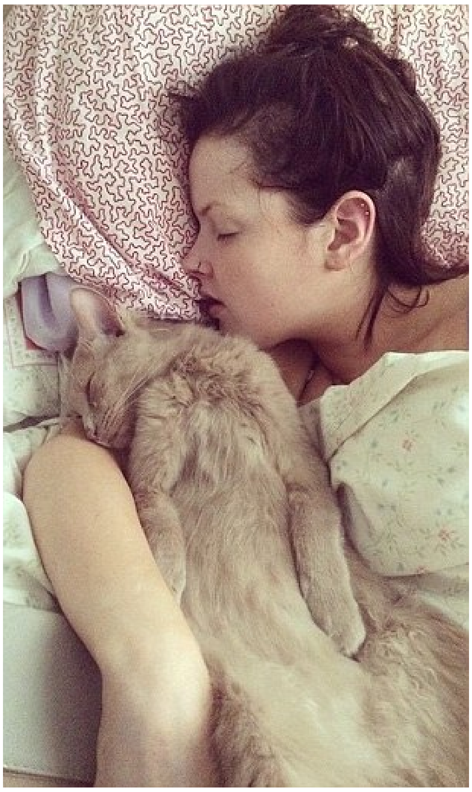
Sleeping Beauty syndrome: Beth fell asleep on the sofa one day and didn't wake up for SIX MONTHS. Five years on, aged 22, she sleeps most of the time - victim of a baffling condition

- **Beth Goodier, 22, has been diagnosed with Kleine-Levin syndrome (KLS)**
- **The incredibly rare condition is also known as Sleeping Beauty syndrome**
- **She fell asleep in November 2011 and didn't wake up properly for months**

By Tanith Carey for the Daily Mail

Published: 23:05, 28 November 2016 | Updated: 02:03, 29 November 2016



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Beth Goodier, 22, (pictured) fell asleep in November five years ago and did not wake up properly for six months

By rights, Beth Goodier should have finished university by now and started her training as a child psychologist. With a string of impressive exam results as well as a confident, outgoing personality, she was a young woman who had every reason to believe she had a bright future ahead of her.

But then in the run-up to her 17th birthday in November five years ago, Beth fell asleep — and didn't wake up properly for six months. For 22 hours a day, she kept sleeping, only waking in a dream-like trance to take a little food and drink and go to the toilet.

Over the past five years, Beth's mother, Janine, calculates that her daughter has been asleep 75 per cent of the time.

Beth, now 22, is one of more than 100 young people in Britain diagnosed with Kleine-Levin syndrome (KLS) — known as Sleeping Beauty syndrome.

But that fairy-tale name is far from the grim reality faced by those youngsters who are sleeping through the most formative times of their lives.

Tonight, the condition will be highlighted as part of a TV series on medical mysteries — for KLS is certainly that. Little is known about what triggers the sleep disorder and even less about how to cure it.

What is known is that it mainly hits teenagers — the average age it strikes is 16 — and lasts around 13 years, destroying young people's hopes of passing exams, going to university or forging a career.

At the moment, Beth is two-and-a half months into another deep sleep episode. Nothing — not drugs, loud noises, pleading or cajoling — will wake her.

So her life is spent in pyjamas in bed or asleep on the sofa. On the rare occasions she leaves her home in Stockport, Cheshire, to see a doctor, she must be pushed in a wheelchair because she is too tired to walk.

All Janine can do is sit and wait desperately for the 'on' switch to flick back in her daughter's head.

'It is like night and day,' says Janine, 48. 'She might wake up tomorrow and then it's a race against time to live the life she should have had. She rushes off to catch up with her friends and get her hair done. But no one knows when she might fall asleep again.'

Beth first started feeling exhausted as a 16-year-old and Janine assumed it was normal teenage torpor.

Then, one evening, Beth fell asleep on the couch and wouldn't wake up. When Janine tried to rouse her, she was horrified when Beth could only babble incoherently in the voice of a five-year-old.

She is one of more than 100 young people in Britain diagnosed with Kleine-Levin syndrome (KLS) — known as Sleeping Beauty syndrome

One person who has stood by Beth, however, is her boyfriend Dan (pictured), a 25-year-old primary school teacher she met during an 'awake' phase three years ago

Naturally, her mother assumed the worse: that she had a brain tumour or haemorrhage, and Beth was rushed to hospital. But all tests drew a blank.

