

# Supporting a Friend with Narcolepsy



If your friend or loved one was diagnosed with narcolepsy, you may wonder the best way show support. You want to help your friend through this difficult time, but it can be hard to know what to say or do. While there are no set rules for supporting a friend with narcolepsy, I hope these tips will help!

## Preparing yourself:

Take a few minutes to learn about narcolepsy. Your friend may be overwhelmed and not sure how to explain narcolepsy. Familiarize yourself with basics:

- Watch a few short videos
- Narcolepsy Quick Facts
- Frequently Asked Questions

## Helpful tips when supporting a friend or loved one with narcolepsy:

Although each person with narcolepsy is different, here are some general suggestions for showing support:

- **Make flexible plans** that can be easily changed in case your friend needs to cancel or reschedule. If your friend needs to cancel or change plans – do not express hostility or negativity. Believe me, your friend feels badly. Let them know it's okay.
- **Allow for sadness** – do not ignore uncomfortable topics or feelings.
- **Practice “Active Listening”** – Listen without shifting focus to yourself or others. Paraphrase and validate what your friend says in your own words. Examples: “I’m sorry to hear that ... [rephrase their experience]” or “I’d be upset too if... [rephrase their experience]”.
- **Offer to help with specific tasks**, such as taking care of children, taking care of a pet, or preparing a meal. Many people find it hard to ask for help, and your friend will likely appreciate the offer. Follow through on a commitment to help.
- **Let them know it's okay to nap** or take breaks. No need to constantly ask, but it's nice to mention once in private. Your friend may feel uncertain about napping in certain settings, especially social occasions with friends or family. Give your friend permission and mention a quiet bedroom or sofa.
- **Offer positive reinforcement:** “You are incredible to take this on as ...[a student, parent, in your teens, etc.]” or “I’m inspired by your strength.” or “I’m proud of you.”

# What to say:

Here are some simple guidelines to use when talking to your friend with narcolepsy.

## Avoid saying:

*I know just how you feel.*

*You're lucky you get to nap.*

*I know just what you should do.*

*I'm sure you'll be fine.*

*Don't worry.*

*Let me know what I can do.* (Instead, offer specific ways you can help or other things you can provide if they need it.)

*Jokes about falling sleep* (Narcolepsy's sleepiness is more serious and pervasive than jokes imply. Your friend will likely have a sense of humor about aspects of narcolepsy, but follow your friend's lead and tread cautiously).

## Do say:

*If you feel like talking, I am here to listen.*

*I was learning about narcolepsy online. What symptoms do you experience?*

*I'm thinking about you.*

*How are you feeling?*

*How are the medications making you feel?*

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

*I don't know what to say.* (It is better to be honest than to simply stop calling or visiting out of fear/uncertainty.)

I'm a HUGE fan of "I don't know what to say" or "I'm not sure how to ask this in a sensitive way". Admitting uncertainty is endearing and a beautiful bridge for starting any difficult conversation.

## Specific Offers to Help:

Be creative and sincere. Remember that your friend's needs may change, so be flexible in shifting your plans as needed. Here are some suggestions:

- Help with chores around the house, such as getting the mail, taking care of pets, cleaning, doing laundry, taking care of plants and flowers, and taking out the garbage.
- Schedule a night-in with takeout food and movies.
- Baby-sit children, take them to and from school and evening activities, and arrange for play dates.
- Call, email, or text but let your friend know it's okay if he or she doesn't reply.
- Drive your friend to an appointment or a support group meeting. You can take notes during a doctor's appointment.
- Go for a walk together.



## **Narcolepsy Super-Fans Welcome!**

Want to show more support? Awesome. You rock!

- Order Awareness Bracelets
- Read *Wide Awake and Dreaming: A Memoir of Narcolepsy*
- Join the NARCOLEPSY: NOT ALONE campaign
- Download Julie Flygare's Narcolepsy Mobile App

Supportive friends makes a world of difference in coping with narcolepsy. People with narcolepsy often feel misunderstood, lost and alone. Your support will stand out as exemplary.



***Thank you for your support!***