

Living with Idiopathic Hypersomnia is lonely. It's hard to make and keep friends when people think you're not interested in them or what they're saying. But it's not true - I am interested. I just have difficulty concentrating on what's being said and following the story. I'd love to go to a party, a concert or even the movies with friends but I can't drive far for fear of falling asleep at the wheel. Not only that, but I'll fall asleep during the event anyway and there's nothing I can do to stop it. Many people make friends through their work place but not me. I lost my job almost a year ago when my manager, who knew about my condition, bullied me and made work conditions unbearable. I was branded as being unsociable by my colleagues because I opted to focus on my work instead of being drawn into social chit-chat during working hours; they didn't understand how much the chit-chat broke my concentration and prevented me from completing my workload. So I don't have friends from my last workplace and, being unemployed, I don't have any colleagues to befriend.

You might ask "but what about your family?" I don't have any children, my mother is no longer with us and my four siblings live interstate with families of their own. They've never spent time with me when I'm struggling to be 'awake' so they don't understand what it's like for me. They've never seen my sudden change in awareness level: the change from being coherent and articulate to slurring my speech, forgetting simple words or what I'm saying; the change that turns the simple act of bending down and standing up again into bending down and falling to the ground. So they don't understand what it's like to live in a world where you just can't get yourself together and it takes forever to do simple tasks. It's hard to share your life with family when one day blends into another, nothing new or exciting happens, and you don't have any news to tell. It's hard finding out what's happening in their lives through Facebook instead of through personal contact. It hurts to learn about their overseas family holiday via a Facebook airport check-in posted days earlier. Things such as this only add to the feeling of loneliness and isolation. Do they think I'm not interested in them? How can I make them understand how hard it is to call them when I have nothing to say, when I know so little about their lives that I don't know what questions to ask them, and when talking on the phone without visual clues to help interpret how they feel is both difficult and exhausting? They don't know how to support me or how much support I need, so over time we've drifted apart.

And what about my partner? He has experienced my symptoms and tries to be patient. But he doesn't understand how I can forget something he's just told me, how I can be so easily distracted or how I can lose track of time so easily. If I ask him to repeat himself he gets annoyed and says I don't listen, if I ask questions that will help me follow his meaning he thinks I'm being argumentative or difficult. So although we share our day or tell each other about something we've found interesting, we don't really

discuss anything. I don't think he wants to understand my condition either. He gets upset when I take too long to do a chore so if we are going out we're invariably late, but he won't help me finish the chore either. He knows it takes me all day to clean a relatively small house and 3 hours to mow the lawns, and that these household chores are both mentally and physically exhausting for me, but he won't do these jobs himself or help me with them. I have tried helping him understand my disorder by giving him reading material but he won't read it or come to my sleep specialist appointments. I've asked him to make notes of my behaviour when I'm having time off or changing medications but he can't be bothered. So although I have a partner that I see on a daily basis, I can't discuss anything with him and he isn't giving me the help and support I need. I know my condition is hard for him too and that he is genuinely concerned for me and my wellbeing so I try to get on with things and remember everything he does for me instead of focusing on what he doesn't do. Sadly, he doesn't have any friends either and I wonder, is that my fault? Does he stay home at night to make sure I'm ok? How many invitations from friends has he turned down so I'm not at home alone? I know my condition has impacted on his life too and it makes me feel terrible and selfish. But somehow it also makes me feel a little less alone.

Written by Robyn for the Idiopathic Hypersomnia Awareness Week 2018



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