

Blindness and Non-24-Hour Sleep Wake Disorder

Poor quality or quantity of sleep is a common complaint, especially in blind individuals with no light perception. Non-24-hour sleep wake disorder (N24HSWD) occurs in some individuals who are totally blind and lack the light sensitivity necessary to reset the “body clock”. As a result, these individuals suffer from cyclic insomnia and sleep deprivation¹⁻³ which may lead to difficulties with concentration and memory, as well as an increased risk of errors and accidents. For some totally blind individuals, the sleeplessness and daytime fatigue have significant impacts on their social and occupational lives and are considered the most disabling aspect of their blindness^{4;5}. Current knowledge on the nature of this condition, symptoms, diagnosis, and state of research is summarized below.

How Is Our Sleep Regulated?

- The timing of human sleep is governed by the length of time since a person last slept and by their internal body clock
- The internal body clock or circadian pacemaker controls the timing of human sleep with a rhythm that is regulated by a tiny region of the brain called the suprachiasmatic nucleus (SCN). Signals from the SCN help us stay awake and counteract the effects of fatigue. These signals peak in the evening, when the drive for sleep is high, and then diminish when bedtime approaches⁶.

What Happens When The Body Clock Does Not Keep Good Time?

- The intrinsic circadian body clock regulates biological functions in an approximate, 24-hour cycle. The cycle is usually longer than 24 hours and requires regular input from the environment to help maintain synchrony to the 24-hour day. In most people, circadian rhythms are precisely synchronized to the 24-hour day by exposure to environmental synchronizers such as light⁷⁻⁹. Without light, an individual may “free run” slightly longer or shorter than 24-hours, causing a slight delay or advance in his/her body clock each day¹⁰.
- A misalignment between an individual’s body clock and their sleep/wake schedule may result in a Circadian Rhythm Sleep Disorder (CRSD). Examples of CRSDs include Shift Work Sleep Disorder, Delayed Sleep Phase Disorder, Jet Lag, and Non-24-Hour Sleep Wake Disorder.

Why Do Some Blind Individuals Suffer From Non-24-Hour Sleep Wake Disorder?

- Non-24-Hour Sleep-Wake Disorder is a chronic circadian rhythm sleep disorder that occurs when individuals are unable to synchronize their internal clock to the 24-hour light-dark cycle. As a result, the sleep-wake cycle of these individuals moves

gradually later and later each day if their circadian period is more than 24 hours or earlier and earlier if it is less than 24 hours.

- This condition occurs almost entirely in subjects who are totally blind and lack the light sensitivity necessary to reset the circadian clock.

How Common is Non-24-Hour Sleep Wake Disorder among Blind Individuals without Light Perception?

- It is estimated that about 1.3 million Americans are legally blind¹¹ including, approximately 10% with no light perception². Clinical studies estimate that about 50% of totally blind individuals suffer from N24HSWD^{2;9}. Thus, approximately 65,000 Americans can be estimated to suffer from this disorder.

What Are the Symptoms Associated With Non-24-Hour Sleep Wake Disorder?

- In addition to problems sleeping at the desired time, individuals with N24HSWD experience daytime sleepiness that often results in daytime napping.
- The severity of nighttime sleep complaints and/or daytime sleepiness complaints varies depending on where in the cycle the individual's body clock is with respect to their social, work, or sleep schedule. The "free running" of the clock results in approximately a 1-4 month repeating cycle where the clock continually shifts a little each day (about 15 minutes on average) until the cycle repeats itself³. Initially, when the circadian period moves out of synchrony with the 24h light-dark cycle, individuals with N24HSWD have difficulty initiating sleep. As time progresses, the internal circadian rhythm of these individuals moves further and further away from the 24h light-dark cycle, which gradually makes sleeping at night virtually impossible, and leads to extreme sleepiness during daytime hours¹².
- Eventually, the individual's sleep-wake cycle moves back into alignment with the night, and "free-running" individuals are able to sleep well during a conventional or socially acceptable time. However, the alignment between the internal circadian rhythm and the 24-hour light dark cycle is only temporary.
- In addition to cyclical nighttime sleep and daytime sleepiness problems, this condition can cause daily shifts in body temperature and hormone secretion, and is sometimes associated with depressive symptoms and mood disorders¹⁰.

How is Non-24-Hour Sleep Wake Disorder Diagnosed?

- A diagnosis of N24HSWD can be made with the help of sleep history information, captured in a sleep diary or questionnaire, and by the analysis of biological markers of the circadian rhythm present in the blood and the urine, usually collected over several days.

Is There a Treatment for Non-24-Hour Sleep Wake Disorder?

- Individuals should address any questions they have about treatment of N24HSWD with their healthcare provider. At this time, there is no treatment approved by the U.S. Food and Drug Administration for N24HSWD in blind individuals without light perception.

What Kind of Research is Being Done to Better Understand and Treat Non-24-Hour Sleep Wake Disorder?

- Several clinical studies have investigated the effect of natural and synthetic molecules to reset the internal clock in individuals with circadian rhythm sleep disorders, including N24HSWD. While some promising results have been obtained, more studies are needed to develop an effective and safe treatment.
- Clinical trials are currently planned to investigate the efficacy and safety of a new experimental treatment in blind individuals with N24HSWD. If you are totally blind with no light perception, have problems sleeping at night or trouble with daytime sleepiness, you can help researchers by taking a brief phone survey (see announcement below). In addition, you will have the opportunity to be informed of upcoming clinical studies recruiting in your area.

Information on this web site is provided for educational purposes only and is not intended to replace discussions with a healthcare provider. You should not use the information on this web site for diagnosing or treating a medical or health condition. All decisions regarding patient care should be made with your healthcare provider

References

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