

## RESEARCH UNLOCKED: Research summaries for families

# Measuring the chronic sleep issues of families caring for medically fragile children at home

**Important Note!** This summary represents the results of an observational research study describing sleep in caregivers of medically fragile children. There are no specific interventions as a direct result of this research.



### What is this study about?

Caring for a child who relies on life-sustaining equipment – such as ventilators to breathe and tubes to feed – is a 24-hour effort. Being fully responsible for a child's round-the-clock care at home is another level of care.

Caring long-term for a medically fragile child takes a toll on family members. This role can introduce chronic sleep problems, beginning in hospital and extending home. Daily sleep deprivation can negatively impact the health of the caregivers (refers to parents and others caring for the child) as well as hurt their ability to provide long-term, highly- skilled care to a child who needs them to survive.

For years, healthcare professionals have heard from these families that sleep is a major issue. This is the first project to objectively measure sleep patterns among caregivers, in order to provide researchers with precise information to help them study potential new interventions to support sleep in caregivers.

### What is 'observational' research?

In observational studies, researchers follow participants for a predetermined time and measure specific outcomes. The goal is to understand certain behaviors and, based on the results, researchers can develop targeted new treatments or interventions.



### What is 'complex medical technology'?

Complex medical technology (CMT) are electronic devices like tubes and pumps that deliver oxygen and nutrition to young people with medical complexities. Using this technology requires training and skill.



### What did the study team find?

This observational study reports on a diverse sample of family caregivers of children with complex medical technology (CMT). Researchers compared 42 people living this experience to a similarly sized group of caregivers of healthy children.

Data showed that caregivers managing CMT averaged 40 fewer minutes of sleep each night, and had poorer sleep quality overall. They routinely fell below the seven-hour sleep mark per night, which is considered optimal for our bodies and minds.

Far more of these caregivers had symptoms of depression, fatigue and daytime sleepiness – each of which places a unique demand on families already facing unique daily challenges.

These findings will be helpful in advocating for improvements in the quality and deliver of home care services to better support these families.



## What this means for caregivers

Home care is on the rise in Canada, and around the world. It's important to recognize the consequences of poor sleep, which can result from a lack of strategies to better support families caring for children at home.

This study provides scientific data showing that these caregivers average 40 fewer minutes of sleep a night, which nets out to 20 fewer hours a month. The effects of sleep deprivation can snowball, with each night building on the last, especially if this is broken sleep.

This type of sleep pattern causes:

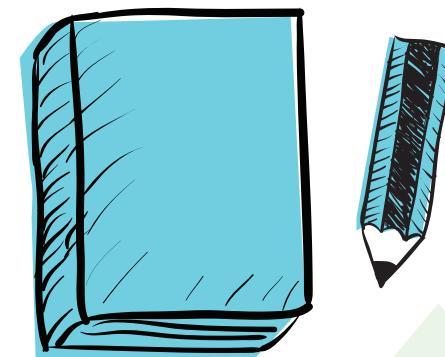
- Daytime sleepiness, which makes it harder to concentrate on monitoring a sick child, or driving to a therapy appointment.
- Fatigue, which can disrupt social activities and creates a sense of isolation, where a family may feel cut off from support.

It also raises the risk of depression, which is connected to sleep deprivation.

While caregivers already know this, they should not feel alone with this stress. With this new data, researchers and policy makers are working towards novel sleep-promoting strategies to support caregivers, so they can in turn better support themselves and their children.

## Tips for caregivers

- Seek support from specialized medical providers for sleep concerns
- Track your sleep patterns
- Speak with home care providers about what sleep support you need and what they can do
- Find further resources at:
  - Canadian Sleep Society: <https://css-scs.ca>
  - National Sleep Foundation: [www.sleepfoundation.org](http://www.sleepfoundation.org)
  - SickKids About Kids Health: [www.aboutkidshealth.ca](http://www.aboutkidshealth.ca)
  - Sleep and Depression Lab: <http://drcolleencarney.com>
  - Better Nights Better Days: <http://betternightsbetterdays.ca/>



## For more information

Find the [abstract here](#) or visit your local library:

Keilty, K., Cohen, E., Spalding, K. Pullenayegum, E., & Stremler, R. (2017). Sleep disturbance in family caregivers of children who depend on medical technology. *Archives of Disease in Childhood*, 103(2). doi:10.1136/archdischild-2016-312205

