

attend regular classes, if treatment fails, Non-24 is a disability. Schools and employers in the U.S. are required, under the Americans with Disabilities Act, to provide reasonable accommodations, including part-time or modified work schedules. Sleep disorders qualify students for a Section 504 plan. Consult a lawyer for details. Other countries may have similar requirements for accommodation.

**What accommodations would help?** Greater flexibility in work hours. Working from home, at the times they can. Shorter work hours, at correspondingly lower pay, for those that need this because of chronic tiredness. For students, allowing them to take courses at non-standard times, or recorded on video, or online; or recognizing that they may miss some classes, but may be able to keep up with the coursework nonetheless. Providing for exams to be given at an appropriate time. Allowing a lighter course load, even if this means delaying graduation.

**Does Non-24 affect learning in school?** Non-24 does not affect intelligence. But study, concentration, memory, and attention span are affected by sleepiness. Adjustments in study habits may be necessary. This can best be accomplished with the cooperation of school personnel. It is important to identify children with Non-24 at the earliest possible age to prevent a pattern of failure from developing, thus fostering low self-esteem.

**What research is underway?** There is work being done on the basic nature and function of sleep, which is still not really understood. There is progress on the genetic, neurological, and chemical pathways involved in the circadian clock. Studies have been done with animals, and in some cases with normal human subjects, but seldom with Non-24 patients. There is continuing research on the effects of light, dark, and melatonin on the circadian rhythm. More needs to be done to unravel the underlying causes of this disorder..

**What is the Circadian Sleep Disorders Network?** Circadian Sleep Disorders Network is a 501(c)(3) nonprofit organization promoting awareness, accommodation, support, and research around the issues of Circadian Rhythm Sleep Disorders. Please see our web site, [www.CircadianSleepDisorders.org](http://www.CircadianSleepDisorders.org) (shortcut: [csd-n.org](http://csd-n.org)) for details, for more information about these disorders, and to print this and similar documents, which may be freely distributed. And please [join](#) if you or your child is among those affected by Non-24!



## NON-24-HOUR SLEEP-WAKE DISORDER

### Questions & Answers

**What is Non-24-Hour Sleep-Wake Disorder?** *Non-24-Hour Sleep-Wake Disorder (Non-24)* is a neurological sleep disorder in which a person's sleep/wake cycle is longer than 24 hours. The person is unable to adjust his sleep/wake cycle to the length of the day, and his sleep time progresses around the clock. For example, if he goes to sleep at midnight and sleeps until 8 am one day, he may not be able to fall asleep until 1 or 2 am the next night, and will need to sleep correspondingly later the following morning. The delay does not stop at 1 or 2am but continues to get worse every day until the person is going to sleep at 4am, 10am, 2pm etc. Eventually he comes around the clock again to his starting point and the process continues on. For some people the length of their cycle varies from day to day, and they cannot predict their sleep/wake schedule in advance.

**Does it have other names?** Its official designation according to the International Classification of Sleep Disorders (ICSD-3, published in 2014) is *Non-24-Hour Sleep-Wake Rhythm Disorder*. The previous edition (ICSD-2, 2005) called it *Circadian Rhythm Sleep Disorder - Free Running Type*. It has also been called *Hypernycthemeral Syndrome* or simply *Free-Running Disorder (FRD)*. The DSM-5 (2013) refers to it as *Circadian Rhythm Sleep-Wake Disorder – Non-24-Hour Sleep-Wake Type*.

**Doesn't it only affect blind people?** No. While Non-24 is believed to affect over half of all totally blind individuals, it does affect some sighted people as well. However, the underlying causes are different, and these should be seen as two distinct disorders: Blind Non-24 and Sighted Non-24.

**Is Non-24 a psychological disorder?** No. Non-24 is a neurological disorder. However the stress of living with Non-24 can lead to psychological problems including depression. This is compounded by the lack of understanding from family, friends, employers and even some doctors. It is difficult for most people to understand that abnormal sleep hours may be inflexible and out of a person's control. The resultant lack of acceptance may seriously undermine the employment, relationships, and self-esteem of a person with Non-24.

**Why is it often misdiagnosed?** Many people try to cope with Non-24 by forcing themselves to keep a normal schedule. This results in a chronic sleep deficit, with symptoms that can mimic depression, attention deficit hyperactivity disorder, chronic fatigue syndrome, fibromyalgia, or just plain fatigue. A patient who complains about not being able to fall asleep may be misdiagnosed with primary insomnia, and prescribed sleep medication. A patient who complains about being tired all the time may be misdiagnosed as suffering from depression, and prescribed antidepressant medication. In some cases, of course, the patient is

suffering from depression, but that may be secondary, a result of constant struggle with fatigue or failure at work or school.

