



FRIENDS + FAMILY + NARCOLEPSY TOOLKIT

Created by:

projectsleep



TOOLKIT INDEX

Welcome	3
About the Toolkit	4
Meet the Panelists	6
Supportive Actions	7
Supportive Communication	13
Supporting Supporters	18
Resources	21



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. 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 the toolkit are from participants who joined us for the live broadcast.

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.



ABOUT THE TOOLKIT

Supporters mean everything!

On April 28, 2021, Project Sleep hosted the "Friends + Family + Narcolepsy" live event to discuss how people with narcolepsy and their loved ones can foster mutual support and communication. This toolkit is a compilation of insights shared by panelists and community members.

- Watch the ["Friends + Family + Narcolepsy" videos](#)
- Learn more about the [Narcolepsy Nerd Alert Series](#)



WHAT HAS SOMEONE SAID OR DONE THAT MADE YOU FEEL SEEN, HEARD, OR SUPPORTED?



WHAT RESOURCES HAVE HELPED YOU BETTER UNDERSTAND & COMMUNICATE ABOUT NARCOLEPSY?



HOW TO USE THIS TOOLKIT

Whether you are a person living with narcolepsy or a supporter, the fact that you are looking for resources is HUGE and very meaningful. This shows how much you care about your relationships. We hope some of the ideas shared here will resonate and help spark new conversations and connections.

In this toolkit, we discuss ways that friends and family can support their loved one with narcolepsy through actions and communication strategies. We also discuss strategies for supporting our supporters.

The tips offered here are by no means an exhaustive list. More research is needed to better understand what types of support are most effective for people with narcolepsy. Specific needs will differ from person to person and based on circumstances.

Please take what helps! If you see something that looks good to you, take it with you and try it. No need to take on all these suggestions at once. You can always come back for more later. Perhaps not everything here is for you, and that's okay too! Everyone's needs and preferences are different.



MEET THE PANELISTS

Two featured panelists joined our host, Julie, for this broadcast.



LAUREN THOMAS

Lauren Thomas is an advocate, a daughter, and a friend living with narcolepsy with cataplexy. She was diagnosed in 2019 after a long journey with misdiagnosed sleepiness. Lauren loves to share her story and resources to help others make their situation a little better.



ANNE TAYLOR

Anne Taylor, RN, BSN, is a mom to two daughters, a nurse of over 22 years, and with her husband runs a company that offers evidence-based music intervention in hospitals. Anne also serves on the Board of Directors for Project Sleep, and is a supporter for her sixteen-year-old daughter living with narcolepsy.



JULIE FLYGARE

MEET THE HOST

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*.



SUPPORTIVE ACTIONS

Here are some ways one can support a friend or loved one with narcolepsy through one's actions.

- **Learning about narcolepsy:**

Narcolepsy resources are available in many formats including **videos, books, audiobooks, essays, podcasts, and medical journals**. Everyone has their own learning style, so if your loved one is looking for resources, you may ask them, "How do you like to learn?" and then recommend resources accordingly.

It feels really supportive when family or friends go out of their way to learn more about narcolepsy. A member of Lauren's family bought Julie's memoir, *Wide Awake and Dreaming*. Many of her supporters have read the book.

Anne says, "We often play [podcasts] in the house and everybody can listen in, whether they're drawing or cooking at the same time. There's so much power in hearing other people's stories."

- **Use educational resources as a conversation**

starter. After reviewing a resource, a supporter can check back with the person with narcolepsy in their life to share what they learned and ask how the information resonates or compares to their own experience.

- **Helping with medical needs:**

Keeping track of appointments, medications, and medical records can be complex. Loved ones can provide emotional and practical support in navigating the medical management of narcolepsy.

Lauren's mom attended most of her medical appointments in the beginning, and Lauren says, "It's really helpful in terms of my memory and the effectiveness of the appointment."

If Lauren has an appointment on a day when she's feeling extra sleepy or didn't sleep well the night before, sometimes she will call her mom and say, "I know we didn't plan this, but I'm not sure if I'm gonna be able to comprehend everything that's going on in this appointment. Can you come meet me here or can I put you on speakerphone?"

"I read Julie's book, *Wide Awake and Dreaming*, and that brought me a whole new vocabulary. I felt that, finally, I had found my village."

- Anne



SUPPORTIVE ACTIONS

"I know the sooner I teach her how to deal with the healthcare system, the better off she will be when she becomes an adult."

