

your life

“I went to bed and woke up eight months later...”

Alanna Wong, 22, suffers from “Sleeping Beauty Syndrome”, a rare neurological disorder. This condition didn’t just rob her of her precious teenage years, it also affected her emotional well-being, social life, schoolwork, and career dreams, in ways nobody could have imagined. BY sasha gonzales

“I was diagnosed with Kleine-Levin Syndrome (KLS) at 18. Also known as the “Sleeping Beauty Syndrome”, the condition is so rare that only about 500 people in the world have it. My symptoms started when I was 10. Prior to that, I was a healthy, vibrant, energetic child. Then, I noticed that I began needing more sleep. It was very uncharacteristic because I was always the first in my family to wake up in the morning, but now, I could barely drag myself out of bed. I missed a lot of school as a result.”

Excessive sleeping dominated most of Alanna’s teen years.

THE NIGHTMARE BEGINS

“At first, my parents didn’t think there was anything seriously wrong with me, but then, other weird stuff started happening. For one, I began craving massive amounts of food — I shocked my mother once by asking her to cook me more eggs for breakfast. “But Alanna, you just had five!” she answered incredulously. My stomach was like a bottomless pit. Although I was eating at all hours, it seemed like no amount of food could satisfy me.

Then, there were the mood swings. I went from being happy and well-mannered to angry and rude. I got into verbal fights with my classmates, argued with my parents and older sister, and would get upset and depressed for absolutely no reason. I got into trouble at school, but I had no control over my behaviour; often, I wasn’t even aware of how I was acting. And, as suddenly as my KLS episodes came on, they would disappear, sometimes after a few days or several weeks, and I’d go back to being my regular self again. So, I’d alternate between ‘normal Alanna’ — kind, caring, and good-tempered — and ‘loud, angry Alanna’, and at times, ‘lazy, unmotivated Alanna’. It was like having different personalities.”

AWAKE, BUT LIVING A BAD DREAM

“Every time KLS struck, I became so lethargic and listless that I just wanted to sleep. I had no energy even for the simplest things, like brushing my hair. In June 2009, when I was 20, I went to bed and didn’t wake up until eight months later. Well, I got out of bed to eat, use the bathroom and was able to talk with my family, but I wasn’t exactly ‘awake’. I was in a semi-conscious state. Nothing felt real to me; it was like being in a dream. When I wasn’t asleep, my brain was behaving as if it were. In February 2010, I ‘woke up’ from this dream-like state, feeling completely normal again.

For many years, I functioned this way, going in and out of episodes, not knowing what was happening to my brain or my body. The countless doctors I saw had no explanation for my symptoms; a few even misdiagnosed me as schizophrenic and manic-depressive. It was a very scary and unpredictable time in my life.

Once, in my mental haze, I ran away



Alanna was featured in *Strange Brain*, a 2007 BBC documentary on unusual neurological conditions. Here, the doctor is seen sharing Alanna’s KLS diagnosis with her parents.

from home. I don’t even recall doing that, but my parents told me that I ran out in my pyjamas and the police found me a few hours later in a dark alley. Sometimes, my episodes would get so bad that I’d actually overdose on pills and had to be hospitalised. I don’t remember doing that either, because the ‘normal Alanna’ would never have done such a thing.”

“I would get upset and depressed for absolutely no reason.”



Alanna with her parents, Randy and Diane Wong.

MISSED TIME, MISSED OPPORTUNITIES

“Your teen years are supposed to be the best of your life, full of new discoveries, fun times, and exciting challenges. But I lost a good few years between the ages of 10 and 20 because I was either asleep in bed or functioning sick. It makes me sad whenever I think about all the years I will never get back.

My schoolwork suffered because I had trouble concentrating and couldn’t do my assignments. Before KLS, I had been a good student, but now, my teachers dismissed me as stupid or lazy. They would scold me for falling asleep in class and accuse me of being a troublemaker because I’d interrupt them while they were talking.

I excelled at tennis and had dreams of becoming a professional player like my idol, Martina Hingis, but KLS changed all that. At 18, I had to turn down a tennis scholarship because of my illness.

My closest friends also distanced themselves from me because they couldn’t understand what I was going through. Many called me names, and some even accused me of faking my episodes just so I could get attention! I had to be home-schooled for a while because I couldn’t bear being in the same class as those kids. On dates, guys would try to take advantage of my fragile emotional and mental state.

