Crip time in the arts

When people ask me what I do for a living, I tell them that I'm a professional poet. Technically speaking, that's true-I write poems, and people pay me to do it. But saying I'm a poet doesn't feel very honest, because I'm only a part time poet, and I have another job. One that I do full time. But I don't bring it up because most people don't understand *how* it's a job to be a cripple.

To put it simply, I spend a lot (a LOT) of my time doing or thinking about things that uncrippled people just don't have to do. What exactly I'm doing during that time is something I'll get into later, but for the purposes of this article I'm going to refer to those things collectively as "being disabled". I do them for at least 35 hours a week, so as far as I'm concerned, that's full time. Much like a job, the work of being disabled is involuntary, necessary for survival, and for the most part entirely unfun. Some disabled people might get paid by the government for being disabled, but most don't, and those who do are not paid anywhere near enough for their labour. I spend much more of my time being disabled than I do working on poetry. On any given day, if you ask me what I've been up to, the answer is probably that I've been being disabled.

I don't really like describing my disability as a job, because it feels like by doing that, I'm ceding something to capitalism. If I call it work, people are more readily able to understand its value, because under a capitalist framework, work is valuable. But capitalism is inherently hostile to disabled people (and honestly also just people in general!), so I would much rather be able to conceptualise myself outside of that framework entirely. It's helpful, though, as a way in for nondisabled people to understand a concept that I think is much more useful, and that's crip time. Where the job metaphor starts to fall down for me, I think, is when I'm asked to explain what I'm actually materially doing when I'm being disabled. Because if I am honest, the answer is nothing. It's easier to say that I'm attending appointments or managing treatments, because those are things that anybody can understand as activity. I do spend some of my time doing those things. But not a lot of it. Mostly I don't really do anything different to nondisabled people. What's different is the amount of time that things take up. This is where crip time comes in.

Crip time is a term that disabled people use to explain the way we experience time, and how it's different from time for nondisabled people. Though it's theoretically objective, in practice we're all aware that a huge part of how we understand time is by how much of it it takes for us to do things. How long is an hour? It depends on what you're doing. It's a long time to brush your teeth, but a short time to write an essay. The same is true of a day, a week, or even a month. Of course some people might be very quick at reading and others might be slow at cooking, but most nondisabled people average out to live in approximately the same time as each other, and this is the time that society is built to function around. Everyone has 24 hours in the day, and in that time we're supposed to travel to and from work, work for seven hours, make and eat three meals, take a shower, maybe do some laundry, exercise, socialise, and do it all again tomorrow. If we're measuring time by how long it takes us to do things, it would take me about a week to get done what a nondisabled person can achieve in 24 hours. For a start, I'm unconscious for at

least 12 of them. What this means is that even though in theory I have the same amount of time as everyone else does, only about 1/7th of it is actually usable to me.

When you're consistently unable to do things at the same rate as most people, you start to fall behind. Other people's lives move forwards faster than yours, and it's easy to become disconnected from the people and the world around you.

One of the most striking accounts of crip time I've seen is in <u>this article</u>, where Jennifer Brea describes what she calls Whitney time. Whitney Defoe is a very severely ill ME patient, who is bedridden and mostly unable to move or speak. He can only communicate with people when he takes an anti-seizure medication called Ativan.

"When we got to the hospital, they brought Whitney into a special room. One of the first things he asked was that his iPod be charged. Janet carefully handed me the brown towel. I carefully unwrapped it. Whitney motioned to us to be careful. "Don't worry, we're being careful," I said. I started digging around in a duffle bag until I found a pair of brand new charger cables.

"The last time he had Ativan, he asked Ron to order these cables on Amazon," Janet explained.

Wow. Just to be clear, this means that several months ago, the last time Whitney was on Ativan, he asked for charger cables for a 15 year-old iPod so that the next time he was on Ativan, a few months later, he could ask someone to charge his iPod. There is **Whitney Sign Language** (WSL) and there is **Whitney Time** (WT), I thought."

Crip time is different for everyone. To me, Whitney time is unimaginably slow. If I want to charge my ipod, that's something I am still able to do about as fast as a nondisabled person could. But there are lots of other things, like leaving my house, sending emails, making phone calls, washing, that use a lot more of my time than they're supposed to. For some people, things will take longer because they physically must; communicating through an alphabet board, for example, takes much longer than communicating verbally. For other people, like me, doing things takes longer because of the extended periods of recovery time necessary after even very simple tasks. Either way, the outcome is a life lived very slowly, much slower than society is equipped for.

