

What To Expect, Level 2: The Inner Circle:

Information for Collaborators & PAs

by Miranda

If you're receiving this document it probably means that in the course of working together Miranda expects you will see her when she's not at her best, when she's fading, when her [cognitive function](#) starts to slip. The way that manifests can sometimes be confusing, so here's a little extra info that might be helpful.

Firstly, ups and downs are normal.

As much as we talk about stopping before symptoms worsen, it's not a perfect science. Symptoms fluctuate and some of the warning signs to stop are gradual. It's not like a magic switch flips.

Planning and breaks:

Front-loading decision making is helpful. People often say "You just tell me when you need a break", but that requires Miranda to vigilantly monitor herself whilst simultaneously doing other activities. Planning breaks and other decisions ahead of time reduces mental load. It also reduces the likelihood of Miranda trying to be a hero later.

Tone:

As fatigue grows, Miranda often runs out of energy to modulate her tone or to have an expressive face. Her faculty for language may also fade. If Miranda starts to become direct, flat, and unexpressive, it can be helpful to know that she's not cross. She's just extremely tired.

Heads up, Miranda has an above average faculty for language. It's not a brag, it's a warning. When it fades she can still sound extremely articulate, even when she's in pretty dire straits. It's best not to assume that she's well just because she's talking. She's got stealth fatigue under the cover of blah blah blah. Tone is generally a better indication of fatigue than linguistic ability.

Literal language:

Miranda often uses literal language when she is fatigued and doesn't have the energy for extra words. For example, "why did you do that?" doesn't mean, "you did this wrong". It means, "I am interested in how you made these choices." If you're unsure it can help to ask "do you mean that literally?"

Other Warning Symptoms:

Symptoms that warn us to stop or break early:

Worsening headache = Need physical &/or mental rest &/or food &/or water

Low back pain = Physical rest required. Lie down.

Confusion, [brain fog](#), disorientation, anxiety, slow thinking, dizziness = Total rest time.

Rest:

What is restful for a healthy person is unlikely to be restful enough for a person with ME/CFS. Here are what different types of rest look like for Miranda:

- **Physical rest** means zero physical exertion: lying down or reclining with feet up.
- **Mental rest** means zero mental exertion: no conversation or otherwise interacting with information. Reduced sensory stimulus is ideal.
- **Total rest** is the most effective and efficient rest. Total rest means lying down quietly without stimulus for 5-20 minutes, i.e. with an eye mask and earplugs. Please support total rest by reducing noise & NOT making conversation.

You:

Your needs matter too. Communicate your own needs early and often. This will benefit both of you. Don't be a hero, be a good communicator.

When in doubt, ask questions, ask for clarification, and check in.

Trust that Miranda has years of experience handling her health and is here to collaborate with you. There is no need to panic.

More:

If you'd like to learn more about how Miranda manages her illness and needs throughout the day and during activities, and how you can support her, see [The Protocol Overview](#).