Before I was diagnosed, my sister thought I was being spiteful towards her on purpose, and we stopped talking and being close like we used to.

It was hard having to go from doctor to doctor and undergoing all kinds of medical tests, only to be told that there was no explanation for what I was experiencing. I can’t begin to tell you how frustrating it was for my parents and me.”



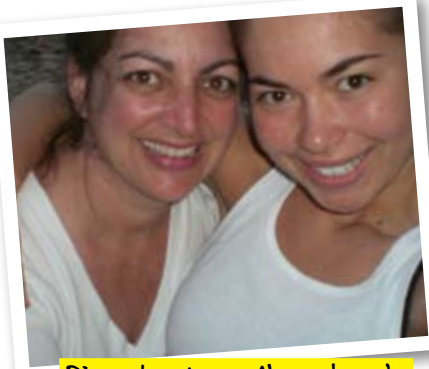
Alanna's episodes are no longer as severe.

WAKING UP TO A MORE POSITIVE FUTURE

"I was finally diagnosed at 18. That gave my family some relief, but then the doctors informed us that KLS has no cure. It does, however, end eventually, and is believed to take 10 to 15 years to go away. The Magnetic Resonance Spectroscopy, taken during an episode, showed restricted blood flow to my hypothalamus — the part of the brain that controls sleep, hunger, and mood — but the doctors couldn't even tell me what had caused it.

I know KLS will leave me for good one day, but I don't know when. I still experience episodes from time to time, some longer and more severe than others, and I'm on medication to manage the symptoms, but that's about all I can do. I'm lucky to have a wonderful family who understands my condition and knows how to help me feel better.

KLS makes it hard for me to work or go to school, so I spend most of my time doing whatever I can to raise awareness of the disorder. My mission in life is to get everyone talking about KLS. I hope that some day, someone will find a cure for it, but in the meantime, I want to be a source of strength and support for other KLS sufferers, and help them understand that, despite what they're going through, their life needn't be a nightmare."



Diane has been Alanna's rock throughout her entire KLS ordeal.

Are you sleeping too much? (Or not at all?)

Dr Lim Li Ling, a neurologist at the Singapore Neurology & Sleep Centre, Gleneagles Hospital, and president of the Singapore Sleep Society, explains the differences between the two conditions.

■ Hypersomnia

SYMPTOM: When you snooze for eight to 10 hours, but are still tired and sleepy when you wake up.

CAUSES: Various disorders, including narcolepsy, a genetically-linked condition characterised by excessive sleepiness and daytime sleep "attacks", and obstructive sleep apnea, a condition in which pauses in breathing occur during shut-eye due to the obstruction of the upper airway.

WHY IT'S BAD: "Narcolepsy can be dangerous because you could fall asleep while driving or operating machinery. Thus, it can kill. Sufferers may have trouble at school and at work too — people might think that

they're lazy, so there's this unfair social stigma against them. As sleep apnea affects your quality of sleep, you may feel tired, irritable or depressed during the day. Sleep apnea, in the long term, is associated with depression, weight gain, hypertension, and heart attack," says Dr Lim.



■ Insomnia

SYMPTOM: You have difficulty sleeping and find yourself staying up all night. Most times, Dr Lim says, it's likely by choice, because young people don't usually have much of a problem hitting the sack. "Teens tend to go to bed late, so if they don't get enough sleep, it's because they decided to stay up to study, play computer games or watch TV. Coffee and energy drinks can also keep a person awake through the night."

CAUSES: Usually extreme stress, anxiety or depression. If your insomnia has been going on for at least two weeks, you should speak to a medical professional, especially if simple stress management techniques do not help.

WHY IT'S BAD: In the long run, a lack of sleep caused by voluntary sleep deprivation can affect brain performance, and may even lead to diabetes, heart disease, and an increased risk of obesity, so make sure you get enough ZZZs every night, advises Dr Lim.

SEEK HELP: Sleep disorders can be harmful if not treated, so if you need help, visit any of the sleep disorder clinics at NUH, KKH, SGH, TTSH, CGH, or the private hospitals.

Visit www.klslife.com for more on Alanna's KLS experience and how she is helping the KLS community around the world.

PHOTO OF ALANNA LAURA KOVACS