



NARCOLEPSY AT WORK TOOLKIT

Created by:

project[★]sleep



TOOLKIT INDEX

| | |
|----------------------------|----|
| Welcome | 3 |
| Narcolepsy at Work | 4 |
| ADA Overview | 16 |
| Sample Application | 17 |
| Sample Doctor Letter | 19 |
| Resources | 20 |



WELCOME!

We are so glad you are here. This toolkit is designed for people living with narcolepsy and their loved ones to offer new tools, tips, and perspectives on navigating narcolepsy. Project Sleep created this toolkit as part of the **Narcolepsy Nerd Alert** series.

Narcolepsy Nerd Alert is an educational series diving deeper into specific topics relevant to narcolepsy. For each episode, Project Sleep broadcasts a live event via Facebook, hosted by Julie Flygare, JD, Project Sleep's President & CEO.

After each live broadcast, we create a corresponding toolkit (like this one!) to capture our collective knowledge to help others down the road. Quotes featured throughout the toolkit are from panelists and participants who joined us for the live broadcast. Narcolepsy Nerd Alert videos and podcasts are also available via our website, YouTube, and wherever you listen.

PLEASE NOTE

The **Narcolepsy Nerd Alert** series is intended for educational and awareness purposes and is not a substitute for medical attention. If anything in this toolkit sparks questions for you about your medical management, please bring those questions to your sleep doctor or narcolepsy specialist.



NARCOLEPSY AT WORK

Managing narcolepsy in the workplace is an individualized process depending on the circumstances. In the United States, many employers are obligated to make **reasonable accommodations** for a **person with a disability** under the Americans with Disabilities Act (ADA) to help employees meet their essential job duties. Reasonable accommodations for a disability may help a person with narcolepsy succeed at work.

On August 31, 2022, Project Sleep hosted the "Narcolepsy at Work" live broadcast to discuss how people with narcolepsy can work with their employers to maximize opportunities for success. This toolkit is a compilation of insights from Julie Flygare's scholarship on this topic, along with input from our panelists and community members.

- Find more info in the "Narcolepsy at Work" video and podcast: <https://project-sleep.com/narcolepsy-nerd-alert-narcolepsy-at-work/>
- Learn more about the Narcolepsy Nerd Alert Series: <https://project-sleep.com/narcolepsy-nerd-alert/>

IMPORTANT:

Please note that the scope of this toolkit does not include short-term and long-term disability or filing for Social Security Disability. These are important topics and we highly recommend the **Hypersomnia Foundation's Disability Claims** resources online at: <https://www.hypersomniafoundation.org/disability-claims/>



MEET OUR GUESTS



Tre Burge is a proud Iowa native working with elementary school students with disabilities. He was diagnosed with type 1 narcolepsy with cataplexy at age 18, and advocates for narcolepsy awareness through content creation, local outreach, and his clothing brand, SLEpPY.



Lindsey Kizer is from Belmont, NC and leads her workplace's Chronic Illness and Disabilities employee group. She was diagnosed with type 1 narcolepsy with cataplexy at age 29 after living with many of the symptoms for over 15 years. She loves to bake, listen to live music, and spend time in her garden and with her husband and rescue pup.



Nicole Zamary is a hard-working Human Resources professional at the University of West Florida. After more than 15 years of struggling with unexplained exhaustion and sleepiness, she was diagnosed with type 2 narcolepsy without cataplexy at the age of 44. She is a compassionate individual, enthusiast of all things crafty, and a grandmother.

MEET THE HOST



Julie Flygare, JD, currently serves as President & CEO of Project Sleep. She was diagnosed with type 1 narcolepsy with cataplexy in 2007 while in law school. Julie is an internationally recognized patient-perspective leader, an accomplished advocate, and the award-winning author of *Wide Awake and Dreaming: A Memoir of Narcolepsy*.



DOES NARCOLEPSY QUALIFY AS A DISABILITY?

In the United States, determining who qualifies as a person with a disability in a work setting is an individualized evaluation made on a case-by-case basis. U.S. law defines an individual with a disability as "any person who has a mental or physical impairment that substantially limits one or more **major life activity**."

What are "major life activities?"

- Major life activities include caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.
- In 2008, new activities were added: eating, **sleeping**, standing, lifting, bending, reading, concentrating, thinking, and communicating.
- While narcolepsy affects many aspects of life, the **inclusion of sleeping** as a major life activity is helpful for people with narcolepsy and other sleep disorders to gain a favorable disability determination toward receiving accommodations.

