

Narcolepsy Plan of Care for: _____
(Name of Student)

School: _____

School Year: _____ Birth Date: _____ Grade: _____

References:

Definitions and Terms Used in This Plan of Care:

Narcolepsy: Narcolepsy is a neurological disorder characterized by overwhelming daytime sleepiness for long periods of time, regardless of the circumstances. Narcolepsy can cause serious disruptions in daily routines.

Cataplexy: Cataplexy is sudden muscle weakness triggered by strong emotions like embarrassment, laughter, surprise, or anger. Cataplexy can cause the head to drop, the face to droop, the jaw to weaken, or the knees to give way. Attacks can also affect the whole body and cause falls. Cataplexy can be hard to recognize in children and adults. It can range from small muscle twitches to full body collapse. Cataplexy attacks in children are often most noticeable as odd facial movements, such as:

- Droopy eyelids or eyes closing
- Mouth opening or mouth movements
- Tongue sticking out
- Grimacing
- Slowed or slurred speech
- Urinary incontinence

Idiopathic Hypersomnia: a chronic neurological disorder marked by an insatiable need to sleep that is not eased by a full night's slumber. People with idiopathic hypersomnia sleep normal or long amounts of time each night but still feel excessively sleepy during the day. They may take long naps but wake up feeling no better or worse than when they fell asleep.

Excessive Daytime Sleepiness: People with narcolepsy fall asleep without warning, anywhere, anytime. For example, the person may be working or talking with friends and suddenly they nod off, sleeping for a few minutes up to a half-hour. When they awaken, they feel refreshed, but eventually get sleepy again. They may also experience decreased alertness and focus throughout

the day. Excessive daytime sleepiness usually is the first symptom to appear and is often the most troublesome, making it difficult for people with narcolepsy to concentrate and fully function.

Microsleeps: Individuals with narcolepsy may experience temporary sleep episodes that can be very brief, lasting for a few seconds to a few minutes at a time. A person falls asleep during an activity (e.g., eating, talking) and automatically continues the activity for a few seconds or minutes without conscious awareness of what they are doing. During microsleeps, the brain goes into REM stage sleep instantly. This happens most often while people are engaged in habitual activities such as typing or driving. They cannot recall their actions, and their performance is almost always impaired. Their handwriting may, for example, degenerate into an illegible scrawl, or they may store items in bizarre locations and then forget where they placed them. If an episode occurs while driving, individuals may get lost or have an accident. People tend to awaken from these episodes feeling refreshed, finding that their drowsiness and fatigue has temporarily subsided.

Microsleeps can be difficult to identify because the person may nod off while their eyes are still open. Symptoms associated with this condition include:

- not responding to information
- a blank stare
- dropping head
- experiencing sudden body jerks
- unable to remember the last one or two minutes
- slow blinking

Sleep Attacks: A sleep attack is the sudden and irresistible urge to fall asleep, regardless of mood, activity or setting. Sleep attacks tend to happen suddenly and without warning, and can be extremely jarring to those around. Sleep attacks can last between a few seconds and a few minutes, and in extreme cases can happen multiple times a day.

In narcoleptics, because of the quick onset of REM sleep characteristic of a sleep attack, a sufferer will likely experience some muscle paralysis. They may also feel as though they're dreaming and be disoriented or frightened upon waking.

Memory Problems: People with narcolepsy function as if they have been awake, with no naps, for 48-36 hours. The most immediate, most obvious impact of sleep deprivation is on brain performance. Sleepiness affects working memory, the memory needed to process in real time, like when holding several numbers in your head. It is also important for the formation of more long-lasting memories. The brain transforms an experience into a memory in two discrete steps, encoding an event as a temporary memory and then consolidating it into long-term storage. In order to do this well, it is important to have good sleep both before and after an experience.

Hypnagogic/Hypnopompic Hallucinations: Vivid dreamlike experiences—called hypnagogic or hypnopompic hallucinations—can seem real and are often frightening. They may be mistaken for nightmares, and they can occur while falling asleep (hypnagogic) or waking up (hypnopompic). During these hallucinations, the person may feel someone touching them, hear sounds or words, or see people or creatures near them or even lying next to them.

Sleep Paralysis: Sleep paralysis is the inability to move or speak for a short time when a person is falling asleep or waking up. This can be a frightening or disturbing experience. Episodes usually

last seconds to minutes and can end by themselves or from being touched, shaken, or spoken to, or after trying hard to move.

