Delayed Sleep Phase Syndrome and Non-24-hour Circadian Rhythm Disorder
Symptoms, Characteristics and Complications

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In modern societies, people with difficulty rising at the desired time in the morning and those with difficulty staying alert during the daytime have been regarded as lazy or unmotivated.[1] But scientific research shows that many people considered "night owls" actually suffer from a biological disorder known as Delayed Sleep Phase Syndrome.

My 13-year-old son was diagnosed with Delayed Sleep Phase Syndrome by Dr. Kristin Avis at Kennedy Krieger Institute in June of 2003 and by Dr. Ann Halbower at Johns Hopkins Children's Hospital in February of 2004. Dr. Halbower diagnosed his non-24-hour Circadian Rhythm Disorder in February as well. This additional diagnosis helps explain why the treatment prescribed by Dr. Avis did not work as expected. Dr. Halbower prescribed a different treatment regimen for him which has been quite successful; however, no treatment is 100% effective for any sleep disorder. The purpose of this document is to list circumstances and events that have an impact on his circadian rhythm, as well as to explain why his sleep patterns are so different from other students his age.

Delayed Sleep Phase Syndrome (DSPS) is a Circadian Rhythm Disorder (CRD) marked by a patient's sleep/wake cycle being later than what is considered typical or normal for others in the patient's time zone. For instance, someone with DSPS may not be able to fall asleep until around 3:00am and is then unable to wake up until around noon. *DSPS differs from a behavioural or lifestyle preference for late bedtime and arising time although the symptom presentation in these two patient groups is similar; patients who have a circadian disorder often fail to adjust to societal schedules and demands despite greater attempts to do so.*[2] According to research, this rhythm is inherent in the genetic code of a person with DSPS and is not something that can be cured; however, it is possible to artificially adjust the patient's sleep/wake cycle with daily AM treatments of bright-light therapy (at least 10,000 lux) and daily PM doses of melatonin. These treatments, administered together and at precise times, can (in many cases) adjust the sleep-wake cycle to a more socially acceptable pattern. The timing of the treatments is based upon careful observation of the patient's regular (non-treated) sleep and wake times, and requires careful follow-up and feedback for determination of necessary adjustments. *Going to bed earlier cannot achieve substantial advances of sleep onset and wake time.*[1]

Non-24-hour Circadian Rhythm Disorder is a condition whereby a patient's internal clock runs longer than 24 hours. A person with such a disorder has the misfortune of trying to adjust to only 24 hours in a day when the person's body insists there are actually more hours available. Blind people tend to have this disorder, since their retinas aren't receptive to the light cues that allow others' internal clocks to reset. When left untreated, the person's sleep-wake cycle will change every day, eventually going around the clock and returning to "normal" for a day or two before going around again. This is known as "free-run." Persons with this disorder have a particularly difficult time "retraining" or "resetting" their clocks to a socially acceptable pattern.

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For persons with DSPS, if the sleep/wake cycle is adjusted too quickly, the rest of the body's rhythms don't adjust at the same time. Lack of synchronization in the circadian rhythm can lead to physical dullness, poor appetite, lack of sound sleep, decreased state of alert, impaired thinking ability and depressed mood.

> *If the behavioral sleep/wake schedule changes too much too fast, the endogenous bodily timing systems do not reset commensurately. This is known to jet travelers who, after they fly suddenly through several time zones, only gradually resynchronize their circadian rhythms to new clock times. If sleep schedules are forced to change by circumstantial factors other than circadian timing mechanisms (e.g., by exhaustion, sudden change of work shift, or use of sedatives) there will be a mismatch between the sleep/wake rhythm and other circadian rhythms such as metabolic, hormonal, CNS electrical, or neurotransmitter rhythms. This mismatch produces internal physiological incoordination among rhythms, and hence physiological inefficiency that likely induces poor sleep and daytime fatigue. Because of the endogenous tendency to shift sleep progressively later, programmed shifts to later sleep times are more easily accomplished than shifts toward earlier sleep times.*[3]

Persons with really long internal circadian rhythm periods (longer than 25.5 hours, like my son's) have to make even larger readjustments to their internal cycle.

