



# NARCOLEPSY + RELATIONSHIPS TOOLKIT



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Created by:

projectsleep



# 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. Throughout the year, Project Sleep broadcasts live events featuring stories, insights, and expertise from people with narcolepsy, researchers, clinicians, and other community members.

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.

## 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. If anything in this toolkit sparks questions for you about your medical management, please bring those questions to your doctor.



# NARCOLEPSY + RELATIONSHIPS

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In a special Valentine's Day live broadcast, our panel discussed narcolepsy and relationships, from early stages of dating to long-term partnerships and marriage.

This toolkit includes our panelists' personal anecdotes, challenges, and advice, aiming to offer validation, support, and spark ideas for navigating relationships with narcolepsy. These stories offer a window into the many aspects of relationships impacted by narcolepsy. They do not cover exhaustive explanations of each topic or evidence-based relationship advice, but rather highlight various approaches based on real lived experiences. Our panelists' experiences vary, proving how different every relationship—and everyone's experience of narcolepsy—can be.

- Watch the **Narcolepsy + Relationships** video or listen to the podcast: <https://project-sleep.com/narcolepsy-nerd-alert-narcolepsy-and-relationships/>
- Learn more about the **Narcolepsy Nerd Alert Series**: <https://project-sleep.com/narcolepsy-nerd-alert/>



# MEET OUR GUESTS

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**Taylor Dillon** is a Filipina-American NERD who loves hiking and dancing in Los Angeles. She was diagnosed with narcolepsy at age 18, and now creates educational resources, the Narcolepsy Nerd Alert toolkits, with Project Sleep. As a speaker with Project Sleep's Rising Voices program, Taylor shares her story to increase public understanding of narcolepsy and decrease stigma around sleep disorders.



**Lindsay Scola** is an entertainment impact strategist and outdoor enthusiast living in Los Angeles. She was diagnosed with narcolepsy at 35 and is now a speaker with Project Sleep's Rising Voices program. Lindsay shares her story of experiencing mysterious symptoms and advocating for her diagnosis to help others with sleep related issues get answers and seek the treatment they need.



**Jeff Discount** is a father of three who enjoys a career as a sales engineer and business development consultant, and has a passion for building both his physique and meaningful relationships. He was diagnosed with narcolepsy at age 40, which provided considerable challenges in maintaining high levels of fitness and balancing important facets of his life. Jeff encourages other people with narcolepsy to connect and learn from each other, and is thrilled to share some of the ways he has overcome his own challenges with this neurological condition.



# MEET OUR GUESTS

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**Bob Cloud** is a retired lawyer living in Northern Vermont. He grew up in Ohio and married an Indiana girl, Margaret, with whom he has two children. His excessive sleepiness, cataplexy, and related symptoms appeared at age 33, during his first year of night law school. Bob practiced family, criminal, and general law for 30 years, during which time he learned to live with narcolepsy. As a Rising Voices speaker, Bob shares how supportive family, creative doctors and pharmaceutical providers, and understanding friends stood by him as a husband, father, lawyer, patient, and occasional fisherman with narcolepsy.



**Margaret Cloud** has been married to Bob for 52 years. Following a career of 30 years in clinical laboratory leadership for major medical centers and national labs, she moved with Bob to northern Vermont. Margaret's insights into supporting a spouse with narcolepsy raise issues not often discussed by individuals, families, and professionals.

## MEET THE HOST

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**Julie Flygare, JD**, currently serves as President & CEO of Project Sleep. She was diagnosed with 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.*



# BREAKING DOWN THE EXPERIENCE

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When talking about living with a chronic condition, it can be helpful to break it down into different facets: medical, social, and internal.



## **Medical**

Managing symptoms and accessing healthcare, doctors, and treatments



## **Social**

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



## **Internal**

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

Daily realities of relationships and dating often involve **all three** of these areas, sometimes even overlapping, so you may find it useful to frame your own lived experiences through these lenses.



