

Shorthand: Concepts and phrases for Collaborators & PAs

By Sarah & Miranda

Below are examples of phrases and concepts Miranda may use to describe her symptoms or energy levels. They help save the time and energy needed for larger explanations

Buffering

Miranda says this when her brain has stalled & is working to catch up. Please do not interrupt.

I Am Empty

This means Miranda's battery is dead and she has no more energy to give to this moment.

I Have No Thoughts

Miranda often says this when she has reached [decision fatigue](#). Offer Miranda options and if she still has no thoughts, make a decision to the best of your abilities.

I Can't Drive the Bus

This is Miranda asking for someone else to take the lead for the time being.

Crash

An exacerbation or "flare up" of symptoms. Small crashes should be used as warning signs to stop & rest to prevent Post Exertional Malaise ([PEM](#)), which can have long term consequences.

The Tornado

A Tornado represents a crash: an exacerbation of symptoms requiring prolonged rest.

Tornado Watch or Danger Zone

Ingredients for a crash are present. Reduce stressors. Calmly & expediently move towards rest.

Tornado Warning or The Tornado Is Next Door

A crash is looming. Prolonged damage may be avoided if The Protocol is swiftly implemented.

The Tornado Is Inside The House

This means Miranda is crashing, though she may not yet be showing outward signs of distress.

I'm Not Okay

This may sound mild, but Miranda often says this when she is incapable of saying anything else. It means that Miranda has totally crashed, and it is urgent that she be in a calm, restful place with water and snacks as soon as possible to mitigate damaging effects.

Engage The Protocol

Exactly what it sounds like, start at the top of [The Protocol](#) and work your way down.

"Having A Really Bad Headache" During A Conversation

In very specific circumstances, Miranda will request help to exit a situation, by demonstrating a headache - rubbing her head, squinting, sighing in pain, and saying "I have a headache".

Usually it is because someone, often a stranger, has charged into an in-depth conversation about disability or Miranda's illness without awareness of, or interest in, the [emotional labour](#) and energy cost to her, and has ignored polite attempts to end the conversation. Generally any time Miranda has a headache it's good for her to rest, so don't worry about confusing a genuine headache for a request for escape, just help her get out of there.

Spoons, Forks, & Pace Points

You may have heard of the concept of Spoon Theory, originated by [Christine Miserandino](#), a tool many disabled &/or chronically ill people use to describe their limited energy and how it is used. Essentially a "spoon" is a unit of energy, to be spent throughout the day, and people with energy-limiting disabilities have fewer "spoons" than those without, making it important to closely monitor and conserve how they're spent.

Miranda uses technology to continuously monitor her heart rate and calculate exertion into literal "Pace Points" which she must pace throughout her day. These are her spoons.

An addition to Spoon Theory is Fork Theory, coined by blogger [Jenrose](#), that uses 'forks' as a metaphor for stressors. Imagine stressors as forks, being jabbed into a person. Stressors can be many different things: pain, sensory sensitivities, distraction, or even needing to pee. Some stressors are large forks, and maybe can't be pulled out right away. Some stressors are smaller forks. A key element of this theory is that **removing any forks, even small ones reduces the overall stress load.**

Talking About Symptoms: The Weather

It can be helpful to think of Miranda's symptoms like the weather. On an average day, most people will check in with the weather to be informed. Maybe it's drizzling and you need a light jacket or an umbrella, maybe it's colder and you need your parka.

Checking in with Miranda about her symptoms is much the same. You don't need to panic when you see it's raining, you just grab your raincoat; similarly, you don't need to panic if Miranda mentions a headache, you just ask if she needs something to manage it. Like the weather, symptoms are just information about the circumstances we are operating in.

We get the information, and then we make decisions about how to proceed.

Preparing for Extreme Weather

It's also important to be prepared for the weather. If it starts raining, it's harder to deal with if you don't already have a raincoat or umbrella. The same is true when the weather becomes intense. It's important to know what to do *when* a tornado arrives *before* the tornado arrives.

Most of the time you don't need to be a meteorologist. Most of the time Miranda can tell you what she needs. However, knowing the signs of a storm and being prepared can help in the event of unexpected extreme weather. Similarly, knowing the warning signs of a crash, being prepared and offering support will minimize damage to Miranda and improve longevity.

The weather doesn't go away completely by being prepared for it, and neither do Miranda's symptoms, but often the severity of the damage can often be reduced by taking action soon enough.