

Did you know? There is now a newly launched Antiracism & Equity Podcast. Hooray! Designed to be brief moments (less than 20 minutes), each episode offers food for thought and pause. Perfect for a bridge-containing commute, or an autumn walk.



New episodes drop on Wednesdays.

This week’s questions to consider:

Two questions. One: what exactly do people mean when they talk about invisible disability? Actually, what kinds of disabilities qualify as invisible? Two: isn’t it better to frame it in person-first language, as in, *person with disability*, rather than *disabled person*? I have seen mixed messages about that. Can you clarify?

Pro tip: There are three generally agreed-upon main categories of disabilities. I’ll walk you through a day in the life of a person living with one invisible disability, which will perhaps begin to show you how nuanced it can be when a person lives with one. As for person-first vs descriptive language, there are two schools of thought, both with beautiful intentions, but the bottom line is this: use the language that disabled people introduce, the language that people with disabilities use themselves, rather than imposing either convention. If you can’t settle, flip back and forth, like I did in the previous sentence. Nuance, friends. It’s everywhere. It’s important.

I’ve never been a morning person. You know, one of those people who wakes up with a smile, excited to greet the day filled with possibilities and time and maybe also a full, cooked, breakfast, and... joy. That sort of human? We all know one.

I am not one. When I was a teenager, my circadian rhythm followed that which is typical of teenagers: sleep in, stay up until 3 am without noticing, be miserable and brain-fogged in the early morning, rinse and repeat.

But then, that circadian rhythm was fossilized. I am still like that. In summer and right up until the day before I return to work in the school system, I remain awake each night well into the dawn, and sleep in until 11am, until noon, until 4pm, until who knows when. Time doesn’t exist in the same way in the summer.

What can I say? I’m a night creature. It’s the most delicious of times, when darkness envelops the world and my creativity wakes up and wants to play.

Thing is, this world is built for day humans, particularly when we consider our school system. This is unrelated to disability, but it is already a disadvantage for those of us who are not fascinated by the notion of “early”. There’s a reason I was so drawn to high school as a place to teach, you see.

None of what I’ve described so far is a disability, but rather, a natural tendency. It matters because it intersects with my invisible disability by making mornings extra challenging. I end up having to take extra measures to set myself up for success.

Disability is [...] a multidimensional experience for the person involved. There may be effects on organs or body parts, and there may be effects on a person's participation in areas of life. Correspondingly, three dimensions of disability are recognized [...] [as]:

- 1. Body structure and function**
(and impairment thereof)
- 2. Activity**
(and activity restrictions)
- 3. Participation**
(and participation restrictions)

source: <https://www.disabled-world.com/disability/types/>
retrieved: 7 October 2022

Day in the Life of Human Living with an Invisible Disability

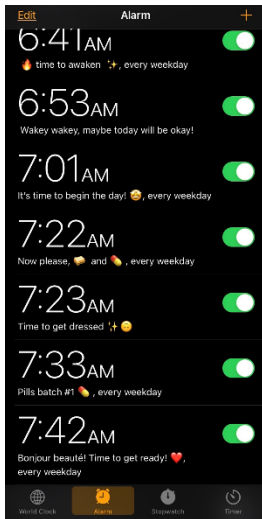
In case it hasn't been obvious until now, it's me. I'm going to describe a day in the work life of me, a person living with an invisible disability. Hi!

For the purposes of this description, it's helpful to know a bit about my disability; I have a degenerative disc in my spine. This deterioration of vertebrae causes a pinched nerve that sends unnecessary and randomized jolts of pain. Occasionally my back seizes out of nowhere. Once it happened mid stride, which was especially weird because gravity had to take over. It is a condition of chronic pain, managed with a careful cocktail of medications, avoiding excessive stress, specific food habits, and rest.

I have been dealing with this condition for 15 years, and it is currently being managed extraordinarily well. Peak management! There is no cure; it is degenerative and genetic, and many in my family who have lived with this condition have taken a variety of routes with a range of success or failure with their approaches.

A Day in the Life of Someone Doing Very Well Managing their Invisible Disability

6:41 am to 7:42 am



Wake up in there somewhere. There are six alarms, all set to varying ringtones, at different numbers, with different messages of encouragement. I am still annoyed every time I wake up to an alarm. It's horrible and it doesn't matter what alarm noise I set; I wake up feeling mad or annoyed or both.

