

# ME/CFS CRASH SURVIVAL GUIDE

The Art of Living with ME/CFS



# Introduction

*The considerations offered in this guidebook do not replace the medical interventions prescribed by the user's care team and should be evaluated prior to implementation.*

## Guidebook Utilization

The ME/CFS Crash Survival Guide is designed for the patient, their support network, and care team to:

- Understand ME/CFS and its defining characteristic of post-exertional malaise (PEM).
- Help the individual prepare in advance for a crash/PEM episode ensuring their critical needs are met.
- Offer adaptive guidance in carrying out everyday living activities that support energy conservation with ME/CFS.

Chapters can serve as stand-alone handouts or as a part of the guidebook's entirety. Select information is repeated or expanded upon in each chapter.

A glossary and terms section is located in the back of the book addressing commonly used abbreviations, terms, and diseases referenced throughout the guidebook.

## Appreciation

This guidebook was made possible with the collaborative effort and expertise shared by eight professionals impacted by ME/CFS. Their time, dedication, and heart are the foundation of this inclusive product and BHC offers our sincerest appreciation for their work.

**ME/CFS Crash Survival Guide 1st Edition**  
Copyright © 2022 Bateman Horne Center  
All rights reserved.

All material found in this publication is owned or licensed by BHC. Users may: post material from this publication to another website or on a computer network for personal, noncommercial use; view, download, and print materials from this publication for personal, noncommercial use. Materials from this publication may be reproduced by media personnel for use in traditional public news forums. Users may not: modify the materials, use the materials for any commercial purpose or for any public display (commercial or non-commercial), attempt to decompile or reverse engineer any software contained in the publication, remove any copyright or other proprietary notations from the materials, use information or materials found in this publication for any other purpose including any use by organizations or legal entities without our prior written permission. Bateman Horne Center reserves sole discretion and right to deny, revoke, or limit use of this publication. Any claim relating to this publication shall be governed by the laws of Utah without regard to its conflict of law provisions.



# Table Of Contents

<a href="#">What is ME/CFS and Understanding a Crash</a> .....	1
<a href="#">When a Crash Strikes</a> .....	4
<a href="#">Emergency Contact and Health Information</a> .....	6
<a href="#">Conserve Energy</a> .....	7
<a href="#">Communication</a> .....	10
<a href="#">Turn Down the Volume &amp; Allow Recovery</a> .....	11
<a href="#">Medication</a> .....	13
<a href="#">Nutrition and Hydration</a> .....	15
<a href="#">Activities of Daily Living</a> .....	17
<a href="#">Nurture Yourself</a> .....	21
<a href="#">Living with a Chronic Illness &amp; Avoiding a Crash</a> .....	22
<a href="#">Thoughts of Suicide and Holding On</a> .....	24
<a href="#">Making the Decision to Seek Emergency Care</a> .....	26
<a href="#">Travel and Crash Considerations</a> .....	28
<a href="#">Appendix</a> .....	29
<a href="#">Crash Care Kit Essentials</a> .....	30
<a href="#">Caregiver Guidance</a> .....	31
<a href="#">Glossary</a> .....	33
<a href="#">Downloadables</a>	



# What is ME/CFS and Understanding a Crash

Living with diseases like ME/CFS requires the affected individual to understand the defining characteristic of the disease, post-exertional malaise (PEM), and what it means when the body is pushed into a deep state of PEM, known as a crash. Awareness about how crashes occur, and how to meet the body's critical needs during a crash, will afford the individual more control over their healing process and living with the disease.

## What is ME/CFS?

*Myalgic encephalomyelitis/chronic fatigue syndrome, commonly referred to as ME/CFS, is a disease characterized by profound fatigue, cognitive dysfunction, sleep abnormalities, autonomic manifestations, pain, and other symptoms that worsen with activity.*

## Understanding ME/CFS, PEM, and a Crash

The body functions on an energy consumption and production system. When energy is expended an equal or greater amount of restoration is needed to return to baseline. This often comes in the form of rest, supportive medication, nutrition, and rehydration. Each day this energy balance must be restored for the body to function and perform properly.

In ME/CFS when the cellular energy expenditure exceeds the body's ability to produce energy, the result is a drastic reduction in functional capacity, which was not present prior to disease onset. This physiological phenomenon is known as post-exertional malaise (PEM) which represents a temporary worsening of all aspects of the illness until some degree of energy stores are restored.

**PEM is the body's inability to recover normally following physical, cognitive and emotional effort, as well as orthostatic, environmental, and sensory stress.** The onset of PEM is often delayed in presentation, occurring 12- 72 hours after the trigger(s), and can last hours to weeks and even months at a time depending on the severity of the energy insult.

Patients experiencing PEM often describe "flu-like symptoms" (profound fatigue, weakness, fever, headache, dizziness, sore throat, chills, muscle and joint pain, enlarged lymph nodes), worsened cognitive symptoms (insomnia, brain fog, word-finding and concentration difficulties), and increased sensitivity to stimuli (noise, light, sound, odor, movement). **Periods of prolonged and severe PEM are referred to as a crash.**

Crashes can vary from person to person and episode to episode. Some may be mild resulting in an inability to carry on with daily activities such as cognitive processing or physical tasks. Others can be so severely debilitating it becomes life-threatening due to the individual's inability to walk, talk, eat, drink, or sit upright.

Once in a crash, the individual **must allow** their body to recover before resuming activities. It is critical to allow restoration and to avoid a repetitive push-crash cycle.



## The Push-Crash Cycle

*It is important to understand that crashes harm the body. Repeated crash sequences will threaten an individual's ability to return to their former baseline function, worsen or expedite harmful disease processes, and hinder the recovery process.*

A push-crash cycle is when the individual pushes through the PEM, worsening their physical state, resulting in a crash. Further harm occurs when an individual pushes during the crashed state, never allowing for true energy restoration. This is a repeated injury and insult to the body, which over time will have lasting consequences and decrease overall functional ability.

**Consider a stubbed toe:** when you stub the toe once, it hurts but heals back quickly. When you continually stub the toe each day, the injury and recovery time worsen and grow exponentially. The body's cellular energy demands function in the same way. When constantly depleted and pushed into a "debt zone" the body will need even more time, and shifting of body functions, to replenish those stores.

Think of a crash as the body's way of forcing hibernation to heal. A patient experiences a physical and mental shutdown while their body tries to protect itself as it focuses energy utilization on basic bodily functions. It is critical not to push through a task or activity during a crashed state to avoid perpetuating harm.

Crash restoration takes time, knowledge, patience, and support.

## What Causes a Crash?

There are many ways in which the body uses energy. Each of these accumulates an energy debt throughout the day that must be paid back. While much of life is performed at a subconscious level, it is important to be mindful of the ways the body is taxed to ensure adequate restoration is accounted and planned for.

Energy consumers and stressors come in the form of:

- **Physical** (movement, metabolism, respiration, sitting, standing, etc.)
- **Cognitive** (thinking, processing)
- **Emotional** (eustress, distress)
- **Orthostatic** (upright posture = time with feet on the floor, sitting or standing)
- **Environmental and Sensory Stimuli** (noise, light, sound, chemicals, movement, etc.)

The threshold response to energy utilization is much lower in ME/CFS, and it is important to be mindful of the ways everyday functioning impacts your cellular energy. Let's take a common activity such as an audio or video phone call and dissect how we tap into each of these energy consumers.



**Example: A 10-minute audio or video call**

Physical	Cognitive	Emotional	Orthostatic
Sitting upright Holding phone Speaking Actively listening, visual processing Maintaining: blood pressure, heart rate, body temperature, respiration Filtering external and sensory stimuli: noise, light, movement, odors Reacting: laughing, crying, etc.	Filtering external and sensory stimuli: noise, light, movement, odors Interpreting: facial expressions, tone, language used Processing: what is being said, formulating a response, paying attention, memory and conversation recall	Good or bad emotions based on: discerning moods and emotions of others, interpreting tone of voice, non-verbal cues, language used, topics discussed, etc.	Time with feet on the floor: sitting, standing, walking (Even when you are sitting with your feet propped up, you are still sitting against gravity which will force neurological and circulatory compensatory mechanisms to kick in if you have dysautonomia.)

