

Parent's Guide to Sleep and Melatonin Use for Children with Autism



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Acknowledgments

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Introduction

Children with ASD have problems with sleep. Improving sleep habits helps many children, including those with ASD, to get better sleep. For some children with ASD, sleep problems happen even with good sleep habits. Melatonin is a common medicine your doctor or healthcare provider may suggest to help improve sleep. This tool kit is designed to provide parents with information about melatonin.

What is melatonin?

Melatonin is made in the pineal gland of the brain. It is part of the brain's internal clock system. This system tells the body when to go to sleep and when to be awake. Melatonin levels usually begin to rise in the early evening and are highest in the hours after midnight. They slowly get lower by morning and remain low during the day. Melatonin is also important for other time-related changes such as seasonal changes and puberty.

Melatonin is made by the brain when there are changes in light. Melatonin is sometimes referred to as the 'hormone of darkness' as it is high when light levels are low, like in the evening. Melatonin is low when light is high, like in the morning.

Why might supplemental melatonin help children with autism spectrum disorders (ASD)?

Children and teens with Autism Spectrum Disorder (ASD) often have problems with sleep; about two thirds have sleep difficulties. This can include problems falling asleep, waking up overnight, and waking too early in the morning. Low or uneven



levels of melatonin in people with ASD may be part of the problem, although this needs more study.

Taking supplemental melatonin helps some children with ASD to sleep better. For children with poor sleep that did not get better with improved sleep routines, melatonin may decrease the time it takes to fall asleep.

There is no information on the effect of melatonin on sleep in children with ASD younger than 2 years of age.

How is melatonin used for sleep problems?

Melatonin is taken by mouth to help with sleep problems. It is used to help with jet lag and is sometimes used by shift workers to assist with falling asleep during daytime hours. It is also used by people who cannot fall asleep until very late at night. The idea is that taking melatonin will help to reset the brain's internal clock or add to the brain's natural melatonin to help improve sleep.

Melatonin stays in the blood for a short time so it is taken by mouth every night. It is taken 30 minutes before the intended sleep time and started at a low

dose (0.5 mg to 1 mg) regardless of age or weight. The dose may be increased if a lower dose is not improving sleep. Most studies show that 6 mg or less is helpful. Some experts recommend giving melatonin at a lower dose (0.5 mg) 2-5 hours before bedtime to reset the internal clock. Speak to your doctor or healthcare provider about the right time for your child to take melatonin.

What are the risks with using melatonin?

Most children tolerate melatonin well. Melatonin is not habit-forming.

Some children may experience nightmares, sleepiness, headache, upset stomach, dizziness during the day, low blood pressure, bedwetting, or grogginess when they wake up. One report found that melatonin may affect seizure control but newer studies have shown that melatonin does not increase seizures and may reduce seizures. It does not interfere with seizure medications. A few children may become more active and have more problems with sleep while taking melatonin. Melatonin may not be safe to take if you are pregnant or breast-feeding.

What should I do if I think melatonin might help my child's sleep problems?

The first step for better sleep is to work on sleep habits. Decide on a regular sleep and wake time. Use a calm bedtime routine. Make sure that you have a consistent response to nighttime waking. These practices should be used with any sleep medicine or supplement.



It is important to talk to your child's doctor or healthcare provider before starting any new medicine or supplement for your child. This includes melatonin. This is because melatonin does not help with all sleep problems. It may interact with other medicines or supplements that your child is already taking. Your child's doctor or healthcare provider can review your child's medical history and sleep habits. Treatment of some medical conditions like stomach problems or snoring can help with sleep. Working on sleep habits can improve sleep problems. It is important to think about these things before starting melatonin.

How will I know if melatonin is working?

If your child's doctor or healthcare provider agrees that melatonin could work for your child, it is important to have a plan so that you will know if melatonin is helpful. Work with your doctor or healthcare provider to make a plan. You should have a sleep diary to keep track of your child's sleep for a week or two before starting melatonin and then do this again after starting melatonin. It is also helpful to think about how your child behaves during the day.

Better sleep can help with daytime sleepiness, attention, and activity level. Some children do not change how they act during the day when they take melatonin, even if they are sleeping better.

Are there different types of melatonin?