Let's say I wake up around 7:30am after the above machinations from Nighttime Me.

By the way, Morning Me *loathes* Nighttime Me. Morning Me does not agree with anything Nighttime Me decides. So first we contend with those feelings. Sometimes a cat is nearby, which is nice.

Then there is the evaluation of how stiff the body feels. Is this a bad day? Is this a flare up day? Let's stretch a little. How's the nausea? (For me, nausea is a reaction to pain, so it is a horrible, helpful indicator.) Evaluation of how I feel, and what to do about it if it is very bad. Think of the day ahead. Can I work through this one, or do I need to stay home? Time to get ready and see how we feel afterward. Hot water on the back: divine.

7:42 am

Morning ablutions. Fancy way to say getting ready, no? I like it.

7:55 am

Morning medications. They take 20 minutes to come into effect, and I am nauseated until they do. And then I'm only half as nauseated because they cause nausea. (I live with constant nausea.) Wait for the medication to kick in and make a nice latte, put in favourite to-go mug, make peanut butter sandwich on untoasted toast (to me, "bread" means "pita bread" so toast is a loaf of untoasted toast). Try to eat as quickly as possible but give up and bring it to eat in the car. Bring cloth napkin to catch crumbs and be super fancy while eating plain peanut butter sandwich. In car, in traffic.

8:15 am to 4:30 pm

Workday. Sometimes a bit longer, sometimes the times shift, sometimes a tad shorter, it depends on what's happening that day, how much travel was required, and how hard it was to get to this point in the morning. I have a unique job. It allows for flexibility since sometimes I'm required to work later, and sometimes I'm required to work earlier.

in·vis·i·ble
dis·a·bil·i·ty
/in'vizəb(ə)/ /disə'bilədē/

noun

refers to symptoms such as debilitating pain, fatigue, dizziness, cognitive dysfunctions, brain injuries, learning differences and mental health disorders, as well as hearing and vision impairments. These are not always obvious to the onlooker, but can sometimes or always limit daily activities, range from mild challenges to severe limitations, and vary from person to person.

source: <https://invisibledisabilities.org/what-is-an-invisible-disability/>
retrieved: 7 October 2022

4:30 pm

Time for second dose of medications. Evaluation: how many [spoons](#) left? Plan afternoon and evening based on reserves of energy. Sometimes this means I am eating eggs for supper and getting in PJs and knitting. Sometimes this means I can meet friends for a drink. Sometimes I can do one errand before I go home. It's a day-by-day evaluation.

You may have been confused a moment ago when seeing me refer to spoons in this way. [Spoon theory](#) is a helpful analogy for explaining to able-bodied humans what it is like to live with an invisible disability. Click the link for the origin story. Here is a paraphrased version:

Imagine for a moment that anything you'd like to do has a cost, and we measure this cost in spoons. For example, getting out of bed, one spoon. Make the bed, one spoon. Shower that includes washing your hair, four spoons. Make a hot breakfast, three spoons.

Able-bodied people wake up in the morning with an **infinite** number of spoons. So doing anything they'd like to do is a non-issue. It's purely about the desire to do it. Want to make the bed? You have now made the bed. Fantastic feeling. No pain, no negative feelings of guilt, just a nice, made bed. Now the accounting: infinite number of spoons, minus one. Still an infinite number of spoons remaining. (Math is gorgeous.)

Those of us with invisible disability wake up in the morning with a **finite** number of spoons. It's never the same number, and it's always a surprise. So, if we wake up with, say, 10 spoons, it's a very limited day indeed. We think carefully about how to spend those spoons. One whole spoon to make the bed? Bed's staying unmade. I only have 10 spoons today. Using 10% of the day's allotment of energy to make the bed is just not going to happen. I'm going to eat breakfast, which will be a non-cooking breakfast, and that will cost me one spoon. Breakfast sets up the day for me and helps to mitigate the ongoing nausea. It's a priority. And then the rest of the spoons are allocated on a priority basis. Cause here's the thing; once you run out of spoons, there are no more spoons. You're done today. No more things. Get thee back home to recover because there's nothing left.