As you can see, this 10-minute conversation tapped into each piece of the body's energy reserve. This is not to imply that an individual should not engage in conversation, but to point out how seemingly "simple" activities still contribute to the overall energy demand in a day.

Management of energy consumers is key to crash prevention and can affect recovery time.

The remainder of this guidebook will offer ways to approach living with diseases like ME/CFS and equip the reader with knowledge about how to prevent and survive ME/CFS crashes.



# When a Crash Strikes

This chapter can serve as a stand-alone handout to share or reference when in a crash. Select information is repeated or expanded upon in each chapter of the guidebook.

1. Alert Emergency Contacts
2. Meet Critical Needs
3. Conserve Energy
4. Turn Down the Volume & Recover
5. Maintain Wellness
6. Prevent the Next Crash

## Step 1. Alert Emergency Contacts

Inform your emergency contacts and ensure they have access to any pertinent health information in case they need to act on your behalf.

- Ask your contacts to check on you periodically with the understanding that you may not be able to engage in conversation at various stages of your recovery.
- Have medication cards with medical provider contact information, a list of your known diagnoses and allergies in your bedside Crash Care Kit, purse or wallet, and on your refrigerator.

## Step 2. Meet Critical Health Needs

Have your critical crash care needs prepared at your bedside. See the [Crash Care Kit Essentials](#) sheet for a quick one-page checklist.

### Vitals

- Automated blood pressure cuff
- Pulse oximeter (measures oxygen and heart rate)
- Thermometer
- Watch/device to measure heart rate and allow you to reference date/time
- Life Alert or have the means to contact emergency services (if warranted)
- Medical bracelet

### Hydration

- Bottled water and pre-made bottles with rehydration solution
- Electrolyte drinks (such as Gatorade, Powerade, etc.)

### Nutrition

- Consider foods that can be consumed in various ways (chewed, drank, sucked on).
- Avoid foods that trigger known intolerances or mast cell response.

### Medication

- Medication and allergy cards
- Pill reminder alarms
- Pill boxes
- Set aside as needed (PRN) medications and indicate why you take them.



### **Communication devices and cards**

- Pre-made cards that communicate essential needs
- Devices that can be utilized in place of speaking: phone, iPad/iMac, laptop
- Keep your communication devices charged.

## **Step 3. Conserve Energy**

### **Aggressively minimize all movement and activity**

- Delay unnecessary tasks
- Delegate tasks to others
- Decrease speed and frequency of movements
- Stage environment (in advance) to accommodate for rest breaks if/when movement is necessary.
- Have your Crash Care Kit by your bedside to ensure critical needs are met.

## **Step 4. Turn Down the Volume & Recover**

Decreasing environmental and physiological stimuli can help you conserve energy and recover sooner. Consider the following ways to minimize external energy demands.

### **Sensory and environmental stimulus**

- Vision (lights, sunlight, device lights, reading, watching media)
- Sound (excess, recurrent, overstimulating noise)
- Touch (clothing, sheets, physical touch, points of pressure)
- Odors (good and bad)
- Ambient temperature
- Chemicals

### **Brain events**

- Cognitive demands (working, talking, reading, processing TV shows, conversations)
- Emotional stressors (positive and negative emotions utilize significant energy)

### **Physiological fluctuations** (may occur in a crash and need periodic attention)

- Body temperature
- Metabolism
- Heightened reactivity to normally tolerated food, medications, environment, etc.
- Body positioning
- Headache and neuroinflammation

## **Step 5. Maintain Wellness**

It can be easy to fixate on what caused the crash or engage in self-blame, but this will not help your emotional, cognitive, or physical energy recuperation. Instead find ways to practice self-compassion and wellness to expedite your recovery.

## **Step 6. Avoid the Next Crash**

While crashes are an inevitable part of ME/CFS, it is important to try and avoid continual push-crash cycles and prolonged deep crashes. Think of these as an injury to your body, and the more severe the injury the harder it is for your body to recover. Be patient with yourself as you learn your thresholds and don't beat yourself up if you go into a crash. That's why you have your pre-made Crash Care Kit full of your essentials to help you through it!



# Emergency Contact & Health Information

Meeting the body's basic and critical needs during a crash is essential to recovery. This starts with setting up assurances that someone can check on you and is informed about your medical needs.

**Contact someone** in your household or on your emergency care list (family member, neighbor, co-worker, friend, etc.) to let them know you are experiencing a crash and may need help. For those living alone, planning ahead may include utilizing a medical alert system to summon for help when needed.

- Keep a list of your emergency contacts in your bedside Crash Care Kit, on your refrigerator, and in your purse or wallet.
- Include the contacts' name, phone number, and relation to you.
- Program ICE (in case of emergency) contacts into your phone. Emergency personnel will look for these names first.
  - Have these individuals labeled with ICE in front of their name and keep them in your "favorites" section for ease of access.
  - Consider creating a pre-formed text group that can be quickly accessed to ease memory recall. These may be the same or different than your ICE contacts.
  - Indicate their relation to you in one of the contact fields.

**Keep your medical and physician contact lists accessible** to you, your support network, and emergency personnel. Consider printing a copy of your patient summary from your last visit with your ME/CFS provider and have it available for reference.

The following downloadable lists, which can be typed in and printed, are in the [appendix](#) of this guide.

## Medication list

- Include current medications with date, time taken, and reason for taking.
- Include rescue and PRN (as needed) medications.
- Discontinued medications list.
  - This list is helpful for your tracking purposes and for providers to know what you have tried, what has/hasn't worked, and why.

## Allergy list

- List allergies, symptoms, interventions that help, and indicate if the reaction is dangerous (anaphylaxis) or is an allergy/intolerance.

## Diagnoses list

- List your known diagnoses, how long you have had them, and the provider that diagnosed you (if known).
- If not yet diagnosed, but is suspected, list these and make a clear distinction that it is not a confirmed diagnosis.

## Physician list

- List your doctors' names with specialty(ies), phone number(s), and why you see them.



## Conserve Energy During Movement & Daily Life

A crash is an indication that the body is in danger. Movement and energy expenditure needs to be aggressively minimized to shorten the length and intensity of the crash.

The following acronym can be used to help guide one's choices around movement and energy expenditure: **PEO** which stands for **PERSON, ENVIRONMENT, and OCCUPATION**.

### P = Person

What choices can you make (regarding your “**PERSON**”) or have someone help you do by way of positioning, speed and frequency of movement, sequencing of activities, and duration of movement to make movement and energy conservation more successful?

### Considerations

- What is your **position**? Are you lying flat, minimizing the impact of gravity; or are you upright, partially upright, or moving limbs above “flat” off of the bed or sofa?
- Maximize rest by lying **HORIZONTALLY** or flat, such as on a bed or couch. More energy is required by the body to maintain positions that are not flat or horizontal.
- Performing activities in a lying, side-lying or semi-reclined position conserves more energy over doing the same in sitting or standing positions.
- Keeping the limbs close to the body minimizes energy demands.
  - Keep elbows tucked and supported including using pillows, thighs, tables, etc.
  - Take small steps to avoid greater energy demands on the legs and trunk.
- Move slowly and monitor for shortness of breath, changes in breath pattern as a sign of moving too fast for your energy system.
- **Chunk activities**. Do one or two pieces of the task, rest, and then go back to the task.
  - When eating, bring the fork/spoon to your mouth for 3 separate bites of food. And then stop and rest for 3-4 minutes. Repeat this pattern until finished.
  - When dressing, put on one clothing item at a time then rest (lay horizontal for 1-2 minutes before putting on the next clothing item).
- Avoid completion compulsion as it is contraindicated for people living with ME/CFS. Adopt kindness for yourself, set limitations and protect your boundaries.
- When orthostatic intolerance is a factor, decrease the effects of gravity by avoiding standing or upright body positions and use adaptive device(s) such as a reacher device or a sock donner.