# TIPS AND TAKEAWAYS

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## **Compromise creatively**

Before fully saying “no” to an activity that’s meaningful to your partner, try to get creative. Brainstorm ways in which you can still participate while being mindful of symptoms.

## **Laugh!**

Humor can offer levity in even the hardest of times. Life with narcolepsy is challenging, and so are relationships! Laughing about it together won’t change this, but it can make it more bearable.

## **Embrace flexibility**

The challenges narcolepsy brings will likely change over time based on what stage of life you’re in. Accept that you’ll need to learn to cope with new obstacles as you (and your relationship) evolve.

## **Plan ahead, together**

When you are feeling up to it, plan together for times when nobody in the relationship has much energy.

## **Troubleshoot cataplexy together**

Share your triggers and discuss how best to plan for them. For example, if your cataplexy is triggered by laughter, your partner can encourage you to sit down before you exchange jokes or funny stories.

## **Consider red flags**

Did your date make an offensive comment or suggest a “cure” when you disclosed your narcolepsy? If you don’t like how they respond to it, be open to the idea that they maybe aren’t the best fit for you.

**\*** *Pro tip for partners:* Take some time to learn about narcolepsy yourself. It both helps you understand and shows you care.



### **Create transition time after naps**

To avoid hurt feelings or misunderstandings after waking up from a nap, consider initiating a rule: don't interact with each other for, say, 30 minutes after you wake up from a nap.

- \* *Pro tip for partners:* While it can be helpful to gently remind your partner that they can take a nap if you see them struggling with daytime sleepiness, be aware they may not always receive this well. Discuss ahead of time what would be most helpful for them.

### **Utilize analogies and metaphors**

Looking for a way to better communicate your energy levels to your partner? Try describing it in a new way. Read about The Spoon Theory and the Gardener/Garden Theory on pages 21-22 of this toolkit for ideas.

### **Talk about it**

Have open, honest conversations with each other about your feelings around narcolepsy. You might not naturally think about the feelings and concerns of your partner without narcolepsy—and vice versa.

- \* *Pro tip for partners:* If your partner's narcolepsy comes up in conversation with friends, consider sharing some of the educational responsibility. Perhaps take the reins if it's clear they have no energy or hop in to validate their experience.

### **Develop a support network**

Expanding your support network beyond the relationship helps take pressure (emotional support, childcare, etc.) off of each partner.

### **Recognize what narcolepsy offers you**

Without negating any of the serious challenges of living with narcolepsy, many people find it beneficial to think of its "silver lining" in their relationship (i.e. growing closer by learning and growing together).

**Remember: Narcolepsy affects each partner in a relationship.**



# EARLY DATING

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## DISCLOSURE

One of the most common questions around dating with narcolepsy is when to disclose your diagnosis. The short answer is... there is no right answer!



Everyone's experience is different. Your decision will be based on what is right for you at that moment. Here are a few stories to illustrate that decision-making process.

### Taylor

When she started dating her current boyfriend, Taylor was working on some projects for Project Sleep and was proud to share the details with him on their first date. This naturally led him to ask her if she had narcolepsy. He didn't know what it was, but after their date, he looked it up and learned a little about it himself.

### Julie

Soon after she was diagnosed, Julie started dating someone new. She didn't mention her narcolepsy for the first few dates, but this proved to be too complicated, given her new treatment considerations (i.e., scheduling a dinner date based on the time she took her medication). After four dates, she burst into tears and told him she had narcolepsy.

“ It was so emotional for me and he was like, ‘Oh, okay. Why didn't you just tell me? That's fine.’ I built the disclosure up as such a big deal, and he was like, ‘Cool, no problem.’ After that, I thought to just bring it up sooner and let it flow more naturally into the conversation.

