ME/CFS CRASH SURVIVAL GUIDE

The Art of Living with ME/CFS

Bateman Horne Center
RESEARCH | CLINICAL CARE | EDUCATION

batemanhornecenter.org

Preface

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ME/CFS Crash Survival Guide 1st Edition

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Living with 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 as a result of exertion.

ME/CFS can be incredibly debilitating due to the body's inability to produce energy the way it did prior to illness onset. When the cellular energy expenditure in ME/CFS exceeds the body's ability to produce energy, the result can be a drastic reduction in functional capacity. This is known as post-exertional malaise (PEM), which is the inability to recover normally following physical, cognitive, emotional and/or orthostatic (upright posture) exertion. The onset of PEM is often delayed and occurs 12-72 hours after the event. The causes of ME/CFS are largely unknown, but in many cases an infection, virus, or other triggering event may have activated the disease process.

Living with diseases like ME/CFS require the affected individual to understand what PEM is, how it occurs, and how to meet the body's critical needs for survival when in a severe or prolonged state of PEM (often referred to as a crash).

Crashes can vary in severity and duration, ranging from mild physical and cognitive disruption to severe debility where an individual cannot walk, talk, eat, drink, or sit upright for days/weeks/months at a time. While this can be scary for the patient and their support network, it is important to provide a safe, low stimulation environment that allows the individual to focus solely on rest and restoration.

It is essential to avoid PEM and crashes. **Crashes are cumulative and can lead to a worsening of functioning and overall health status.**

This guidebook intends to:

1. Equip you with a deeper understanding of PEM and crashes and suggest ways to avoid them.
2. Help you put together a Crash Kit which can be easily accessed during a crash to meet your critical needs.
3. Offer guidance to your support network with ways to support you during a crash.
4. Highlight areas of daily living that may be high in energy demands and offer adaptive suggestions.

Crash
What is it, and what causes a crash?

What is a crash?

Our body functions on an energy consumption and production system. When we expend energy 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 our body to function and perform properly.

In diseases like ME/CFS, when the energy expenditure exceeds the body's ability to produce energy, the result can be a drastic reduction in functional capacity. This physiologic phenomenon is known as post-exertional malaise (PEM). PEM is the inability of the body to recover normally following physical, cognitive, emotional and/or orthostatic (upright posture) exertion.

PEM is often delayed in presentation, occurring 12- 72 hours after the exertional 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" (fever, headache, sore throat, chills, muscle and joint pain), worsened cognitive symptoms (insomnia, brain fog, word finding and concentration difficulties) and increased sensitivity to stimuli (noise, light, sound, smell). 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 causing a person to be unable to carry on with daily activities (cognitive processing, physical tasks); while 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 that restoration is allowed to avoid a repetitive push-crash cycle.

It is important to recognize that crashes do harm to the body, and repeated crash sequences will threaten an individual's ability to return to their former baseline function, exacerbate or expedite harmful disease processes, and delay recovery.

Crash restoration takes time, knowledge, patience and support. Advanced preparation (planning ahead for possible crash) is important to ensure that a person's critical needs are met. The remainder of this guidebook will offer ways to approach living with diseases like ME/CFS, and equip you with knowledge surrounding how to survive ME/CFS crashes.

What is a Push-Crash Cycle?

A push-crash cycle is just that-when the individual pushes through the PEM and ends up in a crash. Further harm occurs when the individual pushes during the crashed period never allowing for full energy restoration. This is a repeated injury and insult to the body, which overtime will have lasting consequences and decrease overall functional capacity.

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 continue to worsen and grow exponentially. Your body's cellular energy demands are the same, and when constantly depleted or pushed into a "debt zone" it will require more time and shifting of body function to replenish those stores.

It is important to understand that crashes, and pushing yourself through them, can have a negative and long term impact on your overall health and ability to return to baseline functioning. Prepare your crash kit in advance, ensuring your basic needs can be met, and have a contingency plan in place to allow yourself the space and environment to focus on a restorative crash recovery.

What causes a crash?