## **E = Environment**

What can be done to your environment to make movement and energy conservation more successful? Think about your environments such as work, home, and outside surroundings.

### **Considerations**

- Stage chairs or stools throughout the living environment to enable rest periods between the bedroom, bathroom, kitchen, etc.
- Keep necessary items in your Crash Care Kit near your bed.
- Have staging areas in your home where you place things to be taken to another part of the house to avoid unnecessary trips.
- Are there changes to your home environment that may assist you? Make your home more accessible for you and add mobility aids if helpful.
  - Consider utilizing one level of your home rather than navigating stairs and multiple floors.
  - Decrease clutter in the home (when not in a crash).
  - Is there a mobility aid or device that can help you move around in a particular environment, or during times where extra support and energy conservation is vital such as during a crash? These may include, a power wheelchair or scooter, wheeled walker with a seat, or a folding cane.
  - What changes to your environment would help you to use a mobility device?



## O = Occupation

Occupations are the things that you do to take care of yourself (dressing, showering, brushing teeth, managing your medications), your environment (taking care of pets, housekeeping, meal preparation), and interacting in the world around you (work, play, leisure, social interactions).

It's important to set limits and protect your boundaries. Go with the flow and know that when you are in a crash it is prescriptive to do the bare minimum required to complete tasks. Recover and allocate energy only for what is essential or most important to you.

### Considerations

- Is the activity truly necessary, or can it wait until the crashed period has resolved?
- How important is it for you to do this particular activity yourself?
- Can the activity or task be delegated or postponed?
- Can the task be adapted in technique? Can it be simplified or modified to use less energy to complete? (frozen pre-cut vegetables vs. preparation to chop/peel vegetables).
- Can the activity be broken down into smaller segments (chunks) that you can space out and allow rest between the steps? For example, with a task that requires a more upright posture, consider breaking this into segments that accommodate 5 minutes of activity followed by a 10-15 minute rest break before engaging in the next part of the task.
- Can the goal or task be achieved without the same level of detail to ensure the need is met without unnecessary energy expenditure? In other words, **can you simplify the activity?**

In the end, energy conservation is vital to both crash recovery and lifestyle management when living with ME/CFS. Listen to your body, hone in on your physiological cues (increased heart rate, respiration, brain fog, etc.) and heed the warning signs. **Lifestyle adjustments and modifications are key to managing your illness and decreasing incidences of crashing.**



# Communication

## Meeting Your Critical Needs

During a crash, it can be difficult to communicate with others. This section references [downloadable and printable communication cards \(located in the appendix\)](#) to help you communicate your needs. Consider keeping these in your bedside Crash Care Kit or on your electronic device to point/show your caregiver, loved one, or support services.

### Communication cards

When in a crash you may be unable to think clearly, form words or sentences, and process information. Utilize the communication cards in a way that helps you and your supporters reach an understanding of your needs. For example, if you are unable to process looking at the cards, have your support person say the word and point to the item on the card until they reach your needs.

### Communication considerations

- Emergencies
  - In the event of an emergency, have a life alert device on or near you, and pre-programmed emergency contacts in your phone.
  - Add emergency contacts to “Favorites” and in the “Emergency Medical ID” section of your phone (as applicable).
- Consider pre-programming text groups which can be easily accessed in a crash.
- Label ICE (in case of emergency) next to your emergency contacts in your phone.
- Have pre-made cards available to communicate:
  - Critical needs (food, water, medicine, toileting, etc.)
  - Symptoms and sensitivities (nausea, light or sound sensitive, etc.)
  - Comfort needs (blanket, heating pad, etc.)
  - Emergencies (call 911, chest pain, etc.)
- Devices and modes of communication
  - Keep your electronic devices charged.
  - Consider a long charging cable that is accessible to you in bed or on the couch.
- Pre-make lists of your own needs if they are not already available on the communication cards provided in the [appendix](#).



# Turn Down the Volume & Allow Recovery

There are many environmental triggers and stimuli that can precipitate and/or prolong crash recovery. Try to minimize all energy demands, sensory and physical stimuli, and allow your body the space to restore and recharge.

The following provide supportive interventions and considerations to take into account while you recover from a crash.

## Sensory and environmental stimuli

- Sight/visual
  - Eye mask
  - Tinted lenses
  - Hat with visor (to block overhead light)
  - Light blocking curtains
  - Dim electronics (put in nighttime mode)
  - Blue light reflective glasses (for phone and computer use)
- Sound
  - Earplugs
  - Noise-cancelling headphones
  - Noise machines (blue, red, pink, brown, white noise)
- Touch
  - Loose clothing
  - Non-abrasive linens and bedding
  - Be mindful of contact with perfumes, colognes, detergents, dyes, cleaning products.
  - Weighted blanket (deep pressure can be soothing, or it could be too much)
  - Be mindful of positional pressure points.
- Odor
  - Keep cooking odors to a minimum.
  - Ask caregivers and visitors not to wear perfumes or utilize body care products with fragrance when visiting.
  - Avoid odorous plants, trees, candles, scented products, etc.
  - Use low or non-perfumed soaps and detergents.
  - Avoid chemicals as much as possible. Consider natural or plant-based products.

## Cognitive processing and brain events

- Minimize cognitive demands.
- Limit reading, speaking, texting, processing TV shows and media.
- Try to avoid making any big decisions during a crash.



## Emotional stress/stressors

- The crash itself can be emotionally draining, however, it is important to avoid or minimize contact with triggering stimuli.
- Avoid engaging in emotionally charged conversations, movies, shows, social media or news.
- Keep in mind positive and negative emotions both utilize energy.

## Physiological fluctuations

- Body temperature may fluctuate when in a crash, so have layers to put on and take off.
- For body positioning, make sure you have support for the spine and limbs to prevent muscle tightening, soreness, or poor circulation.
- For headaches and symptoms of neuroinflammation, consider using compresses for eyes and ice caps for the head.

## Orthostatic stressors

- Being upright can drain energy stores and exacerbate the crash itself.
- If you must be upright during your recovery, utilize orthostatic supports.
- Compression clothing (be mindful of creases and indents)
  - Try to cover as much surface area on the body as possible.
    - Thigh-high or above (abdominal) compression clothing have been shown to be the most helpful.
    - Consider compression tops to account for arms and abdominal surface area.
- Rehydration solutions
- Saline IV fluids (ordered by your provider)
- Salt food liberally unless otherwise directed by your healthcare provider.



# Medication

**Disclaimer: consult with your medical care team prior to introducing any new medication or supplement to your regimen. Ensure your provider is aware of your supplementation and is monitoring closely.**

Brain fog can make it easy to forget your medication routine when you are experiencing PEM or moving into a crash. Delayed or missed medications can exacerbate a crash and/or slow your crash recovery.

- Make a list
  - Utilize the [downloadable medication lists](#) in this guidebook or create your own.
  - Include current medications with date, time you take it, reason for taking it, and the prescribing doctor.
  - Be sure to include a list of the medications that you use PRN (as needed) or are considered your rescue medication during a crash (such as Zofran for nausea).
- Set medication alarms
  - In the alarm description, label out what meds you are to take or add a prompt that will remind you to double-check the medications you are taking at that time.
- Double-check yourself
  - Put colored labels or a sticker/marker stripe on med bottles based on when you take them during the day. Consider aligning these colors with your [medication cards](#).
  - Use pill containers that have day and time containers and pre-fill when not in a crash.
  - Leave the pill flap open after you have taken those meds so you know where you left off.
  - Consider mixing medications in pudding or yogurt to ease swallowing demands while also receiving some nutrients and coating an empty stomach (unless contraindicated).



# Possible Rescue Meds and Supportive Interventions

**Disclaimer:** consult with your medical care team prior to introducing any new medication or supplement to your regimen. Ensure your provider is aware of your supplementation and is monitoring closely.

Each patient's crash and PEM recovery will be different and require an adaptable patient-specific approach. Work with your medical care team to establish the most appropriate interventions for you.

The following are not prescriptive for each patient, and only represent areas of consideration listed by symptom or physiologic driver.

