

**SEND Sleep disorder guidelines for Melatonin Use**

**The aim of these guidelines is to improve the services offered to children, young people and their families and to reduce reliance on melatonin.**

This pathway applies to children and young people age 2-19 with Special Educational Needs and Disabilities (SEND) who have identified sleep difficulties

It applies to those who are treatment naïve and those already taking melatonin

It does not include children with neurotypical symptoms:

* Night terrors and other sleep problems in the preschool group should be dealt with by health visitors (with guidance from the SEND Sleep service)
* Sleep apnoea
* Nocturnal epilepsy

**Melatonin**

Melatonin is a naturally occurring hormone produced by the pineal gland in the brain. It is involved in coordinating the body’s sleep-wake cycle and helping to regulate sleep. It is commonly used for the treatment of sleep disorders in children with SEND but the evidence is poor.

Only 1 form of melatonin (Circadin) is currently licensed in the UK for the short term treatment of primary insomnia, in adults who are aged 55 years or over. All other melatonin products are unlicensed “specials”. Thus there is no licensed product available for use in children.

Unlicensed “specials” such as melatonin can be very expensive. GP prescribing costs for melatonin were approximately £143,000 in 2014/15 (July 14 to June 15), with additional prescribing costs incurred by City Health Care Partnership, Hull and East Yorkshire NHS Hospitals Trust and Humber NHS Foundation Trust.

Given the poor evidence base and the high costs NHS Hull CCG has agreed that melatonin is unlikely to be a cost-effective intervention for children and young people with SEND who have identified sleep difficulties and are encouraging prescribers not to use melatonin as a first line intervention. NHS Hull CCG has commissioned KIDS Yorkshire and The Humber to deliver and coordinate a SEND Sleep Service and this should be the first line of treatment.

**Treatment naïve children and young people**

The first line treatment is referral of the child/young person/family to the SEND Sleep service.

A referral will be accepted by a health or education or social care professional, or self-referral.

Melatonin should not be considered unless confirmation can be obtained from the SEND Sleep service that the family have completed the recommended treatment programme and that this has been unsuccessful.

**Melatonin is only to be initiated where a child/young person has failed to gain improvement after parental/carer attendance and completion of the sleep interventions recommended by the service and its sleep practitioners.**

**Children already taking melatonin**

Existing patients are to remain under the shared care arrangements between the consultant and the GPs until such time it is appropriate for them to stop treatment. These children/young people are to be invited to/referred to a paediatrician clinic review if they have not been reviewed in the last 6 months.

Aims for the review meeting for all children/young people:

* Discuss research information on melatonin and other medications
* Emphasise the benefit of behavioural approach
* Referral to the SEND Sleep Service/Sleep practitioner whilst melatonin is reduced
* Joint sleep plan
* Reduce melatonin dosage
* Stop melatonin treatment

Refer to the SEND Sleep service with clear messages about the added benefit of behavioural approach.

**Appendix 1 provides the pathway to support these guidelines**

**Appendix 1**

**HULL CYP SEND SLEEP PATHWAY (aged 2 to 19 years)**

Child or Young Person with SEND aged 2-19 years who has a sleep problem as identified by parent/carer or any health or care practitioner



1-1 Support and follow up telephone support

Telephone Support

Workshop and follow up telephone support

Melatonin prescribed under shared care agreement

Initial triage, contact and confirmation of agreed intervention with parent/carer (within 7 days of referral)

Refer to SEND Sleep service via referral form

**Telephone:** 467540

**Email:** enquiries.yorkshire@kids.org.uk

Refer to known accredited Sleep Practitioner

(Within existing services. e.g. CTLD, Paediatric Neurology, Health and Social Care practitioners, Paediatric Community Nursing, CYP Disability Team)

**Melatonin Prescribers where primary need is to support sleep improvement (Primary, Secondary or Community Physician):**

Where there is a concern or comorbidities (e.g. developmental delay, neuro-disability, mental health, autism) in addition to sleep problems, refer to appropriate service.

E.g. Autism refer to Autism Assessment and Diagnosis Service

Inappropriate referral to be communicated to lead professional/initial referrer

**DISCHARGE**

Outcome of intervention, DNA or discharge MUST go back to referral source/lead professional and CYP GP within 7 days of discharge

Initial 3 month review followed by on-going six monthly melatonin reviews as per shared care arrangement, to include sleep behaviour