

## ME / CFS Patient: Post Exertional Malaise Avoidance Toolkit

### Introduction

Post Exertional Malaise (PEM) is one criteria of ME/CFS diagnosis defined by a worsening of symptoms occurring after physical, mental or emotional exertion. As an adjunct to the clinical guidance of your physician, reducing PEM (also known as “crashes”), can improve baseline functionality of CFS patients.

Avoiding PEM can be challenging. This toolkit is designed to help patients build crash avoidance plans, monitor triggers, and understand symptoms to enhance recovery.

### Avoiding post-exertional malaise

Every patient has a different set of causes and barriers that need to be considered when building a strategy for crash avoidance. While every patient has a unique situation, there are a common set of causes, barriers and strategies. The broad categories are listed in the below table, and they are expanded upon in the Crash Avoidance Plan template included at the end of this document.

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Causes of PEM	Barriers to Avoiding PEM	Successful Strategies
<ul style="list-style-type: none"><li>• Physical over-exertion</li><li>• Mental over-exertion</li><li>• Emotional over-exertion</li><li>• Sleep regulation</li><li>• Diet and nutrition</li><li>• Other medical issues</li></ul>	<ul style="list-style-type: none"><li>• No signal of coming PEM</li><li>• Lack of a support team</li><li>• Maintaining motivation</li><li>• Psychological challenges</li><li>• Social pressure</li><li>• Challenges of an invisible illness</li><li>• Financial pressure</li><li>• Logistics in managing the disease</li></ul>	<ul style="list-style-type: none"><li>• Plan your day</li><li>• Pace yourself</li><li>• Learn your health patterns</li><li>• Build your support community</li><li>• Give your body good nutrition</li><li>• Ensure appropriate sleep</li><li>• Maintain emotional health</li><li>• Treat other medical conditions</li></ul>

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### Steps for building a post-exertional malaise avoidance plan

- 1) **Find your causes and barriers.** Refer to the list of causes and barriers on the following pages. Read through and check off the causes and barriers that apply to you. This template is not fully exhaustive, so you may find that you have causes and barriers that are not on the list. There is room at the bottom of each page for you to add those items specific to you.
- 2) **Pick the strategies to include in your plan.** The third page contains a collection of strategies that you may want to use. Consider which strategies will help you overcome your barriers and which strategies you are motivated to use. Write down your Crash Avoidance Plan using the attached template. An example is provided.
- 3) **Share with your support team.** Share your plan with the people in your life who can help. Don't get discouraged by set-backs as it's not about being perfect. Implement your plan to the best of your ability.
- 4) **Track your progress.** Tracking is an excellent way to better understand how your activities and strategies correlate with your symptoms. It provides a valuable way for families, friends and caregivers to understand how a patient is doing and what kind of support is needed at different times. The tracking worksheet that will be tested in the Pilot Study is included in this package.

## Typical Causes of Post-Exertional Malaise

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### Physical Over-Exertion

- Doing too much in a day:** driving, standing, work, childcare, social activity, etc.
  - Doing anything fast:** walking, chores, cleaning, cooking, etc.
  - Anything that drives a significant (10 BPM) jump in heartrate**
  - Sudden changes in temperature:** either hot or cold
  - Other physical challenges:** menstrual cycle, flu shot, blood draws, altitude
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### Mental Over-Exertion

- Too much time mentally exerting:** reading, studying, working, etc.
  - Concentrating too much:** pushing hard on particularly difficult tasks
  - Mental exertion after physical exertion:** compounded impact
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### Emotional Over-Exertion

- Emotional hit:** death of loved one or pet; huge loss of any kind
  - Negative emotional burst:** such as arguing with a spouse
  - Strong positive emotion:** such as watching a favorite sports team win
  - Increased stress:** prolonged or episodic re: financial, work, school, etc.
  - Anxious thoughts:** the emotional exertion due to anxiety
  - Sensory overload:** parties, movies, lots of people, lots of noise, etc.
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### Sleep Regulation

