

SESSION AGENDA Postural Care during Lying

- Share a little about ourselves and why we're here (all)
- Provide a brief overview of 24-hour postural care and postural care for rest and sleep (Jenny)
- Brainstorm who, what, when, where, why considerations (small groups)
- Describe resources that can be used for those wanting to develop intervention programs (Jenny)
- Explore existing resources in order to begin developing your own postural care program (small groups)

• Wrap up

OBJECTIVES

Postural Care during Lying

- · Consider who, what, when, where, why and how
- Recognize key service delivery steps (virtual and in-person)
- Know where and how to access freely available information
- Identify supports and barriers for initiating postural care intervention programs

WHY WE ARE HERE About Me

- Roles: Occupational Therapy teacher, Sleep care positioning educator/consultant, history of 20+ years providing seating and positioning for wheeled mobility services
- Settings: University, primarily outpatient clinics working primarily with children with cerebral palsy or other childhood onset disabilities, Twin cities
- Spent the last 7+ years learning about postural care for lying / nightlime postural care, collaborating with others to develop and share service delivery processes and resources
- Passion and purpose: Facilitate health-related changes especially as it relates to sleep

4

WHY WE ARE HERE

- About You
- Current role, setting?
- Interested in sleep and sleep-positioning, thinking about starting a postural care program, wanting to refine an existing program, other?
- · Passion and purpose?

5

24 HOUR POSTURAL CARE

Around the clock wholebody positioning meant to gently support person in lying, sitting and standing



POSTURAL CARE DURING SLEEP AND REST An intervention that/that's:

- · Intended for individuals with limited independent movement
- Incorporates sleep systems for whole-body positioning which is new to the U.S. and commonly practiced within the U.K.
- Aimed to promote health and decrease need for more invasive interventions by preventing or reducing body shape distortions which are associated with pain and correspondingly relate to disrupted sleep
- Involves a team approach and series of service delivery steps: training, referral, evaluation, trial, funding, ordering, fit and follow-up

(Public Health England, 2018)

7

CONSIDERATIONS: POSTURAL CARE SLEEP AND REST



GATHERING RESOURCES Service delivery models and other resources

- Tool kit for developing an intervention @
 <u>https://ctb.ku.edu/en/developing-intervention</u>
- · Sample service delivery process "sleep care positioning flow chart" (Hutson et al., 2022)
- (Hotor et al., 2022) 24-7 Posture Care Management (24-7 PCM) Bibliography with hyperlinks to relevant articles, videos and websites covering topics relevant to postural care for lying like: assessments, outcomes, service delivery, training, secondary complications common for those who are candidates for the intervention (Toole P. et al., 2021)

CREATING POSTURAL CARE INTERVENTION PROGRAM

Group Activity

Scenario: You are developing a postural care intervention program that involves sleep-positioning with a goal of increasing _____ Who should be involved? (identify target population and your wish list of team members)

- · What are the target population's goals?
- What do you need to learn? Identify 3 things you want to learn and three sources/resources from the shared bibliography that will help you gain that knowledge
- How will the intervention be delivered? From training to follow-up, consider who might be involved at each step and which aspects should/could be virtual and which in-person
- What challenges do you anticipate? Identify 1-2 hurdles or barriers you expect to encounter when developing the program
- How will you succeed? Identify key resources (people, \$, articles, videos, websites, etc.) that will make it possible for you to develop the program.

10

WRAP UP

REFERENCES

- Public Health England (May 8, 2018). Guidance Postural care and people with learning disabilities. Retrieved from <u>https://www.gov.uk/government/publications/postural-care-services-making-reasonable-adjustments/postural-care-and-people-with-learning-disabilities</u>
- Toole, P.; Hutson, J.A.; Hoffman, L.A.; and Reed, K. (2021). 24-7 Posture Care Management (24-7 PCM): What is the body of evidence? What questions remain? [pdf]

24-7 Posture Care Management (24-7 PCM): What is the body of evidence? What questions remain?

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The authors (Toole, P.; Hutson, J.A.; Hoffman, L.A.; and Reed, K.) created this reference list based on literature known to us from our own teaching and scholarly work. The list is the intellectual property of the authors and may be shared in whole for non-commercial educational purposes provided that this statement appears on the reproduced materials and the authors are cited. This reference list was produced in good faith and stands on the shoulders of those cited herein and we are grateful to each of them for their work.

The purpose of this resource is to gather in one place, and with publicly available full text links wherever possible, reference to the published body of evidence as related to 24-7 Posture Care Management, *specifically focusing on supported lying positions*, but also touching on appropriate assessments, outcome measures, supported standing, service delivery, and potential risks of failing to intervene. If you know of any additional works that should be included, please email <u>trishtooleot@gmail.com</u>. At the time of this publication, all links included are publicly available and accessed in June 2021.

ASSESSMENTS:

The following publications reference measures of sleep quality/disturbance, postural control, level of motor function, and movement during sleep. At the end of this document, links to full text versions of many of the assessments can be found.

