



## Narcolepsy Perspectives: A blog about anything & everything Narcolepsy

### Importance of Intentional Rest For People with Narcolepsy

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**November 4, 2024** - When people see me constantly falling asleep on the bus, in cafes, at parks (and everywhere in between), it can be easy to assume that I already get enough sleep. Maybe even too much.

However, this isn't actually the case...



The [National Institute of Health states that](#), “While individuals with narcolepsy are very sleepy during the day, they usually also experience difficulties staying asleep at night. Sleep may be disrupted by insomnia, vivid dreaming, sleep apnea, acting out while dreaming, and periodic leg movements.”

#### Why Intentional Rest?

Rest is essential to helping the body recover and restore energy levels for daily activities. Since people with Narcolepsy experience excessive daytime sleepiness (EDS), quality rest is critically important. Our condition already impacts our overall health, daily functioning and quality of life.



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Adequate rest also helps restore immune function. When this happens, we become less susceptible to illnesses. Additionally, sleep disorders can disrupt the body's hormonal balance. This can affect appetite, metabolism and even the body's stress responses. Investing in intentional rest supports hormonal and immune system regulation, promoting better overall health.

#### Symptom Management

One way to honor our increased need for intentional rest is through Narcolepsy symptom management. The National Institute of Health lists [several lifestyle changes](#) that can reduce our symptoms.

First, scheduled naps are a great way to increase the amount of rest we receive on a daily basis. The NIH mentions that scheduling naps during the time(s) of day during which we are the sleepiest can be very effective.

Second, it is important to maintain strict bedtime and wake-up routines. It makes the time we invest into our sleep more efficient by improving the quality. Imagine that! Not to mention, incorporating strict periods of rest can reinforce good sleep hygiene practices.

The NIH also recommends avoiding caffeine, nicotine, and other substances close to bedtime. Exercise during the day as well as relaxation techniques before bed are encouraged.

#### Resting from Stressing

Incorporating mindfulness practices or relaxation techniques can help reduce anxiety and promote a sense of calm, making it easier to transition to sleep at night. Activities such as gentle stretching, deep breathing or progressive muscle relaxation can help manage stress levels and prepare the body for better sleep.

Creating a restful sleep environment—dark, cool, and quiet—can also enhance the quality of sleep. Personally, I find it really helpful to have a comfy, cuddly and warm sleep space.

#### *Some ways I make my sleep comfy:*

- Stuffed animals
- Warming blanket
- Thick, warm comforter



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- Clean sheets
- Charging station for electronics
- Books

### **Avoiding Burnout is Difficult...**

As a person with Narcolepsy, I frequently experience brain fog. This symptom impacts my memory, attention and even my decision-making! Making time for adequate rest can help improve cognitive functions, such as processing information, and enhance overall mental performance.

According to [Johns Hopkins Medicine](#), sleep disorders are often associated with depression. Increased intentional rest can help improve mood and emotional stability, making it easier to cope with the psychological aspects of sleep disorders.

While quality sleep is important, so too is making sure you get enough of it! Individuals with sleep disorders may benefit from pacing their daily activities to avoid overexertion and burnout. Scheduled rest breaks can help manage energy levels and prevent exhaustion.

But for me, it can be hard to convince myself to set aside time specifically for napping. We are already so time-constrained in terms of wakefulness... so, in the moment, investing my limited time into resting can seem like a waste. But it definitely is not.

Not listening to my body's signals around needing rest can result in negative consequences that leave me completely burned out, and even physically ill. Avoiding burnout as a person with Narcolepsy is not an exact science. It takes a lot of trial and error.

Mostly, this is difficult for me because I struggle to set boundaries based on my energy levels. Saying "no" to something that I really want to do is the hardest thing!

### **Advocacy is Self-Care**

Self-advocacy can be intimidating. However, we are deserving of advocacy! Some ways I advocate for my needs include communicating openly with my healthcare providers about my symptoms and the importance of rest in my treatment plan. I also make sure to have these conversations with the people closest to me in my life.

When it comes to setting boundaries around my energy levels I like to start small, especially when meeting new people. For example, a new friend may ask me to drive them to and from an



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event. I might offer to drive them to the event but state that I need to leave them there to take an Uber or Lyft home without me. By doing this, I can gauge peoples' reactions to my limitations. Whether they react positively or negatively can impact how much effort I put into the relationship. For example, if they react negatively I might not want to invest as much time with them because they are likely to push my boundaries for their own agendas. But, if they react positively, I can feel safe enough to establish boundaries with them in the future with less and less fear.

Whether or not people handle our limitations well, practicing self-compassion is so very important. There are so many challenges posed by Narcolepsy. Acknowledging these challenges can be painful. However, practicing self-compassion can help us cope with the frustrations that come along with managing our condition.

Personally, I have a large group of friends that also have Narcolepsy. When I judge myself internally for my condition, I think, "Would I treat my friend this way?" Obviously, I wouldn't! It doesn't make sense to beat myself up for things that are out of my control, especially my Narcolepsy symptoms. My condition is a part of who I am now.

As mentioned previously, it can be difficult to prioritize rest when living with Narcolepsy. However, understanding how important it is to prioritize intentional rest can serve as a good motivator for doing so. Each person's experience with Narcolepsy is unique. It's important to recognize your own personal needs for rest and be proactive in addressing them.

### **Moving Forward**

Prioritizing rest is essential for individuals with Narcolepsy. It supports recovery, helps manage symptoms, and promotes physical and mental health. Although I am not perfect in my continual journey of practicing intentional rest with a condition like Narcolepsy, I am slowly making progress as I grow older and learn the costs and benefits of intentional, guilt-free rest.

### **How will you go forward and practice intentional rest?**



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