- Julie



## Jeff

With his current girlfriend, Jeff's narcolepsy symptoms showed up in an unrelated conversation—he found himself falling asleep while they were talking. He didn't want her to think that he found her boring, so he used it as an opportunity to explain why he was struggling to stay awake. Interestingly enough, she surprised him—she knew what narcolepsy was because her own daughter (fellow panelist Taylor!) also has narcolepsy. She asked him follow-up questions that proved how educated she was on the topic. Usually, this would be an “educational type of discussion,” Jeff says. This time, however, he took it as a “blessing or a sign.”

“ I think you almost have to talk about it soon, because of narcolepsy's impact on daily activities.

- Lola

## BAD DATING STORIES

If a prospective romantic partner has a negative response to your disclosure or symptoms, it could potentially help weed out someone who's not the best match for you. Our panelists share some of their own cringe-y tales.

### Taylor

When narcolepsy came up naturally on a first date, her date offered some “interesting” suggestions for how Taylor could “cure” herself. While she knew his only reference for chronic illness was what he'd heard on podcasts and he was just trying to keep the conversation going, she still didn't like it.

“ He suggested I cut out all food groups except for red meat and maybe my sleepiness would go away. I was not enjoying that connection, so I didn't see him again.

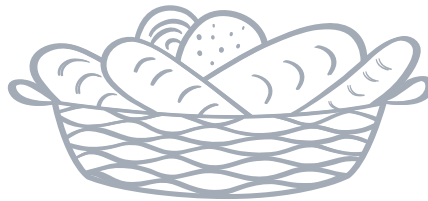
- Taylor

## Julie

Eventually, Julie brought up her narcolepsy as a point of pride on dates, given all of her professional accolades related to it. The sentiment wasn't shared by one man on their first date at an upscale restaurant.

“ I brought it up to him like, ‘I have narcolepsy. I’m so proud of what I’ve accomplished.’ And he literally said to me, ‘Is there anything else I should know that’s wrong with you?’ I think we were only at the bread basket phase...

- Julie



There may be less obvious cues that someone isn't the right fit for you. Narcolepsy symptoms and their impact on daily life can present challenges for any relationship. If your date or partner approaches these with flexibility, creativity, and understanding, that's a great sign! But if they don't, it could indicate an underlying incompatibility.

“ That was the beginning of the end for me and my college boyfriend—I'd always fall asleep when we were hanging out at night.

- Lindsay

“ I had a friend who just couldn't deal with our different 'energy levels'... Basically, me taking naps was too boring.

- Lola



# DEALING WITH SYMPTOMS

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## CATAPLEXY

### Julie

Like many others with type 1 narcolepsy, for Julie, cataplexy can occur during sexual experiences. She says that, for her, it's not the worst place to have cataplexy because at least she is in a bed.

While cataplexy can be serious, Julie is able to laugh at her experience with one past partner who recognized her cataplexy episodes before she could. He'd even encourage her to sit down before telling him a joke, noticing right away that she was already having cataplexy.

“ He could hear it in my voice before I even realized I had it. He didn't even have to be looking at me and he could tell.

- Julie

While Julie loved that they were so in tune, his awareness sometimes made it difficult for her to keep her feelings private. For example, when he mentioned he was going to hang out with a friend that she secretly thought was a bad influence on him, her annoyance could trigger cataplexy, exposing her true feelings.

“ I didn't want to say I was annoyed, so I'd say, 'Oh that's fine, that's fine!' but then my knees would start to buckle, so he'd ask, 'What's wrong?' And I'd say, 'That is not fair! That is so not fair!' He could draw that out of me.

- Julie



## Lindsay

Lindsay says that someone having cataplexy and someone *watching* a loved one have cataplexy “exist in two different realms.” She knows cataplexy can be confusing and scary to see. Once, after she got a painful shot at the doctor’s office, her husband Steve thought she was having a stroke. He began to worry about what he’d say when he called her parents—not knowing she was simply having cataplexy in response to the shot.

“ It's just a weird added layer for somebody to figure out cataplexy when they're watching something happening but not actually able to deal with it.

- Lindsay

## Bob & Margaret

Both refer to a stage in their marriage when Bob’s cataplexy was particularly bad. It got to the point that, when they went to their kids’ baseball games, Margaret would follow behind him no matter where he went, just in case she needed to catch him before he fell. Thankfully, they had a supportive community.

