

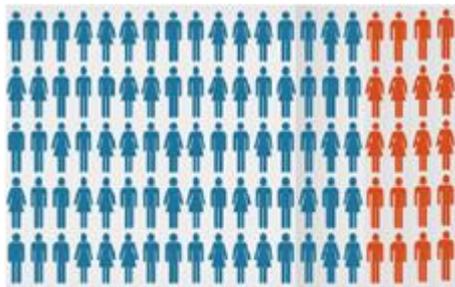


NORTHERN IRELAND
CEREBRAL PALSY REGISTER

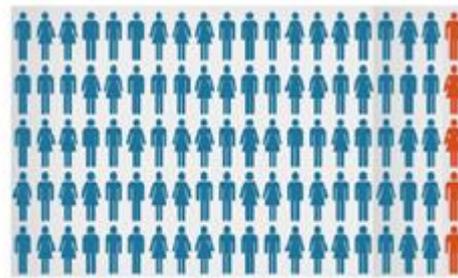
Sleep disturbances in cerebral palsy

Welcome to the third newsletter from the Northern Ireland Cerebral Palsy Register (NICPR). This short newsletter on sleep disturbances in cerebral palsy (CP) has been prepared by Mary-Elaine McCavert (PhD student, Queen's University Belfast).

Sleep disturbances have been found to affect 1 in 5 children living with CP, which is four times higher than for children with neurotypical development.



CP



Non-CP

The impact of sleep disturbances

Sleep disturbances can impact everyone in the home - the child with CP, their parents and siblings. While research is relatively new in this area, findings to

date indicate that if sleep disturbances are present, the:

Child who has CP:

- Experiences reduced general health and increased frequency of illnesses, with mood, behaviour, learning, memory, attention and executive functioning being particularly affected (Jan et al 2008).
- Challenges with sleep are persistent, even as the child ages, due to the pervasive nature of CP (Simard-Tremblay et al 2011). Lack of sleep can in turn result in increased symptom presentation for that child the next day.
- Due to their extra needs, these children can experience a lack of privacy, independence and control (Underhill 2018).

Caregivers:

- Manage fewer hours of sleep a night due to meeting their child's night-time needs, with 40% of children with CP requiring parental support at least once a night (Wayte et al 2012).
- Increased stress due to increased care demands, impaired daytime functioning, increased fatigue, reduced mood and increased parental hypervigilance has also been reported (Raina et al 2005).
- May change their own sleep habits to accommodate the sleep disturbances i.e. share a bed or nap during the day (Jacquier & Newman 2016).
- Key variables which appear to increase the likelihood of parental night-time input include epilepsy, feeding, helping their child change position and pain management (Lelis et al 2016).
- Strained interpersonal relationships and financial worries have also been repeatedly reported (McCoyd et al 2010; Bourke-Taylor et al 2010).

Siblings:

- The impact on siblings has not yet been reported. Research is required to determine if they too experience decreased sleep or adverse family functioning due to, or assisting with, their sibling's needs (Waters et al 2013).



Practice implications

Increased awareness of the presence and nature of sleep disturbances in CP could improve child functioning and development, whilst reducing family stress.

NICE guidelines ([Cerebral palsy in under 25s: assessment and management](#) 2017, NG62) recommend that clinicians always ask about pain, sleep and distress as part of any clinical consultation, recognise that parents and familiar carers have the primary role in sleep management and that use of sleep questionnaires or diaries should be considered.

In managing sleep disturbances in CP, the NICE guidelines recommend:

- (1) Optimising sleep hygiene for children and young people with CP.
- (2) Managing identified treatable causes of sleep disturbances.
- (3) If no treatable cause is found, consider a trial of melatonin to manage sleep disturbances for children and young people with CP, particularly for problems with falling asleep.
- (4) Refer the child or young person to specialist sleep services for multidisciplinary team assessment and management if there are ongoing sleep disturbances.

Furthermore, the guidelines advocate that clinicians do not offer regular sedative medication to manage primary sleep disorders in children with CP without seeking specialist advice; and do not offer sleep positioning systems solely to manage primary sleep disorders in children and young people with CP.

NICPR News



Saturday 6th October is 'World Cerebral Palsy Day', a movement of people with CP, their families and the organisations that support them, in over 65 countries. We will be using World CP Day to help raise awareness of CP in our local communities through poster displays in the School of Nursing & Midwifery and use of social media ([@QUBSONM](#)). Click [here](#) to add your story to the World CP Day international community map and show your support to the CP community.



We recently launched a new NICPR community mailing list for people with CP, their families, friends and carers. This mailing list will let people know about NICPR news, events, research and ways to get involved in our work. You can download our flyer [here](#) and sign up to the mailing list by following this [link](#). We would appreciate your support in publicising this mailing list so we can reach as many people as possible who are affected by CP in Northern Ireland.

We welcome your comments

Feedback and suggestions for further content are welcome at nicpr@qub.ac.uk at any time - we look forward to hearing from you!