

## Pain Prevalence

People with conditions which include increased muscle tone and/or spasticity are likely to experience pain in their wheelchair seating system. Frank and De Souza (2017) conducted a study which looked at individuals with cerebral palsy (GMFCS levels IV and V) who use power wheelchairs. Of the 102 participants, 20 reported problematic pain (20%) caused by spasticity, spinal curvatures, back pain, hip pain and/or spasticity. The pain was significant; 18 of the 20 participants required medical management (90%). These same researchers in 2012 interviewed 64 power wheelchair users and found that pain is frequently experienced by this group and may be severe. They concluded that clinicians need to distinguish between wheelchair-related pain and pain due to an underlying health condition. Finally, the researchers noted that improved power wheelchair design and additional features should reduce this pain and suffering, but at a financial cost. This study also showed that pain was better managed in children than in adults.

**Research shows that up to 54% of people with cerebral palsy experience pain.**

A study of 252 participants, aged 3 to 19 years, across all levels of severity of cerebral palsy found that 54.8% of participants reported some pain (Penner, et al., 2013). Further, 24.4% of caregivers reported participant pain that affected level of activity, and 38.7% of physicians reported participant pain.

Novak, et al. (2012) performed a systematic review with meta-analysis of 30 studies on cerebral palsy and found that 3 out of 4 children with cerebral palsy were in pain. Another group of researchers (Kembhavi, et al., 2011) reviewed 12 studies on pain in adults with cerebral palsy and found the three most common themes were 1) prevalence of pain, 2) the effect of pain on functional activities, and 3) coping or intervention strategies for pain.

## Pain Etiology

**Pain may be caused by lack of movement or be related to the wheelchair itself.**

Lyons (2017) states that discomfort increases over the time an individual is unable to change their position in the wheelchair. Frank and De Souza (2017), as mentioned above, found that pain in individuals with cerebral palsy using power wheelchairs was caused by spasticity, spinal curvatures, back pain, hip pain and/or spasticity. Penner, et al. (2013) stated that physicians identified hip dislocation/subluxation, dystonia and constipation as the most frequent causes of pain in wheelchair users in their study. Over half of the participants in the Frank and De Souza 2012 study reportedly believed that their pain was related to the wheelchair itself.

## Pain Interventions

Typically, we respond to discomfort in sitting by changing our position. If a wheelchair user is unable to change their position, discomfort increases over time (Lyons, 2017). Many wheelchair users must rely on caregivers to note and intervene to alleviate their pain, particularly if the user is non-verbal and/or has intellectual disabilities (Lyons, 2017). Frank and De Souza (2012) indicate that changing position relieves discomfort. Dicianno, et al. (2015) reported that use of the tilt feature on wheelchairs can reduce pain. Use of appropriate seating interventions, as well as competent seating assessment, may also reduce pain (Frank and De Souza, 2012).

**Movement and changing position can both reduce pain.**

## Conclusions

Research has demonstrated a strong prevalence of pain among wheelchair users, up to 75% in one study (Novak, et al., 2012). Most of the studies focused on wheelchair users who have cerebral palsy, though pain may occur in anyone who is unable to change their position (Lyons, 2017). Much of the research related to pain in people with spinal cord injuries reports shoulder and other upper extremity pain related to self-propulsion, rather than pain related to the wheelchair itself.

These studies found that the following factors may contribute to pain: spasticity, spinal curvatures, back pain, hip pain and/or spasticity (Frank and De Souza, 2017), hip dislocation/subluxation, dystonia and constipation (Penner, et al., 2013). Pain, or the relief of pain, was also linked to the wheelchair seating and mobility equipment (Frank and De Souza, 2012).

Pain research has not focused on pain interventions for wheelchair users, though a shift has occurred from seeing pain as related to a medical condition only to pain also being related to the wheelchair (Frank and De Souza, 2012; Kembhavi, et al., 2011). Several studies concurred that movement and/or a change in position can alleviate pain (Lyons, 2017; Frank and De Souza, 2012). Studies that specifically addressed other pain interventions are now dated and did not specifically focus on wheelchair interventions.

