



# NARCOLEPSY ROADMAP TOOLKIT

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# TOOLKIT INDEX

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# WELCOME!

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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. Each month, 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 in speech bubbles throughout toolkit are from participants who joined us for the live broadcast.

## PLEASE NOTE

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The Narcolepsy Nerd Alert series is intended for educational and awareness purposes and is not a substitute for medical attention. We want to empower people with information. 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 ROADMAP

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## **Navigating narcolepsy doesn't come with a roadmap, but it should.**

On January 27, 2021, we hosted the "Narcolepsy Road Map" live event to discuss what narcolepsy community members wish they'd known at diagnosis. This toolkit is our attempt to build that roadmap for others in the future.

- Watch the Narcolepsy Roadmap [Video](#)
- Learn more about [Narcolepsy Nerd Alert Series](#)



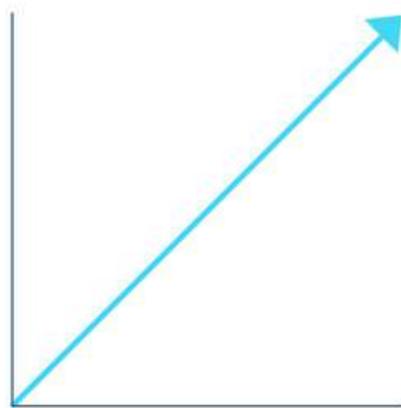
## **WHAT DO YOU WISH YOU'D KNOWN AT DIAGNOSIS?**



# "SO, YOU ARE FEELING BETTER, RIGHT?"

This question can be frustrating when you're newly diagnosed or adjusting to narcolepsy. Someone might think that living with a chronic condition like narcolepsy is like the graph below on the left, where you take treatments and you feel all better. In reality, sometimes we don't feel better right away. Adjusting to narcolepsy is not always a linear process and can be overwhelming at times, as depicted in the graphic below on the right. However, using resources like this toolkit can help make narcolepsy more manageable over time.

## Feeling "better" with a chronic condition



What people **think** it looks like



What it **actually** looks like



# A STARTING POINT

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There are many aspects to navigating narcolepsy. One useful way to think about this is to break the experience down into three categories:



## MEDICAL EXPERIENCE

Managing symptoms, accessing healthcare, doctors, and treatments



## SOCIAL EXPERIENCE

Managing relationships, societal roles, cultural expectations, communications, and disclosure



## INTERNAL EXPERIENCE

Feelings and intrinsic characteristics, self-perception, stress management, acceptance of the condition



Living with a chronic condition is an ongoing process of inner negotiation between social and medical needs... shifting between illness-on-the-foreground and wellness-on-the-foreground."

- DR. JANE SATTOE



# MEDICAL EXPERIENCE

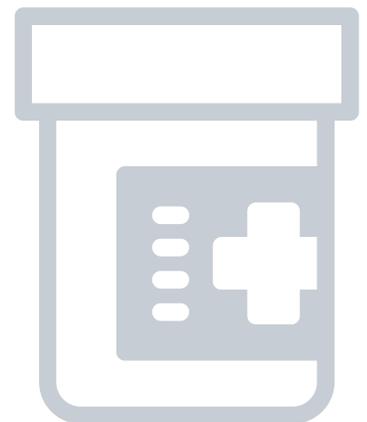
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Here are some common themes and practical tips related to managing symptoms, accessing healthcare, doctors, and treatments.

- **Expertise matters.** Not all sleep specialists have the same expertise in narcolepsy or idiopathic hypersomnia. It is important to find a specialist who has a fair amount of experience treating people with narcolepsy and who stays current with the latest research, treatment options, and clinical trials.
- **Second opinions:** If you are not sure about your diagnosis or the treatments your doctor is recommending, seek a second opinion at any point in your journey. Often people might feel bad about getting another opinion, but think of this as an information-gathering exercise.
- **Finding optimal treatment:** There is no one "right" treatment for everyone and the first approach you try may not work well for you. This is okay. Finding optimal treatment can be an evolving process that involves subtle tweaking of dosages, timing, etc. Likewise, it can be helpful to know how different treatment options work for you. We sometimes hear people discounting a treatment option due to logistical considerations *before* trying that treatment. While logistical considerations are important, seeing how a treatment impacts your symptoms and quality of life may allow for making a more informed decision about how you might negotiate other considerations to prioritize a certain treatment.
- **Incorporating napping, lifestyle changes, and social support** can be helpful to consider and explore in addition to traditional medications.
- **"Cure culture"** In our society, there is an emphasis on feeling better or getting better. We're all for finding ways to improve, but this overarching societal pressure that people with narcolepsy should be able to cure themselves or get fully better can be overwhelming, harmful, and toxic.