So, all these extra considerations are built in my day. I have automated a few things to keep brain space free, and so I will be eating a peanut butter breakfast sandwich for as long as I can, because I have learned that eating that kind of protein with bread first thing in the morning sets me up until lunchtime, when my appetite actually emerges, and I can eat a nice variety of things. It enables me to go through a morning with minimum nausea.

All of this has been **one** example of **one** kind of disability and how it manifests in **one** body. And this is after 15 years of learning what is within my control to help set me up for a successful day. This is also an example of **beautifully managing** a disability. Doctors were no immediate help. I was not correctly diagnosed until about two years ago. And that's when I began being able to fully live my life in the ways I wanted to, with travel beyond the 15-minute limit in a car, with saying yes to *doing* things with people.

I lived with this condition disabling me for more than 13 years.

As a contrast, here are examples of what it can look like when the invisible disability is running the show

Years of no highway driving. There are highways that connect the different ends of my widespread town. So, years of saying no to visiting friends in other countries, provinces, cities, neighbourhoods. Years of having to call in sick because of pain. My world was physically small.

Moments of experiencing such acute pain that I once sat on a bench in a grocery store unsuccessfully trying to hold back sobs borne of pain, waiting for the pharmacist to fill a prescription that would take the sharp edge off.

Countless days of laying in bed staring at the ceiling because that was the only position that I wasn't in excruciating pain. The jarring feeling of tears leaking into my ears because they wouldn't stop. Having to say no to new friends who wanted to do things I knew I couldn't do, avoiding taking about why, often giving the impression that I didn't want to connect because I would retreat in frustration.

Finding myself on a yoga mat that I kept in my classroom, on the floor, at 8:00 pm at night, considering that although I was stuck there, unable to get up at the moment, alone in the building, I had 71% battery charge on my cell phone and a downloaded episode of a comfort show, so I could work myself up to getting to my car within 45 minutes, and

then drive myself home. So, I dragged myself up off the floor by gripping the door, then gripping the ramp I was so grateful existed in that corridor, then crawled to my car, and drove home. Somehow.

Cancelling plans with no notice because I didn't get any notice. I just ran out of spoons.

During the worst of it all, no one knew. You get adept at hiding pain levels when living with chronic pain. It's boring to talk about all the time, and you get used to almost anything over time. And that contributes to making disability very isolating.

Any person with disability accumulates countless such stories. There's a lot to unpack in the experiences of disability. The intersections of who I am, a brown woman in a fat body, have added to this experience. Because of course they have. Doctors [not believing how much pain](#) was truly there, common in all doctors when treating a [BIPOC woman](#) especially.

The unbelievable number of hours of physiotherapy, massage therapy, body talk, chiropractor visits, and... I don't even know anymore. The financial cost, the emotional cost, the time, the spoon cost. It's an indescribably steep cost, all said. And the sum of the experience is, in a word, demoralizing.

Person-first vs. Disability first Language

Knowing what you know now about my disability, when I say I am a *person living with an invisible disability*, I say it that way, with person-first language, because I now know what it is. I also have it managed, as best as it can be managed, am in relatively manageable levels of pain most of the time, so don't need to talk about it as much. I prefer person first language now for these reasons. I have preferred this for about two years.

Previously, I didn't. It was important to talk about because of all the times I had to suddenly say no to things. It gave extra context, that I found helpful. It put the problem of managing spoons at the forefront of conversation. Gave reason for why it was difficult to do certain things, to move in the world in certain ways. It was helpful, for example, in telling my friends why I couldn't join the book club unless it was going to be happening within a fifteen-minute radius drive to my home.

I didn't have a correct diagnosis, but I did have one, and I liked having a name to give so people could look things up on their own if they were curious. I was rarely turning down things because I didn't *want* to do the thing; I physically *couldn't* do the thing; I just didn't have the spoons. I needed to communicate that somehow.

I've since learned how to better manage my spoon allotment, so I rarely find myself in a situation where I am out somewhere with one measly spoon left. By now, those close to me who have lived through that period with me understand; if I've got to go, I'm going. They're not insisting on explanations, which have a spoon cost too, anymore. And anyway, I'm not explaining anymore. I have finally learned that "no" is a full sentence.

