Finding information, help and support

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Where to get overnight help

Parents may need help with their child overnight. This is called respite care and may be provided in the home or outside the home.

For respite care:

- Ask your therapist for a “Starting Point” booklet that lists respite services.
- Call 905-522-6057 for “Contact Hamilton” for Children's Developmental Services: 140 King Street East, Suite 4, Hamilton, Ontario.

How your doctor can help

Your family doctor or pediatrician can help you:

- keep your children as healthy as possible
- manage health problems that can affect your child's sleep
- decide if medications can help with sleep problems
- decide if help with communication or family relationships could ease sleep problems
- get help from specialized services, consultants or clinics if needed

Where to get more information

A list of books and websites that we recommend is included with this book. If you don’t have this list, please ask your therapist.

Here are some places where you can get more information about sleep problems:

- “COPEing with bedtime” is a 2 session workshop to help parents develop successful bedtime routines. Check the Community Service Course Schedule to find out when the workshops are held.
- Visit one of the Family Resource Centres for a list of resources about sleep. One centre is at Chedoke on the first floor of the Evel Building. The other centre is at the McMaster Medical Centre in the 3F Clinic.
- Visit your local public library for books and other materials.
Learning about sleep problems

Why is sleep so important?
Everyone needs sleep to:
- stay as healthy as possible
- grow
- think and act in appropriate ways

“Lack of sleep can be weakening to a body that is already tired and painful.”

Do families of children with physical disabilities have more sleep problems?
Yes. Sleep problems are more common in these families than in families of children without physical disabilities. Children with physical disabilities are more likely to have sleep problems. The caregivers of these children also said they have sleep problems such as less sleep, interrupted sleep and poor quality sleep.

“I haven’t slept over 5 hours in 3 years.”

“She fusses until very late so I am late getting to bed. I feel like I have no time for myself.”

What types of sleep problems do children with physical disabilities have?
Children with physical disabilities may take longer to fall asleep and may wake up more often during the night.

One out of 5 children with physical disabilities woke 3 to 5 times a night and some woke more than 5 times a night.

Some caregivers told us that their children were not comfortable at night. Others did not think that their child was safe at night.

“If your child is up 2 to 3 times a night, you are ... therefore you are both exhausted.”

“She complains of stiffness and soreness.”

“I’m worried one day she will hurt herself thrashing about.”

Keep your child safe while sleeping
Parents who worry about their child’s safety during the night gave us these suggestions.

To prevent your child from falling:
- use a crib or hospital bed with side rails
- push the bed against the wall or against another bed
- use a portable side rail
- place the mattress on the floor

To reassure yourself or your child use an intercom or monitor. This lets you hear if your child needs you.

If you are worried that your child may wander out of the house:
- lock your outside doors
- register your child with the wandering persons registry by contacting the Hamilton Police Services
- close the bedroom door or install a gate in the doorway to keep your child from wandering out of his or her room

If your child wakes, help him or her get back to sleep
Parents whose children woke during the night shared these suggestions for helping children get back to sleep:

- Follow the bedtime routine that you developed to help your child fall asleep by him/herself.
- Stay calm and quiet while reassuring your child.
- Ask your health professional about specific suggestions for "behaviour modification". Start at an early age.

“If your child is up 2 to 3 times a night, you are ... therefore you are both exhausted.”

“She complains of stiffness and soreness.”

“I’m worried one day she will hurt herself thrashing about.”

“Don’t give in because you are tired. Think of night time behaviour as acquiring skills, just like daytime. These skills need to be taught.”
Help your child get in a comfortable position

For children who are not able to move very well, parents had these suggestions to make their sleep position more comfortable.

- Find a comfortable mattress, or mattress cover such as an "egg crate" foam. There are some easy to use, basic products to start with. Your therapist may have some suggestions.
- Have your child hug a long "body pillow" when sleeping on his or her side.
- Ask a physiotherapist or occupational therapist to recommend any special positions, equipment or devices.
- Think ahead about how your child's sleep position could protect his or her body shape during daytime activities.
- If your child has difficulty with good posture, your therapist may refer your child for a consultation about 24 Hour Postural Care at the Children’s Developmental Rehabilitation Programme at CDRP. This program helps parents and caregivers learn how to position their child in a way that protects the shape of the body and gives support and comfort.

Help your child fall asleep

Here are some ways to soothe your child and help him or her get to sleep:

- cuddle or "snuggle" with your child
- rub your child's back
- play soft music
- make the room dark or light enough for your child to feel comfortable
- have bubbling noises such as from an aquarium, a bubble lamp or an ocean sound machine

Your child may fall asleep easier if he or she feels safe, secure and loved. You can help by reassuring your child.

What causes children’s sleep problems?

A poor position during sleep can:

- affect blood circulation
- affect muscles, bones and joints
- cause pain
- affect breathing

As well, families said the following health problems affect sleep in children with physical disabilities:

- pain in muscles, joints or stomach
- swallowing and digestive problems such as drooling, thirst, or heartburn
- seizures
- breathing problems such as asthma, apnea, frequent colds or snoring
- problems with muscle tone such as spasticity, spasms or low muscle tone
- bowel or bladder problems such as constipation, bed wetting, passing urine often or catheter issues
- skin problems such as itchiness, pressure sores, sweating or sensitive skin
- problems with blood circulation such as cold or discoloured feet
- behavioural problems

“I’m concerned about muscles being tight at night and maybe causing spasms.”
How do sleep problems affect children and their caregivers during the day?

Children who do not get enough sleep may be drowsy or irritable during the day. They may not be able to pay attention or may have behaviour problems.

Without enough sleep, caregivers of children with physical disabilities said they are more likely to be sleepy, irritable, impatient and forgetful during the day. They also took caffeine products such as coffee or tea more often.

“He has to take a nap at school. Our concern is that it takes away from other things at school.”

“She is not able to function during the day, very moody, can’t think.”

“Too tired to concentrate, gets in fights because of irritability.”

How to help your family sleep better

Follow a routine at bedtime

Parents of children with disabilities told us that bedtime routines are as important for their children, as they are with all children. A bedtime routine means doing similar activities, in the same order, every night before bed. It is also helpful to set a consistent time for bed.

Parents said to “start young”. Once the routine is set children can carry it on by themselves as they get older.

The bedtime routine will be different for each child, depending on the child’s:

• age
• health and abilities
• likes and dislikes

At bedtime, your child may enjoy such activities as:

• reading a story
• playing music
• gentle stretching
• a bath
• cuddling
• a massage
• having a warm drink

Other tips for bedtime:

• have a calm, quiet time before bed
• limit caffeine, which is found in cola, chocolate, coffee and tea
• make bedtime a pleasant and positive time for your child
• encourage your child to fall asleep on his or her own, without your help
• let your child sleep with a favorite toy that is safe
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Helping your family sleep better
A guide for families of children with physical disabilities

Sleep problems are common in families of children with physical disabilities. Children and their caregivers may have sleep problems. We have developed this booklet to help families learn ways to get a better night's sleep and what resources are available to help.

Our information has come from research findings and the results of our:
- surveys of families of children with physical disabilities
- surveys of families of children without physical disabilities
- interviews with children and teenagers
- discussion groups with parents
- discussion groups with health care providers

We thank all the families who gave us this valuable information to share with you. We have included quotes in the margins of this booklet so you can hear how other families described their experiences.

This project was supported by the Hamilton District Society for Physically Disabled Children and the Ministry of Health and Long Term Care, Ontario.