

# How to Talk About Narcolepsy

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## WHY TO TELL:

There are many reasons why this is very important. For one, narcolepsy doesn't present like a cast on your arm. It isn't apparent like some other conditions. This means that on the outside, we look like we are totally fine, when we aren't. This can be good and bad. As teenagers, we all know that saying, "I'm tired," is common and standard. Therefore, how would your teacher know that you fell asleep in class because of health and not boredom or partying the night before? If you tell them, you won't face situations where you are accused of misbehaving or sleeping during class. Also, teachers will understand why you may need extra time on tests, homework extensions, classroom breaks, etc. They can't do this unless you tell them you have narcolepsy and give them examples of how they can help you be successful. Outside of school, there are situations such as sleep-overs, when the supervising adult needs to know about your medications and symptoms.

## PERSONAL EXPERIENCE:

I attended a school overnight retreat. We slept under the stars. When I take Xyrem, I sometimes become confused. On this retreat, I woke up in the middle of the night and wandered into the woods. The following night, my teachers had me sleep in a tent with an adult. On future retreats, I will always be placed in a room with an adult. They also check in with me to make sure I have taken my medications or administer them directly to me.

## HOW TO TELL:

Telling people you have narcolepsy can be scary, especially if you are new to informing others. A parent or adult may be the person to tell others about their son or daughter's narcolepsy. However, as a child matures, it is important for them to advocate for themselves. This is a process, with the goal of independence.

## WHO TO TELL?

It is important to inform TEACHERS, COACHES, and close FRIENDS. Consider who is important in your life, and also your unique circumstances, such as situations outside of school (sleep-overs, work place/volunteer work, community events).

## WHAT TO TELL:

You could go on for hours telling people about narcolepsy but it's important that you keep your message concise so they do not feel overwhelmed or confused. The first thing to do is to tell them you have narcolepsy. Give a clear one sentence definition of narcolepsy. Briefly explain your symptoms and how it could affect you in a specific situation. Tell them what you need and how they can help you.

## WHEN TO TELL:

This all depends on your circumstance. However, I think it's more beneficial to inform others

early on. This shows that you are responsible and it should be taken seriously. Here's a few examples:

Early discussion: (recommended)

"Hi Ms. Brown, I am so excited for biology this year! I want to let you know that I have narcolepsy, a neurological sleep disorder. This means that I have excess fatigue during random times of the day, and when I laugh, I have something called cataplexy. Cataplexy causes me to lose muscle control, and possible slump on my desk or even fall, for a brief period of time but I am conscious. I can still hear what is going on. What I need from you is to understand that if I fall asleep in class, I am experiencing one of these symptoms and would appreciate being woken up. If I do laugh and fall down, I would want one person to sit by me until I get up and then I will be fine. I have also emailed you my Formal Learning Plan, which lists accommodations I may need to help me do my best in your class. If you have more questions or concerns, feel free to talk to me further or look at the narcolepsy website."

In the moment: (not recommended)

"Oh, hey Coach Taylor, umm by the way, I am not going to go to practice today because I'm really tired. I have this thing called Narcolepsy, it's like a sleeping disorder, and ya, it makes me tired. So can I be excused today?"

What's wrong with this way of informing?

WHERE TO TELL:

There are many places you can inform other people. For faculty at school I prefer email because I can get my words across better through writing, but it's up to you. Whatever way you feel the most comfortable is the best way to inform people. However, if you're doing it in person, try to find a private, quiet place to talk. This shows that you take it seriously and also protects your privacy.

Which places would be good and why?

Cafeteria (TEACHER, FRIEND)

Teacher's office (TEACHER)

During passing time in class (TEACHER, FRIEND)

At a party (FRIEND)