**Movement can be provided through other technologies, including Dynamic Seating.**

Pain is common in wheelchair users. Wheelchair seating strategies to reduce that pain certainly include maintaining an optimal body position, pressure distribution (using appropriate contours and materials), and pressure relief (providing a change of position). Another important factor which can alleviate pain is movement. For wheelchair users unable to move within their wheelchair seating system (perhaps due to inability or required postural supports), movement can be provided through other technologies, including dynamic seating. Dynamic seating is movement which occurs within the seat and/or wheelchair frame in response to force from the user. Dynamic components absorb force which, in turn, assists the user back to a starting position. Movement can be provided at the hips, knees and head.

Movement also can reduce spasticity in some clients (Phadke, et al., 2015). Spasticity was identified as a source of pain in wheelchair users (Frank and De Souza, 2017; Penner, et al., 2013).

**A critical goal of wheelchair seating and mobility evaluation is to alleviate user pain.**

## Literature Review

The following is a review of the literature, specifically to review studies of pain experienced by people using wheelchairs.

1. Elizabeth A. Lyons, Diana E. Jones, Veronica M. Swallow, Colin Chandler. (2017) An Exploration of Comfort and Discomfort Amongst Children and Young People with Intellectual Disabilities Who Depend on Postural Management Equipment. *Journal of Applied Research in Intellectual Disabilities* 30:4, pages 727-742.

“Positioning discomfort first presents itself as an unconscious desire to change body posture, which diminishes when the individual is able to initiate a change of posture. The discomfort increases across time and may be associated with one or more factors such as instability, sliding, excessive heat buildup, stiffness, excessive localized soreness or pain, spasticity, or stretch.”

**Study:** 13 children with physical and intellectual disabilities, non-verbal using adaptive seating. Subjective.

**Results:** These children rely on caregivers to note and intervene to relieve their discomfort.

**Possible Application:** *Positioning discomfort diminishes when the wheelchair user can change their position. Dynamic Seating provides a change in position in response to force and therefore may reduce pain.*

2. **Andrew O. Frank & Lorraine H. De Souza (2017) Problematic clinical features of children and adults with cerebral palsy who use electric powered indoor/outdoor wheelchairs: A cross-sectional study, Assistive Technology, 29:2, 68-75.**

DOI: 10.1080/10400435.2016.1201873

**Study:**

First study to describe a cohort of individuals with CP GMFCS levels IV and V, prescribed a PWC.

CP is now considered a lifespan condition with associated health factors, e.g., musculoskeletal impairments, medical complications, speech impairments, pain, and fatigue (Kembhavi et al., 2011). It is unclear if these are part of the natural course of CP, a consequence of long-term disability, or unrelated comorbidity.

Clinical features such as spasticity and problematic pain appeared less well managed in adults than in children.

**Results:**

**Of 102 participants, 20 reported problematic pain (over half of those had spastic CP).**

“We found nine features of CP, of which eight were reported by Novak et al., the most frequent being problematic pain (n = 20), hip problems (n = 18), and **problematic spasticity (n = 15)** (Table 3). Specified causes of **problematic pain were spasticity (n = 7), (kypho)scoliosis (n = 6), back pain (n = 5), hip pain (n = 2), back pain, and spasticity (n = 2), no specified cause (n = 4), or more than one of the above. Nine users reported back pain thought to be treatable with standard approaches.**”

**18 required medical management for problematic pain.**

**Possible Application:** *People with spastic cerebral palsy who use power wheelchairs are prone to problematic pain. Providing movement may help to reduce this pain.*

3. **Frank, A. O., De Souza, L. H., Frank, J. L., & Neophytou, C. (2012). The pain experiences of powered wheelchair users. Disability and rehabilitation, 34(9), 770-778.**

**Purpose:** To explore the experience of pain and discomfort in users of electric-powered indoor/outdoor wheelchairs (EPIOCs) provided by a National Health Service.