There are two types of melatonin: standard preparation and slow release preparation. Slow release means that the melatonin is released over several hours. The slow release form may help more with night waking though we need to study this more to see if this is the case. Melatonin comes in tablet, capsule or liquid form. Standard release tablets should be swallowed whole, crushed, or made into a liquid by a pharmacist. Slow release tablets and most capsules should only be swallowed whole. Some capsules can be opened to put in a small amount of liquid or food. Check with your doctor or healthcare provider about which type of melatonin your child should be using. Slow release and liquid formulations are not available in all areas. Talk to your pharmacist about the choices in your area and whether it is possible to make a special form of melatonin that meets your child's needs.

Do I need a prescription for my child to take melatonin?

In some places in the world, melatonin is medication that is prescribed by a doctor or other type of licensed healthcare provider. In Canada and the United States melatonin is a natural health product or a dietary supplement and is available over the counter without a prescription. Your doctor or health care provider may be able to provide you with a prescription so your insurance company will cover the cost of the melatonin.



There is a downside to buying melatonin over the counter as a health supplement. Regulation of health supplements is different from medicines that require a prescription. The amount and purity of melatonin cannot be guaranteed. This means that 1 mg in one brand may not be the same as 1 mg in another brand. Check with your pharmacist for more information before buying melatonin over the counter.

How long will my child take melatonin?

Stop melatonin immediately if your child experiences any serious side effects. Report all side effects to your doctor or health care provider to determine if continuing melatonin is appropriate.

Stop melatonin if sleep is not improving on the maximum dose recommended by your doctor or healthcare provider. There are other ways to improve sleep if melatonin is not working.

You can continue melatonin as long as it helps your child's sleep. Because sleep changes as children get

older, you can try to lower the dose or to stop melatonin from time to time. The best time to try stopping melatonin is when your child is doing well and when it will not be a problem to have less sleep. If sleep problems start again after you lower or stop melatonin, you can start again at the last dose that helped your child sleep well. While long-term studies have not been done on melatonin treatment, it is generally believed to be safe. In a study of children 3-9 year olds, melatonin did not affect other brain hormones. Further study of melatonin's long term effects, and how it works in teenagers, is needed.

What if melatonin does not improve my child's sleep?

If your child's sleep does not improve after starting melatonin, you should talk to your child's doctor or healthcare provider. Melatonin will not help all sleep problems so it is important to tell your doctor or healthcare provider if your child snores, has breathing problems or other behaviors during sleep. Medical problems can cause sleep problems so it is important to review your child's health history to see if there are other reasons your child is not sleeping well. There are other medicines that can be used to improve sleep in children. Your doctor or healthcare provider may want your child to see a sleep specialist before trying other medicines to improve your child's sleep.



Resources

Autism Speaks offers resources, tool kits, and support to help manage the day-to-day challenges of living with autism. Learn more at **AutismSpeaks.org/Family-Services**.

If you are interested in speaking with a member of the **Autism Speaks Autism Response Team (ART)**, call **888-288-4762** (En Español al 888-772-9050) or email **FamilyServices@AutismSpeaks.org**.

Suggested Readings for Parents

The ATN/AIR-P Sleep Tool Kits

are designed to provide parents with strategies to improve sleep in their children and in their teens affected by ASD and helps tackle the problems of falling asleep and staying asleep through the night.

AutismSpeaks.org/ScienceResources-Programs/Autism-Treatment-Network/Tools-You-Can-Use/Sleep-Tool-Kit

The National Autistic Society

Many children have sleep issues. But for those with autism, sleeping well may be particularly difficult. Here we look at how families can help their child to sleep well.

Autism.org.UK/About/Health/Child-Sleep.aspx

Research

Rossignol DA, Frye DE. Melatonin in autism spectrum disorders: a systematic review and meta-analysis. *Developmental Medicine & Child Neurology* 2011; 53(9): 783-92.

Andersen IM, Kacamarska J, McGrew SG, Malow BA. *Journal of Child Neurology* 2008; 23(5): 482-485.

**Have more questions or need assistance?
Please contact the Autism Response Team for
information, resources and tools.**

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Autism Speaks is the world's leading autism science and advocacy organization. It is dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. Autism Speaks was founded in February 2005 by Suzanne and Bob Wright, the grandparents of a child with autism. Mr. Wright is the former vice chairman of General Electric and chief executive officer of NBC and NBC Universal. Since its inception, Autism Speaks has committed more than \$500 million to its mission, the majority in science and medical research. Each year Walk Now for Autism Speaks events are held in more than 100 cities across North America. On the global front, Autism Speaks has established partnerships in more than 40 countries on five continents to foster international research, services and awareness.

To learn more about Autism Speaks, please visit AutismSpeaks.org.