



Sleeping issues

Children with a neurological disorder do not always sleep well, which can be exhausting for the whole family

What may happen

Your child may find it difficult to go to sleep, or may go to sleep easily but then wake up several times a night. You may find that they are then tired during the day, needing to rest or nap more often.

What you can do

For children, following a strict routine before bed can help, perhaps starting with a bath, then a massage or a story, before going to bed with the lights out and some gentle music. For adults, calm and quiet before bed can help, along with a warm bath and relaxing music. Ensuring that the bed is comfortable, especially if the person is unable to move around, is important. Your occupational therapist can provide help in obtaining special beds or sleeping systems.

Where possible doctors will try to avoid prescribing sleep medications that make the person sleepy the next day (these are known as narcotics). A first medication of choice is often melatonin. This is a naturally occurring hormone and is often not produced in adequate amounts by people with neurological problems. Alternative medications that may be prescribed include sedatives such as Vallergan, chloral hydrate or temazepam. Your consultant will discuss the most appropriate options with you.



How we managed ...one family's story

We tried everything to help our young daughter sleep. At first our medical team said it was just her age, so we tried every tactic in the baby books to help her (and us!) to have a peaceful night's sleep. Eventually, after nothing seemed to work, we began to think her sleep disturbances were linked to NP-C. We took advice from our consultant and were given a medication called melatonin, which did help.

Who can help?

Your GP, consultant or community nurse will provide advice about medication. Your physiotherapist can advise about massage techniques and your occupational therapist will help with specialist equipment. The NPDG (UK) can also provide help and advice in this area.

Cerebra is an organisation which has various fact sheets dealing with sleeping issues and sleep counsellors who can provide specialist advice over the telephone. Visit www.cerebra.org.uk for further information.

This leaflet forms part of a resource pack published by the Niemann-Pick Disease Group (UK). It is intended to be read in conjunction with the other parts of the pack. If you do not have the other documents in the pack or you would like further information, please contact us at the email address below.

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