

LIVING WITH IDIOPATHIC HYPERSOMNIA

How time became a conundrum.

A quick google search explains a conundrum to be a *confusing and difficult problem or question*. Time though seems obvious right. You probably wouldn't need to google that word to understand it. Yet, for me it is inexplicitly elusive now. Idiopathic hypersomnia has broken my understanding of time for some reason. To me, I wonder if it is a time-based disorder. If somehow it causes me to fail to regulate and understand time with respect to normal subconscious timestamps that we lay down. Like, first sun normally equals morning. Smell of coffee equals morning. Cars and buses for first time means later in morning enroute to work. And then a phone call that comes as we pass the bridge and in seeing the name of the caller pop up as "mum" who never knows how to end a conversation quickly and we inherently know how much time has passed so far, how the traffic is and how much time is normally left in our trip to work to quickly decide not to answer as there won't be time... Well, I remember that feeling as it related to time passed and left in a day and its relationship to sleep, and now I struggle to feel it or understand it during my day.

Can you imagine?

When I wake up, there is the phenomenon of just not bloody knowing what's going on. Turning up to work without a belt around my waist and just not being able to reverse my memory backwards to know when exactly I missed that normal moment of putting it on. Which adds to disorientation. It's very similar to driving when you are tired and scarily becoming aware your how your now somehow on a bridge and can't recall the last few minutes and think to yourself, wow better wake up otherwise something bad might happen so you refocus again. Except I don't. Not until some passage of time passes, but I can't ever tell you how long or what retriggers the focus. I think this is what they call sleep drunkenness.

How about, when I do get to work fully clothed but then you're stuck in conversation with me? Yeah well, I didn't even know I was stuck in time with you but the look on your face says your unhappy with me. I just thought we were always somewhere in the middle of our good conversation except we weren't. It's the feeling of just not knowing how long ago we started talking. Like there was a failure to subconsciously timestamp that moment and so my brain just assumes it was only a short moment ago. 30 seconds to me and 30 minutes to you.

No idea with time. It continues...

Time for lunch, I wonder? Okay, well I am so yeah, it's been a while since breakfast cause I'm starving I say to myself. Nope, only 10:00am, breakfast was 2 and half hours ago, only half way to lunch time. What the hell...

Lunch time. Finally. But man, I feel like it should be home time cause why do I feel like its bedtime already. Uh oh, sleep pressure moment. Building, building, building... my eyelids are instantly hard to hold up, absolute zero concentration.

It's like I've been on a long hike from sunrise to sunset, physically exhausted I come home, walk through the front door and I'm not going to brush my teeth, I'm not going to go to the toilet, I just need to get my head on that pillow now before I'm asleep at the doorway.

Better act quick. I will change what I'm looking at, move my neck or my eyes. I will try to get to some sunlight or start a conversation to reverse it. Great, my manager is walking by. Yes, yes..ha-ha.. etcetera etcetera just keep me awake. I keep thinking about sleep while they are talking don't I... Yawn. Yep, I just yawned at my manager. Well, they did give me the look just before or maybe yesterday, nope that was just this morning, like they wanted the short version so whatever if I'm yawning now, this should shorten it up for you. Conversation done. Thank God, I can't even remember what we were talking about which is just so weird. Well, I've distracted myself enough, maybe I will go get that bite to eat. Shit. Lunch break is over. What the hell just happened?

Home time and as I walk into the family room to greet everyone the lounge catches the corner of my eye and like the sirens that called them into the water in that movie with George Clooney, O' Brother Where Art Thou? all I can think about is that lounge calling my name to nap. My 2 year old is crying. Dinner needs to be cooked and somehow my wife looks at me like you'd better not bloody go to sleep! What a fool I am anyway, napping doesn't help anyway. Ah well, might as well just feel redundantly invisible again and not express my immense feelings or anything. Best to just keep it inside, remain resilient and just stay awake. Better then saying anything like I'm tired, just need to nap, sorry long day or anything that might be considered a fight starter. What, are you saying I do nothing all day while you're at work?

The above is the fragment of my thoughts that occur in relation to time which I find utterly interesting. I have chatted to a couple of other people who also find the concept of time has changed since their teenager years, yearly twenties and also of the concept of sleep drunkenness. The description of how to describe sleep pressure in italics (above) is interesting. In anecdotal evidence (meaning only in my experience rather than anything scientifically proven) - I have not met someone who when given that word for word description and says yes they feel that during the day has not gone on to have a sleep disorder. And those with feeling of fatigue never answer yes to feeling like that. Perhaps an important question to prove scientifically? I also chose to introduce the concept of resilience and of the struggles with trying to comprehend the internal thoughts that occur between real relationships and conversations with others who don't know what we are thinking or feeling inside and the turmoil that is brewing. It is not easy. Resilience to me for IH remains the most important thing in a series of multiple most important things. But just like you feel

worse when you give into the sleep pressure, you feel worse if you give in the constant perpetuating thoughts that rattle on as well. None of them are generally more than our minds waffling on and they rarely are helpful. So don't listen to these thoughts if they aren't helpful. As tough as it is, get on with it. Which I know sounds isolative in general mental health care terms but for me, people living with IH have some of the highest degrees of resilience and self care required to just stay awake for a normal amount of time and the utilisation of this is just absolutely required with this condition; its instrumental. A conundrum in its own right is to get on with it versus speaking out - I know. But there is always a difference between reasonable dismissal of thoughts to push through and that of being unwell and needing to seek help. Don't expect this to tell you which is which. See your GP about that.

Otherwise, my final message to someone reading this is that you are okay. It's funny when I read a lot of the other personal stories. Not many are of hope or inspiration, right? Not many of joy or success. It's really hard to write this last part - for so many reasons but mostly out of fear that people might find out who I am and then say because of my condition, my care is inferior. But I am a General Practitioner (GP). I worked undiagnosed in the hospital as a Junior Doctor. I don't know many doctors with IH. One in the USA that I reached out to had to stop working. Too hard. Well, I was nominated for Junior Doctor of the year and then for GP Registrar (trainee) of the year. I was nominated to local and then regional boards for safety. I was one of two selected over the course of a couple of years to be an Emergency Doctor. I was sought out for other specialities including Ear Nose and Throat and Psychiatry. And I successfully finished my exams for General Practice despite this condition, despite a motor vehicle accident during those exams' periods and COVID and falling asleep between patients before getting a diagnosis and treatment.

I have a wife, a 2 year old and another child on the way. And whilst the story above were my thoughts and experience of literally yesterday, I absolutely, do not ever think that anyone has to ever give up on their dreams. Resilience is my friend and when I take care of it, they take care of me.

Tim – 2023