**Study:** EPIOC users receiving their chair between February and November 2002 (N = 74) were invited to participate in a telephone questionnaire/interview and 64 (aged 10–81 years) agreed. **Both specific and open-ended questions examined the presence of pain/discomfort, its severity, minimizing and aggravating factors, particularly in relation to the EPIOC and its use. Results: Most EPIOC users described experiences of pain with 17% reporting severe pain. Over half felt their pain was influenced by the wheelchair and few (25%) considered their chair eased their symptoms.** The most common strategy for pain relief was taking medication. Other self-help strategies included **changing position**, exercise and complementary therapies. Respondents emphasized the provision of backrests, armrests, footrests and cushions which might alleviate or exacerbate pain, highlighting the importance of appropriate assessment for this high dependency group.

**Results:** Users related pain to their underlying medical condition, their wheelchair or a combination of the two. User feedback is essential to ensure that the EPIOC meets health needs with minimal pain. This becomes more important as the health condition of users changes over time.

**Implications for Rehabilitation:**

Pain is frequently experienced by users of powered wheelchairs and may be severe.

Clinicians need to distinguish between wheelchair-related pain and pain due to an underlying health condition.

Improved design and additional features to powered wheelchairs should reduce this pain and suffering but at a financial cost.

***Possible Applications:** Most power wheelchair users experienced pain and over half believed this pain was related to the wheelchair itself. One strategy that improved pain was changing position.*

4. Novak, I., Hines, M., Goldsmith, S., & Barclay, R. (2012). Clinical prognostic messages from a systematic review on cerebral palsy. *Pediatrics*, 130(5), e1285–e1312.

doi:10.1542/peds.2012-0924

**Study:** Systematic review with meta-analysis of 30 studies on CP, included users with pain requiring further investigation or management.

**Results:** Among children with cerebral palsy, 3 in 4 were in pain.

***Possible Applications:** Pain needs to be addressed during wheelchair seating interventions.*

5. Kembhavi, G., Darrah, J., Payne, K., & Plesuk, D. (2011). Adults with a diagnosis of cerebral palsy: A mapping review of long-term outcomes. *Developmental Medicine and Child Neurology*, 53(7), 610–614.

doi:10.1111/j.1469-8749.2011.03914.x

<https://onlinelibrary.wiley.com/doi/full/10.1111/j.1469-8749.2011.03914.x>

“The first article to discuss pain in adults with CP was published in 1999.(23) Since then, the number of articles with a focus on pain has increased. Between 2000 and 2010, 11 studies examined pain as an

outcome in adults with CP.(7-9, 17-19, 22, 26, 30-32) Of the 12 studies published since 1999, however, seven have been based on data derived from two study samples (see Table SI).(18, 23) Engel et al.. have published six of the 12 studies about pain since 1999.(7-9, 22, 23, 31) The three most common themes related to pain in the research literature are the prevalence of pain in adults with CP,(7-9, 17-19, 22, 23, 26, 30-32) the effect of pain on functional activities,(7, 9, 23, 31) and coping or intervention strategies for pain.(7-9, 22, 31) These themes mark a shift away from an impairment-based focus on pain to examining pain from the perspective of Activity and Participation, and contextual (Personal or Environmental) factors.”

**Possible Applications:** *In a literature review of 12 studies on pain in adults with cerebral palsy, the three most common themes are 1) prevalence of pain, 2) the effect of pain on functional activities, and 3) coping or intervention strategies for pain.*

#### Other References related to pain in wheelchair users:

6. Dicianno, B. E., Lieberman, J., Schmeler, M., Souza, A., Cooper, R., Lange, M., ... Jan, Y.-K. (2015). RESNA position on the application of tilt, recline, and elevating leg rests for wheelchairs: 2015 current state of the literature. Arlington, VA: RESNA.