This to say, some prefer "Disabled Person", others prefer "Person with Disability". Take your cues from the human in question. Neither is perfect, neither is wrong, and the best we can do is pay attention to others' cues.

Consider too that because so many disabilities are invisible, there are many of your colleagues, students, and people in this community who are living with a disability. But disclosure is not always an advantage. When they do disclose, people are often not believed when they share that they live with pain. Especially women. Especially BIPOC people.

And then Come the Good-Natured Suggestions

Here are frequently offered suggestions. Though I owe my response to no one, I'm happy to offer this context:

comment	my response
"Have you tried yoga?"	Yep, for years. But... I don't exactly practice yoga; I stretch due to necessity.

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“Have you tried yoga?”	Yep, for years. But... I don't exactly practice yoga; I stretch due to necessity.
“What about drinking more water?”	I couldn't possibly drink more water, and that's not how compressed vertebrae work. They don't... like... rehydrate themselves. The degenerative aspect means that the cushiony part has deteriorated. I've seen the x-rays. (Fascinating to see the progression over time.)
“Have you tried working out?”	Oh, loads. Swimming, dancing, yoga, gym-going, walking, running, cycling, every exercise regime ever devised by the many physiotherapists and massage therapists I've consulted. Conclusion: consistent physical movement of that nature results in consistent and increased flare ups of pain.
“I know a nutritionist that can help.”	Okay. But it's a pinched nerve. Only so far nutrients can go for a physical block. Also, and this is something I am very grateful for, I have a healthy relationship with food. I don't want to mess with it. Hard enough to maintain a healthy approach to food in this culture.
“You take pills? Oh, that's not good for you, you should stop.”	Stop taking specialist-prescribed medication that works, and live with debilitating pain? Thanks, I tried that. I'd rather risk the potential of eventual long term side effects and endure a few annoying side effects now than live with constant lifestyle-affecting pain.
“Work out, develop strong core muscles, protect your spine.”	This from doctors, friends, physiotherapists, strangers. Because that's easy, right? Exercising when already in pain? Have you tried doing that? It's how you injure yourself further and make things more difficult. I would know. Because I have. Many times.

There's a lot to think about here. Please know that if you are a person living with a disability, you are not alone. Statistics suggest 10% to 80% of the population live with an invisible disability. There's really no way to know.

If you are one of the lucky humans who wake up with unlimited spoons, recognize that magic. Don't give unsolicited advice, because it feels like a microaggression, like we must justify our right to bodily autonomy and explain our choices of how to live. If you can, allow for space, and exercise compassion. That's all you can really do. Well, that, and learning about what it means to live with a disability.

Recommended Resources

- The Spoon Theory by C. Miserandino (2003) | [But You Don't Look Sick, PDF version](#)
- Northwell Health Article (2020) | [Gaslighting in women's health: No, it's not just in your head](#)
- Academic Emergency Medicine paper by E. H. Chen et al. (March 2008) | [Gender Disparity in Analgesic Treatment of Emergency Department Patients with Acute Abdominal Pain](#)
- Harvard Health Blog Article by L. Kiesel (2017) | [Women and pain: Disparities in experience and treatment](#)
- USNews.com Article by G. Levy (April 2018) | [Why Women Struggle to Get Doctors to Believe Them](#)
- AAMC Article by J. A. Sabin (2020) | [How We Fail Black Patients in Pain](#)
- American Bar Association article by K. M. Bridges (n. d.) | [Implicit Bias and Racial Disparities in Health Care](#)
- BBC News Article by J. Bollock (May 2018) | [Pain bias: The health inequality rarely discussed](#)
- SSRN paper by D. E. Hoffman and A. J. Tarzian (2001) | [The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain](#)
- University of Gothenburg Master thesis in Medicine by J. Robertson (2014) | [Waiting Time at the Emergency Department from a Gender Equality Perspective](#)
- Women and Health Protection Article by A. Lippman (2006) | [The Inclusion of Women in Clinical Trials: Are We Asking the Right Questions?](#)
- Euractiv Article by H. Jacobsen (March 2013) | [Health experts urge greater gender balance in clinical trials](#)

Under control and finally at peace with how things are in this body,

Your friendly neighbourhood Anti-Racism & Equity Coach
Therese Trofimencoff (*she/they*)