

20 October 2014 Last updated at 00:54

## **Kleine-Levin Syndrome: Why the rare 'Sleeping Beauty' illness is no fairytale**

**By Bronwyn Jones**  
BBC News

**While many of us dream of a few extra hours' sleep due to the pressures of work and family, such an idea is the stuff of nightmares for one young woman.**

For during episodes of her extremely rare illness, which can last for weeks, Beth Goodier is awake for only two hours a day.

The 20-year-old from Stockport in Greater Manchester has Kleine-Levin Syndrome (KLS), also known as 'Sleeping Beauty' syndrome.

But living with KLS is far from being a fairytale, she says of her condition, which only affects around 40 people in the UK, the majority of whom are teenage boys.

"It's nothing beautiful, it's nothing romantic, it's horrible."

### **Child-like behaviour**

Experts do not know what causes KLS, whose symptoms first appeared in Beth when she was 16, and there is no known cure.

Along with episodes of extended sleeping, the condition also typically causes behaviour changes such as feeling in a dream-like state, acting in a child-like manner, and binge eating.

It begins in adolescence and those affected just have to wait to grow out of it after about 10-15 years.

KLS can be very isolating, not least because life and time moves on for those around Beth whilst she is consumed by an episode.

But during the periods when she is well, she uses her time to blog about KLS and express herself through YouTube videos.

"I want to be able to do something productive in the time when I'm well... to be productive for society," she tells BBC Inside Out North West.

Beth is entirely dependent on her mum, Janine, who had to give up work to care for her.

Mrs Goodier explains that excessive sleeping is only part of the problem because when awake during an episode, her daughter is in a child-like state and confused about what is real and what is a dream.

"When she's up, all she does really is, she's either in bed or on the sofa and she'll watch telly, often the same things over and over again as she likes predictability."

The family now make the most of every opportunity when Beth is well to do as much as possible.

"On the odd time she's well we don't say any more, 'We'll do that next week.' We do it now when she's well because that might be the only time you get."

KLS has prevented Beth from going to university and it also means she is not able to get a place of her own.

"I'm at the age now where I would love to move out because I'm ready," she says. "But I can't because I need my mum's supervision for when I'm ill... It's really frustrating."

### 'Very devastating condition'

Dr Guy Leschziner, a consultant neurologist at Guy's Hospital in London, says KLS is devastating for young people as they are already at a particularly vulnerable stage in their lives when they first display symptoms.

"They are at a crucial point in terms of their education, in terms of their social life, in terms of their family life and in terms of their working life.

"It's a very, very devastating condition in that regard because of its unpredictability," he said.

"In most individuals, the condition burns out after a number of years and on average it goes on for about 13 years."

Those suffering from KLS can wait a long time to be diagnosed as there is limited awareness of the condition amongst the medical profession and the general public.

Beth hopes that by speaking out, she can help raise awareness of her condition. This goal has also been taken up by a group of UK parents who set up a charity in 2011.

[KLS Support UK](#) aims to raise awareness, help those affected, and support medical research with the hope of better understanding the causes and treatment of the condition.

Follow Beth's story on [Inside Out North West](#) on Monday, 20 October at 19:30 BST and nationwide on the iPlayer for 30 days thereafter.

---

#### [Things To Do](#) RUN BY THE BBC AND PARTNERS



TUE 21 OCT  
[Autumn Deer Walk](#)  
Tatton Park -  
National Trust



THU 23 OCT  
[Golf Taster Session](#)  
Get Into Golf

[See Manchester Activities >](#)

Find activities near you

Town, city, postcode