- Anne

Because Anne's daughter with narcolepsy is still a minor, Anne has attended all of the doctor's appointments so far, and she is making a folder with copies of lab results and other important medical documents.

In the last year she has deliberately started to prepare her daughter to navigate the healthcare system independently. Before each appointment, they sit down to plan and write down answers to questions like: "What goals do we have?" and "What do we want to talk to the doctor about?"

Anne adds, "Doctors don't always talk to each other. It is *our job as patients and loved ones* to make sure that Dr. X has talked to Dr. Y. That means we need to know the fax and phone number for each doctor, and that can be overwhelming." If you have this information organized in one place, it can make facilitating communication much easier and more efficient.

If you have a close loved one who doesn't seem to understand your narcolepsy symptoms or medications, you may consider inviting them to attend a doctor's appointment with you. This can be one way for them to hear from a medical professional. Another option would be sharing a medical journal paper about narcolepsy or an interview with a narcolepsy expert. Many people hold medical professionals in high esteem, so speaking with one can really help some people come along in their journey of understanding and support.

"My mom believed that something was wrong with me despite what doctors said and that was so important to me. She pushed me to find answers and didn't let me give up."

- Jenn



SUPPORTIVE ACTIONS

- **Attending conferences and/or support groups:**

There are many in-person and online support groups for people with narcolepsy and supporters, including some groups specifically for loved ones.

Meeting other people with narcolepsy and their supporters can be powerful and effective to increase empathy. For Julie's dad, attending the Narcolepsy Network conference was a big moment.

Even if the person with narcolepsy in your life is not interested or comfortable attending a conference or support group, you can attend by yourself.

"Not every day is the same [for people with narcolepsy], and you can only understand that as a caregiver or other family member if you've heard it from other people."

- Anne

- **Participating in awareness or advocacy activities, social media, or fundraising campaigns:**

Participating in awareness days and advocacy alerts can strengthen relationships and spark conversations. Opportunities include World Narcolepsy Day, Sleep Awareness Week, the Sleep In, or Project Sleep's Advocacy Alerts, just to name a few.

The narcolepsy community is active on social media platforms like Twitter and Instagram. Lauren's dad engages with the community on Twitter, and Lauren says he's "all in on sleep advocacy." Seeing what people and organizations are posting builds understanding of what's important to those with narcolepsy and the different perspectives within the community.

Donations of all sizes are deeply meaningful. It can take a lot of courage to participate in a fundraising event like the Sleep In or to host a Facebook Fundraiser for your birthday. Asking your friends and family for contributions creates new opportunities for your supporters to show up for you.



SUPPORTIVE ACTIONS

- **Being flexible with plans:**

Flexibility with plans is so helpful, because narcolepsy symptoms can vary from day to day and hour to hour.

Anne emphasized that flexibility has been extremely important for her family. She gave the example of having company over for dinner instead of going out, so her daughter can take a break and rest in her room if needed.

"I've always struggled with guilt when I need to cancel or change plans, so the support and non-judgment I've received in those cases has meant a lot."

- Richelle

"My mom used to bring me groceries and take my clothes home to wash and bring back to me each week. She did A LOT for me. I was freshly diagnosed and wasn't on a medication that truly worked for me yet."

- Lauren P.

- **Providing tangible help:**

Depending on one's circumstances, narcolepsy can interfere with one's ability to accomplish various daily tasks. Offering help with groceries, transportation, errands, housework, or childcare can make a HUGE difference.

- **Balancing support with independence:**

Everyone, including people with narcolepsy, wants to feel independent and capable of making their own decisions. Finding a balance offering help while also supporting someone's desire for independence can be tricky. Support needs are also likely to change over time. Open and honest conversations are important to maintain a balance of support and independence.



SUPPORTIVE ACTIONS

"Boundaries are essential in all my relationships. Boundaries both ways."

- Matt

- **Respecting boundaries:**

Certain types of support are more welcome than others. If you are uncertain about your loved one's boundaries or what types of help would be meaningful to them, asking them can be a way to build mutual understanding. If you are concerned that a loved one may be in crisis, it's a good idea to reach out for professional support (see Resources).

- **Showing up in different ways and on different timelines:**

Everyone is on their own journey. Supporters may show up in different ways and on different timelines. Some supporters will be engaged right away, while others may need a nudge in the right direction. And there will be individuals who never seem to "get it" or show support.

Supporting a person with narcolepsy may come more naturally to some people than others, often depending on the person's past life experiences and familiarity with chronic health conditions or other forms of adversity.