## Medications or supportive interventions to alleviate or minimize

### Body aches, nerve pain, headaches

- heating pads
- foot warmers
- ice packs/hats
- acetaminophen
- topical agents
- prescription meds

### Sleep disturbances

- melatonin
- sedating antihistamines
- supplements
- prescription medications

### Orthostatic intolerance

- oral fluids
- sodium and electrolyte packets
- IV fluids
- prescription medications

### Nausea, reflux, heartburn

- ginger
- peppermint
- anti-nausea agents
- antacids
- famotidine
- omeprazole
- prescription medications

### Diarrhea or constipation

- probiotics
- digestive enzymes
- Imodium
- stool softeners
- prescription medications

### Allergies, asthma, or mast cell activation syndrome (MCAS)

- low histamine diet
- antihistamines (H1 blockers)
- famotidine (H2 blocker)
- prescription medications

**Note:** many of these treatments are available over-the-counter, while others are prescriptive and require professional supervision or a written script from your provider.



# Nutrition and Hydration

**Disclaimer: consult with your medical care team prior to making any drastic diet changes or adding additional supplements. Increased sodium consumption may be contraindicated based on medication and pre-existing conditions. Ensure your provider is aware of your supplementation and is monitoring closely.**

The following are examples of quick, easy, nutrient-rich foods and hydration options that can be integrated into everyday living with ME/CFS, OI, and during a crash. In living with ME/CFS you may experience fluctuating motility, stomach and body sensitivities, nausea, etc. Be careful when introducing any new items into your system. Start slow, work with your medical care team while being mindful of any known intolerances or mast cell triggering substances.

This list is not exhaustive nor prescriptive and serves only as a reference point to keep you thinking. You must make your own patient-specific choices and consult with your medical team on what is most appropriate for you.

## Rehydration and OI examples

- Electrolyte options such as Pedialyte, Ultima, Liquid IV, Nunn, Triorals, Goos, Bonks, Drip Drop, Nunn, Zipfizz, HydroMATE, etc.
- Sports drinks such as Gatorade, Powerade
- Vegetable or fruit drinks such as V8 juice, coconut water
- Sources of additional sodium may include S! Caps, Himalayan salt, mustard packets, pickle juice, beef or chick broth

(Be sure to follow your provider's instructions surrounding increased sodium consumption.)

When unable to chew, consider pre-made options that can both hydrate and provide nutrients.

- Freezing and sucking on electrolyte, fruit/veggie juice, beef/chicken broth cubes
- Smoothies
- Protein or meal replacement options such as Ensure or Boost
- Fruit and vegetable juices such as celery, carrot, cucumber, watermelon

## Bars that provide nutrients and calories

- Honeycomb or protein bars
- Rx bars

Packaged or dried food options that offer quick nutrition to the body and are easy to keep in your Crash Care Kit or in areas of the home you frequent. Some examples include:

- Dried fruit (mango, pineapple, apples, cherries, coconut)
- Nuts (cashews, pistachios, Brazil nuts, macadamia nuts, almonds)
- Trail mix
- Seeds (pumpkin, sunflower, pepitas, chia)
- Dried/seasoned spinach, snap peas
- Peanut butter stuffed pretzels, crackers, tortillas
- Tuna or chicken packets
- Jerky (beef, salami, bison, etc.)
- Honey sticks
- Nut butters (almond, cashew, peanut, multi-seed)
- JELLO or pudding



### Pre-made or easy to make foods

- Lentils, rice, quinoa
- Smoothie blocks (just add milk or water)
- Soups, broth, ramen, Pho, etc. that can be frozen or thawed
- Oatmeal, yogurt, Just Crack An Egg (add an egg cups)
- Pre-made meal delivery options
- Baby food can be good for food sensitivities (such as histamine intolerance) and when there is limited energy for chewing.

### Fruit and vegetable considerations that are high in nutrients and minerals

- Cucumbers
- Carrots
- Strawberries
- Peaches
- Spinach
- Blueberries
- Tangerines/clementines
- Raisins
- Potatoes
- Broccoli
- Avocados
- Edamame
- Bananas

Be mindful of diet restrictions and slowed gut motility during a crash.



# Activities of Daily Living

Activities of daily living, known as ADLs, are tasks that involve self-care. Common ADLs include personal hygiene, bathing, toileting, dressing, eating, sleeping, and moving around in our environments. These tasks are often carried out without awareness of the energy demand that can be placed on our bodies while performing the task.

People with ME/CFS may experience movement challenges due to a number of factors such as how much, what way, sensory overload, energy utilization, orthostatic intolerance, neuroinflammation, etc. When performing ADLs, it is important to **move in an intentional way** that allows your body to function, while accommodating symptoms that are specific to you.

This resource outlines ways to approach self-care while conserving energy during a crash and as a part of living with ME/CFS.

For more on energy conservation, please refer to the guidebook's section on person, environment, and occupation ([PEO](#)).

## Adaptive devices

Adapted devices can be helpful with energy conservation, but it is also important to be strategic in their utilization. Those which require more energy and steps to use are counterproductive to your efforts.

Adapting your technique, approach, and position may be more beneficial in some instances rather than using an assistive device. **Be strategic and only utilize what will truly assist and make your life easier and more functional.**

There are some items that your medical provider could deem necessary to maintain your health and independence. Consider asking him/her to write a letter of medical necessity (LMN) and see how much your insurance may cover.

**Note:** purchasing items can become expensive. This list is only intended to serve as a reference guide and requires you to work within your means.

Slowly accumulate what you need over time. Many of these items can be found in thrift or second-hand medical equipment stores. Others may be easier and more cost effective to acquire online.



## Crash Considerations

When in a severe crash, you may be unable to maintain even basic hygiene. Be kind to yourself wherever you are in the crash recovery process. Prioritize how important the self-care task is and whether assistance is needed.

### Bathing

- Body
  - No-rinse bathing wipes
  - No-rinse body wash
  - No-rinse peri wash (for sensitive areas)
- Hair
  - Pre-moistened shampoo wash gloves
  - No-rinse shampoo or shampoo caps
  - No-rinse conditioner
- Teeth
  - Spitless/rinseless toothpaste
  - Oral care swabs

### Toileting

- Bedside commode
  - Adjustable handle rails will help you lower yourself while transferring directly from the bed's surface or on and off the commode.
  - Consider using commode liners which are absorbent hygienic bags that eliminate cleaning soiled commode pails.
- Bedpan
  - When using a bedpan in severe instances, be mindful of pressure points or skin breakdown while lying on a bedpan.
  - Practice post-bedpan hygiene by ensuring the body and bed are both dry.
- Tongs and other long-handled toileting aids
- Personal cleaning/toileting wipes
- Raised toilet seat
- For men's urinals, consider disposable urinal bags.
- Bed pads or Chux pads for leaks, or as an aid during in-bed toileting
  - These can also be used under your fitted sheet to absorb body sweat (be sure to change frequently).

### Eating

- Bedside snacks and hydration that are premade and easy to consume
- Reference the [nutrition and hydration section](#) of the guidebook for more details.
- Adaptive eating utensils

### Dressing

- Dressing should be a low priority concern when in a crash, however, keep in mind:
  - Clothing should be loose fitting, breathable, and changed every 2 days.
  - If clothing is constricting (compression clothing) be mindful of skin indents and blood pooling on either side of a fold or elastic band.
  - Placing easy to put on/take off clothing next to your bed can be helpful.