Hutson, J., & Snow, L. (2020). Sleep assessments for children with severe Cerebral Palsy: A scoping review. Archives of Rehabilitation Research and Clinical Translation, 2(4), 1-8. https://www.sciencedirect.com/science/article/pii/S2590109520300756?via%3Dihub

Masek, M., Lam, C. P., Tranthim-Fryer, C., Jansen, B., & Baptist, K. (2018). Sleep monitor: A tool for monitoring and categorical scoring of lying position using 3D camera data, *SoftwareX*, 7, 341-346. <u>https://www.sciencedirect.com/science/article/pii/S2352711018301079</u>

Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. (1997). Development and reliability of a system to classify gross motor function in children with Cerebral

Toole., P., Hutson, J.A., Hoffman, L.A., & Reed, K. (2021). RESNA: buzz session. RESNA 2021 Page1 of 15 Palsy. *Developmental Medicine & Child Neurology, 39*, 214-223. <u>https://onlinelibrary.wiley.com/doi/epdf/10.1111/j.1469-8749.1997.tb07414.x</u>

Pountney, T. E., Green, E., Mulcahy, C., & Nelham, R. (1999). Chailey levels of ability. *Physiotherapy*, *85*(12), 693. https://www.sciencedirect.com/science/article/abs/pii/S0031940605612436

 Rodby-Bousquet, E., Ágústsson, A., Jónsdóttir, G., Czuba, T., Johansson, A. C., & Hägglund, G. (2012). Interrater reliability and construct validity of the posture and postural ability scale in adults with Cerebral Palsy in supine, prone, sitting and standing positions. *Clinical rehabilitation*, *28*(1), 82-90. https://journals.sagepub.com/doi/pdf/10.1177/0269215512465423

Rodby-Bousquet, E., Persson-Bunke, M., & Czuba, T. (2015). Psychometric evaluation of the posture and postural ability scale for children with Cerebral Palsy. *Clinical Rehabilitation*, 697-704. <u>https://journals.sagepub.com/doi/10.1177/0269215515593612</u>

Sato, H., Iwasaki, T., Yokoyama, M., & Inoue, T. (2014). Monitoring of body position and motion in children with severe cerebral palsy for 24 hours. *Disability and Rehabilitation*, 36(14), 1156-1160. <u>https://www.tandfonline.com/doi/abs/10.3109/09638288.2013.833308?journalCode=id</u>

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OUTCOMES:

These publications report on the measured outcomes associated with carrying out a program of supported night time positioning. It includes articles, pilot studies, original research and systematic reviews and scoping reviews.

Aburto, N., & Brown, S. (2015). Pilot research study into the effects of sleep systems on quality of sleep, pain, and joint range. *The Medifab Knowledge Base*. <u>https://www.medifab.co.nz/sites/default/files/Aburto%20and%20Brown%20Symmetrisl</u> <u>eep%20Case%20Study.pdf</u>

Blake, S.F., Logan, S., Humphreys, G., Matthews, J., Rogers, M., Thompson-Coon, J., & Morris, C. (2015). Sleep positioning systems for children with cerebral palsy. *Cochrane Database of Systematic Reviews*, 1-35. <u>https://www.semanticscholar.org/paper/Sleep-positioning-</u> <u>systems-for-children-with-palsy.-Blake-</u> Logan/eb5ccd2f750cbcf0784b070d927cc3f35e754a37

Crombie, S., Cowan, D., Morris, C., Porter, D., Underhill, J., & Humphreys, G. (2015). Exploring the challenges in conducting a randomised controlled trial (RCT) into night-time positioning for children with Cerebral Palsy. *Developmental Medicine and Child Neurology EACD Abstracts*, 57(4). <u>https://doiorg.pearl.stkate.edu/10.1111/dmcn.12778_15</u>

Dawson, N. C., Padoa, K. A., Bucks, R. S., Allen, P., Evans, H., McCaughey, E., & Hill, C. M. (2013). Ventilatory function in children with severe motor disorders using night-time postural equipment. *Developmental Medicine & Child Neurology*, *55*(8), 751-757. <u>https://onlinelibrary.wiley.com/doi/10.1111/dmcn.12149</u>

Toole., P., Hutson, J.A., Hoffman, L.A., & Reed, K. (2021). RESNA: buzz session. RESNA 2021 Page2 of 15

Farley, R., Clark, J., Davidson, C., Evans, G., MacLennan, K., Michael, S., & Thorpe, S. (2003). What
is the evidence for the effectiveness of postural management? International Journal of
Therapy & Rehabilitation, 10(10), 449-455.
https://www.magonlinelibrary.com/doi/abs/10.12968/bjtr.2003.10.10.13476