"Even after being diagnosed for 17 years, I still recently had to relearn that my treatment will always be a journey and that I will never have 'arrived' at a final destination."

- Katie





"I blamed myself for not recovering... as if not regaining my health was my fault, a failure of will, somehow, or a deficit of character."

- TONI BERNHAM,  
*HOW TO BE SICK*



# SOCIAL EXPERIENCE

Here are some common themes and practical tips related to managing relationships, societal roles, cultural expectations, communications, and disclosure.

- There are going to be **people who don't "get it,"** and that's a really big challenge. In future broadcasts and toolkits, we'll cover skills & best practices for communicating about narcolepsy, but some people still won't get it. Know you're not alone if this is your experience.
- **Finding resources and community:**  
Over time, you can find new people in your life who will get it, whether that's other people with narcolepsy through some of the great narcolepsy communities (see Resources), or even other people who have faced different kinds of adversity in life.
- **Emotional vs transactional:**  
When communicating about narcolepsy with close friends and family, it is understandable to hope that your loved ones "get it" on an emotional level. When communicating about narcolepsy in employment and school settings, consider approaching these interactions in a more goal-oriented and transactional manner. Disclose the information needed in order to work through the process and acquire reasonable accommodations to help you succeed. More on this topic in a future broadcast & toolkit!

"I'll explain to new people what narcolepsy is and they'll just assume it must be nice to get to sleep all the time and that it doesn't sound like a bad thing. Many people don't understand the inconvenience of constant excessive sleepiness on a daily basis. The fear of missing out on important events/moments because I'm too sleepy to stay awake and be in the moment is a big factor."  
-Lilly

"It's definitely difficult to lose people/friends at the beginning, but over time it tends to leave us with really meaningful and fulfilling relationships, those who you can be confident you can count on and who simply accept you as you are."  
- Katie



# SOCIAL EXPERIENCE

Here are some common themes and practical tips related to managing relationships, societal roles, cultural expectations, communications, and disclosure.

“Love the spoon theory... still use this daily, my partner will check in with me throughout the day on my ‘spoon count.’”

- Alex

- **Limited energy expenditure** or “The Spoon Theory” can help explain aspects of living with a chronic condition that aren't limited to the basic symptoms.

- **Creating boundaries *and* knocking them down** are really important for social relationships. For example, you might set a boundary and tell friends that you can only drive 45 minutes, so that they understand that someone else will have to drive if it's a longer trip. It's also good to know that you can knock those boundaries down when it makes sense for you.

- **Building a strong "no" muscle:** Prioritizing and negotiating time might mean choosing between commitments, opportunities, groups of friends, etc. This is tough, we understand. We do suggest building a strong "no" muscle in order to truly show up for yourself, your priority goals, and your loved ones. Remember, you do not need to explain your "no" to others. You can simply say, "Thank you for thinking of me. I am unable to make it this time."

“I have to remind myself that just because my daughter has a good day or two in a row - doesn't mean her narcolepsy is gone! It is a daily reminder to stop myself when she needs more naps or says 'no' and change my thinking to 'she is doing what is best and healthy for her.' As a supporter, I have to keep reminding myself of this so my daughter has a safe zone of unconditional love and support.”

- Heidi





"I have this weird relationship with my chronic illness where I spend 75% of my time trying to pretend it DOESN'T exist and the other 25% trying to explain that it DOES exist to a bunch of people who don't believe me."

- ANONYMOUS



# INTERNAL EXPERIENCE

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Here are some common themes and practical tips related to feelings & intrinsic characteristics, self-perception, stress management, and acceptance of narcolepsy.

- **Pretending narcolepsy doesn't exist:** We've been there. Julie describes, "I thought that if I somehow put narcolepsy in a corner or brushed it under the rug, I was in control and not letting narcolepsy become a bigger part of my life. Narcolepsy was just going to stay in a small little compartment of my life – and if I kept it there, than I was somehow stronger than narcolepsy and I was 'winning.' I was not letting narcolepsy get the best of me. Over time, I realized that approach actually made me weaker and did not prepare me to be the best version of myself with narcolepsy. And so by opening up to learn more, and meet other people, it did not mean that narcolepsy was beating me—it actually meant that I was creating a stronger version of myself, and being the best I could be with narcolepsy."