- Not sticking to a schedule** that works best. Waking up too early or too late.
  - Not sleeping the right number of hours** each night.
  - Sleep disruptions:** noise, light, night sweats, insomnia
  - Managing time change** during travel
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### Diet and Nutrition

- Too many carbs/sugar:** alcohol, bread, heavily-processed grains, sweets
  - Not enough healthy food:** protein, vegetables, fiber, whole grains, healthy fats
  - Low blood sugar** from skipping a meal or not eating at the right time
  - Dehydration;** low minerals/electrolytes
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### Other Medical Conditions

- Depression:** Could be an escalation or simply baseline depression
  - Anxiety:** Increased episodes or baseline; could include panic attacks
  - Getting Sick:** Typical cold or flu
  - Pain:** Managing chronic pain
  - GI issues:** that cause nausea, digestion challenges, or constipation (e.g. SIBO)
  - Adjustments to medications:** May cause a decrease in overall health
  - Positional Changes:** with or without formal orthostatic intolerance diagnosis
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### Other Causes

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## Typical Barriers to Avoiding Post-Exertional Malaise

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### No Signal of Coming PEM

- No explanation:** Post-exertional malaise seems to appear randomly.
- No warning:** My body doesn't tell me when I've overexerted until it's too late
- No playbook:** Not knowing how much I can handle on a particular day
- Lack of knowledge:** Not sure how I will react to activity level or specific foods
- Not Immediate:** Crash can be delayed by days, making trigger hard to identify

### Lack of a Support Team

- No one who provides physical support:** making breakfast, driving, etc.
- No one who helps plan a PEM-free approach** or records daily symptoms
- Tasks are hard to hand off:** working, parenting, caring for sick parents, etc.
- Hard to let go** of responsibilities as I don't want to rely on others
- Feeling of guilt** when my family needs to do more (e.g. house chores)

### Maintaining Motivation

- No one who provides encouragement** and emotional support
- Sometimes I don't eat healthy** because I want comfort food or social fun
- Making packaged food is easier** to prepare than healthy food
- Trade-off between physical and psychological wellness:** staying in and conserving energy vs. going out and enjoying time with friends

### Emotional or Psychological Challenges

- Emotional triggers** (positive or negative) can come out of nowhere
- Anxiety** about the future or anxiety/phobias that I cannot control
- Too tired to go to the therapist** or session is exhausting
- Depression** from being sick for so long
- Falling behind in school or work** depresses me, so I try to keep up

### Social Pressure

- Reputation:** I don't want to be known as the "sick kid" or "lazy co-worker"
- Lack of control:** Out with friends and don't have control of when I get home
- Fear of missing out:** If I say no, I worry my friends won't invite me next time.
- Asking friends to make sacrifices:** Friends miss out if I ask them to stay in
- Embarrassment:** To use a wheelchair, handicapped parking card, etc.

### Challenges of an Invisible Illness

- Some people don't believe ME / CFS is real** which is very challenging
- Friends who don't understand** the illness, its constraints or its unpredictability
- Hard to explain the disease:** how I can do some things but not others, why visits need to end suddenly, why I cancel, why I need to stay in; etc.

### Financial Pressure

- Need to work** to provide for family or self
- Poor health insurance** resulting in avoiding medications or doctor visits
- High cost of healthy food** and/or recommended medical supplements
- Lack a stable place to live** which places a lot of stress on my health

### Logistics in Managing the Disease

- Tracking my activities and symptoms is a lot of work**
- Hard to keep up with filling prescriptions** and filling my pill boxes
- It's easy to forget to take a dose** when going out for lunch or dinner
- Attending doctor appointments can be exhausting**
- Travel** can cause dehydration, poor diet, long walks, mismanaged meds

### Other Barriers

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## Strategies for Avoiding Post-Exertional Malaise

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### Plan your schedule effectively

