Treatment & Management

There is no cure for KLS at present. KLS usually ends spontaneously but episodes may continue for ten years or more.

Medications

There are currently no recommended medications. Occasionally some medications may be prescribed by specialists for use during some episodes to try and reduce particularly troublesome symptoms.

Management

During an episode it is recommended that individuals with KLS should be looked after at home by their family or carers to reduce anxiety and to keep them safe. They should be allowed to sleep and should be checked on regularly to ensure they are drinking and eating (but not overeating) and going to the toilet. Their mood should also be monitored. They should not go out alone and should not drive during an episode.

In between episodes it is recommended that individuals with KLS have a regular sleep routine, avoid alcohol and contact with infectious people. It is useful to keep a sleep and symptom diary particularly before diagnosis.

Practical Advice

It is important to have a plan with school and work to manage the start of an attack and the periods of absence.

Research

To take part in research into KLS currently being carried out at Stanford University in the United States please contact
Mali Einen einen@stanford.edu

UK research will be starting soon. Please keep in touch with KLS Support UK to find out more.

Who is KLS Support UK?

KLS Support UK is a small charity started by parents of KLS children. Our aims are:

- to provide support to persons affected by KLS in the UK and their families.
- to raise awareness of KLS in the UK amongst the medical profession and the general public.
- to support medical research with the aim of finding the cause, treatment and cure for KLS.
- to co-operate with other KLS groups around the world to further these aims.

We are pleased to be associated with the KLS Foundation www.klsfoundation.org

Our Medical Advisers

Dr Paul Gringras
Professor of Paediatric Sleep Medicine at Kings College London and Consultant Paediatric Neurology and director Evelina Paediatric Sleep Disorder Service at Guy's and St Thomas' Hospital, London.

Dr Catherine Hill
Consultant Paediatrician, Southampton Children's Sleep Disorder Service and Senior Lecturer in Child Health, Faculty of Medicine, University of Southampton.

For Further Information

Arnulf I, Rico T, Mignot E (2012) Diagnosis, disease course, and management of patients with Kleine-Levin syndrome. Lancet Neurol [online] available from:
www.ncbi.nlm.nih.gov/pubmed/22995695

www.kls-support.org.uk
Facebook: kls-support.org.uk
Email: kleine.levin.syndrome.uk@gmail.com

KLS Support UK

Helping Families affected by Kleine-Levin Syndrome

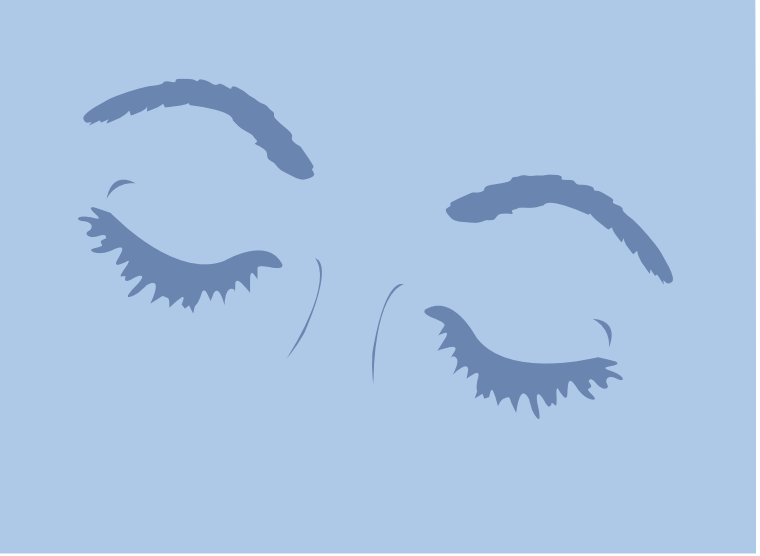
Kleine-Levin Syndrome (KLS)

Bouts of prolonged sleep (lasting days, weeks or months)

With cognitive impairment and behavioural changes

Normal health between bouts

www.kls-support.org.uk



What is Kleine-Levin Syndrome (KLS)?

KLS is a rare disorder characterised by recurrent bouts of excessive sleep associated with reduced understanding of the world and altered behaviour. KLS usually starts in the teenage years but can occur in younger children and adults.

Each episode lasts days, weeks or months during which time all normal daily activities stop. Individuals are not able to care for themselves or attend school and work. People with KLS snap out of episodes and have little or no memory of what happened during an episode.

Between episodes they have normal sleep, understanding and behaviour. KLS episodes may continue for 10 years or more. KLS is sometimes referred to in the media as “Sleeping Beauty” syndrome.

What are the symptoms?

Symptoms vary between individuals with KLS but the following first 3 symptoms are always present during a bout:

Hypersomnia (Excessive prolonged sleep)

Someone with KLS will “sleep” 15 to 22 hours for days, weeks or even months. They feel and look exhausted. Sleep may be disturbed.

Cognitive Impairment

They experience confusion, reduced understanding and feel in a dreamlike state (derealisation). They cannot concentrate, have difficulty communicating, speaking and reading and do not remember events after an episode.

Altered Behaviour

Their demeanour is altered so that they appear spaced out or childlike. They are affected by apathy, are uncommunicative and may engage in automatic and repetitive behaviour. Teenagers will stop normal activities such as using mobile phones, seeing friends and showering and may listen to the same music or watch the same programme repeatedly.

Some individuals with KLS have:

Compulsive Eating (known medically as Hyperphagia)

Sometimes those with KLS eat compulsively and mechanically during a bout and have food cravings for sweets, snacks or foods they would not normally eat. Some eat less.

Other Symptoms

Some individuals, generally boys, experience hypersexuality or other disinhibited behaviour. Some experience migraine headaches with hypersensitivity to noise and light. If they are not in their home environment then some may become anxious, aggressive or irritable particularly if prevented from sleeping. Some have autonomic symptoms including disturbed body temperature control, and altered blood pressure and heart rate. Some may have hallucinations and delusions in some bouts. Towards the end of an episode some get depressed and some experience elation and insomnia for 1 to 3 days afterwards.

What causes KLS?

The cause of KLS is not known. An episode of KLS is often triggered by an infection or sometimes by head injury, alcohol intake or sleep deprivation. Researchers are looking into genetic, auto-immune, inflammatory or metabolic involvement. Contact with KLS individuals cannot pass on the condition.

Who gets KLS?

KLS is extremely rare, estimated at 1-2 cases per million people. KLS usually starts in adolescence but can occur in younger children and adults. KLS affects boys more than girls.

Diagnosis

The diagnosis of KLS is often missed because it is rare and there is lack of awareness. For some it has taken years before the correct diagnosis was made. It is important for the person with KLS and their family to have a diagnosis.

There are no tests for KLS. Diagnosis is based on a clinical interview with the patient and their family and exclusion of other similar conditions. As the person with KLS has little or no memory of an episode it is important for the parents to be present at medical consultations. Parents will usually describe a teenager who is different from before.
Questions about sleep, food, personal hygiene, use of mobile phones and socialising with friends are therefore important.

Before a diagnosis of KLS is reached it is important to rule out other causes such as narcolepsy, encephalitis, tumours, drugs, migraine and psychological disorders. Sometimes investigations such as EEG, sleep studies, memory studies, MRI, CT and SPECT scans and blood tests will be carried out.