I actually don't mind living in crip time all that much. It's just my life. My nondisabled husband has chosen to slow to my speed, and I live pretty happily alongside him and my other crip friends. I am more productive, more comfortable, and much happier when I stop trying to keep up with regular (noncrip) time. It only gets painful when I have to communicate and maintain connections with people who live by noncrip time, which is why I don't really have any nondisabled friends. It's very difficult for people to understand what my life is like, and why I seem to do so little with it. When I talk to people who are uncrippled, they usually ask me what I've been up to lately, and mostly the answer is that I haven't been doing anything at all. Maybe I phoned social services on Thursday. That was me done for the week. And I'm so tired of getting back blank faces when I tell people that. I'm tired of people thinking I have nothing to say. Other

cripples ask me how are you feeling? What have you been thinking about? These are questions I'm much more able to answer, that lead to conversations I can contribute to, because even if I am not able to "do" I am still able to think and feel. Thinking and feeling are not temporally weighted in the way that doing is.

I am not particularly interested in talking to people who think that *doing* nothing is the same as *being* nothing, so for the most part I only talk to disabled people. But there's one area of my life where relationships with nondisabled people are entirely unavoidable, and that's when I'm working. I rarely feel so disabled as I do in my professional life. I am very good at poetry, but I am very bad at all the other things you have to do to be a poet, and it makes me feel awful about myself. I feel as though I am constantly behind, never doing enough, and constantly failing to live up to my potential. I feel as though I am drowning.

Up until recently I've really struggled to understand why I feel that way. My instinct has been to understand it as a personal failure. According to the social model of disability, in a properly supportive environment my physical setbacks could be accommodated away, and put me on a level playing field. Most of the people I work with want to do everything they can to help me, but somehow no amount of accommodation seems to be enough to help me keep up. Even now, in this new age of zoom meetings, where theoretically things should be more accessible than they've ever been, I still don't feel any less disabled. These are problems that make a lot more sense if I understand myself as not just physically disabled, but temporally disabled too.

One of the biggest problems I have in my working life is that a lot of things which are everyday work activities to other people are a major undertaking for me. For example, because I am so rarely able to leave the house and meet people in person, a face to face meeting with an industry peer has a fundamentally different meaning for me than it does for them. An hour's conversation over coffee is likely to be the most meaningful social contact I've had in a month, but for the person I'm talking to, it's just their lunch break. They have conversations like that every day. I will be thinking about it for weeks, while they will probably not think about it much at all going forwards. The outcome of that disconnect is me feeling that I've made a quite close professional connection with someone who genuinely might not remember my name, because a month's worth of work for me is an afternoon's worth for them.

This is an issue that extends beyond the physical. Writing emails is another big area of trouble for me. It's something I find really really difficult. With the help of my partner, I am able to reply to all my emails *maybe* every three days or so. I'd honestly be quite proud of a turnaround like that. The people I'm contacting will probably respond to those replies the same day I send them, but for the next three days my initial replies are still recent to me, because in terms of how much work I can get done, three days is just not that much time.

A lot of what typically determines an individual's ability to succeed in the arts is their ability to be present. We call this Hustling. Show up. Talk to people. Charm people. Make sure everyone knows your face. Always follow up with an email. Look busy. Even if you're not busy. *Especially* if you're not busy. Big yourself up on social media. Check in with people every month to remind them you exist. People cannot hire you if they don't know that you exist. I don't know how helpful it would actually be for me to do all these things, because it's simply never going to be an option. I cannot hustle.

Or, more accurately, I AM hustling. But compared to what everyone else is doing, my hustle is laughably insignificant. I am moving so slowly that it looks like I've stopped. Early this year, a fellow disabled artist (and my close personal friend) told me that she was frustrated because people kept asking her whether she was still making art. I couldn't believe that was happening to her, because I knew how hard she'd been working. I knew she'd been working herself sick. I was able to recognise this because the two of us share an understanding of crip time. Nondisabled people seemingly couldn't. Instead, they made assumptions about how much effort she was putting in based on her creative output. This is something I worry about a lot working as a cripple; the idea that people- my audience, my peers, my potential employers- will look at the amount I'm achieving, and when that doesn't match up to the output of my nondisabled peers, assume that I'm not really putting the work in. And if people think I'm not putting the work in, they're not going to commission me to do more of it!

The truth is that I am working as hard as everyone else is. I just don't have as much time. I've noticed that the successful disabled creatives I admire are almost always about a decade older than me. I wonder if this is a result of the cumulative effects of living in crip time. I wonder if, when all is said and done, we have to wait a whole extra decade to get where we're trying to go. That wouldn't surprise me. Disabled travellers are accustomed to delays.

At the end of The Great Gatsby, Fitzgerald famously describes us all as "boats against the current, borne back ceaselessly into the past." The inelegant truth that he omits from that metaphor is the fact that not everyone can swim, and some people know how to drive a speedboat.

It's possible that somewhere out there, there's an access budget big enough to fundamentally alter the passage of time, but I haven't found it yet. And until I do, I will spend my career being beaten back harder and faster than the people whose bodies are well enough to keep them afloat.