- Set yourself up for success:** Do a bit less; don't push to maximize output
- Have a daily activity plan:** Break tasks into smaller pieces; take breaks; prioritize essential activities; plan strenuous tasks for times with energy
- Schedule Rest:** Even if you don't think it is needed
- Build a meal plan:** Start day with healthy pre-prepared breakfast, plan meals
- Plan the week:** schedule rest before and/or after big activities

### Pace yourself appropriately

- Reduce overall activity levels:** delegate, simplify, eliminate, let go of anything that isn't critical such as keeping a perfectly tidy house
- Use timers** to measure physical activity and to set end times
- Set your constraints BEFORE you begin an activity:** Set a time limit (e.g. when going shopping at the mall so that you don't get 'caught up in the moment')
- Be flexible:** Adjust plans in accordance with your body's signals
- STOP immediately** as soon as you realize you are at risk of overexerting
- Practice task switching** between mental and physical exertion
- Conduct self-assessments frequently** to make sure you are not over-doing it

### Learn your health patterns

- Track activities and symptoms:** Activities could include hours of sleep & naps; diet; exertion; medication compliance. Symptoms might include heart rate and BP; nausea, fatigue, aches, night sweats, brain fog, headaches, etc.
- Keep a health journal:** Track each day with qualitative descriptions
- Engage your support team** for tracking and pattern recognition
- Use a Tracking Device:** Count steps, measure heart rate, etc.

### Build your Support Community

- Identify your support community:** Family, co-workers, friends, more than one
- Get outside help:** If affordable, use housekeeping, meal service, etc.
- Delegate whatever you can:** Fill pill boxes, fix food, run errands, clean, etc.
- Help your support community understand ME/CFS:** Leverage websites & articles; can effectively explain limitations from ME/CFS
- Maintain the strength of your support community:** don't become dependent upon just one person; have them join or establish a caregiver support group

### Give your body good nutrition

- Consult a nutritionist**
  - Try specific dietary plans:** For example, gluten free, dairy free, low carb/sugar
  - Determine what works best for your body**
  - Carry healthy snacks** to avoid low blood sugar
  - Consider many small meals** throughout the day
  - Ensure hydration.** Bring water, track hydration with app, use flavor packets
  - Eat when you need to eat.** Not what's best for the family or coworkers
  - Never skip a meal,** even if nauseous.
  - Always have food you love to eat available,** to eat when not feeling well
  - Create meal plans in advance:** Plan for a week to reduce shopping and stress
  - Stock up:** Make sure the pantry and freezer have long-lasting options
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**Ensure appropriate sleep**

- Know how much sleep you need** and stay consistent
- Don't oversleep or undersleep**
- Create an effective sleep environment:** quiet, dark, correct temperature, etc.

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**Maintain Emotional Health**

- Actively treat anxiety and depression** with therapy, medications, meditation, or whatever works for you
- Create a Mindfulness Practice** with meditation, restorative yoga, breathing, or visualization to relax the sympathetic nervous system
- Find enjoyable stimulating activities:** Schedule and make time for "fun"
- Participate in something that simulates your mind** (without overexerting)
- Join or establish a support group for patients**
- Live for yourself:** Don't worry about what others may think or say
- Let stresses go** to reduce your emotional overexertion
- Be optimistic:** Treat each day as an opportunity to take another step forward.
- Be kind to yourself:** sometimes crashes happen involuntarily or unknowingly and accept that this is not your fault

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**Treat other medical conditions**

- Identify other medical afflictions** that impact ability to recover from ME / CFS
- Actively treat other afflictions** such as sleep disorders, hormone driven disorders, POTS, SIBO, etc.
- Manage pain** with medications and mindfulness or visualization practice

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**Other Strategies**

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## Example Crash Avoidance Plan

