

'It has devastated my life': Woman 22, suffers from rare sleep disorder that turns her into a toddler

By [Deborah Arthurs](#)

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Plenty of young students eat junk food, sleep a lot and talk back to their parents.

But for 22-year-old Alanna Wong, this sort of behaviour is taken to a startling extreme.

Alanna suffers from Kleine-Levin Syndrome (KLS), a sleep disorder that means she can fall into a trance without warning, sleep for 22 hours at a time and throw terrifying tantrums.

The episodes, which see Alanna spend weeks almost entirely unaware of her surroundings, cause her to act entirely out of character. She babbles like a baby and is unable to read or communicate.



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Alanna Wong suffers from rare neurological condition Kleine-Levin Syndrome (KLS) that means she falls into long trances and fall into a deep sleep for up to 22 hours a day

Her behaviour becomes erratic and unpredictable. Usually a polite, healthy, clean-living girl, Alanna becomes rude and argumentative.

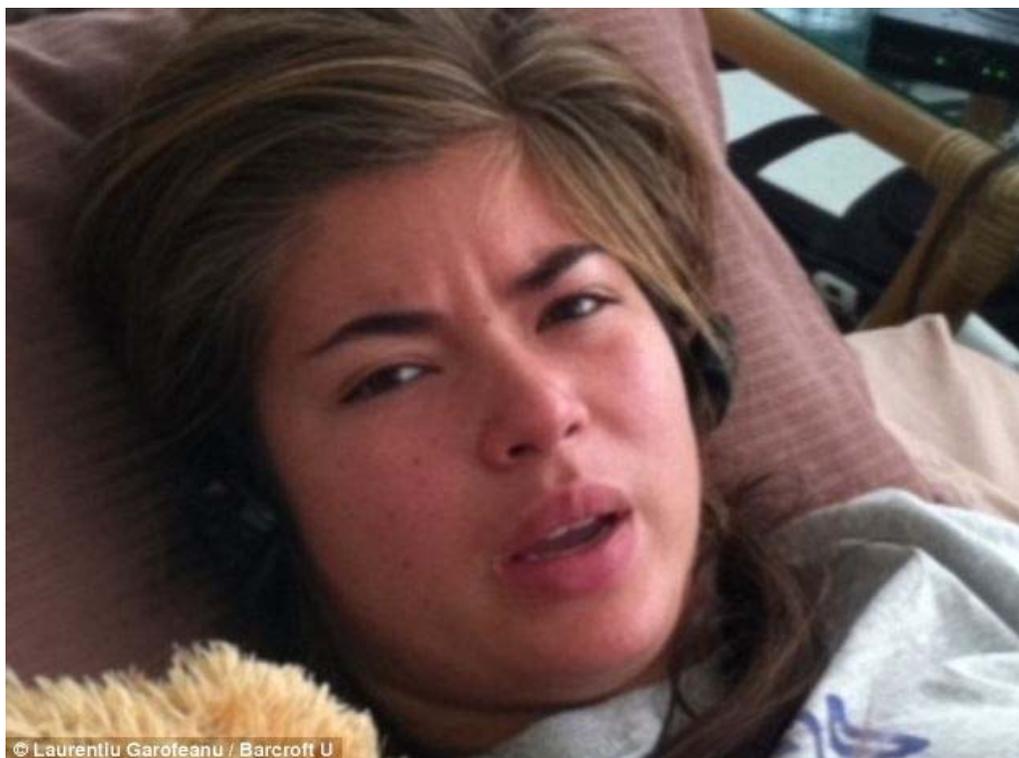
The incurable condition sees her crashing into 'episodes' that leave her in a baby-like state and wandering around like a zombie.

And because of KLS - which she got age 10 - she loses her ability to control her behaviour and speaks in a babbling baby voice. She even forgets how to read and, feeling like she is in a dream, is confused by everything around her.

Mother Diane, 52, a telecommunications worker, said: 'It's like she just reverts to being a little girl.

'She acts like she did when she was age five. She starts crying and gets so upset, thinking everyone hates her. I'll try to make her read a book with me to calm her, but she suddenly can't do it.

'It was so scary when she first got KLS - I thought she'd lost skills like reading and basic maths forever.'



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Misdiagnosed: Doctors struggled for years to find out the cause of her condition, and wrongly diagnosed her as suffering from severe depression and even schizophrenia



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Zombie-like state: During her episodes, Alanna throws terrifying tantrums and babbles incoherently. She even forgets how to read and- is confused by everything around her



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Alanna, whose symptoms started when she was aged 10, feels confused when she comes out of an episode and has no memory of what she has said or done

Diane crosses the days out on Alanna's calendar when she is in the throes of an attack.

'They are like lost days that Alanna will never get back, and never have a memory of,' added Diane.

Even when she's awake during regular episodes, Alanna remembers nothing of them. It gives her the feeling she's 'time-travelled'.

'It's like those days never even happened,' said Alanna.

'When I eventually come out of the episode, which happens as suddenly as it comes on, I have no idea of what I have been doing.'

