

CLINICIAN  
GUIDE



# Narcolepsy in Pediatric Patients

A Practical Guide for Recognizing Narcolepsy Symptoms  
in Pediatric Patients



# Narcolepsy Can Start in Childhood

This brochure can help you:

## **RECOGNIZE**

Manifestations of the 5 main narcolepsy symptoms in pediatric patients

## **SCREEN**

Pediatric patients who present with excessive daytime sleepiness using a validated screening tool



Narcolepsy Link is an innovative, evidence-based education and resource support program. Its mission is to increase narcolepsy awareness and help improve recognition, screening, and diagnosis of narcolepsy.

## Table of Contents

<b>Narcolepsy in Pediatric Patients.....</b>	<b>4</b>
<b>Narcolepsy Symptoms in Pediatric Patients.....</b>	<b>5</b>
Recognizing Cataplexy.....	6
Recognizing Hallucinations.....	8
Recognizing Excessive Daytime Sleepiness.....	8
Recognizing Sleep Paralysis.....	10
Recognizing Sleep Disruption.....	10
<b>Clinical Interview.....</b>	<b>11</b>
Clinical History and Symptom Assessment.....	11
Questions to Ask During the Clinical Interview.....	12
<b>Differential Diagnosis.....</b>	<b>15</b>
Distinguishing Narcolepsy From More Common Conditions...	15
Other Disorders.....	18
<b>Screening.....</b>	<b>21</b>
Epworth Sleepiness Scale for Children and Adolescents.....	21

## Narcolepsy in Pediatric Patients

Although narcolepsy is often thought of as a disease of adulthood, symptom onset most commonly occurs in childhood and adolescence.<sup>1-4</sup> Studies indicate onset of symptoms occurs most commonly between 10 and 25 years of age.<sup>5</sup>

Patients may suffer for more than a decade before receiving an accurate diagnosis.<sup>2,6,7</sup> In one study, pediatric onset of symptoms (17 years of age or younger) was a strong predictor of delayed diagnosis.<sup>6</sup>

Delayed diagnosis may be attributed to misdiagnosis of narcolepsy symptoms as another common pediatric condition<sup>1,2,8-10</sup> and the overall lack of awareness of narcolepsy and its symptoms among patients and caregivers.<sup>9,11-13</sup>

Understanding how symptoms manifest and differentiating them from common conditions may be key to recognizing narcolepsy in pediatric patients<sup>6</sup>



## Narcolepsy Symptoms in Pediatric Patients

Symptoms of narcolepsy may present differently in pediatric patients.<sup>5,6,14</sup> The 5 main symptoms of narcolepsy are referred to by the acronym **CHES** (Cataplexy, Hallucinations, Excessive daytime sleepiness, Sleep paralysis, Sleep disruption).<sup>15</sup> **All patients with narcolepsy experience excessive daytime sleepiness<sup>5</sup>; however, not all patients with narcolepsy experience the other 4 symptoms.**<sup>5,16,17</sup>

As children become adolescents and adults, the symptoms of narcolepsy may manifest differently and change over time.<sup>5,6,14</sup> Therefore, ongoing monitoring for changes in symptom presentation and comorbid medical and psychiatric conditions is important when managing patients with narcolepsy.<sup>12,18,19</sup>

- The possibility of an evolving disorder, with cataplexy developing over time, should be considered in all pediatric patients with narcolepsy type 2 (narcolepsy without cataplexy).<sup>5</sup>
- As a child with narcolepsy type 1 ages, atypical cataplexy develops into the more typical form observed in adults.<sup>8,12,14,20,21</sup>
- Hypnagogic/hypnopompic hallucinations and sleep paralysis may be age-dependent phenomena that slowly appear and progress along the disease course.<sup>5,8,22</sup>

Symptoms of narcolepsy may present differently in pediatric patients<sup>5,6,14</sup>