<b>My Causes of Post-Exertional Malaise</b>	<b>My Barriers to Avoiding Post-Exertional Malaise</b>	<b>My Strategies</b>
Doing too much in a day: driving, shopping, work, childcare	I don't have the support and understanding of family	<ul style="list-style-type: none"><li>• Send educational course information to family members</li><li>• Ask family members to help build and support a daily activity plan</li></ul>
Menstrual Cycle	Comes every month	<ul style="list-style-type: none"><li>• Plan a day of rest on the calendar when period anticipated to start.</li><li>• Proactively take pain medication.</li></ul>
Attend social event	Want to keep up with friends. Need for social interaction to be happy	<ul style="list-style-type: none"><li>• Set time aside to rest before event and the next day</li><li>• Go to party but don't stay too late</li></ul>
Eating too many carbohydrates	I love sugar. It's too much work to prepare healthy food	<ul style="list-style-type: none"><li>• Ask for help with meal prep.</li><li>• Make healthy freezable option ahead of time.</li><li>• Do NOT stock un-nutritious food in the house</li></ul>
Dehydration; low minerals/electrolytes	I don't like the taste of the water at work. I get distracted and forget to drink	<ul style="list-style-type: none"><li>• Download app on phone to track ounces consumed</li><li>• Purchase water flavor packets to bring to work</li></ul>



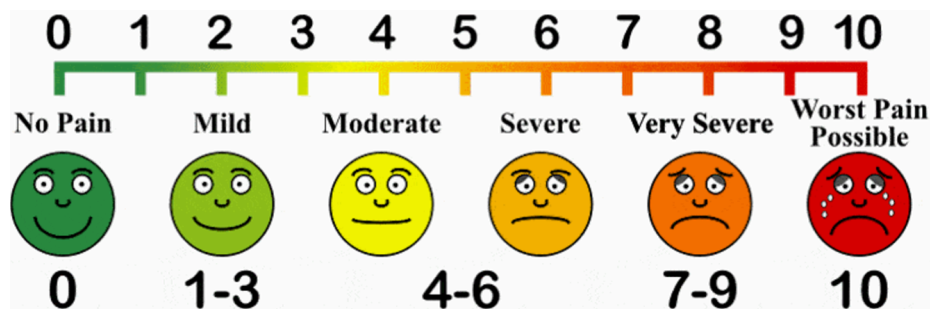
## Activity and Symptom Tracking

Patients find it challenging to avoid crashes as they can be caused by many reasons and patients face a broad set of barriers to avoiding crashes. Those who track their activities and symptoms find it easier to determine what might be causing crashes and which strategies help reduce their crashes.

The Pilot Study will test the attached weekly tracking sheet for ease of use and effectiveness. Each day, patients are asked to measure their activity level and symptoms. It is best if patients complete each row of the worksheet, however if this is not possible the minimum required information is the Overall Activity Level and the Overall Symptom Score. These rows are highlighted in color.

### Worksheet Definitions:

- Physical, Mental, and Emotional Activity Level Scores
  - The three major drivers of activity (physical, mental, and emotional) are rated separately
  - Rated on a scale of 0-10. A “0” represents a very low or negligible amount of activity. A “10” represents a level of activity that the patient undertook when fully healthy.
- Overall Activity Level Score (REQUIRED)
  - This is a required entry and represents the composite score for the day incorporating all aspects of activity (physical, mental and emotional)
- Not refreshing sleep
  - Simple yes or no response pertaining to the night of sleep the evening prior
- Major Symptoms
  - Four of the most common symptoms have been called out specifically: fatigue, pain, nausea or GI issues, and brain fog. A fifth category of “Other” has been included so that patients can track a symptom that’s important to them (e.g. anxiety, dizziness, heart rate)
  - Symptoms should be rated on a scale of 0-10. A “0” should represent no evidence of that symptom. A “10” represents the worst level that the patient has experienced for this symptom. This is modeled after the pain scale shown below:



- Symptoms should be measured morning, mid-day, and evening
- Overall Symptom Score (REQUIRED)
  - Overall assessment of ME/CFS symptoms using a 0-10 scale with “0” representing no symptoms and “10” representing the worst set of ME/CFS symptoms experienced.
  - This should be measured morning, mid-day and evening
- Crash
  - A crash refers to a significant set-back in ability to perform daily functions. It represents a temporary worsening of symptoms. Simple yes or no response.
- Comments
  - Just a few words to serve as a reminder of what the day entailed. For example, “Shopping for 3 hours”. It’s not intended to be exhaustive but a simple descriptor.