- Goldsmith, S. (2000). The Mansfield Project: Postural care at night within a community setting: A feedback study. *Physiotherapy*, *86*(10), 528-534. <u>https://www.sciencedirect.com/science/article/abs/pii/S003194060560987X</u>
- Hankinson, J. & Morton, R. (2002). Use of lying hip abduction system in children with bilateral cerebral palsy: A pilot study. *Developmental Medicine and Child Neurology, 44* (3), 177-180. <u>https://www.cambridge.org/core/journals/developmental-medicine-and-childneurology/article/abs/use-of-a-lying-hip-abduction-system-in-children-with-bilateralcerebral-palsy-a-pilot-study/21F16E30F8DE7AB7B242F93B0BB8D122</u>
- Haworth, L., Summer, S. C., Mercado-Palomino, E., Mbuli, A. M., Stockley, R. C., & Chohan, A. (2019). Postural management system for bedbound patients. *PRM+ Journal of Quantitative Research in Rehabilitation, 2*(2), 24-28. Postural management system for bedbound patients. http://clok.uclan.ac.uk/29585/1/Haworth%20et%20al.%202019%20Postural%20management%20of%20bed%20bound%20patients.pdf
- Hill, C. M., Parker, R. C., Allen, P., Paul, A., & Padoa, K. A. (2009). Sleep quality and respiratory function in children with severe cerebral palsy using night-time postural equipment: A pilot study. Acta Paediatrica, 98(11), 1809-1814. <u>https://www.thefreelibrary.com/Night-time+positioning+equipment%3a+A+review+of+practices.-a0514566291</u>
- Humphreys, G., King, T., Jex, J., Rogers, M., Blake, S., Thompson-Coon, J., & Morris, C. (2019).
 Sleep positioning systems for children and adults with a neurodisability: A systematic review *British Journal of Occupational Therapy*, *82*(1), 5–14.
 https://journals.sagepub.com/doi/pdf/10.1177/0308022618778254
- Kittelson-Aldred, T. (2017). Montana Postural Care Project: A 24-Hour Postural Care Model. *33rd International Seating Symposium*, 177-179. <u>https://www.researchgate.net/publication/324212248 The Montana Project A 24 H</u> <u>our Postural Care Model</u>

Kittelson-Aldred, T. (2019). Montana Postural Care Project: Pilot Program in a Frontier State. *35th International Seating Symposium.* March 20-22. 287-289.<u>https://ln4.sync.com/dl/d7e43dad0/4inra9pz-qqkpkzkr-9mv2xa9i-</u> <u>hi2czwig/view/default/11748989570008</u>

 Miller, S. D., Juricic, M., Hesketh, K., Mclean, L., Magnuson, S., Gasior, S., Schaeffer, E., O'Donnell, M & Mulpuri, K. (2017). Prevention of hip displacement in children with cerebral palsy: a systematic review. *Developmental medicine and child neurology*,59(11), 1130-1138. <u>https://onlinelibrary.wiley.com/doi/epdf/10.1111/dmcn.13480</u>

Mol, E. M., Monbaliu, E., Ven, M., Vergote, M., & Prinzie, P. (2012). The use of night orthoses in cerebral palsy treatment: Sleep disturbance in children and parental burden or not?

Toole., P., Hutson, J.A., Hoffman, L.A., & Reed, K. (2021). RESNA: buzz session. RESNA 2021 Page3 of 15 *Research in Developmental Disabilities, 33*(2), 341-349. <u>https://www.sciencedirect.com/science/article/abs/pii/S0891422211004136</u>

- Piccinini, P., Costi, S., Paoli, S. (2016). Sleep disorders in cerebral diseases in pediatric age: single case study and qualitative analysis about the use of night-time postural equipment. *Associazione Italiana Fisioterapisti Scienza riabilitativa*, Vol.18 (2), p.13. Note: Italian language abstract in English
- Pountney, T., Mandy, A., Green, E., & Gard, P. (2002). Management of hip dislocation with postural management. *Child: Care, Health and Development, 28*(2), 179-185. https://onlinelibrary.wiley.com/doi/abs/10.1046/j.1365-2214.2002.00254.x

 Pountney, T., Mandy, A., Green, E., & Gard, P. (2009). Hip subluxation and dislocation in Cerebral Palsy: A prospective study on the effectiveness of postural management programmes. *Physiotherapy Research International*, 14(2), 116-127. <u>https://research.brighton.ac.uk/en/publications/hip-subluxation-in-cerebral-palsya-prospective-study-on-the-effe
</u>

Reed, K. (2019). Outcomes of a therapeutic nighttime positioning (NTP) program: 24-Hour
 Postural Care. American Journal of Occupational Therapy,
 73(4 Supplement 1):7311505143. https://ajot.aota.org/article.aspx?articleid=2755031

Robertson, J., Baines, S., Emerson, E., & Hatton, C. (2016). Postural care for people with intellectual disabilities and severely impaired motor function: A scoping review. *Journal of Applied Research in Intellectual Disabilities*, 1-18. <u>https://eprints.lancs.ac.uk/id/eprint/83878/1/JARID Postural Care Accepted Version.p</u> <u>df</u>

Royden, H., Mithyantha, R., Clarke, S., Birch, J., & Bassi, Z. (2013). Impact of sleep systems (SS) on posture and quality of life (QOL) in children with neurological disabilities. *Archives of Disease in Children, 98,* A51-A52. doi:10.1136/archdischild-2013-304107.120 4. <u>https://www.semanticscholar.org/paper/G108%E2%80%85Impact-of-Sleep-Systems-(SS)-on-Posture-and-of-Royden-</u> <u>Mithyantha/7c73feaeb3a8cf8b99583abf0290abbdbe996a91</u>

Stephens, M., & Bartley, C. (2020). Use of night-time positioning equipment in care home residents with postural asymmetry: A pilot study. *Nurs Older People*, *32*(3). 17-24. <u>http://usir.salford.ac.uk/id/eprint/56806/1/RCN%20older%20person%20manuscript%20</u> <u>%281%29%20%281%29.pdf</u>