A diagnosis does not, by itself, qualify an individual as having a disability under United States law. This evaluation is always an individualized process that considers the person's unique circumstances. That being said, it's important to know that many people with narcolepsy in the U.S. are deemed to have a disability and do receive accommodations.

What about medications or other mitigating measures?

- The positive effects of treatment must be ignored in determining if a person meets the definition of disability.
- Furthermore, some medications have negative side effects. If an individual experiences negative effects, this may be considered in the disability determination.



SEE PAGE 16 FOR MORE ABOUT THE AMERICANS WITH DISABILITIES ACT (ADA)



WHAT ARE REASONABLE ACCOMMODATIONS?

To obtain accommodations at work, you and your sleep specialist should clearly explain to your employer what *your specific limitations* are and how *reasonable accommodations* will allow you to perform your essential job duties.

What is a reasonable accommodation?

It's a change or adjustment that allows a person with a disability to perform the essential duties of a job. This may include:

- changing the employee's work schedule
- assigning non-essential functions of the job to other employees
- providing special equipment, devices, or software
- restructuring the job
- providing additional training
- providing paid or unpaid leave needed due to the disability

What would be an unreasonable accommodation?

Unreasonable accommodations would be those that would not help the employee perform the essential functions of the job, or would impose a significant financial hardship on the employer.

What is your doctor's role in helping secure accommodations?

When you formally disclose to your employer, they will likely ask for documentation from a doctor. The doctor's report can confirm your diagnosis, provide a list of symptoms, and discuss specific ways that narcolepsy affects you. The letter should also include ideas for accommodations. See page 19 of this toolkit for a sample letter from a physician.



Most accommodations for narcolepsy have a very low cost to no cost. For example having a nap space — that doesn't really inhibit anything for the employer.

- Nicole



THINKING ABOUT ACCOMMODATIONS

Receiving accommodations is NOT letting narcolepsy win or take control.

Making adjustments for narcolepsy in the workplace means you're being smart and strategic; working *with* your narcolepsy to do your job more effectively and efficiently. Accommodations may help you better manage narcolepsy's symptoms so you are able to better showcase your strengths and talents at work.

It can take time and effort to gain accommodations.

Learning about legal protections, the accommodations process, and accommodations ideas will empower you, your employer, and your doctor to work together. Perseverance and communication are key.

Your situation is unique, and your accommodations may be too.

You may be the first person with narcolepsy to get accommodations at your workplace. Plus, narcolepsy affects each person differently, and some types of accommodations may not fit for certain jobs. What works best for you may be a creative combination of tools and strategies, such as:

- nap breaks
- space to nap
- flexible or consistent scheduling
- working from home
- equipment such as a standing desk or recording pen
- addressing cognitive issues



ACCOMMODATION IDEAS

These examples of work accommodations were compiled directly from people living with narcolepsy. Additional ideas can be found on the Job Accommodations Network's database: <https://askjan.org/soar.cfm>

Taking Nap Breaks:

- A nap during lunch
- Additional breaks to take medication
- An early lunch (10:30am) to take a nap
- A nap daily for 20-30 minutes
- A 15-minute nap every 3-4 hours

Providing Space to Nap:

- Creating a "nap room" for naps
- Providing the new mothers' nursing room as a nap space with sofa and locked door for naps
- Allowing naps in the general quiet room with couches
- Providing a key to various first aid rooms to use as crash room for sleep attacks
- Allowing naps in the workplace's clinic if needed

Flexible Scheduling:

- Flexibility in arrival time
- Not scheduling clients back to back
- Flexible working hours to avoid peak traffic hours
- Allowing up to 5 minutes late arrival for shift, given difficulty waking up
- Flexibility to work outside of usual hours when needed

Working from Home:

- Working from home office once or twice a week
- Working from home with internet to still participate in web meetings
- Option of working from home on days when brain fog is strong
- Providing a laptop and permission to work from home

Consistent scheduling:

- Assignment to the morning shift to allow for routine sleep schedule
- Not required to do "clopening" shifts - closing shift one night and then opening the next morning
- Assignment to afternoon shifts because unable to wake up consistently with alarm in the morning



ACCOMMODATION IDEAS

Working Environment:

- Not working in "high noise level" area of the workplace if it triggers EDS and/or cataplexy
- Providing a more comfortable desk in an area that has a window with plenty of natural light
- Permission to stand or take breaks during meetings
- When traveling longer than two hours for a business trip, permission to stay overnight at a hotel
- Permission to bring a service dog into the workplace

Addressing Cognitive Issues:

- Providing dictation software or a "smart pen" to record meetings
- Reviewing and writing down tasks with supervisor in case of brain fog



TYPES OF ACCOMMODATIONS

What accommodations would be most helpful for me?