## **Movement aids**

- Bedrail (help with rolling and getting in and out of bed)
- Walker or cane when moving around
- Grab bars in bathroom and throughout house
- Wheelchair (manual or power)
- Transfer or pivot disc to help when transferring between surfaces

## **Living with ME/CFS**

**Remember, some adaptive equipment may not be conducive to energy conservation as a whole. Implement items that aid you in your daily functioning.**

**Note:** some items may be repeated from the previous section.

## **Self-care**

- Time of day
  - Consider taking a shower in the evening so you have the night to replenish your energy stores.
- Minimize drying effort
  - Terry cloth bathrobe to be used instead of a bath towel
  - High absorbency microfiber turban for use after washing hair
- Minimize need for hair washing
  - Shorter hairstyles
  - Dry shampoo
  - Shampoo caps
- Teeth
  - Spitless/rinseless toothpaste
  - Oral care swabs
  - Electric toothbrush (if noise/vibration are not an issue)
- Possible adaptive aids
  - Long-handled sponge
  - Adjustable shower head
  - Shower chair with handles (especially if orthostatic intolerance is present)

## **Toileting**

- Orthostatic intolerance and positioning considerations
  - Minimize bending and positional changes
    - Long-handled toilet aid or toilet tongs
    - Bidet
  - Toilet riser to help get on/off more easily
  - Be mindful of leaving your legs hanging against gravity for too long. A footstool may be helpful.



## **Dressing**

- Consider clothing that is easier to put on and take off.
- Have clothing items laid out the night before and keep close to the bed for ease of access.
- Loose clothing
- Compression clothing if OI is present
- Adaptive equipment considerations
  - Reacher
  - Shoehorn
  - Slip-in shoes
  - Sock aid
  - Dressing stick
  - Leg lifter
  - Elastic shoelaces
  - Button or zipper assist devices

## **Mobility and assistive devices**

- Bed assist ladder or bedrail to help with rolling/positioning and getting out of bed
- Rollator with seat and capacity to carry small objects
- Wheelchair
- Grab bars in bathroom and throughout house (as needed)
- Stand assist bars for couch or sofa chair
- Walker or cane for stability
- Reacher/grabber
- Home modifications for improved accessibility, such as a ramp, stairlift, walk-in shower



# Nurture Yourself

When living with ME/CFS, it may be tempting to let your mind fixate on what caused the illness or a crash. You may even feel yourself slipping into a state of self-blame. Simply put, this is not helpful to your crash recovery and is not supportive when living with the disease.

Remember, not every crash can be timed, explained, or understood; and neither can disease onset. Consider taking an opposite approach and rest in the moment rather than analyze the unexplained.

Be mindful of cognitive and emotional energy drainers that may lead to a crash and/or prolong your crashed state. Allow yourself to heal and restore your health, this is the only *necessary* task when in a crash.

***Lay back and let the boat carry you until you feel healed enough to get back up.***

## **Let yourself rest!**

- Stay horizontal
- Decrease sensory stimuli
- Utilize calming techniques

## **Cultivate wellness**

- When not in a crash, practice wellness techniques that help calm your system.
- Meditation
- Deep breathing
- Mindfulness practice

## **Nurture self**

- Practice self-compassion
- Body gratitude
- Acceptance
- **Give yourself permission to rest and heal.**



# Living with a Chronic Illness and Avoiding the Crash

While living with ME/CFS it is vital to learn the art of preventing and minimizing PEM and a subsequent crash. While not in a crash state, familiarize yourself with resources that can assist you in conserving energy and apply these following concepts to your everyday life.

## Pacing

Pacing is the golden rule when living with ME/CFS, however, it can be one of the hardest to implement and master. **Pacing applies to all activities.** Energy consumers come in the form of physical, emotional, cognitive, and orthostatic demands. Environmental and sensory stimuli also contributes to energy depletion.

### • Strategies

- Take frequent and restorative breaks.
- Set timers during activities to give reminders and prompts to rest.
- Aim to use 80% of your energy, while saving 20% each day so you generate a reserve and avoid entering a state of PEM.
- Go horizontal for 10-15 minutes every couple of hours if possible.
- Schedule “brain breaks.”
- Time management = pace management
- **Break up or modify activities or tasks into smaller and more manageable increments.**
  - Sit or keep legs elevated when performing activities that you might otherwise complete while standing.
    - Dishes, folding laundry, doing your hair/makeup, etc.
    - Shower chairs can sometimes mean the difference between an episode of PEM or a restoring shower.
- **Wearable devices that track heart rate**
  - Increases in heart rate, no matter the activity or stressor, can serve as a physiological cue to stop and rest.
- **Be mindful of the energy utilized with cognitive processing (and filtering) activities.**
  - Reading, writing, talking, processing a TV show/movie, etc.
  - High stimulating environments can overwhelm cognitive processing.
- **Emotional responses, whether positive or negative can trigger PEM (sometimes unavoidable).**
  - Set appropriate boundaries to protect your energy utilization of information consumption (media, news, conversing with family/friends, etc.).
- **Don't beat yourself up if and when you crash.**
  - Sometimes crashes are completely outside of your control.
  - Fixating on the how's and why's do not help you to relax and restore.
  - Give yourself grace and trust your body.



## Other Considerations

**Do not introduce any additional sodium or supplements into your diet without consulting with your medical team. Additional consumption of these items may be contraindicated for your specific conditions (heart, kidney concerns, etc.).**

### Target and treat underlying health conditions which can trigger, worsen, or prolong PEM episodes

- Mast cell activation syndrome (MCAS)
- Orthostatic intolerance (OI) syndromes
- Kidney and liver disease
- Endocrine disorders/diseases
- Autoimmune
- Pain amplification disorders
- Sleep disturbances

### Eat well and stay hydrated

- Your body needs fuel/energy to use and store.

### Orthostatic intolerance

- Pre-hydrate with electrolyte products 15 minutes prior to activity.
- Use electrolyte products as a rescue supplement when you feel yourself starting to become symptomatic.
- Consider the two-bottle method:
  - One bottle with rehydration product that you sip on all day.
  - Have a second “chugging” bottle filled with electrolytes used to pre-hydrate for an event.
- Your provider can help you to find the right sodium-to-water ratio. You can use your urine output and color as a guiding point, assuming you are drinking 2-3L of fluid a day. Aim for a normal output which is:
  - Approximately 20 seconds of steady stream
  - Light yellow color
  - Normal frequency (5-6 times/day)
- Consider asking your provider to prescribe saline IVs which will be administered by a healthcare professional to stave off a crash, or speed up recovery.
  - 0.9% Normal Saline solution @ 1.5L over 60-90 minutes
- Seek pharmacological interventions as appropriate.
- When using compression clothing aim to have as much body surface covered as feasible.
  - Target core/abdomen, legs and arms

### Target restorative sleep

- Maintain good sleep hygiene.
- Identify sleep disturbances.
  - Pain amplification
  - Sensory amplification
  - Central overload
- Address reversible sleep disturbances.
  - Caffeine, alcohol, decongestants, stimulants
  - Avoid brain activating activities before bed and utilize blue light blockers while operating electronic devices.
  - Address or treat primary sleep disorders and secondary sleep disorders like restless leg syndromes, sleep apnea, etc.
- Work with your medical team to identify which type of sleep aids you need.
  - Sustaining
  - Initiating
  - Falling back to sleep



## Thoughts of Suicide

When the body first becomes sick, it can be mentally, emotionally, and physically draining to the affected individual as the body struggles to regulate itself. This process can be incredibly overwhelming as the patient tries to find the vocabulary to describe what is happening to them. As a result, the individual's support network and medical care team may find it challenging to approach care and support, thus perpetuating the feelings of isolation and hopelessness on the part of the patient.

Sometimes that hopelessness can lead to feelings that taking your life would be easier than trying to navigate your body, explaining to family and friends, trying to find treatments, and surviving the disease.

**When in these moments, it is important to hold on, access resources, and take the pressure off yourself.**

**If you are feeling hopeless or suicidal, reach out, you do not need to battle this burden alone.**

### Crisis and Suicide Prevention Resources

(Website descriptions pulled directly from referenced webpages)

#### National Suicide Prevention Lifeline

- Dial 988
- Call 1-800-273-8255
- Visit online: <https://suicidepreventionlifeline.org/>

The National Suicide Prevention Lifeline is a national network of local crisis centers that provides free and confidential emotional support to people in suicidal crisis or emotional distress 24 hours a day, 7 days a week in the United States. We're committed to improving crisis services and advancing suicide prevention by empowering individuals, advancing professional best practices, and building awareness.

