

MELATONIN FACT SHEET

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Melatonin has been successfully used in improving the sleep of individuals with MPS and related diseases. Melatonin is a hormone secreted by the pineal gland. Melatonin secretion is inhibited by environmental light and stimulated by darkness. Secretion of melatonin at night is highest in children and decreases with age. Melatonin use has been suggested for easing insomnia and combating jet lag. Although melatonin is not approved by the FDA as a drug product, it has been classified as an orphan drug since November 1993 for the treatment of circadian rhythm sleep disorders in blind people with no light perception.

Children with an MPS disorder may experience difficulty getting to sleep, frequent waking or a combination of both. Melatonin has been used with success by increasing the blocks of sleep, but it's important to be aware that melatonin will not lead to normal sleep.

A week prior to beginning melatonin, keep a sleep diary noting the time the child falls asleep, how long he/she sleeps, and periods of waking. Continuing the diary after initiation of melatonin provides assessment of potential benefits.

Melatonin is available in the following forms, tablet, capsule, liquid, lozenges (dissolves in the mouth), and sublingual tablets (dissolves under the tongue). The suggested dose of melatonin is 1mg - 10mg, and it's recommended that the lowest dose be initially given. For optimal benefit, develop a bedtime routine that is followed every night and give the melatonin at the same time every night. Avoid use of lights in the bedroom, keeping the room as dark as possible.

Melatonin may cease to work if a change is made in the time it is administered. Most studies with melatonin do not report any adverse effects. Past studies have included blind and mentally retarded children, children with school phobia and children with multiple disabilities. A letter in *Lancet* * reported six children with multiple neurological deficits, including seizures, who had chronic sleep complaints. Treatment with 5mg of melatonin improved total sleep time and sleep continuity, although four of the children had increased seizure activity. The seizure activity returned to the previous level after the melatonin was stopped.

There is no regulation of melatonin manufacturers and preparations by the FDA. Many companies make melatonin, but we recommend using a reputable manufacturer that makes multiple nutritional supplements. A pharmacist can recommend a specific brand. If one product is ineffective after a 1-2 week trial, we suggest trying another manufacturer since each preparation may be different.

* Sheldon, Stephen, "Proconvulsant effects of oral melatonin in neurologically disabled children", *Lancet* 1998; 351; 1254.