

LIVING WITH IDIOPATHIC HYPERSOMNIA

My daughter suffers from Idiopathic Hypersomnia, a chronic neurological sleep disorder that leaves her fighting for energy and alertness every day.

It is hard to watch her struggle to make it through the day without sleep overcoming her. School is difficult. She tries to listen and take in what is going on around her but retaining information while you are fighting to stay awake isn't easy. It's made worse when people assume she is lazy or should be able to stop herself from falling asleep. They don't understand that she is in fact working doubly hard to stay on top of things. I know it is important to help her advocate for herself and to support her mental health. I just wish there was more we could do for her. IH can be isolating by definition but we have encouraged her to connect with other people with IH as we hope this will lessen some aspects of that isolation.

She is 17, she was diagnosed a year ago. I worry about her future but I am so proud of her strength and determination to make it through each day.

Dee – 2023

