

Sleeping problems in Rett syndrome

Caroline Lietaer, *parent of a daughter with Rett syndrome, President of RSE*

Robert James Goddard, *MMT, PT & parent of a daughter with Rett syndrome*

Patients suffering from Rett syndrome are more likely to suffer from sleeping disorders than other children due to an immature brain stem. Sleep disturbances affect 80 percent or more patients with Rett syndrome [1]. These sleeping disorders often present themselves as: screaming, laughing, bruxism (grinding), epileptic seizures or apnoea. Nightmares, head banging, bedwetting and sleepwalking are also reported. While this paper is concerned with sleeping problems for Rett children much of it also applies to Rett adults.

Some children suffer from hypersomnia: an excessive need for sleep during the day and the tendency to fall asleep during social moments. Sleep disorders not only affect the child itself, but also the entire family. For the child suffering from Rett syndrome, insomnia may exacerbate existing behavioural problems epileptic seizures and disturbances of social and emotional interactions.

There are various factors involved in these sleeping disorders, some of them are specific to Rett syndrome, some are environmental factors, others are of a medical origin.

Behavioural problems

A child may be afraid of going to sleep due to changes in its daily environment (changes at school, the loss of a relative, divorce, birth, moving house, etc.). As parents in an attempt to console our child we tend to cultivate "bad habits" by being too explicitly present: giving a bottle, watching television, driving in the car, rocking the child to sleep. This may result in the child not being able to fall asleep without this form of comfort. From an educational point of view, this is not a good solution.

Sleep and rhythm disorders

Normal sleep pattern is regulated by several areas in the central nervous system, notably the brainstem, hypothalamus and SCN. and this is often disturbed in Rett syndrome. Sleepiness develops when melatonin [2] is created in the glands of the brain, which occurs under the influence of darkness. The slightest light can already prevent the formation of melatonin. The use of melatonin in the form of a pill may attribute to our sleep and wake cycle. Consult your doctor!

Try to make sure your child develops a clear concept of time. Making a distinction between day- and night-time attributes may help.

Expose your child to daylight sufficiently during the day (also during afternoon naps). Try to have a clear schedule of set times regarding feeding, personal care, activities, medical care, and sleep. Provide sufficiently structured activities and exercise during the day and provide relaxing activities with a set sleep ritual in the evening.

Pay attention to sleeping comfort. Avoid toys near the bed and ensure adequate humidity and temperature (no more than 18 degrees), if possible soundproof the room. If the child is especially excitable remove bright coloured objects and avoid contrasts in the room. Consider a custom mattress or the use of a weighted blanket (if your child is often excited, this is not allowed in all

countries). If your child has a tendency to escape from her bed, one can provide a sleeping bag that is attached to the mattress.

If you are worried, then make use of a webcam to avoid going to check on your child too often.

If you must intervene at night to change the sleeping position or feed the child; try to do this with the least possible disturbance, don't talk and light the room as little as possible.

Tips

- social interactions should occur during the day and not at night
- difference between day and night must be made clear by light and darkness
- observe regular feeding times
- observe regular wake and sleeping times
- provide adequate and structured activities during the day

Medication

The use of medicines may cause sleeping problems: some anti-epileptics facilitate sleep, whilst others just disturb the sleep pattern. Always consult your doctor for advice.

Medical causes

Epilepsy, pain, organic problems, respiratory distress, uncontrolled movements, or unbalanced nutrition may also be a cause of insomnia.

The relationship between epilepsy and sleep is very complex. Sleep deficiency may cause epilepsy however on the other hand epileptic seizures may negatively influence the quality of sleep.

The absence of mobility, muscle weakness or paralysis means that a child cannot move at night and relieve pressure points. Some devices (corsets, splints, preformed mattresses) can be a source of discomfort and pain due to the resulting body position.

Try to make sure that the child is in its favourite sleeping position:

- Use pillows to increase comfort, help the child to take on other positions at night if it cannot do this itself.
- If your child uses a corset, mattress, or foot orthosis, make sure that it is comfortable. Redness on pressure points when using a corset is normal but make sure that they disappear when the corset is removed.

Organ-related pain

Determine whether pain is causing sleep disturbance. The most common causes are: ear infections, toothache, constipation, and gastric reflux.

Respiratory distress

There may be several reasons for this, the most common of which is apnoea, a temporary respiratory stop during sleep.

Bad dietary habits

Nutrition can also play a part in sleeping problems: it may be insufficient, unbalanced or too low in fat, too rich in sugars and / or grains or contain insufficient iron. Consult a dietician who can determine the number of meals and required nutritional value or look at the necessary amount for tube feeding. Sometimes there may also be intolerances or allergies.

Uncontrolled movements

Cramps or uncontrolled movements specific to certain syndromes can prevent the child from falling asleep. These movements can be reduced by using a weighted blanket, which should only be used on the advice of a medical doctor.

Dyssomnia

Unwanted movements, fears, nightmares, teeth grinding (bruxism), head banging, bedwetting, and sleepwalking. If they occur too often this should be investigated.

Hypersomnia

Excessive sleep during the day and tendency to fall asleep during social moments (conversations, nutrition, etc.) may be caused by: poor day and night rhythm, sedatives, epilepsy, apnoea and uncontrolled lower limb movement patterns.

Parents

Sleep disturbances are often underestimated, or parents assume that they are inherent to Rett syndrome however they can have important implications for family life.

They can lead to physical and mental fatigue and, in the worst case, to social isolation or depression.

Tips

- also leave the care tasks to professionals every now and then
- enlist the help of people (family or friends) who can take over when it becomes too much to handle
- check with a doctor to see if a solution to the sleep problem can be found
consult experts; the institutions and therapists (ergo / physiotherapist/ psychologists)

Together, you can look for solutions to provide the child with sufficiently structured activities during the day with a clear perception of time. They can provide tips on how to maximize the child's sleep time and how children can comfortably be positioned in bed.

- Parent associations: knowing you are not alone can help with the problem, parent forums can be used to exchange tips and experiences
- Don't be afraid to delegate: entrust your child to friends, family or an institution for a night or weekend. This is not a sign of weakness or incompetence but a sign of responsible behaviour.

Source: summary and edited by Lietaer Caroline of the issue 'Troubles du sommeil et Handicap' du Réseau Lucioles, 2011. The full version of this study is available in French at www.reseau-lucioles.org.

Translated and revised into English language by Robert James Goddard

References

- [1] [Young D, Nagarajan L, de Klerk N, et al. Sleep problems in Rett syndrome. Brain Dev 2007; 29:609.](#)
- [2] is a hormone that is produced in humans in the epiphyseal (pineal gland) and affects the sleep alertness of humans