

Sleep Well, Live Well! OT Interventions for Sleep Disturbances for Individuals With Hypermobile Ehlers-Danlos Syndrome

Susan S. McDonald, EdD, OTR/L¹, Allison Johnson, Nicole Curtis, Elizabeth Smiddy, Anthony Foster¹, David Levine, DPT, FAPTA²

¹University of Tennessee at Chattanooga, Chattanooga, Tennessee, United States; ²Erlanger Health Care System, Chattanooga, Tennessee, United States

DOI: [10.5014/ajot.2023.77S2-PO316](https://doi.org/10.5014/ajot.2023.77S2-PO316)

Date presented: April 22, 2023

Primary Author and Speaker: Susan S. McDonald, susanmcdonald.ot@gmail.com

PURPOSE: The purpose of this study was to investigate common sleep disturbances in individuals with hypermobile Ehlers-Danlos Syndrome (hEDS) and occupational therapy interventions commonly utilized to facilitate sleep.

DESIGN: This quantitative, anonymous, survey was conducted in collaboration with the Ehlers-Danlos Society (EDS) and was administered worldwide.

METHOD: A survey was distributed through the EDS Society website from January 2022 - May 20, 2022. Data included sociodemographic characteristics (age, sex, race/ethnicity, etc.), sleep disturbances (pain, body temperature regulation, insomnia, etc.) and common interventions utilized (positioning, sleep routines, medication, etc.). A measure of mental and physical health related quality of life (HRQOL) from the Short Form Survey (SF-36) was also utilized to assess the impact of sleep on HRQOL. There were 2,011 respondents with hEDS that responded to the survey.

RESULTS: The majority of individuals with hEDS reported their sleep as not being restful (92.2%). Respondents frequently got less than the recommended number of hours of sleep (7) per night (66.4%). Pain was reported as interfering with sleep at least weekly by 97.8% of subjects with 36.0% reporting pain interfering with sleep daily. 95.2% reported sleep quality as very poor, poor, or fair. Difficulty getting into a comfortable position to sleep was reported by 88.4%. Temperature regulation was also found to impact sleep (twice a week or greater) with respondents feeling too hot (62.4%) or too cold (46.1%). 69.6% reported fatigue interfering with everyday activities 5 days a week or more or greater. The most common OT sleep interventions used by participants was maintaining a routine sleep schedule (64.6%), positioning with pillows or wedges (20.1%), room temperature (17.3%), ambient light modifications (14.1%), and weighted blankets (7.5%). The use of prescription (41.5%), and over the counter medications (20.1%) to improve sleep was common. Both mental and physical HRQOL were impacted by poor sleep (less than 7 hours nightly) ($p < 0.01$).

CONCLUSION: Individuals with hEDS reported significant sleep disturbances due primarily to pain, and temperature regulation. Many participants use medications, sleep positioning, and sleep routines to combat these sleep difficulties. More research is needed to determine optimal interventions to improve the overall quality of sleep in individuals with hEDS.

IMPACT STATEMENT: OT practitioners are uniquely qualified to work with individuals with hEDS to optimally facilitate efficient sleep habits and routines, and to address the ramifications of sleep insufficiency on occupational performance and participation.

References

- Smith, T. O., Bacon, H., Jerman, E., Easton, V., Armon, K., Poland, F., & Macgregor, A. J. (2014). Physiotherapy and occupational therapy interventions for people with benign joint hypermobility syndrome: a systematic review of clinical trials. *Disability and Rehabilitation*, 36(10), 797–803. <https://doi.org/10.3109/09638288.2013.819388>
- Watson, N. F., Badr, M. S., Belenky, G., Bliwise, D. L., Buxton, O. M., Buysse, D., Dinges, D. F., Gangwisch, J., Grandner, M. A., Kushida, C., Malhotra, R. K., Martin, J. L., Patel, S. R., Quan, S. F., & Tasali, E. (2015). Recommended Amount of Sleep for a Healthy Adult: A Joint Consensus Statement of the American Academy of Sleep Medicine and Sleep Research Society. *Sleep*, 38(6), 843–844. <https://doi.org/10.5665/sleep.4716>
- Ho, E., & Siu, A. (2018). Occupational Therapy Practice in Sleep Management: A Review of Conceptual Models and Research Evidence. *Occupational therapy international*, 2018, 8637498. <https://doi.org/10.1155/2018/8637498>
- Levine, D., Work, B., McDonald, S., Harty, N., Mabe, C., Powell, A., & Sanford, G. (2021). Occupational Therapy Interventions for Clients with Ehlers-Danlos Syndrome (EDS) in the Presence of Postural Orthostatic Tachycardia Syndrome (POTS). *Occupational therapy in health care*, 1–18. Advance online publication. <https://doi.org/10.1080/07380577.2021.1975200>