# Tracking Sheet: Week 1

Date: \_\_\_\_\_

	Desc	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
Physical Activity	0-10							
Mental Activity	0-10							
Emotional Activity	0-10							
Overall Activity	0-10							
Unrefreshing Sleep	Yes or No							
Fatigue	0-10 AM/Mid/PM							
Pain	0-10 AM/Mid/PM							
Nausea or GI issues	0-10 AM/Mid/PM							
Brain Fog	0-10 AM/Mid/PM							
Other: _____	0-10 AM/Mid/PM							
Overall Symptom	0-10 AM/Mid/PM							
Crash	Yes or No							
Comments	Open Text							

# Tracking Sheet: Week 2

Date: \_\_\_\_\_

	Desc	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
Physical Activity	0-10							
Mental Activity	0-10							
Emotional Activity	0-10							
Overall Activity	0-10							
Unrefreshing Sleep	Yes or No							
Fatigue	0-10 AM/Mid/PM							
Pain	0-10 AM/Mid/PM							
Nausea or GI issues	0-10 AM/Mid/PM							
Brain Fog	0-10 AM/Mid/PM							
Other: _____	0-10 AM/Mid/PM							
Overall Symptom	0-10 AM/Mid/PM							
Crash	Yes or No							
Comments	Open Text							

# Tracking Sheet: Week 3

Date: \_\_\_\_\_

	Desc	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
Physical Activity	0-10							
Mental Activity	0-10							
Emotional Activity	0-10							
Overall Activity	0-10							
Unrefreshing Sleep	Yes or No							
Fatigue	0-10 AM/Mid/PM							
Pain	0-10 AM/Mid/PM							
Nausea or GI issues	0-10 AM/Mid/PM							
Brain Fog	0-10 AM/Mid/PM							
Other: _____	0-10 AM/Mid/PM							
Overall Symptom	0-10 AM/Mid/PM							
Crash	Yes or No							
Comments	Open Text							

# Tracking Sheet: Week 4

Date: \_\_\_\_\_

	Desc	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
Physical Activity	0-10							
Mental Activity	0-10							
Emotional Activity	0-10							
Overall Activity	0-10							
Unrefreshing Sleep	Yes or No							
Fatigue	0-10 AM/Mid/PM							
Pain	0-10 AM/Mid/PM							
Nausea or GI issues	0-10 AM/Mid/PM							
Brain Fog	0-10 AM/Mid/PM							
Other: _____	0-10 AM/Mid/PM							
Overall Symptom	0-10 AM/Mid/PM							
Crash	Yes or No							
Comments	Open Text							

## APPENDIX: CASE STUDIES

To illustrate how patients have used the above framework, we will offer a few stories from real patients (names have been disguised). The stories are simplified, but they do describe how knowing your specific causes and barriers will help you build a successful post-exertional malaise avoidance plan.

### **A story about knowing your causes and asserting your limits**

Maria is a teenager living with ME / CFS. She tends to have two main causes of post-exertional malaise:

**Physical over-exertion:** Like any teenager, Maria enjoys having fun with her family and friends. She is a big sports fan, particularly Stanford football. One of her recent instances of post-exertional malaise occurred when she took friends to the Stanford football game. It was a beautiful evening; the game was fun and the group of friends were having a fantastic time. Maria felt great that night, but she stayed too late. The next morning, she felt awful.