> *Individuals whose endogenous circadian periods are particularly long (25.5 hours or longer), have larger readjustments to make in the presence of external timing information (e.g., the light/dark cycle) when such information would reentrain rhythms to a shorter cycle length. For instance, if in the course of normal life activities such individuals retire to bed later than usual, they may find it more difficult to regain earlier sleep hours.*[3]

Persons without these disorders may have difficulty resetting their clocks due to jet-lag and such, but most tend to "bounce back" within a day or two and function well otherwise. This is not the case with DSPS and other circadian rhythm disorders. In fact, as my son says, "It's like having to reset the clock for daylight savings time every day."

External and internal events that may have an impact on my son's sleep/wake cycle and his ability to adjust and/or readjust to a "normal" sleep/wake cycle could include (but are not limited to) the following:

- Time Change (e.g., Daylight Savings Time)
- Illness
- Medications (especially adjustments to new medications and anything with a stimulant or sedative effect)
- Seasons (less daylight hours tend to negatively affect him)
- Disruption in weekly schedule (school suspension, holidays, etc.)
- Growth spurts (typically cause him to sleep longer than the currently calibrated 9 hours)

- Evening school activities and events that cause a delay in melatonin administration and/or bedtime (e.g., evening Choir Concert)
- Stress (especially school-related stress)
- Travel (especially to another time zone)
- Any event that causes him to get less sleep than the 9 hours his body requires

In addition to the daily physical and scheduling challenges that DSPS causes, there are some common psychological characteristics in patients with DSPS: *(1) an excessive defense mechanism, which increases conflicts and develops neurosis; (2) a high level of intellectual aspiration with compulsivity and poor problem-solving skills that cause patients to feel self-defeated, powerless and disappointed, leading to defensiveness and frustration when they cannot attain their goals; and (3) egocentric emotion, inhibition and perseverance.*[4] My son certainly exhibits most of these characteristics, which should be taken into account when interacting with him in the classroom. His defensiveness arises from DSPS as well as AD/HD and his Non-Verbal Learning Disability. Excluding him from classroom instruction whenever he becomes defensive should be minimized, since his defensiveness is a manifestation of three different disabilities.

My 13-year-old son differs from the average student at his core. His basic biological rhythms are not inherently the same as other thirteen-year-olds and must be artificially adjusted and set. The effects of his circadian rhythm disorders are extensive and should be considered carefully before any placement and/or disciplinary decisions are made.

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[1] Makoto Uchiyama, Masako Okawa, Kayo Shibui, Keiko Kim, Hirokuni Tagaya, Yoshihisa Kudo, Yuichi Kamei, Tatsuro Hayakawa, Jujiro Urata and Kiyohisa Takahashi, Altered phase relation between sleep timing and core body temperature rhythm in delayed sleep phase syndrome and non-24-hour sleep-wake syndrome in humans, Neuroscience Letters, Volume 294, Issue 2, 17 November 2000, Pages 101-104. (http://www.sciencedirect.com/science/article/B6T0G-41HHNGW-9/2/4b2dbd344609618630ae80f0d8423999)

[2] N Zisapel. Circadian rhythm sleep disorders: pathophysiology and potential approaches to management. *CNS Drugs.* 2001;15(4): **311–328**.

[3] Quentin R. Regestein and Milena Pavlova, Treatment of delayed sleep phase syndrome, General Hospital Psychiatry, Volume 17, Issue 5, September 1995, Pages 335-345. (http://www.sciencedirect.com/science/article/B6T70-3Y6PCPV-F/2/d71146c55942bb86e95e87fe45e95687)

[4] Masako Shirayama, Yukihiko Shirayama, Hideharu Iida, Masaaki Kato, Naofumi Kajimura, Tsuyoshi Watanabe, Masanori Sekimoto, Shuichiro Shirakawa, Masako Okawa and Kiyohisa Takahashi, The psychological aspects of patients with delayed sleep phase syndrome (DSPS), Sleep Medicine, Volume 4, Issue 5, September 2003, Pages 427-433. (http://www.sciencedirect.com/science/article/B6W6N-49CSV3F-2/2/1f002e178a96cb3f5b07fad4790461ab)