"Understanding that not everyone can show up for me in the same way has helped me recognize and appreciate all the different types of support I do get."

- Richelle

For example, one friend may start educating themselves right away. Another friend may not know what to say, but may post or donate on World Narcolepsy Day.

Julie shares, "I try not to focus in a negative way on those who do not [show up at a particular time], but take the love and support from wherever or whoever it comes from and appreciate different types of support that different people give over time."



"Do you want to vent or do you want advice? Just learning now, after 40 years on earth, that this might be the most important question to ask when a friend or loved one is upset."

- JADA YUAN
@JADABIRD



SUPPORTIVE COMMUNICATIONS

Here are some insights for communicating with friends and loved ones about narcolepsy.

- **Asking for help is hard:**

For anyone, including those living with narcolepsy, admitting we cannot "do it all" can be challenging. Lauren says, "I think the hardest part has been to take that first step and say, 'This is going to be a difficult day for me. I'm going to need help,' and then take that [support] as it comes, instead of being in complete distress all day and ending up really upset in the afternoon."

"It's just knowing your support system has your back, even if they can't fight your battles."

- Lauren T

- **Assessing invisible and shifting symptoms:**

The symptoms of narcolepsy can be invisible or hard to detect. Before diagnosis, a person with narcolepsy may have tried to cope by hiding or ignoring unwelcome new sensations. Once diagnosed, acknowledging unwelcome symptoms may still be challenging.

Symptoms shifting throughout the day makes it hard to know when to speak up to a loved one to ask for a raincheck or when something like a quick nap could help allow you to keep plans. Communicating in advance with supporters, even if to express uncertainty, is helpful.

Supporters can do their part by checking in on the day of plans to see how the person with narcolepsy is feeling. It's important to believe what the person with narcolepsy says, even if there are no visual cues of something being "wrong" and even if the person with narcolepsy was able to do that same thing yesterday or last week. It may be helpful to offer back-up plans or say something like, "Let's reconnect again soon to reschedule."



SUPPORTIVE COMMUNICATIONS

- **Knowing when to just listen:**

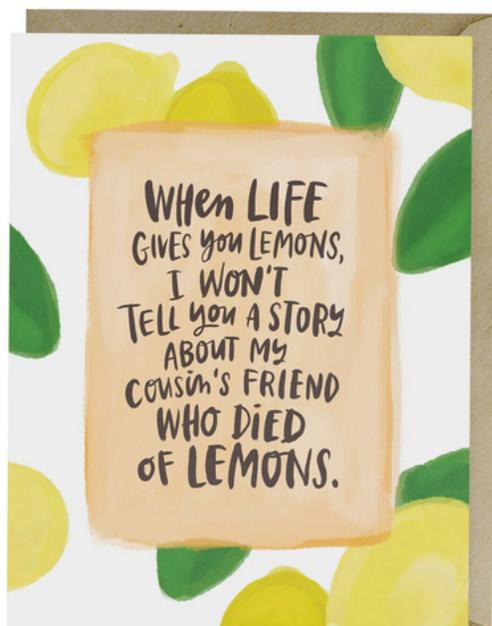
Sometimes people just want to talk about what's going on, and are not looking for advice. For many supporters, it can be difficult not to talk about solutions right away because they care and want to help "fix" the problem. (See Resources section for Communications + Mental Health.)

As a parent and nurse, Anne is familiar with this dilemma. She says, "Sometimes I might not have any good words, any band-aids to put on, so it could just be, 'I can see that you're upset. I'll sit here with you.' It actually comes from a place of **daring to be present** in an otherwise uncomfortable situation. Just that another human being will sit with you reduces your isolation instantaneously."

- **Allowing for sadness:**

Many people are inclined to look for the bright side, or "silver lining." While those *living* with narcolepsy may find meaning or positives from their experience, this is a personal process. If you do *not* have narcolepsy yourself, try to avoid pointing out possible bright sides. This often comes from a good place, but can feel dismissive.

When Lauren shares about narcolepsy, she finds that people often respond with something like, "You're lucky you get to nap." These kinds of responses make her wonder, "Are you actually listening to and absorbing what I'm saying, or are you just waiting to say something positive?"



- **Avoiding the temptation to make it about you:**

We all have such a desire to connect with each other, and it's common to want to share a related story when someone is looking for support. Julie says, "It's very hard, but I've learned to stay present with someone and listen without shifting the conversation away from them too quickly."