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

- Energy consumers come in the form of:
- Physical (movement, metabolism, respiration, etc.)
- Cognitive (thinking/processing)
- Emotional (eustress/distress)
- Orthostatic (upright posture)

These energy consumers add to the tab we must pay back each day. In those with illness like ME/CFS, their threshold response to energy utilization is much lower and requires more time to build reserves back up.

Let's take a look at a common activity, such as talking on the phone, and break down the ways our body is utilizing energy during this 10 minute phone call.

Example: Take into consideration a 5-10 minute phone call:

Physical energy is utilized to sit upright, hold the phone, speak, listen, maintain body temperature, blood pressure, heart rate, filter out sensory stimuli (background noise, light, distractions). Length and mode of conversation also impacts physical demands (ie: FaceTime now requires visual processing and can often lead to longer phone calls because of the interactive dialogue).

Cognitive energy is utilized to process what is being said, to formulate your response, to maintain alertness and pay attention. Memory and conversation recall also utilizes a lot of energy to retain what is being discussed or presented.
Depending on the location in which you take this phone call, additional external stimuli may simultaneously be draining your energy reserves. While taking the phone call in a quiet room still utilizes energy, it has fewer energy demands (not having to filter out noise, light, smells, movement) than if the call was taken in the coffee shop or restaurant.

Emotional energy is utilized no matter how good or bad the discussion may be. Happy and excited emotions drain the body in the same way that sad or challenging emotions do. Discerning moods and emotions from others based on tone of voice, non-verbal cues, language used, etc. impact your emotional interpretation and reaction.

Orthostatic stress. This refers to 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.

In just a 5–10-minute conversation, you have taxed every piece of the puzzle. This is not to say that you should not engage in talking to your friends, family, or loved ones when you crash, it is merely an example of how you are receiving more stimuli and energy stressors than you may be aware of.

Planning in advance and utilizing ways to minimize these stressors can help you get through your crash sooner and more restoratively. Lifestyle modifications and careful pacing of activity and rest are key strategies for prevention of PEM and crashing. Each period or state of a prolonged crash may lead to a decline of overall functional abilities.

Management of energy resources are key to crash prevention and can greatly impact your recovery time. The remaining sections of this guidebook aim to assist you with this process.

When a Crash Strikes

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

Step 1: Alert Emergency Contacts:

Inform one of your emergency contacts and ensure they have access to any pertinent health information should they need to act on your behalf.

- Ask that they check in 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 provider contact information, a list of your known diagnoses and of your allergies placed in your bedside crash care kit, your purse/wallet, and on your refrigerator.

Step 2: Meet Critical Health Needs

Have your critical crash care needs prepared at your bedside. See Crash Care Essentials sheet for more details [hyperlink to the one-pager].

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

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

Nutrition
- Consider food 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
- Day-of-the week and/or time-of-day pill boxes
- Write on pill bottles when and why you take it
- Set aside as needed (PRN) medications and indicate why you take them

Communication cards/devices

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 Kit by your bedside, ensuring critical needs are met

Step 4: Turn Down the Volume & Recover

Sensory and environmental stimulus

- Vision (lights, sunlight, device lights, reading, watching media)
- Sound (excess, recurrent, overstimulating noise)
- Touch (clothing, sheets, physical touch)
- Smell (good and bad smells)
- Ambient temperature

Brain events

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

Physiologic Fluctuations

- 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 participate in self-blame, but this will not help your emotional, cognitive, nor physical energy stores build back up. Instead, find ways to practice self-compassion and wellness (guided meditation, visualization exercises, Nidra yoga, etc.) to expedite your recovery.

Step 6: Avoid the Next Crash

While crashes are an inevitable part of chronic illnesses like ME/CFS, severe FM, and Long COVID, it is important to try and avoid continual push-crash cycles and/or prolonged deep crashes. Think of these as an injury to your body, and the more severe the injury (or crash) 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 slip and 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 in on you and is informed about your medical needs.

Contact someone in your household or on your emergency care list (family member, neighbor, coworker, 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/wallet.

