

Not all fairytales have a happy ending: sleeping beauty syndrome

[Environment](#), [Air](#)



Have you ever wondered what it would be like to sleep forever? It won't seem like a bad thing for us sleep-deprived-busy-bodies. But for those who suffer from Sleeping Beauty Syndrome, will it be like a fairy tale? In the fairy tale a simple kiss can wake up the princess and there's always a happy ending. But did you notice that when the princess fell asleep, she was unable to move forward and remained stuck in bed while the world outside keeps on living? Did you notice that the princess became oblivious to what was happening around her and that life passed her by? She was fortunate because she had her Knight in shining armor to wake her. But will that be the same if it were to happen to us? In real life a simple kiss can't save those who suffer from Sleeping Beauty disorder. In real life, the world will continue on living while they sleep and leave them behind.

Time won't wait for them and they won't have a whole castle that will fall asleep with them. For them, it's always a never ending nightmare. But first, is there even such a thing as Sleeping Beauty Syndrome?

According to the description found at the KLS Foundation (2009) site:

Kleine-Levin Syndrome (KLS), also known as Sleeping Beauty Syndrome, is a rare and complex neurological disorder characterized by periods of excessive amounts of sleep and altered behavior. It is not to be confused with Sleeping Princess syndrome or Somnophilia. People affected by KLS may sleep for up to 20 hours per day (hypersomnia), waking only to eat or go to the bathroom. The start of each episode is characterized by progressive drowsiness and episodes may last for days, weeks, or even months (Southern Cross Healthcare Group, 2009).

This disorder occurs among adolescents, most commonly males. A 2008 study of 108 KLS patients found that the majority of cases were present in adolescent males, with a mean sex ratio of 3: 1. The average age of onset was 15. 7 years, with 81. 7% experiencing their first episode between 10 and 20 years of age.

Age ranged from 6 to 59 years when patients experienced their first episode. Females tended to be slightly older than males at first onset, even though they tended to experience puberty earlier. In the US population, KLS presents in Caucasians with three times the expected frequency, and with six times the expected frequency in those of Jewish heritage (Wikipedia, 2010). During the brief periods when the patient is awake but is still having an episode, their behavior changes and as families would say often: ??? They turn into a completely different person. ??? Patients would appear ??? spacey??? or childlike and they have experiences of confusion, disorientation, complete lack of energy (lethargy), and lack of emotions (apathy).

Most patients report that everything seems out of focus, and they they are hypersensitive to noise and light. In some cases, food cravings (compulsive hyperphagia) are exhibited. Instances of uninhibited hypersexuality during an episode have also been reported (KLS Foundation, 2009). Kleine-Levin Syndrome episodes are cyclical. When present, KLS symptoms persist 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. Most are bedridden, tired and uncommunicative even when awake. However, not everyone affected by KLS exhibits all of the symptoms previously described (KLS Foundation, 2009). On recovery, total or partial loss of memory (amnesia) of what has happened is usual. There may be a short period of depression, or sometimes euphoria and sleeplessness.

Episodes may not occur for weeks, months or even years, but then reappear without warning. Between episodes, physical and mental health is usually normal. There appears to be no relationship between Kleine-Levin syndrome and other neurological disorders, such as epilepsy (Southern Cross Healthcare Group, 2009). According to KLS Foundation (2009), the longest episode among KLS victims is four years. Imagine going to bed at the age of 17 and waking up as a 21 year old. But no matter how long an episode is, the patient is never aware of it.

For them it would only seem like it??? s for a few hours or day when in truth they have been sleeping for years. And when they wake up they will find out that they??? ve missed a lot of birthdays, Christmas, proms, etc. Then they will suddenly be bombarded by a lot of information such losing loved ones and such. Events like these are difficult and heartbreaking for both the patient and the patient??? s family. As most parents would complain: ??? It??? s like I lost my child. ??? The exact cause of Kleine-Levin syndrome is not known.

However, researchers believe that in some cases, hereditary factors may cause some individuals to have a genetic predisposition to developing the disorder. It is thought that symptoms of Kleine-Levin syndrome may be related to malfunction of the portion of the brain that helps to regulate functions such as sleep, appetite, and body temperature (hypothalamus). Some researchers speculate that Kleine-Levin syndrome may be an autoimmune disorder (Healthwise, 2007). There is also no formal treatment for Kleine-Levin syndrome due to the lack of knowledge regarding its underlying cause. Stimulant medications, such as amphetamines, may be prescribed to treat sleepiness.

