

KLS is Rare

KLS is a rare condition. Not everyone with the condition gets a diagnosis due to its episodic nature and no one yet knows why it happens and how to prevent it. There are only about a 1000 diagnosed cases worldwide which include just 60 in the UK and 3 in Australia.

This guide is aimed at friends, family, colleagues, professionals and interested parties who come across Kleine Levin Syndrome and want to know how to help and what to do.

Your understanding and support can make an incredible difference to patient's lives

More information is available from:

- www.kls-support.org.uk
KLS Support UK - set up by 3 parents in the UK with the aim of supporting and advising other families
- www.klsfoundation.org
Kleine-Levin Syndrome Foundation - provides information and support to those diagnosed with KLS and their families. The Foundation exchanges information with patients and the medical community to help in the diagnosis and care of those affected by KLS and supports research programs. Their goals are to raise awareness, support scientific research, to find effective treatment and ultimately find a cure for Kleine-Levin Syndrome
- www.klslife.com
KLS Life, read Alanna's story about what it is like to live with KLS and the stories of others, including some videos which explain in detail what happens during an episode
- Southampton Sleep Disorder Service - Solent NHS Trust clinical nursing team, Hampshire, UK on 023 8074 3015

Kleine Levin Syndrome



Time travelling but not as you know it

For many young people with Kleine Levin Syndrome it feels like time travelling - their last clear memory is being at a certain place doing whatever normal people do and suddenly they wake up somewhere else, they have no idea time has travelled forward and they have missed 2 days, a week, a month or even a year of their life. They can miss their own birthday, Christmas, a family crisis, moving house, the breaking up of a relationship, even a death and have no idea what has happened when they return.

Imagine waking up to discover your best friend moved away to university, your dog died, you have lost your job, failed your qualifications, there has been a traumatic global event and this is just the tip of the iceberg - think back to the last four months - what would you miss if you just jumped that period of time and what would the consequences be. Imagine coming to terms with that and then imagine what it is like every time you wake up not knowing whether it really is the day you think it is....

They have not travelled in time - but the rest of the world has....

Imagine living with the frightful reality that you could become sick again at any moment, KLS episodes may reoccur for a decade or longer with devastating effects on the adolescent education, the start of their careers, their whole life and their families. KLS robs children and young adults of big chapters of their lives one agonising episode at a time.

What is it?

Kleine-Levin Syndrome is a very rare and complex neurological disorder which seriously affects sleep and behaviour, which can have a major impact on the lives of sufferers and their families. KLS primarily strikes in adolescence but can occur in younger children and adults.

Kleine-Levin Syndrome episodes are cyclical. KLS episodes last for days, weeks or even months, during which time all normal daily activities stop. Individuals are not able to attend school, work or care for themselves.

In between episodes patients return to full health and their normal behaviour although they may have a period of insomnia after an episode and often report sleep disturbances when an episode is brewing.

Be prepared that they may go into an episode at any time and without warning. If you are concerned call their next of kin who will know what to do and will be able to advise you.

Try not to worry...
He/she will come out of an episode...
They will be OK!

KLS - sometimes known as "Sleeping Beauty Syndrome" - there is nothing beautiful about the condition and it is so much more than excessive sleeping.

KLS symptoms may include:

- Hypersomnia/hypersomnolence (excessive sleep and disturbed sleep)
- Complete and utter exhaustion (of mind and body)
- Altered demeanour when awake (looking spaced out, pale, panda eyes and lack of expression)
- Altered behaviour (which can include child-like behaviour, oversensitivity, aggression and panic attacks)
- Aching muscles or severe headaches
- Hypersensitivity to noise and light
- Hyperphagia (altered or excessive appetite and food cravings)
- Confusion, brain fog, disorientation
- Inability to distinguish between dreaming and reality (possible hallucinations and sleep walking)
- Disturbed body temperature control (cold extremities and excessive sweating)
- Nausea, diarrhoea, vomiting and stomach aches
- In some cases hypersexuality

So how can you help?

Life doesn't stop for KLS, but you can make it easier...

During an episode:

- Let them sleep
- Make sure someone who cares for them is aware they are in episode
- Ensure they have got all their basic needs met - simple quick to reheat meals, nutritious drinks and watch they don't become dehydrated
- Do not pressurise them, they may appear at times to be feeling normal when in an episode, but will not be
- Do not leave them alone, take away their car keys and ensure there is someone who will take responsibility of them

Be guided by their moods - this may mean:

- Keep quiet and calm, use simple words. They almost certainly will not be able to cope with answering questions
- Be prepared to sit and watch the same films over and over again with them

When coming out of an episode be prepared for upset, frustration and anger. Be aware they may not know where they are - they have lost a period of time.

Be a good friend:

- Maybe you could offer to walk the dog or sit with them so their carers get a break
- Show you care - ring them to see how they are doing, drop in round, keep them in the loop - they might not want to see you, but they value your friendship, support and understanding everyday
- Collect information about trips, events, news so that they don't miss out as they were not told
- Invite them out still on the hope that they will be better soon
- Try not to get frustrated and upset by the feelings of helplessness

After an episode

- Fill them in with what they have missed gently
- Be aware that if they don't do something they said they would or stand you up - it might be the KLS not them - they may need reminding
- If they have hurt your feelings they may not have meant too, so talk to them about how you feel
- Be understanding
- Talk about it, how you can make it easier for them next time and help them catch up

KLS effects everything - the young person with KLS, their family, their relationships, their education, their employment, their friends - showing you care really can make a difference, but now treat them normally... they are normal!!!