#### Vibrant

- Call 888-NYCWell (888-692-9355)
- Text "Well" to 65173
- Visit online
  - <https://www.vibrant.org/>
  - <https://safespace.vibrant.org/en/>

Formerly the Mental Health Association of New York City (MHA-NYC), Vibrant Emotional Health's groundbreaking solutions have delivered high quality services and support, when, where and how people need it for over 50 years. Through our state-of-the-art technology-enabled services, community wellness programs, and advocacy and education work, we are building a society in which emotional wellness can be a reality for everyone.



## Veterans Crisis Line

- Call: (1-800-273-8255, press #1)
- Text: 838255
- Visit online: <https://www.veteranscrisisline.net/>

The Veterans Crisis Line is a free, confidential resource that's available to anyone, even if you're not registered with the VA or enrolled in VA health care. The caring, qualified responders at the Veterans Crisis Line are specially trained and experienced in helping Veterans of all ages and circumstances.

## Warm Line (not for crisis, but when you need a listening ear)

- Call: 833-773-2588

Talk to a peer specialist who has been through mental illness, substance abuse, or their own personal struggles and has been trained. If you need to talk to someone but are not in crisis, you can call the warm line for support. It is free for all callers.

## MyStrength- a free online tool that will help you live your best life.

- Visit: <https://web-ui.mystrength.livongo.com/go/udhs/utahdhs>

You will find help for stress, anxiety, chronic pain and more. It is safe, secure and personalized for you. Track your health, enjoy activities, and become inspired.

## Bateman Horne Center

Support Groups

- Visit: <https://batemanhornecenter.org/events/>

Every month on the second and third Tuesdays from 1-2 pm (Mountain Time) the Bateman Horne Center and a licensed clinical social worker hold support group sessions open to anyone living with a debilitating chronic illness.

## Crisis Resources Page

- Visit: <https://batemanhornecenter.org/outreach/crisis-resources/>

The emotional and mental impact of living with chronic illness can leave individuals feeling desperate for relief. The resources on this page intend to connect you with immediate support and living resources.

**Please remember that your chronic illness  
does not define you, and you are not alone.**



## Making the Decision to Seek Emergency Care

First and foremost, **KEEP IT SIMPLE!** It is not your job to diagnose what is wrong. If you or your caregiver think you should go to urgent care or the ER, then you should probably go.

If you call 911, you are asking for evaluation from skilled EMTs or paramedics. They will assess the situation with more knowledge and tools than you have at home and guide you in the decision to go to the ER. Calling 911 doesn't automatically mean you will be transported to the hospital.

Many insurance providers have phone triage services. Calling this service can help you make the decision whether to seek emergency care or not.

When it doesn't feel so clear, here are some things to consider when making the decision to call 911 or go to the ER or Urgent Care.

- **Dehydration** is a medical emergency and quickly improves with 1-2 liters of IV Normal Saline. Most ERs and urgent care centers are willing to provide this service. Rehydration can make all the difference in feeling better. Untreated dehydration prolongs the crash and, at worst, can lead to kidney failure and death. Signs and causes of dehydration include:
  - Decreased urine output
  - Urine is dark yellow or even brown (in severe dehydration)
  - Repeated vomiting and/or diarrhea
  - Feeling too weak to drink or chew (ice chips are not adequate hydration)
  - Increased or increasing confusion
  - While a fever can be a sign of dehydration, a prolonged fever can cause dehydration.
- Many ME/CFS patients experience **chest pain** during a crash making it difficult to tell if it's a cardiac event or not. Here are a few things to consider:
  - Is the chest pain different from what you usually experience?
  - Is the chest pain accompanied by shortness of breath, dizziness, or nausea?
  - Does the pain radiate from the chest to the jaw and/or arm?
  - Are you or your caregiver uncomfortable or scared?

**If you answered yes to any of these, call 911, go to the nearest urgent care or ER.**

- **Severe allergic reactions** are when you react to a food or medication that causes anaphylaxis, a severe skin rash, or severe GI upset.
  - Anaphylaxis is when you have swelling of the face, mouth, or tongue that can quickly obstruct your airway. **This is a medical emergency, immediately call 911!**
  - Whole-body skin rash, while not an emergency, can be extremely uncomfortable and can sometimes become very severe. Additionally, it can be a precursor to anaphylaxis. Seek immediate care.
  - GI upset, like diarrhea and vomiting, can result in dehydration. Monitor for signs of dehydration and seek immediate care if needed.



## Expectations for ER or Urgent Care Treatment

Many of you have felt misunderstood or even degraded in urgent care or emergency settings. We are working to educate providers on ME/CFS which will translate into more effective interventions within emergency care. However, this process takes time. This resource can help guide your experience and expectations by gaining insight into the purpose and role of the medical setting you are entering.

**Understanding the responsibilities of paramedics and ER staff** can help you establish realistic expectations on the type and level of care they can offer. The primary objective in an emergency is to identify, stabilize, and treat life-threatening situations and/or to identify conditions requiring immediate hospitalization. Fortunately, ME/CFS and related conditions are not generally acutely life-threatening. But remember, that is why you go to the ER, to rule out that there isn't something more severe going on. If it is determined that your condition is not life-threatening or needs immediate stabilization, the ER staff may appear less attentive because they will arrange for you to complete your workup and care in a non-urgent setting to make room for more severe emergencies.

**In an urgent care facility**, the goal is to decide if you need to transfer to an ER or hospital, and if urgent medical attention is necessary, or if you can be triaged and followed at a later date in a non-urgent situation.

### Expectations and tips

- Receiving IV fluids is an intervention that will generally help most patients with ME/CFS. Inform the staff if you have orthostatic intolerance and could benefit from IV fluids while they are assessing your urgent status. Mention any situational factors that might worsen orthostatic intolerance, such as dehydration, poor oral intake, low-grade fever, diarrhea, nausea and vomiting, dizziness, etc.
- The medical staff will also assess your neurocognitive status, monitor heart activity, check oxygen saturation, draw blood, and get a urine sample to check urgent health metrics. This is critical information that rules out major life-threatening concerns (heart attack, stroke, severe bacterial infection, etc.).
- Know that ER and urgent care staff are hesitant to give some medications while you are waiting, especially pain medications, because they might mask a severe problem and delay care, or even put your life at risk!
- Have useful information ready.
  - Include your current med list, allergies or intolerances, problem list (diagnoses) and a **clear explanation of your current concerning symptoms that brought you to the ER.**
  - Having a copy of the summary from your last visit with your ME/CFS provider may be instrumental in guiding and acknowledging your care needs.
  - While it is not your job to educate providers, there are resources that may help inform their decision and interventions while validating your condition.
    - [ER and Urgent Care Considerations in ME/CFS](#)
    - [U.S. ME/CFS Clinician Coalition Treatment Guidelines](#)
- Plan to be there a while. In urgent care and emergency departments, the most endangered lives receive priority attention.

So, the bottom line is, if you are worried for your life and safety, go to the ER or urgent care. Understand the process, have information available to help inform the staff, be patient, and know that what you are experiencing deserves attention too.



# Travel and Crash Considerations

## Travel tips

Traveling, while wonderful, can put you at risk for a crash. The increased energy expenditure physically, cognitively, and emotionally can use up your energy reserves more quickly than you would think. Here are some tips that may help you have less chance of crashing and use your energy more slowly.

- Make sure you rest and hydrate well for a number of days prior to travel. Consider seeking IV hydration therapy one to two days prior to departure.
- Make sure you have enough medications with you, especially any controlled substances.
- Make sure you have a current medication list and contact information for your health care providers.
- Anticipate a few days of needing to rest when you get to your destination and when you get home.
- Plan a gentle itinerary allowing for rest throughout the day.
- If your destination is at a lower elevation you may have more energy. This is great, but remember to pace yourself and listen to your body. Higher elevations can be more taxing.
- Eat regular small meals and stay hydrated. If you have food intolerances, be careful to avoid food triggers.

