Sleep and Physical Disability
What does the evidence tell us?

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Content

• Brief overview of why sleep might be an issue for children with and physical disability.

• A summary of international and Australian evidence that explores sleep quality or quantity for children with physical disability.

• Demonstrate the impact of poor sleep.

• Identify the gaps in current knowledge.
Sleep can be a silent problem

- “Bad sleep is just part of physical disability”
- Sleep conversations are complex. Does not fit easily into a routine clinic appointment.
- Lack of sleep science taught across medical/nursing/allied health courses.
Published Evidence to Date

- <20 papers that quantify sleep problems and their causes or impact.
Overall Prevalence

• Between 19%\textsuperscript{1} and 88%\textsuperscript{2} of children with CP or physical disability have sleep problems.

• A Malaysian study\textsuperscript{3} that compared children with CP to their typically developing siblings.
  • 30% of children with cerebral palsy had sleep problems.
  • 5% of the typically developing children had sleep problems.

\textsuperscript{1} Romeo et al., 2014 \textsuperscript{2} Ikeda et al. 2012 \textsuperscript{3} Atmawidjaj et al. 2015
Reasons for night waking

Positioning, pain, seizures and continence are the most commonly reported care and comfort reasons for sleep disturbance.

Care need linked to sleep concern (number of papers that support link)
- Anxiety (1)
- Body position/repositioning (5)
- Comfort/pain (6)
- Constipation (1)
- Continence/toileting (5)
- Cramps (2)/spasticity (2)
- Enteral feeding (1)
- General behaviour and communication (1)
- Health issues (1)
- Medication (1)
- Pressure care (1)
- Reflux digestion (3)
- Restless sleep/movement (3)
- Safety (1)
- Seizures/epilepsy (6)
- Sensory Issues (3)
- Settling routines (1)
- Sleep environment/temperature (1)
Impact of sleep problems on children with Physical Disability
Impact on parents/caregivers

Sleep Quality or Quantity

• One study found 71% of the parents of children with physical disability also had a clinically significant sleep problem\(^1\).

• Another study 40% of children with physical disability needed overnight attention and 10% needed support five times a night or more\(^2\).

From these studies we can conclude:

A child with a physical disability who does not sleep well, has a parent that does not sleep well.

\(^1\) Tietze et al. 2014 \(^2\) Hemingsson et al., 2009
Impact on parents/caregivers

Quality of life or mental health

• There is a correlation between poor sleep of mothers and higher depression scores\(^1\).

• Two studies found that quality of life of parents of children with severe motor impairment significantly affected if their child has sleep problems\(^2,3\).

\(^1\)Wayte et al. 2012  \(^2\)Tietze et al., 2014  \(^3\)Zuculo et. al., 2014  \(^4\)Bourke-Taylor et. al., 2013
Impact on parents/caregivers

Co-Sleeping

• Parents co-sleeping with their children occurs between 9.2%\(^1\) and 70% \(^2\) amongst parents of children with physical disability.

• 92%\(^2\) parents who do sleep with their children demonstrated disturbed sleep on a sleep survey tool.

\(^1\)Newman et al., 2006  \(^2\)Adiga et al., 2014
Impact on parents/caregivers

Co-Sleeping

Only one study has investigated reasons for co-sleeping it found:

• One third of parents of children with a motor disability co-slept with their child because of fear of an adverse event; epilepsy, breathing.

• Two thirds stated it was because of need for special care overnight.

• Parents reported that co-sleeping had a positive impact on the child’s sleep, but a negative impact on the parents.

• 9.4% of parents said co-sleeping caused conflict between parents.

• 11% said that co-sleeping caused conflict between parent and child.
Hypervigilance

A 2012 report by the Victorian Equal Opportunities commission highlighted that night-time vigilance is a risk factor for surrendering a child with disability into care.
Australian Research

ORIGINAL ARTICLE

Children with cerebral palsy: why are they awake at night?
A pilot study
Sacha Petersen, Adrienne Harvey, Dinah Reddihough, and Fiona Newall

ORIGINAL ARTICLE

Sleep concerns in children and young people with cerebral palsy in their home setting
Susan M McCabe,1,2 A Marie Blackmore,2 Chris R Abbiss,1 Katherine Langdon3 and Catherine Elliott4,5
McCabe 2015

- Retrospective review of sleep concerns for a home based sleep service (WA).