“ One of our best friends, he said to me, ‘Don’t worry about it. I’m behind ya. I’m going to catch him if he falls down.’

- Margaret

“ If I'm going to have what feel like arguments or hard conversations, I ask to have them seated because I know it will trigger my cataplexy.

- Lain



## HALLUCINATIONS

### Lindsay

Miscommunication in relationships is natural, but when arguments break out over things that never happened, tensions can run high. Lindsay's hallucinations are almost always auditory. She recalls times when she would get angry with Steve for "saying things he didn't say that were actually a hallucination."

“ The hallucinations have gotten worse for me. Thankful for my husband to comfort me when I wake up with those.

- Amanda

“ I started sleeping in separate beds with cohabitating partners and that has been very helpful.

- Lola

## EXCESSIVE DAYTIME SLEEPINESS

### Bob

Naps, either sudden or planned, are one of Bob's biggest ways to manage excessive daytime sleepiness. Years ago, he used short naps to cope with unplanned sleepiness while driving with his kids.

“ If I felt myself getting sleepy, I'd tell them, 'I'm going to pull over and take a 15 minute nap. I'll set my alarm. You guys can talk, listen to the radio, do what you want to do. And when I wake up in 15 minutes, we'll be good to go.' It always worked. It was amazing how refreshing a 15-minute nap could be.

- Bob



## Lindsay

“ I get refreshed from the 15 minute nap; it works every time. And yet, every single day, I’m still a 41-year-old woman who’s like, ‘You should take a nap’ while the other side of me says, ‘No, you shouldn’t.’ And then, usually while I’m having this conversation with myself, Steve will poke in and say, ‘I think you should take a nap.’

- Lindsay

Lindsay’s reaction to this suggestion, however, depends on the day.

“ Sometimes I appreciate it. And then sometimes I’m like, ‘You’re not the boss of me!’...and then I usually end up taking a nap.

- Lindsay

## Taylor

Sleepiness is unpredictable. Sleep drive, or the need to sleep, in people with narcolepsy isn’t necessarily higher than that of people without narcolepsy; it’s *wakefulness* that drops out at inopportune times throughout the day.

Taylor cites this as why it can be annoying when a partner suggests you nap.

“ I could take a nap now and then still get really sleepy an hour later. So, sometimes the suggestion to take a nap might help me in that moment, but it’s not going to guarantee that later in the day I’ll be awake for the thing that you want me to be awake for. I know it’s tricky. It’s still nice to point out, ‘Oh, you look pretty tired,’ but I don’t respond as well to a suggestion that I nap right now.

- Taylor



## Julie

Julie says she wakes up from naps as either “beauty or the beast.” A solution with a past boyfriend was creating a rule: for 30 minutes after her naps, they wouldn’t interact with each other. This gave her time to transition out of whatever post-nap state she was in.

“ Sometimes I wake up in a very negative mood, so it was a much better fix for us to just live around each other for 30 minutes and give myself time to transition.

- Julie

“ When I was young and unmedicated, I changed personality-wise after waking up from naps. Now that I'm older/medicated, I have wake-up time after naps before engaging in something.

- Hanna

“ I’m more reluctant to take a nap when my girlfriend phrases it, ‘Do you think you need to go down for a nap?’ It kind of reminds me of when you’re putting your kids to bed.

- Jeff

“ Now I can't even eat dinner without Margaret asking me 'Did you take a nap? I don't want you falling asleep during dinner!'

- Bob



See our **Narcolepsy & Napping** broadcast for more on napping: <https://project-sleep.com/new-nerd-alert-napping-narcolepsy/>.



# COMPROMISE, COPING, & COMMUNICATION

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## COMPROMISE

Compromises are a major facet of any healthy relationship and can come in the form of creative solutions.

