

My son and Kleine-Levin Syndrome - the "Sleeping Beauty" syndrome

By KLS Support UK | 17 May 2016

The carer's story

I came home from work on November 29th 2011 and was expecting my 16-year-old son to have been home after school. Instead the house was dark and there was no response to my calling and no answer from his phone. Eventually I went up to his bedroom to find he was in bed fully clothed, unarousable and hot to touch. I checked he had no neck stiffness, pulse was normal and he pushed me away. When told there was food downstairs he walked down like a zombie and sat eating with his head bowed over the plate, shovelling food into his mouth like a two-year-old child before going to sleep on the sofa. He was able to get undressed and go to bed but unable to respond with conversation. An emergency appointment with a GP who had never met him but who agreed that he was not behaving as a normal grammar school boy would, led to a referral to the local medical unit. A full blood count, urea and electrolytes, blood glucose and ECG were all normal. No diagnosis was made and he slept on there for several hours and then woke up back to his normal self. He had no memory of events of the last day. We explained what had happened and he himself suggested he had Kleine-Levin Syndrome on the basis of a television programme he had seen six months previously. I Googled KLS and showed the Wiki page to the medical registrar, who agreed he fitted the description. We were told an outpatient appointment with the local sleep specialist would be sent to us – it arrived a few days later for August 2012 – 10 months hence. After complaining, the appointment was brought forward and we saw the specialist who had never seen a case of KLS and asked me what investigations I thought he should do. Talking to my neurologist colleagues we were referred on to Dr. Guy Leischziner. He ordered a brain MRI for Luke, which was normal. Luckily we were able to perform sleep studies during an episode and they were consistent with KLS.

Life took on a strange and increasingly disrupted pattern over the spring. My son would text me from school to say he was going into an episode – the text would be poorly spelt and he would either go to the school sick bay and wait to be picked up or, in the early days, somehow find his way home on the bus, to his bedroom, without the school noticing. However, after the first year the episodes meant that he didn't get up and when I tried to rouse him it was impossible. During a KLS episode he is like a zombie – he will walk around the house in a trance-like state, not registering others but able to shower and go to the toilet and eat and drink if food is left beside the bed. During an episode his voice is at a lower register and he can only use simple words. He doesn't like noise and his bedroom is in the eaves of the house where it is quietest. Sometimes during an episode he isn't heavily asleep and he will play with Lego figures or watch children's cartoons on the television. There was a period when I could not understand why the cable bill was so large until I discovered he was downloading Disney films to watch in the middle of the night! Then one day there will be a light-footed patter down the stairs instead of his slow zombie-like heavy-footed pace and he will be awake and be back to normal. He can respond to emergencies. When we lost a

friend's dog, which escaped and we didn't know where he was, Luke came down from his bedroom to say he could hear him barking and indeed the dog had escaped through a hole in the back garden fence and was nearby.

During this period he developed symmetrical arthralgia and was exhausted following a day at school, needing a few hours sleep on arriving home. It took a visit to a bright rheumatologist to find he had **hypothyroidism** and his arthralgia melted on thyroxin, although his **fatigue** and sleepiness between episodes has been a continuing problem — he was exhausted after a day at school and needed a few hours sleep on arriving home from school.

He gradually became hopelessly behind with schoolwork. He had achieved A and A* in 10 GCSEs and was doing 4 AS levels. His attendance at school dropped to less than 50% and he needed to repeat the year again. His school felt this would be better at another school to prevent him being "stigmatised". We found another school and a fresh start was marred by frequent episodes throughout the year. Again he missed AS levels — sleeping nearly continuously for 34 days.

After much heartache he started the second A level year with initially 3 A levels, which was changed to two A levels after missing over half the term. But on average he has attended only 35% of the school term in the winter term and slept through the summer exams for the third year running. Now he has left school and is in episode too often to benefit from education or be of use in a full-time job. He plans to help at a local school when he is awake.