## Recognizing Cataplexy

### Cataplexy may manifest differently in pediatric patients.

Cataplexy typically presents at the same time as or within a year from onset of excessive daytime sleepiness.<sup>20,23</sup> In some cases, onset of cataplexy may be delayed for years or decades.<sup>5</sup> Therefore, the potential for cataplexy to present later in the disease course should be considered in all pediatric patients with narcolepsy type 2.<sup>5</sup>

- Cataplexy may manifest as a complex movement disorder, which includes<sup>1,8,14,20,21,23</sup>:
  - “Negative” (hypotonic) motor features, such as head drop, persistent facial hypotonia, persistent eyelid drooping, and tongue protrusion



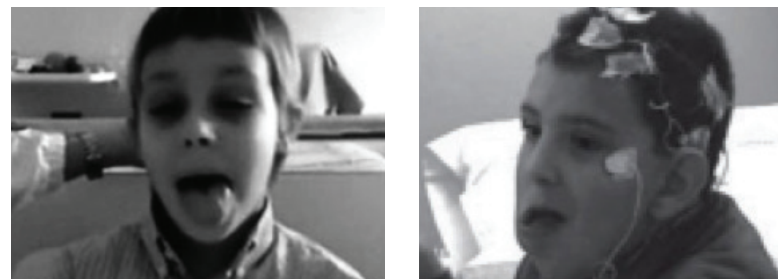
Negative motor feature: head drop

- “Active” movement abnormalities or dyskinesia, such as raising eyebrows, lip licking, lip biting, lip chewing, grimaces, and tongue protrusion



Active motor feature: raising eyebrows

- Close to disease onset, children may present with cataplectic facies,<sup>23</sup> a localized version of status cataplecticus, which<sup>20,21,23</sup>:
  - Affects facial muscles, often without any clear emotional triggers
  - Manifests as repetitive mouth opening, tongue protrusion, and drooping eyelids



- As children age, cataplexy presentation changes into the classical forms observed in adults.<sup>8,12,20,21</sup>

Look for cataplectic facies during the Clinical Interview (page 11)

See additional examples at [PediatricCataplexy.com](http://PediatricCataplexy.com)

## Recognizing Hallucinations

Hypnagogic (occurring at sleep onset) and hypnopompic (occurring while awakening) hallucinations include primary visual hallucinations, such as seeing shadowy figures, animals, people, and formed shapes in the room.<sup>1,10</sup> Up to 66% of patients report experiencing hypnagogic/hypnopompic hallucinations.<sup>10</sup> Therefore, uncovering the presence of these hallucinations can be helpful when looking for narcolepsy.

- For younger children, hallucinations can be scary and, in some cases, may cause them to fear going to bed.<sup>10,24</sup>
- Young children may be unable to distinguish hallucinations from reality, making obtaining an accurate history of this symptom difficult.<sup>14</sup>

## Recognizing Excessive Daytime Sleepiness

Excessive daytime sleepiness, the cardinal symptom of narcolepsy,<sup>5</sup> may present differently in children, making it more difficult to identify in this patient population.<sup>8,14</sup>

- Younger children may present with elongation of daytime naps and nighttime sleep, with earlier bedtimes.<sup>5,8,14</sup>
- Older children may restart regular daytime napping after naps have been discontinued.<sup>1,5,8</sup>
- Nap durations are generally longer compared with adults and may be unrefreshing.<sup>8,25</sup>
- Confusional arousals, or awakening without becoming fully aware,<sup>1</sup> lasting up to 15 to 30 minutes, can occur upon awakening in the morning or from naps.<sup>8,25</sup>
- Children and adolescents with excessive daytime sleepiness may present as aggressive, irritable, or hyperactive in an attempt to cope with or counteract sleepiness.<sup>8,14</sup>
- Excessive daytime sleepiness is often not recognized as abnormal until cataplexy appears.<sup>25</sup>

Because of its unusual presentation in children, excessive daytime sleepiness is often mislabeled or overlooked as laziness or inattention.<sup>14</sup> When associated with irritability and hyperactivity, it is often misdiagnosed as another behavioral condition, such as attention-deficit/hyperactivity disorder (ADHD).<sup>6,14</sup>