### Taylor

Taylor wanted to check out her boyfriend's favorite TV show, since she knew how important it is to him. Plus, it sounded interesting! But watching graphic or violence scenes would make her nightmares much worse—so they compromised.

“ He's seen it a few times and knew when those scenes were coming up, so he would warn me or cover my eyes. That way, we could watch the parts that we would enjoy together but not have more fuel for my nightmares.

- Taylor

“ I can only handle going out/driving at most two nights a week. Friends/partners can decide the two, but only two!

- Lain

## COPING TOGETHER

It's natural and normal to deal with stress in relationships, as partners will always have differences and conflicts. However, you can cope using constructive tools. Coping strategies can help manage challenging situations or difficult emotions in the face of stress.

Our panelists share a few of their coping strategies:



## Jeff

For Jeff and his girlfriend, watching movies together was a challenge; when he'd sit on the couch, he found himself falling asleep. He turned this into an opportunity to feel closer to his partner by **multitasking during low-stimulus activities**.

“ I'd massage her feet during the movie. One foot for the first 45 minutes, the other foot for the next 45 minutes. It worked and had a double benefit. She liked it, of course. The challenging part was we'd finish the feet 5 minutes before the movie ended, and I'd sit back and fall asleep in seconds.

- Jeff

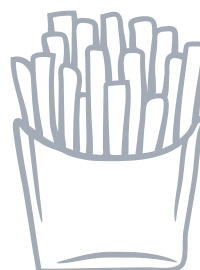
## Lindsay

A big coping method for Lindsay and Steve has been humor.

“ On days when symptoms are worse and you're already feeling bad for canceling plans or being behind, laughing just makes everything a little bit better. Most of the time it's me looking at him and saying, 'Why am I so tired?' and him responding, 'You have narcolepsy.'

- Lindsay

A **shared sense of humor** can offer levity in hard situations. In Lindsay's case, new medications can sometimes cause her to lose control of her emotions. Once, Steve rearranged the letters on her pegboard to say, "Days since meltdown: 0" and told her she'd get a prize when she reached 10 days—but Lindsay thought he said "fries." On Day 10, they laughed at the misunderstanding and went on a date to get fries.





“ We have to laugh about it because it affects both of us. It’s always in our relationship—when I need a last minute nap or need to change tonight’s plans. Laughing makes it, if not less challenging, more fun.

- Lindsay

### **Bob & Margaret**

By the time narcolepsy entered their relationship, Bob and Margaret had been married for six years and had two kids. As a family, they experienced the sudden onset of Bob’s symptoms.

Bob’s diagnosis was a big relief. They spent another year adjusting to life with narcolepsy until Bob developed a new set of challenges—cataplexy.

Margaret learned to cope by **embracing flexibility**. She believes how you cope depends on what stage of life you’re in. To her, living with narcolepsy also means learning to cope with evolving careers, relationships, and family structure—and the new challenges that come with them.

“ Our son was mentioning to me the other day 'Mom, I remember you'd have dinner ready on the table and the phone would ring and it would be Dad saying 'Oh I missed my bus stop, could you come pick me up?' So I would have to drop everything and go pick him up and bring him home so we could have dinner together. We laugh about it now, but at the time, it was frustrating.

- Margaret





## ANALOGIES

Some people with narcolepsy communicate their energy levels to their partners using analogies and metaphors.

### The Spoon Theory

The spoon theory expresses the idea of limited bandwidth using “spoons” as a unit of energy. It shows how chronic conditions impact one’s ability to complete everyday activities and could help you explain your limits and boundaries. You might say, “I just don’t have the spoons for that right now.”



“ I was in this relationship where this partner was very extroverted and interested in doing something every night of the week. It wasn't always that I was afraid I would need to sleep if we went every night or that I would have cataplexy, it was just that I had limited spoons so I would prefer to have plans just one or two nights a week. Being able to say that I didn't have the spoons to do an activity helped because it wasn't always exactly about a specific symptom, just more that I had limited bandwidth.

