

Doctor Discussion Guide for Nighttime Sleep Disturbances in Smith-Magenis Syndrome (SMS)

If you think you or your child may have Nighttime Sleep Disturbances in Smith-Magenis Syndrome (SMS), you'll want to discuss diagnosis and treatment options with your doctor. SMS is a developmental disorder caused by a small deletion of human chromosome 17p that occurs in 1 out of 15,000 to 25,000 births.

To help get that conversation started, use this helpful Doctor Discussion Guide.

After you review it, you can send it to your smartphone and share it with your doctor. Or, you may want to print out the Doctor Discussion Guide and bring it with you to your next appointment.

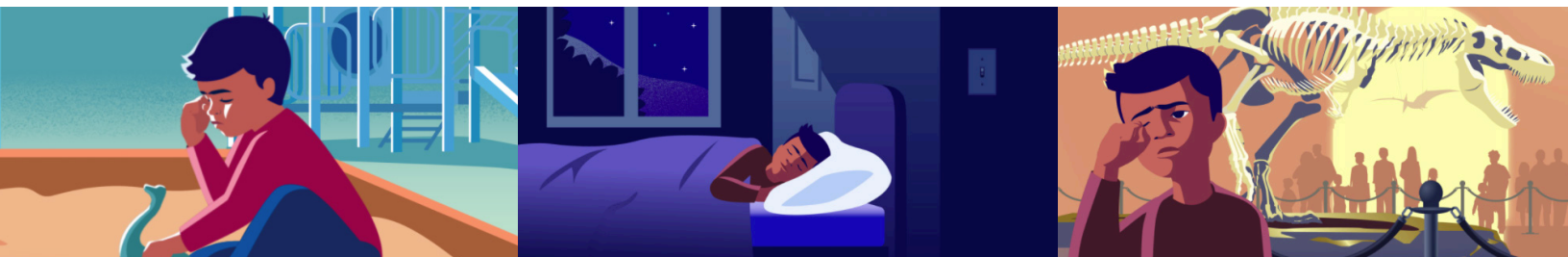
Here's a list of sleep issues. Be sure to discuss the ones you may be experiencing with your doctor. It's important to share all symptoms, and their impact, with your doctor, so you can develop a treatment plan together.

- I, or a child I know, have trouble falling asleep or staying asleep
- I, or a child I know, have a strong urge to sleep during the day or fall asleep unexpectedly
- I, or a child I know, have sleep patterns that are different from those of most people I meet
- I, or a child I know, must fight to stay awake during the day or at school
- I, or a child I know, wake up groggy or not feeling as if I/they have gotten enough rest
- I, or a child I know, experience sleeplessness, which often leads to feeling exhausted

Considerable sleep disturbances are among the many challenges individuals with SMS face.

SMS is a genetic condition defined by pervasive and progressive behavioral and sleep disturbances. Most people with SMS have trouble sleeping. In addition, there is a sleep disturbance defined by an altered circadian rhythm with frequent nighttime waking and daytime sleepiness.

Data shows that near 5 years of age, children with SMS typically get on average ~6.5h of sleep per night, compared to age-matched typically developing children that average ~8.5-9h/night. Reported sleep issues among patients with SMS include reduced total nighttime sleep, frequent nighttime awakenings, early wake times, and daytime sleepiness.



To speak with a health educator about nighttime sleep disturbances in SMS and potential treatment options, call 833-433-4331 or visit smithmagenis.info.