Distinguish between symptoms of narcolepsy and common pediatric conditions through a Differential Diagnosis (page 15)



## Recognizing Sleep Paralysis

Because children may have difficulty describing sleep paralysis and appropriately reporting the inability to move when falling asleep or waking up, it may be difficult to confirm sleep paralysis in children.<sup>5,8</sup>

- In addition to being unable to move when falling asleep or waking up, children with sleep paralysis may describe difficulty breathing, despite normal respiratory function.<sup>10,26</sup>
- Sleep paralysis usually lasts for a few seconds to a few minutes and can end spontaneously or when the child is touched, shaken, or spoken to.<sup>10,16</sup>
- Sleep paralysis may be an age-dependent phenomenon, as its appearance slowly progresses in young patients along the disease course.<sup>5,8,22</sup>

## Recognizing Sleep Disruption

Children and adolescents with narcolepsy may have difficulty maintaining sleep,<sup>5,27</sup> and may experience frequent nighttime awakenings.<sup>5,27,28</sup>

- In children and adolescents, disrupted nighttime sleep may impact cognition, emotional regulation, and neurobehavioral functioning.<sup>1</sup>
- Disrupted nighttime sleep may not be reported by pediatric patients or their caregivers unless targeted questions are asked.<sup>25</sup>

## The Clinical Interview

For pediatric patients, including a caregiver in the clinical interview can be helpful to corroborate or refute the patient's report of sleepiness or to uncover cataplexy, especially in the case of younger patients who may not be able to describe their own symptoms.<sup>10,29</sup>

## Clinical History and Symptom Assessment

- Obtain a detailed clinical history of associated symptoms.<sup>10,30</sup>
  - Caregivers may be the primary source of information for younger children.
  - Older children and adolescents should be questioned directly about their symptoms; caregivers may help provide additional insight and observation.
- Identify complaints of excessive daytime sleepiness.<sup>10</sup>
  - Children and adolescents may use terms such as “tiredness” or “lack of energy” to describe sleepiness.
  - Caregivers or teachers may report hyperactivity, poor concentration, and “bad behavior.”
- Look for cataplectic facies during physical examination.<sup>10</sup>
- Home or school videos may also help confirm cataplexy attacks.<sup>10</sup>



## Questions to Ask During the Clinical Interview

To assess excessive daytime sleepiness, ask patients and caregivers<sup>25,30</sup>:

- Is your child very difficult to wake up in the morning?
- Is your child constantly tired or sleepy during the day?
- Does your child fall asleep during school or other activities?
- Does your child take a nap during the day? If so, how long does it last and is it refreshing?
- Does your child exhibit hyperactivity, poor concentration/cognitive problems, or “bad behavior”?

Use the Epworth Sleepiness Scale for Children and Adolescents (ESS-CHAD) with patients and their caregivers to identify excessive daytime sleepiness

*The ESS-CHAD is not intended to make a narcolepsy diagnosis or replace complete evaluation by a sleep specialist.*



To assess cataplexy, ask patients and caregivers<sup>31,32</sup>:

- Has your child ever reported feeling sudden weakness in their legs, arms, head, or face when having fun or feeling excited, angry, or laughing?
- How often have you noticed the following in your child:
  - Falling down?
  - Head dropping?
  - Tongue sticking out, mouth opening, eyelids drooping, eyes closing, or eyes rolling?

Patients and caregivers can use the Sleep/Cataplexy Diary to identify possible events and discuss them with a sleep specialist

*The Sleep/Cataplexy Diary is not intended to make a narcolepsy diagnosis or replace complete evaluation by a sleep specialist.*

To assess hallucinations, ask patients and caregivers<sup>4,5,25,30</sup>:

- How often does your child have vivid dreamlike experiences?
- How often does your child see or hear things that are not really there when falling asleep or waking up?

To assess sleep paralysis, ask patients and caregivers<sup>10,26</sup>:

- How often does your child feel unable to move or speak when falling asleep or waking up?

