CASE HISTORY

When slumbers never cease

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In June 2009, Alanna Wong went to sleep and didn't wake up until February of last year.

For eight months, she spent 14 to 16 hours a day in bed, breaking her slumber only to eat and use the bathroom. When she wasn't asleep, Wong remembers feeling like she was in a dream. "Nothing seemed real," she says, and her brain "felt foggy". When she eventually woke up at the end of winter, she felt like her old self again – vibrant, alert and full of energy. "It was hell," she recalls of her sleeping spell. "I was basically very sick."

Wong, now 22, suffers from Kleine-Levin syndrome (KLS), a neurological disorder so rare that only 500 people in the world are believed to have it. Also known as sleeping beauty syndrome, the illness is characterised by recurrent hypersomnia, or severe bouts of excessive sleepiness.

According to sleep specialist Dr Nathaniel Watson, associate professor of neurology at the University of Washington and co-director of the University of Washington Sleep Institute – KLS is also marked by several other symptoms, including cognitive disturbances, behavioural problems such as binge eating and hyper-sexuality. The disorder typically begins in adolescence or young adulthood and, in many cases, lasts eight to 12 years.

KLS sufferers experience episodes where some or all of the symptoms are present. These episodes may continue for days, weeks, months or even years before disappearing, only to come back again – but no one can predict when.

Wong's symptoms began when she was 10. Her parents noticed that she was sleeping a lot and eating more than usual. A mild-mannered and cheerful girl, she became temperamental and moody. She also had trouble understanding what was being taught in school, which caused her grades to plunge.

Her altered sleeping pattern, unusual behaviour and cognitive difficulties would last a few days or weeks, after which she would revert to her normal self again. Often, when she came out of it, she would have little or no memory of how she felt or behaved during an episode.

As the years progressed, the episodes got longer, and the symptoms became more severe with each episode.

Wong's parents had no idea what was wrong with their daughter. For a while, they assumed she was just going through some teenage angst, but when her behaviour got out of hand in her mid-teens, they sent her to the doctor. Many months and specialists later, they still had no reasonable explanation for the change in their little girl's behaviour and mood. They were told that Wong might have schizophrenia or manic depression.

When she was 18 years old, Wong was finally diagnosed with KLS. A magnetic resonance perfusion test, taken during an episode, showed reduced blood flow to one side of her thalamus – the part of the brain that regulates sleep, appetite and mood.

The diagnosis gave Wong and her family some relief, but then they were told that KLS has no known cause or cure. According to Watson, the illness is also difficult to diagnose, and is in fact commonly misdiagnosed as depression with psychotic features, schizophrenia or bipolar disorder.

KLS is an orphan disease, which may contribute to the fact that it is not particularly treatable – because it is so rare, pharmaceutical companies aren't willing to spend millions developing drugs to manage it, says Watson.

Lithium, however, has been shown to reduce the severity of episodes, and stimulants are often prescribed for sleepiness, but such medications can trigger the other symptoms. "One way we help our patients get through the disorder is to educate them about it. We also reassure them they might eventually outgrow the illness," he says.

KLS is not fatal, but it does present a range of complications. "It is a socially devastating disorder," Watson points out. "The excessive sleeping and other symptoms limit the patient's ability to go to school or work. Second, KLS sufferers are often unable to take care of themselves while in an episode. The constant bingeing can also lead to obesity."

Illustration: Angela Ho

Before she knew she had KLS, Wong and her family struggled to understand what was wrong with her. But even after her diagnosis, Wong says finding information about KLS was tough. Most people she knew hadn't even heard of the disorder.

"Educating people is key to raising awareness of KLS," says Watson. "If we educate doctors and the public, there will be less confusion about the symptoms."

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Wong's episodes are no longer as lengthy or severe, and her parents hope that this is a sign that the disorder is finally leaving her. She plans to dedicate the rest of her life to spreading global awareness of KLS and helping other sufferers cope with the dreaded illness, and she is working on several projects to help her realise these dreams.

ASK THE DOCTORS
DR JENNY TSANG

Q: Do you have any relaxation techniques for combating insomnia? I have been having trouble falling asleep. Even if I do, I often wake up at 3.30am for no reason. I am unable to fall asleep again.

A: Insomnia is a medical condition when a person experiences any of the following: difficulty falling asleep, difficulty staying asleep (trouble going back to sleep after awakening), waking up too early or poor quality of sleep (not feeling refreshed after sleep). Sometimes insomnia occurs along with another medical, psychiatric or psychological condition.

Simply changing your lifestyle or sleeping environment might do a lot to help improve your sleep. You can establish a relaxing bedtime routine, like taking a warm bath, reading a good book or listening to relaxing music before bed.

You can also try abdominal breathing exercises for 15 to 20 minutes beforehand. Lie on your back with both hands placed comfortably on your tummy. Begin to follow your breath. Notice the sensations as you take a breath of air through your nose, inhale it through your throat and into your lungs. Notice the sensations as the lungs and abdomen expand. Hold the breath for a moment and notice how that feels. Then exhale slowly and completely, through the mouth, and notice the release of tension in the lungs and rib cage. Pause briefly again before taking the next breath.

Now just allow your breathing to be natural. Focus your attention on the subtle sensations of breathing. Imagine that you are sending warm, healing energy to every cell in your body with every breath you take.

Finally, avoid coffee, tea, chocolate and caffeinated sodas late in the day. Do not use alcohol to fall asleep. Research shows it results in a poor quality of sleep and waking up.

Dr Jenny Tsang, a specialist in psychiatry, is on the *Health Post* advisory panel