**Why not just go to bed at the proper time?** Non-24 people really are unable to fall asleep at the normal time. Their body clocks are not just free-running, but also inflexible, and they are unable to entrain to a 24 hour day-night schedule.

**But if a person gets tired enough, won't he fall asleep at the proper time?** Most cannot fall asleep earlier no matter how tired they feel. And they've tried.

**Why are some Non-24 people often late for work?** Many people with Non-24 sleep very soundly. If they have to get up for work at a time their free running body clocks consider sleep time, they may not hear alarm clocks. They may be awakened, with difficulty, only to fall back to sleep again. This is especially true if they have already become sleep deprived.

**Why is Non-24 a problem?** People with Non-24 who try to work fixed work hours, such as 9 am to 5 pm, or students who have to attend regular classes, become sleep deprived. This is because, no matter how tired they get, they cannot fall asleep at the same time every night. Yet they still have to get up at the same time in the morning. So they may get little or no sleep during the night and be working at the time their body says they need to sleep. Their work suffers. They may become accident prone. Continuing sleep deprivation affects their health, both physical and mental.

Parents who have Non-24 may have to be awake early in the morning to feed their kids and get them off to school. Other issues can include difficulty finding and maintaining relationships on such an unusual schedule, shopping when the stores are open, and being awake for appointments with repair people and doctors. These are particularly difficult for people whose day length varies, as they cannot predict in advance when they will be awake.

More awareness that Non-24 is a real disability is needed, together with greater willingness to discuss it in terms which don't blame the individual. Such understanding would also further efforts to find suitable accommodations.

**What are the long-term health effects?** There are many long-term health effects of sleep deprivation. These can include depression, lowered immune response, anxiety disorders, weight gain, fibromyalgia, diabetes, and cancer.

**What about chronic tiredness?** Many people with Non-24 feel rested and alert if they can sleep during the hours their bodies require. But others are chronically tired, even if they can sleep as their circadian rhythms dictate. Research suggests that some of their internal systems may be out of sync with others - for example, their digestive system may not be in sync with their sleep/wake system, similar to jet lag.

**How many people are affected?** Non-24 is quite rare. An incidence of 0.03% has been quoted. Non-24 occurs primarily among blind individuals, though some sighted persons have the disorder also.

**At what age does it start?** For some, Non-24 starts in infancy or early childhood. For others, it starts during puberty. Still others start out having Delayed Sleep Phase Disorder, and progress to Non-24 as they get older.

**How is Non-24 diagnosed?** A sleep specialist will generally discuss a patient's history and complaints. If a circadian rhythm disorder is suspected, the doctor will require a log of when the patient sleeps and wakes. This may be obtained by monitoring sleep-wake patterns using an wrist activity monitor, a device worn like a wristwatch which tracks movement. The sleep history is most useful if it can be obtained when the patient is sleeping on her natural schedule, without attempting to meet the requirements imposed by work or school. Many patients will have already researched circadian disorders, and come prepared with a sleep log.

Often the sleep doctor will order an overnight *polysomnogram* (sleep study), to detect or to rule out other disorders such as sleep apnea or PLMD (Periodic Limb Movement Disorder). For people with Non-24, this test should be performed when the patient can sleep normally, i.e. during the patient's sleep period which may occur at any point during the day. Some doctors will ask for a *Multiple Sleep Latency Test* (MSLT) to be conducted during the patient's day, to evaluate the possibility of narcolepsy. In some patients, multiple disorders may be present, or another disorder may be the cause of the reported symptoms.

**How is Non-24 treated?** Sleep doctors treat Non-24 by attempting to entrain the patient to a 24-hour cycle. The patient must first wait until her sleep hours have cycled to the desired time. She is then instructed to use bright light in the morning, restrict light exposure in the evening, and/or take the hormone melatonin in the evening, in an attempt to stabilize the body's circadian rhythm at the desired time. This may be effective for some people, but is not for others. Many doctors prescribe medication to help people sleep. This can help some people get to sleep when desired, but often it does not improve the quality of sleep, and the patient remains tired during the day. Many people react to the medications and must stop taking them, and some people find them ineffective.

For many Non-24s, sleeping on a normal schedule may be difficult or impossible and trying to do so only results in sleep deprivation and stress, with all the harmful effects that can cause. They find they can be much more productive and much happier living on the rotating schedule to which their body naturally reverts. For people with severe cases, this may be the only realistic option.

**Is Non-24 a disability?** For those for whom treatment is ineffective, Non-24 can make it impossible to maintain a fixed work or school schedule. For those who have jobs requiring a fixed schedule, as well as students who are required to