- Include the contact's: 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 in one of the contact fields, their relation to you.

Keep your medical and physician contact lists accessible to you, your support network, and emergency personnel.

Place these lists next to your bedside, in your crash care kit, on your refrigerator, and in your purse/wallet. Downloadable lists, which can be typed in and printed off are located in the back of this guide book.

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 own tracking purposes and for your providers to know what you have tried, what has/hasn't worked, and why.

Allergy list
- List allergies, symptoms/presentation, interventions that help, and if the reaction is dangerous or simply an intolerance.

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

Physician list
- List your doctor's names with specialty, phone number(s), and why you see them.

Conserve Energy
During Movement and Daily Life

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

During 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 is your **position**? Are you lying flat, minimizing the impact of gravity; or are you upright, partially upright, or moving limbs into positions above "flat" on the bed or sofa? A position of fully resting the body is when you are HORIZONTAL being supported by a firm surface, such as a bed or couch. As your body becomes more upright, more energy is required by the body to maintain this position. CONSIDER: are there activities that you can do in a lying, side-lying or semi-reclined position instead of a sitting or standing position?

If moving the arms is needed for a task, are the arms close to the body with the elbows tucked and supported, or are the arms partially or fully outstretched away from the body? If moving the legs, are the motions small and near to the body? In both cases, **keeping the limbs close to the body minimizes energy demands and expenditure.** CONSIDER: could you perform an activity with your arms close to your sides, use the support of a surface to take the weight of your arms (ie: resting elbows on table while you eat) or use pillows to provide support?

Decreasing speed and frequency of movements conserves energy. Move slowly. Monitor your breath patterns. A sign that you are moving too fast for your body, is when your breathing pattern increases or you find yourself struggling to catch your breath. Doing an activity at a slow, unhurried pace is best. Chunk activities. Do one or two pieces of the task, rest, and then go back to engaging in the activity. If performing repetitive motions, perform only a few of these motions at a time and then stop-and-rest. Repeat this stop-and-rest cycle creating blocks of movement.

Example: When eating and moving the fork/spoon to mouth: Eat three bites. Stop and rest for 3-4 minutes and then repeat 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).

When orthostatic intolerance is a factor, limit the range of movement required to complete a task, keeping your position as neutral as possible. Consider utilizing an adaptive device to help you extend your reach (a reacher device) and/or decrease the amount of movement required to complete the task.

While completion compulsion is a very real thing for human beings, it is not healthy and is contraindicated for ME/CFS. Surviving a crash and living with ME/CFS requires a modification in how you approach expectations of yourself. You are not the task, but the task itself may rule how you get to utilize your energy for the remainder of the day or week. Adopt kindness for yourself, set limitations and protect your boundaries. Go with the flow, and know that when in a crash it is prescriptive to do the bare minimum required to complete a task. Recover and allocate energy to only what is most important to you or that which is essential when in a crash.

Considerations:

Adapt positions so less energy is expended.

- Sit to perform a task rather than standing.
- Pull objects you must manipulate closer to you by placing them in your lap to keep your arms close to your sides.
- Delegate tasks as much as possible.
- Chunk activities into smaller steps allowing time to rest in between tasks.
- Lower expectations, dismiss completion compulsion, and set boundaries to protect your energy threshold.

E = Environment

What can be done to your environment to make movement and energy conservation more successful? Think about the different environments in which you live: work, home-life, outside environment(s).

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 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 (add mobility aids if helpful).
    - Consider utilizing one level of your home rather than navigating stairs and multiple floors.
    - Decrease clutter in the home.
    - Is there a mobility aid or device that may 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 (ie: power wheelchair or scooter, wheeled walker with a seat, folding cane with a seat on it)?
    - What changes to your environment would help you to use a mobility device in your environment?

O = Occupation

Occupations are the things that you do to take care of yourself (e.g. 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).