- Julie



### Read “The Spoon Theory”:

<https://www.butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/>

### 80/20 Plan or Gardener/Garden

These analogies represent the *give-and-take* in relationships.

The Gardener/Garden approach illustrates how a Gardener provides support and creates a safe environment in which the Garden can grow and bloom, with the understanding that the roles will swap.





In the 80/20 plan, one partner is at 80 percent and another is at 20 percent. The partner at 80 might need to provide more support to the partner at 20. Sometimes, everyone might be at 20. It helps to plan ahead for this.

“ You’re allowed to throw up the flag that says ‘I need help,’ acknowledging that you’re also going to be the person to catch the flag when the other person needs help.

- Lindsay



## PLANNING AHEAD

### Lindsay

Lindsay shares how she and Steve take advantage of time when they *do* have energy to prepare for moments in the future when neither of them will, which has taken additional drama out of already stressful situations.

“ You make a plan: ‘We’re going to get takeout tonight so no one has to cook,’ or ‘The laundry can wait until we both have some energy and can do it together,’ or ‘We’re going to drop some plans for this weekend, and instead take care of all of the things we didn’t get done personally this week.’ We have a conversation to prepare for when there are no spoons, so that it doesn’t feel like one person is taking up the slack—and so the other person doesn’t feel guilty for when their slack needs to be taken up.

- Lindsay



## HONEST CONVERSATIONS

Sharing your experiences as a person with narcolepsy can help partners understand your needs, behaviors, and emotions. It's also important for partners without narcolepsy to have space to share their side of the experience. **Narcolepsy doesn't solely affect the person with the condition; it affects the whole relationship.**

### Bob & Margaret

“ All of this makes me ask the question, ‘Is it harder to have narcolepsy, or to live with a partner who has it?’ I don't often think about all the questions, feelings, reactions, wonderings, and unknowns that Margaret has to live with. She wonders, ‘When's the next fall? Am I helping or making it worse? What might happen in bed tonight?’ We don't think about what they have to wonder about.

- Bob

Margaret shared how, in the years before his diagnosis, Bob's narcolepsy symptoms caused her to second guess their relationship.

“ There were times when I felt like, ‘He's bored with me. He doesn't find me attractive anymore.’ Or, ‘Gosh, this isn't the man I married. He's changed a lot.’ If we went out for dinner, he'd be sleepy at the table, and I would try to think of things to talk about that were more exciting and interesting, but oftentimes, it didn't work. You can't help but feel frustrated and that you're not being appreciated for who you are. It is inevitable, I think.

- Margaret



So, what is Bob & Margaret's secret to dealing with these separate experiences?

“ We talk about it. That's all you can do.

- Bob

Bob says educational moments are important to him and Margaret. When he'd have cataplexy in social settings, they'd both take advantage of it to explain narcolepsy to their friends. Sometimes Margaret would take the reins.

“ It doesn't bother me that somebody sees it. As long as somebody's there to explain it.

- Bob

“ You definitely need to develop a support network—not just your partner, but others available to pitch in. Otherwise you put so much pressure on yourself and can get depressed because you are not supermom.

- Lola





# LOOKING FORWARD

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While narcolepsy can certainly make relationships complicated, some people also appreciate recognizing how it might end up having a positive impact.

## Julie

Julie believes that living with challenges like narcolepsy and grief has made her more empathetic.

“ I know this has made me more in tune with other people when they bring things up to me. It affects how I respond. I know I can't take away their problems, but sometimes the best we can do is validate and be there for them in the moment.

- Julie

## Taylor

Early on in their relationship, Taylor had an open conversation with her boyfriend about how she navigates between wake and sleep states. She knows there are times when she might be mostly asleep but can still hear a nearby conversation. He valued that she told him so quickly. By emphasizing honesty and sleep health in her own life, she's able to put her best foot forward in her relationships.

“ Without consolidated, restful sleep, it is very hard to make a good decision. This is neurologically, scientifically true. And I'm not saying that to justify the messiness in my relationships early on with narcolepsy, but to say that it is so important to prioritize my sleep and keep a routine—not just to have energy throughout the day, but to be that better version of myself.