During sleep paralysis, a person can experience:

- Eye fluttering
- Moaning
- Limb numbness or tingling
- Rapid or strong heartbeat
- Sweating
- Sensation of struggling to move
- Chest pressure
- Difficulty breathing

Ketogenic Diet: The Ketogenic Diet for Narcolepsy is a high fat, moderate protein, low carbohydrate diet which switches the body from burning glucose (which carbs provide) to burning ketones (which fat produces) for energy. This special diet alters genes involved in energy metabolism in the brain, which in turn helps stabilize the function of neurons in the hippocampus, the area of the brain impacted by narcolepsy. Ketogenic Diet treatment significantly increases the number of mitochondria per unit area in the hippocampus, enhancing energy production in the hippocampus. People with narcolepsy on a Ketogenic Diet usually experience an 18% - 50% reduction in medication use.

Stimulant: Drugs that stimulate the central nervous system are the primary treatment to help people with narcolepsy stay awake during the day.

1. Nature of Disability

This student has _____ Idiopathic Hypersomnia _____ Narcolepsy with/without (*circle one*) cataplexy. Idiopathic Hypersomnia and Narcolepsy are chronic neurological disorders that affects a person's ability to wake and sleep. People with idiopathic hypersomnia and narcolepsy have excessive, uncontrollable daytime sleepiness. They may also suddenly fall asleep at any time, during any type of activity.

People with narcolepsy go into REM sleep almost immediately in the sleep cycle and sometimes while they're awake.

Changes in cognitive function including compromised attention and concentration, reduced capacity to process information, disruptions in memory and reduced ability to multitask are also manifestations of these diseases.

This student's treatments include:

2. The Student's Symptoms and Needs:

_____ (the student) has the following symptoms and needs, which may change over time:

- _____ Excessive daytime sleepiness which may require daytime naps
- _____ Memory impairment
- _____ Ketogenic Diet
- _____ Requires frequent bathroom breaks
- _____ Requires Water throughout the day

_____ Student takes medication during the school day: _____

_____ Student takes medications at home: _____

- Side effects of medications may cause: _____

_____ Student receives treatments/office visits that require absences from school

- Frequency: every _____ weeks/months (*circle one*)
- Expected duration of absence: _____ days per treatment/visit

3. Accommodations Recommended by Physician (*check those that apply*)

A. _____ The student will be encouraged to engage fully in all school activities and will not be discouraged from taking medication on time, eating snacks on time, complying with all dietary restrictions, or any of the other accommodations set forth in this plan. All of the provisions of this Plan shall be provided without penalty to the student.

B. _____ The student will be permitted to participate in all field trips and extracurricular activities without restriction and with all accommodations and modifications set forth in this plan.

- i.** The student will not be penalized for sleeping on the bus when in route to any extracurricular activity.

- C.** _____ The student may alter location in classroom seating charts to suit their needs, for example:
- i.** Have a seat at the back of the class or end of the row so he/she can stand as needed, or
 - ii.** Have a seat at the back of the class in order to avoid embarrassment when falling asleep during class
 - iii.** Have a seat near a window to allow for natural light.
- D.** _____ The student will be permitted to carry and drink water, eat small meals, candy (to treat dry mouth), or snacks throughout the day, in or out of class, as the student deems necessary or appropriate due to medically necessary dietary restrictions.
- E.** _____ The student will be allowed unlimited access to the nurse any time the student requests.
- F.** _____ The student will be permitted to administer his/her own medications in school.
- i.** If for medical reasons the student is not permitted to administer his/her own medications, the medications will be left with the school nurse, who will administer them to the student at times consistent with prescribing instructions
 - ii.** If the school nurse requires training in administration of the student's medication, the 504/SPED Plan Coordinator shall ensure that the school nurse receives such training within ten business days.
- G.** The classroom teacher will adapt classroom instruction when narcolepsy symptoms are present, or at the request of the student, by:
- i.** _____ The classroom teacher will provide clarification or rewording of vocabulary, complex sentences, and concepts when requested by the student.
 - ii.** _____ The student will be given extra time for oral responses.
 - iii.** _____ The classroom teacher will repeat and re-explain instructions as needed.
 - iv.** _____ The teacher will check for understanding and reteach/reread materials as indicated
 - v.** _____ The student will be able to use highlighters, markers, or colored pencils as tools to assist with memory deficits as needed.
 - vi.** _____ The classroom teacher will supply the student with class notes when the student has left for a nap, or otherwise experiences symptoms in the classroom.
 - vii.** _____ The student will be allowed to re-do assignments/ quizzes/tests when the student's work does not resemble his/her normal level of work production
 - viii.** _____ The student will be given extra time (time and a half) for completing all homework assignments.

