



DOCTOR DISCUSSION GUIDE

Managing Chronic Fatigue Syndrome

Chronic fatigue syndrome (ME/CFS) can involve dozens of symptoms that range from mild to severe, so understanding your condition is the first step to taking control of it. Asking the right questions during your conversation will help you know what to expect and how to better navigate your condition. Familiarize yourself with these common terms before your appointment to help facilitate your discussion.

Vocabulary to Know

Your doctor might mention these common terms. Here's what they mean.

Post-Exertional Malaise (PEM)	A hallmark symptom of ME/CFS. After exertion—which can be vigorous exercise in some but as little as walking to the bathroom for others—symptoms increase significantly for a period of time. PEM involves multiple documented abnormalities in how the body responds to activity.
Cytokines	Proteins produced by the immune system that help regulate your body's inflammatory responses. Multiple types of cytokines exist, but in ME/CFS, special attention has been paid to those that increase inflammation, called pro-inflammatory cytokines. Elevated pro-inflammatory cytokine levels are common in this disease and are considered a marker of an over-active immune system.
Central Sensitization	The most widely accepted theory about the underlying mechanisms of ME/CFS. Having central sensitization means that your body may overreact to pain, noise, light, fragrances, or just about anything.
Neurotransmitter	Chemicals in your brain that transmit electronic messages from one cell to the next. In ME/CFS, several neurotransmitters are believed to be out of balance or used improperly by the brain.
Hyperalgesia	A rare type of excessive pain that some people with ME/CFS experience. The nervous system (brain and nerves) amplify pain signals, essentially "turning up the volume." This means that something that would normally be mildly uncomfortable can be severely painful.
Allodynia	Another rare pain type common in ME/CFS that's caused by something that shouldn't be painful. This can include clothes brushing against your skin, a light touch, or moderately cold air.
Cognitive Dysfunction	An umbrella term for multiple problems that can include poor short-term memory, inability to multitask, slow mental processing, and more. These symptoms can range from mild to severe.
SSRI/SNRI Drugs	Classes of antidepressant medications that are often prescribed for ME/CFS. These drugs are believed to be effective against symptoms because they help correct neurotransmitter dysregulation.



Questions to Ask

These questions will help you start a conversation with your doctor about how to best manage your ME/CFS.

About Symptoms

- Are my symptoms typical of ME/CFS?
- Will my symptoms get worse over time?

About Causes & Risk Factors

- Are you able to pinpoint why I got ME/CFS?
- Are my children (or close relatives) at risk? What can they do to lower their risk?

About Diagnosis

- What tests will I need?
- How long will the diagnostic process take?
- Do my tests indicate that anything else may be going on?

About Treatment

- What medications are likely to help?
- What side effects should I watch for?
- How can I wean off of my medications safely?
- What if this drug doesn't work?
- What about supplements or complementary/alternative treatments?

About Coping

- How do I deal with depression?
- Should I see a therapist to adjust to living with a chronic illness?
- Do you know of any good support groups in the area?

About Living With Fibromyalgia

- What kinds of activities should I do?
- What kinds of activities should I avoid?
- Should I stop working?
- What positive changes can I make to my diet?