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? (ie: frozen pre-cut vegetables versus 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. It is important to avoid an unhealthy push-crash cycle which both perpetuates and exacerbates symptoms while reducing your overall level of functioning and quality of life. **Remember that every time you crash you do harm to yourself. Lifestyle adjustments and modifications are key to managing your illness and decreasing incidence of crashing.**

Communication
Meeting your Critical Needs

During a crash, it can be difficult to communicate with others, however, communication is essential to meeting your safety and recovery needs.

The following outlines areas in which you may need to communicate your needs. This section of the guide also contains downloadable/printable communication cards. You may need to adapt your communication system with your care supports in the event you are unable to speak, process, or read what is displayed on the card system.

Consider keeping these in your bedside or on your electronic device to point/show your caregiver, loved one, or support services.

Communication Considerations:

- In case of emergency
- In the event of an emergency, have a life alert device on/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 essential needs to helpers or emergency contacts.
    - Food
    - Pills
    - Water
    - Toileting
    - Positioning
    - Environmental stimulus
    - Temperature (cold, hot needs)
    - Symptoms
    - Hygiene
    - Better day vs. Bad day
        - Battery image
        - Facial expressions
        - Pain scale
        - Gas tank

- Devices and modes of communication
    - Keep your communication devices charged.
    - Consider a long charging cable that is accessible to you in bed/on the couch.
        - Phone
        - iPad/iMac
        - Laptop
- Pre-make lists of your known needs when in a crash, which you can point to for nonverbal communication.
- Utilize the communication cards on the next page, and adapt as necessary to your needs.

Communication Cards

When in a crash you may be unable to think clearly, form words/sentences, and process information. Utilize the communication cards in a way that helps you and your supporters reach an understanding of your needs.

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 need.

Utilize these downloadable and printable communication cards to help communicate your needs.
[INSERT THE CARDS or LINK TO THE CARD SECTION]

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 restoratively recharge.

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

Sensory and environmental stimulus

- Sight/visual
    - Eye mask
    - Tinted lenses
    - Light blocking curtains
    - Dim electronics (put in nighttime mode)
    - Blue light reflective glasses (for phone and computer use)
- Sounds
    - Ear plugs
    - Noise cancelling headphones
    - Noise Machines (blue, red, pink, brown, white noise)
- Touch
    - Loose clothing
    - Non-abrasive linens and bedding
    - Be mindful of contact with perfume/cologne, detergent, dyes, cleaning products
    - Weighted blanket (deep pressure can be soothing)
- Smells
    - Keep cooking smells to a minimum
    - Ask caregivers and visitors to not wear perfumes or utilize body care products with fragrance when visiting
    - Avoid odorous plants, trees, candles, Plug-ins, etc.
    - Use low or non-perfume soaps and detergents
    - Avoid cleaning chemicals, try natural products

Processing and brain events

- Minimize cognitive demands
- 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/news
- Positive and negative emotions both utilize energy

Physiologic fluctuations

- Body temperature may fluctuate-have layers to take off/put on
- Body positioning: make sure you have support for spine/limbs so as to not create muscle tightening, soreness, or poor circulation
- Headache and neuroinflammation: use compresses for eyes; 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)
    - Thigh high or above (abdominal) compression have been shown to be the most helpful.
    - Try to cover as much surface area on the body as possible.
    - Consider compression tops to account for arms and abdomen surface area.
- Rehydration solutions
- Saline IV fluids (ordered by your provider)
- Food/nutrients- salt food liberally unless directed not to by your healthcare practitioner.

Crash Care Toolkit 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, keep it handy, and check it for expirations, replenishment every six months or as needed.

Consider having a few crash care kits that you can access in areas you frequent: living area, bedroom, a "go kit" to take with you when you leave the home. Review the contents of this kit with those close to you, inform them of where you keep it. If you live alone, place in a prominent place, well labeled in the event you need support from others unfamiliar with your situation.

