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MailOnline

I'm a real-life sleeping beauty: Nurse with rare syndrome nods off for a week at a time

By [Claire Ellicott](#)

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Her story may sound like a familiar fairytale.

But for Poppy Shingleton, being a real-life Sleeping Beauty means missing birthdays, Christmases and holidays rather than waking up to a handsome prince.

The nursing student, 24, has a rare condition which means she can fall asleep with no warning for up to a week at a time.

She is one of just 1,000 worldwide sufferers of Kleine-Levin Syndrome, also known as Sleeping Beauty Syndrome.



Disorder: During an episode Poppy wakes only to eat or go to the bathroom

Miss Shingleton said: 'I slept through my 18th birthday. I hadn't planned anything massive but I wanted to go out with friends for a few drinks and flash my ID,' she said.

'I've slept through Christmas and not woken up until after the New Year. It does get me down and I miss out on the social side.

'My friends will talk about it for weeks afterwards but I've missed it.'

She studies at Southampton University to stay close to parents Graham, 57, and Jenny, 48, both teachers in the city. 'Mum and dad come and pick me up if I fall into an episode, put me in the car and take me home,' she said.

'I had to drop out in the second year. I'd missed so much of university I'd fallen behind and not got the grades.'



The nursing student developed the condition when she was 18

Miss Shingleton developed the disorder when she was 18. Her condition meant she missed weeks of school at a time and was forced to re-sit her A-levels. Fearing her drink had been spiked at the party, Miss Shingleton confided in her parents Graham, 57, and Jenny, 48, both teachers, who took her to hospital.

She was sent home after doctors told her it was too late to run toxicology tests.

But when it happened again three weeks later, Miss Shingleton didn't wake up for another week.

She said: 'That's when I knew my drink hadn't been spiked - something was definitely wrong with me. It was very frightening.'

Her worried parents immediately took her to their local GP who referred her to a neurologist at Bath Royal United Hospital.

Over the next couple of years, doctors carried out various tests including brain scans and a muscle biopsy. One specialist even misdiagnosed her condition as depression and chronic fatigue.

Eventually, some friends of hers saw a documentary about a girl with Kleine-Levin Syndrome and told her they thought she had it.

After speaking to members of the Kleine-Levin Syndrome Foundation, she was put in touch with sleep specialists at Chelsea and Westminster Hospital, who diagnosed her with the condition last year.

Experts don't know what causes it and there is no known cure, but it can be controlled by a combination of stimulant drugs to stay awake and sleeping tablets to help get a better quality of sleep. Most people grow out of the condition as they reach adulthood.

Miss Shingleton added: 'I seem to only have episodes about every three months now. I don't know if that's because I'm growing up.'

'I finish university in September and I'm applying for jobs at the moment. I'm determined not to let my condition get in the way of life.'



Out for the count: Once she's asleep, Poppy will stay there for up to a week before she wakes up again

Experts don't know what causes the condition, but most sufferers grow out of it, and Miss Shingleton hopes she will too.

Speaking about how her condition affects her she said: 'I feel totally detached and spaced out. It's very hard to describe. It's almost like I'm watching myself.

'I have to be left alone and I don't like people talking. I sign like I'm writing on a blackboard or I point.

'I want things done my way and I like to be surrounded by familiar things to reassure myself I'm not in a dream.'

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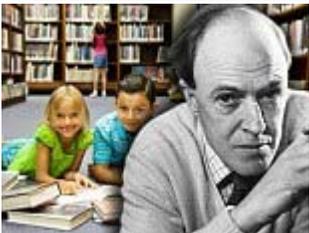
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linda sheffield - your comment is nasty

- lizzie, kussnacht, switzerland, 24/6/2011 20:18

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I am concerned for her future. What if the same thing continues even after having kids? Poor lady. wish you a speedy recovery.

- Naveen, India, 23/6/2011 19:02

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How typical to have to find the diagnosis yourself after being branded as having the dreaded Chronic Fatigue Syndrome and needing a psychologist by the NHS, they always seem bit too keen to call any illness this when they haven't got a clue what's really wrong. My two daughters were misdiagnosed for over 4 years in this way until I found out what was wrong after having to go private. They had Lyme Disease and could have died.

- karen h , gillingham kent, 23/6/2011 15:44

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She diagnosed the "beauty" part wrong...!

- Tom O, Newcastle, UK, 23/6/2011 10:56

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MancMan, I dont think you understand. KLS sufferers do not fall asleep suddenly at random times; their difficulty is that they do not wake up. Therefore you would have no need to fear anyone with KLS who was working in that situation. It is a condition that robs people of time.

- Robyn, New Zealand, 23/6/2011 08:31

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Kleine-Levin Syndrome is a neurological disorder that affects thousands of patients around the world. (Would Mary-Ann talk about a bra with someone with MS, also a nuerological disorder? ...come to think of it...probably.) Victims of this cruel disease wake up to bathe and use the restroom, but their bedroom is like a hospital room for weeks at a time. The hardest part of this disorder is the patients never know WHEN or HOW LONG they will sleep before fully becoming normal again. They miss chunks of time of their lives one episode at a time.

- Lori, Brea, USA, 23/6/2011 05:00

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I wouldn't want her working in theatre with me!

- MancMan, Manchester, UK, 22/6/2011 22:55

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I'm pretty sure I saw the documentary her friends saw. It was a BBC documentary of a girl who had this disorder too but worse. Shed be out of it for more than a week and would be nearly impossible to wake up in order to quickly eat and drink before falling into the next sleeping episode. It was so sad she couldn't help miss a chunk of her exam dates, and I think she missed the big school prom thing too.

- ThePaperclipGuy, East sussex, UK, 22/6/2011 22:34

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I've just read up about the toilet and food questions - the "sleepers" are woken up (with difficulty) to be fed and toileted by their family members.

- R Green, Berkshire, UK, 22/6/2011 22:27

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So I don't understand how she just sleeps for a whole week, what about toilet and food..??

- Leigh, Essex, 22/6/2011 21:55

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