Stephens, M., Bartley, C.A., & Priestley, C. (2018) Evaluation of night time therapeutic positioning system for adults with complex postural problems. *Semantic Scholar*. University of Salford. http://usir.salford.ac.uk/id/eprint/48470/1/Simple%20Stuff%20Works%20Final%20Repo

rt%20Sept%202018%20amended%20version%20for%20SSW%20%28002%29.pdf

Stinson, M., Crawford, S., & Madden, E. (2021). Current clinical practice in 24-hour postural management and the impact on carers and service users with severe neurodisability. *British Journal of Occupational Therapy, 84*(6), 355–365. <u>https://journals.sagepub.com/doi/pdf/10.1177/0308022620944739</u>

Toole., P., Hutson, J.A., Hoffman, L.A., & Reed, K. (2021). RESNA: buzz session. RESNA 2021 Page4 of 15 Underhill, J., Bryant, E., & Pountney, T. (2012). The effect of sleep systems on sleep-wake patterns and pain levels in non-ambulant children and young people with cerebral palsy. *Journal of the Association of Paediatric Chartered Physiotherapists*, *3*(1), 57-64. <u>https://journals.sagepub.com/doi/abs/10.1177/02692155211009484</u>

Wynn, N., & Wickham, J. (2009). Night-time positioning for children with postural needs: What is the evidence to inform best practice? *British Journal of Occupational Therapy*, 72(12), 543-550. <u>https://doi.org/10.4276/030802209x12601857794817</u>

SERVICE DELIVERY:

Publications listed in this section report on service delivery to consumers, care pathway, and "how to" information.

- Agústsson, A., & Jónsdóttir, G. (2018). Posture management 24/7. In M.L. Lange & J.L. Minkel (Eds.), *Seating and wheeled mobility: A clinical resource guide* (pp. 121-136). Thorofare, NJ: SLACK Incorporated. <u>http://ebooks.healio.com/product/seating-wheeled-mobility</u>
- Casey, J., Hoffman, L. A., Hutson, J., & Kittelson-Aldred, T. (2019). Supporting the occupation of sleep through night time positioning equipment. SIS Quarterly Practice Connections, 4(2), 7–9.
- Collins, F. (2007). The JCM Moonlite sleep system: Assisting in the provision of 24-hour postural support. *International Journal of Therapy and Rehabilitation, 14*(7), 324-328. <u>https://www.magonlinelibrary.com/doi/abs/10.12968/ijtr.2007.14.7.23856</u>
- Crawford, S., & Stinson, M. (2015). Management of 24-h-body positioning. In I. Söderback. (Ed.), International Handbook of Occupational Therapy Interventions (pp.189-203). Springer International. <u>https://link.springer.com/chapter/10.1007%2F978-3-319-08141-0_14</u>

Gericke, T. (2006). Postural management for children with cerebral palsy: Consensus statement. *Developmental Medicine & Child Neurology, 48,* 244. <u>https://www.cambridge.org/core/journals/developmental-medicine-and-child-</u> <u>neurology/article/postural-management-for-children-with-cerebral-palsy-consensus-</u> <u>statement/AE89240FCAF0B5DA4431F54C316E1A9D</u>

- Hill, S., & Goldsmith, J. (2010). Biomechanics and prevention of body shape distortion. *Tizard Learning Disability Review*, 15(2), 15-32. <u>https://www.nhsggc.org.uk/media/250664/tizard-fulltext.pdf</u>
- Hoffman, L.A. (2017). 24hr posture care management: Sleep positioning and sleep positioning systems. *Directions, 5,* 26-37. https://cdn.coverstand.com/3586/446874/009c9d21f19fbfc3f37f3920f2efe18181367cfa .pdf

Humphreys, G., Mandy, A., & Pountney, T. (2012). Posture and sleep in children with cerebral palsy: A case study. *Journal of the Association of Paediatric Chartered Physiotherapists, 3*(1), 48-56.

https://www.researchgate.net/publication/275349647 Posture and Sleep in Children with Cerebral Palsy A Case Study

Humphreys, G., & Pountney, T. (2006). The development and implementation of an integrated care pathway for 24-hour postural management: A study of the views of staff and carers. *Physiotherapy*, *92*, 233-239.
 <u>https://www.researchgate.net/publication/223555103</u> The development and implem entation of an integrated care pathway for 24-hour postural management a study of the views of staff and carers

Toole., P., Hutson, J.A., Hoffman, L.A., & Reed, K. (2021). RESNA: buzz session. RESNA 2021 Page6 of 15 Innocente, R. (2014). Night-time positioning equipment: A review of practices. *New Zealand Journal of Occupational Therapy, 61*(1), 13-19. <u>https://www.thefreelibrary.com/Night-time+positioning+equipment%3a+A+review+of+practices.-a0514566291</u>

Kittelson-Aldred, T., & Hoffman, L. A. (2017). 24-hour posture care management: Supporting people night and day. *Rehab Management*. <u>http://www.rehabpub.com/2017/09/24-hour-posture-care-management-supporting-people-night-day/</u>

