

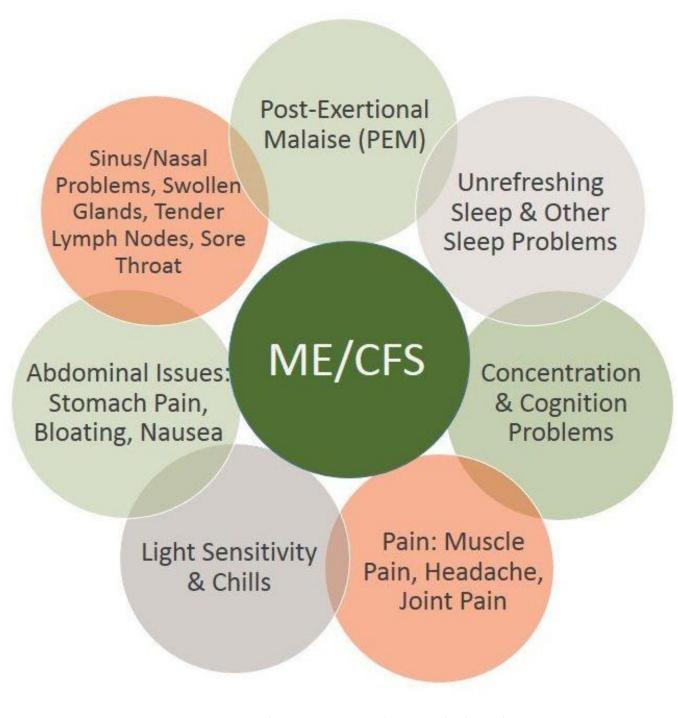
Solve M.E. Patient and Caregiver Resource Guide: Tracking Your Symptoms

Keeping track of your symptoms through journaling or charting can help you identify your personal limitations and lead to a quicker and more efficient stabilization of your condition. While this illness can be unpredictable and come with many ups and downs, overtime, you may be able to find recognizable patterns that can help you manage.

The symptoms of ME/CFS or Long Covid are many and varied. Symptoms may be constant, worse some days, better some days. Or, you may experience a symptom for a while, and then it may dissipate as a different symptom appears. This is part of the frustration for both persons with ME/CFS or Long Covid, and for physicians treating these illnesses. Below, you will find a list of typical symptoms shared by many with ME/CFS or Long Covid. You may experience any of these at different times, in different ways, in different levels of severity.

You may share calendar notations with your physician to assist in treatment decisions. Early charting can be focused on symptoms and their severity. You should chart the main symptoms that prevent you from living your former normal life. As you get more comfortable with tracking your experience, you may also want to record your medication, diet, stress level, and anything else that may impact your symptoms.

If your stamina is extremely limited, ask a friend or family member to assist with charting on days you are unable. On the difficult days, pitching in to keep the record clear and current is a valuable contribution a caregiver or family member can offer.



Symptoms Checklist

ME/CFS symptoms, which can often be made worse by standing upright, include:

- Post-exertional malaise (PEM), the worsening of symptoms following even minor physical or mental exertion, with symptoms typically worsening 12 to 48 hours after activity and lasting for days or even weeks
- Non-restorative sleep/sleep disturbance
- Brain fog/cognitive impairment
- Joint pain
- Inflamed lymph nodes
- Persistent sore throat
- Severe headache
- Neurological abnormalities
- Complete organ system shutdown
- Sensitivity to light, sound, odors, chemicals, foods, and medications
- Persistent fatigue for six months or more
- Headaches
- Migraine
- Dizziness
- Muscle Pain
- Sore Throat
- + Add Other Symptoms that are Personal to You

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Journal Example:

This is an example of a random week, selected by opening a 2017 calendar to this page by chance. The script is actually what was written on each day by a person with ME/ CFS, who had been recently diagnosed. It illustrates the possible ups and downs of this illness. By transferring this information onto a chart it can become a valuable tool to use with your physicians. It can help with knowing when a new treatment may

be indicated, or if a current medication is proving to be effective, or not. – Susan Rebecca

MAY 2017		
Friday 12	Better day – Couldn't drive, but out of the house, extreme fatigue returned about 3 pm	
Saturday 13	Medium day - Drove car about 5 miles. Very shaky. Extreme fatigue about 2pm. Went to mall with spouse about 5pm - had to have help to the car leaving the mall - carried upstairs	
Sunday 14	Mother's Day. In bed all day. Major aches. Extreme Fatigue all day	
Monday 15	Very bad day. Crawled up & down stairs to bathroom. Unable to prepare food in microwave - ate apple. Extreme fatigue, dizzy, aches, heavy chest	
Tuesday 16	Went shopping with Mother. Fair in morning - some tiredness. Extremely fatigued by mid-afternoon	
Wednesday 17	Bad day - in bed all day. Extreme tiredness, heavy chest, difficulty in climbing stairs - was able to microwave food	
Thursday 18	Blank	
Friday 19	Bad Day. In bed until evening	
Saturday 20	Good day. Some achiness. Rested on couch	

14 Day Chart

Date:	
Date:	

Date:	
Date:	
Date:	
Date:	
Date:	

Symptom Progress Sheet

Date Range: From ______ to _____

Key		
Mild	0	
Moderate	1	
Moderate Severe	2	
Severe	3	
Fleeting	F	
Steady	S	

Remitting	R
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Activity	
Sleep	
Appetite	
Post Exertion	
Malaise	
Fatigue	
Headache	
Mental Confusion	
Fever	
Dizziness	
Sore Throat	
Infection	
Muscle Pain	
Joint Pain	
General	