The attacks come without warning and can last days, weeks, or even months.

Her longest episode lasted eight months - bringing her life to a complete halt.

Normally clean-living, Alanna eats healthily and works out regularly with tennis and paddle-boarding when she's not in an episode.



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Alanna Wong, right, aged 12 with her sister Melinda at Disneyland before the condition overtook her life. Alanna and her sister were both keen tennis players - but once Alanna began suffering from KLS, she found continuing normal life difficult

But during KLS trances she loses her ability to regulate what she eats.

'I binge on junk food,' she said. 'I pack in chocolate, pizza and other fatty foods.'

'At age 18 I was losing control of my eating through episodes and weighed 13st.'

'I'm only 5ft 5inches so I was really big for my size.'

'I could gain a stone in just three weeks if an episode lasted long enough.'

'Once I come out of episodes I just work out a lot and stay conscious of what I eat to lose the weight again.'

She added: 'During episodes you lose the ability to regulate what you are doing - like you are a toddler in a woman's body.'

'You make embarrassing decisions without considering the consequences, and you remember nothing of them.'

Now for the first time ever Alanna has moved out of home her Seattle-based parents Randy, 53, and Diane's home.

At 22 she is starting to get control of the disorder. She moved to Honolulu, Hawaii, to focus on living healthily.



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Alanna with her parents, Diane and Randy Wong, who say their daughter seems like another person entirely when she falls into a trance

Incredibly it took doctors eight years to diagnose her correctly - and now she is finally trying to have a normal life.

She said: 'At school I started having problems after I got ill. I'd go into episodes and fall asleep or shout something in class.'

'I got bullied because of my behaviour. Nobody knew what was wrong with me or why I started acting so strangely.'

'Nobody, including myself, knew why it was happening. I'm shy so it was really embarrassing.'

Because KLS is so rare - mainly affecting men in their 20s - doctors failed to recognise the syndrome in Alanna.

During school years, baffled health professionals suspected Alanna was taking drugs because of her bizarre behaviour, but discovered she wasn't.

Alanna said: 'They even misdiagnosed me with schizophrenia when I was 15.'



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Alanna Wong, now 22 and living a calmer life as a student in Hawaii, has seen her condition improve with age. KLS is incurable, but in most sufferers gets better with age and disappears by the time they are in their mid-thirties

'The medicine they gave me for it triggered even more attacks. It was horrible. I just wanted someone to tell me what was happening to me.'

Indeed, it is not uncommon for those with KLS to struggle to find a diagnosis.

Professor Tom Solomon, chair of Neurological Science at the University of Liverpool says that it is not uncommon for many KLS sufferers to be given psychiatric diagnoses first.

'Many of the features: depression, altered sleeping patterns, increased eating - are the same. It's thought they've got a psychiatric illness,' he says.

After suffering for eight years, Alanna was at her wits' end. 'I was just losing my life to the episodes, with no memory of what happened during them. It's like somebody was turning off the 'record button' in my head.'

Alanna was finally told she had KLS at age 18 - after mum Diane read about KLS online. A specialist confirmed she had it after brain scans revealed the thalamus - the area responsible for normal sleep and wake functions - was lacking in activity when she was going through one of her episodes.

'To know what was causing everything was a huge relief,' said Alanna.

'I was finally able to say to people what was wrong with me and explain that I wasn't just weird.'

'It changed my life, and now I'm trying to rebuild. Teens and high school years are hard enough, but KLS makes it a million times worse.'

Her condition - which includes a malfunction of the area of the brain that controls sleeping and appetite - means she still can't work or study with others.



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Alanna is keen to raise awareness of KLS, and has started her own charity - klslife.com - and also appears at conferences. She has a book on the condition coming out later this year

'It's just too difficult,' said Alanna. 'I can't do jobs where an episode can trigger and stop me from doing what's needed at work.'

'At college, nobody would understand if I went into an episode during a class. And I might miss weeks of coursework because I had an attack.'

'I'll be focusing on a career I can manage from home with flexible hours.'

Alanna is now studying an online course in web marketing which she can do in her own time.

Desperate to help others affected by KLS, she runs the charity klslife.com from her apartment - raising awareness and offering support to families.

She also speaks at conferences on KLS and is penning a book of her experiences - due out later this year.

Doctors have yet to define what caused KLS. Many sufferers - who total around 1000 worldwide - grow out of it in their 30s but some have it for life.

Some theories suggest patients have a genetic predisposition to the syndrome which is then triggered by environmental factors.

Dr Christian Jensen, said: 'KLS is a rare condition and, therefore, is relatively unknown.'

'It can be devastating for people who suffer with it and, sadly, there's no definitive treatment.'

Incredibly, Alanna manages to put a positive spin on her condition. 'I no longer look at having KLS as a horrible thing,' she says.

'If I can help just one person get diagnosed and find support, I know I will have contributed to society in a very positive way.'

'Looking back on the 20 years that I've lived, even though KLS had devastated many parts of my life, I am grateful for the life lessons it has taught me.'

For more information on Alanna Wong's charity, visit www.klslife.com

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