CRASH KIT ESSENTIALS

- List of current medications with date, reason for taking them, frequency, and dosage
- List of doctor's names, specialty, and phone number(s)
- List of emergency contacts (Include relatives, family, nearby neighbors who are willing to come and help you as needed)
- Rescue medicines such as: acetaminophen (Tylenol), ibuprofen (Motrin), diphenhydramine (Benadryl), famotidine (Pepcid), dextromethorphan (Delsym, Robitussin DM), ondansetron (Zofran, anti-nausea), gravol ginger (anti-nausea), and appropriate/prescribed pain interventions. ***Confirm with your doctor that these medications are right for you.***
- High protein snacks such as protein/breakfast bars, nuts, dried fruit.
- Nutrition rich/meal replacement drinks to supplement calories during a severe crash (such as Ensure)
- Bottled water and rehydration packets (such as Liquid IV, Normalyte, etc)
- Pad of paper and pen/pencil
- Eye mask, sunglasses, hat with visor (to block overhead light)
- Ear plugs, noise reduction headphones
- Heating pad or microwaveable "warmie"
- Ice pack (keep in freezer), cold compress
- Towel, washcloth, or pre moistened wipes that are tolerable to your skin
- Extra battery charger for phone
- Crash care communication cards **[Tahlia will hyperlink to cards]**

CAR CRASH KIT ESSENTIALS

- Extra rescue meds
- Emergency phone numbers
- Pillow
- Blanket
- Snacks and water
- Rehydration packets
- Phone charger
- Mobility device (if indicated)

Caregiver Crash Essentials

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 a caregiver-to-a-caregiver on ways to support and alleviate the suffering of the person experiencing the crash (referenced below as the patient).

1. Get 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 patient:
    - Comfortable
    - Horizontal
    - Hydrated

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:
    - Vision (lower or eliminate all forms of light and avoid visual stimulation such as quick movements and bold/bright clothing).
    - Sound (reduce excessive, recurrent, overstimulating noise. This includes high or low pitched noises, heavy bass, and/or those that are vibratory in nature)
    - Touch (consider soft clothing, sheets, and have limited or no physical touch with crashed individual)
    - Smell (reduce good and bad smells)
    - Ambient temperature (keep moderate heat/cool)

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.
    - Should the patient be unable to talk, use communication cards or devices only as necessary.

6. Encourage rest, reduce movement, and help the patient conserve energy. This is your #1 goal!

7. Provide light, easy to digest food as can be tolerated by the patient.

8. Continue medication schedule as possible.

9. Have available for patient:
    - Ice pack
    - Heating pad
    - Towel, washcloth
    - Ear plugs
    - Additional bottled water or hydration packets

10. Have available rescue medicines such as acetaminophen (Tylenol), ibuprofen (Motrin), diphenhydramine (Benadryl), famotidine (Pepcid), dextromethorphan (Delsym, Robitussin DM), ondansetron (Zofran, anti-nausea), Gravol ginger (anti-nausea), and appropriate/prescribed pain interventions. *Confirm with the doctor that these medications are right for the patient.*

11. When the patient is safe, calm and relaxed, take a deep breath.

12. Now, start to read the reference guide for details on what's happening and how to proceed.

Do we add something about when to take to the emergency room? When does the crash become emergent and require outside intervention???

Medication

Disclaimer: Consult with your medical care team prior to introducing any new medication to your regime. This includes over-the-counter medications or supplements.

Brain fog can make it easy to forget your medication routine when you are experiencing PEM or moving into a crash. Delayed or missed medication 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 each, and reason for taking it/what the medication helps with, and the prescribing doctor.
    - Be sure to include a list of the medications that you use "as needed" or are considered your rescue medication during a crash (ie: Zofran for nausea).

- Set medication alarms
    - In the alarm description, label out what meds you take or add a prompt which will remind you to double check the medications you are taking at that time.

- Double checking 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 (the printable cards located in this guide)
        - Example: morning = orange/yellow; midday = green; evening = purple
    - Use pill containers that have day-of-the-week and time-of-day 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.