## Air travel

- Book flights that enable you to stay on a normal sleep/wake cycle.
- If the trip is long, consider a layover day en route.
- Try to minimize multiple connections.
- Use sidewalk services such as Sky Cap to take care of your bags. This way you won't be carrying luggage around.
- Try to minimize carry-on luggage.
- Your carry-on bag should have at least a few days worth of medications in case your luggage gets lost. Or, if possible, carry all your medications with you.
- If you have connections, give yourself plenty of time to get from one gate to the next.
- Utilize in-terminal transportation such as wheelchairs or motorized carts to get to your gate.
- Wear sunglasses and earplugs to limit stimulation.
- Once through security, make sure you prioritize getting water and have electrolytes with you.
- Wear compression clothing.

## Driving

- Try to minimize long days of driving. Even though you are “just sitting,” you will still burn through more energy than you realize.
- Try to have someone else drive or frequently switch off driving.
- Try to keep your feet elevated as much as possible.
- Wear compression clothing.
- Minimize stimulation by wearing sunglasses and earplugs.
- If you are driving and feel yourself starting to show signs or symptoms of a crash:
  - Pull over and put the car in park.
  - Inform an emergency contact.
  - Try to go horizontal, and rest if it is a safe location.
  - Chug a rehydration packet, and de-stimulate the environment.
- Do not continue driving if you feel a crash coming on, as this is a safety concern for your health and those on the road with you.
- If after your rest break you do not improve, call for help and have them transport you home. You can always get your car at a later time, or another person can drive your car back to your residence.



## Appendix

<a href="#">Crash Care Kit Essentials</a> .....	30
<a href="#">Caregiver Guidance</a> .....	31
<a href="#">Glossary</a> .....	33

### Downloadables

#### Med Sheets

[Morning](#)

[Midday](#)

[Evening](#)

[Med Sheet \(General\)](#)

[Discontinued](#)

[Diagnoses](#)

[Allergies](#)

[Medical Providers & Emergency Contacts](#)

#### Communication Cards

[Critical Needs](#)

[Symptoms & Sensitivities](#)

[Comfort](#)

[Emergency & Severe Status](#)

[Blank Cards](#)



# Crash Care Kit Essentials

## Prepare a “Crash Care Kit”

Just as every well-stocked home has a first-aid kit, every home with a person with ME/CFS should have a Crash Care Kit. Place these items in a box or bag and keep it handy. Check for expirations and replenish items every six months or as needed.

Consider having a few Crash Care Kits that you can access in areas you frequent, such as your living area and bedroom. It's highly recommended to have a “go kit” to take with you when you leave your home. Review the contents of this kit with those close to you and inform them of where you keep it. If you live alone, keep it in a prominent place and well labeled, in case you need support from others unfamiliar with your situation.

## Crash Care Kit Essentials

- ✓ List of current medications with date, reason for taking them, frequency, and dosage
- ✓ List of doctors' names, specialty, and phone number(s), printed recent patient visit note
- ✓ List of emergency contacts
- ✓ Tools to measure vitals such as: blood pressure, oxygen, temperature, heart rate
- ✓ High protein snacks such as protein or breakfast bars, nuts, dried fruit
- ✓ Ways to supplement calories during a severe crash (meal replacement drinks such as Ensure)
- ✓ Bottled water and rehydration packets (such as Liquid IV, Normalyte, etc.)
- ✓ Pad of paper, pen/pencil, and means to reference date and time
- ✓ Eye mask, sunglasses, hat with visor (to block overhead light)
- ✓ Earplugs or noise-reduction headphones
- ✓ Heating pad or microwaveable “warmie”
- ✓ Ice pack or cold compress
- ✓ Towel, washcloth, or pre-moistened wipes that are tolerable to your skin
- ✓ Extra battery or phone charger
- ✓ [Crash care communication cards](#)
- ✓ Rescue medications

These may include those intended to decrease inflammation and muscle/joint pain, alleviate nausea and neuroinflammatory symptoms, aid with sleep and relaxation, and stabilize mast cell and histamine activity. Work with your medical care team to find the right pharmaceutical support for you, and always consult with them prior to introducing any new over-the-counter medication or supplement.

## Crash Care Kit Essentials for Your Car

- ✓ Extra rescue meds
- ✓ Emergency phone numbers
- ✓ Pillow
- ✓ Blanket
- ✓ Snacks and water
- ✓ Rehydration packets
- ✓ Phone charger



# Caregiver Guidance

When someone you care about experiences a crash, it can be scary and leave you feeling helpless. This resource aims to equip you with knowledge and insights from caregiver-to-caregiver on ways to support and alleviate the suffering of the person experiencing the crash (referenced below as the patient).

1. Get the patient to a safe place
  - If on the floor, provide a pillow and blanket.
  - If you can get them onto the bed or couch safely, do so, otherwise keep the patient comfortable where they are.
2. Keep the patient:
  - Hydrated
  - Comfortable
  - Horizontal
3. Contact their primary care doctor and emergency contacts to inform them of the crash.
4. Reduce or limit sensory stimuli such as light, noise, touch, smell, and other distractions to provide a quiet sensory-free environment. This includes both the direct and indirect contact the patient may have with you or their environment.
  - Visual considerations: lower or eliminate all forms of light and avoid visual stimulation such as quick movements and bold or bright clothing.
  - Sound considerations: reduce excessive, recurrent, overstimulating noises.
  - Touch considerations: limit or soften physical touch with the crashed individual and use non-abrasive clothing and bedding.
  - Smell considerations: reduce or eliminate odorous foods, plants, perfumes, body lotions, chemicals, detergents, animals, candles, etc.
  - Temperature considerations: keep ambient temperature stable and utilize heating and cooling devices to assist the individual with their temperature fluctuations.
5. Recognize that the patient may not want to talk, or is unable to talk, other than to provide you with needed information.
  - As a caregiver, talk only as required to aid the patient.
  - If the patient is unable to talk, use communication cards or devices only as necessary.
6. Your #1 goal is to encourage rest, reduce movement, and help the patient conserve energy.
7. Provide light, easy to digest food as can be tolerated by the patient. It's important to note if the patient is unable to consume food, priority should still be on adequate hydration.



8. Try to continue their medication schedule as much as possible.
9. Have the following available for the patient.
  - Ice pack
  - Heating pad
  - Towel or washcloth
  - Earplugs
  - Additional bottled water or hydration packets
10. Have rescue medications available intended to decrease inflammation and muscle or joint pain, alleviate nausea and neuroinflammatory symptoms, aid with sleep and relaxation, and stabilize mast cell and histamine activity. Work with your medical care team to find the right pharmaceutical support for you, and always consult with them prior to introducing any new over-the-counter medication or supplement.
11. When the patient is safe, calm and relaxed, take a deep breath. Know that you're doing the best you can.
12. Seek further guidance on ways to support the individual's progress in the ME/CFS Crash Survival Guide.

### **When you suspect an emergency**

There may be times when the patient is in a severe state of health. If you or the individual you are caring for are concerned about the status of their condition, then it is always best to call for a professional medical assessment (whether 911 or via the emergency room or urgent care).

It is not your burden to diagnose what is wrong, so if you are questioning their safety, then you should probably seek medical evaluation.

**Note:** your patient may have had negative experiences in the past with emergency room visits. See the section on [Making the Decision to Seek Emergency Care](#) for guidance on how to prepare and support them throughout the visit.



# Glossary

**ADL:** Activities of Daily Living

**ICE:** In Case of Emergency

**MCAS:** Mast Cell Activation Syndrome

**ME/CFS:** Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

**OI:** Orthostatic Intolerance

**PEM:** Post-Exertional Malaise

**PEO:** Person, Environment, Occupation

**POTS:** Postural Orthostatic Tachycardia Syndrome

**PRN:** Per Request Needed (as needed)

...

## **Orthostatic Intolerance (OI):**

Orthostatic intolerance (OI) refers to the abnormal development of symptoms upon standing that are relieved by lying down. There are many potential causes of OI. Neurally mediated hypotension (NMH), orthostatic hypotension (OH), and postural orthostatic tachycardia syndrome (POTS) are medical terms used to describe several possible physiologic phenomena or measurements of these phenomena associated with the initiation of symptoms of OI.

