

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.

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It is important that those supporting people with physical disabilities make the time to assist them in accessing health professionals. Knowledge of an individual's pain levels, causes of pain, and expressions of pain can be shared with health professionals, making the consultation process far easier.

Health professionals can assist people to find the best way to communicate their pain, using methods such as visual analogue scales or Wong Baker Faces.

A cautionary note: studies have found that parents and support workers can misinterpret what the adult or teenager with a physical disability thinks is painful or uncomfortable when they compare it to self-reporting by the adult or teenager. This is often the case for those who are more physically impaired. Health professionals also note that the actual source or area of pain is often misinterpreted by those who support people with physical disabilities. It is for this reason that pain should not be self-diagnosed or ignored. Support from a health professional must always be sought in treating pain.



The role of the health professional

Health professionals, when seeing people with physical disabilities, need to provide time and access and ask specific questions about pain and fatigue regardless of the reason the person is seeing them. Health professionals need to complete a comprehensive assessment to establish what the cause of pain is and how it is to be managed. Assessment needs to consider whether the pain is a secondary condition to CP, or something else altogether causing the pain.

Yorkston, Johnson, Boesflug, Skala, & Amtmann, (2010) discusses that health professionals should screen for pain and fatigue, ask about multiple dimensions of pain and fatigue, gauge the level of information needed at each stage, provide accommodations for communication, identify the goals of management and identify what has worked in the past.

Sometimes interventions from health professionals can be painful. It is important that health professionals consider whether pain is appropriate to achieve the desired result. Some tasks are uncomfortable but the end result is positive: stretching, for example, can be uncomfortable or painful but leads to feeling relaxed and comfortable. It is important that health professionals check that there is a positive outcome at the end of any interventions.

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Equipment

Equipment must be fitted correctly and comfortable to use. Any additional supports can greatly reduce the risk of pain. It is important that equipment is reviewed regularly as changes can happen quickly. Ill-fitting or uncomfortable materials can be a cause of pain and create an opportunity for deterioration. Lying and sitting positions should be reviewed regularly to ensure pain is minimised.

What can be done about pain and fatigue?

There are a variety of intervention methods that can assist people in pain and the activities used to manage pain can often be the same for fatigue. Methods used are not confined to people with physical disabilities: they are similar approaches as used for anyone experiencing pain.



Medications are commonly prescribed and a consultation with a GP or specialist should be sought to discuss suitable medication-based pain management. All medications should be reviewed regularly, and discussions should be had about any long-term use. It is very important that the cause of pain is diagnosed and addressed, rather than relying solely on medication to manage pain.

There are many other options for pain management: exercise, physical activity on land or in water, pacing, relaxation, counselling, cognitive therapy, using equipment and other assistive technologies, adapting and planning how to do activities. Many individuals who explore these options find that their pain is managed better through a combination of approaches, rather than simply via medication alone.

Monitoring to identify problems early can reduce or eliminate pain from occurring later in life. By determining the best way to be supported to walk or transfer, sit in mobility devices or position in bed or other seating can help prevent pain and injury and help people manage their fatigue.



Pain and fatigue, while caused by the physical condition, often has an impact on mental health. Consultation with health professionals on management of pain and its impact on mental health is important. Managing pain and fatigue to enable people to participate in activities that are important to them will have a positive impact on mental health.

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References and further reading

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