To assess sleep disruption, ask patients and caregivers<sup>25,30</sup>:

- Does your child still take naps?
- Is your child very difficult to wake up in the morning?
- How often does your child wake up during the night? For how long?
  - Does your child have trouble getting back to sleep after waking up during the night?



## Differential Diagnosis

Narcolepsy in pediatric patients is often misdiagnosed as a more common medical condition, such as ADHD, epilepsy, depression, syncope, or other sleep disorders.<sup>1,8-10,21</sup> Further complicating diagnosis, children with narcolepsy commonly present with behavioral or mood disorders, such as ADHD, depression, and anxiety, which may be part of the clinical spectrum of the disease itself, reactive to the disease, or a comorbid psychiatric condition.<sup>8,14,33</sup> Therefore, when making a differential diagnosis, it's important to remember that narcolepsy is a rare illness that can sometimes be comorbid to other conditions.<sup>1,8,14,33</sup>

## Distinguishing Narcolepsy From More Common Conditions

### Narcolepsy and/or ADHD?

Manifestations of excessive daytime sleepiness in narcolepsy can be mistaken for symptoms of ADHD.<sup>6,14</sup>

- Children with excessive daytime sleepiness may present as aggressive, irritable, or hyperactive in an attempt to cope with or counteract sleepiness.<sup>8,14</sup>
- Excessive daytime sleepiness is frequently mislabeled as laziness or can manifest as hyperactivity, inattention, or behavioral problems, which may be misdiagnosed as ADHD.<sup>14</sup>
- Treatment of ADHD may improve sleepiness-related hyperactivity, further confounding the narcolepsy diagnosis.<sup>1,8</sup>

## **DISTINGUISH NARCOLEPSY**

**Patients with narcolepsy may have difficulty maintaining sleep but fall asleep easily,<sup>5</sup> while patients with ADHD can demonstrate objective and subjective sleep onset difficulties.<sup>34</sup>**



### Narcolepsy and/or Epilepsy?

The sudden, recurrent, and intensifying nature of cataplexy may be confused with a seizure disorder.<sup>12,21,23</sup>

- Sudden loss of muscle tone associated with cataplexy can be mistaken as seizures.<sup>21</sup>
- Cataplexy attacks that present as asymmetric loss of muscle tone or facial cataplexy that resembles twitching may be mistaken for focal seizures.<sup>21</sup>
- Microsleeps can clinically resemble absence seizures.<sup>21</sup>

#### **DISTINGUISH NARCOLEPSY**

- **Consciousness is maintained during a cataplexy attack.**<sup>21</sup>
- **Electroencephalogram abnormalities are present during epileptic attacks and in between attacks.**<sup>21</sup>
- **Triggers for cataplexy attacks are typically emotions; triggers for reflex seizures are usually sensory stimuli, such as light, photostimulation, or touch.**<sup>21</sup>

### Narcolepsy and/or Mood Disorder?

Several symptoms associated with narcolepsy may be attributed to depression, anxiety, or other psychiatric disorders.

- Children with narcolepsy frequently present as overweight/obese, particularly close to disease onset.<sup>12,35</sup>
- Symptoms such as fatigue, disrupted nocturnal sleep, and weight change may be attributed to mood disorders.<sup>14</sup>
- Hypnagogic hallucinations may be confused with night terrors, nightmares, or panic attacks, or they may be mistaken for symptoms of psychiatric disorders.<sup>10</sup>

#### **DISTINGUISH NARCOLEPSY**

**Seek objective measures of sleep characteristics using polysomnography (PSG)/multiple sleep latency test (MSLT) to differentiate from sleepiness associated with mood disorders.**<sup>8,14</sup>

### Narcolepsy and/or OSA?

Weight gain is common at the onset of narcolepsy, which may predispose patients to develop sleep-disordered breathing.<sup>12,35</sup> As a result, these patients may receive a diagnosis of obstructive sleep apnea (OSA).<sup>12</sup> Although OSA and narcolepsy can occur together, misdiagnosis of OSA as the primary cause of sleepiness can cause a delay in the diagnosis of narcolepsy.<sup>12</sup>