Her condition baffled medical staff until a doctor remembered a colleague who had dealt with a similar case.

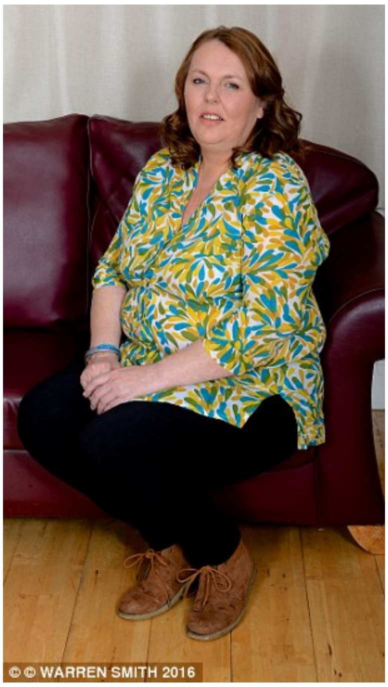
At the time, Beth had just recovered from tonsillitis, and her medical team suspects the illness was the trigger.

Researchers believe an infection may set off inflammation in the brain in people with a genetic predisposition, and this may damage the thalamus and hypothalamus, the areas responsible for sleep and sensory input.

Since her diagnosis, Beth has been asleep more than she has been awake, sleeping through many of her birthdays and Christmases, as well as holidays. When she wakes up, she has no recollection she was ill or realisation that time has moved on.

Beth's hopes of getting the four A-levels she needed to train to be a child psychologist faded as she was forced to drop out of college.

And Janine, a single mother, had to give up her job to look after her daughter round the clock.



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Over the past five years, Beth's mother, Janine (pictured), calculates that her daughter has been asleep 75 per cent of the time

'The most horrible symptom is her confusion,' says Janine. 'When she wakes for a few hours a day, she does not know where she is and becomes very agitated.

'The toughest year was when her friends finished their A-levels and went off to university, because Beth knew when she woke up that it should have been her, and that hurt her badly. And when she hurts, I hurt.'

One person who has stood by Beth, however, is her boyfriend Dan, a 25-year-old primary school teacher she met during an 'awake' phase three years ago.

'He will come round and sit with her nearly every day, talk to her and wait for the girl he fell in love with to come back. When she is awake, they resume their normal adult relationship. He is a good man.'

But normally, Beth has no more than two weeks before the syndrome drags her back under again.

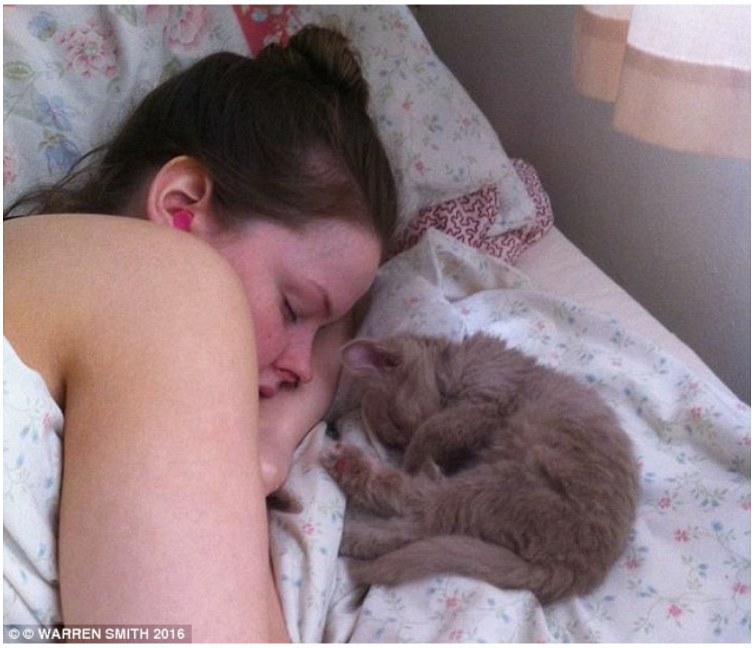
Janine says: 'Each time, you pray she's had her last episode — and then your heart sinks as you see the signs coming back. Her voice regresses, she starts to find light and noise too much and then she's gone again.

'It breaks my heart to see the best years of her life slipping away.'

One of the leading experts on the condition is Dr Guy Leschziner, a consultant neurologist at Guy's and St Thomas' NHS Trust.