  - 16 factors found. Most children and young people had multiple factors.

- Severity of CP impacted on the type of sleep concerns.

Commenced 2015 expected completion April 2019
Impact of poor sleep

“Absolutely! From the nurse that weighs them... the paediatrician, GPs, everyone I saw everyone and I- everyone would just be like “He'll be alright. He'll be normal. He will work it out.”

“How did it feel when people said that?”

Well, terrible because I don't believe that... That is... I just can't believe that that is normal... or that for me to be... for a parent having to be awake for such extended periods of time. Like, maybe another family could have just lost the plot? Maybe? you know what I mean? I don't know.”
Thankyou
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Acknowledgements

The parents who participated in the research.

Supervisors: Prof Fiona Newall, Prof Dinah Reddihough, Dr. Adrienne Harvey, Dr. Sally Lima,

Royal Children’s Hospital League of Former Trainees

Pelican Auxiliary – RCH Auxiliaries

Nurses Memorial Centre

Vera Scantlebury Brown Child Welfare Memorial Scholarship

Windermere Foundation
The ‘Sleep Comfort Map’
to uncover and explore sleep issues in the home setting

Sue McCabe
Occupational Therapist
PhD Candidate, Edith Cowan University
What’s sleep got to do with it?

True stories....

“I’m getting about 2 hours sleep a night; I think I might crash my car, or something crazy like that”
(mother of 5y.o. triplets, one who has CP, GMFCS V)

“Well, I sit beside his bed all night, so when he coughs or chokes I can tilt his head forward and wipe his mouth”
(father of 18yo son who has CP, GMFCS V)

“Something’s not right; usually I only get up to him about 5 times a night, but lately it’s been more than 10 times”
(76yo mother of 54yo son who has CP, GMFCS III)

“Yeah, I’m off work for two weeks; chopped the tip off my finger. Shouldn’t operate machinery when I’m this tired”
(father of 13 yo daughter who has CP, GMFCS I with autism)
Key points

• ICF underpins approach to sleep
• Context is everything – home, family, community, culture
• Community practitioners are already out there, engaging with families in their home settings
• We need good sleep knowledge, to guide our exploration and resolution of sleep difficulties
• We need to CONNECT practitioners and specialists and clinics and community for synchronised support
In the home setting...

ICF and sleep and every domain of function...

Sleep affects ....

Sleep affected
The sleep BEARS

- B = Bedtime problems
- E = Excessive daytime behaviours
- A = Awakenings during the night
- R = Regularity and duration of sleep (and Routines!)
- S = Sleep Disordered Breathing (and Safety!)

What’s behind the BEARS

- culture, season, environment
- family, age
- primary condition, co-morbid conditions
- daily occupations, activities, habits and routines
We all need to know about ... SLEEP

• Importance of sleep, to explore why this matters
• Circadian factors, to explore environment, rhythms, routines
• Sleep architecture, to explore and explain the timing of sleep onset and waking events
• Sleep changes with age, to explore and discuss expectations
• Sleep disorders, to explore and identify and to know when to refer on
• Sleep assessment tools, to know how to explore
• Sleep interventions and resources, to know what can be done
Sleep information resources
Sleep information resources

Sleep disorders in children with cerebral palsy

Christopher J Newman* MD, Central Remedial Clinic; Myra O’Regan MSc PhD, Department of Social Science, Trinity College; Owen Hensey MD, Central Remedial Clinic.

To determine the frequency and predictors of sleep disorders in children with cerebral palsy (CP) we are evaluating the effectiveness of an educational programme for parents. This will help to identify the common sleep problems and potential influences on the sleep of children with CP.

On the basis of clinical experience and previous research, sleep problems in children with cerebral palsy (CP) are a common occurrence; however, there is a lack of research to support this observation. Several factors that are common to children with CP may influence sleep. These factors include impaired muscle tone, elevated muscle tone, and the presence of nocturnal seizures.

