Lifestyle and ABC-DS Study

3rd Edition

Promoting Healthy Aging in Down Syndrome: Sleep

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ABC-DS Participant sleeping at home as a part of the Lifestyle Study

Importance of Sleep

Sleep is essential for the healthy brain and body functioning of individuals with Down syndrome.

Brain function Supports memory, focus, and learning	Heart and Weight Health Supports a healthy heart and weight	Emotion Regulation and Mood Reduces stress and improves mood	Immune system Strengthens immune function
Growth and Development Crucial for growth in children and teens	Reaction time Improves reaction speed	Decision Making Sharpens ability to make good choices	Energy Level Restores energy for the day ahead

Sleep Problems Common to Individuals with Down Syndrome

Children and adults with Down syndrome often experience sleep problems.

- **Obstructive Sleep Apnea (OSA)**: Individuals with Down syndrome can experience OSA due to differences in their airway structure (e.g., smaller airways, low muscle tone, larger tongues). This condition causes interruptions in breathing during sleep. Studies indicate that 30% to 70% of children with DS are affected by OSA (Seither et al., 2023). In adults with DS, the prevalence remains high, with research showing that 79% of participants aged 25-61 screened positive for OSA, and 44% experienced moderate to severe forms (Giménez et al., 2021).
- **Insomnia and Behavioral Sleep Issues**: Some individuals with Down syndrome struggle to fall asleep or stay asleep due to behavioral or environmental factors such as anxiety, overstimulation before bed, or irregular routines. Behavioral sleep disturbances are one of the most common cause of insomnia, with bedtime resistance, delayed sleep onset, and nighttime awakening present in 52 to 69% of children with DS. In adults with DS, the prevalence of BSD ranges up to 86% (Giménez et al., 2021).
- **Sleep Fragmentation**: Individuals with Down syndrome often have more fragmented sleep patterns, which means they may wake up multiple times during the night without fully entering deep sleep cycles.

What are some ways to improve Sleep Quality

There are several strategies that can help improve sleep quality for individuals with Down syndrome. Strategies that work for one individual may not always work for someone else.



Consistent Bedtime Routine: A predictable bedtime routine helps signal to the body that it's time to wind down. Try incorporating calming activities like reading, gentle music, or a warm bath before bed.



Create a Sleep-Friendly Environment: Ensure that the bedroom is cool, quiet, and dark. Using white noise machines or blackout curtains can minimize disruptions from outside noise or light.



Monitor Diet and Exercise: Avoid heavy meals or caffeine close to bedtime. Encourage physical activity during the day, which can help promote better sleep at night.



Sleep aids. Consult with your physician about the usefulness of melatonin or other supplements or aids for evoking sleepiness.



Sleep Studies for Diagnosis: If there are concerns about obstructive sleep apnea (snoring, choking sounds, or gasping for breath during sleep), a sleep study can help diagnosis the problem. Interventions can include continuous or bilevel positive airway pressure (CPAP or BPAP) therapy or small implanted devices like INSPIRE that stimulate the airway muscles.





Behavioral Interventions: For those with sleep-onset difficulties or night waking, behavioral strategies such as scheduled waking, positive reinforcement, and relaxation techniques can help.

Sleep and Alzheimer's Disease in Individuals with Down syndrome



Participant wearing the WatchPAT 300 Home Sleep Test

There is evidence that sleep problems increase in adulthood for people with Down syndrome. Engaging in screening for sleep problems at different points in the lifespan is thus important for individuals with Down syndrome. In a recent study, 81 adults with DS aged showed higher levels of 25-61 years did a home sleep test to screen for sleep quality and sleep disordered breathing.

Results revealed that 79% of participants tested positive

for OSA, with 44% experiencing moderate to severe forms. Notably, 68% of participants who had not previously been diagnosed with OSA tested positive, indicating a high prevalence of undetected and untreated sleep-disordered breathing in adults with Down syndrome.

One of the key findings was the link between sleep problems and biomarkers of brain changes due to Alzheimer's disease specifically high levels of proteins called amyloid-beta and tau. Adults with Down syndrome who had more nighttime awakenings or shorter total sleep times these proteins in brain scans, suggesting a possible connection between sleep problems and early Alzheimer's disease brain changes. Additionally, adults with Down syndrome with

frequent nighttime awakenings performed worse on cognitive tasks involving memory and motor skills.

The study also found a connection between sleep problems and mood. Adults with Down syndrome who had shorter sleep times and who screened positive for OSA were more likely to experience depressive symptoms - including symptoms like having low energy, not wanting to socialize with others, not being interested in hobbies or activities, and feeling sad.

Together, these findings highlight that sleep plays an important role in brain functioning, memory and motor skills and with mood in adults with Down syndrome.

Yoon, D. M., Plante, D., Fleming, T., Handen, B.L., Peven, J.C., Bradley, C., Okonkwo, O., Lao, P., Laymon, C., & Ha rtley, S.L. (2024, June 5-8). Obstructive sleep apnea and Alzheimer's disease in Down syndrome [Conference sessi on]. 5th International Conference of the Trisomy 21 Rese arch Society, Rome, Italy.

2 or more



Distribution of OSA Levels

Sleep Resources for Individuals with Down syndrome

- National Down Syndrome Society (NDSS): <u>www.ndss.org</u>
- Sleep Foundation: <u>www.sleepfoundation.org</u>
- American Academy of Sleep Medicine: <u>https://www.sleepeducation.org/</u>
- National Institutes of Health (NIH) Sleep and Down Syndrome Resources: https://www.nichd.nih.gov/health/topics/down/conditioninfo/treatment/sleep
- Down Syndrome Resource Foundation: <u>https://www.dsrf.org/resources/information/health-and-medical/sleep/</u>
- UW-Madison University Health Services: <u>https://www.uhs.wisc.edu/medical/sleep/</u>
- The LowDOWN Podcast, Episode 2-3: Dr Rafael Pelayo Sweet Dreams: Down Syndrome and Sleep, Part 1 (Sept. 23, 2020): <u>https://www.dsrf.org/resources/the-lowdown-podcast/sweet-dreams-downsyndrome-and-sleep-part-1</u>
- The LowDOWN Podcast, Episode 2-4: Dr Rafael Pelayo Sweet Dreams: Down Syndrome and Sleep, Part 2 (Sept. 30, 2020): <u>https://www.dsrf.org/resources/the-lowdown-podcast/sweet-dreams-downsyndrome-and-sleep-part-2</u>
- The LowDOWN Podcast, Episode 2-11: Dr Katie Frank, PhD, OTR/L Good Night: Sleep Hygiene and Sleep Routines (Nov. 18, 2020): <u>https://www.dsrf.org/resources/the-lowdown-podcast/sweet-dreams-down-syndrome-and-sleep-part-3/</u>

A special thanks goes out to all our participants in both the ABC-DS and Lifestyle Studies Our research would not be possible without YOU



Interested in learning more about how you can get involved? Visit: https://abc-ds.org/participants/