Possible Rescue Meds and Supportive Interventions

Neuroinflammation
DM (dextromethorphan)

Mast cell activation
H1: Diphenhydramine (Benadryl), Loratadine (Claritin), Cetirizine (Zyrtec), Fexofenadine (Allegra), Levocetirizine (Xyzal)

H2: Famotidine (Pepcid), Ranitidine (Zantac)

Stomach (Nausea, Cramping, Pain)
Ginger, ginger tabs/ginger chews
Nauzene
Emetrol
Alka-Seltzer Tums
Pepto Bismol
Gaviscon
Ginger
Soda water
Peppermint/mint
Probiotics
Prescription: Zofran, Phenergan

Motility and constipation
Soft laxative (increase gut motility again)
Senna
Tea w/peppermint
Imodium (for diarrhea)

Headaches
Tylenol, NSAIDs (such as Ibuprofen or Aspirin)
Lavender
Peppermint
Ice hats
Cooling bands for neck, forehead
Prescription: Fioricet

Pain/Body aches
NSAIDs
Muscle relaxants
Heating pads
Foot warmers
Ice packs, ice hats
CBD oils
Tea tree oil (topically)
Magnesium glycinate
Turmeric with black pepper extract

Sleep Aids
Benadryl
Unisom
Melatonin & Vitamin D
Prescribed medications

Calming nerve pain
Lyrica
Gabapentin

Respiratory
Rescue inhaler
Humidifier (or dehumidifier if indicated)

Saline IVs
This must be ordered by your medical provider and administered by a professional under supervision.

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.

Adequate hydration and nutrition is essential to fueling the body. In diseases like ME/CFS and orthostatic intolerance(OI) syndromes, there may be periods where the affected individual does not feel hungry, is nauseous, or is unable to eat/drink (during a severe crash).
The considerations outlined below take into account hydration and nutrition options that optimize consumption to be as supportive as possible during a crashed period and/or everyday living with ME/CFS.
Consume small, steady amounts of nutrition so as to not overwhelm the digestive system.
As a general rule, any new food or supplement should be introduced slowly and with the supervision of your medical provider.

Hydration

Hydration, Rehydration and OI considerations

- Water bottles
- Flavored water
- Coconut water
- BLK water
- Keep electrolyte/rehydration packets in your crash kit(s)
  - Ultima, Liquid IV, Nunn, Triorals, Goos, Bonks, Drip Drop, Nunn, Zip Fizz
- Optimum Nutrition (ON): Aminos & BCAA options
- Gatorade, Power Aids, Sports Drinks
- Salt/sodium tablets
  (to be dissolved appropriately with water!)
  - S! Caps
  - Salt stick caps
  - Himalayan salt
  - Mustard packets
  - Pickle juice
- Frozen cubes to suck on or melt
  - Pedialyte
  - V8 cubes

Pre-made

- Frozen fruit/water popsicles
- Broth (beef, chicken broth)
- Smoothie mixes
- Coconut water

Hydrating veggies & fruit

- Pickles/pickle juice
- Celery/celery juice
- Carrots/carrot juice
- Cucumbers/cucumber water/juice
- Watermelon

Soda (be mindful of sugar content)

- Coca Cola
- Ginger Ale
- Sprite/7 Up

Nutrition

The following may be added to your emergency Crash Kit and/or be integrated as quick/easy nutrition options while living with ME/CFS and OI.

Liquid Options

- Protein drinks (keep next to bedside, and consider a jar or lid opening tool for assistance)
- Optimum Nutrition (ON): protein options
- V8 (fruit, veggie)
- Meal replacement drinks (Ensure, Boost)

Bars

- Honeycomb or protein bars (REI, online)
- Rx bars

Dried food

- Dried fruit (mango, pineapple, apples, cherries, coconut)
- Nuts (cashews, pistachios, Brazilian nuts, macadamia nuts, almonds)
- Trail mix w/M&Ms (unless chocolates are a trigger)
- Seeds (pumpkin, sunflower, pepitas, chia)
- Dried/seasoned spinach
- Edamame, snap peas
- Peanut butter stuffed pretzels, pretzels
- Crackers
- Dry cereal
- Tortillas