Kittelson-Aldred, T., & Wakefield, T.S. (2019).Multi-Joint Muscle Action on the Pelvis. *Rehab Management*. <u>https://rehabpub.com/conditions/pressur-injury/multi-joint-muscle-action-on-the-pelvis/</u>

Kittleson-Aldred, T. (2017). Clients with low muscle tone: Etiology, issues, and wheelchair seating challenges. *Directions*, 6, 26-34. https://mydigitalpublication.com/publication/?m=3586&i=459099&p=34&ver=html5

Kittleson-Aldred, T. (2019). 24-7 Posture Care Management: Making a difference for all ages. *Directions*, 6, 36-38.

https://www.bluetoad.com/publication/?m=3586&i=639330&p=36&pre=1&ver=html5

Lange, M. (2017). Tissue Biomechanics. *Directions, 5,* 22. <u>https://mydigitalpublication.com/publication/?m=3586&i=446874&p=24&ver=html5</u>

Lange, M. (2017). Joshua: A Sleep Positioning Journey. *Directions* v.5 39-41. <u>https://mydigitalpublication.com/publication/?m=3586&i=446874&p=24&ver=html5</u>

Pope P.M. (1985). Physical management in long term disability. Published by the Royal Hospital and home for Incurables. London. Booklet 1/85.

Pope, P. M. (2007). Night-time postural support for people with multiple sclerosis. Way Ahead 11(4):6-8 Pountney, T. E., Green, E., Mulcahy, C., & Nelham, R. (1999). Chailey

Posture 24/7. (n.d.). What is 24 hour postural care? <u>https://posture24-7.org/about-</u> us/#:~:text=Posture%2024%2F7%20focuses%20on%20raising%20awareness%20of%202 <u>4,neuromuscular%20impairments%20affecting%20their%20motor%20control%20and%2</u> <u>0posture</u>

Toole, P. (2019). Posture Care Management: From better sleep to better sitting. *Directions.v6.* 28-35.

https://www.bluetoad.com/publication/?m=3586&i=639330&p=28&pre=1&ver=html5

Waugh, A., & Hill, S. (2009). Body shape distortion: Promoting postural care at night. *Learning Disability Practice*, 12(7), 25-29. <u>http://journals.rcni.com/journal/ldp</u>

STANDING:

Supported standing is used in a comprehensive 24-7 PCM approach that encompasses supported sitting, standing, and laying during activity and resting periods. While there are many more studies available and an excellent RESNA position paper on this topic, several useful publications are referenced here.

Dalen, Y., Saaf, M., Rignertz, H., Kelfbeck, B., Mattsson, E. & Haglund-Ackerlind, Y. (2010). Effects of standing on bone density and hip dislocation in children with severe cerebral palsy. *Advances in Physiotherapy*, *12*, 187-193.
 https://pubmed.ncbi.nlm.nih.gov/31370944/

Goodwin, J., Lecouturier, J., Crombie, S., Smith, J., Basu, A., Colver, A., Kolehmainen, N., Parr, J.
 R., Howel, D., McColl. E., Roberts, A., Miller, K., & Cadwgan, J. (2017). Understanding frames: A qualitative study of young people's experiences of using standing frames as part of postural management for Cerebral Palsy. *Child Care Health Development, 44*, 203-211. <u>https://onlinelibrary.wiley.com/doi/pdf/10.1111/cch.12540</u>

Martinsson, C., & Himmelmann, K. (2011). Effect of weight-bearing in abduction and extension on hip stability in children with Cerebral Palsy. *Pediatric Journal of Physical Therapy*, 23, 150-157. <u>https://pubmed.ncbi.nlm.nih.gov/21552077/</u>

Paleg, G. S., Smith, B. A., & Glickman, L.B. (2013). Systematic review and evidence-based clinical recommendations for dosing of pediatric supported standing programs. *Pediatric Physical Therapy*, 232-247. <u>https://pubmed.ncbi.nlm.nih.gov/23797394/</u>

TRAINING:

Family members, caregivers and other direct supporters are the primary providers of daily positioning, and repositioning support. Their needs for training are an essential consideration to the success of this approach and have been explored in a number of useful publications listed below.

Bacon, H. (2013). Does a postural management training programme improve understanding of the importance of postural management for children with complex movement disorders? *Associated Paediatric Chartered Physiotherapists, 4*(1), 27-36. <u>https://apcp.csp.org.uk/journal/apcp-journal-volume-4-number-1</u>

Castle, D., Stubbs, B., Clayton, S., & Soundy, A. (2014). A 24-hour postural care service: Views, understanding and training needs of referring multidisciplinary staff. *International Journal of Therapy and Rehabilitation*, *21*(3), 132-139. <u>https://www.magonlinelibrary.com/doi/abs/10.12968/ijtr.2014.21.3.132?journalCode=ijtr</u>

Toole., P., Hutson, J.A., Hoffman, L.A., & Reed, K. (2021). RESNA: buzz session. RESNA 2021 Page8 of 15