#### **DISTINGUISH NARCOLEPSY**

- **Other symptoms of narcolepsy, such as hypnagogic hallucinations, automatic behavior, sleep paralysis, and excessive and unusual dreaming, can be present in addition to excessive daytime sleepiness.**<sup>12</sup>
- **Cataplexy is present.**<sup>12</sup>



## Narcolepsy Symptoms May Appear Similar to Other Disorders

### Myopathy

- Close to disease onset, cataplexy can mimic a spectrum of motor disorders and muscle diseases, resulting in a misdiagnosis of myopathy.<sup>14,20,23</sup>

### Syncope

- Loss of muscle tone and rapid recovery associated with cataplexy may be confused with syncope.<sup>21</sup>
- To differentiate cataplexy attacks from syncope, thorough screening for cardiac arrhythmias, head up tilt table testing, and video recordings of the attacks may be necessary.<sup>21</sup>
- Preserved consciousness distinguishes cataplexy from syncope.<sup>21</sup>

### Sydenham Chorea and PANDAS

- Sydenham chorea and pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections (PANDAS) are brain autoimmune poststreptococcal diseases that occur in pediatric patients.<sup>20</sup>
- Narcolepsy with cataplexy is often confused with Sydenham chorea or PANDAS due to overlap of certain characteristics, such as episodic course, childhood onset with acute presentation following streptococcal infection, and coexistence of motor and behavioral symptoms that present similarly to cataplexy and excessive daytime sleepiness in narcolepsy in pediatric patients.<sup>20</sup>



### Myasthenia Gravis

- Facial weakness and ptosis in cataplexy can mimic myasthenia gravis; however, these symptoms are not triggered by emotion and fluctuate throughout the day.<sup>21</sup>

### Tardive Dyskinesia

- Tardive dyskinesia is a drug-induced movement disorder caused by long-term use of neuroleptic drugs.<sup>36</sup>
- Symptoms include facial grimacing, tongue protrusion, sucking, or fish-like movements of the mouth.<sup>36,37</sup>
- The arms and/or legs may also be affected by involuntary rapid jerking movements or slow writhing movements.<sup>37</sup>
  - Symptoms of tardive dystonia include slower twisting movements of larger muscles of the neck, trunk, and face.<sup>37</sup>
- Cataplexy can present as active motor phenomena ranging from raising of the eyebrows, perioral and tongue movements, facial grimaces, swaying of the head and/or trunk, stereotyped motor behavior, and dyskinesic or dystonic movements.<sup>20</sup>

### Consider narcolepsy for pediatric patients presenting with:

- Manifestations of excessive daytime sleepiness and abnormal motor phenomena<sup>5,38</sup>
- Excessive daytime sleepiness with episodic loss of muscle tone, poor attention, and/or weight gain<sup>19</sup>



## Narcolepsy Screening in Pediatric Patients

### Epworth Sleepiness Scale for Children and Adolescents (ESS-CHAD)

The ESS-CHAD is a validated screening tool for use in pediatric patients.<sup>31,39</sup> This tool is a modified version of the ESS that has been validated to measure sleepiness in patients 12 to 18 years of age.<sup>31,39</sup>

**Minor changes were made to the instructions and descriptions of some activities on the ESS to improve relatability and comprehension by children and adolescents of the ESS-CHAD.<sup>31</sup>**

Scoring and interpretation of the ESS-CHAD is the same as that for the ESS.<sup>31,39-41</sup>

Use ESS-CHAD to screen pediatric patients who present with excessive daytime sleepiness

*The ESS-CHAD is not intended to make a narcolepsy diagnosis or replace complete evaluation by a sleep specialist.*

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to help in making a narcolepsy diagnosis

# Narcolepsy Can Start in Childhood and Adolescence

Symptoms of narcolepsy may present differently in pediatric patients.<sup>5,6,14</sup> As children become adolescents and adults, the symptoms of narcolepsy may manifest differently and change over time.<sup>5,6,14</sup>

For patients who report these symptoms...



**RECOGNIZE**



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