What to Expect When You're Expecting Miranda, Socially.

So, you're going to be hanging out with Miranda, and she's real sick, and that might feel weird. Even weirder, she's sent you a document about how to hang out with her? Um what?
Don't panic.
The point of this weird lil' handout is to save us both time and energy by getting some of the most important and frequently asked information out of the way first. It's still okay to ask questions, but this saves me energy by not having to repeatedly explain the whole shebang. Hopefully it will also help you feel more prepared and comfortable.

Scary Stuff First - "What's Wrong with You?"

I live with a chronic illness. It's an energy limiting neurological disease called ME/CFS. My cells produce half the energy (ATP) of a healthy person.
I must budget my energy extremely carefully, conserving it whenever possible by minimising mental, physical, and emotional labour; reducing exposure to overstimulation; and taking regular periods of quiet rest.
If I overspend my energy I won't have enough for my organs to function properly, and that is *NOT FUN.*

People may not think I look sick or may think that I am not too seriously affected by activity and stress because they don't see the consequences.
The most dangerous feature of this condition is Post Exertional Malaise (PEM), which means **the consequences of exertion do not arise at the time of exertion. They show up *12-72 hours later*.** Few people are ever around to see those consequences by the time they arrive.

PEM can last for days, weeks, or months. If PEM is induced too frequently it will result in progression of the disease and overall deterioration of health. "Pushing through" is NEVER a good idea for people with ME/CFS.
For more detailed info about Miranda's health, click here.

Soooooo…. Now that I've possibly scared the shit out of you…

How We Handle It

Energy management strategies you are likely to see Miranda using:

- Taking frequent short breaks to lie down and rest quietly, like a mini-nap.
- Sitting, preferably with raised legs, or lying down whenever possible.
- Resting quietly upon arrival & before departing (getting places is exhausting).
- Using a mobility aid, or a combination of mobility aids, some or all of the time.
- Frequently snacking and drinking lots of water
- Reducing sensory intensity by wearing sunglasses, earplugs, &/or a hat with a brim.

Things you can do to help:

- Plan in advance, and be willing to keep those plans flexible.
- Pass me things.
- Offer a place to put my feet up.
- Offer a quiet space &/or a horizontal surface where I can take rest breaks.
- Avoid interrupting or talking over me &/or other people (it can be very confusing).
- Try to have conversations away from other conversations or background noise.
- One thing at a time.
- Know that I can be sensitive to certain light and sudden, loud, or distracting sounds.
- Trust that I have years of experience handling my health and am here to collaborate with you. There is no need to panic.

Note: When I am particularly fatigued it is often easier for me to process specific offers/options or yes/no questions rather than open ended questions. Multiple choice is easier than essay format.

Communication & Language

Here are a few pointers that might help you feel more comfortable:

I am **disabled**. It's okay to say it. Disability is not a dirty word.
The Social Model of Disability states that people are not disabled by their impairments, but rather disabled by the barriers of a society that is not set up to include them.
It would mean a lot to me if you would read more about the Social Model of Disability.

PS: Don't say "differently-abled", "handi-capable", "super-abled", etc. unless you want to catch my eyeballs as they roll out of my head.

I am an **ambulatory wheelchair user**. That means I can walk a little and I use a wheelchair or other mobility aids when necessary.

Finally, to paraphrase Tim Minchin, "only a cripple can call another cripple 'cripple'". Which sucks for all the non-cripples out there, because cripple is a very fun word to say :P

Talking About Symptoms: The Weather

Symptoms are a big part of my life now, that's just the reality of the situation. When I mention symptoms it can, understandably, freak people out - they don't know what to say or do!

It can be helpful to think of symptoms like the weather. There is always weather. Everywhere. Everyone experiences it. It's just part of life.
On an average day, most people will check the weather to be informed. Maybe it's drizzling and you need a light jacket or an umbrella, maybe it's freezing and you need your parka.

Talking about my 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 I mention a headache. Like the weather, symptoms are just information about the circumstances we are operating in. We get the information, and then we either make decisions about how to proceed or we make random small talk about it.

Extremes

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 I can tell you what I need and if my symptoms are getting rough. However, knowing the signs of a storm and being prepared can help in the event of unexpected extreme weather. If you'd like to know more about the warning signs of bad symptoms, check out What to Expect: Level 2, and Shorthand.
If you'd like to know more details about how to support me in rough weather, check out The Protocol Overview.

About Making Plans

When it comes to making plans, people often leave a lot of planning, decision making, and/or researching activities to me because they are afraid of making the wrong decision for my needs. This can make even the act of making plans energy prohibitive for me. It puts too much on my plate. The most supportive way to both conserve my energy and let me make choices about what suits my needs is to collect what information you can and then offer me options.

Front-loading planning & decision making is helpful. People often say, "You just tell me when you feel well enough to hang out". I appreciate the generous offer of flexibility, but it requires a great deal of mental energy to remember ambiguous plans. It's much easier to put something in my calendar. Secondly, I will almost never spontaneously feel well enough. However, if plans are made in advance I can usually budget my energy throughout the week around those plans.