He says the number of cases of KLS, named after the doctors who identified the syndrome a century ago, appears to be rising as more young people are diagnosed.

'In the past, milder cases were blamed on teens being lazy and swinging the lead. Otherwise, they were viewed as psychiatric cases or having symptoms of a bipolar disorder.'



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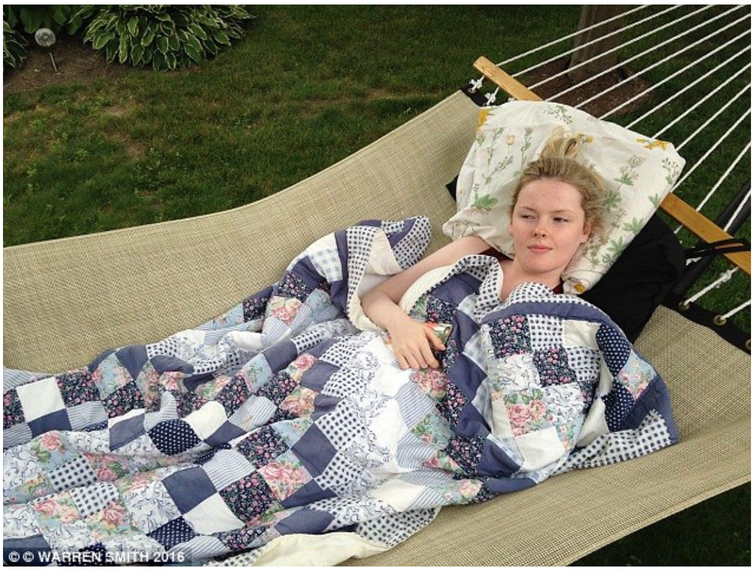

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Beyond sleeping for up to 22 hours a day, the difference with other sleep disorders is that these young people will also show clear personality changes, says Dr Leschziner.

'They feel as if they are in a dream-like state very separate from the world around them. It has a massive impact on their lives. When they wake up and realise what they've missed, they may be depressed and anxious.

'While it's not terminal, young people with KLS can see their lives slipping away in their most formative and important years.'

That is how it is for 15-year-old Carew Harris, from Cobham, Surrey, who features in tonight's documentary. A promising footballer, he had been picked to play for a football academy when, after a day spent at a health spa pool four years ago, he was unable to keep his eyes open.

There followed ten days of severe migraines and hallucinations. Carew was sent for an MRI to see if he had a brain tumour. When he recovered, his mother, Danielle, assumed he had just been hit by a virus.

But six weeks later, Carew had another attack of migraines, vomiting and hallucinations after which he was unable to stay awake for more than two hours a day.

Tragically, the closest he now gets to the football pitch are the trophies that line the shelves of the bedroom where he spends most of his life. So far this academic year at his private school, Carew has only been able to attend for just over two weeks.

Danielle, 45, a divorced mother of four, says: 'The longest stretch Carew has slept in one go is 40 hours.

'When he is in an episode, you can't wake him up — even if you were standing next to his bed with a brass band playing.'

Yet for years, doctors told Danielle to simply give him headache remedies or suggested he was a lazy teenager trying to avoid school, even though he would fall asleep in front of them.

After keeping a diary to show he was asleep more than he was awake, she was referred to a neurologist, who recognised the condition. Footage taken by Danielle on her phone to show doctors how serious it was highlights the marked difference between the thoughtful, polite young man Carew really is — and the terrified little boy he becomes when hallucinations hit during one of his long sleeps.

It makes for uncomfortable viewing, as he calls for his mother like a toddler, crying out that he's scared.

More recently, the affect of the condition on the teen's hypothalamus, which controls behaviour, means that when Carew is awake, he is increasingly bad-tempered.

But while Danielle has the reassurance of having a diagnosis, there is still no treatment.

'Every morning, I check on him and I don't know what the day will hold,' she says.

'If he will be up, dressed, ready to go to school, in an angry mood or fast asleep.

'The second he comes out of an episode, he realises what he has missed and becomes terribly anxious. Carew is a superb sportsman, but though he does not lose his skills when he is asleep, he wakes up weaker because he has not moved for weeks.