Medications to treat mood disturbances and depression may also be recommended (Southern Cross Healthcare Group, 2009). This disease can also bring a lot of stress and anxiety for the patient. Feeling lost and confused after waking up from your years of deep slumber is truly frustrating and at one point, also depressing. According to an article by Sylvestri (2009), after symptoms subside, a short reaction phase with elation, sleeplessness, or depression may occur. As discussed in Frances' and First's book entitled *Am I Okay?* (2000), being depressed happens all the time to mammals, both wild and in the laboratory.

The four major triggers of human depression are the loss of a loved one, a stress that can't be handled, a loss of status, or a feeling of guilt. If all mammals can experience depression, it is no surprise that it is the most frequently encountered of all the psychiatric disorders in humans. As many as 20 percent of women and 10 percent of men will suffer an episode of

depression at some point in their lives. At any given time, 5 to 10 percent of women and 3 percent of men are depressed. Having depression on top of another medical condition can also be dangerous to your health ??? causing complications and a much higher risk of death. There are two forms of Mood Disorder ??? one called unipolar depression because the person has only downs, and no ups.

The other ??? Bipolar Disorder ??? describes mood oscillations in both directions (Frances & First, 2000). Either one of these types of depression has the potential to manifest from Kleine-Levin Syndrome. As stated in a review of all 186 cases of KLS by Arnulff, Zeitzer, File, Farber, and Mignot (2005), half of the patients had a depressive mood during episodes. Fifteen percent of the patients reported suicidal thoughts and two patients attempted suicide. In most cases, the depressed mood resolved at the end of each episode, although in rare cases it persisted longer.

So depression may not be commonly pervasive in all cases of KLS (p. 6). Although many symptoms of KLS and depression overlap ??? such as irritability, oversleeping, weight gain, lack of energy, and slow movements ??? it is stressed by the National Institute of Neurological Disorders and Stroke or NINDS (2009) that mood can be depressed as a consequence, but not a cause, of the disorder. As the patient comes back to reality and realizes that things are not the same as before, it is only natural that the person may feel lost and anxious. And when the patient can no longer handle the stress of missing a big part of their lives, they break down.

It becomes hard for them to accept their condition and that even though they want to turn back time, they couldn't.

The time when a person comes back to reality is a truly emotional experience and one has to have a strong will to be able to move on. The feeling of being so helpless with one's condition can make a person fall into major depression. As episodes increase and parts of a patient's life decrease, they began to have what we call learned helplessness. It is a mental state in which a subject forced to bear aversive stimuli becomes unable or unwilling to avoid subsequent applications, even if they are "escapable," presumably through having learned that situational control is generally out of one's hands.

They begin to feel helpless since they can't control their sleeping behavior much less their own life. This in turn leads to depression. The theory of learned helplessness was then extended to human behavior, providing a model for explaining depression, a state characterized by a lack of affect and feeling. Depressed people became that way because they learned to be helpless. Depressed people learned that whatever they did is futile.

During the course of their lives, depressed people apparently learned that they have no control (His Yen, 1998). Everyday, we wake up, do whatever it is we do, go home, and sleep without even looking back at what happened throughout the day. Most of the time we don't even notice that life is passing us by and we complain about the littlest things. It sounds cliché but

we take too much of life for granted. Those with Klein-Levin Syndrome continuously struggle to fight for time. You may think that getting lots of sleep isn't that bad but imagine the experiences they missed and how much time they have lost.

Unlike us, at least they have a reason to be depressed about. A whole chunk of their life is taken away with every episode! We can only live once so it's important that we cherish every moment and live every moment to the fullest. As James Dean would say: Dream as if you'll live forever, live as if you'll die today. But unfortunately victims of KLS can only continue to dream and feel like they're in a never ending nightmare. They feel alone, lost and afraid and it's very important that they have a complete support system to be with them through the most troubling times.

The good news is that this illness won't last forever. Maybe a prince or princess will come give them a kiss and wake them from their deep slumber. But the long agonizing wait to wake up is very depressing. I believe that having someone with you during the darkest moments of your life is less depressing than being alone. References http://en.wikipedia.org/wiki/Klein-Levin_syndrome