- **Your biggest critic** is sometimes living in your own head. Julie says, "Often we think about other people not being supportive of our narcolepsy, but we must also ask ourselves if we are being supportive of our own experience." How are we talking to ourselves? Are we telling ourselves that we are awesome for overcoming adversity every day or scolding ourselves for our every misstep?

"You can't bully yourself into doing something that your body just can't do, so the negative self talk concept breaks down and becomes a negative spiral."

- Richelle

- **Learning to recognize and respond to one's inner critic** is a major part of Acceptance and Commitment Therapy (ACT). An easy tool to begin exploring ACT exercises is *The Happiness Trap* by Russ Harris. However, this is just one approach. Consulting a trained therapist could also be helpful to find an individualized approach for addressing one's inner critic.



# INTERNAL EXPERIENCE

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Here are some common themes and practical tips related to feelings & intrinsic characteristics, self-perception, stress management, and acceptance of the condition.

- **The space between health and sickness:** In our society, we often see "healthy" and "sickness" as two opposite ends of a spectrum. Living with narcolepsy can sometimes feel less distinct, like living somewhere in the grey zone between the land of "healthy" and the land of "sickness." Narcolepsy's symptoms can be subtle, unpredictable, and shift throughout a day. A challenging morning may or may not mean the whole day is a wash. This uncertainty can make it difficult to make certain decisions (like when to take a sick day) and may be hard for others to understand why some days you can do things and other days you cannot.
- **Now vs the future:** Right after a new diagnosis, it is understandable to start wondering how narcolepsy might impact the future. As much as possible, try not to make longterm projections, especially while still adjusting to treatments. There is a concept articulated by Dr. Eric Cassel that our greatest suffering is ***in our fears of future experiences*** as opposed to things that are actually happening right now. As much as possible, try to focus on what you can control now. "Cross each bridge when you get to it," as they say, and know that you are part of a team and community (fellow #NarcolepsyNerds!) who will be there to help you through future challenges and stages of life.
- The **Universal Law of Impermanence** is a Buddhist concept called *anicca* which says that everything is changing or evolving, for better or worse. Julie says, "I think what gives me hope is that my own personal experience with narcolepsy has evolved so much over time... I know it's overwhelming at the beginning, and it might be for a while longer, but it might not be exactly how it is right now forever. I truly believe it gets better and we get better at managing narcolepsy."





"This is a planet full of people evolving."

-ALLISON SATTINGER  
*THIS IS NOT WHAT I ORDERED PODCAST EP. 31*



# RESOURCES

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Resources are so important. Here are some of our favorites and we look forward to hearing what our fellow #NarcolepsyNerds find most useful for navigating narcolepsy!

## PATIENT ORGANIZATIONS

- Major US Organizations:
  - [Hypersomnia Foundation](#)
  - [Narcolepsy Network](#)
  - [Project Sleep](#)
  - [Wake Up Narcolepsy](#)
- International Organizations:
  - Listed on Project Sleep's [World Narcolepsy Day webpage](#)

## BOOKS

- [\*How To Be Sick\*](#) by Toni Bernhard
- [\*Sleepyhead\*](#) by Henry Nicholls
- [\*Surviving and Thriving with an Invisible Chronic Illness\*](#) by Ilana Jacqueline
- [\*The Happiness Trap\*](#) by Russ Harris
- [\*There is No Good Card for This\*](#) by Kelsey Crowe
- [\*Waking Mathilda\*](#) by Claire Crisp
- [\*Wide Awake and Dreaming: A Memoir of Narcolepsy\*](#) by Julie Flygare

## MORE RESOURCES

- [\*Narcolepsy 360\*](#) - Podcast by Wake Up Narcolepsy
- [\*This Is Not What I Ordered\*](#) - Podcast by Lauren Selfridge
- [\*Suffering the Silence\*](#) - Patient-Driven Chronic Illness Non-Profit
- #Nchat is a monthly twitter chat on narcolepsy
- Follow #Narcolepsy on Instagram or TikTok



# 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](http://www.project-sleep.com)