- Gough, M. (2009). Continuous postural management and the prevention of deformity in children with cerebral palsy: An appraisal. *Developmental Medicine and Child Neurology*, 51(2), 105-110. <u>https://pubmed.ncbi.nlm.nih.gov/19191843/</u>
- Hill, S. (2011). A one year postural care training programme for the workforce supporting the needs of those with complex and continuing healthcare needs: Project evaluation. *Postural Care CIC*, 1-59.
- Hutson, J. A., Hodges, J.S., & Snow, L. (2021). Educating caregivers of persons with cerebral palsy in night-time postural care: A randomized trial comparing two online training programs. *Clinical Rehabilitation*. <u>https://pubmed.ncbi.nlm.nih.gov/33858230/</u>

Hutson, J. A. (2020). *Nighttime postural care sleep-based outcome measures and education: Preparing care providers of children with Cerebral Palsy*. University of Minnesota Digital Conservancy. <u>https://conservancy.umn.edu/handle/11299/213112</u>

Novak, I., & Honan, I. (2019). Effectiveness of paediatric occupational therapy for children with disabilities: a systematic review. *Australian Occupational Therapy Journal*, 66, 258-73. https://pubmed.ncbi.nlm.nih.gov/30968419/

SECONDARY COMPLICATIONS:

Failing to provide appropriate intervention in time for persons with mobility limitations carries risk of secondary complications such as hip dislocation, scoliosis, reduced chest capacity, reduced lung capacity, pain, disturbed sleep, complex body shapes, and reduced sitting tolerance. These complications arise following the development of body shape distortion rather than from the primary condition which caused the impairment in mobility.

 Ágústsson, A., Sveinsson, T., Pope, P., & Rodby-Bousquet, E. (2019). Preferred posture in lying and its association with scoliosis and windswept hips in adults with cerebral palsy. *Disability and Rehabilitation*, 41(26), 3198-3202.
 https://pubmed.ncbi.nlm.nih.gov/30010440/

Cary, D., Collinson, R., Sterling, M., & Briffa, N.K. (2016). Examining the relationship between sleep posture and morning spinal symptoms in the habitual environment using infrared cameras. *Journal of Sleep Disorders*: Treat Care, 5(2), <u>https://www.scitechnol.com/peer-review/examining-the-relationship-between-sleepposture-and-morning-spinal-symptoms-in-the-habitual-environment-using-infraredcameras-pUfm.php?article_id=4826</u>

Casey, J., Rosenblad, A., & Rodby-Bousquet, E. (2020). Postural asymmetries, pain, and ability to change position of children with cerebral palsy in sitting and supine: A cross-sectional study. *Disability and Rehabilitation, 3, 1-9*. <u>https://pubmed.ncbi.nlm.nih.gov/33142069/</u>

Fulford, G.E., & Brown, J.K. (1976). Position as a Cause of Deformity. *Children Developmental Medicine and Child Neurology*, 18(3), 305-314. <u>https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1469-8749.1976.tb03652.x</u>

Toole., P., Hutson, J.A., Hoffman, L.A., & Reed, K. (2021). RESNA: buzz session. RESNA 2021 Page9 of 15

 Hilberink, S.R., Roebroeck, M.E., Nieuwstraten, W., Jalink, L., Verheijden, J., & Stam, H.J. (2007). Health issues in young adults with cerebral palsy: Towards a life-span perspective. <i>Journal of Rehabilitation Medicine, 39</i>(8), 605- 611. <u>https://www.medicaljournals.se/jrm/content/abstract/10.2340/16501977-0103</u>
 Holmes, L., Karatas, A., Kirk, D., Connor, J., Rogers, K., & Miller, F. (2012). 1817 discovered dead during sleep in causal pathway of mortality among children with cerebral palsy: Case series and systematic review. Archives of Disease in Children, 97 (Suppl. 2), A514. https://adc.bmj.com/content/97/Suppl_2/A514.3
Hosking, J. (2017). A pilot study comparing custom contoured and planar support surfaces for pressure ulcer risk over the heels for night time postural management using interface pressure mapping and discomfort scores. <i>Journal of Tissue Viability, 26</i> (3), 189-195. <u>https://www.sciencedirect.com/science/article/abs/pii/S0965206X17300669</u>
Jeffries, L., Fiss, A., Westcott McCoy, S., & Bartlett, D. (2016). Description of primary and secondary impairments in young children with Cerebral Palsy. <i>Pediatric Physical Therapy, 28</i> (1), 1-8. <u>https://pubmed.ncbi.nlm.nih.gov/27088676/</u>
Lyons, E.A., Jones, D.E., Swallow, V.M., & Chandler, C. (2017). An exploration of comfort and discomfort amongst children and young people with intellectual disabilities who depend on postural management equipment. <i>Journal of Applied Research in intellectual Disabilities, 30</i> (4), 727-742. <u>https://doi.org/10.1111/jar.12267</u>
Porter, D., Michael, S., & Kirkwood, C. (2007). Patterns of postural deformity in non-ambulant people with cerebral palsy: what is the relationship between the direction of scoliosis, direction of pelvic obliquity, direction of windswept hip deformity and side of hip dislocation? <i>Clinical Rehabilitation</i> , 21(12), 1087-1096. <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2630002</u>
 Porter, D., Michael, S., & Kirkwood, C. (2008). Is there a relationship between preferred posture and positioning in early life and the direction of subsequent asymmetrical postural deformity in non ambulant people with cerebral palsy? <i>Child: Care, Health and Development</i>, <i>35</i>(5), 635-641. <u>https://www.academia.edu/10684814/Is there a relationship between preferred posture and positioning in early life and the direction of subsequent asymmetrical posture and positioning in early life and the direction of subsequent asymmetrical posture deformity in non ambulant people with cerebral palsy</u>
Rodby-Bousquet, E., Czuba, T., Hägglund, G., & Westbom, L. (2013). Postural asymmetries in young adults with cerebral palsy. <i>Developmental Medicine & Child Neurology,</i> 55(11),1009-1015. <u>https://pubmed.ncbi.nlm.nih.gov/23834239/</u>
Sato, H. (2020). Postural deformity in children with cerebral palsy: Why it occurs and how is it managed. <i>Physical Therapy Research, 23</i> (1), 8-14. https://pubmed.ncbi.nlm.nih.gov/32850273/
Sprigle, S., & Sonenblum, S. (2011). Assessing evidence supporting redistribution of pressure for pressure ulcer prevention: A review. <i>Journal of Rehabilitation Research & Development</i> , 48(3), 203-214. <u>https://pubmed.ncbi.nlm.nih.gov/21480095/</u>