It's important to think about this and discuss with your doctor *before* requesting accommodations from your employer. Your employer will not know what will best help you, so it's important that you bring ideas for accommodations to the table. You may also want to have backup ideas in case your employer doesn't approve your initial suggestions for accommodations.

Accommodations should reflect potential needs *on your worst day*. You may not always need to use them, but it's better to have a plan before a difficult situation arises. For example, **Nicole** has an accommodation that allows her a flexible schedule when she has a rough morning, and she communicates with her supervisor when that happens.

What if my needs change over time?

Your needs may evolve depending on your role, responsibilities, symptoms, and medications. As circumstances change, you and your employer can re-evaluate and make adjustments as needed.

Lindsey's position within her company has changed, as well as her medications and daily symptoms, so she and her employer have adjusted her accommodations to fit her current situation. She explains, "What I needed when I started was very different from what I need now. A lot of it has been me communicating my needs directly with my supervisor."



We're people, and we don't know from moment to moment exactly how we're going to feel and what we're going to need. And we can't always document every aspect of it.

- Nicole



DISCLOSURE

When should I disclose my narcolepsy diagnosis to my employer?

There is no hard and fast rule about when to disclose one's narcolepsy to an employer. Potential employers cannot make disability inquiries until after a **conditional offer of employment** is made. Drug tests and medical exams should only be conducted after the offer of employment is made as well. There are rules about confidentiality.

It's a good idea to discuss narcolepsy with an employer *before* problems arise. For example, many employers may be able to accommodate an employee taking a nap or arranging a more flexible schedule. However, if narcolepsy affects one's performance before disclosure, an employer may misinterpret symptoms as laziness, inattentiveness, or poor performance.

Individuals may be reprimanded for actions related to narcolepsy, like falling asleep on the job, while the employer is unaware of the disability. Misperceptions and poor performance will hurt the trust and mutual respect between an employee and employer.

When requesting reasonable accommodations due to disability, be prepared to disclose your diagnosis exactly along with specific examples of the reasonable accommodations you would like. Also, a letter from your sleep specialist providing basic narcolepsy information and detailing your symptoms and treatment will be helpful for securing accommodations.



Disclosing narcolepsy and asking for accommodations — it's open communication with your employer, so that they have an understanding of what you're going through and what you need.

- Nicole



DISCLOSURE

It may feel uncomfortable discussing your diagnosis and requesting accommodations. Yet, if narcolepsy might impact your work, bringing this up is important. Many employers are obligated to make reasonable accommodations under the ADA to help employees meet their essential job duties. In some settings, an informal disclosure may be appropriate. After establishing good rapport with an employer, an honest discussion about narcolepsy may be a good idea.

When disclosing your diagnosis, there are **three main points** to include for a positive and productive conversation with your supervisor or Human Resources:

Basic narcolepsy facts

Lack of awareness about narcolepsy and misperceptions may lead to exaggerated concern or lack of concern. Here's a **narcolepsy fact sheet** you can share with your employer:

<https://project-sleep.com/wp-content/uploads/2019/08/Narcolepsy-Quick-Facts.pdf>

“When I get hired, I disclose about my narcolepsy. Never before, never during an interview. As soon as I get hired, I'm having that conversation.

- Tre

How narcolepsy affects you

No two people with narcolepsy are exactly the same. Some people experience great improvements with proper diagnosis and treatment, while others struggle to find adequate therapies to manage symptoms, side effects, and other complexities. Some individuals may find short naps restful while others do not. It's important to clearly communicate how narcolepsy affects *you* in order to identify the accommodations that will be most helpful.

It's a good idea to highlight strengths and skills along with the challenges you experience. For example, you might mention you are very organized, which helps you stay on task if you're having brain fog, or you take excellent notes because you sometimes struggle with memory issues.

Accommodations suggestions

You and your doctor should have a discussion and prepare a list of specific adjustments that would help you fulfill your essential job duties. A list of example accommodations from people with narcolepsy is on pages 9-10 of this toolkit, or search the Job Accommodations Network's database:

<https://askjan.org/soar.cfm>



TELLING CO-WORKERS

Should I tell my co-workers about my narcolepsy?

Deciding how, when, and with whom you share your diagnosis is a personal decision. Like most people, your co-workers may have misperceptions of narcolepsy or may not know what to ask or say. Remember that you're the expert on your experience and consider sharing with co-workers as an educational opportunity.