**Emotional over-exertion:** Maria works at a pool teaching children to swim. Her ME / CFS makes it difficult for her to wake up before 11:00 am. She loves her job and it is doable because she only works in 1-2 hour increments. The other week, the pool had a big event that needed workers starting at 8:00 am. Maria's boss said she really needed her, so Maria agreed to 8:00 am. Her parents were concerned. This put Maria in a difficult spot. Would she let down her boss or her parents? The worry caused her to not sleep which not only caused her to miss work but also caused post-exertional malaise.

As Maria reviewed her history, she realized that she allowed the fun of the group or the importance of work supersede her health needs. She realized that she can take stronger control over her activities and do a better job of setting her limits in advance. She's working with her employer, her friends and her family to communicate better about her limits and is finding that they are all quite supportive.

### **A story about knowing your barriers and building a plan to overcome them**

Toshi is an adult living with ME / CFS. His baseline level of performance is relatively high. He can work part-time and his financial situation is such that he can afford his current standard of living. He struggles with post-exertional malaise and faces two barriers.

**No Signal of PEM:** Toshi doesn't typically know what causes his post-exertional malaise. Maybe it was staying up too late? Or maybe it was working more hours than usual ... but he has worked hours like that previously. Or it could have been that he drank three glasses of wine. While he knows the broad set of causes, he rarely knows specifics ... or how to avoid them.

**Lack of a Support Team:** Toshi is functional enough that he doesn't appear to need help, although he does. He isn't tracking his activities and symptoms, and there is no one who is also watching to help him understand how to avoid post-exertional malaise or to help him avoid poor nutrition.

While Toshi is fortunate to be as functional as he is, his barriers are the lack of visibility into his PEM and the lack of a support team to help him get better. He asked his girlfriend for help in tracking his activities and symptoms so they could work together to understand his causes of PEM. Interestingly, by looking at his experience for a full week before a downturn they found that his PEM triggers are not usually caused by activities the day before but typically by what he does 3-5 days in advance.

## **A story about sharing worries and adjusting expectations**

Janelle is a wife and mother of one child who is living with ME / CFS. She has been working part time, taking care of her daughter, and doing most of the housework, while her husband works long hours to keep the family one step ahead of the bills. Janelle faces a few connected barriers to managing her post-exertional malaise better:

**Emotional & Financial Challenges:** Janelle always wanted to have several children, and, daily, she agonizes over whether she is healthy enough to get pregnant again. She gets particularly stressed when she thinks about that fact that she could manage being pregnant if only she had enough money to get help with housework, and she has learned that the anger triggers her symptoms.

**Invisible Illness:** Janelle knows that her husband does not understand how her fatigue gets in the way of everyday tasks, since she often feels at her best when he is home in the evenings. Thus, she worries that he won't understand if she postpones getting pregnant.

Once Janelle shared her worries with her husband, she found that he helped her let go of a lot of stress. He helped her realize that taking care of her health was the top priority, and that having more children might not be in their future. With this perspective, she was better able to catch herself before falling into a cycle of distress and PEM.

## **A story about finding your successful strategies**

John is a teenager living with ME / CFS. He is deploying several effective strategies for managing his disease. A few are highlighted here:

**Effective Support Team:** John is fortunate to have an excellent support team. His mother and his brother are highly attuned to his condition and provide a supportive environment. His mother helps him plan his days, ensures good nutrition, and tracks his activities. More than that, she understands his disease and provides him excellent guidance on managing it.

**Tracking and Pacing:** John loves playing basketball. Sometimes his ME / CFS allows him to play, but this creates the temptation to overdo it. His support team encourage him to play when he is feeling well, but they do a fantastic job of ensuring that his physical output isn't more than he can handle. They time him (currently for 15 minutes) and stop him from overdoing it.

**Maintaining Emotional Health:** For John, being happy means being with his family or friends, watching sports, or playing basketball. While he likes school, it's having a balance of these other activities that keeps him happy. He and his support team actively make sure that he has enough fun activities to maintain his positive outlook to continue making progress in his recovery.