Toole., P., Hutson, J.A., Hoffman, L.A., & Reed, K. (2021). RESNA: buzz session. RESNA 2021 Page10 of 15

Toole., P., Hutson, J.A., Hoffman, L.A., & Reed, K. (2021). RESNA: buzz session. RESNA 2021 Page11 of 15

SLEEP:

Sleep is essential for health. Studies have explored the importance of sleep on daytime functioning, mental and physical health. This is important to consider especially with an intervention that is carried out during rest and sleeping hours, and which must respect this important and culturally influenced occupation.

Almklov, E. L., Drummond, S.P.A., Orff, H., & Alhassoon, O.M. (2015). The effects of sleep deprivation on brain functioning in older adults. *Behavioral Sleep Medicine*, 13(4), 324-345. doi: 10.1080/15402002.2014.905474. <u>https://pubmed.ncbi.nlm.nih.gov/24787041/</u>

American Occupational Therapy Association. (2017). *Occupational therapy's role in sleep.* <u>https://www.aota.org/AboutOccupational-Therapy/Professionals/HW/Sleep.aspx</u>

Cerebral Palsy Alliance (2018). *Sleep difficulties*. <u>https://www.cerebralpalsy.org.au/services/resources/sleep-difficulties-children-with-cp/</u>

Chen, J-H., Lauderdale, D., & Waite, L. (2016). Social participation and older adults' sleep. *Social Science Medicine*, *149*, 164-173. <u>https://pubmed.ncbi.nlm.nih.gov/26724432/</u>

Dutt, R., Roduta-Roberts, M., & Brown, C. A. (2015). Sleep and children with cerebral palsy: A review of current evidence and environmental non-pharmacological interventions. *Children, 2*(1), 78–88. <u>https://doaj.org/article/427a0fc3eb684b12b7ac2056aa6783af</u>

Galland, B. C., Elder, D. E., & Taylor, B. J. (2012). Interventions with a sleep outcome for children with cerebral palsy or a post-traumatic brain injury: A systematic review. *Sleep Medicine Reviews*, *16*(6), 561-573. <u>https://www.ncbi.nlm.nih.gov/books/NBK117051/</u>

Ghorbanpour, Z., Hosseini, S.A., Akbarfahimi, N., Rahgozar, M. (2019). Correlation between sleep disorders and function in children with spastic Cerebral Palsy. *Iranian Journal of Child Neurology*, 13(3), 35-44. <u>https://pubmed.ncbi.nlm.nih.gov/31327967/</u>

Gould, C. E., Beaudreau, S. A., O'Hara, R., & Edelstein, B. A. (2016). Perceived anxiety control is associated with sleep disturbances in young and older adults. *Aging and Mental Health*, 20(8), 856-860. <u>https://pubmed.ncbi.nlm.nih.gov/26023761/</u>

Leland, N. E., Marcione, N., Schepens-Niemiec, S. L., Kelkar , K., & Fogelberg, D. (2014). What is occupational therapy's role in addressing sleep problems among older adults? *Occupational Therapy Journal of Research*, *34*(3), 141-149. <u>https://pubmed.ncbi.nlm.nih.gov/24844879/</u>

Lélis, A. L., Cardoso, M. V., & Hall, W. A. (2016). Sleep disorders in children with cerebral palsy: An integrative review. Sleep medicine reviews, 30, 63–71. <u>https://pubmed.ncbi.nlm.nih.gov/26874066/</u>

Malinowska, K. B., Okura, M., Ogita, M., Yamamoto, M., Nakai, T., Numata, T., Tsuboyama, T., & Arai, H. (2015). Effect of self-reported quality of sleep on mobility in older adults. *Geriatrics and Gerontology International, 16*(2), 266-271.