If you choose to share your diagnosis with a colleague, they may be able to help support your experience. For example, **Lindsey's** coworker would 'ping' her (via online chat system) if she was "dazing out," and **Tre** sometimes asks a colleague to chat with him when he's feeling sleepy.

“ I work on a pretty small team and most of them had never even heard of narcolepsy. Explaining what it is and how it affects me — I think that made an impact.

- Lindsey

For those with supportive employers, the workplace can even be a place for broader narcolepsy education and advocacy. **Tre**, who works with elementary school students, is very open about his diagnosis. "My principal allowed me to speak to the school about it, and sometimes I'll ask the kids, 'What's my sleep disorder called?' and they'll say, 'Narcolepsy!'"

After her disclosure, **Lindsey** took the lead on forming an employee resource group for people with disabilities at her company. "So many people tell me how helpful it is to have a safe space with others who understand what it's like to be working and applying for accommodations. It's a very cool experience."

“ I had a friend at work who knew about my narcolepsy, and sometimes I would go in her office and say, 'Let's get out of the building.' So we'd walk outside, get some fresh air, and then I'd feel like, 'Okay, I got this.'

- Nicole



KEY TAKEAWAYS

- Disclosing your diagnosis and seeking accommodations are personal decisions, and not a sign of weakness.
- Address concerns before problems arise.
- Brainstorm what accommodations you'd like before starting the formal process with your employer. Think about what you would need on your worst days.
- It may take time and effort to gain accommodations. Work with your sleep doctor and employer throughout this process.
- Accommodations may need to be periodically adjusted, depending on your circumstances, health, and job role.
- Keep personal copies of all documents (e.g. application, doctor letter) and written communication about disclosure and accommodations.
- Educational and advocacy resources can help you learn about your rights, the accommodations process, and your options in the case that your accommodations are denied. See additional resources on page 20.



I don't use my accommodations too often because I put a lot of pressure on myself to be in the office with my team. But I'm learning that I need to prioritize self-care and advocate for myself. I have to take care of me first.

- Nicole



ADA OVERVIEW

What is the Americans with Disabilities Act (ADA)?

The American with Disabilities Act of 1990 is a federal civil rights law that prohibits discrimination against people with disabilities.

What is a disability under the ADA?

Under the ADA, a disability is defined as having one of the following: a physical or mental impairment that "substantially limits" one or more "major life activities"; a record of such an impairment; or regarded as having such an impairment (Title II of the Americans with Disabilities Act of 1990).

Interestingly, "substantially limits" is not specifically defined, but the Amendments Act of 2008 provided guidance stating that the determination "is intended to afford a broad scope of protection to eligible persons." The question of whether an impairment is substantially limiting requires an individualized assessment, but does not require extensive analysis. In other words, it does not usually require scientific, medical, or statistical evidence. However, this evidence may be used if appropriate.

What is a "major life activity"?

Major life activities consist of functions such as caring for yourself (including bathing, dressing, shaving, preparing a meal, and going to the restroom), performing manual tasks, eating, sleeping, standing, walking, lifting, reaching, bending, seeing, hearing, speaking, breathing, learning, reading, concentrating, thinking, communicating, interacting with others, and working (ADA Amendments Act of 2008). While narcolepsy affects many aspects of life, the inclusion of sleeping as a major life activity is helpful for people with narcolepsy and other sleep disorders to gain a favorable determination.

It was also added in 2008 that **mitigating measures** (such as medication) cannot be considered in making the determination. Instead, the determination of disability must focus on whether the individual would be substantially limited in performing a major life activity without the mitigating measure. As narcolepsy's effects on quality of life are often underappreciated by outsiders, the fact that ameliorating factors like medication will no longer be considered in the determination is helpful.

Furthermore, some mitigating measures, such as medications, have negative side effects. If an individual experiences negative effects, this may be included in the disability determination.



SAMPLE APPLICATION

This is a typical application for accommodations; section II is filled out with example language.