- ix. _____ The student will be given extra time (time and a half) for completing all tests and quizzes.
 - x. _____ The student will not be given more than 2 major tests in one day.
 - xi. _____ The student will be provided with word banks for tests.
 - xii. _____ The student will receive testing in a small group environment and will be allowed to stand during tests, stretch and/or move around as needed, and will not be penalized for falling asleep during testing.
 - xiii. _____ All tests and quizzes will be given orally and read out loud to the student.
 - xiv. _____ The Student will be allowed the use of a calculator in all math classes and during all math quizzes and tests.
- H. _____ The student will be allowed to manage the excessive daytime sleepiness of narcolepsy by assigning the student a designated area for scheduled nap time, allowing the student to go to the nurse when he/she needs a nap or feels the he/she is about to have a sleep attack, giving the student a “study hall” period in the middle of the day for a nap, and/or scheduling more challenging academic periods at a time of day when the student normally feels less drowsy.
- i. The student will not be penalized for taking naps or visiting the nurse during the day.
- I. _____ There will be "stop the clock testing." "Stop the clock testing" means that, when the student is taking an exam, if he/she falls asleep for any reason, the time for completing the test will be extended by the amount of time the student spends away from the testing room. This accommodation shall be provided without penalty and shall apply to all tests including but not limited to State Standardized Testing and course exams.
- J. _____ If, because of his/her narcolepsy symptoms or medical treatments, the student is unable to take an exam or submit a major project on a given day, the exam or major project deadline will be rescheduled.
- i. Cumulative term grades will not be determined until the student has had opportunity to take the make-up exam or complete the major project. This accommodation shall be provided without penalty and shall apply to State Standardized Testing as well as course exams, term papers and projects.
- K. _____ If the student is unable to meet a deadline on any project due to anything related to his/her narcolepsy symptoms and treatment requirements, the project deadline will be rescheduled. This accommodation shall be provided without penalty. "Major projects" are defined as those that are assigned more than one week before they are due.
- L. _____ The student will be given assistance to help him/her make up any classroom time missed due to the student's narcolepsy, as set forth below.

requires extra help to make up missed work and, if so, shall coordinate with the teacher(s) to ensure that in-school tutoring is provided as necessary.

- iii. If in-home or hospital tutoring is appropriate, the school shall provide a sufficient number of hours a day of tutoring so as to keep the student current in his/her classes and assignments.
 - 1. Teachers shall accept any and all work performed under the supervision of a tutor as if it were done at the teacher's instruction.
 - 2. Work performed under the supervision of the tutor shall be designed to keep the student current in his or her assignments.
 - 3. Any and all assignments shall be designed to show the student's competence in the subject area; quality rather than quantity of the work shall be emphasized. This accommodation shall be provided without penalty.

N. _____ We strongly encourage our patients to attend school on a regular basis. But it's important for you to know that narcolepsy can interfere with the ability to perform some academic tasks or functions at school.

- i. The student will not be penalized for tardiness or absences required for medical appointments and/or illness.
- ii. If the school gives an award for perfect attendance, the student will remain eligible for that award if his/her only absences are due to medical appointments and/or treatment.
- iii. If the student is tardy, he/she will be permitted to participate in school for that portion of the day for which he/she is in attendance.

4. Emergency Contacts:

<i>Parent/Guardian Name</i>	<i>Home Phone</i>	<i>Cell Phone</i>
-----------------------------	-------------------	-------------------

<i>Parent/Guardian Name</i>	<i>Home Phone</i>	<i>Cell Phone</i>
-----------------------------	-------------------	-------------------

5. Additional Emergency Contacts:

<i>Name</i>	<i>Home Phone</i>	<i>Cell Phone</i>
-------------	-------------------	-------------------

<i>Name</i>	<i>Home Phone</i>	<i>Cell Phone</i>
-------------	-------------------	-------------------

6. General Physician:

Name *Address* *Phone*

7. Specialists:

1. _____

Name *Address* *Phone*

Specialty: _____

Diagnosis: _____

2. _____

Name *Address* *Phone*

Specialty: _____

Diagnosis: _____

3. _____

Name *Address* *Phone*

Specialty: _____

Diagnosis: _____

8. Signatures:

Signing Physician's Name: _____ **Date:** _____

Physician's Signature: _____

Parent Name: _____ **Date:** _____

Parent's Signature: _____