

Supporting People with Pain and Fatigue

A note to people experiencing pain and fatigue and those who support them

Both pain and fatigue are experienced by many people with physical disabilities; recent studies have indicated that these are by far the most common health issues experienced by people with cerebral palsy (CP).

Pain and fatigue impact each other and can exacerbate other symptoms being experienced. Some people with physical disabilities experience chronic pain and require support to live life while in pain. Fatigue for some people seems to occur no matter what activity is being done – it is simply a constant.

Kemp (2005) discusses that researchers have found that across a variety of disabilities, there is a consistent “post-impairment syndrome” of pain, fatigue and weakness as people get older and that these symptoms impact daily activities.

While declining ability to participate in activities can occur for many reasons, pain and fatigue are almost always included. Studies have reported that pain increases as adults with CP get older. Other causes include changes in muscle flexibility, arthritis, falls, fractures and osteoporosis risk.

A spiral effect can be created whereby these changes make pain and fatigue worse and in turn pain and fatigue can make these changes worse.

People with physical disabilities commonly experience pain in the back, hips, knees, ankles and feet, stomach, neck, mouth (dental), shoulders and from pressure injuries on bony prominences. While some types of pain are more common, every body is different and at risk of pain in different ways. Pain in muscles and joints can be due to a specific injury, while other pains are from general wear and tear or how activities are performed.

Fatigue and pain tend to be higher in people who have moderate impairments, compared to those who have mild or severe impairments.



This could be due to the increased strain on the body caused by efforts to remain walking, at work, doing household tasks or as independent as possible.

Assessments for pain and fatigue

People with complex communication needs, those who require increased mobility support or those with an intellectual disability can have trouble accessing health professionals and communicating pain may be difficult.

Supporting People with Pain and Fatigue cont.

References and further reading

Andersson, C., & Mattsson, E. (2001). Adults with cerebral palsy: a survey describing problems, needs, and resources, with special emphasis on locomotion. *Developmental Medicine and Child Neurology*, 43(2), 76. <https://doi.org/10.1017/S0012162201>

Benner, J. L., Hilberink, S. R., Veenis, T., Stam, H. J., van der Slot, W. M., & Roebroek, M. E. (2017). Long-Term Deterioration of Perceived Health and Functioning in Adults With Cerebral Palsy. *Archives of Physical Medicine and Rehabilitation*, 98(11), 2196-2205.e1. <https://doi.org/10.1016/j.apmr.2017.03.013>

Jahnsen, R., Villien, L., Aamodt, G., Stanghelle, J. K., & Holm, I. (2004). Musculoskeletal pain in adults with cerebral palsy compared with the general population. *Journal of Rehabilitation Medicine*, 36(2), 78-84. <https://doi.org/10.1080/16501970310018305>

Jahnsen, R., Villien, L., Stanghelle, J. K., & Holm, I. (2003). Fatigue in adults with cerebral palsy in Norway compared with the general population. *Developmental Medicine & Child Neurology*, 45(5), 296-303. <https://doi.org/10.1017/S0012162203000562>

Jensen, M. P., Engel, J. M., & Schwartz, L. (2006). Coping with Cerebral Palsy Pain: A Preliminary Longitudinal Study. *Pain Medicine*, 7(1), 30-37. <https://doi.org/10.1111/j.1526-4637.2006.00086.x>

Kemp, B. J. (2005). What the rehabilitation professional and the consumer need to know. *Physical Medicine and Rehabilitation Clinics of North America*, 16(1), 1-18, vii. <https://doi.org/10.1016/j.pmr.2004.06.009>

Malone, L. A., & Vogtle, L. K. (2010). Pain and fatigue consistency in adults with cerebral palsy. *Disability and Rehabilitation*, 32(5), 385-391. <https://doi.org/10.3109/09638280903171550>

Murphy, K. P. (2010). The adult with cerebral palsy. *The Orthopedic Clinics of North America*, 41(4), 595-605. <https://doi.org/10.1016/j.ocl.2010.06.007>

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. <https://doi.org/10.1111/j.1469-8749.2008.03250.x>

Parkinson, K. N., Dickinson, H. O., Arnaud, C., Lyons, A., Colver, A., & SPARCLE group. (2013). Pain in young people aged 13 to 17 years with cerebral palsy: cross-sectional, multicentre European study. *Archives of Disease in Childhood*, 98(6), 434-440. <https://doi.org/10.1136/archdischild-2012-303482>

Pruitt, D. W., & Tsai, T. (2009). Common medical comorbidities associated with cerebral palsy. *Physical Medicine and Rehabilitation Clinics of North America*, 20(3), 453-467. <https://doi.org/10.1016/j.pmr.2009.06.002>

VOGTLE, L. K. (2009). Pain in adults with cerebral palsy: impact and solutions. *Developmental Medicine & Child Neurology*, 51, 113-121. <https://doi.org/10.1111/j.1469-8749.2009.03423.x>

Yorkston, K. M., Johnson, K., Boesflug, E., Skala, J., & Amtmann, D. (2010). Communicating about the experience of pain and fatigue in disability. *Quality of Life Research*, 19(2), 243-251. <https://doi.org/10.1007/s11136-009-9572-1>