APPLICATION FOR REASONABLE ACCOMMODATION

| Section I – Applicant/Employee Information | | | |
|---|------------|---------------------------------|--|
| Applicant/Employee Name | | Employee Number (if applicable) | |
| Home Address | | Home Phone Number | |
| City | State | Zipcode | Alternate number |
| Job Title | Department | Supervisor | |
| Do you have a previous request for accommodation on file? | | | <input type="checkbox"/> No <input type="checkbox"/> Yes, date: |

| Section II – Request for Accommodation |
|---|
| <p>a) Describe the condition requiring accommodation. Attach any pertinent medical note/report from your healthcare provider.</p> <p>Narcolepsy is a chronic neurological condition of the sleep/wake cycle. Symptoms include excessive daytime sleepiness (EDS), disrupted nighttime sleep, cataplexy, hypnagogic hallucinations, and sleep paralysis.</p> |
| <p>b) Describe the job functions you are unable to perform due to your medical condition.</p> <p>Due to my narcolepsy, my brain enters a foggy state once or twice a day, and to relieve this, I take 1 or 2 naps daily as part of my treatment. These naps last 10-20 minutes each, reducing my EDS & improving my cognitive functioning.</p> |
| <p>c) Describe the specific accommodation(s) you are seeking to facilitate performance of your essential job functions. Include alternative accommodations.</p> <p>I seek a quiet, secluded room within the work building to be able to close the door for privacy and rest in a reclined or laying position, once or twice daily as necessary.</p> |



SAMPLE APPLICATION

Section III - Certification

I certify that all information contained in this application is true and correct. I understand that if I am granted an accommodation and it is subsequently determined that the decision was based upon a misrepresentation or false information, I may be subject to disciplinary action, my request or accommodation may be withdrawn, and I may be required to reimburse related costs.

I further understand that this application, attachments, and all medical information subsequently requested will be considered confidential medical information and will be retained except where released by me for other use or otherwise as may be required by law.

Applicant/Employee Name

Employee Number (if applicable)

Signature

Date

Phone Number

Email Address

Deliver to:

Manager, Department of Human Resources



SAMPLE DOCTOR LETTER

An example may be helpful for the doctor writing a letter on your behalf; please feel free to share the language provided.

January 1, 2023
RE: John Doe DOB:7/4/1990

To whom it may concern:

I am writing to confirm John Doe's diagnosis of narcolepsy with cataplexy. Narcolepsy with cataplexy is a chronic neurological disorder with symptoms including excessive daytime sleepiness, disrupted nighttime sleep, cataplexy, hypnagogic hallucinations, and sleep paralysis.

As part of John's treatment, he takes short (10-20 minute) naps once or twice daily. The ability to take these naps in a private space would be a helpful accommodation to help him succeed in the workplace.

If you have any questions regarding this matter, please contact my office and request to speak with Nurse One, RN or Nurse Two, LVN at (***) ***-**** or for fax transmissions (***) ***-****

Sincerely,

Signature

Doctor Name, MD



MORE RESOURCES

Hypersomnia Foundation: Disability Claims

<https://www.hypersomniafoundation.org/disability-claims/>

Sleep Disorders and Your Job

<https://www.hypersomniafoundation.org/social-security-disability-series-part-1/>

ADA website <https://www.ada.gov/>

Equal Employment Opportunity Commission - Your Employment Rights as an

Individual with a Disability <https://www.eeoc.gov/laws/guidance/your-employment-rights-individual-disability>

Narcolepsy Quick Facts [https://project-sleep.com/wp-](https://project-sleep.com/wp-content/uploads/2019/08/Narcolepsy-Quick-Facts.pdf)

[content/uploads/2019/08/Narcolepsy-Quick-Facts.pdf](https://project-sleep.com/wp-content/uploads/2019/08/Narcolepsy-Quick-Facts.pdf)

Youth, Disclosure, and the Workplace; Why, When, What, and How

<https://www.dol.gov/agencies/odep/publications/fact-sheets/youth-disclosure-and-the-workplace-why-when-what-and-how>

Disability Disclosure <https://askjan.org/topics/Disability-Disclosure.cfm>

Disability Discrimination in the Workplace: An Overview of the ADA by Lisa Guerin,

J.D.: <https://www.nolo.com/legal-encyclopedia/disability-discrimination-workplace-overview-of-30123.html>

Disability Rights Legal Center <https://thedrlc.org/>

Law Help <https://www.lawhelp.org/resource/legal-aid-and-other-low-cost-legal-help>

PATIENT ORGANIZATIONS

- **Hypersomnia Foundation** www.hypersomniafoundation.org
- **Narcolepsy Network** www.narcolepsynetwork.org
- **Project Sleep** www.project-sleep.com
- **Wake Up Narcolepsy** www.wakeupnarcolepsy.org

International Organizations:

- Listed on Project Sleep's **World Narcolepsy Day webpage** www.project-sleep.com/worldnarcolepsyday



THANK YOU!

We are so grateful that you took the time to check out this toolkit!

Project Sleep is a 501(c)(3) nonprofit organization dedicated to raising awareness about sleep health and sleep disorders.

More resources at: www.project-sleep.com