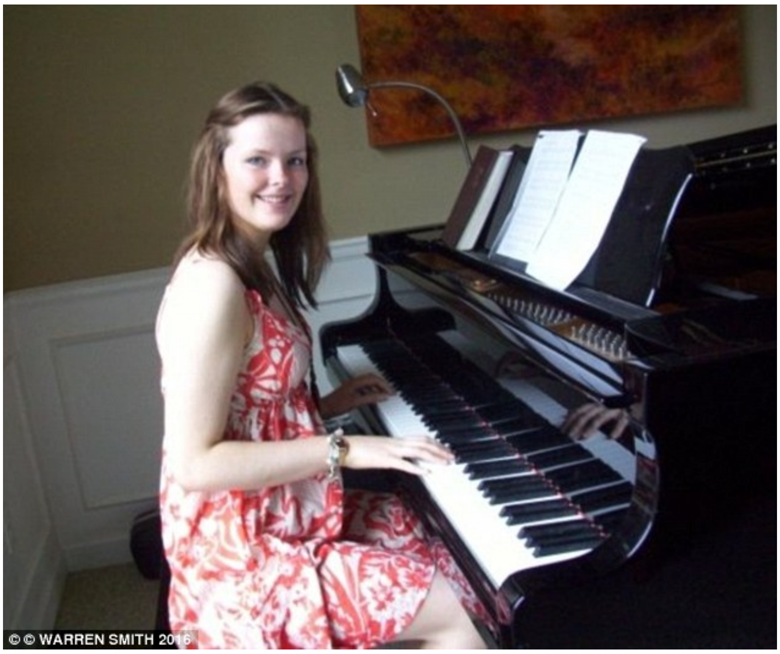
'At the moment, exams and university are not on the horizon, but maybe they will be one day. For now, I am happy if wakes up tomorrow.'

Adele Clarke, one of the parents who has set up the KLS Support UK group for families, says boys and girls often react differently to the illness.

Adele, 52, an interior designer from Surrey, says: 'It used to be the thinking that the split was 70:30, with more boys getting it than girls.

'Now we are finding it's the other way round, though the genders experience it differently. Girls suffer more anxiety, while boys become aggressive.'

Many of her own daughter Lily's hopes for the future were snatched away in November 2007.



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It's been over a year since her last episode, but Lily, 26, still lives with the fear that she could be sucked back into her sleeping nightmare at any time.

Still deeply traumatised by what has happened to her, she would rather not talk about her condition and get on with her life, leaving it to her mother to fill in the lost years.

The family were on a day out skating at the Natural History Museum in London when Lily, then 17 and preparing to take her A-levels, was struck down.

'Lily was uncharacteristically quiet. She kept saying: 'My head feels strange. I don't feel well,' ' says Adele. 'I just thought she was coming down with a cold. Then when the family went to a restaurant for dinner that night, Lily slept through the whole meal.'

By the end of her first year with the condition, Lily had been asleep for a third of it. Her longest episode was three months.

Yet, like many families, it took years to get a diagnosis. After seeing ten private doctors, it was only when Adele read a story in the Mail about another girl Lily's age with similar symptoms that she finally found a name for it.

She contacted the teen's family and was referred to her specialist, who confirmed it.

'I was told by some people to pour water over her, to stop over- indulging her and to tell her to stop being a brat,' says Adele. 'I had doctors suggest it was anything from depression to drug-taking.'

Adele hates the term Sleeping Beauty syndrome. 'When she is in an episode, Lily behaves like a three-year-old, cuddling her teddy, sucking her thumb and crying in a child-like voice, saying: 'Mummy make it go away.' She says it feels as if her head is exploding.

'It may be known as Sleeping Beauty syndrome, but there's nothing romantic or sweet about it.

'When she wakes, Lily has to come to terms with what she has missed. Then the depression sets in.'

It means that rather than spreading her wings, Lily lives close to home, so Adele can give her round-the-clock care.

Despite missing so much time at university, Lily managed to get a degree and is a manager for a cosmetics company.

She could not fulfil her goal of becoming a special effects make-up artist for films because to avoid a relapse, she must get plenty of normal sleep and work regular hours.

For Beth's mum Janine, it's a long waiting game for her daughter to wake up and resume her life. All she can do is watch and try to look forward to the day Beth finally wakes for good.

Normally this happens at some point in a sufferer's mid-20s, when the time between episodes become longer before the conditions burns itself out. At the moment, that day seems a long way off.

'One day, I want Beth to be able to travel, to have a family, to go back to university, to be the woman she was meant to be,' says Janine.

'When I watch her, I think of that quote: 'Let her sleep, for when she wakes, she will shake the world.' '

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