QUICK PHRASES:

Everyone is different in what makes them feel supported or triggers them to shut down. Supporters: consider asking the person with narcolepsy in your life how they feel about these word choices.

THINGS TO SAY:

- ***How are you feeling?***

This is a good, open-ended question.

- ***If you need a break or nap, you can use my bedroom/car/shoulder.***

Knowing that resources are available, especially in a new situation, can be comforting. Also, phrasing this an *option* allows the person with narcolepsy to choose for themselves whether or not to use this resource.

- ***I don't know what to say exactly.***

When in doubt, admitting uncertainty is endearing and a beautiful bridge for starting any difficult conversation.

THINGS TO AVOID SAYING:

- ***I know how you feel.***

- ***Don't worry. Don't be upset.***

- ***You're lucky you get to nap.***

For people with narcolepsy, daily naps are often prescribed because they are necessary. This may feel inconvenient and take away from already limited waking hours, and not feel lucky or like a luxury.

- ***Have you tried...?***

Often people with narcolepsy are trying many different things to improve their symptoms. Healthy lifestyle habits like diet changes, yoga, meditation, mindfulness, and exercise can be helpful for some individuals, but these are not substitutes for medical treatment and will not cure this neurological condition.

- ***Are you okay?***

Lauren explains that the honest answer to this yes/no question is often, "No. I'm absolutely not okay," whereas a more open-ended question like, "How are you feeling?" gives room to describe a full range of emotions and experiences.



WHEN NOT TO TALK

For some people with narcolepsy, communication is a big challenge at certain times of the day. Having important or emotional conversations is best done during times of peak alertness. In general, these are some times that it might be best not to try to communicate too much:

- **Right before a nap**
- **Waking up from a nap**
- **First thing in the morning**
- **Late at night**
- **When low on medication or off of medications**

Anne gave an example of a way to show support when a loved one is too sleepy to have a conversation:

"I've come to find that if I just put a glass of water or coconut water next to [my daughter], after she wakes up, she'll come to me 20 minutes later and say 'thank you.'

Also just know as a caregiver, this is not the time to say, 'Hey did you do your homework?' You have to be flexible and feel the room a little bit. And all these things are easier to do when you have an understanding of what narcolepsy is, how it presents itself, and how each day is different."

It's a good idea to ask your friend or loved one about their individual needs and preferences for communication. If you have questions, don't be afraid to ask, "Is this a good time to discuss..." Asking shows you care.



JUST CHECKING IN

It can be difficult to know what to say when you're concerned about a friend or loved one. This infographic, recommended by panelist Lauren, gives examples of supportive questions to use as a starting point.

IDONTMIND

Just Checking In

Ten simple questions to check in on someone's mental health

1. How are you feeling today, really? Physically and mentally.
2. What's taking up most of your headspace right now?
3. What was your last full meal, and have you been drinking enough water?
4. How have you been sleeping?
5. What have you been doing for exercise?
6. What did you do today that made you feel good?
7. What's something you can do today that would be good for you?
8. What's something you're looking forward to in the next few days?
9. What's something we can do together this week, even if we're apart?
10. What are you grateful for right now?

Source: @idontmind



SUPPORTING SUPPORTERS

We all need and deserve help, resources, understanding from others, and time to recharge, whether we have narcolepsy ourselves or support someone who does.

- **Recognizing where you are in your journey:**

It's important to take this one step at a time and know that your loved one's experience will evolve over time. Especially as a parent, it is natural to think ahead far into the future and have big picture concerns like, "Will my child be able to go to college? Succeed at a job? Start a family?"

Anne explains, "When my daughter was newly diagnosed at age 13, I confided in Julie about some of my long term concerns. Julie said to focus on the current stage of my daughter's life and cross future bridges when we get there. This really helped focus me on what we could control at the time and know that we didn't have to solve everything at once."

- **Attending a support group or joining an online forum:**

There are online forums and support groups for parents/caregivers too. Connecting with others who have similar experiences can be a valuable opportunity to give and receive support.

- **Knowing your limits:**

Anne says, "Once I get to 8 pm, it's like my clock goes out. I have nothing more to give, and my family knows that. I can do most of my good advocacy and fighting for my kids and my loved ones during the day, but once I hit eight o'clock, I just can't do any more."

"Nobody here is a superhuman, and humans have flaws. I have physical and mental health like everybody else."

