police.](#)

Web address: <https://www.callblackline.com/>

- [Click here to access “Don’t Call the Police, Resources by City”.](#)

Web address: <https://dontcallthepolice.com/>

- [Click here to access the Firewood Collective, Crisis Toolkit.](#)

Web address: <https://fireweedcollective.org/crisis-toolkit/>

- [Click here to access Project LETS, Crisis Support.](#)

Web address: <https://projectlets.org/crisis-support>

- [Click here to access Project LETS, Peer Mental Health Advocates Long-Term](#)

Web address: <https://projectlets.org/peer-support>

Remember, living in or being held in a psychiatric facility does not mean you do not have rights. These sites may help you learn about your rights while in a facility:

- [Click here to access the Mental Health America Website](#)

Web address: <https://mhanational.org/issues/mental-health-rights>

- [Click here to access the National Alliance on Mental Health resource regarding HIPPA and mental health hospitalization.](#)

Web address: <https://helplinefaqs.nami.org/article/254-hipaa>

- [Click here to access the 42 U.S. Code § 9501 - Bill of Rights](#)

Web address: <https://www.law.cornell.edu/uscode/text/42/9501>

I hope these tools are of helpful if you ever need them. These tools are not always accessible to everyone and are not a replacement for treatments and cures. My hopes are that they may help alleviate suffering, while navigating the societal and institutional level barriers that exist.

## **Part 6: Tools for Caregivers, Supporters, Friends, and Others**

“I wanted to tell them that rest is what we make possible through resistance to racialized capitalism, imperialism, cisheteronormativity, transphobia, fatphobia, and ableism”. – Trey Washington in “Rest is Not Resistance, and that is okay”.

For those who wish to support people with ME/CFS, we need you. My motto is “see a need, fill a need”. Support can come in many different forms.

We need advocacy but we also need action. Everyday. We need understanding, empathy, and real steps towards larger changes.

Support can look like creating and supporting mutual aid efforts, creating and donating to crowdfunding campaigns, donating ppe and purifiers to local mask blocs, supporting rights to gender affirming care, supporting reproductive justice, opening your house to house those in need, sending groceries and hygiene products, helping people fill out forms or calling doctors, and sharing information about new medications or talking to caregivers who may not be well versed in this disease.

Support also looks like preventing the worsening of ME/CFS by helping to stop the spread of viruses which may prevent ME/CFS from occurring in the first place. Mitigation of viral spread includes learning about the contexts in which respiratory illnesses spread, being mindful of societal issues such as climate change, educational system issues, labor issues, inadequate airflow and lack of clean air standards in hospital and clinical

settings, war, and genocide.

It is vital that we make the connections between and across our movements for liberation, or else efforts towards curing, managing, or treating ME/CFS may replicate harmful processes that already exist. Here are a two of my favorite zines:

- Sabrina Sims, “Masking through Blackness”<sup>31</sup>

[Click here to access Sabrina’s work](#)

- Rimona Eskayo & Sheyam Ghieth, “Mask Up We Need You”<sup>32</sup>

[Click here to access Mask Up We Need You](#)

If you are an organization or involved in philanthropic efforts, please do not forget the dire need for individuals to have access to funds to survive their day-to-day. While research and funding for biomedical solutions is urgent, there is a critical need for funds meant to help people survive **now**. **People are dying from lack of access to housing, medication, and accessibility aids**. We need more funds to go directly into the pockets of the most impacted.

---

<sup>31</sup> Sims, S. (2024). masking through blackness: mask fitting, self expression & community care? <https://www.starlyart.studio/shop/p/masking-thru-blkness-phys>

<sup>32</sup> Eskayo, R. & Ghieth. (2024). MASK UP, WE NEED YOU: Palestinian Solidarity, Covid-19, and the Struggle for Liberation. <https://rimoskyo.com/shop/p/mask-up-we-need-you-palestinian-solidarity-covid-19-and-the-struggle-for-liberation>

We also need more people with platforms to speak up about the lack of funding for ME/CFS which has led to mass and persistent suffering. We could use your help sharing our stories, with consent, helping us reach larger news stations and other forms of mass media. Help us push for new treatments, harm reduction, equitable care, and accessible treatment pipelines.

## **Floating into a Different Realm**

I hope this zine has helped you. It is difficult to exist in a world that spends money on policing and war — causing mass suffering. You, are not alone. Rejecting individualism will help us continue to survive in this world. We need each other, and we are all we got.

I hope this zine will inspire more questions and analysis about how we can center disability justice and the impact of organized abandonment into our advocacy, frameworks, and everyday lives.

We were never meant to do this alone.

I am sorry for how people have treated you.

There are people fighting for you, and for me.

We take it one day at a time.

You are worthy of treatment and support.

Your worth is not defined by what you can *produce* for others.

You are valued, treasured, and loved just by being you.

Sincerely,

Victoria