Sleep quality and respiratory function in children with severe cerebral palsy using night-time postural equipment: a pilot study

Catherine M Hill (cmh2@southampton.ac.uk)¹, Rachel C Parker¹, Penny Allen², Annette Paul³, Kathryn A Padoa⁴

REGULAR ARTICLE

Keywords
Cerebral palsy, Night-time postural equipment, Respiratory function, Sleep systems

Sleep Hygiene for Children With Neurodevelopmental Disabilities

James E. Jan, MD, FRCP(C)⁵, Judith A. Owens, MD, MPH⁶, Margaret D. Weiss, MD, PhD, FRCP(C)⁷, Kyle P. Jefferson, MD, Roger D. Freeman, MD, FRCP(C)⁸, Osman S. Ipsioglu, MD, MBA, MASH⁹

SPECIAL ARTICLE

¹Child and Family Research Institute and Divisions of °Child Psychiatry and Developmental Pediatrics, University of British Columbia, Vancouver, British Columbia, Canada; ²Ambulatory Pediatrics, Brown Medical School, Providence, Rhode Island; ³Division of Health & Science University, Portland, Oregon; ⁴Melatonin Research Group, BC Children’s Hospital, Vancouver, British Columbia, Canada; ⁵Professor Emeritus, Neuropsychiatric Clinic, British Columbia, Canada.
We need to listen, observe, explore, describe..

Guided narrative
- Overview discussion
- Sleep profile
- Safety checklist

Observe and record
- Sleep diaries
- Behaviour logs
- Day-night activity log
- Photography
- Video
- Actigraphy

Focused measures
- Pulse oximetry
- Pressure mapping
- Pain mapping
- Temperature
- Sound
- Light

Link with others
- Medical
- Psycho social
- Teachers
- Nursing
- Allied health

Ipsiroglu, O., McCabe S. EACD 2017
sue.mccabe7@gmail.com
In the home: listen, observe and explore

We are concerned about day as well as night, 24/24
If we don’t ask, people won’t tell us
We may need to ask the same question again, and again
In the home, observe...

A home visit allows you to observe

• The child
• The child and family
• The household
• The bedroom
• The bed and mattress and bedding

Allow time

Feel

• the child (tone, range of movement, uncontrolled movements)
• the bed, mattress, pillows, bedding
In the home, explore

* be aware of impact on families when we assess, assess, assess
In the home, explore...

Things that go bump in the night....

Videosomnography = extremely important
‘Mapping’ sleep comfort...

SLEEP COMFORT

getting it JUST RIGHT for me

POSITION & MOVEMENT comfort

SLEEP SETTING comfort

THERMAL comfort

ACTIVITIES & Routines comfort

SENSORY comfort

SOCIAL EMOTIONAL comfort

HEALTH & MEDICAL comfort

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acne, adenoids, allergies, asthma, bowel obstruction, constipation, dehydration, diabetes, diarrhoea, ear infection, eczema, epilepsy, flu, growing pains, gum disease, hay fever, headache, head-cold, head-lice, hormone changes, hunger, incontinence, indigestion, ingrown toenail, joint pain, medications, migraine, nightmares, obesity, pain, parasomnias, periodic limb movement disorder, pmt, reflux, restless legs syndrome, rhinitis, sinusitis, skin breakdown, sleep disordered breathing, spasm, surgery, thirst, tonsils, uti, vomiting, worms ……..
Explore the **calming vs arousing** effects of daytime, pre-sleep and sleep-time sensory experiences.

- Sounds
- Movements
- Deep pressure
- Touch
- Smells
- Visual input
Habits and routines
What we do, and when we do it..

Meals
Bath or shower
Action play, quiet play
Screen time
Exercise
Therapy sessions
Appointments
Swimming
Riding
The patterns of change of core body temperature, skin temperature and ‘thermal comfort’ are essential parts of the timing and rhythms of sleep onset, and sleep maintenance.

Bedroom temperature and humidity

Bed temperature and humidity

Affected by...
air-flow, air-conditioning, bedding materials, fans, mattress, overlays, positioning equipment, pyjamas, timing and type of shower or bath and food or drink and activity and medications
Location of the bedroom
Light / darkness of bedroom
Ambient sounds
Clutter
Allergens
Type of bed
Type of mattress
Bedding materials
POSITION & MOVEMENT comfort

Independent movements
Uncontrolled movements
Habitual lying positions
Painful positions
Musculo-skeletal effects
Respiratory effects
Gastro-intestinal effects
Pressure injury
Shearing injury
Manual handling

Safety
Anxiety
Arousal levels
Attachment
Behaviour
Cognition
Communication
Expectations
Friendships
Grief
Self-regulation
Thankyou

Families  I  Clinical colleagues  I  Research supervisors
Research colleagues  I  CRE-CP
References


References


