

Schoolgirl, 15, sleeps through her GCSEs because of rare 'Sleeping Beauty' syndrome that leaves her in bed for months at a time

- Stacey Comerford, 15, from Telford, Shropshire, has a rare condition called Kleine-Levin syndrome, which makes her nod off for lengthy periods
- She has recently come out of her longest episode, which lasted two months
- Despite being predicted straight As in her GCSEs, she has managed just a 30 per cent attendance record this year because of her crippling condition

By [Jill Reilly](#)

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A schoolgirl missed nine exams and even her birthday because of a rare condition which leaves her sleeping for weeks at a time.

Stacey Comerford, 15, from Telford, Shropshire, suffers from Kleine-Levin syndrome and has recently come out of her longest episode, which lasted two months.

She is just one of 1,000 people worldwide to suffer from the disorder which is commonly known as Sleeping Beauty syndrome.



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Missing out: Stacey Comerford, 15, from Telford, Shropshire, suffers from Kleine-Levin syndrome and has recently come out of her longest episode, which lasted two months

Despite being predicted straight As in her GCSEs, she has managed just a 30 per cent attendance record this year because of her crippling condition.

Her mother Bernie Richards, 53, said: 'There's never any warning. I've even found her fast asleep on the kitchen floor.'

'When she's in an episode, she might get up to go to the toilet or get a drink but she's not awake. I call it sleep mode.'



Disorder: She missed nine exams and even her birthday because of a rare condition which leaves her sleeping for weeks at a time

'When she wakes, she thinks it's the following day. She doesn't have any memory of it.'

During an episode, Stacey can be in a deep sleep for more than 20 hours a day.

She only rises to go to toilet or sip water in a trace-like state.

Amazingly in this state she is up just long enough for her mother to give her some food before she goes back to bed.

Stacey has lost almost two stone because of her condition.

Ms Richards, who is a full-time mother-of-six, describes it like 'living with Jekyll and Hyde' because the change in her daughter is like a switch flicking.

She said: 'She needs reassurance during an episode. It's like she reverts back to being five years old. When she talks, she sounds like a child.'

'When she's in sleep mode she can be quite moody but she can't help it. She's like a toddler who wants to do things her own way. She stamps her foot if she doesn't get what she wants.'

'It's like having two different kids in the house.'



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Changes: Ms Richards, who is a full-time mother-of-six, describes it like 'living with Jekyll and Hyde' because the change in her daughter is like a switch flicking

Stacey started experiencing symptoms about a year ago, but she was only diagnosed in March as the condition is so rare.

When her illness first emerged, doctors put it down to her being a 'moody teenager.'

Bernie said: 'Stacey was tired all the time. She couldn't concentrate at school.'

WHAT IS KLEINE-LEVIN SYNDROME?

KLS is a disease of adolescence, and sometimes will begin after infection or illness,

There is no known cause or cure for the sleeping disorder.

Stacey is just one of 1,000 people worldwide to suffer from the disorder which is commonly known as Sleeping Beauty Syndrome.

Tom Rico of the Center for Narcolepsy & KLS Research at Stanford University, California told the BBC:

'An individual with KLS will have sleep episodes, typically lasting between one and three weeks, with coinciding cognitive disturbance in the few hours of wakefulness.

'During this time period, a patient will sleep anywhere between 16 to 22 hours a day, every day, until the conclusion of the episode.'

She'd come home zonked out and have to sleep the whole weekend. When it came to Monday morning, I couldn't wake her up.

'Then one day I got a call from school to come and pick her up because she wasn't very well.

'I took her to our GP. I had to pull Stacey's legs to get her out of the car and get her into the surgery.

All she wanted to do was sleep.

'The GP said: 'I know it sounds awful but she looks like a moody, depressed teenager'.'

Stacey was referred to the Princess Royal Hospital, Telford, where doctors feared she had a brain tumour.

She was given a brain scan and was also checked for conditions like narcolepsy and epilepsy.

When the results came back clear, doctors were left baffled until a neurologist at Birmingham Children's Hospital eventually diagnosed Stacey with Kleine Levin Syndrome.

Ms Richards, said: 'Having a diagnosis means Stacey knows it's not all in her mind. She's had that much stick off people. They don't understand.

'I was even investigated by the local education authority because Stacey's school thought I was deliberately keeping her out of school. They've stopped now we've got a diagnosis.

'I always knew there was something wrong. I know my daughter.

'She's gone from a fresh faced teenager, full of energy to sleeping all the time.

'We can't plan anything because Stacey might be asleep.

'She could go to sleep tonight and wake up next week.

'We try and laugh and joke about it because it's the only way to get through it.'

There is no known cure for Kleine Levin Syndrome, although some experts believe that some sufferers do grow out of it.

Since her diagnosis, Stacey has been put on a high dose of a stimulant drug called modafinil to help keep her awake.

Ms Richards, said: 'It seems to be working. She's more awake and it's improving her quality of life. We will have to see how she gets on.'

Stacey, who hopes to go back to school on a part-time basis soon, said: 'I've missed nine exams and my birthday in November.

'It's easier now people know what it is. It's easier to explain to them. Before, people didn't believe me.

That was the hardest thing.

'People would pull faces at school if I said I was tired and needed to go home.'

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