

## Sleep Issues in Kleefstra Syndrome

Research suggests that children with Kleefstra syndrome have varying sleep patterns.

There are reports that some individuals with Kleefstra syndrome wake up many times at night and wake early in the morning. This has led to the suggestion that there might be excessive day-time wakefulness in Kleefstra syndrome.

A small group of children with Kleefstra syndrome are diagnosed with sleep apnoea, which is a period during sleep when the flow of air to the lungs is obstructed causing pauses of breath.

In addition, reflux can affect sleep and contribute to night time wakefulness in individuals with intellectual disability.

Sleep disturbances often get worse with age. For more information on this and other age-related changes in Kleefstra syndrome, <u>click here.</u>

For families who experience their child consistently waking in the night, frequent respite care is strongly advised. It is also advisable to seek sleep advice from your GP. They may then refer you to a psychologist or behavioural nurse, who will be able to develop an individualised sleep support plan.

## Treatment

Melatonin is a medication that may be useful in alleviating some mild sleep difficulties; however, it might not resolve the issues entirely or permanently. According to kleefstrasyndrome.org most families believe melatonin is at least partly effective, but quite a few children need other prescribed medication to ensure they stay asleep. Click here for more information on sleep from the syndrome support group.

If sleep apnoea is diagnosed, removing enlarged tonsils and/or adenoids, may prove helpful.

The Cerebra Charity provides a Sleep Service for support and advice, as well as videos discussing sleep problems that a child may experience. Please click the following link to access this information:

Cerebra Sleep Service

They also provide useful tips on what to do if your child is experiencing sleep difficulties:

## CLICK AND DOWNLOAD

Cerebra Sleep Checklist

For more information on the nature of sleep in children with intellectual disability, and what can be done to reduce or improve sleep problems, click <a href="https://example.com/here\_to/read/Cerebra's full Sleep Guide">here\_to/read/Cerebra's full Sleep Guide</a>.

The information on this website was developed in collaboration with <a href="www.kleefstrasyndrome.org">www.kleefstrasyndrome.org</a>. This is the parental support group for Kleefstra, a well-developed community with an active facebook group and parent support conference. Please visit their website for further information and to get in touch with families of individuals with Kleefstra syndrome.