Symptoms may include, lightheadedness or fainting, heart palpitations, headaches, mental confusion (difficulty concentrating, staying on task, paying attention, or finding the right words), chest discomfort, cold hands and feet, chronic fatigue, or nausea.

## **Mast cell activation syndrome (MCAS):**

Mast cell activation syndrome is a condition where the immune system overreacts to the presence of environmental exposures, such as foods, medications, chemicals, odors, sunlight, temperature, etc. as if these exposures represent a foreign infectious invader. Mast cells are a specific type of white blood cell that is present in nearly all tissues throughout the body. Their job is primarily to determine “self vs. non-self.”

When they are activated, thinking an exposure is non-self, they release many local inflammatory molecules, including but not limited to, high levels of histamine that can trigger allergic-like reactions within the tissues into which histamine is released. Activated mast cells also communicate with other mast cells and with parts of the autonomic peripheral nervous system and can cause exaggerated reactions in these systems as well.



# Morning Med Sheet

Time	Medication & Purpose	Dose & Directions	Shape Color & Type	Prescribing Provider & Phone

Notes:

# Midday Med Sheet



Time	Medication & Purpose	Dose & Directions	Shape Color & Type	Prescribing Provider & Phone

Notes:

# Evening Med Sheet



Time	Medication & Purpose	Dose & Directions	Shape Color & Type	Prescribing Provider & Phone

Notes:

# Med Sheet

Consider grouping medications by time of day and/or reason for taking

Time	Medication & Purpose	Dose & Directions	Shape Color & Type	Prescribing Provider & Phone

Notes:

# Discontinued Med Sheet

Medication & Purpose	Dose & Directions	Reason for Stopping	Prescribing Provider & Phone

Notes:

# Diagnoses

Diagnoses & Date	Doctor / Contact	Symptoms	Things That Help My Symptoms

Notes:





# Critical Needs

Download, print, and cut these out to communicate your needs. Two blank cards are included to fill out as needed.



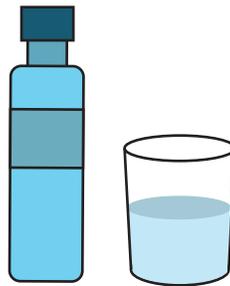
Bateman Horne Center

RESEARCH | CLINICAL CARE | EDUCATION

[batemanhornecenter.org](http://batemanhornecenter.org)



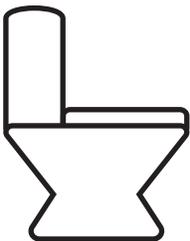
Food



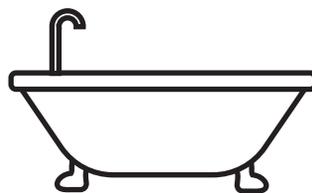
Hydration



Medicine



Toilet



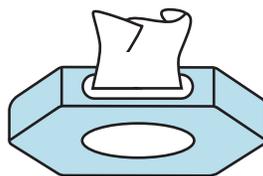
Bathe



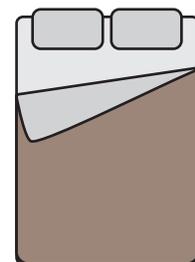
Brush Teeth



Fresh Clothes



Hygiene Wipes



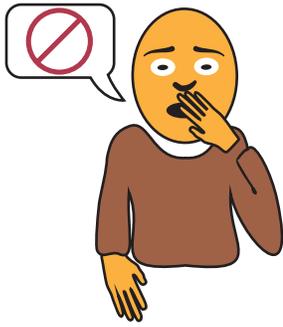
Change Sheets

# Symptoms & Sensitivities

Download, print, and cut these out to communicate your needs.



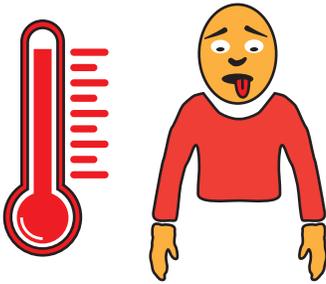
Bateman Horne Center  
RESEARCH | CLINICAL CARE | EDUCATION  
batemanhorncenter.org



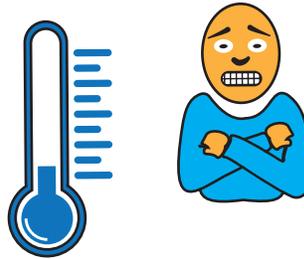
I Can't Speak



I Can't Think



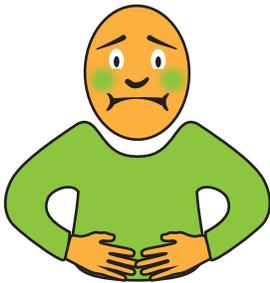
I Am Hot



I Am Cold/Chills



In Pain



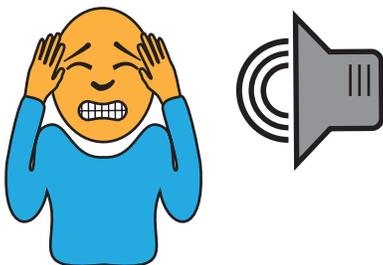
Nausea



Cramps



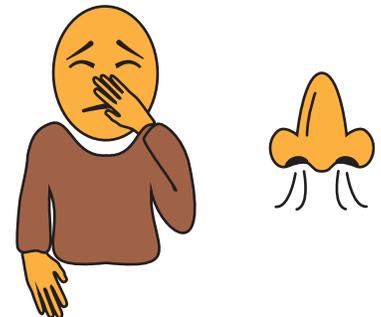
Touch Sensitivity



Sound Sensitivity



Light Sensitivity



Smell Sensitivity



Do Not Disturb

# Comfort

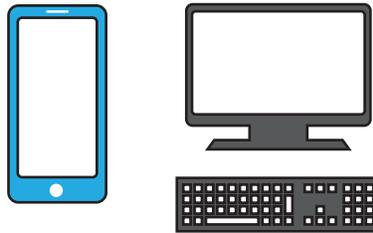
Download, print, and cut these out to communicate your needs. A blank card is included to fill out as needed.



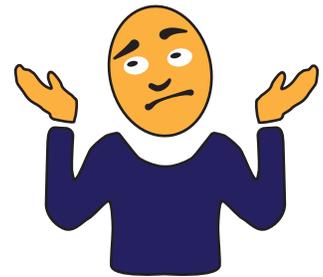
Bateman Horne Center  
RESEARCH | CLINICAL CARE | EDUCATION  
[batemanhornecenter.org](http://batemanhornecenter.org)



TV Remote



Phone/Computer/Tablet



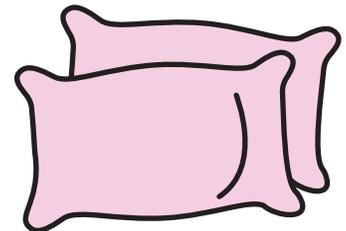
Decide For Me



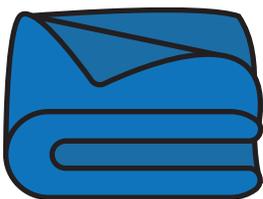
Hot Pack



Cold Pack



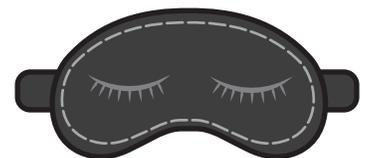
Pillow(s)



Blanket



Wash Cloth



Eye Mask

# Emergency & Severe Status

Download, print, and cut these out to communicate your needs. Two blank cards are included to fill out as needed.



Bateman Horne Center  
RESEARCH | CLINICAL CARE | EDUCATION  
batemanhornecenter.org

911

Severe Reaction



Call Doctor



Emergency Room



Can't Eat/Drink



Can't Sit Up



Can't Move Body



Can't Swallow



Difficulty Breathing



Chest Pain

# Blank Cards

Customize these cards to communicate your needs.



Bateman Horne Center

RESEARCH | CLINICAL CARE | EDUCATION

[batemanhornecenter.org](http://batemanhornecenter.org)