- Taylor



## Bob & Margaret

Margaret appreciates her kids' acceptance and admiration for their dad.

“ Both of our kids told me, ‘You know, I really admire Dad for what he has done and coped with, with narcolepsy. I can’t believe how he has managed it as well as he has.’ They don’t feel short-changed. They’ve learned that he’s strong and able to cope. Jokes get funnier because of Bob’s cataplexy when we’re all together. There’s acceptance there.

- Margaret

Still, Margaret says it’s easier for her and Bob when it’s just the two of them, and social gatherings can be challenging. She worries he will fall asleep in front of others and be perceived as “not with it.”

“ I think that’s a struggle that the partner of someone who has narcolepsy has all of their lives—knowing how to protect the other person from perceptions that people have.

- Margaret

After 52 years of marriage, Bob and Margaret accept Bob’s narcolepsy and celebrate how it’s made them a stronger couple.

“ I don’t think narcolepsy helps marriage one bit. The essence of narcolepsy is fragmented sleep; it fragments lives and families, colleagues, friends and so on. But learning about it and choosing coping strategies helps you learn to live with it, and you can have a richer relationship because of it. You can grow closer.

- Bob



# RESOURCES

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Here are some of our favorite resources. We look forward to hearing what our fellow #NarcolepsyNerds find helpful for navigating relationships.

## RECOMMENDED MEDIA

- ***The Spoon Theory*** by Christine Miserandino  
<https://www.butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/>
- **Narcolepsy & Relationships - Candid Conversations with Rising Voices** <https://www.youtube.com/watch?v=3sbW4XPmOjk>
- **Women's Health Magazine - How Having Narcolepsy Messes with My Love Life** by Julie Flygare  
<https://www.womenshealthmag.com/relationships/a19928456/dating-with-narcolepsy/>
- **Vice News - We Both Have Narcolepsy. This Is How We Have Sex** by Mark Hay (EXPLICIT CONTENT)  
<https://www.vice.com/en/article/how-to-have-sex-with-narcolepsy/>

## PATIENT ORGANIZATIONS

- Major US Organizations:
  - Hypersomnia Foundation  
<https://www.hypersomniafoundation.org/>
  - Narcolepsy Network <https://narcolepsynetwork.org/>
  - Project Sleep <https://project-sleep.com/>
  - Wake Up Narcolepsy <https://www.wakeupnarcolepsy.org/>
- International Organizations:
  - Listed on Project Sleep's World Narcolepsy Day webpage  
<https://project-sleep.com/worldnarcolepsyday/>



## MORE RESOURCES

- ***The Project Sleep Podcast*** <https://project-sleep.com/podcast/>
- **Narcolepsy Nerd Alert - Friends & Family** <https://project-sleep.com/narcolepsy-nerd-alert-friends-and-family/>
- ***Narcolepsy 360*** - Podcast by Wake Up Narcolepsy <https://www.wakeupnarcolepsy.org/podcast/>
- ***This Is Not What I Ordered*** - Podcast by Lauren Selfridge <https://laurenselfridge.com/listen>
- Follow **#Narcolepsy** on Instagram or TikTok.
- Wake Up Narcolepsy's online **support groups** <https://www.wakeupnarcolepsy.org/online-narcolepsy-support-groups/>
- **Finding Your Sleep Healthcare Team** <https://project-sleep.com/finding-your-sleep-healthcare-team/>

## SLEEP HELPLINE

Project Sleep's Sleep Helpline™ is a nonprofit-led free national helpline providing personalized support and resources for people facing sleep issues and sleep disorders.

**Contact the Sleep Helpline:** 1-800-819-2043, [helpline@project-sleep.com](mailto:helpline@project-sleep.com), or <https://project-sleep.com/helpline/>





# 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, sleep equity, and sleep disorders.

More resources at: [www.project-sleep.com](http://www.project-sleep.com)