Canned/packaged

- Tuna or chicken packets (chicken = lower histamine levels)
- Canned fish (Kippers)
- Olives
- Pickles
- Jerky (beef, salami, bacon, etc.)
- Peanut butter packs (peanut butter & jelly sandwiches)
- Honey sticks
- Mustard packets

Pre-made or easy-make foods

- Lentils
- Smoothie blocks (just add milk or water)
- Simple soup recipes that could be kept frozen and thawed
- Oatmeal with milk (milk adds protein, carbs, calcium, and vitamins/electrolytes)
- Broth (chicken, beef)
- Ramen, Pho, canned soup
- Rice, quinoa (microwavable)
- Just Crack An Egg (Add an Egg cups)
- Hungry Man
- Bear Cakes
- MREs (meals ready to eat)
- Pre-made meal delivery
- Baby food in shelf packaging: good for food sensitivities (histamine intolerance) and when limited energy for chewing

Fruit/veggies (be mindful of sugar content)

- Cucumbers
- Carrots
- Strawberries
- Peaches
- Spinach
- Blueberries
- Tangerines/clementine
- Raisins
- Potatoes
- Broccoli
- Avocados
- Banana

Mini fridge next to bedside

- Balanced Breaks (pre-packed snacks)
- Yogurt
- Sliced cheese, cheese sticks, cubed cheese
- JELLO or pudding cups

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 (whether on foot or by transferring from one surface to another-bed to wheelchair, chair to bed, etc.). These tasks are often carried out without awareness surrounding the energy demand and drain that can be placed on our bodies while performing the task.

People with ME/CFS may experience challenges to how much, and in what way, they can move due to a number of factors (energy utilization, sensory overload, 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 being mindful of person, environment, and occupation (PEO). **[link to PEO section]**

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, position, may be more beneficial in some instances than utilizing an assistive device. Example: Dressing. Wearing loose clothing, keeping a change of clothes near your bedside, and putting on/taking off shoes/socks in a seated position may be more helpful in then trying to use a dressing aid. **Be strategic and only utilize what will truly assist and make your life easier and more functional.**

There are some items which 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 what (or 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 and second-hand medical equipment stores. Others may be easier and more cost effective to access online.

Crash Considerations

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

Bathing

- Body
  - No rinse bathing wipes
  - No rinse body bath
  - 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

- Have one with adjustable handle rails which you can lower if transferring directly from the bed's surface, and also raise to help stand on/off the commode.
- Consider commode liners: absorbent hygienic bags that eliminate cleaning soiled commode pails.

- Bed pan in severe instances (be mindful of pressure points/skin breakdown while laying on a bed pan; practice post-bed pan hygiene; ensure body and bed are both dry).
- Tongs and other long handled toileting aids
- Personal cleaning/toileting wipes
- Raised toilet seat
- Men's urinals
  - Consider disposable urinal bags
- Bed pads or Chux pads for leaks, or as an aid during in-bed toileting
  - 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/options **[hyperlink to section]**
- Adaptive eating utensil devices are available

Dressing

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

Movement Aids

- Bedrail (help with rolling and getting in/out of bed)
- Walker or cane when moving around
- Grab bars in bathroom/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 what aids you in your daily functioning.

Note: some items may be repeats from the previous section.

Self-Care

- Minimize drying
    - Terry cloth bathrobe to be used in lieu of a bath towel
    - High absorbency microfiber turban for use after washing hair
- Minimize need for hair washing
    - Shorter hair styles
    - 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
    - Toilet riser to help get on/off more easily
    - Be mindful of leaving your legs hanging against gravity for too long. A foot stool may be helpful
    - Consider a riser with handles to help you with balance and conserving energy to get on/off the toilet

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 garments if OI is present, and you will be upright and moving around
- Adaptive equipment considerations.
    - Reacher
    - Shoehorn
    - Non-slip slip-in shoes
    - Sock aid
    - Dressing stick
    - Leg lifter
    - Elastic shoelaces
    - Button or zipper assist devices