Toole., P., Hutson, J.A., Hoffman, L.A., & Reed, K. (2021). RESNA: buzz session. RESNA 2021 Page12 of 15 https://www.deepdyve.com/lp/wiley/effect-of-self-reported-quality-of-sleep-onmobility-in-older-adults-tQdHSMHh72

- Miyata, S., Noda, A., Iwamoto, K., Kawano, N., Okuda, M., & Ozaki, N. (2013). Poor sleep quality impairs cognitive performance in older adults. *Journal of Sleep Research*, *22*(5), 535-541. <u>https://pubmed.ncbi.nlm.nih.gov/23560612/</u>
- Newman, C.J., O' Regan, M. & Hensey, O. (2006). Sleep disorders in children with cerebral palsy. *Developmental Medicine & Child Neurology, 48*(7), 564–568. <u>https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1469-</u> <u>8749.2006.tb01316.x#references-section</u>
- Simard-Tremblay, E., Constantin, E., Gruber, R., Brouillette, R. T., & Shevell, M. (2011). Sleep in children with cerebral palsy. *Journal of Child Neurology*, *26*(10), 1303–1310. <u>https://pubmed.ncbi.nlm.nih.gov/21670393/</u>

Smagula, S. F., Stone, K. L., Fabio, A., & Cauley, J.A. (2016). Risk factors for sleep disturbances in older adults: Evidence from prospective studies. *Sleep Medicine Review*, 25, 21-30. <u>https://pubmed.ncbi.nlm.nih.gov/26140867/</u>

Underhill, (2018). Understanding sleep among children with Cerebral Palsy, their siblings, and parents: A qualitative multi-perspectives study of the social context of family sleep. University of Surrey. <u>https://ethos.bl.uk/OrderDetails.do?uin=uk.bl.ethos.736931</u>

Woodward, M. (2012). Sleep in older people. *Reviews in Clinical Gerontology*, 22(2), 130-149. <u>https://www.cambridge.org/core/journals/reviews-in-clinical-gerontology/article/sleep-in-older-people/D31F1681A4C4CC079CE4AFEAB2B3A7DE</u>

Additional Resources:

ASSESSMENTS:

Body Symmetry & Posture

Goldsmith Observations: <u>https://www.simplestuffworks.com/wp-content/uploads/2016/10/GIoBS-Obs-</u> <u>Result-Sheet-March-2015.pdf</u>

Posture and Postural Ability Scale: <u>http://primeengineering.com/wp-content/uploads/2017/08/PPAS-</u> Posture-and-Postural-Ability-Scale.pdf

Gross Motor Functional Classification System: <u>https://canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r</u>

Critical Chest Measurements

Range of Motion (ROM)

Tone

► Sleep

Pittsburgh Sleep Quality Index:

http://uacc.arizona.edu/sites/default/files/psqi_sleep_questionnaire_1_pg.pdf

Sleep Disturbance Scale for Children

► Pain

Pediatric Pain Profile: <u>http://www.ppprofile.org.uk/</u>

Non-communicating Children's Pain Checklist-Revised (NCCPC-R) <u>http://www.community-networks.ca/wp-content/uploads/2015/07/PainChklst_BreauNCCPC-R2004.pdf</u>

Quality of Life

Caregiver Priorities & Child Health Index of Life with Disabilities (CPCHILD)

Oxygen Saturation & Breathing

Toole., P., Hutson, J.A., Hoffman, L.A., & Reed, K. (2021). RESNA: buzz session. RESNA 2021 Page14 of 15

WEBSITES:

Posture 24-7, <u>https://posture24-7.org/resources/</u> Montana Postural Care Project (DDA Grant, scroll down for article): <u>https://posture24-7.org/blog/</u> Good source to find upcoming 24-7 PCM live trainings.

RESNA: https://www.resna.org/about/leadership/committees/special-interest-groups-sigs

Born at the Right time (family perspective): <u>http://www.bornattherighttime.com/</u>

Simple Stuff Works: https://www.simplestuffworks.com/

Summary of References for Positioning for Children GMFCS Levels IV-V: Focus on Hip Health http://www.childdevelopment.ca/GMFCSHipHealth/GMFCSHipHealthEvidence.aspx http://www.childdevelopment.ca/GMFCSHipHealth/GMFCSHipHealthEvidence.aspx

VIDEOS:

Why try Postural Care?: https://www.facebook.com/kelli.baker3/videos/10153266906561895/

A simple Story (parent perspective): <u>https://youtu.be/CeWMltvzgOg</u>

John's Poem (adult postural care client perspective): https://youtu.be/Q-GO0fuS6MY

Video of setting up the bed: <u>https://youtu.be/MP13O94eNgk</u>

Never too old (postural care for adults) https://youtu.be/1V0ODuPkrTs

Hammie a simplified anatomical model for teaching support: <u>https://www.meethammie.com/?fbclid=IwAR0LR1ADIp4Aho14sb1RuziwXUDkXIxPgqH3FWb8T4XLQHuPpXyP0mFngcQ</u>

Nighttime Postural Care Training https://stkatentpc.weebly.com/

Prevalence of disability worldwide:

World Health Organization (2016a). Disability and Health. Retrieved from http://www.who.int/mediacentre/factsheets/fs352/en/

Some search terms 5/27/2021 (JAH)

- hip subluxation lying interventions
- Outcomes Nighttime Positioning
- Night-time Positioning
- Use of Night Time Postural Management Equipment