This goes for breaks as well. People often say "You just tell me when you need a break". That works well if we are just hanging out quietly in someone's living room where there isn't a bunch of extra sensory input, but it's quite challenging on outings. It requires me to vigilantly monitor myself whilst simultaneously doing activities and dealing with other things, often in a chaotic &/or unfamiliar environment. Planning breaks and other decisions ahead of time reduces mental load and significantly improves the quality and quantity of my time out.

Lastly, please be flexible and patient. I value your time and I never cancel or change plans lightly, but sometimes I have to.
It can also take a long time to make plans. I only have a few usable hours every day so they get booked up really quickly! Remember that outings will always require a bigger energy block out of my week than quiet hangs at home.

This doesn't mean I don't want to be invited to things! It really is always wonderful to be asked, as long as you won't hold my frequent "no's" against me. They are never personal. I'm just doing my best.

Logistical Things

If logistics aren't relevant right now you can skim them, BUT please do read them when it is relevant, like if we are making plans to meet in a physical place that I need to physically access.

Immunology

My immune system is weak. Please do your best to avoid exposing me to colds, flus, bacteria, viruses, contagious fungi, or alien spawn.

Temperature

My body isn't great at regulating temperature. I need to be careful/prepared in temperatures below 15C and over 23C.

Physical Accessibility

Walking:

- I can comfortably walk short distances, say 20 meters. I usually store my wheelchair and walk inside my own home, the homes of others, and small venues like cafes.
- For 80-100 meters I might walk with a rollator (wheeled walking frame) and would need to physically rest afterwards.
- I can easily walk up a few stairs, say 4, but I would probably crawl up a full flight and would limit subsequent walking. It's generally best to avoid venues that have stairs and no lift, but in the event that I decide to take the plunge don't you dare be embarrassed by my crawling! Also, anywhere with stairs requires 2 people to carry my 27kg/60lb wheelchair up the stairs after me. Please don't surprise me with stairs.

Wheelchair:

- Wheelchairs don't drive over steps or curbs. They don't. "But what about those stair climbing ones?" Don't get me started unless you are prepared to get me started.
- Most days I can handle my wheelchair over a single step, maybe 2 if they are several meters apart, but it's not convenient or pretty. It requires me to stand up and maneuver the chair. I don't mind doing it to get into people's houses, but I find it stressful in busy/public places like the entrance to shops.

Wheelchair dimensions, folded: L 55 cm x W 64 cm x H 75-98 cm (with/without headrest)
Weight: 27kg/60lb

Sensory Accessibility

- Sudden loud sounds and background noise drain me more quickly, especially if I'm expected to converse at the same time.
- Bright light, overhead light, fluorescent lights, and flashing lights drain me more quickly. The first two can be managed with sunglasses for a while. The last one just sucks.
- Chaotic places with lots of people moving in disorganized ways drain me more quickly. This can be mitigated by having a calm place to step away to for breaks.
- Sometimes I have a sense of smell like a bloodhound. It's not usually a problem, but limiting perfume, cologne, and chemical smells is appreciated.

Dietary Accessibility

My body is not great at maintaining blood sugar and I have to eat every 2-3 hours.
I also have some food intolerances, which are probably only relevant if you're inviting me to dinner. Hopefully not enough of them to un-invite me..

- Gluten intolerant. Gluten is found in wheat, barley, rye, malt, brewers yeast, seitan, and is often used in packaged foods and sauces as a stabilizer (esp. soy sauce).
- Lactose intolerant. A little butter or milk in *baked goods* is fine. Otherwise, no cow's milk, cream, cheese, whey, &/or yogurt. Eggs are fine. Goat and sheep dairy are fine.
- I also cannot consume caffeine, alcohol, grapefruit/grapefruit products, or CBD (cannabidiol). Love a good herbal tea or sparkling water though.

Travel/Transit Tolerances

Barriers to travel include extended periods sitting upright, chaotic environments, the mental load of navigating, & physical access.

Local Public Transit

Public transit is difficult. I can occasionally tolerate 10-15 minutes, maybe 20 during off peak hours (when it's quiet). Must be wheelchair accessible.

Car

30 minutes comfortably. 1 hr tolerably. 1 - 3.5 hours counts as an "outing" & no other activity can happen that day. Car comfort is significantly improved by being able to put my legs up and by smooth driving. Rushing to get me there faster will not help if it increases stress and jostles me around (I have a low tolerance for jostling).
Lifting my wheelchair into the trunk/boot of a car requires 2 people (I shouldn't be one of them).

Trains/overground rail

Love a train. Trains are usually much smoother than cars. 40 minutes comfortably. 1 hr tolerably. 1.5 - 3.5 hours counts as an "outing" & no other activity can happen that day. Train comfort is significantly improved by being able to put my legs up.
Must be wheelchair accessible. In most places wheelchair access requires arriving early &/or arranging in advance. Train travel is often complicated by getting to and navigating a station.

So if you don’t know, now you know.
Thanks for reading.
Can’t wait to hang out.

Love,
Mir

Extremely Unlikely To Be Necessary, but why not be on the safe side, Emergency Info:
Emergency Contacts:
Richard Lee, (partner) Phone: (587) 643 0439 Email:
Elizabeth Hobbs, (friend) Phone: (780) 504 7654 Email:
Medical history and medication information can be found here.