*Tilt benefits users with pain*

7. Penner, M., Xie, W. Y., Binopal, N., Switzer, L., & Fehlings, D. (2013). Characteristics of pain in children and youth with cerebral palsy. *Pediatrics*, 132(2), e407–e413.

doi:10.1542/peds.2013-0224

**Study:** 252 participants aged 3 to 19 years across all levels of severity of cerebral palsy.

**Results:** 54.8% of participants reported some pain, 24.4% of caregivers reported pain that affected level of activity, and 38.7% of physicians reported pain and identified hip dislocation/subluxation, dystonia and constipation as the most frequent causes.

8. De Knecht, N. C., Pieper, M. J., Lobbezoo, F., Schuengel, C., Evenhuis, H. M., Passchier, J. & Scherder, E. J. (2013). Behavioral pain indicators in people with intellectual disabilities: a systematic review. *The Journal of Pain*, 14, 885-896.

doi:10.1016/j.jpain.2013.04.01

9. Van Der Slot, W. M., Nieuwenhuijsen, C., Van Den Berg-Emons, R., Bergen, M., Hilberink, S., Stam, H., & Roebroeks, M. (2012). Pain in adults with spastic bilateral cerebral palsy. *Developmental Medicine and Child Neurology*, 54, 69–70. doi:10.1111/j.1469-8749.2012.04371.x

10. Aisen, M. L., Kerkovich, D., Mast, J., Mulroy, S., Wren, T. A., Kay, R. M., & Rethlefsen, S. A. (2011). Cerebral palsy: Clinical care and neurological rehabilitation. *The Lancet Neurology*, 10(9), 844–852.

doi:10.1016/S1474-4422(11)70176-4

11. Haak, P., Lenski, M., Hidecker, M. J. C., Li, M., & Paneth, N. (2009). Cerebral palsy and aging. *Developmental Medicine and Child Neurology*, 51(Suppl 4), 16–23.  
doi:10.1111/j.1469-8749.2009.03428.x
12. Opheim, A., Jahnsen, R., Olsson, E., & Stanghelle, J. K. (2009). Walking function, pain, and fatigue in adults with cerebral palsy: A 7-year follow-up study. *Developmental Medicine & Child Neurology*, 51(5), 381–388.  
doi:10.1111/(ISSN)1469-8749
13. Opheim A, Jahnsen R, Olsson E, Johan K. Walking function, pain, and fatigue in adults with cerebral palsy: a 7 year follow-up study. *Dev Med Child Neurol* 2009; 51: 381–8.

*Prevalence of pain in adults with CP*

14. Crane, B. A., Holm, M. B., Hobson, D., Cooper, R. A., Reed, M. P. & Stadelmeier, S. (2005).  
Test-retest reliability, internal item consistency, and concurrent validity of the wheelchair seating discomfort assessment tool. *Assistive Technology*, 17, 98-107.  
doi:10.1080/10400435.2005.10132100

**Study:** Purpose was to establish the test-retest reliability, internal item consistency, and concurrent validity of a newly developed Wheelchair Seating Discomfort Assessment Tool (WcS-DAT).

**Results:** The tool was shown to be reliable and stable for quantifying wheelchair seating discomfort.

**Reference for movement reducing spasticity:**

15. Phadke, C. P., Ismail, F., & Boulias, C. (2015). Current challenges to clinical assessment of spasticity. *International Journal of Neurology Research*, 1(1), 1-4.

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### **About the Author**

Michelle Lange is an occupational therapist with 30 years of experience and has been in private practice, Access to Independence, for over 10 years. She is a well-respected lecturer, both nationally and internationally and has authored numerous texts, chapters, and articles. She is the co-editor of *Seating and Wheeled Mobility: a clinical resource guide*, editor of *Fundamentals in Assistive Technology*, 4th ed., NRRTS Continuing Education Curriculum Coordinator and Clinical Editor of *Directions* magazine. Michelle is a RESNA Fellow and member of the Clinician Task Force. Michelle is a certified ATP, certified SMS and is a Senior Disability Analyst of the ABDA.