- Anne



SUPPORTING SUPPORTERS

- **Getting it all out via "vexting" or journaling:**

Venting via text (Julie calls this "vexting") to a supportive friend or journaling can relieve some pressure. Julie says, "I even tell my friend, I'm about to vext you and I don't expect or need a response to everything I write, I just need to get it out into the universe."

"The feeling that telling my family's stories can bring about change fills my 'bucket' so much and makes me feel so incredibly empowered."

- Anne

- **Taking time to recharge and do things for yourself:**

We officially give you permission to "treat yo'self!" Taking time to do things for yourself is not selfish, and can help you have the energy you need to support others.

- **Breathing deeply:**

Deep breathing techniques are a scientifically proven, free way to calm your nervous system. Lauren describes that her mom uses deep breathing techniques to center herself.

- **Participating in advocacy:**

For some people advocacy gives a sense of purpose and control. It can feel empowering to use your own insights and experiences to work for positive change. Remember, advocacy is not a substitute for self-care. Make sure your needs and those of your family are adequately managed before jumping into advocacy.

- **It's okay to not be okay.**

Your mental and emotional health matter. If you feel sad, scared, helpless, angry or overwhelmed, please know that these feelings are valid and understandable. You are not alone and you deserve support too. If professional help is accessible to you, counselors, therapists, and/or coaches can be great resources for effective communication strategies, mental health care, and specific health needs (see Resources).



FRIENDLY REMINDERS

- **This is too heavy to carry alone.**

You deserve support, and there is no shame in reaching out. Confiding in trusted others and asking for help can relieve pressure to handle everything on your own. Project Sleep and other non-profit organizations offer resources and support for people with narcolepsy and loved ones.

"I hope when [my daughter] becomes an adult she knows this wonderful supportive environment of sleep advocates and people living with narcolepsy is going to be here for her."

- Anne

- **Despite your best efforts, some may not get it.**

Whether you are living with narcolepsy or supporting someone who does, not everyone you encounter will understand your experiences. This isn't your fault; no matter how well you communicate or provide information, there may be some people in your life who just don't get it.

- **Finding people who do get it will be invaluable.**

Identifying supportive, understanding people is worth the effort. These people may be from within the narcolepsy community or outside of it. Lauren says, "The people I've stayed closest to since my diagnosis have been those I've naturally felt comfortable being able to ask for help or be sad around, without having to think twice about how they may perceive it. It's a load off of me."

Express gratitude to supporters!

A simple thank you goes a long way. Say it often: out loud, in a card, via text.

Lauren cooked a dinner for her family to thank them for helping her get through a rough time that she described as "all hands on deck."

Julie pointed out that there is no "Supporters Day," and community members agreed that there should be a day to thank supporters. If you support someone with narcolepsy, know that you are appreciated!



RESOURCES

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

- [*There is No Good Card for This*](#) by Dr. Kelsey Crowe & Emily McDowell
- [*Wide Awake and Dreaming: A Memoir of Narcolepsy*](#) by Julie Flygare
- [*Waking Matilda: A Memoir of Childhood Narcolepsy*](#) by Claire Crisp
- [*Sleepyhead: The Neuroscience of a Good Night's Rest*](#) by Henry Nicholls

NARCOLEPSY RESOURCES

- [Narcolepsy Quick Facts](#)
- [Narcolepsy Infographic](#)
- [Narcolepsy: Not Alone website](#)
- [Harvard's Narcolepsy website](#)
- [Stanford's Narcolepsy website](#)
- [Narcolepsy 360](#) - Podcast by Wake Up Narcolepsy
- [World Narcolepsy Day page](#) - Narcolepsy infographics and information in English, French, Spanish, Polish, and Portuguese



RESOURCES

COMMUNICATION + MENTAL HEALTH

- [Support Network Worksheet](#)
- [Nonviolent Communication Technique](#)
- [Mental Health First Aid Training](#)
- [National Crisis Helpline](#)

RESEARCH ON FAMILY IMPACTS OF NARCOLEPSY

[Family functioning among adolescents with narcolepsy.](#)

Parmar, A., Yeh, E. A., Korczak, D. J., Weiss, S. K., Lu, Z., Zweerink, A., Toulany, A., Murray, B. J., & Narang, I. (2019). *Paediatrics & Child Health*, 24(8), 490-494.

[Clinical characteristics and burden of illness in pediatric patients with narcolepsy.](#)

Giuseppe Plazzi, Heather M. Clawges, Judith A. Owens, (2018). *Pediatric Neurology*, 85, 21-32.



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