Mobility and Assistive Devices

- Bed assist ladder or bed rail 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/sofa chair
- Walker or cane for stability if/when weak
- Reacher/grabber
- Home modifications for improved accessibility, such as a ramp, stair lift, 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
- Calm music
- Soft/sensory

Cultivate Wellness

- Learn how to practice when not in a crash so it can be an effective tool when in a crash
- Meditation
- Deep breathing
- Mindfulness practice
- Gratitude journal

Nurture Self

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

Living with a Chronic Illness and Avoiding the Crash

One of the best things you can do to manage ME/CFS is to learn as much as you can about how crashes occur both in general and specifically in response to your energy expenditures. 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 to live by with these diseases, however, it can be one of the hardest to implement and master.

- **Pacing applies to all activities.** Energy influencers or taxers come in the form of: physical, emotional, cognitive, and orthostatic demands.
- **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 – minutes every hour if possible.
    - Schedule "brain breaks"
    - Time management = pace management
- **Break up activities or tasks into smaller and more manageable increments**
    - Modify activities
        - Sit or keep legs elevated when performing activities that you might otherwise complete while standing.
            - Dishes, folding laundry, doing your hair/makeup, etc.
            - Shower chair: this 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 help you track the physiological stress and cue you to stop and rest.
    - For resources on heart rate tracking, please visit Bateman Horne's For guidance on heart rate tracking, see resources page. **[HYPERLINK TO WORKWELL PDF]**
- **Remember that cognitive exertion utilizes a significant amount of energy.**
    - Reading, writing, talking, processing a TV show/movie, etc.
    - High stimulating environments can overwhelm cognitive processing.
        - Multiple sensory signals: noise, smells, lights, etc.
- **Emotional responses, whether positive or negative can trigger PEM, as unavoidable as this may be.**
- **Don't beat yourself up if and when you crash.**
    - Sometimes crashes are completely outside of your control. It does not help your body to relax and restore if it remains in a state of perseveration surrounding "how/why" the crash occurred.

Other Considerations

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

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

Eat well and stay hydrated.

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

Orthostatic intolerance

- Pre-hydrate with electrolyte products 15 minutes prior to activity.
- Use electrolyte products as rescues 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
- As you are finding the right electrolyte balance for yourself, follow your urine output. If you are taking in tons of fluid and are urinating all the time = high volume and diluted urine = then you are not getting enough sodium.
    - When urination returns to a normal volume (approximately 20 seconds of steady stream), normal color (light yellow), and a normal frequency (5-6 times/day) then you have hit your sodium target (assuming you are still taking in 2-3L of fluid as well).
    - 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 patient's specific needs (ie: heart, kidney concerns).*
- Consider asking your provider to prescribe "rescue" IVs which will be administered by a healthcare professional to starve off a crash, or speed recovery.
    - 0.9% normal saline solution @ 1.5L over 60-90 minutes.
- Seek pharmacological interventions-as appropriate.
- Compression clothing: aim to have as much body surface area covered as is feasible.
    - Target core/abdomen, legs, 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 technology devices (phones, tablet, computer)
    - Address/treat primary sleep disorders; secondary sleep disorders like restless leg syndromes, sleep apnea, etc.
- Work with your medical team on identifying what type of sleep "help" you need:
- Sustaining
- Initiating
- Falling back to sleep

Thoughts of Suicide

Due to a wide variety of factors which include: a lack of understanding surrounding ME/CFS, not having a diagnostic biomarker, and difficulty finding effective treatments there may be moments of hopelessness experienced by the individual suffering from this disease.

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/friends, trying to find treatments, and surviving the disease.

When in these moments, it is important to hold on, reach out, 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

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/**
    - **nycwell.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 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://appv2.mystrength.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/category/support-groups/list/**

Every month on the second and third Tuesday of the month from 1 pm MST- 2 PM MST. Chat in a group with a licensed specialist about a specific topic that people with chronic illness cope with.

Crisis Resources Page

- **Visit: https://batemanhornecenter.org/outreach/crisis-resources/**

The emotional and mental impact of living with chronic illness can leave us 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.