Sleep Series for Individuals with 22q11.2 Differences

Insomnia & Delayed Sleep Phase Disorder (DSPD)

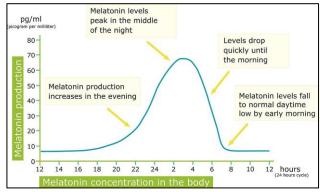
Many individuals with 22q differences experience sleep problems. These problems can negatively affect their mental health, which then in turn cause more sleep issues. This sheet describes **insomnia** and **delayed sleep phase disorder (DSPD)** and their management. It also shares tips on the care of children who resist going to bed.

Insomnia

- Insomnia is a common problem that occurs when people have at least one of these:
 - Trouble falling asleep
 - Trouble staying asleep
 - · Waking up too early
- Insomnia makes people tired and affects their:
 - Alertness
- Motivation
- Attention
- Performance at
- Concentration
- school or work
 Behavior (increases aggression)
- MemoryMood
- Insomnia can lead to errors and accidents
- Possible causes of insomnia:
 - Predisposition e.g. Easily awaken, having a busy mind, anxiety
 - Events or experiences that bring strong emotions and trigger insomnia:
 - Positive events and excitement, e.g. before a vacation, moving, wedding, start of a job etc.
 - Negative events and stresses such as loss of a job, death of a loved one, social issues (e.g. bullying, problems in a friendship or a relationship) etc.
 - Coping with daytime sleepiness with methods that make night time insomnia worse:
 - Caffeine long lasting effect makes it hard to fall asleep and stay asleep
 - o Alcohol makes sleep fragmented
 - Long nap makes it difficult to fall asleep at night

Delayed Sleep Phase Disorder

 Melatonin is a hormone made by the pineal gland in our brain. Normally, the level of melatonin rises when the sky gets dark in the evening (see graph below). This natural rise helps the body go into a quieter state, which makes it easier to sleep.



Melatonin production in a 24 hour cycle https://www.physio-pedia.com

- If the melatonin level in the body rises too late, it becomes difficult to fall asleep, and the person has delayed sleep phase disorder (DSPD)
- People who have DSPD fall asleep and wake up very late. They have severe daytime sleepiness as well as trouble with memory, thinking, behavior, and mood. DSPD may increase the risk of mental health problems.
- Teenagers tend to go to sleep later and wake up later than normal because their melatonin level rises later than when they were younger. If they are still able to function well during the day, they are night owls and don't have DSPD.
- DSPD likely has a genetic component. However, it gets worse if people have irregular sleep schedules (e.g. shift work) or unhealthy sleeping habits (e.g. drink coffee, use screens, or use bright lights before sleep)



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Insomnia and Delayed Sleep Phase Disorder (DSPD) (continued)

Managing Insomnia & Delayed Sleep Phase Disorder

- · Go to sleep and wake up at around the same time every day
- Avoid electronics and bright lights before sleep. Unwind and relax.
- Use the bed only for sleeping (not for homework, TV, gaming etc.)
- Keep the bedroom quiet and dark when sleeping
- Be active during the day (not right before sleep)
- Avoid naps after 4 pm

Additional help

- <u>Cognitive behavioral therapy for insomnia</u> can change attitudes and behavior that affect sleep.
- Don't use sleep medications unless instructed by your healthcare provider. They can lead to dependency and have side effects.
- Your healthcare provider may recommend:
 - Melatonin supplements (for early evening)
 - Light therapy (for morning)
 - **Chronotherapy** (delaying sleep for 1.5 to 2 hours per day for multiple days to reach the desired time)

What to do if your child refuses to go to sleep

- · Manage any health and social issues that make it hard to fall asleep
 - Low iron, stomach reflux, unrealistic expectations, bullying etc.
- If your child is **anxious**, sit near the bed. Over the course of a few weeks/months, move your chair farther away little by little
- Put your child to bed when he/she is actually **sleepy**. Over the course of a few weeks, move up the bedtime little by little
- Avoid electronics, bright light, caffeine, excitement, and large meals before bedtime
- Start the pre-sleep routine (e.g. bath, stories) earlier to avoid rushing
- Do <u>not</u> scare or punish for sleep-related issues
- Be <u>calm</u> and stay firm with a consistent routine that works

Resources

- Overcoming Insomnia (video) American Academy of Sleep Medicine
- <u>Insomnia</u> Mayo Clinic
- Insomnia Cleveland Clinic
- Delayed Sleep Phase Mayo Clinic
- Delayed Sleep Phase Syndrome Cleveland Clinic
- <u>Teens and Healthy Sleep Habits</u> Mayo Clinic
- <u>Child sleep: Put preschool bedtime problems to rest</u> Mayo Clinic



The mission of the <u>International 22q11.2 Foundation</u> is to improve the quality of life for individuals affected by chromosome 22q11.2 differences through family and professional partnerships.

This information is brought to you by the Foundation for educational purposes only. It is <u>not</u> intended to be taken as medical advice. If you have concerns, please talk to your healthcare provider.

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Sleep disorders and 22q differences

Both 22q11.2 deletion and duplication syndromes are associated with sleep problems. These problems have a greater impact on some aspects of mental health for 22q11.2 deletion compared to duplication carriers.

Poor sleep leads to:

- Daytime sleepiness
- Worse mental health anxiety, ADHD, psychotic symptoms
- Difficulty with memory, problem-solving, and emotions
- Possibly more aggressive behavior

Poor mental health can also worsen sleep. It is a vicious cycle.



- Melatonin Task Force International Pediatric Sleep Association
- Updated clinical practice recommendations for managing [children | adults] with 22q11.2 deletion syndrome – 2023
- <u>Sleep difficulties related to psychopathology and neurocognition in people with 22q11.2 deletion syndrome</u> [Summary] 2025
- Polysomnographic findings in children with 22q deletion & duplication syndrome: relationship to genetic diagnosis, parentreported symptoms, and calcium levels – 2024

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