As I write he has been asleep all through Xmas, his presents are still under the tree, while his many postal parcels containing presents for us, remain unopened. He is a "sleeping beauty". As his mother I spent the first 18 months mourning for my son's lost life. In the first year he was in episode for 98 days, the second 154 and in 2014 it was an awful 175. Walking, chatting, being with his friends, going to school, debating, watching TV, are lost to him. His ability to learn and grow is reduced because he is not awake. Someone said to me "As a mother you are only as happy as your unhappiest child" and it's true. And when he was in an episode life was hard, always thinking of him. Expectations gradually dropped from anticipating he would become a dentist to hoping he would get to university, to hoping he might get two A levels, to just wishing he would be conscious more frequently.

The KLS episodes last from one day to five weeks, are always more frequent and are longer in the winter. Sometimes they are precipitated by viral infections; most of the time there is no obvious external explanation. When episodes are close together, he doesn't feel well in between them and sleeps until after 1 pm, then going back to sleep at 11 pm. He is tired after walking the dog, going back to bed to sleep — it seems he isn't truly back to normal. In contrast, last summer he was awake for over six weeks, was bright and cheerful and regained a lot of strength so he was able to play cricket and go for long walks. He loses mental capacity to make decisions for himself when he is in episode, and legally it is difficult to know what to do because the Mental Capacity Act does not suit such intermittent loss of capacity.

For a long time we have both been grounded, due to the unpredictability of his episodes. I gave up lecturing abroad unless I could fly in and out in one day and no longer can be at my desk in the morning by 8 am if he is in an episode. The irony of being at the cutting edge of medicine at work — where I take up the challenge of difficult clinical cases and don't accept "no" as an answer, to coming home to an illness with uncertain cause and no treatment — is not lost on me.

More latterly we have a carer on duty and I make a point of going out to the theatre, to compensate for the grimness of home when he is in an episode. He won't leave the house in a KLS episode; indeed it is no longer possible to take him out at all. He stays in bed and will kick out if we try to help him get up. During an episode he avoids other people- if he is downstairs and the front door bell rings he runs upstairs to his bedroom. He is accepting of his carer, with whom he has a close and loving bond because she has **Behcet's disease** and thus understands chronic illness. Sometimes during an episode he lets me hug him and then sags in my arms — he has fallen asleep. If I stroke his face in the morning to check his temperature, which always rises during an episode, he will push me away. Sometimes he will come and sit on my lap for a cuddle — an interesting experience, as he is over 6 feet tall. Speech is limited to one to two words and he will usually not reply to "Hello" or "How are you?", but will look at you with dead eyes.

We have tried modafenil- a stimulant-but this did not reduce the frequency of episodes, and made him very irritable during a KLS attack. *Carbamazepine* similarly had no effect. He is not able to butter toast normally in an episode but on lithium able to do complex tasks such as making a cup of hot chocolate or boiling an egg — impossible during a normal episode. However, the frequency of episodes was unabated, and it is difficult to take blood for lithium levels from him during an episode.

During the first episodes he seemed to crave carbohydrates and would eat a packet of biscuits very quickly. Now three years on he will eat three boiled eggs but won't eat much carbohydrate.

Although hypersexuality is said to be a feature, I have not seen evidence of it.

Dealing with other people can be a challenge. There is an assumption among many of the lay public these days that if an illness cannot be explained, then the cause must be psychological, and their supposition is that all episodes "must be precipitated by stress". This has led to some unkind comments. But the majority of friends and family have been very supportive.

There have been silver linings to this illness. We value the moments when he is awake. It's a thrill to hear him coming rapidly down the stairs and saying "Hello mum" instead of the zombie-like heavy-footed way he walks around the house in an episode. We now have a dog that will sit with him and is much loved by all of us.

We would like to thank [KLS Support UK](#) and [KLS Foundation](#) for providing us with this article. If you want to learn more about the symptoms and signs read [KLS Support UK's article here](#)

If you would like to support the charities or learn more about KLS then follow them at [@KLSSupportUK](#) and [@KLS_Foundation](#)



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